



Quality of Life of Amyotrophic Lateral Sclerosis Patients in Iran

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Abstract

Background: Amyotrophic Lateral Sclerosis (ALS) is a rare disease that can bring different emotional, physical, and psychological burdens. This study aimed to investigate the quality of life in patients with ALS.

Methods: This is a cross-sectional study. Fifty-two patients contributed in this study. The setting was an ALS clinic in Iran. A mixed method was used in this study. We applied a short form of the WHO Quality of Life questionnaire (WHOQOL) to measure the quality of life of patients. Also, all participants were interviewed through the semi-structured interview guide. To measure physical strength and functioning the Appel ALS Rating Scale (AALS) was employed in this study. To analyze the data, a two-tailed t-test and x2 test were used.

Results: 42.3% of the participants were female. The age of the participants ranged between 28 to 81 (mean=57.6). The disease duration ranged from 0.07 to 14 years (mean=1.8). The overall mean QOL was 58.7 (± 8.1). The overall mean of the AALS score was 74.4 (± 24.2). The results of the qualitative part of the study showed four psychosocial themes: (1) internal personality traits, communicating with friends and family; (2) religion and spirituality; (3) stress, mood changes, and difficult relationship; and (4) changes in lifestyle, work, leisure time and financial situation.

Conclusion: Despite recent advances, ALS is still one of the diseases for which there is no effective treatment. Paying attention to psychosocial issues in patients with ALS can play a very important role in increasing the quality of life of patients.

Keywords: Amyotrophic Lateral Sclerosis, Quality of Life, Appel ALS Rating Scale, Iran

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Introduction

Amyotrophic Lateral Sclerosis (ALS) is a disease related to the nervous system and usually, after 3 to 5 years from the onset of the disease, it leads to respiratory complications, which eventually lead to paralysis and death (1–5). As the disease progresses, some disorders appear in these

patients. These disorders can include limb weakness, respiratory system, digestive system, and swallowing, which increases the patient's dependence on the family and surrounding people (2–6).

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↑What is “already known” in this topic:

ALS is a fatal and progressive disease. Until now, no definitive treatment has been identified for it. ALS patients have many difficulties in their daily life. However, these patients seek to improve their quality of life through positive activities and changing their outlook on life.

→What this article adds:

Internal personality traits, along with positive relations with relatives, are among the most important sources of support for ALS patients and have positive effects on their quality of life. Another source that affects the quality of life in these patients is religion and spirituality, which provides significant foundations and solutions for these patients. Stress is a factor which reduces the quality of life and must be controlled with appropriate interventions. The role of health service providers and providing useful and effective interventions in this field is very important.

Quality of life (QOL) is accepted as a global index, although there are ambiguities and contradictions in many of its aspects (7). By using this index, the health status of people and patients can be compared with each other by considering the results of treatment and medical interventions (8, 9). In addition, this index includes the non-medical aspects of people's lives, which can include family, friends, work status, economic status, and other life conditions. (7, 10, 12–16). In different studies, the quality of life is examined from different perspectives (13). This index can examine some mental areas, such as people's needs, perceptions, and experiences (14). Also, communication between people and the employment status and leisure abilities of people are measured with the help of this index (17–19). Usually, the term "health-related quality of life" (HRQOL) is used to measure the physical health and functions of individuals to evaluate therapeutic interventions. However, the patient's experiences and his understanding of the disease have received less attention (13–15).

The quality of life of ALS patients was first noticed in clinical trial studies (3, 20, and 21) and especially in the CARE Database studies (22). The tools used in these studies included two tools, "the Sickness Impact Profile" questionnaire (23) and SF-36 (24). Muscle strength and motor activities are measured by the Tufts Quantitative Neuro-muscular Examination (TNQE) (25–27). Recent studies (16, 28) have raised new questions about whether these tools can properly identify psychological factors that threaten patients' lives (15, 16). Recently, a special questionnaire was designed for ALS patients, and it is called the Amyotrophic Lateral Sclerosis Assessment Questionnaire 40 (ALSAQ-40). In this questionnaire, 25% of the items examine emotional performance and 75% examine physical performance (28).

