

Review Article

Tools for Assessment of Pain in Nonverbal Older Adults with Dementia: A State-of-the-Science Review

Keela Herr, PhD, RN, FAAN, Karen Bjoro, RN, MSN, PhD,
and Sheila Decker, PhD, APRN-BC

*Adult & Gerontological Nursing (K.H.), College of Nursing, The University of Iowa;
The University of Iowa (K.B.), Iowa; and The University of Texas Health Science
Center at Houston (S.D.), School of Nursing, Texas, USA*

Abstract

To improve assessment and management of pain in nonverbal older adults with dementia, an effective means of recognizing and evaluating pain in this vulnerable population is needed. The purpose of this review is to critically evaluate the existing tools used for pain assessment in this population to provide recommendations to clinicians. Ten pain assessment tools based on observation of behavioral indicators for use with nonverbal older adults with dementia were evaluated according to criteria and indicators in five areas: conceptualization, subjects, administration, reliability, and validity. Results indicate that although a number of tools demonstrate potential, existing tools are still in the early stages of development and testing. Currently, there is no standardized tool based on nonverbal behavioral pain indicators in English that may be recommended for broad adoption in clinical practice. J Pain Symptom Manage 2006;31:170–192. © 2006 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Pain measurement, pain assessment, aged, dementia, cognitively impaired, nonverbal communication, behavioral

Introduction

An estimated 4.5 million Americans suffer from dementia, a prevalence that is expected to triple by 2050.¹ Dementia, which includes Alzheimer's disease and other forms of dementia, is a progressive and debilitating disease

characterized by severe cognitive deficits, loss of language, and the ability to carry out activities of daily living. One-half of older adults 85 years and older are afflicted with Alzheimer's disease and an estimated 28% of these older adults have severe disease.¹

The burden of dementia in the older adult population is compounded by the burden of painful conditions such as arthritis, cancer, and trauma such as hip fracture. A number of studies have documented a high prevalence of pain in older adults with dementia.^{2–6} The consequences of untreated pain include physiological risks,⁷ depression,^{4,8,9} impaired

Address reprint requests to: Keela Herr, PhD, College of Nursing, 452 NB, The University of Iowa, 50 Newton Road, Iowa City, IA 52242, USA. E-mail: keela-herr@uiowa.edu

Accepted for publication: July 6, 2005.

cognitive function,^{10–12} sleep disturbance,^{13,14} impaired functional abilities,^{7,15–17} diminished socialization,^{13,14} and increased health care utilization and costs.^{18,19} Thus, pain can profoundly impact the quality of life of older adults with dementia.

Despite the high prevalence and consequences of pain among older adults with dementia, health care professionals remain ineffective at both pain assessment^{20–23} and treatment.^{2,3,5,24–27} Older adults with dementia receive less pain medication than those who are able to communicate, even though they are just as likely to experience painful illnesses.^{2,25,28} Also of concern are data noting that pain is undertreated in racial/ethnic minority patients.^{29–32} Although multiple factors contribute to poor pain management in this population, the most troublesome is the failure to recognize pain in older adults who are unable to communicate their pain experience.

Assessment of pain provides critical information used to guide the selection of interventions, monitor the effectiveness of treatment, and communicate care planning across health providers and care settings. Whereas self-report of pain is the “gold standard” for pain assessment, other approaches, such as observational and surrogate report, are necessary in patients with advancing dementia. Over the past decade a number of observational tools for use with nonverbal older adults with dementia have been developed. Although a precise and accurate method for interpreting the expression of pain in older adults with dementia is an area not yet fully explored, there is critical need for evaluation of the existing tools to guide practice decisions in this important area.

The purpose of this review is to critically evaluate existing tools for pain assessment in nonverbal older adults with dementia to provide recommendations to clinicians regarding assessment of pain in this population.

Literature Review

Alzheimer’s dementia, the most common form of dementia in older adults, is characterized by multiple cognitive impairments including impaired recent memory. Loss of communication skills affects the older adult’s ability to quantify his or her pain experience and represents a serious barrier to pain

assessment, placing the individual at high risk for nondetection and undertreatment of pain. Research findings among older adults who reside in the nursing home suggest that many patients with moderate to severe dementia can report pain reliably at the moment or when prompted, however, pain recall and integration of pain experience over a period of time may be less reliable.^{2,33–36} Also, the number of pain complaints decreases as dementia progresses.^{33,37–39} Because the ability to respond to direct questioning is impacted in older adults with dementia,³⁴ it is likely that fewer reports of pain are related to difficulty communicating pain presence rather than decreased pain sensation. There is no consistent evidence to indicate that persons with dementia experience significantly less pain sensation.^{40–43} To further complicate the assessment of pain in older adults with dementia, pain expression sometimes takes on less obvious forms, such as confusion, social withdrawal, aggression, or subtle changes in behavior, which are not *typical* pain manifestations.

Observation for pain behaviors at rest can be misleading, with increased indicators of pain observed during activities such as transferring, 33,37–39

suggest that nurses, family/caregivers, and certified nursing assistants (CNAs) can recognize the presence, but not intensity, of pain in cognitively impaired patients.⁵⁹⁻⁶³ Clearly, further investigative efforts must take place to refine the process of pain rating by both professional and family caregivers. Until a more reliable method of detecting pain in older, nonverbal patients is determined, direct observation of patient behavior and surrogate reporting of pain is necessary for determining the presence of pain in this population.

A number of potential behavioral indicators that suggest the possible presence of pain in older adults with dementia have been identified. Based on an extensive review of existing literature, behavioral pain indicators have recently been organized in a comprehensive framework in the American Geriatrics Society (AGS) guidelines for persistent pain in older adults.⁵¹ This framework identifies six main types of pain behaviors and indicators with specific examples of observable behaviors.

- *Facial expressions*: slight frown, sad, frightened face, grimacing, wrinkled forehead, closed or tightened eyes, any distorted expression, rapid blinking
- *Verbalizations, vocalizations*: sighing, moaning, groaning, grunting, chanting, calling out, noisy breathing, asking for help
- *Body movements*: rigid, tense body posture, guarding, fidgeting increased pacing, rocking, restricted movement, gait, or mobility changes
- *Changes in interpersonal interactions*: aggressive, combative, resisting care, decreased social interactions, socially inappropriate, disruptive, withdrawn, verbally abusive
- *Changes in activity patterns or routines*: refusing food, appetite change, increase in rest periods or sleep, changes in rest pattern, sudden cessation of common routines, increased wandering
- *Mental status changes*: crying or tears, increased confusion, irritability, or distress.

In an effort to enhance the reliability and validity of pain behaviors for quantifying pain in older adults with severe dementia, assessment tools that focus on behavioral observation are being developed and evaluated. The existing literature provides evidence for several promising tools; however, most of the existing

published instruments have limited psychometric evaluation and clinicians are often not clear on the appropriateness of these tools for use in practice.

In an effort to address the issue of inadequate pain treatment and special concerns of pain in older adults, the AGS published clinical practice guidelines specific to the assessment and management of persistent pain in older persons⁵¹ and the American Medical Directors Association (AMDA) published clinical practice guidelines for the management of pain in long-term care settings.⁶⁴ A revised evidence-based practice guideline for acute pain management in the older adults⁶⁵ will soon be available. These guidelines provide useful sources from which to base clinical practice decisions, although the expert panels strongly recommend that investigations into the assessment and management of pain among older persons continue in an effort to build upon and further refine recommendations for clinical practice that attend to the needs of all older adults, including those of diverse racial/ethnic backgrounds.

