

Title: Palliative Care in Dementia: Literature review of nurses' knowledge and attitudes towards pain assessment.

Acknowledgements

A small grant for this research project was obtained from Macmillan Cancer Relief.

Abstract

Background: Pain is prevalent among older people, yet is often under recognised and under treated in people with dementia. The nurse has a central role in identifying and appropriately assessing pain in order to provide effective treatment. Research however suggests there are significant deficits in this area.

Aim: To explore the evidence on nurses' knowledge and attitudes to pain assessment in older people with dementia.

Design: A systematic review of peer reviewed articles published between 2000 and 2014.

Data Sources: Seven electronic data bases (CINAHL, MEDLINE, PsycInfo, Wiley, Pubmed, ProQuest and OVID) were searched and articles focusing on nurses knowledge and attitudes on pain assessment towards people with dementia.

Methods: Research participants within the studies reviewed were to include registered nurses involved in the assessment and management of pain in older adults with dementia from across all health care settings (e.g. dementia units, nursing homes, community and acute settings).

Results: Data were systematically analysed from 11 papers. Using an inductive approach for thematic content analysis informed by the theory of planned behaviour five themes was identified. These included: 1) Challenges in diagnosing pain in dementia 2) Inadequacies of pain assessment tools 3) Time constraints and workload pressures 4) Lack of interdisciplinary teamwork and communication 5) Training and education.

Conclusion: Nurses play a key role in the effective management of pain through the use of pain assessment tools, behavioural observation, and analgesic choice. Pain assessment in dementia remains challenging for nurses due to the complexity and individualisation of pain behaviours. The accessibility of appropriate training, workforce stability and a standardised approach to pain assessment are key to the successful management of pain in older people with dementia.

Keywords: pain assessment, dementia, palliative care, older people, knowledge and attitudes

Introduction

Over the next 40 years, it is anticipated that globally the number of dependent older people will increase from 101 million in 2010 to 277 million by the year 2050. Of these approximately 50% will experience some form of dementia (Alzheimer's Disease International, 2013). Within the UK there has been a significant shift in health and social care services from hospital to community informed by policy following local strategic reform in order to provide an equitable service (DHSSPSNI, 2011; DOH, 2012). This presents challenges for long-term and community care settings not only due to the increasing prevalence of the older people but also and the existence of co-morbidities (European Commission of Health, 2013). Dementia is a life limiting disease (Neale et al, 2001), which requires a palliative care approach to improve quality of life and person centered care (Van der Steen et al, 2013). Palliative care in dementia remains challenging due to the unpredictability of prognosis and disease trajectory (Murray et al, 2005; Zanetti et al, 2009). Furthermore, the behavioural and psychological symptoms associated with dementia can lead to significant difficulties in providing effective symptom management (Husebo et al, 2011).

Background

Pain is highly prevalent among older people (Horgas et al, 2008; Pautex et al, 2005; Leoang and Nuo, 2007; Asghari et al, 2006). However it is often not recognised and under treated in people with dementia (Husebo et al, 2008; Reynolds et al, 2008; Closs et al, 2004) with people losing the ability to self-report pain (Herr et al, 2006). The nurse has a central role in identifying and appropriately assessing pain in order to provide effective treatment (Buchanan et al, 2014). This requires nurses to have sufficient knowledge and skills, however research suggests there are deficits in this area (Barry et al, 2013; Barry et al, 2012; Zwakhalen et al, 2007; Jones et al, 2004). The purpose of this literature review is to explore and evaluate the evidence on the knowledge and attitudes of registered nurses towards pain assessment in older people with dementia.

There are numerous definitions of pain that collectively suggest that it is a complex phenomenon, which presents as an unpleasant sensory experience that is uniquely individual (Merskey and Bogduk, 1994; McCaffery et al; 1990; Bonica; 1990). It cannot be adequately defined, identified, or measured by the observer due to the subjectivity of the experience. Therefore pain has often been defined as 'pain is what the patient says hurts' (Forbes and Faull, 1998). Pain that is ineffectively treated has the potential to cause psychological responses such as fear, anxiety and depression. It can also affect activities of

daily living such as mobility, appetite and sleep. According to Riva et al (2011), unrelieved pain can result in an individual experiencing distressing cognitive impairment, such as disorientation, mental confusion and a reduced ability to concentrate. For individuals with existing cognitive impairment such as dementia, the experience of pain can manifest into behavioural disturbances such as agitation and aggression (Cohen-Mansfield, 2005). This can lead to increased distress not only for the individual but also for their care givers (Husebo et al, 2008; Hennings et al, 2010). According to Nygaard and Jarland (2005), pain in people with dementia can often be undetected, leading to anti-psychotic drug use being first line for the management of agitation (Husebo et al, 2011). Therefore it can be argued that the overall effective management of undiagnosed pain can reduce behavioural disturbances and distress (Ahn and Horgas, 2013; Husebo et al, 2011; Calvin, 2011).

Pain assessment in people with dementia is particularly challenging due to the difficulty for the individual remembering their pain, interpreting the question and maintaining information (Scherder et al, 2005; Cohen-Mansfield, 2005). Therefore assessment of pain in dementia largely relies on emotional and behavioural observation (Monroe et al, 2012). There are a number of tools available for the assessment of pain in dementia (Lin et al, 2011; Morello et al, 2007), but the quality and utility of these tools have been widely debated (Cohen-Mansfield, 2014; Fuchs-Lacelle et al, 2008; Buffum et al; 2007).

Nurses have an overall responsibility to ensure that individuals experiencing pain are adequately assessed and effectively managed. They have a key role not only in the provision of individualised and holistic care, offering treatment options based on pain assessment and ensuring review of treatment interventions, but also acting as patient advocates in co-ordinating effective pain management. Whilst there are many studies examining nurses' knowledge and attitudes towards pain in older people in general, few studies have focused specifically on pain for people with dementia (Barry et al, 2013; Barry et al, 2012; Zwakhalen et al, 2007; Jones et al, 2004).

Conceptual Framework –Theory of Planned Behaviour

The theory of planned behaviour has been widely used in health care as it offers a clear theoretical model in order to predict an individual's behaviour; with beliefs, perceived behavioural control and subjective norms being influential factors. Perceived control is an

individual's perception of how easy or difficult it is to perform certain behavior (Ajzen, 1985; 1988) which can be influenced by internal factors (i.e skills, information, ability, knowledge) and external factors (barriers, opportunities, dependence on others). The TPB identifies that perceived behavioural control has both an indirect effect through behavioural intentions, and a direct effect on behaviour.