Another study, using a composite instrument, simultaneously assessed the physical functions, psychological dimensions, and conceptual dimensions of patients (16). This study had 96 participants, all of whom accomplished the ALS Functional Rating Scale (ALS-FRS) (29) and the SIP/ALS-192 (30) for physical function and general health status, respectively. The existential and psychological domains were measured by the McGill Quality of Life (MQOL) Questionnaire (15), and the spiritual dimensions were measured using the Idler Index of Religiosity measured (31). According to the results of this study, a high quality of life was observed in patients with ALS, which indicated that existential and social factors had a significant effect on the quality of life of these patients (16). More investigations using a comprehensive approach that includes the measurement of different physical, psycho-emotional, physical, and spiritual domains in ALS patients seem necessary. This study aimed to evaluate the QOL for patients with ALS.

Methods

This study was conducted using a cross-sectional design. Data was collected in 2021 using a mix-method approach. The short form of the World Health Organization Quality of Life questionnaire (WHOQOL) was used as an instrument. This instrument included 26

questions that measure the QOL in four dimensions (physical, psychological, community relationship, and social life). Each Question has a 5-point Likert score. The total score of the questionnaire was ranged from 24 to 120. The validity and reliability of this instrument were calculated by the WHO in different countries and cultures (32, 33). The reliability values with intra-cluster correlation coefficient were 0.77, 0.77, 0.75, and 0.85, respectively. The internal consistency between the four domains was 0.85 (34, 35). In this study, Cronbach's alpha was 0.81. To investigate the QOL through this questionnaire, a ten-member panel of experts in the field of psychology, psychiatry, neurology, and nursing with at least five years of work experience reviewed all questions. Patients who scored 60 and more on this questionnaire were placed in the positive group of QOL (P-QOL), and patients with a score less than 60 were placed in the negative group of QOL (N-QOL). Also, for purposes of this study, several interviews were conducted guide with the agreement of the expert panel in assessing the quality of life in ALS patients. The interview guide was designed with 15 open-ended questions (Appendix 1). The face validity of this guide was confirmed by experts. To check the reliability, a test-retest was used in the form of an interview-re-interview procedure, and the responses were compared in 5 patients.

Fifty-two patients consecutively enrolled in the Department of Neurology, movement disorders clinic of a teaching hospital in Tehran for 1 year. All patients completed the WHOQOL questionnaire. Eligibility criteria include a definite or probable diagnosis of ALS (36), Persian language, and without cognitive impairment. The average time required for patients to complete the questionnaire was 35 minutes. One of our team members distributed and collected the questionnaire. We send a reminder by calling patients through a telephone call. The response rate was 87%.

AALS was used to determine the individual function, level of disease, and progress of the disease (2, 5). The total score of this tool ranged from 30 to 164. A score of 30 shows normal functioning, and a score of 164 shows severe impairment. A score of 80 indicates a patient who needs assistance with travel and daily activities. Score 115 represented a patient that needed a wheelchair and had difficulties in speech and swallowing. Patients that received a score of 164 had paralysis, dependence on a ventilator, and full assistance in activities of daily living (ADLs) (2, 3, and 5).

Was categorized the qualitative data using a comparative model (37). Two team members read all responses and categorized them. The final themes emerged through a joint discussion. Disagreements were resolved through a consensus between two researchers. The mean duration of interviews was 43 minutes.

We used descriptive statistics to interpret the data. The difference between groups was investigated using a Two-tailed t-test. Age, disease duration, AALS means, and combined scores were compared between the two groups.

Chi-square test was used to interpret the results related to the categorical variables. A *p*-value of 0.05 or less is considered statistically significant.

Results

Fifty-two patients with ALS participated in this research. The number of male participants in the study was higher ($n = 32$, 57.7%). The age of the participants ranged from 28 to 81 with a mean of 57.6. The overall mean QOL was 58.7 (± 8.1). Thirty-three participants (63%) stated their QOL positive, and the remaining ($n = 19$, 37%) stated their QOL negative. About 55% ($n = 18$) of the group with positive QOL and 84% ($n = 16$) of the negative group had inadequate income ($P < 0.001$).

