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ORIGINAL ARTICLE

Retrospective Study

Associative stigma in family members of psychotic patients in Flanders: An exploratory study

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Data sharing: Technical appendix, statistical code, and dataset available from the corresponding author at kirstencatthoor@yahoo.com. Participants did not give informed consent for data sharing at the time of the interviews.

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Abstract

AIM: To assess presence and severity of associative stigma in family members of psychotic patients and factors for higher associative stigma.

METHODS: Standardized semi-structured interview of 150 family members of psychotic patients receiving full time treatment. This study on associative stigma in family members of psychotic patients was part of a larger research program on the burden of the family, using "Interview for the Burden of the Family" and the chapters stigma, treatment and attribution from the "Family interview Schedule". The respondents were relatives, one per patient, either partner or parent. The patients had been diagnosed with schizophrenia or schizo-affective disorder. All contacts with patients and relatives were in Dutch. Relatives were deemed suitable to participate in this research if they saw the patient at least once a week. Recruitment took place in a standardized way: after obtaining the patient's consent, the relatives were approached to participate. The results were analyzed using SPSS Version 18.0.

RESULTS: The prevalence of associative stigma in this sample is 86%. Feelings of depression in the majority of family members are prominent. Twenty-one point three percent experienced guilt more or less frequent, while shame was less pronounced. Also, 18.6% of all

respondents indicated that they tried to hide the illness of their family member for others regularly or more. Three six point seven percent really kept secret about it in certain circumstances and 29.3% made efforts to explain what the situation or psychiatric condition of their family member really is like. Factors with marked significance towards higher associative stigma are a worsened relationship between the patient and the family member, conduct problems to family members, the patients' residence in a residential care setting, and hereditary attributional factors like genetic hereditability and character. The level of associative stigma has significantly been predicted by the burden of aggressive disruptions to family housemates of the psychotic patient.

CONCLUSION: Family members of psychotic patients in Flanders experience higher associative stigma compared to previous international research. Disruptive behavior by the patient towards in-housing family members is the most accurate predictor of higher associative stigma.

Key words: Associative stigma; Risk factors for higher stigma; Family members; Psychotic patients; Burden

Core tip: Associative stigma is an extension of psychiatric stigma to those who care for patients, like family members. Scientific evidence on associative stigma in family members of psychotic patients is abundant, but culturally determined. This study tried to study the presence and severity of associative stigma in family members of psychotic patients in Flanders (Belgium) and evaluate factors to delineate subgroups vulnerable for higher associative stigma. The results show that associative stigmatization is a marked problem for parents and partners of psychotic patients: it is higher than so far demonstrated in previous international research. Disruptive behavior by the patient towards in-housing family members is the most accurate predictor of higher associative stigma. A better understanding of this complex phenomenon is certainly warranted, in order to perform more adequate clinical interventions towards family members of psychotic patients, to lower this destructive burden.

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INTRODUCTION

Stigma is defined as a discrediting and disgracing mark[1-5] usually leading to negative behavior for its bearer[6-10]. Different approaches have been used to conceptualize psychiatric stigma[1-5]. The definition and conceptualization of psychiatric stigma are still in full evolution. Aspects of devaluation, discrimination, decreased self-esteem, self-restricted behavior, and dysfunctional coping are almost always mentioned[1-4]. Most studies have consistently reported that patients with psychotic disorders[8-14], affective disorders[14], and alcohol dependence[14] experience stigmatization as a serious hindrance in daily life.

Associative stigma does not refer to the patients themselves, but is an extension of psychiatric stigma to those who care for patients, such as family members[15-24] and mental health care workers[6,7]. Subjective feelings of associative stigma are solely caused by the relationship with another stigmatized individual[15-18,20-24]. It is considered to be an important source of mental burden[19-24]. Marked stress, shame and blame, diminished self-worth, depression, anxiety and avoidance of social contacts are often mentioned. Multiple factors may contribute to the substantial associative stigma of family members[17], although there is evidence that some somatic diseases induce the same kind of stigma[18]. There is, for example, the widespread public assumption that bad parenting skills trigger mental illness. Besides, genetic models emphasize biological vulnerability and inheritance. And last but not least is the fact that family members are often blamed for non-compliance and thus relapse in the patient.

