Cultural adaptation of the scale *Pain Assessment in Advanced Dementia – PAINAD to Brazil**

ORIGINAL ARTICLE

ADAPTAÇÃO CULTURAL PARA O BRASIL DA ESCALA *PAIN ASSESSMENT IN ADVANCED DEMENTIA* – PAINAD

ADAPTACIÓN CULTURAL PARA BRASIL DE LA ESCALA *PAIN ASSESSMENT IN ADVANCED DEMENTIA* – PAINAD

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ABSTRACT

Objective: To translate and culturally adapt to Brazil the scale *Pain Assessment in Advanced Dementia* (PAINAD). **Method:** The cultural adaptation process followed the methodology of a theorical reference, in five steps: translation to Brazilian Portuguese, consensual version of translations, back-translation to the original language, revision by a committee of specialists in the field and a equivalency pre-test. The instrument was assessed and applied by 27 health professionals in the last step. **Results**: The *Escala de Avaliação de Dor em Demência Avançada* was culturally adapted to Brazil and presented semantic equivalency to the original, besides clarity, applicability and easy comprehension of the instrument items. **Conclusion:** This process secured the psychometric properties as the reliability and content validity of the referred scale.

RESUMO

Objetivo: Traduzir e adaptar culturalmente para o Brasil a escala *Pain Assessment in Advanced Dementia* (PAINAD). **Método:** O processo de adaptação cultural do instrumento seguiu a metodologia de um referencial teórico, realizada em cinco etapas: tradução para o português brasileiro, versão consensual das traduções, retrotradução para o idioma original, revisão por um comitê de especialistas na área do instrumento e pré-teste de equivalência. Na última etapa o instrumento foi avaliado e aplicado por 27 profissionais da saúde. **Resultados:** A *Escala de Avaliação de Dor em Demência Avançada* foi adaptada culturalmente para o Brasil e apresentou equivalência semântica com o original, além de clareza, aplicabilidade e fácil compreensão dos itens do instrumento. **Conclusão:** Este processo permitiu assegurar as propriedades psicométricas como confiabilidade e validade de conteúdo da referida escala.

RESUMEN

Objetivo: Traducir y adaptar culturalmente para Brasil la escala *Pain Assessment in Advanced Dementia* (PAINAD). **Método:** El proceso de adaptación cultural del instrumento utilizó la metodología de un referencial teórico, realizada en cinco etapas: traducción para el portugués - brasileño, versión consensual de las traducciones, retro-traducción para el idioma original, revisión por un comité de expertos en el área del instrumento y prueba piloto de equivalencia. En la última etapa, el instrumento fue evaluado y aplicado por 27 profesionales de la salud. **Resultados:** La *Escala de Evaluación del Dolor en Demencia Avanzada* fue adaptada culturalmente para Brasil y mostró equivalencia semántica con la original, así como claridad, aplicabilidad y fácil comprensión de los elementos del instrumento. **Conclusión:** Este proceso garantizó las propiedades psicométricas tales como confiabilidad y la validez de contenido de esa escala.

INTRODUCTION

During the dementia process people can stop interpreting sensations, as the painful ones. In many situations they are not able to remember their pain or they are not capable to verbally communicate it to their caregivers, which makes it harder to detect and measure, characterizing its evaluation as a problem to be considered for those patients[1-3].

However, in most severe dementia cases, non-verbal expressions and behavior change becomes more frequent. Behavior changes in patients with severe dementia are frequently understood as symptoms from a base disease, when they can be a pain manifestation[3]. In those cases, social withdraw, aggression, psychomotor agitation or humor changes can be manifestations of pain[4].

The inadequate management of pain in people with severe dementia is frequently attributed to difficulties in its evaluation[5]. Findings points to difficulties to recognize pain from health professionals and its evaluation in elderly with cognitive impairment[6].

Facing this reality, researchers have been looking for solutions to better manage the pain in this fragile population, through the development of specific assessment instruments, based on the observation of behaviors that allow identification and evaluation of pain in non-communicative patients[4]. In the clinical scenario, the assessment by an instrument is fundamental to identify interventions and to assess efficacy of the chosen strategies, therefore avoiding subjectivity and allowing adequate pain management[7].

