

Pain assessment in hospitalized patients with dementia

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A general literature analyses

“Nursing is an art: and if it is to be made an art, it requires an exclusive devotion as hard a preparation as any painter’s or sculptor’s work; for what is the having to do with dead canvas or dead marble, compared with having to do with the living body, the temple of God’s spirit? It is one of the Fine Arts: I had almost said, the finest of Fine Arts.”

(Florence Nightingale, 1868)



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Abstract

Introduction: Pain in patients with dementia is often under-assessed, overlooked or miss assessed. Nurses experience difficulties in assessing pain in patients with dementia, as patients with dementia tend to have problems in memory, language, and speaking and a decreasing ability to recognize pain.

Purpose: To shed light on pain in hospitalized patients with dementia, with focus on pain assessment.

Method: A literature review was completed. Thirteen original research articles were used from the period between 2006 and 2016.

Results: Characteristics of dementia and a lack of knowledge among nurses causes difficulties in pain assessment in patients with dementia. To assess pain in patients with dementia, a multi-faced approach is necessary, this includes: self-report, observation of pain behaviour, and proxy rating.

Discussion: The results were discussed by using relevant research articles and theories.

Conclusion: To make assessment of pain in hospitalized patients with dementia less difficult, nurses should be educated about pain in patients with dementia and how to recognize pain. More research should be done into available pain assessment tools for patients with dementia in hospitals.

Keywords: pain, dementia, pain assessment, hospitalized, nurses.

Table of contents

| | |
|--|----|
| Introduction..... | 3 |
| 1. Method..... | 6 |
| 1.1 Article search..... | 6 |
| 1.2 Inclusion and exclusion criteria..... | 7 |
| 1.3 Data analysis..... | 7 |
| 1.4 Ethical considerations..... | 8 |
| 2. Results..... | 10 |
| 2.1 Characteristics of dementia and pain..... | 10 |
| 2.2 The nurse and assessing pain..... | 10 |
| 2.3 Techniques to assess pain in patients with dementia..... | 11 |
| 2.4 Consequences of unrecognized pain in patients with dementia..... | 12 |
| 3. Discussion..... | 13 |
| 3.1 Discussion of the results..... | 13 |
| 3.1.1 Characteristics of dementia and pain..... | 13 |
| 3.1.2 The nurse and assessing pain..... | 14 |
| 3.1.3 Techniques to assess pain in patients with dementia..... | 15 |
| 3.1.4 Consequences of unrecognized pain in patients with dementia..... | 17 |
| 3.2 Methodological consideration..... | 18 |
| 3.2.1 Credibility..... | 18 |
| 3.2.2 Dependability..... | 19 |
| 3.2.3 Transferability..... | 19 |
| 4. Conclusion..... | 20 |
| References..... | 22 |
| Appendices..... | 25 |
| Appendix 1 – Overview of searching strategy..... | 25 |
| Appendix 2 – Analysis Table..... | 27 |
| Appendix 3 – Overview of included articles..... | 29 |

Introduction

The prevalence of elderly (>65 years) in the Netherlands is growing every year. In the beginning of 2015 the prevalence of elderly was 3 million, the estimation is that there will be 4.7 million elderly in the Netherlands in 2040 (Ouderenfonds, 2015). When the population of the elderly is growing, the prevalence of elderly with dementia will grow likewise. Dementia is a disease which normally occurs with age. It is estimated that the population of people with dementia will grow with 70% between 2011 and 2030 (Deltaplan Dementie, 2015).

The estimation of chronic pain in elderly people is 84%, and at least 55% of elderly with dementia are in pain (Cunningham, 2006). Pain has impact on aspects of a person's emotional, social, and physical functioning and their general well-being. Generally, pain in the elderly is often under-assessed, overlooked or miss assessed, but most of the time this problem occurs in patients with dementia. Assessing pain in patients with dementia can be difficult. The following concerns are issues that can affect pain assessment in patients with dementia: the thought that pain is common for elderly, fears about possible addiction to opioids, sensory and cognitive impairment, and unconcern that leads to less report of pain by elderly (Hadjistavropoulos, et al., 2007). Assessing pain in patients with dementia is experienced as being difficult by nurses, as patients with dementia tend to have problems in memory, language, and speaking and a decreasing ability to recognize pain (Herr, 2011).

Two third of patients in a hospital experience pain (VMS, 2010). The description of pain that is used during this research: "Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does" (McCaffery, 1968). As this description says, pain is a subjective experience, and there does not exist an objective test to measure pain (Herr, et al., 2006).

While two third of hospitalized patients suffer from pain, patients with dementia do not receive the same pain management as patients without dementia (Cunningham, 2006; Herr, 2011). When patients with dementia are confused and disorientated, they will receive less analgesics (Cunningham, 2006). It is estimated that 64% of patients without dementia receive sufficient pain medication set against 33% of patients with dementia (Achterberg, 2010; Herr, 2011; Cunningham, 2006).

There is a need for adequate pain measurement according to the Dutch Veiligheidsmanagement Systeem (VMS) (safety management system) as many as "two third of de patients in hospitals are in pain. Poorly treated acute pain can cause serious medical complications and may delay the healing. The basis of the reduction of pain is early recognition. The lack of systematic pain measurement is one of the most important reasons for inadequate pain management" (VMS, 2013).

It is important to assess pain in the elderly, as information from pain assessment is necessary for diagnosis, clinical decision-making and for research (Hadjistavropoulos, et al., 2007).

The nurses do not use any special pain measurement tool for people with dementia in the hospital because they believe that the pain scale they are using at the moment, is not effective. The nurses' view who the researcher interviewed in the Netherlands, was that the patients with dementia could not understand the pain scale that was used at the moment they experienced pain (Ortse & Zwart, 2016). The pain scales used, were the VAS (Visual analogue scale) and the NRS (Numeric rating scale). Studies show the same outcome: Nurses often do not ask patients with dementia about their pain, because they question the reliability about self-report in patients with dementia (Cunningham, 2006).

The VAS is a pain scale where the patient tells which facial expression reflects their current situation. The NRS is a pain scale where the patient give a number to the pain they are feeling at that moment, from 0 (which is no pain) to 10 (which is the most pain they can imagine) (VMS, 2009).

The patients gave a high pain intensity rating while they said they were not in pain, or they gave a low pain intensity rating while the nurses observed changes in behaviour, facial expression which expressed pain or a change in posture.

The outcome of the prevalence of pain in patients with dementia was not valid, because the pain scales that are used, are self-rating scales. Thus, the use of self-reporting pain scale is problematic for the patients with dementia due to their functions of impaired vision, hearing and, memory (both verbal and cognitive). The outcome was that pain does occur less in patients with dementia than in patients without dementia. This outcome could partly be a result that nurses could not recognise pain in patients with dementia (Achterberg, 2010; Herr, 2011).

The perspective in this study is the nurse perspective, because the recommendations are going to be written for the nurses. It is the task of the nurse to observe painful behaviour, rate the pain and to collect information by observing and asking questions to the patient. The outcome of the interviews shows that nurses have not enough knowledge about which care they should provide to patients with dementia in regards to pain management (Ortse & Zwart, 2016).