Research has shown that associative stigma appears to be greater in family members who have mental health problems themselves, whereas there is doubt if the diagnosis of the patient is of any significance[20,24]. In addition, there is substantial evidence that family members with higher socio-economic status show higher levels of stigma compared with others[8,15]. Several studies focusing on psychotic disorders demonstrated that a higher level of subjective stigma in family members is related with illness-related symptomatic behavior[15], a higher degree of positive symptoms[8], and male gender[17]. Half of the family members of psychotic patients use concealment about their relatives' psychiatric condition[15], and that a longer duration of illness is also associated with a higher degree of stigma[8,25].

Although evidence in literature is not conclusive, the abovementioned findings strongly indicate a stigmatizing effect of the diagnosis of a psychotic disease on family members of the patient. It should also be emphasized that family interactions and caregiver burden[26] are strongly influenced by cultural factors (widespread beliefs about the origin of disease, like demon possessions in Africa and patients' or family's misconduct in China). As previous studies on this topic investigated North-American[15,24], Chinese[8], Swedish[20] and African populations[19,22], it is worth questioning whether these effects are present in a Belgian sample too. The goals of the current study

Table 1 Socio-demographic data of patient and respondent, and schematic representation of the patient's case history *n* = 150 (%)

Diagnosis	
Schizophrenia/schizo-affective disorder	129 (86.0)/21 (14.0)
Treatment	
Inpatient/outpatient	81 (54.0)/69 (46.0)
Gender of patient	
Male/female	103 (68.7)/47 (31.3)
Average age of patient (SD)	33 yr (8.7 yr)
Gender of respondent	
Male/female	46 (30.7)/104 (69.3)
Relationship respondent/patient	
Parent/partner	118 (78.7)/32 (21.3)
Average age of respondent (SD)	56 yr (11.9 yr)
Education of respondent	
A-Level, FE or University/primary or GCSE (O-Level)	74 (49.3)/76 (50.7)
Total household income of respondent	
< €20K per annum/ > €20K per annum	122 (81.4)/28 (18.6)
Number of contact hours respondent/patient (SD)	5.4 h (1.8 h)
Duration of illness in years (SD)	9.1 yr (6.4 yr)
Number of times patient was taken into care (SD)	3.8 (3.2)
Psychopharmacological treatment	
With/without antipsychotic drugs	148 (98.6)/2 (1.4)
Behaviour	
Disorganised/not disorganised	132 (88.0)/18 (12.0)
Negative/not negative	44 (29.3)/106 (70.7)
Patient's place of residence	
At home/in institution	117 (78.0)/33 (22.0)

are two-fold: First we aim to determine the presence and severity of associative stigma in family members of psychotic patients in a Belgian sample. Second, we aim to exploratively determine factors that could help to delineate subgroups vulnerable for high levels of associative stigma, based on those factors that already have been suggested in previous studies.

MATERIALS AND METHODS

Participants

The respondents were relatives, one per patient at his or her own suggestion, either partner or parent. The patients had been diagnosed with schizophrenia or schizo-affective disorder (DSM-Ⅳ, TR, American Psychiatric Association)[27], according to SCID[28]. All patients were receiving full-time treatment, either in a day centre or as an outpatient in the University Centre in Kortenberg or the Night Hospital of Sint-Alexius in Elsene (Table 1), both in the Flemish part of the country. All contacts with patients and relatives were in Dutch. Relatives were deemed suitable to participate in this research if they saw the patient at least once a week. Recruitment of family members took place in a standardized way: after obtaining the patient's consent, the case psychiatrist would request relatives to participate in research about the burden of care of relatives of psychotic patients. Patients were selected in a third-line, university centre and respondents were only included if the patient gave permission. It should be taken into account that patients from a stigma-sensible environment could refuse to participate in this study. The declaration of Helsinki was followed during the whole procedure of the study.

Conceptualization

This study on associative stigma in family members of psychotic patients was part of a larger research program on the burden of the family[29]. Therefore, the interview consisted in several different parts. First we used the complete set of items pertinent to "Interview for the Burden of the Family"[30]. Additionally we went through the chapters stigma, treatment and attribution from the "Family interview Schedule", which in fact was part of a World Health Organisation study (WHO, 1992) on course and outcome of schizophrenia, that were already included in the Burden of the Family interview. For details on the questionnaire, we refer to Sartorius *et al*[31]. We interviewed relatives of 150 patients. The average duration of the interview was 105 min. The duration of patient's illness was operationalised as the number of years they had been ill since they had first been taken into psychiatric care.

