# *Advanced Care Directives in Residential Aged Care for Residents with Major Neuro-Cognitive Disorders (Dementia): A Scoping Review*

Hormazábal-Salgado, Raúl, Osman, Abdi D, Poblete-Troncoso, Margarita, Whitehead, Dean and Hills, Danny (2024) Advanced Care Directives in Residential Aged Care for Residents with Major Neuro-Cognitive Disorders (Dementia): A Scoping Review. Journal of Social Work in End-of-Life and Palliative Care, 20 (1). pp. 83-114. ISSN 1552-4256

# Advanced care directives in residential aged care for residents with major neuro-cognitive disorders (dementia): A scoping review

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Running head: Advance care directives in residential dementia care.

# Advanced care directives in residential aged care for residents with major neuro-cognitive disorders (dementia): A scoping review

## Abstract

The aim of this review was to identify, assess, collate, and analyze existing research that has made a direct contribution to aiding understanding of the ethical and decision-making issues related to the use of advance care directives for people with dementia and/or other major neurocognitive disorders and/or their surrogate decision-makers on treatment.

The Web of Science, Scopus, PubMed, CINAHL, Academic Search Ultimate and MEDLINE databases were searched between August and September 2021 and July to November 2022 limited to primary studies written in English, Spanish or Portuguese.

Twenty-eight studies of varying quality that addressed related thematic areas were identified. These themes being support for autonomy in basic needs (16%), making decisions ahead/planning ahead and upholding these decisions (52%), and support in decision-making for carers (32%).

Advance care directives are an important mechanism for documenting treatment preferences in patient care planning. However, the available literature in the topic is limited in both quantity and quality. Recommendations for practice include involving decision makers, promoting educational interventions, exploring how they are used and implemented and promoting the active involvement of social workers within the healthcare team.

Key words: advance care planning, advance directives, decision-making, dementia, personal autonomy

## Introduction

Major neurocognitive disorders, also known as dementia, are defined in the Diagnostic and Statistical Manual of Mental Disorders version 5 (DSM-5) as acquired brain syndromes characterized by a decline from a previous level of cognitive functioning with impairment (American Psychiatric Association, 2013; WHO, 2021b). Affecting 50 million people, major neurocognitive disorders are one of the leading causes of disability and dependence among older people, with a physical, psychological, social, and economic impact on caregivers, family, and society at large (WHO, 2021a). The most common major neurocognitive disorders are Alzheimer's disease, vascular dementia, dementia with Lewy body and frontotemporal lobar degeneration, with a potential overlap in all these dementias (McDonald, 2017).

Due to the high prevalence of dementia and other major neurocognitive disorders across the globe and the high proportion of sufferers requiring residential care, it is important that healthcare-related needs and rights are considered and addressed. A direct means to safeguard people's rights is advance care planning. Experts describe advance care planning as a multi-stage process which involves supporting adults at any age or health status in sharing and understanding personal preferences, goals, and values of future care (Sudore et al., 2017). A component of advance care planning are advance care directives, which are documents that specify the kinds of medical procedures a patient would like to receive and/or who is allowed to make decisions on their behalf, frequently in the context of residential and end-of-life care (Gupta et al., 2021). These directives are meant to serve as a guide for healthcare providers and the patient's family in situations where the patient is unable to express their wishes due to serious sickness or mental incapacity (Gupta et al., 2021). In addition to being an aid for surrogate decision-makers, advance care directives refer to the exercise of prospective autonomy once the person is no longer capable of deciding about their medical care (Davis, 2018). While conceptual definitions of advance care directives have been established, these definitions vary across countries and regions (Cheung & Dunn (Eds.)., 2023). The main reason for these conceptual differences are the local policies and legislations of every country, leading to a variety of terms and tools that may complicate to make provision for a future after losing decisional capacity (Cheung & Dunn (Eds.)., 2023). These discrepancies are reflected in the clinical practice and scientific literature, where there are widespread misconceptions about what kind of documentation could be considered advance care directives. To illustrate, the “Physician Orders for Life-Sustaining Treatment” (POLST) forms for Life-Sustaining Treatment like do-not-resuscitate, do-not-intubate, or do-not-hospitalize orders are commonly considered as advance care directives (Yadav et al., 2017).

Although advance care directives are a component of advance care planning, the existence of advance care directives does not ensure that advance care planning occurs, and advance care planning does not always result in advance care directives (Silveira, 2021).

Both advance care planning and advance care directives promote decision-making in individuals with dementia and/or other major neurocognitive disorders and/or their families as surrogate decision makers. Advance care planning promotes shared decision-making while respecting the autonomy of people with dementia, providing opportunities to discuss and understand the care preferences of these people (Bosisio & Barazzetti, 2020). Additionally, the main goal of advance care directives, particularly living wills, is to alleviate the burden often experienced by surrogate decision-makers when making decisions on behalf of their loved one (Hickman, 2014). Weiss and Fain (2017) state that advance care directives should be discussed in the early stages of a major neurocognitive disease, when the individual’s cognitive capacities still allow them to make their own choices (Weiss & Fain, 2017). This leads to better decision-making outcomes through specific written guidance and facilitating the care process in later stages of the disease, once decision-making capacity becomes impaired (Gaster, 2019). Nevertheless, according to Allen et al. (2003), older adults with dementia disorders living in long-term care facilities who retain some decisional capacity can be actively engaged in their own care decisions assisted by healthcare providers. In this context, people with dementia and/or other major neurocognitive disorders and surrogate decision-makers require concerted support with decision-making through advance care planning in order to prepare for end-of-life care. Accordingly, healthcare professionals must be trained to understand and facilitate effective advance care planning (Harrison et al., 2019).

Despite the importance of advance care planning and advance care directives for people with dementia and/or other major neurocognitive disorders and their families as surrogate decision makers, variable and often lower-than-expected uptake of advance care directives have been observed in residential care in the international literature. For example, in Taiwan, it has been estimated that around 39% of residential aged care residents with dementia have some form of advance care directive (Huang et al., 2018), while only 4.9 % of residents with dementia in the Netherlands have an advance care directive (Hendriks et al., 2017). Masukwedza et al. (2019) conducted a study with a sample of two hundred and eight registered nurses working in residential care in Australia to understand how these professionals use advance care directives for individuals with dementia. The authors found that less than 45% of nurses never or rarely assisted individuals with dementia who live in residential care and/or their families to complete advance care directives (Masukwedza et al., 2019).  These notable gaps in advance care planning are transversal to diverse settings around the world, which are substantially different in terms of the culture of their populations and policies. Since the studies do not provide any causes for the low completion rates, these gaps may represent low engagement in health care decisions by individuals with dementia and/or other major neurocognitive disorders and surrogate decision makers, compromising their human rights and negating healthcare-related decision-making. To increase rates of advance care planning, it is necessary to promote the active involvement of other healthcare professionals as well as physicians. Where this occurs, this strategy has proven to be effective (Clark et al., 2017).

Other reviews exist related to advance care planning and related areas such as end-of-life decision-making, end-of-life communication strategies, end-of-life and palliative research, and advance care planning perceptions and effectiveness (Jimenez et al., 2019). While barriers for advance care planning in dementia care have been described in the literature, Jimenez et al. (2018) identified that no reviews focused on the use of advance care directives in long-term care/residential facilities. In addition, a preliminary search of Medline, PROSPERO, the Joanna Briggs Institute of Evidence Synthesis, and the Cochrane Database of Systematic Reviews revealed no reviews on the use of advance care directives in the target population described in this study. Therefore, a further scoping review of peer-reviewed journal articles was conducted identify, assess, collate and analyze research that has made a direct contribution to aiding understanding of the ethical and decision-making issues related to the use of advance care directives for people with dementia and/or other major neurocognitive disorders and/or their surrogate decision-makers on treatment. Through the process of identification, assessment and collation of existing research, this review explores the specific research question, ‘What are the main ethical and decision-making issues related to the utilization of advance care directives on care strategies, treatments, and decision-making in older adults with dementia and/or other major neurocognitive disorders?'

