

Evaluation of quality of life and mood disorders in caregivers of patients with amyotrophic lateral sclerosis: A single-center cross-sectional study

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Keywords

Amyotrophic Lateral Sclerosis; Caregiver; Anxiety; Depression; Quality of Life

Abstract

Background: Caregivers of patients with amyotrophic lateral sclerosis (ALS) may suffer from anxiety, depression, and reduced quality of life (QoL). Our goal was to evaluate the QoL and mood disorders in caregivers and their correlation with the patients' demographic, physical, and mental conditions.

Methods: We analyzed data from 39 patients with ALS and their caregivers. Patients completed questionnaires of anxiety assessed by Generalised Anxiety Disorder Assessment (GAD-7), depression using the Beck Depression Inventory-II (BDI-II), and QoL via 40-item Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ-40). Physical impairment was also measured in the patients using the revised Amyotrophic Lateral Sclerosis Functional

Rating Scale (ALSFRS-R). Caregivers were also assessed by BDI-II, GAD-7, and 36-item Short-Form Health Survey questionnaire (SF-36).

Results: The prevalence of depression and anxiety in the patients was 82.1% and 71.8%, respectively. Caregivers also had higher rates of anxiety and depression and lower levels of QoL in comparison with the general population (anxiety: 66.7%, depression: 43.6%). Depression and anxiety were considerably associated with worsened QoL in the caregivers. None of the demographic, physical, or mental characteristics of patients with ALS were related to either mood status or QoL of the caregiver population.

Conclusion: Caregivers experience higher rates of

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anxiety and depression and lower QoL in comparison with the general population. The severity of mood disorders is inversely associated with the physical and mental domains of caregivers' QoL. Nonetheless, QoL in the caregivers is not affected by the physical or mental disability of the patients.

Introduction

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive neurodegenerative disease characterized by the involvement of upper and lower motor neurons leading to weakness and disability of the skeletal muscles as well as the inability to speak normally or swallow, respiratory problems, and eventually death.^{1,2} Despite extensive researches, curative therapy for ALS has not been known until today; hence, palliative care should be considered with the aim of reducing the symptoms of the disease and increasing the quality of life (QoL).¹ Patients and caregivers may suffer from anxiety and depression during ALS disease, influencing their QoL.^{3,4}

Caregivers of patients usually endure a significant burden as the symptoms progress in their patients. Patients with ALS need assistance with all of their daily living activities since their ability to speak or write is impaired. Physical demands for appropriate care become more severe by the progression of the disease. It is estimated that ALS caregivers spend 11 hours a day with the patient and feel a profound responsibility for their patients.⁵ Findings are controversial regarding the correlation between the mood status of the patients and their caregivers;⁵ some studies indicated that anxiety and depression in caregivers had a relation with physical and mental disability in patients while other studies did not find such an association.⁵⁻⁷ Since caregivers' wellbeing may have an impact on the psychological and physical status of patients, attention to the caregiver's mental health can help patient distress.^{6,8}

Considering the inconsistent results regarding mood disorders and QoL in ALS caregivers and their contributing etiologies, as well as the fact that such a study in Persian patients with ALS was lacking, we intended to study the QoL as well as depression, anxiety, and physical status and their interactions in both patients and caregivers.

Materials and Methods

Settings: In this cross-sectional study, we enrolled 39 patients with ALS and their caregivers in ALS Clinic of Shariati Hospital, affiliated to Tehran

University of Medical Sciences, Tehran, Iran, from March 2018 to October 2019. Written informed consent was obtained from patients and their caregivers following the description of their ability to withdraw from the study without any adverse effect on their healthcare. The protocol of the study was in accordance with the latest versions of the Declaration of Helsinki⁹ and was approved by the Ethical Committee of Tehran University of Medical Sciences (IR.TUMS.MEDICINE.REC.1397.685).

Participants: Eligible participants were patients who met the criteria for definite or probable ALS diagnosis according to the revised El Escorial criteria,¹⁰ as well as their caregivers. A caregiver was defined as a person who lives with the patient and who provides the patient with the most care and assistance.⁶ The exclusion criteria for both patients and caregivers were: inability to complete the questionnaires, Mini-Mental State Examination (MMSE) score ≤ 24 , paid caregivers, and history of fatal diseases such as malignancy.

Demographic information was collected, including age, gender, and education, along with clinical data, including disease duration and disease onset (bulbar onset or limb onset). The 40-item Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ-40) and 36-item Short-Form Health Survey questionnaire (SF-36) were used to evaluate the QoL of patients with ALS and their caregivers, respectively. The Beck Depression Inventory-II (BDI-II) and the Generalized Anxiety Disorder Assessment (GAD-7) were employed to quantify depression and anxiety in patients and caregivers. Patients' physical function was assessed by the revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R).

