

Review Article

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Instruments for pain assessment in patients with advanced dementia: A systematic review of the evidence for Latin America

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Abstract

Objective. Pain treatment is an essential component of care for elderly patients with advanced dementia. The objective of this study was to identify and analyze the different scales used for pain assessment in elderly persons diagnosed with dementia, in the literature available at the Latin American level.

Method. A systematic review was performed on the existing scales for pain assessment in elderly people diagnosed with Alzheimer's disease, vascular dementia, and dementia with Lewy bodies.

Results. 226 articles were retrieved from the PUBMED, BIREME, and Scielo databases, of which a total of 10 articles entered the systematic review. The instruments identified in these publications were PAINAD, Abbey, McGill, and PACSLAC, while the Colored Pain Scale, Faces Pain Scale, and VAS scales were used as the silver standard. In Spanish, the Abbey scale, and in Portuguese, the PACSLAC scale showed the best reliability and validity coefficients.

Significance of results. It is concluded that there are only two appropriate scales for the assessment of pain in people with dementia in the region of interest of this study. It is recommended to generate more evidence for a more accurate assessment of pain in people with dementia.

Introduction

According to Ferri et al. (2005), it is estimated that there are 4.6 million new cases of dementia every year in the world (a new case every 7 s) and that the number of people affected will double every 20 years, reaching 81.1 million in 2040. The prevalence of dementia in people over 65 in developed countries is between 6% and 9%, while in Latin American countries, the prevalence ranges from 4% to 8% (Molero et al., 2007; Custodio et al., 2008). Latin American countries are not exempt from this epidemiological problem (Manrique Espinoza et al., 2013).

In elderly patients with dementia, pain is a frequent problem (Domenichiello and Ramsden, 2019), which produces alterations at the cardiovascular, muscular, skeletal, urological, metabolic, gastrointestinal, hepatic, endocrine, and central nervous system levels. Although described some years ago (Franco and De Lucas, 2001; Helme and Gibson, 2001; Jakobsson et al., 2003), research in this field in the Ibero-American region seems not to have made sufficient progress.

Pain perception is usually reported by most people who have both the physical and mental ability to communicate it; however, people who are disabled, due to whatever cause, may not be able to report their pain experience. In this regard, some authors (De Souza Rolim et al., 2014a) report that the inability of persons with advanced dementia to communicate and express themselves makes it difficult to correctly assess pain. Consequently, if there is no adequate treatment of pain, suffering that can be avoided for elderly people with dementia is generated (De Souza Rolim et al., 2014b; Papiol Espinosa and Abades Porcel, 2015).

Dementia is a chronic degenerative syndrome that produces a high degree of disability characterized by a severe cognitive deficit, loss of language, and the ability to perform activities of daily living (Herr et al., 2006). With the progression of dementia, an increase in comorbidities is observed, and in more advanced stages dementia itself is the main cause of pain. Based on advances in research, anatomical changes in different types of dementias could be verified to determine the degree of injury in areas of processing or transmission of pain (Kumar and Elavarasi, 2016).

Some authors (Scherder et al., 2003) have observed alterations in heart rate responses before, during and after venous puncture in elderly patients with altered cognitive abilities and in patients with dementia, which indicates the presence of alterations of emotional responses, as well as the evaluation of pain thresholds. They revealed no significant differences

in patients with dementia as compared to normal subjects, suggesting that the sensory-discriminative component of pain is preserved in dementia.

Several instruments (scales) have been described for the evaluation of pain in people with dementia (Zwakhalen et al., 2006), which nurses apply in clinical settings or in the home. However, the applicability of these scales (originally published in English) is not clear in Latin America, where Spanish and Portuguese are mainly spoken. With this basis, the objective of this study was to identify and analyze the different instruments used for the evaluation of pain in elderly people diagnosed with dementia in the Latin American region.

Methods

A bibliometric investigation was carried out adhering to the PRISMA guidelines for conducting systematic reviews. The question in this review was:

What instruments are currently used for pain assessment in elderly people diagnosed with dementia?

