Pain Assessment in Nonverbal Older Adults with Advanced Dementia

Marianne Smith, MS, ARNP, CS

**TOPIC:** Pain assessment is a particular challenge among individuals with advanced dementia who lack the ability to formulate and express their experience of discomfort.

**PURPOSE:** Awareness of pain scales and methods specifically designed for use with nonverbal individuals with dementia is critical to expanded use and testing in clinical settings.

**SOURCES:** Computerized literature searches using four databases revealed the five observational scales and two caregiver reports methods reviewed.

**CONCLUSIONS:** A small number of valid, reliable, and sensitive scales are available for use by nurses and allied health personnel. Each has strengths and limitations and all would benefit from additional testing.

**Search terms:** Dementia care, pain assessment, advanced dementia

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**Overview of the Problem**

The role of discomfort, both emotional and physical, is well known and accepted as an antecedent to behavioral disturbances among people with dementia (Hall & Buckwalter, 1987; Teri & Logsdon, 2000; Volicer & Hurley, 1999). The loss of ability to process, understand, and describe internal and external experiences regularly leads to behavioral expressions of distress, particularly as the disease progresses (Kovach, Weissman, Griffie, Matson, & Muchka, 1999; Volicer, 2001). Like other aging individuals, those with dementia are likely to have one or more chronic health conditions that cause pain, which, in turn, contributes to unnecessary discomfort, dysfunctional behavior, and diverse behavioral symptoms, and potential worsening of comorbid conditions. As a result, pain is an important factor to assess in older adults with dementia.

Nurses, and other allied healthcare providers that provide day-to-day care, are in key positions to facilitate accurate assessment and adequate treatment of pain, particularly among individuals in late-stage dementia who lack the ability to process their experiences and communicate needs verbally. No matter what the care setting—home, nursing home, or inpatient unit—both advanced practice and generalist nurses regularly play pivotal roles in managing complex patient care problems like pain assessment in advanced dementia. Through direct care, supervisory, educational, consultation, and interdisciplinary roles, nurses may positively influence care practice. Enhanced awareness of methods to accurately depict the pain experiences of nonverbal individuals with advanced dementia are critically important to effective care, treatment, and management across the healthcare continuum.
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Purpose

This review of literature highlights factors related to pain assessment among older adults with advanced dementia who are unable to communicate verbally. Background factors, including rates of pain among older adults as a group, common barriers to pain assessment among elderly, and problems inherent to usual pain assessment methods, are briefly reviewed to provide a framework for understanding pain assessment in advanced dementia. Specific problems created by dementia are then reviewed, including the need for pain definitions and methods that address the unique needs of those who are unable to communicate verbally (alternatively called nonverbal and noncommunicative throughout this paper). Seven assessment methods are reviewed, including brief discussion of items and psychometric properties. Conclusions related to possible future steps to further strengthen assessment scales and their use in practice are offered.

Sources of Literature Reviewed

Articles describing pain assessment methods that did not rely on verbal report were identified as part of a larger literature review related to pain measurement among older adults (Smith & Bjoro, 2002). Computerized literature searches of four databases (i.e., MEDLINE, CINAHL, PubMed, and EMB Reviews) used various combinations of search terms related to pain and older adults, and limited searches to older adults, research, and to a lesser extent, review articles. Narrower searches using combinations of dementia and pain focused on pain assessment methods. Assessment tools developed for use with cognitively impaired and nonverbal individuals were identified, reviewed, and included here. In addition to computerized literature searches, additional resources related to pain assessment in advanced dementia were identified via professional colleagues engaged in the field and review of key references. Five observational scales and two proxy methods that rely on the report of a caregiver who knows the person with dementia well are reviewed here. Psychometric properties are summarized in table format to allow easy comparison and evaluation for potential inclusion in clinical practice and research.

Pain in Older Adults

Consideration of pain in advanced dementia is perhaps best understood from the perspective of the larger picture of pain in late life. Pain is a common problem among older adults, affecting as many as 25% to 86% of community-dwelling older adults (Herr, 2002) and 40% to 80% of individuals living in long-term care facilities (AGS, 1998; Cutson, 2001; Thomas, Flaherty, & Morley, 2001). Pain directly causes suffering and is associated with the worsening of many health conditions including decreased physical function, impaired mobility, decreased socialization, depression, sleep disturbance, and increased health utilization costs (AGS, 1998; Ferrell, Ferrell, & Rivera, 1995). In spite of its known prevalence and associated risks, pain is often unrecognized and frequently undertreated, particularly in older adults with cognitive impairment (Ferrell, 1995; Mobily & Herr, 2001; Weissman & Matson, 1999).

A variety of barriers to pain assessment and treatment have been identified. Myths about older adults contribute to under-treatment of pain, including the common misconceptions that pain is a “natural” consequence of aging and cannot be avoided, that if older adults do not complain of pain, they must not experience it, and that older adults have decreased sensitivity to pain (Herr, 2002). Political and social pressures to control illicit drug use, fear of producing addiction, and concern about differing effects of pain medications on older adults also contribute to problems (Thomas et al., 2001). Staffing shortages and staff who are inadequately trained to assess pain are also believed to contribute to problems in long-term care settings (Blomqvist & Hallberg, 2001; Cutson, 2001). Finally, the beliefs of older adults themselves, like being afraid to complain or bother busy nurses, and thinking they need to learn to live with pain, further contribute to problems.
Although older adults, as a group, are at risk for under-treatment of pain, problems among cognitively impaired older people are even more severe (AGS, 1998; Miller, Nelson, & Mezey, 2000).

