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Title: Pain assessment and pain treatment for community-dwelling people with dementia: A systematic review and narrative synthesis

Short running title: Pain in community-dwelling people with dementia

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Abstract

Objectives
To describe the current literature on pain assessment and pain treatment for community-dwelling people with dementia.

Method
A comprehensive systematic search of the literature with narrative synthesis was conducted. Eight major bibliographic databases were searched in October 2018. Titles, abstracts, and full-text articles were sequentially screened. Standardised data extraction and quality appraisal exercises were conducted.

Results
32 studies were included in the review, 11 reporting findings on pain assessment tools or methods, and 27 reporting findings on treatments for pain.

In regard to pain assessment, a large proportion of people with moderate to severe dementia were unable to complete a self-report pain instrument. Pain was more commonly reported by informal caregivers than the person with dementia themselves. Limited evidence was available for pain focused behavioural observation assessment.

In regard to pain treatment, paracetamol use was more common in community-dwelling people with dementia compared to people without dementia. However, non-steroidal anti-inflammatory drugs (NSAIDs) were used less. For stronger analgesics, community-dwelling people with dementia were more likely to receive strong opioids (e.g. fentanyl) than people without dementia.

Conclusion
This review identifies a dearth of high quality studies exploring pain assessment and/or treatment for community-dwelling people with dementia, not least into non-pharmacological interventions. The consequences of this lack of evidence, given the current and projected prevalence of the disease, are very serious and require urgent redress. In the meantime, clinicians should adopt a patient and caregiver centred, multi-dimensional, longitudinal approach to pain assessment and pain treatment for this population.
Systematic review registration: PROSPERO CRD4201705790

Keywords:
Dementia; Community; Pain, Pain Assessment; Pain Treatment; Pain Measurement; Pain Management; Analgesics

Key points:
- Timely recognition of pain for people with dementia is important to ensure effective management and reduce adverse effects of medication.
- Clinicians should adopt a multidimensional approach to pain assessment including self-report assessments, pain history information, physical examination, informant-based ratings, and observation of pain behaviours.
- For patients with dementia, regular and structured medication reviews to assess the use, efficacy, and side effects of analgesic prescriptions are essential.
- Further high quality, longitudinal research is essential to examine the management of pain and the most effective pain management strategies for community-dwelling people with dementia throughout the progression of disease.
1 Introduction

The world’s population is ageing, with the global population of people aged 65 years and older projected to grow from 901 million in 2015, to almost 2.1 billion by 2050.1,2 Aligned to this population rise, is the increasing prevalence of dementia. In 2015, approximately 47 million people were living with dementia worldwide; this rate is projected to increase to 131 million by 2050.3,4 One common comorbidity associated with aging is painful conditions (e.g. musculoskeletal pain),5 and it is estimated that approximately 50% of people with dementia have a painful condition, concordant to older adults without dementia.6

Symptoms associated with dementia (e.g. diminished language capacity, memory impairment, and behavioural symptoms) may lead to difficulties articulating a pain experience.7 Consequently, caregivers and clinicians may not recognise or interpret expressions of pain correctly, and thus may inadequately assess and treat pain.8 Poor pain management for people with dementia can cause adverse outcomes, such as neuropsychiatric symptoms, decreased quality of life, increased caregiver burden, and avoidable institutionalisation. It can also result in adverse drug events such as confusion, falls, and opioid overdose.9-12 Research conducted in residential, palliative, and acute care settings show that people with dementia are often treated differently compared to those without dementia.13-20 Furthermore, recent randomised control trials within these settings provide evidence that a step-wise prescription of analgesics can lead to a reduction in a range of neuropsychiatric symptoms and mood syndromes.21,22

Whilst this evidence shows the benefits of assessment and treatment of pain in people with dementia, the focus of such research has been largely restricted to formal care settings (e.g. nursing homes), as reflected in a number of existing systematic reviews23-29 and a recent meta-review.30 As a consequence, the evidence is almost exclusively based on people with high severity dementia (i.e. those without verbal communication capacity)26-28 and very little research into pain assessment and/or treatment has been conducted amongst community-dwelling populations.29 This highlights a significant knowledge gap in understanding the needs of community-dwelling people with dementia; this population will have greater diversity in the capacity to self-report their pain, and differences may exist in proxy reports from informal caregivers compared to caregivers within formal settings who may have professional training in assessment. Given that upward of 60% of people with dementia reside within community settings in the UK,31 this is a pressing concern.

This review aims to describe the current literature on pain assessment and pain treatment for community-dwelling people with dementia. Specific objectives are to: i) synthesise the evidence on the use of pain assessment tools and methods, and assess their utility within community-dwelling people with dementia; and ii) synthesise the evidence on the use of pain treatments and evidence of efficacy for community-dwelling people with dementia.

2 Methods

2.1 Patient involvement

A patient and public involvement meeting was organised with caregivers of people with dementia during project development. Caregivers shared their personal experiences of the complexity of pain assessment and management for their relative with dementia, reiterating the importance of systematically reviewing the evidence on pain assessment and pain treatment for community-dwelling people with dementia.

2.2 Search strategy

A comprehensive search strategy was applied within the following electronic databases: MEDLINE, EMBASE, AMED (Allied & Complementary Medicine Database), AgeLine, CINAHL, PsycINFO, Web of Science Core Collection, and The Cochrane Library from inception to October 2018 (see supplementary Table S1 for the MEDLINE search strategy). Searches were designed and conducted.
by LB with agreement and oversight from PC, JB, and JJ (research information specialist). No search limits were applied for study design, date, or language of publication. Further supplementary searches were conducted in Google Scholar, and all reference lists of all included papers were hand screened. A citation search of all included papers were tracked to ascertain subsequent potential publications, as well as a screen of all reference lists of relevant commentaries, literature reviews, and systematic reviews.

