

REVIEW

Family perspectives on and experiences with advance care planning in nursing homes: A thematic synthesis

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Abstract

Objectives: To synthesize family members' experiences and perspectives on advance care planning (ACP) in nursing homes.

Methods: The thematic synthesis is reported following the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement. A systematic search of the APA PsycINFO, CINAHL Plus, Embase and PubMed databases is initially conducted in October 2022, and the search is updated in January 2024. Qualitative studies that presented family members' quotes regarding advance care planning in nursing homes published in a peer-reviewed journal were included. Screening and data extraction were independently performed by two reviewers, and any discrepancies were resolved with the assistance of the third author.

Results: A total of 1027 articles were identified, and 23 articles were included in the full-text review. Subsequently, a total of 17 studies were ultimately included, and 127 quotes were extracted and analysed. The main findings were categorized into three themes: (1) invitation to conversation and care, (2) the resident's surrogate and (3) nurses. Considering the importance of family members' roles in ACP conversations in a nursing home setting, this study provided an in-depth understanding of family members' perceptions and experiences of ACP by synthesizing qualitative studies. Family members' lack of knowledge regarding the timing and pursuits of ACP was also identified.

Conclusion: The findings of this study provide synthesized qualitative evidence of family members' perspectives on ACP, which can inform care and treatment in nursing homes. As this study synthesizes the experiences of family members in nursing homes about ACP, the findings of this study contribute to reflecting family members' experiences and providing evidence for nursing home healthcare professionals.

Patient or Public Contribution: This study reports the experiences of family members in ACP nursing homes. The findings of this study contribute to reflecting family members' experiences and building evidence for nursing home healthcare professionals.

Ho Nee Chu: co-first author.

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KEYWORDS

advance care planning, end-of-life decision-making, meta-synthesis, nursing home, qualitative approaches

1 | INTRODUCTION

Advance care planning (ACP) has been defined as 'a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care' (Rietjens et al., 2017; Sudore et al., 2017). The process includes structured conversations to assist people in deciding, communicating and documenting their end-of-life care wishes, which may include the instruction of advance directives (Flo et al., 2016; Sævareid et al., 2019; Weathers et al., 2016). The benefits of ACP have been identified by some studies as avoidance of unnecessary hospitalization at the end of life (Cornally et al., 2015; Ouslander et al., 2010) and cost-effectiveness (Dixon et al., 2018; Klingler et al., 2016). Most importantly, ACP contributes to the increased use of palliative care and comfortable dying and death at the person's end of life (Brinkman-Stoppelenburg et al., 2014) because the achievement of a person's wishes regarding personal values and needs strongly justifies ACP (Rietjens et al., 2017).

In this review, a nursing home refers to a residential facility or residential care home that provides 24-h care to aged residents by healthcare professionals. The potential contributions of ACP to nursing homes are particularly significant due to its high incidence of death and the philosophical importance of humanism and personhood (Sussman et al., 2022). Since nursing home residents are often frail and aged, the incidence of acute hospitalization is high among nursing home residents (Fassmer & Hoffmann, 2020; Graverholt et al., 2011). Acute hospitalizations not only reduce the quality of nursing home residents' dying and death but also burden family members financially and emotionally (Brinkman-Stoppelenburg et al., 2014; Martin et al., 2016). ACP contributes to a reduction in the length of acute hospitalizations and the use of life-sustaining treatment by increasing the rate of advance directives (Houben et al., 2014; Martin et al., 2016; Ng et al., 2022; Weathers et al., 2016). Additionally, ACPs play a significant role in resident's and family member's awareness of dying and death. ACP increases residents' use of palliative and hospice care and contributes to their comfortable dying and death at nursing homes (Martin et al., 2016). The concordance of residents' wishes and preferences for end-of-life care and the delivered end-of-life care was also enabled by ACP (Martin et al., 2016; Ng et al., 2022; Weathers et al., 2016). Accordingly, satisfaction with residents' quality of life is perceived positively by family members/informal caregivers (Martin et al., 2016; Ng et al., 2022).

Although the achievement of a person's wishes at their end of life justifies the benefit of ACP, nursing home residents often cannot articulate their own wishes and preferences due to a lack of mental or physical capacity (McGlade et al., 2017; Verreault et al., 2018). Therefore, family members are often invited to play a surrogate role and to support residents in ACP conversations (Sudore et al., 2018).

Family members can contribute to the reflection of residents' wishes regarding ACP by remembering residents' words and lives before their loss of capacity (Cornally et al., 2015; Garland et al., 2022; Gilissen et al., 2017). Therefore, family members' willingness and ability to participate are important preconditions for successful ACP in nursing homes (Gilissen et al., 2017).

