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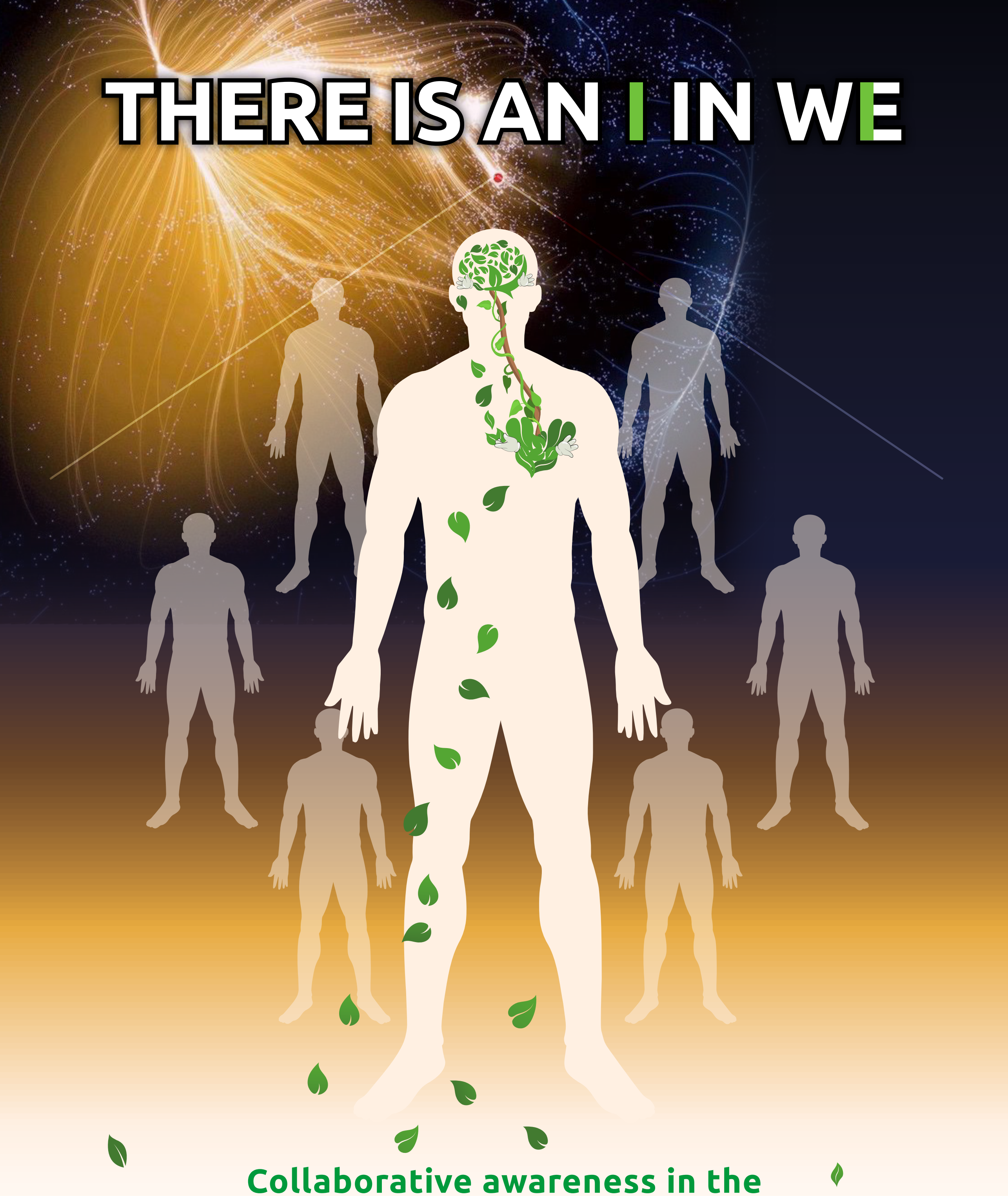

Collaborative awareness in the DEDICATED palliative care approach for persons with dementia

CHANDNI KHEMAI

THERE IS AN I IN WE

COLLABORATIVE AWARENESS IN THE DEDICATED PALLIATIVE CARE APPROACH FOR PERSONS WITH DEMENTIA

Chandni Khemai

The research presented in this thesis was conducted at CAPHRI Care and Public Health Research Institute, Department of Health Services Research, of Maastricht University. CAPHRI participates in the Netherlands School of Public Health and Care Research CaRe.

This thesis is part of the Living Lab in Ageing and Long-Term Care, a formal and structural multidisciplinary network consisting of Maastricht University, nine long-term care organizations (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Intermediate Vocational Training Institutes Gilde and VISTA college and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands. In the Living Lab we aim to improve quality of care and life for older people and quality of work for staff employed in long-term care via a structural multidisciplinary collaboration between research, policy, education and practice. Practitioners (such as nurses, physicians, psychologists, physio- and occupational therapists), work together with managers, researchers, students, teachers and older people themselves to develop and test innovations in long-term care.

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The cover of this thesis was devised by Chandni Khemai. The cover displays a laniakea, which is a supercluster consisting of more than 100.000 galaxies. Through galaxy collisions, which can be perceived as a natural automatic form of collaboration in the universe, elements in the universe were created such as iron. Iron fulfils an important role since it binds to oxygen and thereby enables transport of oxygen throughout the body. In this way, we could plead that we are connected with the universe and experience positive effects of natural collaboration outcomes that occur in the universe. The red dot and the two lines zooms out on a group of people pictured in a circle, which indicates that people on earth collaborate but everyone needs to put effort in it (everyone has a role). The person with dementia is enlarged to show that even though the person with dementia experiences cognitive decline (brain loses leaves), the most important and early memories remains close to the heart (the heart has hands to grab the falling leaves). Therefore, the wishes and needs of persons with dementia regarding life in its whole need to be identified before the brain loses too many leaves.

Graphic designer Ilse Modder designed the cover page and conducted the layout of this thesis (www.ilsemodder.nl).

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COLLABORATIVE AWARENESS IN THE DEDICATED PALLIATIVE CARE APPROACH FOR PERSONS WITH DEMENTIA

PROEFSCHRIFT

Ter verkrijging van de graad van doctor
aan de Universiteit Maastricht,
op gezag van de
Rector Magnificus, Prof. dr. Pamela Habibović,
volgens het besluit van het College van Decanen,
in het openbaar te verdedigen op
woensdag 15 november 2023 om 13:00 uur.

door

Chandni Khemai

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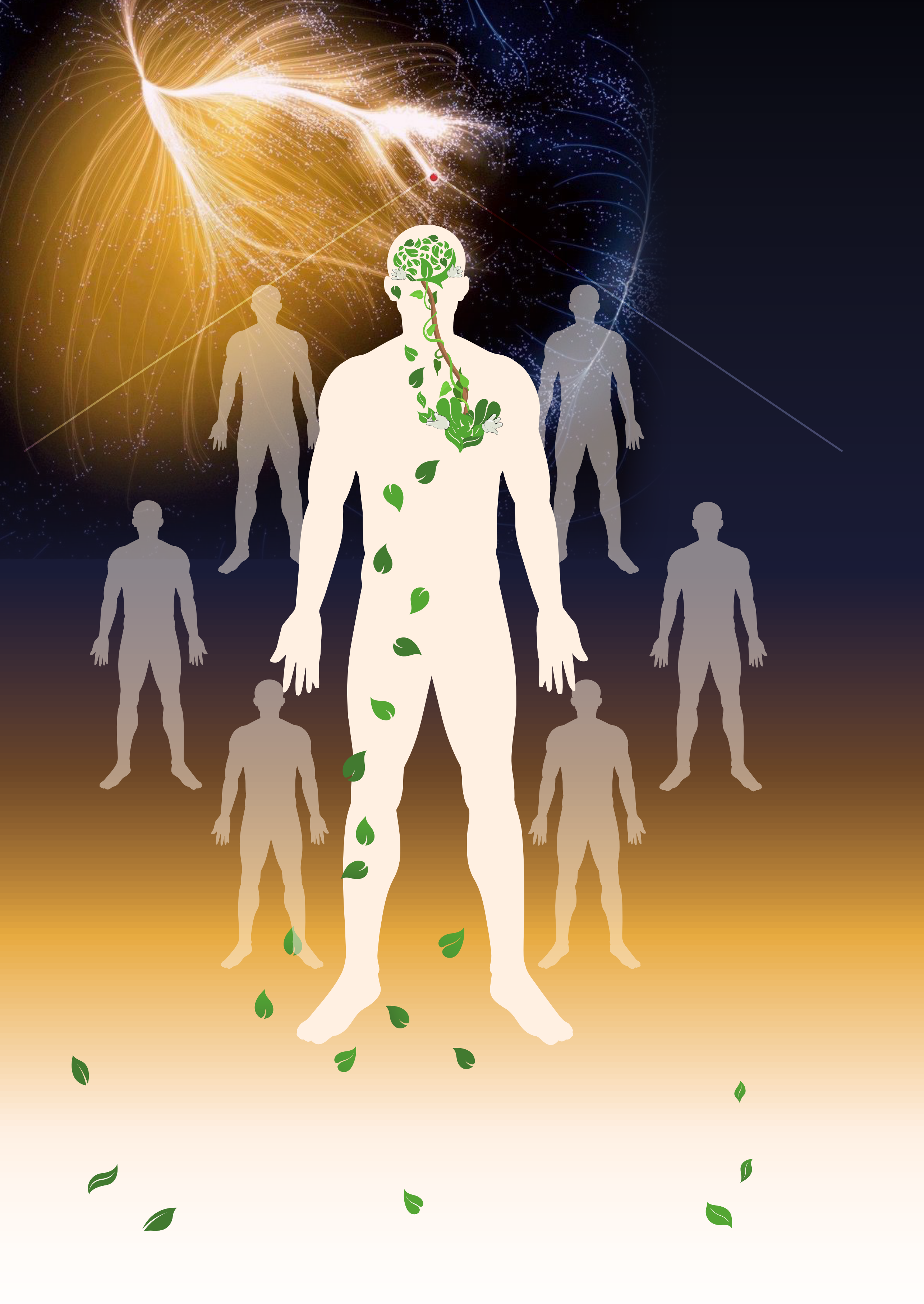
Dr. M. Engel (Universitair Medisch Centrum Utrecht)

No man is an island. Entire of itself;
Every man is a piece of the continent. A part of the main;
Any man's death diminishes me, because I am involved in mankind;
Therefore never send to know for whom the bell tolls. It tolls for thee.
~ John Donne

I dedicate this PhD thesis to my lovely parents Chittra Khemai-Ghurahoo and Dewanand Khemai, and my little brother Dayand Khemai.

CONTENTS



CHAPTER 1

GENERAL INTRODUCTION

PALLIATIVE CARE: USING A HOLISTIC VIEW FOR LIFE-LIMITING DISEASES

One of the pioneers in the field of palliative care was Dr. Cicely Saunders, who had several professions (nurse, chaplain, physician and researcher specialised in pain in terminal care[1]) and founded the first hospice *St. Christopher's Hospice* in London in 1967[2]. She emphasised the importance of identifying the multidimensional needs of patients and their families[3], and introduced the principle of 'total pain'[4]. The principle 'total pain' indicated that pain does not only contain physical aspects, but psychological, social, spiritual and practical aspects as well[5]. Originally, this holistic care principle merely addressed the dying phase[6] and targeted cancer patients[2]. This is why terms such as hospice care, terminal care, and end-of-life care dominated[7-10]. Over time, the focus of caring for the dying and patients with cancer gradually shifted towards additionally caring for those with a life-threatening non-cancer disease[11, 12] and supporting them from the time of diagnosis[13, 14]. In 1974, Balfour Mount, a surgeon, officially announced the term palliative care[15, 16], which is derived from the Latin noun *pallium* (cloak)[15] and descended from the Latin verb *palliate* (mitigate)[17]. Up to date, many definitions for palliative care have been reported during the past decades[18-24]. Radbruch et al. (2020) provided the most recent definition, which stated that *'Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end-of-life. It aims to improve the quality of life of patients, their families and their caregivers'*[25]. Palliative care can be provided during any stage of the chronic illness[26] and may simultaneously coexist with disease-modifying treatments[27].

Palliative care has been shown to increase the quality of life of patients[28, 29], increase caregiver experience[30], decrease symptom burden[28, 31], increase psychosocial health[30], improve care planning[30], increase the chance of dying at home[32], and decrease hospitalisation[31]. Apart from the abovementioned positive care outcomes, palliative care is also identified as a human right[33-35] as every patient has the right to be free from pain and suffering[36, 37]. Palliative care is ideally offered by an interprofessional team, and entails support to patients and their informal caregivers. Moreover, it acknowledges dying as a normal part of life, does not hasten or postpone death, and includes bereavement care[2, 9, 15, 25, 38, 39]. Some studies also mention the palliative care approach as term[40-42]. The palliative care approach is a manner to incorporate palliative care principles throughout the entire progressive disease trajectory, and integrate palliative care in all healthcare settings[41, 43]. These palliative care principles include person-centred care[41], family-centred care[43], therapeutic relationship[43], clear communication about care goals[14] and advance care plans[43], respect for autonomy and dignity[15], comfort care and maintenance of functional capacity and quality of life[41].

THE PATH OF DEMENTIA

> *"Gradually, Alison felt that her father John found it increasingly difficult to function in daily life. Things such as resetting the computer, which John could do easily before as IT specialist, now became an immense task for him. Alison also noticed that John was not able to follow long conversations. He was getting more repetitive in conversations and had started to lose his temper very easily. Alison took John to the general practitioner who referred him to the neurologist. After a few tests, the neurologist concluded that John has Alzheimer's disease and prescribed medications to manage his symptoms.'' (Adapted from Forman et al. (2015) and Ooi et al. (2018))*[44, 45]

It is estimated that 6.5% of people aged 65 years and older will have dementia[46]. Dementia is identified as an acquired major neurocognitive disorder affecting at least two cognitive domains (complex attention, executive functioning, learning and memory, language, perceptual motor or social cognition)[47, 48] and is estimated to be a major cause of death by 2040 in the Netherlands[49]. There are four broad subtypes of dementia: Lewy body dementia (less than 5%), Frontotemporal dementia (between 5% and 10%), Vascular dementia (between 20% and 30%), and Alzheimer's disease (between 50% and 75%)[50]. Common consequences for persons with dementia include cognitive decline[51], a decline in basic functions[52], and pain and neuropsychiatric symptoms[53, 54]. Many persons with dementia also suffer from comorbidities (such as hypertension and diabetes mellitus)[55-58], which may aggravate the progression of cognitive and functional decline[56, 59]. This could eventually result in increased hospitalisations and institutionalisations[60], and increased risk of mortality[61].

The disease trajectory of dementia differs for each subtype and each individual[62-64], and exhibits a protracted gradual decline[65-69]. This gradual decline is usually accentuated with acute illnesses or events[53, 70] leading to a lower baseline functioning[71]. However, most persons with dementia encounter the general three stages: the early stage (about two to four years), the middle stage (about two to ten years) and the end stage (about one to three years)[64, 72, 73]. The early stage of dementia is characterised by loss of short-term memory, confusion, difficulty in making decisions, anxiety, agitation, and difficulty with daily activities[64]. Persons with dementia in the middle stage need more support in daily life and fail to recognise familiar persons. They also may display distress, aggression and anger, and wander and/or experience hallucinations[64]. Towards the end stage of dementia, the ability to recognise familiar objects, environments and persons slowly diminishes, physical frailty increases, problems occur with eating and swallowing[64] and the chance of infections increases[74]. During the path of dementia, care needs to be adjusted according to the needs in each stage[75]. The common path of dementia starts with the recognition of symptoms and receiving the diagnosis (in the early stage), moves on to increasing loss of independence and receiving home care or/and respite services (in the middle stage), and usually ends with moving to the nursing home and receiving end-of-life care (in the late stage)[75, 76].

THE IMPORTANCE OF A PALLIATIVE CARE APPROACH FOR PERSONS WITH DEMENTIA

A plethora of studies has emphasised the importance of a palliative care approach in dementia[54, 77-84]. There are four core reasons for adopting a palliative care approach in dementia. First, dementia is a life-limiting disease[85] because it shortens the life expectancy ranging from two to eight years[86]. Second, dementia exhibits an unpredictable disease trajectory[68] for which no curative medicine is available at this moment[68, 87]. Third, literature has highlighted the need for person-centred care[88] and the need to anticipate to preserve the personhood, dignity and autonomy of persons with dementia[89]. Fourth, persons with dementia have several complex needs under which physical, social, psychological, spiritual, and environmental needs[84, 90-92], which a palliative care approach can address. For example, physical needs include basic care needs, social needs involve relationships, psychological needs comprise emotional needs, and environmental needs concern ambience or/and institution-related needs[90]. Previous literature has shown that palliative care may improve quality of care[93], improve symptom management and care satisfaction at the end-of-life[94], reduce hospital admissions[95], and stimulate person-centred care[96, 97] for persons with dementia.

Existing literature does not describe the best method to incorporate a palliative care approach in dementia care. However, an international Delphi study reported a framework to provide optimal palliative care to persons with dementia[98]. This framework describes eleven domains: 1) Applicability of palliative care; 2) Person-centred care, communication and shared decision-making; 3) Setting care goals and advance care planning; 4) Continuity of care; 5) Prognostication and timely recognition of dying; 6) Avoiding overly aggressive, burdensome or futile treatment; 7) Optimal treatment of symptoms and providing comfort; 8) Psychosocial and spiritual support; 9) Family care and involvement; 10) Education of the health care team; and 11) Societal and ethical issues. Even though the additional value of a palliative care approach in dementia care is evident, more persons with dementia receive suboptimal palliative care compared to persons diagnosed with cancer[99]. This results in unmet palliative care needs for persons with dementia[100], such as untreated pain[62, 101, 102], aggressive treatments[103, 104], unnecessary hospitalisations[105], inappropriate medication[106], and an unpreferred place of death[106].

THE IMPORTANCE OF COLLABORATION IN PALLIATIVE DEMENTIA CARE

> *"John lived alone, and received support from a home care organisation in activities of daily living and the municipality in household tasks. Alison lived next to John and supported John on a daily basis. She often communicated with the home care nurses and articulated on his behalf what he prefers in the care process. The home care organisation arranged a dementia case manager (Patty) for John and Alison to monitor the situation at home. Patty discussed the physical and environmental challenges with the home care nurses and updated the general practitioner about John's situation. The general practitioner made referrals to the occupational therapist and physiotherapist who supported John with executing physical exercises and making home adjustments. Patty had several conversations with John (often accompanied by Alison) in which she asked him how he felt, what he needed and what would make it untenable for him at home. John initially did not want to talk about a possible future move, but stated that he would not manage double incontinence to save his soul and mentioned that he would prefer a nursing home in his neighbourhood. Patty also addressed the burden that Alison experienced, referred her to a support group or counsellor to talk about her experiences, and supported her with arranging respite care services.'' (Used findings of Sideman et al. (2021)[107])*

Many studies have highlighted the presence of fragmentation in palliative care for persons with dementia[108-111]. A frequently reported barrier to provide continuous and integrated palliative dementia care is the lack of collaboration between various healthcare professionals and throughout different care settings[112-116]. Diverse healthcare professionals surround a person with dementia[117, 118] to optimise symptom control and quality of life[119]. These healthcare professionals include for example physicians, nurses, allied health professionals, social workers, dementia case managers, and spiritual caregivers, whom have different tasks in dementia care[120]. Physicians diagnose dementia, can estimate the prognosis, treat symptoms, prescribe medicines, provide referrals[121], provide person-centred integrated care[122], and perform care planning[123]. Nurses provide basic care[124], monitor symptoms[121], guide medication adherence, and have the closest relationship with the person with dementia to understand their needs[124]. Allied health professionals cover a range of therapists such as physiotherapists (focus on promoting balance and mobility)[124], psychologists (focus on behaviour and mood)[124], occupational therapists (focus on environmental modification)[125], dieticians (focus on nutrition and weight management)[126], and speech therapists (focus on communication abilities)[127]. Social workers support the person with dementia and informal caregivers in receiving resources, liaise with agencies and services, and counsel them to cope with changes, conflicts and crises[121, 124, 128]. Spiritual caregivers could support persons with dementia to deal with the loss of functioning, relationships and social status, and guide them through the grieving process and dying phase[121]. For informal caregivers, spiritual support also increases their confidence in problem solving and their capacity to reframe problems, and decreases caregiver burden[129]. In the Netherlands, dementia case managers are often social workers or nurses who received additional education on case management and guide persons with dementia and their informal caregivers at home till institutionalisation[130]. They provide educational and emotional support[131, 132], coordinate home care and social service[133], refer to caregiver resources[134], advice on legal matters[134], monitor the care plan[132, 135], and closely collaborate with other healthcare professionals to integrate and manage the care process[134]. Moreover, they could delay admissions to long-term care institutions for persons with dementia[136].

INTERPROFESSIONAL COLLABORATION: WHAT IS IT?

Various terms exist to describe and distinguish the process of collaboration. The most frequently described terms are multiprofessional collaboration and interprofessional collaboration[137]. In multiprofessional collaboration, diverse healthcare professionals work towards a common goal[138] and exchange information with each other[139]. However, in this type of collaboration healthcare professionals assess the patient independently from each other[139], make autonomous decisions[140] and create their own care plans for the patient. In interprofessional collaboration, integration occurs among healthcare professionals. This manifests in healthcare professionals incorporating each other's knowledge and expertise[141], formulating the problem together[138], making shared decisions[142], and creating one care plan together[139]. Therefore, interprofessional collaboration is considered superior to multiprofessional collaboration. Interprofessional collaboration leads to significantly higher effects on teamwork (i.e. person orientation, task accomplishment, cohesion and willingness to accept responsibility) and team effectiveness (i.e. organisation, communication and satisfaction)[143]. In this thesis, we use the term interprofessional collaboration.

The WHO defines interprofessional collaboration as a '*collaborative practice when multiple health workers from different professional backgrounds work together with patients, families, carers and communities to deliver the highest quality of care across settings*'[144]. Within interprofessional collaboration, patients and their informal caregivers in fact are part of the interprofessional team[145]. Patients are considered as active participants in the decision-making process[146] and their informal caregivers are involved as advocators in the care process[147]. Interprofessional collaboration improves patient safety[148], improves patient satisfaction[149], improves care quality[150, 151], increases job satisfaction[149, 151], reduces clinical errors[152, 153], improves communication[154, 155], enhances problem solving[156], enhances continuity of care[157], and improves coordination of care[158].

THE MOVE TO A NURSING HOME FOR PERSONS WITH DEMENTIA

> *"John experiences more and more difficulties coping with everyday life challenges due to his severe Alzheimer's disease. Alison explains that the burden of taking care of her father as well as working and supporting her teenage children is becoming too much for her. Together with Patty, John and Alison talk about a possible move to the nursing home. John had stated months ago that he would be ready to move to a nursing home if he had become doubly incontinent but this is not the case yet. However, he feels that everything is getting a bit much for him and his daughter. He does not want to become a burden to his daughter. John and Alison will start to explore which nursing homes have vacancies in the neighbourhood and Patty put John's name down on their waiting lists."*
> *(Adapted from Forman et al. (2015) and Ooi et al. (2018))*[44, 45]

About 70% of the persons with dementia live at home and receive care from informal caregivers[159] next to general practitioners[160], home care services (including nurses and dementia case manager[130]), and community[161] and social services[162]. Living at home supports persons with dementia to maintain their continuity in life and feeling of being in control of their life[163]. Aging-in-place is preferred by persons with dementia[164], stimulated by national policies[165] and endorsed by nursing home eligibility criteria that have been tightened[166-168]. Certain tipping points in the dementia care process inevitably result in the move to a nursing home[169]. These tipping points could be crisis events (such as hospital admissions)[169], increased symptoms of persons with dementia[170], overall health deterioration of the person with dementia[169, 171], increased caregiver burden[170], and realisation and concession of informal caregivers of not being able to care anymore[169, 171]. These consequently cause approximately 75% of persons with dementia to move to a nursing home by the age of 80 years[172]. Moreover, about 90% of the persons with dementia move to a nursing home during the end-of-life and eventually die in a nursing home[173].

Deciding to move to a nursing home is a difficult, emotional and stressful decision in dementia care[174, 175]. Persons with dementia wish to have a role in the decision-making process[176]. However, they are often passive partners during the move[177] due to the cognitive decline[178], and are therefore unable to realise the impossibility of staying at home[179]. This makes it difficult to negotiate or discuss the move with them[178] and subsequently places this responsibility on the shoulders of informal caregivers, who feel unprepared and lonely in this process[180]. Moreover, informal caregivers experience feelings of guilt for abandoning their relative with dementia[180-182]. This is the reason why healthcare professionals should anticipate the move to the nursing home with persons with dementia[178] and support their informal caregivers in the decision-making process[171, 183]. Furthermore, the move to the nursing home in dementia care increases the risk of unique challenges[184], disorientation[185], unmet needs[186, 187], and adverse outcomes[188]. Therefore, collaboration between the care settings[189] (especially adequate communication and information transfer[190]) is crucial for optimal coordination of the move[179]. Likewise, information transfer[191] together with consultation with colleagues, assessment of preferences and needs, and advance care planning are facilitators for a seamless move[192, 193].

ADVANCE CARE PLANNING FOR PERSONS WITH DEMENTIA

> *"Three weeks after the moving day, a family meeting was planned together with John, Alison and her brother Cam. The elderly care physician from the nursing home suggested to make an advance care plan. Since John had been unable to prepare an advance care directive earlier, it was up to the family, with the support of the care team, what John would have wanted and how John should be treated in case of acute medical situations." (Adapted from two references)*[44, 45]

Rietjens et al. (2017) defines advance care planning as a process that *'enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare professionals, and to record and review these preferences if appropriate'*[194]. The objectives of advance care planning are to respect autonomy, improve quality of care, bolster relationships, prepare for end-of-life care, and reduce overtreatment during[195]. Traditionally, advance care planning is seen as a process solely focusing on medical decisions such as decisions about resuscitation or feeding tubes[196-198]. However, advance care planning views the future in a holistic way[199]. Thereby, advance care planning conversations also cover changes in the dementia trajectory[200]; care goals[200]; the preferred care location[201]; activities that a person wants to pursue[201]; support for informal caregivers[200]; and the dying phase and bereavement care[200]. Compared to persons without dementia, persons with dementia are more likely to receive insufficient pain treatment[202] and more invasive treatments[203] such as feeding tubes or antibiotics during end-of-life[204]. Advance care planning could positively impact persons with dementia as it can decrease hospitalisations[205], decrease invasive treatments[206], and increase the concordance between expressed wishes and received care during end-of-life[205]. Advance care planning conversations with persons with dementia should be conducted in an early phase in which the communication, decision-making and reflection capacities are still intact[207]. However, globally, less than half of the persons with dementia participate in an advance care planning conversation and document their preferences[208]. Hence, in most cases, persons with dementia cannot participate in advance care planning[209]. Consequently, informal caregivers act as proxy decision makers and make decisions about end-of-life care for their relatives with dementia[210-212]. Apart from the involvement of informal caregivers, advance care planning may require the presence of an interprofessional team to make joined decisions[213, 214].

THESIS AIM AND OUTLINE

The main objective of this PhD thesis was to investigate what is important and what is needed in interprofessional collaboration in palliative dementia care. These findings are covered in the studies reported in this thesis, as part of the DEDICATED (Desired Dementia Care Towards the End of Life) research project. Most of these studies mapped the perspectives of diverse collaborators (persons with dementia, informal caregivers, and healthcare professionals) and focused on living at home, moving to a nursing home and living in a nursing home (see Figure 1).

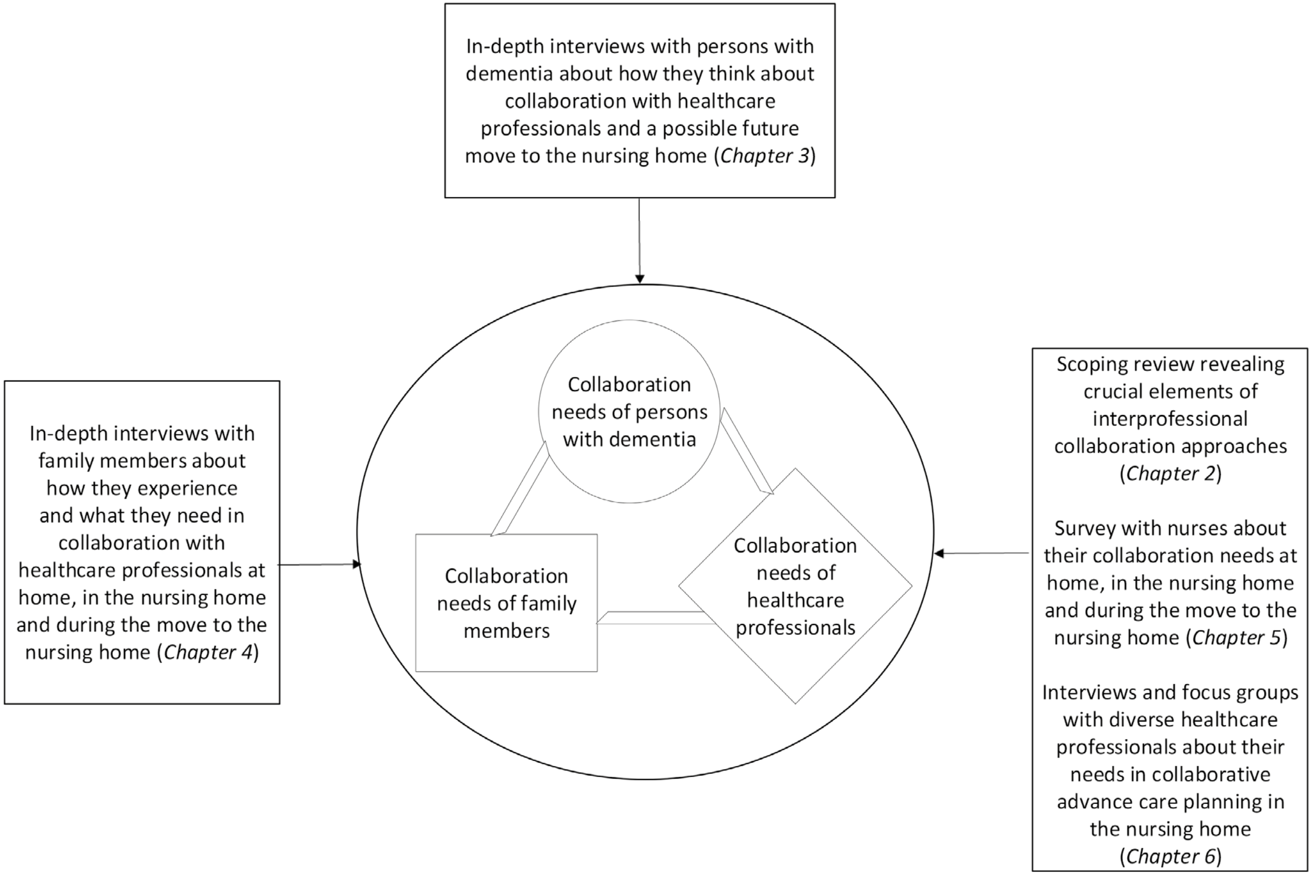


Figure 1. Description of the focus of the studies in relation to the various investigated perspectives and collaboration needs of the collaborators in palliative dementia care.

This thesis addresses the following research questions:

1. What are the elements that constitute interprofessional collaboration approaches in palliative dementia care?
2. What do persons with dementia need in collaboration with healthcare professionals, and how do they think about a possible future move to a nursing home?
3. How do informal caregivers experience collaboration among and with healthcare professionals in palliative dementia care?
4. What are the needs of nurses in interprofessional collaboration in palliative dementia care?
5. What are the key elements for interprofessional collaboration in advance care planning in dementia care?

This thesis is structured as follows:

- Chapter 2 provides a scoping review on existing interprofessional approaches in palliative care for persons with dementia.
- Chapter 3 identifies the perspectives and needs of persons with dementia regarding collaboration with healthcare professionals and a possible future move.
- Chapter 4 explores the experiences and needs of informal caregivers of persons with dementia regarding collaboration with healthcare professionals.
- Chapter 5 reports the needs of nurses concerning collaboration with other healthcare professionals in palliative dementia care.
- Chapter 6 shows the perspectives of various healthcare professionals about collaboration regarding advance care planning for persons with dementia and presents a guidance document on collaborative advance care planning.
- Chapter 7 summarises and discusses the findings, and reflects on this thesis' methodological and theoretical aspects.

DESIRED DEMENTIA CARE TOWARDS END-OF-LIFE (DEDICATED)

The studies in this PhD dissertation are conducted as part of the Desired Dementia Care Towards End-of-life (DEDICATED) research project. The main aim of DEDICATED is to improve palliative care for persons with dementia living at home and in nursing homes[215]. DEDICATED consists of two sub-projects that address different target groups and topics within palliative dementia care. Sub-project one specifically focuses on the competencies of home care and nursing home nurses concerning basic palliative care and end-of-life care, while sub-project two namely focuses on the needs of an interprofessional group concerning interprofessional collaboration in the home care, nursing home and during the move from home to the nursing home. Both sub-projects complemented each other as they focused on different areas within palliative dementia care and contributed to the development of the overall DEDICATED approach. The DEDICATED approach, consisting of the materials developed by both sub-projects, is a practical work approach that healthcare professionals working in home care and nursing homes could use to provide palliative care for persons with dementia.

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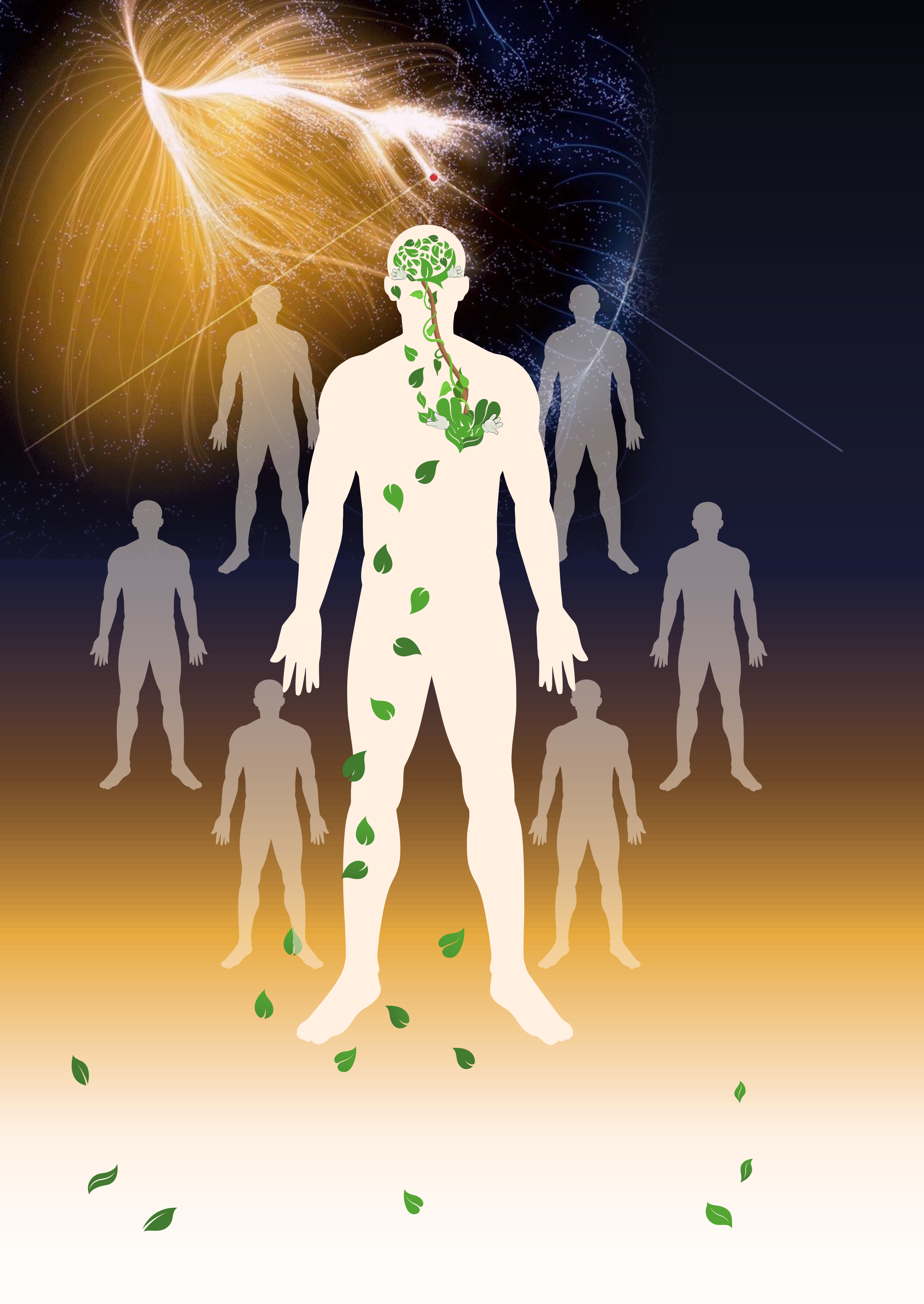

CHAPTER 2

INTERPROFESSIONAL COLLABORATION IN PALLIATIVE DEMENTIA CARE: A SCOPING REVIEW

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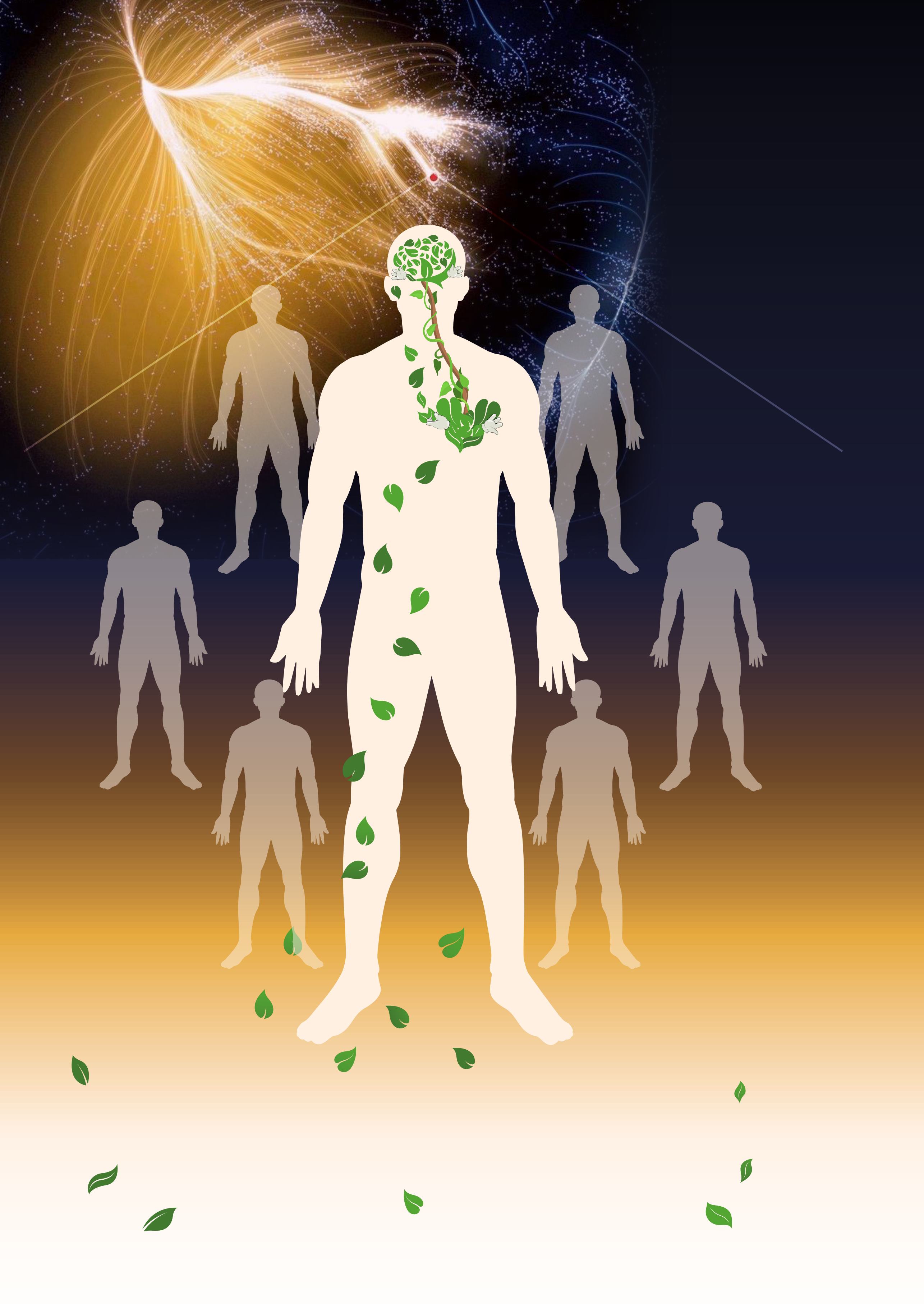
Submitted



CHAPTER 3

I WANT TO BE SEEN AS MYSELF: NEEDS AND PERSPECTIVES OF PERSONS WITH DEMENTIA CONCERNING COLLABORATION AND A POSSIBLE FUTURE MOVE TO THE NURSING HOME IN PALLIATIVE DEMENTIA CARE

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ABSTRACT

INTRODUCTION

Interprofessional collaboration (IPC) within and during movements between care settings is crucial for optimal palliative dementia care. The objective of this study was to explore the experiences of persons with dementia regarding collaboration with and between healthcare professionals (HCPs) and their perceptions of a possible future move to the nursing home (NH) in palliative dementia care.

METHOD

We conducted a cross-sectional qualitative study and performed semi-structured interviews with a purposive sample of persons with dementia living at home (N=18). Data analysis involved content analysis.

RESULTS

Our study demonstrated that even though most persons with dementia find it difficult to perceive the collaboration amongst HCPs, they could describe their perceived continuity of care (*Theme 1. My perception of collaboration among HCPs*). Their core needs in collaboration with HCPs were receiving information, support from informal caregivers, personal attention and tailored care (*Theme 2. My needs in IPC*). Regarding a possible future move to the NH, persons with dementia cope with their current decline, future decline and a possible future move to the NH (*Theme 3. My coping strategies for a possible future move to the NH*). They also prefer to choose the NH, and continue social life and activities in their future NH (*Theme 4. My preferences when a NH becomes my possible future home*).

CONCLUSION

Persons with dementia are collaborative partners who could express their needs and preferences, if they are willing and able to communicate, in the collaboration with HCPs and a possible future move to the NH.

Keywords

Dementia; Collaboration; Transitions; Home; Nursing home

INTRODUCTION

Palliative care (PC) is defined as '*the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end-of-life. It aims to improve the quality of life of patients, their families and their caregivers'*[1]. PC is important to enhance the quality of life for persons with dementia[2], since dementia is a life-limiting [3] and an incurable disease[4]. PC in dementia care may result in positive outcomes such as improved symptom management[5], and personalised care addressing holistic (physical, social, psychological, and spiritual) needs[6, 7]. As persons with dementia have holistic care needs[7] and comorbidities[8], interprofessional collaboration (IPC) is one of the cornerstones of palliative dementia care[9, 10]. IPC, described as a collaborative process between clients, informal caregivers and healthcare professionals (HCPs)[11], is necessary within and between care settings throughout the dementia care journey[12] to ensure continuity and quality of PC, and optimal information transfer[13]. Existing IPC approaches in palliative dementia care have been shown to reduce unmet needs[14]; improve symptom management[15]; improve medication management[16]; increase care satisfaction[17]; and increase quality of life[14].

The dementia journey is often characterised by several involved HCPs within care settings and during movements between care settings[18-20]. Even though a person with dementia prefers to live[21] and receive care at home[22], the move from home to the NH is a common event in dementia care[23]. Continuous IPC is essential during care movements[24-26] in order to avoid fragmented care[27]. Listening to the voice of persons with dementia as collaborative partners in care exceeds the principle of solely taking a person-centred approach[28] and enables them to contribute to collaborative activities[29] such as decision-making[30]. Previous studies have focused on the perceptions and needs of persons with dementia in the moving process to a NH, and the needs of persons with dementia in a NH after the move[31-33]. These studies did not explore their thoughts about a possible future move to the NH. These prior studies plead that, because persons with dementia experience cognitive decline[34], timely preparation for a possible future move to the NH is imperative[35] to identify their perspectives and preferences regarding a possible future move[32, 36]. Our study addresses two research questions: 1) How do persons with dementia experience IPC with HCPs? and 2) How do persons with dementia perceive a possible future move to the NH?

METHODS

DESIGN AND SETTING

We performed a qualitative cross-sectional study as part of the Desired Dementia Care Towards End of Life (DEDICATED) research project aiming to improve palliative dementia care[37]. Semi-structured in-depth interviews were performed with community-dwelling individuals with dementia. The Consolidated criteria for Reporting Qualitative research (COREQ) guidelines were used to conduct the interviews and report the results (*Supplement I*)[38].

HOUSING AND CARE IN THE NETHERLANDS

In the Netherlands, there is a three-layered system: 1) Living at home with or without home care, 2) Living in shelter homes, and 3) Living in NHs[39]. Dutch shelter homes can be described as apartments connected with the NH in which residents can receive services such as short-time care[39]. Other housing options include care homes with different levels of support but without 24/7 care, and day care facilities that can be provided by NHs as respite service for informal caregivers[39-41].

INTERVIEW GUIDE

The themes of the interview guide '*IPC with professionals at home*' and '*Possible future move to the NH*' (*Supplement II*) were based on a Dutch quality framework for PC[42], a white paper on palliative dementia care[2], and a systematic review of end-of-life in dementia care[7]. These two themes are a subset of the integral interview guide on palliative dementia care, which also included future and end-of-life care. These topics were not included in this study, and the related manuscript of this study is published in the *Journal of Clinical Nursing*[43]. Preliminary questions were developed by three researchers (J.M.M., S.B., and S.P.) together with the DEDICATED research team, and validated by a working group consisting of nurses, dementia case managers, chain directors, policy makers, and patient representatives, which were informal caregivers of persons with dementia. The most important feedback that we processed was to make the questions shorter and easily understandable for the persons with dementia. After discussing the questions twice and reaching consensus, the interview guide was evaluated for feasibility through one pilot interview with a person with dementia and a patient representative.

RECRUITMENT

We applied a criterion-based method (Table 1) to recruit persons of 65 years and older with dementia who received care from home care organisations and NHs. The recruitment procedure aimed to include a heterogeneous group and followed a purposive sampling method, because it entailed a subjective sampling method, did not entail accidental sampling[44], and primarily focused on data saturation[45]. The recruiters were dementia case managers, geriatricians and nurses from the care organisations participating in the DEDICATED project. The recruitment assessment was based on their expertise as HCPs, and their direct knowledge and relationship with the person with dementia. The researchers decided not to choose a scale to assess cognitive abilities since these scales do not often accurately reflect the communication skills of persons with dementia. Potential candidates were identified by clinical judgements of the recruiters about the cognitive capacities, communicative abilities and willingness of the person with dementia to participate with the interview. The recruiters provided eligible candidates and (if applicable) their informal caregivers information about the study objective and interview. They provided interested candidates and (if applicable) their informal caregivers a flyer and an information letter, and asked for their consent to share their contact information with the researchers. Details about the recruitment procedure (*Supplement III*) are provided.

Table 1. Inclusion criteria

Persons diagnosed with dementia were included when:	
1.	They were 65 years or older and living at home.
2.	They received care from the partner organisation of the DEDICATED project.
3.	They were aware that they had dementia.
4.	They were able to understand the Dutch language.
5.	They were physically and cognitive able to participate with the interview
6.	They were informed about the research and willing to participate.

DATA COLLECTION

The interviews took place between September 2018 and October 2019 at the participants' own homes. Two female members of DEDICATED were present at every interview, one of whom guided the interview. The other member observed and asked follow-up questions (*Supplement IV*). Interviews were audio recorded and all participants received a code to create anonymous transcripts. Prior to conducting the interviews, the interviewers were trained by a nurse specialist to ask questions understandably, provide the person with dementia sufficient time to answer the questions, and pay attention to their facial expressions. The transcripts were prepared in clean-read verbatim transcripts by a professional transcription service.

DATA ANALYSIS

Transcripts were analysed using NVIVO version 11, and applying deductive and inductive approaches in the content analysis[46, 47]. The data analysis procedure is depicted in Figure 1. We applied a deductive approach for the topic IPC at home because we developed two a priori themes based on previous studies that investigated the perceptions and experiences of (older) patients regarding IPC and described two layers of experiences, namely their perception of and their needs in IPC[48, 49]. We choose a deductive approach for this topic because we aimed to build further on these existing results about IPC but simultaneously further enrich our data by using an unconstrained matrix and thereby additionally developing inductive categories through grouping, categorisation and abstraction[50]. For the topic *Possible future move to the NH*, an inductive approach was applied because no prior research was conducted that captured the perceptions of older people concerning a possible future move. Therefore, we directly choose for open or initial coding to identify important units derived from the data itself to formulate codes and categories, and then organising the categories into themes for this topic[51]. Deductive and inductive coding were performed concomitantly. Two researchers analysed the data in chunks throughout four meetings to achieve optimal categorisation and abstraction of the data. Investigator-triangulation was employed to ensure the internal reliability of the data[52]. The entire data analysis and saturation process is described in *Supplement V* and the coding tree is shown in *Supplement VI*. The results are described through key quotes from the participants, to whom we assigned pseudonyms.

ETHICAL CONSIDERATIONS

Prior to conducting the interviews, written informed consent was obtained from persons with dementia or, if they were not capable from their informal caregivers. When informal caregivers signed the informed consent, the persons with dementia provided oral consent for their participation. We used pseudonyms to report the quotations of the participants. This study adhered to the principles of the Declaration of Helsinki[53] and received confirmation from the Medical Ethics Committee Zuyderland that the Medical Research Involving Human Subject Acts did not apply (registration number METCZ20180085).

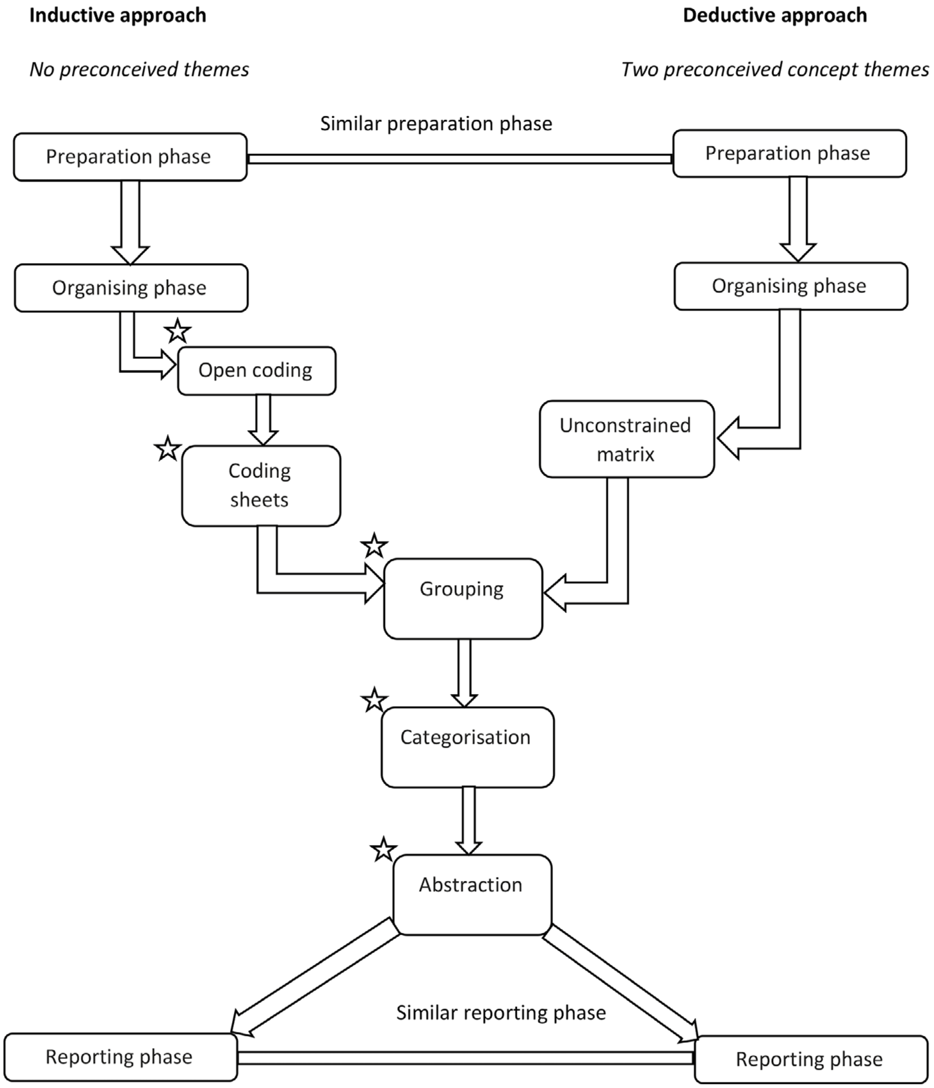

Figure 1. Data analysis scheme. Adapted from the figure depicted in Elo & Kyngäs (2008). The stars indicate the steps in inductive content analysis.

RESULTS

Of the twenty-two candidates, four withdrew due to physical reasons, being overburdened or personal pursuits. The participants (N=18) had a mean age of 82 years (range between 77-93) and 61% were men (Table 2). The majority lived at home (83%) and had informal caregivers (72%). The mean interview time was 53 minutes (SD=19).

We identified the following four themes: 1) My perception of collaboration among HCPs (Figure 2), 2) My needs in IPC (Figure 3), 3) My coping strategies for a possible future move to the NH (Figure 4) and 4) My preferences when a NH becomes my possible future home (Figure 5).

Table 2. Characteristics of persons with dementia (N=18)

Pseudonym	Age	Residence	Involved informal caregiver
Mr Jones	80	Home	Volunteer
Mr Williams	81	Home	Spouse
Mr Smith	83	Home	Spouse
Mr Robinson	83	Home	Spouse
Mrs Jackson	85	Sheltered home	None
Mr Henderson	77	Home	Spouse
Mr Fox[b]	93	Nursing home	Son
Mr Thatcher[b,c]	86	Home	None
Mr Brewer	93	Home	None
Mrs Peters	89	Home	Niece
Mr Miller	73	Home	Spouse
Mrs Baker	94	Sheltered home	Daughter
Mr Johnson[a]	72	Home	None
Mr Fisher	65	Home	None
Mrs O'Brink	88	Home	Daughter
Mrs Newhouse	87	Home	Daughter
Mrs Garrison	67	Home	Daughter
Mrs Damcott[c]	82	Home	Volunteer

[a] *Participant was in an early stage of dementia, had high concentration and communication capacities and had not yet experienced any physical or cognitive deterioration.*

[b] *Participant had advanced dementia, was not able to optimally concentrate or communicate and was not able to realize the presence of healthcare professionals in their daily life.*

[c] *During this interview a dementia case manager or volunteer was present.*

THEME 1. MY PERCEPTION OF COLLABORATION AMONG HCPs

Theme 1 describes the visibility of collaboration among HCPs and the impact on the care experience from the perspectives of persons with dementia (Figure 2).

