

## Research Paper

# Factors Affecting Burden on Caregivers of Patients with Major Mental Disorders: The Role of Patients' Functionality and Caregivers' Sense of Family Support

A. EVMOLPIDI, A. TSELEBIS, A. PACHI, K. GIOTAKIS, D. BRATIS, D. LEKKA, A. KARKANIAS, G. MOUS-SAS

### Summary

**Keywords:** burden, family support, major mental disorders, primary caregiver

*Literature suggests that the care of patients with major mental disorders can place a significant burden on caregivers. Aim of this study was to assess burden and sense of family support in caregivers of patients with major mental disorders in relation to disease severity and level of functionality. The Zarit Burden Interview and the Family Support Scale (FSS) were administered in a sample of 152 primary caregivers of a corresponding number of patients hospitalized in a Psychiatric Department of a General Hospital during one year, diagnosed with schizophrenia or mood disorder according to ICD-10. Patients' functionality was assessed with Global Assessment of Functioning Scale (Global Assessment of Functioning, GAF). Individual and demographic variables of patients and their caregivers along with clinical variables from the psychiatric history of patients were recorded. Parents as caregivers ( $p=0.02$ ), unemployed caregivers ( $t=2.99$ ,  $p=0.003$ ), caregivers of patients diagnosed with schizophrenia compared with caregivers of patients diagnosed with mood disorders ( $t=2.4$ ,  $p=0.018$ ) and of patients who were hospitalized under compulsory admission ( $t=3.18$ ,  $p=0.002$ ), stated higher burden levels. Disease duration ( $r=0.188$ ,  $p=0.002$ ), number of hospitalizations ( $r=0.329$ ,  $p=0.000$ ) and caregiver's age ( $r=0.239$ ,  $p=0.003$ ) correlated positively with scores on burden scale. Negative correlations were observed between scores on burden scale and family support scale ( $r= -0.337$ ,  $p=0.000$ ), and between the burden scale and scores on Global Assessment of Functioning Scale ( $r= -0.511$ ,  $p=0.000$ ). Therefore, increased disease severity, patient's reduced level of functionality and the advanced caregiver's age, emerge as important variables predicting high rates of caregivers' burden. Family support, as a protective factor, appears to moderate the burdensome consequences of care.*

## Introduction

Major mental illnesses, mainly schizophrenia and affective disorders, are usually expected to run a chronic course with varying trajectories, sometimes in the form of a steady or gradually deteriorating course and other times with improvements and acute exacerbations with unpredictable effects on outcome<sup>1,2</sup>. These disorders are associated with a substantial degree of distress and daily functional impairment, since the combination of symptoms that a patient exhibits alters thoughts, feelings, and behaviors in distinct ways<sup>3,4</sup>.

Psychiatric symptoms listed in mental disorders display significant heterogeneity among patients, sometimes affecting behavior in varying degrees and causing mild to very severe functional impairment in different areas of life (work, interpersonal relations). Often patients exhibit disorganized behavior and related symptoms that have disruptive consequences for the patient and lead to negative repercussions in the family, as they affect all aspects of life (self-care, vocational, social, family relationships, lack of autonomy)<sup>5,6</sup>.

Taking care of a relative with mental illness raises all sorts of feelings in caregivers who usually belong to the care recipient's immediate family<sup>7</sup>. In this way families are overwhelmingly the primary and often the major source of support for their family member with mental disorder, who exerts a strong influence upon other family members<sup>8</sup>. Family burden implies the negative outcomes of the home care situation. Studies more or less agree about the different aspects of burden and most of them make some distinction in objective and subjective consequences<sup>9</sup>. Objective consequences include any agent disrupting family life due to problems associated with taking care of the patient. These agents impact on family finances, interpersonal relations, members' health, social life, work, leisure time. Subjective consequences arise from the psychological distress that caregivers experience while coping with these caregiving tasks and problems. Most frequently reported feelings experienced by caregivers are sadness, anger, embarrassment, frustration, despair, shame, guilt.