### Pain in Older Adults with Dementia

Alzheimer’s disease and related progressive disorders create additional disabilities that interfere with pain detection and treatment. The essential features of dementia, including memory impairment, disturbance in executive function, aphasia, apraxia, and agnosia (APA, 2000), progressively interfere with all aspects of function. Loss of ability to use language is perhaps the most widely recognized confounding factor in pain identification (Farrell, Katz, & Helme, 1996). Of equal or more importance is the increasing loss of ability to introspect and comprehend internal states (Kovach et al., 1999), a process that is necessary to accurately identify sensations, feelings, and experiences. Finally, two cultural beliefs, that nothing can be done for individuals with dementia, and that persons with dementia do not experience pain so do not require medication or other interventions (Miller et al., 2000) create additional barriers to pain assessment in dementia.

Over the last decade, numerous investigators have established that cognitively impaired older people are able to report pain using one or more method (Ferrell, 1995; Ferrell et al., 1995; Herr, 2002; Mobily & Herr, 2001; Parmelee, Smith, & Katz, 1993). However, these studies have systematically eliminated cognitively impaired patients who are noncommunicative. For example, Ferrel and colleagues’ pioneering work (1995) on pain in cognitively impaired patients excluded 21% of subjects because they were “mute and unresponsive, and no meaningful information could be obtained” (p. 594). This perspective is echoed elsewhere in the literature and underscores the current emphasis placed on self-report of pain. Given the fact that language loss is inevitable in the most advanced stages of dementia, valid and reliable methods to assess pain in noncommunicative older adults are clearly needed.

### Definitions of Pain and Advanced Dementia

Common definitions of pain include the fact that it is a complex, multidimensional, subjective, unpleasant, and emotional experience that is mediated by sensory experiences and nociceptive events, and influenced by social, cultural, and individual differences (Mobily & Herr, 2001). McGuire conceptualized the multidimensional, subjective and personal experience of pain as having six primary dimensions: physiologic, sensory, affective, cognitive, behavioral, and sociocultural (McGuire, 1992). The important emphasis placed on pain as a subjective and personal experience simultaneously stresses self-report as the most valuable indicator. For example, the widely used definition of pain as being “whatever the experiencing person says it is and exists whenever he or she says it does” (McCaffery & Beebe, 1989) underscores this belief. For some, pain report is the “gold standard” of pain assessment in older adults (Pickering, Eschalier, & Dubray, 2000), a perspective that is illustrated by belief that the only reliable evidence of pain is a patient’s self-report to the question, “Do you have pain right now?” (Thomas et al., 2001). While pain experienced by those with advanced dementia will likewise be a personal experience that is unpleasant, emotional, complex, and multidimensional, the definition of pain used must not rely on self-report.

In the limited work that has been conducted in pain assessment among nonverbal patients with advanced dementia, the term discomfort is often used interchangeably with pain. Hurley and colleagues (1992) defined discomfort in advanced dementia as “a negative emotional and/or physical state subject to variation in magnitude in response to internal or environmental conditions” (p. 369). This definition was operationalized as being the presence of behaviors that signal negative emotional and/or physical states and that can be observed by a trained rater who is unfamiliar with the patient’s usual behavior (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992). Other definitions of pain and/or discomfort among nonverbal patients...
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with advanced dementia often are based on this early definition (Kovach, Noonan, Griffie, Muchka, & Weissman, 2001; Simons & Malabar, 1995). Of interest, Hurley and colleagues most recently used the term pain instead of discomfort, defining pain simply as a multifactorial symptom expressed by several signs but forming a single construct (Warden, Hurley, & Volicer, 2003). Thus, observable behaviors, or signs, are the foundation of pain assessment in advanced dementia. In this review of literature, the terms discomfort and pain are assumed to address the same construct when applied to nonverbal persons with advanced dementia.

Assessing Pain in Advanced Dementia

Measurement of pain in nonverbal patients with advanced dementia has progressed slowly over the last 15 years. The pioneering work conducted by Volicer, Hurley, and colleagues (Hurley & Volicer, 2001; Hurley et al., 1992; Volicer, Fabiszewski, Rheame, & Lasch, 1988; Warden et al., 2003) continues to be the backbone of assessment methods today. The following review of assessment methods targets observational methods that may be used by any trained provider and thus may be especially valuable in clinical settings. Two additional pain assessment methods that rely on caregiver report, and which may be more valuable in consultation and liaison roles, are also described. Information about the scales’ items (Table 1) and psychometric properties (Table 2) are summarized and provided in table format to facilitate comparison.

Comfort Checklist

The importance of meeting comfort needs in advanced dementia was first described by Volicer and colleagues (1988) as part of a text that addressed clinical management of people with Alzheimer’s disease. The variety of factors that could easily predispose persons with advanced dementia to discomfort was emphasized and included contractures, arthritic events, unwitnessed injuries, and an array of intercurrent illnesses (Volicer et al., 1988). The need for objective assessment of noncommunicative patients led to the development of the Comfort Checklist, a descriptive scale that focuses on documentation of behavioral symptoms that signal distress and possible pain.

