Internalized stigma and perceived discrimination among people with a mental illness in six European countries

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Abstract

Aim: Little is known about the degree to which the diverse sublevels of self-stigma are experienced by people with a mental illness from different countries. This study aims to describe and compare the sublevels and intensity of self-stigma across six European countries.

Methods: A cross-sectional study was conducted including 1223 persons with a psychiatric disorder who were members of a national mental health non-governmental organisation in the following countries: Croatia (N=101), Israel (N=125), Lithuania (N=200), Malta (N=115), Romania (N=104) and Sweden (N=151). The "Internalized Stigma of Mental Illness Scale" was chosen to measure internalized stigma.

Results: Moderate-to-high levels of internalised stigma ranged from 15.2% in Sweden to 57.4% in Croatia. Mean of perceived discrimination and devaluation was predominantly above the midpoint, and hence showed a high level of perceived discrimination and devaluation across the countries. Nevertheless, there was evidence of a huge amount of variation from 27.2% of the Israeli participants to 88.7% of the Swedish individuals reporting a moderate-to-high level. General Linear Models with self-stigma as the dependent variable showed very divergent results with no, positive, and negative significant relationships between internalised stigma and the psychometric measures as covariates. Concerning socio-demographic characteristics, only in Lithuania two variables were to a certain degree related to self-stigma, the highest level of education and the number of social contacts.

Conclusion: These findings suggest that in of the six countries a certain amount of people with a psychiatric disease suffer both self-stigma and perceived discrimination and devaluation. However, between-country variations in self-stigma and perceived discrimination and empowerment exist. It seems that the "one size fits all" approach does not apply to interventions against self-stigma.

Keywords: alienation, discrimination experience, psychiatric disorder, self-stigma, social withdrawal, stereotype endorsement, stigma resistance, sublevel.

Introduction

Etymologically, the term stigma was originated by the Greeks "*to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier.*" (1). Nowadays it denotes a mark of disgrace "*that extensively discredits an individual, reducing him or her from a whole and usual person to a tainted, discounted one.*" (2). Research regarding the concept of stigma emerged in the second half of the 20th century. In 1963 Erving Goffman published his pioneering book 'Stigma: Notes on the Management of Spoiled Identity' (1). Most topics that researchers on stigma have addressed since then have been associated with health conditions, especially HIV/ Aids, and mental illness (3). Generally, stigma adds additional distress to the already existing disease burden. Considering psychiatric disorders stigma takes an especial position. It can be both an effect and the cause of a mental illness.

The amount of people suffering from a mental illness is not exactly known and so the caused burden cannot be calculated exactly. Hence, a variety of estimations are published. Based on these between 27 % (4) and 38 % (5) of the EU population is affected by a psychiatric disorder yearly, and the impacts are divergent. Regarding the quality of life it is estimated that all neuropsychiatric conditions are responsible for 30 % of the total burden of disease of women and 23 % of men (5). Thus, the disease burden of mental illnesses is larger than that of all cancer diseases together. Furthermore, globally five of the top ten leading disability causes are mental illnesses (6).

The burden of psychiatric disorders is exacerbated by stigmatisation. Hence stigma can become a 'second disease'. Due to the fact that stigmatisation is both a risk factor and a consequence of mental disorder, it can cause a critical downward spiral. Accordingly stigma is a major public health issue. Though there is no consensus in the scientific community about the concept of stigma, but that there is no consent. That is why over the years stigma has converted to an under-defined, vague and overused concept (7,8). Nevertheless, Crocker et al. give an elementary definition: "*Stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context.*" (9).

All in all, it is evident that stigma addresses three interacting levels, as well the individual, and therefore psychological (*self-stigma*), as well as the interpersonal (*social stigma*) and the institutional (*structural stigma*) level (10,11). Essential of the concept of self-stigma is that the awareness of social stigma is necessary, but not sufficient; only agreement to the stigma about oneself leads to self-stigma (12). Thus, self-stigma develops through internalization of public beliefs, that are social stereotypes, by the stigmatized person (13,14). Ritsher et al. provide an explicit definition: "*Internalized stigma is the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself*". (14).

