

Psychometric evaluation of the Pain Assessment in Advanced Dementia scale in an acute general hospital setting

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Abstract

Background: People with dementia are at risk of unplanned hospital admissions and commonly have painful conditions. Identifying pain is challenging and may lead to undertreatment. The psychometric properties of the Pain Assessment in Advanced Dementia (PAINAD) scale, in medical inpatients with dementia have not been evaluated.

Methods: A secondary data analysis from a longitudinal study of 230 people with dementia admitted to two acute general hospitals in London, UK. Internal consistency, inter-rater reliability, test-retest reliability, concurrent validity, construct validity and discriminant validity of PAINAD were tested at rest and in movement.

Results: This predominantly female (65.7%) sample had a mean age of 87.2 (Standard Deviation; SD = 5.92) years. Inter-rater reliability showed an intra-class correlation (ICC) of 0.92 at rest and 0.98 in movement, test-retest reliability ICC was 0.54 at rest and 0.66 in movement. Internal consistency was 0.76 at rest and 0.80 in movement (Cronbach's α). Concurrent validity was weak between PAINAD and a self-rating level of pain (Kendall's Tau; $\tau = 0.29$; $p > 0.001$). There was no correlation between PAINAD and a measure of behavioural and psychological symptoms of dementia, suggesting no evidence of convergent validity. PAINAD scores were higher during movement than rest, providing evidence of discriminant validity ($z = -8.01$, $p < 0.001$).

Conclusions: We found good inter-rater reliability and internal consistency. The test-retest reliability was modest. This study raises concerns about the validity of the PAINAD in general acute hospitals. This provides an insight into pain assessment in general acute hospitals which may inform further refinements of the PAINAD.

KEYWORDS

dementia, hospitals, pain assessment, reliability, validity

Key points

- The Pain Assessment in Advanced Dementia (PAINAD) demonstrated strong reliability but poor overall validity for patients with dementia in the acute general hospital.

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- The PAINAD may not be capturing the unique behavioural presentations of pain in people with dementia admitted to acute general hospitals.
- Future studies should investigate whether refinements of the tool could be made to ensure only pain is being assessed in patients with dementia in acute general hospitals.

1 | BACKGROUND

Pain in people with dementia admitted to general acute hospitals remains common, under-assessed and under-treated.¹ Approximately 16% of patients with dementia admitted to general acute hospitals experience pain at rest, whilst 57% experience pain during movement.¹

Poor pain detection in general acute hospitals may lead to inadequate prescription of analgesics. Further adverse consequences of unrelieved pain include caregiver distress, increased functional decline and risk of falling.² Untreated pain has been associated with behavioural and psychological symptoms of dementia (BPSD), primarily aggression and anxiety.¹ This further increases the risk of inappropriate medication prescriptions, increasing polypharmacy and heightening the risk of adverse drug reactions.³

The Pain Assessment in Advanced Dementia (PAINAD) scale assesses breathing, negative vocalisations, facial expression, body language, and ability to be consoled.⁴ However, interpreting the behaviours in PAINAD is complex; there is considerable overlap between behavioural symptoms of dementia and behavioural symptoms of pain,⁵ which may further manifest as generalised distress. A positive score on PAINAD might be ascribed to pain when there is some other cause of distress, including boredom, hunger, or fear.⁶ This highlights the challenge of identifying pain in people with dementia and raises concerns about the validity of PAINAD.⁵

PAINAD has been evaluated in community or home care settings^{6,7} and emergency departments.² However, whilst the psychometric properties of PAINAD have been assessed in older orthopaedic patients,⁸ no studies have evaluated PAINAD for people with dementia in acute medical settings. This is despite hospitalised patients with dementia usually having greater disease severity than in the community and more likely to have admissions for pain.⁹ Therefore, we aimed to further evaluate the PAINAD by investigating its psychometric properties in people with dementia in acute general hospitals. The specific objectives were (1) to investigate internal consistency, inter-rater reliability and test-retest reliability of PAINAD; (2) to investigate concurrent validity and discriminant validity of PAINAD; (3) to assess convergent validity of PAINAD and whether this observational pain tool is solely measuring pain or behaviours of general distress.

