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Translation and psychometric validation of the Persian version of amyotrophic lateral sclerosis cognitive behavioral screen (ALS-CBS) and revised amyotrophic lateral sclerosis functional rating scale (ALSFRS-R)

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Abstract

Background: The Amyotrophic Lateral Sclerosis Cognitive Behavioral Screen (ALS-CBS) and the Revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R) are widely recognized tools for evaluating cognitive, behavioral, and functional changes in patients with amyotrophic lateral sclerosis (ALS). Given the increasing number of ALS cases in Persian-speaking communities, there is a critical need for culturally and linguistically adapted versions of these instruments. The objective of this study was to translate the ALS-CBS and ALSFRS-R into Persian and evaluate their validity and reliability to ensure their applicability in clinical practice and research.

Methods: The Persian versions of the ALS-CBS and ALSFRS-R questionnaires were developed using the translation-back translation method. The translated questionnaires were administered to 36 individuals diagnosed with ALS. To assess content validity, neuromuscular specialists evaluated each item based on relevance, clarity, simplicity, necessity, and comprehensiveness, using content validity ratio (CVR) and content validity index (CVI) measures. Internal consistency reliability was assessed using Cronbach's alpha coefficient. Test-retest reliability was evaluated using the intra-class correlation coefficient (ICC). Statistical analysis was conducted using SPSS software.

Results: All questionnaire items demonstrated satisfactory face validity after expert-guided revisions. The minimum acceptable values for CVI (≥ 0.78) and CVR (≥ 0.62) were achieved by correcting items that initially scored below the threshold. Reliability analysis revealed ICC values of 0.969 and 0.816 for the cognitive and behavioral sections of the ALS-CBS, respectively, and 0.909 for the ALSFRS-R. Cronbach's alpha coefficients were 0.791 for the ALS-CBS behavioral section and 0.825 for the ALSFRS-R, indicating acceptable internal consistency.

Conclusion: The Persian versions of the ALS-CBS and ALSFRS-R have been shown to be both valid and reliable. These adapted tools provide valuable resources for assessing the cognitive, behavioral, and functional status of patients with ALS in Persian-speaking populations, ultimately supporting more accurate diagnosis, monitoring, and disease management.

Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease characterized by the degeneration of both upper and lower motor neurons. Patients with ALS experience severe and progressive weakness in the limb, bulbar, and respiratory muscles, typically leading to death within 2 to 5 years of symptom onset.[1,2] According to a 2019 systematic review, the global prevalence of ALS is 4.42 per 100000, whereas a 2010 study from Iran reported a crude prevalence of 1.57 per 100000.[3,6]

The non-motor symptoms of ALS have gained increasing attention in recent years, with cognitive and behavioral disturbances – often following a frontotemporal pattern – emerging as key clinical features.[1,2] Executive function, language, and fluency are the most commonly affected cognitive domains,[7] while apathy appears to be the most frequent behavioral symptom. Unfortunately, no studies to date have examined the spectrum of cognitive and behavioral symptoms in Iranian patients with ALS. While the motor manifestations of ALS are well documented, these non-motor impairments have only recently been recognized for their clinical significance. Such symptoms may negatively impact treatment adherence and are often associated with specific genetic mutations and a more aggressive disease course.[8,9] As such, early detection and accurate measurement of cognitive and behavioral impairment in patients with ALS is critical.

ALS is a profoundly debilitating condition, not only for patients but also for their caregivers, imposing a substantial emotional and physical burden.[10,11] Addressing the needs of this population requires locally relevant research, beginning with the adaptation of reliable tools to assess disease severity. The Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSFRS-R) and the Amyotrophic Lateral Sclerosis Cognitive Behavioral Screen (ALS-CBS) are two widely used instruments for evaluating motor and cognitive-behavioral impairments in ALS. Both are brief, easy to administer, and suitable for clinical and research settings.[8,9,12-14] These tools have been translated into multiple languages,[15-18] yet validated Persian-language versions are still lacking. This represents a significant gap in clinical assessment and research for Persian-speaking ALS populations.

The absence of validated Persian versions of the ALSFRS-R and ALS-CBS hinders accurate diagnosis, monitoring, and treatment planning. Culturally and linguistically adapted tools are essential to ensure appropriate evaluation across diverse populations. Psychometric validation of such tools is typically guided by Classical Test Theory (CTT), which emphasizes the assessment of internal consistency, reliability, and content validity.[19] CTT provides a practical and well-established framework for developing robust,

culturally sensitive measurement instruments.