This study is relevant, because the research is about an intervention by a nurse. It is a nurse's task to observe and measure pain in patients, share the outcome of the measurement with the doctors, and it is these doctors will write a treatment for the patient. When the pain measurement is invalid, the treatment will not be suited to the patient, which can lead to further physical damage (Weitzel, et al., 2011; Hadjistavropoulos, et al., 2007). As a nurse, you want the best care for the patient, which

means there should be an effective pain measurement tool so the quality of care and quality of life of the patient is improved. Nurses are integral in guaranteeing pain assessment and treatment of vulnerable patients like elderly with dementia (Herr, 2011).

The Dutch code of ethics for a nurse, describes that as a nurse, you need to keep your knowledge and skills high. So you need to read literature, make sure the care you give is scientifically approved and to keep an eye on social developments (V&VN, 2015). In the Code of Ethics for nurses states that nurses need to provide and plead for humane and appropriate care. So as a nurse, it is your role to assure that all the patients receive qualitative care. A nurse shows this by giving care with compassion and by not being influenced by personal attributes, economic status or the nature of the health problem (Herr, 2011; American Nurses Association, 2015).

The purpose of this study is to shed light on pain in hospitalized patients with dementia, with focus on pain assessment.

1. Method

To answer the main purpose of the literature research, the researcher used qualitative literature.

This means the literature will not contain facts and numbers, but subjective data, which may contain, questionnaires, observations and interviews (Verhoeven, 2011; Ofringa, 2008). This means, for the research regarding the assessment of pain in patients with dementia, that original scientific articles and, information will be collected and analysed to answer the main purpose.

1.1 Article search

When searching for articles, a different combination of key words were used to illuminate the purpose. The key words were used in different databases, such as Medline and PubMed. These databases contain articles on health topics, which are necessary in this study. Medline and PubMed are found and used through the website of the Nord University. Synonyms of keywords were used to expand the results of articles and, all the keywords and their synonyms were used in the databases. Keywords which were used include: hospitals, in-patients, pain measurement, dementia, acute pain, pain, post-operative, dementia and nursing assessment.

After reading through the articles that were found, the references list in the articles were checked and scanned to find useful literature by selecting on titles and/or authors. Searching for literature by using the references list is described as 'manual search'. An overview regarding the used searching strategy can be found in appendix one.

This is an small example of the table of article search

| Database | Limitations | Keywords | Matches | Selected 1 | Selected 2 | Selected 3 | Selected 4 |
|-----------------------|-----------------------------------|---|---------|------------|------------|------------|------------|
| Medline 29-02-2016 | 2006-2016 Dutch and English | Hospitals OR in patients. Pain measurement AND Dementia AND Acute Pain OR Pain OR Postoperative OR Pain Measurement | 5 | 5 | 4 | 3 | 2 |
| Medline 29-02-2016 | 2006-2016 Dutch and English | Dementia AND pain. Inpatients OR hospitals. Pain measurement OR nursing assessment | 4 | 4 | 2 | 2 | 2 |

Selected 1: red the title

Selected 2: red the abstract

Selected 3: Red the entirely

Selected 4: Selected for further review

1.2 Inclusion and exclusion criteria

Before the literature search was started, a list with inclusion and exclusion criteria was made. The purpose focuses on patients with dementia. This means the articles selected, only pertained to patients who meet the criteria of the description of dementia in DSM-V, a MMSE score <24 or a doctor's diagnosis of dementia. Also, the articles selected contained information about pain assessment or pain measurement. Articles containing information about hospitals and nursing homes were included. Although the purpose focuses primarily on the hospital, the researcher also chose to include literature about pain measurement in nursing homes. This is because patients with dementia in hospitals generally, arrive there by way of a nursing home. Nursing homes are specialised in caring for elderly with dementia, so the literature contains scientific information about measuring pain in patients with dementia in a nursing home. This nursing home information can be useful when comparing it to a situation in a hospital setting. Articles that contained information about patients with dementia below the age of 65 were excluded from the research. Lastly, all kinds of differing pain were included. The description of pain used in this study is: "Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does" (McCaffery, 1968). Although this description is dated, the description focuses on the pain experience of the patient, which is useful and needed in self-report of pain.

Besides the inclusion and exclusion criteria, the articles had to meet the following requirements:

- The articles were to be written in English or Dutch
- The publishing date of the article had to be between 2006 and 2016
- The articles had to be original research articles.

An overview of the included articles can be found in appendix three.

1.3 Data analysis

The analysis used in the study is an analysis of the results in the included articles. The text analysis is inspired by the 'content analyses' as described in Graneheim & Lundman (2003). "Qualitative research is about exploring the significance that people attach to certain situations and behaviour" (Verhoeven, 2011, p. 289). The included articles were read and then reread several times to gain understanding of the content of each article. The articles are read critically, while keeping the purpose of the study and the inclusion and exclusion criteria in mind. Also, sections of the articles were identified as helpful material for the building of the questionnaires used in this study. Out of these identified sections, a new result chapter is written. The article texts are broken into important chapters and made into a new text. While analysing the articles, differences and similarities are

identified and subcategories are made. The subcategories with similar content are placed together and a new category is created. The results chapter contains four categories;

1. Characteristics of dementia and pain
2. Consequences of unrecognized pain in patients with dementia
3. Available techniques to assess pain in patients with dementia
4. The nurse and assessing pain

These categories are used as headings in the results chapter in the study. The table of data analysis can be found in appendix two.

An example of used data analyses

| Meaning unit | Sub-categories | Category |
|---|---|-----------------------------------|
| Professional caregivers experiences stress and burnout due to Patient’s disruptive and aggressive behaviour. <i>Consequences:</i> <ul style="list-style-type: none"> - Functional decline - Social isolation - Depression - Increased prevalence of suicidality - Increased health care utilization - Delirium Awareness of pain in patients with dementia can help caregivers to provide more effective care for these groups of patients, resulting in an improvement in their quality of life and reduction in health care costs. | Unrecognized pain leads to numerous consequences, for the patient, but also for the caregiver. Awareness of pain improving quality of life | Consequences of unrecognized pain |

1.4 Ethical considerations

The articles included in this study were selected with care and all the articles are scientifically approved. This study is meant to be written in an objective way, with no intention to plagiarize, and references are referred with the APA system. Literature written by the teacher and assessor of the researcher is not included, so the grade of the study will not be influenced by the chosen literature. The study is written with use of various articles, written by different authors so as to increase the trustworthiness of the findings. The research is written with the following quote in mind: *“Reality can be interpreted in various ways and the understanding is dependent on subjective interpretation.”* (Graneheim & Lundman, 2003, p. 106)

Ethical considerations were made in this study, the population of this study (patients with dementia) cannot make the decision on their own in whether they want to participate in a study or not. Proxy

consent was necessary in the used articles, to make the study ethical approved. The privacy of the participants was always guaranteed, this means that the names and personal information of the participants were not mentioned in the used articles.

2. Results

In this chapter, the results of the literature analysis is described in four categories. These categories are an outcome of the literature analysis and will give the reader insight and knowledge of dementia, pain assessment and recommendations for assessing pain in patients with dementia according to the used literature.