## Methods

The conduct and reporting of this scoping review was guided by the Preferred Reporting Items for Systematic Review - Scoping Review (PRISMA-ScR) checklist (Tricco et al., 2018). Research-based scholarly publications about advance care directives for people with major neuro-cognitive disorders (dementia), aged 60 years or older, living in residential aged care institutions were analyzed.

### *Inclusion and exclusion criteria*

Primary studies published in the peer-reviewed literature were included if they were written in English, Spanish or Portuguese, considered aged care residents, age ≥60 years, residents with advance care directives, and with at least one of the following conditions: major neuro-cognitive disorders, dementia, Alzheimer's disease, vascular dementia, dementia with Lewy body, frontotemporal lobar degeneration. Considering the widespread conceptions about what is an advance care directive across the literature, research where the authors claimed to have focused on advance care directives was included to further explore this conceptual discrepancy. In addition, the retrieved findings may help in understanding the use of this documentation in long-term care for people with dementia.

Because of the multiple variations in the definition of "later life," "elderly" or "older person" across research, studies were considered for this review if these terms were defined considering the age cut-off points used by the United Nations (WHO, 2020). This means that the reported population was exclusively individuals aged 60 years or older.

Studies were excluded based on the following criteria: secondary studies and any other study that is not peer reviewed, aged care residents less than 60 years, residents with cognitive impairment other than Dementia or Alzheimer's, residents with minor neuro-cognitive disorders.

### ***Search strategy***

The search strategy combined Medical Subject Headings (MeSH) terms and free text. Databases searched for relevant and related literature were the Web of Science, Scopus, PubMed, CINAHL Complete, Academic Search Complete, MEDLINE Complete and Google Scholar. The search was undertaken in two rounds, from August to September 2021, and July to November 2022 including only items published during the period of August 2011 to October 2022 limiting it to 11 years and two months in consideration of changing evidence, policies, and international legislation that could influence the conceptualizations of advance care planning and advance care directives used by the authors as well as their findings that may be relevant to a broader audience and therefore worthy of inclusion. The following search strategy was applied: (“advance directives” OR "advance care directives") AND (ethic* OR “ethical aspects”) AND (aging OR ageing OR aged OR elder*) OR (“old people” OR “late* life” OR “old age*” OR young-old OR old-old) AND (dementia OR “major neuro-cognitive disorders” OR Alzheimer* OR “vascular dementia” OR “dementia with Lewy body” OR “frontotemporal lobar degeneration”) AND decision-making. The search terms for Google Scholar were “advance care directives” AND “older adults” AND “dementia” since the search strategy described above did not match any articles. Screening involved the selection of retrieved citations by title, abstract and full text. Study records were managed in EndNoteTM 20 (The EndNote Team, 2013) and Covidence systematic review software (Veritas Health Innovation, 2022), where study selection and data extraction were undertaken. Data analysis was performed within an interpretive paradigm, interpreting others' interpretations by inductively grouping results from studies into themes of similar ideas and data synthesis was conducted using thematic analysis (Braun & Clarke, 2021). The data was refined and presented in a Covidence auto generated screening flow chart.

### ***Study selection and criteria***

The articles were selected in three separate stages: analysis of the titles, analysis of the abstracts, and analysis of full texts. During the first stage, two authors (R.H. and A.O.) undertook title screening in Covidence by selecting the potentially eligible studies according to the key words contained in their title. The next stage was the abstract screening, where the same authors separately read the abstracts of the previously selected articles and tested them against the inclusion criteria. In the third stage, the full text of each potentially eligible article was read independently by R.H. and M.P. with votes moderated by A.O. before a final decision was reached within the research team about its inclusion. Discussions among the study team members regarding any potential inclusion were used to solve disagreements, being these moderated by D.H. After completing this stage, data were extracted and summarized using a data extraction form to provide the foundation for appraising, analysing, summarizing, and interpreting the evidence.

### ***Data extraction***

Data were extracted based on the Joanna Briggs Institutes' PICO tool (Joanna Briggs Institute, 2019) was used as a guide. Demographic information collected from original research studies included the study's country of origin, participants’ gender, sample size, participants’ age range(s) and participants’ age cohort split (if any) used in the analysis.

### ***Quality Assessment***

The quality of studies was assessed by retrieving scientific studies reported in peer-reviewed journals only, which included a relevant sample for the studied phenomenon and relevant research outcomes. The full text of each potentially eligible study was read by two researchers before a final decision was reached about its inclusion in the present review. Disagreements were moderated by D.W. and resolved by discussion within the study team. The selected studies were further assessed for quality using the following quality appraisal tools: The Joanna Briggs Institute (JBI) critical appraisal tools – namely the Checklist for case reports, the Checklist for qualitative research (Joanna Briggs Institute, 2022), the Study Quality Assessment Tools from the National Heart Lung and Blood Institute (2021) for Controlled Intervention Studies, Case-Control studies, and Observational Cohort and Cross-Sectional Studies in addition to the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). Upon assessment, twelve studies were rated ‘good’, based on the study’s methodology, with the remainder rated as ‘fair’ (fourteen) (Table 1). The three studies rated as “poor” quality were excluded from the final analysis.

## **Results**

The initial search yielded 4339 articles of which 215 were left after the removal of duplicates. After title and abstract screening, 3571 records were excluded, resulting in 48 studies, 20 of which were further excluded due to reasons provided in the screening flow chart (Figure 1), leaving 28 studies qualifying for quality assessment. The final size of the sample is 25 studies.

*[please insert figure 1 here]*

The selected studies addressed three themes that emerged from thematic analysis, namely support for autonomy in basic needs (Table 2), making decisions ahead (planning ahead) and upholding these decisions (Table 3), and support in decision-making for carers (Table 4). Considering that there might be an overlap of themes among the retrieved articles, the decision to classify them in one of the themes was based on the main goal of the article or research question since this represents the focus of the study as well as their main findings.

*[please insert table 2, table 3, and table 4 here]*

### ***Support for autonomy in basic needs***

Four of the 25 included studies were focused on support for autonomy for people with advanced dementia. The studies discussing support for autonomy were focused on basic needs, such as withdrawing oral intake of food and fluids by advance directive as well as the main ethical issues that may arise in the process of caring for people with advanced dementia.

The support for autonomy in people with dementia is not devoid of ethical challenges in long-term care, because this could be considered neglect or abuse, especially in the context in which a person is dependent of care (Menzel & Chandler-Cramer, 2014). For these reasons, comfort feeding, and clear advance care directives are recommended (Menzel & Chandler-Cramer, 2014). Volicer and Stets (2016) further highlighted the primacy of the decision-making capacity of people with dementia, in communicating their wishes by requesting oral intake of food and fluids, and thus revoking any advance care directive. The use of feeding tubes is also discussed extensively. According to

Clifton et al. (2020), the quality of life in people with dementia does not improve by using feeding tubes. In this regard, health care professionals must be prepared to counsel people with dementia and their families as surrogate decision-makers in the context of advance care planning. Davies and George (2013) discussed the ethical implications of deceiving people with dementia, especially when they no longer hold decisional capacity, and where this stands with patient autonomy. Caregivers usually deceived or lied to the person with advanced dementia to prevent distress or anxiety, fearing they may be unable to cope with it (Davies & George, 2013).

