



Bachelor's Thesis

**THE CHALLENGES OF PAIN ASSESSMENT IN
DEMENTIA PATIENTS**

A Literature Review from a Nursing Perspective

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Degree Thesis

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The Challenges of Pain Assessment in Dementia Patients

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Abstract:

Dementia is an umbrella term for various memory diseases, such as Alzheimer's disease, that cause cognitive functions to deteriorate. Signs and symptoms of dementia include facial expressions, body movements, vocalization, and changes in mood and vital signs. Due to expressions of pain being difficult to recognize and often being interpreted as symptoms of dementia, it is vital for nurses to have knowledge and access to tools that help when assessing pain to ensure proper pain management. This thesis aims to identify any challenges of assessing pain in dementia patients from a nursing perspective while enhancing and maintaining the care of pain. This literature review examines dementia, its symptoms, and signs as well as its multiple subtypes. In addition, pain and pain assessment tools are analyzed in-depth. This literature review contains 19 articles that are no more than 10 years old, written in English or Finnish, peer-reviewed, relevant to the topic, and found on scientific databases. Data was systematically collected from databases PubMed, CINAHL (EBSCO), and ScienceDirect, and further analyzed by using an inductive content analysis. The results of this literature review concluded that the amount of experience and educational backgrounds of nurses and the lack of reliable pain tools designed specifically for patients with dementia are the main obstacles to pain assessment. Although many pain scales have been proven appropriate for dementia, they still require additional testing. Limitations include restricted time and a limited number of free articles relevant to the thesis topic.

Keywords:

Pain assessment, challenges, dementia, tools, instruments, scales, pain scale, pain tools

Lärdomsprov

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Utmaningar med att bedöma smärta hos patienter med demens

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Sammandrag:

Demens är ett samlingsnamn för olika minnessjukdomar, till exempel Alzheimers sjukdom, som påverkar människans kognitiva funktion. Tecken och symptom på demens innehåller ansiktsuttryck, kroppsrörelser, vokalisering, och ändringar i humör samt vitalparametrar. Eftersom smärtuttryck är svåra att identifiera och ofta tolkas som symptom av demens, är det ytterligt viktigt för sjukskötare att ha kunskap samt tillgång till verktyg som hjälp i smärtskattning för att garantera korrekt smärtlindring. Syftet med detta lärdomsprov är att identifiera eventuella utmaningar relaterade till smärtbedömning hos demenspatienter ur ett omvårdnadsperspektiv medan samtidigt förbättra samt bibehålla smärtvård. Denna litteraturrecension innehåller 19 artiklar inte mer än 10 år gamla, skrivna på engelska eller finska, kvalitetsgranskade, relevanta för ämnet, och samlade från vetenskapliga databaser. Datainsamling genomfördes systematiskt med bruk av databaserna PubMed, CINAHL (EBSCO), och ScieceDirect, och insamlade artiklar analyserades som en induktiv innehållsanalys. Resultaten visar att erfarenhet och utbildningsbakgrund, samt brist på pålitliga smärtskalor gjorda specifikt för patienter med demens är huvudsakliga hinder för smärtskattning. Även om ett mångtals smärtskalor har bevisats vara lämpliga för demens behövs ytterligare provning. Begränsningar inkluderar begränsad tid för att fullfölja detta lärdomsprov och en smal mängd med gratis artiklar relevanta för denna rubrik.

Nyckelord:

Smärtskattning, utmaningar, demens, verktyg, instrument, skalor, smärtskala, smärtskattningsverktyg

Opinnäyte

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Haasteet dementiapotilaan kivun arvioimisessa

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Tiivistelmä:

Dementia on kattotermi monelle erilaisille muistisairauksille, kuten Alzheimerin taudille, jotka aiheuttavat kognitiivisten toimintojen heikkenemistä. Dementian oireita ja ennusmerkkejä ovat kasvon ilmeet, kehonkieli, fonaatio ja muutoksia mielialassa ja vitaalielintoiminnoissa. Koska kivun ilmenemismuotoja on vaikea tunnistaa ja ne voidaan tulkita dementian oireiksi, on erittäin tärkeää, että sairaanhoitajilla on tietoa sekä käytettävissään työkaluja, jotka auttavat kivun arvioinnissa oikean kivunhallinnan varmistamiseksi. Tämän opinnäytetyön tarkoitus on havaita dementiapotilaiden kivun arvioinnin haasteet hoitotyön näkökulmasta ja samalla edistää ja ylläpitää kivunhoitoa. Kirjallisuuskatsaus tutkii dementiaa, sen oireita ja ennusmerkkejä, sekä dementian monia alatyyppejä. Näiden lisäksi, kirjallisuuskatsauksessa analysoidaan syvällisellä tasolla kipua ja siihen liittyviä kivunarviointimenetelmiä. Tämä kirjallisuuskatsaus sisältää 19 artikkelia, jotka ovat enintään 10 vuotta vanhoja, jotka ovat kirjoitettu englanniksi tai suomeksi, vertaisarvioituja, aiheeseen liittyviä ja löydetty tieteellisistä tietokannoista. Tiedot kerättiin systemaattisesti tietokannoista PubMed, CINAHL (EBSCO), ja ScienceDirect ja analysoitiin induktiivisessa sisältöanalyysissä. Kirjallisuuskatsauksen tuloksissa pääteltiin, että sairaanhoitajien kokemuksen ja koulutustaustan määrä sekä luotettavien, erityisesti dementiapotilaille suunniteltujen kivunarviointimenetelmien puutteet ovat suurimmat esteet kivun arvioinnissa. Vaikka monet kipuasteikot ovat todistettu sopiviksi dementiapotilaille, ne silti vaativat lisätestejä. Rajoituksiin sisältävät rajoitteeton ajan ja rajallisen määrän ilmaisia opinnäytetyön aiheeseen liittyviä artikkeleita.

Avainsanat:

Kivun arviointi, haasteet, dementia, apuväline, työkalu, mittari, kipumittari, kivun arvioinnin apuväline

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Abbreviations

APS – Abbey Pain Scale

ADD – Assessment of Discomfort in Dementia

CMAI – Cohen-Mansfield Agitation Inventory

CNPI – Checklist of Nonverbal Pain Indicators

DS-DAT – Discomfort Scale for Dementia of the Alzheimer’s Type

DSD – Delirium Superimposed Dementia

ePat – electronic Pain Assessment Tool

FPS – Faces Pain Scale

MOBID-2 – Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale

MPS – Mahoney Pain Scale

NOPPAIN – Non-Communicative Patient’s Pain Assessment Instrument

NRS – Numeric Rating Scale

PACSLAC – Pain Assessment Checklist for Seniors with Limited Ability to Communicate

PADE – Pain Assessment for the Dementing Elderly

PAINAD – Pain Assessment in Advanced Dementia

PAINE – Pain Assessment in Noncommunicative Elderly Persons

REPOS – Rotterdam Elderly Pain Observation Scale

VAS – Visual Analogue Scale

VDS – Verbal Descriptor Scale

VRS – Verbal Rating Scale

1 Introduction

Dementia as a patient group is vastly growing due to the aging population, making pain assessment an increasingly important part of patient care. Due to the various difficulties resulting from dementia, such as limited communication and underestimation of pain, it is of utmost importance for nurses to assess pain holistically from an observational position.

An overview of symptoms and signs of dementia, as well as different subtypes of dementia will be discussed thoroughly in the background chapter. To ease the pain assessment, many pain assessment tools have been designed for healthcare workers that focus on dementia patients' pain.

2 Background

Duodecim Käypä hoito defines pain as an uncomfortable experience resulting from disease or injury (Duodecim Käypä hoito, 2017). The nurse has a significant role in pain assessment and care as a whole as they must diagnose pain in patients with the help of proper pain assessment tools. The foundation of pain assessment is the patient's own experience of pain (Kipu, 2017). This can however be difficult to implement into nursing care of elderly patients with dementia, for they might be unable to express pain. Studies suggest that pain in patients with dementia often goes unnoticed and thus undertreated due to difficult pain assessment (Kim et al., 2017). This is partly due to signs of pain in memory disorders having similarities with behavioral and psychological symptoms of dementia BPSD (Malara et al., 2016).

Dementia is an umbrella term for diseases that affect cognitive functioning (World Health Organization, 2023). It is a syndrome that is always caused by a disease, such as Alzheimer's disease, Lewy-Body Dementia (LBD), stroke-associated dementia, vascular dementia, and long-term advanced Parkinson's disease (Juva, 2021). Approximately 60% of patients suffering from memory disorders are diagnosed with Alzheimer's disease, making it the most common form of dementia (Muistiliitto, n.d.). In 2021, approximately 150,000 people were suffering from dementia in Finland and this number is expected to rise to 247,000 in the year 2024 (Terveyden ja Hyvinvoinnin laitos, 2024). According to the World Health Organization, there are over 55 million people who have memory disorders globally (World Health

Organization, 2023). Approximately 60% to 80% of patients living with memory disorders experience pain daily (Achterberg et al., 2020).

