



# **Successful Pain Assessment in Older Adults with Dementia: Barriers and Strategies**

## **Review**

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The complete document including appendices is available on the ACEBAC website at [www.latrobe.edu.au/acebac](http://www.latrobe.edu.au/acebac)

## TABLE OF CONTENTS

|   |           |
|---|-----------|
| <b>Executive Summary .....</b>  | <b>4</b>  |
| <b>Introduction .....</b>   | <b>6</b>  |
| <b>Background .....</b>   | 6         |
| <b>Objectives .....</b>   | 6         |
| <b>Review Method .....</b>  | <b>7</b>  |
| <b>Inclusion Criteria .....</b>   | 7         |
| Types of studies .....  | 7         |
| Types of participants.....  | 7         |
| Issues of interest .....  | 7         |
| <b>Search Strategy .....</b>  | 8         |
| <b>Search Terms .....</b>   | 8         |
| <b>Critical Appraisal.....</b>  | 8         |
| <b>Data Extraction .....</b>  | 9         |
| <b>Data Synthesis .....</b>   | 9         |
| <b>Results .....</b>  | <b>9</b>  |
| <b>Barriers to successful pain assessment .....</b>                           | 9         |
| (a) Staff considerations .....  | 9         |
| (b) Patient considerations .....  | 13        |
| <b>Strategies for overcoming barriers to successful pain assessment .....</b> | 15        |
| <b>Discussion .....</b>   | <b>18</b> |
| <b>Implications for Practice .....</b>  | <b>23</b> |
| <b>Implications for Research .....</b>  | <b>25</b> |
| <b>Conclusion .....</b>   | <b>26</b> |
| <b>References.....</b>  | <b>29</b> |
| <b>Appendices.....</b>  | <b>32</b> |

## **Executive Summary**

### **Objectives**

The objectives of this review were to (a) identify barriers to successful pain assessment in older adults with dementia, and (b) identify possible strategies for overcoming these barriers.

### **Method**

A database search was conducted for literature relating specifically to barriers to pain assessment in dementia. In addition, further studies that were initially retrieved following a database search for literature for a systematic review on *Assessment of Pain in Older Adults with Dementia in Acute, Sub Acute, and Residential Care* were earmarked for this paper when it became apparent that there was a need for a separate paper focusing on barriers to, and strategies for, successful pain assessment in older adults with dementia. All studies were critically appraised by two independent reviewers and data was extracted using instruments specifically developed for the systematic review. Where disagreement existed between reviewers regarding inclusion or level of evidence, a third reviewer or the Expert Reference Group was consulted.

### **Results**

A number of barriers to successful pain assessment in older adults with dementia were identified in the literature. These barriers can be divided into two realms: staff considerations and patient considerations. Staff considerations included lack of recognition of pain in patients with dementia; lack of sufficient education and/or training regarding pain in patients with dementia; misdiagnosis or late diagnosis; and non-use of assessment tools. Patient considerations included insufficient evidence that pain is present; the possible existence of a 'no pain' subset of people with dementia; the type of pain experienced; and stoic attitudes. Several strategies were proposed to overcome these barriers and included knowing the person; knowing by diversity/intuitive perception; improved training and education; the development and implementation of adequate tools.

### **Conclusions**

This review has found that pain is frequently undetected, misinterpreted, or inaccurately assessed in older adults with dementia. At particular risk are those patients who are non-communicative and are therefore unable to articulate or convey their pain, who are often dismissed as being incapable of perceiving or recalling pain. More extensive training and education regarding pain in the dementia patient is urgently needed, as is the development and implementation of an effective pain assessment tool specifically designed for detecting and measuring pain in older adults with all stages of dementia.

## **Introduction**

### **Background**

Older people form the population most at risk of having their pain inadequately assessed, and this is especially so for those with dementia (Weiner & Hanlon, 2001). An increasing amount is being written on pain assessment in the older adult with dementia, however the bulk of research to date has focused on the measurement of pain (e.g. Abbey et al., 2004; Ferrell et al., 1995; Fuchs-Lacelle & Hadjistavropoulos, 2004; Kovach et al., 1999; Warden et al., 2003), rather than on the actual process of pain assessment. Yet in order for pain to be measured, it is first necessary that it be detected.

Barriers to pain assessment exist for all older adults, but particularly so for older adults with dementia, a population for which the recognition of pain can prove quite challenging. Aside from problems related to sensory impairment and communication difficulties, the assessment of pain in older adults with dementia is further complicated by a multitude of other factors, including evidence that indicates the experience of pain is unusual for at least some people with dementia (Fisher-Morris & Gellatly, 1997). It is perhaps not surprising, then, that several studies have indicated that pain is under recognized in this population (Madjar & Higgins, 1996; Sengstaken & King, 1993), with analgesic administration found to occur less often for adults with, as opposed to without, dementia (Horgas & Tsai, 1998; Scherder & Bouma, 1997). Difficulties with the detection of pain hinder successful assessment, which is crucial for the implementation and evaluation of appropriate interventions.

