Assessment of Pain in Older Adults with Dementia in Acute, Sub Acute and Residential Care

Systematic Review

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The complete document including appendices is available on the ACEBAC website at www.latrobe.edu.au/acebac

NB An update of this systematic review is currently in progress

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Executive Summary

Background
The prevalence of pain amongst older adults is higher than amongst the general population. Similarly, dementia is more common in older people, however little is known about the experience of pain in people who have dementia. It is thought that because of communication challenges and impaired memory, a large percentage of adults with cognitive impairment suffer from unrelieved pain. If clinicians are informed and aware of the most effective strategies for assessing pain in this population, unrelieved pain should be reduced.

Objectives
The objective of this systematic review was to present the best available evidence on the assessment of pain in older adults with a diagnosis of dementia.

Inclusion criteria
This review considered any randomised controlled trials (RCTs) that evaluated the effectiveness of pain assessment for people aged 65 years or older with a diagnosis of dementia. In the absence of any RCTs, other research methodologies such as non-randomised controlled trials, longitudinal studies, cohort or case control studies, or descriptive studies, were included in this review.

Search strategy
A literature search was performed using the following databases for the years 1992-2005: CINAHL, Medline, PsycINFO, Ageline, Cochrane Library, Embase, APAIS Health, Current Contents, Social Science Citation Index and Dissertation Abstracts. Hand searching of reference lists and bibliographies of retrieved articles was conducted. Searches were limited to published and unpublished literature in the English language[1].

Critical appraisal
All studies identified as being relevant to the systematic review were critically appraised by two independent reviewers using the approach recommended in Cochrane Reviewers' Handbook 4.2 (Alderson, Green & Higgins, 2004) for appraising quantitative studies.

Data extraction
Data extraction was undertaken by two independent reviewers using a data extraction instrument developed by the Joanna Briggs Institute. Where there was disagreement between reviewers regarding inclusion, the Expert Reference Group or a third reviewer were consulted.

[1] Funding did not allow for translation costs

Data synthesis
No RCTs were identified. Statistical data presented was from quasi experimental studies with disparate goals, using a range of interventions, therefore pooling of this data and meta–analysis was not possible.

Results
Thirty studies were included in this systematic review. Key approaches became apparent, and accordingly the results are organised under the following headings: self-report of pain in older adults with dementia; proxy/observational assessment of pain in older adults with dementia; and combination of self-report and proxy/observational assessment of pain in older adults with dementia. The studies included are considered to be mainly of lower level evidence according to NHMRC (National Health and Medical Research Council, 1999) classifications, commonly due to methodological limitations, such as small sample size and inconsistent definitions of cognitive impairment. The results are presented in a narrative summary.

The most effective method of pain assessment identified was self-report, regardless of the cognitive status of the older adult. Proxy pain reports should only be considered as a last resort. Observation of behavioural symptoms was thought to assist in the identification of unrelieved pain, and the diagnosis of medical conditions was a good predictor of pain.

Conclusion
This systematic review confirmed that pain is under assessed in older adults with dementia, and showed that most assessment scales used were inadequate and not designed for this population. A need for scales suitable for older people with dementia was identified. Further research is necessary to clarify many issues surrounding the assessment and treatment of pain in older adults with dementia.

While the use of self-report measures in cases of cognitive impairment may seem counter intuitive, the evidence suggests that they remain the most reliable and practicable measures available. The continued and increased use of self-report can therefore be cautiously recommended. However, a number of conditions may increase the accuracy of self-report, including questioning only on current pain and considering the capacity of the individual to respond. As impairment increases it may be necessary to augment self-report with proxy ratings, or in patients who are entirely non communicative, rely on proxy ratings alone.

Introduction

Background

The prevalence of pain experienced by older people and especially residents of aged care facilities is high (Ferrell, Ferrell & Rivera, 1995; Parmelee, Smith & Katz, 1993), with most residents having one or more chronic pain causing medical conditions (Parmelee et al., 1993; Feldt, Warne & Ryden, 1998; Fink, 2001; Cohen-Mansfield & Lipson, 2002; Horgas & Tsai, 1998; Proctor & Hirdes, 2001). Self-report is the usual method of assessment of location, duration, and intensity of pain, however the subjective nature of pain makes assessment and quantification difficult. This difficulty is exacerbated when a resident or patient has dementia. Much of the evidence is based in residential settings.

There has been a substantial amount of research conducted into pain assessment, however this research has mainly involved patients who are able to respond verbally to questioning (Simons & Malabar, 1995). Little is known about the experience of pain and its impact on the behaviours of people with dementia, however studies show that pain can amplify confusion in the person with dementia, leading to behaviours that complicate medical and nursing management (Liu, Raji, Twersky, & Riggs, 2000). It is thought that a significant number of people living with dementia have pain that remains undiagnosed and untreated, and in many cases this is demonstrated in the form of behavioural symptoms such as restlessness and aggression (Morrison & Siu, 2000; Geda & Rummans, 1999).

Chronic pain has been shown to correlate closely with cognitive symptoms such as depression, which can exacerbate the effects of an existing cognitive impairment. This relationship is multi-directional, as people with depression are more likely to report painful symptoms than non-depressed, and older people with pain score higher on depression scales (Gagliese & Melzack, 1997). The presence of pain disrupts sleep, impairs mobility, and results in a reduction of social activities (Closs, 1996; Klinger, Spaulding, Polatajko, MacKinnon, & Miller, 1999). If pain is inadequately assessed and treated, the result could be perceived loss of control and thus exacerbation of depression. Furthermore, some side effects of pain, such as reduced mobility, may lead to psychosocial complications.

While it has been suggested that older adults with dementia experience pain to a lesser extent than an older adult who is cognitively intact (Fisher-Morris & Gellatly, 1997; Scherder & Bouma, 2000a), this has been refuted by others who claim that it is reduced communication skills and impaired memory that affect the reporting of pain (Verma, 2000; Chefetz, 2000). Several studies (Gibson, Voukelatos, Ames, Flicker & Helme, 2001; Benedetti et al., 1999) that tested pain thresholds and pain tolerance in patients with Alzheimer's Disease (AD) concluded that there was no difference in the stimulus detection or pain thresholds between these patients and people without AD, however there was a positive relationship between pain tolerance and the severity of

cognitive impairment. Farrell, Katz and Helme (1996) warned that while the global deterioration of cortical functions progresses in dementia, care should be taken not to assume that all patients with dementia have less pain, an assumption which would result in them being excluded from treatment. It is well established that less analgesia is prescribed and administered to people who have dementia (Morrison & Siu, 2000; Geda & Rummans, 1999; Farrell et al., 1996; Dehaan, 1996).

Most researchers have agreed that where pain assessment scales are applied to patients in the clinical setting, management of pain is improved (Chibnall & Tait, 2001; Fries, Simon, Morris, Flodstrom, & Bookstein, 2001; Kamel, Phlavan, Malckgoudarzi, Gogel, & Morley, 2001). There have been a number of assessment scales developed which attempt to quantify pain in older people, however they typically rely on the ability of the person to describe their experience. Studies have reported a discrepancy of at least 10% between staff estimations of pain levels and those reported by residents with cognitive impairment (Madjar & Higgins, 1996).

Many studies conducted between 1992-2005 have recommended further research, some suggesting that assessment scales need improvement, and that behavioural symptoms need to be observed more closely to gain a better understanding of their relationship to pain (Morrison & Siu, 2000; Huffman & Kunik, 2000). This systematic review aims to appraise the available evidence in order to inform clinical practice.

Objectives

The objective of this systematic review was to present the best available evidence on the assessment of pain in older adults with a diagnosis of dementia. This systematic review originally investigated best practice relating to the management of pain, which incorporated assessment and treatment. However, as it was found that this focus was far too broad, the review was restricted exclusively to the assessment of pain.

Whilst conducting the review it became obvious that, despite the existence of a variety of assessment measures, there are numerous barriers to pain assessment. Articles relating to barriers to, as well as strategies for, successful pain assessment have been incorporated into a literature review entitled ‘Successful pain assessment in older adults with dementia: Barriers and strategies’ (McAuliffe, O’Donnell, & Nay, 2006).

Review Method

Inclusion Criteria

Types of studies

This review considered any randomised controlled trials (RCTs) that evaluated the effectiveness of pain assessment in older adults. In the absence of any RCTs, other research methods such as non-randomised controlled trials, longitudinal studies, cohort or case control studies, or non-experimental studies, were considered for inclusion. These were included in a narrative summary.

Types of participants

Participants were people aged 65 years or older, with a diagnosis of dementia. Participants from all settings were included (e.g. residential aged care, dementia clinics, community settings, rehabilitation settings, acute and subacute care).

Types of interventions

Interventions of interest were assessment strategies for the measurement of the presence, duration, location and/or intensity of pain.

Types of outcome measures

Outcomes of interest were accurate identification of pain; reliable measurement of the presence, duration, location and/or intensity of pain; and valid measurement of the presence, duration, location and/or intensity of pain.

Search Strategy

A search was conducted for published and unpublished literature in the English language over the period 1992-2005. Earlier articles were included if recommended by the Expert Reference Group. Searching was conducted in three stages.

The initial search stage consisted of a limited search of the CINAHL and Medline databases to identify keywords contained in the title and abstract, and relevant MeSH headings and descriptor terms.

The second stage consisted of a second, more extensive search using the appropriate keywords for each of the following databases: PsycINFO, Ageline, Cochrane Library, Embase, APAIS Health, Current Contents Connect, Dissertation Abstracts International, and Social Sciences Citation Index.

The third stage involved hand searching reference lists and bibliographies of articles retrieved. Seminal works published outside of 1992-2005 referred to in the literature were also considered for inclusion.

Search Terms

Search terms used included pain and dementia, in addition to the following terms, which were used to refine the search where necessary: assessment, pain measurement (where measurement was synonymous with assessment), elderly, advanced nursing practice, case management, evidence based practice, home health care, hospice, hospice palliative care nursing, palliative, gerontologic, randomi?ed control trial, residential care, nursing home, discomfort, cognitive impairment, analgesia.

Critical Appraisal

All identified studies that met the inclusion criteria were appraised for suitability by two independent reviewers in accordance with methods described in the Cochrane Reviewers' Handbook 4.2.2 (Alderson et al., 2004). Appraisal for all studies adhered to the checklist developed for this review. (Appendix A). Critical appraisal focussed on sources of bias in the studies, including those found in selection, method, attrition and detection. The studies were categorised according to the level of evidence they offered as defined by NHMRC criteria (see Table 1 below). Where there was disagreement regarding inclusion, the Expert Reference Group or third reviewer provided consensus.

