# Original Article

# The Need of Primary Caregivers of Schizophrenia Patients and Its The Effect on Care Giving Burden: A Cross-Sectional Study

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## Abstract

**Background:** Patients' relatives usually care for patients of with schizophrenia. Caregivers can experience some difficulties during the caregiving process. This can increase the burden of caregivers. This study aimed to determine the requirements of primary caregivers of schizophrenia patients and its effect on caregiver burden.

**Methods:** The sample of the cross-sectional study consisted of 94 caregivers of patients with schizophrenia who were treated at the university hospital in western Turkey and agreed to participate in this study. A questionnaire form and Caregiving Burden Scale were used to collect data. The data were collected from individual interviews between March-December 2015.

**Results:** The average score of Caregiving Burden Scale of the primary caregivers is was determined as 38.47±15.05. Based on this the primary caregivers had difficulty in giving medication to their patients, the requirement of knowledge about drug treatment and side effects, coping with symptoms of schizophrenia, early warning signs, communication skills, coping with stress, psychosocial treatment methods, planning of the patients' leisure activities, and contribution of the patient to home life affected the caregiving burden having a p value of ($p<0.05$).

**Conclusions:** The overall Caregiving Burden Scale mean score of caregivers was considered moderate. It can be conclude that caregivers' requirements affect the burden of care during the caregiving process. It was considered that the feeling of burden care for caregivers will be able to reduce by giving consultancy services related to what they need and with the creation of comprehensive, systematic, continuous education programs including the difficulties faced by caregivers and the requirements being able to cope easily with the difficulties during caregiving. [*Ethiop. J. Health Dev.* 2023; 37(1) 000-000]

**Keywords:** Care, caregiving burden, caregiver, needs, schizophrenia

## Introduction

Schizophrenia is a mental disorder and an important public health issue, which has an early onset, affects both genders, leads to important changes in structure and physiology of brain, impairs thinking, attention, speech, motor behaviours, and functionality, affects interpersonal relations, has recurrences during its course and causes emotional, social and economic problems (1-3). Now -days y, it has been emphasized that patient families should be involved in the treatment and care of patients, that families play a complementary role in the lives of many individuals ,and that they are an important part of the treatment of people with chronic psychiatric illness (4,5). However, schizophrenia is an intense source of stress for both patients and families due to cognitive impairments, disabilities, and social and economic losses in individuals (4).

The main person who supports the patient and that provides the most care and lives in the same house is defined as "primary caregiver" (6). Families usually perform the caregiver role without any support, and the caregiver role is usually carried out by the patient's mother, wife, child or sibling (7). Medical staff is with the patient for a short and temporary period in which the patient is hospitalized. Caregivers spend all their time with patients, and they are primarily responsible for the care of the patient, voluntarily maintain the care, and in doing so, they need of having emotional and social support in terms of disease process and patient care (7,8). Increasing stresses, difficulties, and responsibilities of caregivers during the caregiving process have led to the emergence and investigation of "caregiving burden" concept and attempts to decrease it (9). The concept of "caregiver burden" describes difficulties and adverse events that the caregiver experiences because the caregiver lives inthe same house as the patient (10). Change in roles and balance due to a family member getting ill and his roles being performed by other members cause caregiver burden by leading to social, emotional, physical and economic difficulties for the caregiver (7). It is reported that the burden which is experienced by caregivers affects their mental health; and it is clear to see that mental health status becomes worse when the severity of the burden increases. As a result of the burden and stress felt by schizophrenic individuals, they also experience psychological problems such as anxiety, hopelessness, anger, depression, insomnia, and social isolation together with caregiver role and their family roles (11,12).

It is advisable that caregivers should be taken both professional support and information in fulfilling their caregiving roles for schizophrenic patients (13). The key areas where caregivers consider during the care giving process include knowledge of illnesses, treatments, and symptoms, side effects of medications, coping with patient behaviour, management of patient treatment at home, communication skills, development of stress management skills of caregiver and stress

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management, awareness of social support resources, and use of these resources (14). According to a study, it has been reported that caregivers have some needs to find a job and work, get information about schizophrenia, have daily life skills, communication and cope with stress. Moreover, it has been stated that these requirements increase the care burden (15). There are some studies on the burden of care of caregivers for schizophrenic patients (5,12,16) and the needs of caregivers (13,15,17). It is thought that the study will make a significant contribution to the literature because of the limited studies which have evaluated the effects of caregivers.