Given the lack of validated ALS assessment tools in Persian and the growing need for culturally adapted clinical instruments, this study aimed to address these gaps by: (1) translating the ALSFRS-R and ALS-CBS into Persian, (2) assessing their content validity through expert evaluation using content validity ratio (CVR) and content validity index (CVI) indices, (3) evaluating their reliability using internal consistency and test-retest methods, and (4) confirming their feasibility and applicability for use in Persian-speaking clinical contexts. The resulting tools are intended to enhance the quality of ALS assessment and care in Persian-speaking populations.

Materials and Methods

Study design and participants: This cross-sectional study was conducted on 36 patients diagnosed with ALS by neuromuscular specialists between 2020 and 2023, using data from the Mashhad Motor Neuron Disease Registry (MNDR) (code:981736). Participants provided written informed consent prior to enrollment. Illiterate individuals, those diagnosed with dementia, or those unable to provide informed consent were excluded from the study. The study protocol was approved by the Ethics Committee of Mashhad University of Medical Sciences, Mashhad, Iran (IR.MUMS.MEDICAL.REC.1399.412 and IR.MUMS.MEDICAL.REC.1399.408).

Questionnaires: The ALS-CBS consists of two main components: (a) a cognitive screen section and (b) a behavioral screen section. It requires approximately five minutes to complete and is applicable in patients with limb or bulbar weakness. The cognitive section is administered by the physician, while the behavioral section is completed by the caregiver. The cognitive section assesses attention, concentration, mental tracking and monitoring, and word initiation and retrieval. The behavioral section includes 15 items evaluating domains such as apathy, inhibition, empathy, emotional control, frustration tolerance, cognitive flexibility, insight, judgment, food preferences, decision making, and language. Additionally, four items assess mood-related symptoms, including depression, anxiety, fatigue, and emotional lability.[8,20]

The ALSFRS-R evaluates functional abilities across four domains: bulbar, fine motor, gross motor, and respiratory. It comprises 12 items rated by the physician through a patient interview, addressing speech, salivation, swallowing, handwriting, cutting food and handling utensils (with or without gastrostomy), dressing and hygiene, turning in bed and adjusting bedclothes, walking, climbing stairs, dyspnea, orthopnea, and respiratory insufficiency.[13] Each item is scored from 0 to 4, with a maximum total score of 48 indicating normal function and 0 indicating severe disability.

Persian versions of ALS-CBS and ALSFRS-R: After receiving permission from the original developers, the ALS-CBS and ALSFRS-R were translated into Persian using a standard translation-back translation approach. Initially, three native Persian-speaking neurologists fluent in English independently translated the questionnaires. These versions were synthesized into a single consensus version (Tr1). Back translation into English was performed by three independent translators with expertise in neurology and psychometrics, all semi-native in English and unaware of the original versions. The back-translated versions were reviewed by three Persian-speaking neurologists fluent in English to refine and improve the Persian translation. The second version (Tr2) was finalized and assessed for validity and reliability.

Content validity of the Tr2 versions was evaluated by 10 neuromuscular specialists who independently rated each item based on five criteria: relevance, clarity, simplicity, importance, and comprehensiveness. Experts were asked to select from the following options for each criterion: "It is necessary", "It is useful but not necessary", or "It is unnecessary". The CVR and CVI were calculated using the following formulas:

$$CVR = \frac{[Ne - N/2]}{N/2} \quad (1)$$

$$CVI = \frac{\text{Raters with 3 or 4 score}}{\text{All of the raters}} \quad (2)$$

where Ne is the number of experts selecting "It is necessary" and N is the total number of raters. Based on Lawshe's table for 10 experts, the minimum acceptable values were set at 0.62 for CVR and 0.78 for CVI.[21] Items falling below these thresholds were revised, and the final version (Tr3) was developed for administration.

Reliability was assessed using Cronbach's alpha to evaluate internal consistency, with values ≥ 0.70 considered acceptable.[16] In addition, test-retest reliability was examined using the intra-class correlation coefficient (ICC). To avoid recall bias and ensure reliability of the responses, the retest was conducted two weeks after the initial

administration, a time interval recommended by consulting neurologists for cognitive and behavioral questionnaires. ICC values closer to 1.0 indicated stronger reliability.

All statistical analyses were performed using SPSS software (version 23, IBM Corporation, Armonk, NY, USA), and a significance level of 0.05 was considered for all tests.

Results

A total of 36 patients were included in the study, of whom 14 (38.9%) were women and 22 (61.1%) were men. The mean age of participants was 54.64 ± 11.69 years. Educationally, 50% of the participants had a high school diploma or lower, while the remaining 50% had attained university-level education. All participants were native Persian speakers.

Regarding the site of initial symptom onset, 8.3% of patients presented with bulbar symptoms, 50% with upper limb involvement, and 41.7% with lower limb onset. The mean disease duration was 22.33 ± 25.53 months, ranging from 2 to 120 months.

