



ORIGINAL ARTICLE

# The Burden of Schizophrenia on Caregivers

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## ABSTRACT

**Objective:** Most patients with schizophrenia need personal support and care for their own health and safety. This long-term and comprehensive care needed can increase the susceptibility of the caregivers to physical and mental problems by exhausting their mental and physical resources. In this study, we aimed to examine the emotional burden level of family members who take care of patients diagnosed with schizophrenia.

**Methods:** It is a descriptive and cross-sectional study. All family caregivers of schizophrenia patients who came to outpatient clinics during the specified period were included. The Participatory Caregiver Burden Scale was administered to all participants who provided informed consents.

**Results:** Among the 100 caregivers recruited; 68% female and 54% were female. We found that the vast majority of caregivers had emotional care giving burdens (69%), especially low-level burdens (66.67%, 46/69). Emotional care burden was frequent among caregivers (93.75%, 15/16), fathers (94.11%, 16/17), and nonparticipants (80.00%, 8/10).

**Discussion:** The burden of care for the family members was quite large. The results show that there is a need for interventions that allow identification and control of this problem, especially focusing on partners, parents, and less educated caregivers.

**Keywords:** Schizophrenia caregiver, family, quality of life

## INTRODUCTION

Patients diagnosed with schizophrenia often need personal support and care in terms of their own health and safety. These patients need caregivers who can respond directly to their problems because of their constant need for various social, cultural, and economical conditions (1-3). This ongoing care also affects the health of the caregiver in different dimensions. This becomes an increasing burden on the involved individuals, causing them to be affected both physically and spiritually, resulting in diminished quality of life in different ways in families (2,4). Studies have shown that caregivers of patients with schizophrenia perceive their

emotional burden too much. In this group, the proven burden level is high and varies depending on many factors that vary according to geographical, social, and cultural levels (1,5-7).

There are several factors related to caregiver burden (both subjective and objective): the intensity and type of symptomatology of the schizophrenia patient, who the family caregiver is, the level of education, the age of the patient and caregiver, and the duration of the illness. These factors emphasize that burden levels can change depending on geographical conditions (with regional variability), and the importance of conducting research to determine the magnitude of this problem (3,8-10). The burden of the caregiver can be defined or established in a limited manner. In addition, the cultural characteristics of a region cannot exclude the results of many studies, especially in the United States and Europe, nor can it adequately assess the magnitude of the problem. For example, in the family culture of Latin

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American countries, it is stated that, compared to the people in North America and Europe, patients were more directly supported and viewed as more vulnerable (11).

In a collective society like Turkey, various studies have been carried out in order to examine the effect of schizophrenia on caregivers and society and important findings have been concluded. Sengun-Inan et al. (12) reported that gender, education, working status, participation in programs related to schizophrenia, and coping with problems were the main variables affecting mental health of caregivers of schizophrenia patients. Cetin et al. (13) showed that the higher independence status of the patients with schizophrenia in daily life activities reduced the expressed emotional state of caregivers. It has been reported that the presence of alcohol and/ or substance use disorder, which makes the needs of schizophrenic patients more intense and complicated, is associated with increased caregiver burden and reduced quality of life (14). Instead of stigmatizing schizophrenia patients and removing them from society, it is necessary to provide them appropriate care with re-integration by training them. Treatment of patients with schizophrenia who were ignored and removed from the society as individuals who are accepted and meeting their own needs would also reduce the burden on caregivers (15-17).

Presently, there are a number of tools developed to measure the subjective and/ or subjective burden faced by people with chronic disorders such as schizophrenia. Unfortunately, these tools are too complex, comprehensive, or unable to adequately measure the perception of caregivers (11). In order to do the necessary interventions, it is important to make a burden assessment that allows caregivers to know their own situation, reduce the problem, and prevent further negative effects in the health of caregivers. This study was conducted to determine the level of emotional burden of family members who take care of patients with schizophrenia followed-up and treated in the psychiatric outpatient clinic of our hospital.

