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Level of expressed emotion and courtesy stigma in the families of patients with severe mental disorders: an obstacle to the recovery process?

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KeyWords:
Courtesy stigma; Caregiver; Family members; Expressed emotion; Recovery; Psychiatric rehabilitation; Stigma.

Abstract

The general concept of stigma finds wide application in the field of psychiatry by indicating prejudice, stereotypes and discrimination towards patients diagnosed with psychiatric illness. Among the different declinations of this concept, we find courtesy stigma: a form of stigma by association experienced by people in close contact with the stigmatised person.

Those who are most likely to experience this type of discrimination are the family members of the psychiatric patient, as they are particularly connected to the person with mental health problems. This experience contributes to increasing levels of expressed emotion (EE), i.e. the index of the emotional climate within the family.

This study is based on two samples: a group of patients with a diagnosis of severe mental disorder from the Department of Psychiatry of the University of Campania "Luigi Vanvitelli" and another group of family caregivers. This study aimed to: a) assess the impact of courtesy stigma on the levels of recovery and EE perceived by the patient; b) assess the relationship between the latter and the recovery process.

To this purpose, the RAS-DS (Recovery Assessment Scale - Domains and Stages) and LEE (Level of Expressed Emotion Scale) scales were administered to patients, whereas caregivers were administered the CPMI (Stigma scale for Caregivers of People with Mental Illness) scale.

Data processing showed that high levels of courtesy stigma reported by caregivers are an obstacle to the patients' recovery and increase the EE levels as perceived by the patients.

Introduction

In the past decade, psychiatry has introduced into its practice the achievement of a new goal: the beginning of a recovery process. This concept has been increasingly advancing in the field of mental health, replacing the old goals of response-remission, and it is understood as a process whose real protagonist is the patient in their entirety and no longer the symptoms associated with their pathology: recovery means living a fulfilling life, full of purpose and meaning while coping with the difficulties of living with illness [1].

However, another aspect not to be overlooked is that human beings are characterized as a bio-psycho-social system and therefore every condition of health or illness is the consequence of the interaction between biological, psychological, and social-environmental factors [2,3]. In more detail, the social-environmental aspect also, and above all, includes significant relationships. Therefore, we cannot consider the patient separately from the social-relational context in which they are embedded. This is how the concept of recovery is further extended: it is, therefore, a process of discovering one's own limits and possibilities and of active coping that the patient does not carry out alone, but which takes place in the context of relationships with those who play a significant role for them. Therefore, families, and caregivers in particular, can't be excluded from the recovery programme of their relatives. Families may be either promoters or a barrier of such a programme. In fact, in the patient-caregiver dyad, there are some caregiver's behaviours, beliefs and features that influence the patient's life and vice-versa [4].

An example in this regard concerns "courtesy stigma", a term that refers to a form of stigma by association experienced by those who are in close contact with the stigmatized person [5].

It is intuitive to understand how those who are most likely to experience this type of discrimination are the family members of the psychiatric patient [6,7]. In fact, as caregivers are particularly connected to the person with mental health problems, they suffer, directly or indirectly, the effects of stigma.

Moreover, the family member/caregiver, having to cope with a multitude of rather high stressors, will present a higher or lower level of EE, i.e. "... the index of emotional temperature in the family environment: an indicator of the intensity of the emotional response of the family member at a mo-

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ment in time. Essentially a detector of the family member's lack of affection or overly intrusive interest in the patient" [8]. We can therefore define EE as a characteristic of the family environment in which the patient lives permanently and which can be a main predictor for symptom relapse [9].

On this basis, caregiver's behavior is expected to influence the course of the illness and therefore the recovery process. With the present study, we want to identify other possible barriers in the recovery pathway of patients with severe mental disorder, considering not only the patient but also the family context in which they are placed as the protagonists of the process. In particular, the primary endpoint of this study is to assess whether the caregiver stigma interferes with the recovery process of the patient with severe mental disorder. The working hypothesis is that in dyads in which the caregiver feels the burden of affiliated stigma more strongly, there is a greater difficulty in beginning and proceeding with recovery and that, therefore, this proves to be a barrier in the process. Secondary endpoints are to assess how EE, as perceived by the patient rather than by the family member, influences the beginning or the development of the recovery process and whether there are correlations between perceived EE and stigma in caregivers.

