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Effectiveness of advance care planning programmes in improving end-of-life outcomes for individuals with dementia and their caregivers in nursing homes: protocol for a systematic review and meta-analysis

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ABSTRACT

Introduction With advances in medicine and the resultant increased ageing population, dementia, including Alzheimer's disease, has become a leading cause of death in individuals aged over 65 years in nursing homes. The unpredictable trajectory of the disease, marked by cognitive and functional decline, necessitates intensive healthcare and poses challenges to end-of-life (EoL) care decisions, particularly because majority of the affected individuals become unable to make their own decisions. This highlights the importance of advance care planning (ACP) programmes that enable individuals with dementia to define and communicate their EoL care decisions in advance. In this systematic review and meta-analysis, we aim to evaluate the effectiveness of ACP in nursing homes for patients with dementia and their caregivers.

Methods and analysis This systematic review and meta-analysis will include randomised controlled trials (RCTs) and observational studies that evaluate the effectiveness of ACP programmes in improving EoL outcomes in individuals with dementia and their caregivers in nursing homes. EoL outcomes include (1) quality of life; (2) caregiver satisfaction; (3) advance directives completion rate, which refers to the proportion of individuals with completed, documented EoL care preferences; (4) uptake of ACP discussion indicating the frequency or occurrence of these discussions between healthcare providers, patients and/or family members; and (5) comfort in the last week of life. Studies will be retrieved from PubMed, Embase, Cochrane Library and ClinicalTrials.gov between their inception and 31 January 2024. Eligible articles will be selected according to prespecified inclusion and exclusion criteria. The quality of the included articles will be assessed using the Cochrane risk-of-bias tool 2.0 for RCTs and risk of bias in non-randomised studies of interventions for observational studies. The certainty of evidence will be evaluated using the Grading of Recommendations Assessment, Development and Evaluation framework. Publication bias will be assessed using a funnel plot and Egger's test to detect any asymmetry in the distribution of effect sizes across studies. Sensitivity and subgroup analyses will be conducted to address heterogeneity.

Ethics and dissemination Ethics approval was not required for this systematic review and meta-analysis, as it involves the synthesis of existing literature without direct data collection or patient participation. The results of this study will be compiled into a detailed report, which will be submitted for publication in a peer-reviewed journal. Additionally, the findings will be shared with academic partners, healthcare professionals and organisations involved in dementia care, as well as policymakers and stakeholders in the field of long-term care for individuals with dementia.

PROSPERO registration number CRD42023489126.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study will include both randomised controlled trials and observational studies, allowing for a comprehensive analysis of data on the effectiveness of advance care planning programmes in patients with dementia in nursing homes.
⇒ A variety of end-of-life outcomes, such as quality of life, caregiver satisfaction and comfort in the last week of life, will be evaluated, offering a well-rounded view of the impact of advance care planning programmes.
⇒ The overall quality of evidence will be assessed using the Grading of Recommendations, Assessment, Development and Evaluation, allowing for assessment of certainty of evidence for the meta-analysis.
⇒ Given the diversity in advance care planning programmes, significant heterogeneity is anticipated.

INTRODUCTION

Dementia is a leading cause of death in individuals aged over 65 years, with prevalence rising dramatically in recent years. Between 2000 and 2015, deaths attributed to Alzheimer's disease in the USA increased by >123%.[1–3] In 2022, dementia and Alzheimer's disease were the leading causes of death in

England and Wales, accounting for 11.4% of all deaths.[2] Unlike other terminal illnesses, the disease course of dementia is characterised by prolonged cognitive and functional decline, with a median survival from diagnosis ranging from 3 to 12 years.[4–6] This gradual deterioration leads to increased healthcare use, including frequent hospitalisations and intensive medical interventions, resulting in higher healthcare costs.[5 7]

Owing to the progressive and unpredictable nature of dementia, many treatment-related decisions, including potentially unadvisable treatments, such as aggressive interventions, may need to be made as the disease advances, often if patients are unable to make these decisions themselves.[8 9] Therefore, early discussion of end-of-life (EoL) care preferences is crucial to ensure that it aligns with the wishes of the patients and their caregivers. Notably, the EoL experience is exceedingly personal and individualised, further emphasising the need for discussions about tailored care preferences. Advance care planning (ACP) enables individuals to define and communicate their goals and preferences regarding future medical treatment and care. It involves a discussion of these preferences with family members and healthcare providers and documenting them as appropriate.[10] Hence, for individuals with dementia, the unpredictable progression of the disease makes the early clarification of EoL preferences important.[11]

