

What are essential elements of end-of-life communication for people with dementia and their informal caregivers in healthcare?

A scoping review

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Abstract

Background: To date, dementia cases are increasing due to an ageing population. Knowing that dementia reduces life-expectancy, timely end-of-life (i.e. EOL) care planning is important. The process of having these conversations and documenting this, is referred to as ‘advanced care planning’ (i.e. ACP). These conversations concern healthcare, the future and wishes regarding healthcare. Acquiring a sufficient EOL care plan through conversation is challenging in people with cognitive impairment as the ability to consider future thoughts and actions becomes comprised, thus affecting the ability to make decisions. The aim of this scoping review is to gather information about the essentials that underpin good EOL communication which, in turn, provides a basis for proper ACP in general.

Methods: A scoping review method. Data sources were found through a search in the bibliographic database of PubMed. The PCC framework of Aromataris and Munn (2020) guided the search for eligible literature. Included articles considered people with dementia and the communication process concerning EOL care. The study design of articles had to be qualitative. Data were analysed using thematic analysis in order to identify relevant themes from the findings of the included records.

Results: The literature search yielded 478 articles, of which 10 met the inclusion criteria. Themes that were found were: 1) Clear explanation of clinical information and ACP; 2) Clear role differentiation; 3) Facilitating communicative skills; 4) Building relationships; 5) Education; 6) Sufficient time; 7) Emotional support for Health Care Professionals; 8) Tools; 9) Enough resources and funding.

Discussion: The outcomes of the scoping review represent elements facilitating EOL conversations. This is also confirmed in other studies. The elements found in this scoping review, are often intertwined. However, in current practice the facilitating elements are sometimes considered a barrier. Therefore, future research should focus on finding a feasible method on how to introduce these facilitating elements in practice.

1. Introduction

Worldwide, there are 50 million cases of dementia with an incidence of 10 million per year. The incidence increases with age, and as we have a worldwide aging population this is a growing problem (World Health Organization, 2020). The WHO (2020) describes dementia as: *‘A syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities’*. It is a progressive neurodegenerative disease which significantly reduces survival (Denning, Jones, & Sampson, 2011). Therefore, planning the end-of-life (i.e. EOL) care is more important, especially in people with dementia (i.e. PWD) as this subject must be broached timely while they retain cognitive capacity (Bamfort et al., 2018; Chmelik et al., 2016).

The process of having these conversations and documenting this, is referred to as ‘advanced care planning’ (i.e. ACP). These conversations concern healthcare, the future and wishes regarding healthcare. There are a lot of different terms, definitions and recommendations concerning ACP worldwide. Research and discussions about ACP would benefit from a uniform definition in practice. Hence, Rientjes and colleagues (2018) defined ACP – in short – as: *‘A process that empowers people to set goals and formulate preferences for future medical treatment and care, discuss these goals and preferences with family and caregivers, and document these preferences and, if necessary, revise’*. This paper will use ACP accordingly.

ACP can be itemised into multiple goals. Fleuren and colleagues (2020) state these goals as the following: 1) respect individual autonomy, 2) enhance quality of care, 3) reinforce relationships with loved ones, 4) prepare for EOL phase, and 5) reduce undesirable or unnecessary treatments. As ACP is a process of communication and focusses on the EOL care, EOL communication is of high importance within this process.

However, when it comes PWD and their informal caregivers, it seems more challenging to have proper, integral and timely conversations about the desired care for the last phase of their life. Because of the gradual functional decline in dementia, ACP – and the accompanying communication process – it is difficult for PWD as well as health care professionals (i.e. HCPs) (Zieschang et al., 2012). Due to the gradual functional decline in PWD the ability to consider future thoughts and actions becomes compromised, thus affecting the ability to make decisions (Denning, Sampson & De Vries, 2019). Also, the disease trajectory in their individual case is not possible to predict (Poppe, Burleigh, & Banerjee, 2013). Furthermore, while people with, for instance, cancer face a relatively clear terminal phase, dementia is often not recognised by

physicians as a terminal condition (Zieschang et al., 2012). Therefore, it is challenging to time the initiation of ACP and the accompanying conversations (Poppe et al., 2013).

Furthermore, multiple studies elucidate that people with dementing illnesses receive fewer referrals to EOL care or poorer EOL care than people who are not cognitively impaired (Sampson et al., 2005; Sampson et al., 2006; Cavalieri et al., 2002). Moreover, it becomes apparent from research by Dening and colleagues (2011) that prompts for discussions about EOL care are often triggered by medical events and changes to the financial and living situation of the PWD. Similarly, Banerjee et al. (2007) states that some studies sought to clarify when a ‘window of opportunity’ concerning ACP presents itself. However, this might indicate that the triggers are the leading cause of initiating a conversation about the EOL. Instead, Meeussen et al., (2012) conclude that early communication in order to explore wishes and appoint proxy decisionmakers is an important component of a timely ACP approach which appears to be initiated too infrequently.

Presently, EOL communication with regard to PWD is not optimally executed. Discussing the EOL phase is often very difficult for PWD as most people are frightened by their indistinct prognosis and by death in general (Sellar et al., 2019; Nordtug et al., 2021). Furthermore, inadequate communication can create unnecessary emotional distress for informal caregivers (i.e. family members, friends, surrogates) and place additional burdens of stress and workload on staff (Stirling et al., 2014). Informal caregivers are often left unprepared to talk about EOL care and make effective decisions (Forbes, Bern-Klug, and Gessert, 2000). Also, Toles et al., (2018) state that proxy decisionmakers for PWD reported poor quality of EOL communication as they thought clinicians did not perform many communication behaviours that contribute to high-quality communication. According to Sellars (2019), good EOL communication would contribute to the families and/or carers experience and empower them.

Consequently, the healthcare professional plays a big role in the ACP process. The HCP is responsible for initiating ACP and guiding the EOL care and conversation (Bolt et al., 2021). This is a challenging task for HCPs. HCPs have reported distress when caring for dying patients in general (Liu et al., 2011) and starting the conversation about EOL without a clear (palliative) prognosis of the condition (Perin, Ghirotto, & De Panfilis, 2020). Furthermore research implies that it is unclear in ACP who takes the lead in EOL communication (Bolt et al., 2021).

To date, from research it seems that – in general – EOL care in PWD is insufficient and that communication about EOL care is challenging from multiple perspectives. According to Poppe and colleagues (2013) ACP has the potential to improve EOL care in dementia. However, to date it is not clear what ‘good EOL communication for PWD’ entails in general. Hence, this

review aims to gather information about the essentials that underpin good communication which, in turn, provides a basis for proper ACP in general. A better understanding of how to have these conversations, may help to cultivate the quality of the ACP process for PWD, their informal caregivers, and the HCPs. Furthermore, this scoping review aims to identify areas for future research and practice.

In conclusion, this scoping review aims to provide a summary of the elements that could facilitate EOL communication adopting the following research question: ‘What are essential elements of end-of-life communication for people with dementia and their informal caregivers in healthcare?’ In this research, multiple perspectives will be considered as they provide important information for the improvement of the ACP process.

2. Method

2.1 Research design

The design of this article is a scoping review. According to Khalil and colleagues (2016) scoping reviews: ‘(...) are used to assess the extent of a body of literature on a particular topic, and often to ensure that further research in that area is a beneficial addition to world knowledge.’ Scoping reviews do not tend to produce results that have been acquired from multiple evidence resources. Rather, scoping reviews aim to provide an overview or map of the existing evidence (Peters et al., 2020). This study design is useful as this research is performed in order to obtain an overview of the essential elements of EOL communication for people with dementia in healthcare. An analysis will be performed on scientific, qualitative literature related to this subject, in order to obtain an overview of the necessary elements.

This review was conducted, based on the scoping review framework from Arksey and O’Malley (2005) as described by Aromataris and Munn (2020). Peters and colleagues (2020) proposed some enhancements to the scoping review framework of Arksey and O’Malley (2005). With these adjustments the framework entails: ‘1) defining and aligning the objective(s) and question(s); 2) developing and aligning the inclusion criteria with the objective(s) and question(s); 3) describing the planned approach to evidence searching, selection, data extraction, and presentation of the evidence; 4) searching for the evidence; 5) selecting the evidence; 6) extracting the evidence; 7) analysis of the evidence; 8) presentation of the results; 9) summarizing the evidence in relation to the purpose of the review, making conclusions and noting any implications of the findings’ (Peters et al., 2020).

2.2 Data sources

In order to find relevant data concerning EOL communication in PWD, the search engine: 'PubMed' was used. This is a database which provides access to scientific articles concerning biomedical and genomic information. Therefore this database fits the research subject.