In contrast to the difficulty of definition there is unanimity that self-stigma in people with a mental illness affects several levels with diverse consequences. On societal level it can lead to 'lost productivity' and lower rates of employment and income, and a higher amount of benefit payments (15). On individual level it can cause lower self-esteem (16), self-efficacy and empowerment (17-19), less treatment-seeking (20,21), and more hospitalizations (22).

Even though a huge amount of studies from all over the world show a negative association between self-stigma and both psychosocial and psychiatric variables, as stated above, some mentally ill persons remain unaffected or develop righteous anger (23,24). That is the reason why this association is often called as the "paradox of self-stigma and mental illness" (23). Thus, it is hypothesised that the development of self-stigma is highly conditional upon the social context (2,23). Therefore, studying variations between self-stigma-concepts in different countries is essential for understanding the underlying processes.

To the best of our knowledge, only two studies explored differences in more than two nations (10). Therefore, this paper aims to identify country-specific disparities relating to self-stigma of people with mental illnesses according to Ritsher et al. (14). They developed a concept of internalized stigma which encompasses five dimensions – alienation, stereotype endorsement, discrimination experience, social withdrawal and stigma resistance.

Cross-national research on self-stigma can be an essential basis for a variety of groups, such as policy-makers to choose and support interventions, clinicians to take the impact of self-stigma into account and researchers themselves.

Methods

The following analyses were based on the sample of a survey conducted by Gamian-Europe in 24 countries in 2010. Gamian-Europe, the 'Global Alliance of Mental Illness Advocacy Networks-Europe' is a patient-driven, non-profit organisation, which acts for persons with mental illnesses. Currently more than 80 national associations from 37 countries are members of Gamian-Europe. Central to the pan-European federations' work are the following overarching goals "*advocacy, information and education, anti-stigma and discrimination, patients' rights, co-operation, partnerships and capacity building*" (25).

Study design and sample

Overall, 1223 persons with a psychiatric disorder partook in the survey. Because of scarce participation in some nations those countries which had less than 100 cases were excluded from the data analysis so that the participants of the following six sites are analysed in this paper: Croatia (N=101), Israel (N=125), Lithuania (N=200), Malta (N=115), Romania (N=104), and Sweden (N=151). Hence, this cross-sectional study includes 796 participants with a mental illness.

Firstly, Gamian-Europe sent an e-mail with detailed information about the study to all partner organisations and the request to invite their individual members to partake in the survey. Means to reach potential participants comprised announcements in monthly magazines, distribution of paper questionnaires, information at meetings and mostly a link on the associates' website. Due to this the sample is both not representative and no response rate can be calculated.

Translation procedure

In accordance with the cross-cultural adaptation process the survey packets were translated into each national language by professional translators. Additionally, the coordinators of the partner organisations reviewed the material and modifications were made when required.

The Internalized Stigma of Mental Illness Scale (ISMI)

The 'Internalized Stigma of Mental Illness Scale' was chosen to measure internalized stigma. This instrument was selected, because the 29-item questionnaire assesses five separate dimensions of self-stigma among people suffering mental illness and it is the most commonly used scale to measure subjective experience of stigma due to positive rating of all measurement properties, i.e. internal consistency, test-retest reliability, content and construct validity (26). Another advantage is the existence of numerous foreign-language versions of the ISMI (10). The scale encompasses the following five subscales: alienation, stereotype endorsement, discrimination experience, social withdrawal, and stigma resistance. Each item is composed of a first person statement and respondents rate on a four-point Likert scale whether they strongly disagree (1), disagree (2), agree (3), or strongly agree (4). Thus, higher scores imply higher self-stigma (14).

