

1 regulations should be investigated and solutions should be produced for the caregivers of
2 COPD patients.

3 **Key words:** Burden, caregiver, COPD

4 **1. Introduction**

5 The duration of time together with chronic diseases is increasing all over the world,
6 because of the aging of societies, newly developed drugs and developments in the field
7 of medicine. This situation increases the burden of caregiver [1]. Caregiver burden is used
8 to express the physical, psychological, social or financial reactions that can be
9 experienced while providing care [2]. Furthermore, caregiver burden has been identified
10 as a risk factor for worsening caregiver physical and psychological health, worsening
11 health-related quality of life, compromised immunity and mortality [3-5]. Determining
12 the care burden levels of caregivers is important for increasing the quality of life of both
13 caregivers and patients [6-8].

14 Chronic obstructive pulmonary disease (COPD) is an important global health problem
15 associated with increased mortality and morbidity [9]. COPD causes symptoms such as
16 dyspnea, cough, phlegm, loss of appetite, insomnia, fatigue, depression, anxiety, and
17 insufficiency in cognitive functions [10]. All of these physical and psychosocial problems
18 decrease the functional performance of individuals, cause limitations in their daily life
19 activities, and increase both the dependence and care needs of individuals [11,12].

20 In Europe and the USA, 4–10% of the adult population have COPD and its prevalence is
21 increasing [13,14]. In the Burden of Obstructive Lung Disease (BOLD) study which is
22 performed in Adana, 19% of adults over 40 years old are estimated to have COPD [15].

23 The burden of COPD on the health care system and society is increasing day by day [16].

1 There are little data on the burden of caregivers and the awareness of the disease in COPD,
2 which is the third most common cause of death among chronic diseases [17]. Even, there
3 is almost no data on the number of workday loss of informal caregivers of COPD patients
4 and the number of nights spent outside home [18].

5 The aim of the study that in caregivers of COPD patients to determine caregiver burden,
6 the workday loss and the awareness of caregivers about COPD disease and treatment.

7

8 **2. Material- Method**

9 This is a prospective, cross sectional, questionnaire study. Between September 1, 2017
10 and December 31, 2017, 252 patients with COPD and 252 their informal caregiver were
11 included in the study, from 12 centers. The only inpatients and their primary caregivers
12 who were included in the study were informed about the purpose of the study, their
13 written and verbal consents were obtained, and they were made to sign the participant
14 consent form. It was approved by Ethical Committee of Ufuk University Faculty of
15 Medicine.

16 **2.1 Definition of COPD**

17 Patients with forced expiratory volume in 1 second (FEV1 / FVC) less than 70% in the
18 pulmonary function tests (PFTs) in the stable condition were diagnosed as COPD.
19 Patients with COPD for at least for 6 months were included in the study. All patients were
20 staged according to Global Obstructive Lung Disease (GOLD) 2017 combined
21 assessment as GOLD stage A, B, C and D [19]. Spirometric staging have not used in this
22 new classification. Staging have been made according to the degree of symptoms, and the
23 number of COPD exacerbations in the last 1 year. Accordingly, GOLD-A defines the
24 patient who has the least symptoms (mMRC 0-1 or CAT<10) and 1 or less exacerbation

1 in the last year. GOLD-B defines the patient who has more symptomatic (mMRC_≥2 or
2 CAT_≥10) and 1 or less exacerbation in the last year. GOLD-C defines the patient who
3 has less symptomatic (mMRC 0-1 or CAT<10) and _≥2 exacerbation or _≥1 hospitalization
4 in the last 1 year. GOLD-D defines the patient who has more symptomatic (mMRC_≥2 or
5 CAT_≥10) and _≥2 exacerbation or _≥1 hospitalization in the last 1 year.

6 **2.2. Definition of caregivers**

7 Caregivers were defined as family members who were involved in the patient's daily care
8 needs, such as; transport to the hospital, application of the treatment at home, personal
9 care, shopping.

10 **2.3. Data collection**

11 Data of questionnaires and socio-demographic informations were collected by conducting
12 face-to-face interviews with COPD patients and their caregivers.

