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The process of pain management in people with dementia living in nursing homes: a scoping review protocol

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Title page:

Title: The process of pain management in people with dementia living in nursing homes: a scoping review protocol

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ABSTRACT

Introduction: The prevalence of dementia is dramatically increasing. Pain is a common symptom in people with dementia; untreated, it reduces quality of life and causes suffering. 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, which can be challenging due to reduced cognitive function. The proposed scoping review is the first step in the development of a systematic pain management model for people with dementia living in nursing homes. It aims to identify, categorize, and summarize knowledge on how pain management processes in this population are described in the literature, focusing on how healthcare professionals can integrate self-reporting in the recognition, assessment, and evaluation of pain in this context.

Methods and analysis: The scoping review will be conducted following the six-stage framework developed by Arksey and O'Malley and advanced by Levac et al.: (1) identify research question, (2) identify relevant studies, (3) select studies, (4) chart data, (5) collate, summarize, and report results, and (6) consult practitioners and consumers. Systematic searches in CINAHL, Embase, Medline, and PsycInfo will be conducted. The protocol follows the PRISMA-P and PRISMA-ScR checklists, and the scoping review will adhere to the PRISMA-ScR checklist. The review will include research that concerns the management of pain in people with dementia living in nursing homes. Studies will be assessed for quality and ethical standards. The summarizing and reporting of findings will follow Bradbury-Jones et al.'s PAGER framework. 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 disseminations: The scoping review aims to collect and summarize 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/

Keywords: dementia, pain, pain assessment, pain management, nursing, healthcare professionals, nursing homes

Strengths and limitations

- The proposed scoping review is the first step in developing an intervention targeting systematic pain management for people with dementia living in nursing homes, adhering to the Medical Research Council's (MRC) framework for the development and evaluation of complex interventions. It aims to promote sustainable research and reduce research waste, by mapping the field early in the development process.
- This review will use an established scoping review methodology and standardized reporting guidelines.
- 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. Moderate to severe stages of dementia have been described as an extended and intensive palliative care phase, often characterized by a loss of independence and autonomy, and reduction in physical and cognitive function.[5] The trajectory is often unpredictable and palliative care initiation should therefore reflect need, not prognosis.[6] A 5-round Delphi study resulted in 57 consensus-based recommendations for optimal palliative care in dementia, of which 8 are clinical.[2] One of these clinical domains is symptom relief, considered one of the main aspects of palliative care.[7]

Pain is a common symptom among people with dementia living in nursing homes.[8-11] In a recent study, van Dam et al. found that 43.3% of participants with dementia had clinically relevant pain scores.[8] Helvik et al. state that 35.5% of their participants had clinically relevant pain upon admittance to a nursing home.[9] 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.[10] Pain in this patient group is often related to musculoskeletal, gastrointestinal, and cardiac conditions, genitourinary infections, and wounds.[10] Discomfort caused by pain in people with dementia can be expressed as behavioral and psychological symptoms (BPSD), such as agitation, apathy, restlessness, or wandering.[2,12] 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.[13]

Pain can be defined as *an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.*[14] Pain is a symptom, which is a subjective experience, as opposed to signs, which can be observed.[15,16] These definitions implies 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[5,17]—their pain may therefore go unrecognized and unmanaged.[11] One recommendation is the systematic use of standardized observational tools and skills to chart pain, which can compensate for patients' lack of verbal communication.[2,13,18,19] However, nurses often rely on experience-based knowledge when interpreting signs of pain, and less-experienced nurses may fail to recognize pain in people with dementia.[20] 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.[21] Achterberg et al. highlight how self-reporting can also be adapted to individual capabilities during the course of dementia.[11] They recommend an initial use of simple numerical or verbal scales, and then the later use of "yes" or "no" questions; when cognitive and linguistic impairment 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.[15] When caring for people with dementia this is complex and challenging.[22-24] It relies on healthcare professionals' knowledge of individuals' normal level of functioning and communication methods[22,25]—and thus continuity of care. Healthcare professionals providing individualized 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.[22,25]