In order for unrelieved pain to be reduced in people with dementia, clinicians need to be aware of the most effective strategies for assessing pain in this population. This can only be facilitated by the identification of barriers to the assessment of pain in patients with dementia and potential strategies that may be used to overcome these barriers to assessment.

### **Objectives**

The initial aim of the systematic review *Assessment of Pain in Older Adults with Dementia in Acute, Sub Acute, and Residential Care* (Wilson, O'Donnell, McAuliffe, Nay & Pitcher, 2006) was to present the best available evidence on the assessment

and treatment of pain in this population. However, it became apparent that there was a need for a separate review delineating the barriers and strategies associated with the assessment endeavour. The aims of the current review were therefore to (a) identify barriers to successful pain assessment in older adults with dementia and (b) identify potential strategies for overcoming such barriers.

## **Review Method**

### **Inclusion Criteria**

#### **Types of studies**

This review considered both quantitative research studies (e.g. randomised controlled trials, time series, cross over design, case series, cross-sectional, cohort, prospective, case control, retrospective) and qualitative research studies (e.g. case reports, phenomenological studies, grounded theory, ethnographic studies, naturalistic studies, utilising methods such as focus groups, interviews, questionnaire/survey). Studies were included in a narrative summary.

#### **Types of participants**

Participants were aged care residents and patients aged 65 years or more with a diagnosis of dementia (any type or stage), their families and health care staff. Participants from all settings were included (e.g. nursing homes, dementia clinics, community settings, acute and subacute care).

#### **Issues of interest**

Issues of interest were (a) barriers to the successful assessment of pain in older adults with dementia and (b) strategies used for the successful assessment of pain in older adults with dementia.

## **Search Strategy**

The first phase of the search strategy involved a limited search of CINAHL and MEDLINE databases in order to set the parameters for a more specific examination of the literature. In this phase, key words contained in the title and abstract, relevant MeSH headings and descriptor terms were identified. The second phase involved a more extensive search of 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 1993-2007 referred to in the literature, and articles retrieved for the systematic review but were excluded, were also considered for inclusion in the current review. See Appendix A for search history.

## **Search Terms**

Search terms used included pain, dementia, assess\*, barrier\*, and obstacle\*.

## **Critical Appraisal**

All studies were critically appraised by two independent reviewers using the quantitative and qualitative appraisal tools developed for the review (see Appendix B) based on those published by the Joanna Briggs Institute (JBI). Critical appraisal focussed on sources of bias in the studies, including those found in selection, method, attrition and detection. Where there was disagreement between reviewers, a third reviewer or the Expert Reference Group was consulted.

Quantitative studies were categorised according to the level of evidence they offer as defined by the National Health and Medical Research Council (NHMRC) criteria (National Health and Medical Research Council [NHMRC], 1999; see Appendix C). Qualitative studies were categorised according to the levels of evidence defined by the Joanna Briggs Institute (Joanna Briggs Institute [JBI], 2000; see Appendix D).

## **Data Extraction**

Data were extracted by two reviewers independently, using the quantitative and qualitative data extraction instruments developed for the review (Appendix E). Where disagreement between reviewers existed, a third reviewer or the Expert Reference Group was consulted.

## **Data Synthesis**

As only one quantitative study was identified for inclusion in this review, no statistical pooling was conducted. Findings of the studies were synthesised in a narrative summary.

## **Results**

Database searches for studies yielded a total of 77 potentially relevant articles. These studies were sourced from the following databases: CINAHL (18), Medline (18), PsycINFO (18), Ageline (2), Cochrane Library (0), Embase (10), APAIS Health (0), Current Contents Connect (5), Dissertation Abstracts (0), Social Sciences Citation Index (6). Duplication of articles between databases was noted and eliminated from the search. Overall, 10 articles met the final inclusion criteria and were deemed appropriate for inclusion in the current review. Summaries of these articles and the levels of evidence assigned to each are presented in Appendix F.

### **Barriers to successful pain assessment**

A number of perceived barriers to successful pain assessment in patients with dementia were identified in the literature. Discussion of these barriers appears under two main headings: (a) staff considerations and (b) patient considerations.

