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# Structural Stigma, Affiliated Stigma and Consequences of Caregiving for the Family Members of Inpatients with Dementia: A Comparative Approach

Catalina TUDOSE[1], Raluca SFETCU[2], Cristiana DOBRE[3], Maria MOGLAN[4]

## Abstract

Stigma has been identified as one of the major causes for delayed help-seeking in patients with psychiatric disorders. However, the family members of the psychiatric patients are also affected by the negative image of the disease at societal level, phenomenon referred to as courtesy or affiliated stigma. Affiliated stigma is acquired through having a relationship with a stigmatized individual and it refers to a set of negative believes and affects which may lead to withdrawal from interpersonal relationships. Another adverse consequence of the psychiatric disorders for relative is encompassed in the concept of family or caregiver burden. *The objective* of this study was to assess the perceptions and experiences of stigma (associated stigma and structural stigma) as well as the burden of care among the relatives of persons with mental disorders who were admitted in a psychiatric hospital in Bucharest and to compare between relatives of patients with dementia versus other mental health disorders. In terms of structural stigma 43.7% consider that the existing services are not adequate for the needs of the patient. In conclusion affiliated stigma rates are similar to the ones experienced in other European countries but the burden of care, especially in the areas of tension and supervision is higher. The lack of services can contribute to this situation as the perception of the family members is that the current system provides inadequate care for their family members. Further research in the area is needed in order to better understand the needs of family members.

*Keywords*: affiliated stigma, burden of care, Involvement Evaluation Questionnaire (IEQ), structural stigma.

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## Introduction

Stigma has been identified as one of the major causes for delayed helping-seeking in patients with psychiatric disorders. However, the family members of the psychiatric patients are also affected by the negative image of the disease at societal level, a study in Israel showing that family stigma may prevent adult child, spousal, and other family caregivers from seeking services for their loved ones (Werner & Heinik, 2008). The stigma of the family members, also called courtesy or affiliated stigma, is acquired through having a relationship with a stigmatized individual and it refers to a set of negative believes and affects which may lead to the withdrawal of the affected individual from interpersonal relationships and has been described as the caregivers' internalized public stigma towards the patient (Mak & Cheung, 2008). Studies of the affiliated stigma phenomenon have been conducted in different geographical and cultural settings in the last few decades. Courtesy stigma was reported by 16% of family members of psychiatric patients in U.S.A. (Phelan, Bromet, & Link, 1998), by 41% in Morocco (Kadri, Manoudi, Berrada, & Moussaoui, 2004), by 6% to 40% (for individual stigma items) in Sweden (Östman & Kjellin, 2002), 20% in Canada (Stuart, Koller, & Milev, 2008) and 28% of relatives in China reported a moderate to severe impact of stigma on family life (Phillips, Pearson, Li, Xu, & Yang, 2002).

A recent study which explored the relationship between family stigma and caregiver burden among adult children of persons with Alzheimer's disease in Israel showed that caregiver stigma increased caregiver burden more than either layperson or structural stigma (P. Werner, Mittelman, Goldstein, & Heinik, 2012).

The family or caregiver burden is a concept that refers to the adverse consequences of psychiatric disorders for relatives and it has its origins in the early 1950s when feasibility studies of discharging patients into the community were conducted. More recently, the burden of care has become an outcome variable in program evaluations and controlled clinical trials (A. H. Schene, Tessler, & Gamache, 1996). Currently, the concept of caregiver burden is viewed as a construct encompassing both subjective and objective components, representing a multidimensional response that includes the physical, psychological, emotional, social, and financial consequences experienced by family members (Zarit, Reever, & Bach-Peterson, 1980). The burden of care was found to have negative repercussions both on the mental health of the informal caregivers of dependent people (e.g. higher depression, anxiety and stress levels) as well as on the physical health (e.g. negative evaluations of their own health, psychosomatic and immunological disorders, cardiovascular problems, and dependency in order to perform the activities of daily life. But the caregiver's burden can also lead to major negative consequences for the dependent person, which often includes premature institutionalization and mistreatment (Carretero, Garcés, Ródenas, &

Sanjosé, 2009). A recent study conducted in Romania offers a potential explanation for this situation, by highlighting a set of behavioral problems which causes distress for Romanian caregivers and can become reasons for hospitalization, behaviors such as: aggressive behavior, over activity, psychosis and delirium but also non-aggressive behavior that required constant monitoring, such as aimless wandering, trying to reach a different place, and restlessness (Szalontay, Burtea, & Ifteni, 2015).