According to Aromataris and Munn (2020) a search strategy should aim to be comprehensive in order to identify scientific literature. The limitations in terms of the breadth and comprehensiveness of the search strategy should be detailed and justified. This was achieved through defining a comprehensive search string and establishing clear inclusion and exclusion criteria.

To specify the search in PubMed, a search string was developed. This was done using the PCC framework of Aromataris and Munn (2020). This framework requires the research question to specify the Population, Concept ('EOL communication in people with dementia') and Context ('healthcare'). The population is not specified as this scoping review aims to provide an overview of general experiences, opinions, models and theories concerning EOL communication with people PWD and their informal caregivers.

The following search string was employed: *((Dementia[Title/Abstract] OR Dementia[Mesh Terms] OR Alzheimer[Title/Abstract] OR Alzheimer[Mesh Terms] OR Alzheimer's[Title/Abstract]) AND (End-of-life[Title/Abstract] OR End of life[Title/Abstract] OR Palliative care[Title/Abstract] OR Terminal care[Title/Abstract])) AND (Communication[Title/Abstract] OR Conversation[Title/Abstract] OR Conversations[Title/Abstract] OR Documentation[Title/Abstract] OR Advance care planning[Title/Abstract] OR ACP[Title/Abstract]).*

Studies obtained by the search string were screened for their relevance based on in- and exclusion criteria. The PCC framework of Aromataris & Munn (2020) was leading in selecting these criteria.

In order to be included, studies had to focus on PWD, the EOL phase (i.e. palliative care or EOL care), and communication processes. Moreover, only qualitative studies were included in order to obtain an in-depth understanding of the subject. Additionally, the studies had to be written in either English or Dutch. Furthermore, studies were not excluded when different perspectives on EOL communication with PWD were discussed (i.e. PWD, HCPs and informal caregivers).

In order to restrict the number of included articles, an exclusion criterium was formulated. When articles did not focus specifically on the EOL communication process, the articles were excluded.

2.3 Data-collection

At first, EndNote X8 was used in order to find duplicates. The articles, resulting from the search, were selected on their eligibility through scanning the title and abstract of each hit by the inclusion and exclusion criteria. The remaining records were imported to EndNote X8 for further examination on full text. The full text was looked at, using the inclusion and exclusion criteria, and therefore more articles were excluded. Eventually, the possibly relevant systematic reviews that were excluded – due to study design – were screened for eligible articles in their reference list. Through peer review, a consensus on the final list of included article was reached.

From the eventually relevant studies, data was extracted using an extraction form. This is a common method in literature reviews (Aromataris, & Munn, 2020). This form comprised the following aspects: authors, year of publication, country, title, study design, study objective(s), main findings regarding EOL communication in PWD, and reported recommendations. In this extraction form, all relevant information extracted from the articles, is described.

2.4 Data-analysis

A qualitative approach on this subject which allows open discussion was deemed necessary due to the scarcity of available data and this studies' exploratory nature. Consequently, the data were analysed using thematic analysis.

Aromataris and Munn (2020) state that: '*A descriptive summary should accompany the tabulated and/or charted results and should describe how the results relate to the review objective/s and question/s*'. So, data were extracted from the selected articles and qualitatively analysed using the NVivo 11 program. The author looked at relevant findings of the included studies, focussing on the result section and the recommendations of the study. Sentences that represented different outcomes of the included studies were separated. These fragments were labelled with codes using an inductive approach. This means that codes were derived from the data, and were not established in advance using existing literature. Throughout the process, these codes were modified. Eventually, after coding all relevant data from the articles, the author conceptualised the codes into 9 themes. These themes were used to provide an answer to the research question. Subsequently, the collected data were tabulated, described and it was argued why this relates to the reviews' objective. Therefore, the results are presented in a descriptive manner and each theme is discussed thoroughly.

3. Results

3.1 Literature search

In order to find eligible records, the final search string was applied in the database of PubMed at the 18th of May 2021. This search accumulated 478 records. Subsequently, records that were not eligible were excluded. Figure 1 shows the selection procedure and indicates the reasons for exclusion.

After removal of duplicates (n=1), 477 articles remained. Scanning the title and abstract of the records resulted in the exclusion of 437 records. These records were excluded due to lack of information on the right topics (n=348), language of the publication (n=3) and the study design (n=86). The remaining 40 potentially relevant articles were assessed on their full texts eventually leading to a total of 10 eligible articles for this scoping review. Excluded systematic reviews were screened on eligible records in their reference list, however, this did not accumulate extra articles.

3.2 Article information

Eventually, 10 articles are included in this scoping review (Hill et al., 2018; Ingravallo et al., 2018; Kim et al., 2018; Kim et al., 2019; Lawrence et al., 2011; Poppe et al., 2013; Spacey et al., 2021; Stirling et al., 2014; Perin et al., 2020; Saini et al., 2016). Of these records, one study (Stirling et al., 2014) was part of a larger mixed-methods study. In order to keep in line with the inclusion criterion, only the qualitative data of this study were included. Furthermore, the studies were conducted in the United States (n=3), Italy (n=2), the United Kingdom (n=4), and Australia (n=1). The year of publication ranges from 2011 to 2021. Table 1 provides a limited summary of the study characteristics of the included articles. A more elaborate depiction of the study characteristics can be found in Appendix A.

3.3 Summary of the identified themes

The identified themes represent the essential elements facilitating EOL communication for PWD and their informal caregivers. The themes are: 1) Clear explanation of clinical information and ACP; 2) Clear role differentiation; 3) Facilitating communicative skills; 4) Building relationships; 5) Education; 6) Sufficient time; 7) Emotional support for HCPs; 8) Tools; 9) Enough resources and funding. Appendix B shows citations from the articles that refer to the established themes. It should be noted that the term ‘informal caregiver’ is used in broad context to include multiple terms utilised by the articles such as ‘family members’, ‘relatives’, ‘carers’ and ‘surrogates’.

