

# Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration



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## RESEARCH ARTICLE

## Care burden and related factors among informal caregivers of patients with amyotrophic lateral sclerosis

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### Abstract

**Objective:** Amyotrophic lateral sclerosis (ALS) affects the life of the family caregiver as well as the patient. This study aimed to determine the care burden and related factors among family caregivers of Turkish ALS patients. **Methods:** This descriptive study was conducted with 108 ALS patients and their informal caregivers through face-to-face interviews at home. The data were collected using the ALS Functional Rating Scale, Zarit Burden Interview, European Quality of Life-Five Dimensions Questionnaire, Multidimensional Scale of Perceived Social Support, and the Hospital Anxiety and Depression Scale. **Results:** The mean age of the caregivers was  $48.1 \pm 13.4$  years; the vast majority were female, and they were either spouses or children of the patients. While 49.1% reported moderate or severe burden, the quality of life was moderate (mean  $70.4 \pm 22.8$ ). The caregiver burden was related to sex and the functional state of the patient, as well as caregiver factors such as the relation to the patient, sex, health status, time spent for care, and living in the same house with a limited environment. Walking ability, percutaneous endoscopic gastrostomy, tracheostomy, and communication problems were not associated with the burden. Furthermore, burden was associated with the caregiver's quality of life, social support, anxiety, and depression. **Conclusions:** The present study draws attention to the fact that the care burden in family caregivers of ALS patients is high and their quality of life is impaired. Our findings reveal that not only ALS patients but also caregivers need to be supported with an organized and planned system.

**Keywords:** Amyotrophic lateral sclerosis, caregivers, quality of life, caregiver burden, psychosocial outcomes


### Introduction

Amyotrophic lateral sclerosis (ALS) is a chronic, progressive, and life-limiting disease characterized by motor neuron degeneration. Comparative analysis of ALS across European Registers has provided incidence rates of 1.5–2.6/100,000 person-years and prevalence rates of 7–9/100,000 persons (1,2). Although there is no nationwide prevalence study in Turkey, regional studies (Thrace and the Mediterranean region) in the country have shown incidence and prevalence rates comparable to European countries (3,4).

Motor atrophy caused by ALS impairs the patient's functional status over time, causing them to experience problems in mobility, breathing, feeding/swallowing, etc. These problems can seriously affect the quality of life of patients, as well as shorten their lifespan (5,6). Moreover, by causing deterioration of physical and mental health in family members, it deeply affects not only the patients but also the family caregivers (6–8).

Although it is known that the caregiving burden is usually high in neurological diseases, it has been reported that the caregivers of ALS patients

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experience a higher burden compared to many neurological diseases (multiple sclerosis, Parkinson's disease, mild/moderate dementia, etc.) (9). It is known that ALS patients cared for at home need care and support in many subjects, especially respiration and nutrition (10,11). In particular, in countries like Turkey where home care and palliative care services have just been established, the system may work well for some diseases (12,13), but it is far from being effective for patients who require complex care such as ALS patients (11). Therefore, patients with advanced disease, and their families, may experience many issues (12). It is known that in societies like Turkey, where collectivism is seen as an important value and where the transition from traditional to modern is experienced, there is a need for more studies that specifically address family caregivers in terms of gender roles (14,15). The aim of the present study was to evaluate the caregiving burden and related factors among family caregivers of ALS patients in Turkey.

## Materials and methods

### *Sample and setting*

This study was conducted as a descriptive study as a part of a home care project between September 2015 and March 2016. A convenience sampling method was used to select the participants. The research was conducted with ALS patients and their caregivers living in Istanbul and Izmir (two active chapters of the Association), registered with the ALS-MND Association. Participants applied to the project invitation announcement made on the website (<https://yasatmaklazim.wordpress.com/proje-about>). Patients with definite ALS and their family caregivers aged  $\geq 18$  years and able to communicate were included. The study was completed with 108 patients and their caregivers ( $n = 67$  for Istanbul,  $n = 41$  for Izmir).