Pain assessment tools and approaches for use with cognitively intact older persons who are able to self-report their pain have been identified⁶⁶ and recommendations are included in the AGS, AMDA Clinical Practice Guidelines, and Acute Pain Management in the Elderly Evidence-Based Protocol.⁶⁷ However, pain assessment of those with severe dementia who are unable to communicate their discomfort with standard approaches remains a major challenge. No specific tools have been recommended in the guidelines for use with persons with dementia who are unable to report their pain experience. Adoption of a pain assessment tool for use in patients with dementia should be based on sound evaluation of tool conceptualization, subject comparability, feasibility of tool administration and scoring, reliability, and validity.

Methods

Following is the methodology used to complete the state-of-the-science review of tools for assessment of pain in nonverbal older adults.

To be included in this review, assessment tools met the following criteria: (1) based on

behavioral indicators of pain, (2) developed for assessment of pain in nonverbal older adults with severe dementia or evaluated for use with nonverbal older adults, (3) available in English, and (4) at least one published research report of psychometric evaluation available in English.

A bibliographic search was conducted to identify existing tools for assessment of pain in nonverbal older adults in the following electronic databases for the period 1990 through July, 2004: Medline, Cumulative Index to Nursing & Allied Health (CINAHL), PsycINFO and Health, and Psychosocial Instruments. Medical subject headings/key words included pain measurement, pain assessment and aged, dementia, cognitively impaired, nonverbal communication, and behavior. The electronic database of the National Guideline Clearinghouse was searched to identify guidelines on pain management in older adults that may include assessment tools. Additional sources included abstracts from pain and gerontological conferences as well as the personal reference databases of the authors.

The search strategy resulted in 14 tools. Ten tools met inclusion criteria and were included in this critique: Abbey Pain Scale (Abbey);⁶⁸ assessment of discomfort in dementia (ADD) protocol;⁴⁹ checklist of nonverbal pain indicators (CNPI);⁴⁴ discomfort in dementia of the Alzheimer's type (DS-DAT);⁶⁹ the Doloplus 2;⁷⁰ the Face, Legs, Activity, Cry, and Consolability Pain Assessment Tool (the FLACC);⁷¹ Noncommunicative Patient's Pain Assessment Instrument (NOPPAIN);⁷² Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC);⁷³ Pain Assessment for the Dementing Elderly (PADE);⁷⁴ and pain assessment in advanced dementia (PAINAD).⁷⁵

Four tools identified through the electronic database search did not satisfy inclusion criteria: one tool was developed for pain assessment in confused older adults with delirium⁷⁶ and one for use with children,⁷⁷ for two tools psychometric evaluation data were not available in a published research report.^{78,79}

A critique guide was developed based on measurement theory⁸⁰⁻⁸² with criteria and indicators in five areas: conceptualization, subjects, administration, scoring and feasibility, and reliability and validity. Geriatric pain literature, in particular the AGS guidelines on

persistent pain in older adults,⁵¹ was consulted to establish a framework for evaluation of content and comprehensiveness of nonverbal pain indicators.

- *Conceptualization* was a composite including tool purpose; conceptual clarity; item generation method and appropriateness; whether item development is consistent with the literature, clinical observation, and qualitative methods; whether tool items address pain behaviors identified in literature and evidence-based guidelines; whether the tool items adequately sample the content area; and soundness and appropriateness of scoring procedure.
- *Subjects* included indicators for setting; representativeness of the subjects based on age, gender, and ethnic/racial background; assessment of dementia based on a standardized method; and sufficiency of sample size based on a minimum of five subjects per item as a rule of thumb.
- *Administration, scoring, and feasibility* included indicators for clarity of method of administration and scoring procedures; interpretation of tool score; and inclusion of information related to clinical utility (e.g., time, training, and skill needed to use the tool).
- *Reliability* was evaluated as a composite including internal consistency, interrater reliability, and test-retest reliability. Within each type of reliability indicators relate to appropriateness of the test for the type of data produced by the tool; appropriateness of the characteristics of the raters; and whether the correlation coefficient reported was within acceptable levels. An additional indicator of test-retest reliability related to the appropriateness of the interval between assessments.
- *Validity* was a composite for criterion-related validity, construct, and concurrent validity. Indicators related to appropriateness of the type of validity testing; appropriateness of any gold standards used for comparison; sufficiency of detail regarding procedures; and appropriateness of analysis techniques for the data and type of validity procedure.

Each tool was critiqued independently by each of the three authors and rated for evidence that supported the criteria and

indicators as defined by using a 4-point scale: 3 = available evidence is strong, 2 = available evidence supports need for further testing, 1 = available evidence is insufficient and/or tool revisions are needed, and 0 = evidence is absent. Ratings were then compared and discussed in detail until consensus was reached for each criterion. The preliminary critique was mailed to the tool developer for review for accuracy and submission of additional data or publications was invited. When new data were submitted tool critiques were discussed by the review team members and adjustments made when appropriate. A final score was assigned based on the available data.

As a result of funding from The Mayday Fund, a comprehensive Web resource has been developed that provides electronic access to a more detailed, in-depth critique of each instrument, downloadable files of available articles, and author contact information. The reader is encouraged to visit www.cityofhope.org/prc/elderly.asp for more detailed critiques.

Results

The results of the review are presented through summary critiques of each available assessment tool. An overview of evaluation results based on final score is provided in Table 1. Table 2 provides a comparison of tool items in relation to the behavioral pain indicators in the AGS guidelines.

The Abbey⁶⁸ is an Australian tool developed to measure intensity of pain in people with late-stage dementia that was described as

efficient, effective, and able to be used by a variety of care staff. Although there is no presentation of the conceptual basis for the tool, it is apparent that the tool attempts to measure *acute pain*, *chronic pain*, and *acute on chronic* in the same tool.

The tool includes six items: vocalization, facial expression, change in body language, behavioral change, physiological change, and physical change. Each item is leveled on a 4-point scale for intensity of the behavior (absent = 0, mild = 1, moderate = 2, severe = 3) with total score ranging from 0 to 18. The total score is then interpreted as intensity of pain: no pain = 0–2, mild = 3–7, moderate = 8–13, and severe = 14+. The rater is asked to indicate which type of pain the older adult has: chronic, acute, or acute on chronic.

A few limited instructions are provided on the tool schema. Instructions for using the Abbey are presented on a poster. Nurses are asked to use the tool when pain is suspected. However, it is unclear what triggers the pain assessment. Clinicians considering this tool need to be aware that pain assessment should be conducted on an ongoing basis—as well as when pain is suspected—to ensure greatest likelihood of detection. The tool apparently takes 1 minute to score, although there are no published data to support this.

The Abbey tool was evaluated in 24 long-term care facilities with a sample of 61 older adults with late-stage dementia with a median age of 83 years (range 60–97) of whom 66% were female based on a total of 236 pain episodes. Internal consistency reliabilities for pre- and postintervention are reported with

Table 1
Pain Assessment Tools for Nonverbal Older Adults with Dementia Rated on Evaluation Criteria

	Conceptualization	Subjects Setting	Administration, Scoring, Feasibility	Reliability	Validity	Sum of Scores
Abbey ⁶⁸	1	1	1	1	1	5
ADD ^{49,a}	2	2	2	1	2	9
CNPI ⁴⁴	2	1	2	2	1	8
DS-DAT ⁶⁹	3	3	1	3	2	12
Doloplus 2 ⁷⁰	1	2	2	2	1	8
FLACC ⁷¹	0	1	0	1	1	3
NOPPAIN ⁷²	2	3	2	2	2	11
PACSLAC ⁷³	2	1	2	1	2	8
PADE ⁷⁴	1	2	1	1	1	6
PAINAD ⁷⁵	1	1	2	1	2	7

Key to rating: 3 = available evidence is strong, 2 = available evidence supports need for further testing, 1 = available evidence is insufficient and/or tool revisions are needed, and 0 = evidence is absent.

