Development and Psychometric Evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale

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Objectives: To develop a clinically relevant and easy to use pain assessment tool for individuals with advanced dementia that has adequate psychometric properties.

Design: Instrument development study using expert clinicians and behavioral observation methods. Measurement of sensitivity of the instrument to detect the effects of analgesic medications in a quality improvement activity.

Setting: Inpatient dementia special care units in a Veterans Administration Medical Center.

Participants: Nineteen residents with advanced dementia who were aphasic or lacked the ability to report their degree of pain and six professional staff members. Additionally, data from medical records of 25 residents who were receiving pain medications as required (PRN) were collected.

Measurements: Based on the literature review, related assessment tools and consultation with expert clinicians, a five-item observational tool with a range of 0 to 10 was developed. The tool, Pain Assessment in Advanced Dementia (PAINAD), was compared with the Discomfort Scale and two visual analog scales (discomfort and pain) by trained raters/expert clinicians in the development study, and used for detection of analgesic efficacy in a quality improvement activity.

Results: Adequate levels of interrater reliability were achieved between dyads of the principal investigator with each clinical research rater and between two raters. PAINAD had satisfactory reliability by internal consistency with a one factor solution. PAINAD and the Discomfort Scale–Dementia of Alzheimer Type (DS-DAT) were significantly correlated, providing evidence of construct validity. PAINAD detected statistically significant difference between scores obtained before and after receiving a pain medication.

Conclusions: The PAINAD is a simple, valid, and reliable instrument for measurement of pain in noncommunicative patients. Since the patient population used for its development and testing was limited to a relatively small number of males, further research is needed before it can be universally recommended. **(J Am Med Dir Assoc 2003; 4: 9–15)**

Keywords: Alzheimer's disease; pain; assessment; dementia.

Pain in elderly nursing home residents is a prevalent problem, estimated to occur in 26 to 83% of residents.[1–5] Many residents have several diagnoses that may be directly related to pain, such as degenerative arthritis and diabetic neuropathy.[6,7] The cognitively intact elderly often underreport pain, believing that pain goes along with aging. Reported pain is often dismissed with statements such as "What do you expect at your age?"[8] Because pain is underreported, it is frequently undertreated in the elderly.[9] This attitude and acceptance of pain as a consequence of aging may lead to less pain assessment in general[8] and even less treatment of pain in those cognitively impaired elders who cannot self-report pain.[10]

The importance of pain detection and treatment was recognized in several reports and practice guidelines.[11,12] Untreated pain can cause secondary symptoms of sleep disturbance, weight loss, and depression. In cognitively impaired individuals, pain can manifest itself as agitation, increased confusion, and decreased mobility. Untreated pain increases disability, and decreases quality of life.[8]

Readily understandable, accurate, and easy for the elderly to use scales are available for measuring the degree of pain .[2,4,8] However, identifying and measuring pain in the most cognitively impaired elders has remained difficult. Most pain scales rely on self-report.[13,14] In the early stages of dementia, visual analog scales have been used to accurately report levels of pain.[15] By the mid-stage of dementia, due to

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loss in abstract reasoning, the concept of the scales is often not understood.[15,16] Although all reports of pain, even in the cognitively impaired, should be taken seriously,[9] individuals with advanced dementia are unable to comprehend and therefore unable to use even the simplest of these scales for pain measurement.[17] In the most advanced stage of dementia, individuals are nonverbal and unable to report pain.[18]

The need for an easy to use, valid and reliable pain assessment tool for the advanced dementia population has been discussed in the literature.[5,9] Several research scales exist, for example the Discomfort Scale for Dementia of the Alzheimer Type (DS-DAT),[17] but these tools require more training time than is realistic for clinicians in long-term care or have cumbersome scoring schema. DS-DAT was adapted and included in an Assessment of Discomfort in Dementia Protocol,[19] but this modified assessment does not provide a quantitative evaluation of pain severity. A Checklist of Nonverbal Pain Indicators (CNPI) was developed and showed good interrater reliability.[20] However, the six items in this checklist are scored only for presence and absence, and their simple presence may not reflect the actual pain severity. The score of CNPI is 0 to 6 and does not compare readily with other scales measuring pain that express the severity of pain on the scale from 0 to 10. Similarly, a proxy pain questionnaire (PPQ) assesses global presence, frequency, and intensity of pain and does not provide a simple overall score.[21] For these reasons, we decided to develop a tool for measuring pain in noncommunicative individuals that would be simple to administer and had score from 0 to 10.