The experience of structural stigma is also a prominent topic in the narratives of the family members, being often related to both the affiliated stigma and burden of caregiving experienced, as shown by recent qualitative research (Werner, Goldstein, & Buchbinder, 2010). Structural stigma has been defined as the imbalances and injustices in social structures, political decisions, and legal regulations. It includes poor quality of health care services and inadequate behavior of professionals (Corrigan, 2005). Structural stigma includes cognitive or causal attributions (i.e. insufficient knowledge among primary care physicians and other professionals, as well as to a restricted range of available services and/or access to those services) and behavioral attributions (i.e. patients and relatives themselves receiving differential and poorer treatment because of the disease of the patient). While the relation between affiliated stigma and structural stigma as well as the one between affiliated stigma and burden of care have been previously studied, to our knowledge this is the first study that aims study all three above mentioned concepts. Furthermore, we also investigate these relations in a comparative way, by separating between people with a memory related diagnostic (i.e. dementia) and people with other psychiatric diagnostics.

## Methods

The relatives of persons admitted for two consecutive months (1 February – 31 March 2017) to an acute inpatient unit of a psychiatric hospital in Bucharest have been invited to complete a questionnaire that included: a) a demographic data section for the patient (date of birth, gender, marital status, educational status, accommodation type, services used in the last 2 months, psychiatric diagnostic, date since first diagnostic); b) a demographic data section for the family member (date of birth, gender, marital status, educational status, the relationship with the patient, whether the relative lives with the patient or not, period of time for which the relative has been provided care to the patient, the average number of hours spent caring for the patient, whether the relative is caring for the patient alone and whether the relative has benefited from services for family members in the past); c) the Affiliate Stigma Scale (ASS); d) the structural stigma component of The Family Stigma in Alzheimer's disease Scale (FS-ADS); and e) the Involvement

Evaluation Questionnaire (IEQ). The 75 beds psychiatric unit has no diagnostic limitation for admission and, additionally, no diagnostic based exclusion criteria have been employed, provided that the relatives have given their consent to participate to this research. The invitation to participate has been extended to a total number of 311 relatives by a nurse (all admissions made in the time interval of two months), with the indication to anonymously fill in the questionnaire and deposit it in a box at the end of the visit.

### *Affiliate Stigma Scale*

The Affiliate Stigma Scale was initially developed and used to assess the self-stigma of caregivers providing care to a family member with a mental illness or intellectual disability (Mak & Cheung, 2008), and subsequently adapted for use with caregivers of a family member with dementia (Chang, Su, & Lin, 2016). The instrument has 22 items rated on a 4-point Likert scale with three domains: a) cognitive(7 items; e.g. “Others will discriminate against me if I am with my family member with a mental disorder”); b) affective (7 items; e.g. “I feel inferior because one of my family member has a mental disorder”); and c) behavior(8 items; e.g. “I avoid communicating with my family member with a mental disorder”). A higher score indicates a higher level of affiliate stigma. The Affiliate Stigma Scale was found to have good internal consistency ($\alpha = 0.85 - 0.94$) as well as predictive and concurrent validity (Chang *et al.*, 2015; Mak & Cheung, 2008).

### *Involvement Evaluation Questionnaire (IEQ)*

The Involvement Evaluation Questionnaire assesses the frequency of a broad array of consequences of caregiving (e.g. feelings, cognitions, behaviors) within the previous 4 weeks. All items are scored on 5-point Likert scales (never, sometimes, regularly, often, always) Besides its total score, the IEQ includes four subscales: worrying (6 items), urging (8 items), tension (9 items) and supervision (6 items). Tension refers to the strained interpersonal atmosphere between patient and relatives, supervision to the caregiving tasks of ensuring and guarding related to e.g. patient’s intake of medication, sleep or dangerous behaviors, worrying to painful cognitions and concerns about patient’s safety or future, and urging to issues related to activating and motivating the patient (e.g. to take care of himself, to eat). Higher scores mean higher levels of caregiver consequences. The IEQ was originally developed in Dutch and proved to have a good internal consistency with á values between 0.74-0.85 for the four sub-scales and 0.90 for the sum score

