Original Research

Internalized Stigma of Mental Illness in Tehran, Iran

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Abstract

Purpose: There are an increasing number of studies on the subjective experience of stigma amongst mentally ill persons but still few coming from low- and middle-income countries, and very few from Muslim countries. The objective of this study was to look into the experience of internalized stigma in mentally ill persons in Tehran, Iran.

Methods: A total of 138 patients with an affective disorder or schizophrenia from three psychiatric institutions in Tehran responded to the Internalized Stigma of Mental Illness Scale. This is a 29-item self-report questionnaire with good psychometric properties. An open-ended question about personal experiences of discrimination was included at the end of the questionnaire.

Results: The experience of stigma because of mental illnesses was high in this Iranian sample. The level of stigma was similar to studies from Europe that used the same questionnaire.

Conclusion: This is the first study of self-perceived stigma in mentally ill persons in Iran. Stigma is a reality even in an Islamic setting in spite of the teachings of the Koran and a rather well-developed mental health service.

Implications: These results call for actions to reduce the experience of stigma in mentally ill persons in Iran.

Key words: Internalized stigma, Iran, Islam, mental illness, perceived discrimination

Introduction

Research on stigma has expanded dramatically over recent decades, both in the social sciences and in the psychiatric field (Byrne, 1997; Link & Phelan, 2001). One common approach has been to study attitudes of the general population towards the mentally ill and mental illnesses (Angermeyer & Dietrich, 2006). Most of these studies are from the Western industrialized world, but there are now also a number of studies from low- and middle-income countries, confirming the picture of mental illnesses as highly stigmatizing disorders (Thara & Srinivasan, 2000; Gureje, Lasebikan, Ephraim-Oluwanuga, Olley & Kola, 2005). The consequences of stigma associated with mental illnesses are also now well recognized, including loss of social status and self-esteem, delayed seeking of treatment and prolonged course of illness, to mention a few (Link, Struening, Neese-Todd, Asmussen & Phelan, 2001; Link & Phelan, 2006).

The issue of self-stigmatization is probably as important as that of stigmatization by others. There are a number of studies on the self-perception of people who experience a mental disorder. Few are from middle and low-income, or from non-Western cultures (Wahl, 1999; Schulze & Angermeyer, 2003; Corrigan, 2004; Botha, Koen & Niehaus, 2006; Corrigan, Larson & Rusch, 2009; Thornicroft, Brohan, Rose, Sartorius & Leeaw, 2010). In their review, Angermeyer and Dietrich (2006, p. 174) found that people from non-Western cultures *tend to attribute the cause of mental illness more frequently to the afflicted individual*. It is possible that discrimination against the mentally ill differs in an Islamic culture where mental illnesses and other ailments are, to some extent,

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considered to be due to the will of God, rather than evil forces, bad behaviour, or other personally devaluating factors. According to the holy Koran, people with a mental disorder should be treated with respect, and this might result in a less stigmatizing attitude. Such a perception of causality would also reasonably apply to the individual, and might be a factor that reduces self-blame. One must bear one's predicament and wait for the mercy of God! *Allah is your patron, and he is the best of helpers* (Bolhari, Nouri Ghassem Abadi & Ramezani Farani, 2002, p. 22).

There are a number of scales measuring the subjective experience of stigma and discrimination (Stuart, Koller & Milev, 2008) with the Internalized Stigma of Mental Illness Scale being one of the most comprehensive and recent (Ritsher, Otilingam & Grajales, 2003). The measure of internalized stigma developed by Ritsher and co-workers is based on the idea that stigma associated with illness is caused by the perception of a difference or deviance, which is negatively perceived not only by people and society around the person, but also by the person themselves. Internalized stigma is *the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself* (Ritsher *et al*., 2003, p. 32). This negative perception results in social isolation and, in more severe cases, marginalization and discrimination. The Internalized Stigma of Mental Illness Scale has been used in a number of studies (Ritsher & Phelan, 2003; Ritsher *et al*., 2003; Botha *et al*., 2006; Hwang, Lee, Han & Kwon, 2006; Ersoy & Varan, 2007; Lysaker, Roe & Yanos, 2007; Lysaker, Buck, Taylor & Roe, 2008; Brohan, Elgie, Sartorius & Thornicraft, 2010).