The Comfort Checklist includes five domains of assessment: vocalization, motor signs, behavioral indicators, facial expressions, and miscellaneous symptoms. Specific signs are specified for each domain with suggested rating from none to moderate to severe. Refer to Table 1, “Comparison of Pain Scale Items,” to review assessment parameters. Although the checklist does not assign numeric rating of discomfort, it clearly points to the complex and multifactorial assessment that may be needed to assure comfort among nonverbal patients with Alzheimer’s disease. The accompanying text emphasizes the importance of using behavioral cues as indicators of discomfort or pain, and likens assessment processes to those used with infants and children who lack language. Although the care needs of adults with dementia and children are not analogous, the “process of elimination” used to assess possible causes of crying in infants parallels the type of assessment required for nonverbal patients with Alzheimer’s disease. In many care situations, descriptive methods like the checklist are valuable early in the assessment process when deciphering possible antecedents to behavioral symptoms is underway.

Discomfort Scale in Dementia of the Alzheimer’s Type (DS-DAT)

Work to develop and refine a valid and reliable method to assess discomfort in advanced dementia was described by Hurley and colleagues (1992). As noted earlier, discomfort was conceptually defined as “a negative emotional and/or physical state subject to variation in magnitude in response to internal or environmental conditions” (p. 369) and operationalized as “the presence of behaviors considered to express a negative and/or physical state that are capable of being observed by a trained rater unfamiliar with the
Table 1. Comparison Pain Scale Items

<table>
<thead>
<tr>
<th>Comfort Checklist</th>
<th>Observed Pain Behavior Scale</th>
<th>Discomfort Scale in Dementia of the Alzheimer's Type (DS-DAT)</th>
<th>Checklist of Nonverbal Pain Indicators (CNPI)</th>
<th>Pain Assessment in Advanced Dementia (PAINAD)</th>
<th>Pain Assessment in the Dementing Elderly (PADE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Five categories of comfort/potential discomfort are described and rated on a 3-point scale from none to moderate to severe.</td>
<td>Seven domains are rated as follows:</td>
<td>Nine behavioral indicators of discomfort are included:</td>
<td>Six pain behaviors are scored as present or absent with a total score ranging from 0 to 6 pain behaviors observed.</td>
<td>Five domains are rated from 0 to 2 with specific item definitions provided for each parameter included in the rating scheme.</td>
<td>Twenty-four items in three domains are rated from 1 to 4. Fifty items are rated with descriptive anchors and nine include descriptors for each point.</td>
</tr>
<tr>
<td>1. Vocalizations</td>
<td>■ Verbalizes complaint</td>
<td>■ Noisy breathing</td>
<td>■ Verbal complaints such as “ouch,” “that hurts,” or “stop”</td>
<td>Breathing: independent of vocalization</td>
<td>Physical signs</td>
</tr>
<tr>
<td>■ Wailing</td>
<td>■ Negative vocalizations</td>
<td>■ Sad facial expression</td>
<td>■ Nonverbal vocalization such as sighs, gasps, moans, groans, or cries</td>
<td>0 = Normal</td>
<td>1. “Sad” facial expression</td>
</tr>
<tr>
<td>■ Crying</td>
<td>■ Content of facial expression</td>
<td>■ Frightened facial expression</td>
<td>■ Facial grimacing or wincing, clenched teeth, furrowed brow, tightened lips, or narrowed eyes</td>
<td>1 = Occasional labored breathing; short period of hyperventilation</td>
<td>2. “Anxious/frightened” facial expression</td>
</tr>
<tr>
<td>■ Moaning</td>
<td>■ Frowned</td>
<td>■ Relaxed body language</td>
<td>■ Bracing behavior characterized by clutching or holding an affected area during movement</td>
<td>3 = Noisy labored breathing; long period of hyperventilation; Cheyne-Stokes respirations</td>
<td>3. Frowning</td>
</tr>
<tr>
<td>2. Motor signs</td>
<td>■ Responsive and alert</td>
<td>■ Relaxed body language</td>
<td>■ Massaging the affected area</td>
<td>Negative vocalization</td>
<td>4. “Tense” body language</td>
</tr>
<tr>
<td>■ Restlessness</td>
<td>■ Responsive on approach by nurse</td>
<td>■ Fidgeting</td>
<td>■ Restlessness characterized by constant or intermittent shifting of position, rocking, or inability to keep still</td>
<td>0 = None</td>
<td>5. Restlessness</td>
</tr>
<tr>
<td>■ Agitation</td>
<td>■ Responsive on approach by significant others</td>
<td>■ Each item is following a complex rating scale that includes nine combinations of each of three characteristics of pain that are then rated from 0 to 3 per item. Each combination includes a determination of the following three variables:</td>
<td>■ Massaging the affected area</td>
<td>1 = Occasional moan or groan; low level of speech with negative or disapproving quality</td>
<td>6. Grimacing, bracing, groaning during transfers</td>
</tr>
<tr>
<td>■ Pacing</td>
<td>■ Responsive on approach by member of multidisciplinary team</td>
<td>■ Frequency: number of episodes during a 5-min period</td>
<td>■ Restlessness characterized by constant or intermittent shifting of position, rocking, or inability to keep still</td>
<td>2 = Repeated troubled calling out; loud moaning or groaning; crying</td>
<td>7. Guarding affected area</td>
</tr>
<tr>
<td>■ Fidgeting</td>
<td>■ Responsive on approach by significant others</td>
<td></td>
<td>§ Frequency: number of episodes during a 5-min period</td>
<td>Facial expression</td>
<td>8. Moaning, groaning</td>
</tr>
<tr>
<td>■ Posture/gait change</td>
<td>■ Responsive on approach by member of multidisciplinary team</td>
<td></td>
<td></td>
<td>0 = Smiling or inexpressive</td>
<td>9. Distress speech, vocalizations</td>
</tr>
<tr>
<td>■ Muscular rigidity</td>
<td>■ Responsive on approach by member of multidisciplinary team</td>
<td></td>
<td></td>
<td></td>
<td>10. Language coherence, complexity</td>
</tr>
<tr>
<td>■ Tense fingers</td>
<td>■ Responsive on approach by member of multidisciplinary team</td>
<td></td>
<td></td>
<td></td>
<td>11. Loud, gasping breathing</td>
</tr>
<tr>
<td>■ Guarding</td>
<td>■ Responsive on approach by member of multidisciplinary team</td>
<td></td>
<td></td>
<td></td>
<td>12. Rapid breathing, hyperventilation</td>
</tr>
<tr>
<td>3. Behaviors</td>
<td>■ Responsive on approach by member of multidisciplinary team</td>
<td></td>
<td></td>
<td></td>
<td>13. Grooming, overall appearance</td>
</tr>
<tr>
<td>■ Anxiety</td>
<td>■ Responsive on approach by member of multidisciplinary team</td>
<td></td>
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</table>
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## Table 1. Continued