The TPB proposes that positive behavioural change occurs when intentions are changed through either behaviour, subjective norms or perceived control. **The TPB is a promising theoretical framework for the study of identifying nurses' knowledge and attitudes to pain in dementia as it includes beliefs about control factors which may influence or inhibit the performance of effective pain assessment.** Perceived behavioural control is an important factor in the intention to pain assessment. If nurses perceive pain assessment as difficult to do, intention will be low. The major themes identified in this review are displayed in the context of this model which includes (figure 1): 1) Challenges in diagnosing pain in dementia 2) Inadequacies of pain assessment tools 3) Time constraints and workload pressures, 4) Lack of interdisciplinary teamwork and communication 5) Training and education. These factors are discussed further in the literature review.

Please insert Figure 1 here

Methods

A systematic review, defined by Fink (2005) as a method of identifying, evaluating and synthesising existing research, was employed to explore the evidence on nurse's knowledge and attitudes to pain assessment towards people with dementia.

The literature search was conducted on seven databases CINAHL, MEDLINE, PsycInfo, Wiley, Pubmed, ProQuest and OVID databases. Key words and search terms were refined to include pain, assessment, dementia, knowledge and attitudes. The search range included relevant studies available from 2000-2014.

The search strategy applied strict criteria and papers were included if they met the following criteria: 1) peer reviewed 2) published between 2000-2014 3) study participants included nurses involved in the assessment and management of pain in older adults with dementia 3) Located across all health care settings i.e. dementia units, nursing homes, community and

acute settings 4) original research that explored knowledge and attitudes to the assessment and management of pain in dementia. Studies published prior to 2000, studies focusing on pain assessment tools, research dissertations and papers in languages other than English were excluded from the search.

A total of 128 records were retrieved from the initial database search with the majority of studies focusing on the quality and utilisation of pain assessment tools. The identified literature was peer reviewed for consensus on the relevance of the articles for inclusion and exclusion in the review: A total of 28 potentially relevant articles were retrieved following a search of the research databases. These results included cross sectional surveys, exploratory studies, concept analysis, training needs analysis, and randomised control trials. Results were as follows: CINAHL (11), Psycinfo (2), OVID (2), ProQuest (9), Wiley (0), Cochrane (0), and Citations (2) (See figure 2). Duplication of papers was noted and eliminated in the search. Following the inclusion criteria 11 papers were included in the review with the majority being qualitative research designs.

Please insert Figure 2 here

Findings

A summary of all the main findings of the studies included in the review are outlined in table 1. Overall sample size varied for each study depending upon the research design i.e sample size varied from 7 to 244 registered nurses. The majority of the review consisted of Canadian, Australian and American papers published between 2000-2007; however since then, European studies have emerged and appear to be leading the way in recent studies.

Please insert Table 1

Relevant data were extracted by one researcher and was systematically reviewed using thematic summaries drawing from the theory of planned behaviour as a conceptual framework. The studies were synthesised using tabulation of the findings into a thematic framework informed by the theory of planned behaviour. Findings from each study were categorised into attitudes, subject norm and perceived behavioural control. This allowed for the analysis and divergence of findings into each theme. Using this methodology five themes were identified.

Challenges in diagnosing pain in dementia

A large proportion of older people with dementia experience pain (Horgas et al, 2008; Pautex et al, 2005; Leoang and Nuo, 2007; Asghari et al, 2006) but this is often undertreated. Some reasons for this include difficulty in identifying pain in cognitively impaired people due to unaltered, unrecognised or unacknowledged responses to pain (Neville et al, 2006; Chang et al, 2009). Evidence from the literature suggests that nurses recognise that pain is highly prevalent in older people and highlight the difficulty in identifying and assessing pain in dementia (Barry et al, 2012). Kaasalainen et al (2007) in a focus group study in Canadian long term care facilities found that nurses and physicians identified that an underassessment of pain in dementia was often due to the assumption that the absence of reported pain meant the absence of pain itself. The identification of pain for people with dementia mainly relies on nurses' observation and clinical judgment in the effective assessment and management of pain. Kovach et al (2000) found that nurses working in long term care facilities in the USA, who had undertaken a pain education programme one year previously, considered the identification and assessment of pain in dementia as a guessing game. However, Chang et al (2011), in an qualitative study of nursing home nurses in South Korea (n=13), found that pain identification in people with dementia relied largely on nurses' individual intuition, developed through clinical experience in working with people with dementia. Cohen-Mansfield and Creedon (2002) examining nurses' perception of pain indicators in dementia, found that nurses who worked consistently with cognitively impaired patients were able to identify pain through behavioural responses- whilst junior and less experienced members of staff were less likely to recognise this. Therefore, it can be suggested that nurses' knowledge of their patient's habits and behavioural patterns are essential in determining pain experience in dementia (Chang et al, 2011; Cohen Mansfield and Creedon, 2002; Blomqvist and Hallberg, 2001).

There was general consensus throughout the literature that diagnosing pain in dementia is difficult largely due to individuals' inability to self-report pain. Nurses acknowledged that pain identification in dementia largely relied on behavioural observation (Brorson et al, 2014, Chang et al, 2011; Cohen Mansfield and Creedon, 2002; Blomqvist and Hallberg, 2001). They expressed a lack of confidence in determining behavioural disturbances as part of an individual's dementia or as a response to pain. Chang et al (2011) identified that nurses working in nursing homes had a lack of confidence in distinguishing between pain and other problems such as delirium in dementia (Martin et al, 2005; Cohen Mansfield and Creedon;

2002; Kovach et al, 2000). Pain is therefore often mistaken for psychiatric problems leading to the potential inappropriate of treatment – with psychotropic drug use being the first line treatment response (Cohen-Mansfield and Creedon; Kovach et al, 2000).

Inadequacies of pain assessment tools

Pain assessment in individuals with cognitive impairment relied on behavioural observation, and the use of standardized instruments for pain measurement the absence or presence of physiological changes. This required nurses to have sufficient knowledge regarding pain identification for people with dementia, alongside the use appropriate pain assessment tools. It was found that the majority of nurses identified that traditional pain assessment models could not be used in people with dementia (Chang et al, 2009). However, Kaasalainene et al (2007) found inadequacies in the use of pain assessment tools in practice. Martin et al (2005) in Canadian study exploring nurses' perspectives of the management of pain in dementia found that nurses expressed the need for better and more accessible pain assessment tools particularly for people with severe dementia.