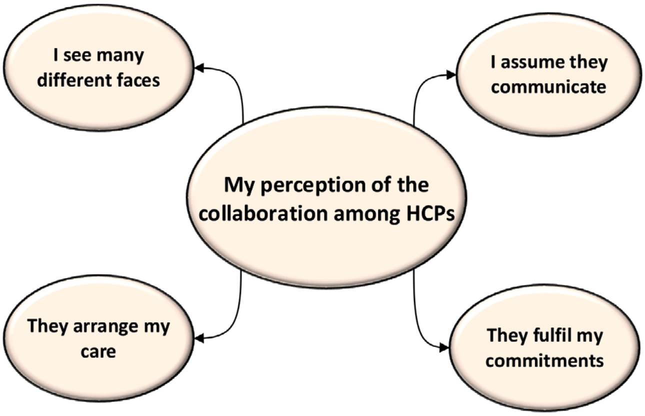

Figure 2. Theme 1. My perception of collaboration among healthcare professionals.
Abbreviations: HCPs = healthcare professionals.

I see many different faces

Most participants could not identify all involved HCPs or identify the specific disciplines to which they belonged. However, most of them knew the faces or names of those who frequently provided care to them, under which the general practitioner, domestic workers and district nurses. Some of the participants mentioned that initially the presence of various HCPs gave them a chaotic or crowded feeling. *'The peaceful life we had has become hectic.' (Mr Henderson)* However, as time passed, they became familiar with HCPs, got used to their involvement and enjoyed conversations with them.

I assume they communicate

The majority indicated that they did not know whether HCPs communicated with each other, but assumed that they did communicate. *'I have the feeling that they meet each other weekly to talk about all the clients.' (Mrs Newhouse)* One participant noticed that HCPs often used the client file at home to communicate with each other. Two respondents said that they knew nothing about it. *'It is up to them whether they want to communicate. That is not something I should interfere with.' (Mr Jones)*

They arrange my care

HCPs supported them in arranging their care process by contacting and involving other professionals or organisations. *'My general practitioner had approached the municipality* *to apply for the Dutch Social Support Act so that we could receive support at home.' (Mr Robinson)* This support gave them a feeling of relief, because they knew that there was someone, apart from their informal caregiver, who took care of them. *'It is reassuring to know that the right people are at the right place.' (Mr Miller)*

They fulfil my commitments

The interviewees experienced the overall collaboration among HCPs as optimal when HCPs executed care tasks according to their care preferences, were up-to-date, were on time and notified other HCPs who took over their shifts. '*You do not have to wait for their arrival, they are always on time. And if someone is not able to come, they send someone else.' (Mr Williams)*

THEME 2. MY NEEDS IN IPC

Theme 2 sums up the four main collaborative needs of persons with dementia (Figure 3).

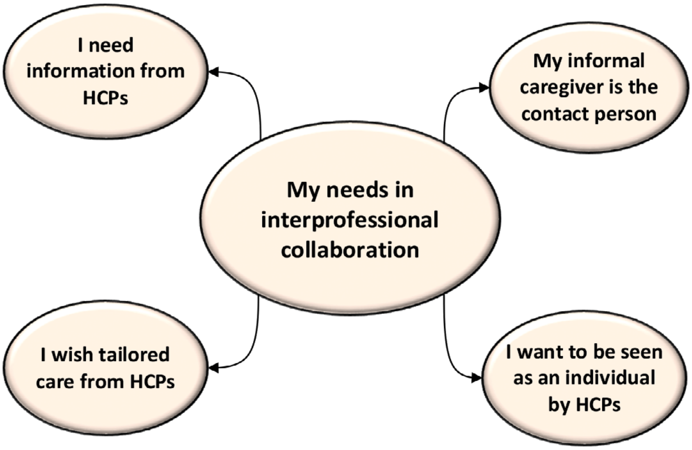

Figure 3. Theme 2. My needs in interprofessional collaboration.
Abbreviations: HCPs = healthcare professionals.

I need information from HCPs

The majority wanted to receive concise and simplified information about dementia and their overall health status. *'I thought dementia: what is that? Is it Alzheimer? What phase? You have all these questions.' (Mr Miller)* A few also wanted to know the effects on their future life. One participant alluded to a support centre for informal caregivers where they received practical information about living with dementia. '*It is important that the person with dementia and her or his informal caregivers are well informed about what is going on.' (Mr Henderson)* The majority did not want to know what HCPs discussed at team meetings, because they were not able to understand the information or were afraid to hear disturbing information. Two participants did want to participate themselves or designate informal caregivers to attend team meetings.

My informal caregiver is the contact person

Most interviewees had informal caregivers who assisted in the care process, communicated and made decisions on their behalf with HCPs. *'I have limited contact with my dementia case manager, because my wife always talks with her. But afterwards my wife always tells me what they talked about.' (Mr Thatcher)* During the interviews, many participants referred to their informal caregivers when talking about how many HCPs were involved and how they collaborated with each other. They also mentioned that their informal caregiver was the contact person for HCPs, arranged the care process (together with HCPs) and monitored their appointments with HCPs for them.

I want to be seen as an individual by HCPs

All participants wanted to be seen as an individual with their own voice and to maintain their independence for as long as they could. *'The things I am able to do, I still want to do and I will do, and they should not tell me to do this and that.' (Mr Jones)* Almost all participants preferred having personal contact i.e. seeing familiar and friendly faces, and taking the time to have (short) conversations.

I wish for tailored care from HCPs

According to persons with dementia, important HCPs' competencies were having knowledge and a professional (proactive) attitude, and being skilled in executing care tasks. The majority was satisfied with their care; however, one participant explained that her general practitioner did not take her seriously: *'She started to laugh and said it was nothing when I told her that my skin turned blue. But the other general practitioner told me that I had bruises because of the platelets, and that is why I had pain and felt nauseous.' (Mrs Jackson)* Most participants indicated that HCPs knew their preferences in the care process, such as when showering or receiving skin care. One participant mentioned that she was satisfied with the way nurses showered her. *'I do not prefer to stand when they wash and dry me, so I sit on a chair in the bathroom.' (Mrs Baker)* Some participants mentioned how they appreciated if HCPs were interested in their personal life or had the same cultural background.

THEME 3. MY COPING STRATEGIES FOR A POSSIBLE FUTURE MOVE TO THE NH

Theme 3 specifies six coping strategies processed in three categories: coping with their current decline, coping with a possible future move to the NH and coping with future decline (Figure 4). Every category portrays two coping strategies, which either have a reciprocal relationship (i.e. respondents use both strategies) or not (i.e. respondents apply one strategy but are aware of the other strategy).

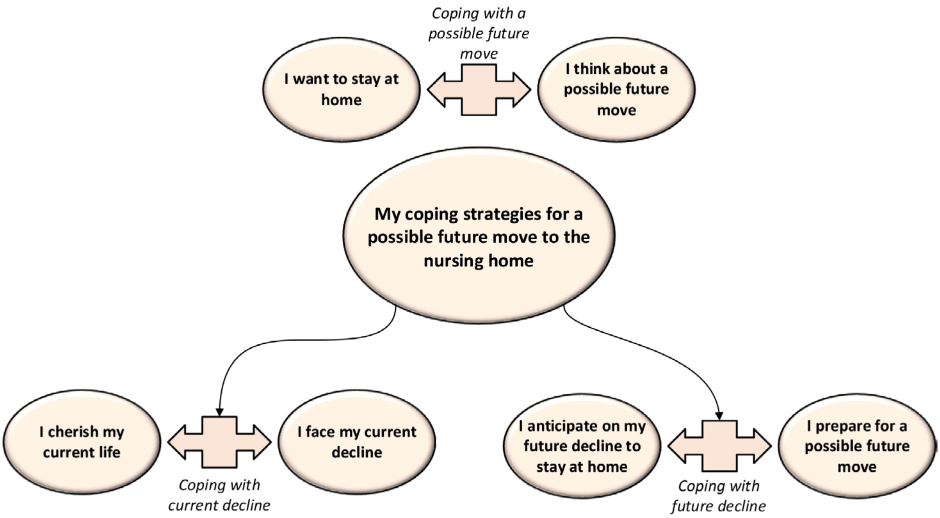

Figure 4. Theme 3. My coping strategies for a possible future move to the nursing home. Abbreviations: NH = nursing homes and o/a = or/and.

1. Coping with current decline:
I cherish my current life ⟷ I face my current decline

All participants cherished life by spending time with close persons and executing meaningful (daily) activities or hobbies, such as walking, playing darts and pool, or going to NH adult day care services. *'I have always been an outdoorsman so every now and then I grab my bicycle.' (Mr Fisher)* Nonetheless, the majority was aware of their overall decline and the increasing number of care tasks that informal caregivers performed. In response, they made adaptations (for example writing down important information), took precautions and/or ceased certain activities. Six participants received personal care from formal caregivers and appreciated the assistance from HCPs, since they could continue with their life and could focus on things they could still do. However, they also often remembered and missed the times when they could take care of themselves.

2. Coping with a possible future move:
I want to stay at home ⟷ I think about a possible future move

All participants wanted to stay at home for as long as possible to keep material and emotional attachments, and autonomy (i.e. freedom, uniqueness, privacy and independence). Material attachment meant living in their own house, with their informal caregivers and/or personal possessions and located in their familiar environment. Emotional attachment refers to their memories, their social interactions, and the feeling of being in charge of their life. Most referred to the NH as a place for the 'end stage of life' and described a possible future move to the NH as a threat because they were afraid to lose their meaningful life and autonomy. *'You become just one of the other NH residents and do not have your own environment.' (Mr Jones)* Half of the participants did not want or were not able to think about a possible future move to the NH because they were not willing or able to imagine their future decline. '*I do not wish to explore what I need to do when this or that happens.' (Mr Brewer)* Others, who were able or willing to imagine their future decline, mentioned the possibility of a possible future move. They preferred moving to a sheltered home due to their incremental decline and the burden on their informal caregivers. Two participants indicated their fear of being alone and realised their inability to maintain their house.

3. Coping with future decline: I anticipate my future decline to stay at home ⟷ I prepare for a possible future move

Half of the participants anticipated their future decline by seeking information and support, and adjusting their homes. Several of these participants were postponing the time to further think or talk about it as they saw it as an event in the far future. The minority, however, mentioned that they had let go of their wish to stay at home (i.e. ending the struggle to be independent, and enjoying receiving care), and also discussed and/or prepared for a possible future move (by, for example, performing NH visits). Two participants joined in day care centre activities at a sheltered home or a NH to get used to the new environment. *'I visit the day-care centre twice a week to get a feeling how it would be to live there.' (Mrs Damcott)*

THEME 4. MY PREFERENCES WHEN A NH BECOMES MY POSSIBLE FUTURE HOME

Theme 4 describes what persons with dementia believe is important to feel at home in a NH (Figure 5).

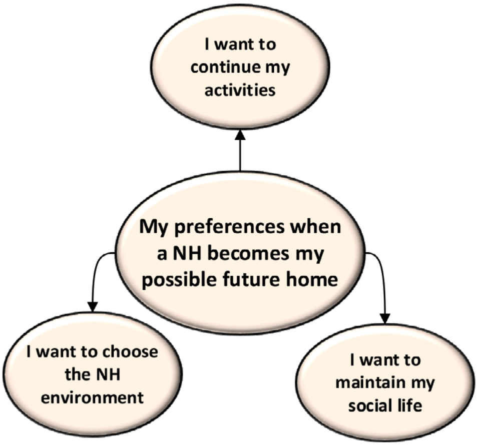

Figure 5. Theme 4. My preferences when a nursing home becomes my possible future home. Abbreviations: NH = nursing home.

I want to choose the NH environment

Some participants said that they would prefer a NH in their familiar environment, close to their informal caregivers' home, which contains familiar attributes such as having a garden, and provides a familiar feeling such as the presence of previous or current informal caregivers as residents. '*As long as they do not send me to another city, because I come from *name town*, I know this environment.' (Mr Miller)*

I want to continue my activities

All participants wanted to maintain their daily activities or hobbies in NHs. For example, *'I visited the sheltered homes and I could not say that it was terrible, but they said that they would not bring me to the church where I sing every week. But I really like to sing.' (Mrs Damcott)*

I want to maintain my social life

Participants find it important to remain connected with their informal caregivers, and have friendly HCPs and residents. '*Harmony in contact with NH staff and with the other residents is important.' (Mr Johnson)*

DISCUSSION

Overall, our study demonstrated that important needs of persons with dementia in collaboration with HCPs were receiving information, support from informal caregivers, personal attention and tailored care. Moreover, we showed that persons with dementia display six coping strategies when thinking about a possible future move and express three preferences when moving to a NH. The collaboration among HCPs at the process level was largely invisible to them. However, they could describe their perceived continuity of care. The collaboration needs we identified are concordant with previous studies demonstrating that many persons with dementia are still able to express their care preferences and expectations[54]; request information about dementia[55]; and prefer skilled and respectful HCPs[56]. Moreover, they want to be valued as individuals[57]; and maintain dignity, autonomy, and self-respect[43, 58]. Many of the abovementioned needs belong to important principles of PC[54, 59, 60]. The needs about a possible future home we described are also in line with previous studies, which investigated the needs of persons with dementia after making the decision to move to a NH: requesting a familiar environment[61], remaining able to perform meaningful activities[62], and establishing meaningful relationships[63].

The fact that our study shows that persons with dementia wish to maintain their independence for as long as possible, continue with their activities, and maintain their social life is underlined by previous studies[64, 65]. This finding indicates that even though persons with dementia depend on informal caregivers and HCPs for preserving their personhood[66] and executing several tasks[67], they are able to contribute to joint activities themselves (such as for example getting dressed) as collaborators[29, 68]. A PC approach in an early dementia stage[69] could enable HCPs to proactively capture and deliver care according to these needs[70] before severe cognitive decline occurs[71].

With respect to the move to the NH, many persons with dementia wish to concentrate on the present[56] and perceive the move to the NH as the 'end'[72]. However, some persons with dementia do realise their difficulties[31] and do not want to be a burden for their informal caregivers[73]. Our study showed that even though persons with dementia did not want to move to a NH, most of them were still able to express their needs to feel at home in a NH or to feel at home in their current environment. Therefore, it is crucial to regularly conduct personalised conversations by identifying coping strategies of persons with dementia[74] regarding a possible future move to the NH. Preparing the move enables informal caregivers and HCPs to identify the needs of persons with dementia in an early stage[32]. This preparation could aid future decision-making[60] and preserve their relational and prospective autonomy[75]. Since persons with dementia and their informal caregivers might accept a NH move more easily when their personal needs and difficulties are discussed, preparation through actually involving persons with dementia prior to the move could influence the way they feel in a NH[31] and improve familiarisation with the NH environment[76]. Furthermore, Brownie et al. (2014) showed that persons involvement in the decision-making process regarding a care transition is pivotal to NH adjustment while keeping in mind that the needs and preferences of persons with dementia of course may change when their illness progresses making this a continuous dialogue[77]. It is important for HCPs to prepare for this move together with the person with dementia and their informal caregivers by organising NH visits, home visits and assembling information about the person's life story, and current valuable routines and hobbies. This will help to become familiarised with the HCPs and NH, and is needed to build relationships and improve relational and prospective autonomy[25]. Building these relationships is crucial, as this could positively influence future NH experiences[78, 79].

The importance of identifying the meaning of a move for persons with dementia was pinpointed by previous studies[36, 72]. However, we additionally revealed coping strategies that HCPs may support in understanding the person with dementia, and adapting the conversation approach about a possible future move to the NH. Knowing collaborative and needs concerning a possible future move of persons with dementia in time could improve person-centred care; preserve identity; facilitate shared decision-making; and support in preparing for the move to the NH. These processes are described in the domains to provide optimal palliative dementia care[2], and are mediated through IPC[74, 80, 81]. HCPs should take a collaborative approach in which they aim to include persons with dementia to hear their voice[82], and informal caregivers since they are advocators and proxy-decision makers[83, 84]. Moreover, different HCPs, such as for example dementia case managers[32], nurses[85] or general practitioners[86], could explore the thoughts and needs of persons with dementia regarding a possible future move, and transfer this information to HCPs from the NH. This collaborative approach may optimise person-centred information transfer[87] and coordination of the move[88, 89].

METHODOLOGICAL CONSIDERATIONS

The main strength of our study is that it captured the experiences and perspectives of persons with dementia living at home. Our study provides insight into how dementia affects people's lives and shows how they process their thoughts about a possible future move by looking at their past, present and future. However, there are four limitations to consider when interpreting our results. First, during two interviews, a volunteer and dementia case manager were present, who sometimes interfered or asked questions themselves that might have influenced the responses of the participants. Second, there may have been sampling bias, because the recruiters selected candidates based on their clinical expertise and did not objectively measure the cognitive performance of persons with dementia. Therefore, we could not identify the severity of dementia of the participants. However, the aim of this study was to capture the experiences and needs of persons with dementia concerning IPC and a possible future move to the NH. Moreover, even though two persons with dementia displayed more advanced dementia symptoms, of which one participant had just moved to a NH, they were still able to express themselves and touched upon the same themes as the other participants. This finding that even though persons with dementia may show minor communication difficulties such as repetition, or memory difficulties such as not remembering whether they receive care, they still may provide insightful responses[72]. This suggests that our findings may be include general themes that are applicable to persons with dementia during different stages, and inclusion of persons with dementia in research should consider a person-centred approach. Third, since 70% of the participants were men, our findings could compromise the generalisability of our findings. Our hypothesis is that perhaps in our study setting more men with dementia live at home because they are being taken care of by their female spouses, while women with dementia tend to end up in NHs more quickly than men do because women outlive men. This hypothesis is underlined by a Swedish study that mentioned that more men with dementia lived at home compared to women, while more women lived in NHs compared to men[90]. Lastly, we did not include persons with dementia living in a NH, whereas Mjørud et al. (2017) showed that they are able to communicate their feelings and thoughts about living in a NH, and could identify factors that influence their quality of life in NHs [91].

CONCLUSION

Persons with dementia are able to express their needs and preferences as collaborative partners regarding the collaboration with HCPs and a possible future move to the NH. By sharing and respecting these needs and preferences, persons with dementia could engage in joint activities and thereby receive personalised PC. The coping strategies showed that most persons with dementia are willing and capable of realising their current and future decline, and half of them are open to conversations about a possible future move to the NH. Based on our findings, we recommend HCPs to proactively identify the needs, coping strategies and preferences of persons with dementia in an early phase, when they are willing and able to communicate.

CONFLICT OF INTEREST

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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DISCLOSURE STATEMENT

The authors report there are not competing interests to declare.

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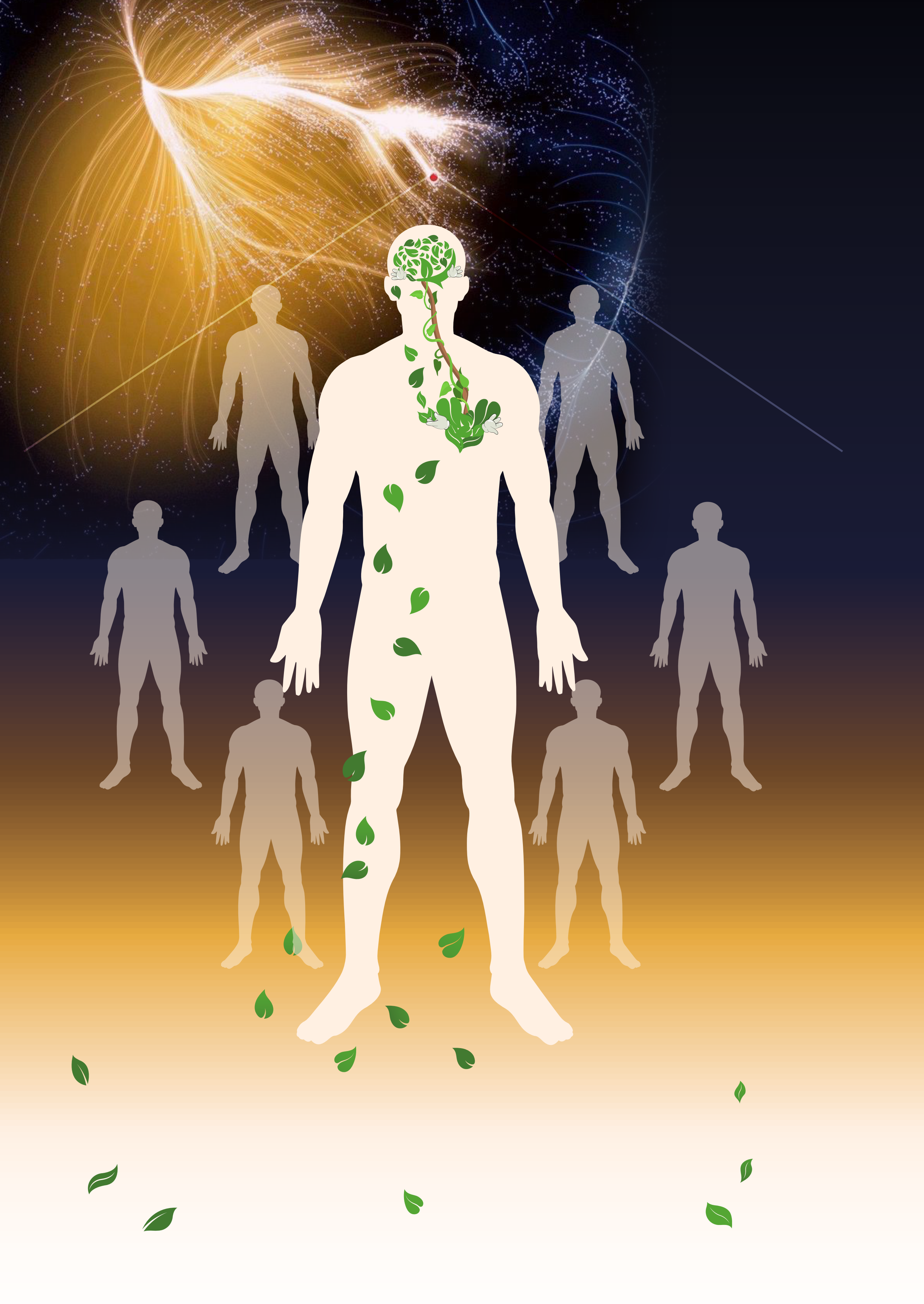

CHAPTER 4

INTERPROFESSIONAL COLLABORATION IN PALLIATIVE DEMENTIA CARE THROUGH THE EYES OF INFORMAL CAREGIVERS

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ABSTRACT

A qualitative study was conducted to examine the experiences of informal caregivers of persons with dementia pertaining interprofessional collaboration with and among healthcare professionals in home care (HC), nursing homes, and during home to nursing home transitions in palliative care. Semi-structured interviews were performed with bereaved informal caregivers. Data were analysed using a critical realist approach. The two main themes that emerged were: *1) Informal caregivers' roles in interprofessional collaboration with healthcare professionals* and *2) Informal caregivers' perception of interprofessional collaboration among healthcare professionals*. Informal caregivers' roles were identified in three collaboration processes: information exchange, care process, and shared decision-making. Interprofessional collaboration among healthcare professionals was more perceptible on the collaboration outcome level (e.g. being up to date with the health status of the person with dementia; acting proactive, being adequate and consistent in the care process; and giving a warm welcome) than on the collaboration processes level (e.g. communicating and being involved in team processes). Our study revealed that intrinsic and extrinsic factors, and interprofessional collaboration among healthcare professionals affected informal caregivers' collaborative roles. In summary, our study showed that informal caregivers have important roles as team members in the continuity and quality of palliative care for persons with dementia.

INTRODUCTION

Persons with dementia have complex care needs and problems involving cognitive, physical, behavioural, psychosocial, and spiritual domains[1-4]. As no curative treatments are currently foreseen for this life-limiting disease, a palliative care approach is paramount[5]. One of the main components for optimal palliative dementia care comprises interprofessional collaboration[4, 6, 7]. According to the World Health Organization, interprofessional collaboration is defined as *'a situation when multiple health workers from different professional backgrounds work together with patients, families, caregivers and communities to deliver the highest quality of care.'*[8] Interprofessional collaboration results in positive outcomes for the person with dementia and informal caregivers (e.g. person-centred care, participation, empowerment and satisfaction), healthcare professionals (e.g. job satisfaction, performance, and mental health) and the entire care process (e.g. effectiveness, efficiency, safety, quality and continuity of care)[9-11]. Within interprofessional collaboration, the person with dementia and informal caregivers (referring to families, close acquaintances or friends) are identified as crucial collaborative partners[9, 12, 13].

While persons with dementia retain their position in the centre of interprofessional collaboration, their ability to communicate their needs and wishes, and make decisions independently decline as dementia progresses[14]. Therefore, informal caregivers need to contribute to the relational autonomy[15] and person-centred care throughout the entire life journey of persons with dementia[16]. Even though the majority of persons with dementia prefer to live at home[17], 75% to 95% of persons with dementia die in nursing homes. These home to nursing home transitions are often due to overburdened informal caregivers, and constitute one of the most common transitions in dementia care[18].

Several studies have explored interprofessional collaboration between informal caregivers of persons with dementia and healthcare professionals in home care (HC), in nursing homes and during nursing home transitions. These studies mainly showed that informal caregivers act as caregivers[19]; provide person-centred information to stimulate tailored dementia care[20]; make decisions regarding assessments and care plans[21, 22]; facilitate continuity and management of care[23]; and contribute to the overall quality of life[22] of persons with dementia in HC. Furthermore, in nursing homes, interprofessional collaboration between informal caregivers and nursing home staff is important as well due to their continued involvement[24] in for example providing personal care[20, 25]; watching over the care process[26]; providing psychosocial support[27]; and providing support in solving problems[28]. Furthermore, collaboration with informal caregivers progresses during nursing home transitions[29], as they are actively involved in making transition-related decisions[30] and transferring person-centred information[31, 32].

Garvelink et al. (2019) used an interprofessional collaboration model[33] to describe the components important in shared decision-making concerning nursing home transitions such as informing and explaining the decision, identifying values and preferences, and providing an overview of the feasible options[30].

However, to our knowledge, merely one study addressed the experiences of informal caregivers concerning both interprofessional collaboration together with and among healthcare professionals[34]. Stephan et al. (2015) revealed that informal caregivers wish for one permanent contact person, notice that healthcare professional lack time to optimally collaborate with each other, and fill in the care gaps when they experience insufficient interprofessional collaboration among healthcare professionals. Hence, our study aimed to examine the experiences of informal caregivers of persons with dementia concerning both interprofessional collaboration together with healthcare professionals and among healthcare professionals themselves within HC, nursing homes and as well as during nursing home transitions.

METHODS

STUDY DESIGN

This qualitative study is part of the larger Desired Dementia Care Towards End of Life (DEDICATED) research project executed in three Dutch care organisations (located in the southern region) offering HC and nursing home care. DEDICATED aims to improve the quality of palliative care for persons with dementia in HC, nursing homes and during nursing home transitions[35]. Semi-structured in-depth interviews were done with bereaved informal caregivers of persons with dementia. This study followed the Consolidated criteria for Reporting Qualitative research (COREQ) [36] available in *Supplement I*.

RECRUITMENT OF PARTICIPANTS

Nurses from the three partner organisations of DEDICATED recruited participants using purposive sampling[37]. The closest informal caregiver of a deceased person with dementia was eligible when their informal caregiver with dementia was 65 years of age or older, received care from one of the three care organisations and died between six weeks and six months prior to the inclusion period. Participants provided written informed consent prior to the interviews.

INTERVIEW LIST

The interview questions exploring the themes 'interprofessional' and 'transmural collaboration' were distilled from a Delphi study defining optimal palliative care elements[4], a literature review identifying the needs of persons with dementia[3] and the Dutch quality framework for palliative care[38]. Three researchers together with the research team of DEDICATED established preliminary questions. These questions were discussed with healthcare professionals from the three care organisations, patient representatives, and experts in the field of dementia and palliative care in order to evaluate face validity. Subsequently, consensus with the research team of DEDICATED was reached and feasibility of the interview questions was evaluated through three pilot interviews with informal caregivers (*Supplement II*).

DATA COLLECTION

The interviews were conducted between February and July 2018 and took place either in the care organisation or at the participants' own home. Three female researchers performed the interviews in pairs (one guided the interview and the other one observed and asked follow-up questions). Data were audio recorded and transcribed according to the clean-read verbatim method (*Supplement III*).

DATA ANALYSIS

IBM SPSS statistics version 25 was used to carry out the descriptive analyses. For the qualitative analysis, NVIVO version 11 was used, and a critical realist approach was employed[39], underpinned by a transformative paradigm[40]. The analysis was based on two collaboration levels (collaboration with and collaboration among healthcare professionals), and guided by theories about informal caregiver involvement and collaboration experiences[34]. The coding procedure was an iterative process combining inductive, deductive[41], abduction, and retroduction methods[39]. Details about the data analysis procedure are described in *Supplement IV*, and the coding tree is provided in *Supplement V*.

FINDINGS

In total, 32 informal caregivers participated (response rate = 71.1%). 13 candidates refused participation because they were either not interested or found the topic too sensitive. The majority of informal caregivers were female, had a mean age of 62.0 years (SD = 9.3), and were children of the deceased person with dementia. Most persons with dementia were female, had a mean age of 86.6 years (SD = 6.3) and died in a nursing home (75%) (Table 1). The mean interview time was 92.0 minutes (SD = 17.6 and IQR = 27.8). The findings were divided into two main themes related to the study objectives (Figures 1 and 2).

Table 1. Characteristics of informal caregivers and persons with dementia

	N = 32
Demographic characteristics of informal caregivers	
Age, mean (range)	62 (44-87)
Female gender, number (%)	22 (68.8)
Education level, number (%)	
Preparatory secondary vocational education	9 (28.2)
Senior secondary vocational education & training	11 (34.4)
Senior general secondary education and university preparatory education	4 (12.5)
Applied science or university education	8 (25.0)
Relationship between informal caregivers and persons with dementia	
Type of informal caregivers, number (%)	
Spouses (married and divorced)	4 (12.5)
Children (biological, step and in-law)	23 (71.9)
Siblings	1 (3.1)
Cousins (biological and in-law)	3 (9.4)
Friends	1 (3.1)
Demographic characteristics of the persons with dementia	
Age, mean (range)	87 (70-97)
Female gender, number (%)	23 (71.9)
Care characteristics of persons with dementia	
Type of care setting in which the person with dementia died, number (%)	
Home care setting	4 (12.5)
Nursing home setting	25 (78.1)

Table 1. CONTINUED.

	N = 32
Hospital	3 (9.4)
Duration of receiving home care, number (%)	8 (25.0)
0-1 years	2 (6.2)
1-2 years	3 (9.4)
2-5 years	3 (9.4)
Duration of receiving nursing home, number (%)	24 (75.0)
0-1 years	9 (28.1)
1-2 years	9 (28.1)
2-5 years	6 (18.8)

THEME 1. INFORMAL CAREGIVERS' ROLES IN INTERPROFESSIONAL COLLABORATION WITH HEALTHCARE PROFESSIONALS

We identified three different types of processes in which informal caregivers had collaborative roles in interprofessional collaboration with healthcare professionals and two types of factors influencing these roles (Figure 1). The findings contain key quotes of informal caregivers, which are described using pseudonyms (Table 2), and describe key differences of informal caregivers' collaborative roles in HC, nursing homes and during nursing home transitions (Table 3).

Table 2. Pseudonyms of informal caregivers

Pseudonym	Age	Relationship with person with dementia	Healthcare setting
Mr. Deitman	63	Son of a woman with dementia	Nursing Home
Mrs. Fendaal	59	Daughter of a woman with dementia	Nursing Home
Mrs. Pike	58	Daughter of a woman with dementia	Home Care
Mrs. Glewen	56	Daughter-in-law of a man with dementia	Home Care
Mrs. Camping	59	Daughter of a man with dementia	Nursing Home
Mrs. Covers	60	Daughter of a woman with dementia	Nursing Home
Mrs. Pas	55	Stepdaughter of a woman with dementia	Nursing Home
Mrs. Mink	64	Niece by marriage of a woman with dementia	Nursing Home
Mr. King	44	Son of a woman with dementia	Nursing Home
Mrs. Kappas	74	Friend of a woman with dementia	Nursing Home
Mrs. Fink	61	Daughter of a man with dementia	Nursing Home
Mrs. Veldboom	53	Daughter of a woman with dementia	Nursing Home
Mr. Neckers	72	Ex-husband of a woman with dementia	Nursing Home
Mrs. Hengfeld	67	Daughter of a woman with dementia	Nursing Home
Mrs. Wordes	61	Daughter of woman with dementia	Nursing Home
Mr. Wellhouse	63	Son of a woman with dementia	Nursing Home
Mrs. Rordink	53	Daughter of a woman with dementia	Nursing Home
Mrs. Armslow	62	Daughter of a woman with dementia	Nursing Home
Mr. Peters	85	Brother of a woman with dementia	Nursing Home
Mrs. Fox	75	Wife of a man with dementia	Nursing Home
Mr. Jackson	53	Son of a man with dementia	Home Care

Table 2. CONTINUED.

Pseudonym	Age	Relationship with person with dementia	Healthcare setting
Mrs. Johnson	62	Daughter of a woman with dementia	Nursing Home
Mr. Garrison	61	Son-in-law of a man with dementia	Nursing Home
Mr. Damcott	51	Son-in-law of a man with dementia of	Home Care
Mrs. Miller	54	Niece of a man with dementia	Home Care
Mrs. Brewer	65	Wife of a man with dementia	Home Care
Mr. Lomis	63	Son of a man with dementia	Home Care
Mrs. Williams	87	Wife of a man with dementia	Home Care
Mrs. Smith	72	Daughter of a woman with dementia	Nursing Home
Mrs. Robinson	55	Daughter of a woman with dementia	Nursing Home
Mrs. Fisher	56	Daughter-in-law of a woman with dementia	Nursing Home
Mrs. Thatcher	60	Niece of a woman with dementia	Nursing Home

Table 3. Key differences of informal caregivers' roles in interprofessional collaboration with healthcare professionals between HC, nursing home and nursing home transitions

Care setting	*Informal caregivers' roles in interprofessional collaboration together with healthcare professionals*
HC	*More focus on:* • *Caregiving & monitoring* • *Making every day, goals of care and medical decisions* • *Coordinating care at home (seeking information and support, and executing care arrangements)* • *Anticipating nursing home transitions* • *Being an intermediary among healthcare professionals*
Nursing home transition	*More focus on:* • *Making nursing home transitions decisions* • *Coordinating the nursing home transition* • *Filling the information gap* • *Providing personal information*
Nursing home	*More focus on:* • *Asking for information about the nursing home life and health situation of their relative* • *Filling the information gap* • *Additional caregiving, monitoring & coordinating* • *Making every day, goals of care and medical decisions*

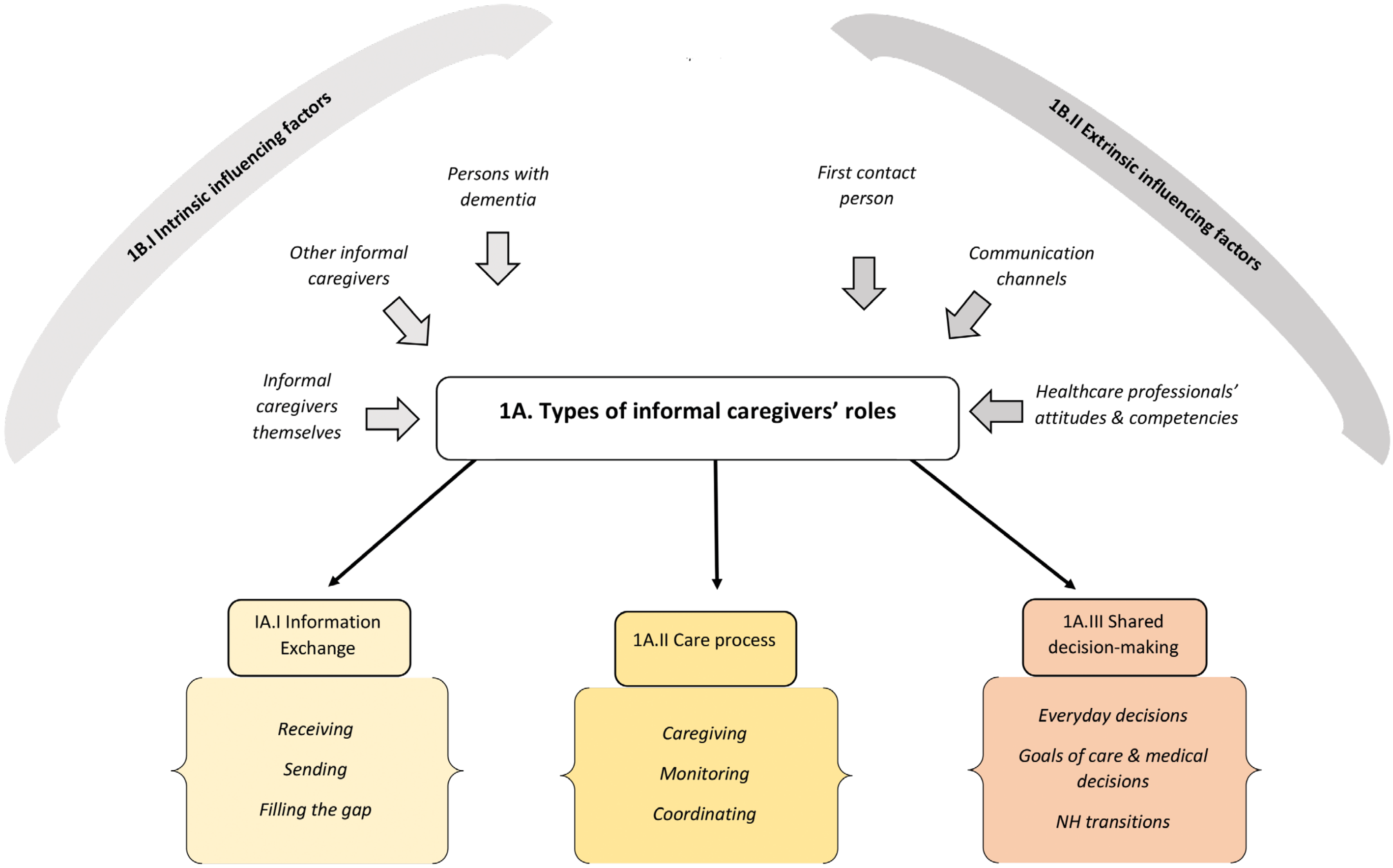

Figure 1. *Analysis scheme of Theme 1. Informal caregivers' roles in interprofessional collaboration with healthcare professionals*

Types of informal caregivers' roles

<u>Information exchange</u>*: Receiving, Sending,* and *Filling the gap*

Receiving

All informal caregivers needed information from healthcare professionals about dementia, palliative care, end-of-life care, and the progression of the disease, and requested regular updates about the current health status, medication list, care process and overall wellbeing of the person with dementia to understand the current situation and anticipate the future. *'After she passed away, they explained us that it is normal that her eyes were open. But we did not know that, so at the time of her death we were worried because we thought that she was still conscious.' (Mrs Rordink)* Besides, informal caregivers from HC also required practical information to execute care arrangements. *'That support group guided us. Otherwise, you do not know where to be. Especially, when my dad could not wash himself any more and more care provision was needed.' (Mr. Lomis)* Next, informal caregivers in nursing homes preferred general information about the nursing home life. Informal caregivers indicated the importance to receive information about the general care process or care experience of the person with dementia.

In dementia care, informal caregivers required information from healthcare professionals, as persons with dementia often displayed recall issues or were not able to communicate what they experienced. However, about half of the informal caregivers expressed a lack of receiving adequate or timely information. In response, informal caregivers either proactively asked healthcare professionals for information, searched for information on the internet or approached their informal network to gain information. *'I attached a plastic bag to the wheelchair and put a notebook in it, so that they could write down what my dad did at day-care.' (Mr. Jackson)*

Sending

All informal caregivers provided personal information about the person with dementia to healthcare professionals. This information included their life history, likes and dislikes in daily life, daily habits, hobbies, care needs and capabilities in daily care, preferences concerning social and religious activities, and end-of-life wishes. Informal caregivers explained that taking into account personal information provided by them satisfied persons with dementia, because they were not able to express these themselves. Moreover, it could also benefit healthcare professionals as it smoothens cooperation with the person with dementia and might prevent escalations: '*I saw the nurse and my aunty slapping each other. I told the nurses many times that my aunty wanted to wash herself, because she was afraid that someone would touch her.*' *(Mrs. Thatcher)* Personal information was often transferred through verbal communication; however, two informal caregivers were also asked to document this information in a life story book together with healthcare professionals. Most informal caregivers were asked to provide personal information, especially during the intake conversation at the nursing home admission.

Filling the gap

About half of the informal caregivers repeated information to, actively relayed information between or functioned as an information intermediary among healthcare professionals. Nine informal caregivers in nursing homes noticed that the care needs and preferences of persons with dementia were not taken into account. In response to this observation, they either repeated information *('I decided to write it on the board but even then, they still did not put her hearing aids.' (Mrs. Wordes))*, or actively relayed information *('If I had my iPad with me, I could have showed you how many emails I sent to them due to lack of communication among them.' (Mrs. Thatcher))*. Furthermore, seven informal caregivers described that they filled the information gap during nursing home transitions. Of these seven informal caregivers, five informal caregivers repeated information and two informal caregivers actively relayed information during nursing home transitions: '*It was already an emotional situation and I also had to tell them twice to hand off the patient file to the nursing home. I really felt overburdened.' (Mr. Deitman)* However, informal caregivers in HC functioned more as an intermediary among healthcare professionals, but did not experience this as exhausting, as they did not have to repeat information, but namely passed through information. Moreover, in HC, healthcare professionals themselves transferred information through the patient file, which they left at the residence of the person with dementia.

<u>Care process</u>*: Caregiving, Monitoring,* and *Coordinating*

Caregiving

Informal caregivers in HC performed general care tasks such as basic care tasks (i.e. meal preparation, feeding, toilet guidance and skin care) and household tasks. Especially, their contribution to managing medication, financial tasks and appointments of the person with dementia were important due to the cognitive decline. In HC, most informal caregivers expressed feeling part of the team, because they had close interactions with healthcare professionals (often district nurses), directly accessed information (through reading the patient file at home), and divided care tasks. *'The district nurses and I form one team. When something happened or changed, we always discussed it together.' (Mrs. Brewer)* In nursing homes, most informal caregivers did not feel part of the team, because they had to chase the first contact persons and other healthcare professionals to exchange information. Further, even though informal caregivers in nursing homes performed activities to make the person with dementia feel at home such as playing music, walking outside, eating out at restaurants and visiting with other informal caregivers, less than a quarter performed additional caregiving roles in response to inadequate care provision. *'My aunty had a bladder infection and sometimes had to wait half an hour for a nurse to go the toilet, so that is why I helped her myself when I was there.' (Mrs. Mink)*

Monitoring

Monitoring refers to verifying whether healthcare professionals took into account the personal needs and preferences of persons with dementia, reviewed their care provision and signalled changes in their health situation. *'It took me half a year to ensure that she received clean clothes every day.' (Mrs. Rordink)* Three quarters of the informal caregivers in nursing homes showed additional monitoring roles such as noticing when care tasks were not executed and responding to it by communicating their dissatisfaction and/or reactive caregiving. On top of that, informal caregivers signalled changes themselves when healthcare professionals did not identify those changes. '*The nurses did not find it necessary to call the physician, but I saw that there was something wrong with her eye, and indeed when the physician came he diagnosed stroke.*' *(Mrs. Covers)* Moreover, when healthcare professionals did not act quickly upon changes, informal caregivers themselves took control. '*When I saw my mom in pain and asked for paracetamol, they said they have to ask the physician. If she had pain on Tuesday, she had to wait one week, because the physician was only available on Monday. Therefore, I secretly gave her paracetamol myself.*' *(Mrs. Robinson)*

Coordinating

Coordinating covers filling the information gap, performing care arrangements or actively approaching healthcare professionals and care organisations to ensure that care is person-centred, safe and continuous. Informal caregivers in HC ensured adequate medication supply; arranged sufficient HC support; requested supporting materials to live at home as long as possible; involved necessary healthcare professionals; functioned as an intermediary; organised transport for appointments; and anticipated nursing home transitions. '*The district nurse told me that my dad has been removed from the client list and she was not allowed to do anything with the extension approval from the Social Support Act. Therefore, I have been alone with my dad that whole weekend.*'*(Mr. Lomis)* During nursing home transitions, informal caregivers coordinated the transition through initiating the transition; looking for the appropriate nursing home; contacting healthcare professionals from the nursing home; applying to the Dutch care needs assessment centre to receive permission for the nursing home transition; clearing and selling the house; arranging transport to the nursing home; and furnishing the nursing home room. Moreover, two informal caregivers coordinated the information transfer between HC and nursing home, and three informal caregivers applied the Care and Compulsion act to execute an involuntary nursing home transition. In nursing homes, informal caregivers coordinated through filling the information gap, contacted healthcare professionals when no responsibility was taken to monitor care and follow the rules, and emphasised the presence of supporting materials (i.e. motion sensors, pressure ulcer mattress, wheel chair cushions or safety belts). *'I saw hydration protocols in her room which were not filled in. I showed them and asked who was then responsible for doing that and taking care of her during mealtimes. One day her soup was cold because she waited 1.5 hours but no one came to feed her so I asked whether they took into account the Hazard Analysis Critical Control Points rules.' (Mrs. Pas)* In addition, most informal caregivers felt rushed and emotional when making the nursing home transition decision and transporting the person with dementia to the nursing home, and therefore wished support from healthcare professionals during this process. After the death of the person with dementia, informal caregivers (in HC and nursing homes) coordinated the funeral such as contacting the mortician and arranging finances.

<u>Shared decision-making:</u> *Everyday decisions, Goals of care & medical decisions* and *nursing home transitions*

Everyday decisions

All informal caregivers (in HC and nursing homes) were involved in making everyday decisions about personal care and supporting materials, as persons with dementia were not able to make these decisions. Informal caregivers also developed methods to cope with distressed behaviours of persons with dementia, made sure that they maintained their activities and remained connected with their familiar environment. Informal caregivers (mostly in nursing homes) pointed out that healthcare professionals did not always align with them when making everyday decisions. *'I came to know that the recreational therapist did reminiscence through painting with my stepmom. My stepmom painted a very intense life event. Afterwards, she got delirium and relived that event in her dreams. I was so angry about that, because it was not pre-discussed with me.' (Mrs. Pas)*

Goals of care & medical decisions

The majority of informal caregivers (in HC and nursing homes) focussed on comfort, enjoyment, and satisfaction in life when communicating personal preferences of the person with dementia. They also emphasised on relief of suffering and prevention of burdensome treatments when setting goals of care and making medical decisions for the person with dementia. Medical decisions about administration of opioids, hospital admissions, medication, food and fluid administration, palliative sedation and resuscitations were made together. Healthcare professionals initiated discussions to ask informal caregivers what they wanted and what the person with dementia would have preferred. In this way, they both tried to reach consensus and make the best suitable and shared decision for the person with dementia. '*The physician proposed to give our mother antibiotics, but we did not agree, discussed this together with the physician and decided to stop with the medication.*' *(Mrs. Hengfeld)*

Nursing home transitions

Eleven transitions occurred from care homes or sheltered homes to nursing homes, ten transitions took place from home to nursing homes, and three transitions from somatic to psychogeriatric nursing home wards. In addition, four persons with dementia living at home or in a care home were not able to return home after their stay at the hospital or revalidation centre, and therefore had to move directly to a nursing home. More than half of the informal caregivers initiated nursing home transition conversations, as they noticed the increasing physical and cognitive decline of the person with dementia, safety issues and burden of other informal caregivers and themselves. Most of them did not feel supported when making the transition decision, as healthcare professionals did not anticipate with and/or guide them. Two informal caregivers even had to persuade their physician of their inability to cope with increasing care demands and request support towards a nursing home transition. Even though most informal caregivers made the transition decision, some informal caregivers afterwards felt supported by healthcare professionals as they had the opportunity to carry out conversations about institutionalisation during family meetings or visits. In all cases, informal caregivers were involved in choosing a nursing home and paid attention to the following preferences: appropriate ambiance, home-like feeling, available activities, familiar environment and short travel distance to their home. Some informal caregivers mentioned that they preferred a nursing home in which residents were in the similar stage of dementia as the person with dementia. They explained that when the other residents were in a more advanced stage of dementia in comparison to the person with dementia, they saw the person with dementia declining faster.

Factors influencing informal caregivers' roles

Intrinsic factors: *Informal caregivers' themselves, Other informal caregivers* and *Persons with dementia*

The type of and extent of informal caregivers' collaborative roles, in the first place, depended on informal caregivers themselves (i.e. willing to be involved, being assertive and having knowledge of or a previous experience in the care process). Second, when other informal caregivers were involved they felt supported. About one-third of the informal caregivers had a more active role because they were healthcare professionals themselves, worked in the healthcare sector or/and had informal caregivers who were healthcare professionals. Finally, the capabilities of persons with dementia to express themselves and their place of residence also influenced informal caregivers' roles.

Extrinsic factors: *First contact person, Communication channels* and *Healthcare professionals' attitudes & competencies*

The majority emphasised the importance of having a first contact person, as informal caregivers find it important to know who to approach to exchange information, coordinate care and seek support. First contact persons were often nurses (in HC and nursing home), dementia case managers (in HC) or physicians (in HC). Communication channels used in HC and nursing homes to exchange information were phone calls, e-mails (usually to inform, update or check) and one-on-one conversations (mostly with first contact person or physician to inform, discuss or decide). In addition, informal caregivers in HC had patient files (usually to document actions and changes, and transfer information), while in nursing homes informal caregivers were able to participate with multidisciplinary team meetings (usually twice a year to discuss overall health, care plans, problems and complaints). *'I would have preferred a second intake conversation after the nursing home transition together with the multidisciplinary team in order to have everyone on the same page, directly from the start. Additionally, I would organise these meetings to conduct mid-term evaluations to ask how we experienced the care process and discuss their performance.' (Mrs. Fink).* Informal caregivers often requested communication with the first contact person and the physician. However, in nursing homes, their first contact person was not always available or constantly changed and most physicians were physically present only once a week.

When healthcare professionals had a proactive attitude and adequate competencies, informal caregivers felt more part of the team and showed fewer reactive roles such as asking for information; filling the information gap; and additional caregiving; monitoring; and coordinating. According to informal caregivers, healthcare professionals' proactive attitudes comprised exchanging information with informal caregivers; taking into account preferences and needs of the person with dementia; having attention for the person with dementia; listening to informal caregivers; involving informal caregivers in decision-making processes; exchanging information with other healthcare professionals; and seeking for solutions. Adequate competencies of healthcare professionals were described as having knowledge; signalling changes; having communication skills; coping with distressed behaviours of the person with dementia; and acting proactively and adequately in the care process.

THEME 2. INFORMAL CAREGIVERS' PERCEPTION OF INTERPROFESSIONAL COLLABORATION AMONG HEALTHCARE PROFESSIONALS

Informal caregivers had little insight into the collaboration processes among healthcare professionals, but could notice the collaboration outcomes that effected their collaborative roles and the person with dementia (Figure 2). Informal caregivers additionally described two factors influencing these collaboration outcomes.

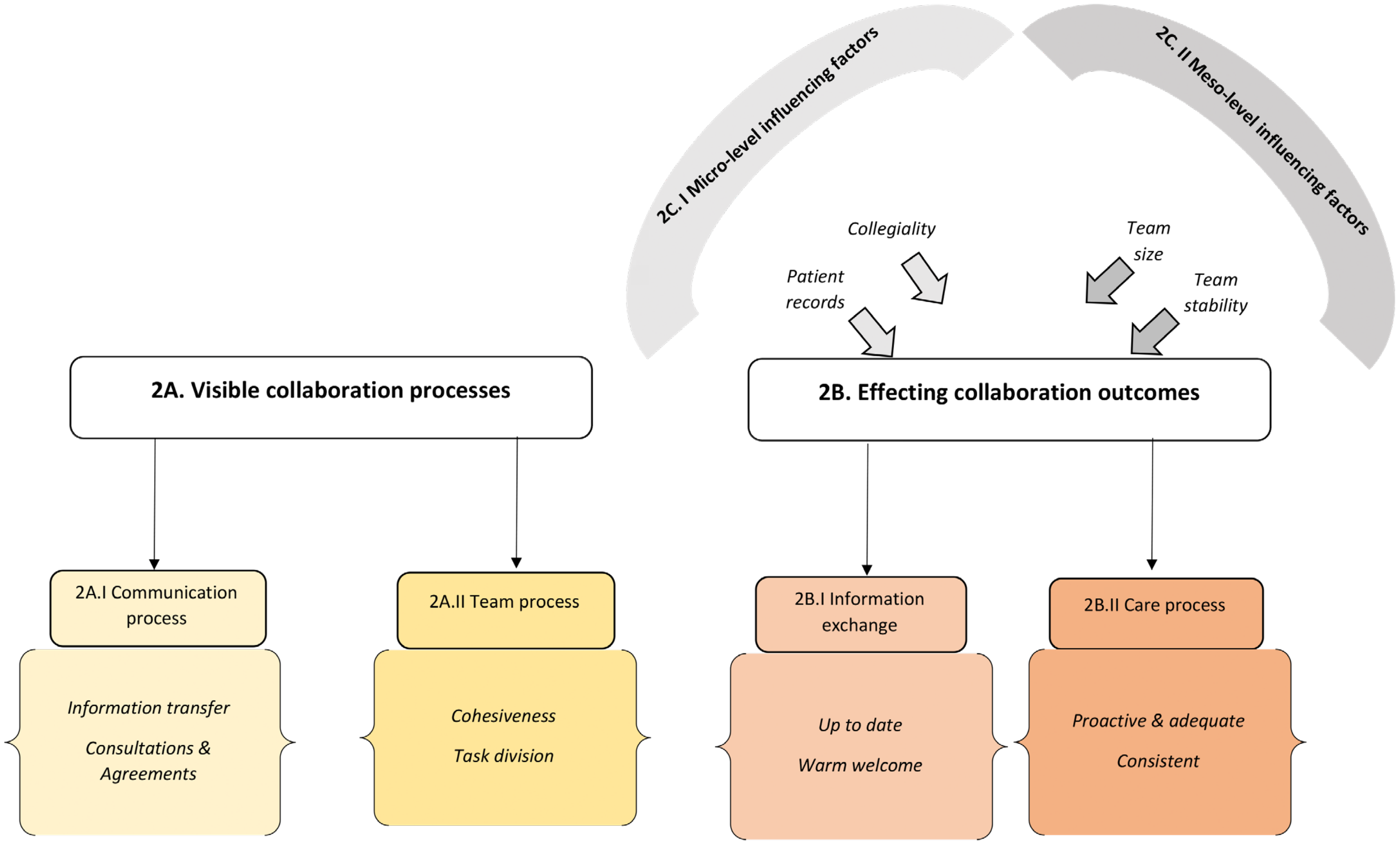

Figure 2. *Analysis scheme of Theme 2. Informal caregivers' perception of interprofessional collaboration among healthcare professionals*

Visible collaboration processes

Communication process: *Information transfer* and *Consultations* & *Agreements*

Informal caregivers were able to report to healthcare professionals that were closely involved in the care process (Table 4). In most cases, nurses, physicians, volunteers, physical therapists, occupational therapists, recreational therapists and psychologists were involved. The majority of informal caregivers assumed that healthcare professionals communicated with each other (via phone calls and meetings) to transfer information, consult with each other and develop collaboration agreements. The communication process among healthcare professionals was visible to informal caregivers in HC and nursing home, respectively when they wrote in the patient files and performed home visits together, and called each other or talked with each other in front of them. During nursing home transitions, some informal caregivers were aware of the information transfer. *'The general practitioner and elderly care physician from the nursing home exchanged information. After the transition, the general practitioner also called me.' (Mrs. Pas)*

Table 4. *Informal caregivers' perception of all involved healthcare professionals*

Healthcare setting	Nurses	Physician	CM	CA	V	RT	PT	OT	Psy.	RD	Others*
HC	All	All	Some	-	All	Half	Half	Half	-	One	One
Nursing homes	All	All	-	-	Major.	Major.	Half	Half	Half	Some	One third
Nursing home transitions	Some	Some	One	Some	-	-	-	-	-	-	-

The quantifiers 'one third', 'some', 'half', 'major.' and 'all' are used to indicate how many informal caregivers reported the involvement of the HCP.
Abbreviations: Major. = Majority; CM = Case manager dementia; CA = Client advisor from the nursing home; V = Volunteers; RT = Recreational therapist; PT = Physical therapist; OT = Occupational therapist; Psy. = Psychologist; RD = Registered dietician.
Others = One social worker in HC; three speech therapists, one podiatrist, two dentists and two spiritual caregivers in nursing homes.*

Team process: *Cohesiveness* and *Task division*

Seven informal caregivers (in nursing homes) observed and accentuated that team cohesiveness, which refers to the feeling that all healthcare professionals are equal to each other, belong to one team and work towards the same goal, is important in the collaboration process. *'Those who carried out household tasks and those who executed care tasks did not form one team. Even though it was clearly written down in the file to close the curtains, they did not do it. Due to this, she still fell two to three times afterwards (while trying to do it herself).' (Mrs. Thatcher)* Apart from the feeling of working together, all informal caregivers knew their distinct professional tasks and assumed that healthcare professionals did divide their tasks as team members, but did not know or want to know the details. A few informal caregivers noticed differences among healthcare professionals in terms of eligibility to perform certain care tasks. *'The nurse said: 'Yes, I am level four and officially allowed to administer morphine by myself, but during the night I am level three, because the organisation wants to save money. Then a second nurse has to be there too. Those are the rules.' (Mr. Damcott)*

Effecting collaboration outcomes

<u>Information exchange:</u> *Up to date* and *Warm welcome*

One third of the informal caregivers in nursing homes and half of the informal caregivers during nursing home transitions experienced that healthcare professionals were not up to date with the current health situation of the person with dementia, and in reaction to this, informal caregivers filled the information gap. *'I was bewildered when the nurses did not know that we stopped with the antibiotics, so I tried to keep up the communication with them. (Mrs. Armslow)* Half of the informal caregivers mentioned that healthcare professionals were not aware of the complete health situation, needs and preferences of the person with dementia. They provided (additional) personal details about the person with dementia during the intake conversation at the nursing home admission. Further, seven informal caregivers were actively involved in the handoff of patient information (e.g. sharing patient record or personal details). *'I had to repeat a lot of information. The medication list was also incorrect. I do not understand why they did not involve me during the handoff of patient information?'(Mrs. Wordes)* However, according to most informal caregivers, nursing home healthcare professionals provided a warm welcome to the person with dementia when they prepared sweets and drinks, carried out intake conversations and provided a guided tour. *'We received a warm welcome, it was great, there was a table ready, there was cake present, and it all gave us a celebratory feeling.' (Mrs. Fink)*

<u>Care process:</u> *Proactive & adequate* and *Consistent*

For the most part, informal caregivers in nursing homes experienced that healthcare professionals acted proactive and adequate in the care process. In nursing homes, some informal caregivers experienced communication delays between nurses and physicians, and therefore expressed the need for shorter communication lines between them. In HC, informal caregivers either called the physicians themselves or asked the nurses to call a physician. Moreover, one third of the informal caregivers noticed that not all healthcare professionals executed their care tasks in the same way. One informal caregiver described the consequence of inconsistent handling of opioid administration: *'They were allowed* *to use the fentanyl nasal spray six times per day, but sometimes they only sprayed two or three times while my mom indicated that she experienced pain.' (Mrs. Johnson)*

Factors influencing collaboration outcomes

Micro-level factors: *Patients records* and *Collegiality*

Eight informal caregivers (in nursing homes) reasoned that when healthcare professionals were not up to date with the health situation of the person with dementia or did not consistently execute the care tasks, they probably did not read the patient record themselves (individual responsibility) and/or did not inform each other about the changes (collegial responsibility). *'A substitute nurse called me to ask whether we could bring a razor, while I already told them and it was also written in the file that she did not want to shave. Therefore, we already arranged a beautician for her.' (Mrs. Fendaal)*

Meso-level factors: *Team size* and *Team stability*

The majority of informal caregivers (in nursing homes) had the feeling that healthcare professionals probably did not have time to transfer information, could not optimally inform all healthcare professionals and therefore could not always act proactive and adequate in the care process. They also mentioned the lack of staff and the continuous change of team compositions that influenced staff performance and the way they provided personal attention to the person with dementia, which is a relevant aspect of dementia care. *'They did not have time to give personal attention, because there were not enough nurses.' (Mr. Neckers)* Furthermore, informal caregivers noticed high staff turnovers and many different or temporary substitutes, such as volunteers and interns, which could make it difficult to build a strong and stable team.