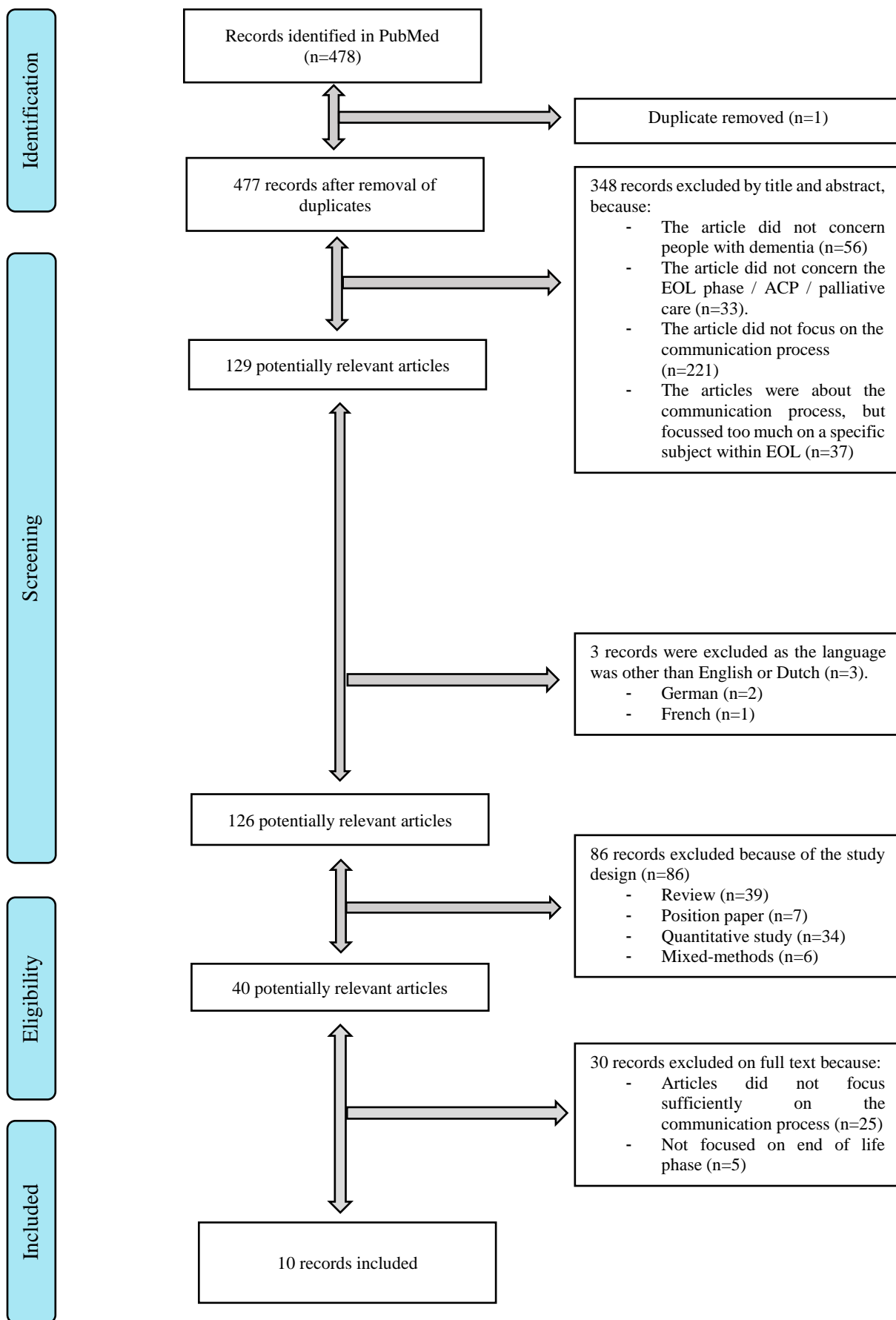


Figure 1. Flow diagram

Table 1: *Summary of study characteristics*

Authors, Year of Publication, Country	Title	Study objectives
Hill et al., (2018) United States	‘Staff perspectives of barriers to access and delivery of palliative care for persons with dementia in long-term care.’	This study investigated experiences of long-term care staff delivering palliative care to PWD and the way care is delivered. Also, the study aimed to learn which guidelines were used, and whether policies affected the delivery of palliative care.
Kim et al., (2018) United States	‘Surrogates’ experiences of engaging in physician orders for life-sustaining treatment discussions for persons with advanced dementia.’	This studies describes the experiences of family surrogates’ with POLST ¹ discussions with primary care providers.
Ingravallo et al., (2017) Italy	‘Discussing advance care planning: insights from older people living in nursing homes and from family members.’	This study aimed to explore the attitudes of NH residents and family members toward ACP ² 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.
Kim et al., (2019) United States	‘Exploring provider-surrogate communication during POLST discussions for individuals with advanced dementia.’	This study explored the communication between provider and surrogate during POLST discussions for PWD.
Lawrence et al., (2011) United Kingdom	‘Dying well with dementia: qualitative examination of end-of-life care’	This study aimed to define good EOL care for PWD and it aimed to identify how to deliver this across care settings in the UK.
Poppe, Burleigh, & Banerjee (2013) United Kingdom	‘Qualitative evaluation of advanced care planning in early dementia (ACP-ED)’	The aim of this study was to explore if ACP could be discussed with PWD, shortly after diagnosis.
Stirling et al., (2014) Australia	‘A tool to aid talking about dementia and dying – Development and evaluation.’	The objective of the study was to evaluate a tool aimed at facilitating communication between Advanced Care Facilities staff and family members of PWD.
Spacey et al., (2021) United Kingdom	‘A critical realist evaluation of advance care planning in care homes.’	The aim of this study was to evaluate ACP of EOL care in care homes.
Perin, Ghirotto, & De Panfilis (2020) Italy	‘“Too late or too soon”: The ethics of advance care planning in dementia setting.’	This study aimed to frame the perception of physicians caring for PWDs regarding ACP. Another aim was to describe the physicians difficulties and needs.
Saini et al., (2016) United Kingdom	‘An ethnographic study of strategies to support discussions with family members on end-of-life care for people with advanced dementia in nursing homes.’	This study aimed to examine practices relating to EOL discussions with family members of PWD in NHs and to explore strategies to improve practice.

¹ POLST: Physician orders for life-sustaining treatment

² ACP: Advance care planning

3.3.1 Clear explanation of clinical information and ACP

Findings from multiple studies showed that a providers' clear explanation of clinical information helps informal caregivers to process this information and is an important part of having proper conversations (Kim et al., 2018; Kim et al., 2019; Ingravallo et al., 2019). Because, when informal caregivers understand what the conversation is about, the decision making process is improved. This will increase the participation rate of informal caregivers in the conversation, which will result in higher quality-communication (Kim et al., 2018; Kim et al., 2019). Furthermore, clear explanation of the ACP process will clarify misunderstandings (Poppe, et al., 2013) and therefore contribute to the communication process. In addition, providers need to be aware of the possible low education level of PWD and informal caregivers: *“Many residents expressed little confidence in their communication skills, (...), or due to their low educational level (...).”* (Ingravallo et al., 2018).

Thus, clear explanation of clinical information – tailored to the education level of the PWD and/or informal caregivers – facilitates the communication process (Kim et al., 2018; Kim et al., 2019; Ingravallo et al., 2018).

3.3.2 Clear role differentiation

Within this theme, there is a distinction in two ways of role differentiation. At first, a clear role differentiation between HCPs facilitates the conversation. From the results of Hill and colleagues (2018) it becomes apparent that there is no clarity about whose task it is to initiate conversations about the EOL and EOL care. However, Ingravallo and colleagues (2018) as well as Siani and colleagues (2016) find that an independent outsider can: *“(...) act as a primer and catalyst for ACP conversations”* (Ingravallo et al., 2018). Siani and colleagues (2016) state that this independent person or team can introduce an alternative view on the wishes and needs of PWD. They identified this as a key strategy for promoting EOL discussions. Furthermore, Ingravallo and colleagues (2018) also state that the physician was, followed by the nurse, most frequently cited by residents as the best person to have ACP discussions with.

Another way of looking at role differentiation is the differentiation between informal caregivers and HCPs. According to findings from Kim and colleagues (2019) discussing preferred roles in the communication process is important. Providers should not assume that all informal caregivers wish the same level of responsibility. Therefore, open communication about role differentiation is recommended as it would facilitate the communication process.

3.3.3 Facilitating communicative skills

During the conversation, HCPs can perform several communicative skills which contribute to the conversation. Communicative skills of providers that are found to be helpful include: making time for informal caregivers to ask questions; making time for informal caregivers to comment; making time for informal caregivers to reiterate what providers explained; being sensitive to the informal caregivers; listening to the informal caregivers; understanding the needs of the informal caregivers; being open to the statements of the informal caregivers; being interested in the feelings of the informal caregivers; communicate their personal knowledge about the patient to the informal caregiver; expressing the concerns for the informal caregivers; supporting the informal caregivers opinions and decisions; listening actively to the informal caregivers (Kim et al., 2018). When HCPs execute these skills, informal caregivers feel respected, cared for and understood (Kim et al., 2018). Moreover, Poppe and colleagues (2013) also state in their findings that being perceptive and sensitive about how PWD feels facilitates the discussion.

The quote of Kim and colleagues (2019) in Appendix B shows that: “(...) *asking about a surrogates’ expectations about the trajectory of dementia and life-sustaining treatments (...)*” is something that is not executed optimally but would, also, facilitate the communication process.

3.3.4 Building relationships

From the studies of Ingravallo and colleagues (2018) and Perin and colleagues (2020), it becomes apparent that building a relationship with the HCP is important to PWD and their informal caregivers. In these studies, informal caregivers, PWD and HCPs stated that they found closeness, trust and consistency very important when talking about the EOL, proving that building a good relationship contributes to the conversation. Kim and colleagues (2019) confirm this by stating: “*Our findings also show that all providers demonstrated several strategies for communicating emotional support, which is critical to building relationships with surrogates.*” The focus on the provision of psychological support and building a good relationship is seen as a facilitator for ACP (Lawrence et al., 2011; Poppe et al., 2013; Siani et al., 2016).

HCPs stated that consistent staffing is important (Hill et al., 2018). Inconsistent staffing, in this case, meant too much part-time staff. Relationships with part-time staff are considered less strong than with full-time staff. Reasons were given such as that part-time staff switched between floors, units and facilities and staff participants also stated that: “*Part-time staff were*

also less likely to be trained in palliative care techniques.” (Hill et al., 2018). From this research it becomes apparent that full-time staff would facilitate relationship building which in turn is important in order to have sensitive conversations about the EOL.

Furthermore, HCPs stated that relationships could be fostered by initiating the conversation about the EOL and its care during admission interviews with the informal caregivers (Hill and colleagues, 2018).

3.3.5 Education

From the quotes in Appendix B it becomes apparent that educating informal caregivers about dementia and its dying process facilitates the conversation as the informal caregivers would be able to contribute more into the conversation (Hill et al., 2018; Siani et al., 2016).