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<tbody>
<tr>
<td>- Poor appetite</td>
<td>14. Not relaxed with drawn-up knees</td>
<td>Intensity: low intensity = barely to moderately perceptible or high intensity = present in moderate to great magnitude</td>
<td>1 = Sad; frightened; frowned</td>
<td>14. Caregiver rating of resident’s pain level</td>
<td>14. Caregiver rating of resident’s pain level</td>
</tr>
<tr>
<td>- Lacks animation, spontaneity</td>
<td>15. Not relaxed, touching presumed area of pain</td>
<td>Duration: short duration &lt; 1 min or long duration &gt; 1 min</td>
<td>2 = Facial grimacing</td>
<td>Functional abilities</td>
<td>Functional abilities</td>
</tr>
<tr>
<td>- Lethargy</td>
<td>16. Not relaxed and stiff</td>
<td></td>
<td>3 = Unable to console, distract, or reassure</td>
<td>15. Independence in eating</td>
<td>15. Independence in eating</td>
</tr>
<tr>
<td>- Facial grimacing</td>
<td>17. Vital signs (TPR, BP) within patient’s normal</td>
<td>Body language</td>
<td>0 = Relaxed</td>
<td>17. Location of meal</td>
<td>17. Location of meal</td>
</tr>
<tr>
<td>- Wincing</td>
<td>18. Vital signs changed: specify</td>
<td>1 = Tense; distressed, pacing; fidgeting</td>
<td>2 = Rigid; fists clenched; knees pulled up; pulling or pushing away; striking out</td>
<td>18. Time awake in 24 hours</td>
<td>18. Time awake in 24 hours</td>
</tr>
<tr>
<td>- Wrinkled brow</td>
<td>19. Other physiological change</td>
<td>Consolability</td>
<td>0 = No need to console</td>
<td>19. Hours out of bed while awake</td>
<td>19. Hours out of bed while awake</td>
</tr>
<tr>
<td>- Frightened appearing</td>
<td>Behavioral change</td>
<td>1 = Distracted or reassured by voice or touch</td>
<td>3 = Unable to console, distract, or reassure</td>
<td>20. Hours interacting with others</td>
<td>20. Hours interacting with others</td>
</tr>
<tr>
<td>5. Miscellaneous</td>
<td>Feedback from others</td>
<td></td>
<td></td>
<td>22. Level of agitation</td>
<td>22. Level of agitation</td>
</tr>
<tr>
<td>- Shallow or rapid breathing</td>
<td>22. In pain/uncomfortable</td>
<td></td>
<td></td>
<td>24. Indications of wanting to leave facility</td>
<td>24. Indications of wanting to leave facility</td>
</tr>
<tr>
<td>- Family/staff report discomfort</td>
<td>Conscious state</td>
<td></td>
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</tr>
</tbody>
</table>
Table 2. Pain Scale to Assess Advanced Dementia: Comparison of Reported Psychometric Properties

