

There is an I in WE

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IMPACT

This dissertation focuses on various collaborative elements and needs of persons with dementia, informal caregivers and healthcare professionals in palliative dementia care. Based on the findings presented in this thesis, we co-created materials with education professionals and healthcare professionals that contribute to the DEDICATED approach. This approach consists of practical materials to support healthcare professionals working in home care or in nursing homes to provide palliative care to persons with dementia and their informal caregivers. The overall DEDICATED approach is based on five themes: 1) Awareness, 2) Know your client, 3) Advance care planning, 4) Pain and challenging behaviour and 5) Warm transfer during the move. This thesis contributes to themes 1, theme 3 and theme 5. For more information about the DEDICATED approach, we refer to the Impact paragraph of the dissertation of Bolt, S.R. (2021)¹ and the Dutch website www.dedicatedwerkwijze.nl

PRACTICE AND EDUCATION

To increase awareness about interprofessional collaboration in palliative dementia care, we co-created five practical materials with healthcare professionals and education professionals. The [infographic *Moving together DEDICATED*](#) describes how to take an interprofessional collaborative approach in the three phases of the move from home to the nursing home in dementia care (Figure 1)². The [infographic *DEDICATED Collaboration in advance care planning*](#) focuses on six important elements in interprofessional collaboration regarding advance care planning for persons with dementia living in nursing homes³. Both infographics are summaries of the guidance documents ([Guidance *Moving together DEDICATED*](#))⁴ and ([Guidance *DEDICATED Collaboration in advance care planning*](#))⁵ in which detailed information about interprofessional collaboration and referrals of other existing materials are provided. Besides these written materials, we also developed a video ([WEI move DEDICATED](#))⁶ in which a dementia case manager, an informal caregiver (Ruud Lenssen moviemaker of the documentary WEI) and two researchers from the DEDICATED-team talked about the collaborative approach when transitioning from home to the nursing home.

Moving together DEDICATED

Collaborate with all those involved (the person with dementia, loved and/or informal caregivers and all healthcare professionals involved) before, during and after the move to a nursing home*.

Pay attention to the expectations, wishes and preferences of people with dementia, loved ones and/or informal caregivers.



1. Looking ahead together at home

Agree with everyone involved who will be the central point of contact in the home setting

- As an involved healthcare professional, discuss:
 - The wishes and preferences regarding advanced care planning (i.e. living at home, daily life, care and the end-of-life)
 - The joint decision to move

Regularly discuss and evaluate the cooperation concerning living at home and advanced care planning with all involved

2. Preparing a warm welcome together

As an involved healthcare professional in the nursing home, agree who will be the central point of contact

- Transfer the person with dementia and loved ones and/or informal caregivers
- Contact the central contact person of the other setting
- Collect, document, share and discuss wishes and preferences regarding advanced care planning with the central point of contact in the nursing home
- Indicate personally who the central point of contact in the nursing home is

As the central point of contact in the nursing home, perform the following:

- Inform the involved caregivers of the wishes and preferences regarding advanced care planning
- Discuss with all involved whether there is a need for a home visit, a nursing home visit and activities to promote adjustment in the nursing home.
- Give an indication of the waiting time until the moving day
- Plan the moving day with the warm welcome of the person with dementia and loved ones and/or informal caregivers as a point of attention
- Use personal instead of clinical words, such as "move" instead of "admission"
- Pay attention to the processing of relatives and/or informal caregivers

As an involved healthcare professional from the home setting, gradually reduce contact with the person with dementia and loved ones and/or informal caregivers

Discuss and evaluate the cooperation on the warm welcome with all involved

3. Creating a feeling of home together

As an involved healthcare professional perform the following:

- Perform the warm welcome
- Pay attention to familiarizing with the nursing home
- Offer holistic care (four dimensions)
- Have regular conversations about the wishes and preferences regarding advanced care planning (i.e. living at home, daily life, care and the end-of-life)

Regularly discuss and evaluate the cooperation concerning living at home and advanced care planning with all involved



*Our focus in the guidance moving together DEDICATED is the transition from home to nursing home, but these key steps can also be applied in the transitions to other intramural or residential care facilities such as the hospice and the care apartment.