METHODS

Design

The Pain Assessment in Advanced Dementia (PAINAD) scale was developed after extensive review of the literature and available pain assessment tools. PAINAD is based on categories and behaviors from the Face, Legs, Activity, Cry, Consolability Scale (FLACC),[22] the DS-DAT,[17] and descriptions of pain taken from the literature and cited by experienced dementia care clinicians.

Study Population

The projects were carried out on a Dementia Special Care Unit (DSCU) where 96 in-patients receive care for dementia. The research project was approved by the hospital's Institutional Review Board, and consent to participate was obtained from the surrogate decision maker who had the authority to make a research decision for the veteran. Inclusion criteria included: (1) diagnosis of dementia written on the medical record, (2) no planned discharge, (3) inability to report pain or discomfort to caregivers, and (4) a proxy decision maker identified in the medical record.

The principal investigator (V.W.) presented the study at informal educational meetings held for staff and separate meetings for families. Signed informed consent was obtained on behalf of the first 20 veterans (no refusals) whose family decision maker was approached by V. W. One veteran died before data collection, and a second died before the third observation was conducted. Analyses were conducted on data from the 19 participants.

In addition, data were collected from charts of 25 participants of an ongoing quality improvement project, "Take 5: Pain the 5th Vital Sign." No quantitative demographic or disease characteristics are available on those 25 patients. However, patients were included in the quality improvement project if they had severe dementia, could not report pain, and received a medication to treat pain symptoms. Analgesic administration was precipitated by clinical evaluation indicating presence of pain, and the most commonly used analgesics were acetaminophen and morphine.

Instruments

Overall dementia disease severity was determined by scores on scales: the Mini Mental Status Examination (MMSE)[23] ($\alpha = 0.92$), and Bedford Alzheimer Nursing Severity Subscale (BANS-S)[24] ($\alpha = 0.80$). Each scale was administered to each participant a week preceding testing of the PAINAD. A member of the research team administered the MMSE, and a member of the nursing staff who had first-hand knowledge of the veteran completed the BANS-S scale. Demographic information was abstracted from the veteran's medical record.

One visual analog scale (VAS) was present on both the DS-DAT and the PAINAD forms. On the PAINAD form it consisted of a 10-cm line, labeled "no pain," (0), on the left and "severe pain," (10), on the right. On the DS-DAT form, the 10-cm VAS was labeled "completely comfortable" on the left and "extremely uncomfortable" on the right. The rater was asked to mark the point on the line that he or she felt best indicated the degree of pain or discomfort the person being observed was experiencing. Raters completed the VAS at the same time that the PAINAD or DS-DAT was done.

Procedure

Initially, three licensed practical nurses and two nursing assistants assisted in the pilot testing by administering an early version of the PAINAD scale concurrently with the principal investigator. Scores were compared and rationales for scoring each category were discussed. Expert professional nurses with extensive experience on the DSCUs provided additional input regarding clarity of items and ease of using the PAINAD. Several areas of confusion were clarified, and definitions were revised accordingly. For instance, the insertion of "independent of vocalization" into the *Breathing* item helped to differentiate *Breathing* from *Negative Vocalization*, and "low level speech with a negative or disapproving quality" was added to *Negative Vocalization* to encompass a number of unpleasant or offensive words and speech patterns. The final version of the PAINAD and accompanying item definitions with behavioral descriptors was completed (Appendix).

