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

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Citation

Bavelaar-von Oerthel, L. (2023, February 28). *Thinking ahead: supporting family caregivers of nursing home residents with dementia in advance care planning*. Retrieved from https://hdl.handle.net/1887/3566618

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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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