Literature suggests that the term primary- informal caregiver<sup>10</sup> is assigned to relatives or friends or even people beyond the immediate family, who are caring for a patient with a severe disease and chronic care needs (dementia, cancer, brain damage, mental illness). In other words, caregivers

are those who bear the entire burden of care, so we relate the meaning of caregiving with the concept of burden. The term burden signifies what is difficult to endure either physically or emotionally.

As one result of deinstitutionalization policy over the last 60 years, most of the care for people with serious mental illnesses now resides with informal caregivers, who are often required to compensate for the lack of community resources. Available data show that 40-90% of patients with severe mental illnesses live with their families<sup>11</sup>, often served as an extension of the mental health system. As a result, families constitute the basic source for receiving support and feedback, while also appearing to function protectively against stressful events<sup>12</sup>. Family environments play a central role as moderators of the course of severe psychiatric illnesses, even if the direct causal role of family factors cannot be established<sup>13</sup>. Alternatively stated, underlying disturbances in family systems may be evoked by the emergence of illness symptoms in one or more family members, but these disturbances have recursive effects on the course of the individual's disorder. The lack of a family network or the existence of disturbed relations inside the nuclear or extended family environment appears to relate with higher stress levels and depression, impacting family caregivers<sup>14</sup>. On the other hand, a high degree of sense of family support that a caregiver receives from the members of his family appears to alleviate the burden<sup>15</sup>.

The mental and physical health implications of caregiving depend on the characteristics of recipients of care and their disease (age, gender, severity and type of symptoms, number of episodes), their own characteristics (gender, proximity to patient, personality characteristics, socioeconomic and cultural characteristics, subjective beliefs and attitudes)<sup>16,17</sup>, and other external factors (social and family support, stigma, accessibility to health services)<sup>18</sup>.

Research indicates that<sup>19</sup>, classification of mental disorder, type and severity of psychiatric symptoms<sup>20</sup>, duration and course of the disorder, aberrant behavior (aggressive, disorganized, bizarre behavior)<sup>21</sup>, functional impairment<sup>22</sup>, insight, degree of caregiver- patient mutual contact<sup>23</sup>, a supportive environment, the adequacy of mental health services<sup>25</sup> and accessibility to them<sup>26</sup> along with the stigma associated with mental illness<sup>27</sup>, are all factors that contribute to the burden of care.

Previously, caregivers' burden has been studied for determining the feasibility of discharging

a patient into community, usually under the family's protection, considering that the majority of these patients remain functionally impaired with inter-episodic symptoms. Afterwards, the scientific interest has been broadened to involve the physical, psychological, social, and financial problems experienced by families caring for a relative with a chronic or mental illness<sup>28</sup>. In recent years, there is a global movement toward enhancing the positive and protective factors that could mediate or moderate caregiver burden or ways to promote caregivers' resilience<sup>29</sup>. Family and social support appears to be an important protective factor counteracting family burdens in diverse cultures<sup>30,31</sup>.

## Aim

Purpose of the study is to evaluate burden and sense of family support in caregivers of patients diagnosed with major mental disorders, in relation to disease severity and level of functionality. Secondary purpose is to answer the following research questions:

- 1Is there any correlation between burden or sense of family support in caregivers of patients with mental illnesses and severity of mental illness?
- 2Is there any correlation between the hospital admission process (voluntary or compulsory) and burden or sense of family support?
- 3Is there any correlation with demographic or clinical variables (e.g. illness duration) and the relationship between patient and kinship caregiver?
- 4Are there any predictors of burden and number of hospitalizations among available variables and what is the relative contribution to their variation while controlling for other predictors?

## Method

### Sample

The study included patients diagnosed with schizophrenia or mood disorder according to ICD-10, hospitalized in a psychiatric clinic of a General Hospital, from 1/1/2017 until 31/12/2017, and their caregivers who had the main responsibility for their care. Only one caregiver was recruited per patient. Selection criteria for the caregivers were:

- a Having the most frequent contact with the patient from all other family members.
- b Having the primary responsibility for the

care of the patient for at least one year.

- c Does not exhibit any kind of psychiatric illness, physical or mental disability or substance-related disorder, situations that hinder the caregiver's ability to provide care.

