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# Process of pain assessment in people with dementia living in nursing homes: a scoping review protocol

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## ABSTRACT

**Introduction** Pain is a common symptom in people with dementia; untreated, it reduces quality of life and causes suffering. People with dementia living in nursing homes most often have dementia in moderate to severe stages. The cognitive impairment, including language and communication difficulties, challenges pain assessment. Since pain is a subjective experience, self-reporting is the gold standard of assessment methods. Healthcare professionals are advised to help people with dementia communicate about their pain. The proposed scoping review is the first step in the development of a systematic pain assessment model for people with dementia living in nursing homes. The scoping review aims to identify, categorise and summarise knowledge on how pain assessment processes in this population are described in the literature, with a special focus on self-reporting.

**Methods and analysis** The scoping review will be conducted following the six-stage framework developed by Arksey and O'Malley, in addition to recent methodological developments. Systematic searches in CINAHL, Embase, Medline and PsycInfo will be conducted. The protocol follows the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklists, and the scoping review will adhere to the PRISMA-ScR checklist. The review will include research that concerns assessment of pain in people with dementia living in nursing homes. Studies will be evaluated for quality and ethical standards. The analysis process will follow Bradbury-Jones *et al*'s PAGER framework. Patterns will be formed using thematic analysis. An overview of advances, gaps, evidence for practice and research recommendations associated with each pattern will be prepared. The research questions and results will be presented to and discussed in a reference group comprising nursing home residents, relatives, healthcare professionals and nursing home managers.

**Ethics and dissemination** The scoping review aims to collect and summarise data from available publications and does not require ethical approval. The final manuscript will be submitted to a peer-reviewed, open-access journal.

**Registration in open science framework** https://osf.io/8kaf5/

## STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This review will use an established scoping review methodology and standardised reporting guidelines.
⇒ To minimise the risk of personal biases, two reviewers will independently assess the studies for inclusion or exclusion; if disagreement arises, an additional reviewer will be consulted.
⇒ The included studies will be assessed for quality and ethical standards.
⇒ The review may miss relevant literature, as it will not include grey literature nor studies not published in English/non-Nordic languages.

## INTRODUCTION

In 2016, dementia was the fifth leading cause of death worldwide,[1] and the palliative perspective is important throughout the whole dementia trajectory.[2] As most people with dementia live their final days in a nursing home or similar,[3 4] healthcare professionals play an essential role in offering quality palliative care in this context. The prevalence of dementia in nursing home residents worldwide differs by location, nation and region.[5] In Norway as many as 80% of nursing home residents have dementia, and the majority has dementia in moderate to severe stages.[6] Moderate to severe stages of dementia have been described as an extended and intensive palliative care phase, often characterised by a loss of independence and autonomy, and reduction in physical and cognitive functions.[7] The trajectory is often unpredictable and palliative care initiation should therefore reflect need, not prognosis.[8] A five-round Delphi study resulted in 57 consensus-based recommendations for optimal palliative care in dementia, of which eight are clinical.[2] One of these clinical domains is symptom relief, considered one of the main aspects of palliative care.[9]

Pain is a common symptom among people with dementia living in nursing homes.[10–13] In a recent study, van Dam *et al* found that

43.3% of participants with dementia had clinically relevant pain scores.[10] Helvik *et al* state that 35.5% of their participants had clinically relevant pain on admittance to a nursing home.[11] A review conducted by Corbett *et al* indicates that 50% of people with dementia regularly experience pain and that the prevalence of pain in nursing home patients might be higher.[12] Pain in this patient group is often related to musculoskeletal, gastrointestinal and cardiac conditions, genitourinary infections, and wounds.[12] Discomfort caused by pain in people with dementia can be expressed as behavioural and psychological symptoms (BPSD), such as agitation, apathy, restlessness or wandering.[2 14] In Norway, the national clinical guidelines for dementia recommend that people with BPSD or other signs of discomfort should be assessed for pain as part of palliative care.[15] Pain assessment is frequently compromised by cognitive impairment,[16] including aspects of language and communication difficulties[17] in nursing home population.