The *alienation* subscale(α=0.80) consists of six items and addresses the subjective feeling of not being a full member of society, e.g. 'I feel out of place in the world because I have a mental illness'. The *stereotype endorsement* scale (α=0.74) is composed of seven items, like 'Because I have a mental illness, I need others to make most decisions for me' and measures the respondents agreement to public stereotypes about people with psychiatric disorders. The *discrimination experience* subscale (α=0.76) encompasses five items, which reflect the feeling of being disadvantaged because of having a mental illness. One item is: 'People ignore me or take me less seriously just because I have a mental illness' Furthermore, the subscale *social withdrawal* (α=0.80) consists of six items, such as 'I don't talk about myself much because I don't want to burden others with my mental illness' At last, the *stigma resistance* subscale (α=0.60) is reverse coded and reflects opposition or not being influenced by stigma. This scale contains items like 'In general, I am able to live life the way I want to' (14,27).

With regard to the 29-item version of the total scale both a good internal consistency (Cronbach's α=0.90) and a good stability over time (test–retest reliability coefficient: r=0.92) has been attested. Furthermore, construct validity has been positively rated by comparisons against instruments, which measure related constructs with the same methodology. This encompassed the 'Center for Epidemiological Studies-Depression scale', the

'Rosenberg self-esteem scale', the 'Perceived devaluation-discrimination scale' and the 'Boston University Empowerment Scale' (14,26).
Because of weaker psychometric properties and in accordance with previous studies the *stigma resistance* subscale was excluded in the data analysis regarding the overall ISMI scale (14,17,26).

Socio-demographic, clinical and social contact items

In addition to the measures stated above questions about the socio-demographic, illness-related and social contact were asked, too. These included sex, age, the highest level of education obtained, employment status, housing situation, and source of income representing the socio-demographic items. Items with regard to clinical questions consisted of self-reported diagnosis, age at first diagnosis, agreement with diagnosis, present treatment status and current main type of mental healthcare. Concerning social contact variables, participants were asked about their living situation, relationship status, degree/ extent of contact with the family, existence of a friend and existence of a best friend.

Data analysis

The data analysis was carried out using SPSS Statistics Version 20. The between-country differences were assessed in calculating a descriptive analysis of ISMI. This contains the mean averages and standard deviations of all subscales. In this regard a high level of self-stigma is experienced if a score above the average of 2.5 is attained (14,27). Based on several previous studies four categories of self-stigma can be differentiated: scores of 2 or less are labelled 'minimal stigma', scores between 2 and 2.5 are termed 'low stigma', scores between 2.5 and 3 'moderate stigma', and scores higher than 3 are labelled 'high stigma' (17,18,28).

Results

For internal consistency Cronbach's alpha was calculated for each scale and subscale comprising the selected countries. Thus, the internal consistency of the overall ISMI scale was $\alpha=0.91$ (excluding the stigma resistance scale). The subscales of the ISMI showed the following internal consistencies: alienation ($\alpha=0.79$), stereotype endorsement ($\alpha=0.67$), discrimination experience ($\alpha=0.62$), social withdrawal ($\alpha=0.79$), and stigma resistance ($\alpha=0.60$). Table 1 presents the country-specific distribution of the 'Internalized Stigma of Mental Illness Scale' (ISMI) and the according subscales.

Table 1. Country-specific distribution of ISMI: mean (SD)

Variable	Croatia	Israel	Lithuania	Malta	Romania	Sweden
ISMI (excluding SR)	2.65 (1.11)	2.02 (0.86)	2.3 (0.69)	2.25 (0.84)	2.02 (0.86)	1.62 (0.79)
Alienation (A)	2.54 (1.16)	2.01 (0.98)	2.33 (0.84)	2.35 (1.01)	2.16 (1.00)	1.51 (0.77)
Stereotype Endorsement (SE)	2.57 (1.13)	2.09 (0.89)	2.01 (0.74)	2.14 (0.82)	1.87 (0.93)	1.45 (0.70)
Discrimination experience (DE)	2.68 (1.07)	2.14 (0.90)	2.14 (0.82)	2.11 (0.99)	2.10 (0.96)	2.17 (1.08)
Social withdrawal (SW)	2.59 (1.13)	1.70 (0.87)	2.28 (0.80)	2.10 (0.92)	1.91 (1.03)	1.46 (0.78)
Stigma resistance (SR)	2.08 (1.07)	1.77 (0.84)	2.59 (0.73)	3.02 (0.81)	1.86 (0.96)	1.86 (0.90)