MATERIALS AND METHODS

Experimental Design.

The present study involved 15 patients suffering from severe mental disorder from the General Psychiatry outpatient clinic of the Department of Psychiatry of the University of Campania "Luigi Vanvitelli" and a caregiver indicated by each one of them. All collected data were stored with the utmost respect for privacy, pursuant to art. 7 and art. 13 of Legislative Decree no. 196/03, in force since 1 January 2004, on the protection of natural persons with regard to the processing of personal data.

The sample of patients was selected according to the following inclusion criteria: a) age between 18 and 65 years; b) diagnosis of schizophrenia, other psychotic disorder, bipolar disorder, major depression or obsessive-compulsive disorder, according to the criteria established in DSM-V; c) ability to provide informed consent to participate in the study. Patients were excluded if they: a) had comorbidities with major organic pathologies; b) suffered from intellectual disability or severe cognitive impairment; c) were undergoing psycho-educational interventions.

The sample of caregivers was selected according to the following inclusion criteria: a) age over 18 years; b) caregiver who has had the greatest influence on the patient in the last three months or more; c) caregiver who lives with the patient or devotes most of their time to the patient; d) ability to give informed consent to participate in the study. The following were excluded from the study: a) caregivers bound to the patient for work purposes only; b) caregivers who care for the patient for a few hours a day and a few days a week; c) caregivers who care for more than one relative; d) caregivers involved in psycho-educational interventions.

When the written informed consent was obtained, each patient and caregiver underwent several neuropsychological tests shown in Table 1 and 2, respectively.

Table 1. *Rating scale administered to patients.*

Socio-demographic and clinicalcharacteristics ?	SSDCP	Socio-demographic and clinical characteristics
Global Assessment of Functioning	GAF(10)	Global functioning
Brief Psychiatric Rating Scale	BPRS(4)	Severity of symptomatology
Recovery Assessment Scale - Domains and Stages	RAS-DS(11)	Recovery levels
Level of Expressed Emotion Scale	LEE(12)	Expressed emotion levels (perception)
Coping Orientation to Problems Experienced – New Italian Version	COPE-N-VI(13)	Most frequently used coping mechanisms

Table 2. *Rating scales administered to caregivers.*

Family behavior questionnaire	QCF	Family members' behavior towards their relative suffering from psychiatric disorder
Mental Health Knowledge Schedule	MAKS-I(14)	Knowledge of mental healt disorders
Stigma scale for Caregivers of People with Mental Illness	CPMI(15)	Measurement of courtesy stigma in relatives of patients suffering from prsychiatric disorder
Coping Orientation to Problems Experienced – New Italian Version	COPE-NVI(26)	Most frequently used coping mechanisms

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Statistical Analysis.

Patients' socio-demographic and clinical characteristics and caregivers' characteristics (Tab. 3; Tab. 4) were analysed by means of descriptive statistics and frequencies. Levels of family burden, coping strategies and stigmatized behavior were analyzed by means of descriptive statistics or frequency analysis. In addition, Pearson's Rho coefficient was calculated to assess the degree of correlation between the main socio-demographic characteristics of family members and socio-demographic and clinical characteristics of patients and the type of coping strategies and level of stigmatisation reported by family members. Data analysis was performed using SPSS statistical software, version 18.0 (2009); the level of statistical significance was set at $p < 0.05$.

RESULTS

Socio-demographic and clinical characteristics

22 patients were recruited, of whom 7 did not complete the interview. The study was offered to 22 caregivers, of whom 12 accepted and completed the interview. Therefore, the final sample consists of 12 patients and 12 caregivers.

