Thinking Ahead

Supporting family caregivers of nursing home residents with dementia in advance care planning

Laura Bavelaar-von Oerthel

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Academic network for research in elderly care

The studies in this thesis took place in the University Network for the Care Sector South Holland (UNC-ZH). In this network, the Leiden University Medical Center (LUMC) collaborates structurally with 12 elderly care organisations in South Holland (Marente, Pieter van Foreest, Florence, Topaz, Argos Zorggroep, Saffier, Laurens, Zonnehuisgroep Vlaardingen, Woonzorgcentra Haaglanden, Aafje, ActiVite, Haagse Wijk- en Woonzorg).

Caregivers, policy makers, researchers, students, residents and relatives work together to improve the quality of care and quality of life for vulnerable older people. The UNC-ZH is a regional platform, inspirator and learning network for innovation in long-term care. Research, education and training, and practice are closely related.

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General introduction

When Anne and her mother arrived at the nursing home, Anne knew: this would be her mother's "final destination". She knew that her mother would not recover from dementia. The nursing home would become her home for the final years of her life, where loving nursing assistants would take good care of her. For Anne, the most important thing was for her mother not to suffer, but to enjoy her days in the nursing home. Although she could not talk with her mother about her mother's wishes anymore, she knew her mother well and knew her mother would think the same.

When the COVID-19 pandemic hit, Anne suddenly had to think about this comfortable nursing home life for her mother more concretely. What if her mother was infected? Would she want to be hospitalized where ICU-treatment was possible? Would she want to stay in the nursing home where treatment options were limited? Anne had never thought about these issues before and felt stifled to answer any of these questions in the midst of a pandemic where panic and anxiety prevailed. If forced to decide in the moment, Anne would probably prefer her mother to stay in place and not move to a hospital. But would she then not feel regret or guilt later, was her mother really the most comfortable that way? What would be "the right" choice?

This case illustrates two important matters: first, we often want to strive for our loved ones with dementia to be comfortable. Second, as people with dementia may not be able to express their wishes anymore, it is frequently family who will speak on their behalf. And combining these two requires thinking of future scenarios we may not have been prepared for. This thesis will examine why a proactive and family inclusive care approach to achieve comfort for people with dementia is still sub optimally implemented, and how thinking about future care with family caregivers of people with dementia can be improved.

People with dementia and their family caregivers

Double ageing, or in Dutch: "dubbele vergrijzing", is becoming more evident in society; we are getting older, and, the number of people aged 75 and over is rising in the population. With this increase in age, an increase in the prevalence of age-related diseases is apparent. Dementia is a clinical syndrome that is strongly associated with older age and its prevalence is currently estimated at more than 57 million people worldwide. The number of people living with dementia is expected to increase to 152.8 million in 2050.[1] Aspects that are typical to the dementia syndrome are cognitive deterioration, a decline in the ability to perform activities of daily living, and a reduced ability to take decisions independently. The most common type of dementia is Alzheimer's disease, but there are many other causes such as vascular dementia, frontotemporal dementia, Lewy-Body dementia, and mixed-form dementias. Dementia is a progressive, life-limiting neurodegenerative progress.[2-4] The early stages often involve memory impairment and with advancing disease, language problems, executive function impairment and neuropsychological and behavioral symptoms may develop.[2-4] People with dementia therefore become increasingly dependent on support from others and it is often family or friends that take up the role of informal or family caregiver.

Family caregivers are involved in the care for their loved one by providing care or managing care.[5] Spouses often provide care and help with activities of daily living, while children or other relatives often manage care by arranging professional caregivers or other support for their loved one.[5] Family caregivers are at increased risk for burden and various health problems, with burden often increasing during the disease trajectory.[6] Several factors are known to predict or protect from distress, such as the perceived competence in caregiving.[5] One of the self-perceived needs of family caregivers is for information and knowledge related to managing their loved one with dementia.[7, 8] Also when a person with dementia moves into a nursing home when more support and care is needed than can be provided at home, family caregivers require guidance and knowledge.[9] These information needs range from information about living in a nursing home to specific information about family caregivers' role in decision making regarding care and the end of life with dementia.[9]

Family caregivers are thus essential in the care for people with dementia, but they need information and support. If we know what support is available and what elements are most effective, this can inform new evidence-based interventions to address family caregivers' needs. This raises the question: *"What interventions support family caregivers of people with dementia at the end of life in nursing homes?"* that we answer in **Chapter 3** of this thesis.

Palliative care for people with dementia

As dementia is caused by a life-limiting disease, a palliative approach to care is indicated.[10] Palliative care aims to improve the quality of life of people living with life-threatening illnesses and their families, by preventing and relieving suffering in the physical, psychological, social and spiritual domain.[11] To address the disease specific needs of people with dementia and their family caregivers, the European Association for Palliative Care developed a definition of and recommendations for palliative care for older people with dementia.[10] The recommendations for palliative dementia care were structured in 11 domains, and included domains related to person-centered care, communication and shared decision making (Domain 2), setting care goals and advance care planning (Domain 3) and family care and involvement (Domain 9).[10] A family inclusive approach, involving family in care and decision making, and advance care planning are thus key elements of a palliative approach to dementia care.

Advance care planning (ACP) has been defined as a process of reflecting on goals and preferences for future care and treatment by individuals, together with their family and healthcare providers, discussions of these goals, and potentially documentation and review of these preferences.[12] Because people with dementia generally experience cognitive decline during the disease trajectory, ACP is especially important for them. Early initiation ensures that people with dementia can express their preferences for future care for when they are no longer able to contribute to conversations about care, while involving family from the start facilitates the proxy decision making role they will fulfill in later stages.[13] ACP with and for people with dementia is found to result in increased ACP documentation, reduced hospitalization, increased goal-concordant care and people with dementia and their family caregivers being more satisfied with care.[14] These outcomes relate to goals such as respecting autonomy, reducing overtreatment and improving quality of care, but ACP can also benefit other underlying goals such as preparing for the end of life and strengthening relationships.[15]

The cognitive decline that is part of dementia not only requires a proactive approach to care, but also highlights the importance of family involvement. When a person with dementia is unable to contribute to conversations about care, family caregivers often fulfil the role of surrogate decision maker, representing their loved one in conversations about care with healthcare providers.[16] Family caregivers can find it difficult to engage in decision making regarding end-of-life care and in addition to their general information and support needs, they need support from healthcare professionals in shared decision making specifically,[17] like we saw with Anne in the opening paragraph.

Advance care planning with family caregivers is thus important for good palliative dementia care. In **Chapter 4** of this thesis, we explore ACP and family involvement further by answering the question: *"How do advance care plans of nursing home residents with dementia change following pneumonia, what factors are associated with changes and what factors are associated with the person perceived by the elderly care physician as most influential in decision making?"*

Suboptimal palliative care for people with dementia and their family caregivers

Despite the need for a palliative care approach in dementia and the consensus regarding its components,[10] a body of literature suggests that a palliative approach to dementia care is still suboptimal. Leniz and colleagues found that the identification of palliative care needs only occurs for a relatively small group of people with dementia and for only 19.7% of people with dementia this happened before their last three months of life.[18] Given that the EAPC recommends that a palliative care approach can be appropriate throughout the disease trajectory,[10] this late initiation clearly poses a barrier. Telling in that respect is the scoping review protocol by Gilissen and colleagues that aims to identify the key components of palliative care that is initiated early in the disease trajectory: the reason for conducting this research simultaneously poses a difficulty in the conduct, namely, the lack of a definition of 'early' initiation.[19] Furthermore, there is still a lack of evidence about how palliative care is best organized and delivered for people with dementia and their family caregivers.[20] Specifically, there is gap in research about the development and implementation of ACP interventions, and the assessment of the interventions' effectiveness, while research into the barriers to ACP implementation is more abundant.[21] Systematic reviews about family caregivers' needs suggest that these needs are often unmet,[7, 8] adding another element of palliative care that is sub optimally addressed. We therefore explore the barriers to palliative dementia care in **Chapter 2** of this thesis, where we answer the question: *"What are the barriers to providing high-quality palliative care in dementia according to elderly care physicians in the Netherlands, and what solutions do they propose to address these barriers?"*

The mySupport study

In 2014-2015, a paired cluster randomized trial was conducted in 24 nursing homes in Northern Ireland. This RCT introduced a family focused ACP intervention in 12 nursing homes, that aimed to improve ACP practice, support family caregivers in decision making, and reduce overtreatment of nursing home residents with advanced dementia.[22] In this way, several of the lacunas in palliative dementia care could potentially be tackled. Compared with the control group, family caregivers who received the intervention experienced less conflict regarding care decisions for their loved one with dementia. They also evaluated care more positively in the domains of family support and communication. However, care and documented ACP were not clearly impacted: no significant differences were found between the control and intervention groups in the number of advance directives and hospitalizations nor in the location of death.[22]

The intervention was called Family Carer Decision Support (FCDS) and consisted of five elements: a trained ACP facilitator, family education, family care conferences, ACP documentation and orientation of GPs and nursing home staff towards the intervention. The trained ACP facilitator was a registered nurse external to the nursing homes, who received specific training in ACP and dementia. Family education consisted of an informational booklet that was originally developed in Canada, in response to frequently asked questions by family caregivers of nursing home residents with dementia.[23] The booklet described the natural evolution of the disease, potential complications, a palliative care approach to symptom management and the dying phase.[24] The trained ACP facilitator invited the family caregiver for a family care conference, which was based on clinical practice guidelines.[25] During this meeting, the contents of the booklet were discussed and potentially, advance decisions were documented. The ACP facilitator would then draft an advance care plan and after review by the family caregiver, the advance care plan was added to the resident's medical records and shared with the attending nurse and physician.

Since the results of the original RCT were promising, the mySupport study was set up to scale up the intervention. The mySupport study is a transnational effectiveness-implementation evaluation study in six countries: United Kingdom, Ireland, the Netherlands, Canada, the Czech Republic and Italy. The aim was to adapt the FCDS intervention to local context and needs, implement the intervention and assess outcomes associated with the intervention.[26] Adaptations to local context included the translation and revision of the educational booklet that originated in Canada. We describe this further in **Chapter 5** of this thesis, where we answer the question: *"What should be the content of educational and advance care planning materials for different contexts, considering (i) transnational legal and socio-cultural differences and developments over time, plus (ii) evidence and expert consensus-based recommendations regarding palliative dementia care?"*

In addition, two adaptations to the original intervention were made. One, nursing home staff were trained by an external facilitator to conduct family care conferences themselves (train the trainer). The train the trainer model addresses recommendations regarding the role of nursing staff in ACP: nursing staff is currently not well aware of their role in ACP and physicians do not always acknowledge nursing staff's role in ACP, hence training may empower nursing staff.[27] We study the effects of this train the trainer model on ACP practice in **Chapter 7**, by answering the question: *"How do family caregivers of nursing home residents with dementia and nursing home staff experience collaboration in advance care planning during the mySupport study?"*

Two, family caregivers were stimulated to take lead in the family care conference by providing them with a question prompt list. A question prompt list is a list of example questions or topics that patients and family can use to ask healthcare professionals about topics important to them. A question prompt list may therefore support patient engagement and thus person-centered care.[28] Previous studies suggest that a question prompt list indeed increases question asking and information provision by the healthcare professional.[29] This raises the question: *"What questions should be included in question prompt lists for family caregivers, and what is the importance of the local context?"* We answer this question in **Chapter 6**.

Aim and outline of this thesis

The overall aim of this thesis is to examine why a palliative care approach in dementia that is proactive and family inclusive is still sub optimally implemented, and how advance care planning with family caregivers of people with dementia can be improved. This thesis is therefore structured in two parts. Part 1 consists of three chapters that describe palliative dementia care practice to highlight possible avenues for improvement. The research questions are:

1. *“What are the barriers to providing high-quality palliative care in dementia according to elderly care physicians in the Netherlands, and what solutions do they propose to address these barriers?”*
2. *“What interventions support family caregivers of people with dementia at the end of life in nursing homes?”*
3. *“How do advance care plans of nursing home residents with dementia change following pneumonia, what factors are associated with changes and what factors are associated with the person perceived by the elderly care physician as most influential in decision making?”*

Part 2 consists of four chapters that describe the development and implementation of the mySupport study intervention as a way to potentially address the avenues for improvement, and a general discussion of the findings. The research questions of part 2 are:

1. *“What should be the content of educational and advance care planning materials for different contexts, considering (i) transnational legal and socio-cultural differences and developments over time, plus (ii) evidence and expert consensus-based recommendations regarding palliative dementia care?”*
2. *“What questions should be included in question prompt lists for family caregivers, and what is the importance of the local context?”*
3. *“How do family caregivers of nursing home residents with dementia and nursing home staff experience collaboration in advance care planning during the mySupport study?”*

Part I. Palliative dementia care: avenues for improvement

Chapter 2 focuses on palliative care for people with dementia. It presents the results of a survey that asked elderly care physicians in the Netherlands what they perceived to be barriers to providing high-quality palliative care in dementia, and what solutions they proposed to address these barriers. **Chapter 3** focuses on palliative care for family caregivers of people with dementia. This chapter presents a mixed-methods systematic review that aimed to synthesize information on interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes. **Chapter 4** focuses on the proactive element of palliative dementia care by addressing advance care planning specifically, and presents a secondary data analysis of randomized-controlled trial data. The aim was to explore changes in advance care plans of nursing home residents with dementia following pneumonia, factors associated with changes, and second, to explore factors associated with the person perceived by elderly care physicians as most influential in decision making.

Part II. The mySupport study intervention

The mySupport study intervention includes three elements that target the educational and support needs of healthcare professionals and family caregivers that were identified in **Chapters 2 and 3**, and that build on the role of family caregivers in advance care planning (identified in **Chapter 4**) to facilitate palliative care: an informational booklet for family caregivers, a question prompt list for family caregivers, and a family care conference with the primary family caregiver and nurse (assistant) of the person with dementia. **Chapter 5** presents an analysis of the educational booklet. The aim of this study was to provide guidance for future educational and advance care planning materials for different contexts, considering (i) transnational legal and socio-cultural differences and developments over time, plus (ii) evidence and expert consensus-based recommendations regarding palliative dementia care. **Chapter 6** describes the development of the question prompt list for family caregivers. This is a tool to support family caregivers in asking questions about their relative's end-of-life care to stimulate their involvement in advance care planning conversations. Country-specific lists were developed by consulting current and bereaved family caregivers in each of the mySupport study countries separately using nominal groups, and differences between the resulting question prompt lists were investigated to assess the importance of the local context. **Chapter 7** focuses on the implementation of the educational booklet, question prompt list and family care conference. This chapter presents a two-site case study that explores the perception of collaboration in advance care planning with family caregivers of nursing home residents with dementia, expressed by family caregivers and nursing home staff during the mySupport study. Finally, in **Chapter 8**, a general discussion of all findings is included. This chapter concludes with recommendations and implications for practice.

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2

Physicians’ perceived barriers and proposed solutions for high-quality palliative care in dementia in the Netherlands: Qualitative analysis of survey data

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Abstract

Background The literature indicates that palliative care for people with dementia needs to be enhanced.

Objectives To assess barriers to providing high-quality palliative dementia care and potential solutions to overcome these barriers, as perceived by physicians responsible for end-of-life care with dementia.

Design Cross-sectional study.

Setting The Netherlands.

Participants A representative sample of 311 elderly care physicians of whom 67% (*n*=207) responded.

Measurements A postal survey in 2013 containing open-ended items probing for barriers in the elderly care physicians' practices and possible solutions. Answers were coded and grouped using qualitative content analysis and presented to expert physicians in 2021.

Results Barriers to palliative care in dementia were (1) beliefs held by family, healthcare professionals or the public that are not in line with a palliative care approach, (2) obstacles in recognizing and addressing care needs, (3) poor interdisciplinary team approach and consensus, (4) limited use or availability of resources, and (5) poor family support and involvement. Suggested solutions were improving communication and information transfer, and educating healthcare staff, families and the public about palliative care in dementia. Timely and frequent communication with the family, including advance care planning, and more highly skilled nursing staff were also proposed as solutions.

Conclusions The results suggest a strong need for ongoing education for healthcare professionals about palliative dementia care. Strengthening interprofessional collaboration and shared responsibility for advance care planning is also key. Increasing public awareness of the dementia trajectory and the need for a proactive approach call for a broader societal agenda setting.

Introduction

As the number of people living and dying with dementia increases, dementia has been declared a public health priority.[1] Because dementia is a terminal disease, a palliative care approach is appropriate in principle. In 2014, the European Association for Palliative Care (EAPC) published a white paper[2] that provided evidence- and expert consensus-based recommendations to guide clinical practice and policy in shaping palliative care in dementia. However, palliative and end-of-life care in dementia are still perceived to be suboptimal according to family and healthcare professionals because the recommendations are not always implemented.[3-5] Improving care and services for people with dementia and their families is thus necessary.

The majority of people with dementia in the Netherlands die in nursing homes, estimates vary by setting of sampling between 70% and 93%.[6, 7] Nursing home teams in the Netherlands are multidisciplinary teams, supervised by elderly care physicians who carry the primary responsibility for the care of nursing home residents.[8, 9] The Netherlands is unique in having these care (instead of cure) oriented physicians as staff who have received specialist education in geriatrics, dementia and palliative care.[8] Compared to, for example, the United States, it is more common in the Netherlands that physicians decide, together with the family, to withhold curative treatment and focus on achieving a goal of comfort for nursing home residents with dementia.[10] Specialized palliative care teams are mostly serving hospital and hospice settings and are rarely called upon for nursing home residents with dementia.[11]

Due to their significant role and expertise in providing end-of-life care for people with dementia, elderly care physicians are key informants as to why implementation of palliative care in dementia is still suboptimal and how to address these barriers. The main question we address in this study is: What are the barriers to providing high-quality palliative care in dementia in the Netherlands according to elderly care physicians, and what solutions do they propose to address these barriers?

Methods

Participants and procedure

This study was part of a larger cross-sectional survey in the Netherlands and Northern Ireland[12-14] from which we present the Dutch qualitative data. A representative sample of elderly care physicians in the Netherlands participated in a postal survey in 2013. We used systematic random sampling by e-mailing a self-administered postal survey to every fourth elderly care physician from an alphabetical list of the 1248 members of the Dutch Association of Elderly Care Physicians and Social Geriatricians (Verenso). This member list includes more than 80% of Dutch registered elderly care physicians. The inclusion criteria were: (i) experience with end-of-life care for people living with dementia and (ii) practicing at Autumn 2012. Two reminders and a prize draw to win a 100-euro gift card were used to maximize responses.

The survey contained a quantitative evaluation of the priorities of elderly care physicians in the end-of-life care for people with dementia (see Additional file 1). Its components were based on the EAPC white paper recommendations domains (Box 2 in[2]). Additionally, the survey included an open-ended item, asking:

"*Finally, in your opinion, what are the three most significant barriers to providing good quality palliative care in dementia in your practice, and importantly, how would you suggest these barriers are best addressed?*".

In February 2021, we presented the most frequent pairs of barriers and solutions that emerged from this survey to expert elderly care physicians with a minimum of three years of experience in caring for people living with dementia, and who were affiliated with an academic center in the role of teacher, supervisor or researcher. They were asked to indicate whether the results were still relevant and up-to-date, soliciting for additional comments.

Data management and analysis

The responses were analysed using conventional content analysis[15, 16] in Atlas.ti (version 7.5.10, 2015) and Excel. First, all responses were read and reread to gain familiarization with the barriers and solutions mentioned by the respondents. Next, codes were created from the data based on the specific barriers and solutions identified. Because there was no one-to-one relation, proposed solutions were coded separately from the barriers to maintain meaningful differentiation between the categories and codes for both solutions and barriers. To ensure validity and rigor,[17] codes developed by LB (PhD student trained in quantitative and qualitative methods) were peer checked by HJ (elderly care physician) and HS (BSc student trained in quantitative and qualitative methods). Finally, codes were reviewed and grouped into larger categories inspired by the literature[14, 18] and based on discussions between the researchers (LB; HS; JS, associate professor in end-of-life care). Codes were quantified to describe the frequency of their occurrence.

Codes were developed in the original language (Dutch) and translated to English for reporting. Quotations used to support findings were translated to English by a professional translator as recommended.[19]

Ethical procedure

The Medical Ethics Review Committee of the VU University Medical Center approved the survey as part of series of studies on end of life in nursing homes (2010/157; 14 June 2010). Consent was implied with receiving a completed questionnaire. Returned surveys were pseudonymized with a numbering system. The expert physicians were informed of the purpose of the study and consented to use their evaluation and relevant demographics (gender and experience) for publication while not personally identifiable in the report.

Results

Characteristics of respondents

A response rate of 67% was achieved with 207 out of 311 self-complete postal surveys returned. Nineteen were excluded from analysis because the physicians did not meet the inclusion criteria of experience with end-of-life care (*n* = 13) or currently practicing (*n* = 6). Of the included 188 respondents, 171 mentioned one to four barriers and associated solutions. The majority of the elderly care physicians was female, visited their residents daily and had lost more than one resident with dementia in the past year (Table 1). The demographics of the respondents correspond with the entire population of elderly care physicians in the Netherlands (mean age: 48.4, percentage women: 64%)[20] and we assume that the respondents are geographically representative of the entire population, as this was the case in a study conducted at the same time using the same sampling approach.[21]

Table 1 Characteristics of the 2013 survey respondents

Characteristics	Total (n = 188)
Sex	67.0% women
Mean age, years (SD)	48.4 (9.2)
Years in practice, mean (SD)	20.8 (9.0)
How often do you visit a typical nursing home resident? % (n)	
At least daily	63.8 (118)
At least weekly	24.3 (45)
At least monthly	8.6 (16)
Every two months	3.2 (6)
Less than every 6 months	0
Please estimate the number of dying dementia patients you cared for in the past year, % (n)	
None	3.8 (7)
1 to 4	6.5 (12)
5 to 9	32.3 (60)
10 to 19	37.6 (70)
20 or more	19.9 (37)

Barriers

The barriers to providing good quality palliative care in dementia were clustered into five categories (cf. [14]) and are listed in Table 2 in order of frequency together with the underlying codes and example quotes.

1. **Beliefs and lack of knowledge, awareness or understanding.** A perceived lack of knowledge about dementia and palliative care appeared to be the most prominent barrier according to the elderly care physicians. Consequently, families, hospital doctors, nursing staff, and the public did not see the need for a palliative approach for people with dementia.

2. **Obstacles in recognizing and addressing care needs**. The respondents mentioned difficulties in identifying and managing decline, discomfort, and diagnosing and managing dementia in general. The start of the palliative phase was often recognized late. Additionally, care goals or treatment plans were not documented or vague.

3. **Poor interdisciplinary team approach and consensus**. The elderly care physicians indicated that care was not continuous because of high staff turnover, poor information transfer, and poor collaboration between healthcare professionals. This could delay starting palliative care. Moreover, the respondents stated that palliative care terminology was used inconsistently, and uncertainty remained about what a palliative care approach entailed.

4. **Limited use or availability or resources.** The next most frequently mentioned barrier was limited staff resources. Elderly care physicians often mentioned a lack of time and poor staffing to negatively impact the care provided.

5. **Poor family support and involvement***.* The respondents indicated that frequently family did not feel ready to part with their relative–hence resisting palliative care. Underlying this resistance was insufficient support for families, as elderly care physicians and the nursing staff were not able to timely discuss the end of life. Further, family and nursing home staff sometimes disagreed about the quality of life of the person with dementia.

Proposed solutions

Table 3 shows five clusters of solutions that the respondents proposed for various barriers. First, we discuss three clusters in chronological order of patient transitions across care settings. Next, we present two clusters that address barriers at a broader, societal level.

Healthcare

Improving healthcare professional – patient or family interaction

Starting in *community practice*, the elderly care physicians proposed a stronger involvement of general practitioners (GPs) in palliative or dementia care. The respondents called for an early start of patient support, dementia diagnosis and advance care planning (ACP), to prevent emergency actions in nursing homes. This was most frequently mentioned as a solution for a lack of continuity of care, palliative care or dementia knowledge, and resources.

Transitioning to *nursing home practice,* the respondents stated that improved communication and family support could be a solution to the suggested barriers. Nursing home staff needed to increase the frequency of their conversations with family and provide counseling (“psychoeducation”). Together with timely conversations about end of life and an early start of ACP, this could assist families in accepting or understanding their relative’s prognosis, and to recognize palliative care as an appropriate approach. Potentially, this would ameliorate disagreements between family and nursing home staff.

Further, nursing home staff should focus more on person and family-centered care. This includes attention for spiritual care and providing compassionate care, with an emphasis on social and emotional bonding, and less on a medical approach. It was suggested that nursing home staff should engage family in daily care tasks and improve their interaction with other cultures. This was highlighted in case of limited resources, obstacles in recognizing and addressing care needs and poor family involvement. Finally, respondents proposed to expand facilities, activities or services for patients and families to facilitate family support and involvement.

Improving the quality of care provided

In nursing home practice, barriers to palliative dementia care could by countered by nursing staff receiving specific training in palliative care. Many respondents suggested that multidisciplinary training could enhance palliative care knowledge and overcome several barriers related to limited staff resources and a lack of consensus about palliative care terminology.

Another important solution proposed by many elderly care physicians was to train nursing staff in symptom recognition and in using standardized instruments, such as pain observation scales and the Liverpool Care Pathway.[22] If correctly used as a supportive tool and not as a ‘protocol’, the respondents believed that this could help improve recognizing and addressing care needs, and increase staff knowledge about dementia and palliative care.

Table 2 Barriers: categories, codes and illustrative examples

Category	Codes (number of elderly care physicians)	Quote
1. Beliefs and lack of knowledge, awareness or understanding	• Healthcare staff that is insufficient knowledgeable of dementia or palliative care (65)	• *[There is] insufficient specific knowledge about palliative care in dementia among the care team (in particular [among] nurse assistants/aids)* (P9).
	• Insufficient family understanding of dementia or end-of-life care (28)	• *Family who suddenly bring up IV fluids in [the] late stages = lack of knowledge/understanding of policy and its consequences* (P130).
	• Insufficient acceptance of appropriateness of palliative care in dementia by healthcare professionals, families and the public (24)	• *So far there is not enough awareness that dementia is also about palliative care* (P140).
	• Insufficient public understanding of dementia or end-of-life care (16)	• *A 'natural' death before reaching the final stage of a dementia is considered preventable and [there is a belief that] therefore it must be prevented* (P77).
2. Obstacles in recognizing and addressing care needs	• Inadequate diagnostics, observation or treatment of symptoms (51)	• *Insufficient recognition of 'suffering' in people with dementia* (P87).
	• Lack of clear guidance such as advance care plans, living wills and legislation (19)	• *Too many people still don't have an advance directive that would give me extra support for the decision to switch to a palliative approach* (P175).
	• Inappropriate medical treatments, interventions and hospitalizations (15)	• *Monodisciplinary (specialist) interventions by hospital professionals complicate implementation of the care plan. They often raise unrealistic hope/expectations, especially among representatives* (P81).
3. Poor interdisciplinary team approach and consensus	• Lack of continuity in care or personnel within and across care settings (46)	• *[There is] insufficient transfer of information between care providers (GP – elderly care physician – case managers)* (P18).
	• Lack of consensus or understanding between healthcare professionals (27)	• *A large group of people involved using a variety of concepts that are not open to one and the same interpretation; for example: [interpretation of] palliative care, warm care, etc., even comfort* (P58).

4.	Limited use or availability of resources	• Limited staff resources, causing practice and time pressures (44)	• *More time is needed for personal attention/support* (P14).
		• Limited nursing home funding (17)	• *[There are] no individual rooms, which means a move to [a] private room in [the] terminal stage [is necessary]* (P94).
		• Limited use or availability of specialists in dementia or palliative care (7)	• *Inadequate utilization by GP/care home of specialist knowledge [about] palliative care for people with dementia* (P65).
5.	Poor family support and involvement	• Family resistance (33)	• *Denial by family who are unable to let go of their loved one* (P84).
		• Insufficient or late support for families and patients (29)	• *In my opinion dementia care is specialized palliative care. Of the four palliative domains [that is: physical, psychological, social and existential], spiritual care is insufficiently addressed in dementia* (P63).
		• Disagreements (27)	• *Family and physician disagree about the stage of dementia (usually [the] physician is one step ahead of the family regarding the disease process* (P136).

Both barriers could also be countered if nursing staff were able to consult a specialist, and if elderly care physicians consulted peers. The respondents further suggested that consulting a specialist or specializing staff could improve continuity in practice, although some, both in the survey and expert consultation, regarded themselves palliative care specialists.

Improving the continuity of care provided

To improve the continuity of care in the nursing homes, many elderly care physicians suggested to increase staff resources. More staff and decreased (administrative) workload would reduce lack of time. Additionally, investing in having the same healthcare professional attending the same patient and family would facilitate relationships and improve acceptance of dementia diagnosis or prognosis.

Another proposed solution to increase continuity was to provide further training for nursing home staff in communication to facilitate initiating or conducting end-of-life conversations and ACP. This would also help connect with family and enhance the quality of information transfer between healthcare professionals. Specifically, a clear use of terminology was needed. This could improve families' and staff's knowledge and acceptance of appropriateness of palliative care in dementia.

Many respondents proposed improved collaboration, coordination and information transfer, both within nursing home practice and in transfers to and from *secondary care*. This could address barriers related to lack of continuity in care or personnel, misunderstandings between healthcare professionals, and to obstacles in recognizing and addressing care needs. In particular, multidisciplinary meetings and collaboration were considered key, also to support ACP. Respondents also suggested to specifically improve collaboration between nursing home staff and medical specialists. Hospital doctors (and GPs) were suggested to benefit from nursing home staff's expertise in providing good care for people living with dementia. This could foster continuity in care and ameliorate problems with overtreatment.

In relation to the latter, the elderly care physicians proposed to have more discussions about futile treatment and focus on care rather than cure. This could also help overcome disagreements about care goals between healthcare professionals, within the nursing home and in the interaction with hospital doctors.

Society

In addition to specific changes of healthcare, the elderly care physicians proposed more general solutions to address barriers for palliative dementia care at a broader, societal level.

Improving policy to support palliative care provision. The respondents suggested that an increase and reallocation of government funding for palliative care could address barriers such as poor staffing and a lack of time, and support the enhanced education of nursing staff to increase their knowledge in palliative and dementia care. Funding could support the provision of palliative care in practice by enabling more facilities, activities or services for the patient or family.

Another policy improvement was clarification of law and regulation. This was proposed to help resolve perceived ambiguity in legislation regarding (foregoing) treatment.

Improving public perception. The elderly care physicians expressed a need for public education on palliative care and end of life. This could help address barriers to providing high-quality palliative care in dementia such as the perceived unrealistic public image of prolonging or ending life, the denial of dementia diagnosis or prognosis by some families, and the difficulties in recognizing and addressing care needs.

The respondents also proposed that public education to increase awareness around the medical futility of life-prolonging treatment in people with advanced dementia could solve a variety of barriers related to overtreatment and a lack of knowledge and acceptance. It could also diminish the stigma around dementia and myths around prolonging or ending life. Finally, public education on ACP or advance directives could be a solution for the lack of clear guidance for their practice.

Expert checking

These results from the 2013 survey were presented to 26 expert physicians in 2021, ten of whom were men and the average years of experience in caring for people living with dementia was 19.6 years. All barriers and solutions were indicated to still be relevant by at least 12 physicians (range: 12-25 confirmations per barrier and solution). The barriers and solutions related to the availability of resources, information transfer, and symptom recognition and control were endorsed by the lowest numbers of physicians (13, 16 and 12, respectively). Nearly all physicians endorsed the barriers and solutions related to palliative dementia care knowledge (*n* = 25) and family support (*n* = 22).

Table 3 Solutions: categories, codes and illustrative examples across settings

Setting	Category	Codes (number of elderly care physicians)	Quote
Health care			
Community practice	1. Improving healthcare professional – patient or family interaction	• Extending general practitioners' engagement in or collaboration with palliative or dementia care (20)	• *Encourage first-line advance decision making with patients. For example, not to be resuscitated* (P26).
		• Improving communication with and support of families (68)	• *Early psychoeducation of 'those close [to the patient]': guidance/support by a professional social-psychiatric nurse/psychologist* (P169).
		• Focus on person and family-centeredness of care (26)	• *Training of the team by a spiritual caregiver; a spiritual caregiver part of the multidisciplinary team with clear coaching role* (P121).
		• Expansion of patient or family facilities (10)	• *Organize additional space for family to retire to and as an option to stay overnight* (P17).
Nursing home practice	2. Improving the quality of care provided	• Nursing staff training in dementia and palliative care (79)	• *Initiating [a] palliative dementia nursing training program; upgrading carers in the dementia sector* (P45).
		• Nursing staff training in symptom recognition and using standardized instruments (50)	• *Introducing [the] Liverpool Care Pathway*[22] *on psychogeriatric wards, with training, education, etc.* (P179).
		• Increase the consultation of specialists (18)	• *More accessible consultation/advice from colleagues; stronger embedding of palliative consulting teams in [the] regular consultation structure* (P7).
	3. Improving the continuity of care provided	• Increase staff resources (46)	• *More large contracts; avoid multiple changes of treating physicians* (P162).
		• Nursing staff communication training (25)	• *Training (at least for MDs without specialization) on how to make [prognosis and care policy] a topic for discussion (e.g. Royal Dutch Medical Association guideline)* (P176).
		• Improved collaboration, coordination and information transfer (51)	• *Coordinating with medical specialists (and GPs) to create a common approach / language* (P171).

Secondary care		• Emphasis on care instead of cure or discussion of futile treatment (8)	• *To make both doctors and treatment team aware that each treatment must serve a purpose by questioning each other in the multidisciplinary treatment team* (P121).
Society			
	4. Improving policy to support palliative care provision	• Increase and reallocate government funding for palliative care (25)	• *Invest in care for older people perhaps less in cure* (P182).
		• Clarification of law and regulation (2)	• *Adaptation and clarification [of] laws and regulation. (Dutch Association of Elderly Care Physicians and Royal Dutch Medical Association came up with rather evasive answers and concepts too vague to use)* (P131).
	5. Improving public perception	• Education on dementia and inappropriate medical interventions (44)	• *Better explanation by physician / nursing staff, but also more knowledge nationwide about [the] severity of the disease* (P43).
		• Education on palliative care and end of life (41)	• *Adjust the social image that reaching an advanced age is a blessing: death is sometimes an outcome of a declining lifeline and should not be fought with medical technology just because it is available* (P77).
		• Public education on advance care planning or directives (4)	• *Discuss [advance directive] in [the] media at earlier stage (i.e. pre-nursing home admission)* (P130).

Discussion

Dutch elderly care physicians see most people living with dementia in the last phase of their life as they are responsible for providing nursing home care and most people with dementia in the Netherlands die in a nursing home. Specialist training supports their competency; the Netherlands is a country where withholding curative treatment based on quality-of-life care goals is more common than elsewhere.[10] Therefore, we expected this particular setting to be promotive of palliative and end-of-life care provision to persons with dementia. Yet, this representative sample of elderly care physicians raised a variety of barriers to providing high-quality palliative care in dementia.

Interestingly, the barriers perceived by the elderly care physicians mirror the barriers reported in international literature (e.g. [18]). Apparently, having a skilled elderly care physician on the staff of nursing homes is not enough to overcome these barriers to high-quality palliative care. Families having insufficient awareness of the terminal nature of dementia and a poor understanding of palliative care[23-25] still remain as barriers, causing families to resist a palliative approach and insisting on curative treatment. Also continuity of care is not assured. A strong upstream orientation to palliative care that addresses palliative care early on is missing.[26] GPs would not usually discuss palliative care and ACP when their patients with dementia were still able to contribute. Living wills that elderly care physicians can use to guide treatment and thus provide continuity in care remain uncommon. In addition, the extended palliative phase in dementia is not being recognized by all healthcare professionals.[27] The elderly care physicians reported that hospital doctors did not consider the dementia of their patients in the treatment plans. Continuity of palliative care was therefore disrupted upon hospitalization.

A broader support base for palliative care is thus required and this refers to all involved in caring for people living with dementia: families, GPs, hospital doctors and nurses. Figure 1 visualizes the solutions that the elderly care physicians proposed to overcome these barriers. To improve the quality and continuity of palliative care in dementia (overall aims), increased understanding of palliative care and dementia and improved communication is needed (objectives). The means necessary to achieve increased understanding and improved communication are ACP, education and communication training. With their expertise, elderly care physicians function as the key consultants to facilitate this process, supported by palliative care specialists. Rather than have healthcare professionals refer cases to the elderly care physician or palliative care specialists, this means that elderly care physicians and palliative care specialists need to support GPs, hospital doctors and nursing staff in providing palliative dementia care themselves. It is thus important that consulting a specialist in palliative dementia care does not reinforce the lack of support for palliative dementia care in certain healthcare settings.

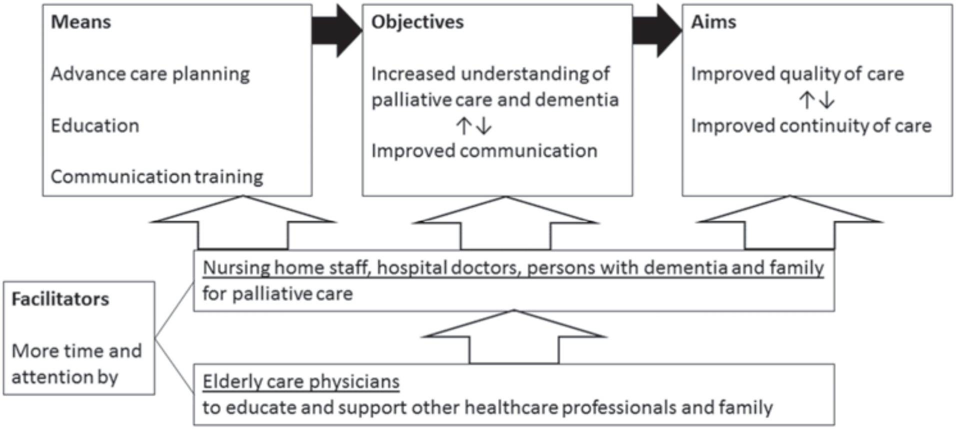

Figure 1 Schematic of process to overcome barriers to high-quality palliative care in dementia

Public education on palliative care has been labeled a key priority by international experts to support integrated palliative care[28] and several studies found a positive effect on palliative care delivery.[29-31] The effectiveness of education on dementia, however, remains unclear.[32] This is why improving communication that was frequently proposed is an important solution. Families want more information about dementia, preferably provided by healthcare professionals that follow-up on this information.[33] Communication between healthcare providers and families is thus important to educate families. In addition, ACP, if perceived as an ongoing dialogue, can serve as a means to support education and communication. This ongoing dialogue is further important as families need repeated information about their relative's condition and palliative care options to foster acceptance.[34] Timely discussions of death and dying are important in orienting families to palliative care.[35] To support an early start of ACP, the physicians called for public education on ACP or advance directives, end of life and the lack of added value of curative medical treatments in advanced dementia. Moreover, families, nurses and physicians should use consistent language in ACP.

In addition to pointing to complexities around families not being on the same page, many solutions targeted nursing staff. Nurses are especially important to address barriers to providing high-quality palliative care that are specific to dementia: difficulties in assessing discomfort and the start of the dying phase.[36] Having an elderly care physician on the staff does not suffice, as proper assessment involves continuous monitoring. Nursing staff are in a better position to perform this. Continuous monitoring requires time, training and communication with team members. However, the elderly care physicians stated that there was a lack of time and poor staffing levels, as frequently observed before,[18] causing high workload. In addition, they expressed a lack of trust in nursing staff being sufficiently equipped to deliver high-quality palliative care. Nurses indeed express difficulties in recognizing and addressing care needs.[37] Training in using tools is therefore necessary[38] and was often suggested by the elderly care physicians. This training should underline the use of the tools as supportive instruments and not as standardized protocols or as a tick box approach, to retain a person-centered approach. This specific issue was also raised by one of the respondents.

There are some limitations of this study. Brief answers to the open-ended survey items complicated interpretation and elaboration could not be sought. Another limitation is the time between data collection (2013) and reporting. This could affect the relevance of the results. However, the findings were considered to be relevant–and the interpretation of answers appropriate–as the perceived barriers and proposed solutions were confirmed by expert physicians in 2021. Additionally, developments in nursing home care in the years following data collection[39] lead us to believe that the barriers were stable or even increasing. For example, nursing home staff was found to feel less competent. A strength of this study is the inclusion of a large and representative sample of elderly care physicians and the two-stage approach, adding expert views. The representative sample led to the inclusion of more women than men in this study, as the proportion of women working in nursing home care in the Netherlands is higher than in medical specialist care.[40] Future research could investigate if men and women in healthcare experience different barriers to palliative dementia care.

In conclusion**,** elderly care physicians in the Netherlands experience several barriers to providing high-quality palliative care in dementia. The current study suggests a strong need for specialist training of nursing staff, stronger networks between healthcare professionals to ensure continuity of care, and raising public awareness in the domains of dementia, palliative care, ACP and end of life. Palliative dementia care is shared care as families, nurses and physicians all have a role to play. Better education could overcome barriers in several contexts: both in nursing homes and in society.

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Conflict of interest

The authors declare that they have no competing interests.

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Appendix

Additional file 1 Survey - Care for Patients with Dementia at the End of Life (DOC 380 Kb)

Care for Patients with Dementia at the End of Life

A survey about physicians' priorities in caring for people with dementia at the end of life

Northern Ireland version developed by:

Professor Kevin Brazil and Dr Karen Galway, School of Nursing and Midwifery, Queen's University Belfast, Dr Jenny Van der Steen, VU University Medical Centre Amsterdam, and Professor Max Watson, University of Ulster, Northern Ireland Hospice, Princess Alice Hospice, Esher

Dutch version available upon request

Care for Patients with Dementia at the End of Life

Increasingly, people are dying with or from dementia. This survey study is about physicians' priorities in caring for people with dementia at the end of life. The items are based on a proposed set of European guidelines. Your opinions can help shape future policy and practice. We count on your contribution, thank you very much in advance for this.

Section A: Statements

Please rate your level of agreement with the following statements by circling the appropriate number in each row.

