Tool: **Discomfort Scale-Dementia Alzheimer Type**
Tool developer: **Hurley, A.C., Volicer, B.J., Hanrahan, S.H., Volicer, L.**
Country of origin: **USA**

Conceptualization **Panel rating: 3** ***Revised: 2***	
Purpose	The purpose of the Discomfort Scale-Dementia Alzheimer Type is to measure discomfort in elders with dementia of the Alzheimer's type.
Conceptual basis	Discomfort is defined as: "A negative emotional and/or physical state subject to variation in magnitude in response to internal or environmental conditions." Discomfort is operationally defined as the presence of behaviors considered to express a negative emotional and/or physical state that is capable of being observed by a trained rater unfamiliar with the usual behavior pattern of the patient. Tool development was based on the assumption that discomfort can be observed, even though it may not be verbally expressed by the patient. Since individuals with Alzheimer's disease cannot voluntarily control their expressions or demeanor, observed markers would be considered as external markers of internal states. An assumption underlying development of the DS-DAT is that indicators of discomfort in patients with Alzheimer's disease would be similar to those in infants and children.
Item Generation	<u>Tool items</u> • Noisy breathing • Negative vocalization • Content of facial expression • Sad facial expression • Frightened facial expression • Frown • Relaxed body language • Tense body language • Fidgeting Each item is measured for absence or presence of indicators of discomfort, which if present are scored for frequency, duration and intensity. <u>Study 1: Item generation</u> Items were generated through interviews with 45 nursing staff in VA units. Content validity was then evaluated by 9 clinical experts. Content analysis was conducted by the research team to derive 26 themes. Congruence with infant/children pain research was evaluated. The tool items were reviewed by content judges and rated for relevance on a 4-point scale. 18 items scored 3 or 4 on 4 point content validity index by all 9 judges and were retained→ Content validity index (CVI)=1.0. <u>Study 2 : Item reduction</u> Eighteen items were rated on 100 mm visual analog scale (absent=0 – extreme=100). Field notes documented defining characteristics observed, length of time and

	degree present. Overall discomfort was recorded on separate 100 mm visual analog scale (completely comfortable=0 - extremely uncomfortable=100). 68 subjects in two LTC facilities were observed by the primary investigator. Five minute observations were made and discomfort was rated by the researcher and unit nurse. The 18 items rated were repeated after 1 hour. After item reduction, 9 items were retained.
Content Validity	The initial list of 26 items developed in study 1 was reviewed for content validity by 9 nurses with advanced nursing degrees holding clinical/ leadership positions that brought them in contact with patients who required long-term inpatient care for DAT. Content experts practiced at one of three Alzheimer centers in the northwest, midwest and northeast of the USA.
-Panel Commentary	Conceptually, the focus of this tool is on discomfort and not pain. Thus, the original testing of the tool focused on elders' experience of discomfort during a fever episode, not a painful condition. Measuring presence or absence of discomfort behaviors is appropriate, as is assessing frequency, duration and intensity of behaviors. Thus, the tool does not attempt to measure severity or intensity of pain. Behaviors seen in children were used for item development although commonalities between children and nonverbal older adults is not established in the literature. Content validity was established by subjecting the tool to independent external review by experts in pain in elders with dementia in the long term care setting. <u>Comprehensiveness of items</u> The DS-DAT addresses obvious and some subtle pain behaviors. Of 9 tool items on the DS-DAT 4 items are related to facial expression, 3 to body language and 2 to vocalization and breathing. The tool is heavily weighted on facial activity. The tool covers 3 of 6 categories of non-verbal pain behaviors in the AGS Persistent Pain Guidelines: Facial expression, Verbalizations/vocalizations and Body language. Three items are not addressed: Changes in activity patterns or routines, Mental status changes, Changes in interpersonal interactions. Although noisy breathing is listed as a discomfort behavior, it may not be a salient indicator of pain and may also be impacted by other disease states. *Scoring for this item was revised to reflect this review's focus on pain assessment instruments.*
Subjects **Panel rating: 3** ***Revised: 2***	
Subjects	<u>Hurley et al. (1992)</u> Three studies are reported in the original testing of the instrument: <u>Study 1</u> The study involved 45 of 46 registered and practical nurses and nurse assistant staff with an average of 5 years of experience in dementia care. The setting was 3 special care Alzheimer units of Veterans' Administration

