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Older Adults and Family Experiences with Advance Care Planning in Nursing Homes: A Qualitative Synthesis

Kristin S. Klock[1], **Sara Vianna Vettore**[2*]

[1]*Faculty of Health Sciences and Social Care, Molde University College, Molde, Norway.*
[2]*The Norwegian National Centre for Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway.*

Abstract

As populations around the world age, ensuring high-quality care and meaningful end-of-life experiences for older adults has become a pressing public health priority. Advance care planning (ACP) has been shown to improve end-of-life care, minimize unnecessary medical interventions, and reduce stress for family members. In nursing homes, however, the engagement of residents and their families in ACP is influenced by a range of personal, cultural, and organizational factors. This review and meta-synthesis aimed to synthesize qualitative evidence on how nursing home residents and their families experience and perceive ACP, identifying challenges, facilitators, and practical insights to inform strategies for more effective ACP implementation. A systematic search was conducted in PubMed, Web of Science, Embase, EBSCO, The Cochrane Library, Sinomed, CNKI(China National Knowledge Internet), and WanFang (up to October 2024) to locate qualitative and mixed-method studies (qualitative data only) on ACP experiences in nursing home settings. Studies were eligible if participants were residents or family members, the publication was in English or Chinese, and the study included qualitative data. Methodological quality was assessed using the Joanna Briggs Institute checklist for qualitative research. Thematic synthesis was applied to integrate findings across studies, following ENTREQ and PRISMA guidance. From 1,097 records, 21 studies were included. Analysis revealed three central themes: (1) attitudes toward ACP among residents and families, (2) individualized needs and preferences for ACP, and (3) factors influencing ACP implementation. Most participants valued ACP for fostering communication and emotional expression and recognized its educational benefit. Nonetheless, some family members expressed ambivalence or reluctance. ACP needs were highly individualized, shaped by personal and contextual factors. Effective facilitators included accessible information, adequate cognitive capacity, supportive policies, an open cultural climate, empathetic multidisciplinary teams, and strong trust between residents, families, and staff. Nursing home residents and their families increasingly acknowledge ACP as valuable for expressing care preferences and supporting meaningful communication. Cultural sensitivities and sociocultural norms, however, can limit participation. To enhance ACP uptake, policymakers and healthcare organizations should strengthen legal frameworks, provide clear guidelines, and ensure tailored decision-support resources. Training staff in compassionate communication and fostering interdisciplinary collaboration are also essential to meet the diverse needs of nursing home populations.

Keywords: Advance care planning, Older adults, Nursing homes, Families, Palliative care, Qualitative synthesis

Introduction

Global life expectancy has steadily risen due to medical advancements and improvements in living conditions, resulting in a rapidly aging population. This demographic shift presents major public health challenges worldwide.

Corresponding author: Sara Vianna Vettore
Address: The Norwegian National Centre for Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway.
E-mail: ✉ Saravettore1964@yahoo.com
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According to the United Nations, declining fertility rates have contributed to the growing proportion of older adults, with 761 million people aged 65 and above in 2021, projected to reach 1.6 billion by 2050 [1]. By the late 2070s, those over 65 are expected to outnumber individuals under 18 years of age [2]. Changes in family structures and declining fertility rates in many countries have weakened traditional family support systems for older adults [3]. In China, for example, the one-child policy implemented in the late 1970s further reduced familial caregiving capacity [4]. Consequently, more older adults are relying on institutional care as traditional family-based support diminishes [5].

Residents in long-term care facilities often experience complex health challenges, including cognitive decline and dementia [6, 7], alongside difficulties in performing daily activities [8]. Many face diminished decision-making capacity [9], and nursing homes have increasingly become the setting for end-of-life care [10, 11]. This context has heightened interest in ensuring a “good life” and a “good death,” with person-centered care at the end of life recognized as a crucial component [12].

Advance care planning (ACP) has emerged as a structured approach to support these goals. ACP involves discussions between competent individuals, healthcare professionals, and family members to clarify treatment preferences, develop advance directives, and guide future care decisions [13, 14]. While ACP originated in palliative care, evidence supports its use earlier in the chronic disease trajectory [15]. For nursing home residents, initiating ACP early is essential to preserve autonomy amid potential cognitive and communicative decline. Research has shown that ACP in long-term care settings can reduce family stress, decrease hospitalizations and in-hospital mortality, and lower overall healthcare costs [9, 16, 17]. ACP also enables residents to make informed decisions aligned with their values, promoting a preferred end-of-life experience.

While ACP is well-established in countries such as the United States and across Europe [18, 19], implementation remains limited in many regions, including parts of Asia, where family-centered decision-making predominates [20, 21]. In such settings, older adults often play a passive role in care decisions, with family members acting as surrogate decision-makers [22–25]. This is particularly important for residents with cognitive impairment, who may lack the capacity to participate in decisions directly [25].

