

The fundamentals of a dedicated palliative approach to care for people with dementia

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IMPACT

'The colleagues are all enthusiastic. We really feel like we can become of greater significance to the client.' (Quote from an interview by the Dutch Nursing Society V&VN with one of the DEDICATED ambassadors)¹

This dissertation introduces a contemporary view on the need for integration of palliative nursing care into dementia care. The research provides a comprehensive basis for further development of nursing practice and education in the provision of palliative care for people with dementia. This chapter reflects on the impact of the research described in this dissertation on practice, education, and science. It also describes the societal impact and the future of this DEDICATED project.

PRACTICE AND EDUCATION

'Stirring up old memories went with a smile and a tear. A beautiful process, doing this together. I learned more about the client, because I heard stories that are not documented in a care plan, and that are not told during an intake. The family caregivers were very enthusiastic as well. We collected a variety of materials to fill the poster: photos, stickers, clippings from magazines. The daughter framed and hanged the poster. The client, his daughter, his wife and I were all very happy with the result. Everyone had to come and see the poster.' (DEDICATED ambassador talking about creating a 'life story poster' with a client with dementia, see photo)



The chapters in this dissertation reflect the thorough groundwork that was carried out to inform the development of practical tools and materials to support palliative dementia care. Since September 2019, parallel to the scientific groundwork described in this dissertation, a design team has been working on the development of the 'DEDICATED approach'. The design team includes nurses working in the home and nursing home setting, nurse educators, dementia case managers, and researchers. Results from the studies in this dissertation informed four of the main themes addressed in the DEDICATED approach. The themes include:

- 1) Awareness of a palliative care approach in dementia
- 2) Familiarity (getting to know each other)
- 3) End-of-life communication
- 4) Dealing with pain and responsive behaviors

During regular meetings, the design team brainstormed about themes and related challenges. The design team inventoried existing tools, methods, and 'best practices' that related to these themes and that suited the nursing context of the project. When

needed, the team also developed new support materials. The inventory and development process took into account the organizational context by exploring each organization's current practices, possibilities, and barriers concerning the use of existing and newly developed materials and methods. After finalizing a theme, design team members took the theme's materials into practice to test and evaluate them with their colleagues. This was an ongoing and iterative co-creation process of developing, testing, and adapting materials.

This dissertation came forth from the larger DEDICATED project. DEDICATED consists of two parts. Part 1 focuses on palliative caregiving in dementia by nursing staff and on end-of-life communication. Part 2 focuses on interprofessional collaboration in palliative dementia care, and on continuity in transfers between home and the nursing home. This dissertation is a product of the first part; the second part will result in a separate dissertation. Nonetheless, both parts of the DEDICATED project are complementary and, since April 2020, we worked on the gradual integration of part 1 and 2. The DEDICATED approach therefore incorporates elements from both project parts. The nurses, case managers, and other care professionals who participated in the design team of either project part were designated and trained as 'DEDICATED ambassadors'. Professionals from intermediate and higher vocational nursing education participated in the co-creation process as well. At first, they gave advice on the formats and content of support materials, from a didactic perspective. For instance, they provided feedback on the use of language to facilitate understanding by nursing staff from a variety of educational levels. Moreover, together with the education professionals, we developed a training for DEDICATED ambassadors. The ambassador's training aims to:

- 1) Introduce palliative care for people with dementia
- 2) Teach ambassadors how to enthuse and motivate their colleagues
- 3) Familiarize ambassadors with the DEDICATED approach and materials; teach them how to identify learning goals within their teams; teach them how to match the DEDICATED approach to these learning goals within their organizational contexts
- 4) Create a peer support and intervision group of ambassadors; teach them how to implement, disseminate, and sustain the DEDICATED approach together.

A DEDICATED ambassador should ideally lead care teams that want to use the DEDICATED materials. The ambassadors have an important role in stimulating awareness about palliative care and dementia, introducing the DEDICATED approach and its belonging materials to their colleagues, and sustaining the use of the DEDICATED approach in practice. The DEDICATED ambassadors have proven to be truly 'dedicated' and they have contributed to increasing recognition of the project. Six care teams in the project's partner organizations (nursing home and home care) are currently using DEDICATED materials as a pilot. Ambassadors and their colleagues can retrieve

the developed materials via the webpage of the DEDICATED approach (see dedicatedwerkwijze.nl, or scan QR code).