2.1 Characteristics of dementia and pain

People with dementia have cognitive damage in memory and learning skills, as well in communication, reasoning, recognition, and planning skills. Study shows that patients with dementia complain less about their pain and report shorter duration of their pain (Fuchs-Lacelle, Hadjistavropoulos, & Lix, 2008; Miu & Chan, 2014). Patients with dementia do not experience less pain than patients without dementia. However, due to impairment in memory and language, they are less likely to express their painful experiences, to recognize the presence of pain and to verbally communicate about their pain (Horgas, Nichols, Schapson, & Vietes, 2007; Horgas, Elliott, & Marsiske, 2009). These patients are unable to determine whether their pain has changed over time, unable to describe the characteristics of their pain and are unable to compare their current pain experience to their earlier pain experience (Kelley, Siegler, & Carrington Reid, 2008). Patients with dementia are less able to recognize and communicate their experience of pain. Also patients with dementia report less “every-day pain” compared to those patients who are cognitively intact (Horgas et al., 2009). Also, patients with dementia report shorter duration of pain compared to cognitively intact patients. Further, patients with dementia report less intense pain after activity compared to cognitively intact patients, and are thus are less likely to report pain (Horgas et al., 2007; Fuchs-Lacelle et al., 2008; Kelley et al., 2008; Miu & Chan, 2014).

Patients with dementia are likely to show their pain through behaviour, such as facial expressions, limping, bracing, aggressiveness, verbal agitation, and restlessness (Fuchs-Lacelle et al., 2008; Lints-Martindale, Hadjistavropoulos, Lix, & Thorpe, 2012; Miu & Chan, 2014; Husebo, 2014). Stronger facial expressions are shown in patients with dementia compared to patients without dementia, and facial expressions in general may be a key indicator of pain in patients with dementia (Lautenbacher, Niewelt, & Kunz, 2013; Kunz et al., 2009).

2.2 The nurse and assessing pain

Because patients and their families have fears about pain and pain treatments, it is a nurse’s task to reduce these fears and to cooperate with the patient and their family. This will increase the quality of life, functional capacity, and the effectiveness of pain management of the patient. To fulfil this task, caregivers must keep abreast of new knowledge about pain and its treatment (Brown, Kirkpatrick, Swanson, & McKenzie, 2011). Because the nursing staffs, in general, have limited knowledge and

misconceptions about pharmaceutical treatments, these can affect pain assessment and its treatment (Zwakhaleh, van't Hof, & Hamers, 2012). A lack of knowledge is the most divisive factor in the application of pain treatment (Zwakhaleh et al., 2012). Concerns among health care providers exist regarding the potentially negative effects of powerful drugs such as nonsteroidal anti-inflammatory drugs or narcotic drugs (Miu & Chan, 2014).

The personal opinion of a nurse regarding the patient's pain can influence the choice the nurse makes regarding the medication that the patient will receive. A study shows that nonverbal clues given by a smiling patient made it difficult for the nurse to assess pain in that only an observation of behaviour of the patient was assessed, thereby making it difficult to choose the correct pain medication (Kjällman Alm & Norbergh, 2013). The training of nurses probably does not contain adequate guidance in how to read and interpret the facial display of pain in patients with dementia (Lautenbacher et al., 2013).

To alleviate pain, the nurse needs to communicate with the patient. Communication includes verbal information and non-verbal behaviour. Both types of communication influence one another within the same communication context (Kjällman Alm & Norbergh, 2013). Caregivers who ask repeated open-ended questions, will collect supplementary pain information from the patient or its family (McDonald, 2009).

Study shows that patients were hindered in their communication with regards to their pain by nurses' personalities. When nurses show stress and concern about the patients' pain, patients feel hindered to report their pain. Also, nurses with work experience of more than 10 years are less sensitive to patients' needs than nurses with less work experience (Kjällman Alm & Norbergh, 2013).

2.3 Techniques to assess pain in patients with dementia

Study shows that 46% of a group of 35 patients, were not able to provide scorable self-report ratings. Patients who could not provide a self-report rating, were those who had a decrease in cognitive functioning (Kunz et al., 2009). The use of self-report rating in patients with dementia is an inadequate tool. Pain assessment tools which use the tool of observation is needed (Horgas et al., 2009).

The most frequently observed pain behaviour in patients with dementia in the study of Horgas et al. (2007) were bracing and pain noises. According to Lints-Martindale et al. (2012), facial expressions, vocalization/verbalizations and body movements may be the most significant for identifying pain in patients with dementia. In the study of Lautenbacher et al. (2013), patients with dementia showed the strongest facial expressions of pain, compared to patients without dementia. They also showed that the face alone is able to show the essential signals needed to identify pain. Self-report and

observed behaviour are related to each other in patients without dementia, so this outcome supports the use of a behavioural observation tool in combination with self-report (Horgas et al., 2007). Although this outcome shows validity as a pain behaviour observation tool, these tools should be used with caution. Pain is subjective and it is not possible to define the patients' pain. Behaviour is often difficult to interpret and can lead to misinterpretation (Horgas et al., 2007).

The American Society for Pain Management Nursing recommends an extensive, hierarchical approach of pain assessment in the nonverbal patient. This includes self-report, observations of pain behaviour, and proxy ratings (Horgas et al., 2007). The American Geriatrics Society recommends assessing pain in the nonverbal patient through observing behaviour in six behaviour domains: facial expressions, verbalizations and vocalizations, body movement, changes in interpersonal interactions, changes in activity patterns and routines, and changes in mental status (Lints-Martindale et al., 2012).

2.4 Consequences of unrecognized pain in patients with dementia

Unrecognized pain can lead to persistent pain, which can lead to consequences for the patient. The consequences for the patients consist of morbidity in later life, along with functional decline, social isolation, anxiety, increased prevalence of suicide, and depression (Kelley et al., 2008).

Study shows that persistent pain can lead to aggressive and disturbing behaviour in patients with dementia, which can lead to stress and burnout among nurses. Uncertainty among nurses about the treatment needs of the patient, lead to distress and burden. This stress is related to inadequate preparation, lack of support, and uncertainty concerning the treatment. This study also show that assessing pain through a systematic way, can decrease work-related stress, emotional exhaustion, and burnout (Fuchs-Lacelle et al., 2008; Husebo, 2014).

Another outcome of research shows that unrecognized pain, increases health care utilization and health care costs (Kelley et al., 2008; Miu & Chan, 2014). These consequences can be reduced by making caregivers more aware of pain in patients with dementia, and by so, effective care will be provided which will results in an improvement of the quality of life in this group of patients (Miu & Chan, 2014).

3. Discussion

3.1 Discussion of the results

Purpose: to shed light on pain in hospitalized patients with dementia, with focus on pain assessment.

Assessing pain in patients with dementia is a difficult problem because of the underlying characteristics of dementia which make pain assessment a struggle for nurses. There are a variety of pain assessment strategy tools for assessing pain in dementia, but there is no single tool which has proven to be the best. When acute pain is not recognized, the pain will be persistent, which leads to numerous consequences for the patient, but also for the caregiver.

3.1.1 Characteristics of dementia and pain

The results shows that due to impairment in language and memory, these patients are less able to recognize pain and to verbally communicate to their caregivers about their pain experience.

