Pain in dementia: existing approaches and prospective developments – a narrative review

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ABSTRACT

Pain is an unpleasant sensory and emotional experience that can lead to inadequate care for people with dementia. Due to the subjective nature of pain, assessing pain in dementia presents persistent challenges. Pain within the context of this patient group is noted for its various nuances and inconsistencies regarding standard care and assessment. This review explores the definitions, diagnosis, and management of pain in dementia. This review was based on an electronic search of existing literature, using PubMed as a primary source. Nineteen papers met the inclusion criteria, ranging from exploratory qualitative analysis of pain management in People with Dementia (PwD) to quantitative validation of assessment tools and novel interventions. Common themes of difficulty in assessing pain among PwD due to cognitive impairment-related communication difficulties and the subpar current standard practices regarding management and assessment of pain were identified, with nuanced and specific assessment and management procedures for PwD consistently supported. There is growing support for using pain assessment tools designed for patients with cognitive impairment, particularly those that involve guided movement, because of the current problems with both medication and non-medication pain management for these patients and the increasing evidence that their ability to handle pain is reduced. Qualitative analysis considering caregiver and patient perspectives and experiences is essential if the health-related quality of life of PwD relating to pain is to be improved.

Introduction

Dementia is an umbrella term that describes a set of symptoms associated with disorders of the brain that progress over time. The cognitive and behavioral profile of the patient varies depending on the type of dementia and the progression of the disease, as well as individual differences among patients.[1]

One of the most common symptoms of dementia is pain, with 50-80% of People with Dementia (PwD) experiencing pain regularly.[2-6] Despite this high prevalence, pain is frequently underdiagnosed and inadequately treated in this population.[7] Previous research has highlighted the importance of assessing and managing pain in PwD,[8] since untreated pain can lead to reduced quality of life, sleep disturbances, and depression, and may worsen agitation and other neuropsychiatric symptoms.[9] Untreated pain is also strongly associated with behavioral and psychological symptoms of dementia (BPSD), including agitation, aggression, restlessness, irritability, depression, apathy, and lack of motivation.[10-12] These symptoms often lead to inappropriate pharmacological interventions, such as antipsychotics, which pose serious risks, including increased mortality and cerebrovascular events.[7,13,14]

The International Association of Pain (IASP) defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage.[15] This suggests that pain has both a nociceptive and a subjective element to its perception. This multifaceted nature becomes even more important in the context of dementia, where the brain's pain-processing mechanisms, especially in the medial pain system, might be affected.[7,16] Neuroimaging research has indicated that, while PwD may preserve their sensory, discriminative responses to pain, the emotional and motivational, affective elements, governed by areas such as the anterior cingulate cortex and the prefrontal cortex, can be notably impaired. This disruption may result in an increase in pain tolerance, coupled with heightened distress that often remains unexpressed.[13,14]

Further to the above, many PwD lose the ability to self-report pain due to cognitive and communicative decline, especially in the moderate to severe stages of the disease. As a result, pain is often inferred from behavioral and physiological signs such as facial grimacing, vocalizations, changes in activity, or agitation, symptoms that may also overlap with other neuropsychiatric symptoms of dementia.[14,17]

Given these challenges, in this review, our primary objective is to gain a comprehensive understanding of pain in dementia, including its definition, diagnostic measures, and the assessment of interventions for pain management.

For the purpose of this review, the following specific research questions were addressed:

R1. What is the conceptualization of pain in dementia?
R2. What methods are utilized for pain assessment in dementia care?
R3. What approaches are employed for pain management in dementia care?
R4. What are the potential avenues for research on pain in dementia?

Methods

Compliance with ethics guidelines

This article is based on previously conducted research and does not contain any studies with human participants performed by any of the authors. Therefore, ethical approval was not required.

Literature review strategy

The electronic database PubMed was searched on May 2024 using two Medical Subject Heading (MeSH) terms that had to be present in the title. Term A was "dementia" or "cognitive impairment" and Term B was "Pain" OR "Painful". A filter was applied to include only free full-text publications in the search. The reference lists of articles that met the eligibility criteria were further perused to identify additional studies that may fall within the scope of this review.

Inclusion and exclusion criteria

Studies eligible to be included in this review had to meet the following inclusion criteria: i) human subjects were involved; ii) the full article was written in English; iii) papers studied pain in dementia. The exclusion criteria were i) publications where the study of pain in dementia was not the primary aim of the study; ii) publications that were not original studies (*i.e.*, review articles, letters, medical hypotheses, *etc.*); iii) publications that presented trials studying subjects less than 18 years old; iv) duplicate publications or studies referring to the exact same population; v) publications whose abstract was not accessible; vi) publications whose full text could not be obtained.

