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ORIGINAL PAPER

Aygun Ertugrul · Berna Uluğ

Perception of stigma among patients with schizophrenia

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Abstract *Background* Many individuals with schizophrenia are stigmatized by society. It is necessary to understand the factors contributing to stigma. This study investigated the relation of symptoms and other patient characteristics with perceived stigmatization in patients with schizophrenia. *Method* Sixty patients with schizophrenia were included in the study. Symptomatology was assessed with the Positive and Negative Syndrome Scale. Perceived stigmatization was measured by several questions which were included in the World Health Organization-Disability Assessment Schedule-II (WHO-DAS-II). Patients were grouped as positive or negative for perceived stigmatization. Characteristics of patients and severity of symptoms were compared between the two groups. *Results* The results showed that patients who reported to perceive stigmatization had more severe symptoms than the patients who did not perceive stigmatization. Positive symptoms and general psychopathology scores were significantly higher in the group perceiving stigmatization. Patients reporting stigmatization were significantly more disabled than the group negative for perceived stigmatization. Demographic variables were not different between the two groups. Stepwise regression analysis showed that depression and active social avoidance were the items which could predict the perception of stigmatization. *Conclusion* The relation between perception of stigmatization and symptoms is a vicious circle in which the elements reinforce each other. Interruption of this circle will increase the adaptive abilities and decrease the disability of these patients.

Key words schizophrenia – symptoms – stigmatization – disability

A. Ertugrul, M. D. · B. Uluğ, M. D., M. P. H.
Dept. of Psychiatry
Hacettepe University School of Medicine
Ankara, Turkey

A. Ertugrul, M. D. (✉) · B. Uluğ, M. D., M. P. H.
Hacettepe Üniv. Tıp Fak.
Psikiyatri Bl.
06100 Sıhhiye, Ankara, Turkey
Tel.: +90-312/3051873
Fax: +90-312/3101938
E-Mail: aygune@hotmail.com

Introduction

Many studies have shown that stigmatizing attitudes towards people with mental illness, such as schizophrenia, are widespread (Link et al. 1997; Jorm et al. 1999). Torrey (1995) has stated that schizophrenia is the modern-day equivalent of leprosy. The public tends to overemphasize social handicaps among the mentally ill, contributing to further social isolation and distress among sufferers (Crisp et al. 2000).

Stigmatization results in a number of negative consequences, such as reduced employability (Link et al. 1992) and difficulties in obtaining housing (Page 1995). It has important implications for the integration of the person with schizophrenia into the community. An important goal in mental health research and policy is to determine ways to reduce stigma. To achieve this goal, it is necessary to understand the factors which contribute to stigma.

One of these factors is the societal impression that persons with schizophrenia are dangerous (Thompson et al. 2002) and the labels used to describe mental illness (Ohaeri and Fido 2001) are a further factor. However, these factors alone do not account for stigma. Patients with more severe symptoms may be more likely to experience mental illness stigma. Studies indicate that persons with mental illness who have conspicious symptoms and poorer social skills engender more negative responses from others (Farina 1998). Symptoms such as disorganized behavior and flat affect may scare others and reinforce the fear of mental illness. In Penn et al.'s study (2000), negative, but not positive, symptoms had a fairly robust relationship with social distance, which was used as a measure of stigmatization. In a recent study,

Dickerson et al. (2002) reported that, contrary to their expectation, symptoms or social functioning measures were not related to the extent of stigma and discrimination experience. They found that 'perceived adequacy of current finances' was the only patient characteristic related to the extent of stigma.

Scambler and Hopkins (1986, 1989) studied the stigmatization in patients with epilepsy and suggested the 'hidden stress model' which relied on the distinction between 'enacted' and 'felt' stigma. The former referred to actual discrimination against individuals with epilepsy solely on the grounds of their social unacceptability and inferiority, while felt stigma referred both to the shame that many people with epilepsy felt and, most significantly for the hidden stress model, to the fear of encountering stigma. They also reported that nine out of every ten people they had interviewed admitted to suffering from felt stigma, while only a third could recall having encountered enacted stigma in any of their roles or life activities. They concluded that felt stigma, and particularly the fear of enacted stigma, has a more disruptive effect on people's biographies than enacted stigma.

