The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia

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Abstract

The need for a specialized clinical regimen for patients with dementia who require palliative care has only recently been recognized. Structured approaches to palliative care are not well developed. The recognition and treatment of pain is an important part of this management task. However, pain is consistently underdiagnosed and undertreated in this population. A factor contributing to this has been a lack of appropriate tools to help recognize and document pain. This study sought to develop and validate an easy-to-use pain scale for use in residential aged care homes. The tool was developed with residents with end- or late-stage dementia who were unable to articulate their needs, identified by the registered nurses who knew them. Results showed that following pain-relief intervention the average pain score recorded using the scale fell by more than half. A paired Student's *t*-test showed the reduction to be highly significant ($P<0.001$). Validity and internal reliability, assessed by calculating Gamma and Cronbach's alpha, were found to be satisfactory. Qualitative evidence gathered from users of the scale indicated that it was considered a useful clinical device that could be completed within 1 minute. Further analysis of the use of the scale in clinical settings, testing of inter-rater reliability and examination of the limitations found in this study will commence early in 2004.

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Studies looking at the need for palliative care in residential aged care facilities have found that failure to recognize and treat pain adequately is a major issue (Maddocks et al, 1997). Other researchers have found that the detection, diagnosis and management of pain in the institutionalized older population is often poor, and worse for those who are cognitively impaired (Ferrell et al, 1990; Marzinski, 1993; Sengstaken and King, 1993; Huffman and Kunik, 2000). Marzinski (1993) found considerable anguish among staff in regard to inadequate pain relief for the people with dementia in their care. Conflicts over the amount of pain perceived to be experienced by people with end-stage dementia have also been observed in residential aged care facilities, causing stress for both staff and residents (Abbey, 2001).

Residential aged care facilities in Australia provide care for approximately 150 000 people. These people have all been assessed by an aged care assessment team as needing 24-hour care. A combination of demographic change and scarcity of places has produced a resident population that is becoming older, more dependent and more likely to have dementia. In Australia a national instrument, the Resident Classification Scale, is used to assess an aged person's dependency level before admission to long-term residential care. It has been estimated that up to 90% of residents now classified as needing high care and 54% of those in low-care categories have dementia (Access Economics, 2003). Research has shown that, despite new standards and guidelines for pain management being introduced for all residential aged care facilities in Australia (Department of Health and Ageing, 1998), the undertreatment of pain, especially for those residents who cannot verbalize, is still prevalent (McClean and Higginbotham, 2002).

Projections estimate that the number of Australians with dementia will grow from approximately 162 000 in 2002 to about a 500 000 by 2040 (Access Economics, 2003).

Overall, the evidence is sufficient to conclude that the risk of undiagnosed or undertreated pain in the population of people suffering from dementia is unacceptably high.

Project overview

The aim of this project was to develop a highly reliable pain scale for people with end-stage dementia that was efficient, effective and able to be used by a variety of care staff. The research took place in two stages between 1997 and 2002 in 24 residential aged care facilities in four Australian states: South Australia, New

South Wales, Queensland and Victoria. The first stage focused on the development of a tool likely to meet the project's objectives and a trial on small, accessible research populations in facilities with staff and residents willing to participate in the project. The second stage focused on modifying the tool in the light of the results of the first stage followed by application to larger nursing home populations across the four states. This report concludes with a brief summary of progress so far and an indication of the limitations of this study that need to be addressed in future work.

Development of pain measures for people with dementia

Two pain assessment tools for people who are unable to respond verbally had been developed before this study was undertaken (Hurley et al, 1992; Simons and Malabar, 1995) and one was published during the trial (Feldt, 2000). Earlier attempts at pain assessment tools for this population (Craig and Prkachin, 1983; Linton et al, 1985) had been abandoned because of doubts about reliability in relation to variable cultural and social differences, different coping styles and the impact of conditions such as depression. At the start of this study the researchers could find no scale that had been specifically designed for and tested on elderly people with dementia who were unable to verbalize their needs living in residential aged care settings.