DISCUSSION

This is the first study that investigated the roles of informal caregivers in interprofessional collaboration as well as their perception of interprofessional collaboration among healthcare professionals in palliative dementia care. Our findings showed that informal caregivers' main roles in interprofessional collaboration with healthcare professionals were exchanging information, acting in the care process, and making shared decisions. Further, we revealed intrinsic factors (related to informal caregivers themselves, other informal caregivers and the persons with dementia) and extrinsic factors (related to the healthcare professionals and the care organisations) which influence to which magnitude and which (additional) roles informal caregivers performed. Moreover, next to these factors, interprofessional collaboration among healthcare professionals, which informal caregivers noticed on the level of collaboration process and outcomes, affected informal caregivers' collaborative roles. This illuminates that interprofessional collaboration among healthcare professionals and interprofessional collaboration between informal caregivers and healthcare professionals exhibit a mutual dependence, as they influence each other.

In concordance with our findings, previous research showed that informal caregivers need general information about dementia[19, 42], and information about and support during nursing home transitions[29]. Further, in HC, they face diverse healthcare professionals and care organisations, which make it difficult for informal caregivers to coordinate the care process for persons with dementia[19, 43-45]. Correspondingly, Häikiö et al. (2020) illustrated that informal caregivers of persons with dementia used assertive strategies in interprofessional collaboration with healthcare professionals such as alerting healthcare professionals, using social relationships and filling complaints[20].

The importance of family involvement has been emphasised earlier in general care for older persons[46, 47] and general palliative care[48, 49 50]. In dementia care, informal caregivers act as person-centred information sources[51], advocators[23] and decision-makers[52], which is especially important to provide person-centered[53] due to the cognitive decline and communication difficulties of persons with dementia[54]. Moreover, through expressing the personal wishes and needs of the persons with dementia, informal caregivers contribute to ensuring comfort, enjoyment, and satisfaction[6], and support healthcare professionals in understanding distressed behaviours of persons with dementia[22]. We have described in our findings that by sharing personal information and needs, family members may prevent escalations due to challenging behaviours. Existing literature confirms the relation between unmet needs and challenging behaviour in dementia[55, 56]. Furthermore, Huis in het Veld et al. (2016) showed that family members could also contribute to managing challenging behaviours through sharing the self-management strategies they have used themselves under which calming down and stimulation[57].

Informal caregivers' continuous involvement secures informational continuity of PC[58], which is indispensable during the care process in HC, nursing home and peculiarly during nursing home transitions. Without optimal coordination between the care settings (e.g. referrals, collaboration and information transfer)[59], these nursing home transitions are susceptible to adverse outcomes such as miscommunication and medication errors[60]. Known effective components for an optimal nursing home transition for persons with dementia include: 1) shared decision-making; 2) preparing and supporting the person with dementia and their informal caregivers for the nursing home transition; 3) collecting all information of the person with dementia; 4) transferring information between the care settings; 5) using this information to prepare the welcome of the person with dementia and their informal caregivers; 6) performing follow-up by healthcare professionals from HC; and 7) assisting in adjusting to a new environment by healthcare professionals from nursing home[29, 30, 59, 61].

As informal caregivers are the 'constant factor' throughout the entire transition process[62], it is prominent to incorporate their views from the start through an interprofessional shared decision-making process[63, 64]. Little is known about shared decision-making regarding nursing home transitions in dementia care[30]. However, similar to the findings of Garvelink et al. (2019), we found that most informal caregivers proactively proposed the nursing home transition decision, convinced healthcare professionals of the importance of the nursing home transition, and acted more as autonomous decision makers during nursing home transitions[30]. Moreover, during information transfer between care settings, informal caregivers in our study mentioned that they play an immense role in making sure that accurate person-related information and the correct medication list is transferred. Likewise, two previous studies have shown that family involvement could prevent medication errors that frequently occur during care transitions in dementia care[65, 66]. Furthermore, we have shown that family members mostly wished for and selected a nursing home with a home-like environment in which persons with dementia have the opportunity to perform meaningful activities. This is known to facilitate the adjustment process to the nursing home[67], which is crucial in dementia care[68] since these transitions can lead to additional disorientation and agitated behaviour in persons with dementia[69, 70]. On top of that, the care preferences mentioned by the informal caregivers in our study, under which providing comfort care and preventing burdensome treatments, suit the principles of optimal palliative dementia care[4].

With respect to the collaborative needs of informal caregivers, we highlighted the need of a first contact person on behalf of the professional care team for informal caregivers.

Within the interprofessional collaboration model described by Légaré et al. (2011), which focuses on general healthcare, a first contact person for informal caregivers is recommended[33]. This HCP could identify the problem or challenge and can support decision-making. Specifically, in dementia care, the contact person could take the responsibility to guide informal caregivers, inform informal caregivers, manage services, facilitate communication with other healthcare professionals, and could facilitate overall collaboration between informal caregivers and healthcare professionals[34, 45, 71, 72]. Moreover, our finding that many informal caregivers lacked support from healthcare professionals during nursing home transitions in dementia care (for example when making transition-related decisions) is supported by other studies[73, 74]. Next, adopting a proactive attitude as a healthcare professional in providing timely information to informal caregivers about dementia, palliative and end-of-life care to informal caregivers[19, 75] and anticipating with informal caregivers on for example future transitions[45, 59] are essential to enhance interprofessional shared decision-making.

Even though informal caregivers from our study did not express the need to clarify roles with healthcare professionals, existing literature emphasised the importance of role clarification and negotiation[76]. Indeed, role negotiation is conducive since healthcare professionals and informal caregivers complement each other[20]. Furthermore, role clarification can reduce informal caregivers' burden[76], and role conflicts between informal caregivers and healthcare professionals[77]. Especially, during nursing home transitions role clarification is required[78], as informal caregivers may adopt their roles[31] from focussing more on housekeeping[79], personal care, and vigilance[51] in HC to emphasising attention on advocating[80], decision-making and additional monitoring in nursing homes[26]. Apart from identifying and discussing the types of roles, conversing about the participation level[81] is also part of clarifying informal caregivers' position within interprofessional collaboration. Besides talking about the participation level, we recommend healthcare professionals to continuously monitor[82] and regularly evaluate the interprofessional collaboration with informal caregivers[83], and request informal caregivers for feedback about the outcomes of interprofessional collaboration among healthcare professionals. This process could pinpoint the additional collaborative roles of informal caregivers, which they perform in response to the lack of responsibility of healthcare professionals or adequacy interprofessional collaboration among healthcare professionals[34, 84].

Methodological considerations

In our study, strengths include the inclusion of informal caregivers with experience of interprofessional collaboration in HC, nursing homes and during nursing home transitions. Further, different researchers were involved in data collection and analysis, investigator triangulation took place (through an independent coding procedure and consultation meetings with the DEDICATED research team), and data saturation was achieved. Moreover, even though selection bias might have occurred as the recruiters (nurses) could have selected candidates they frequently saw or which they were familiar with, our study population was diverse (i.e. different types of informal caregivers, representative mix of man and woman and diverse educational backgrounds). Nevertheless, we only interviewed one informal caregiver per person with dementia. This informal caregiver was the closest involved informal caregiver. However, in general more informal caregivers surround a person with dementia. Of course, collaboration with all involved informal caregivers is relevant, but this was not covered in our study. In addition, we did not examine the perspectives of the involved healthcare professionals to compare the collaborative experiences from both sides. Finally, Dutch cultural and health care aspects may influence the generalisability of the outcomes.

CONCLUSION

Our findings imply that informal caregivers in fact are key team members in palliative dementia care. We have shown that their collaborative roles could shift depending on which care setting the person with dementia resides. In HC, informal caregivers' roles focussed more on personal caregiving, coordinating care at home and anticipating possible nursing home transitions for the person with dementia. During nursing home transitions, they felt that they were initiating, coordinating, filling the information gap and providing personal information about the person with dementia. In nursing homes, informal caregivers emphasised on asking information about the person with dementia, filling the information gap and performing additional caregiving, monitoring and coordinating roles to ensure person-centred care for the person with dementia. Moreover, we revealed that interprofessional collaboration among healthcare professionals could affect informal caregivers by urging them to take additional collaborative roles. Therefore, we recommend healthcare professionals to discuss the collaborative roles and evaluate the interprofessional collaboration with informal caregivers. In conclusion, healthcare professionals should take into account different roles of informal caregivers in interprofessional collaboration. This might optimise the continuity and quality of palliative care in dementia.

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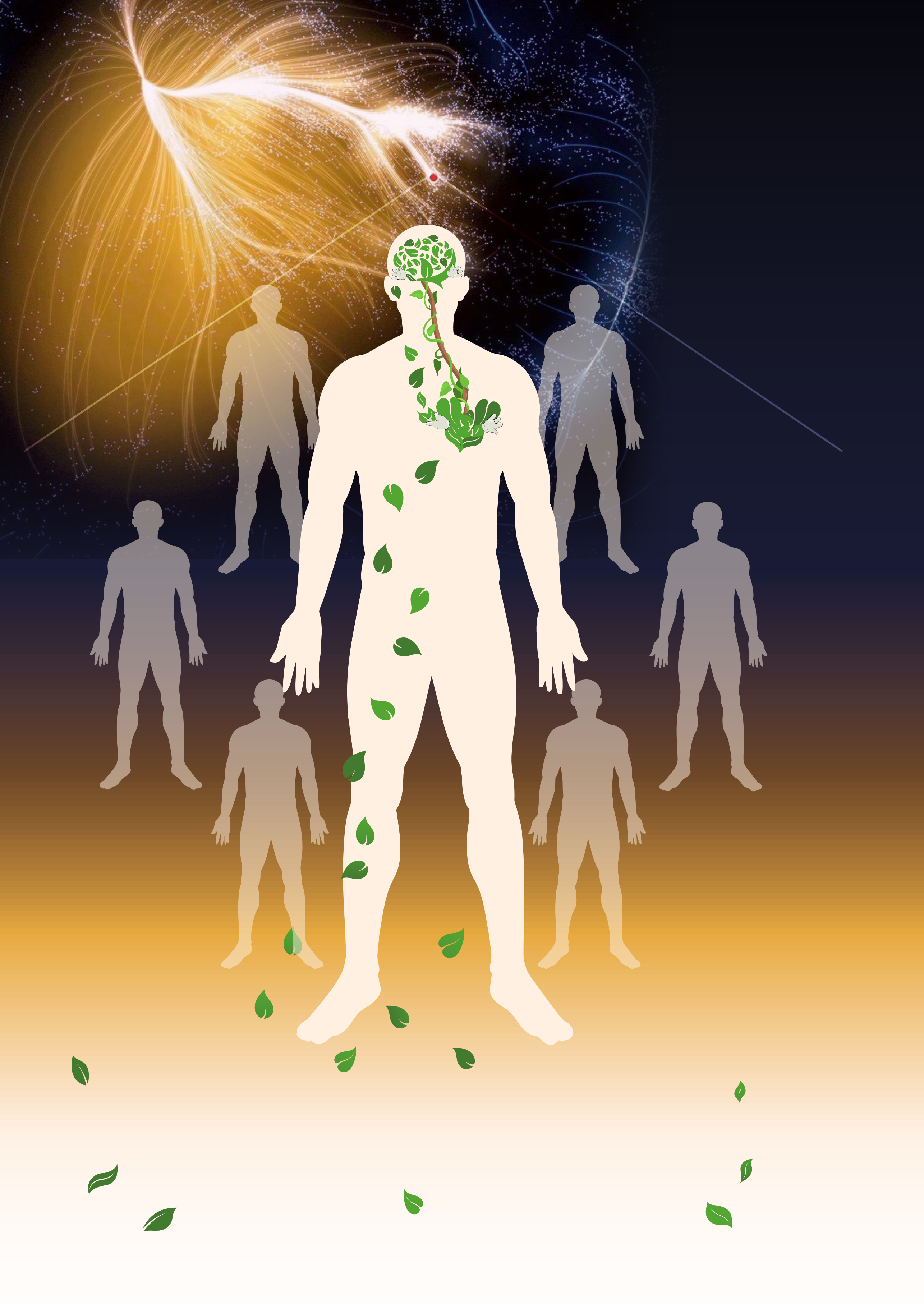

CHAPTER 5

NURSES’ NEEDS WHEN COLLABORATING WITH OTHER HEALTHCARE PROFESSIONALS IN PALLIATIVE DEMENTIA CARE

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ABSTRACT

Adequate interprofessional collaboration is essential to provide high quality palliative dementia care across different care settings. Within interprofessional collaboration, nurses are the frontline healthcare professionals (HCPs), who interact closely with people with dementia, their loved ones, and other HCPs. A survey was conducted to explore the needs of nurses regarding interprofessional collaboration in home care (HC) organisations, nursing homes (NH) and during NH admissions. The survey identified the perceived quality of and preferred needs regarding interprofessional collaboration. In total, 384 participants (53.9% home care nurses) completed the survey. The most frequently reported collaboration needs in HC organisations and NH were optimal communication content e.g. information transfer and short communication lines (i.e. being able to easily contact other disciplines), and coordination e.g. one contact person, and clear task division and responsibilities. During NH admissions, it was important to create transparency about agreements concerning end-of-life wishes, optimise nurse-to-nurse handover during NH admissions (through performing visits prior to admissions, and receiving practical information on how to guide relatives), and improve coordination (e.g. one contact person). In conclusion, the key collaboration needs were organising central coordination, establishing optimal communication, and creating transparency on end-of-life care agreements.

INTRODUCTION

Dementia is a life-limiting and an incurable disease[1], for which early palliative care (PC) is advocated to improve the quality of life for people with dementia[2]. In order to meet the complex care needs (in physical, behavioural, psychosocial, and spiritual domains) of people with dementia[3] and provide holistic person-centred care[4], the involvement of healthcare professionals (HCPs) from different disciplines in PC is required[5]. One of the main factors influencing the continuity of PC includes interprofessional collaboration processes within healthcare settings and during admissions[6-9]. Interprofessional collaboration is defined as *'multiple health workers from different professional backgrounds working together with patients, families, caregivers, and communities to deliver the highest quality of care.'*[10].

In the Netherlands, 55% of people with dementia live at home[11], and this percentage will increase due to the current ageing-in-place policies and patients' preferences to live at home as long as possible[12]. In home care (HC), basic care is largely provided through informal care by loved ones, supported through formal care via district nurses and other HCPs[13]. Nevertheless, the majority of people with dementia die in nursing homes (NHs)[14, 15]. Therefore, NH admissions are common events in dementia care and are often caused by increased neuropsychiatric symptoms, the increased burden on loved ones, and increased care demands[15, 16]. These NH admissions can lead to medical errors, inefficiency in care[17], mental confusion, and decline in quality of life for people with dementia[18, 19]. In order to overcome these admission-associated risks, interprofessional collaboration during NH admissions in dementia care is vital[20].

Amongst all HCPs involved in palliative dementia care, nurses are frontline HCPs who spend the most time with people with dementia[21, 22]. Moreover, nurses have different roles in the care process[23] such as signalling clinical symptoms[24, 25] and identifying patients' preferences[26]. They also play a crucial role in maintaining the continuity of PC[27, 28]. One of the barriers to providing PC reported by nurses is achieving adequate interprofessional collaboration[29]. Furthermore, during NH admissions, nurses interact with patients and their loved ones to collect important information required to plan the admission and develop the admission plan, act as integral players in the care coordination, and execute nurse-to-nurse handovers during admissions[26]. In this article, the nurse-to-nurse handover is described as the clinical handover of patient information and care responsibility between nurses[30]. Thus, nurses are core members in interprofessional collaboration[26, 28, 31, 32]. To this data and to our knowledge, no study has identified nurses' needs in palliative dementia care regarding interprofessional collaboration both within and outside their own discipline. Hence, the aim of our study was to examine both the perceptions and needs of nurses with regard to collaboration with other nurses, other disciplines, people with dementia and loved ones. Additionally, we also investigated whether these perceptions and needs differ between healthcare settings (HC, NH and during NH admissions), and among three levels of nursing (registered nurses, certified nurse assistants and uncertified nurse assistants).

METHODS

STUDY DESIGN

This cross-sectional study is embedded in the DEDICATED project (Desired Dementia Care Towards End of Life). DEDICATED is a four-year research and implementation project that aims to improve the quality of PC for people with dementia living at home, in a NH and during NH admissions. The DEDICATED project consists of two separate but interrelated subprojects. Subproject 1 focuses on the competencies in care provision, while subproject 2 focuses on interprofessional collaboration processes. The current study is part of subproject 2 and explores the needs of nursing staff regarding interprofessional collaboration in PC for people with dementia using an online questionnaire, which was distributed by the survey tool Qualtrics.

SAMPLE AND SETTING

Recruitment followed a convenience sampling method and took place from July to October 2018. Nurses (uncertified nurse assistants (UNAs), certified nurse assistants (CNAs) and registered nurses (RNs) were recruited from care organisations linked to three Dutch regional academic collaborative centres (Living Lab in Ageing & Long-term Care in South Limburg, University Network for the Care sector Zuid-Holland, and Tranzo Scientific Centre for care and welfare in Tilburg) and care organisations linked to three national organisations (Dutch Nurses Association, National Prevalence Measurement of Quality of Care, and Alzheimer Netherlands). In the Netherlands, RNs follow a four-year education programme and can be either baccalaureate-educated or vocationally trained. CNAs receive vocational training, which lasts two to three years. The hyperlink to the questionnaire was disseminated by contact persons (on a regional level) and associate partners (on a national level). Nurses who had worked at a HC (care service delivered at home) or NH organisation for at least six months, had provided PC for people with dementia aged 65 years and older, and had signed an informed consent were allowed to access the questionnaire. UNAs refer to unlicensed nurse assistants but not nurse aides. For this study, only respondents who completed the survey questions regarding interprofessional collaboration within healthcare settings and during NH admissions were included. See Supplement I for more details about the inclusion procedure.

QUESTIONNAIRE DEVELOPMENT AND STRUCTURE

The development of the questionnaire was based on four themes of the DEDICATED project (Palliative basic care and comfort, Communication in the final phase of life, Continuity of care and Collaboration between healthcare professionals), which were derived from three articles[2, 3, 33], and two existing surveys[34, 35]. The preliminary questionnaire was developed by three researchers (J.M.M., S.B., and S.P.) through meetings with the entire DEDICATED research team, and was discussed in working group meetings with HCPs (from our partner organisations Zuyderland, Vivantes, and Envida), dementia case managers, and patient representatives in order to establish face validity. Subsequently, a test panel consisting of UNAs, CNAs and RNs (n=18) from the abovementioned three partner organisations assessed the face validity and feasibility (content and language). The definitive questionnaire encompassed six sections: A. General, B. Palliative caregiving and communication, C. Interprofessional collaboration, D. Transitions to care (home to nursing home), E. Preferred forms of support, and F. Open-ended questions. In this study, we exclusively explored the needs of the sections A. 'General', C. 'Interprofessional collaboration', and D. 'Transitions to care (home to nursing home)'. The section A. 'General' includes demographic-, work-, and educational-related items (e.g. level of nursing), perceived quality of PC provision in their team or at the department (on a scale from 1 (worst) to 10 points (best)), self-perceived competency in providing PC (on a rating scale from 1 (lowest) to 10 points (highest)), additional training in PC, additional training in dementia care, and opinion on whether PC is a basic task or in fact a specialised one. The sections C. 'Interprofessional collaboration' and D. 'Transitions to care (home to nursing home)' consist of rating scale questions and checklists to explore the perceived quality of and preferred needs concerning collaboration. All questions in the checklists were preceded by the following sentence '*Regarding the provision of PC to people with dementia, I am in need of*…' See Supplement II for more details.

DATA ANALYSIS

IBM SPSS version 25 was used to conduct the quantitative analyses. Primary outcomes entailing demographic work and educational characteristics of the participants, as well as their needs concerning interprofessional collaboration were described and ordered by respectively descriptive and frequency analyses respectively. Secondary outcomes included differences between work settings (HC and NH) and levels of nursing staff (UNAs, CNAs and RNs) with regard to educational characteristics, perceptions and preferred needs. These secondary outcomes were analysed by Chi-square, independent T- and ANOVA-tests, as appropriate. With regard to the secondary analyses, we corrected for Type I errors by performing Post hoc Chi-square[36] tests to compare binary outcomes, and Post hoc ANOVA Bonferroni tests to compare means. The significance level was set at a p-value of 0.01.

ETHICAL CONSIDERATIONS

The Medical Ethics Committee Zuyderland confirmed that the rules of Medical Research Involving Human Subjects Act were not applicable (registration number METCZ20180079). All participants signed the informed consent document.

RESULTS

CHARACTERISTICS AND PERCEPTIONS ABOUT PC AND COLLABORATION

In total, 384 participants completed the questionnaire. Almost all participants were female (96.1%) (Table 1). They had a mean (SD) age of 45.7 (12.1) years and a mean working experience as a nurse of 15.8 (10.9) years. Most of the nurses were CNAs (53.1%), worked in an HC setting (53.9%), and almost half of the nurses had received additional training (for a minimum of two hours) in dementia care (49.0%) and PC (45.8%) in the previous two years. According to 74.0% of the participants, PC is a basic task. Nurses rated their competences in providing PC and the quality of collaboration with other nurses relatively high.

NEEDS REGARDING INTERPROFESSIONAL COLLABORATION WITHIN HEALTHCARE SETTINGS (HC AND NH)

The top five interprofessional collaboration needs were respectively: ‘the availability of one contact person for persons with dementia and their loved ones’ (37.5%), ‘an explicit information transfer’ (37.2%), ‘ability to approach other disciplines directly within my own organisation’ (31.0%), ‘clarity about who is responsible for which task(s)’ (30.7%), and ‘clarity about the tasks of all care providers’ (30.5%) (Figure 1). The less frequently indicated needs were the ‘the availability of one contact person for myself’ (17.4%), ’clarity about how and where care agreements are recorded’ (16.4% and 15.9%), and ‘consultation with colleagues outside my own organisation’ (11.7%).

NEEDS REGARDING INTERPROFESSIONAL COLLABORATION DURING NH ADMISSIONS

The top five interprofessional collaboration needs were respectively: ‘transparency with regards to agreements made earlier about end-of-life wishes’ (42.4%), ‘ability to visit the persons with dementia in their home situation or to visit the nursing home together with persons with dementia and loved ones before the admission’ (41.9%), ‘practical information and advice to guide relatives and persons with dementia in the admission process’ (39.5%), ‘one point of contact in the coordination of the admission’ (35.7%), and ‘insight into the coordination of the admission (who arranges what)’ (31.4%) (Figure 2). The less frequently reported needs were ‘practical information and advice on how to contribute to a personal and warm welcome’ (30.8%), ‘standard guidelines for the content of transfer’ (26.8%), and ‘practical information and advice to prepare myself for an admission’ (15.1%).

Table 1. Participants' characteristics and perceptions stratified for work settings and nursing level of education

Characteristics	**Total (n=384)**	**HC (n=207)**	**NH (n=177)**	**p value**	**RN (n=149)**	**CNA (n=204)**	**UNA (n=31)**
Female, number (%)	369 (96.1)	202 (97.6)	167 (94.4)	0.103	141 (94.6)	198 (97.1)	30 (96.8)
Age, mean (SD)	45.7 (12.1)	46.9 (11.9)	44.4 (12.1)	0.043	42.9 (12.5)	47.6 (11.5)	47.0 (11.4)
Years of experience, mean (SD)	15.8 (10.9)	16.6 (11.1)	14.8 (10.6)	0.108	14.9 (10.8)	16.7 (10.8)	13.9 (10.2)
Pursued additional training in dementia care, number (%)	188 (49.0)	79 (38.2)	109 (61.6)	<0.001	81 (54.4)	98 (48.0)	9 (29.0)
Pursued additional training in palliative care, number (%)	176 (45.8)	102 (49.3)	74 (41.8)	0.143	81 (54.4)	84 (41.2)	11 (35.5)
Perceptions concerning							
Palliative care is a basic task, number (%)	284 (74.0)	147 (71.0)	137 (77.4)	0.155	116 (77.9)	114 (70.6)	24 (77.4)
Self-rated competence, mean score (SD)	7.6 (1.4)	7.3 (1.1)	7.9 (1.2)	<0.001	7.5 (1.1)	7.6 (1.5)	7.1 (1.6)
Quality of palliative care at department or within team, mean score (SD)	7.1 (1.1)	7.1 (1.1)	7.2 (1.2)	0.341	7.1 (1.0)	7.2 (1.3)	7.1 (0.9)
Quality of collaboration within nurses' discipline, mean score (SD)	7.4 (1.1)	7.5 (1.0)	7.3 (1.2)	0.046	7.4 (1.0)	7.4 (1.1)	7.1 (1.7)
Quality of collaboration outside nurses' discipline, mean score (SD)	7.0 (1.2)	7.1 (1.1)	6.9 (1.2)	0.052	7.1 (1.1)	7.0 (1.2)	6.7 (1.6)
Quality of collaboration outside work organisation, mean score (SD)	6.4 (1.4)	6.6 (1.3)	6.0 (1.5)	<0.01	6.4 (1.2)	6.4 (1.6)	6.4 (1.2)
Quality of nurse-to-nurse handover during NH admissions, mean score (SD)	6.4 (1.5) (n=370)	6.9 (1.0) (n=198)	6.0 (1.6) (n=172)	<0.001	6.1 (1.1) (n=142)	6.5 (1.7) (n=197)	6.6 (1.4) (n=31)

Abbreviations: HC = Home Care; NH = Nursing Home; UNAs = Uncertified Nurse Assistants; CNAs = Certified Nurse Assistants; RNs = Registered Nurses

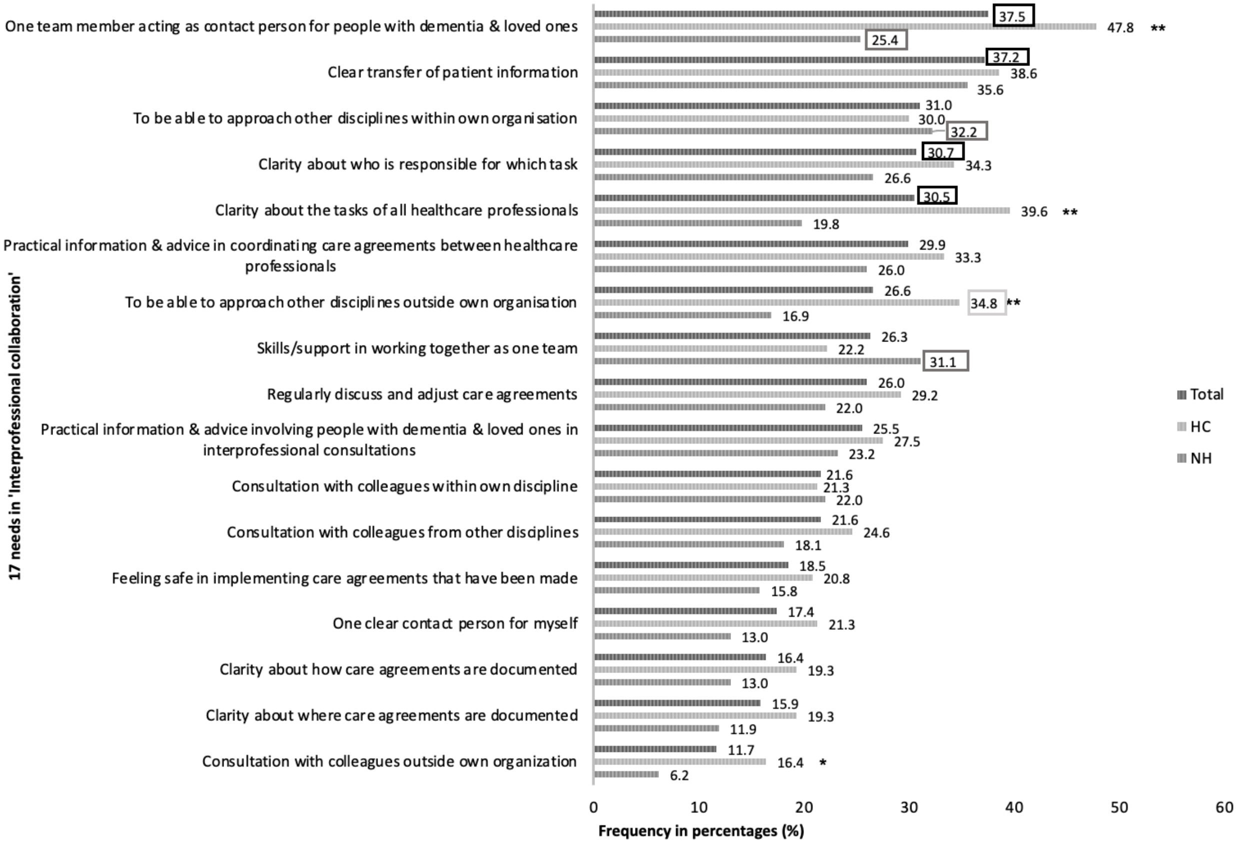

Figure 1. General needs regarding interprofessional collaboration and differences within needs between HC and NH.
Abbreviations: HC = Home Care; NH = Nursing Home
** Significant difference between HC and NH nurses ($p < 0.01$)*
*** Significant difference between HC and NH nurses ($p < 0.001$)*

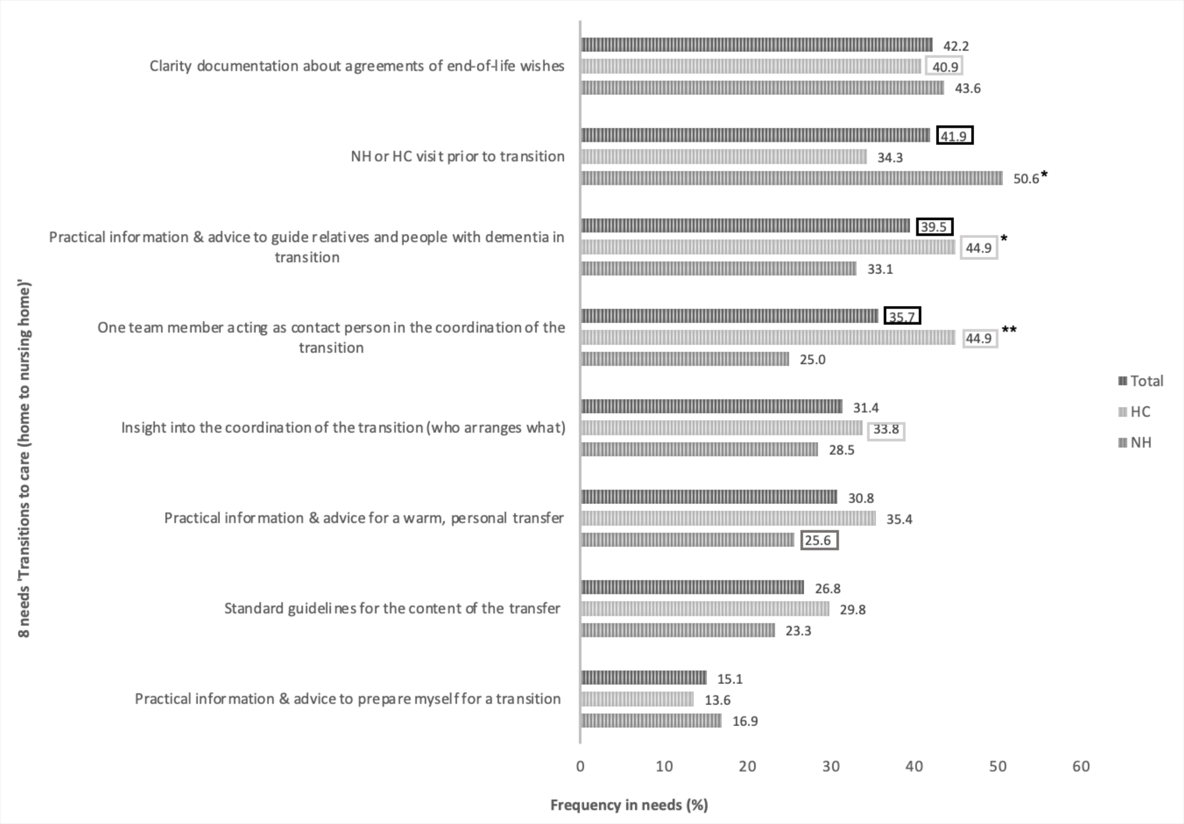

Figure 2. General needs regarding transmural collaboration and differences within needs between HC and NH.
Abbreviations: HC = Home Care; NH = Nursing Home
** Significant difference between HC and NH nurses ($p < 0.01$)*
*** Significant difference between HC and NH nurses ($p < 0.001$)*

DIFFERENCES REGARDING CHARACTERISTICS AND PERCEPTIONS ABOUT COLLABORATION BETWEEN WORK SETTINGS

NH nurses received significantly more additional dementia training (61.6% vs. 38.2%, $p < 0.001$) and had a higher self-perceived competency score (7.9 vs 7.3 points, $p < 0.001$) than HC nurses (Table 1). With regard to interprofessional collaboration, HC nurses rated the quality of collaboration outside the work organisation (6.6 vs 6.0 points, $p < 0.01$), and the quality of nurse-to-nurse handover during NH admissions (6.9 vs 6.0 points, $p < 0.001$) higher than the NH nurses did.

DIFFERENCES IN NEEDS REGARDING INTERPROFESSIONAL COLLABORATION WITHIN HEALTHCARE SETTINGS (HC AND NH) BETWEEN WORK SETTINGS

Compared to the general top five needs, for HC nurses it was also important to be able to approach other disciplines directly within my own organisation (34.8%), while NH nurses needed ‘practical information and advice in aligning care agreements between care providers’ (26.0%), and ‘more skills or support in working together as one team’ (31.1%) (Figure 1). HC nurses had significantly higher needs in the ‘availability of one contact person for persons with dementia and their loved ones’ (47.8% vs 25.4%, $p < 0.001$), ‘clarity about the tasks of all care providers’ (39.6% vs 19.8%, $p < 0.001$), ‘ability to approach other disciplines directly outside my own organisation’ (34.7% vs 16.9%, $p < 0.001$), and ‘consultations with colleagues outside my own organisation’ (16.4% vs 6.2%, $p < 0.01$) than NH nurses.

DIFFERENCES IN NEEDS REGARDING INTERPROFESSIONAL COLLABORATION DURING NH ADMISSIONS BETWEEN WORK SETTINGS

NH nurses more often reported the need to ‘visit the nursing home together with persons with dementia and loved ones or to visit the persons with dementia in their home situation before the admission’ (50.5% vs 34.3%, $p < 0.01$), while HC nurses more frequently reported the needs ‘practical information and advice to guide people with dementia and their loved ones in the admission process’ (44.9% vs 33.1, $p < 0.01$), and ‘one point of contact in the coordination of the admission’ (44.9% vs 25.0%, $p < 0.001$) (Figure 2).

DIFFERENCES IN CHARACTERISTICS, PERCEPTIONS AND NEEDS REGARDING INTERPROFESSIONAL COLLABORATION WITHIN HEALTHCARE SETTINGS (HC AND NH) AMONG NURSING LEVELS

RNs (of both HC and NH settings) followed significantly more additional trainings in PC than CNAs and UNAs (54.4% vs 41.2% and 35.5%, $p < 0.01$). In addition, RNs had a significantly higher need ‘to be able to approach other disciplines directly outside my own work organisation’ than UNAs (38.9% vs 0%, $p < 0.001$), who did not report any needs with respect to this item (see Supplement III). Additionally, RNs reported a significantly higher need regarding ‘consultation with colleagues outside my own institution’ (18.1% vs 8.3% and 3.2%, p < 0.01), compared to CNAs and UNAs (see Supplement III). Concerning interprofessional collaboration during NH admissions, RNs and CNAs reported significantly higher needs to perform home or NH visits (see Supplement IV) together with persons with dementia and their loved ones prior to admission (42.3% and 45.7% vs 16.1%, p < 0.01) than UNAs.

DISCUSSION

The present study found that the need for one HCP to act as a contact person for people with dementia and their loved ones or themselves appeared to be crucial for nurses in interprofessional collaboration. In HC and NH settings, nurses also expressed the need for optimal transfer of patient information, direct communication with other disciplines, and clear responsibilities and division of tasks among HCPs. During NH admissions, nurses additionally reported needs related to end-of-life care agreements, visits prior to admission, practical information and advice to guide people with dementia and their relatives in the admission process, and insight into coordination of the admission. Our findings align with the results of previous studies which described the importance of optimal communication[37], information exchange[38-40], role clarity[40-43], collaboration with other disciplines (mostly between nurses and physicians)[25, 44], visits prior to admission[28], and clarity about end-of-life wishes[28, 45].

SPECIFIC COLLABORATION NEEDS IN HC AND NH SETTINGS

The need for one HCP acting as a central contact person for people with dementia and their loved ones is not surprising, since fragmentation of care services is recognised as a well-known issue in dementia care[13, 46, 47]. On top of that, people with dementia and their loved ones themselves need to navigate among various HCPs, and they therefore indicate the need for a named and preferably permanent HCP and stable contact person that is responsible to guide people with dementia and their loved ones throughout the disease trajectory[39].

The decision concerning whom to appoint as a central contact person for persons with dementia and their loved ones also interrelates with task division and responsibilities. The awareness of having distinctive roles and responsibilities could be raised through role clarification among different HCPs[48]. Even so, coordination comprises role clarification[49]. In order to achieve role clarification, Brault et al. (2014) recommended developing individual professional competencies (such as understanding one's own roles, and those of colleagues and other HCPs), and establishing organisational processes (such as implementing formal time schedules to discuss each other's roles)[48]. With regard to the transfer of patient information, communicational aspects[50] such as the type of communication channel (i.e. modalities through which information is shared) and communication content style (i.e. which kind of information is shared) should be taken into account[51]. For example, information transfer through multiple communication channels (e.g. face-to-face communication, written communication or telephone communication) can lead to a loss of information[52]. Moreover, differences in communication content styles among HCPs also influence the effectiveness of communication[53]. For example, nurses prioritise to provide descriptive information, discuss goals of care, and state the clinical problem, while physicians prefer to provide concise information, and receive information in a logical and structural order[53]. In order to enhance information transfer among HCPs, several standardised tools, checklists, or information systems to share information could be deployed[52, 54].

Notably, the need to establish direct communication with other disciplines directly aligns with the results of Uitdehaag et al. (2019)[28]. For example, communication between nurses and physicians is required to make clinical decisions about acute illnesses or acute events including injuries[55]. On the contrary, consultation with other nurses was ranked as one of the lowest needs, while Skår et al. (2010) indicated that nurses find consultation with colleagues important to reflect upon their work, and to receive feedback and practical information to improve their nursing practice. However, our results could imply that nurses in our population already have sufficient opportunities to consult with their colleagues, as the quality of collaboration among nurses was rated relatively high. Moreover, having direct communication with other disciplines and consultations with other colleagues outside their own organisations seemed significantly more important for HC than NH nurses. These specific needs of HC nurses could be explained by the fragmented character of the primary care in which different disciplines work in different organisations[56]. Additionally, our results showed that RNs have significantly higher needs in establishing direct communication lines with other disciplines and participating in consultations together with other colleagues outside their own institution. This finding correlates with the characteristics of RNs who, unlike CNAs and UNAs, also act as team managers, innovators[57], and partners in interprofessional collaboration[58].

Furthermore, optimal documentation concerning care agreements (e.g. treatment preferences, or hospitalisation, resuscitation, and tube-feeding wishes) is essential to deliver person-centred PC[2, 59, 60]. Nonetheless, nurses in our study ranked ‘clarity about where healthcare agreements are recorded’ and ‘clarity about how care agreements are passed on’ as some of their lowest reported needs. However, this might also suggest that these nurses are able to easily find and understand these care agreements.

SPECIFIC COLLABORATION NEEDS DURING NH ADMISSIONS

Nurses indicated agreement about end-of-wishes as the main need with regard to interprofessional collaboration during NH admissions. This correlates with the findings of Uitdehaag et al. (2019)[28]. Especially, during unplanned admissions (mostly preceded by acute events)[19], information transfer concerning preferences and wishes about end-of-life treatments from HC to NH organisations becomes difficult[45]. For this reason, we suggest to implementing standardised admission protocols, which include documentation of end-of-life wishes. The majority of the nurses indicated the need to conduct visits prior to NH admissions. These pre-visits could contribute to a warm welcome at NHs through enabling face-to-face communication between nurses[61], maintaining relationships with people with dementia and their loved ones, and ensuring continuity in care[62]. At discharge and/or admission, RNs as well as CNAs indicated that performing visits prior to admissions was one of the highest needs during NH admissions. Moreover, Bokberg et al. (2014) illuminated that day-care visits enhanced the admission process, and therefore this could also promote a warm welcome at NHs[45].

To be able to guide people with dementia and their loved ones, nurses require certain skills, such as interpersonal skills, and knowledge to understand people with dementia[63]. This need to acquire skills is confirmed by our study, as about 45% of the nurses reported the need for practical information and advice in order to guide people with dementia and their loved ones. In addition, it appeared that HC nurses had significantly higher needs with respect to receiving practical information, and advice on how to guide people with dementia and their loved ones in the admission process. These HC nurses could be involved in identifying overburdened loved ones and unbearable living circumstances of people with dementia, thereby informing and preparing them for a possible admission. The need to designate one HCP as a central contact person during the coordination of the admission is supported by the finding of Tew Jr et al. (2012)[64]. In the Netherlands, three types of HCPs could probably function as the contact person, namely general practitioners (GPs), district nurses and dementia case managers. GPs often inform persons with dementia and their loved ones about the diagnosis, provide information about dementia and are considered as the gatekeepers in the care process[65-67]. Furthermore, district nurses support people with dementia in activities of daily living[68], and provide personal care[69] and bereavement support[70]. They could guide people with dementia and their loved ones in the NH admissions[64], provide them emotional support during admissions[71], and assist them with adjustments[69]. Next to district nurses, dementia case managers carry out coordination tasks, maintain regular contact with people with dementia living at home to monitor their health situation and guide them through the care process[72].

METHODOLOGICAL CONSIDERATIONS

Since we were not able to find a suitable available validated questionnaire that fit our sample, setting, and research questions, we had to self-develop a questionnaire that could limit our study results even though this self-developed questionnaire was used for explorative purposes, and tested for face validity and feasibility. The development of the questionnaire was undertaken by researchers, nurses (from different levels), and patient representatives, and the feasibility was tested by 18 nurses. Additionally, we used a convenience sampling technique, and therefore selection bias may have occurred since nurses who were interested were possibly more likely to participate. Strengths of the present study are the participation of nurses from regional as well as national organisations, different work settings, different nursing levels, and identification of interprofessional collaboration needs in HC, NH, and during NH admissions. Moreover, there is a paucity of research, which has been conducted on collaboration in HC settings involving district nurses, whereas in our study we combined both HC and NH settings. In addition, our study had a relatively large and representable study population because the majority of the nurses were women and CNAs[73]. Nevertheless, male nurses were underrepresented.

CONCLUSION

With regard to interprofessional collaboration in palliative dementia care in HC, NH and during NH admissions in palliative dementia care, nurses expressed a core need embedded within coordination, namely appointing a HCP to act as a central contact person. Moreover, in HC and NH settings, nurses indicated needs related to task coordination (e.g. task responsibility and division) and communication (e.g. information transfer and approachability of other disciplines). During NH admissions, nurses found it important to have care agreements about end-of-life wishes and to optimise a warm welcome (through performing pre-visits prior to admission and receiving practical information to guide people with dementia and loved ones). Future studies should explore and compare the needs of HCPs from different disciplines involved in providing palliative dementia care. This is needed to develop a strategy to improve collaboration among different HCPs in healthcare settings and during admissions.

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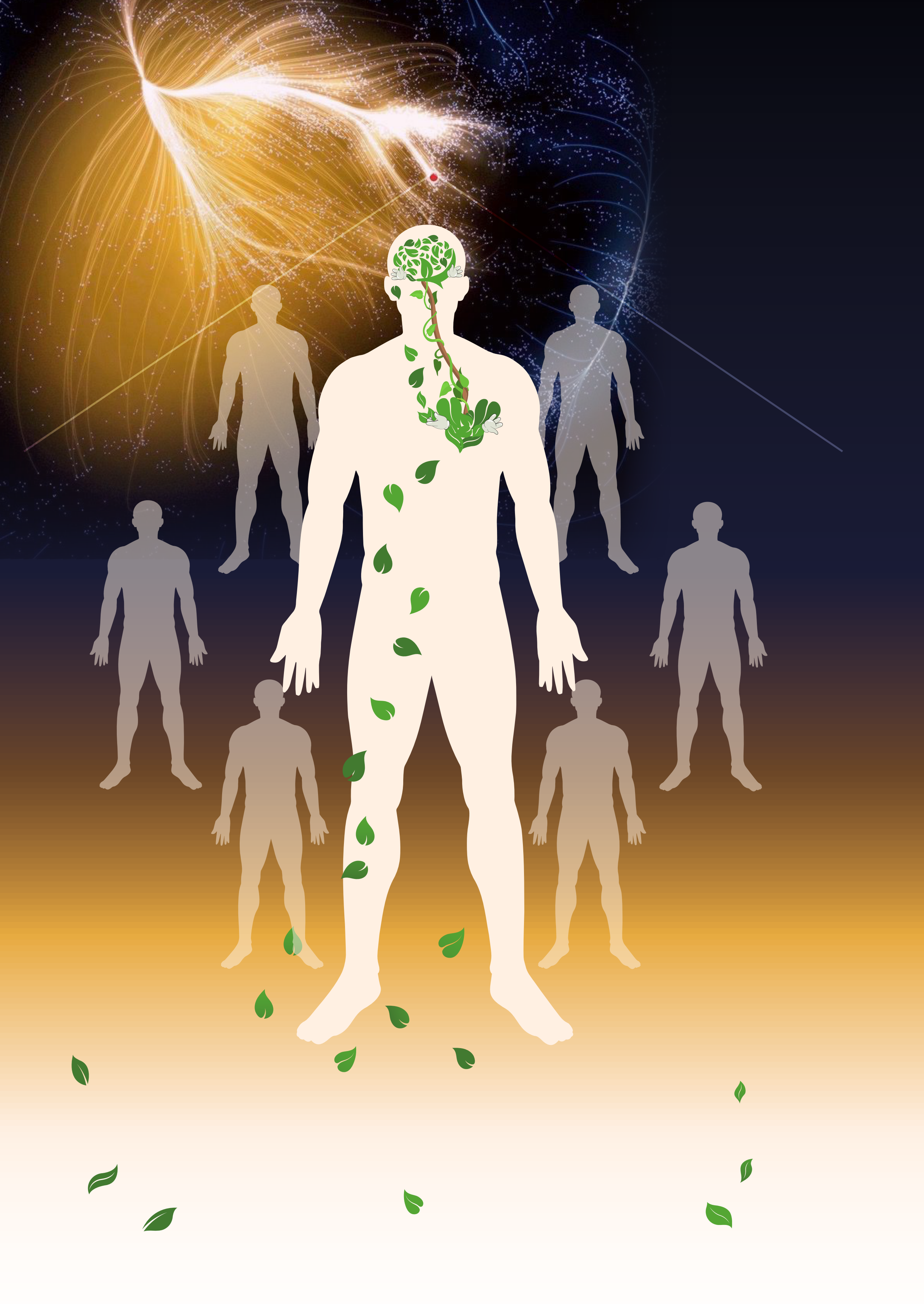

CHAPTER 6

THE DEVELOPMENT OF A GUIDANCE DOCUMENT FOR INTERPROFESSIONAL COLLABORATIVE ADVANCE CARE PLANNING IN DEMENTIA CARE

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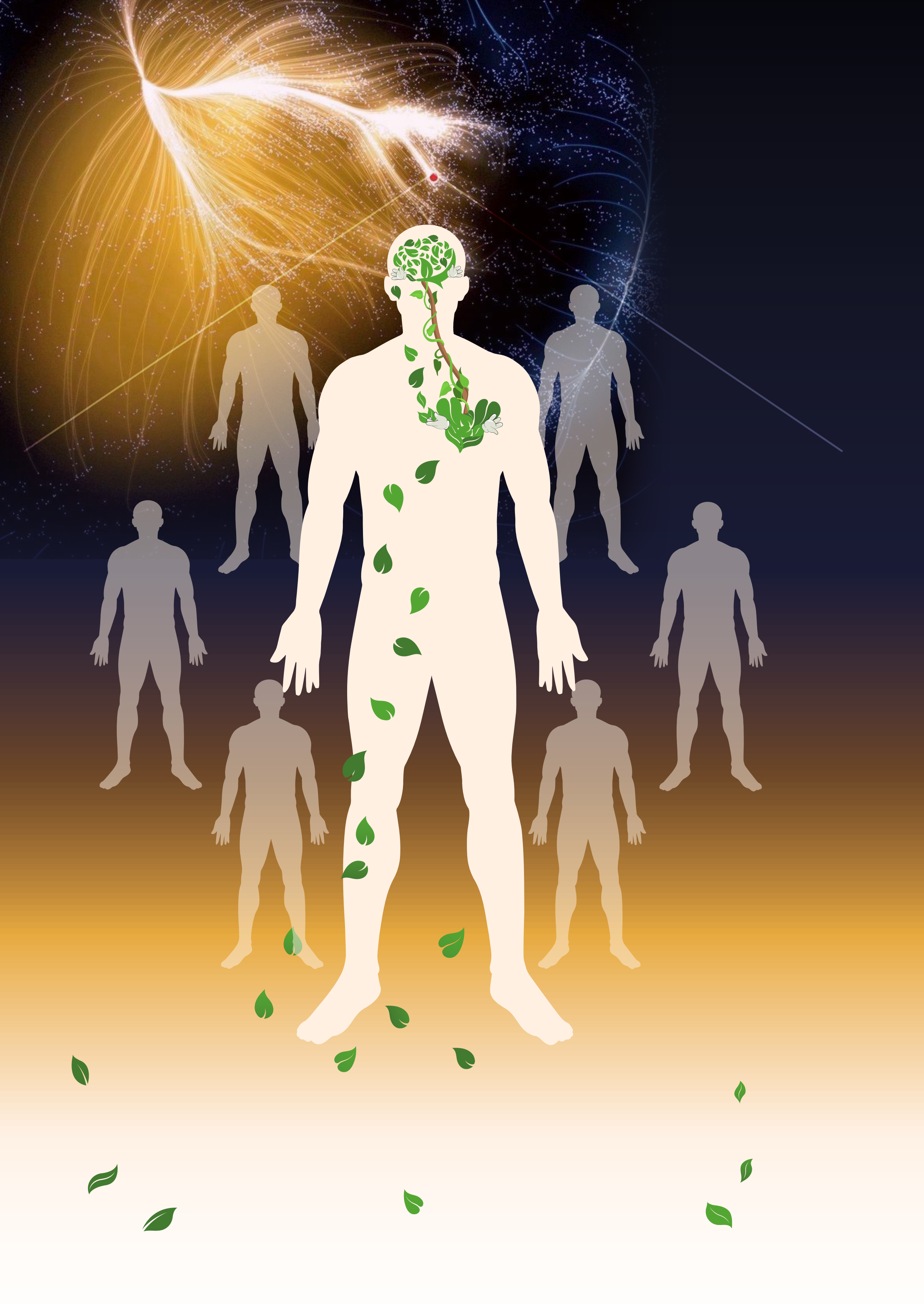
Submitted



CHAPTER 7

GENERAL DISCUSSION

GENERAL DISCUSSION

In this thesis, we focused on various collaborative elements and needs in palliative dementia care (Figure 1). We explored the core elements in the literature *(Chapter 2)*, captured the needs of persons with dementia *(Chapter 3)*, identified the needs of informal caregivers *(Chapter 4)*, and examined the needs of nurses *(Chapter 5)* regarding interprofessional collaboration in palliative dementia care. In *Chapter 6,* we investigated the needs of various healthcare professionals concerning interprofessional collaboration in advance care planning in dementia in nursing homes, and developed a guidance document for healthcare professionals. In Figure 1, we show the collaboration needs of persons with dementia, informal caregivers and healthcare professionals when persons with dementia live at home, moving to and living in a nursing home. This general discussion outlines the main findings, compares these findings to existing literature, discusses methodological strengths and weaknesses, and concludes with practical implications.