Although previous systematic reviews have explored ACP in older adults and families [26–28], many have excluded residents with cognitive impairments, leaving a knowledge gap regarding the perspectives of these individuals and the role of their families in ACP. This review aims to fill that gap by synthesizing qualitative studies on the experiences and perspectives of nursing home residents—including those with cognitive decline—and their family members regarding ACP, providing current, context-specific evidence to guide ACP practices in long-term care settings.

Materials and Methods

This review followed the ENTREQ (Enhancing Transparency in Reporting Qualitative Research Synthesis) statement [29] and PRISMA guidelines [30] to ensure rigorous reporting. The methodological quality of included studies was evaluated using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research [31]. The review protocol was registered with PROSPERO (CRD42024626800), accessible at crd.york.ac.uk/PROSPERO/display_record.php?RecordID=626800.

A comprehensive literature search was conducted in PubMed, Web of Science, Embase, EBSCO, The Cochrane Library, Sinomed, CNKI, and WanFang from inception to October 2024. Search terms combined keywords and controlled vocabulary to capture studies on three domains: nursing home settings (e.g., “nursing home resident*,” “long-term care,” “retirement home*”), advance care planning (e.g., “ACP,” “advance directive*,” “advance medical planning”), and qualitative research methods (e.g., “qualitative study,” “ethnograph*,” “grounded theory,” “narrative”). Reference lists of included studies were also screened for additional relevant articles. Both English and Chinese language studies were considered

Eligibility criteria

Inclusion criteria

Studies were considered eligible if they: (1) involved older adults living in nursing homes or their family members who shared experiences or perspectives regarding participation in advance care planning (ACP) within the facility; (2) were published in either English or Chinese; and (3) employed qualitative or mixed-method designs, with only qualitative findings extracted from mixed-method studies. For studies including multiple participant groups, only data relevant to older residents and their families were included.

Exclusion criteria

Studies were excluded if they: (1) focused exclusively on describing the characteristics or prevalence of ACP in nursing homes; (2) centered on developing ACP management frameworks or protocols; (3) evaluated the outcomes of ACP intervention programs; or (4) lacked access to the full-text article.

Data screening and extraction

The study selection and data extraction process followed PRISMA guidelines, as depicted in **Figure 1**. All retrieved articles were imported into EndNote 21, and duplicates were removed. Two reviewers (YP-L and FL) independently screened titles, abstracts, and full texts to identify studies that met the inclusion criteria. Disagreements were resolved through discussion, with a third reviewer consulted when consensus could not be reached.

For eligible studies, data were extracted into a Microsoft Excel spreadsheet. The extraction process was guided by a modified Joanna Briggs Institute (JBI) standardized form [31], adapted to suit the review's themes and synthesis methodology. Extracted information included study authors, country, design, participant characteristics, sample size, objectives, and key findings. Extraction was performed independently by both reviewers, and the study team reviewed the compiled data to ensure completeness and accuracy.

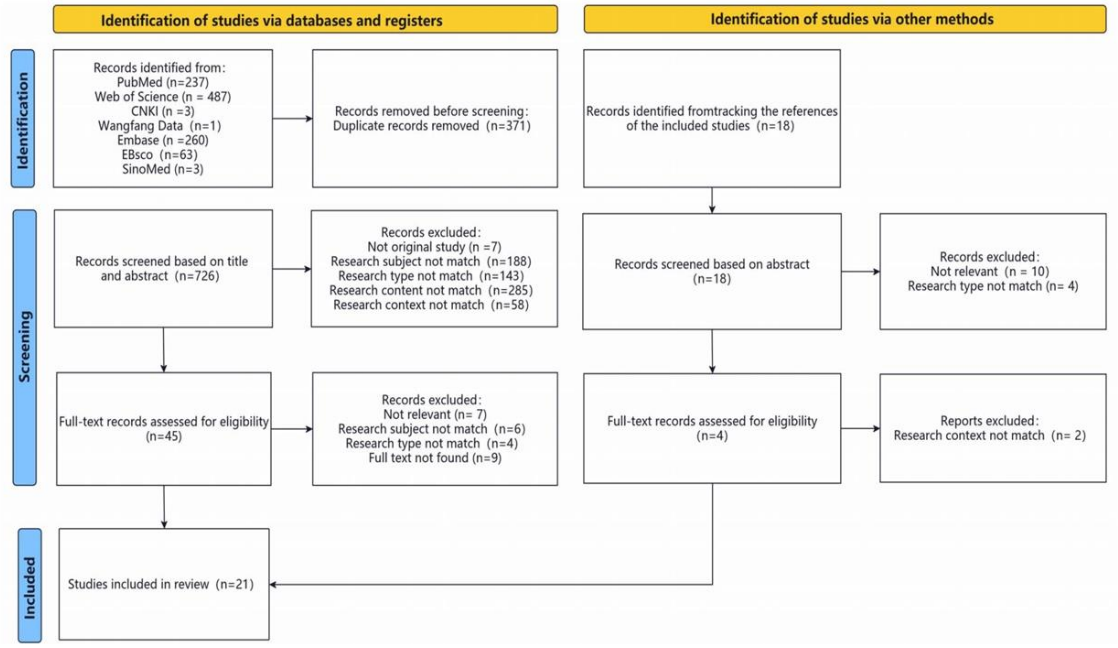

Figure 1. PRISMA flow chart of the study screening process

Here's a paraphrased version of the table with the same structure:

Table 1. Summary of included studies

Study	Country	Year	Design	Participants	Aims	Themes/Results
Andrews *et al.* [32]	United Kingdom	2023	Ethnography	2 Nursing homes: 6 elderly residents, 4 relatives, 7 healthcare providers, 19 staff	To investigate how multidisciplinary teams engage in advance care planning (ACP) in long-term care settings and to examine the views of older adults and their families on ACP.	Two themes: (1) Maintaining relationships and sharing information to support ACP execution; (2) Importance of coordinating multidisciplinary teams and involving families.
Ingravallo *et al.* [33]	Italy	2018	Phenomenological method	30 elderly residents, 10 family members	To examine the perspectives and attitudes of older adults and their families in nursing homes toward ACP.	Two themes: (1) Perspectives on future planning and ACP attitudes; (2) Content and approach of ACP discussions.
Bollig *et al.* [34]	Norway	2015	Phenomenological method	9 Nursing homes: 25 elderly residents, 18 relatives	To explore the views of cognitively intact older adults and their relatives on ACP, end-of-life care, and decision-making processes.	Three themes: (1) Obstacles to ACP; (2) Preferences for end-of-life care; (3) Perspectives on decision-making.

Fan *et al.* [35]	Taiwan, China	2019	Phenomenological method	28 elderly residents	To investigate the experiences and decision-making processes of older adults participating in ACP in residential care facilities and factors affecting their decisions.	Three themes: (1) Achieving a "good death"; (2) Uncertainty in decision-making; (3) Family's role in ACP decisions.
Lee *et al.* [36]	Taiwan, China	2022	Descriptive study	10 elderly residents, 12 relatives	To examine challenging questions faced by older adults and families in end-of-life decision-making and their attitudes toward ACP in nursing homes.	Six themes: (1) Accepting the inevitable; (2) Defining a good death; (3) Balancing traditional culture; (4) Preferring death over suffering; (5) Respecting older adults' choices; (6) Willing but unable to provide care.
Kastbom *et al.* [37]	Sweden	2020	Phenomenological method	18 relatives of deceased residents	To explore family experiences with ACP in nursing homes and their perceptions of communication about end-of-life issues between older adults and caregivers.	Five themes: (1) Challenges in discussing end-of-life issues; (2) Unspoken understanding between families and older adults; (3) Importance of small details; (4) Absent doctors, supportive nurses; (5) Family feelings of guilt.
Rainsford *et al.* [38]	Australia	2021	Descriptive study	2 Nursing homes: 4 relatives, 6 healthcare providers, 4 staff	To explore the experiences of families, staff, and healthcare professionals with ACP in multidisciplinary case conferences.	Four themes: (1) How the project functions; (2) Addressing implementation challenges; (3) Impact of multidisciplinary case conferences on ACP; (4) Looking beyond the project.
Zhou *et al.* [39]	China	2024	Phenomenological method	4 Nursing homes: 12 elderly residents, 10 relatives, 14 healthcare providers	To investigate the perspectives and preferences of older adults, families, and medical staff regarding ACP in China.	Four themes: (1) Limited end-of-life care discussions; (2) Relational decision-making as a dual factor in ACP; (3) Culture of low trust and insecurity; (4) Addressing psychosocial needs of older adults.
Carter *et al.* [40]	United Kingdom	2018	Descriptive study	20 families of residents with dementia	To understand family members' decision-making experiences in nursing homes and their challenges and support needs.	Three themes: (1) Impact of caregiving for dementia on family well-being; (2) Accessing support: online resources; (3) Understanding dementia trajectories by families and caregivers.
Cousins *et al.* [41]	United Kingdom	2023	Case study	8 Nursing homes: 19 relatives, 35 healthcare providers	To explore feedback from families and staff on barriers and facilitators of ACP implementation, including intervention content and information.	Four themes: (1) Needs for training and information; (2) Access to training and information; (3) Background context for training and information; (4) Promoting open dialogue.

