

Translation and cross-cultural adaptation of the Meta instrument with 7 items to assess the pain intensity in dementia: “Pain Intensity Measure for Persons with Dementia – PIMD”

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Abstract

Background: Pain is prevalent among the elderly including those with dementia and there is still a need to evaluate the pain in those individuals by practical and trust worthy forms and also to evaluate the pain according its intensity. The PIMD is a meta instrument very recently proposed for this situation.

Materials and Methods: Methodological study of translation and cross-cultural adaptation of measurement tool following some steps: 1) translation; 2) back-translation; 3) evaluation by a committee of specialist; 4) pre-test.

Results: The PIMD was translated and adapted to Brazilian Portuguese and observed appropriate semantic, idiomatic, experiential, cultural and conceptual equivalences. In a pre-test involving 20 elderly with moderate to severe dementia and some potential cause of pain the PIM-P was applied and obtained good interpretations of its.

Conclusion: A Brazilian Portuguese version of PIMD have been adequately translated and adapted cross-culturally.

Key words: elderly, dementia, pain, measurement tools

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I. Introduction

Pain is a highly prevalent condition in the elderly population including those with dementia and difficulties to communication. And is considered a problem to determine presence of pain in elderly with difficulty in expressing it. Some studies involving this condition are still scarce.¹

The evidences have shown a high prevalence of pain in elderly people with dementia (around 50% in some studies) and with no significant differences between the subtypes of the dementia.^{2,3}

When observed no analgesic treatment, the pain causes important consequences, especially in demented individuals, such as depression, anxiety, delirium, sleep disorder, and others. Thus, to identify and to treat these are essential to keep them minimally comfortable, besides bringing benefits in quality of life and functionality.^{4,5} The moderate to advanced dementia of various etiologies seem to compromise the ability to interpret and express symptoms, which often makes pain a condition rarely diagnosed and treated in these population.^{5,6} No recognition of pain and no analgesic treatment for that condition are related to inadequate evaluations.⁷

In individuals with moderate to advanced dementia the assessment of pain to require auxiliary methods like to observe behaviors suggestive of pain, like facial expression, body language and vocalization, among others.^{7,8}

Constructs to assess pain in dementia have been widely described and utilized.⁵ And these specific constructs are also available in Brazil, such as PACSLAC-p, PAINAD-p and PATCOA.⁹⁻¹² However, these are not so practical and also, these were not proposed principally for measure the intensity of pain.

The adequate assessment of pain in individuals with difficulties to communication imply direct observation of some behaviors.¹³ Despite the variety of tools available to such situations, all those involving to observed behaviors, have not yet been so well defined the foremost behaviors suggesting presence of pain, and also a few tools have been proposed to evaluate its intensity. The constant observation the behaviors in several constructs led recently to creation, in North America, of a meta-instrument (“evaluation of evaluations of

instrument”) to assess and measure the pain in the dementia: the "Pain Intensity Measure for Persons with Dementia – PIMD".¹⁴ This instrument was developed in 2018 aiming to simplify the use of a clinical instrument for assessing pain in patients with advanced dementia through the observation of signs that suggest the presence of pain. The development of the PIMD involved a Delphi consensus and psychometric evaluations that involved the identification and compilation of items of behavioral observation instruments, pre-existing, for dementors. This construct includes seven items identified as better clinically correlated with pain intensity in the presence of the cognitive impairments.¹⁵

The aim of the present study was to translate and to adapt cross-culturally for the Brazilian Portuguese the PIMD.

II. Material and Methods

Methodological Study of translation and cross-cultural adaption following the Guillemin's proposal (1993).¹⁶ Initially, the authorization of the author of the original PIMD was requested and obtained. After, a sequential steps were followed: 1) translation; 2) back-translation; 3) evaluation by an experts's committee (composed by 5 expertises); 4) pre-test.

First step: translation

The translation into BrazilianPortuguese was realized by two independent and qualified translatorsselected according to indications and curriculum analysis, and chosen those with experience with translations and/or related area training. The translated terms were analyzed according to the best meanings in Portuguese of Brazil and obtained by theresearchers in this study a consensual synthesis for only one translated form.

Second step: back-translation

The back-translation step followed are-translation into the English language (original language) by a native English teacher who has a good connoisseur of the two languages: English and Portuguese. This professional did not participate in the initial stage of translation and was not aware of the purpose of the translation. Then, the back translated form was compared with original instrument in English to verified possible divergences.