Furthermore, the insecurity of staff about initiating EOL conversations was a recurrent theme. They were anxious to upset PWD or their informal caregivers in the process (Hill et al., 2018; Poppe et al., 2013; Spacey et al., 2021; Perin et al., 2020). This becomes apparent from the following: *“Participants reported that communication between staff and family was challenging. Families, especially those ill-informed about the dying process, could become emotional, aggressive, irrational, and distressed (...).”* (Hill et al., 2018); *“Staff considered end of life care the most challenging aspect of the ACP discussion because they felt the topic could cause some anxiety in patients.”* (Poppe et al., 2013); *“Discussing future treatments at the very beginning of the care path triggers emotional concerns.”* (Perin et al., 2020). Hence, HCPs would, at times, avoid sensitive discussions, rush them, or directly go to the next of kin and avoid PWD (Spacey et al., 2021).

Because HCPs are often not prepared for the possible reactions PWDs and informal caregivers (Perin et al., 2020), education in order to prepare staff better would be facilitating to the conversation (Hill et al., 2018; Poppe et al., 2013; Perin et al., 2020; Siani et al., 2016).

Siani and colleagues (2016) find multiple education methods for staff that seem to be helpful. The first method was shadowing (observation of other colleagues). This was used to train less experienced staff to engage in EOL conversations: *“(…) assistants found methods such as shadowing to be effective due to the ‘practical’ nature of their job rather than having more formal education.”* (Spacey et al., 2021). The second and third method are workshops and videos. These methods were advantageous mainly because they tend to include more diverse NH staff (e.g. housekeeping).

Subsequently, if these education methods are effective, HCPs become more confident in engaging into the conversation about the EOL care which, in turn, contributes to a higher quality communication process.

3.3.6 Sufficient time

To better the EOL conversation, time is an important factor (Hill et al., 2018; Ingravallo et al., 2018; Kim et al., 2018; Lawrence et al., 2011; Poppe et al., 2013; Spacey et al., 2021; Siani et al., 2016). HCPs need time in order to build relationships with informal caregivers and deliver continuous care and EOL conversations. However, time is often lacking: *“Getting to know the individual’s (...) was identified as a difficulty within general hospitals, as staff did not have the advantage of spending time with the individual and their families over a long period.”* (Lawrence et al., 2011). Multiple studies confirm that having proper and continuous conversations about the EOL (care) requires time, which is often discrepant with the current task-oriented nature of care settings (Hill et al., 2018). Mainly because HCPs deal with high workload and multiple demands (Siani et al., 2016).

Besides the fact that having these conversations is – necessarily – time consuming, education and implementation of certain tools to improve communication is time-intensive (Spacey et al., 2021). From these findings, it is evident that creating time for education and conversations would be an essential element for EOL communication.

3.3.7 Emotional support for HCPs

Appendix B highlights examples showing that HCPs often encounter difficulties when caring for PWD, especially when talking about the EOL phase and providing care in this phase (Lawrence et al., 2011; Spacey et al., 2021). However, from findings in the study of Lawrence and colleagues (2011) it appears that the need for emotional support is still unrecognised in dementia care. Spacey and colleagues (2021) found that: *“It was apparent staff’s emotional attachment to residents impacted on their ability to discuss death and dying as part of advanced care planning. Analysis implies that staff’s close attachments with residents led to them feeling uncomfortable discussing sensitive and potentially upsetting topics, such as death and dying.”* (Spacey et al., 2021). As stated earlier in the theme ‘Education’, HCPs struggled with anxiety to upset PWD and informal caregivers when engaging in EOL discussions. Emotional support could make HCPs feel more comfortable in initiating as well as having the conversation. Hence, emotional support can be seen as a facilitating factor to EOL communication.

3.3.8 Tools

Two studies, evaluated tools that could contribute to the communication process (Pope et al., 2013; Stirling et al., 2014). The article of Pope and colleagues (2013) concerned a training package and the ACP-ED tool. In this study, staff found that they lacked confidence in discussing ACP in general: *“The training package and the ACP-ED tool were seen as ways of addressing this.”* The tool provided HCPs with open-ended questions, automatically generating new questions during the conversation. Hence, this tool can be seen as a facilitating element that can contribute to the EOL communication process.

Stirling and colleagues (2014) evaluated a tool that supported skill development of HCPs and – subsequently – improved the communication. Due to this tool informal caregivers gained confidence as decision makers in the dialogue. They also improved in their ability to discuss the details because of their increased knowledge. The following quote suggests that the tool was positively received: *“(…), in post-tool engagement interviews, families spoke of their previous experience of formal communication around their loved one’s care as ‘being told’ rather than engaging in conversation. In contrast, conversation/dialogue was their predominant experience of trialling the discussion tool through family meetings, with families being very positive about this.”* (Stirling et al., 2014). Accordingly, this tool is also a way of facilitating the communication process.

Two other studies both stated that providing written support (Siani et al., 2016) such as a POLST form (Kim et al., 2018) was a tool to support the discussion.

3.3.9 Enough resources and funding

Spacey and colleagues (2021) find that: *“It was apparent that the type and size of care home influenced their financial and organizational ability to deliver and sustain intervention mechanisms.”* In this study, it is evident that some care home structures do have the funds and resources to improve EOL communication through, for instance, education. However, some care home structures do not have these funds and resources (Hill et al., 2018; Spacey et al., 2021). *“While costs need to be taken into account and minimized, the evidence presented in this study highlights important quality issues in the provision of advance care planning which justify the need for care homes to incorporate greater support for their workforce into their cost base.”* (Spacey et al., 2021). Hence, sufficient resources and adequate funding is an essential element, which facilitates the communication process through enabling education and support.

3.4 Barriers to initiating the EOL conversation

While previous themes are facilitating elements, a recurrent barrier is discussed in multiple articles which involves initiation of EOL communication. Failing to initiate EOL communication was found to be a barrier in delivering a good ACP and communication process. Quotes in Appendix C support these findings. This barrier can be explained with two reasons. The first reason involves failing to find the right time to initiate the conversation (Hill et al., 2018; Ingravallo et al., 2018; Poppe et al., 2013; Perin et al., 2020). The insecurity of engaging and initiating the conversation came from the unpredictable dying trajectory of PWD. Staff members in the research of Stirling and colleagues (2014) stated that they felt that they took a rather reactive way, relying on their intuition. They stated there was no guidance to initiating these conversations and engaging them. Quotes of Ingravallo and colleagues (2018) and Lawrence and colleagues (2011) show the different perspectives on when to initiate the conversation (Appendix C). For instance: *“Some (...) said that a person should think about care options only when facing impairment or at the beginning of the disease. Other residents believed that it is useful to introduce ACP when health conditions are “still good” (...). Other residents and several family members focused on cognitive impairment, highlighting the need to discuss ACP “as soon as possible” or “when one is still competent.”* (Ingravallo et al., 2018). Because initiation of an EOL conversation depends on different preferences, this remains a problematic topic.

The second reason was the reluctance of PWD or informal caregivers to talk about this topic before substantial cognitive deterioration, because of the weighty character of the subject: *“For residents, the main reasons for not having discussed their care preferences in case of future incompetence were that they (...) had not considered it necessary because they thought they were still fairly healthy and preferred to postpone the issue or because it was an unpleasant/sad topic.”* (Ingravallo et al., 2018). This also accounts for family members: *“(…) their children were unwilling to talk about ACP.”* (Ingravallo et al., 2018).

Open communication is a facilitating factor which has been addressed multiple times. In order to minimise the barriers to initiating conversations, open communication may be the most facilitating and improve the communication process. Mainly because ‘being on the same level of understanding’ contributes to the conversation.

4. Discussion

4.1 Main findings

This scoping review focussed on the communication processes behind EOL conversations with PWD and their informal caregivers. The research question was: ‘What are essential elements of end-of-life communication for people with dementia and their informal caregivers in healthcare?’ As a result, 9 themes were conceptualised, representing the facilitating elements for EOL communication with PWD and their informal caregivers. These themes mainly involved resources, organisational aspects and communication skills. When looking at these facilitating factors from an overarching perspective, it stands out that open communication is particularly important. This comprises open communication about what the PWD and informal caregivers expect from the HCPs when it comes to communication skills, clinical information, the ACP process, and role differentiation. This would support a shared level of understanding between HCPs, PWD and their informal caregivers, which facilitates the conversation. In contrast, when there is no shared level of understanding, it could lead to misunderstandings or conflicts.

Overall, the themes were highly intertwined with each other. For instance, in order to feel confident in engaging in conversations, HCPs need education, which subsequently asks for more time. In order to achieve this, there is need for sufficient resources and funding. Hence, one facilitating element cannot hold if others are not accomplished. It remains important to be conscious of the barriers. However, the facilitating elements as a result from this scoping review provide information about which strategies could help to overcome these barriers.

