**Tool:** The Assessment of Discomfort in Dementia (ADD)  
**Tool developer:** Kovach, C.R. and colleagues  
**Country of origin:** USA

<table>
<thead>
<tr>
<th>Conceptualization</th>
<th>Panel rating: 2</th>
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| **Purpose**       | The Assessment of Discomfort in Dementia (ADD) Protocol 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 Protocol is not a typical pain measurement tool.

The author currently states the tool is an intervention. However, it is included in this review because of its ability to detect pain in this population. |

| Conceptual basis | The ADD Protocol focuses on evaluation of persons with difficult behaviors that may represent discomfort. Assessment of pain and discomfort is addressed by the protocol. ADD encompasses physical, affective and social dimensions of pain. |
|------------------| The protocol is based on the following definitions:  
Pain: an unpleasant internal state that results from physiologic stimuli.  
Affective discomfort: an unpleasant internal state that results from non-physiologic stimuli.  
Discomfort: a condition of either physical pain or affective discomfort. |

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<th>Item Generation</th>
<th>Tool item</th>
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| **Tool item**   | In the 2002 version, the main categories of pain behaviors are specified as indicators of discomfort that could trigger use of the ADD Protocol:  
Facial expression: Grimacing, frowning, blinking, tightly closed or widely open eyes, frightened, weepy, worried, sad  
Mood: Irritability, confusion, withdrawal, agitation, aggressiveness  
Body language: Tense, wringing hands, clenched fists, restless, rubbing/holding body part, hyper- or hypoactive, guarding body part, noisy breathing  
Voice: Moaning, mumbling, chanting, grunting, whining, calling out, screaming, crying, verbally aggressive  
Behavior: change in appetite, sleep mobility, gait, function, participation, exiting, wandering, elopement, physically aggressive, socially inappropriate or disruptive, resists cares  
Other |

If potential pain behaviors are identified, the protocol consists of the following steps:  
Step 1 Assessment of physical signs and symptoms  
Step 2 Current / past history of pain  
Step 3 If steps 1 and 2 are negative assess environmental press, pacing of activity/stimulation, meaningful human interaction and intervene with non-pharmacological Rx’s.  
Step 4 If unsuccessful, medicate with non-narcotic analgesic per written order.  
Step 5 If symptoms persist, consult with physician/other health professional or medicate with prn psychotropic per written order. |
A Guide for Common Assessment Parameters is provided to support step 1. The Protocol includes a list of non-pharmacologic comfort interventions.

The most recent update includes two alternative versions of the protocol, one for LTC and one for the acute care setting, however no evidence for use in acute care is provided.

**Item generation process**

The behavioral indicators are based on an extensive literature review and on focus groups and include behaviors representing all 6 categories of persistent pain behaviors in the AGS Persistent Pain Guidelines.

**Content Validity**

The ADD Protocol was not subjected to external review by independent content experts in the field of pain in dementia.

**Panel Commentary**

The protocol attempts to differentiate between behavioral changes caused by affective discomfort and those related to pain.

Pain and discomfort are viewed as a multidimensional construct with physical, affective and social dimensions. This is carried over in the items which cover all 6 pain behavior categories in the AGS Persistent Pain Guidelines. The potential pain indicators are comprehensive in scope.

Identification of the non-verbal cues is the trigger for initiation of the ADD protocol. The non-verbal pain behaviors are measured as present/absent. Thus, the tool does not attempt to measure pain severity, which is consistent with the limitations of interpretation of pain behaviors in elders with dementia.

The assessment is divided into a step-by-step process. The protocol is unique in using interventions (both non-pharmacological and as needed analgesics) as a part of the assessment process.

### Subjects

**Panel rating: 2**

#### Study 1 (1999)

- Setting: 32 long term care facilities
- Subjects: Convenience sample of 104 residents
- Average age: 85 years; Range: 46-100 years
- Most subjects had a diagnosis of Dementia Alzheimer Type, were unable to communicate unmet needs and exhibited signs or symptoms commonly indicating the presence of physical pain or affective discomfort.

#### Study 2 (2001)

- Setting: 6 LTC facilities in a Midwestern city
- Subjects: A convenience sample of 143 subjects
- Average age: 86.65 years (±6.16), Range: 56-100 years
- Gender: 81% female and 19% male
- Caucasian sample
- Average length of stay in LTC: 39.12 months (1 to 220, ±35.07)
- Average MMSE score: 5.45 (±6.16), Range 0 – 20.

**Panel Commentary**

Focus on long term care setting is clearly identified. The number of facilities may be excessive especially in study 1 which opens for wide variability of results. Limiting number of facilities to 6 in study 2 may decrease variability.