To identify the evidence, the PICOS structure was followed according to the following points:

- Patients: Alzheimer's, vascular dementia, dementia with Lewy bodies.
- Intervention: pain assessment.
- Comparison: patients without Alzheimer's diagnosis, vascular dementia, dementia with Lewy bodies.
- Outcomes: instruments for assessing pain in non-communicative patients, measures of validity and reliability.
- Studies (type of): quantitative studies, clinical trials, cases and controls, cohorts, cross-sectional studies.

The search was carried out in the PubMed, BIREME, and Scielo databases (the last two are the most important for the Latin American area). The references of the selected articles were also reviewed for an integral reading to include additional studies not indexed in these databases. The search strategies included the following keywords: pain, acute pain, chronic pain, palliative care, nursing assessment, pain measurement, dementia, Alzheimer's disease, vascular dementia, Lewy body disease, cognitive dysfunction, and frail elderly.

Studies that met the following criteria were included: (I) Quantitative studies, clinical trials, cases and controls, cohorts, cross-sectional studies; (II) Studies that included patients with Alzheimer's, vascular dementia, or dementia with Lewy bodies; (III) Published between 2012 and 2018; (IV) Published in English, Spanish, or Portuguese; and (V) Studies conducted in Latin American countries (Latin America, Spain, and Portugal). The exclusion criteria were (I) Non-availability of the full text and (II) Sample size smaller than 20 patients.

All references were managed with Mendeley® software. The selection of the articles began with the removal of duplicate articles, and proceeded with the reading of the title and abstract, carried out independently by reviewers 1 and 2. The final decision in cases of disagreement was based on the criteria of a third reviewer. In the second phase, the same reviewers read the full text of the studies to define which would be included for the extraction and synthesis of data. The data were stored in Microsoft Office Excel spreadsheets and organized in an instrument constructed by the authors considering: characteristics of the study (author, year, and country), characteristics of the patients (diagnosis,

ages, diagnostic instruments, and statistical analysis), and characteristics of the results (measures of reliability and validity).

The methodological quality of the studies was evaluated using the Mixed Methods Appraisal Tool (MMAT) version 2018 (Rostad et al., 2017; Hong et al., 2018; Tsai et al., 2018). All of the studies included were independently assessed by reviewers 1 and 2 (Table 1), based on the following criteria: (I) Is the sampling strategy relevant to address the research question? (II) Is the sample representative of the target population? (III) Are the measurements appropriate? (IV) Is the risk of nonresponse bias low? (V) Is the statistical analysis appropriate to answer the research question?

Quality, in terms of reliability and validity of the instruments located in the articles, was evaluated with the tool developed by Zwakhalen et al. (2006), which evaluates 10 criteria in each pain measurement instrument: (1) origin of the items; (2) number of participants; (3) content validity (the items cover all pain dimensions); (4) validity of criteria (uses a gold standard); (5) validity of construct I (in relation to another pain scale); (6) validity of construct II (difference between pain/no pain); (7) homogeneity (alpha Cronbach); (8) reliability between observers (correlation between observers); (9) test-retest reliability (test-retest correlation); and (10) applicability (practical, easy to apply). The total score can range from 0 to 20 points for each instrument used in each study.

The review protocol was registered on the PROSPERO platform (CRD42019133892).

Results

A total of 226 studies were retrieved from the databases. After the removal of 10 duplicates, 216 articles were read in the title and abstract, eliminating 193, resulting in 23 articles for full-text reading. Ten articles were finally included in the data extraction and synthesis of results (Figure 1).

In those 10 studies, four scales for pain measurement were identified: PAINAD, Abbey, McGill, and PACSLAC. Three other similar scales were used as a silver standard: Faces Pain Scale, VAS, and Colored Pain Scale. The languages used in the scales were Spanish (from Spain) and Portuguese (from Brazil and Portugal) (Table 2).