Data collection process

Following the identification of the eligible publications, all relevant data were collected in a structured coding scheme using an Excel file. The data collected included titles, type of pain studied, definition of pain used, instruments/measurements of pain, reliability of instruments, interventions to manage pain, outcomes, and type of intervention. When there was uncertainty regarding how the data should be interpreted or utilized, a cross-reliability test between three authors was performed.

Data synthesis

This study used aggregated data where possible, in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines.

Results

Search results

This search strategy resulted in the identification of 326 articles. After the eligibility assessment, 307 articles were excluded. In total, 18 papers met the inclusion criteria and were used for this review (Table 1). These studies were published between 2003 and 2024. Figure 1 illustrates the study selection process.

Definitions of pain in dementia

The definition of pain has been a challenge since 1942.[42] Many attempts have been made to clearly define pain, leading to the conclusion that the definition needs to be updated regularly. Greater attention to the phenomenology of pain, the social «intersubjective space» in which pain occurs, and the limitations of language can achieve a fuller understanding of the pain experience and clinical care of those experiencing pain.[43,44]

Patients with dementia and other neurogenic communication disorders may face difficulties in expressing their pain verbally.[45,46] This makes it difficult to accurately define and address their pain. After an extensive search, we found only six studies that presented a preliminary definition of pain,[24,26,27,35,41] with the most common theme describing it as an "unpleasant sensory and emotional experience",[24,33,35,41] with differing details such as pain being "associated with actual or potential tissue damage", "an important bio-alarm system",[24] and "induced by sensory stimuli and interpreted and modulated by individual emotions, memories, and expectations".[41] The varying definitions pertaining to the fundamental nature of pain reflect its multidimensional characteristics. These definitions underscore the subjective aspect of pain[24] and its association with both actual and potential injury/trauma.[35]

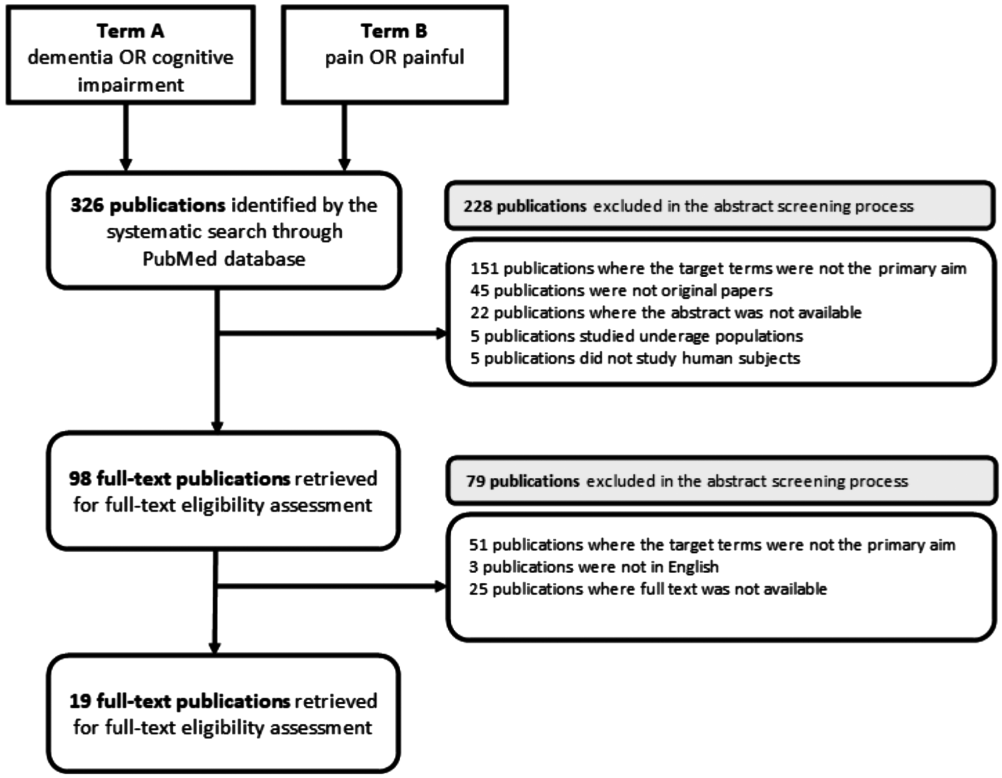

Figure 1. This figure illustrates the study selection process, detailing the number of studies meeting inclusion or exclusion criteria through each stage of screening.

Table 1. Types and definitions of pain, demographic characteristics of the participants and main findings of the reviewed studies.