Communication and Interdisciplinary Teamwork

Effective communication between nurses and physicians was noted as essential for effective treatment of pain (Martin et al, 2005). Communication and trust between nurse and physician was considered paramount in the management of pain in dementia (Kaasalainene et al, 2007; Martin et al, 2005). Kaasalainene et al (2007) explored the attitudes affecting decision making in pain management for people with dementia in long term care facilities. They found that GPs had a lack of trust in the pain assessment skills of nurses with poor communication skills. This lack of trust in the assessment skills of nurses led to a reluctance by physicians to prescribe appropriate analgesia, which ultimately inhibited optimal pain treatments. It was noted in the literature, that some nurses described feelings of powerlessness in the management of pain in people with dementia (Blomqvist and Hallberg, 2001; Brorson et al, 2014). **Brorson et al (2014) in an interview of hospital nurses caring for patients with dementia at end of life (n=7) found that nurses described feelings of frustration due to physician's lack of trust about their pain assessment skills, even though the nurses felt that they had the knowledge and skills to discuss pain management with the physician.** This study has a relatively small sample size in one hospital unit which may not represent the opinions of the general population. However, a similar finding was highlighted by Blomqvist and Hallberg (2001), in a focus group study (n=24), identifying the challenges of caring for

people with advanced dementia. They found that an overall feeling of powerlessness made nurses less likely to ask questions about pain.

Time constraints and workload pressure

High staff workloads, staff shortages, and time constraints are emergent themes throughout the literature as nurses' perceived barriers to effective pain assessment (Martin et al, 2005; Barry et al, 2012; Kaasalainene et al, 2007). Nurses were aware of the importance of pain identification in dementia (Chang et al, 2009) but felt that they have a limited amount of time to accurately assess pain and review treatment (Martin et al, 2005). Time constraints and work pressures led to lack of continuity between shifts, poor knowledge transfer between healthcare professionals and a lack of interdisciplinary teamwork (Kaasalainene et al, 2007).

Training and Education

Nurses recognised the importance of having a sound knowledge of pain assessment, analgesic choice and side effects (Chang et al, 2011). However misdiagnosing pain, over medicating patients, analgesic side effects and risk of addiction remained an utmost concern to nurses (Neville et al, 2006; Zwakhalen et al, 2007; Barry et al, 2012; Kaasalainene et al, 2007; Chang et al, 2009; Brorson, 2014). In the studies focusing on education needs, nurses identified their own need for further education and training in the assessment and management of pain in dementia (Neville et al, 2006; Kaasalainene et al, 2007). Following a regional training needs analysis of nurses (n=197) caring for people with dementia in the aged care facilities in Australia, Neville et al (2006) found that approximately 53% considered their knowledge in the assessment and management of pain was average-identifying a lack of availability and appropriateness of pain education programmes. According to Zwakhalen (2007), in a cross sectional survey examining nursing home nurses knowledge and attitudes to pain assessment in the Netherlands (n=123), it was found that whilst the care was considered as 'satisfactory' there were knowledge deficits with regards to pain assessment. It is important to note, however, that this was a relatively small sample drawn from two nursing homes.

Discussion

Throughout the literature it has been highlighted that nurses play a key role in the management of pain for people with dementia. However, lack of knowledge, training and

increased workload pressures has been identified as barriers to effective pain management (Neville et al, 2006; Martin et al, 2005; Kaasalainene et al, 2007; Zwakhalen, 2007). Diagnosing pain in people with dementia, using the most appropriate pain assessment tool, and interdisciplinary communication remains an utmost concern to nurses (Blomqvist and Hallberg, 2001; Barry et al, 2012; Brorson et al, 2014).

It is apparent that nurses are aware of the importance of recognising behavioural cues when assessing and identifying pain for people with dementia (Brorson et al, 2014, Chang et al, 2011; Cohen Mansfield and Creedon, 2002; Blomqvist and Hallberg, 2001). However nurses lack confidence in diagnosing pain as an indication of their behavioural disturbances (Chang et al, 2011). As a consequence, the treatment of pain in people with dementia is often misdirected – with anti-psychotics being used as first line treatment (Cohen-Mansfield and Creedon 2014; Kovach et al, 2000). It is imperative that nurses gain confidence in distinguishing pain as part of a distress reaction in people with dementia. This can be achieved through the facilitation of education programmes focusing on the signs and symptoms of pain, and treatment options in individuals with cognitive impairment (Neville et al, 2006).

It is also noted that pain assessment tools are not regularly used in practice as they are considered insufficient for an accurate assessment (Kaasalainene et al, 2007). Better assessment requires the use of an adequate pain assessment tool specially designed for pain in dementia (Martin et al, 2005). There are a number of tools available for pain assessment in dementia (Lin et al, 2011; Morello et al, 2007), despite the fact the quality and utility of these tools have been widely debated (Cohen-Mansfield, 2014; Fuchs-Lacelle et al, 2008; Buffum et al; 2007). There is now a wealth of choice of validated tools available depending upon the needs of the individual. Difficulties arise regarding the evidence base for their use in practice.

Several studies highlighted the importance of familiarity of the person when conducting an accurate pain assessment for people with dementia (Chang et al, 2011; Cohen-Mansfield and Creedon, 2002; Blomqvist and Hallberg, 2001). For experienced nurses who consistently cared for individuals with dementia, behavioural cues and mood changes which indicate pain were more detectable and easier to assess. It has been suggested, however, that staff shortages and workload pressures have diminished continuity and familiarity when caring for the same individuals (Martin et al, 2005; Kaasalainene et al, 2007; Barry et al, 2012). This

has implications on the overall quality of care. Greater workforce stability is required in order to provide continuity of care and increase the likelihood of successful pain detection and assessment.

Effective communication and trust between nurse and physician was considered paramount in the management of pain in dementia (Martin et al, 2005). However, due to poor communication, the clinical skills and decision making of some nurses in relation to pain assessment has been deemed questionable by some physicians leading to inadequate patient treatment (Kaasalainene et al, 2007; Brorson et al, 2014). Good communication and interdisciplinary teamwork is required to provide integrated holistic care and effective pain management. This highlights the need for better co-ordination and communication of patient care. The use of communication templates specifically focusing on pain assessment, and interdisciplinary flow charts is recommended to help improve multidisciplinary collaboration (Kaasalainene et al, 2007).