However, study shows that despite these changes, patients with dementia still experience pain to a degree similar to that of the pain experienced by the cognitively intact elderly person (Herr et al., 2006).

Self-report is the most reliable and accurate method for identifying and characterizing pain, and is considered to be the golden standard in assessing pain (Herr, 2011). Attempts to obtain self-report of pain from all patients should be done, this includes patients with dementia (Herr et al., 2006). Asking the patient with dementia about their pain can improve the treatment and its outcome (Cunningham, 2006). This attempt can be a simple yes/no question (Herr et al., 2006).

Although results show that patients with dementia are less likely to report pain, the studies of Herr et al. (2006) and Herr (2011) show that self-report is sometimes possible in patients with mild to moderate dementia, but that as dementia progresses, the ability to self-report decreases and self-report is no longer possible, due to the reliability. The decision whether the patient with dementia is no longer able to self-report is a challenging problem for clinicians (Herr, 2011). It is recommended to reevaluate the self-report by using understanding and by deciphering information as reliable or not before confirming a standard pain scale. This can be done by asking the patient where on the scale 'severe' pain might be and where 'mild pain' might be. Another option is to ask the patient to rate their pain, distract them for a while and ask the same question again. The answer should be the same if they are reliably reporting their current pain (Herr, 2011).

As said in the results, language skills change with dementia, which can affect the ability to report pain. This means that these patients have difficulties in word findings, naming objects and following instructions. When questioning a patient with dementia about their pain, phrasing is an important factor in the information obtained from older adults (Herr, 2011). Results show that repeating open-

ended questions results in helpful pain information from the patient. The three most responses received from open-ended pain questions are: about pain location, pain timing, and pain intensity. According to Herr (2011), open-ended questions solicit more pain information than close-ended questions. This also appears in patients with dementia. Studies suggests that patients with moderate dementia can still report pain when the pain questions are presented clearly and when there is adequate time for the patient to respond (Weitzel et al., 2011).

It is important to understand and find out how patients communicate about their pain (Cunningham, 2006). Patients with dementia may have difficulty in finding the right words and might even invent new words to describe familiar objects and words (Weitzel et al., 2011). Patients often deny the presence of 'pain', but confess pain when synonyms of the word 'pain' are used (Herr, 2011). Use synonyms for pain such as hurt, aching and discomfort. This helps the patient to understand the question and to encourage self-report (Hadjistavropoulos et al., 2007).

An important result shows that patients with dementia show pain through behaviour, such as facial expressions and other non-verbal behaviour. Previous study findings correspond to these results (Lu & Herr, 2012; Herr et al., 2011; Herr, 2011; Cunningham, 2006). To see if pain is present, an observed change in the patient's "normal" pattern can be observed (Herr, 2011). As Herr (2011) documents and as the results show, facial grimacing and facial expressions may be key indicators of pain in patients with dementia, and are useful and important in assessing pain in patients with dementia.

3.1.2 The nurse and assessing pain

Results show that patients and their families have fears about pain and pain treatments. Lu & Herr (2012) show that there are misconceptions about reporting pain in patients with dementia including a belief that nothing can be done to relieve the pain, a fear of consequences of acknowledging the pain, and/or a desire to not want to be bother to anyone.

Fears about pain and its treatment do not only appear in patients and their families, it also appears in the nursing staff. As shown in the results, limited knowledge and misconceptions about pharmaceutical treatment are common among nursing staff, and these misconceptions can affect pain assessment and its treatment. Cunningham (2006) points out that nurses have concerns about the addictive nature of narcotic analgesic drugs and the risks associated within these drugs. They also question the reliability of patients with dementia reporting their pain.

As is said in the results, nurses should work together with patients and their families. When this is done, the quality of life and the effectiveness of the pain management will increase. Herr, Coyne, McCaffery, Manworren, & Merkel (2011) says that nurses are the most important factor in ensuring proper assessment and treatment to vulnerable populations, like patients with dementia.

Communication problems between nurses and patients with dementia are likely to create a scenario wherein insufficient pain treatment is given due to the unrecognized pain in the patient.

3.1.3 Techniques to assess pain in patients with dementia

Self-report

As discussed earlier, self-report can primarily be successfully used with patients with mild to moderate dementia, but when dementia progresses, self-report is no longer possible. When questioning a patient with dementia about pain, not only verbal feedback can be used, but also alternative methods, such as head nods, hand squeezes, eye movement, or finger raising (Herr, 2011). The use of a pain assessment instrument is recommended by several studies such as (Hadjistavropoulos, et al., 2014). The Verbal Descriptor Scale (VDS) is valid, reliable, tested in acute care settings, is able to be completed and is preferred by most elderly patients with dementia. This tool is considered to be the easiest to understand and to implement (Herr, 2011). However, with this said, it is important to remember that nearly all the patients within the first stadium of dementia can complete self-report.

Pain behaviour

The results show that behaviour and pain are strongly related to each other. Change in behaviour in patients with dementia can be a signal for present pain. Patients with dementia showed the strongest facial expressions of pain, compared to patients without dementia. These results point out that the use of a behavioural observation tool is valid in assessing pain in patients with dementia. However, Herr (2011) shows that the number and type of pain behaviour presented by patients with dementia may vary and based upon the setting and activity level of the patient. Therefore making an assessment of pain difficult.

Many pain observation tools are developed and tested, but there are only a few pain observation tools which are studied and tested within the acute care setting, like that of a hospital. Pain behaviour tools can be used to evaluate the treatment effects, and to identify pain, but not to rate the pain intensity (Herr et al, 2011).

To choose a valid pain observation tool, the following conditions should be assured according to Herr et al (2006); reliability and validity, clinical feasibility (training required, time to complete), and support for population of interest and setting. In this case, the population of interest is patients with dementia in the hospital setting (acute care).

The following three pain behaviour tools are selected to examine according to their popularity, validity and research.

PACSLAC (Pain Assessment Checklist for seniors with Severe Dementia) is developed for non-communicative patients with severe dementia and consists of sixty items. This tool includes the categories listed in the American Geriatrics Society Guidelines. It is reliable, has good internal consistency and is clinically usable. It takes approximate five minutes to complete by a caregiver who is familiar with its use (Herr, 2011). Nurses who use the PACSLAC are positive about it, as they find it useful, user-friendly and feasible.

PAINAD (Pain Assessment in Advanced Dementia) is a short and simple tool with five items.

CNPI (Checklist of Non-verbal Pain Indicators) is a six item score tool, and is the only tool that has been tested for assessing acute pain in elderly. It is preferred tool to use in a hospital setting (Herr, 2011; Hadjistavropoulos et al, 2007).

Although these short behavioural tools may be more clinically feasible, they might not detect pain in patients with dementia who show less obvious behaviours. And, longer behavioural tools may be more sensitive, but they also might identify pain which may not be present (Herr et al, 2006). This problem shows that a multi-faceted approach to assessment of pain is necessary, as is shown in the results. This multi-faceted approach consists of self-report, observations of pain behaviour, and proxy rating.