4.2 Relation to other research

In this scoping review it was found that building relationships with PWD and their informal caregivers contributes to the conversation. In their review, Bosisio and colleagues (2018) state that PWD and their informal caregivers are more open to discussing ACP when they have a good relationship with a HCP. This is stimulated by an understanding of the needs, preferences and fears of the PWD. Also, continuity and trust is involved in building good relationships (Keijzer-van Laarhoven et al., 2020; Wendrich-van Dael et al., 2020). The literature review of Piers and colleagues (2018) confirms this by emphasising a holistic approach for EOL communication. According to Lee and colleagues (2015), knowing PWD, listening to informal caregivers and respecting them, supports existing relationships. This shows that some themes, such as ‘building relationships’ and ‘communicative skills’ are often intertwined.

Other research found that, in practice, there is no clear role differentiation between HCPs in initiating and guiding the ACP process (Bolt et al., 2021; Bosisio et al., 2018). However, Bolt and colleagues (2021) suggest that having a clear task division between HCPs on the EOL communication would be advantageous. The authors suggest, as a solution, nursing staff may have the best position to take on this task. Mainly because they are, for instance, crucial in the care of patients; they provide continuity; they are close to the PWD; they often notice the first changes in a patients behaviour (Bolt et al., 2021). Lee and colleagues (2015) state that role differentiation is needed in practice and they state that tools and education would enable HCPs to take on this role. These outcomes support the idea that clear role differentiation can contribute to the ACP process and the EOL communication, as found in this scoping review.

Subsequently, education and training of HCPs were recurrently identified as important elements of EOL communication with PWD and their informal caregivers by multiple articles with non-qualitative study designs (Lee et al., 2015; Caplan et al., 2006; Forbes et al., 2000; Robinson et al., 2005; Wendrich-van Dael et al., 2020; Erel, Marcus, & Dekeyser-Ganz, 2017; Caplan et al., 2006). Sachs, Shega, and Cox-Hayley (2004) and Mataqi and Aslanpour (2020) state that current practice is not optimal and more needs to be done on educational level to teach HCPs on EOL care communication for PWD and their informal caregivers. Likewise, these authors state that public education might contribute as well. Robinson and colleagues (2005) found that improved skills of HCPs through education would help with empathetically discussing the diagnosis which would help PWD to express their wishes. They, however, state that training packages already exist in practice. Just like findings in this scoping review, Wendrich-van Dael and colleagues (2020) state that education is needed because HCPs are scared of causing stress in PWD and/or their informal caregivers and lack confidence in their own skills (Sellars et al., 2019). This is also found in the scoping review of Erel and colleagues (2017), which confirms that HCPs often are uncertain about the EOL conversation and their own skills. The authors confirm that education could address the level of confidence of HCPs in having EOL conversations. This previous research supports the findings of this scoping review, and also supports 'education' as a facilitating element of the EOL communication process.

Additionally, Erel and colleagues (2017) and Wendrich-van Dael and colleagues (2020) describe several organisational issues. This supports the themes 'sufficient time' as well as 'enough funding and resources' of the current scoping review. Funding shortfalls were found to be a barrier to EOL care. Erel and colleagues (2017) stated that limited time for quality EOL conversations are not included in reimbursement calculations. This directly proves the time

constraints. In the same review the authors found that time pressure was an important barrier in clinical practice. This, together with staffing shortages underscores the need for more time, funding and resources. Also, Sachs and colleagues (2004) state that as PWD require more time, care facilities often end up with increased cost without additional reimbursements.

Furthermore, in this scoping review a recurrent barrier was found. Namely, failing to initiate the EOL communication was found to be a barrier in delivering a good ACP and communication process. Other reviews also stated that HCPs often are unsure about when to broach the subject of EOL care (Bosisio et al., 2015; Denning et al., 2019; Wendrich-van Dael et al., 2020). Keijzer-van Laarhoven and colleagues (2020) also confirms that a reason for not having EOL conversations is that PWD and their informal caregivers do not want to discuss this difficult subject. Piers and colleagues (2018) and Denning and colleagues (2019) recommend to start the ACP process as early as possible, ideally before cognitive decline.

Lastly, in some reviews facilitating elements or recurrent barriers were found that were not described in this current scoping review. Keijzer-van Laarhoven and colleagues (2020), amongst others, focussed on religious beliefs and socio-cultural norms. Taking these elements into account might be considered important. However, this current scoping review did not focus on these domains. Also, Erel and colleagues (2017) found that there can be conflicts between staff from different disciplines. Reasons of these conflicts are, amongst others, different training, poor communication, time pressure, and funding mechanisms. This may lead to hesitancy in addressing the EOL in conversations, which was not taken into account in the current review. Furthermore, from previous literature it is known that dementia is often not recognised as a terminal condition (Erel et al., 2017; Mataqi, & Aslanpour, 2020; Zieschang et al., 2012). This is not found in the current scoping review. However, it is found that timing of initiating EOL conversations and ACP in general is difficult (Hill et al., 2018; Ingravallo et al., 2018; Lawrence et al., 2011; Poppe et al., 2013; Stirling et al., 2014; Perin et al., 2020). When dementia would be recognised as a terminal condition, the procedure of initiating the ACP process and the EOL conversations can be executed more easily. This would, thus, also be a facilitating factor in improving EOL conversation. So, some topics were not identified in the scoping review. However, the facilitating elements found in this scoping review may contribute to resolving these barriers.

4.3 Strengths and limitations

The first strength is that this scoping review is, to my knowledge, the first to focus on essential elements of EOL conversations in PWD and their informal caregivers. Another strength is the systematic process of this scoping review as the process is replicable, transparent and rigorous.

A limitation of this research is, first, the inclusion criterion that limited the search to articles either published in English or Dutch. Because of this, three articles were excluded whilst their content might have been useful. Second, grey literature was not included as the focus was solely on scientific literature. Third, the methodological consideration to only include qualitative designs may have caused that relevant information of studies with different designs was not captured. Fourth, this scoping review is conducted and written by one author and may therefore be prone to researcher bias. However, another author occasionally peer reviewed the process of the scoping review. This reduces the likelihood of researcher bias and ensures a higher level of objectivity. Fifth, it is important to consider the fact that the search string might not have been integral. Some articles might have been missed because they used different keywords. Lastly, in accordance with the principles of the scoping review design, articles were not excluded based on methodological quality. Hence, the included articles are not critically appraised on their quality of methods and analysis. This indicates that studies of poor quality might have been included.

4.4 Implications for practice

The main implication for research is to execute more scoping reviews on this subject, also including different study designs and grey literature. These studies with different designs may, namely, include more perspectives and relevant themes which may have been missed by the current scoping review. An example would be the racial and cultural differences. In this context, research could, for instance, focus more on religious beliefs and socio-cultural norms.

In practice, not all facilitating elements for EOL communication are present. Hence, these elements can also be considered barriers. For instance, having enough time to execute proper EOL communication would be facilitating, but to date it is often not feasible because of high workload. Therefore, it is important to be aware of the barriers in the current practice. Accordingly, research should also focus on the feasibility of facilitating elements. Both research and practice should look at how to make time and ensure sufficient resources and funding in order to educate HCPs, informal caregivers and PWD; find objective professionals to facilitate the conversation; built relationships, and so on. Hence, future research should also focus on policies and guidelines that may facilitate these elements.

4.5 Conclusion

This review summarised information about essential elements that underpin good EOL communication between HCPs, PWD and their informal caregivers. This scoping review has shown that there are multiple facilitating elements that can contribute to EOL communication with PWD and their informal caregivers. To a large extent, these elements are in line with findings of other reviews that were also focussed on PWD. However, the facilitating elements are often precarious topics in practice. This review provides information that can be used to guide improvement in practice. Therefore, research should mainly focus on studying the feasibility of the identified, facilitating elements in practice and ways of implementing them.