Table 1.
NHMRC Levels of Evidence

Level of Evidence	Description
Level I	Evidence obtained from a systematic review of all relevant randomised controlled trials
Level II	Evidence obtained from at least one properly designed randomised controlled trial
Level III.1	Evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method)
Level III.2	Evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies, or interrupted time series with a control group
Level III.3	Evidence obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group
Level IV	Evidence obtained from case series, either post-test or pre-test and post-test

Data Extraction

Data were extracted by two reviewers independently, using the quantitative data extraction instrument developed by the Joanna Briggs Institute (Appendix B). Where there was disagreement between reviewers, the Expert Reference Group or third reviewer was consulted and consensus was obtained.

Data Synthesis

No RCTs were identified. Statistical data presented was from quasi experimental studies with disparate goals, using a range of interventions, therefore pooling of this data and meta–analysis was not possible.

Results

A total of 400 studies were flagged for likely relevance to this systematic review from the following databases: Medline (46), PsycINFO (34), Current Contents (37), Dissertation Abstracts (12), CINAHL (89), Ageline (46), Cochrane Abstracts (17), APAIS Health (2), Embase (40), Social Sciences Citation Index (77).

Duplication of articles found in multiple databases was noted and eliminated. A hand search of reference lists of the retrieved articles yielded another 13 possible articles for inclusion. In addition to the database search, a comprehensive private collection of the literature surrounding pain in older persons with dementia or cognitive impairment spanning the last 20 years was perused. From that, 15 likely articles were retrieved. From this total of 428, 180 articles were retrieved for critical appraisal.

Excluded papers

An overall total of 150 articles did not meet the inclusion criteria (and are tabled in Appendix C). Articles were excluded for a number of reasons, including poor study design, participants aged younger than 65 years, article was an opinion piece or review, article was about pain but with little or no mention of dementia, article discussed pain in cognitively impaired persons where the impairment was related to aetiology other than dementia, article focus was on treatment of pain rather than assessment, or the article was about dementia and older people but made little or no mention of pain.

Included papers

Thirty articles met the criteria for inclusion in the review (Appendix D). No randomised or non-randomised controlled trials were found, although several

quasi experimental studies with and without controls were retrieved. A number of articles providing Level III.2 evidence were included, the majority of which were cohort studies with controls. Three of the studies of Level III.3 evidence were surveys and the remainder were longitudinal studies, uncontrolled cohort studies, cross over design and correlation studies.

This systematic review includes literature that addressed the assessment of pain in older adults with dementia. As dementia and cognitive impairment are by nature amorphous and variable, methods of quantifying impairment are important. Most of the studies (Ferrell et al., 1995; Cohen-Mansfield & Lipson, 2002, Buffum, Miaskowski, Sands, & Brod, 2001; Fisher et al., 2002; Warden, Hurley & Volicer, 2003; Feldt, 2000; Wynne, Ling, & Remsburg, 2000; Manfredi, Breuer, Meier, & Libow, 2003; Closs, Barr, Briggs, Cash, & Seers, 2002) used the Mini Mental State Examination (MMSE[2]; Folstein, Folstein, & McHugh, 1975) as a measure of cognitive impairment, including the shortened 12 item version of the MMSE (Scherder & Bouma, 2000b) or the Modified Mini Mental State Examination (3MS)[3] (Hadjistavropoulos, La Chapelle, MacLeod, Snider, & Craig, 2000). Other studies used a specific dementia measure, such as the Bedford Alzheimer Nursing Severity Scale (BANS-S) (Warden et al., 2003) or the Global Deterioration Scale (GDS) (Buffum et al., 2001) as an additional measure to the MMSE. One study (Parmelee et al., 1993) used only scores on Fuld's modification of the Blessed Memory-Information-Concentration test to measure cognitive impairment and a further study (Abbey et al., 2004) relied on the identification of dementia by a senior registered nurse, which was confirmed by the resident's completion of a Katzman test. Another study (Lang Porter et al., 1996) used a battery of psychometric tests, including the Clinical Dementia Rating (CDR).

Many of the studies used some form of a Visual Analogue Scale (VAS) to assess pain. Types identified in studies included a vertical VAS (v-VAS), horizontal VAS (h-VAS) and the coloured VAS (CAS). Other visual scales included the Facial Affective Scale (FAS) and Faces Pain Scale (FPS).

Presented below are the findings of the studies included in this systematic review, which have been organised according to the type of assessment included in each study: self-report of pain in older adults with dementia; proxy/observational assessment of pain in older adults with dementia; and combination of self-report and proxy/observational assessment of pain in older adults with dementia.

Self-report of pain in older adults with dementia

The following studies focused on the self-report of pain in older people with dementia. Self-report refers to the ability of an individual to indicate either verbally or by physical demonstration the presence, intensity or severity of pain. Several papers were retrieved that discussed the validity of self-report of

[2] MMSE – score of 23 and below indicates cognitive impairment
[3] 3MS – score of 77 and below indicates cognitive impairment

pain amongst the population of interest. Studies used a variety of approaches to determine the validity of self-report by comparing it with the following: chart review, video-tapes of activities, identification of behavioural responses by residents, and interviews with residents regarding the presence of medical conditions.

Ferrell et al. (1995) conducted randomly selected cross-section chart reviews and interviewer-assisted surveys with 217 residents of ten skilled nursing homes. Their objectives were to determine (a) the prevalence of pain complaints and (b) the percentage of residents with pain that could be assessed by using a 33-item questionnaire developed by researchers, the McGill Pain Questionnaire, and five uni-dimensional scales: Present Pain Inventory (PPI); Verbal Rating Scale (0-10); 100mm horizontal Visual Analogue Scale (h-VAS); Memorial Pain Card (modified Tursky scale); and the Rand COOP Chart for pain. Cognitive status was assessed by the Mini Mental State Examination (MMSE) (mean = 12 ± 7.9) and functional status using the Katz activities of daily living scale.

The McGill Pain Questionnaire is a 78 word descriptor scale. Residents were shown eight by eleven inch flash cards and the researcher simultaneously read aloud the words on the card. Residents were asked to concentrate on the main problem causing pain and indicate words that described their pain. The McGill Pain Questionnaire was scored by the sum of the rank values of words chosen in each of the four pain rating indexes: sensory, affective, evaluative, and miscellaneous.

Most participants (80%) were able to identify several words on the McGill Pain Questionnaire that described their pain. Of the five uni-dimensional scales, 83% of residents were able to complete at least one. The PPI was most successfully completed, with 87 (65%) able to respond, while under half (44%) could complete the 100mm h-VAS. Seventeen percent of participants could not complete any of the five uni-dimensional scales. However, there was a moderately strong correlation ($r = 0.38\text{-}0.79$; $p < 0.0001$) between a participant's performance on those completed, leading the authors to conclude that self ratings for present pain were a reliable and valid method of assessment.

Parmelee et al. (1993) investigated the association between self-report of pain and cognitive impairment amongst 758 older adults living in a large residential facility. Participants were divided into three groups (markedly impaired cognition, mildly impaired cognition, cognitively intact), according to their scores on Fuld's modification of the Blessed Memory-Information-Concentration test. Using an interview format, participants were asked to respond about two aspects of pain - pain intensity and identification of localised pain complaints. Pain intensity was assessed by asking participants to respond to the following six items: pain over the past several weeks; pain at the moment; pain at its worst; pain at its least; number of days per week the pain was "really bad"; and the extent to which pain interfered with daily living.

All items except item 5 ('days per week') were measured on 5 point scales. Days per week were converted to a 5 point scale and averaged out over the 6 items. Cronbach's alpha for the composite was 0.84. Test-retest of this composite yielded a Cronbach correlation of 0.84. Identification of localised pain complaints was assessed by the participants responding about the presence and intensity of local pains (e.g. headache, joint pain, stomach pain, chest pain). There were 12 items in all. Examination by physician or staff provided information about physical health and functional disability.

Results showed that 79.9% of the residents identified one localised pain complaint, and 46.8% identified three or more localised pain complaints. Average rated pain intensity for the whole sample was 1.74 (SD = 1.02) on the 5 point composite scale, indicating that the majority of participants did not regularly experience severe pain. The authors concluded that there was a negative correlation between self-report of pain complaints and increasing cognitive impairment although this was 'surprisingly small'. Where musculoskeletal pain was identified, there were small differences in self-reporting related to cognitive impairment, but for other types of pain such as cardiac or gastro-intestinal there was no difference between groups. The authors suggested that even though older adults with cognitive impairment may slightly under-report pain, their reports are still valid.

Not all research, however, has been supportive of the validity of self-report. To investigate the question "Are patients with dementia reliable reporters of pain?", Buffum et al. (2001) applied the Pain Screening Tool (PST) to 33 nursing home residents. Inclusion criteria were that the residents were aged over 60 years[4], had a diagnosis of dementia (mean MMSE = 14 ± 9.6; mean Global Deterioration Scale (GDS) = 4.8 ± 1.9), had at least one diagnosed painful condition, and had at least one agitated behaviour observed daily. The PST is a three-item interview designed to evaluate a patient's ability to reliably self-report pain. Residents were asked to rate the intensity of their pain using the 0-3 scale of the PST and suggest a word that described their pain. The researcher distracted the resident for a minute with unrelated conversation, then asked the resident to recall the rating between 0-3 and the word they had suggested. Residents able to recall both the number and the word were pronounced capable of reliably self-reporting pain and received the top score of three. Of the 33 residents however, 14 were nonverbal and unable to respond to the PST questions. Of the 19 able to respond, 13 were able to complete the first stage however were unable to recall the number and word they had suggested a minute prior. In summary, 82% of the whole sample was unable to reliably self-report pain.

Several studies have investigated the usefulness of self-report pain assessment tools according to degree of cognitive impairment. Closs et al. (2002) presented five different pain assessment tools in random sequence to

[4] Although this study was open to participants over 60 years old, the age range of the participants was between 64-96 years old, with a mean age of 78.5 (SD = 7.2). In this case, participants below the inclusion criteria cut-off of 65 years old represented a very small portion of the study sample (3%). The Expert Reference Group determined that the study's quality merited inclusion despite this breach of the inclusion criteria.

113 nursing home residents (mean age 84.5 ± 8.9 years). Degree of cognitive impairment was assessed using the MMSE and used to divide most of the participants into four groups for the purpose of analysis (MMSE 24-30, n = 22; MMSE 18-23, n = 24; MMSE 10-17, n = 31; MMSE 0-9, n = 28). Scores were missing for eight participants due to reasons such as dysphasia and drowsiness. Depression was measured using the Geriatric Depression Scale (GDS). A pilot study was conducted, which included using the Discomfort Scale – Dementia of the Alzheimer's Type (DS-DAT). However, the five minute observation period of the DS-DAT was considered too intrusive for residents who did not have severe cognitive impairment, and was therefore not used in the main research study.

The aim of the study was to 'assess the usability of a range of approaches to pain assessment for people with cognitive impairment' (p. 33). The five uni-dimensional pain assessment scales administered were a 4 point Verbal Rating Scale (VRS), Numeric Rating Scale (NRS), Faces Pain Scale (FPS), Colour Pain Analogue Scale (CS), and a mechanical Visual Analogue Scale (m-VAS). The VRS was completed by all residents with no or mild cognitive impairment (n = 46) and by 68% of the residents with moderate to severe impairment (n = 59). Completion rates were lowest on the FPS and m-VAS.