## METHODS

### Study Design

This research is cross-descriptive and conducted in Adiyaman University Training and Research Hospital psychiatry clinic. The study group was formed from caregivers of patients with schizophrenia who were referred to our outpatient clinic. All the family caregivers who came to the psychiatry outpatient clinic for the follow-up visit and who met the inclusion criteria and who agreed to attend the study were informed about the study. It was accepted as a inclusion criteria when the patient was between the ages of 18 and 60, the duration of the schizophrenia between 3 and 50 years, the patients were following a regular psychiatrists, presence of no additional psychiatric disorders, and the caregiver was a family member over the age of 18 years. Patients with family caregivers who live outside the province and patients with serious illnesses such as chronic renal failure, liver cirrhosis and congestive heart failure have not been included in the study. The involvement of study participation was based on volunteerism and confidentiality, and there was the possibility of withdrawal without the need. Participants in the study voluntarily signed the informed consent form. The present study was approved by the Ethics Committee of our university (Ethics Committee Protocol Number 2017 / 7-12).

### Data Collection

The first scale was used to evaluate the stress experienced by caregivers of dementia patients who need personal care (18). The scale, which can be filled in by the caregivers themselves or by the researcher, consists of 22 phrases that determine the effect of care on the individual's life. The scale has a Likert-type rating that ranges from 1 to 5, rated as never, rarely, sometimes, often, or almost always. The higher the scale scores, the higher the frequency of experiencing. The validity and reliability study of the Turkish version was conducted by Inci and Erdem (19). The Cronbach's coefficient of the scale was 0.95, the mean total score of the item was  $20.37 \pm 16.54$  and the item-total correlation coefficients were

0.43-0.85 in the moderate, strong and very strong levels and the test-retest reliability coefficient was 0.90. According to the Turkish version, caregiver burden includes three factors or sub-dimensions: care effect, interpersonal burden, and self-efficacy expectations. The scale has 3 possible outcomes: "no overload" ( $\leq 46$  points), "light overload" (47-55 points), and "significant overload" ( $\geq 56$  points). Positive and negative symptoms were determined by the Positive and Negative Syndrome Scale (20).

### Statistical Analysis

All statistical analyses were performed by using SPSS Version 22.0 for Windows. The variables in the present study were examined with the Kolmogorov-Smirnov's test of normality. Descriptive statistic was reported using means and standard deviations for continuous variables and frequencies and percentages for categorical variables and the Chi-square test ( $\chi^2$ ) was performed to examine the caregiver's emotional overload. A p value less than 0.05 was considered statistically significant.

## RESULTS

100 family members were included in the study. 69.00% (69/100) of participants were found to have emotional overload. 33.33% (23/69) of them had intense emotional overload and 66.67% (46/69) had mild emotional overload (Figure 1). The majority of caregivers were

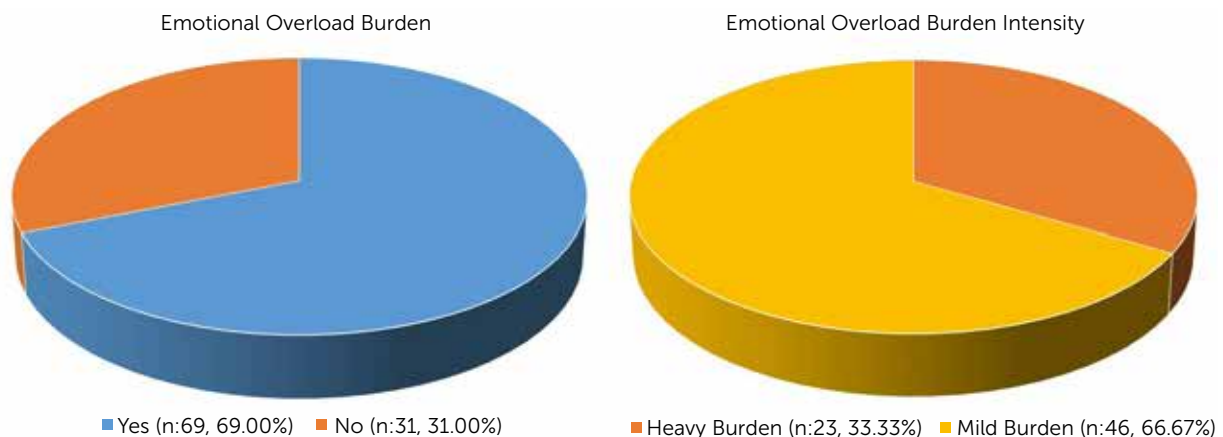
68.00% (68/100) of women and they had a slight burden of 36.76% (25/68) emotional overload. Emotional overload percentages in males and females were similar to each other with 65.63% (21/32) and 75% (51/68), respectively (Table 1).