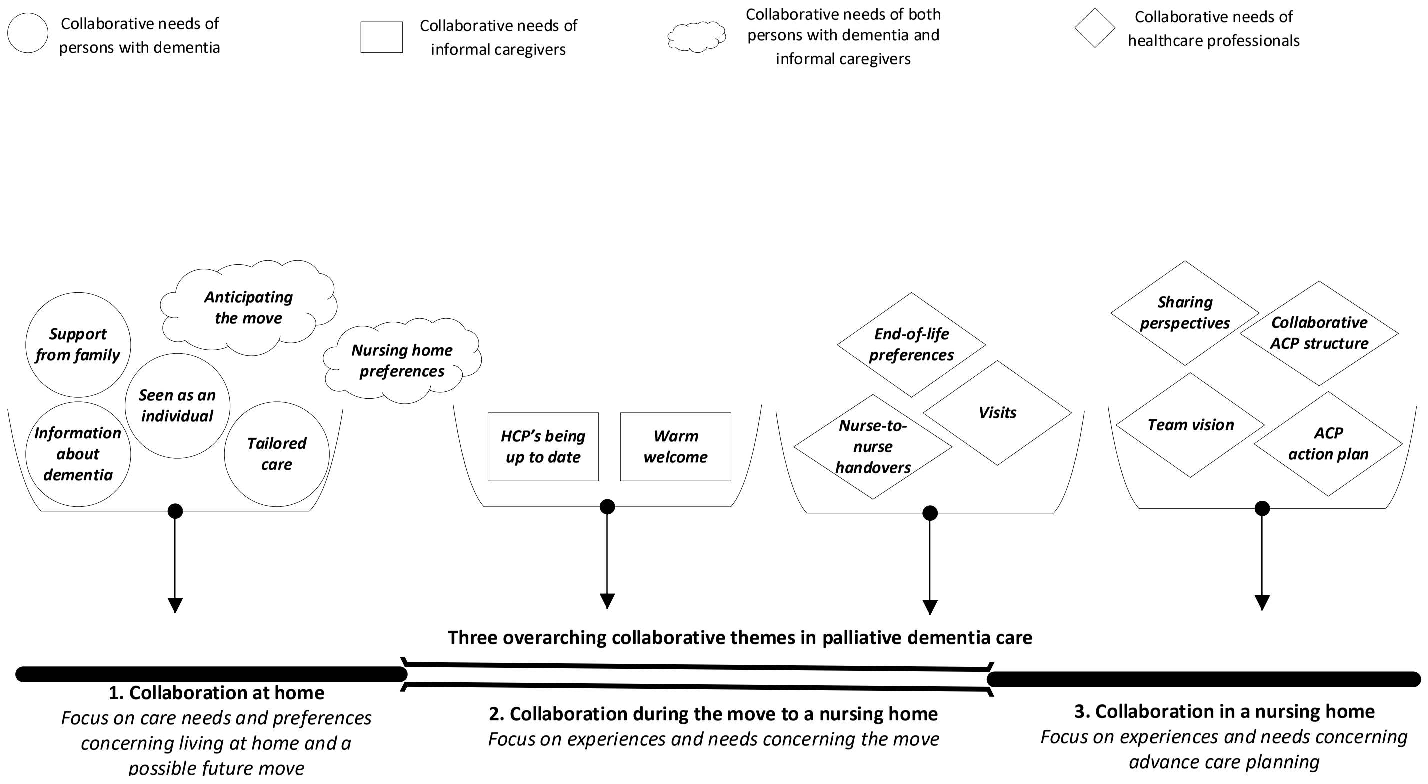


Figure 1. Overview of the collaborative needs of persons with dementia, informal caregivers, and healthcare professionals in palliative dementia care at home, during the move from home to a nursing home and in a nursing home. *Abbreviations: ACP (advance care planning); HCPs (healthcare professionals).*

COLLABORATION THEMES

We categorised the various collaborative needs in palliative dementia care into three overall collaborative themes following the common dementia care pathway: 1) Collaboration needs at home, 2) Collaboration needs during the move to a nursing home, and 3) Collaboration needs in a nursing home.

COLLABORATION NEEDS AT HOME

Both persons with dementia and informal caregivers have a bidirectional role in the communication exchange process: they wish to receive information about the dementia progression from healthcare professionals as well as provide information about their wishes and needs to healthcare professionals *(Chapters 3 & 4)*. For persons with dementia, our research highlighted the need to provide information about how they prefer to be cared for *(tailored care)* *(Chapter 3)*. Moreover, they want to be seen as an individual and receive the space to do the things they still want to do and are capable of doing *(Chapter 3)*. Focusing on the care needs and preferences is central to person-centred care[1], which is an essential principle of palliative care for persons with dementia[2]. Moreover, this thesis confirmed that some persons with dementia living at home have several needs for a future move to a nursing home, suggesting that they can have an active role in anticipating a future move to a nursing home *(Chapter 3)*. This is an important finding, since persons with dementia are not often seen as active collaborative partners during the move to the nursing home[3-5]. Most of these decisions about care movements between care settings are often based on safety and physical health considerations, but not on the imperative meanings of feeling and living at home from the perspective of persons with dementia[6, 7]. For example, some persons with dementia could refer to their home as a place of choice, of freedom, to express their functional competence, and to engage in meaningful activities[7].

A major challenge in anticipating a possible future move to the nursing home relates to the finding of this thesis *(Chapter 3)* and another study is that most persons with dementia do not wish to think about this move[8]. Most persons with dementia wish to live in the moment and feel frightened when confronted with the possible future thought of leaving their home[9]. Some even threaten to harm themselves if they need to move to a nursing home in the future[10]. Moreover, Sussman et al. (2021) described that most persons with dementia find it more challenging to think about their future decline than to think about their death[11]. In this thesis, we showed that persons with dementia who were willing and able to think about their current and future decline were more willing and able to think about moving to a nursing home in the future *(Chapter 3)*. This emphasises the need to identify how persons with dementia cope with their future decline[9] and a possible future move[6]. We recommend that healthcare professionals should introduce these topics in an early phase of dementia *(Chapter 3)* because about

90% of persons with dementia eventually die in a nursing home[12], and the average time from receiving the diagnosis to the move to a nursing home is approximately four years[13, 14]. Moreover, the current Dutch policy stimulates ageing in place[15-18]. This policy pressurises informal caregivers to cope with the high care needs that consequently affect their health and well-being[19]. In addition, most persons with dementia reach a more progressed stage of dementia when entering a nursing home[20, 21]. Thus, anticipating a future move to a nursing home for persons with dementia is important[4, 22], because it allows persons with dementia to explore their needs and preferences, consider available options and mentally prepare for this move[6]. We therefore emphasise the importance of advance care planning about a possible future move to the nursing home in this thesis *(Chapter 3)*, which is also recommended by Garvelink et al. (2019). Garvelink and colleagues (2019) mentioned that advance care planning should not only address end-of-life decisions, but also include the move to the nursing home[23]. This could result in improved decision-making, alleviated guilt and regret feeling for informal caregivers, and improved ability to adjust to a new environment for persons with dementia[23]. This thesis additionally implies that introducing the subject of moving to a nursing home early in time and exploring the thoughts associated with this may result in identifying and addressing preferences of persons with dementia regarding the future nursing home *(Chapter 3)*.

This thesis showed that informal caregivers informed healthcare professionals about the holistic care needs of their relative with dementia, which does not solely refer to indicating their physical care preferences, but also articulating their life history, daily life habits, hobbies, social and religious needs, end-of-life wishes, and medical-related information *(Chapter 4)*. Informal caregivers also play a central role in coordinating care at home and anticipating moving to a nursing home (*Chapter 4*). However, most of the informal caregivers felt alone in anticipating the nursing home move, and wished to receive more support and guidance from healthcare professionals *(Chapter 4)*. Informal caregivers often face challenges of lack of communication among and sharing client records between care services during a move[24]. One solution for this, proposed by this thesis *(Chapter 4)* and other studies, is to appoint one healthcare professional as the contact person for persons with dementia and their informal caregivers[24, 25]. Informal caregivers must know which healthcare professional they can approach directly for their questions and concerns (their contact person)[24, 25]. This healthcare professional can build a relationship with the person with dementia and their informal caregivers, and connect the important care services that are needed[26]. Healthcare professionals also emphasise the need to designate one contact person, who is responsible for that person with dementia and his or her informal caregivers, and can keep other healthcare professionals updated[25]. The decision of which healthcare professional is appropriate for a specific client must to be made collaboratively[27]. So, appointing one contact person is one of the essential components of integrated (community) palliative dementia care[26]. Fox et al. (2020) described that this contact person should be involved from diagnosis until after death to provide bereavement care to informal caregivers[26]. In the home care setting, general practitioners, dementia case managers, social workers and district nurses can fulfil the role of a contact person[26, 28, 29]. This contact person could contribute to the informational continuity (information transfer that follows the client) and cross-boundary continuity (care that follows the client across settings)[30]. However, continuity in contact among healthcare professionals is a challenge in current practice, because the person with dementia often changes from care places and meets many healthcare professionals along the care pathway who are not familiar with the preferences and wishes of the person with dementia[31]. This can lead to difficulties maintaining relational or interpersonal continuity in dementia care (ongoing relationship between clients and healthcare professionals)[30, 32]. In particular, during the move between care settings, informational discontinuity could lead to medication errors and a lack of tailored care[33].

COLLABORATION NEEDS DURING THE MOVE TO A NURSING HOME

A person with dementia does not solely experience the move to a nursing home as an event that occurs to them, because this experience is also influenced by how the move is organised, and whether and how the person with dementia is involved in the move[34]. This thesis confirmed that some persons with dementia living at home are able to express their preferences for a possible future move to the nursing home and suggested that they could indeed perform an active role *(Chapter 3)*. Thein et al. (2011) underlined that the role of persons with dementia in the preparation of the move and their wish to conduct pre-move visits are integral to feeling more involved in the decision-making process of the move[35]. Nurses in this thesis also mentioned the importance of conducting visits (home visits and/or visits to the future nursing home) prior to the move (*Chapter 5*). A facilitating aspect of the move from home to nursing home reported by informal caregivers is the preparation for a *warm welcome* on the moving day for the person with dementia (*Chapter 4*). Informal caregivers described this personal way of welcoming, for example, by preparing sweets, which gave them and their relative with dementia a celebratory feeling (*Chapter 5*). The concept of preparing a warm welcome is also mentioned by the TRANSCIT-model as a method to support persons with dementia and informal caregivers on the moving day[36]. Therefore, (partly) based on the findings of this thesis, we have developed a guidance document describing the practical elements of a warm welcome and the crucial steps to take for healthcare professionals (*Impact paragraph*). We suggest that by including the person with dementia in the move and preparing a warm welcome may positively contribute to how the person with dementia experiences the move (*Impact paragraph*).

Moving to the nursing home mainly occurs in the progressed phase of dementia[12, 19, 37]. Due to the increasing cognitive decline experienced by the person with dementia, informal caregivers gradually become more involved in articulating the preferences and making several decisions on behalf of the person with dementia such as the moving process (*Chapter 4*). The decision about the move to the nursing home is one of the most difficult decisions to make for informal caregivers, particularly when this decision is poorly planned or not timely discussed[38, 39]. When informal caregivers are involved in planning the move to the nursing home, they are more satisfied with the move since they can relay the needs and preferences of their relative with dementia[40-42]. Moreover, this thesis shows and supports that most informal caregivers proactively make decisions regarding the move in dementia care[43]. This finding (*Chapter 4*) is underlined by another study that described that informal caregivers have proactive roles in initiating and persuading the move[23]. On the contrary, another study has shown that informal caregivers could also delay the move because they want to fulfil their relative's wish to live at home as long as possible[44]. This finding could also lead to situations in which persons with dementia are moved too late to nursing homes[45] or increase the risk of crises (such as fall incidents)[46], which does not allow them to prepare for the move[47] and indicate nursing home preferences such as articulating the place of preference (*Chapter 4*). Informal caregivers may also find it difficult to 'let go'[48], and deciding for their relative with dementia to move to the nursing home is loaded with contrasting emotions of guilt and relief together with emotional and mental exhaustion[44]. Moreover, one of the reasons to move to the nursing home in dementia care is the caregiver burden[49]. These challenges show that informal caregivers are in need of emotional support and care for themselves next to their role of being a collaborator and part of the care process[50]. Statz et al. (2021) outlined that healthcare professionals should be trained to explore the source of guilt, reframe negative perceptions and conduct constructive self-talk as methods to support and counsel informal caregivers during the move[51]. Apart from the recognition of informal caregivers as 'clients', informal caregivers should also be considered as equal members of the team[52]. As informal caregivers adopt new roles in the care process of their relative with dementia after the move to the nursing home[44], healthcare professionals should discuss their changing roles[36], preferably prior to the move. In this thesis, most informal caregivers stated they did not feel part of the team in nursing homes (*Chapter 4*). Taking care of informal caregivers throughout the move is essential, because after the decision-making, informal caregivers act as essential information sources for their relatives with dementia[44, 45]. This support from healthcare professionals is needed to ensure that informal caregivers can continue to be involved and execute their roles as they wish in the care process of their relative with dementia[44]. As both persons with dementia and informal caregivers have a paramount role, healthcare professionals' role is to balance both needs[53].

One important collaborative need of informal caregivers is that healthcare professionals working in the home care setting should anticipate and provide support throughout the moving process, and healthcare professionals working in the nursing home should _be up to date_ with the health situation, and needs and preferences of their relative with dementia (*Chapter 4*). Healthcare professionals mentioned the importance of _nurse-to-nurse handovers_, and transferring _end-of-life care preferences_ of persons with dementia when moving to a nursing home (*Chapters 5 and 6*). During care movements between care settings, handovers are essential to ensure continuity and safety[54] including verbal and written communication to transfer information[55]. This thesis showed that informal caregivers play important roles in interprofessional collaboration such as sharing information and making decisions; however, we also touched upon the finding that informal caregivers unwillingly take additional roles such as proactively asking information, and filling the information gap in situations during the move to the nursing home. Based on these findings, we suggest that the contact person from the home care and nursing home setting should exchange information about the care process and meaningful activities of the person with dementia to maintain cross-boundary continuity[56]. Apart from appointing one healthcare professional to coordinate the move[57, 58], strategies such as using multipath communication (for example both documents and personal contact) to transfer information[59], having a protocol or standardised procedure for care movements between care settings[60], and including informal caregivers to share information about their relatives with dementia could be applied[59].

COLLABORATION NEEDS IN A NURSING HOME

Finding the right time is a major challenge in conducting advance care planning conversations with persons with dementia[61, 62]. The initiation of advance care planning is preferred in an early phase of dementia due to cognitive decline[63, 64]; however, there is an ambiguity about when to start advance care planning in dementia care. While Dening et al. (2019) described trigger points when executing advance care planning, such as the time of the diagnosis of dementia, changes in the setting of care, and changes to the health status, Ampe et al. (2016) emphasised the importance of conducting advance care planning prior to these events[65]. This is in accordance with the results of this thesis that accentuate the need for timely advance care planning in dementia care. Healthcare professionals recommend not to conduct these conversations directly after the diagnosis as persons with dementia first need time to process and accept the diagnosis[64]. Phenwan et al. (2020) suggested that advance care planning ideally should start after persons with dementia in the mild or moderate stage accepted the diagnosis[66]. However, this acceptance process could vary for each individual and may last many years after the diagnosis[67]. Interestingly, advance care planning could also support accepting the diagnosis of a terminal disease, which stipulates timely application of a palliative care approach in dementia care[68]. Dementia is not always viewed as a terminal illness by persons with dementia as well as informal caregivers and healthcare professionals[69-73], and this forms a well-known barrier to timely palliative care[74]. Conversely, when the focus on care is not marked as palliative care, the need to conduct advance care planning also becomes less clear[75]. Therefore, advance care planning and palliative care are linked to each other[76] and raising awareness and knowledge about both topics are considered essential[77, 78]. Healthcare professionals should take the responsibility to inform persons with dementia and their informal caregivers about the importance of a palliative care approach in dementia[79], and initiate timely advance care planning conversations[80].

Meaningful advance care planning conversations are not confined to the early stages of dementia since studies found that persons with moderate dementia and confined decision-making capacity could participate in advance care planning[81, 82]. Nonetheless, it depends on whether the person with dementia can execute the four components of decision-making (i.e. understanding, communicating a choice, appreciating and reasoning) and the type of decision[83]. For example, persons with moderate to severe dementia are usually unable to make medical decisions[84], but they could be able to express their values[5, 85], indicate their choice[83] and make everyday decisions[86]. These abilities to articulate their voice and make non-medical decisions can be part of advance care planning (for example choice of place of care), and everyday decisions (for example, things that enable persons with dementia to enjoy life as long as possible)[87]. These decisions are not only about finalising medical orders but also contemplates the conversations and discussions about personal goals and values for specific future events[88, 89], and important things in life[90]. This underlines the notion that healthcare professionals should perpetually endeavour to include persons with dementia in advance care planning by adapting to their cognitive, psychological and emotional capacities. Healthcare professionals should identify the coping strategies that persons with dementia use to deal with future thoughts[91] because they may passively or actively avoid advance care planning[92]. Research has shown that some persons with dementia are willing and capable of sharing their thoughts about the future[9, 91]. This thesis showed that persons with dementia and informal caregivers receive insufficient information about dementia, which is confirmed by several studies[61, 71, 93, 94]. We could imply that receiving information about dementia, its prognosis and advance care planning from healthcare professionals is important, because it enables persons with dementia and informal caregivers to accept the inevitable decline and death in dementia, think about future scenarios, and consider the available options regarding advance care planning[67, 95, 96]. Timely advance care planning is also important for informal caregivers, because if they do not receive enough time and support to explore all decision options from healthcare professionals, they may feel uncertain and guilty about whether they are making the right decisions for their relative with dementia[96].

This thesis showed that healthcare professionals experience a lack of role clarity when performing advance care planning (*Chapter 6*). Task division is often not clear in collaborative advance care planning in dementia[97]. Previous studies mentioned that physicians are the most appropriate healthcare professionals to start the advance care planning conversation with persons with dementia[98-100]. More recent studies have highlighted the pivotal involvement of other healthcare professionals, such as nurses, dementia case managers, social workers and chaplains[101-104]. This thesis supports the findings of Perin et al. (2021) that nurses are one of the central players in advance care planning, and contact persons for persons with dementia, informal caregivers and other healthcare professionals to clarify the current situation[105]. Nurses are well positioned to conduct advance care planning conversations[106], because they can create a close relationship with older adults to understand their personal needs, and make them feel safe and calm[107]. This thesis showed that team leaders and psychologists may also have a role in collaborative advance care planning in dementia care (*Chapter 6*). However, there are also other involved healthcare professionals, which were not included in our study about collaborative advance care planning. For example, dementia case managers could play a role in stimulating timely instigation of advance care planning[64], because they have regular contact with persons with dementia (thereby could function as the contact person), make individualised care plans, educate informal caregivers about dementia and coping skills used in dementia, and contribute to the coordination of care[101, 102, 108]. They could additionally educate persons with dementia and their informal caregivers about dementia and legal matters regarding advance care planning[101, 102]. Nursing home managers could have roles in facilitating the implementation of advance care planning for persons with dementia in organisations, and enabling nurses to become active leaders in this process[78].

This study indicated that healthcare professionals prefer a structured way of conducting *collaborative conversations* about advance care planning for persons with dementia living in nursing homes (*Chapter 6*). Based on this finding, we plead that all healthcare professionals should exhibit competencies to conduct advance care planning conversations[109]. Even though we acknowledge that advance care planning is a joint responsibility[110], we do endorse designating one healthcare professional who takes the initiative and acts as a coordinator (*Chapter 6*), has the responsibility to manage advance care planning, and preferably has a close relationship with the person with dementia and their informal caregivers[80]. Moreover, we suggest that their contribution to advance care planning also depends on whether the persons with dementia and their informal caregivers are willing to communicate with various involved healthcare professionals (*Chapter 6*). Various healthcare professionals complement each other in advance care planning (*Chapter 6*) and cover the full spectrum of the holistic perspective in advance care planning[64]. A major barrier underlined by many studies concerns the lack of competencies and confidence of healthcare professionals to conduct advance care planning in dementia care[66, 78, 99, 111]. Moreover, even though the abovementioned studies and this thesis have described the roles of several healthcare professionals, studies indicated that healthcare professionals find it difficult to define their role within collaborative advance care planning[78, 88]. This thesis emphasised the need for acting as an interprofessional team with the same understanding about what advance care planning in dementia care entails; and the importance of having a <u>*team vision*</u> and working towards an <u>*action plan*</u> to implement advance care planning in practice *(Chapter 6)*.

METHODOLOGICAL CONSIDERATIONS

STRENGTHS

A strength of the current thesis is the involvement of persons with dementia, informal caregivers, and healthcare professionals. Before 1990, limited research focused on the perspectives of persons with dementia[112]. However, current research has emphasised the need to capture the 'lived experience' of persons with dementia[113]. This provides a deeper understanding of dementia and its impact on the life of persons with dementia[114]. This dissertation did not only focus on the perspectives of persons with dementia on the care process but also on a possible future move to the nursing home, which concerns a research area rarely explored[115]. We performed in-depth interviews with persons with dementia and took into account three principles to enable participation: providing accessible information, obtaining legal consent for participation, and checking whether they wish to continue with the research during interactions[116]. In our research with persons with dementia, the interviewers were trained by experts to ask the questions understandably, provide the persons with dementia sufficient time to answer the questions, and pay attention to their facial expressions. We decided to use the perspective of informal caregivers after experiencing the move to the nursing home, because we wanted to have their insight on the entire moving process (pre-, mid- and post-phase). Involving informal caregivers in research also improves the value and relevance of research outcomes[117], because they provide the majority of the care needed by their relative with dementia living at home[118, 119], and have several roles in the care process of their relative with dementia when living at home, moving to a nursing home and living in nursing homes. The role of informal caregivers is important when addressing the palliative care needs of persons with dementia[120]. Therefore, during the entire research period (2017-2022), we involved healthcare professionals and patient representatives in the co-creation process of developing the research objectives to align with the needs in practice. Moreover, we applied appreciative inquiry principles, which is a method that suits the principles of palliative care. Some of these principles are the constructionist principle (i.e. reality is constructed through social and meaningful relationships, and changes are continuous and co-creative processes), the anticipatory principle (i.e. participatory process to discuss end-of-life aspects), and the wholeness principles (i.e. holistic care to integrate the different aspects of a person)[121]. Furthermore, previous studies illuminate that appreciative inquiry is used for person-centered care[122] and interprofessional collaboration in dementia care[123]. For the qualitative analyses, we applied the Consolidated Criteria for Reporting Qualitative Studies[124] and investigator triangulation[125] to increase the credibility and reliability of our findings.

LIMITATIONS

Concerning the move from home to the nursing home, we solely identified the coping strategies and needs of persons with dementia living at home, and needs of bereaved informal caregivers of persons with dementia who had died after living in a nursing home. However, we did not explore the needs of the entire moving process of both persons with dementia and informal caregivers as a 'real life event', and therefore we could not compare whether these needs changed during the pre-, mid- and post-moving phase. Regarding the inclusion method of persons with dementia, we did not use objective methods to measure the cognitive performance, and therefore could not identify the severity of dementia of the participants[126]. Moreover, we did not include persons with dementia living in nursing homes, while Mjørud et al. (2017) showed that they are able to communicate their thoughts and feelings about living in a nursing home and could identify factors that influence their quality of life[127]. We did not study the views of persons with dementia recently admitted to a nursing home because persons with dementia may experience difficulties in the first weeks after the move and need time to settle in, fit in and find meaning after the move in order to adjust in the nursing home[128]. Likewise, we did not include persons with dementia who were about to move or just moved to a nursing home to explore how their preferences and needs expressed at home are followed up, and how they act as collaborators throughout the moving process. We also did not explore the perceptions of both persons with dementia and informal caregivers in pairs to make comparisons because they have different perceptions[129]. Moreover, although we did not include healthcare professionals from various care settings, we involved physicians, nurses, psychologists and team leaders to contribute to the interprofessional research field[130]. So, we did not include all important healthcare professionals that cover the holistic care approach in palliative care (physical, social, psychological and spiritual), such as social workers and spiritual caregivers[131]. Lastly, since we performed video-based focus groups due to the COVID-19 pandemic, we could not optimally observe the participants' body language to determine whether they felt comfortable when participating to the focus group[132].

IMPLICATIONS FOR RESEARCH, PRACTICE, EDUCATION AND POLICY

This dissertation reveals the important needs in and elements of interprofessional collaboration in palliative dementia care, and highlights the need to increase awareness and clarification of each other's (persons with dementia, informal caregivers and healthcare professionals) roles and expectations in palliative dementia care.

RESEARCH

We studied collaborative needs and elements in co-creation with researchers, educators and healthcare professionals, and developed collaborative materials as part of the DEDICATED approach: a guidance document displaying an overview of the essential elements of the interprofessional collaboration process during the move from home to the nursing home, and a guidance document for collaborative advance care planning in nursing homes for persons with dementia (See Impact paragraph). We are currently evaluating the implementation of the DEDICATED approach including these guidance documents through a survey consisting of a subset of questions about reactions and perceptions regarding interprofessional collaboration in palliative dementia care, which will be reported in future articles. However, the current evaluation does not focus on team effectiveness. Future research should be more focused on this, by for example, including the Integrated Team Effectiveness Model, which also considers psychosocial traits and team processes (for example, decision-making)[133]. Another possibility could be to include the questionnaire Assessment of Interprofessional Team Collaboration Scale (AITCS), which addresses four subscales (partnership, cooperation, coordination and shared decision-making)[134].

Concerning the move from home to a nursing home, we recommend future research to focus on the impact of interprofessional collaboration on a warm handoff[135] and warm welcome[36, 136] in dementia care. Regarding advance care planning in nursing homes, we included physicians, nurses, team leaders and psychologists in our study as central collaborators (*Chapter 5*). Nonetheless, Dutch nursing homes are characterised by more comprehensive interprofessional teams[137]; therefore, we recommend future research to additionally include other healthcare professionals such as occupational therapists and pastoral workers who contribute to other non-medical aspects, and thereby enrich the holistic approach of advance care planning[138] and palliative care in general[139-141]. Moreover, advance care planning should be initiated in an early phase of dementia[93], and persons with dementia and their informal caregivers prefer these conversations at their home[64], which should involve healthcare professionals from primary care such as general practitioners, district nurses and dementia case managers[99, 138]. Therefore, we also recommend future studies to investigate interprofessional collaboration concerning advance care planning for persons with dementia living at home. Next, as one of our studies (*Chapter 5*) revealed the lack of information about advance care planning from the home care setting, we additionally wish to investigate how interprofessional collaboration during the move from home to the nursing home specifically affects the information transfer about advance care planning topics during the move to the nursing home. Besides, this thesis addressed interprofessional collaboration as a general process, but did not specifically look at interprofessional processes such as for instance resolving conflicts in palliative dementia care. Future research could for example focus on three types of conflicts that could either be task-based (Opinions about executing team tasks), relationship-based (Tension due to interpersonal differences) or process-based (Disagreements about task division and responsibilities)[142]. Furthermore, future studies should determine whether the care delivered through our collaborative guidance documents is cost-effective.

PRACTICE

Our guidance document about the move from home to a nursing home (largely built on the studies of this thesis; See Impact paragraph) provides the following core recommendations: appointing one central contact person during the entire care process; anticipating a possible move when living at home; preparing a warm welcome; transferring personal information and end-of-life care preferences; and making the persons with dementia feel at home in the nursing home. Current practice in the Netherlands requests more attention to the warm handoff and smoothening of the move from home to nursing homes[143, 144]. Since most persons with dementia die in a nursing home[145] and these care movements could be preceded by crises or acute events[115, 146], we find it important to anticipate a possible move to the nursing home. During the anticipation phase at home, we recommend that healthcare professionals ask questions to persons with dementia and informal caregivers. These questions could be about living at home (for example about how they experience living at home, and what the person with dementia finds important to feel at home); collecting personal information about the person with dementia (for example exploring whether they have nursing home preferences); conducting advance care planning conversations; and continuously monitoring the home situation together with other healthcare professionals. By anticipation, persons with dementia are still able to discuss their preferences for future care[147], which allows them to feel that they are in charge of making choices and managing their lives[148]. This is especially important related to a possible future move to a nursing home, which has a major impact on the lives of persons with dementia[5]. The questions provided in the guidance document could support exploring the (meaningful) activities and preferences in the daily life of persons with dementia, which contribute to their self-esteem and continuation of their habits in nursing homes[149, 150].

Core elements of our guidance document regarding collaborative advance care planning in nursing homes for persons with dementia (completely built on the studies of this thesis) are: collaborative awareness (awareness about the need for interprofessional collaboration), role clarifications, and a shared direction about collaborative advance care planning. This guidance document pinpoints that advance care planning conversations should start at home, and this information should be part of the information transfer during the move from home to the nursing home. Moreover, this guidance document also explains what is essential for optimal communication with other healthcare professionals in the nursing home setting, which is one of the main barriers in practice regarding advance care planning in nursing homes for persons with dementia[151]. We believe that the steps described in our guidance document could improve the interprofessional approach in advance care planning in nursing homes. Furthermore, it is crucial that persons with dementia and their informal caregivers are considered as dignified collaborative partners without stigmatised perspectives of persons with dementia who have no own voice[152] or a hierarchical atmosphere between them and the healthcare professionals[153].

For the implementation of our collaboration guidance documents, we recommend that each care organisation and (more specifically) care team or nursing home location should ascertain whether their protocols for collaborative advance care planning, and collaborative organising of the move from home to nursing homes include the core elements from our guidance documents, which are built upon the needs and elements captured in this thesis. We thereby advocate a bottom-up as well a top-down approach in which healthcare professionals working in daily practice, policy makers or/and managers could also play a role in the implementation process. For example, this could be through assisting in adapting the existing protocols through adding knowledge from our guidance documents, building a collaborative team vision, and providing resources to support the collaborative process.

EDUCATION

In the Netherlands, generalist basic palliative care is not considered a distinct medical specialty but is seen as part of regular healthcare, which any healthcare professional should be able to provide[154]. Palliative care principles, however, are not sufficiently enough covered in the Dutch basic medical and nursing curricula[155-158]. For general practitioners, there are educational interventions such as interactive workshops to stimulate advance care planning as part of palliative care, focusing on medical and non-medical items[159]. Elderly care physicians in the Netherlands follow an education in geriatrics, dementia and palliative care[160]. In the Dutch current education plan for psychologists, the core competencies regarding interprofessional collaboration are to know the guidelines about interprofessional collaboration, make a social map, and coordinate with other disciplines, but they do not address (collaborative) palliative dementia care[161]. In the education program for dementia case managers, the two topics of palliative care for persons with dementia and interprofessional collaboration are separately described but do not focus on an interprofessional collaborative approach in palliative dementia care[162]. Bavelaar et al. (2021) mentioned that lack of interprofessional collaboration (for example having a shared way of performing advance care planning) is one of the main barriers to achieve high quality palliative dementia care in practice, which stresses the need to improve education[151]. Our guidance documents could contribute to increasing understanding and knowledge about collaborative palliative dementia care in education. We plead to include our guidance documents in the basic education of various healthcare professionals (for example nurses, physicians, occupational therapists, dementia case managers, and spiritual caregivers), as they are all built in co-creation with educators from intermediate vocational education, higher vocational education and university. Moreover, our guidance documents may add value to the topic dementia of the educational framework palliative care 2.0 that addresses interprofessional collaboration in palliative care, and focuses on nurses from several nursing levels and physicians[163]. Future educational activities for healthcare professionals should also address the educational needs of persons with dementia and informal caregivers regarding collaboration in palliative dementia care.

In our implementation study, the trainings provided to the healthcare professionals solely focused on raising awareness about the need for and core elements of an interprofessional collaborative approach in palliative dementia care. Future interprofessional education could focus on interactive exercises such as case studies in which various healthcare professionals together interactively learn how to agree on each other's roles, and how to complement each other in interprofessional collaboration regarding the move from home to the nursing home, and advance care planning at home and in nursing homes in dementia care[164]. Regarding advance care planning in practice, a major need is indeed interprofessional education[109]. Our guidance document about collaborative advance care planning provides elements that could be useful in the basic education of various healthcare professionals in palliative dementia care. For example, our guidance document describes the roles of various healthcare professionals in advance care planning in dementia, and refers to the basic interprofessional skills such as how to optimally communicate and conduct effective meetings with other healthcare professionals. Further steps in interprofessional education would be integrating the voices of persons with dementia, informal caregivers and other involved healthcare professionals.

POLICY

In line with the recommendations of Bavelaar et al. (2021), this thesis accentuates the need to increase public awareness about the life-limiting character of dementia, the need for a palliative care approach to dementia, and the early initiation of advance care planning in dementia[151]. On an international level, the European Association for

Palliative care (EAPC) Whitepaper described 11 domains and 57 recommendations for a palliative care approach in dementia[2]. The EAPC Whitepaper described the importance of interprofessional collaboration in several domains, but did not provide specific recommendations for an interprofessional collaborative approach in palliative dementia care. For example, based on our guidance document about collaboration in advance care planning, we recommend that all healthcare professionals should be able to conduct advance care planning conversations in dementia care and collaborate in the process of advance care planning. Based on our guidance document about collaboration concerning the move from home to nursing home, we suggest that the central contact persons from both care settings should connect and exchange information to each other to provide a warm transfer, and welcome during a move between care settings in dementia care. We showed in *Chapter 5* that nurses identified the importance of providing a warm welcome during the move from home to the nursing home through guiding persons with dementia and their informal caregivers, and performing pre-visits prior to the move as one of their needs in palliative dementia care. Garvelink et al. (2019) recommended that dementia case managers could also fulfil this role[23], and stay involved after the nursing home admission to create a bridge between home care and nursing home for persons with dementia and their informal caregivers[143]. However, the financial barrier between the care settings impedes the role taking of the central contact person from the home care setting (for example, district nurses or dementia case managers)[143] in contributing to a warm transfer and warm welcome for the person with dementia during the move from home to the nursing home. The Dutch Healthcare Authority (*NL: Nederlandse Zorgautoriteit*) provides financial options that healthcare professionals could apply for to receive payments if they want to collaborate with healthcare professionals from other care settings[165]. We suggest that transmural collaboration should intrinsically be part of the professional tasks of the healthcare professional for which they do not need to additionally request reimbursement. One of the pillars of a current national initiative 'National Program Palliative Care II' that runs from 2023-2026 is to improve interprofessional collaboration to maintain continuity in palliative care[166]. Our guidance documents could provide this program with insights to specify the aims and essence of an interprofessional collaborative approach in palliative dementia care within and between care settings.

The Dutch quality framework for palliative care (*NL: kwaliteitskader palliatieve zorg*) describes six criteria that are important for interprofessional collaboration in palliative care, but is not specified for the entire chain of care in dementia, does not mention including a team vision, and does not clarify the roles of those involved including the participation of client and informal caregivers in advance care planning[167]. In the Netherlands, there is also a quality framework for nursing homes (*NL: kwaliteitskader verpleeghuiszorg*) in which advance care planning is mentioned as a quality indicator but it does not provide information on how to take an interprofessional collaborative approach in advance care planning[168]. In our guidance document about collaborative advance care planning in nursing homes for persons with dementia, we specified the steps to develop a team vision and identify team objectives for collaboration in advance care planning in nursing homes. Our team vision could provide input to incorporate an interprofessional collaborative approach regarding palliative dementia care in the organisational vision on care of nursing homes. Additionally, one of the team objectives that this thesis revealed is to include interprofessional collaboration regarding advance care planning in dementia as an agenda point during structured (interprofessional and family) meetings in nursing homes. This could provide practical suggestions on how to collaborate in advance care planning to policy advisors or managers of nursing home organisations. Apart from having clear policies, organisational requirements such as time, space and resources are needed to support optimal communication in palliative dementia care[109, 151]. Based on this thesis, we emphasise the need to implement aligned documentation tools (as an important resource) within care organisation policies for nursing homes. This could improve the efficacy of sharing information and documents about advance care planning conversations among various healthcare professionals, persons with dementia and their informal caregivers[109].

CONCLUSION

The aim of this thesis was to discover important elements of and needs in interprofessional collaboration in palliative dementia care. Based on our studies and additional focus groups about collaboration during the move from home to a nursing home in dementia care, we developed a guidance document for an interprofessional collaborative approach during the move from home to a nursing home for persons with dementia. Concerning the move from home to a nursing home in dementia care, we emphasised the need for collaboration in anticipation, the preparation of a warm welcome, and the providence of a feeling of being at home in the nursing home. Based on our studies presented in this thesis, we developed a guidance document for collaborative advance care planning in nursing homes in dementia care. Regarding advance care planning in the nursing home, we mainly pinpointed increasing awareness of collaborative advance care planning, clarifying roles (in which one healthcare professional is the central coordinator), and creating a team vision. Altogether, this thesis provides a knowledge base for interprofessional collaboration in palliative dementia care, aims to increase awareness of the conjunction of collaboration and palliative dementia care, and centralises the triad of collaborators (persons with dementia, informal caregivers and healthcare professionals).

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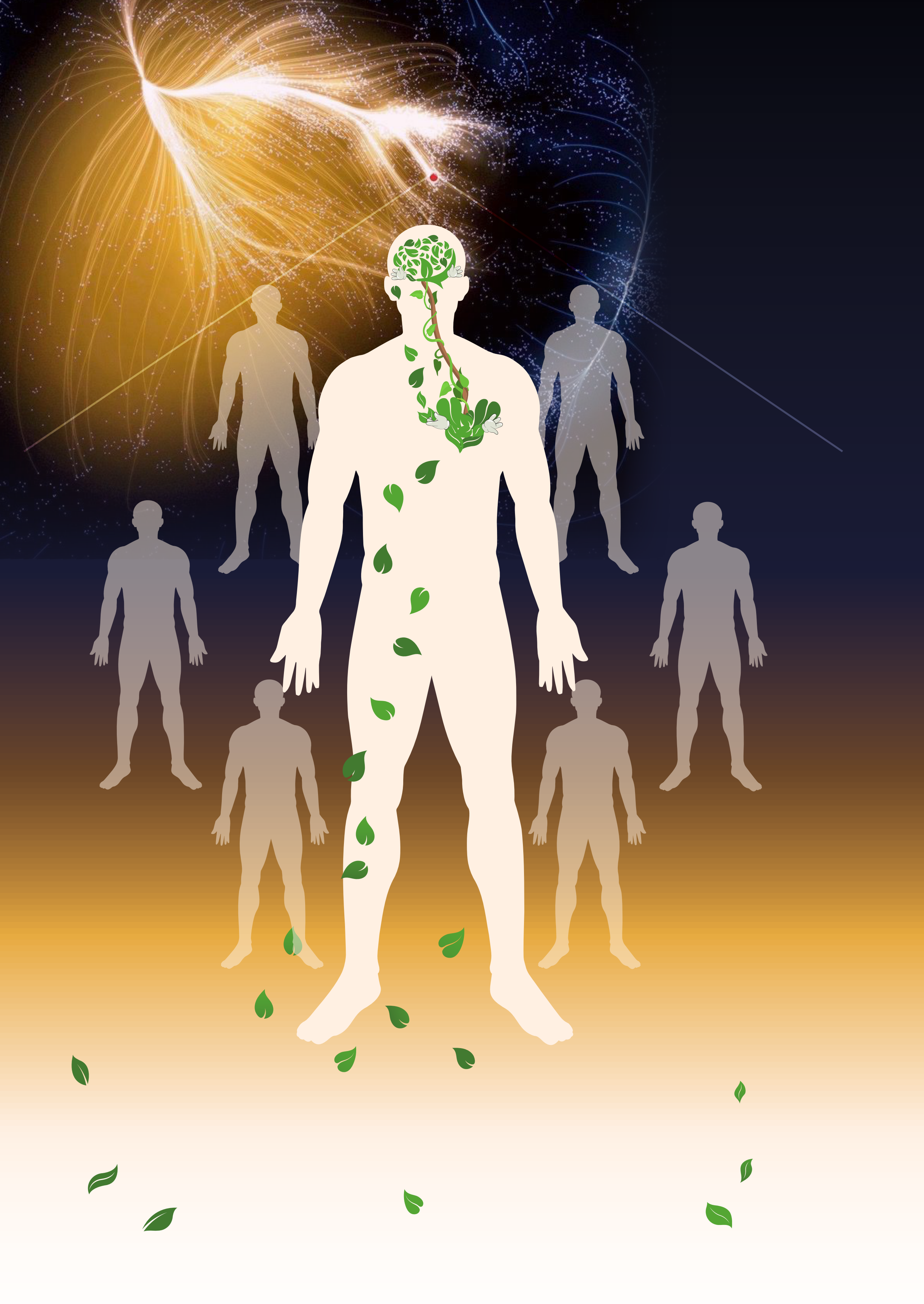


SUMMARIES

ENGLISH SUMMARY
DUTCH SUMMARY

ENGLISH SUMMARY

A palliative care approach is essential for persons with dementia, since dementia is a progressive and life-limiting disease. This care approach is characterised by holistic principles covering physical, psychological, social and spiritual domains, and aims to improve the quality of life. One of the main barriers in providing optimal palliative care for persons with dementia concerns interprofessional collaboration within and between care settings. Our thesis emphasises that triad collaboration (persons with dementia, informal caregivers and healthcare professionals) is crucial in interprofessional collaboration in palliative dementia care. All collaborative partners have their own perspectives, needs and roles, which need to be timely explored and addressed. In our thesis, we focused on the common care pathway of dementia, starting at home and ending in the nursing home, and highlighted the move from home to the nursing home and advance care planning in nursing homes. Some key elements include exchanging information, providing tailored care, anticipating, acknowledging persons with dementia as individuals with their own voice, supporting informal caregivers, organising warm handovers, having shared visions, and having collaborative structures within care organisations. This PhD thesis contributes to raising awareness regarding interprofessional collaboration when adopting a palliative care approach in dementia care. Based on our findings, we developed two guidance documents, two infographics and one video to increase awareness about what interprofessional collaboration in palliative dementia care entails concerning the move from home to the nursing home, and advance care planning in nursing homes.

Chapter 1 provides a general description about two care topics (palliative care and dementia care) and three care processes (interprofessional collaboration, the move from home to the nursing home and advance care planning). Alongside, this chapter substantiated the reason why palliative care is important for persons with dementia and why interprofessional collaboration is one of the main facilitators to provide optimal palliative dementia care. Next, the impact of the move from home to a nursing home and advance care planning in nursing homes for persons with dementia is highlighted. Lastly, this chapter describes the Desired Dementia Care Towards End of Life (DEDICATED) project, and ends with the overall aim and outline of this thesis.

Chapter 2 reviews the literature on existing interprofessional collaboration approaches in palliative dementia care and investigates main elements of these approaches. The search of this scoping review, conducted in august 2021, yielded 28 studies that reported 16 various interprofessional collaboration approaches. The results accentuated the triad collaboration as various healthcare professionals, informal caregivers and persons with dementia were involved in half of the identified interprofessional collaboration approaches. The interprofessional collaboration approaches composed of mainly three elements, identified through content analysis, and included: 1) *Collaborative themes*, 2) *Collaborative processes*, and 3) *Resources in collaboration*. The collaborative themes refer to the topics addressed in palliative dementia care and concerned symptom management, end-of-life care, shared decision-making, informal caregiver support, advance care planning, and care movements between care settings. The collaborative processes that healthcare professionals executed in these approaches were communicating, assessing and monitoring, coordinating, reflecting, and evaluating. The resources that healthcare professionals needed to collaborate with each other encompassed written and physical products, a facilitating working environment, and professional competencies. This scoping review sheds light on the important elements needed for interprofessional collaboration in palliative dementia care.

Chapter 3 presents the findings of a cross-sectional qualitative study that examined the experiences in interprofessional collaboration and perceptions about a possible future move to the nursing home of persons with dementia. In total, eighteen persons with dementia living at home participated. Content analysis identified four main themes: 1) *My perception of collaboration among healthcare professionals*; 2) *My needs in interprofessional collaboration*; 3) *My coping strategies for a possible future move to the nursing home*; and 4) *My preferences when a NH becomes my possible future home*. Participants were able to describe the positive impact of collaboration among healthcare professionals on the arrangements and commitments in their care process. However, they were not able to identify all various involved healthcare professionals by profession and did not know for sure whether they communicated with each other. All participants emphasised that they wanted to be seen as an individual with their own voice and receive tailored care. Most of them also wanted to receive information about dementia and realised the importance of the support they received from their informal caregivers when collaborating with healthcare professionals. When asked about their thoughts regarding a possible future move to the nursing home, the majority mentioned that they coped with their current decline by cherishing their current life and at the same time realising their current decline. All participants wanted to stay at home as long as possible, but half of the participants were able or/and willing to think about a possible future nursing home. These participants were able to express their future preferences about living in a nursing home and mentioned that they wanted to choose their own nursing home environment, continue with their daily activities or hobbies and maintain their social life. This study showed that persons with dementia living at home are collaborative partners with their own needs and preferences in collaboration with healthcare professionals.

Chapter 4 describes the experiences of informal caregivers of persons with dementia about interprofessional collaboration at home, in nursing homes and during the move from home to the nursing home. The sample included 32 informal caregivers of which the majority was female. A critical realist analysis method revealed two themes: 1) *Informal caregivers' roles in interprofessional collaboration with healthcare professionals* and 2*) Informal caregivers' perception of interprofessional collaboration among healthcare professionals*. Informal caregivers played a role in three processes (information exchange, care process and shared decision-making) when collaborating with healthcare professionals. Their involvement in information exchange concerned a two-way process, because they needed information about their relative with dementia, but also provided personal information about their relative. Moreover, some informal caregivers in nursing homes had to repeat themselves and a few informal caregivers had to actively relay information during the move from home to the nursing home. For informal caregivers, collaboration among healthcare professionals was not directly visible on communication and team process level, but they described the direct impact of inadequate information exchange among, and inadequate and inconsistent attitudes of healthcare professionals. We illuminated that when healthcare professionals showed a more proactive attitude and displayed adequate competencies, as perceived by informal caregivers, informal caregivers showed fewer reactive roles such as asking for information, filling the information gap, and performing additional caregiving, monitoring, and coordinating tasks.

Chapter 5 presents the results of a cross-sectional online survey study to identify the perceptions and needs of nurses with respect to interprofessional collaboration when providing palliative care for persons with dementia. More than half of the participants (total N=384) consisted of certified nurse assistants (53.1%) and worked in the home care setting (53.9%). The highest ranked collaboration needs were to have one available contact person for persons with dementia and their informal caregivers (37.5%), achieve optimal information transfer (37.2%), approach other disciplines within own care organisation (31.0%), achieve clarity about the responsibilities among the involved healthcare professionals (30.7%), and achieve clarity on the tasks of the involved healthcare professionals (30.5%). The highest ranked collaboration needs during the move from home to the nursing home were to have transparency about end-of-life agreements (42.4%), visit the person with dementia and their informal caregivers prior the move to the nursing home (41.9%), receive information and advice to guide persons with dementia and their informal caregivers (39.5%), have one point of contact in the coordination process (35.7%), and gain insight into the coordination process (31.4%). These results could inform the practice and provide direction on how to improve interprofessional collaboration in palliative dementia care for nurses working at home and in nursing homes, and to guide the move from home to the nursing home.

Chapter 6 outlines the results of a mixed-method study to discover crucial elements for interprofessional collaboration regarding advance care planning and process these elements in a guidance document for healthcare professionals working in a nursing home. The development process of the guidance document consisted of five steps. This study is about the fifth step, which concerns online interviews and focus groups with nurses, psychologists, team leaders and elderly care physicians. We interviewed eighteen participants with a mean age of 43.8 years (79% female). Content analysis revealed nine themes: *1) The meaning of advance care planning; 2) Timing and continuity of advance care planning; 3) Lacking information from the home care setting; 4) Creating role clarity in advance care planning; 5) Having a shared direction; 6) Sharing perspectives and making shared-decisions; 7) From advance care planning information to actions; 8) Having a facilitating organisation; and 9) Evaluating interprofessional collaboration and end-of-life care*. These nine themes are processed into six elements of the guidance document for interprofessional collaboration in advance care planning for persons with dementia living in nursing homes. This study emphasises the importance of raising awareness about the collaborative approach in advance care planning in dementia. Moreover, we showed the relevance of building a shared team vision and communicating about each other's roles in collaborative advance care planning in dementia care. We suggest that this study provides a practical guidance document for healthcare professionals to identify lacking elements on how to conduct collaborative advance care planning in dementia care.

Chapter 7 includes a summary of the main results of this thesis, and reflects on the methodological and theoretical aspects of these results. The chapter 'general discussion' mainly focused on the challenges associated with advance care planning in dementia concerning a possible future move and end-of-life preferences. Moreover, this paragraph also discusses the coordination within interprofessional collaboration and the collaborative approach in performing advance care planning in dementia care. The implications paragraph described how our results could add value for the current and future manner of interprofessional collaboration in palliative dementia care in the context of research, practice, education and policy.

NEDERLANDSE SAMENVATTING

Een palliatieve zorgbenadering is essentieel voor mensen met dementie aangezien dementie een progressieve en levensbedreigende ziekte is. Deze zorgbenadering is gekarakteriseerd door holistische principes, waaronder aandacht voor fysieke, psychologische, sociale en spirituele domeinen, en beoogt de kwaliteit van leven te verbeteren. Een van de barrières voor het verlenen van optimale palliatieve zorg aan mensen met dementie betreft interprofessionele samenwerking binnen en tussen de zorgsettingen. Dit proefschrift benadrukt dat de driehoekssamenwerking tussen mensen met dementie, informele zorgverleners en zorgprofessionals cruciaal is bij interprofessionele samenwerking in de palliatieve zorg bij dementie. Het is daarom belangrijk om de perspectieven, behoeftes en rollen van alle samenwerkingspartners in de palliatieve zorg bij dementie tijdig te identificeren en in acht te nemen. In dit proefschrift hebben wij gefocust op het meest voorkomende zorgpad van dementie dat meestal start in de thuissetting en eindigt in de verpleeghuissetting. Dit proefschrift richt zich in het zorgpad op twee processen: 1) Verhuizing van thuis naar het verpleeghuis en 2) Proactieve zorgplanning in het verpleeghuis. Een aantal kernelementen zijn: uitwisselen van informatie, leveren van zorg op maat, anticiperen, erkennen van mensen met dementie als individuen met een eigen stem, ondersteunen van informele zorgverleners, organiseren van warme overdrachten, opstellen van gezamenlijke visies en het hebben van samenwerkingsstructuren binnen zorgorganisaties. Dit proefschrift draagt bij aan het vergroten van de bewustwording omtrent interprofessionele samenwerking bij het inzetten van een palliatieve benadering voor mensen met dementie. Op basis van de resultaten die voortkomen uit dit proefschrift hebben wij twee handreikingen, twee infographics en één video ontwikkeld om zorgprofessionals inzicht te bieden in de kernaspecten van interprofessionele samenwerking tijdens de verhuizing van thuis naar het verpleeghuis en proactieve zorgplanning in het verpleeghuis.

Hoofdstuk 1 biedt een algemene beschrijving aan van twee zorgonderwerpen (palliatieve zorg en dementiezorg) en drie zorgprocessen (interprofessionele samenwerking, de verhuizing van thuis naar het verpleeghuis en proactieve zorgplanning). Daarnaast legt dit hoofdstuk uit waarom een palliatieve benadering belangrijk is in de dementiezorg en waarom interprofessionele samenwerking een van de belangrijke bevorderende factoren is om optimale palliatieve zorg te verlenen aan mensen met dementie. Verder beschrijft dit hoofdstuk de impact van een verhuizing van thuis naar het verpleeghuis en proactieve zorgplanning in het verpleeghuis op de dementiezorg. Tot slot omschrijft dit hoofdstuk het onderzoeksproject Desired Dementia Care Towards End of Life (DEDICATED) en de onderzoeksdoelen van dit proefschrift.

Hoofdstuk 2 beschrijft een scoping review met als doel bestaande interprofessionele samenwerkingsstrategieën in de palliatieve zorg bij dementie in kaart te brengen en de kernelementen van deze strategieën te identificeren. Het literatuuronderzoek is in augustus 2021 uitgevoerd en heeft geresulteerd in 28 studies die 16 verschillende interprofessionele strategieën documenteren. De resultaten accentueren de driehoekssamenwerking aangezien zorgprofessionals, informele zorgverleners en mensen met dementie waren geïdentificeerd in de helft van de interprofessionele samenwerkingsstrategieën. Er zijn in totaal drie kernelementen, voortkomend uit de content analyse, geïdentificeerd: 1) Samenwerkingsthema's, 2) Samenwerkingsprocessen en 3) Middelen om samen te werken. De samenwerkingsthema's refereren naar de onderwerpen binnen de palliatieve zorg bij dementie: symptoom management, levenseindezorg, gezamenlijke besluitvorming, ondersteuning voor informele zorgverleners, proactieve zorgplanning en verhuizingen tussen zorgsettingen. De samenwerkingsprocessen die de zorgprofessionals uitvoeren om de strategieën toe te passen zijn communicatie, beoordelen en monitoren, coördineren, reflecteren en evalueren. De middelen die zorgprofessionals nodig hebben om met elkaar samen te werken zijn documenten en fysieke producten, een faciliterende werkomgeving en professionele competenties. Deze scoping review geeft de elementen weer die belangrijk zijn voor interprofessionele samenwerking bij de palliatieve zorgbenadering voor mensen met dementie.

Hoofdstuk 3 presenteert de resultaten van een cross-sectionele kwalitatieve studie met als doel om de perspectieven en behoeftes van mensen met dementie in de samenwerking met zorgprofessionals en omtrent een mogelijke toekomstige verhuizing van thuis naar het verpleeghuis te onderzoeken. De geïnterviewden waren achttien mensen met dementie. De content analyse identificeerde de volgende vier hoofdthema's: 1) *Mijn percepties omtrent de samenwerking tussen zorgprofessionals onderling*, 2) *Mijn behoeftes in de interprofessionele samenwerking*, 3) *Mijn copingstrategieën voor een mogelijke toekomstige verhuizing naar het verpleeghuis* en 4) *Mijn voorkeuren wanneer een verpleeghuis mijn toekomstige thuisplek wordt*. De participanten beschreven dat interprofessionele samenwerking een positieve impact heeft op hun zorgproces, omdat de betrokken zorgprofessionals zaken regelden en beloftes nakwamen. Echter, de participanten vonden het lastig om alle betrokken zorgprofessionals te identificeren op basis van hun professie en konden niet met zekerheid zeggen of de zorgprofessionals met elkaar communiceerden. Alle participanten benadrukten dat zij als individuen met een eigen stem gezien willen worden en dat ze zorg op maat willen ontvangen. De meeste participanten wilden ook informatie ontvangen over het ziekteproces van dementie en realiseerden dat zij in de samenwerking met zorgprofessionals ondersteuning nodig hebben van hun informele zorgverleners. Bij de gedachte dat zij ooit in de toekomst wellicht zouden moeten verhuizen naar een verpleeghuis, gaf de meerderheid aan dat zij het enerzijds waarderen wat zij nog kunnen doen maar anderzijds hun achteruitgang wel inzien. Alle participanten willen graag zo lang mogelijk thuis blijven wonen, maar de helft was wel in staat en gaf aan ook bereidwillig te zijn om na te denken over een mogelijke toekomstige verhuizing naar een verpleeghuis. Deze participanten konden hun voorkeuren ook aangeven, waaronder de mogelijkheid om zelf de omgeving uit te kiezen, hun dagelijkse activiteiten te continueren en hun sociaal leven te behouden. Deze studie toont aan dat mensen met dementie in de thuissetting samenwerkingspartners zijn in de palliatieve zorgbenadering met hun eigen behoeftes en voorkeuren in de samenwerking met zorgprofessionals.