### ***Making decisions ahead (planning ahead) and upholding these decisions***

Out of the 25 selected studies, 13 studies discussed planning ahead and upholding these decisions. This category refers mainly to surrogate decision-making, and how complex this process can be for all parties involved, e.g., family members and healthcare providers. This category also includes decision-making from people living with advanced dementia living in long-term care facilities.

A recurrent issue found in the literature was decision-making uncertainty and complexity. Uncertainty of family surrogate decision-makers in shared decision-making, on behalf of a person with dementia, especially when the person was the one who developed the advance care directive, is not diminished by the mere existence if this documentation. People who have made decisions on behalf of a person with dementia described the decision-making process as complex and difficult (Fetherstonhaugh et al., 2016). Knowing the previous preferences of the person with dementia does not always clarify decision-making since it is often uncertain whether the person still held those wishes or otherwise (Fetherstonhaugh et al., 2016). According to Ramos et al. (2021), issues in end-of-life care decisions occur even if a patient has an advance care directive. These issues arise after the progression of the disease, advance care planning and surrogate decision-making (Ramos et al., 2021). In addition to this, Street et al. (2015) found that, although people with dementia were more likely to have a documented advance care plan on arrival at the emergency room compared to other groups of older adults, many of the instructions contained in the advance care directives were contradictory and unclear, adding complexity to decision-making. These findings indicate that the advance care planning must contain clear instructions while maintaining continuous discussions between the person with dementia, their caregivers and healthcare professionals (Street et al., 2015). In this context, Brazil et al. (2018) concluded that advance care planning is effective in reducing family-caregiver uncertainty regarding decision-making in the care of people with dementia.

The studies also discussed the importance of communication of advance care planning and advance care directives in end-of-life care. End-of-life care discussions must be facilitated by the knowledge of healthcare professionals about an existing advance care directive (van Soest-Poortvliet et al., 2015). Palan et al. (2017) discussed the importance of engaging family surrogate decision-makers in end-of-life care goals to support the actions of health professionals in nursing homes.

Besides family surrogate decision makers, people with dementia should also be engaged in this process if they can express their opinions and preferences about their care. According to Goodman et al (2013), it is important to include people with dementia in advance care planning since they can express their care preferences, when given the opportunity. This can create communicative spaces where the person with dementia can inform about how care should be provided and by whom, increasing clarity in decision-making (Goodman et al.,2013).  Notwithstanding that, Robinson et al. (2013) found that healthcare providers expressed uncertainty with regard to the value of advance care planning in dementia care, citing a lack of clarity of their roles and when best to introduce advance care planning. These findings represent a significant challenge to the implementation of effective advance care planning in dementia care.

Further studies were focused on the type of advance care directives in end-of-life care. Leong and Crawford (2018) found, in a sample of 109 aged care residents who were admitted to and died in hospital, that 66% of the total sample had some documentation of advance care directives, with no difference in documentation of advance care directives between residents with/without advanced dementia. Additionally, there was more advance care planning, resuscitation orders (for/against) and do-not-hospitalize orders in residents with advanced dementia compared to those without (Leong & Crawford, 2018). Similar findings were reported by Vandervoort et al. (2012), in Belgium, where advance care directives and general practitioner orders were concerned with the same treatments, such as do-not-hospitalize and do-not-resuscitate orders. It is worth mentioning that Vandervoort et al. (2012) considered general practitioner orders as a form of advance care directive.

Research shows low completion rates of advance care planning documentation among residents with dementia. Bavelaar et al. (2022) found that advance care plans for residents with dementia were usually developed after nursing home admission. Advance care planning changed only for around 10% of residents after receiving a pneumonia diagnosis (Bavelaar et al., 2022). Almost 4% of residents had living wills and only 10% expressed that they were influential in the decision-making process (Bavelaar et al., 2022). Correspondingly, the multicenter audit study conducted by Bryant et al (2021) found that 60% of people with dementia across health and aged care settings in Australia had advance care planning documentation, but only half of them had completed an advance care directive by themselves as the main decision makers, with the support of healthcare providers and family (Bryant et al., 2021). Moreover, Tjia et al. (2018) found that the prevalence of advance directives among nursing home residents by dementia severity is only 58%, where 20% or fewer residents had living wills, or documented evidence related to conversations of advance directives from the early onset of their dementia. It is important to note that the authors defined advance directives as the presence of a living will, medication restriction, feeding restriction, do-not-hospitalize order, and do-not-resuscitate order (Tjia et al., 2018). Decision-making, consequently, was not reinforced in advance care planning when older adults still held decisional capacity.

### ***Support in decision-making for carers***

Support in decision-making for caregivers was addressed in eight of the included studies. The studies included in this category show the main areas where further support would be required for those making decisions on behalf of a person with advanced dementia living in a long-term care facility.

Wilkins (2018) discussed the complexity of advance care directives in people with dementia due to the changes in their preferences and that little consideration is usually given to routine decisions e.g., the foods they may want to eat, in advance care planning documentation. Information to clarify the pros and cons of any decision should be provided as long as the older adult is able to articulate their preferences, thus placing them at the center of the decision-making process (Wilkins, 2018). In addition, Fewing et al. (2014) affirmed that people with dementia have the right to change their minds, thus revoking advance care directives. People with dementia who retain decisional capacity have the right to participate in the decision-making process although they might not be fully aware of the implications, so further support from healthcare providers towards decision-makers is required (Fewing et al., 2014).

Some studies discussed the legal validity of advance care directives. According to Droz Mendelzweig (2020), legal standards for advance care directives are not fully assimilated by the public at large, meaning that only a few people have advance care directives before being admitted to nursing homes. The formalization of the completion of advance care planning documentation for end-of-life care from healthcare professionals is thus strongly encouraged (Droz Mendelzweig et al., 2020). Ingravallo et al. (2018) found that the unclear legal status of care directives in Italy, and distrust toward both the appointment of a proxy and living wills, may lead to some people with dementia preferring informal conversations and planning instead of formal advance care directives. Therefore, it is important for both healthcare providers and policymakers to consider these issues when implementing advance care planning interventions to support people in decision-making (Ingravallo et al., 2018)

Interventions as a means of supporting decision-making are discussed by four studies. Reinhardt et al. (2014) implemented an intervention for surrogate decision-makers which consisted of a structured conversation about end-of-life care with six-month follow-up telephone calls. This intervention increased their satisfaction with care as well as documentation about end-of-life care decisions in their relative’s medical record under the form of advance directives such as do-not-resuscitate, do-not-intubate, and do-not-hospitalize orders (Reinhardt et al., 2014). Goossens et al. (2020) determined that multi-level communication training for nursing home staff can improve decision-making by increasing advance care planning conversations. The instructional intervention, “Educational Video to Improve Nursing home Care in End-stage dementia” (EVINCE), has been tested in trials where family surrogate decision-makers participated. Mitchell et al. (2018) found that only tube-feeding was taken into consideration by surrogate decision-makers after watching the instructional video. In contrast, Cohen et al. (2019) found that advance care directives focused on resuscitation (do not resuscitate orders) were more common than those related to treatments, such as withholding tube-feeding and antibiotics, after watching the video support tool.