2.3 Criteria for considering studies for this review

Inclusion

- Study participants must have a confirmed diagnosis of dementia and reside in the community (including living alone at home, with informal caregivers at home, retirement communities, warden-controlled housing, or assisted living).\(^{31}\)
- Studies examining the use of self-report, informant-report, and behavioural observation tools and methods of pain assessment.\(^{32}\)
- Studies examining the use of treatments for pain (including pharmacological, and non-pharmacological treatments for pain).
- Studies evaluating the effectiveness of treatments for pain (both pharmacological and non-pharmacological) with a pain assessment tool.
- Full text peer-reviewed scientific journal articles.
- Studies published in English or other languages translatable via colleagues at the Research Institute.

Exclusion

- Studies with participants with dementia in nursing home, palliative, or hospital settings. If a study includes participants with dementia living in a variety of residential settings (e.g. nursing home and community), the study will be excluded if the results specific to people with dementia living in the community cannot be extracted independently.
- Studies solely focused on malignant pain. Cancer pain and its management is distinctly different from other common pain conditions.

Inclusion of papers involved a number of stages:

- Title screen to remove obviously irrelevant references (LB).
- Abstract screening and full text screening (LB), with 20% of the abstracts and full texts screened independently by PC with good interrater agreement (>95%). Discrepancies were resolved in discussion with a third reviewer (JB).

2.4 Data extraction

Data extraction was completed by LB and checked for consistency and accuracy by two other authors (PC and JB). Data were extracted onto a standardised data extraction form. The extracted data included: participant characteristics and information on the type of pain assessment and pain treatments. LB contacted the authors of potentially eligible papers if additional information or clarification was required.

2.5 Quality appraisal

Study quality was assessed using the National Institute of Health (NIH) Quality Assessment toolkit\(^{33}\) for a number of study designs (case-control, observational cohort, cross-sectional, controlled intervention, and pre-post studies with no control group). Each tool consists of 11 to 14 items (dependent on design type), each evaluated as “yes”, “no”, or “not applicable/cannot decide” as guided by NIH guidance. Each item focused on the concepts, questions, and domains that are integral for the critical appraisal and evaluation of internal validity, including potential biases.
confounding, and study power. Each item was used to guide the overall quality rating of "good," "fair," or "poor". A 20% sample of the studies were blind checked by PC to ensure consistency. Discrepancies were resolved in discussion with a third reviewer (JB).

2.6 Analysis

Due to heterogeneity of the sample populations, settings, study designs, interventions, and reported outcomes, as well as a lack of statistical information to perform a meta-analysis, a narrative approach was adopted. The initial analysis stage assessed and described the quality of the included studies. Each study was assigned to the overarching theme or “cluster” of “pain assessment” and/or “pain treatment”. Studies were further clustered thematically to form sub-domains. Sub-domains for pain assessment were self-report, informant-report, and behavioural observation. Sub-domains for pain treatment were pharmacological (further clustered by analgesic potency) and non-pharmacological treatments. Studies were tabulated based on their domain and sub-domain to allow for preliminary comparison within and across studies. The systematic approach to the narrative synthesis allowed the identification of patterns across the data in order to draw informative conclusions relevant to current research, policy, and practice.

3. Results

Searches identified 6741 unique records (up to October 2018), of which 129 were screened at full-text stage. One potentially eligible paper could not be obtained in full text. Three additional papers were found through the supplementary searching, resulting in 32 studies included within the review (See Figure 1). Of the included studies, 11 reported findings on pain assessment tools or methods (see Table 1), whereas 27 reported findings that explored treatments for pain (see Table 2 for an overview of pain treatment use and Table 3 for pain treatment effectiveness). 16 studies were conducted in North America, 8 in Finland, 2 in Denmark and 1 each in Canada, Northern Ireland, Sweden, France, Japan and Italy.

3.1 Quality assessment

Using the NIH Quality Assessment tools, 4 studies (12%) were assessed as good quality, 21 (66%) as fair quality, and 7 (22%) as poor quality.

Observational study designs were assessed using the NIH Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies. Many questions in the tool received a high percentage of "no" responses largely because of the cross-sectional designs. For example, only seven (22%) studies investigated the exposure prior to the outcome (question 6), four (13%) provided sufficient timeframe for the outcome to occur (question 7), and three (9%) measured the exposure more than once during the study period (question 10). A “no” response did not necessarily lead to a poor quality rating, but rather indicated areas of potential biases that may influence the relationship between the exposure and outcome associated with cross-sectional designs. Intervention studies were quality assessed using the NIH Quality Assessment Tools for Controlled Intervention Studies, or Pre-post Studies with No Control Group depending upon the presence of a comparator group (see supplementary Table S2 for detailed quality assessment).

3.2 Pain assessment tools and methods

Eleven studies investigated pain assessment tools and methods for community-dwelling people with dementia. Five studies examined self-report pain tools, six studies examined informant-based ratings of pain, and one study examined a behavioural observation tool.

Only one study provided an overview of the frequency of pain assessment in primary care, with pain assessment documented in 98% of patients’ medical records. Of the pain assessments documented in this study, 98% used the Numerical Rating Scale (NRS), Visual Descriptor Scale (VDS), or Faces
Pain Scale (FPS), whereas only 2% of medical records reported modifications of pain scales for cognitive impairment.

