



The stigma of severe mental illness: Beliefs and experiences of Tunisian patients

Le stigma de la maladie mentale sévère : opinions et expériences des patients tunisiens

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RÉSUMÉ

Introduction : La stigmatisation des patients ayant un trouble mental est un phénomène mondial, qui peut entraver l'accès aux soins et l'adhérence au traitement, et contribuer à une diminution de l'estime de soi et à une moindre qualité de vie. Le but de la présente étude était d'évaluer la stigmatisation et la discrimination telles que perçues par les patients avec une maladie mentale sévère en Tunisie.

Méthodologie : Il s'agit d'une étude transversale, descriptive, menée à la consultation du service de Psychiatrie A de l'Hôpital Razi à La Manouba. Nous avons inclus les patients cliniquement stabilisés ayant un diagnostic de trouble bipolaire ou de schizophrénie. Les patients ont répondu à un questionnaire contenant des données socio-démographiques et 31 affirmations sur le stigma lié à la maladie mentale.

Résultats : L'échantillon comporte 105 patients avec un âge moyen de 38,3 ans. Les perceptions ou expériences étaient plutôt négatives dans 19 des 31 affirmations, surtout dans les domaines du stigma perçu et « approuvé ». Les participants de l'étude ont exprimé de l'appréhension quant à la divulgation de la maladie mentale, surtout par peur pour la réputation de la famille et les opportunités professionnelles, toutefois, une grande majorité des patients a divulgué sa maladie à son environnement social.

Conclusions : Des campagnes pour améliorer l'image du patient psychiatrique au sein de la population générale, mais aussi des approches centrées sur le patient – les deux adaptées au contexte culturel tunisien – sont nécessaires afin de diminuer le stigma perçu et « approuvé » dans ce groupe de population particulièrement vulnérable.

Mots-clés : stigma, discrimination, schizophrénie, trouble bipolaire

SUMMARY

Background: Stigmatization of patients with mental illness is a worldwide phenomenon which can jeopardize help seeking and treatment adherence and contribute to low self-esteem and quality of life. The aim of our study was to assess stigmatization as perceived and experienced by patients with severe mental illness in Tunisia.

Methods: This is a cross-sectional descriptive study conducted at Razi Hospital La Manouba, Tunisia in clinically stabilized patients with bipolar disorder and schizophrenia followed at our outpatient clinic. Patients gave their opinion on a total of 31 statements related to stigma relevant to the Tunisian cultural context.

Results: The study sample consisted of 105 patients with an average age of 38.3 years and a sex ratio of 1.5. Negative perceptions or experiences prevailed in 19 out of 31 statements, mostly referring to received and endorsed stigma. Study participants expressed apprehension about disclosure of mental illness, mainly due to fears about family reputation and job opportunities, however, a large majority actually disclosed their mental illness to their surroundings. Male participants had less positive opinions than women regarding former mental patients becoming teachers and experienced more stigma than women in the professional field.

Conclusions: Besides actions towards public attitudes, patient-centered approaches, both tailored to the Tunisian cultural context, are necessary to raise awareness of the public and to reduce endorsed stigma in this vulnerable group of the population.

Keywords: Stigma; discrimination; schizophrenia; bipolar disorder

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INTRODUCTION

Stigma can be defined as a specific attribute that tends to “label” and devalue the person as a whole (1). Corrigan and Watson define two broad categories of stigma: public stigma and self-stigma (2). Public stigma is the reaction that the general population shows towards people with this specific attribute. Numerous social groups or illness categories are subject to prejudice and discrimination due to public stigma; however, one of the most persistent and pervasive stigmas is the one related to mental illness. Indeed, the public stigmatizing beliefs can be internalized and lead to negative and self-defeating beliefs and attitudes about the self (self-stigma). It prevents people with mental illness (PWMI) from seeking help from mental health professionals, pursuing education, seeking employment or making friendships, contributing to lowered self-esteem and quality of life (3-5). The use of case-vignettes about mental illness categorizing specific diagnoses and problems revealed that stigmatizing responses increased according to a gradient from “troubled person” to “depression” to “schizophrenia” to “drug dependence” (6-8), indicating that people with severe mental illness such as schizophrenia or bipolar disorders are more stigmatized than people with common mental disorders.