This study aimed to determine the requirements of primary caregivers of schizophrenia patients and their effect on caregiver burden. Results of studies showed that caregiver needs are important as they become a guide in building intervention program content. Furthermore, it is thought that determining the relationship between caregivers' burden and their needs for the disease will contribute to the planning of nursing interventions and family intervention programs so as to reduce the burden of caregivers based on their needs. Considering this purpose, an answer has been sought for the question "Is the disease-related needs of primary caregivers for schizophrenic patients effective on their care burden?".

## Methods

### Study Design, Setting and Sampling method

The study was planned as a cross-sectional study. The target population consisted of primary caregivers of patients who were admitted to the psychiatry department of a university hospital in a western city of Turkey, diagnosed as schizophrenia according to Diagnostic and Statistical Manual of Mental Disorders five criteria, hospitalized or followed as an outpatient and met study criteria. Our inclusion criteria included caregivers to be 18 years or older, caregiving for at least 1 year of the individual who has been diagnosed with schizophrenia, have no mental disability, have no physical and mental health problems, be able to read and comprehend written instructions and self-report instruments. Exclusion criteria have been defined as having a diagnosis other than schizophrenia or a concomitant diagnosis, having a caregiving period of less than 12 months, and having a history of psychiatric disorders by the caregiver.

The samples of the research consisted of all volunteer primary caregivers who agreed to participate in the study and were eligible for inclusion in the study. From 267 schizophrenia outpatients and inpatients in the remission phase, primary caregivers of 94 schizophrenia patients who accepted to participate in this study and they formed the study group. Since the number of outpatients and inpatients in the remission phase was low, both outpatients and inpatients were included in the study. The power of the study was analysed and the effect of size of primary caregivers experiencing difficulty in giving drugs on Caregiving Burden Scale (d=0.86) was found to be strong. For this effect size, the study has been calculated to reach 99% power at 95% confidence level. No data has been lost during the study.

### Measurements

***Information form for patients with schizophrenia:*** It consists of questions that have been prepared by the researchers after the literature review, including the characteristics of the patient such as age, gender, education, marital status, employment and social security status, duration of disease diagnosis, taking medications, and meeting their needs (12,13,15,16).

***Information form for primary caregivers of patients with schizophrenia:*** This form includes the questions which consist of the sociodemographic characteristics of caregivers for schizophrenic patients and the issues they need. It consists of questions that have been prepared by the researchers after the literature review, including the characteristics of the caregivers such as age, gender, closeness to the patient, family type, marital status, education status, employment status, income status and social security (12,13,15,16). Moreover, similar studies on the needs and difficulties of primary caregivers have been examined and some questions have been added. There are some questions about coping with symptoms, drug use, daily living skills, contribution to home life, legal rights, treatment methods and communication in order to determine the difficulties and needs of primary caregivers (13,15,17). It can be said these questions which have been obtained from reference sources is among the limitations of the research.

***Caregiving Burden Scale (CBS):*** CBS was developed by Zarit, Reever, and Bach-Peterson in 1980 and translated to Turkish by İnci and Erdem (18). The scale consists of 22 items that determine the effect of care on the individual's life. The CBS has a 5-point Likert-type scale ranging from 0 (never) to 4 (nearly always). At least 0 and at most 88 points can be taken from the scale. The items in the scale are generally oriented towards social and emotional areas and high scores indicate that the problems experienced are high. Cronbach alpha internal consistency coefficient of the scale was 0.95 (18). The Cronbach alpha internal consistency coefficient of our scale was found to be 0.95 in our study.

### Data collection

Preliminary application has been conducted from ten primary caregivers who have not been included in the study sample to evaluate the comprehensibility of the questionnaire. It has been determined that there is no incomprehensible expression in the form. The data have been obtained b through face-to-face interviews by throught the first author of the study.The interview room of the psychiatry clinic had been conducted between March and December 2015. When the questions are not understood, necessary explanations have been given to the individuals by the resaerchers. The time for answering the questionnaire was given approximately 20-30 minutes.

