



Caregiver Burden in Schizophrenia and Autism Spectrum Disorders: A Comparative Study

Mustafa Yıldız¹ ✉, Yasemin Demir², Ayşe Kırçali², and Aysel İncedere²

¹Department of Psychiatry, Kocaeli University School of Medicine, Kocaeli, Turkey

²Department of Psychosocial Rehabilitation, Kocaeli University Institute of Health Science, Kocaeli, Turkey

Objective There is no study comparing schizophrenia and autism spectrum disorders (ASD) in terms of caregiver burden. This study aims to compare the caregiver burden among family members of the patients with schizophrenia and ASD and investigate the predictive factors.

Methods A cross-sectional study with the family members living with and/or providing care to their patients was carried out. A sociodemographic form, the Beck Depression Inventory, the Self-Stigma Inventory for Families, and the Zarit Caregiver Burden Scale were utilized. Regression analyses were conducted to determine the predictive factors for higher burden.

Results Caregiver burden in ASD was significantly higher than in schizophrenia. Regression analysis showed that the predictors of high caregiver burden were the need for self-care (OR=3.6), self-destructive behaviors (OR=3.4), self-stigma (OR=1.1), depression (OR=1.1), and level of income (OR=1.0) for all family members. When the diagnosis was removed from the equation, the factors determining the high burden did not change.

Conclusion This study suggests that characteristics of the illness are stronger predictors than family members' characteristics in explaining high caregiver burden for both illnesses. Psychological, social, and economic supports should be provided for families to help alleviate their caregiving burden.

Psychiatry Investig 2021;18(12):1180-1187

Keywords Caregiver burden; Schizophrenia; Autism spectrum disorders; Self-stigma; Depression.

INTRODUCTION

Many patients with severe mental illnesses (SMI), such as schizophrenia and autistic spectrum disorders (ASD) rely on relatives for emotional support, instrumental and financial assistance because of their functional impairment. Family members play an essential role as informal caregivers (providing unpaid care and support to a family member in a non-professional capacity) for the people with SMI and have been consistently reported to experience a certain level of burden.¹⁻⁴ As the caregiving burden of the patients is placed on the shoulders of the families, psychological, social, health, financial condition, and as a whole quality of life of the family mem-

bers are also affected.^{2,5-8} The family's distress caused by caregiving, deterioration of the quality of life, negative effects on work and social life, and psychological problems are considered as caregiver burden. Although there is no exact conceptual definition of the family or caregiver burden, Zarit et al.⁹ defined the burden as the extent to which caregivers perceived their emotional, physical health, social life, and financial status as suffering because of caring for their relative. The burden has two components as objective referring to the quantifiable challenges faced by the family members in everyday life such as financial costs, loss of free time, and disrupted social relations, and subjective burden referring to the intangible or emotional costs faced by the family members because of their loved one's illness. Likewise, terms such as stress, distress, tension, and burnout could be used instead of the burden. Caregiver burden can be shortly ascribed as the level of multifaceted strain perceived by the caregiver from caring for a family member.¹⁰ Despite cultural variations, the caregiver burden is a global issue that family members encounter in many parts of the world.¹¹

Caregiver burden has been studied for different SMIs and burden predictors have often been considered as not receiv-

Received: May 13, 2021 Revised: August 28, 2021

Accepted: September 27, 2021

✉ Correspondence: Mustafa Yıldız, MD

Department of Psychiatry, Kocaeli University School of Medicine, Umuttepe, 41001, Kocaeli, Turkey

Tel: +90-(262)3037505, Fax: +90-(262)3037079, E-mail: myildiz60@yahoo.com

© This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<https://creativecommons.org/licenses/by-nc/4.0>) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

ing help with caregiving, lack of social support, lower-income, older age, lower level of education, depression, having another family member needing care, and more days in contact with the patient as for the family characteristics, and duration of illness, early onset of the illness, disability or level of functioning, number of hospitalizations, violent behavior, suicidal behavior, comorbid illnesses, and more relapse regarding the illness characteristics.¹²⁻²² When the data of longitudinal and cross-sectional studies are evaluated in conjunction, the duration of the illness and the level of disability stand out in terms of contributing to the family burden. It was shown that the caregiver burden for chronic illnesses was not significantly associated with the clinical changes in symptoms over time.^{23,24}

Schizophrenia is one of the mental illnesses in which caregiver burden is most studied. Factors, such as the early onset of the illness, functional losses, the unpredictability of pathological behaviors, the uncertainty of the illness's course, and loss of expectations are influential for family burden.^{4,25} Increasing family distress and experiencing stigmatization during long-term care further increases the burden.²⁵ ASD is an SMI that begins even earlier and causes long-term distress than schizophrenia.²⁶ The caregiver burden is prominent in ASD families as well. Studies conducted in ASD families have determined the duration of illness, symptom severity, level of disability, comorbidity, and insufficient social support as prominent factors predicting the family burden.^{22,27-29}

There are studies comparing caregiving burdens in different SMI families. For example, a study comparing schizophrenia with affective disorders and a study comparing schizophrenia with other mental disorders show that the burden is higher in families caregiving to patients with schizophrenia.³⁰⁻³³ Also, the study compared ASD with Down Syndrome and Diabetes Mellitus showed that the burden was higher in families of the patients with ASD than others.²⁸ To the best of our knowledge, there is no study comparing schizophrenia with ASD in terms of caregiver burden. Comparing the family burden for both diseases might shed light on the question of which illness is more burdensome for family members. Our hypothesis is that ASD, which is started earlier than schizophrenia, has more burdensome than schizophrenia.