(A. Schene & Van Wijngaarden, 1992). The questionnaire was subsequently translated in a number of languages and cross-culturally validated in Europe in the EPSILON study. The reliability of the IEQ in the five EPSILON was also found to be satisfactory, with á values ranging from 0.68 to 0.86 for the sub-scales and from 0.87 to 0.91 for the sum score (Wijngaarden *et al.*, 2000).

### *Structural stigma (FS-ADS)*

To assess the structural stigma, we have used a scale from The Family Stigma in Alzheimer's disease Scale (FS-ADS) (Werner, Goldstein, & Heinik, 2011). The scale was developed based on a qualitative study (P. Werner *et al.*, 2010) and consist of two factors: a) one reflecting structural discrimination (e.g. "To what extent do you think that there are adequate community services for persons with mental disorders") and the other professionals' attitude to the person with mental illness. Both factors had excellent internal consistency with Cronbach's $\alpha$ values of 0.96, respectively 0.88v (Werner *et al.*, 2011)

Originally the affiliated stigma scale and the structural stigma FS-ADS have been developed for use with relatives of patients with dementia and the Involvement Evaluation Questionnaire for relatives of persons suffering from schizophrenia. However, both have been used with other population categories. For our study we have translated and adapted these instruments by replacing the specific diagnostic categories with the more generic term of mental disorders. In terms of data analysis, group comparisons were carried out with the Student's t test for continuous variables. For categorical variables, differences in proportions were tested with the chi square test. The statistical software package IBM SPSS 23.0 were used for all analyses.

## Results

A total number of 76 questionnaires (24.4%) have been returned. The relatives were mostly female (60.5%), aged m=52.4 (min= 28, max = 84, STD =11.4) from urban areas (71.1%), married (92.1%) and they were not the only career of the patient (52.6%). In terms of education, the majority of the respondents have finalized a secondary education program (55.3%) and around one third (36.8%) had a bachelor diploma. The patients were also mostly females (61.8%), had an average age of m=63.9 years (min= 27, max = 86, STD =14.8) and had mostly a diagnostic of Dementia (53.9%), followed by Psychotic (18.4%) and Depressive disorders (17.1%). Most of the patients were still married (55.3%) followed by the category of widowers (28.9%). In terms of education, half of the patients have finalized a secondary education program (50.0%) and around one quarter (26.3%) had a bachelor diploma. Most of the patients still lived with their partners (48%)

or alone (with children=17.3% or without children=14.7%). Only 12% of the patients still lived with their parents.

*Table 1.* Distribution of participants by the diagnostic of the family member they care for

| Diagnostic category | Frequency | Valid Percent | Cumulative Percent |
|---|---|---|---|
| Psychotic disorder | 14 | 18.4 | 18.4 |
| Depressive disorder | 13 | 17.1 | 35.5 |
| Bipolar disorder | 6 | 7.9 | 43.4 |
| Anxiety disorder | 2 | 2.6 | 46.1 |
| Dementia | 41 | 53.9 | 100.0 |
| Total | 76 | 100.0 | 100.0 |

In terms of affiliated stigma, the percentage of family members affected ranges from 10,4% (for the behavioral dimension) to 22,6% for the affective dimension (for details see *Table 2*).