Questionnaires: ALSAQ-40 consists of 5 subscales, including physical mobility, daily living activities and independence, eating and drinking, communicational abilities, and emotional reactions. The score of items ranges from 0, representing a high level of QoL, to 100, representing a low level of QoL. The ALSAQ-40 was previously translated and validated in the Persian language.¹¹

The SF-36 questionnaire is a self-administered measure that combines eight general health subscales: physical function, physical role function, bodily pain, general health, vitality, social function, emotional function, and mental health. Besides, the eight items are summarized into two main domains: physical health dimension (PHD) and mental health dimension (MHD). All scores were interpreted

with a 0-100 score, where higher scores represent better QoL (in contrast to ALSAQ-40). The questionnaire had been previously standardized in the Iranian population.¹²

BDI-II is a self-reporting questionnaire consisting of 21 questions that provide a total score between 0 to 63, in which scores of 0-13, 14-19, 20-28, and 29-63 represent normal, mild, moderate, and severe depression, respectively.¹³ We used the Persian validated version of questionnaire.¹⁴

GAD-7 is a 7-item scale with total score ranging from 0 to 21, while the cutpoints for mild, moderate, and severe symptoms are 5, 10, and 15, respectively.¹⁵

The ALSFRS-R includes 12 questions that measure upper extremity, lower extremity, and bulbar functions, and respiration. The score varies between 0 (maximum impairment) and 48 (normal function).¹⁶

We used SPSS software (version 24, IBM Corporation, Armonk, NY, USA) to analyze the data. The Shapiro-Wilk test and probability graphs were used to check for the normal distribution of the data. For the correlations between QoL domains (physical and mental domains) and other scales, when the distribution was normal, we used the Pearson correlation test. In case of non-normal distribution, we used the Spearman correlation test. Variables with normal distribution were presented as mean \pm standard deviation (SD) while the data with abnormal distribution were presented as median [interquartile range (IQR), 25th-75th percentile]. The P-values $<$ 0.05 were regarded significant.

Results

Demographic characteristics: In this study, 39 patients and 39 caregivers were enrolled. The mean age was 57.7 ± 8.8 for the patients and 43.3 ± 13.8 for the caregivers. From 39 patients and caregivers, 18 patients (46.2%) and 19 caregivers (48.7%) were women. The ALSFRS-R score in patients was 27.9 ± 10.0 and the average disease duration was 4.0 ± 2.9 years. Other demographic and descriptive features of the caregivers and patients are summarized in table 1. In the caregivers, the PHD score of SF-36 was 52.6 ± 11.0 and 36.6 ± 12.4 for the MHD (Table 1). For the patients, the highest (worst) score was for physical mobility (70.2 ± 33.3) and the least was for emotional aspects (50.6 ± 24.8) (Table 1).

Mood disorders: In the general Iranian population, the prevalence of depression using BDI was estimated at 37.3% based on a recent meta-analysis; and in a large cohort, the prevalence

of anxiety was 15.6%.^{17,18} In our study, the prevalence of depression and anxiety in the patients was 82.1% and 71.8%, respectively, which were both considered higher than the prevalence of mentioned mood disorders in the general population [odds ratio (OR) for depression = 2.2, $P <$ 0.001; OR for anxiety = 4.72, $P <$ 0.001]. In the caregivers, the prevalence of depression and anxiety was 43.6% and 66.7%, respectively, both higher than that in the general Iranian population;¹⁷ however, the prevalence of depression was not significantly different in comparison with the general population (OR for depression = 1.17, $P =$ 0.270; OR for anxiety = 4.39, $P <$ 0.001).

The patients compared to the caregivers demonstrated significantly higher BDI score (19.8 ± 9.0 vs. 13.6 ± 8.3 , $t = 3.18$, $P = 0.001$), whereas GAD-7 score was not significantly different between two groups (8.7 ± 5.8 vs. 7.7 ± 4.8 , $t = 0.85$, $P = 0.200$).

QoL in caregivers: Concerning the relationship between mood disorders and QoL in caregivers, a significant correlation was found between BDI score and PHD ($r = -0.38$, $P = 0.020$) as well as MHD ($r = -0.50$, $P <$ 0.001). In terms of anxiety, the correlation between GAD-7 score and PHD was not significant ($r = -0.29$, $P = 0.080$) whereas the correlation between GAD-7 score and MHD was significant ($r = -0.51$, $P <$ 0.001).