^aADD is not included as an assessment tool, but as a protocol for validating presence of pain.

Cronbach's alpha 0.74 at both time points. Although these are acceptable levels, it is unclear what data were used in the analysis (e.g., pain episode, resident, or mean score). Interrater reliability was assessed for two staff members pre- and postintervention in a sample of 18 residents with intraclass correlation coefficients of 0.63 ($P = 0.02$) and 0.44 ($P = 0.12$), respectively. These interrater reliabilities were low particularly for postintervention evaluation. No test-retest reliability is available.

Concurrent validity of the scale was evaluated against the holistic impression of pain as assessed by the nurse (gamma 0.586, $P < 0.001$). Predictive validity was assessed by a change in mean pain score from preintervention (9.02; SD .48) to postintervention (4.21; SD .41). A paired *t*-test was statistically significant ($P < 0.001$). However, it is unclear what unit of analysis was used for examining prepost score changes (e.g., pain episode, resident, or mean score).

Clinicians considering this tool need to be aware of conceptual issues. There is conceptual blurring between acute and chronic pain with no discussion in the paper on distinguishing characteristics of the pain types. Moreover, there is blurring between pain behaviors and pain etiology. Although the tool does include at least one cue from each of the six categories of nonverbal pain behavior indicators from the AGS guidelines, the inclusion of physiological indicators is not supported in the literature to assess chronic pain. Thus, an individual with chronic pain being scored on this tool may lose three points toward the overall intensity score. Moreover, the ability of health care providers to determine intensity of pain from behavioral indicators has not been established.

In conclusion, the Abbey lacks conceptual clarity and based on available information of test results, tool reliability has not been adequately established. Validity testing based on nurse judgment of pain intensity is not substantiated in the literature, particularly, as in this case, without evidence supporting the expertise of the raters. Thus, tool revision and additional testing in controlled circumstances are recommended.

The ADD protocol^{49,83,84} is a systematic approach to be used by nurses to make a differential assessment and treatment plan for both physical pain and affective discomfort experienced by people with dementia. Thus, it

should be noted that the ADD is not a typical pain assessment tool. The author currently states the tool is an intervention; however, it is included in this review because of its potential for detecting pain in this population.

The ADD focuses on evaluation of persons with difficult behaviors that may represent discomfort. Assessment of pain and discomfort is addressed by the protocol and encompasses physical, affective, and social dimensions of pain.

In the 2002 version of the ADD,⁸⁴ a checklist of five categories of pain behaviors with dichotomous items specified within each category is used to identify potential pain behaviors and includes the following: facial expression (eight items), mood (five items), body language (nine items), voice (nine items), and behavior (11 items). If potential pain behaviors are identified, the protocol consists of five steps: assessment of physical signs and symptoms; current/past history of pain; if Steps 1 and 2 are negative assess environmental press, pacing of activity/stimulation, meaningful human interaction, and intervene with nonpharmacological treatments; if unsuccessful, medicate with nonnarcotic analgesic per written order; if symptoms persist, consult with physician/other health professional, or medicate with prn psychotropic per written order.

The method of administration is adequately described in articles on the ADD. Although no documentation of the amount of time involved in using the protocol is currently available, the protocol involves multiple steps and may require additional documentation to complete. Thus, use of the ADD would appear to require a considerable amount of time. Moreover, the protocol involves complex clinical decisions, thus its use also requires extensive education.

The ADD was tested in two studies. Study 1 was conducted in 32 long-term care facilities in a convenience sample of 104 residents with a mean age 85 years (range 46–100) most of whom had dementia of the Alzheimer type.⁴⁹ Study 2 was conducted in six long-term care facilities in a convenience sample of 143 subjects with severe dementia with an average age of 86.7 years (SD 6.16; range 56–100), all Caucasian, and predominantly female (81%).⁸³

Internal consistency reliability has not been provided and may not be appropriate considering the nature of the protocol. However,

Table 2
Items on Pain Assessment Tools for Nonverbal Older Adults with Dementia Compared to AGS Guidelines Behavioral Pain Indicators^{41,a}

AGS Guidelines ⁵¹	Abbey Scale ⁶⁸	ADD ⁴⁹	CNPI ⁴⁴	Doloplus 2 ⁷⁰	DS-DAT ⁶⁹
Facial expressions					
Slight frown; sad, frightened face Grimacing, wrinkled forehead, closed or tightened eyes Any distorted expression Rapid blinking	Frowning, grimacing, looking frightened, looking tense	Sad or frightened facial expression	Facial grimacing or wincing, (clenched teeth, furrowed brow, tightened lips, narrowed eyes)	Expression: - Showing pain - Unusually blank look (voiceless, staring, blank looks)	Frown Sad facial expression Frightened facial expression Content of facial expression
Verbalizations, vocalizations					
Sighing, moaning, groaning Grunting, chanting, calling out Noisy breathing Asking for help Verbally abusive	Whimpering, groaning	Intense repetitive verbalization Verbal outburst toward another person Noisy breathing	Vocal complaints (that hurts, ouch, stop) Nonverbal vocalization (sighs, gasps, moans, cries)	Somatic complaints: - Expressed upon inquiry only - Occasional involuntary - Continuous involuntary	Negative vocalization Noisy breathing
Body movements					
Rigid, tense body posture, guarding Fidgeting Increased pacing, rocking Restricted movement Gait or mobility changes	Guarding part of body Fidgeting Rocking	Tense body language Fidgeting Tense repetitive movement During transfers: grimace, brace himself, groan	Massaging the affected area Restlessness (shifting, rocking, inability to sit still) Bracing behavior (clutching or holding affected area during movement)	Somatic reactions: Protective body postures at rest: - Avoiding certain positions - Protective postures - Protection of sore areas Mobility: - Usual activities reduced - Resistive to movement	Tense body language Fidgeting Relaxed body language
Changes in interpersonal interactions					
Aggressive, combative, resisting care Decreased social interactions Socially inappropriate, disruptive Withdrawn	Withdrawn	Physical aggression Withdrawn behavior		Communication: - Heightened, demanding attention, lessened, absence/refusal of any form of communication Social life: - Participation in activities: normally, only when asked to do so, sometimes refuses, refuses to participate in anything Behavioral problems	

**Changes in activity patterns
or routines**

Refusing food,
appetite change
Increase in rest periods
Sleep, rest pattern changes
Sudden cessation
of common routines
Increased wandering

Alteration in
usual patterns
Refusing to eat

Wandering requiring
intervention
Repetitive waking
during the night

Psychomotor reactions:
- Changes in ability to wash and/or dress
Somatic reactions:
- Sleep pattern changes with
waking and restlessness
or insomnia