Among the characteristics of the studies included in the systematic review, the scale most utilized was PAINAD, which was included in five studies in its Spanish (Spain) and Portuguese (Brazil) versions (Batalha et al., 2012; De La Rica Escuin and González Vaca, 2014; Gallego Valera et al., 2014; García-Soler et al., 2014; Pinto et al., 2015). The Abbey scale was only used in Spain (Chamorro and Puche, 2013), while the PACSLAC and McGill scales were used only in Brazil (De Souza Rolim et al., 2014a, 2014b; Bezerra Thé et al., 2016). Some validation studies used an analogous scale, fulfilling the function of the silver standard for pain assessment; as there is no gold standard for pain diagnosis in persons who lack the ability to communicate their pain, such as in cases of dementia (De Souza Rolim et al., 2014b; García-Soler et al., 2014; Santos and Castanho, 2014; Bezerra Thé et al., 2016).

The studies that presented the most important samples were Chamorro and Puche (2013), with a sample of 119 patients older than 60 years of age with a diagnosis of Alzheimer's and vascular dementia in a hospital geriatric unit, and Santos and Castanho (2014) with a sample of 121 patients from Portugal

Table 1. Analysis of the quality of studies included in the systematic review using MMAT version 2018

Studies Authors	Screening questions		Quantitative studies				
	S1. Are there clear research questions?	S2. Do the collected data address the research questions?	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?
Batalha et al. (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Chamorro and Puche (2013)	No	Yes	Yes	Yes	Yes	Yes	Yes
García-Soler et al. (2014)	No	Yes	No	Yes	Yes	Yes	Yes
Pinto et al. (2015)	No	Yes	Yes	Yes	Yes	Yes	Yes
De La Rica Escuín and González Vaca (2014)	No	Yes	Yes	Yes	Yes	Yes	Yes
De Souza Rolim et al. (2014a)	No	Yes	Yes	Yes	Yes	No	Yes
Santos and Castanho (2014)	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes
De Souza Rolim et al. (2014b)	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes
Bezerra Thé et al. (2016)	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes
Gallego Valera et al. (2014)	No	Yes	Cannot tell	Cannot tell	Yes	Yes	Yes

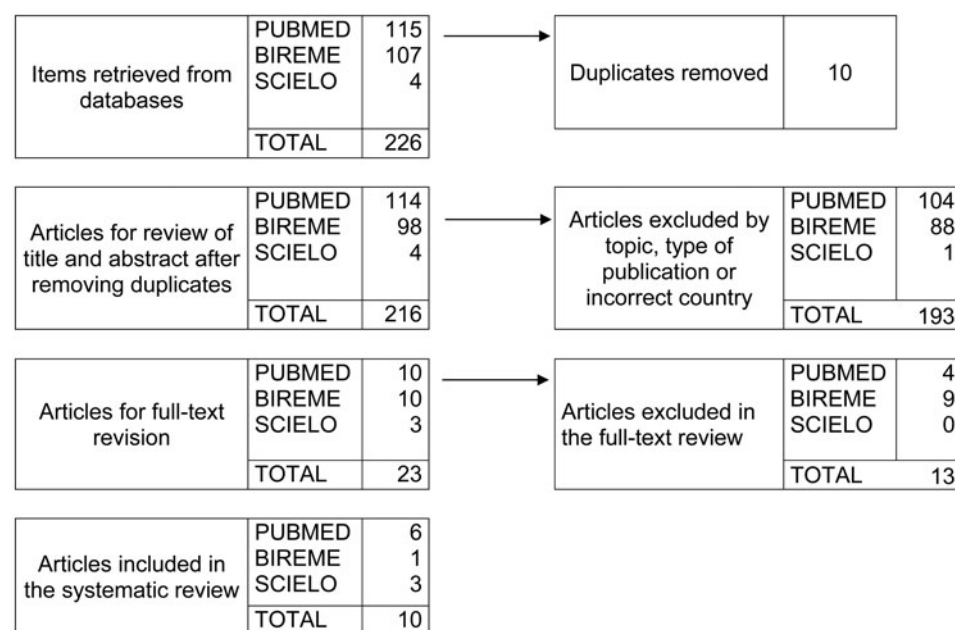


Fig. 1. PRISMA flowchart of the inclusion process in the systematic review.

