



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

MONOGRAPH



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

Review

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TABLE OF CONTENTS

Executive Summary	1
Introduction	3
Background.....	3
Objectives.....	4
Review Method	5
Criteria for considering studies for this review.....	5
Search strategy.....	5
Search terms.....	6
Critical appraisal.....	6
Data extraction.....	6
Data synthesis.....	7
Results	8
1. Barriers to successful pain assessment.....	8
2. Strategies for overcoming barriers to successful pain assessment.....	13
Discussion	18
Implications for Practice	23
Implications for Research	26
Conclusion	27
References	29

Executive Summary

Objectives

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

Method

A database search was conducted for literature relating specifically to barriers to pain assessment in older adults with a diagnosis of dementia and methods for overcoming these barriers. 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, an Expert Reference Group or third reviewer 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; inadequate assessment tools; restrictions imposed by nursing role; and the need for objective and sufficient evidence. Patient considerations included the subjective nature of pain; the possible existence of a 'no pain' subset of people with de-

mentia; 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; the use of existing data; and increasing diligence when working with this population.

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 the experience, assessment, and management of 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 in 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, Ferrell, & Rivera, 1995; Fuchs-Lacelle & Hadjistavropoulos, 2004; Kovach, Weissman, Griffie, Matson, & Muchka, 1999; Warden, Hurley, & Volicer, 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 abnormal 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 recognised in this population (Madjar & Higgins, 1996; Sengstaken & King, 1993), with analgesic administration found to occur less often for adults with dementia (Horgas & Tsai, 1998; Scherder & Bouma, 1997). Difficulties in 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 older adults with dementia and potential strategies that may be used to overcome these barriers to assessment.

The purpose of this review is, therefore, to investigate existing barriers to successful pain assessment in older adults with dementia and to identify some of the strategies that have been suggested in the literature as possible ways of overcoming these barriers.

Objectives

The initial aim of the systematic review *Assessment of Pain in Older Adults with Dementia in Acute, Sub Acute, and Residential Care* (Nay, Wilson, O'Donnell, McAuliffe, & Pitcher, 2006) was to review articles concerning, and present the best available evidence on, both the assessment and treatment of pain in this population. However, it soon became apparent that there was a need for a separate paper delineating the barriers and strategies associated with the assessment endeavour. This is the focus of the current paper.

Review Method

Criteria for considering studies for this review

Types of studies

Studies included in this review were (a) retrieved following a specific search for papers investigating barriers to pain assessment or (b) initially retrieved for the systematic review of Assessment of Pain in Older Adults with Dementia in Acute, Sub Acute, and Residential Care (Nay et al., 2006), but were referred to this paper due to their relevance to the topic of barriers to, and strategies for, successful pain assessment.

Types of participants

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

Types of issues of interest

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

Search strategy

The search strategy for the current review involved a search of published and unpublished literature in the English language over the period January 1993 – June 2005. Searches were performed using the following databases: CINAHL, Medline, PsycINFO, Ageline, Cochrane Library, Embase, APAIS Health, Current Contents Connect, Dissertation Abstracts International, and Social Sciences Citation Index.

The search strategy for the systematic review Assessment of Pain in Older Adults with Dementia in Acute, Sub Acute, and Residential Care (Nay et al., 2006) was conducted in three phases. It consisted of a search of published and unpublished literature in the English language over the period January 1993-June 2005.

The initial phase 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. A second more extensive search was performed 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. In addition, a comprehensive private collection of the literature surrounding pain in older persons with dementia or cognitive impairment spanning the last 20 years was also perused. Seminal works published outside of 1993-2005 referred to in the literature were also considered for inclusion in the systematic review.

Search terms

Search terms used for the current review were as follows: pain, dementia, assess*, barrier*, and obstacle*.

Search terms used for the systematic review included pain and dementia, in addition to assess?, pain measurement, elderly, advanced nursing practice, case management, evidence based practice, home health care, hospice, hospice palliative care, nursing, palliative, gerontologic, randomised control trial, residential care, nursing home, discomfort, cognitive impairment, analgesia.

Critical appraisal

All relevant studies identified were appraised for methodological quality by two independent reviewers in accordance with methods described in the Cochrane Reviewers' Handbook 4.2.2 (Alderson, Green, & Higgins, 2004). Appraisal was carried out for all studies using the checklists developed for the review. Critical appraisal focussed on sources of bias in the studies, including those found in selection, method, attrition and detection. 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). Qualitative studies were categorised according to the levels of evidence defined by the Joanna Briggs Institute (Joanna Briggs Institute [JBI], 2000). Where there was disagreement about inclusion or level of evidence, a third reviewer (for both reviews) or the Expert Reference Group (for the systematic review only) provided consensus.

