Detecting pain or distress in people with dementia: an appraisal of two strategies

What is the best approach to recognise pain or distress in people with dementia who cannot express themselves verbally? Jenny T van der Steen, Claud Regnard, Ladislav Volicer, Nele J A Van Den Noortgate and Elizabeth L Sampson have critically appraised two assessment tools: the pain tool PAINAD and the distress documentation tool DisDAT for people with dementia.4 Comfort theory refers to three types of comfort:

- Relief from discomfort when specific needs are met
- Ease – a state of calm or contentment
- Transcendence – the state in which one rises above problems or pain.5

Clearly, comfort is more than the absence of discomfort, problems or pain.

Development of tools

Over the past decades, various tools have been developed to systematically observe signs of pain and discomfort and/or distress in people with moderate-to-severe dementia. In this article, using two key tools as examples, we discuss some of the considerations and controversies involved.

Global (dis)comfort and distress tools

Some tools assess discomfort, comfort or distress in severe dementia or at the end of life. Among them is the classical Discomfort Scale-Dementia Alzheimer Type (DS-DAT) from 1992, which uses nine items to observe negative (for example, negative vocalisation) and positive (for example, relaxed body language) expressions.6 It has excellent psychometric properties and has inspired the development of pain tools such as the preliminary version of the Pain Assessment in Impaired Cognition (PAIC)7 and the Pain Assessment in Advanced Dementia (PAINAD).8

The more recent Disability Distress Assessment Tool (DisDAT) was developed for people with severe communication difficulties, mostly those with severe intellectual disability, whether or not accompanied by dementia.9,10

Assessment tools

The assessment and monitoring of signs and symptoms is key in palliative care. However, with severe dementia and closer to the end of life, communication problems may complicate the assessment of symptoms such as pain. As in many other conditions, the prevalence of (reported) pain varies considerably in dementia.1 Longitudinal studies in the Netherlands and the USA have shown that physicians and nurses report increased frequency of pain in the months before death and with progressive dementia.2,3 Pain may result in observable signs and behaviours indicative of discomfort or distress. However, discomfort or distress can also be due to other causes, such as being bored, agitated, cold or constipated.

Comfort was suggested as an important goal of care in an international Delphi study that resulted in the European Association for Palliative Care’s White Paper on palliative care for people with dementia.4 Comfort theory refers to three types of comfort:

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Key points

- There are many tools to assess behavioural signs in non-verbal people with dementia or other cognitive impairment: many to measure pain and a few to measure (dis)comfort or distress.
- Item pools overlap substantially, but approaches and formats can differ widely between the different tools and types of tools.
- Comparing a pain tool such as the Pain Assessment in Advanced dementia (PAINAD) and a distress documentation tool such as the Disability Distress Assessment Tool (DisDAT) shows that signs and behaviours can be assessed in different ways.
- Direct comparison of the psychometric properties, feasibility and effects on patients’ outcomes of different approaches and tools is needed to build a sound evidence base of the assessment of pain and other causes of discomfort and/or distress in dementia.
It documents a person’s signs and behaviours when they are distressed and when they are content or neutral.

**Pain assessment tools**

At least 28 observational pain assessment tools are available, mostly based on experience rather than on research evidence. Only recently have some groups turned to a more evidence-based approach to develop or redesign tools. For example, the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) was revised on the basis of the increasing evidence base, and the 31-item PACSLAC-II outperforms the 60-item original.

The recently developed PAIC tool abstracted behaviours from 12 other tools and includes 36 very descriptive items referring mostly to directly observable behaviour (facial expressions, verbalisations and vocalisations, and body movements), not including, for example, changes in activities of daily living.

**PAINAD and DisDAT**

We conducted a content mapping of four pain and four (dis)comfort and/or distress tools, including the PAINAD and DisDAT, in which we classified items in six different domains. We concluded that item pools used in pain tools and in (dis)comfort and/or distress tools overlap substantially. Restlessness, for example, was included in all. Only a few items were specific to either type of tool, such as guarding (which means, for example, protecting a painful part of the body) in pain tools and serenity in comfort tools.