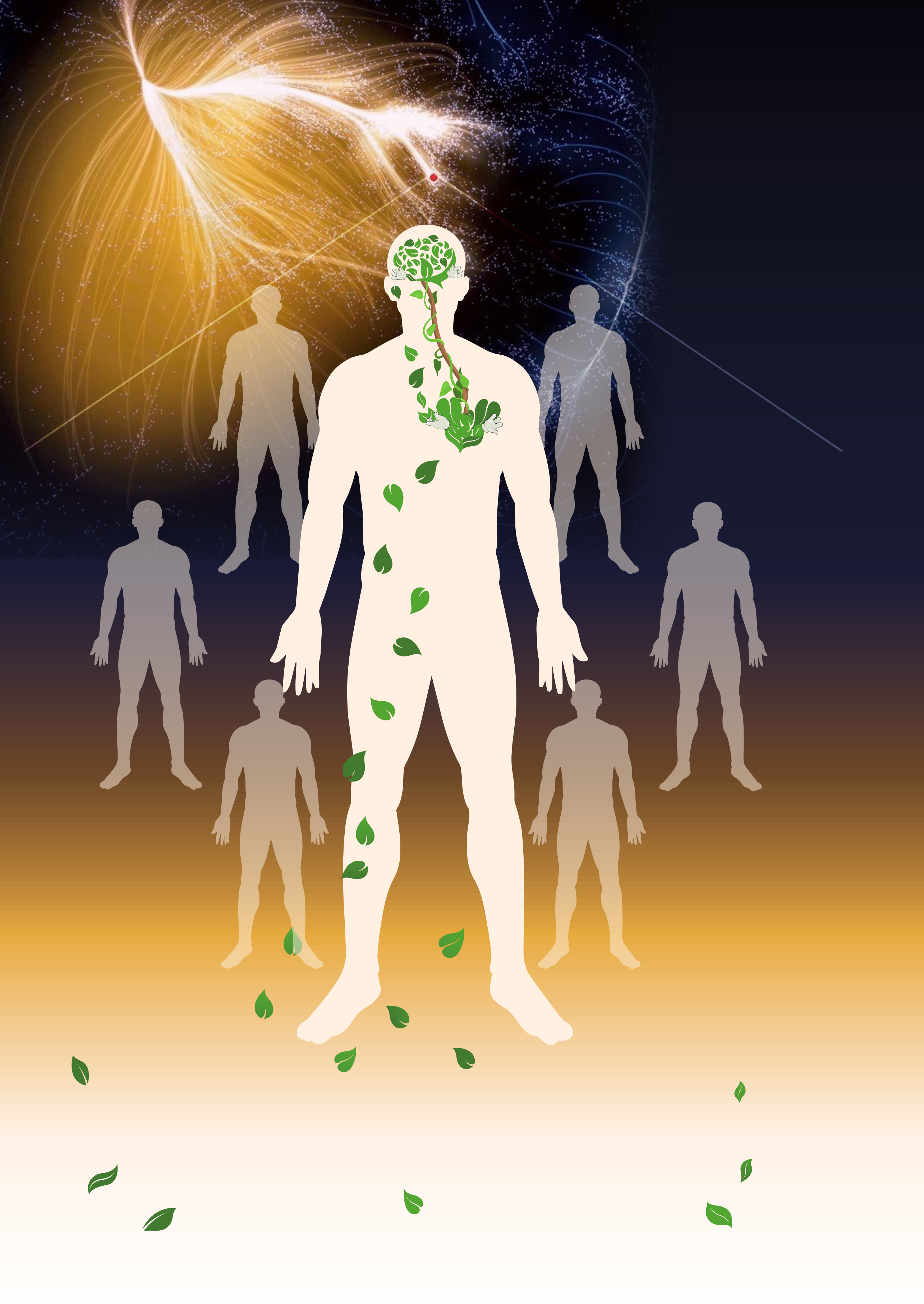
Hoofdstuk 4 beschrijft de ervaringen van informele zorgverleners van mensen met dementie omtrent interprofessionele samenwerking in de thuissetting, tijdens de verhuizing van thuis naar het verpleeghuis en in de verpleeghuissetting. In totaal namen er 32 participanten, waarvan de meerderheid vrouwen waren, deel aan dit onderzoek. De kritisch realistische analyse resulteerde in twee thema's: 1) *Rollen van informele zorgverleners in de interprofessionele samenwerking met zorgprofessionals* en 2) *Percepties van informele zorgverleners omtrent interprofessionele samenwerking tussen zorgprofessionals onderling*. Deze studie toont aan dat informele zorgverleners een grote rol spelen in drie processen wanneer ze samenwerken met zorgprofessionals: informatie-uitwisseling, zorgproces en gezamenlijke besluitvorming. Hun betrokkenheid in de informatie-uitwisseling is een bidirectionele communicatie, omdat ze enerzijds informatie willen ontvangen van zorgprofessionals over de huidige status van hun familielid met dementie maar anderzijds ook persoonsgerichte informatie over hun familielid met dementie willen geven aan zorgprofessionals. Bovendien gaven een aantal informele zorgverleners aan dat ze vaak informatie moesten herhalen in het verpleeghuis en enkelen moesten zelfs actief informatie doorgeven tijdens de verhuizing van thuis naar het verpleeghuis. Voor informele zorgverleners was de samenwerking tussen zorgprofessionals onderling niet direct zichtbaar op het niveau van de communicatie en het teamproces, maar konden zij de impact van de samenwerking tussen zorgprofessionals onderling wel afleiden uit de suboptimale informatieoverdracht en de inconsistente wijze van handelen in het zorgproces. De resultaten wijzen er tevens op dat wanneer informele zorgverleners merken dat zorgprofessionals een proactieve houding hebben en competenties bezitten, zij minder additionele rollen op zich hoeven te nemen zoals het proactief vragen naar informatie, het proactief overdragen van informatie en het uitvoeren van extra zorg-, monitor- en coördinatie-gerelateerde taken in het zorgproces.

Hoofdstuk 5 rapporteert de bevindingen van een cross-sectioneel vragenlijstonderzoek om de percepties en behoeftes van verpleegkundigen omtrent interprofessioneel samenwerken bij de palliatieve zorg voor mensen met dementie te onderzoeken.

Meer dan de helft van de participanten (totaal N=384) zijn verzorgenden (53.1%) en werken in de thuissetting (53.9%). De meest onderschreven interprofessionele samenwerkingsbehoeften waren: het hebben van een contactpersoon voor mensen met dementie en hun informele zorgverleners (37.5%), het bereiken van optimale informatieoverdracht (37.2%), het benaderen van andere zorgprofessionals binnen de eigen organisatie (31.0%), het verduidelijken van de verantwoordelijkheden van de betrokken zorgprofessionals (30.7%) en het verduidelijken van de taken van de betrokken zorgprofessionals (30.5%). De meest onderschreven interprofessionele samenwerkingsbehoeftes tijdens een verhuizing naar het verpleeghuis waren: het hebben van transparantie omtrent afspraken voor de levenseindezorg (42.4%), het bezoeken van mensen met dementie en hun informele zorgverleners voor de verhuizing (41.9%), het ontvangen van informatie en advies om mensen met dementie en hun informele zorgverleners te begeleiden (39.5%), het hebben van een contactpersoon tijdens het coördinatieproces (35.7%) en het verkrijgen van inzicht in het coördinatieproces (31.4%). Deze resultaten kunnen de praktijk informeren en richting geven op de manier waarop interprofessionele samenwerking in de palliatieve zorg bij dementie verbeterd kan worden voor verpleegkundigen (van alle niveaus) die werken in de thuissetting en verpleeghuissetting, en begeleiding bieden tijdens de verhuizing van thuis naar het verpleeghuis.

Hoofdstuk 6 beschrijft de resultaten van de mixed-methods studie met als doel de cruciale elementen voor interprofessionele samenwerking omtrent proactieve zorgplanning te identificeren en deze te verwerken in een handreiking voor zorgprofessionals die in een verpleeghuis werken. Het ontwikkelproces van de handreiking bestaat uit vijf stappen. Deze studie richt zich enkel op de vijfde stap, die online interviews en focusgroepen met verpleegkundigen, psychologen, teamleiders en specialisten ouderengeneeskunde omvat. We hebben achttien participanten geïnterviewd met een gemiddelde leeftijd van 43.8 jaar (79% vrouw). De content analyse identificeerde negen thema's: *1) De betekenis van proactieve zorgplanning; 2) De timing en continuïteit van proactieve zorgplanning; 3) Gebrek aan informatie uit de thuissetting; 4) Rolverduidelijking in proactieve zorgplanning; 5) Gezamenlijke richting; 6) Delen van perspectieven en nemen van gezamenlijke besluiten; 7) Van informatie omtrent proactieve zorgplanningsgesprekken naar acties; 8) Een faciliterende organisatie; en 9) Evalueren van interprofessionele samenwerking en levenseindezorg*. Deze negen thema's zijn verwerkt in zes elementen van de handreiking omtrent interprofessioneel samenwerken bij proactieve zorgplanning voor mensen met dementie in het verpleeghuis. Deze studie benadrukt het belang om de bewustwording omtrent een interprofessionele aanpak bij proactieve zorgplanning in dementie te vergroten. Daarnaast toont deze studie de relevantie aan voor het opstellen van een gezamenlijke visie en het communiceren over elkaars rollen in het gezamenlijk uitvoeren van proactieve zorgplanning voor mensen met dementie. Deze studie biedt zorgprofessionals een handreiking aan om de ontbrekende elementen te identificeren die belangrijk zijn voor interprofessionele samenwerking bij proactieve zorgplanning in de dementiezorg.

Hoofdstuk 7 vat de belangrijkste resultaten van alle studies samen, en reflecteert op de methodologische en theoretische aspecten van deze resultaten. Het hoofdstuk 'general discussion' focust zich met name op de uitdagingen van proactieve zorgplanning omtrent een toekomstige verhuizing naar een verpleeghuis en voorkeuren voor de levenseindezorg. Daarnaast discussieert deze paragraaf ook de coördinatie binnen de interprofessionele samenwerking en het gezamenlijk uitvoeren van proactieve zorgplanning in de dementiezorg. De paragraaf 'implications' beschrijft op welke manier de studieresultaten waarde kunnen toevoegen aan de huidige en toekomstige manier van interprofessioneel samenwerken in de palliatieve dementiezorg op het gebied van onderzoek, praktijk, educatie en beleid.



IMPACT

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 homes[3]. 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.*

Figure 1. Infographic *Moving together DEDICATED*

For the development of both guidance documents, we applied a participatory action research approach[7], 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 approach[9]. 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).

Ga naar **www.wooclap.com** en gebruik de code **MINOR**

Wat ga jij straks als zorgprofessional doen om optimaal interprofessioneel samen te werken?

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 guide[10] 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 system[13].

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 care[14-17]. 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 system[14]. 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 together[15]. 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 planning[18]. 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 needs[20]. 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 competencies[21] and how they still can be involved in collaborative activities in an active way[22-25]. 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 care[26].

During the thesis period, we collaborated with the Transition Care Innovation in Senior Citizens (TRANS-SENIOR) research project[27]. 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 published[28]. 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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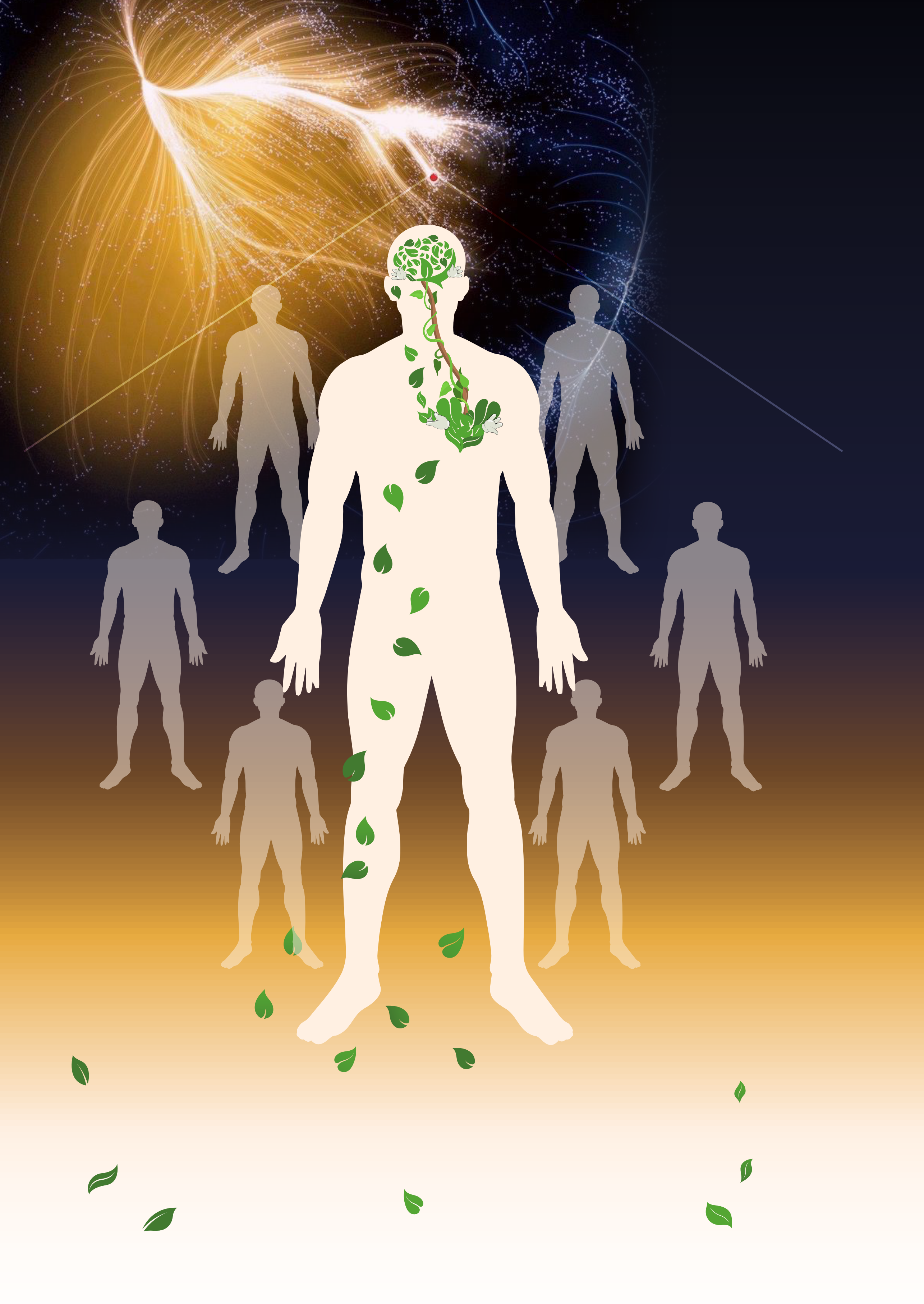

SUPPLEMENTS

CHAPTER 2
CHAPTER 3
CHAPTER 4
CHAPTER 5
CHAPTER 6

SUPPLEMENTS CHAPTER 2

Supplement I. PRISMA-ScR checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Page 37 of the PhD thesis
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Page 38 of the PhD thesis
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Page 39 of the PhD thesis
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Page 39 of the PhD thesis
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Page 40 of the PhD thesis
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Page 40 of the PhD thesis
Information sources*	7	Describe all information sources in the search (e.g., database with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Page 40 and 41 of the PhD thesis
Search	8	Present the full electronic search strategy for at least 1 database), including any limits used, such that it could be repeated.	Supplement II (page 238 and 240)
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Page 40 and 41 of the PhD thesis, Supplement III and IV (page 241 and 242)
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Page 40 and 41 of the PhD thesis, Supplement III and IV page 241 and 242)
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Supplement V (page 243 till 246)

Supplement I. CONTINUED

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not applicable
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Page 41 of this PhD thesis and Supplement V (page 243 till 246)
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Page 42 the PhD thesis, and Figure 1 (page 42).
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Page 43 of the PhD thesis, Table 2 (page 44 till 49) and Supplement VI (page 247 till 267)
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Supplement VI and VII (page 247 till 285)
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Page 50 till 54 of the PhD thesis and Supplement VIII (page 286 till 292)
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Page 53 till 58 of the PhD thesis
Limitations	20	Discuss the limitations of the scoping review process.	Page 58 of the PhD thesis
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Page 59 of the PhD thesis
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Page 59 of the PhD thesis

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic dataBehaviour analytics and support enhancement (BASE)s, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

Supplement II. Search strategy

PICo elements		Key words	A few search terms
1.	P = Participants	Persons with dementia in PC	"dementia*", "alzheimer disease", "Palliative care", "Palliation" and "end of life"
2.	I = Intervention/ Phenomena of Interest	IPC	"Interprofessional", disciplin*", "integrat*", "collab*" and "intervent*"
3.	Co = Context	Home care and Long-term care	"Home care", "Residential care", "sheltered accommodation*", "assisted living facilit*" and "nursing home*"

PUBMED

("Dementia*"[Mesh] OR "dementia*"[Title/Abstract] OR "alzheimer*"[Mesh] OR "alzheimer*"[Title/Abstract] OR "alzheimer disease"[Mesh] OR "alzheimer disease"[Title/Abstract] OR "dementia vascular"[Title/Abstract] OR "Dementia, Vascular"[Mesh:NoExp] OR "frontotemporal lobar dementia"[Title/Abstract] OR "Frontotemporal Dementia"[Mesh:NoExp] OR "lewy body disease"[Title/Abstract] OR "Lewy Body Disease"[Mesh] OR "geriatric*"[Title/Abstract] OR "geriatrics"[Mesh]) AND ("Palliative care"[MeSH Terms] OR "Palliative"[Title/Abstract] OR "Palliative care"[Title/Abstract] OR "Palliative treatment"[Title/Abstract] OR "Palliative therap*"[Title/Abstract] OR "Palliation"[Title/Abstract] OR "Hospice and Palliative Care Nursing"[MeSH Terms] OR "Hospice care"[MeSH Terms] OR "Hospice care"[Title/Abstract] OR "terminal care"[Title/Abstract] OR "Terminal Care"[Mesh] OR "Pain"[Title/Abstract] OR "end of life"[Title/Abstract] OR "end-of-life"[Title/Abstract] OR "Bereavement care"[Title/Abstract] OR "behaviour "[Title/Abstract] OR "Holistic"[Title/Abstract] OR "Shared decision making"[Title/Abstract] OR "Advance care planning"[Title/Abstract] OR "psychosocial care"[Title/Abstract]) AND ("Multidisciplinary"[Title/Abstract] OR "Interdisciplinary"[Title/Abstract] OR "Multiprofessional"[Title/Abstract] OR "Interprofessional"[Title/Abstract] OR "Transprofessional"[Title/Abstract] OR "Transdisciplinary"[Title/Abstract] OR "Multi-disciplinary"[Title/Abstract] OR "Inter-disciplinary"[Title/Abstract] OR "Multi-professional"[Title/Abstract] OR "Inter-professional"[Title/Abstract] OR "Trans-professional"[Title/Abstract] OR "Trans-disciplinary"[Title/Abstract] OR "Interagency"[Title/Abstract] OR "Inter-agency"[Title/Abstract] OR "Transagency"[Title/Abstract] OR "Trans-agency"[Title/Abstract] OR "profession*"[Title/Abstract] OR "disciplin*"[Title/Abstract] OR "multiple disciplines"[Title/Abstract] OR "team*"[Title/Abstract] OR "network*"[Title/Abstract] OR "integrat*"[Title/Abstract] OR "relation*"[Title/Abstract]) AND ("team work"[Title/Abstract] OR "care team*"[Title/Abstract] OR "teamwork"[Title/Abstract] OR "team-work"[Title/Abstract] OR "Working together"[Title/Abstract] OR "collab*"[Title/Abstract] OR "cooperat*"[Title/Abstract] OR "strateg*"[Title/Abstract] OR "intervent*"[Title/Abstract] OR "management"[Title/Abstract] OR "communicat*"[Title/Abstract] OR "Interprofessional relations"[Mesh] OR "approach"[Title/Abstract] OR "guideline*"[Title/Abstract]) AND ("Home care service*"[Mesh] OR "Home care"[Title/Abstract] OR "Primary Health Care"[Mesh] OR "Community"[Title/Abstract] OR "nursing home*"[Title/Abstract] OR "Nursing homes"[Mesh] OR "Nursing"[Title/Abstract] OR "Residential care"[Title/Abstract] OR "sheltered accommodation*"[Title/Abstract] OR "Care home"[Title/Abstract] OR "Aged care"[Title/Abstract] OR "hospice*"[Title/Abstract] OR "hospices"[MeSH Terms] OR "hospice care"[MeSH Terms] OR "assisted living facilit*"[Title/Abstract] OR "long-term care"[Mesh] OR "long term care"[Title/Abstract] OR "long-term care"[Title/Abstract] OR "long-term"[Title/Abstract])

PsychINFO

S1 = MA "Dementia" OR MA "Alzheimer disease" OR DE "Dementia with Lewy Bodies" OR DE "Senile Dementia" OR DE "Vascular Dementia" OR MM "Dementia with Lewy Bodies" OR MA "Geriatric*") OR TI ("dementia*" OR "Alzheimer disease*" OR "Alzheimer*" OR "vascular Dementia*" OR "frontotemporal lobar dementia” OR “lewy body disease” OR “Geriatric*”) OR AB (“dementia*” OR “Alzheimer disease*” OR “Alzheimer*” OR “vascular Dementia*” OR “frontotemporal lobar dementia” OR “lewy body disease” OR “Geriatric*”

S2 = MA “Palliative Care” OR TI (“palliative” OR “palliative care” OR “palliative treatment” OR “palliative therap*” OR “palliation” OR “Hospice and Palliative Care Nursing” OR “Hospice Care” OR “terminal care” OR “pain” OR “end of life” OR “end-of-life” OR “bereavement care” OR “behaviour” OR “holistic” OR “shared decision making” OR “advance care planning” OR “psychosocial care”) OR AB (“palliative” OR “palliative care” OR “palliative treatment” OR “palliative therap*” OR “palliation” OR “Hospice and Palliative Care Nursing” OR “Hospice Care” OR “terminal care” OR “pain” OR “end of life” OR “end-of-life” OR “bereavement care” OR “behaviour” OR “holistic” OR “shared decision making” OR “advance care planning” OR “psychosocial care”)

S3 = MM “Interdisciplinary Treatment Approach” OR TI (“Multidisciplinary” OR “Interdisciplinary” OR “Multiprofessional” OR “Interprofessional” OR “Transprofessional” OR “Transdisciplinary” OR “Multi-disciplinary” OR “Inter-disciplinary” OR “Multi-professional” OR “Inter-professional” OR “Trans-professional” OR “Trans-disciplinary” OR “Interagency” OR “Inter-agency” OR “Transagency” OR “Trans-agency” OR “profession*” OR “disciplin*” OR “multiple disciplines” OR “team*” OR “network*” OR “integrat*” OR “relation*”) OR AB (“Multidisciplinary” OR “Interdisciplinary” OR “Multiprofessional” OR “Interprofessional” OR “Transprofessional” OR “Transdisciplinary” OR “Multi-disciplinary” OR “Inter-disciplinary” OR “Multi-professional” OR “Inter-professional” OR “Trans-professional” OR “Trans-disciplinary” OR “Interagency” OR “Inter-agency” OR “Transagency” OR “Trans-agency” OR “profession*” OR “disciplin*” OR “multiple disciplines” OR “team*” OR “network*” OR “integrat*” OR “relation*”)

S4 = DE “Collab*” OR DE “Cooperat*” OR DE “Teamwork” OR DE “Team-work” OR DE “Team-work” OR DE “Communicat*” OR DE “Strateg*” OR DE “Intervent*” OR DE “working together” OR DE “Management” OR TI (“team work” OR “care team*” OR “teamwork” OR “team-work” OR “collab*” OR “cooperat*” OR “working together*” OR “strateg*” OR “intervent*” OR “collab*” OR “communicat*” OR “management” OR “interprofessional relation*” OR “approach*” OR “guidelin*”) OR AB (“team work” OR “care team*” OR “teamwork” OR “team-work” OR “collab*” OR “cooperat*” OR “working together*” OR “strateg*” OR “intervent*” OR “collab*” OR “communicat*” OR “management” OR “interprofessional relation*” OR “approach*” OR “guidelin*”)

S5 = DE “Home Care” OR MM “Primary Health Care” OR MA “Nursing Homes” OR MM “Residential Care Institutions” OR MA “Long-term-care” OR MA “Long term care” OR MA “Hospices” OR MM “Nursing” OR MA “Hospice care” OR TI (“Home Care Services” OR “Home Care” OR “Primary Health Care” OR “community” OR “Nursing Home*” OR “Nursing” OR “residential care” OR “sheltered accommodation*” OR “care home” OR “aged care” OR “hospice*” OR “hospice care” OR “assisted living facilit*” OR “long term care” OR “long-term care” OR “long-term”) OR AB (“Home Care Services” OR “Home Care” OR “Primary Health Care” OR “community” OR “Nursing Home*” OR “Nursing” OR “residential care” OR “sheltered accommodation*” OR “care home” OR “aged care” OR “hospice*” OR “hospice care” OR “assisted living facilit*” OR “long term care” OR “long-term care” OR “long-term”)

CINAHL

S1 = MH (“Dementia+” OR “Alzheimer Disease” OR “Alzheimer*” OR “Dementia, Senile+” OR “Geriatric*”) OR TI (“dementia*” OR “Alzheimer*” OR “Alzheimer disease” OR “Dementia, Vascular” OR “Frontotemporal Lobar Degeneration” OR “Lewy Body Disease” OR “Geriatric*”) OR AB (“dementia*” OR “Alzheimer*” OR “Alzheimer disease” OR “Dementia, Vascular” OR “Frontotemporal Lobar Degeneration” OR “Lewy Body Disease” OR “Geriatric*”)

S2 = MH “Holistic” OR MH “End-of-life” OR MH “End of life” OR MH “palliation” OR MM “Terminal

Care” OR MH “Palliative Care” OR MH “Palliative treatment” OR MM “Hospice Care” OR MM “Hospice and Palliative Nursing” OR MH “Advance care planning” OR MH “Shared decision making” OR MH “Bereavement care” OR MH “behaviour” OR MH “Pain” OR TI (“holistic” OR “Bereavement care” OR “palliative care” OR “palliative” OR “Palliative treatment” OR “palliation” OR “Palliative therap*” OR “Hospice care” OR “terminal care” OR “Pain” OR “end of life” OR “end-of-life” OR “psychosocial care” OR “behaviour” OR “Hospice and Palliative Care Nursing” OR “Shared decision making” OR “Advance care planning”) OR AB (“holistic” OR “Bereavement care” OR “palliative care” OR “palliative” OR “Palliative treatment” OR “palliation” OR “Palliative therap*” OR “Hospice care” OR “terminal care” OR “Pain” OR “end of life” OR “end-of-life” OR “psychosocial care” OR “behaviour” OR “Hospice and Palliative Care Nursing” OR “Shared decision making” OR “Advance care planning”)

S3 = MM “Multidisciplinary Care Team” OR MH “Interprofessional Relations+” OR MH “Multidisciplinary” OR MH “Interdisciplinary” OR MH “Multiprofessional” OR MH “Interprofessional” OR MH “Transprofessional” OR MH “Transdisciplinary” OR MH “Multi-disciplinary” OR MH “Inter-disciplinary” OR MH “Multi-professional” OR MH “Inter-professional” OR MH “Trans-professional” OR MH “Trans-disciplinary” OR MH “Interagency” OR MH “Inter-agency” OR MH “Transagency” OR MH “Trans-agency” OR MH “profession*” OR MH “disciplin*” OR MH “multiple disciplines” OR MH “team*” OR MH “network*” OR MH “integrat*” OR MH “relation*” OR TI (“Multidisciplinary” OR “Interdisciplinary” OR “Multiprofessional” OR “Interprofessional” OR “Transprofessional” OR “Transdisciplinary” OR “Multi-disciplinary” OR “Inter-disciplinary” OR “Multi-professional” OR “Inter-professional” OR “Trans-professional” OR “Trans-disciplinary” OR “Interagency” OR “Inter-agency” OR “Transagency” OR “Trans-agency” OR “profession*” OR “disciplin*” OR “multiple disciplines” OR “team*” OR “network*” OR “integrat*” OR “relation*”) OR AB (“Multidisciplinary” OR “Interdisciplinary” OR “Multiprofessional” OR “Interprofessional” OR “Transprofessional” OR “Transdisciplinary” OR “Multi-disciplinary” OR “Inter-disciplinary” OR “Multi-professional” OR “Inter-professional” OR “Trans-professional” OR “Trans-disciplinary” OR “Interagency” OR “Inter-agency” OR “Transagency” OR “Trans-agency” OR “profession*” OR “disciplin*” OR “multiple disciplines” OR “team*” OR “network*” OR “integrat*” OR “relation*”)

S4 = MH (“Teamwork” OR “Team work” OR “Team-work” OR “collab*” OR “communicat*” OR “working together” OR “Management” OR “cooperat*” OR “strateg*” OR “intervent*”) OR TI (“team work” OR “care team*” OR “teamwork” OR “team-work” OR “collab*” OR “cooperat*” OR “working together*” OR “strateg*” OR “intervent*” OR “collab*” OR “communicat*” OR “management” OR “interprofessional relation*” OR “approach*” OR “guidelin*”) OR AB (“team work” OR “care team*” OR “teamwork” OR “team-work” OR “collab*” OR “cooperat*” OR “working together*” OR “strateg*” OR “intervent*” OR “collab*” OR “communicat*” OR “management” OR “interprofessional relation*” OR “approach*” OR “guidelin*”)

S5 = MH “Nursing Homes+” OR MH “Home care” OR MH “Nursing” OR MH “sheltered accommodation” OR MM “Assisted Living” OR MM “Primary Health Care” OR MH “residential care” OR MH “aged care” OR MH “assisted living facilit*” OR MH “long term care” OR MH “long-term care” OR MH “hospice*” OR MH “care home” OR MH “Hospice care” OR TI (“Home Care Services” OR “Home Care” OR “Primary Health Care” OR “community” OR “Nursing Home*” OR “Nursing” OR “residential care” OR “sheltered accommodation*” OR “care home” OR “aged care” OR “hospice*” OR “hospice care” OR “assisted living facilit*” OR “long term care” OR “long-term-care” OR “long-term”) OR AB (“Home Care Services” OR “Home Care” OR “Primary Health Care” OR “community” OR “Nursing Home*” OR “Nursing” OR “residential care” OR “sheltered accommodation*” OR “care home” OR “aged care” OR “hospice*” OR “hospice care” OR “assisted living facilit*” OR “long term care” OR “long-term-care” OR “long-term”)

Supplement III. Title and abstract screening form

Questions	Yes	Unclear	No
1. Does the abstract indicate that this study concerns an interprofessional, interdisciplinary or multidisciplinary intervention/strategy/guideline/ collaborative approach/team/integrated care?			
2. Does the abstract indicate that the participants include persons with dementia, informal caregivers of persons with dementia or/and professionals working with persons with dementia?			
3. Does the abstract indicate that the study focusses on palliative care? Palliative dementia care domains: ➢ Applicability of palliative care ➢ End-of-life communication ➢ Shared-decision making ➢ Prognostication and timely recognition of dying ➢ Avoiding over aggressive, burdensome or futile treatment ➢ Comfort care, optimal treatment, pain symptoms/management or behavioural disturbances ➢ Psychosocial and spiritual support ➢ Bereavement care			
4. Does the abstract indicate that the setting include either home care, assisted living (sheltered homes) or nursing home?			

Search is filtered by language (English) and Timeframe (2010-2021).

Supplement IV. Full-text screening form

Questions		Yes	Unclear	No
5.	Are there two or more different disciplines involved in collaboration?			
6.	Does it concern palliative dementia care (participants could be people with dementia, informal caregivers or healthcare professionals working with people with dementia)?			
7.	Does it concern home care, nursing home, care home or assisted living facilities?			
8.	Does it provide a description about the intervention procedure and components?			

Search is filtered by language (English) and Timeframe (2010-2021).
All articles that are eligible for full-text screening have been included after title-abstract screening.

Supplement V. Data extraction form

GENERAL INFORMATION

1. Author information

First author

Second author

Third author

2. Country

3. Publication year

4. Study aim

METHODOLOGY

1. Design
☐ RCT ☐ Retrospective cohort ☐ Prospective cohort ☐ Literature review
☐ Cross-sectional ☐ Case Report ☐ Case Series ☐ Systematic review
☐ Scoping review ☐ Meta-analysis

☐ Other (please specify)

2. Research method (please specify)
☐ Qualitative

☐ Quantitative

☐ Mixed-methods

3. Participants
☐ Professionals working with people with dementia ☐ Informal caregivers
☐ People with dementia
4. Sample size

N =

5. Sampling technique
☐ Simple random ☐ Stratified random ☐ Cluster sampling ☐ Systematic sampling
☐ Multistage sampling ☐ Quota sampling ☐ Snowball sampling
☐ Judgment/purposive sampling ☐ Convenience sampling

☐ Other (please specify)

6. Data analysis

7. Study duration

8. Setting
☐ Home care ☐ Assisted living facility ☐ Nursing home

DEMOGRAPHIC CHARACTERISTICS

1. Mean age
2. Percentage female

INTERVENTION CHARACTERISTICS

1. Aim

2. Components/elements

3. Participants (who executes the intervention)
☐ GP ☐ Elderly care physician ☐ Registered nurse ☐ Certified nurse assistant
☐ Uncertified nurse assistant ☐ Speech therapist ☐ Physiotherapist
☐ Occupational therapist ☐ Psychologist ☐ Spiritual caregiver ☐ Social worker
☐ Dietician ☐ Recreational therapist

☐ Other (please specify)

4. Control group

5. Procedure/structure/mechanism (provide a description of how the intervention is carried out)

6. Outcomes

Primary outcomes ☐

Secondary outcomes ☐

PALLIATIVE ASPECTS

1. Healthcare domains
☐ Physical domain ☐ Social domain ☐ Psychological domain ☐ Spiritual domain

2. Domains important in dementia care
☐ End-of-life care ☐ Shared-decision making
☐ Unnecessary treatments ☐ Comfort care ☐ Holistic care
☐ Pain symptoms ☐ Behaviour symptoms ☐ Bereavement care

☐ Other (please specify)

RESULTS

1. Key findings of the intervention

2. Summary of the results

LIMITATIONS

1. Reported by the author

2. Identified by reviewers

S

CONCLUSION

RELEVANT ADDITIONAL INFORMATION

Supplement VI. Comprehensive version of Table 2

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
1. Agar et al. (2015)[1] *Australia*	Compare the efficacy of a facilitated approach to family case conferencing with usual care, provide insights into nursing home- and staff-related processes influencing the implementation and sustainability of case conferencing, and evaluate cost-effectiveness.	Pragmatic parallel cluster randomized controlled trial (study protocol)	Nursing home	Registered nurses and persons with dementia	Family case conferencing consists of four elements: 1) identifying persons with dementia that will benefit from case conferencing based on evidence-based triggers, 2) organizing case conference, 3) developing and implementing palliative care plans, and 4) training other nursing home staff in person-centred palliative care.	Primary Symptom management, comfort and satisfaction with care at the end of life of persons with dementia Secondary Quality of life of persons with dementia, staff attitudes and knowledge of nurses, and cost effectiveness	Including informal caregiver and goals of care.
2. Agar et al. (2017)[2] *Australia*	Compare the efficacy of a facilitated approach to family case conferencing with usual care regarding end of life care for persons with dementia	Pragmatic parallel cluster randomized controlled trial	Nursing home	Persons with dementia (N=286)	Family case conferencing consists of four elements: 1) identifying persons with dementia that will benefit from case conferencing based on evidence-based triggers, 2) organizing case conference, 3) developing and implementing palliative care plans, and 4) training other nursing home staff in person-centred palliative care.	Primary Informal caregiver-related quality of end of life care Secondary Nurse-rated EOLD scales, resident quality of life and quality of care over the last month of life	Including informal caregiver and goals of care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
3. Amador et al. (2016)[3] *United Kingdom*	Evaluate an organizational intervention in order to promote integrated work between visiting HCPs (GPs and DNs) and staff	Mixed methods study	Care home	Care Home Managers, Deputy Managers, General Practitioners and District Nurses (N=12)	*The organisational intervention consists of 3 components:* - Appreciative conversations, AKA "Good Gossip" - Development of future directed statements, AKA Common "Vision" for the home - Resident Death Reviews (RDR)	Primary Action and guidance plans, models and suggestions and strategies for improvement Secondary Changes in terms of trust between stakeholders and organizations, more open communication and cooperative capacity	End-of-life care
4. Brody et al. (2016)[4] *United States*	Test the ability of Dementia Symptom management at Home (DSM-H) program to improve knowledge, confidence and attitudes of HCPs in assessing and managing pain, depression and other neuropsychiatric symptoms in persons with dementia	Mixed-methods	Home care	Registered nurses, physical therapists and occupational therapists (N=191)	DSM-H consists of three components: 1) online training, 2)clinician champions, and 3) workflow changes	Primary Knowledge, confidence and attitudes about pain, depression and other neuropsychiatric symptoms Secondary Clinician champions perceptions of educational outcomes	Symptom management and comfort care

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
5. Coleman et al. (2017)[5] *United Kingdom*	Asses how the Intergrated Personalized Plan (IPP) document worked in practice and collect feedback from staff about their experiences	Pilot study	Care home	Care staff and informal caregivers of residents with cancer or dementia (17 care homes)	The IPP document provides guidance for anticipatory prescribing for symptoms and end-of-life and includes three sheets *(1. Recognising, making and reviewing decisions concerning the last days of life, 2. Communication sheet for staff and external visiting HCPs and 3. Communication sheet for informal caregiver/ friends)*, three sections *(1. Initial assessment (joint assessment by doctor and nurse), 2. Ongoing assessments, and 3. Care after death)*, and an Anticipatory medication guidance.	The findings are in relation to the core sections of the IPP document: - Recognising dying - Involvement of GP - Reviewing resident's condition: - Encouraging communication decision making. - Assessing symptom control and care needs	End-of-life care, Symptom management, Spiritual care, Medication management, Comfort care, and Basic care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
6. Elliott et al. (2014)[6] *United Kingdom*	Understand how the Compassion Intervention operates in practice, in 2 care homes, in 2 different health and social care economies and collect process and outcome data on feasibility, acceptability and economic costs in order to inform the planning of a future phase II trial	Mixed methods study	Care home	People with advanced dementia, Informal caregiver carers and Health and social care professionals (N=55)	The Compassion Intervention will be delivered by what we describe as an 'Interdisciplinary Care Leader (ICL): Intervention pathway: The Core Team: The ICL will meet weekly with the existing core team responsible for the care of residents; The Wider Interdisciplinary Team: Monthly meetings will be held with the wider interdisciplinary team	Primary (residents) - Demographic information, presence of advance directives, advance care plans and specific requests regarding hospitalisation and resuscitation, prescribed medications, the number and reason for acute hospital admissions, 'burdensome interventions' and 'sentinel events' Primary (informal caregiver carers) - Demographic data including age, gender, employment, relationship to the resident, the number of years spent caring and any other caring responsibilities	End-of-life care, Basic care, Functional care, Symptom management, Psychosocial care, Spiritual care and Medication management.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
7. Garvelink et al. (2019)[7] *Netherlands*	Assess the extent to which housing decisions for persons with dementia with their formal and informal caregivers correspond to an interprofessional shared decision making (IP-SDM) approach	Qualitative study (with longitudinal multi-perspective design)	Home care	Persons with dementia, informal caregivers, home care workers, day- and night care personnel or nursing home staff (N=20)	IP-SDM is an model that describes the steps: 1) the context, 2) identifying all those involved and their roles, 3) explaining the decision to be made, 4) exchanging information, 5) exploring values and preferences, 6) describing the feasibility of the available options, 7) discussing the preferred choice, 8) discussing the actual decision that is made, 9) implementing the decision, and 10) evaluating the outcomes of that decision	Primary Experiences of persons with dementia, formal and informal caregivers on shared-decision making regarding an nursing home transition Secondary Identifying sociodemographic information of the participants	Care transition, Psychosocial care, and Functional care.
8. Hanson et al. (2016)[8] *United States*	Describe the Goals of Care (GOC) randomized trial and the methods used to monitor and promote fidelity to a GOC decision and intervention	RCT	Nursing Home	Informal caregivers (n=151)	*GOC intervention consists of 2 components:* - Video decision aid about GOC care choices in advanced dementia Structured nursing home care plan meeting to address GOC	Primary Quality of communication and decision-making Secondary Number of palliative care domains in the treatment plan, informal caregiver satisfaction with care, patient comfort, patient quality of life, hospice referral, and hospitalizations	Palliative care goals

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
9. Hanson et al. (2016)[9] *United States*	Test a goals of care (GOC) decision aid intervention to improve quality of communication and palliative care	Single-blind cluster randomized clinical trial	Nursing home	Persons with dementia and their informal caregiver (N=302)	*GOC intervention consists of 2 components:* - Video decision aid about GOC care choices in advanced dementia Structured nursing home care plan meeting to address GOC	Primary Informal caregiver-related measures of quality of communication and decision-making Secondary Quality of palliative care	Palliative care goals
10. Hopkinson et al. (2020)[10] *United Kingdom*	Identify the critical factors for resolving crisis for a person with dementia	Mixed-methods	Home care	Persons with dementia, informal caregivers, nurses, support workers, and physicians (N=42)	The Home Treatment Crisis Team described the following factors: 1) immediate action to reduce risk of harm/ death, expertise in managing symptoms of dementia, communication skills, shared-decision making, medication management, addressing needs of informal caregivers, and arranging availability of respite and other services.	Experiences of persons with dementia, informal caregivers, and HCPs regarding the home treatment crisis team intervention	Symptom management, Psychosocial care, Medication management, Including informal caregiver and Functional care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
11. Jones et al. (2015)[11] *United Kingdom*	Develop an integrated evidence-based intervention that is pragmatic and feasible to improve end-of-life care for people with advanced dementia, as well as support those around them	Mixed methods study	Care Home	Health and social care providers (N=30)	Rapid review of the literature and policy documents; Research team field observations; Advice from the program expert steering group; Emerging results from our cohort study; Preliminary workshops and interactive qualitative interviews with professional and informal carers and Workshop with people with early dementia.	Level at which intervention must operate, implications derived from rapid literature review, evidence emerging from quantitative cohort study, suggestions for Whole Systems Intervention component statements	End-of-life care, Basic care, Functional care, Symptom management, Psychosocial care, Spiritual care and Medication management.
12. Klapwijk et al. (2018)[12] *Netherlands*	Examine whether implementation the STA OP! intervention for challenging and pain affects QoL of nursing home residents with dementia	Mixed methods study	Nursing home	People with dementia (N=288)	*STA OP! Intervention consists of 6 steps*: - Step 0: basic care needs assessment - Step 1: pain and physical needs assessment - Step 2: affective needs assessment - Step 3: trial of non-pharmacological comfort treatment - Step 4: trial of analgesic agents but also the prescribed as needed analgesic agent - Step 5: consultation or a trial	Primary QoL, ADL functioning, pain assessment, behavioural and psychological problems	Symptom management, Psychosocial care, Medication management, comfort care and Basic care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
13. Klapwijk et al. (2020)[13] *Netherlands*	Understand how the Liverpool Care Pathway (LCP) is being used in the context of the nursing home, and experienced from the perspectives of HCPs responsible for medical treatment in nursing home	Mixed-Methods study	Nursing home	Elderly care physicians, general practitioners, medical graduates, physician assistants, psychologist, and nurse practitioners (N=159)	LCP consists of three elements: 1) Assessing physical condition, comfort care, and preferences regarding religious and spiritual care needs	Primary Experiences of HCPs about working with the LCP (practical use of LCP), and its availability and motivation for use.	End-of-life care and Spiritual care.
14. Luckett et al. (2017)[14] *Australia*	Explore HCPs' perceptions of the benefits of facilitated case conferencing and identify factors influencing implementation	Qualitative study	Nursing home	Palliative care planning coordinators, directors (these are registered nurses), managers, nurses, assistants, physiotherapists, diversional therapists, dietician, general practitioner, medical officer and geriatrician (N=40)	Family case conferencing consists of four elements: 1) identifying persons with dementia that will benefit from case conferencing, 2) organizing case conference, 3) developing and implementing palliative care plans, and 4) training other nursing home staff in person-centred palliative care.	Primary Perceptions of HCPs regarding facilitated case conferencing Secondary Perceptions of HCPs the role of palliative care planning coordinators	Supporting informal caregiver and Goals of care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
15. Nakanishi et al. (2018)[15] *Japan*	Investigate the effects of the program on the attitudes towards dementia care among professionals	Mixed methods study	Home care	Care managers and professional caregivers (N=46)	Behaviour analytics & support enhancement program (BASE): - Training: 2-day training course for participants; - Baseline assessment of clients: participants launched input of measures of their clients; - Action plan: multi-agency discussion meeting with the participants and afterwards establish an action plan; - Ongoing monitoring and reassessment: participants implemented an ongoing monitoring for the challenging behaviour. Then, they conducted a monthly multi-agency discussion; - Follow-up meeting for debriefing: 1-day follow-up meeting for debriefing was held for all participants	Attitudes towards dementia care, sense of competence, burden of care, and personal characteristics of the participants, reflections from the participants (after the meeting)	Symptom management, Psychosocial, Basic care and Comfort care.

Supplement VI. CONTINUED

	Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
16.	Nakanishi et al. (2017)[16] *Japan*	Investigate the effects of BASE on challenging behaviour of persons with dementia living at home	Cluster-randomized controlled trial	Home care	Persons with dementia (N=283)	Behaviour analytics & support enhancement program: - Training: 2-day training course for participants; - Behaviour analytics and support enhancement (BASE)line assessment of clients: participants launched input of measures of their clients; - Action plan: multi-agency discussion meeting with the participants and afterwards establish an action plan; - Ongoing monitoring and reassessment: participants implemented an ongoing monitoring for the challenging behaviour. Then, they conducted a monthly multi-agency discussion; - Follow-up meeting for debriefing: 1-day follow-up meeting for debriefing was held for all participants	Challenging behaviour of persons with dementia	Symptom management, Psychosocial, Basic care and Comfort care

Supplement VI. CONTINUED

	Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
17.	Nakanishi et al. (2018)[17] *Japan*	Identify a key component of the developed program that is associated with a reduction in challenging behaviour.	Cluster-randomized controlled trial	Home care	Persons with dementia, care managers, nurses and other care workers (N=305)	Behaviour analytics & support enhancement program: - Training: 2-day training course for participants; - Baseline assessment of clients: participants launched input of measures of their clients; - Action plan: multi-agency discussion meeting with the participants and afterwards establish an action plan; - Ongoing monitoring and reassessment: participants implemented an ongoing monitoring for the challenging behaviour. Then, they conducted a monthly multi-agency discussion; - Follow-up meeting for debriefing: 1-day follow-up meeting for debriefing was held for all participants	Primary Key component of the intervention Secondary Symptoms of persons with dementia, medication prescription, and competencies of healthcare professionals	Symptom management, Psychosocial, Basic care and Comfort care

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
18. Moore et al. (2017)[18] *United Kingdom*	Understand how the Intervention operated in nursing homes in different health economies; To collect preliminary outcome data and costs of an interdisciplinary care leader; To facilitate the Intervention; To check the Intervention caused no harm	Mixed methods study	Nursing Home	People with dementia, Informal caregivers interviewed and Nursing homes and external healthcare professionals (N=62)	*Components of the Compassion Intervention:* - Facilitation of integrated care for people with advanced dementia Training and support for those working with and caring for people with advanced dementia	Symptoms of people with dementia and costs of interdisciplinary care leader	End-of-life care, Basic care, Functional care, Symptom management, Psychosocial care, Spiritual care and Medication management.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
19. Park et al. (2019)[19] Korea	Explore interdisciplinary collaborative care approach between nurses and related HCPs for the demented and complex-disabled elderly in nursing home that focused on palliative care based on an ethical point of view.	Interview survey	Nursing home	Nurses, physical therapists, occupational therapists and social workers (N=29)	The framework for interdisciplinary palliative care consists of three themes: 1. Tracking down clues to gradual functional deteriorations 2. Consistently responding to subtle expressions of elderly 3. Expanding the optimized opportunity for an improved quality of life	The results describe the themes of the framework: 1. HCPs should continuously reset cooperative care plans through continuing assessment based on subtle changes in function status 2. It is important to create a communication channel between residents and healthcare professionals by establishing a cooperative committee from an interdisciplinary team. 3. Healthcare professionals need to clearly explain residents' conditions to their informal caregivers to help understand. healthcare professionals should show respect for elderly to the end.	Symptom management, End-of-life care, Psychosocial care, Comfort care, Including framework, and Functional care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
20. Pieper et al. (2016)[20] *Netherlands*	Assess if the implementation of the STA OP! intervention effectively reduces challenging behaviour and use of antipsychotics and enhances the mood in nursing home residents with advanced dementia	RCT	Nursing home	People with dementia (n=288)	*STA OP! Intervention consists of 6 steps*: - Step 0: basic care needs assessment - Step 1: pain and physical needs assessment - Step 2: affective needs assessment - Step 3: trial of non-pharmacological comfort treatment - Step 4: trial of analgesic agents but also the prescribed as needed analgesic agent - Step 5: consultation or a trial	Primary Agitation Secondary Psychotropic medication use, neuropsychiatric symptoms, symptoms of depression	Symptom management, Psychosocial care, Medication management, comfort care and Basic care.
21. Pieper et al. (2017)[21] *Netherlands*	Assess whether implementation of the STA OP! intervention also reduces pain and improves pain management	RCT	Nursing home	People with dementia (n=288)	*STA OP! Intervention consists of 6 steps*: - Step 0: basic care needs assessment - Step 1: pain and physical needs assessment - Step 2: affective needs assessment - Step 3: trial of non-pharmacological comfort treatment - Step 4: trial of analgesic agents but also the prescribed as needed analgesic agent - Step 5: consultation or a trial	Pain symptoms	Symptom management, psychosocial care, medication management, comfort care and basic care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
22. Pieper et al. (2018)[22] *Netherlands*	Describe the experiences of the implementation of the STA OP! intervention Examine the extent to which the STA OP! intervention was delivered and implemented as intended Understand factors influencing the implementation process	Mixed methods study	Nursing home	People with dementia (n=288)	*STA OP! Intervention consists of 6 steps*: - Step 0: basic care needs assessment - Step 1: pain and physical needs assessment - Step 2: affective needs assessment - Step 3: trial of non-pharmacological comfort treatment - Step 4: trial of analgesic agents but also the prescribed as needed analgesic agent Step 5: consultation or a trial	Experiences of HCPs and factors at organizational, team and individual level influencing implementation	Symptom management, psychosocial care, medication management, comfort care and basic care.
23. Saini et al. (2016)[23] *United Kingdom*	Examine practices relating to end-of-life discussions with informal caregivers of people with advanced dementia residing in nursing homes and explore strategies for improving practice	Ethnographic study	Nursing home	People with dementia, staff interviews conducted and informal caregivers (N=32)	*Components of the Compassion Intervention:* - Facilitation of integrated care for people with advanced dementia Training and support for those working with and caring for people with advanced dementia	Points of education of informal caregiver and staff about dementia progression and end-of-life care	End-of-life care, basic care, functional care, Symptom management, psychosocial care, spiritual care and medication management.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
24. Samus et al. (2014)[24] *United States*	Assess whether MIND-S intervention delays time to transition from home and decreases unmet needs	Randomized controlled trial	Home care	Persons with dementia (N=265)	MIND-S is a comprehensive, home-based care coordination intervention designed to systematically assess and address unmet needs, while maintaining their and their caregiver health and wellbeing; The MIND-S model is delivered by Memory Care Coordinators (MCCs), working within an interdisciplinary team; Depending on needs, MCCs may also interact with the health providers and other community resource agencies of the people with dementia; MCCs receive initial training and ongoing structured support and mentoring	Primary outcomes Time to transfer from home and total percentage of unmet care needs Secondary outcomes Quality of life, depression and neuropsychiatric symptoms	Symptom management, Care transition, Psychosocial care and Functional care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
25. Samus et al. (2018)[25] *United States*	Determine the efficacy of MIND-S on time to long-term care (LTC) placement, death, costs, unmet care needs, neuropsychiatric symptom, quality of life , and to explore whether the intervention's effect on time to transition varies as a function of participant cognitive impairment, socioeconomic status, or race (moderators) and whether impact on predicted persons with dementia's and caregivers' clinical outcomes mediate the impact of MIND-S on time to transition to long-term care or death (mediators)	Mixed methods study	Home care	Persons with dementia and informal caregiver (N=300)	MIND-S is a comprehensive, home-based care coordination intervention designed to systematically assess and address unmet needs, while maintaining their and their caregiver health and wellbeing; The MIND-S model is delivered by Memory Care Coordinators (MCCs), working within an interdisciplinary team; Depending on needs, MCCs may also interact with the health providers and other community resource agencies of the people with dementia; MCCs receive initial training and ongoing structured support and mentoring	Sociodemographic characteristics, cognitive status, Physical frailty, Medications, Medical diagnoses, Quality of life-self report, Quality of life-proxy report, ADL Function, Mental/behaviour disturbances, caregiver burden, and caregiver depression	Symptom management, care transition, psychosocial care and functional care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
26. Sternberg et al. (2019)[26] *Israel*	Examine outcomes of quality improvement project to provide home hospice care for advanced dementia patients	Mixed methods study	Home care	People with dementia (N=20)	The hospice home program was delivered through staff training and education via two workshops, visits by physicians, team social worker and spiritual care provider, staff availability by telephone or physically, primary assessment by speech and language pathologist, and multidisciplinary team meetings were held every 2 weeks.	Primary Interviews with informal caregivers, symptom management, satisfaction with care and caregiver burden Secondary Health services' outcomes (number of medications that were deemed unnecessary by the medical team and then discontinued) and potential hospitalizations prevented	Symptom management, end-of-life care, psychosocial care, spiritual care, medication management, comfort care, and including informal caregiver.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
27. Van den Block et al. (2019)[27] *Netherlands*	Investigate the effect of the Palliative Care for Older People (PACE) Steps to Success Program on resident and staff outcomes	Mixed methods study	Nursing home	Care staff of nursing homes (n=78)	PACE Steps to Success Program Using a train-the-trainer approach, an external trainer supports staff in nursing homes introduces a palliative care approach over the course of 1 year. *Components:* - Advance care planning with residents and informal caregiver; - Assessment, care planning, and review of needs and problems; - Coordination of care via monthly multidisciplinary review meetings; - Delivery of high-quality care focusing on pain and depression; - Care in the last days of life; - Care after death.	Primary (resident) Comfort in the last week of life Primary (staff) Knowledge of palliative care Secondary (resident) Quality of care in the last month of life reported by staff Secondary (staff) Self-efficacy in communicating with residents and their informal caregivers at the end of life, self-perceived educational needs regarding communication and cultural and ethical values and opinions on palliative care	Symptom management, end-of-life care, spiritual care, medication management and comfort care.