On the other hand, family members are not only surrogate decision-makers for nursing home residents but also vulnerable care recipients who need support while experiencing the resident's death. Family members face difficulties and barriers in making surrogate decisions regarding life-threatening situations (Dekker & Bolt, 2022; Sævareid et al., 2019). Studies have shown that family members' participation in ACP helps them overcome the period of grief after the resident's death by being taken care of by staff members (Küpper & Hughes, 2011; Rabow et al., 2004; Saini et al., 2016).

Although many review studies have been conducted regarding ACP in nursing home settings (Brinkman-Stoppelenburg et al., 2014; Dixon et al., 2018; Gilissen et al., 2017; Houben et al., 2014; Klingler et al., 2016; Martin et al., 2016; Weathers et al., 2016), a small number of qualitative meta-synthesis studies have been conducted on the experiences of residents, staff and family members of ACP (Johnson et al., 2016; Ryan et al., 2017; Silies et al., 2022). The meta-synthesis focused on the challenges of ACP (Ryan et al., 2017), family members' roles in ACP (Johnson et al., 2016) and informal caregivers' experiences with ACP (Silies et al., 2022). Therefore, this qualitative meta-synthesis study was designed to synthesize family members' experiences with and perspectives on ACP in nursing homes.

2 | METHODS

2.1 | Study design

The thematic synthesis is rooted in meta-ethnography and grounded theory (Barnett-Page & Thomas, 2009). The reciprocal translation of meta-ethnography and constant comparison of grounded theory informed thematic synthesis to develop themes (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). The inductive approach of thematic synthesis contributes to a higher order of analytical themes (Barnett-Page & Thomas, 2009; Nicholson et al., 2016). The choice of research approach was to contribute to in-depth knowledge from the participants' perspectives and experiences across health-care contexts (Tong et al., 2012). This thematic synthesis study was reported following the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement (Tong et al., 2012). The findings of this review were not considered relevant to health outcomes, and as a result, it was not registered with PROSPERO.

2.2 | Search strategy

The search terms were planned by the authors considering the setting (nursing homes), condition (advance care planning), perspectives (family members) and study type (qualitative). The search was conducted in APA PsycINFO, CINAHL Plus, Embase and PubMed in October 2022 and updated in January 2024. The search was filtered by full-text availability. The full search terms can be found in Appendix S1.

Qualitative studies that presented family members' quotes regarding advance care planning in nursing homes published in a peer-reviewed journal were included. Therefore, publications without full text, such as editorials and conference abstracts, were excluded from the screening. Qualitative studies are identified as methodologies such as phenomenology, ethnography, grounded theory or narrative, which are also included in the search terms. Mixed-method studies that presented family members' quotes as supporting evidence for the findings were also considered. However, mixed-method studies were not included in the final decision since the participants' quotes did not concern advance care planning. Additionally, some qualitative studies that did not present participants' quotes to support the findings were excluded.

2.3 | Study selection, data extraction and study appraisal

The search results were independently screened by two reviewers following the inclusion criteria. The authors used Rayyan and Excel to screen the titles and abstracts of the search results. The screening process involved close communication and comparison between the first and second reviewers. The quality of the included articles was also independently evaluated by the modified critical appraisal skills programme (CASP) qualitative checklist tool (Long et al., 2020). The modified CASP checklist considers the theoretical underpinnings of qualitative research in addition to the conventional CASP checklist (Long et al., 2020). Although the modified CASP checklist categorized into four decisions, 'yes', 'somewhat', 'can't tell' and 'no', the authors considered that it does not influence the final decision of appraisal. Therefore, the full-text articles were appraised on three basis: 'yes', 'can't tell' and 'no'. The results of the quality appraisal of the included studies are presented in Table 1.

Discrepancies between the first and second authors in the results of the full-text review for eligibility were resolved, and the appraisals asked the third author to make the decision of inclusion. After the included articles were confirmed by all the authors, the first and third authors performed the data extraction. Participants' direct quotations from each included study were extracted following the thematic synthesis data extraction (Thomas & Harden, 2008). Subsequently, participants' direct quotations were extracted from the included articles by two reviewers and confirmed after the comparisons.

2.4 | Data synthesis

The thematic synthesis of qualitative research was used for this meta-synthesis (Thomas & Harden, 2008). First, the extracted data were coded line-by-line. Subsequently, the codes were organized into descriptive themes. Finally, analytical themes and their relationships were developed from descriptive themes (Thomas & Harden, 2008). The thematic synthesis was performed by the first author and confirmed by the other authors of this study.