Stewart *et al.* [42]	United Kingdom	2011	Phenomenological method	14 elderly residents, 15 relatives, 34 healthcare providers	To examine the perspectives of older adults, families, and staff on ACP in nursing homes and factors influencing its implementation.	Two themes: (1) Advantages of ACP; (2) Challenges to implementing ACP.
Rosemond *et al.* [43]	United States	2017	Phenomenological method	16 families of residents with dementia	To explore family experiences with ACP for older adults with advanced dementia in nursing homes.	Two themes: (1) Trust fosters positive end-of-life experiences; (2) Trust has no impact on end-of-life discussions.
Lee *et al.* [44]	Taiwan, China	2024	Descriptive study	18 elderly residents, 20 relatives	To investigate barriers faced by older adults and families in initiating ACP discussions in Taiwanese elderly care facilities.	Five themes: (1) Cultural or spiritual concerns; (2) Prioritizing family involvement; (3) Waiting for the right moment; (4) Experiencing uncertainty; (5) Following older adults' preferences.
Sussman *et al.* [45]	Canada	2022	Phenomenological method	4 Nursing homes: 35 elderly residents, 16 relatives	To explore the perspectives of older adults and families on ACP in nursing homes and barriers to enhancing ACP participation.	Three themes: (1) Relationships with ACP staff outweigh staff expertise; (2) Limited time for meaningful engagement with staff; (3) Creating a compassionate environment for living and dying.
Stone *et al.* [46]	United Kingdom	2013	Descriptive study	11 elderly residents, 6 relatives, 6 staff	To describe the experiences of older adults, families, and staff in initiating and completing ACP in nursing homes.	Three themes: (1) Understanding ACP; (2) Engaging in ACP discussions; (3) Outcomes and responses from ACP discussions.
Lambert *et al.* [47]	Canada	2005	Grounded theory	9 elderly residents	To describe the decision-making process for advance directives among older adults in nursing homes and influencing factors.	Two themes: (1) Sources of ACP information; (2) Mental, emotional, and social factors influencing decision-making.
Sævareid *et al.* [48]	Norway	2019	Phenomenological method	4 Nursing homes: 11 residents with cognitive impairment, 6 relatives, 6 healthcare providers	To examine the importance of ACP implementation in nursing homes and the perspectives of older adults, families, professionals, and managers.	Two themes: (1) Value of ACP experiences; (2) Significance of ACP implementation.
Jeong *et al.* [49]	Australia	2011	Case study	3 elderly residents, 11 relatives	To explore the experiences, emotions, attitudes, challenges, and supportive factors of older adults and families participating in ACP in nursing homes.	Three themes: (1) Initial discomfort with ACP; (2) Resolving issues and shifting attitudes; (3) Factors supporting or hindering the process.

Klemmt *et al.* [50]	Canada	2020	Descriptive study	7 Nursing homes: 24 elderly residents, 8 relatives	To describe the preferences and needs of older adults and families for medical care planning in nursing homes, including communication processes and documentation.	Eight themes: (1) End-of-life care preferences; (2) Establishing communication based on needs; (3) Documenting preferences; (4) Decision-making approaches; (5) Understanding autonomy and dignity; (6) Desire to support older adults; (7) Knowledge levels and formality; (8) Effective communication and interaction.
Thoresen *et al.* [24]	Norway	2016	Descriptive study	8 Nursing homes: 7 elderly residents, 10 relatives	To describe the experiences of older adults and families participating in ACP in nursing homes.	Three themes: (1) Older adults and families as an interconnected unit; (2) Importance of family involvement in ACP for deeper patient understanding; (3) Sharing end-of-life and death experiences.
Gjerberg *et al.* [51]	Norway	2015	Phenomenological method	6 Nursing homes: 35 elderly residents, 33 relatives	To examine the experiences and perspectives of older adults and their families in nursing homes regarding ACP.	Three themes: (1) Lack of communication about hospice care; (2) Desire for clear information; (3) Importance of shared decision-making.

PS: All studies conducted in China were published in international English-language journals

Critical appraisal

The quality of the studies included in this review was evaluated using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research [31]. The checklist comprises 10 criteria, each marked as “yes,” “no,” “unclear,” or “not applicable.” Studies were considered satisfactory if at least 60% of items were rated “yes,” categorized as good if 70–90% were “yes,” and deemed high quality if all criteria were met [52]. Two reviewers (YP-L and FL) independently carried out the assessment, with a third reviewer (QB-Z) consulted to resolve any disagreements.

Data synthesis

To integrate the qualitative evidence, thematic synthesis following Thomas and Harden’s approach [53] was applied. This involved three stages: (1) coding all relevant findings in Nvivo 20 by two researchers (YP-L and FL); (2) examining the codes to identify patterns and grouping them into descriptive themes; (3) developing broader analytical themes based on the descriptive themes. Each stage was conducted independently by the two reviewers, and any conflicts were resolved through discussion with a third researcher (YL-L).

Results and Discussion

Study selection

The initial database search identified 1,097 articles. After removing duplicates, 726 remained. Screening titles and abstracts led to the exclusion of 651 studies, and the full texts of the remaining 75 articles were assessed. Ultimately, 21 studies met all inclusion criteria and were incorporated into the meta-synthesis **(Figure 1)**.

Quality of included studies

Quality assessment results are summarized in **Table 2**. Of the 21 studies, twenty were rated as good quality, while one study met all checklist criteria and was classified as high quality.