2.1 Symptoms and Signs of Dementia

The severity of the symptoms related to dementia varies depending on the stage of the disease. Common symptoms of the early stage of dementia include short-term memory problems, such as forgetting notable events, difficulty finding words, apathetic behaviour and signs of hopelessness, frequent falls, or imbalance, and avoiding social interactions (Arvanitakis et al., 2019). Individuals may lose or misplace belongings, become easily confused, experience decision-making difficulties, and get lost in familiar environments (Alzheimer's Society, 2021a).

Middle-stage dementia causes signs and symptoms of the initial stages to become exceedingly visible, also including anxiety and distress, possible hallucinations and delusions, shouting, repetitive and inappropriate behaviour, trailing or following people, and sleep problems (Alzheimer's Society, 2021b).

These symptoms become progressively worse in the advanced stages of the disease, and oral communication can be limited to a couple of words or non-existent (Alzheimer's Society, 2021c). Individuals with dementia in this stage also experience decreased function of working memory, wandering during the night, repetitive behaviour, and aggressive behaviour, and they are unaware of the disease (Arvanitakis et al., 2019).

2.2 Pain

When assessing pain in patients, nurses must detect the type and location of pain. Pain is classified as either acute if it lasts for less than 1 month, or as chronic, also called persistent pain, if it continues for more than 3 months (Duodecim Käypä hoito, 2017). These can also be further divided into nociceptive pain, neuropathic pain, or visceral pain (Duodecim Käypä hoito, 2017) Untreated pain can lead to sleep problems, loss of appetite, delirium, and lack of performance.

It is inevitable that once time passes by people get older. The way the human body reacts to pain depends on the life stage, as aging affects pain mechanisms. The peripheral nervous system degenerates and the tactile sense weakens, while the heat-sensing threshold grows (Löppönen, 2023). Elderly patients with dementia also have diminished emotional experiences of pain and pain memory (Löppönen, 2023). Mullins et al. mentions that presbylagos results from aging (2022). This means that peripheral and central nervous system pathways involved in the processing of painful stimuli have a reduced ability to recognize negative signals due to the deterioration of structure (Mullins et al., 2022). Also, the maximum pain intensity that an individual can bear is either reduced or unchanged with aging (Mullins et al., 2022).

2.2.1 Non-verbal Signs of Pain

Identifying signs and symptoms of pain is vital to appropriately assess pain and maintain functional ability (Löppönen, 2023). Verbal expression of pain becomes challenging as dementia progresses and can instead be indicated through behaviour change, such as anxiety, withdrawal, restlessness, and agitation (Löppönen, 2023). The American Geriatrics Society suggests observing facial expressions, vocalization, body movements, mental state, and daily activity to reliably assess pain once verbal communication is not possible anymore (Löppönen, 2023).

Facial expressions are a vital part of non-verbal communication as they are a direct indication of an individual's feelings, such as sadness, happiness, fear, and anger. Furrowed brows, clenched jaw, wrinkled nose, narrowed or closed eyes, and a raised upper lip are all strong indicators of discomfort (Booker & Haedtke, 2016).

Body movements are, similarly to facial expressions, strong signs of pain. These include a change in gait, rubbing or guarding a body area, a tense body, a decrease in movement activity, rocking, fidgeting, and repetitive behaviour (Booker & Haedtke, 2016).

Autonomic symptoms can be indicators of the presence of pain, such as changes in vital signs and breathing, including fast and shallow breaths (Booker & Haedtke, 2016). These

should, however, not be trusted alone, for underlying diseases or medications can impact vital signs (Booker & Haedtke, 2016).

Vocalization that is abnormal from the normal behaviour of a patient requires nurses to know them to an extent. Behaviour such as shouting, swearing, crying, moaning, sighing, and praying can indicate that the patient is in pain (Booker & Haedtke, 2016).

Social interactions become increasingly difficult as dementia progresses. Signs include aggression in care situations, such as showering and isolating oneself from social situations (Booker & Haedtke, 2016).

Change in mood consists of delirium, depressive symptoms, agitative behaviour, irritability, crying, diminished executive function, worsening condition, and decline of cognition issues (Booker & Haedtke, 2016).

2.2.2 Pain Assessment Tools

Pain assessment scales are divided into either self-observing tools or observational tools, depending on how a patient is able to communicate. Verbal Rating Scale (VRS), Numerical Rating Scale (NRS), Visual Analogue Scale (VAS), and Faces Pain Scale are well suited for patients able to self-report pain (Löppönen, 2023). Booker and Haedtke state that studies have found the most reliable pain assessment tools to be Pain Assessment in Advanced Dementia Scale (PAINAD), Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC or PACSLAC-II), Discomfort in Dementia of the Alzheimer's Type (DS-DAT) when assessing pain in patients with dementia unable to communicate pain verbally (2016). Furthermore, several pain scales have been found reliable when assessing pain in patients with dementia unable to communicate pain verbally (Löppönen, 2023).

3 Theoretical Framework

A theoretical framework is a key variable as it works as a guide in nursing research. A theoretical framework is a fundamental evaluation of numerous theories whose sole purpose is to act as a guide to evolve beliefs and theories that will be used in own works. Different

theories are supposed to illustrate the phenomenon of a study. A theoretical framework aids in justifying a phenomenon from a specific viewpoint and expands knowledge while staying within the borders of that viewpoint (Luft et al., 2022). In other terms, it means that the theoretical framework is a basis for each study giving more meaning to the aim and research questions (Luft et al., 2022).

With the use of a theoretical framework, a better understanding will deepen the intention of how nurses can assess pain with the use of different pain assessment tools that are designed for patients with dementia who cannot verbally express their pain level.

3.1 Deliberative Nursing Process Theory by Ida Jean Orlando

Ida Jean Orlando published the literature *The Dynamic Nurse-Patient Relationship: Function, Process, and Principles* (NLN Classics in Nursing Theory) in 1961, which includes the Deliberative Nursing Process theory. Ida Jean Orlando's theory of the *Deliberative Nursing Process* was created to examine a patient's behaviour since any kind of behaviour can be a sign of distress and pain even if a patient is verbal or non-verbal, and especially when a patient has a memory disorder. (Petiprin, 2016).

The Deliberative Nursing Process is made up of five separate phases: assessment, diagnosis, planning, implementation, and evaluation. (Petiprin, 2016). The Nursing Process takes an initiative in patient-fixed care with the steps mentioned above. Orlando's theory is still in use today. The theory is defined as a precise attitude towards care with the use of analytical reasoning, patient-centered care, target driven tasks, empirical-based practice, and nursing instinctiveness (Toney-Butler & Thayer, 2023). Orlando's theory is called Deliberative because she believed that a nurse should function in a deliberative manner rather than impulsively. (Petiprin, 2016).

Assessment is the first phase of the Nursing Process. A holistic overview assessment is applied by the nurse. A nurse must have analytical skills to evaluate the need for care. This includes subjective and objective information-gathering. Subjective information-gathering is a method where the patient approaches the nurse verbally with their own experiences. Objective information-gathering is a data collection method that relies solely on every

method that focuses on tactile and numerical results, such as vital signs (Toney-Butler & Thayer, 2023).

Diagnosis requires clinical awareness in order to appropriately formulate a nursing care plan that proceeds to fulfil the patient's needs (Toney-Butler & Thayer, 2023).

Planning is the third essential phase where end objectives are conducted and taken into consideration in the nursing care process. A nursing care plan plays a significant role, which contributes to a desired path for taking care of a patient (Toney-Butler & Thayer, 2023).

Implementation focuses on the acts that were planned in the previous phase, this includes nursing interference (Toney-Butler & Thayer, 2023).

Evaluation is the end outcome of the whole nursing process. A nurse must assess if the nursing care plan has met the end goal and whether any changes have happened (Toney-Butler & Thayer, 2023).

Although the Deliberative Nursing Process has significant phases, this theory also includes a more in-depth description. Orlando focused more on the nurse-patient relationship as an entirety. Orlando believed that the way the nurse acted towards a patient somewhat affected them and vice versa. Orlando also believed that a nurse should not assume anything about the patient but instead have their full focus on the care of the patient. (Alligood, 2013, pp. 285–302).

The Deliberative Nursing Process was chosen for the theoretical framework for this study as the theory includes an assessment phase. Although Orlando's theory consists of other significant phases that are included in the nursing process, the research question and aim focus is more on the assessment aspect.