Nursing homes are a common setting for caring for individuals with advanced dementia. In 2017, 55.0% of dementia-related deaths in the USA occurred in nursing homes,[5] and similar patterns have been observed in other countries, with approximately 65.9% of individuals with dementia dying in nursing homes.[12 13] Research has shown that EoL conversations with care providers are essential for nursing home residents.[14 15] However, despite the recognised importance of ACP, individuals with dementia are often excluded from such studies.[16–18] Furthermore, family members of nursing home residents with advanced dementia often feel unprepared and unsupported in making EoL decisions for their loved ones.[19]

ACP is effective in improving EoL outcomes for individuals with dementia, such as reduced emergency hospital admissions, fewer burdensome treatments and better pain and symptom management.[20] Additionally, ACP increases documentation of patient preferences for care and concordance between the care received and the documented EoL wishes of patients with dementia.[21] It also improves communication between healthcare providers, patients and family members, making it easier to make informed decisions as the disease progresses.[8] However, studies often vary in healthcare settings and measurement of ACP outcomes, such as hospitalisation, hospice use and concordance between the care received and the documented wishes.[20] This variability makes it challenging to draw definitive conclusions regarding the effectiveness of ACP interventions in patients with dementia in nursing homes. Nursing home ACP programmes improve compliance with best practices and care satisfaction.[22–24] Nevertheless, comprehensive evidence on the effectiveness of these programmes for individuals with dementia remains lacking.

To address this inconsistency and provide a clearer understanding of the effectiveness of ACP interventions for individuals with dementia in nursing homes, this study aims to conduct a systematic review and meta-analysis to analyse existing evidence and determine the overall impact of ACP programmes on EoL outcomes in this population. Specifically, the review will focus on (1) identifying the contents and components of ACP interventions implemented in nursing homes for individuals with dementia; (2) evaluating the categories of EoL outcomes associated with these interventions, such as reduced hospitalisations, decreased use of aggressive treatments and improved alignment between care received and patient preferences; and (3) assessing the overall effectiveness of nursing home ACP programmes in improving EoL care quality for individuals with dementia. By consolidating and analysing data from various studies, this review aims to fill the current knowledge gap and provide evidence-based recommendations for the implementation of effective ACP programmes in nursing homes, ultimately enhancing the quality of EoL care for individuals with dementia.

METHODS AND ANALYSIS

This systematic review protocol is reported in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols guidelines. The study will explore the impact of ACP programmes on EoL outcomes in individuals with dementia and their caregivers in nursing homes.[25] The question posed in this systematic review is based on population, intervention, control and outcome (PICO): 'P' refers to individuals with dementia and their carers residing in nursing homes; 'I' refers to an ACP programme; 'C' refers to usual care; and 'O' refers to EoL outcomes (quality of life, caregiver satisfaction, advance directives completion rate (refers to the proportion of individuals with completed, documented EoL care preferences), uptake of ACP discussion (indicating the frequency or occurrence of these discussions between healthcare providers, patients and/or family members) and comfort in the last week of life).[26]

Search strategy

The search strategy will use keywords such as 'dementia', 'advance care planning programmes', 'nursing homes' and 'end-of-life outcomes', combining synonyms and MeSH or Emtree terms with the Boolean operators 'OR' and 'AND', to search relevant papers in PubMed, Embase, Cochrane Library and ClinicalTrials.gov for studies published between their inception and 31 January 2024. Table 1 details the PubMed search strategy. We will manually search for additional eligible articles from the reference lists of the relevant articles. No limitations will be imposed on language, geographical location, age, sex,

