





## The Turkish Version of Pain Assessment in Advanced Dementia (PAINAD) Scale

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### ABSTRACT

**Introduction:** This study was conducted to test the reliability and validity of the Turkish version of the "Pain Assessment In Advanced Dementia (PAINAD) Scale".

**Methods:** One hundred and six older adults with advanced dementia (AD) were recruited in the study. Detailed medical history and demographic data of the participants were recorded. Initially, the Turkish version of PAINAD (PAINAD-TR), which was prepared by means of "back-translation", was applied. Along with this scale, Mini Mental State Examination, Clinical Dementia Rating scale, and Visual Analog Scale were also used.

**Results:** The Cronbach's  $\alpha$  coefficient was 0.82 and 0.85 for the test and re-test, respectively. For the test-retest reliability of the PAINAD-TR scale, values of the intraclass correlation coefficient (ICC) and 95% confidence interval (CI) were 0.812 and 0.763-0.850 respectively. According to the results of a factor analysis carried out on the scale, a 2-domain structure was proved.

**Conclusion:** The PAINAD-TR scale can be used for the assessment and management of pain in non-communicative older adults with AD.

**Keywords:** aged, assessment, dementia, pain, pain assessment in advanced dementia (PAINAD)

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### INTRODUCTION

According to the definition of the International Association for the Study of Pain, pain is an unpleasant sensorial and emotional experience associated with actual or potential tissue damage (1). It is currently interpreted as a condition originating from emotional and/or physical integrity impairment and is considered as an integrated and conscious "pathway" coming from different body segments (2). In later stages of dementia, however, non-verbal communication and behavioral changes are very common. While these changes can be a pain manifestation, they are frequently mistaken for a symptom of an underlying disease (3). Social withdraw, aggression, psychomotor agitation or mood changes can all be signs of pain in similar ways (4). Health professionals face challenges in recognizing, evaluating and managing pain in elderly with cognitive impairments (5). Especially, difficulties in evaluating pain in patients with AD generally result in a poor management (5, 6). As a solution, specific assessment instruments have been looked for to identify and evaluate pain based on the observation of the behaviors that may indicate pain in non-communicative patients (4). To avoid subjectivity, objective assessment by means of specific tools and instruments is particularly

important for identifying necessary interventions, evaluating the efficacy of the chosen ones, and providing better management of pain (3).

There are several observation-based pain scales that are used for people with dementia (7-13). However, none of these scales have been tested for validity and reliability in Turkish. Created in 2003, the PAINAD scale was originally adopted from the DS-DAT and the Face, Legs, Activity, Cry, Consolability pediatric scale, in order to provide an easy approach to quantify pain in older adults (7, 13, 14). Validated in older patients receiving both short and long term care, this scale was reported to have good inter-rater agreement and internal consistency (15-17). The scale, which was introduced and validated by many countries, was found by healthcare professionals very user-friendly and time-efficient, as it required less than 5 minutes to be completed (15-19).

The present study was aimed to test the validity and reliability of the Turkish version of the PAINAD, as there are no validated Turkish tools to assess pain in older adults suffering AD.

## METHODS

### Participants

One hundred and six older patients hospitalized in the palliative or intensive care units in Ahi Evran University, Training and Research Hospital were included in the study. The inclusion criteria were as follows: (i) diagnosed with AD; (ii) having spent minimum of 4 weeks in either the palliative or intensive care unit; (iii) inability to communicate about pain or discomfort, and (iv) age  $\geq$  65 years. Individuals with respiratory problems, those on analgesic or sedative treatment, those with acute psychiatric symptoms, those in need of mechanical ventilation, and those receiving “end-of life” care were excluded from the study. Written informed consent in accordance with the guidelines approved by the local ethical committee and the Declaration of Human Rights, Helsinki was obtained from the participants’ legal representatives.

At the beginning of the study, the age, gender, medical history, stage of dementia (20), duration of hospitalization (week), and medications of all participants were recorded.

### Instruments

All the evaluations were done at the bedside of the patients. Mini Mental State Examination (MMSE), Clinical Dementia Rating (CDR) scale, Visual Analog Scale (VAS), and PAINAD-TR were used for the evaluation. These scales were applied by the trained nurses who had experience in neuropsychological tests. The nurses were re-trained by the researchers for 4 hours in total. While the first 2 hours of the training included theoretical introduction of the scale, the remaining 2 hours consisted of practical training alongside the patients. All evaluations were completed within the same day. Also PAINAD-TR was applied at intervals of 2 weeks.