Study	Type of pain	Study population	Main findings	Definition of pain
Bunk *et al*. (2021)[23]	Induced pain (pressure and heat stimuli) at the upper border of the trapezius muscle	23 PwD (MAge=72.8, male=14; female=7). 35 healthy older adults (Mage=69.2, male=24; female=11).	Amplified pain responses in PwD may be due to loss of pain-inhibitory functioning from structural prefrontal changes	N/A
Shigihara *et al*. (2021)[24]	Lower back pain	23 patients with cognitive dysfunction (MAge=72.8, male=16, female=7) and 35 controls (MAge=69.2, male=24, female-11)	Emphasized importance in the treatment of pain before cognitive function diminishment becomes persistent. Proposed that low-frequency oscillatory activity may represent a transient bridge between pain and cognitive dysfunction	A common, subjective, unpleasant sensory and emotional experience associated with actual or potential tissue damage
Bullock *et al*. (2020)[25]	Varied pain conditions (e.g spinal injury, osteoarthritis, tooth pain, back pain etc.)	8 PwD (Mage=73.5, male=6, female=2),9 Family Caregivers (MAge=68, male=4, female=5), 14 HCPs	Noted minimal concerns associated with non-pharmacological strategies, and multiple concerns associated with analgesic treatment. Highlighted the responsibility and potential burden associated with managing pain from a caregiver perspective	N/A
Shaw *et al*. (2023)[26]	Pain during care encounters	26 PwD (male=9, female=7) and HCPs (n=53).	Rejection of care behaviours were common, and noted as helpful for pain identification in PwD	N/A

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Table 1. Continued from previous page.

Study	Type of pain	Study population	Main findings	Definition of pain
Nowak *et al*. (2018)[27]	Pain during care encounters and movement	96 participants (MAge=84, male=18, female=78) with symptoms of dementia	Supports the hypothesis that pain is a relevant underlying cause of behavioural disturbances in PwD, and emphasises the importance of pain management and assessment	N/A
Scuteri *et al*. (2022)[28]	Pain during movement, visceral pain	11 PwD (MAge=85.9)	Concluded that the I-MOBID2 was useful and valid in a healthcare setting for pain assessment in PwD	N/A
Browne *et al*. (2019)[29]	Pain during physiotherapy examination, general pain	102 participants (MAge=78.84, male=32, female=70) either with (N=48) or without (N=52) dementia, and 61 undergraduate students (MAge=22.72, male=20, female=41)	Emphasised the importance of multiple angles of observation when identifying pain behaviours in PwD	N/A
Atee *et al*. (2017)[30]	Varied pain conditions, pain during movement	40 PwD (MAge=79.7, male=12, female=28)	Concluded that the ePAT is viable for pain assessment in non-communicative PwD, and emphasises the advantages of automated systems within this domain	An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage
Maltais *et al*. (2018)[31]	General pain	91 PwD (age>65) participated in either the exercise (n=44) or social interaction intervention (n=47)	No significant differences between exercise and social interventions were found in PwD	N/A
Atee *et al*. (2018)[32]	General pain, pain during movement	10 PwD (MAge=74.4, male=5, female=5) and 11 aged care staff (MAge=44.1, female=9, male=2)	Supported the use of ePAT in clinical settings with people with advanced dementia	N/A
Demange *et al*. (2019)[33]	Pain during care	57 HCPs (Age 20-50, male=12, female=45) and 12 PwD	Supported the implementation of a robot-assisted intervention framework for pain management in PwD	An unpleasant sensory and emotional experience
Kunz *et al*. (2015)[34]	Pain responses to electrical stimulation & pressure stimulation	70 participants (Age MAge=75.6 Male=30, female=40) with varying dementia-related cognitive impairment (no cognitive decline to severe dementia)	Supported the hypothesis that executive functioning (from dementia-related neurodegeneration in prefrontal areas) results in a loss of pain inhibitory potency, supporting the combination of pain assessment in PwD with cognitive function tests	N/A
Husebo *et al*. (2007)[35]	General pain, pain during movement	26 participants (MAge=87, male=17, female=70) with severe cognitive impairment and their primary caregivers	Emphasises the importance of active, guided movements during pain assessment in severely cognitively impaired patients	An unpleasant sensory or emotional experience associated with actual or potential tissue damage
Hadjistavropoulos *et al*. (2018)[36]	Pain during physiotherapy examination	48 PwD (MAge=82.5, male=13, female=36) and without dementia (N=52, MAge=75.46, male=23, female=33)	Suggested that simpler observational measures are valid and potentially superior to more resource-intensive approaches in clinical settings	N/A

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Table 1. Continued from previous page.