Mental status changes

Crying or tears
Increased confusion
Irritability or distress

Increased confusion
Crying

Tearfulness
Delusions
Phobias or fears
Hallucinations

AGS Guidelines ⁵¹	FLACC ⁷¹	NOPPAIN ⁷²	PACSLAC ⁷³	PADE ⁷⁴	PAINAD ⁷⁵
Facial expressions					
Slight frown; sad, frightened face	No particular expression or smile	Pain faces? (Grimaces, furrowed brow, wincing)	Facial expressions: grimacing, sad look, tighter face, dirty look	Frowning Sad facial expression	Facial expression
Grimacing, wrinkled forehead, closed or tightened eyes	Occasional grimace or frown		Change in eyes, frowning, pain expression, grim face	Anxious/ frightened	
Any distorted expression	Withdrawn		Clenching teeth, wincing	facial expression	
Rapid blinking	Disinterested		Opening mouth, crasing forehead, screwing up nose		
Verbalizations, vocalizations					
Sighing, moaning, groaning	Cry:	Pain words? ("That hurts!", "Ouch!", "Stop that!", cursing)	Screaming/yelling, calling out (i.e., for help), a specific sound or vocalization for pain "ow," ouch, moaning and groaning, mumbling, grunting, verbal aggression	Moaning/ groaning	Negative vocalization
Grunting, chanting, calling out	- No cry (awake or asleep)				

Table 2 (Continued)

AGS Guidelines ⁵¹	FLACC ⁷¹	NOPPAIN ⁷²	PACSLAC ⁷³	PADE ⁷⁴	PAINAD ⁷⁵
Body movements					
Rigid, tense body posture, guarding, fidgeting	Legs: Normal position or relaxed	Rubbing? (Massaging affected area)	Activity/body movement: fidgeting, pulling away, flinching, restless, pacing, refusing to move, thrashing, decreased activity, moving slow, impulsive behavior (repetitive movements), guarding sore area, touching/holding sore area, limping, clenched fist, going into fetal position, stiff/rigid	Tense body language	Body language:
Increased pacing, rocking	Uneasy, restless, tense kicking, legs drawn up	Restlessness? (Frequent shifting rocking, inability to stay still)		Guarding affected area	0. Relaxed
Restricted movement	Activity: Lying, quietly, normal position, moves easily			Restless	1. Tense, distressed pacing, fidgeting
Gait or mobility changes	Squirming, shifting back and forth			Fidgeting	2. Rigid, fists clenched, knees pulled up, pulling or pushing away, striking out
	Tense			Pacing	
	Arched, rigid, or jerking				
Changes in interpersonal interactions			Social/personality/mood: Physical aggression Not wanting to be touched Not allowing people near Angry/mad, throwing things	Language coherence and complexity (Pattern of social interaction) (Pattern of cooperation)	
Aggressive, combative, resisting care					
Decreased social interactions					
Socially inappropriate, disruptive					
Withdrawn					
Changes in activity patterns or routines			Changes in sleep Changes in appetite Trying to leave	(Eating pattern) (Sleep/wake pattern) (Pattern of wandering)	
Refusing food, appetite change					
Increase in rest periods					
Sleep, rest pattern changes					
Sudden cessation of common routines,					
Increased wandering					
Mental status changes			Increased confusion		
Crying or tears					
Increased confusion					
Irritability or distress					

^aIn addition to the behavioral indicators listed above, tools include additional items as indicated below:

The Abbey includes two nonbehavioral categories: physiological change (e.g., temperature, pulse or blood pressure outside normal limits, perspiring, flushing, or pallor) and a category for etiological factors, physical changes (e.g., skin tears, pressure areas, arthritis, contractures, previous injuries).

FLACC includes an item named "consolability."

PACSLAC includes physiological items (pale face, flushed, red face, teary eyed, sweating shaking/trembling, cold, and clammy).

PADE includes an item for global assessment of pain severity.

PAINAD includes an item called "consolability."

NOPPAIN includes a pain thermometer for global assessment of pain.

the behavior checklist could and should be evaluated for internal consistency. Interrater reliability for the protocol was established in Study 1 in a very small subsample of four residents with percent agreement of 86% for the total tool, 100% for medication use, 76% for nonpharmacological interventions, and 87% for discomforting symptomatology. Test-retest reliability has not been established, but is appropriate and needed.

Predictive validity of the ADD was tested in Study 1. Preintervention sample had an average of 32.9 (SD 16.8) behavioral symptoms associated with discomfort compared to 23.5 (SD 16.5) for postintervention, a significant decrease in discomfort ($t = 6.56$, $P = 0.000$). Use of the ADD protocol was associated with a significant increase in the use of pharmacologic ($t = 2.56$, $P = 0.012$) and nonpharmacologic comfort interventions ($t = 3.37$, $P = 0.001$).

The ADD provides a comprehensive approach to recognition of potential pain conditions through observation and validation procedures that are conceptually sound. The tool addresses diverse potential pain indicators in this population and uses an assessment validation approach that focuses on positive changes in behavior. The behavior checklist is comprehensive as compared to the AGS guidelines indicators. However, data are limited regarding its reliability. Preliminary testing of the protocol suggests its potential usefulness; however, additional testing of reliability and validity is needed, particularly larger samples including minority subjects. The clinical utility is also unclear regarding time for training and time to complete the protocol.

In conclusion, the ADD protocol appears to be a comprehensive and conceptually sound approach to recognition of pain in this population. However, it may be too complex for routine use and streamlining of the steps may be needed. Although there is preliminary support for validity of the protocol, reliability remains to be established.

The CNPI⁴⁴ is an itemized list designed to measure pain behaviors in cognitively impaired older adults. The tool includes six pain behavioral items commonly observed in older adults including nonverbal vocalizations, facial grimacing or wincing, bracing, rubbing, restlessness, and vocal complaints. Each item is scored on a dichotomous scale (1 = present,

0 = not present) both at rest and on movement, for a possible range of scores from 0 to 6 points for each situation and a total of 12 points.

The CNPI was tested in a convenience sample of cognitively intact and cognitively impaired hospitalized older adults with hip fracture ($n = 88$) with a mean age of 83.2 years (SD 7.7; range 65–101) of whom 86% were female. The cognitively impaired group ($n = 53$) with Mini Mental State Examination (MMSE) scores ≤ 23 , had a mean MMSE score of 12.2 (SD 8.0), indicating that the sample included individuals who were not severely demented. Moreover, observations were made on the third postoperative day, which may indicate that the patients would be experiencing less severe postoperative pain.

Method of administration and scoring procedures are clearly described and appear simple to follow. No interpretation of tool score is provided, however. Although the time needed to administer the tool has not been formally evaluated, it is short and appears easy to use. In the initial testing two gerontological nurse practitioners conducted the assessments. It is not reported how the tool performs when administered by staff nurses.

Internal consistency reliabilities of KR-20 alphas of 0.54 (95% confidence interval, CI 0.38–0.68) at rest and 0.54 (95% CI 0.38–0.68) with movement were noted. Although alphas were low this may relate to the few items in the tool. Interrater reliability between two independent raters is reported for a subgroup of 12 subjects. Percent agreement was 93% and kappa statistic ranged from 0.625 to 0.819 for behaviors observed. Test-retest reliability was not deemed an appropriate parameter to examine when assessing acute pain due to its changing nature. However, test-retest reliability should be established if used with persistent pain states.

Concurrent validity was evaluated by comparing CNPI scores with Verbal Descriptor Scale (VDS) scores for 64 subjects for whom both CNPI and VDS scores were available. For the total population, Spearman correlation coefficients at rest were 0.37 ($P = 0.001$) and with movement 0.43 ($P < 0.001$). In the impaired group ($n = 32$), coefficients at rest were 0.30 ($P = 0.076$) and with movement 0.46 ($P = 0.009$). In the intact group ($n = 32$), coefficients at rest were 0.50 ($P = 0.003$) and with

movement 0.39 ($P = 0.032$). Thus, pain at rest correlated poorly within the impaired group, leading the tool developer to conclude that the tool is only valid for assessment of pain with movement. However, construct validity was demonstrated by the data with higher scores on the CNPI attained during periods of movement eliciting discomfort than during periods of rest.