### *Data collection*

The data were collected in the home setting through face-to-face visits by well-trained nurses using paper-based forms. The caregivers completed forms in a separate room. Home care nurses evaluated and documented the patient's health status. Ethics approval was obtained from the Medical Research Ethics Committee of Izmir University Faculty of Medicine (05.03.2015/08). Written consent was obtained from the participants.

### *Data collection tools*

A participant information form was used to collect the data including the sociodemographic and caregiving characteristics. Also, the first of the scales

listed below were administered to the patients and the rest to the caregivers.

The ALS Functional Rating Scale (ALS-FRS) was developed by Cederbaum et al. (1999) (16) and adapted to Turkish by Koç et al. (2016) (17). Higher scores indicate better functional state.

Hospital Depression and Anxiety Scale (HADS) is used to measure depression and anxiety (18). The cutoff score is 10 for anxiety (HADS-A) and 7 for depression (HADS-D) (19).

European Quality of Life-Five Dimensions Questionnaire (EQ-5D) is used to evaluate quality of life (20,21). The visual analogue scale (EQ-5D<sub>VAS</sub>) of the EQ-5D was used to assess QoL. Higher scores reflect better QoL.

Zarit Burden Interview (ZBI) is used to assess caregiver burden (22). The possible scores vary between 0 and 88, and higher scores indicate the severity of caregiver burden (23).

Multi-dimensional Scale of Perceived Social Support (MSPSS) is used to evaluate perceived social support (24,25). Higher scores indicate better social support.

### *Data analysis*

Statistical analysis was carried out using the SPSS (v.21.0, IBM) program (SPSS, Chicago, IL). The descriptive statistics, correlation analysis, independent samples t-test, ANOVA, and the Kruskal Wallis tests were used to evaluate the study data. The results were evaluated at the 95% confidence interval and  $p < 0.05$  significance level.

## Results

The sociodemographic and caregiving characteristics of the caregivers have been presented in Table 1. The majority of the caregivers were female (81.5%). Most of the caregivers lived in the same house with the patient (83.3%) (Table 1).

The patients had been diagnosed with ALS for 4.8 years, half (53.3%) were on invasive mechanical ventilation, and about half (46.3%) were fed via a tube. The mean ALS-FRS score was 16.7 points (Table 2).

Nearly half of the caregivers (49.1%) stated moderate/severe or excessive burden, and their mean QoL score was 70.4 on a scale of 0–100. Scores on HAD Scale showed that 51.9% of caregivers were anxious and 57.7% depressed (Table 3).

The caregivers of the male patients obtained higher scores than the caregivers of the females ( $p < 0.001$ ) (Table 4). Furthermore, ALS-FRS scores of the males and females were similar ( $Z = -1.103$ ,  $p = 0.270$ ) ( $15.85 \pm 1.14$  in males,  $18.58 \pm 1.15$  in females) (analysis not shown in tables). There was no difference in the caregiver burden between the caregivers of the patients with

Table 1. Sociodemographic and caregiving characteristics of the caregivers.

	<i>n</i>	%
Relation to the patient		
Spouse	66	61.1
Daughter/son	29	26.9
Parent	6	5.6
Sibling/ relative	7	6.5
Age (mean $\pm$ sd, range) <sup>b</sup>	48.1 $\pm$ 13.4	(20–81)
Sex		
Female	88	81.5
Male	20	18.5
Education <sup>a</sup>		
Illiterate	5	4.7
Primary or secondary school	36	33.6
High school	29	27.1
University	37	34.6
Working status		
Employed	17	15.7
Retired	31	28.7
Homemaker	47	43.5
Other (unemployed, student)	13	12.0
Family monthly income		
Good	17	15.7
Moderate	73	67.6
Bad	18	16.7
Health insured	95	88.0
Marital status		
Single/divorced/widow	19	17.6
Married	89	82.4
Having any health problem <sup>a</sup>	55	51.4
Duration of caregiving (y) (mean $\pm$ sd, range) <sup>b</sup>	3.9 $\pm$ 4.0	(0.5–21)
How much of the day does caregiver spend on care? <sup>a</sup>		
Less than 50% of a day	29	27.1
Between 51% and 75% of a day	23	21.5
More than 75% of a day	55	51.4
Living in the same house with the patient	90	83.3
Limitation in space at home	33	30.6