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Appendices

Appendix A: Table of study characteristics

Authors, Year of Publication, Country	Title	Study design	Study objective(s)	Main findings regarding EOL communication in PWD ³	Reported recommendations
Hill et al., (2018) United States	‘Staff perspectives of barriers to access and delivery of palliative care for persons with dementia in long-term care.’	Qualitative design with interviews, analysed using phenomenological methodology. Participants: Nursing home staff.	This study investigated experiences of long-term care staff delivering palliative care to PWD and the way care is delivered. Also, the study aimed to learn which guidelines were used, and whether policies affected the delivery of palliative care.	Staff indicated that communication with PWD made it more difficult to provide palliative care. <u>Staff-family communication:</u> Families could become emotional, aggressive, etc. which made it difficult to make care decisions collaboratively. <u>Staff-resident communication:</u> Staff felt uncertain if they met the needs of PWD because of the lack of meaningful communication with them. <u>Staff-co-worker communication:</u> Nurses stated that they lacked communication with physician. Other professionals sometimes felt excluded from the communication process by physicians.	Education for families would facilitate palliative care. This could be done by the staff and would concern the dying process, nature of dementia, etc.
Kim et al., (2018) United States	‘Surrogates’ experiences of engaging in physician orders for life-sustaining treatment discussions for persons with advanced dementia.’	Qualitative descriptive design. Data from semi-structured interviews with surrogates were analysed using directed content analytic methods. Participants: surrogates.	This studies describes the experiences of family surrogates’ with POLST ⁴ discussions with primary care providers.	The clear explanation of clinical information is found to be important for surrogates and stimulates the conversation. Also, surrogates found it important that HCPs ⁵ , in conversation, are sensitive, listened, understood the surrogate’s need and gave the surrogate time to ask questions. When the HCP exhibited these communication skills and was ‘warm’ and ‘caring’ and ‘open to the opinion of the surrogate’, surrogates felt respected and understood.	The VALUE mnemonic approach by Lautrette et al., (2007) was supported by the outcomes of this study. This, according to the outcomes, namely demonstrates strong communication skills. Furthermore, it is recommended that HCPs think about the presentation of clinical information as clarity helps facilitate the conversation and helps with relationship building.
Ingravallo et al., (2017) Italy	‘Discussing advance care planning: insights from older people living in nursing homes and from family members.’	Qualitative study using face-to-face interviews. Data were analysed using content analysis. Participants: NH ⁶ residents and family members.	This study aimed to explore the attitudes of NH residents and family members toward ACP ⁷ 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.	The results of this article mainly focus on barriers which, when tackled, could eventually facilitate good conversation. Some PWD were more interested in informal care planning rather than formal. Educational level of participants sometimes provided difficulties in the conversation. Also, timing the initiation of a conversation about EOL ⁸ is different for everyone which can be considered a barrier. Moreover, participants stated that physicians were not always available to discuss health concerns.	Family members seem important in discussing ACP for NH residents. This indicates that intimacy is important for PWD. However, this does not account for everyone. Some family members were unwilling to talk about ACP with PWD. These results identify the need for a facilitator outside the family who can stimulate ACP conversations. Furthermore, the study recommends that the readiness of a person to be involved in conversations about ACP should be assessed before engaging in conversation.

³ PWD: People with dementia

⁴ POLST: Physician orders for life-sustaining treatment

⁵ HCP: Health care professional

⁶ NH: Nursing home

⁷ ACP: Advance care planning

⁸ EOL: End of life

Authors, Year of Publication, Country	Title	Study design	Study objective(s)	Main findings regarding EOL communication in PWD'	Reported recommendations
Kim et al., (2019) United States	'Exploring provider-surrogate communication during POLST discussions for individuals with advanced dementia.'	Qualitative descriptive study design. Data from audio-recordings of POLST discussions were analysed using directed content analysis. Participants: surrogates and providers.	This study explored the communication between provider and surrogate during POLST discussions for PWD.	Surrogates place high importance on understanding clinical information of POLST. However, HCPs rarely conveyed comprehensive information during these discussions. Findings of this study shows that all providers executed strategies for communicating emotional support. This was found to be important in building relationships with surrogates. Two elements were not observed often: 1) communication about expectations; 2) decision making roles between providers and surrogates.	Findings of this study show that higher emphasis should be placed on providers conveying information about life sustaining treatments. Furthermore, the conversation would be facilitated if HCPs asked surrogates about their expectations of the trajectory of dementia and life-sustaining treatments. Also, it would be facilitating if HCPs discussed preferred DM ⁹ roles and levels of participation in DM.
Lawrence et al., (2011) United Kingdom	'Dying well with dementia: qualitative examination of end-of-life care'	Qualitative study with in-depth interviews which were analysed using the constant comparison method. Participants: bereaved family carers and care professionals.	This study aimed to define good EOL care for PWD and it aimed to identify how to deliver this across care settings in the UK.	When communication was infrequent and plans were not followed, individuals indicated a poor experience of communication. Data showed that staff placed emphasis on holistic care characterised by 'getting to know the person'. This was achieved through spending time with PWD and their family. However, staff stated that building relationships with PWD and their informal caregivers could be distressing. Furthermore, HCPs have difficulties knowing when to discuss ACP.	Because HCPs experience that building close relationships with PWD (especially in the last phase) is distressing, it is recommended that HCPs are provided support in managing anxieties.
Poppe, Burleigh, & Banerjee (2013) United Kingdom	'Qualitative evaluation of advanced care planning in early dementia (ACP-ED)'	Qualitative study design with in-depth interviews. Data were analysed with the constant comparison method to identify themes. Participants: PWD. Carers of PWD and staff from memory service and CMHTs ¹⁰ .	The aim of this study was to explore if ACP could be discussed with PWD, shortly after diagnosis.	From findings it seems that the ACP-ED tool enables ACP in PWD. This tool was perceived as a useful intervention. Knowing PWD's wishes in case of being a proxy decisionmaker in the future was perceived as helpful to carers. However, the timing of having conversations about ACP is difficult. This study reflects that ACP should be discussed as soon as possible.	The authors of this study recommend that the topic should be initiated by HCPs, as PWD and their informal caregivers are less likely to initiate the conversation. This needs to be acknowledged as a core part of their job. Furthermore, this study recommends that memory services and CMHTs are needed to decide the timing of initiation of the conversation. Data from this study also suggests that staff found training and supervision important in order to increase their confidence in initiating these conversations.
Stirling et al., (2014) Australia	'A tool to aid talking about dementia and dying – Development and evaluation.'	The study was part of a larger mixed method study, not yet reported. Data was qualitatively evaluated via thematic analysis. Participants: HCPs and surrogates	The objective of the study was to evaluate a tool aimed at facilitating communication between Advanced Care Facilities staff and family members of PWD.	Data showed that HCPs felt that communication about dying could be improved. There were no structured approaches to initiating EOL discussions. Often HCPs relied on their intuition when talking about issues when death is approaching. Barriers to the conversation was prognostic confusion and a lack of knowledge on dementia. The 'discussion tool' supported HCPs in their communication skills which improved quality of communication between staff and families.	The authors of this study recommend that nurses need to indicate the future care issues and discuss the place of a palliative approach. A tool such as the 'discussion tool' used in this study, can help staff gain their confidence. This could potentially facilitate situations where unfamiliar and uncomfortable practices might be normally avoided.

⁹ DM: Decision making

¹⁰ CMHTs: community mental health teams

Authors, Year of Publication, Country	Title	Study design	Study objective(s)	Main findings regarding EOL communication in PWD	Reported recommendations
Spacey et al., (2021) United Kingdom	‘A critical realist evaluation of advance care planning in care homes.’	Qualitative study with data collected through the use of focus groups and semi-structured interviews. Data were analysed using thematic analysis. Participants: nurses, care assistants, bereaved relatives and domiciliary staff.	The aim of this study was to evaluate ACP of EOL care in care homes.	Data showed that HCPs encounter emotional difficulties in frequently engaging in discussions about the EOL. When emotional needs of HCPs are not met, they rushed and avoided these discussions, also because they are scared to upset PWD. Also, a lack of education, especially in informal caregivers of NHs, appeared to be a barrier to engage in EOL conversations. This is often due to preconceived assumptions and communication barriers. Educational mechanisms which were common were, for instance, shadowing. This helped staff learn the practicalities. However, data showed that more support for care home staff is needed.	Findings show that a lack of resources prevent change as the need for education and support is not met. While this study acknowledges that costs need to be taken into account, the results show that quality issues in providing EOL care proofs the need of more resources. The authors recommend that care homes need to incorporate greater support for HCPs in their cost base. Findings recommend education for supporting HCPs emotionally to improve their ability to engage in EOL discussions.
Perin, Ghirotto, & De Panfilis (2020) Italy	‘‘Too late or too soon’’: The ethics of advance care planning in dementia setting.’	Phenomenologically oriented qualitative study with semi-structured interviews analysed with IPA ¹¹ methodological indications. Participants: HCPs	This study aimed to frame the perception of physicians caring for PWDs regarding ACP. Another aim was to describe the physicians difficulties and needs.	From the results it appears that initiating ACP is difficult for physicians. These HCPs also find that building a relationship with the family is important in order to gather information on a PWDs’ wishes and care preferences. However, HCPs also state that connecting with family is not always easy.	The authors from this study recommend special training for HCPs in communicating with PWD and their families. This would support HCPs and their emotional burden of these communication processes. Another important facilitating factor of the ACP discussion is the relationship between HCPs and family members. This helps overcoming some direct discussions between HCPs and PWD.
Saini et al., (2016) United Kingdom	‘An ethnographic study of strategies to support discussions with family members on end-of-life care for people with advanced dementia in nursing homes.’	Ethnographic study using qualitative data extracted from a reflective diary kept by a professional delivering the intervention and from interviews with HCPs and family members of PWD in NHs. Participants: professionals delivering the intervention (ICL), HCPs and family members.	This study aimed to examine practices relating to EOL discussions with family members of PWD in NHs and to explore strategies to improve practice.	Education on dementia for family and staff seems to be facilitating EOL conversations. For HCPs training would help as HCPs often lacked confidence. Training was a useful tools in order to increasing confidence and seeing things from the families’ perspective. Data also showed that delivering continuous care and ongoing conversation facilitated the building of relationships, provide reassurance and allowed time for the family to process all information. Having these discussions appeared to increase the family’s capacity to make decisions on EOL care. Results showed that family members often preferred informal EOL discussions over formalised discussions in writing. HCPs however, preferred formalised documentation of EOL discussions in order to meet requirements and prove the conversation took place.	It is recommended that EOL discussions are ongoing rather than a ‘one-off task driven conversation’. Furthermore, planning time for these conversations seems to be facilitating in order to develop good and sensitive conversation. The authors of this study also recommend a coordinator who has time, knowledge and communication skills to have EOL conversations. This person could train and support staff and therefore promote these discussions in a NH setting.