Nevertheless, widely different approaches exist, which we illustrate with the tools that, in our content mapping, were the most different regarding the use of time: the PAINAD pain tool and the DisDAT distress tool.

The PAINAD is a five-item tool for a short bedside assessment of pain by a rater who may be unfamiliar with the person with dementia (see Box 1). Item scores of 0, 1 or 2 add up to a total score between 0 and 10. A score of 2 probably reflects pain while a score of 3 is specific for pain, but pain may be missed in some people with lower scores. The assumption is that the observed signs and behaviours in the population frequently reflect pain (see Table 1).

The DisDAT, by contrast, assumes that expressions of distress are highly individual.

**Box 1. Detection of pain illustrated by the vocalisation item with the Pain Assessment in Advanced Dementia (PAINAD) tool**

<table>
<thead>
<tr>
<th>Input and interpretation principles: one-time assessment of standardised items, interpretation of quantified observations (in later work: cut-off to indicate possible pain; intensity may not be valid).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct bedside assessment as obvious through the item ‘consolability’</td>
</tr>
<tr>
<td><strong>Response options for negative vocalisations:</strong></td>
</tr>
<tr>
<td>0 = None: is characterised by speech or vocalisation that has a neutral or pleasant quality</td>
</tr>
<tr>
<td>1 = Occasional moan or groan: occasional moaning is characterised by mournful or murmuring sounds, wails or laments. Groaning is characterised by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending</td>
</tr>
<tr>
<td>2 = Repeated troubled calling out: is characterised by phrases or words being used over and over in a tone that suggests anxiety, uneasiness or distress</td>
</tr>
<tr>
<td>Low moaning or groaning: loud moaning is characterised by mournful or murmuring sounds, wails or laments in much louder than usual volume. Loud groaning is characterised by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending</td>
</tr>
<tr>
<td>Crying: is characterised by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping</td>
</tr>
</tbody>
</table>

For full tool, see appendix to Warden et al, 2003

**Box 2. Detection of distress illustrated by the vocalisation item with the Disability Distress Assessment Tool (DisDAT)**

<table>
<thead>
<tr>
<th>Input and interpretation principles: compares a wide range of individual signs and behaviours at the time of assessment and previously, against the baseline of a previous standard of interpretation as content or distressed</th>
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For full tool, see: www.disdat.co.uk

Although it lists similar signs to the PAINAD (for example, moaning and groaning – see Box 1), it allows for individualised expression of distress (see Box 2). DisDAT assessments are compared with a baseline assessment of individual expressions of experiencing distress.
This baseline is built by interviewing an informal caregiver, or over days by observing patients when they receive interventions known to cause distress. The DisDAT does not have an integrated scoring system.

Table 1 shows the contrasting underlying assumptions, as well as the possible benefits and pitfalls, of the two approaches and of these two particular tools. The PAINAD is appealing for practice because the assessment only takes a few minutes, and it is also a good research tool. It is used throughout the world. It may improve undertreatment of pain, at the risk of overtreatment. In contrast, the DisDAT is the starting point for identifying a cause of global distress. Evaluation of the DisDAT so far has been limited to people with Alzheimer’s dementia in a UK specialist intellectual disability inpatient setting and three UK specialist nursing home caring for people with advanced dementia (‘EMI homes’).

What should we assess and with which tool?