	facilities. Study 2 and 3 Setting: 9 LTC units of 2 VA hospitals Subjects : 97 of 103 eligible candidates provided informed consent. Study 2 involved the first 68 enrolled subjects. Study 3 involved 82 residents who were alive for the entire 6 months of data collection. Subject characteristics for study 3: Age of subjects is not provided. Gender: Male: 77 and Female: 5 Length of time with Alzheimer's Disease: average 8 years. Length of time in residence: average 2.5 years. Severity of DAT was assessed as follows: -A language assessment score: average was 3 points above being completely mute. -MMSE: Range of scores 0 – 2 of possible 30, indicates severe dementia. -Katz ADL Index: 5.6 on 6 point scale (6= completely dependent). Miller et al. (1996) Additional psychometric evaluation of the DS-DAT was conducted by Miller et al. (1996) in the acute care setting. Setting: two medical units of a large, tertiary care hospital in the SE USA. Subject characteristics: Total sample: 46 patients Average age: 83 years, Range 73-95 years. Gender: Female: 63%, Male: 37% NEECHAM score upon admission was 18.43 (±5.11), Range: 7-26 indicating severe confusion. Fifty-four pecent had underlying chronic cognitive impairment. Thirty percent had arthritis and wounds or decubiti at high risk for discomfort. Young (2001) Additional psychometric evaluation of the DS-DAT was also conducted by Young (2001) in long term care. Setting: 3 long-term care facilities in the Midwest. Subject characteristics: Total sample: 104 residents Average age: 86.3 years, Range: 59-100 years Gender: Female: 79%, Male 21% Length of time in residence: 3 to 151 months (average 37.63 months). Racial/ethnic background: American Indian: 1 resident, Caucasian: 103 residents.
-Panel Commentary	Using 5 subjects per item as a rule of thumb for all studies, a sample size of 45 (9 items x 5 subjects per item) would be needed. Thus, the sample sizes in all studies mentioned above are sufficient. Hurley et al., 1992 Focus on long term care setting is clearly identified. Subjects in both studies were identified as having severe dementia using appropriate measurement tools. Few women were included in the study.

	No information on age of subjects is provided. No information regarding racial/ethnic diversity is available. Miller et al. (1996) and Young (2001) These additional studies were conducted in samples of sufficient size and with gender diversity. *Scoring was revised to reflect this review's considerations of diversity.*
Administration, Scoring, Feasibility **Panel rating: 1**	
Administration, Scoring, Feasibility	The rater waited 15 minutes after any event that might invoke discomfort (such as being turned) before beginning the observation. The subject was observed for five minutes. Subjects are observed at rest only. The frequency, intensity, and duration for each of the nine behavioral items during a 5 minute observation is recorded and a composite score for each item is derived using a special scoring schema. Items are scored by: 1. Frequency – number of episodes 2. Intensity: Low: barely to moderately perceptible High: present in moderate to great magnitude 3. Duration – refers to the time frame of the behavior Short: <1 minute Long: >1 minute Each item may achieve a score of 0 to 3 points. If an item cannot be observed, the item is scored 0. The range of the composite score is: 0=no observed discomfort to 27=high level of discomfort. A rater training program was developed to reduce variability in scoring. Patients with DAT who were experiencing different conditions were videotaped and these tapes were used for training purposes. A standard script is provided to instruct a rater concerning administration of the tool.
-Panel Commentary	The method of administration and scoring procedures are described. However, it is complex, especially scoring of intensity and duration. Thus, the tool is recommended for research use with well trained raters. Although interpretation of scores 0 and 27 are provided, the meaning of the scores between these values is unclear and justification for score interpretation is not provided. The tool assumes that high frequency, intensity and duration correlate with high pain intensity, which may not be a valid assumption for patients in this population with diverse pain presentations. Clinical utility • Time: Use of the tool requires waiting 15 minutes after a possible discomfort event. The subject is observed at rest for a minimum of 5 minutes. The actual time needed to administer the tool has not been reported, but may be considerably longer than the 5 minutes of direct observation due to the complexity of the scoring. • Skill needed: This tool requires extensive training to be used accurately. It is not easily used in clinical practice. It is difficult to achieve interrater reliability because the tool is complex.
Reliability **Panel rating: 3**	