Data extraction

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

Data synthesis

No RCTs were identified. Statistical data presented was from quasi-experimental studies with disparate goals, using a range of interventions and therefore pooling of data was not appropriate.

Results

Database searches for studies for the current review of barriers to, and strategies for, successful pain assessment in older adults with dementia yielded a total of 46 potentially relevant articles. These studies were sourced from the following databases: CINAHL (5), Medline (13), PsycINFO (5), 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, resulting in 20 articles retrieved for critical appraisal, of which 4 articles were deemed appropriate for inclusion in the current review. A further 6 articles excluded from the systematic review Assessment of Pain in Older Adults with Dementia in Acute, Sub Acute, and Residential Care (Nay et al., 2006) on the grounds that they focused on barriers to pain assessment, rather than on pain assessment per se, were also found suitable for inclusion. Overall, 10 articles were deemed appropriate for inclusion in the current review.

1. 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. All 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 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 the 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 behavioral change may be an instance of 'trained incapacity'. Habit was also identified as a barrier to pain detection and assessment; behavioral problems were 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.

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 regarding pain in elderly patients with dementia found that changes in behavior were sometimes attributed to a psychiatric problem rather than seen as indicating an unmet need. Even behaviors 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) lent further support to the notion that behavioral problems can act as a barrier to successful pain assessment in patients with dementia, finding that distinguishing between difficult behaviors and pain behaviors 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.

Lack of adequate assessment tools

The lack of adequate assessment tools for measuring pain is commonly referred to in the literature as an impediment to accurate pain assessment in patients with dementia.

Parke (1998) found behavioral measurement tools commonly used unsuitable measures, such as behaviors that required skills and knowledge outside the realm of that possessed by older adults with cognitive impairment.

Another criticism of pain assessment tools was made by Kovach et al. (2000) who suggested that behavioral assessments were not sensitive enough to detect the more subtle changes in patients with dementia reported by nurses.

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 Service centres, 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 behavior. 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 be used in a variety of settings.

The study of Madjar and Higgins (1996) further highlighted the problem of insufficient 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 a pain assessment tool was not part of usual clinical practice, with pain addressed neither systematically nor comprehensively. Even when pain was recorded in progress notes, details regarding pain intensity and qualitative and temporal information were found to be lacking.

The survey conducted by Allcock et al. (2002) found that 75% of nursing homes did not use a pain tool. The authors concluded that there was a need for more formal research for the development of assessment scales.

Restricted by nursing role

Cohen-Mansfield and Creedon (2002) found that one of the barriers to pain assessment associated with staff issues was the hierarchy that exists amongst nursing staff and the implications this has on the ability to act on pain if, and when, it is recognised in patients. Although behavioral changes indicative of pain were reported by nursing assistants, dealing with pain became more complicated as one moved up through the levels of command due to competing concerns related to such factors as risk of pain medication addiction. The authors suggest that charge nurses may give undue weight to diagnosis at the expense of pain assessment, which may in turn deter nursing assistants from reporting suspect pain and prevent its assessment.

Need for objective and sufficient evidence

The requirement that evidence conform to scientific research standards has been labelled by some authors as a barrier to the assessment of pain in older adults with dementia.

Parke (1998) observed that in order to assess pain in patients with dementia, nurses are required to obtain objective data in order to validate their assessments. The requirement to objectify assessments, she argues, hinders assessments that are made using "intuitive knowledge" (p.25).

Cohen-Mansfield and Creedon (2002) also identified the need for sufficient evidence as a barrier to pain assessment. The authors directed attention towards the necessity for behaviors to be repeated, and observed by the same caregiver, in order for them to be linked to suspected pain.

A study by Adams et al. (1997) suggested that both district and residential nurses may also overemphasize diagnosis when assessing for pain, with pre-exist-

ing condition rated by nurses as the most useful piece of knowledge facilitating assessment.

(b) Patient considerations

Subjective nature of pain

In addition to several of the barriers to pain assessment discussed above, Parke (1998) acknowledged that the subjective nature of the experience of pain was in itself an intrinsic factor. Findings of the study (details of which appear in section 2) indicated that pain cues are specific to each individual's experiences, raising the possibility that an individualized approach to pain assessment is perhaps more appropriate than a standardized approach.

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.