To evaluate the PAINAD's psychometric properties, the research team expanded to include four experienced DSCU professional nurses and a master's level social work intern (K.S.). V.W. and K.S. developed a training program using archival footage from previous instrument development projects to measure discomfort,[17] agitation,[25] and resistiveness.[26] V.W. wrote a 2-hour curriculum and oriented raters

Table 1. *Descriptive Data on PAINAD**

Data Source and Patient Condition		Descriptive Data				
Project/Rater	**Observational Condition**	**Total Observations (n)**	**Observations when PAINAD = 0**	**Median**	**Mean (SD)**	**Cronbach's alpha**
Research	No stimulation	19	7	1	1.3 (1.3)	.57
Research/1	Pleasant or rest	18	9	0.5	1.0 (1.3)	.59
Research/2	Pleasant or rest	18	10	0	1.0 (1.3)	.63
Research/1	Unpleasant	19	1	3	3.1 (1.7)	.50
Research/2	Unpleasant	19	1	4	3.5 (2.1)	.67
Research	All conditions	93	28	2	2.1 (2.0)	.72
Quality improvement	Pre pain medication	25	0	7	6.7 (1.8)	.30
Quality improvement	Post pain medication	25	10	1	1.7 (2.2)	.80
Quality improvement	All conditions	50	10	4	4.3 (3.2)	.83

*PAINAD = Pain Assessment in Advanced Dementia Scale.
Total of 19 patients was included in the research study and 25 patients in the quality improvement activity.

who memorized the items and behavioral definitions and scored training tapes until each rater's PAINAD scores agreed with those of V.W. Because the DS-DAT was designed for research and requires extensive training to be used accurately[17] and familiarity with the tool improves inter rater reliability,[26] only two of the raters used this scale.

For each observation period during the research project, two raters simultaneously viewed the participants on the DSCUs for 5 minutes. This was done three times, first during rest or time of no activity. Participants were typically either sitting in a chair or lying in bed. For this observation, the first rater used the PAINAD and pain-VAS, whereas V.W. or S.M. administered the DS-DAT and discomfort-VAS. A second observation was made during a presumably pleasant activity, but when movement could have actually led to pain. Activities included visiting with family or friends, watching TV or an old movie, as well as ward activities such as socials or reminiscence and "Bright Eyes" groups.[27] A third observation was made during caregiving (toileting, transfers, and bathing or showering) that might be unpleasant for the patient and lead to refusal to conduct the activity or other negative emotions. Movement during this activity might also cause pain due to contractures or underlying conditions such as arthritis. During the second and third observations, two raters simultaneously administered the PAINAD and pain-VAS.

Data obtained from medical records during the first month Quality Improvement Project included all residents who routinely received pain medication on a "whenever necessary" (PRN) basis (n = 25). Clinical staff trained in the use of the PAINAD used the PAINAD as an assessment tool along with clinical judgement to determine if the resident required medication. Thirty minutes after medication the PAINAD was administered the second time.

Statistical Analysis

Pain was conceptualized as a multifactorial symptom, expressed by several signs, but forming a single construct. Therefore, Cronbach's alpha was selected as the measure for verifying internal consistency. To achieve 10 participants per item, both the research and quality improvement data were combined and examined for internal consistency.[28] A principal components factor analysis with varimax rotation was performed to examine score variance.

Construct validity was determined using the contrasted groups and hypothesis testing methods.[29] The ANOVA statistic was used to examine PAINAD scores within participants exposed to three different conditions. Paired *t* test was used to compare PAINAD scores before and after PRN medication in the quality improvement project.

RESULTS

Research participants had a mean age of 78.1 ± 5 (SD, range 66–85) years, suffered from dementia for 8.7 ± 4.7 years (range, 1–20 years) and were institutionalized for 16.5 ± 13.5 months (range, 1–50 months). They had severe dementia with the MMSE score of 2.8 ± 4.5 (0–16), BANS- S score of 16.4 ± 4.4 (9–23), and were clearly unable to verbally report symptoms of pain.