Measures

Assessment of stigma: The sum total of all scores from the stigma chapter (Likert-scale from 0 to 3) determined the total stigma, with a minimum of 0 and a maximum of 42[31]. Because data are homogeneous, means and standard deviations are added in the result section. The presence of just one positive answer on the stigma questionnaire was enough to represent a form of perceived stigma[22].

Statistical analysis

The data were analysed using the Statistical Package for Social Sciences, version 18.0 (SPSS Inc., Chicago, IL). Patients and respondents were characterized with descriptive statistics to differentiate on associative stigma.

The Kruskal Wallis test (outcome measure = *P*-value) was chosen as a conservative non-parametric method because the distribution of the data was not-normal. It was used to assess differences in mean stigma score (continuous dependent variable) between groups. Categorical dependent group variables were factors we found in the literature: the relationship between the patient and the interviewed family member, the evolution in time of this relationship, disruptive behavior of the patient, treatment in inpatient or outpatient unit, disruptive eruptions towards family members, the patient's residence, attribution of the disease to heredity, character of biological brain problems, and contact between the interviewee and a mental health professional.

A multiple regression analysis (method = backward) was conducted in order to investigate the predictive

Table 2 Complete results of stigmatization questionnaire, ordered by item *n* = 150 (%)

	Never	Sometimes	Regularly	Often
Concerned about the neighbours	121 (80.7)	20 (13.3)	5 (3.3)	4 (2.7)
Concerned about people discovering what is going on	106 (70.7)	33 (22.0)	4 (2.6)	7 (4.7)
Tendency to conceal	89 (59.3)	38 (25.3)	11 (7.3)	12 (8.0)
Explanation about the situation	71 (47.3)	60 (40.0)	13 (8.7)	6 (4.0)
Secrecy	95 (63.3)	32 (21.3)	6 (4.0)	17 (11.3)
Concerned about being avoided or ignored	136 (90.7)	11 (7.3)	1 (0.7)	2 (1.3)
Explanation of the illness	106 (70.7)	26 (17.3)	11 (7.3)	7 (4.7)
Concerned about being accused	129 (86.0)	13 (8.7)	5 (3.3)	3 (2.0)
Concerned about a hesitation to marry	122 (81.3)	15 (10.0)	7 (4.7)	6 (4.0)
Concerned about leaving the house	120 (80.0)	24 (16.0)	3 (2.0)	3 (2.0)
Shame	129 (86.0)	19 (12.7)	0 (0.0)	2 (1.3)
Contact with other families	103 (68.7)	34 (22.7)	6 (4.0)	7 (4.6)
Feeling depressed or sad	55 (36.7)	44 (29.3)	25 (16.7)	26 (17.3)
Guilt	118 (78.7)	22 (14.7)	7 (4.6)	3 (2.0)

value of several variables on the level of stigma experienced by family members of psychotic patients. Level of stigma was entered as the dependent variable. Predictors (independent variables) were patient characteristics (diagnosis, gender, age, duration of illness, number of hospital admissions and relation between patient and respondent), socio-economic status of the respondent (educational background of family member and family income) illness related symptomatic behavior (positive symptoms: hallucinations and paranoia, disruption experienced by co-housing family members) contact with a mental health professional and biological attribution of illness (inheritability and bad biological functioning). Outcome measures are standardized β, *t*-values with p-values to indicate significance, with $\alpha \leqslant 0.05$ no correction for multiple testing due to interdependecy of the variables. Dummy variables were computed for nominal data.

Biostatistical review was performed after peer review by Luykx J.

RESULTS

Patients and respondents

The data of patients and respondents are shown in Table 1. Mean age of the participating patients was 33 with a male preponderance (male/female ratio: 103/47). There were more female participating relatives (mean age was 56), probably because most of them were parents. This disequilibrium between the number of male and female patients and respondents is a bias in the study. Patients were mostly diagnosed with schizophrenia, showed a relatively long illness course and were already taken several times into psychiatric care.