Our results showed that older age of caregivers was correlated with lower PHD in caregivers ($r = -0.47$, $P <$ 0.010); however, no significant correlation with MHD was detected ($r = -0.13$, $P = 0.420$).

Considering gender in caregivers, we found no significant difference of PHD and MHD between two genders [PHD (women): 49.5 ± 11.7 , PHD (men): 55.6 ± 9.6 , $P = 0.080$; MHD (women): 33.4 ± 12.7 , MHD (men): 39.6 ± 11.6 , $P = 0.120$].

The association between patients' factors and QoL and mood status of caregivers: None of the demographic and clinical features in subjects with ALS were related to mood status or QoL of their caregivers ($P >$ 0.05) (Table 2). Neither the scores of mood disorders (BDI and GAD-7) nor those of QoL (ALSAQ-40 subscales) in the patients were associated with SF-36 subdomains in the caregivers ($P >$ 0.050) (Table 2).

Discussion

In this study, we sought to describe the status of QoL and mood in caregivers of patients with ALS. The results showed a higher prevalence of depression and anxiety in patients and their caregivers than the general population.

Table 1. Demographic and descriptive features of the patients and caregivers

Variables		Patients (n = 39)	Caregivers (n = 39)
Age (year) (mean ± SD)		57.7 ± 8.8	43.3 ± 13.8
Gender (F/M)		18/21	19/20
ALSFERS-R (mean ± SD)		27.9 ± 10.0	-
Duration (year) (mean ± SD)		4.0 ± 2.9	-
Disease onset (limb/bulbar)		23/16	-
Education [n (%)]			
Not educated		6 (15.4)	0 (0)
Less than diploma		4 (10.3)	7 (17.9)
Diploma		25 (64.1)	18 (46.2)
University degree		4 (10.3)	14 (35.9)
Depression [n (%)]			
Minimal		7 (17.9)	22 (56.4)
Mild		13 (33.3)	7 (17.9)
Moderate		14 (35.9)	8 (20.5)
Severe		5 (12.8)	2 (5.1)
Anxiety [n (%)]			
No		11 (28.2)	13 (33.3)
Mild		11 (28.2)	12 (30.8)
Moderate		8 (20.5)	11 (28.2)
Severe		9 (23.1)	3 (7.7)
ALSAQ-40 subdomains (mean ± SD)			
Physical mobility		70.2 ± 33.3	-
Activities of daily living		63.0 ± 29.3	-
Eating and drinking		53.8 ± 26.6	-
Communication		53.7 ± 36.3	-
Emotional aspect		50.6 ± 24.8	-
SF-36 (mean ± SD) Subdomains			
Vitality		-	48.0 ± 8.9
Physical functioning		-	49.7 ± 9.6
Bodily pain		-	50.7 ± 11.0
General health perceptions		-	47.6 ± 8.8
Physical role functioning		-	45.0 ± 13.7
Emotional role functioning		-	34.7 ± 18.7
Social role functioning		-	39.9 ± 9.8
Mental health		-	41.2 ± 8.7
Dimensions			
Physical health		-	52.6 ± 11.0
Mental health		-	36.6 ± 12.4

ALSFERS-R: Revised Amyotrophic Lateral Sclerosis Functional Rating Scale; ALSAQ-40: 40-item Amyotrophic Lateral Sclerosis Assessment Questionnaire; SF-36: 36-item Short-Form Health Survey; SD: Standard deviation

Besides, in the caregivers, the severity of mood disorders was negatively associated with the physical and mental aspects of QoL. In contrast, none of the demographic, clinical, or mood characteristics of patients with ALS influenced mood status and QoL of the caregiver population.

It has been well established that caregivers of patients with terminal or progressive diseases usually experience high levels of distress. For instance, several studies have shown significant mood problems among caregivers of patients with dementia,^{19,20} cancer,²¹ multiple sclerosis (MS),²² acquired immunodeficiency syndrome (AIDS),²³ Parkinson's disease (PD),²⁴ and brain injury.²⁵ Caregivers of patients with ALS also deal with emotional, social, and even physical problems and, therefore, are susceptible to various mood disorders.⁶ However, in the results obtained from previous studies, there is controversy about whether the prevalence of depression and anxiety in caregivers differs from

either patients with ALS or healthy controls.^{3,26,27}

In the present study, the prevalence of depression and anxiety in patients with ALS was much higher than previous studies conducted in other countries,^{3,28-30} which may stem from variable supportive care in different countries, different cultural and demographic features, religion, willingness to express personal feelings and beliefs to medical personnel, different medications, or using different scales for the assessment.³¹ Regarding the rate of mood disorders in the caregivers, we identified that it was higher than the general population but lower than the patients.