Validity analysis: In order to investigate face validity of questionnaire, 10 test-takers have been interviewed face to face, and questions and items have been investigated for clarity and cultural relevance. As previously described, the Tr2 versions of both questionnaires underwent sequential revisions until all items met the minimum acceptable values for CVR (≥ 0.62) and CVI (≥ 0.78). No items were removed from either questionnaire during this process. The CVR and CVI scores for the Tr2 versions are presented in supplementary 1 and 2. The final Tr3 versions were developed following all necessary revisions.

Reliability analysis: Test-retest analysis demonstrated a significant correlation between the initial and follow-up administrations of both questionnaires, confirming the reliability of the final Tr3 versions (Table 1). Cronbach's alpha was 0.791 for the ALS-CBS behavioral section and 0.825 for the ALSFRS-R, indicating acceptable internal consistency for both translated scales.

Discussion

While several Persian versions of ALS-specific questionnaires, such as the ALS-Specific Quality of Life-Revised (ALSSQOL-R),[22] Edinburgh Cognitive and Behavioral ALS Screen (ECAS),[23] 40-item ALS Assessment Questionnaire (ALSAQ-40),[24] and Motor Neuron Disease Behavioral Instrument (MiND-B),[25] have been validated for use in patients with ALS, the Persian versions of the ALS-CBS and ALSFRS-R have not been validated until now. Thus, the primary aim of this study was to evaluate the clinical applicability and psychometric properties of the Persian translations of the ALS-CBS and ALSFRS-R scales. Our findings demonstrated that both instruments possess acceptable face validity and internal consistency. The demographic profile of our participants, including a mean age of 54.64 ± 11.69 years and a gender distribution of 38.9% women and 61.1% men, closely aligns with previous epidemiological data reported in ALS populations globally.[26-28]

Table 1. Intra-class correlation coefficient (ICC) values for cognitive and behavioral subscales of the Persian versions of the Amyotrophic Lateral Sclerosis Cognitive Behavioral Screen (ALS-CBS) and Revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R) questionnaires

Scale	ICC	95% CI	P
ALS-CBS			
Attention	0.776	0.561-0.886	< 0.001
Concentration	0.838	0.682-0.917	< 0.001
Tracking/ monitoring	0.922	0.847-0.960	< 0.001
Initiation and retrieval	0.833	0.673-0.915	< 0.001
Cognitive screen	0.969	0.639-0.984	< 0.001
Behavioral screen	0.816	0.640-0.906	< 0.001
ALSFRS-R	0.909	0.834-0.951	< 0.001

ALS-CBS: Amyotrophic Lateral Sclerosis Cognitive Behavioral Screen; ALSFRS-R: Revised Amyotrophic Lateral Sclerosis Functional Rating Scale; CI: Confidence interval; ICC: Intra-class correlation coefficient

Internal consistency, which assesses the extent to which items within a test measure the same construct, was confirmed for both questionnaires. Cronbach's alpha coefficients were 0.791 for the behavioral section of ALS-CBS and 0.825 for ALSFRS-R. These values exceed the commonly accepted threshold of 0.70, indicating satisfactory reliability.[29,30] Furthermore, test-retest reliability assessed via ICC showed strong agreement, with values of 0.969 for the cognitive section and 0.816 for the behavioral section of ALS-CBS, and 0.909 for ALSFRS-R. These results reflect a high level of stability and consistency over time.

Content validation was carried out using CVR and CVI indices, with expert input guiding the iterative revision of items in the Tr2 versions of both tools. All items in the final Tr3 versions met

the minimum acceptable thresholds of CVR (≥ 0.62) and CVI (≥ 0.78), suggesting that the Persian versions adequately represent the constructs measured and are culturally appropriate for the Iranian context.

The psychometric properties of our Persian version of ALSFRS-R compare favorably with several validated translations. The Arabic version, tested in an Egyptian cohort of 162 patients with ALS, demonstrated high reliability with test-retest correlation coefficients of r = 0.99 and Cronbach's alpha values ranging from 0.85 to 0.93.[31]

However, that study did not assess content validity using CVI or CVR, nor did it report item-level revisions based on expert evaluation. These methodological differences likely contributed to the need for revisions in specific domains in our study, particularly in items related to salivation and respiratory function, which required cultural and linguistic adjustment.

The Russian validation of ALSFRS-R reported an ICC of 0.83, indicating good test-retest reliability.[32] Our higher ICC of 0.909 may reflect the additional rigor of our content validation process, which incorporated systematic expert review and item modifications to ensure clarity and conceptual alignment with the original version.

Similarly, the Turkish adaptation of ALSFRS-R demonstrated excellent inter-rater reliability, with ICC values above 0.80 across subscales.[33] While both studies affirm the reliability of the translated instruments, our study adds value by including a structured evaluation of content validity, an element not emphasized in the Turkish validation.