Orlando's theory supports this study because in the healthcare field and working with dementia patients, signs of pain and distress can go unnoticed due to poor pain assessment skills endured by nurses. Assessing pain can be rather difficult, but the use of specifically designed pain assessment tools for patients with dementia might be beneficial for nurses and the improvement of care. In any circumstance, assessment is the key answer.

4 Aim and Research Questions

This literature review aims to identify the challenges of assessing pain in dementia patients and explore tools that can be used to enhance the care of pain from a nursing perspective.

Two research questions have been created to answer the aim of the study.

Research questions:

1. What are the challenges that nurses encounter in assessing a dementia patient's pain?
2. What tools are available for nurses to optimally treat pain in dementia patients?

5 Methodology

This thesis was conducted as a qualitative literature review to inspect prevalent research about the challenges of assessing pain in dementia patients. This included a large analysis of pre-existing research aiming to answer the research questions (Brodsky, n.d.). Knowledge production is constantly and quickly evolving, which makes it difficult to keep up with the most current knowledge (Snyder, 2019). The amount of pre-existing data is the reason for why literature review was chosen as the method of this thesis, for the authors aimed to analyse a large quantity of diverse information in a brief time. By conducting a literature review, the authors of this thesis were able to “provide an overview of areas in which the research is disparate and interdisciplinary” (Snyder, 2019).

5.1 Data Collection

The data used for this literature review was searched from different academic databases such as ScienceDirect, PubMed, and CINAHL (EBSCO) to ensure credible and reliable articles from the search. *Figure 1* provides a flowchart of the data collection. This figure consists of different academic databases including keywords and the number of hits resulting from each search. The search included keywords such as “pain assessment”, “challenges”, “dementia”, “tools”, “instruments”, “scales”, “pain scale”, and “pain tools”. All these keywords are related to the topic of this literature review. Boolean operators, i.e., the words ‘AND’ and ‘OR’ were used to ensure a specified and broader search result. Inclusion and exclusion factors were created for the search outcome to be desirable and acted as a leading example when searching for valid publications (*Table 1*). Titles that contained words related to the thesis aim and questions were saved to a shared Word document after which each abstract was read. Articles that provided information in their abstracts relevant to this thesis were then picked for further analysis. Titles that contained words irrelevant to this thesis were excluded from abstract reading. Altogether, 19 articles were selected to be analyzed and form the results chapter of this thesis.

Figure 1: Flowchart of data collection

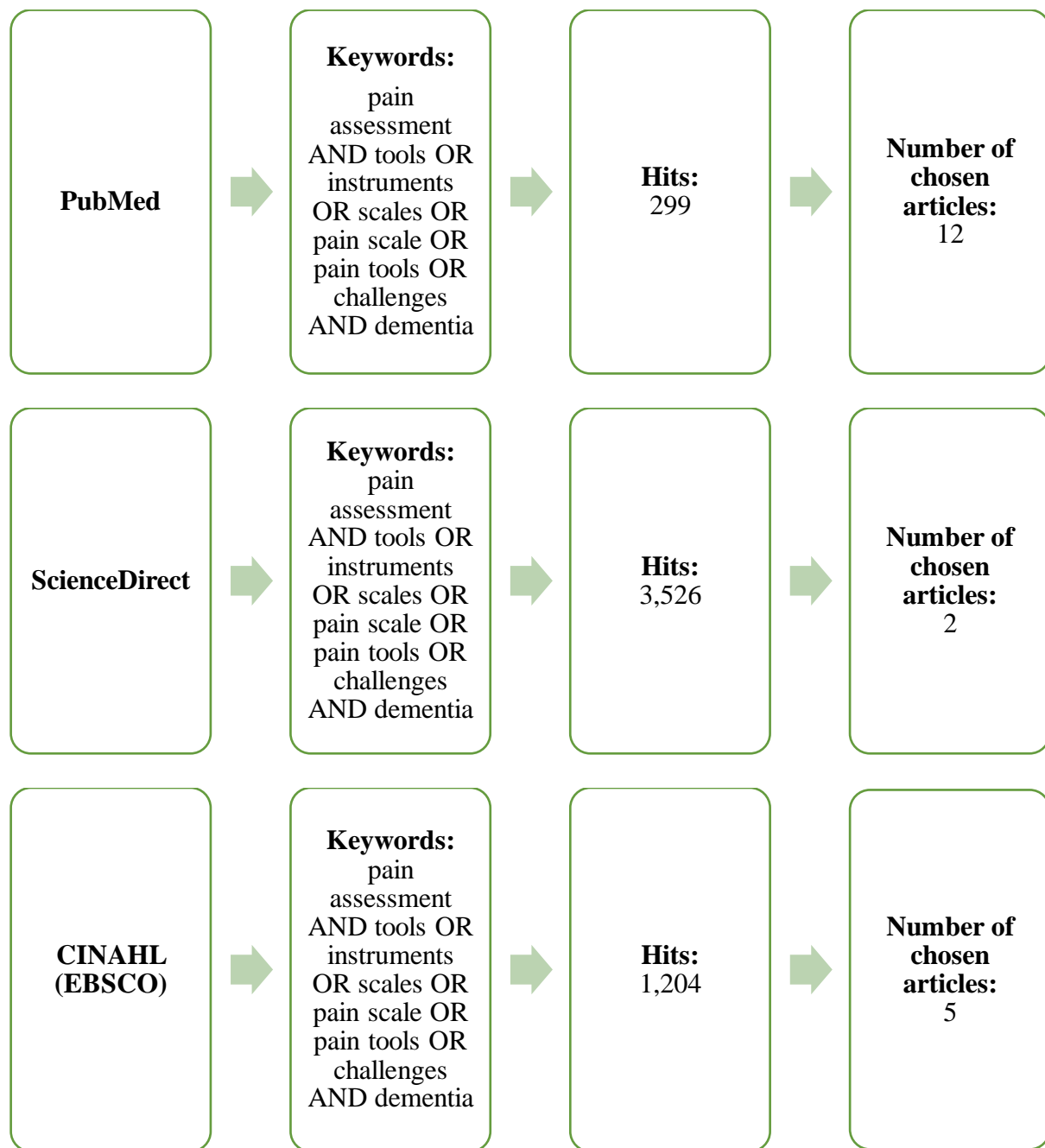


Table 1: Inclusion and exclusion criteria

<u>Inclusion Criteria</u>	<u>Exclusion Criteria</u>
Articles published during 2014–2024.	Articles published before the year 2014.
Articles that are reliable and relevant to the topic.	Articles that did not focus on the topic of pain assessment in dementia patients.
Articles must be from academic databases such as PubMed, ScienceDirect.	Articles from unreliable sources.
Free of charge for university students.	Articles requiring payment to be read.
Articles in the English or Finnish language.	Articles in different languages other than the previously mentioned ones.
Peer-reviewed publications.	Publications not properly validated.

5.2 Data Analysis

This literature review focused on already existing research articles that have utilized either a quantitative or qualitative research method, which of the majority were qualitative.

Qualitative research allows authors to gain a deeper understanding of real-life topics (Tenny et al., 2022). Researchers are also able to present data objectively and in a structured manner (Elo et al., 2014). This is suitable for this literature review, for it aims to understand the topic in depth to notice possible gaps in research. All data was collected, analysed, and presented as an inductive process.

The authors followed the process of inductive content analysis to finalize and analyse the data that was searched in the various databases mentioned before. Content analysis uses a qualitative method to study existing research and clarify its meaning (Elo et al., 2014).