Study	Type of pain	Study population	Main findings	Definition of pain
Atee *et al*. (2018)[37]	General pain, pain during movement	40 PwD (Mage=79.7, male=12, female=28)	Concluded that PainCheck is a valid pain assessment and management system in non-communicative PwD	Emphasised individualized experience of pain, IASP definition "an unpleasant sensory and emotional experience …"
Lichtner *et al*. (2015)[38]	General pain	31 PwD (MAge=88, male=11, female=20), 52 healthcare staff, and 4 family members	Emphasised the relativity of numerical pain scores in PwD, and supported the inclusion of personalized cut-off scores for individual patients with temporal considerations	N/A
Closs *et al*. (2004)[39]	General pain	113 participants (MAge=84.5, male=27, female=86) with varying degrees of (from no cognitive decline to severe dementia) cognitive impairment	Showed no significant difference in pain scores between cognitive impairment groups, but increased difficulty in completing the scales among the severely cognitively impaired, supporting alternate approaches in that population	N/A
The *et al*. (2016)[40]	Musculoskeletal pain of moderate to severe intensity	50 PwD (MAge=87.8), male=21, female=29)	Concluded the validity of the Portuguese PACSLAC scale with elderly PwD with limited communicative abilities	A complex sensory experience, modifiable by one's memory, expectations and emotions
Manfredi *et al*. (2003)[41]	Pain during dressing changes of decubitus ulcers	9 PwD (MAge=84.8, male=2, female=7), 8 medical students, and 10 nurses	Supported the validity of observations of facial expressions and vocalisations for the assessment of pain, but not for its intensity in patients with severe dementia	An unpleasant sensory and emotional experience induced by sensory stimuli and interpreted and modulated by individual emotions, memories, and expectations

The definition of pain in the context of dementia has also been studied but less commonly.[24,28,32,33,35,40,41] Pain in dementia is associated with specific characteristics; for example, stress[27] is a common theme associated with behavioral disturbances and rejection of care behaviors.[26] Pain in movement related/interactive settings was also a common theme, whether presented during guided movements characteristic of assessment tools,[28,35] during physiotherapy sessions,[29,36] or during care encounters.[26] As previously identified, the commonly referenced base definition of pain is "unpleasant sensory and emotional experience". Within the context of PwD, the relative nature of pain and its potential variations based on cognitive impairment are highlighted.[38] There is particular emphasis on the potential reduction in inhibitory potency,[23] as well as the challenge of distinguishing between behavior disturbances rooted in cognition and those rooted in pain.[27,38,40]

We found that the choice of measurement tools in each study significantly influences the effectiveness of the respective definitions. For instance, the temporal aspect of pain presence is relevant, as assessment tools could focus on recalling recent pain episodes, current pain, or overall pain/health related quality of life (HRQoL). Therefore, it is imperative to explicitly delineate the type of pain under study, the instruments employed, and the definition of pain prior to conducting comprehensive analyses of pain in dementia. In summary, the consensus in studies meeting our inclusion criteria is that pain is defined by unpleasant sensory and emotional experience(s). Defining specific aspects of pain requires consideration of measures and situational context specificity to the broad, subjective nature of pain.

Diagnosis of pain in dementia

Diagnosis of pain in PwD often requires measures with minimal reliance on patients' self-reporting due to their impaired cognitive abilities. The need becomes more critical as the disease progresses. This was addressed in multiple ways across the 19 studies, including staff-administered scales (n=9),[27-30,35-38,40] observational measures (n=15),[23,26-31,34-41] and automatic identification systems that utilize AI-driven facial recognition software (with the last to be accompanied by a staff-administered observational measure) (n=3).[30,32,37]

Overall, the analysis identified a range of instruments for measuring pain, including quantitative and qualitative and single or multi-measure approaches. Among the quantitative measurements, two types of scales were noted: those specifically designed for PwD and general scales. The scales specifically designed for PwD include the Pain Assessment in Advanced Dementia (PAINAD), Mobilization-Observation-Behaviour-Intensity-Dementia Pain Scale (MOBID1/2), or Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC-II) scales,[26,28,29,35,36,4]0 or patients with difficulties expressing and articulating concepts (*e.g.*, the Abbey Pain Scale [APS]).[27,30] Furthermore, general scales that are not specifically targeted to any population, such as the Visual Analogue Scale (VAS) and Numeric Rating Scale (NRS) scales were also used.[25,40,41] Further to the above, in one study focusing on pain processing in PwD, measurements also included pressure algometers/temperature of heat pulses,[23] so that a quantifiable measure of stimulus intensity could be analyzed alongside the self-report ratings used.

Aside from short-form self-report measures such as the Verbal Rating Scale (VRS), VAS, and NRS utilising Likert scale measurements with varying qualifying statements for participants,[23,24,26,35,39,40] the most common measures utilised either Likert or dichotomous items in broader, observational scales identifying pain expressed through vocalisations, body language, and movement, whilst occasionally implementing items involving patient interaction aiming to pinpoint painful areas or movements.[28,35] Observational measures have emerged as the preferred approach for pain assessment in PwD, primarily due to the challenges posed by communicative deficits associated with cognitive impairments. This issue is particularly pronounced in patients who are entirely non-verbal. The other category of measure maintained a primarily observational nature, but also implemented technological assistance with facial recognition, and multiple projects[30,32,37] have commented on potential use-cases and optimisations of this technology for the given population.