2.5 | Rigour, trustworthiness and reflexivity

The priorities of this study were family members' experiences and perspectives on the ACP. Therefore, family member quotes in the included studies were analysed only after excluding the results of the analysis by the authors. The authors are international nursing researchers registered in different countries of South Korea, Hong Kong, Mainland China and Taiwan. Additionally, they have research expertise in end-of-life care in various care settings, such as nursing homes, hospitals and critical care. As an experienced qualitative researcher, the first author systematically guided the meta-synthesis process and supported the co-authors. Subsequently, the second and third authors independently screened and evaluated the articles. Each step of this study was shared and confirmed by all the authors from the time of the research design to the time of the writing.

3 | FINDINGS

A total of 1027 peer-reviewed qualitative study articles from four databases, APA PsycINFO, CINAHL Plus, Embase and PubMed, were identified. A total of 371 articles were removed as duplicates, while another 169 articles were removed due to publication types such as conference abstracts or editorials. Additionally, 13 articles were excluded because they were written in languages other than English. Furthermore, 271 articles did not focus on the topic of ACP. Moreover, 225 studies were eliminated due to their focus on the nursing home context and the participation of family members as the study population. Finally, 344 studies were excluded because they were not qualitative studies. Next, the full-text eligibility of 23 studies was checked. Of those, six studies were ultimately excluded due to a lack of participant direct quotations. Consequently, a total of 17 articles were chosen for the meta-synthesis (Andrews & Myall, 2023; Bollig et al., 2016; Cousins et al., 2022; Dekker & Bolt, 2022; Hickman et al., 2021; Ingravallo et al., 2018; Jeong et al., 2011; Kastbom et al., 2020; Klemmt et al., 2020; Lee et al., 2019; Mayahara et al., 2018; Rainsford et al., 2021; Sævareid et al., 2019; Stewart et al., 2011; Stone et al., 2013; Sussman et al., 2022; Thoresen & Lillemoen, 2016). See Figure 1.

The study participants were family members, relatives and next of kin of the nursing home residents who experienced advance care planning. There were a total of 10 studies conducted in European countries, with three from the United Kingdom, three from Norway and one

TABLE 1 Modified CASP appraisal for included studies.

	1	2	3	4	5	6	7	8	9	10	11
Andrews and Myvall (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Bollig et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Cousins et al. (2022)	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Dekker and Bolt (2022)	Yes	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Yes
Hickman et al. (2021)	Yes	Yes	Can't tell	Can't tell	Can't tell	Can't tell	No	Can't tell	Can't tell	Yes	Yes
Ingravallo et al. (2018)	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
Jeong et al. (2011)	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Can't tell	Yes	Yes
Kastbom et al. (2020)	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Yes
Klemmt et al. (2020)	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Yes
Lee et al. (2019)	Yes	Can't tell	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes
Mayahara et al. (2018)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes
Rainsford et al. (2021)	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sævareid et al. (2019)	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
Stewart et al. (2011)	Yes	Yes	Yes	Can't tell	Yes	Yes	No	Yes	Can't tell	Yes	Yes
Stone et al. (2013)	Yes	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Yes	Can't tell	Yes	Can't tell
Sussman et al. (2022)	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Can't tell	Yes
Thoresen and Lillemoen (2016)	Yes	Yes	Yes	Yes	Yes	Can't tell	No	Yes	Can't tell	Can't tell	Yes

Note: The following 11 criteria were included: (1) Was there a clear statement of the aims of the research? (2) Is a qualitative methodology appropriate? (3) Was the research design appropriate to address the aims of the research? (4) Are the study's theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent? (5) Was the recruitment strategy appropriate to the aims of the research? (6) Was the data collected in a way that addressed the research issue? (7) Has the relationship between researcher and participants been adequately considered? (8) Have ethical issues been taken into consideration? (9) Was the data analysis sufficiently rigorous? (10) Is there a clear statement of findings? (11) How valuable is the research?