Healthcare professionals need tools to systematically assess and manage pain in people with dementia. The proposed scoping review is the first step in developing a care model to facilitate pain management in people with dementia living in nursing homes, and is rooted in the initial steps of the MRC framework for developing and evaluating complex interventions.[26] To promote sustainable research and reduce research waste, it is important to obtain a preliminary overview of the field of research.[27] To the best of our knowledge, no study has reviewed the literature on self-reporting in pain management processes in people with dementia living in nursing homes, and how healthcare professionals can integrate self-

reporting in recognizing, assessing, and evaluating pain in this group and context. The aim of this scoping review is therefore to identify, categorize, and summarize 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[28] and Levac et al.'s recommendations for each stage.[29] This will facilitate examination of the research concerning pain management in the target population, and the identification of knowledge gaps. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P)[30] and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklists[31] were used to prepare this protocol (supplementary files 1 and 2). PRISMA-ScR[31] will be used in the review.

Stage 1: Identify the research question(s)

Levac et al.[29] highlight that research questions as comprehensive and broad as those recommended by Arksey and O'Malley[28] 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.[29] A Population, Concept, Context (PCC) framework has informed the research questions (table 1), and will guide the database searches and eligibility criteria.

Table 1. PCC framework informing research questions and search strategy

Criteria	Determinants
Population	People with dementia
Concept	Pain management processes
Context	Nursing home

The following preliminary research questions were developed:

- How do healthcare professionals recognize, assess, and evaluate pain in people with dementia living in nursing homes?
- How are the management 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 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.[28] 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 (supplementary 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.[28] 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,[28] and any revised criteria will be applied to all citations. The selection process will be documented in a PRISMA-flowchart[32] (figure 1), including reasons for exclusion.[30] 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.

Table 2. Preliminary eligibility criteria guiding study selection

Eligibility criteria	Inclusion criteria	Exclusion criteria
Source	Peer-reviewed journals Published in English, Norwegian, Swedish, or Danish	Grey literature

Population	People with dementia (e.g., patients, service users, or residents)	Mixed samples (e.g., mild cognitive impairment/cognitive impairment + dementia) Dementia in people with Downs Syndrome Cognitive impairment not caused by dementia
Context	Nursing home	
Concept	Literature that describes: How healthcare professionals (including nurses, nurse assistants, and doctors), recognize, assess, and evaluate pain in the population Whether and/or how self-reporting of pain is integrated in pain management processes in the population 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 nonempirical studies

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.[29] 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 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.[29] Study quality will be therefore be assessed using appropriate appraisal tools, e.g., the Critical Appraisal Skills Programme (CASP)[33] and Mixed Methods Appraisal Tool (MMAT).[34] An additional researcher will be included in the decision making if disagreement or uncertainty arise 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, study population, and the assessment tool. 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.[29] A preliminary data-charting form has been developed based on Arksey and O'Malley's template (table 3).[28] Ethical mapping is included in the data-charting form, in response to Weingarten et al.'s emphasis on increasing ethical awareness in reviews.[35] Articles that do not adhere to ethical standards will be excluded.

Table 3. Data-charting form

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, summarize, and report results

As Arksey and O'Malley point out, unlike systematic reviews, scoping reviews do not synthesize evidence but instead provide an overview of the reviewed material.[28] In this stage, an overview and summary of the extracted information will therefore be prepared and presented, following the PAGER framework,[36] which consists of five categories: patterns, advances, gaps, evidence for practice, and research recommendations. 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 complex intervention aiming to facilitate pain management 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.[28] 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 unecessary.[37] However, following Weingarten et al.,[35] 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 management 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.[27]

ACKNOWLEDGEMENTS

We would like to thank Annelie Ekberg-Andersson and Linda Borg—Information Specialists at Karlstad University—for their contribution to the search strategy presented in this protocol.