A systematic review about mental illness-related beliefs and attitudes in the general population published before March 2011, elucidated two major trends: there was a coherent tendency to greater mental health knowledge and adoption of a biological model of mental illness, and greater acceptance and seeking of mental health professional help. In contrast, attitudes towards people with mental illness did not change or even changed to the worse (9).

However, most of the studies about the stigma of mental illness have been conducted in Western countries. A review of all population-based studies (n=61) on beliefs and attitudes about mental illness published between 1990 and 2004 found only six studies from Eastern countries, one study from Africa and no study from Middle East North Africa (10). Even up to now, studies on the stigma of mental illness in the Arab world are scarce compared to the number of studies conducted in Western societies. A systematic review of stigma associated with mental illness and its treatment in the Arab culture, published in 2018, retrieved a total of only 33 studies (11).

Two studies conducted in Tunisia, one in the general population and one in family members of patients with schizophrenia found that schizophrenia or psychosis was associated with the connotation of dangerousness, violence and unpredictability (12, 13). A comparative study conducted in Germany and Tunisia showed however, that Tunisian respondents had more prosocial reactions and less fear than their German counterparts regarding patients with schizophrenia (14). Indeed, stigma operates in different ways from culture to culture and what might have been considered as a ‘universal’ pathway in Western societies might not apply to Arab cultures (15). Besides, most research on stigma focused on public perceptions and did not take into account how patients themselves manage these perceptions and attitudes about their illness (10). Our study aims to fill this gap by assessing the phenomenon of stigma in Tunisian society as perceived and experienced by patients with severe mental illness.

METHODS

Study design and Participants

We conducted a cross-sectional descriptive study at Department Psychiatry A of Razi Hospital from April 2010 to January 2011. We included all patients that consulted at our outpatient clinic and fulfilled the following inclusion criteria: age ≥ 18 years, DSM IV diagnosis of Bipolar Disorder type I or Schizophrenia, clinically stable and no inpatient admission for at least 3 months. Patients with major cognitive decline or mental retardation, which did not allow them to understand the questions, were excluded.

Measures

The different aspects of Self-stigma were assessed with the help of a self-established questionnaire developed for the purpose of this study and relevant to the Tunisian cultural context. The main reason for developing our own assessment was the intention of the authors to capture all the cultural and social experience of the patient as closely as possible. The assessment is comprised of 31 items scored on a 4-point Likert scale. Twenty-seven items originate from existing scales on mental illness stigma, and items were either taken in their original form or were slightly modified. Items 1 – 10 originate from Corrigan’s Self

Stigma of Mental Illness Scale (5), items 11-13, 21, 22, 24, and 25 from Link's Devaluation- Discrimination Scale (16), and items 15-20 and 27-30 from Ritsher's Internalized Stigma of Mental Illness Scale (17). From Corrigan's scale, we chose the items that represented an agreement with common stereotypes about people with mental illness also prevalent in Tunisian culture. From Link's scale, we extracted items referring to perception or anticipation of acceptance of PWMI in different societal roles. Finally, from Ritsher's scale, we selected items corresponding to actually experienced stigma and endorsed stereotypes. Four items were newly created: « Most men/women wouldn't marry a PWMI »; « It is better to hide my mental illness in order to protect the reputation of my family »; « When I plan to engage, I explain my mental illness to my future spouse », and « Because of my mental illness, I can't find or keep a regular job ». These items were obtained after conducting qualitative interviews with 10 patients with severe mental illness which yielded themes related to the importance of family and the role in society.

All of the 31 items were clustered into the four different types of self-stigma **as indicated hereafter**: (i) Perceived stigma represents agreement with a statement that prejudice and discrimination exist towards a labeled group (18) (ii) Endorsed stigma occurs when the labeled individuals adopt this statement as being their own characteristic or attribute. (iii) Anticipated stigma refers to patients' expectations that others will discriminate against them. (iv) Received stigma inquires about the discrimination experienced by the patients (18).