Emotional care burden was found to be 93.75% (15/16) in partners, 94.11% (16/17) in fathers, and 80.00% (8/10) in non-participating partners (Table 2). The tendency of emotional overload according to education level was 88.89% (8/9) in the illiterate, 23.40% (11/47) in the elementary school graduates, 75% (24/32) in the middle school graduates, and 58.33% in the high school and higher education levels (7/12) (Table 3).

16% (16/100) of the caregivers were single, 47% (47/100) were married, and 37% (37/100) were widows. Emotional overload rates in caretakers were 87.50% (14/16) in single, 83.78% (31/37) in widowed women, and 80.85% (38/100) in married couples (Table 3).

According to the relationship with the patient, the mothers (54%, 54/100) were the majority of the caregivers. And 77.78% (42/54) of the mothers have emotional overload. The highest level of emotional overloading in caregivers in the family was with parents (76.81%; (53/69) followed by partners (63.64%; (7/11).

In terms of the symptoms of the patients; 43% (43/100) were positive and 57% (57/100) were negative. The overloading frequency of carers of positive persons was higher by 68.42% (39/57) than those of those with negative statements 74.42 (32/43) (Table 4).



**Figure 1: The frequency of burden of emotional overload**

**Table 1: Characteristics of Schizophrenic Patients and Caregivers by Sociodemographic Variables**

Caregiver	n	%	Mean	SD
<b>Gender</b>				
Female	68	68.00		
Male	32	32.00		
<b>Age (year)</b>			36.42	7.28
<b>Marital Status</b>				
Single	16	16.00		
Married	47	47.00		
Widow	37	37.00		
<b>Education</b>				
No	9	9.00		
Primary	47	47.00		
Secondary	32	32.00		
Highschool or up	12	12.00		
<b>Relation Grade</b>				
Mother	54	54.00		
Father	15	15.00		
Child	8	8.00		
Partner	11	11.00		
Other	12	12.00		
<b>Schizophrenia Patients</b>				
	n	%	Mean	SD
<b>Gender</b>				
Female	41	41.00		
Male	59	59.00		
<b>Age (year)</b>			23.62	9.02
<b>Duration of Disease (year)</b>			12.98	5.89

n: Number, %: Percentage, SD: Standard Deviation

**Table 2: Burden According to Proportion of Proximity**

Burden		
93.75%	15/16	Partner
94.12%	16/17	Father
80.00%	8/10	Other

When the dimensions of the Zarit Scale were examined; the most affected dimension 2 ("Personality Load") was measured as 61.32% followed by dimension 1 ("Care Effect") 51.86% and dimension 3 ("Self-sufficiency expectations") 49.11%. The percentage of positive responses in a total of 22 questions was almost the same and indicates a concern about the feeling of fear of the future of the caregiver. According to bivariate analysis, mothers had more emotional burden than the children ( $p = 0.047$ ), the spouses ( $p = 0.041$ ), and the others ( $p = 0.071$ ). Compared with the level of overload between the mother and the spouses; the spouses were observed to have a higher level of emotional overload ( $p = 0.001$ ).