2 | METHODS

2.1 | Participants and procedure

This validation and reliability study uses cross-sectional data from a larger, longitudinal study.¹⁰ Participants were recruited from two

National Health Service (NHS) acute general hospitals in London, United Kingdom (UK) between April 2011 and March 2012. Four trained researchers assessed all patients within 72 h of being admitted to the general acute hospital from accident and emergency; they were under the care of geriatricians.

Participants were included if they met the following inclusion criteria:

- Aged ≤ 70 years with an unplanned acute hospital admission
- Abbreviated mental screening test score of $\leq 7/10$ (AMTS;¹¹)
- Able to give informed consent or had an informal caregiver or 'professional consultee' that could consent to participation in the study.

Participants were ineligible to take part in the study if they indicated verbally or non-verbally they did not wish to participate, did not have an adequate command of English or were moribund.

Participants were assessed for delirium using the Confusion Assessment Method (CAM;¹²), which has a specificity of 89% and a sensitivity of 94%.¹³ Patients who had capacity gave fully informed consent to participate. For those who lacked capacity to consent, we used a personal or professional consultee using the framework of the 2005 UK Mental Capacity Act.

Consenting participants were assessed using the Mini-Mental State Examination (MMSE;¹⁴) and those scoring ≤ 24 were included. Patients who had delirium were excluded except for those who had a clear diagnosis of dementia documented in their medical notes. Dementia diagnosis was confirmed using operationalised criteria from the Diagnostic and Statistical Manual-4th edition classification, cognitive tests, case notes and discussions with families and ward staff.

2.2 | Ethical approval

Ethical approval was received the Central London Research Ethics Committee 3 on 01/12/2010.

2.3 | Measures

2.3.1 | Pain

The Pain Assessment in Advanced Dementia scale is an observational pain tool.⁴ The tool is a 5-item scale including: breathing, negative vocalisations, facial expression, body language and

consolability. Each behavioural domain is scored for severity from 0 to 2 points, where 0 represents no pain and 2 represents a high severity of pain. The maximum score is 10. The tool has shown acceptable-good internal consistency as measured by Cronbach's α ranging from 0.72 to 0.85. PAINAD has demonstrated concurrent validity (Kendall's $\tau = 0.73$), high test-retest (ICC = 0.81) and inter-rater reliability ($r = 0.80$)⁸ for older orthopaedic patients. Pain was measured at rest and during movement, for example, during a routine care task such as standing from chair or repositioning in bed.

Pain was also assessed with the Wong-Baker FACES scale.¹⁵ This self-report ordinal scale consists of six faces, numbered from 0 to 5 points: 0 portrays a happy face (no pain) and 5 depicts a crying face (the worst possible pain). The patient is expected to point to the face, which describes the severity of their pain. It may be an effective measure of pain for people with dementia,¹⁶ however a study found only 36% of people with severe dementia were able to use the FACES scale.¹⁷

2.3.2 | Behavioural and psychological symptoms of dementia

We measured behavioural and psychological symptoms of dementia using the Behavioural Pathology in Alzheimer Disease Scale (BEHAVE-AD;¹⁸). This clinician-rated instrument is divided into two parts. Part 1 is grouped into 7 domains: (A) paranoid and delusion ideation, (B) hallucinations, (C) activity disturbances, (D) aggressiveness, (E) diurnal rhythm disturbance, (F) affective disturbance, and (G) anxieties and phobias. Part 2 evaluates the global impact of behavioural symptoms on the caregiver and patient. The item in each domain is scored on a 4-point scale to represent the severity of the symptoms (0 = no symptoms, 1 = mild, 2 = moderate, 3 = severe). The total score is 73. The instrument has demonstrated high inter-rater reliability, inter-rater consistency (ICC = 0.95 and 0.96, retrospectively) and construct validity.^{18,19} BEHAVE-AD was completed by observing participants and gathering information from various sources, including discussions with families, healthcare professionals and case notes.