Although both tools support direct (bedside) observation (as opposed to the recall of a specific change over a preceding period, such

<table>
<thead>
<tr>
<th></th>
<th>PAINAD</th>
<th>DisDAT</th>
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</thead>
<tbody>
<tr>
<td>Purpose</td>
<td>Detection of pain</td>
<td>Detection of distress regardless of cause (pain or other)</td>
</tr>
<tr>
<td>Practical use</td>
<td>Short-term observation (by a person who need not be familiar with the patient)</td>
<td>Development of a baseline of distress signs (by a person familiar with the patient) and comparison of the current state with that baseline</td>
</tr>
<tr>
<td>Clinical use</td>
<td>Widely used in several countries and in different cultures throughout the world</td>
<td>- Widely used in the UK in intellectual disability settings (home, residential and inpatient) - Recommended in the UK by the GMC, BILD and mental health charity Mencap</td>
</tr>
<tr>
<td>Research use</td>
<td>Scale with excellent psychometric properties</td>
<td>No integrated scoring system (but additional scoring systems can be used)</td>
</tr>
<tr>
<td>Assumptions</td>
<td>Pain is expressed by a limited number of specific observable signs</td>
<td>Expression of distress caused by pain is highly individual, does not point to a specific cause and does not change over time</td>
</tr>
<tr>
<td>Evidence</td>
<td>• Clinical and research studies, including independent studies in different settings and countries, support use as a research tool and as a screening tool in practice15 • Evidence of improved pain16</td>
<td>• Clinical quantitative and qualitative studies in the UK by the tool’s developers have provided some evidence for its value in identifying distress signs and behaviours15 • Carers report value in advocating for the patient9</td>
</tr>
<tr>
<td>Potential benefits for the patient</td>
<td>May increase awareness of pain as a possible cause of behaviour and trigger concrete follow-up actions that remedy undertreatment of pain</td>
<td>• May help in patient being seen as a unique individual • Allows for signs of distress that may not be present in pain scales or other discomfort/distress scales with fixed items</td>
</tr>
<tr>
<td>Potential pitfalls for the patient</td>
<td>Administration of analgesics despite a different cause for a positive score (when in fact, there was no pain); however, that may result in a therapeutic trial, which is stopped when analgesics are not effective</td>
<td>• Risk that baseline is no longer applicable with changing condition of patient as dementia progresses • Baseline assessment relies on availability of a carer who is familiar with the patient • Does not indicate the cause of distress, and has not been validated to assess pain</td>
</tr>
</tbody>
</table>

Key: BILD = British Institute of Learning Disabilities; DisDAT = Disability Distress Assessment Tool; GMC = General Medical Council; PAINAD = Pain Assessment in Advanced Dementia
as a change in sleep patterns), they may best fit different situations.

Regardless of which tool is chosen, good communication between nurses, relatives or caregivers of the person with dementia reporting pain or distress, and the physicians treating these, is needed to improve the person’s comfort. If needed, assessments with both types of tool should be followed by a diagnosis of pain or other causes of discomfort/distress.

Noting facial and vocal expressions and body language, and interpreting them after further examination, stimulates and empowers professional and family caregivers to find and treat the cause of distress or pain, which may also be psychosocial or spiritual (‘total pain’).

**What should happen next?**

Although no gold standard exists (except for self-reporting tools, but these can only be used if patients have the ability to do so), and the subjective interpretation of behaviour is a problem with any tool, validity is particularly important for pain tools, which suggest that behaviours reflect or are caused by pain. Therefore, pain tools\(^2\) and discomfort/distress tools urgently need to be tested in a head-to-head comparison in different situations. Similarly, pain tools need to be tested in parallel with discomfort and/or distress tools, and also against probable non-pain distress. This will tell us whether certain behaviours can point to specific sources of distress.

The inclusion, in discomfort and/or distress tools, of items that so far are unique to pain tools, such as guarding, should be considered. However, constructing a tool that would have both excellent specificity and sensitivity from signs unique to pain may be difficult. A debate between developers, such as the one that resulted in this paper, is helpful to inform new research. Testing different approaches and a broad item pool – including when they are applied at the end of life, when assessment may be the most difficult – for feasibility, psychometric properties (especially sensitivity and specificity) and effects on patients’ outcomes should result in optimal tools for research and for a range of clinical practices.

**Declaration of interest**
The authors declare that there is no conflict of interest, apart from an intellectual conflict of interest to define their own tools, which is balanced by the developers of both tools under study being authors of this article.

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