AUTHORS' CONTRIBUTIONS

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

FUNDING STATEMENT

This research received no grant from any funding agency in the public, commercial, or not-for-profit sectors.

COMPETING INTERESTS STATEMENT

None declared

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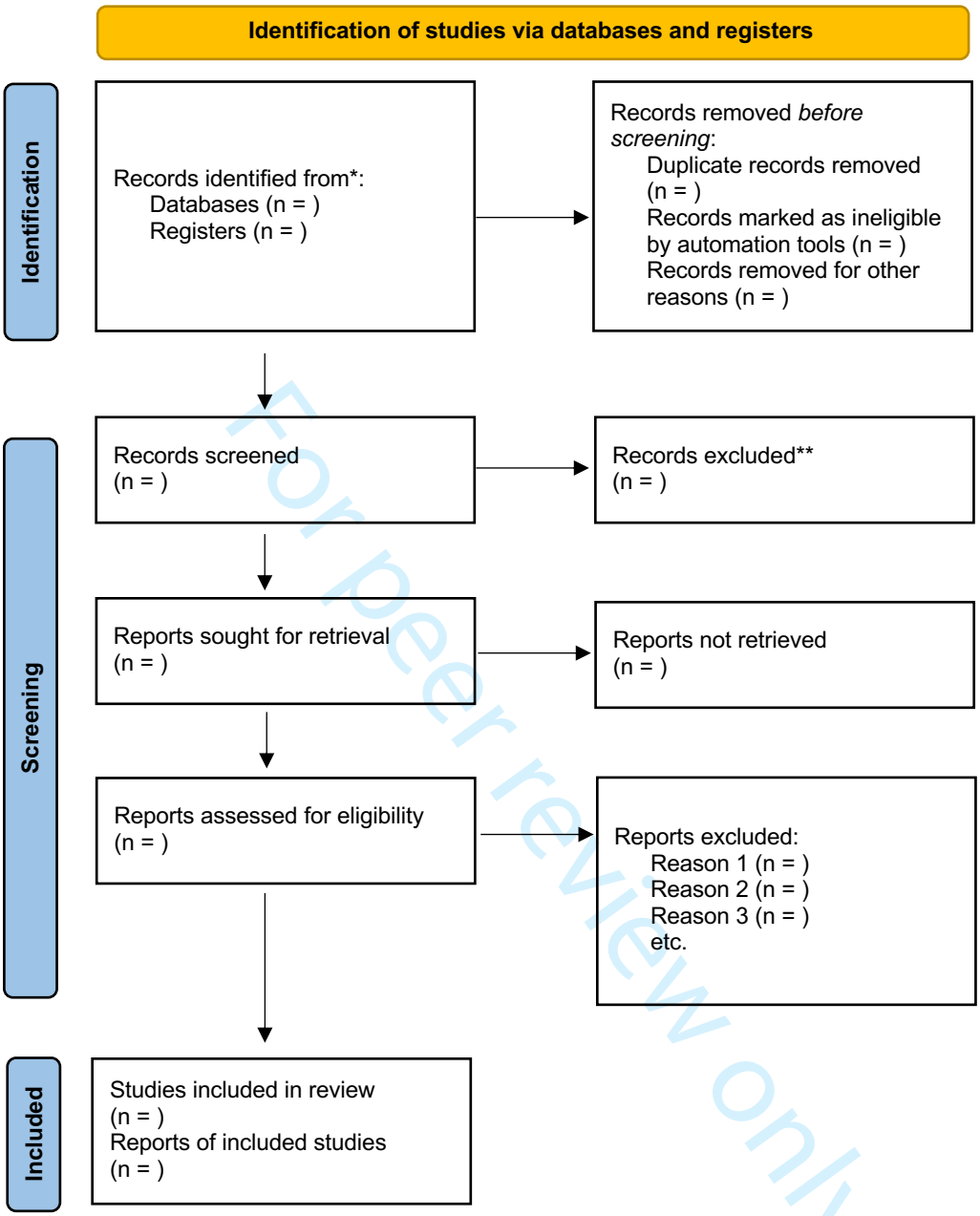
Figure legends:

Figure 1: Overview study selection process using PRISMA Flow Diagram.[32]



*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.

