

BMJ Open Non-pharmacological interventions for improving quality of life of long-term care residents with dementia: a scoping review protocol

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ABSTRACT

Introduction Evidence concerning the effectiveness of non-pharmacological interventions that are applied to people with dementia living in long-term care facilities is inconsistent. The purpose of this protocol is to describe the methodological considerations that will guide the completion of a scoping review that will inventorise and assess the effectiveness of the various non-pharmacological interventions that are documented in literature for improving quality of life of people with dementia living in long-term care.

Methods and analysis This scoping review will combine the methodology outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews and Guidance for conducting systematic scoping reviews by Peters *et al.* PubMed; MEDLINE; CINAHL; Embase; Cochrane Database of Systematic Reviews; Cochrane Central Register of Controlled Trials; Emcare; Sociological Abstracts and PsycINFO databases will be searched. Grey literature databases will also be explored. A two-stage screening process consisting of a title and abstract scan and a full-text review will be used to determine the eligibility of studies. Studies, irrespective of design, will be included that quantitatively assess quality of life of long-term care residents who receive non-pharmacological interventions for dementia. A pair of reviewers will independently assess all articles for eligibility, and all eligible articles will be abstracted and charted using a standardised form. The extracted data will undergo a 'narrative review' or a descriptive analysis of the contextual or process-oriented data and quantitative analysis reflecting the objectives of this scoping review.

Ethics and dissemination Research ethics approval is not required for this scoping review. This review started off in October 2018, anticipated end date is June 2020. We plan to disseminate this research through publications, presentations at relevant national and international conferences and meetings with relevant stakeholders. This scoping review protocol has been registered at Open Science Framework (<https://osf.io/tupbv>).

INTRODUCTION

The worldwide rapid increase in the number of people with dementia represents one of the greatest social and economic challenges of the 21st century. Dementia is a complex

Strengths and limitations of this study

- This review topic and objectives were codeveloped by people involved in the network of long-term care of people with dementia.
- This study will apply established scoping review methods.
- A comprehensive literature search strategy of electronic bibliographic sources and grey literature will be used to capture available evidence.
- Due to incorporating broad research methodologies, the heterogeneity in type, method and timing of administration of the various interventions may yield data that might be difficult to synthesise into a unified conceptual framework.

syndrome¹ encompassing not only cognitive function deficits but also problems in other domains such as personality, mood, language and behaviour. The lifetime risk of developing neuropsychiatric symptoms in the dementia trajectory is as high as 90%,² and they can occur universally at all dementia stages irrespective of the underlying aetiology.³ Furthermore, dementia influences important aspects of daily life, such as autonomy, activities of daily living⁴ and ability to perform meaningful activities. Thus, dementia dramatically changes not just the lives of people who live with it, but also their families and the society at large.

Until now, there is no known treatment modality, either pharmacological or non-pharmacological that can cure dementia or halt its progression. As there is no cure for dementia, the main goal of caring for people with dementia is the maintenance and promotion of their quality of life.⁵ Aside from traditional use of medications, management strategies in dementia often include non-pharmacological interventions. Non-pharmacological interventions that have been (systematically) reviewed in literature include

exercise interventions,⁶ music therapy,⁷ art therapy,⁸ animal assisted therapy,^{9 10} sensory stimulation/integration,¹¹ psychosocial interventions,^{12–14} recreation therapy, reminiscence therapy,¹⁵ behavioural therapy¹⁶ and cognitive therapy¹⁷ with outcome(s) of interest including cognition, neuropsychiatric symptoms,^{14 18} mood,¹⁰ mobility and quality of life.^{10 19} While there is a growing number of studies and reviews of studies on non-pharmacological interventions in dementia, there is an information gap in terms of an overview of interventions or groups of interventions that are effective, for who they are effective and why. A literature preliminary search conducted in October 2018 in Cochrane Database of Systematic Reviews, JBI Database of Systematic Reviews and Implementation Reports, CINAHL and PubMed indicated that no scoping review has addressed this topic. Therefore, this scoping review will systematically map the known literature about non-pharmacological interventions to improve quality of life of people with dementia that are living in long-term care facilities with a view to determining the effectiveness of these interventions and the potential characteristics that might determine their effectiveness.

Study objective

The scoping review is aimed at mapping the available evidence on the effectiveness of non-pharmacological interventions for improving quality of life of people with dementia living in long-term care.

The specific objectives are to:

1. Inventorise the existing non-pharmacological interventions for improving quality of life of people with dementia living in long-term care.
2. Determine the effectiveness of the interventions for improving quality of life in people with dementia.
3. Determine for who (person's characteristics) the intervention(s) is/are effective and if possible determine why.

Context and concept

The review will consider studies that are conducted in long-term care settings in which non-pharmacological interventions were administered directly to people with dementia, and in whom quality of life was measured as an outcome parameter. For the purpose of this review, the following definitions will be applied:

Quality of life: defined as the multidimensional evaluation of the person-environment system of the individual, in terms of adaptation to the perceived consequences of dementia.²⁰ It results from successful or unsuccessful adaptation of the individual to the physical, psychological and social consequences of the dementia syndrome.