Third Step: evaluation by a experts committee

Experts from different health areas and presenting good experience in management of pain in the elderly people was invited to compose a committee to judge the processes involved in this study, i.e judged whether the final version of the translation was understandable for use by health professionals in Brazil, considering cultural aspects. These experts had at least five-years of experience in assessment and clinical interventions in the field of gerontology.

The multidisciplinary and multiprofessional committee presented knowledges in geriatrics and pain, and were from different specialties: geriatrics, neurology, physiotherapy, psychology and nursing.

Its were intended to obtained a content validity. This validity indicate different cultural perceptions for certain items.

This process was completed in two meetings lasting approximately two hours each. A minimum interrater agreement of 80% was required

Fourth step: pre-test

A pre-test allows to evaluate possible errors in the translation as well as ease and feasibility of applying the instrument. Also, information on the interpretations of the items can be obtained.

It was select a convenience sample, a type of non-probabilistic sampling which depends on the collection of data from individuals conveniently available to participate in the study. For this process,selected outpatientsfrom unit of a public hospital in the city of Sao Paulo, being these dementors of any etiologies and in moderate to advanced stages according to the "Clinical Dementia Rating" (CDR), and being these presenting some potential pain.^{17,18}

Some health professionals were invited to participate in the pre-test, a total of 8 individuals, being 5 geriatricians and 3 professionals specialized in gerontology (1 nurse; 1 physiotherapist; and 1 social worker). These observed the aged participants for about 5 minutes, at rest and when a potential movement for their pain was triggered; and then, a given intensity score was applied for each item of the instrument (possible range: 0 - 21), with higher scores indicating greater pain intensity: a rater scores each item on a 0 (behavior not observed) to 3 (severe) scale of intensity.

To an additional evaluation, those profissionals invited to applied the PIMD-p answered a questionnaire about the clarity of the instrument under test and its practicality.

Here, its were intended to obtain the face validity evaluation according to the opinion of various experts. The number of participants in face validity tests is usually less than 20 people.

This study was approved by an Ethics Committee following good practices in clinical research (CAAE 43324221.2.0000.5505). All participants responsible signed a “Informed Consent Form”.

III. Results

Appropriate equivalences between the original and translated versions were achieved in the process of translation and cross-cultural adaptation of PIMD by the invited committee following the aspects: 1-Semantic (evaluates the vocabulary and grammar of each item); 2-Idiomatic (verifies the equivalence of colloquial expressions after translation); 3-Cultural (considers culture, contextualization, and experiences lived by the target population in the cultural context of the country; 4-Conceptual (words and concepts, and points out whether some of them could be equivalent in terms of meaning, but different in terms of the concept).

After the process above, it were obtained a tool henceforth entitled "Pain intensity assessment for people with dementia-Brazilian Portuguese – PIMD-p" (Fig. 1).

To the pre-test phase, 20 elderly people were evaluated, mean age of 77.3 years and majority male (67%).

According to the etiology of dementia mostly Alzheimer disease (n=18), and according to the staging of dementia by the CDR classification a majority CDR 2 (n=16), thus a sample demented elderlies in moderate phase.

The professionals who applied the instrument had no maked any suggestions to PIMD-p and had declared it a very simple and practical, which requires only a short time to apply (maximum 5 minutes). Those professionals judged the items of PIMD-p very clear.

Thus, obtained an instrument with adequate “content validity” to referring PIMD-p to be representative related to cultural aspects. And also, obtained a “face validity” to referring judgement by a committee about the PIMD-p to measure what was proposed to measure. In other words, observed good equivalence between the original English version and the final version and the Brazilian version following the cross-cultural adaptation process.