This study was reported upon further in a later article (Closs, Barr, Briggs, Cash, & Seers, 2004). The analysis considered the usefulness of the five scales across the four levels of impairment. Not only was the VRS the scale most completed by those participants with severe impairment, it was also completed by those with MMSE scores as low as 2.3 (SD = 3.6). In comparison, the NRS required a mean MMSE score of 4.9 (SD = 6.3), while the m-VAS required the highest level of functioning, a mean MMSE score of 8.9 (SD = 8). The number of explanations required to elicit a response was also measured: the VRS required the least repetitions (M = 1.47), whereas the CS required the greatest (M = 1.89). Analysis via Kruskall-Wallis testing indicated that across all scales and all levels of impairment there was no significant difference in the intensity of pain reported. Generally, the scales correlated moderately with each other for participants with no impairment or mild/moderate impairment, however there was little correlation between scores in the highly impaired group. This raises concerns regarding the validity of the scales in highly impaired populations. Furthermore, the reliability of the scales in the severely impaired group was low. The authors recommended the VRS as the most useful uni-dimensional self-report tool in elderly populations with or without impairment, but noted that where there is significant impairment the tool becomes markedly less useable and accurate.

Scherder and Bouma (2000b) compared comprehension rates of three visual analogue scales - CAS, Facial Affective Scale (FAS), and FPS - in a case control study involving three groups of nursing home residents. Twenty residents were assigned to one of three groups according to MMSE[5] scores: mid-stage dementia (mean MMSE = 3.7; mean age = 86.8 years); early stage

[5] Shortened 12 item version MMSE (score 0-12) where <11 indicates mild cognitive impairment

dementia (mean MMSE = 8.0; mean age = 82.3 years; and cognitively intact (mean MMSE = 11.35; mean age = 87.1 years).

Residents across the groups were matched for educational status and four categories of chronic painful conditions: arthritis/arthrosis; recent fracture (within 1 year); post-operative state (hip replacement); and miscellaneous (tendonitis, diabetic neuropathies). On administration of the three scales, the CAS was correctly interpreted by all cognitively intact participants and those with early stage dementia, and by 80% of participants with mid-stage dementia. The second best interpreted scale was the FPS, also completed by all cognitively intact participants, however completed by only 60% of those with early stage dementia and by only 30% with mid-stage dementia. Performance was lowest on the FAS; five out of the 20 (25%) cognitively intact participants misinterpreted the FAS, as did 50% of participants with mild dementia and 80% of those with mid-stage dementia. The researchers concluded from this study that the CAS could be used successfully to give an accurate interpretation of intensity of pain whereas the other two scales could not.

Wynne et al. (2000) compared four instruments assessing the severity of pain (VRS, VAS, Wong Baker Faces Pain Scale, and the McGill Word Scale) with three pain identification strategies (pointing to self, doll, or a picture). The study aim was to establish the effectiveness of pain severity instruments and pain identification instruments in locating pain among nursing home residents. Participants were 37 residents (mean age 78.4 years) involved in a progressive mobility program. Of these, 16 had a MMSE score of <15 and 21 had a MMSE score of >15. Pain scales were administered monthly for one year to ascertain both the severity and the location of pain. For residents with a score of <15 MMSE, the McGill Word Scale was completed most successfully (73% able to use the McGill Word Scale to indicate pain severity), in contrast to only 50% of residents being able to complete the VAS or Wong Baker Faces Pain Scale. Residents with a MMSE <15 had a lower response rate to all severity instruments than residents with an MMSE >15. The most useful method of locating pain was for the resident to point to his/her own body (86% success rate), whereas only 75% could use the picture or doll. The least useful method of locating pain for the <15 MMSE group was use of the doll ($p = 0.009$).

Proxy/observational assessment of pain in older adults with dementia

As previously mentioned, older adults with severe cognitive impairment may be unable to verbalise or physically indicate their pain. In these instances, a proxy (e.g. nurse, family caregiver, physician) may attempt to assess the presence, quality and/or intensity of pain, often by using behavioural cues such as changes in body movement, changes in regular routines, changes in facial expression, or changes in other behavioural symptoms. The following

studies report on proxy/observational pain assessment tools for use in older people with dementia.

The primary aim of a study by Fisher et al. (2002) was to evaluate whether a correlation existed between scores on the pain items of the Minimum Data Set (MDS) and an independently collected Proxy Pain Questionnaire (PPQ). Developed by Fisher et al., the PPQ is a 4 item scale measuring the presence, frequency, and intensity of pain and nurses' beliefs about the relationship between pain and disruptive behaviour (the last item was not included in analyses because there was no comparable item in the MDS). The MDS is completed routinely four times per year in the United States to measure a range of issues relating to patient well being. The two pain assessment items measure the frequency and intensity of pain on 3 point Likert scales with verbal descriptors. Completion of pain items on the MDS is either by asking the resident or by proxy. For their study, Fisher et al. made the assumption that the MDS data they were using was collected by a proxy (Certified Nursing Assistant, CNA), given that it came from 57 nursing home residents with a mean MMSE score of 11.1 (93% with a diagnosis of dementia) who most likely would not have been able to self-report pain. The PPQ was administered in a standard interview with 40 CNAs.

Scores on the PPQ were not significantly correlated with either scores on the MDS pain frequency item ($r = 0.18$; $p = 0.18$) or the MDS pain intensity item ($r = 0.22$; $p = 0.11$). Pain was reported more frequently on the PPQ than the MDS pain items (48.2% vs. 19.6% of residents were identified as having some level of pain). Forty-six percent of sampled residents were receiving analgesic medication, however pain was reported on the MDS pain items for only 20% of residents, compared to 48% detected by the PPQ. As PPQ scores were reported to be more significantly related to the total amount of analgesic medication received during the study period than MDS scores, this adds further weight to the sensitivity of the PPQ as a proxy pain assessment measure.

Lang Porter et al. (1996) focused on facial expressions in their investigation of the effect of dementia on pain resulting from a needle stick puncture. Facial expressions of participants were video taped during three stages of receiving an injection (baseline, preparation, and insertion of needle), noting Action Units (AU) such as 'brow lowered, cheek raised, neck tightened, lip wiped'. Participants were 51 community dwelling, generally healthy, cognitively intact adults aged 65 years or older and 44 community or nursing home dwelling adults, also aged 65 years or older, with varying degrees of dementia. Cognitive status was assessed by a battery of psychometric tests, including the Clinical Dementia Rating (CDR), Trail-making Test Part A (TRAILSA), Verbal Fluency (VF), 15 item Boston Naming Test (BNT), Digit Symbol Test (DST) and the Lexical Memory (LM) subtest of the Wechsler Memory Scale. Differences in facial expression were noted between participants with dementia and cognitively intact participants during the preparation and needle insertion stages. Those without dementia showed fewer AU than participants with dementia. The researchers were unable to place the facial movements into anatomical or emotional categories, but did conclude that there was more

change in facial expression related to pain shown by adults with cognitive impairment.

As part of a study exploring the relationship between pain and aggressive behaviours, Feldt, Warne and Ryden (1998) asked nursing assistants (NAs) and families of nursing home residents whether they believed the resident (mean MMSE = 6.4) experienced pain. Just under 45% of families (n = 7) identified the resident as having pain. There was a tendency for families to refer to a history of pain when identifying the pain status of their relative. Twenty-five NAs (65.8%) identified residents as having pain, and tended to refer to verbal or behavioural cues the resident might display, such as wincing. Family and staff reports of pain were congruent in 47.3% of participants, despite all residents having at least one pain-related diagnosis (arthritis, cancer, fracture, localised pain and/or osteoporosis). Student t tests showed that residents with two or more pain-related diagnoses had significantly higher overall mean aggression scores than those with one or no painful diagnosis (T 1.93; p = 0.031). Feldt and colleagues advised that NAs should be aware of pain related diagnoses that may act as a trigger for aggressive behaviour.

Closs, Cash, Barr and Briggs (2004) aimed to create a checklist of cues for determining pain via observational assessment. A total of 113 residents from nursing homes and 65 staff participated in the study. Additionally, 36 informal carers who visited more than once a week were included as participants. Carers (formal and informal) were asked via interview if they could describe actions or behaviours that indicated pain, describe any speech or sounds indicative of pain, identify which cues definitely indicated pain, and describe any other signs that the resident/relative was experiencing pain.

Transcripts were coded and analysed using NVivo by two independent coders. Cues were grouped into three categories: verbal and body language cues, acute behavioural cues, and general changes in behaviour. Verbal and body language cues included grimacing, wincing, restricted movement, shuffling, hitting, restlessness, and expression in the eyes. Acute behavioural cues included swearing, appetite loss, change in colour and patterns of speech. General behavioural changes included social withdrawal and excessive sleepiness, however there was some overlap across categories. The cue types were then analysed by cognitive impairment category. For all levels of cognition, body movement was the most commonly used cue. Second was facial movement, though this was used less as impairment increased. Self-report verbalisation was used less with patients with severe impairment, in which case incoherent speech and cries were used more frequently. From this work the authors suggest a preliminary model of pain assessment in older people with dementia. The model suggests that the use of self-report is less reliable, and therefore should be used less, as impairment increases. Instead, general behaviours, acute response behaviours, and reactive self-report should receive greater emphasis respectively.

Fuchs-Lacelle and Hadjistavropolous (2004) developed the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC). The study was conducted in three phases. Initially 28 care givers in long term care facilities were interviewed to create a list of commonly observed pain behaviours. All the participants were registered nurses, licensed practical nurses, or special care aides and cared for residents over 65 years of age who, as a result of their dementia, had impaired communication. From this a summary list was complied, which formed the original PACSLAC. This was done independently by two researchers, with a correlation of 0.94 ($p < 0.01$). These items were arranged conceptually within the scale for clarity. Similar items were combined for brevity, for instance screaming, yelling, and hollering were combined into a 'screaming/yelling' item. Seven subscales were extracted and assessed for reliability: activity/body movement, facial expressions, vocal behaviours, aggressive behaviours, social/personality/mood indicators, eating/sleeping changes and physiological indicators. During the second phase, item analysis to assess internal consistency was conducted on the scale, with Cronbach's alpha analysis indicating that this was very high ($\alpha = 0.92$). Subscales were also analysed for internal consistency. Some of the subscales reported high alphas (facial expression $\alpha = 0.80$; activity/body movement $\alpha = 0.84$; social/personality/mood indicators $\alpha = 0.82$). However, aggressive behaviours ($\alpha = 0.49$), physiological changes ($\alpha = 0.62$), vocal behaviours ($\alpha = 0.37$), and eating/sleeping changes ($\alpha = 0.31$) were low. Despite removing the items of whimpering/whining and nonsensical chatter, the internal consistency remained unacceptably low. To remedy this, scales were combined resulting in a total of only four subscales: facial expressions, activity/body movement, social/personality/mood indicators, and physiological indicators/eating/sleeping changes/vocal behaviours. This increased alphas to acceptable levels in excess of 0.74 for all subscales.