#### **(a) Staff considerations**

### ***Lack of recognition***

Pain is often not assessed because it fails to be recognised and subsequently diagnosed. Madjar and Higgins (1996) conducted a descriptive field study in a nursing home that involved a review of medical and nursing records, as well as focus group interviews with nurses (n=21), and individual interviews with both residents (n=94, 66% with and 34% without dementia) and family members (n=23). Medical records indicated that chronic pain was experienced by 70% of all residents. Of the remaining 30% of residents for whom chronic pain was not recorded, residents with dementia were significantly over represented (81%). Yet residents with dementia who were able to be interviewed (i.e. those with only mild cognitive impairment) indicated that only 23% of this group was without pain. Findings of the study indicated that there was a high prevalence of chronic pain in nursing home residents, some of which went unrecognised by staff, and that chronic pain was rarely listed either as a medical or nursing diagnosis, or detailed in nursing plans. Moreover, chronic pain experienced by residents with dementia was especially unrecognised, even for residents in the early stages of dementia who were able to indicate current pain.

### ***Lack of sufficient education and/or training***

Insufficient education and/or training have been identified in the literature as contributing barriers to effective pain assessment in patients with dementia.

The study of Kovach, Griffie, Muchka, Noonan and Weissman (2000) used purposive sampling to select for interview 30 nurses working in long-term care who had experience working with patients with dementia, had received extensive education in pain management 1 year previous, had adopted formal procedures to improve care for patients in pain, and who were considered by administrators to be knowledgeable and experienced in pain assessment and treatment in patients with dementia.

Despite fulfilling these criteria, the nurses interviewed reported a need for more education regarding the assessment process and signs and symptoms of discomfort in such patients.

The need for more education was echoed by Cohen-Mansfield and Creedon (2002), who investigated how nurses working in nursing homes diagnose pain in non-verbal

residents, as well as their perceptions of barriers to the detection of pain in this population. The study consisted of three separate components: staff interviews, surveys, and focus groups. The training of nurses was identified as commonly biased, and, as a consequence, constraining. The authors suggested that using diagnoses to explain behavioural change may be an instance of 'trained incapacity'. Habit was also identified as a barrier to pain detection and assessment, with behavioural problems more often than not viewed as having psychological as opposed to physical origins, and treated by administering, or adjusting the level of, psychotropic medication.

From a survey of 68 nursing home managers combining quantitative and qualitative methodologies, Allcock, McGarry, and Elkan (2002) found that only 44% provided education for staff regarding the use of non-verbal cues for the recognition of pain in people with dementia. The authors' conclusion stressed the need for training and education in order to effect better pain detection and management.

In a recent study investigating nursing staff knowledge and beliefs about pain in older residents with dementia, Zwakhalen and colleagues (2007) found knowledge deficits in regards to pain assessment despite respondents' satisfaction about the way pain was assessed on their wards.

### ***Misdiagnosis or late diagnosis***

Pain is often not accurately assessed because its symptoms are misinterpreted. The study of Kovach et al. (2000) investigating the perceptions of nurses working in long term care in regards to pain in elderly patients with dementia found that changes in behaviour were sometimes attributed to a psychiatric problem rather than seen as indicating an unmet need. Even behaviours known to be associated with dementia were sometimes viewed solely in terms of mental health, with analgesics only administered following unsuccessful treatment with psychotropic drugs.

Cohen-Mansfield and Creedon (2002) further lent support to the notion that behavioural problems can act as a barrier to successful pain assessment in patients with dementia, finding that distinguishing between difficult behaviours and pain behaviours in such patients can be challenging. Furthermore, interviews and surveys with nursing home staff revealed examples of late detection of pain and a

belief that not all nursing homes are diligent in providing timely care to those experiencing pain.

Kaasalainen and colleagues (2007) found from a study exploring pain management decision making among long term care physicians and nurses that resident behaviours were mostly considered to be indicative of something other than pain, with pain often investigated and assessed as a last resort in residents with dementia.

### ***Non-use of assessment tools***

Non-use of adequate and appropriate assessment tools for measuring pain is commonly referred to in the literature as an impediment to accurate pain assessment in patients with dementia.

The survey conducted by Allcock et al. (2002) found that 75% of the nursing homes in their study did not use a standardised pain assessment tool with at least 84% relying on self-report and/or observation by nursing care staff.

Adams, Goldman, and Ferguson (1997) surveyed nurses' views regarding ways in which pain could be assessed and acted upon in patients with dementia.