This study investigated the experience of internalized stigma in mentally ill persons in Tehran, Iran. A further aim was to examine the feasibility of using the Internalized Stigma of Mental Illness Scale by field testing it in an Iranian setting and describing its basic psychometric properties. This could not only contribute to our understanding of the role of culture and Islamic thinking in particular in the development of stigma, but could also establish stigma reduction as a treatment goal in addition to a reduction of symptoms.

Methods

Setting and Sample

The study was conducted in Tehran, Iran, an Islamic country with strict adherence to Islamic teaching. Tehran has around eight million inhabitants and greater Tehran almost 15 million. The great majority are Shia Muslims. Healthcare is well organized and covers all inhabitants. There are a number of mental hospitals and psychiatric clinics attached to general hospitals in the city. Mental health is also incorporated into the primary healthcare system (Yasamy *et al*., 2001).

We collected data on a convenience sample (n=138) recruited from outpatients and inpatients at the Psychiatric Institute of Tehran, which covers north and northwest Tehran, Navab Hospital, covering the suburbs of Tehran, and Razi Mental Hospital, covering southeast Tehran. The study was conducted in autumn/winter 2008. The patients had been diagnosed with depressive disorders, bipolar mood spectrum disorders, and schizophrenia spectrum disorders.

Eligible patients completed the questionnaire, after which the first author asked the open-ended question about personal experience of stigma and discrimination. Data were collected by the first author and a psychologist who guided the patients in understanding the questions and in some cases helped them respond to the questions. The interview was conducted in private in a separate room at the respective clinic. Patients who were not capable of responding to the questionnaire due to more severe illness were excluded.

The study was approved by the research ethics committee of the Medical School of the Iran University of Medical Sciences. Participation was voluntary and the study as a whole was conducted according to the principles of the Helsinki Declaration. Individual responses cannot be identified in the presentation of the results.

Measures

We used the Internalized Stigma of Mental Illness Scale (Ritsher *et al*., 2003), which was developed in close collaboration with members of the target population, people with personal or family histories of mental illness, groups of people with major psychiatric disabilities, and consumer organizations dealing with stigma. Twenty-nine items are grouped into five subscales reflecting, Alienation, Stereotype endorsement, Perceived discrimination, Social withdrawal, and Stigma resistance. The Alienation subscale, with six items, measures the subjective experience of being *less than a full member of society*. The Stereotype Endorsement subscale, with seven items, measures the degree to which respondents agreed with common stereotypes about people with a mental illness. The Discrimination Experience subscale, with five items, measures respondents' perceptions of the way they tend to be treated by others. The Social Withdrawal subscale, with six items, measures aspects of social withdrawal such as; I *don't talk about myself much because I don't want to burden others with my mental illness*. The Stigma Resistance Subscale, with five items, measures a person's ability to resist or be unaffected by internalized stigma. All items were measured on a 4-point Likert-type agreement scale (1 = strongly disagree to 4 = strongly agree). We also added an open-ended question at the end asking

about personal experience of discrimination due to mental illness.

We translated the scale into Farsi and back-translated it into English. This was done by psychologists and psychiatrists with a good knowledge of English. A pilot study with 30 individuals was conducted to determine the feasibility and reliability of the Farsi version of the Internalized Stigma of Mental Illness Scale. The internal consistency in the pilot test (Cronbach's alpha), was 0.87.

Table 1 presents the Cronbach's alpha values for the subscales for the current study, together with similar data from a Turkish and a European study (Ritsher *et al*., 2003; Ersoy & Varan, 2007; Brohan *et al*., 2010). The internal consistency for full scale was 0.91. All of the Farsi sub-scales performed above the 0.70 threshold.

Results

Table 2 presents socio-demographic data. The mean age was 30 years with a range of 17 to 60 years. The majority were male and the group as a whole had a high school educational diploma or higher. In spite of this, 79% were unemployed. Thirty percent of the males were employed, but only four of the 55 females were in work (not shown). Males were more often single (64%) than the females (45%) (not shown).