Supplement VI. CONTINUED

Study	Research aim	Design	Setting	Participants (N)	Intervention	Outcomes	Palliative care domain
28. Zwijsen et al. (2014)[28] *Netherlands*	Determine the effects of the Grip on Challenging Behaviour care program	Mixed methods study	Nursing home	People with dementia (N=659)	Grip on Challenging Behaviour care program: - Expert meetings with nurses, psychologists, and elderly care physicians; - Representatives of the professional associations were consulted; - The intervention program consists of detection, analysis, treatment and evaluation; - A full day of training was organized on the unit before the Grip on Challenging Behaviour care program was implemented.; - The training was split-up into 2 sessions: 1 kick-off and 1 follow- up meeting 2 weeks after the care program was implemented	<u>Primary</u> Challenging behaviour <u>Secondary</u> Data on psychoactive drug	Symptom management, Medication management and Comfort care.

Supplement VII. Themes sorted per IPC approach

IPC approaches in palliative dementia care	Generic information	Theme 1. Collaborative themes
1. Organisational intervention[3]	Common ground • *Finding consensus regarding care goals and end of life care*: Shared social identity (common values and goals in providing end-of-life care) • *Having a feeling of 'us'* Collaborators • *Informal caregivers of persons with dementia* • *Managers:* Care home managers and Deputy managers • *Physicians:* General practitioners • *Nurses:* District nurses	Shared decision making • *Using each other's expertise* Advance care planning • *Identifying wishes and preferences regarding end-of-life:* End-of-life discussions with informal caregiver; End-of-life Documentation • *Being a team when conducting advance care planning conversations* Care in the dying phase • *Creating advance directives:* Medical treatment plans including Do Not Attempt Resuscitation (DNACPR) orders • *End-of-life wishes:* Preferred place of death
2. Dementia symptom management at home (DSM-H)[4]	Collaborators • *Nurses:* Registered nurses • *Allied healthcare professionals:* Physical therapists and Occupational therapists Task division • *Leaders:* Registered nurses were champions • *Initiators:* Registered nurses, Physical therapists and Occupational therapists • *Assessors:* Registered nurses, Physical therapists and Occupational therapists • *Practitioners:* Physical therapists and Occupational therapists	Managing pain • *Treating symptoms:* Pain, depression and other neuropsychiatric symptoms (such as agitation) Managing neuropsychiatric symptoms • *Applying non-pharmacological treatments:* Identify, recommend and implemented evidence-based non-pharmacological treatments (this article did not specify which non-pharmacological treatments were considered)

	Theme 2. Collaborative processes	**Theme 3. Resources facilitating collaboration**
	Communication • *Exchanging information and discussing with other HCPs:* Review meetings (between general practitioners and care home staff); District Nurse Coffee mornings (between district nurses and care home staff) • *Having short communication lines:* Exchanging phone numbers to have short communication lines Reflecting & Evaluating • *Reflecting on work practices for end-of-life care:* Resident Death Review (review of actual practice preceding the death of a resident from within each home)	Products • *Client-related documents:* Treatment plan • *Information sheet*: Out-of-hour (OOH) information sheet (comprehensive life history of the client) • *Guidance's, protocols or checklists:* Dying Matters Coalition (resource to discuss end of life wishes); End-of-life care tools and frameworks (prompts discussing End-of-life wishes and do not attempt resuscitation (DNAR) policies) Competences • *Conducting advance care planning conversations* • *Having respect:* Having respect of each other's roles
	Communication This article did not describe the type and frequency of meetings were hold. Assessing & Monitoring: • *Symptoms and or needs:* Recognize and assess pain, depression and other neuropsychiatric symptoms Coordination • *Clinical leading:* Champions were those with interest in clinical care of dementia patients • *Mentoring or/and providing peer support:* Champions who were well-respected role models to their peers	Products • *Incorporating evidence-based instruments:* Incorporating evidence-based instruments and care plans to assess and manage pain, depression and other neuropsychiatric symptoms • *Communication tools:* Situation-Background-Assessment Recommendation (SBAR) technique • *Measurement tool:* Evidence-based include PAINAD, Cornell Scale for Depression, Cohen Mansfield Agitation Inventory and AD8 Competences • *Symptom management, communicating, advance care planning and palliative care:* Online training offering four modules (assessing pain, assessing depression, assessing neuropsychiatric symptoms and effective communicating with HCPs) • *Assessing and managing symptoms and distress:* Champions receive training from experts in assessing and managing dementia through didactic and case-based work with group discussions (symptom management communication, palliative care, advance care planning, and functional capacity) • *Communicating with other healthcare professionals:* Learning how to clearly and concisely communicate with other healthcare professionals (with the SBAR method) • *Mentoring and coaching skills:* Champions receive training in peer mentorship skills to reinforce the online program with peers and answer questions from their peers and Champions provide peer support and mentor their peers

Supplement VII. CONTINUED

IPC approaches in palliative dementia care	Generic information	Theme 1. Collaborative themes
3. Family case conferencing[1, 2, 14]	Collaborators • *Nurses:* Registered nurses as palliative care planning coordinators and Assistants in nursing • *Managers or directors:* Assistant director of nursing and Clinical manager • *Allied healthcare professionals:* Physiotherapists, Diversional therapists and Dietician • *Physicians:* General practitioner, Medical officer and Geriatrician • *Informal caregivers of persons with dementia* Task division • *Initiators/Detectors:* Registered nurses work as palliative care planning coordinators and initially identify persons with advanced dementia who will benefit from case conference, organize multidisciplinary case conferences, develop and oversee implementation of palliative care plans and train other nursing home staff. • *Carers:* Nurses • *Assessors:* Allied healthcare professionals and physicians • *Practitioners:* Allied healthcare professionals and physicians • *Decision-makers:* informal caregivers together with the involved healthcare professionals	Care in the dying phase • *Supporting informal caregiver:* Described as sowing a seed, and providing informal caregivers support and time towards accepting that their loved one with dementia was dying Advance care planning • This article did not describe how advance care planning was performed Shared-decision making • This article did not describe how shared-decision making was performed
4. Liverpool Care pathway (LCP)[13]	Collaborators • *Informal caregivers of persons with dementia* • *Physicians:* Elderly care physicians, Physician assistants and General physicians • *Nurses:* Nurse practitioners • *Allied healthcare professionals:* Psychologist Common ground • *Recognizing the need to identify the right moment to start end-of-life care:* Identify persons with dementia that is expected to die within the next days	Shared-decision making • *Marking the last phase of life together:* Physician or nurse practitioner together with a member of the nursing staff make the decision whether the person with dementia is expected to die within a few days Care in the dying phase • *Looking at end-of-life issues:* Performing regular assessments of symptoms such as pain and dyspnoea • *Identifying religious or cultural preferences, needs or practices at this moment, at death and after death:* Discuss religious/spiritual customs or rituals. • *Performing bereavement care:* Assessing care for informal caregivers and performing communication regarding procedures after death

Theme 2. Collaborative processes	**Theme 3. Resources facilitating collaboration**
Communication • *Exchanging information and discussing with informal caregiver:* Providing informal caregivers information about palliative care • *Exchanging information and discussing with other healthcare professionals:* Receive information from all those involved, especially assistants in nursing or personal carers who worked closely with persons with dementia on a daily basis was mentioned especially useful; Involved healthcare professionals learn more about persons with dementia; Teleconferencing or face-to-face meetings Coordinating • *Organizing meetings and overseeing the implementation:* Palliative care planning coordinators coordinated the case conferences (organizing conferences, developing and overseeing implementation plan) • *Clinical leading:* Palliative care planning coordinators are clinical champions (clinical leaders) • *Supporting leadership roles, Encouraging collaborators, Providing access to resources, and Providing reimbursement:* Management provided trust and flexibility for the role of palliative care planning coordinators, encouraged staff and informal caregivers to participate in case conferences and provided access to resources.; General practitioners received remuneration	Competences • *Raising awareness of dementia as a terminal and palliative care disease:* Palliative care planning coordinators train other nursing home staff in person-centred palliative care (raising awareness of dementia profession, palliative approach) • *Conducting advance care planning conversations:* Palliative care planning coordinators execute the train-the-trainer principle and train registered and unregistered nurses to develop expertise in facilitating advance care planning discussions (increasing confidence in discussing end of life wishes and improving attitudes) Products • *Guidance's:* Protocols for identifying persons with dementia that will benefit from case conference • *Palliative care toolkits* Facilitating environment • *Structuring agenda and taking into account availability of collaborators:* Palliative care planning coordinators scheduled case conferences around general practitioner's routine visits and structured the agenda to enable participation for only part of the case conference • *Including specialists:* In-house palliative care team • *Spaces:* Palliative care room for the dying person with dementia
Communication • *Exchanging information and discussing with other HCPs:* Multidisciplinary team meetings*;* Communication between nursing staff and physicians was acknowledged as contributing to quality*;* Clear communication about actual expected death and informing informal caregivers and other healthcare professionals was a positive aspect of Liverpool Care Pathway Assessing & monitoring • *End-of-life care:* End-of-life symptoms	Products • *Guidance's:* Paper or digitalized checklist (included or separate from the electronic health record) This intervention was implemented through education (healthcare professionals in training participated) by specialist in palliative care, but this intervention does not describe the educational activities provided to the healthcare professionals in training.

Supplement VII. CONTINUED

IPC approaches in palliative dementia care	Generic information	Theme 1. Collaborative themes
5. Home hospice program[26]	Collaborators • *Persons with dementia* • *Informal caregivers of persons with dementia* • *Physicians* • *Nurses* • *Social worker* • *Spiritual care provider* Task division • *Initiators:* Homecare nurse case manager and head nurse of the home hospice program performed the first home visit and discussed informal caregiver expectations and preferences of the hospice care, and created a care plan. • *Carers:* Nurses and informal caregivers • *Assessors:* Nurses, Allied healthcare professionals, physicians, social workers and spiritual care worker • *Practitioners:* Allied healthcare professionals and physicians Common ground • *Seeing dementia as a terminal disease:* Thinking of dementia as terminal disease is cultural shift	Managing pain and neuropsychiatric symptoms • *Treating pain and neuropsychiatric symptoms:* Pain, behavioural problems, and agitation Informal caregiver support • *Giving guidance:* Explaining patients' rights and social benefits and providing ongoing caregiver support Care in the dying phase • *Looking at end-of-life issues:* Swallowing problems and hand feeding • *Identifying religious or cultural preferences, needs or practices at this moment, at death and after death*: Informal caregivers indicated that involvement of a spiritual caregiver improved their wellbeing and the wellbeing of the person with dementia
6. Goals of Care (GOC) intervention[8, 9]	Collaborators • *Informal caregivers of persons with dementia* • *Physicians:* Physicians and Physician assistants • *Nurses* • *Social workers* Task division • *Initiators:* Nurses or social workers initiated the goals of care discussions • *Carers:* Nurses • *Decision-makers:* Informal caregivers were decision-makers (often together with nurses or social workers)	Advance care planning • *Prolonging life* • *Supporting function* • *Improving comfort* Each goal was described along with treatment options consistent with prioritizing that goal Shared decision-making • *Using each other's expertise and valuing each other's opinion in making care decisions or creating care plans*: Value opinion of informal caregivers

Theme 2. Collaborative processes	Theme 3. Resources facilitating collaboration
Communication • *Exchanging information and discussing with other HCPs:* Multidisciplinary team meetings every twee weeks to review patient status and plans of care • *Exchanging information and discussing with informal caregiver:* Early and repeated discussions of care preferences, repeated instruction of informal caregivers about what to expect and how to respond in different situations; Diverse disciplines conducted independent visits and phone calls with persons with dementia and their informal caregivers Assessing & Monitoring • *Client status* • *Symptoms or/and needs* • *Goals of care* • *Caregiver burden*	Products • *Client-related documents:* Care plan • *Practical toolkits:* Kit for every home containing intravenous fluids and sets, medication, and oxygen. Competences • *End-of-life issues:* Workshops to enhance knowledge about dementia and end-of-life issues such as swallowing problems, hand feeding and managing behavioural problems • *Defining goals of care:* Defining goals of care • *Assessing and managing symptoms and distress:* Identifying suffering and pain Collaborator skills *Communicating with other healthcare professionals:* Workshop to improve communication between teams
Communication • *Exchanging information and discussing with other healthcare professionals:* nursing home healthcare team meeting Assessing & Monitoring • *Caregiver satisfaction* • *Quality of life*	Products • *Video:* Video-decision aid about goals of care • *Client-related documents:* Treatment plan • *Guidance:* Structured discussion guide to address goals of care; Toolkit advance care planning • *Communication tools:* Quality of communication instrument Competences • *Implementation skills:* Training staff in implementing the Goals of Care intervention (this article did not describe which training was provided) • *Communicating with informal caregiver:* VALUE principles (Value everyone's input, Acknowledge emotions, Listen, Understand the patient as a person and Elicit questions)

Supplement VII. CONTINUED

IPC approaches in palliative dementia care	Generic information	Theme 1. Collaborative themes
7. Interprofessional shared decision-making (IP-SDM model)[7]	Collaborators • *Persons with dementia* • *Informal caregivers of persons with dementia* • *Other involved care workers:* Home care workers and Day- and night care personal • Nursing home staff (this article did not specify the disciplines involved from the nursing home) Task division • This article did not describe a clear task division, but informal caregivers acted as initiators, final decision-makers and persuaders regarding nursing home transitions	Care transitions • *Environmental needs*: Distance to nursing home, nice room/house etc. • *Feeling at home* Shared decision-making • *Weighting the feasibility of moving to a nursing home*: Looking at the context, the persons involved and their roles, exchanging information, identifying preferences and values, identifying the options and their feasibility, identifying preferred choice, making the actual decision, implementing the decision and evaluating the outcomes of the decision.
8. STA OP![12, 20, 21, 22]	Collaborators • *Nurses* • *Allied healthcare professionals:* Psychologists, Occupational therapists, and Physiotherapists • *Physicians* • *Social worker* Task division • *Leaders:* Nurses are in the lead • *Initiators:* Nurses fill in the PACSLAC-D • *Assessors:* physicians perform a more comprehensive physical assessment, psychologists or social workers can look at the other needs, and psychiatrists psychotropic drugs • *Practitioners:* Physicians and Allied healthcare professionals	Managing pain and neuropsychiatric symptoms • *Treating pain and neuropsychiatric symptoms:* Pain, Behaviour, Agitation, depression etc. • *Applying non-pharmacological treatments:* Sensory-stimulating or -calming activity

Theme 2. Collaborative processes	Theme 3. Resources facilitating collaboration
<u>Communication</u> • *Exchanging information and discussing with other healthcare professionals:* Multidisciplinary team meetings (held by nursing home staff, but not home care workers); Communication occurred face-to-face or by phone • *Exchanging information and discussing with informal caregiver:* Primary informal caregiver caregivers) were central in exchanging information between the person with dementia and healthcare professionals	This article did not describe any resources or any education to improve competencies.
<u>Communication</u> • *Exchanging information and discussing with other healthcare professionals:* Asking other disciplines for advice during consultations; Gain insight into each other's expertise and learn from each other; Daily or weekly team meetings • *Having short communication lines:* Easier to contact others; Contact at an earlier stage; Easily accessible <u>Assessing & Monitoring</u> • *Symptoms or/and needs:* Basic care needs; Physical and observational pain; Comprehensive physical assessment; Affective needs <u>Coordination</u> • *Acting on problems, questions or queries regarding the interventions:* Core team (consisting of certified nursing assistant or registered nurse, psychologist, elderly care physician or physiotherapist) facilitated the implementation at the team level, and acted as a coach regarding problems, questions or queries about utilisation of the intervention • *Motivating and providing support, resources and organisational matters:* Key person with stimulating and motivational leadership style, this was often a female that respected, motivated and involved healthcare professionals. This key person (motivational leader) was enthusiastic, open to change and encouraged healthcare professionals to use this intervention, created support and acted on organisational matters.	<u>Products</u> • *Client-related documents:* Patient file • *Guidance's:* Steps of STA OP!; Guidelines of the WHO and Verenso (Dutch Association of Nursing home physicians) <u>Competences</u> • *Steps or working method of the intervention:* Multidisciplinary team was trained in stepwise working method of the STA OP! protocol • *Assessing and managing symptoms and distress:* Assess pain symptoms using the PACSLAC-D checklist; Assessing behavioural and psychological problems using Neuropsychiatric Inventory – nursing home version (NPI- nursing home); Multidisciplinary team received training in physical and affective assessment that target unmet needs of persons with dementia; and Assessing quality of life with QUALIDEM • *Provide feedback to other disciplines:* Multidisciplinary team received training in providing feedback to and communicating with other disciplines <u>Facilitating environment</u> • *Structuring agenda and taking into account availability of collaborators:* Secure the intervention to daily or frequently used internal structures or meetings. To support implement the protocol in practice, it was linked to structurally or weekly team meetings.; Pain assessment and management was integrated in standardized daily (nursing) care • *Making sure no other innovations or changes occur at the same time*

Supplement VII. CONTINUED

IPC approaches in palliative dementia care	Generic information	Theme 1. Collaborative themes
9. Grip on challenging and behaviour[28]	Collaborators - *Nurses* - *Physicians* - *Allied healthcare professionals:* Psychologist Task division - *Carers and Initiators:* Nurses detect symptoms - *Analysers and practitioners:* Psychologist or physician analyse symptoms and makes an outline of a treatment plan (psychosocial treatments)	Managing neuropsychiatric symptoms - *Treating neuropsychiatric symptoms:* Apathy, Disinhibition, Aberrant motor behaviour and Depression Shared decision-making - *Integrating analyses performed by diverse healthcare professionals*: After the analysis, the treatment goal, outline of the treatment plan and an evaluation date was defined in a multidisciplinary meeting with all involved disciplines
10. Palliative Care for Older People (PACE) program[27]	Collaborators - Nursing home residents (71.8% had dementia) - *Informal caregivers* - *Nurses:* Nurses and Care assistants - *Physicians:* General physician (off-site) Managing pain and neuropsychiatric symptoms - *Treating pain symptoms* - *Treating neuropsychiatric symptoms:* Depression Care in the dying phase - *Recognizing and marking the death phase:* Looking at dying symptoms - *Looking at end-of-life issues*: nutrition and hydration at end-of-life - *Supporting informal caregiver:* Communication with informal caregiver and providing information about bereavement services - *Identifying religious or cultural preferences, needs or practices at this moment, at death and after* death: Identify traditions, persons' priest or facility spiritual advisor.	Advance care planning - *Identifying wishes and preferences about living well and end of life care:* Advance care planning discussions with residents and/or informal caregivers are conducted to elicit wishes and preferences around end-of-life care

Theme 2. Collaborative processes	Theme 3. Resources facilitating collaboration
Communication - *Exchanging information and discussing with other HCPs:* Multidisciplinary team meetings Assessing & Monitoring - *Symptoms and/or needs*: Symptoms of challenging behaviour and contributing factors	Products - *Client-related documents:* Treatment plan - *Communication tools or evaluation forms:* Evaluation form - *Measurement tools:* Structured analysis form; Neuropsychiatric Inventory- nursing home version (NPI- nursing home) - *Guidance's:* Explanatory models of challenging behaviour and national guidelines*;* Protocols for pressure ulcers, feeding problems and use of antibiotics Competences - *Steps or working method of the intervention:* Two training sessions about the program (1 kick-off meeting in which the intervention was introduced and one follow-up meeting after which the intervention was implemented)
Communication - *Exchanging information and discussing with other HCPs:* Multidisciplinary team meetings Assessing & Monitoring - *Symptoms and/or needs*: Needs and problems; Comfort; Deterioration and improvement (by nurses and care assistants); Pain symptoms Coordination - *Organizing meetings or conferences and setting agendas and Overseeing the implementation of the intervention*: Care was coordinated on a team basis via monthly multidisciplinary PC review meetings; PACE program was coordinated by PACE coordinators - *Mentoring or/and providing peer support and Providing support, resources and organisational matters:* PACE coordinators (this article did not specify which disciplines were PACE coordinators) Reflecting & Evaluating - *Reflecting on working practices for end-of-life care*: Monthly reflective debriefing meetings to support staff following death and encourage experiential learning	Products - *Guidance:* Six Steps to Success for CH; Looking and Thinking Ahead document; Last Days of Life checklist - *Measurement tools:* Mapping Changes in Condition chart; Pain Assessment and Management Tool including numerical pain scale or PAINAD in case of advanced dementia; 'Geriatric Depression Scale' (short version) or 'Cornell Depression Scale for people with dementia' - *Client-related documents:* Care plan - *Information or summary sheet:* Summary sheet (this was sent to physicians who were not able to attend the meeting) Competences - *Steps or working method of the intervention:* PACE coordinators followed a workshop (provided by international trainers) about the PACE program - PACE coordinators organized workshops, provided support and education to nursing home staff to develop their knowledge and skills regarding the PACE program *Mentoring and coaching skills:* PACE coordinators followed group-coaching sessions (provided by international trainers) in order to train all nursing home staff (train-the-trainer principle Facilitating environment: - *Digital systems*: Palliative care register

Supplement VII. CONTINUED

IPC approaches in palliative dementia care	Generic information	Theme 1. Collaborative themes
11. Behavioural analytics & Support Enhancement (BASE)[15-17]	Collaborators - *Informal caregivers of persons with dementia* - *Managers or directors:* Care managers - *Allied healthcare professionals:* Physical therapists and Occupational therapists - *Physicians* - *Nurses:* Nurses and Nursing assistants - *Other care workers* (not specified in this article) Task division *Assessors:* Informal caregivers, nurses, Allied healthcare professionals, and physicians	Managing pain and neuropsychiatric symptoms - *Treating pain and neuropsychiatric symptoms* - *Applying non-pharmacological treatments:* Calm environment, music/ song and massage

Theme 2. Collaborative processes	Theme 3. Resources facilitating collaboration
Communication • *Exchanging information and discussing with other HCPs*: Multi-agency meetings between care managers and professional caregivers of HC services to establish care plan. Assessing/Monitoring • *Symptoms and/or needs*: Evaluate challenging behaviours of each person, specify unmet needs and revise action plans. Coordination • *Review, debriefing or management meetings*: Care managers scheduled mandatory monthly meetings with healthcare professionals from the home care to talk about the management of the monthly amount of care for client as per public benefit schedule.	Products • *Guidance:* National guidelines for dementia • *Client-related documents:* Action plan Competences • *Raising awareness of dementia as a terminal disease and PC disease:* healthcare professionals were trained in addressing dementia as an illness and challenging behaviour as a communication of unmet needs • *Assessing and managing symptoms and distress:* healthcare professionals were trained in assessing challenging behaviour and exploring unmet needs and action plans • *Implementation skills:* healthcare professionals received three workshops (1. Sharing good examples for the action plan, 2. Discussing implementation of BASE, and 3. Proposing solutions for the action plan implementation challenges). Facilitating environment: • *Digital systems:* BASE web-based working tool (in which unmet needs, contents of the action plan and type of caregivers involved in the meeting were categorized and recorded)

Supplement VII. CONTINUED

IPC approaches in palliative dementia care	Generic information	Theme 1. Collaborative themes
12. Compassion intervention[5, 11, 18, 23]	Collaborators • *Informal caregivers* • *Nurses* • *Managers* • *Physicians:* Geriatricians (external healthcare professionals) and General practitioners (external healthcare professionals) Task division • *Leaders and Initiators:* The interdisciplinary Care Leader (social care background and experience of working with persons with dementia) performed holistic assessments of persons with dementia, which included discussions with informal caregivers and staff, reviewing care plans and discussions or observations of the persons with dementia. • *Carers:* Nurses • *Assessors:* Interdisciplinary care leader together with nurses and physicians • *Practitioners:* Physicians • *Decision-makers*: informal caregiver together with healthcare professionals	Managing pain and neuropsychiatric symptoms • *Treating pain and neuropsychiatric symptoms* Shared decision-making • *Using each other's expertise and valuing each other's opinion in making care decisions or creating care plans*: Discussions with informal caregivers appear to increase their capacity to make informed decisions (for example about cardiopulmonary resuscitation) Advance care planning • *Identifying wishes and preferences about living well and end of life care:* Identifying end of life wishes of the persons with dementia (through discussions with informal caregivers); Discussion of anticipated needs • *Developing an escalation plan or anticipatory medication list*: Developing an escalation plan for the most likely 'what ifs' Care in the dying phase • *Creating advance directives:* DNACPR orders • *Looking at end-of-life issues:* Swallowing and eating difficulties and Pressure area care • *End-of-life wishes:* Preferred place of death • *Recognizing and marking death phase:* Recognize dying

Theme 2. Collaborative processes	**Theme 3. Resources facilitating collaboration**
Communication • *Exchanging information and discussing with other HCPs:* Core care team meetings (consisting of general practitioner, geriatrician or old age psychiatrist, and care home manager or floor/ unit manager from care home); Multidisciplinary team meetings (consisting of representatives from specialist palliative care, old age psychiatry, and care of elderly, social care) • *Exchanging information and discussing with informal caregiver:* Interdisciplinary care leaders met with informal caregivers to ensure that their needs and wishes were understood. Assessing & Monitoring • *Symptoms and/or needs:* Functional impairment; Pain; Comfort • *Quality of life* Coordination • *Mentoring or/and providing peer support and Providing support, resources and organisational matters:* The interdisciplinary Care Leader acted as central resource for health and social professionals, care home staff and informal caregivers. Interdisciplinary care leaders identified and supported training needs of care home staff. Interdisciplinary care leaders facilitated understanding and use of personal and advance care plans. Interdisciplinary care leaders encouraged a proactive structured assessment of the needs of persons with dementia. • *Stimulating joint working to integrate available services:* Interdisciplinary care leader develops joint working to enable integrated of available services • *Supporting front line staff in managing risks in persons with dementia and avoiding unnecessary transfers:* Interdisciplinary care leaders provided support to front-line staff to enable them to avoid unnecessary place of care transfer. • *Having a single point of contact for person with dementia and informal caregiver*	Products • *Client-related documents:* Care plan • *Guidance:* Compassion Manuel • *Measurement tools:* Pain Assessment in advanced dementia scale; Functional assessment staging scale Competences • *Symptom management, communicating, advance care planning and palliative care:* Interdisciplinary care leaders provided formal training sessions for staff regarding behavioural symptoms, pain management and end of life care • *End-of-life issues:* Interdisciplinary care leaders provided formal training sessions for informal caregivers the trajectory of dementia, common end of life symptoms and personal experiences of care. • *Assessing and managing symptoms and distress:* Interdisciplinary care leaders provided informal on-the-job advice and support to optimize the management of pain, acute medical events, behavioural disorders (agitation and delirium), feeding decisions, pressure sores and comfort measures. • *Conducting advance care planning conversations:* Interdisciplinary care leaders train healthcare professionals to develop communication skills for end of life conversations with persons with dementia (using simple methods such as tone of voice, touch and eye contact) and their informal caregivers. • *Communication with persons with dementia:* Interdisciplinary care leaders train HCPs to develop communication skills for end of life conversations with persons with dementia (using simple methods such as tone of voice, touch and eye contact) and their informal caregivers. • *Having respect:* Interdisciplinary care leaders fostered a culture of respect, dignity and quality of care for all residents.

Supplement VII. CONTINUED

IPC approaches in palliative dementia care	Generic information	Theme 1. Collaborative themes
13. Maximizing Independence at Home-Streamlined (MIND-S)[24, 25]	Collaborators • *Persons with dementia* • *Informal caregivers* • *Physicians:* Geriatric psychiatrists • *Nurses:* Registered nurses • *Other care workers:* Memory Care Coordinator (external healthcare professionals that is a non-clinical community worker) Task division • *Leaders and Initiators:* Memory Care Coordinator (external HCP that is a non-clinical community worker) are the frontline interventionists • *Carers:* informal caregiver and nurses • *Assessors:* Nurses, physicians and memory care coordinator • *Practitioners:* Physicians	Managing pain and neuropsychiatric • *Treating pain and neuropsychiatric symptoms* Informal caregiver support • *Burden:* Burden and depression of informal caregivers • *Wellbeing:* Mood and Energy • *Looking at autonomy:* Self as a whole • *Activities:* Ability to do things for fun Care transition • *Identifying values and needs related to the current home:* Remain home as long as possible
14. Integrated Personalized Plan (IPP)[5]	Collaborators • *Informal caregivers* • *Nurses*: Nurses and care home carers • *Physicians* • CH managers • *Others involved:* Learning disability specialist and Funeral director No task division description was provided.	Managing pain and neuropsychiatric symptoms • *Treating pain and neuropsychiatric symptoms:* Pain and Agitation Care in the dying phase • *Recognising and marking the death phase:* Recognizing dying • *Performing bereavement care* • *Valuing dignity and honour of the body* Shared decision-making • This intervention did not describe shared decision making

Theme 2. Collaborative processes	Theme 3. Resources facilitating collaboration
Communication • *Exchanging information and discussing with other healthcare professionals;* Care team rounds; Team meetings; Telehealth visits Assessing & Monitoring • *Symptoms and/or needs*: Symptoms, Personal needs; Environmental needs; Contextual factors Coordination • *Stimulating joint working to integrate available services:* Memory Care Coordinators provide persons with dementia and informal caregivers resource referrals, support with long-term care services, support with navigation and coordination; Memory Care Coordinators facilitate the continuity, coordination of medical, social and supportive care.	Products • *Client-related documents:* Individualized care plan • *Guidance:* Caregiver Resource Binder with information about general and individualized aging and dementia care; Copy of Aging and Caregiver Resource Guide; Johns Hopkins Dementia Care Needs assessment 2.0; MIND at Home intervention Handbook; Structured MIND-S care planning template; Structured case-conferencing case presentation template; Standard operating procedures manual Facilitating environment: • *Digital systems:* Dementia Care management system (software) Competences • *Raising awareness of dementia as terminal disease and PC disease:* Memory Care Coordinators provide dementia education to persons with dementia and their informal caregivers; Memory Care Coordinators receive training and support and mentoring from geriatric psychiatrist and registered nurse specialized in dementia care • *Assessing and managing symptoms and distress:* Memory Care Coordinators provide Behaviour management skills, on-going monitoring, assessment and planning for emergent needs to persons with dementia and their informal caregivers; Memory Care Coordinators provide problem-solving strategies to persons with dementia and their informal caregivers
Communication • *Exchanging information and discussing with other healthcare professionals:* Interdisciplinary care team meetings; Reflective debriefing meetings • *Exchanging information and discussing with informal caregiver:* Exploring needs of informal caregivers Assessing & Monitoring • *Symptoms and/or needs*: Symptoms; Care needs & Comfort	Products • *Client-related documents and Guidance:* Integrated Personalized plan (IPP) consisting of sections such as communication sheet for staff and external visiting professionals, communication sheet for informal caregiver/friends, • *Guidance:* Guidance published by Leadership Alliance for Care of Dying people; National institute for Health and Care excellence guidance Competences • *Steps or working method of the intervention:* healthcare professionals were trained to use the IPP document

Supplement VII. CONTINUED

IPC approaches in palliative dementia care	Generic information	Theme 1. Collaborative themes
15. Interdisciplinary palliative care approach framework[19]	Collaborators • *Persons with dementia and complex disabilities* • *Informal caregivers of persons with dementia* • *Nurses* • *Allied healthcare professionals:* Physical therapists; Occupational therapists • *Social workers* Common ground • *Finding consensus regarding care goals and end of life care:* Consensus on top priorities, unify the ultimate care goals, respond promptly to subtle changes and provide customized interventions. No task division description was provided.	Managing pain and neuropsychiatric symptoms • *Treating pain symptoms* • *Applying non-pharmacological treatments:* Multisensory interventions such as aromatherapy combined with abdominal/hand/food massages Care in the dying phase • *Accompanying person with dementia at death phase (beside care)* Informal caregiver support • *Involving informal caregiver in care:* Connecting informal caregivers with persons with dementia through stimulating memories
16. Home treatment crisis team[10]	Collaborators • *Person with dementia* • *Informal caregivers* • *Physicians:* Old age psychiatrists and Speciality doctor • *Nurses:* Community psychiatric nurses • *Other care works:* Healthcare assistants and Carer support worker • *Allied healthcare professionals:* Psychologists No task division description was provided.	Managing pain and neuropsychiatric symptoms • *Treating pain and neuropsychiatric symptoms:* Pain and Behavioural and psychological symptoms of dementia such as agitation and aggression Shared decision-making • *Using each other's expertise and valuing each other's opinion in making care decisions or creating care plans* mapping decision making; Negotiating treatment plan

Theme 2. Collaborative processes	**Theme 3. Resources facilitating collaboration**
Communication • *Exchanging information and discussing with other healthcare professionals and person with dementia:* Sharing top priority issues of the person with dementia; Cooperative committee (communication channel between persons with dementia and healthcare professionals from an interprofessional team) Assessing/Monitoring • *Symptoms and/or needs*: Functional capacity in everyday life; Subtle changes in daily life such as changes in sleep pattern, meal patterns, program participation.	Products • *Client-related documents:* Care plan Competences • *Assessing and managing symptoms:* Experienced nurses that has medical knowledge and professional judgment to maintain the baseline conditions associated with pressure ulcers, meals, excretions, and sleep. • *Building relationship with the person with dementia:* Building partners with the person with dementia to end of life (those healthcare professionals which accompany the person with dementia to the end) • *Communicating with person with dementia:* Identifying non-verbal communication of persons with dementia such as gestures or facial expressions when they express their discomfort such as pain
Communication • *Exchanging information and discussing with other healthcare professionals and informal caregiver:* Twice-daily team meetings; Home visits; Seeking feedback on the effects of medication from informal caregivers and other healthcare professionals; Listening to the needs of informal caregivers; Gathering information from multiple perspectives for assessment Assessing & Monitoring • *Symptoms and/or needs*: Monitoring holistic care ('looking at the whole thing')	Products • *Client-related documents:* Treatment plan Facilitating environment • *Networks or support services:* Network of support services and emergency respite Competences • *Symptom management:* Educate informal caregivers and care staff in management of symptoms of dementia such as resistance and aggression • *Assessing and managing symptoms and distress:* Expertise in managing mental health problems • *Having respect:* Using an approach that respects personhood • *Building relationship and trust with person with dementia and informal caregiver:* Maintaining a trusting relationship with person with dementia and their informal caregivers; Being kind using non-confrontational probing; Expertise in building rapport and establishing trust with persons with dementia, their informal caregivers and persons in their support network; Listening to informal caregivers and encouraging them to express their feelings and needs

Supplement VIII. Coding tree

Theme	Categories	Codes	Identified in the following IPC approaches:
1. Collaborative themes	Managing pain	*Treating pain symptoms*	• Dementia Symptom Management at Home (DSM-H) • Home hospice program • STA OP! • Palliative Care for Older People (PACE) • Grip on challenging behaviour • Behaviour analytics and support enhancement (BASE) • Compassion • Maximizing Independence at Home-Streamlined (MIND-S) • Integrated Personalized Plan (IPP) • Practical framework • Home Treatment Crisis Team
	Managing neuropsychiatric symptoms	*Treating neuropsychiatric symptoms (such as agitation and depression)*	• Dementia Symptom Management at Home (DSM-H) • Home hospice program • STA OP! • Behaviour analytics and support enhancement (BASE) • Maximizing Independence at Home-Streamlined (MIND-S) • Home Treatment Crisis Team
		Applying non-pharmacological treatments	• Dementia Symptom Management at Home (DSM-H) • STA OP! • Grip on challenging behaviour • Behaviour analytics and support enhancement (BASE) • Practical framework
	Advance care planning	*Talking about goals of care such as prolonging life, supporting function and improving comfort.*	• Goals of Care (GOC) • Family case conferencing
		Being a team when conducting advance care planning conversations.	• Organisational intervention
		Discussing treatment options together.	• Goals of Care (GOC)
		Identifying wishes and preferences about living well and end of life care.	• Palliative Care for Older People (PACE) • Compassion • Integrated Personalized Plan (IPP) • Organisation intervention
		Developing an escalation plan or anticipatory medication list	• Compassion • Integrated Personalized Plan (IPP)
	Care in the dying phase	*Creating advance directives*	• Organisational intervention • Compassion • Family case conferencing
		Recognizing and marking the death phase	• Palliative Care for Older People (PACE) • Compassion • Integrated Personalized Plan (IPP)
		Looking at End-of-life issues (such as swallowing problems and hydration concerns)	• Home hospice program • Palliative Care for Older People (PACE) • Compassion
		End-of-life wishes (such as preferred place of death)	• Organisational intervention

Supplement VIII. CONTINUED

Theme	Categories	Codes	Identified in the following IPC approaches:
		Accompanying the person with dementia at death phase (bedside care)	• Practical framework
		Valuing dignity and honour of the body	• Compassion • Integrated Personalized Plan (IPP) • Palliative Care for Older People (PACE)
		Identifying religious or cultural preferences, needs or practices at this moment, at death and after death	• Liverpool Care Pathway (LCP) • Home hospice program • Integrated Personalized Plan (IPP)
	Care movements	*Identifying values and needs related to the current home (such as feasibility of staying at home)*	• Interprofessional Shared Decision-Making (IP-SDM) • Maximizing Independence at Home-Streamlined (MIND-S)
		Identifying values and needs related to housing options (under which environmental needs and feeling at home)	• Interprofessional Shared Decision-Making (IP-SDM)
	Informal caregiver support	*Giving guidance to informal caregivers*	• Home hospice program
		Paying attention to caregiver burden	• Maximizing Independence at Home-Streamlined (MIND-S)
		Involving informal caregivers in care (such as to stimulate memories of persons with dementia)	• Practical framework • Home treatment crisis team
		Performing bereavement care	• Liverpool Care Pathway (LCP) • Integrated Personalized Plan (IPP)
	Shared decision-making	*Using each other's expertise and valuing each other's opinion in making care decisions or creating care plans*	• Organisational intervention • Goals of Care (GOC) • Home Treatment Crisis Team • Compassion
		Marking the last phase of life together	• Liverpool Care Pathway (LCP)
		Weighting the feasibility of moving to a nursing home	• Interprofessional Shared Decision-Making (IP-SDM)
		Integrating analyses performed by diverse healthcare professionals	• Grip on challenging behaviour

Supplement VIII. CONTINUED

Theme	Categories	Codes	Identified in the following IPC approaches:
2. Collaborative processes	Communication	*Exchanging information and discussing with other healthcare professionals via meetings, phone calls or teleconferencing*	• Organisational intervention • Family case conferencing • Liverpool Care Pathway (LCP) • Home hospice program • Goals of Care (GOC) • Interprofessional Shared Decision-Making (IP-SDM) • STA OP! • Grip on challenging behaviour • Palliative Care for Older People (PACE) • Behaviour analytics and support enhancement (BASE) • Compassion • Maximizing Independence at Home-Streamlined (MIND-S) • Integrated Personalized Plan (IPP) • Practical framework • Home Treatment Crisis Team
		Having short communication lines (i.e. through exchanging phone numbers)	• Organisational intervention • STA OP!
		Exchanging information and discussing with persons with dementia and/or informal caregiver	• Family case conferencing • Liverpool Care Pathway (LCP) • Home hospice program • Interprofessional Shared Decision-Making (IP-SDM) • Compassion • Integrated Personalized Plan (IPP) • Practical framework • Home Treatment Crisis Team
	Assessing & Monitoring	*Client status*	• Home hospice program
		Goals of care	• Home hospice program
		Caregiver burden and/or satisfaction	• Home hospice program • Goals of Care (GOC)
		Symptoms (such as pain) and/or needs	• Dementia Symptom Management at Home (DSM-H) • Home hospice care program • Interprofessional Shared Decision-Making (IP-SDM) • STA OP! • Grip on challenging behaviour • Palliative Care for Older People (PACE) • Behaviour analytics and support enhancement (BASE) • Compassion • Maximizing Independence at Home-Streamlined (MIND-S) • Integrated Personalized Plan (IPP) • Practical framework • Home Treatment Crisis Team
		End-of-life care	• Liverpool Care Pathway (LCP)
		Quality of life	• Goals of Care (GOC) • Compassion

Supplement VIII. CONTINUED

Theme	Categories	Codes	Identified in the following IPC approaches:
	Coordination	*Organizing meetings or conferences and setting agendas*	• Family case conferencing • Palliative Care for Older People (PACE)
		Overseeing the implementation of the intervention	• Family case conferencing • Palliative Care for Older People (PACE)
		Acting on problems, questions or queries regarding the interventions	• STA OP!
		Stimulating joint working to integrate available services	• Compassion • Maximizing Independence at Home-Streamlined (MIND-S)
		Having a single point of contact for person with dementia and informal caregiver	• Compassion
		Supporting front line staff in managing risks in persons with dementia and avoiding unnecessary transfers	• Compassion
		Information transfer	• Interprofessional Shared Decision-Making (IP-SDM)
		Review, debriefing or management meetings	• Palliative Care for Older People (PACE) • Behaviour analytics and support enhancement (BASE) • Integrated Personalized Plan (IPP)
		Clinical leading	• Dementia Symptom Management at Home (DSM-H) • Family case conferencing
		Mentoring and/or providing peer support	• Dementia Symptom Management at Home (DSM-H) • Palliative Care for Older People (PACE) • Compassion
		Motivating	• STA OP! • Compassion
		Providing support, resources and organisational matters	• STA OP! • Palliative Care for Older People (PACE) • Compassion • Maximizing Independence at Home-Streamlined (MIND-S)
	Reflecting & Evaluating	*Reflecting on working practices for end-of-life care*	• Organisational intervention • Palliative Care for Older People (PACE)
		Evaluating effects of the medication from informal caregivers and diverse healthcare professionals	• Home Treatment Crisis Team

Supplement VIII. CONTINUED

Theme	Categories	Codes	Identified in the following IPC approaches:
3. Resources facilitating collaboration	Products	*Client-related documents (such as care plans, treatment plans or patient files)*	• Organisation intervention • Home hospice care program • Goals of Care (GOC) • STA OP! • Grip on challenging behaviour • Palliative Care for Older People (PACE) • Behaviour analytics and support enhancement (BASE) • Compassion • Maximizing Independence at Home-Streamlined (MIND-S) • Integrated Personalized Plan (IPP) • Practical framework • Home Treatment Crisis Team
		Information or summary sheets	• Organisation intervention • Palliative Care for Older People (PACE)
		Guidance's, protocols or checklist	• Organisation intervention • Family case conferencing • Liverpool Care Pathway (LCP) • Goals of Care (GOC) • STA OP! • Grip on challenging behaviour • Palliative Care for Older People (PACE) • Behaviour analytics and support enhancement (BASE) • Compassion • Maximizing Independence at Home-Streamlined (MIND-S) • Integrated Personalized Plan (IPP)
		Measurement tools	• Dementia Symptom Management at Home (DSM-H) • Grip on challenging behaviour • Palliative Care for Older People (PACE) • Compassion • Maximizing Independence at Home-Streamlined (MIND-S)
		Communication tools (such as SBAR) or evaluation forms	• Dementia Symptom Management at Home (DSM-H) • Goals of Care (GOC) • Grip on challenging behaviour
		Videos	• Goals of Care (GOC)
		Practical toolkits (such as kit with end-of-life instruments)	• Family case conferencing • Home hospice care program
	Facilitating environment	*Digital systems (such as the dementia care management system software)*	• Maximizing Independence at Home-Streamlined (MIND-S) • Palliative Care for Older People (PACE) • Behaviour analytics and support enhancement (BASE)
		Spaces (such as palliative care room)	• Family case conferencing
		Networks or support services (such as organisation providing respite care)	• Home Treatment Crisis Team
		Supporting leadership roles	• Family case conferencing
		Encouraging collaborators	• Family case conferencing

Supplement VIII. CONTINUED

Theme	Categories	Codes	Identified in the following IPC approaches:
		Providing access to resources	• Family case conferencing
		Providing reimbursement	• Family case conferencing
		Making sure no other innovations or changes occur at the same time	• STA OP!
		Incorporating evidence-based instruments	• Dementia Symptom Management at Home (DSM-H) • STA OP!
		Structuring agenda and taking into account availability of collaborators	• Family case conferencing • STA OP!
		Having specialists (i.e. in-house palliative care team)	• Family case conferencing
	Competencies	*Understanding symptom management*	• Dementia Symptom Management at Home (DSM-H) • Compassion • Family case conferencing • Home Treatment Crisis Team
		Understanding end-of-life issues (such as swallowing problems)	• Home hospice care program • Compassion
		Acknowledging dementia as a terminal illness and a palliative care disease	• Family case conferencing • Behaviour analytics and support enhancement (BASE) • Maximizing Independence at Home-Streamlined (MIND-S)
		Knowing the steps or working method of the IPC approach	• STA OP! • Grip on challenging behaviour • Palliative Care for Older People (PACE) • Integrated Personalized Plan (IPP)
		Conducting advance care planning conversations	• Organisation intervention • Family case conferencing • Compassion
		Assessing and managing symptoms and distress (such as pain and suffering)	• Dementia Symptom Management at Home (DSM-H) • Home hospice care program • STA OP! • Behaviour analytics and support enhancement (BASE) • Compassion • Maximizing Independence at Home-Streamlined (MIND-S) • Practical framework • Home Treatment Crisis Team
		Defining goals of care	• Home hospice care program
		Targeting unmet needs	• STA OP! • Behaviour analytics and support enhancement (BASE)
		Assessing quality of life	• STA OP!
		Implementation skills (learning how to implement the intervention)	• Goals of Care (GOC) • Behaviour analytics and support enhancement (BASE)
		Having respect (i.e. for each other's roles but also for care for persons with dementia)	• Organisation intervention • Compassion • Home treatment crisis team

Supplement VIII. CONTINUED

Theme	Categories	Codes	Identified in the following IPC approaches:
		Communicating with other healthcare professionals	• Dementia Symptom Management at Home (DSM-H) • Home hospice care program
		Mentorship and coaching skills	• Dementia Symptom Management at Home (DSM-H) • Palliative Care for Older People (PACE)
		Communicating with informal caregivers	• Goals of Care (GOC)
		Communicating with persons with dementia	• Compassion • Practical framework
		Providing feedback to other disciplines	• STA OP!
		Building relationship with person with dementia and/or informal caregivers	• Practical framework • Home Treatment Crisis Team

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SUPPLEMENTS CHAPTER 3

Supplement I. The Consolidated criteria for Reporting Qualitative research (COREQ)

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 77 of the PhD thesis and Supplement IV (page 300)
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Supplement IV (page 300)
3. Occupation	What was their occupation at the time of the study?	Supplement IV (page 300)
4. Gender	Was the researcher male or female?	Page 77 of the PhD thesis and Supplement IV (page 300)
5. Experience and training	What experience or training did the researcher have?	Supplement IV (page 300)
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Supplement IV (page 300)
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Supplement IV (page 300)
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. bias, assumptions, reasons and interests in the research topic	Supplement IV (page 300)
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Page 77 and 78 of the PhD thesis
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 76 and 77 of the PhD thesis, and Supplement III (page 299)
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Supplement III (page 299)
12. Sample size	How many participants were in the study?	Page 80 of the PhD thesis
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Page 80 of the PhD thesis
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Page 77 of the PhD thesis and Supplement IV (page 300)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Supplement IV (page 300)
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 80 of the PhD thesis, and Table 2 (page 80)

Supplement I. CONTINUED

No. Item	Guide questions/description	Reported on Page #
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 76 of the PhD thesis, and Supplement II (page 298)
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No repeat interviews were carried out. Supplement IV (page 300)
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 77 of the PhD thesis
20. Field notes	Were field notes made during and/or after the interview or focus group?	Supplement IV (page 300)
21. Duration	What was the duration of the interviews or focus groups?	Page 80 of the PhD thesis
22. Data saturation	Was data saturation discussed?	Supplement V (page 301 and 302)
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	The transcripts were not returned to participants. Supplement IV (page 300)
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Supplement V (page 301 and 302)
25. Description of the coding tree	Did authors provide a description of the coding tree?	Supplement VI (page 303)
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 77 till 79 of the PhD thesis and Supplement V (page 301 and 302)
27. Software	What software, if applicable, was used to manage the data?	Page 77 of the PhD thesis
28. Participant checking	Did participants provide feedback on the findings?	Participants did not provide feedback on the results. Supplement IV (page 300)
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Quotations were accompanied by pseudonyms and presented in the page 81 till 86 of the PhD thesis, and Table 2 (page 80)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Data and findings were consistently presented in the page 81 till 86 of the PhD thesis
31. Clarity of major themes	Were major themes clearly presented in the findings?	Themes were presented in the page 81 till 86 of the PhD thesis
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, for example only 2 participants (from the 18 in total) wished to receive information that was discussed during interprofessional team meetings in the page 81 till 86 of the PhD thesis

Supplement II: Interview List

Topic 1: Interprofessional collaboration at home

1. Do you receive support from anyone?
    - A. What type of healthcare professionals were involved in the care process?
    - B. How did you experience the involvement of these healthcare professionals?
    - C. How do these healthcare professionals support you?
    - D. How do you experience their support?
    - E. How do you receive support from your informal caregivers?
2. How do you perceive collaboration among healthcare professionals?
    - A. Why do you think their collaboration is important for you?
    - B. Are you able to say anything about how they communicate with each other? If yes, how do they communicate with each other? If no, why not?
    - C. How do you know they are up-to-date with everything?
    - D. Could you describe whether you need to repeat information? If yes, could you give an explanation or describe what you mean.
    - E. Would you like to know what they discuss with each other? Why?

Topic 2: Possible future move to the nursing home

1. How do you experience living at home at this moment?
    - A. What would make it difficult for you to stay at home?
    - B. What would help you to stay at home as long as possible?
    - C. What do you think about living somewhere else?
2. What do you think about moving to a nursing home?
    - A. What do you think about nursing homes?
    - B. What would you need in a nursing home in order to feel at home?
    - C. With whom do you want to prepare for a possible future move to the nursing home?

Supplement III: Additional information about recruitment

The recruiters (dementia case managers, geriatricians and nurses) from the participating care organisations located in the southern region of the Netherlands informed potential candidates and/or (if applicable) their informal caregivers about the study through face-to-face meetings or phone calls. The interviewers (C.K. and S.B.) had no initial contact with the participants during the recruitment procedure, and were only allowed to approach potential candidates when they had provided oral consent to the recruiters. If the potential candidates or (if applicable) their informal caregivers were interested in the study and gave oral consent, they were given the DEDICATED information letter and flyer with information about the aim of the study and interview. The recruiters then passed on their contact information in a secured Word document, which was saved on the Maastricht University database. After sending this document, the recruiters and the researchers all removed this document from their e-mail and their own computers. Eventually, the researchers contacted the candidates or (if applicable) their informal caregivers to provide detailed information about the interview and ask whether they were interested in participating. If they were certain about their participation, an interview date and time was scheduled, and the researchers sent the participants or (if applicable) their informal caregivers an informed consent form and the information letter via e-mail. The interviews were conducted between August 2018 and October 2019 at the participant's own home.

Supplement IV: Additional information about data collection

S.B. (BSc and MSc in psychology) and C.K. (BSc in Biomedical Sciences and MSc in Vitality and Ageing) received trainings on the job in performing interviews through piloting and receiving advices from the DEDICATED research team. Both S.B. and C.K. were female PhD students at the DEDICATED project. During each interview, either S.B. and C.K. guided the interview and mainly asked questions. The other researcher functioned as an observer and asked additional or follow-up questions. If either S.B. and C.K. was not able to be present at the interview as an observer, a project member of the DEDICATED team replaced her.

Before conducting the interviews, the interviewers contacted (via phone or e-mail) the recruiters to acquire background information about the person with dementia, such as whether he or she received home care in order to establish the credibility and dependability of the interview data. Prior to asking the interview questions, S.B. and C.K. briefly introduced themselves and explained the reasons and aims off the study. They expressed their interest in performing research into elderly care, and for this study, identifying the experiences of persons with dementia. The interviewers knew that that the move to the nursing home and end-of-life care were sensitive topics and assumed that persons with dementia would find it difficult to talk about. Therefore, they paid attention to introducing themselves and the topics and making the persons with dementia feel comfortable. The interviewers adopted several strategies to optimise communication with the persons with dementia such as restructuring questions when needed, active listening, looking at facial expressions, monitoring behavioural changes, allowing time to respond and offering to take a break or stop the interview if someone felt emotional or did not want to talk about a specific topic[1]. No field notes were made during the interviews. None of the interviewers knew the participants. No transcripts were returned to persons with dementia or their informal caregivers for comments or corrections. Apart from the interviewers and informal caregivers, one volunteer and a dementia case manager were present during two interviews. Finally, no repeat interviews were performed.

Supplement V: Data analysis and saturation

We used deductive as well as inductive approaches throughout the entire data analysis (See Figure 1).

We applied a deductive approach for the topic Interprofessional collaboration at home because we developed two themes My perception of the collaboration among healthcare professionals and My needs in the collaboration with healthcare professionals prior to the data analysis. We developed these two a priori themes based on the results of Dahlke et al. (2018) and Jarrett (2009)[2, 3]. These previous studies investigated the perceptions and experiences of (older) patients regarding interprofessional collaboration and described two layers of experiences regarding interprofessional coloration, namely their perception and their needs (Dahlke et al., 2018; Jarrett, 2009)[2, 3]. We choose a deductive approach for this topic because we aimed to build further on these existing results about interprofessional collaboration and further enrich our data by using an unconstrained matrix. The preconceived categories were The effects on my care process, I need them to listen and answer me, I want to understand what is happening, and I want to be recognised as an unique person. These preconceived categories were rewritten and redefined through grouping, categorisation and abstraction (Assarroudi et al., 2018)[4]. Through these similar three steps, some inductive categories for this topic emerged such as My informal caregiver is the contact person, and all the codes were rephrased and redefined.

For the topic Possible future move to the nursing home, an inductive approach was applied because no prior research was conducted that captured the perceptions of older people concerning a possible future move. We could not find a study that described these perceptions and therefore we directly choose for open or initial coding to identify important units derived from the data itself.

Two main researchers S.B. and C.K. analysed the data over a period of four months. S.B. and C.K. independently read and coded a few transcripts using both coding strategies described by Saldana et al. (2013)[5], produced their own coding list, discussed both coding lists and adapted the previous versions of the codebook via negotiated agreements to increase the discriminant capability of the codebook. The template outlined in Macqueen et al. (1998) was used for the development of the definitive codebook[6]. S.B. and C.K. divided the eighteen transcripts over four meetings to analyse the data in chunks. The division was based on the order of the taken interviews. No prior selection was made. In the first meeting S.B. and C.K. discussed three transcripts, in the second meeting another three transcripts, in the third meeting another five transcripts, in the fourth meeting another three transcripts, and in the fifth meeting the remaining four transcripts. S.B. and C.K. identified meaningful segments for both topics from the transcripts during meeting by using several coding strategies (namely structural coding, attribute coding, descriptive coding, in vivo coding, process coding, emotion coding, values cording, versus coding, provisional coding, and causation coding)[5], and processed those in the preliminary codebook[7, 8]. We applied axial coding and theoretical coding for both topics in order to bring structure, organise to the data, and abstraction of the data to create final categories and the themes[7, 8]. We did not want to analyse all transcripts at once, but analyse transcripts in chunks to achieve optimal categorization and abstraction of the data[8].