Although depression and stigmatization are generally analyzed in caregiver burden studies, the self-stigmatization experience that might be a contributory factor for the burden of caregiving was not studied enough.³³ There is little work on self-stigma and burden relations. This study aims to compare the caregiver burden and related factors in schizophrenia and ASD families. Identifying the factors associated with the burden will inform the professionals about the relevant protective interventions to prevent the devastating effects of the caregiver burden for both illnesses.

METHODS

Participants

Family members were recruited from a university hospital outpatient clinic for patients with schizophrenia and ASD, and three rehabilitation centers for patients with ASD in the same catchment area. The reason for choosing rehabilitation centers to interview ASD families was that these patients use the outpatient clinic less frequently. It was possible to meet with more family members in these centers. The inclusion criteria were that patients diagnosed with schizophrenia or ASD according to the DSM-5,²⁵ having diagnosed for a minimum of one year, that family member-caregiver living with the patient for at least one year and being intimately involved in their care, being more than 18 years of age, and having no diagnosed chronic physical illness that leads to disability. One hundred ASD and 80 schizophrenia family members were eligible for the study. Of those, 96 ASD and 67 schizophrenia family members accepted to participate in the study.

Procedures

Ethical approval of the study was obtained from Kocaeli University Non-Invasive Clinical Research Ethical Committee (KÜ GOKAEK 2019/135). Informed consent was taken from all the participants. Data were collected from the hospital files and the interviews with family members when they come to a psychiatric out-patient clinic appointment and/or while attending rehabilitation centers. All interviews were conducted between April 2019 and September 2019. Caregivers completed the Beck Depression Inventory (BDI), the Self-Stigma Inventory for families (SSI-F), and the Zarit Caregiver Burden Scale (ZCBS).

Measures

The socio-demographic form

The form included the sociodemographic characteristics of the patients (age, gender, marital status, education, employment status, age of illness onset, illness duration, number of hospitalizations, self-destructive behaviors, need for self-care, physical aggression, verbal aggression, sexual aggression, suicide attempt) and the caregivers (age, gender, marital status, education, employment status, monthly income per person in a family, having a psychiatric illness, having another person needing care in the family, having guardian's allowance, and relationship to the ill person).

Beck Depression Inventory (BDI)

The BDI was developed by Beck³⁴ to assess physical, emotional, and cognitive symptoms observed in depression and

the study of its Turkish adaptation was conducted by Hisli.³⁵ It is a 21-item self-assessment scale. Cronbach's alpha coefficient was found as 0.90. Higher scores indicate a greater level of depression.

Self-Stigma Inventory for Families (SSI-F)

The SSI-F is a self-report scale developed by Yildiz et al.³⁶ to evaluate the self-stigmatization of the family members of patients with schizophrenia. The Cronbach's alpha coefficient of the scale was 0.88. It is a 14-item self-assessment scale and has a 3-factor (perceived devaluation, social withdrawal, and concealment of the illness) structure. Higher scores indicate greater self-stigmatization. Since there is no Turkish self-stigma scale for the families of ASD patients, we used the SSI-F for this group as well. The internal consistency ($\alpha=0.85$) of the scale for this sample was good.

Zarit Caregiver Burden Scale (ZCBS)

ZCBS was developed by Zarit et al.³⁷ for assessing the burden of caregivers of patients with Alzheimer's disease. Özlü et al.³⁸ conducted its reliability and validity study with relatives of the patients with schizophrenia. The Turkish version of the scale consisted of 19 items and 5-factor (distress and impairment of private life, nervousness and restrictedness, impairment of social relations, financial strain, dependence) structure. The internal consistency of the scale was 0.83. Higher scores (range=19–95) indicate a greater burden.

Statistical analysis

All analyses were carried out using the Statistical Package for the Social Sciences for Windows, version 22 (IBM Corp., Armonk, NY, USA). Comparisons between two groups were carried out using chi-square for categorical variables and independent t-test or Mann Wittney U test for continuous variables according to normality. Univariate ANCOVA test was used to compare the two groups' caregiver burden, self-stigma, and depression levels by controlling statistically significant demographic factors between the family groups. Correlation coefficients among the caregiver burden, self-stigma, and depression for both illnesses were calculated. To assess the contribution in predicting caregiver burden, binary logistic regression analysis was performed with high burden scores (HBS) as the dependent variable, and other parameters which had demonstrated the significant associations ($p<0.05$) with the HBS on bivariate analyses as independent variables.