DEDICATED

Figure 1. Infographic Moving together DEDICATED

For the development of both guidance documents, we applied a participatory action research approach⁷, as we co-created this approach through close collaboration with various stakeholders. These stakeholders were nurses, dementia case managers, coordinators of a dementia care chain, general practitioners, client counsellors, physicians, team leaders, psychologists, researchers, and education professionals. The current thesis focuses on the knowledge that informed the development of these materials. The healthcare professionals who co-created, implemented and evaluated the materials are called the DEDICATED ambassadors.

Together with the education professionals from Zuyd University of Applied Sciences, we built a train-the-trainer approach to reach a larger audience. We first trained healthcare professionals to become ambassadors and subsequently some of them received a training to become a trainer to support other healthcare professionals to become DEDICATED ambassadors^{8, 9}. These ambassadors are healthcare professionals (nurses, dementia case managers, team leaders, psychologists and elderly care physicians). The ambassadors learned what the DEDICATED approach entails and how to implement the approach in practice step by step, and received exercises to execute their role as ambassadors in practice. We defined the role of DEDICATED ambassadors as healthcare professionals that use the materials themselves; can raise awareness of the DEDICATED approach in their department or location; and educate and motivate their colleagues to support them in using the materials. The ambassadors from three different care organisations (Zuyderland, Vivantes and Envida) are connected through peer support groups in which they can exchange information and experiences, learn from each other and build a learning network of DEDICATED ambassadors. Building this type of capacity allows collaboration among the ambassadors, and sustains the trainings in practice, which is one of the core advantages of the train-the-trainer approach⁹. In total, we trained 36 ambassadors, of which four additionally were trained as trainers to train new ambassadors, and to implement and disseminate the DEDICATED approach in practice. We are currently collaborating with the Dutch Palliative Care Consortium Limburg South-East Brabant for further dissemination of our DEDICATED materials.

Most DEDICATED ambassadors were nurses and dementia case managers. We asked one of the DEDICATED ambassadors what she specifically learned from the guidance document *Moving together DEDICATED*.

'I am more aware of the impact of the move from home to the nursing home. During my next home visit, I collected a lot of information about the care for the client, but also the wishes she had. I also took a lot of information about the nursing home such as the location, the rooms and formal papers to fill in. Moreover, I also made sure that I was present on

moving day, so that the meeting felt familiar to her. She recognised me directly and was relieved to see someone she already knew. We did not perform any formal tasks on the moving day, but took the time as a whole department to give her and her family a pleasant welcome.’ (DEDICATED ambassador, registered nurse from the nursing home)

The education professionals from Zuyd University of Applied Sciences that co-created the DEDICATED approach as one of the stakeholders mentioned that they use the DEDICATED approach in the curricula of their nursing students, and implement the collaborative aspects in the minor Growing Older, which is accessible to an interprofessional group of students. The students mentioned that their awareness about an interprofessional approach increased, and resulted in paying more attention to the future regarding optimal communication, connecting each other (i.e. getting to know each other and understanding each other’s profession) and having a clear documentation among various healthcare professionals (Figure 2).



Figure 2. Screenshot of the results of the Wooclap presentation about interprofessional collaboration in advance care planning in dementia during the minor Growing Older at Zuyd University of Applied Sciences.

During the research period, we have aimed to incorporate knowledge about interprofessional collaboration in palliative dementia care of this thesis into the education system of Zuyd University of Applied Sciences. For the dual education for nurses and the education for dementia case managers at Zuyd University of Applied Sciences, we organised one lecture and workshop. Our DEDICATED materials were also part of the nursing education of nurses provided by Gilde education, which is an intermediate vocational education institution. During this thesis period (2019-2022), we also guided seven students (from the Bachelor of Health Sciences and Master Healthcare Policy,

Innovation and Management) on the topic of interprofessional collaboration in palliative dementia care with their internship theses that resulted in one conversation guide¹⁰ and two publications^{11, 12}.

SOCIETY

During the entire research period, a working group, a design group and a national advisory board supported the DEDICATED research team. The working group consisted of healthcare professionals, policymakers, managers, patient representatives and educational professionals. During the work group meetings, the researchers worked with these stakeholders on the research questions, the methodology, the inclusion of participants and the interpretation of the results. The advisory board consisted of directors and representatives from regional and national organisations such as the Dutch Alzheimer's Association, a Dutch health insurance company (CZ), Vilans, the Dutch professional registered nurses and certified nurse assistants organisation (V&VN), and the Netherlands comprehensive cancer organisation (IKNL). This advisory board monitored whether the needs of all stakeholders were taken into account and how the results affects their organisations and society in general. In this way, DEDICATED co-created between researchers and professionals from several layers of the healthcare system¹³.