Qualitative methods were generally utilized as a tool to enhance comprehension of the pain in PwD regarding its identification,[38,41] treatment,[38] feasibility, and acceptability of potential interventions.[33] The outcomes and implications drawn from these studies highlight the efficacy of interviews, particularly those involving formal and informal caregivers, in revealing deficiencies within current conventional practices.[25] This revelation may catalyse the development and implementation of more pertinent quantitative methods to evaluate and manage pain experienced by PwD.

Interventions for pain management in dementia

The studies reviewed underscore the significance of effective pain assessment and management interventions in PwD, given the complex challenges of assessment, especially in cases of severe dementia where reduced pain inhibition is observed compared to healthier older adults.[23] Further to the above, the studies included in this review primarily focused on assessing the efficacy, reliability, and practical applications of pain assessment tools and interventions for managing pain in PwD. These results highlight various validated tools and methods used to assess and manage pain effectively in cognitively impaired populations, emphasizing both the need for reliable measures and the diversity of tools and techniques applied. Table 2 provides a comprehensive overview of the non-pharmacological interventions utilized in these studies, with one notable exception, which investigated analgesic and sedative prescriptions in PwD.[27]

Several studies confirmed the reliability and validity of specific pain assessment tools in PwD. For instance, a study[30] demonstrated that the electronic Pain Assessment Tool (ePAT) shows significant validity and reliability for PwD, a finding further supported by a second study,[37] which recommended larger-scale testing. Additionally, another study provided a broader perspective by examining the PainChek system, supporting its effectiveness for non-verbal PwD and emphasizing the advantage of regular, interval-based assessments.[32]

Table 2. Assessment measures utilised in each study, and implications of their results on the use of said measures.

Study	Instruments	Type of instruments	Conclusions/implications
Bunk *et al*. (2021)[23]	VRS, FACS	VRS: verbal pain rating corresponding to 0 (no pain) to 4 (severe pain). FACS: the facial action coding system describes 44 visual action units (AUS) that are identified for frequency and intensity	N/A
Shigihara *et al*. (2021)[24]	Pain-VAS	Pain-VAS: scored from 0-10 with higher values corresponding to greater pain	N/A
Bullock *et al*. (2020)[25]	Semi-structured interviews	Qualitative	N/A
Shaw *et al*. (2023)[26]	PAINAD, NRS, CNPI	PAINAD: Five-item scale scored from 0 (minimum) to 2 (maximum) per item on breathing, vocalization, facial expression, body language, and controllability containing a cutoff for the presence of pain (>2). NRS: a segmented numerical scale from 0-10. CNPI: an observational tool incorporating vocalisation, grimaces, bracing, rubbing, restlessness, and verbal complaints	Proposed that recording rejection of care behaviours can be beneficial

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Table 2. Continued from previous page.

Study	Instruments	Type of instruments	Conclusions/implications
Nowak *et al*. (2018)[27]	APS	APS: 6-item observational Likert scale (*i.e.*, vocalization, facial expression, changes in body language, behavioural, physiological, and physical); ranges: 0 to 3 — higher scores yield more pain	N/A
Scuteri *et al*. (2022)[28]	I-MOBID2	I-MOBID-2: A two-step HCP-administered instrument observing the presence of pain indicators during guided movements and pain drawings. Each pain behaviour and pain area is scored on an 11-point NRS (0=no pain, 10=as bad as it possibly could be) in addition to an overall pain intensity rating	Supported use of the I-MOBID-2, interrater and test-retest agreement, and short execution time
Browne *et al*. (2019)[29]	FACS, PACSLAC-II	FACS: the facial action coding system describes 44 visual action units that are identified for frequency and intensity. PACSLAC-II: observational assessment tool for use by HCPs using a checklist of 31 pain behaviours	Supported use of multiple viewing angles in observational measures recording facial expressions
Atee *et al*. (2017)[30]	ePAT, APS	APS: 6-item observational Likert scale (*i.e.*, vocalization, facial expression, changes in body language, behavioural, physiological, and physical); ranges: 0 to 3 - higher scores yield more pain. ePAT: An automated facial recognition pain assessment tool utilising 6 domains (the face, the voice, the movement, the behaviour, the activity, and the body)	Showed strong concurrent validity, interrater reliability, and internal consistency of the ePAT automated facial recognition pain assessment solution
Maltais *et al*. (2018)[31]	Algoplus	Algoplus: pain assessment tool for non-communicative patients with each item scored 0 (no pain) or 1 (presence of pain) across 5 items	N/A
Atee *et al*. (2019)[32]	PainChek system	PainCheck: automated system designed to identify facial action units that indicate the presence of pain resulting in a pain intensity score	Supported the use of the automated facial recognition pain assessment and intensity solution 'PainChek'
Demange *et al*. (2019)[33]	Feasibility and acceptability measures	Mixed methods – five focus groups, 18-item questionnaire	N/A
Kunz *et al*. (2015)[34]	Self-report ratings, FACS	FACS: The facial action coding system describes 44 visual action units (AUS) that are identified for frequency and intensity	Noted variance in pain indicators being associated with executive function
Husebo *et al*. (2007)[35]	MOBID, NRS	MOBID: a HCP-administered that observes the presence of pain indicators during standardized guided movements resulting in a pain intensity score (each item scored 0-10). NRS: a segmented numerical scale from 0-10	Supported the use of the MOBID scale, with emphasis on the inclusion of movement-guided procedures