Table 2. Methodological quality assessment of included studies

Study	①	②	③	④	⑤	⑥	⑦	⑧	⑨	⑩	percent of "Yes"
Andrews *et al.*[32]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
Ingravallo *et al.*[33]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y	90%
Zhou *et al.*[39]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y	90%
Bollig *et al.*[34]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	90%
Fan *et al.*[35]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	90%
Lee *et al.*[36]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	90%
Kastbom *et al.*[37]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	90%
Rainsford *et al.*[38]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	90%
Carter *et al.*[40]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Cousins *et al.*[41]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Stewart *et al.*[42]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Rosemond *et al.*[43]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Lee *et al.*[44]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Sussman *et al.*[45]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Stone *et al.*[46]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Lambert *et al.*[47]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Sævareid *et al.*[48]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Jeong *et al.*[49]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Klemmt *et al.*[50]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Thoresen *et al.*[24]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%
Gjerberg *et al.*[51]	Y	Y	Y	Y	Y	U	U	Y	Y	Y	80%

PS:① Congruity between the stated philosophical perspective and the research methodolog
②Congruity between the research methodology and the research question or objectives
③Congruity between the research methodology and the methods used to collect data
④Congruity between the research methodology and the representation and analysis of data
⑤There is congruence between the research methodology and the interpretation of results
⑥Locating the researcher culturally or theoretically
⑦Influence of the researcher on the research
⑧Representation of participants and their voices
⑨Ethical approval by an appropriate body
⑩Relationship of conclusions to analysis or interpretation of the data U = unclear; Y = yes.

Study characteristics

The 21 included studies were conducted across a range of countries: the United Kingdom (5 studies), China (4), Norway (4), Canada (2), Australia (2), and one study each from Germany, the United States, Sweden, and Italy. Fourteen studies collected perspectives from both nursing home residents and their family members [24, 32–34, 36, 39, 42, 44–46, 49–51], while seven studies additionally included insights from nursing home staff [32, 38, 39, 41, 42, 46, 48].

Key findings

Analysis of the included studies resulted in the identification of three overarching themes and eleven corresponding subthemes. The thematic framework and detailed subthemes are presented in **Table 3**.

Table 3. Themes and sub-themes identified through thematic synthesis

Themes	Sub-themes
Perspectives of older adults and families on ACP	- Emotional expression supported by ACP - ACP enhances communication between stakeholders - Educational value of ACP - Resistance to engaging in ACP - Mixed feelings and uncertainty about ACP
Personalized requirements	- Health-specific needs - Needs for institutional and emotional support - Involvement

for ACP	of stakeholders in ACP
Influences on ACP implementation	- Relevance and availability of ACP information - Cognitive capacity of older adults - Cultural obstacles and regulatory constraints - Lack of sufficient staff - Empathetic multidisciplinary teams - Building trusting relationships

\PS: ACP Advance Care Planning

Attitudes of older adults and families toward ACP

Emotional expression through ACP

Most older residents and their relatives viewed advance care planning (ACP) as a constructive and essential element of the nursing home environment. Many residents expressed a readiness to engage in ACP discussions and make end-of-life decisions as a means to secure what they considered a “good death” [36, 46, 50]. Families similarly recognized ACP as a helpful tool to clarify residents’ preferences and better understand their care priorities [33, 46]. For both groups, ACP often acted as a channel for self-expression within the institutional setting. For example, one family member reflected, “My father felt his comments were listened to and taken seriously” [46], while a resident explained, “It means a lot to have a chance to share the thoughts I’m preoccupied with” [48]. These conversations also allowed relatives to plan ahead and communicate their own expectations (“At least now they know what we want … because we discussed it” [46]).

ACP as a communication bridge

ACP also appeared to strengthen relationships and trust among residents, their families, and healthcare professionals. Open dialogue reduced guesswork and promoted shared decision-making. As one participant noted, “I feel safe because they are interested in knowing my mother … to inform me” [48]; another added, “You can learn what everyone is thinking instead of constantly guessing” [38].

The informational role of ACP

Several family members described ACP as an important learning process. It provided them with clearer knowledge about disease trajectories and available treatment pathways (“They were able to explain the different options” [38]). Some online ACP platforms also offered accessible, comprehensive information (“It was very comprehensive, very clear and relevant” [41]).

Avoidance of ACP

Despite these benefits, a portion of relatives displayed marked avoidance of end-of-life discussions with residents, often due to anxiety or deep-rooted fears [34, 44]. Some residents, meanwhile, considered ACP only applicable to the terminally ill and resisted such conversations because they felt healthy [16]. Others adopted a fatalistic stance, believing that planning would not influence their eventual outcomes (“Making plans in advance won’t change how we die … it’s all down to fate” [44]).