Proxy ratings

In elderly patients who are unable to self-report, more sources of information are important to obtain as part of a multi-faceted pain assessment. As noted, nurses should work together with the family of the patient, and proxy rating is an example of an extra source of information. Family members or other persons who know the patient well, can give the nurse information about the social support, coping resources, normal behaviour, and pain behaviour of the patient (Hadjistavropoulos et al, 2007). Lu & Herr (2012) point out that changes in behaviour should raise suspicion of potential pain and again shows that behaviour observation is important in assessing pain in patients with dementia. As the results show, behaviour is often difficult to interpret and can lead to misinterpretation. While Herr et al. (2011) makes clear that there can be differences between opinions given by caregivers and family members about observed pain intensity, what is clearly apparent is that family members tend to overestimate the intensity of pain and caregivers tend to underestimate the intensity of pain. However, in acute care settings, family members are an important source of information, because nurses do not have a history with the patient and family members are most familiar with typical pain behaviour or changes in the 'normal' behaviour of the patient.

To understand the patient's pain experience and its effect on that patient, insight into the patient's history and social circumstances is crucial and fundamental to pain assessment (Hadjistavropoulos et al, 2007). When possible, use self-report and observational measurement strategies in patients with limitations in their ability to communicate. As stated in the results, self-report alone in patients with dementia is inadequate and the use of pain observation behaviour tools are needed.

3.1.4 Consequences of unrecognized pain in patients with dementia

The results show that pain can lead to persistent pain, which can lead to consequences for the patient, as well as for the nurses who care for the patient. Consequences named in the results do not show how the effects of persistent pain relate to the on the cognition of the patient with dementia. But, Cunningham (2006) shows that chronic pain has an effect on the cognition of patients who do not suffer from cognitive impairment. These consequences are; forgetfulness, difficulty finishing tasks, and attention difficulties. At least one of these consequences were reported by 55% of patients and these results can lead to an exacerbation of symptoms of dementia in patients who already suffer from cognitive impairment. This shows that persistent pain needs to be assessed early and needs to be managed properly.

Another affected group, are the nurses who care for patients with dementia. As shown, persistent pain can cause stress and burnout among nurses. Through assessing pain in a systematic way, it is proven that nurses will experience less distress and burden. An example of this is by employing a pain behaviour observation tool.

3.2 Methodological consideration

In this chapter the trustworthiness of this study will be discussed and described in relation to aspects of trustworthiness of qualitative studies. These chapters are; credibility, dependability, and transferability (Graneheim & Lundman, 2003). These chapters will be discussed separately, but need to be viewed as intertwined and interrelated.

3.2.1 Credibility

“Credibility deals with the focus of the research and refers to confidence in how well data and processes of analysis address the intended focus” (Graneheim & Lundman, 2003, p. 109), which will be described in this chapter.

The decision regarding what the study should focus on was the first priority in the process of this general literature analyses. The focus in this study was on ‘pain in dementia’ and ‘how to assess pain in patients with dementia’. This was chosen, because of its importance to the topic of pain assessment. The purpose of the study needed to be adapted, due to the outcome of the categories. The main purpose of the study was ‘how to assess pain in hospitalized patients with dementia’. However, the categories did not adequately answer the main purpose, but only gave information about pain in patients with dementia, the consequences of unrecognized pain, nurses and assessing pain, and the techniques for assessing pain. This is why the main purpose of the study changed to: “Pain in hospitalized patients with dementia, with focus on assessing pain.”

To select and find articles, a combination of key words were chosen and used in different databases. By using the same set of keywords in different databases, it was possible to improve the amount of research articles found which met the purpose of the study. When writing the results section, the keyword ‘pain management’ appeared several times in the found articles. This keyword could have been used while searching for articles, and could have resulted in finding more suitable articles.

Another useful method used to search for articles was ‘manual searches’ and ‘hand searches’. By screening the reference list of useful articles, other articles were selected and used in the study. This sort of search was used multiple times, and resulted in a limited use of databases employing keywords. Therefore, the use of databases could have been implemented more, but because the articles found through ‘hand- and manual searches’ were sufficient, the article search via a large number of databases was discontinued. Thirteen original articles were used. However, when the keywords were extended, the number of articles found, did increase.

The participants in the articles used for this study were two groups: patients with dementia and pain, and nurses/caregivers. The perspective of the articles were from those of a nurses. While this study is

written with a nursing perspective, it would be useful to include articles with the perspective of patients. Including information about the thoughts and behaviours of patients with dementia would be useful in improving their quality of care, as would glean more information from nurses' about their thoughts on this subject. However, the perspective of the patient with dementia can be seen as primarily unreliable, because of the impairment of cognition.

3.2.2 Dependability

"Dependability seeks means for taking into account both factors of instability and factors of phenomenal or design induced changes" (Lincoln & Guba, 1985, p. 299).

For this study, the literature that was sought and found, dates from 2006 until 2016. There is a ten year overlap in this literature, which might lead one to think that the results of those studies changed over time. However, comparing the results from 2006 and 2016, a major difference was not found. The results are currently still included in the further research section.

3.2.3 Transferability

"Transferability is the extent to which the findings can be transferred to other settings or groups" (Polit & Hungler, 1999, p. 717).

The articles used for this study include research in nursing homes and hospitals. The findings do not show great differences between the two settings where assessing pain is concerned. This increases the transferability of the findings, because the findings seem to appear in nursing homes, as well as in hospitals.

The outcome of this study is focused on the hospital setting, but can for all practical purposes be transferred to another care setting, like a nursing home. According to the literature used, this is because the character of dementia is the same in nursing homes as in hospitals, and because the way care is given in nursing homes is comparable to that of a hospital setting. The nurse is always the important link between assessing pain and the pain treatment administered.

The studied population were elderly (>65 years) with dementia and nurses/caregivers. The results showed characteristics of patients with dementia, but also showed that dementia is a wide concept and is a word that includes different types of dementia. This means that the characteristics of dementia enumerate different kinds of behaviour, but may not appear in all types of dementia. So, this necessitates that all the different stages and types of dementia and their characteristics be kept in mind while assessing pain in patients with dementia. This is a complex task, at best.

4. Conclusion

The purpose of this study is to shed light on pain in hospitalized patients with dementia, with focus on pain assessment. This conclusion is based on findings from the results and discussions

The characteristics of dementia and the lack of knowledge among nurses about pain in patients with dementia makes pain assessment difficult. This problem shows that the role of a nurse is important in ensuring assessment and treatment to this vulnerable patient category. To ensure proper pain assessment, a variety of implications to this dilemma need to be numerated. First of all, nurses should increase their knowledge about the characteristics of dementia and the influence of these characteristics on the perception and expression of pain. Second, nurses need to assess pain with a multi-faceted approach, this includes; self-report, observation of pain behaviour, and proxy rating while keeping in mind that no matter which stage of dementia the patient is in, self-report is the golden standard and it is the first thing to do with every patient. Third, nurses should learn which facial expressions and non-verbal behaviours are common in expressing pain, and how to assess pain with the help of these expressed pain behaviours. Fourth, the nurse needs to cooperate with the patient's family. This is an important intervention in the hospital, because the nurse does not know the patient and his/her history, nor does the nurse know the patient's 'normal' behaviour. Fifth, communication is very important in the care of a patient with dementia, therefore, the nurse needs to know how to properly communicate with this patient category to make pain assessment less difficult.