Excluded from the study were individuals with a low level of credibility in terms of their ability to respond to interviews and filling in the questionnaires (insufficient knowledge of the Greek language), not consenting caregivers and patients who did not fulfill the criteria for the diagnosis of schizophrenia or mood disorders according to ICD-10.

## Instruments

*Sociodemographic and clinical variables.* Sociodemographic characteristics of the participants, both patients and their caregivers were recorded, such as age, gender, employment status, relationship of the caregiver to the patient, along with patient's legal status at admission (voluntary or compulsory) and number of hospitalizations.

*Zarit Burden Interview (ZBI).* To assess the degree of subjective burden a 22-item questionnaire<sup>32</sup> was administered to the primary caregiver during the evaluation interview. The questions covered the areas most frequently mentioned by caregivers as problems in providing care for patients with chronic mental illness, including caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the impaired person. The 22 statements reflect the feelings of burden reported by primary caregivers about the impact of the patient's disabilities on their lives and for each item participants are asked to indicate how often they felt that way. The responses are rated on a Likert scale of 0 (never) to 4 (almost always) with a total score of 0–88. The Burden Interview is scored by adding the numbered responses of the individual items. Higher scores indicate higher levels of caregiver burden. Clinical cut-off scores graded ZBI severity as mild (range 0–20), mild to moderate (21–40), moderate to severe (41–60) and severe (61–88). Though the ZBI was initially developed to assess caregiver burden in dementia, it has also shown satisfactory psychometric properties in assessing caregiver burden in schizophrenia<sup>33</sup> and bipolar disorder<sup>34</sup>. ZBI has been translated and validated in Greek in a sample of caregivers of patients with mental disabilities<sup>35</sup>.

*Family Support Scale (FSS).* To evaluate perception

of family support we used the family support scale which aims to record the sense of support that a subject receives from the members of his/her family (with whom he/she lives). The scale consists of 13 items, which are answered on a Likert scale, ranging from 1 "I disagree a lot" to 5 "I agree a lot". The scale is self-administered and it is not recommended to be given to individuals that live alone, since all of the items focus on the interrelations of individuals that live together. High scores correspond to an increased sense of family support. The particular scale has been translated and standardized in Greek language<sup>36</sup>.

*Global Assessment of Functioning (GAF)*. Patients' level of functioning was assessed during their hospitalization with the Global Assessment of Functioning scale of DSM-IV<sup>37</sup>. This is a numerical scale (1-100) used by mental health specialists to measure the social, occupational and psychological functioning of adults<sup>38 30</sup>. The GAF is the modified version of the Global Assessment Scale<sup>38</sup>, which has proven validity and reliability in Greek language<sup>39</sup>.

### **Procedure**

The study protocol was approved by the ethics committee of the Hospital and all participants gave written informed consent. Their participation in the survey was voluntary. Patients were interviewed by a psychiatrist and evaluated on the severity of their disorder and other clinical variables. Caregivers completed the Zarit burden interview and the Family Support Scale between the 3rd and 5th day after patients' admission to the hospital, so that relief for caregivers from hospitalization does not interfere with results. The study was cross-sectional and conducted between January 2017 and December 2017.

### **Statistical Analysis**

SPSS software, version 24, was used for the statistical analysis. All variables were assessed with the use of descriptive statistics and values were expressed as the mean  $\pm$  standard deviation for continuous variables. Statistical significance was set at  $p < 0.05$  (two-tailed).

### **Results**

#### *Sociodemographic profile of caregivers*

The study included 152 primary- informal caregivers with a mean age of  $54.87 \pm 12.84$  years,

predominantly females (54 men, 98 women). The majority of the caregivers were parents (48%), then spouses of patients (21.1%), siblings (18.4%), offsprings (5.3%) and neighbors or friends (7.3%). Regarding employment status 44.7% of caregivers reported being employed and the rest (55.3%) were involved in housekeeping (table 1).

#### *Sociodemographic and clinical variables of patients*

A total of 152 patients participated in the study, 73 men and 79 women, with a mean age of  $41.03 \pm 13.14$  years. The vast majority stated being unemployed (83.4%) whereas only 16.6% reported having a job. Mean duration of illness was  $11.21 \pm 10.34$  years and average number of hospital admissions was  $3.09 \pm 2.59$ . 46.1% of patients were involuntary admitted and the rest (53.9%) were voluntary admitted. Regarding patients' diagnosis 58.6% were diagnosed with schizophrenia and 41.4% with mood disorders (table 2).