Revised: 2	
Internal consistency	Hurley et al. (1992) A longitudinal study (study 3) was conducted to establish internal consistency. Sample characteristics are provided above (see subjects). DS-DAT was administered monthly for 6 months to all subjects by two trained raters who alternated between study sites. Raters had graduate degrees in nursing and no previous contact with the subjects. Scores ranged from 0 (no observed discomfort) to high scores of 21 to 24. Alpha coefficient using recoded scores with 4-point system=.79 Cronbach's alpha: .86 to .89 over 6 months. Young (2001) Sample characteristics are provided above (see subjects). Raters were the principal investigator who was a doctoral student in gerontological nursing and a trained nursing research assistant. Cronbachs alpha: .74.
Interrater reliability	Hurley et al. (1992) Interrater reliability is based on data from study 3. The degree of agreement between different raters in assigning scores was measured using a paired t-test. Interrater reliability at 4 time points, 5-9 subjects, r=.86 to .98 Paired t-test scores ranged from .06 to 1.6 (p=.12-.54). Scores were low and non-significant indicating that both raters had given the subjects similar scores on the average. Miller et al (1996) Sample characteristics are provided above (see subjects). The raters were gerontological research nurses. Interrater reliability at 2 time points: Time 1: 15 pairs of observations r=.611 Time 2: 17 pairs of observations r=.770 Total: 32 pairs of observations r=.669 Young (2001) Sample characteristics are provided above (see subjects). Raters were the PI, a doctoral student in gerontological nursing, and a trained research assistant. After an initial 30 hours of training and data collection with 12 subjects to establish interrater reliability, an additional 5 hours of DS-DAT administration was needed to increase percent agreement from 84% to 94% (n=12, n=32).
Test-retest reliability	Hurley et al. (1992) Test-retest was conducted in conjunction with study 2 (see under subjects) For each of 68 enrolled subjects the scale was administered twice one hour apart by a rater (PI) and a unit nurse simultaneously and independently. Each of the nine items was rated on a 100 mm visual analog scale with anchors absent (0) to extreme (100). In addition, field notes were kept on defining characteristics observed and length of time and degree to which they were present. The correlation r=.60, p<.001 for test-retest reliability of the measurement was noted at baseline. Paired t-test (67)=.74, p=.46 indicates no change after one hour. No test-retest was completed by Miller et al. (1996) or Young (2001).
-Panel commentary	Internal consistency The method of establishing internal consistency is appropriate for the data. The correlation coefficients available are strong

	Interrater reliability The r-statistic and t-test are appropriate for the data. The levels of the coefficient are acceptable in the original study. However, in the study conducted by Miller, interrater reliabilities were moderate and the authors recommended deletion of 3 tool items for which interrater agreement could not be reached at an acceptable level. In Young (2001) percent agreement was strong, but only after repeated training and practice of the raters. Test-retest reliability The test-retest stability coefficient (r=.6) is in the moderate range and is appropriate for the measurement of baseline discomfort. The qualifications of the raters are appropriate. The paired t-test is appropriate and indicated tool stability. *Scoring was revised for this review's consideration of interrater reliability.*
Validity: Criterion or construct **Panel rating: 2**	
Construct validity/ **Criterion validity**	Hurley (1992) 20 subjects identified by staff as having a fever episode were rated using the DS-DAT at peak and on resolution of illness with significant results ($F_{1,19}$=167.02, p<.001): Baseline Peak Resolution Average scores: 7.7 (±1.2) 11.9 (±1.0) 8.1 (±1.2) Thus indicating that the DS-DAT was able to detect differences in discomfort by fever episode. Miller et al. (1996) Sample characteristics are provided above (see subjects). A significant relationship was found 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. Young (2001) Sample characteristics are provided above (see subjects). Significant correlations between DS-DAT and other pain and pain related scores were reported: DS-DAT and CMAI, aggressive scale r=.251 DS-DAT and VDS r=.345
-Panel commentary	The original validity data presented are in the expected direction. However, use of fever as the condition of discomfort limits the generalizability to pain conditions that are aggravated by movement. Also, observation at rest would seriously impact ability to detect pain-related behaviors. Additional studies by Miller et al. (1992) and Young (2001) provide support for tool validity although revision of items and conducting observations on movement may increase validity for assessing pain-specific discomfort.
Summary of panel evaluation of pain assessment tool	
The DS-DAT is well established as a reliable tool for researchers to assess discomfort in persons with dementia. However, validity for persons with pain specific conditions warrants further study. The tool is not comprehensive in the pain related indicators. Because the tool prescribes observation at rest, pain may not be detected in those with pain indicators evident only on movement. The extensive training required to achieve acceptable interrater reliability limits the usefulness of the DS-DAT in its current format for use by clinicians.	

Source of evidence

Hurley, A.C., Volicer, B.J., Hanrahan, S.H., Volicer, L. (1992). Assessment of Discomfort in advanced Alzheimer Patients. Research in Nursing & Health, 15,(3), 69-377.

Miller, J., Neelon, V., Dalton, J., Ng'andu, N., Bailey, D., Layman, E., Hosfeld, A. (1996). The assessment of discomfort in elderly confused patients: a preliminary study. Journal of Neuroscience Nursing. 28(3), 175-182.

Young, D.M. (2001). Pain in institutionalized elders with chronic dementia.Unpublished doctoral dissertation, University of Iowa, Iowa City, (UMI No. AAI3034162).

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

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