*Table 2.* Absolute and relative frequencies for individual items of the Cognitive (C), Affective (A) and Behavioral (B) dimensions of the Affiliated Stigma Scale (evaluation on 4 point Likert scales; 1=Strongly agree; 2=Agree; 3=Disagree; 4=Strongly disagree)

|  | Strongly Agree & Agree | Strongly Disagree & Disagree |  | Strongly Agree & Agree | Strongly Disagree & Disagree |  | Strongly Agree & Agree | Strongly Disagree & Disagree |
|---|---|---|---|---|---|---|---|---|
| C1 | 16 (31.4%) | 35 (68.6%) | A1 | 10 (13.2%) | 66 (86.8%) | B1 | 9 (11.8%) | 67 (88.2%) |
| C2 | 12 (15.8%) | 64 (84.2%) | A2 | 15 (20.0%) | 60 (80.0%) | B2 | 6 (7.9%) | 70 (92.1%) |
| C3 | 13 (17.1%) | 63 (82.9%) | A3 | 11 (14.7%) | 64 (85.3%) | B3 | 5 (6.6%) | 72 (93.4%) |
| C4 | 18 (23.7%) | 58 (76.3%) | A4 | 16 (21.1%) | 60 (78.9%) | B4 | 9 (12.0%) | 66 (88.8%) |
| C5 | 5 (6.6%) | 68 (93.4%) | A5 | 42 (55.2%) | 34 (44.8%) | B5 | 10 (13.3%) | 65 (86.7%) |
| C6 | 8 (10.5%) | 68 (89.5%) | A6 | 10 (13.2%) | 66 (86.8%) | B6 | 8 (10.7%) | 67 (89.3%) |
| C7 | 4 (5.3%) | 72 (94.7%) | A7 | 16 (21.1%) | 60 (78.9%) | B7 | 7 (9.6%) | 66 (90.4%) |
| - | - | - | - | - | - | B8 | 9 (12%) | 66 (88%) |
| Avr | 15.7% | 84.3% | Avr | 22.6% | 87.4% | Avr | 10.4% | 89.6% |

The highest agreement frequency (55.2%) for individual questions was found for an item from the ASS affective dimension (A5: "I feel sad because I have a family member with mental disorder") while the lowest agreement frequency was or an item from the ASS cognitive dimension (C7: "Having a family member with a mental disorder makes me lose face". When separated by diagnostic category into dementia versus other (includes psychotic, depressive, bipolar, anxiety disorders), the only scale for which significant differences appeared is the affective dimension, on which relatives of people with a diagnostic other than dementia being more affected by the affiliated stigma than the relatives of people suffering from dementia.

*Table 3:* Differences between dichotomized frequencies for agreement (i.e. total mean score lower vs. higher than the average) on the three Affiliated Stigma Scale dimensions by diagnostic category (dementia vs. other (psychotic, depressive, bipolar, anxiety disorders))

| Frequencies | Dementia | Other | Total |
|---|---|---|---|
| Lower than the average Cognitive dimension | 11 (26.8%) | 12 (34.3%) | 23 (30.3%) |
| Lower than the average Affective dimension* | 13 (31.7%) | 23 (65.7%) | 36 (47.4%) |
| Lower than the average Behavioral dimension | 12 (29.3%) | 15 (42.9%) | 27 (35.5%) |

Note: Significant at $p<0.05$ (Chi-square test)

In terms of burden of care, mean differences as compared with the Epsilon study have been found for the dimension Tension (for other diagnostics) and for the dimension urging (al diagnostics). Significant differences between dementia and other diagnostic categories have been found for the dimension Tension and for Supervision. While tension seem to affect more the relatives of people suffering from mental disorders other than dementia, supervision contributes more to the burden of care of relatives with dementia (for details see *Table 4*).

*Table 4.* Average scores for the four dimensions of the Involvement Evaluation Questionnaire (IEQ)

| | Diagnostic category | N | Mean | Std. Deviation |
|---|---|---|---|---|
| Tension* | Other diag. | 33 | 20.0 | 5.4 |
| | Dementia | 36 | 15.4 | 5.0 |
| | EPSILON study | 278 | 14.6 | 5.3 |
| Supervision* | Other diag. | 34 | 17.0 | 4.9 |
| | Dementia | 40 | 20.4 | 6.5 |
| | EPSILON study | 278 | 8.3 | 3.8 |
| Worrying | Other diag. | 29 | 17.0 | 4.4 |
| | Dementia | 34 | 16.7 | 6.0 |
| | EPSILON study | 278 | 15.6 | 6.3 |
| Urging | Other diag. | 34 | 29.1 | 7.0 |
| | Dementia | 36 | 29.4 | 7.8 |
| | EPSILON study | 278 | 15.4 | 6.4 |

*Note:* Mean diferences are significant at $p<0.05$ (calculated with t-test)
*Results from our study as compared with results from the EPSILON study (Wijngaarden* et al.*, 2000)*

In terms of structural stigma, 99.3% of the respondents consider that the professionals' attitude to the person with mental illness is not a stigmatizing one. However, in terms of availability of the services, 43.7% consider that the existing services are not adequate for the needs of the patient. When comparing the relatives of patients with a dementia diagnostic with the patients of other psychiatric diagnostic categories, significant differences are visible only for the professional relations dimension, with the relatives of persons with dementia holding a more positive view than the other relative categories.