#### *Scores on outcome variables*

The mean scores of the caregivers on Zarit Burden Interview and the Family Support Scale were  $39.05 \pm 15.179$  and  $48.06 \pm 11.569$ , respectively. 8.6% of the caregivers expressed severe burden, 35.5% moderate to severe, 44.7% mild to moderate and 11.2% little or no burden. Female caregivers stated reduced sense of family support compared with males ( $45.55 \pm 11.094$  versus  $52.06 \pm 11.283$ ,  $t=3.198$ ,  $p=0.002$ ), results that do not differ significantly from the reference values in the general population (Summary independent t-test  $p>0.05$ )<sup>36</sup>. Mean GAF scores of our patients were  $54.97 \pm 16.04$ .

#### *Differences on outcome variables as to sociodemographic characteristics and the illness profile of patients*

As to caregiver's gender no differences were observed on Zarit Burden Interview scores, but caregiver's relationship to patients revealed significant differences on burden scores (one-way ANOVA,  $p=0.02$ ). Parents as caregivers stated higher burden scores compared with children ( $t=2.027$ ,  $p=0.046$ ) and friends ( $t=2.49$ ,  $p=0.015$ ), (ANOVA Bonferroni). Unemployed caregivers reported higher burden scores ( $t=2.99$ ,  $p=.003$ ) and reduced sense of family support ( $t=-2.012$ ,  $p=0.046$ ).

Caregivers of patients with schizophrenia compared with caregivers of patients with mood disorders had significantly higher burden scores ( $t=2.4$ ,



$p=0.018$ ) and reduced sense of family support ( $t= -2.262$ ,  $p=0.026$ ). No differences were observed as to sociodemographic characteristics (age, gender, relationship with patients, employment status) among caregivers of patients diagnosed with schizophrenia and caregivers of patients diagnosed with mood disorder, indicating that the differences in the caregiving experience and sense of family support between the two groups could not be accounted for by these variables.

Patients with schizophrenia were younger compared with patients with mood disorder ( $38.14\pm 12.69$  versus  $44.86\pm 12.82$ ,  $t= -3.19$ ,  $p= .002$ ), but no other differences in sociodemographic characteristics (gender, employment status) were observed. As to clinical characteristics, there was no significant difference in duration of illness, but patients with schizophrenia were significantly more often hospitalized under compulsory admission compared with patients with mood disorder ( $\chi^2=14.624$ ,  $p= .001$ ). Also, patients with the diagnosis of schizophrenia compared with patients diagnosed with mood disorder had a significantly lower level of functioning ( $t= -3.40$ ,  $p= .001$ ).

Caregivers of patients who were involuntary admitted stated higher burden scores ( $t=3.18$ ,  $p=0.002$ ) and compulsory admitted patients compared with voluntary admitted patients had a significantly lower level of functioning ( $t= -2.85$ ,  $p=0.005$ ).

#### *Correlations among continues variables*

Scores on Zarit Burden Interview correlated positively with total duration of patient illness ( $r=0.188$ ,  $p=0.002$ ), number of hospital admissions ( $r=0.329$ ,  $p=0.000$ ) and number of compulsory admissions ( $r=0.290$ ,  $p=0.000$ ). Also, the age of caregiver correlated positively with burden scores ( $r=0.239$ ,  $p=0.003$ ).

Negative correlations were observed among scores on Zarit Burden Interview and scores on Family Support Scale ( $r=0.337$ ,  $p=0.000$ ) indicating that poor family support was associated with higher burden scores. Total number of admissions ( $r= -0.195$ ,  $p=0.028$ ) and compulsory admissions ( $r= -0.263$ ,  $p=0.003$ ) were negatively associated with the sense of family support. Finally, scores on Global Assessment of Functioning scale correlated negatively with scores on Zarit Burden Interview ( $r= -.511$ ,  $p= .000$ ) and positively with scores on Family Support Scale ( $r=0.257$ ,  $p=0.004$ ).