Level of associative stigma

The average total sum of all subjective stigmatization experienced by the family members was 6.0 (± SD 5.6), with scores ranging from 0 to 30. The complete set of results of the stigmatization questionnaire is shown in Table 2. If 1 positive answer on the questionnaire is considered as the experiencing of at least some kind of associative stigma (Shibre, 2001), the prevalence of associative stigma is 86% in the current sample.

At the individual item level, the most important finding of the study are feelings of depression being present in the majority of respondents (63.3%). More than 1 in 5 (21.3%) experienced guilt more or less frequent, while shame was less frequent (14%). Also, 18.6% of all respondents indicated that they tried to hide the illness of their family member for others regularly or more. Thirty-six point seven percent really kept secret about it in certain circumstances and 29.3% made efforts to explain what the situation or psychiatric condition of their family member really is like. Twenty percent was concerned about how and when the patient could leave the house. What is striking is that more than 10% of the respondents indicate to experience almost all items "sometimes" (except "concerned about being avoided or ignored" and "concerned about being accused").

Vulnerable subgroups

Table 3 shows the significant differences in the subjective experience of stigmatization as suffered by all respondents, taking into account the patient- and respondent-specific variables. The Kruskal Wallis Test revealed that all independent variables showed at least marginally significant differences in subjective feelings of stigma. Factors with marked significance towards higher associative stigma are a worsened relationship towards the family member (mean total stigma score 8.6 ± SD 1.1 *vs* 5.3 ± SD 0.5, $P = 0.003$), conduct problems to family members (mean total stigma score 9.6 ± SD 1.5 *vs* 5.5 ± SD 0.5, $P = 0.004$), the patients' residence in a residential care setting (mean total stigma score 8.9 ± SD 1.1 *vs* 5.3 ± SD 0.5, $P = 0.001$), and hereditary attributional factors like genetic hereditability (mean total stigma score 7.4 ± SD 0.7 *vs* 4.8 ± SD 0.5, $P = 0.006$) and character (mean total

Table 3 Differences in subjective stigmatization experience taking into account patient- and respondent-specific variables with the relevant *P*-value

Patient- and respondent-specific variables	Stigmatization-score (± SD)	*P*-value
Relation		
Parent/partner	6.4 (± 0.5)/4.9 (± 1.1)	0.030
Evolution of relation		
Worse/not worse	8.6 (± 1.1)/5.3 (± 0.5)	0.003
Disruptive		
Yes/no	8.1 (± 1.1)/5.7 (± 0.5)	0.020
Nature of patient		
Inpatient/outpatient	6.8 (± 0.6)/5.3 (± 0.7)	0.043
Disruption to family members		
Yes/no	9.6 (± 1.5)/5.5 (± 0.5)	0.004
Patient's residence		
Institution/at home	8.9 (± 1.1)/5.3 (± 0.5)	0.001
Attribution to heredity		
Yes/no	7.4 (± 0.7)/4.8 (± 0.5)	0.006
Attribution to character		
Yes/no	7.4 (± 0.7)/4.8 (± 0.5)	0.008
Attribution to biological brain problem		
Yes/no	7.1 (± 0.8)/5.6 (± 0.6)	0.050
Contact with psychotherapist		
Yes/no	6.8 (± 0.6)/4.5 (± 0.5)	0.060

stigma score 7.4 ± SD 0.7 *vs* 4.8 ± SD 0.5, $P = 0.008$). It is also worth mentioning that contact with a mental professional lead to a tendency of higher associative stigma (mean total stigma score 6.8 ± SD 0.6 *vs* 4.5 ± SD 0.5, $P = 0.06$).

Predictive factors

As Table 4 presents, the level of associative stigma has significantly been predicted by the burden of aggressive disruptions to family housemates of the psychotic patient (β = 0.223, $t = 2.074$, $P = 0.041$). The higher the burden of family members living together with the patient, the higher the level of associative stigma in the responding relative. The predictive capacity of hallucinations (β = 0.204, $t = 1.827$, $P = 0.072$) and the attribution of psychotic illness to inheritability (β = 0.190, $t = 1.716$, $P = 0.090$) correspond with a tendency towards statistical significance ($P = 0.05$-0.1) but were not significant.

DISCUSSION

This quantitative study into experiences of associative stigma in relatives of psychotic patients aimed to assess previously internationally reported presence and severity of associative stigma in a large Flemish sample, and tried to determine factors that could help to predict higher subjective associative stigma in the current cohort. Flemish parents or partners of adult patients receiving treatment for schizophrenia or schizo-affective disorder reported levels of associative stigma that are higher compared to other similar studies.