### Mini Mental State Examination Test

MMSE test was used to assess participants’ cognitive status. This test evaluates mental state on a 30-point system including 7 different cognitive areas. While any results equal to or greater than 24 indicate normal cognition, scores lower than 24 indicate cognitive impairment. If the patients could not understand the test questions or were unable to answer, they were scored as “0” (21).

### Clinical Dementia Rating Scale

CDR scale was used to identify the stage of dementia. The information was obtained through interviews with patients and informants. The 6 domains of cognition and function are rated in CDR. Each domain is scored on a 5-point scale where 0 indicates no impairment; 0.5, questionable impairment; 1, mild impairment; 2, moderate impairment; and 3, severe impairment (personal care domain is scored on a 4-point scale where 0.5 rating is unavailable). The global CDR score was computed via Washington University online algorithm (22). Two researchers entered the domain scores into the online algorithm and double-checked discrepancies in computed global CDR scores ( $n=8$ ) to avoid entry errors. Adding up each of the domain scores, ranging from 0 to 18, resulted in the CDR score.

### Visual Analog Scale

During evaluation and completion of PAINAD, the trained nurses were asked to mark a point between “0 (no pain) and 10 (very severe pain)” on VAS thinking about the pain felt by the patient being assessed (13).

### Pain Assessment in Advanced Dementia

The PAINAD scale was developed to evaluate pain in non-communicative individuals with AD. This scale consists of five items: breathing, vocalization, facial expression, body language and consolation. These five items contain 3 out of 6 of the general pain behaviors suggested by the American Geriatric Association (13). Each item of the scale is scored

between 0-2 depending on the severity of the behavior. The total score reflects the average value of the pain. The cross-cultural adaptation procedure of the PAINAD scale was made according to the guideline recommended by Beaton et al (23). This guideline was implemented as follows:

Content equalization of PAINAD scale and translation into Turkish: The PAINAD scale was translated from the original language into Turkish. The translation of the scale was completed by a Turkish translator who was fluent in English along with a native English translator fluent in Turkish. The translation quality can be assured when it is carried out by at least two experienced translators as they can prevent the errors resulting from terms that may cause different interpretations.

Consensual version of the PAIN-AD scale in Turkish and “Back Translate” study: Translators and researchers compared the two translations and decided for the best meaning compromise according to the Turkish language, and the scale was named PAINAD-TR. Then, “Back Translate” of PAINAD-TR was done by three independent bilingual translators who did not participate in the first translation. At this stage, in order to improve the quality of the PAINAD-TR, errors and inconsistencies that could have occurred during the translation were detected by comparing with the original PAINAD.

Content validity: The content equivalence of PAINAD-TR was examined by a total of 12 experts, including physiotherapists, geriatricians, neurologists, and nurses who were fluent in both languages (English and Turkish) and had experience and methodological knowledge about preparing questionnaires and scales. Scale items were evaluated on a 4-point Likert scale in terms of content equivalence (4=very relevant, 3=relevant, 2=slightly relevant, 1=irrelevant). This committee initially examined the “semantic, idiomatic, conceptual and experimental” equivalence of PAINAD-TR with the original version of PAINAD. Corrections were suggested for the identified inconsistencies or differences in meaning. As a result, the final version of PAINAD-TR was prepared.

Pre-test; Preliminary tests were performed on 15 patients with advanced dementia hospitalized at intensive care or palliative care units. Two volunteer staff nurses who had minimum 10 years of experience and held a certificate in intensive care unit were assigned as testers. The nurses observed the patient for at least 5 minutes before evaluating with PAINAD-TR. The two testers completed the evaluations independently without talking to each other.

### Statistical Analysis

Statistical Package for the Social Sciences version 21.00 (SPSS Inc.; Chicago, IL, USA) was used for conducting all analyses. The variables were expressed in terms of standard deviation (SD) and arithmetic means ( $X$ ). The critical level of significance was set at  $p<0.05$ . Reliability and validity of the psychometric properties of the PAIN-AD scale were evaluated. In order to determine test-retest reliability, intraclass correlation coefficient (ICC) was calculated. This reliability shows the strength of agreement. ICC values are defined as fair ( $<0.40$ ), moderate (0.40-0.59), substantial (0.60-0.79), and excellent ( $\geq 0.80$ ). The Kaiser-Meyer-Olkin test was used for the suitability of the factor analysis. Cronbach’s alpha, which was expected to be above 0.70, was used in assessing internal consistency. This demonstrates that all scale items measure various aspects of a single construct. The strength of the linear relationships was assessed by means of a Pearson correlation coefficient (24). Pearson’s correlation coefficient was used to estimate convergent validity of the PAINAD scale with other measurement tools. Construct validity, on the other hand, was evaluated by the principal component and factor analysis method.