<sup>a</sup>Data of one person is missing.<sup>b</sup>Data of three person is missing.

or without mobility, respiratory, speech or feeding problems ( $p=0.173$ ,  $p=0.679$ ,  $p=0.363$  and  $p=0.385$ , respectively). Furthermore, the caregiver burden was weakly correlated with the functional state ( $r=-0.216$ ,  $p=0.025$ ). The burden of patients who had a paid caregiver was lower than those who had a family caregiver ( $p=0.026$ ). However, these patients were found to have better ALS-FRS scores than the others ( $F=9.218$ ,  $p<0.001$ ) ( $30.38 \pm 18.79$  in patients who cared for themselves,  $17.09 \pm 10.25$  by a family member, and  $11.79 \pm 8.05$  by a paid caregiver) (analysis not shown in tables).

The burden varied according to the relation with the patient ( $p=0.012$ ) (Table 5). The burden was lower in siblings/relatives than the spouses ( $p=0.002$ ) and children ( $p=0.003$ ) (analysis not shown in tables). Females had higher burden than males ( $p=0.085$ ). The burden was higher when a male patient was cared for by a female caregiver

Table 2. Sociodemographic and clinical characteristics of the patients.

	<i>n</i>	%
Age (mean $\pm$ sd, range) <sup>b</sup>	57.3 $\pm$ 1.2	(26–83)
Sex		
Female	34	31.5
Male	74	68.5
Education <sup>a</sup>		
Illiterate	5	4.7
Primary or secondary school	56	52.4
High school	20	18.7
University	26	24.3
Marital status <sup>a</sup>		
Single/divorced/widowed	12	11.2
Married	95	88.8
Having any other health problems	33	30.6
Time since diagnosis (y) (mean $\pm$ sd, range) <sup>b</sup>	4.8 $\pm$ 4.5	(0.5–24)
Cared for by <sup>b</sup>		
Himself/herself	8	7.5
Family member	74	69.8
Paid caregiver	24	22.7
Mobility <sup>a</sup>		
Normal functioning	7	6.5
Can walk with assistance	21	19.7
Cannot walk	79	73.8
Respiration <sup>c</sup>		
Normal functioning (spontaneous)	39	37.2
Non-invasive mechanical ventilation	10	9.5
Invasive mechanical ventilation	56	53.3
Speech/communication <sup>b</sup>		
Normal speech	25	23.6
Communication with non-technological aids	65	61.3
Communication with technological aids	16	15.1
Feeding		
Oral normal feeding	58	53.7
Tube feeding	50	46.3
ALS-FRS-R bulbar (mean $\pm$ sd, range)	5.9 $\pm$ 4.4	(0–12)
ALS-FRS-R motor (mean $\pm$ sd, range)	4.2 $\pm$ 6.4	(0–24)
ALS-FRS-R respiratory (mean $\pm$ sd, range)	6.6 $\pm$ 4.1	(0–12)
ALS-FRS-R (mean $\pm$ sd, range) (median, IQR)	16.7 $\pm$ 11.4	(0–48)

ALS-FRS-R: Amyotrophic Lateral Sclerosis Functional Rating Scale.

<sup>a</sup>Data of one person is missing.<sup>b</sup>Data of two person is missing.<sup>c</sup>Data of three person is missing.

( $42.37 \pm 15.05$ ) than a female patient cared for by a male caregiver ( $29.93 \pm 18.15$ ,  $p=0.029$ ) or a female caregiver ( $30.26 \pm 14.98$ ,  $p=0.017$ ) (analysis not shown in tables). The caregiver burden was found to be moderate-weakly correlated with the EQ-5D, MSPSS, and HADS (Table 6).

Differences were found between four burden categories in the EQ-5D, MSPSS, and HADS scores ( $p=0.023$ ,  $p=0.013$ ,  $p<0.001$ , and  $p=0.004$ , respectively) (Supplementary Table 1).