Table 4 Predictors of stigma experienced by family members of psychotic patients ($n = 89$)

	β	*t*	*P*-value
Constant		0.999	0.321
Gender of patient	0.072	0.648	0.519
Relation with patient	0.025	0.194	0.847
Education of family member	-0.013	-0.11	0.913
Age of patient	-0.238	-1.595	0.115
Number of years of illness	0.109	0.714	0.477
Number of hospital admissions	-0.033	-0.26	0.796
Positive psychotic symptom: hallucinations	0.204	1.827	0.072
Positive psychotic symptom: paranoia	0.134	1.283	0.203
Burden by housemates	0.223	2.074	0.041
Family income	0.062	0.526	0.601
Spoken to therapist	0.173	1.578	0.119
Biological background of illness: inheritability	0.19	1.716	0.09
Biological background of illness: bad biological functioning	0.005	0.044	0.965

Footnote: $R^2 = 0.25$.

Presence and severity of associative stigma

Regarding the presence and severity of associative stigma in our sample, an average total subjective stigma of 6 was observed; compared to a possible maximum score of 42, this score did not seem very pronounced. However, 86% of our respondents gave 1 or more positive answers on the questionnaire and thus experienced at least some sort of associative stigma. Note that Shibre *et al*[22] came to 75% of "stigmatized" relatives in Ethiopia, using the same questionnaire and scoring. In our cohort, a significant majority of respondents (63.3%) appeared to feel "episodically depressed or sad", which is substantially more than the 40% in Ostmann and Kjellin's study[20]. This study, comparable to ours with a semi structured interview, also asked family members directly about their own mental health problems as a result of the mental illness of their relative. In China[8], only 28% of relatives think that stigmatization has a mild to severe negative influence on healthy family members; it should be mentioned that in this country, the development of schizophrenia is attributed to totally different cultural contents, and the family is more responsible for the behavior of its members. Although we emphasize that all studies had different study designs and methods, and that study results are not easily generalizable, our data confirm the international findings on the extent of associative stigma, and even indicate that family members of psychotic patients in Flanders experience still higher levels of stigma as compared with previous research.

The finding that parents exhibited a greater level of subjective stigmatization in comparison to partners can be linked to the parents' assumption that they at least partially originated the emergence of the illness and have to deal with the associated sadness and sorrow of their child. Besides, they might experience

the demand for continuity of care and the underlying sense of responsibility. We suggest that the higher stigmatization level in relatives who attribute the psychotic disorder to hereditary factors and consider it as a "genetic" phenomenon confirms this hypothesis. Contact with a mental health professional resulted in a marginally significant increase in stigmatization, which is difficult to understand. It could be that respondents are more likely to approach a therapist because of their increased stigmatization experience. Conversely, they could also feel that approaching a professional might reflect badly on them. Ostmann and Kjellin[20] interpret this feeling of inferiority towards the psychotherapist as the most important luxating factor of this phenomenon. The absence of a significant correlation between the diagnosis of the patient (schizophrenia *vs* schizo-affective disorder) and the total subjective stigma is in line with results of previous research[15,20].

Predictive factors

The experience of disruptive behavior by in-housing family members of the psychotic patient was the most accurate predictor of higher associative stigma in family members of psychotic patients. The importance of positive and disease-related symptoms has already been mentioned in previous studies[8,15], and it is not surprising that disruption directed towards own family members is one of the most shocking and shaming experiences a relative can imagine. The interviewed relatives did not suffer solely, but also their closest family members had to deal with the patient's unpredictability and outbursts. The possibility of blame for incompetence to stop this acting out, and the fear of being avoided by others, leads to even more burden, diminished self-esteem and inevitably also more stigma. For mental health professionals, the knowledge of violent disruptions in the family environment of a psychotic patient, should be a warning signal for associative stigma and offers a chance to discuss it with the family members involved.