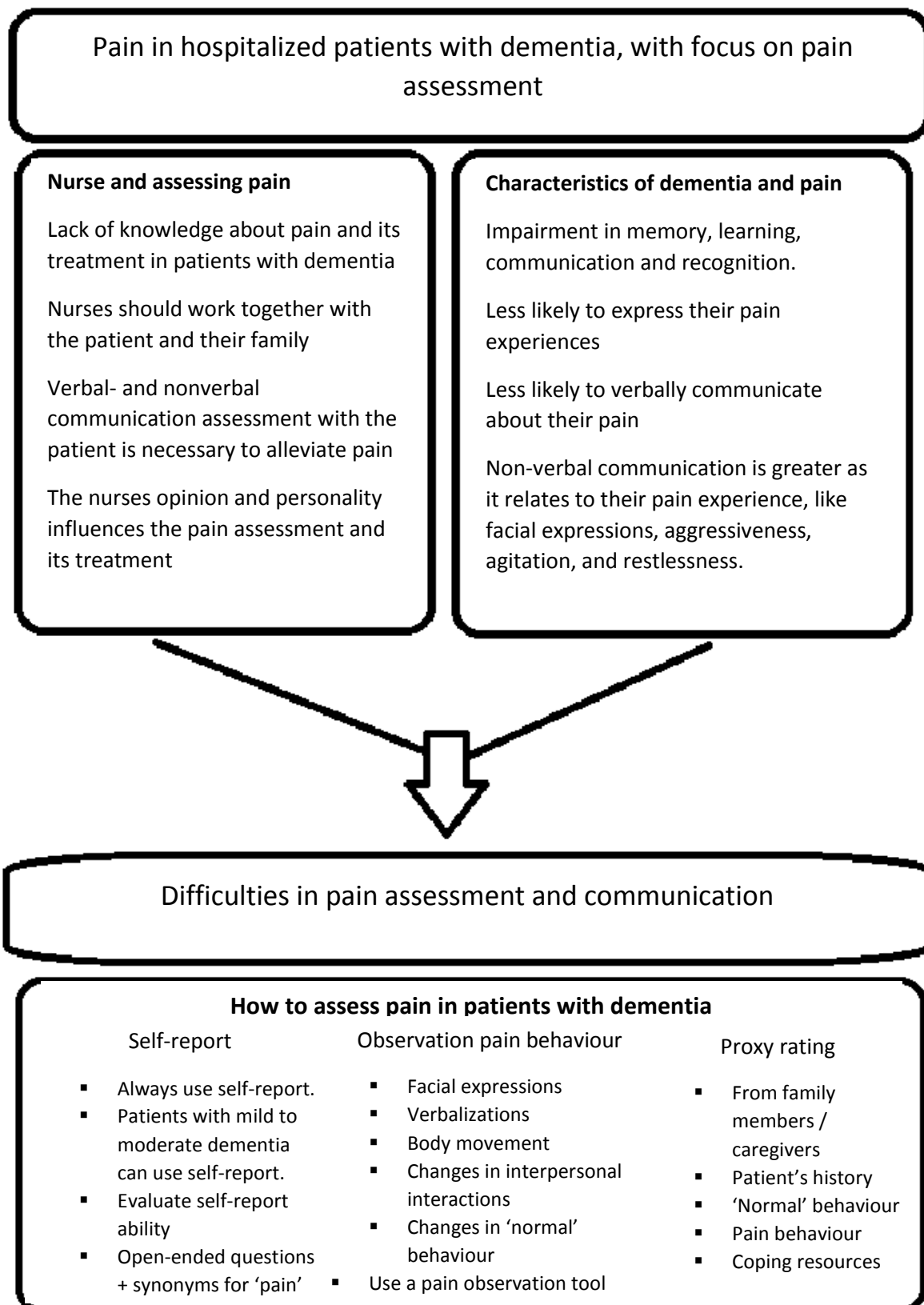
To assess pain in patients with dementia, a variety of pain assessment tools are available. However, the support for the patient with dementia and the setting are important to keep in mind while choosing a valid tool. Not all the tools are valid to use, and the chosen tool needs to be adjusted to the patient.

The main results of this study is illustrated in table 1.

Recommendations

To assess pain in patients with dementia, a pain assessment tool needs to be developed specifically for hospitalized patients with dementia and who suffer with acute pain. Another recommendation is to do a practical study about which pain assessment tool is most valid to use in hospitalized patients with dementia.

Table 1 'Conclusion pain in hospitalized patients with dementia, with focus on pain assessment.'



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Appendices

Appendix 1 – Overview of searching strategy

| Database | Limitations | Keywords | Matches | Selected 1 | Selected 2 | Selected 3 | Selected 4 |
|-----------------------|--------------------------------|--|---------|------------|------------|------------|------------|
| Medline 29-02-2016 | 2006-2016 Dutch and English | Hospitals OR in patients. Pain measurement AND Dementia AND Acute Pain OR Pain OR Postoperative OR Pain Measurement | 5 | 5 | 4 | 3 | 2 |
| Medline 29-02-2016 | 2006-2016 Dutch and English | Dementia AND pain. Inpatients OR hospitals. Pain measurement OR nursing assessment | 4 | 4 | 2 | 2 | 2 |

Selected 1: red the title

Selected 2: red the abstract

Selected 3: Red the entirely

Selected 4: Selected for further review

| Method of search <i>Date</i> | Limitations | Author or Title of article or Keywords | Results | Included |
|---------------------------------|-------------|--|---------|----------|
| Manual search 29-02-2016 | 2006-2016 | A.L. Horgas | 7 | 2 |
| Hand search 04-04-2016 | 2006-2016 | The response of agitated behaviour to pain management in persons with dementia | 1 | 1 |
| Hand Search 05-04-2016 | 2006-2016 | A comparative investigation of observational pain assessment tools | 1 | 1 |
| Hand search 05-04-2016 | 2006-2016 | Nurses' opinions of pain and the assessed need for pain medication for the elderly | 1 | 1 |
| Hand search 05-04-2016 | 2006-2016 | Decoding pain from the facial display of patients with dementia | 1 | 1 |
| Hand search 05-04-2016 | 2006-2016 | Older adults' pain descriptions | 1 | 1 |

| | | | | |
|---------------------------|-----------|--|---|---|
| Hand search 05-04-2016 | 2006-2016 | Under-detection of pain in elderly nursing home residents with moderate to severe dementia | 1 | 1 |
| Hand search 15-04-2016 | 2006-2016 | Influence of dementia on multiple component of pain | 1 | 1 |