## Discussion

Being a chronic, progressive, and disabling disease ALS not only affects the patients but also profoundly affects family caregivers. In this study, the

Table 3. Caregiver burden, quality of life, social support, anxiety and depression scores of the caregivers.

	Mean $\pm$ SD	Range
ZBI	38.5 $\pm$ 16.3	(0–76)
No/minimal burden (0–20 points) ( <i>n</i> , %)	15	13.9
Mild/moderate burden (21–40 points) ( <i>n</i> , %)	40	37.0
Moderate burden (41–60 points) ( <i>n</i> , %)	43	39.8
Severe burden (61–88 points) ( <i>n</i> , %)	10	9.3
EQ-5D <sub>VAS</sub>	70.4 $\pm$ 22.8	(10–100)
MSPSS <sup>a</sup>	63.9 $\pm$ 16.8	(21–84)
Family	23.1 $\pm$ 6.3	(5–28)
Friends	18.7 $\pm$ 7.9	(4–28)
Significant other	22.1 $\pm$ 6.6	(6–28)
HADS-anxiety <sup>b</sup>	11.2 $\pm$ 4.6	(1–22)
Non-anxious ( <i>n</i> , %)	50	48.1
Anxious ( <i>n</i> , %)	54	51.9
HADS-depression <sup>b</sup>	8.5 $\pm$ 3.8	(1–18)
Non-depressive ( <i>n</i> , %)	44	42.3
Depressive ( <i>n</i> , %)	60	57.7

ZBI: Zarit Caregiver Burden Interview; EQ-5D: European Quality of Life Instrument; MSPSS: Multidimensional Scale of Perceived Social Support; HADS: Hospital Anxiety and Depression Scale.

<sup>a</sup>Data of two person is missing.

<sup>b</sup>Data of four person is missing.

care burden among informal caregivers of ALS patients and its determinants were evaluated. The study showed a significant burden among caregivers. The majority of the patients had walking and speech/communication problems, and about half were on invasive mechanical ventilation and tube feeding.

#### *Patient characteristics and caregiver burden*

In this study, the burden of caregivers of male patients was found to be higher than those of female patients. This may be due to the fact that female patients, even if they are sick, try to fulfill their expected roles and do not express their needs to their caregivers due to adopted gender roles (26). This may show that it is important to ensure extra support for female patients.

It is expected that the care needs of patients with mobility problems would be higher than those without mobility problems (8). Contrary to expectations, in this study, mobility problems and functional impairment did not affect the caregiver burden. In our study, the more severely impaired patients received care from paid caregivers in addition to their relatives; therefore, their caregiver burden was lower. This result may vary depending on the health care system (27) and sample characteristics. Behavioral changes have been reported as much more significant predictors of the burden among caregivers of ALS patients than the physical functioning of the patients (28). In this study, no difference was found in the caregiver burden between patients with and without respiratory, speech, and feeding problems, confirming the findings of earlier studies (29,30). By changing the progression of cognitive impairment, mechanical

ventilation may improve the patient's QoL, and in turn, decrease the caregiver burden (31). On the other hand, there are also studies reporting that tracheostomy increases the caregiver burden related to various factors such as long-term ventilation time, the severity of the disease and hopelessness (32). It is stated that there is insufficient evidence about the effect of PEG, which is another invasive procedure frequently used in ALS, on preventing aspiration, improving quality of life, and increasing survival (33,34). In our study, similar to Schischlevskij et al. (2021), the burden was found to be similar in caregivers of patients that were fed orally or through gastrostomy (29).

#### *Caregiver characteristics and caregiver burden*

Similar to previous studies (8,10), in this study, the caregivers were mostly spouses and children, and the burden was higher among them than parents/siblings/relatives. Our finding that the caregiver burden tended to be higher in female caregivers was similar to the results of other studies (10,35). In a recent study of caregivers of dementia patients (2020), it was reported that female caregivers were also responsible for daily housework in line with their traditional gender roles, and that male caregivers sought/demanded more help than females (36). Our study also revealed that the burden in females giving care to male patients was higher. In the same study, a finding similar to ours was reported and it was speculated that this may be related to the fact that being a female caregiver for a person who is physically heavier than herself is a challenging experience in diseases that require direct care (especially positioning, transferring,



Table 4. Caregiver burden scores according to the patients' characteristics.