	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree	Don't know
1. Dementia and the End of Life						
a) Dementia can be regarded as a disease you can die from	1	2	3	4	5	0
b) Palliative care applies equally from the time of diagnosis to the stage of severe dementia	1	2	3	4	5	0

2. Informing Patients and Families						
Informing patients and families around the time of diagnosis on what severe dementia looks like:						
a) Will increase patients' and families' anxiety unnecessarily	1	2	3	4	5	0

	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree	Don’t know
b) Facilitates later decision-making because families are better prepared	1	2	3	4	5	0
c) Is not needed because families will witness patient’s decline later and this will sufficiently facilitate decision-making	1	2	3	4	5	0
d) Is not necessary as most patients will not progress to severe dementia	1	2	3	4	5	0
e) Will increase requests for inappropriately high levels of pain relieving medication	1	2	3	4	5	0
f) Will increase requests for hastening death	1	2	3	4	5	0

3. Advance Care Planning About Future Care at the End of Life

a) Advance care planning on end of life care should be initiated at the time of diagnosis of dementia	1	2	3	4	5	0
b) The process of advance care planning should involve revisiting plans with the patient and the family on a highly frequent basis	1	2	3	4	5	0
c) When a patient cannot participate in treatment decisions an advance directive is essential	1	2	3	4	5	0

d) The pace of advance care planning is primarily determined by patient's and family's willingness to face the end of life	1	2	3	4	5	0
e) Families and patients who are involved in advance care planning should become informed about commonly occurring health problems associated with severe dementia, such as pneumonia and intake problems	1	2	3	4	5	0
f) In the case of severe dementia, the patient's best interest may be increasingly served with a primary goal of maximising comfort	1	2	3	4	5	0
g) The physician should take the initiative to introduce and encourage advance care planning	1	2	3	4	5	0
h) There should be an agreed format for advance care plans	1	2	3	4	5	0
i) Physicians need improved knowledge to successfully involve families in caring for dementia patients at the end of life	1	2	3	4	5	0
j) The advance care planning process requires my making family members agree with the physician on goals of care	1	2	3	4	5	0
k) The physician cannot make family members accept their loved one's prognosis, the advance care planning process fails	1	2	3	4	5	0

l) When family members have difficulty understanding the limitations and complications of life sustaining therapies, the physician cannot successfully guide the advance care planning process	1	2	3	4	5	0

	Strongly disagree	**Moderately disagree**	**Neither agree nor disagree**	**Moderately agree**	**Strongly agree**	**Don't know**
4. Decision-Making						
a) Shared decision making including the patient and family caregiver as partners should be a clinical practice goal	1	2	3	4	5	0
b) The health care provider should always prioritize the patient's needs in decision making	1	2	3	4	5	0
c) The physician should be responsible for making the final decision on the patient's needs	1	2	3	4	5	0

Section B: Aspects of Palliative Care in Dementia

Please consider the following aspects of palliative care in dementia and place a score from 0 to 10 in each cell of the grid to indicate your opinion of their importance, the barriers to achieving optimal care and the amount of effort needed to address each barrier.

Aspect of palliative care in dementia	**How important is this to palliative care in dementia?** 0 = Not important 10 = Very important	**How significant is this as a barrier in your clinical practice?** 0 = Not significant 10 = Very significant	**To what extent does addressing this barrier require effort in terms of time and cost, for you, the institution or national level** 0 = No effort 10 = A lot of effort
a) Acceptance amongst **professionals** that palliative care applies to dementia			
b) Acceptance amongst **the public** that palliative care applies to dementia			
c) Person-centred palliative care in dementia involving optimal communication and shared decision making			
d) Setting care goals as part of producing advance care plans			
e) Continuity within palliative care in dementia			
f) Accurate prognosis to allow for timely recognition of dying			
g) Minimising aggressive, burdensome, or futile treatment that will not extend life or provide comfort.			
h) Treatment and care of symptoms that is designed to provide comfort			

Aspect of palliative care in dementia	**How <u>important</u> is this to palliative care in dementia?** 0 = Not important 10 = Very important	**How significant is this as a barrier in your clinical practice?** 0 = Not significant 10 = Very significant	**To what extent does addressing this barrier require effort in terms of time and cost, for you, the institution or national level** 0 = No effort 10 = A lot of effort
i) Psychological and spiritual support			
j) Family involvement and associated support for families in caring for the patient			
k) Education and training specific to palliative care in dementia for the health care team			
l) Availability to specialist support in palliative care for dementia			

Section C: Barriers and Solutions

Finally, in your opinion, what are the **three most significant barriers** to providing good quality palliative care in dementia in your practise, and importantly, how would you suggest these barriers are best addressed?

Barrier	**How best might this be addressed?**
Example: the inconsistent use of the term palliative care among and between physicians and carers	***Example:*** multidisciplinary training on site
1.	
2.	
3.	

Section D: Some Questions About You Will Help Our Analyses

1. Please indicate today's date: ________________

2. Please indicate your gender:

☐ Male ☐ Female

3. Please indicate your age: ________________ years

4. How long have you practiced as a physician? ________________ years

5. What proportion of your time is spent providing clinical care?

Please indicate a proportion between 0 FTE to 1.0 FTE (full-time equivalent)________________

6. What percentage of your practice time involves clinical care in the nursing home?

- ☐ None
- ☐ < 10%
- ☐ 10 - 24%
- ☐ 25 - 49%
- ☐ 50 - 74%
- ☐ 75 - 90%
- ☐ > 90%

7. How often do you visit a typical nursing home patient?

- ☐ at least Daily
- ☐ at least Weekly
- ☐ at least Monthly
- ☐ Every 2 months
- ☐ Every 6 months
- ☐ Less than every 6 months
- ☐ Never

8. Please estimate the number of dying dementia patients you cared for in the past year.

- ☐ None
- ☐ 1 to 4
- ☐ 5 to 9
- ☐ 10 to 19
- ☐ 20 or more

3

Interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes: A mixed-methods systematic review

Published as

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Abstract

Background Most people with dementia transition into nursing homes as their disease progresses. Their family caregivers often continue to be involved in their relative's care and experience high level of strain at the end of life.

Aim To gather and synthesize information on interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes and provide a set of recommendations for practice.

Design Mixed-Methods Systematic Review (PROSPERO no. CRD42020217854) with convergent integrated approach.

Data Sources Five electronic databases were searched from inception in November 2020. Published qualitative, quantitative and mixed-method studies of interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes were included. No language or temporal limits were applied.

Results In all, 11 studies met the inclusion criteria. Data synthesis resulted in three integrated findings: (i) healthcare professionals should engage family caregivers in ongoing dialogue and provide adequate time and space for sensitive discussions; (ii) end-of-life discussions should be face-to-face and supported by written information whose timing of supply may vary according to family caregivers' preferences and the organizational policies and cultural context; and (iii) family caregivers should be provided structured psychoeducational programmes tailored to their specific needs and/or regular family meetings about dementia care at the end of life.

Conclusion The findings provide useful information on which interventions may benefit family caregivers of people with advanced dementia at the end of life and where, when, and how they should be provided.

Key statements

What is already known about the topic?

- Several people with advancing dementia move permanently into nursing homes due to increasing disability and dependence.
- Family caregivers of people with dementia experience the highest level of strain when their relative's death is nearing and they often live in nursing homes.
- Family caregivers of people with dementia at the end of life have specific information and support needs related to the emotional impact of dementia and their decision-making role.
- Supporting family caregivers during the end-of-life stage prepares them emotionally for their relative's death and helps them cope with their caregiving role.

What this paper adds?

- This paper focuses on support for family caregivers of people with dementia at end of life in nursing homes while most literature addresses family caregivers of people living in the community or during the transition to the nursing home.
- Ongoing discussions between family caregivers and healthcare professionals facilitates partnership, promotes informed and shared decisions, is a source of emotional support, and essential to family caregivers' empowerment.
- Preferred timing of information provision about care options in advanced dementia is highly influenced by individual preferences and context.
- Psychoeducational programmes and regular meetings with trusted healthcare professionals tailored to family caregivers' specific and changing emotional and information needs can promote self-care and empowerment.
- Interacting with peers and healthcare professionals independent from the nursing home or experienced in psychological care may help family caregivers to identify their dementia education needs, manage distress and develop problem-solving skills.

Implications for practice, theory or policy

- Interventions to support family caregivers of people with advanced dementia at the end of life should include timely and ongoing face-to-face discussions complemented by written information and structured psychoeducational programmes which provide targeted socio-emotional care in addition to tailored information, while involving a multiprofessional team and possibly peers.
- Governments must acknowledge support of family caregivers of people with advanced dementia as a public health priority and invest resources in programs to provide them evidence-based support.
- Optimal support for family caregivers of people with advanced dementia at the end of life can promote their empowerment resulting in improved self-care attitudes and greater engagement in shared decisions for their relative's end-of-life care.
- Further research could assess how peer support and professional support for family caregivers of people with dementia in the nursing home may complement each other.

Introduction

Dementia is a cluster of terminal neurodegenerative disorders characterized by progressive and irreversible cognitive and functional decline, particularly among older adults.[1] It is estimated that around 50 million people currently have dementia worldwide, and there are nearly 10 million new cases every year.[2] The total number of people with dementia is projected to reach 82 million in 2030 and 152 in 2050.[2, 3] Most people with dementia and their family caregivers desire that they remain at home for as long as possible[4] and there is growing research about interventions which aim to postpone transition to nursing homes.[5, 6] These facilities are also known as aged-care or long-term care homes and provide nursing care and assistance in activities of daily living in addition to room and board.[7] However, about 75% of people with dementia move permanently into nursing homes at some point of the disease trajectory due to increasing disability and dependence.[4, 8] This means that healthcare professionals working in nursing homes increasingly care for people living with dementia and their family caregivers.[9]

Family caregivers of people with dementia are at increased risk of burden, stress, and depression.[10, 11] Despite literature shows that some family caregivers experience less clinically significant burden and depressive symptoms once their relative moves to a nursing home, particularly for those who lived with the person with advanced dementia in the community as their caregiving responsibilities decrease,[12] often the burden of caregiving persists after a relative moves to a nursing home[13, 14] and levels of strain increase near the end of life.[15] Indeed, most family caregivers continue to occupy a pivotal position in the decision-making process as surrogate decision-maker after their relative's move to the nursing home.[16, 17] This suggests that entering a nursing home does not necessarily signal the end of caregiving but rather identifies a new phase of the caregiving trajectory, which may be as challenging as or even more than caregiving at home.[18] Therefore, family caregivers of people with dementia need continuous support, from a relative's move to a nursing home to realign their role[19] until death since high level of family caregivers' anticipatory grief was suggested to be associated with worse well-being outcomes post-death.[20, 21]

The World Health Organization recognizes support for family caregivers of people with advanced dementia as a public health priority.[2] Particularly, family caregivers need both guidance in taking decisions for their relative's end-of-life care[22] and social and emotional support.[23]

Supporting family caregivers during the end-of-life stage may be particularly worthy not only with respect to offering them resources to tackle their strain thus avoiding prolonged or complicated grief,[20, 24] but also to help them cope with their caregiving role as a best interest decision-maker on behalf of their relative who may lack capacity.[23] Caring for family caregivers by providing information about the course of dementia and treatment options as well as attending to their emotional, psychosocial, and spiritual needs should be planned for throughout the overall disease trajectory.[23] However, literature mainly focuses on the support that family caregivers of people with dementia receive when they are still at home[25] and during the transition towards the nursing home,[26, 27] while knowledge about the support in taking challenging decisions about goals of care and treatments during the final weeks or a few months of their relative's life (hereafter end of life) is poor and fragmented. Therefore, this literature review aims to gather and synthesize information on interventions to support family caregivers of people with advanced dementia at the end of their relative's life in nursing homes and provide a set of recommendations for practice.

The central question driving this research is: what interventions support family caregivers of people with advanced dementia at end of life in nursing homes?

Methods

Design

A systematic review according to the Joanna Briggs Institute methodology for Mixed-Methods Systematic Review was performed.[28]

This review has been reported in accordance with the Synthesis Without Meta-analysis (SWiM) guidelines[29] (Appendix 1) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[30] (Figure 1) to enhance the quality and transparency of reporting. The review protocol was registered on PROSPERO register of systematic reviews on 5 November 2020 (registration number CRD42020217854), available at https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020217854.

Search Strategy

A three-step search strategy was employed: 1. an explorative search on PubMed and CINAHL EBSCO was conducted in October 2020 followed by an analysis of title, abstract and the index terms to identify the most appropriate keywords; 2. five databases (PubMed, CINAHL EBSCO, PsycInfo EBSCO, Joanna Briggs Institute, and Scopus) were searched from inception on November 5th 2020. Searches employed both controlled vocabularies and free terms, without temporal or language limits. Search strategies were adapted for each database (Appendix 2); 3. the references of included articles were screened to identify further relevant publications.

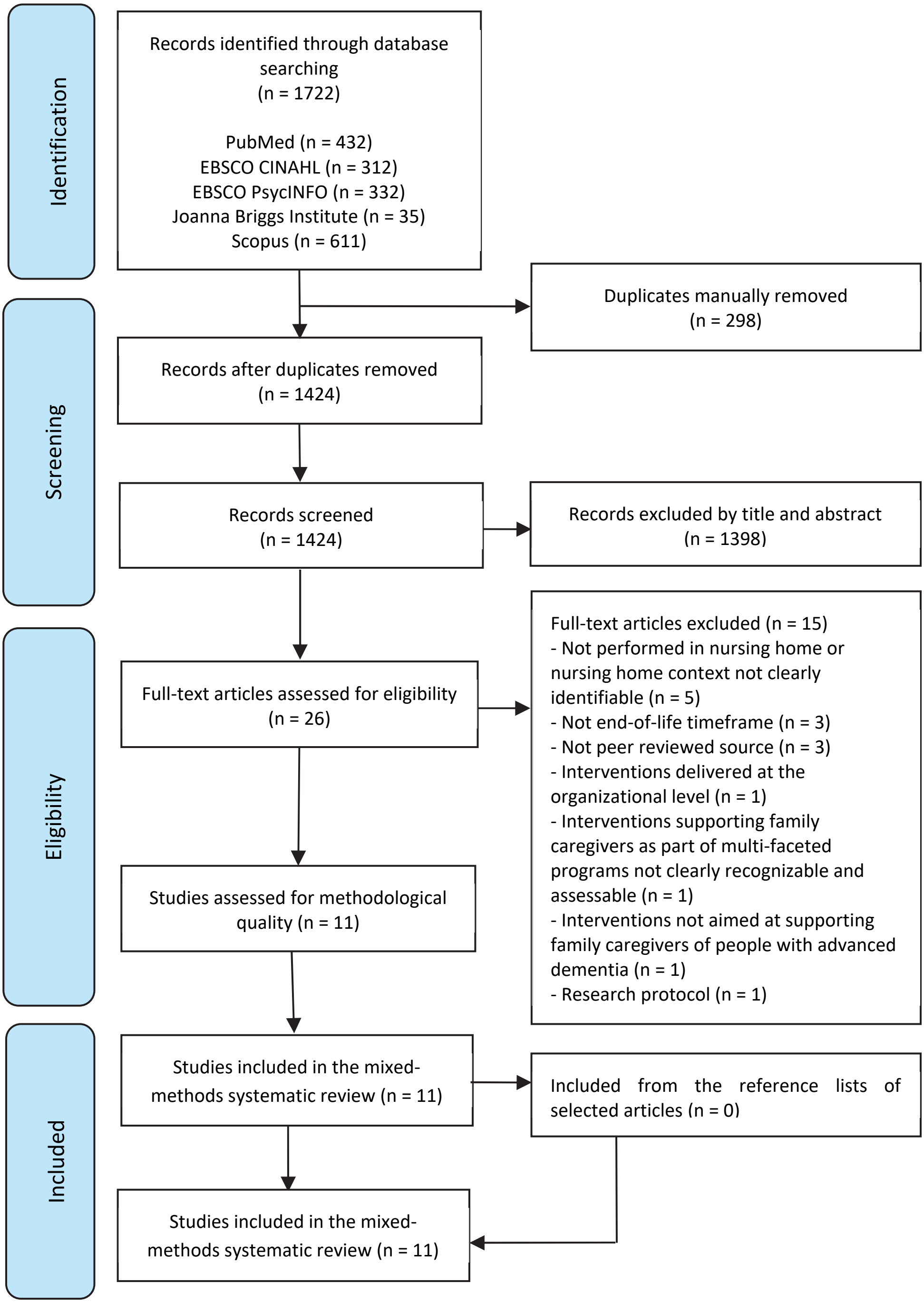


Figure 1 PRISMA flow-chart depicting the main stages of the systematic review process

Inclusion and exclusion criteria

Population

Studies were included if they focused on any type of interventions aimed at supporting family caregivers of people with advanced dementia at the end of life in nursing homes by promoting their awareness and resilience. End of life was defined as the final weeks or a few months of a relative's life.[31]

Interventions delivered at the organizational level (e.g., care coordination program, respite program) or at the societal/policy level (e.g., payment rules, waiver programs, direct services to caregivers of people with dementia, policies regarding unpaid or paid leave for caregivers) as well as resident-oriented support interventions were excluded. Interventions at the organizational level were excluded since they are usually delivered in community settings and aimed at relieving caregiving responsibilities on a temporary or periodic basis during the disease trajectory, rather than promoting family caregivers' awareness and resilience, thus not providing an ongoing support for the end-of-life phase. Interventions at the societal/policy level were excluded since public support may widely vary across jurisdictions, thus preventing from providing generalizable recommendations. Caregiver-oriented support interventions as part of multi-faceted programmes were included only when caregiver-oriented support interventions were clearly recognizable and assessable.

Family caregivers of people with advanced dementia were defined as the relative, partner, close friend, or neighbor who provides assistance in activities of daily living, or social or emotional support to the person with dementia, or assumes an advocacy role.[32]

Phenomena of interest

The review considered studies that investigated all forms of interventions delivered at the caregiver level (e.g., educational, psychosocial, and psychological interventions) which are employed to support family caregivers of people with advanced dementia at the end of life in nursing homes.

Context

Studies merging caregiver-oriented support interventions across different settings (i.e. home, public hospital, hospice, private hospital and assisted living) were included only when the results related to the nursing homes were clearly distinguishable. Nursing home was defined as a facility that provides room and board, as well as management of chronic medical conditions and nursing care and interventions with activities of daily living for patients who are physically and/or cognitively impaired.[7]

Types of studies

Quantitative, qualitative and mixed methods studies were considered. Quantitative studies included cross-sectional studies, pre-post studies, clinical trials, controlled clinical trials, and randomized controlled trials; qualitative studies included qualitative descriptive, phenomenology, grounded theory, ethnography, case study, and action research design. Mixed methods studies were considered if data from the quantitative or qualitative components were clearly recognizable. When studies were quantitative according to the study authors but also reported qualitative data, the study was considered "quantitative" but both qualitative and quantitative data were included.

Theses, dissertations, abstracts in proceedings and other papers published in non-peer-reviewed publications (e.g. government working papers) as well as research protocols were excluded.

Screening and study selection

All identified articles were loaded into EndNote X9 (Clarivate Analytics, PA, USA) and duplicates removed. Titles, abstracts, and finally full texts, were screened by two independent reviewers for assessment against the inclusion and exclusion criteria.

Assessment of methodological quality

The selected papers were independently assessed by two reviewers for methodological validity using Joanna Briggs Institute critical appraisal tools for survey designs reporting frequencies/proportions,[33] randomized controlled trials,[34] qualitative studies,[35] and case reports.[36] Details of the items contained in each critical appraisal tool are reported in Appendix 3. No studies were excluded on the basis of methodological quality.

Data extraction

Two independent reviewers extracted data including author(s), year, type of study (i.e., quantitative, qualitative, and mixed methods), methodology (e.g., cohort, phenomenology), geographical context and other context-related information, number and characteristics of participants, phenomena of interest, data collection, data analysis, and main findings according to the Joanna Briggs Institute mixed methods data extraction form following a convergent integrated approach.[28] Moreover, details regarding the interventions delivered to support family caregivers were extracted, when available.

Quantitative data comprised of averages or percentages that profiled the sample as well as all relationships between study variables and outcome. Qualitative data comprised of themes or subthemes relevant to the review question with corresponding illustrations (i.e., participants' direct quotations or the exact words of the authors), which were assigned a level of credibility based on the congruency of the finding with supporting data: unequivocal (evidence beyond reasonable doubt); credible (plausible in light of the data and theoretical framework); or unsupported (no relationship between findings and data).[37] Only findings unequivocal and credible were included in the synthesis. Each finding was identified by an alphanumeric code (e.g. A1, A2, B1, …). Each letter corresponded to a study and each number to a unique finding. The progressive letters indicate the order of study inclusion in the review, while the progressive numbers indicate the order of findings in the original article (Table 1, Table 2, Table 3).

Data transformation

The quantitative data was converted into 'qualitized data' because codifying quantitative data is less error-prone than attributing numerical values to qualitative data.[28] Qualitized data comprised textual descriptions or narrative interpretation of the quantitative results (e.g., 'Undergoing some type of educational programme as a significant factor in predicting less role overload, less stress related to the caregiving situation, more frequent use of reframing, and greater competence dealing with healthcare professionals' is the transformation identified from a three-arm randomized study aimed at testing the efficacy of a psychoeducational programme compared to a comparison programme or no programme in enhancing mental health of women caregivers of a relative with dementia living in a long-term care setting that used prediction analysis).[38]

Data synthesis and integration

The convergent integrated approach to synthesis according to the Joanna Briggs Institute methodology for Mixed-Methods Systematic Review,[28] based on previous work of Sandelowski[39] and Hong[40] was adopted. Qualitized data were assembled with the qualitative data directly extracted from qualitative studies. Assembled data were categorized and pooled together based on similarity in meaning (i.e., a category may integrate two or more types of data: qualitative data, qualitized data or a combination of both). Categories were aggregated to produce a set of integrated findings in the form of a set of recommendations or conclusions.

Appraisal of level of evidence

The level of evidence was assessed at the study level. The level of evidence for quantitative studies was assessed using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system,[41] that ranks evidence as very low, low, moderate, and high. According to this approach, all randomized controlled trials start with a ranking of 'high' while all other study designs start with 'low'. This a-priori rank can then be adjusted (i.e., downgraded or upgraded) after considering eight assessment criteria and making a judgement about quality based on these.

The ConQual system was used to establish the confidence for qualitative evidence which included qualitative studies and integrated findings.[42] According to the ConQual approach, all qualitative studies start with a ranking of 'high' on a scale of very low, low, moderate, and high. This ranking system then allows the findings of individual studies to be downgraded based on their dependability (i.e., appropriateness of the conduct of the research with research aims and purpose) and credibility (i.e., findings classified as unequivocal, credible, or unsupported).[37] The integrated finding may then be downgraded based on the aggregate level of dependability from across the included findings. Downgrading for credibility may occur when not all the findings included in an integrated finding are considered unequivocal.[42]

Any disagreements during the selection process, quality assessment, data extraction, transformation, synthesis and integration, and appraisal of the level of evidence was resolved by involving a third reviewer.

Results

Review process

Of the 1722 articles identified, after duplicate removal (*n* = 298) and screening for title and abstract (*n* = 1398), 26 entered the full text review process. Fifteen articles were further excluded according to the above-mentioned criteria; no articles were included from the reference lists of selected papers. Finally, eight quantitative studies and three qualitative studies were included in the review (Figure 1). Quality assessment is reported in Table 1 and Appendix 3.

Characteristics of included studies

The included studies were conducted in seven countries: two in the United Kingdom,[43, 44] two in the United States,[45, 46] two in Canada,[38, 47] one in Australia,[48] one in the Netherlands,[49] and three were transnational studies.[50-52] All except two studies[38, 47] on the same cohort of patients were conducted after 2010.

Studies involved a median of twelve nursing homes, from one[45, 46] to 44;[43] only two studies reported the nursing home size which ranged from 40 to 99 beds.[43, 44] Nursing homes had a main for-profit[43] or not for-profit[38, 47, 50] profile. No information was provided about physician availability in the facilities.

The qualitative studies employed an ethnographic,[44] qualitative descriptive,[48] or longitudinal case study[46] methodology. The quantitative studies adopted randomized controlled[38, 45, 47] and cross-sectional[43, 49-52] designs.

Qualitative data were collected from face-to-face semi-structured individual interviews with family caregivers (n = 2)[38, 44] and healthcare professionals (n = 2),[44, 48] healthcare professionals' reflective diary (n = 1),[44] and email letters (n = 1).[46] Quantitative data were collected from postal questionnaires (n =4),[49-52] family caregivers' structured face-to-face interviews with the questionnaire format (n = 3),[38, 47, 51] telephone questionnaires (n = 1),[45] and online surveys (n = 1).[43]

Sample sizes ranged from one[46] to 188,[50] with the qualitative studies having smaller samples. A total of 443 healthcare professionals, 437 family caregivers, and 49 nursing home directors are represented in the review findings.

Studies explored the views of family caregivers,[38, 45-47, 51] healthcare professionals,[50, 52] and nursing home managers,[43] with two studies[48, 49] including both family caregivers and healthcare professionals and one study[44] family caregivers, healthcare professionals and nursing home managers (Table 1).

Interventions to support family caregivers in included studies

In all, seven unique interventions across 11 studies were identified. A booklet about comfort care in advanced dementia[49-52] and a psychoeducational programme[38, 47] were evaluated in multiple studies. Interventions were gathered into three main categories including a) provision of information (n=5);[43, 49-52] b) psychoeducational programmes (n=2);[38, 47] and c) family meetings associated with written information,[48] psychosocial support,[45] education,[44] or all these three aspects simultaneously[46] (Table 2). Specifically, included studies explored practices adopted to inform family caregivers of people with dementia about end of life;[43] acceptability and usefulness of written information alone[49-52] or in association with family meetings[48] to improve end-of-life discussions about dementia care; benefits of psychoeducational programmes for family caregivers' psychological health and competence in dealing with healthcare professionals;[38, 47] and benefits of family meetings associated with psychosocial support,[45] educational programmes,[44] or written information and education[46] (Table 1).

Table 1 Characteristics of the included studies

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest
Arcand et al. (H)	Quantitative	Cross-sectional	French Canada (n=2), English Canada (n=3), France (n=4), Japan (n=3)/ all not-for-profit NHs; Catholic affiliation for one NH	188 nurses *Gender* = female 156 (83%) *Age* = 36.8-49.1 (10.8-12.7)	Nurses' perception of acceptability and usefulness of a family booklet about comfort care in advanced dementia aimed to educate and reassure family
Ducharme et al. (G)	Quantitative	Randomized controlled trial	Canada/ 27 public NHs (NR)	137 daughters Experimental psychoeducational programme entitled 'Taking care of myself' (n=45) *Age* = 57 (6.5) Comparison programme (n=51) *Age* = 54.5 (7.0) No programme (n=41) *Age* = 51.5 (8.4)	Family caregivers' psychological distress, role overload, stress appraisal, coping strategies, and competence dealing with HCPs three months after a psychoeducational programme
Ducharme et al. (F)	Quantitative	Randomized controlled trial	Canada/ 27 public NHs (NR)	137 daughters Experimental psychoeducational programme entitled 'Taking care of myself' (n=45) *Age* = 57 (6.5) Comparison programme (n=51) *Age* = 54.5 (7.0) No programme (n=41) *Age* = 51.5 (8.4)	Family caregivers' psychological distress, role overload, stress appraisal, coping strategies (i.e., problem solving, reframing, and stress management), and competence dealing with HCPs following a psychoeducational programme Family caregivers' perception of the psychoeducational programme relevance in producing changes in their daily life

Data collection	Data analysis	Findings	Methodol. quality appraisal	Level of evidence
Postal questionnaire	Descriptive and inferential analyses	1. The booklet was generally well accepted with some variations among countries; 2. The majority of nurses felt the booklet could be useful for the majority of families to provide education about end-of-life care in advanced dementia; 3. About three quarters or more of the nurses indicated that the best moment to provide the booklet was when there are discussions about a medical problem for which comfort care is an option.	7/9	●●○○ Low
Structured face-to-face interview with the questionnaire format two weeks prior to the start of the programme, at the end of the programme, and three months later	Descriptive and inferential analyses	1. At the 3-month follow up, a higher proportion of family caregivers undergoing some type of educational programme reported less stress related to their caregiving situation, more frequent use of coping strategies, and greater competence dealing with HCPs compared to those family caregivers who did not receive any educational programme; instead, the perception of less role overload was not maintained; 2. Outcomes non-significant at the end of the programme failed to reach significance at the 3-month follow up as well.	6/12	●●●○ Moderate
Structured face-to-face interview with the questionnaire format two weeks prior to the start of the programme and at the end of the programme Semi-structured open-ended interview at the end of the programme	Descriptive and inferential analyses Undefined qualitative data analysis	1. A higher proportion of family caregivers undergoing some type of educational programme reported less role overload, less stress related to their caregiving situation, more frequent use of reframing, and greater competence dealing with HCPs compared to those family caregivers who did not receive any educational programme; no improvement in psychological distress, problem solving skills, and stress management; 2. To communicate better with their relative and to render their visits more pleasant - '*I'm more patient during the visits. I can follow what my mother says instead of frustrating her*' (U); 3. To express their point of view to the nursing staff - *'I managed calmly to let my dissatisfaction with my mother's diet be known. We managed to find ways of correcting the situation'* (U); 4. To practice reframing - *'The programme allowed me to step back from my situation'* (U); 5. To reflect upon the acceptance of loss - *'I became aware of how I responded to loss and of my resources for dealing with it'* (U); 6. To take care of myself - '*Everything having to do with guilt . . . it helped me a lot to change things in that regard and to try to dedicate more time to me and my husband*' (U);	6/12	●●●○ Moderate

Table 1 (Continued) Characteristics of the included studies

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest
Moore et al. (E)	Quantitative	Cross-sectional	UK/ 44 NHs, 86% Gold Standard Framework accredited, 77% privately owned, 66% with between 40-99 beds	44 NH managers/deputy managers *Gender* = female 38 (86.4%) *Age* = NR	Practices adopted to inform family caregivers of people with dementia about end of life
Reinhardt et al. (C)	Quantitative	Randomized controlled trial with 6-month follow-up	USA/ 1 large skilled NH (NR)	87 family caregivers Intervention group (n=47) *Gender* = female 37 (78.7%) *Age* = 59.6 (12.3) *Kinship* = child (n=20), spouse (n=3), friend (n=4), other (n=20) Control group (n=40) *Gender* = female 32 (80.0%) *Age* = 58.9 (11.9) *Kinship* = child (n=28), spouse (n=3), friend (n=1), other (n=8)	Family caregivers' depressive symptoms and life satisfaction following a face-to-face, structured conversation about end-of-life care options for their relative in addition to 2-month interval follow-up calls

Data collection	Data analysis	Findings	Methodol. quality appraisal	Level of evidence
		7. To become aware of their strengths (empowerment) - *'I tell myself that I'm able and I feel less impotent'* (U).		
Online survey	Descriptive analyses	1. 68.2% (n=30) of survey participants reported that family meetings were offered to support family caregivers; 2. Only 3 NHs offered family education sessions; 3. Survey participants provided family caregivers verbal discussions and information about (i) dementia as a progressive illness (68.2%), a life-shortening illness (61.4%), a disease you can die from (59.1%), and a terminal illness (56.8%); (ii) spirituality or interpretation of the meaning of death (59.1%); (iii) importance of support for family caregivers from their social network (63.6%); (iv) meaning and implications of loss of mental capacity (72.7%); (v) Advance Care Planning discussions about patient's wishes for the future (77.3%); (vi) legal health care arrangements (52.3%); and legal financial arrangements (38.6%); 4. The provision of information in leaflet form ranged according to the topic: from 20.5% for the importance of support for family caregivers from their social network to 68.2% for Advance Care Planning discussions about patient's wishes for the future.	9/9	●●○○ Low
Questionnaires via telephone at study entry, 3- and 6-months after	Descriptive and inferential analyses	1. Structured conversations with follow-up calls hold by palliative care physicians and social workers did not have any significant effects on family caregivers' depressive symptoms and life satisfaction nor a significant effect by time.	8/11	●●●○ Moderate

Table 1 (Continued) Characteristics of the included studies

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest
Sabat et al. (J)	Qualitative	Longitudinal 3-year case study	USA/ 1 NH (NR)	1 wife *Age* = NR	Dynamic experience of a spousal caregiver receiving education, counseling and psychosocial support by email and in-person meetings
Saini et al. (A)	Qualitative	Ethnografic	UK/ 2 NHs (99 and 77 beds, respectively)	4 family caregivers (two daughters, a husband, and a son, between the ages of 54 and 76) 19 HCPs [healthcare assistants (n = 6), deputy managers (n = 3), managers (n = 2), activity coordinators (n = 2), general practitioner (n = 2), nurses (n = 2), palliative care nurse (n=1), and geriatrician (n=1)]	Practices relating to end-of-life discussions with family caregivers of NH residents with advanced dementia Strategies for improving practice of end-of-life discussions

Data collection	Data analysis	Findings	Methodol. quality appraisal	Level of evidence
Email letters	Undefined qualitative data analysis	1. Understanding that she cannot fix everything – '*Accepting the fact that you cannot fix some things is a huge, but necessary, step to take. Not to accept what cannot be changed is just not healthy or helpful in any way to anyone. To work as best you can to make things as good as they can be within the limits that exist is a very, very important thing to do*' (U); 2. Understanding and reducing her emotional reactivity – '*You also told me to stop resenting what was happening in my life. That wasn't easy either. However, though there are . . . times I do still resent what has happened to [my husband], they are less frequent, and on some days I can almost believe there is a reason*' (U); 3. Reflections – '*With your help, I stopped and thought about what I was going to say and made sure I wanted to respond in that way*' (U); 4. Flourishing – '*It is like I found another person inside of me. I like the person I found*' (U).	7/7	●●●● High
Reflective diary reporting fieldwork notes and observation by an interdisciplinary care leader HCP Semi-structured and open-ended interviews with family caregivers (10 to 25 min in length) and HCPs (5 to 35 min in length)	Thematic analysis	1. Discussions with family appear to increase their capacity to make informed decisions – '*I started telling her why this (cardiopulmonary resuscitation) can be inappropriate for someone in the advanced stages of dementia…the likelihood of it being successful was very low. She said that when you put it that way it made more sense…'* (U); 2. Family sessions generated much discussion and appeared a good avenue for education - *There was a lot of discussion… about dementia… diagnosis process…acceptance of dementia amongst family and…society…how this hindered the diagnosis process… early part about dementia identification, diagnosis, symptoms…family inheritance'* (U); 3. Usefulness of written information to support discussions – '*She [ICL] was the one who spoke to me and gave me a very good leaflet to read, the stages she would go through and that did make… it a lot clearer… So in that sense that was excellent and …she was very caring and she was the one that explained it all to me'* (U); 4. Importance of ongoing dialogue with family to build relationships, provide reassurance and allow time for family to process information – *'When I have plenty of time and sometimes talk to family members for well over an hour, we don't usually get to a point where they are ready to complete an Advance Care Planning or change goals of care…requires ongoing discussions… reflections… perhaps some involvement from the GP'* (U);	10/10	●●●● High

Table 1 (Continued) Characteristics of the included studies

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest
van der Steen et al. (I)	Quantitative	Cross-sectional	Italy/ 4 NHs (NR) Netherlands/ 29 NHs (NR) Canada/ 5 NHs	138 bereaved family caregivers *Gender* = female 98 (71%) *Age* = 58.7-61.1 (7.7-12)	Family caregivers' perception of acceptability and usefulness of a booklet about comfort care in advanced dementia aimed at their

Data collection	Data analysis	Findings	Methodol. quality appraisal	Level of evidence
		5. Importance of addressing family members' current issues and concerns before discussing future plans – '*in the first scenario… the nurse was trying to talk about end-of-life care and DNRs while the 'family member' was talking about (as per the scenario) her concerns about the care at the care home…the nurse did not pick up and try to alleviate the family member's concerns about the quality of care… We talked about how if she had talked more about comfort care …what was happening to the resident today and that that would have addressed the concerns that the family member was raising'* (U); 6. Need to acknowledge family members' grief and guilt – *'She cried at one stage… She felt that dementia was a horrible disease and hated what it did to her loving gentle husband who was now aggressive and agitated'* (U); 7. Importance of information provided in a sensitive way – *'I find that the nurses tend to feel they don't really know how to start the conversation. It is often a very difficult conversation for them to initiate and then even if they can initiate it is then the depth of that discussion is often lacking'* (U); 8. Not suitable having sensitive conversations with family in communal areas such as lounge or dining room - ' *It is very difficult having a conversation in the main lounge with all the other residents… family members and staff in the room'* (U); 9. Spending sufficient time with family to address their questions and explore their concerns, including follow-up sessions/ongoing dialogue – '*I think takes time; because it's not one that you can do in one sitting. That often you need to build the relationship and then go it step by step. And I think that's where [ICL] role is quite unique in that she can come back and have a second conversation, a third conversation and a fourth if that is required'* (U); 10. Having an independent healthcare professional or team with responsibility for end-of-life discussions – *'We feel it's helpful because she has got a different way of looking at the situation. The areas where we don't normally see… it will help and improve in the care of these service users'* (U).		
Face-to-face interview with the questionnaire format	Descriptive analyses (SPSS version 15.0.1)	1. The booklet was found highly acceptable by Canadian and Dutch family caregivers and acceptable by Italian family caregivers; 2. Almost all family caregivers (94%) perceived the booklet as useful;	9/9	●●●● High

Table 1 (Continued) Characteristics of the included studies

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest
					education and reassurement
van der Steen et al. (K)	Quantitative	Cross-sectional	Netherlands/ NHs (NR)	30 physicians *Gender* = female 19 (63%) *Age* = 48 (9) 38 nurses *Gender* = female 36 (95%) *Age* = 39 (9) 59 bereaved family caregivers *Gender* = female 39 (66%) *Age* = 60 (10) *Kinship* = child (n=41), spouse (n=8), other (n=10)	Physicians', nurses' and family caregivers' perception of the need, acceptability and usefulness of a family booklet about comfort care in advanced dementia aimed to educate and reassure family caregivers
van der Steen et al. (D)	Quantitative	Cross-sectional	Italy/ 14 NHs (NR) Netherlands/ 21 NHs (NR)	87 physicians *Gender* = female 54 (62.1%) *Age* = 46.3-48.3 (6.8-10) 81 nurses *Gender* = female 75 (92.6%) *Age* = 38.6-42 (9.0-11.3)	Physicians' and nurses' perception of acceptability and usefulness of a family booklet about comfort care in advanced dementia aimed to educate and reassure family caregivers
Stirling et al. (B)	Qualitative	Descriptive	Australia/ 4 NHs (NR)	5 dementia care nurses 11 family caregivers	Need for and usefulness of a booklet aimed to aid talking about dementia and dying during family meeting

HCP, Healthcare professional; NH, Nursing home; SD, Standard deviation

The progressive letters next to author(s)' name indicate the order of study inclusion in the review, while the progressive numbers within the column of findings indicate the order of findings in the original article.

Age is reported as mean (SD)

Studies code: A,[44] B,[48] C,[45] D,[52] E,[43] F,[38] G,[47] H,[50] I,[51] J,[46] K[49]

Data collection	Data analysis	Findings	Methodol. quality appraisal	Level of evidence
Postal questionnaire		3. Those family caregivers not finding the booklet useful stated that they preferred talking over reading; 4. There was large variation in preference of when to obtain the booklet, but the dying phase was the least preferred time; 5. Almost all family caregivers (96%-100%) accepted any HCPs to have a role in providing the booklet and about half (42%-58%) endorsed availability not through practitioners.		
Postal questionnaire	Descriptive (SPSS version 15.0)	1. All respondents reported a need of written information about comfort care and end-of-life issues for family caregivers; 2. High acceptability of the booklet for nurses and family caregivers, moderate to high acceptability for physicians; 3. The booklet was found useful by all respondents; 4. Variability in the preferred timing of receiving the booklet among all respondents with discrepancy between family caregivers and physicians; 5. All respondents agreed that HCPs such as the attending physician or nurse should have a role in providing the booklet, and half favoured availability also not through practitioners.	7/9	●●○○ Low
Postal questionnaire	Descriptive analyses (SPSS version 15.0.1)	1. Both Italian and Dutch HCPs found the booklet acceptable with high acceptability by Dutch nurses; 2. HCPs' perception that a family booklet about comfort care in advanced dementia would be useful for most families to make them understand the risks and benefits of care options and reassure those who opt for comfort care that this is an acceptable option and probably the most appropriate one in advanced dementia.	9/9	●●●● High
Open-ended interviews with family caregivers (about one hour in length) and dementia nurses	Thematic analysis	1. Moving to engaged dialogue – '*I found it [dementia dialogue] beneficial because it enabled me to ask a few questions and speak on a more one to one basis than perhaps we would otherwise. . .than we do in the [traditional] care plan meetings*' (U); 2. Providing a format for discussion of future care needs – '*...we did talk about palliative care and I said, 'yes, here. There's no need to go the [hospital]'* (U).	8/10	●●●○ Moderate

Table 2 Description of interventions provided to family caregivers of people with advanced dementia at the end of life in nursing homes and their contribution to integrated findings

Author(s) (code)	Intervention	Contribution to integrated finding(s)
Provision of information (n=5)		
Arcand et al. (H)	Nurses working in long-term care settings were asked to rate the acceptability and usefulness of a **booklet** which informed on the course of the dementia, expected complications, the decision-making process, symptom management, dying, and grief.	2
Moore et al. (E)	Online survey among a random sample of nursing homes with Gold Standards Framework in Care Homes accreditation. The survey explored the current practice regarding **information provided by the service** (e.g., dementia progression, the terminal nature of dementia, spirituality, mental capacity, end-of-life preferences, and legal arrangements) **and the format of this information** (in direct discussion with the person with dementia or carer, in a group setting or in written format).	2 and 3
van der Steen et al. (I)	Family caregivers were asked to rate the acceptability and usefulness of a **booklet** which informed on the course of the dementia, expected complications, the decision-making process, symptom management, dying, and grief.	2
van der Steen et al. (K)	Family caregivers, physicians, and nurses were asked to rate the need, acceptability and usefulness of a **booklet** which informed on the course of the dementia, expected complications, the decision-making process, symptom management, dying, and grief.	2
van der Steen et al. (D)	Physicians and nurses were asked to rate the acceptability and usefulness of a **booklet** which informed on the course of the dementia, expected complications, the decision-making process, symptom management, dying, and grief.	2
Psychoeducational programmes (n=2)		
Ducharme et al. (G)[a]	Family caregivers participated in a **psychoeducational group programme** called 'Taking Care of Myself'. This programme consists of 10 90-minute weekly sessions for groups of six to eight caregivers. It covers the following six themes: (1) how to feel at ease with my relative; (2) how to express my point of view to health care staff; (3) how to avoid emotional torment; (4) how to deal with small daily losses and prepare myself for the ultimate loss of my relative; (5) how to identify and call upon my support network and community services; and (6) how to reorganize my life after my relative moves to a nursing home and take care of myself. A participatory approach is used (e.g. discussions, written exercises between sessions, role playing), centred on the actual concerns of caregivers in order to foster transfer of the strategies learned.	1 and 3

Ducharme et al. (F)[a]	Family caregivers underwent a **psychoeducational group programme** called 'Taking Care of Myself'. For details see Ducharme et al., 2005 (G).	3
Family meetings associated with written information (n=1)		
Stirling et al. (B)	Family caregivers of people living with dementia were invited to a **family meeting** held by the resource nurse of the facility. A **booklet** was employed as a meeting guide to facilitate discussion about a resident's dementia and disease trajectory. The booklet included information about the need for a palliative approach in dementia, guidance for communicating with families about death and a palliative approach, and advice to support the 'real world' situations faced by nursing home staff.	1 and 2
Family meetings associated with psychosocial support (n=1)		
Reinhardt et al. (C)	The intervention was delivered by a palliative care team which included two certified palliative medicine physicians and a palliative care social worker. A **structured, face-to-face meeting** with an ''ask-tell-ask'' model was employed. Family members were asked what they understood about dementia, where they think their relative is in the disease process, and what they expect as the disease progresses. Further, the physician shared the assessment of the resident's condition, and the palliative care team discussed the family's goals of care for the resident, made recommendations of how to achieve those goals, and provided **psychosocial support**, such as empathic and active listening and rephrasing. These meetings took an average of 47 minutes (range 20-75 minutes) and included the following topics: (a) resuscitation, (b) hospitalization, (c) artificial nutrition and hydration, and (d) pain and symptom management. As part of the intervention, the palliative care social worker delivered a **telephone follow-up** every 2 months for six months to address family caregivers' potential concerns about their relative. Each of these three telephone calls lasted an average of 10 minutes.	3
Family meetings associated with educational programmes (n=1)		
Saini et al. (A)	An interdisciplinary care leader with social science background and experienced in working with people with severe dementia delivered the intervention, which has two core components: (i) facilitation of integrated care for people with advanced dementia and (ii) training and support for those working with and caring for people with advanced dementia. To facilitate integrated care, the leader attended weekly meetings with nursing home nurses and when possible the general practitioner. In these meetings residents' care needs were discussed, the need for external referral reviewed and end-of-life plans agreed. Wider multidisciplinary team meetings were conducted on a monthly basis. **Discussions with family** covered concerns raised by the family, common symptoms in advanced dementia, end-of-life care and whether the family member was coping or needed more support. The leader ran **formal training sessions** for staff and family and informal on-the-job advice and support. Staff training sessions covered behavioural symptoms, pain management and end of life, and family sessions covered the trajectory of dementia, common end-of-life symptoms and the personal experiences of care.	1, 2, and 3

Table 2 (Continued) Description of interventions provided to family caregivers of people with advanced dementia at the end of life in nursing homes and their contribution to integrated findings

Author(s) (code)	Intervention	Contribution to integrated finding(s)
Family meetings associated with written information, psychological support, and education (n=1)		
Sabat et al. (J)	Email communication over a 3-year period with a total of 1276 letters, averaging approximately 38 per month, between the wife of a man with dementia and a psychologist. Letters informed the spousal caregiver about a variety of issues, including aspects of her husband's memory and selfhood, how she could interact with him to their mutual advantage, her husband's subjective experience of, and his reactions to, the losses he was experiencing, and how his responses affected her. **Frequent email communication constituted the main source of education, counseling and psychosocial support.** This information was associated with **in-person meetings** which occurred every three to four months to help the spousal caregiver to understand her husband's condition more clearly, interact with him more effectively, and gain a measure of control over what was happening in their lives.	1 and 3

The progressive letters next to author(s)' name indicate the order of study inclusion in the review. [a] Data collected on the same cohort of patients
Studies code: A,[44] B,[48] C,[45] D,[52] E,[43] F,[38] G,[47] H,[50] I,[51] J,[46] K[49]

Data synthesis

Of the 46 findings extracted, 23 were qualitative and 23 quantitative (Table 1, Table 3). All qualitative findings were rated as unequivocal and thus included in the synthesis in addition to the qualitized data. The level of credibility for each qualitative finding with participants' direct quotations is reported in Table 1. Qualitative and qualitized data were assembled into seven categories, then combined in the following three integrated findings (Table 3, Figure 2):

Integrated finding 1. End-of-life dialogue should be ongoing and provide adequate time and space for sensitive discussion to establish a family caregivers-healthcare professionals partnership, promote shared decision-making and improve the quality of family caregivers' remaining time with their relative while offering emotional support

Twelve qualitative findings from four studies[38, 44, 46, 48] formed two categories which constituted the first integrated finding. This integrated finding revealed that end-of-life discussions should start as early as possible in the disease trajectory when the first cognitive problems arise and be ongoing: this provides family caregivers emotional support and enough time to process information, thus establishing a partnership between family caregivers and healthcare professionals and promoting shared decisions about end-of-life care.