In conclusion, the CNPI is a brief, clinically useful approach to assessing pain in older

indicating that both raters had given the subjects similar scores on the average. Miller et al.⁸⁵ achieved Pearson correlation coefficients of 0.61 at Time 1 based on 15 pairs of observations and 0.77 at Time 2 with 17 pairs of observations for an overall correlation coefficient of 0.67 based on a total for 32 pairs of observations. Young⁶ obtained a percent agreement between two research assistants of 84% after an initial 30 hours of training and data collection with 12 subjects. After an additional 5 hours of training and data collection with 32 subjects, percent agreement reached 94%. Test-retest reliability was reported only in the original study.⁶⁹ Sixty-eight residents were scored twice at 1 hour intervals by two independent raters attaining Pearson correlation coefficients of 0.60 ($P < 0.001$) and nonsignificant paired t -test ($P = 0.46$) indicating no change after 1 hour.

The DS-DAT was able to detect significant differences in discomfort in a sample of 20 subjects identified by staff as having a fever episode ($F_{1,19} = 167.02$, $P < 0.001$): the mean score at baseline was 7.7 (SD 1.2), at peak 11.9 (SD 1.0), and on resolution 8.1 (SD 1.2).⁶⁹ Miller et al.⁸⁵ reported a significant relationship between self-report on a question of discomfort and discomfort thermometer and the DS-DAT. However, no reliability coefficients are reported on which to base the strength of the relationship. Young⁶ reported significant correlations between the DS-DAT and the aggressive subscale of the Cohen-Mansfield Assessment Inventory ($r = 0.25$) and Verbal Descriptor Scale ($r = 0.35$), respectively.

In conclusion, although the DS-DAT is well established as a reliable tool for use in research to assess discomfort in persons with dementia, validity for persons with pain specific conditions warrants further study. The tool is not comprehensive in addressing the pain-related indicators identified in recent literature. The tool includes only those pain indicators that are most common, excluding more subtle indicators related to change in behavior, mental status change, and changes in interpersonal interactions. The tool prescribes observation at rest, which may result in nondetection of pain indicators evident only on movement. The tool requires extensive training to achieve acceptable interrater reliability, thus limiting its use as a clinical assessment tool in routine

nursing care of older adults with dementia who may be experiencing pain.

The Doloplus 2^{70,86} is a French tool developed for the multidimensional assessment of pain in nonverbal older adults. The tool consists of three subscales and a total of 10 items: somatic reactions (five items), psychomotor reactions (two items), and psychosocial reactions (three items). Each item is leveled with four behavioral descriptions representing increasing intensity of pain rated from 0 to 3. Individual item scores are summed to arrive at a total score ranging from 0 to 30 points. Five points are identified as the threshold indicating pain. However, as the tool developers point out, pain can not be ruled out if the older adult has less than five points.

The Doloplus 2 is based on sound assumptions of multidimensionality of pain in older adults with pain that are supported in the literature on pain in older adults with dementia. The tool is comprehensive, covering five of six pain behavior categories in the AGS guidelines. The tool is based on the assumption that caregivers can reliably rate the intensity of older adults' pain, an assumption that is not supported by current literature. Moreover, no evidence to support appropriateness of leveling of behaviors within each item is provided.

Method of administration and scoring procedures are clearly described. The developers state that the tool only takes a few minutes to complete, but no data are reported to support this. The tool is intended for use by health and social care providers as well as family of the older adult. However, training requirements for reliable use of the tool by these different groups are not reported.

Several items in the English translation appear to need refinement as a number of items seem foreign when compared to the words and expressions most commonly used in English literature on pain in dementia. Moreover, there are currently no published reports of testing of the English version of the tool. However, the French version of the Doloplus 2 has been tested in diverse populations and settings including long-term care, geriatric clinics, and palliative care in France and Switzerland as reported below.

Internal consistency was tested in a pooled sample of 501 older adults from centers participating in the Doloplus Group. Average

age of subjects was 82.5 (SD 8; range 55–96) with 173 males and 337 females. Cronbach's alpha was 0.82. Interrater reliability was tested in two samples at palliative care hospitals in France. The sample at one site included 43 patients (28 males and 15 females) with a mean age of 73.5 (SD 7.2). The total mean score for Rater A was 11.4/30 (SD 5) and for Scorer B 10.9/30 (SD 4.8). In the second site, the sample included 41 patients (nine males and 32 females) with an average age of 82 years (SD 8.3). Scorer A had a total mean score of 17.3/30 (SD 4.0) and Scorer B 17.1/30 (SD 4.6). Test-retest reliability was evaluated in a pooled sample of 83 patients from divergent settings including 16 males and 67 females with an average age of 82.5 years (SD 8.0; range 66–96). Pain scores were measured twice at 4 hour intervals: at Time 1 the mean score was 9.33/30 (SD 5.17) and at Time 2 it was 9.36/30 (SD 5.47). A student's *t*-test was not statistically significant.

Convergent validity was established between the Doloplus 2 and a Visual Analogue Scale (VAS) in a mixed sample of 143 older adults from various geriatric or palliative care units in France and Switzerland. The sample included 44 males and 99 females with a mean age of 80.7 years (SD 8.9; range 65–101). Mean VAS scores were 5.46 (SD 2.27; range 1–10). The convergent validity of the two instruments was reported to be significant ($P < 0.001$). Sensitivity was tested at 11 centers in a pooled sample of 183 older adults, 73 males, and 110 females, average age 80.7 years (SD 8.6; range 65–101). Scores were reported as D0 = 10.6 (SD 5.3), D1 = 7.5 (SD 4.4), and D7 = 4.9 (SD 4.2), but it is not clear what these data points represent. However, although these test results provide evidence of the reliability and validity of the Doloplus 2, little information is provided concerning sample characteristics, such as method of assessment of dementia severity, and methodology used for establishing psychometric properties.

In conclusion, the Doloplus 2 is a comprehensive tool for assessing pain in nonverbal older adults. The tool addresses many key indicators noted in the literature and AGS guidelines. Via their Web site information the tool developers report extensive testing in Europe.^{70,86} However, information in English is

limited and available reports do not provide sufficient detail on which to base sound judgment of the tool evaluation. Translation issues are evident and further study or description regarding the use of Doloplus 2 in English-speaking populations is needed.

The FLACC⁷¹ is a behavioral scale for measuring intensity of postoperative pain in young children. Although this purpose does not align with the purpose of tools to assess pain in older adults with dementia, the FLACC is being used in some clinical settings with older adults and was evaluated for reliability and validity for clinical application with cognitively impaired older adults.⁸⁷ The tool includes five items, face, legs, activity, cry, and consolability, each of which is leveled on a 3-point scale for intensity by behavioral descriptors for a total score range from 0 to 10.

Although this tool has been suggested as a tool for older adults with dementia, the conceptual soundness of selected items for older adults has not been established. In particular, items such as leg kicking, arched or jerking activity, squirming, and quivering chin have not been reported in the literature to be pain behaviors in dementia and do not appear appropriate in older adults with dementia. Consolability is a tool item, although this would appear to be a response to an intervention rather than a pain behavior. The relationship between consolability and pain in persons with dementia has not been fully established, but may be an area for further study. Furthermore, the behavioral categories on the FLACC do not address three of the behavioral categories in the AGS guidelines: changes in interpersonal interactions, changes in activity patterns or routines, and mental status changes. The method of administration used in the study on older adults (see below) is not described. Information on the clinical usefulness of the tool in older adults is unknown.

The FLACC has been tested in long-term care in a sample of six cognitively impaired older adults predominantly female with a mean age of 83 years (SD 11) with a documented history of late-stage dementia and an identified source of pain.⁸⁷ This sample size severely limits generalizability of findings.

