Thinking ahead: supporting family caregivers of nursing home residents with dementia in advance care planning

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1

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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