Questionnaires were delivered to randomly selected nursing homes and royal district nursing services, and were returned by 100 registered district nurses and 169 registered nurses working in nursing homes. Two, one-hour focus groups were also conducted with an average of 6 representatives from each group of nurses. It was found that 60% of nurses felt they had a good knowledge about pain and 64% had a good knowledge about dementia. Ninety-eight percent of nurses agreed that people with dementia suffer from pain. Yet only 51% of respondents indicated that they would conduct a pain assessment if a patient with dementia was experiencing pain. The remaining respondents generally cited lack of an adequate pain assessment tool as the sole reason for not conducting a pain assessment. The respondents also reported that acute pain was more easily recognised than chronic pain, as acute pain could be identified by observing changes in vital signs, physiology and behaviour. The importance, therefore, of differentiating between the two when developing an assessment tool was noted. Respondents (71%) felt that there was a need for the development of a specific tool that could provide information over a period of time, and which could be used in a variety of settings.

The study of Madjar and Higgins (1996) further highlighted the problem of inadequate pain assessment. Pain was found to be inadequately assessed and documented upon admission, when initially reported, and thereafter. Although regular health assessments and two yearly reviews were conducted, the use of any pain assessment tool (let alone an adequate tool) was not usual clinical practice, with pain addressed neither systematically nor comprehensively. Even when pain was recorded in progress notes, details were found to be lacking in regards to pain intensity and qualitative and temporal information.

## **(b) Patient considerations**

### ***Insufficient evidence***

Cohen-Mansfield and Creedon (2002) identified a lack of sufficient evidence as a barrier to the detection of pain in older adults with dementia. The authors found that behaviours need to be repeated several times and observed in the presence of the same caregiver before they are linked to pain.

### ***Possible 'no pain' subset of patients with dementia***

It has been suggested in the literature that people with dementia may not experience pain to the same degree as those without dementia. Fisher-Morris and Gellatly (1997) hypothesised that there was a subset of people with AD who did not experience pain in the normal way. In a discussion paper they presented two cases in which one patient underwent surgery for a fracture of the femur and post-operatively was able to walk around the ward without any pain complaints. The other case concerned a woman with a suppurating cancerous lesion of the breast, who at no stage indicated that she was in pain even when staff were dressing the wound. These cases were followed by a small scale national survey of predominantly informal carers' experiences (n=47) in caring for people with dementia who by all accounts should have expressed pain in relation to an adverse event. In all cases responses to pain were absent despite apparently intact emotional and verbal communication. This research cannot by any means be extrapolated to reflect the experience of all patients with cognitive impairment. It does, however, highlight

the range of possible individual responses to what are normally categorised as 'painful' conditions, it also highlights that a possible inability to feel and express pain can present barriers to the effective care of medical conditions that nevertheless require treatment.

### ***Type of pain***

Several studies have found that distinguishing between different types of pain can be a difficulty that prevents successful pain assessment. The study of Cohen-Mansfield and Creedon (2002) described physiological factors that nurses identified as being important in the assessment of pain in older people with dementia. The focus group produced a long list of pain indicators and a number of these related to physiological change. Some of these included skin discoloration, changes in vital signs, and change in face colour. The nurses interviewed were asked to rate the importance of the indicators in pain identification on a six point Likert scale. Of the ten indicators identified as most important in identifying pain (mean ranking 5.1 to 4.7), six were physiological signs. The survey focussed on behavioural indicators, such as joint rubbing or touching, moaning, decreased appetite, refusal to eat, and reluctance to move. The authors concluded that the changes in physical signs and physiology may be more indicative of acute pain than chronic pain, suggesting that the chronicity of pain is itself a barrier to pain detection and assessment. Another type of pain experienced by the non-communicative elderly that was found to be subject to inferior treatment was emotional (as opposed to physical) pain, due to the difficulty involved in detecting pain of this nature.

This conclusion was supported by a study by Adams et al. (1997) that surveyed nurses' views regarding ways in which pain could be assessed in people with dementia. It found that nurses relied on physiological changes such as changes in vital signs, guarding, and pallor to alert them that a dementia patient was experiencing pain. Such signs were found to be indicative of acute, but not chronic, pain. Coupled with the finding that nurses stress the use of behavioural change to indicate pain, this suggests that chronic pain may be especially susceptible to under-detection.

### ***Stoic attitudes***

Certain attitudes held by older adults experiencing pain may also serve as obstacles to accurate pain assessment.

Madjar and Higgins (1996) revealed interesting insight into the attitudes of nursing home residents (both with and without dementia) who experienced pain. Findings indicated that most residents expressed stoic attitudes and accepted their pain as part of the ageing process. Common themes identified included a fear of drug addiction, reporting of pain seen as complaining, and doubts that effective pain relief was actually possible. These expectations and attitudes are considered barriers to pain assessment, as they prevent nursing home residents from reporting pain when it is experienced.

### **Strategies for overcoming barriers to successful pain assessment**

Several strategies have been proposed in the literature as means of overcoming some of the barriers identified in this review and are presented below.