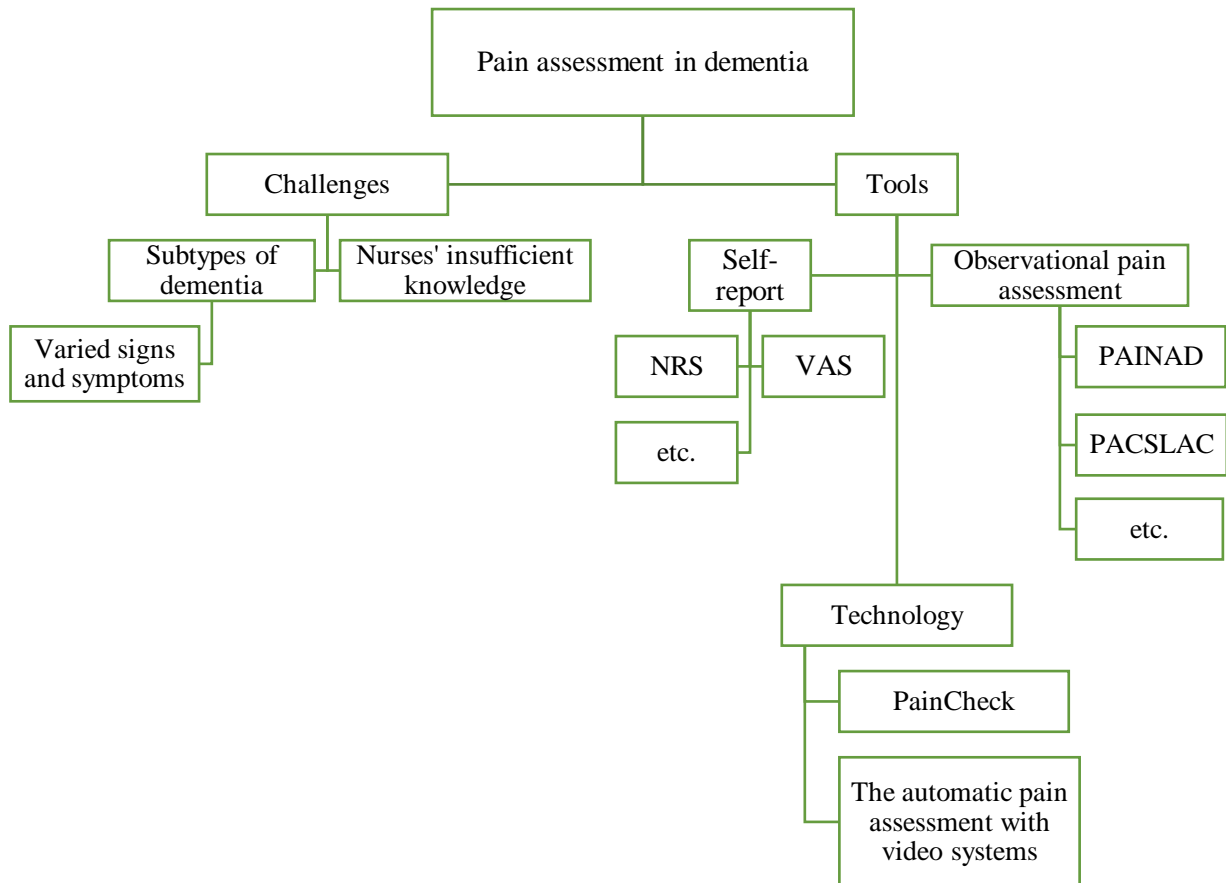
Content analysis means to examine already existing data (Drisko et al.2016). It also helps authors to understand pre-existing reports and studies (Hurst, 2023).

The inductive process is composed of three phases: preparation, organization, and presentation of results (Elo et al., 2014). The first step, i.e., preparation, involves collecting relevant data and choosing the material to be analysed for the literature review (Elo et al., 2014). Credible articles selected during the data collection phase were saved to a shared Word document accessible for both authors. The second phase, i.e., organization, means to organize the collected data (Elo et al., 2014). All articles saved in the Word document were thoroughly analysed and divided into categories by saving them as PDFs. Each article was read individually by both authors and relevant information was color-coded. General knowledge about dementia, challenges, pain scales, and results were highlighted. The highlighted data was then divided into two categories and further into subcategories depending on the information and saved to a Word document separate from the saved articles. Category 1 included articles discussing the challenges of assessing pain in dementia patients, and category 2 provided tools designed for dementia patients (*Figure 2*). The inductive approach is completed by writing the results, i.e., the presentation of results (Elo et al., 2014).

Table 2: Categorization

Themes	Challenges of pain assessment		Pain assessment tools		
Generic categories	Subtypes and varied symptoms of dementia	Nurses' insufficient knowledge in pain assessment	Self-report	Observational	Technology
Subcategories	Alzheimer's Dementia (AD) Vascular Dementia (VaD) Mixed Dementia (AD-VaD) Dementia with Lewy bodies (DLB) Frontotemporal Dementia (FTD) Delirium Superimposed Dementia (DSD)	Misdiagnosing pain as a psychological and behavioral symptom of dementia Under-, over- or no treatment of pain Economic and educational barriers Absence of standardized pain assessment scale Not knowing the patient Communicational barriers	NRS VRS VDS FPS VAS	PAINÉ PADE PAINAD MOBID-2 DS-DAT Doloplus-2 NOPPAIN APS CMAI PACSLAC CNPI MPS ADD REPOS	PainCheck (AI-based) The Automatic Pain Assessment with Video Systems ePat
Unit of analysis	7, 9, 10, 15, 18, 19	1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 13, 14, 15, 16, 17	1, 4, 7, 16, 17, 19	1, 2, 3, 4, 6, 8, 10, 12, 13, 14, 16, 17, 18, 19	7, 3, 10, 15

Figure 2: Content analysis code chart



5.3 Ethical Considerations of Research

The Finnish National Board on Research Integrity Tenk advises researchers in their articles about ethical and responsible research (Finnish National Board on Research Integrity TENK, 2012). The Responsible Conduct of Research (RCR) guidelines provide a model and encourage the responsible conduct of research. There are nine different steps that RCR advises to take to follow the responsible conduct of research. Some of these steps are that the methods used in the research are ethically sustainable and comply with scientific criteria. When writing a literature review, one should consider respecting other people's work by citing everything correctly and giving the potential credit to the researcher. Using proper research skills enhances the validity and reliability of the search outcome and results. (Finnish National Board on Research Integrity TENK, 2012).

Ethics was taken into consideration whilst undertaking this literature review on identifying the challenges of assessing pain in dementia patients. A correct form of referencing according to university guidelines was noted. The use of appropriate academic search bases was used to find credible and reliable research articles that accommodated this literature review's purpose.

Plagiarism is one of the key factors to be noted when conducting a research paper, in this case, a literature review. All data used in this thesis have been cited correctly by using the authors' own words, respecting other researchers' findings and opinions. The process of writing this literature review has been approved and supervised by university supervisors.

6 Results

This section is based on all 19 articles that were selected for this literature review. By reading each article separately, they were formed into themes, categories, and subcategories. The themes relate to the research questions and aim, challenges of pain assessment, and different pain assessment tools.

6.1 Challenges

Nurses deal with various challenges over time that they must overcome. In general, pain assessment seems simple enough especially when assessing pain with people who can verbally communicate. However, challenges arise when nurses must know how to identify and treat a patient who is not capable of verbally communicating. Diagnosing pain in dementia patients is an ongoing issue, for there are numerous subtypes and symptoms of dementia that can result in under- or overtreatment.

6.1.1 Subtypes and Varied Symptoms of Dementia

Dementia has various subtypes and symptoms that can be difficult to differentiate from each other. Subtypes are *Alzheimer's Dementia (AD)*, *Vascular Dementia (VaD)*, *Mixed Dementia (AD-VaD)*, *Dementia with Lewy Bodies (DLB)*, *Frontotemporal Dementia (FTD)*, and *Delirium Superimposed Dementia (DSD)* (15, 19). There are similarities to symptoms within these subtypes, which can be demanding to assess, treat, or diagnose (18, 19). This is why it is beneficial for nurses to be familiar with the usual challenges associated with each type of dementia, for some symptoms may vary (7).

DSD is a subtype of dementia which in other words is delirium superimposed on dementia. Symptoms of *DSD* are commonly hypoactive, hyperactive, or both mixed (18).

Subtype *AD-VaD* is a mixed form of advanced dementia and vascular dementia (19). Patients with *AD-VaD* are inclined to suffer from neuropathic and central pain because, in the brain, the white matter interferes with the pain formation (19).

Results uncover that a dementia subtype *AD* was by 40,9% the most common type (15). However, disregarding the most common subtype, patients who have *AD-VaD* which of 78,6% with *DLB* had an elevated association with pain. After that, pain was associated with subtypes *AD* (64,3%), *VaD* (62,3%), and lastly *FTD* (54,6%) (15). As the severity of the pain grew, the order of subtypes changed. *AD-VaD* was the highest (17,9%), then *AD* (12,3%), *VaD* (11,5%), *FTD* (9,1%), and lastly, with the least, *DLB* (7,1%) (15).

Studies suggest that pain in patients with *AD* is highly prominent and patients with *VD* experience stronger pain (7). It is also shown that pain intensity in *VD* is comparable to that of a healthy person but experience it stronger (7). Studies also mention that *FTD* is associated with a higher threshold and tolerance for pain (7).

6.1.2 Insufficient Knowledge Among Nurses

Insufficient knowledge among nurses can have a huge effect on the rest of the care path of a patient, especially someone with dementia. Challenges include diagnosis of pain, absence of a standardized pain assessment scale, economic and workload barriers, lack of documentation, and staff education (1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 13, 14, 15, 16, 17).