### Data analysis

The data were analysed by using the Statistical Package for the Social Sciences (SPSS) 18.0 package program. Continuous variables are expressed as mean ± standard deviation and categorical variables as numbers and percentages. It is controlled whether all data are suitable for normal distribution with the Kolmogorov–Smirnov test or not. Considering the parametric methods, the Independent Sample-t test has been applied to compare the measurement values of two independent groups and the One-Way ANOVA test method has been conducted to compare the measurement values of three or more dependent groups. Considering the non-parametric methods, the Mann-Whitney U test has been applied to compare the measurement values of two independent groups and the Kruskal-Wallis Analysis of Variance method has been conducted to compare the measurement values of three or more dependent groups. Both Spearman Correlation analysis and Linear Regression Analysis have been used to analyse the relationships between continuous variables. In all analyses, $p<0.05$ and $p<0.001$ are considered statistically significant.

**Ethical considerations**

Ethical approval has been taken from the Non-interventional Clinical Research Ethics Committee of Medical Faculty with the decision number 56989545/050.04 on the date of 27.11.2014. Written permissions were obtained from the department of psychiatry of the university hospital, where the study was conducted and the scale used for the study. In addition to this, written consents were obtained from the primary caregivers of patients with schizophrenia.

## Results

The distribution of demographic characteristics of primary caregivers for schizophrenic patients is given in Table 1. It was noted that the mean age of the patients was 41.12±13.72 and the mean of disease diagnosis process was 11.93±8.63 years. Among the patients with schizophrenia, 61.7% were male, 53.1% were single, 43.6% were secondary school graduates, 85.1% were not working, 95.7% had social security insurance and 53.2% regularly take their medications. In addition, it is determined that 59.6% of schizophrenic patients have met their needs with occasional support from their caregivers (Table 1).

**Table 1: Distribution of demographic characteristics of primary caregivers of schizophrenia patients (n=94)**

| Demographic Characteristics | | n | % |
|---|---|---|---|
| **Gender** | Female | 36 | 38.3 |
| | Male | 58 | 61.7 |
| **Education Status** | Primary school or lower | 39 | 41.5 |
| | Secondary school | 41 | 43.6 |
| | College or higher | 14 | 14.9 |
| **Marital Status** | Single | 50 | 53.1 |
| | Married | 29 | 30.9 |
| | Divorced/ Separated | 15 | 16.0 |
| **Employment Status** | Unemployed | 80 | 85.1 |
| | Employed | 14 | 14.9 |
| **Social Security** | No | 4 | 4.3 |
| | Yes | 90 | 95.7 |
| **Prevalence of Hospitalization** | Once a year | 64 | 73.6 |
| | Twice a year and above | 23 | 26.4 |
| **Regularly Taking Pills** | Taking | 50 | 53.2 |
| | Not Taking | 44 | 46.8 |
| **Requirement Fulfillment Status** | Always Self Sufficient | 25 | 26.6 |
| | Wants our support sometimes | 56 | 59.6 |
| | Always we do | 13 | 13.8 |

| | Mean±SD |
|---|---|
| **Age** | 41.12±13.72 |
| **Disease diagnosis process** | 11.93±8.63 |

The distribution of demographic characteristics and care of primary caregivers for schizophrenic patients is given in Table 2. When the demographic characteristics of primary caregivers were examined, the mean age was 52.08±14.59 years, 67.0% were female and 31.9% were mothers of the patients. Among primary caregivers, 76.6% were married, 61.7% were primary graduates or below and 52.1% were not working (Table 2).

**Table 2: Distribution of demographic and patient care related characteristics of primary caregivers of schizophrenia patients (n=94)**

| **Demographic Characteristics** | | **n** | **%** |
|---|---|---|---|
| **Gender** | Female | 63 | 67.0 |
| | Male | 31 | 33.0 |
| **Closeness** | Mother | 30 | 31.9 |
| | Father | 15 | 16.0 |
| | Spouse | 21 | 22.3 |
| | Other (girl, boy, sibling, etc.) | 28 | 29.8 |
| **Family type** | Nuclear family | 59 | 62.8 |
| | Extended family | 18 | 19.1 |
| | Single parent family | 17 | 18.1 |
| **Marital status** | Single | 72 | 76.6 |
| | Married | 17 | 18.1 |
| | Divorced/ separated | 5 | 5.3 |
| **Education status** | Primary school or lower | 58 | 61.7 |
| | Secondary school | 22 | 23.4 |
| | College or higher | 14 | 14.9 |
| **Employment status** | Unemployed | 49 | 52.1 |
| | Employed | 21 | 22.3 |
| | Retired | 24 | 25.5 |
| **Income status** | Income less than expenditure | 31 | 33.0 |
| | Income equal to or more than expenditure | 63 | 67.0 |
| **Social security** | No | 7 | 7.4 |
| | Yes | 87 | 92.6 |
| **Living in the same house with the patient** | No | 15 | 16.0 |
| | Yes | 79 | 84.0 |
| **Presence of someone that help with care** | No | 44 | 46.8 |
| | Yes | 50 | 53.2 |
| **Giving care to someone else** | No | 85 | 90,4 |
| | Yes | 9 | 9,6 |
| **Preventing daily lives of family members** | Not preventing | 33 | 35.1 |
| | Preventing | 61 | 64.9 |
| | **Mean±SD** | | |
| **Age** | 52.08±14.59 | | |