In the global literature, 12 instruments were found proposing the evaluation of pain in people with severe dementia published until 2013, being those: *Abbey Pain Scale*[8]; CNPI – *Checklist of Nonverbal Pain Behaviors*[9], CPAT – *Certified Nursing Assistant Pain Assessment Tool*[10]; DOLOPLUS-2[11]; MPS – *Mahoney Pain Scale*[12]; MOBID – *Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale*[13] e MOBID-2[14]; NOPPAIN – *Non-communicative Patient's Pain Assessment Instrument*[15]; PACS-LAC – *Pain Assessment Checklist for Seniors With Limited Ability to Communicate*[16]; PADE – *Pain Assessment for the Dementing Elderly*[17]; PAINAD – *Pain Assessment in Advanced Dementia*[18], PAINE – *Pain Assessment in Non communicative Elderly Persons*[19] and ADD – *Assessment of Discomfort in Dementia*[20].

Only two of those instruments were culturally adapted to Brazil, the instrument PACSLAC[3] and the NOPPAIN[21], but they were not validated in Brazilian Portuguese.

The scale *Pain Assessment in Advanced Dementia* – PAINAD presented good validity and reliability, as the instrument was able to detect the difference within the associated pain in different conditions or by the management of analgesics.

This scale is based on the physiological state and behavior assessment, as breathing; vocalization; facial expression; body language and consolability. The scoring vary from 0 to 2 for each of the five assessed areas, in which 0 (zero) equals the lower intensity and 2 (two) to the higher intensity. It is a simple tool, easy to apply and it presents a list of definitions for each of its items. The scoring varies from 0 to 10 points based in an established pain scale. The authors propose the scoring interpretation as follows: 1 to 3 points is considered mild pain; 4 to 6 points as moderate pain and from 7 to 10 points as severe pain[18].

Due to the lack of instruments adapted and validated to Brazil for assessment of pain in elderly with severe dementia, the present study aimed to culturally adapt to Brazil the PAINAD instrument.

METHOD

This is a methodological study to translate and culturally adapt to Portuguese language an instrument to assess pain in people with severe dementia known as *Pain Assessment in Advanced Dementia* – PAINAD, originally from the English language.

The process of cultural adaptation of the instrument PAINAD followed the methodology proposed by Guillemin, Bombardier e Beaton[22], vastly utilized for this type of study. The propose has five steps:

1ª – Translation of the instrument PAINAD to Brazilian Portuguese

To translate the instrument PAINAD from the original language, English, to the targeted language, the Brazilian Portuguese. It was conducted by two independent translators, fluent in the original language and with experience in translations; one translator had English as her mother tongue. A translation of good quality can be guaranteed when executed at least by two independent translators because it allows the identification of errors and divergent interpretations of ambiguous terms in the original language.

2ª – Consensual version of PAINAD in Portuguese (Brazilian) language

This step was obtained after comparing the two translated versions looking for a consensus of the best meaning of the words in Brazilian Portuguese, and it was denominated as PAINAD-VCP (*Escala de Avaliação de Dor em Demência Avançada – Versão Consensual em Português*/ Consensual Version in Portuguese).

3ª – Consensual retro translation in Portuguese language of the instrument PAINAD

The consensual version in Brazilian Portuguese, the PAINAD-VCP, was submitted for translation of the in-

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strument original language, the English language (*back-translation*), by three qualified fluent bilingual translators who works independently and they did not participate in the first step of the study. This step allowed comparison with the original and the eventual detection of errors and discrepancies in the translation, improving the final version quality.

4ª – Specialists Committee – Content validation

The committee was multidisciplinary, composed by six specialists with knowledge in both languages, specialists in the field of which the instrument is referred to, with methodological knowledge about questionnaires and scales development. The committee had as one of their functions the verification of the semantic, idiomatic, conceptual and experimental equivalence as function between the PAINAD original version and the PAINAD-VCP consensual version in Portuguese. They also suggested modifications or elimination of items considered ambiguous, redundant and inadequate, avoiding the colloquial language, therefore, proposing a more functional and comprehensive version to the targeted population.

The content validity analysis of the PAINAD – VCP elements was done with a Likert scale of 1 (one) to 4 (four) points for each item, being as: 1= not equivalent, 2= a little equivalent; 3= equivalent and 4= really equivalent. After, the index calculation for content validity (IVC) was used, in which all judges had to be in agreement with the item evaluation as being valid in its content (IVC=1). In case of six or more, it is recommended a rate not inferior to 0.78[23-24]. In the three re-translations analysis, the agreement percentage between specialists was the direction for the best version choice.