Findings reveal that there are several obstacles concerning pain assessment among nurses regarding patients suffering from dementia. Obstacles may be inadequate education and understanding about elderly patients on a general level as well as in dementia (3, 10, 17). As far as pain assessment and a holistic approach to care go, proper education plays a major role. Studies indicate that not documenting the pain level of a patient can cause severe misjudgements that interfere with pain assessment and management. Interpreting pain as other behavioural and psychological symptoms is common (1, 2, 5, 8, 9, 16). There may be a lack of self-trust among nurses when reading signs of pain (9). Situations like these require sufficient knowledge, professional judgement, and good observation skills (3, 10).

The absence of a clearly defined pain assessment instrument and appropriate documentation are also major challenges of pain assessment in patients with dementia (1, 3). Inconsistency between a patient's self-judgement and healthcare professionals' evaluation of pain is also

mentioned to be an obstacle (5). Pain is subjective, which makes self-reporting pain scales the standard of pain evaluation (3, 5, 7). However, no pain scale has been accepted as the standard instrument for patients with cognitive decline (5, 10). Studies show that observational pain scales meant for patients with dementia lack reliability and proof for their validity (7), which leads to doubt among healthcare workers when giving analgesics due to distrust in those pain evaluation tools (3). Further challenges include limited knowledge and skills and communication difficulties (3). Also, (10) implies that having a standardized pain tool does not solve this problem alone, but rather has a positive impact on clinical decision-making when used as a support during pain assessment.

More so, intervening in pain management requires a baseline of knowledge from a nurse. Findings indicate that nurses are conscious of the significance of assessing pain, but as behavioural and psychological symptoms collide with symptoms from dementia, nurses feel a shortage of credence. This results in treating pain with anti-psychotics. This heavily kneels towards analgesics being under, over, and not treating at all (2, 3, 5, 11, 16, 17).

Workload is also an occurring challenge in healthcare. Overwhelming workload and too little time can be rather strenuous to give proper and quality care to patients with advanced dementia (11, 13). This study reveals that some nurses rely on their intuition whether to give pain medication or not since it is challenging to assess pain. Nurses face uncertainty while administering pain medication and all of this is a result of poor education in advanced dementia (13).

Not knowing the patient is another factor that brings out challenges when assessing pain. Understanding and knowing long-term patients with advanced dementia can significantly help assess pain levels (4, 5, 10, 13).

6.2 Tools

Pain assessment tools act as a guide for healthcare workers to identify possible symptoms of pain with the use of suitable pain tools. However, some pain assessment tools are rarely used in clinical practice for it is thought to be unreliable (11). Pain assessment tools can be self-reported, observational, or technology based.

6.2.1 Self-Report

Patients can evaluate their pain by using verbal, numerical, or visual pain scales (3). Studies suggest that these scales are suitable for patients able to communicate and for early-stage dementia (3).

An example of a self-report pain scale is the NRS. The NRS is a numerical scale where the patient rates the intensity of the pain from 0 and 10, where 0 = no pain, and 10 = worst pain (4, 17).

The verbal descriptor scale known as VDS was shown to have measured the highest amount of pain (17). Tools such as self-reporting should be first-handily used by those who can verbally communicate and express their pain level (17).

In addition to NRS and VDS, certain studies suggest that VAS and FPS are valid for elderly patients, and some suitable for patients with mild to moderate dementia (4). However, a study shows that 42.5% of patients with dementia who self-reported their pain by NRS provided a reliable answer (1). 20.4% of them reported no pain, 14.4% mild pain, 3.9% moderate pain and 2.9% extreme pain (1).

Studies suggest that VAS is not suitable for patients with dementia, even in the initial stages of the disease (7). VAS, a visual scale, consists of a line where the left side is labeled as no pain and the right side as extreme pain (4, 7). Studies also suggest that simple verbal or numerical scales and tools consisting of only yes or no questions should be used in the later stages of dementia (7).

FPS includes various faces representing different severities of pain (4). This has been shown to be reliable and valid for patients with dementia (4). VDS has also been tested to be reliable and valid for patients with cognitive decline (4). VDS contains statements of different intensities of pain (“no pain”, “mild pain”, “moderate pain”, “severe pain”, “extreme pain”, and “the most intense pain”) (4).

Self-reporting scales are not suitable for advanced stages of dementia and in patients who are not able to properly communicate their pain (2).

6.2.2 Observational

Behavioral pain assessment tools focus on pain-provoked behavior, expressions of the face, and phonation (3). Commonly used observational pain scales include the PACSLAC, Abbey Pain Scale, Doloplus-2, Comprehensive Pain Assessment, PAINAD, Checklist of Nonverbal Pain Indicators, Non-Communicative Patients Pain Assessment Instrument, Automatic Pain Assessment with Video Systems (3).

PAINAD is acknowledged as a suitable tool for pain assessment in dementia in clinical situations due to its simplicity (3) and is used in moderate and severe dementia (1). It assesses “breathing”, “negative vocalization”, “facial expression”, “body language”, and “the ability of the patient to be consoled” (3, 4, 8, 18). All these five behaviours are scored from 0-2 and the end score ranges 0-10 (18). Before using the tool, 2-5 minutes must be used for observing the patient (4). The suggested tool to be used in nursing homes, for hospitalized adults and patients with DSD is PAINAD (18). It is suggested that PAINAD should be used consistently every four hours for patients with acute or chronic pain (18).

Doloplus-2 assesses five “somatic” parts (“somatic complaints”, “protective body posture adopted at rest”, “protection of sore areas”, “expression”, and “sleep pattern”), two “psychomotor” parts (“washing and/or dressing”, and “mobility”), as well as three “psychosocial” parts (“communication”, “social life” and “behaviour problems”) (4, 17). Each part is then numbered 0-3 giving a total score of 0-30, where 5 is the criterion for pain (4, 17). It has been completed in 6-12 minutes when applied to a clinical setting by nurses (4). Studies have found Doloplus-2 useful for evaluating the progression of pain rather than pain experienced at the time (2).

PACSLAC is designed for patients who are unable to properly communicate (4). It evaluates pain by assessing four parts: “facial expressions” (13 objects), “activity/body movement” (20 objects), “social/personality/mood indicators” (12 objects), “physiological indicators/eating and sleeping changes/vocal behaviour” (15 objects) (4, 8). Each item is labelled as either absent or present for a total score of 0-60 (4). Studies mention that nurses can differentiate between disorders associated with pain and painless illnesses when using PACSLAC (3). This pain tool has been found to be both reliable and valid (3) and has been completed in less

than 5 minutes by nurses (4). Also, this pain assessment tool allows for holistic patient evaluations (9).

Abbey Pain Scale is designed for patients with advanced dementia (4, 14). The tool assesses “vocalization”, “facial expression”, “behavioural change”, “change in body language”, “psychological change” and “physical change” (4, 8). Each item is numbered 0-3 (0-2 indicates “no pain”, 3-7 “mild pain”, 8-13 “moderate pain”, and 14 or more “extreme pain”) (4). Nurses have been able to finish it within 1 minute (4). It is certified by the Australian Pain Society and often used in pain assessment (10).

CNPI is meant for patients with communication difficulties and advanced dementia (4). Each part of the tool is marked as either “present” or “absent”, including “vocalization”, “facial expression”, “stimulus friction”, “agitation”, and “verbal complaints” (8). The total score range is 0-6 (1-2 indicates “mild pain”, 3-4 “moderate pain”, and 5-6 extreme pain) (4).

PADE is divided into different parts, where the “physical” section observes “facial expressions”, “breathing” and “posture”, and “global assessment” which includes “getting dressed”, “feeding” and “transfer from bed to wheelchair” (4, 8). The tool is designed to aid in assessing behaviour that may be associated with pain (4). It has been completed in 5-10 minutes when tested by nurses (4).

CPAT includes observing “facial expressions”, “behavior”, “mood”, “body language” and “activity level” (4, 8). Each part is scored as either 0 (“no pain”) or 1 (“pain indicators”) with a total score of 0-5 (4).

MOBID requires nurses to aid patients with various movements. These include “opening of both hands”, “lifting of both arms towards the head”, “extending and bending of knees and hip joints”, “rolling to each side and sitting on the edge of the bed” (8). Each movement must be discontinued whether possible signs of pain arise, such as “pain utterances”, “facial expressions” or defensive behavior (8).

MPS observes “facial expression”, “breathing”, “vocalization”, “body language”, “signs of agitation in behaviour”, “signs of changes in sleep/appetite”, “symptoms and changes in vital parameters”, and “history of pain” (8). Studies suggest that the tool can tell pain and agitation

apart and can locate pain (8). The observer completing the scale is directed to touch 22 areas on the patient and mark the corresponding body area on a drawing of the human body with an 'x' whether a behavioural sign is observed (8).

NOPPAIN contains four segments where 9 items show "situations of daily care", 6 items showing "pain behaviours", pain intensity for each item, and a feature of a pain intensity scale (8). Results show that using the pain scale NOPPAIN was set up to be justifiable to use in recognizing behaviours of pain in dementia patients (16).