In the third phase the modified scale was analysed psychometrically. Thirty four registered nurses and six registered psychiatric nurses participated (13 of these participants had also participated in phase two). Correlation of subsequent pain events was used to determine consistency between events. These correlations were found to be high ($r = 0.80$). To determine the scales' concurrent validity, correlations between the global intensity rating and PACSLAC score were calculated; these were shown to be 0.39 ($p < 0.05$) at time point one and 0.54 ($p = 0.54$) at time point two. Internal consistency was shown to be very high, reporting scores of 0.82 at time point one and 0.87 at time point two. The authors concluded that the PACSLAC is a reliable and valid scale suitable for use in long term care.

Snow et al. (2004) conducted an analysis of the Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN). The study used actors to portray pain behaviours for a series of videos. Twenty-one nursing assistants were then asked to rate these videos according to the NOPPAIN scale. The nursing assistants were asked to determine from a series of paired videos in which video the person demonstrated the most pain. This more subjective assessment was used as the 'gold standard' against which the accuracy of the NOPPAIN was rated. Generally, the NOPPAIN score and the nursing

assistants' own ratings were well matched, with a weighted kappa of .87 reported (SE = 0.2; 95% CI: 0.82-0.91). Where discrepancies existed, these were commonly minor and within one point on the Likert scale used. The Bradley-Terry model of paired comparisons was used to examine the scale further. In this analysis, non-significant scores are indicative of positive results. The NOPPAIN reported a significance of p = 0.0527, suggesting poor fit. However, the authors point out that the results were borderline (in this case not significant at the p = 0.001 level). These results were found to be due to rater difficulty distinguishing between mild and moderate pain levels. The study was limited by the difficulties in establishing a gold standard in the absence of reliable self-report. Furthermore, the use of actors may have introduced a confounding variable regarding the accuracy of the actor's portrayal. The validity of the scale is somewhat convincing, however no reliability data was presented.

Kovach, Weissman, Griffie, Matson, and Muchka (1999) developed the Assessment of Discomfort in Dementia (ADD) Protocol with the intention of assisting nurses to (a) more accurately assess discomfort in people with dementia who are unable to verbally report pain, (b) more thoroughly treat physical pain and affective discomfort, and (c) reduce inappropriate use of "as needed" psychotropic medication. The dimensions addressed by the ADD Protocol are physiological, environmental, and psychosocial factors, as well as analgesic use. Application of the ADD Protocol in Kovach et al.'s study of 104 nursing home residents with severe cognitive impairment produced a significant decrease in discomfort (t = 6.56, p = 0.000). Residents ranged in age from 46-100 years, however the mean age was 85 years. Whilst the majority had a probable diagnosis of Alzheimer's disease, multi-infarct dementia, or dementia of unknown aetiology, two were developmentally disabled, one had Huntington's disease, and a number had dementia associated with Parkinson's disease or a stroke. Inter-rater reliability was 86% for the total ADD Protocol, 100% for medication use, 76% for non-pharmacologic measures used, and 87% for behavioural assessment of discomforting symptomatology.

The Pain Assessment for Dementing Elderly (PADE) was developed by Villanueva et al. (2003) using naturalistic observation and reference to the literature. The PADE is comprised of 24 items divided into three parts, each part assumed to be associated with pain. Part I, physical aspects, relates to observable facial expression, breathing, and posture. Part II, global assessment, concerns carers' rating of pain; Part III, functional levels, refers to dressing, feeding and transfer. The reliability of the PADE was investigated with a sample of 25 residents of a care facility and dementia unit. All residents had advanced levels of dementia (mean GDS = 5.60; SD = 0.71) and 60% suffered from a diagnosed painful condition. Independent administration of the PADE by two staff members to the residents over a 10 day period revealed adequate reliability coefficients - inter-rater reliability was found to be 0.5-0.95, stability 0.7-0.98, and internal consistency 0.24-0.88.

The second stage of the study aimed to replicate reliability findings and assess the validity of the PADE. Construct validity was assessed by

correlating scores on the PADE and the Cohen-Mansfield Agitation Inventory (CMAI). The rationale for using the CMAI as a comparator was based on research indicating that out of three subtypes of agitation (verbal, physically aggressive, and physically non-aggressive), verbal agitation is most associated with pain. Villanueva et al. hypothesised that the PADE would correlate significantly with verbally, but not physically, aggressive agitation. The PADE was administered to 40 residents (mean GDS = 5.28, SD = 0.78) on two separate occasions, twenty days apart, by two independent assessors. The CMAI was administered on the second occasion and the results correlated. The results indicated that the PADE and the CMAI could differentiate between residents for whom pain was a significant clinical factor and those for whom it was not. Despite the authors' conclusion that the PADE is a reliable and valid tool to assess pain in older adults with dementia living in long term care, there was some inconsistency in reporting of results and appeared to be some questionable assumptions made about the correlation between behavioural symptoms and pain in the study group.

The Abbey Pain Scale was developed and tested by Abbey et al. (2004) amongst a sample of non-verbal nursing home residents with late stage dementia. The scale was originally developed from the Discomfort Scale - Dementia of the Alzheimer's Type (DS-DAT) developed by Hurley, Volicer, Hanrahan, Houde and Volicer (1992) and a scale by Simons and Malabar (1995) that measured pain over six physical indicators. The aim was to create a scale that was both simple and accurate. The scale was developed through consultation with nurses, medical practitioners, and gerontological and pain experts. Residents were identified as having end or late stage dementia by a senior registered nurse, and were then given Katzman tests to confirm the nurse's reports of patients having dementia and being non-verbal. The Abbey Pain Scale is comprised of six items: vocalisation (e.g., whimpering, groaning, crying), facial expression (e.g., tense appearance, frowning, grimacing, frightened appearance), behaviour change (e.g., increased confusion, refusal to eat, alteration in usual patterns), physiological change (e.g., temperature, pulse, respirations), physical change (e.g., skin tears, ulcers, contractures), and change in body language (e.g., guarding, fidgeting, withdrawal).

The two-stage study, conducted from 1997–2002, assessed the psychometric properties of the Abbey Pain Scale. In the initial stage, the scale was trialled across 12 nursing home sites with 52 residents, recording a total of 770 pain episodes. Ratings were recorded by registered nurses (55% of recordings), enrolled nurses (43% of recordings), and personal care attendants (2% of recordings). Administration was initiated when a staff member considered a resident to be in pain. The staff member rated each of the six dimensions listed above in terms of incidence (0 = absent, 1 = intermittent, 2 = constant), severity (0 = absent, 1 = mild, 2 = moderate, 3 = severe), and a holistic impression of the pain (1 = no pain, 2 = mild, 3 = discomforting, 4 = distressing, 5 = severe). All of the ratings were repeated 45 minutes after a pain-relieving intervention had occurred.

In the second stage of the study, the Abbey Pain Scale was administered to 43 of the 61 participants by a single rater and by two independent raters for

the remaining 13 participants. In addition, qualitative data was collected. Results showed that the severity item was a more accurate predictor of the nurses' holistic impressions of pain than measures of incidence of pain. All items except the physical component appeared to be strong indicators of pain. These items were still considered to be important for inclusion because lack of statistical significance may have been attributed to an absence of conditions such as fractures. The authors concluded that facial observation may not be a strong predictor of pain in instances of masking of features in conditions such as Parkinson's disease. Concurrent validity was assessed against the nurses' overall holistic pain assessment, and a reasonable degree of validity was reported ($\hat{g} = 0.586$, $p \leq 0.001$). Validity was further assessed by comparing mean score before and after intervention; the score reduced by half, a reduction found to be highly significant ($p < 0.001$). This further supported the validity of the scale. Internal reliability was assessed, with Cronbach's alpha found to be 0.74 at both pre and post intervention time points. Interrater reliability showed only a moderate correlation. These lower scores were perhaps partially attributable to decreased sample size. Furthermore, the use of the nurse's holistic assessment as gold standard could be questioned. The Abbey Pain Scale was shown to be reasonably, though not exceptionally, valid and reliable in aged populations with little communicative ability.
The study is included with caution because of limiting factors such as not using a comparison tool to test validity, and inconsistency in number of raters in the second stage.

Warden et al. (2003) developed the Pain Assessment in Advanced Dementia (PAINAD) scale, using categories and behaviours in the Face, Legs, Activity, Cry, Consolability Scale (FLACC) and the Discomfort in Dementia of the Alzheimer's Type (DS-DAT), as well as expert opinion, literature review, and behavioural observation. The PAINAD is a five item observational tool giving a rating from 0-10 (0 = no pain; 10 = severe pain). The developers acknowledged the existence of other pain assessment scales (e.g. DS-DAT and CNPI) for the dementia population. However, their rationale for developing the PAINAD was to develop a scale that required a shorter training time than the DS-DAT, and differed from the CNPI in that it included a severity of pain rating and was scored 0-10, rather than 0-6.

To assess the reliability and validity of the PAINAD, the scale was compared with the DS-DAT and two proxy rated VAS (discomfort and pain).The scales were administered to two groups in a Dementia Special Care Unit (DSCU). One group (referred to as the research group) comprised of 19 residents with severe dementia (MMSE = 2.8 ± 4.5; Bedford Alzheimer Nursing Severity Scale (BANS-S)[6] = 16.4 ± 4.4), all unable to verbally report pain. Four experienced DSCU nurses and a Master's level social work intern participated in a training program about the PAINAD. For each observation period, two raters simultaneously viewed each resident for 5 minutes, on three different occasions: the resident at rest (lying in bed, sitting), during an enjoyable activity (with visitors, watching TV), and during exercise (e.g. transfers or bathing). On the first observation, a rater from DSCU administered the

[6] BAN-S score of 0 = no impairment, 28 = complete impairment

PAINAD and pain-VAS, whilst one of the researchers administered the DS-DAT and discomfort-VAS. On the second and third observations, both raters simultaneously administered the PAINAD and pain-VAS.

Analysis of Variance (ANOVA) statistical methods were used to examine PAINAD scores of participants exposed to the three different conditions. Analyses showed a significant correlation between both of the VAS and the observational scales (i.e., PAINAD and DS-DAT) at rest, and during pleasant and unpleasant activities. Inter-rater reliability was claimed to be high, however the authors did not state what coefficient was used to determine this. The tool had good construct reliability and validity.