Appendix 2 – Analysis Table

| Meaning unit | Sub-categories | Categories |
|---|--|---|
| <p>Persons with dementia:</p> <ul style="list-style-type: none"> - Memory and learning deficits - Difficulties with communication, reasoning, planning and recognition - Less likely to report pain than intact elders. - Reported pain experience every day than intact patients. - Reports shorter duration of pain - Less able to recognize and verbally communicate the presence of pain - Cannot determine if their pain has changed over time - Unable to describe characteristics of their pain - Unable to compare their current pain to their pain experience earlier. - Complain less about their pain and receive less pain medication in addition to cognitive intact patients. <p>Memory and language capabilities hinder the ability to recall and report pain in elders with dementia. Behavioural disturbance is often caused by pain in patients with dementia and can result in distress and burden among nurses. Patients with dementia showed stronger facial expressions of pain than without dementia. Persons with dementia display pain behaviours (facial expressions, limping, bracing) that are useful in pain assessment.</p> <p>Self-report and behaviour observations were highly related. Behaviours are often difficult to interpret and may be subject to bias and misinterpretation. Self-report alone is insufficient, observational pain assessment is needed. Facial expression, vocalization/verbalization and body movements may be the most important for identifying pain. The face alone is able to convey the necessary signals needed to notice pain in different groups of individuals to different degrees</p> <p>Use a hierarchical approach:</p> <ul style="list-style-type: none"> - Self-report - Observation - Proxy rating | <p>Difficulties in pain assessment</p> <p>Pain experience and dementia</p> <p>Behaviour and pain</p> <p>Facial expressions in general may be key indicators of pain in patients with dementia.</p> | <p>Characteristics of dementia</p> |
| <p>Self-report and behaviour observations were highly related. Behaviours are often difficult to interpret and may be subject to bias and misinterpretation. Self-report alone is insufficient, observational pain assessment is needed. Facial expression, vocalization/verbalization and body movements may be the most important for identifying pain. The face alone is able to convey the necessary signals needed to notice pain in different groups of individuals to different degrees</p> <p>Use a hierarchical approach:</p> <ul style="list-style-type: none"> - Self-report - Observation - Proxy rating | <p>Pain assessment through self-report and behaviour observation</p> <p>Pain behaviour measurements should be used in conjunction with self-report, not as a replacement.</p> <p>Assessing pain in patient with dementia, should include proxy. Family member should have input in assessing pain.</p> | <p>Techniques to assess pain in patients with dementia</p> |

Nurses who ask repeated open-ended questions are likely to collect additional helpful pain information from the patient

Professional caregivers experiences stress and burnout due to Patient's disruptive and aggressive behaviour.

Consequences:

- Functional decline
- Social isolation
- Depression
- Increased prevalence of suicidality
- Increased health care utilization
- Delirium

Awareness of pain in patients with dementia can help caregivers to provide more effective care for these groups of patients, resulting in an improvement in their quality of life and reduction in health care costs.

Nurses should encourage patients to report their pain and alleviate the fears associated with pain and treatments

- Communicate with the patient, verbal information and non-verbal behaviours.

Registered nurses who displayed stress or showed concern about pain caused the patient to be silent.

Opinion about patient influences the choice of medication.

Nonverbal clues given by the smiling patient made it difficult for the nurse to assess the pain and therefore administer correct pain medication.

Nurses with longer work experience are less sensitive to their patients' needs than nurses with less experience.

Professional training of nurses and caregivers probably does not include sufficient guidance in how to read and interpret the facial display of pain in others and that such a competence does not develop out of itself due to experience.

Health care providers may worry about the potentially adverse effect of more powerful drugs such as nonsteroidal anti-inflammatory drug or narcotic drugs.

Nurses have limited knowledge and misconception about pharmacological treatment, which can influence pain assessment and its treatment.

Unrecognized pain leads to numerous consequences, for the patient, but also for the caregiver.

Consequences of unrecognized pain in patients with dementia

Awareness of pain improving quality of life

Nurses do have an important role in the treatment of the patient.

The nurse and assessing pain

Knowledge and actions of nurses

Appendix 3 – Overview of included articles

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|--|--|---|---|---|
| 1 | Ann. L. Horgas Austin Lee Nichols, Caissy A. Schapson, Krystal Viets (2007) USA <i>Pain management Nursing</i> | Evaluating reliability of the NOPPAIN (Patient's pain assessment instrument) | Qualitative study Observations Observations by using NOPPAIN. An observation tool for assessing pain in patients with dementia. | 20 cognitively impaired elderly (mean MMSE score: 17) 20 cognitively intact elderly (mean MMSE score: 27) The mean age of the participants was 83 years and the majority were female. | In 95% of the participants, at least one pain indicator on the NOPPAIN was observed. Bracing (90%) and pain noises (43%) were the most frequently indicators to be observed. The least observed indicators were, pain words (5%) and rubbing (2, 5%). There is a correlation found between the NOPPAIN worst pain rates and self-report of cognitively intact participants on both VDS and NRS. NOPPAIN overall intensity rating was significantly correlated with self-reported pain intensity, but only in cognitively intact elders. The NOPPAIN can be reliably and easily used to assess behavioural indicators of pain without extensive staff or training burden. |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|--|--|--|---|---|
| 2 | Shannon Fuchs-Lacelle, Thomas Hadjistavropoulos, Lisa Lix (2008) Canada <i>The clinical journal of pain</i> | Determining whether systematic pain assessment leads to improved pain management practices and decreases nursing stress in comparison with a control condition | Qualitative and quantitative study Pain assessment checklist and survey's PACSLAC Nursing stress scale | 101 patients with presence of dementia and severe communication impairment and over the age of 65. 61 Nurses working in a unit which was included in the research. | Studies provided additional prospective information and showed that the PACSLAC had good reliability and validity and that nurses preferred it over two other pain assessment measures that were also designed for seniors with dementia. Resident pain can lead to patient disruptive and aggressive behaviour, which could lead to caregiver stress and burnout. Use of PACSLAC results in increased usage of medications that were prescribed on an "as needed" basis, but it also led to reduces levels of caregivers stress and burnout. Use of PACSLAC did not affect administration of regularly scheduled medications. |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|---|--|---|---|---|
| 3 | Ann. L Horgas Amanda F. Elliott. Michael Marsiske (2008) USA | Investigation about the relationship between self-report and behavioural indicators of pain in cognitively impaired and intact older | Qualitative and Quantitative design Interviews, pain measurements MMSE, activity based protocol | 126 adults, mean age of 83 years. 64 cognitively intact and 62 cognitively impaired elderly | 86.5% of the participants reported experiencing pain every day or almost every day. But less cognitively impaired elderly reported pain (77.4%) against 95.3% of the cognitively intact elderly. Also cognitively impaired elderly reported shorter pain duration than intact elderly. There are no differences found in behavioural pain indicators between de impaired and intact elderly. |