From the data summarized in Table 3, it emerges that, of the 15 patients recruited, 53.4% had a diagnosis of schizophrenia or other psychotic spectrum disorder, 13.3% bipolar disorder, 6.7% depressive disorder, 13.3% anxiety disorder and another 13.3% obsessive-compulsive disorder. 53% of the patients were male and the sample had an average age of 45+12 years, while the average age of onset of the disorder was 27+11.3. With regard to marital status, 53.3% of the patients are married, while the others are single or separated. 70.0% of the patients live with their partner/spouse or with their family of origin and only 6.7% of the patients live alone out of necessity.

The severity of clinical symptoms was assessed by experienced professionals using the Brief Psychiatric Rating Scale (BPRS). Data analysis showed an average score of 31.13÷11.24. The patients' psychosocial and occupational functioning assessed by the Global Assessment of Functioning (GAF) was 62.2+22.72 (Tab. 3). Moreover, the sample presents a medium-low level of perceived expressed emotion (LEE: 0.31±0.19) and a rather high level of recovery (RAS-DS: 103.73+18.55). In particular, the domain presenting a better level of recovery is "doing things I value" (71.16+16.38), whereas "mastering my illness" appears to be the most impaired (64.04:15.94) (Tab. 3).

Table 3. *Socio-demographic and clinical characteristics of the patient sample.*

Sex M, % (N)		53.3 (8)
Age, M (ds)		45 (±12)
Marital status, %		
	Married	53.3
	Separated	20.0
	Single	26.7
Household composition, %		
	They live alone out of necessity	6,7
	Unmarried, they live with their family of origin	20.0
	They live with their spouse and their family of origin	20.0
	They live with a partner	40.0
	Other	13.3
Children, M (ds)		2.4 (±12)
Employment, %		
	Employed	40.0
	Unemployed	53.3
	Unable to work	6.7

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Education, %		
	Middle school degree	53.5
	High school degree	40.0
	Bachelor's or Master's degree	6.7
Years of education, M (ds)		10.6 (±3.15)
Current disorder, %		
	Schizophrenia/other related psycotic disorders	53.4
	Bipolar and related disorders	13.3
	Depressive disorder	6.7
	Anxiety disorder	13.3
	Obsessive-compulsive disorder	13.3
Comorbidity, %		
	Schizophrenia/other related psycotic disorders	13.3
	Bipolar and related disorders	6.7
	Depressive disorder	20.0
	Anxiety disorder	20.0
	Obsessive-compulsive disorder	40.0
Onset age, M (ds)		27 (±11.3)
Family history for psychiatric pathology, Yes%		46.7
Previous admissions, Yes %		53.4
Current suicidal ideation, No %		86.6
Previous suicidal ideation, No %		80.0
Current suicidal ideation, No %		93.3
Previous suicidal ideation, No %		93.3
Brief Psychiatric Rating Scale, M (ds)		31.13 (±11.24)
Global Assessment of Functioning, M (ds)		62.2 (±22.72)
Coping Orientation to Problems Experienced – New Italian Version, M (ds)		
	Social support	2.46 (±0.41)
	Avoidant strategies	1.75 (±0.31)
	Positive attitude	2.71 (±0.42)
	Problem solving	2.46 (±03.8)
	Turning to religion	1.63 (±0.51)

Level of Expressed Emotion Scale, M (ds)	0.31 (±0.19)
Recovery Assessment Scale - Domains and Stages, M (ds)	
Tot	103.73 (±18.55)
Doing things I value	71.66 (±16.38)
Looking forward	68.24 (±12.78)
Mastering my illness	64.04 (±15.94)
Connecting and belonging	69.52 (±13.55)

Regarding the sample of caregivers, they are predominantly female (75%), with an average age of 45.2 (±5,3) years, they are generally patients' spouses (93.3%) and they spend an average of 8.3 hours a day (±3,9) with them (Tab. 4). The caregivers of the interviewed patients present an average level of courtesy stigma (CPMI: 1.98±0.61) and the highest levels of stigma are found mainly concerning the affective component (2.32±0.83) (Tab. 4). The Mental Health Knowledge Schedule (MAKS-I) reveals average/poor knowledge regarding mental health (3.4±0.52) (Tab. 4).