Category 1: Ongoing discussion between healthcare professionals and family caregivers is pivotal to promote informed decisions, establish a partnership, provide emotional support and improve the relationship between family caregivers and their relative at the end of life

Ongoing dialogue helped building trusting relationships between family caregivers and healthcare professionals, provided reassurance, and allowed time for family caregivers to process information about their relative's health conditions.[44, 46] Ongoing discussions appeared to increase family caregivers' awareness about their relative's worsening conditions and prognosis and increased their capacity to make informed decisions,[44, 46] in addition to helping them feel less emotionally unsettled.[46, 48]

Family caregivers usually desired to be engaged in discussions rather than 'being told',[48] and when this happened they felt able to successfully express their dissatisfaction with their relative's care to the healthcare professionals and to collaborate together to find solutions.[38] Moreover, family caregivers described the benefits of the dialogue process for the relationship with their relative, reporting better communication and more pleasant visits.[38]

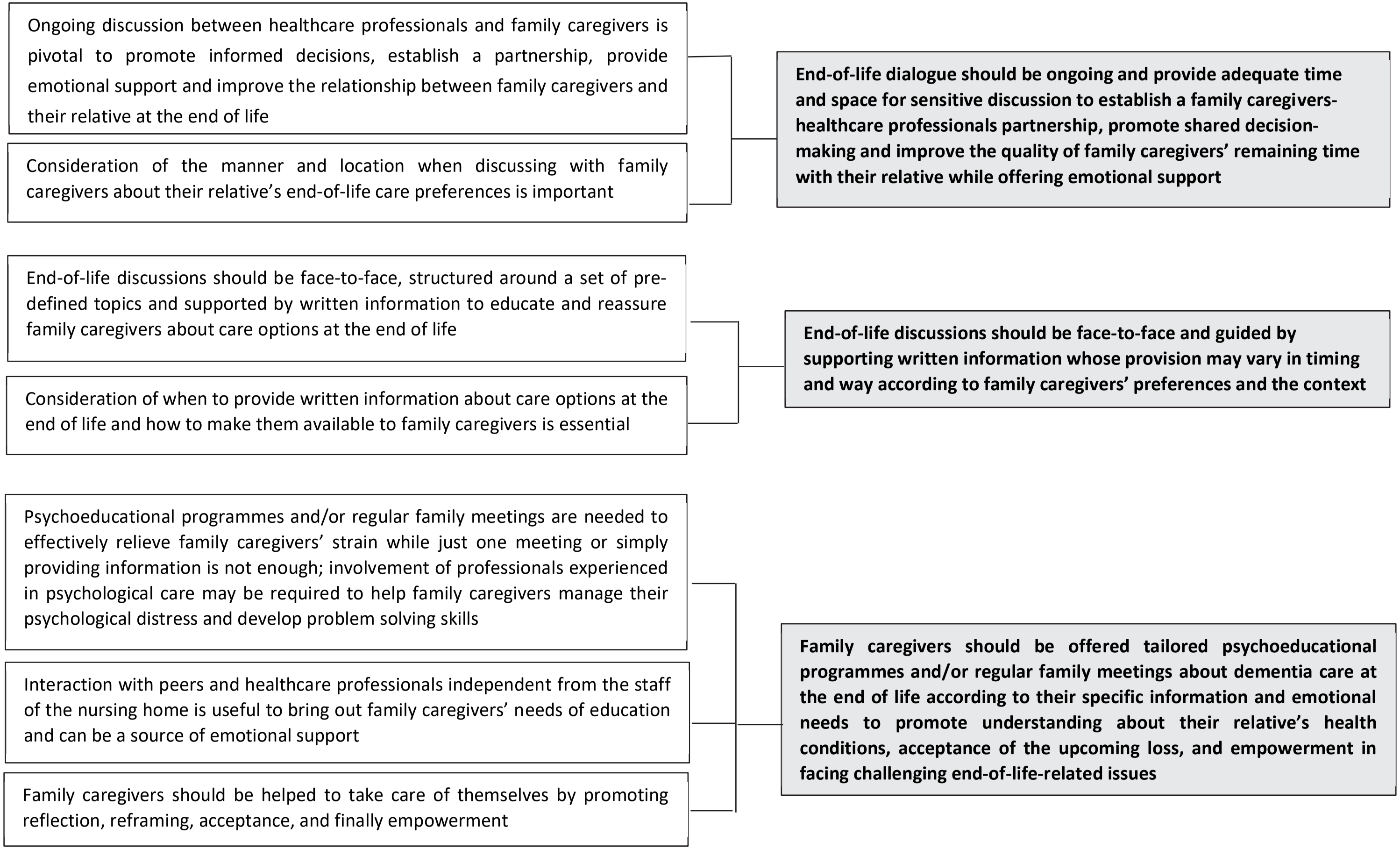
Table 3 Integrated findings, categories and qualitized and qualitative findings extracted from the included studies

Qualitized (QZ) and qualitative (QT) findings (alphanumeric code)	Categories	Integrated findings	Level of evidence
QT. Discussions with family appear to increase their capacity to make informed decisions (A1) **QT**. Importance of ongoing dialogue with family to build relationships, provide reassurance and allow time for family to process information (A4) **QT**. Moving to engaged dialogue (B1) **QT**. To communicate better with their relative and to render their visits more pleasant (F2) **QT**. Understanding and reducing her emotional reactivity (J2) **QT**. Spending sufficient time with family to address their questions and explore their concerns, including follow-up sessions/ongoing dialogue (A9) **QT**. To express their point of view to the nursing staff (F3)	1. Ongoing discussion between healthcare professionals and family caregivers is pivotal to promote informed decisions, establish a partnership, provide emotional support and improve the relationship between family caregivers and their relative at the end-of-life	**1. End-of-life dialogue should be ongoing and provide adequate time and space for sensitive discussion to establish a family caregivers-healthcare professionals partnership, promote shared decision-making and improve the quality of family caregivers' remaining time with their relative while offering emotional support**	●●●○ Moderate
QT. Importance of information provided in a sensitive way (A7) **QT**. Not suitable having sensitive conversations with family in communal areas such as lounge or dining room (A8) **QT**. Need to acknowledge family members' grief and guilt (A6) **QT**. Importance of addressing family member's current issues and concerns before discussing future plans (A5) **QT**. Having an independent healthcare professional or team with responsibility for EOL discussions (A10)	2. Consideration of the manner and location when discussing with family caregivers about their relative's end-of-life care preferences is important		
QT. Usefulness of written information to support discussions (A3) **QT**. Providing a format for discussion of future care needs (B2) **QZ**. HCPs find a booklet about comfort care in advanced dementia acceptable (D1) **QZ**. HCPs perceive that a family booklet about comfort care in advanced dementia would be useful for most families (D2) **QZ**. Difference in the provision of information in leaflet form according to the topic (E4) **QZ**. A booklet about comfort care in advanced dementia is well accepted among countries (H1)	3. End-of-life discussions should be face-to-face, structured around a set of pre-defined topics and supported by written information to educate and reassure family caregivers about care options at the end of life	**2. End-of-life discussions should be face-to-face and guided by supporting written information whose provision may vary in timing and way according to family caregivers' preferences and the context**	●●●○ Moderate

QZ. The majority of nurses feel a booklet about comfort care in advanced dementia could be useful for the majority of families to provide education about EOL care in advanced dementia (H2) **QZ**. Family caregivers find a booklet about comfort care in advanced dementia acceptable to highly acceptable (I1) **QZ**. Almost all family caregivers perceive the booklet about comfort care in advanced dementia as useful (I2) **QZ**. Most NHs provide family caregivers verbal discussions and information (E3) **QZ**. All physicians, nurses and family caregivers report family caregivers' need of written information about comfort care and EOL issues (K1) **QZ**. High acceptability of the booklet for nurses and family caregivers, moderate to high acceptability for physicians (K2) **QZ**. Physicians, nurses and family caregivers find the booklet about comfort care in advanced dementia useful (K3) **QZ**. Family caregivers not finding useful a booklet about comfort care in advanced dementia prefer talking over reading (I3)	
QZ. Most nurses indicate that the best moment to provide the booklet is when there are discussions about a medical problem for which comfort care is an option (H3) **QZ**. There is large variation among family caregivers in preference of when to obtain a booklet about comfort care in advanced dementia, but the dying phase is the least preferred time (I4) **QZ**. Variability in the preferred timing of receiving the booklet about comfort care in advanced dementia among physicians, nurses and family caregivers with discrepancy between family caregivers and physicians (K4) **QZ**. Almost all family caregivers accept any HCPs in providing the booklet and about half endorse availability not through practitioners (I5) **QZ**. Physicians, nurses and family caregivers agree that HCPs such as the attending physician or nurse should have a role in providing the booklet, and half favour availability also not through practitioners (K5)	4. Consideration of when to provide written information about care options at the end of life and how to make them available to family caregivers is essential

Qualitized (QZ) and qualitative (QT) findings (alphanumeric code)	Categories	Integrated findings	Level of evidence
QZ. Structured conversations with follow-up calls hold by palliative care physicians and social workers did not have any significant effects on family caregivers' depressive symptoms and life satisfaction nor a significant effect by time (C1)	5. Psychoeducational programmes and/or regular family meetings are needed to effectively relieve family caregivers' strain while just one meeting or simply providing information is not enough; involvement of professionals experienced in psychological care may be required to help family caregivers manage their psychological distress and develop problem solving skills	**3. Family caregivers should be offered tailored psychoeducational programmes and/or regular family meetings about dementia care at the end of life according to their specific information and emotional needs to promote understanding about their relative's health conditions, acceptance of the upcoming loss, and empowerment in facing challenging end-of-life-related issues**	●●●○ Moderate
QZ. Family caregivers undergoing some type of educational programme report less role overload, less stress related to their caregiving situation, more frequent use of reframing, and greater competence dealing with HCPs; no improvement in psychological distress, problem solving skills, and stress management (F1)			
QZ. Some months after some type of educational programme, family caregivers continue to report less stress related to their caregiving situation, more frequent use of coping strategies, and greater competence dealing with HCPs, while the perception of less role overload is not maintained (G1)			
QZ. Outcomes non-significant at the end of the educational programme do not improve in the following months (G2)			
QT. Flourishing (J4)			
QZ. Most NHs offer family meetings to support family caregivers (E1)			
QZ. A few NHs offer family education sessions (E2)			
QT. Family sessions generated much discussion and appeared a good avenue for education (A2)	6. Interaction with peers and healthcare professionals independent from the staff of the nursing home is useful to bring out family caregivers' needs of education and can be a source of emotional support		
QT. Having an independent healthcare professional or team with responsibility for EOL discussions (A10)			
QT. To practice reframing (F4)	7. Family caregivers should be helped to take care of themselves by promoting reflection, reframing, acceptance, and finally empowerment		
QT. Reflections (J3)			
QT. Understanding that she cannot fix everything (J1)			
QT. To take care of myself (F6)			
QT. To become aware of their strengths (empowerment) (F7)			
QT. To reflect upon the acceptance of loss (F5)			

HCP, Healthcare professional; NH, Nursing home. The progressive letters indicate the order of study inclusion in the review, while the progressive numbers indicate the order of findings in the original article. Studies code: A,[44] B,[48] C,[45] D,[52] E,[43] F,[38] G,[47] H,[50] I,[51] J,[46] K[49]



Ongoing discussion between healthcare professionals and family caregivers is pivotal to promote informed decisions, establish a partnership, provide emotional support and improve the relationship between family caregivers and their relative at the end of life

Consideration of the manner and location when discussing with family caregivers about their relative's end-of-life care preferences is important

End-of-life dialogue should be ongoing and provide adequate time and space for sensitive discussion to establish a family caregivers-healthcare professionals partnership, promote shared decision-making and improve the quality of family caregivers' remaining time with their relative while offering emotional support

End-of-life discussions should be face-to-face, structured around a set of pre-defined topics and supported by written information to educate and reassure family caregivers about care options at the end of life

Consideration of when to provide written information about care options at the end of life and how to make them available to family caregivers is essential

End-of-life discussions should be face-to-face and guided by supporting written information whose provision may vary in timing and way according to family caregivers' preferences and the context

Psychoeducational programmes and/or regular family meetings are needed to effectively relieve family caregivers' strain while just one meeting or simply providing information is not enough; involvement of professionals experienced in psychological care may be required to help family caregivers manage their psychological distress and develop problem solving skills

Interaction with peers and healthcare professionals independent from the staff of the nursing home is useful to bring out family caregivers' needs of education and can be a source of emotional support

Family caregivers should be helped to take care of themselves by promoting reflection, reframing, acceptance, and finally empowerment

Family caregivers should be offered tailored psychoeducational programmes and/or regular family meetings about dementia care at the end of life according to their specific information and emotional needs to promote understanding about their relative's health conditions, acceptance of the upcoming loss, and empowerment in facing challenging end-of-life-related issues

Figure 2 Categories and integrated findings

Category 2: Consideration of the manner and location when discussing with family caregivers about their relative's end-of-life care preferences is important

The physical environment where end-of-life discussions took place as well as how healthcare professionals sustained such discussions were key aspects. Communal areas such as a dining room or lounge were deemed unsuitable for sensitive discussions with family caregivers, and privacy and intimacy emerged as essential aspects to be considered.[44] Moreover, great emphasis was put on the importance of providing information in a sensitive way, while addressing family caregivers' grief and guilt and their current issues and concerns before discussing future plans of care.[44]

Integrated finding 2. End-of-life discussions should be face-to-face and guided by supporting written information whose provision may vary in timing and way according to family caregivers' preferences and the context

Nineteen findings (17 qualitized and 2 qualitative) from eight studies[38, 43, 44, 48-52] formed two categories which constituted the second integrated finding. This integrated finding showed that end-of-life discussions about dementia care with family caregivers should be face-to-face and supported by written information; the timing and way to provide written information may be influenced by family caregivers' preferences and the organizational policies and cultural context.

Category 3: End-of-life discussions should be face-to-face, structured around a set of pre-defined topics and supported by written information to educate and reassure family caregivers about care options at the end of life

Most nursing homes provided family caregivers face-to-face information and rates of discussing depended on the topic: 77.3% of discussions explored advance care planning about resident's wishes for the future care while only 38.6% focused on legal financial arrangements.[43] Moreover, both healthcare professionals and family caregivers reported the need[48, 49] and value[44] of providing written information about care options at the end of life for people with dementia to support discussion. All findings relating to written information to support face-to-face discussion highlighted the acceptability and usefulness of a booklet to provide information and reassure family caregivers about care options in advanced dementia at the end of life, according to both the healthcare professionals'[49, 50, 52] and family caregivers' perspective.[49, 51] Family caregivers reported that they gained confidence as decision makers and felt better able to engage in discussion when a discussion tool structured around a set of pre-defined topics was available.[48] Witten information emerged as useful regardless of the organizational and cultural context.[50]

Category 4: Consideration of when to provide written information about care options at the end of life and how to make them available to family caregivers is essential

Variability in the preferred timing of information provision about care options in advanced dementia emerged among healthcare professionals and family caregivers.[49] However, preference of timing was highly variable also across individuals and countries.[50, 51] Most nurses indicated that the best moment to provide written information was when there are discussions about a medical problem for which comfort care is an option, however, the proportion of nurses who thought an informational booklet could be provided at the time of dementia diagnosis or before moving to a nursing home was higher in Japan and English Canada than in French Canada.[50] The dying phase was the least preferred time among family caregivers, however, the proportion of Italian family caregivers who would have wanted to receive an informational booklet at the time of dementia diagnosis or shortly afterwards was higher than among Canadian and Dutch family caregivers.[51] Both family caregivers and healthcare professionals agreed that the attending physician or nurse should have a role in providing written information.[49, 51]

Integrated finding 3. Family caregivers should be offered tailored psychoeducational programmes and/or regular family meetings about dementia care at the end of life according to their specific information and emotional needs to promote understanding about their relative's health conditions, acceptance of the upcoming loss, and empowerment in facing challenging end-of-life-related issues

Fifteen findings (6 qualitized and 9 qualitative) from six studies[38, 43-47] formed three categories which constituted the third integrated finding. This integrated finding highlighted that psychoeducational programmes should be tailored to family caregivers' needs to empower them when confronted with end-of-life issues and promote their understanding about their relative's prognosis and proximity to dying.

Category 5: Psychoeducational programmes and/or regular family meetings are needed to effectively relieve family caregivers' strain while just one meeting or simply providing information is not enough; involvement of professionals experienced in psychological care may be required to help family caregivers manage their psychological distress and develop problem solving skills

Most nursing homes offered family meetings to support family caregivers, while only a few offered family education sessions.[43] When family caregivers were involved in regular in-person meetings with a psychologist and provided with personalized information and advice in step with the evolution of the disease, they perceived education, counseling and psychosocial support, thus flourishing and feeling happy with themselves most of the time, while deepening their relationship with and becoming an advocate for their relative.[46] Also, psychoeducational programmes structured in up to 10 weekly sessions for small groups (i.e., 6 to 8) of family caregivers which employed a participatory approach (e.g. discussions, written exercises between sessions, role playing) and were centred on their actual concerns emerged as beneficial; family caregivers reported less role overload, less caregiving-related stress, more frequent use of reframing, and greater competence in dealing with healthcare professionals,[38] and most benefits appeared to be retained in the months following the educational intervention.[47] However, no effects on psychological distress, problem solving skills and stress management were identified.[38] Moreover, just one in-person meeting delivered by palliative care physicians or social workers did not have any significant effects on family caregivers' depressive symptoms and life satisfaction, despite providing structured information about the pros and cons of treatment decisions and follow-up psychosocial support via telephone.[45] Furthermore, regardless the type of intervention, when improvement was not reached at the end of the intervention, no significant benefit emerged over time.[45, 47]

Category 6: Interaction with peers and healthcare professionals independent from the staff of the nursing home is useful to bring out family caregivers' needs of education and can be a source of emotional support

Two qualitative findings from one study[44] contributed to this category. Eliciting family caregivers' needs for dementia education may be challenging. Strategies such as interacting with other family caregivers in structured family sessions and with healthcare professionals or teams independent from the nursing home eased talking and generating questions about dementia and its progression, as well as provided an alternative view of the residents' needs and how to improve their care.[44]

Category 7: Family caregivers should be helped to take care of themselves by promoting reflection, reframing, acceptance, and finally empowerment

Family caregivers reported that educational programmes helped them to take care of themselves, they learned to dedicate more time to themselves without feeling guilt.[38] According to family caregivers' perspective, educational programmes worked at two levels by 1) promoting the development of coping strategies such as reflection, reframing and acceptance of unchangeable negative events such as their relative's loss to counteract stressors,[38, 46] and 2) by making them aware of their strengths.[38] Educational programmes allowed family caregivers to stop, step back from their current situation, take time to think and change their way of looking at things.[38, 46] The more family caregivers understood including the fact that they could not fix some things[46] and not to accept what could not be changed was just not healthy or helpful in any way to anyone,[38] the less anxious and the more empathetic they felt. Moreover, educational programmes seemed to help family caregivers to exercise control through an increased belief in their potential.[38]

Level of evidence

Among quantitative evidence (n=8), three studies received a ranking of low,[43, 49, 50] three studies of moderate,[38, 45, 47] and two studies of high[51, 52] (Table 1). Main reasons to downgrade and upgrade the a-priori ranking of quality were the risk of bias and large magnitude of effect, respectively (Appendix 4a).

Two qualitative studies[44, 46] were ranked as providing high evidence and one study[48] received moderate evidence due to the downgrading of the dependability criterion by one level (Table 1, Appendix 4b).

The quality of evidence for the three synthesized findings received moderate ranking due to the downgrading of the dependability criterion by one level (Table 3, Appendix 4c).

Discussion

The purpose of this Mixed-Methods Systematic Review was to gather and synthesize knowledge about interventions employed to support family caregivers of people with advanced dementia at the end of life in nursing homes in the form of recommendations for daily practice. We found that the evidence which sustains recommendations was of moderate quality and comprehensively advises (i) ongoing dialogue between healthcare professionals and family caregivers and adequate time and space for sensitive discussions, (ii) face-to-face discussions supported by written information whose timing of supply may vary according to family caregivers' preferences and the organizational policies and cultural context; and (iii) structured psychoeducational programmes and/or regular family meetings about dementia care at the end of life tailored to family caregivers' specific needs. Overall, the small number of included empirical studies suggests large room of improvement for evidence-based interventions to support family caregivers of people with advanced dementia at the end of life living in a nursing home. Moreover, studies were mostly concentrated in the last decade, suggesting increasing attention to the need to educate and reassure family caregivers about care options for their relative with advanced dementia at the end of life, despite facilities differing in organizational policies and cultural context.

Recommendation 1

A regular open dialogue is essential to facilitate partnerships between family caregivers and healthcare professionals and promote both the provision of preference-based care and family empowerment.[38, 44, 46, 48] Moreover, quality communication provides emotional support to family caregivers, builds trusting relationships and informs good decision-making processes.[53, 54] When family caregivers trust healthcare professionals, they are usually satisfied with their decision-making experience and the care provided aligns with family caregivers' and residents' wishes.[55] Instead, when a sense of belonging and attachment lacks, family caregivers experience detachment and isolation.[56] Good relationships with the nursing home staff is a source of emotional support for family caregivers[57] and essential to provide good quality end-of-life care.[54]

Establishing a dedicated space for sensitive end-of-life communication can provide family caregivers both privacy and proximity at end of life.[58] Environmental design which improves social interaction and a home-like atmosphere has been found to positively impact end-of-life care.[58, 59] However, even when attention is paid to the environment, end-of-life communication remains emotionally challenging for both healthcare professionals and family caregivers.[57, 60] Family caregivers usually expect that healthcare professionals start communication about end-of-life care,[60] while healthcare professionals may struggle to initiate and sustain such sensitive discussions.[61] Therefore, it is important that healthcare professionals support each other[62] to engage family caregivers in decision making which may reduce the uncertainty of choices taken at times of crisis and promote palliative-oriented care.[63] How/when to engage family caregivers is highly variable and requires a personalized approach, as discussed below in Recommendation 2.

Recommendation 2

The Covid-19 pandemic has further challenged end-of-life communication due to visiting restrictions which prevented family caregivers' in-person presence.[64, 65] However, also during pandemic times, family caregivers need to be involved in the decision making process, in a timely manner, to provide care consistent with their relative' wishes[66] and avoid their caregiving role to be disrupted with negative impact on their psychosocial and emotional well-being.[67] This has forced a change in the way of communication between family caregivers and healthcare professionals by necessitating the use of remote Information and Communication Technologies.[68, 69] Worthy examples of remote communication in the nursing home setting showed that bereaved family caregivers who reported effective remote communication with healthcare professionals had a better overall experience of end-of-life care.[68] This suggests that despite in-person discussions remain the first choice for end-of-life communication, Information and Communication Technologies-based discussions may be a valuable alternative when family caregivers' presence in nursing homes is not possible (e.g., visitation restrictions, long distance family caregivers).

Complementing end-of-life communication with written information may facilitate shared decision-making and help family caregivers to make an informed choice about their relative's end-of-life care.[43, 44, 48-52] Written information promotes family caregivers' understanding of disease progression, prognosis and care options, while providing family caregivers the opportunity to go through information several times and process information at their own pace.[70, 71] In addition, written information may help healthcare professionals to introduce the issue of end-of-life care and guide family caregivers to reflect on their relative's values and preferences for future care.[72] This suggests that end-of-life communication may be supported through a hybrid model of face-to-face communication, either in-person or using

Information and Communication Technologies, complemented by written materials. A transnational ongoing study, known as mySupport, that involves a consortium of six countries is exploring the benefits of structured in-person or Information and Communication Technologies-based family care conferences associated with written information, as perceived by family caregivers of residents with advanced dementia and healthcare professionals.[73] This study will inform about the feasibility to implement such a structured hybrid educational intervention and its impact on family caregivers and nursing home staff.

Consistent with previous authors,[60, 70] our findings suggest a great variability in the preferred timing of information despite the dying phase was the least preferred and most family caregivers desired discussions when medical problems arise or at the time of admission to a nursing home.[49-51] Similarly, the responsibility for end-of-life discussions appears to vary across care settings, professional scope of practice and countries, and has been described as a ‘hot potato’,[74] whereby everyone and no one is taking ownership. Our review confirms Dixon and Knapp’s suggestion that the optimum approach both from an economic and quality effectiveness standpoint is a multi-disciplinary one.[75] When a team-based approach is employed, family caregivers report higher quality communication and feel more involved in care planning that allows for a better-perceived death for their relative.[76] Therefore, it is the role of all healthcare professionals to create an environment of openness so that patients and their family caregivers feel comfortable to voice their concerns regarding end-of-life issues and can be involved in planning end-of-life care.

Recommendation 3

Consistently with previous literature,[77] our findings advocate that healthcare professionals should support family caregivers-centred care at the end of life through the provision of targeted information and socio-emotional care. Family caregivers of people with advanced dementia have unique disease-specific information and support needs[78] and experience significant stress during the transition from curative-oriented to palliative-oriented care.[79, 80] Therefore, educational interventions should be preceded by in-depth assessment of family caregivers’ positionality[81] and incorporate strategies to promote their wellbeing during this transitioning period and beyond, in addition to providing tailored education.

Our review suggests that psychoeducational programmes, which involve weekly small groups of family caregivers for up to 10 weeks, reduce their role overload and caregiving-related stress, and improve use of reframing and competence in dealing with healthcare professionals despite not significantly affecting psychological distress.[38, 47] Moreover, we found that just one family meeting with palliative care physicians or social workers does not improve family caregivers’ depressive symptoms and life satisfaction.[45] Instead, when family caregivers are involved in regular meetings with a psychologist and receive personalized information and advice as the disease evolves, they are more aware about their relative’s disease trajectory, perceive better relationships with healthcare professionals and are more engaged in a shared decision-making process at the end of life.[46] Also, regular meetings with healthcare professionals having a social science background and experienced in working with people with dementia increased family caregivers' perceived capacity to make informed decisions and provided reassurance.[44] Thus, our findings highlight that psychoeducational programmes and regular meetings with healthcare professionals experienced in dementia care tailored to family caregivers' specific and changing emotional and information needs can promote self-care and empowerment. This is noteworthy since empowered family caregivers are more prone to understanding the nature of dementia and being engaged in shared decisions, and feel more prepared to advocate for their relative's dignity.[82-85]

This review also suggests that family sessions may be an important means for education and emotional support.[43, 44] A study involving family caregivers of community dwelling people with dementia showed that the majority of their unmet needs related to their mental health and caregiver support groups.[86] Similarly, findings from an European cross-country evaluation of a meeting centers support programme highlighted that peer support can help to increase the capacity to deal with the challenges caused by dementia and can promote emotional balance.[87] Those family caregivers who were most satisfied with the discussion groups offered in such programme, had experienced strong emotional support.[87] It may be postulated that family caregivers find comfort and support with each other in sharing and discussing matters related to the emotional impact of dementia. Structured family sessions facilitated by professionals experienced in psychological care may thus be a promising avenue to be considered when planning interventions to support family caregivers of nursing home residents with advanced dementia. In the community setting, professionally facilitated peer support has already shown positive effects on mental health outcomes of family caregivers of people with dementia.[88]

Strengths and weaknesses

This study provides a set of recommendations about interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes by synthetizing the relevant qualitative and quantitative literature of interventions delivered at the caregiver level. A strength of this study is the convergent integrated approach[28] which minimizes methodological differences between qualitative and quantitative studies and allows to present results together because both are viewed as addressing the same research question. Our recommendations are limited by not considering organizational and policy level interventions and may suffer from bounded transferability to Eastern cultures since they are mainly based on studies conducted in Western countries. Moreover, the limited available literature prevented from making recommendations more actionable. Further methodologically sound studies are needed to clearly point out which, how, when and by whom interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes should be delivered to maximize their effectiveness.

Conclusions

Despite interventions that may benefit family caregivers of people with advanced dementia at the end of life in nursing homes and where, how, when and by whom they should be provided is a topic which has been gaining increasing interest in the recent years, available evidence is still limited.

Our findings are supported by evidence of moderate quality and advise healthcare professionals to establish ongoing and sensitive discussion with family caregivers to promote partnership, informed and shared decisions around their relative's end-of-life care and provide emotional support. Discussions should be face-to-face, structured around a set of pre-defined topics and supported by written information to reinforce messages. Discussions should take place in a private environment avoiding communal areas and preference of timing may be variable across individuals and contexts.

This review also suggests that family caregivers may benefit from structured psychoeducational programmes and/or regular family meetings tailored to their specific information and emotional needs to promote understanding about their relative's prognosis, acceptance of the approaching death, and enhance belief in their inner strengths and potential. Interacting with peers and healthcare professionals independent from the nursing home or experienced in psychological care may help family caregivers to identify their dementia education needs, manage distress and develop problem solving skills.

Future research should explore the potential benefit of structured hybrid psychoeducational interventions which complement face-to-face discussion with written materials as well as professionally facilitated peer support to promote the psychosocial and emotional well-being of family caregivers of people with advanced dementia at the end of life.

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Appendix 1: Synthesis Without Meta-analysis (SWiM) guidelines

SWiM is intended to complement and be used as an extension to PRISMA

SWiM reporting item	Item description	Page in manuscript where item is reported	Other*
Methods			
1 Grouping studies for synthesis	1a) Provide a description of, and rationale for, the groups used in the synthesis (e.g., groupings of populations, interventions, outcomes, study design)	8	
	1b) Detail and provide rationale for any changes made subsequent to the protocol in the groups used in the synthesis	No changes made to the protocol	
2 Describe the standardised metric and transformation methods used	Describe the standardised metric for each outcome. Explain why the metric(s) was chosen, and describe any methods used to transform the intervention effects, as reported in the study, to the standardised metric, citing any methodological guidance consulted	8	
3 Describe the synthesis methods	Describe and justify the methods used to synthesise the effects for each outcome when it was not possible to undertake a meta-analysis of effect estimates	8	
4 Criteria used to prioritise results for summary and synthesis	Where applicable, provide the criteria used, with supporting justification, to select the particular studies, or a particular study, for the main synthesis or to draw conclusions from the synthesis (e.g., based on study design, risk of bias assessments, directness in relation to the review question)	7	
5 Investigation of heterogeneity in reported effects	State the method(s) used to examine heterogeneity in reported effects when it was not possible to undertake a meta-analysis of effect estimates and its extensions to investigate heterogeneity	Not applicable. Quantitative data was converted into 'qualitized data' and a qualitative synthesis was performed	
6 Certainty of evidence	Describe the methods used to assess certainty of the synthesis findings	8-9	

SWiM reporting item	Item description	Page in manuscript where item is reported	Other*
7 Data presentation methods	Describe the graphical and tabular methods used to present the effects (e.g., tables, forest plots, harvest plots) Specify key study characteristics (e.g., study design, risk of bias) used to order the studies, in the text and any tables or graphs, clearly referencing the studies included	7	
Results			
8 Reporting results	For each comparison and outcome, provide a description of the synthesised findings, and the certainty of the findings. Describe the result in language that is consistent with the question the synthesis addresses, and indicate which studies contribute to the synthesis	11-15, Table 1, Table 2, Figure 2	
Discussion			
9 Limitations of the synthesis	Report the limitations of the synthesis methods used and/or the groupings used in the synthesis, and how these affect the conclusions that can be drawn in relation to the original review question	18	

PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses
* If the information is not provided in the systematic review, give details of where this information is available (e.g., protocol, other published papers (provide citation details), or website (provide the URL)).

Appendix 2: Search strategies

1. Pubmed (Searched on 5th November 2020)

Search	Query	Items
#1	next of kin*[Title/Abstract] OR "Spouses"[Mesh] OR "Family"[Mesh] OR "Caregivers"[Mesh] OR "Siblings"[Mesh] OR Adult Children [Mesh] OR child[Title/Abstract] OR children[Title/Abstract] OR wife[Title/Abstract] OR wives[Title/Abstract]) OR niece*[Title/Abstract] OR nephew*[Title/Abstract] OR husband*[Title/Abstract] OR relative* [Title/Abstract] OR surrogate*[Title/Abstract] OR grandchild[Title/Abstract] OR grandchildren[Title/Abstract] OR carer* [Title/Abstract] OR friend* [Title/Abstract] OR neighbor*[Title/Abstract]	3,073,235
#2	"Dementia"[Mesh] OR dementia* [Title/Abstract] OR "Cognition"[Mesh] OR "Cognition Disorders"[Mesh] OR "Mental Competency"[Mesh] OR "Psychomotor Agitation"[Mesh] OR ‘Cognitive dysfunction*’[Title/Abstract] OR ‘functional decline’[Title/Abstract] OR ‘functional limit*’[Title/Abstract] OR ‘physical decline’ [Title/Abstract] OR ‘physical limit*’ [Title/Abstract] OR ‘functional impair*’[Title/Abstract] OR ‘cognitive impair*’[Title/Abstract] OR ‘cognitive decline’[Title/Abstract]	437,070
#3	"Education"[Mesh] OR ‘Training Program*’[Title/Abstract] OR ‘Educational Activit*’[Title/Abstract] OR ‘information provision’[Title/Abstract] OR Information[Title/Abstract] OR “Teach-Back Communication"[Mesh] OR "Health Communication"[Mesh] OR "Social Support"[Mesh] OR "Counseling"[Mesh] OR ‘Psychosocial support*’ [Title/Abstract] OR "Emotional Adjustment"[Mesh] OR "Mind-Body Therapies"[Mesh] OR "Mental Health/prevention and control"[Mesh] OR "Behavior Therapy"[Mesh] OR ‘Behavior modification*’ [Title/Abstract] OR "Stress, Psychological/prevention and control"[Mesh] OR ‘psychoeducation*’ [Title/abstract] OR ‘psycho-education*’ [Title/abstract]	2,168,881
#4	("Nursing Homes"[Mesh] OR "Homes for the Aged"[Mesh] OR "Long-Term Care"[Mesh] OR residential care home*[Title/Abstract] OR long term facilit*[Title/Abstract])	66,469
#5	(next of kin*[Title/Abstract] OR "Spouses"[Mesh] OR "Family"[Mesh] OR "Caregivers"[Mesh] OR "Siblings"[Mesh] OR Adult Children [Mesh] OR child[Title/Abstract] OR children[Title/Abstract] OR wife[Title/Abstract] OR wives[Title/Abstract]) OR niece*[Title/Abstract] OR nephew*[Title/Abstract] OR husband*[Title/Abstract] OR relative* [Title/Abstract] OR surrogate*[Title/Abstract] OR grandchild[Title/Abstract] OR grandchildren[Title/Abstract] OR carer* [Title/Abstract] OR friend* [Title/Abstract] OR neighbor*[Title/Abstract]) AND ("Dementia"[Mesh] OR dementia* [Title/Abstract] OR "Cognition"[Mesh] OR "Cognition Disorders"[Mesh] OR "Mental Competency"[Mesh] OR "Psychomotor Agitation"[Mesh] OR ‘Cognitive dysfunction*’[Title/Abstract] OR ‘functional decline’[Title/Abstract] OR ‘functional limit*’[Title/Abstract] OR ‘physical decline’ [Title/Abstract] OR ‘physical limit*’ [Title/Abstract] OR ‘functional impair*’[Title/Abstract] OR ‘cognitive impair*’[Title/Abstract] OR ‘cognitive decline’[Title/Abstract]) AND ("Education"[Mesh] OR ‘Training Program*’[Title/Abstract] OR ‘Educational Activit*’[Title/Abstract] OR ‘information provision’[Title/Abstract] OR Information[Title/Abstract] OR “Teach-Back Communication"[Mesh] OR "Health Communication"[Mesh] OR "Social Support"[Mesh] OR "Counseling"[Mesh] OR ‘Psychosocial support*’ [Title/Abstract] OR "Emotional Adjustment"[Mesh] OR "Mind-Body Therapies"[Mesh] OR "Mental Health/prevention and control"[Mesh] OR "Behavior Therapy"[Mesh] OR ‘Behavior modification*’ [Title/Abstract] OR "Stress, Psychological/prevention and control"[Mesh]) AND (("Nursing Homes"[Mesh] OR "Homes for the Aged"[Mesh] OR "Long-Term Care"[Mesh] OR residential care home*[Title/Abstract] OR long term facilit*[Title/Abstract])	432

2. EBSCO CINAHL (Searched on 5th November 2020)

Search ID	Search Terms	Search Options	Actions
S5	S1 AND S2 AND S3 AND S4	Limiters - Exclude MEDLINE records Search modes - Boolean/Phrase	312
S5	S1 AND S2 AND S3 AND S4	Search modes - Boolean/Phrase	627
S4	MH ("Education" OR "Support, Psychosocial+" OR "Counseling+" OR "Emotional Support (Iowa NIC)" OR "Emotional Support (Saba CCC)" OR "Mind Body Techniques" OR "Mental Health Care (Saba CCC)" OR "Mental Health Promotion (Saba CCC)" OR "Behavior Therapy" OR "Cognitive Therapy" OR "Behavior Modification" OR "Stress, Psychological/PC" OR "Psychoeducation") OR AB (“Training Program*” OR “Educational Activit*” OR “information” OR "Teach-Back Communication" OR “Psychosocial support*” OR “psychoeducation*” OR “psycho-education*”) OR TI (“Training Program*” OR “Educational Activit*” OR “information” OR "Teach-Back Communication" OR “Psychosocial support*” OR “psychoeducation*” OR “psycho-education*”)	Search modes - Boolean/Phrase	560,568
S3	MH ("Nursing Home Patients" OR "Nursing Homes" OR "Long Term Care" OR "Residential Facilities") OR AB ("homes for aged" OR “residential care” OR “nursing home*” OR “residential care home*” OR “long term facilt*”) OR TI ("homes for aged" OR “residential care” OR “nursing home*” OR “residential care home*” OR “long term facilt*”)	Search modes - Boolean/Phrase	65,780
S2	MH ("Dementia+” OR "Cognition Disorders+" OR "Cognition (Omaha)" OR "Mental Disorders" OR "Psychomotor Agitation+") OR AB (dementia OR “cognitive dysfunction” OR “functional decline” OR “functional limit*” OR “physical decline” OR “physical limit*” OR “functional impair*” OR “cognitive impair*” OR “cognitive decline”) OR TI (dementia OR “cognitive dysfunction” OR “functional decline” OR “functional limit*” OR “physical decline” OR “physical limit*” OR “functional impair*” OR “cognitive impair*” OR “cognitive decline”)	Search modes - Boolean/Phrase	193,129
S1	MH "Spouses" OR MH "Siblings" OR MH "Guardianship, Legal" OR MH "Family+" OR MH "Extended Family+" OR MH "Caregivers" OR MH "Adult Children" OR AB (surrogate* OR relative* OR child OR children OR husband* OR wife OR wives OR niece* OR nephew* OR grandchild OR grandchildren OR "Caregiver*" OR "next of kin*" OR carer*) OR TI (surrogate* OR relative* OR child OR children OR husband* OR wife OR wives OR niece* OR nephew* OR grandchild OR grandchildren OR "Caregiver*" OR "next of kin*" OR carer*)	Search modes - Boolean/Phrase	826,851

3. EBSCO PsycInfo (Searched on 5th November 2020)

Search ID	Search Terms	Search Options	Actions
S5	S1 AND S2 AND S3 AND S4	Search modes - Boolean/Phrase	332
S4	DE ("Education" OR "Educational Counseling" OR "Social Support" OR "Counseling" OR "Mindfulness-Based Interventions" OR "Behavior Therapy" OR "Cognitive Therapy" OR "Psychoeducation") OR AB (“Training Program*” OR “Educational Activit*” OR “information” OR "Teach-Back Communication" OR “Psychosocial support*” OR “psychoeducation*” OR “psycho-education*”) OR TI (“Training Program*” OR “Educational Activit*” OR “information” OR "Teach-Back Communication" OR “Psychosocial support*” OR “psychoeducation*” OR “psycho-education*”)	Search modes - Boolean/Phrase	634,316
S3	AB (“Homes for the Aged” OR “residential care” OR “nursing home*” OR “residential care home*” OR “long term facilt*”) OR TI (“Homes for the Aged” OR “residential care” OR “nursing home*” OR “residential care home*” OR “long term facilt*”) OR DE (“Nursing Homes” OR "Long Term Care" OR "Residential Care Institutions")	Search modes - Boolean/Phrase	28,536
S2	DE ("Dementia" OR "Dementia with Lewy Bodies" OR "Cognitive Impairment" OR "Mental Disorders") OR AB (dementia OR “cognitive dysfunction” OR “functional decline” OR “functional limit*” OR “physical decline” OR “physical limit*” OR “functional impair*” OR “cognitive impair*” OR “cognitive decline”) OR TI (dementia OR “cognitive dysfunction” OR “functional decline” OR “functional limit*” OR “physical decline” OR “physical limit*” OR “functional impair*” OR “cognitive impair*” OR “cognitive decline”)	Search modes - Boolean/Phrase	249,789
S1	AB (relatives OR child OR children OR husband* OR wife OR wives OR niece* OR nephew* OR grandchild OR grandchildren OR carer* OR relative* OR next of kin*) OR TI (relatives OR child OR children OR husband* OR wife OR wives OR niece* OR nephew* OR grandchild OR grandchildren OR carer* OR relative* OR next of kin*) OR DE ("Family" OR "Caregivers" OR "Extended Family" OR "Surrogate Parents (Humans)" OR "Parents" OR "Guardianship" OR "Siblings")	Search modes - Boolean/Phrase	981,370

4. Joanna Briggs Institute (Searched on 5th November 2020)

Query	Items
(famil* or caregiver* or relative* or surrogate*) and (dementia or “cognitive impair*” or “cognitive decline”) and ("nursing home*" or "residential care home*" or "homes for the aged" or "long term facilit*") and (education or counseling or “social support” or “psychosocial support” or psychoeducation OR psycho-education).mp. [mp=text, heading word, subject area node, title]	35

5. Scopus (Searched on 5th November 2020)

Query	Items
TITLE-ABS-KEY (famil* OR caregiver* OR relative* OR surrogate*) AND (dementia or “cognitive impair*” or “cognitive decline”) and ("nursing home*" OR "residential care home*" OR "homes for the aged" OR "long term facilit*") AND (education or counseling or “social support” or “psychosocial support” or psychoeducation OR psycho-education)	611

Appendix 3: Assessment of methodological quality

Appendix 3a: Assessment of methodological quality: survey designs reporting frequencies/proportions[a]

Author(s) (code)	C1. Sample frame appropriate to address the target population	C2. Study participants sampled in an appropriate way	C3. Sample size adequate	C4. Study subjects and the setting described in detail	C5. Data analysis conducted with sufficient coverage of the identified sample	C6. Valid methods used for the identification of the condition	C7. Condition measured in a standard, reliable way for all participants	C8. Appropriate statistical analysis	C9. Response rate adequate or appropriate management of low response rate	Quality appraisal[a]
Arcand et al. (H)[50]	N	Y	Y	Y	Y	Y	Y	Y	N	7/9
Moore et al. (E)[42]	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9
van der Steen et al. (I) [51]	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9
van der Steen et al. (K)[46]	Y	N	Y	Y	Y	Y	Y	N	Y	7/9
van der Steen et al. (D)[47]	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9

Abbreviations: C, criteria; JBI, Joanna Briggs Institute; N, no; NA, not applicable; U, unclear; Y, yes.