2.3.3 | Data analysis

We described participants' demographic and clinical characteristics. We calculated frequencies and percentages for categorical variables and means and SDs for continuous variables. An independent *t*-test or one-way ANOVA was calculated to assess the differences in the demographic characteristics and PAINAD scores at baseline. As the sample size was larger than $n > 30$, because of the Central Limit Theorem, the normality assumption did not apply.²⁰ The frequencies and percentages of each item in the PAINAD at rest and in movement were calculated.

2.4 | Validity

2.4.1 | Concurrent validity

Concurrent validity refers to the extent of agreement between two or more different and validated measures, which hypothetically measure a similar construct. The ability to self-report is considered the gold-standard for assessment of pain for people with dementia.²¹ FACES is a self-report tool validated for assessing pain intensity in people with dementia.²² Concurrent validity was assessed by collecting the measurements for FACES at the same time as PAINAD at rest. Kendall's Tau correlation was chosen to determine the correlation, as this is most suitable for ordinal variables that are not normally distributed.²³ We interpreted the significance of the correlation coefficients according to Munro's classification: 0–0.25, little if any correlation; 0.26–0.49, low correlation; 0.5–0.69, moderate correlation; 0.7–0.89, high correlation; 0.9–1, very high correlation.²⁴

2.4.2 | Convergent validity

Convergent validity is the degree to which a measurement relates to other measurements of a similar construct it is proposed to be related to.²⁵ We used data from BEHAVE-AD as there is a consensus observational pain tools and behavioural and psychological symptoms of dementia assessment scales both capture signs of distress.²⁶ We, therefore, investigated convergent validity to assess how well PAINAD measures pain, in terms of a physical insult that is trying to protect the body,²⁶ as opposed to this broader view of distress.

Convergent validity was evaluated by the same researcher applying BEHAVE-AD simultaneously with PAINAD at rest and during activity. Consistency between the measurements was analysed using Kendall Tau's correlation, as scores were not normally distributed.

2.4.3 | Discriminant validity

Discriminant validity is the degree to which an instrument can sufficiently discriminate between two related, but distinct, concepts.²⁷ Discriminant validity was determined by comparing PAINAD scores at rest and during activity using the Wilcoxon signed-rank test. This assesses whether PAINAD can discriminate between periods of likely pain (in movement) and less pain (at rest).

2.5 | Reliability

2.5.1 | Internal consistency

Cronbach's alpha coefficient was used to analyse internal consistency at rest and during activity. This included Cronbach's alpha if each item was deleted. Cronbach's alpha range from 0 to 1: Cronbach's

alpha of 0.6–0.7 was considered acceptable and Cronbach's alpha ≥ 0.80 indicates very good internal consistency.²⁸

2.5.2 | Inter-rater reliability

Inter-rater reliability was assessed by two trained researchers independently applying the PAINAD, during activity and at rest, to one participant simultaneously. Intraclass correlation (ICC), which analyses the agreement between the two observations, was calculated. ICC range from 0 to 1, where a value closer to 1 portrays a higher level of similarity between the raters' measurements. Values ≤ 0.5 represent poor reliability, 0.50–0.74 represent moderate reliability, 0.75–0.90 represent good reliability and >0.90 represent excellent reliability.²⁹

2.5.3 | Test-retest reliability

PAINAD was administered by one trained researcher at initial admission and then 4 (± 1) days later for each participant during rest and activity. An intraclass correlation was calculated to analyse the level of agreement between the scores.

3 | RESULTS

3.1 | Patient characteristics

We included data from 230 participants (113 from hospital 1 and 117 from hospital 2). The mean age was 87.2 (Standard Deviation; SD = 5.92) years and participants were predominantly female (65.7% vs. 34.3%). The majority were white (85.7%), 20 of the participants (8.7%) were black African/Caribbean and 3 (1.3%) from other ethnic groups. The mean PAINAD score was 0.35 (SD = 1.00) at rest and 1.69 (SD = 2.08) during activity. Pain scores were not statistically significantly different by gender, age and ethnicity. Pain scores during movement were significantly different depending on place of residence with the 'other' residential groups having the highest scores, followed by residential homes, and home or sheltered accommodation having the lowest scores. There were significant differences in the mean pain scores, at rest and in movement, by reason for admission (Table 1).