#### ***Knowing the person***

Several studies highlighted the importance of knowing the person in making an accurate assessment of pain in patients with dementia.

Parke (1998) conducted an ethnographic study using judgement sampling to investigate the way gerontological nurses 'know about' pain in their clients. Informant selection guided by established criteria yielded six participants, all registered nurses who were knowledgeable about pain and who had one year full time or four years part time experience as part of a health team in aged care. The nurses were asked to relate a current experience in caring for someone with cognitive impairment who had pain and then imagine a similar situation and describe the person and the experience. The nurses reported that they used pain cues such as changes in overt behaviours, and these necessitated being familiar with the person. They reported that they used an individual approach for each person that relied upon knowing the person's regular patterns, characteristics, likes, and dislikes,

and referred to an intuitive approach to guide assessment. The assessment was reported to be a trial and error process relying on consultation with a multidisciplinary team. Knowing the person enabled nurses to obtain crucial individualized knowledge regarding each individual dementia patient's pain cues, which, when clustered, facilitated nurses' ability to recognize change and triggered pain assessment.

Kovach et al. (2000) conducted semi-structured interviews with thirty nurses from six long-term care facilities in order to describe the perceptions of nurses regarding the assessment and treatment of pain in late-stage dementia residents. Length of experience working with patients with dementia ranged from 0.5 – 25 years. All of the nurses had received extensive education in pain management 1 year prior, had introduced procedures to improve care of pain patients, and were considered to be both knowledgeable and experienced with the assessment and treatment of pain in late stage dementia. During the 30-60 minute interviews, nurses were asked to share their experiences with pain in patients with dementia, including the identification and assessment of pain and its treatment with both narcotics and non-narcotics. Data analysis involved triangulation, whereby initial results were validated and refined during a focus group meeting attended by a second group of 16 nurses. Results found consistency in the nurses' descriptions of symptoms and assessment, which suggested the assessment of pain is systematic and discernable. Factors identified as facilitating the assessment of discomfort in patients with dementia were knowing the resident (by working consistently with the same patient and spending time with them); watching for any changes in behaviour (subtle changes only detectable by staff who work consistently with the same patient); and being aware of the possible symbolic message of behaviours (eg. exiting behaviour as an attempt to escape from pain).

Cohen-Mansfield and Creedon (2002) lend further support to the notion that knowing the person can assist in detecting and assessing their pain. They found that the knowledge of a person's personal habits was used far more to assess pain than were formal procedures, and that nurses were found to be more likely to detect pain in those residents to whom they felt connected emotionally. However, there was considerable variation in opinion regarding the length of time required for a nurse to

become familiar enough with a patient to be able to detect pain in that patient, with responses ranging from one week to 3 months.

Falls and Stevens (2004) conducted a grounded theory based study aimed at discovering those factors that are crucial to reliable pain assessment in persons with moderate to severe dementia. Thirty-one formal and non-formal carers of aged care residents were interviewed regarding their perceptions of pain in the person they cared for. Thematic and categorical analysis revealed several themes, including that all carers claimed to be able to identify pain in the person they cared for, and that they did this by recognizing even subtle deviations from normal behaviour. From this finding, the authors proposed the hypothesis that effective pain assessment in this population depends on carers having an intimate knowledge of the individual's normal state with dementia.

Familiarity with the client has been found to be one of the most useful aids to assessment of pain in patients with dementia according to both district and residential nurses alike (Adams et al., 1997).

### ***Knowing by diversity / intuitive perception***

In addition to highlighting the importance of knowing the person, Parke (1998) identified a second way of knowing, knowing by diversity, or knowing by intuitive perception. The nurses in the study appeared to be efficient at detecting subtle changes in dementia patients in pain despite not being able to clearly put their perceptions into words. Parke explained this knowledge as intuitive in nature, derived from each nurse's diverse range of clinical experiences of dementia patients in pain.

### ***Training & education***

Many of the barriers to pain assessment in older adults with dementia can be overcome with the introduction of more extensive and informative training and education regarding both the manifestation of pain in the dementia patient and the process of assessment that is needed in order for the pain to be detected.

The nurses interviewed in the study by Kovach et al. (2000) were consistently able to associate unrelieved pain with behavioural symptoms such as anger, pulling away, changes in gait, crying, increased confusion, and decreased appetite. However, although these nurses had an average 11 years of experience working with patients with dementia, received extensive education in pain management only one year prior to the study, had introduced procedures to improve care of pain patients, and were identified as knowledgeable and experienced with the assessment and treatment of pain in late stage dementia, they expressed a need for more education on the process of assessment and on common signs and symptoms of pain in patients with dementia.