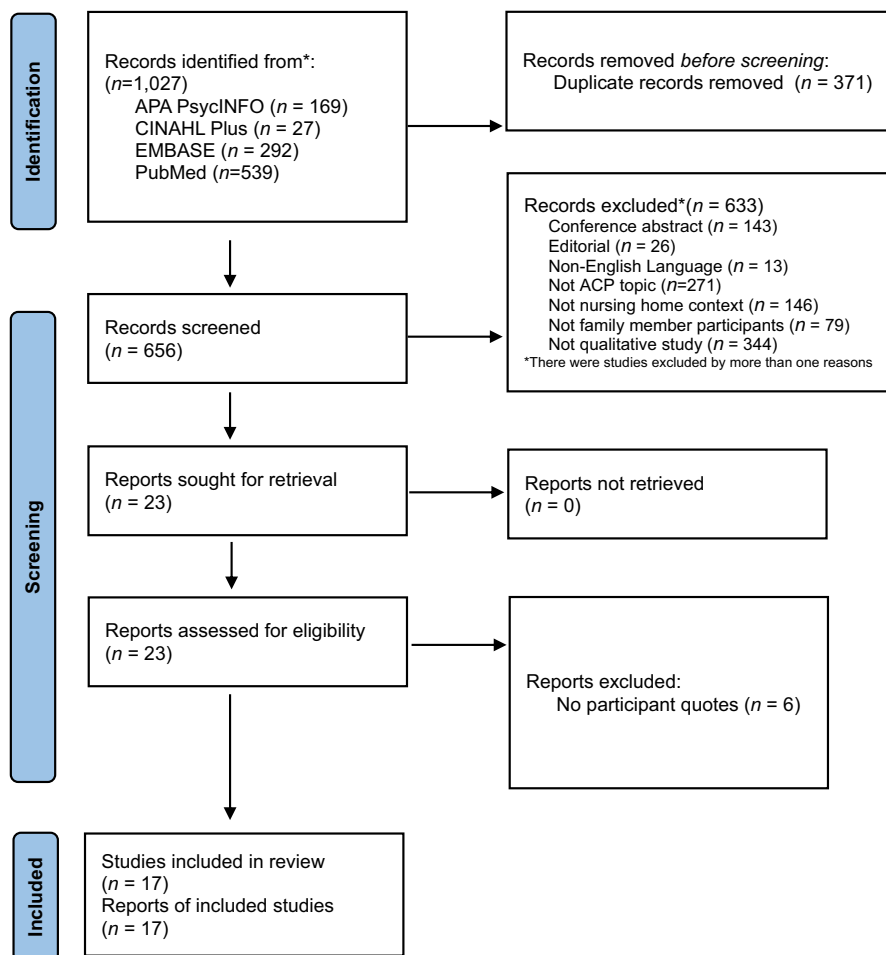


FIGURE 1 PRISMA flow chart of searching literature.

each from the Netherlands, Italy, Sweden and Germany. Additionally, three studies were conducted in North America, with two from the United States and one from Canada. Furthermore, two studies were conducted in Australia, and one study was conducted in Taiwan.

Regarding the methodology, three studies used a qualitative descriptive approach, two studies used an interpretative descriptive approach, two studies used a case study design, one study used action research, and one study used an inductive latent approach. Five studies did not specify the methodology but mentioned the use of qualitative methodology. Additionally, two studies utilized secondary data analysis. These two secondary data analyses were included because they identified ACP experiences from the data, despite the primary findings not focusing on ACP. A summary of the included articles is presented in Table 2.

From the 17 articles, 127 quotes were extracted and analysed. Accordingly, three analytical themes were developed: (1) invitation to conversation and care, (2) residents' surrogates decision-maker and (3) nurses are the key.

3.1 | Invitation to conversation and care

The first theme, 'invitation to conversation and care', concerns family members' experience of the initial ACP conversation. The ACP

conversation initiated discussions about dying and death for the residents since family members considered the discussion very difficult. Additionally, in the ACP conversation, family members needed support from nursing home staff for their decision-making.

Although the importance of timely discussion regarding ACP was shared by family members, ACP and subsequent death were difficult subjects to discuss with residents. Some residents could not accept their death, and others were unwilling to talk about ACP with their spouses and children.

I have never talked about that with my husband because he had not accepted that he was ill. So, we have not talked about his wishes. (Bollig et al., 2016)

In her [the patient/mom] world, I was a child. Her child. She wished to spare me a little ... I think she wanted them to avoid speaking about it [end-of-life issues] when I was there. (Kastbom et al., 2020)

When the ACP conversation for the resident could be started by invitation from the nursing home staff, not only the resident but also family members may not be prepared for the resident's dying and death. Therefore, the initiation of ACP conversations helped family members realize residents' deaths.

TABLE 2 Summary of included articles.