PAINNE consists of 22 items of which 15 are divided into 4 groups (8). These include "motor repetitive behaviors" ("facial distortions", "restlessness", and others), "vocal repetitive behavior" ("moaning", "crying", "screaming", and others), "unusual behaviours" ("posture", "apathy", "rigidity", and others), and "activities" ("music", "arts", and others) (8). The remaining 7 items contain "falls", "trembling", "changes in vital signs", "edema", "blood stains", and "broken bones" (8).

ADD is developed to observe "facial expressions", "mood", "body language", "voice" and "behavior" (8).

The results of a study done in 2020 shows that the majority (54%) of nurses favored the PAINAD over the PACSLAC, which the remaining 46% of nurses liked better (6). The study found, however, that when comparing the overall scores after pain medications, the PACSLAC was more reliable (6). When PAINAD was applied, 16 cases indicated no reliable change in total score, while the PACSLAC showed a reliable decrease in two of those 16 cases (8.3%) and a reliable increase in three cases (12.5%) (6).

A multicentre prospective observational study discusses an option of an observational scale called REPOS, the Rotterdam Elderly Pain Observation Scale. The study resulted in a positive outcome for the pain tool for it was found to be valid and reliable (12). REPOS is an observational tool created in 2008 for assessing pain in chronic and sub-acute pain for patients in hospitals and nursing homes who could not verbally report pain using self-report mechanisms (12). This current study reveals that there were major distinctions between REPOS and PAINAD. REPOS was found to be more successful in patients in palliative care (12).

In this study (14), APS was used by professional nurses to determine the presence of pain. APS is an observational pain assessment tool that allows nurses to assess patients by doing a movement-based assessment (14). The scale focuses on behaviour: facial expression, body language, behavioural change, psychological change, and physical change. The total score from this tool is 18 and scores go as follows: 14 or more is severe pain, 8-13 is moderate pain, 7-3 is mild pain, and 0-2 is no pain at all (14). The study reveals that APS was found to be valid.

The two pain assessment tools that showed significant response in assessing pain were PAINAD and PAINÉ (19). MOBID-2 scale is a Mobilization-Observation-Behavior-Intensity-Dementia-2 pain scale that has been trialed with dementia patients regarding responsiveness out of NRS, DS-DAT, and PAINAD (19). However, the study does not descriptively inform about the pain assessment tool DS-DAT.

Another tool that is used is CMAI, which focuses on patients' agitation. The Cohen-Mansfield Agitation Inventory assesses 29 different behaviour traits of agitation. The total score can be between 29 and 203 points (14). Findings in this study say that almost identical results were obtained with the usage of APS and CMAI (14).

6.2.3 Technology

The new technology methods depend on many tools such as facial expressions and facial muscle movements, vocal cord responses, and behavioral changes due to pain (3). In a retrospective cross-sectional analysis, the correlation between symptoms of dementia and neuropsychiatric behaviours that relate to pain were studied. In this study, pain was assessed using an AI-powered pain assessment device called PainCheck that was brought out in 2017. This pain assessment application is for dementia patients as well as people who are non-verbal. The application recognizes many things, such as facial expressions, behaviour, movement, tone of voice, body movements, and activity. Results indicate that pain was an indicator of all different subtypes of dementia including AD and VaD. PainCheck was used as a tool for this study. With the use of PainCheck, it allows to classify pain into four sections; no pain, mild pain, moderate pain, and severe pain, and then construct the finalized results into a score (15).

Another example of a technological pain tool is the Automatic Pain Assessment with Video Systems. The tool assesses mostly expressions of the face (3). Automatic pain identification is video-based and focus on the face, and can also include electrocardiography (ECG), vital signs, and electroencephalography (EEG) (7). These have, however, been tested on younger patients whose wrinkles are not as dominant as those in older individuals, which influences the appropriateness in assessing elderly patients (7).

The ePat is developed in Australia and uses automatic face recognition technology to recognize facial signs of pain from a 10 second video of a patient (10). It consists of 42 parts that are divided into 6 groups: face (9 parts), voice (9 parts), movement (7 parts), behaviour (7 parts), activity (4 parts), body (6 parts) (10). The tool is available in an application form for smart devices, making it accessible for the majority of individuals (10). The study compared the ePat to the APS and found no major differences among the total scores of the two pain tools, making the ePat a reliable pain assessment instrument (10).

7 Discussion

This literature review aimed to identify challenges that nurses face when assessing pain in dementia patients while enhancing the care of pain. The 19 articles reviewed for this aim and research topic demonstrate the current challenges nurses face but also provide a variety of tools that can be used for assessing pain in patients who can't self-report.

It is well-known that as people get older, diseases like dementia arise. With dementia, comes other health troubles that can cause sufficient pain. It has been highly reviewed and examined that pain assessment is an ongoing challenge. However, to ensure quality care among patients with dementia, proper pain assessment with the use of pain assessment tools should be included (Carezzato, N. L., 2014). It is acknowledged that the nurse's role in pain assessment is vital. Nonetheless, although numerous pain scales have been developed, evaluating pain remains a challenge for nurses. These include PAINAD, MPS, APS, ADD, NOPPAIN, PACSLAC, MOBID, PADE, PAINE, MOBID-2, CMAI, DS-DAT, CNPI, REPOS, and Doloplus-2. All of these allow nurses to observe patients holistically. The main reasons behind the challenges of assessing pain in patients with dementia include the lack of standardized observational pain assessment tools that allow nurses to diagnose possible pain in patients unable to verbally communicate, the educational backgrounds of nurses, the lack

of trust in pain scales designed for cognitive decline, and symptoms of dementia that are indistinguishable from pain indicators.

The theoretical framework that was used in this literature review was important, as it helped in understanding the meaning and value of, since it highlights the importance of all the phases that are used in the care of patients. The link between the theoretical framework and the findings of this thesis reveals that critical thinking is a must while undergoing patient care. As mentioned earlier, to follow Ida Jean Orlando's theory of The Deliberative Nursing Process, a nurse must never assume anything about the patient but instead use their critical thinking skills to ensure the quality of care (Petiprin, 2016). The use of Ida Jean Orlando's five phases of assessment, diagnosis, planning, implementation, and evaluation will act as a guide, in this case, pain assessment (Petiprin, 2016).

An important statement arose, as there is a theoretical framework that focuses on the significance of critical thinking especially involving assessment, on how the findings reveal that there are issues regarding education within patients with dementia, pain assessment, and knowing different symptoms and subtypes of dementia. As Löppönen says, "Identifying signs and symptoms of pain is vital to appropriately assess pain and maintain functional ability" (2023). As the results show, various observational pain assessment tools require critical thinking. For nurses to use critical thinking in observational pain assessment tools, it is required to have lore regarding symptoms of dementia and its subtypes. Since there are a variety of subtypes such as AD, VaD AD-VaD, DLB, FTD, and DSD, it can be difficult to differentiate all of the subtypes including the symptoms and signs.

The importance of knowledge and education cannot be stressed enough. The knowledge of dementia's subtypes and varied symptoms can substantially endure better care of pain if pain assessment tools are used correctly, and their validity is reliable. Because there are varying symptoms among the subtypes of dementia, properly recognizing pain requires prior knowledge of signs that arise in each type of dementia. Moreover, insufficient experience, mentioned in the results, impacts how signs of pain are interpreted, as there is inadequate knowledge of which of those signs are truly valid indicators of pain. These factors are supported by the Deliberative Nursing Process theory which mentions critical judgment, patient-centred care, goal-oriented tasks, evidence-based practice (EDP), and nursing instinct (Toney-Butler & Thayer, 2023).

When evaluating patients for pain, nurses should not solely rely on pain scales, but instead lean toward their intuition and holistically see the patient, making the patient the focus. Also, as mentioned in the results, the substantial amount of work that nurses face leads to limited time for assessing patients which contraindicates Orlando's belief that nurses treat patients with a purpose and not hastily. She also believed that nurses should not presume that signs are related to dementia, but instead make the patient the focus (Alligood, 2013, pp. 285-302). It is shown that patients are administered anti-psychotics instead of analgesics due to hurried pain assessment and uncertainty of whether the signs that patients express are provoked by pain related to dementia (Burns, M. & McLlpatrick, S., 2015). Therefore, improper patient assessment results in over-, under-, or nontreatment of pain. This proves that using the proper tools, good observation skills, and thinking critically can greatly improve the care of pain in patients with memory disorders. The majority of the articles chosen for this thesis mentioned the PAINAD, a scale that assesses five behaviours, making it the most common observational pain scale used among nurses, and PACSLAC was also preferred by nurses in clinical settings. Several pain assessment tools have a positive outcome and some on the other hand may have not been in clinical practice that much. Nowadays, technology is a major concept that is evolving all the time. Artificial Intelligence (AI) has been mentioned to cause pain evaluation to be more reliable, especially in patients with moderate to severe dementia (Atee, M. et al., 2020).