### ***Use of adequate tools***

It is evident from the literature that increasing the success of pain assessments in the older adult with dementia is largely dependent on the development and implementation of an adequate pain assessment tool for this population.

Focus groups conducted by Adams et al. (1997) with registered community and residential nurses suggested that certain assessment tool formats are preferable to others. Tick boxes were unanimously found to be unsuitable for pain assessment, with strong support for flow charts including prompts for navigating the pain assessment process. Findings from the study also indicated support for longitudinal recording of treatment data (medication and other) and evaluations of such treatments. Baseline assessment was viewed as important for discerning patient changes and it was believed that for continuity of both care and information, assessments should be conducted by the same person when at all possible.

## **Discussion**

Although this review has focused on studies relevant to a discussion of barriers to and strategies for successful pain assessment in older adults with dementia, it is important to note that this review is not exhaustive and that a systematic review of the literature may inform of additional barriers and strategies not outlined in this

review. Nonetheless, the proposed strategies may serve well in paving the way forward towards more comprehensive, timely, accurate and effective detection and assessment of pain in the cognitively impaired older adult.

## **Barriers to successful pain assessment**

### **(a) Staff considerations**

#### ***Lack of recognition***

Research has indicated that there is a high prevalence of pain in nursing home residents, and that those with dementia are at particular risk of having their pain go undetected. This was found to be the case even for those residents with mild cognitive impairment who were able to report current experiences of pain (Madjar & Higgins, 1996). The use of pain complaints by some purely as a means of 'gaining attention' further exacerbates the potential for pain in patients with dementia to go unrecognised (Cohen-Mansfield & Creedon, 2002).

#### ***Lack of sufficient education and/or training***

Education and training in assessing pain in patients with dementia has been found to be infrequent, with existing education of poor quality. Current training has been labelled as biased and limiting due to such practices as using diagnoses alone to explain changes in patient behaviour (Cohen-Mansfield & Creedon, 2002). Lack of adequate training has also been identified as responsible for other barriers to successful pain assessment in patients with dementia, such as a reliance on habit and viewing behavioural problems as primarily psychological. Even nurses with extensive education and knowledge in pain management and treatment in patients with dementia reported a need for further training (Kovach et al., 2000). Specifically, nurses wanted more education regarding (i) the pain assessment process and (ii) signs and symptoms of discomfort in patients with dementia.

#### ***Misdiagnosis or late diagnosis***

Symptoms associated with pain in dementia are often misinterpreted, resulting in misdiagnosis and/or late diagnosis of pain. Behavioural changes in patients with dementia are commonly attributed to a psychiatric problem rather than viewed as symptomatic of an unmet need (Kovach et al., 2000). Behavioural changes exhibited by patients with dementia are also frequently labelled as difficult behaviours rather than pain behaviours (Cohen-Mansfield & Creedon, 2002), with pain often investigated and assessed as a last resort (Kaasalainen et al., 2007).

### ***Non-use of assessment tools***

Instruments used for assessing pain in the cognitively impaired were found to be deficient, with pain assessment tools used by only 25-51% of nurses in the studies reviewed. Criticisms included that behavioural assessments were not sensitive enough to detect more subtle changes (Kovach et al., 2000), and that tools did not cater for the distinction between acute and chronic pain (Adams et al., 1997).

## **(b) Patient Considerations**

### ***Insufficient evidence***

Attention was directed by some researchers (Cohen-Mansfield & Creedon, 2002) toward the need for sufficient evidence in prompting a pain assessment, with a need for patient behaviours to be repeated and observed by the same caregiver in order for pain to be suspected.

### ***Possible 'no pain' subset of patients with dementia***

One study extended the observation that patients with dementia report pain less often by suggesting that the actual experience of pain in at least some patients with dementia differs from those who are cognitively intact (Fisher-Morris & Gellatly, 1997). Two cases and findings from a small scale survey supported the existence of a 'pain-free' subset of patients with dementia for whom pain is not experienced in the normal manner despite having physiological conditions that are known to induce pain. Findings of this study have interesting implications, both legally and in terms of pharmacological treatment.

### ***Type of pain***

The nature of the pain itself was viewed by some as a barrier to its detection, with emotional pain not as well detected or treated as physical pain (Cohen-Mansfield & Creedon, 2002), and with acute pain easier to detect and treat than chronic pain (Adams et al., 1997) in the non-communicative dementia patient.

### ***Stoic attitudes***

The commonly held belief that pain is just part of the ageing process is another barrier identified in the literature as complicating the detection and assessment of pain in patients with dementia. Nursing home residents in one study expressed a reluctance to report pain due to concerns about drug addiction, doubt that effective pain relief is possible, and a fear of being perceived as complaining (Madjar & Higgins, 1996).