No	Author (first), year	Country	Aim	Setting	Participants	Methods	Findings (themes)
1	Andrews and Myall (2023)	United Kingdom	To understand the social process and interactions that underpin multi-professional working in United Kingdom nursing homes focusing on the meanings motivating the actions of all involved in ACP	Two nursing homes in United Kingdom	Six nursing home residents, Four relatives, 19 nursing home staff, and Seven visiting health and social care professionals	Ethnography	<ul style="list-style-type: none"> Relationship continuity Information sharing Coordinating multi-professional ACP Relatives' involvement in ACP
2	Bollig et al. (2016)	Norway	To study the views of cognitively able residents and relatives on ACP, end-of-life care, and decision-making in nursing homes	Nine different Norwegian nursing homes	43 informants including 25 nursing home residents and 18 relatives	Interpretive description Semi-structured in-depth interviews with nursing home residents Focus group interviews with relatives	<ul style="list-style-type: none"> ACP: wait and see Wishes for end-of-life care: pain relief and company Decision-making: It will be all right!—Won't it?
3	Cousins et al. (2022)	United Kingdom	To understand: barriers and facilitators to implementing the intervention; feedback regarding the content and information of the intervention; perceived impact of the intervention in relation to knowledge and changes to practice.	Eight nursing homes (three from Northern Ireland, three from England and two from Scotland)	35 care staff and 19 family members	Qualitative case study design	<ul style="list-style-type: none"> Training and information needs Training and information accessibility Training and information context Encourage conversations
4	Dekker and Bolt (2022)	Netherlands	To explore how end-of-life care planning for people with dementia is experienced and perceived in practice	Nursing homes in different regions in Netherlands	People with dementia, family caregivers, professional caregivers and bereaved family caregivers (Number not specified)	Secondary analysis of qualitative data	<ul style="list-style-type: none"> A paradox of control Present and future wishes A matter of responsibility Avoiding end-of-life conversations
5	Hickman et al. (2021)	United States	To better understand the reasons for discordance between current preferences and documentation	26 nursing facilities in Indiana	26 residents and 25 surrogates	Qualitative descriptive	Reasons for discordance <ul style="list-style-type: none"> Problematic nursing facility practices Missing information Deferring to others Re-evaluating what is best Inability to remember or explain Reasons for discordance <ul style="list-style-type: none"> No change/unlikely to improve Substituted judgement Stable preferences/no insight

(Continues)

TABLE 2 (Continued)

No	Author (first, year)	Country	Aim	Setting	Participants	Methods	Findings (themes)
6	Ingravallo et al. (2018)	Italy	To explore the attitudes of nursing homes residents and family members toward ACP and their opinions as to the right time to broach the subject, the manner in which it should be approached, and the content of ACP	Four Italian nursing homes	30 residents and 10 family members	Qualitative study	<ul style="list-style-type: none"> Life in the nursing home Future plans and attitudes toward ACP Contents and manner of ACP
7	Jeong et al. (2011)	Australia	To report the findings of a case study that explored the phenomenon of ACP and advanced care directives in residential care settings in Australia.	Two teaching hospitals and 20 residential facilities	11 family members	Case study	The participants' early experiences with ACP were expressed in unpleasant, hostile and negative ways. However, those emotions and concerns were transformed to more stable, amenable and positive attitudes and feelings as issues were resolved. The factors that enhanced or inhibited the transition were described.
8	Kastbom et al. (2020)	Sweden	To explore family members' experiences of ACP in nursing homes.	Four nursing homes in Sweden	18 family members	Inductive latent approach with thematic analysis	<ul style="list-style-type: none"> Elephant in the room Also silent understanding Significance of small details Invisible physician, supporting nurse Feeling of guilt
9	Klemmt et al. (2020)	Germany	To explore wishes and needs, such as existing and preferred communication processes, of residents and relatives regarding medical and nursing planning at the end of life.	Seven nursing homes in Germany	24 residents and 8 relatives	Qualitative descriptive	<ul style="list-style-type: none"> Wishes and needs in relation to the end of life Communication structuring for wishes and needs Documentation of wishes and needs Decision orientation and decision behaviour Understanding of autonomy and dignity at the end of life
10	Lee et al. (2019)	Taiwan	To develop an ACP interview guideline and care model to facilitate the process of ACP for residents and their families in long-term care facilities	A nursing home in Hualien city	Ten residents, 20 families and four medical staff	Action research	<ul style="list-style-type: none"> Opening the conversation with the interview guidelines about the life story of residents Continuing life stories to the quality of remaining years of the residents Gradually changing the topic to the end-of-life care issues Concluding the conversation by explaining the content of advance directives and hospice care

TABLE 2 (Continued)

