

Tools for Pain Assessment in Older Adults with End-Stage Dementia

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Use of standardized pain assessment tools promotes consistency among care providers and care settings and facilitates communication and evaluation of pain treatment. In recent years, a number of standardized behavioral pain assessment tools have been developed for use by older adults with end-stage dementia. However, there are a number of considerations that should impact the selection of a standardized behavioral tool. This article addresses criteria for evaluation and selection of a behavioral pain assessment tool, reviews selected tools, and provides recommendations for their use.

An estimated 4.5 million Americans suffer from dementia, a figure expected to reach 16 million by 2050 due to the aging American population.¹ Although younger individuals may develop dementia, it is most commonly associated with advanced age. About one-tenth of people older than 65 years and about half of those older than 85 years have dementia. A progressive and debilitating disease for which there is no cure, dementia leads to severe cognitive impairment, inability to carry out daily activities, and ultimately death. Individuals with dementia are prone to infections, fractures, pressure ulcers, constipation, and other painful conditions. Their inability to communicate verbally presents a serious barrier to assessing pain in these individuals and places them at a higher risk for undertreated pain.²

Pain relief is a hallmark of quality palliative care. Regular ongoing assessment is the key to identifying pain and providing optimal pain management. Clinical practice guidelines recommend using

validated pain assessment instruments when available.³ The self-report is the gold standard of pain assessment. A number of self-report instruments are available and may be used reliably by individuals with mild to moderate cognitive impairment.⁴ However, after the individual loses language skills in the final stages of Alzheimer's disease, they are no longer able to verbally communicate their levels of pain. It is then necessary to use alternate strategies, including surrogate reports of behavior and observation of pain-related behaviors, to detect pain.

Criteria for Selecting a Behavioral Pain Assessment Tool

Recent critiques of behavioral pain assessment tools commonly used with older adults with end-stage dementia indicate that there is currently no tool that has sufficient reliability and validity to support broad adoption in clinical practice. Published studies evaluating existing tools are largely based on limited testing conducted in small samples or in a limited number of clinical settings.^{5,9}

One comprehensive review of tools may be accessed at www.cityofhope.org/prc/elderly.asp and as an article by Herr, Bjoro, and Decker.⁵ Ten behavioral pain assessment tools were reviewed for conceptual soundness, characteristics of population and setting in which tool testing has been conducted, strength of data to support reliability and validity, and feasibility for use in clinical practice.

Conceptual Soundness

Older adults with end-stage dementia present with wide variability in pain behaviors. The American Geriatrics

Society (AGS) developed a comprehensive list of six categories of potential nonverbal pain behaviors and indicators¹⁰ (Table 1). Although some behaviors are common and typically associated with pain (eg, facial grimacing, moaning, groaning, rubbing a body part), other indicators are more subtle and less common (eg, agitation; restlessness; irritability; confusion; combativeness; changes in appetite, sleep, or other daily activities). The AGS pain behaviors and indicators provide a benchmark against which to evaluate the comprehensiveness and appropriateness of behavioral items included in a behavioral pain assessment tool.

A tool that includes a comprehensive selection of behaviors and indicators is more likely to detect pain. However, some behaviors that may indicate pain are also associated with other conditions, such as general distress. Thus, a particular behavior (eg, aggressiveness) may not necessarily mean the individual is experiencing pain. If only a limited number of common indicators are included in a behavioral pain tool, however, pain may go undetected in individuals with atypical pain presentations.

Absence of common pain behaviors does not mean the patient is not in pain. More subtle indicators may be needed to detect pain in an individual with an atypical pain presentation. Moreover, physiologic indicators (eg, changes in heart rate, blood pressure, respiratory rate) are not sensitive indicators for discriminating pain from other sources of distress. Little research supports using vital-sign changes to identify pain.