### 3.2.1 Self-report

Four studies (1 good quality, 1 fair quality, and 2 poor quality) examined the utility of the FPS, Visual Analogue Scale (VAS), Pain Intensity Scale (PIS), and the Philadelphia Geriatric PIS. The completion rates of the FPS, VAS and PIS were between 53-67% for people with largely moderate to severe dementia (Mini Mental State Examination (MMSE) of 15.6, ± 5.9 SD; MMSE of 15.7, ± 5.9 SD). Two studies considered the Philadelphia Geriatric PIS and results show it was predictive of negative psychosocial events at 4 months follow up, and identified a greater percentage of pain than reported in the medical records using the NRS, VDS, or FPS (94% vs 36%, respectively).

### 3.2.2 Informant pain ratings

In total, seven studies (4 fair, 3 poor quality) investigated informant-pain ratings of pain for community-dwelling people with dementia using a variety of tools (VDS, EQ5D, the Philadelphia Geriatric PIS, FPS, VAS, PIS). Five of these studies compared the percentage of self-reported and informant-reported pain for community-dwelling people with dementia. Caregivers reported pain presence in the person with dementia more frequently than the person with dementia themselves (see Figure 2). In the three studies investigating the congruence between people with dementia and their caregiver’s rating of pain an inter-rater reliability ranged from 0.25 to 0.34 with an average agreement of 58.6% in the two fair quality studies (range 58.2% to 59%).

[Insert Figure 2]

### 3.2.3 Observation of pain behaviours

One poor quality study investigated the Hospice Approach Discomfort Scale, a rating tool for observation of behaviours. Such tools aim to identify pain using non-verbal cues (e.g. behaviour, facial expression, body language). Poor correlations between the Hospice Approach Discomfort Scale and self-reported pain scales (FPS, VAS, and PIS) were reported; however, the author did not provide statistical evidence to support the findings and therefore estimations of concordance cannot be reported.

### 3.3 Treatments for pain

27 papers provided an overview of treatments for pain for community-dwelling people with dementia. 22 papers (3 good, 16 fair, 3 poor quality) provided an overview of the pain treatments used by people with dementia.

#### 3.3.1 An overview of analgesic use

Two papers investigated the use of analgesics for community-dwelling people with dementia over time, irrespective of their analgesic potency. Hamina et al examined analgesic use during the first 180 days after dementia diagnosis, stratified by the year of diagnosis (from 2005 to 2011). People diagnosed with dementia in 2011 were 2.3 times more likely to be prescribed analgesic medication during the first 180 days after diagnosis than people diagnosed with dementia in 2005. Alternatively, Gilmartin et al examined analgesic use from the time of dementia diagnosis, to five years after dementia diagnosis. Analgesic use remained largely consistent. These fair and good quality studies point more strongly towards changes with prescribing practices over time (cohort effect), irrespective of age and dementia severity.

11 papers reported an average 41.4% (range 24.7% to 63%) of people with dementia used analgesic medication. Four papers found that 47.7% (range 30.3% to 68%) of people with dementia reporting pain did not use analgesic medication. When exploring the prevalence of
analgesic use by community-dwelling people with dementia compared to a reference group, four papers (fair quality) found a mixed trend, with community-dwelling people with dementia having a lower\textsuperscript{51,52} or similar\textsuperscript{19,55} prevalence of analgesic medication compared to community-dwelling older adults without dementia.

3.3.2 Categories of Analgesics prescribed

3.3.2.1 Paracetamol

Paracetamol was used by an average 23.9\% (range 12\% to 32\%) of people with dementia.\textsuperscript{19,38,40,55} The amount of paracetamol used by community-dwelling people with dementia (with the exception of Hamina et al\textsuperscript{55}) included over-the-counter and prescribed paracetamol. Evidence suggests community-dwelling people with dementia used paracetamol more commonly than community-dwelling people without dementia.\textsuperscript{19,55}

Longitudinal research suggests that the use of paracetamol increased from the first year after dementia diagnosis to five years post-diagnosis.\textsuperscript{47}

3.3.2.2 Nonsteroidal anti-inflammatory drugs (NSAIDs)

Across all studies the combined prevalence of over-the-counter and prescribed NSAID use was 12\% (range 5.9\% to 21\%).\textsuperscript{19,38,40,55} Lower rates of NSAID use\textsuperscript{19} and prescriptions\textsuperscript{55} was found for community-dwelling people with dementia compared to community-dwelling people without dementia (5.9\% vs 12\%, respectively),\textsuperscript{19} and matched controls (13.2\% vs 17.3\%, respectively).\textsuperscript{55}

NSAID use decreased from the first year after dementia diagnosis to five years post-diagnosis.\textsuperscript{47} Additionally, the amount of NSAIDs prescribed during the first 180 days after dementia diagnosis also decreased each year from 2005 to 2011 for community-dwelling people with dementia,\textsuperscript{55} suggesting a change in the practice of prescribing NSAID medication over time, irrespective of age and dementia progression.

3.3.2.3 Opioids

The prevalence of opioid use for community-dwelling people with dementia was on average 14.3\% (range 7.1\% to 27.5\%).\textsuperscript{19,38,40,48,50,53,55,56} Three studies (two fair quality,\textsuperscript{55,56} and one good quality\textsuperscript{48}) show that community-dwelling people with dementia were prescribed less opioids than age, sex, and region of residence matched controls without dementia. However, two studies\textsuperscript{19,53} (both of fair quality) showed that more community-dwelling people with dementia used\textsuperscript{19} or were prescribed\textsuperscript{53} opioid medication compared to community-dwelling people without dementia (see Figure 3).

The use of opioids for community-dwelling people with dementia was relatively consistent from the first year after dementia diagnosis to five years post-diagnosis.\textsuperscript{47} However, the amount of opioids prescribed during the first 180 days of dementia diagnosis increased each year from 2005 to 2011,\textsuperscript{55} with those diagnosed in 2011 being 3.7 times more likely to be prescribed an opioid during the first 180 days after dementia diagnosis compared to those diagnosed in 2005.