No	Author (first), year	Country	Aim	Setting	Participants	Methods	Findings (themes)
11	Mayahara et al. (2018)	United States	To describe the ACP process for nursing home residents and identify common concerns regarding ACP	One nursing home located in the poorest neighbourhoods in New York City	Four nursing home residents and 10 family members or friends	Secondary data analysis of videotaped palliative care consultations	Three primary phases: <ul style="list-style-type: none"> • assess resident's status regarding end-of-life care, which includes establishing common language; identifying resident's unrealistic goals and wishes and identifying inconsistencies between resident's expressed wishes and the preferences documented in medical record; • negotiate realistic plan of care, which includes addressing inconsistencies between resident's and family's goals; rephrasing goals and wishes in hypothetical scenarios and clarifying goals; • create action plan, which includes complete advance directives and revisit/revise in the future as needed.
12	Rainsford et al. (2021)	Australia	To explore the experience of participating in ACP discussions facilitated through multidisciplinary case conferences from the perspectives of families, staff and health professionals.	Two residential aged care facilities in one Australian rural town	Four family members, five staff, six health professionals	Qualitative study	<ul style="list-style-type: none"> • How the project works (implementation) • Traversing difficult terrain • Impact of case conferencing on ACP • Thinking beyond the project
13	Sævareid et al. (2019)	Norway	An implementation study including key stakeholder patients, next of kin, and healthcare personnel using a whole ward system approach to ACP	Four nursing homes	Nine nurses, one physician, four nursing aide, five patients, seven next of kin	Qualitative study	<ul style="list-style-type: none"> • ACP—a valued experience • The significance of ACP <ul style="list-style-type: none"> - For a stronger patient focus - For building trusting relations - For discussing end-of-life care - For the nursing homes
14	Stewart et al. (2011)	United Kingdom	To explore views on ACP in care homes for older people	All care homes for the elderly in two London Boroughs	34 staff (nurses and care assistants), 15 family and friends and 14 residents	Qualitative exploration	<ul style="list-style-type: none"> • Benefits • Barriers • Facilitators
15	Stone et al. (2013)	United Kingdom	To explore the experience of staff, residents, and families having ACP discussions in nursing care home context	Three nursing care homes	15 resident-family-staff triads	Qualitative descriptive	<ul style="list-style-type: none"> • Understanding ACP • Undertaking ACP discussions, • Impact of and reactions to ACP discussions

(Continues)

TABLE 2 (Continued)

No	Author (first, year)	Country	Aim	Setting	Participants	Methods	Findings (themes)
16	Sussman et al. (2022)	Canada	To (1) explore when, how, and with whom ACP discussions should be introduced and (2) identify conditions thought to challenge and support ACP communication between residents and/or their families/friends and staff within a long-term care environment	Four long-term care homes	35 residents and 16 family members	Interpretative descriptive approach	<ul style="list-style-type: none"> Relational connections with staff are more important than staff rank for ACP engagement Time and opportunities for meaningful exchanges with all staff in long-term care are limited A compassionate environment for the living and the dying is an important precondition for ACP engagement
17	Thoresen and Lillemoen (2016)	Norway	To add insights to the complexity of ACP-conversations and illuminate how a family ethics perspective may improve the quality of the ACP and promote nursing home patients' participation in ACP	Eight nursing homes	Seven patients, 10 relatives 19 staff	Qualitative study	<ul style="list-style-type: none"> Patients and relatives are perceived as an intertwined unit Relatives' involvement and participation in ACP-conversations is significant to get to know what is important in the patients' lives Families share experiences of dying and death

Then she [nurse] said, well, shall we start the IV? And I said, how? Start the IV? But then he will die. Yes, she replied, but we discussed this, right? I said yes, we did discuss it, but- (...) And then it started to hit me, Jesus, he is going to die. (Dekker & Bolt, 2022)

However, when ACP conversations include medical perspectives, it can be difficult for family members to understand and make care decisions. After the nursing home staff provided information to family members using ACP, family members felt empowered and supported in the ACP conversation by the staff members.

... Who's the one to make the decision [about treatment limits]? It was so difficult for me to make the decision, but I didn't know who else would make it. Maybe, it's me, but I also wanted health care staff to tell me that this would be the best in this case ... What if I say the wrong thing... (Kastbom et al., 2020)

It's made me realise...I have the right to be involved...I can say, I want to be involved. I want to be made aware...on a regular basis of any decisions that are made. (Cousins et al., 2022)

Additionally, conversations with the nursing home staff supported family members by ensuring the residents' safety and comfort.

I feel safe because they are interested in knowing my mother better, kind of learning about her situation, how it was before and how things are now, and at the same time to inform me... The most important part of the conversation is to know that my mother is in safe hands and this is comforting me. (Sævareid et al., 2019)

3.2 | Residents' surrogate decision-makers

The second theme, the resident surrogate decision-makers, considers the family member's role in the end-of-life decision-making process. Some residents invited family members to play a surrogate role in the ACP decision-making process. However, other family members' involvement in ACP decision-making on behalf of the resident is due to the resident's lack of capacity.

He has a cognitive impairment which has already been evident for some time, so I don't think he is able to make decisions. (Ingravallo et al., 2018)

I think just the role that I'm in now, that as soon as somebody asks him a question, he talks to me about it. (Andrews & Myall, 2023)

The family member's surrogate role in ACP decision-making was justified by the reflection of the resident's wishes. Family members were confident in representing the residents' wishes in the ACP decision-making process. Some family members had conversations with the resident regarding their wishes at the end of life, whereas other family members considered that they knew the resident very well to notice the resident's wishes.