The distribution of the difficulties and needs which have been experienced by the primary caregivers for schizophrenic patients during the caregiving process is given in Table 3. When the difficulties and the distribution of needs of the primary caregivers of schizophrenia patients were examined, it was noted that 48.9% had difficulty in coping with symptoms and 34.0% had difficulties in taking their medications. It was determined that 67.0% of caregivers needed to cope with schizophrenia symptoms, 64.9% needed medication and its side effects, 61.7% needed medications and patients' contributions to home life. It was observed that 60.5% of the caregivers needed the patient's legal rights, 58.5% of them needed warning signs, 57.4% of them planned leisure activities for the patients and 50.0% of them needed communication skills. In addition, it was determined that 50% of the participants needed to cope with stress and 47.9% of them needed daily living activities (toilet, bathroom, cleaning, etc.) (Table 3).

**Table 3: Distribution of difficulties and requirements of primary caregivers of schizophrenia patients during caregiving process (n=94)**

| *Difficulties in Caregiving* | | **n** | **%** |
|---|---|---|---|
| **Dealing with disease symptoms** | No | 48 | 51.1 |
| | Yes | 46 | 48.9 |
| **Use of medicines** | No | 62 | 66.0 |
| | Yes | 32 | 34.0 |
| **Furious and aggressive behavior** | No | 78 | 83.0 |
| | Yes | 16 | 17.0 |
| **Daily life skills** | No | 82 | 87.2 |
| | Yes | 12 | 12.8 |
| **Contribution to home life** | No | 86 | 91.5 |
| | Yes | 8 | 8.5 |
| **Communication** | No | 87 | 92.6 |
| | Yes | 7 | 7.4 |
| *Required Topics* | | | |
| **Coping with symptoms** | No | 31 | 33.0 |
| | Yes | 63 | 67.0 |
| **Medications and side effects** | No | 33 | 35.1 |
| | Yes | 61 | 64.9 |
| **Drug education** | No | 36 | 38.3 |
| | Yes | 58 | 61.7 |
| **Contribution to home life** | No | 36 | 38.3 |
| | Yes | 58 | 61.7 |
| **Legal rights of patients** | No | 37 | 39.4 |
| | Yes | 57 | 60.6 |
| **Early warning signs** | No | 39 | 41.5 |
| | Yes | 55 | 58.5 |
| **Planning patient's leisure activities** | No | 40 | 42.6 |
| | Yes | 54 | 57.4 |
| **Communication skills** | No | 47 | 50.0 |
| | Yes | 47 | 50.0 |
| **Coping with stress** | No | 47 | 50.0 |
| | Yes | 47 | 50.0 |
| **Psychosocial treatment methods** | No | 48 | 51.1 |
| | Yes | 46 | 48.9 |
| **Skills related to daily life (such as toilet, bathroom, housekeeping)** | No | 49 | 52.1 |
| | Yes | 45 | 47.9 |
| **Groups and associations related to schizophrenia** | No | 60 | 63.8 |
| | Yes | 34 | 36.2 |

Table 4 indicates the comparison of the primary caregivers for schizophrenic patients in terms of their demographic characteristics of the caregiving burden scale mean scores. The average score of CBS was 38.47±15.05. A weak positive correlation was found between the age of the caregivers and the CBS score. There were statistically significant differences in education levels, income status and social security status of caregivers and CBS scores ($p<0.05$). According to post hoc analyzes, the scores of the caregivers with secondary school graduates were found to be significantly lower than those of primary school and university graduate caregivers. The caregiving load of caregivers with incomes less than their expenditures was found to be significantly higher than those with incomes equal to or more than their expenditures. The caregiving load scale scores of participants with Social Security is statistically higher than those without social security. The gender of caregivers, closeness to the patient, place of residence family type, demographic characteristics such as marital status and occupational status were not found to affect the CBS score ($p>0.05$) (Table 4).