[a] According to the JBI critical appraisal tool for studies reporting prevalence data. Munn Z, Moola S, Lisy K, Riitano D, Tufanaru C. Methodological guidance for systematic reviews of observational epidemiological studies reporting prevalence and incidence data. Int J Evid Based Healthc. 2015;13(3):147–153.

Appendix 3b: Assessment of methodological quality: randomized controlled trials[a]

	Author(s) (code)		
	Ducharme et al. (G)[37]	Ducharme et al. (F)[48]	Reinhardt et al. (C)[44]
C1. True randomization used for assignment of participants to treatment groups	U	U	U
C2. Allocation to treatment groups concealed	U	U	U
C3. Treatment groups similar at the baseline	N	N	Y
C4. Participants blind to treatment assignment	NA	NA	NA
C5. Those delivering treatment blind to treatment assignment	Y	Y	NA
C6. Outcomes assessors blind to treatment assignment	U	U	Y
C7. Treatment groups treated identically other than the intervention of interest	Y	Y	Y
C8. Follow up complete or differences between groups described and analyzed if not complete	Y	Y	Y
C9. Participants analyzed in the groups to which they were randomized	N	N	N
C10. Outcomes measured in the same way for treatment groups	Y	Y	Y
C11. Outcomes measured in a reliable way	Y	Y	Y
C12. Appropriate statistical analysis used	N	N	Y
C13. Trial design appropriate and any deviations from the standard design accounted for in the conduct and analysis of the trial	Y	Y	Y
Quality appraisal[a]	6/12	6/12	8/11

Abbreviations: C, criteria; JBI, Joanna Briggs Institute; N, no; NA, not applicable; U, unclear; Y, yes.

[a] According to the JBI critical appraisal tool for randomized controlled trials. Tufanaru C, Munn Z, Aromataris E, Campbell J, Hopp L. Chapter 3: Systematic reviews of effectiveness. In: Aromataris E, Munn Z (Editors). JBI Manual for Evidence Synthesis. JBI, 2020.

Appendix 3c: Assessment of methodological quality: qualitative studies[a]

	Author(s) (code)	
	Saini et al. (A)[43]	Stirling et al. (B)[49]
C1. Congruity in philosophical perspective	Y	Y
C2. Congruity in research objective	Y	Y
C3. Congruity in methods used to collect data	Y	Y
C4. Congruity in data analysis	Y	Y
C5. Congruity in interpretation of the results	Y	Y
C6. Cultural or theoretical orientation of the researcher(s)	Y	N
C7. Potential influence of the researcher on the research and vice-versa	Y	N
C8. Representativeness of the participants' voices	Y	Y
C9. Ethical approval	Y	Y
C10. Conclusions drawn from the analysis	Y	Y
Quality appraisal[a]	10/10	8/10

Abbreviations: C, criteria; JBI-QARI, Joanna Briggs Institute - Quality Assessment Review Instrument; N, no; NA, not applicable; U, unclear; Y, yes.

[a] According to the JBI-QARI critical appraisal tool. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. Int J Evid Based Healthc. 2015;13(3):179–187.

Appendix 3d: Assessment of methodological quality: case reports[a]

	Author(s) (code)
	Sabat et al. (J)[45]
C1. Patient's demographic characteristics clearly described	Y
C2. Patient's history clearly described and presented as a timeline	Y
C3. Current clinical condition of the patient on presentation clearly described	NA
C4. Diagnostic tests or assessment methods and the results clearly described	Y
C5. Intervention(s) or treatment procedure(s) clearly described	Y
C6. Post-intervention clinical condition clearly described	Y
C7. Adverse events (harms) or unanticipated events identified and described	Y
C8. Takeaway lessons provided	Y
Quality appraisal[a]	7/7

Abbreviations: C, criteria; JBI, Joanna Briggs Institute; N, no; NA, not applicable; U, unclear; Y, yes.

[a] According to the JBI critical appraisal tool for case reports. Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. Chapter 7: Systematic reviews of etiology and risk. In: Aromataris E, Munn Z (Editors). JBI Manual for Evidence Synthesis. JBI, 2020.

Appendix 4: Assessment of the level of evidence

Appendix 4a: Assessment of the level of evidence: quantitative studies[a]

		Reasons to downgrade the evidence quality					Reasons to upgrade the evidence quality			
Author(s) (code)	**Pre- ranking**	Risk of bias	Inconsistency	Indirectness	Imprecision	Publication bias	Large magnitude of effect	Dose response	Effect of all plausible confounding factors	**GRADE assessment**
Arcand et al. (H)[50]	Low	↔	↔	↔	↔	↔	↔	↔	↔	●●○○ Low
Ducharme et al. (G)[37]	High	↓	↔	↔	↔	↔	↔	↔	↔	●●●○ Moderate
Ducharme et al. (F)[48]	High	↓	↔	↔	↔	↔	↔	↔	↔	●●●○ Moderate
Moore et al. (E)[42]	Low	↔	↔	↔	↔	↔	↔	↔	↔	●●○○ Low
Reinhardt et al. (C)[44]	High	↓	↔	↔	↔	↔	↔	↔	↔	●●●○ Moderate
van der Steen et al. (I)[51]	Low	↔	↔	↔	↔	↔	↑↑	↔	↑	●●●● High
van der Steen et al. (K)[46]	Low	↔	↔	↔	↔	↔	↔	↔	↔	●●○○ Low
van der Steen et al (D)[47]	Low	↔	↔	↔	↔	↔	↑↑	↔	↔	●●●● High

Note. According to the GRADE approach to establish confidence in quantitative evidence, all RCTs start with a ranking of 'high' while all other study designs start with 'low' on a scale of high, moderate, low to very low. This baseline rating can then be adjusted after considering 8 assessment criteria and making a judgement about quality based on these.[a] Ryan R, Hill S. How to GRADE the quality of the evidence. Cochrane Consumers and Communication Group, 2016. Available at http://cccrg.cochrane.org/author-resources. Version 3.0 December 2016.↔ ranking unchanged ↑ ranking upgraded one level ↑↑ ranking upgraded two levels ↓ ranking downgraded one level

Appendix 4b: Assessment of the level of evidence: qualitative studies[a]

Author(s) (code)	Type of research	Pre-ranking	Dependability	Credibility	ConQual	Comments
Sabat et al. (J)[45]	Qualitative	High	↔	↔	●●●● High	Dependability unchanged since 4-5 criteria were positive Credibility unchanged since all findings were unequivocal
Saini et al. (A)[43]	Qualitative	High	↔	↔	●●●● High	Dependability unchanged since 4-5 criteria were positive Credibility unchanged since all findings were unequivocal
Stirling et al. (B)[49]	Qualitative	High	↓	↔	●●●○ Moderate	Dependability downgraded one level as only 2-3 criteria were positive Credibility unchanged since all findings were unequivocal

Note. According to the ConQual approach to establish confidence in qualitative evidence, all qualitative research studies start with a ranking of 'high' on a scale of high, moderate, low to very low. This ranking system then allows the findings of individual studies to be downgraded based on their dependability (i.e., appropriateness of the conduct of the research with research aims and purpose) and credibility (i.e., findings classified as unequivocal, credible, or unsupported).

[a] Munn Z, Porritt K, Lockwood C, Aromataris E, Pearson A. Establishing confidence in the output of qualitative research synthesis: the ConQual approach. BMC Medical Research Methodology 2014; 14:108. https://doi.org/10.1186/1471-2288-14-108.

↔ ranking unchanged

↓ ranking downgraded one level

Appendix 4c: Assessment of the level of evidence: integrated findings[a]

Integrated findings	Type of research	Dependability	Credibility	ConQual	Comments
1. End-of-life dialogue should be ongoing and provide adequate time and space for sensitive discussion to establish a family caregivers-healthcare professionals partnership, promote shared decision-making and improve the quality of family caregivers' remaining time with their relative while offering emotional support	Qualitative	Moderate	High	●●●○ Moderate	Dependability downgraded one level since two[43, 45] studies were ranked high and two[43, 45] studies were ranked moderate.[48, 49] Credibility unchanged since all findings were considered unequivocal
2. End-of-life discussions should be face-to-face and guided by supporting written information whose provision may vary in timing and way according to family caregivers' preferences and the context	Qualitative Quantitative	Moderate	High	●●●○ Moderate	Dependability downgraded one level since three[43, 47, 51] studies were ranked high, one[49] study was ranked moderate, and three[42, 46, 50] studies were ranked low. Credibility unchanged since all findings were considered unequivocal
3. Family caregivers should be offered tailored psychoeducational programmes and/or regular family meetings about dementia care at the end of life according to their specific information and emotional needs to promote understanding about their relative's health conditions, acceptance of the upcoming loss, and empowerment in facing challenging end-of-life-related issues	Qualitative Quantitative	Moderate	High	●●●○ Moderate	Dependability downgraded one level since two[43, 45] studies were ranked high, three[37, 44, 48] studies were ranked moderate, and one[42] study was ranked low. Credibility unchanged since all findings were considered unequivocal

Note. The integrated finding may be downgraded based on the aggregate level of dependability from across the included findings. Downgrading for credibility may occur when not all the findings included in an integrated finding are considered unequivocal.

[a] Munn Z, Porritt K, Lockwood C, Aromataris E, Pearson A. Establishing confidence in the output of qualitative research synthesis: the ConQual approach. BMC Medical Research Methodology 2014; 14:108. https://doi.org/10.1186/1471-2288-14-108.

4

Change in advance care plans of nursing home residents with dementia and pneumonia: secondary analysis of RCT data

Published as

Bavelaar L, Visser M, Schlicksupp P, Tilburgs B, van der Maaden T, Achterberg WP, van der Steen JT. Change in advance care plans of nursing home residents with dementia and pneumonia: secondary analysis of RCT data. JAMDA. 2022:23(10):1741.e19-1741.e26.

Abstract

Objectives To explore changes in advance care plans of nursing home residents with dementia following pneumonia, and factors associated with changes. Second, to explore factors associated with the person perceived by elderly care physicians as most influential in advance treatment decision making.

Design Secondary analysis of physician-reported PneuMonitor trial data.

Setting and Participants The PneuMonitor trial took place between January 2012 and May 2015 in 32 nursing homes across the Netherlands; it involved 429 residents with dementia who developed pneumonia.

Methods We compared advance care plans before and after the first pneumonia episode. Generalized logistic linear mixed models were used to explore associations of advance care plan changes with the person most influential in decision making, with demographics and indicators of disease progression. Exploratory analyses assessed associations with the person most influential in decision making.

Results For >90% of the residents, advance care plans had been established before the pneumonia. After pneumonia, treatment goals were revised in 15.9% of residents, 72% of all changes entailed refinements of goals. Significant associations with treatment goal changes were not found. Treatment plans changed in 20.0% of residents. Changes in treatment decisions were more likely for residents who were more severely ill (odds ratio 1.5, 95% CI 1.2-1.9) and those estimated to live less than 3 months (odds ratio 3.3, 95% CI 1.9-5.8). Physicians reported that a family member was often (47.4%) most influential in decision making. Who is most influential was associated with the resident's dementia severity.

Conclusions and Implications Overall, changes in advance care plans after pneumonia diagnosis were small, suggesting stability of most preferences or limited dynamics in the advance care planning process. Advance care planning involving family is common for nursing home residents with dementia, but advance care planning with persons with dementia themselves is rare and requires more attention.

Introduction

Advance care planning (ACP) entails the person concerned, family and healthcare professionals discussing wishes, preferences and values, and documenting plans to guide future care and treatment. ACP anticipates situations in which a person is unable to contribute to decision making, for example in case of cognitive impairment due to severe dementia.[1] It can support the future provision of care in line with personal wishes and contribute to high-quality care.[2] A key aspect of ACP is shared decision making.[3] When a person's condition or wishes change, advance care plans should be revisited.[4] Several moments can trigger (re)engaging with ACP.[1]

Many people with dementia in western countries are admitted to nursing homes when their needs are no longer met at home.[5] Pneumonia occurs frequently among nursing home residents[6] and is a common cause of death.[7] ACP may guide treatment of pneumonia, and pneumonia and possible burdensome treatment may trigger discussion and updating of care plans. In the Netherlands, ACP is usually initiated shortly after nursing home admission.[8] Dutch nursing homes are required to establish care plans within six weeks after a resident's admission and revisit these biannually.[9] Such plans must contain agreements about care goals,[9] but may lack detail beyond decisions on cardiopulmonary resuscitation and hospitalization.[8] Certified elderly care physicians, trained in care for older people including a palliative approach,[10] are responsible for care plans, which, in the case of dementia, often focus on comfort.[11] Elderly care physicians are employed by nursing homes, on average attending to 103 residents per FTE.[12] They, rather than an external palliative team, provide end-of-life care.[13]

In this study, we examine ACP practice in Dutch nursing home residents with dementia who develop pneumonia. As good ACP practice is responsive to health changes and implements shared decision making, we explore any advance care plan changes following pneumonia and the influence of the people involved in shared decision making. We focus on change regardless of the direction because there is no assumption that changes only occur in the direction of less aggressive treatment and changes may be more nuanced. For example, there is no expectation of increased forgoing hospitalization as hospitalization is rare (1%) in this population.[14] Further, antibiotics are also used to relieve symptoms:[14] a wish for treatments may thus not always express a wish for life prolongation. We describe the prevalence and content of advance care plans before and after pneumonia diagnosis, and explore factors associated with changes in treatment goals and advance decisions following pneumonia. Our secondary objective was to explore what factors are associated with the person who is perceived by elderly care physicians as most influential in the decision making.

Methods

Design and setting

We performed secondary data analysis of the PneuMonitor study, a longitudinal single-blind, multicenter, cluster-randomized controlled trial to improve symptom relief in 32 Dutch public, non-profit nursing homes conducted between January 2012 and May 2015 (Netherlands Trial Register NTR5071).[15, 16] Nursing homes were selected to cover the provinces of the Netherlands. The homes provided care as usual during a pre-intervention phase. Data collection continued after randomization to the intervention arm (introducing a practice guideline) or the control arm (continued usual care). As no intervention effect of the guideline was found regarding treatments or outcomes such as discomfort,[15] we used data collected in control homes and intervention homes, before and after the intervention, to examine changes in advance care plans following pneumonia. Physicians were aware of the PneuMonitor study aim. As the current study focuses on ACP around a pneumonia episode, which is not directly related to the PneuMonitor study aim, negligible bias in physician-reported data is expected.

During the study period, elderly care physicians included residents with dementia diagnosed with pneumonia. Some residents experienced multiple pneumonia episodes during the study period. For the current study, we selected the first episode. The Medical Ethics Review Committee of the VU University Medical Center Amsterdam approved performing the PneuMonitor study (2011/155 and 2012/318). The common procedure for obtaining consent was considered disproportionate and infeasible due to the acute nature of pneumonia and other aspects of the trial and therefore an opt-out approach to consent was used; residents' families were informed about the study by letter and they could refuse transfer of the resident's data for this research.

Measures

All data were reported by the resident's attending physician; 131 reported on 1-22 (median, 2) residents. We distinguished a prioritized treatment goal, living will, and advance treatment decision. A prioritized treatment goal is a general care goal deemed most important in guiding treatment decisions and is established by the attending physician and the resident or family. A living will is a written, legal document drawn up (prior to admission) by the resident when still competent that indicates wishes regarding care, treatment or representation in medical decision making. An advance treatment decision stipulates specific agreements that the attending physician and resident or family make regarding treatments in the nursing home. Advance treatment decisions are often informed by the prioritized treatment goal or living will.

At pneumonia diagnosis (T0), the attending physicians completed a 'pneumonia notification form' with 8 questions. We analyzed prioritized treatment goals before pneumonia: prolongation of life, maintenance of function, or maximization of comfort. We also analyzed sex and age, and the physicians' estimate (free text) of how close the resident was to the end of life at the time of pneumonia diagnosis. We further included illness severity at the time of pneumonia diagnosis rated on a scale of 1 ('not ill') to 9 ('moribund').[17] This scale measures physicians' clinical judgement and was an accurate estimate of illness severity.[17, 18] Further, within 48 hours after diagnosis, the physicians reported pneumonia symptoms, behavioral changes after pneumonia and treatments received.

One to three weeks after pneumonia diagnosis (T1), the attending physicians completed another questionnaire, comprising 60 questions. We analyzed the presence and type of living wills, the prioritized treatment goal and advance treatment decisions before and after the pneumonia diagnosis. The physicians also reported changes, including in open-ended items. Changes reflected aggressiveness of treatment and refinements of orders such as stipulating conditions. Further, we identified the person whom the attending physician had listed first in a top-3 of persons that they perceived as most influential in their decision making regarding prioritized treatment goals and treatment (person with dementia, family, attending physician, nurse, other). Additionally, we included length of stay, type of dementia and severity of dementia assessed with the 7-item Bedford Alzheimer Nursing Severity-Scale (BANS-S, range 7 (no impairment)–28 (complete impairment)).[19] The physicians also reported dependency on seven activities of daily living (ADL) items in the two weeks prior to pneumonia diagnosis.[20]

Analyses

We performed descriptive statistics for the residents' characteristics and the prevalence of advance care plans (that is: living wills, prioritized treatment goals, advance treatment decisions) before and after pneumonia diagnosis. We categorized free text answers about how close the resident was to the end of life at the time of pneumonia diagnosis in: (1) 'less than 1 week', (2) '1 to 6 weeks', (3) '6 weeks to 3 months', (4) '3 months to 6 months', (5) '6 months to 1 year', (6) 'more than 1 year', (7) 'unclear.'

We explored which factors were associated with changes in the prioritized treatment goal (model 1) or in advance decisions (model 2), using logistic generalized linear mixed models. We added a random intercept for 'nursing home' to adjust for possible effects of nursing home culture on ACP practice. The outcome variables were dichotomized (yes (1) or no (0)) into change in prioritized treatment goal and change in any treatment decision. We investigated sex and age,[21] indicators of health status and disease progression (namely: length of stay, dementia severity, illness severity at pneumonia diagnosis and closeness to the end of life at pneumonia diagnosis),[1, 8, 21] and variables related to shared decision making: who (resident, family or physician) was most influential in decision making as perceived by the physician. We focused on these three main groups. The factor closeness to the end of life was dichotomized into terminal prognosis ((1), ≤ 3 months to live) versus (0), > 3 months to live or unclear. In the Netherlands, having less than 3 months to live is considered the terminal phase, which is when community-dwelling people are granted access to hospice care services.[22] Two binary dummy variables (yes (1) or no (0)) were created for the person most influential in decision making: 'resident most influential,' and 'family most influential.' Although shared decision making is considered good practice, final responsibility for decisions rests with physicians and Dutch physicians are influential in ACP and treatment decisions for pneumonia;[23-26] attending physicians therefore served as reference category. We first conducted univariable analyses for each factor to explore its associations with advance care plan changes, with Bonferroni correction for the number of tests (16 in total). We then performed stepwise regression with backward elimination of factors to construct a multivariable model of changes that only included strongly contributing factors. All factors were included at the first iteration, after which factors were removed from the multivariable model with p-values > .10 until only factors with a p-value < .10 remained. Overall, 6% of data was missing, ranging 0-14% per variable. Because mixed models were used, imputing missing data was not needed.

We additionally performed exploratory analyses to assess factors associated with whether the resident, the family or the attending physician was most influential in decision making. We examined the factors sex, age, length of stay, dementia severity, illness severity, and terminal prognosis. ANOVA, Chi-square, Kruskal-Wallis and post-hoc t-tests were used according to type and distribution of the data. All statistical analyses were performed with SPSS version 25.0 (IBM Corporation, New York, 2017).

Results

We included all 429 residents with dementia from the PneuMonitor trial in our analyses. The mean age was 84.5 years (SD 7.4) and the majority (59.7%) was female. A minority (14.2%) was fully dependent in ADL. Most residents were severely ill at pneumonia diagnosis (41.6%) and prognosis varied (Table 1).

Advance care plans: presence, content and (re)engagement

Only 3.8% (15 residents) had a living will (Table 2). For 2.0% (8 residents) this was a euthanasia statement and 1.3% (5 residents) had documented in advance refusing treatment in specified situations.

A prioritized treatment goal was common (95.1%, n = 408). For most residents (61.8%, n = 265) maximization of comfort was prioritized.

Physician-reported advance treatment decisions were also common (94.6%, n = 369). Figure 1 shows treatment orders before and after pneumonia diagnosis (also supplementary Table S1). Orders regarding cardiopulmonary resuscitation were present in most cases (92.3%, n = 360), followed by antibiotics (85.4%, 333) and hospitalization (80.3%, n = 313). Orders regarding hypodermoclysis for hydration were present least often (52.6%, *n* = 205); this pertains to subcutaneous hydration when oral or intravenous (IV) hydration is insufficient or impractical. Most orders requested to withhold treatments, almost all residents had at least one (supplementary Table S1); however, antibiotics and any life-prolonging treatment orders were mostly 'do' orders.

Table 1 Resident characteristics assessed at (T0) or after diagnosis of the pneumonia (T1)

Characteristics	*Timing of Assessment*	*n = 429**
Demographics		
Mean age, years (SD)	T0	84.5 (7.4)
Sex, female n (%)	T0	256 (59.7)
Illness progression indicators		
Median length of stay, months (IQR)	T0	16.0 (5.0–34.0)
Illness severity[17] at pneumonia diagnosis n (%)	T0	
Not ill (1-2)		12 (2.8)
Mild illness (3-4)		81 (18.9)
Moderate illness (5)		122 (28.4)
Severe illness (6-7)		178 (41.6)
Moribund (8-9)		36 (8.4)
Prognosis: closeness to the end of life n (%)	T0	
≤ 1 week		71 (17.1)
1 - 6 weeks		28 (6.7)
6 weeks - 3 months		18 (4.3)
3 months - 6 months		96 (23.1)
6 months - 12 months		82 (19.7)
> 12 months		69 (16.6)
Unclear prognosis		52 (12.5)
Dementia type n (%)	T1	
Alzheimer's dementia		161 (37.5)
Vascular dementia		88 (20.5)
Mixed Alzheimer's-Vascular		64 (14.9)
Other		29 (6.8)
Unknown		87 (20.3)
Dementia severity, mean BANS-S[†] score (SD)	T1	16.1 (4.6)
Severe dementia[‡] n (%)	T1	171 (45.0)
Full ADL[§] dependency[18] prior to pneumonia diagnosis n (%)	T1	53 (14.2)
Pneumonia severity	T0	
Mean number of pneumonia symptoms newly presented or aggravated due to pneumonia (SD)		5.2 (2.1)
Median number of sudden behavioral changes compared with before pneumonia (IQR)		2 (1-2)
Treatments n (%)	T0	
Antibiotic treatment		345 (82.5)
Artificial nutrition		7 (1.6)
Rehydration		1 (0.2)
Symptom control		272 (65.1)

Table 1 (Continued) Resident characteristics assessed at (T0) or after diagnosis of the pneumonia (T1)

Characteristics	*Timing of Assessment*	*n = 429**
Person most influential in decisions regarding treatment goals and treatment of pneumonia n (%)	T1	
Person with dementia		39 (10.3)
Family/representative of person with dementia		180 (47.4)
Attending physician		135 (35.5)
Other physician		18 (4.7)
Nurse		1 (0.3)
Other		3 (0.8)
Unknown		1 (0.3)
Not discussed		3 (0.8)

*Age was missing for 2 persons, Length of stay was missing for 61 persons, Prognosis was missing for 13 persons, BANS-S was missing for 49 persons, Full ADL dependency was missing for 55 persons, Behavioral changes was missing for 24 persons, Antibiotic treatment was missing for 11 persons, Artificial nutrition was missing for 46 persons, Rehydration was missing for 46 persons, Symptom control was missing for 12 persons, Person most influential in decisions was missing for 49 persons †BANS-S: Bedford Alzheimer Nursing Severity-Scale (range 7-28) ‡Severe dementia: BANS-S scores ≥ 17[27] §ADL: activities of daily living

Changes in advance care plans

For 15.9% (61 residents), prioritized treatment goals changed following pneumonia (Table 2). The prioritization of "maintenance of function" as a treatment goal decreased from 22.1% before diagnosis to 18.4% after pneumonia diagnosis (-3.7%). For 44 cases (72% of all changes), the change entailed further refinements of goals. None of the pre-identified factors were significantly associated with changes in prioritized treatment goals (all *p* > .05; Table 3).

For 20.0% (72 residents), advance treatment decisions changed following pneumonia (Figure 1). In 51 cases 'do' orders changed to 'do-not' orders, for 31 a 'do-not' order was established, for 7 a 'do-not' order changed to a 'do' order and for 5 a 'do' order was established. Orders regarding artificial nutrition, IV therapies and hypodermoclyses were discussed more often; decisions increased by 3.1%, 3.8% and 5.1% respectively (Figure 1, supplementary Table S1). Table 3 shows that illness severity and terminal prognosis were significantly associated with changes in advance treatment decisions and these associations remained in the multivariable model. More severe illness (OR 1.3, 95% CI 1.1-1.7, *p* = .010) and a terminal prognosis (OR 2.2, 95% CI 1.1-4.3, *p* = .019) both increased the odds of changes in treatment decisions. In the adjusted multivariable model, length of stay showed a small association with changes in advance treatment decisions. The odds of changes decreased for a longer length of stay (0.99/month, 95% CI 0.97-1.0, *p* = .048). There was no significant random effect of the nursing home level in any of the models.

Table 2 ACP and decision making before and after diagnosis of the pneumonia

Care Plans and Decisions n (%)*		
Presence of living will		
No	376 (96.2)	
Yes	15 (3.8)	
Type:		
Euthanasia statement	8 (2.0)	
Advance Decision to Refuse Treatment†	5 (1.3)	
Do Not Resuscitate Order	4 (1.0)	
Self-drafted statement	3 (0.8)	
Power of Attorney	2 (0.5)	
Other	1 (0.3)	
Prioritized treatment goal	**Before Pneumonia Diagnosis**	**After Pneumonia Diagnosis**
No - no treatment goal established	12 (2.8)	9 (2.1)
Yes - treatment goal established	408 (95.1)	398 (92.8)
Prioritized goal:		
Prolongation of life	48 (11.2)	43 (10.0)
Maintenance of function	95 (22.1)	79 (18.4)
Maximization of comfort	265 (61.8)	276 (64.3)
Other – partial or context-specific goals	9 (2.1)	22 (5.1)
Advance treatment decisions	**Before Pneumonia Diagnosis**	**After Pneumonia Diagnosis**
No decisions or discussions	21 (5.4)	
Decisions	369 (94.6)	
Treatments with a decision (do or do-not):		
Cardiopulmonary resuscitation	360 (92.3)	358 (91.8)
Antibiotics	333 (85.4)	339 (86.9)
Hospitalization	313 (80.3)	322 (82.6)
Intubation	287 (73.6)	290 (74.4)
Artificial nutrition	252 (64.6)	264 (67.7)
IV therapies (antibiotics, hydration)	256 (56.6)	271 (69.5)
Hypodermoclysis (hydration)	205 (52.6)	225 (57.7)
Any other life-prolonging treatments	298 (76.4)	306 (78.5)

*Presence of living will was missing for 38 persons, Advance treatment decisions was missing for 39 persons.
†Advance Decision to Refuse Treatment can comprise one to several specific treatments that a person does not want to receive in specified situations, for example cardiopulmonary resuscitation, intubation, etc.

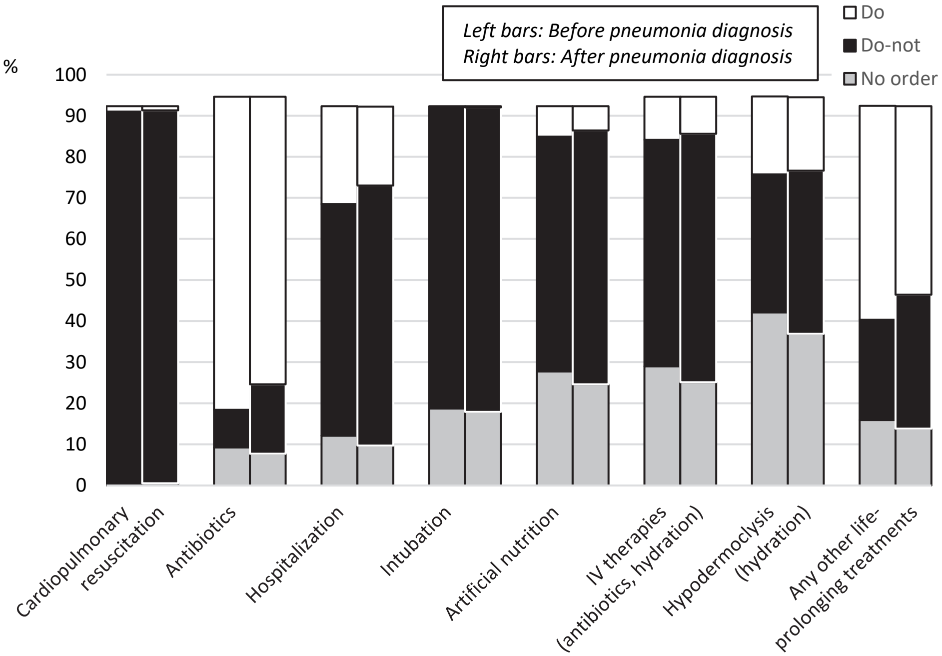

Figure 1 Advance decisions regarding treatments: residents' treatment orders before and after the first pneumonia diagnosis during the trial period (N = 390)

Table 3 Factors associated with changes in prioritized treatment goals or any advance treatment decisions after pneumonia diagnosis compared with before pneumonia diagnosis (odds ratio, 95% confidence interval)

Factor	**Change in Prioritized Treatment Goal**	**Change in any Advance Treatment Decision**
	Univariable	*Univariable*
Demographics		
Sex (male)	0.9 (0.5–1.7)	0.9 (0.6–1.6)
Age (years)†	1.0 (1.0–1.1)	1.0 (1.0–1.0)
Illness progression indicators†		
Length of stay (months)	1.0 (1.0–1.0)	1.0 (1.0–1.0)
Dementia severity (BANS-S)§	1.0 (0.9–1.1)	1.0 (1.0–1.1)
Illness severity	1.1 (0.9–1.4)	1.5 (1.2–1.9)*
Terminal prognosis	1.3 (0.7–2.4)	3.3 (1.9–5.8)*
Person most influential in decision making‡		
Resident	1.7 (0.8–3.9)	0.9 (0.4–2.1)
Family	0.8 (0.7–2.2)	1.1 (0.6–1.9)
Attending physician (reference)	1	1

*Significant association at *p*-level < .05 (Bonferroni corrected) †Odds ratios per 1 point increment, ‡odds ratios for specified person as most influential in decision making compared with the attending physician as most influential §BANS-S: Bedford Alzheimer Nursing Severity-Scale

Person most influential in decision making

The attending physicians reported that the person most influential in their decisions regarding prioritized treatment goals and treatment was a family member or representative of the person with dementia in most cases (47.4%, *n* = 180), followed by themselves (35.5%, *n* = 135), and the person with dementia (10.3%, *n* = 39) (Table 1). There were no significant differences in the residents' age, sex, length of stay, illness severity or terminal prognosis between these three groups (Table 4) but dementia severity differed (*F*(2, 351) = 6.864, *p* = .001). Dementia was less severe when the resident was most influential in decision making compared with the family or physician. Also, the prevalence of severe dementia differed between groups, with higher prevalence when the family was most influential compared to the resident ($X^2(2)$ = 9.912, *p* = .007).

Table 4 Resident characteristics in the case the resident, the family or the attending physician was most influential in the physician's decision making

	Person Most Influential in the Physician's Decision Making			
	Resident *(n = 39)*	*Family* *(n = 180)*	*Attending Physician (n = 135)*	*p-value (overall differences)*
Demographics				
Mean resident age, years (SD)	84.1 (8.6)	84.7 (7.0)	84.2 (7.8)	.83
Resident sex, female n (%)	22 (56.4)	110 (61.1)	81 (60.0)	.86
Illness progression indicators				
Median length of stay, months (IQR)	11.0 (3.0-23.0)	20.0 (5.25-36.0)	14.0 (5.0-34.5)	.06
Dementia severity, mean BANS-S (SD)[*]	13.8 (4.3)[†,‡]	16.7 (4.6)[†,§]	15.9 (4.2)[‡,§]	.001
Severe dementia n (%)[*]	9 (23.1)[ǁ,**]	91 (50.6)[ǁ,††]	59 (43.7)[**,††]	.007
Illness severity n (%)				.45
Not ill (1-2)	3 (7.7)	5 (2.8)	4 (3.0)	
Mild illness (3-4)	8 (20.5)	35 (19.4)	26 (19.2)	
Moderate illness (5)	13 (33.3)	49 (27.2)	42 (31.1)	
Severe illness (6-7)	12 (30.7)	75 (41.7)	58 (43.0)	
Moribund (8-9)	3 (7.7)	16 (8.9)	5 (3.7)	
Terminal prognosis n (%)	7 (18.9)	52 (29.2)	33 (24.8)	.38

[*] BANS-S: Bedford Alzheimer Nursing Severity-Scale, Severe dementia: BANS-S scores ≥ 17 (range 7–28)[27] [†] *p* = .001 (post-hoc comparison) [‡] *p* = .028 (post-hoc comparison) [§] *p* = .39 (post-hoc comparison) [ǁ] *p* = .006 (post-hoc comparison) [**] *p* = .06 (pos-hoc comparison) [††] *p* = .68 (post-hoc comparison)

Discussion

This study found that physician-reported advance care plans were usually developed after nursing home admission, and only changed for a minority of residents with dementia after pneumonia diagnosis. Illness severity and having less than 3 months to live were associated with any changes in advance treatment decisions. There were no such associations with changes in prioritized treatment goals. Often, the physicians perceived family as most influential, in particular when residents had severe dementia.

Few residents had living wills or were most influential in the decision making. This mirrors Belgian findings, where living wills were rare and physicians did not discuss end-of-life care regularly with residents.[28] Documented ACP with people with dementia themselves is thus not standard practice in primary[29] and long-term care, and several barriers have been identified.[30, 31] One barrier is capacity; many had severe dementia (45%) and probably limited capacity, or temporally diminished capacity due to the acute illness. The majority of residents did not have a power of attorney despite family being most influential in decision making, highlighting the need to identify who people with dementia would want to involve in future decision making.

Absence of living wills did not imply absence of care guidance. Treatment goals were prioritized, and advance treatment decisions were recorded for nearly all residents. It is remarkable that cardiopulmonary resuscitation, antibiotics and hospitalization were discussed for most residents although content of care plans was not regulated. This may reflect a general consensus among healthcare professionals to address these topics, and the fact that this is routine may decrease hesitance to initiate discussions. Artificial nutrition and hydration were discussed least often, but that increased after the pneumonia. Pneumonia might serve as a trigger to discuss relevant treatment orders,[1] indicating declining health. Especially in case of artificial nutrition and hydration, sensitive topics for which decisions are challenging,[32, 33] discussions may have been postponed until after an acute event.

For 16% of the residents, prioritized treatment goals changed, but no factors significantly associated with a change were found. Multiple treatment goals can apply simultaneously, with the priority of treatment goals shifting over time.[3] This process may be influenced by interacting factors which may not have been included in our analyses. For 20% of the residents, treatment decisions changed. The odds of changing treatment decisions was largest for residents who were close to the end of life or more severely ill. Despite an indicator of the residents' health,[34] there was no association with dementia severity. Dutch physicians base their decision to treat pneumonia with antibiotics mainly on prognosis;[35] more so than on dementia severity.[14] They often focus on quality of life and avoiding futile treatment in medical decision making,[36] the majority already upon admission.[11] The relationship between dementia severity and quality of life is complex[37] and survival (and hence medical futility) can be difficult to predict.[5] Using a model that orients decision makers to consider frailty in a holistic way resulted in lower preference of aggressive treatment[38] that may prolong suffering for people with advanced dementia.[39] This suggests that a diagnosis of dementia alone offers insufficient basis to forego treatment, but other illness and frailty should be considered. This holistic approach may also apply to other changes in advance care plans that we found, such as specifying conditions for specific treatments.

In the current study, physicians were asked to report changes in advance care plans made 1-3 weeks after pneumonia diagnosis. Longer time frames might have given more opportunity for change. Further, in contrast to findings from, for example, the United States,[40] goals already favored symptom management rather than life prolongation before the pneumonia in the majority of cases. However, there was still room for changes in the direction of more conservative specific treatments such as foregoing antibiotic treatment or other life-prolonging treatment. Moreover, we found that most changes entailed detailing of plans rather than a change of direction.

We did not find that changes in prioritized treatment goals or treatment decisions were more likely when physicians perceived the family or resident as most influential in their decision making instead of themselves as responsible for medical decision making. The person that the attending physician had listed as "most influential in decision making" is thus not the person taking decisions in the Netherlands.[23] The physicians may have been thinking about the person who provided relevant information that guided their decisions. Future research may examine physician variability regarding shared decision making and ACP.

Strengths and limitations

The strengths of this study include the sample that is representative of nearly all Dutch provinces.[15] We reported on ACP around a pneumonia episode using data that were partly collected prospectively. We used the physicians' estimation of terminal prognosis, assessed prospectively. Thus we have described ACP practice in a realistic, frequently occurring[6, 7] and therefore relevant situation in nursing home residents with dementia.

A limitation relates to power with infrequent outcomes. The models with outcome change of prioritized treatment goal and of treatment decisions showed considerable uncertainty around the coefficients. Further, all data are physician-reported. Family representatives or residents may have a different perspective on their influence in shared decision making and the prioritized treatment goals. Next, the time between data collection (2012-2015) and reporting may limit the relevance of the findings for current practice. However, the incidence of pneumonia in people with dementia is stable.[6, 14] The prevalence of living wills has increased between 2012 and 2018 in the general population from 13% to 21%, but it remains rare for people with dementia.[29, 41] As ACP practice varies across jurisdictions according to local culture, care practice and legislation, cross-national research is needed to examine generalizability of findings in the Dutch context.

Conclusions and Implications

There is a strong ACP practice in Dutch nursing homes involving family, but ACP with persons with dementia themselves is rare and requires more attention. Overall, changes in advance care plans after pneumonia diagnosis were small, suggesting stability of most preferences or limited dynamics in the process of ACP. Changes in specific treatment decisions following pneumonia diagnosis were associated with severe illness and a terminal prognosis. The pneumonia triggered discussions about artificial nutrition and hydration in particular and led to refinement of plans. Future research could investigate if educating the general public, or family caregivers and healthcare professionals specifically, can lower barriers to conduct ACP conversations.

Competing interests

The authors declare that they have no competing interests.

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Appendix

Supplementary Materials. Table S1. Advance decisions regarding treatments: residents’ treatment orders before and after a pneumonia diagnosis

Table S1 Advance decisions regarding treatments: residents’ treatment orders before and after a pneumonia diagnosis (n=390)*

	Before pneumonia diagnosis n (%)			**After pneumonia diagnosis n (%)**		
Treatment	*No order*	*Do-not*	*Do*	*No order*	*Do-not*	*Do*
Cardiopulmonary resuscitation	0 (0)	355 (91.0)	5 (1.3)	2 (0.5)	354 (90.8)	4 (1.0)
Antibiotics	36 (9.2)	36 (9.2)	297 (76.2)	30 (7.7)	66 (16.9)	273 (70.0)
Hospitalization	47 (12.1)	220 (56.4)	93 (23.8)	38 (9.7)	247 (63.3)	75 (19.2)
Intubation	73 (18.7)	286 (73.3)	1 (0.3)	70 (17.9)	289 (74.1)	1 (0.3)
Artificial nutrition	108 (27.7)	223 (57.2)	29 (7.4)	96 (24.6)	241 (61.8)	23 (5.9)
IV therapies (antibiotics, hydration)	113 (29.0)	215 (55.1)	41 (10.5)	98 (25.1)	236 (60.5)	35 (9.0)
Hypodermoclysis (hydration)	164 (42.1)	131 (33.6)	74 (19.0)	144 (36.9)	155 (39.7)	70 (17.9)
Any other life-prolonging treatments	62 (15.9)	95 (24.4)	203 (52.1)	54 (13.8)	127 (32.6)	179 (45.9)
Any of these treatments	**208 (53.3)**	**365 (93.6)**	**308 (79.0)**	**190 (48.7)**	**366 (93.8)**	**284 (72.8)**

*Cardiopulmonary resuscitation was missing for 30 persons, Antibiotics was missing for 21 persons, Hospitalization was missing for 30 persons, Intubation was missing for 30 persons, Artificial nutrition was missing for 30 persons, IV therapies was missing for 21 persons, Hypodermoclysis was missing for 21 persons, Any other life-prolonging treatments was missing for 30 persons

5

Guidance for family about comfort care in dementia: a comparison of an educational booklet adopted in six jurisdictions over a 15 year timespan

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**A full list of members appears in the Appendix (Additional File 6).*

Abstract

Background To support family caregivers of people with dementia in end-of-life decision making, a family booklet on comfort care has been adapted and adopted by several European jurisdictions since the original publication in Canada in 2005.