Table 1 PubMed search strategy

Search	Query
#1	Advance Care Planning
#2	(("advance care plan") OR "advance care plans") OR "advance care planning"
#3	("advance statement") OR "advance statements"
#4	("advance decision") OR "advance decisions"
#5	("advance directive") OR "advance directives"
#6	"end of life care"
#7	("end of life plan") OR "end of life plans" OR "end of life planning"
#8	("end of life discussion") OR "end of life discussions"
#9	("end of life communication") OR "end of life communications"
#10	("end of life decision making") OR "end of life decision" OR "end of life decisions"
#11	"living will"
#12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11
#13	Nursing Homes OR "Nursing home"
#14	"Retirement Home" OR "Long-term Care Facility" OR "Assisted Living Facility" OR "Elderly Care Facility" OR "Convalescent Home" OR "Senior Care Facility" OR "Care Home" OR "Residential Care" OR "Residential Aging" OR " Aged Care Facility"
#15	#13 OR #14
#16	Dementia
#17	dement*
#18	Amentia*
#19	#16 OR #17 OR #18
#20	#12 AND #15 AND #19
#21	(cohort studies[mh] OR cohort*[tw] OR controlled clinical trial[pt] OR case-control studies[mh] OR (case*[tw] AND (control*[tw] OR crossover[tw] OR cross-over[tw] OR comparison*[tw])) "control group"[tw] OR "control groups"[tw] OR risk*[tw] OR incidence*[tw] OR (epidemiologic methods[mh:noexp] AND ("1966"[dp]:"1989"[dp])))
#22	(Cross-Sectional Studies[mh:noexp] OR "cross section*"[tiab] OR crosssection*[tiab] OR crossection*[tiab])
#23	(randomized controlled trial[pt] OR controlled clinical trial[pt] OR randomized[tiab] OR randomised[tiab] OR placebo[tiab] OR clinical trials as topic[mesh:noexp] OR randomly[tiab] OR trial[ti] NOT (animals[mh] NOT humans [mh]))
#24	#20 AND (#21 OR #22 OR #23)

race, ethnicity and the specific ACP regimen used. The study protocol has been registered with the International Prospective Register of Systematic Reviews (PROSPERO registration number CRD42023489126).

Study selection

The retrieved studies will be managed using EndNote V.20. After removing duplicate studies automatically using EndNote and manually, two authors (J-YW and Y-JC) will evaluate the eligibility of the studies by screening the titles and abstracts as well as reviewing the full text based on the inclusion and exclusion criteria. The inclusion criteria for the analysis are as follows: (1) studies that match the PICO question, (2) randomised controlled trials (RCT) and observational studies and (3) studies presenting EoL outcomes. The exclusion criteria are as follows: (1) studies lacking full-text availability and (2) non-original studies (conference papers, editorial letters and protocols without data). In case of any disagreements during the study selection process, a discussion will take place with a third reviewer (Y-TL) to help reach a consensus. Figure 1 shows the selection flow diagram.

Data extraction

Two authors (J-YW and Y-JC) will independently extract data from the included articles using a standardised predefined template, which will be discussed and agreed upon by the authors. The remaining author (Y-TL) will join the discussion and verify the accuracy of the extracted data, including the author's name, publication year, study design, study location, study participants, study intervention, study comparison and outcomes.

Quality assessments

Two authors (J-YW and Y-JC) will independently evaluate the methodological quality of the included articles using the Cochrane risk-of-bias tool 2.0 for RCTs and risk of bias in non-randomised studies of interventions for observational studies.[27 28] The certainty of evidence for each outcome will be assessed independently by the two authors based on the Grading of Recommendations Assessment, Development and Evaluation framework.[29] Disagreements will resolve through discussion and consensus with a third investigator (Y-TL).

Statistical analysis

We will conduct a meta-analysis using the Mantel-Haenszel and inverse variance-weighted random-effects models to estimate the overall pooled effect.[30] Continuous variables will be presented as mean difference or standard mean difference with 95% CI, depending on the scale of the variable. For interpatient variability in continuous data, we will calculate the change values from baseline to the end of the follow-up period using baseline and end-of-study values and their associated SD, using a correlation coefficient of 0.5 if the change values are unreported.[31 32] For dichotomous variables in the RCTs, the effect size will be expressed as relative risk with 95% CI. In observational studies, the adjusted estimate of the effect will be reported, including the OR and 95% CI.[33] This study will use the Cochran's Q test and the I^2 metric to assess heterogeneity. I^2 metric values >50% will be considered large and values >75% will be considered extremely large. Subgroup analyses according to study design, study sites and ACP regimen will be conducted.[32] Publication bias will be assessed using funnel plot and Egger's test to

