

Tool: Disability Distress Assessment Tool (Dis DAT)
Tool developer: Regnard, C., Mathews, D., Gibson, L., Clarke, C.
Country of origin: UK
Reviewed: 06/08

Conceptualization	
Panel rating: 1	
Purpose	The purpose of the Dis DAT is to help observe and identify distress cues in people who have severely limited communication because of cognitive impairment or physical illness.
Conceptual basis	<p>There is great similarity between pain behaviors and the “alternative communication of distress”. The authors raise the issue that, while easier and often successful, it is not in patients’ best interest to treat all distress with efforts at pain relief.</p> <p>Distress can be caused by physical symptoms, psychological problems and social or spiritual issues. Distress is what the person says or expresses it to be. Comfort eases and relieves distress and is central to effective care.</p> <p>This tool speaks to distress that cannot be communicated due to severe learning difficulties and dementia. It operationalizes distress as silence, or reduction or increase in activity all of which are frequently misinterpreted by caregivers.</p> <p>Tool development was based on the assumption that “the language of distress” can be interpreted in context, presents as a pattern of cues which are individual for each patient, and that carers often intuitively recognize these cues. There are 4 steps to making intuitive recognition explicit:</p> <ol style="list-style-type: none"> 1. Document signs/behaviors of the content and the distressed individual along with the context in which they occur. 2. Systematically follow a screening decision checklist to guess at the general category of distress (fear vs. pain) 3. Follow-up with more specific checklist to narrow down the cause of distress within the general category (fear of what?) 4. Test the treatment and reassess distress. <p>The Dis DAT posits that documentation of carers’ intuitive interpretation along with patients’ distress patterns and the context in which they occur allow for more differential interventions to achieve comfort.</p>
Item Generation	<p>Items were pooled from literature review and expert caregivers on the palliative care team at Northgate Hospital in England.</p> <p><u>Tool items</u></p> <p>The tool asks the rater to select from a series of identical adjectives for each of 5 categories to describe patient expression in both content and distressed states. There are a total of 77 descriptors of content and distressed states between all five categories.</p> <p>Facial signs</p> <ul style="list-style-type: none"> • appearance (passive, grimace, smile, frown, laugh, startled, frightened, other) • jaw movement (relaxed, biting, drooping, rigid, grinding, other) • appearance of eyes (good eye contact, little eye contact, avoiding eye contact, closed eyes, staring, sleepy eyes, smiling, winking, vacant, tears, dilated pupils, other) • Skin appearance (normal, sweaty, pale, clammy, flushed, other)

	<p>Vocal sounds</p> <ul style="list-style-type: none"> • Write down commonly used sounds and their meaning. How are they vocalized when content vs. distressed volume: hi, med, lo pitch: hi, med, lo duration: short, intermittent, long • Is it a cry out, wail, moan,/groan, shout, gurgle, scream, other • Speech: write down commonly used words or phrases • Is speech clear, stutters, slurred, unclear, muttering, fast, slow, loud, whisper, soft, other <p>Habits and mannerisms</p> <ul style="list-style-type: none"> • Describe habits/mannerisms and list comforters (possessions or toys) • How comfortable is the patient with physical closeness: close with strangers, close only if known, no one allowed close, withdraws if touched. <p>Body posture</p> <ul style="list-style-type: none"> • Describe how this person sits and stands (normal, rigid, floppy, jerky, restless, slumped, tense, still, able to adjust position, leans to side, poor head control, normal or abnormal way of walking, other) <p>Body observation</p> <ul style="list-style-type: none"> • Describe pulse, breathing, sleep, appetite, eating pattern
Content Validity	<p>There is extensive literature review on prevalence and expression of both distress and pain in the cognitively population. The authors argue that no definitive signs for either pain or distress in the cognitively impaired population have been identified rather that many patients present atypically. Because all pain causes distress but not all distress is due to pain it is logical to identify distress prior to probing for pain. The authors posit that treating all distress as presumably due to pain exposes patients to unnecessary sedation and side effects of analgesics. Face validity of the Dis-DAT is based on this review of the literature and experts in palliative care in a British institution for intellectually disabled adults.</p>
-Panel Commentary	<p>Conceptually, the focus of this tool is on distress and not pain. Only preliminary testing of content validity is available.</p> <p>Measuring presence or absence of distress behaviors is appropriate, as is assessing frequency, duration and intensity of signs and behaviors indicative of distress. It is grounded in a content (i.e. not distressed) base-line assessment in order to detect changes resulting from distress.</p> <p>Behaviors seen especially in Down’s related dementia were used for item development. Commonalities between Down’s dementia and Alzheimer’s Disease need to be verified. This tool is not directed at a specific age group. It loosely incorporates all 6 AGS indicators of pain plus physiological parameters in “skin appearance” and “body observations”. We therefore recommend follow-up work for content validity and the tool’s ability to differentiate distress from pain in non-verbal older patients.</p>
<p>Subjects Panel rating: 1</p>	