Figure 1. PIMD original version x PIMP-p Brazilian Portuguese version

Behavior, with Description	PIMD original version				
	Intensity of Behavior				
	Absent	Mild	Moderate	Severe	Not Applicable
1.Bracing: applying weight unevenly to relieve pressure from one body part by taking more weight onto another body part	0	1	2	3	N/A
2.Rigid or stiff body or body part (including rigidity and stiffness related to contractures)	0	1	2	3	
3.Sighing: exaggerated exhale that you can hear, usually accompanied by shoulders rising and falling	0	1	2	3	
4.Complaining: verbally expressing dissatisfaction, grumbling	0	1	2	3	
5.Grimacing: distressed or distorted appearance that involves 1) furrowed brow and/or narrowed or closed eyes AND 2) one or more of the following: a) tightened lips, b) corners of the mouth pulled back, c) nose wrinkling, d) cheeks raised	0	1	2	3	
6.Frowning: increased facial wrinkling in the forehead and/or eyebrows lowered/pulled together; may also be present: downward turn of the corners of the mouth; other mouth positions are not consistent with frown (e.g., smiling, grimacing)	0	1	2	3	
7.Expressive eyes: eyes are open wide or bulging; eyebrows are lifted high; eyes are narrowed or squeezed shut	0	1	2	3	

PIMD-p Brazilian Portuguese version

Comportamento com Descrição	Intensidade do Comportamento				
	Ausente	Leve	Moderada	Intensa	Não Aplicável
1. Posicionamento: aplicar o peso de forma desigual para aliviar a pressão de uma parte do corpo, levando mais peso para outra parte.	0	1	2	3	N/A
2. Corpo ou parte dele rígida ou tensa (incluindo rigidez ou tensão relacionadas a contraturas).	0	1	2	3	
3. Suspirando: expiração exagerada e audível, geralmente acompanhada pela elevação e abaixamento dos ombros.	0	1	2	3	
4. Reclamando: expressar verbalmente a insatisfação. Resmungar.	0	1	2	3	
5. Fazendo careta: semblante aflito ou distorcido que implica: 1. Sobrancelhas franzidas e/ou olhos entreabertos ou fechados E 2. Um ou mais dos seguintes: a) Lábios apertados; b) Cantos da boca puxados para trás; c) Nariz franzido; d) Bochechas levantadas.	0	1	2	3	
6. Franzindo a testa: enrugamento da testa e/ou sobrancelhas caídas/ juntas; podem também estar presentes: cantos da boca para baixo, outras posições da boca não consistentes com franzimento (sorriso, careta).	0	1	2	3	
7. Olhar expressivo: olhos bem abertos ou arregalados; sobrancelhas levantadas; olhos entreabertos ou bem fechados.	0	1	2	3	

IV. Discussion

It is very important to choose measure instruments appropriate for certain populations and for certain pathologies. The PIMD is a very recent meta-instrument developed and others studies about it has not yet been found in the literature. The present study is the first to translate the PIMD and adapt it culturally for other language.

Studies involving process of translation and adaptation cross-cultural of measure instruments have epidemiological relevances.¹⁹ These processes are faster, cheaper and more efficient than to develop a new one, and yet provide data to comparisons from different countries.²⁰

In this study it was followed the suggested steps to translation and cross-cultural adaptation of the PIMD according nationally and internationally recommendations.¹⁶ Here, it was considered adequate the translation and cross-cultural adaptation of the PIMD to Brazilian Portuguese. Equivalences semantic, idiomatic, conceptual and cultural were achieved, hence reflects probably the quality of the final version of the PIMD to Brazilian Portuguese. Therefore, obtained a “content validity” for PIMD-p (according to the process of cultural adaptation) and a “face validity” (according to the judgement by committee of experts).

A pre-test allowed to evaluating the adequacy in the way data is collected and to detect of problems related to the content, as is recommended.¹⁹ And this pre-test have also showed preliminary data. The professionals who applied the PIMP-p did no find difficulties or make questions about its interpretation, and considered it very easy and practical to apply.

As limitation in this study, verified that the size sample to pre-test step was small. Another study on PIMD-p will still be necessary involving larger sample and capable to provide others important psychometrics properties, such as reliability and reproducibility.

There is no recommended cutoff score for original PIMD so far, but it is suggested that the higher the score, the greater the possibility of pain being present and, perhaps, still being present at a strong intensity. Studies are necessary for such purposes

V. Conclusion

The PIMD-p was considered with adequate translation validity and cross-cultural adaptation for Brazilian Portuguese. The application of this to require a short time allowing the health professionals to evaluate the presence and intensity of pain in dementors in a practical way and better.