[Insert figure 3]

When opioid use was stratified further based on strength defined by the World Health Organisation’s (WHO) Analgesic Ladder, an average 9.8\% (range 2.7\% to 16.8\%) of people with dementia were prescribed weak opioids, whereas the proportion prescribed strong opioids was 5.3\% (range 0.95 to 17.4\%).\textsuperscript{37,53,55,56} The annual prevalence of strong opioid use was higher among community-dwelling people with dementia compared to the reference group.\textsuperscript{53,56} Community-dwelling people with dementia had a 1.44 higher odds of being prescribed fentanyl than matched controls,\textsuperscript{56} and a two times higher odds than a comparison group without dementia.\textsuperscript{53} Additionally, community-dwelling people with dementia had a two times higher odds of being prescribed buprenorphine than community-dwelling people without dementia.\textsuperscript{53}
3.4. The effectiveness of treatments for pain

Five papers investigated the effectiveness of treatments for pain for community-dwelling people with dementia by measuring the result of an intervention upon pain assessment scores (1 fair quality, 4 poor quality). Two papers investigated analgesic treatments with three investigating a non-pharmacological treatment/intervention for pain.

Elliot and Horgas investigated the effectiveness of scheduled paracetamol in reducing pain behaviours (e.g. rubbing, grimacing, and sighing) among those with musculoskeletal pain. Observed pain behaviours were lower in treatment phases than during baseline phases. Benedetti et al found no difference in pain scores between an expected or unexpected application of 1% lidocaine during the insertion of a needle. However, the difference between the open applications decreased between baseline and follow up.

One study investigated the effectiveness of a non-pharmacological music intervention upon pain for this population. Informal-caregivers assessed pain 30 minutes before, during, and after listening to music. Many comparisons indicated non-significant findings; however, pain was significantly lower after listening to music than before listening to music. Two studies investigated the effectiveness of psychosocial interventions with mixed efficacy (see Table 3).

4 Discussion

This review provides an overview of the current evidence on both pain assessment and pain treatment for community-dwelling people with dementia. These two areas will be discussed in turn, contextualised by contrasting with comparative population groups, and considering implications for practice, research and policy.

Pain assessment

The first aim of this review was to synthesise evidence on the use of pain assessment tools and methods, and their utility for community-dwelling people with dementia. A large proportion of those who have moderate to severe dementia were unable to complete a self-report pain instrument, suggesting a threshold effect for their efficacy in this population. Such findings are in line with the British Pain Society (BPS) recommendations that encourage the use of self-report measures for people with dementia (irrespective of their degree of cognitive ability); however certain adaptations (e.g. simplified language and large fonts) may be required, especially for those with moderate and severe cognitive impairment. Overall, whilst self-report pain assessments can be used in community-dwelling people with dementia, a reliance on self-report methods in isolation is not recommended, especially for people with moderate-to-severe dementia.

Informant-ratings by informal caregivers show a discrepancy compared to the person with dementia’s self-report rating of pain, with caregivers reporting the person with dementia to be in pain more commonly than the person themselves. Interestingly in nursing home settings, similarities across informant-ratings are evident, however nurses and nursing assistants rate people with dementia to experience less pain than self-ratings. Such findings contradict findings from this review, indicating potential differences dependant on the environment of care. Certainly informant “over and under” estimations of pain are likely to have negative implications for treatment of pain for people with dementia. Studies investigating informant-ratings of pain included in this review used self-report instruments (such as the VDS and EQ5D) to compare informant and self-reports of pain. Tools created specifically for caregiver informant-use (e.g. Pain Assessment for the Dementing Elderly; PADE, Pain Assessment in Noncommunicative Elderly Persons; PAINE, Abbey Pain Scale) are yet to be tested, or validated within community-dwelling people with dementia.

This review identified only one, low quality study examining a behavioural observation pain assessment tool and the conclusions from this study suggest a poor correlation with self-report methods. Previous reviews have evaluated behavioural observation pain tools for people with dementia.
dementia residing in formal care settings. These reviews suggest that behavioural observation pain tools hold promise to identify pain for people with dementia (e.g. PAIN, PACSLAC, DOLLOPLUS2 and ECPA). However further psychometric development and testing is essential. Behavioural observation tools may be suitable for community-dwelling people with dementia however, the lack of testing and development in this setting, as illuminated by this review, hinders the ability to provide definitive conclusions.

**Treatment of pain**

In the second aim of this review, the synthesis of evidence on the use of pain treatments for community-dwelling people with dementia indicates that community-dwelling people with dementia had less or similar analgesic prescriptions than comparator groups. This mixed evidence may be explained by the varying healthcare organisation and funding models across each region (USA, Finland, and Sweden). In nursing home settings, the large majority of evidence to date has found people with dementia are prescribed less pain medication than their matched controls.

When analgesic medications were stratified into therapeutic classifications, community-dwelling people with dementia more commonly used paracetamol compared to community-dwelling older adults without dementia, with similar findings also evident in nursing home settings. The notable preference towards paracetamol is consistent with recommendations suggesting paracetamol as a first-line analgesic treatment. The recent focus of pain in people with dementia may have contributed to increased paracetamol use, as an attempt to provide adequate treatment for this vulnerable population.

This review found that NSAID prescribing is lower for people with dementia compared to those without a dementia diagnosis, and that NSAID use decreased over time for people with dementia. The findings from this review reflect National Institute for Health and Care Excellence (NICE) guidelines (2015) that advises that NSAIDs should be prescribed with caution for older adults due to the associated risks of gastrointestinal bleeding/perforation, renal dysfunction, and cardiovascular events, and only if alternative safer treatments have not provided sufficient pain relief. Similar trends in NSAID use are also evident for people with dementia living nursing home settings. Cognitive impairment and certain vascular-based types of dementia may be perceived as an additional risk factor for NSAID treatment and may contribute to caution in prescription. The reduction of NSAID prescriptions may have contributed to the increased use of paracetamol as a compensatory treatment.