Prevalence of Internalized Stigma

Table 3 presents the item responses. With respect to the Alienation factor, more than half of the respondents agreed or strongly agreed with three of the six statements: *People without mental illness could not possible understand me*; *Having a mental illness has spoiled my life,* and *I am disappointed in myself for having a mental illness.* On the Stereotype endorsement factor, 40% or more agreed with two of the seven statements: *Because I have a mental illness, I need others to make most decisions for me* and *People with mental illness cannot live a good, rewarding life*. There was high endorsement for three additional statements: *Stereotypes about the mentally ill apply to me* (38%); *Mentally ill people tend to be violent* (38%), and *People can tell that I have a mental illness by the way I look* (34%). Items belonging to the Discrimination experience factor similarly showed a high prevalence of negative experiences. Seventy-two per cent of participants agreed or strongly agreed that *People discriminate against me because I have a mental illness*, and 50% agreed or strongly agreed that *People often patronize me, or treat me like a child just because I have a mental illness*. Respondents also reported considerable social withdrawal. More than 50% agreed or strongly agreed with the statements: *I don't talk about myself much because I don't want to burden others with my mental illness*, and *Negative stereotypes about mental illness keep me isolated from the normal world*. Over a third (37%) agreed or strongly agreed that *I avoid getting close to people who don't have a mental illness to avoid rejection*. However, the Stigma Resistance factor showed that respondents possessed considerable strength. For example, over half of respondents agreed or strongly agreed that *People with mental illness make important contributions to society* (51%) or *Living with mental illness has made me a tough survivor* (56%).

Table 2: Socio-demographic data (n = 138)

Characteristic	% (n)
Gender	
• Male	60% (83)
• Female	40% (55)
Marital Status	
• Ever married	43% (59)
• Single	57% (79)
Education	
• Less than high school diploma	28% (40)
• High school diploma or higher	72% (98)
Occupation	
• Employed	21% (29)
• Not employed	79% (109)
Diagnosis*	
• Depressive disorders	49% (67)
• Bipolar mood spectrum disorders	18% (24)
• Schizophrenia spectrum disorders	21% (29)

* missing diagnosis (n=17)

Table 1: Psychometric data for Internalized Stigma of Mental Illness Scale (Cronbach's alpha)

Subscales	Original English version n = 127	Turkish version n = 203	European version n = 1211	Farsi version n = 138
Alienation	0.84	0.79	0.84	0.81
Stereotype endorsement	0.71	0.72	0.72	0.77
Perceived discrimination	0.87	0.75	0.73	0.80
Social withdrawal	0.85	0.80	0.84	0.77
Stigma resistance	0.63	0.58	0.55	0.89

Experiences of Discrimination Described in the Open-ended question

Almost all participants (n=123) responded to the open-ended question. Responses indicated feelings of alienation, sharing stereotypes about the mentally ill, experiences of discrimination, social withdrawal, and resistance to being stigmatized and discriminated against. For example, responses included: *Yes, they discriminate against us; They don't count on us; Our society has no capacity for us; I mean there is no cultural understanding in our society; They ridicule, insult and harm us; I wish they could understand that psychiatric patients are like other patients, like patients with cancer or cardiac disease and that they can live their lives.* A recurring theme was the idea of the mentally ill as dangerous and aggressive: *They all believe a mentally ill patient is a natural born killer and that's why I try to keep myself to myself and not even claim what I'm entitled to; When the police came they were acting as if I was a criminal, but they ought to know that I'm a patient, not a criminal; Neighbours are scared of us.* Experiences of discrimination were reported by many: *When I am sick they discriminate against me; Thank God, nobody knows – if my family realized (that I am sick) they would abandon me because they think it is in the genes; I am a young girl, because I am sick my family thinks I'll be lucky if an old man agrees to marry me; People help a blind man across the street and in new cars there are options for the disabled, but nothing is provided for us.* Social withdrawal was exemplified by the following sentences: Nobody knows I am sick, and *nobody in my family knows that I have been admitted to hospital*. Resistance against stigma was illustrated by the following sentences: *I only got sick because I loved Imam Khomeni. I was fighting for him*, and *When I go and pray in the mosque, I feel better.*

Discussion

We studied 138 patients, predominantly males with higher education, in order to field test a Farsi version of the Internalized Stigma of Mental Illness Scale, originally developed by Ritsher & Phelan (2003), among patients recruited from psychiatric treatment settings in Tehran and its suburbs. All the participants were positive about the study. Many expressed their appreciation as the study gave them the opportunity, often for the first time, to talk openly about their experiences of living with a mental disorder. Many of them told their individual stories and almost all had comments on the open-ended question at the end of the investigation.