**Table 4: Comparison of the mean caregiving burden scale scores of primary caregivers of schizophrenia patients according to demographic characteristics (n=94)**

| **Demographic Characteristics** | | **Caregiving Burden Scale** | | | | |
|---|---|---|---|---|---|---|
| | | **n** | **min-max** | **Mean±SD** | **test value** | **p value** |
| **Gender** | Female | 63 | 6-78 | 37.76±15.61 | -0.656[a] | 0.513 |
| | Male | 31 | 15-69 | 39.93±13.98 | | |
| **Closeness** | Mother | 30 | 12-78 | 40.00±16.80 | 0.540[b] | 0.656 |
| | Father | 15 | 15-69 | 41.46±15.30 | | |
| | Spouse | 21 | 6-72 | 36.90±17.01 | | |
| | Other (girl, boy, sibling, etc.) | 28 | 19-60 | 36.42±11.30 | | |
| **Family type** | Nuclear family | 59 | 6-72 | 37.11±14.11 | 1.335[c] | 0.268 |
| | Extended family | 18 | 15-78 | 37.88±18.31 | | |
| | Single parent family | 17 | 22-69 | 43.82±14.20 | | |
| **Marital status** | Single | 72 | 6-72 | 37.45±15.06 | 4.654[d] | 0.098 |
| | Married | 17 | 21-62 | 38.47±13.42 | | |
| | Divorced/ separated | 5 | 37-78 | 53.20±15.25 | | |
| **Education status** | Primary school or lower | 58 | 12-78 | 39.65±14.42 | 6.246[d] | **0.044*** |
| | Secondary school | 22 | 20-69 | 33.13±13.90 | | |
| | College or higher | 14 | 6-69 | 42.00±18.15 | | |
| **Employment status** | Unemployed | 49 | 12-78 | 38.10±15.73 | 0.337[c] | 0.715 |
| | Employed | 21 | 6-63 | 37.00±13.55 | | |
| | Retired | 24 | 20-69 | 40.54±15.28 | | |
| **Income status** | Income less than expenditure | 31 | 21-78 | 43.19±15.19 | 2.172[a] | **0.032*** |
| | Income equal to or more than expenditure | 63 | 6-69 | 36.15±14.55 | | |
| **Social security** | No | 7 | 6-52 | 26.42±14.87 | -2.204[b] | **0.028*** |
| | Yes | 87 | 12-78 | 39.44±14.72 | | |
| **Age** | | | | | r=0.217[e] | **0.036*** |

min-max = minimum-maximum values; SD = standard deviation.

[a] Student's t-test; [b] Mann-Whitney U Test; [c] One-Way ANOVA (Post Hoc Tukey); [d] Kruskal-Wallis Analysis of Variance; [e] Spearman Correlation Analysis.

*p<0.05.

The comparison of the difficulties which have been experienced by the caregivers for schizophrenic patients and the issues they need with have registered a mean scores of the caregiver burden scale is shown in Table 5. Comparison of the difficulties and requirements of caregivers and the mean CBS scores demonstrated that caregivers who had difficulty when giving drugs to their patients had significantly higher mean CBS scores (p<0.001). The daily life skills of caregivers, communication, disease symptoms, patient's angry and aggressive behaviours; and the contribution to domestic life were not found to affect the mean CBS scores (p>0.05). The mean CBS score of primary caregivers who had a requirement for psychosocial treatment methods was found to be statistically significant which is lower than those who did not need them (p<0.05). No statistically significant correlation was found between the mean CBS scores and education about drugs, groups and associations about schizophrenia, legal rights of the patients, and skills about patients' life (toilet, bath, housekeeping) (p>0.05) (Table 5).