This review identified three studies that found less community-dwelling people with dementia were prescribed opioids, however, two studies found that more community-dwelling people with dementia used opioid medication compared to comparator groups without dementia. Differences between the studies may contribute to the unclear findings; opioid prescriptions were identified at the time of the research interview, during a six-month period of dementia diagnosis, or a one-year period (during 2005). A much larger percentage of opioid prescriptions were evident when the length of investigation increased to a 5-year period potentially because of cohort effects. A recent systematic review investigating opioid use for people with dementia (irrespective of residential status) found that they used less opioids than people without cognitive impairment. High quality research to further explore opioid use for community-dwelling people with dementia is essential to determine if the findings align to those found in other residential settings, and to further understand the implications for effective management.

When opioid prescriptions were stratified into weak and strong opioids, this review found that fentanyl and buprenorphine were prescribed more commonly to people with dementia compared to matched controls. In nursing home settings, research suggests that older adults with cognitive impairment were more likely to receive fentanyl transdermal patch formulations as a first line treatment for pain. Fentanyl and buprenorphine may be favoured for people with dementia due to the benefits of...
transdermal patch formulations for those with swallowing difficulties, impaired gastrointestinal function, and/or a reduced analgesic compliance.\textsuperscript{85,88}

Finally, this review aimed to evaluate the effectiveness of pharmacological and non-pharmacological treatments; however, evidence was limited and low quality. Scheduled paracetamol treatment reduced pain scores for people with dementia. Such findings are comparable to larger trials conducting in nursing home settings.\textsuperscript{21,22} Additionally, experimental evidence suggests people with dementia may require more analgesia to reach the appropriate level of pain relief, questioning the current efficacy of analgesic treatment for people with dementia based on routine prescribing regimes.\textsuperscript{68} However more research is essential prior to confirm this finding. This review identified only poor quality papers investigated the efficacy of non-pharmacological treatments (including music, and psychosocial interventions) for pain in community-dwelling people with dementia. Other systematic reviews report that non-pharmacological treatments (e.g. music therapy, Reiki, reflexology, person-centred showering or bathing) can be effective in reducing pain for people with dementia living in formal care.\textsuperscript{89}

4.3 Strengths and limitations

This review has notable strengths. It is the first to provide a broad overview of the evidence on pain assessment and treatment for pain for community-dwelling people with dementia. The search strategy developed in collaboration with experienced information specialists is comprehensive with extensive supplementary searches. This review reports on the quality of evidence from the included studies, which has highlighted a low level of quality evidence on this topic within community-dwelling populations of those with dementia.

There are, however, limitations that are important to consider. Some studies\textsuperscript{90-96} provided information on pain assessment or pain treatment for people with cognitive impairment, using standardised instruments such as the MMSE, however these studies did not provide sufficient information to confirm that participants had a diagnosis of dementia and were therefore not included in the review. Finally, the conclusions of this review need to be contextualised within the limited research to date; 12 studies actively recruited participants with mild-to-moderate, or newly diagnosed dementias, with many more recruiting an insufficient number of participants with severe dementia. Therefore, the extent of evidence on more severely affected community-dwelling people with dementia is limited and more evidence is required in this sub-population.

4.4 Clinical implications

Due to the minimal high quality research to date, this review was unable to provide definitive conclusions regarding a pain assessment tool or method to recommend for use with community-dwelling people with dementia. Clinicians should therefore adopt a multidimensional approach using “a hierarchy of pain assessment techniques” including self-report assessments, pain history information, physical examinations, informant-based ratings, and observation of pain behaviours, in line with previous recommendations.\textsuperscript{96} Reliance on one method alone may lead to suboptimal assessment and treatment.

In terms of analgesic use, adverse effects, comorbidities, and polypharmacy are common in older adults, with the added complexity of cognitive impairments associated with dementia and the already outlined challenges in pain assessment. Due to these complexities, regular and structured medication reviews are needed to assess the use, efficacy, and side effects of analgesic prescriptions, especially so as changes to cognitive ability are evident over the course of the disease. Care is particularly needed when new medications, particularly transdermal analgesics that are initiated to manage pain,\textsuperscript{97} to balance the risk of adverse drug reactions against the ease of transdermal patch administration of opioids.\textsuperscript{56} In conjunction with pharmacological strategies, prescribing clinicians should consider the use of non-pharmacological strategies to minimise drug related adverse events.
4.5 Research Implications

In regard to pain assessment, research comparing multiple pain assessment instruments for a range of dementia severities using a clear, and pre-defined protocol within a community sample is required. High quality evidence is essential to assess the psychometric properties and clinical utility of pain assessment instruments (including self- and informant-based measures, and behavioural observation pain tools) for community-dwelling people with dementia.

Future research investigating treatments for pain should stratify analgesia by therapeutic classification, with a focus towards high quality longitudinal evidence to encompass the person with dementia’s progression. Such evidence is essential to provide a basis for future randomised control trials, alike to those conducted in nursing home settings.21,22,98

5 Conclusions

This review identifies a dearth of high quality studies exploring pain assessment and/or treatment for community-dwelling people with dementia, not least into non-pharmacological interventions. The consequences of this lack of evidence, given the current and projected prevalence of the disease, are very serious and require urgent redress. In the meantime, clinicians should adopt a patient and caregiver centred, multi-dimensional, longitudinal approach to pain assessment and treatment in this population.

