

Review article/Pregledni znanstveni članek

## Impact of advance care planning for older adults with dementia in nursing homes: A literature review

Učinek vnaprejšnjega načrtovanja oskrbe starejših odraslih z demenco v domovih starejših: pregled literature

Suzana Koštomaj<sup>1, 2, \*</sup>

**Keywords:** advance directive; palliative care; empowerment; dignity

**Ključne besede:** vnaprejšnja direktiva; paliativna oskrba; opolnomočenje; dostojanstvo.

<sup>1</sup> Retirement home Šentjur, Svetinova ulica 1, 3230 Šentjur, Slovenia

<sup>2</sup> Alma Mater Europaea-ECM, Slovenska 17, 2000 Maribor, Slovenia

\* Corresponding author/  
Korespondenčni avtor:  
suzana.kostomaj@almamater.si

### ABSTRACT

**Introduction:** Advance care planning is a very important challenge in the field of palliative and hospice care. The aim of this study was to review empirical evidence on the effectiveness of advance care planning in palliative and hospice care for older adults with dementia, focusing on nursing home residents.

**Methods:** The literature search was conducted in the PubMed, ScienceDirect and Scopus databases. The search terms included "advance care planning," "dementia," "palliative care," and "nursing home." The review included quantitative, qualitative and mixed-methods studies focussing on advance care planning for older adults with dementia published in English up to 2023. A narrative synthesis approach was used.

**Results:** The review included a total of 10 studies. We identified two distinct concepts: advance care planning and empowerment of older adults with dementia.

**Discussion and conclusion:** Our literature review revealed a clear relationship between the preferences expressed by older adults with dementia concerning their end-of-life care, their will to live and desire for less emotional distress at the end of life. Future research should employ a multidisciplinary approach to investigate the long-term impact and financial aspects of timely implementation of advance care planning, as well as appropriate strategies to empower its providers.

### IZVLEČEK

**Uvod:** Vnaprejšnje načrtovanje oskrbe je za področje paliativne in hropske oskrbe zelo pomemben izziv. Namen prispevka je bil pregledati empirične dokaze v zvezi z učinkovitostjo vnaprejšnjega načrtovanja paliativne in hospic oskrbe starejših odraslih z demenco s poudarkom na bivanju v domovih starejših.

**Metode:** Pregled literature je potekal v PubMed, ScienceDirect in Scopus. Iskalni nizi so zajemali: »vnaprejšnje načrtovanje oskrbe«, »demenca«, »paliativna oskrba«, »dom starejših«. Pregled vključuje kvantitativne, kvalitativne in raziskave mešanih metod o načrtovanju vnaprejšnje oskrbe za starejše odrasle z demenco, objavljene do 2023 angleškem jeziku. Uporabljena je bila narativna sinteza.

**Rezultati:** V analizo je bilo vključenih 10 raziskav. Identificirali smo dva koncepta: koncept načrtovanja napredne oskrbe in koncept opolnomočenja starejših odraslih z demenco.

**Diskusija in zaključek:** Pregled literature kaže na jasno povezavo med izraženimi preferencami starejših odraslih z demenco glede zdravljenja ob koncu življenja, volje do življenja in umiranja z manj čustvene stiske. Nadaljnje raziskave se bi morale osredotočiti na dolgoročne učinke pravočasnega izvajanja vnaprejšnjega načrtovanja oskrbe, opolnomočenje izvajalcev, multidisciplinarni pristop in finančne vidike izvajanja vnaprejšnjega načrtovanja oskrbe.



Received/Prejeto: 1. 6. 2023  
Accepted/Sprejeto: 21. 10. 2023

© 2024 Avtorji/The Authors. Izdaja Zbornica zdravstvene in babiške nege Slovenije - Zveza strokovnih društev medicinskih sester, babic in zdravstvenih tehnikov Slovenije./Published by Nurses and Midwives Association of Slovenia. To je članek z odprtim dostopom z licenco CC BY-NC-ND 4.0./This is an open access article under the CC BY-NC-ND 4.0 license.

## Introduction

One of the most important issues affecting the public health system is the global shift towards an ageing population (Fang et al., 2020). As a result, a growing number of people will require palliative care that adequately addresses and meets their needs (Van den Block et al., 2020), thereby improving the quality of life for people with chronic or terminal diseases. Ageing is undoubtedly the primary contributor to a wide range of chronic diseases associated with poorer quality of life in older adults (Fang et al., 2020). In order to improve the accessibility of palliative care, we must first examine and evaluate the level of need in society (Etkind et al., 2017). The main challenges many countries face in relation to older adults include frailty, sarcopenia, neurodegenerative diseases, incurable chronic conditions, cardiovascular diseases, mental health disorders, etc. (Fang et al., 2020).

As a progressive neurodegenerative chronic disease with an average survival time of 7–10 years (World Health Organisation, 2021), dementia is undoubtedly one of the most significant challenges for palliative care in social care institutions. Currently, there are approximately 55 million people living with dementia worldwide and this number is projected to increase to 131.5 million by 2050 (World Health Organisation, 2021). Providing adequate care to a growing number of older adults with dementia is therefore of immense clinical and public health importance (Walsh et al., 2021).

It should be noted that modern end-of-life care is not feasible without high-quality advance care planning (ACP), as such planning helps older adults with dementia to express their preferences regarding treatment and care (Konno et al., 2020). In this context, the spiritual aspect of palliative care is equally important. Spiritual care or spiritual interaction between the nurse and the older adult with dementia hinges on the nurse's ability to listen and build a quality relationship with the nursing home resident, i.e. to recognise and nurture the true essence of their experience, a skill that is central to advance care planning palliative care (Haugan, 2022).