The evaluation by specialists resulted in the back-translation final version and in the instrument pre-final version in Brazilian Portuguese, named as PAINAD–Br, sent to the authors of the original PAINAD scale, to guarantee that all steps were strictly followed.

5ª – Pre-test of the semantic validation

This step was done through the instrument application. Twenty-seven health professionals (nurses, nursing technicians and physiotherapists) who applied the instrument in elderly with severe Alzheimer disease, residents of two long-term institutions and hospitalized at the moment of the data collection, in two cities from the interior of São Paulo state.

All participants after assessing the patients and scoring the PAINAD-Br scale answered a general questionnaire that evaluates the comprehension and clarity of the scale. The 27 participants were divided in three groups of 9 people each, in accordance with the professional category and answered a specific instrument about the items' clarity (all items in the scale were distributed in 3 subseries). When convenient, participants could suggest

modifications for better comprehension. The development of those instruments was based in those used by researchers from the DISABKIDS group[25].

The group division and the items subseries guaranteed the reliability of answers, as a detailed analysis of all items regarding its comprehension and clarity by one professional can be an exhausting task[25].

Ethical Aspects

The present study was submitted and approved by the Ethics in Research Committee from the Universidade Federal de São Carlos nº 143.366 on 13/11/2012, respecting the Resolution 466/12 of the Brazilian National Health Council that provides guidelines for researchers in human beings. The patterns for research in human beings were followed for this step and all professionals and those responsible for the elderly participating in the research signed the Free Informed Consent, securing the confidentiality condition of their names.

RESULTS

The PAINAD instrument was culturally adapted to Brazilian Portuguese. The researchers compared the two translated versions to Brazilian Portuguese to obtain the Consensual Version in Brazilian Portuguese PAINAD, the PAINAD-VCP. This comparison aimed to facilitate the conceptual and literal translation simultaneously and to guarantee the better signification of words in Brazilian Portuguese language. The three PAINAD-VCP back-translations to English presented high similarity with the original PAINAD instrument in English.

The back-translations and the PAINAD-VCP were sent to the committee composed by six specialists, a fundamental step considered important to obtain an instrument contemplating all characteristics from the original instrument adapted to the inserted culture. Two physiotherapists, two nurses, one neurologist physician and one psychologist professor master in Linguistic composed the committee.

In accordance with the decisions made by the specialists committee, there were modifications in the PAINAD-VCP, prioritizing the terms significance and guaranteeing the semantic, idiomatic, experimental and conceptual equivalence of the adapted instrument. Some words were substituted by its synonym and some items were grammatically adapted, without altering its meaning, to obtain a more adequate and comprehensible item.

The Content Validity Index, the absolute number and the percentage, obtained by an agreement analysis between specialists in the 75 items – the first 40 are referred to items in the scale relate to pain behavior analysis and 35 items revised related to the scale items definitions – those are presented in Table 1.

Table 1 – Content Validity Index (IVC), Absolut number of items (n) and the equivalent percentage – Brazil, 2013

IVC	N	%
1	46	61.3%
0.83	16	21.3%
0.67	7	9.3%
0.5	4	5.3%
0.33	2	2.7%
Total	75	100%

We can observe in Table 1 the proportion of agreement in the results between specialists: 83% (62) of items presented IVC ≥ 0.75, that is, content equivalence was reached and 17% (13) of items presented IVC ≤ 0.75, not needing a review and following the suggestions formulated by the judges to reach a consensus. After meticulous analysis done by the researchers a pre-final PAINAD version was obtained in Portuguese; denominated *Escala de Avaliação de Dor em Demência Avançada – PAINAD-Br*.

The three back-translations were independently analyzed by specialists, who chose the items with identical words or the closer word to the original version, that is, those that presented the highest semantic equivalence with the constructs from the original PAINAD version.

The pre-final PAINAD-Br was submitted to pre-test after the analysis of specialists as mentioned in the method session, consisting in its application by 27 health specialists who observed patients with a medical diagnose of severe dementia and evaluated them regarding pain presence and intensity.

The PAINAD-Br application task was done in two different moments. The patients were observed when daily basic care was being conducted and others, while resting. The distribution of patients observed during the application of the PAINAD-Br scale by the health professionals is demonstrated in the Table 2. Professionals assessed the patients for 5 minutes and the time to fill in the PAINAD-Br scale was an average of 2 to 3 minutes.