Internal consistency reliability data are not available. Interrater reliability was evaluated based on 69 valid FLACC observations rated

by three trained research observers independently recording pain assessments. Kappa statistic was 0.404 or less.⁸⁷ These researchers concluded that the FLACC is not a useful pain assessment tool for cognitively impaired elderly; however, small sample limits conclusions. No data are available regarding test-retest reliability.

Based on 69 valid FLACC observations and 56 observations on the Modified University of Alabama (UAB Pain Behavior Scale), the FLACC and UAB Pain Behavior Scale were significantly correlated. However, Spearman's rho data are not reported. Moreover, the UAB has not been validated in older adults with dementia and is questionable as an appropriate criterion measure for establishing construct validity in this population.

In conclusion, the FLACC is a tool conceptually developed and tested for use in assessing pain in young children, not older persons with dementia. The tool items are not conceptually established as appropriate for this population and are not consistent with AGS guidelines potential indicators of persistent pain in older adults. Preliminary testing with older persons with dementia suggests that the tool's reliability and validity has not been established. Without item revision and additional testing in appropriate samples, this tool is not appropriate for use in older adults with dementia.

The NOPPAIN⁷² is a nursing assistant-administered instrument for assessing pain behaviors in patients with dementia. This tool focuses on observation of specific pain behaviors while doing common care tasks. Pain is assessed at rest and with movement. The tool has four main sections: care conditions under which pain behaviors are observed such as bathing, dressing, transfers; six items about presence/absence of pain behaviors (pain words, pain noises, pain faces, bracing, rubbing, and restlessness); pain behavior intensity ratings using a 6-point Likert scale; and a pain thermometer for rating overall pain intensity.

The method of administration for using the NOPPAIN is described; however, scoring procedures are unclear. Moreover, no criteria are provided for establishing low to high intensity of pain behavior. Interpretation of tool score is unclear and there is no indication on how to proceed once rating of individual items is completed. The tool requires little time to

complete following a period of observation consistent with time to complete care activities. It is unclear what investment in training of nursing assistants is needed to assure accuracy in tool completion.

The NOPPAIN has been evaluated in two studies. Study 1 involved research assistants who viewed videos of an actress portraying an individual with severe dementia receiving care from a nursing assistant.⁷² The nursing assistants were 37 years of age on average (SD 11.5; range 21–60), predominantly female (86%), and African-American (76%), with high school diploma or equivalent (71%), and an average of 9.8 years of experience. In Study 2,⁸⁸ the NOPPAIN was evaluated in four Houston nursing homes and one Veterans Health Administration nursing home unit. The sample of 83 severely demented residents were 83.2 years on average (SD 8.8; range 50–100), was predominantly female (70%), and culturally diverse. The nursing assistants ($n = 20$) were 37 years of age on average (SD 10.5; range 21–60), mainly female (86%), African-American (81%), and a high school diploma or equivalent was held by 59%.

No report of internal consistency is currently available. Interrater reliability was evaluated in Study 2 using videotapes of nursing assistants performing morning care tasks with residents with dementia. Twenty-six videos were shown to six untrained nursing assistants and to six nursing assistants who received 1 hour of training on use of the NOPPAIN. Interrater reliabilities were moderate to strong for all tool items and improved with 1 hour of training. Test-retest reliability was evaluated in Study 2 with a subset of untrained nursing assistants. Results indicate low to moderate test-retest reliability at both 2 and 24 hours. Only the pain thermometer was stronger at 2 than 24 hours.

Construct validity was evaluated in Study 1 using standard videotaped patient scenarios representing a continuum of pain intensity levels using an actor to portray a bed-bound patient with severe dementia receiving care from a nursing assistant. Nursing assistants watched and rated videos using the NOPPAIN assessment process and completed global pain rating for each video. Nursing assistant's global pain rating on the NOPPAIN and pain levels portrayed in the videos resulted in a weighted kappa statistic of 0.87. Nursing assistants

identified videos showing the most pain from each of 15 pairs. The parameter estimates conformed to expected responses, although borderline. The lowest intensity pain condition had the smallest parameter, with parameter size increasing with each subsequent level of the pain response scale. All pain level comparisons were 82%–100% correct. To assess construct validity in Study 2, sensitivity and specificity were evaluated comparing NOPPAIN ratings by untrained nursing assistants to physician NOPPAIN ratings and physician pain classification (pain/no pain). For the Pain Activity Summary Score sensitivity and specificity were moderate to strong. For the Pain Behaviors Summary Score sensitivity was strong. However, specificity scores were low, suggesting that the tool may classify patients as having pain when they are not. Moreover, caution is warranted due to low levels of pain in the sample that limits evaluation of tool ability to detect pain in patients with higher pain levels.

The NOPPAIN was developed for the purpose of nursing assistant's screening for pain in older adults with dementia. The tool has limited comprehensiveness with behaviors addressing only obvious and not subtle cues or changes indicated in the literature. However, preliminary testing has established that the screening tool is reliable and has preliminary validity, and thus may be useful when combined with a more comprehensive screen for other indicators. Use of proxy report for pain intensity in a nonverbal population has not been supported in the literature and this aspect of the tool should be evaluated in clinical samples. Although the tool has been tested in a racially/ethnically diverse sample, the psychometrics were not reported, thus warranting further study. The tool appears to be clinically useful given the ability of nursing assistants to use and the limited time required for completion. Further psychometric testing is encouraged, including consideration of items to tap nursing assistant's knowledge of baseline behavior and recognition of subtle changes that might reflect presence of pain. Because assessment activities are outside the scope of nursing assistant practice, it will be important to determine if the expectations of the tool for nursing assistants are actually screening activities.

In summary, the NOPPAIN has limited comprehensiveness of nonverbal pain behaviors. Moreover, the NOPPAIN is conceptually grounded on validity of proxy report of pain intensity in nonverbal older adults with dementia, an assumption that is not supported by available research evidence. Ease of administration by nursing assistants is a strength of the tool. There is preliminary support for tool reliability and validity, but testing in clinical situations is needed.

The Pain Assessment Checklist for Seniors with Severe Dementia,⁷³ developed by a Canadian team, is an observational tool for assessment of both common and subtle pain behaviors. The tool is a checklist with four subscales and a total of 60 items: facial expressions (13 items), activity/body movements (20 items), social/personality/mood (12 items), and physiological indicators/eating and sleeping changes/vocal behaviors (15 items). Each item is scored on a dichotomous scale as present or absent. Subscale scores are summed to arrive at a total score ranging from 0 to 60. However, no interpretation of the total score is currently available. Simple instructions on how to administer and score the tool are clearly described on the tool form. Although the tool has 60 items, it requires a limited amount of time to administer and appears easy to use.

The PACSLAC was tested in a sample of 40 registered nurse/resident dyads in which the nurse recalled a resident who had been under his/her care for at least 6 months and who experienced pain. Nurses were 44 years old on average with an average of 19 years experience. The 40 corresponding residents were 85 years old on average and predominantly female (75%). Thirty-three had a diagnosis of dementia and 34 a diagnosis associated with pain.

Internal consistency was evaluated based on four remembered events including two painful events, one distressing but not pain-related, and one calm event. Alpha based on the average of the two pain events was 0.85, with alphas ranging from 0.55 to 0.85 for the four subscales. The methodology of using remembered events is appropriate in preliminary stages of tool development, but is subject to recall bias. Interrater reliability data have not been reported. Test-retest reliability has not been reported.