#### *Differences on illness course (number of hospitalizations) as to burden and family support*

In order to give some indication of the magnitude of the difference between high and low family support and burden, we contrasted patients above and below the median value of scores on family support and burden scales. In this way patients with caregivers defined as high on family support had significantly less compulsory admissions than patients with caregivers defined as low on family support ( $0.61\pm 1.2$  versus  $1.41\pm 1.8$ ,  $t=2.885$ ,  $p=0.005$ ). As expected, patients with caregivers reporting high burden had significantly more total admissions ( $3.73\pm 2.9$  versus  $2.55\pm 2.16$ ,  $t= -2.791$ ,  $p=0.006$ ), and more compulsory admissions ( $1.57\pm 1.86$  versus  $0.72\pm 1.39$ ,  $t= -3.136$ ,  $p=0.002$ ), than patients with caregivers reporting low burden.

#### *Predictors for burden*

Stepwise multiple regression analysis was conducted to identify the best predictors of the dependent variable 'scores on Zarit Burden Interview' among the independent variables that showed significant relationships in the correlation analyses (scores on Global Assessment of Functioning, scores on family support scale, total hospital admissions, compulsory admissions, caregivers' age and illness duration) and to examine their contribution to the variation (expressed as  $R^2$ ) in the dependent variable. The final regression model showed that from all variables entered into the equation, 'scores on Global Assessment of Functioning', 'scores on family support scale' and 'age of caregiver' were significant predictors of 'scores on Zarit Burden Interview', explaining 36.3% of the variance ( $F_{3,121}=23.024$ ,  $p=0.000$ ). 'Scores on Global Assessment of Functioning' explained 25.1% of the variance ( $\beta$  coefficient  $-0.411$ ,  $p=0.000$ ), 'scores on family support scale' explained 8.1% (Beta coefficient  $-0.298$ ,  $p=0.000$ ), and 'age of caregiver' accounted for an additional 3.1% of the variance of Zarit Burden Interview scores (Beta coefficient  $0.177$ ,  $p=0.017$ ), (table 3).

#### *Predictors for number of compulsory admissions*

On the basis of the results of the bivariate analyses, a stepwise multiple regression test was performed to identify the best predictors of the dependent variable 'number of compulsory admissions' among the independent variables that

showed significant relationships (scores on Global Assessment of Functioning, scores on burden scale and family support scale and illness duration) and to examine their contribution to the variation (expressed as  $R^2$ ) in the dependent variable. The final regression model showed that from all variables entered into the equation, 'scores on Global Assessment of Functioning', and 'scores on family support scale' were significant predictors of 'number of compulsory admissions' explaining 21% of the variance ( $F_{2,122}=16.228$ ,  $p=0.000$ ). 'Scores on Global Assessment of Functioning' explained 18.4% (Beta coefficient  $-0.386$ ,  $p=0.000$ ) and 'scores on family support scale' accounted for an additional 2.6% (Beta coefficient  $-0.168$ ,  $p=0.046$ ), (table 4).

Again, on the basis of the results of the bivariate analyses, a stepwise multiple regression test was conducted to determine the best predictors of 'number of compulsory admissions', for the schizophrenic patients of our sample, using scores on Global Assessment of Functioning, scores on burden scale and family support scale as predictor variables. The results indicated that 'scores on Global Assessment of Functioning' and 'scores on family support scale' together accounted for 20.9% of the variance ( $F_{2,71}=9.363$ ,  $p=0.000$ ). Of these variables 'Scores on Global Assessment of Functioning' explained 14.3% (Beta coefficient  $-0.38$ ,  $p=0.001$ ) and 'scores on family support scale' accounted for an additional 6.6% (Beta coefficient  $-0.256$ ,  $p=0.018$ ). Scores on burden scale did not contribute significantly to the regression model, (table 5).