RESULTS

Participant characteristics

The main characteristics of the caregivers and patients are

presented in Table 1. The key caregivers were the mothers of the patients for both illnesses. Regarding the patients, the majority were men and had been ill for almost 7 and 9 years (respectively for ASD and schizophrenia). Differences between the groups were shown in Table 1. Based on the bivariate analysis, several sociodemographic and clinical factors were found to be significantly associated with HBS for both illnesses. The results were shown in Table 1.

Caregiver burden, self-stigma, and depression

As shown in Table 1, the levels of caregiver burden, self-stigma, and depression were statistically different between the two groups. To understand the degree of difference between the groups univariate ANCOVA was used by controlling confounding variables (i.e., family members' age, gender, employment position, having guardian's allowance, and relationship). The analysis yielded a significant difference between the groups regarding the caregiver burden (partial beta square=0.121) and depression (partial beta square=0.026). The results are shown in Table 2.

Correlation coefficients among the caregiver burden, self-stigma, and depression were shown for each group in Table 3. A high correlation coefficient was in between the caregiver burden and self-stigma in ASD families. Because the correlation coefficients were below 0.60, thinking that there was no collinearity among the burden, self-stigma, and depression, we assumed the self-stigma and depression as independent factors for the prediction of caregiver burden.

Predictors of the caregiver burden

When both illnesses were evaluated together to determine the predictive factors for caregiver burden, logistic regression analysis was preferred because the distribution of the data did not comply with normality. To this end, firstly, a median ZCBS score of ≥ 51 was used to dichotomize the sample into the low and high levels of burden scores. The rate of the high burden was 48.5% in total sample. High burden score (HBS) was significantly more in ASD families (63.5%) than schizophrenia families (26.9%) ($\chi^2=21.121$, $df=1$, $p<0.001$). Afterward, significantly related sociodemographic factors with the HBS were determined in the total sample (Table 1). These factors were analyzed by the binary logistic regression using enter method. The model was fit into the analysis (Hosmer and Lemeshow Test: $\chi^2=6.406$, $df=8$; $p=0.602$). Logistic regression analysis yielded that the patients' need for self-care, patients' self-destructive behaviors, family members' level of self-stigma, depression, and level of income were predictive factors for caregiving burden. The results are shown in Table 4. When the diagnosis was removed from the equation, the factors determining the HBS did not change, but the OR for the need

Table 1. Sociodemographic characteristics of the patients and the family members, and their associations with the high burden score (HBS \geq 51)

Characteristics	ASD (N=96)	Schizophrenia (N=67)	Group differ*	Relation with HBS (N=163)	
	Mean \pm SD (range)	Mean \pm SD (range)	p	t/ χ^2	p
Patients					
Age (years)	9.1 \pm 4.7 (4–24)	32.0 \pm 10.8 (18–64)	<0.001 [†]	3.115 [†]	0.002 [†]
Gender/male	77 (80)	46 (69)	0.093	0.050	0.824
Education (years)	2.8 \pm 3.6 (0–12)	11.7 \pm 2.8 (5–16)	<0.001 [†]	3.158 [†]	0.002 [†]
Marital status/single	96 (100)	56 (84)	<0.001 [†]	0.688	0.407
Unemployment	94 (98)	48 (72)	<0.001 [†]	1.03	0.310
Age of illness onset	2.3 \pm 1.2 (0–6)	22.6 \pm 7.0 (13–45)	<0.001 [†]	4.427 [†]	<0.001 [†]
Illness duration (years)	6.8 \pm 4.7 (2–23)	9.3 \pm 8.5 (1–44)	0.031 [†]	-0.675	0.501
Number of hospital	0.03 \pm 0.3 (0–3)	2.0 \pm 1.7 (0–10)	<0.001 [†]	2.671 [†]	0.008 [†]
Self-destructive beh	27 (28)	11 (16)	0.083	10.059 [†]	0.002 [†]
Need for self-care	73 (76)	7 (10)	<0.001 [†]	28.929 [†]	<0.001 [†]
Physical aggression	47 (49)	24 (36)	0.097	9.130 [†]	0.003 [†]
Verbal aggression	39 (41)	24 (36)	0.537	1.237	0.266
Sexual aggression	22 (23)	2 (3)	<0.001 [†]	7.885 [†]	0.005 [†]
Suicide attempt	1 (1)	12 (18)	<0.001 [†]	0.163	0.687
Family members					
Age (years)	39.5 \pm 9.5 (20–70)	52.4 \pm 10.8 (26–73)	<0.001 [†]	2.397 [†]	0.018 [†]
Gender/female	81 (84)	40 (60)	<0.001 [†]	6.906 [†]	0.009 [†]
Education (years)	10.1 \pm 3.7 (5–18)	9.2 \pm 4.2 (3–17)	0.158	-0.471	0.638
Marital status/marr	87 (91)	54 (81)	0.066	1.482	0.223
Relationship/mother	72 (75)	25 (37)	<0.001 [†]	8.184 [†]	0.004 [†]
Employment	23 (24)	38 (57)	<0.001 [†]	4.492 [†]	0.034 [†]
Monthly income [‡]	1167.5 \pm 908.4 (250–6,000)	1358.3 \pm 953.5 (250–5,000)	0.198	2.008 [†]	0.046 [†]
Guardian's allowance	30 (31)	2 (3)	<0.001 [†]	8.682 [†]	0.003 [†]
Another FM need care	7 (7)	6 (9)	0.701	0.030	0.862
Psychiatric illness	15 (16)	10 (15)	0.903	1.563	0.211
Caregiver burden	57.0 \pm 14.6 (26–88)	41.5 \pm 14.5 (19–79)	<0.001 [†]		
Depression	12.6 \pm 7.8 (0–32)	7.3 \pm 7.7 (0–28)	<0.001 [†]		
Self-stigma	25.2 \pm 9.4 (14–53)	21.4 \pm 7.6 (15–43)	0.007 [†]		