Discriminant validity was evaluated based on retrospective recall of painful events by the

nurse for four events as indicated above. The total PACSLAC score was able to discriminate among painful, calm, and nonpain-related distress events ($F_{3,117} = 108.1$, $P < 0.001$). Three subscales discriminated among painful, distressing, and calm events ($P < 0.001$): facial expressions, activity/body movement, and physiological indicators/eating and sleeping changes/vocal behaviors. The fourth subscale, social/personality/mood indicators, discriminated between pain and calm events but not between pain and distress events. Criterion-related validity was evaluated using global pain intensity ratings of the nurses' perception of the patient's pain as the gold standard. Pearson correlation coefficient for Pain Event 1 was 0.35 ($P < 0.05$) and for Pain Event 2 was 0.54 ($P < 0.001$) indicating moderate correlation.

In conclusion, the PACSLAC is a potentially clinically useful behavior checklist that appears simple to use for assessing and monitoring changes in persons with dementia and diverse presentations of pain-related behavior. The tool is comprehensive and addresses all six pain behavior categories included in the AGS guidelines. However, the tool needs prospective evaluation, (e.g., assessment of present pain rather than remembered pain), including factor analysis, with a larger sample size to establish tool reliability and validity.

PADE⁷⁴ is a tool for assessment of pain in individuals with advanced dementia developed to help caregivers assess patient behavior that may indicate pain. The tool has three parts with a total of 24 items: Part I, physical, includes observable facial expression, breathing pattern, and posture; Part II, global assessment, involves proxy evaluation of pain intensity; and Part III, functional, includes activities of daily living including dressing, feeding oneself, and transfers from wheelchair to bed.

Although the tool includes five categories of pain indicators noted in the AGS guidelines, operationalization is not clearly supported. The tool is based on the assumption that caregivers can reliably rate the intensity of older adults' pain, an assumption that is not supported by current literature.

Several issues have been identified related to construction, administration, and scoring. Three parts to the tool are described, yet 24 individual components are presented without clarity as to which part of the tool the

individual items belong. Relevance of some indicators to assessment of pain is lacking (e.g., neatness of grooming). Caregiver judgment of pain intensity as the gold standard has not been substantiated. There is inconsistency in narrative description of the tool and the tool illustration in the appendix. The narrative documents 4-point Likert rating, but the tool illustrates a semi-VAS format. Different anchors are used for each item, which may contribute to complexity of interpretation. Interpretation of overall tool score is unclear. Items 15–24 related to functional activities of daily living (ADL) are assessed retrospectively from the resident's chart. However, all other items are rated based on the resident's current situation. Differences in timing of assessment components could be problematic. The relationship of the ADL section in documenting pain is unclear. However, if the tool is used regularly and consistently, it may show changes over time (e.g., percent of time out of bed, percent of time awake, amount of meals eaten) that could be potential indicators of pain impact. There is an expectation of finding data for some items in the patient chart. However, based on current documentation practice, accurate information may not be available. Finally, a score of zero is given if an item is marked as "not applicable." The impact of this on the overall result and underestimation of pain is not addressed.

An instruction manual has been developed for the tool. Further explanation or clarification regarding administration and scoring of the tool may be documented; however, the instruction manual was not available for this review. It is suggested that tool administration takes 5–10 minutes. However, data to support this are not provided. Moreover, considering the complexity of the items, the variety of scaling approaches, and the expectation of finding answers in the patient record, this tool may take considerably longer to administer than the suggested 5–10 minutes. The raters in the research report are primarily nursing assistants; however, there is no discussion related to nursing assistants' scope of practice.

The research report of the PADE includes two evaluation studies. Study 1 was conducted in four long-term care facilities involving 25 residents with advanced dementia, a majority of whom were female (64%) and an average

age of 85 years. Study 2 was conducted in one long-term care facility in a sample of 40 residents with advanced dementia, predominantly female (80%) with an average age 81.3 years (SD 7.7; range 66–92). The sample size is small considering the number of items in the tool, which limits generalizability of findings.

Internal consistency was evaluated in both studies. Across studies alphas for Part I were acceptable, ranging from 0.76 to 0.88 but poor to moderate for Part III, ranging from 0.23 to 0.63. Thus, preliminary internal consistency of the tool is not well established for all components. Interrater reliability was evaluated in both studies. Intraclass correlations for Part I ranged from 0.93 to 0.95, for Part II from 0.54 to 0.89, and for Part III from 0.93 to 0.94. Thus, interrater reliabilities were mostly good. Test-retest reliability was also evaluated in both studies with intraclass correlations for Part I ranging from 0.70 to 0.98, for Part II from 0.34 to 0.70, and for Part III from 0.89 to 0.98. Thus, although reliabilities were good for Parts I and III, test-retest reliability for Part II varied from poor to acceptable.

The PADE Part I correlated significantly with the Cohen-Mansfield Agitation Inventory (CMAI), Verbal subscale ($r = 0.296$; $P < 0.01$), and PADE Part III with all three CMAI subscales ($r = 0.40, 0.40$, and 0.42 ; $P < 0.01$). PADE Part II did not significantly correlate with any CMAI subscale. Criterion validity was evaluated in Study 2. Residents were grouped with or without painful conditions using chart review. There were no statistically significant differences between groups with and without painful conditions on the PADE subtests or the CMAI. Residents were also grouped based on whether pain was a significant clinical factor or not. The “pain as a significant factor” group had significantly higher scores on the CMAI Verbal and PADE Parts I–III. Finally, residents were grouped based on whether they were on prescribed psychoactive medications or not. The group on psychoactive drugs had significantly higher scores on the CMAI Verbal, CMAI Aggressive, PADE I, and PADE III. Although use of psychoactive medication differentiates groups, control of agitated behavior, as well as analgesic use, could impact the behavioral presentations of pain and agitation/aggression.

Validity testing has not established the usefulness of the PADE in identifying those with

and without pain conditions, suggesting that relevant pain-related behaviors may not be present. Moreover, although agitation and pain have been associated in older adults with dementia, validation of this relationship should complement examination of other validity constructs. Usefulness of the PADE Part II is not supported based on psychometric evaluation conducted to date.

In conclusion, the PADE was developed to provide a simple tool for assessing pain in individuals with advanced dementia. However, issues related to tool construction, presentation, clarity in scoring and interpretation, and validity suggest the need for revision and further testing.

The PAINAD Scale⁷⁵ was developed to provide a clinically relevant and easy to use pain assessment tool for individuals with advanced dementia. The tool is an adaptation of the DS-DAT and the FLACC and includes five items: breathing, negative vocalization, facial expression, body language, and consolability. Each item is leveled on a 3-point scale from 0 to 2 for intensity.

The tool covers only three of six categories of nonverbal pain behaviors in the AGS guidelines: facial expression, verbalizations/vocalizations, and body language. Although these are common pain indicators, the more subtle pain indicators such as changes in activity patterns or routines, mental status changes, and changes in interpersonal interactions are not included. The tool is based on the assumption that caregivers can reliably rate the intensity of older adults' pain, an assumption that is not supported by current literature.

Method of administration is described and a guide with definitions of items is provided. Scoring procedures are clearly described, although no guide to interpretation of the tool score is provided. Subjects in the pilot study were observed for 5 minutes, but a clear recommendation for length of observation is not provided. The tool appears simple to understand and appears to be easy to use with limited training.

Initial testing of the PAINAD was conducted in two studies, both in Veterans Health Administration long-term care dementia special care units.⁷⁵ Study 1 involved a sample of 19 severely demented veterans, all male Caucasians, with an average age of 78.1 years (SD 5; range

66–85). Study 2 was a quality improvement study that involved charts of 25 residents. However, no demographic data or disease characteristics were available. Thus, limited sample size and demographic details of subjects limit generalizability of study results.