All items selected from the different scales were translated into Tunisian Arabic with the help of a bilingual (Tunisian-Arabic/English) translator. We then tested the newly created assessment with six patients of the target population to identify any problematic or unclear terms. The translation was then finalized with the help of a team of linguists and psychiatrists using the input of the test-phase.

All 31 statements were classified into categories of experiential variants (table 1), and respondents indicated to what extent they were agreeing or disagreeing with the statement ("1" meaning "Totally agree", "2" meaning "Rather agree", "3" meaning "Rather disagree" and "4" meaning "Totally disagree"). A score of "2.5" represented a shift from a negative perception to a positive one for the

negative statements, and "2.5" represented a shift from a positive to a negative perception for positive statements. We then calculated the mean score of the sample for each statement.

Table 1. Socio-demographic and clinical data of study participants

Variables		N=105		%
Socio-demographic data	Age (years old)		38.3 (18-74)	
	Sex	Male	63	60%
		Female	42	40%
	Level of education	Illiterate	2	1.9%
		Primary	23	21.9%
		Secondary/professional	51	48.6%
		Baccalaureate	7	6.7%
		University	15	14.3%
	Marital status	Single	73	69.5%
		Married	5	4.8%
		Divorced	22	21%
		Widowed	4	3.8%
	Current Professional status	Employed	36	34.3%
		Unemployed	69	65.7%
Clinical data	Diagnosis	Bipolar disorder	51	48.6%
		Schizophrenia	54	51.4%
	Mean onset age of the disease		25.2 (14-53) years	

Procedure

After obtaining oral informed consent from each study participant, three trained researchers, authors of the study, conducted face to face interviews which lasted an average of 45 minutes per patient. First, socio-demographic and clinical data were collected. Patients were asked who knew about their mental illness among the family (parents, siblings, children), social (neighbors, friends) and the professional networks (colleagues and employers). Patients then gave their opinion on the 31 statements related to stigma. Information concerning clinical data was completed through patients' files.

Statistical analysis

Statistical analysis was performed using the Statistical Package for the Social Sciences in its 22th version. We calculated simple frequencies and relative frequencies (percentages) for qualitative variables (sex, level of education, marital status, diagnosis and disclosure of the diagnosis). We calculated means and standard deviations for the quantitative variables (age, means of statements). Analyses of differences in overall scores according to sex and diagnosis were made using the Student's t test.

RESULTS

The study sample consisted of 105 patients, with an average age of 38.3 years and a sex ratio of 1.5. Socio demographic and clinical characteristics are presented in table 1.

PWMI's perceptions and experiences concerning different aspects of stigma are presented in table 2. Negative perceptions or experiences prevailed in 19/31 statements, whereas in 12/31 statements, positive perceptions prevailed. All four items of the "received stigma" category were negatively scored suggesting that stigmatizing experiences were frequent in our patient sample. On the other hand, in the perceived stigma category, only 8 / 15 category items were scored negatively by study participants.

We found that male participants had less positive opinions than women regarding PWMI becoming teachers and experienced more stigma than women in the professional field (table 3). No differences were found between statements according to the clinical diagnosis.

Most patients disclosed their illness to their families, friends, neighbors and colleagues but not to their employers, as is shown in table 4.