¹¹ IPA: Interpretative phenomenological analysis

Appendix B: Table of example phrases from included studies per theme

Table 2 Example phrases from included studies per theme

Themes	Clear role differentiation	Facilitating communicative skills
<p data-bbox="40 229 757 368">“(...) some residents and family members outlined possible difficulties in understanding treatment options or expressing opinions on health issues due to the resident’s low educational level.” (Ingravallo et al., 2018)</p> <p data-bbox="40 395 757 475">“Findings emphasized that providers’ clear explanations during POLST conversations assisted surrogates to process information.” (Kim et al., 2018)</p> <p data-bbox="40 502 757 582">“(...) giving surrogates the opportunity to ask questions and explain treatments using their own words can promote surrogates’ understanding (...)” (Kim et al., 2018)</p> <p data-bbox="40 609 757 721">“Clinical information is critical for surrogates to make sound decisions; thus, nurse practitioners should think about what information is necessary for surrogates and how the information should be presented.” (Kim et al., 2018)</p> <p data-bbox="40 748 757 828">“Our findings highlight areas that require providers’ attention to conduct effective communication, such as conveying comprehensive information about life-sustaining treatments, (...)” (Kim et al., 2019)</p> <p data-bbox="40 855 757 1023">“Others said that some patients were worried that by discussing advance care planning, they would no longer be allowed to make decisions. They stressed the importance of giving patients and carers detailed information about ACP before the discussion took place, so that patients would not feel threatened by the discussion and so they could decide whether to proceed.” (Poppe et al., 2013)</p>	<p data-bbox="763 229 1473 341">“(...) staff at homes with no formal palliative care committee expressed frustration in making end-of-life decisions with no protocol to guide them and no one willing to lead in decision-making.” (Hill et al., 2018)</p> <p data-bbox="763 368 1473 448">“Regarding the person who it would be better to discuss ACP with, the physician, followed by the nurse, was the healthcare provider who was more frequently cited by residents (...)” (Ingravallo et al., 2018)</p> <p data-bbox="763 475 1473 555">“This result highlighted the need for the intervention of a facilitator outside the family, who can act as a primer and catalyst for ACP conversations.” (Ingravallo et al., 2018)</p> <p data-bbox="763 582 1473 662">“(...) it is important for providers and surrogates to engage in open discussions about preferred roles in decision-making rather than assume all surrogates prefer the same level of responsibility.” (Kim et al., 2019)</p> <p data-bbox="763 689 1473 769">“One subtheme (...) reflected the value of the independence of the ICL role, (...). This allowed family members more ease in talking to the ICL.” (Siani et al., 2016)</p>	<p data-bbox="1480 229 2190 368">“(...) surrogates appreciated that providers were open to surrogates’ statements, were interested in knowing surrogates’ feelings, listened carefully, communicated their personal knowledge about the patient, and gave surrogates opportunities to comment.” (Kim et al., 2018)</p> <p data-bbox="1480 395 2190 475">“Other surrogates felt that the provider cared because the provider expressed their concern for the surrogate or the family member.” (Kim et al., 2018)</p> <p data-bbox="1480 502 2190 582">“Also, providers’ openness to and support for surrogates’ opinions and decisions helped surrogates feel understood by providers.” (Kim et al., 2018)</p> <p data-bbox="1480 609 2190 721">“Nine surrogates described features of the providers’ communication that contributed to feeling respected and understood, providing one or more examples of how providers were sensitive, listened, and understood their needs” (Kim et al., 2018)</p> <p data-bbox="1480 748 2190 887">“Moreover, providers’ active listening, giving surrogates the space to comment, and answering questions made surrogates feel cared for and understood by providers: “Well, it was interactive, that [the provider] could hear what I said. There was space for me to comment and [the provider] would go over something a second time”.” (Kim et al., 2018)</p> <p data-bbox="1480 914 2190 1082">“(...) providers need to demonstrate strong communication skills, such as using the VALUE mnemonic approach or other valid communication strategies. (...), giving surrogates the opportunity to ask questions and explain treatments using their own words can promote surrogates’ understanding and feelings of being respected and understood.” (Kim et al., 2018)</p> <p data-bbox="1480 1109 2190 1189">“Family members spoke positively about staff interacting with their relative. (...) Staff described getting to know individual’s interests, sensitivities and preferences.” (Lawrence et al., 2011)</p> <p data-bbox="1480 1216 2190 1390">“Staff said it was important to be perceptive about how the patient felt during the discussion, to conduct the discussion in a sensitive way and to be able to listen and let the patient guide the discussion as much as possible. They highlighted the importance of being open minded and not judging patients for their wishes. Good communication skills were another key competency that was identified by staff as well as the ability to manage conflict.” (Poppe et al., 2013)</p>

Table 2: Example phrases from included studies per theme

Themes		
<p>Building relationships</p> <p>“Participants reported that residents’ relationships with ever-increasing parttime staff were not as strong as with full-time staff.” (Hill et al., 2018)</p> <p>“Participants stated that a better relationship could be fostered with the family if there was a discussion about the dying process with the family during the admission interview. Specifically, participants expressed that it was imperative that long-term care home staff explain in detail what care could be given and discuss the wishes of the resident, including advance directives.” (Hill et al., 2018)</p> <p>“Other participants (both residents and family members) stressed the importance of both closeness and trust when talking about these issues.” (Ingravallo et al., 2018)</p> <p>“Our findings also show that all providers demonstrated several strategies for communicating emotional support, which is critical to building relationships with surrogates.” (Kim et al., 2019)</p> <p>“The provision of psychosocial support is a fundamental tenet of end-of-life care, and family members were unequivocal in the value that they placed on it.” (Lawrence et al., 2011)</p> <p>“Having built a good relationship with the patient and the patient’s family was seen as a facilitator for advance care planning by staff members. Staff felt a patient would be more open to discuss ACP if they knew and trusted the person delivering the intervention.” (Poppe et al., 2013)</p> <p>“A mutual understanding between the patients and their professional caregivers, closeness and intimacy as well as continuity and constancy in the relationship are perceived as necessary aspects that should be considered to dissect sensitive matters implied in the shared ACP.” (Perin et al., 2020)</p> <p>“(…) one subtheme (…) was the importance of ongoing dialogue with family to build a trusting relationship, provide reassurance and allow time for family to process information.” (Siani et al., 2016)</p>	<p>Education</p> <p>Educating families and the public was a facilitator for palliative care identified by participants, (…). Most participants felt there was a general lack of knowledge about the dying process.” (Hill et al., 2018)</p> <p>“(…) factors that facilitated better palliative care in more progressive homes. Firstly, staff were trained formally in palliative care. Most felt confident in their skills and were willing to evaluate their own performances and learn from their mistakes.” (Hill et al., 2018)</p> <p>“Moreover, they thought good training and refreshers made staff feel more confident about ACP, and good preparation was seen as important for facilitating the discussion.” (Poppe, Burleigh, & Banerjee, 2013)</p> <p>“Staff identified knowledge about dementia, knowledge about available resources and knowledge of one’s own limitations as key skills and competencies for discussing ACP.” (Poppe et al., 2013)</p> <p>“Further training and an educational course about the specific communication skills needed are urgently required to ease the implementation of ACP, as well as a broader involvement of institutions and other professionals.” (Perin et al., 2020)</p> <p>“Through interviews and the ICL diary it was evident that educating family and staff about the progression of dementia was essential for underpinning EOL conversations and guiding care.” (Saini et al., 2016)</p> <p>“Two subthemes related to staff confidence in initiating EOL conversations and included staff lacking confidence and that training and case scenarios were useful tools for increasing staff confidence and seeing things from the families’ perspective.” (Saini et al., 2016)</p> <p>“A similar subtheme which was only reported in interviews was the importance of the ICL in role modelling EOL conversations with family with NH staff present to observe.” (Saini et al., 2016)</p>	<p>Sufficient time</p> <p>“Good quality palliative care is inherently more time-intensive (…). This is discrepant with the current task-oriented nature of care in most long-term care homes.” (Hill et al., 2018)</p> <p>“(…) but some of them reported a lack of availability of physicians when discussing health issues, or that they did not have much time.” (Ingravallo et al., 2018)</p> <p>“First, she pointed out that the provider seemed overwhelmed and distracted (…)” (Kim et al., 2018)</p> <p>“Getting to know the individual’s (…) was identified as a difficulty within general hospitals, as staff did not have the advantage of spending time with the individual and their families over a long period.” (Lawrence et al., 2011)</p> <p>“Staff were concerned that discussing ACP might be time consuming. They thought in some cases the discussions might require more than one session and advance care plans would have to be reviewed.” (Poppe et al., 2013)</p> <p>It was acknowledged that the GSFCH provided useful education and training (…). However, managers from care homes one and two spoke about the time commitments with setting up such training interventions (…)” (Spacey et al., 2021)</p> <p>“The subthemes were interrelated reflecting the need for adequate time for sensitive conversations, which was enabled by the ICL, and that NH staff and GPs had difficulty managing high workloads and multiple demands.” (Siani et al., 2016)</p> <p>“In this study we aimed to identify strategies for promoting EOL discussions (…). We identified four key strategies including: (…); (iii) providing time and space for sensitive discussions (…)” (Siani et al., 2016)</p>