Pain can be defined as *an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.*[18] Pain is a symptom, which is a subjective experience, as opposed to signs, which can be observed.[19 20] These definitions imply that self-reported information is the most appropriate for assessing pain. This represents a challenge in the target population, who may have difficulty communicating their symptoms because of reduced cognitive function[7 21]—their pain may therefore go unrecognised and unmanaged.[13] One recommendation is the systematic use of standardised observational tools and skills to chart pain, which can compensate for patients' lack of verbal communication.[2 15 22 23] However, nurses often rely on experience-based knowledge when interpreting signs of pain, and less-experienced nurses may fail to recognise pain in people with dementia.[24] Moreover, Pautex *et al* argue that the routine use of observational scales in severe dementia may not be justified and that self-assessment can be reliably performed among this population.[25] Achterberg *et al* highlight how self-reporting can also be adapted to individual capabilities during the course of dementia.[13] They recommend an initial use of simple numerical or verbal scales and the later use of 'yes' or 'no' questions; when cognitive and linguistic impairments reach a certain level, an observational tool can be added to the self-report to strengthen the validity of the pain assessment.

Pain management requires continuous mapping, assessment and treatment evaluation.[19] When caring for people with dementia this is complex and challenging.[26–28] It relies on healthcare professionals' knowledge of individuals' normal level of functioning and communication methods.[26 29] Healthcare professionals providing individualised care in nursing homes may be in a unique position to support and help people with dementia communicate their subjective experience of pain, if they have knowledge of and frequent contact with the residents.[26 29]

Healthcare professionals in nursing homes need tools to systematically manage pain in people with dementia, which consider individual variation in pain expressions and ability to self-report. The proposed scoping review is the first step in developing a care model for systematic pain assessment in people with dementia living in nursing homes, which also includes how healthcare professionals recognise pain and evaluate initiated measures. The development of this model is rooted in the initial steps of The UK Medical Research Council (MRC) framework for developing and evaluating complex interventions.[30] To promote sustainable research and reduce research waste, it is important to obtain a preliminary overview of the field of research.[31] To the best of our knowledge, no study has reviewed the literature on self-reporting in pain assessment processes in people with dementia living in nursing homes, and how healthcare professionals can integrate self-reporting in recognising, assessing and evaluating pain in this group and context. The aim of this scoping review is therefore to identify, categorise and summarise knowledge about these processes from the literature.

## METHODS AND ANALYSIS

The proposed scoping review will follow Arksey and O'Malley's six-stage methodological framework[32] and Levac *et al*'s recommendations for each stage.[33] This will facilitate examination of the research concerning pain assessment in the target population and the identification of knowledge gaps. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P)[34] and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklists[35] were used to prepare this protocol (online supplemental files 1; 2). PRISMA-ScR[35] will be used in the review. The scoping review will be carried out in the period March 2022–September 2023.

### Stage 1: identify the research question(s)

Levac *et al*[33] highlight that research questions as comprehensive and broad as those recommended by Arksey and O'Malley[32] may lack the direction, clarity and focus needed to inform later steps in the research process. The concept and target population have therefore been defined to clarify the scoping review's focus and establish an effective search strategy, combined with a clear objective.[33] A population, concept, context (PCC) framework has informed the research questions (table 1) and will guide the database searches and eligibility criteria.

The following preliminary research questions were developed:

Table 1 Population, concept, context framework informing research questions and search strategy

| Criteria | Determinants |
|---|---|
| Population | People with dementia |
| Concept | Pain assessment processes |
| Context | Nursing home |

- How do healthcare professionals recognise and assess pain in people with dementia living in nursing homes?
- How are the assessment processes of self-reported pain in the target group described?

In accordance with Arksey and O'Malley, these may be adjusted as the review progresses.