In all observation moments, all patients presented values indicating mild to severe pain intensity, that were detected by the PAINAD-Br scale.

Table 2 – Characteristics regarding the gender and age of assessed patients, as well as the condition in the moment of observation, associated pathologies and pain intensity in accordance with the PAINAD-Br – Brazil, 2013

Gender	Years	Conditions in the moment of observation	Associated pathology	Pain intensity with PAINAD
F	94	Resting	Renal failure	MILD
F	88	Resting	Skin cancer	MILD
M	81	Resting	Dehydration	MILD
M	66	Resting	Dehydration	MILD
M	76	Resting	None	MILD
M	70	Resting	Pneumonia	MILD
F	82	Resting	Stroke + Acute Pulmonary Edema	MODERATE
F	86	Resting	Infected ulcers	MODERATE
M	67	Resting	Down Syndrome + Urinary tract infection	MODERATE
F	86	Resting	Infected ulcers	MODERATE
F	85	Resting	Abdominal pain	SEVERE
F	81	Resting	Femur fracture	SEVERE
M	84	Receiving hygiene care	None	MILD
F	92	Receiving hygiene care	Stroke	MODERATE
F	93	Receiving hygiene care	Respiratory insufficiency	MODERATE
F	85	Receiving hygiene care	Abdominal pain	MODERATE
F	86	At dressing change	Infected Ulcers	MODERATE
M	84	Transferring to bed	None	MODERATE
F	85	Aspersion bath	Abdominal cancer	SEVERE
F	82	Aspersion bath	Stroke + Acute Pulmonary Edema	SEVERE
F	86	Aspersion bath	Infected Ulcers	SEVERE
F	77	Aspersion bath	Gluteal Abscess	SEVERE
F	78	Aspersion bath	Pulmonary cancer	SEVERE
M	72	Motor physiotherapy	None	MODERATE
F	66	Motor physiotherapy	Stroke	MODERATE
F	91	Respiratory physiotherapy	Pneumonia	MODERATE
F	86	Respiratory physiotherapy	Infected ulcers	SEVERE

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Table 3 refers to the analysis of the general comprehension questionnaire of the scale. The PAINAD-Br was considered very good and easy to comprehend, with no difficulties to apply and with very important questions to assess pain by the professionals of different categories.

When the professionals answered the specific instrument that constitutes the group of items of the scale to evaluate clarity of those, no difficulties were observed between nurses. From the nursing technicians, one of them (33.3%) presented difficulty in one item related to breathing *Cheyne-Stokes respiration*, however, he understood after reading the item definition proposed by the scale. The item related to negative vocalization *None is characterized by speech or vocalization that has a neutral or pleasant quality* generated doubts for a nursing technician (33.3%), who could not differ speech from vocalization. In this case, the researcher needed to explain the significance of vocalization, which is the action of producing voice without pronouncing words.

Table 3 – Results from the professionals' evaluation, interviews regarding clarity of the scale PAINAD –Br – Brazil, 2013

Item	Response Alternatives	Nurses (n=9)	Nursing Technicians (n=9)	Physiotherapists (n=9)
What do you generally think about our questionnaire?	*Very good* *Good*	77.8% 22.2%	88.9% 11.1%	77.8% 22.2%
Are the questions comprehensive?	*Easy to understand* *Difficult sometimes*	88.9% 11.1%	77.8% 22.2%	100%
Did you have any difficulty to apply it?	*None* *Some difficulties*	100%	88.9% 11.1%	100%
Are the questions important to assess the patient's pain?	*Very important*	100%	100%	100%

In a similar way, the item referred to facial expression *facial grimacing*, one physiotherapist (33.3%) initially considered it not clear and after reading its definition, it became comprehensible. In the definition of the item referred to body language *pulling or pushing away is characterized by resistiveness upon approach or to care*, one physiotherapist (33.3%) reported the term *trying to escape abruptly* as not clear and suggested to change it by *to become free quickly*. This way, *trying to escape abruptly* was substituted by its synonym *to become free quickly*.

This step aimed to evaluate clarity and comprehension of each item and its definitions and register suggestions for the difficulties presented regarding the items comprehension. After analyzing the results from this step, the changes to adequate the instruments to a higher level of comprehension were done. From that, the final version of PAINAD- Br was originated (Chart 1).

Chart 1 – Final version of the scale "Avaliação de Dor em Demência Avançada PAINAD-Br". - Brazil, 2013.