### **Strategies used to overcome barriers to successful pain assessment**

Whilst some of the obstacles to effective pain assessment identified above require considerable thought as to possible solutions, most of the other barriers identified imply strategies that may be used to overcome those barriers. These are discussed below.

### ***Knowing the person***

The importance of knowing the person in assisting the pain assessment process has been underscored in the literature. Knowing the person has been described as knowing a person's regular patterns, characteristics, likes, and dislikes (Parke, 1998) and can be achieved by working consistently and spending time with the same patient (Kovach et al., 2000). Knowing the person has been identified as a major factor in the recognition of a patient's unique pain cues, which, in turn, results in better detection and assessment of pain (Falls & Stevens, 2004). Knowing the person has been reported to facilitate recognition of pain-related changes and trigger

pain assessment (Parke), increase the likelihood of pain being detected in a patient (Cohen-Mansfield & Creedon, 2002), and has been described by both district and residential nurses as one of the most useful aids to pain assessment in patients with dementia (Adams et al., 1997).

### ***Knowing by diversity/intuitive perception***

Another way of knowing identified in the literature is knowing by diversity, or knowing by intuitive perception. Although seemingly incompatible with knowing the person, knowing by diversity has been proposed as a strategy for overcoming the barriers to pain assessment associated with the cognitively impaired older adult. It has been argued that the intuitive knowledge bank accumulated as a result of each nurse's diverse clinical experiences of patients with dementia with pain can be used for the better detection and assessment of pain in this population (Parke, 1998).

### ***Training and education***

Increased and improved training and education are key steps toward greater detection and assessment of pain in patients with dementia. Providing nurses with the knowledge and skills required to recognize pain in the cognitively impaired older adult is crucial if pain assessment is to improve in this population. Training programmes should be aimed at providing more education regarding both the assessment process and recognizing common signs and symptoms of pain in the dementia patient (Kovach et al., 2000). Training programmes should highlight the dangers of relying only on diagnosis and habit, and instead need to encourage nurses to be aware of behavioural as well as other more subtle indicators of pain (Cohen-Mansfield & Creedon, 2002). Education should include delineating between behavioural problems with psychological origin and those with a physical basis, and the role of medication should also be discussed (Cohen-Mansfield & Creedon).

### ***Adequate tools***

Although nurses report the frequent use of behavioural symptoms to trigger pain assessments (Kovach et al., 2000), there is an urgent need for the development and

use of an adequate pain assessment tool for use with patients with dementia. Further research is needed in order to determine how best to develop an adequate pain assessment tool for this purpose. A number of important factors require careful consideration, including whether the tool should be standardized or individualized; whether it can be used for both mild and severe dementia (related issues include the role of self report and the use of non-verbal forms of communication such as picture boards); whether the behavioural measures used are appropriate for a cognitively impaired population; the contribution of type of pain; the timing of assessments or context in which they occur; the degree of sensitivity to include; and details to include (eg. pain intensity, and qualitative and temporal information).

### **Discussion Summary**

It is evident from the above discussion that there are a considerable number of barriers to effective pain assessment in the dementia patient. These barriers can be divided into two realms, staff considerations and patient considerations. Staff considerations include, but are not limited to, a lack of recognition of the signs and symptoms of pain in patients with dementia, lack of sufficient education and/or training of nursing staff in the areas of pain and dementia, misdiagnosis or late diagnosis, and non-use of adequate pain assessment tools. Patient considerations that can be regarded as barriers to effective pain assessment in the cognitively impaired include insufficient evidence that pain is present, the possibility of a 'no pain' subset of patients with dementia, the type of pain experienced, and stoic attitudes towards pain held by aged persons. Several strategies have been proposed in the literature as means of overcoming the barriers described, such as knowing the person, knowing by diversity/intuitive perception, training and education, and the use of adequate tools. Although this is by no means an exhaustive list, the proposed strategies may serve well in paving the way forward towards more comprehensive, timely, accurate, and effective detection and assessment of pain in the cognitively impaired older adult.