*independent t-test or Mann-Wittney U test for continuous variables according to the normality and χ^2 test for categorical variables; [†]statistically significant; [‡]per person in a family as Turkish Lira. ASD, autism spectrum disorders; FM, family member.

for self-care and self-destructive behaviors slightly changed to 4.5 and 3.3 respectively.

DISCUSSION

The results of the study showed that the caregiver burden assessed using the ZCBS was found to be higher in ASD families than schizophrenia families both in total and in all subscales. It is noteworthy that the biggest difference is in the financial strain subscale (Table 2). Despite the families of patients with ASD were taken guardian's allowance more than those of the patients with schizophrenia ($p<0.001$) and there was no

statistical difference between the monthly income for both illnesses (Table 1), the results highlighted the issue of the financial strain for the ASD families. Likewise, the level of monthly income was a predictive factor for caregiver burden for both illnesses. It can be said that economic support is essential in reducing the caregiver burden especially for the families of patients with chronic and debilitating illnesses. Financial strain as a prominent predictor for the caregiving burden has been demonstrated in other studies for both illnesses.^{3,4,16,19,27,39} However, it should be kept in mind that the financial burden associated with caregiving is attributable not only to the care expenses and providing financial support to the care recipient

Table 2. Comparison of the caregiver burden, self-stigma, and depression scores between the groups after controlling the confounding factors

Measurement tools	ASD (N=96)	Schizophr. (N=67)	F-test*	p-value	η^2
	Mean \pm SD (range)	Mean \pm SD (range)			
Zarit Caregiver Burden Scale	57.0 \pm 14.6 (26–88)	41.5 \pm 14.5 (19–79)	21.374	<0.001	0.121
Distress and impairment of private life	19.2 \pm 6.6 (7–35)	14.2 \pm 6.2 (7–29)	14.626	<0.001	0.086
Nervousness and restrictedness	9.0 \pm 2.8 (3–15)	6.6 \pm 2.6 (3–13)	16.407	<0.001	0.095
Impaired social relations	5.9 \pm 2.8 (3–14)	4.8 \pm 1.9 (3–10)	5.386	0.022	0.033
Financial strain	15.0 \pm 4.0 (4–20)	10.1 \pm 3.9 (4–20)	20.283	<0.001	0.115
Dependence	7.8 \pm 2.3 (2–10)	5.9 \pm 2.6 (2–10)	12.428	0.001	0.074
Self-Stigma Inventory-Family	25.2 \pm 9.4 (14–53)	21.4 \pm 7.6 (15–43)	0.803	0.371	0.005
Perceived devaluation	9.5 \pm 4.1 (6–27)	8.2 \pm 2.7 (6–17)	1.087	0.299	0.007
Social withdrawal	10.7 \pm 4.4 (6–25)	7.9 \pm 3.0 (6–19)	4.201	0.042	0.026
Concealment of the illness	4.9 \pm 3.1 (3–15)	5.3 \pm 3.8 (3–15)	1.456	0.229	0.009
Beck Depression Inventory	12.6 \pm 7.8 (0–32)	7.3 \pm 7.7 (0–28)	4.154	0.043	0.026