### Stage 2: identify relevant studies

The research questions and key concepts will inform the search strategy. The CINAHL, Embase, Medline and PsycInfo databases will be searched to identify relevant studies. The databases have been selected to cover a comprehensive range of healthcare research. A search strategy will be developed for each database with the assistance of an experienced librarian; these strategies will include medical subject headings (MESH), and search terms and synonyms combined using Boolean operators. The search strategy will consist of three main blocks informed by the PCC framework (table 1): people with dementia (population), pain assessment processes (concept of interest) and nursing home (context). The different search terms in each block will be combined with OR, and the blocks will be combined with AND. The reference lists of included studies will be manually searched. In line with Arksey and O'Malley, the search process will be iterative, and search terms may be adapted as the research team gains familiarity with the literature.[32] A pilot search will be conducted, where the first ~80 references will be reviewed; the search strategy will be adjusted if needed. A preliminary search was conducted on 11/2/22 (online supplemental file 3).

### Stage 3: select studies

Following Arksey and O'Malley, the scoping review will identify all relevant literature regardless of study design, to obtain a broad picture of the existing research on the chosen topic.[32] Similarly, no time limit for publication will be specified. The inclusion and exclusion criteria are presented below (table 2)—these may be revised as the study progresses,[32] and any revised criteria will be applied to all citations. The selection process will be documented in a PRISMA-flowchart[36] (figure 1), including reasons for exclusion.[34] Duplicates will be removed using endnote and the duplicates not detected by endnote will be removed manually as the abstracts are reviewed. If the relevance of a study is unclear from the title and abstract, the full article will be reviewed. Traditionally, scoping reviews do not include secondary research, such as literature reviews. However, literature reviews will be included; as interventions targeting pain management in people with dementia may have been developed based on literature reviews, it would be inappropriate to exclude articles that could help answer the research questions.

Study selection will begin with a review of the title and abstract. If these correspond to the research questions and aim, a full-text review will be conducted. The studies will be reviewed by at least two researchers; in line with Levac *et al*, the research team will meet to discuss study inclusion and exclusion decisions in the beginning, middle and final stages of the abstract review process, and refine the search strategy as needed.[33] At least two reviewers will independently review full-text articles for inclusion; if disagreement arises, an additional reviewer will be consulted to determine final inclusion.

Levac *et al* argue that identifying gaps in the existing literature without assessing the quality of the included studies may lead to false conclusions about the nature

Table 2 Preliminary eligibility criteria guiding study selection

| | Eligibility criteria | |
|---|---|---|
| | **Inclusion criteria** | **Exclusion criteria** |
| Source | Peer-reviewed journals<br>Published in English, Norwegian, Swedish or Danish | Grey literature |
| Population | People with dementia (eg, patients, service users or residents) | Mixed samples (eg, mild cognitive impairment/cognitive impairment + dementia)<br>Dementia in people with Downs syndrome<br>Cognitive impairment not caused by dementia |
| Context | Nursing home | |
| Concept | Literature that describes:<br>How healthcare professionals (including nurses, nurse assistants and doctors) recognise, assess and evaluate pain in the population<br>Whether and/or how self-reporting of pain is integrated in pain assessment processes in the population<br>How healthcare professionals can support people with dementia in self-reporting of pain | |
| Study design | All study designs | Editorials, commentaries or letters, discussion papers, opinion papers and non-empirical studies |