Although the beginnings of advance care planning can be traced back to 1960, an extremely important turning point occurred in 1990 when the Patient Self-Determination Act was passed in the USA (Brown, 2003). Advance care planning makes it possible to document the wishes of a person with dementia regarding their treatment and care for the time when they may no longer be able to express such wishes or make decisions. We can therefore define advance care planning as an ongoing process that enables individuals to make decisions about their future health care before they lose the capacity to do so. This includes various measures such as discussing end-of-life care with relatives or healthcare providers, appointing a proxy decision-maker and completing or revising an advance directive (Rietjens et al., 2017).

The benefits of advance care planning, underpinned by rigorous formal training, are recognised as a foundation for end-of-life care (Fulmer et al., 2018). A systematic review of 113 studies conducted by Brinkman-Stoppelenburg et al. in 2014 outlines the outcomes of effective advance care planning. These include consistency between the wishes of terminally ill older adults and the end-of-life care provided, the appropriateness of medical care, the location of end-of-life care, and the place of death (hospital, hospice, nursing home, home). The use of advance care planning improves end-of-life care (O'Halloran et al., 2020). However, refining advance care planning for older people with dementia requires additional knowledge and skills on the part of its implementers.

For this reason, lack of formal knowledge or educational preparation for advance care planning represents an extremely important barrier (Fulmer et al., 2018). Among health professionals, understanding of dementia as a palliative condition and cause of death remains limited, as does awareness of advance care planning (Tilburgs et al., 2018). Compared to palliative care for older cancer patients, the provision of services (including advance care planning) for older adults with dementia in social care institutions worldwide is notably inadequate (Walsh et al., 2021).

Advance care planning presents a significant challenge for palliative care, particularly for older adults with dementia who are anticipated to experience significant cognitive decline and difficulty or inability to express their will and decisions regarding end-of-life care. One of the greatest challenges in advance care planning is the difficulty to accurately predict disease progression and end-of-life care needs. Moreover, communication barriers that may arise between older adults with dementia and their caregivers or healthcare providers add to the complexity of the situation.

### *Aims and objectives*

The objective of this literature review was to analyse empirical evidence on the barriers, facilitators, and effectiveness of advance care planning in palliative care for older adults with dementia, focusing on nursing home residents.

Research questions:

- What is the impact of advance care planning on end-of-life outcomes for older adults with dementia?
- What are the barriers and facilitators of advance care planning for older adults with dementia, their families and caregivers?

## Methods

### *Review methods*

We adopted a literature review approach to elucidate the effectiveness of advance care planning in palliative

**Table 1:** Search terms**Tabela 1:** Iskalni nizi

Database/Baza podatkov	Search terms/Ključne besede
Scopus	"advance care plan*" OR "advance directive" OR "advance decision*" OR "living will" OR "end of life decision*" OR "end-of-life decision*") AND (dementia OR "cognitive impairment" OR Alzheimer* AND "palliative care*" AND dignity AND "nursing home*"
PubMed	("palliative care"[MeSH Terms] OR (palliative[All Fields] AND care[All Fields]) OR "palliative care"[All Fields]) AND (("advance care planning"[MeSH Terms] OR (advance[All Fields] AND care[All Fields] AND planning[All Fields]) OR "advance care planning"[All Fields]) AND (dementia[MeSH Terms] OR dementia[All Fields] OR dementias[All Fields] OR "dementia s"[All Fields]) AND ("nursing homes"[MeSH Terms] OR (nursing[All Fields] AND homes[All Fields]) OR "nursing homes"[All Fields] OR (nursing[All Fields] AND home[All Fields]) OR "nursing home"[All Fields]))
ScienceDirect	("advance care plan" OR "advance directive") AND (dementia OR "cognitive impairment") AND "palliative care" AND "nursing home" AND dignity

and hospice care for older adults with dementia, focusing specifically on nursing home residents. Our method of analysis involved a detailed examination of sources, and our method of compilation entailed a synthesis and summary of findings from a broader body of literature. The literature review followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines as specified by Page et al. (2021).

In order to identify papers that would be beneficial for answering our research question, we developed a careful search strategy using both direct and indirect synonyms for our target terms. The search terms included "advance care planning," "dementia," "palliative care," and "nursing home." The Boolean operators "AND" and "OR" were used to construct the search string so as to ensure precise and inclusive retrieval of relevant studies. The search strings or keywords used are listed in Table 1.

The search was conducted in international databases, namely PubMed, Scopus and ScienceDirect (Elsevier). In addition, certain search limitations were implemented, specifically targeting research papers published in English up to 2023.

The inclusion criteria for this literature review were as follows: 1) Studies involving older adults over 65 years of age conducted within nursing home settings. 2) Studies specifically addressing advance care planning in the context of older adults living with dementia (encompassing different types of dementia, such as Alzheimer's disease, dementia with Lewy bodies, vascular dementia, and frontotemporal dementia, etc.). 3) Studies exploring interventions or strategies aimed at improving the understanding of the barriers and facilitators of advance care planning.

The exclusion criteria were: 1) Studies involving individuals under 65 years of age and conducted in settings other than nursing homes. 2) Studies not specifically addressing advance care planning in the context of palliative and hospice care for older adults with dementia. 3) Studies focusing exclusively on non-dementia-related conditions. 4) Studies not addressing advance care planning interventions or strategies, or barriers or facilitators of advance care planning.

## Results of the review

Our literature search included a review of the PubMed (117), Scopus (133) and ScienceDirect (87) databases. After the search, all relevant articles were imported into the Zotero application, and all duplicates were removed. The results of our search are shown in the PRISMA diagram (Page et al., 2021) in Figure 1.