The Spanish version of ALSFRS-R, validated in a sample of 73 patients with ALS, showed strong internal consistency (Cronbach's alpha = 0.77-0.91) and test-retest reliability (Spearman's rho = 0.80-0.95). It also demonstrated convergent validity through correlations with ALSAQ-40 and Severe Respiratory Insufficiency (SRI) scales, and explained 73.3% of variance across three factors in factor analysis.[16] In contrast, our study did not conduct factor analysis or external validation due to the limited sample size (n = 36) but, nonetheless, confirmed high internal consistency and reliability through expert-based content validation.

The Japanese validation study reported an ICC of 0.97 and item-wise kappa coefficients ranging from 0.48 to 1.00.[34] While these results indicate excellent reliability, differences in study design – such as the inclusion of multiple raters and longitudinal sensitivity analysis – make direct comparison challenging. Our study focused primarily on test-retest reliability and expert-guided content validation, which may explain minor discrepancies in reliability indices. Additionally, cultural differences in the interpretation of items related to bulbar and respiratory functions may have influenced item-level clarity and consistency.

The Persian version of the ALS-CBS also exhibited robust psychometric characteristics. Reliability was high, with ICC values of 0.969 for the cognitive and 0.816 for the behavioral sections. The behavioral section showed acceptable internal consistency, with a Cronbach's alpha of 0.791. All items met the predefined CVR and CVI thresholds after iterative revisions. These findings indicate that the Persian version reliably captures the cognitive and behavioral dimensions of ALS.

When compared to the Italian validation studies, which included large samples (e.g., 293 for the cognitive and 265 for the behavioral sections), our sample was smaller but benefited from an intensive expert review process. Tremolizzo et al. reported cognitive impairment detection in 12% and behavioral symptoms in 55.5% of patients with ALS.[35] Aiello et al. further demonstrated strong correlations between ALS-CBS cognitive scores and ECAS (r = 0.54-0.71), and an internal consistency (McDonald's ω) of 0.74 for the cognitive and 0.90 for the behavioral sections.[36-39] Although our study did not assess diagnostic accuracy or convergent validity, it emphasizes cultural and linguistic adaptation, offering a complementary validation approach.

Similarly, the Spanish validation of ALS-CBS by Turon-Sans et al. reported high diagnostic performance with area under the curve (AUC) of 84.7% for the cognitive and 83.3% for the behavioral sections, and sensitivities of 86.2% and 93.3%, respectively.[18] Our study did not include diagnostic thresholds or classification accuracy but confirmed content adequacy through expert-driven revisions and test-retest reliability, with an ICC of 0.969 for cognitive and 0.816 for behavioral domains.

In the Brazilian validation by Branco et al., the ALS-CBS cognitive section demonstrated strong diagnostic performance (AUC = 0.906, sensitivity = 0.900, specificity = 0.872), based on comparison with a full neuropsychological battery.[15] While we did not assess criterion validity, our study focused on enhancing content validity through culturally

sensitive revisions, particularly in domains affected by language structure and caregiver understanding.

Strengths and limitations: This study has several key strengths. It is the first to validate Persian translations of the ALSFRS-R and ALS-CBS, addressing a critical need for culturally adapted assessment tools for Persian-speaking patients with ALS. A rigorous translation-back translation process was followed, supported by expert panel reviews to ensure linguistic and conceptual accuracy. Content validity was thoroughly evaluated using CVR and CVI, with all items revised until they met the minimum acceptable thresholds (≥ 0.62 for CVR and ≥ 0.78 for CVI). In addition, both tools showed strong internal consistency and test-retest reliability, supporting their psychometric soundness. However, several limitations should be noted. The small sample size (n = 36) limited statistical power and prevented more advanced analyses such as factor analysis and convergent validity testing. Furthermore, the back-translation process was conducted by a semi-native neurologist, whereas standard practice typically recommends that back-translation be performed by a native speaker of the target language.

This ensures greater linguistic and conceptual accuracy. The study also lacked normative data, as no healthy control group was included, and external validity was not assessed due to resource limitations.

Future research should involve larger and more diverse samples, include normative comparisons, and assess cross-tool validity to further streng1then the utility of these translated scales.

Conclusion

The successful validation of the Persian versions of the ALS-CBS and ALSFRS-R represents significant progress in the assessment of cognitive, behavioral, and functional changes in Persian-speaking patients with ALS. These tools provide clinicians with reliable instruments to monitor ALS progression more effectively, enhancing patient care in Iranian clinical settings. Additionally, researchers can utilize these validated versions to conduct more relevant and culturally appropriate studies in this population. Ultimately, the availability of these tools will contribute to improved outcomes and better understanding of ALS in Persian-speaking communities.

Conflict of Interests

The authors declare no conflict of interest in this study.

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