By analyzing the results, an ongoing issue repeatedly emerged; the main reason for pain being under, over-, or not treated at all is the absence of a clearly defined pain assessment tool for patients with dementia. This then further affects the confidence of nurses, for they lack trust in available pain scales, thus affecting the management of pain. This makes the challenges of pain assessment a never-ending cycle. This impacts the correlation between pain and quality of life, resulting in an increased likelihood of stress and depression in patients with dementia.

7.1 Strengths and Limitations

Time restrictions and a limited quantity of articles with open access prevented a broader search from being completed, resulting in a narrow number of articles. Strengths included the authors' previous knowledge and experience of pain assessment in dementia patients, as well as interest for the development of the matter, which allowed for a deeper understanding of the topic and the discovery of new information beneficial for the results.

Conclusion

To further enhance the assessment of pain in patients with impaired memory, continuous education about different subtypes of dementia and their signs and symptoms could be beneficial for nurses. Other suggestions for future research include additional use and testing of the already existing observational pain scales, as well as developing pain scales that could locate the source of pain and recognize pain types. This could stop the never-ending issue by increasing the trust in observational pain scales and assertiveness of nurses to administer analgesics, thus leading to optimal management of pain.

References

- Achterberg, W., Lautenbacher, S., Husebo, B., Erdal, A., & Herr, K. (2020). Pain in Dementia. *PAIN Reports*, 5(1). <https://doi.org/10.1097/pr9.0000000000000803>
- Alligood, M. R. (2013). Nursing Theory: Utilization & Application. In *Google Books* (pp. 285–302). Elsevier Health Sciences.
https://books.google.fi/books?hl=en&lr=&id=adLsAwAAQBAJ&oi=fnd&pg=PA285&dq=orlando+nursing+process+theory&ots=qvbLZkd71o&sig=kZrYs3tYwEtSxHAWaSKE0BAeiEM&redir_esc=y#v=onepage&q=orlando%20nursing%20process%20theory&f=false
- Alzheimer's Society. (2021a, February 24). *The early stage of dementia*.
Www.alzheimers.org.uk. <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/early-stages-dementia>
- Alzheimer's Society. (2021b, February 24). *The middle stage of dementia*.
Www.alzheimers.org.uk. <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/middle-stage-dementia>
- Alzheimer's Society. (2021c, June 18). *The later stage of dementia*. Wwww.alzheimers.org.uk.
<https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/late-stages-dementia>
- Arvanitakis, Z., Shah, R. C., & Bennett, D. A. (2019). Diagnosis and Management of Dementia: A Review. *JAMA*, 322(16), 1589–1599.
<https://doi.org/10.1001/jama.2019.4782>

- Atee, M., Hoti, K., Parsons, R., & Hughes, J. D. (n.d.). Pain Assessment in Dementia: Evaluation of a Point-of-Care Technological Solution. *Journal of Alzheimer's Disease*, 60(1), 137–150. <https://doi.org/10.3233/JAD-170375>
- Atee, M., Morris, T., Macfarlane, S., & Cunningham, C. (2020). Pain in Dementia: Prevalence and Association With Neuropsychiatric Behaviors. *Journal of Pain and Symptom Management*, 61(6), 1215–1226. <https://doi.org/10.1016/j.jpainsymman.2020.10.011>
- Boerlage, A. A., Sneep, L., Rosmalen, J., & Dijk, M. (2021). Validity of the Rotterdam Elderly Pain Observation Scale for institutionalized cognitively impaired Dutch adults. *Journal of Intellectual Disability Research*, 65(7), 675–687. CINAHL Complete. <https://doi.org/10.1111/jir.12843>
- Booker, S. Q., & Haedtke, C. (2016). Controlling Pain and Discomfort, Part 2: Assessment in Non-verbal Older Adults. *Nursing*, 46(5), 66–69. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4991889/>
- Brodsky, M. (n.d.). *LibGuides: Literature Reviews: What is a literature review?* Retrieved 29 February 2024, from <https://guides.lib.utexas.edu/c.php?g=1060589&p=7710318>
- Bullock, L., Chew-Graham, C. A., Bedson, J., Bartlam, B., & Campbell, P. (2020). The challenge of pain identification, assessment, and management in people with dementia: A qualitative study. *BJGP Open*, 4(2), bjgpopen20X101040. <https://doi.org/10.3399/bjgpopen20X101040>

Burns, M., & McIlfratrick, S. (2015). Palliative care in dementia: Literature review of nurses' knowledge and attitudes towards pain assessment. *International Journal of Palliative Nursing*, 21(8), 400–407. CINAHL Complete.

<https://doi.org/10.12968/ijpn.2015.21.8.400>

Carezzato, N. L., Valera, G. G., Vale, F. A. C., & Hortense, P. (2014). Instruments for assessing pain in persons with severe dementia. *Dementia & Neuropsychologia*, 8(2), 99–106. <https://doi.org/10.1590/S1980-57642014DN82000003>

Duodecim Käypä Hoito. (2017, August 22). *Kipu*. Wwww.kaypahoito.fi.

<https://www.kaypahoito.fi/hoi50103>

Drisko, J. W., & Maschi, T. (2016). *Content Analysis*. Oxford University Press.

<https://books.google.fi/books?hl=fi&lr=&id=07GYCgAAQBAJ&oi=fnd&pg=PP1&dq=content+analysis&ots=nqPOSeTUbD&sig=et0s6PMVb3iZBMnjf3L8URxQyVI&redirectesc=y#v=onepage&q=content%20analysis&f=false>

El-Tallawy, S. N., Ahmed, R. S., Shabi, S. M., Al-Zabidi, F. Z., Zaidi, A. R. Z., Varrassi, G., Pergolizzi, J. V., LeQuang, J. A. K., & Paladini, A. (n.d.). The Challenges of Pain Assessment in Geriatric Patients With Dementia: A Review. *Cureus*, 15(11), e49639.

<https://doi.org/10.7759/cureus.49639>

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014).

Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, 4(1), 1–10.

Sagepub. <https://doi.org/10.1177/2158244014522633>

Felton, N., Lewis, J. S., Cockburn, S.-J., Hodgson, M., & Dawson, S. (2021). Pain Assessment for Individuals with Advanced Dementia in Care Homes: A Systematic Review. *Geriatrics*, 6(4), 101. <https://doi.org/10.3390/geriatrics6040101>

Finnish National Board on Research Integrity TENK. (2012, November). *Responsible conduct of research and procedures for handling allegations of misconduct in Finland*. Finnish National Board on Research Integrity TENK. <https://tenk.fi/en/advice-and-materials/RCR-Guidelines-2012>

Hurst, A. (2023). *Chapter 17. Content Analysis*. <https://open.oregonstate.edu/qualresearchmethods/chapter/chapter-17-content-analysis/>

Husebo, B. S., Achterberg, W., & Flo, E. (2016). Identifying and Managing Pain in People with Alzheimer's Disease and Other Types of Dementia: A Systematic Review. *CNS Drugs*, 30(6), 481–497. <https://doi.org/10.1007/s40263-016-0342-7>

Juva, K. (2021, August 10). *Muistihäiriöt ja dementia*. Duodecim Terveyskirjasto. <https://www.terveyskirjasto.fi/dlk00706>

Kankkunen, P., & Välimäki, T. (2014). Pain among Persons with Dementia: The Family Caregiver's View Point. *International Journal of Caring Sciences*, 7(2), 460–467. CINAHL Complete. <https://web-p-ebshost-com.ezproxy.arcada.fi:2443/ehost/detail/detail?vid=0&sid=696f64fa-8b8b-4ce3-9f65-e15624b04b34%40redis&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#AN=96010778&db=ccm>

Kim, Y.-S., Park, J.-M., Moon, Y.-S., & Han, S.-H. (2017). Assessment of pain in the elderly: A literature review. *The National Medical Journal of India*, 30, 203.

<https://doi.org/10.4103/0970-258X.218673>

Lichtner, V., Dowding, D., Esterhuizen, P., Closs, S. J., Long, A. F., Corbett, A., & Briggs, M. (2014). Pain assessment for people with dementia: A systematic review of systematic reviews of pain assessment tools. *BMC Geriatrics*, 14, 138.