Limitations

It must also be highlighted that the majority of studies in this review focused on long term care settings which may not represent the perceptions of nurses in other healthcare settings. However, this review systematically examined nurses' knowledge and attitudes towards pain assessment for people with dementia and demonstrated general consensus within the literature.

Conclusions and Implications for Practice

This review highlighted that pain assessment in dementia is challenging for nurses due to individuals inability to self-report pain. Nurses recognised that they cannot rely on traditional models of pain assessment in dementia; instead they must consider pain indicators such as changes in mood and behaviour to provide an accurate assessment. Promoting patient comfort, ensuring optimal pain treatment, and limiting analgesic side effects remains the utmost concern to nurses caring for people with dementia. The literature identified knowledge deficits for nurses in the identification, diagnosis and treatment of pain in dementia. Nurses can be indecisive when distinguishing between pain and other problems such as delirium as part of behavioural disturbances in dementia - often resulting in the misdirection of treatment. This review also revealed that lack of training, poor interdisciplinary communication and workload pressures are perceived barriers to effective

pain assessment. Therefore there is a need to develop pain education programmes specifically designed for nurses caring for older people with dementia in order to improve knowledge in the effective assessment and management of pain. In order to achieve success, it is recommended that the strategies such as in-service training programmes, educational facilitators, communication templates and pain management guidelines are investigated further and adopted in clinical practice. This review also suggests that the theory of planned behaviour may be useful in identifying the determinants of nurses' knowledge and attitudes to pain assessment in dementia, and can assist in the development of strategies to address the identified barriers.

Implications for future research

Further research is required focusing on the strategies identified in improving nurses' knowledge and attitudes to pain assessment in dementia. In particular, research is required to focus on the evaluation and accessibility of current pain education programmes for nurses in relation to the care of people with dementia- with comparative studies on accessibility of education across healthcare sectors. Further research is also required to examine the practical concerns relating to the interpretation and clinical use of pain assessment tools for people with dementia in dementia – with a particular focus on providing guidance for nurses.

Word count (3,962)

Conflict of Interests

There has been no conflict of interests throughout the development of this review.

List of figures

Figure 1: Conceptual Overview of nurses' knowledge and attitudes to pain assessment towards people with dementia based on Theory of Planned Behaviour

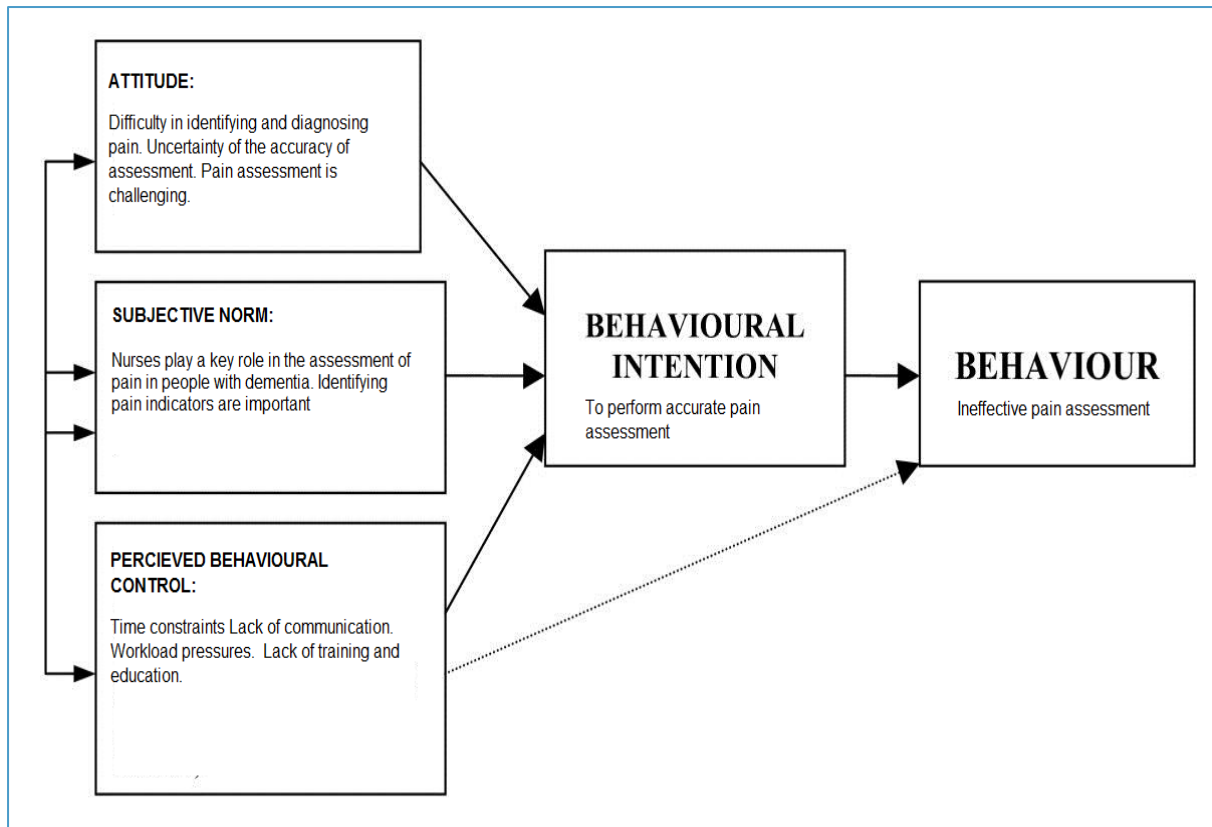
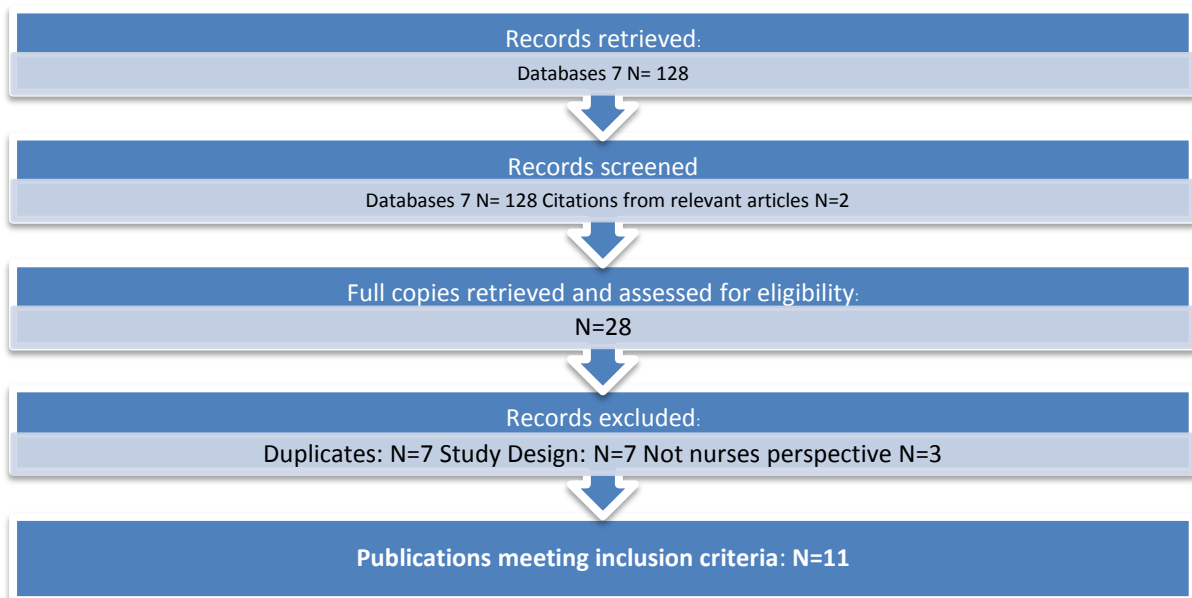


