

Pain and distress in advanced dementia: Choosing the right tools for the job

Palliative Medicine
26(7) 873–878
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DOI: 10.1177/0269216311412227
pmj.sagepub.com



Alice Jordan *Northumbria Healthcare NHS Foundation Trust, UK*

Claud Regnard *St Oswald's Hospice, Newcastle Hospitals NHS Trust and Northumberland Tyne and Wear NHS Trust, UK*

John T O'Brien *Institute for Ageing and Health, Newcastle University, UK*

Julian C Hughes *Northumbria Healthcare NHS Foundation Trust and Institute for Ageing and Health, Newcastle University, UK*

Abstract

Objective: There is a concern that pain is under-recognized in dementia. However, there may be other causes of distress. We wished to evaluate the utility of a distress tool and a pain tool.

Methods: Nursing home residents with advanced dementia were observed using pain (Pain Assessment in Advanced Dementia scale (PAINAD)) and distress (Disability Distress Assessment Tool (DisDAT)) assessment tools. Those in pain were treated. Reassessment occurred at one and three months.

Results: From 79 participants, 13 were assessed as being in pain. Psychosocial factors explained the behaviour of a false positive group. Both tools showed a significant decrease in pain following intervention ($p = 0.008$). Behaviours were similar in both groups.

Conclusions: Both tools are useful. However, the pain tool also picks up distress, which is not caused by pain. It could potentially lead to false ascriptions of pain. The distress tool picks up a broader array of signs, which may be useful both in practice and in research.

Keywords

Dementia, distress, pain, pain assessment

Introduction

There are estimated to be 35.6 million people in the world with dementia and in every country the prevalence is rising.¹ The progressive dementias remain largely incurable, despite symptomatic treatments. In common with other progressive life-threatening conditions, the principles of palliative and supportive care should apply to patients with dementia throughout the course of the disease.^{2,3} This includes the need to treat pain and distress where they occur.

In a systematic review, the prevalence of pain in non-cognitively impaired elderly patients was 49%–83%.⁴ Meanwhile, studies have demonstrated under-treatment of pain in people with advanced dementia.⁵ Recognition and treatment of pain in people with severe dementia, who cannot communicate their discomfort effectively,

can be difficult.⁶ Hence, a plethora of pain behavioural assessment tools has emerged. However, a recent review has not been able to recommend any particular tool.⁷ Furthermore, it cannot be presumed, where there are communication difficulties, that the cause of a person's distress is pain.^{8,9} In a study that assessed Doloplus-2 it was not possible to demonstrate a valid relationship between the behavioural assessment tool and an expert's assessment of pain.¹⁰ So, important cues might be overlooked or misinterpreted: a grimace might be a smile or a manifestation of pain. A further concern is that a positive score on a pain assessment tool might be ascribed to pain, whereas there may be some other cause of distress. Inappropriate treatment might then result. Hence, distress needs to be assessed individually.

Corresponding author:

Dr Alice Jordan, Consultant in Palliative Medicine, Hartlepool and District Hospice, Wells Avenue, Hartlepool, UK
Email: ajordan@hartlepoolhospice.co.uk

The relationship between pain and distress is complex. At a conceptual level, pain can be partly defined in terms of, and will usually involve, distress. In the context we are considering, pain is defined in terms of physical insult to tissues causing stimulation of nociceptors, which act to protect the body. We can also speak of emotional pain, but in this paper we are considering pain as the consequence of a physical event that will respond to analgesia or to removal of the physical cause of the pain. In contrast, we take distress to be an over-arching concept, meaning that it may be caused by pain, but may have a variety of other causes (e.g. fear, hallucinations, etc.). The particular cause(s) of distress will have to be worked out in specific contexts. Clinically, therefore, recognizing distress can be regarded as a first step. Defining the cause of distress (e.g. as being pain) comes subsequently. With these conceptual thoughts in mind, it can be seen that the motivating concerns of this study were to understand whether 'pain tools' only picked up pain and, if not, what are the broader aspects of distress that are also manifest in advanced dementia, which might look like pain.

The aim of this study, therefore, was to evaluate the utility of a distress tool and a pain tool in a UK population with severe dementia. Are these the right tools for the job? What do they tell us?

Method

The research involved a National Health Service (NHS) continuing care unit for people with severe dementia and three private elderly mentally infirm (EMI) nursing homes in North Tyneside, UK. Local research ethics approval was obtained. The participants in the study had an established clinical diagnosis of dementia. All the residents in the homes were screened using the Clinical Dementia Rating (CDR) score.¹¹ Only those scoring three (indicating advanced disease) were included. There were no specific exclusion criteria.

The details of the methodology for the study are recorded elsewhere,¹² but a brief outline follows.