<table>
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<th>Measure</th>
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<td>Discomfort Scale for Dementia of the Alzheimer’s Type (DS-DAT)</td>
<td>Hurley, A. C., Volicer, B. J., Hanrahan, P. A., Houde, S., &amp; Volicer, L. (1992). Assessment of discomfort in advanced Alzheimer patients. Research in Nursing &amp; Health, 15(5), 369–377.</td>
<td>Scale development underwent three studies. Study 1: Content validity index (CVI) = 1.0; CVI probability was beyond .05 Study 2: 9 items retained; internal consistency α = .77; test-retest r = .6, p &lt; .001; paired t-test yielded t(67) = 0.74, p = .46 indicating no change in scores from baseline to retest in 1 hour Study 3: Cronbach’s α = .86 to .89 over 6 months Inter-rater reliability: conducted at 4 points and included 5 to 9 patients, resulted in r = .86, .89, .91 and .98; Construct validity: supported by mean baseline 7.7 to 11.9 at peak to 8.1 at resolution of intercurrent illness; repeated measures ANOVA F(1, 19) = 167.02, p &lt; .001; 2 orthogonal contrasts support construct validity No psychometric properties are reported.</td>
</tr>
<tr>
<td>Checklist of Nonverbal Pain Indicators (CNPI)</td>
<td>Feldt, K. S. (2000). The checklist of nonverbal pain indicators (CNPI). Pain Management Nursing, 1(1), 13–21.</td>
<td>Inter-rater reliability: simultaneous observation by two master’s prepared gerontological nurse practitioners and a subset of patients (n = 13); 93% agreement (κ = 0.625 to 0.819, p = .19 to .0057) Internal consistency: Kuder Richardson 20 (KR 20) at rest, alpha coefficient = .54 (confidence interval [CI] = .36 to .68); during movement alpha = .64 (95% CI = .49 to .75). Criterion validity: correlations between the CNPI and a 6-point verbal descriptor scale (VDS) for all 64 patients included: Rest: CNPI with VDS, Spearman correlation rₜ = .372, p = .001; Movement: CNPI with VDS, Spearman correlation rₜ = .428, p = .0001</td>
</tr>
</tbody>
</table>
Correlations between CNPI and VDS for cognitively impaired patients (who were able to reply verbally) included:

- **Rest:** CNPI with VDS, \( r_s = .299, p = .076 \)
- **Movement:** CNPI with VDS, \( r_s = .4629, p = .009 \)

### Pain Assessment in Advanced Dementia (PAINAD)


- **Inter-rater reliability:** described as “adequate”; specifics not reported
- **Internal consistency:** two raters for each of three different conditions (below) using Cronbach’s \( \alpha \):
  - **Observation 1:** rated during rest or no activity
    - Mean score for 19 patients = 1.3 ± 1.3
    - Cronbach’s \( \alpha = .57 \)
  - **Observation 2:** rated during pleasant activity
    - Mean score for 19 patients = 1.0 ± 1.3
    - Cronbach’s \( \alpha = .59, .63 \)
  - **Observation 3:** rated during unpleasant activity
    - Mean score for 19 patients = 3.1 ± 1.7
    - Cronbach’s \( \alpha = .50, .67 \)

ANOVA for 3 conditions: \( F(1, 17) = 10.93, p < .001 \)

- **Construct validity:** Chart audit data for 25 patients; Prior to medication: mean = 6.7 ± 1.8; After medication: mean = 1.8 ± 2.2; \( t(24) = 9.6, p < .001 \)
  - DS-DAT and DS-VAS: \( r = .81, p < .001 \)
  - PAINAD and Pain VAS: \( r = .75, p < .001 \)
  - PAINAD and DS-DAT: \( r = .56, p < .016 \)
  - DS-VAS and Pain VAS: \( r = .85, p < .001 \)

### Pain Assessment for the Dementing Elderly (PADE)


- **Reliability \( (n = 24 \) residents):**
  - **Inter-rater:** 2 raters over 10 days for a total of 784 observations; Intraclass correlation coefficients (ICC) were high; Part I ICC = 0.93, Part II = .81, Part III = .96
  - **Internal consistency:** Cronbach’s \( \alpha \) for Part I and III were .77 and .63 respectively

- **Test–retest:** Part I ICC = .70, Part II ICC = .34, Part III ICC = .89, Validity \( (n = 40 \) residents)

- **Construct validity:** Part I and verbal agitation scale: \( r = 0.29, p < .01 \) Part II and physically, verbally, and nonphysically agitated subscales: \( r = 0.396, 0.398, \text{and} 0.421 \) respectively, all \( p < .01 \)
Criterion validity: Significant painful conditions rated by chart review: 10 positive compared to 30 negative; no statistically significant differences in PADE or agitation scale scores. Significant painful conditions as judged by nurse: 8 positive compared to 32 negative; statistically significantly higher scores in the pain group on verbal agitation ($z = -2.83, p < .01$), Part I ($z = -3.44, p < .01$), Part II ($z = -4.30, p < .01$) and Part III ($z = -2.31, p < .01$).

Psychoactive medication use: number of subjects in each group not reported; those on psychoactive medications had statistically significantly higher scores on physical agitation subscale ($z = -3.34, p = .01$) verbal agitation subscale ($z = -1.95, p = .05$) and Part III ($z = -3.25, p < .01$).

Proxy Pain Questionnaire (PPQ)


Test–retest reliability: All three items were significantly and highly correlated with each other at the two time points (presence of pain, $r = .84, p = .0007$; frequency of pain, $r = .87, p = .0003$; intensity of pain, $r = .84, p = .0006$).

Construct validity: PPQ scores were also significantly related to amount of pain medication used by residents during that time (presence of pain, $r = .37, p = .0075$; frequency of pain, $r = .55, p = .0011$; intensity of pain, $r = .41, p = .0022$).

Inter-rater reliability: calculated as percentage of agreement between two nurses assessing four residents, was 86% for the total tool.

Inter-rater reliability was 100% for medication use, 76% for nonpharmacological interventions and 87% for behavioral assessment of symptoms.