**Table 5: Comparison of difficulties that caregivers of schizophrenia patients experience, subjects their require and the mean caregiving burden scale scores (n=94**)

| *Difficulties in Caregiving* | | Caregiving Burden Scale | | | | |
|---|---|---|---|---|---|---|
| | | **n** | **min-max** | **Mean±SD** | **test value** | **p value** |
| **Daily life skills** | No | 82 | 6-78 | 39.07±15.52 | 1.001[a] | 0.320 |
| | Yes | 12 | 19-53 | 34.41±11.01 | | |
| **Communication** | No | 87 | 6-78 | 38.22±15.25 | -0.800[b] | 0.424 |
| | Yes | 7 | 21-62 | 41.57±12.94 | | |
| **Dealing with disease symptoms** | No | 48 | 6-78 | 36.31±16.85 | -1.433[a] | 0.155 |
| | Yes | 46 | 19-72 | 40.73±12.70 | | |
| **Use of medicines** | No | 62 | 6-71 | 34.40±13.57 | -3.926[a] | **<0.01**[*] |
| | Yes | 32 | 19-78 | 46.37±14.82 | | |
| **Furious and aggressive behavior** | No | 78 | 6-78 | 37.28±15.00 | -1.719[a] | 0.089 |
| | Yes | 16 | 21-71 | 44.31±14.37 | | |
| **Contribution to home life** | No | 86 | 6-78 | 38.66±14.87 | -0.610[b] | 0.542 |
| | Yes | 8 | 15-69 | 36.50±17.93 | | |
| *Required Topics* | | | | | | |
| **Medications and side effects** | No | 33 | 6-71 | 32.24±14.21 | -3.086[a] | **0.003**[**] |
| | Yes | 61 | 12-78 | 41.85±14.51 | | |
| **Coping with symptoms** | No | 31 | 6-60 | 31.58±12.64 | -3.275[a] | **0.001**[**] |
| | Yes | 63 | 12-78 | 41.87±15.07 | | |
| **Early warning signs** | No | 39 | 6-69 | 33.07±13.88 | -3.058[a] | **0.003**[**] |
| | Yes | 55 | 13-78 | 42.30±14.78 | | |
| **Groups and associations related with schizophrenia** | No | 60 | 6-78 | 40.13±15.45 | 1.423[a] | 0.158 |
| | Yes | 34 | 12-72 | 35.55±14.07 | | |
| **Communication skills** | No | 47 | 6-69 | 34.87±14.90 | -2.380[a] | **0.019**[*] |
| | Yes | 47 | 19-78 | 42.08±14.47 | | |
| **Coping with stress** | No | 47 | 6-69 | 34.97±14.24 | -2.305[a] | **0.023**[*] |
| | Yes | 47 | 19-78 | 41.97±15.18 | | |
| **Legal rights of patients** | No | 37 | 15-71 | 38.24±14.13 | -0.122[a] | 0.904 |
| | Yes | 57 | 6-78 | 38.63±15.74 | | |
| **Psychosocial treatment methods** | No | 48 | 15-78 | 41.56±15.62 | 2.064[a] | **0.042**[*] |
| | Yes | 46 | 6-72 | 35.26±13.87 | | |
| **Skills related to daily life (such as toilet, bathroom, and housekeeping)** | No | 49 | 6-69 | 35.95±15.23 | -1.552[b] | 0.121 |
| | Yes | 45 | 19-78 | 41.22±14.53 | | |
| **Planning patient's leisure activities** | No | 40 | 6-69 | 34.87±15.09 | -2.030[a] | **0.045**[*] |
| | Yes | 54 | 15-78 | 41.14±14.59 | | |
| **Contribution to home life** | No | 36 | 6-69 | 34.41±14.61 | -2.098[a] | **0.039**[*] |
| | Yes | 58 | 12-78 | 41.00±14.89 | | |

min-max = minimum-maximum values; SD = standard deviation.
[a] Student's t-test; [b] Mann-Whitney U Test.[*] p<0.05; [**] p<0.01.

Moreover, the final model of the linear regression analysis, it was found that the caregivers' having requirements in such areas as using patient drugs (Standard Beta (SB)=0.379), medication side effects (SB=0.306), coping with the symptoms of the disease (SB=0.323), drug education (SB=0.221), early warning signs (SB=0.304), communication skills (Std. Beta=0.241), coping with stress (SB=0.234), planning the patient's activities (SB=0.207), contribution to the household life of the patient (SB=0.214) increase their caregiving load scale scores (*p*<.05). It was found that the difficulties experienced by the caregivers in such areas as daily life skills, communication, coping with the symptoms of the illness, patients' anger and aggressive behaviour, contribution to the household life, legal rights, and skills related to their lives do not affect their caregiving load scale scores (p>0.05). The need for psychosocial treatment was found to decrease the caregiving load scale score (p<0.05; SB=-0.210).