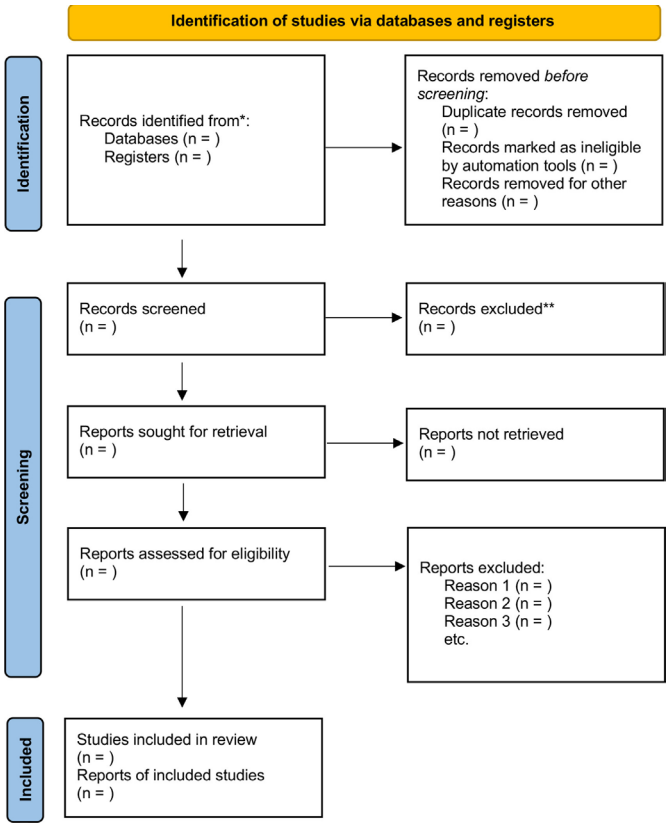


**Figure 1** Overview of study selection process using PRISMA flow diagram.[36] *Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers). **If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

and extent of those gaps; they also assert that quality assessment of the included studies will increase the likelihood that findings will be useful for practice.[33] Study quality will therefore be assessed using appropriate appraisal tools, for example, the Critical Appraisal Skills Programme (CASP)[37] and Mixed Methods Appraisal Tool (MMAT).[38] An additional researcher will be included in the decision making if disagreement or uncertainty arises around the quality assessment.

### Stage 4: charting data

This stage involves 'charting' key items of information obtained from the included studies by sorting material according to relevant issues and themes. In the proposed scoping review, this will be a mixture of general and specific information relating to study design and relevant findings. The charting process is also considered an iterative process, which means that the researchers may continuously update the data-charting form. In line with Levac *et al*, two researchers will independently extract data from the first five studies using the data-charting form and determine together whether the approach is consistent with the research questions and aim.[33] A preliminary data-charting form has been developed based on Arksey and O'Malley's template (Box 1).[32] Ethical mapping is included in the data-charting form, in response to Weingarten *et al*'s emphasis on increasing ethical awareness in reviews.[39] Articles that do not adhere to ethical standards will be excluded.

**Box 1 Data-charting form**

- ⇒ Author, date and country
- ⇒ Study title
- ⇒ Aim, objective and/or research questions
- ⇒ Ethical assessment (financial support, conflicts of interest, informed consent, research committee approval, data protection)
- ⇒ Study context
- ⇒ Participant characteristics
- ⇒ Sampling method
- ⇒ Design and methods
- ⇒ Relevant findings

### Stage 5: collate, summarise and report results

As Arksey and O'Malley point out, unlike systematic reviews, scoping reviews do not synthesise evidence but instead provide an overview of the reviewed material.[32] In this stage, an overview and summary of the extracted information will therefore be prepared and presented, following the PAGER framework,[40] which consists of five categories: patterns, advances, gaps, evidence for practice and research recommendations. Patterns, or key themes, will be formed by using thematic analysis[41] of key findings from each study included in the review. We will then create an overview of advances, gaps, evidence for practice and research recommendations associated with each pattern.[40] The advances, gaps and research recommendations will guide further research needed to develop the pain assessment model, and the evidence for practice will guide the content of the model. Throughout the process, there will be regular meetings of the research group to discuss and agree on aspects of the analytical process and how the findings should best be presented.

### Stage 6: consult with reference group

This scoping review is the first step in developing a care model for systematic pain assessment in people with dementia living in nursing homes. Correspondingly, a reference group will be formed, consisting of nursing home residents, relatives, healthcare professionals and nursing home managers. Arksey and O'Malley recommend consulting with practitioners and consumers to validate findings and make the research more useful for practice.[32] The findings will therefore be presented to and discussed with the reference group. In addition, the research team is part of a larger group of researchers, with whom the findings will also be discussed.

### Patient and public involvement

The proposed scoping review's research questions and aim will be presented to and discussed with the reference group, as will the findings. These latter will support the

development of an intervention promoting systematic pain management for people with dementia living in nursing homes.