## Discussion

Via the process of identification, assessment and collation of existing research, this review helps in understanding the implications about the main considerations for the use of advance care directives in older adults with major neuro-cognitive disorders (dementia) residing in long-term care facilities. In this scoping review, the authors found that the utilization of advance care planning in people with dementia mainly comprised advance care directives, which were focused more on end-of-life care related educational interventions for the families of people with dementia and/or other major neurocognitive disorders, surrogate decision-making, and legal and ethical concerns. Advance care directives are a necessary step for documenting the treatment preferences in advance care planning due to the complexity of making decisions on behalf of a person with advanced dementia. However, this process is not devoid of ethical challenges involving the autonomy of the person with dementia in end-of-life care treatment, including food and fluid intake and life-support treatment.

The main issues related to the care of people with dementia were food and fluid intake withdrawal and tube feeding and being dishonest with them. The decision of voluntarily stopping eating and drinking is significant for the person with dementia, but the advance care documentation does not always facilitate decision-making due to the unexpected situations that may arise in care as dementia progresses. The systematic review of Sellars et al. (2019) pointed out the insufficient consideration of specific scenarios in advance care directives that make decision-making more challenging. This includes advocating for the autonomy of the patient with dementia by reinforcing their end-of-life care preferences towards health care providers, which may prevent unwanted interventions such as inserting a feeding tube or central line (Sellars et al., 2019). Therefore, advance care directives should explicitly contain clear information about surrogate decision-making once the person with dementia becomes severely impaired by the disease in order to facilitate decision-making in End-of-Life care respecting food and fluid intake. Being dishonest or deceitful to elderly people with dementia and/or other major neurocognitive disorders is another controversial ethical issue. Casey et al. (2020) discussed that deceiving with the intention to harm and deceit is unacceptable, albeit there might be circumstances were doing so is justified by carers, like avoiding emotional distress for people with dementia. People with advanced dementia will not fully understand their current life circumstances, besides their tendency to detach from reality due to cognitive impairments. Health professionals must educate the families and/or caregivers of the older adult about this, explaining the main reasons for deceiving them and how this can improve the older adult's well-being.

The literature also reveals that advance care planning and advance care directive emphasizes more on life-sustaining treatments than living wills. The systematic review of Yadav et al. (2017) showed that, in the United States, around one in three adults have completed advance care documentation. The authors suggested that of both physician orders and advance care directives as living wills document preferences of care, advance care directives enable broader care goals which help surrogate decision-makers and healthcare providers in decision-making (Yadav et al., 2017). These misconceptions may decrease the completion of advance care directives (Yadav et al., 2017). In addition, physician orders can be used with existing advance care directives, making them more accessible while respecting end-of-life care decisions in all healthcare settings (Meyers et al., 2004). Misconceptions could lead to confusion regarding completion and implementation for both healthcare professionals and surrogate decision makers. However, knowing the misconceptions that patients and their families may have about advance care planning documentation is not always a straightforward process. By consequence, healthcare workers must elicit this critical information from patients and family because they are skilled in investigating patient's health related problems while addressing their unique unmet needs (Wagle et al., 2021). For this reason, healthcare professionals in general and social workers in particular must know the difference between advance care directives and other documentation about health care decisions because they must support decision-makers by clarifying the main aspects of the process.

Two main research gaps have been detected in this review, namely person-centered research in decision-making, and the role of the social worker in the use and implementation of advance care directives in long-term care for people with dementia. Only one out of the 25 studies included in this scoping review was focused directly on the person with dementia and their participation in decision-making about their own care. The scoping review carried out by Jones et al (2019), reflects that only three studies out of 25 were focused on the person with dementia who was the subject of decision-making. Moreover, discrepancies between the preferences of caregivers of people with dementia and healthcare providers have been observed (Jones et al., 2019). Given that social workers play a role of communication brokers by gathering information from the patients about their desired type and quantity of care, these professionals open opportunities for patients to freely express their care preferences to their families and healthcare providers (Nedjat-Haiem et al., 2023). The active role of social workers in communicating with the patient is thus essential for fostering their participation in advance care planning. Considering the existing gaps in literature, research should explore the decision-making capacity and willingness to participate in this process by people with dementia and/or other major neurocognitive disorders, instead of following a deficit-oriented approach (Wright, 2019). This can help to improve the autonomy and wellbeing of people with dementia (Wright, 2019). For this reason, further research is warranted to reach a better understanding on the use and complexity of advance care planning in people with dementia and/or other major neurocognitive disorders living in residential care settings. In addition to that, these people should be engaged in decision-making, thus giving their opinions and the importance they have in terms of care. Likewise, none of the retrieved studies approached advance care planning and/or advance care directives from social work perspective. This is a knowledge gap social workers are well positioned to support patients and families in the advance care planning process because these professionals understand how healthcare barriers are impacted by community, culture, and discrimination (Otis-Green et al., 2019). Consequently, skilled social worker practitioners play key roles in communicating and engaging with patients, patients' caregivers, healthcare team members and community resources while providing competent health care that addresses diversity (Otis-Green et al., 2019; Wagle et al., 2021). Social workers have the responsibility to promote and implement advance care planning by means of specific duties e.g., advocating patient's rights, initiating advance care planning discussions, facilitating communication and conflict resolution, patient and family education or counselling, as well as documenting discussions or advance directives (Wang et al., 2017). The role of social workers within the interdisciplinary team is crucial to assist people with dementia and their families in decision-making through standardized process of advance care planning, specifically the completion of advanced care directives. Social workers are skilled professionals with a great potential for leadership and patient empowerment in the context of advance care planning and interdisciplinary work. Therefore, interdisciplinary collaboration between these high-skilled professionals and other healthcare members would allow them to integrate their disciplinary knowledge into practice, advocating for the human rights of people with dementia living in long-term care facilities.

## Limitations

There are limitations in this review that are necessary to point out. Firstly, the context differences in the definition, stages of implementation/progress and legislation about advance care directives across countries make it very difficult to find a comprehensive synthesis that may allow a comparison of research findings. In this review, papers where their authors declared to have researched or discussed advance care directives were included. The authors, however, tend to use context-specific definitions, potentially leading to interpretation bias when trying to bring their conclusions and recommendations into a global context. Secondly, given the comprehensive nature of this review, studies from many different countries were included. Consequently, an understanding of context-specific differences in the use of advance care directives may not have been fully captured. Thirdly, when interpreting the results of this scoping review, it is important to note that although all the included studies fitted with the inclusion criteria, nine studies were classified as poor quality. Even so, they provide relevant information to understand the use of advance care directives and show the need for further high-quality research in this field.  Lastly, the inclusion criteria were limited to studies published in English, Spanish and Portuguese, automatically excluding studies published in any other language.

## Conclusion

Advance care directives are essential given the potential for health implications in relation to either with-holding beneficial treatment against the patient’s wishes or administering futile treatment against the patient's wishes which can have medical-legal implications. However, the evidence of effective strategies to engage people with dementia and their family surrogate decision-makers on advance care directives in residential aged care is scarce. Therefore, there is a need for stakeholders to promote dialogue on advance care directives between surrogate decision makers, people with dementia and healthcare providers to clarify all relevant aspects, to facilitate surrogate decision-making. Some recommendations for practice are that both people with dementia and their surrogate decision-makers should be involved in advance care planning and advance care directives as long as they are able to retain decisional capacity. Likewise, educational interventions for family members should be promoted, since they have been shown to be effective in increasing documented advance care directives, specifically those relating to comfort care. Additionally, social workers must play a fundamental role in terms of providing clear guidance to decision makers, in the process of deciding about and/or on behalf of the person with dementia and/or major neurocognitive disorders. Considering that the available literature in the topic is limited in both quantity and quality, further adherence to the standards of high-quality research is strongly encouraged. High quality research on the role of social workers in advance care planning as well as specific aspects of advance care directives in health care settings, beyond the extent of their existence, needs to be the focus of future inquiry.

