



## RESEARCH ARTICLE

# Disease burden and associated factors in caregivers of patients with obsessive-compulsive disorder

Didem Suculluoglu-Dikici<sup>1</sup>, Fikret Poyraz Cokmus<sup>1</sup>, Funda Akin<sup>2</sup>, Erhan Eser<sup>3</sup>, Mehmet Murat Demet<sup>2</sup>

<sup>1</sup>Manisa Mental Health and Diseases Hospital, Department of Psychiatry, Manisa - Turkey

<sup>2</sup>Manisa Celal Bayar University, Faculty of Medicine, Department of Psychiatry, Manisa - Turkey

<sup>3</sup>Manisa Celal Bayar University, Faculty of Medicine, Department of Public Health, Manisa - Turkey

### ABSTRACT

**Objective:** Obsessive-compulsive disorder (OCD) is one of the leading causes of disability and poor quality of life, with impairment in many areas. It can also adversely affect family members and friends that the person lives with, and this results in a burden. We aimed to evaluate the disease burden in caregivers of patients with OCD and the factors that negatively affect caregiver burden.

**Method:** The study population consisted of 94 patients with OCD and their caregivers. The Yale-Brown Obsessive-Compulsive Scale (YBOCS), the Hamilton Depression Rating Scale, and the World Health Organization Quality of Life Questionnaire Brief Form were filled out by the patients, and the Burden Assessment Scale (BAS) by the caregivers.

**Results:** Longer duration of treatment, higher YBOCS obsession and compulsion scores of the patients, and lower environmental quality of life dimension scores of the patients were found to increase the BAS scores of the caregivers. Additionally, these variables were found to be significant predictors for disease burden (BAS score) ( $p < 0.05$ ).

**Conclusion:** Our study revealed that many variables affect burden, even in caregivers who have no extra burden (who has no disease to cause a burden). Caregivers of patients with OCD should be included in the behavioral and pharmacologic treatment process for the benefit of both the OCD treatment management and the protection of family health.

**Keywords:** Burden, caregiver burden, disease burden, family burden, obsessive compulsive disorder

## INTRODUCTION

Treatments in psychiatric disorders have started to be community-based, thus the importance of rehabilitation services has increased. The adoption of the approach suggesting the treatment of patients within the society and in their own environment has caused for patients long time spent with the family, and for families to take a more active role in the treatment of patients. This development brought with it several problems, and it

was shown that family members had problems in many areas (1,2). "Family burden" is the term used to describe the impact of the disease on the family, such as the difficulties family members face in their daily lives due to living with a sick individual; the problems affecting their lives and adverse events have gained importance in psychiatry (3). Although the concept of caregiver burden is used in family studies due to the need for physical care in physical diseases, the concepts of "family burden", "disease burden", and "caregiver

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**Correspondence:** Fikret Poyraz Cokmus, Manisa Mental Health and Diseases Hospital, Department of Psychiatry, 814 Street, Manisa - Turkey

**E-mail:** fikretpoyrazcokmus@hotmail.com

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burden" replace each other in psychiatry. The family burden turns relatives into invisible patients, and also disrupts the support for the patient and causes problems in the treatment of the disease (4).

Obsessive-compulsive disorder (OCD) is one of the leading causes of disability and poor quality of life (QoL), with impairment in a various areas. It can also adversely affect family members and friends that the person lives with (5,6). The patient's obsessions, indecision, requests for approval, trust-seeking behaviors, avoidance behaviors, compulsions, and rituals may result in excessive dependence on family members (7). Families are often more involved in the patient's symptoms than the families of other patients with psychiatric disorders due to the nature of OCD (6,8). Family members can take on many tasks and responsibilities of the patient.

With the need for support and/or care for the patient, the social and professional functions of family members may be impaired. In addition, with the patient's inability to work due to illness, the economic burden may increase (9). In the literature, it was reported that the caregiver burden in OCD is similar to that of schizophrenia (10-12). In a study conducted with patients with OCD and depressive disorder, it was found that although the QoL and functionality of patients with OCD were better, the caregiver burden was higher in OCD (13). Disease severity, disease duration, disability, and low socioeconomic status were found to be factors affecting caregiver burden (14-16).