Data were also extracted from the medical records of an additional 25 residents, who were participants in a quality improvement program (Take 5: Pain the 5th Vital Sign), and were receiving PRN pain medication. Quantitative demographics and disease characteristics were unavailable for these 25 participants, however all would have had to have met the following criteria for admittance to the quality improvement program: severe dementia, unable to report pain, and receiving medication to treat pain symptoms. Staff applied the PAINAD, along with clinical judgement, to determine if the resident required medication. Thirty minutes post medication, the PAINAD was administered a second time. Mean PAINAD scores were shown to decrease from 6.7 ± 1.8 to 1.8 ± 2.2, 30 minutes after receiving PRN pain medication ($t(24) = 9.6$, $p < 0.001$). The results showed that the PAINAD was able to detect differences in pain associated with different medical conditions and analgesic administration.

Internal consistency of the PAINAD was lower than expected and this was attributed to the fact that there were only five items representing disparate symptoms. Poorly performing items were identified as being the 'breathing' item or combination of 'breathing' and 'negative vocalisations'. The researchers chose not to remove these items from the PAINAD however, because of the fact that many people with advanced dementia suffer from concurrent respiratory disorders and for almost 50% of these people pneumonia closely precedes death. The authors further noted that changes in breathing were closely associated with pain. Generalisation of study findings is limited by the small sample size, which included only white, male middle class war veterans.

Table 2.
Pain assessment approaches used in the included studies

Name of Tool	**Study**
McGill Pain Questionnaire	Ferrell et al. (1995) Scherder et al. (2001)
McGill Present Pain Intensity (PPI) Scale	Ferrell et al. (1995) Kaasalainen & Crook (2003) Stolee et al. (2005)
Verbal Rating Scale (VRS)	Ferrell et al. (1995)

	Closs et al. (2002, 2004) Wynne et al. (2000) Pautex et al. (2005)
Horizontal Visual Analogue Scale (h-VAS)	Ferrell et al. (1995) Pautex et al. (2005)
Memorial Pain Card (modified Tursky scale)	Ferrell et al. (1995)
Rand COOP Chart	Ferrell et al. (1995)
Pain Screening Tool (PST)	Buffum et al. (2001)
Numeric Rating Scale (NRS)	Closs et al. (2002, 2004) Williams et al. (2005) Kaasalainen & Crook (2003)
Faces Pain Scale (FPS)	Closs et al. (2002, 2004) Scherder & Bouma (2000b) Stolee et al. (2005) Scherder et al. (2003) Scherder & van Manen (2005) Pautex et al. (2005) Kaasalainen & Crook (2003)
Colour Pain Analogue Scale (CS)	Closs et al. (2002, 2004)
Mechanical Visual Analogue Scale (m-VAS)	Closs et al. (2002, 2004)
Coloured Visual Analogue Scale (CAS)	Scherder & Bouma (2000b) Hadjistavropoulos et al. (2000) Alexander et al. (2005) Scherder et al. (2003) Scherder & van Manen (2005) Scherder et al. (2001)
Facial Affective Scale (FAS)	Scherder & Bouma (2000b)
Visual Analogue Scale (VAS)	Wynne et al. (2000) Warden et al. (2003) Scherder et al. (2001)
Wong Baker Faces Pain Scale	Wynne et al. (2000)
McGill Word Scale	Wynne et al. (2000)
Pointing to self/doll/picture	Wynne et al. (2000)
Proxy Pain Questionnaire (PPQ)	Fisher et al. (2002) Stolee et al. (2005) Scherder et al. (2001)
Facial expression	Lang Porter et al. (1996)
Asking Nursing Assistants / family	Feldt et al. (1998)
Checklist of cues	Closs et al. (2004)
Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)	Fuchs-Lacelle & Hadjistavropolous (2004)
Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN)	Snow et al. (2004)
Assessment of Discomfort in Dementia (ADD) Protocol	Kovach et al. (1999)
Pain Assessment for the Dementing Elderly (PADE)	Villanueva et al. (2003) Stolee et al. (2005)
Cohen-Mansfield Agitation Inventory (CMAI)	Villanueva et al. (2003)
Abbey Pain Scale	Abbey et al. (2004)

Pain Assessment in Advanced Dementia (PAINAD) Scale	Warden et al. (2003)
Discomfort Scale for Dementia of the Alzheimer Type (DS-DAT)	Warden et al. (2003) Stolee et al. (2005)
Memorial Pain Assessment Card	Stolee et al. (2005)
Facial Action Coding System (FACS)	Stolee et al. (2005) Hadjistavropoulos et al. (2000)
Pain Behaviour Measurement (PBM)	Stolee et al. (2005) Hadjistavropoulos et al. (2000)
List of pain behaviours	Weiner et al. (1999)
Numeric Graphic Rating Scale (NGRS)	Weiner et al. (1999)
Vertical Verbal Descriptor Scale (VVDS)	Weiner et al. (1999)
Pain target behaviours	Alexander et al. (2005)
Philadelphia Geriatric Centre - Pain Intensity Scale (PGC-PIS)	Williams et al. (2005) Stolee et al. (2005)
Number of Words Chosen – Affective (NWC-A) of the McGill Pain Questionnaire	Scherder et al. (2003) Scherder et al. (2001)
Checklist of Nonverbal Pain Indicators (CNPI)	Scherder et al. (2003) Scherder & van Manen (2005) Feldt (2000) Scherder et al. (2001)
Vertical Visual Analogue Scale (v-VAS)	Pautex et al. (2005)
Doloplus	Pautex et al. (2005)
Geriatrician / Resident pain rating scale	Cohen-Mansfield & Lipson (2002)
Videotape of facial expression	Manfredi et al. (2003)
Pain Assessment in the Communicatively Impaired (PACI) Tool	Kaasalainen & Crook (2003)
Verbal Descriptor Scale (VDS)	Feldt (2000)
Interview resident / pain scale	Parmelee et al. (1993)

Combination of self-report and proxy/observational assessment of pain in older adults with dementia

Many of the studies reviewed employed both self-report and proxy/observational pain assessment tools for older adults with dementia.

Stolee et al. (2005) conducted a broad review of pain assessment tools commonly used in older populations. The authors reported on 18 self-report instruments and 11 proxy measures of pain. Most of the self-report instruments were single item scales that measured intensity, with the remaining self-report instruments comprising of between two and 22 items. Completion rates varied in cognitively impaired individuals. The Faces Pain Scale, McGill Present Pain Intensity Scale, and the Memorial Pain Assessment Card rated best with completion between 90-100%. In general, completion by cognitively impaired patients was better for scales rating intensity only. Few scales had psychometric evaluation reported; the

Philadelphia Pain Intensity Scale reported weak reliability and validity results, and for the remainder of the scales for which data was reported, findings were incomplete and weak.

Of the 11 proxy scales, the majority (9 scales) rated pain via behavioural observation. The reporting of validity and reliability testing was sporadic. Two tools, the Pain Assessment for the Dementing Elderly (PADE) scale and the Proxy Pain Questionnaire (PPQ), reported very strong reliability but only weak validity. The Facial Action Coding System (FACS) reported excellent validity but no reliability data was presented. The DS-DAT and PBM presented both reliability and validity data but the authors did not report whether these were acceptable or not. The remainder of the scales had uninterpretable results, weak findings, or no measurement at all. Furthermore, results were confounded by discrepancies in the MMSE scores used to define impairment.

Hadjistavropoulos et al. (2000) video-taped 58 inpatients (mean age 76.7 years; SD = 8.1) of a rehabilitation facility whilst they were participating in a range of physical activities (sit, stand, walk, recline). Of these, 29 had a mean Modified Mini Mental Status Examination score (3MS) of 56.2 (i.e. cognitive impairment) and 26 a mean 3MS of 89.9 (i.e. not cognitively impaired). The study aim was to compare the usefulness of three methods of pain assessment: (a) objective assessment of facial reactions using the Facial Action Coding System (FACS); (b) observational assessment of reactions to both face and entire body using the Pain Behaviour Measurement (PBM); and (c) self-reported pain using the Coloured Visual Analogue Scale (CAS). It was hypothesised that pain ratings would be higher when the participant was engaged in physical activity, compared with being physically inactive.

Coding of body movement was performed by a research assistant, who watched the body and facial video-recordings and noted the presence or otherwise of five different behaviours: guarding, bracing, rubbing, grimacing, and sighing. The FACS is a validated system that purports that different facial expressions (referred to as Action Units), such as tightening eye lids or wrinkling nose, represent particular emotions.

Participants rated their pain levels on the CAS prior to filming and then after each activity. The CAS is completed by moving a plastic guide along a triangular shape varying in width and hue (light pink at the bottom corresponding to “no pain” graduating to deep red at the top corresponding to “most pain”). Approximately 5% (n = 3) of participants with cognitive impairment were unable to provide a rating using the CAS. No significant difference was observed between reports of the magnitude of pain by cognitively intact participants and those with significant cognitive impairment, leading the authors to conclude that there is no reason to believe that older adults with cognitive impairment are less sensitive to pain. Results of verbal and nonverbal indices indicated that more pain was felt on movement and that guarding was the most sensitive indicator of pain or the potential for pain. The researchers concluded that the fear of pain was as substantial as the pain itself and that guarding was a robust index for both groups.

Weiner, Peterson, and Keefe (1999) examined the correlation between self identified pain related behaviours in residents of a nursing home and a community based facility (n = 42) who had the ability to respond to questioning, and assessments of pain made by nurses (n = 27) and family caregivers (n = 15). Residents with cognitive impairment (as defined by MMSE scores) were read a list of 26 pain behaviours (modified from two established pain behaviour checklists) and asked to identify those behaviours they engaged in when they experienced pain. They were also asked to rate the intensity of their pain using two uni-dimensional scales (11 point Numerical Graphic Rating Scale (NGRS) and vertical Verbal Descriptor Scale (v-VDS). The v-VDS was in the form of a pain thermometer. Responses were compared with similar interviews held with nurses and family caregivers. Half of the residents identified 19 of the 26 behaviours as being pain related behaviours in which they engaged. Eleven behaviours were overwhelmingly identified by 75% of residents as being associated with pain. Results indicated good test-retest agreement on resident self-report (Kappa 0.62-1.0). One behaviour (use of mechanical support), showed no variance and therefore had perfect test-retest, eight showed moderate test-retest agreement (Kappa 0.41-0.60), two demonstrated fair test-retest (Kappa 0.21-0.40), and three showed poor to slight agreement. Thus the majority (21/26) of items showed moderate or better test-retest reliability, confirming the validity of self-report.

However, despite both nurses and family caregivers being confident that they could rate resident pain (7.2 and 6.7 respectively, confidence rating 0-10), there was poor agreement between the nurses and family caregivers about pain ratings compared with resident self-report. Kappas to test nurse-family caregiver and resident agreement ranged from –0.40 to 0.30, with agreement on 22 of the 26 pain behaviours being < 0.20. Kappas testing resident – family caregiver agreement ranged from –0.23 to 0.65, with 17 of 26 pain behaviours < 0.20, and only 4 of the 26 behaviours having agreement > 0.30. The single behaviour that held good agreement between residents, nurses, and family caregivers was ‘lie down’. Explanations provided for the discrepancy in identifying pain behaviours between nurses and residents were that nurses may not observe the person during moments of exacerbated pain (e.g. when they roll over in bed at night), desensitisation of staff to residents’ pain experience, or that staff may have been preoccupied with other tasks. The authors maintained that the behavioural manifestation of pain is a strategy that is used to communicate suffering, although it is culture dependent and therefore generalisation must be approached with caution. Use of Kappa values to determine the inter-rater agreement should also be viewed with caution. They are useful in as much as they can be used to test a null hypothesis, however they are rarely comparable among studies, methods, or populations (Thompson & Walter, 1988).