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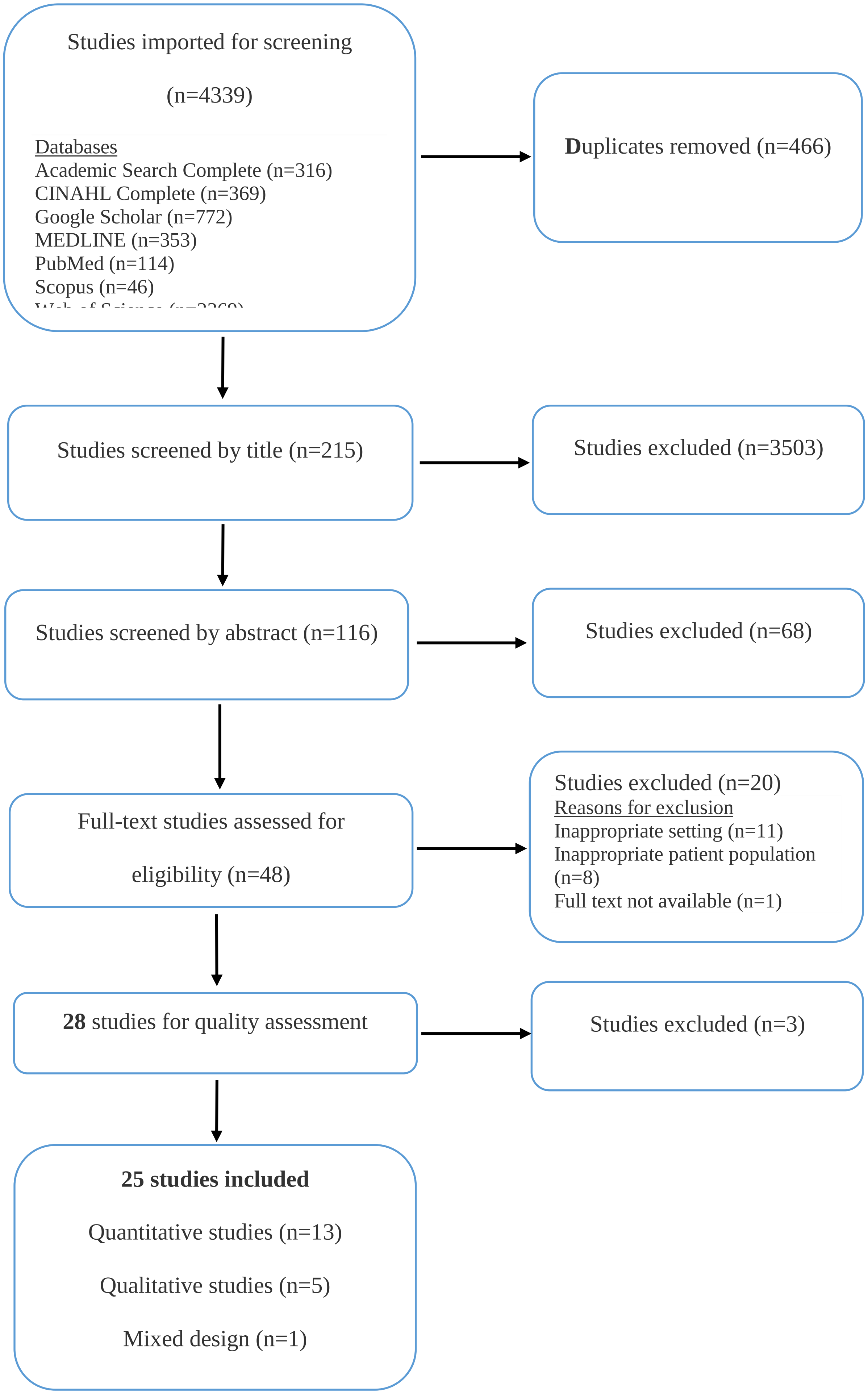
**Figure 1: Screening flow chart**



## Table 1 – Quality assessment of each article

| N° | Type of article/ Study design | Quality assessment tool | Rated quality |
|---|---|---|---|
| 1 | Quantitative, multicentre audit | Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (QAOCCS) | Good |
| 2 | Case study | JBI Critical Appraisal Checklist for case reports (CACCR) | Good |
| 3 | Case study | JBI Critical Appraisal Checklist for case reports (CACCR) | Good |
| 4 | Qualitative exploratory | JBI Critical Appraisal Checklist for qualitative research (CACQR) | Good |
| 5 | Case study | JBI Critical Appraisal Checklist for case reports (CACCR) | Good |
| 6 | Qualitative exploratory | JBI Critical Appraisal Checklist for qualitative research (CACQR) | Good |
| 7 | Qualitative | JBI Critical Appraisal Checklist for qualitative research (CACQR) | Good |
| 8 | Retrospective case-note review of nursing home residents with dementia | Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (QAOCCS) | Fair |
| 9 | Case study | JBI Critical Appraisal Checklist for case reports (CACCR) | Good |
| 10 | Qualitative descriptive | JBI Critical Appraisal Checklist for qualitative research (CACQR) | Fair |
| 11 | Case study | JBI Critical Appraisal Checklist for case reports (CACCR) | Good |
| 12 | Qualitative | JBI Critical Appraisal Checklist for qualitative research (CACQR) | Good |
| 13 | Cross-sectional | Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (QAOCCS) | Good |
| 14 | Qualitative descriptive | JBI Critical Appraisal Checklist for qualitative research (CACQR) | Fair |

| | | | |
|---|---|---|---|
| 15 | Retrospective, cross sectional | Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (QAOCCS) | Fair |
| 16 | Qualitative | JBI Critical Appraisal Checklist for qualitative research (CACQR) | Fair |
| 17 | Case study | JBI Critical Appraisal Checklist for case reports (CACCR) | Good |
| 18 | A comprehensive approach called the Panoramic Situational Contextualization Analysis method. | Mixed Methods Appraisal Tool (MMAT), version 2018 | Fair |
| 19 | Cluster Randomized Clinical Trial | Quality Assessment of Controlled Intervention Studies (QACIS) | Fair |
| 20 | Paired cluster randomized controlled trial | Quality Assessment of Controlled Intervention Studies (QACIS) | Fair |
| 21 | Cluster Randomized Clinical Trial | Quality Assessment of Controlled Intervention Studies (QACIS) | Fair |
| 22 | Pretest-posttest cluster randomized trial | Quality Assessment of Controlled Intervention Studies (QACIS) | Fair |
| 23 | Quantitative, cross sectional | Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (QAOCCS) | Fair |
| 24 | Cluster Randomized Clinical Trial | Quality Assessment of Controlled Intervention Studies (QACIS) | Fair |
| 25 | Cluster Randomized Controlled Trial | Quality Assessment of Controlled Intervention Studies (QACIS) | Fair |