Methods We analyzed and compared the adaptations to the family booklets used in Canada, the Czech Republic, Italy, the Netherlands, the UK and Ireland that were made up to 2021. Qualitative content analysis was used to create a typology of changes to the original booklet. Interviews with the teams that adapted the booklets contributed to methodological triangulation. Further, using an established framework, we assessed whether the contents of the booklets addressed all domains relevant to optimal palliative dementia care.

Results The booklets differed in the types of treatment addressed, in particular tube feeding, euthanasia, and spiritual care. There was also variability in the extent to which medical details were provided, an emphasis on previously expressed wishes in medical decision making, addressing of treatment dilemmas at the end of life, the tone of the messages (indirect or explicit) and the discussion of prognosis (as more or less positive), and the involvement of various healthcare professionals and family caregivers in care. All booklets addressed all domains of palliative dementia care.

Conclusions We identified core elements in providing information on end-of-life care to family caregivers of people with dementia as related to optimal palliative care in dementia. Additionally, local adaptations and updates are required to account for socio-cultural, clinical, and legal differences which may also change over time. These results may inform development of educational and advance care planning materials for different contexts.

Background

Alzheimer's disease and other neurodegenerative diseases causing dementia are progressive and life-limiting illnesses, characterized by symptoms such as behavioral symptoms and cognitive decline and, in later stages, food and fluid intake problems.[1] Therefore, a palliative care approach is appropriate. When dementia progresses to more severe stages, goals of care may shift from prolongation of life to maximizing comfort.[2] In order to provide person-centered care, these care goals should reflect individual wishes.[2] Due to cognitive impairment, family caregivers advocate for their relatives with dementia in conversations about goals of care and decision-making.[3, 4] This is a difficult task for which many family caregivers feel ill-prepared. They may not be aware of the terminal course of dementia and may lack knowledge about palliative care.[5] Such information may be crucial as nursing staff have reported higher comfort in dying for people with dementia whose family are aware of the disease prognosis, in part because their healthcare professionals are being able to provide better end-of-life care.[6]

The World Health Organisation (WHO) urges to assist family caregivers with information about dementia and palliative care.[1] In Canada in 2005 the Comfort Care Booklet,[7] a guide for caregivers of people with dementia, was developed with this aim and has been adopted by the WHO as an example of good practice.[1] This informational booklet informs family caregivers regarding the course of dementia and palliative care options. The booklet intends to help family caregivers understand that a palliative approach to care is appropriate and does not imply that ”nothing can be done”. Instead, a palliative approach to care can be considered a 'low-tech', but 'high-touch' approach.[8] Retaining its core, the booklet has been translated and adapted for use by healthcare professionals and researchers in several European jurisdictions since 2005: Italy (2008),[9] the Netherlands (2011),[10] the Czech Republic (2017),[11] Ireland (2020)[12] and the UK (2021).[13] Further, in 2021, a new edition of this Canadian Booklet was developed.[14]

Cross-national work about the Japanese, Italian, Dutch and original Canadian version showed that solely translating the information does not suffice. Adaptations to the local context are necessary for the booklets to be applicable and acceptable.[15] In addition, it is important that educational information is based on current evidence-based practice,[16] such as the recommendations by the European Association for Palliative Care (EAPC) about optimal palliative dementia care in older people first issued in 2013.[2] Furthermore, developments in evidence and evolving public perception require that information should be reviewed regularly to remain up to date.[17, 18]

In this paper, we aim to provide guidance about the contents of informational booklets for family caregivers about dementia and palliative care, considering (i) transnational legal and socio-cultural differences and developments over time, plus (ii) evidence and expert consensus-based recommendations regarding palliative dementia care. We compared informational booklets from six jurisdictions to determine key topics and we performed content analysis to highlight contextual differences. The EAPC recommendations for optimal palliative dementia care[2] were mapped onto the contents of the booklets.

Methods

This qualitative descriptive study[18] was conducted as part of an international multiple case study called *mySupport study*, which involves Canada, the Czech Republic, Italy, the Netherlands, Ireland and the UK. The *mySupport study* aims to support family caregivers of nursing home residents with advanced dementia in decision making about end-of-life care.[19] In addition to training staff in conducting family care conferences, family caregivers are provided with information about the progression of dementia and end-of-life care for nursing home residents with dementia via the Comfort Care Booklet.[20]

Comparison of content

To compare the booklets' contents transnationally, we took a deductive approach to identify (i) key topics of the Comfort Care Booklets, as they are presented in all the booklets, and (ii) topics that require adaptation to the specific socio-cultural, legal or temporal context, as they differ between the booklets.

First, the Czech, Dutch and Italian booklets were translated back to English. Next, two researchers (LB and JTvdS) read all the booklets thoroughly and compared the contents of all the booklets with the original Canadian booklet. Differences were marked and listed in a matrix. Then, semi-structured interviews with the editors of the local booklets provided input for methodological triangulation verifying the comparison exercise for completeness.[21, 22] A comparison between the original Canadian, the Italian and the Dutch version of the booklet has been reported previously.[15] Therefore, LB and JTvdS selected the editors of the Czech, UK, Irish and updated Canadian versions of the booklets for an interview. The interview guide asked about topics that were added, deleted, or revised compared with the original Canadian booklet, and about the stakeholders involved in adapting the booklet. Interviews were transcribed, summarized and fed back to the developers for member checking, clarification and elaboration.

Finally, qualitative directed content analysis was performed on the identified differences of each booklet compared with the original Canadian booklet.[23] The tabulated differences were first read repeatedly to create familiarity with the data. Then, the differences were assorted into categories that were informed by the literature.[15, 24] Differences that could not be coded in this manner were identified and were assorted in an additional category or labeled as a subcategory of the existing categories. Next, the categories were reviewed and finalized.

Quality appraisal

A transnational quality appraisal was performed using a deductive approach to identify (i) if key topics according to evidence and expert consensus-based guidelines were represented in the

Comfort Care Booklets (cf. [25]), and (ii) if this differed for the various booklets. To facilitate a comparison between the booklets (aim ii), the quality appraisal was performed with a single international (EAPC) framework, rather than multiple national guidelines on palliative dementia care.

To support methodological validity, AM and LB first developed a protocol with accompanying grid for mapping the content of the booklets against the recommendations presented in the EAPC framework[2] as depicted in Box 1 (Additional File 1). The mapping did not include Domain 10: Education of the healthcare team and Domain 11: Societal and ethical issues, as these domains are not expected to be *explicitly* stated in the booklets—although ethical and moral challenges may be considered within the booklets. For each booklet, this protocol was shared with a researcher fluent in the local language and who was familiar with the content of the local booklet. The outcomes of the final consensus mappings were entered in a grid to facilitate comparison across the booklets.

Results

Comparison of content

When comparing the contents of the booklets, two versions appeared: booklets that were based on the 2005 Canadian Comfort Care Booklet (the 2021 Canadian booklet, the Czech booklet, the Italian booklet, the Dutch booklet and the UK booklet) and booklets that were based on the 2017 UK booklet (the Irish booklet and sections of the 2021 Canadian booklet), see Table 1 (Additional File 2). The booklets that were based on the UK booklet thus had not used the original Canadian booklet as the starting point, but were based on the UK booklet - retaining the adaptions that were made in the UK booklet. Both healthcare professionals and family caregivers were involved in evaluating the contents of the booklets and the adaptations. This involvement ranged from participation in a study leading up to the development of the booklet (indirect involvement), to “collaboration and co-production” which entailed team membership and contributing to key decisions.[27] Healthcare professionals largely influenced the content revisions. Revisions often concerned the local legal frameworks and shared decision making practice.

The key topics that were present in all the booklets were the progression of dementia and possible complications such as eating difficulties and infections, the decision-making process about treatment options at the end of life, palliative care and managing symptoms such as pain, breathing problems and anxiety, the dying process and common emotions and procedures after death. These key topics were retained from the original Canadian Comfort Care Booklet.

We arranged the textual revisions of the booklets compared with the original texts in six categories: 1.Typology of treatments and symptoms at the end of life, 2. Patient and family rights and wishes, 3. Typology of decisions at the end of life, 4. Indirect or explicit messages, 5. More or less positive about prognosis, and 6. Relationship between healthcare professionals and family caregivers.

1. Typology of treatments and symptoms at the end of life

The booklets differed in the treatment options that they described, and the level of medical detail that was provided about symptoms and treatments. Three topics related to treatment differed the greatest between the booklets: artificial nutrition, life-terminating or life-limiting treatments and spiritual care. Whereas all booklets discussed eating difficulties in advanced dementia, the UK booklet did not contain information about tube feeding or any objections to it (Table 2 (Additional File 3), quote A). Instead, extensive information about oral hygiene was provided and this was also included in the Irish and updated Canadian booklet. The Czech booklet provided detailed information about alternative feeding and food options to address eating difficulties. The Czech and Italian booklet provided more medical information about the complications of artificial nutrition during the dying process than the other booklets. This was included because it was considered difficult to convince family caregivers not to start artificial feeding at end of life. Regarding information about euthanasia, this was not included in the Irish and UK booklets, while more elaborate information was provided in the Dutch booklet and updated information in the Canadian booklet. The Czech and Italian booklets mentioned euthanasia only to state that it is not a viable option. The Dutch and Canadian booklets had included additional information about palliative sedation. The UK, Irish and updated Canadian booklet offered information on spiritual care, which was not included in the Czech, Dutch and Italian booklets.

The extent to which the booklets offered detail about medical issues varied, and this may relate to difference in whether healthcare professionals or family caregivers were the most influential in the revision process (see also Table 1 (Additional File 2) Stakeholder Involvement). The Czech, Dutch and Irish booklets contained the most information regarding medications and physical health and the UK booklet the least. For example, the Czech, Dutch and Irish booklet provided detailed information about the breathing pattern during dying or extra information about pain management options. In contrast, the UK booklet did not speak about the medical complications that could arise after hospitalization when addressing why transfer to hospital may not be appropriate, while the other booklets did.

2. Patient and family rights and wishes

The varying legal systems of the jurisdictions were apparent in diverging emphasis on patient rights and wishes between the booklets. The Czech and Irish booklets stood out the most in this respect. The Czech booklet included an entire section about living wills and legally binding wishes to refuse care, driven by the Health Services Act, No. 372/2011 Coll.[29] Emphasis was placed on acting in accordance with living wills throughout the booklet. The Irish booklet contained several sections that asked family caregivers to think about previous wishes of the person with dementia, to ensure that any decision making is aligned to the person's previously stated will and preference. Reference was made to Ireland's Assisted Decision-Making (Capacity) Act 2015.[30] The UK booklet and Dutch booklet only referred to patient wishes for specific treatment decisions, such as CPR and the use of antibiotics, respectively.

The Italian booklet clearly stated that family members provide only information for the decision-making process. This mirrors the updated Canadian booklet, that had adapted the terminology to current legislation regarding shared decision making (Table 2 (Additional File 3), quote B). That is: the family caregiver was referred to as "the patient's legal representative" instead of "the mandatory" (a term formerly used to indicate a representative by law) and a statement was added about variations in provincial laws across the country regarding the role and rights of this person. The updated Canadian booklet, and the Dutch booklet, introduced family wishes only in the section on providing the last care after death.

Further, no mentioning of settling disagreements in court was made in the Czech, Italian and Dutch booklets. The Czech booklet also did not refer to the assistance of ethics committees. A final difference between the booklets was that only the Dutch and Canadian booklets contained information about the legal requirements for life terminating treatments.

3. Typology of decisions at the end of life

A similar category of differences between the booklets related to the description of end-of-life decision making. The Irish and Czech booklets emphasized best interest decision making, involving the family caregiver. The UK booklet underscored the responsibility of the clinician or medical team to facilitate this.

When describing considerations for decisions or treatment, the booklets varied in whether they stated the underlying dilemma. The UK and Italian booklets often did not include the dilemma. For example, they did not refer to pneumonia as "the older person's best friend" (an argument against curative treatment of pneumonia, Table 2 (Additional File 3), quote C). Dilemmas were sometimes emphasized in the Czech booklet, for instance by adding the statement "even at the cost of reduced comfort" which suggests curative treatment can be incongruent with comfort care. The moral acceptability of treatment decisions was, at some places, omitted from the Dutch and Irish booklet. The decision to increase doses of morphine at the end of life to reduce suffering was therefore more a medical than a moral decision, for instance.

4. Indirect or explicit messages

An evident difference between the booklets was their layout. While the Dutch and original Canadian booklets contained images of moments of caring, the UK booklet contained images of nature. The Italian, Czech, Irish and updated Canadian booklets were in the middle of this spectrum and showed images of their local nursing home contexts. In addition, the Irish booklet contained images of nature.

Differences between explicit messages or more softened, indirect messages were also found in the text in terms of style. The UK booklet used more softened language, for example comparing breathing problems to asthma. This booklet also spoke about nausea or discomfort, similar to the Italian and Irish booklet. The Czech, Dutch and Canadian booklets instead mentioned vomiting and pain. The Czech booklet typified useless or harmful treatment in the last days or hours of terminal illness as “dysthanasia”, detained death, and mentioned more confrontational treatment details.

All booklets considered dementia as a terminal condition, but some booklets were more explicit about this. The Czech booklet further contained explicit statements about the non-curable and terminal nature of the disease causing dementia syndrome. Also the Irish booklet explicitly mentioned the dying phase several times. The Dutch booklet clearly related not eating and drinking to the dying phase (Table 2 (Additional File 3), quote D).

All booklets recommended a palliative care approach based on physical and psychological comfort; the Canadian and Italian booklets concluded with the statement that “That’s because the majority of people perceive that advanced and prolonged dementia is worse than death”. This statement was not incorporated in the other booklets.

5. More or less positive about prognosis

There was some variation within and between the booklets regarding the description of the prognosis. The Czech booklet started with the limited life expectancy and cause of death in the introduction (Table 2 (Additional File 3), quote E) and therefore appeared less positive about the prognosis compared with the other booklets. The symptoms that were described in this booklet were mainly possible causes of death, as was the case for the Canadian, Dutch and Irish booklets. The UK and Irish booklets had additionally included symptoms related to activities of daily living, describing less severe stages of dementia. This encompassed a more holistic tone and upstream approach regarding prognosis than referring only to symptoms around the end of life.

The Czech booklet was less positive about prognosis throughout the booklet, for example stating how certain treatments may not be tolerated by the person with dementia. The more positive tone about prognosis of the UK booklet was also present throughout, for example by not stating some negative consequences of treatments. The Dutch booklet was more positive about prognosis in some sections: a maximum estimate of survival was provided for people who do not eat (instead of a time window that included a shorter time estimate). However, in other sections, the Dutch booklet was less positive about prognosis: it included the statement that the “final stage can be long and exhausting”.

6. Relationship between healthcare professionals and family caregivers

Two booklets stood out regarding the relationship between healthcare professionals and family caregivers: the updated Canadian and Irish booklet. Both had included information about family involvement in care and this was particularly present throughout the Irish booklet

(Table 2 (Additional File 3), quote F). The other booklets did not include this information, apart from sitting in at the end of life. The Irish booklet additionally referred to several healthcare disciplines throughout the booklet, which supports the multidisciplinary nature of palliative care. The other booklets mainly referred to physicians and nursing staff.

Quality appraisal

According to the final consensus mapping, all EAPC first nine domains defining optimal palliative dementia care were addressed in all the booklets, as depicted in Table 3 (Additional File 4). However, not all specific recommendations within the domains were addressed by all booklets. Recommendations with regards to `setting care goals and advance care planning' were addressed the least, especially in the Canadian and Italian booklet, while the Irish booklet addressed some of the specific recommendations. Supporting people with mild dementia in advance care planning (recommendation 3.4) was not mentioned in any of the booklets, as all booklets described the advanced stages of dementia since the booklets are positioned at the end of life, where decision making capacity may be limited. Recommendations that were also not addressed by any of the booklets related to `Continuity of care' (having a central care coordinator and appropriate information transfer between healthcare professionals) and to `Optimal treatment' (interdisciplinary consultation between dementia and palliative care specialists).

The Czech booklet was the only booklet that addressed recommendation 2.5 about previously expressed preferences regarding place of care (domain 2: Person-centered care). An explicit statement about avoiding the use of restraints (recommendation 6.3, domain: Avoiding burdensome treatment) was found only in the Irish Booklet.

Based on our overall findings, we present guidance statements regarding the contents of informational booklets for family caregivers about dementia and palliative care in Box 2 (Additional File 5). This may inform future updates or wider adoption of the booklets and support the development of other educational materials for family caregivers in this area.

Discussion

The Comfort Care Booklet provides family caregivers with information concerning the trajectory of advanced dementia and a palliative approach to care. In this paper, we compared Comfort Care Booklets across six jurisdictions that were developed between 2005 and 2021. One of the most striking differences between the booklets was the distinction between the UK booklet and the original Canadian booklet. The UK booklet has been under extensive review in practice by various stakeholders since 2014, originally used in Northern Ireland, it was adapted for broader application in the UK between 2019 and 2021. In the Irish and updated Canadian booklets, the involvement of family caregivers over the last year was evident from the addition of sections that engaged family caregivers, stipulating their role in providing comfort care. Interesting in this respect is the addition of a new section on spirituality for the UK, Irish and updated Canadian booklets. This addition could thus reflect increasing awareness for spiritual care as a key component in palliative care.[32] Also, it is likely that the dominant ideology in the stakeholders' jurisdiction and the greater representation of stakeholders involved, healthcare professionals or family caregivers, influenced topics to be included in the booklets. These findings highlight the need to involve stakeholders and have appropriate levels of representation in the development and evaluation of family and patient educational materials[16] and to be transparent in reporting the process.

In addition to the impact of stakeholder involvement, sociocultural differences emerged too. End-of-life decision making and disclosing prognostic information are both significantly influenced by socio-cultural factors.[33, 34] The UK booklet was more positive about prognosis and did not include many medical details or explicit messages, as one of the developers stated: "we tend not to talk about death". The aim of the booklet was therefore to inform family caregivers without causing distress. In contrast, the Czech booklet was less positive about prognosis and included more detailed information and explicit messages. The historically strong paternalistic culture in the Czech health care is reported to be a barrier for patient engagement;[35] although health care regulations recognize this, reform is in progress to be more inclusive of patient autonomy. The primary aim of the booklet was thus to inform and prepare family caregivers to stimulate family caregiver engagement.

Differences in legal contexts between jurisdictions were further apparent in the status of best interests and patient autonomy or previously expressed wishes in medical decision making, and the extent to which family was involved in shared decision making. While the Czech and Irish booklet emphasized best interest decision making informed by living wills and advance directives, the updated Canadian booklet did not refer to advance directives as this term is not consistent within the legal frameworks for all Canadian provinces. Differences in legislation[34] and interpretation of decision-making processes[35, 36] are therefore important to consider when providing information about end-of-life decision making.

Finally, differences over time were apparent from our analysis. The evidence base for advance care planning for people with dementia has been growing.[37] While hardly present in most of the booklets, the recent Irish booklet contained information about end-of-life care planning to ensure that any decision making is aligned to the person's previously stated will and preference. The updated Canadian booklet included information about Medical Assistance in Dying, while the original version referred to an illegal status of euthanasia. In addition, the text was gender-neutral and did not include male pronouns. The UK booklet had removed information about tube feeding due of the wider consensus on tube feeding being inappropriate for people with dementia at the end of life; this could reflect developments in public perception making such a statement obsolete.[18]

Compared with a systematic review that mapped the components of palliative care interventions according to the EAPC domains,[25] the outcome of our mapping was different. The systematic review found that interventions hardly addressed 'applicability of palliative care'. Further, 'prognostication and timely recognition of dying', 'avoiding overly aggressive, burdensome or futile treatment' and 'setting care goals and advance care planning' were not always included in interventions. The Comfort Care Booklets addressed all these domains as they formed the key message of the information, except for 'setting care goals and advance care planning'. Possibly, more information about end-of-life care planning practice could be included in future editions; advance care planning that includes the person with dementia needs to be addressed at earlier disease stages.

A strength of this study is that this cross-national comparison not only focuses on different cultures, but also captured some key developments over time. This is also a limitation of this study that compared the booklets at one point in time, and we propose to review and update information materials regularly to adopt socio-cultural and evidence-base developments. Intervals for updating the booklets should be determined by developments in evidence and public perception.[17, 18] Furthermore, although both English speaking/Northern European cultures and Mediterranean/Eastern European cultures were included in our analysis,[33] our study primarily focused on western documents that were all based on an original Canadian piece and does not provide information about possible issues to consider for documents in other cultures.

Conclusions

In conclusion, the Comfort Care Booklet covers all domains of good-quality palliative care for older people with dementia,[2] but more attention for end-of-life care planning and spirituality is required. We present guidance statements regarding family information. When developing informational materials that are appropriate for the local context, it is important to consider the legal and socio-cultural environment and developments over time. We also recommend stakeholder involvement throughout the development process, end-users in particular.

Abbreviations

CPR: cardiopulmonary resuscitation; EAPC: European Association for Palliative Care; WHO: World Health Organisation

Declarations

Ethics approval and consent to participate

Formal ethics approval was not required as the Medical Research Involving Human Subjects Act (1998, 26 March, https://wetten.overheid.nl/BWBR0009408/2021-07-01) was not applicable. All editors provided verbal consent to participate in the interviews.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

LB and JS contributed to the concept and design of the work; acquisition, analysis and interpretation of the data; drafted the article and substantially revised it. AM contributed to the design of the work; acquisition and analysis of the data and substantially revised the article. KB contributed to the concept of the work and substantially revised the article. NC, IH, SK, PG, HV, LV and MA contributed to the analysis and interpretation of the data and substantially revised the article. All authors read and approved the final manuscript.

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Appendix

Additional File 1

Box 1 Protocol for mapping the Comfort Care Booklets' contents against the EAPC framework

To be performed by two individuals independently:

1. Read the Comfort Care Booklet
2. Per section, assess if and which recommendation(s) of the first 9 EAPC domains is addressed, including the explanatory text[26]*

To be performed in a consensus discussion between the two individuals:

3. Compare and discuss the mappings to reach consensus, using the following criteria:
    - The text addressed the EAPC statement as found in the *recommendation and/or the explanatory text*
    - The text addressed the EAPC statement *explicitly*, a statement that is implied is not specifically addressed
    - The *context* of the statement may differ between the text in the Comfort Care Booklet and the EAPC framework (that is: the EAPC framework states that family caregivers need explanation without providing detail and the Comfort Care Booklet directly provides the explanation)

*The first 9 EAPC domains and 47 recommendations:

Domain 1. Applicability of palliative care

- 1.1 Dementia can realistically be regarded as a terminal condition. It can also be characterized as a chronic disease or, in connection with particular aspects, as a geriatric problem. However, recognizing its eventual terminal nature is the basis for anticipating future problems and an impetus to the provision of adequate palliative care.
- 1.2 Improving quality of life, maintaining function and maximizing comfort, which are also goals of palliative care, can be considered appropriate in dementia throughout the disease trajectory, with the emphasis on particular goals changing over time.
- 1.3 Palliative care for dementia should be conceived as having two aspects. The baseline is a palliative care approach. For patients with complex problems, specialist palliative care should be available.
- 1.4 A palliative care approach refers to all treatment and care in dementia, including adequate treatment of behavioural and psychological symptoms of dementia, comorbid diseases, and (inter- or concurrent) health problems.

Domain 2. Person-centred care, communication and shared decision making

- 2.1 Perceived problems in caring for a patient with dementia should be viewed from the patient's perspective, applying the concept of person-centred care.
- 2.2 Shared decision making includes the patient and family caregiver as partners and is an appealing model that should be aimed for.
- 2.3 The health care team should ask for and address families' and patients' information needs on the course of the dementia trajectory, palliative care and involvement in care.
- 2.4 Responding to the patient's and family's specific and varying needs throughout the disease trajectory is paramount.

Box 1 (Continued)

- 2.5 Current or previously expressed preferences with regard to place of care should be honoured as a principle, but best interest, safety and family caregiver burden issues should also be given weight in decisions on place of care.
- 2.6 Within the multidisciplinary team, patient and family issues should be discussed on a regular basis.

Domain 3. Setting care goals and advance planning

- 3.1 Prioritizing of explicit global care goals helps guide care and evaluate its appropriateness.
- 3.2 Anticipating progression of the disease, advance care planning is proactive. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited.
- 3.3 Formats of advance care plans may vary in terms of preferences, the amount of detail required, and what is available in the specific setting for the individual.
- 3.4 In mild dementia, people need support in planning for the future.
- 3.5 In more severe dementia and when death approaches, the patient's best interest may be increasingly served with a primary goal of maximization of comfort.
- 3.6 Advance care planning is a process, and plans should be revisited with patient and family on a regular basis and following any significant change in health condition.
- 3.7 Care plans should be documented and stored in a way that permits access to all disciplines involved in any stage and through transfers.

Domain 4. Continuity of care

- 4.1 Care should be continuous; there should be no interruption even with transfer.
- 4.2 Continuous care refers to care provided by all disciplines.
- 4.3 All patients should benefit from the early appointment of a central coordinator from within their care team.
- 4.4 Transfers between settings require communication on care plans between former and new professional caregivers and patient and families.

Domain 5. Prognostication and timely recognition of dying

- 5.1 Timely discussion of the terminal nature of the disease may enhance families' and patients' feelings of preparedness for the future.
- 5.2 Prognostication in dementia is challenging and mortality cannot be predicted accurately. However, combining clinical judgement and tools for mortality predictions can provide an indication which may facilitate discussion of prognosis.

Domain 6. Avoiding overly aggressive, burdensome or futile treatment

- 6.1 Transfer to the hospital and the associated risks and benefits should be considered prudently in relation to the care goals and taking into account also the stage of the dementia.
- 6.2 Medication for chronic conditions and comorbid diseases should be reviewed regularly in light of care goals, estimated life expectancy, and the effects and side effects of treatment.
- 6.3 Restraints should be avoided whenever possible.
- 6.4 Hydration, preferably subcutaneous, may be provided if appropriate, such as in case of infection; it is inappropriate in the dying phase (*only moderate consensus*).
- 6.5 Permanent enteral tube nutrition may not be beneficial and should as a rule be avoided in dementia; skillful hand feeding is preferred (*only moderate consensus*).

Box 1 (Continued)

- 6.6 Antibiotics may be appropriate in treating infections with the goal of increasing comfort by alleviating the symptoms of infection. Life-prolonging effects need to be considered, especially in case of treatment decisions around pneumonia.

Domain 7. Optimal treatment of symptoms and providing comfort

- 7.1 A holistic approach to treatment of symptoms is paramount because symptoms occur frequently and may be interrelated, or expressed differently (e.g., when pain is expressed as agitation).
- 7.2 Distinguishing between sources of discomfort (e.g., pain or being cold) in severe dementia is facilitated by integrating views of more caregivers.
- 7.3 Tools to assess pain, discomfort and behaviour should be used for screening and monitoring of patients with moderate and severe dementia, evaluating effectiveness of interventions.
- 7.4 Both non-pharmacological and pharmacological treatment of physical symptoms, challenging behaviour or discomfort should be pursued as needed.
- 7.5 Nursing care is very important to ensure comfort in patients near death.
- 7.6 Specialist palliative care teams may support staff in long-term care settings in dealing with specific symptoms, while maintaining continuity of care. In managing behavioural symptoms, however, palliative care teams may need additional dementia care specialist expertise.

Domain 8. Psychosocial and spiritual support

- 8.1 In mild dementia, as also in the later stages, patients may be aware of their condition, and patients and families may need emotional support.
- 8.2 Spiritual caregiving in dementia should include at least assessment of religious affiliation and involvement, sources of support and spiritual well-being; in addition, referral to experienced spiritual counsellors such as those working in nursing homes may be appropriate.
- 8.3 Religious activities, such as rituals, songs, and services may help the patient because these may be recognized even in severe dementia.
- 8.4 For dying people, a comfortable environment is desirable.

Domain 9. Family care and involvement

- 9.1 Families may suffer from caregiver burden, may struggle to combine caring with their other duties and may need social support.
- 9.2 Families may need support throughout the trajectory, but especially upon diagnosis, when dealing with challenging behaviour, with health problems, with institutionalization, with a major decline in health and when death is near.
- 9.3 Families need education regarding the progressive course of the dementia and (palliative care) treatment options; this should be a continuous process addressing specific needs in different stages, examining family receptiveness.
- 9.4 Family involvement may be encouraged; many families may wish to be involved in care even when the patient is admitted to an institution providing long-term care.
- 9.5 Families need support in their new role as (future) proxy decision maker.
- 9.6 Professional caregivers should have an understanding of families' needs related to suffering from chronic or prolonged grief through the various stages, and with evident decline.
- 9.7 Bereavement support should be offered.
- 9.8 Following the death of the patient, family members should be allowed adequate time to adjust after often a long period of caring for the patient.

Additional File 2

Table 1 Summary of comfort care booklet development process

Location, ed (year)	Based on	Stakeholder involvement [type of involvement]*	Most influence on revisions	Focus of revisions [derived from interview]
CA, 1 (2005)	*Literature; [28]*	*Researchers / Healthcare professionals; current and bereaved family caregivers [undefined involvement]*		
IT, 1 (2008)	CA, 1 (2005)	Researchers; ethicists, physicians (LTC), nurses (LTC), bereaved family caregivers [targeted consultation]	?	Layout (showing Italian setting), legal context of shared decision making and euthanasia[14]
NL, 2 (2011)	CA, 1 (2005)	Researchers; ethicists, physicians (LTC), nurses (LTC), bereaved family caregivers [targeted consultation]	LTC physicians	Order of topics (and Table of contents), legal context of shared decision making and euthanasia, treatment considerations[14]
CZ, 1 (2017)	CA, 1 (2005)	Researchers; nurses, geriatricians, palliative team members, physicians (hospice care, palliative care), psychologists, social care professionals, ethicist, law specialist, family caregivers [targeted consultation]	All (multidisciplinary approach)	Adaptation to the Czech laws; the role of family in shared decision making [derived from interview]
IE, 1 (2020)	UK, 2 (2017)	Researchers; GP, geriatricians, speech and language therapist, nurses, family caregivers [collaboration and co-production]	GP, geriatricians	Legal context of shared decision making; focus on end-of-life care planning; addition of family involvement [derived from interview]
UK, 3 (2021)	CA, 1 (2005)	Researchers; geriatricians, nurses (dementia, palliative care), nursing home manager, facilitator (oncology and palliative care), hospice consultant, Alzheimer Society consultant, service user, policy officers, family caregivers [embedded consultation]	Facilitator (oncology and palliative care), hospice consultant, Alzheimer Society	Deletion of not-applicable material (PEG, euthanasia); addition of a section on spirituality; use of softer language and layout to prevent distress [derived from interview]

Table 1 (Continued) Summary of comfort care booklet development process

Location, ed (year)	Based on	Stakeholder involvement [type of involvement]*	Most influence on revisions	Focus of revisions [derived from interview]
CA, 2 (2021)	CA, 1 (2005); UK, 2 (2017)	Researchers; care director (LTC), nurses (LTC), family caregivers [undefined involvement]	Family caregivers	Additions of sections on spirituality, Medical Assistance in Dying, oral hygiene and mouth care; use of inclusive language and (shared decision making) terminology in accordance with current legal framework [derived from interview]

CA: Canada, IT: Italy, NL: the Netherlands, CZ: the Czech Republic, UK: the United Kingdom, IE: Ireland, LTC: Long Term Care

*Undefined involvement: stakeholders act as participants/respondents/research subjects in a study leading up to the development of the booklet, thus were indirectly involved; Targeted consultation: stakeholders are approached to provide feedback/comments; Embedded consultation: stakeholders are regularly consulted throughout the process; Collaboration and co-production: stakeholders are part of the team and contribute to key decisions; User-led research: stakeholders take lead in designing and conducting research[27]

Additional File 3

Table 2 Themes of textual revisions across the booklets with example quotes

Theme	Example quote (identifier, source)
Typology of treatments and symptoms at the end of life	UK editor about the deletion of the section on tube feeding treatment: *In the UK, there was a PEG-tube plead. So some of the carers were a bit confused about why [information on tube feeding] was in the book, because they then said, you know: can we have that? Or: I don't actually want that to happen. So our facilitator felt it be better to not include that part of it, because it wasn't standard practice in the nursing homes.* (A, interview)
Patient rights and wishes	Canada editor (of updated Canadian booklet) about the adaptions in terminology referring to the status of the family caregiver in decision making: *(…) we have this very strict legal framework (..) and there's a lot of emphasis right now within our palliative care organizations to make sure that all of our advance care planning, goals of care programs and educational materials are compliant with that legal framework. (…) And then we have consent as well. So for any kind of treatment, you have to have consent from families. So that's why we had to change the language around values and goals and wishes and then treatment plans (…).* (B, interview)
Typology of decisions at the end of life	Original Canadian text, with section about the moral dilemma underlying treatment decisions excluded in Italian version in **bold**: *(…) The doctor can prescribe an antibiotic if the individual develops a fever and if it is judged, from a medical standpoint, that the individual has pneumonia. However, as mentioned earlier, the chance of recovering from pneumonia in the advanced stages of these types of neurological diseases is limited, and the possibility of this problem re-occurring shortly thereafter is elevated.* ***William Osler, a well-known early 20th-century doctor, said that pneumonia may very well be the older person's best friend because it can bring suffering to an end. That is why many doctors prefer to abstain from prescribing antibiotics for pneumonia at the end of life, and select a palliative care approach such as the one described further on in this document.*** *Each situation is evaluated on a case-by-case basis. (…)* (C, comfort care booklets)

Table 2 (Continued) Themes of textual revisions across the booklets with example quotes

Theme	Example quote (identifier, source)
Indirect or explicit messages	Original Canadian version: *People who are lucid and who are suffering from cancer or degenerative, neurological diseases say that the feeling of thirst and hunger is not common near the end of life. Most patients refuse all or even small amounts of food that are offered to them and say that they feel a sensation of dryness in the mouth.* Netherlands version with added explicit message about the dying phase: *Patients with dementia often gradually start drinking or eating less. The body adapts to this, which makes the patient appear not to be hungry or thirsty. Patients barely want to eat or drink in the final phase. A well-known saying is: 'people do not die because they do not eat and drink; they do not eat and drink because they are dying'. (…)* (D, comfort care booklets)
More or less positive about prognosis	Original Canadian introduction, first paragraph: *This guide is intended for caregivers of a person whose health has been severely affected by Alzheimer's disease or by another type of degenerative disease of the brain, such as Parkinson's disease, the effects of multiple strokes, or even certain forms of multiple sclerosis.* Czech Republic version introduction, first paragraph with added section implying a less positive perspective on prognosis: *This guide is intended for those who care for people with Alzheimer's disease or any other type of brain disease, such as Parkinson's disease or vascular dementia. All these diseases can cause dementia syndrome. A disease causing dementia is a life-limiting disease in its effects. Everyone knows someone who has been living with dementia for ten or even fifteen or more years. However, the most common survival time from the diagnosis of dementia is four to five years. Some people also have other serious illnesses at the time of diagnosis of dementia, such as heart disease, while others develop cancer. Others, however, die because dementia reduces their life expectancy. This guide focuses on the challenging times of the very advanced and final stages of the disease.* (E, comfort care booklets)
Relationship among healthcare professionals and family caregivers	Irish editor about the addition of sections for family caregivers as partners in care: *Yes, like I think, in particularly, some of the information was very kind of, kind of soft touch in one sense, and it was kind of 'nice to know'-material, you know. But we weren't sure exactly what the family could learn from it, in one sense. So that's why we divided sections up in two: 'What the healthcare professional does' and 'What you can do as a family'. Kind of around the oral care in particular, you know, so it's kind of giving them something to do, they feel useful, but it's also informing them this is what to expect the healthcare professional is going to be doing, you know.* (F, interview)

Additional File 4

Table 3 Outcome of the EAPC Framework mapping: recommendations* addressed from domains 1-9

Location, ed (year)	Domain 1 Applicability of palliative care (1.1-1.4)	Domain 2 Person-centered care, communication and shared decision making (2.1-2.6)	Domain 3 Setting care goals and advance care planning (3.1-3.7)	Domain 4 Continuity of care (4.1-4.4)	Domain 5 Prognostication and timely recognition of dying (5.1-5.2)	Domain 6 Avoiding overly aggressive, burdensome or futile treatment (6.1-6.6)	Domain 7 Optimal treatment of symptoms and providing comfort (7.1-7.6)	Domain 8 Psychosocial and spiritual support (8.1-8.4)	Domain 9 Family care and involvement (9.1-9.8)
IT, 1 (2008)	1.1-1.4	2.1-2.4, 2.6	3.5	4.1-4.2	5.2	6.1-6.2, 6.4-6.6	7.1-7.5	8.2	9.2-9.5, 9.7-9.8
NL, 2 (2011)	1.1-1.2, 1.4	2.1-2.4, 2.6	3.3, 3.5	4.1-4.2	5.2	6.1-6.2, 6.4-6.6	7.1-7.5	8.2-8.4	9.2-9.5, 9.7
CZ, 1 (2017)	1.1-1.2, 1.4	2.1-2.5	3.2, 3.3, 3.5	4.1-4.2	5.2	6.1-6.2, 6.4-6.6	7.1-7.5	8.2, 8.4	9.2-9.5, 9.7-9.8
IE, 1 (2020)	1.1-1.4	2.1-2.4, 2.6	3.1-3.3, 3.5-3.7	4.1	5.1-5.2	6.1-6.6	7.1-7.5	8.1-8.3	9.2-9.7
UK, 3 (2021)	1.1-1.2, 1.4	2.1-2.4, 2.6	3.2, 3.5, 3.7	4.1-4.2	5.1-5.2	6.1-6.2, 6.4-6.6	7.1-7.5	8.1-8.4	9.1-9.5, 9.7-9.8
CA, 2 (2021)	1.1-1.2, 1.4	2.1-2.4, 2.6	3.5	4.1-4.2	5.1-5.2	6.1-6.2, 6.4-6.6	7.1, 7.3-7.5	8.1-8.4	9.2-9.5, 9.7

*Numbers in the table refer to recommendation numbers as listed in the EAPC Framework[2]

Additional File 5

Box 2 Guidance statements

Core statements of information for family caregivers about dementia and comfort care

Information for family caregivers of nursing home residents with advanced dementia should advise a palliative approach and cover

the course of the dementia and expected complications:

1. Advanced dementia should be considered a terminal illness with the majority of patients dying from nutrition/hydration or infectious problems, especially pneumonia.*

the decision-making process:

2. In decisions regarding whether or not to use life-prolonging therapy in advanced dementia, the ideal decision-making process is to reach a consensus between the physician, the substitute decision maker and other significant relatives or friends of the patient.*
3. In the decision-making process, the medical options that are most suited to the patient’s best interests (e.g. according to patient values and written or verbal advance directives) should be strived for and options that would not presumably be acceptable to the patient should be refused.**

symptom management:

4. Use of parenteral hydration (IV or hypodermoclysis) may be helpful in selected cases but can also contribute to discomfort.**
5. A patient who no longer eats and drinks will generally not experience discomfort if there is adequate mouth care.**
6. When ‘comfort care without life prolongation’ is the goal of care, antibiotics can be withheld and treatment will then aim at symptom control.*
7. Prescription of opioids may be necessary to control pain or breathing difficulties to relieve the patient.**

avoiding burdensome treatment:

8. Cardiopulmonary resuscitation is not recommended in advanced dementia because it can harm the patient and has very little chance of success.*
9. Hospital transfer of the patient with advanced dementia should be exceptional e.g. only to provide comfort by technical means not available in the nursing home (such as hip fracture surgery).*

dying and grief:

10. It is difficult to estimate the moment of death, family caregivers should be accommodated to stay with the patient during the end of life.
11. Family caregivers should be offered bereavement support to cope with feelings of grief, relief, anger, loneliness, exhaustion and guilt.

Box 2 (Continued)

In addition, information needs to be provided about

advance care planning:

12. Prioritizing explicit care goals, if possible together with the patient, should start as soon as possible and should be evaluated regularly to help guide care.

spiritual care:

13. Patients and family caregivers should be offered spiritual care, religious activities or support by spiritual counsellors for psychosocial and spiritual support.

Flexible elements of information for family caregivers about dementia and comfort care

Information for family caregivers of nursing home residents with advanced dementia that requires adaption to the local context includes:

- Information about withholding/withdrawing of artificial nutrition/hydration
- Information about the roles and responsibilities of the patient, substitute decision makers, healthcare professionals and others involved in medical decision making and caregiving
- Information about life terminating treatments
- Information about (palliative) sedation to relieve anxiety or agitation
- The use of medical details or terminology
- The expression of moral considerations underlying treatment decisions
- The use of imagery and tone of voice

Process of developing information for family caregivers about dementia and comfort care

Information for family caregivers of nursing home residents with advanced dementia should be developed

1. with the involvement of stakeholders (family caregivers, healthcare professionals, ethicists, law specialists) in constructing and evaluating the content
2. continuously, that is: regularly updated to keep information in line with current practice and public perception
3. in a manner that is sensitive to the legal and socio-cultural context
4. with a clear reporting about the process and people involved

** These statements are retained from the core statements by Arcand et al.*[31] ***These statements are adapted from the core statements by Arcand et al.*[31]

Additional File 6

mySupport study group

mySupport study group members:

Marcel Arcand, Jackson Hagner, Danielle Just, Sharon Kaasalainen, Tamara Sussman, Martin Loucka, Hana Vankova, Karolina Vlckova, Ladislav Volicer, Marco Clari, Paola Di Giulio, Silvia Gonella, Laura Simionato, Wilco Achterberg, Laura Bavelaar, Jenny T. van der Steen, Mandy Visser, Catherine Buckley, Nicola Cornally, Serena Fitzgerald, Tony Foley, Siobhan Fox, Irene Hartigan, Dominika Lisiecka, Ronan O'Caoimh, Selena O'Connell, Catherine Sweeney, Suzanne Timmons, Kevin Brazil, Christine Brown Wilson, Gillian Carter, Emily Cousins, Kay De Vries, Josie Dixon, Andrew Harding, Karen Harrison Dening, Catherine Henderson, Adrienne McCann, Sophie Morris, Nancy Preston, Catherine Walshe

6

Developing country-specific questions about end-of-life care for nursing home residents with advanced dementia using the nominal group technique with family caregivers

Published as

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Abstract

Objective We aimed to develop question prompt lists (QPLs) for family caregivers of nursing home residents with advanced dementia in the context of a study involving Canada, the Czech Republic, Italy, the Netherlands, the United Kingdom and Ireland, and to explore cross-national differences. QPLs can encourage family caregivers to ask questions about their relative's end-of-life care.

Methods We used nominal group methods to create country-specific QPLs. Family caregivers read an information booklet about end-of-life care for people with dementia, and generated questions to ask healthcare professionals. They also selected questions from a shortlist. We analysed and compared the QPLs using content analysis.

Results Four to 20 family caregivers per country were involved. QPLs ranged from 15-24 questions. A quarter (24%) of the questions appeared in more than one country's QPL. One question was included in all QPLs: "*Can you tell me more about palliative care in dementia?"*.