The disease duration ranged from 0.07 to 14 years with an average of 1.8. In terms of disease duration, patients included in the positive group had a shorter mean of 0.9 years ($P = 0.021$). Based on the overall score of AALS 74.4 (± 24.2), the level of physical disability was at a moderate level. Two groups of positive and negative QOL were different regarding physical strength and functioning. The disease symptoms were lower in the positive group. Also, muscle strength, upper limb function and breathing status showed fewer changes in the positive group ($P < 0.001$). Regarding vital capacity scores, they showed less adaptation in terms of respiratory function ($P < 0.001$). Changes in some functions such as breathing, eating, drinking, and speaking, were reported to be almost equal between the two groups. Response regarding non-medical concerns is categorized into three themes: change in lifestyle, supporting resources, and psychological scopes. Each of the main themes contained three sub-themes: change in lifestyle (leisure, work status, and financial issues); supporting resources (inner personality traits, nonphysical issues, and supports from family and community); and psychological factors (changes in mood, level of relationships, and stresses related to disease).

Most of the participants in both groups stated that they had made significant changes in their lifestyles, which apply to leisure time, working conditions, and financial affairs. Patients in the negative group usually reported more worries about financial issues and stated that they have fewer activities in their free time. Regarding how patients cope with the condition of the disease, most of the participants stated that positive personality factors and characteristics such as optimism, humor, and flexibility have helped them to cope with the condition disease. About 15% ($n = 5$) of patients in the positive group expressed humor, 24% ($n = 8$) flexibility, and 48% ($n = 16$) optimism. These values in the negative group were reported as 16% ($n = 3$), 21% ($n = 4$), and 32% ($n = 6$) respectively.

Some patients have found factors such as spirituality helpful in dealing with ALS. Practices such as prayer and meditation have been reported by these patients. The proportion of people who confirmed the belief in these factors in coping with the disease was higher in the negative group (74% ($n = 14$) vs. 67% ($n = 22$)). In both positive and negative groups, a large number of patients have reported that the support and help of family, friends, and relatives is useful in coping with the disease. Twenty-one

percent ($n = 4$) and 33% ($n = 11$) of the participants in the negative and positive groups, respectively, expressed sadness and depression as major mood changes. Distress due to emotional lability or bulbar-like signs (excessive crying or laughter) was reported in 39% ($n = 13$) of the positive group and 21% ($n = 4$) of the negative group, respectively. The presence of anger and frustration was reported more in the negative group (42% ($n = 8$) vs. 30% ($n = 10$)). Ten percent ($n = 2$) of the negative group and 42% ($n = 14$) of the positive group reported some changes in relationships and a decrease in quality. Stresses that were related to the disease were reported more in the negative group (63% ($n = 12$) vs. 21% ($n = 7$)). Regarding categorical variables, only stresses that were related to the disease distinguished between the two groups significantly ($P < 0.001$).

Discussion

Many factors affect the quality of life, including meaning in life, spirituality, personality, and social aspects. The results of many studies have confirmed the results of this study (16, 28, and 38).

Several factors affect the QOL of ALS patients. Among these factors, the progression of the disease and the decrease in physical function are among the most important factors (6, 23, 28). Also, variables such as age, income status, and disease duration, along with factors such as vital capacity and extent of symptoms, can be among the variables that distinguish two groups of patients and have a significant impact on the QOL.

In both groups of patients participating in the study, changes in lifestyle, such as leisure activities, work activity, and financial activity, were reported. These results are consistent with the results of another study so that for patients who are in the early stages of ALS, work and financial adaptations can affect their QOL (39). To maintain their mental and physical condition, patients should perform activities that have positive effects on their lives. Some of these factors include proper communication with family, friends, and community. Also, playing games and working with the computer, fun sports such as bowling and jogging, daily study, and artistic activities such as music can be among these activities.

Based on the results of this study, patients with ALS stated that internal personality traits and sympathetic communication are factors that helped them better manage the disease. The findings of similar studies confirm our results and show that the mentioned factors help patients cope with the disease better. (16, 38, 40–43).

Although we did not directly address issues such as spirituality and religious beliefs in our study, many participants did mention these things. For example, in the group of positive patients, more people mentioned spiritual factors and considered them to be effective in the quality of life. Activities such as going on vacation and communicating with friends and family were reported in the early stages of the disease. In advanced stages, religious beliefs and spirituality have helped to control stress and anxiety. The results of a study have been aligned with our results

and have shown that factors such as spirituality and religiosity can be considered as a support factor for patients and increase their adaptation to the disease (42).