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Table 2. Continued from previous page.

Study	Instruments	Type of instruments	Conclusions/implications
Hadjistavropoulos *et al*. (2018)[36]	FACS, PACSLAC-II	FACS: The facial action coding system describes 44 visual action units (AUS) that are identified for frequency and intensity. PACSLAC-II: Observational assessment tool for use by HCPs using a checklist of 31 pain behaviours	Showed strong validity of PACSLAC measure, and highlighted inefficiency of more resource-intensive alternatives
Atee *et al*. (2018)[37]	ePAT, APS	APS: 6-item observational Likert scale (*i.e.*, vocalization, facial expression, changes in body language, behavioural, physiological, and physical); ranges: 0 to 3 - higher scores yield more pain. ePAT: An automated facial recognition pain assessment tool utilising 6 domains (the face, the voice, the movement, the behaviour, the activity, the body)	Further supported validity and reliability of ePAT in healthcare settings
Lichtner *et al*. (2015)[38]	National Early Warning Score (EWS)	This qualitative study identified different standards for pain identification and assessment that were "standardized within, not across hospitals"	Emphasised subjectivity and uncertainty associated with numeric scores for pain in PwD. Supported use of technology and personalisation
Closs *et al*. (2004)[39]	VRS, NRS, FS, CS	NRS: a segmented numerical scale from 0-10. VRS: a verbal pain rating corresponding to 0 (no pain) to 4 (severe pain)	Supported the use of simpler self-report scales in PwD with mild-moderate cognitive impairment, but not those with severe impairment
The *et al*. (2016)[40]	VAS, PACSLAC-P	PACSLAC-P: Observational assessment tool consisting of 60 observational items (present/not present) with 4 sub-scales (facial expressions, body movements, vocalisations, others)	Concluded adequate reliability and validity of the PACSLAC-P scale with excellent reproducibility
Manfredi *et al*. (2003)[41]	Videotape analysis	Utilised two key questions, one scored for the likelihood of pain experience (definitely not – definitely yes), and one scored for pain intensity (mild-severe [with additional option "cannot rate"])	Results supported the accuracy of observers when noting the presence of pain in PwD, but not its intensity

In terms of observational approaches, a study explored the influence of viewing angles on the accuracy of observer pain judgments, finding that profile views enhanced accuracy for observing pain expressions.[29] This suggests that multidimensional observation strategies could improve pain assessment accuracy in PwD.

Also, several studies investigated specific interventions for managing pain in PwD.[24,31,33] In particular, a study examined the effectiveness of the PARO robot, an animal-like device used to manage acute pain through therapeutic interactions, concluding that it offered a viable and consistent framework for pain management. However, it warrants further exploration.[33] Further to the above, another study[31] tested an exercise intervention in nursing homes but found no significant differences between the intervention and control groups, despite improved outcome scores in the intervention group. In a separate study[24] involving patients with lower back pain, it was found that Selective Nerve Root Block (SNRB) not only alleviated pain but also correlated with changes in neural activity. This suggests that neural response could serve as a potential indicator of the effectiveness of pain relief.

The review also included comparisons of various pain assessment scales.[23,28,36,39] For example, a study[39] evaluated five different scales, recommending further research on the impact of scale training and repeated explanations for healthcare providers (HCPs) in pain assessment to increase reliability. Another study[36] assessed PACSLAC-II and FACS tools, concluding that both successfully differentiated between painful and non-painful states, underscoring their potential efficacy in clinical settings. In specific population-focused validations, an Italian version of the MOBID-2 scale was tested in PwD. However, no further outcomes were detailed, suggesting that additional trials are necessary to confirm its application and reliability across diverse populations.[28] Finally, a study[23] investigated the relationship between pain and neurodegeneration, finding that cognitively impaired participants displayed heightened facial responses to pain, with reduced pain inhibition, likely due to variations in gray matter density, adding a new perspective on pain expression linked to cognitive decline.