13 **2.4. Patient and Caregiver Information Form**

14 The demographic characteristics, disease information (GOLD grade and stage, the dyspnea
15 scale of modified medical research council (mMRC), COPD assessment test (CAT)), the
16 number of comorbidities, treatment and disease conditions in the last 1 year (emergency
17 service admissions, hospitalization, number of exacerbations) of the patients were
18 recorded. The demographic characteristics, the number of co-morbidities, working
19 conditions, educational levels, marital status of the caregivers were recorded. In addition,
20 a questionnaire consisting of 12 questions related to disease awareness (5 questions),
21 treatment awareness (5 questions) and work day loss (2 questions), and Zarit Burden
22 Interview Scale (see below) was applied.

23 **2.5. Zarit Burden Interview (ZBI)**

1 The scale (ZBI) was developed by Zarit et al [20], and the study of Turkish validity and
2 reliability was conducted by Inci and Erdem and the internal consistency coefficient of
3 the scale was determined to be 0.92 [20]. The scale consists of 22 statements determining
4 the effect of caregiving on the life of individuals. The ZBI measures subjective burden in
5 terms of the degree (from ‘never:0’ to ‘almost always:4’) to which the caregiver
6 experiences physical, psychological, emotional, social and financial problems as a result
7 of their care-giving role. As the score increases, the care burden increases and with the
8 maximum score at 88 [20].

9 **2.6. Statistically Analysis**

10 SPSS software (version 22.00; SPSS Inc., Chicago, IL, USA), was used for statistical
11 analyses. A $p < 0.05$ was considered statistically significant. In statistical analysis,
12 categorical variables were given as numbers and percentages, and continuous variables
13 were presented with mean \pm standard deviation (SD) for descriptive analyses. Chi-square
14 tests were used for comparison of categorical variables between the groups. In the
15 comparison of categorical groups, if the percentage of the expected value less than 5 for
16 each unit is greater than 20%, chi-square analysis was performed using the Monte Carlo
17 method. In order to identify variables increasing the burden of care, multiple linear
18 regression analysis were performed. The linear regression analyses data are presented as
19 beta coefficient with p value. In the relationship between the dependent variable and the
20 independent variables, when significant correlations in which greater than 0.70 were
21 found between independent variables, only one of those variables was taken. For the
22 control of multiple linearity, the VIF value below 5 was applied. Backward method was
23 applied while creating the linear regression model. Variables with $p < 0.05$ indicated a
24 significant association between the variables and the outcomes.

1 3. Results

2 Of the 252 patients, 221 (87.7%) were male and 31 (12.3%) were female and the mean
3 age was 66.8 ± 9.7 years. Fifty-four (21.4%) patients were active smokers and 159
4 (63.1%) were exsmoker. Eighty-three (32.9%) patients had one, 45 (17.9%) patients had
5 two, 28 (11.1%) patients had three and 10 (4%) had more than 3 comorbidities. 25.4% (n
6 = 64) of the patients live in the countryside and 68.3% (n = 172) in urban. Disease
7 characteristics related to COPD are shown in *Table 1*. Accordingly, approximately half
8 of the patients (50.8%) were GOLD-D. Seventy seven (30.6%) patients had long term
9 oxygen therapy (LTOT), 42 (16.7%) had bi-level positive airway pressure (BPAP) and
10 123 (48.8%) had nebuliser.

11 Sociodemographical characteristics and comorbidities of caregivers are shown *Table 2*.
12 41.3% (n=104) of the caregivers were spouse, 42.8% (n=108) were the child and 15.9%
13 (n=40) were other relatives. Of the 252 caregivers, 167 (66.3%) were female and 85
14 (33.7%) were male. The mean age were 48.1 ± 13.4 /years. Almost half of caregivers
15 (n=125, 49.6%) had never smoked, and 55 had biomass exposure. Eighty-two (32.5%)
16 caregivers had at least one comorbidity. The number of comorbidity of the caregivers is
17 as follows; 43 (17.1%) had 1 comorbidity, 17 (6.7%) had 2 comorbidities, 10 (4%) had 3
18 comorbidities and 3 (1.2%) had ≥ 3 comorbidities. 39.6% (n=98) of caregivers were
19 employee.

20 The questions that were asked to caregivers about COPD disease awareness, treatment
21 awareness and loss of the working days are shown in *Table 3*. Two-hundred thirty eight
22 of the caregivers (94.4%) were aware of that COPD is a lung disease and 232 (92.1%)
23 knew the most common cause of COPD is smoking. Only 52.2% (n=131) of caregivers
24 knew that COPD is a treatable disease. 62 (46.3%) caregivers suffered at least one work

1 day loss and 125 (53.5%) caregivers spent at least 1 night outside home because of their
2 stay in the hospital.