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	☒	☐	61
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	☒	☐	316-320
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	☒	☐	320-322
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	☒	☐	105-165
Objectives	7	Provide an explicit statement of the question(s) the review will address with	☒	☐	186-193

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	☒	☐	222-223
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	☒	☐	197-203
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	☒	☐	Supplementary file 3
STUDY RECORDS					
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	☒	☐	214-215
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)	☒	☐	210-230
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	☒	☐	342-255
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	☒	☐	254-255
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	☒	☐	242-255
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	☒	☐	256-563
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	8

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.	13

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

BMJ Open

The process of pain assessment in people with dementia living in nursing homes: a scoping review protocol

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Title: The 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, categorize, and summarize 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 and advanced by Levac et al.: (1) identify research question, (2) identify relevant studies, (3) select studies, (4) chart data, (5) collate, summarize, and report results, and (6) consult practitioners and consumers. Systematic searches in CINAHL, Embase, Medline, and PsycInfo will be conducted. The protocol follows the PRISMA-P and 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 disseminations: The scoping review aims to collect and summarize 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/

Keywords: dementia, pain, pain assessment, pain management, nursing, healthcare professionals, nursing homes

Strengths and limitations

- This review will use an established scoping review methodology and standardized reporting guidelines.
- To minimize 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 differ 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 stage. [6] Moderate to severe stages of dementia have been described as an extended and intensive palliative care phase, often characterized by a loss of independence and autonomy, and reduction in physical and cognitive function.[7] The trajectory is often unpredictable and palliative care initiation should therefore reflect need, not prognosis.[8] A 5-round Delphi study resulted in 57 consensus-based recommendations for optimal palliative care in dementia, of which 8 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 upon 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 behavioral 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 implies 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 unrecognized and unmanaged.[13] One recommendation is the systematic use of standardized 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 recognize 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 then the later use of "yes" or "no" questions; when cognitive and linguistic impairment 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 individualized 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 recognize pain and evaluate initiated measures. The development of

this model is rooted in the initial steps of the 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 recognizing, assessing, and evaluating pain in this group and context. The aim of this scoping review is therefore to identify, categorize, and summarize 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 (supplementary files 1 and 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.

Table 1. PCC framework informing research questions and search strategy

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

The following preliminary research questions were developed:

- How do healthcare professionals recognize 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 (supplementary 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.

Table 2. Preliminary eligibility criteria guiding study selection

Eligibility criteria	Inclusion criteria	Exclusion criteria
Source	Peer-reviewed journals Published in English, Norwegian, Swedish, or Danish	Grey literature
Population	People with dementia (e.g., patients, service users, or residents)	Mixed samples (e.g., mild cognitive impairment/cognitive impairment + dementia) Dementia in people with Downs Syndrome Cognitive impairment not caused by dementia
Context	Nursing home	
Concept	Literature that describes: How healthcare professionals (including nurses, nurse assistants, and doctors), recognize, assess,	

	and evaluate pain in the population Whether and/or how self-reporting of pain is integrated in pain assessment processes in the population 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 nonempirical studies

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 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 be therefore be

assessed using appropriate appraisal tools, e.g., 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 arise 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 (table 3).[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.