## Ethics and dissemination

As the scoping review will not involve the collection of primary empirical data, ethical approval is unnecessary.[42] However, following Weingarten *et al*,[39] who state that ethical assessments of included studies should be conducted, ethical considerations are included in the data-charting process. Studies that do not adhere to ethical standards will be excluded. Findings from the scoping review will be published in an open-access, peer-reviewed journal. The scoping review is an important step in developing a pain assessment model for people with dementia living in nursing homes. Findings will enable the identification of existing models or interventions that may be further developed and tailored to the nursing home context, preventing research waste.[31]

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**Contributors** CKO was responsible for the preliminary study design, conceptualised the review approach, and led the writing of this protocol. ML, AHH and SE contributed to the protocol's development and approved the final version. SE led the supervision of the protocol's preparation.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.



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**SUPPLEMENTARY FILE 1**

# PRISMA-P 2015 Checklist

This checklist has been adapted for use with protocol submissions to *Systematic Reviews* from Table 3 in Moher D et al: Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* **2015** 4:1

| Section/topic | # | Checklist item | Information reported | | Line number(s) |
|---|---|---|---|---|---|
| | | | Yes | No | |
| **ADMINISTRATIVE INFORMATION** | | | | | |
| **Title** | | | | | |
| Identification | 1a | Identify the report as a protocol of a systematic review | ☒ | ☐ | 5-6 |
| Update | 1b | If the protocol is for an update of a previous systematic review, identify as such | ☐ | ☒ | |
| **Registration** | 2 | If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract | ☒ | ☐ | 67 |
| **Authors** | | | | | |
| Contact | 3a | Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author | ☒ | ☐ | 12-25 |
| Contributions | 3b | Describe contributions of protocol authors and identify the guarantor of the review | ☒ | ☐ | 357-361 |
| **Amendments** | 4 | If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments | ☐ | ☒ | |
| **Support** | | | | | |
| Sources | 5a | Indicate sources of financial or other support for the review | ☒ | ☐ | 362-364 |
| Sponsor | 5b | Provide name for the review funder and/or sponsor | ☐ | ☒ | |
| Role of sponsor/funder | 5c | Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol | ☐ | ☒ | |
| **INTRODUCTION** | | | | | |
| **Rationale** | 6 | Describe the rationale for the review in the context of what is already known | ☒ | ☐ | 130-197 |
| **Objectives** | 7 | Provide an explicit statement of the question(s) the review will address with | ☒ | ☐ | 222-229 |

| Section/topic | # | Checklist item | Information reported | | Line number(s) |
|---|---|---|---|---|---|
| | | | Yes | No | |
| | | reference to participants, interventions, comparators, and outcomes (PICO) | | | |
| **METHODS** | | | | | |
| **Eligibility criteria** | 8 | Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review | ☒ | ☐ | 272-273 |
| **Information sources** | 9 | Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage | ☒ | ☐ | 239-240 |
| **Search strategy** | 10 | Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated | ☒ | ☐ | 244-247 Supplementary file 3 |
| ***STUDY RECORDS*** | | | | | |
| Data management | 11a | Describe the mechanism(s) that will be used to manage records and data throughout the review | ☒ | ☐ | 259-262 |
| Selection process | 11b | State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis) | ☒ | ☐ | 254-290 |
| Data collection process | 11c | Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators | ☒ | ☐ | 292-303 |
| **Data items** | 12 | List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications | ☒ | ☐ | 305-306 |
| **Outcomes and prioritization** | 13 | List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale | ☐ | ☒ | |
| **Risk of bias in individual studies** | 14 | Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis | ☐ | ☒ | |
| ***DATA*** | | | | | |

| Section/topic | # | Checklist item | Information reported | | Line number(s) |
|---|---|---|---|---|---|
| | | | Yes | No | |
| **Synthesis** | 15a | Describe criteria under which study data will be quantitatively synthesized | ☐ | ☒ | |
| | 15b | If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., $I^2$, Kendall's tau) | ☐ | ☒ | |
| | 15c | Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression) | ☐ | ☒ | |
| | 15d | If quantitative synthesis is not appropriate, describe the type of summary planned | ☒ | ☐ | 308-320 |
| **Meta-bias(es)** | 16 | Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies) | ☐ | ☒ | |
| **Confidence in cumulative evidence** | 17 | Describe how the strength of the body of evidence will be assessed (e.g., GRADE) | ☐ | ☒ | |