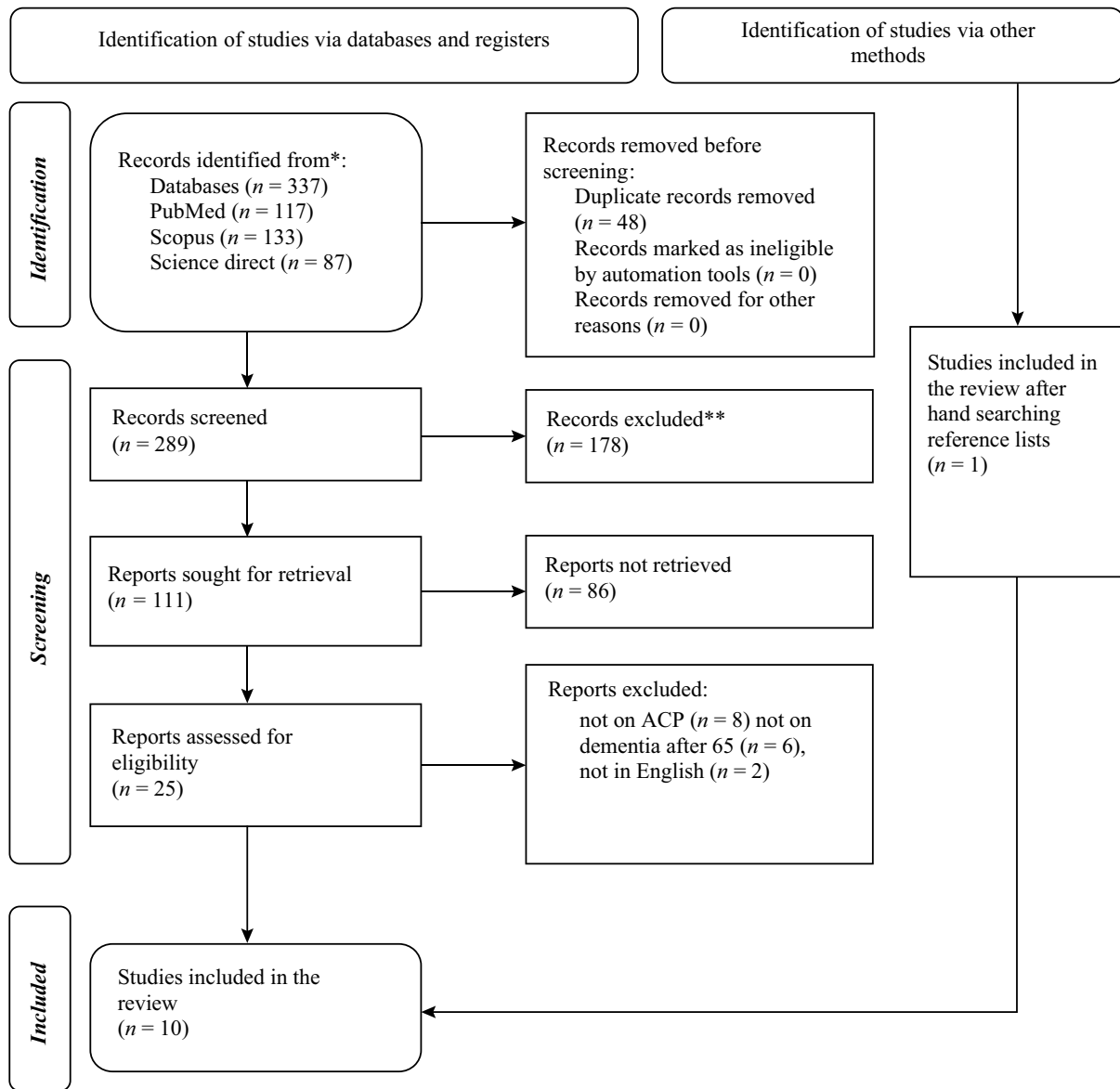
## Quality assessment of the review and description of data processing

Each published study was reviewed by the author for methodological quality. The Mixed Methods Appraisal Tool (MMAT) was used to evaluate the quality of the studies. The MMAT comprises methodological quality criteria for the evaluation of quantitative, qualitative and mixed methods studies. These criteria are scored on a nominal scale (Yes, No, Can't tell) and allow the assessment of five main types of studies, namely qualitative studies, randomised controlled trials, non-randomised quantitative studies, quantitative descriptive studies, and mixed-method research (Hong et al., 2018). The MMAT classification generates five levels of methodological quality, as proposed by Hong et al. (2018). The criteria for methodological quality of the different types of studies are listed in Table 2.

In the first phase, the author performed data extraction from the selected papers, following a predetermined set of data extraction criteria. These criteria included essential elements such as author's name, year of publication, country, research design, research aims and objectives, sample characteristics, and main findings. During the data collection and synthesis phase, the author followed the guidelines for narrative synthesis proposed by Popay et al. (2006).

## Results

A total of 10 studies that met the inclusion and exclusion criteria were selected for review Mitchell et al., 2003; Gozalo et al., 2011; Livingston et al., 2013; Nicholas et al., 2014; Vandervoort et al., 2014; Garden



**Figure 1:** PRISMA flow chart diagram (Page et al., 2021)  
**Slika 1:** PRISMA diagram poteka (Page et al., 2021)

et al., 2016; Brazil et al., 2018; Cohen et al., 2019; Lall et al., 2021; Handley et al., 2022). The majority of these studies were conducted in the United States of America (USA) (4), followed by the United Kingdom (UK) (2), Belgium (1), Asia (1), UK & Australia (1) and Ireland (1).

The selected studies focused on the following:

- the effectiveness of advance care planning (healthcare utilisation, quality of life, economic outcomes, and satisfaction with nursing and care), and
- the facilitators and barriers to advance care planning (time constraints, knowledge gaps).