OCD is a common disease and affects family functionality in many areas. It creates a burden for caregivers, and it requires a detailed assessment of the factors affecting caregiver burden, both to protect the mental health of the caregiver and to lead in the planning of initiatives to better manage of the disease. However, studies evaluating variables related to the patients and their caregivers together and making detailed analysis are insufficient. In this study, we aimed to determine disease burden and associated factors in the caregivers of patients with OCD.

## METHOD

### Participants

The study protocol was approved by the Scientific Research Ethics Committee of Manisa Celal Bayar University Faculty of Medicine (Approval date: November 27<sup>th</sup>, 2019; Number: 20.478.486). The participants (OCD patients and their caregivers) were informed about the study and written informed consent forms were obtained before being included in the study.

The Structured Clinical Interview for DSM-5/ Clinical Version (SCID-5/CV) was conducted with the patients with OCD in the psychiatry outpatient clinic of a university hospital. Following the SCID interview, patients with OCD completed a sociodemographic data questionnaire, the Yale-Brown Obsessive-Compulsive Scale (YBOCS), the Hamilton Depression Rating Scale (HAM-D), and the World Health Organization Quality of Life Scale Brief Version (WHOQOL-BREF). Patients with OCD with a comorbid psychiatric disorder according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (excluding depressive disorder, depressive symptomatology, nicotine addiction), the presence of neurologic/or physical illness, and intellectual disability were excluded.

Caregivers aged  $\geq 18$  years living with patients with OCD for at least one year were eligible for this study. The eligible caregivers of the patients completed the sociodemographic questionnaire and the Burden Assessment Scale (BAS) after a structured clinical interview. The exclusion criteria in the caregivers' group were the presence of a comorbid psychiatric disorder according to the DSM-5 (except nicotine addiction), the presence of neurologic/or physical illness, and intellectual disability.

A total of 112 patients with OCD and their caregivers were included in the study. Ten patients with comorbidities that could affect their QoL and the burden of their caregivers (epilepsy [n=3], rheumatoid arthritis [n=2], alcohol abuse [n=3], diabetic neuropathy and retinopathy [n=1], multiple sclerosis [n=1]) and 8 caregivers who failed to complete the self-reported scales were excluded. The remaining 94 patients with OCD and 94 caregivers who met the research criteria were enrolled in the study.

### Measures

**Structured Clinical Interview for DSM-5 Axis I Disorders (SCID-5):** This is a semi-structured interview to conduct major DSM-5 Axis I diagnoses. It was translated into Turkish by Elbir et al. (17).

**Questionnaire for Sociodemographic and Disease-related Variables:** This questionnaire was used to investigate the socio-demographic characteristics of the participants and caregivers (e.g. age, sex, marital status, income perception, occupational status, and residence), and the clinical characteristics of the patients including the duration of the disease and detailed treatment history.

**Yale-Brown Obsessive-Compulsive Scale (YBOCS):** This semi-structured scale was developed to rate the severity and type of symptoms in patients with obsessive

compulsive disorder by Goodman (18). YBOCS consists of 19 items, the first 5 items assess obsessions and 6-10 assess compulsions. Item 11 assesses the insight of the individual insight. The validity and reliability of the Turkish version of BAS was shown by Tek et al. (19).

**Hamilton Depression Rating Scale (HAM-D):** The scale was developed by Hamilton (20) to determine the severity of depression. A total score of 0 to 51 is obtained from this 17-item scale. The cut-off point for the Turkish version has been set to 7. The validity and reliability of the Turkish version of BAS was shown by Akdemir et al. (21)

**World Health Organization Quality of Life Scale Brief Version (WHOQOL-BREF):** This is a shorter version of WHOQOL-100, which was developed in a multicenter study in 1998 (22) to measure four domains; physical health, psychological health, social relationships, and the environment. The WHOQOL-BREF was validated for Turkish by Eser et al. (23). The possible score range for each domain is between 4 to 20, and higher scores indicate a better QoL.