Figure 2: Search Strategy



Author	Aim of Study	Design	Sample	Key Findings	Limitations	Location
Barry, H. E., Parsons, C., Passmore, P. A., Hughes, C. M	To explore the knowledge, attitudes and beliefs of nursing home managers in relation to pain in residents with dementia.	Cross sectional survey	Purposive sample. 244 nursing home managers in Northern Ireland	<ul style="list-style-type: none"> • The majority of nurse managers felt that dementia can affect the physiological processing of pain. More experienced nurses disagreed that pain is a natural consequence of aging. Nurse Managers recognised the difficulty of identifying pain in dementia. Respondents were unsure if pain assessment tools used in cognitively intact residents could be used in residents with dementia. Nearly all respondents recognised the importance of considering residents behaviour when assessing pain. Nurse Managers less certain about how pain should be managed, respondents unsure about the safety of opioid use. • The most common barriers to pain management were obtaining an accurate pain assessment, lack of knowledge or education and lack of a standardised approach to pain management. • Poor staffing levels and lack of time to assess and lack of general understanding from GPs also identified. 	Low response rate (39%) affecting external validity. Social desirability of nurses responses may show bias	Northern Ireland

<p>Zwakhalen, S Jan P H , Peijnenburg, Rieneke H A , Berger, Martijn P F</p>	<p>To explore knowledge and beliefs of nursing staff regarding pain in elderly patients with dementia</p>	<p>Cross sectional survey</p>	<p>Convenience sample. 123 staff members of psychogeriatric wards in two nursing homes in the Netherlands</p>	<ul style="list-style-type: none"> • The majority of nursing home staff felt that pain was being correctly assessed and treated in residents with dementia. The majority of respondents had uncertainty about the treatment of pain in people with dementia including the side effects of medication and the risk of addiction. • There was a lack of consensus that pain is part of the aging process and that elderly people were more likely to be affected by pain than younger people. 	<p>Relatively small group for comparisons (n=20 and n=25), and study was only sampling 2 nursing homes in the Netherlands - limiting the generalizability of the study. Social desirability of nurses' responses may have shown bias.</p>	<p>Netherlands</p>
<p>Neville, C., Mc Carthy, A. and Laurent, K.</p>	<p>To identify a needs analysis of the management skills of regional nurses caring for older people with dementia.</p>	<p>Exploratory Survey</p>	<p>Convenience sample. 197 nurses working within 13 aged care facilities</p>	<ul style="list-style-type: none"> • The majority of respondents believed that older people with dementia do experience pain; and they also felt that people with dementia verbalise at least some pain to indicate that there pain management is ineffective. • 17% of respondents felt that patients experiencing 'a lot of pain' are necessary before delivering pain medication. • Nurses were asked to rate their knowledge of pain assessment and management in dementia - 52% felt that their knowledge was average. • 66% respondents were not aware of any of any formal training. • The analysis indicated that nurses in this setting might not have the knowledge base to manage pain effectively; and that respondents have essentially negative perceptions of the availability and appropriateness of current pain management education programs 	<p>Low response rate of 47% affecting external validity. Social desirability of nurse responses may show bias.</p>	<p>Australia</p>

