The use of a self-reported pain measure, a nurse-reported pain measure and the PAINAD in nursing home residents with moderate and severe dementia: a validation study

IAN YI-ONN LEONG1, MEI SIAN CHONG1, STEPHEN J GIBSON2

1Department of Geriatric Medicine, Tan Tock Seng Hospital, 11 Jalan Tan Tock Seng, Singapore 308433
2National Ageing Research Institute, PO Box 31, Parkville 3052, Australia

Address correspondence to: I. Y.-O. Leong, Fax: (65) 63577837. Email: ian_leong@ttsh.com.sg

Abstract

Objectives: to assess the construct validity of three measures of pain and to determine a categorical version of the Pain Assessment in Advanced Dementia (PAINAD) scale. Design: validation study determining the concurrent validity of a self-reported pain score (SRPS), a nurse-reported pain score (NRPS) and the PAINAD; the divergent validity of the three pain measures with the Abbreviated Mental Test (AMT) and the Cornell Scale for Depression in Dementia (CSDD). Setting and subjects: eighty-eight nursing home residents with moderate and severe dementia. Methods: residents were asked to rate the severity of their pain in the previous week on a verbal descriptor scale (VDS). Nurses rated the resident's pain on a VDS, scored the PAINAD scale and the CSDD scale. Research assistants administered the AMT. Results: the PAINAD correlated with the NRPS (Kendall's tau [τ] = 0.842); both scales correlated poorly with the SRPS (τ = 0.304 for both correlations). The PAINAD was significantly different for each level of the NRPS. On the SRPS, the PAINAD for the group with moderate+ pain was significantly different from the groups with mild pain and no pain. There was a difference between the SRPS and the NRPS when residents were depressed, but no difference when they were not. Our categorical version of the PAINAD showed good agreement with the NRPS. Conclusion: the NRPS and the PAINAD measure pain differently from the SRPS, especially in the presence of depression. Our categorical version of the PAINAD shows good agreement with the NRPS.

Keywords: aged, dementia, elderly, nursing home, pain measurement

Introduction

Pain is common among nursing home residents with dementia [1], yet there are many gaps in our knowledge of how it can be reliably measured [2]. Failures in assessing pain effectively have resulted in undertreatment and undertreatment of pain [3], especially in residents with dementia who cannot communicate verbally.

Pain in older people with dementia can usually be measured by self-report measures, carer-observed report measures and formalised pain behaviour rating scales. Self-reports of pain are the reference standard for pain measurement in people with normal cognitive function [4]. Recall inaccuracy and incorrect completion of measures increase with advancing dementia [5]. Self-reports are only applicable when the resident is communicative and may be affected by mood states and cultural beliefs [6]. Carer-observed reports tend only to correlate moderately with self-reports and medication requirements [7]. Carers may not agree as to what behaviours communicate pain and may also misinterpret atypical pain behaviour. A score can be obtained in both communicative and non-communicative demented older people. Formalised behavioural pain rating scales provide a
Validation of three pain measures in dementia

standardised platform from which pain can be assessed. However, the current behaviours measured may not be specific and may only reflect the presence of distress; for example, distress arising from negative affective states [8]. Most studies have involved observers monitoring patients for 5–10 min, which would, at best, represent acute pain, whereas in nursing homes, it is chronic pain that is the concern. They, however, remain the only way pain can be assessed in the non-communicative. We therefore set out to study the concurrent validity of self-reported pain, nurse-reported pain and the Pain Assessment in Advanced Dementia (PAINAD) Scale [9], their divergent validity from a measure of depression and cognition, and their performance under different mood states. We also wanted to determine an ordinal structure for the PAINAD, and if possible, to determine a range of scores that would allow for the development of a categorical scale comparable with a verbal descriptor scale (VDS) for pain.

Methods

Subjects
The study was approved by the Institutional Review Board of Tan Tock Seng Hospital, Singapore, and the nursing home where the study was conducted. This study was part of a larger epidemiological study of pain involving three local nursing homes. Residents from a single nursing home were included in this study if they had moderate to severe dementia, as diagnosed by a psychogeriatrician, using DSM-IVR criteria [10] and a Functional Activity Staging (FAST) score of at least 5 [11]. Residents needed to be able to answer queries about the presence of pain and the severity of pain. We excluded residents who had any acute, fluctuating change in mental status, which could have been deemed to be delirious. We did not exclude patients who had chronic behavioural problems secondary to their dementia.