Respondents claimed that contact with outsiders was not problematic, but similarly they exhibited a marked tendency to conceal or explain their situation. Relatives also denied feelings of guilt or shame but at the same time they confirmed that they felt depressed. There is thus a marked difference between what relatives say and do on the one hand and the way they think and feel on the other hand. These discrepancies between the results at the individual item-level could point to an interaction between feelings of stigmatization and previously existing emotional, cognitive and even psychopathological phenomena. This makes us assume that relatives are not aware of the effect of stigmatization on their subjective burden experience as they often deny feelings of stigmatization. It is unclear whether this phenomenon could be explained in terms of shame, *i.e.*, an internalized fear that inhibits recognizing the stigmatization, or whether relatives no longer recognize the difference between the experience of stigma and the need to deny it. To explain these apparent contradictions, it might be useful to redefine associative stigma, or at least broaden the concept. The subjective stigmatization experiences in relatives of psychotic patients should be understood as a complex concept, in which negative cognitions, dissociative mechanisms, fear, shame and partial denial all play an important role. We also would like to refer to substantial similarities with the concept of self stigma, and its paradoxes, as described by Corrigan *et al*[32]. Recognizing stigmatization in itself already appears to have a stigmatizing effect, which often leads to a denial of this feeling.

The results of our research give a clear picture of the subjective stigmatization experience in relatives of psychotic patients in Flanders, Belgium. Although there is an increasing interest in literature to emphasize positive aspects in caregiving for psychotic patients by family members[33], we would like to highlight the importance of more fundamental research into the nature of stigmatization in different populations of patients, relatives and even professionals, in order to perform more adequate interventions to lower this destructive phenomenon.

Limitations and strengths

Our study is limited because of a selection bias: patients were selected in a third-line, university centre and respondents were only included if the patient gave permission. It should be taken into account that patients from a stigma-sensible environment could refuse to participate in this study. Besides that, there was disequilibrium between the number of male and female patients and respondents, and there were only parents and partners included, no children of patients. The current study's strengths are the large study cohort, and the possibility to compare results to previous international research.

In conclusion, the current study clearly demonstrates a high prevalence of substantial feelings of associative stigma in family members of psychotic patients in Flanders, Belgium. Factors with marked significance towards higher associative stigma are a worsened relationship between the patient and the family member, conduct problems to family members, the patients' residence in a residential care setting, and hereditary attributional factors like genetic hereditability and character. The experience of disruptive behavior by in-housing family members of the psychotic patient was the most accurate predictor of higher associative stigma. A better understanding of this complex and multidimensional phenomenon, and integration into daily patient care and family interventions is certainly warranted.

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cooperation in this study.

COMMENTS

Background

Stigma is defined as a discrediting or disgracing mark, usually leading to negative behavior on the part of its bearer. Different approaches have been used to conceptualize psychiatric stigma, and are still evolving. Aspects such as devaluation, discrimination, decreased self-esteem, self-restricted behavior, and dysfunctional coping are almost always mentioned. Associative stigma is an extension of psychiatric stigma to those who care for patients, such as family members and mental healthcare workers. Associative stigma in family members is determined by cultural, psycho-social and personal factors from patient as well as from family member.

Research frontiers

Scientific data on associative stigma among family members of psychiatric patients differ substantially, depending on patient- and relative characteristics. Given the current world wide treatment paradigm shifts, from inpatient to outpatient, it is important to better understand the mental burden and stigma experiences of family members of patients, in order to provide better clinical support and advice.

Innovations and breakthroughs

Flemish parents or partners of adult patients receiving treatment for schizophrenia or schizo-affective disorder report levels of associative stigma that are higher compared to other similar international studies. Factors with marked significance towards higher associative stigma are a worsened relationship between the patient and the family member, conduct problems to family members, the patients' residence in a residential care setting, and hereditary attributional factors like genetic hereditability and character. The experience of disruptive behavior by in-housing family members of the psychotic patient was the most accurate predictor of higher associative stigma.

Applications

This study highlights the importance of more fundamental research into the nature of stigmatization in different populations of patients, relatives and even professionals, in order to perform more adequate clinical interventions to lower this destructive phenomenon, given the current treatment paradigm shifts towards more outpatient treatment in the natural environment of the patient.

Terminology

Associative stigma is an extension of psychiatric stigma to those who care for patients, such as family members and mental healthcare workers. Coping mechanisms are conscious psychological adaptations to environmental stress, in order to obtain more comfort.

Peer-review

It is a well designed and correctly conducted survey. The topic is important and the results are interesting.

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