## Table 2 – Summary of the characteristics of the selected studies - Support for Autonomy

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
|---|---|---|---|---|---|---|---|---|---|
| **Support for Autonomy in basic needs** | | | | | | | | | |
| 1 | Clifton et al, 2020 | The United States | Feeding a person with advanced Alzheimer's disease: An update. | Nutrition Today, 55(5). | Case study.<br>To discuss the typical trajectory of Alzheimer Disease, involuntary weight loss, advance care planning related to nutrition, and hydration and alternatives to tube feeding. | A 92-old woman with advanced dementia. | Case presentation and ethical analysis. | - The quality of life or the survival in people with dementia does not improve by using feeding tubes; unnecessary interventions in advanced dementia can be avoided while making well-through-out decisions regarding care goals and advance care planning. | - Not applicable. |
| 2 | Davies and George, 2013 | United Kingdom | Advance decision to refuse treatment in cases of dementia. | End of life Journal, 3(2). | Case study.<br>To explore the principle of truth telling in older adults with advanced dementia. | An 80-year-old woman with advanced, multi-infarct dementia. | Case presentation and ethical analysis. | - Lying to a patient with dementia can cause several ethical and legal consequences for all parties involved. Although truth telling is an essential aspect of patient autonomy, | - Not applicable. |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | once patient's cognition becomes severely impaired, they no longer hold decisional capacity. | |
| 3 | Menzel and Chandler-Cramer, 2014 | The United States | Advance directives, dementia, and withholding food and water by mouth. | The Hastings Center report, 44(3). | Case study.<br>To discuss the use of advance directives to withhold food and fluids in people with advance dementia. | Three cases of people with advanced dementia (2 females and 1 male). | Case presentation and ethical analysis. | - The implementation of advance care directives regarding withholding food and water by mouth for people with dementia must be clear, and it is justified by critical interest of the individual's autonomy. | - Not applicable. |
| 4 | Volicer and Stets, 2016 | The United States | Acceptability of an Advance Directive That Limits Food and Liquids in Advanced Dementia. | The American journal of hospice & palliative care, 33(1). | Qualitative.<br>To find out how acceptable would be an advance directive that includes discontinuation of feeding at certain stage of dementia for relatives of | 15 people: 12 spouses (4 husbands and 8 wives), 2 daughters, and 1 son-in-law of people with dementia. | - Participants divided in two focus groups.<br>- Discussion of their experiences.<br>- Discussion of nine possible scenarios that may occur in advance dementia.<br>- Thematic analysis. | - Advance care directives specifying withdrawal of food and water at a certain stage of dementia would be acceptable for family members.<br>- Advance care directives could be revoked if the person with dementia asks or indicates nonverbally their desire. | - Findings may not be generalizable due to the small number of participants.<br>- A procedure for preparation and acceptability of an advance directive that limits administration of food and liquids was not evaluated.<br>- Limited scenarios were used (nine |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
|---|---|---|---|---|---|---|---|---|---|
|  |  |  |  |  | persons who died with dementia. |  |  |  | versus 48). |

## Table 3 – Summary of the characteristics of the selected studies – Planning ahead

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
|---|---|---|---|---|---|---|---|---|---|
| **Making decisions ahead (Planning ahead) and upholding these decisions** | | | | | | | | | |
| 1 | Bavelaar et al, 2022 | The Netherlands | Change in Advance Care Plans of Nursing Home Residents with Dementia and Pneumonia: Secondary Analysis of Randomized Controlled Trial Data. | Journal of the American Medical Directors Association, 23(10). | Cluster-randomized controlled trial.<br>To explore changes in advance care plans of nursing home residents with dementia following pneumonia, and factors associated with changes. Second, to explore factors associated with the person perceived by elderly care physicians as most | 429 residents with dementia who developed Pneumonia from 32 nursing homes. | - Comparison of advance care plans before and after the first pneumonia episode.<br>- Associations explored through generalized logistic linear mixed models.<br>- Exploratory analyses. | - Physician-reported advance care plans were usually developed after nursing home admission, and only changed for a minority of residents with dementia after pneumonia diagnosis.<br>- Few residents had living wills or were most influential in the decision making. | - The models with outcome change of prioritized treatment goal and of treatment decisions showed considerable uncertainty around the coefficients.<br>- All data are physician-reported.<br>- Relevance of the findings for current practice potentially limited due to the time between data collection and reporting (seven years). |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | influential in advance treatment decision making. | | | | |
| 2 | Brazil et al, 2018 | Northern Ireland, United Kingdom | Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial. | Palliative medicine, 32(3). | Paired cluster randomized controlled trial.<br>To evaluate the effectiveness of advance care planning with family carers in dementia care homes. | - Family carers of nursing home residents from 24 nursing homes. | Randomized selection of participants.<br>A training intervention about advance care planning.<br>A follow-up after six weeks of the intervention.<br>Meta-analysis models were used. | - Advance care planning is effective in improving perceptions of quality of care in nursing homes and reducing uncertainty in families' decision-making concerning the care of their loved one with dementia. | - Inability to blind the allocation between randomization and data collection.<br>- Accuracy of data depended on nursing home manager access to records and records keeping. |
| 3 | Bryant et al, 2022 | Australia | Inadequate completion of advance care directives by individuals with dementia: national | BMJ Supportive & Palliative Care, 12. | Prospective multicentre Audit Community-based cohort.<br>To describe the prevalence and type | A total of 1388 people with dementia from 96 sites were included. | Multicentre audit undertaken in Australian hospitals, general practices and residential aged care facilities.<br>Extraction of | - Sixty per-cent of people with dementia across health and aged care settings in Australia had advance care planning documentation in their health record, but only half of them | - The distribution of participating sites was not representative across jurisdictions.<br>- Heterogeneous distribution of people across the settings. |

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| | | | audit of health and aged care facilities. | | of advance care directives (ACDs) and other advance care planning (ACP) documentation completed by persons with dementia, healthcare providers and others on behalf of a person with dementia. | | demographic and ACP data from the records of eligible patients.<br>ACP programme characteristics were provided by a site representative.<br>Logistic and multinomial regression were used. | had completed an advance care directive by themselves. | |
| 4 | Fetherstonhaugh et al, 2017 | Australia | Decision-making on behalf of people living with dementia: how do surrogate decision-makers decide? | Journal of Medical Ethics, 43(1). | Qualitative exploratory.<br>To investigate how surrogate decision-makers make important decisions on behalf of a person living with dementia. | 34 family members who had formally or informally taken on the role of surrogate decision-maker. | - Semi-structured interviews.<br>- Thematic Analysis. | - People who have made decisions on behalf of a person with dementia described the decision-making process as difficult; knowing the previous preferences of the person with dementia not always clarify decision-making. | - The study only describes the experiences of people able to be interviewed in English.<br>- The experiences of those with limited, or no English language skills has not been explored. |

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| 5 | Goodman et al, 2013 | England, United Kingdom | Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. | International journal of nursing studies, 50 (12). | Qualitative exploratory.<br>To explore how older people with dementia discuss their priorities and preferences for end-of-life care. | 18 people with dementia, living in six care homes. | - Guided interviews.<br>- Thematic Analysis. | - People with dementia can articulate their care preferences in a nursing home, when given the opportunity; careful attention to what they identify as important can enrich care planning assessment and documentation. | - Small number of interviewees.<br>- Exploratory interviews only.<br>- Some interviews were short or wide ranging in focus and content.<br>- Lack of knowledge about the older person's history and daily ongoing relationships from the researchers.<br>- Alternative methods of communicating ideas and views were not explored. |
| 6 | Leong and Crawford, 2018 | Australia | Residential aged care residents and components of end-of-life care in an Australian hospital. | BMC palliative care, 17(1). | Retrospective case-note review of nursing home residents with dementia.<br>To study a sample of RAC residents who attended and died in | 109 cases from 27 residential aged care facilities surrounding a hospital in the suburbs of Adelaide, South Australia. | - Comparison between residents with and without advanced dementia.<br>- Statistical analysis | - Advance care directives, resuscitation orders (for/against) and do-not-hospitalize orders are more common in old adults with dementia living in nursing homes than those without. | - The complexity of End-of-Life Care was not captured by the care measures.<br>- Secondary data were analised (hospital records).<br>- There may be underestimation of presence of advance care planning documents. |