Measures
A self-reported pain score (SRPS) was obtained by asking residents if they had experienced pain in the past week and if they had, they were to grade its average severity using a 4-point VDS (no pain, mild pain, moderate pain and severe pain). A VDS was used as it has the best completion rate among patients with advancing dementia, and would be the most applicable instrument in settings where patients have varying cognitive abilities [1].

A nurse-reported pain score (NRPS) was obtained by asking nurses if they felt that the resident had experienced pain in the previous week. If they felt that the resident had experienced pain, they were asked to rate what they felt was the resident’s average pain severity according to the same four verbal descriptors as the SRPS. They could form their judgement from the behaviours exhibited by the resident, or by any verbal report that the resident may have given. No explanation was given as to what parameters would constitute average pain.

In addition, nurses were asked to recall the behaviours on the PAINAD that the patient may have exhibited in the past week [9]. The PAINAD consists of five pain behaviours - breathing not including vocalisation, vocalisations, consolability, facial expression and body posturing. Each behaviour can be graded from 0 to 2 according to the severity of behaviour exhibited, thus giving a total score of 10. Warden et al., in their validation paper, indicated that it may be comparable to other 11-point scales, such as the 0–10 numerical rating scale. However, this was not empirically proven. Their study of 19 observations showed that the PAINAD score correlated with an observer-rated pain severity visual analogue scale (r = 0.75, P = 0.001). The median PAINAD score was 0–0.5 in the presence of a pleasant condition and 3–4 in the presence of an unpleasant condition.

We also measured depression using the Cornell Scale for Depression in Dementia (CSDD), which consists of 19 items [12]. Each item is scored from 0 to 3. A score of 8 or more is indicative of depression. It has demonstrated good inter-rater reliability and validity. There were five residents who did not have a CSDD score, but were assessed with the 15-item version of the Geriatric Depression Scale [13]. In these, they were defined as depressed if they scored 6 and above. They were not included in any analysis that involved the CSDD. We used the Abbreviated Mental Test (AMT) to gauge the cognitive function. In a local validation study, a decrease in the AMT score was found in advancing dementia [14]. In our study, we used it as a surrogate of worsening cognitive function. Details on the type of dementia and demographic details were derived from entries in the resident’s case records.

A resident’s functional status was measured based on the Human Activities Profile [15], which is scored based on 94 activities of increasing metabolic demand. The actual activities score (AAS) reported here is the number of activities the resident was still doing.

Statistical analysis
Concurrent and divergent validity was determined by bivariate correlational analysis using the Kendall’s tau statistic. Concurrent validity was said to be present if there was at least a strong correlation (Kendall’s tau [τ] > 0.5 or < −0.5). Divergent validity was said to be present if there was less than minor correlation between the 2 measures (τ < 0.3 and > −0.3).

The mean and standard deviation (SD) of the PAINAD for varying severities of pain on the SRPS and the NRPS were determined. A one-way between-group analysis of variance was used to determine if the mean scores for different severities of pain were statistically different. Post hoc analysis using the Tukey honestly significant difference (HSD) test was used to determine where the difference lay. As our results were positively skewed, the Kruskall–Wallis test was used to confirm this relationship.

Post hoc, as the three pain measures correlated with depression differently and as the NRPS and the SRPS were measured on the same scale, we used the paired sample t-test to measure the difference in the mean scores of the SRPS and the NRPS in the presence and absence of depression. In addition, a Wilcoxon rank-signs test was used to confirm the significance of the determined relationships.
As the NRPS correlated with the PAINAD, we converted the PAINAD into a categorical version based on the NRPS. This was done visually by means of plotting the frequency of the PAINAD scores based on the three levels of NRPS. The agreement between the categorical version of the PAINAD and the NRPS was measured using the kappa statistic.

Results

Eighty-eight residents met our inclusion criteria. The mean age of our sample was 79.6 years, with an SD of 8.3 years. Of the 88 residents, 61.4% were females. As very few residents had severe pain, we amalgamated the severe pain and moderate pain categories. Based on the SRPS, 66 residents had no pain, 15 had mild pain and seven had at least moderate pain. However, based on the NRPS, 41 had no pain, 39 had mild pain and eight had pain of moderate severity and above. The cause of pain in residents who reported pain was musculoskeletal in 59.1%, visceral in 22.7%, neuropathic in 4.5%, cutaneous in 4.5% and not definable in 9.1%. The mean AMT score was 1.8 with an SD of 1.9. The proportion of residents with an AMT score of 0–1 was 53.4%, while the rest had higher AMT scores. The median AAS score was 2, with a range from 0 to 40; 49.4% of subjects had a score of 0.