I know that's what dad wanted and he and my mom had both, they had everything all planned out so it wasn't hard to go ahead and do that because I knew what he wanted. (Hickman et al., 2021)

I know her so well, I know what matters to her.
(Thoresen & Lillemoen, 2016)

Therefore, family members perceived respect for residents' wishes as the fundamental purpose of residents' surrogate role in ACP decision-making. When the residents expressed a wish for a comfortable and natural death, their family members felt relieved to continue ACP decision-making. Family members were devoted to ensuring the residents' comfort at their end of life. However, sometimes, if the resident's wishes do not agree with natural death, the ACP decisions become difficult and problematic.

So [the nurse] said 'sure, the notes tell me that's what your wishes are...I'll take these things away, but I'm going to ring your daughters because they'll want to come and make sure you're comfortable'. And she was just very comfortable and drowsy and we just sat with her. [Two days later] she was gone...it was perfect, it was everything she wanted. (Rainsford et al., 2021)

My mother will not do this. She expressed no such wish. Sadly this is the case. She is someone who goes along with things, and whatever is decided will be done. Sometimes, this can also be a problem, because even the employees may not know what she actually wants or what she says to us. Indeed, it is difficult. (Klemmt et al., 2020)

3.3 | Nurses are the key

Family members considered nurses to play a key role in the ACP decision-making process. The ACP decision at the nursing home was not considered a medical decision but rather a communication to achieve the resident's comfort and to respect the resident's wishes. Additionally, ACP in nursing homes was not a decision but rather a beginning of the continuum of end-of-life care. Family members wished to connect with the nursing home staff to ensure the residents' comfort.

It should be someone that connects with your family member. So, for example, my grandma has a few PSWs [personal support workers] that she loves, but the ones that show the affection you know she feels comfortable with. Even being there, I think, would be really important for the resident to feel like they're being heard and they have someone that cares about them (Sussman et al., 2022)

Although family members valued communication with nursing home staff regarding the residents' ACPs, physicians were not available on a continuum. Family members illustrated that they had few chances to speak to physicians after the resident's nursing home admission.

We only saw the physician once or twice for the whole period [NH resident living at the NH for 14 months]. I cannot say anything about him ... How he was ... (Jeong et al., 2011)

Therefore, family members appreciated the nurse's presence next to the resident since they could approach nurses when they wished. The nurses met the family members' needs for availability and supported them through communication.

When I looked for him [the nurse] he always had time for me when I caught him in the corridor ... And he always said I could contact him whenever I needed, and also afterwards if I wished to have a support dialogue or something like that. (Kastbom et al., 2020)

Last, family members recognized nurses' care as the key to achieving residents' comfort at their end of life. Family members considered that nurses' care contributed to the purpose of ACP and residents' wishes for comfortable and peaceful dying and death.

...actually, I think she's doing better since she is there. They make her get up and they can get her to the bathroom and they can get her to do the things that she needs to do... I think her health is a little bit better. So that's probably a little bit of [the reason for the change in preference]. (Hickman et al., 2021)

Well, the good things were when the time was to come, you know they [the staff] did make them comfortable. They did put them in the bed, you know like if they were really close to that time and made sure that they had the cloth on them and they were changed. I have to say the staff is very good that way ... so yeah they still looked after the residents that way when it came time. (Sussman et al., 2022)

4 | DISCUSSION

The findings of this meta-synthesis study show the experiences of family members with ACP in nursing homes across different countries. When dying and death are difficult topics to discuss in a family, the ACP and nursing home staff initiated conversations regarding a resident's dying and death in the nursing home. The value and priority in the ACP process were very clear, as the residents were comfortable with dying and dying. Additionally, ACP was considered not a momentary decision but a continuum of conversations between residents, family members and nursing home staff until the resident's death. From the perspective of ACP as a continuum of conversation, nurses' roles were distinctly recognized by family members due to their presence next to residents and family members.

First, family members considered that ACPs enabled conversations about nursing home residents' death because they considered the topic difficult to discuss between residents and family members. Accordingly, family members were satisfied with the ACP conversation and the subsequent quality of life of nursing home residents (Martin et al., 2016; Ng et al., 2022). However, studies have reported insufficient timing of ACP initiation before a nursing home resident's imminent death (Paque et al., 2019; Ten Koppel et al., 2019; Walczak et al., 2017). Indeed, a high proportion of ACP discussions were initiated when nursing home residents were dying (Cheng et al., 2019). The difference between family members' satisfaction with the quality of life of nursing home residents after ACP conversation and the delay in ACP conversation initiation reflects differences in their perceptions of ACP. While the effectiveness of ACP could be evaluated by its timing and outcome (Dixon et al., 2018; Garland et al., 2022), family members' perceptions value the process as a continuum of conversation and trustful relationships between the resident, family members and nursing home staff (Sævareid et al., 2019).