Patient characteristics	ZBI scores		
	Mean $\pm$ SD	<i>t/F</i>	<i>p</i>
Age ( <i>r</i> , <i>p</i> ) <sup>b</sup>		0.011	0.915
Sex			
Female	30.11 $\pm$ 16.19	3.830	<b>&lt;0.001</b>
Male	42.31 $\pm$ 14.97		
Education <sup>a</sup>			
<High school	39.47 $\pm$ 15.65	2.377	0.098
High school	32.15 $\pm$ 18.80		
University	42.15 $\pm$ 14.03		
Having any other health problems			
Yes	35.48 $\pm$ 17.64	1.265	0.208
No	39.78 $\pm$ 15.64		
Time since diagnosis ( <i>y</i> ) ( <i>r</i> , <i>p</i> ) <sup>b</sup>		0.017	0.862
Cared for by <sup>b</sup>			
Himself/herself	29.38 $\pm$ 18.61	3.762	0.026
Family member	40.77 $\pm$ 14.83		
Paid caregiver	32.63 $\pm$ 17.36		
Walking ability <sup>a</sup>			
Normal functioning	28.42 $\pm$ 14.75	1.785	0.173
Can walk with assistance	36.33 $\pm$ 17.79		
Cannot walk	39.81 $\pm$ 15.93		
Respiration <sup>c</sup>			
Normal functioning (spontaneous)	36.82 $\pm$ 19.61	0.389	0.679
Non-invasive mechanical ventilation	38.40 $\pm$ 15.30		
Invasive mechanical ventilation	39.87 $\pm$ 14.41		
Speech/communication <sup>b</sup>			
Normal speech	35.52 $\pm$ 19.35	1.025	0.363
Communication with non-technological aids	39.95 $\pm$ 15.03		
Communication with technological aids	35.00 $\pm$ 15.97		
Feeding			
Oral feeding	37.08 $\pm$ 16.03	−0.873	0.385
Tube feeding	39.86 $\pm$ 16.78		
ALS-FRS-R ( <i>r</i> , <i>p</i> )		−0.216	<b>0.025</b>
ALS-FRS-R			
Lowest tertile (0–12, 33.3%)	39.86 $\pm$ 14.46	0.452	0.638
Middle tertile (13–18, 66.7%)	39.16 $\pm$ 16.54		
Highest tertile (>18, 100%)	36.38 $\pm$ 18.01		

ZBI: Zarit Caregiver Burden Interview; ALS-FRS-R: Amyotrophic Lateral Sclerosis Functional Rating Scale. Spearman correlation analysis, independent samples *t*-test, and ANOVA test were used.

<sup>a</sup>Data of one person is missing.

<sup>b</sup>Data of two person is missing.

<sup>c</sup>Data of three person is missing.

Bold values show the statistical significance.

etc.) (36). Qualitative studies can further clarify this issue.

As expected, the caregiver burden was found to be higher in caregivers with health problems compared to those without (29,36). The burden of caregivers was higher in those who shared the same house with the patient and reported limitation of living space at home. Sharing the same house includes sharing the same economic difficulties and also lack of space for personal and social life (37). One of the findings of this study, which supports previous studies, was that the time allocated to care affected the caregiver burden (8,38,39).

In our study, the finding of higher anxiety and depression, less social support, and worse QoL in the group with a high caregiver burden confirms

the results of previous studies (37,40). Social support has been reported as a determinant of caregiver burden (39) and a protective factor for psychosocial problems among caregivers (41,42). The fact that caregiver anxiety and depression were correlated with burden in this study supports previous studies (7,43).