The characteristics of the studies included in the review are presented in Table 2. The studies examined a range of advance care planning interventions, including

written advance planning, different types of end-of-life discussions, and different staff training interventions. Six studies examined advance care planning implemented with an older adult with dementia prior to the loss of agency or decision-making capacity (Livingston et al., 2013; Nicholas et al., 2014; Vandervoort et al., 2014; Brazil et al., 2018; Cohen et al., 2019; Lall et al., 2021). Three studies focused on advance care planning in the context of best interest (Gozalo et al., 2011; Garden et al., 2016; Handley et al., 2022). The studies showed consistency between the chosen methodology and the research question, the methods used and the interpretation of the results.

All studies evaluate the effectiveness of advance care planning. Five studies additionally define the

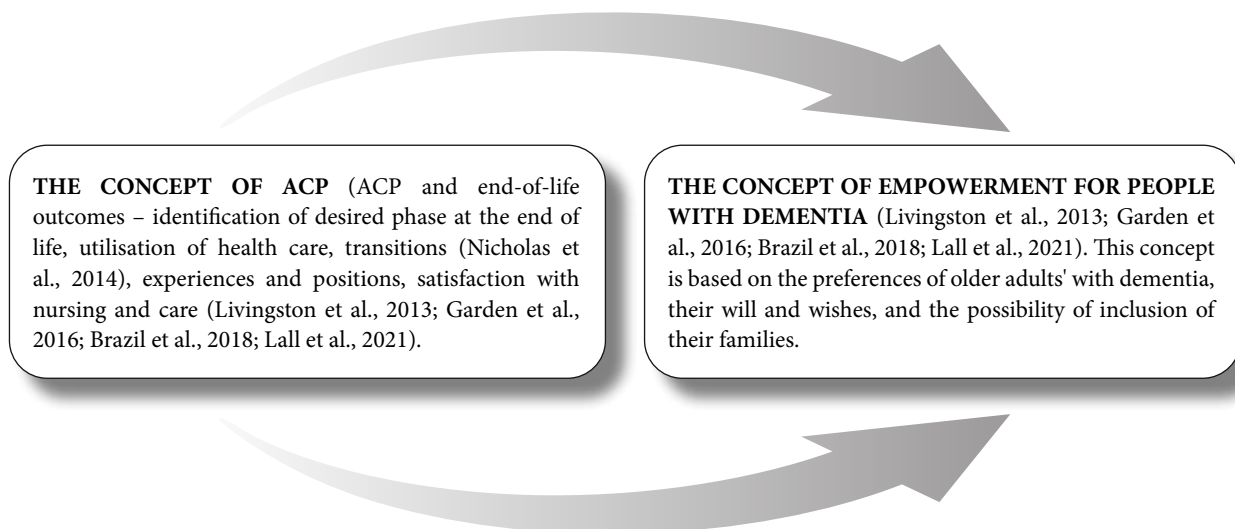
**Table 2: Characteristics of the studies included in the review**  
**Tabela 2: Karakteristike vključenih raziskav v pregled literature**

<i>Author, year, and country/Avtor, leto in država</i>	<i>Research design/ Vrsta raziskave</i>	<i>Aims and objectives of research/ Namen in cilji raziskave</i>	<i>Characteristics of the sample/Značilnosti vzorca</i>	<i>Key findings/ Glavni rezultati</i>	<i>MMAT evaluation score/ ocena kakovosti</i>
Brazil et al., 2018 Ireland	Randomised control study	To assess the effectiveness of advance care planning and define the empowerment of family carers.	$n = 197$ family carers $I - n = 80, C - n = 117$	advance care planning ↑ effectiveness, ↓ uncertainty in decision-making, ↑ quality of care in the home, training of informal carers, ↑ communication between family carers and formal care providers' ↑ level of information, ↑ level of support, ↑ preparedness, ↑ Effectiveness of decision-making.	4*
Cohen et al., 2019 United States of America	Randomised control study	To study consistency between advance care planning and priority care preferences with the professional care of people with end-stage dementia.	People with dementia aged $\geq 65$ years (average age 86.6 years, 19.5% men)  90 days stay in NH, FAST 7C	Consistency advance care planning – level of preferences – ↑ DNR, ↓ use of antibiotics, ↑ Comfort care In the case of advanced dementia, better consistency is needed between care preferences and comfort-focused care and advance care planning.	5*
Garden et al., 2016 United Kingdom of Great Britain and Northern Ireland	Intervention study	To demonstrate the advantages of advance care planning in connection with hospital admissions, place of death and satisfaction with care.	$n = 283$ older people with dementia 250 staff	advance care planning ↓ hospital admissions, ↑ place of death consistent with wishes ↑ satisfaction with care	3*
Gozalo et al., 2011 United States of America	Longitudinal study	To study transitions within the HC system in the last three months of life and factors affecting the rate of burdensome transitions (NG tube, hospitalisation in ICU, pressure sores).	$n = 474,829$ people with dementia. Age at time of death 85.7 years (SD = 7.6); 78.0% women.	Healthcare providers, relatives → care goals → risk assessment → benefit of transition – burdensome transitions Burdensome transitions → last three days of life and multiple, frequent hospital admissions (last three months) Poor from the financial point of view, poor for the person living with dementia, ↓ QOL.	3*
Handley et al., 2022 United Kingdom of Great Britain and Northern Ireland, Australia	Qualitative study – focus group study	To research the views and experiences of nursing staff and palliative care specialists and understand how elements of the organisational structure have influenced the provision of palliative care in the United Kingdom and Australia.	$n = 49$ providers – 28 basic care, 21 palliative care specialists, eight focus groups	Building an organisational culture → high-quality palliative care with advance care planning → Cooperation ↑ the organisation of care and routine methods of work ↑ continuity of care ↑ personalised holistic end-of-life care ↑ documentation ↑ priority aspects of end-of-life care – life story ↑ staff expectations when providing end-of-life care, support for processing grief and bereavement	5*