3.2 | Item analysis

Most items were assessed as 0 (no pain) for both observations at rest and during activity. Items assessed in movement had more scores assessed at 1 (moderate pain) and 2 (severe pain).

3.3 | Concurrent validity

There was a low positive correlation found between FACES and PAINAD, which was significant (Kendall's Tau; $\tau = 0.29$; $p > 0.001$) (Table 2).

3.4 | Convergent validity

There was no evidence of a correlation between BEHAVE scale and PAINAD scores at rest ($\tau = 0.09$; $p = 0.13$) and during activity ($\tau = 0.06$; $p = 0.24$) (Table 3).

3.5 | Discriminant validity

There was strong evidence PAINAD scores were higher following movement than at rest ($z = -8.01$, $p < 0.001$), providing evidence the PAINAD has discriminant properties (Table 4).

3.6 | Internal consistency

Internal consistency for the total scale was acceptable at rest (Cronbach's $\alpha = 0.76$), and good during activity ($\alpha = 0.80$). We also calculated the difference in the α value if each item was deleted in turn. For observations at rest, all items were worthy of retention and would not improve the alpha level if deleted. However, for observations during activity, four items were worthy of retention, except for the breathing item, increasing α to 0.82 if deleted (Table 5).

3.7 | Test-retest reliability

Test-retest reliability of PAINAD showed an ICC of 0.54 (95% CI = 0.38–0.66; $p > 0.001$) at rest and 0.66 (95% CI = 0.55–0.75) during activity. This indicates moderate test-retest for PAINAD scores at rest and movement, with a higher ICC value and smaller confidence intervals for observations in movement.

3.8 | Inter-rater reliability

Inter-rater reliability was analysed with 35 participants (female = 24 [70.6%], mean age = 85.94, SD = 6.62). The ICCs were 0.92 (95% CI = 0.84–0.96; $p > 0.001$) at rest and 0.98 in movement (95% CI 0.95–0.99; $p > 0.001$), indicating excellent inter-rater reliability (Table 6).

4 | DISCUSSION

This study addresses the gap in the literature relating to the psychometric properties of the PAINAD in medical settings. We found strong evidence of inter-rater reliability, acceptable internal consistency, and moderate test-retest reliability. However, findings on validity were less consistent. There was evidence of discriminant validity, demonstrated by higher scores during periods of likely pain than of unlikely pain. In contrast, concurrent validity with the FACES scale was found to be weak; there was no evidence of convergent validity with the BEHAVE-AD.

TABLE 1 General and pain-related patient demographics at initial admission to the general hospital ($n = 230$)

	N (%) or M (SD)	PAINAD (during rest) t or F (p)	PAINAD (during activity) t or F (p)
Demographics			
Gender			
Female	151 (65.7)	0.22 (0.83)	1.11 (0.27)
Male	79 (34.3)		
Age (years)			
75–84	85 (37)	0.59 (0.56)	2.84 (0.06)
85–94	118 (51.3)		
95+	27 (11.7)		
Ethnicity			
White	175 (85.7)	0.39 (0.68)	1.48 (0.23)
Black	15 (8.7)		
Other	40 (1.3)		
Place of residence ($n = 219$)			
Home/Sheltered accommodation	147 (63.9)	2.46 (0.07)	2.66 (0.05)
Residential home	26 (11.3)		
Nursing home	41 (17.8)		
Other	5 (2.2)		
Reason for admission ($n = 229$)			
Infections	115 (50.0)	2.90 (0.004)	2.85 (0.005)
Other	114 (49.6)		
Clinical characteristics			
FAST scores			
3–5 (objective functional deficit, difficulties with activities of daily living)	86 (37.4)	2.09 (0.10)	2.19 (0.09)
6a–6c (help requiring putting on clothes, toileting, or bathing)	39 (17.0)		
6d–6e (urinary and faecal incontinence)	74 (32.2)		
7a–7f (less than 6 words, can no longer walk, sit up, smile, hold up head)	31 (13.5)		
Type of dementia ($n = 161$)			
Alzheimer's	43 (18.7)	0.78 (0.57)	0.48 (0.80)
Dementia	68 (29.6)		
Lewy body	4 (1.7)		
Mixed	5 (2.2)		
Vascular	30 (13.0)		
Unknown	11 (4.8)		
Charlson comorbidity score			
0–1	57 (24.8)	0.49 (0.62)	0.61 (0.54)
2–3	124 (53.9)		
4+	49 (21.3)		