| | | | |
|--|------------------------------|------------------------------|---|
| <i>The American Geriatrics Society</i> | adults with persistent pain. | NRS, Pain behaviour Measure. | The research confirms that reliance on self-report alone is not enough to assess pain in older adults with dementia, because the pain experience may be underestimated. |
| | | | Pain is subjective and pain behaviour can be difficult to interpret. Behavioural observation must be used in conjunction with self-report, not as a replacement. |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|---|--|---|---|---|
| 4 | Amy S. Kelly, Eugenia L. Siegler, m. Carrington Reid. (2008) USA <i>American Academy of Pain Medicine</i> | To review cases of older demented adults with pain admitted to an inpatients geriatric medicine service, and to identify difficulties in their management, which arise as a consequence of patients' dementia. | Qualitative study Case series | Adults aged 70 years and older with dementia and pain | <p>Patients with dementia often lack the ability to determine whether their pain has materially changed over time.</p> <p>They also may not remember to request or dose medication as needed. Also they may not recognize when pain represents a side effect, leading to inappropriate escalation of pain regimes.</p> <p>Patients with dementia are unable to recognise the variations in the level of pain or compare the current pain to their experience earlier that day or hours before.</p> <p>Patients with dementia may be able to self-report pain and ascribe a scaled value to its severity. They are frequently unable to describe the qualitative characteristics and associated features of their pain. This may lead to delayed or incorrect diagnosis.</p> <p>There is a need to conduct a cognitive assessment of older hospitalized patients with pain with a particular focus on the patients' short-term memory.</p> |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|---|--|--|---|--|
| 5 | M. Kunz, v. Mylius, S. Scharmman, K. Schepelman, S. Lautenbacher. (2009) Germany and Canada <i>European Journal of Pain</i> | To research the influence of dementia on multiple components of pain | .Qualitative study Observation, self-report | 35 patients with dementia, according to MMSE score and 46 cognitive healthy elderly above 65 years. | <p>46% of the patients with dementia could not provide a self-report rating, these patients had a decreased level of cognitive function.</p> <p>Frequency and intensity of facial expressions among patients with dementia were higher than cognitive intact patients.</p> |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|---|---|--|--|---|
| 6 | D.D. McDonald (2009) USA <i>The American Society for Pain Management Nursing</i> | To describe the types of pain information described by older adults | Qualitative study Focus groups, Content Analysis, questionnaires. | 207 community dwelling older adults with osteoarthritis. | Three most responses to open-ended pain questions are: <ul style="list-style-type: none"> - About pain location - About pain timing - About pain intensity The most response to closed-ended pain questions about pain intensity are: <ul style="list-style-type: none"> - 90.6% responded about pain intensity Practitioners who ask repeated open-ended pain questions are likely to elicit additional helpful pain information. |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|---|--|--|---|---|
| 7 | Brown, S. T. et al (2011) USA <i>Pain Management Nursing</i> | To assess the prevalence of pain in elderly in the community, to describe their pain experience and to describe the strategies they found useful in managing pain. | Qualitative study Questionnaires SF-MPQ, BPI, Pain Assessment Tool | 124 elderly (>60 years), speaking English, living at home or in assisted living residence | Over 85% of the participants experienced moderate to severe pain in the months preceding the interviews. And 28% of those participants experienced continuous pain. 75% of the participants reported the pain to be in the musculoskeletal regions of the body. 60% reported experiencing pain occasionally and the pain was at its worst in the morning and evening. The occasions where the pain interferences, were walking, general activity, mood and enjoyment of life. Consequences of chronic pain: <ul style="list-style-type: none"> - Depression - Social isolation - Sleep disturbance - Decreased ambulation - Decreased enjoyment in life - Altered social relationships Nurses need to stay abreast of new management strategies. Patients should also be encouraged to report their pain. Nurses should inform the patient and its family about pain, and to alleviate the fears that are associated with pain and pain treatments. |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|--|---|---|--|--|
| 8 | Zwakhalen et al (2012) The Netherlands <i>Journal of Clinical Nursing</i> | To investigate the feasibility of regular pain assessment using an observational scale in nursing home residents with dementia. | Qualitative study Observations and interviews PACSLAC-D | 22 residents of a psychogeriatric nursing home ward Six nursing staff members | <i>PACSLAC-D</i> PACSLAC-D is clinical useful because of its high completion rate by the study findings. The staff experience about the PACSLAC-D was positive, it is useful, user friendly and feasible. Although score interpretation and interpreting pain cues were reported as complicated. Adequate pain registration (90%) did not result in the frequent use of pain relieving nursing interventions. |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|---|---|--|---|---|
| 9 | Lints-Martindale et al. (2012) Canada Clinical journal of Pain | to compare observational pain assessment measures for seniors with dementia with respect to Psychometric properties directly. | Qualitative study Observations Observations assessment scales | 124 residents of long term care facilities with moderate to severe dementia and limitations in ability to communicate | The PACSLAC accounted for significant variance in the differentiation over and above any of the other measures (after all other measures were controlled for and even after the delirium-related items were excluded) provides strong support for the validity of the tool and for the importance of incorporating a comprehensive coverage of the AGS-pain assessment domains in a pain tool. That facial expressions, vocalizations/verbalizations, and body movements may be most important for identifying pain, whereas the last 3 domains may provide additional information regarding general distress. scores on observational tools can be affected by factors such as duration of observation (ie, the longer the duration, the more behaviours will be observed) and situational characteristics |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|---|---|---|--|---|
| 10 | Kjällman et al (2013) Sweden <i>The American Society for pain management nursing</i> | To investigate the opinions of registered nurses regarding pain and the assessed need for pain medication for elderly patients using patient scenarios. | Qualitative study Questionnaires (56) Patient scenarios | Registered nurses working daytime in elderly care in municipal nursing homes and municipal home care in the mid-Sweden region. | Discrepancy between the patient's reported pain and the registered nurses' opinion is due to conflicting nonverbal cues that differed from metacommunication. The nonverbal clues given by the smiling patient in the scenarios made it difficult for the nurses to assess pain and therefore administer correct pain medication. Nurses with longer work experience (>10 years) were less sensitive to their patients' needs than their colleagues with less experience. |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|--|---|---|-------------------------------|---|
| 11 | Lautenbacher et al. (2013) Germany <i>Pain Medicine</i> | To investigate whether the competence of observers to decode pain from the facial display of patients with dementia is indeed comparable to the decoding competence for young and older individuals without cognitive impairment. | Qualitative study Observation | Nurses and non-professionals' | Professionals and non-professionals do not differ in rating pain intensity. Pain was rated as being more intensive in women and older individuals. Most pain was seen when the observed individual was cognitively impaired. Professional training of nurses probably does not include sufficient guidance in how to read and interpret the facial display of pain. And that this competence does not develop out of itself due to experience. The facial expression alone is able to convey the necessary signals needed to notice pain in different groups of individuals to different degrees. |

Patients with dementia showed the strongest facial display of pain.

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|---|--|---|--|---|
| 12 | Miu et al (2014) China <i>Journal of Clinical Gerontology & Geriatrics</i> | To describe the prevalence of pain in patients with dementia residing in nursing homes, to identify the association of pain with the use of analgesic drugs and to identify the risk factor for pain in this group of patients | Qualitative study Observations PAINAD-C | 309 patients living in nursing homes with moderate to severe dementia. | 54% of the participants showed behavioural disturbance. 58% showed verbal disruption Pain was present in 61.5% in the patients, only 31% of these patients were treated with analgesic drugs. The higher the level of cognitive impairment, the more intensely pain was experienced. Pain in dementia with severe dementia was both under-detected and under-treated. |

| Article | Author, Year Country Journal | Purpose of the study | Design/ Intervention/ Instruments | Sample | Main results |
|---------|--|---|---|---|---|
| 13 | Husbo et al (2014) Norway <i>American Journal of Geriatric psychiatry</i> | To research which specific agitated behaviours respond to individualized pain treatment | Qualitative study Cluster randomized clinical trial 60 clusters | 352 patients with moderate to severe dementia and clinically significant behavioural disturbances | Verbal agitation behaviours responded to pain treatment. Restlessness and pacing were sensible to pain medicines. Such behaviour should lead to an assessment of pain and pain treatment. |