**Table 3: Relationship of burden severity with some variables**

Mild Burden			
<b>Gender</b>			
Female	36.76%	25	68
Male	34.38%	16	32
<b>Overload Burden</b>			
<b>Gender</b>			
Female	51	75.00%	68
Male	21	65.63%	32
<b>Education</b>			
No	8	88.89%	9
Primary	11	23.40%	47
Secondary	24	75.00%	32
High School or up	7	58.33%	12
<b>Marital Status</b>			
Single	14	87.50%	16
Married	38	80.85%	47
Widow	31	83.78%	37
<b>Relationship Grade</b>			
Mother	42	77.78%	54
Father	11	73.33%	15
Child	5	62.50%	8
Partner/Wife-Husband	7	63.64%	11
Other	7	58.33%	12
Ebeveynlerde	53	76.81%	69

**Table 4: Relationship of results with patient identification**

According to patient symptoms			
Pozitive	43	43.00%	100
Negative	57	57.00%	100
Overloaded Burden			
Pozitive	32	74.42%	43
Negative	39	68.42%	57

## DISCUSSION

Although there are several ways to assess the overloading of caregivers of schizophrenia patients, many studies also acknowledge that they have a significant caring burden that affects their lives in their social, economic and health domains (3). In some studies it has been found that there is a high level of emotional overload in the caregivers, especially the parents of patients with schizophrenia. In our study, parental emotional overload was slightly higher and it was thought that these people might be due to a lower coping capacity to negative emotions about a stressful situation (e.g., care taking) (21-23). It is seen that there is a greater emotional overload in spouses. This explains the importance of the position of the mother who takes care of the patient with schizophrenia and assumes her feelings of responsibility for the patient's treatment. In a study conducted, she also showed that her mother was more involved in monitoring medication and integrating the patient into the community (9).

There are three sides to the maintenance burden-patient, family, and community. It is known that improvements in these three areas have an important place in reducing psychiatric disorder-related problems. Within the framework of the protected home project established in Elazığ Mental Health and Disorders Hospital in Turkey, patients who are placed in the houses and participated in the rehabilitation programs should be informed about social skills, communication, self-sufficiency, improvement of family relations and family support, it was observed that there were great differences related to-increasing of compliance with treatment and decreasing of recurrences (15). Harmanci and Cetinkaya-Duman (24) stated that the caregivers of patients with schizophrenia have high risk for their mental health problems, their burdens affect their mental health status, and mental health problems also increase if the burden of

care increases. Sagut and Cetinkaya-Duman (25) studied the relationship between disease duration and caregiver burden. Patients with chronic psychosis were found to have a higher level of caregiving burden than patients with first episode psychosis. All this information about caregiver burden shows us that one of the duties of mental health professionals is to plan development of interventions for the family that are effective in reducing the burden of care. It is thought that the spread of psychiatric rehabilitation services as a country policy, the extension of community mental health centers and the expansion of the scope of protected home project have the potential to seriously reduce the caregiver problems (15).

As a result, it was observed that emotional overloading was observed in the family carers examined. These group-focused interventions can be developed to improve the quality of life of these persons and, therefore, their responsibilities (26), by identifying vulnerable groups (e.g., having a male nurse, being a father's nurse or a hospital partner, and having a low education level). The health system should deal more with family members who have a more active role in the care of patients with schizophrenia, especially since direct caregivers are significantly affected by lowering their quality of life.

This present study has certain limitations. It is suggested to increase the number of sample size in future studies. Although caregivers have some factors that affect emotional overload, they are not considered in the study because of the difficulty of obtaining objective information from these points, such as the onset of symptoms or the diagnosis of disorder. It is important that this information is included in future studies to develop specific interventions. On the other hand, participants may have reduced emotional overload due to direct interaction with the interviewer, while the non-caregivers did not believe that this fact influenced the final outcome of the study, as the they were unable to fill the questionnaires in writing.

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