Link et al. (1987, 1989) also argued that because persons with mental illness internalize the devaluing or discriminatory attitudes of society at large, they anticipate discrimination or rejection by others and develop coping strategies, such as secrecy about the illness or withdrawal from social interaction, in an effort to avoid the rejection they anticipate. The adoption of coping strategies that reduce the stigmatized person's range of social contacts, like withdrawal, may, in fact, further handicap social adaptation and delay recovery.

Stigmatization is present in both western and eastern societies (Angermeyer and Matschinger 1997; Chou and Mak 1998). In a WHO-NIH joint project, in which the cross-cultural views on stigma, valuation, parity and societal values towards different health conditions were studied, chronic mental disorder was found to be the eighth most stigmatized condition among 18 health conditions according to the results of 16 countries. It was stigmatized less than conditions like HIV positivity and drug addiction, but more than conditions like depression, dementia or being wheelchair-bound (Room et al. 2001). Considerable variability was reported between countries; it was the second most stigmatized condition after drug addiction in Japan, while it was the tenth among 18 health conditions in Turkey.

In developing countries like Turkey, prognosis of schizophrenic patients is known to be better due to more handling of patients in the family and less institutionalization. This allows schizophrenic patients to have more chance of having contact with society. In this study, our aim is to see the relation between perceived stigmatization and symptoms in schizophrenic patients in our culture.

Subjects and methods

Subjects

The sample comprised 60 patients with DSM-IV diagnosis of schizophrenia who were being followed in the outpatient clinic of the Department of Psychiatry in Hacettepe University Faculty of Medicine. Twenty-eight (46.7%) of them were female, 32 of them were male (53.3%) and the mean age of the patients was 34.4 ± 11.07.

Measures

Positive and Negative Syndrome Scale (PANSS)

Symptoms were assessed by using the PANSS (Kay et al. 1987). PANSS is an interviewer-administered scale scored on the basis of a clinical interview lasting 30–45 min. It consists of three subscales: positive syndrome scale, negative syndrome scale and general psychopathology scale. The reliability and validity of the PANSS in the Turkish population had been tested in a previous study in our department (Kostakoglu et al. 1999).

World Health Organization-Disability Assessment Schedule-II

Stigmatization perceived by the patients was evaluated by two questions in the WHO-DAS-II (Disability Assessment Schedule). The WHO-DAS-II was developed to assess the activity limitations and participation restrictions actually experienced by an individual, irrespective of diagnosis. The past 30 days is selected as the timeframe for evaluation. The instrument consists of 32 questions and the respondent rates the degree of difficulty on a scale of 1–5. It has six major domains encompassing activities that are considered important in many cultures. These are: 1) understanding and communicating with the world; 2) moving and getting around; 3) self-care; 4) getting along with people; 5) life activities; and 6) participation in society. Two questions in the sixth domain measure the stigmatization perceived by the patients. These are: 'In the last 30 days, how much of a problem did you have because of barriers or hindrances in the world around you?' and 'How much of a problem did you have living with dignity because of attitudes and actions of others?'.

The international reliability and validity study of WHO-DAS-II has been conducted in a multicentered study of WHO Colloborating Centers including our department (Ustun et al. 2001). WHO-DAS-II has been studied previously by the researchers of this study in a test-retest design and conveyed a good level of reliability (Ulug et al. 2002).

Statistical analysis

Patients who had scores of 3 or more for either of the two questions were considered as positive for perceived stigmatization. Patients with scores less than 3 in both of the questions were considered as negative for perceived stigmatization. Demographic and clinical characteristics of patients reporting or not reporting stigmatization were compared by student's t test and chi-square tests. Correlations of the scores of PANSS items with the means of the two questions which were used as a measure of stigmatization were analyzed. Stepwise regression analysis was done to find out the PANSS items predicting the means of questions which were used as a measure of stigmatization.