Alexander et al. (2005) conducted the first phase of their study in a secure dementia long term care unit and the second phase in a general open unit at the same long term care facility. Nursing staff on the units were trained in the use of the Coloured Visual Analogue Scale (CAS) and a behavioural observational tool. The CAS was administered twice daily before pain medication was given and, time allowing, again 30-60 minutes after the

medication. A pain flow sheet was used to track alterations in the residents' pain levels throughout the day. The Short Portable Mental Status Questionnaire (SPMSQ) was used to rate cognitive impairment, as this was the measure already in use at the facility. Based on criteria (supplied by the authors of the CAS) that require residents to give documentable answers to the tool for a consecutive period of two months, few residents were able to complete the CAS. Residents of the dementia specific unit generally experienced greater cognitive impairment, reporting a mean SPMSQ score of 9.41 (± 1.30). In this unit only 6 out of 24 residents were able to complete the CAS. The open unit reported a higher level of cognitive functioning (M = 5.75, ± 3.01) however response rates were still low; a total of 5 residents were able to use the scale from 17 eligible residents. Due to the low response rates the tool could not be compared with the proxy report measures. The study states that in the use of the CAS, moderate impairment may be as significant a barrier as severe impairment. The proxy measures used were shown to be more useful in this setting.

Nurse proxies assessed residents' pain using a number of pain target behaviours as a guide. Participants in the dementia specific unit experienced significantly higher degrees of cognitive impairment that those in the open unit, however some residents in the open unit experienced a moderate level of impairment. A number of target pain behaviours were identified from the American Geriatric Society's Panel of Persistent Pain in Older Person's list of pain behaviours. Behaviours such as grimacing, wincing, and limping were observed by nursing staff and recorded at the end of each shift. A pain flow summary sheet was used to track changes in resident's pain over time. The pain behaviours were successfully monitored for both units. Differences in the types of behaviours expressed were observed between the dementia specific and open units. On the dementia specific unit pain behaviours commonly included verbalisation of pain, facial grimacing, crying out, and limping or gait disturbance. In comparison, on the open ward verbalisation of pain was used almost exclusively, which is in keeping with the respective levels of impairment. Measuring the accuracy of the proxy assessment was hindered by the low completion rates of the CAS comparison scale. However during the use of the target behaviours tool in the dementia specific unit the use of analgesia was increased and the frequency of pain behaviours decreased. The authors suggest that the proxy approach was useful in improving resident quality of life by reducing pain, however they also recommended general education in pain management and awareness for staff of long term care facilities.

Williams, Zimmerman, Sloane, and Reed (2005) compared the NRS with the Philadelphia Geriatric Centre-Pain Intensity Scale (PGC-PIS) in 331 residents of 10 nursing homes and 35 residential care/assisted living facilities. The average age of the residents was 84.4 years and the majority were female (82%). Ninety-two (27.8%) of the residents were considered cognitively intact (as evidenced by a MMSE score exceeding 10). For all participants, the measures were administered to the supervisor overseeing their care. In addition, those residents who were considered cognitively intact were also administered the scales. The PCG-PIS showed strong internal consistency for

both the supervisor (Cronbach's α = 0.89) and resident samples (Cronbach's α = 0.88). The two scales also correlated well in both samples (Spearman r = 0.69, supervisor; r = 0.68, resident). There were no significant differences found between the prevalence of pain reported in the nursing home and residential care/assisted living settings. However, there was greater discrepancy between supervisor report and resident self-report. The supervisor reports recorded less pain (20-23% of the population) than resident self-report (25-39%). For residents whose self-report was able to be matched with the supervisor report, there was only 62% agreement on presence of pain. This suggests that proxy report may underrate the presence of pain. Supervisor and self-report of pain was then compared against treatment and assessment rates. In excess of one third of residents had received no pain assessment (34.7%) and post hoc analysis indicated that residents in for-profit facilities were significantly less likely to receive pain assessment (54% vs. 81%, p = 0.008). Accordingly, fewer residents in for-profit facilities received analgesic medication (53% vs. 91%, p = 0.041). Generally, the study suggested that assessment and analgesia in nursing home and residential care/assisted living facilities was insufficient and was worse in facilities run for profit.

Scherder et al. (2003) reported on five common pain assessment scales. Four of these were self-report measures and one was an observational checklist, the Feldt Checklist of Nonverbal Pain Indicators (CNPI). The four self-report measures used were the Coloured Analogue Scale (CAS) for pain intensity, the CAS for pain affect, the Faces Pain Scale, and the Number of Words Chosen – Affective (NWC-A) of the McGill Pain Questionnaire. The study sought not only to trial the use of these measures in a cognitively impaired population but also to rate variations in pain presence and intensity between cognitively impaired and intact populations. Twenty patients with vascular dementia (VaD) and 20 cognitively intact elderly participants residing in nursing homes participated in the study. The MMSE 12 was used to rate the level of impairment in participants. The participants with VaD reported a mean MMSE 12 score of 7.30 (7 is equivalent to a score of 18 on the full 30 item scale), while intact participants reported a mean score of 10.65 (a score of 10 is equivalent to a score of 24 on the full scale).

The scales were administered to participants in the same order (the CAS for pain intensity, the CAS for pain affect, the FPS and the NWC-A), followed by the CNPI. Analysis of variance was used to determine differences between the two groups. The participants' ability to comprehend the scale was also recorded. The CAS for pain intensity was understood by all participants, and no significant differences were found between the groups despite a marked increase in score between the intact (M = 17.48) and impaired (M = 29.96). The CAS for pain affect was also understood by all participants, however a significant difference was shown between the two groups with the impaired participants reporting greater affect ($F = 2.7$, $df = 1,38$, $p = 0.05$). Four of the impaired participants and two of the intact participants were unable to comprehend the FPS, the impaired participants reported significantly more pain than the intact participants ($F = 2.79$, $df = 1,32$, $p = 0.05$). The NWC-A displayed no significant difference between the groups and usability was not

reported upon. The CNPI reported higher pain scores for the impaired sample group, indicating a non significant trend. The scale displayed poor correlation with the other scales (ranging between 0.26 and -0.18), and did not correlate well with use of paracetamol (r = 0.18) or the use of non steroidal anti-inflammatory drugs (r = 0.21), however these results were not significant. Generally, the CAS scales were shown to be most useful in impaired residents as comprehension was high; the lack of significant difference between groups on the pain intensity scale suggests that the scale accurately measured the same factor in both groups (assumed to be pain intensity). The cognitively impaired group did not, however, have a mean MMSE score indicative of severe impairment, and therefore results may not be generalisable to a severely impaired population. The limited populations also impaired the generalisability of the study.

In a similar study, Scherder and van Manen (2005) compared self and proxy report using the CAS for pain intensity, CAS for pain affect, FPS and the Checklist for Non Verbal Pain Indicators (CNPI). In a case-control study, the residents of two nursing homes were grouped according to diagnosis. One group (n = 20) comprised residents with suspected stage 5 Alzheimer's disease, while the other comprised of 17 older adults without dementia. Participants in both groups had one or more painful condition, and the groups were largely equal (χ = 0.09, df = 1, NS). The groups were also well matched for age and education levels. The three self-report scales were administered to residents before and after walking a short distance. They were then also completed by the residents' personal nursing assistant. The CNPI was completed during the walking activity by the authors. The nursing assistants were not required to complete the CNPI.

The two CAS were well understood by both groups of participants, however the FPS could only be understood by 65% of the Alzheimer's disease group. Similarly, for both CAS the absolute differences between self and nursing assistant report increased for the Alzheimer's disease group. For both scales the nursing assistants significantly over estimated the pain intensity and affect of the Alzheimer's disease group ($p < 0.05$). The FPS showed no significant differences between groups for self and proxy agreement, however self-report responses showed a trend toward lower pain in the Alzheimer's group. The CNPI showed no significant differences between the groups. The authors suggested that people with Alzheimer's disease type dementia may perceive less pain than those without. In this case, nursing assistants may over rate pain in people with Alzheimer's disease type dementia.

Pautex et al. (2005) studied the feasibility and reliability of four pain scales: the Verbal Rating Scale (VRS), the horizontal Visual Analogue Scale (h-VAS), the vertical Visual Analogue Scale (v-VAS) and the Faces Pain Scale (FPS). These measures were also correlated with an observational rating scale, Doloplus. A sample of 160 participants was drawn from inpatients of hospital dementia wards. These participants were diagnosed with a dementia according to the Diagnostic and Statistical Manual of Mental Disorders IV (DSM–IV). The four scales were presented in random order to each participant. Nearly half of the participants reported feeling pain, and of these

24% were receiving no analgesia. Dementia severity appeared to have no effect on reports of pain or rates of analgesia. None of the severely impaired participants were able to use the self-report measures. There was a non-significant trend toward improved comprehension of the h-VAS in the mild to moderate dementia group and the VRS in the severe dementia group. The FPS generally reported the lowest rates of comprehension. Correlation between the scales was strong (ranging from 0.81-0.95, $p < 0.001$), however correlation with the Doloplus observational measure was only moderate (ranging from 0.31-0.40, $p < 0.05$). The Doloplus rating consistently underestimated pain when compared to the self-report scales. The authors note that although the VRS appeared to rate better in the severely impaired group, this sample was small and results are not conclusive. The study recommends that observational scales should not be used routinely in patients with dementia as they often have the capacity to rate their own pain well.

Cohen-Mansfield and Lipson (2002) conducted a cross sectional analysis of four groups of nursing home residents to compare the reliability and validity of physicians' assessments of pain with residents' self-reports. Residents in Group A (n = 19) had mild to moderate dementia and did not take pain medication, whilst those in Group B (n = 12) also had mild to moderate dementia but received pain medication. Similarly, residents in Group C (n = 24) had severe dementia and did not take pain medication, whilst residents in Group D (n = 24) also had severe dementia but received pain medication. The mean MMSE score for residents with mild to moderate dementia was 16.0 and the mean MMSE score for residents with severe dementia was 1.9. Two geriatricians who were external to the nursing home were blinded to the cognitive status and pain medication intake of a representative sample of 39 residents drawn from the four groups. The geriatricians examined laboratory reports (differential and platelet count) and conducted chart reviews and physical examinations, noting medical diagnoses (active or inactive) and rated each diagnosis in terms of degree of pain. The geriatricians also rated the level of pain they perceived the resident to be experiencing during the physical examination, using a 6-point scale (no further scale specifications were provided). The regular physicians conducted the same assessments as the geriatricians, independent of the geriatricians.