**Burden Assessment Scale (BAS):** This is a 19-item self-report scale developed by Reinhard et al. (24) to assess the burden of families with a member having a severe mental illness. The validity and reliability of the Turkish version of BAS was shown by Aydemir et al. (25). The scale has no cut-off score; as the scale score increases, the burden of disease increases.

### Statistical Analysis

The dependent variable of this study was the disease burden in caregivers of patients with OCD assessed using BAS scores. BAS scores were also used as a continuous variable in the analyses due to the uncertainty of using any cut-off value for BAS. The sociodemographic characteristics of the patients and caregivers and, patients' clinical characteristics and quality of life dimensions were used as independent variables in our study. Both univariate and multivariate analyses were performed. Mann-Whitney U test was used for post-hoc analyses where necessary. The normality of data distribution was tested using the Shapiro-Wilk test. During univariate comparisons, Student's t-test and Pearson correlations were used in parametric distributions, and the Mann-Whitney U, Kruskal-Wallis analysis of variance, and Spearman's Rho were used where parametric test criteria could not be met.

Multiple linear regression analyses were performed to determine the association between disease burden and variables that had been found to be significant in univariate analyses. The critical variance inflation

factors (VIF) were taken as 5.0 for detecting the collinearity among independent variables in the multiple regression analyses. Statistical analyses were performed using SPSS version 23.

## RESULTS

### Descriptive Results

The mean age was  $36.03 \pm 12.03$  years for the patients and  $43.28 \pm 14.76$  for the caregivers. The majority (74.5%) of the patients were female, whereas only 46.8% of them were female in the caregiver group. Half of the caregivers (50%) were patients' spouses, and parents represented almost a quarter (22%); the rest were siblings, children or friends. The demographic characteristics of the patients and caregivers are summarized in Table 1.

The mean duration of disease was  $8.10 \pm 6.60$  years and the mean duration of treatment was  $4.04 \pm 4.47$  years. The caregiver's mean BAS score was  $39.52 \pm 12.99$ . The YBOCS, HAM-D, and WHOQOL-BREF dimension scores of the patients are given in Table 1.

### Univariate Analyses

The univariate analyses results are presented in Table 2. BAS score was the dependent variable in all the univariate analyses presented in Table 2. The critical p-value for all analyses was taken as 0.05.

### The Association Between the Sociodemographic Characteristics of Caregivers and the Disease Burden

The BAS scores of caregivers living in urban areas were significantly lower ( $p=0.032$ ); and those who perceived their income as low had significantly higher BAS scores than others ( $p=0.012$ ) (Table 2).

We used Student's t-test in parametric conditions where the two means are compared, and Mann Whitney U test in nonparametric conditions. The Kruskal Wallis Anova test was applied in nonparametric situations where three means were compared.

### The Association Between Sociodemographic, Clinical Characteristics, Quality of Life and Disease Burden of Patients

Caregivers whose patients perceived their income as low had significantly higher BAS scores than the others ( $p=0.013$ ) (Table 2).

The educational level of patients' education level was inversely correlated with the BAS score ( $r=-0.25$ ,  $p<0.05$ ). The duration of disease ( $r=0.29$ ), duration of treatment ( $r=0.28$ ), and number of hospitalizations ( $r=0.27$ ) were positively correlated with the BAS scores ( $p<0.05$ ).