*ANCOVA analysis of covariance; η^2 partial eta-squared. ASD, autism spectrum disorders; SD, standard deviation

but also to the lost income of the family members.^{4,40,41}

There was no difference between the groups regarding the total self-stigma score, but the social withdrawal subscale score was higher in ASD families than schizophrenia families (Table 2). Regression analysis showed that self-stigma was a predictive factor for the HBS for the whole group alongside the depression and low income for families caring for patients with ASD and schizophrenia independent from the diagnosis. The level of depression was also higher in ASD families than schizophrenia families even though it's small effect size. There was a significant correlation among these parameters (Table 3). The correlations between the burden and self-stigma and depression in ASD families, and the correlation between the burden and depression in schizophrenia families are prominent. It is noteworthy that there might be reciprocal relations among depression, self-stigma, and burden. The fact that depression, self-stigma, and low income determine the high caregiver burden can be interpreted as the indirect effect of other variables that are significant in bivariate analyses (i.e., the age of illness onset, number of hospitalizations, sexually or physically aggressive behaviors, suicide attempts of the patients, and family member's age, gender, employment, etc.). Negative characteristics of chronic illnesses impose a significant risk in terms of self-stigmatization.^{33,42,43} Self-stigma is related to the factors like low self-esteem, depression, shame, hopelessness, and helplessness which could be resulted from struggling with the negative aspects of chronic illnesses. There may be an inter-relationship between self-stigmatization, depression, psychiatric illnesses, and caregiving burden. For example, the caregivers who experience both stigma and financial strains are likely vulnerable to social isolation which may hinder access to support, intensifying the overall negative effect upon mental health. Further, it is reasonable to expect that caregivers who have a

Table 3. Correlation coefficients among the caregiver burden, self-stigma, and depression for both illnesses

	ASD (N=96)		Schizophrenia (N=67)	
	Self-stigma	Depression	Self-stigma	Depression
Caregiver burden				
r	0.559	0.481	0.256	0.492
p	<0.000	<0.000	0.037	<0.000

ASD, autism spectrum disorders

vulnerability of psychological problems may be particularly prone to experiencing stigma and its negative effects which could result in a reluctance to take help from others, which might lead to the extra burden.^{2,3} Professionals should be cognized that any family member experiencing self-stigma and depression, also has a risk of caregiver burden that might complicate the situation as well.

ASD and schizophrenia as an illness that starts at an early age, requiring long-term supports and services, causes more caregiving burden. Family members of the patients with ASD and schizophrenia should be evaluated and supported in terms of depression and self-stigmatization in clinical settings. Professionals should be mindful of the families' psychosocial problems which may play a role as a moderator for the caregiving burden alongside the patients' mental and behavioral problems.²⁰ Interventions focused on caregivers' psychological and social requirements are likely to be more effective in reducing caregiver burden and thereby that might improve outcomes related to the patients' management.

Caring for patients with SMIs, which will last for a lifetime, whose future is full of uncertainty, and who have no hope for recovery, living with them may cause additional psychological problems for family members over time. Studies highlight the importance of depression and psychiatric illnesses on

Table 4. The predictive factors for high caregiver burden (N=163)

Variables*	B	SE	Wald	df	Sig.	Exp (B)	95% CI for Exp (B)
Diagnosis	1.573	1.379	1.301	1	0.254	4.821	0.323–71.951
Patient's age	0.065	0.038	2.949	1	0.086	1.067	0.991–1.149
Patients' education	0.037	0.074	0.253	1	0.615	1.038	0.897–1.201
Age of illness onset	-0.033	0.058	0.326	1	0.568	0.968	0.864–1.084
Number of hospitalizations	-0.002	0.223	0.000	1	0.992	0.998	0.644–1.545
Self-destructive behavior	1.210	0.580	4.358	1	0.037†	3.354†	1.077–10.446
Need for self-care	1.287	0.559	5.293	1	0.021†	3.622†	1.210–10.842
Physical aggression	0.365	0.478	0.584	1	0.445	1.440	0.565–3.673
Sexual aggression	1.083	0.719	2.270	1	0.132	2.953	0.722–12.076
FMs gender	-0.710	0.825	0.742	1	0.389	0.492	0.098–2.474
FMs age	0.018	0.023	0.596	1	0.440	1.018	0.973–1.065
Relationship	-0.406	0.668	0.369	1	0.543	0.666	0.180–2.469
Guardian's allowance	-0.320	0.624	0.264	1	0.608	0.726	0.214–2.465
FMs employment	-0.746	0.645	1.339	1	0.247	0.474	0.134–1.678
Monthly income	-0.001	0.000	5.335	1	0.021†	0.999†	0.999–1.000
Self-stigma	0.066	0.032	4.278	1	0.039†	1.069†	1.003–1.138
Depression	0.121	0.035	12.223	1	0.000†	1.128†	1.054–1.207
Constant	-3.345	1.545	4.688	1	0.030	0.035	

*predictive factors did not change after removing the diagnosis from the equation. Hosmer and Lemeshow Test: chi-square=6.406, df=8; p=0.602.

†statistically significant. FM, family member; CI, confidence interval

families of patients with ASD and schizophrenia.^{13,17,21,31,44-46} The reason why there was no correlation between the family members' psychiatric illness and caregiver burden in our study might be due to the self-report information. If the family members were examined by a psychiatric interview, the results could have been different. Therefore, we can say that psychological strains like self-stigma and self-report depression were important factors that predict family caregiving burden, and psychiatric illnesses experienced by the family members due to the chronic illness should not be overlooked. It could be addressed that family members having patients with ASD, and schizophrenia should be provided the necessary support for mitigating their depression and self-stigma experiences.