For the collaboration theme 'Collaboration during the move to a nursing home', we built upon the documentary WEI that was made by moviemaker Ruud Lenssen, who displayed the society how his father with vascular dementia changed and how it affected the lives of his informal caregivers. WEI evoked several public reactions and thereby contributed to the societal awareness of what living with dementia means for the person with dementia and their informal caregivers. In the video WEI move DEDICATED, Ruud Lenssen explained his experience when his father moved to a nursing home. He described that his father had to move four times before he moved to the appropriate nursing home where he actually felt at home. Therefore, he emphasised that it is important to anticipate the move and involve informal caregivers during the entire move.

Our guidance documents add to the existing pool consisting of guidance documents that mention interprofessional collaboration in palliative dementia care¹⁴⁻¹⁷. The guidance document 'This is how you connect palliative care and dementia' (NL: *Zo verbindt u palliatieve zorg en dementie*) from Vilans mentioned some collaborative initiatives among healthcare professionals such as improving the structure of interprofessional meetings and setting up an integrated digital system¹⁴. Another guidance document 'Care planning in the last phase of dementia' (NL: *Het plannen van zorg in de laatste levensfase van*

dementie) has pinpointed specific actions in interprofessional collaboration regarding advance care planning in dementia, such as how to make shared care goals together¹⁵. In this thesis, we entirely focus on interprofessional collaboration as a topic within palliative care and could add value to these existing guidance documents.

RESEARCH

To our knowledge, Tolson et al. (2017) is the only study that focused on interprofessional collaboration in palliative dementia care and emphasised the importance of paying attention to the role of healthcare professionals in advance care planning¹⁸. This thesis contributes to knowledge about interprofessional collaborative palliative care in dementia (*Chapter 2*), and specifically adds knowledge about the roles of physicians, psychologists, team leaders and nurses in advance care planning in dementia care (*Chapter 6*). Optimal collaboration involves all collaborative partners (persons with dementia, informal caregivers and healthcare professionals)¹⁹. Every collaborative partner in this dementia care triad has his or her own contribution, roles and needs²⁰. We therefore involved all collaborative partners in this thesis, and explored their perspectives and needs concerning palliative dementia care. Regarding the collaborative needs of persons with dementia, there is a paucity of research about their collaborative competencies²¹ and how they still can be involved in collaborative activities in an active way²²⁻²⁵. A recent study also discovered that having a sense that they make choices and can be control of their life is supported through collaboration with others. In this thesis, we identified the collaborative needs of persons with dementia when applying a palliative care approach. We also provided recommendations for future research about how persons with dementia could be involved in and feel empowered through collaborative processes with other collaborators regarding palliative care²⁶.

During the thesis period, we collaborated with the Transition Care Innovation in Senior Citizens (TRANS-SENIOR) research project²⁷. TRANS-SENIOR also focuses on the move from home to the nursing home in dementia care. They conducted a secondary data analysis on our data (interviews with persons with dementia and informal caregivers), leading to two joint articles, of which one is recently published²⁸. We additionally developed a concept version of a moving scan for informal caregivers together with TRANS-SENIOR based on their findings and the findings presented in this thesis. The aim of this moving scan is to capture the experiences of informal caregivers throughout the moving process.

DISSEMINATION OF THE FINDINGS

Next to the international peer-reviewed articles, we focused on dissemination within the Netherlands. Palliaweb (a Dutch platform that collects products and research results about palliative care) will publish one of our articles. We additionally wrote Dutch public summaries and made vlogs about the published articles regarding interprofessional collaboration in palliative dementia care. These summaries and vlogs were included in our DEDICATED newsletters and disseminated to all our partner organisations. Moreover, our guidance document *Moving together DEDICATED* has been shared by and was published on three national platforms: Palliaweb (national platform for professionals in palliative care), Zorg voor Beter (knowledge platform for care organisations about healthcare in general) and Waardigheid en trots (knowledge platform about how to improve care in nursing homes). Our guidance document *DEDICATED collaboration in advance care planning* has also been published on Palliaweb. Lastly, we also presented our study results at several national and international scientific conferences (such as the Dutch National Congress of Palliative Care) and symposia organised by care organisations (such as the Preuvenemint of Envida).

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