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References


Table 1 Summary of pain assessment studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Sub-theme</th>
<th>Design</th>
<th>Origin</th>
<th>Diagnosis</th>
<th>n (reference/control)</th>
<th>Quality</th>
<th>Pain assessment tool</th>
<th>Completion rate %</th>
<th>PWD (caregivers) % [p]</th>
<th>Informant agreement</th>
<th>Convergence with alternative pain assessment</th>
<th>Predictive validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orgeta et al [42]</td>
<td>Informant rating</td>
<td>Cross-sectional</td>
<td>USA</td>
<td>Dementia</td>
<td>488</td>
<td>Fair</td>
<td>EQ5D</td>
<td>-</td>
<td>45 (59) [p&lt;.001]</td>
<td>58.2% (Kappa = 0.25)</td>
<td>-</td>
<td>Pain diagnosis in previous year (β=.20, t132=2.17, p&lt;.05)</td>
</tr>
<tr>
<td>Shega et al [43,100]</td>
<td>Informant rating</td>
<td>Cross-sectional</td>
<td>USA</td>
<td>Dementia</td>
<td>115</td>
<td>Fair</td>
<td>VDS</td>
<td>-</td>
<td>32 (53)</td>
<td>59% congruent (Kappa = 0.34) (X² = 71.7, df = 4; p&lt;.001)</td>
<td>-</td>
<td>Increased depression (z=2.70) agitation (z= 2.33) decreased pleasant events (z=2.38)</td>
</tr>
<tr>
<td>Jensen-Dahm et al [41]</td>
<td>Informant rating</td>
<td>Cross-sectional</td>
<td>Denmark</td>
<td>AD or DLB</td>
<td>321</td>
<td>Fair</td>
<td>EQ5D</td>
<td>-</td>
<td>32.9 (52)</td>
<td>40% over report</td>
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<tr>
<td>Breland et al [38]</td>
<td>Self-report</td>
<td>Cross-sectional</td>
<td>USA</td>
<td>Dementia</td>
<td>136</td>
<td>Fair</td>
<td>PGC PIS</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Snow et al [36]</td>
<td>Self-report</td>
<td>Cohort</td>
<td>USA</td>
<td>Dementia</td>
<td>171</td>
<td>Good</td>
<td>PGC PIS</td>
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Table 1 cont. Summary of pain assessment studies

<table>
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<tr>
<th>Author</th>
<th>Barry et al&lt;sup&gt;40&lt;/sup&gt;</th>
<th>Li et al&lt;sup&gt;37&lt;/sup&gt;</th>
<th>Brummel-Smith et al&lt;sup&gt;48&lt;/sup&gt;</th>
<th>Krulewitch et al&lt;sup&gt;39&lt;/sup&gt;</th>
<th>Hunt et al&lt;sup&gt;44&lt;/sup&gt;</th>
<th>Kunik et al&lt;sup&gt;45&lt;/sup&gt;</th>
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<tr>
<td>n (reference/control)</td>
<td>75†</td>
<td>203</td>
<td>154 (255)</td>
<td>156‡</td>
<td>802 (802)</td>
<td>203</td>
</tr>
<tr>
<td><strong>Quality</strong></td>
<td>Fair</td>
<td>Fair</td>
<td>Poor</td>
<td>Poor</td>
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<tr>
<td><strong>Pain assessment tool</strong></td>
<td>VDS</td>
<td>PGC PIS</td>
<td>FPS, VAS, PIS</td>
<td>FPS, VAS, PIS, HADS</td>
<td>VDS</td>
<td>PGC PIS</td>
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<tr>
<td><strong>Completion rate %</strong></td>
<td>-</td>
<td>-</td>
<td>32.5</td>
<td>PIS, 62; FPS, 53; VAS, 53</td>
<td>-</td>
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<tr>
<td><strong>PWD (caregivers) prevalence % [p]</strong></td>
<td>Pain now - 36 (53.3) [p=.033]</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Activity limit 40.1 (46.6) [p=.03]</td>
<td>-</td>
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<tr>
<td></td>
<td>Average day – 57.3 (70.7) [p=.089]</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Bothersome 62.7 (64.4) [p=.59]</td>
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<tr>
<td><strong>PWD (caregiver) mean pain score</strong></td>
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<td><strong>Informant agreement</strong></td>
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<td>kappa = .32</td>
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<tr>
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<td>PIS (rho=.452; p&lt;.001)</td>
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<td>VAS (rho=.420; p&lt;.001)</td>
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<td>FPS (rho=.417; p&lt;.001)</td>
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<td>HADS: NR</td>
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<tr>
<td><strong>Convergence with alternative pain assessment</strong></td>
<td>-</td>
<td>94% PGC PIS</td>
<td>-</td>
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<td></td>
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<td>36.4% medical record</td>
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<tr>
<td><strong>Predictive validity</strong></td>
<td>-</td>
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* dyadic paired participants (e.g. person with dementia and their caregiver).
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<td>Cross-sectional</td>
<td>Cross-sectional</td>
<td>Cross-sectional</td>
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<td><strong>Origin</strong></td>
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<td>Finland</td>
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<td>Denmark</td>
<td>Denmark</td>
<td>Sweden</td>
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<td>Dementia</td>
<td>Dementia</td>
</tr>
<tr>
<td><strong>n (reference)</strong></td>
<td>75 (446)</td>
<td>75 (446)</td>
<td>100 (420)</td>
<td>321‡</td>
<td>35,455 (870,645)</td>
<td>119 (2199†, 186‡)</td>
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<tr>
<td><strong>Quality</strong></td>
<td>Fair</td>
<td>Fair</td>
<td>Fair</td>
<td>Fair</td>
<td>Fair</td>
<td>Fair</td>
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<td><strong>Analgesic use %</strong></td>
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<td>33.3 (47.3)</td>
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<tr>
<td><strong>Analgesic use, PWD vs control [OR (95% CI)]</strong></td>
<td>-</td>
<td>-</td>
<td>0.54 (0.39 to 0.75)</td>
<td>-</td>
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<tr>
<td><strong>Paracetamol use %</strong></td>
<td>58 (paracetamol and NSAID)</td>
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</tr>
<tr>
<td><strong>Paracetamol use vs control [OR (95% CI)]</strong></td>
<td>58 (paracetamol and NSAID)</td>
<td>-</td>
<td>-</td>
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</tr>
<tr>
<td><strong>NSAID use %</strong></td>
<td>58 (paracetamol and NSAID)</td>
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<td>-</td>
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</tr>
<tr>
<td><strong>NSAID use vs control [OR (95% CI)]</strong></td>
<td>13</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td><strong>Opioid use %</strong></td>
<td>13</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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</tr>
<tr>
<td><strong>Opioid use vs control [OR (95% CI)]</strong></td>
<td>27.5 (16.9)</td>
<td>-</td>
<td>-</td>
<td>-</td>
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</tr>
<tr>
<td><strong>Non-pharm (%)</strong></td>
<td>-</td>
<td>-</td>
<td>-</td>
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<td>-</td>
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<tr>
<td>Author</td>
<td>Design</td>
<td>Origin</td>
<td>Diagnosis</td>
<td>n (reference)†</td>
<td>Quality</td>
<td>Analgesic use % (control %)</td>
</tr>
<tr>
<td>-----------------</td>
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<td>------------</td>
<td>-----------</td>
<td>----------------</td>
<td>---------</td>
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</tr>
<tr>
<td>Brummel-Smith et al 38</td>
<td>Cross-sectional</td>
<td>USA</td>
<td>Dementia</td>
<td>154 (255)</td>
<td>Poor</td>
<td>49 received &gt;1</td>
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<tr>
<td>Gallini et al 54</td>
<td>Cohort, nested case control</td>
<td>France</td>
<td>AD</td>
<td>595</td>
<td>Fair</td>
<td>26</td>
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<tr>
<td>Gilmartin et al 47</td>
<td>Cohort</td>
<td>Finland</td>
<td>AD</td>
<td>236¶</td>
<td>Good</td>
<td>13 persistent</td>
</tr>
<tr>
<td>Hamina et al 48</td>
<td>Cohort</td>
<td>Finland</td>
<td>AD</td>
<td>62,074 (62,074)</td>
<td>Good</td>
<td>-</td>
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<tr>
<td>Hamina et al 55</td>
<td>Cohort</td>
<td>Finland</td>
<td>AD</td>
<td>67,215 (67,215)</td>
<td>Fair</td>
<td>-</td>
</tr>
<tr>
<td>Barry et al 40</td>
<td>Cross-sectional</td>
<td>Northern Ireland</td>
<td>Dementia</td>
<td>75¶</td>
<td>Fair</td>
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### Table 2 cont. Summary of pharmacological pain treatment studies