A separate assessment was conducted by a research assistant, who asked residents if they suffered pain. Those that answered affirmatively were then asked "how much pain are you in?" and how they would rate their pain on a four point scale (1 = none; 4 = a lot). Findings indicated that evaluation of pain was valid for those with mild to moderate cognitive impairment but inconclusive for residents with severe cognitive impairment. The authors noted that there was no difference between groups in terms of medical diagnoses, however there was a consistent tendency to perceive lower levels of pain in the severely impaired. The authors concluded that there was a need for increased awareness of health professionals regarding the pain experienced by severely cognitively impaired people and improved methodologies to aid identification. Results indicated that overall there was a

significant positive correlation between patients' responses and physicians' ratings of pain levels.

Manfredi et al. (2003) used a randomised controlled correlational design to assess the validity and reliability of facial expressions in patients with severe dementia (based on medical diagnosis and MMSE score) undergoing a painful procedure (dressing change of decubitus ulcer). In the first phase, interviews were conducted with nine nursing home residents, whom staff had identified as capable of self-reporting pain (Group A). Analysis of the interviews identified ulcer characteristics associated with pain during dressing change. In the second phase, the facial expressions of nine patients with residents unable to report pain were videotaped before and after a dressing change of their decubitus ulcers (Group B).

The film clips were randomly shown to 10 nurses and 8 medical students, who were asked to rate on a short questionnaire whether they believed the patient experienced pain during any part of the procedure and if so, whether it was mild, moderate or severe. The authors concluded that observations of facial expression were valid and reliable even when viewed out of clinical context. However, there were omissions in the reporting of results. Analgesia was administered to five out of eight people in Group B, but there was no information about what was given, when or how much, or why the remaining three patients did not receive any analgesic. Furthermore, inconsistent information was provided about Group A concerning analgesic administration. There appeared to be unsubstantiated assumptions made about the cognitively impaired group based on verbal report of Group B, and it is not reported whether a pain assessment instrument was used to rate pain.

Kaasalainen and Crook (2003) conducted a comparison between four pain scales across four population groups. The sample was drawn from residents of a 240 bed long term care facility and was split into four populations: those that had normal cognitive functioning; those with a mild cognitive impairment; those with moderate cognitive impairment; and those with extreme cognitive impairment. All were at least 65 years of age and had resided in the facility for longer than three months. Residents with significant hearing impairment, visual impairment, or were non English speaking were excluded from the study. The study compared the Pain Assessment in the Communicatively Impaired tool (PACI), the Faces Pain Scale (FPS), the Present Pain Intensity (PPI), and the Numerical Rating Scale range (NRS). The PACI, a proxy administered observational scale, was compared against the three visual self-report scales. The investigator and a research assistant were trained in the use of the PACI, their interrater reliability was high (ICC = 0.80-0.92). Pain was assessed in the morning as this was considered a generally painful time for residents. The two raters assessed the residents' pain during a painful period, such as transferring from bed to chair. The resident was then asked immediately afterwards to rate their own pain on the three visual scales. This process was repeated 48 hours later. The PACI was conducted first to blind the raters to the residents' self-report.

The group with extreme dementia was unable to complete any of the verbal self-report scales and hence comparison between the PACI and the verbal self-report scales could not be conducted. Pain was reported as present for between 56-77% of the total sample. Generally, less pain was reported via the PACI than the self-report measures. The highest PACI reports of pain were in the extremely impaired group. Intraclass correlations were performed for all the scales, and were moderate to strong for all groups on the PACI - between 0.70 for the mildly impaired group to 0.62 for the extremely impaired group. No intraclass correlations were applicable for the other scales in the extremely impaired group as they were not conducted. For the mild and moderate impairment groups, the FPS reported correlations of 0.39 and 0.32 respectively; the PPI reported 0.40 and 0.51 respectively; and the NRS reported 0.38 and 0.45 respectively. Correlation between the PACI scores and those of the other scales were generally low. None of the correlations in the mild cognitive impairment group were significant. In the group with moderate impairment, significant correlations were found between the PACI and the FPS ($r = 0.63$, $p < 0.001$) and the PPI ($r = 0.64$, $p < 0.001$). The study suggests that PACI may be a useful measure when compared to self-report. The results suggest that the visual self-report scales are not a good measure for cognitively impaired people and become less valid and reliable as impairment increases.

Feldt (2000) developed the Checklist of Nonverbal Pain Indicators (CNPI) in response to difficulty finding a reliable and valid pain measurement scale for adults with cognitive impairment. The CNPI was developed from the University of Alabama Birmingham Pain Behaviour Scale (UAB-PBS) by removing the ‘ambulation’ component and adding a component for ‘vocalisations’. The UAB-PBS was designed for the assessment of chronic pain of people in outpatient or rehabilitation settings and is a 10 item scale that includes observations of vocal complaints, grimacing, body language, and stationary restlessness. The UAB-PBS contains criteria that were considered inappropriate for people with dementia (e.g., asked how many minutes per day spent in bed because of pain). In addition the tool was developed for younger cohorts and so the mobility criteria were inappropriate.

Using the Ferrell Pain Experience Interview and the Verbal Descriptor Scale (VDS), Feldt interviewed 53 post surgical patients with cognitive impairment (MMSE < 23) and 23 post surgical patients without cognitive impairment (MMSE > 23). Feldt also observed the patients at rest and during movement, using the CNPI. The CNPI showed that during movement, the group with cognitive impairment expressed significantly more vocalisations (mean 1.56 SD = 1.4) than the cognitively intact group (mean 0.94 SD = 1.1). However, at rest there was no significant difference between groups (mean 0.89 SD = 1.1; mean 0.53 SD = 1.1). The summed scores at rest ($r_s = 0.372$, $p = 0.001$) and on movement ($r_s = 0.428$, $p < 0.0001$) of the CNPI were significantly correlated with the VDS score for the whole sample. However, when the observed pain behaviours were correlated, the cognitively impaired group’s CNPI scores showed a significant correlation with the results of the VDS on movement only ($r_s = 0.4629$, $p = 0.009$). Feldt concluded that the CNPI needs further reliability tests and recommended that results be tested on a larger

population. She also suggested that the CNPI may be more useful for observing patients during activities rather than at rest. Other results from the study indicated that cognitively intact patients received significantly more analgesia than patients with cognitive impairment.

A study by Scherder et al. (2001) was initiated because of concerns that previous research tended to administer pain scales on only one occasion, thereby not controlling for the possibility that a participant with AD may have forgotten previous pain. Scherder and colleagues administered the CAS, VAS, McGill Pain Questionnaire, CNPI, and Number of Words Chosen-Affective (Dutch version) on a number of occasions. Participants were 14 older adults with early stage dementia (GDS = stage 5) and 17 older adults without dementia. Both groups were matched for chronic painful conditions and did not significantly differ in the prevalence of arthritis, recent fractures, and miscellaneous conditions. In the initial stage, all scales were administered once per day for 5 days, over 4 weeks. Following a two month interval, the scales were then administered once per day over 5 days. In the second stage, conducted two months later, the scales were administered 3 times per day at random times for 5 days. A chart review of NSAIDs and other analgesic use was carried out by an independent pharmacist.

Scherder et al. reported that the CAS was a valuable instrument for the detection of pain in adults with AD and further noted that there was lower comprehension of scales in the AD group than in those without dementia. However, this study is included with caution because the sample size was small and there was a high attrition rate of participants; three participants with AD and eight without AD were not involved in the second stage of the study. Furthermore, there appeared to be some crossover with respect to allocation to groups on the basis of cognitive impairment. A score of 7-10 was said to indicate cognitive impairment. However, the mean score for the control group was 10.18, with a range of 7-12, suggesting that some in this group in fact had cognitive impairment.

A secondary study aim was to investigate whether a relationship existed between cognitive status, pain reports, and analgesic medication use. Data were gathered on a tracking form. Spearman rank-order correlation tests were used for all analyses that involved analgesic use and pain reports as well as reliability estimates of test -retest measurements. The three items of the PPQ showed significant correlation with each other when measuring test-retest reliability (presence of pain, $r = 0.84$, $p = 0.0007$; frequency of pain, $r = 0.87$, $p = 0.0003$; intensity of pain, $r = 0.84$, $p = 0.0006$). The PPQ and the MDS measures were not significantly correlated on frequency ($r = 0.18$, $p = 0.18$) or intensity ($r = 0.22$, $p = 0.11$). Nursing staff found that pain was reported more often on the PPQ (48.2%) than the MDS (19.6%). The PPQ and the MDS were significantly associated with the amount of analgesia administered - PPQ presence of pain ($r = 0.37$, $p = 0.0075$), frequency ($r = 0.55$, $p = 0.0001$), intensity ($r = 0.41$, $p = 0.0022$); MDS frequency and intensity ($r = 0.33$, $p = 0.02$). The PPQ and MDS pain items were not significantly correlated on either the frequency or intensity items. Pain was reported more often on the

PPQ, suggesting it is a more sensitive indicator of pain than the pain items of the MDS.

Discussion

This systematic review of the assessment of pain in older adults with dementia has summarised the best available evidence published and unpublished over the period 1992-2005. No RCTs were found that examined the effectiveness of pain assessment methods. The findings of this systematic review are generally considered to be of low level evidence according to the NHMRC (National Health and Medical Research Council, 1999) criteria.

Self-report of pain in older adults with dementia

Self-report is the ability of an individual to indicate the presence and severity of their pain and is the single most important indicator of pain. Self ratings were seen to be clearest when comparing situations of mobility with those of inertia and were considered valid and reliable. Self-report may be verbal or by deliberate demonstration (e.g. nod or hand-squeeze) and the assessment process should involve asking the person in the first instance (Fink, 2001; Acello, 2001). Results showed that there was very little difference in frequency of self-report between adults with and without cognitive impairment, however there was suggestion that there might be lower sensitivity in the former related to neurological changes. Research indicated that while adults with cognitive impairment may fail to self-report at times, when they did so these reports were reliable and valid.

Pain assessment tools for use with older adults with dementia

Assessment scales that were used in the studies included in this review varied, ranging from uni-dimensional (scales that measure only one aspect of pain, for example sensory quality, intensity or unpleasantness) to multi-dimensional (scales that measure multiple dimensions of pain, for example, such as intensity, temporal characteristics and unpleasantness).

Assessment scales used in the studies collected pain information in a number of different ways, including self-report, measurement of physiological changes, observation of behavioural symptoms and motor function, and survey or questionnaire (gathered from interview with the adult with dementia or the caregiver or by postal survey).