The DEDICATED webpage guides its users to the appropriate support materials, sorted according to themes as well as according to the place of care (home, nursing home, or in transition). The teams' learning goals function as a basis to navigate the webpage and find the support they need. Most of the materials have digital formats, which users can download and open on their digital device or print. A few of the materials are physical. For instance, we collaborated with 'Bureau MORBidee', an expert business in end-of-life communication, to develop communication aids. The aids consist of a pack of photo cards and a sack of dices with symbols, which can be used to have conversations with persons with dementia about the future, the end of life and related topics (see photo).



The aids were well received by our ambassadors and by nursing students. They are currently being used in practice and education to ease (end-of-life) communication with persons with dementia. Another example of a support material, which was developed in response to a contemporary practice need, was a guidance document with practical recommendations for nursing staff on how to provide palliative dementia care in times of COVID-19. These recommendations were retrieved from the scoping review (*chapter 4*), summarized, and translated into Dutch. Several regional and national project partners (e.g., the Dutch Nursing Society V&VN, Vilans, Palliative Care Networks, Palliaweb) and a Dutch practice journal of nursing (TvZ) disseminated the formalized guidance document. Thereby, the guidance document reached a broad audience of clinicians in dementia care. Table 1 provides an overview of developed materials within part 1 of DEDICATED.

Nursing staff, including registered nurses and nurse practitioners, certified nurse assistants (i.e., licensed nurses), and nurse assistants, together with dementia case managers, make up the primary target groups for all these materials. Applying the materials in practice should help them to feel more competent and better prepared to deliver high-quality and person-centered palliative dementia care. Moreover, the ambassadors' involvement in the project as co-creators stimulates a general movement within their care teams to think and talk about palliative care and to reflect on what this means in relation to dementia. From anecdotal evidence, the current ambassadors working in nursing homes underscore the usefulness and potential of using DEDICATED materials to support palliative caregiving for people with dementia. For instance, during one of the ambassador's training sessions, an ambassador said that *'The support materials offer guidance and they actually help to establish low-threshold conversations with residents and with their families. It can really help to increase their involvement.'*

Table 1. Overview of developed materials

	Elaborate instruction	Overview / condensed	Physical material / other
Awareness of a palliative care approach in dementia			
Case discussions within the care team	X	X	
Reflection within the care team	X	X	
'Chatter jar' ('Kletsplot')			X
Short movie to stimulate awareness			X
Practical nursing recommendations for palliative dementia care during COVID-19		X	
Familiarity (getting to know each other)			
Method life story book	X	X	
Method life story poster	X	X	
'Good practice example' life story book		X	
'Good practice example' life story poster		X	
End-of-life communication			
Communication aid: dices		X	X
Communication aid: photo cards		X	X
Overview of other communication aides		X	
Dealing with pain and responsive behaviors			
PACSLAC-D: short movie			X
PACSLAC-D: poster to stimulate awareness		X	X
Overview of other pain signaling instruments		X	
ABC-method: poster to stimulate awareness			X

The investment in a group of *dedicated* (DEDICATED) ambassadors will facilitate the dissemination and preservation of the approach in the future. In collaboration with the participating educators and the current ambassadors, we will train ambassadors from new care teams and organizations. In a subsequent stage, we will also set up a train-the-trainer program to educate new trainers who can provide the ambassadors' training (and thereby replace the educators that are involved now). Nurses and dementia case managers are the primary target group for the train-the-trainer program. The existing DEDICATED ambassadors can evolve into trainers if they please. This will lead to a solid and self-sustaining network of DEDICATED trainers and DEDICATED ambassadors, who pass on their knowledge and stimulate awareness.

Next to their role in the development of materials and a training program for ambassadors, the education professionals contribute to the uptake of DEDICATED into nurse students' education and curricula. For instance, they are using DEDICATED materials in their classes as a part of palliative care education (see photo). One of the educators reported that 'students felt DEDICATED' after joining a



workshop with one of the ambassadors. Another educator noted that the integration of DEDICATED into palliative care education triggers awareness among students about the inextricable link between palliative care and dementia care. This awareness, in turn, rouses their interest in and motivation to further explore the topic. It contributes to the realization that they can still be of great significance to people with dementia, even in the case of severe impairment. Therein, the 'short movie to stimulate awareness' is considered to be a great tool, that speaks to students' imagination and touches their feelings.