Researchers S.B. and C.K. redefined and re-described our categories, codes, and sub-codes during all meetings, and consulted with three researchers from the DEDICATED team to improve the investigator triangulation process, and thereby the validity of the analysis. In the last stage, S.B. and C.K. used the definitive codebook to order all results (shown in Supplement VI). We reconciled discrepancies through comparing the different perspectives about a code and develop a shared code together. The final deductively derived themes were *My perception of collaboration among healthcare professionals* and *My needs in interprofessional collaboration with healthcare professionals*. The final inductively derived themes were *Coping strategies for a possible future move to the nursing home* and *My preferences* *when a nursing home becomes my possible future home*. We selected discrete quotations that illustrate the findings, represent how both the majority and minority of the participants expressed themselves, and increase the readability of the results section as key quotes[9]. These key quotes are shown in the results section.

Data saturation for the theme *My needs on collaboration with healthcare professionals* was reached at the second meeting for the theme *My preferences when a nursing home becomes my possible future home* during the third meeting, and for the themes *Coping strategies for a possible future move to the nursing home* and *My perception of collaboration among healthcare professionals* during the fourth meeting[10]. We reached code saturation at the 16th transcript, and meaning saturation at the last transcript[11].

Supplement VI: Coding tree

Themes	***Categories***	***Codes***
1. My perception of collaboration among healthcare professionals	My visibility of collaboration among healthcare professionals	*I see many different faces*
		I assume they communicate
	My care experience of collaboration among healthcare professionals	*They arrange my care*
		They fulfil my commitments
2. My needs in collaboration with healthcare professionals	I need information from healthcare professionals	*I want to understand my health status*
		I want to understand how dementia affects my life
	My informal caregiver is the contact person	*My informal caregivers do the talking*
		My informal caregivers connect the dots
	I want to be seen as an individual by healthcare professionals	*They should have respect for my autonomy*
		I wish personal contact
	I wish tailored care from healthcare professionals	*They need to be competent*
		They need to know my care preferences
3. My coping strategies for a possible future move to the nursing home	I cherish my current life vs. I face my current decline	*I enjoy meaningful activities*
		I appreciate the people around me
		I want to stay independent as long as possible
		I adapt to physical and cognitive decline
		I see the burden of informal caregivers
	I want to stay at home vs. I think about a possible future move	*My home is part of my identity*
		I see many negative aspects of nursing homes
		When I think about my future decline
		When I think about my informal caregivers
		When I think about my fears
	I anticipate my future decline aiming to stay at home vs. I prepare for a possible future move	*I seek information and support*
		I perform home adjustments
		I let go
		I talk about it with my informal caregivers
		I perform visits o/a participate in activities
4. My preferences when a nursing home becomes my possible future home	I want to choose the nursing home environment	*Connecting with a familiar environment*
		Suitable physical characteristics
	I want to continue with my activities	*Maintaining daily routines*
		Maintaining activities
	I want to maintain my social life	*Maintaining existing contacts*
		Building new contacts

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SUPPLEMENTS CHAPTER 4

Supplement I. Criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 103 of the PhD thesis and Supplement III (page 310)
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Supplement III (page 310)
3. Occupation	What was their occupation at the time of the study?	Supplement III (page 310)
4. Gender	Was the researcher male or female?	Page 103 of the PhD thesis
5. Experience and training	What experience or training did the researcher have?	Supplement III (page 310)
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Supplement III (page 310)
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Supplement III (page 310)
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Supplement III (page 310)
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Page 103 and 104 of the PhD thesis
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 103 of the PhD thesis
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Supplement III (page 310)
12. Sample size	How many participants were in the study?	Page 104 of the PhD thesis
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Page 104 of the PhD thesis
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Page 103 of the PhD thesis
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Supplement III (page 310)
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 104 and 105 of the PhD thesis

Supplement I. CONTINUED

No. Item	Guide questions/description	Reported on Page #
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 103 of the PhD thesis and Supplement II (page 308 and 309)
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	Supplement III (page 310)
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 103 of the PhD thesis
20. Field notes	Were field notes made during and/or after the inter view or focus group?	Supplement III (page 310)
21. Duration	What was the duration of the interviews or focus group?	Page 104 of the PhD thesis
22. Data saturation	Was data saturation discussed?	Supplement IV (page 311)
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Supplement III (page 310)
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Supplement IV (page 311)
25. Description of the coding tree	Did authors provide a description of the coding tree?	Supplement V (page 312)
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 104 of the PhD thesis and Supplement IV (page 311)
27. Software	What software, if applicable, was used to manage the data?	Page 103 of the PhD thesis
28. Participant checking	Did participants provide feedback on the findings?	Supplement III (page 310)
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, page 105 till 117 of the PhD thesis
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, page 113 till 126 of the PhD thesis
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, page 105 till 117 of the PhD thesis
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, page 105 till 117 of the PhD thesis

Supplement II: Interview List

Theme 1: Interprofessional collaboration

3. Which type of healthcare professionals were involved in the care process and during the last months?
    F. How did you experience the involvement of these healthcare professionals?
4. How were you involved in the care process?
    F. Did you feel that you had control in the care process?
    G. Did you feel acknowledged as informal caregiver?
    H. Did the healthcare professionals ask for your experiences in the care process?
    I. Did the healthcare professionals consider your advices?
5. Did one person coordinate the care?
    A. How did information transfer occur between healthcare professionals?
    B. Did you often have to repeat information to healthcare professionals?
6. What is your general impression of the collaboration between healthcare professionals?
    A. How was the collaboration between healthcare professionals visible for you?
    B. Did the healthcare professionals know which task they have?
    C. Was the communication process between healthcare professional optimal according to you?
    D. Where the collaboration agreements written down?
    E. Did all healthcare professionals execute the collaboration agreements in the same way?
7. What would you like to change in the collaboration process?
    A. Do you have any advices?

Theme 2: Transmural collaboration
In case relatives with dementia died in a nursing home

1. How did you experience the nursing home transition?
    A. How did you and your relative experience the admission day?
    B. Where you and your relative prepared for the admission? If yes, please explain in which way you were prepared.
    C. Could the admission be prevented according to you?
    D. How were you as informal caregiver involved with the admission?
2. Where the healthcare professionals in the nursing home prepared for the admission of your relative with dementia?
    A. Did you have the impression that they were aware of the healthcare situation of your relative at the admission?
    B. Was the transition process coordinated by one person?
    C. Was it clear for you who your first contact person was?
    D. Could you ask the first contact person everything?
3. How did you experience the handover communication?
    J. Who was responsible for the handover, according to you?
    K. Did you experience the handover as warm, personal and complete?
    L. Are there any factors of which you believe were during this handover?
4. What would you wish to change in the transition process?
    A. Are there any advices that you would like to give to the healthcare professionals?

In case relatives with dementia died at home

3. Were there any preparations made prior to the nursing home admission?
    D. If there were any preparations, could you please explain which kind of preparations you had made and whether you had a conversation with a healthcare professional about this topic?

    E. What was the reason for admission?
4. Where the healthcare professionals aware of your burdensome as informal caregiver?
    A. How did you notice their awareness?
    B. Did you feel overburdened?
    M. How did the healthcare professionals cope with your burdensome?
5. How could the healthcare professionals support you in the entire process?
    D. What would you like to change in the collaboration process?
    E. Do you have any advices?

Supplement III: Additional information about data collection

Nurses from the participating care organisations informed potential candidates about the study through phone calls, or by post through information letters and flyers. The interviewers had no initial contact with the participants during the recruitment procedure, and were only allowed to approach potential candidates when they provided oral or written consent to the nurses. S.B. (MSc in psychology) and L.V. and S.P. (MSc in nursing) received trainings on the job in performing interviews through piloting and receiving advices from the DEDICATED research team. L.V. was an intern and S.B. and S.P. were PhD students at the DEDICATED project. Prior to asking the interview questions, S.B and S.P. shortly introduced themselves and explained the reasons and aims for the study. They expressed their interest in performing research in the elderly care and for this study, identifying the experiences of informal caregivers. No field notes were made during the interviews. In case S.B. or S.P. could not be present and function as observer, a research assistant or project member of DEDICATED replaced them. None of the interviewers knew the participants. No transcripts were returned to participants for comments or corrections. Apart from the interviewers and informal caregivers, no one else was present. Finally, no repeat interviews were performed.

Supplement IV: Stages in data analysis

The critical realist approach consists of several steps, namely defining the research question that is guided by theory, collecting data, coding data and identifying demi-regularities (key patterns in data), abduction (theoretical redescription of the outcomes) and retroduction (causal mechanisms of the demi-regularities). Prior to the data analysis, we defined the research question *'How did informal caregivers experience IPC with healthcare professionals and how did informal caregivers perceive IPC among healthcare professionals?'*. This division of two collaboration levels was described and explored by Stephan et al. (2015)[1]. We used this study as theoretical guidance to explore IPC with informal caregivers. The coding procedure was executed in two stages. In the first stage, C.K. and I.M. read the first transcript together, identified meaningful segments in the data, assigned primary codes to the segments using the first cycle coding strategies (such as structural coding) of Saldana et al. to optimize unitization, and processed those in the preliminary codebook. In the second stage, all 32 transcripts were coded in four cycles, which resulted in four codebook versions. In each cycle, C.K. and I.M. independently coded eight transcripts using both the first and second cycle coding strategies (such as axial coding) described by Saldana et al. and produced their own coding list, discussed both coding lists and adapted the previous versions of the codebook via negotiated agreements to increase the discriminant capability of the codebook[2]. In the last stage, C.K. and I.M. used the definitive codebook to order the themes, sub-themes and key quotes in Table 1. For the development of the definitive codebook, the template outlined in Macqueen et al. was utilised[3]. During all coding cycles, researchers C.K. and I.M. redefined and re-described our categories, codes, sub-codes based on existing theories and concepts in literature (abduction), and consultation with DEDICATED research team to improve the investigator triangulation process, and thereby the validity of the analysis. The identified demi-regularities were types of involvement, insight into structural collaboration, and perceived collaboration outcomes. An example of abduction concerned the deciding what constitutes shared decision-making as previous literature showed that decision-making occurs for minor as well as major decisions, which also includes nursing home transitions. At the end we carried out retroduction, in which we identified factors influencing the types of involvement and the information exchange among healthcare professionals. Afterwards, codes and sub-codes have been rephrased three times (together with DEDICATED research team). We also identified quotations that underline the outcomes, represent how both the majority and minority of the informal caregivers expressed themselves, and increase the readability of the results[4]. These key quotes are shown in the results. Both code saturation (identifying of new codes) and meaning saturation (identifying new meanings of the developed codes) was reached during the third coding cycle[5]. Participants were not asked to provide feedback on the results.

Supplement V. Coding tree

Themes	*Categories*	*Codes*	*Sub-codes*
1. Informal caregivers' roles in interprofessional collaboration with healthcare professionals	1A. Types of informal caregivers' roles	1A. I Information exchange	*Receiving*
			Sending
			Filling the gap
		1A. II Care process	*Caregiving*
			Monitoring
			Coordinating
		1A. III Shared decision-making	*Everyday decisions*
			Goals of care and medical decisions
			Nursing home transitions
	1B. Factors influencing informal caregivers' roles	1B. I Intrinsic factors	*Informal caregivers themselves*
			Other informal caregivers
			Persons with dementia
		1B. II Extrinsic factors	*First contact person*
			Communication channels
			Healthcare professionals' attitudes & competencies
2. Informal caregivers' perception of interprofessional collaboration among healthcare professionals	2A. Visible collaboration process	2A. I Communication process	*Information transfer*
			Consultations & Agreements
		2A. II Team process	*Cohesiveness*
			Task division
	2B. Effecting collaboration outcomes	2B. I Information exchange	*Up to date*
			Warm welcome
		2B. II Care process	*Proactive & adequate*
			Consistent
	2C. Factors influencing collaboration outcomes	2C. Micro-level factors	*Patient records*
			Collegiality
		2C. Macro-level factors	*Team size*
			Team stability

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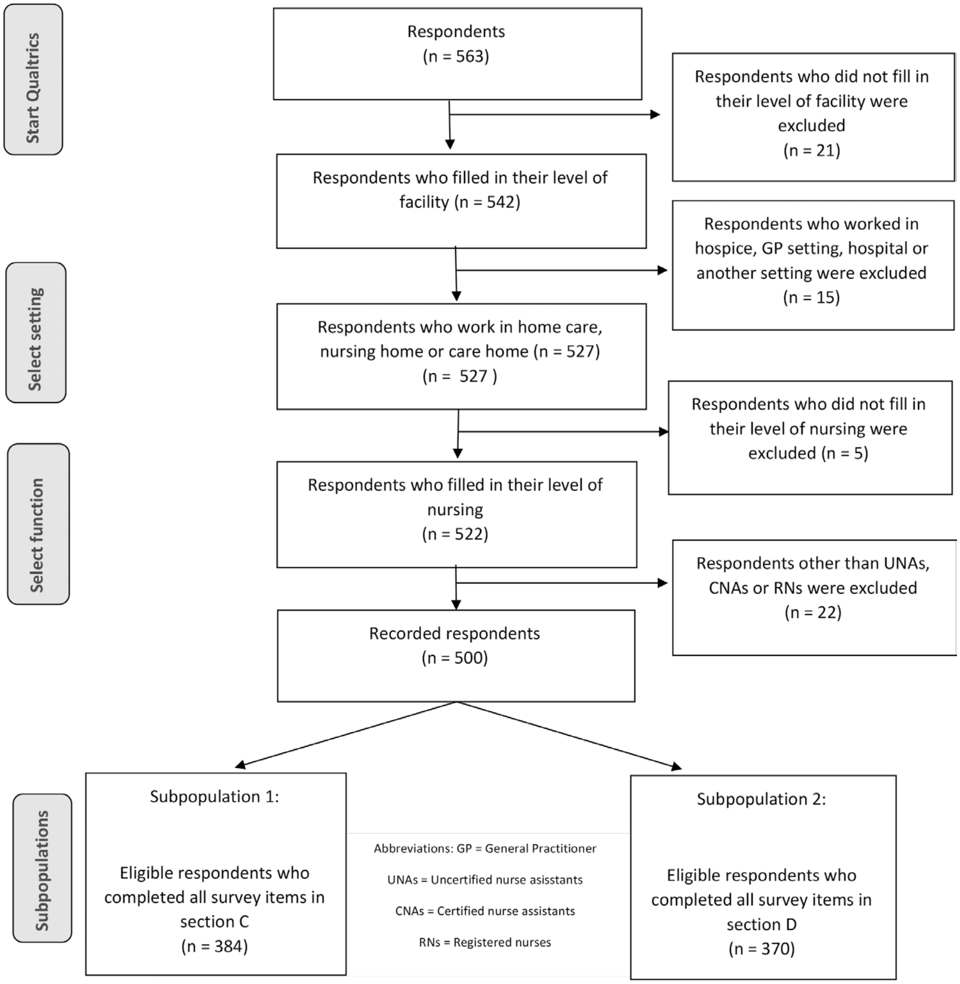
3. Macqueen K, McLellan-Lemal E, Kay K, et al. *Codebook Development for Team-Based Qualitative Analysis*. 1998, p.pp. 31–36.
4. Eldh AC, Årestedt L and Berterö C. Quotations in Qualitative Studies: Reflections on Constituents, Custom, and Purpose. *International Journal of Qualitative Methods* 2020; 19: 1609406920969268. DOI: 10.1177/1609406920969268.
5. Hennink MM, Kaiser BN and Marconi VC. Code Saturation Versus Meaning Saturation:How Many Interviews Are Enough? *Qualitative Health Research* 2017; 27: 591-608. DOI: 10.1177/1049732316665344.

SUPPLEMENTS CHAPTER 5

Supplement I: Flowchart of subpopulations selection



Supplement II: Questionnaire

The questionnaire used in this study was originally in Dutch. It was translated using a forward-backward approach. First, all items were translated in English by the authors. A native English speaker with excellent command of the Dutch language checked and improved the translated items. A native Dutch speaker with excellent command of the English language translated the items back to Dutch. Apparent incongruities were discussed with the Dutch translator and subtle language improvements were made jointly to convey the meaning of the items from the original questionnaire. The full English version of the questionnaire is included here as supplemental material. Note that the current study describes findings related to sections A, B, E and F.

A QUESTIONNAIRE FOR NURSING STAFF:

Providing palliative care for persons with dementia

Developed by S.R. Bolt, J.T. van der Steen, S.M.G. Zwakhalen, J.M.G.A. Schols, D.J.A. Janssen, S. Pieters, C. Khemai and J.M.M. Meijers

Translated with the support of I. Mujezinović and J. Houtermans

A. GENERAL

1. What is your age? ☐

2. What is your gender?
   - ☐ Female
   - ☐ Male

3. In which setting do you currently predominantly work?
   - ☐ Home care
   - ☐ Nursing home
   - ☐ Care home
   - ☐ General practice
   - ☐ Hospice
   - ☐ Hospital
   - ☐ Different, namely:

4. In what way did this questionnaire reach you?
   - ☐ Partner of the project (Envida, Zuyderland, Vivantes)
   - ☐ V&VN (Dutch Nurses' Association)
   - ☐ LPZ (National Survey of Care Indicators)
   - ☐ Alzheimer Nederland (Dutch Alzheimer's Association)
   - ☐ Other

5. In which province do you work at the time?
   - ☐ Limburg
   - ☐ Noord-Brabant
   - ☐ Zeeland
   - ☐ Zuid-Holland
   - ☐ Noord-Holland
   - ☐ Utrecht
   - ☐ Gelderland
   - ☐ Flevoland
   - ☐ Overijssel
   - ☐ Drenthe
   - ☐ Friesland
   - ☐ Groningen

6. What is your current job title?
   - ☐ Nurse practitioner
   - ☐ Registered nurse, baccalaureate-educated (level 6)
   - ☐ Registered nurse, vocationally trained (level 5)
   - ☐ Registered nurse, vocationally trained (level 4)
   - ☐ Certified nurse assistant (level 3)
   - ☐ Nurse assistant (level 2)
   - ☐ Different, namely:

7. How many years of experience do you have in working with persons with dementia?

8. Did you attend any additional training in palliative care during the <u>past two years</u>?*
   - ☐ No
   - ☐ Yes, namely:

9. Did you attend any additional training in dementia care during the <u>past two years</u>?*
   - ☐ No
   - ☐ Yes, namely:

* By additional training, we refer to courses, clinical lessons, skills training, workshops or study programs of **<u>at least 2 hours.</u>**

10. On a scale from 1 to 10, how would you rate the quality of palliative care for persons with dementia within your unit or team?
    - ☐ 1
    - ☐ 2
    - ☐ 3
    - ☐ 4
    - ☐ 5
    - ☐ 6
    - ☐ 7
    - ☐ 8
    - ☐ 9
    - ☐ 10

11. To what extent do you feel competent to provide palliative care for persons with dementia and their loved ones?

0 1 2 3 4 5 6 7 8 9 10

Not at all *Completely*

12. In my opinion, providing palliative care is...
    ☐ ... a standard task for all nursing and care staff with a basic education
    ☐ ... a task for nursing and care staff specialized in palliative care

B. PALLIATIVE CAREGIVING AND COMMUNICATION

Please choose from the options below in which areas you need support in providing palliative care for persons with dementia (multiple answers are allowed). These could be needs regarding practical matters, but also regarding knowledge, emotional support or contacts with others.

Regarding palliative caregiving, I need increased competencies or support in…

1.	… providing daily care/assisting self-care (ADL and IADL)	☐
2.	… recognizing and dealing with certain behaviours, such as agitation or aggression	☐
3.	… recognizing and dealing with emotions, such as sadness, anxiety, or anger	☐
4.	… recognizing and optimizing physical comfort	☐
5.	… recognizing discomfort and dealing with pain	☐
6.	… communicating with persons with severe dementia	☐
7.	… dealing with religious and existential questions	☐
8.	… using (validated) instruments, e.g. for measuring symptoms	☐
9.	… recognizing (the start of) the dying phase	☐
10.	… guiding persons with dementia and their loved ones in the dying phase	☐
11.	… involving loved ones in the entire care process	☐
12.	… supporting loved ones after bereavement	☐
13.	… opportunities to get to know the person with dementia and their loves ones well	☐
14.	… feeling more comfortable when caring for persons with dementia	☐
15.	… feeling more comfortable interacting with loved ones	☐
16.	… my personal contribution to meaningful activities for persons with dementia	☐

Regarding end-of-life communication, I need increased competencies or support in…

17.	… feeling comfortable talking about the end of life with persons with dementia and their loved ones	☐
18.	… deciding on the right time to initiate end-of-life communication	☐
19.	… having a conversation about the end of life	☐
20.	… involving persons with dementia in end-of-life decision-making	☐
21.	… involving loved ones in end-of-life decision-making	☐
22.	… dealing with disagreement between loved ones about end-of-life care	☐
23.	… guiding persons with dementia and their loved ones to document end-of-life wishes	☐
24.	… being able to retrieve documented end-of-life wishes	☐

C. INTERPROFESSIONAL COLLABORATION

1. On a scale from 1 to 10, how would you rate the quality of interprofessional collaboration with colleagues <u>within your own discipline</u>?

☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10

2. On a scale from 1 to 10, how would you rate the quality of interprofessional collaboration with colleagues <u>from other disciplines</u>?

☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10
☐ I do not have to deal with this in my job

3. On a scale from 1 to 10, how would you rate the quality of collaboration with colleagues <u>from other organizations than the one where you work</u>?

☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10
☐ I do not have to deal with this in my job

Please choose from the options below in which areas you need support in collaborating with other care professionals in palliative care for persons with dementia (multiple answers are allowed). These could be needs regarding practical matters, but also regarding knowledge, emotional support or contacts with others.

Regarding collaboration with other care professionals in providing palliative care for persons with dementia and their loved ones, I need…

4.	**… the availability of one contact person for persons with dementia and their loved ones**	☐
5.	… the availability of one contact person for myself	☐
6.	**… clarity about the tasks of all care providers**	☐
7.	**… clarity about who is responsible for which task(s)**	☐
8.	… more skills or support in working together as one team	☐
9.	… tips and advice in aligning care agreements between care providers	☐
10.	… consultation with colleagues within my own discipline	☐
11.	… consultation with colleagues from other disciplines	☐
12.	… consultation with colleagues outside my own organization	☐
13.	… tips and advice on how to involve persons with dementia and / or their loved ones in interdisciplinary consultations	☐
14.	… clarity about where healthcare agreements are recorded	☐
15.	… clarity about how care agreements are passed on	☐
16.	… to feel safe when carrying out care agreements made (for example, a non-CPR policy)	☐
17.	… regular discussion about and adjustment of care agreements if necessary	☐
18.	**… to be able to approach other disciplines directly within my own organization**	☐
19.	… to be able to approach other disciplines directly outside my own organization	☐
20.	**… an explicit information transfer**	☐

D. TRANSITIONS OF CARE (HOME TO NURSING HOME)

1. On a scale from 1 to 10, how would you rate the content of the nurse transfer as issued at your institution? *

☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10
☐ I do not have to deal with this in my job

2. On a scale from 1 to 10, how would you rate the content of the nurse transfer as it is received at your institution? **

☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10
☐ I do not have to deal with this in my job

** Item only shown to people working in the extramural setting*

*** Item only shown to people working in the intramural setting*

Please choose from the options below in which areas you need support in transitions from home to the nursing home for persons with dementia (multiple answers are allowed). These could be needs regarding practical matters, but also regarding knowledge, emotional support or contacts with others.

Regarding transitions from home to the nursing home of persons with dementia, I need…

3.	**… insight into the coordination of the admission (who arranges what)**	☐
4.	**… one point of contact in the coordination of the admission**	☐
5.	**… tips and advice to guide relatives and persons with dementia in the admission process**	☐
6.	… tips and advice to prepare myself for an admission	☐
7.	… tips and advice for a warm, personal transfer	☐
8.	… standard guidelines for the content of the transfer	☐
9.	**… transparency with regards to agreements made earlier about end-of-life wishes ***	☐
10.	… exact information about where the agreements made earlier about end of life wishes can be found **	☐
11.	**… to visit the nursing home, together with persons with dementia and / or loved ones, before the admission ***	☐
12.	**… to visit the persons with dementia in their home situation, before the admission ****	☐
13.	… tips and advice on how to contribute to a personal and warm welcome **	☐

** Item only shown to people working in the extramural setting*

*** Item only shown to people working in the intramural setting*

E. PREFERRED FORMS OF SUPPORT

Please choose from the options below what *forms* of support you need in palliative care for persons with dementia (multiple answers are allowed).

In the aforementioned aspects of palliative care for persons with dementia *(basic care, communication, collaboration and transitions to the nursing home)* I would prefer receiving support in the form of…

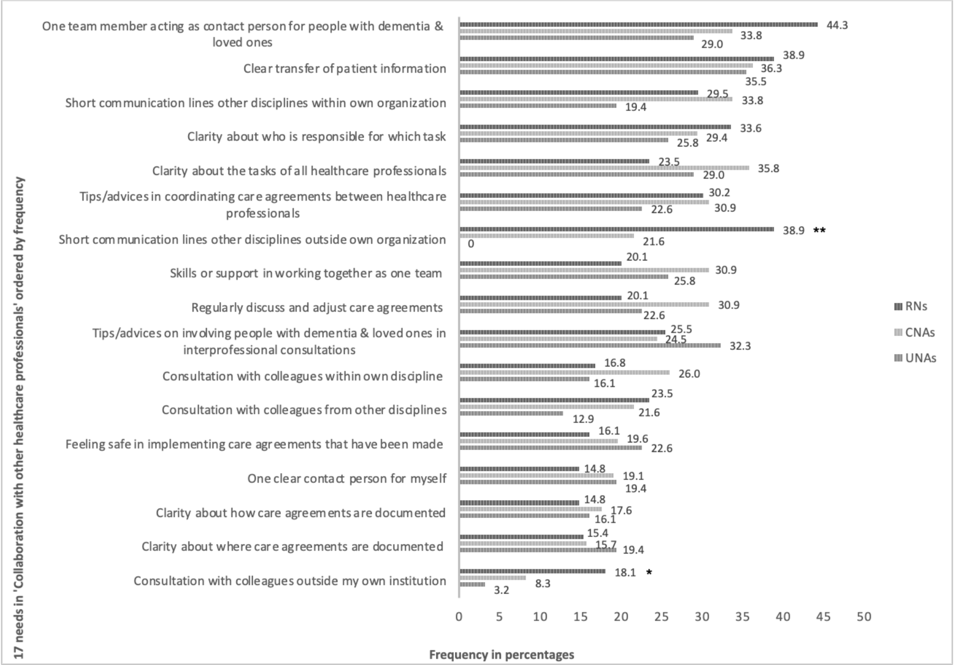
1.	… classical education (e.g. clinical lessons)	☐
2.	… e-learning	☐
3.	… coaching/supervision on the work floor ('coaching on the job')	☐
4.	… exchanging experiences with colleagues ('peer-to-peer learning')	☐
5.	… jointly discussing cases	☐
6.	… training by means of actors or puppets	☐
7.	… mobile apps	☐
8.	… serious gaming (games with an educative goal)	☐
9.	… electronic client or patient files with access by all involved caregivers	☐
10.	… digital communication medium with access by all involved caregivers	☐
11.	… digital informative movies, animations, or podcasts	☐
12.	… digital support on the work floor (e.g. measuring instruments, checklists)	☐
13.	… emotional support from direct colleagues	☐
14.	… emotional support from the organization (e.g. trustees)	☐
15.	… (being referred to) professional emotional support	☐
16.	… a palliative care expert or team to ask for advise	☐
17.	… more opportune moments to consult a palliative care expert or team	☐
18.	… care processes depicted in care paths (e.g. care path in the dying phase)	☐
19.	… collaboration agreements within own organization	☐
20.	… collaboration agreements with professionals outside own organization	☐
21.	… a guide to or overview of available care providers	☐
22.	… general organizational support (e.g. sufficient time, resources, staffing)	☐

F. OPEN-ENDED QUESTIONS

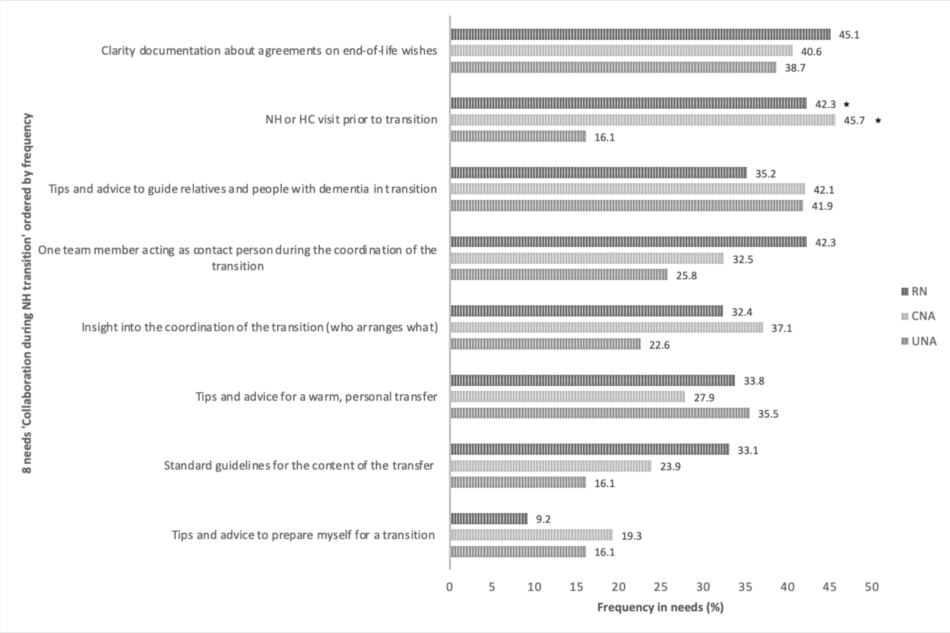
23. Are there any other aspects of palliative care for persons with dementia in which you need support? We kindly request that you fill this out below, along with additional forms of support that you would prefer.

24. If you had more time to do your work, what would you use it for?

Supplement III: Differences regarding interprofessional collaboration needs among RNs, CNAs and UNAs



Supplement IV: Differences regarding transmural collaboration needs among RNs, CNAs and UNAs.



SUPPLEMENTS CHAPTER 6

Supplement I. Details about the development process of the guidance document

The development processes of the guidance document consisted of five steps. Step I) A scoping review on interprofessional collaboration interventions used in palliative dementia care (under review); Step II) A survey to identify interprofessional collaboration needs of nurses regarding providing palliative dementia care[1]; Step III) In-depth interviews with persons with dementia (under review) and their informal caregivers regarding interprofessional collaboration in palliative dementia care[2]; and Step IV) Grey literature search to explore existing advance care planning (ACP) tools in dementia care.

Several studies were conducted during Step I. The scoping review found that six interprofessional collaboration approaches in palliative dementia care focused on advance care planning. These interprofessional collaboration approaches mentioned ACP conversations about expected changes, care goals, treatment options, anticipatory medication and care in the dying phase. Our interview study with persons with dementia (N=18) revealed that they display several coping strategies when thinking about a possible future move to the nursing home and are able to express future needs for nursing homes (under review). Previous studies about ACP with persons with dementia explained that they perceived ACP conversations to be confined to the dying phase and funeral arrangements[3], the variability of their capacity and willingness to engage[4], and that this could create a conflicting feeling about whether they are in control of their life[5]. The scoping review emphasised building a trusting relationship between healthcare professionals and informal caregivers, and applying a team approach (under review) with respect to conducting ACP conversations (under review). The reported guidance documents included practical tools for interventions in the literature about ACP in dementia care that involve decision-making processes[6] and the participation of informal caregivers[7, 8]. The involvement of informal caregivers in ACP is also supported by our interview study with informal caregivers (N=32), which indicated that they are actively involved in making decisions about everyday life, care goals, medical decisions and the move to the nursing home[9]. The survey with nurses (N=384) highlighted the importance of having transparency about end-of-life wishes in interprofessional collaboration during the move from home to the nursing home[10], which could imply the importance of ACP for persons with dementia at home and the continuity of ACP information during the move.

Supplement II. Consolidated criteria for Reporting Qualitative (COREQ) research-checklist

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 160 of the PhD thesis and Supplement III (page 329)
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Supplement III (page 329)
3. Occupation	What was their occupation at the time of the study?	Supplement III (page 329)
4. Gender	Was the researcher male or female?	Page 160 of the PhD thesis and Supplement III (page 329)
5. Experience and training	What experience or training did the researcher have?	Supplement III (page 329)
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Supplement III (page 329)
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Supplement III (page 329)
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Page 160 of the PhD thesis
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowballing	Page 160 of the PhD thesis
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Supplement III (page 329)
12. Sample size	How many participants were in the study?	Page 161 of the PhD thesis
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Page 161 of the PhD thesis
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Supplement III (page 329)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Supplement III (page 329)
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 161 of the PhD thesis
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Supplement IV (page 330 and 331)
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	Supplement III (page 329)
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 160 of the PhD thesis
20. Field notes	Were field notes made during and/or after the inter view or focus group?	Page 160 of the PhD thesis
21. Duration	What was the duration of the interviews or focus groups?	Page 161 of the PhD thesis
22. Data saturation	Was data saturation discussed?	Page 160 of the PhD thesis

Supplement II. CONTINUED

No. Item	Guide questions/description	Reported on Page #
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Page 160 of the PhD thesis
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Page 160 of the PhD thesis
25. Description of the coding tree	Did authors provide a description of the coding tree?	Supplement V (page 332 and 333)
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 160 of the PhD thesis, and Supplement I (page 326)
27. Software	What software, if applicable, was used to manage the data?	No software was used.
28. Participant checking	Did participants provide feedback on the findings?	Participants did provide feedback on the results through the reflection meeting. Page 167 and 168 of the PhD thesis and Supplement VIII (page 336)
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Quotations were presented in Table 1 (page 162)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Data and findings were consistently presented in the page 161 till 169 of the PhD thesis
31. Clarity of major themes	Were major themes clearly presented in the findings?	Themes were presented in page 161 till 169 of the PhD thesis
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, for example only healthcare professionals from one care organisation mentioned the existence of two separate systems in page 161 till 169 of the PhD thesis

Supplement III. Details about data collection

The online focus groups and interviews took place between September 2020 and March 2021 via Microsoft Teams or Zoom. Potential candidates were contacted via e-mail to provide background information about the study objective, and ask whether they were willing to participate. Two female DEDICATED-team members were involved during every interview and focus group. PhD student C.K. (MSc in Vitality and Ageing) guided the interviews and focus groups and either the project leader and Assistant Professor J.M.M. (MSc in Health Sciences and Epidemiology) or the project manager L.D. (MSc in Healthcare Management) asked follow-up and additional questions. The interviewers received trainings in performing interviews on the job through piloting and receiving advice from the research team. Some participants were familiar to the interviewers, because they had been contacted in an earlier phase of the DEDICATED-project. The interviewers briefly introduced themselves and explained the study objective prior to asking the interview questions. They also explained their interest in performing research into care for elderly people, and in identifying the wishes of various HCPs for this study. No repeat interviews were carried out.

Supplement IV: Interview guide

Discovery phase: Current collaborative state regarding advance care planning in dementia care

8. Introducing advance care planning
   G. What does palliative care mean to you?
   H. What does advance care planning mean to you?
   I. When do you think advance care planning should start?
   J. What is your role in advance care planning?
   K. What is discussed during advance care planning?
   L. What are the advantages of collaboration with other disciplines regarding advance care planning?
   M. What needs to be improved in collaboration with other disciplines regarding advance care planning?
9. Talking about advance care planning
   N. When do you talk about advance care planning with each other?
   O. What is everyone's contribution to these meetings?
   P. What are the advantages of meetings about advance care planning?
   Q. What needs to be improved regarding meetings about advance care planning?
   R. What is the role of the person with dementia and their informal caregivers?
10. Documenting decisions and updating the care plan
   A. Who makes notes during the meetings about advance care planning?
   B. Where are the advance care planning decisions documented?
   C. How are the perspectives of different disciplines integrated when making decisions about advance care planning?
   D. When are the decisions about advance care planning and the care plan updated?
11. Collaborating with informal caregivers of persons with dementia
   A. How do you take into account the opinions of informal caregivers when taking decisions about advance care planning?
   B. What are the advantages of collaboration with informal caregivers regarding advance care planning?
   C. What needs to be improved in collaboration with informal caregivers regarding advance care planning?

Dream and Design phase: Discussing initial results

3. Initial results
   F. What do you think about these themes?
   G. Would you add, remove or adjust any themes? Which ones and why?
4. Theme: Becoming aware in order to anticipate on the end of life together
   A. Category (topic): What would you add to the description of advance care planning?
   B. Category (shared aim): What is your vision and mission regarding advance care planning?
   C. Category (diverse roles): Which type of roles do you have within advance care planning?
5. Theme: Acting together to decide and anticipate the end of life
   A. Category (contacting others): Which disciplines approach you and how do they approach you and which disciplines do you approach or involve?
   B. Category (delivering and receiving input): How can you constructively provide input to other disciplines and how do you wish to receive input from other disciplines?
   C. Category (receiving consensus): How do you reach consensus?
   D. Category (documenting and transferring): How are agreements documented and transferred?

Destiny phase: Processing feedback and refining results

1. Theme 1. Shared awareness
   A. What do you think about the description and content of this theme? Would you add, remove or adjust anything? In case yes, please explain why.
2. Theme 2. Collaborative partners
   A. What do you think about the description and content of this theme? Would you add, remove or adjust anything? In case yes, please explain why.
3. Theme 3. Shared aim
   A. What do you think about the description and content of this theme? Would you add, remove or adjust anything? In case yes, please explain why.
4. Theme 4. Collaborative communication
   A. What do you think about the description and content of this theme? Would you add, remove or adjust anything? In case yes, please explain why.
5. Theme 5. Shared decision-making
   A. What do you think about the description and content of this theme? Would you add, remove or adjust anything? In case yes, please explain why.
6. Theme 6. Shared coordination
   A. What do you think about the description and content of this theme? Would you add, remove or adjust anything? In case yes, please explain why.
7. Theme 7. Looking back together
   A. What do you think about the description and content of this theme? Would you add, remove or adjust anything? In case yes, please explain why.

Supplement V: Coding tree

Themes	*Categories*	*Codes*
6. The meaning of advance care planning	1A. Removing the fog around palliative care	1A. I Dementia is a life-limiting disease
		1A. II Palliative care is not the same as end of life care
	1B. Clarifying the term advance care planning	1B. I Use one term
		1B. II Holistic care
7. The timing and continuity of advance care planning	2A. Conducing advance care planning in an early phase	2A. I Start in the home care setting
		2A. II Continue in the nursing home setting
	2B. Conducting personalized advance care planning conversations	2B. I The dynamic nature of advance care planning conversations
		2B. II Advance care planning is not a checklist task
		2B. III Acknowledging coping styles
8. Lacking information from the home care setting	3A. Acknowledging cognitive decline	3A. I The base from which to conduct follow-up advance care planning conversations
		3A. I The role of a healthcare professional is to collect information
	3B. Supporting informal caregivers	3B. I Prevents making unprepared acute decisions
		3B. II Prevents repeating information
9. Creating role clarity in advance care planning	4A. General roles	7A. I Conducting advance care planning conversations
		7A. II Involved in making decisions (except team leader)
	4B. Discipline-specific roles	7B. I Central coordinator and first contact person (nurses)
		7B. II Psycho-educator and supporter (psychologists)
		7B. III Head practitioner and referrer (physicians)
		7B. IV Facilitator and mediator (team leaders)
	4C. Creating a collaborative roadmap	7C. I First contact person should initiate advance care planning
		7C. II Physician should join second advance care planning conversation
		7C. III Other healthcare professionals should ascertain how they could contribute
10. Having shared visions	5A. Setting a base for everyone	6A. I Developing a vision and a mission
		6A. II Writing down values
		6A. III The role of team leaders
	5B. Working towards actions	6B. I Formulating objectives
		6B. II Formulating action points
11. Sharing perspectives & making shared decisions	6A. Having an equal say	8A. I The existence of a hierarchal structure
		8A. II Being proactive
		8A. III Handling conflicts
	6B. Having competencies	8B. I Having knowledge
		8B. II Being able to report objectively
	6C. Reaching consensus with all collaborators	4A. I Sharing information
		4A. II Understanding perspectives
		4A. III Transparent atmosphere
	6D. Building a relationship with informal caregivers	4B. I Providing general information about end-of-life
		4B. II Supporting informed shared decision-making

CONTINUED

Themes	*Categories*	*Codes*
12. From advance care planning information to actions	7A. Discontinuity of information transfer	5A. I A single nurse representative 5A. II Background information about the made decisions
	7B. Connecting with each other	5B. I Short communication lines 5B. II Taking individual responsibility 5B. III Shared digital systems
13. Having a facilitating organisation	8A. Having resources	9A. I Available advance care planning materials 9A. II Suitable digital systems
	8B. Receiving support	9B. I Improving advance care planning competencies 9B. II Specialists & steering groups 9B. III Securing advance care planning in practice 9B. IV Supporting advance care planning vision
14. Evaluating interprofessional collaboration and end-of-life	9A. Learning from experiences	10A. I Evaluating cases 10A. II Reflecting on collaboration
	9B. Asking informal caregivers	10B. Advance care planning and end-of-life care experience 10B. Role of informal caregivers in advance care planning

Supplement VI. Overview of the attendance of the participants

Participants	**Interprofessional focus group / interview**	**Unidisciplinary focus group / interview**	**Reflection meeting**
Participant 1. Registered nurse	*Focus Group 1*	*Focus group with nurses*	-
Participant 2. Psychologist	*Focus Group 1*	*Trio-interview with psychologists*	✓
Participant 3. Nurse specialist	*Focus Group 1*	*Trio-interview with elderly care physicians*	✓
Participant 4. Registered nurse	*Focus Group 1*	-	-
Participant 5. Certified nurse assistant	*Duo-interview*	*Focus group with nurses*	✓
Participant 6. Psychologist	*Duo-interview*	*Trio-interview with psychologists*	-
Participant 7. Nurse specialist	*Individual interview*	-	-
Participant 8. Team leader	*Individual interview*	-	-
Participant 9. Certified nurse assistant	*Focus Group 2*	*Focus group with nurses*	✓
Participant 10. Psychologist	*Focus Group 2*	*Trio-interview with psychologists*	-
Participant 11. Team leader	*Focus Group 2*	*Duo-interview with team leaders*	-
Participant 12. Quality nurse	*Focus Group 2*	*Focus group with nurses*	✓
Participant 13. Elderly care physician	*Individual interview*	-	-
Participant 14. Registered nurse	-	*Focus group with nurses*	-
Participant 15. Team leader	-	*Duo-interview with team leaders*	-
Participant 16. Elderly care physician	-	*Trio-interview with elderly care physicians*	-
Participant 17. Elderly care physician	-	*Trio-interview with elderly care physicians*	-
Participant 18. Teacher/Researcher	-	-	✓

Supplement VII. From shared vision to shared action points in interprofessional collaboration for advance care planning in dementia care

Working towards shared actions	Quote
Shared vision	*"We conduct collaborative advance care planning to improve the quality of life and end-of-life of persons with dementia."*
Shared mission	*"Our mission is to focus on the wellbeing and comfort of the person with dementia, and to achieve this through the joint involvement of the resident, family and diverse healthcare professionals in advance care planning."*
Shared core values	*"Paying attention to each other: We take time to listen to each other's needs and wishes, make contact with each other (verbally and non-verbally), express empathy for one another and discuss challenges regarding advance care planning."*
	"Treating each other equally: The person with dementia, informal caregivers and all involved healthcare professionals have an equal role in advance care planning."
	"Working together: We achieve agreements and make shared decisions together with the person with dementia, their family and involved healthcare professionals to provide person-centred care in advance care planning."
	"Having respect for each other: We honour everyone's worth, autonomy, expertise and talents. We respect the personal choices of the person with dementia and their informal caregivers regarding the last phase of life for the person with dementia."
	"Trusting each other: We are open towards each other, prepared to be dependent on the tasks, roles and actions of other collaborators to build on each other and be able to support each other and have each other's backs."
	"Reflecting on each other: We provide and receive constructive feedback to value, maintain and improve collaboration with each other."
Shared objectives	*"We support persons with dementia and their informal caregivers to integrate end-of-life in the context of their personal life."*
	"We stimulate the negotiability of advance care planning with the person with dementia and informal caregivers."
	"We conduct advance care planning conversations with the person with dementia and informal caregivers on a proactive and regular basis."
	"We pay attention to advance care planning and communicate as standard about formal and informal contact moments with the person with dementia and informal caregivers."
	"We ask each other about perspectives or explanations, and create a balance of advantages and disadvantages to make shared decisions regarding advance care planning."
	"We keep each other up to date with the advance care planning conversations conducted and changes that occurred in the care process."
	"We ensure that documents with wishes, needs, and decisions regarding advance care planning are easily accessible to all team members and simultaneously offer protection to guard personal information."
Shared action points	*"Advance care planning should become a standard agenda point in family, team and one-on-one meetings."*
	"Every healthcare professional should takes at least one course, workshop or training session regarding advance care planning."

Supplement VIII. Reflection meeting

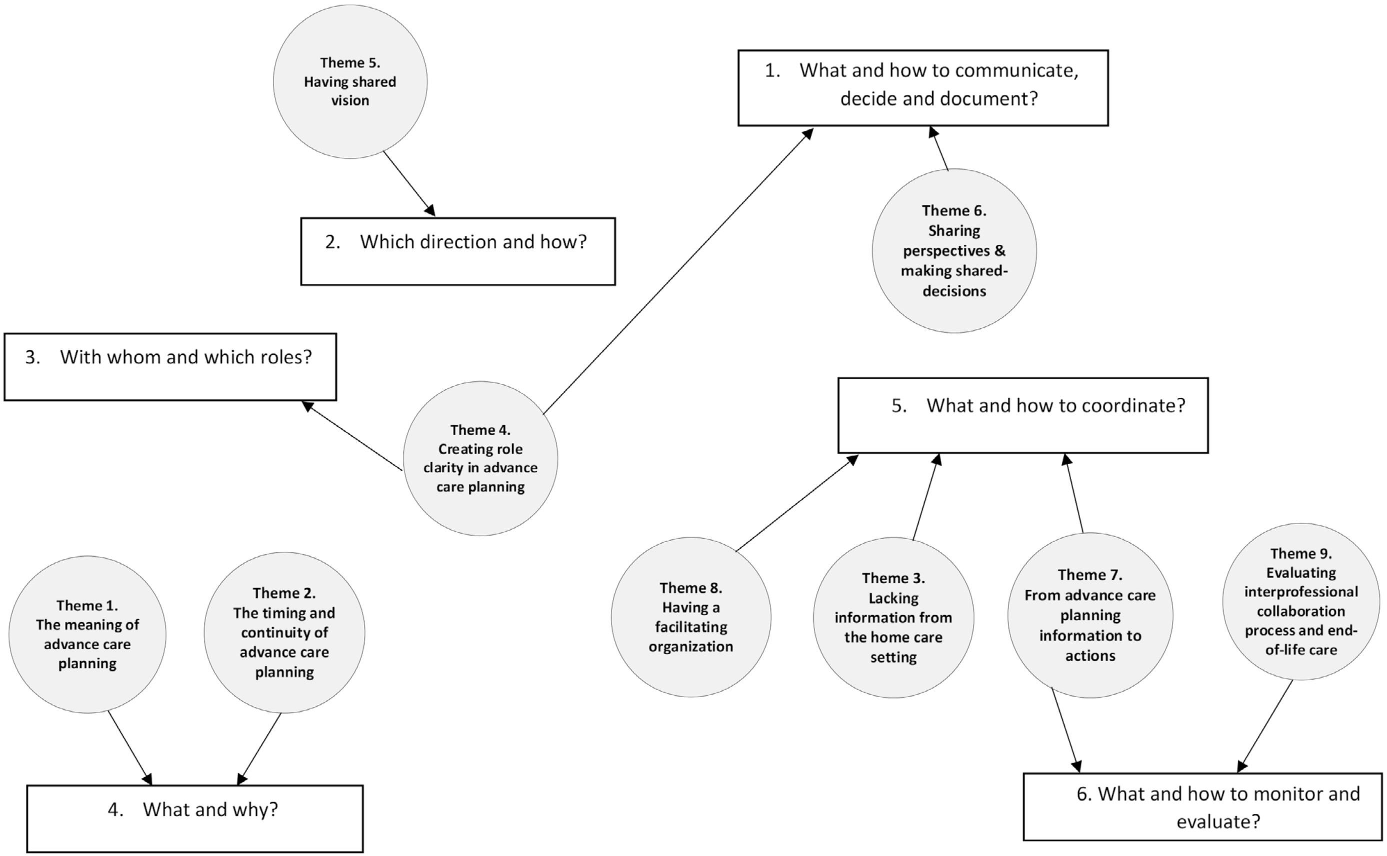
Prior to the reflection meeting

A first draft of the guidance document was developed based on the interviews and focus groups. This draft consisted of seven items: Collective Awareness, Collaborative Partners, Shared Goals, Collaborative Communication, Shared Decision-making, Collaborative Coordination, and Collaborative Reviewing. Every item included an introduction and existing practical tools for the individual healthcare professional, the entire care team, and persons with dementia and their informal caregivers. We also refined the difference between reflection and evaluation.

After the reflection meeting

The draft version was discussed with the participants, who indicated that overall the guidance document is valuable for increasing the overall awareness of interprofessional collaboration regarding advance care planning, and describes practical information. The participants suggested adding the following information: collaborative leadership, an ecogram showing all collaborative partners, information about the team roles (as described by Belbin), competencies required for interprofessional collaboration, practical information about bereavement care, and instruments with which to reflect and evaluate. Based on their feedback we adapted the seven items to six items and rephrased the items into main questions (Figure 3). Figure 3 provides a summary of the guidance document. Each of the main questions consists of sub-questions addressing the components of that topic. The definitive guidance document is provided in Supplement X.

Supplement IX. Relationship between themes of Step V and the main questions of the guidance document DEDICATED-collaborative approach for advance care planning in dementia care



Supplement X: Guidance document

DEDICATED collaboration in advance care planning

A guidance document for collaborating about the end-of-life for persons with dementia in the nursing home

Do I/we know…………..

DEDICATED
Desired dementia care towards end of life

INTRODUCTION

WHAT IS THIS GUIDANCE DOCUMENT ABOUT?

Dementia is an incurable disease with an uncertain prognosis and an average life expectancy ranging from 3 to 12 years[1]. It is therefore important to think about palliative care after a diagnosis of dementia. The goal of palliative care is to improve quality of life by preventing and alleviating suffering through the early identification, assessment and treatment of the needs or problems that may arise in the four different dimensions (physical, social, psychological and spiritual)[2]. Since palliative care looks at the person with dementia through this holistic view (i.e. the four dimensions), the collaboration between healthcare professionals (from various fields) themselves, but also with persons with dementia and their informal caregivers (i.e. partners, relations by marriage, family members, acquaintances, friends, local residents and/or volunteers) is important for maintaining and improving the quality of life of the person with dementia. We call this interprofessional collaboration.

Interprofessional collaboration in dementia care is important within care settings, but also during transitions between care settings[3]. Since approximately 90% of persons with dementia die in a nursing home[4], interprofessional collaboration in a nursing home is also important for the provision of optimal palliative care. Research also shows that persons with dementia live on average for 2.5 years in a nursing home[5]. In order to also provide optimal palliative care in the last phase of life (*which is part of palliative care and therefore does not equate to palliative care*), it is important to consider the wishes and preferences regarding the end of life of the person with dementia and his/her informal caregivers. Since dementia is characterised by cognitive decline, it is important as a healthcare professional to discuss the goals and wishes for future care at an early stage with the person with dementia and his or her informal caregivers. This process is called advance care planning[6].

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[1] Todd, S., Barr, S., Roberts, M., & Passmore, A. P. (2013). Survival in dementia and predictors of mortality: a review. *International journal of geriatric psychiatry*, *28*(11), 1109–1124. https://doi.org/10.1002/gps.3946

[2] World Health Organisation. WHO definition of palliative care. [cited 2016 April 09]. Available from: http://www.who.int/cancer/palliative/definition/en/.

[3] Bernstein Sideman, A., Harrison, K. L., Garrett, S. B., Naasan, G., & Ritchie, C. S. (2021). Practices, challenges, and opportunities when addressing the palliative care needs of people living with dementia: Specialty memory care provider perspectives. *Alzheimers Dement (N Y), 7*(1), e12144. doi:10.1002/trc2.12144

[4] Houttekier, D., Cohen, J., Bilsen, J., Addington-Hall, J., Onwuteaka-Philipsen, B. D., & Deliens, L. (2010). Place of death of older persons with dementia. A study in five European countries. *J Am Geriatr Soc, 58*(4), 751-756. doi:10.1111/j.1532-5415.2010.02771.x

[5] Joling, K. J., Janssen, O., Francke, A. L., Verheij, R. A., Lissenberg-Witte, B. I., Visser, P. J., & van Hout, H. P. J. (2020). Time from diagnosis to institutionalization and death in people with dementia. *Alzheimers Dement, 16*(4), 662-671. doi:10.1002/alz.12063

[6] Rietjens, Judith & Sudore, Rebecca & Deliens, Luc & Ott, Brenda & Connolly, Michael & Delden, Johannes & Korfage, Ida & Drickamer, Margaret & Heyland, D.K. & Houttekier, Dirk & Janssen, Daisy & Orsi, Luciano & Payne, Sheila & Seymour, Jane & Jox, Ralf. (2018). Internationale definitie van advance care planning. Huisarts en wetenschap. 61. 10.1007/s12445-018-0224-y.

Advance care planning is a joint process in which collaboration with the entire interprofessional team (*consisting of the person with dementia, his or her informal caregivers and involved healthcare professionals*) is central.

PURPOSE OF THIS GUIDANCE DOCUMENT

This guidance document outlines six key questions that are essential for, and provides information about interprofessional collaboration on advance care planning, describing tips/advice about how an individual healthcare professional and the interprofessional team can improve collaboration, and referring to existing resources/tools to improve interprofessional collaboration. Since the core questions are generally described, this process description may also be applied to other residents (residents without cognitive impairment or dementia) in the nursing home. Each core question is described at both individual and team level, and focuses on the strength and individual contribution that a healthcare professional can make to improve collaboration.

DEDICATED collaboration in advance care planning

Do I/ we know…………..

Core question 1.
Do I /we know what and why?

Below are three sub-questions:

Do I know/ Do we know………

2.1 Why palliative care is important?

2.2 Why advance care planning is important?

2.3 Why inter-professional collaboration is important?

1.1 DO I/WE KNOW WHY PALLIATIVE CARE IS IMPORTANT?

WHAT IS IMPORTANT TO KNOW?

Why is palliative care important for persons with dementia?

Dementia is a life-threatening and progressive disease for which there is no cure yet. Persons with dementia die from or due to dementia, and therefore, it is important to pay attention to their quality of life.

Which processes are important in order to provide optimal palliative care to persons with dementia?

1. Understanding how to apply palliative care for persons with dementia
2. Delivering person-centred care, communicating and joint decision-making
3. Determining care goals and implementing advance care planning
4. Maintaining continuity of care
5. Avoiding excessive invasion, and burdensome and futile actions
6. Providing optimal symptom management and comfort care
7. Providing psychosocial and spiritual support
8. Caring for and involving informal caregivers
9. Prognosis and timely recognition of the dying phase
10. Educating healthcare professionals
11. Taking into account social and ethical issues

The above processes are described in the European whitepaper on palliative care for persons with dementia[7].

What does quality of life mean for persons with dementia?

Quality of life is the subjective and objective assessment of various life domains of a person with dementia in their environment based on how they cope with the consequences of dementia[8].