Overall, with regard to an average level above the midpoint of 2.5 it seems that a high level of self-stigma was experienced in Croatia only. However, averages below 2.5 do not imply that self-stigma does not exist in those countries. The calculated mean scores just represent averages of the experienced self-stigma of all participants in the particular nation. With regard to the standard deviation it is evident that in each country people with mental illness suffered self-stigma. Hence, the mean plus and minus the standard deviation represents the level of experienced self-stigma of 95% of the participants.

Thus, the ranges of 95% of the respondents in the particular nations were from 1.54 to 3.76 in Croatia, between 1.16 and 2.88 in Israel, from 1.61 to 2.99 in Lithuania, between 1.41 and 3.09 in Malta, from 1.16 to 2.88 in Romania and between 0.83 and 2.41 in Sweden. These ranges indicate that in each country self-stigma exists, but the span is very divergent. On average, Croatians with a mental illness experienced the highest level of self-stigma (2.65), followed by Lithuanians (2.3), Maltese (2.25), Israelis and Romanians (both 2.02) respondents. Swedish participants with a psychiatric disorder suffered the least (1.62). Thus, the studied countries could be categorised according to their mean ISMI score as follows: first Croatia with the highest level of self-stigma (2.65), second Lithuania and Malta (2.25 and 2.3), third Israel and Romania (2.02) and Sweden (1.62). With regard to this classification it is expected that a grouping pursuant to the *stigma resistance* subscale would reflect this, as this scale is reverse-coded. However, the data did confirm this hypothesis partially. Countries with the lowest level of self-stigma, Israel (1.77), Romania and Sweden (both 1.86), revealed also the lowest *stigma resistance scale* and therefore yielded high stigma resistance. These are followed by Croatia (2.08), which showed the highest level of self-stigma. At last, countries with an average level of self-stigma showed the lowest *stigma resistance*, Lithuania (2.59) and Malta (3.02).

Concerning the remaining subscales of the ISMI, solely Croatia showed levels above the midpoint of 2.5 and therefore moderate self-stigma on average. Astonishing are the diverse levels of the subscales between the countries. With regard to all subscales in Croatia, Israel and Sweden the *discrimination experience* subscale yielded the highest level. In Lithuania, Malta and Romania the *alienation* subscale showed the highest level. This could indicate that the concept of self-stigma differs according to the culture or country.

Altogether, it is crucial to notice the widespread standard deviations in each country. This shows the broad range of levels of self-stigma in the studied nations and could be a sign of intra-country-differences.

Discussion

The primary aim of this paper was to describe and compare the levels of self-stigma and according subscales across six countries. Despite low mean scores in five countries, it can be suggested that various participants in each country reported moderate or even high levels of self-stigma. Furthermore, due to the fact that all respondents were members of a mental health charity organization they could feel more comfortable regarding their psychiatric disorder. Hence, the levels of both self-stigma and its' subscales could be higher in the total population of people with a mental illness.

In general, the results of this study indicate that the concept of self-stigma is context-dependent and the shares of the subscales contributing to the overall self-stigma vary considerably. This suggestion is in accordance with the concept of Corrigan and Watson (23), who emphasize that stigma is not inherent in the person but in a social context.