Table 2. Pain measurement instruments identified in the reviewed studies

No.	Instrument	Author	Instrument language	Country
1	PAINAD	Batalha et al. (2012)	Portuguese	Brazil
		García-Soler et al. (2014)	Spanish	Spain
		Pinto et al. (2015)	Portuguese	Brazil
		De La Rica Escuin and González Vaca (2014)	Spanish	Spain
		Gallego Valera et al. (2014)	Portuguese	Brazil
2	Abbey	Chamorro and Puche (2013)	Spanish	Spain
3	McGill	De Souza Rolim et al. (2014a)	Portuguese	Brazil
		De Souza Rolim et al. (2014b)	Portuguese	Brazil
4	PACSLAC	Bezerra Thé et al. (2016)	Portuguese	Brazil
5	VAS	García-Soler et al. (2014)	Spanish	Spain
		De Souza Rolim et al. (2014b)	Portuguese	Brazil
		Bezerra Thé et al. (2016)	Portuguese	Brazil
6	Colored Pain Scale	Santos and Castanho (2014)	Portuguese	Portugal
7	Faces Pain Scale	Santos and Castanho (2014)	Portuguese	Portugal

Table 3. Main characteristics of the studies included in the systematic review

No.	Author	Instrument	Sample	Institution	Ages	Diagnosis
1	Batalha et al. (2012)	PAINAD	99	Two hospitals	≥65	Inability to self-report (with or without dementia)
2	Chamorro and Puche (2013)	Abbey	119	Geriatric unit in a hospital complex	≥60	Alzheimer's and vascular dementia
3	García-Soler et al. (2014)	PAINAD + VAS	20	Gerontological Center	≥66	Dementia Alzheimer's type in advanced stage, vascular, mixed or associated with Parkinson's disease
4	Pinto et al. (2015)	PAINAD	66	Israelite Hospital	20–104	Dementia and other diseases with an inability to self-report
5	De La Rica Escuin and González Vaca (2014)	PAINAD	20	Nursing home	≥70	Advanced dementia
6	De Souza Rolim et al. (2014a)	McGill	29	Clinical Hospital Sao Paulo	Not informed	Alzheimer's
7	Santos and Castanho (2014)	Colored Pain Scale + Faces Pain Scale	121	Hospital database of Portugal	Average 68.8 (SD 7.2)	60 with Alzheimer's, 61 with cognitive impairment
8	De Souza Rolim et al. (2014b)	McGill + VAS	59	USP Neurology Department	59–91	29 with Alzheimer's and 30 controls without Alzheimer's
9	Bezerra Thé et al. (2016)	VAS + PACSLAC	50	Israelite Hospital	≥60	Dementia of any type
10	Gallego Valera et al. (2014)	PAINAD	27	Long-Term Institutions	≥66	Severe dementia

diagnosed with Alzheimer's disease and cognitive impairment with a mean age of 68 years (Table 3).

Regarding reliability and validity indicators analyzed in each of the scales used by the 10 studies, it was identified that in Spanish, the Abbey scale shows the best validity and reliability coefficients, given that the study sample was large ($n = 119$); in Portuguese, the PACSLAC scale shows the best reliability and validity coefficients, although the sample was small ($n = 50$). The Abbey and PACSLAC scales obtained the best scores, as

both are multidimensional and have been developed specifically for patients with dementia who are unable to communicate (Table 4).

The PAINAD scale, although widely used, did not demonstrate adequate reliability and validity coefficients, in part because of the small sample numbers in the studies, and because it was not initially constructed for patients with the diagnoses of interest in the present study but was an adaptation of a previously existing scale (Batalha et al., 2012; Table 4).