### **Implications for Practice**

Implications for practice resulting from the findings of this review are presented below with levels of evidence assigned:

### **Knowing the person**

A comprehensive knowledge of the person is a major factor in detecting pain and making an accurate pain assessment in older people with dementia

**unequivocal evidence**

Pain cues are individually defined; nurses should use validated tools but individualize the approach taken to assessment

**credible evidence**

Care delivery systems should be structured in a way that allows caregivers to remain with the same clients for an extended period of time

**credible evidence**

Subtle changes in the behaviour of patients with dementia who are in pain are only detectable by members of staff who consistently work with that same person

**credible evidence**

### **Knowing by diversity**

The knowledge bank accumulated as a result of diverse clinical experiences of patients with dementia in pain can be used for the better detection and assessment of pain in this population

**credible evidence**

### **Training and education**

Training programmes should provide more education regarding both the assessment process and recognizing the common signs and symptoms of pain in the dementia patient

**credible evidence**

### **Adequate tools**

Pain assessment tools are more useful if they are tailored to an individual's abilities

**credible evidence**

Pain assessments should be conducted using a tool that is sensitive to the difference between acute and chronic pain

**credible evidence**

As some assessment tool formats are preferable to others, due attention should be given to the format of the pain tool and its suitability for pain assessment in patients with dementia

**credible evidence**

Conducting baseline assessment is important for discerning patient changes

**credible evidence**

Assessments should be conducted by the same person when at all possible

**credible evidence**

### **Implications for Research**

Further research needs to be directed towards expanding on existing barriers and investigating the effectiveness of the proposed strategies.

In particular, research is required to examine in detail the feasibility of developing an adequate pain assessment tool for use with patients with dementia. Specifically, the following should be investigated: (i) whether an accurate pain assessment tool for patients with dementia can be developed that accounts for individual differences whilst still providing an objective measure of pain; (ii) factors surrounding nurses' current recognition and assessment of pain, including pain cues, and their frequency of use; (iii) factors associated with accurate and inaccurate assessment; (iv) the extent to which pain is documented, and the relationship between good documentation and accurate initial and continuing assessment; (v) the need for certain properties of pain to be included in pain assessment tools (e.g., intensity, location, quality); (vi) the quality and degree of training and education of nurses working with older adults with dementia regarding the signs and symptoms of pain in that population.

## **Conclusion**

Pain is frequently undetected, misinterpreted, or inaccurately assessed in older adults with dementia. At particular risk are those patients who are non-communicative and therefore unable to articulate or convey their pain, who are often dismissed as being incapable of perceiving or recalling pain. The existence of numerous other barriers (both patient and staff related) to successful pain assessment further complicates matters.

Suggestions for overcoming barriers to pain assessment in patients with dementia have included knowing the person and using intuitive perception. It seems logical that in order to be able to interpret a patient's behaviour as indicative of pain, one needs to be familiar with that same patient's usual behaviour. It also makes good sense that in order to gain an appreciation of the various types of pain cues that exist, one needs to be exposed to a variety of patients with dementia who experience pain. However, it would seem that an emphasis on one of these ways of knowing would preclude the other. The question then, as Parke (1998) highlights, is how to delicately balance optimising opportunities for knowing the person with opportunities for knowing by diversity.

At the present time, one could argue that the current climate is more conducive to knowing by diversity than knowing the person. The increasing number of agency staff employed in aged care means that there are ample opportunities for staff to gain experience working with a wide range of patients but few for getting to know any one patient well enough to become familiar with that patient's usual habits and behaviour. Greater workforce stability is therefore required in order for staff to be able to know and consistently work with individual patients so that they can increase the success of the detection, assessment, and ultimately treatment of pain in the older adult with dementia. As Kovach et al. (2000) argue, not only is the consistent assignment of nurses to the same group of patients crucial for pain assessment, it also supports the case for reducing staff turnover rates in aged care facilities.

A significant barrier to successful pain assessment in older adults with dementia is the popular mistaken view that pain behaviours or complaints are synonymous with mental health needs. The consequences of this view are dire in that many older adults with dementia who experience pain are incorrectly administered antipsychotics rather than analgesics or other pain relief interventions. It is imperative that this attitude be challenged both at the staff and facility level so as to ensure duty of care requirements are met. This can be achieved through increased training and education regarding the signs and symptoms of pain in the dementia population.

It is apparent from the literature that many nurses already conduct informal pain assessments and use some of the behavioural cues identified above. It is also clear that perhaps the main reason pain assessment tools are not regularly used as part of standard practice is that existing tools are deficient. Better assessment of pain in the older adult with dementia is contingent on increased use of pain assessment tools, however this is itself dependent on the development of an adequate tool specifically designed for assessing pain in this population. The type of tool designed will determine whether clinical practice uses a standardized approach towards pain assessment or whether a more individualized approach is taken, one that accounts for each patient's unique circumstance and needs.

Much can be done to increase the success of pain assessments in the older adult with dementia. More extensive training and education regarding the relationship between pain and dementia is urgently needed, as is the development and

implementation of an effective pain assessment tool specifically designed for detecting and measuring pain in older adults with all stages of dementia.

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## Appendices

Complete appendices for this systematic review are available on the ACEBAC website at [www.latrobe.edu.au/acebac](http://www.latrobe.edu.au/acebac)