PAINAD mean scores (± SD) of the 19 participants who were observed during three different conditions went from 1.3 ± 1.3 during no stimulation to 1.0 ± 1.3 during pleasant activity or rest, and to 3.1 ± 1.7 during an unpleasant event (Table 1) ($F(1,17) = 10.93$, $P < 0.001$). PAINAD mean scores (± SD) of the 25 residents in the quality improvement project who were assessed to determine PRN pain medication needs and effectiveness decreased from 6.7 ± 1.8 before PRN medication to 1.8 ± 2.2, 30 minutes after receiving medication ($t(24) = 9.6$, $P < 0.001$).

PAINAD scores were not normally distributed, and many scores clustered around 0, especially during a pleasant condition or 30 minutes after pain medication. With the exception of the time 30 minutes after pain medication, Cronbach's alpha was lower than the desired 0.70[28] for a new scale.

Factor structure analysis of combined PAINAD data obtained during the scale development showed one main factor that explained 50.1 percent of variance (eigenvalue 2.51) and a minor factor (breathing alone) that explained an additional 20.6 percent of variance (eigenvalue 1.03). However, the

Table 2. *Associations Between Simultaneous Observations of Pain and Discomfort at Rest*

	DS-VAS			PAINAD			PAIN-VAS		
	r	*P*	n	*r*	*P*	n	*r*	*P*	n
DS-DAT	.81	.001	19	.76	.001	19	.56	.016	18
DS-VAS				.76	.001	19	.85	.001	18
PAINAD							.75	.001	18

r = Pearson correlation; *P* = probability; n = number of participants; DS-DAT = Discomfort Scale—Dementia of Alzheimer Type; VAS = visual analog scale; PAINAD = Pain Assessment in Advanced Dementia Scale.

quality improvement data showed a one-factor solution that explained 61 percent of variance (eigenvalue 3.05). The quality improvement project is probably a better representation of the actual use of PAINAD scale in clinical practice.

There were significant correlations among visual analog scales and observational scales at rest (Table 2), and between simultaneous ratings of pain during both presumed pleasant and unpleasant conditions (Table 3). Comparison of *z*-score transformations of PAINAD and DS-DAT scores by paired *t* tests yielded $t(18) = 0.0$, $P = 1.0$. Comparison of raw PAINAD scores obtained by two observers during a pleasant condition yielded $t(17) = 0.0$, $P = 1.0$ and during unpleasant condition $t(18) = 1.7$, $P = 0.11$.

DISCUSSION

The PAINAD successfully measured pain in individuals with advanced dementia, who were unable to use any of the available pain assessment tools that have been used with cognitively impaired individuals. Fifteen of 19 research participants had MMSE scores under five, and the four that were still able to verbally interact did so on a social level only and were unreliable in their reporting. Although other scales measuring pain are appropriate for research studies, some such as the DS-DAT require extensive training that is, in our experience and experience of others,[7] too time intensive to be used in clinical settings, making DS-DAT too complicated and difficult for routine use.

Results of this study show that PAINAD has good construct validity and reliability. PAINAD was able to detect differences in pain associated with different conditions or caused by an analgesic administration, and DS-DAT and PAINAD produced similar mean *z*-scores that were positively correlated. Similar PAINAD scores observed within similar conditions by two different raters provided evidence for interrater agreement in this project and demonstration that the PAINAD can be used accurately after a 2-hour training session.

Internal consistency of PAINAD is lower than what is desired for a new scale.[28] However, the PAINAD has only five items to make one concept operational, and each item reflects disparate individual symptoms. However, results of factor analysis showed that despite the diversity of symptoms (and items) that make pain operational in the PAINAD, there is one single underlying construct.

During the initial review of the alpha coefficients, the item-total correlations were examined to identify "poorly performing" items that could be removed. In all cases, the alpha could be increased with the deletion of the *Breathing* item or combination of *Breathing* and *Negative Vocalization*. However, given the fact that many patients with advanced dementia suffer from intercurrent respiratory diseases and for approximately 50 percent, the immediate proximal cause of death is pneumonia,[30] our team believed that for maintaining content validity, *Breathing* needed to remain as a separate item in the PAINAD. Changes in respiration have been noted in the literature when pain occurs, particularly when acute pain occurs.