*Continues/Se nadaljuje*

Author, year, and country/Avtor, leto in država	Research design/ Vrsta raziskave	Aims and objectives of research/ Namen in cilji raziskave	Characteristics of the sample/Značilnosti vzorca	Key findings/ Glavni rezultati	MMAT evaluation score/ ocena kakovosti
Lall et al., 2021 Asia	Qualitative component of mixed methods, qualitative study	To qualitatively study the experiences of patients and caregivers with the advance care planning programme.	n = 28 participants 13 healthcare workers involved in patient decision-making (PDM), other people with dementia aged ≥ 65	A conceptual framework for advance care planning taking into account preferences – ↑ relatives' feelings Choice of PDM, ↑ Impact of advance care planning on bereavement outcomes in relatives, ↑ quality of life of relatives after the death of a loved one. Patient autonomy can be incompatible with the concept of autonomy in Asian cultures, where families make decisions together.	4*
Livingston et al., 2013 United Kingdom of Great Britain and Northern Ireland	Intervention study	To improve the end-of-life care for individuals with dementia, taking into account their specific wishes	n = 56 individuals with dementia before intervention and 42 after the intervention, eight relatives	↑ Documentation of desire for advance care planning, resuscitation, dying at home rather than at the hospital, ↑ the satisfaction of relatives, ↑ Consistency of end-of-life care with patient's wishes, and decisions. ↓ Hospitalisations in the last three months of life, ↑ the self-confidence of staff.	4*
Mitchell et al., 2003 United States of America	Correlation study	To examine the effectiveness of advance care planning from the point of view of the refusal of medical intervention.	n = 186,835 residents with advanced dementia aged 65 or over, with NG tube in place for one year or more	↓ QOL. Feeding via NG tube ↓ positive effects on a person with dementia. People without advance care planning, with NG tube ↑ pressure sores, ↑ aspiration pneumonia	3*
Nicholas et al., 2014 United States of America	Retrospective cohort study	To study the differences in the use of advance care planning related to treatment, expenditure on medicines, and use of intensive treatments.	n = 3,302 deceased dementia sufferers aged over 65	advance care planning – limitations of end-of-life care; ↓ consumption of medicines, ↓ the likelihood of death in the hospital, ↑ use of care in regions characterised by higher levels of end-of-life expenditure, ↓ intensive treatments	4*
Vandervoort et al., 2014 Belgium	Correlation study Retrospective cohort study	To study the extent to which advance care planning in the form of a written communication plan by the person with dementia and their relatives is linked to the quality of dying in a nursing home.	n = 101 people living with dementia advance care planning (17%) A stratified random sample of nursing homes 63% (85+), 15% (85).	advance care planning ↑ quality of life and dying ↓ stress levels, advance care planning ↓ fear and anxiety – but not physical distress. Conversations in the context of advance care planning – exclusion of time limit, effectiveness, early starts; advance care planning – relatives – equal partners.	4*

*Legend/ Legenda: Advance care planning – advance care planning/vnaprejšnje načrtovanje oskrbe; ICU – intensive care unit/enota za intenzivno nego; DNR – do not resuscitate/ne oživljaj; NH – nursing home/dom starejših; NG tube – a nasogastric tube/nazogastrična sonda; I – intervention group/intervencijska skupina; C – control group/kontrolna skupina; PDM – patient decision-making/odločanje pacienta; EAST 7C – functional assessment staging test for people living with dementia/ocena funkcijskega stanja oseb z demenco; DNI – do not intubate/ne intubiraj; QOL – the quality of life/kakovost življenja; HC – health care/zdravstvena oskrba; ↑ increase/povečanje; ↓ decrease/zmanjšanje; → leads to/vodi v; n – number/število; MMAT – quality score/ocena kakovosti; 1\* – 20% quality criteria met/20 % kriterijev kakovosti; 2\* – 40% quality criteria met/40 % kriterijev kakovosti; 3\* – 60% quality criteria met/60 % kriterijev kakovosti; 4\* – 80% quality criteria met/80 % kriterijev kakovosti; 5\* – 100% quality criteria met/100 % kriterijev kakovosti*



**Figure 2:** *Identified concepts*

**Slika 2:** *Identificirana koncepta*

outcomes related to health care utilisation, including determination of place of death, level of care, and details of treatment procedures (Gozalo et al., 2011; Livingston et al., 2013; Nicholas et al., 2014; Garden et al., 2016; Cohen et al., 2019). Four studies link their key findings to the quality of life (Livingston et al., 2013; Vandervoort et al., 2014; Brazil et al., 2018; Lall et al., 2021), while satisfaction with nursing and care related to advance care planning is defined by by Livingston et al., (2013), Garden et al., (2016), Brazil et al., (2018) and Lall et al., (2021). Barriers and facilitators of advance care planning are defined by Livingston et al., (2013), Garden et al., (2016), Brazil et al., (2018) and Lall et al., (2021). None of the studies address the costs associated with implementing advance care planning within the institution, whether financial, material, or in terms of human resources.

The key topics identified through the literature review can be synthesised into two common interpretation sets and condensed into two primary concepts: 1) advance care planning, and 2) empowerment for people with dementia (Figure 2).

Advance care planning can improve end-of-life outcomes by reducing hospitalisations and increasing the likelihood of dying in the preferred place. Satisfaction with nursing care is an important outcome to consider when developing advance care planning for older adults with dementia. Effective advance care planning for older adults with dementia should involve open communication and collaboration between healthcare providers and family members.