The Internalized Stigma of Mental Illness Scale had strong psychometric properties and appeared to be a useful instrument for measuring internalized stigma in this sample. With one exception, the concepts were easily understood by the patients. The item, *Living with mental illness has made me a tough survivor*, was difficult to translate and convey to subjects. The first author often had to explain further the idea behind this question.

Regarding the level of internalized stigma experienced by our subjects, if we use the midpoint of each item score as an indication of high stigma (on a scale of 1–4 points), 40% of respondents had an average score of 2.5 or above. Lysaker *et al*. (2007), who used the Internalized Stigma of Mental Illness Scale in a sample of people with schizophrenia in the United States suggested that a score of 2 or less could be labelled 'minimal stigma', scores greater than 2 but less than 2.5 could be labelled 'mild stigma', scores greater than 2.5 but less than 3 could be labelled 'moderate stigma', and scores greater than 3 could be labelled 'severe stigma'. In our case, this would mean that minimal stigma was reported by 40%, mild stigma by 21%, moderate stigma by 27% and severe stigma by 12%. This approach also suggests that approximately 40% of our patients experienced moderate or severe stigma.

Comparing our results to those of Brohan *et al*. (2010) (Table 4) who used the Internalized Stigma of Mental Illness Scale in 14 European countries, we note that the subjective experience of high stigma is similar in the two settings with approximately 40% of respondents reporting moderate-to-severe stigma. However, 40% of those in Tehran reported mild stigma compared to 23% in Europe. Similar results are reported in a South African study by Botha *et al*. (2006) with some important exceptions. For example, 60% of the respondents in the South African sample agreed that m*entally ill people tend to be violent*, compared to 37% in our study. In the South African sample 30% concurred that; I *am embarrassed or ashamed that I have a mental illness*, compared to 41% in our study. In the South African sample 24% agreed that *mentally ill people shouldn't get married*, while in our sample 31% agreed. Forty-three percent of the South African sample agreed that *I stay away from social situations in order to protect my family or friends from embarrassment* compared to 45% in our study. Finally, in the South African study 78% agreed that; *I can have a good and fulfilling life despite my mental illness* compared to 30% of the Iranian sample.

The comments to the open-ended question in our study were also illuminating. Many expressed a concern about being recognized as having a mental illness causing problems in their family. Many told that they tried to conceal the fact that they were mentally ill from their family and from those close to them in order to avoid problems for themselves, their relatives, and

Table 3: Responses to Internalized Stigma of Mental Illness Items (N = 138, except where otherwise noted)

	Strongly disagree (%)	Disagree (%)	Agree (%)	Strongly agree (%)
Alienation				
I feel out of place in the world because I have mental illness	42	23	22	13
Having a mental illness has spoiled my life	22	22	41	15
People without mental illness could not possibly understand me	15	30	36	19
I am embarrassed or ashamed that I have a mental illness	31	26	27	16
I am disappointed in myself for having a mental illness	28	20	36	16
I feel inferior to others who don't have mental illness	31	28	33	8
Stereotype endorsement				
Stereotypes about the mentally ill apply to me	29	33	26	12
People can tell that I have a mental illness by the way I look	28	38	28	6
Mentally ill people tend to be violent	26	36	29	9
Because I have a mental illness, I need others to make most decisions for me	25	24	37	14
People with mental illness cannot live a good, rewarding life	28	29	31	12
Mentally ill people shouldn't get married	31	36	24	9
I can't contribute anything to society because I have a mental illness*	30	36	28	6
Discrimination experience				
People discriminate against me because I have mental illness	20	27	41	12
Others think that I can't achieve much in life because I have a mental illness	20	36	35	9
People ignore me or take me less seriously just because I have a mental illness	28	29	30	13
People often patronize me, or treat me like a child, just because I have a mental illness*	26	23	35	16
Nobody would be interested in getting close to me because I have a mental illness	31	36	22	11
Social withdrawal				
I don't talk about myself much because I don't want to burden others with my mental illness	23	22	39	16
I don't socialize as much as I used to because my mental illness might make me look or behave "weird"	33	21	33	13
Negative stereotypes about mental illness keep me isolated from the "normal" world**	24	24	39	13
I stay away from social situations in order to protect my family or friends from embarrassment	29	25	34	12
Being around people who don't have a mental illness makes me feel out of place or inadequate	35	29	25	11
I avoid getting close to people who don't have a mental illness to avoid rejection	30	32	25	13
Stigma resistance (reverse-coded items)				
I feel comfortable being seen in public with an obviously mentally ill person	5	31	35	29
In general, I am able to live my life the way I want to	24	45	25	6
I can have a good, fulfilling life, despite my mental illness	26	44	20	10
People with mental illness make important contributions to society	10	38	39	13
Living with mental illness has made me a tough survivor	13	30	40	17