When interpreting our results, it should be taken into account that the study participants were responders to the call made by the association, most of our patients were dependent on nutritional or respiratory support and may not be representative of the wider population. Studies in a more heterogeneous patient group may be recommended. The lack of cognitive and behavioral evaluations of the patients included in the study is another limitation.

Table 5. Caregiver burden scores according to the caregivers' characteristics.

Caregiver characteristics	ZBI scores		
	Mean $\pm$ sd	<i>t/F</i>	<i>p</i>
Relation to the patient			
Spouse	40.18 $\pm$ 16.02	3.807	<b>0.012</b>
Daughter/son	40.17 $\pm$ 14.44		
Parent	32.83 $\pm$ 19.39		
Sibling/ relative	20.14 $\pm$ 14.48		
Age ( <i>y</i> ) ( <i>r</i> , <i>p</i> ) <sup>b</sup>		-0.108	0.272
Sex			
Male	32.80 $\pm$ 17.87	-1.738	<b>0.085</b>
Female	39.76 $\pm$ 15.77		
Education <sup>a</sup>			
<High school	38.53 $\pm$ 18.38	0.024	0.976
High school	39.06 $\pm$ 16.77		
University	38.16 $\pm$ 13.95		
Income			
Good or moderate	36.97 $\pm$ 15.91	-2.164	<b>0.033</b>
Bad	45.94 $\pm$ 16.71		
Marital status			
Single /divorced /widow	37.95 $\pm$ 19.11	-0.154	0.878
Married	38.58 $\pm$ 15.77		
Having any health problem <sup>a</sup>			
Yes	41.69 $\pm$ 17.70	2.060	<b>0.042</b>
No	35.26 $\pm$ 14.25		
Duration of caregiving ( <i>y</i> ) ( <i>r</i> , <i>p</i> ) <sup>b</sup>		0.066	0.505
How much of the day does caregiver spend on care? <sup>a</sup>			
Less than 50% of a day	33.96 $\pm$ 13.08	5.758	<b>0.004</b>
Between 51% and 75% of a day	32.47 $\pm$ 19.35		
More than 75% of a day	43.54 $\pm$ 15.22		
Living in the same house with the patient			
No	29.55 $\pm$ 14.46	-2.607	<b>0.010</b>
Yes	40.25 $\pm$ 16.15		
Limitation in space at home			
Yes	46.18 $\pm$ 17.54	-3.415	<b>0.001</b>
No	35.08 $\pm$ 14.62		

ZBI: Zarit Caregiver Burden Interview. Spearman correlation analysis, independent samples *t*-test, and ANOVA test were used.

<sup>a</sup>Data of one person is missing.

<sup>b</sup>Data of three person is missing.

Bold values show the statistical significance.

Table 6.. Correlations of caregiver burden and quality of life, social support, anxiety, and depression scores.

	<i>r</i>	<i>p</i>
EQ-5D <sub>VAS</sub> QoL	-0.298	<b>0.002</b>
MSPSS <sup>a</sup>	-0.275	<b>0.004</b>
Family	-0.353	<b>&lt;0.001</b>
Friends	-0.070	0.478
Significant other	-0.269	<b>0.005</b>
HADS-anxiety <sup>b</sup>	0.440	<b>&lt;0.001</b>
HADS-depression <sup>b</sup>	0.335	<b>0.001</b>

EQ-5D QoL: European Quality of Life Instrument; MSPSS: Multidimensional Scale of Perceived Social Support; HADS: Hospital Anxiety and Depression Scale. Spearman correlation analysis was used.

<sup>a</sup>Data of two person is missing.

<sup>b</sup>Data of four person is missing.

Bold values show the statistical significance.

In conclusion, in this study, the burden among caregivers of ALS patients was found to be associated with social support, anxiety, depression, and QoL. Our research revealed that the caregiver

needs more support especially if the caregiver is a spouse/child, is a woman, cares for a male patient, and lives in the same house with the patient. Evaluation of the needs of caregivers is suggested. Accordingly, psychosocial support and in-home support facilities should be provided. Further qualitative studies would be helpful to understand the families' caregiving experiences. Furthermore, transcultural differences should be studied with multinational studies.

### Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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## Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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