As shown in Table 1, major correlation was demonstrated between the NRPS and the PAINAD but not between either of these scales and the SRPS. There was divergent validity between the three pain measures and the CSDD and the AMT.

The PAINAD was different between the different severity levels of the NRPS ($P < 0.001$) and the SRPS ($P < 0.001$) (see Table 2). Post hoc analysis showed that the mean PAINAD score was statistically different among all levels of pain on the NRPS. However, the mean PAINAD score was statistically different between the group with moderate pain and those with mild or no pain on the SRPS. There was no difference between the group with mild pain and the group without pain. In addition, the mean scores of the NRPS (mean = 0.79, SD = 0.64) and the SRPS (mean = 0.35, SD = 0.66) were statistically different in the presence of depression ($P < 0.001$), but not in the absence of depression ($P = 1.0$).

Table 1. Correlation matrix of the self-reported pain score (SRPS), nurse-reported pain score (NRPS), Pain Assessment in Advanced Dementia (PAINAD) scale, the Cornell Scale for Depression in Dementia (CSDD) and the Abbreviated Mental Test (AMT) score

<table>
<thead>
<tr>
<th></th>
<th>SRPS</th>
<th>NRPS</th>
<th>AMT score</th>
<th>CSDD score</th>
</tr>
</thead>
<tbody>
<tr>
<td>PAINAD score</td>
<td>0.304*</td>
<td>0.842***</td>
<td>-0.198</td>
<td>0.292**</td>
</tr>
<tr>
<td>SRPS</td>
<td>0.304*</td>
<td>0.185*</td>
<td>-0.093</td>
<td>-0.312**</td>
</tr>
<tr>
<td>NRPS</td>
<td></td>
<td>0.248*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AMT score</td>
<td></td>
<td></td>
<td>-0.312**</td>
<td></td>
</tr>
</tbody>
</table>

* $P < 0.05$.
** $P < 0.005$.
*** $P < 0.001$.

Figure 1 shows the frequency of residents reporting various scores of the PAINAD as it relates to the Nursing-Reported Pain Score (NRPS).

Figure 1 shows the frequency of residents reporting various scores of the PAINAD for the various pain severities on the NRPS. We transposed the PAINAD into a categorical scale as follows: a score of 0–1 would correspond to no pain, 2–3 would correspond to mild pain and a score of 4 and above would correspond to moderate and above pain. This transposed version showed good agreement with the NRPS (kappa = 0.85, $P < 0.001$).

Discussion

Our main findings were the following:
(i) The NRPS and the PAINAD showed concurrent validity, but there was no concurrent validity of these two scales with the SRPS.
(ii) The difference between the mean scores of the NRPS and the SRPS could not be demonstrated in the absence of depression, although there was a difference in the mean scores when residents were depressed.
(iii) There was good divergent validity of all three pain scales with the CSDD and the AMT.
(iv) The PAINAD has an ordinal structure and our categorical version of the PAINAD showed good agreement with the NRPS.

The presence of concurrent validity suggests that both the NRPS and the PAINAD do measure pain, in particular,
pain behaviours. The absence of concurrent validity with the SRPS either suggests that the SRPS measures another aspect of pain, or the SRPS is inaccurate in measuring pain in older people with moderate and severe dementia, or some other factor may confound the relationship between the three scales. We believe it is concurrent depression that confounds this relationship.

Hadjistavropoulos and Craig [16] suggest that behavioural scales (and possibly observer-based ratings) measure a more automatic phenomenon, whereas self-reported ratings measure a phenomenon predominantly controlled by our higher cognitive centres. Self-reported ratings of pain can therefore be influenced by factors such as cognitive ability, mood and cultural circumstances. Based on this hypothesis, we would expect the SRPS to give similar or more severe ratings of pain compared with the NRPS or the PAINAD score for a particular subject in the presence of depression. However, our study found that the SRPS gave lower ratings in the presence of depression and similar ratings in the absence of depression. Pain behaviours may possibly be confounded by depression as there is an overlap in the behaviours for pain and for depression [12, 17].