Table 2. Perceptions and experiences with different aspects of stigma

Perceptions and experiences	N	Means	Ecart type	Valence*
1) Most of the PWMI are responsible for their problems	103	2.57	1.249	+
2) Most of the PWMI can't get or maintain a regular job	104	2.23	1.209	-
3) Most of the PWMI are unpredictable	104	2.52	1.061	+
4) Most of the PWMI are dirty and neglect their appearance	104	2.44	1.197	-
5) Most of the PWMI do not improve or heal	104	2.36	1.190	-
6) One cannot trust most of the PWMI	104	2.58	1.244	+
7) Most of the PWMI have an intelligence below average	104	2.46	1.206	-
8) Most of the PWMI are horrible	104	2.58	1.259	+
9) Most of the PWMI are dangerous	103	2.42	1.225	-
10) Most of the PWMI can't take care of themselves	104	2.27	1.108	-
11) Most people have no objection that PWMI become teachers	104	2.17	1.186	+
12) Most people wouldn't ask a PWMI to keep their children, even though he's been well for a long time	104	2.57	1.221	+
13) Most employers would happily hire a former PWMI if he/she has the qualifications for the position	104	2.11	1.033	+
14) Most men/women wouldn't marry a PWMI	104	2.49	1.106	-
15) PWMI can contribute important things to society	104	1.59	1.832	+
16) I am ashamed because of my mental illness	104	2.16	1.278	-
17) I feel inferior to others because of my mental illness	104	2.24	1.311	-
18) In general, I can live suitably despite my mental illness	103	1.87	1.082	+
19) People can recognize that I have a mental illness by my appearance	103	2.14	1.205	-
20) Because of my mental illness, others have to decide for me most of the time	103	2.33	1.263	-
21) A former psychiatric inpatient must hide the story of his hospitalization in order to find a job.	103	2.26	1.188	-
22) There is no reason to hide the fact of being a psychiatric patient	103	2.10	1.089	+
23) It's better to hide my mental illness to protect the reputation of my family	103	2.26	1.188	-
24) I sympathize more easily with patients that used to be PWMI	103	2.34	1.209	-
25) I avoid people that hold negative opinions about PWMI	102	2.62	1.275	+
26) When I plan to engage, I explain my mental illness to my future husband/wife	103	1.70	1.092	+
27) I frequent people less than before because my mental illness makes me seem strange/ makes my behavior seem strange.	103	2.21	1.234	-
28) Others think that I can't succeed in life because I have a mental illness	103	2.26	1.220	-
29) Some people ignore me or take me less seriously because I have a mental illness	103	2.31	1.245	-
30) People often patronize me or treat me like a child because of my mental illness	102	2.37	1.258	-
31) Because of my mental illness, I can't find or keep a regular job	103	2.11	1.196	-

(+) equals positive valence; (-) equals negative valence

Table 3. Participants' opinions and experiences in the professional field

	Male	Female	p
Most people have no objection that PWMI become teachers	2.40	1.83	0.012
Because of my mental illness, I can't find or keep a regular job	1.92	2.39	0.050

Table 4: Disclosure/ knowledge of the mental illness in the different social networks of the patient

Knowledge of patient's mental illness		
	%	n*
Partner	82.3%	28
Parents	98%	96
Siblings	99%	102
Children	59.2%	16
Neighbors	77.5%	79
Friends	79.2%	80
Work colleagues	66.6%	44
Employers	48.2%	28

*n differs according to the different networks because of non-applicable items

DISCUSSION

Our first important finding was the high number of study participants that reported negative perceptions and experiences related to their mental illness, mainly concerning aspects of endorsed and received stigma. However, the second important finding was the consistent number of more positive perceptions and attitudes, especially items related to perceived stigma and items related to disclosure of mental illness.

Negative perceptions were expressed by the participants about the ability of PWMI to get or maintain a job, to improve or to take care of themselves. Respondents tended also to see PWMI as dirty and dangerous but neither unpredictable nor horrible nor responsible for their illness. However, patients' perceptions of perceived stigma may not reflect the public's ones. A previous study by Angermeyer et al (10) comparing public beliefs and attitudes about patients

with schizophrenia in Tunisia and Germany found that expectations that the person with schizophrenia under treatment will completely recover and will be able to lead a normal life was more prevalent among individuals from Tunisia. There was a stronger trend among Tunisian respondents to hold the PWMI responsible for the onset of the disorder as well as the ability to pull himself together to recover again. The stereotype of unpredictability was more adopted by Tunisian respondents, who at the same time were more frequently opposed to considering people with schizophrenia as dangerous (10).