Table 4. *Characteristics of the caregiver sample.*

Sex F, % (N)	75% (9)
Age, M (ds)	45.2 (±5.3)
Relationship, %	
Coniuge	93.3
Genitore	6.7
Hours per day spent with the patient, M (ds)	8.3 (±3.9)
Stigma scale for Caregivers of People with Mental Illness, M (ds)	
Tot	1.98 (±0.61)
Affective component	2.32 (±0.83)
Cognitive component	1.96 (±062)
Behavioral component	1.70 (±0.50)
Coping Orientation to Problems Experienced – New Italian Version, M (ds)	
Social support	1.62 (±1,06)
Avoidant strategies	1.20 (±0.68)
Positive attitude	2.24 (±1.19)
Problem solving	2.38 (±0.49)
Turning to religion	2.39 (±1.45)

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Family behaviour questionnaire, M (ds)		
	Information	1.62 (±0.64)
	Positive communicazion	4.0 (±0.81)
	Avoidance	1.20 (±0.33)
	Resignation	1.63 (±0.62)
	Social involvement of the patient	3.63 (±1.61)
	Collusion	4.45 (±1.05)
	Coercion	4.0 (±0.78)
	Mantening social interests	2.59 (±0.68)
	Spirituality	4.0 (±2.08)
	Talking to friends	1.66 (±0.38)
	Alcohol and drugs	1.0 (±0)
Mental Health Knowledge Schedule - I (I), M (ds)		3.4 (±0.59)

Correlation analysis

Pearson's linear correlation analysis of the collected data shows that all the investigated domains of recovery correlate negatively with stigma in its three components (affective, behavioral and cognitive) (Tab. 5). As the levels of courtesy stigma in the caregiver increase, the patient's levels of recovery decrease. In particular, the domains of recovery and stigma that present a more significant correlation are looking forward-cognitive component.

Table 5. *Pearson's linear correlation analysis between caregiver courtesy stigma (CPMI) and level of recovery (RAS-DS).*

	Affective	Cognitive	Behavioral	CPMI Tot
Recovery Assessment Scale - Domains and Stages				
Tot	-0.928**	-0.881**	-0.890**	-0.944**
Doing things I value	-0.848**	-0.718**	-0.739**	-0.813**
Looking forward	-0.862**	-0.876**	-0.796**	-0.887**
Mastering my illness	-0.828**	-0.712**	-0.717**	-0.796**
Connecting and belonging	-0.626*	-0.618**	-0.827**	-0.712**

Notes: $^{*}p<0.05$; $^{**}p<0.01$

Moreover, patients' recovery also correlates with their perceived expressed emotion (Tab. 6): as perceived EE levels increase, recovery levels decrease. Specifically, the negative correlation is particularly evident between perceived EE and the domain of recovery "doing things I value", but no correlation was found with the domain "mastering my illness". Finally, a positive correlation also emerged between the patient's perceived EE and the degree of courtesy stigma in the caregiver (Tab. 6): thus, as the level of perceived EE increases, so does the level of affiliated stigma (specifically within the affective component).

Table 6. *Pearson's linear correlation analysis between level of recovery (RAS-DS) and perceived EE (LEE) and between the latter and caregiver courtesy stigma (CPMI)*

		Level of expressed emotion scale Tot
Recovery Assessment Scale - Domains and Stages		
	Tot	-0.664**
	Doing things I value	-0.724**
	Looking forward	-0.563*
	Mastering my illness	-0.488
	Connecting and belonging	-0.556*
Stigma scale for Caregivers of People with Mental Illness		
	Tot	0.595*
	Affective	0.683*
	Behavioral	0.551
	Cognitive	0.433