## Discussion

According to the findings obtained from this study, majority of the patients with schizophrenia received care were male (5,19,20), single (21,22), has education at secondary school level (23,24), do not work (20-22) and had social security. Our findings are consistent with the literature. Considering that about 2/3 of the patients in our research were males, getting marriage is more difficult for them because of cultural reasons and because of the expectation of business life and economic responsibility of the house. Schizophrenia may prevent patients' graduation from school and working in a job because it affects perception, thinking, movement, attention and causes problems in daily life, job, school and social areas (2).

In a study, it was reported that the majority of patients with schizophrenia were admitted to hospital 1-3 times per year (8). We also found that the vast majority of patients experienced hospitalization. This may be due to the noncompliance with treatment.

We suggest that the reason for the majority of the primary caregivers being female was the maintenance of the traditional caregiver role of women. Our findings are similar to national and international research results (5,19,22). In addition to this, the fact that the majority of the primary caregivers of schizophrenia patients were not employed in our study and the majority of them being females might have affected this subject. Studies show that women are primarily giving up their jobs when someone at home needs to care (5,22).

In this study, the vast majority of primary caregivers were found to be married. This finding was supported by national (8,25) and international (19,26) studies. It can be argued that the reason for most of the caregivers of schizophrenia patients may be the facilitation of caregiving by marriage. This result supports the finding that half of the primary caregivers receive support during the caregiving process. Getting social, economic, emotional, or physical support that caregivers receive when they care for their patients alleviates the caregiver's burden (5,8,19).

Half of the primary caregivers of schizophrenia patients were found unemployed. Our findings are consistent with the finding of the literature (27). It can be said that no time is left for the caregiver to work because caregiving takes all the time of the caregiver (14).

In our study, the majority of primary caregivers were living in the same house with the patient they care for. Our study findings seem to overlap with findings of national and international studies in the literature (6,19). Individuals living in the same household with schizophrenia patients are voluntarily or involuntarily involved in the caregiving process. Culturally, caregivers living in the same house with patients they care for spend their full time with the patients and they have to pay close attention to all the needs of the patients (nutrition, bathing, medication, coping with symptoms) (5). This may be due to clinical-centred recovery as a marker of patient healing.

Requirements of the caregivers during caregiving process in our study were dealing with disease symptoms (15,28), drug treatment and side effects, education about drugs, contribution of the patient to domestic life, the legal rights of patients (14,15,28), early warning signs, planning the patient's leisure activities, communication skills (14,28), coping with stress, psychosocial treatment modalities, information about life skills (WC, bathroom, housekeeping), information on schizophrenia-related groups and associations (14,15). Although these findings are consistent with the studies in the literature, there are differences in the priority order. The difference in order may be related to the demographic features of caregivers, attitudes towards the patient and disease, and the level of knowledge about the disease. In our study, it seemed that the issues that primary caregivers need and the issues that cause stress were similar. Mental illness in one of the family members may cause stress due to uncertainties in other family members. Caregivers are reported to experience feelings of shame, guilt, and anger when they give care to schizophrenia patients (26,28).

People with schizophrenia may not want to use medicines because they denied illness or side effects (29). Since the patients who don't use their medications can have psychotic exacerbations, a more complicated and distressing situation occurs for both the patient and the family members. Delusions and hallucinations which are among positive signs of schizophrenia cause stress both for the patient and for the caregiver (30). Some family members stated that they also responded violently to their patients. The inability of patients to tell their complicated and sometimes frightening emotions and experiences to their families due to impairment in communication skills may cause stress for the families (31). This seems to be consistent with our finding that caregivers could not communicate well with their patients. When the literature in Turkey was investigated, it was found that caregivers need education topics like general information on schizophrenia, coping with schizophrenia symptoms, communication and social relationships, coping with stress, stress and disorder interaction, early signs of relapses, side effects of the medication, improving skills to live by themselves (17, 32,33). Bademli et al. (17) reported that primary school graduate caregivers had more difficulty in coping with schizophrenia symptoms, and caregivers who had no education about the disorder had significantly different “daily life skills” scores and “coping with stress” scores.

The mean CBS score of the primary caregivers of schizophrenia patients in our study was similar to some previous studies in Turkey (23,24), and lower than some other studies in Turkey and the world (32,34). Primary caregivers of schizophrenia patients told that they face difficulties while giving care to schizophrenia patients, they got rid of this process, and they couldn't accept the schizophrenia diagnosis in their relative. But they told that they had to take care of their patients because nobody can take care of their patients like them. The lower mean primary caregiver burden score in our study than Caqueo-Urizar et al. (32) and Kaya and Öz (34) may be due to regional differences,the use of different scales, and attempts of the caregivers to show themselves well.