(Continues)

TABLE 1 (Continued)

	N (%) or M (SD)	PAINAD (during rest) t or F (p)	PAINAD (during activity) t or F (p)
PAINAD (rest) (n = 229)	0.35 (1.00)		
PAINAD (activity) (n = 229)	1.69 (2.08)		
FACES (n = 229)	1.50 (1.56)		
BEHAVE-AD	4.19 (5.07)		

Abbreviations: BEHAVE-AD, Behavioural Pathology in Alzheimer's Disease; FACES, Wong-Baker FACES scale; FAST, Functional Assessment Staging Scale; PAINAD, Pain Assessment in Advanced Dementia.

	Correlation between PAINAD ^a and FACES ^b (τ)	p value	n/N (%)
All observations	0.29	>0.001	127/229 ^c
Mild ^d	0.38	0.005	46/229
Moderate ^e	0.31	0.11	23/229
Moderate-severe ^f	0.19	0.11	57/229

Abbreviations: FACES, FACES scale; PAINAD, Pain Assessment in Advanced Dementia.

^aThere is 1 PAINAD assessment missing for participants unable to use the self-reported pain question.

^bThere is 1 FACES assessment missing for participants unable to use the self-reported pain scale.

^cCorrelations for severe dementia could not be analysed due to a lack of measurements that could be obtained of the FACES scale for severe dementia.

^dMild severity defined by stages 3 and 4 on the Functional Assessment Staging Tool (FAST) scale.

^eModerate severity defined by stage 5 on the FAST scale.

^fModerate-severe severity defined by stages 6a–7f on the FAST scale.

TABLE 2 Correlations between PAINAD and FACES at rest by Kendall's Tau (n = 229)

TABLE 3 Correlation between PAINAD and BEHAVE-AD scale by Kendall's Tau on different groups (n = 229)

	At rest			In movement		
	n/N	Correlation between PAINAD and BEHAVE (τ)	p value	n/N	Correlation between PAINAD and BEHAVE (τ)	p value
All observations ^a	229/229	0.09	0.13	229/229	0.06	0.24
Mild ^b	54/229	–0.11	0.36	54/229	–0.20	0.09
Moderate ^c	32/229	–0.16	0.33	32/229	0.01	0.96
Moderate-severe ^d	112/229	0.14	0.09	112/229	0.10	0.18
Severe ^e	31/229	0.10	0.47	31/229	0.02	0.90

Abbreviations: BEHAVE-AD, Behavioural Pathology in Alzheimer's Disease; PAINAD, Pain Assessment in Advanced Dementia.

^aThere is 1 PAINAD assessment missing.

^bMild severity defined by stages 3 and 4 on the Functional Assessment Staging Tool (FAST) scale.

^cModerate severity defined by stage 5 on the FAST scale.

^dModerate-severe severity defined by stages 6a–6c on the FAST scale.

^eVery severe dementia defined by stages 6d–7f on the FAST scale.

Regarding internal consistency, the instrument yielded a Cronbach $\alpha = 0.76$ at rest and $\alpha = 0.80$ in movement. These values are sufficient³⁰ and similar to those obtained in the emergency department ($\alpha = 0.80$;²). Further evaluation of the internal consistency

during movement found the Cronbach α coefficient increased to $\alpha = 0.82$ on elimination of the breathing item. This is consistent with other studies³¹; thus, this item may require modification. There are challenges in assessing whether changes in intensity of breathing are

in response to pain or dyspnea.³² In acute general hospitals, people with dementia in intense acute pain may hold their breath, a factor not considered on the PAINAD.⁸ People with dementia are commonly admitted to hospital for pneumonia or lung disease,³³ which would affect the specificity of this item. This highlights how an individual's behavioural pain presentation is unique.³⁴ One standardised tool is unlikely to capture the range of complex behaviours indicative of pain in all individuals.