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Published quarterly by the American Academy of Hospice and Palliative Medicine

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Nonverbal pain indicators that reflect a change in behavior (eg, change in appetite, sleep pattern) require baseline knowledge of the patient's typical behavior. A comprehensive tool that requires monitoring subtle changes in behaviors may be more appropriate in a long-term care setting. In the acute care setting, however, it may be appropriate to limit indicators to those that are more commonly observed.

Behavioral pain tools are different from tools that measure pain intensity. A behavioral pain tool can help detect the presence but not the intensity of pain. Although some behavioral pain tools attempt to quantify pain, the score produced is not the same as a pain-intensity rating. The behavioral pain score cannot be compared with standard pain-intensity ratings or categories of pain severity.^{11,12}

Reliability and Validity

Strength of tool reliability and validity based on evaluation data is a crucial consideration when selecting a behavioral pain tool for use in a particular clinical setting and patient population. Tools must be repeatedly tested in different settings (eg, acute care, long-term care) and populations to accumulate supporting evidence of tool reliability and validity. Tool reliability addresses consistency of tool measurements, including internal consistency, interrater reliability, and test-retest reliability. Validity addresses whether the tool measures pain and how well the tool distinguishes between pain and other phenomena. Validity may be measured as criterion-related validity and construct validity. Establishing reliability is essential because an unreliable tool is useless regardless of its validity.

Feasibility of Use

Assessing the feasibility of using a particular tool in clinical practice includes issues such as ease of use, clarity of instructions on how to use the tool, and how to interpret the scoring instructions and the scores one generates using the tool. The time needed to complete the pain assessment and the skill level and training required to use a particular tool are also pertinent issues to address.

Table 1. Common Pain Behaviors in Cognitively Impaired Older Adults

Facial Expressions

Slight frown; sad, frightened expression

Grimacing; wrinkled forehead; closed or tightened eyes

Any distorted expression

Rapid eye blinking

Verbalizations, Vocalizations:

Sighing, moaning, groaning

Grunting, chanting, calling out

Noisy breathing

Asking for help

Verbal abuse

Body Movements:

Rigid, tense body posture; guarding

Fidgeting

Increased pacing, rocking

Restricted movement

Gait or mobility changes

Changes in Interpersonal Interactions:

Aggression, combativeness, resistance to care

Decreased social interactions

Social inappropriateness, disruptiveness

Withdrawn

Changes in Activity Patterns or Routines

Refusal of food, appetite change

Increased rest periods

Sleep, rest pattern changes

Sudden cessation of common routines

Increased wandering

Mental Status Changes:

Crying or tears

Increased confusion

Irritability or distress

From AGS Panel on Persistent Pain in Older Persons. The management of persistent pain in older persons. J Am Geriatr Soc 2002;50(6 Suppl):S205-24. Used with permission

Table 2. Overview of Strengths and Weaknesses of Selected Behavioral Pain Assessment Scales for Older Adults with End-Stage Dementia*

Nonverbal Pain Behavior Scale	Description	Comprehensiveness†	Validity	Reliability	Feasibility/Clinical Utility
CNPI ^{15,18-21}	6 items Pain present/not present	Limited	Moderate	ICR: Moderate IRR: Good TRR: Fair to moderate	Easy to use Score interpretation not clear Tested in AC and LTC
Doloplus 2 ²²⁻²⁶	10 items 0-3 scale	Good	Mostly moderate	ICR total scale: Moderate ICR subscales: Fair to moderate IRR and TRR: Not established	English version not tested Tool is difficult to use and interpret Time to complete: 5 minutes Tested in AC and LTC
NOPPAIN ²⁷⁻²⁹	6 items Pain present/not present 0-5 scale	Limited	Validity supported with video standard	ICR: Not reported IRR and TRR: Good using video standard	Easy to use Score interpretation: Not provided Not tested in clinical setting
PACSLAC ^{24,30}	60-item checklist Pain present/not present	Good	Moderate to good	ICR total scale: Moderate to good ICR subscales: Low to moderate IRR: Excellent TRR: Good	Easy to use Time to complete: 5 minutes Tested in LTC
PACSLAC-D-Revised ³	24-item checklist Pain present/not present	Good	Correlates with original PACSLAC	ICR: Good IRR and TRR: Not tested	Not yet evaluated
PAINAD ^{15,24,29,31-37}	5 items 0-2 scale	Limited	Moderate	ICR: Moderate IRR: Good TRR: Good	Easy to use Time to complete: 5 minutes Tested in LTC and AC
PAINE ^{14,15}	22 items	Good	Moderate to good	ICR, IRR, TRR: Adequate	Complex tool Time to complete: Unknown Tested in LTC