* n=137; **n=134

those near to them. Another issue was the feeling that mentally ill people are considered violent and dangerous—a recurring theme in studies of perceptions of the mentally ill worldwide. Their willingness to talk about their situation strongly suggests that further qualitative studies would be of great interest to enable us to find out more about how people view mental illness and the mentally ill, and the consequences for those with a mental illness.

Over the last decade, the World Health Organization and the World Psychiatric Association have been working to reduce the stigma of mental illness, and improve mental health literacy including in low-

Table 4: Comparison of Internalized Stigma of Mental Illness subscales in Tehran and Europe

ISMI subscales mean (SD)	Tehran (n = 138)	Europe (n = 1211)*
Subscale means (SD)		
• Alienation	2.33 (0.73)	2.53 (0.70)
• Stereotype endorsement	2.30 (0.60)	2.19 (0.53)
• Discrimination	2.32 (0.67)	2.43 (0.61)
• Social withdrawal	2.64 (0.83)	2.48 (0.66)
• Resistance	2.46 (0.39)	2.47 (0.51)
Level of stigma (%)		
• Minimal (<2)	40%	23.0%
• Mild (2–2.49)	21%	34.0%
• Moderate (2.5–3)	27%	29.4%
• Severe (>3)	12%	12.3%

* Data from Brohan *et al*. (2010)

income countries and traditional societies (Sartorius & Schultze, 2005). One way is to inform the public about mental illness, its causes, and the possibilities of receiving effective treatment. In many countries there have also been anti-stigma campaigns dealing with mental illness. Probably the most important way to reduce stigma is to improve the treatment and care of the mentally ill. Another interesting and promising route would be to improve the ability of those with mental illness to cope with stigma. This could be an important tool for clinicians working with the mentally ill (Corrigan, 2002).

Although research suggests that traditional societies are less stigmatizing and discriminatory towards the mentally ill, stigma is found even in such societies, as has been shown in a number of studies (Thornicroft *et al*., 2009). However, there are clear differences regarding stereotypes, prejudices, and resulting discrimination. In a recent study of the perception of stigma among family members of individuals with schizophrenia and major affective disorders in rural Ethiopia, for example, only a small proportion *felt that somehow it might be their fault* that their family member had become sick (with 4.5% endorsement)—a figure that is low in comparison with those reported in the Western world (Shibre *et al*., 2001).

Limitations of the Study

The study sample was recruited from Tehran, where people are knowledgeable about different kinds of mental disorders. There are many treatment possibilities and our sample is relatively highly educated. The question is the extent to which this group is representative for all mentally ill persons in Tehran, not to say the whole of Iran. We believe that the patients in our study are quite representative of persons with a relatively severe mental disorder requiring hospitalization; however, there were also patients attending outpatient clinics. The most severe cases were excluded because of problems in communication. It would of course be of interest to study other ethnic groups in Iran as well as people living in rural areas, where the availability of effective treatments and possibly also the value system and the level of knowledge differ.

Regarding data collection, the first author and a psychologist were present when the patient responded to the questions in the questionnaire and sometimes helped the patient to respond. This might have influenced the responses of the patients in some way; however, overall we believe the presence of the investigators was helpful and did not direct the patients to answer in one way or another.

Conclusion

Stigma and discrimination experienced by mentally ill patients in Tehran was high and, as in other countries, should be taken seriously. Further qualitative studies would be of value to better understand how those with mental illnesses perceive themselves and their illness, what kind of reactions they encounter, and how they are treated. The importance of Islamic thinking would also be of interest for further to study. The establishment and empowerment of user organizations is important as well as increasing the awareness of the problem of stigma in professional groups working with the mentally ill.

Acknowledgements

The authors are grateful for the support of Professor Joghatai and Dr Malakuti at the Iran University of Medical Sciences, Tehran, Iran.

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