Ambivalence and uncertainty

During the early stages of ACP, family members sometimes reported feelings of guilt or the perception that discussing care plans equated to “giving up” on their loved one (“I feel terrible about it” [49]). Residents themselves voiced doubts about their ability to anticipate all possible circumstances (“How can I know everything? … Would I need to decide for every condition?” [35]) and worried about whether their documented wishes would ultimately be honored (“People might prolong life out of guilt … that worries me” [49]). Determining the right moment to begin ACP was also contentious. Whereas some families preferred to wait until noticeable deterioration (“I assume we’ll be included when they get sick” [51]), others felt early planning was essential to avoid losing decision-making capacity (“I want to think it through now and prepare myself” [51]; “Beforehand you’re frightened, but afterwards you lose capacity” [33]).

Individualized needs for ACP

Health-related concerns

Residents in nursing homes most often emphasized maintaining their health and staying active (“I don’t want to get dementia … it’s as bad as becoming bedridden” [50]; “I don’t want to become a vegetable” [34]). When considering disease progression, many expressed a preference to forego aggressive, life-prolonging interventions (“If I took a turn for the worse at this age, I’d prefer to be allowed to go peacefully” [51]). Pain relief and comfort were repeatedly identified as central goals of care [50] (“I wish to die calmly and peacefully without pain” [34, 50]). For these residents, dying free of pain was closely tied to dignity and autonomy at life’s end.

Institutional and psychosocial support needs

Residents in nursing homes frequently emphasized the importance of having companionship, particularly near the end of life, as many expressed a strong wish not to be alone [34, 50]. Although some were interested in advance care planning (ACP), several older adults were unsure how to participate in structured discussions (“ACP seems beneficial, but I don’t know how decisions are actually made” [35]). Family members often reported feelings of guilt when making decisions on behalf of cognitively impaired residents, especially regarding institutionalization (“Placing her in care was one of the hardest things I’ve done; it broke my heart” [38]). Both residents and families highlighted the importance of having adequate time and opportunities to discuss and reach agreement on care decisions (“We had to ask each other repeatedly, ‘What should we do? Will she accept it?’ … we needed more preparation” [38]). Participants also recommended that such conversations occur regularly to allow for ongoing reflection and dialogue (“Monthly meetings between staff and family would be helpful” [34]).

Engagement of key stakeholders

Many older adults preferred to first share their wishes with close family members before involving healthcare staff (“I would discuss it with my children first—they understand my situation” [50]). When communicating with facility personnel, residents often valued trust and familiarity over professional rank, highlighting strong connections with nursing staff (“Talking to the nurse made me feel at home” [33]). While nurses were recognized as central points of contact, limited access to physicians was noted (“I often declined seeing the physician; the nurse was my main contact” [37]). Despite this, both residents and family members generally felt physicians should lead ACP discussions, given their responsibility to explain medical decisions and potential outcomes (“Physicians need to explain both benefits and risks; nurses cannot fully do this” [33]). In some cases, families suggested involving legal advisors to ensure the decisions were formally recognized [33].

Factors affecting ACP participation

Clarity and accessibility of information

Families reported that ACP materials were often difficult to understand due to complex medical terminology (“The booklet was too technical; I couldn’t follow it” [49]). Some residents, especially those with limited education, misinterpreted ACP as an immediate end-of-life plan (“Doesn’t advanced care mean near death?” [46]). Limited literacy and cognitive challenges reduced residents’ confidence in expressing their wishes, causing delays or avoidance (“We didn’t know how to express our thoughts … we didn’t know anything” [33]). Some family members noted needing time to process ACP forms and communicate decisions to older adults (“I needed time to understand and explain do-not-resuscitate orders to my children” [44]).

Cognitive abilities of residents

Cognitive decline strongly influenced residents’ participation in ACP. Families often questioned the decision-making capacity of cognitively impaired individuals (“He’s had cognitive issues for some time, so I don’t think he can decide” [33]). As residents lost decision-making ability, the responsibility fell solely on family members, increasing emotional strain and sometimes discouraging engagement in ACP discussions (“By the time we had to make decisions, she could no longer participate” [40]). Nevertheless, residents with mild cognitive impairment were sometimes able to engage meaningfully in ACP when provided with guidance and supportive communication (“Being able to share my thoughts is very meaningful to me” [48]).

Cultural and policy-related barriers

Discussions surrounding end-of-life care in nursing homes remain limited, with many older adults and family members perceiving death as a culturally sensitive or taboo topic (“I feared talking about this would upset them, and they might stop visiting me” [44]; “She’s doing well now, so discussing this could make her anxious—it might seem like I want her to die sooner” [44]). In many cultural contexts, particularly in Asia, family-centered decision-making is emphasized, with an expectation that relatives will make choices in the best interest of the older adult (“My husband didn’t say anything, but the family knew exactly what to do; we are used to family making these decisions” [44]). In regions lacking clear ACP legislation, families sometimes expressed concern over potential legal disputes arising from conflicting opinions regarding end-of-life care (“Without legal frameworks, disagreements among siblings could escalate, potentially resulting in accusations of wrongdoing” [39]).