The concept of empowerment for people with dementia (Livingston et al., 2013; Garden et al., 2016; Brazil et al., 2018; Lall et al., 2021) is based on the preferences of older adults with dementia, their will and wishes, and the possibility of involving their families. This concept relies on a person-centred

approach, which means that care should be tailored to individual preferences, needs and values. Empowering older adults with dementia through advance care planning can help ensure that they receive care that is in line with their values and preferences, and that they can maintain a sense of control and agency over their lives even as their condition progresses.

## Discussion

This study sought to review the empirical evidence related to the effectiveness of advance planning in the palliative care of older adults with dementia, focusing on those living in social care institutions. We found that advance care planning, which defines the boundaries for end-of-life care, is associated with significantly lower rates of medication use, lower likelihood of in-hospital death and increased utilisation of care in regions characterised by higher funding for end-of-life care (Gozalo et al., 2011; Nicholas et al., 2014). Consequently, this can lead to a significantly higher quality of life. The patterns of hospital transitions incompatible with the goals of advance care planning place an extremely high burden on the entire health system. At the same time, they have been shown to degrade the quality of life when they occur in the last 90 days of life (Gozalo et al., 2011).

Research shows that the level of advance care planning providers' training impacts both family satisfaction and staff confidence, resulting in improved quality of care for older adults with dementia (Livingston et al., 2013). Adequately responding to the wishes, needs and capabilities of the terminally ill older adults is extremely important. Health and social care for older adults with advanced dementia should be based on managing symptoms, offering psychosocial support and addressing their spiritual needs (Rietjens et al., 2016). The preferences of older people with dementia regarding specific

advance care planning structures should be prioritised. Aggressive treatments aimed primarily at prolonging life often outweigh care that focuses on treating distressing symptoms, alleviating suffering and improving quality of life (Rietjens et al., 2016).

Significant barriers to advance care planning identified in our study include uncertainty regarding advance care planning timing, planning for an uncertain future, lack of knowledge about dementia, difficulty in assessing the urgency of decision making, and changing preferences (Livingston et al., 2013; Vandervoort et al., 2014). Facilitators for advance care planning included starting early when cognitive decline is still mild, involving all interested parties, and addressing social and health issues aimed at maintaining a normal life (Vandervoort et al., 2014).

While implementing advance care planning for older adults with dementia can be extremely demanding, it is important to note that it requires well-equipped staff, a point also emphasised by the studies reviewed. This approach allows older adults with dementia to express their wishes about where they would like to be treated, what the goals of their treatment should be and what procedures they would like to avoid.

This literature review has certain limitations that must be taken into account when interpreting its findings. These include the involvement of a single author at all stages of the review, limited scope of literature, limited diversity of sources, limited perspective, limited experience, potential bias, heterogeneity, language limitations (only English-language publications), and limited transparency. Our literature review offers only a partial view of this very important topic.

Nevertheless, this review shows that the use of advance care planning is extremely important for older adults with dementia, as well as for their families and those who provide formal and informal care in social care institutions. Older adults with dementia develop different care needs at different stages of disease progression towards the end of life, requiring integrated services with effective components of a person-centred approach to palliative care (Chen et al., 2022).

Our review helps to identify and bridge the gaps in empirical and practical experience. It highlights the critical importance of timely initiation of advance care planning and the collaboration between stakeholders. It also outlines the key aspects of advance care planning discussions and the preconditions for advance care planning. The review concludes by identifying two key concepts, the concept of advance care planning and the concept of empowering people with dementia.

## Conclusion

Our literature review establishes a clear link between the preferences expressed by older adults with dementia regarding end-of-life care, their living will, and desire

to die with less emotional distress. Regardless of the specific mechanisms, it is crucial to initiate advance care planning sufficiently early enough. The evidence supporting the advantages of advance care planning highlights the need for further work in this area to ensure that advance care planning practices are appropriately developed and recognised as a strategic demographic initiative. In the context of clinical practice and the formulation of national strategies, emphasis should be placed on the impact of advance care planning, multidisciplinary approaches, the integration of health and social care, and the essential coordination of primary, secondary and tertiary levels of health care, including ensuring the provision of integrated and systemically regulated palliative care.

Many studies focus on specific populations or settings, which may limit the generalisability of findings to a broader context. There is an urgent need for research that includes diverse populations of older adults with dementia, including people from different cultural and socioeconomic backgrounds and care settings.

## Conflict of interest/Nasprotje interesov

The author declares that no conflict of interest exists./Avtorica izjavlja, da ni nasprotja interesov.

## Funding/Financiranje

The study received no funding./Raziskava ni bila finančno podprta.

## Ethical approval/Etika raziskovanja

No approval by the Ethics Committee was necessary to conduct the study due to the selected research methodology./Za izvedbo raziskave glede na izbrano metodologijo raziskovanja soglasje Komisije za etiko ni bilo potrebno.

## Author contributions/Prispevek avtorjev

The author carried out all the phases of the research process, performed the search, reviewed the literature, assessed the quality of the selected sources and wrote the article./Avtorica je izvedla vse faze raziskovalnega procesa, opravila iskanje, pregledala literaturo, ocenila kakovost izbranih virov in spisala članek.