<p>Subjects</p>	<p><u>Preliminary phase to test content validity and clinical feasibility</u> 16 carers recruited from the following group: the patient’s named nurse, a keyworker, another health professional who saw the patient regularly (i.e. every few days), a health professional who saw the patient infrequently (e.g. once weekly or less often), a health professional who had never met the patient, and a relative. 8 patients from the pool of patients with intellectual disability (ID) at Northgate and Prudhoe NHS Trust.</p> <p><u>Assessment phase to test content validity and clinical feasibility</u> 56 carers (named nurse and keyworker, 2 for each patient) 25 patients, of whom 10 patients participated as case studies.</p> <p>Median age of patients: 55 years Gender: 64% male All patients had a severe ID, some with Down’s and Alzheimer-type dementia. Most had profound communication difficulties (using an adapted Kidderminster curriculum communication scale for children and adults with a profound multiple intellectual difficulty for assessment of ID).</p> <ul style="list-style-type: none"> • 1 (3%) was assessed at level 4 (able to communicate detail, qualify, specify and/or indicate opinions); • 3 (9%) were assessed at level 3 (at best, able to ask for and anticipate their like or dislike of something); • 9 (27%) were assessed at level 2 (at best, able to show that they want more, or have had enough of something); • 17 (52%) were assessed at level 1 (at best, able to show that they like or do not like something); and • 3 (9%) were assessed as level 0 (unable to show likes or dislikes).
<p><i>-Panel Commentary</i></p>	<p>Study subjects seem to be convenience samples from one institution for the intellectually disabled in England. Subjects are younger, with more males than most typical NH populations and there is no mention of diversity. There is no mention of physical disability or chronic illness and pain in the sample population. Caregiver characteristics are not described beyond their job categories and that they are familiar with the patients. It appears that more caregivers refused to participate than consented, especially for the pilot phase. Both samples are combined for descriptive statistics and analysis.</p> <p>Using 5 subjects per tool item as a minimum requirement for this review, a minimum sample size of 15 subjects to answer 3 questions re. ease of administration was needed for the preliminary phase. In the assessment phase, 56 caregivers responded to one question about simplicity. Therefore, minimum sample size requirements were met for evaluation of this aspect of clinical utility. The sample size of 25 patients to evaluate 5 domains for construct validity is acceptable but does not merit conclusions about the 77 imbedded characteristics.</p>
<p>Administration, Scoring, Feasibility Panel rating: 1</p>	
<p>Administration, Scoring, Feasibility</p>	<p>The test booklet is comprised of 4 pages. Page 1 gives a brief description of the tool, suitable to be read to the patient, caregiver or family member. It also holds a summary section for content and distressed behaviors specific to this one patient, including space to note known triggers of distress.</p> <p>Page 2 and 3 ask to rank the patient in 5 communication categories and give specific behaviors (see item generation).</p> <p>Page 4 outlines how to use the Dis DAT in daily practice and holds the “Clinical decision distress checklist” to help identify underlying causes of</p>