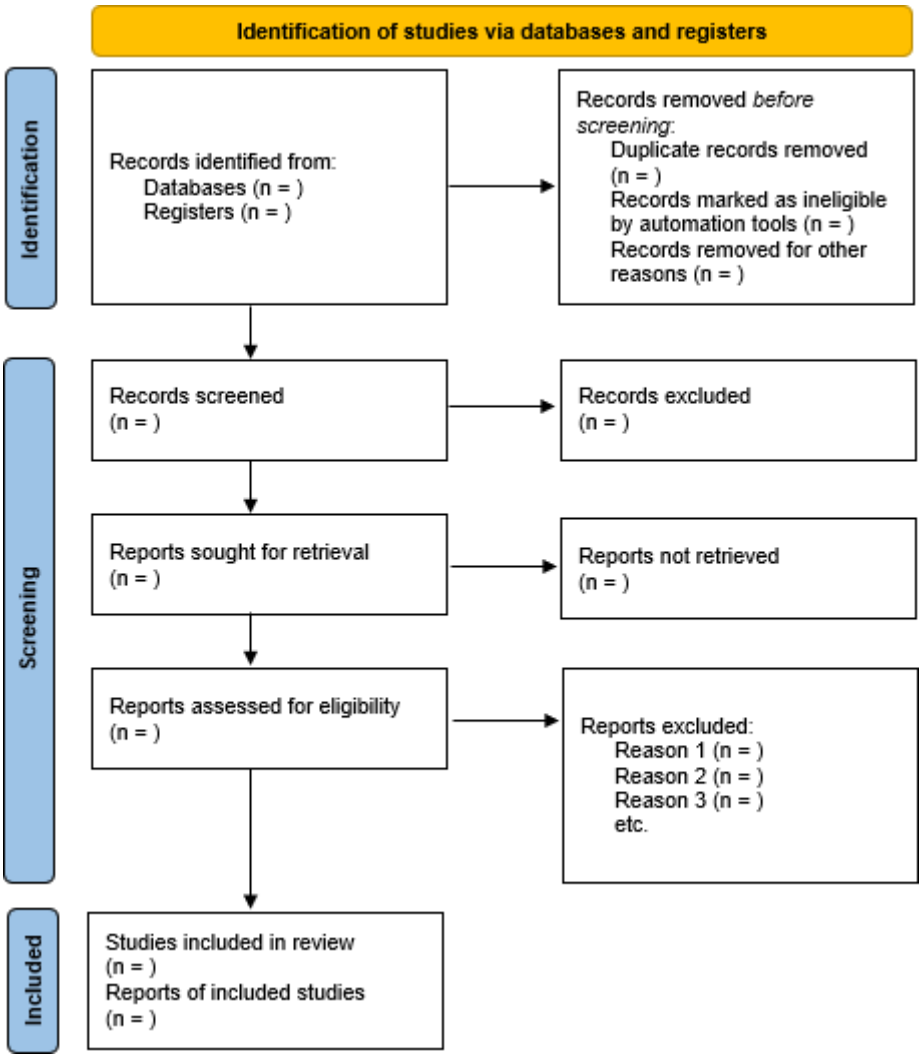

Figure 1 Flow diagram describing the process of the systematic review and meta-analysis.

detect any asymmetry in the distribution of effect sizes across studies. Sensitivity and subgroup analyses will be conducted to address heterogeneity.[26]

Patient and public involvement

None.

ETHICS AND DISSEMINATION

Ethics approval was not required for this systematic review and meta-analysis, as it involves the synthesis of existing literature without direct data collection or patient participation. The results of this study will be compiled into a detailed report, which will be submitted for publication in a peer-reviewed journal. Additionally, the findings will be shared with academic partners, healthcare professionals and organisations involved in dementia care, as well as policymakers and stakeholders in the field of long-term care for individuals with dementia.

DISCUSSION

Considering the increasing population and trends in places of death for individuals with dementia, individuals with dementia residing in nursing homes and their families should be able to express their preferences and wishes in an informed and timely manner. Despite the generally positive attitude towards nursing home ACP and the fact that some studies have demonstrated the beneficial effects of nursing home ACP programmes in individuals with dementia,[34 35] evidence supporting the effectiveness of ACP in improving the care of individuals with dementia in nursing homes remains lacking.

This systematic review and meta-analysis aims to help update the knowledge of and provide guidance regarding the effectiveness of nursing home ACP programmes for individuals with dementia. We plan to use a rigorous methodology according to the Cochrane Handbook, which will enable the examination of all available ACP interventions for individuals with dementia in nursing homes to offer

a comprehensive overview of the current clinical gaps.[26 32 36] One strength of this study is that it will include RCTs and observational studies to increase the abundance of data. However, one limitation is that the outcomes may be heterogeneous and the planned meta-analysis may not be possible.

Considering the unpreferred treatments patients receive before death and the burden on family members who participate in EoL decision-making, identifying effective ACP programmes for individuals with dementia and their caregivers in nursing homes is important. This study will contribute to the development of better knowledge on the effects and domains of outcomes in nursing home ACP programmes for individuals with dementia. Moreover, the findings of this study will have a valuable impact on clinical care and policymaking eventually, as individuals with dementia and their caregivers are important stakeholders in ACP in nursing homes.

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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.

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