Finally, a common theme across these studies is the potential undertreatment of pain in PwD due to diagnostic challenges and behavioral disturbances. For instance, a study examining behavioral responses to pain highlighted that rejection behaviors, such as yelling, crying, or turning away, were strongly associated with severe pain, especially in cognitively impaired patients.[26] The study concluded that consistent observation of these behaviors could serve as a valuable indicator of pain in PwD, advocating for more standardized observational assessment protocols in healthcare settings to improve QoL for PwD.

As aforementioned, when studying pain in PwD, it has been observed that patients with the ability to communicate effectively confirmed that dressing changes for pressure ulcers were painful.[41] However, a similar type of pain in severe dementia patients is much more challenging. Nine patients with severe dementia were exposed to pressure ulcers, to analyze their facial expressions during the dressing changes. The results indicated that the caregivers were highly accurate in identifying the presence of pain but less reliable in rating pain intensity. This suggests that while basic methods may be enough to identify pain, more specific tools are needed to measure pain intensity.[41] For this reason, a new application has been developed to integrate facial recognition and clinical data for pain assessment and monitoring. The application has demonstrated strong internal consistency and promising psychometric properties and shown accuracy in detecting pain in PwD.[32] In another study, HCPs showed high accuracy in pain assessment from both profile and panoramic views, while untrained observers performed better from the profile view.[29] This has implications for the optimization of observer training and outlines the benefits of the development of automated pain detection algorithms that can potentially utilize multiple viewpoints automatically to maximize accuracy.[30]

Overall, these findings emphasize the importance of using comprehensive pain assessment tools that utilize technology and acknowledge the subjectivity (due to rather interpretation) of most models.

Discussion

The growing body of scientific research on pain in dementia is noteworthy, with over 70% of the studies included in this review having been published after 2018. Broadly, the defining foundations of pain in dementia are agreed upon, with multiple specific measures providing promising validity and consistency (shown in Table 3) although a comprehensive system integrating the most well-supported findings and recommendations is somewhat lacking.

The majority of papers reviewed indicate that the current understanding of pain in dementia (and in patients with cognitive impairment overall) is inadequate in terms of accurate measurement and healthcare protocols. There is a heavy reliance on subjective measures (with some degree of subjectivity inherent to every observation), with a focus on challenges in interpreting patient behaviour due to the absence of accurate self-reported methods affected by the nature of dementia. Additionally, the incorrect prescription of analgesics (in cases of both under and over-administration) due to unclear pain assessment protocols is highlighted,[25] with several noted side effects of misdiagnosis. For example, untreated pain can lead to symptoms resembling even more severe cognitive decline than is already present, irritability, and rejection of care behaviours, whilst unnecessary prescription of pain medication has widely documented health-related drawbacks.[47] Consequently, improving the understanding and/or diagnosis of pain in PwD (especially within specific sub-populations and levels of cognitive impairment) would have significant positive implications for patients' HRQoL, as well as noteworthy benefits for informal and formal caregivers regarding confidence in measures, standardization of procedures, and more consistent frameworks for observation measures.

To optimize traditional pain assessment measures, recent studies have introduced innovative solutions utilizing smart technology.[30-33,38] Two main technological advancements were explored. The first involved automated facial recognition technology to identify pain-related expressions, while the second utilized robot-assisted interaction. The automated facial recognition systems, while partly subjective to user-provided information, offer an objective assessment layer, showing potential for widespread use on more easily accessible phone and web platforms. These systems demonstrated adequate reliability and validity and are expected to improve as technology advances.[30,32,37] The robot-assisted interaction served as a comforting and distracting tool, showing promise in reducing discomfort for PwD during painful procedures.[33] PwD were able to express their pain effectively using this system. Both examples highlight the valuable role of technology in pain assessment and treatment for PwD.

Regarding accurate measurement of pain in PwD, both the presence and intensity of pain are crucial if optimal action is to be taken based on assessment. A consistent theme of observational measures focusing on patient behavior, facial expression, and vocalization is present in current specific measures. In addition to these factors, our review supports the inclusion of guided movement within the pain assessment,[28,29,36] as this may more accurately reveal the presence of pain and identify the physical areas associated with it. Consistent measurement over time is essential for maximizing the utility of a pain assessment system, particularly considering the subjectivity and potential patient-to-patient differences in reports of pain intensity. This allows for comparisons between time points and analysis of pain responses to treatment or intervention at different temporal resolutions.

Limitations

This narrative review offers important insights into current and prospective approaches to pain assessment and management in PwD, yet several limitations must be acknowledged. Firstly, the scope of the literature search was restricted to studies available through PubMed and limited to free full-text articles published in English. Consequently, relevant studies published in other databases or behind paywalls may have been excluded, potentially narrowing the comprehensiveness of the findings.