<p>Kaasalainene, S., Coker, E., Dolovich, L., Papaioannou, A. Hadjistavropoulous, T., Emili, A. and Ploeg, J.</p>	<p>To explore attitudes and beliefs that affect decisions about prescribing and administering pain medications in older adults with dementia.</p>	<p>Qualitative using focus groups</p>	<p>Stratified random sample. 4 long term care facilities. 3 separate focus groups LTC Physicians, RPNs and RNs</p>	<ul style="list-style-type: none"> • There is a lack of confidence in the assessment of pain due to inability to distinguishing between pain and other problems such as delirium in people with dementia. It also identified inadequacies in the use of current pain assessment tools in practice. • There's uncertainty in the cause of patients behaviour during assessments often resulting in pragmatic and experimental approach to treatments. Nurses and physicians identified that an underassessment of pain in dementia often due to the assumption that the absence of pain reports in people with dementia means the absence of pain. • They also felt that older people are often reluctant to report pain as it is considered an expected consequence of ageing or have fears that reporting pain will be seen as an annoyance for staff– therefore unless residents report their pain it is likely to go unnoticed. Managing pain medication side effects was an utmost concern for nurses. They acknowledge that patient comfort is essential but were concerned with overmedicating residents. • GPs need to rely on nurses on the monitoring and evaluation of the effectiveness of pain medication but lack of trust and respect for the nurses clinical skill and decision making ability had been identified in nurses with poor communication skills. Ineffective communication and lack of time identified as barriers to effective pain management. 	<p>Respondents can feel peer pressure to give similar answers to the moderator's questions in interviews.</p>	<p>Canada</p>
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<p>Chang, Sung OK; Oh, Younje; Park, Eun Young; Kim Geun Myun; Kil Suk Young</p>	<p>To develop a conceptual structure of pain in demented patients.</p>	<p>Concept analysis</p>	<p>Purposive sample.</p> <p>Interview of nurses (n=13) in 3 nursing homes.</p>	<ul style="list-style-type: none"> • Pain identification in people with dementia largely relies on nurses' individual intuition which is developed through clinical experience in working with people with dementia. • Pain identification in dementia mainly relies on nurses' observation and clinical judgement in the effective assessment and management of pain. • Nurse's knowledge of their patient's habits and behavioural patterns is essential in determining pain experience in dementia. • Fieldwork reaffirms that nurses are able to identify pain in dementia by behavioural cues. Experienced nurses identified pain in people with dementia by behavioural cues and are able to do an effective physical assessment. • Experienced nurses identified that it is important to identify origins of pain. They recognised the importance of having a sound knowledge of analgesia and side effects. 	<p>The sample size of 3 nursing homes is relatively small which may affect the generalizability of the results. Social desirability of nurse responses may show bias. No method of validity of interviews identified.</p>	<p>South Korea</p>
<p>Martin, R Williams J, Hadjistavropoulos, T. Mac Lean M.</p>	<p>To explore the perspective of seniors, and front line nursing staff on the assessment and management of pain in dementia.</p>	<p>Qualitative-separate focus groups with seniors and healthcare professionals</p>	<p>Stratified random sample.</p> <p>Four focus groups - Seniors, nursing staff, Nursing home administrators, and informal care givers</p>	<ul style="list-style-type: none"> • Pain in dementia is likely to go unrecognised and untreated in residents with dementia due to communication difficulties. • Seniors with dementia are at increased risk for escalating and aggressive behaviours. There were concerns that behavioural disturbances, mood changes are related to dementia and not pain - as a result resident's treatments are misdirected. • Staff reported that effective pain assessment are facilitated by good communication and documentation amongst healthcare professionals. Pain assessment communication between nurses is poor. • Barriers to good pain assessment included staff shortages and poor communication. Pain in dementia is difficult to manage once 	<p>Small focus group numbers (n=4) - larger group would have produced richer material.</p>	<p>Canada</p>

				behavioural disturbances are escalated.		
Cohen-Mansfield, Jiska; Creedon, Michael.	To determine factors affecting the differentiation of pain behaviours; and assess nurses' perception of indicators of pain in dementia.	Mixed Methods cross sectional survey, focus groups and follow up interviews.	Systematic random sample. 72 staff members of 3 nursing homes were interviewed or surveyed. Focus groups were conducted with staffs own ability to identify pain. One to one interviews of 29 nurses were conducted in a 558 bedded non-profit nursing home.	<ul style="list-style-type: none"> 93% respondents relied on knowledge of a resident's habits and needs to identify pain in cognitively impaired resident Nursing staff felt that pain would go unrecognised and staff would feel guilt and upset. New staff members would not realise when someone was in pain. Nurses fell more empathy for residents of whom they are emotionally attached to - and therefore are more likely to detect pain in those residents. Nursing staff felt that barriers to pain assessment include restrictions on pain management due to concerns of the side effects of pain medication and risk of addiction. Nurses can think that behavioural problems stem more from psychological distress rather than looking at physical pain. Pain assessment can be restricted due to time constraints and work demands. RNs tend to focus unduly on diagnosis in charts for explanations of patient behaviour. 	Respondents can feel peer pressure to give similar answers to the moderator's questions in interviews.	USA

<p>Kovach, C., Griffie, J., Muchka, S., Noonan, P. and Weissman, D.</p>	<p>To identify nurses' knowledge and experience with assessing and treating pain with individuals with dementia.</p>	<p>Interviews of nurses. Followed by focus groups.</p>	<p>Purposive sample. Interview of nurses (n=30) in 6 LTCs. Nurses had received pain education programme 1 year earlier.</p>	<ul style="list-style-type: none"> • Nurses identified that assessing pain in dementia was not taught during training. Nurses identified that assessment of pain in dementia is a guessing game. • Nurses recognised that pain in behaviour and mood can be related to pain - but only staffs who work consistently with would recognise it. Staffs feel that they need further education about the assessment process and common signs and symptoms of discomfort. Psychotropic drugs were perceived to be commonly misused - pain mistaken for psychiatric problems. • Nurses had positive feelings regarding the use of narcotic analgesia and consider pain treatment to be a systematic process. Comfort was the primary concern of the nurses, and felt the side effects of medications such as drowsiness can lead to falls and decreased ability to eat. However the benefits of analgesia in providing comfort and relieving suffering outweighed the risks of side effects. 	<p>Nurses interviewed had received training 1 yr. prior to interview so it may not represent the perceptions of nurses with no education. It is unclear how accurately nurses' perceptions reflect the actual efficacy of pain management interventions.</p>	<p>USA</p>
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<p>Chang E1, Daly J, Johnson A, Harrison K, Easterbrook S, Bidewell J, Stewart H, Noel M, Hancock K.</p>	<p>To identify challenges when caring for persons with advanced dementia</p>	<p>Focus groups and follow up interviews</p>	<p>Systematic random sample. 5 focus groups (n=24) Participants included palliative care, aged care and dementia specialist nurses, medical specialists from an area health service, residential aged care staff and general medical practitioners. And 20 individual interviews from staff of 10 aged care facilities</p>	<ul style="list-style-type: none"> • Several participants reported that pain management in dementia is especially difficult as it can be difficult to identify behavioural cues as indicators of pain. • One third of participants were reluctant to use appropriate amounts of analgesia, especially opiates. • Nurses recognised that we cannot use traditional models of pain assessment for residents with dementia. 	<p>Respondents can feel peer pressure to give similar answers to the moderator's questions. Some participants for interview had been nominated by Directors of Nursing and direct approach by the researcher which may have caused coercion of participants. Research conducted over three years - participants views may have changed over time. Sample size is small and may not represent the opinions of general population. Interview focused on knowledge and skills so topics featured strongly in the results. Other challenges might have emerged had different questions been asked.</p>	<p>Australia</p>
<p>Blomqvist, K. and Hallberg, I. R</p>	<p>To highlight nurses' and older adults views about how to recognise the presence of pain in older adults living in special needs housing.</p>	<p>Interviews conducted using open ended questions.</p>	<p>Purposive sample. Interviews of 56 nurses working in one general nursing home and service apartments.</p>	<ul style="list-style-type: none"> • Pain common is common in people with and without cognitive impairment. Majority of older adults experience pain daily. • Nurses caring for older adults with cognitive impairment assessed paralinguistic language, change in body position and gait as ways to express pain. Pain would be interpreted by reflecting about the cause of pain/pain characteristics/checking medical history. Validates pain by asking about presence of pain touching and observing for reactions. Would review interventions and evaluate its effect. • Nurses spoke of feelings of powerlessness made them less eager to ask questions 	<p>Limited sample size - risk of generalizability of results. Number of internal drop outs</p>	<p>Sweden</p>