At several occasions, the DEDICATED research team itself organized lectures and classes on palliative dementia care for students from intermediate and higher vocational nursing education as well as for employed nursing staff. For instance, we organized a practical lecture at a hospice for nurse students using DEDICATED materials to have a joint case discussion and reflection. One of the ambassadors joint and co-led this meeting. Further, we organized digital lessons about palliative care and dementia for nursing students from higher and intermediate vocational education and for care professionals as part of an interprofessional palliative care course. Such activities contribute to the awareness of nurse students and professional nursing staff about the meaning and importance of a palliative approach to dementia care. Our collaboration with the education section of the Dutch Palliative Care Consortium (Limburg Zuid-Oost Brabant) has led to the inclusion of DEDICATED materials into the current training of 20 lecturers. The educators involved in the DEDICATED project provide this training. By the end of 2021, it is planned that around 200 lecturers from intermediate and higher vocational education will have been trained.

Within the DEDICATED project, 13 students (from BA Health Sciences, MA Healthcare Policy, Innovation and Management and MA Nursing Science) wrote their theses on topics related to palliative care and dementia. Laura Verbeek, a student from the Master of Nursing Science won the scientific Johanna Diepeveen-Speekenbrink award for our publication that was based on her thesis (*chapter 5*).

SOCIETY

"Dementia is an incurable and neurodegenerative condition. Persons with dementia experience increasing deterioration and loss of functions. Therefore, a palliative approach, which starts after a diagnosis of dementia, is of importance throughout the dementia trajectory, with the goal of maximizing and preserving quality of life until the end." - Dementia Care Standard 2020

As a research group, DEDICATED played an important role in the integration of palliative care in the newly developed Dutch Dementia Care Standard.² From the studies in this dissertation, we learned that an early adoption of a palliative approach is important in the care provision for people with dementia. Based on our specific expertise, the

authors of the standard (one of whom is also a member of DEDICATED's advisory board) requested our advice. Draft versions of the standard mentioned palliative care merely in relation to the end of life and dying with dementia. In multiple feedback rounds, we advocated for a clear and explicit early palliative approach to care, which is now adopted throughout the standard, together with recurrent references to the Netherlands Quality Framework for Palliative Care.³ Thereby, the work in this dissertation contributed to the advancement of the national vision and knowledge on dementia care. The Dementia Care Standard is an important guideline that supports the organization and delivery of tailored dementia care in integral networks and chains of care. It reaches a broad population of professionals working in the field of dementia, including healthcare providers, policy makers and managers.²

The DEDICATED project involved structural groups of stakeholders. Besides the design group, the project involved a working group (with healthcare professionals and managers, educators, patient representatives) and an advisory board (with care directors, representatives from national and regional partners such as from the Dutch Alzheimer's Association, Vilans and the Dutch Nursing Society V&VN). Figure 1 (in Dutch) depicts all project partners. Co-creation by means of involving stakeholders in several steps of the research process is key to generating societal and practical impact of the results.⁴ The DEDICATED project engaged many stakeholders from a variety of disciplines (e.g., nursing, geriatrics, psychology, spiritual counselling) and participating on different levels. Thereby, the research was highly practice-oriented and responded to needs and demands arising from the field. The swift response to the COVID-19 outbreak by means of performing a scoping review and providing practical recommendations, as shown in this dissertation, clearly demonstrates this practice-sensitivity. Moreover, the advisory board members helped to create visibility of the project and awareness of palliative dementia care among national professional organizations, such as V&VN and Vilans. The advisory board also involved a representative of a Dutch health insurance company (CZ), which is an important stakeholder when aiming to improve care delivery.