We found excellent inter-rater reliability. This was similar to (ICC = 0.98;⁸) and higher than in other studies (ICC = 0.76, $p > 0.001$;³⁵). PAINAD is a simple instrument and high agreement was

found in clinical practice, despite raters having no formal training.³⁶ Therefore, it may be feasible for hospital practitioners to use.

The PAINAD showed moderate test-retest reliability. Pain at rest was reported using PAINAD by 22/43 (51%) of participants at baseline, and for 21/43 of participants (49%) pain started during their hospital admission.³³ For pain experienced during an activity, 96/131 (73%) reported pain at baseline; however, for 34/131 (26%) of the participants, pain was present after the first assessment.³³ This is lower than in the Chinese version of the PAINAD which found an ICC of 0.80–0.86³⁶ but similar to the Spanish version with an ICC of 0.55, despite their retest being performed after a longer 30-day interval.³¹ People with dementia in acute general hospitals are more likely to experience intense episodic acute pain which reduces over time, compared to chronic pain, seen more commonly in community and nursing homes.⁸ As our study focused on acute general hospitals, pain experience was more liable to fluctuate. Patients in substantial pain should have been given analgesics and other medical interventions during these 4 days may explain the changes in pain scores over time.

The strong reliability and weak validity may demonstrate the PAINAD is consistently measuring a different 'unmeasured' concept of pain in the acute general hospital. Although the PAINAD is a highly sensitive instrument (92%), it has a high false positives rate⁶: PAINAD has greater specificity for identifying people with dementia without pain, rather than identifying people with dementia with pain.²³ Observed behaviour can be influenced by a multitude of factors, not just pain.³⁷ To ensure the PAINAD is a valid measure of pain, it is important to explore potential causes of behavioural change or other unmet needs. This would ensure the PAINAD is not assessing other behaviours indicative of distress including hunger, depression and agitation.²⁶

TABLE 4 Comparison of PAINAD scores for activity and rest among people with dementia in acute settings

	n	Mean (SD)	Wilcoxon signed rank test (z)	p value
All observations				
Rest	229	0.35 (1.00)	-8.01	<0.001
Activity	229	1.69 (2.08)		
Mild ^a				
Rest	54	0.33 (0.95)	-2.83	0.005
Activity	54	1.11 (1.82)		
Moderate ^b				
Rest	32	0.06 (0.25)	-3.74	0.001
Activity	32	1.94 (1.98)		
Moderate-severe ^c				
Rest	112	0.36 (0.96)	-5.60	<0.001
Activity	112	1.66 (2.09)		
Severe ^d				
Rest	31	0.68 (1.51)	-3.20	0.001
Activity	31	2.52 (2.34)		

Abbreviation: PAINAD, Pain Assessment in Advanced Dementia.

^aMild severity defined by stages 3 and 4 on the Functional Assessment Staging Tool (FAST) scale.

^bModerate severity defined by stage 5 on the FAST scale.

^cModerate-severe severity defined by stages 6a–6c on the FAST scale.

^dVery severe dementia defined by stages 6d–7f on the FAST scale.

TABLE 5 Internal consistency (Cronbach's α) value for the PAINAD scores at rest and activity

Items	At rest		During activity	
	Correlated item-total correlation	Cronbach's α if deleted	Correlated item-total correlation	Cronbach's α if deleted
Breathing	0.49	0.74	0.38	0.82
Vocalisation	0.54	0.72	0.71	0.72
Facial expression	0.56	0.73	0.73	0.73
Body language	0.62	0.69	0.71	0.72
Consolability	0.58	0.72	0.51	0.80
Cronbach's α		0.76		0.80

Abbreviation: PAINAD, Pain Assessment in Advanced Dementia.