Recruitment

Recruitment was in accordance with the provisions of the Mental Capacity Act 2005. Thus, personal and nominated consultees for each potential participant were approached as part of the recruitment process and to gather history. All relevant and available clinical notes were reviewed.

Observations

Participants were observed on three occasions for approximately 5 minutes at a time of rest, at a mealtime

and at a time of intervention (e.g. bathing), usually on the same day. At each of the three observations, one tool (i.e. either the Pain Assessment in Advanced Dementia scale (PAINAD) or the Disability Distress Assessment Tool (DisDAT)) was completed by the researcher (AJ) and, at the same time, the other tool was completed by a member of the nursing team (after training in its use). The tools were randomly assigned to the researcher or the nurse and completed independently. An immediate decision was made concerning whether or not any observed behaviours were caused by pain, irrespective of the scores on the pain tools. The final determination about the presence or absence of pain was based upon the following: the review of the notes; information from relatives; judgements based on the three observations by a doctor specializing in palliative medicine and by a nurse familiar with the patient; further physical examinations where appropriate; further observations if necessary; and second opinions when required.¹²

The assessment tools

We chose the PAINAD as the pain tool on the grounds that it is user friendly, has well established psychometric properties, but has not yet been used in a UK population with advanced dementia. We chose the DisDAT, which has been evaluated in people with Down's syndrome and Alzheimer's dementia, but has not been previously evaluated in older people with a sole diagnosis of dementia. The DisDAT was also chosen in order to allow a broader assessment of distress in the absence of other suitable instruments.

The development and psychometric properties of the PAINAD tool are well-recorded elsewhere.¹²⁻¹⁴ It is easy to use and has reasonable inter-rater reliability and validity.¹⁵ It measures five domains: breathing, negative vocalization, facial expression, body language and consolability. Each of these is rated on a three-point scale (from zero to two), giving a maximum score of 10. The PAINAD has been demonstrated to record improvements following the administration of analgesia.^{13,16} The use of two as the cut-off score for potential pain was derived from the initial research.¹³

The DisDAT was devised specifically for those with severe communication difficulties, but was not intended to be age or disease specific.¹⁷ Its basis is that distress is the primary observation. Having identified distress, the cause must be sought. This might be pain, but could also be fear, anxiety, hallucinations and so on. The DisDAT requires carers and families to create a list of (possibly idiosyncratic) signs and behaviours, which indicate when the individual is distressed, and signs and behaviours that indicate he or she is content or in a neutral state. Idiosyncratic signs and behaviours can be recorded. Using the DisDAT, signs of content or distress

were listed for a particular participant at the start of the study by the researcher (AJ) in discussion with both nursing staff and, where possible, relatives. The DisDAT has been evaluated in a population with profound communication difficulties, most of whom had Down's syndrome and Alzheimer's dementia.¹⁷ The tool was not designed to be scored, although a change in a sign or behaviour can be monitored based on the Palliative Care Assessment Tool (PACA) scoring system.¹⁸ This system was used in the study in order to monitor potential changes in behaviour in response to specific interventions.

The number of distress signs and behaviours for each participant was noted, as was the frequency of the documented signs and behaviours.

Treatment phase

Those who were assessed as being in pain entered the treatment phase (P group), along with a false positive (FP) group, which was made up of those assessed as being not in pain, who had nonetheless scored over two on the PAINAD. A 'no pain' (NP) group, those scoring under two on PAINAD, did not proceed to the treatment phase and were not further considered (because a broader aim of the study was to consider the results of an intervention, which this group were not receiving). After discussion with those involved in the person's care, a careful decision was made concerning the management of the pain for those in the P group. A similar discussion took place concerning the likely cause of the high score for those in the FP group. Any potential alleviating measures for the distress were then pursued.

Follow-up

Participants in both P and FP groups were reassessed weekly to monitor the effects of any treatments. At one month, both groups were reassessed using both the DisDAT and the PAINAD, again in three different circumstances, and again by a nurse from the home and the researcher scoring the same instruments as before. This process was repeated at three months and, in addition, clinical notes and medication were again reviewed.

Statistical analysis

All statistics were analysed using SPSS-14 software. Changes in scores obtained using the PAINAD were analysed using the Wilcoxon signed ranks test, since the data were non-parametric. Differences in mean scores between the three groups (P, FP and NP) were analysed using the Kruskal–Wallis Test, and then differences between individual groups analysed further using the Mann–Whitney exact test.