In this study, primary caregivers of schizophrenia patients who experienced more difficulty with use and side effects of drugs were found to have higher levels of caregiver burden. The findings of our study are consistent with the literature (15,25). It is also consistent with the finding that caregivers who required education about drugs had a higher caregiver burden. This is thought to be related to caregivers having difficulties in persuading their patients to treatment, increased responsibilities, and conflicts with their patients. Sometimes patients may not want to use their medication because of the side effects of the medications, the route of use, or denial of their illness (30). Caregivers can coerce the patient while they are trying to persuade him or they may not do anything and cause the failure of treatment. Rejection of treatment can lead to exacerbation of psychotic symptoms and increased burden to the caregiver (31,35). Frequent hospitalization of the patients in our study and increased caregiver burden caused by this also support this hypothesis.

Primary caregivers who require education about dealing with disease symptoms, early warning signs and communication skills had a higher level of burden. Our findings are consistent with the findings of the literature (14,15,25). Caregivers may feel uncomfortable with their patients' disorganized behaviour and speech. They may not know how to approach patients with delusions and hallucinations. All these factors may cause the increased perception of caregiver burden during the caregiving process. The caregiver burden of primary caregivers who require education about coping with stress was higher. Our study findings are similar to the study findings of Yavaş Ayhan (15). The more stress the caregiver's experience during the caregiving process, the more bothersome is this process for them. For this reason, caregivers need information on how to deal with stress. Caregivers who require education about planning the leisure time activities of the patient are found to have more caregiving burden. If the patient can't find good leisure time activities and spend all his time with the individual who cares for him/her, caregiver burden may increase. Our study findings are similar to the study findings in the literature (14,28).

Caregivers who require education about the contribution of the patient to domestic life were found to have more burdens. The patient is male and has a father role but is unable to maintain this role may increase the perception of caregiver burden (19). Similarly, the fact that the patient is a woman or a mother and cannot fulfil her responsibilities due to illness may also be a burden for the caregiver (36). In the final model of the linear regression analysis, it was found that the caregivers' having requirements in such areas as using patient drugs, medication side effects, coping with the symptoms of the disease, drug education, early warning signs, communication skills, coping with stress, planning the patient's activities, and contribution to the household life of the patient increase the caregiving load scale scores of the caregivers. The findings of this study are similar to the findings of the respective literature (14,15,22). The fact that psychoeducation programs are not applied systematically on these issues in our country may lead to this outcome.

## Limitations of the study

This study has its own limitationsthat limitations include it was conducted with patients who could be reached between certain dates, and it was carried out in a single location. Thus, the findings only are generalizable to the population studied. Most of the family members with schizophrenia were not hospitalized immediately upon becoming ill. Thus, their duration of illness was calculated after hospitalization took place and once a diagnosis of schizophrenia was made. Their illness duration might have been longer than reported.

## Conclusion

As a result, it was observed that information and experience requirements of patients about drug treatment and side effects, coping with schizophrenia symptoms, early warning signs, communication skills, coping with stress, psychosocial treatment methods, planning leisure time activities of the patients and patient’s contribution to domestic duties were observed to affect the caregiver burden.

Determining the needs of caregivers of patients with schizophrenia is important in designing acceptable and effective training programs. It is thought that the factors affecting the maintenance burden will contribute to the design of the intervention programs to be done. All these reasons make the study worthwhile.

## Recommendations

Considering all these findings, schizophrenia affects individuals directly, but also indirectly affects their caregivers. Therefore, the scope of health care for patients with schizophrenia should include the well-being of caregivers. In this context, comprehensive, regular and continuous training programs and consultancy services can be provided on the issues that caregivers need to help them cope with the difficulties they encounter during the caregiving process. In addition, family-oriented interventions, including the caregiver, may be required within the scope of schizophrenia treatment. On the other hand, the results of this study can contribute to the literature in this respect by guiding qualitative and quantitative studies on the subject.

## Conflicts of interest

The authors report no conflicts of interest.

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## Contribution of authors

**NÇK:** Conceptualization, Methodology, Formal analysis, Investigation, Resources, Writing-original draft, Writing-review & editing, Project administration.
**HA:** Conceptualization, Methodology, Investigation, Resources, Visualization, Project administration, Writing -Review & Editing.

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