Results

The group who reported stigmatization and the group who did not report were compared for the demographic variables. There were no significant differences between the two groups considering age, sex, marital status, education and occupational status (Table 1).

Table 1 Comparison of the demographic variables of groups in which stigmatization is reported to be present or absent

	Perceived stigmatization		
	Present (n: 27) n (%)	Absent (n: 33) n (%)	Comparison
Gender			
Female	11 (40.7)	17 (51.5)	$\chi^2 = 0.69$, p = 0.4
Male	16 (59.3)	16 (48.5)	
Marital status			
Married	8 (29.6)	12 (36.4)	$\chi^2 = 0.30$, p = 0.6
Single	19 (70.4)	21 (63.6)	
Occupational status			
Working	13 (48.1)	15 (45.5)	$\chi^2 = 0.04$, p = 0.8
Not working	14 (51.9)	18 (54.5)	
Education (mean years ± SD)	12.4 ± 2.5	12.4 ± 1.8	t = –0.03, p = 0.9
Age (mean years ± SD)	33.3 ± 10.8	35.3 ± 11.4	t = 0.7, p = 0.5

Table 2 Comparison of the clinical characteristics of the groups in which stigmatization is reported as present and absent

	Perceived stigmatization	
	Present (n = 27)	Absent (n = 33)
Duration of illness	10.8 ± 8.2	11.6 ± 11.6
Age at onset of illness	22.5 ± 5.6	23.7 ± 7.0
PANSS total score	69.9 ± 16.4	53.5 ± 14.3*
Positive symptoms subscores	15.3 ± 4.8	11.2 ± 3.5*
Delusions	4.0 ± 1.8	2.3 ± 1.3*
Conceptual disorganization	1.9 ± 1.1	1.6 ± 0.9
Hallucinatory behavior	2.1 ± 1.5	1.5 ± 1.2
Excitement	1.2 ± 0.5	0.5
Grandiosity	1.3 ± 0.9	1.4 ± 1.8
Suspiciousness	3.7 ± 1.7	2.2 ± 1.5*
Hostility	1.1 ± 0.3	1.0 ± 0.2
Negative symptoms subscores	19.9 ± 7.0	16.6 ± 6.2****
Blunted affect	3.2 ± 1.8	2.8 ± 1.6
Emotional withdrawal	4.0 ± 1.1	3.0 ± 1.2*
Poor rapport	2.8 ± 1.6	2.6 ± 1.5
Passive/apathetic social withdrawal	4.5 ± 1.4	3.5 ± 1.3**
Difficulty in abstract thinking	1.4 ± 0.7	1.4 ± 0.9
Lack of spontaneity and flow of conversation	2.3 ± 1.4	2.0 ± 1.0
Stereotyped thinking	1.8 ± 1.2	1.4 ± 0.6
General psychopathology subscores	34.7 ± 8.0	25.7 ± 6.6*
Somatic concern	1.9 ± 1.4	1.1 ± 0.3**
Anxiety	2.5 ± 1.1	1.9 ± 1.0***
Guilt feelings	2.5 ± 1.4	1.9 ± 0.9
Tension	1.7 ± 0.9	1.3 ± 0.7
Mannerisms and posturing	1.8 ± 0.9	1.4 ± 0.6
Depression	2.8 ± 1.2	1.5 ± 0.9*
Motor retardation	1.8 ± 0.9	1.7 ± 0.4
Uncooperativeness	1.2 ± 0.4	1.2 ± 0.5
Unusual thought content	2.9 ± 1.3	1.8 ± 1.1*
Disorientation	1.0	1.0
Poor attention	2.5 ± 1.3	2.4 ± 1.1
Lack of judgement and insight	2.1 ± 1.1	1.1 ± 1.0
Disturbance of volition	2.1 ± 1.2	1.6 ± 1.1
Poor impulse control	1.3 ± 0.6	1.1 ± 0.4
Preoccupation	3.0 ± 1.2	1.9 ± 1.2*
Active social avoidance	3.9 ± 1.5	2.3 ± 1.2*
Disability domains		
Understanding and communicating with the world	50.6 ± 14.6	20.2 ± 14.0*
Moving and getting around	21.1 ± 16.2	9.5 ± 10.0*
Self-care	23.4 ± 16.7	7.0 ± 9.9*
Getting along with people	51.9 ± 10.6	16.1 ± 18.6*
Life activities	43.6 ± 18.9	19.6 ± 10.6*