Second, family members perceived their role in the ACP conversation as that of the resident's surrogate decision-maker. Considering the high prevalence of cognitive impairment among nursing home residents (McGlade et al., 2017; Verreault et al., 2018), family members are often invited to make end-of-life decisions in nursing homes. Family members' participation in a person's end-of-life decision-making has been justified by the notion of family members as the closest and next-of-kin of a person without capacity (Batteux et al., 2019) and legal and cultural duty as a family member (Choi et al., 2023; Lin et al., 2017). The findings add to the justification of family members' surrogate decision-making role as the resident's voluntary invitation.

Since family members perceived and justified their role as surrogate decision-makers, the achievement of the ACP goal, a resident's comfortable and natural death, relied on the family member's considerations of the ACP. These findings are linked to the impact of family members' willingness and ability to participate in ACP (Gilissen et al., 2017) and a study in which staff members considered that family members are either facilitators of or barriers to ACP

conversation (Sharp et al., 2018). Therefore, awareness that family members are not only surrogate decision-makers in ACP conversations but also in need of support from professionals is needed. Awareness was also found in the findings of family members' appreciation of ACP.

Many Asian research studies have reported that elderly residents in nursing homes rely on their family members to make important medical decisions, including do-not-resuscitate orders (Cheng et al., 2019; Hong et al., 2019; Ivo et al., 2012; Lee et al., 2016; Ni et al., 2021; Tang et al., 2016), which affects the autonomy of residents and leads them to rely on family members to make EOL decisions (Chan et al., 2018; Cheng et al., 2019; Lee et al., 2016; Mo & Mak, 2009).

Finally, the theme of 'nurses are the key' is meaningful for identifying nurses' roles in the ACP process from the perspective of family members. Nurses were considered key persons in the continuum of ACP communication and carers who played an essential role in residents' comfort in dying and death. This theme supports the findings of a meta-synthesis study regarding nurses' role in palliative care, which identified nurses' role in coordinating and being present (Sekse et al., 2018). Although Sekse et al. (2018) had the limitation of using nurses' perspectives only to clarify nurses' roles in palliative care, the findings of this study provide a family member perspective that recognizes nurses' roles. However, the description of the nurse's role from the family member's perspective cannot be as detailed as the nurse's description. The role of nurses in ACP communication identified in this review differed from that identified in other studies. For example, nurses' involvement in the end-of-life decision-making process in intensive care units was not distinct due to their cautiousness in their relationship with family members (Choi et al., 2023). Similarly, a thematic synthesis reported that nurses' roles in the end-of-life decision-making process in intensive care units varied by context due to the tensions between interdependent collaboration and hierarchical roles (Choi et al., 2024). The reasons for nurses' invisible roles in the end-of-life decision-making process in intensive care units were external, relationships with family members or physicians, not internal limitations regarding professional capacity. Therefore, the findings of this study can support the potential of nursing professionals to expand their roles in end-of-life decision-making processes in different settings.

4.1 | Limitations

This study may have methodological limitations in terms of meta-synthesis since the ontology and epistemology of qualitative studies and review studies could differ. Meta-synthesis has been criticized since it quantifies qualitative studies for the purpose of generalization by aggregating qualitative findings (Sandelowski & Barroso, 2006). Therefore, this study chose thematic synthesis, which aims at interpretation, instead of generalization (Thomas & Harden, 2008).

The other limitation of the findings in this review is the lack of information on cultural aspects of ACP experiences, as none of the included studies were conducted using ethnography. This means that studies focusing on the cultural context of ACPs have not been conducted.

5 | CONCLUSION

Considering the importance of family members' roles in ACP conversations in a nursing home setting, this study provided an in-depth understanding of family members' perceptions and experiences of ACP by synthesizing qualitative studies. However, the limitations of this review inform that future studies could explore the cultural aspects of the ACP process in nursing homes to contribute to person-centred care, acknowledging contextual diversity. Additionally, the contextual rationales and justifications of the surrogate decision-making process for ACP nursing home residents should be explored through empirical studies.

AUTHOR CONTRIBUTIONS

Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data: H.R.C., H.N.C., S.J., X.L., T.W., C.-C.L. Involved in drafting the manuscript or revising it critically for important intellectual content: H.R.C., H.N.C. Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content: H.R.C., H.N.C., S.J., X.L., T.W., C.-C.L. Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: H.R.C., H.N.C., S.J., X.L., T.W., C.-C.L.

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CONFLICT OF INTEREST STATEMENT

The authors declare there is no conflict of interest.

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DATA AVAILABILITY STATEMENT

Data available on request from the authors.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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