According to our results, increasing anger and frustration are among the factors that disturbed and worried both groups of patients. Communication with family and relatives is mentioned by participants, but they stated that the quality of these relationships decreases to some extent with the progress of the disease. For example, when there are changes in speech or when they are physically dependent on others, stress increases in them. Such changes can lead to patients' communication problems and hinder their social interactions. People with a more severe form of the disease and in advanced stages reported more things like sadness, anger, and hopelessness. In this context, healthcare professionals must assess the mental performance of these patients in addition to clinical evaluations so that they can adopt appropriate solutions for the treatment of these cases.

More than half of the negative group reported stresses related to the disease. These include changes in activities, increased fatigue, and distress regarding the future. Usually, most patients have mentioned low income. In this regard, healthcare professionals should be aware of these income limitations and ask patients to share their conditions with them so that they can help them and reduce their worries in this regard. Having a competent counselor is essential for the patient and their family and can support these patients and reduce their depression and anxiety. To control this depression and anxiety and other psychological factors, timely referral to social organizations, religious missionaries, and mental health professionals is recommended.

Despite recent advances, ALS is still one of the diseases for which there is no effective treatment. However, most of these patients have a positive view of life and existence and are looking for meaning and purpose in their lives. Based on the results of our study, psychosocial issues were classified into 4 groups. These groups include internal personality traits, communicating with friends and family; religion and spirituality; stress, mood changes, and difficult relationship; and changes in lifestyle, work, leisure time, and financial situation.

To interpret the results of this study and generalize the results, attention to some aspects of the study is necessary. The participants in this study were similar in many characteristics, and the severity of the disease of patients was moderate. Also, in terms of gender, the number of male participants was almost double that of female participants. One of our limitations in this study was not directly examining the dimension of spirituality. Considering that many of the participants in our study have mentioned the factors related to this dimension, we advise researchers to consider this dimension in future studies and to use appropriate tools to measure it. Another limitation related to the small sample size of our study. Although some characteristics of patients such as the financial status of individuals and the severity of their illness, cannot be adjusted, it can be useful to examine some other factors such as marital status and family support that affect the quality of life of

these patients. According to the results of this study and other similar studies in this field (16, 28), it is recommended that studies that investigate the quality of life can be supported by including holistic characteristics of ALS patients and merging different instruments (44, 13), and different methods of quantitative and qualitative (10, 45). Carrying out such activities can lead to a better understanding of ALS patients and their real knowledge of the disease.

Ethical Considerations

The Research Ethics Committee of Hormozgan University of Medical Sciences approved this study (ethic code: IR.HUMS.REC.1399.143). The research process followed the Helsinki and Tokyo Declarations. All members of the research team assessed ethical issues in various domains, including confidentiality. Non-acceptance to participate in the study has not hindered the provision of services to patients, and people have full discretion in this field. The principle of information confidentiality has been respected in this study and all participants have been guaranteed that the information is only used for research purposes.

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Authors Contributions

All the authors contributed to the study, MF and HA: Idea, data collection, and manuscript preparation. MF and MS: data analysis. MF Manuscript edition. All activities were supervised by HA.

Conflict of Interests

The authors declare that they have no competing interests.

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Appendix 1. The Interview Guide for Assessing the QUALITY OF LIFE (QOL) in ALS Patients

1. How do you perceive your present quality of life (QOL)? (circle one) Life couldn't be better; usually good; sometimes good; and not good.
2. What changes in your physical strength have you noticed since your diagnosis? How do these changes affect your QOL?
3. Do you have trouble speaking? Yes/No- How do these changes affect your QOL?
4. Do you have problems with eating? Yes/No- How do these changes affect your QOL?
5. Does your breathing interfere with your activities of daily living (i.e. dressing, bathing, toileting)? Yes/No- How do these changes affect your QOL?
6. What changes in your moods or emotions have you noticed since your diagnosis? How do these changes affect your QOL?
7. Describe changes in your leisure or recreation.
8. Describe changes in your work.
9. Describe changes in your finances.
10. Any changes in relationships with others? Yes/No- How do these changes affect your QOL?
11. Examples of stress and tension. How do these changes affect your QOL?
12. What in your personality helps you cope?
13. What family and/or community resources have you sought? How have they been helpful?
14. Compare your present physical health with your health when diagnosed.
15. What are the most significant QOL changes since you were diagnosed?