**Table 1: Sociodemographic, clinical characteristics and scale scores of the patients and caregivers**

	Patients		Caregivers	
	Mean/(n=68)	SD/%	Mean/(n=68)	SD/%
<b>Age (Mean±SD)</b>	36.03	12.03	43.28	14.76
<b>Sex (n, %)</b>				
Male	24	25.5	50	53.2
Female	70	74.5	44	46.8
<b>Marital status (n, %)</b>				
Married	59	62.8	72	76.6
Single, widowed	35	37.2	22	23.4
<b>The length of education (years) (Mean±SD)</b>	9.45	4.28	8.89	4.90
<b>Occupational status (n, %)</b>				
Working	24	25.5	41	43.6
Not working	70	74.5	53	56.4
<b>Settlement (n, %)</b>				
Rural	39	41.9	39	41.9
Urban	55	58.1	55	58.1
<b>Perceived income level (n, %)</b>				
Low	14	14.9	17	18.1
Middle	64	68.1	58	61.7
High	16	17.0	19	20.2
<b>Caregiver's relation with the patient (n, %)</b>				
Parent	-	-	25	26.6
Spouse	-	-	47	50.0
Sibling, child, friend	-	-	22	23.4
<b>Duration of the disease (years) (Mean±SD)</b>	8.10	6.60		
<b>Duration of the treatment (years) (Mean±SD)</b>	4.04	4.47		
<b>Depressive disorder as a comorbidity (n, %)</b>	56	59.5		
<b>History of hospitalizations (n, %)</b>	21	22.3		
<b>YBOCS obsession score (Mean±SD)</b>	11.22	4.51		
<b>YBOCS compulsion score (Mean±SD)</b>	10.02	5.36		
<b>HDRS score (Mean±SD)</b>	7.38	5.72		
<b>WHOQOL-BREF</b>				
Physical dimension (Mean±SD)	13.20	3.30		
Psychological dimension (Mean±SD)	12.30	2.97		
Social relations dimension (Mean±SD)	12.02	3.76		
Environmental dimension (Mean±SD)	13.76	2.64		
<b>BAS Score (Mean±SD)</b>	39.52	12.99		

YBOCS: Yale Brown Obsession Compulsion Scale; HDRS: Hamilton Depression Rating Scale; BAS: Burden Assessment Scale; WHOQOL-BREF: World Health Organization Quality of Life Questionnaire Brief Form; SD: Standard deviation

Similarly, patients' YBOCS obsession ( $r=0.47$ ) and compulsion scores ( $r=0.47$ ), YBOCS total scores ( $r=0.52$ ), and HAM-D scores ( $r=0.32$ ) were positively correlated with disease burden (BAS score) ( $p<0.05$ ). Also, the disease burden was found to be inversely correlated with the patients' QoL in all dimensions ( $p<0.05$ ).

### Multivariate Analyzes

Multiple linear regression analysis was performed to determine the predictors of disease burden variables found to be significant in the univariate analyzes. The BAS score is the dependent variable in these regression models. The regression analysis results are presented in

**Table 2: The association between burden and the socio-demographic characteristics of the patients and caregivers**

Variable	Patient BAS Score		Caregiver BAS Score	
	Mean	SD	Mean	SD
<b>Gender</b>				
Male	42	15.58	38.92	12.01
Female	38.67	11.99	40.20	14.13
	p=0.448*		p=0.225**	
<b>Marital status</b>				
Married	39.66	12.75	39.93	13.82
Single, widowed	39.29	13.57	38.18	9.98
	p=0.817**		p=0.778*	
<b>Perceived income level</b>				
Low	45.79	16.78	48.82	14.77
Middle	40.14	12.01	38.26	11.87
High	31.56	9.54	35.05	11.13
	p=0.013***		p=0.012***	
Post hoc**	a<(b=c)		a<(b=c)	
<b>Occupational status</b>				
Working	38.21	12.89	38.10	11.11
Not working	39.97	13.09	40.85	15.33
	p=0.474*		p=0.126**	
<b>Settlement</b>				
Rural			42.92	13.72
Urban			37.11	11.99
	p=0.032*			
<b>Relation to the patient</b>				
Parent			39.72	15.35
Spouse			40.36	13.28
Sibling, friend, child			37.50	9.26
	p=0.803***			

BAS: Burden Assessment Scale; SD: Standard deviation; \*Student's t test; \*\*Mann Whitney U testi; \*\*\*Kruskall Wallis Anova testi

Table 3. The regression model showed good R2 value (0.62), and VIF analyses showed no collinearity between the independent variables. Duration of treatment, YBOCS obsession scores, YBOCS compulsion scores, and patient WHOQOL-BREF environmental dimension scores were found to be predictors for disease burden (BAS score) in the final reduced stepwise model (p<0.05).