As anticipated with a behavioral observation tool that measures only negative versus a complete range of behaviors, and zero means the absence of the condition, PAINAD scores were not normally distributed. PAIN scores often were or clustered around 0, especially during a pleasant condition or 30 after pain medication.

To obtain a precise PAINAD score, alternative causes of

Table 3. *Associations Between Simultaneous Observations in Different Conditions*

	Observational Condition	PAIN-VAS (1)		PAINAD (2)		PAIN-VAS (2)	
		r	n	*r*	n	*r*	n
PAINAD (1)	Pleasant activity	.92	18	.97	19	.89	18
	Unpleasant activity	.82	19	.82	19	.90	19
PAIN-VAS (1)	Pleasant activity			.93	18	.87	18
	Unpleasant activity			.90	19	.83	19
PAINAD (2)	Pleasant activity					.95	18
	Unpleasant activity					.91	19

r = Pearson correlation, n = number of participants, *P* = .001 for all correlations; VAS = visual analog scale; PAINAD = Pain Assessment in Advanced Dementia Scale.

indicators that are included in the PAINAD scale have to be excluded. These causes include resistiveness to care leading to negative vocalization or striking out, negative emotions leading to sad expression or crying, or anxiety leading to hyperventilation or frightened expression. However, it also needs to be considered that some of these causes could be aggravated by pain. The relationship between pain, discomfort, and affect in individuals with advanced dementia needs to be further investigated.

This study has some limitations because the number of participants was small and included only white, elderly, middle class male veterans. But, these limitations may also be viewed as suggestions for future research and additional evidence that the PAINAD is a clinical tool. Since the majority of persons with advanced dementia are female, the PAINAD needs to be examined in sites that provide care for a more diverse population including women and racial/ethnic minorities. Research observations were limited to three times per patient. Future validation studies should increase the number of trained raters to allow observation to take place at all times of the day. Future research needs also to compare utility of all available instruments for this population. However, the important point is that clinical staff learned to use the PAINAD with a few hours of training. Furthermore, the clinical staff liked the PAINAD and continues to use it in routine clinical care.

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APPENDIX

Pain Assessment in Advanced Dementia (PAINAD)

	0	1	2	Score
Breathing Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling, or inexpressive	Sad. Frightened. Frown	Facial grimacing	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
				TOTAL

APPENDIX: ITEM DEFINITIONS

Breathing

1. *Normal breathing* is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. *Occasional labored breathing* is characterized by episodic bursts of harsh, difficult or wearing respirations.
3. *Short period of hyperventilation* is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. *Noisy labored breathing* is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
5. *Long period of hyperventilation* is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. *Cheyne-Stokes respirations* are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative Vocalization

1. *None* is characterized by speech or vocalization that has a neutral or pleasant quality.
2. *Occasional moan or groan* is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. *Low level speech with a negative or disapproving quality* is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. *Repeated troubled calling out* is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. *Loud moaning or groaning* is characterized by mournful or murmuring sounds, wails or laments in much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. *Crying* is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial Expression

1. *Smiling or inexpressive*. Smiling is characterized by upturned corners of the mouth, brightening of the eyes and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. *Sad* is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. *Frightened* is characterized by a look of fear, alarm or heightened anxiety. Eyes appear wide open.
4. *Frown* is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. *Facial grimacing* is characterized by a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

Body Language

1. *Relaxed* is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. *Tense* is characterized by a strained, apprehensive or

worried appearance. The jaw may be clenched. (exclude any contractures)

3. *Distressed pacing* is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.

4. *Fidgeting* is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also be observed.

5. *Rigid* is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding. (exclude any contractures)

6. *Fists clenched* is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.

7. *Knees pulled up* is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (exclude any contractures)

8. *Pulling or pushing away* is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.

9. *Striking out* is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability

1. *No need to console* is characterized by a sense of well being. The person appears content.

2. *Distracted or reassured by voice or touch* is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction with no indication that the person is at all distressed.

3. *Unable to console, distract or reassure* is characterized by the inability to sooth the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.