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<tr>
<th>Author</th>
<th>Bell et al&lt;sup&gt;46&lt;/sup&gt;</th>
<th>Hunt et al&lt;sup&gt;44&lt;/sup&gt;</th>
<th>Thakur et al&lt;sup&gt;47&lt;/sup&gt;</th>
<th>Breland et al&lt;sup&gt;55&lt;/sup&gt;</th>
<th>Li et al&lt;sup&gt;47&lt;/sup&gt;</th>
<th>Shega et al&lt;sup&gt;59&lt;/sup&gt;</th>
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<td>Cross-sectional</td>
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<td>Dementia</td>
<td>Dementia</td>
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<td>Dementia</td>
<td>Dementia</td>
</tr>
<tr>
<td>n (Reference)†</td>
<td>28,089 (28,089)</td>
<td>802 (802)</td>
<td>202</td>
<td>136</td>
<td>203</td>
<td>115†</td>
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<tr>
<td><strong>Quality</strong></td>
<td>Fair</td>
<td>Poor</td>
<td>Fair</td>
<td>Fair</td>
<td>Fair</td>
<td>Fair</td>
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<tr>
<td><strong>Proportion taking analgesic % (control %)</strong></td>
<td>-</td>
<td>69.7††</td>
<td>56††</td>
<td>49</td>
<td>59.7</td>
<td>32††</td>
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<td>Analgesic - pwd vs control [OR (95% CI)]</td>
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<td>-</td>
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<tr>
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<td>-</td>
<td>40 (non-narcotics)</td>
<td>32.5 (paracetamol/NSAID)</td>
<td>19††</td>
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<td>Paracetamol use vs control [OR (95% CI)]</td>
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<td>-</td>
<td>-</td>
<td>40 (non-narcotics)</td>
<td>32.5 (paracetamol/NSAID)</td>
<td>8††</td>
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<tr>
<td>Opioid % (control %)</td>
<td>All 3.56 (4.62); Weak 2.68 (3.83); Strong 0.95 (0.76)</td>
<td>-</td>
<td>-</td>
<td>9</td>
<td>Weak 16.8</td>
<td>4††</td>
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<tr>
<td>Opioid vs control [OR (95% CI)]</td>
<td>All 0.77 (0.71 to 0.84); Weak 0.70 (0.64 to 0.77); Strong 1.26 (1.05 to 1.51); Fentanyl 1.44 (1.13 to 1.83).</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Strong 1.5</td>
<td>0‡‡</td>
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<td>Non-pharm (%)</td>
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<td>Exercise 45.8</td>
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<th>Proportion taking analgesic % (control %)</th>
<th>Analgesic - pwd vs control [OR (95% CI)]</th>
<th>Paracetamol % (control %)</th>
<th>Paracetamol use vs control [OR (95% CI)]</th>
<th>NSAID % (control %)</th>
<th>NSAID use vs control [OR (95% CI)]</th>
<th>Opioid % (control %)</th>
<th>Opioid vs control [OR (95% CI)]</th>
<th>Non-pharm (%)</th>
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<td>596†</td>
<td>Fair</td>
<td>40.1</td>
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<tr>
<td>Nakanishi et al</td>
<td>Before-after (baseline data)</td>
<td>Japan</td>
<td>Dementia</td>
<td>219</td>
<td>Poor</td>
<td>24.7</td>
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<td>Hamina et al</td>
<td>Cohort</td>
<td>Finland</td>
<td>AD</td>
<td>3327 opioid initiators (3325 non-opioid initiators)</td>
<td>Good</td>
<td>-</td>
<td>-</td>
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<td>-</td>
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<tr>
<td>Grace et al</td>
<td>Cross-sectional</td>
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<td>Dementia</td>
<td>543</td>
<td>Fair</td>
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<td>-</td>
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Abbreviations: AD, Alzheimer’s disease; CI, confidence interval; NSAID, Non-Steroid Inflammatory Inhibitors; OR, Odds Ratio; PWD, people with dementia, USA, United States of America