Table 2. Continued

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| Proxy Pain Questionnaire (PPQ)     | Fisher, S. E., Burgio, L. D., Thorn, B. E., Allen-Burge, R. A., Gerstle, J., Roth, D. L., & Scott, J. A. (2002). Pain assessment and management in cognitively impaired nursing home residents: Association of certified nursing assistant pain report, minimum data set pain report, and analgesic medication use. Journal of the American Geriatrics Society, 50(1), 152–156. | Criterion validity: Significant painful conditions rated by chart review: 10 positive compared to 30 negative; no statistically significant differences in PADE or agitation scale scores. Significant painful conditions as judged by nurse: 8 positive compared to 32 negative; statistically significantly higher scores in the pain group on verbal agitation ($z = -2.83, p < .01$), Part I ($z = -3.44, p < .01$), Part II ($z = -4.30, p < .01$) and Part III ($z = -2.31, p < .01$).

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Inter-rater reliability was 100% for medication use, 76% for nonpharmacological interventions and 87% for behavioral assessment of symptoms.

usual behavioral patterns of the person” (p. 370). Refer to Table 1 to review the nine behavioral indicators of discomfort included on this scale.

Three underlying assumptions grounded tool development. First, discomfort can be observed although it may not be verbally expressed by patients with advanced dementia of the Alzheimer’s type (DAT). Second, patients with DAT cannot verbally control their expressions or demeanor; thus, observed behaviors can be considered external markers of internal states.
Finally, states of normal development are reversed in DAT. As a result, indicators of discomfort would be similar to those in infants and children.

Three separate studies were conducted in Veterans Administration facilities to develop and test the Discomfort Scale. Refer to Table 2, “Comparison of Psychometric Properties,” for additional detail relating to content validity, internal consistency, inter-rater reliability, and construct validity. Psychometric evaluation of the Discomfort Scale demonstrated that it had the required properties of a new scale. As noted by the authors, external validity was limited because the scale was tested exclusively with men and thus additional studies that include women were needed. Likewise, questions remained about the timing and duration of discomfort assessments, particularly during aversive care procedures, and the sensitivity of the tool to changes-related interventions designed to reduce discomfort.

In the years since its publication, practical concerns about the DS-DAT have emerged, including the complexity of the scoring schema, associated difficulties achieving inter-rater reliability in clinical settings, and the requirement of 5 min of nursing time to rate the scale (Bachino, Snow, Kunik, Cody, & Wristers, 2001; Hooker, Barrick, Mitchell, & Sloane, 1997; Krulewitch et al., 2000; Miller, Neelon, Dalton et al., 1996). In spite of these difficulties, it remains the gold standard by which nearly all additional observational pain assessment tools are evaluated by their developers. Of perhaps most importance, conceptual grounding of the DS-DAT laid the foundation for others to build upon, including the later development of the Pain Assessment in Advanced Dementia or PAINAD (described later).

Observable Pain Behaviors Scale

A third pain scale developed and pilot tested for use with nonverbal elderly patients targeted individuals with dementia and others. The research hypothesis was that “the phenomenon of pain in the elderly patient who cannot communicate verbally can be systematically assessed and effectiveness of interventions to relieve pain [can be] evaluated” (Simons & Malabar, 1995, p. 665). Although the investigators reviewed the DS-DAT for possible use in their study, the scale was rejected because the definition of discomfort could not be considered to mean pain alone. However, neither a conceptual or operational definition of pain among nonverbal patients was provided. The investigators chose to develop their own rating system using an “amalgam of pain behaviors” adopted from an observation method for chronic low back pain (Keefe & Block, 1982).

The Observable Pain Behaviors Scale includes seven domains including verbal responses, facial expression, body language, physiological change, behavioral change, and conscious state. Each domain is rated by selecting the verbal description that best fit the patient’s presentation. The number of verbal descriptions per domain ranges from three to eight and are not mutually exclusive categories. Refer to Table 1 to review specific descriptions. No information about reliability or validity is provided. Likewise, the adaptation of items from the original scale is not described. As a result, a number of steps are needed to establish the validity and reliability of this scale prior to further use. Of note, the outcomes of this study are often reported in the literature (Bachino et al., 2001; Cook, Niven, & Downs, 1999; Feldt, 2000; Huffman & Kunik, 2000) despite the lack of documentation about tool’s psychometric properties.

Checklist of Nonverbal Pain Indicators (CNPI)

The Checklist of Nonverbal Pain Indicators (CNPI) offers a brief, easy-to-use assessment method for determining pain in cognitively impaired older adults. Instrument testing was conducted with elderly hip fracture patients (Feldt, 2000), including both cognitively impaired (n = 53) and cognitively intact (n = 35) patients. The CNPI is composed of six items that are rated as present or absent. Refer to Table 1 to review items included. Checklist items were adapted from the University of Alabama Birmingham Pain Behavior
Scale, a 10-item scale was developed for use in rehabilitative medicine that is rated on three-point scale (Richards, Nepomuceno, Riles, & Suer, 1982).

Feldt (2002) reported that the CNPI has good face validity, and established inter-rater reliability for periods of rest and movement. The CNPI was also compared to a six-point verbal description scale (VDS) using a subsample of patients who were able to rate their pain verbally. Correlations between the VDS and CNPI at rest and during movement, both for cognitively intact and impaired patients, are detailed in Table 2.