3 *Table 4* shows the number of lost working days due to accompanying COPD patients in
4 the hospital. According to *Table 4*, as the severity of the COPD increases, the loss of
5 working days of caregivers increases. Caregivers of GOLD D group patients have lost
6 working days the most.

7 According to GOLD combined evaluation, Zarit total scores were 19.3 ± 10.1 (median=18)
8 in group A, 24.9 ± 15.1 (median=22) in group B, 22.1 ± 13.9 (median=19) in group C and
9 30.5 ± 15.6 (median=29) in group D patients.

10 The factors that increase the burden of care in the univariate linear regression analysis
11 were the age ($p < 0.001$), mMRC ($p < 0.001$), CAT ($p < 0.001$), the number of comorbidities
12 of patients ($p = 0.02$), FEV1 (ml) ($p = 0.009$), FEV1% ($p < 0.001$), LTOT ($p = 0.03$), using
13 nebuliser ($p = 0.002$) and the presence of comorbidities of caregivers ($p = 0.006$). The
14 factors that increase the burden of care in the multivariate linear regression analysis were
15 age, CAT score, the number of comorbidities of patients, FEV1% and the presence of
16 comorbidities of caregivers (*Table 5*).

17 **4. Discussion**

18 The most important results of this study are that Zarit Scale of caregivers and workday
19 losses increased as the severity of the COPD increases. Another result is that awareness
20 of disease and treatment in caregivers is relatively high. This study is the first study in the
21 literature for the evaluation of COPD disease-treatment awareness and it is the second
22 study that assessed workday loss of caregivers of COPD patients [21].

23 Caregiver burden was investigated in many chronic diseases [22-25]. Due to the
24 psychological, physical and social difficulties they are exposed to, the caregivers of

1 chronic patients have been described as "hidden patients" in the literature [26].

2 In the study Goris et al, mean scores of the care burden of caregivers were found to be
3 40.91 ± 20.58 [27]. Similarly, Tel et al showed that mean scores of care burden of
4 caregivers of patients with COPD were 39.64 ± 15.07 [28]. The literature involves
5 different studies in which the care burden is higher (50.2 ± 8.7) as well as lower
6 (22.80 ± 14.45) [29,30].

7 In a study in which 179 COPD and chronic heart failure patients were analyzed, only 10%
8 of caregivers reported no burden [31]. In our study, the Zarit Burden Scale mean score
9 were 19.3 ± 10.1 (median=18) in group A and 30.5 ± 15.6 (median=29) in group D patients.
10 We did not find any other study that calculated the Zarit score in relation to COPD groups.
11 In our study, Zarit score was lower in Group A and C, and was higher in Group B and D.
12 That is, the caregiver burden was proportional to the severity of the dyspnea, but not with
13 the spirometric severity. According to GOLD, COPD Group B and D patients have higher
14 dyspnea than Group A and C [18]. Therefore, we think that dyspnea increases caregiver
15 burden.

16 The relationship between the age of patient and caregiver burden differs from disease to
17 disease. In a study conducted by Goris et al [27] including caregivers of patients with
18 COPD, there was no significant relationship between the patient's age and the caregiver
19 burden. But in our study, there was correlation between age and caregiver burden. To
20 date, age has been correlated with caregiver burden in many chronic diseases [32,33]. In
21 the study of MacNabney et al., Age and COPD were found to be among the most
22 important predictors of care commitment [34].

1 In another study, it was found that caregiver burden increased as age increased in
2 oncology patients [35]. In our study, neither the age of patients nor the age of the caregiver
3 was correlated with the caregiver burden. This difference may be due to the different
4 patient populations, different caregiver populations and different nations in the both
5 studies.