Table 2: Example phrases from included studies per theme

Themes		
<p>Emotional support for HCPs</p> <p>“However care professionals acknowledged that seeing a person that they cared for dying could be difficult to bear. It was considered a challenge to balance personal and professional feelings, yet these demands often went unrecognised within dementia care.” (Lawrence et al., 2011)</p> <p>“The most significant factor identified was the emotional difficulty that staff experienced in initiating discussions about death and dying.” (Spacey et al., 2021)</p> <p>“It was evident that some care home staff found it emotionally difficult delivering EoLC to residents, especially towards the end stages of their life.” (Spacey et al., 2021)</p> <p>“It was apparent staff’s emotional attachment to residents impacted on their ability to discuss death and dying as part of advanced care planning. Analysis implies that staff’s close attachments with residents led to them feeling uncomfortable discussing sensitive and potentially upsetting topics, such as death and dying.” (Spacey et al., 2021)</p> <p>“Specifically, the quotes imply that care home staff are avoiding discussions about death and dying, (...), but to also protect themselves from upset.” (Spacey et al., 2021)</p> <p>“The findings of this study showed that (...), the emotional labour of frequently engaging in discussions about death and dying was a problem for some care home staff.” (Spacey et al., 2021)</p> <p>“In some cases, care home staff’s unmet emotional needs led them to rushing and avoiding discussions about death and dying with residents and relatives.” (Spacey et al., 2021)</p> <p>“There was evidence to suggest that some care home staff’s avoidance of conversations about death and dying was also about protecting their own emotional wellbeing.” (Spacey et al., 2021)</p>	<p>Tools</p> <p>“Another two surrogates pointed out that using and reviewing the actual POLST form facilitated their understanding of life-sustaining treatment. (Kim et al., 2018)</p> <p>“In addition, the POLST form itself is viewed by clinicians as an effective tool that promotes surrogates’ understanding.” (Kim et al., 2018)</p> <p>“Staff, patients and carers believed that all relevant issues were covered in the ACP-ED tool. Staff found it useful that the tool provided structure to guide them in the discussion. They thought it was helpful that the tool was open-ended, as it provided flexibility and the given questions could generate further questions.” (Poppe et al., 2013)</p> <p>“The evaluation suggests that the ACP-ED tool can, with training enable advanced care planning in people with mild dementia following diagnosis” (Poppe et al., 2013)</p> <p>“(…) the tool helped the resource nurses to navigate the sensitive area of death and dying and move from being reactive to relatives’ concerns to initiating conversations, (...).” (Stirling et al., 2014)</p> <p>“In post-discussion tool interviews, families spoke of their enhanced relationship with the resource nurse following the dialogue and their feelings of comfort about engaging in future discussions.” (Stirling et al., 2014)</p> <p>“The discussion tool supported the development of new skills during the project resulting in improved quality of communication between participating staff and families in ACFs. (...) The tool provided a process, and clear examples of ‘what to say’.” (Stirling et al., 2014)</p> <p>“Another related subtheme (...) was the value of providing written information to support discussion.” (Siani et al., 2016)</p>	<p>Enough resources and funding</p> <p>“Long-term care homes lacked funds to hire staff to address psychosocial care needs (...).” (Hill et al., 2018)</p> <p>“(…) most staff were not trained in palliative care during their formal education and relied on work experience and training which employers did not have the resources to fund.” (Hill et al., 2018)</p> <p>“It was apparent that the type and size of care home influenced their financial and organizational ability to deliver and sustain intervention mechanisms. Specifically, care home one was a small residential home with 32 beds, which delivered EoLC a few times a year, while care home three was a 75-bed nursing home where EoLC was delivered far more frequently.” (Spacey et al., 2021)</p> <p>It was acknowledged that the GSFCH provided useful education and training (...). However, managers from care homes one and two spoke about (...), compounded by the implementation costs which were not viable in their smaller homes.” (Spacey et al., 2021)</p> <p>“This data suggests that financial and organizational contexts are preventing these homes from benefiting from many of the supportive mechanisms that come with the GSFCH, (...).” (Spacey et al., 2021)</p> <p>“Despite the need for more education and support, findings suggest that a lack of resources inhibited change.” (Spacey et al., 2021)</p> <p>“While costs need to be taken into account and minimized, the evidence presented in this study highlights important quality issues in the provision of advance care planning which justify the need for care homes to incorporate greater support for their workforce into their cost base.” (Spacey et al., 2021)</p>

Appendix C: Table of example phrases of the recurrent barrier

Table 3: Example phrases of the recurrent barrier

Barrier
Timing of initiating the EOL conversation
“Participants in the current study, (...), stated that dementia’s unpredictable dying trajectory made it difficult to (...) determine when palliative care should be initiated.” (Hill et al., 2018)
“Some (...) said that a person should think about care options only when facing impairment or at the beginning of the disease. Other residents believed that it is useful to introduce ACP when health conditions are “still good” (...). Other residents and several family members focused on cognitive impairment, highlighting the need to discuss ACP “as soon as possible” or “when one is still competent”.” (Ingravallo et al., 2018)
“Finding the right time for ACP discussions with people with dementia and with their family remains challenging.” (Ingravallo et al., 2018)
“(…) some residents and family members reported that their children were unwilling to talk about ACP.” (Ingravallo et al., 2018)
“Care professionals (...) concurred that timing was crucial: introducing the topic too soon after diagnosis might engender distress or despair; too late in the illness and the person with dementia might lack capacity to make such decisions.” (Lawrence et al., 2011)
“Staff within care homes and NHS continuing care wards felt that this should be discussed around the time of diagnosis, whereas staff within community mental health teams stated that they preferred to be optimistic at that stage.” (Lawrence et al., 2011)
“Staff found it difficult to pinpoint a specific time in the dementia pathway for discussing ACP.” (Poppe et al., 2013)
“Many felt we kind of take a reactive role in a way, we answer people’s questions (DPRN2) when talking about care needs. (..) It was clear that there were no structured approaches to addressing end of life discussions early in the course of resident admissions, and that often nurses relied on an intuitive sense of talking about issues as someone approached dying.” (Stirling et al., 2014)
“Physicians are worried about beginning ACP ‘too late’ when it is no longer possible for them to directly share anything with the patients because their cognitive competences and functioning are already too impaired.” (Perin et al., 2020)
“Our findings confirmed that the future lack of decision-making capacity and the impossibility of ongoing evaluation and patient-doctor communication represent specific barriers to initiation of ACP by physicians.” (Perin et al., 2020)