Conclusion Family caregivers have many questions about dementia palliative care, but the local context may influence which questions specifically. Local end-user input is thus important to customize QPLs.

Practice implications Prompts for family caregivers should attend to the unique information preferences among different countries. Further research is needed to evaluate the QPLs' use.

Highlights

- We developed country-specific question prompt lists about dementia palliative care
- In five countries, family caregivers were consulted to finalize a list of questions
- All caregivers selected: *"Can you tell me more about palliative care in dementia?*"
- Included topics differed across countries, namely artificial nutrition and fluids

Introduction

Healthcare professionals are increasingly adopting patient-centered care that is sensitive to the patient's preferences and needs.[1] This requires patients to be engaged in the decision-making process, to be informed about the positive and negative features of each option and to be aware of their own values and preferences that can guide the decision.[2]

Patient engagement in the context of advanced dementia can be challenging. There are numerous quality and ethical issues, such as the cognitive ability of the person with dementia to understand and contribute to the conversation.[3, 4] Consequently, family caregivers -for example partners or adult children- are expected to represent their relatives with dementia when they are no longer able to express own wishes.[5] However, family caregivers may lack a good understanding of dementia and end-of-life care.[6, 7] To address this issue, Arcand and colleagues developed an informational booklet about comfort care for nursing home residents with advanced dementia: the Comfort Care Booklet.[8] The aim of the booklet is to prepare family caregivers for the end of life and reassure them about the patient's comfort. The Comfort Care Booklet has been translated and adapted for use in various countries.[9-13] The Comfort Care Booklets were developed by healthcare professionals with input from patients and family caregivers. Involving end-users can lead to more user-friendly information.[14]

Although family caregivers welcome information about dementia and end-of-life care, information provision itself is not enough: there is a need for follow-up conversations with healthcare professionals.[15] As families will often not explicitly share their information and support needs with healthcare providers, they need assistance in expressing these needs so that they can be met.[15] An aid to increase patient or family caregiver engagement is a question prompt list (QPL).[16] A QPL is a list of typical questions, that can encourage individuals to ask questions about their relative's care. Thus, healthcare professionals can provide personally relevant information. Hyatt, Lipson-Smith and colleagues[17] found that patients with cancer experienced a QPL to be supportive to their care, but also recommended that QPLs should be culturally-tailored and patient-driven. For example, the development of a QPL for patients with cancer in the US and Australia led to two different versions as some aspects were deemed less acceptable or useful in the US compared with Australia.[18]

Currently, available QPLs about illness and treatment to support decision making (e.g. [19-22]) are mostly tailored for patients with cancer. A QPL to support family caregivers of nursing home residents with advanced dementia is not internationally available. Therefore, the objective of this study was to develop a QPL for family caregivers of nursing home residents with advanced dementia. The purpose of the new QPLs was to complement the Comfort Care Booklet[8-13] by encouraging question asking and aid conversations about care.

In this study, we consult current and bereaved family caregivers in five countries to ensure family-driven and culturally-tailored QPLs for dementia. We assessed differences between countries in the resulting QPLs to examine importance of the local context.

Methods

This study is part of an international EU Joint Programme – Neurodegenerative Disease Research (JPND) project to support family caregivers of nursing home residents with advanced dementia in decision making, called 'mySupport study', involving Canada, the Czech Republic, Italy, the Netherlands, the UK and Ireland. The QPLs were developed with the targeted consultation of family caregivers. The aim of the development process was to agree on the final QPLs with 20-25 questions. This process took 13 months and was divided into three phases as described below and depicted in Figure 1. An evaluation of the QPLs in practice was outside the scope of the current study and will be addressed during the larger mySupport study.[23]

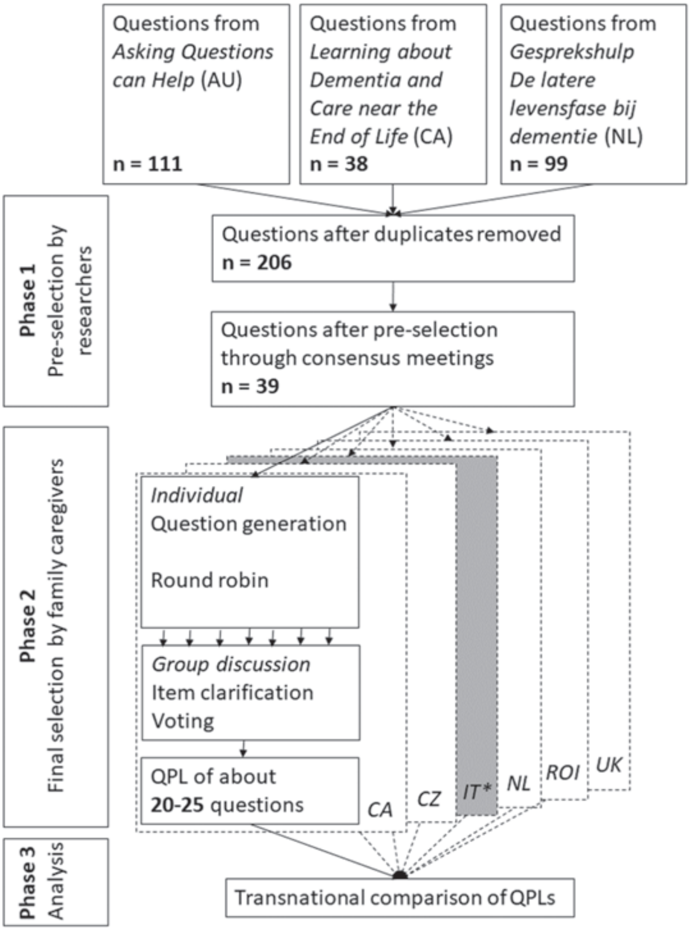

Figure 1 Outline of the three-phase process for developing country specific question prompt lists
*QPL = question prompt list; AU = Australia, CA = Canada, CZ = the Czech Republic, IT = Italy, NL = the Netherlands, ROI = Republic of Ireland, UK = the United Kingdom. *In Italy, Phase 2 could not be performed due to the large impact of COVID-19.*

Phase one

Phase one (July 2019 – September 2019) involved an elderly care physician, two researchers specialized in palliative care, a researcher trained in psychology and a researcher educated in neuroscience. This team selected a set of questions from three available QPLs (two about dementia care and one about palliative care). The QPLs originated in three different countries (Australia,[24] Canada,[25] the Netherlands),[26] providing a transnational overview of questions (248 questions in total, 206 without duplicates).

The team aimed to reduce the number of questions to < 50 and to include at least one question per topic discussed in the Comfort Care Booklets: dementia, end-of-life decision making, symptom relief, and end of life. Questions were deemed appropriate for inclusion if they were relevant to the nursing home setting and within the scope of the Comfort Care Booklets. ‘Nursing home’ is used to refer to a collective institutional setting in which care is provided to older adults 24 hours a day, including nurses and medical staff. Question selection took place in three consensus rounds and was informed by the inclusion criteria in Box 1. In the Netherlands, three researchers (LB, WPA, JTvdS) independently selected questions and discussed to reach consensus. In parallel, two researchers from the UK followed the same procedure (SM, KB). Next, the results of these two independent consensus rounds were discussed between the researchers from the two countries in a third consensus round. A preliminary selection of 39 questions was thus completed in preparation for Phase two.

Box 1 Criteria for question pre-selection by research team (Phase 1)

1. The question is not already answered in the Comfort Care Booklet.
2. The question probes for relevant information or more personal or in-depth information.
3. The question is of cultural, care practice or legislative relevance to at least one of the participating countries.
4. The question is not purely medical or medical-technical, and can thus be addressed by a long-term care staff member from the relevant occupation (for example, by a nurse or a social worker).
5. The question cannot be answered or on the contrary, is already covered by the Comfort Care Booklet, but is still pressing to family caregivers (according to literature and researchers’ experience in practice) and bringing it to the table would be beneficial.

Phase two

Phase two (November 2019 – July 2020) involved the targeted consultation of end-users of the QPLs. End-users in each country independently compiled the final selection of questions for the QPL to address local needs. End-users were defined as current or bereaved family caregivers of people with dementia. The eligibility requirements for participating family caregivers were: over 18 years of age; sufficient capacity of the local language to read the Comfort Care Booklet and participate in the discussion; and able to agree to terms and conditions of participation. The consultation protocol was reviewed by local ethics committees in Canada (Hamilton Integrated Research Ethics Board: 2019-5837-GRA) and the Netherlands (Medical Ethical Committee Leiden-Den Haag-Delft: N19.114) and written informed consent was obtained from all participants. In the Czech Republic, Ireland and the UK, the consultation was considered 'Public and Patient Involvement' and therefore the process was exempt from review by ethics committees and did not require formal consent procedures. Int Italy, the consultation could not be performed due to COVID-19.

Convenience recruitment strategies included local invitations and snowballing. In Canada, family caregivers involved at the nursing home that participates in the larger project were invited by the site's social service coordinator to take part. The Czech team recruited participants using the Facebook page of the Center for Palliative Care and by using the snowball method, that is: participants invited others from their social networks to participate. In collaboration with Alzheimer Nederland, the Dutch team invited family caregivers who are part of the Alzheimer panel from a west and middle region over email. The team in Ireland posted flyers in public spaces and on Facebook, and invited potential participants via personal and professional networks. In the UK, researchers recruited family caregivers through their local patient and public involvement connections around Leicester and through the network of a family caregiver that was involved in previous projects in Lancaster.

The consultation process was structured in the four steps (see below) of a nominal group technique.[27, 28] Although normally conducted in a group setting, the first two steps were adapted to allow family caregivers to complete them individually at home. This was done to ensure that participants were sufficiently prepared for the group discussion. The group discussion was virtually conducted in some cases using email, phone calls or videoconferencing (see Supplementary information Text S1). The steps were conducted as follows:

Silent-generation step (individually at home)

Upon reading the Comfort Care Booklet, family caregivers wrote down any questions that came to mind and that they would wish to discuss with a healthcare professional. They also wrote down their reasoning for posing these questions.

Round-robin step (individually at home)

Afterwards, the family caregivers selected approximately 15 questions of the 39 pre-selected questions that they felt may arise when a family member reviews the Comfort Care Booklet. Finally, the family caregivers could add any outstanding questions that were not yet addressed; once again, they wrote down their rationale for posing these questions.

Discussion/item clarification step

A moderator presented all individually generated and selected questions to the family caregivers at the group discussion. The moderator was not involved in the preliminary question selection to minimize bias in the facilitation of the discussion. Family caregivers read all the questions as a group and discussed each item's similarities, differences, and reasons for its inclusion in the final list. Observers took notes on reasons for inclusion and exclusion of questions.

Voting step

After the group discussion, participants voted on which items to include in the QPL by raising hands or highlighting them on a collective list. The 20-25 questions that received the most votes were included in the final list. The research team mapped the questions from the final list onto the relevant sections of the Comfort Care Booklet to ensure that there was at least one question per topic.

Phase three

Phase three (June 2020 – August 2020) involved two researchers (MN, Canadian and LB, Dutch), who compared the final QPLs from each country to highlight similarities and differences across contexts using conventional content analysis.[29] First, LB and MN familiarized themselves with all of the questions. They then inductively derived a set of codes from the questions and labelled each question with a code. Next, codes were sorted into themes when referring to a similar overarching topic. Finally, code names were adjusted after defining the themes, and themes were refined after adjusting the codes. Reasons for including questions that were available in field notes or participants' answer sheets were collected and also underwent a content analysis to explore any cross-national differences in the rationale for including questions in the QPLs.

To ensure validity and rigor,[30] all steps of the analyses were independently performed by two individual coders (LB, MN). Codes, themes and interpretations were discussed at each step to reach consensus.

Results

Phase one

Out of the 206 questions, the UK team selected 33 and the Dutch team 49. Ten questions were selected by both teams, totaling 72 questions. The two teams agreed on the in- and exclusion of 75% (186/248) of the questions. Cross-national differences were apparent during the consensus discussion. For example, questions about life termination and prognosis seemed inappropriate to the UK team because they were difficult to answer adequately, and end of life and euthanasia were not considered topics that people tend to discuss. They were pressing to the Dutch team because people will often ask about these issues and there was a concern of creating taboo when excluding such questions. Table 1 shows the 39 questions that were pre-selected by the research teams upon reaching consensus.

Phase two

Table 2 shows an overview of the nominal group for each country. Forty-three people participated, ranging from 4 to 20 per country. The ages ranged from 25 to 87 years, and the majority (72%) was female. The participants were current or bereaved family caregivers (n = 41) or living with dementia (n = 2). Six participants had professional experience with dementia. The group discussions took 40 to 140 minutes. The characteristics of the moderators and observers are included in the supplementary information (Table S1). The group discussion resulted in a final list of questions in each of the countries. Canada decided upon 15, the Czech Republic had 20, Ireland had 22, and the Netherlands and the UK each had 24 (Table 1 and Supplementary information Table S2).

Phase three

Questions were scanned for overlap and similarity, leading to a list of 76 distinct questions from the total of 105 selected questions. Almost a quarter (24%, 18/76 questions) were selected by more than one country. Question 2 from the pre-selected list of 39 questions was selected by all groups:

> *"Can you tell me more about palliative care in dementia?"*

For 55/105 questions (52%) the reason for inclusion was clearly described in the field notes or participants' answer sheets. The Czech Republic (70%), Canada (67%) and the Netherlands (63%) had more information about the rationale available than the UK (37%) and Ireland (32%). The reasons that were provided for selecting questions were aggregated into the following six themes, in order of frequency: just obtaining information, preparation for end of life, reassurance, preparation for shared decision making, informing staff about the resident's needs and informing staff about the family caregiver's needs (Table 3). The reason provided most often per country was just obtaining information in the UK, preparation for end of life in Ireland, and just obtaining information and preparation for shared decision making in the Czech Republic. In the Netherlands, informing staff about the resident's needs was directly followed by reassurance and just obtaining information. Canada had mentioned reassurance, just obtaining information and preparation for end of life at equal frequency.

The inductive content analysis of the QPLs resulted in 18 codes (Table 4). The most common codes were communication with staff, care protocols, palliative care information, and roles and responsibilities. The codes were aggregated into seven broader themes. These include Request for (services or) information about (1) Symptoms and Disease, (2) Treatment, (3) Death, (4) Care staff, (5) Care setting, (6) Request for the increase or use of patient values and wishes, or (7) Request for information about shared decision-making. Overall, the three most common themes across all countries were Requests for Services or Information pertaining to Care Setting (5), Treatment (2), and Care Staff (4).

Symptoms and Disease: Questions about symptoms and disease focused on the prognosis of the person with dementia in terms of upcoming death or the signs and symptoms related to dementia stages, and disease-related complications such as problems with nutrition or hydration. Questions about how the disease or various methods of treatment would affect the resident's nutrition and hydration were only included in the Czech QPL. The reasons for including questions from this theme mainly related to preparation for end of life and just obtaining information.

Treatment: Questions in this theme consisted of general questions about treatment options or information about palliative care, but also specific questions about pain management options, and treatment options for pneumonia or problems with nutrition or hydration. All five countries submitted questions that were related to this theme. Most Dutch questions on treatment were specific to learning more about palliative care and comfort care. The Czech Republic focused more on treatment of specific conditions with pneumonia and problems with nutrition or hydration. The rationale for including questions from this theme focused on just obtaining information.

Controlling Death Circumstances: The questions in this theme were about controlling the circumstances of death such as active life termination and choosing the place of death. Family members from all the countries, except for Ireland, asked questions that were specific to changes (in setting or treatment) or preferences for circumstances at the end-of-life. There was limited information about the reasons for including questions from this theme, which varied.

Table 1 List of pre-selected questions (Phase 1) and selection per country (Phase 2)

	Question	Selected by
1	Can you tell me more about palliative care in dementia?	CA†, CZ, NL, ROI, UK
2	What changes can I expect, still, such as worsening of symptoms or behavior?	CA†, CZ, ROI, UK*
3	When there is no solution for very unpleasant symptoms such as pain or shortness of breath, will the doctor have other options (such as lower the level of consciousness, put to sleep by means of 'palliative sedation'), so my/our loved one is less aware of them, or can we discuss the level of awareness we prefer?	CA*, CZ, NL, UK*
4	What do you want to know about my loved one, so you can provide appropriate and quality care, now and later on?	CA*, NL, UK
5	What role might I or other family members be expected to play in decision making such as decisions about to transfer to hospital or change medication?	CA, CZ*, ROI*
6	Is it possible to record wishes regarding end-of-life care now, and if so: how, and how often are these being reviewed?	CA*, NL, UK*
7	Can you tell me what "comfort care" means?	CA†, CZ, NL*
8	Can you tell me how much time is left?	CA* CZ, UK
9	Can you warn me, the relative, when death is near?	CA†, CZ*, ROI*
10	Can my loved one be admitted into a hospice?	CA, CZ*, UK
11	I would like to talk about how my family member would want to be cared for. When can I discuss this and with whom?	NL, UK

Table 1 (Continued) List of pre-selected questions (Phase 1) and selection per country (Phase 2)

	Question	Selected by
12	Can you arrange for me to talk with someone from my culture, someone who may understand me better?	NL, UK
13	Can someone help me to communicate with other members of my family about what is happening?	ROI, UK
14	How do we ensure positive experiences?	CZ, ROI
15	What are advantages and disadvantages of resuscitation in this case?	ROI*, UK
16	What spiritual or religious care is available to us?	NL, ROI*
17	Is it feasible for my loved one to die at home?	CZ*, UK
18	What should or can I, the relative, do at the moment of death and afterwards?	NL, ROI†
19	What is the best way for me and my family member to communicate our needs, concerns, and questions to the staff?	CA*
20	How can I make arrangements to meet with the doctor?	UK*
21	Is it possible for me to see someone else if I don't get along with the nurse or doctor? How do I go about this?	UK
22	What are the worst days going to be like, and what are the best days going to be like?	CZ
23	Can you alleviate symptoms and provide some comfort?	NL
24	How do we ensure incontinence does not affect dignity?	NL
25	My loved one has dementia but also other medical conditions. How might this affect their care at the end of life?	UK
26	Do people die from dementia?	ROI
27	What might the final days and hours of my family member's life look like?	ROI†
28	Who can help me sit up with my dying loved one/relative? Are there volunteers we can call in?	CA*
29	What if my loved one/relative dies when I am not there?	NL
30	What possibilities are there not to prolong life in a natural way?	NL
31	Can we ask for life-terminating treatment, if things really go worse?	NL
32	What can help me or my loved one accept that my loved one is no longer able to do things, or know things (cope with/prepare for losses)?	
33	How confidential is the information? For example: are other family members allowed to know about medical problems or behavior problems?	
34	When could hospitalization be necessary and when is it not a good idea?	
35	Can you help me to work out questions I may wish to ask my other doctors/specialists?	
36	Are medications necessary [for the problem] or can we try something else first?	
37	How do I recognize that I am overburdened?	
38	How might your care of my family member change in his/her final days?	
39	What aftercare is available to me, like speaking to the doctor again?	

*The original question was rephrased by the participants †The original questions were combined into one question

Table 2 Nominal group information (Phase 2)

	Month, year of phase 2	Number of participants in phase 2	Duration of group discussion (minutes)	Setting of group discussion	Number of questions in final QPL
CA	Nov 2019 – Jan 2020	4	140	Nursing home	15
CZ**	Feb 2020 – April 2020	5*	120	Online (home)	20
NL	Nov 2019 – Dec 2019	20	(i): 135 (ii): 120	(i): Alzheimer Nederland Offices (ii): LUMC conference room	24
ROI**	March 2020 – July 2020	6*	(i): 40 (ii): 60	(i): Health care facility conference room (ii): Family caregiver's garden	22
UK**	March 2020 – June 2020	8	60 (video call)	Video call, phone, email (home)	24

**Number of participants providing individual input; 2 Czech participants and 1 Irish participant could not join the group discussion. **Group discussions had to be performed in alternative formats to accommodate for COVID-19 restrictions. (i) = group discussion 1, (ii) = group discussion 2*

Table 3 Family caregivers' reasons for selecting questions

Reason	Explanation
Just obtaining information	The answers to these questions are important for people to know and could address misunderstandings; the answer does not necessarily influence preparations or plans
Preparation for end of life	The answers to these questions would allow for family caregivers to obtain knowledge that will inform preparation for end of life
Reassurance	The answers to these questions would allow for family caregivers to feel better about (future) scenarios by soothing concerns and providing confirmation
Preparation for shared decision making	The answers to these questions could set up the family caregiver to prepare for or make decisions in an informed manner
Informing staff about the resident's needs	Asking these questions would allow the family caregiver to inform or prepare staff about the resident's needs and wishes
Informing staff about the family caregiver's needs	Asking these questions would allow the family caregiver to inform or prepare staff about their own needs and wishes for support and involvement

Table 4 Themes and codes derived from the question prompt lists, with example questions (Phase 3)

Themes	Codes	Example questions (country)
1. Request for (services or) information about **symptoms and disease**	*Prognosis: death*	How close is my loved one to the end of their life? (ROI)
	Dementia trajectory	What changes can I expect, still, such as worsening of symptoms or behavior? (CZ, ROI, UK)
	Pneumonia	What is the association between pneumonia and introducing a PEG? (CZ)
	Nutrition/hydration	How can swallowing disorder be alleviated while food intake is conserved? (CZ)
2. Request for (services or) information about **treatment**	*Pain management*	What pain management is available and which one do you advise and why? (NL)
	Treatment options	What are some alternatives to medication that can be provided at this LTC? (CA)
	Palliative care information	Can you tell me more about palliative care in dementia? (CA, CZ, NL, ROI, UK)
	Intervention risks and benefits	What are the advantages and disadvantages of going to hospital? (ROI)
3. Requests for (services or) information about **death**	*Controlling death circumstances*	Can we ask for life-terminating treatment, if things really go worse? (NL)
4. Requests for (services or) information about **care staff**	*Staff competence*	What training/support is given to care staff to enable them to support my loved one? (UK)
	Communication with staff	Is it possible for me to see someone else if I don’t get along with the nurse or doctor? How do I go about this? (UK)
5. Requests for (services or) information about **care setting**	*Long term care setting policy*	Who is appropriate to come visit and how often? (ROI)
	Care protocols	Do staff continue care, such as patient turning/repositioning, at the end of life? (CA)
	Specialist services	Does this long-term care facility have a “palliative team”? (CA)
	Coordination of care	If equipment is needed, where will it come from and how quickly can it be obtained? For example, wheelchair, mattress, syringe driver, etc. (UK)
6. Request for the increase or use of **patient values and wishes**	*Living will*	How can I support my loved one to make a will? (UK)
	Dignity	How are we going to protect dignity during personal care? (ROI)
7. Request for information about **shared decision-making**	*Roles and responsibilities*	Who has the final say? The physician, the nurse or I (the relative or mandatory)? (NL)

Care Setting: Care setting-related questions concerned possibilities in terms of specialist services that could be accessed (spiritual, support, medical specialists). It also included questions about how day-to-day care is being managed, about general policies in the care facility and about the logistical procedures that coordinate care and responsibilities. All countries—except the Czech Republic—asked a large proportion of questions about the services and coordination offered by the nursing home. Canada focused on specialist services, while Ireland was the only group that submitted questions regarding the specific policies and protocol that the home followed, such as security measures and visiting policies. The reasons for including questions within this theme related to reassurance and preparation for end of life.

Care Staff: These questions related to concerns about communication with staff, including whom to contact (and how), and concerns about staff competence in providing palliative care. While all groups expressed the need for clear information on communication with staff, the UK group had the highest proportion of questions related to this. The questions surrounding staff competence were only asked by the UK and Czech Republic groups. Questions from this theme were included for various reasons; reassurance and informing staff about the resident's needs were mentioned most often.

Patient Values and Wishes: The questions in this theme were about specific preference statements such as living wills. This theme also contained questions about values guiding decisions such as the patient's dignity. The questions pertaining to dignity were most often asked in the Czech Republic, Ireland and the Netherlands. The questions were asking for reassurance that the patient's dignity would not be compromised as a result of the treatment options or otherwise. The reasons for including question from this theme varied, informing staff about the resident's needs was mentioned most frequently.

Shared Decision-Making: This theme consisted of questions about the shared decision-making process and the roles and responsibilities of different people involved in this process. Questions related to the status of clinicians' and families' perspectives and living wills. Although none of the countries' QPLs concentrated on this topic, at least one question from each group was about shared decision-making. The rationale for including questions from this theme most often related to informing staff about the family caregiver's needs.

Discussion and Conclusion

Discussion

We have developed question prompt lists about end-of-life care in collaboration with family caregivers of nursing home residents with dementia in Canada, the Czech Republic, the Netherlands, Ireland and the UK. QPLs for this area were not internationally available. Despite cross-country differences, all lists contained a question requesting more information about palliative care in dementia and another question about the roles and responsibilities of the people involved in shared decision making. Overall, the questions focused mainly on treatment.

During the pre-selection phase, the UK and Dutch researchers had different perspectives on 'appropriateness', focusing on sensitivity versus not avoiding taboo subjects respectively. After the consultation phase, the Dutch, Irish and Canadian QPLs focused on questions related to palliative treatment and the care setting. The UK QPL focused on communication with care staff and staff competence. A large part of questions selected in the Czech QPL were about symptoms and disease. The cross-country differences may reflect socio-cultural differences and how well palliative care is established locally. The focus of the Dutch QPL on palliative care may portray that palliative care for people with dementia may be less well-known (and had not been part of Dutch dementia plans).[31] The Dutch participants indeed often provided 'just obtaining information' as reason for selecting questions, but reassurance and informing staff about the resident's needs were also frequently mentioned. The Irish QPL lacked questions about controlling death circumstances. This suggests that this topic felt less appropriate to the Irish family caregivers. However, the Irish family caregivers most often provided 'preparation for end of life' as a reason to include questions. The large number of questions about communication with staff in the UK QPL could indicate that patient engagement in healthcare is well established in the UK.[32] As the reason most often provided for including questions was 'just obtaining information', this could also suggest that family caregivers prefer being informed by staff members in personal conversations rather than searching for information themselves. The Canadian QPL focused on questions about specialist services and care protocols. One interpretation could be that the family caregivers had experienced that care coordination and accessibility to services can be improved.[33] The reasons for selecting questions varied.

The Czech QPL seemed to be the most different from the other countries, indicating concern about the quality of palliative care in dementia and questions regarding nutrition and hydration. The main reasons for question selection among Czech family caregivers included just obtaining information and preparation for shared decision making. Cross-national work indicated that artificial feeding and fluids is a sensitive topic[34] and recommendations on nutrition and hydration from the European Association for Palliative Care received only moderate consensus.[35] The concerns surrounding the quality of palliative care in dementia might relate to the poor resources for palliative care in the Czech Republic, where palliative care is not well known[36] and not yet officially acknowledged as necessary for people with dementia.[37] This could also explain the focus on curative treatment in the questions, rather than palliative options.

It is important to note some limitations of this study. Differences in how and when the group discussions were conducted, due to COVID-19 or local practice, may have influenced the results. Adapting the group discussion from an onsite activity to a thread of emails,[38] phone calls[39] or videoconferencing[40] could have impacted the engagement process. Furthermore, group sizes differed between the countries. The resulting QPLs are based on input from a convenience sample of family caregivers and may not be representative of general cross-country differences. Possibly, (larger) cultural differences within groups rather than between countries have affected the results. The consultation process took place prior to the pandemic in Canada and the Netherlands, but during the pandemic in the Czech Republic, Ireland and the UK. This could have affected the type of questions that were pertinent to family caregivers. Also, we did not have clear information on the rationale for selecting questions for almost half of the questions. Finally, the use and acceptability of the QPLs in real-time practice settings have not yet been evaluated.

However, we can explore the quality of the QPLs. According to the International Patient Decision Aids Standards (IPDAS) Collaboration,[41] decision aids should contain the six key elements of shared decision making: (1) situation diagnosis, (2) choice awareness, (3) option clarification, (4) harms and benefits discussion, (5) patient preferences deliberation and (6) making the decision.[42] Interestingly, the themes and codes derived from the content analysis overlap strongly with these six elements of shared decision making, with two exceptions: questions about care staff and care setting are not included among the six elements. Care staff and care setting form the context of shared decision making, which is thus not well represented by the six elements. The importance of the relational context of shared decision making has been proposed before,[43] but the care setting has not been included in shared decision making definitions yet.[44] Our results mirror the findings of Thompson and colleagues[15] that family caregivers need general information about nursing home life in addition to specific information about treatment and disease, to support them in decision making.

Conclusion

Given divergent preferences for sample questions, engaging end-users such as family caregivers of persons with advanced dementia in the development of materials is vital, especially when these materials aim to increase family caregiver engagement. Cultural differences may influence the information needs of family caregivers and should therefore be considered. The family caregivers in this study expressed a general need to be informed about palliative care in dementia, and about the process of shared decision making. The differences in questions generated between the countries underpin the value of cross-country exercises when developing materials for implementation into practice.

Practice implications

Person-centered care calls for patient and family engagement, that requires facilitation via communication tools such as QPLs. QPLs can be used by families to prepare for advance care planning conversations with healthcare professionals by reflecting on the questions, or provide possible topics to help start conversations about care and reassure families that their information needs will be met. Healthcare professionals need to be aware of the different informational needs of their patients and their families, possibly related to their cultural background. Service planning and training programs for healthcare professionals should have more attention for shared decision making and general information provision about dementia palliative care, as these subjects raised many questions across the countries. This study also highlighted areas where further guidance is needed, such as artificial hydration and nutrition in advanced dementia in the Czech Republic. More research is necessary to explore the use of QPLs in conversations in healthcare and possible cross-country differences in these conversations.

Declaration of interest

None

Informed consent

Informed consent was obtained according to country-specific guidelines. I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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Contributors and authorship

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Appendix

SUPPLEMENTARY INFORMATION - Text S1. Methodological adaptations due to COVID-19 or local practice

The COVID-19 pandemic necessitated adaptations of the protocol at several sites. In the Czech Republic, the group discussion took place online due to social distancing policies. The in-person group discussion for the Irish group was split in two smaller groups -both reduced in time- to limit risk of exposure. In the UK, the discussion steps took place over the phone, via email, and via video call. Participants were asked to select 5 questions (instead of 15) of the 39 pre-selected questions in the Round Robin step. In line with local Public and Patient Involvement practice, persons living with dementia were also invited to partake in the conversation, along with family caregivers. The moderator had separate discussions with each of the participants and shared the contents of each discussion with the next participant. In this way, participants exchanged ideas with each other via the moderator. In the Netherlands, local Public and Patient Involvement practice required two rounds (groups) of end-user involvement. That is, one group was involved in all steps of Phase 2 and selected 20-25 questions. Then, a second group participated in all steps of Phase 2, and was invited to discuss the selected 20-25 question of group 1 before deciding on a final list of questions. Adaptations due to COVID-19 were not necessary in Canada and the Netherlands as phase two was completed prior to the pandemic. The study could not be performed in Italy due to the large impact of COVID-19 which limited access to nursing homes and family caregivers.

SUPPLEMENTARY INFORMATION - Table S1. Characteristics of moderators and observers involved in the group discussions

Country	Role*	Sex	Profession	Background	Credentials	Relation to stakeholders
CA	Moderator 1	F	Research coordinator	European studies and political sciences	MA, BAH	
	Observer 1	F	Research coordinator	Psychology, neuroscience and behavior	BSc	
	Observer 2	F	Research assistant	Health leadership and policy	MSc, BSc	
	Observer 3	F	Research assistant, nurse	Nursing	BN	2 family caregivers had participated in a previous study
CZ	Moderator 1	F	Researcher	Sociology	MA, BA	
	Observer 1	F	Researcher	Psychology	MA, BA	1 family caregiver was family, 1 family caregiver was friend
NL	Moderator 1	M	Researcher, Nurse	Nursing, psychology	PhD, MSc, BN	
	Assistant - moderator 1	F	Scientific research advisor (Alzheimer Nederland)	Biology, neuroscience and cognition	MSc, BSc	Familiarity with family caregivers as they were part of the Alzheimer panel
	Observer 1	F	Researcher	Engineering, epidemiology	PhD, MSc	
	Observer 2	F	Researcher	Cognitive neuroscience	MSc, BSc	
ROI	Moderator / observer 1	F	Researcher, Speech & Language Therapist	Speech & Language therapy	PhD, MSc	
UK	Moderator / observer 1	M	Researcher	History and politics, governance and policy, health and social sciences	PhD, MA, BSc	1 family caregiver had participated in a previous study
	Moderator / observer 2	F	Researcher	Dementia research, healthcare management	PhD, MA, MSc, BA	

**In some cases, one person took on the role of both moderator and observer to reduce the number of people gathering together, in line with COVID-19 policy*

SUPPLEMENTARY INFORMATION - Table S2. Selected questions for the question prompt list per country (Phase 2)

	Additional questions generated by family caregivers
CA	• What are some alternatives to medication that can be provided at this LTC? • What are the accommodations for overnight stay for family of the dying? Are we allowed to stay in the room? • Do staff continue care, such as patient turning/repositioning, at the end of life? • Does this long-term care facility have a “palliative team”? • What additional personnel are available to care for my loved one at the end of life, without additional cost to the family?
CZ	• Is it possible that at the end of life, the person with dementia does not have problems with nutrition? • What is the association between pneumonia and introducing a PEG? • Can antibiotics medication alleviate pneumonia and enhance quality of life? • How can swallowing disorders be alleviated while food intake is conserved? • When is the time to decide that because of dehydration the patient will not be transferred to the hospital? • How to arrange that a person living in a nursing home will not be transferred to the hospital for curative treatment, such as artificial nutrition, respiration support or resuscitation? • Are nursing homes able to provide good care for the person with dementia at the end of his or her life, including good palliative care? • In case we will leave a PEG, but we will end the artificial nutrition, isn’t that a lie to the patient? Can he or she understand it at some moment? • What doctor can indicate hospice care?
NL	• How is care being managed at night; for example, does everybody know the care plan? • What can be done about swallowing problems, and should we do that, is it useful? • What can be done about pneumonia, and should we do that, which alternative would you recommend? • Is the process the same in younger people or are younger people stronger and will they live longer? • How do I know when the final stage of dementia starts? • What pain management is available and which one do you advise and why? • What is a dignified life? • Can the physician make decisions that are not in line with the living will of the patient? • Who has the final say? The physician, the nurse or I (the relative or mandatory)? • Is it possible for us to recognize that the end is near, and how?

Table S2 (Continued) Selected questions for the question prompt list per country (Phase 2)

	Additional questions generated by family caregivers
ROI	• What are the advantages and disadvantages of going to hospital? • How close is my loved one to the end of their life? • What is the role of the doctor and medical team in decision making at end of life? • Is there anything we as a family need to discuss now? • How do I know my relative is not feeling hunger, pain or thirst? • What options are there to manage unpleasant symptoms such as pain, shortness of breath, or eating and drinking difficulties? • How are we going to protect dignity during personal care? • Why does my relative have to be turned often during those final days and does turning him/her often hurt? • Who is appropriate to come visit and how often? • What is my relative's daily routine? • What are the security measures in this nursing home? • What personal belongings can I bring from home and how are they going to be used?
UK	• Can I address questions or concerns about religion/spirituality at the end of life? • What training/support is given to care staff to enable them to support my loved one? • If equipment is needed, where will it come from and how quickly can it be obtained? For example, wheelchair, mattress, syringe driver, etc. • Would you call in specialist services if required? For example, palliative care, dentist, neurologist, etc. • How often do you use temporary staff? Will my relative receive care in the last days and hours from someone who knows them? • How quickly can you get medication for when it's needed? • How responsive are you to personal suggestions about care? For example, how do you balance health and safety with common sense and dignity? • How can I support my loved one to make a will? • Will the care staff be aware of how to relieve pain relating to muscles or joints (contractures) which might happen at the end of life?

7

Changing and shifting tasks from physicians to nursing staff in advance care planning with family caregivers of nursing home residents with dementia: mySupport case study

Submitted as

Bavelaar L, Visser M, Billekens PFA, Geerds PL, Brazil K, Achterberg WP, van der Steen JT, on behalf of the mySupport study group. Changing and shifting tasks from physicians to nursing staff in advance care planning with family caregivers of nursing home residents with dementia: mySupport case study. International Journal of Geriatric Psychiatry.

Abstract

Objectives We aimed to investigate how family caregivers, nursing staff, physicians and other multidisciplinary team members experience their collaboration in advance care planning (ACP) for nursing home residents with dementia during the mySupport study. The mySupport study introduced an intervention that changed and shifted tasks regarding ACP from physicians to nursing staff.

Methods A two-site case study design was used. In the Netherlands, two nursing homes were included as separate cases. Family caregivers and nursing home staff were interviewed between September 2020 and February 2022, before and after the mySupport study intervention. Interview transcripts were analyzed using descriptive thematic analysis using a priori codebooks.

Results The analysis of 46 interviews resulted in five themes regarding collaboration in ACP: Organizational structure for ACP in place unfit for nurse-led family conferences; Ambiguity about family enthusiasm to engage in ACP with nursing staff and about perceived responsibilities in ACP; ACP as relationship-based process fits nurse-led family conferences; Nursing staff being well positioned to use ACP as support for good EOL care practice despite no leading role traditionally; Communication, skills and knowledge required for ACP asks for support from the multidisciplinary team in nurse-led family conferences.

Conclusions The multidisciplinary team and family caregivers consider nursing staff to be a good ACP initiator with family caregivers because of strong relationships, but their ACP competence is questioned. All team members need a clear role in ACP based on their expertise. Accessible documentation systems can support ACP engagement by staff and family caregivers.

Key points

- Multidisciplinary collaboration and family involvement is key to providing person-centered dementia care and advance care planning.
- Our two-site case study shows that the organizational basis for collaboration in advance care planning was minimal and care conversations mainly pertained to current care.
- Nursing staff is well positioned to orient family caregivers and multidisciplinary team members to conversations about future dementia care, but may lack the necessary education and empowerment in the team.
- More awareness and interprofessional education about advance care planning is required to use the full potential of all people that are involved in the care for a person with dementia to enrich advance care planning conversations.

Introduction

Family caregivers are important in the care for people with dementia and they often remain involved throughout the disease trajectory.[1] In the Netherlands, most people with dementia who require intensive support move to a nursing home.[2] Nursing home staff in the Netherlands consist of multidisciplinary teams, including nurses, physicians, psychologists, physiotherapists, occupational therapists, dietitians, speech therapists, social workers, and spiritual counsellors.[3] Daily care is provided by nursing staff, comprising mostly certified nurse assistants (European Qualification Framework (EQF) 3), nurse assistants (EQF 2), nurse aides (EQF 1) and some registered nurses (EQF 4-6).[4] These teams are usually supported by an elderly care physician on staff, who is also part of the multidisciplinary team.[2]

To provide person-centered dementia care, multidisciplinary collaboration is key.[5] Multidisciplinary collaboration is defined as a group of professionals from several disciplines that share responsibility for decision making and carry out a care plan to achieve a common goal.[6] Often, family caregivers represent their relative with dementia in decision making when their relative's capacity is impaired. Multidisciplinary collaboration thus involves family caregivers as well.[7] We therefore use the term 'collaboration' in this paper, referring to professionals *and* family caregivers.

In addition to care planning that guides daily care, advance care planning (ACP) guides potential future care. ACP is a continuous process of defining and discussing goals and preferences for future care and treatment, and documenting and reviewing these wishes.[8] In case of advanced dementia, these conversations are held between family caregivers and care providers.[9]

Previous work suggested that multidisciplinary meetings can support ACP in nursing homes through informed decision making and shared responsibility.[10] Still, multidisciplinary collaboration in ACP is suboptimal due to unclear roles and expertise in ACP.[11] Hierarchical relationships between team members may hinder nursing staff to engage, thinking ACP is the responsibility of leading team members.[12] However, nursing staff develop strong relationships with residents and play an essential role in providing psychosocial support to family caregivers near the end of life.[13] The personal relationships between nursing staff and family caregivers suggest that nursing staff is well positioned to conduct ACP conversations.[14] Formalizing nursing staff's role in ACP may impact on multidisciplinary collaboration in ACP, addressing a perception that ACP is solely a physician's task[13] and thereby empowering other team members to engage.

This study aims to explore perspectives on collaboration in ACP for nursing home residents with dementia, expressed by family caregivers and staff during the mySupport study. The mySupport study is an international EU Joint Programme – Neurodegenerative Disease Research (JPND) project.[15] In Canada, the Czech Republic, Italy, Ireland, the Netherlands and the UK, the mySupport study intervention was adapted to local context, implemented and evaluated. Family caregivers were provided with an educational booklet about dementia and end-of-life (EOL) care, and nursing staff received training to conduct family care conferences to proactively discuss care goals and to support the family caregivers of people with advanced dementia in decision making at the EOL.

In the Netherlands, the intervention entailed a change and shift in ACP tasks from physicians to nursing staff, specifically certified nurse assistants. ACP is a core task of physicians since they are responsible for their residents' medical care.[3] Dutch ACP guidelines emphasize the proactive focus of ACP and to involve nursing staff, though not specifically trained in ACP, as informants signaling residents' needs and indicating their values.[16] However, in practice (trained) physicians perform most of the ACP in the Netherlands. Proactively, they set do-not-resuscitate orders when a resident moves to a nursing home and reactively, more in-depth conversations take place when health problems occur.[17] During the mySupport study, we oriented staff to a more proactive ACP style. The first step was delegated to trained nursing staff, exploring family caregivers' knowledge and support needs regarding dementia and palliative care in family care conferences.

This study examines what the impact is of the mySupport study intervention on the perceived collaboration in ACP. We therefore explore experiences and perceptions of collaboration in ACP for nursing home residents with dementia, expressed by family caregivers and staff during the mySupport study.

Materials and Methods

Design

We used a multiple case study design; two nursing homes were included as separate cases.[18] A mixed methods approach was employed that included interviews. We used the COREQ guideline to report this study.[19]

Setting and participants

Nursing home was defined as a collective institutional setting that provides care to older adults on-site 24/7. Two nursing homes were selected via consecutive sampling from 12 long-term care organizations that participated in the university's academic long-term care network: a general call was circulated and the first two (out of six) responders were included. One organization declined, five did not respond. Including two cases would allow for a detailed inquiry of differential care home features. The two organizations each identified one facility with two or more psychogeriatric care wards for participation.

Participants constituted a convenience sample and included primary family caregivers of nursing home residents with dementia who lack decisional capacity. Residents with dementia were identified by nursing home staff. Other participants included team managers, nursing staff trained in delivering the mySupport study intervention (registered nurses, (certified) nurse assistants) and key individuals from the multidisciplinary team (such as physicians or nurse practitioners, psychologists). Nursing staff was trained in conducting family care conferences by two nurse consultants, the trainers. The period during which nursing staff received the training and conducted family care conferences was ‘the intervention period’.

The nursing home identified eligible nursing staff and key individuals from the multidisciplinary team and the research team informed them in writing and in personal meetings. In turn, nursing staff identified eligible family caregivers who were informed by the research team via a telephone call and information letter. In total, 64 people were identified; 28 participated in all study phases (Figure 1).

Data collection

Semi-structured interviews with participants were held using an interview guide that included questions about participants’ experiences with information sharing, shared decision making, ACP and their expectations about or evaluation of the mySupport study intervention. At time point 1 (T1), before the intervention period, we aimed to interview two to three family caregivers, and all nursing staff that would deliver the intervention and their team managers in an environmental scan. These interviews about current practices informed the intervention implementation strategy. At time point 2 (T2), after the intervention period, all participating family caregivers, nursing staff, their team managers and key individuals from the multidisciplinary team were invited for an interview, and the two trainers. These interviews evaluated the implementation and effect of the mySupport intervention.