The control/reference group is community-dwelling people without dementia unless noted otherwise. However, for Haasum (2011) community-dwelling people without dementia (†) is labelled regardless for clarification between the multiple reference groups.
† people without dementia living in the community
‡ people with dementia living in a nursing home
§ comparison of nursing home dwelling people with dementia to community-dwelling people with dementia as the reference population.
¶ dyadic paired participants (e.g. person with dementia and their caregiver).
†† analgesic medication in a sample of people with dementia reporting pain
‡‡ analgesic medication in a sample of people with dementia reporting no pain
§§ baseline, year 1, year 2, year 3, year 4, and year 5.
††† percentage of each analgesic in a sample of people with dementia prescribed analgesic medication

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<table>
<thead>
<tr>
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<th>Intervention</th>
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<th>Results</th>
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<td>Before-after ABAB within subjects</td>
<td>Pharmacological</td>
<td>USA</td>
<td>Poor</td>
<td>Dementia</td>
<td>3</td>
<td>Coded pain behaviours</td>
<td>Paracetamol 1.3g every 8hrs during treatment phases</td>
<td>24 day</td>
<td>Ppt 1: 32.1 (A1), 18.6 (B1), 27.5 (A2), 17.5 (B2) Ppt 2: 33 (A1), 22.5 (B2), 31.1 (A2), 20.1 (B2) Ppt 3: 57.8 (A1), 30 (B1), 53.3 (A2), 29.8 (B2). The effects of the open treatment lowered in AD after 1 year (t(27) = -5.151, p&lt;.001).</td>
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<tr>
<td>Benedetti et al</td>
<td>Non-RCT</td>
<td>Pharmacological</td>
<td>Italy</td>
<td>Fair</td>
<td>AD</td>
<td>38 (16)</td>
<td>NRS</td>
<td>Open-hidden application of 1% lidocaine during insertion of needle</td>
<td>1 year</td>
<td>8 week A = Baseline = 3, 4, 7, 8. B = Week 1, 2, 5, 6. Pain during vs before (p=.06). Pain during vs after (p=.86). Intervention weeks vs baseline (p=.22). Pain after vs before (t=2.21; df=28; p&lt;.05)</td>
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<tr>
<td>Park</td>
<td>Before-after ABAB within subjects</td>
<td>Non-pharmacological</td>
<td>USA</td>
<td>Poor</td>
<td>Dementia</td>
<td>15</td>
<td>M-PADE</td>
<td>Preferred music initiated 30 minutes prior to peak agitation time.</td>
<td></td>
<td>Decreased pain after the intervention compared to before (t(218)=2.63, p=.009). No difference in analgesics after the intervention compared to before (X²(1)=2.00, p=0.5).</td>
</tr>
<tr>
<td>Nakanishi et al</td>
<td>Non-pharmacological</td>
<td>Japan</td>
<td></td>
<td>Poor</td>
<td>Dementia</td>
<td>219</td>
<td>Abbey Pain Scale</td>
<td>2-day training course, a web-based tool for ongoing monitoring and assessment for challenging behaviour, and multi-agency discussion meetings for formal caregivers. Improving: caregivers pain recognition, communication, making daily activities pleasant</td>
<td></td>
<td>Decreased pain over time for treatment group (PWD overall pain: F(3, 412) = 4.59, p=.004. No difference between groups. 64% of caregivers highlighted skills: recognising signs of pain, pain treatment with analgesic or other strategies.</td>
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<tr>
<td>Kunik et al</td>
<td>RCT</td>
<td>USA</td>
<td>Poor</td>
<td>Dementia</td>
<td>101¶ (102¶)</td>
<td>PGC PIS</td>
<td>6 to 8 weekly sessions of 45-minute home visits targeted to informal caregivers. Improving: caregivers pain recognition, communication, making daily activities pleasant</td>
<td></td>
<td>3, 6, 12 months</td>
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† dyadic paired participants (e.g. person with dementia and their caregiver).
United States of America, NRS numerical rating scale, AD Alzheimer’s Disease, PGC Philadelphia Geriatric Centre, PIS Pain Intensity Scale, PWD person with dementia, M-PADE Pain Assessment in Dementing Elderly, RCT randomised control trial
**Figure 1** PRISMA flow chart
Figure 2 Percentage of pain self-reported by people with dementia compared to informant-reported pain by an informal caregiver
Figure 3 Percentage of opioid analgesics for people with dementia and comparator groups without dementia.