Another limitation relates to the underrepresentation of di-

Table 3. Interventions and results found in studies in this review.

Study	Aim	Intervention	Outcome
Bunk *et al*. (2021)[23]	Investigate the link between pain and neurodegeneration in PwD	Induced pain (pressure and heat stimuli) on PwD to investigate neurological links	Facial responses were significantly different based on the level of cognitive decline, with cognitively impaired participants showing increased facial responses and decreased pain inhibition, with gray matter mediating this effect
Shigihara *et al*. (2021)[25]	(Investigate bridges between pain and cognitive impairment utilising MEG)	Selective Nerve Root Block (SNRB) used on patients with lower back pain, and their neural activity was analysed	SNRB successfully reduced the subjective level of pain, and resulted in changes in neural activity corresponding to the reduction in pain
Scuteri *et al*. (2022)[28]	Validate an Italian version of the MOBID-2 scale	Use of the MOBID-2 pain scale with PwD	N/A
Browne *et al*. (2019)[29]	Investigate the validity of observer pain judgements from multiple angles of observation	Tested panoramic and profile facial views for observer pain assessment accuracy of PwD	Found that profile views are advantageous for observing pain expressions, and multiple viewing angles could improve observation accuracy
Atee *et al*. (2017)[30]	Evaluate the ePAT (electronic Pain Assessment Tool) in PwD	Use of the ePAT with PwD	Suggested the validity and reliability of ePAT in PwD
Maltais *et al*. (2018)[31]	Assess the effect of an exercise intervention on PwD in nursing homes	Implemented an exercise intervention and assessed pain data	Although the exercise group showed better outcome scores, no significant difference between groups was found
Atee *et al*. (2018)[32]	Evaluate the reliability properties of the ePAT pain assessment tool	Use of the ePAT with PwD	Results supported the validity of ePAT and large-scale testing of the method
Demange *et al*. (2019)[33]	Develop, refine, and test the PARO-robot intervention for pain management in PwD	Used an animal-like robot (PARO) for managing acute pain in PwD through therapeutic interaction	Authors concluded that the PARO robot provides a consistent and feasible framework for pain management in PwD requiring further research
Atee *et al*. (2018)[37]	Overview of the conceptual foundation and potential uses of the PainChek system	Use of the PainCheck system with non-verbal PwD	Use of the system as well as use of systems taking measures at regular time intervals were supported
Closs *et al*. (2004)[39]	Compare and evaluate pain assessment scales in cognitively impaired participants	Use of five different pain assessment tools with PwD	Results highlighted that repeated explanation of assessment scales and training of HCP's in using pain measures should be tested in further research.
Hadjistavropoulos *et al*. (2018)[36]	Assess the relative efficacy of PACSLAC-II and FACS approaches to assess pain	Use of two pain assessment tools with PwD	Both the FACS and the PACSLAC-II were successful in differentiating between painful and non-painful states

verse populations. The review did not deeply explore the implementation of pain assessment tools across different stages of cognitive decline. While several studies included individuals with mild to moderate dementia, less focused specifically on those with severe cognitive impairments, particularly non-verbal individuals, who represent one of the most challenging populations for pain assessment and management.

Lastly, while the review highlights the importance of improving both the identification and measurement of pain in PwD, particularly through objective and observational approaches, it remains evident that most existing research focuses on the presence of pain rather than its intensity or progression over time. Future research should prioritize longitudinal studies that integrate physiological, behavioral, and observational data to better assess the temporal dynamics of pain and its impact on the quality of life in PwD. Overall, these limitations underscore the need for continued multidisciplinary research with standardized protocols, larger and more diverse samples, and an emphasis on real-world applicability to enhance pain care in dementia.

Conclusions and future directions

Our review emphasizes the importance of addressing pain in dementia care. It is for this reason that in future research, it would be beneficial to combine established methods that have been proven to be valid and reliable with more objective measures that are not influenced by observer or patient differences. For example, we should further develop automated facial recognition technology, analyze patient behaviors, responses to movements and vocalizations, and implement measures that can be consistently taken at regular time points. Additionally, a relative lack of physiological measures acquired concurrently with the more frequently used ones poses a research area prime for development and investigation. This is further strengthened by the hypothesis that measures should maximize their objectivity and minimize subjectivity wherever possible. Integrating physiological measures with automated facial recognition could provide two relatively objective measures that, when combined with relevant observational notes and measures, could significantly improve assessment accuracy. Moreover, additional research with large, longitudinal samples is necessary to provide theoretical support for exercise-based interventions, especially when compared with multiple control groups representing standard care. Furthermore, further research utilizing novel pain management for PwD could offer a solution for minimizing negative emotions and behavior that challenges during unavoidable pain in PwD, present in daily care practices.

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