## Discussion

The present study confirms that patients' general functionality was the strongest predictor of caregivers' burden among the various factors assessed<sup>40</sup>. Raising levels of functionality and competence reduces the caregiver burden<sup>41</sup>. Suicidal or violent behavior, unjustified or irrational demands, the presence of hallucinations, delusions or disorganization and lack of cooperation<sup>42</sup>, along with greater severity of negative symptoms, persistent depressive symptoms and deficiency in managing basic life skills<sup>43</sup>, are the two behavior-related domains associated with increased caregiver burden. Patients' severity of psychopathology and reduction of psychosocial functioning were identified as important determinants of family functioning in major mental illness and as contributing factors that

affect caregivers' burden and psychological distress<sup>44,45</sup>. Inversely, caregiver burden adds stress to the living environment and can negatively influence the functioning of the patient<sup>46</sup>.

Furthermore, our research revealed the negative correlation between caregiver burden and sense of family support. When caregivers sensed less family support in managing their patients, they experienced and reported greater burden. Strong family values in Mediterranean families contribute to the sense of concern and obligation that family members have to care for their identified patient<sup>47</sup>. Within families of individuals with mental illness extremes in conflict, occupational and financial difficulties, illnesses, losses and changes in family structure are frequently observed (48). Studies indicate that negative emotions and stigma issues create a morbid family environment found to have a significant impact on patient and on the rest of family members, affecting intrafamilial relationships and raising the levels of burden<sup>49,50</sup>.

Family dynamics and roles have to be adjusted to accommodate the illness. The study of intrafamilial transactions, focusing on cohesion, flexibility and communication of the members to the families of people with severe psychiatric disorders, is of paramount importance and can set the foundation for understanding the interaction and communication patterns in families of these patients. Literature suggests that unbalanced levels of family cohesion and flexibility are associated with a highly critical attitude toward the patient, which, in turn, may lead to greater burden and higher levels of psychological distress for caregivers<sup>51</sup>. Thereafter, caregiver-patient relationship seems to shape the bidirectional association between caregiver burden and patient distress<sup>52,53</sup>.

The demographic characteristics of our sample resemble those of other surveys conducted in caregivers<sup>54, 55</sup>. Female caregivers constituted the majority in our study (64.5%), possibly reflecting the fact that according to sociocultural expectations mostly females assume the care of patients<sup>56</sup>. As to caregiver's gender no differences were observed on burden scores, although literature reports that female caregivers are likely to face increasing levels of burden<sup>57</sup>. However, our data indicated that the age of caregiver correlated positively with burden scores<sup>58</sup>. In other words caregiver burden increases with advancing age of the caregiver. Literature suggests both results; either that older caregivers

display increased levels of burden mainly due to limited physical strength, or that they report feeling less burdened as they usually face the problem of caring for a patient with mental illness for longer and have probably adapted to the demands of the situation<sup>59</sup>. Other research supports that younger caregivers are more likely to experience caregiver stress<sup>9</sup>. It is worth mentioning that the sense of subjective burden mainly depends on the meaning attributed by the caregivers themselves, as well as on certain characteristics of their personality<sup>60-63</sup>.

From the patient-related factors, the number of hospitalizations had a positive association with caregiver burden. The higher the burden for caregivers, the more frequent the hospitalizations for the patients, most of times against their will<sup>64,65</sup>. Usually the long-term process of the disease increases the burden on families rendering them unable to provide adequate care for the patient. The demanding work of caregiving can put caregivers at risk of engaging in neglect or constantly seeking support from health-care system usually resulting in frequent hospital readmissions<sup>66</sup>. According to our data, sense of family support independently predicted the number of compulsory admissions, especially in patients with schizophrenia. Whether this is the result of reduced severe relapses or increased ability to respond to them when there is adequate family support, without the need for involuntary hospitalizations, is a matter of debate that cannot be confirmed by our study. A possible mediator between the effect of family support and the outcome might be the degree of compliance with medication<sup>67</sup>. In this regard, family support has an important predictive role in the outcome of the treatment process<sup>68</sup>.

Caregivers of patients who were involuntary admitted stated reduced sense of family support and higher levels of burden. This is possibly justified by the lower level of functioning and the grossly disorganized behavior displayed by patients hospitalized under compulsory admission. These patients are also characterized by medication non adherence and lack of insight. Research indicates that the need for involvement of caregivers in the decision on involuntary hospitalization causes feelings of anxiety, guilt, shame and self-reproach<sup>69</sup>.