TABLE 6 Inter-rater reliability, calculated using ICC, of the PAINAD scores at rest and in movement

	N	ICC (95% CI)	p value	95% CI
PAINAD (at rest)	35	0.92 (0.84–0.96)	>0.001	0.08–0.88
PAINAD (during activity)	35	0.98 (0.95–0.99)	>0.001	0.41–0.86

Abbreviations: CI, confidence interval; ICC, Intra-class correlation; PAINAD, Pain Assessment in Advanced Dementia.

However, we found a lack of an association between the BEHAVE-AD and the PAINAD, suggesting the PAINAD correctly assesses a construct independent of the symptoms measured by the BEHAVE-AD.⁷ This could be a strength of the PAINAD, as it indicates the PAINAD is more likely to be indicating pain, as opposed to general behaviours of distress; this would lead to more accurate pain intervention.

Pain is a subjective experience; therefore, self-report is considered the gold-standard, including in people with dementia. The lack of evidence for concurrent validity could suggest PAINAD does not measure the fundamental construct of pain in acute general hospitals. However, there are alternative explanations. There are barriers to the use of self-report scales as cognitive impairment increases; people with advanced dementia with a loss of verbal communication and abstract reasoning cannot use self-report scales which demands verbal and cognitive skills.³⁸ These concerns are corroborated in our study, with the only evidence of concurrent validity being in people with mild dementia. In this study, only half of the participants (55.2%) could use the FACES scale and the minority (3.2%) were people with severe dementia.¹ Similar findings have been reported elsewhere³⁹; this has led to previous studies only investigating the concurrent validity of PAINAD in people with mild-moderate dementia who are able to self-report.³⁷ Our sample reflected the acute general hospital population, where dementia severity is greater than in the community.⁹ Observational pain tools may not be applicable to advanced dementia, even though these instruments were designed for this group.³⁷ Self-report and observational tools may measure different phenomena of pain experience: self-report scales may measure a phenomenon mainly controlled by our higher cognitive areas, whereas observational tools measure more autonomic phenomena.⁴⁰

When people with dementia lose the ability to self-report, an alternative way to assess the fundamental concept of pain is to measure pain at rest and during movement.³⁷ Whilst pain avoidance at rest may mask observational pain behaviours, movement may allow for the detection of pain.⁴¹ We found the PAINAD could discriminate between pain and non-pain events. Numerous studies demonstrate parallel findings in other settings.⁸ The finding that lower values were present at rest than during movement was consistent for all psychometric properties that established evidence. Observational tools have floor effects⁴²; therefore, as limited pain behaviours may be apparent at rest, making it difficult for the rater to assign an accurate pain score, observational pain assessment should be conducted during or after movement.

Study limitations include the use of secondary data. However, as PAINAD and other measures used in the study have not changed, this is unlikely to impact findings. Participants had to have an adequate command of English to complete study ratings and a high proportion of the sample identified as white and female, which reduces generalisability. However, sample demographics are representative of people with dementia admitted to general acute hospitals.⁹ Participants were ineligible to participate if they did not have a diagnosis of dementia on admission and were assessed to have delirium using the CAM. Findings are potentially non-generalisable to dementia

superimposed on delirium, despite this being very common.⁴³ There was a significant difference found between reason for admission to the general acute hospital and pain scores, which suggests people admitted for infections may be more likely to experience pain than people admitted for 'other reasons'. This may be a chance finding due to multiple analyses.

Untreated pain in people with dementia leads to behavioural and psychological symptoms often assumed to be 'part of the disease' as opposed to an attempt to signal an unmet need or pain.⁴⁴ Due to concerns regarding the validity of PAINAD, future studies should investigate convergent validity using other observational tools of pain, and measures that assess the utility of PAINAD, such as the use of analgesics.

Until further validation, the PAINAD may not be suitable for use on its own better integrated within a comprehensive approach. A standardised pain tool is one factor in a complex diagnostic process and thus should be integrated with clinical expertise and examination.⁴⁵ Further, the low values at rest highlight the necessity of using PAINAD during or immediately after movement, to assess pain in people with dementia.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data underlying this article are available from the corresponding author on reasonable request.

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