In 1992 Hurley et al developed a scale, the Discomfort in Dementia of the Alzheimer's Type scale (DS-DAT), based on nine behavioural indicators: noisy breathing; negative vocalization; content, sad or frightened facial expression; frowning; relaxed or tense body language and fidgeting. This scale was modelled on earlier research with very young children. The DS-DAT, used by educated and experienced nurses who spent 5 minutes observing and recording the subjects' behaviour, was able to detect discomfort caused by fever episodes (Hurley et al, 1992). However, the authors indicated that the scale needed more work and it was not presented in a format that was suitable for clinical use.

Simons and Malabar (1995) used six pain indicators: verbal response; facial expression; body language; physiological change; behavioural change and conscious state. They concluded that attending carefully to non-verbal indicators of pain was vital for those patients unable to communicate verbally. When the scale was completed, however, the findings needed to be interpreted by expert staff.

In 2000, Feldt published the results of her carefully constructed and analysed study that had concentrated on developing a checklist of non-verbal pain indicators (e.g. vocalizations, grimaces, bracing, rubbing and restlessness) to assess pain in the cognitively impaired elderly people. These indicators were developed and tested on postoperative patients (some of whom had some degree of cognitive impairment), and dealt mainly with acute pain. One of the recommendations of the research was that 'the tool should also be tested for use with cognitively impaired residents in long-term care facilities' (Feldt, 2000).

While the work being reported here was in progress, other commentaries dealing with assessment and understanding of pain in patients with dementia were published (Manz et al, 2000; Teno et al, 2001). However, these articles still reported a lack of diagnosis of pain in people with dementia and called for more research. The practical difficulties of putting something useful into the hands of practitioners to assist them in diagnosing, assessing and reporting pain are still to be overcome.

Development of the scale

The draft pain scale was built on the studies by Hurley et al (1992) and Simons and Malabar (1995). It was based on those indicators and prompts that had been tested and that found to have a reasonable degree of validity in these studies. The number of observations was also reduced to create a simple scale. This scale was modified by gerontological and pain experts in both Australia, and the USA through a Delphi study. Further changes were made following discussion with nursing and medical practitioners using focus groups. These consultation processes resulted in a draft pain scale that identified the following six behavioural indicators. These were considered to be markers of pain and descriptive prompts to assist staff with their observations:

- Vocalization, e.g. whimpering, groaning, crying
- Facial expression, e.g. looking tense, frowning, grimacing, looking frightened

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'At the start of the study the directors of nursing of large residential aged care facilities in South Australia were contacted.'

- Change in body language, e.g. fidgeting, rocking, guarding part of body, withdrawn
- Behavioural change, e.g. increased confusion, refusing to eat, alteration in usual patterns
- Physiological change, e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
- Physical change, e.g. skin tears, pressure areas, arthritis, contractures, previous injuries.

Finding participants: residents and staff

At the start of the study the directors of nursing of large residential aged care facilities in South Australia were contacted. If their facility agreed to take part in the study all registered nurses on staff were involved, with one senior registered nurse taking primary responsibility for collecting records and liaising with the researchers. Residents were identified by a senior registered nurse as having end- or late-stage dementia and as being unable to describe their pain coherently and consistently. These residents were then given Katzman tests, a 6-item orientation-memory-concentration test (Katzman et al, 1983). These independently confirmed the nurses' assessment of the residents' late stage dementia and lack of verbal ability. All residents within the aged care facility who met the inclusion criteria were selected.

Both the chief investigator and the research assistant undertook personal visits to the facilities to explain the scale and the research, where possible. In other cases weekly contact was made by phone. Consent was gained from the researchers' university ethics committee and, later, when they came into existence, the ethics committees in the residential facilities themselves. Initially, consent for inclusion of the selected residents was gained from their legal representatives. As the research progressed the university and facilities' ethics committees agreed that, as staff had begun using the pain scale as a routine part of the residents' clinical documentation, individual permission was not required.

Staff members of participating facilities agreed that, whenever they perceived any participating resident as experiencing pain, they would observe and record their judgments of the observed indicators on the draft scale. One registered nurse in each facility was responsible for facilitating the study and was paid a small honorarium. The cost of the honoraria had been factored into the funding application, as it was felt that staff assistance needed some tangible acknowledgement and reward.