## DISCUSSION

In this study, we aimed to evaluate the factors affecting disease burden in caregivers of patients with OCD. By taking variables that were significantly related to disease burden in the univariate analysis, we determined the predictors of caregiver burden in OCD.

A minimum of 1 year was taken for patients with OCD and their co-living caregivers because less than that might not have been enough to place any meaningful measurable burden on the caregiver. Patients with OCD with a comorbid psychiatric disorder (except depressive disorder) and the presence of neurological/or physical disease and intellectual disability were excluded since these disorders have their own burden, as proven in previous studies (26,27), and the additional burden would be added to that of OCD. Comorbid depressive disorder was not excluded because it was mostly secondary to OCD. Although there are studies in the literature showing an association between disease burden and psychiatric comorbidity in the caregivers of patients with OCD, we excluded all caregivers with psychiatric and neurological/or physical disorders to obtain a purer sample and to assess the OCD-specific burden only. In these studies, there was no causality about whether psychiatric disorders generate burden, or high family burden causes psychiatric disorders (28,29).

We found that only perceived income level, residence, and patient's education levels among the sociodemographic variables were significantly

**Table 3: Summary of multiple linear regression reduced final step for variables predicting caregivers' BAS score (n=94)**

Regression analysis final step (R <sup>2</sup> =0.622*)	Disease burden					
	B	SE	Std Beta	t	p	VIF
<b>YBOCS obsession score</b>	0.80	0.28	0.28	2.88	<0.001*	1.355
<b>YBOCS compulsion score</b>	0.62	0.23	0.26	2.70	<0.001*	1.305
<b>Duration of the treatment</b>	0.58	0.25	0.20	2.34	0.02*	1.069
<b>WHOQOL-BREF Environmental dimension</b>	-0.82	0.39	-0.17	-1.90	0.05*	1.206

YBOCS: Yale Brown Obsession Compulsion Scale; HDRS: Hamilton Depression Rating Scale; BAS: Burden Assessment Scale; WHOQOL-BREF: World Health Organization Quality of Life Questionnaire Brief Form; VIF: Variance inflation factor; \*p<0.05

Notes: The variables found significant in the univariate analyses-entered to the Regression Model: Caregiver's income level, domicile; patient's education, duration of illness, duration of treatment, number of hospitalizations, YBOCS obsession and compulsion scores, HRDS score and all four dimensions QoL scores

associated with the disease burden. Caregivers living in rural areas who perceived their income as low had significantly higher BAS scores. There are two studies in the literature similar to our study (13,30); however, only low perceived income level was found significant in one of them (30). These findings may be explained by the difficulty of accessing advanced and qualified healthcare services, including psychoeducation and family therapies as well as medication, due to the fact that psychotherapy is not offered as a routine psychiatric practices in state institutions in our country for various reasons. Individuals should refer to higher level health institutions or private centers for psychotherapy. Additionally, in our study, it was observed that as the patient's education period increased, the caregiver burden decreased. Higher educational levels help to develop disease coping strategies, by facilitating access to information. Our study is the first to show that education years are negatively correlated with BAS scores.

In the literature, there are studies showing that disease duration increases the disease burden (16,31,32), and studies showing that it does not affect the disease burden (15,33). In our study, compatible with Cicek et al.'s findings (31) disease burden was found to be positively correlated with both the disease and treatment duration. As the duration of disease and treatment increases, caregivers may be more exposed to symptoms, lose their positive feelings for recovery, develop inappropriate coping strategies, and this can result in burden. In addition, the prolongation of the treatment increases the cost of treatment and causes an economic burden.

In our study, higher YBOCS-obsession scores, YBOCS-compulsion scores, and HDRS scores increased the disease burden. Also, many previous studies demonstrated that the disease burden is affected by the severity of the disease (13-15,22,31,34). As the severity of the disease increases, the number of hospitalizations and patients' need for care may increase. Therefore, the leisure activities of the caregiver may decrease, its social functionality may deteriorate, its professional life may be disrupted, which can cause the caregiver burden. To support this, we found that, as the number of hospitalizations increased, the disease burden increased, consistent with the previous studies (13,31).