There are two studies using the Turkish version of ZCBS to determine the predictive factors for family members of the patients with ASD and schizophrenia.^{16,21} The caregiver burden for the families of patients with ASD was found to be predicted by depression and behavioral problems, not the caregiver's age and level of education. The caregiver burden of the patients with schizophrenia was found to be predicted by the level of income, functioning of the patients, caregivers' level of education, not the number of hospitalizations, and caregiver's age. Parallel to our study, these results have common features regarding the predictive factors as depression, level of income, and functioning of the patients.

As patients' characteristics, the need for self-care (OR=3.6) and self-destructive behaviors (OR=3.4) were the predictive factors for the HBS. We didn't use any instrument to assess the functioning of the patients which includes patients' self-caring and behavioral problems. Instead, we questioned the aggressive behaviors as verbal, physical, sexual, suicidal, or self-destructive ones whether there were or not. Although there was no difference between the groups in terms of verbal aggression, physical aggression, and self-destructive behaviors, sexually aggressive behavior was significantly more in patients with ASD than patients with schizophrenia, suicide attempt was significantly more in patients with schizophrenia than patients with ASD. Patients' need for self-care was significantly more in patients with ASD than patients with schizophrenia. Physical aggression, sexual aggression, verbal aggression, and suicide attempt were not predictive for the HBS. In our study, among behavioral problems, only self-destructive behaviors were determined as a predictive factor for HBS. Similarly, patients' need for self-care, which might reflect the severe functional impairment, was a predictive factor for the caregiver burden. Patients' functional impairment, sometimes called disability or poor functioning, and self-destructive behavior called in some studies as self-abusive behavior were also reported as predictive factors for caregiving burden by other studies for both ASD and schizophrenia.^{3,12,15,16,28,29,31,42,47} That

means family members of patients who needed to provide more assistance for daily functioning were more likely to have a higher caregiver burden.²⁸

In conclusion, the results of the study pointed out that the patients' self-destructive behaviors and need for self-care, family members' levels of income, self-stigma, and depression are determinative in terms of family burden. There is a great need to develop interventions that address the caregivers' stresses and patients' management. It could be said that the patients' behavioral problems and their need for self-care are more troubling factors for the family members. Accessibility for the treatment and rehabilitation services, availability of the day-care and respite care services, availability of the occupational therapeutic activities in both rehabilitation facilities and board-and-care facilities and at home, should be provided for all the patients and the families who needed. The family members living with the patient should be provided psychological, social, and economical support to buffer the negative effects of depression, self-stigmatization, and financial strains on caregiving. It could be recommended that formal caregiving services should be put in place by the governmental institutions to help the family caregivers minimize the caregiving burden and maximize the families' wellbeing.

Limitations

One main limitation of this study was its small sample size. Thus, larger sample size can increase the power of the study and the accuracy of the results. Another limitation of this study was performing the study in a university psychiatric hospital and rehabilitation centers for patients with ASD. Thus, a generalization of the results to other patients at the national level should be done with caution. Comorbid disorders, such as attention deficit hyperactivity disorder and mental retardation was not evaluated in patients with ASD. Whereas the presence of comorbid disorders in patients with ASD is an important factor that increases the caregiver burden.³⁹ The time spent by family members with their patients has not been evaluated as well. It is known that, as the time spent on caregiving for the patient increases, the burden increases.⁴⁸ Additionally, social support and social stigma which are possible predictive factors for the family burden was not examined in this study.^{1,12,15,18,44} Lastly, because this study is a cross-sectional design it cannot give a causal relationship between caregiver burden and its correlates. Future studies should employ prospective design to clarify this issue.

Availability of Data and Material

The datasets generated or analyzed during the study are available from the corresponding author on reasonable request.

Conflicts of Interest

The authors have no potential conflicts of interest to disclose.

Author Contributions

Conceptualization: Mustafa Yıldız, Yasemin Demir, Ayşe Kırçalı. Data curation: Yasemin Demir, Ayşe Kırçalı, Aysel İncedere. Formal analysis: Mustafa Yıldız, Aysel İncedere. Investigation: Yasemin Demir, Ayşe Kırçalı. Methodology: Mustafa Yıldız, Yasemin Demir, Ayşe Kırçalı. Project administration: Mustafa Yıldız. Resources: Yasemin Demir, Ayşe Kırçalı. Supervision: Mustafa Yıldız. Writing—original draft: all authors. Writing—review&editing: Mustafa Yıldız. All authors have read and agreed to the present version of the manuscript.

ORCID iDs

Mustafa Yıldız	https://orcid.org/0000-0003-0769-1628
Yasemin Demir	https://orcid.org/0000-0002-5116-7009
Ayşe Kırçalı	https://orcid.org/0000-0001-8948-4512
Aysel İncedere	https://orcid.org/0000-0001-8181-1371

Funding Statement

None

Acknowledgments

We are grateful to the family members who gave their time to participate in this study.