Table 3. Data-charting form

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, summarize, and report results

As Arksey and O'Malley point out, unlike systematic reviews, scoping reviews do not synthesize 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 unecessary.[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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AUTHORS' CONTRIBUTIONS

CKO was responsible for the preliminary study design, conceptualized the review approach, and led the writing of this protocol. ML, AH, 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 STATEMENT

None declared

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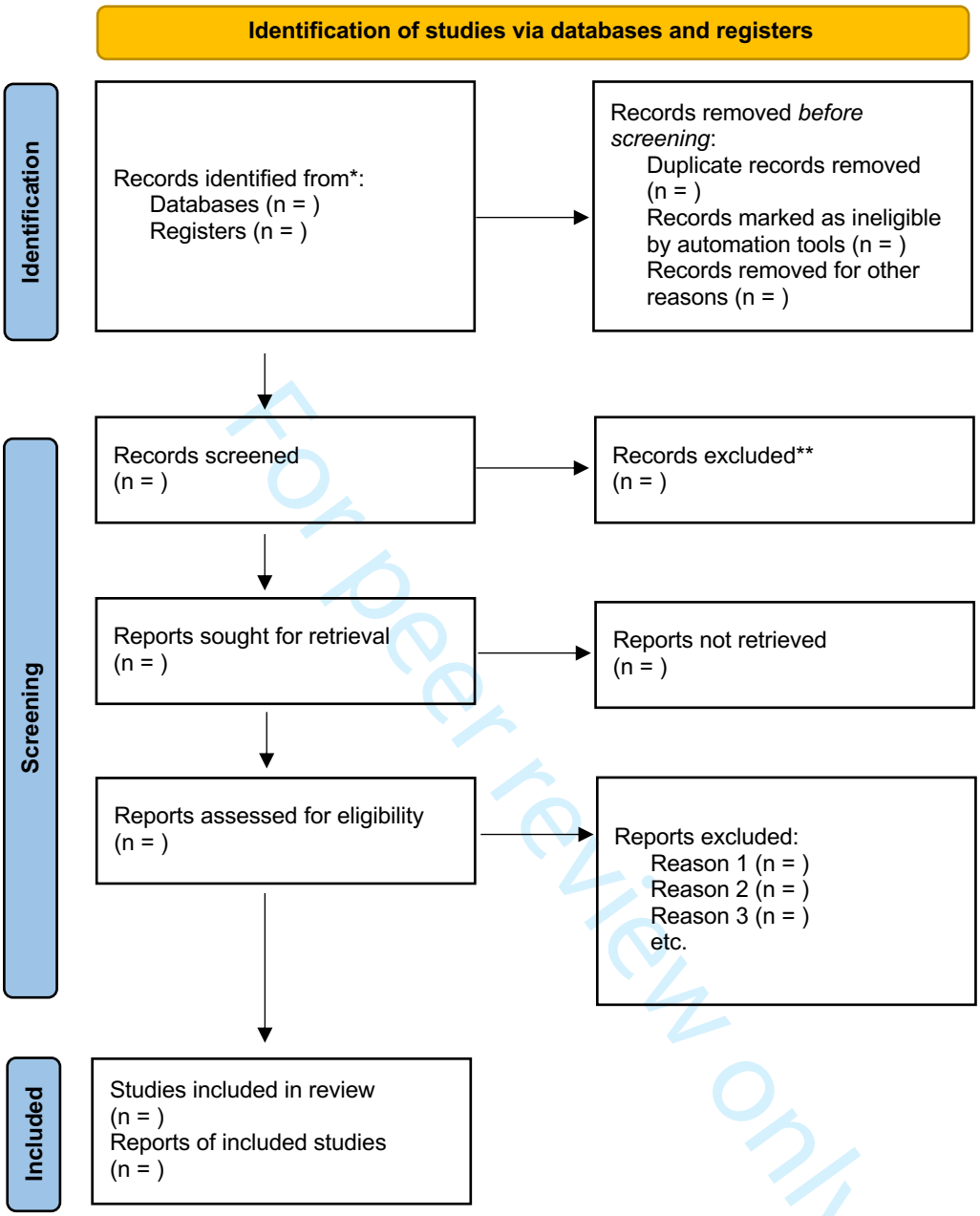
Figure legends:

Figure 1: Overview 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.

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