6 In 2009, Adelman et al reported that an estimated 65.7 million individuals in the United
7 States served as unpaid family caregivers and of these, 43.5 million (66%) provided care
8 for an adult older than 50 years [36]. Also the majority of caregivers were women who
9 took care of a relative (86%) or friend (14%) [36]. In an other study, Goris et al. showed
10 that caregiver burden scores of female caregivers were higher than those of male
11 caregivers [27]. Godoy-Ramirez et al found that the large majority (76.8%) of severe/very
12 severe COPD patients were living with a caregiver, generally a wife or daughter [37]. In
13 a meta-analysis, it was stated that female caregivers had lower physical well-being and
14 higher levels of care burden and depression, compared with male ones [38]. Our findings
15 were similar to previous studies [27,37]. 66.3% of caregivers were female and mostly,
16 they were daughters or sons (42.4%, n = 108) or spouses (41.3%, n = 104) of the patients.
17 Forty percent of the caregivers in our study were both paid workers and informal
18 caregivers of COPD patients. These caregivers accompanied COPD patients during
19 routine hospital visits and access to health services at the time of exacerbations.
20 According to our study the workday loss of caregivers is the least in the GOLD A group
21 and is the highest in the GOLD D group. In the Global Obstructive Lung Disease report,
22 the patients with annual hospitalization number of 1 or more per year due to exacerbations
23 are categorized as group C and D [9]. Therefore, workday loss is expected to be higher in
24 the caregivers of group D patients. According to GOLD report, Group B patients have

1 fewer hospitalization number but they are more symptomatic than Group C. However,
2 the annual workday loss in Group B patients is higher than in Group C in our study. In
3 this case, it would be wrong to evaluate the workday loss of caregivers according to the
4 number of hospitalizations of COPD patients. Because hospitalization of the patients
5 during exacerbation depends on many factors such as availability of access to health care
6 centers, affordability of health expenses, hospital occupancy rate, level of perception of
7 the patient's symptoms. To date, there are not enough studies evaluating the workday loss
8 of caregivers of COPD patients.

9 In our study, FEV1% was found to be associated with care burden. However, there is no
10 other study evaluating the relationship between FEV1 and caregiver burden. Therefore,
11 we could not make a comparison.

12 In GARD study (Turkey's asthma and COPD awareness study) 8527 people from the
13 general population were included and 49.6% said that COPD is a lung disease [39]. In a
14 recent study in China, the COPD awareness rate was 9.2% [40]. However, these studies
15 were conducted in the general population. To the best of our knowledge, there is no study
16 evaluating the awareness of caregivers about COPD disease and its treatment. The level
17 of knowledge of caregivers in chronic diseases is one of the factors influencing the
18 prognosis of the patient [41]. Caregivers are the people who accompany the patient during
19 the disease and its treatment course. Therefore, we believe that the awareness of the
20 caregivers will affect the care course. The results of our study show that caregivers have
21 a relatively high awareness when compared with other studies, although there are limited
22 data in the literature. Approximately 50% of our patients have advanced stage COPD and
23 their severity of symptoms and rate of hospitalization are high in the last 1 year.

1 Therefore, it can be considered that the patient and the caregiver have enough experience
2 with the disease and its treatment course.

3 Major limitation of our study is the low number of patients and their caregivers. The main
4 reason for the low number of patients was the short duration (3 months) of data gathering
5 period. Here we publish not only the data about the caregivers of COPD patients but also
6 data about treatment awareness of patients. Therefore, the questions asked to the patients
7 and their relatives are much more than they appear in our manuscript. The time needed to
8 fill our questionnaires was about 30 minutes per person so that the number of questions
9 were limited. Another limitation of our study is that we did not evaluate the financial and
10 moral losses associated with work losses.

11 As a result; the caregiver burden of the caregivers of COPD patients are high, and
12 caregivers have relatively high awareness of disease. The factors increasing the burden
13 of care are the number of comorbidity and the severity of dyspnea of patients. In addition,
14 caregivers with paid employment experience a workday loss due to accompanying
15 patient. The socioeconomic consequences of the workday loss of caregivers are unknown,
16 but this is a worthwhile investigation. It is a fact that diseases cannot be managed only
17 with drugs or medical methods, and the caregivers are an important part of management
18 of diseases. We think that the socioeconomic problems of caregivers should be
19 determined and supported.

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1 **Table 1.** Characteristics of disease of COPD patients

Parameter		n (%)
COPD Group	GOLD A	37 (14.7)
	GOLD B	61 (24.2)
	GOLD C	24 (9.5)
	GOLD D	128 (50.8)
FEV1 (ml/%) (mean±SD)		1293±622/48.1±19.5
FVC (ml/%) (mean±SD)		2182±965/65.1±19.5
FEV1/FVC (mean±SD)		57.2±10.6
CAT (mean ±SD)		18.94±9.5

2 Abbreviation COPD; chronic obstructive lung disease, FEV1; forced expiratory volume
3 in one second, FVC; forced vital capacity, CAT; COPD assessment test.

