

Disability Distress Assessment Tool (Dis DAT) Brief

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. The tool was developed by a British team of palliative care clinicians caring mostly for aging Down's syndrome patients. It operationalizes distress as silence, or reduction or increase in activity, all of which are frequently misinterpreted by caregivers. 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. 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. It is not directed at a specific age group and only preliminary testing of content validity is available.

Administration and scoring

The Dis DAT 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 the five categories of Facial signs, Vocal sounds, Habits and mannerisms, Body posture and Body observation. The tool loosely incorporates all 6 AGS indicators of pain plus physiological parameters in "skin appearance" and "body observations" and is designed to identify behavior change from a content base line.

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. Page 2 and 3 ask to rank the patient in 5 communication categories and give specific behaviors (see item generation). 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 distress. This list heavily focuses on physical discomfort issues versus fear as source of distress.

The tool was administered by 56 carers (nurses and allied healthcare personnel) and evaluated for content validity and clinical feasibility in a convenience sample of 25 patients (mean age 55, 64% male) most of whom had "profound communication difficulties". Sample size was adequate to answer one question for feasibility, but not large enough to evaluate content validity of 77 descriptors. The team of caregivers and their roles and qualifications to differentiate distress may not be readily found in American nursing homes. Two thirds of these carers found the tool to be either useful or very useful for standardized assessment of distress related behavior changes.

Reliability

Evidence of tool reliability was not reported. Substantiation of reliability is necessary in future research.

Validity

The eight patients evaluated in the preliminary phase for content validity displayed 61 behavior changes (median 24) which constitutes 79% of all behavior changes possible on the Dis DAT. Qualitative analysis of distress behavior in 10 case studies in the assessment phase added the constructs of escalating distress behaviors and sets of signature cues of distress for individual patients, giving initial support for the validity of the tool.

Summary

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 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.

DisDAT is now being evaluated in older adults with Alzheimer's dementia and in children with complex needs (Dr. Claud Regnard, personal communication, July 2008).

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.

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The tool is free to use and available without restriction on www.disdat.co.uk and the authors request feedback from users in either clinical or research settings.

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K. Herr, H. Bursch and B. Black, The University of Iowa (2008).

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