Internal consistency was evaluated based on a pooled sample of both studies. Cronbach's alpha from three situations ranged from 0.50 to 0.65, which is moderate given a new tool with only five items. The approach of combining research and quality improvement data to establish reliability is not methodologically sound. Interrater reliability is reported for 19 subjects with pairs of simultaneous observations by two independent raters. Pearson correlation coefficient during pleasant activity was 0.97 and during unpleasant activity 0.82. No test-retest reliability is reported.

Factor structure analysis for combined PAINAD data identified one factor explaining 50.1% of the variance (eigenvalue 2.51) and one minor factor explaining 20.6% (eigenvalue 1.03). PAINAD was compared to the Pain VAS, DS-DAT, and Discomfort VAS. Correlation coefficients at rest were 0.75, 0.76, and 0.76, respectively. PAINAD was compared to the Pain VAS during presumed pleasant conditions ($r = 0.87\text{--}0.95$) and presumed unpleasant conditions ($r = 0.82\text{--}0.91$). Discriminant validity of the PAINAD was evaluated in Study 1 with subjects observed during a pleasant activity, during rest or time of no activity, during caregiving that might be unpleasant with mean scores 1.0 (SD 1.3), 1.3 (SD 1.3), and 3.1 (SD 1.7), respectively. Using quality improvement data, the PAINAD captured pain and change in pain. Average PAINAD scores 6.7 (SD 1.8) prior to prn medication and 1.8 (SD 2.2) 30 minutes after pain medication were significant ($t_{24} = 9.6$, $P < 0.001$).

In conclusion, the PAINAD was developed as a short, easy to use observation tool for assessing pain in nonverbal older adults. The tool items included are not comprehensive; thus, the ability of the PAINAD to detect pain in persons with dementia with more subtle changes in behavior may be compromised. Although clinicians desire to have a tool that provides a 0–10 score similar to the 0–10 Numeric Rating Scale commonly used as the gold standard in verbal patients, the soundness of establishing a rating scale with pain intensity scoring

of behaviors has not been substantiated in the literature. Tool reliability is good for interrater reliability, but internal consistency is only moderate and stability has not been demonstrated. Some conceptual and methodological issues have been identified with the development and testing of the PAINAD. However, the positive findings in detection of changes in pain behavior following intervention in the quality improvement study reported suggest that additional study in controlled circumstances is warranted.

Discussion

The purpose of the review is to critically evaluate existing tools for pain assessment in nonverbal older adults with dementia to provide recommendations to clinicians. Ten assessment tools based on observation of behavioral indicators for use with this population were evaluated with criteria and indicators in five areas: conceptualization, subjects, administration, reliability, and validity. Results indicate that although a number of tools demonstrate potential, tools are still in early stages of development and testing. Currently, there is no standardized tool based on nonverbal behavioral pain indicators in English that may be recommended for broad adoption in clinical practice. However, clinicians may be interested in evaluating the use of selected tools in their specific settings.

This review has revealed a number of challenges in development of tools for assessment of pain in nonverbal older adults with dementia that warrant further discussion. First, there is considerable variability between patients with dementia in their expression of pain via behavioral demonstration. The effects of dementia on the brain can be quite variable, depending on the part of the brain affected, such that patient's pain responses can be unique.^{37,89,90} One patient may become withdrawn, refuse to eat, and rock in bed, while another may become aggressive and verbally abusive while pacing repetitively. These two very different patterns of behavior could both indicate the presence of pain, but not be represented easily in a tool to quantify pain-related behavior. It is because of these unique behavioral patterns that pain assessment tools that assess a broad range of possible pain

behaviors may have greater clinical utility and capture those pain responses that are less obvious or not typically what one would expect in cognitively intact older adults. This individual uniqueness in behavioral presentation needs to be considered in the development and evaluation of assessment tools for use with this population.

A second closely related issue involves the comprehensiveness of nonverbal pain indicators to include in an assessment tool. Tools included in this review were evaluated for comprehensiveness using a framework of six categories of behavioral indicators identified in the AGS guidelines. The summary of items on each of the assessment tools compared to the six categories in the AGS guidelines shows that all 10 tools in this review included a core of more obvious nonverbal indicators of pain including facial expressions, verbalizations/vocalizations, and body movements. However, there are greater differences between tools when comparing inclusion of more subtle nonverbal indicators of pain such as changes in interpersonal interactions, changes in activity patterns or routines, and mental status changes. Only three tools include indicators in all six areas.

It might be argued that tools that include a greater number of potential indicators would have greater sensitivity, increasing the likelihood of detecting pain if present. However, many subtle indicators, such as mental status change, are not exclusive to pain. Thus, including these indicators in a pain assessment tool may increase the likelihood of identifying pain when it is not present (false positives) and thus result in decreased specificity. Research has not yet established the sensitivity of presence of individual behaviors as indicators of pain. For example, if verbal abusiveness were present in only 1:100 nonverbal older adults with pain, it may not be clinically useful to include in a pain assessment tool.

Given limitations in the current state of the science of pain assessment in nonverbal older adults with dementia, we have taken the position that assessment tools used for screening for possible presence of pain need to be comprehensive. It would be more humane to identify patients with possible pain indicators and use follow-up in-depth assessment to validate pain presence than to not recognize pain in many because of limited pain indicators.

Moreover, we would emphasize that identification of pain indicators using a standardized tool is only one step in a complex diagnostic process. Use of a tool to identify pain behaviors should be integrated within a comprehensive approach to pain assessment in this population. One of the toolscha(that)-45(of)-3-7.8(ie)-376.6(t

Although a standardized assessment tool is not yet available for widespread use, a comprehensive approach to pain assessment is recommended in nonverbal older adults with dementia. A detailed approach to pain assessment with this population has been described in detail elsewhere.⁹¹ Briefly, a comprehensive approach to pain assessment in this population may include several steps as outlined below:

- Anticipate and assume the presence of pain based on the pathology resulting from the disease, injury, procedure, or surgery.
- Observe the older person for behaviors to establish a baseline of behavior. Monitor for pain on a regular basis using a comprehensive list of behavioral indicators. Whenever possible, pain-related behaviors should be observed during activity, such as transfers, ambulation, and repositioning, since behavior at rest can be misleading.
- All older adults can be observed for typical nonverbal cues of pain and behavioral changes. However, it is important to remember that there may be no such behaviors or cues in older adults with dementia or they may present with less obvious indicators such as agitation, aggression, or increased pacing.
- If the presence of pain is uncertain, an analgesic intervention may be warranted to evaluate presence of pain. If the interventions appear to provide pain relief, pain may be assumed as the likely cause and intervention continued.

Assessment of pain in nonverbal older adults with dementia remains a challenge for clinicians and researchers. The distant future for pain assessment in this vulnerable population may unfold options for recognizing pain through enhanced brain imaging techniques and monitoring of pain-related chemical substances currently under study. However, for the immediate future our focus must be on strategies to assist clinicians recognize pain with readily available methods and resources. Until a strong tool emerges that can be used with confidence, clinicians may choose to pilot selected tools if preliminary testing matches their setting and population. Of utmost importance is raising awareness of pain presence and potential indicators to screen for potential

pain in those not presenting with typical pain behaviors. A strategy for assessing pain in this group is described in current literature and readers are encouraged to integrate procedures that will assist staff in recognizing, validating, and treating pain in this vulnerable population.

Acknowledgments

This project was supported by a grant from The Mayday Fund, New York, NY.

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