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13 **Table 2.** Smoking status, working status, working hours, marital status and educational
14 level of caregivers.

Parameters		Caregivers
Smoking status (n-%)	Smoker	76 (30.2)
	Exsmoker	51 (20.2)
Smoking pack-year		20.6±14.2
Working status	Unemployed	151 (60.4)
	Employee	98 (39.6)
Working hours	Full day	66 (73.3)
	Half day	9 (10)
	Shift	15 (16.7)
Marital status	Married	189 (75.6)
	Single	58 (23.2)
Educational level	Not literate	19 (7.6)
	Primary school	78 (31.3)
	Secondary school	33 (13.3)
	High school	61 (24.5)
	University	53 (21.3)
	Others	5 (2)

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5 **Table 3.** The questions that were asked to caregivers about COPD disease awareness,

6 treatment awareness and loss of the working days.

Questions	Yes, n (%)	No, n (%)	No Idea, n (%)
1. COPD is a lung disease.	238 (94.4)	-	13 (5.2)
2. The most common cause of COPD is smoking	232 (92.1)	6 (2.4)	14(5.6)
3. Exposure to occupational dust and chemicals and indoor air pollution may result in COPD.	198 (78.9)	17 (6.8)	36 (14.3)
4. COPD is a treatable disease.	131 (52.2)	59 (23.5)	61 (24.3)
5. The reason for hospital admissions in COPD is not only lung problems, but also the severity of comorbidities.	138 (55.2)	41 (16.4)	71 (28.4)
6. Using inhalation therapy with the right technique reduces cough, sputum and shortness of breath.	206 (82.7)	3 (1.2)	40 (16.1)
7. Do you apply non-drug method to reduce cough, sputum, and dyspnea?	61 (24.3)	190 (75.7)	-
8. Using inhaled therapy with the right technique reduces the frequency of emergency department visits and the frequency of hospitalization.	172 (68.3)	20 (8)	58 (23.2)
9. Do you apply non-drug method to reduce the frequency of hospital admission and the frequency of emergency services?	34 (13.5)	217 (86.5)	-
10. Have you received training on behavior change in the treatment of COPD?	87 (34.7)	137 (54.6)	27 (10.8)
11. How many working days did you lose in the last year because of accompanying the patient in the hospital?	0 day	72 (53.7)	27 (10.8)
	1-7 days	36 (26.9)	
	8-14 days	17 (12.7)	
	>14 days	9 (6.7)	
12. How many nights have you spent outside the house in the last year because of accompanying the patient in the hospital?	0 day	108 (46.4)	
	1-7 days	73 (31.3)	
	8-14 days	23 (9.9)	
	>14 days	29 (12.4)	

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Table 4. The number of lost working days in relation to the severity of COPD

COPD Group	0 n (%)	1-7 days n (%)	8-14 days n (%)	>14 days n (%)	Total n (%)	p
GOLD A	26 (74.3)	8 (22.9)	-	1 (2.9)	35 (100)	<0.001
GOLD B	37 (66.1)	8 (14.3)	8 (14.3)	3 (5.4)	56 (100)	
GOLD C	7 (33.3)	11 (52.4)	1 (4.8)	2 (9.5)	21 (100)	
GOLD D	37 (31.1)	45 (37.8)	14 (11.8)	23 (19.3)	119 (100)	

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15 **Table 5.** The factors that increase the burden of care in the multiple linear regression
 16 analysis.

	Unstandardized Coefficients		Standardized Coefficients	t	P	95,0% Confidence Interval for B	
	B	Std. Error	Beta			Lower Bound	Upper Bound
Age	-0.238	0.109	-0.136	-2.187	0.03	-0.453	-0.023
CAT score	0.393	0.107	0.241	3.677	<0.001	0.182	0.604
The number of Comorbidities	3.571	0.817	0.273	4.373	<0.001	1.961	5.18
FEV1%	-0.092	0.05	-0.119	-1.833	0.068	-0.19	0.007
The number of comorbidities of caregivers	5.975	1.953	0.186	3.059	0.003	2.125	9.824
(Constant)	33.337	8.371		3.982	<0.001	16.834	49.839

1 Abbreviations: CAT; COPD assessment test.