## RESULTS

The mean age of all included subjects (n=106) was  $72.5 \pm 4.2$  and 51% (n=54) of the population was female. All participants scored 3 on the clinical dementia rating scale. The socio-demographic data, MMSE, VAS, and PAINAD-TR scores of the included subjects included were shown in Table 1.

**Table 1.** Demographic characteristics of older adults with AD

Parameters	Mean±SD or %(n)
Age (years)	72.5±4.2
Gender (female)	%51 (54)
MMSE (0-30)	2.15±0.84
Duration of hospitalization (week)	40.45±10.74
PAINAD-TR (0-10)	2.19±1.44
VAS (0-10)	5.14±2.71

### Content and semantic equivalence of PAINAD-TR

Content equivalency was evaluated by the average percentage of the scores obtained from all the evaluations with those who were rated 3 or 4 by the experts participating in the study. The content validity index (CVI) of content equivalence for total items was 0.84. In semantic equivalence evaluation of PAINAD-TR, "Consolability" was the only item rated as 2 by one expert who believed that the Turkish translation of this item was not clear enough to be understood. Preserving the meaning of the original English text, we modified the Turkish translation into a more clear form, as was recommended by the expert. Thus, the CVI of semantic equivalence for the total items changed to be 0.94.

### Reliability

The Cronbach  $\alpha$  coefficient of the PAINAD-TR scale was 0.82 for the test and 0.85 for the re-test. The "item-total correlations" score of all items of the scale were found to be changed between 0.514 and 0.847. For the test-retest reliability of the PAINAD-TR scale, the ICC value was 0.812 and the 95% CI value was 0.763-0.850. When the ICC values of all scale items were individually examined, the lowest score was found to be 0.692 for respiration, while the highest score was found to be 0.925 for body language (Table 2).

**Table 2.** Test-retest reliability and Item Total correlations of the PAINAD-TR

	r	ICC	95% CI	
			Lower	Upper
Breathing	0.514	0.692	0.598	0.786
Negative vocalization	0.785	0.864	0.831	0.897
Facial expression	0.847	0.925	0.914	0.936
Body language	0.740	0.829	0.791	0.867
Consolability	0.658	0.724	0.683	0.765
Total		0.812	0.763	0.850

### Convergent validity

Statistical correlations between the scores obtained from the first application of the PAINAD-TR scale and other parameters were as follows:

$r=0.217$ ,  $p=0.124$  for MMSE;  $r=0.324$ ,  $p=0.084$  for CDR;  $r=0.456$ ,  $p=0.048$  for duration of hospitalization; and  $r=0.921$ ,  $p<0.001$  for VAS.

### Construct validity

In order to estimate the dimensions of the PAINAD-TR scale, the main component factor analysis Varimax rotation was used. The Kaiser-Meyer Olkin value was found to be 0.719 ( $p<0.0001$ ), and the sample was found to be factorial. The main component analysis revealed two factors with "eigenvalues" greater than 1 and explained variance of 68.89% (Table 3).

**Table 3.** Varimax Rotated two-factor solution of PAINAD-TR Scale.

PAINAD-TR	Factor 1	Factor 2
Body language	0.845	0.212
Facial expression	0.915	-0.041
Negative vocalization	0.704	0.285
Consolability	0.412	0.684
Breathing	-0.083	0.924
Eigenvalues	2.26	1.02
% of variance explained	48.45	20.44
% of variance cumulative	48.45	68.89

## DISCUSSION

Pain is not perceived as a simple sensation as it used to be; it is now regarded as a very complex sensorial experience that is modified for each person depending on memory characteristics, emotions, and expectations. It is believed that the difficulties to assess pain are originating from the individual's personal characteristics, particularly in those with cognitive alterations. Besides comprehensive pain assessment requires the individual to remember and verbally share pain characteristics such as its location and intensity (25). Hence, more attention should be paid to assessing pain in patients with AD. Initially -even if the experienced pain is not reported- the patient with AD should be considered to be experiencing pain similar to other patients. Difficulties in assessing pain in patients with dementia might be due to the incapacity of the health professionals to recognize the pain as a result of the patients' cognitive and communicative inabilities. Therefore, proper scales are needed to identify pain in older patient with dementia (17).