Our findings suggest that poorer QoL of patients in all four dimensions (physical, psychological, social, environmental) led to a significantly increased burden of disease. To our knowledge, this is the first study to evaluate the patients's quality of life quality as a variable

of the caregiver burden. Previous studies have focused on the relationship between functionality and disease burden, showing that the burden increases as disability increases (30,31). However, the concept of QoL includes functionality and relevant subjective satisfaction (35); this makes us think that our findings are more valuable. Already in recent years, researchers have focused on QoL as a criterion that should be improved in the treatment process.

According to the regression analysis, duration of treatment, YBOCS-obsession scores, YBOCS-compulsion scores, and patients' environmental QoL scores were predictors of the disease burden. As a predictor of caregiver burden, finding the duration of treatment rather than the duration of disease suggests that the persistence of symptoms despite treatment causes more burden than the total disease duration. Because in psychiatry, patients often present for treatment when it becomes severe, not at the onset of the disease. Due to the nature of OCD, obsessive-compulsive symptom severity is inevitably a predictor of disease burden because it can be seen from the outside and caregivers can adapt to the symptoms. As the severity of obsessive-compulsive symptom increases, the caregiver can be involved in the patient's rituals in order to alleviate the stress associated with the disease, reduce the time spent on the symptoms, and facilitate daily functioning, and can take on the responsibilities of the patient. This may cause the deterioration of domestic order and may limit the caregiver's daily life (36). Finding patients' environmental QoL as a predictor of disease burden is a first in the literature. In the validity study of the WHOQOL scale, the environmental dimension was reported as an indicator of the economic status of the individual (37,38). Due to OCD, the patient's working power may decrease, professional functionality may deteriorate, treatment costs may increase, the need for caregiver support may increase, all of which result in burden. In addition, components such as recreational and leisure opportunities, physical circumstance and safety, house conditions, access to healthcare to new knowledge and skills constitute the environmental dimension of QoL. Impairment in any of these can lead to difficulties in the daily routine and treatment of the patient, causing a burden on the caregiver.

In conclusion, our study contributes to the literature with its detailed statistics and new findings. Our study shows that many variables affect burden, even in caregivers without any extra burden. Among these variables, obsessive-compulsive symptom severity, treatment duration, and patients' environmental QoL

are predictors of the disease burden. In the light of these findings, physicians should focus on social and professional expectations of patients, their relationships with people they live with, the caregivers' attitudes towards the patient with OCD, as well as the treatment of the symptoms. Also, the needs of the caregiver should not be ignored. For the benefit of the OCD treatment management and to protect the family health, caregivers of patients with OCD should be included in the behavioral and pharmacological treatment process. Family interviews and family treatments should be included in routine psychiatric practices. In addition, group therapies should be organized according to the needs of patients and caregivers. However, our findings should be repeated with large-sample follow-up studies with large samples. Future studies may focus on how much the family burden is over time and how it is affected by treatment interventions.

Contribution Categories		Author Initials
Category 1	Concept/Design	D.S.D., E.E., M.M.D.
	Data acquisition	D.S.D., F.P.C., F.A.
	Data analysis/Interpretation	D.S.D., F.P.C., E.E.
Category 2	Drafting manuscript	D.S.D., F.P.C., F.A.
	Critical revision of manuscript	D.S.D., F.P.C., E.E., M.M.D.
Category 3	Final approval and accountability	D.S.D., F.P.C., F.A., E.E., M.M.D.
Other	Technical or material support	F.A.
	Supervision	E.E., M.M.D.

**Ethics Committee Approval:** The study protocol was approved by the Scientific Research Ethics Committee of Manisa Celal Bayar University Faculty of Medicine (Approval date: November 27<sup>th</sup>, 2019; Number: 20.478.486).

**Informed Consent:** The participants (OCD patients and their caregivers) were informed about the study and written informed consent forms were obtained prior to their inclusion in the study.

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