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 behavioral 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 Adams et al. (1997) in their survey of nurses' views regarding ways in which pain could be assessed in people with dementia. It was 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 behavioral 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.

2. Strategies for overcoming barriers to successful pain assessment

Several strategies have been proposed in the literature as means of overcoming some of the barriers described above.

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 behaviors, 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 recognise change and triggered pain assessment.

Kovach et al. (2000) conducted semi-structured interviews with 30 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 behavior (subtle changes only detectable by staff who work consistently with the same patient); and being aware of the possible symbolic message of behaviors (eg. exiting behavior 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 as to their perceptions of pain in the person for whom they cared. Thematic and categorical analysis revealed several themes, including that all carers claimed to be able to identify pain in the person for whom they cared, and that they did this by recognizing the even subtle deviations from normal behavior. 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 intuitive perception, or knowing by diversity. 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 people with dementia 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 behavioral symptoms such as anger, pulling away, changes in gait, crying, increased confusion, and decreased appetite. However, although these nurses had an average of 11 years' experience working with patients with dementia, received extensive education in pain management only 1 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.

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.

Kovach et al. (2000) contended that bias in observation may decrease, and pain recognition increase, if a pain assessment method is used that is both systematic and consistent.

Parke (1998) reviewed other studies and suggested that pain assessment tools are more useful if they are suited to a person's abilities, and that self-report is a valid means of obtaining pain information. Parke also noted that research is needed to determine the effect, if any, of possible external contributors such as type of pain (chronic or acute), the timing of assessments, or the context in which the pain assessments are conducted.

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.

Several of the nursing home managers who completed a questionnaire sent by Allcock et al. (2002) identified strategies for overcoming barriers to pain assessment caused by limited communication ability. These strategies included the use of aids, such as picture boards, and observation.

Use existing data

The utility of existing information regarding pain in the patient with dementia should not be overlooked.

Kovach et al. (2000) made several suggestions for improving pain recognition and assessment in older people with dementia. The authors called for a more detailed examination of the factors that influence nurses' assessment of pain, as well as an examination of factors related to accuracies and errors in pain detection.

Increase diligence

Several studies indicated that an increase in awareness and diligence may improve the likelihood of successful pain assessment in older adults with dementia.

The nursing staff interviewed and surveyed in the study of Cohen-Mansfield and Creedon (2002) were able to provide examples of late detection of pain in patients with dementia and expressed a view that not all nursing homes are diligent in providing care in a timely fashion to patients with dementia who are experiencing pain. This suggests that late detection of pain in patients with dementia can be minimised by increasing the level of diligence of nursing homes when caring for patients with dementia.

Cohen-Mansfield and Creedon (2002) and Adams et al. (1997) raised the possibility that type of pain experienced may in itself be a factor that hinders proper assessment. Increased diligence may therefore result in better detection of chronic pain, which has been found to be harder to assess than acute pain due to its relatively few outward manifestations.

The importance of awareness of pain was also highlighted by Alexander et al. (2005) in their pilot study of a structured program for routine pain assessment and

treatment that included as its setting a secure dementia long-term care unit. On the basis of their findings the authors concluded that an increase in awareness of pain may facilitate an improvement in the assessment and management of pain in long term care residents.

Discussion

This review of barriers to, and strategies for, the successful assessment of pain in patients with dementia has summarised the best available evidence published and unpublished over the period of 1993-2005. The findings of this review are generally considered to be of low level evidence according to the NHMRC criteria, indicating the need for more research in this area.

A total of 9 studies were included in this review. Of these, 3 were studies providing either level III.2 or level IV evidence according to the NHMRC criteria for quantitative research; 1 provided 'unequivocal' evidence according to the JBI criteria for qualitative research; and 5 provided 'credible' evidence according to the JBI criteria for qualitative research.

1. 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 behavior (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 behavioral 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 (a) the pain assessment process, and (b) signs and symptoms of discomfort in people with dementia.

Misdiagnosis or late diagnosis

Symptoms associated with pain in dementia are often misinterpreted, resulting in misdiagnosis and/or late diagnosis of pain. Behavioral 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). Behavioral changes exhibited by patients with dementia are also frequently labelled as difficult behaviors rather than pain behaviors (Cohen-Mansfield & Creedon, 2002).

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 behavioral 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).

Need for objective and sufficient 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 behaviors to be repeated and observed by the same caregiver in order for pain to be suspected.

(b) Patient Considerations

Subjective nature of pain

The subjectivity involved in the experience of pain was noted in one study (Parke, 1998), the findings of which indicated that pain cues are individual specific, and that an individual rather than a standardized approach should be adopted when assessing for pain.