Notes: *$p<0.05$; **$p<0.01$

Discussion

The living conditions of people with mental disorders depend not only on the severity of their pathology, but also on the degree of acceptance of the illness within their family and society. It is very evident how public opinion tends to spread a prejudiced image of psychiatric patients, reinforcing the image of the latter as bizarre, different, dangerous. In this context, the negative experience of stigma is realised. Family plays a central role in the life of a person with a mental disorder and, unfortunately, stigma also involves the family members of the patient with a mental disorder [16]: in a study by Angermayer [17] almost two thirds of the interviewed caregivers experienced stigma (social exclusion, loss of friends, being ignored by medical personnel, being blamed by others for the relative's mental illness). A more recent study by Gaolaolwe [18, 19] highlights how caregivers of psychiatric patients experience community rejection (by relatives, friends, neighbours, employers), feelings of guilt and shame, and how this condition implies impaired physical health as well as emotional distress, frustration and anger. Wong et al [20] analyse how they begin to question their place in society as a result of discrimination experienced due to the presence of a family member with mental health difficulties; while Chang et al [21] note how these family members would also experience a greater decrease in self-esteem, increased anxiety and more severe depression. However, among the concepts relating to stigma in mental health and its possible declinations, affiliated stigma appears to be the least explored; in fact, there are not many studies in the literature on the influence of courtesy stigma on the course of patients' psychiatric illness, i.e. on the recovery process and EE levels.

Therefore, the present study focused on this aspect with the aim of assessing whether courtesy stigma in the caregiver interferes with the patient's recovery process. The hypothesis that the caregiver's affiliated stigma can negatively influence the recovery process was confirmed by our results: it was found that there is a negative correlation between the patients' level of recovery and the affiliated stigma. Other studies had already shown that caregivers on the one hand are often the only source of social support and provide the patient with basic care, but on the other hand they can experience the destructive influence of courtesy stigma, making support for the patient insufficient [22]. In particular, if we consider stigma in its three components (affective, cognitive, and behavioral) and recovery in its four domains (doing things I value, looking forward, mastering my illness, connecting and belonging), it is observed that the strongest correlation concerns the domain "looking forward" and the stigma cognitive component. Therefore, in the context of a high courtesy stigma perceived by the caregiver, the patient's chances of developing feelings of confidence and hope regarding their ability to manage the future and their symptomatology are very low.

In addition, there are several studies in the literature which point out that another important factor in the recovery process is EE, which is an index of family stress: some of them demonstrate the significant predictive power of family EE towards relapse [23]; others focus on the correlation between high levels of EE and poor outcome [24] or treatment

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abandonment [25]. A secondary endpoint was to test the relationship between the levels of EE perceived by the patient and the levels of recovery: data show that as perceived EE levels increase, recovery levels decrease [26]. In particular, the negative correlation is quite evident between perceived EE and the recovery domain "doing things I value", while there is no correlation with the domain "mastering my illness". Finally, the relationship between the patient's perceived EE and the degree of courtesy stigma in the caregiver was also investigated: the results show that as the former increases, so does the level of affiliated stigma (particularly its "affective" component).

Although the final results coincide with the initial hypothesis and with what was found in the literature, this study presents some limitations: the small sample size; the heterogeneity of the pathologies taken into account and their seriousness; the relatively homogeneous sample of caregivers. Therefore, these correlations should be reconfirmed by enlarging the sample size and using a sample that takes into account the above-mentioned limitations. On the other hand, a strength of this study is the presence of a fairly heterogeneous sample by pathology. However, it would be appropriate to extend the results to patients with mental disorders other than those considered in this study, in particular patients with obsessive compulsive disorder and patients with eating disorders.

CONCLUSIONS

Stigma is a phenomenon that affects not only the patient, but inevitably also the patient's entire family. Family, being in most cases the patient's main source of support, should be protected from the destructive influence of courtesy stigma, which has clear negative implications on the patient's medical history as well as on the recovery pathway.

Similarly, high levels of EE perceived by the patient also negatively affect his or her recovery. Therefore, family members cannot be totally excluded from the recovery programmes of people with mental disorders, as they are an active party in hindering or facilitating this pathway. Useful for this purpose may be the provision of anti-stigma and psycho-educational interventions for family members of people with mental disorders, in order to promote the idea of families as allies in the recovery process and to meet the needs expressed by families for inclusion, information, support, behavior management and problem solving.

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Informed consent was obtained from all subjects involved in the study.
No additional data were created over and above those reported.
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