Therefore potential sources of self-stigma with regard to the context are addressed in the following section. First of all, the connection of public view, respectively social stigma, and self-stigma seems to be obvious at first sight. If a society keeps internalised negative beliefs, attitudes and behaviours towards people with a psychiatric disorder it is assumed that self-stigma of individuals with a mental illness is higher. However, a recently published study by Evans-Lacko et al. (29) does not support this suggestion. The authors found just one very weak, significant negative correlation between the country-level attitude 'Feeling comfortable when talking to someone with a mental health problem' with self-stigma ($r=0.03$; $p<0.0001$).

Additionally, public stigma can arise through the negative representation of mentally ill people in the media, which also varies across the studied countries (30).

Besides this, persons with psychiatric disorders perceive stigmatising attitudes and discrimination often via people with whom they are in regular contact. Usually these are family members, partners, friends, and certainly mental health care professionals. The last mentioned persons take a particular position, because of frequently, sometimes even daily contact with the mentally ill and their specific relationship to them as therapists, psychiatric nurses, or psychologists. Though essential initiators of social stigma, and therefore origin of self-stigma

Table 2: Mental health indicators ***[Sources: Health for All Database (33,34)]***

Country	Croatia	Israel	Lithuania	Malta	Romania	Sweden
Mental Health Index (2008)	56	*	58	53	54	67
Mental disorders incidence per 100,000 (HFA 2009)	*	65.21	267.17	103.38	1149.72	*
Number of psychiatrists per 100,000 (2008)	8	8.8	18	4	4.7	24
Share of the total health budget or expenditure (%)	*	6.1	9.0	6.0	3.0	10.0
Access to community-based early intervention (2008)	No	No	No	No	Yes	Yes

**** No information available***

Since this paper directs the question of cultural, respectively national differences in mental illness stigma health statistics can be beneficial. In general there is huge variation in the public health status across the nations measured, according to presented health indicators. This divergence is partly caused by diverse law regulations and health systems, but is additionally due to social and economic inequalities which affect the (mental) health status of citizens substantially. The European Quality of Life Survey (EQLS) used the WHO Mental Health Index to give an overview about the mental health status of European citizens. The Mental Health Index is the average of the answers to five statements about the participants' feelings in the last two weeks (34).

With regard to the studied countries it is evident that the Swedish seem to have the best mental health, and both Maltese and Romanian the worst. Unfortunately for Israel no index is available. This could indicate that in nations with overall happier and satisfied citizens, mentally ill people do not internalise stigma immediately. Further possible connections between the presented mental health indicators and self-stigma cannot be made, as for instance a higher number of psychiatrists or a higher share of the total health budget do not inevitably lead to lower levels of internalised stigma (Lithuania) or access to community-based early interventions (Romania).

These results indicate that a closer look at each country is needed to explore mental health care indicators and their effect on internalised stigma and therefore to understand the underlying processes of self-stigma. For instance in Lithuania the allocated mental health care budget is solely spend on the treatment by medical professionals, like general practitioners or psychiatrists, but not psychologists or social workers (35). And the fact that the expenditure on mental health care in Malta has decreased over the last years from about 10% of health budget in 2005 to 6% in 2008 (33,35). Or that all beds available for psychiatric care in Sweden are in general hospitals (36). And at least the fact that scarce rehabilitation and employment programs for Croatian with severe mental illness exist (37).

It is evident that these indicators are very specific and would lead to an in-depth analysis of each country. However, exploring cross-cultural differences probably requires an analysis from a different angle. Detailed explorations with regard to the interconnection of mental illness stigma and cultural dimensions are lacking. Nevertheless, concerning general mental health and the development of psychiatric disorders Papadopoulos states that *"the more individualistic or collectivist a particular culture is, the more likely it will be effective in explaining positive or negative mental health attitudes respectively."* (38).

Thus, going back to the definition of self-stigma, it is the *"co-occurrence of its components–labelling, stereotyping, separation, status loss, and discrimination–and [furthermore] for stigmatization to occur, power must be exercised."* (8). It is evident that power emerges in a specific situation and therefore the degree depends on the setting. Nonetheless, culture is a framework which defines the general power distance between members of each society.