The research team did not know the participants before this study. Participants were informed about the aims of the mySupport study. LB (MSc, female PhD student trained in qualitative methods) conducted all interviews, except one interview with the trainers. A research assistant (BSc, female medical student) conducted this interview as some questions pertained to the research team.

In nursing home 1 (NH1), interviews took place September 2020-December 2020 (T1) and March 2021-August 2021 (T2). In nursing home 2 (NH2), interviews were conducted April 2021-August 2021 (T1) and September 2021-February 2022 (T2). During the study period, several COVID-19 waves occurred and restrictions fluctuated. Interviews were held in-person at the nursing home or family caregiver’s home, or via phone or videoconferencing depending on the participant’s preference and COVID-19 regulations. The interviews lasted 10-60 minutes (median: 20). All interviews (n = 46, including 7 group interviews with 2-3 nursing staff) were audio recorded with consent from the interviewees. The interviewer made field notes after the interview to summarize key impressions. Field notes and transcripts were not shared with the participants. Rich information from diverse perspectives was obtained and we did not formally monitor data saturation.

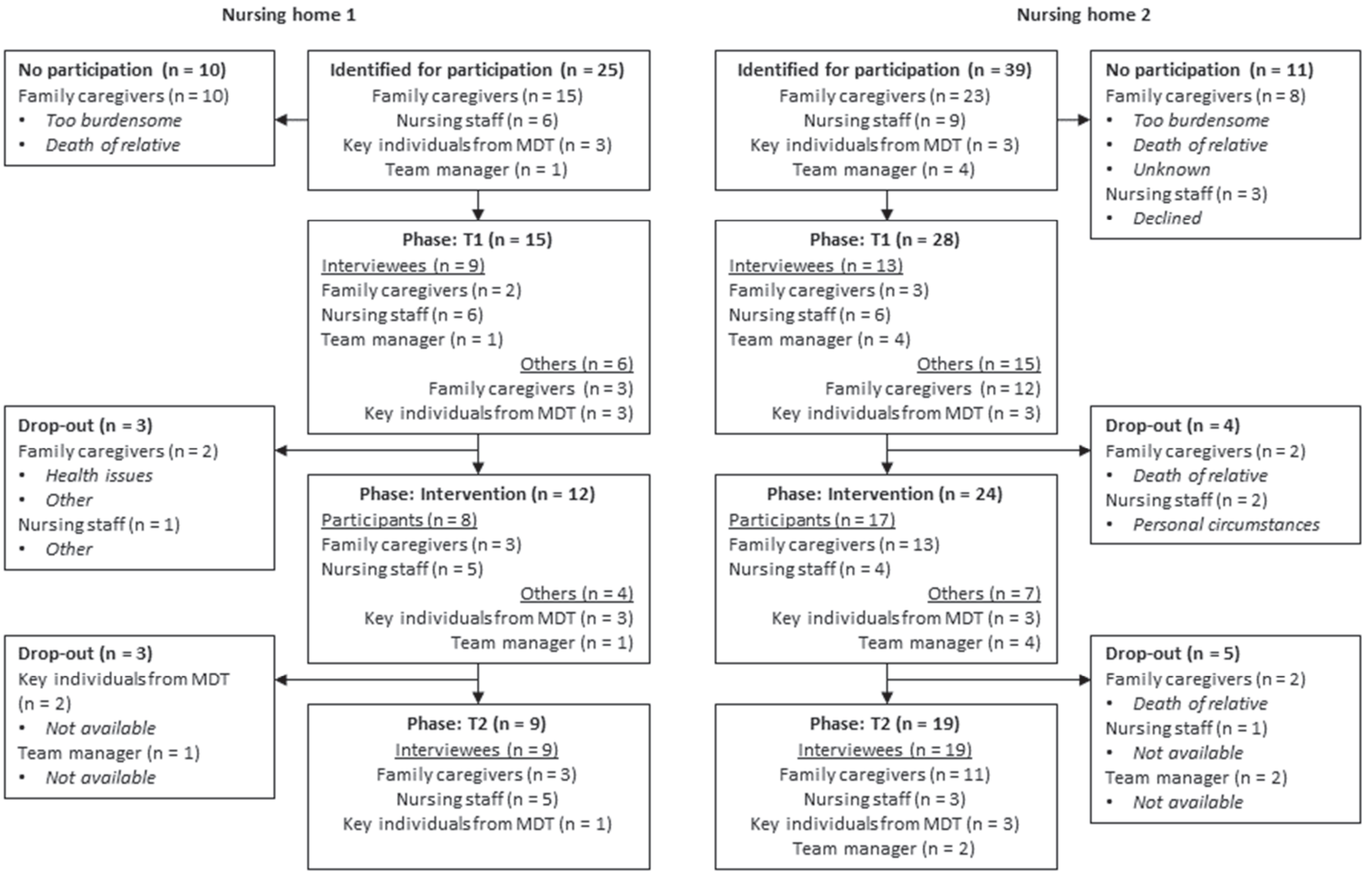

Figure 1 Participants flowchart. MDT = Multidisciplinary Team

Data analyses

Braun and Clarke's six steps of qualitative analysis guided descriptive thematic analysis.[20] We followed a pragmatic constructivist approach[21] with the aim to provide a holistic description of family caregivers' and nursing home staff's experiences with collaboration and nursing staff-led ACP. First, interviews were transcribed verbatim by LB or a research assistant and read thoroughly. Second, initial coding was performed using Word, Excel and Atlas.ti 9 (2020). The international mySupport consortium had developed a priori codebooks per interview type (e.g., family caregiver T1, trainer T2) based on literature and clinical experience. The codebooks evolved iteratively, informed by the first interviews. Using these codebooks, LB and MV or a research assistant deductively coded all interviews from the Netherlands independently, and discussed their individual coding to reach consensus. Data-driven inductive codes were added for themes that were not in the codebooks.[22] Third, LB created 21 groups of related codes. Ten groups related to our research question and were developed with MV into 5 themes derived from the data. Fourth, LB reviewed the themes and generated a thematic overview. The themes and thematic map were discussed with all authors to reach step five: defining and naming the themes. Step six involved selecting exemplary quotations and writing up the report. Participants were not asked to provide feedback on the findings.

Ethics

The Medical Ethics Review Committee Leiden Den Haag Delft (METC LDD, Leiden, the Netherlands) declared that the study protocol did not require a full review (N20.031, 14-05-2020) as exempt from the Medical Research Involving Human Subjects Act (WMO). The participants provided written informed consent before study participation and consent was verbally confirmed before the interview started.

Results

The nursing homes were private but non-profit, located in urbanized areas and each was part of a multi-chain long-term care organization. NH1 provided residency and care to 105 people, including people with dementia. NH2 provided residency and care to 165 people with dementia specifically (Table 1).

Table 1 Description of the nursing homes (NHs) and study participants

Case	NH1		NH2	
NH Characteristics				
Ownership	Chain		Chain	
Profit status	Non-profit		Non-profit	
Location	Urban		Urban	
Size, total number of beds	105		165	
Dementia care beds, n (%)	45 (42.9)		165 (100)	
Timing of interview	**T1**	**T2**	**T1**	**T2**
Participant characteristics				
Family caregivers				
Family caregivers, n	2†	3	3†	11
Relationship to resident (n)	(Step)Child (2)	Child (3)	Child (1) Spouse (2)	Child(-in-law) (7) Spouse (4)
Nursing staff				
Registered nurse (EQF 4-6), n	3	3	0	0
Certified nurse assistant (EQF 3), n	3	2	5	2
Nurse assistant (EQF 2), n	0	0	1	1
Median years of experience (range)	19.5 (2-33)	19 (2-31)	16 (3-27)	15 (3-17)
Key individuals from MDT, n				
Physician / nurse practitioner	0†	1	0†	2
Psychologist	0†	0‡	0†	1
Team manager	1	0‡	4	2

†A subsample of participating family caregivers was interviewed during T1; MDT members were interviewed only at T2 (see Figure 1) ‡Psychologist and team manager were not available (drop-out) at T2 in NH1
NH: Nursing home, EQF: European Qualifications Framework, MDT: Multidisciplinary team

In NH1, 15 interviews were held with family caregivers, nursing staff, a team manager, a physician and the two trainers. In NH2, 31 interviews were held with family caregivers, nursing staff, physicians, a psychologist, team managers and the two trainers. From these interviews, we identified five themes regarding collaboration and nursing staff-led ACP (Table 2): Organizational structure for ACP in place unfit for nurse-led family conferences; Ambiguity about family enthusiasm to engage in ACP with nursing staff and about perceived responsibilities in ACP; ACP as relationship-based process fits nurse-led family conferences; Nursing staff being well positioned to use ACP as support for good EOL care practice despite no leading role traditionally; Communication, skills and knowledge required for ACP asks for support from the multidisciplinary team in nurse-led family conferences. Below, we describe each theme.

1. Organizational structure for ACP in place unfit for nurse-led family conferences

In both nursing homes, care planning started upon the resident's move to the nursing home with a documented intake conversation by a registered nurse or certified nurse assistant and a physician. The nurse (assistant) inventoried daily care needs. The physician inventoried medical care needs, including the presence or wishes for do-not-resuscitate or do-not-hospitalize orders. The trainers noted that these advance orders were not explicitly called 'ACP' and the intake conversation mainly focused on initiating the care relationship rather than future care planning. Family caregivers experienced this type of intake as overwhelming. Both nursing homes did not formally provide information after intake other than general information about the nursing home; family caregivers were advised to seek out information about dementia themselves. Prior to the COVID-19 pandemic, informational family meetings were organized but they had not yet been reinstated since.

Care plan discussions continued structurally during the residents' stay, in multidisciplinary meetings. These semiannual meetings were attended by the physician, registered nurse or certified nurse assistant and any discipline relevant to the resident's care. In NH1, nursing staff contacted family caregivers before the meeting to inventory questions and concerns and afterwards to provide feedback. Family caregivers were not invited to attend. In NH2, family caregivers used to attend the multidisciplinary meetings, but since the COVID-19 pandemic only family caregivers who explicitly requested this participated. Most family caregivers experienced minimal involvement in care planning:

> "(...) but actually everything has already been discussed, while I think, well, I think you can do much more if you first get all the input, and then reach a conclusion together, than when I can only give feedback on what they are thinking." (Family caregiver 23101, NH2, T2)

Thus, collaboration in care planning was limited to professionals; ACP was not clearly established in the nursing homes.

During the intervention period, ACP was initiated by having nursing staff conduct family care conferences. Team managers facilitated this nursing staff-led ACP by providing protected time for it and in NH2 staff was paid for additional time needed. Organizational barriers to nursing staff-led ACP pertained to documentation and follow-up. In NH1, the electronic client file system used by nursing staff did not include a 'future care' section. In NH2, family caregivers therefore missed a report for future reference and multidisciplinary team members were concerned that they could not follow-up as needed.

Table 2 Themes, categories and codes

Themes	Categories	Codes
1. Organizational structure for ACP in place unfit for nurse-led family conferences	Intake conversations	Intake with standard documentation DNR or other treatment policy is discussed with physician at intake Intake is overwhelming for family caregivers Intake provides input for multidisciplinary meeting
	Information provision	Nursing home information is provided before admission Organized family meetings No formal provision of information Admission brochure Website referral
	Multidisciplinary meetings and family involvement	Multidisciplinary meetings according to protocol Nursing staff discuss family's input in multidisciplinary meetings Some family caregivers attend multidisciplinary meetings Family caregivers are only asked to agree with care plans Family involvement has no impact Family caregivers are not involved
	Organizational support for nurse-led ACP	Team managers are aware of nursing staff's activities Team managers can acknowledge nursing staff's time for ACP Planners can create time for ACP
	Organizational barriers for nurse-led ACP	Nursing staff's documentation system is not designed for ACP Need for clear ACP documentation and follow-up Nursing staff did not document ACP conversations Nursing staff should follow up with multidisciplinary team members
2. Ambiguity about family enthusiasm to engage in ACP with nursing staff and about perceived responsibilities in ACP	Experience of family involvement in care	Family caregivers feel appreciated by nursing staff Family caregivers appreciate nursing staff Family caregivers feel valued Family caregiver is partner in care Family involvement varies between nursing staff members
	Staff's attitude towards family involvement in ACP	Considered inappropriate Would scare family caregiver Fear for negative reactions Fear to lose the lead in care Fear for conflicts with colleagues Low valuation of conversations Staff-family collaboration starts too late

Table 2 (Continued) Themes, categories and codes

Themes	Categories	Codes
		Assertive family caregivers
		Family caregivers are considered a nuisance
		Fear that family caregiver does not act in client’s best interest
		Family caregivers experience difficulty in care planning and decision making
		Fear for requests that cannot be met
		Staff-family collaboration is difficult
	Perceived responsibility for ACP	Nursing staff need EOL conversations to take place earlier
		Family caregivers should initiate EOL conversations
		ACP should start at admission or in the community setting
		ACP requires team awareness regarding EOL conversations
		Nursing staff should initiate EOL conversations
		Family caregivers need structured conversations initiated by nursing staff
3. ACP as relationship-based process fits nurse-led family conferences	ACP as a process	ACP requires frequent conversations
	ACP according to readiness and needs	Nursing staff knows family caregiver’s readiness
		Information provision according to family’s individual needs
		Staff-family collaboration requires awareness of family caregiver’s emotions and concerns
		One step at a time
	Nursing staff has good relationship with family caregivers	Nursing staff has many informal conversations with family caregivers about the residents’ health
		Nursing staff have more family contact than other disciplines and are more aware of family’s needs
		Family would ask nurse questions in hallway
		ACP with nursing staff felt spontaneous
		Nursing staff is close to family caregivers
		Family caregivers get to know nursing staff over time
		Family caregivers show a need for contact with nursing staff
		Personal connection
		Nursing staff is experienced supporter for families
	Nurse-led ACP can fit in process of conversations	ACP can fit with care plan discussions
		ACP can be add-on in-depth conversation
		ACP can fit with care pathway discussions
		Nursing staff-led ACP is expected to facilitate EOL conversations with physician or psychologist

Table 2 (Continued) Themes, categories and codes

Themes	Categories	Codes
4. Nursing staff being well positioned to use ACP as support for good EOL care practice despite no leading role traditionally	Nurse needs support from other staff disciplines in EOL care practice	Nursing staff need physician support in EOL care practice Nursing staff need empowerment in relation to reticent physician Nursing staff have difficulty to convince others of palliative care approach Nursing staff would like a stronger role in ACP
	Nurse-led ACP is expected to improve family caregivers' understanding of staff's EOL care practice and overcome resistance	Nursing staff implement EOL care Nursing staff is experienced in dementia care Family caregivers know resident is in good (experienced) hands at EOL ACP with nursing staff is expected to increase family's understanding of EOL care practice ACP with nursing staff creates common ground regarding EOL care Transparency to set expectations fosters understanding Relationship-building fosters understanding Preventing misunderstandings Family feels taken seriously Family is confident in all staff members' EOL care competence
	Nurse-led ACP is expected to improve EOL care practice	Nursing staff need support in EOL care Knowing how to reach each other Working together ACP will limit emotional decision making Nursing staff-led ACP is expected to facilitate person-centered care Increased nursing staff awareness for families' needs fosters understanding Nursing staff knows residents well
5. Communication, skills and knowledge required for ACP asks for support from the multidisciplinary team in nurse-led family conferences	Nurses' conversational skills are limited to daily care	Nursing staff report only daily care Nursing staff update family caregivers Nursing staff talk about EOL only when problems occur
	Variation among nurses regarding communication skills	Nursing staff did not follow up with family caregiver Individual differences in communication skills Nursing staff is too emotionally involved Nursing staff lack cultural sensitivity Lack of educated nursing staff Lack of in-depth conversations Lack of experience Feeling nervous or insecure

Table 2 (Continued) Themes, categories and codes

Themes	Categories	Codes
		ACP requires courage
		Lack of conversations between nursing staff and family caregivers about daily care
		Nursing staff does not conduct intake properly
		Nursing staff need peer support in ACP
	Nurses function as information hub for family caregiver in multidisciplinary team	Clear demarcation of ACP topics for nursing staff versus physician needed
		Physician is responsible and knowledgeable of medical care and treatment policy
		Physicians fear that nursing staff discuss medical topics
		Nursing staff lack knowledge
		Family caregivers feel questions are answered properly
		Nursing staff refer to relevant expertise of other staff members
		Family caregivers want to involve relatives in ACP
		Psychologist can support nursing staff and family caregivers
		Spiritual counsellor can support EOL conversations and during ethical dilemmas
		Social worker can provide practical support
		Nursing staff require aftercare

2. Ambiguity about family enthusiasm to engage in ACP with nursing staff and about perceived responsibilities in ACP

In daily care, communication fostered mutual appreciation between family caregivers and nursing staff, but family involvement varied. Some family caregivers were involved in care decisions and felt they were partners in care, while others experienced this only with some staff members and not with others.

Also in conversations about future care (ACP), nursing staff's and family caregivers' attitude towards family involvement varied. Some nursing staff considered discussing EOL care, which was how 'future care' was often interpreted in the nursing home, with family caregivers early during the resident's stay as inappropriate, they anticipated negative reactions. In NH2, nursing staff feared to lose the lead in care practice and possible conflicts with colleagues, including the physician, when involving family caregivers in ACP. In NH1, nursing staff was apprehensive about family caregivers who do not act in the resident's best interests and in both nursing homes, nursing staff was concerned that family would request unfeasible care. Related, some family caregivers were perceived as assertive, family involvement was then experienced as inviting complaints and family caregivers felt collaboration with nursing staff was difficult. Not all family caregivers wished to be involved in ACP however, as some thought it was too hard.

Perceptions regarding who is responsible for initiating ACP differed between family caregivers and nursing staff, also after nursing staff had conducted family care conferences. In NH1, nursing staff thought family caregivers should initiate ACP conversations and responsibility for ACP should be shared with the wider team. In NH2, nursing staff felt EOL conversations should take place earlier than in current NH practice, and ACP should therefore start in the community setting. In contrast, family caregivers considered nursing staff responsible for initiating EOL or future care conversations. They also expressed needs for more frequent, structured conversations, initiated by nursing staff.

3. ACP as relationship-based process fits nurse-led family conferences

The trainers observed that ACP requires frequent conversations and that before the intervention in NH2, this process was complicated by physician turnover. According to them, having nursing staff conduct family care conferences may support continuity in the ACP process. Nursing staff expected that they were able to align ACP with family caregiver's readiness and needs, a registered nurse stated that she provided information "step by step". Nursing staff knew family caregivers well and could pinpoint who was open to having EOL conversations, which was considered the basis for ACP conversations. Further, they were aware of family caregivers' concerns and this may be important for good collaboration. In general, nursing staff stated that information provision and family involvement should align with the individual context.

Nursing staff was aware of individual readiness and needs because they had good relationships with family caregivers through frequent contact, this was endorsed by the psychologist and physicians. Family caregivers and nursing staff stated that they regularly had informal conversations about the residents' health when family caregivers visit. Some family caregivers experienced the nursing staff-led ACP conversation during the study as spontaneous and nursing staff noticed that the questions asked during these conversations were usually posed to them "in the hallway" near the EOL. One certified nurse assistant stated that family caregivers often show an increased need for contact with nursing staff in the palliative phase and nursing staff and family caregivers expressed that they were close, they got to know each other well over time. In NH2, the family care conferences contributed to this feeling of personal connection and the psychologist and physicians considered this a benefit of nursing staff-led ACP. Nursing staff, family caregivers and psychologists in both nursing homes considered nursing staff as very experienced in supporting families near the EOL.

Multidisciplinary team members and nursing staff thought that ACP conversations would fit naturally with other conversations between nursing staff and family caregivers. ACP conversations could be additional, in-depth conversations. Contrary to the view on responsibilities in ACP, the multidisciplinary team considered nursing staff-led ACP conversations to fit well within current practice when considering ACP as a continuous process and expected that they would ease follow-up conversations and guidance by physicians or psychologists.

4. Nursing staff being well positioned to use ACP as support for good EOL care practice despite no leading role traditionally

In NH2, the mySupport study met nursing staffs' wishes of having a stronger role in ACP and empowerment in relation to physicians who were sometimes reticent to start palliative care. Physicians were responsible for medical care, so certified nurse assistants needed physicians' support to start palliative care while they were sometimes unable to convince others that a palliative approach was indicated:

> "(...) I also notice doctors don't always listen to certified nurse assistants. Because we see this [decline] and we point it out and then they say: 'well, we won't start yet [with palliative care], because she still eats half a sandwich or she still drinks three sips of water.' So then I think: but the person isn't comfortable or is anxious or - And I may not be a doctor, but I am an expert at observation." (Certified nurse assistant 207, NH2, T1)

In both nursing homes, nursing staff-led ACP was thought to improve family caregivers' understanding of staff's EOL care practice and overcome resistance. As nursing staff deliver EOL care and was experienced in dementia care, family caregivers perceived ACP conversations with nursing staff as reassuring, they were confident their relative was in good hands:

> "Yes, well, it's, you have absolutely no idea what it [EOL care] will be like in a home, what will happen there. But you notice that, that, there is so much dedication and loving care for the people who live there, that basically everything is possible." (Family caregiver 13102, NH1, T2)

Family caregivers felt understood during the conversations and reassured that nursing staff knew their relative well. They were confident that nursing staff and the multidisciplinary team were competent in providing EOL care. Nursing staff thought discussing EOL care with family caregivers would increase family's understanding of care options and limitations, and prevent misunderstandings in the moment. Family caregivers and nursing staff considered transparency essential for understanding. Family caregivers felt the ACP conversation created common ground regarding their relative's EOL care. Building a relationship this way was deemed important.

Further, nursing staff expected that ACP would improve their EOL care practice. Some nursing staff wanted more family involvement near the EOL, for example having family caregivers sitting in during the dying phase. These conversations created a sense of collaboration. Nursing staff was also more aware of families' needs due to the ACP conversations, helping them understand families' perspectives better. Nursing staff and physicians thought nursing staff-led ACP conversations with family caregivers could improve person-centered EOL care as wishes were discussed earlier. Proactive discussions would limit emotional decisions.

5. Communication, skills and knowledge required for ACP asks for support from the multidisciplinary team in nurse-led family conferences

Nursing staff talked about EOL care only when health problems occurred. During the mySupport study, nursing staff proactively discussed future care with family caregivers and some family caregivers felt these conversations lacked depth. Family caregivers, the trainers and physicians in both nursing homes thought daily care conversations occurred too infrequently and this “overdue maintenance” shifted the focus during the ACP conversations from future to daily care. In part, this was caused by visiting restrictions during the COVID-19 pandemic.

In addition, there were individual differences in nursing staff’s communication skills according to family caregivers and the multidisciplinary team. In NH1, nursing staff included certified nurse assistants and registered nurses. One registered nurse expected that certified nurse assistants may struggle to find the courage to discuss EOL care proactively. NH2 was in short of registered nurses and the mySupport study was implemented by certified nurse assistants and a nurse assistant. The team managers expressed that (certified) nurse assistants have limited experience with family communication, some did not conduct intake conversations properly or lacked cultural sensitivity. The multidisciplinary team feared that (certified) nurse assistants were too emotionally involved to conduct ACP conversations adequately. The (certified) nurse assistants felt nervous to conduct the family care conferences, arranging peer support during the conversations.

Some family caregivers thought that nursing staff lacked knowledge during the ACP conversation, because they were not provided with new information. However, on a day-to-day basis, most family caregivers felt that their questions were answered properly. Nursing staff functioned as an information hub in the multidisciplinary team, relaying questions from family caregivers to the relevant expert when questions were beyond their scope of practice. All staff members considered the multidisciplinary team essential for ACP: a spiritual counsellor could support talking about death and ethical dilemmas, a psychologist could provide guidance for family, a social worker could help with practical matters. Family caregivers further mentioned that they wanted their relatives involved in ACP. Furthermore, the psychologist and spiritual counsellor were deemed important to also support nursing staff in managing people with dementia, family caregivers and their own personal emotions around the EOL. For family caregivers’ questions about medical care and treatments, nursing staff referred to physicians. Nursing staff also considered these topics, such as morphine use and effects, to be beyond their expertise:

> “Family often also has medical questions and well, I just don’t have the answers. And on some things you also have to, like of course we're not allowed to make a diagnosis, and obviously we are not able to, you know? Or, when people want more in-depth, also about medication and stuff. Yes, yes, those are things-. Well, you know, I just have my own level.” (Certified nurse assistant 203, NH2, T1)

The trainers and the physicians thought it was crucial to clearly demarcate topics that nursing staff can discuss during ACP conversations versus the physician. In NH2, physicians feared that nursing staff may “sit in the physician’s chair” and discuss medical topics.

Discussion

During the mySupport study, nursing staff’s role in ACP was strengthened as nursing staff conducted conversations about future care with family caregivers of nursing home residents with dementia. This entailed a change and shift in ACP tasks in the Netherlands, where ACP is commonly perceived as the physician’s responsibility. We found that collaboration in ACP was experienced as challenging, although family caregivers and nursing home staff thought that a stronger role for nursing staff in ACP would support good EOL care. Family involvement was limited by organizational barriers and nursing staff’s apprehension. In addition, information transfer between nursing staff and other team members regarding future care emerged as a barrier to collaboration. Multidisciplinary team members such as physicians and psychologists were considered important for ACP, which required clearly defined tasks for all people involved in ACP to complement each other without overstepping boundaries of personal expertise.

Some of the experiences with ACP collaboration mirror the barriers and facilitators to interprofessional collaboration in long-term care and geriatric rehabilitation in general: team performance, sharing information and organizational conditions.[23] Themes from our findings that were more specific to collaboration in ACP are 1), the apprehension to initiate conversations about future care and EOL; and 2), the need for clearly demarcated roles in ACP to define and acknowledge each person’s expertise and responsibility.

1), ACP can be emotionally demanding for nursing staff especially, since they often bond with residents and may therefore avoid thinking and talking about their final phases of life.[24] In our study, some nursing staff indeed preferred that others conduct EOL care conversations. Team managers and psychologists acknowledged that nursing staff need emotional support and thought that personal emotions may hinder a stronger position for nursing staff in ACP. However, some nursing staff longed for a stronger role in ACP because they were emotionally involved in their residents’ care and believed that EOL care should be improved, similar to previous findings.[12, 13] Recommendations for nursing homes regarding palliative dementia care stress the importance of attending to nursing staff’s grief and moral distress during the COVID-19 pandemic,[25] but this may apply to ACP in general.

2), the need to clearly demarcate individuals’ roles in ACP was expressed by all nursing home disciplines and has been described before. Dixon and Knapp concluded that a team-based approach to ACP was most effective, where physicians conducted shorter and medically oriented conversations, complemented by nurses conducting lengthier conversations.[26] Similar to our findings, they found that physicians were not always confident that others were skilled in ACP, or were reluctant to share ownership of ACP. Therefore, nursing home teams need to be clear about the expertise of the persons involved in ACP and the scope of the conversation to ensure collaboration in ACP functions optimally. Clearly demarcating individuals' roles may support shared responsibility and accountability for ACP, acknowledging each individual's contribution.

Dixon and Knapp further found that in nursing homes specifically, ACP was not always adequately documented: best interest decision making and ACP based on pre-expressed wishes were not clearly distinguished.[26] While decision-making was not apparent in our data, we did observe that ACP conversations often tended towards discussing present care. Interestingly, in these cases, family caregivers expressed that conversations about daily care had not happened, while team managers and nursing staff indicated to call family caregivers regularly about care issues. Family caregivers perhaps did not perceive these phone calls as conversations, contrary to scheduled, seated meetings with nursing staff in a private setting during the study. Previous studies have reported that sitting down during communication in a care setting impacts patients' satisfaction and their perception of the conversation duration.[27, 28] Perhaps clearly marking conversations as formal meetings and explicitly orienting attendees to future scenarios can overcome these issues. Our findings suggest that adequate ACP practice requires to "set the stage": stating the scope of the conversation (for example, medical issues when physicians conduct the conversations versus exploring knowledge and support needs when nursing staff conduct them) and the orientation (present or future care).

Further research could explore the roles of nursing staff and physicians in ACP in the Netherlands, and across countries. While physicians appreciate and rely on nursing staff for adequate palliative dementia care, differences in communication styles and hierarchical relationships can impede their collaboration.[29] This was apparent in nursing home 2, where nursing staff did not always felt heard by physicians. Further research may investigate if demarcation of roles and responsibilities in ACP is related to underlying goals of ACP and how this may facilitate collaboration in ACP. Fleuren and colleagues distinguished five underlying goals of ACP: respecting individual patient autonomy, improving quality of care, strengthening relationships, preparing for end-of-life, reducing overtreatment.[30] While family caregivers, nursing staff and other multidisciplinary team members agreed that 'strengthening relationships' between family and professionals is core when nursing staff conduct ACP conversations with family caregivers, perspectives on the other goals varied. While some nursing staff wanted to prepare family caregivers for the EOL, others considered this a psychologist's task. Additionally, some nursing staff wanted to reduce overtreatment, while physicians preferred ownership over this theme.

Implications

Our findings highlight that nursing staff need training and support to engage in ACP with family caregivers, as their involvement enriches ACP processes because of their extensive knowledge of their residents and strong relationships with family caregivers.[14] Training may help nursing staff to overcome knowledge and skills-related barriers to ACP (e.g.[31]) and can complement related competences and tasks within their current curriculum such as planning daily care, while support from psychologists or spiritual counsellors may help them overcome personal or emotional barriers.[24, 25] To overcome barriers related to information sharing and transfer, ownership of ACP documentation should not rest with one care provider but for example with the person with dementia and family caregiver, while access should be shared with all people involved in this person's care. This means that (1) the general public should be informed about ACP to have ACP start in the community, and (2) national guidelines should facilitate ACP across (care) settings and support access to the documentation by all involved. Involving family caregivers in early stages of (advance) care planning and decision making, rather than informing them of established plans and decisions, should be a priority for nursing home staff. Family caregivers can then act as true partners in care. However, attention should be paid to different styles and preferences in shared decision making, respecting family caregivers' wishes of delegating decisions to experienced care professionals.[32]

Strengths and limitations

This study combined insights from all perspectives involved in collaboration in ACP for nursing home residents with dementia: family caregivers, nursing staff, physicians and psychologists. The analyses were informed by literature and data in an international parallel design, contributing to rigor. The convenience sample may limit diversity in perspectives as, for example, participating family caregivers may have been more involved in their relative's care than the general population. However, as the sample was heterogenous we do not expect that the convenience sampling has impacted our findings. The option to attend the interviews online or by phone provided more people the opportunity to participate, such as full-time working family caregivers, given the flexibility in location and timing of the interview. The timing of the study during the COVID-19 pandemic may have affected participants' responses because visiting restrictions and other pressures affected communication and family involvement in nursing homes.[33] Moreover, ACP practice changed, with physicians discussing ICU admissions for a potential COVID-19 infection as additional topic for example.[34] The presented findings may therefore not generalize to ACP outside the context of a pandemic. However, most participants were able to reflect on pre-COVID times.

Conclusions

ACP and end-of-life care conversations require and support durable partnerships between family caregivers and nursing staff. Organizational support from managers and explicitly defined collaboration with other multidisciplinary team members is required for ACP to function optimally. Nursing home staff and family caregivers all have responsibility for initiating and following up on ACP conversations within their expertise, with nursing staff functioning as an information hub in the multidisciplinary team for family caregivers.

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Data availability statement

The interview data that support the findings of this study are not available due to privacy restrictions.

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Conflict of interest

The authors declare no conflict of interest.

Author contributions

All authors meet criteria for authorship as stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals. All authors gave final approval of the submitted manuscript and agreed to be accountable for all aspects of the work. All authors' specific contributions are listed below.

- Study concept and design: KB, WPA, JTvdS
- Acquisition of data: LB
- Analysis and interpretation of data: LB, MV, PFAB, PLG, KB, WPA, JTvdS
- Preparation of manuscript: LB, MV, PFAB, PLG, KB, WPA, JTvdS

Ethics approval statement

The Medical Ethics Review Committee Leiden Den Haag Delft (METC LDD, Leiden, the Netherlands) declared that the study protocol did not require a full review (N20.031, 14-05-2020) as exempt from the Medical Research Involving Human Subjects Act (WMO). The participants provided written informed consent before study participation and consent was verbally confirmed before the interview started.

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8

General discussion

Main results

The primary aim of this thesis was to examine why a palliative care approach in dementia that is proactive and family inclusive is still sub optimally implemented, and how advance care planning (ACP) with family caregivers of people with dementia can be improved. Palliative dementia care was therefore investigated in **Chapters 2 to 4** (part 1) of this thesis, and **Chapters 5 to 7** (part 2) provided an overview of an intervention to improve practice.

Chapter 2 asked: *"What are the barriers to providing high-quality palliative care in dementia according to elderly care physicians in the Netherlands, and what solutions do they propose to address these barriers?"* Elderly care physicians responded to this question in a survey. Reported barriers were (1) beliefs and lack of knowledge, awareness or understanding, (2) obstacles in recognizing and addressing care needs, (3) poor interdisciplinary team approach and consensus, (4) limited use or availability of resources, and (5) poor family support and involvement. Educating healthcare staff, families and the public about palliative care in dementia, and improving communication and information transfer were proposed as solutions. This pertained to more highly skilled nursing staff and timely and frequent communication with the family, including ACP.

Chapter 3 asked: *"What interventions support family caregivers of people with dementia at the end of life in nursing homes?"* A mixed-methods systematic review was conducted that resulted in three recommendations that advise: (1) ongoing dialogue between healthcare professionals and family caregivers and adequate time and space for sensitive discussions, (2) face-to-face discussions supported by written information whose timing of supply may vary according to family caregivers' preferences, the organizational policies and cultural context, and (3) structured psychoeducational programs and regular family meetings about dementia care at the end of life tailored to family caregivers' specific needs.

Chapter 4 asked: *"How do advance care plans of nursing home residents with dementia change following pneumonia, what factors are associated with changes and what factors are associated with the person perceived by the elderly care physician as most influential in decision making?"* A secondary data analysis of the PneuMonitor study was presented in this chapter. Following pneumonia, treatment goals were revised, mostly refined, in 16% of the residents, and in 20% advance treatment decisions changed. More severe illness and a terminal prognosis both increased the odds of changes in treatment decisions. Family caregivers were often most influential in decision making according to elderly care physicians, and this was particularly the case for nursing home residents with severe dementia.

Summarizing, part 1 found that a palliative care approach in dementia that is proactive and family inclusive is still sub optimally implemented because: healthcare staff and family caregivers need education about dementia and palliative care, their communication should be ongoing, timely, sensitive and well-informed, including ACP, but advance care plans show limited dynamics that indicate an ongoing process. These factors were addressed in part 2.

Chapter 5 explored the question: *"What should be the content of educational and advance care planning materials for different contexts, considering (i) transnational legal and socio-cultural differences and developments over time, plus (ii) evidence and expert consensus-based recommendations regarding palliative dementia care?"* Informational family booklets about dementia and palliative care from six jurisdictions were compared. Additionally, recommendations for optimal palliative dementia care were mapped onto the contents of the booklets. This qualitative descriptive study concluded that the booklets covered all recommended domains. Transnational differences and developments over time were apparent in the variability across the booklets in the extent to which medical details and information about certain treatments were provided, pre-expressed wishes were emphasized in decision making and treatment dilemmas were addressed. The booklets also varied in the tone of the messages and the discussion of prognosis, and in describing the involvement of various care professionals and family caregivers in care.

Chapter 6 asked: *"What questions should be included in question prompt lists for family caregivers, and what is the importance of the local context?"* Current and bereaved family caregivers were consulted in nominal groups to develop question prompt lists in five countries. All lists contained the question: 'Can you tell me more about palliative care in dementia?' The question prompt lists differed in the specific questions included and the reasons for selecting these questions, indicating cultural differences and variation in how well palliative care is established.

Chapter 7 explored the question: *"How do family caregivers of nursing home residents with dementia and nursing home staff experience collaboration in advance care planning during the mySupport study?"* Interviews that were conducted during a two-site case study were thematically analyzed and the results were presented in this chapter. Experiences with collaboration in ACP related to: Organizational structure for ACP in place unfit for nurse-led family conferences; Ambiguity about family enthusiasm to engage in ACP with nursing staff and about perceived responsibilities in ACP; ACP as relationship-based process fits nurse-led family conferences; Nursing staff being well positioned to use ACP as support for good end-of-life care practice despite no leading role traditionally; Communication, skills and knowledge required for ACP asks for support from the multidisciplinary team in nurse-led family conferences.

Summarizing, in part 2 an intervention was explored to support ACP with family caregivers of people with dementia. This intervention entailed: providing information about dementia and palliative care that is tailored to the local context, complementing the information with a question prompt list that is context-specific and user-centered, and orienting nursing home staff members and family caregivers to collaborate in ACP.

Methodological considerations

When reflecting on the findings in this thesis, there are several methodological strengths and limitations to consider. They relate to the timing of the studies, the perspectives involved and the frameworks and definitions that were used.

Timing

In **Chapter 5** it was found that developments over time are important to take into account for evidence-based practice. While **Chapters 2 and 4** are based on data from a decade ago, the findings in **Chapter 2** were corroborated by physicians currently. However, ACP and communication between healthcare professionals and family caregivers has changed dramatically during the COVID-19 pandemic that was ongoing during the studies in **Chapters 6 and 7**. General practitioners and the general public became more aware of ACP due to media attention and COVID-guidelines that stimulated advance decisions about ICU-admission.[1] A similar development occurred in nursing homes.[2] However, palliative care that focused on quality of life and involved family caregivers was extremely complicated due to visiting restrictions,[3] and ACP was frequently conducted in formats that were alternatives to face-to-face conversations.[1, 2] Barriers to a proactive and family inclusive approach to palliative care have thus persisted over time, but the exact nature of these barriers has changed during the pandemic.

Perspectives and involvement

A strength of the studies in part 2 of this thesis is the international perspective. Not only was the mySupport study informed by international literature, the mySupport study team consisted of an international group of people with various backgrounds: social, epidemiological and psychological researchers, nurses, physicians, family caregivers and more. The mySupport study could thus benefit from various insights, while the local teams ensured the study was fit for context by tailoring the insights to national practice. The diversity in perspectives is also reflected in the participants across the studies in this thesis, several key stakeholders in palliative dementia care are represented: physicians (**Chapters 2 and 4**), family caregivers (**Chapters 3 and 6**), nursing staff and other key stakeholders (**Chapters 5 and 7**). Another strength was the Strategic Guiding Council that was established, a Patient and Public Involvement panel that consisted of members of the public who have experience in caring for a family member with dementia.[4] Having a panel of family caregivers informing and guiding the study ensured the mySupport study was user centered. However, on an individual level, some family caregivers perceived they had limited impact and this may be related to late or limited opportunities for involvement.[5] Another limitation was the lack of involvement of people with dementia themselves in informing the study or as study participants. Although the focus on advanced dementia complicated their participation and their family caregivers were involved as representatives, people with dementia themselves may have a different perspective on good care than their family caregivers.[6]

Frameworks and definitions

Part 2 of this thesis described the mySupport study. A logic model was developed for the mySupport study, which is recommended for planning and evaluating interventions[7] and this can be considered a methodological strength. Furthermore, **Chapter 2** presented the results of a survey that was based on the EAPC white paper framework for optimal palliative care in dementia[8] and **Chapter 5** used this framework to evaluate the contents of informational family booklets about dementia and comfort care. Using these evidence and expert consensus-based recommendations as part of our methods strengthens the interpretability of our findings. A limitation is related to the variation in the definition or interpretation of 'palliative care' across the studies in this thesis. The systematic review in **Chapter 3** focused on the end of life, and this perspective was also expressed by the participants in the study presented in **Chapter 7**. The mySupport study in **Chapter 7** focused on advanced dementia and there is international consensus about the applicability of palliative care in this phase.[8] The studies in the other chapters share a broader definition of palliative care. This variation is likely related to the "extended palliative phase" in dementia that corresponds to difficulties in assessing the different, and in particular advanced, disease stages of dementia.[9] Also regarding ACP, there is a variation in interpretations across this thesis. For example, although ACP was defined as an ongoing process anticipating future changes in health in **Chapter 4**, the results of the secondary data analysis presented in this chapter showed that changes in advance treatment decisions were related to the proximity to the end of life. This suggests that updates in the ACP process are still largely oriented towards end of life, similar to some interpretations of palliative care. On the contrary, in **Chapter 7**, ACP was not always clearly differentiated from daily care planning by family caregivers and nursing staff. Their interpretation of ACP reflected a more holistic, flexible and relational approach, as recommended by van Rickstal and colleagues.[10] Another factor that may be related to the variation in ACP definitions is the difference in terminology and legislation across countries, as touched upon in **Chapter 5**. For example, in Canada a clear distinction is made between 'goals of care' and 'ACP',[11] while this may not be so clearly differentiated in the Netherlands.[12] This variation in definitions or interpretations of palliative care and ACP is of note, since it was identified as a barrier to optimal palliative dementia care (**Chapter 2**).

Design and scope

Some final methodological considerations concern the design and scope of the studies. **Chapter 3** presented a mixed-methods systematic review that was thoroughly performed using methods that support evidence-based decisions. However, the scope of the review did not include policy and organizational level interventions, while findings from the survey presented in **Chapter 2** and from the interview analyses presented in **Chapter 7** showed that organizational support is important for optimal palliative dementia care and ACP. Another limitation relates to the secondary data analysis reported in **Chapter 4**. The PneuMonitor study was not originally designed to answer the question of the secondary analysis, but included informative data about reported changes in advance care plans. The study design was not optimal to look into specific nature of changes, however, or whether ACP discussions had taken place but did not result in documented changes which may often be the case.[13]

Reflections on the findings

Paradox in ACP to support palliative care in nursing homes: process or documentation?

This thesis builds on existing trends that promote process-oriented ACP, involving family caregivers, rather than documentation-driven ACP.[14] In **Chapter 4** it was found that changes in advance care plans were small, they occurred infrequently and pertained to details. The documented outcomes of ACP may therefore not be as informative or helpful as the process of continued communication and education itself. To facilitate a proactive and family inclusive palliative approach to dementia care, it may be more important to use ACP as a means to foster relationships between family caregivers and healthcare professionals,[15] or to prepare family caregivers for the end of life and in-the-moment decision making.[16] This is also apparent from **Chapters 3, 6 and 7**, where family caregivers and nursing staff express how ACP is a tool for expectation management. This process-oriented ACP counters critiques to more static, document-driven ACP. For example, the notion that true preparation is impossible due to unexpected situations that require acute actions[17] and therefore ACP cannot serve as a tool to ensure goal-concordant care.[18] ACP is more apt to prepare family caregivers for the end of life and prevent complicated grief in this context.[18] Not by meeting documented wishes, but by educating family caregivers about dementia and palliative care and by discussing the end of life, which improves their perception of the quality of end-of-life care and promotes a palliative approach to dementia care.[19, 20]

Fundamental to this process of ongoing communication and guidance is that family caregivers experience continuity of care.[21] Yet high rates of staff turnover in nursing homes limit relational continuity. Both healthcare professionals (**Chapter 2**) and family caregivers (**Chapter 7**) experienced staff turnover to hinder a proactive, palliative approach to dementia care. Also process-oriented ACP therefore requires adequate documentation. Records support informational continuity and facilitate transfer of the ACP process between individuals upon transitions between care settings or between attending care professionals. Rather than serving as an outcome of ACP, documentation (review) can serve as a means to keep the conversation process ongoing and on track.[22] Somewhat paradoxical, adequate documentation is thus necessary for a continuous process that can be transferred between individuals.