First stage

Data collection

The first stage was conducted across 12 sites and yielded data for 770 pain episodes from 52 residents. The number of pain episodes recorded per resident ranged from 1 to 83, with a median of 7.5 episodes. Data were recorded by a registered nurse for 55% of the pain episodes, by an enrolled nurse for 43% of the pain episodes and by an assistant in nursing for 2% of the pain episodes.

When staff first considered the resident to be in pain, two observations were recorded for each of the six behavioural indicators. The staff member was first asked to rate the presence or absence of the indicator using the scale: 0=absent, 1=intermittently present, and 2=constantly present. Staff then recorded the degree of severity of the pain, using the scale: 0=absent, 1=mild, 2=moderate, and 3=severe. Then, as a distinct exercise, the staff member was asked to classify the pain as acute, chronic or acute on chronic and to provide a holistic impression or unstructured judgment of the observed pain on a scale of 1=no pain to 5=severe pain. This latter rating was intended to provide an overall holistic subjective assessment of the observed pain that would serve as a standard or baseline against which the variability in the individual indicators could be assessed. Finally, all the same observations were made again 45 minutes after the chosen pain-relieving intervention had been administered.

Throughout the project each staff member completing a scale was also invited to supply further descriptive information by adding a note to the reverse side of the completed scale so that some qualitative analysis could be added to enrich the quantitative data (Nieswiadomy, 2002).

Details of the pain relieving intervention(s) used were also recorded. The most common intervention, used in 95% of cases, was analgesics, usually paracetamol, followed by repositioning (73% of cases), massage (27%) and heat packs (3%). The same staff member recorded both the pre- and post-intervention ratings.

'Internal reliability was assessed by Chronbach's alpha. This was measured on both the pre-intervention and post-intervention scale items.'

Analysis

Overall, the analysis showed that all 12 pain measures were suggesting less pain post intervention. A reliability analysis provided a Chronbach's alpha of 0.81, demonstrating a high degree of reliability and that a summative scale was suitable. The analysis also showed that the observations regarding the presence or absence of pain indicators, as distinct from the pain indicator severity observations, added little extra reliability or discriminatory or predictive power to the scale.

Refinements to the scale for second stage data collection

At this point the six separately recorded presence of pain indicator measures were omitted, reducing the scale to six severity of pain indicator measures. A summative scale was created by allocating a numerical score for each item, weighting each question equally and summing the scores. The indicators and prompts remained the same. The six items, each with three grades of severity, gave a total possible score of 18. The scores 0–2 indicated no pain, 3–7 indicated mild pain, 8–13 indicated moderate pain and 14+ indicated severe pain. The interpretation of the pain score was based on a crosstabulation of the new pain score against the holistic measure. Although there will always be some element of arbitrariness in grouping ordinal variables, the data suggested that the structuring of the categories was reasonable. Respondents were also asked to tick a box that matched the type of pain, with the options: chronic, acute or acute on chronic. The holistic assessment was also retained.

At this stage the researchers also intended to test for inter-rater reliability. Participating staff were asked if, wherever possible, different staff members could each complete a scale for the same resident independently and at the same time, but not to disclose the results to each other.

Second stage

Data collection

A number of additional residential facilities were included in the second stage along with those that participated in the first round, bringing the total of participating institutions to 24 and increasing the variety of facilities from which data was collected. The same process was used to recruit large interstate facilities as was used with South Australian facilities in the first round. Despite more residents being involved in the second stage, the number of pain episodes recorded was lower. The reasons for this are discussed later. Sixty one residents were studied in the second stage with 236 pain episodes being recorded. Of the 61 staff completing the pain scale, 45 (74%) were registered nurses, 7 (11%) were enrolled nurses and the remaining nine (15%) were assistants in nursing. Eighteen residents (30%) were assessed by two staff members independently, allowing some measure of inter-rater reliability; with 43 residents (70%) assessed by a single staff member. Data on sex and age were collected in the second stage. The majority of residents (66%) included in the study were female. Age was highly skewed with a range of 60–97 years and a median of 83 years.