## Literature

Brazil, K., Carter, G., Cardwell, C., Clarke, M., Hudson, P., Froggatt, K., McLaughlin, D., Passmore, P., & Kernohan, W. G. (2018). Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomised controlled trial. *Palliative Medicine*, 32(3), 603–612. <https://doi.org/10.1177/0269216317722413> PMID:28786323



- Brinkman-Stoppelenburg A., Rietjens J. A., & van der Heide A. (2014). The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*, 28(8), 1000–1025.  
<https://doi.org/10.1177/0269216314526272>  
PMid:24651708
- Brown, B. A. (2003). The history of advance directives: A literature review. *Journal of Gerontological Nursing*, 29(9), 4–14.  
<https://doi.org/10.3928/0098-9134-20030901-04>  
PMid:14528744
- Chen, P. J., Smits, L., Miranda, R., Liao, J.-Y., Petersen, I., Van den Block, L., & Sampson, E. L. (2022). Impact of home healthcare on end-of-life outcomes for people with dementia: A systematic review. *BMC Geriatrics*, 22(1), Article 80.  
<https://doi.org/10.1186/s12877-022-02768-3>  
PMid:35081914; PMCid:PMC8793202
- Cohen, S. M., Volandes, A. E., Shaffer, M. L., Hanson, L. C., Habtemariam, D., & Mitchell, S. L. (2019). Concordance between proxy level of care preference and advance directives among nursing home residents with advanced dementia: A Cluster randomised clinical trial. *Journal of Pain and Symptom Management*, 57(1), 37–46.  
<https://doi.org/10.1016/j.jpainsymman.2018.09.018>  
PMid:30273717; PMCid:PMC6310643
- Dixon, J., Karagiannidou, M., & Knapp, M. (2018). The Effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: A systematic review and critical discussion. *Journal of Pain and Symptom Management*, 55(1), 132–150.  
<https://doi.org/10.1016/j.jpainsymman.2017.04.009>  
PMid:28827062
- Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2017). How many people will need palliative care in 2040: Past trends, future projections and implications for services. *BMC Medicine*, 15(1), Article 102.  
<https://doi.org/10.1186/s12916-017-0860-2>
- Fang, E. F., Xie, C., Schenkel, J. A., Wu, C., Long, Q., Cui, H., Wang, N. Y., Wu, J., Liu, W., Li, T., Fang, Y., Niu, Z., Yang, G., Hong, J., Wang, Q., Chen, G., Li, J., Chen H.-Z., Kang, L., Su, H., ... Woo, J. (2020). A research agenda for ageing in China in the 21st century (2nd Ed.): Focusing on basic and translational research, long-term care, policy and social networks. *Ageing Research Reviews*, 64, Article 101174.  
<https://doi.org/10.1016/j.arr.2020.101174>  
PMid: 32971255; PMCid:PMC7505078
- Fulmer, T., Escobedo, M., Berman, A., Koren, M. J., Hernández, S., & Hult, A. (2018). Physicians' views on advance care planning and end-of-life care conversations. *Journal of the American Geriatrics Society*, 66(6), 1201–1205.  
<https://doi.org/10.1111/jgs.15374>  
PMid:29797314
- Garden, G., Green, S., Pieniak, S., & Gladman, J. (2016). The Bromhead Care Home Service: The impact of a service for care home residents with dementia on hospital admission and dying in preferred place of care. *Clinical Medicine*, 16(2), 114–118.  
<https://doi.org/10.7861/clinmedicine.16-2-114>  
PMid:27037378; PMCid:PMC4952962
- Gozalo, P., Teno, J. M., Mitchell, S. L., Skinner, J., Bynum, J., Tyler, D., & Mor, V. (2011). End-of-life transitions among nursing home residents with cognitive issues. *New England Journal of Medicine*, 365(13), 1212–1221.  
<https://doi.org/10.1056/NEJMsa1100347>  
PMid:21991894; PMCid:PMC3236369
- Grant, M. J., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, 26, 91–108.  
<https://doi.org/10.1111/j.1471-1842.2009.00848.x>  
PMid:19490148
- Haugan, G. (2022). Spiritual and existential care in nursing homes. *Obzornik zdravstvene nege*, 56(4), 172–177.  
<https://doi.org/10.14528/snr.2022.56.4.3196>
- Handley, M., Parker, D., Bunn, F., & Goodman, C. (2022). A qualitative comparison of care home staff and palliative care specialists' experiences of providing end of life care to people living and dying with dementia in care homes in two countries: A focus group study. *Palliative Medicine*, 36(1), 114–123.  
<https://doi.org/10.1177/02692163211043374>  
PMid:34479468; PMCid:PMC8793290
- Hong, Q. N., Fribregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F., Nicolau, B., O' Cathain, A., Rousseau, M.-C., Vedel, I., & Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, 34(4), 285–291.  
<https://doi.org/10.3233/EFI-180221>
- Kodeks etike v zdravstveni negi in oskrbi Slovenije in Kodeks etike za babice Slovenije.* (2014) Ljubljana: Zbornica zdravstvene in babiške nege Slovenije- Zveza strokovnih društev medicinskih sester, babic in zdravstvenih tehnikov Slovenije.
- Konno, R., Inoue, K., Schultz, T., & Wiechula, R. (2020). Best evidence for advance care planning in older adults with dementia and their families: An umbrella review protocol. *JBI Evidence Synthesis*, 18(4), 841–848.  
<https://doi.org/10.11124/JBISRIR-D-19-00127>  
PMid:32813345
- Lall, P., Dutta, O., Tan, W. S., Patinadan, P. V., Kang, N. Q. Y., Low, C. K., Car, J., & Ho, A. H. Y. (2021). "I decide myself": A qualitative exploration of end of life decision making processes of patients and caregivers through Advance Care Planning. *PLoS One*, 16(6), Article e0252598.  
<https://doi.org/10.1371/journal.pone.0252598>  
PMid:34143798; PMCid:PMC8213132