<https://doi.org/10.1186/1471-2318-14-138>

Luft, J. A., Jeong, S., Idsardi, R., & Gardner, G. (2022). Literature Reviews, Theoretical Frameworks, and Conceptual Frameworks: An Introduction for New Biology Education Researchers. *CBE Life Sciences Education*, 21(3), rm33. <https://doi.org/10.1187/cbe.21-05-0134>

Lundin, E., & Godskesen, T. E. (2021). End-of-life care for people with advanced dementia and pain: A qualitative study in Swedish nursing homes. *BMC Nursing*, 20(1), 1–11.

CINAHL Complete. <https://doi.org/10.1186/s12912-021-00566-7>

Löppönen, M. (2023, December 11). *Kipu ja muistisairaus*.

<https://www.kaypahoito.fi/nix03280>

Malara, A., De Biase, G. A., Bettarini, F., Ceravolo, F., Di Cello, S., Garo, M., Praino, F., Settembrini, V., Sgrò, G., Spadea, F., & Rispoli, V. (2016). Pain Assessment in Elderly with Behavioral and Psychological Symptoms of Dementia. *Journal of Alzheimer's Disease*, 50(4), 1217–1225. <https://doi.org/10.3233/JAD-150808>

Muistiliitto. (n.d.). *Muistisairaudet*. Wwww.muistiliitto.fi. Retrieved March 10, 2024, from <https://www.muistiliitto.fi/fi/muistisairaudet/muistihairiot-ja-sairaudet/muistisairaudet>

Natavio, T., McQuillen, E., Dietrich, M. S., Wells, N., Rhoten, B. A., Vallerand, A. H., & Monroe, T. B. (2020). A Comparison of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) and Pain Assessment in Advanced Dementia Scale (PAINAD). *Pain Management Nursing*, 21(6), 502–509. <https://doi.org/10.1016/j.pmn.2020.04.001>

Nowak, T., Neumann-Podczaska, A., Deskur-Śmielecka, E., Styszyński, A., & Wieczorowska-Tobis, K. (2018). Pain as a challenge in nursing home residents with behavioral and psychological symptoms of dementia. *Clinical Interventions in Aging*, Volume 13, 1045–1051. <https://doi.org/10.2147/cia.s157246>

Paulson, C. M., Monroe, T., & Mion, L. C. (2014). Pain Assessment in Hospitalized Older Adults With Dementia and Delirium. *Journal of Gerontological Nursing*, 40(6), 10–15. <https://doi.org/10.3928/00989134-20140428-02>

Petiprin, A. (2016). *Ida Jean Orlando - Nursing Theory*. Nursing Theory. <https://nursing-theory.org/nursing-theorists/Ida-Jean-Orlando.php>

Sjölund, B.-M., Mamhidir, A.-G., & Engström, M. (2021). Pain prevalence among residents living in nursing homes and its association with quality of life and well-being.

Scandinavian Journal of Caring Sciences, 35(4), 1332–1341. CINAHL Complete.

<https://doi.org/10.1111/scs.12955>

Snyder, H. (2019). Literature review as a research methodology: An overview and guidelines.

Journal of Business Research, 104, 333–339.

<https://doi.org/10.1016/j.jbusres.2019.07.039>

Tenny, S., Brannan, J. M., & Brannan, G. D. (2022). Qualitative Study. In *StatPearls*.

StatPearls Publishing. <http://www.ncbi.nlm.nih.gov/books/NBK470395/>

Terveyden ja Hyvinvoinnin laitos. (2024, March 7). *Muistisairauksien yleisyys - THL*. Thl.fi.

<https://thl.fi/aiheet/kansantaudit/muistisairaudet/muistisairauksien-yleisyys>

Toney-Butler, T. J., & Thayer, J. M. (2023). *Nursing process*. National Library of Medicine;

StatPearls Publishing. <https://www.ncbi.nlm.nih.gov/books/NBK499937/>

World Health Organization. (2023, March 15). *Dementia*. World Health Organization.

<https://www.who.int/news-room/fact-sheets/detail/dementia>

Appendices

Table 3: Presentation of chosen articles

	Title	Author, Year & Journal	Method	Conclusion
1	Pain Assessment in Elderly with Behavioural and Psychological Symptoms of Dementia	Malara A, et al. 2016 Journal of Alzheimer's Disease (PubMed)	Observational Study	Observational- and self-report pain scales used together ensure multidimensional evaluation of pain.
2	Pain Assessment for People with Dementia: a systematic review of systematic reviews of pain assessment tools	Lichtner V, et al. 2014 BMC Geriatrics (PubMed)	Systematic Review	Further psychometric evaluation of pain scales is needed.
3	The challenges of Pain Assessment in Geriatric Patients with Dementia: A Review	El-Tallawy SN, et al. 2023 Cureus (PubMed)	Literature review	Proper education of healthcare personnel is the basis of optimal pain assessment.
4	Assessment of pain in the elderly: A literature review	Kim YS, et al. 2017 The National Medical Journal of India (PubMed)	Literature review	Some self-report pain scales are valid in early-stage dementia and observational tools have moderate validity.

5	The challenge of pain identification, assessment, and management in people with dementia: a qualitative study	Bullock L, et al. 2020 BJGP Open (PubMed)	Semi-structured interviews	Assessing pain in elderly with dementia heavily relies on the experience and knowledge of caregivers.
6	A Comparison of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) and Pain Assessment in Advanced Dementia Scale (PAINAD)	Natavio T, PhD et al. 2020 Pain Management Nursing (ScienceDirect)	Convenience sample	Nurses prefer the PAINAD over the PACSLAC.
7	Pain in Dementia	Achterberg W, et al. 2019 Pain Reports (PubMed)	Report Paper	High quality pain assessment requires the collaboration of diverse healthcare professionals.
8	Instruments for assessing pain in persons with severe dementia	Natália Lindemann Carezzato et al. 2014 Dementia Neuropsychologia (PubMed)	Integrative review	The majority of observational pain tools assess facial expression, breathing, vocalization, mood, and movement.

9	Pain assessment for Individuals with Advanced Dementia in Care Homes: A Systematic Review	Felton N, et al. 2021 Geriatrics (Basel) (PubMed)	Systematic review	Pain assessment tools function as support for clinical judgement.
10	Pain Assessment in Dementia: Evaluation of a Point-of-Care Technological Solution	Atee M, et al. 2017 Journal of Alzheimer's Disease (PubMed)	Systematic review	Results showed that ePat is reliable in moderate to severe dementia.
11	Palliative care in dementia: literature review of nurses' knowledge and attitudes towards pain assessment	Michelle Burns, Sonja McIlfatrick 2015 International Journal of Palliative Nursing (CINAHL)	Systematic approach to a narrative review	Results showed a shortage in communication and education in pain assessment among nurses.
12	Validity of the Rotterdam Elderly Pain Observation Scale for institutionalized cognitively impaired Dutch adults	Boerlage et al. 2021 Journal of Intellectual Disability Research (CINAHL)	Multicentre prospective observational study	The use of REPOS pain scale is valid and reliable.
13	End-of-life care for people with advanced dementia and pain: a qualitative study in Swedish nursing homes	Emma Lundin, Tove E. Godskesen 2021 BMC Nursing (CINAHL)	Individual qualitative, semi-structured interviews	Positive pain management in the elderly relies solely on communication and nursing

				education within the experience.
14	Pain as a challenge in nursing home residents with behavioral and psychological symptoms of dementia	Tomas Nowak et al. 2018 Dovepress Clininal Interventions in Aging (PubMed)	Observation intervention	Abbey Pain Scale showed significant practicality. Pain is often undertreated and misunderstood.
15	Pain in Dementia: Prevalence and Association with Neuropsychiatric Behaviors	Mustafa Atee et al. 2020 Journal of Pain and Symptom Managment (ScienceDirect)	A 1-year retrospective cross-sectional analysis	Pain is linked with symptoms of BPSD.
16	Pain among Persons with Dementia: The Family Caregiver's View Point	Päivi Kankkunen, Tarja Välimäki 2014 International Journal of Caring Sciences (CINAHL)	Literature Review and inductive content analysis	The patient's family members showed affliction towards the patient in pain.
17	Pain prevalence among residents living in nursing homes and its association with quality of life and well-being	Britt-Marie Sjölund et al. 2021 Scandinavian Journal of Caring Sciences (CINAHL)	Cross-sectional correlational design	Self-report and multi-component observation scales validate the connection between quality of life and pain.
18	Pain Assessment in Hospitalized Older Adults with Dementia and Delirium	Christina M. Paulson et al. 2014 HHS Public Access (PubMed)	Clinical Example	PAINAD can decrease the probability of misunderstanding and diagnosing pain.

19	Identifying and Managing Pain in People with Alzheimer's Disease and Other Types of Dementia: A Systematic Review	Bettina S Husebo et al. 2016 Springer (PubMed)	Systematic Review	Elaborate pain assessment is hardly done, and observational tools are rarely tested for its validity.
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