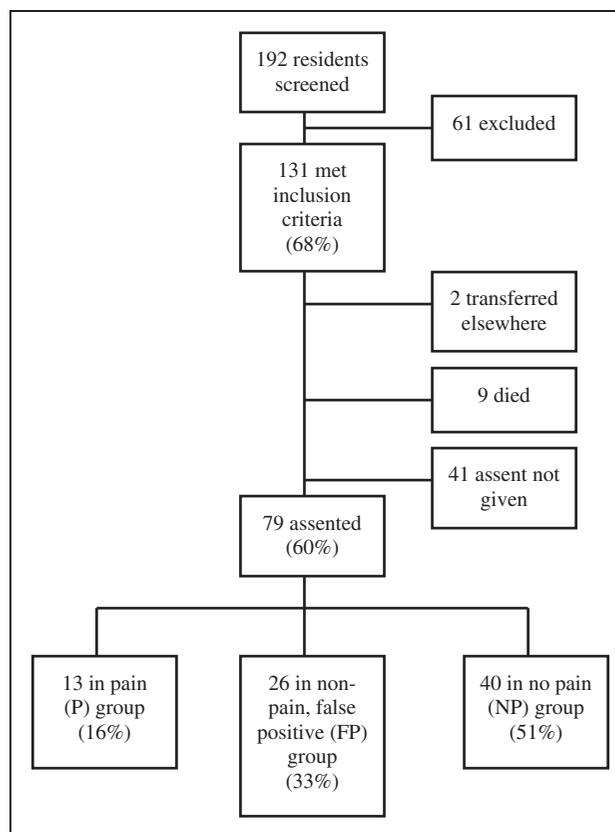


Figure 1. Recruitment and results of initial assessments.

Results

The results of recruitment and the initial assessments are shown in Figure 1. Sixty-one people were excluded on the basis of a CDR score below three.

Of the 79 participants, 72% were female and the mean age was 82 years; 53% had Alzheimer's disease, 29% vascular dementia, 11% mixed vascular and Alzheimer's and 4% had dementia with Lewy bodies. The mean length of time since diagnosis was 71 months (with a range of 15–192 months) and they had been residents in the homes for a mean of 36 months (with a range of 2–108 months).

We have reported the nature of the pain identified and the pharmacological and non-pharmacological treatments given elsewhere.¹² Much of the pain was musculoskeletal. It is of note that there was a significant improvement in both the PAINAD and DisDAT scores one month after a change in management was instigated ($p = 0.008$).

For the FP group there was a variety of causes for the higher scores, often involving the participant not understanding the situation, which therefore caused anxiety, fear or anger. Alternatively, the environment caused distress, sometimes because of the behaviour of others. Once staff recognized the distress, however, different

management strategies were developed to ameliorate the distress.

Analysis of signs and behaviours

Further analyses were carried out to provide information on the breadth of signs and behaviours that were associated with distress in those with severe dementia. From 79 study participants, 129 different signs or behaviours of distress were documented using the DisDAT, with 72 signs or behaviours documented for only one person. From the assessments where the PAINAD score was greater than 2, the distress signs and behaviours from the DisDAT that had been observed were collated. The 20 most frequent signs and behaviours are shown in Table 1, along with the number of the 79 participants showing them.

By collating the signs and behaviours picked up by the DisDAT when the PAINAD scored over 2, it was possible to compare the P and FP groups. The 20 most frequent signs and behaviours, spilt between the P and FP groups, are shown in Table 2. The number of times the sign or behaviour was observed is shown in brackets. This demonstrates that many of the signs and behaviours were the same in both P and FP groups, even though the underlying cause for the signs or behaviours was different.

Discussion

Pain and distress are individual phenomena, experienced uniquely and expressed in potentially idiosyncratic ways. Our aim was to evaluate the utility of a distress tool and a pain tool in a UK population with severe dementia. Are these the right tools and what do they tell us?

Our study has shown the PAINAD to have a high sensitivity (92%) but low specificity (62%) for pain.¹² We have shown that the DisDAT could be used to identify distress caused by pain too. Furthermore, we have shown that both the PAINAD and DisDAT demonstrated a significant change in scores in response to the treatment of pain in people with severe dementia ($p=0.008$). Both tools could be used, therefore, to pick up pain and to assess the effectiveness of treatment. It could be argued that the PAINAD is simpler in this regard, because it does not require personal knowledge of the individual. Given its low specificity, however, the danger is that it is quite likely to pick up non-pain distress and, without personal knowledge of the individual, any judgement about pain is likely to be less secure.