Non-pharmacological intervention: defined as any sort of intervention not directly involving a medication; attempting to optimise a complex patient's healthcare needs²¹ or to better manage their chronic illness.²² For this study, we will consider non-pharmacological interventions that are administered to people with dementia, in which the aim of the intervention is usually not to treat

or control dementia but to control mediators of quality of life.

Long-term care settings: defined as facilities providing permanent custodial assistance to meet both the medical and non-medical needs of people (in this case to people with dementia). Our definition of 'people living in long-term care settings' includes people residential facilities/institutions, care homes or nursing homes. Our definition excludes community or independently dwelling people.

METHODS

Our protocol is based on the methodological framework for scoping reviews described in Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR)²³ and Guidance for conducting systematic scoping reviews by Peters *et al.*²⁴ We will primarily follow the checklist outlined in the PRISMA-ScR. In instances where supplementary information will be needed, we will seek out the explanation stated in the guidance for conducting systematic scoping reviews by Peters *et al.*²⁴ We anticipate the study duration to be from October 2018 to June 2020.

Search strategy

The search strategy aims to find both published and unpublished literature. A three-step search will be used in each component of this review. An initial limited search of PubMed, MEDLINE and CINAHL will be undertaken, followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe relevant articles. A second search using all the identified keywords and index terms will be undertaken across all included databases. Third, the reference list of all included studies will be searched for additional studies. No time limit will imposed on studies for inclusion in this review.

Search in electronic databases

PubMed; MEDLINE; CINAHL; Embase; Cochrane Database of Systematic Reviews; Cochrane Central Register of Controlled Trials; Emcare; Sociological Abstracts and PsycINFO databases will be searched. The search strategy prepared for PubMed is shown in online supplementary file 1. To avoid missing any relevant study in the search, broadly defined heading terms will be used in the search strategy. The design of the electronic search strategy will be done in collaboration with an expert information specialist. Initial keywords in the search terms will include: "dementia" AND "Quality of life" OR "wellbeing" AND "long term care" OR "nursing home" OR "institution".

Secondary search for research evidence via other sources

Additionally, reference lists of key articles will be searched for relevant articles that could have been missed. We will also search through existing networks, relevant organisations and conferences for relevant articles, including unpublished articles. The search for unpublished studies

and grey literature will be done in ClinicalTrials.gov; WorldCAT (global catalog of library collections (<https://www.worldcat.org/>)); GLIN (Grey Literature in the Netherlands); Google; and Google Scholar. Articles that meet our inclusion criteria will be included.

Inclusion criteria

This scoping review will consider studies of various methodologies (randomised, quasi-randomised controlled trials, case-control and case series studies and so on) that include people with dementia irrespective of type (eg, Alzheimer's, Lewy body dementia, vascular dementia and mixed type) that directly receive non-pharmacological intervention(s) while living in long-term care facilities. Studies that include people with cognitive impairment secondary to acute brain disorders such as stroke will be excluded.

Data extraction

All found articles would be imported to Endnote. Two independent reviewers will review the publications on relevance by checking and judging the title and abstract based on the inclusion and exclusion criteria. Discrepancies in reviewers' responses at any stage of the screening will be resolved by asking a third screener to weigh in. Then the full text of potentially eligible articles will be assessed for inclusion.

Data mapping

After the data extraction, we will organise the literature thematically, according to the different intervention types. Thereafter, we will (1) map the key concepts and available evidence, (2) summarise the existing research findings and (3) identify research gaps in the existing literature. A draft data charting form (online supplementary file 2) is developed based on PRISMA-ScR²³ and guidance for scoping review by Peters *et al*²⁴ as part of this protocol to record characteristics of the included studies and the key information relevant to the review question. Information on the extraction field will include author(s), year of publication, source origin/country of origin, study design, aims/purpose, study population and sample size, methodology, intervention type, comparator, concept, method of administration and duration of the intervention, outcomes, key findings that relate to the review question and limitations of the studies. The key findings will be presented in formats reflecting the objectives of this scoping review as appropriate (diagrammatic, tabular summary or descriptive format).

ETHICS AND DISSEMINATION

The findings from the review will be submitted to relevant journals and conferences (national and international). Furthermore, we aim to share our results with key stakeholders involved in both intramural and extramural care of people with dementia to help improve clinical practice. Finally, on the basis of the research gaps that will be

identified during the conductance of this scoping review, we expect that new research questions can be formulated and new insights obtained that will aid creation/review of treatment guidelines and, ultimately, improvement of care of people with dementia living in long-term care.

Patient and public involvement

The research question and primary outcome measure (quality of life) of this study is based on the experiences and preferences of people involved in the academic network for long-term care in the province of South Holland, the Netherlands (Universitair Netwerk voor de Care sector Zuid-Holland (UNC-ZH)). Patients and the public were not involved in the design or planning of the study.

Contributors AAA designed the protocol and wrote the manuscript. MAAC and WPA contributed to the intellectual content of and critically appraised the protocol. All the authors edited and approved the manuscript before submission.

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval Research ethics approval is not required for this scoping review because no primary data will be collected.

Provenance and peer review Not commissioned; externally peer reviewed.

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