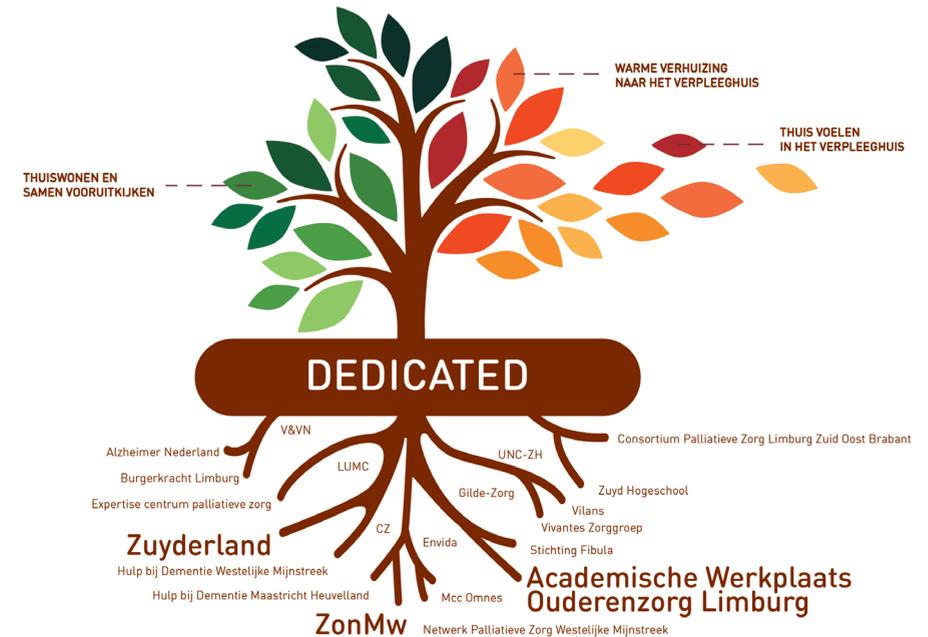


Figure 1. DEDICATED tree depicting project partners as its roots. The leaves say 'living at home and looking ahead together', 'warm transfer to the nursing home', and 'feeling at home in the nursing home'

SCIENCE

The studies in this dissertation contribute to a more profound scientific knowledge base on palliative care for people with dementia. Although the literature on dementia care and palliative care separately is plentiful, the combination of both requires attention. Over the past two decades, there have been growing efforts to study and to improve palliative care provision for people with dementia. However, the timing of palliative care in relation to dementia and its applicability to earlier stages remain questionable. Previous studies generally focused on palliative care at the end of life with dementia, or on palliative care for people with advanced dementia. This dissertation advocates for a clearer and more explicit integration of palliative care and dementia care, both in research and in practice.

The knowledge base on palliative dementia care in the community is particularly limited, even though the majority of people with dementia live at home.⁵ This dissertation targeted both the nursing home and community setting. Thereby, it delivers valuable knowledge for further advancement of palliative dementia care in both settings. In addition, the dissertation described comparisons between both settings. This novel insight into possible differences and similarities between the settings regarding the provision of palliative dementia care may inform future research, practice, and policy. Further, nursing staff from different levels represented the nursing perspective in

the thesis. Thereby, the identified themes apply to a large, heterogeneous group of caregivers that are at the forefront of providing dementia care. Insight into this group's perspective and the finding that the variety of nursing staff have many mutual needs brings forth implications for further research and practice.

The studies in this dissertation reflect a thorough enquiry using a mix of research methods and including three important perspectives to inform palliative dementia care. The perspectives of family caregivers and nursing staff, as the primary care providers for people with dementia, are a valuable source of information. Nonetheless, the involvement of people with dementia themselves is indispensable when aiming to improve the care provided to them. The inclusion of people with dementia in this dissertation sets it apart from most other studies investigating perspectives on palliative dementia care. Moreover, it demonstrates that people with dementia are fit to participate in scientific research. In line with a societal shift towards dementia-inclusivity, research should follow this movement and aim to involve people with dementia as potential study participants. In addition, future efforts should be made to involve people with dementia not only as participants, but also as partners in the research process.⁶

Data collected as a part of the DEDICATED project have been used or shared to use in other scientific studies. Sharing data and combining data from different studies is an important factor to create research impact. For instance, it may help to verify and strengthen findings, and it supports the building of meaningful collaborations with other researchers.⁷ First, our data were used in a national study looking at trends of families' assessments of quality of care and quality of dying. This particular study, which included 1189 family assessments, is also a chapter in this dissertation (*chapter 7*). Our data also informed other studies and articles that are not part of this dissertation, but that do contribute to the advancement of the palliative care knowledge in dementia. For instance, we participated in an international, meta-qualitative study to derive a cross-cultural conceptualization of a 'good end of life' with dementia. Researchers from eight countries in Europe, the Americas, and Asia participated in this study using results from each of their original qualitative studies. Another study involved a combination and secondary analysis of data from our interviews and ethnographic fieldwork to explore how advance care planning for people with dementia is experienced and perceived in practice. Both manuscripts are under review. Lastly, during the project period, a travel grant was obtained to visit the TREC (Translating Research in Elder Care) research group at the University of Alberta in Edmonton, Canada. The visit strengthened our international collaboration and broadened our view in the DEDICATED project to consider aspects of nursing staff's work life (e.g., psychological empowerment, work engagement, job satisfaction) in relation to their care provision.

