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

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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.