* p < 0.001; ** p < 0.01; *** p < 0.05; **** p = 0.06

Clinical characteristics of patients were also compared between patients reporting stigmatization and those who did not. The ages of onset and duration of illness were not significantly different between the two groups (Table 2).

PANSS total scores, positive and general psychopathology symptoms subscores were significantly higher in patients reporting stigmatization. Negative symptoms subscores were more severe in the group reporting stigmatization than in the group that did not report stigmatization; the difference was nearly significant (p = 0.06) (Table 2).

PANSS items were also compared between the two groups. Among the positive symptoms, delusions and suspiciousness were significantly more severe in the patients who reported stigmatization. Emotional withdrawal and passive/apathetic social withdrawal were the negative symptoms which were rated significantly higher in the group with stigmatization. Six of the symptoms in the general psychopathology section were significantly more severe in patients reporting stigmatization compared to those who did not. These were somatic concern, anxiety, depression, unusual thought content, preoccupation and active social avoidance (Table 2).

Disability domains of WHO-DAS-II about understanding and communicating with the world, moving and getting around, self-care, getting along with people and life activities were also compared between the groups of patients reporting and not reporting stigmatization. Patients reporting stigmatization were significantly disabled in all domains of life compared to the other group (Table 2). The sixth domain, named participation in society, was not compared between the two groups, as stigmatization questions belonged to this domain.

When correlations of PANSS items with the answers given to first question measuring stigmatization were checked, suspiciousness (r: 0.44, p = 0.06) and depression (r: 0.57, p = 0.001) were found to have significant correlation. After stepwise regression analysis, depression was found to predict the mean of this question significantly and could explain 33 % of the variance in the answers (r: 0.57, r^2: 0.33, p < 0.001). The second question measuring stigmatization was significantly correlated with delusions (r: 0.56, p < 0.001), suspiciousness (r: 0.48, p < 0.001), emotional withdrawal (r: 0.46, p < 0.001) and active social avoidance (r: 0.63, p < 0.001). Stepwise regression analysis showed that active social avoidance

was the PANSS item which could predict the answers given to the second stigmatization question. It could explain 39 % of the variance in the mean scores of this question (r: 0.63, r^2: 0.39, $p < 0.001$).

Discussion

In this study, we explored the relationship of symptoms with the perception of stigmatization by the patients. Patients who reported perceiving stigmatization had more severe symptoms than those who did not report stigmatization. There are several studies on this subject which have contradictory results. Some of the previous studies found clinical characteristics to be associated with the extent of stigma among persons with serious mental illness (Farina 1998), while in a recent study this relation could not be shown (Dickerson et al. 2002).

Among the positive symptoms, delusions and suspiciousness were significantly more severe in the patients perceiving stigmatization. In correlation analysis, these items were also correlated with questions about stigmatization. This result can be interpreted in various ways. Patients with schizophrenia may prefer to be distant to others due to their delusions and suspicions and may perceive more stigmatization as they expect more negative attitudes from others. It may also be true that symptoms like delusions and suspiciousness may cause florid behavioral change and are attention-taking, which may be scary for others and cause more public reaction. The general psychopathology PANSS items about preoccupation and unusual thought content which were also significantly higher in patients perceiving stigmatization, may also contribute to this situation.