REFERENCES

1. Tsang HWH, Tam PKC, Chan F, Cheung WM. Sources of burdens on families of individuals with mental illness. *Int J Rehabil Res* 2003;26:123-130.
2. Papadopoulou C, Lodder A, Constantinou G, Randhawa G. Systematic review of the relationship between autism stigma and informal caregiver mental health. *J Autism Dev Disord* 2019;49:1665-1685.
3. Siddiqui S, Khalid J. Determining the caregivers' burden in caregivers of patients with mental illness. *Pak J Med Sci* 2019;35:1329-1333.
4. Kamil SH, Velligan DI. Caregivers of individuals with schizophrenia: who are they and what are their challenges? *Curr Opin Psychiatry* 2019;32:157-163.
5. Caqueo-Urizar A, Gutierrez-Maldonado J. Burden of care in families of patients with schizophrenia. *Qual Life Res* 2006;15:719-724.
6. Kaschowitz J, Brandt M. Health effects of informal caregiving across Europe: a longitudinal approach. *Soc Sci Med* 2017;173:72-80.
7. Ribé JM, Salameo M, Pérez-Testor C, Mercadal J, Aguilera C, Cleris M. Quality of life in family caregivers of schizophrenia patients in Spain: caregiver characteristics, caregiving burden, family functioning, and social and professional support. *Int J Psychiatry Clin Pract* 2018;22:25-33.
8. Alnazly EK, Abojedi A. Psychological distress and perceived burden in caregivers of persons with autism spectrum disorder. *Perspect Psychiatr Care* 2019;55:501-508.
9. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist* 1986;26:260-265.
10. Liu Z, Heffernan C, Tan J. Caregiver burden: a concept analysis. *Int J Nurs Sci* 2020;7:438-445.
11. Chan SW. Global perspective of burden of family caregivers for persons with schizophrenia. *Arch Psychiatr Nurs* 2011;25:339-349.
12. Grandón P, Jenaro C, Lemos S. Primary caregivers of schizophrenia outpatients: burden and predictor variables. *Psychiatry Res* 2008;158:335-343.
13. Gülseren L, Cam B, Karakoç B, Yiğit T, Danacı AE, Cubukcuoğlu Z, et al. The perceived burden of care and its correlates in schizophrenia. *Turk Psikiyatri Derg* 2010;21:203-212.
14. Rabinowitz J, Berardo CG, Bugarski-Kirola D, Marder S. Association of