**SUPPLEMENTARY FILE 2**

## Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a scoping review. | 1 |
| **ABSTRACT** | | | |
| Structured summary | 2 | Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives. | 2 |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach. | 4-5 |
| Objectives | 4 | Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives. | 6 |
| **METHODS** | | | |
| Protocol and registration | 5 | Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number. | 1 |
| Eligibility criteria | 6 | Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale. | 7-8 |
| Information sources* | 7 | Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed. | 6-7 |
| Search | 8 | Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated. | Supplementary file 3 |
| Selection of sources of evidence† | 9 | State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review. | 7-8 |
| Data charting process‡ | 10 | Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators. | 9 |
| Data items | 11 | List and define all variables for which data were sought and any assumptions and simplifications made. | 9 |
| Critical appraisal of individual | 12 | If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this | 9 |

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---|---|---|---|
| sources of evidence§ | | information was used in any data synthesis (if appropriate). | |
| Synthesis of results | 13 | Describe the methods of handling and summarizing the data that were charted. | 9 |
| **RESULTS** | | | |
| Selection of sources of evidence | 14 | Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram. | Click here to enter text. |
| Characteristics of sources of evidence | 15 | For each source of evidence, present characteristics for which data were charted and provide the citations. | Click here to enter text. |
| Critical appraisal within sources of evidence | 16 | If done, present data on critical appraisal of included sources of evidence (see item 12). | Click here to enter text. |
| Results of individual sources of evidence | 17 | For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives. | Click here to enter text. |
| Synthesis of results | 18 | Summarize and/or present the charting results as they relate to the review questions and objectives. | Click here to enter text. |
| **DISCUSSION** | | | |
| Summary of evidence | 19 | Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups. | Click here to enter text. |
| Limitations | 20 | Discuss the limitations of the scoping review process. | Click here to enter text. |
| Conclusions | 21 | Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps. | Click here to enter text. |
| **FUNDING** | | | |
| Funding | 22 | Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review. | 11 |

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

*From:* Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

**SUPPLEMENTARY FILE 3**

**MEDLINE, Search conducted 11.02.22**

**Database:**
Ovid MEDLINE(R) ALL <1946 to February 10, 2022>

| # | Query | Results from 11 Feb 2022 |
|---|---|---|
| 1 | dementia/ or alzheimer disease/ or dementia, vascular/ or frontotemporal lobar degeneration/ or lewy body disease/ | 160,450 |
| 2 | Frontotemporal Dementia/ or Dementia, Multi-Infarct/ | 4,719 |
| 3 | Korsakoff Syndrome/ | 530 |
| 4 | Dementia.ab,ti. | 121,195 |
| 5 | "Alzheimer*".ab,ti. | 163,697 |
| 6 | Lewy body.ab,ti. | 4,218 |
| 7 | korsakoff.ab,ti. | 985 |
| 8 | 1 or 2 or 3 or 4 or 5 or 6 or 7 | 265,108 |
| 9 | exp Pain/ or exp Pain Measurement/ or exp Pain Management/ | 471,353 |
| 10 | Pain.ab,ti. | 694,136 |
| 11 | 9 or 10 | 872,991 |
| 12 | "Care home*".af. | 5,045 |
| 13 | Long term care.af. | 46,819 |
| 14 | Residential care.af. | 4,053 |
| 15 | "nurs* home*".af. | 52,581 |
| 16 | exp Residential Facilities/ or exp Nursing Homes/ or exp Homes for the Aged/ or exp Long-Term Care/ | 77,440 |
| 17 | "Home* for the aged".af. | 15,709 |
| 18 | 12 or 13 or 14 or 15 or 16 or 17 | 107,035 |
| 19 | 8 and 11 and 18 | 750 |