Regarding patients' diagnosis, the extent of burden among caregivers of schizophrenic patients was significantly more than those of mood disorder<sup>70,71</sup>. Isolated studies offer contradictory evidence as to whether a caregiver's burden is associated with the patient's psychiatric diagnosis<sup>72</sup>. A

large number of studies have demonstrated that although the extent of burden in terms of scales and scores may be somewhat stronger in schizophrenia, the nature of the burden is largely similar in the two disorders<sup>73,74</sup>. Other studies suggested that it was not the diagnosis that was linked to the burden, but the patient's degree of impairment in daily life<sup>75, 76</sup>. Similarly, in our study, this quantitative difference between the two diagnoses was probably due to the increased functional impairment seen in patients with schizophrenia compared to patients with a mood disorder and to the fact that schizophrenic patients were hospitalized mostly under compulsory admission, indicating increased severity of symptoms. However, this approach in terms of increased clinical severity characterizing patients with schizophrenia is frequently challenged and contrary to expectations caregivers' burden appears to be increased with regard to violent and suicidal behaviors of patients with a mood disorder diagnosis in acute phase<sup>53</sup>. In addition, a recovery model of mental illness does not necessarily imply a return to premorbid level of functioning, which is also true for patients with bipolar disorder who sometimes remain functionally impaired with inter-episodic symptoms<sup>46</sup>.

Finally, significant differences were observed across levels of burden with respect to caregiver occupational status. In our study unemployed caregivers stated higher levels of burden compared with employed caregivers<sup>77,78</sup>. Probably the amount of burden experienced by unemployed caregivers is their reaction against the exclusive care of the patient in combination with the absence of occupational or social life and therefore lack of a meaningful role<sup>54</sup>. Studies indicate that the majority of caregivers may become overwhelmed by the demands associated with the tasks involved in rendering care to a patient<sup>79,80</sup>. Regardless of amount of care provided, caregivers may become increasingly more distressed if they are unable to participate in valued activities and interests, due to the need for constant surveillance and monitoring the patient's behavior. Feelings of loneliness and isolation, fearfulness, and being easily bothered, as the demands of caregiving limit their personal time, in combination with concerns about patients' long-term outcome and fewer financial resources to meet care demands, cause particular distress for caregivers. On the other hand, employment provides some caregivers respite from ongoing care activities and serves as a buffer to distress<sup>34</sup>. Employed

caregivers probably have higher self-esteem because of their occupation and they experience fewer negative reactions in their social settings as a consequence of the illness of their family member, but according to other studies<sup>81,82</sup> attempting to balance caregiving with other activities often also results in an increased sense of burden.

In general, the burden on caregivers imposes negative consequences not only upon themselves but also upon their recipients of care and, by extension, upon health services. Identification and moderation of aggravating factors, as well as the enhancement of protective factors (family and social support, caregiver's skills) can reduce the burden and the negative impact on caregivers and at the same time improve patient outcomes. Where appropriate, clinical counseling (identifying burden, psychoeducation, supportive psychotherapy), or more complex interventions (family psychotherapy) reduce the burden and improve the quality of life for caregivers. Therefore, better understanding of caregiver burden may lead to the development of a more efficient and more effective health care system<sup>83-85</sup>.

## Conclusions

Severe mental illnesses often cause significant functional impairment and loss of autonomy, usually leading family members to assume the caregiving role. Family caregivers experience serious adverse physical and mental health consequences from their physically and emotionally demanding work as caregivers and reduced attention to their own health and health care.

Psychotic-spectrum disorders are complex biopsychosocial conditions, and family issues are important determinants of prognosis. The involvement of the family in the overall treatment plan is of great importance<sup>86, 87</sup>, since sense of family support serves as a buffer, mitigating burden. Mental healthcare providers are often confronted with requests for family support and information on the availability of services for patients and caregivers<sup>88</sup>.