				<ul style="list-style-type: none"> about pain. Personal characteristics of older people facilitate in pain recognition - easier to identify distinct expressions. 		
Brorson H., Plymoth, H. Ormon, K., Bolmsjo, I.	To describe nurses' experience regarding end of life pain relief in patients with dementia.	Semi structure interviews	<p>Purposive sample:</p> <p>7 nurses working on hospital unit interviewed.</p>	<ul style="list-style-type: none"> All nurses interviewed believed that all suffering should be alleviated to the extent possible. Some nurses felt pain in dementia was not managed - people dying with pain and anxiety. Nurses described feelings of powerlessness - difficulty in obtaining adequate analgesia; patients suffering longer than necessary. Some nurses felt that physicians did not listen to them in regards to pain assessment resulting in insufficient analgesia. Nurses felt frustrated patients not receiving therapeutic dose. Nurses felt that they had the knowledge and experience to raise discussion re: pain relief with physician. Nurses felt that patients with dementia are more likely to suffer side effects of analgesia -increased confusion, increased risk of falls and constipation. Nurses recognised the importance of behavioural cues such as agitation, restlessness and facial expressions; however nurses found it difficult to assess nature of pain. 3 out of 7 nurses indicated that family are important in interpreting patients' pain cues. Nurses felt that the ability to interpret patients' needs with dementia improved through experience. Highlighted the importance of knowing the patient to improve pain management. 6 out of 7 nurses mentioned the importance 	Small sample size/ all women - risk of generalizability of results. May not be transferable to other care settings	Sweden

				of good interpersonal relationships - nurses feel that physicians need to listen and trust their assessment. Nurses expressed difficulty in determining pain from anxiety.		
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Reference List

Ahn H, Horgas AL.(2013) The relationship between pain and disruptive behaviour in nursing home residents with dementia. *BMC Geriatrics*. 13 (14):1471-2318

Ajzen, I. (1985). From intentions to actions: A theory of planned behavior. In Kuhl J, and Beckman J. (Eds.), *Action-control: From cognition to behavior* (pp. 11-39). Heidelberg: Springer.

Ajzen, I. (1988). *Attitudes, personality, and behavior*. Milton-Keynes, England: Open University Press and Chicago, IL: Dorsey Press.

Alzheimer's Society (2009). *Counting the cost*. London: Alzheimer's Society.

http://www.alzheimers.org.uk/site/scripts/news_category.php?categoryID=200288 Accessed 23/4/14 (internet)

Alzheimers Disease International: *World Alzheimers Report 2013*. Pg12. www.alz.co.uk accessed 12/12/13 (internet)

Asghari A , Ghaderi N, Ashory A. (2006) The Prevalence of Pain among Residents of Nursing Homes and the Impact of Pain on Their Mood and Quality of Life. *Archive of Iranian Medicine*. 9 (4) 368 – 373

Barry H, Parsons C, Passmore P, Hughes C. (2012) An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. *International Journal of Geriatric Psychiatry*. 27: 1258–1266

Barry H, Parsons C, Passmore P, Hughes, C. (2013) Community pharmacists and people with dementia: a cross sectional survey exploring experiences, attitudes, and knowledge of pain and its management. *British Journal of Geriatric Psychiatry*. 28:1077-1085

Blomqvist K, and Hallberg IR. (2001) Recognising pain in older adults living in sheltered accommodation: the views of nurses and older adults. *International journal of Nursing studies* 38: 305-318

Bonica, J. J. (1990) *The Management of Pain*. (2nd Ed), Philadelphia: Lea and Febiger. (pg. 782-789). Hagerstown, Maryland. USA

Brorson H, Plymoth H, Ormon K, Bolmsjo I. (2014) Pain relief at the end of life: Nurses' Experiences regarding end of life pain relief in patients with dementia. *Pain Management Nursing*.15 (1) 315-323

Buchanan A, Davies A, Geerling J. (2014) Breakthrough Cancer pain: The role of the nurse. *International Journal of Palliative Nursing*. 20 (3) 126-9

Buffum M, Hutt E, Chang VT, Craine MH, Snow L. (2011) Cognitive impairment and pain management: Review of issues and challenges. *Journal of Rehabilitation Research & Development*. 44 (2) 315-330

Calvin, H. (2011) Systematic pain management reduced agitation in nursing home residents with dementia. *Annals of Internal Medicine*. 155:10

Chang Sung OK, Oh Younje Park, Eun Young, Kim Geun Myun, Kil Suk Young.(2011) Concept Analysis of Nurses' Identification of Pain in Demented Patients in a Nursing Home: Development of a Hybrid Model. *Pain Management Nursing*.12(2) 61-69

Chang E, Daly J, Johnson A, Harrison K, Easterbrook S, Bidewell J, Stewart H, Noel M, Hancock K. (2009) Challenges for professional care of advanced dementia. *International journal of nursing practice*. 15: 41-47

Closs J, Barr B, Briggs M. (2004) Cognitive status and analgesic provision in nursing home residents. *British Journal of the Royal College of General Practitioners*. 54(509):919-921

Cohen-Mansfield, J. (2014) Even with regular use of an observational scale to assess pain among nursing home residents with dementia, pain-relieving interventions are not frequently used. *Evidence Based Nursing*. 17 (1) 24-25

Cohen-Mansfield J, and Creedon M. (2002) Nursing staff members' perceptions of pain indicators in persons with severe dementia. *The Clinical Journal of Pain*. 18(1) 64-73

Cohen-Mansfield J, and Libin A. (2005) Assessment of agitation in elderly patients with dementia: correlations between informant rating and direct observation. *International Journal of Geriatric Psychiatry*. 19: 881-91

Department of Health (2012) Future health: A strategic reform of the Health Service 2012 -2015.