- Livingston, G., Lewis-Holmes, E., Pitfield, C., Manela, M., Chan, D., Constant, E., Jacobs, H., Wills, G., Carson, N., & Morris, J. (2013). Improving the end-of-life for people with dementia living in a care home: An intervention study. *International Psychogeriatrics*, 25(11), 1849–1858.  
<https://doi.org/10.1017/S1041610213001221>  
PMid:23924580
- Mitchell, S. L., Kiely, D. K., & Gillick, M. R. (2003). Nursing home characteristics associated with tube feeding in advanced cognitive impairment. *Journal of the American Geriatrics Society*, 51(1), 75–79.  
<https://doi.org/10.1034/j.1601-5215.2002.51013.x>
- Nicholas, L. H., Bynum, J. P. W., Iwashyna, T. J., Weir, D. R., & Langa, K. M. (2014). Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Affairs*, 33(4), 667–674.  
<https://doi.org/10.1377/hlthaff.2013.1258>  
PMid:24711329; PMCID:PMC4159465
- O'Halloran, P., Noble, H., Norwood, K., Maxwell, P., Murtagh, F., Shields, J., Mullan, R., Matthews, M., Cardwell, C., Clarke, M., Morton, R., Shah, K., Forbers, T., & Brazil, K. (2020). Nurse-led advance care planning with older people who have end-stage kidney disease: Feasibility of a deferred entry randomised controlled trial incorporating an economic evaluation and mixed methods process evaluation (ACReDiT). *BMC Nephrology*, 21(1), 478.  
<https://doi.org/10.1186/s12882-020-02129-5>  
PMid:33187506; PMCID:PMC7663906
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., McGuinness, L., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, 372, Article n71.  
<https://doi.org/10.1136/bmj.n71>  
PMid:33782057; PMCID:PMC8005924
- Popay, J., Roberts, H., & Sowden, A., (2006). Guidance on the conduct of narrative synthesis in systematic reviews: A product from the ESRC Methods Programme. Economic and Social Research Council. <https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/fhm/dhr/chir/NSsynthesisguidanceVersion1-April2006.pdf>
- Rietjens, J., Korfage, I., & van der Heide, A. (2016). Advance care planning: Not a panacea. *Palliative Medicine*, 30(5), 421–422.  
<https://doi.org/10.1177/0269216316642963>  
PMid:27095742
- Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden J. J., Drickamer M. A., Droger M., van der Heide, A., Heyland, D. K., Houttekier, D., Janssen, D. J. A., Orsi, L., Payne, S., Seymour, J., Jox, R. J., Korfage, I. J., on behalf European Association for Palliative Care (2017). Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncology*, 18(9), e543–e551.  
[https://doi.org/10.1016/S1470-2045\(17\)30582-X](https://doi.org/10.1016/S1470-2045(17)30582-X)  
PMid:28884703
- Singer, P. A., Martin, D. K., Lavery, J. V., Thiel, E. C., Kelner, M., & Mendelsohn, D. C. (1998). Reconceptualising advance care planning from the patient's perspective. *Archives of Internal Medicine*, 158(8), 879–884.  
<https://doi.org/10.1001/archinte.158.8.879>  
PMid:9570174
- Tilburgs, B., Vernooij-Dassen, M., Koopmans, R., van Gennip, H., Engels, Y., & Perry, M. (2018). Barriers and facilitators for GPs in dementia advance care planning: A systematic integrative review. *PLoS One*, 13(6), Article e0198535.  
<https://doi.org/10.1371/journal.pone.0198535>  
PMid:29924837 PMCID:PMC6010277
- Van den Block, L., Honinx, E., Pivodic, L., Miranda, R., Onwuteaka-Philipsen, B. D., van Hout, H., Pasma, R. W., Oosterveld-Vlug, M., Ten Koppel, M., Piers, R., Van Den Noortgate, N., Engels, Y., Vernooij-Dassen, M., Hockley, J., Froggatt, K., Payne, S., Szczerbińska, K., Kylanen, M., Gambassi, G., Pauntex, S., ... for the PACE trial group. (2020). Evaluation of a palliative care program for nursing homes in 7 countries: The PACE Cluster-randomized clinical trial. *JAMA Internal Medicine*, 180(2), 233–242.  
<https://doi.org/10.1001/jamainternmed.2019.5349>  
PMid:31710345; PMCID:PMC686577
- Vandervoort, A., Houttekier, D., Vander Stichele, R., van der Steen, J. T., & Van den Block, L. (2014). Quality advanced care planning matter: A nationwide postmortem study. *PLoS One*, 9(3), e91130.  
<https://doi.org/10.1371/journal.pone.0091130>  
PMid:24614884 PMCID:PMC3948949
- Walsh, S. C., Murphy, E., Devane, D., Sampson, E. L., Connolly, S., Carney, P., & O'Shea, E. (2021). Palliative care interventions in advanced dementia. *Cochrane Database of Systematic Reviews*, 9(9), Article CD011513.  
<https://doi.org/10.1002/14651858.CD011513.pub3>  
PMid:34582034; PMCID:PMC8478014
- World Medical Association. (2013). World Medical Association declaration Of Helsinki: Ethical principles for medical research involving human subjects. *Journal of the American Medical Association*, 310(20), 2191–2194.  
<https://doi.org/10.1001/jama.2013.281053>  
PMid:24141714
- World Health Organization. (2021). *World Alzheimer's Report 2021: Dementia researcher*. <https://www.dementiaresearcher.nihr.ac.uk/world-alzheimers-report-2021/>

Cite as/Citirajte kot:

Koštomaj, S. (2024). Impact of advance care planning for older adults with dementia in nursing homes: A literature review. *Obzornik zdravstvene nege*, 58(1), 18–27. <https://doi.org/10.14528/snr.2024.58.1.3247>