ESCALA DE AVALIAÇÃO DE DOR EM DEMÊNCIA AVANÇADA – PAINAD-Br				
Instruções: Observe o paciente por cinco minutos antes de pontuar os comportamentos dele ou dela. Pontue os comportamentos de acordo com a tabela a seguir. As definições de cada item são fornecidas na página seguinte. O paciente pode ser observado em diferentes condições (por exemplo, em repouso, durante uma atividade agradável, durante recebimento de cuidados, após receber medicação para dor).				
Comportamento	0	1	2	Pontuação
Respiração Independente de vocalização	• Normal	• Dificuldade ocasional para respirar • Curto período de hiperventilação	• Respiração ruidosa e com dificuldades • Longo período de hiperventilação • Respiração Cheyne-Stokes	
Vocalização negativa	• Nenhuma	• Resmungos ou gemidos ocasionais • Fala baixa ou em baixo tom, de conteúdo desaprovador ou negativo	• Chamados pertubadores repetitivos • Resmungos ou gemidos altos • Choro	
Expressão facial	• Sorrindo ou inexpressiva	• Triste • Assustada • Franzida	• Careta	
Linguagem corporal	• Relaxada	• Tensa • Andar angustiado/aflito de um lado para o outro • Inquietação	• Rígida • Punhos cerrados • Joelhos encolhidos • Puxar ou empurrar para longe • Comportamento agressivo	
Consolabilidade	• Sem necessidade de consolar	• Distraído(a) ou tranquilizado(a) por voz ou toque	• Incapaz de ser consolado(a), distraído(a) ou tranquilizado(a)	
				Total
Pontuação: O total de pontos varia de 0-10 pontos. Uma possível interpretação da pontuação é: 1-3=dor leve; 4-6=dor moderada; 7-10=dor severa. Estas variações são baseadas numa escala padrão de dor de 0-10, mas não foram comprovadas na literatura para essa avaliação.				

DISCUSSION

Pain is not understood as a simple sensation as it used to be; today, it is recognized as a very complex sensorial experience, modified by memory characteristics, expectations and emotions of each person. The difficulties to assess pain is believed to come from subjective characteristics of the painful phenomenon, specifically in situations with cognitive alterations, once an adequate assessment requires the individual to remember and share situations of pain already experienced, requiring preserved cognitive functions to verbalize, for example, the pain location, intensity and other characteristics[2].

Therefore, the pain assessment in elderly is considered a challenge to nursing professionals with the compromise to diagnose and intervene for its relief. For that, tools to help in this complex process are indispensable, as the algic phenomenon assessment[6]. Scales to observe the patient behavior as the facial expression, the body language and vocalizations when pain is present, seems to be the best strategy and an interesting and trustful technique to detect pain in patients with severe dementia[5].

The measurement instruments are key elements to refine the communication between those who feel and those who treat the pain. The success to evaluate pain in elderly with dementia is evidently dependent from the implementation of an assessment tool adequate for this population[6].

Studies showed the PAINAD instrument as clinically useful and trustful to measure pain from observed behavior expressing pain and it can be used by professionals of different levels of background after an adequate training to use the scale. The PAINAD scale was also translated and validated in other languages as German[26], Dutch[27], Chinese[28],

Italian[29] and Portuguese from Portugal[30]. In all versions it seemed to be an instrument with high correlation and adequate levels of construct validity and internal reliability.

As mentioned before, few are the instruments to assess pain in elderly with severe dementia, adapted and validated to Brazilian Portuguese. However, to translate the original instrument from one language to another culture is not enough; it needs to be culturally adapted to the target population and for this reason, it should follow a methodological rigor with criteria to keep equivalence within the original and new language adapted version.

CONCLUSION

The PAINAD instrument was adapted to the Brazilian culture. The application of the instrument to assess pain in people with severe dementia allows the improvement of their quality of life, providing an offer of humanized care once the pain can be detected and managed adequately.

The results from this study demonstrates that PAINAD –Br version kept the semantic, idiomatic, conceptual and cultural equivalence, following the evaluation from the specialists' committee and by the participation of health professionals, confirming the face and content validity of the instrument.

Studies of construct validity and reliability that evaluates the psychometric properties of the instrument are needed; so the PAINAD-Br instrument can be available in the Brazilian culture and it can be used by Brazilian researchers for studies of pain assessment in people with severe cognitive impairment, as well as to be implemented in the daily practice of health professionals for an adequate pain management.

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