Analysis

The researchers assessed the validity of the six-item scale in several ways. Face validity (whether the instrument looks as if it is measuring the right thing) and content validity (whether the instrument encompasses all the domains of the underlying concept in a balanced way) could reasonably be assumed in the light of the results of the extensive expert consultation undertaken in the Delphi process and the focus groups before the start of the field work. Concurrent validity (whether the instrument's findings correlate highly with a gold standard, if one exists) was assessed by adopting the nurse's overall holistic pain assessment as the gold standard and measuring the association between the pre-intervention summative pain score and the holistic score.

Gamma, a measure of the correlation between the two sets of variables, was found to be 0.586 ($P \leq 0.001$) demonstrating a reasonable degree of validity (Agresti, 1990). Validity was also assessed by performing a paired Student's *t*-test on the mean scores before and after the intervention. The mean scores had halved. The extent of the reduction was found to be highly significant ($P<0.001$).

Internal reliability was assessed by Chronbach's alpha. This was measured on both the pre-intervention and post-intervention scale items. For pre-intervention, Cronbach's alpha was 0.74, which is regarded as adequate (Nunnally and Bernstein, 1994). The post-intervention alpha was also 0.74.

These values are lower than those of the first-stage data, which probably reflects

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the fall in the number of multiple observations of the same resident during the second stage. The cause of this is discussed below.

Inter-rater reliability for the pain score was measured for two staff members assessing 18 residents by the intra-class correlation coefficient. The inter-rater reliability scores show, at best, only a modest correlation. Greater levels of agreement were seen with regard to whether the subject was experiencing pain than with regard to how much pain had been reduced by the nursing intervention. This, and the small number of independently assessed pain episodes, is a significant limitation of this study that needs to be addressed, perhaps initially through training in the use of the scale.

Table 1 shows the mean pain scores before and after intervention. As noted above, a paired Student's *t*-test showed the reduction to be highly significant ($P<0.001$). This indicates that the scale has demonstrated the potential to become an effective clinical instrument.

Qualitative results for stages one and two

Qualitative evidence was collected in both phases of the study. Direct staff comments were recorded as diary notes by the research assistant and chief investigator. Written comments were made on the blank page left on the back of each scale for this purpose. The resulting data were analysed by thematic analysis. Comments related very specifically to individual questions and to the use of the scale as a clinical tool. Two significant themes emerged. First, the prompts included in the scale to help staff recognize possible pain indicators were perceived as correlating well with what on-the-spot observers regarded as signs of pain. Second, the scale was reported to have taken less than one minute to complete. The overwhelming balance of comment from staff was favourable on that particular score and on the scale's perceived efficacy in providing guidance in pain management.

Table 1. Mean pain score for second stage data

Scale	*n*	Mean	Standard deviation
Pre-intervention	61	9.02	3.75
Post-intervention	61	4.21	3.20

The scale presented here was the version used in the second stage (*Figure 1*).

Discussion

The study highlighted some of the difficulties in pain research. In particular, difficulties in achieving rigour in clinically-relevant research in busy aged care homes where substantial numbers of subjects are required to achieve the researcher's aims.

Without an agreed physiological or biochemical marker of pain and with the patient unable to communicate, there is no demonstrable, unvarying benchmark or gold standard that would allow a definitive diagnosis of pain, much less a scaled measure of it. However, this situation is not uncommon in psychological and psychiatric research. The research team adopted what it believed to be the best available basis for a simple measure – the staff member's holistic and contextual knowledge of the resident. The team then attempted to construct a compound or multi-item surrogate measure, before testing it and the component parts for different types of validity against the nominated gold standard.

It could be asked whether, if the holistic assessment is accurate, there is any need for a scale such that produced in this study. However, as previously discussed, the holistic assessment of one staff member is often questioned by other staff. A scale based on several items is generally more reliable than any individual item, thus making the six-item scale more reliable over time than the holistic impression or 'top of mind' nurse response (Anastasi and Urbina, 1997). As important, it also provides a record of observations to allow nurses to explain the reason they felt the resident was in pain, especially when the episodes of conflict arise.