The literature identified some general observations about the use of assessment tools and properties necessary for them to be effective. For example, the completion rates of number scales was higher for the vertical version compared with the more commonly used horizontal form (Gift, 1989). The literature also highlighted that assessment tools should be research based to ensure reliability and validity. Teaching the patient how to use the

scale should be done preferably when they are pain free and should not be administered until the person has a good understanding of the scale (Acello, 2001).

One author stated that an assessment tool was only as good as the person administering it. Some studies referred to the lengthy training times required for tools as being a contraindication for their use in the clinical setting. Most authors agreed that there was no single tool that was ideal for everyone, however the older adult with cognitive impairment could usually complete at least one kind or respond to verbal questioning (Hadjistavropoulos et al., 2000). Researchers found that tools were of more use if they were modified to compensate for the sensory deficits encountered in the cognitively impaired older population (e.g. enlarged print) and if other compensations were made when the tool was administered (e.g. allowing adequate time for thought processing and response, carrying out the assessment in a quiet place with minimal distractions). Some researchers maintained that more than one scale should be used to assess pain however it was seen to be essential that the same scale/s be used on the first and subsequent occasions for each resident (Acello, 2001).

Evans (2002) warned that some scales relied heavily on nursing reports of pain with no consideration for self-report from the person. A discussion paper by Acello (2001) referred to the mnemonic PQRST (Strevy, 1998) to assist caregivers in pain assessment. This prompts caregivers to take a holistic approach to pain assessment by considering Precipitating factors (what factors cause or relieve pain), Quality (or description of pain), Radiation (or location), Severity (using a numeric, descriptive or visual pain scale), and Timing of pain (whether constant or intermittent).

The Abbey Pain Scale was a uni-dimensional tool that was specifically developed for the assessment of pain in adults with dementia. It measured incidence and severity and gave a holistic impression of the pain from the caregiver's viewpoint. It was considered to be a valuable tool in predicting pain intensity, with severity of pain also being a good predictor of the nurses' overall impression of pain although it had not been validated against any other tool and therefore its reliability was yet to be proven.

Although uni-dimensional scales were successfully completed by some people with dementia, the utility of such scales is limited because only one aspect of pain is measured. Since the experience of pain is multi-dimensional, it would appear necessary to measure multiple aspects. As most uni-dimensional tools were completed by self-report, multidimensional tools completed by proxy may be especially useful in collecting pain information where communication skills are impaired by the dementing process.

Three studies (Ferrell et al., 1995; Wynne et al., 2000; Scherder et al., 2001) compared the multi-dimensional McGill Pain Questionnaire to other scales, finding that it was more successfully completed. The PADE was found to correlate well with the CMAI, reflecting accurate assessment of behavioural

symptoms, however the study design appeared to be flawed and so reliability of the tool is questioned.

Multi-dimensional tools that provided a pathway for care were seen to be of value, namely the ADD Protocol. The ADD Protocol not only provided a valid assessment of the pain experience for older adults with cognitive impairment but indicated a significant reduction in pain after application. The multi-dimensional scales that assessed pain levels during activities of mobility were said to be of most importance although other researchers maintained that it was important to assess pain during periods of rest as well.

Pain assessment scales that recorded severity of behaviours were popular and some correlated well with other instruments. Those that were shown to be valid and reliable were the CNPI and DS-DAT. These tools were of more use than the uni-dimensional tools, however there were still aspects of the pain assessment that were omitted.

The development of multi-dimensional assessment tools reflected a growing acknowledgement that assessment of pain was a complex process. Their development was also an acknowledgement of the difficulties encountered in the assessment process of an adult with dementia. These tools enable caregivers to elicit information about s number of aspects of pain where verbal response is limited.

Observational methods of pain assessment involved caregivers gathering visual information about the person over a period of time. These observations were focused on noting changes in body movement, changes in regular patterns or routines, changes in facial expression or changes in behavioural symptoms. Pain was more evident on movement, indicated by verbal and non-verbal means, and guarding was seen to be a good indicator of pain. In addition to actual pain, fear of pain was found to be important to address. Changes in behaviour were indicative of pain, but because they could be paradoxical, observations relied on knowing the person's usual behaviours. The absence of behavioural symptoms was not necessarily indicative of a pain free state.

Behaviours most commonly associated with pain were many and varied, and included joint rubbing, touching, holding, resistiveness, clenching mouth, pulling away, lying down, hitting, kicking, scratching, pulling hair, moaning, grunting, crying, verbal threats, name calling, refusing to eat, and poor appetite.

Behavioural symptoms were seen to be an expression of need, indicating unrelieved pain. Nurses commonly associated the overt behaviours of adults with dementia with pain. There was a discrepancy in agreement in interpreting pain behaviours between nurses, family caregiver and residents, with residents reporting higher incidence of pain. A suggestion made for this discrepancy was the preoccupation of staff with other tasks, not being there at the time, or desensitisation of staff to the pain experienced by their patients.

Facial expression was considered by some to be a valid and reliable way of assessing pain even when viewed out of clinical context, however the authors of one Australian study pointed out that observing facial expression may be inappropriate in instances where there was a masking effect, as seen in conditions such as Parkinson's disease.

Implications for Practice

The study design of many of the included studies did not always allow for conclusive results that achieved the initial aims of the research. Findings therefore were sometimes conflicting and generalisation not possible. Where conflict arose, further research has been recommended. Implications for practice resulting from the findings of this review are presented below with grades of recommendation assigned based upon the JBI developed Grades of Effectiveness (see Table 3 below).

Table 3.
Grades of Recommendation based upon the JBI developed Grades of Effectiveness

Grade	Description
A	Effectiveness established to a degree that merits application
B	Effectiveness established to a degree that suggests application
C	Effectiveness established to a degree that warrants consideration of applying the findings
D	Effectiveness established to a limited degree
E	Effectiveness not established

Self-report of pain in people with cognitive impairment is a reliable and valid method of assessment. It is considered to be the single most important method of assessing pain.
(Level C Evidence)

People with dementia should be asked about present pain
(Level C Evidence)

As the severity of dementia increases, self-report may become less reliable and should be used in conjunction with, or replaced by, a proxy measure
(Level C Evidence)

The CAS and the VRS were most recommended by the literature, however were limited in applicability for some levels of impairment

(Level C Evidence)

Multidimensional tools found to be most suitable for older people with dementia were the McGill Pain Questionnaire and ADD Protocol
(Level D Evidence)

Assessment tools should be modified to allow for sensory deficits in patients
(Level D Evidence)

Assessment of pain should be made during periods of activity as well as periods of rest
(Level D Evidence)

Observational methods of pain assessment include any visual or measurable observation of changes to usual patterns of physiology, mobility and range of movement, level of dependency, behavioural symptoms, and facial expression.

Interpretation of behavioural changes must be done on an individual basis because they can be paradoxical.

Physiological changes or deviations from the normal range can be indicators of pain. It is useful to include physiological measures as part of a wider assessment process.
(Level D Evidence)

Guarding was found to be a good indictor of pain
(Level D Evidence)

Proxy reports tend to under report pain
(Level D Evidence)

For use in all levels of impairment, the Abbey Pain Scale was most supported by the literature
(Level C Evidence)

The PACSLAC, ADD, PQQ and PAINAD were also represented favourably
(Level C Evidence)

Implications for Research

Many of the studies included in this review had limitations in their methodology and this, combined with the subjective nature of the topic under investigation, weakened the possibility of generalisation of findings.

Further research is clearly warranted and should be directed towards the following:

- further validation of pain assessment tools suitable for use with older adults with dementia;
- gaining an understanding of the factors that impact on professional caregivers in the assessment and treatment of pain in older adults with dementia;
- establishing the physiological and emotional effect of pain on older adults with dementia;
- examining the relationship between pain and depression in older adults with dementia;
- examining the relationship between dementia and its impact on painful diagnoses;
- examining behavioural change during acute pain in older adults with dementia; and
- evaluating behavioural responses to analgesia in older adults with dementia during an acute pain episode.

Conclusion

The findings of this systematic review have confirmed that pain is under assessed in older adults with dementia and that most assessment scales used are inadequate and not designed for this population. A need for scales with sound psychometric properties that are suitable for older people with dementia was identified. Further research is clearly necessary to clarify the issues that surround the assessment and treatment of pain in older adults with dementia.

While the use of self-report measures in cases of cognitive impairment may seem counter intuitive, the evidence suggests that they remain the most reliable and practicable measures available. The continued and increased use of self-report can therefore be cautiously recommended. However, a number of conditions may increase the accuracy of self-report, including questioning only on current pain and considering the capacity of the individual to respond. As impairment increases it may be necessary to augment self-report with proxy ratings, or in patients who are entirely non communicative, rely on proxy ratings alone.

Glossary of Terms

3MS	Modified Mini-Mental Status Examination
AD	Alzheimer's Disease
ADD	Assessment of Discomfort in Dementia Protocol
BSI	Brief Symptom Inventory
CAS	Colour Visual Analogue Scale
CDR	Clinical Dementia Rating Scale
CMAI	Cohen-Mansfield Agitation Inventory
CNPI	Checklist of Nonverbal Pain Indicators
CS	Coloured Pain Analogue Scale
DS-DAT	Discomfort Scale for Dementia of the Alzheimer Type
FACS	Facial Action Coding Scheme
FAS	Facial Affective Scale
FPS	Faces Pain Scale
GDS	Global Deterioration Scale
h-VAS	Horizontal Visual Analogue Scale
MDS	Minimum Data Set
MMSE	Mini Mental State Examination
m-VAS	Mechanical Visual Analogue Scale
NGRS	Numeric Graphic Rating Scale
NHMRC	National Health and Medical Research Council
NOPPAIN	Non-Communicative Patient's Pain Assessment Instrument
NRS	Numeric Rating Scale
NSAIDs	Non-Steroidal Anti-Inflammatory Drugs
NWC-A	Number of Words Chosen - Affective
PACI	Pain Assessment in the Communicatively Impaired
PACSLAC	Pain Assessment Checklist for Seniors with Limited Ability to Communicate
PADE	Pain Assessment for the Dementing Elderly
PAINAD	Pain Assessment in Advanced Dementia
PBM	Pain Behaviour Measurement
PGC-PIS	Philadelphia Geriatric Centre – Pain Intensity Scale
PPI	Present Pain Intensity
PPQ	Proxy Pain Questionnaire
PQRST	P - precipitating factors, Q - quality of pain, R- radiation, S - severity, T - timing of pain
PRN	Pro re nata
PST	Pain Screening Tool
RAS	Ryden Aggression Scale
RCT	Randomised Controlled Trial
UAB-PBS	The University of Alabama Birmingham Pain Behaviour Scale
VaD	Vascular Dementia
VAS	Visual Analogue Scale
VDS	Verbal Descriptor Scale
VRS	Verbal Rating Scale
v-VAS	Vertical Visual Analogue Scale
VVDS	Vertical Verbal Descriptor Scale

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Appendices

Complete appendices for this systematic review are available on the ACEBAC website at www.latrobe.edu.au/acebac