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| | | | | | hospital, to quantify measurable components of EOL care so as to describe the extent of palliative care required. | | | | - The number of goals of care discussions with family/ caregivers may be underestimated due to inadequate documentation. |
| 7 | Palan et al, 2017 | The United States | Preventing Burdensome Transitions of Nursing Home Residents with Advanced Dementia: It's More than Advance Directives. | Journal of palliative medicine, 20(11). | Qualitative descriptive.<br>To examine how decisions to transfer nursing home residents with advanced dementia are made, from the perspective of nursing home nurses and physicians. | - 20 healthcare providers from 9 nursing homes. | - Semi structured, open-ended interviews.<br>- Thematic analysis. | - Advance care planning and do-not-hospitalize orders alone will not ensure that palliative goals of care are attained.<br>- Conversations about death in acute events between nursing homes providers and family proxies are essential. | - Not applicable. |
| 8 | Ramos et al, 2021 | The United States | End-of-Life Care Decisions for Patients with Dementia. | Journal of nursing practice applications & reviews of | Case report.<br>To explore the end-of-life | A 70-year-old woman with advanced dementia. | Case presentation and ethical analysis. | - Issues in End-of-life care decisions occur even if a patient has an advance care directive. | - Not applicable. |

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|  |  |  |  | research, 11(1). | disease trajectory, advance care planning, decision-making, and ethical considerations of a person living with advanced dementia. |  |  | - Issues arise after the progression of the disease, advance care planning and surrogate decision making. |  |
| 9 | Robinson et al, 2013 | The United Kingdom | A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but…' | Palliative Medicine 27(5). | Qualitative.<br>To explore professionals' experiences on the implementation of advance care planning in two areas of clinical care, dementia and palliative care. | Fourteen focus groups and 18 interviews were held with 95 participants. | Focus group sessions.<br>Individual interviews.<br>Transcriptions verbatim.<br>Thematic analysis. | - Healthcare professionals express uncertainty over the value of advance care planning in dementia care.<br>- A big issue is finding the right time to introduce advance care planning.<br>- There is no clarity in the responsibilities of professionals in advance care planning. | - The study was limited to one area, limiting the generalisability of the findings.<br>- Data present professionals' reported practice with no quantitative measure of their knowledge and experiences.<br>- Findings may not reflect international practice.<br>- Stakeholders and families were not included. |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
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| 10 | Street et al, 2015 | Australia | Advance care planning for older people in Australia presenting to the emergency department from the community or residential aged care facilities. | Health & Social Care in the Community, 23(5). | Retrospective, cross-sectional.<br>To determine the prevalence of advance care planning among older people presenting to an Emergency Department from the community or a residential aged care facility. | 300 older people (aged 65+ years) presenting to three Victorian Emergency Departments :<br>150 patients transferred from residential aged care.<br>150 people who lived in the Community. | - Randomized process of selection of people.<br>- Comparison of those with and without advance care planning documentation.<br>- Analysis performed through descriptive statistics. | - Patients with dementia where a 22, 55% of the total of patients with advance care planning documentation admitted in the emergency room, and they were more likely to have a documented advance care plan on arrival; many of the instructions contained in the advance care directives were contradictory and unclear. | - Results not generalizable to other health services.<br>- Secondary analysis of data, with the impossibility to extract further information.<br>- Causation cannot be determined. |
| 11 | Tjia et al, 2018 | The United States | Advance directives among nursing home residents with mild, moderate, and advanced dementia. | Journal of Palliative Medicine, 21(1). | Cross-sectional.<br>To describe prevalence and content of advance directives (ADs) documentation among | Data from January 1, 2007, to December 31, 2008, to assemble a cohort of NH residents with dementia from all | - Variables of interest were defined (advance directives and resident characteristics).<br>- Descriptive statistics and logistic regression. | - The authors defined advance directives as the presence of a living will, do-not-resuscitate order (DNR), do-not-hospitalize order (DNH), medication restriction, or feeding restriction.<br>- The prevalence of | - Data from 2007 because the newer version of the database does not capture any data on ADs.<br>- The outcome measure describes ADs with restrictions for care, including DNR, DNH, and |

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| | | | | | nursing home (NH) residents by dementia stage. | licensed facilities (N= 3371)<br>in five states (Minnesota, Massachusetts, Pennsylvania, California, and Florida).<br>Residents (n=180621) | | advance directives among nursing home residents by dementia severity is only 58%, where 20% of fewer residents had living wills, or documented evidence related to conversations of advance directives from the early onset of their dementia. | limitations on feeding and medications.<br>- Lack of information regarding the choice of substitute decision makers in this population. |
| 12 | Vandervoort et al, 2012 | Belgium | Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: Prevalence and associated outcomes. | International Psychogeriatrics, 24(7). | Retrospective cross-sectional post-mortem survey.<br>To describe the prevalence of documented advance care planning (ACP) among nursing home residents with dementia in Flanders, Belgium, and | All nursing homes for elderly people recognized as high-care nursing homes (N = 594). | - Questionnaire surveys were administered to nursing administrators and nurses.<br>- Information about the deceased patients was provided.<br>- Statistical analyses were performed. | - Advance care directives and the authorization of a legal representative were quite uncommon among deceased nursing home residents with dementia in Belgium, whereas general practitioner orders were more frequent. In presence of advance directives and general practitioner orders, their main concern | - Only the prevalence of documented care planning was investigated, whereas the quality of the ACP process was not.<br>- Possible recall bias due to the use of retrospective research design.<br>- Background information regarding the respondents was not surveyed. |

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| | | | | | associated clinical characteristics and outcomes. | | | were do-not-hospitalize and do-not-resuscitate orders. | |
| 13 | van Soest-Poortvliet et al, 2015 | The Netherlands | Advance Care Planning in Nursing Home Patients with Dementia: A Qualitative Interview Study Among Family and Professional Caregivers. | Journal of the American Medical Directors Association, 16(11). | Qualitative descriptive.<br>To describe the process of advance care planning (ACP) and to explore factors related to the timing and content of ACP in nursing home patients with dementia, as perceived by family, physicians, and nurses. | Families, on-staff elderly care physicians, and nurses of 26 patients with dementia who died in the Dutch End Of Life in Dementia (DEOLD) study. | - Eight dace-to-face in-depth qualitative interviews.<br>- Coding and thematic analysis. | - Discussions about end-of-life care and treatment decisions for people with dementia are facilitated by physician's knowledge about advance care directives as well as recent or previous expressions of patient wishes by patients or their families. | - Inability to recruit families participating in the DEOLD study with highly variable perceptions about ACP.<br>- Interviews yielded no information that could not also be collected in telephone interviews. |