Positive perceptions towards statements related to the desire of social distance from PWMI were endorsed by our sample as to the acceptance that PWMI become teachers, keep their children or be hired if qualified except for the engagement in intimate relationships. This was partly in accordance with Tunisian public beliefs related to "social rejection" which increased according to a gradient from "distant relationships" (work together, have as a neighbor) to "intimate relationships" (have marry into family, let take care of little children) (10). A study by Coker et al in 2005 found that 85.5% of the participants would not accept a psychotic person as a school teacher and 56.6% would not accept him as a family member (19).

Arab societies seem different from Western societies in the way that, far from being threatened by the potential danger of PWMI, persons from Arab culture seem more concerned about their ability to fulfill their social responsibilities of family protection and well-being which reflects their moral worth and their role in the society dynamics (19). On the other hand, denying PWMI the right to marry into family may be the source of more social exclusion. This may lead to feelings of worthlessness in a culture where family is the keystone of one's 'personhood' as expressed by more negative answers to the statement "PWMI can contribute important things to society".

All four statements of the "received stigma" section were negatively rated by study participants. This denotes of an important rate of over discrimination towards PWMI in our sample in terms of patronizing attitudes, doubt in their ability to succeed and the credibility of their words. The fact of being taken less seriously, being ignored, belittled or patronized, especially by family members, is something that not only appears through our results, but is often noted during our clinical work with patients with severe mental

illness. A qualitative study based on narrative interviews of 46 PWMI found that experiences of overt discrimination (physical violence, verbal abuse, loss of contact with people) were largely targeted at people with psychosis and drug addiction whereas patronizing attitudes from family, friends and work colleagues were more confined to people with depression, anxiety and personality disorders (20). We could not study the influence of diagnosis on the importance of experienced stigma as our sample was exclusively composed of patients with psychosis. Even though we were expecting that stigma would affect more patients with schizophrenia than bipolar disorder in our sample, no significant differences were found between the two groups. One of the reasons might be that all study participants had severe forms of their mental illness with most of the patients with bipolar disorder having had psychotic features during their mood episodes.

In the literature, experiencing stigma was associated with greater internalized stigma by the endorsement of stereotypes by PWMI (21). Endorsing common stereotypes about PWMI as dangerous, unpredictable, defective or weak results in diminished self-esteem (22). This was illustrated in our study by the results of the “endorsed stigma” section. Indeed, four out of the five statements in the “endorsed stigma” section were scored negatively, reflecting an interiorization of negative beliefs about mental illness: participants felt ashamed, inferior, different in their appearance, and unable to take decisions for themselves. On the other hand, participants strongly expressed that they were still able to live their life suitably, despite their mental illness.

Some studies have shown that endorsed stigma occurs when, after experiencing discrimination, PWMI start to anticipate more stigma (23). Anticipated stigma leads to isolation and social withdrawal as was expressed by the majority of our patients in the statements “I frequent people less than before because my mental illness makes me seem strange” and also “I sympathize more easily with patients that used to be PWMI”. It also leads to concealment of the diagnosis and the rejection of treatment and can be a powerful source of anxiety (24). Surprisingly, for the participants of our study, disclosing their mental illness was less an issue when it came to their own image but did become a concern when their families where at risk of courtesy stigma or when their professional life was threatened, as shown by the statements: “It’s

better to hide my mental illness to protect the reputation of my family.” and “A former psychiatric inpatient must hide the story of his hospitalization in order to find a job”. This may reveal again that it is not mental or behavioral disorder per se that is responsible of stigma in Tunisia, but the interpretation of the illness in terms of one’s ability to fulfill certain duties. PWMI are more at risk of stigma if they fail their social responsibilities and financial duties towards family than because of the preconceived ideas of “mental health” itself. This may explain why male participants, still considered the main provider for the family in Tunisia, expressed a more negative perception of experienced stigma in the professional field. In addition, the sense of belonging to the family is important so that Individuals would fear bringing shame and discredit to their families more than to their own person. As long as PWMI are maintained within the realm of family, social interactions are preserved and associated stigma is reduced (19).