Table 3: Dimensions of Culture ***(Source: reference no. 39)***

Country	Croatia	Israel	Lithuania	Malta	Romania	Sweden
Power Distance Index	73	13	42	56	90	31
Individualism Index	33	54	60	59	30	71

According to Hofstede one cultural dimension is 'Power Distance'. It is *"[t]he extent to which the less powerful members of institutions and organisations within a country expect and accept that power is distributed unequally."* (39). Thus, the higher the Power Distance the higher the acceptance of hierarchical relationships as natural, like in Romania. Vice versa, the lower the Power Distance the higher the emphasis on egalitarian values and decentralised power (39). Status differences within a society are defined by various specific values. These differ across cultures and countries and cannot be explored at this point. Nonetheless, two facts are noticeable. First of all participants from a country with a high Power Distance Index (Croatia, Malta and Romania) experienced a higher level of self-stigma, too. Furthermore, those nations revealed a higher level on the subscale *alienation*, too. Especially in Malta and Romania *alienation* showed the highest score among all subscales. This could be an indication that the degree of Power Distance existing in a culture influences the development of specific sublevels of self-stigma. Precisely, a high value level of Power Distance could be connected with a higher degree of *alienation*. This subscale comprises statements like "I am embarrassed or ashamed that I have a mental illness" or "I feel inferior to others who don't have a mental illness". This could be explained with the fact that in nations with a high Power Distance Index usually the underdog is blamed (39).

In addition to this, the Individualism Index is another cultural dimension, which expresses the degree of interdependence in a society. Generally in cultures, which score higher on the Individualism Index, each person is mainly responsible for her-/himself or for the own family. In a society with a high level of Individualism the independent sense of worth, including self-determination and self-efficacy is central. In more collectivistic countries the ties between individuals are strong and self-worth is dependent on the degree of complementing the goals of members of the in-group, usually the extended family (40). This dimension could partially explain that Swedish participants did report high *stigma resistance*, even though suffering mental illness and experiencing discrimination. This could be due to the fact that in Sweden the self-worth is largely independent from the public's opinion according to the high Individualism Index.

All in all, this paper focuses on the concept of explicit self-stigma of people with mental illness, but evidence suggests that implicit self-stigma is a distinct aspect of internalised stigma. Additionally, implicit self-stigma seems to be negatively associated with various outcome variables, like quality of life. Thus, solely simple questioning is not always sufficient to investigate whether patients with a mental illness experience stigma against themselves (41,42).

Conclusion

The aim of this paper was first of all recognising national disparities of self-stigma, and also giving a thought-provoking impulse about the divergence, which exists between countries and possibly within them, too. Overall these findings suggest that in each studied nation a certain amount of people with a psychiatric disease suffer internalised stigma.

It can be suggested that the concept of self-stigma, especially the diverse subscales, varies according to the country, respectively culture. Consequently, on the basis of the presented information there should be caution in implementing similar interventions across countries against stigma of mental illnesses. For instance, tackling discrimination against people with a mental illness is frequently supported as an intervention against internalised stigma. But, as the results of this study indicate, this strategy does probably not suit all patients across countries. The mean *discrimination experience* scores varied a lot. That is why a distinction between interventions directed at the public and those addressing people with a psychiatric disorder is essential.

Consequently, cultural specific analyses of all three concepts of stigma, which entails structural, public

and self-stigma (including implicit self-stigma), with regard to potential (health) effects could contribute essentially to the understanding of the concept of self-stigma and its predictors. Additionally, it needs to be examined whether psychometric limitations are present across countries.

Concluding, there is initial evidence that self-stigma acts and occurs on the basis of diverse mechanisms in different cultural settings and circumstances. At first sight it seems disillusioning that interventions against self-stigma should be adjusted to the country. But then exploring the divergence of (cultural) variations can offer further opportunities, learning from experiences among the countries and exchanging knowledge and information.

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