Department of Health, Social Services and Public Safety of Northern Ireland (DHSSPSNI) (2011). Transforming Your Care: Review of Health and Social Care in Northern Ireland available at <http://www.dhsspsni.gov.uk/index/tyc.htm> accessed 2/2/14

European Commission of Health (2013). A good life in old age? Monitoring and Improving quality in long-term care facilities. OECD Health Policy Studies, OECD Publishing.
<http://dx.doi.org/10.1787/9789264194564-en>

Fink, A. (2005). *Conducting Research Literature Reviews: From the Internet to Paper* (2nd edition) Thousand Oaks, California: Sage Publications. (Pg. 3)

Forbes, K. and Faull, C. (1998) *The Principles of Pain Management*. In: Faull, C., Carter, Y., Wood, R. Handbook of Palliative of Care. (2nd Edition) Blackwell Science. Oxford.

Fuchs-Lacelle S, Hadjistavropoulos T, Lix L. (2008) Pain assessment as intervention: a study of older adults with severe dementia. *Clinical Journal of Pain*. 24(8): 697-707

Hennings J, Froggatt K, Keady J. (2010) Approaching the end of life and dying with dementia in care homes: the accounts of family carers. *Rev Clin Gerontol*. 20: 114-127

Herr K, Coyne P, Key T, Manworren R, McCaffery M, Merkel S, Pelosi-Kelley J, Wild J. (2006) Pain assessment in the nonverbal patient: position statement with clinical practice recommendations for practice. *Pain Management Nursing*. 7 (44-52)

Horgas AL, Elliott AF, Marsiske, M. (2008) Pain assessment in persons with dementia: relationship between self-report and behavioural observation. *Journal of the American Geriatric Society*. 57(1): 126-132

Husebo, BS, Ballard C, Sandvik R, Nilsen OB, Aarsland D. (2011) Efficacy of treating pain to reduce behavioural disturbances in residents of homes with dementia: cluster randomised clinical trial. *British Medical Journal*. 343: 4065.

Husebo BS, Strand LI, Moe-Nilssen R, Borgehusebo S, Aarland D, Ljuggren AE. (2008) Who suffers most? Dementia and pain in nursing home patients: a cross sectional study. *Journal of the American Directors Association*. 9(6): 427-433

Jones KR, Fink R, Pepper G, Hutt E, Vojir CP, Scott J, Clark L, and Mellis K. (2004) Improving nursing home staff knowledge and attitudes about pain. *Gerontologist*. 44(4): 469-478

Kaasalainene S, Coker E, Dolovich L, Papaioannou A, Hadjistavropoulos T, Emili A, Ploeg J. (2007) Pain management decision making among long term care physicians and nurses. *Western Journal of Nursing Research*. 29 (5) 561-580

Kovach C, Griffie J, Muchka S, Noonan P, Weissman D. (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

Leoang IY, and Nuo TH. (2007) Prevalence of Pain in Nursing Home Residents with Different Cognitive and Communicative Abilities. *Clinical Journal of Pain*. 23 (2):119-127

Lin P, Lin L, Shyu YL, Hua M. (2011) Predicators of pain in nursing home residents with dementia: a cross sectional study. *Journal of Clinical Nursing*. 20(13/14):1849-57

Martin R, Williams J, Hadjistavropoulos T, Mac Lean M. (2005) A qualitative investigation of seniors' and caregivers' views on pain assessment and management. *The Canadian Journal of Nursing Research*. 37(2): 142-164

Merskey HM, Bogduk N. (1994) *Classification of Chronic Pain*. (2nd edition). IASP Press, Seattle, p.211

McCaffery M, Ferrell B, O'Neil E, Lester M, Ferrell, B. (1990) Nurses' knowledge of opioid analgesics and psychological dependence. *Cancer Nursing* 13: 21-27.

Monroe T, Carter M, Feldt K, Tolley B, Cowan RL. (2012) Assessing advanced cancer pain in older adults with dementia at the end of life. *Journal of Advanced Nursing*. 68(9) 2070-2078

Morello R, Jean A, Alix M, Sellin-Peres D, Fermanian J. (2007) A scale to measure pain in non-verbally communicating older patients: the EPCA-2 Study of its psychometric properties. *Pain*. 133 (1-3) 87-98

Murray SA, Kendall M, Boyd K, Sheikh A. (2005) Illness trajectories and palliative care. *British Medical Journal*. 330(7498):1007-1011

Neale R, Brayne C, Johnston AL. (2001) Cognition and survival: an exploration in a large multicenter study of the population aged 65 years and over. *International Journal of Epidemiology*. 30: 1383 -8

Neville C, Mc Carthy A, Laurent K. (2006) Pain management skills of regional nurses caring for older people with dementia: a needs analysis. *Collegian* (Royal College of Nursing, Australia), 13(2):31-36

Nyaard HA, and Jarland M. (2005) Are nursing home patients with dementia diagnosis at increased risk for inadequate pain assessment? *International Journal of Geriatric Psychiatry*. 20(8) 730-737

Plautex S, Herrmann F, Le Lous P, Fabjan M, Michel JP, Gold G. (2005) Feasibility and reliability of four pain self-assessment scales and correlation with an observational rating scale in hospitalized elderly demented patients. *Journal of Gerontology and Biomedical Science*. 60 (524-529)

Reynolds KS, Hanson LC, DeVellis RF, Henderson M, Steinhauser KE. (2008) Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *Journal of Pain and Symptom Management*. 35 (4) 388-96

Riva P, Wirth J, Williams KD. (2011) The consequences of pain: The social and physical pain overlap on psychological responses. *European Journal of Social Psychology*. 41: 6, 681–687,

Scherder E, Oosterman J, Swaab D, Herr K, Ooms J, Ribbe M, Segeant J, Pickering G, Beneditti, F. (2005) Recent developments in pain in dementia. *British Medical Journal*. 330 (7489) 461-464

Van de Steen J, Radbruch L, Hertogh C, E de Boer M, Hughes JC, Larkin P, Francke AL, Junger S, Gove D, Firth P, Koopman R, Volicer L. (2013) White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*. 28 (3) 197-209

Zanetti O, Solerte SB, Cantoni F. (2009) Life expectancy in Alzheimer's disease (AD). *Archive of Gerontology Geriatrics*. 49(1) 237-243

Zwakhalen S, Hamers J, Peijnenburg R, Berger M. (2007) Nursing staff knowledge and beliefs about pain in elderly nursing home residents with dementia. *Pain Research and Management: The Journal of the Canadian Pain Society* 12: 177–184.