Sample in study 1 does not indicate method of determining severity of
cognitive impairment. Subject gender is not specified in study 1. In study 2 there is limited male representation. There is no information on ethnic/racial diversity for study 1. In study 2 the sample is limited to Caucasians. The sample in study 2 utilizes the MMSE which is an appropriate tool for screening for dementia. Given the nature of the protocol, it is not possible to evaluate sample size adequacy.

### Administration, Scoring, Feasibility

#### Panel rating: 2

<table>
<thead>
<tr>
<th>Administration, Scoring, Feasibility</th>
<th>For an overview of tool items, see “item generation” above.</th>
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<tbody>
<tr>
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<td>Tool developers indicate that systematic assessment of behavioral symptomatology would occur on admission to LTC, at quarterly reviews, through daily monitoring and at meetings to review resident behaviors. Several triggers that may elicit ongoing monitoring of behaviors are indicated including:</td>
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<td>• Coding on the Minimum Data Set</td>
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<td>• Systematic assessment of behavioral symptomatology.</td>
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<td>A Guide for Common Assessment Parameters is provided to support step 1. Moreover, the protocol includes a list of non-pharmacologic comfort interventions.</td>
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<td>Preliminary testing of the ADD Protocol was conducted in naturalistic settings without controls. Implementation in practice was accompanied by extensive teaching of nurses on how to use the protocol.</td>
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<td>Nurses completed questionnaires after implementation of the first version of the ADD Protocol: 12% thought the protocol had no real impact, 44% found ADD somewhat helpful, 44% found it very helpful. Benefits of using the ADD included increased staff awareness of discomfort and improved assessments.</td>
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<tr>
<td>-Panel Commentary</td>
<td>Method of administration is adequately described.</td>
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<td>“Scoring procedures” are not applicable.</td>
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<td>Interpretation of assessment results at each step in the protocol relies heavily on clinical judgment.</td>
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<td><strong>Clinical utility</strong></td>
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<td>• <strong>Time:</strong> There is no documentation of time involved in using the ADD Protocol. The protocol involves multiple steps and extensive documentation to complete. This indicates that a considerable amount of time may be involved in using the protocol.</td>
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<td>• <strong>Skill needed:</strong> The ADD Protocol involves multiple steps and complex clinical decisions. Use of the protocol requires extensive education. No information on training time or target user is provided.</td>
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### Reliability

#### Panel rating: 1

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<th>Internal consistency</th>
<th>Internal consistency evaluation is not provided.</th>
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<tbody>
<tr>
<td>Interrater reliability</td>
<td>Study 1</td>
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<td>Four residents were assessed by two nurses.</td>
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Percent agreement
For the total tool 86%
For medication use: 100%
For non-pharmacological interventions: 76%
Discomforting symptomatology: 87%.

Test-retest reliability
Test-retest of the ADD Protocol has not been established

Panel commentary
- Internal consistency
  Because of the nature of the protocol, evaluation of internal consistency may not be appropriate. However, the behavior checklist could and should be evaluated for internal consistency.

- Interrater reliability
  The sample size for establishing Interrater reliability is too small for making inference.

  Although percent agreement between two raters was established for 4 residents with good results, kappa statistic would be more appropriate.

- Test-retest reliability:
  Test-retest reliability testing is appropriate, and is needed for evaluating persistent pain.

General
No data on reliability in identification of pain related behaviors used to trigger use of the protocol are provided.

Validity: Criterion or construct
Panel rating: 2

Construct validity/
Criterion related validity
Predictive validity
Study presented in Kovach et al., 1999. (see sample characteristics for study 1 above).
Behavioral assessment of discomforting symptomatology: 87%
7 days prior to instituting the ADD Protocol, the sample had an average of 32.85 (±16.78) behavioral symptoms associated with discomfort. Seven days following ADD protocol, the sample had an average of 23.47 behaviors (±16.52). This represents a significant decrease in discomfort (t=6.56, p=0.000) and a significant increase in use of pharmacologic (t=2.56, p=.012) and non-pharmacologic interventions (t=3.37, p=.001).

The most frequently seen behavioral symptoms pre-intervention were (listed by order of frequency): tense body language, sad facial expression, fidgeting, perseverant verbalizations, verbal outburst. These were also prevalent post-intervention, however fidgeting was slightly more frequent than sad facial expression at post-intervention. Further, the behavioral symptoms showing the largest average changes at post-intervention compared to pre-intervention were tense body language and sad facial expression.

Panel commentary
The behavior changes reported are supportive in the expected direction; however, construct and/or criterion validity as would be established for traditional measurement tools has not been established with the ADD Protocol to date.
Summary of panel evaluation of pain assessment tool

The ADD Protocol 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. 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. Although the protocol is a complete approach to recognition of pain in this population, it may be too complex for routine use and streamlining of the steps may be needed.

Sources of evidence


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Key to panel 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
0= Evidence is absent

Evaluation completed by:
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