Possible subset of people with dementia who experience pain to a lesser extent

One study extended the observation that patients with dementia report pain less often by suggesting that at least some patients with dementia' actual experience of pain differs from those who are cognitively intact (Fisher-Morris & Gellatly, 1997). Two cases and findings from a small scale survey indicated that there may exist 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.

Restricted by nursing role

Chain of command of nursing staff was seen by some as hindering the pain assessment process, with nursing assistants reporting pain more so than higher staff, who were required to balance pain needs with medication addiction concerns (Madjar & Higgins, 1996). The overemphasis that higher staff place on diagnosis when making pain assessments was also identified as a possible barrier to accurate pain assessment in patients with dementia (Adams et al., 1997; Madjar & Higgins).

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 older adult with dementia.

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).

2. 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 in 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 recognise 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 behavioral as well as other more subtle indicators of pain (Cohen-Mansfield & Creedon, 2002). Education should include delineating between behavioral 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 behavioral 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 behavioral 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).

Use existing data

It has been suggested in the literature that a good starting point to improving pain recognition and assessment in older people with dementia is to closely examine the factors surrounding nurses' assessment of pain, both accurate and otherwise. Refining, articulating, and clustering nurses' current observations of pain cues may prove useful in overcoming some of the impediments to pain assessment and measurement in the cognitively impaired (Kovach et al., 2000). It may also be use-

ful to further investigate what nurses perceive to be the barriers to pain assessment in patients with dementia.

Increase diligence

One obvious yet important strategy suggested for better pain detection in the dementia patient is to raise the level of awareness of pain and its associated cues in this population (Alexander et al., 2005). Increased diligence has been proposed as a way of minimizing the incidence of misdiagnosis or late diagnosis of pain in patients with dementia (Cohen-Mansfield & Creedon, 2002), and may lead to better detection of chronic pain, the diagnosis of which is currently often elusive.

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, lack of adequate pain assessment tools, restrictions that are imposed by the nursing role, and a need for evidence to be objective and sufficient. Patient considerations that can be regarded as barriers to effective pain assessment in the cognitively impaired include the subjective nature of pain, 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, adequate tools, the use of existing data, and increased diligence on the part of care providers. 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 according to the NHMRC and JBI criteria:

Studies identified in this review were categorised according to the strength of evidence using the following scale (2):

Level I	Evidence obtained from a systematic review of all relevant RCTs.
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 for 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

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.

level III.2 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 behavior 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

Increased and improved training and education are key steps toward greater detection and assessment of pain in older adults with dementia.

credible evidence

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 assessments in the older adult with dementia should be conducted using a method that is both systematic and consistent.

credible evidence

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

credible evidence

Self-report is a valid means of obtaining pain information.

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.

level III.2 evidence

Conducting baseline assessment is important for discerning patient changes.

level III.2 evidence

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

level III.2 evidence

Assessing for pain in those with limited verbal communication ability can be achieved by employing the use of picture boards, and through writing and observation.

credible evidence

Use existing data

Factors that influence the assessment of pain should be examined in greater detail, as should reasons for accurate and erroneous assessments.

credible evidence

Increase diligence

Level of diligence of nursing homes should be increased in order to minimise late detection of pain in patients with dementia.

credible evidence

Implications for Research

A number of barriers to successful pain assessment in older adults with dementia have been identified in this paper, as have several strategies for overcoming such barriers. 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: (a) 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; (b) factors surrounding nurses' current recognition and assessment of pain, including pain cues, and their frequency of use; (c) factors associated with accurate and inaccurate assessment; (d) the extent to which pain is documented, and the relationship between good documentation and accurate initial and continuing assessment; (e) the need for certain properties of pain to be included in pain assessment tools (e.g., intensity, location, quality, etc.); (f) 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.

Although the current paper has reviewed studies relevant to a discussion of barriers to, and strategies for, successful pain assessment in older adults with dementia, it is important to reiterate that this review is not exhaustive. It is therefore probable that a systematic review of the literature would yield further studies, the results of which may inform of additional barriers and strategies not outlined in this paper.

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, and 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 behavior as indicative of pain, one needs to be familiar with that same patient's usual behavior. 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 person well enough to become familiar with that individual's usual habits and behavior. Greater workforce stability is therefore required in order for staff to be able to know and consistently work with individuals 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 individuals 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 behaviors 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 behavioral 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 individual'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.