## Discussion

To the best of our knowledge, this is the first study in Romania to employ structured instruments to examine the experiences of both stigma and burden among relatives of persons with mental disorders in a comparative way. For the affiliated stigma of the family members, we have found that it ranges between 5.3% and 55.2% for individual items and between 10.4% and 22.6% for the three scales of the Affiliated Stigma Scale, rates which are similar with those found by colleagues in other countries (Kadri *et al.*, 2004; Ostman, 2004; Phelan *et al.*, 1998; Phillips *et al.*, 2002; Stuart *et al.*, 2008). In terms of burden of care, our results show higher levels of burden of care by comparison with averages of pooled datasets from five sites in Europe (i.e. Amsterdam, Copenhagen, Santander and Verona) as they were reported by the EPSILON study (van WIJNGAARDEN *et al.*, 2000), especially for the tension and supervision scales. Tension refers to the strained interpersonal atmosphere between patient and relatives and, taking into account that psychotic disorders was the second most well represented in our total sample (after dementia) the fact that the scores for tension are higher for the relatives of people suffering from other mental disorders by comparison with dementia is not a too surprising finding. It is also conforming to expectation that supervision scores are higher for relatives of dementia by comparison with other disorders. However, a surprising finding is that the scores for supervision are more than double for other mental disorders and almost three times higher for relatives of patients with dementia by comparison with the EPSILON study. This might in fact indicate that in order to care for their ill family members, relatives in our country have to take over on themselves more of the care process to compensate for the lack of availability or diversity of existing services. This hypothesis seems to be also encouraged by the results we obtained on the structural stigma scale, 43,7% of our respondents considering the existing services to be inadequate for the needs of their relative. However, these results should be interpreted with caution as our study is not without limits. One of the main limitation of this research derives from the self-selection of the sample of participants (almost 50% of the participants are relatives of patients with dementia), which combined with the low response rate (24,4%) contributes to a low level of generalizability for our results. Another limitation is total number of respondents (76) which combined with a high heterogeneity of the sample (e.g. in terms of diagnostic) has prohibited us to run more advanced data analysis. However, this being the first study of this kind we consider our results to be useful in informing future research in the area for which we suggest that a narrower design and increased number of participants should be envisaged.

## *Implications for policy and practice*

The need for more research on possible interventions aimed both at the patients and their caregivers in order to maintain the individuals with dementia as long as possible in their settings was previously highlighted (Szalontay, Burtea, & Ifteni, 2015). However, in order to limit the negative consequences of care on the family members, harm reduction and preventive strategies should be taken into consideration. Based on our result we highlight a few implications for policy and practice as well as more specific area for interventions. Developing an anti-stigma program directly targeted to reduce the affiliated stigma of the family members and the development of services to offer more support to burdened caregivers represent two examples of system level interventions. Additionally, if we are taking into account that high level of burden put the family members into a vulnerable position, introducing a screening for burden of care is needed to identify individual family members at risk and target them with tailored mental health prevention programs.

## Conclusion

To the best of our knowledge, this is the first study to look at the experiences of stigma and burden of care among relatives of persons with schizophrenia. We have found affiliated stigma rates to be similar to the ones experienced in other countries but the burden of care, especially in the areas of tension and supervision to be higher than in other European countries. The lack of services can contribute to this situation as the perception of the family members is that the current system provides inadequate care for their family members. Further research in the area is needed in order to better understand the needs of family members in terms of specific services which need to be develop in order to reduce the affiliated stigma and the burden of caregivers of persons with mental disorders in general and of dementia in particular.

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