Emotional withdrawal and passive-apathetic social withdrawal were the negative symptoms which were also significantly more severe in the positive perceived stigmatization group. Penn et al. (2000) found that negative symptoms like anergia appear to be the clinical phenomenon that elicits the greatest negative reaction from others. The mechanism underlying this reaction to negative symptoms was explained by attribution theory; negative symptoms were perceived as under the control of the individual, resulting in the individual being blamed more for her/his condition. Negative symptoms like blunted affect and emotional aloofness may appear odd and peculiar, which also leads to more stigmatization. Passive/apathetic social withdrawal may not only be a cause but also a result of patients perceiving stigmatization. As Link et al. (1987, 1989) reported, patients anticipate discrimination or rejection by others and develop coping strategies, such as withdrawal from social interaction, in an effort to avoid the rejection they anticipate, which, in fact, may further handicap social adaptation and delay recovery.

Regarding general psychopathology items of the PANSS, somatic concern, anxiety, depression and active social avoidance item scores were also significantly more severe in the group perceiving stigmatization. The depression item was also significantly correlated with the answers given to the first stigmatization question which asked about the severity of the problems that the patient had because of the barriers and hindrances in the world around him/her. Depression was the only item which could predict the answer to this question, explaining 33 % of the variance.

This result may be due to the fact that the patients who are more depressed may have more negative cognitions about themselves and the world around them. The depressive thought content of the patient may be influential in the answers given to this question. It is not surprising to find that higher perception of stigma is related to negative perception of the world. It is also true that stigma and discrimination exert a detrimental effect on persons with mental illness by limiting their opportunities and reducing their self-esteem.

Our results are in accordance with previous studies where the patient's mood was reported to be associated with perception and experience of stigma. Expectations of stigma were found to be associated with higher levels of depression and demoralization (Link 1987; Link et al. 1991, 1997; Rosenfield 1997; Markowitz 1998). However, in a previous study, Dickerson et al. (2002) could not find a relation between clinical characteristics including depression and stigma experience.

'Active social avoidance', another item of the PANSS, was positively correlated with the answers given to the second stigmatization question which was about the problems that the patient had in living with dignity because of attitudes and actions of others. Active social avoidance could predict 38 % of the variance in the answers to this question. Patients who actively avoid social situations are the ones who more severely experience difficulty due to the attitudes of others. These results support the view of Mueser and Bellack (1998) who reported that patients with schizophrenia have significant deficits in social skills which may produce uncomfortable and/or aversive interactions with others. Social behavior and active avoidance of the patient may contribute to psychiatric stigma. While patients who avoid social situations perceive more stigmatization, perception of more stigmatization may be leading to more active avoidance of social situations. Perlick et al. (2001) reported that concerns about stigma predicted psychological isolation and higher avoidance of social interactions with persons outside the family in a group of patients with mental illness. Patients exercise avoidant coping strategies selectively in anticipation of rejection. Thus, as Scambler and Hopkins (1990) emphasized, 'felt stigma' may be more disruptive for a patient's life than the 'enacted stigma'.

Patients who reported perceiving stigmatization were also more disabled than the ones who did not perceive stigmatization in domains like understanding and communicating with the world, moving and getting around, self-care, getting along with people and life activities. In a previous study, we found that the level of disability was not correlated with the severity of neu-

rocognitive dysfunction in schizophrenic patients (Ertugrul and Ulug 2002). One of the explanations of this result was that the memory or attention deficit of a patient might not create significant disability in a supportive, protective family and society who expected fewer and simpler tasks from the patient. However, the results of the current study show that 'stigmatization' is correlated with disability and it is also a problem in developing countries in spite of the social cohesion.

This study has some limitations. Perceived stigmatization was measured with two general questions. In the literature, we realize that different questionnaires are used to measure perception of stigmatization. It would give us more useful information if we could compare the subjective experience of patients with actual report of their surroundings, which could help us differentiate what is only 'perception' and what is an actual stigmatization experience.This would help us to understand the causal relationship between symptoms and stigmatization more clearly. Another limitation of our study is that, as patients with symptoms of low-moderate severity were recruited, data which can be obtained from more severe patients are missing.

The relation of perception of stigmatization with symptoms and disability is actually a vicious circle in which the elements reinforce each other. Interruption of this circle will increase the adaptive abilities and decrease the disability of these patients. In addition to adequate control of the symptoms, social skills training and cognitive rehabilitation will make them less 'alien' in the society.

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