In a way that the PAINAD does not, the DisDAT helps to show the breadth of signs and behaviours of distress (e.g. Table 1). There were 79 unique signs or behaviours documented by the DisDAT, which might

Table 1. Twenty most common distress behaviours documented using the Disability Distress Assessment Tool (DisDAT) in 79 participants with severe dementia ($n=79$)

Documented behaviour of distress	Number of participants
Frown	52
Louder words or shouts	35
Restless	30
Tearful or cries	30
Grimaces	28
Becomes tense	25
Moans or groans	24
Eats less or won't eat	22
Frightened expression	20
Screams	19
Stares	18
Flushed skin	18
Hits out	15
Faster breathing	13
Tries to bite staff	13
Clammy skin	12
Rigid posture	12
Swears	11
Won't allow anyone to come close	11
Startled expression	10

Table 2. Distress signs and behaviours (derived using the Disability Distress Assessment Tool (DisDAT)) observed where the Pain Assessment in Advanced Dementia scale (PAINAD) scored > 2

Distress signs and behaviours in false positive group ($n=26$)	Distress signs and behaviours in pain group ($n=13$)
Frown (21)	Frown (4)
Grimace (9)	Grimace (4)
Screaming (8)	Tense (4)
Louder voice/shouts (7)	Moan/groan (3)
Restless (6)	Louder voice/shouts (3)
Tense (6)	Muttering (2)
Cries (5)	Hits out (2)
Flushed skin (4)	Faster breathing (2)
Staring (4)	Looks frightened (2)
Looks frightened (4)	Restless (1)

have been otherwise overlooked. Table 2 further highlights that the signs and behaviours seen as a result of pain are no different from those that have other causes: there seem to be no unique pain behaviours.⁸ At a conceptual level, the DisDAT allows that this is so, whereas

the PAINAD might be taken to indicate the reverse, despite its originally having been developed from a broader instrument that looked at 'discomfort'.¹⁹

The corollary is that the DisDAT encourages broader thinking about distress in severe dementia. It should certainly not be presumed that distress is caused by pain, although it can be. The important thing is that staff should know the person with dementia well in order to understand individual distressful responses. In addition, this study shows that the assessment of pain requires a good deal of expert knowledge. The DisDAT relies on the carers' knowledge of the person in order to identify distress. Capturing this form of expert knowledge is useful. It may be helpful at a later date if, for example, the person had to be transferred to a hospital.

The study shows, in the FP group, the nature of the distress experienced by people with advanced dementia. Much of the distress was caused by not understanding the situation (leading to fear or frustration) or by environmental factors. Other causes identified included low mood and boredom. Distress is undoubtedly a major component of the so-called behavioural and psychological symptoms of dementia (BPSD). Given the importance of the BPSD,²⁰ identifying and managing distress in this group of patients is clearly imperative; the DisDAT may have a role to play in this regard. For instance, simply establishing the primacy of distress is important, for it suggests a rational approach to the behaviours in terms of trying to work out, without pre-suppositions, what the underlying cause(s) might be.²¹ Pain of various types might be an issue, but so too might a host of other emotional and psychological factors.²²

Study limitations and future research

Although the participants were observed on three different occasions, many potentially important signs and behaviours might have been missed between observations. The possibility that pain was under-detected in our study is real, but there is no definitive test for pain beyond the sort of thorough assessment carried out in this research.¹² We acknowledge that some people scoring only 1 on the PAINAD may yet have had pain, but the cut-off of 2 was based on previous research.¹³ As the number of participants in the pain group was small, further research using larger numbers would be helpful. As described, the NP group was not followed up beyond the initial observations. To understand more fully the nature of distress in advanced dementia, further follow-up would be required. It is difficult to demonstrate the psychometric properties of the DisDAT, since it is created specifically for the individual. However some aspects of the tool, such as inter-rater reliability, could be established by further research.

Conclusions

Our research has shown that both the PAINAD and DisDAT are useful: they can both help to identify pain and measure change in response to treatment. However, the pain tool also picks up distress not caused by pain. It could potentially lead to false ascriptions of (and prescriptions for) pain. The distress tool picks up a broader array of signs, which may be useful both in practice and in research. Clinically, the DisDAT emphasizes the importance of assessing distress in the individual from a broad perspective, which includes the expert knowledge of carers. There are numerous manifestations of distress and a variety of causes, one of which is pain, but there are others. The DisDAT could also be used in research to help with our understanding of the BPSD. These tools, therefore, tell us a good deal about the individual manifestations of pain and distress. They can be regarded as the right tools for the job, but only in the right hands. Pain assessment tools can be helpful in monitoring pain, but assessment of pain is a complex and skilled task. These tools also tell us about distress more generally, but a broader view of distress requires a suitably broad tool, such as the DisDAT, which will capture manifestations of individuals' distress.

Acknowledgements

We would like to thank the participants, their families, the nursing staff and other formal carers, without whose help this study would not have been possible. Dr Nick Steen kindly provided statistical advice. Dr Louise Robinson and Dr Richard Walker gave useful advice. Dr Mani Pakresi and Dr Sarah Hepburn helped with data collection. Deficiencies in the study remain the authors' responsibility.

Funding

The project was funded by a Teaching and Research Fellowship awarded to AJ by Northumbria Healthcare NHS Foundation Trust, who also supported the study.

Conflict of interest

The authors declare that there is no conflict of interest.

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