The CNPI is both brief and easy to use, making it an attractive alternative in clinical practice. However, use of dichotomous scoring reduces the scale’s sensitivity to possible changes in pain. Likewise, reevaluation of item validity is warranted based on the failure of some items to detect pain either at rest or during movement. In specific, only two items performed well in detecting pain among cognitively impaired patient during rest, including grimacing (31%) and restlessness (21%) with the remaining four items being observed less than 12% of the time. The CNPI’s low probability of detecting baseline pain (at rest) may reduce the likelihood that pain treatment will be initiated and may easily contribute to acute exacerbations of pain on movement. Additional studies are needed to examine item validity and further evaluate use of the CNPI, particularly with nonverbal populations.

Pain Assessment in Advanced Dementia (PAINAD)

A recently published pain assessment scale extends earlier work with the Comfort Checklist and Discomfort Scale. The Pain Assessment in Advanced Dementia (PAINAD) was developed as a brief, easy-to-administer measure of pain in nonverbal individuals that, by design, provides an overall score and is sufficiently sensitive to detect changes in pain (Warden et al., 2003).

Pain in persons with advanced dementia was defined as a multifactorial symptom expressed by several signs but forming a single construct. Items for the PAINAD were generated through literature review and consultation with experts in the field, and building on both earlier research with the DS-DAT and the Faces, Legs, Activity, Cry, Consolability Scale used with children (Merkel, Shayevitz, Voepel-Lewis, & Malviya, 1997). Five items include breathing, negative vocalization, facial expression, body language, and consolability. Each item is rated on a three-point scale from 0 to 2 with specific descriptions provided for each level of discomfort.

Psychometric properties of the PAINAD were evaluated in a two-phase study that involved direct observation and retrospective chart audits. Direct observation involved rating by two trained raters who assessed patients under three conditions using combinations of the PAINAD, two visual analog scales (the Pain VAS and Discomfort VAS), and the DS-DAT. Retrospective chart audits of pain assessment using the PAINAD supported the tool’s sensitivity to changes in pain. See Table 2 for specific information.

The PAINAD shows promise as a brief, easily administered and yet sensitive measure of pain among nonverbal patients with advanced dementia. As the investigators acknowledged, additional studies related to the tool’s use in other settings, at different times of day, and using a more diverse population of subjects, including women and racial/ethnic minorities, are needed to further establish its psychometric properties and value in clinical practice. In addition, use of patient videotapes to establish inter-rater reliability may not be easily replicated elsewhere.

Pain Assessment for the Dementing Elderly (PADE)

The Pain Assessment for the Dementing Elderly (PADE) consists of 24 items that are divided into three sections, including physical signs, global assessment, and functional activities (Villanueva, Smith, Erickson, Lee & Singer, 2003). Items were developed on the basis of literature review, interviews with nursing staff in long-term care facilities, and naturalistic observation of patients in a dementia unit. Fifteen items are scored
from 1 to 4 using description to anchor item scoring (e.g., none to extreme; calm to extremely restless). The remaining nine items offer four categorical choices that are also scored from 1 to 4 in response to a question. Throughout the scale, lower scores are associated with more functional behavior and higher scores are associated with dysfunctional or distressed behaviors. Content of items is similar to those in other scales but is framed in the form of questions (e.g., “Does the patient have a sad facial expression?”; “During transfers, does the patient grimace, brace him- or herself, groan, etc.”).

Reliability and validity were addressed in two studies that included a total of 65 older adults living in residential and skilled care facilities. Ratings were made by caregivers (e.g., most were nursing assistants) after training and under the supervision of a nurse. Rating required 5 to 10 min to complete. Reliability measures included inter-rater reliability, internal consistency and test–retest. Refer to Table 2 for psychometric properties. Validity measures included comparison of the PADE to a verbal agitation scale to determine construct validity and various comparisons of patients who experienced pain, had painful conditions, and exhibited agitation to establish criterion validity. The authors conclude that the PADE demonstrates good reliability and validity.

Limitations noted by Villanueva and colleagues include the relatively small number of subjects in the study overall, limited minority representation in the sample, and lack of a comfort intervention to determine if the PADE can detect changes in pain status. Other potential limitations include lack of a cutoff score, and the extended amount of time needed (up to 10 min of observation), to rate pain. Although the authors believed that use of regular caregivers was a strength of this study, questions remain about the extent to which prior knowledge of the patient’s behavior may have facilitated use of the scale. As described in the next sections, those who know the patient well often are able to detect subtle changes in behavior that may be oblivious to another (e.g., staff of inpatient care settings).

Proxy Pain Questionnaire (PPQ)

The Proxy Pain Questionnaire (PPQ) is one of two methods described here that specifically rely on the report of a caregiver who knows the patient well. The PPQ was developed as part of a larger study that examined the relationship between Minimum Data Set (MDS) pain scores and nursing assistant assessments of pain (Fisher et al., 2002). The PPQ asks three questions about the presence (i.e., “Within the last week has the resident experienced pain?”), frequency (i.e., “How often does the resident experience pain?”), and intensity (i.e., “When this resident has pain, how would you describe the extent of the pain?”). The first item (presence) is answered yes/no and the remaining items are rated on a 13-point horizontal Likert-type scale that is anchored with verbal descriptors (i.e., never, occasionally, moderately often, often, and always for frequency; mild, moderate, and severe for intensity).

Preliminary findings support the value of the PPQ as a proxy rating method. Test–retest reliability was significantly and highly correlated for all three items. Refer to Table 2 for additional detail. The PPQ scores were deemed a more sensitive measure of pain than the MDS based on its higher correlation with analgesic medication use compared to the MDS. Likewise, the MDS identified pain in only 20% of the sample even though 46% were receiving analgesic medication. In contrast, the PPQ identified pain in 48% of the sample.