**Table 4 – Summary of the characteristics of the selected studies – decision-making support**

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
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| **Support in Decision-Making for carers** | | | | | | | | | |
| 1 | Cohen et al, 2019 | The United States | Concordance Between Proxy Level of Care Preference and Advance Directives Among Nursing Home Residents with Advanced Dementia: A Cluster Randomized Clinical Trial. | Journal of pain and symptom management, 57(1). | Cluster Randomized Clinical Trial.<br>To examine concordance between advance directives and proxy care preferences among nursing home residents with advanced dementia and to determine the impact of an advance care planning video on concordance. | 64 long-term care facilities. | - Facilities were selected and randomly assigned to the control or intervention arm.<br>- Eligible residents were identified and recruited.<br>- Residents' proxies were asked for permission to include them as well as the resident with dementia.<br>- A 12-minute video intervention was administered.<br>- Baseline telephonic | - After watching an instructional video, the concordance between advance care directives about comfort care and proxies was higher compared to those who did not see the advance care directives video support tool. | - Defining concordance between level of care preferences and patterns of directives was somewhat subjective.<br>- Generalizability of the study was limited to a primarily white cohort in Boston nursing homes.<br>- Additional data on treatments to promote comfort, such as pain medications, was unavailable.<br>- Limited power to examine concordance between level of care preferences and actual |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
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| | | | | | | | interviews with proxies.<br>- Data collected baseline and quarterly up to 12 months.<br>- Statistical analyses (logistic regression models). | | treatments received due to the low number of events (e.g., hospital transfers). |
| 2 | Droz Mendelzweig, 2020 | Switzerland | Social regulation activities in end-of-life: a qualitative study on completion of advance directives in Swiss nursing homes. | BMC palliative care, 19(1). | A comprehensive approach called the Panoramic Situational Contextualization Analysis method.<br>To investigate how advance directives interventions in nursing homes strive simultaneously to behave in line with the | 77 people and<br>44 institutional addresses. | - Data collection through a questionnaire.<br>- First data analysis.<br>- Case study by selecting and dividing questionnaire respondents into two groups.<br>- Qualitative one-to-one interviews.<br>- Data analysis and comparison. | - People with dementia have seldomly established advance care directives prior to entering nursing homes, showing that the normative standard given to advance care directives by the Law is not assimilated by the public at large. | - Lack of homogeneity in the format of the advance directive documents.<br>- The perception of the status and format of the guidelines could be different if residents' or residents' family members were also interviewed. |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
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| | | | | | principles of care ethics and with the intention to respond to legally binding instructions. | | | | |
| 3 | Goossens et al, 2020 | Belgium | Improving shared decision-making in advance care planning: Implementation of a cluster randomized staff intervention in dementia care. | Patient education and counselling, 103(4). | Pretest-posttest cluster randomized trial.<br>To increase staff engagement level of shared decision-making in advance care planning for persons with dementia in nursing homes. | 311 staff members from 65 Belgian nursing home wards. | Individuals were recruited.<br>Test and control group were formed.<br>Comparison of audio recordings before and after intervention.<br>Participants filled in questionnaires and provided feedback.<br>Statistical analyses of data.<br>A 6-month follow-up. | - The practice of shared decision-making in advance care planning conversations can be increased after a multi-level communication training for care nursing homes providers, thus helping the families of people with dementia in surrogate decision-making. | - limited information on the similarities and the differences between participating wards and nursing homes and those in the general population.<br>- Results cannot be generalised for all nursing homes.<br>- Possible bias due to the non-random selection of participants.<br>- Limited interpretation of results six months after the intervention due to attrition. |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
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| 4 | Fewing et al, 2014 | Not indicated | A fading decision. | The Hastings Center report, 44(3). | Case study.<br>To discuss whether a voluntarily stopping eating and drinking (VSED) can be carried out for a patient whose advanced dementia makes disciplined voluntary action difficult. | A 75-year-old woman diagnosed with Alzheimer's disease. | Case presentation and ethical analysis. | - Advance care directives are helpful to respect the person's wishes, but they must adapt to the person's wishes as dementia progresses, therefore modifying what they originally decided in an advance care directive. | - Not applicable. |
| 5 | Ingravallo et al, 2017 | Italy | Discussing advance care planning: insights from older people living in nursing homes and from family members. | International Psychogeriatrics, 30(4). | Qualitative.<br>To explore the attitudes of nursing home residents and family members toward advance care planning (ACP) and their | 30 nursing home residents (age range 66–94), and 10 family members from 4 Italian nursing homes. | - Face-to-face interviews.<br>- Content Analysis. | - Advance care directives are considered as an opportunity.<br>- Informal conversations and planning instead of directives are preferred due to distrust toward both the appointment of a proxy and living wills. | - The study may not have captured differences in residents from other geographical areas because all participants were in the same region.<br>- Recruitment independent of data saturation.<br>- The level of |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
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| | | | | | opinions as to the right time to broach the subject, the way it should be approached, and the content. | | | - The possible reason for this distrust is the unclear legal status of care directives in Italy. | functionality of the residents was not investigated.<br>- Interviews were not repeated, transcripts were not returned to participants, and there was no feedback from them. |
| 6 | Mitchell et al, 2018 | The United States | An Advance Care Planning Video Decision Support Tool for Nursing Home Residents with Advanced Dementia: A Cluster Randomized Clinical Trial. | JAMA internal medicine, 178(7). | Cluster Randomized Clinical Trial.<br>To test whether an ACP video (vs usual care) influences documented advance directives, level of care preferences, goals-of-care discussions, and burdensome treatments among nursing | A total of 402 residents with advanced dementia and their proxies (intervention arm, n = 212; control arm, n = 190) from 64 Boston-area nursing homes (32 facilities per arm). | - Experimental and control group were formed.<br>- A 12-minute video intervention was administered.<br>- Statistical analyses (logistic regressions).<br>- Both groups were assessed quarterly for 12 months. | - After watching an instructional video, family proxies considered advance care directives only about tube-feeding; however, the video does not help proxies to promote a better understanding of advance care directives for people with dementia or increase advance care directives focused on other aspects of dementia care. | - Limited generalizability due to the mostly white composition of the sample.<br>- Findings not generalizable to eligible nonparticipants.<br>- Power may have been insufficient to detect significant differences for some secondary outcomes, particularly burdensome treatments. |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
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| | | | | | home residents with advanced dementia. | | | | |
| 7 | Reinhardt et al, 2014 | The United States | Vital conversations with family in the nursing home: preparation for end-stage dementia care. | Journal of social work in end-of-life & palliative care, 10(2). | Cluster Randomized Clinical Trial.<br>To test the effect of an intervention consisting of a face-to-face, structured conversation about end-of-life care options with family members of nursing home residents with advanced dementia. | 110, 96 and 90 surrogate decision makers at baseline, the second and third follow-up interviews, respectively. | - Conformation of a test group and a control group.<br>- A comparison group received only social contact via telephone.<br>- Intervention group had a structured conversation about end-of-life care.<br>- Telephone interviews conducted at three two-month interval.<br>- Advance directives extracted from medical records. | - The intervention increased the satisfaction of surrogate decision makers with care as well as documentation about end-of-life care decisions in their relative's medical record. | - The care satisfaction of the family members who chose not to participate in the study was not explored.<br>- Study findings may not be generalizable to other populations.<br>- The palliative-care intervention was only possible due to the presence of full-time physicians, which is not the norm for nursing homes.<br>- Information about family participation in care plan meetings was not collected. |

| N° | Author(s), year | Country | Article title | Journal, volume, and issue | Design and purpose | Sample | Methods | Findings | Limitations |
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| | | | | | | | - Statistical analyses. | | |
| 8 | Wilkins, 2018 | The United States | Narrative Interest Standard: A Novel Approach to Surrogate Decision-Making for People with Dementia. | The Gerontologist, 58(6). | Case study.<br>To review and critique the standard mechanisms for surrogate decision-making for people with dementia. | An 83-year-old married man with a history of dementia admitted to a skilled nursing facility after discharge from the hospital. | Case presentation and ethical analysis. | - Surrogate decision-making in people with dementia is challenging because of the dramatic changes their face because of dementia; people with dementia are susceptible to change their preferences, thus revoking advance care directives.<br>- Advance care directives do not usually include routine care decisions. | - Not applicable. |