The second difficulty highlighted by this study arose from siting a comparatively large-scale project in a widely dispersed group of busy residential aged care homes where the maintenance of research controls could not be a priority. These factors made it logistically impossible to ensure that two staff could be available in enough cases for an effective analysis of inter-rater reliability to be made. This resulted in a weakness in the study that will be addressed in future work.

A third problem, one commonly encountered in-situ clinically relevant research, was the steady departure from the study of residents as a direct result of what staff believed they had learned from using the

scale. Many residents initially included in the trial were soon prescribed regular analgesia by those caring for them, as a result of what the administration of the scale seemed to the carers to be showing. Although there was no intention for the scale to be used as a clinical tool to this extent during the research, it rapidly became used in this way by the nurses and visiting medical practitioners, significantly restricting the availability of subjects in the study.

Conclusion

The assessment of pain in cognitively impaired people is fraught with uncertainties and many uncontrollable variables. Depression, fatigue and agitation are just some of the factors other than pain that can influence a person's responses. Equally, the observer's ratings could be influenced by numerous factors that have little or nothing to do with the resident's pain levels. However, whatever allowance is made for

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalize

How to use scale : While observing the resident, score questions 1 to 6.

Name of resident.....

Name and designation of person completing the scale : .....

Date : ..... **Time :** .....

Latest pain relief given was.....**at**.....**hrs.**

Q1. Vocalization — Q1 ☐
e.g. whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3

Q2. Facial expression — Q2 ☐
e.g. looking tense, frowning, grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3

Q3. Change in body language — Q3 ☐
e.g. fidgeting, rocking, guarding part of body, withdrawn
Absent 0 Mild 1 Moderate 2 Severe 3

Q4. Behavioural change — Q4 ☐
e.g. increased confusion, refusing to eat, alteration in usual patterns
Absent 0 Mild 1 Moderate 2 Severe 3

Q5. Physiological change — Q5 ☐
e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
Absent 0 Mild 1 Moderate 2 Severe 3

Q6. Physical changes — Q6 ☐
e.g. skin tears, pressure areas, arthritis, contractures, previous injuries
Absent 0 Mild 1 Moderate 2 Severe 3

Add scores for 1–6 and record here → **Total pain score** ☐

Now tick the box that matches the total pain score →

0–2 No pain	3–7 Mild	8–13 Moderate	14+ Severe

Finally, tick the box which matches the type of pain →

Chronic	Acute	Acute on chronic

Figure 2. The interconnectedness of the themes.

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these factors, it is essential that members of this population have their pain measured as accurately as possible so that they are neither undertreated or overtreated for suspected pain. The Abbey pain scale, as with all others, has limitations, but it was shown to be valid, as measured against the holistic measure. It was also easy enough to complete to be used even in busy nursing homes where understaffing is an inescapable part of everyday life.

The scale, together with an explanatory letter to directors of nursing and a teaching poster, was distributed to all residential facilities in Australia in late 2002, as required under the terms of the funding grant. The poster had space left vacant to encourage and allow senior staff to add their own institution's protocols for both using the scale and treating any pain detected. The letter indicated that further studies would be conducted and that feedback from the use of the scale in clinical settings would be sought. Since that time, the scale has been distributed in several other countries in response to requests and the anecdotal evidence collected to this point, from both Australia and overseas, indicates a high acceptance rate. Follow-up studies regarding the use of the scale in clinical settings are about to commence. IJPN

The steering committee acknowledges the financial contribution over more than 5 years of the JH and JD Gunn Medical Research Foundation. Copies of the educational poster, explanatory letter and the scale are available from the corresponding author. The authors also acknowledge the value of the comments made by the *International Journal of Palliative Nursing's* anonymous referees and thank them for the considerable assistance they have provided.

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Key words

- Palliative
- Dementia
- Alzheimer's
- Care of the elderly
- Residential aged-care facilities
- Pain