The present study investigated the content and semantic equivalence, reliability, convergent validity and construct validity of the PAINAD-TR in patients with AD. However, as there was no reliable and validated method for measuring pain in older adults with AD in Turkey, concurrent validity could not be evaluated.

Whether the items of the PAINAD-TR scale measure a single construct or not was determined by test-retest reliability. ICC score of the current study was calculated as 0.812 and found to be "excellent". Similar to our findings, ICC scores were found to be 0.71, 0.88, and 0.90 in different studies. ICC score of the current study was calculated as 0.812 and found to be "excellent" just like the ICC score of PAINAD-I and PAINAD-G (17, 18, 26).

The PAINAD-TR scale showed high internal consistency with non-communicative older adults, similar to the original, Italian, and German versions of the PAINAD scale (13, 17, 26). In the PAINAD-C and PAINAD-Brazil studies, the "Cronbach  $\alpha$ " values of the entire scale were 0.66 and

0.654, respectively. However, the authors of both studies confirmed that by deleting the respiration item this ratio would increase to 0.71 (18, 19). One of the possible reasons of this was thought to be the involvement of older individuals with diseases that cause respiratory problems such as asthma or vascular dementia in Chinese and Brazilian versions (18, 19). In the current study, however, no older individual with any disease that could cause respiratory problems was included.

Although Schuler et al. (26) reported that the German version of PAINAD demonstrated a single-dimensional structure, results of the factor analysis in the Chinese and original version of PAINAD demonstrated that it was consisted of two factors (13, 18). Similarly, in the current study, two factors were extracted. As in the original PAINAD, in this study the first factor was “Consolability” while the second one was “Breathing”. Moreover, in the Chinese version of the scale, “Consolability” and “Breathing” were also among the factors. These factor similarities were not unforeseen as the observations applied in the original and Chinese versions of the scales were pretty similar to the observations applied in this study. One possible reason of this similarity could be the fact that all participants were either in the intensive care or palliative care units of the hospital. In addition, painful breathing in AD may cause respiratory changes and these changes can be an important finding for both caregivers and those who apply the scales. Additionally, as our sample size is large enough for reliable factor analysis, we also suggest that the PAINAD-TR has two dimensions.

Criterion validity of the PAINAD-TR could not be clearly shown, as there was no instrument with which we could compare in Turkish. The participants’ pain was assessed by VAS in addition to the PAINAD-TR scale. This evaluation was based on the observations of the trained nurses. Although the VAS scale is not an “observational” as PAINAD in evaluating pain, it is used in the original PAINAD scale to determine the patient’s pain according to the tester’s observation (13). Similar to the original PAINAD, there was a statistically significant relationship between VAS and PAINAD-TR in the present study.

PAINAD-TR showed good convergent validity in terms of duration of hospitalization and VAS in older adults with AD. Unfortunately, there were no studies so that we could compare these results with the literature. However, these findings provided reliable evidence for the clinical use in pain management.

The limitations of the present study were as follows: Firstly, the participants of this study were limited to the patients at intensive or palliative care units in Turkey, which might restrict the generalization of the findings to other populations in long-term care facilities. Secondly, as there was no other pain instrument for non-communicative patients in Turkey, criterion validity could not be evaluated.

In summary, this is the first study to assess reliability and validity of an observational pain scale in Turkish. This study showed that this adapted scale had good reliability, convergent validity, and construct validity to evaluate pain in long-term care units in Turkey. This is especially important as until now there has been little understanding and applying related with this aspect of pain assessment and management. Further studies are needed to address pain in people with AD and to develop protocols for pain management.

**Ethics Committee Approval:** The study was conducted in accordance with the Declaration of Helsinki and was approved by the ethics committee of the Medical Faculty of Hacettepe University (GO 16/251-32).

**Informed Consent:** Written consent was obtained from the legal representatives of the participants.

**Peer-review:** Externally peer-reviewed.

**Author Contributions:** Concept - ÖB, NK; Design - ÖB, MİN; Supervision - ÖB, NK; Resource - AY, BB; Materials - ÖB, BB, MİN; Data Collection and/ or Processing - ÖB, BB, AY; Analysis and/or Interpretation - ÖB, MİN, BB; Literature Search - ÖB, BB; Writing - ÖB, BB, MİN; Critical Reviews - NK, MİN.

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