Most of the participants in our sample expressed concerns about a possible disclosure of a history of admission as psychiatric inpatients. In fact, Razi Hospital is the only hospital specifically dedicated to the treatment of mental illness in Tunisia, and admission is still associated with the “madness label” in the majority of Tunisian society. Studies have shown that such institutions are rather seen as places for the society’s “unwanted” and “dangerous” than for treatment (25). Anticipated stigma may be especially impactful among individuals with less severe mental illness that are experiencing less discrimination but may remain vulnerable to endorsed stigma.

A third interesting finding was the high percentage of study participants that actually disclosed their mental illness to their surroundings. Indeed, a large majority of patients reported disclosing their illness to family, friends, and neighbors. This contrasts with the apprehension to disclose the mental illness which most of study participants expressed at the same time through the statement: “It’s better to hide my mental illness to protect the reputation of my family”. Indeed, PWMI often face the dilemma of whether to disclose or conceal their diagnosis. This can be a problem in Arab Muslim countries, where family relationships are often closer and therefore MI stigma can easily shift from the patient to the entire family. Family members are thus frequently affected by ‘associative’ stigma and therefore wish to conceal the illness (26). An interesting finding was the high percentage

of neighbors that knew about the mental illness of the study participants. This could be explained by the fact, that people in Tunisia maintain often very close social ties within their neighborhood, which is still, more than in Western societies, a source of social cohesion and solidarity. Also, given the severity of the mental disorders of the study participants, symptoms could have been more difficult to conceal.

In our study, disclosure was least likely in the workplace: Whereas about two thirds of colleagues knew about the mental illness, a little less than half of employers knew about the mental illness of the study participant. This is comprehensible given that, according to a recent review, 54% of employers would never/occasionally employ someone who was currently depressed, and 66% would occasionally/never employ someone with schizophrenia (27). Interestingly, a study in supported employment showed that those who had a mood disorder were significantly less likely to disclose than those with schizophrenia. This might be linked to another finding of the same study: those who displayed no symptoms at work were significantly less likely to have disclosed their illness (28). However, a consistent part of people with severe mental illness in Tunisia can only find an employment in the informal sector or in small, family-run businesses (run by their own family), as supported employment schemes are nonexistent.

Our study has the following strengths and limitations: This study brings a new perspective on mental illness stigma as it investigates the patients' personal beliefs and experiences of stigma related to their mental illness. To our knowledge, this is the first study in Tunisia aimed at assessing stigma in patients with severe mental illness, with a cultural context applied. However, the instrument for the assessment of stigma has been developed empirically and is neither validated nor replicated in other studies allowing comparisons. Furthermore, the study sample is a hospital sample; therefore, the extent of stigma might have been over-estimated and cannot be extrapolated to all patients with severe mental illness. In the future, it would be interesting to conduct an in-depth qualitative study to further explore these perceptions and experiences. It would also be necessary to conduct studies on this subject with a more elaborated approach, in a larger sample, and including patients with different types of mental disorders. The aim is to gain more insight into the different aspects

of stigma and how they translate into daily life by taking into consideration the local culture. This would help in the development of stigma interventions for patients and the general population which are tailored to the Tunisian cultural context.

CONCLUSION

This study aimed at giving a first comprehensive assessment of the stigma of severe mental illness from a patient's perspective, with a cultural context applied. Patients reported a significant amount of received stigma, mainly being ignored, being taken less seriously, or being patronized by their surroundings. Our results also showed an interiorization of negative beliefs about mental illness translating into shame, feelings of inferiority, or lack of empowerment. Study participants expressed apprehension about disclosure of mental illness, mainly due to fears about family reputation and job opportunities, however, a large majority actually disclosed their mental illness to their surroundings. Anti-stigma campaigns are still lacking in the country, and no association standing for PWMI's rights exists so far in Tunisia. Besides actions towards public attitudes, patient-centered-approaches, both tailored to the Tunisian cultural context, are necessary to raise awareness of the public and to reduce endorsed stigma in this vulnerable group of the population.

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