Assessment of Discomfort in Dementia (ADD)

Another promising approach in pain assessment is the Assessment of Discomfort in Dementia (ADD) protocol (Kovach et al., 2001; Kovach, Noonan, Griffie, Muchka, & Weissman, 2002). The ADD protocol was developed for use with persons who have moderate to severe dementia who are unable to clearly and consistently report on their internal states (Kovach et al., 2001). Based on the assumption that behaviors
associated with dementia are symptoms of unmet needs (Kovach et al., 2002), the protocol provides stepwise recommendations that combine assessment and intervention strategies. In the ADD protocol, pain is defined as an “unpleasant internal state that results from physiologic stimuli” while affective discomfort is “an unpleasant internal state that results from non-physiologic stimuli” and discomfort is an “unpleasant physical or affective internal state that results from either physiologic or nonphysiologic stimuli” (Kovach et al., 2002, p. 17).

Behavioral symptoms are believed to be caused by either affective or physical causes which are simultaneously assessed in the protocol. Changes in facial expression, mood, body language, voice, and behavior are used as triggers to initiate use of the protocol when basic needs interventions have failed to provide comfort. The protocol is structured in five steps that include (a) physical assessment, (b) review of history for potentially painful conditions and use of interventions related to the physical assessment findings, (c) affective assessment and implementation of nonpharmacologic comfort measures, (d) use of a prescribed, as needed nonopioid analgesic if behaviors persist, and (e) consultation with the physician or other health provider if behaviors persist, or use of a prescribed, as needed psychotropic drug (Kovach et al., 2002).

Limited information about the psychometric properties of ADD is currently available. Refer to Table 2 for additional detail. Although protocol is not focused on measurement of pain or discomfort, preliminary findings suggest that the method is effective in reducing potentially pain-related behavioral symptoms in dementia, and promotes use of both nonpharmacological comfort measures and pharmacological interventions, primarily use of analgesics (Kovach et al., 1999, 2001). Although additional testing is indicated with both the PPQ and ADD protocol, each shows promise as means to more accurately identify pain among nonverbal older adults with advanced dementia.

Discussion and Conclusions

The tools reviewed here each contribute to the slowly expanding arena of pain instrumentation for the most impaired individuals with dementia—those who have lost their ability to process experiences and communicate them verbally to others. The profound disability experienced by those in end-state dementia makes pain assessment difficult at best. Lacking the ability to differentiate between various sensations and needs, the same type of behavior that signals the need to toilet may emerge when a person experiences discrete physical pain. Each is experienced as form of stress that may erupt in behavioral symptoms (Hall & Buckwalter, 1987; Kovach, Griffie, Muchka, Noonan, & Weissman, 2000).

Although this review focused primarily on tools that may be used by caregivers who do not know the usual habits and patterns of the patient, qualitative research clearly supports the fact that knowing the person is extremely important in the detection of pain among those with dementia (Marzinski, 1991; Parke, 1998). Various studies exploring nurses’ perceptions of pain among their nonverbal elderly patients report that diverse behavioral symptoms are used as a basis for initiating a pain intervention (Blomqvist & Hallberg, 2001; Cohen-Mansfield & Creedon, 2002; Kovach et al., 2000; Parke, 1998). Atypical and seemingly paradoxical behaviors may represent pain in specific patients as described by Marzinski (1991) who reported that pain caused one patient who normally moaned and rocked to become quiet and withdrawn, while in another, blinking rapidly signaled nurses of pain. Parke (1998) concluded that nurses recognize pain by knowing the individual with pain, and by having many relationships and experiences with cognitively impaired patients that leads to “intuitive perception” or knowing by diversity. Of importance, the ability to accurately recognize changes in behaviors that may signal pain extends to nursing assistants (Fisher et al., 2002; Horgas & Dunn, 2001; Parke, 1998) who provide most of the day-to-day care in long-term care facilities, home health, and other settings.
Pain Assessment in Nonverbal Adults with Advanced Dementia

Clearly, the need for assessment methods that accurately identify pain in older adults with advanced dementia who are nonverbal will only increase in the future. As the number of older adults increases over the next five decades as the baby boomers age, so will the number of individuals who experience dementia and survive into the terminal stages. “Intuitive” assessment methods, including use of proxy measures and nursing care protocols that rely on knowing the person well may be useful in identifying pain that would otherwise be undetected. In an ideal situation, care providers would know the care recipients’ personal habits and history. However, in light of early and rapid discharge from acute care settings and staff turnover rates in nursing facility care, this ideal may never be realized. Thus, pain assessment measures that may be used by a person who does not know the usual habits, patterns, and baseline behaviors of the patient are needed to better assure that treatable discomfort is relieved in this complex patient population.

Each method described here has merit in a given context of care, and each has limitations. Nurse clinicians and other healthcare providers must apply methods thoughtfully, considering the goals of pain assessment, the relative complexity of the measure in relation to potential day-to-day users, and environmental factors that may facilitate or deter use in “real time.” Finally, additional structured trials to further test the use of these, or other, methods are needed to assure that reliable and valid measures that are sufficiently sensitive to detect pain, and pain relief, among nonverbal patients with dementia are available for use in day-to-day care settings.

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