Table 4. Characteristics of the scales used for pain measurement identified in the included studies

Scale	Author	Items	Scoring	Interpretation	Item Origin	Sample	Validity				Reliability			Total	
							Content	Criteria	Construct (with another scale)	Construct (differentiation)	Homogeneity	Between observers	Test-Retest		Applicability
Abbey	Chamorro and Puche (2013)	6	0–18	0–2 no pain, 3–7 light, 8–13 moderate, 14+ severe	2	2	2	0	2	2	2	1	0	2	15
PACSLAC	Bezerra Thé et al. (2016)	60	Not reported	Not reported	2	1	2	0	2	0	2	2	1	2	14
PAINAD	Batalha et al. (2012)	5	0–10	Higher values indicate greater pain intensity	1	1	1	0	0	1	2	2	0	2	10
	García-Soler et al. (2014)	5	0–10	Higher values indicate greater pain intensity	1	0	1	0	2	1	1	1	0	2	9
	Pinto et al. (2015)	5	0–10	Higher values indicate greater pain intensity	1	1	1	0	0	1	1	1	0	2	8
	De La Rica Escuin and González Vaca (2014)	5	0–10	1–3 (light), 4–6 (moderate), 7–10 (intense)	1	0	1	0	0	2	0	0	0	2	6
	Gallego Valera et al. (2014)	5	0–10	1–3 (light), 4–6 (moderate), 7–10 (intense)	1	0	1	0	0	2	0	0	0	2	6
McGill	De Souza Rolim et al. (2014a)	1	Not reported	Not reported	Not reported	0	0	0	0	1	0	0	0	0	1
	De Souza Rolim et al. (2014b)	1	Not reported	Not reported	Not reported	1	0	0	0	1	0	0	0	0	2
Colored Pain Scale	Santos and Castanho (2014)	1	0–10	0 no pain, 10 most severe pain	0	2	0	0	0	2	0	0	0	1	5
Faces Pain Scale	Santos and Castanho (2014)	6	0–10	0 no pain, 10 most severe pain	0	2	0	0	0	2	0	0	0	1	5
VAS	García-Soler et al. (2014)	1	0–10	0 no pain, 10 most severe pain	Not reported	0	0	0	2	1	0	0	0	1	4
	De Souza Rolim et al. (2014b)	1	0–10	0 no pain, 10 most severe pain	Not reported	1	0	0	0	1	0	0	0	1	3
	Bezerra Thé et al. (2016)	1	0–10	0 no pain, 10 most severe pain	Not reported	1	0	0	2	1	0	0	0	1	5

Discussion

The perception of pain is highly subjective; consequently, the assessment of pain by nurses becomes very complex in people with dementia. Some authors have identified barriers to pain management in people with dementia including lack of recognition of pain, lack of education or training, diagnostic failures, and lack of pain assessment tools, as well as mentioning the lack of evidence of these tools for pain assessment (Zwakhalen et al., 2006; McAuliffe et al., 2009). On the other hand, among the strategies that have been mentioned to overcome these barriers are knowing the person, education, or training and using the most appropriate tools for pain assessment and management (Franco and De Lucas, 2001; Herr et al., 2006; McAuliffe et al., 2009).

Following the review of the Latin American literature, reliability and validity coefficients of pain measurement scales were reviewed for patients meeting the criteria in this region. The most used scales were PAINAD, Abbey, McGill, and PACSLAC. As there was no gold standard for pain assessment, some studies chose to include analogous scales such as the Faces Pain Scale, VAS, and the Colored Pain Scale as a silver standard.

In practical terms, with the Abbey and PACSLAC scales that have been validated in this region, the nurse can perform a multidimensional assessment of pain in an average of 15 min, and training in the use of these scales requires only a few hours, and it has been suggested that family caregivers may also apply these scales to their relatives with dementia (Franco and De Lucas, 2001; Herr et al., 2006; McAuliffe et al., 2009; Chamorro and Puche, 2013; Montoro-Lorite and Canalias-Reverter, 2015; Papiol Espinosa and Abades Porcel, 2015; Bezerra Thé et al., 2016; Tsai et al., 2018).