	<p>distress. This list heavily focuses on physical discomfort issues versus fear as source of distress.</p> <p><u>Preliminary phase with 16 carers:</u> 83% found the Dis DAT easy to understand with subsequent use 67% found the Dis DAT both simple and useful with subsequent use 17% found the Dis DAT difficult to use with subsequent use</p> <p><u>Assessment phase with 56 carers:</u> 36.4% continued to be unsure or did not answer the question about simplicity of the Dis DAT. 72.7% found the tool either useful or very useful for standardized assessment of distress related behavior changes. Most found that they could complete the form at one sitting. 10 patients from this group were case studies for whom 4 Dis-DATs were completed, one each by the nurse, a keyworker, a family member and an “other professional” for a total of 40 Dis DATs. 66.7% of all family members found the tool simple to use.</p>
<i>-Panel Commentary</i>	<p>While this tool offers a method for documentation of distress behaviors it is as of yet unknown if the specific distress behaviors hold for non-verbal older patients with pain. No cut-off point is determined and usefulness of the Clinical Decision Distress Checklist warrants further study. Given the fact that it requires the practitioner to make differential diagnoses this part of the tool is not appropriate for administration by nursing assistants in the US. Time required for use of the tool remains unclear. More evidence is needed to show that the tool is easy to use for either RNs or LPNs in daily practice. The inclusion of family members is a strength of the study and merits further study.</p>
Reliability	
Panel rating: 0	
Internal consistency	No data available
Interrater reliability	No data available
Test-retest reliability	No data available
<i>-Panel commentary</i>	Evidence of tool reliability was not reported. Substantiation of reliability is necessary in future research.
Validity: Criterion or construct	
Panel rating: 1	
Construct validity/ Criterion validity	<p><u>Preliminary phase:</u> A median of 24 changes in signs or behaviours were observed per patient during episodes when distress was present (range 10–30 out of 77 indicators on the Dis DAT) by the team, less than half of that by an individual carer and the fewest if extraction of information was limited to written records. A total of 61 changes was noted in all eight patients, which is 79% of the changes identified on the DisDAT.</p> <p><u>Assessment phase:</u> Carers of 10 patients participated in semi-structured interviews exploring the signs and behaviors demonstrated by patients when distressed and when content. 24% of these carers associated distress primarily with physical discomfort. Interviews and structured observations confirmed that caregivers mostly associate distress with facial and vocal cues, skin changes and change in base line behaviors. Patients were generally non-specific in their communication of distress leaving carers to “guess from A-Z” re. the cause of distress. Carers also described a pattern of escalation if distress was not addressed successfully. Carers identified both a signature set of distress cues</p>

	for each individual and a set of cues common to most patients when distressed. Compared to key workers, other health professionals and family members, nurses reported the highest number of cues in DisDAT assessments and in the interviews.
-Panel commentary	The qualitative findings of the study give initial support of the validity of the tool. We recommend factor analysis to evaluate the tool for the possibility of item reduction. Validity studies should be focused towards a specific group of users (for example nurses) and consumers (older non-verbal patients with and without pain and stratified for level of communication impairment). The construct of a signature set of distress cues and criterion validity for common distress cues merits further study with larger sample sizes.
Summary of panel evaluation of pain assessment tool	
The Dis DAT is a new tool for clinicians to assess discomfort in persons unable to communicate. Content validity for older persons with pain specific conditions warrants further study. The Dis DAT is currently being evaluated in older adults with Alzheimer’s disease in the UK. The tool would benefit from changes to improve clinical utility. Reliability has not yet been shown for the Dis DAT and preliminary studies need to be conducted for all psychometrics.	

Source of evidence

Regnard C., Matthews D., Gibson L., Clarke C. & Watson B. (2003). Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing* 9, 173–6.

Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., & Clarke, C. (2007). Understanding distress in people with severe communication difficulties: Developing and assessing the disability distress assessment tool (DisDAT). *Journal of Intellectual Disability Research*, 51, 277-292.

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

Contact Information:

The tool is free to use and available without restriction on www.disdat.co.uk. Tool developers invite feedback and comments from users of the Dis DAT, please contact

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