Meanwhile, we did not find an association between depression and anxiety in caregivers' and patients' physical or psychological status. In agreement, several previous studies showed no significant association between physical and mental disability of the patients and caregivers' mental condition.^{3,5,7,32}

Table 2. The association between patients' factors and mood status and quality of life (QoL) of caregivers

Patients	Demographic and clinical factors	ALS type (mean ± SD)	Bulbar Limb P	Caregivers			
				BDI	GAD-7	PHD	MHD
				6.4 ± 4.0	12.4 ± 6.6	52.9 ± 13.3	37.4 ± 12.4
				14.3 ± 9.3	8.5 ± 5.2	52.4 ± 9.3	36.0 ± 12.7
		ALSFRS-R (r)		0.20	0.49	0.89	0.74
		P		0.25	0.24	-0.02	-0.04
		Age of patients (r)		0.12	0.14	0.89	0.82
		P		0.16	0.25	0.12	0.19
		Disease duration (r)		0.33	0.13	0.48	0.25
		P		0.27	0.24	-0.21	-0.10
		BDI (r)		0.10	0.14	0.20	0.56
		P		0.02	0.02	0.16	-0.22
	Mood	GAD-7 (r)		0.92	0.90	0.33	0.19
		P		0.04	0	0.23	-0.09
		PHD (r)		0.80	0.98	0.15	0.58
		P		-0.09	-0.22	-0.01	0.14
	ALSAQ-40	Physical mobility		0.60	0.17	0.98	0.38
		P		-0.19	-0.28	-0.01	0.12
		Activities of daily living		0.23	0.08	0.98	0.46
		P		-0.15	-0.11	0.04	-0.05
		Eating and drinking		0.37	0.52	0.80	0.76
		P		-0.06	0.02	-0.05	-0.06
		Communication		0.71	0.93	0.77	0.72
		P		-0.15	-0.02	0.36	-0.15
		Emotional aspect		0.36	0.92	0.07	0.37
		P					

ALS: Amyotrophic lateral sclerosis; ALSFRS-R: Revised Amyotrophic Lateral Sclerosis Functional Rating Scale; ALSAQ-40: 40-item Amyotrophic Lateral Sclerosis Assessment Questionnaire; BDI: Beck Depression Inventory; GAD-7: Generalised Anxiety Disorder Assessment; PHD: Physical health dimension; MHD: Mental health dimension; SD: Standard deviation

Although the existing mood burden on caregivers might not exert considerable change in the disease course of the patients, according to our findings, it is associated with worse physical functioning and mental health of the caregivers. Hence, the health team must notice and treat the psychological aspects of the illness both for patients and caregivers; even though there is no curative treatment for a progressive disease like ALS, treating depression and anxiety could enhance the QoL in both groups.

Beyond the emotional distress among caregivers, the physical strain has been of great importance, especially during the advanced stages of the disease. Caregiving to patients with ALS generally takes a considerable physical effort as they might need the help of their caregivers for ordinary movements.⁶ In this regard, the physical problems of caregivers could negatively affect their QoL and could result in mood abnormalities. In support, it has been observed that older caregivers represent age-related physical difficulties and subsequently reduced QoL.⁶ Here, we found that the older age of caregivers was related to lowering the physical but not mental aspect of QoL.

Our study has several limitations. First, this study contains a relatively small sample size, which may be inevitable due to the low prevalence of ALS disease. Second, we assigned patients and their caregivers from one particular ALS clinic, while mood disorders and QoL may differ in the different centers due to geographic, ethnic, or religious differences. Multi-center studies of patients with ALS from different countries could improve the generalizability of the findings. Third, different types of measurement tools for the assessment of QoL were administered to patients and caregivers, which might have affected the results. Forth, the BDI might report several patients with ALS as "depressed" false positively since it contains questions that are related to physical function. Finally, longitudinal evaluation of mood disorders and QoL in both patients and caregivers could provide more reliable information since ALS is considered a progressive neurodegenerative condition.

Conclusion

Caregivers of Iranian patients with ALS experience

higher rates of anxiety and depression and lower QoL in comparison with the general population. The severity of mood disorders, including depression and anxiety, is inversely associated with the physical and mental domains of caregivers' QoL. Nonetheless, QoL in the caregivers is not affected by the physical or mental disability of the patients. Further investigations are required to elucidate the exact features that induce

physical and emotional burden in caregivers of patients with ALS.

Conflict of Interests

The authors declare no conflict of interest in this study.

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