In spite of this, the reliability and validity coefficients that these scales have exhibited in the analysis is not entirely convincing, as other authors have reported (Zwakhalen et al., 2006); the Abbey achieved 15 points out of a possible 20, and the PACSLAC achieved 14 out of 20 points. This implies that they cover 75% of the expectations in the analyzed coefficients, and consequently the overall quality of both scales could be substantially improved in future studies with larger samples and with complete validation studies that include test–retests.

Although the analogous scales in the reviewed studies were used only as a silver standard, it is not recommended at the international level that they be used for pain assessment in people with dementia if there are multidimensional scales, especially if family members are evaluating the pain of persons with dementia (Zwakhalen et al., 2006; Tsai et al., 2018).

Implications for nursing practice and research

The findings of this review have important implications for nurses in Latin America. Scientific production in this area of knowledge is in full growth in other regions of the world (Zwakhalen et al., 2006; McAuliffe et al., 2009; Kim et al., 2017; Tsai et al., 2018); however, in Latin America, it is necessary to increase the available evidence regarding pain assessment scales that are culturally sensitive.

The authors of the articles analyzed in this review have not described in depth about the cultural sensitivity of each instrument used in Latin America; nor does the scale developed by Zwakhalen have a dimension referred to the “cultural appropriateness” of pain assessment scales (Zwakhalen et al., 2006).

We consider that the cultural dimension in pain assessment is important because the symptoms referred by patients also reflect their cultural background. In some countries, it is considered that suffering pain in silence is a highly valued response, so some people consider it very acceptable not to express their pain (Jin, 2017). For example, it has been described that in Mexico (Nance et al., 2015), there are very particular ways of experiencing pain as something natural: “Pain is part of life. We always have had pain. Sometimes the doctors can help, sometimes not”, “We come into the world in pain and we leave it in pain”. This cultural dimension is a bit different in patients who do not have the ability to communicate pain since in those cases the people who assess the pain of the patients are nurses. Nurses, like patients, have learned about pain in childhood, as part of their socialization process. They have learned in society the ways of expressing their pain in “normal and right” ways (Narayan, 2010). As well as patients, health professionals, as social beings, also have their own cultural and ethnic background, which can lead to interpreting behaviors in the face of pain in a very particular way.

Finally, some authors affirm that in the multidimensional scales, such as Abbey and PACSLAC when administered by the nurse or by the relatives of the patients, cultural aspects should focus on the evaluator as much as on the patient himself (Narayan, 2010).

This increase in the available evidence should lead to an improved implementation of pain assessment and management for persons with dementia in clinical settings and in the home. Nurses have an important responsibility both in research and in practice; they should only apply scales that demonstrate reliability and validity in their own language. It is recommended that to measure and alleviate pain more accurately for patients with dementia in Spanish-speaking contexts, it is necessary to generate more evidence. Studies with samples of over 100 patients are needed with complete measurements of reliability, validity, and test–retest.

Conclusions

It can be concluded that four scales validated in Spanish or Portuguese were identified in two countries (Spain and Brazil). In Spanish, the Abbey scale shows the best reliability and validity coefficients, with a significant sample; in Portuguese, the PACSLAC scale shows the best reliability and validity coefficients, although with a small sample. Abbey and PACSLAC are multidimensional scales that have been developed specifically for patients with dementia.

Author contribution. All authors (S.M.C. and R.A.A.Z.) developed the research project, performed data collection, analyzed and interpreted the results, and wrote the article. All authors reviewed and approved the final version.

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Authorship declaration. All of the authors have contributed to this study in terms of its design, participated in the data collection, analysis and interpretation of the results, and are responsible for the content and writing of the paper.

Authorship statement. All authors meet the criteria according to the latest guidelines of the International Committee of Medical Journal Editors and agree with this manuscript.

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