ICR indicates internal consistency reliability; IRR, interrater reliability; TRR, test-retest reliability; AC, acute care; and LTC, long-term care.

*A more detailed overview of these behavioral pain assessment scales can be found on the AAHPM Web site at www.aahpm.org

†Comprehensiveness is based on number of American Geriatric Society (AGS) pain behavior categories the tool includes: 0 to 4 of 6 categories=limited comprehensiveness; 5 or 6 of 6 categories=good comprehensiveness.

Strengths and Weaknesses of Currently Available Tools

Behavioral pain assessment tools currently available for use with older persons with end-stage dementia are at different stages of development. Table 2 displays an overview of the strengths and weaknesses of selected tools found to have the strongest conceptual and psychometric support based on the critique by Herr and colleagues,⁵ and the table has been updated with more recently published studies further evaluating these tools. Included in Table 2 is a newly developed second-generation tool, PACSLAC-D-revised.¹³

A new tool called The Pain Assessment in Noncommunicative Elderly Persons (PAINE) has been critiqued for inclusion in this review.^{14,15}

Recommendations for Use of Tools in Older Adults with End-Stage Dementia

Because there is not yet a recommended behavioral pain assessment tool for use in clinical settings where older adults with end-stage dementia receive care, a comprehensive approach to pain assessment has been recommended for use with this population and may include the following^{5,12,16}:

- Attempt to obtain a self-report of pain from all patients. An individual with end-stage dementia may be able to respond “yes” or “no” to a question about the presence of pain. When pain is suspected in older adults with limited verbal abilities, further investigation and observation of behaviors are warranted.
- Search for potential causes of pain. Pain should be anticipated and assumed to be present in patients with a disease or injury known to cause pain and in those who undergo

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painful procedures or surgery. Problems that may be causing pain or discomfort should be considered (eg, fractures, infection, constipation) and either ruled out or treated.

- Observe behaviors recognized as indicators of pain in older adults with end-stage dementia. The AGS categories of behavioral pain indicators provide a comprehensive list that may be used to guide pain assessment. It is important, however, to be aware that there may be no observable behaviors or cues in older adults with severe dementia. Moreover, less obvious or atypical behaviors may indicate pain (eg, aggression, subtle changes in usual activity or appetite, increased confusion or delirium) and warrant evaluation. Healthcare clinicians may select a standardized behavioral pain assessment tool and evaluate its appropriateness for use in that particular setting and patient population.
- Actively solicit surrogate reporting of pain and behavior by family members and other caregivers. Family members are often familiar with the patient's usual pain presentation and behaviors and can help identify subtle and less common potential pain behaviors. In long-term care facilities, certified nursing assistants often have close contact with patients and need to be trained to actively observe and report pain behaviors in the patients they care for.
- Initiate an analgesic trial. If an objective cause of pain is not found or if pain behaviors persist after providing basic care measures, an analgesic trial should be attempted to help determine if pain is the cause of the suspected behaviors. When pain intervention results in behavior returning to normal, it is likely that pain was the causative factor, and continued intervention will be needed. Guidelines for an analgesic trial have been provided in detail elsewhere.¹⁷

Conclusion

Assessment of pain in nonverbal older adults with end-stage dementia is a challenge for clinicians. Although further research is needed, suggested approaches to assessment of pain are available that may improve recognition and treatment of pain for this vulnerable population.

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