DISSEMINATION OF FINDINGS

The collaboration with national and regional partners contributed to the recognition and reputation of the DEDICATED project, which aided the dissemination of our research findings. For instance, it led to our involvement in the revision of the Dementia Care Standard and to the reach of our COVID-19 recommendations via professional networks. Moreover, we disseminated regular newsletters to our partners (e.g., work group participants and advisory board members who further distributed to their colleagues), and within the Living Lab in Ageing and Long-Term Care. The Living Lab, located in the southern part of the Netherlands, is a formal and structural collaborative between Maastricht University, nine long-term care organizations, and three higher and intermediate education institutes. The embedding of DEDICATED within the Living Lab, with its large reach and strong connections between education and practice, provides opportunities to disseminate the DEDICATED approach and to generate impact. We shared public summaries and occasional vlogs of our research findings with our associates after publication of scientific articles. In 2019, we organized a DEDICATED symposium to share our findings and progress with our project partners and others who were interested. The project also received attention in communications from other (partner) organizations. Among others, DEDICATED appeared in newsletters from the Netherlands Organization for Health Research and Development (ZonMw, the funder of the project), in an annual report of the Living Lab in Ageing and Long-Term Care and in an article in the M&G (Society & Health) magazine from the Dutch Nurses' Association V&VN.

Of the seven articles in this dissertation, six were published in peer-reviewed, international journals and the seventh has been accepted for publication. Two articles were published in special issues on dementia care and one article was designated by the journal as a 'continuing education article'. The general introduction of this dissertation was based on an accepted book chapter that will be published in 'The practical handbook of dementia'; an informative book for people with dementia, their family caregivers, and professional caregivers. Three of the articles were translated and published in Dutch practice journals. Apart from the studies included in this dissertation, we wrote a commentary about the nurses' role in advance care planning in the Dutch, practice-oriented 'Tijdschrift voor Gerontologie en Geriatrie' (i.e., journal of gerontology and geriatrics).⁸ We contributed to another book chapter about the conduct of scoping review in a Dutch educative book describing study designs for nurses and nurse students ('Onderzoek langs de meetlat').

We presented study findings at several national and international scientific conferences, such as at the congress of the European Association for Palliative Care (EAPC) and during the Dutch National Congress of Palliative Care. The DEDICATED project and its findings were also disseminated during a number of events for a variety of non-academic audiences. For instance, DEDICATED was presented as part of a guest

lecture at a symposium organized by a catholic bond for older people, which hosted an audience of approximately 100 people with an average age of 80 years. Other events involved keynote lectures and workshops during seminars for care professionals and a presentation at a trade fair in healthcare. On World Alzheimer's Day 2020, we launched a short movie to stimulate awareness about palliative care for people with dementia (see <https://youtu.be/qWz8VBNCa0Y> or scan QR code).



TO CONCLUDE: Desired Dementia Care Towards End of Life

This dissertation forms an important basis for the advancement of palliative dementia care and for the development of a DEDICATED approach. This 'work in progress' involves iterative co-creation with dementia care professionals and nurse educators. After the pilot phase, new DEDICATED ambassadors will be selected from test teams at the participating organizations and they will be trained to implement the finalized approach within their teams. New ambassadors will be linked to former ambassadors and together, they will create a network to support, inform, and motivate each other in their ambassador's role. Originally, the DEDICATED project ran from September 2017 to September 2021. The Netherlands Organization for Health Research and Development (ZonMw) approved extension of the project by one year and we obtained additional funding to carry forward the implementation and further dissemination of the project's deliverables. The test phase will start from September 2021 and involve an effect and process evaluation of the implemented DEDICATED approach. Moreover, together with the educators from higher vocational nursing education (Zuyd, University of Applied Sciences), we will develop a train-the-trainer program. Through this program, we will prepare ambitious care professionals to become DEDICATED trainers, who are responsible for training new DEDICATED ambassadors after the end of the project's term. The goal is to disseminate the DEDICATED approach within the Living Lab in Ageing and Long-Term Care first. Eventually, a rich pool and strong network of DEDICATED trainers and ambassadors facilitates dissemination to other organizations and regions.

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