References

- Abbey, J., Piller, N., De Bellis, A., Esterman, A., Parker, D., Giles, L. et al. (2004). The Abbey pain scale: A 1-minute numerical indicator for people with end-stage dementia. *International Journal of Palliative Nursing*, 10(1), 6-13.
- Adams, A., Goldman, H., & Ferguson, A. (1997). A study to examine how nurses assess pain in people with dementia. *ACCNS: Journal for Community Nurses*, 2(1), 20-23.
- Alderson, P., Green, S., & Higgins, J. P. T. (Eds) (2004). *Cochrane reviewer's handbook 4.2.2 [updated March 2004]*. In *The Cochrane Library*, Issue 1, 2004. Chichester, U.K.: John Wiley & Sons, Ltd.
- Alexander, B. J., Plank, P., Carlson, M. B., Hanson, P., Picken, K., & Schwebke, K. (2005). Methods of pain assessment in residents of long-term care facilities: A pilot study. *Journal of the American Medical Directors Association*, 6, 137-143.
- Allcock, N., McGarry, J., & Elkan, R. (2002). Management of pain in older people within the nursing home: A preliminary study. *Health and Social Care in the Community*, 10(6), 464-471.
- Cohen-Mansfield, J., & Creedon, M. (2002). Nursing staff members' perceptions of pain indicators in persons with severe dementia. *The Clinical Journal of Pain*, 18, 64-73.
- Falls, D., & Stevens, J. (2004). Carers' perceptions of pain in people with dementia: A grounded theory approach. *The Australian Journal of Holistic Nursing*, 11(2), 4-11.
- Ferrell, B., Ferrell, B., & Rivera, L. (1995). Pain in cognitively impaired nursing home patients. *Journal of Pain and Symptom Management*, 10(8), 591-598.
- Fisher-Morris, M., & Gellatly, A. (1997). The experience and expression of pain in Alzheimer patients. *Age and Ageing*, 26, 497-500.
- Fuchs-Lacelle, S., & Hadjistavropoulos, T. (2004). Development and preliminary validation of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC). *Pain Management Nursing*, 5(1), 37-49.
- Horgas, A. L., & Tsai, P. (1998). Analgesic drug prescription and use in cognitively impaired nursing home residents. *Nursing Research*, 47(4), 235-242.
- Joanna Briggs Institute (2000). *Consultant reviewer manual*. Adelaide, S.A.: National Library of Australia.

Kovach, C. R., Griffie, J., Muchka, S., Noonan, P. E., & Weissman, D. E. (2000). Nurses' perceptions of pain assessment and treatment in the cognitively impaired elderly: It's not a guessing game. *Clinical Nurse Specialist*, 14(5), 215-220.

Kovach, C., Weissman, D., Griffie, J., Matson, S., & Muchka, S. (1999). Assessment and treatment of discomfort for people with late-stage dementia. *Journal of Pain and Symptom Management*, 18(6), 412-419.

Madjar, I., & Higgins, I. J. (1996, August). The adequacy of pain relief measures in elderly nursing home residents. Paper presented at the 8th World Congress on Pain, Vancouver, Canada.

National Health and Medical Research Council (1999). A guide to the development, implementation, and evaluation of clinical practice guidelines. Canberra.

Parke, B. (1998). Gerontological nurses' ways of knowing: Realizing the presence of pain in cognitively impaired older adults. *Journal of Gerontological Nursing*, 24(6), 21-28.

Scherder, E. J. A., & Bouma, A. (1997). Is decreased use of analgesics in Alzheimer disease due to a change in the affective component of pain? *Alzheimer Disease and Associated Disorders*, 11(3), 171-174.

Sengstaken, E. A., & King, S. A. (1993). The problems of pain and its detection among geriatric nursing home residents. *Journal of the American Geriatrics Society*, 41, 541-544.

Warden, V., Hurley, A. C., & Volicer, L. (2003). Development and psychometric evaluation of the Pain Assessment In Advanced Dementia (PAINAD) scale. *Journal of the American Medical Directors Association*, 4, 9-15.

Weiner, D. K., & Hanlon, J. T. (2001). Pain in nursing home residents: Management strategies. *Drugs and Ageing*, 18(1), 13-29.

Wilson, J., Nay, R., O'Donnell, M., McAuliffe, L., & Pitcher, A. (2006). Assessment of pain in older adults with dementia in acute, sub acute, and residential care: Systematic review. Manuscript submitted for publication, Australian Centre for Evidence Based Aged Care, Melbourne, Victoria, Australia.