Staffing constraints

Despite residents and families being willing to engage in ACP, healthcare staff frequently face high workloads and limited time, which can hinder meaningful conversations (“They might want to engage, but they simply don’t have the time” [34, 45]).

Role of compassionate multidisciplinary teams

Older adults emphasized the importance of empathy and genuine care from healthcare professionals to effectively communicate their preferences (“Some staff show true empathy; you can feel their sensitivity. Others just complete tasks and leave it at that" [50]). Multidisciplinary collaboration helps facilitate ACP by providing consistent support and guidance for both residents and families [38].

Trusting relationships

Trust is a cornerstone for initiating productive ACP discussions [33, 40, 43, 48, 50]. Developing trust requires staff to understand residents' personal histories, maintain continuity of care, and communicate consistently [32]. Families reported that a trusting environment enhances their willingness to participate in discussions about care goals and contributes positively to the overall end-of-life experience ("At the point when my relative could no longer recover, we shifted to comfort-focused measures; trust helped guide our decisions" [43]).

This meta-synthesis reviewed 21 studies examining the experiences and perspectives of nursing home residents and their families regarding ACP. Three primary themes emerged: attitudes toward ACP, individualized ACP needs, and factors influencing ACP implementation.

Attitudes toward ACP and cultural influences

Residents and families demonstrated a range of attitudes toward ACP. Most recognized its value in improving communication [33–35, 48], clarifying care preferences [33, 34, 36, 48, 50], and supporting emotional expression [42, 48]. Yet, some avoided early discussions due to discomfort, fear, or social taboos surrounding death [44, 46, 49]. ACP was sometimes seen as an early indicator of mortality, which could discourage engagement [35]. Hesitation was particularly common when residents were in good health, with families often perceiving such conversations as premature, resulting in delayed ACP participation [51].

Optimal timing for ACP discussions is essential and often aligns with transitions such as declining health, nonadherence to treatment, or prolonged absence of family visits [54]. During these periods, providers should assess residents' physical and emotional status and approach ACP sensitively to respect personal values [51].

Structured ACP programs, including online resources, were found to enhance understanding and confidence among older adults and families, demonstrating ACP's role as both a decision-making and educational tool [38, 41].

Family involvement across cultural contexts

Families play a critical role in decision-making, regardless of cultural background [44, 47]. ACP can strengthen family relationships by fostering mutual understanding and reducing potential conflicts [32, 39, 48, 49]. In family-oriented cultures, residents may prioritize harmony over personal preferences [44, 55], whereas Western frameworks often emphasize autonomy, dignity, and minimal suffering [56]. In East Asian societies, filial piety may encourage life-prolonging interventions, potentially conflicting with residents' wishes to forgo aggressive treatment, and creating moral dilemmas for family members [36, 57]. These cultural tensions contribute to ambivalence and uncertainty during ACP discussions.

Most studies in this review were conducted in Europe, North America, Asia, and Oceania, with limited evidence from Africa, Latin America, or the Middle East. Consequently, cultural influences on ACP should be interpreted cautiously, and further research in underrepresented regions is warranted.

Identifying ACP needs of nursing home residents and their families

This review demonstrates that advance care planning (ACP) needs for older adults in nursing homes and their families involve health-related preferences, psychosocial support, and clarity regarding participation roles. As residents face irreversible health decline, many shift their priorities from extending life to achieving dignity, autonomy, and comfort in their final stages [34, 50, 51]. Observing others' experiences with overtreatment often reinforces a preference for less aggressive interventions [58]. Despite these preferences, residents frequently lack effective channels to communicate their wishes or access adequate support [35]. Both residents and family members highlighted the importance of sufficient time and communication to reach shared decisions and minimize conflicts [34, 38]. Accordingly, ACP initiatives should incorporate individuals' perceptions of their health and quality of life, ensuring personal preferences are acknowledged. Continuous dialogue is crucial to confirm residents' wishes, and older adults should have the opportunity to make informed choices about pain management, palliative care, and end-of-life control.

Many residents opt for nursing home care due to limited family caregiving but express a strong need for companionship and emotional support [50]. They often prefer not to face the end of life alone and prioritize discussions about their wishes with trusted family members rather than solely relying on healthcare professionals [34, 50]. This reflects that ACP extends beyond clinical decision-making into a social process, emphasizing shared values and emotional connection. The growing recognition of multidisciplinary collaboration is key for effective ACP, involving defined roles for physicians, nurses, social workers, psychologists, and legal advisors [32, 38, 59]. Physicians provide medical explanations and prognostic information [60]; nurses and social workers support emotional communication and help guide decision-making [60, 61]; psychologists assist in addressing family conflicts and decision-related anxiety [62]. Ongoing communication among residents, families, and staff ensures mutual understanding of ACP plans and timely updates [39].