- prominent positive and prominent negative symptoms and functional health, well-being, healthcare-related quality of life and family burden: a CATIE analysis. *Schizophr Res* 2013;150:339-342.
15. Jagannathan A, Thirthalli J, Hamza A, Nagendra H, Gangadhar B. Predictors of family caregiver burden in schizophrenia: study from an inpatient tertiary care hospital in India. *Asian J Psychiatr* 2014;8:94-98.
 16. Yazici E, Karabulut Ü, Yıldız M, Baskan Tekeş S, Inan E, Çakır U, et al. Burden on caregivers of patients with schizophrenia and related factors. *Noro Psikiyatrs Ars* 2016;53:96-101.
 17. Souza ALR, Guimaraes RA, de Araujo Vilela D, de Assis RM, de Almeida Cavalcante Oliveira LM, et al. Factors associated with the burden of family caregivers of patients with mental disorders: a cross-sectional study. *BMC Psychiatry* 2017;17:353.
 18. Yu Y, Liu ZW, Tang BW, Zhao M, Liu XG, Xiao SY. Reported family burden of schizophrenia patients in rural China. *PLoS One* 2017;12:e0179425
 19. Hajebi A, Naserbakht M, Minoletti A. Burden experienced by caregivers of schizophrenia patients and its related factors. *Med J Islam Repub Iran* 2019;33:54.
 20. Peng MM, Zhang TM, Liu KZ, Gong K, Huang CH, Dai GZ, et al. Perception of social support and psychotic symptoms among persons with schizophrenia: a strategy to lessen caregiver burden. *Int J Soc Psychiatry* 2019;65:548-557.
 21. Baykal S, Karakurt MN, Çakır M, Karabekiroğlu K. An examination of the relations between symptom distributions in children diagnosed with autism and caregiver Burden, anxiety and depression levels. *Community Ment Health J* 2019;55:311-317.
 22. Vogan V, Lake JK, Weiss JA, Robinson S, Tint A, Lunskey Y. Factors associated with caregiver burden among parents of individuals with ASD: differences across intellectual functioning. *Fam Relat* 2014;63:554-567.
 23. Chadda RK, Singh TB, Ganguly KK. Caregiver burden and coping: a prospective study of relationship between burden and coping in caregivers of patients with schizophrenia and bipolar affective disorder. *Soc Psychiatry Psychiatr Epidemiol* 2007;42:923-930.
 24. Rhee TG, Rosenheck RA. Does improvement in symptoms and quality of life in chronic schizophrenia reduce family caregiver burden? *Psychiatry Res* 2019;271:402-404.
 25. Shiraishi N, Reilly J. Positive and negative impacts of schizophrenia on family caregivers: a systematic review and qualitative meta-summary. *Soc Psychiatry Psychiatr Epidemiol* 2019;54:277-290.
 26. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (DSM-5®)*. Washington DC: American Psychiatric Pub; 2013.
 27. Marsack-Topolewski CN, Samuel PS, Tarraf W. Empirical evaluation of the association between daily living skills of adults with autism and parental caregiver burden. *PLoS One* 2021;16:e0244844.
 28. Picardi A, Gigantesco A, Tarolla E, Stoppioni V, Cerbo R, Cremonese M, et al. Parental burden and its correlates in families of children with Autism Spectrum Disorder: a multicentre study with two comparison groups. *Clin Pract Epidemiol Ment Health* 2018;14:143-176.
 29. Kissel SD, Nelson WM. Parents' Perceptions of the severity of their child's autistic behaviors and differences in parental stress, family functioning, and social support. *Focus Autism Other Dev Disabl* 2016; 31:152-160.
 30. Chakrabarti S, Raj L, Kulhara P, Avasthi A, Verma SK. A comparison of the extent and pattern of family burden in affective disorders and schizophrenia. *Indian J Psychiatry* 1995;37:105-112.
 31. Grover S, Chakrabarti S, Ghormode D, Dutt A. A comparative study of caregivers' perceptions of health-care needs and burden of patients with bipolar affective disorder and schizophrenia. *Nord J Psychiatry* 2015; 69:629-636.
 32. Gupta S, Isherwood G, Jones K, Van Impe K. Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. *BMC Psychiatry* 2015;21: 162.
 33. Fernando SM, Deane FP, McLeod HJ, Davis EL. A carer burden and stigma in schizophrenia and affective disorders: experiences from Sri Lanka. *Asian J Psychiatr* 2017;26:77-81.
 34. Beck AT. An inventory for measuring depression. *Arch Gen Psychiatry* 1961;4:561-571.
 35. Hisli N. Beck Depresyon Envanterinin üniversite öğrencileri için geçerliliği, güvenirliği. *Psikoloji Dergisi* 1989;7:3-13.
 36. Yıldız M, İncedere A, Kiras F, Abut FB, Kircali A, İpci K. Development of Self-Stigma Inventory for Families of the patients with schizophrenia (SSI-F): validity and reliability study. *Psychiatr Clin Psychopharmacol* 2019;29:463-471.
 37. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20:649-655.
 38. Özlü A, Yıldız M, Aker T. A reliability and validity study on the Zarit caregiver burden scale. *Arch Neuropsychiatry* 2009;46:38-42.
 39. Suresh APC, Benjamin TE, Crasta JE, Alwinesh MTJ, Kannianappan G, Padankatti SM, et al. Comparison of burden among primary caregivers of children with autism and intellectual disability against children with intellectual disability only in a hospital population in India. *Indian J Pediatr* 2014;81(Suppl 2):179-182.
 40. Sruamsiri R, Mori Y, Mahlich J. Productivity loss of caregivers of schizophrenia patients: a cross-sectional survey in Japan. *J Ment Health* 2018; 27:583-587.
 41. Rogge N, Janssen J. The economic costs of autism spectrum disorder: a literature review. *J Autism Dev Disord* 2019;49:2873-2900.
 42. Inogbo CF, Olotu SO, James BO, Nna EO. Burden of care amongst caregivers who are first degree relatives of patients with schizophrenia. *Pan Afr Med J* 2017;28:284.
 43. Mak WWS, Kwok YTY. Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Soc Sci Med* 2010; 70:2045-2051.
 44. Singh P, Ghosh S, Nandi S. Subjective burden and depression in mothers of children with autism spectrum disorder in India: moderating effect of social support. *J Autism Dev Disord* 2017;47:3097-3111.
 45. Zhou T, Wang Y, Yi C. Affiliate stigma and depression in caregivers of children with Autism Spectrum Disorders in China: effects of self-esteem, shame and family functioning. *Psychiatry Res* 2018;264:260-265.
 46. Kate N, Grover S, Kulhara P, Nehra R. Relationship of caregiver burden with coping strategies, social support, psychological morbidity, and quality of life in the caregivers of schizophrenia. *Asian J Psychiatr* 2013; 6:380-388.
 47. Konstantareas MM, Homatidis S. Assessing child symptom severity and stress in parents of autistic children. *J Child Psychol Psychiatry* 1989;30:459-470.
 48. Maguire R, Hanly P, Maguire P. Beyond care burden: associations between positive psychological appraisals and well-being among informal caregivers in Europe. *Qual Life Res* 2019;28:2135-2146.