References

- [1]. Van Kooten J, Binnekade TT, Van der Wouden JC, Stek ML, Scherder EJA, Husebo BS, et al. A review of pain prevalence in Alzheimer's, vascular, frontotemporal and lewy body dementias. *Dement Geriatr Cogn Disord*. 2016;41(3-4):220-32.
- [2]. Hermans K, Cohen J, Spruytte N, Van Audenhove C, Declercq A. Palliative care needs and symptoms of nursing home residents with and without dementia: A cross-sectional study. *Geriatr Gerontol Int*. 2017;17:1501-07.
- [3]. Binnekade TT, Scherder EJA, Maier AB, Lobbezoo F, Overdorp EJ, Rhebergen D, et al. Pain in patients with different dementia subtypes, mild cognitive impairment, and subjective cognitive impairment. *Pain Med*. 2018;19(5):920-27.
- [4]. Van Dalen-Kok AH, Pieper MJ, de Waal MW, Lukas A, Husebo BS, Achterberg WP. Association between pain, neuropsychiatric symptoms, and physical function in dementia: a systematic review and meta-analysis. *BMC Geriatr*. 2015;15:49.
- [5]. Achterberg W, Lautenbacher S, Husebo B, Erdal A, Herr K. Pain in dementia. *Pain Reports*. 2020;5:e803.
- [6]. Bullock L, Bedson J, Jordan JL, Bartlam B, Chew-Graham CA, Campbell P. Pain assessment and pain treatment for community-dwelling people with dementia: a systematic review and narrative synthesis. *Int J Geriatr Psych*. 2019;34:807-21.
- [7]. Chow S, Chow R, Lam M, Rowbottom L, Hollenberg D, Friesen E, et al. Pain assessment tools for older adults with dementia in long-term care facilities: a systematic review. *Neurodegener Dis Manag*. 2016;6:525-38.
- [8]. Herr K, Zwakhalen S, Swafford K. Observation of pain in dementia. *Curr Alzheimer Res*. 2017;14(5):486-500.
- [9]. Lorenzet IC, Santos FC, Souza PMR, et al. Pain assessment in elderly with dementia: translation and cross-cultural adaptation of the PACSLAC instrument into Portuguese. *RBM*. 2011;68(4):129-33.
- [10]. Thé KB, Gazoni FM, Cherpak GL, et al. Pain assessment in elderly with dementia: Brazilian validation of the PACSLAC scale. *Einstein* 2016;14(2):152-57.
- [11]. Pinto MCM, Minson FP, Lopes AC, Laselva CR. Cultural adaptation and validation of the reproducibility of the Portuguese (Brazil) version of the Pain Assessment in Advanced Dementia (PAINAD-Brazil) pain scale in non-communicating adult patients. *Einstein* 2015;13(1):14-19.
- [12]. Saurin G, Crossetti, MGO. Reliability and Validity of the Pain Assessment instrument in Confused Elderly - IADIC. *Rev Gaucha Enferm*. 2013;34(4):68-74.
- [13]. Herr K, Zwakhalen S, Swafford K. Observation of pain in dementia. *Curr Alzheimer Res*. 2017;14(5):486-500.
- [14]. Ersek M, Herr K, Hilgeman MM, et al. Developing a pain intensity measure for persons with dementia: Initial construction and testing. *Pain Med*. 2019;20(6):1078-92.
- [15]. Ersek M, Neradilek MB, Herr K, et al. Psychometric Evaluation of a Pain Intensity Measure for Persons with Dementia. *Pain Medicine*. 2019;20(6):1093-104.
- [16]. Guillemin F, Bombardier C; Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature reviews and proposed guidelines. *J Clin Epidemiol*. 2013;46(12):1417-32.
- [17]. Hughes CP, Berg L, Danzinger WL, Coben LA, Martin RL. A new clinical scale for staging of dementia. *Br J Psych*. 1982;140:566-72.
- [18]. Montaña MB, Ramos LR. Validity of Portuguese version of Clinical Dementia Rating. *Rev Saúde Pública*. 2005;39:912-17.
- [19]. Alexander NMC, Coluci MZO. Content validity in the processes of construction and adaptation of measurement instruments. *Science. Public Health*. 2011;16(7):3061-68.
- [20]. Koller M, West K. Linguistic Validation Manual for Patient-Reported Outcomes (PRO) Instruments, By C. Acquadro, K. Conway, C. Girouard & I. Mear, MAPI Research Trust, Lyon, France, 2004, 184pp, ISBN: 2-9522021-0-9.

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