Awareness, empowerment and collaboration

ACP and shared decision making are strongly interrelated. Various models of shared decision making exist, but they all involve components that relate to (1) informing or educating patients and family about care or treatment options, (2) active participation of the patient and family in (informing or guiding) decision making, and (3) coming to a shared decision together with patients, family and healthcare professionals.[23-25] For a family-inclusive ACP process, these components can be translated into: (1) family caregivers being aware of palliative care options and ACP, (2) family caregivers being empowered to participate in ACP, and (3) family caregivers and healthcare professionals collaborating in the ACP process. However, throughout this thesis a lack of awareness, a lack of empowerment and difficulties in collaboration were observed.

A lack of awareness about ACP and palliative care was apparent from **Chapters 2, 4 and 6**. In **Chapter 2**, elderly care physicians stated that both family caregivers and nursing staff lacked knowledge about ACP and palliative care. A lack of awareness of ACP among people with dementia themselves emerged in **Chapter 4**, where a near absence of living wills was reported. ACP was also not extensively covered in the educational family booklets described in **Chapter 5**. The question prompt lists that were developed with family caregivers all included a question for more information about palliative care, as reported in **Chapter 6**, indicating that family caregivers were not well aware of palliative dementia care. Especially in countries were palliative care was not well established the question prompt lists included many questions about curative and palliative care. It is therefore absolutely necessary to raise awareness of palliative care and ACP to improve family involvement and a proactive style in palliative dementia care. As suggested in **Chapter 7**, nursing staff are well positioned to educate family caregivers. A study in a busy primary care setting found that nursing staff was able to educate patients, patients were satisfied and it improved nurses' job satisfaction.[26]

However, there is a lack of empowerment to engage in ACP for nursing staff. Elderly care physicians sometimes questioned nursing staffs' capabilities in palliative care or ACP (**Chapters 2 and 7**). Nursing staff questioned their own role and competence in ACP too (**Chapter 7**) and a survey by Bolt and colleagues found that a majority of nursing staff indicated a need for support in aspects of end-of-life communication.[27] Also family caregivers expressed a lack of empowerment to engage in ACP (**Chapters 3, 6 and 7**). To improve palliative care practice, empowering nursing staff and family caregivers through education and acknowledgement by the wider healthcare team is therefore key. Care must be taken that empowerment is not interpreted as responsibility: nursing staff and family caregivers should feel they are partners in care, but they should not feel solely responsible for care or treatment decisions.[28]

This relates to the final component of a family-inclusive ACP process: collaboration. Responsibility for a proactive and family inclusive palliative care approach must be shared with all stakeholders involved. Difficulties in collaboration emerged as barriers to good palliative practice throughout this thesis and were explicitly stated in **Chapters 2 and 7**. These collaboration difficulties related to both interprofessional collaboration and collaboration between family caregivers and healthcare professionals. These two types of collaboration are intertwined in palliative dementia care and previous research has found that the role family caregivers fulfill in healthcare teams is influenced by the interprofessional collaboration.[29] It is therefore vital to improve the collaboration between all stakeholders. In this way, responsibility for care and decisions can truly be shared. This does not downplay the empowerment or autonomy of the individuals involved, but rather respects the relational approach to ACP and relational autonomy in decision making. Even when people with advanced dementia are unable to express their wants and needs, it is through their lasting relationships with family caregivers and close nursing staff they can still make decisions that reflect their preferences.[30, 31] Collaboration between family caregivers, nursing staff and other healthcare professionals is thus essential.

Need for normalization of ACP and palliative care in society

Awareness and consequently empowerment starts in society. Elderly care physicians, nursing staff, but also family caregivers expressed in **Chapters 2 and 7** that conversations about future care needs and wishes often occur too late. **Chapters 3 and 7** showed that palliative care is still often interpreted as end-of-life care or solely discussed at the end of life, which hinders proactive discussions about palliative care in earlier disease stages. To facilitate palliative care conversations already in the community setting, the public image of palliative care should be broadened. For example, healthcare professionals in the community can discuss palliative care using the ‘bow tie model’ of palliative ‘enhanced’ care.[32] Palliative care is then more clearly presented as a care approach that enhances the care pathway and does not solely apply to dying patients. This presentation of palliative care is perhaps more mindful of cultural diverse perspectives (**Chapters 5 and 6**) and may speak to some cultures that do not address the dying phase explicitly.[33]

At the same time, a proactive approach to care requires that the threshold to talk about death and dying is lowered and family caregivers feel invited to discuss care with healthcare professionals. **Chapter 3** showed that family caregivers need more support and guidance to prepare for the end of life, while nursing staff expressed apprehension to discuss the dying phase with them in **Chapter 7**. Recently (2021-2022), two campaigns have been launched to raise awareness among the Dutch public about shared decision making (‘Begin een goed gesprek' [Start a good conversation])[34] and talking about death ('De dood. Praat erover, niet eroverheen' [Death. Talk about it, not around it]).[35] Campaigns like these may help in normalizing ACP and talking about death and dying. In addition, a stronger focus on death and palliative care in popular culture such as in TV series may help integrate conversations about the end of life in everyday life.[36] Invitations for an ACP conversation by a trusted GP at specific timepoints may help integrate ACP as a normal part of community care.[37]

Recommendations for practice

In order to improve a palliative care approach in dementia that is proactive and family inclusive, we need to invest in ACP and palliative care education within and across care settings. Below, several recommendations are presented.

Nursing homes

Whom to involve in ACP?

Facilitating a stronger position for nursing staff in ACP responds to recommendations regarding appropriate care for frail older adults[12] and may improve palliative care by overcoming barriers related to interprofessional collaboration that emerged in **Chapters 2 and 7**. Furthermore, improving nursing staff engagement with ACP can facilitate the involvement of family caregivers, given nursing staff's role in end-of-life care and family support as suggested in **Chapters 3 and 7** and described by others.[38, 39] Gilissen and colleagues suggested that involving nursing staff may strengthen a team-based approach to ACP but requires appropriate training,[40] and findings from the mySupport study (**Chapter 7**) and other training programmes[41] indicate that training nursing staff is feasible and effective. For a sustainable impact, ACP training should be incorporated in nationally established educational frameworks that are supported by healthcare professional associations such as Verenso and V&VN, rather than constituting isolated workshops. Clearly stipulating the tasks and roles within ACP for each function in health and social care could support durable team-based ACP practice. A team-based approach to ACP also entails that all partners are acknowledged, including nursing staff. Recognizing nursing staff's contribution not only in practice but also in pay may help to address the high staff turnover in nursing homes as well.[42] This is an important point, since trust-based (and hence durable) relationships between family caregivers and healthcare professionals are fundamental to ACP[43] and collaboration in care.[44] To support collaboration between family caregivers and healthcare professionals in the care for people with dementia and to practically implement ACP with family and nursing staff involvement, it is recommended that ACP is more explicitly integrated in multidisciplinary team meetings (similar to the ACP+ program of Gilissen and colleagues).[45] In this way, all care partners are involved. Another suggestion for improvement is to structure the multidisciplinary meeting according to the relationship to the person with dementia, who is core in person-centered care, to expand each partner's impact compared with the current strong role of physicians in ACP. If possible, the person with dementia should be able to share their views first,[46] followed by an explicit invitation to family caregivers,[47] whereafter first the primary responsible nursing staff can input their thoughts and only then any other discipline and the physician. Using a guided format that clearly sets expectations at the start of the meeting can limit assertive family caregivers in taking over (a fear expressed by nursing staff in **Chapter 7**), while recognizing their input and creating time and space to share perspectives. Finally, to facilitate durable implementation of these 'ACP enhanced' multidisciplinary meetings, it is recommended to involve client councils or other forms of public and patient involvement. Patient and public involvement in implementing healthcare policy and regulation is currently limited, but may have good potential.[48, 49] Amplifying the service user's voice in politics and organizations might be the final push we need for real change in policy and practice.

When to conduct ACP?

Currently, conversations about the terminal nature of dementia, palliative care options and the importance to share values and preferences in care take place too late. This is a missed chance, since the stay of people with dementia in nursing homes provides several windows of opportunity to engage in ACP. For example, during the intake conversation ensuing ACP conversations can already be introduced. It is common nursing home practice in the Netherlands to conduct a multidisciplinary meeting six weeks after the intake conversation. This would provide an excellent opportunity to hand out the educational booklet (**Chapter 5**) to family caregivers to inform them about the dementia trajectory and palliative care options. In this way, they are informed about the fundamentals to be discussed during following multidisciplinary meetings. An additional meeting might be necessary to cover any questions and concerns that family caregivers may have after reading the information. The multidisciplinary meetings that take place every six months can refer to the information in the booklet. A section of these meetings should be clearly marked as ACP to orient all attendees to think about future care. This may address the sometimes unclear distinction between daily care planning and ACP. Furthermore, nursing staff can signal any ACP needs and wants that are (implicitly) expressed by the person with dementia (or family caregivers) during moments of caring. In this way, ACP is stimulated from intake throughout the resident's stay. This approach of implementing ACP within the existing practice and nursing home structure is recommended for countries beyond the Netherlands with varying practices too. Of course, healthcare professionals need to be sensitive to individuals' readiness to engage in ACP as this may vary widely[50] and opportunities should be provided, not forced.

ACP and palliative care education across (care) settings

While a strong ACP practice in nursing homes is important, initiating ACP in the community setting is even more desirable. In that way, people with dementia have more opportunity to participate. It is paramount to develop clear guidelines about the documentation of ACP conversations in electronic client files, such as the uniform ACP forms that were developed in response to the COVID-19 pandemic to support the transfer of advance care plans across care settings.[51] Den Herder and colleagues stated that relationships between care professionals are more important for integrated palliative care across settings than formalized systems for information transfer.[52] In settings with high staff turnover, the importance of formalized systems cannot be underestimated. This does not mean that advance care plans should only cover 'formal' information, such as advance treatment decisions regarding medical interventions. Especially when ACP is initiated early, before any major health issues, or by non-medically trained nursing staff or other care professionals, conversations may be broader. In these cases, ACP may resemble life story work. In life story work, people with dementia record elements of their past or present lives, sometimes together with family caregivers and healthcare professionals.[53, 54] These records can convey the person's preferences, values and wishes and therefore have the potential to improve person-centered care and support care planning.[53, 54] Documentation of life story work may thus constitute an informative element of ACP.

Furthermore, to empower people with dementia and family caregivers in ACP across (care) settings, they need to be informed about dementia and palliative care options in the community setting. Accessible information leaflets should be easily available (**Chapter 3**) and the information shared should be in line with current practice and speak to a diverse audience (**Chapters 5 and 6**). To achieve this, a recommendation is that written information is handed out, monitored by and arranged via an umbrella organization that spans care settings. An arrangement similar to the 'Begin een goed gesprek'-campaign,[34] which was endorsed by various care organizations including medical specialist care, general practice, paramedical care and district nursing, may prove effective.

Recommendations for further research

Further research may help to make the implications for practice more actionable and specific. It would be interesting to interview bereaved family caregivers after they have had ACP conversations such as provided during the mySupport study to investigate their perception of the end of life of their loved one and the value of the ACP conversations. Previous research about comfort care suggested that increasing awareness may be more impactful than implementing specific guidelines.[55] If this is related to ACP with family caregivers, potentially, general communication training and awareness may prove as effective as ACP specific training. Exploring the use and effect of question prompt lists in ACP conversations can provide more information about the impact on the empowerment of family caregivers, adding to research about the perceived acceptability of question prompt lists.[56] Distributing the educational family booklet in the community setting and assessing its effect would provide valuable information about strategies to empower family caregivers and people with dementia. Further, needs of specific groups such as people with a non-Western cultural background or low healthcare literacy would be important to study in relation to information provision, shared decision making and ACP. This can help tailor ACP and palliative care practice to individual needs.

Furthermore, a team-based approach to ACP requires further exploration to assess requirements about specific team roles and tasks in the process. It may be interesting to develop an online training or educational environment accessible to both healthcare professionals and family caregivers to support a team-based approach to ACP, similar to COVID-specific online ACP resources.[57, 58] A next step would be to study whether freely available resources like these stimulate ACP engagement by all partners involved.

Most importantly, further research should be informed and potentially guided by people with dementia themselves.[59] If we want to stimulate empowerment of people with dementia in ACP and acknowledge their vital input in coordinating their care, it is only natural to facilitate the same in research about dementia care.

Final remarks

The primary aim of this thesis was to examine why a palliative care approach in dementia that is proactive and family inclusive is still sub optimally implemented, and how advance care planning with family caregivers of people with dementia can be improved. This thesis showed that education of family caregivers and nursing staff to facilitate conversations between these two trusted parties played an important role. However, it is important to be mindful of all other people involved in the care for people with dementia, including themselves, and the diversity between them. A proactive approach that is family inclusive starts with us, right now. We should be asking ourselves: what if?

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9

Summary

As more people are getting older, the prevalence of dementia is also rising. Dementia is a clinical syndrome characterized, among other things, by cognitive decline. People with dementia therefore become less able to make decisions and become dependent on their family caregivers, also in decision making regarding their care. Because dementia is life-limiting, a palliative approach to care is indicated. As described in **Chapter 1**, core elements of palliative care are a proactive style and the involvement of family caregivers. However, evidence indicates that a palliative care approach in dementia is still sub optimally implemented. Part 1 of this thesis examines why this is, and part 2 examines how advance care planning (ACP) with family caregivers of people with dementia can be improved. Part 2 therefore describes the development and implementation of the mySupport study intervention. The mySupport study is a transnational effectiveness-implementation evaluation study in six countries (United Kingdom, Ireland, the Netherlands, Canada, the Czech Republic and Italy). The study aimed to adapt the Family Carer Decision Support (FCDS) intervention to local context, implement the intervention and assess its impact.

Part I. Palliative dementia care: avenues for improvement

Part I examines why a palliative care approach in dementia that is proactive and family inclusive is sub optimally implemented. It first focuses on palliative care for people with dementia generally, and then homes in on their family caregivers and finally on the proactive element of palliative care.

Chapter 2 presents the results of a survey study among 207 elderly care physicians in the Netherlands. They were asked about barriers and solutions for high-quality palliative dementia care. Their free text answers were analyzed using qualitive content analysis and this resulted in the identification of five main barriers to palliative care in dementia: I) beliefs and lack of knowledge, awareness or understanding, II) obstacles in recognizing and addressing care needs, III) poor interdisciplinary team approach and consensus, IV) limited use or availability of resources, and V) poor family support and involvement. The proposed solutions to overcome these barriers involved community practice, nursing home practice, secondary care and society as a whole. Five clusters of solutions were distinguished: i) improving the interaction between healthcare professionals and patients or family caregivers, ii) improving the quality of care provided, iii) improving the continuity of care provided, iv) improving policy to support palliative care provision, and v) improving public perception. It was concluded that having specialized elderly care physicians on staff in nursing homes is not sufficient for a palliative approach to dementia care. A broader support is required, facilitated by elderly care physicians who can educate and support nursing home staff and other healthcare professionals, people with dementia and their family caregivers to orient towards palliative care. ACP, education and communication training were suggested as means to achieve increased understanding of palliative care and dementia, and improved communication. These two objectives were deemed essential to improve the quality and continuity of care.

The finding that palliative dementia care requires support from and for family caregivers is further explored in **Chapter 3.** In this chapter a mixed-methods systematic review is presented. This literature review focused on interventions to support family caregivers of people with advanced dementia at the end of their relative's life in nursing homes. The aim of the review was to gather and synthesize information about these interventions, and finally, to provide recommendations for practice. Eight quantitative and three qualitative studies were included in the review and they represented seven unique interventions. The review resulted in three integrated findings in the form of recommendations or conclusions: (1) End-of-life dialogue should be ongoing and provide adequate time and space for sensitive discussion. Thus, a family caregivers-healthcare professionals partnership can be established and shared decision-making is promoted. This can also improve the quality of family caregivers' remaining time with their relative while offering emotional support. (2) End-of-life discussions should be face-to-face and guided by supporting written information. The provision of this information may vary in timing and way according to family caregivers' preferences and the context. (3) Family caregivers should be offered tailored psychoeducational programs and regular family meetings about dementia care at the end of life according to their specific information and emotional needs. This can promote understanding about their relative's health conditions, acceptance of the upcoming loss, and empowerment in facing challenging end-of-life-related issues. The small number of included studies and the moderate quality of the evidence show that the evidence base of interventions for family caregivers can be improved.

In **Chapter 4**, shared decision making with family caregivers was examined further in the context of ACP. This chapter describes a secondary analysis of randomized controlled trial data from the PneuMonitor trial. Elderly care physicians identified 429 nursing home residents with dementia who developed pneumonia, across 32 nursing homes in the Netherlands. The study aimed to explore any advance care plan changes following pneumonia and the influence of the people involved in shared decision making. Logistic generalized linear mixed models were used to explore which factors were associated with changes in the prioritized treatment goal or in advance decisions. Only 4% of the residents had a living will, but 95% had a prioritized treatment goal and for 95% advance treatment decisions were made. For 16%, prioritized treatment goals changed following pneumonia. For 20%, advance treatment decisions changed following pneumonia and this was associated with more severe illness (OR 1.3, 95% CI 1.1-1.7, $p = .010$) and a terminal prognosis (OR 2.2, 95% CI 1.1-4.3, $p = .019$). The person most influential in decision making according to elderly care physicians was a family member of the person with dementia in most cases (47%). This was related to residents having severe dementia. The study concluded that advance care plans show limited changes in response to pneumonia. Moreover, ACP with persons with dementia themselves is rare; this requires more attention. People with dementia should at least appoint a power of attorney.

Part II. The mySupport study intervention

From part 1 it can be concluded that a palliative care approach in dementia can be supported by educating healthcare staff and family caregivers about dementia and palliative care, and by stimulating ongoing communication between all stakeholders, such as in advance care planning. This approach is the focus of part 2. In part 2, the mySupport study intervention is explored, that aims to support ACP with family caregivers of people with dementia. The intervention entails information provision about dementia and palliative care that is tailored to the local context, complementing the information with a question prompt list that is context-specific and user-centered, and orienting nursing home staff members and family caregivers to collaborate in ACP.

Chapter 5 addresses education for family caregivers about dementia and palliative care. The qualitative descriptive study presented in this chapter revolves around a family booklet on comfort care in dementia. This booklet was adopted in Canada, the Czech Republic, Italy, the Netherlands, the UK and Ireland after local adaptations. The study aim was to provide guidance about the contents of informational booklets for family caregivers about dementia and palliative care, considering (i) transnational legal and socio-cultural differences and developments over time, plus (ii) evidence and expert consensus-based recommendations regarding palliative dementia care. The family booklets from six jurisdictions were compared to determine key topics and content analysis was performed to categorize differences. Additionally, a quality appraisal was conducted by mapping the contents of the booklets against the recommendations presented in an international framework (European Association for Palliative Care, EAPC). The key topics corresponded to the key topics from the original Canadian booklet. The textual revisions of the booklets were summarized in six categories: (1) Typology of treatments and symptoms at the end of life, (2) Patient and family rights and wishes, (3) Typology of decisions at the end of life, (4) Indirect or explicit messages, (5) More or less positive about prognosis, and (6) Relationship between healthcare professionals and family caregivers. The booklets covered all domains proposed by the EAPC, but not all specific recommendations. The recommendations related to setting care goals and advance care planning were not covered by the booklets. The variation across the booklets underlined the importance of considering the legal and socio-cultural environment and developments over time. Stakeholder involvement, in particular end-users, was deemed fundamental.

The importance of end-user involvement and the impact of the legal and socio-cultural environment in family education was also considered in **Chapter 6**. This chapter describes the development of a question prompt list for family caregivers of nursing home residents with dementia, to complement the family booklet about comfort care. Current and bereaved family caregivers in five countries were consulted in nominal groups to ensure family-driven and culturally tailored question prompt lists for dementia. The final question prompt lists and family caregivers’ reasons for selecting questions were compared between the five countries using inductive content analysis. Reasons for selecting questions were: just obtaining information, preparation for end of life, reassurance, preparation for shared decision making, informing staff about the resident’s needs and informing staff about the family caregiver’s needs. The questions that were selected pertained to symptoms and disease, treatment, death, care staff, care setting, patient values and wishes and shared decision making. Cross-country differences were apparent in the question prompt lists and reasons for selecting questions. However, there was also a general need to be informed about palliative care in dementia, and about the process of shared decision making among the family caregivers. Recommendations for further research included studies into the use of the question prompt lists by family caregivers in conversations with healthcare professionals.

The two-site case study that is presented in **Chapter 7** implemented the family booklet and question prompt list, in addition to a training for nursing staff in conducting family care conferences. The intervention thus entailed a shift in ACP tasks from physicians to nursing staff. In two nursing homes, interviews were conducted with family caregivers and nursing home staff, including physicians, a psychologist, certified nurse assistants and registered nurses, before and after the intervention was implemented. The study examined the impact of the intervention on the perceived collaboration in ACP, expressed by family caregivers and nursing home staff during the mySupport study. In total, 46 interviews were held. A descriptive thematic analysis of the interviews resulted in five themes regarding collaboration and nursing staff-led family conferences: (1) The organizational structure for ACP in place is unfit for nursing staff-led family conferences, (2) There is ambiguity about family enthusiasm to engage in ACP with nursing staff and about perceived responsibilities in ACP, (3) ACP as relationship-based process fits nursing staff-led family conferences, (4) Nursing staff is well positioned to use ACP as support for good end-of-life care practice despite not having a leading role traditionally, and, (5) Communication, skills and knowledge required for ACP asks for support from the multidisciplinary team in nursing staff-led family conferences. It was concluded that nursing staff is well positioned to orient family caregivers and multidisciplinary team members to conversations about future dementia care, but they may lack the necessary education and empowerment in the team. More awareness and interprofessional education about ACP, plus accessible documentation systems may support ACP engagement by staff and family caregivers.

Based on the studies described in this thesis, **Chapter 8** concludes that educating nursing home staff and family caregivers of people with dementia to facilitate conversations between them plays an important role in improving ACP for people with dementia. This can support a palliative care approach in dementia. It is important to consider a process-oriented ACP approach to strengthen relationships and prepare family caregivers for the end of life and decision making. Moreover, adequate documentation is essential to ensure continuity of the process even upon transitions between care settings or attending care professionals. In addition, a team-based and family inclusive ACP approach requires awareness among, empowerment of, and collaboration between all parties involved in the care for the person with dementia. Fundamental in this respect is the normalization of ACP and palliative care in society to stimulate earlier initiation of conversations about future care needs and wishes. National campaigns and popular culture may play a role in achieving this. Recommendations for practice include educating nursing staff to strengthen their position in ACP practice, as this may also facilitate family involvement in ACP. Integrating ACP more explicitly in multidisciplinary team meetings may strengthen collaboration between family caregivers and healthcare professionals in ACP. The educational booklet for family caregivers can serve as preparational material for family caregivers and help inform them about matters yet to come. This information should be accessible already in the community setting, to stimulate ACP initiation before nursing home admission. For future research, more attention for people with a non-Western cultural background or low healthcare literary is required. Most importantly, further research should be informed by people with dementia themselves.

Nederlandse samenvatting

Nu meer mensen steeds ouder worden, neemt de prevalentie van dementie toe. Dementie is een klinisch syndroom dat onder andere wordt gekenmerkt door cognitieve achteruitgang. Mensen met dementie kunnen daardoor steeds minder goed beslissingen nemen en worden hierin afhankelijk van hun mantelzorgers, ook bij de besluitvorming over hun zorg. Omdat dementie een progressieve en ongeneeslijke ziekte is, is een palliatieve zorgaanpak van toepassing. Zoals beschreven in **Hoofdstuk 1**, behoren een proactieve stijl en de betrokkenheid van mantelzorgers tot de kernelementen van palliatieve zorg. Er zijn echter aanwijzingen dat palliatieve zorg niet optimaal is geïmplementeerd voor mensen met dementie. In deel 1 van dit proefschrift wordt onderzocht waarom dit zo is, en in deel 2 wordt onderzocht hoe proactieve zorgplanning (“advance care planning”, ACP) met mantelzorgers van mensen met dementie kan worden verbeterd. Deel 2 beschrijft daartoe de ontwikkeling en implementatie van de mySupport interventie. De mySupport-studie is een internationaal effectiviteits- en implementatie evaluatieonderzoek in zes landen (Verenigd Koninkrijk, Ierland, Nederland, Canada, Tsjechië en Italië). Het doel van de mySupport-studie was om de Family Carer Decision Support (FCDS)-interventie aan te passen aan de lokale context, de interventie te implementeren en de impact ervan te evalueren.

Deel I. Palliatieve dementiezorg: mogelijkheden voor verbetering

In deel I wordt onderzocht waarom een palliatieve zorgaanpak bij dementie niet optimaal is geïmplementeerd. Het richt zich eerst op palliatieve zorg voor mensen met dementie in het algemeen, en zoomt vervolgens in op hun mantelzorgers en ten slotte op het proactieve element van palliatieve zorg.

Hoofdstuk 2 presenteert de resultaten van een vragenlijstonderzoek onder 207 specialisten ouderengeneeskunde in Nederland. Zij werden gevraagd naar belemmeringen en oplossingen voor hoogwaardige palliatieve dementiezorg. Hun antwoorden op open vragen werden geanalyseerd met kwalitatieve inhoudsanalyse. Hieruit volgden vijf belangrijke belemmeringen voor palliatieve zorg bij dementie: I) overtuigingen en gebrek aan kennis, bewustzijn of begrip, II) obstakels bij het herkennen en aanpakken van zorgbehoeften, III) matige interdisciplinaire teambenadering en gebrek aan consensus, IV) beperkt gebruik of beperkte beschikbaarheid van middelen, en V) matige steun en betrokkenheid van mantelzorgers. De voorgestelde oplossingen voor deze belemmeringen hadden betrekking op de eerstelijnszorg, de verpleeghuispraktijk, de tweedelijnszorg en de samenleving als geheel. Vijf clusters van oplossingen konden worden onderscheiden: i) verbetering van de interactie tussen zorgprofessionals en patiënten of mantelzorgers, ii) verbetering van de kwaliteit van de zorgverlening, iii) verbetering van de continuïteit van zorgverlening, iv) verbetering van beleid ter ondersteuning van palliatieve zorgverlening, en v) werken aan opvattingen van het algemene publiek. Er werd geconcludeerd dat de aanwezigheid van specialisten ouderengeneeskunde in verpleeghuizen niet voldoende is voor een palliatieve zorgaanpak bij dementie. Daar is bredere steun voor nodig, gefaciliteerd door specialisten ouderengeneeskunde. Zij kunnen voorlichting geven aan verpleeghuismedewerkers en andere zorgprofessionals, mensen met dementie en hun mantelzorgers en hen ondersteunen om zich te oriënteren op palliatieve zorg. ACP, voorlichting en communicatietraining werden voorgesteld als middelen om het begrip te vergroten van palliatieve zorg en dementie, en om communicatie te verbeteren. Deze twee doelstellingen werden essentieel geacht om de kwaliteit en continuïteit van zorg te verbeteren.

De bevinding dat palliatieve dementiezorg ondersteuning van en voor mantelzorgers nodig heeft, wordt verder onderzocht in **Hoofdstuk 3**. In dit hoofdstuk wordt een mixed-methods systematische review gepresenteerd. Dit literatuuronderzoek ging over interventies om mantelzorgers van mensen met gevorderde dementie te ondersteunen rond het levenseinde van hun familielid in het verpleeghuis. Het doel van de review was om informatie over de interventies te verzamelen en te integreren, om tenslotte aanbevelingen te kunnen doen voor de praktijk. Acht kwantitatieve en drie kwalitatieve studies werden opgenomen in de review, die zeven interventies vertegenwoordigden. De review resulteerde in drie geïntegreerde bevindingen in de vorm van aanbevelingen of conclusies: (1) Levenseindegesprekken zouden geregeld moeten plaatsvinden, op momenten en locaties die geschikt zijn voor een gesprek over een gevoelig onderwerp. Zo kan er een band ontstaan tussen mantelzorgers en zorgprofessionals en wordt gezamenlijke besluitvorming gestimuleerd. Ook kan dit de kwaliteit verbeteren van de tijd die mantelzorgers nog hebben met hun familielid, waarbij emotionele steun wordt geboden. (2) Levenseindegesprekken zouden gevoerd moeten worden tijdens een fysieke ontmoeting, ondersteund door schriftelijke informatie die als leidraad dient. De timing en manier waarop deze informatie verstrekt wordt, hangt af van de voorkeuren van mantelzorgers of de context. (3) Mantelzorgers zouden psycho-educatie programma's op maat moeten krijgen en regelmatige familiebijeenkomsten over dementiezorg rond het levenseinde, passend bij hun specifieke informatiebehoeften en emotionele behoeften. Op die manier krijgen zij een beter begrip van de gezondheid van hun familielid, verbetert hun acceptatie van het aanstaande verlies en worden zij gesterkt in het omgaan met moeilijke zaken rond het levenseinde. Het kleine aantal geïncludeerde studies en de matige kwaliteit van het bewijs laten zien dat de wetenschappelijke onderbouwing van interventies voor mantelzorgers verbeterd kan worden.

In **Hoofdstuk 4** is de gezamenlijke besluitvorming met mantelzorgers nader onderzocht in de context van ACP. Dit hoofdstuk beschrijft een secundaire data-analyse van een gerandomiseerd onderzoek met een controlegroep, de PneuMonitor-studie. Specialisten ouderengeneeskunde identificeerden 429 verpleeghuisbewoners met dementie die longontsteking ontwikkelden, verspreid over 32 verpleeghuizen in Nederland. Het onderzoek was gericht op het in kaart brengen van eventuele wijzigingen in het zorgplan na een longontsteking en de invloed van de mensen die betrokken zijn bij gezamenlijke besluitvorming. Om te onderzoeken welke factoren geassocieerd waren met veranderingen in het belangrijkste zorgdoel of behandelafspraken, werd gebruik gemaakt van logistische regressie met gegeneraliseerde lineaire gemengde modellen. Slechts 4% van de bewoners had een wilsverklaring, maar voor 95% was een zorgdoel vastgesteld en voor 95% waren behandelafspraken gemaakt. Voor 16% veranderde het belangrijkste zorgdoel na een longontsteking. Voor 20% veranderden de behandelafspraken na een longontsteking en dit was geassocieerd met ernstigere ziekte (OR 1,3, 95% BI 1,1-1,7, p = 0,010) en een terminale prognose (OR 2,2, 95% BI 1,1-4,3, p = 0,019). Volgens de specialisten ouderengeneeskunde had in de meeste gevallen een familielid van de persoon met dementie (47%) de meeste invloed op de besluitvorming. Dit had te maken met de gevorderde dementie van de bewoners. De studie concludeerde dat een longontsteking leidde tot beperkte veranderingen in proactieve zorgplannen. Bovendien vindt ACP met personen met dementie zelf zelden plaats; dit heeft meer aandacht nodig. Mensen met dementie zouden tenminste moeten vastleggen wie als vertegenwoordiger mag optreden in toekomstige besluitvorming.

Deel II. De mySupport studie-interventie

Uit deel 1 kan worden geconcludeerd dat een palliatieve zorgaanpak bij dementie kan worden ondersteund door zorgmedewerkers en mantelzorgers voor te lichten over dementie en palliatieve zorg, en door doorlopende communicatie tussen alle belanghebbenden te stimuleren, zoals bij proactieve zorgplanning. Deze aanpak staat centraal in deel 2. In deel 2 wordt de mySupport interventie onderzocht, die het doel heeft om ACP met mantelzorgers van mensen met dementie te ondersteunen. De interventie omvat informatievoorziening over dementie en palliatieve zorg die is afgestemd op de lokale context, een aanvullende gesprekshulp die context-specifiek en gebruikersgericht is, en het oriënteren van verpleeghuismedewerkers en mantelzorgers op samenwerking in ACP.

Hoofdstuk 5 behandelt het voorlichten van mantelzorgers over dementie en palliatieve zorg. De kwalitatieve, beschrijvende studie die in dit hoofdstuk wordt gepresenteerd, draait om een informatieboekje voor familie over palliatieve zorg bij dementie. In Canada, Tsjechië, Italië, Nederland, het Verenigd Koninkrijk en Ierland is dit boekje overgenomen na lokale aanpassingen. Het doel van de studie was om richtlijnen te geven over de inhoud van informatieboekjes voor mantelzorgers over dementie en palliatieve zorg. Specifieke aandacht ging hierbij uit naar (i) internationale juridische en sociaal-culturele verschillen en ontwikkelingen door de tijd heen, plus (ii) wetenschappelijk onderbouwde aanbevelingen over palliatieve dementiezorg die door deskundigen zijn overeengekomen. De informatieboekjes uit zes landen werden vergeleken om de hoofdonderwerpen te bepalen en er werd een inhoudsanalyse uitgevoerd om de verschillen te categoriseren. Daarnaast werd de kwaliteit van de boekjes beoordeeld door de inhoud te vergelijken met de aanbevelingen uit een internationaal kader (European Association for Palliative Care, EAPC). De hoofdonderwerpen kwamen overeen met de hoofdonderwerpen uit het originele Canadese boekje. De tekstuele herzieningen van de boekjes werden samengevat in zes categorieën: (1) Typologie van behandelingen en symptomen rond het levenseinde, (2) Rechten en wensen van patiënten en familie, (3) Typologie van beslissingen rond het levenseinde, (4) Indirecte of expliciete boodschappen, (5) Meer of minder positief over prognose, en (6) Relatie tussen zorgprofessionals en mantelzorgers. De boekjes behandelden alle domeinen uit het kader van de EAPC, maar niet alle specifieke aanbevelingen. De aanbevelingen over het opstellen van zorgdoelen en proactieve zorgplanning werden niet behandeld in de boekjes. De variatie in de boekjes onderstreepte dat het belangrijk is om rekening te houden met de juridische en sociaal-culturele context en ontwikkelingen door de tijd heen. Betrokkenheid van belanghebbenden, met name de gebruikers, werd van fundamenteel belang geacht.

Het belang van de betrokkenheid van de gebruikers en de impact van de juridische en sociaal-culturele context op de voorlichting van mantelzorgers kwam ook aan de orde in **Hoofdstuk 6**. Dit hoofdstuk beschrijft de ontwikkeling van een gesprekshulp, een lijst met voorbeeldvragen, voor mantelzorgers van verpleeghuisbewoners met dementie, als aanvulling op het informatieboekje over palliatieve zorg. Mantelzorgers en nabestaanden in vijf landen namen deel aan nominale groepen. Het doel was om gesprekshulpen voor dementie te ontwikkelen, waarbij mantelzorgers leidend waren en die passend zijn bij de lokale cultuur. De uiteindelijke gesprekshulpen en de redenen van mantelzorgers om vragen te selecteren, werden vergeleken tussen de vijf landen met behulp van inductieve inhoudsanalyse. Redenen voor het selecteren van vragen waren: alleen informatie verkrijgen, voorbereiding op het levenseinde, geruststelling, voorbereiding op gezamenlijke besluitvorming, medewerkers informeren over de behoeften van de bewoner en medewerkers informeren over de behoeften van de mantelzorger. De geselecteerde vragen hadden betrekking op symptomen en ziekte, behandeling, overlijden, zorgmedewerkers, zorginstelling, waarden en wensen van de patiënt en gezamenlijke besluitvorming. De gesprekshulpen en redenen om vragen te selecteren verschilden tussen de landen. Er was echter ook een algemene behoefte onder de mantelzorgers om informatie te krijgen over palliatieve zorg bij dementie en over het proces van gezamenlijke besluitvorming. Aanbevelingen voor verder onderzoek waren onder meer om het gebruik van de gesprekshulp door mantelzorgers in gesprekken met zorgverleners te onderzoeken.

De casusstudie die in **Hoofdstuk 7** wordt gepresenteerd, implementeerde het informatieboekje en de gesprekshulp op twee locaties. Daarnaast werden verpleegkundigen en verzorgenden getraind in het leiden van familiegesprekken. Deze interventie betekende dus een verschuiving van ACP-taken van artsen naar verpleegkundigen en verzorgenden. In twee verpleeghuizen werden interviews gehouden met mantelzorgers en verpleeghuismedewerkers, waaronder artsen, een psycholoog, verzorgenden en verpleegkundigen, voor en na de implementatie van de interventie. De studie onderzocht de impact van de interventie op de samenwerking in ACP, zoals mantelzorgers en verpleeghuismedewerkers die hadden ervaren tijdens de mySupport-studie. In totaal zijn er 46 interviews gehouden. Een beschrijvende, thematische analyse van de interviews resulteerde in vijf thema's over samenwerking en familiegesprekken geleid door zorgmedewerkers: (1) De organisatiestructuur voor ACP is ongeschikt voor familiegesprekken geleid door zorgmedewerkers, (2) Het enthousiasme van mantelzorgers om deel te nemen aan ACP met zorgmedewerkers en verantwoordelijkheden in ACP zijn op verschillende manieren te duiden, (3) Familiegesprekken geleid door zorgmedewerkers passen bij ACP als proces, waarbij een band als basis dient, (4) Zorgmedewerkers zijn in de juiste positie om ACP te gebruiken als steun voor goede levenseindezorg, ondanks dat zij traditioneel geen leidende rol hebben, en (5) Communicatie, vaardigheden en kennis die vereist zijn voor ACP vragen om ondersteuning vanuit het multidisciplinaire team in familiegesprekken geleid door zorgmedewerkers. Er werd geconcludeerd dat zorgmedewerkers in de juiste positie zijn om mantelzorgers en multidisciplinaire teamleden te oriënteren op gesprekken over toekomstige dementiezorg, maar dat ze mogelijk niet de nodige opleiding hebben en zich niet genoeg bekrachtigd voelen in het team. Meer bewustzijn en interprofessionele voorlichting over ACP, plus toegankelijke documentatiesystemen, kunnen betrokkenheid van medewerkers en mantelzorgers bij ACP ondersteunen.

Gebaseerd op de studies beschreven in dit proefschrift, concludeert **Hoofdstuk 8** dat het voorlichten van verpleeghuismedewerkers en mantelzorgers van mensen met dementie om gesprekken tussen hen te faciliteren een belangrijke rol speelt bij het verbeteren van ACP voor mensen met dementie. Dit kan een palliatieve zorgaanpak bij dementie ondersteunen. Het is belangrijk om ACP als proces te benaderen, om relaties te versterken en mantelzorgers voor te bereiden op het levenseinde en besluitvorming. Ook is adequate documentatie van essentieel belang om de continuïteit van het proces te waarborgen, zelfs bij overgangen tussen zorginstellingen of behandelende zorgprofessionals. Daarnaast vereist een teamgerichte ACP-aanpak met betrokkenheid van mantelzorgers bewustwording onder, versterking van, en samenwerking tussen alle partijen die betrokken zijn bij de zorg voor de persoon met dementie. Daarvoor is het van fundamenteel belang om ACP en palliatieve zorg in de samenleving te normaliseren. Op die manier wordt gestimuleerd om eerder gesprekken aan te gaan over toekomstige zorgbehoeften en wensen. Nationale campagnes en populaire cultuur kunnen daarbij een rol spelen. Aanbevelingen voor de praktijk zijn onder meer het opleiden van verpleeghuismedewerkers om hun rol in ACP te versterken, omdat dit de betrokkenheid van mantelzorgers bij ACP kan bevorderen. Het explicieter integreren van ACP in multidisciplinaire overleggen kan de samenwerking tussen mantelzorgers en zorgprofessionals in ACP versterken. Het informatieboekje kan dienen als voorbereidingsmateriaal voor mantelzorgers en hen informeren over zaken die nog moeten komen. Deze informatie zou al in de thuissituatie toegankelijk moeten zijn, om te stimuleren dat men start met ACP vóór opname in een verpleeghuis. Voor toekomstig onderzoek is meer aandacht nodig voor mensen met een niet-westerse culturele achtergrond of lage gezondheidsvaardigheden. Het is van essentieel belang dat verder onderzoek gebaseerd wordt op perspectieven van mensen met dementie zelf.

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Methodological issues and challenges in designing and conducting ethical research at the end of life: findings of qualitative and textual evidence. Vlckova K, Gonella S, Bavelaar L, Mitchell G, Sussman T.

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Portfolio

PhD student: Laura Bavelaar-von Oerthel
Primary thesis advisor: Prof.dr. W.P. Achterberg
Other thesis advisors: Dr.ir. J.T. van der Steen
Dr. M. Visser
Research programme: 31201 Geriatrics in primary care

Courses and training

2019	Ethics in Dementia
2019	Kwalitatief onderzoek in de praktijk van de gezondheidszorg
2020	BROK Course
2020	Children, young patients and family involvement in the design of clinical research
2020	Developing a Dissemination Strategy for Health Research
2020	Research Integrity
2021	PhD Introductory Meeting
2021	Basic Methods and Reasoning in Biostatistics
2021	Regression Analysis
2021	Supervising working groups
2022	TTT: Coach de coach – Leidse Lijnen
2022	the mySupport Early Career Mentorship Programme

Presentations

2020	UNC-ZH Jubileumtour, online. Workshop presentation
2020	GSA 2020 Annual Scientific Meeting, online. Oral presentation
2021	31st Alzheimer Europe Conference, online. Oral presentation
2022	12th EAPC World Research Congress, online. Poster presentation
2022	26th Nordic Congress of Gerontology, Odense. Symposium presentation.

Teaching activities

2022	Workgroup teacher (Collaboration, Health promotion and Leadership) of 3rd year medical students, LUMC

Curriculum Vitae

Laura Bavelaar-von Oerthel was born on November 14th, 1993 in Leiderdorp. She attended secondary school in Leiden at the Bonaventuracollege where she obtained her Gymnasium diploma in 2012. In addition, Laura received her Pre-University College diploma in 2012. Leiden University offered this program for students who would like a scientific challenge besides their secondary school curriculum and already gain some experience in academia. As part of the Pre-University College programme, Laura conducted a study into metacognitive skills as her 'Profielwerkstuk' under supervision of dr. Marcel Veenman, which was published in 2014 (Learn Individ Differ). This introduction into research in psychology sparked her interest and after secondary school, Laura started her study Psychobiology in Amsterdam in 2012. In 2015, Laura graduated cum laude and with honours. The research Master Brain and Cognitive Sciences at the University of Amsterdam was a natural follow-up to her education. Laura was granted access to the selective Master's and graduated cum laude in 2017. In 2018, Laura started a PhD position at the University of Amsterdam. She worked on the Human Brain Project at the Cognitive and Systems Neuroscience lab, but then decided to change direction. Throughout her education at the University of Amsterdam, Laura had worked as a food assistant at the Alrijne Hospital in Leiderdorp. The care setting and interaction with patients, often older people, inspired Laura to change paths from fundamental neuroscience to person-centered care research. She started working as a junior researcher on the mySupport study in 2019 and was subsequently supported in expanding the study into a PhD research project at Leiden University Medical Center, in the Department of Public Health and Primary Care. During her time as PhD student, Laura participated in various committees and organized a Department outing, served as secretary to the mySupport study's Early Career Researchers Committee and hosted and organized a symposium on *'New and emerging models of Advance Care Planning for Older Persons'* and two-day mySupport study consortium workshop. In her free time, Laura volunteers at Zero Waste Groene Hart.

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[Wat Als – Joe Buck]