The validity of recalled self-report of pain in older people with moderate and severe dementia has been controversial. Most authorities feel that such people are unable to recall characteristics of their pain. However, Chibnall and Tait [18] have demonstrated that there was no difference in the week-averaged severity of pain in those with normal cognitive function and in those with cognitive impairment (Mini Mental State Scores of 13–21). In our study, the lack of difference in the SRPS and the NRPS in the absence of depression also suggests that we may have underestimated the ability of older people with moderate to severe dementia to report the severity of their pain. The confounding effect of depression on SRPSs and observer-rated scores suggests that there may be a need to measure multiple aspects of a patient’s pain. A discrepancy may suggest the presence of a mood disorder.

Our study extends our understanding and the utility of the PAINAD by demonstrating its ordinality, by demonstrating its ability to measure pain beyond the short moment of observation by a trained observer and by demonstrating a possible categorical transformation. To our knowledge, prior validation studies of other pain behaviour scales have only demonstrated ordinality in two other scales, the Checklist of Non-Verbal Pain Indicators (CNPI) [19] and the Pain Assessment Tool in Confused Older Adults (PATCOA) [20]. For the CNPI, in a sample of 32 patients with cognitive impairment, the observed correlation with a VDS was 0.299 (P = 0.30) at rest and 0.463 (P = 0.009) on movement. For the PATCOA, in 116 older people with normal cognitive function, there was a correlation of –0.24 with pain reported on a visual analogue scale. Based on these previous correlations, we have demonstrated that the PAINAD has robust ordinal properties. The question to ask, however, is if both the PAINAD and the NRPS are similar in their diagnostic accuracy, what is the benefit of using formalised behavioural pain scales? In our study, the nurses who rated the pain severity had been caring for the resident for a period of time. It is likely that formalised behavioural pain scales will be useful when the resident is transferred to another setting of care where the observer may be unfamiliar with the patient. Formalised behavioural pain scales also allow for longitudinal comparisons.

In previous studies, observation was for a short period of time. In our study, we have demonstrated that ordinal properties can be demonstrated for up to a week of observation. No studies of pain behaviour rating scales to our knowledge have attempted to measure severity of pain persisting beyond a short moment. This would suggest that summed behavioural pain rating scores can give an idea of the severity of chronic pain. However, we would need to demonstrate the accuracy of longer periods of observation. If demonstrable, such a summed score will be as useful as asking for the severity of pain in patients with normal cognitive abilities. The immediate clinical utility of our study would be that pain can be estimated by the use of a recalled PAINAD score at the end of the day or the end of a work shift.

There are several limitations with our present study. Our sample size was small, particularly the number of residents with severe pain, a fact that has also plagued other studies validating pain behaviour scales. As we did not include residents who had delirium, care should be taken when interpreting PAINAD scores in acute medical settings unless delirium has already been excluded. As this was a study based in a nursing home, many of the patients did not have a precise aetiological diagnosis of their dementia. The severity of their dementia cannot be accurately categorised as they did not all have Alzheimer’s disease and their concurrent illness may affect their functional abilities, thus an accurate determination of the FAST would have been difficult.

The strength of our study is in the demonstration of ordinality of the PAINAD in a fairly large sample of older people with moderate and severe dementia. Most studies have patients with milder degrees of cognitive impairment. One use of this would be that it allows us to obtain epidemiological data of pain in nursing homes that include residents with severe dementia and non-communicative older people. This segment of the population has usually been excluded in prior studies [21].

In conclusion, our study demonstrates that observer-rated pain scales and formalised pain behavioural scales measure pain differently from self-reported measures, especially in the presence of depression. We have also demonstrated a categorical version of the PAINAD which shows good agreement with a NRPS.

**Funding**

The study was funded by the Tan Tock Seng Hospital grant RI02/16.

**Conflict of interest**

All authors declare they have no conflict of interest.
Key points

• Observational pain scales and formal pain behaviour rating scales show good correlation in people with moderate dementia.
• These scales do not correlate with self-reported pain scales.
• Depression results in higher pain scores on observational rating scales and formal pain behaviour rating scales as compared to self-reported scales.
• An ordinal version of the PAINAD has good agreement with an observational pain scale.

References


Received 15 September 2005; accepted in revised form 18 January 2006