Addressing barriers to ACP in nursing homes

Older adults and families unfamiliar with ACP often experience fear and anxiety when faced with end-of-life decisions [49]. Such distress is frequently amplified by complex medical language and limited understanding in educational materials [49]. ACP resources should therefore be tailored to users' cognitive and educational levels, and the use of videos or case-based examples can improve comprehension [63].

Uncertainty surrounding ACP-related laws and policies can undermine trust in the process for both residents and families [33, 39]. Policy limitations may also discourage healthcare providers from initiating ACP conversations [59]. In such cases, informal ACP—open-ended discussions about values and care preferences conducted during routine interactions—can serve as a practical first step [64]. These informal conversations allow residents and families to become familiar with ACP, providing a foundation for formalized planning in the future [64]. While informal discussions are valuable, formally documented ACP remains crucial to ensure legally recognized patient preferences are upheld in clinical decisions [49]. Policy advancement is therefore necessary to strengthen ACP frameworks [39].

Nursing homes often face physician shortages, with each physician responsible for many residents, limiting the time available for ACP discussions [34, 45]. In this setting, nurses and nursing assistants, who maintain regular, close contact with residents, play a pivotal role in care delivery [65, 66]. Through these relationships, they offer professional guidance, emotional support, and empathy, assisting both residents and families in navigating care challenges. These staff members are also well-placed to assess ACP needs and initiate informal discussions [65, 67, 68]. According to Singer's compassion model, emotionally sensitive and empathetic healthcare professionals can detect subtle changes in residents' emotions, guiding ACP conversations appropriately and naturally [50, 69]. Therefore, nursing homes should focus on optimizing staffing, reducing workload pressures, and enhancing communication skills training to foster trust, support decision-making, and integrate ACP into daily care routines.

Inclusion of older adults with cognitive impairments

Older adults experiencing cognitive decline encounter multiple challenges when engaging in advance care planning (ACP), including difficulties understanding care options and designating surrogate decision-makers [70]. Some family members perceive that cognitively impaired individuals lack the capacity to make informed decisions [33]. However, compared to those without cognitive impairment, individuals with dementia are more vulnerable to unnecessary medical interventions, repeated hospital admissions, and higher end-of-life healthcare costs [71]. Research indicates that older adults in the early stages of cognitive decline can still actively participate in ACP and value opportunities to express their care preferences [48, 72]. Thus, the stage of mild cognitive impairment should be regarded as a critical period for initiating ACP, including discussions about surrogate appointments and ongoing care throughout the dementia trajectory [73]. Despite cognitive limitations, retained communication skills, autonomy, and life experience enable meaningful engagement in values-based conversations [72]. Decision-support tools have been developed to assist individuals with dementia in expressing preferences [74–77], and long-term care staff should leverage these resources to ensure care aligns with patient values.

Strengths

This review synthesizes the experiences and perspectives of both nursing home residents and their family members regarding ACP from complementary viewpoints. Inclusion of residents with dementia, alongside family members who have engaged in ACP or experienced the loss of a loved one, provides insights often omitted in prior research. The included 21 studies span nine countries, representing both developed regions (e.g., Europe and North America) and developing regions in Asia, yielding a relatively diverse sample. The review adhered to systematic methods, employing the JBI Critical Appraisal Checklist for Qualitative Research to evaluate study quality rigorously.

Limitations

Several limitations should be acknowledged. First, only studies published in English and Chinese were included, potentially excluding relevant research in other languages and limiting the cultural diversity captured in the review. This restriction may introduce cultural bias and affect the generalizability of findings, particularly regarding culturally sensitive aspects of ACP. Second, while most studies were of acceptable quality, many did not adequately report researchers' cultural or theoretical positioning, which could influence findings. To address this, a subgroup analysis was conducted based on quality, using a 90% "yes" threshold on the appraisal checklist, with separate thematic syntheses for each subgroup. This approach confirmed that the core thematic structure remained consistent, demonstrating the robustness of the results. Studies were also grouped by cultural context, revealing some differences in the emphasis and depth of themes, though the overarching thematic framework was preserved. Finally, inclusion of residents with cognitive impairments may influence sample representativeness; however, their participation enriched the review by providing diverse perspectives on ACP experiences in institutional settings.

Conclusion

Residents and families in nursing homes acknowledge the value of ACP in enhancing communication, clarifying care preferences, and supporting emotional expression. Older adults emphasize dignity, comfort, and family presence when considering end-of-life care. ACP also offers educational and emotional benefits, yet its uptake is often hindered by cultural taboos, limited information, and societal attitudes toward death. With the aging population, embedding ACP within long-term care is essential to meet individual needs and facilitate timely expression of personal values. Strengthening legal frameworks and policies can support standardized ACP practices and encourage participation. Future initiatives should focus on interdisciplinary collaboration, culturally sensitive communication, sufficient staffing, and targeted support for residents with mild cognitive impairment to promote a person-centered and sustainable ACP system.

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