Multicomponent interventions for patients and caregivers offer psychological support, counseling sessions, psycho-educational programs (about the nature of the disorder, the available therapies, the hospital admission process, early signs of relapse, seek medical help in time), psychotherapy, problem-solving, and coping skills<sup>89,90</sup>. Psychotherapeutic interventions for caregivers<sup>91</sup>

and psychosocial treatments for patients<sup>92,93</sup> reduce burden, relapses and hospital admissions and increase sense of family support and patients' level of functioning. Improve access to health care services<sup>94</sup>, fight the stigma around mental illness and above all the psychosocial rehabilitation of psychiatric patients<sup>95</sup> are all issues included in the health policy agenda, lagging behind possibly due to limited resources both human and financial.

## Limitations

The cross-sectional design of the study precluded us from making inferences about causality. There may be a selection bias because readmissions were not included in the sample and only caregivers of inpatients were included who may be more burdened than caregivers of outpatients. Also the instrument used to assess caregivers' burden only measured subjective burden.

**Conflict of Interest:** The authors declare that they have no competing interests.



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APPENDIX

TABLES

TABLE 1: Sociodemographic characteristics of caregivers

Sociodemographic characteristics	Caregivers (n=152)
	Mean Value (S.D.)
Age (years)	54.87 (12.84)
	n (%)
Gender	
Male	54 (35.5%)
Female	98 (64.5%)
Relationship with patient	
Parent	73 (48%)
Siblings	28 (18.4%)
Children	8 (5.3%)
Spouses	32 (21.1%)
Neighbors	8 (5.3%)
Friends	3 (2%)
Employment status	
Employed	68 (44.7%)
Unemployed	84 (55.3%)

TABLE 2: Sociodemographic and clinical characteristics of patients

Sociodemographic and clinical characteristics	Patients (n=152)
	Mean Value (S.D.)
Age (years)	41.03 (13.14)
Duration of illness (years)	11.21 (10.34)
	n (%)
Gender	
Male	73 (48%)
Female	79 (52%)
Employment status	
Employed	25 (16.6%)
Unemployed	126 (83.4%)
Diagnosis	
Schizophrenia	88 (58.6%)
Mood disorder	63 (41.4%)
Hospital admission process	
Compulsory	70 (46.1%)
Voluntary	82 (53.9%)



Table 3: Stepwise multiple regression analysis of factors predicting caregiver burden

	Beta	t	p
Caregiver's age	.177	2.424	.017*
Illness Duration	-.017	-.223	.824
Number of admissions	.002	.031	.976
Number of compulsory admissions	.017	.210	.834
FS	-.298	-3.974	.000**
GAF	-.411	-5.495	.000**
<i>R Square</i>	.363		
<i>Durbin-Watson</i>	1.587		
<i>F</i>	23.024		
<i>Sig.</i>	.000**		

GAF: Global Assessment of Functioning Scale  
FS: Family Support Scale

Note: Beta = Standardized Regression Coefficient

Reported correlations are statistically significant at the \*p < 0.05; or \*\*p < 0.01 level

Table 4: Stepwise multiple regression analysis of factors predicting number of compulsory admissions

	Beta	t	p
GAF	-.386	-4.632	.000**
FS	-.168	-2.017	.046*
ZARIT	.048	.484	.630
Illness Duration	.129	1.538	.127
<i>R Square</i>	.210		
<i>Durbin-Watson</i>	1.911		
<i>F</i>	16.228		
<i>Sig.</i>	.000**		

GAF: Global Assessment of Functioning Scale  
ZARIT: Zarit Burden Interview  
FS: Family Support Scale

Note: Beta = Standardized Regression Coefficient

Reported correlations are statistically significant at the \*p < 0.05; or \*\*p < 0.01 level

Table 5: Stepwise multiple regression analysis of factors predicting number of compulsory admissions for patients with schizophrenia

	Beta	t	p
GAF	-.380	-3.601	.001**
FS	-.256	-2.423	.018*
ZARIT	.057	.429	.669
<i>R Square</i>	.209		
<i>Durbin-Watson</i>	2.099		
<i>F</i>	9.363		
<i>Sig.</i>	.000**		

GAF: Global Assessment of Functioning Scale  
ZARIT: Zarit Burden Interview  
FS: Family Support Scale

Note: Beta = Standardized Regression Coefficient

Reported correlations are statistically significant at the \*p < 0.05; or \*\*p < 0.01 level