Important domains of quality of life include feelings and mood, self-esteem/self-image, attachment, social contact, enjoying activities, relationships with healthcare professionals

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[7] van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., Francke, A. L., Jünger, S., Gove, D., Firth, P., Koopmans, R. T., Volicer, L., & European Association for Palliative Care (EAPC) (2014). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative medicine*, *28*(3), 197–209. https://doi.org/10.1177/0269216313493685

[8] Dröes, R.-M., Boelens-Van Der Knoop, E. C. C., Bos, J., Meihuizen, L., Ettema, T. P., Gerritsen, D. L., Hoogeveen, F., De Lange, J., & SchöLzel-Dorenbos, C. J. M. (2006). Quality of life in dementia in perspective: An explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia*, *5*(4), 533–558. https://doi.org/10.1177/1471301206069929

and informal caregivers, feeling at home, appreciating aesthetics in the living environment (such as enjoying beauty, nature and the environment), physical and mental health, financial situation, freedom, spirituality, security and privacy, and feeling useful.

With regard to quality of life, more emphasis will be placed on how persons with dementia experience their illness, how they adapt to the consequences of the illness (adaptation) and how they deal with stress caused by these consequences (coping), which psychosocial factors affect this and which psychosocial interventions healthcare professionals can offer to increase the well-being of persons with dementia. This person-centred approach looks at the person behind dementia, identifies unmet needs and takes into account the adjustment process as it affects the way the person with dementia expresses themselves, such as mood disorders.

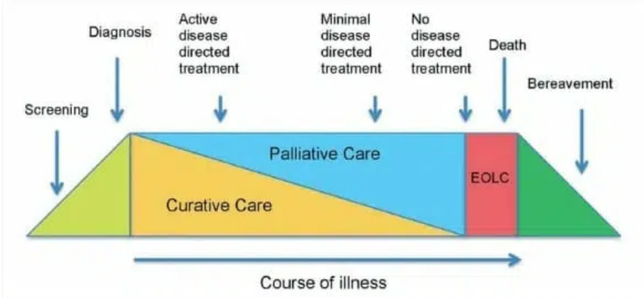
What does the adaptation- and coping process for persons with dementia entail?

There are seven points of attention to take into account as a healthcare professional during this process (see the figure below). Various **psychosocial interventions** have been developed to support persons with dementia during this process, such as reminiscence, snuggle and music therapy. For example, reminiscence (using stimuli such as photos, music, and retrieving beautiful memories) can reduce agitation and improve the mood.

When does palliative care start for persons with dementia?

The National Institute of Health and Clinical Excellence (NICE) and the European whitepaper (EAPC Whitepaper) on palliative care for persons with dementia advise to provide palliative care to persons with dementia immediately **after diagnosis**.

This figure is from the article *Coping with the consequences of dementia: the psychosocial perspective*.



This figure is from *Myatra et al. 2014*

What are the phases of palliative care?

Four phases can be distinguished within palliative care, the first two phases (disease-oriented and symptom-oriented palliation) of which can be intertwined and applied simultaneously to reinforce each other with the aim of improving the quality of life.

1. Disease-oriented palliation focuses on maintaining or improving quality of life by treating the underlying diseases. Life extension can be a goal if this is desirable for the person with dementia.
2. Symptom-oriented palliation focuses on maintaining or improving quality of life by alleviating, and if possible, preventing, the signs and symptoms caused by the underlying diseases.
3. The third phase is the **dying phase**/terminal phase where an irreversible physiological process has started and the person with dementia will die in the short term (three months or less).
4. The fourth phase is the aftercare phase, in which, after the death of the person with dementia, attention is paid to the grieving process of their informal caregivers.

WHAT TOOLS ARE THERE?

Before you take a look at the tools below, it is important to ask your colleagues or employer which existing tools are available or may already be used within your own organisation.

How can I, as an individual, increase ***my*** awareness and knowledge regarding palliative care in dementia?

- You can increase your own knowledge regarding palliative care for persons with dementia by using the following resources: Care for better, EAPC recommendations for palliative care in dementia, quality framework palliative care and Article on palliative care in dementia.
- You can increase your own knowledge on quality of life for persons with dementia by using the following information sources: article coping with the consequences of dementia: psychosocial perspective, A meaningful life in dementia and article Reminiscence approach improves quality of life of persons with dementia.

How can I, as an individual, contribute to the awareness of my ***colleagues*** regarding palliative care in dementia?

- You can talk to the team about palliative care for dementia by using the DEDICATED Chat-jar, palliative care and dementia cards and watching the DEDICATED Film I am a human, until the end.

How can I, as an individual, contribute to the awareness of the *person with dementia and his or her informal caregivers* regarding palliative care in dementia?

- You can refer the person with dementia and informal caregivers to the Life path to provide more information about the disease process.
- You can refer informal caregivers to the folder Coping with elderly persons with dementia, folder points of attention for informal caregivers of persons with dementia and advisory document A good life with dementia?! to provide more information about coping with persons with dementia.

1.2 DO I /WE KNOW WHY ADVANCE CARE PLANNING IS IMPORTANT?

WHAT IS IMPORTANT TO KNOW?

Why is advance care planning important for persons with dementia?

The course of dementia is unpredictable, often with alternations or declines in mental states and periods of lucidity. Many persons with dementia have no awareness of the disease at a later stage, find it difficult to look ahead, and can even deny their disease and its course. In addition to the decline in cognitive ability, persons with advanced dementia have difficulty communicating and expressing themselves[9]. End-of-life care is often sub-optimal for persons with dementia because, for example, they have to undergo unwanted interventions or invasive treatments[10], or because insufficient support is provided in the field of optimal pain management[11].

This is why it is important to start the conversation as early as possible. This conversation should preferably have already taken place in the home situation by the healthcare professionals involved. The care professionals in the nursing home can then build on the conversations that have taken place in the home situation to ensure the continuity of advance care planning. If there have been no discussions about this in the home situation, it is important to introduce this topic in a timely manner, because persons with dementia live in a nursing home for an average of 2.5 years. Conducting these conversations is also one of the preconditions for providing optimal care to residents in a nursing home. This is stated in the *Quality Framework for Nursing Home Care*[12].

Advantages of advance care planning
Increased advance care planning conversations
More persons with dementia receiving palliative care and pain relief
More concordance between the wishes and preferences, and care delivery in the last phase
Less unwanted care movements, use of intensive care, application of artificial feeding, use of ambulance et.
More satisfaction with the preferred place of death
More use of hospice, and a higher quality of life and death
Less depression in persons with dementia and their informal caregivers
More confidence, trust and stability in the choices made by persons with dementia and their informal caregivers

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[9] Z. V. Blasi, A. C. Hurley, and L. Volicer, "End-of-life care in dementia: a review of problems, prospects, and solutions in practice," *Journal of the American Medical Directors Association*, vol. 3, no. 2, pp. 57–65, 2002.

[10] Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life 2015. Available from https://www.nap.edu/ read/18748/chapter/1.

[11] Zwakhalen SMG, Koopmans RTC, Geels PJE, Berger MPF, Hamers JPH. The prevalence of pain in nursing home residents with dementia measured using an observational pain scale. Eur J Pain 2009;13:89e93.

[12] https://www.zorginzicht.nl/binaries/content/assets/zorginzicht/kwaliteitsinstrumenten/kwaliteitskader-verpleeghuiszorg---2021.pdf

Data from the table above is from the following resources:

- *Reinhardt, J. P., Chichin, E., Posner, L., & Kassabian, S. (2014). Vital Conversations with Family in the Nursing Home: Preparation for End-Stage Dementia Care. Journal of Social Work in End-of-Life & Palliative Care, 10(2), 112-126. doi:10.1080/15524256.2014.906371*
- *Wils, M., Verbakel, J., & Lisaerde, J. (2017). Improving advance care planning in patients with dementia: the effect of training nurses to engage in ACP-related conversations. Journal of Clinical Gerontology and Geriatrics, 8. doi:10.24816/jcgg.2017.v8i1.03*
- *Kelly, A. J., Luckett, T., Clayton, J. M., Gabb, L., Kochovska, S., & Agar, M. (2019). Advance care planning in different settings for persons with dementia: A systematic review and narrative synthesis. Palliative and Supportive Care, 17(6), 707-719. doi:10.1017/S1478951519000257*
- *Dael, A., Bunn, F., Lynch, J., Pivodic, L., Van den Block, L., & Goodman, C. (2020). Advance care planning for persons living with dementia: An umbrella review of effectiveness and experiences. Int J Nurs Stud, 107, 103576. doi:10.1016/j.ijnurstu.2020.103576*

What is advance care planning about?

- Dementia and health changes (communication and information needs regarding dementia and the prognosis)
- Care goals, palliative care and end-of-life wishes (communication and information needs regarding all health domains and the end of life)
- Decisions about treatments and care arrangements (desires regarding making decisions and ethical, financial and legal matters)
- Treatment and care in the most common situations (such as swallowing problems, pain and shortness of breath)
- Choice of place of care and change of environment (residence and care location and changes in the environment or in involved healthcare professionals)
- Attention to informal caregivers (collaborating with informal caregivers and supporting relatives)
- Medical treatments (such as resuscitation, admissions, operations, administration of antibiotics, transfusions, etc.)
- Active termination of life (such as euthanasia)
- Death phase (including palliative sedation, location of death, wake support and funeral wishes)
- Aftercare (supporting relatives during the grieving process)

The above substantive topics of advance care planning are from the discussion aid

The later phase of life in dementia. This discussion aid has been developed based on research[13].

What are points of attention in advance care planning?

- Advance care planning is not only about the person with dementia, but a system/group including the persons directly involved around the person with dementia: informal caregivers and healthcare professionals.
- The conversation is a dynamic and continuous process in which person-oriented care, the determination of needs, and retention of autonomy and control are central.
- The aim is not to tick off the discussion topics and identify outcomes/agreements made (such as whether or not to resuscitate) but to execute the conversation and explore the wishes.

WHAT AIDS ARE THERE?

Before you take a look at the tools below, it is important to ask your colleagues or employer which existing tools are already being used within your own organisation.

*How can I as an individual increase **my** awareness and knowledge of advance care planning?*

- You can increase your own knowledge of advance care planning for persons with dementia by using the following resources:
    - Guideline for careful end-of-life care, Concept framework for medically assisted dying, Guideline for concepts and due diligence requirements regarding decision-making on the end of life in nursing home care or Due diligence requirements in end-of-life care
    - Guideline incapacity in older clients with complex care needs
    - Film palliative sedation and Guideline sedation for refractory problem behaviour in dementia
    - Guideline ICD/pacemaker in the last phase of life
    - Dementia does not exclude talking about euthanasia, Guideline written euthanasia request public version and Guideline written euthanasia request doctor's version
    - Guidelines dementia care
    - Guideline aftercare conversation after death

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[13] Van der Steen, J. T., Heck, S., Juffermans, C. C., Garvelink, M. M., Achterberg, W. P., Clayton, J., . . . van der Linden, Y. M. (2021). Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: a mixed-methods evaluation study. *BMJ Open, 11*(4), e044591. doi:10.1136/bmjopen-2020-044591

How can I as an individual contribute to the awareness of my *colleagues* regarding advance care planning?

- You can talk to the team about the end of life by using the DEDICATED Chat jar cards end-of-life.
- You can talk to the team about cases of persons with dementia in the last phase of life, which symptoms were common, was attention paid to for the final phase, how and what could we do differently next time. You can use the DEDICATED case discussion.

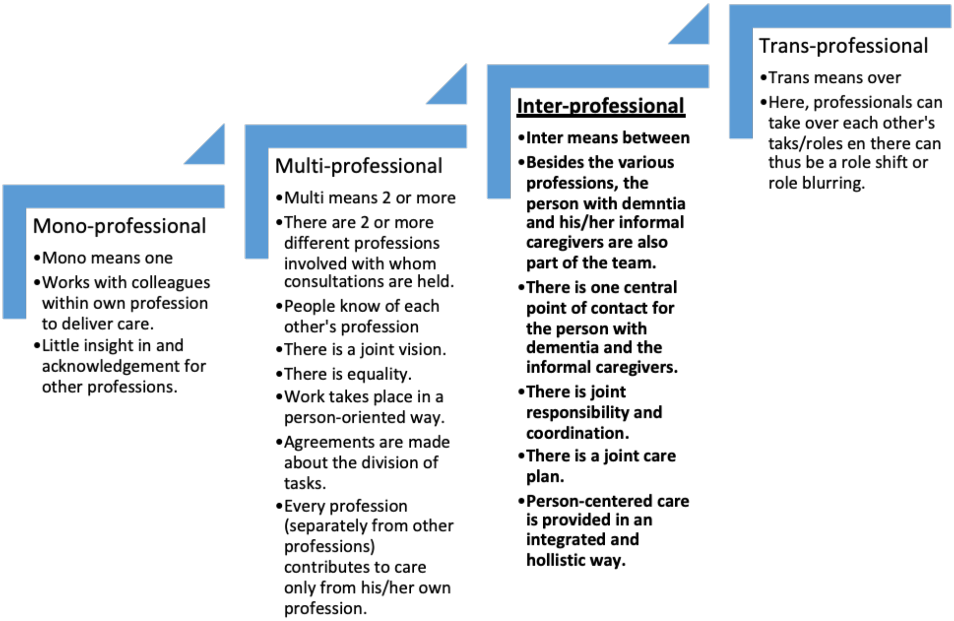
How can I as an individual contribute to the awareness of the *person with dementia and his or her informal caregivers* regarding advance care planning?

- You can refer the person with dementia and their informal caregivers to the brochure Discuss the end of life in time, information folder from Envida (*produced by Maastricht UMC+, Envida, Zio and Network palliative care Heuvelland)*, discussion aid The later phase of life in dementia or Guideline End-of-life care to provide more information on advance care planning in dementia.

1.3 DO I/WE KNOW WHY INTERPROFESSIONAL COLLABORATION IS IMPORTANT?

WHAT IS IMPORTANT TO KNOW?

What is the difference between ‘mono-, multi-, inter- or transprofessional collaboration’?
From DEDICATED we focus on **interprofessional** collaboration.



Mono-professional

- Mono means one
- Works with colleagues within own profession to deliver care.
- Little insight in and acknowledgement for other professions.

Multi-professional

- Multi means 2 or more
- There are 2 or more different professions involved with whom consultations are held.
- People know of each other's profession
- There is a joint vision.
- There is equality.
- Work takes place in a person-oriented way.
- Agreements are made about the division of tasks.
- Every profession (separately from other professions) contributes to care only from his/her own profession.

Inter-professional

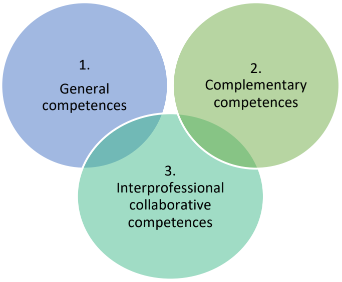
- **Inter means between**
- **Besides the various professions, the person with demntia and his/her informal caregivers are also part of the team.**
- **There is one central point of contact for the person with dementia and the informal caregivers.**
- **There is joint responsibility and coordination.**
- **There is a joint care plan.**
- **Person-centered care is provided in an integrated and hollistic way.**

Trans-professional

- Trans means over
- Here, professionals can take over each other's taks/roles en there can thus be a role shift or role blurring.

Which competences are important in interprofessional collaboration?

A competence is the ability of a healthcare professional to integrate various components including knowledge, skills, values and attitudes. There are three types of competences[14].



Competences that apply to healthcare professionals

Competences that differ between various healthcare professionals and are therefore complementary (additional) to the competences of other healthcare professionals

Competences that apply to all healthcare professionals in the collaboration with each other, but also with the person with dementia, informal caregivers and others within and outside the care organisation or care setting.

What interprofessional collaboration competences are there?

The figure below describes five competence domains that are important in interprofessional collaboration[15].

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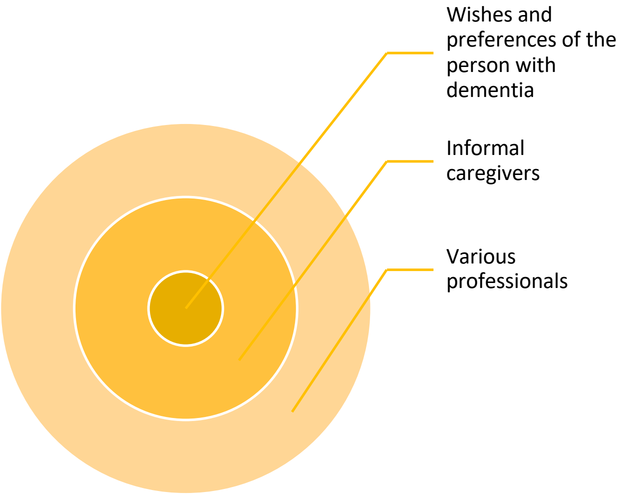
[14] Interprofessional Education Collaborative Expert Panel. (2011). *Core competencies for interprofessional collaborative practice: Report of an expert panel.* Washington, D.C.: Interprofessional Education Collaborative.

[15] Vyt A. *Interprofessioneel En Interdisciplinair Samenwerken in Gezondheid En Welzijn*. Vierde, herziene en uitgebreide druk ed. Antwerpen: Garant; 2017.

Consult and plan together	Involve and stimulate colleagues	Communicate and inform	Learn and reflect	Act purposefully and tactfully
• Formulate responsible and concrete goals from your own profession that are understood by colleagues. • Estimating the contribution a colleague from another profession can make • Collaborate in a constructive way • Selecting and organizing relevant information/data of the person with dementia for colleagues • Making effective use of existing information systems • Present your own point of view in a clear and nuanced manner in consultation situations with several colleagues.	• Adequate and clear informing of colleagues • Spontaneously appeal to the right college from other profession • Stimulate and strengthen consultations with colleagues and their returns • Expressing own ideas clearly and asking colleagues for clarification when something is not clear. • Appreciate, encourage and strengthen input from colleagues • Provide useful and respectful feedback	• Being able to pass on/present relevant information/data correctly and in a structured way to colleagues orally, in writing and digitally • Be able to convert technical jargon into understandable and accessible language • Be able to use the Dutch language correctly in writing and orally • Communicate flexibly and adequately, taking into account the interlocutors • Being able to reflect on own communication and adjust it if necessary	• Recognise and use learning moments with the aim of strengthening own collaboration competences • Actively looking for missing knowledge or information • Asking for targeted feedback from others • Being able to deal with feedback on own behaviour and results • Dare to question oneself and put one's own ideas into perspective • Being able to critically question and assess opinions and claims	• Show respect for other team members and for the individuality of other professions • Exercise tact and caution in dealing with others and in formulating/drawing conclusions and advice • Being able to speak openly and positively about other professionals when in contact with a person with dementia and their informal caregivers • Action-oriented tackling or avoiding problems • Honour existing commitments • Execute assignments on time and in a quality-conscious way

Why is interprofessional collaboration important?



Advantages of interprofessional collaboration
Improved effective communication
Increased knowledge, acknowledgement and use each other profession
Improved quality, continuity and coordination of care
Improved task division
Improved work satisfaction
Decreased burnout and stress

Each involved healthcare professional sees the relationship type and contact moments with the person with dementia and his or her informal caregivers from their own experience, and looks at the person with dementia and his or her informal caregivers according to his or her own profession. It is therefore essential that all relevant healthcare professionals are involved in joint decision-making. Informal caregivers look at the person with dementia from their own experience (depending on the relationship type, and length and involvement in the care process), but also have information/knowledge about them that helps healthcare professionals to provide person-oriented care.

Involving the person with dementia is extremely important for maintaining autonomy and stimulating self-control. If the person with dementia has been declared incompetent, this does not mean that the person with dementia is incompetent for all types of decisions. It is important for any type of decision to consider whether the person with dementia has the capacity to make decisions and whether he or she wants to be involved in making decisions. More information about the types of decisions and levels of involvement is described in Core Process 5. Shared decision-making.

WHAT AIDS ARE THERE?

Before you take a look at the tools below, it is important to ask your colleagues or employer which existing tools are already being used within your own organisation.

How can I as an individual increase *my* awareness and knowledge of interprofessional collaboration?

- You can increase your own knowledge of interprofessional collaboration by using the following resources: Film of Zuyd, Best practices interprofessional collaboration, T-shaped professional, File interprofessional collaboration, Cross-border collaboration and Palliaweb.
- You can increase your own knowledge of various (mono-disciplinary, multi-disciplinary, inter-disciplinary and interprofessional) aspects of collaboration by reading page 292 of the article inter-disciplinary consultation: Is there a need for education on “collaboration”?
- You can increase your own knowledge of interprofessional competences by reading page 105 of the article interprofessional and inter-disciplinary collaboration in Heliomare, page 684 of the article interprofessional collaboration: the key to better oral care for (vulnerable) elderly, EIPEN behavioural indicators and the film about team competences of the Erasmus MC.

How can I as an individual increase *my* awareness and knowledge regarding the collaboration needs of persons with dementia and informal caregivers?

- You can increase your own knowledge of collaborating with persons with dementia by using the following resources: DEDICATED-public summary of the needs of persons with dementia in collaboration with healthcare professionals, Guideline photovoice, information book about dementia and control and the website Care for better about Dementia and meaning.
- You can increase your own knowledge of general collaboration regarding the needs of informal caregivers by using the following resources: DEDICATED-public summary about the needs of informal caregivers in collaboration with healthcare professionals, Toolkit family participation, the workbook In for informal care or the toolkit Collaborating with informal caregivers: this is how it works!.

How can I as an individual contribute to the awareness of my *colleagues* regarding interprofessional collaboration?

- You can talk with the team about interprofessional collaboration by using the DEDICATED Chat jar cards collaborating.

Core question 2. Do I/we know with whom and which roles?

Below are three sub-questions:

Do I/we know………

2.1 Who the team members are?

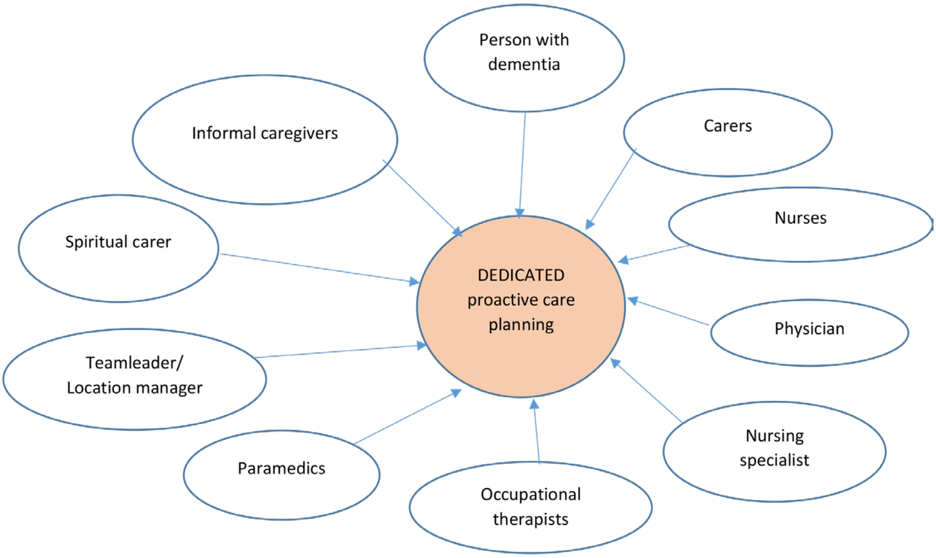
2.2 What substantive roles the team members have?

2.3 What characteristics the team members have?

2.1 DO I/WE KNOW WHO THE TEAM MEMBERS ARE?

The figure below is an example of a collaboration ecogram that provides an overview of who the collaboration partners are in advance care planning. The collaboration ecogram below is based on research into parties involved in advance care planning[16,17].

Collaboration ecogram



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[16] Kwak, J., Jamal, A., Jones, B., Timmerman, G. M., Hughes, B., & Fry, L. (2021). An Interprofessional Approach to Advance Care Planning. *American Journal of Hospice and Palliative Medicine®*. https://doi.org/10.1177/10499091211019316

[17] Arnett, K., Sudore, R. L., Nowels, D., Feng, C. X., Levy, C. R., & Lum, H. D. (2017). Advance Care Planning: Understanding Clinical Routines and Experiences of Interprofessional Team Members in Diverse Health Care Settings. *The American journal of hospice & palliative care*, *34*(10), 946–953. https://doi.org/10.1177/1049909116666358

2.2 DO I/WE KNOW WHAT SUBSTANTIVE ROLES THE TEAM MEMBERS HAVE?

In the tables below, a number of core roles are described as examples of each collaboration partner. Each collaboration partner must first check for themselves whether they actually undertake these roles and whether they are missing roles. It is also important to indicate what their limits are in order to make clear what is not their responsibility.

Persons with dementia

Roles	Role description
Care recipient	The person with dementia receives care and has wishes and preferences in daily life.
Director	The person with dementia finds it important to live their own life as much as possible, to feel proud, to have self-esteem, to value themselves, to feel useful, to have meaning in their life, and to maintain a feeling of equality. The person with dementia retains meaning and autonomy through their contacts or relationships, the activities they can still perform or participate in, and the decisions they can still make themselves.
Represented	The person with dementia trusts that their informal caregivers and the care professionals involved will jointly ensure that they receive optimal quality care.
Life philosopher	The person with dementia has their own expectations, thoughts and feelings about life and the future. The person with dementia may have cultural, spiritual and/or religious expressions.

Informal caregivers

Roles	Role description
Information seeker	The informal caregivers would like to receive information from healthcare professionals (about, for example, the health situation, dementia, palliative care and changes that occur in the medication provision, treatments or in the care process).
Personal expert (information sender)	The informal caregivers know the person with dementia best and want to communicate the personal preferences (for all four dimensions) of the person with dementia to the care professionals regarding how they can offer tailor-made care to and how to optimally cope with the person with dementia.
Informal caregiver	The informal caregivers may still wish to play a role in the nursing home as informal caregivers in providing personal care, practical help or emotional support.
Representative	The informal caregivers represent the wishes and preferences of the person with dementia as care recipient.
Monitor	The informal caregivers have a helicopter view of the person with dementia. They may sometimes notice or see changes that healthcare professionals have not identified and/or responded to.
Coordinator	Some informal caregivers are forced to repeat information or actively contact healthcare professionals and pass on information (if healthcare professionals do not communicate with each other or do not communicate sufficiently) in order to guarantee continuity of care.
Care inquirer	Healthcare professionals should routinely ask informal caregivers if they need support to, for example, be able to perform their role properly, to be guided in making decisions about advance care planning, etc.

Carers and nurses

Roles	Role description
Primary care provider	Carers and nurses are closest to the person with dementia because them every day and provide direct care (at bedside). Carers and nurses record and interpret the patient's symptoms and reactions. Carers and nurses implement care plans, evaluate them together with the practitioners, and, if necessary, give suggestions to adjust, improve or steer these plans. Depending on the level, carry out procedures and actions (such as measuring blood pressure)
Central point of contact	Carers and nurses are the first point of contact for the person with dementia and their informal caregivers. They are also the care professionals who carry out home visits and/or are present on the day of the move, have direct contact with the first contact person from the home setting and support the person with dementia and informal caregivers with early care plans.
Monitor	Carers and nurses have a helicopter view of the person with dementia and their informal caregivers, and can see changes earlier/faster than other healthcare professionals. They also pass on the signals to the other healthcare professionals.
Linchpin	Carers and nurses are in direct contact with the person with dementia and their informal caregivers such as the care professionals involved (care team employees and therapists). They propose agenda items for the consultations and visits, approach other healthcare professionals and provide feedback to other healthcare professionals about the state of affairs (for example, how the care is progressing) and the wishes of the person with dementia and informal caregivers and/or informal care givers.
Information provider	Caregivers and nurses can provide basic information about advance care planning and written statements in plain language.
Moderator	Carers and nurses conduct conversations about advance care planning with the person with dementia and their informal caregivers. They are usually the initiators of advance care planning conversations, because they are close to the person with dementia, informal caregivers and often also signal the first changes. They also perform expectation management and continue to tailor the conversations (when there is a need and the opportunity arises).
Facilitator/Supporter	Carers and nurses facilitate the person with dementia, informal caregivers during the transition process from curative to palliative perspective
Co-decision maker	Caregivers and nurses have a say in joint decision-making, not only because they are healthcare professionals, but also because they have an important role as advocates.

Team leaders/Location managers

Roles	**Role description**
Deployable conversationalist	Team leaders can conduct conversations about advance care planning if the care team itself requests this (for example, because it concerns complex situations) or because this is requested by the person with dementia and his or her informal caregivers.
Coach	Team leaders guide the care team and discuss challenges encountered by the care team.
Facilitator	Team leaders facilitate the collaboration between the care team and the practitioners by creating preconditions such as ensuring that there is a platform for all collaborating partners to enter into discussions with each other (e.g. interprofessional team meetings), making technology available that can support the consultations (e.g. Microsoft Teams, when it comes to digital consultations), and ensuring that there are workable and safe files. Team leaders have an important role in creating unity by ensuring that all collaborating partners are facing the same direction. They can play a leading role in setting a common goal.
Mediator	Team leaders mediate in situations where collaborating partners do not understand each other, consensus is not reached or there are conflicts. The task of the team leader is then to discuss the problem.
Monitor	Team leaders monitor the collaboration process between the collaborating partners.
Coordinator	Team leaders have an overview of who has which task, and whether clear work agreements have been made and monitor the progress of the care process.

Allied healthcare professionals

For this process description only the roles of the psychologist have been described as a paramedic, but other paramedics including occupational therapists, speech therapists and physiotherapists have equally important roles. We advise these other paramedics to write down their roles and to discuss this with the healthcare professionals involved in order to create clarity in what they do and to coordinate it with each other.

Roles	**Role description**
Conversationalist	Psychologists conduct conversations about advance care planning with the person with dementia informal caregivers. They also perform expectation management.
Practitioner	Psychologists analyse behaviour, make diagnoses, perform heterogeneous anamneses, play a role in psychological complaints, mood, behavioural and cognition disorders (such as depression) and end-of-life (for example, they can also play a role in terminal restlessness) and draw up treatment plans (whereby psychological interventions/ methods are prepared, described (giving instructions and coping advice to the care team) and evaluated. Psychologists treat the person with dementia by responding to their life history and underlying needs and in this way offer person-oriented care. Psychologists provide information and education about psychological symptoms to informal caregivers and other healthcare professionals about how best to deal with the person with dementia. Psychologists support the person with dementia and their informal caregivers in informing them about advance care planning, thinking about it and making this subject a topic for discussion. Psychologists support informal caregivers by giving advice and tips on how best to approach and interact with the person with dementia.
Coach	Psychologists guide the care team in coping with pain and misunderstood behaviour and regularly discuss with the care team how they are doing, what behavioural symptoms are affecting the team, and how the care team (mostly nurses) could cope with the persons with dementia. Psychologists can also support healthcare professionals determining whether the chosen ward is the most appropriate place for the person with dementia (involvement differs per case).
Co-decision maker	Psychologists have a say in joint decision-making.

Physicians

Roles	Role dexcription
Director/Head Practitioner	Physicians analyse the person with dementia as a whole (all four dimensions), make diagnoses, perform heterogeneous anamneses, discuss options for end-of-life medical treatments, and draw up treatment plans (prescribing medication or preparing interventions, describing (giving instructions and advice to the healthcare team) and evaluate the medication and the advice and/or instructions given.
Referrer	Physicians play an important role in involving other disciplines such as spiritual counsellors or specialist therapists. In some healthcare organisations, the referral from the doctor is required to switch to another discipline.
Conversationalist	Physicians conduct conversations about advance care planning with the person with dementia and their informal caregivers. They also perform expectation management and discuss medical policy.
Co-decision maker	Doctors have a say in joint decision-making and bear ultimate responsibility.

Spiritual Caregiver

Roles	Role description
Guide	Spiritual caregivers guide and provide support to persons with dementia and their informal caregivers. They focus on questions about illness, health, life, death and coping with the situation.
Conversationalist	Physicians conduct discussions about advance care planning with the person with dementia and his or her informal caregivers. The focus is on the life questions, life events, existential, cultural and religious aspects of advance care planning.
Organiser activities	Spiritual caregivers can ensure that persons with dementia can participate in activities such as church services, group discussions, meditation and reflection meetings. They can also perform rituals (depending on religion) such as the anointing of the sick.
Co-decision maker	Spiritual caregivers have a say in joint decision-making.

Occupational therapists

This role description is a general description for all occupational therapists. The term occupational therapists includes music therapists, drama therapists, psychomotor therapists and art therapists. We advise every occupational therapist to write down their specific roles and to discuss this with the involved healthcare professionals in order to create clarity about what they do, and to coordinate it with each other.

Roles	Role description
Therapist	Occupational therapists help the person with dementia to process experiences, improve communication skills or express emotions and thoughts. They make observations and draw up a treatment plan (they also evaluate this).
Conversationalist	Occupational therapists conduct conversations about advance care planning with the person with dementia and their informal caregivers.
Activities organiser	Occupational therapists treat the person with dementia by means of creative therapy or psychomotor therapy, where they can organise activities, exercises or assignments connected with dance, music and drama, or that are visual in nature.

2.3 DO I/WE KNOW WHAT CHARACTERISTICS THE TEAM MEMBERS HAVE?

TEAM ROLES

In addition to the substantive roles that healthcare professionals play as a proactive care planners, they also have team roles. A team role is a combination of behaviours/ expressions that can be both task-oriented and relationship-oriented. Task-oriented means efficiently completing a task, such as clarifying everyone's role and formulating sub-tasks for everyone. Relationship-oriented has to do with contributing to a positive group feeling, team orientation and cooperative behaviour by, for example, adopting an attitude of active participation and listening attentively to everyone. Belbin is a method that describes nine diverse team roles that are necessary for the effectiveness and mutual dynamics of the team[18,19]. It is notiable here that you do not necessarily need to have one role, you can exercise several roles and make the division for yourself in terms of the main role (primary role) and supporting roles (secondary role, tertiary role, etc.).

Belbin team roles	Kind of role	Team role contribution
Plant	Thinker	Creative, great imagination, unorthodox. Comes with new perspectives. Solves difficult problems.
Source researcher	Person-oriented	Extroverted, enthusiastic, communicative. Explores new possibilities. Makes contacts.
Chair	Person-oriented	High self-confidence, clarifies objectives, accelerates decision-making, is good at delegating. Brings the team together and coordinates.
Shaper	Doer	Challenging, dynamic, functions best under pressure. Driven and courageous to overcome challenges.
Monitor	Thinker	Strategic insight, good discernment, sees all options. Sharp judgment, takes an overview and offers balance.
Group worker	Person-oriented	Cooperative, mild, observant, diplomatic, listens, is constructive, prevents friction, calms, supports and contributes to the team atmosphere.
Business person	Doer	Disciplined, reliable, conservative, efficient, translate ideas and plans into practical actions, task-oriented.
Caretaker	Doer	Critical, precise, alert to mistakes, vigilant, gets things done on time.
Specialist	Thinker	Purposeful, initiative-rich, committed, provides knowledge and skills.

How can I, as an individual healthcare professional, visualise the collaboration partners?

How can I, as an individual, clarify ***my own roles*** *in advance care planning?*

1. It is important to realise that, as a healthcare professional, you fulfil various roles. This is explained, for example, in the CANMED model, a system that describes seven

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[18] Tsakitzidis, G., & Royen, P. V. (2015). *Leren interprofessioneel samenwerken in de gezondheidszorg* (3e druk). De Boeck.

[19] West, M. A. (1994). *Effective teamwork: Practical lessons from organisational research.* Blackwell Publishing.

different roles on the basis of seven competencies. For more information on the CANMED model: CanMEDs-roles in the practice of elderly care, CanMEDS roles and the most important points of action per role, CanMeds roles for doctors, CanMeds roles for nurses, Hanze University of Applied Sciences Groningen, Guideline CanMEDS-roles, CanMEDS-roles and octogram and Guideline CanMEDS-roles in the practice of elderly care.

2. Define your own roles as a healthcare professional in advance care planning.
    - For more information on the roles of helpers: CanMEDs-roles in the practice of elderly care, Network palliative care Zuid Gelderland and Educational framework for palliative care 2.0 (O^2PZ).
    - For more information on the roles of carers: CanMEDs-roles in the practice of elderly care.
    - For more information on the roles of nurses: article from magazine gerontology an geriatrics, article responsibilities of the nurse and the film from Avans university of applied sciences.
    - For more information on the roles of psychologists in behavioural problems: *Guideline Dutch Institute for psychologists*
    - For more information on the roles of doctors: *Aids for competence descriptions for elementary physicians and medical specialists.*
    - For more information on the roles of spiritual caretakers: Association of spiritual caregivers and the article powerlessness at the end of life.
    - For more information on the roles of a paramedic, specifically aimed at the kinesitherapists): Networks Palliative Care East-Vlaanderen
    - For more information on occupational therapists: Professional competence profile and GGZ standards.

How can I, as an individual, clarify ***my own roles*** *as a team player?*

1. You can increase your own knowledge of the Belbin roles by using the following resources: the article The Team role game and overview roles.
2. You can do a test yourself to identify which role or roles you have: https://axisconsultancy.org/talentrijke-test/

How can I, as an individual, ***visualise the roles of the involved healthcare professionals*** *regarding advance care planning?*

1. You can create a collaboration ecogram with the team and discuss the role descriptions of each collaboration partner. You can use the DEDICATED collaboration ecogram for this.
2. You can talk to the team about cases of persons with dementia in the last phase of life and which care professional had which roles. For this, you can use the CanMEDS

game form.

3. You can use page 39 of the team development workbook to talk with all involved healthcare professionals about the tasks and work on advance care planning.
4. You can play the team game with your team.

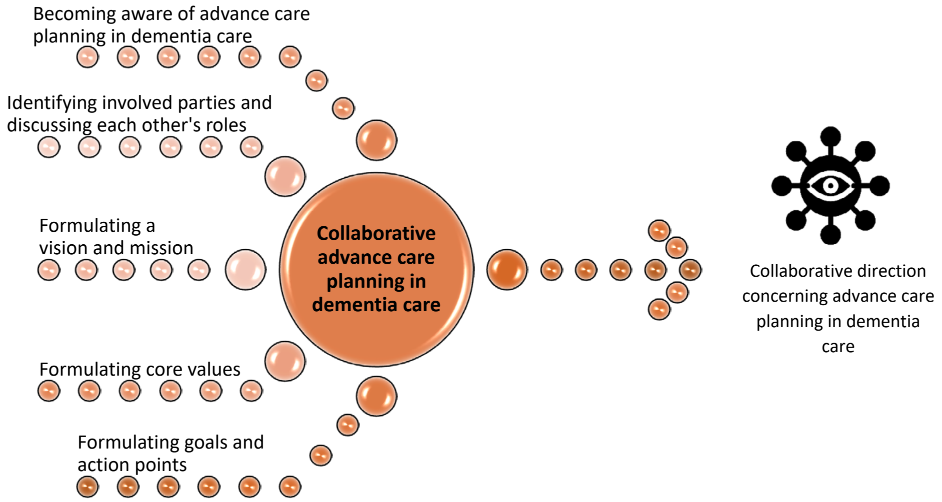
How can I, as an individual, contribute to clarifying the role of the ***person with dementia and his or her informal caregivers*** *regarding advance care planning?*

1. You can increase your own knowledge on working with persons with dementia by using the DEDICATED public summary of the needs of persons with dementia in collaboration with healthcare professionals (appendix), information book about dementia and control and the website Care for better about Dementia and meaning. You can then start a conversation with the person with dementia. The core element Communicating and documenting together refers to communication tools for the conduct of conversations.
2. You can increase your own knowledge on the general collaborative needs of informal caregivers by using existing literature such as the DEDICATED public summary on the needs of informal caregivers in collaboration with healthcare professionals and by using existing tools to improve collaboration with informal caregivers, such as the workbook In for Informal care or the toolkit Collaborating with informal caregivers: this is how it works!. You can then start a conversation with the informal caregivers, using the DEDICATED-conversation aid collaborating with informal caregivers.

Core question 3. Do I / we know which direction and how?

Why is it important to have a shared direction in advance care planning?
‘Teamwork (collaboration between different partners) is important because more can be achieved together than if individuals worked alone or in parallel.’ One of the most important components of team effectiveness is having a common direction (all facing the same direction or with the same glasses on). This is important because it is then clear to everyone what they are all working towards, why they are doing it and what they need in order to do it.

Which steps are important in order to face the same direction in advance care planning?



The above steps are based on an article about team vision[20].

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20 West, Michael A. and Unsworth, Kerrie L. (1998) Developing A Team Vision, in Parker, Glenn M., Eds. Handbook of Best Practices for Teams (Vol 2), chapter 25, pages pp. 295-310. HRD Press.

Below are three sub-questions:

Do I/we know………

3.1

Why a joint vision and mission are important?

3.2

Why joint core values are important?

3.3

Why joint goals and points of action are important?

3.1 DO I / WE KNOW WHY A JOINT VISION AND MISSION ARE IMPORTANT?

Drawing up a common goal starts with awareness about the subject for which a common goal must be set (in this guidance document the common goal is about collaboration regarding advance care planning in dementia). It is then important to work towards this joint direction with all parties involved (care professionals, residents and informal caregivers). This takes place according to five core steps (vision, mission, core values, objectives and action points).

JOINT VISION

- What is a vision?
  - Future dream/wish of the person with dementia, informal caregivers and involved core care professionals regarding advance care planning.
- What are the conditions for developing a vision?
  - Clarity
    - Avoid the use of jargon and use unambiguous words to express the shared values, interests and motivations as clearly as possible.
  - Motivating values
    - Recognising the added value of drawing up a common goal
  - Feasibility
    - Map impeding factors to achieve the vision and formulate a realistic vision
  - Togetherness
    - Develop the vision first with the healthcare professionals involved and then discuss the developed vision with policy/management. Then present this to the person with dementia and informal caregivers to take into account their perspective and wishes.
  - Adaptability
    - Collaboration evolves, organisational strategies change and the practice environment changes over time. For this reason, it is important to also review the vision regularly and adjust it if necessary.
- Which elements are important to work with and/or take into account in the vision?
  - Consistent with organisational goals
  - Taking into account the needs of the person with dementia and informal caregivers
  - Emphasis on quality of care and functioning within the team
  - Thinking about the added value for persons with dementia and their informal caregivers
  - Thinking about the team climate and interpersonal relationships
  - Taking into account the growth and well-being of the team members

- What is an example of a vision for advance care planning?
    - *We conduct joint advance care planning to improve the quality of life and the end of life of the person with dementia.*

JOINT MISSION

- What is a mission?
    - Right to exist
    - The way to achieve a vision
    - What the team stands for, what the team does in daily practice and the added value the that team has.
- What is an example mission in advance care planning?
    - *Our mission is to focus on the well-being and comfort of the person with dementia and to achieve this together with the resident, informal caregivers and various healthcare professionals.*

3.2 DO I / WE KNOW WHY JOINT CORE VALUES ARE IMPORTANT?

JOINT CORE VALUES

- What are core values?
  - Values needed to realise a mission and vision, consisting of the beliefs, behavioural provisions, norms, values and competences of the team members.
- What is an example of a core value in advance care planning?
  - *Attention: We take time to listen to each other's wishes and needs, make contact with each other (verbal and non-verbal) and show empathy about how everyone feels and talk about challenges.*
  - *Equitable: The person with dementia, his or her informal caregivers and all healthcare professionals involved play an equal role.*
  - *Collaboration: We achieve coordination and joint decision-making together with residents, informal caregivers and various healthcare professionals to provide person-oriented care.*
  - *Respect: We respect everyone's value and individuality, expertise and talents. We respect the personal choice(s) of the person with dementia and their informal caregivers for the last part of the person with dementia's life.*
  - *Trust: We are open to each other, are willing to depend on the deeds, roles, tasks or/and actions of everyone in order to build on each other, and can support and lean on each other.*
  - *Reflect: We give and receive constructive feedback to value and possibly improve the collaboration with each other.*

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3.3 DO I / WE KNOW WHY JOINT GOALS AND POINTS OF ACTION ARE IMPORTANT?

JOINT GOALS

- What are goals?
    - What you want to achieve together as a team.
    - Goals must be clearly formulated, and measurable.
- What is an example of a goal in advance care planning?
    - *We help persons with dementia and their informal caregivers to integrate the end of life into the context of their personal life.*
    - *We promote discussion of advance care planning within the circle of informal caregivers.*
    - *We conduct early discussions about advance care planning with the person with dementia and their informal caregivers.*
    - *We pay attention to advance care planning and discuss it as standard during formal and informal contact moments with the person with dementia and their informal caregivers.*
    - *We ask for each other's perspective/explanation and balance the pros and cons to make joint decisions about advance care planning.*
    - *We keep each other informed about conversations regarding advance care planning and changes that occur.*
    - *We record information about advance care planning in such a way that it is easy for the entire team to find, and at the same time protects personal data.*

JOINT ACTION POINTS

- What are action points?
    - The way and working method in which you want to achieve the goals as a team.
    - When drawing up action points, you determine what you will do as a team, how you will do it, which success factors are important (aspects you need to follow an approach), which scenarios can be planned, which options/possibilities exist, and what measures can be taken.
- What is an example of an action point in advance care planning?
    - *Advance care planning becomes a standard agenda item during family meetings and consultations.*
    - *Every healthcare professional should have completed at least one course/workshop/training session on advance care planning.*

HOW CAN I, AS AN INDIVIDUAL HEALTHCARE PROFESSIONAL, CONTRIBUTE TO THE CREATION OF A JOINT DIRECTION?

How can I, as an individual, increase ***my*** awareness about creating a common direction?

1. You can increase your own understanding of having a common direction by looking at the GRPI model in the following information resource: Toolshero
2. You can increase your own knowledge by understanding what the terms “vision”, “mission” and “goals” mean by using the following information resources: Film of University of Applied sciences Windesheim Flevoland and knowledge domain

How can I, as an individual, stimulate the ***team*** to work in the joint direction?

1. You can use the exercises on the pages 8, 10, 12 and 14 of the workbook team development to talk with all involved healthcare professionals about the joint direction.
2. You can play the team game to talk about the goals. You can read the rules of the game here and order the game on the website of management book.

How can I, as an individual, know what the goals of the person with dementia and his or her informal caregivers are *regarding advance care planning?*

1. You can discuss their wishes for now and the future, and the associated goals for care in the advance care planning interview with the person with dementia and their informal caregivers.
2. In order to reach agreement between what you have discussed with other disciplines and what you discuss with the person with dementia and their informal caregivers, it is important that the central point of contact communicates what has been discussed to both parties (1. Involved disciplines, and 2. Person with dementia and his or her informal caregivers).

Core question 4. Do I/we know what and how to communicate, document and decide?

Below are three sub-questions:

Do I/ we know………

4.1 How we can communicate and document together optimally?

4.2 How we can make decisions together optimally?

4.3 How we can handle different perspectives and conflicts?

4.1 DO I/ WE KNOW HOW WE CAN COMMUNICATE AND DOCUMENT TOGETHER OPTIMALLY?

COMMUNICATING INTERPROFESSIONALLY[21]

- What is interprofessional communication?
  1. Communication is not a linear process (consisting of sender, message and receiver), but a circular process (continuous cycle of action and reaction/ feedback) that is affected by factors such as task use, medium, communication and social skills, attitudes, social and cultural perspectives and knowledge.
  2. In interprofessional communication, in addition to the circular process, we also have to deal with the dynamic process because there are several senders and receivers who influence each other.
- Which components are important in the communication process?
  1. Information flow consists of formulating a message, and sending and receiving it:
     - ▪ Sending
       - Sending is the transformation of an idea, mental concept, thought or other observable expression into a message to the cooperation partners.
     - ▪ Message
       - Important points of attention are:
         - o What information it is useful and necessary to share?
         - o Is this the right time to share this information?
         - o Are the important collaboration partners present?
         - o Which language level suits the recipient(s) best?
     - ▪ Receive
       - Translating the message into its presumed meaning and setting out actions. As an action, the persons with dementia and their informal caregivers will think about the subject of advance care planning, discuss it with each other and make joint decisions.

- What are the important elements of effective interprofessional communication?
  1. Use effective communication tools or resources (see a number of resources below)
  2. Use simple and objective language so that it is understandable for everyone
     - ▪ Do not use technical jargon that could cause confusion because it has different meanings in various disciplines. So as an interprofessional team, use a common language where there is consistency in terminology,

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[21] Zaalen, Y. van, Mulderij, M., & Deckers, S. (2020). *Interprofessioneel communiceren in zorg en welzijn*. Uitgeverij Coutinho.

decisions are made jointly and every collaboration partner is seen as equal.

   - Share the facts (your observations) and no opinions (your interpretations). For example: An opinion is '*The person with dementia does not cooperate (sufficiently)*', but the factual statement/ description is '*The person with dementia participated for 10 minutes in therapy/intervention and then requested a pause.*'

3. Be respectful, clear and confident when you communicate
4. Be aware of the way you speak (paralanguage)
   - Your speaking pace, articulation, volume, and intonation may emphasise certain words or phrases.
5. Use active listening techniques and non-verbal communication to encourage open conversation
6. Take and give time to give constructive feedback (more about giving feedback is described in Core Element 7).
7. Use respectful language (even if you are in a difficult or conflict situation)
   - Avoid nouns that make people feel inferior or superior such as "foreigners" or "alcoholics"
   - Avoid polarised language such as good or bad, differentiating between a white and black population etc.
8. Be aware of your background, experiences, influence and authority (these things can lead to bias/prejudice), which can contribute positively or negatively to communication
9. Advocate the importance of cooperation in all situations

- What is the importance of non-verbal communication during interprofessional communication?
  1. Only 7% of communication consists of verbal communication, the remaining communication is non-verbal.
  2. Important elements of non-verbal communication are the physical distance between sender and messenger, body movements, facial expression and eye behaviour.
  3. For the most effective non-verbal communication, the following is important:
     - Use body language that exudes openness (such as leaning the head to one side, keeping arms down and shoulders back)
     - Be aware of your eye contact (continuous eye contact can be perceived as intimidating)
     - Show agreement by smiling or nodding
     - It is better to omit sarcasm, this can lead to misunderstandings
     - Show that you are interested, by for example, bending forward
- Which factors influence interprofessional communication?

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1. Personal factors: self-confidence, conflict management, fear and uncontrolled emotions
2. Training: courses/workshops/training, feedback, role models and exercising.
3. Interpersonal factors: respect, equality (no hierarchy), familiar feeling (i.e. already knowing the healthcare professional you are going to work with) and team spirit.
    - The informal interaction between the healthcare professionals, creating a familiar environment, becoming familiar with each other's fields of expertise/professional field and having a safe feeling to entrust the person with dementia and their informal caregivers to each other are points of attention.
4. Environmental factors: high work pressure, time pressure or performance pressure, changes in team composition and availability of electronic systems.

CONDUCT ADVANCE CARE PLANNING CONVERSATIONS WITH THE PERSON WITH DEMENTIA AND THEIR INFORMAL CAREGIVERS[22,23,24,25,26]

- What are the important steps? These steps correspond to the stages of behavioural change. It is not the intention, of course, to discuss one step per conversation; the aim is not only to discuss the topics but also to have personal conversations. One must take the time for this and each conversation must be tailored to the personal situation.
    1. Introduce
        - Trust is necessary to start this conversation, so it is essential that you, as a healthcare professional work on a relationship of trust.
        - Finding out how the person with dementia and his or her informal caregiver experience dementia (sickness perception) is then important in

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[22] Ampe, Sophie & Sevenants, Aline & Smets, Tinne & Declercq, Anja & Audenhove, Chantal. (2015). Advance care planning for nursing home residents with dementia: Policy vs. practice. Journal of advanced nursing. 72. 10.1111/jan.12854.

[23] Fahner, J. C., Beunders, A. J. M., van der Heide, A., Rietjens, J. A. C., Vanderschuren, M. M., van Delden, J. J. M., & Kars, M. C. (2019). Interventions Guiding Advance Care Planning Conversations: A Systematic Review. *J Am Med Dir Assoc, 20*(3), 227-248. doi:10.1016/j.jamda.2018.09.014

[24] van der Plas, AGM., Onwuteaka-Philipsen, BD., Willems, D. L., Eliel, M., de Wit-Rijnierse, M., Klinkenberg, M., Appeldoorn, P., van den Berg, D., Schuilenburg, W., & van Beest, R. (2019). *Vroegtijdig spreken over behandelwensen (proactieve zorgplanning) in de eerste lijn. DEEL 1: WERKBESCHRIJVINGEN en HULPMIDDELEN.* https://palliatievezorgnoordhollandflevoland.nl/Portals/0/Documenten/2019_Handreiking%20voor%20implementatie%20van%20proactieve%20zorgplanning_werkbeschrijvingen%20en%20hulpmiddelen_def.pdf?ver=2019-08-02-104027-200

[25] van der Plas, AGM., Onwuteaka-Philipsen, BD., Willems, D. L., Eliel, M., de Wit-Rijnierse, M., Klinkenberg, M., Appeldoorn, P., van den Berg, D., Schuilenburg, W., & van Beest, R. (2019). *Vroegtijdig spreken over behandelwensen (proactieve zorgplanning) in de eerste lijn. DEEL 2:TOELICHTING bij de werkbeschrijvingen en hulpmiddelen.* https://palliatievezorgnoordhollandflevoland.nl/Portals/0/Documenten/2019_Handreiking%20voor%20implementatie%20van%20proactieve%20zorgplanning_toelichting_def.pdf?ver=2019-08-02-104055-737

[26] Zwakman, M., Milota, M.M., van der Heide, A. *et al.* Unraveling patients' readiness in advance care planning conversations: a qualitative study as part of the ACTION Study. *Support Care Cancer* **29,** 2917–2929 (2021). https://doi.org/10.1007/s00520-020-05799-x

order to discover the thoughts and wishes he or she has for this period, and also for the future. A tool you can use for this is Leventhal's model of disease perceptions, which consists of five dimensions. These dimensions are described on page 13 of the brochure Giving back the end-of-life to persons.

  - Identity (nature of the complaint): 'Can you describe what you have?'
  - Cause: 'Do you know what the cause is?'
  - Timeline: 'What do you know about the course of dementia?'
  - Consequences: 'What kind of an effect does dementia have on your life'?
  - Treatment: 'What do you wish for and expect from us?'
- Possible questions you can ask about this can be found in the information document My wishes for my healthcare
- It is important in this step, as a healthcare professional, to explain dementia and its prognosis, but also especially to ask what the person with dementia and his or her informal caregivers already know about it, and what questions they have. Prior to the interview, you can give the Conversation Aid for the later stage of life in dementia and the accompanying sample questions to the person with dementia and/or informal caregivers in preparation.

2. Inform
   - If other healthcare professionals (also from the home setting) have had these conversations, it is important to read the information so that you know what has already been discussed (it is preferable to request this information before the move). If a conversation has already taken place, it is important to first ask what they still remember about the conversation and what they think has already been agreed and recorded.
   - Providing information about advance care planning is crucial: explain why advance care planning is important (and what can happen if not discussed in time) for now and later, what palliative care entails and how it differs from terminal care.
   - Raise awareness of 'postponing' or 'waiting until', by explaining what consequences this could have for the person with dementia, but also for informal caregivers if acute situations arise.
   - Describe the most common misunderstandings about advance care planning clearly, such as that advance care planning means that the person is no longer (actively) treated, or that advance care planning is something unnatural (against natural or divine laws), and that it only concerns the current and future needs and expectations that you as a healthcare professional would like to understand in order to provide optimal care,

now and in the future. Emphasise that it is your duty to inform them about this, so that you can give them autonomy in the care process.

- Clearly state that needs in all care domains are included, and not just physical needs.
  - Topics of advance care planning are the following:
    - Dementia and the possible health changes: communication and information needs about dementia and the prognosis
    - Care goals, palliative care and end-of-life wishes: communication and information needs regarding all health domains and the end-of-life
    - Decisions about treatments and care arrangements: mapping wishes and preferences regarding decision making and ethical, financial and legal matters
    - Treatment and care in the most common situations: eating, drinking and/or swallowing problems, pneumonia or other infections, shortness of breath, pain and feeling uncomfortable (this includes pain relief and palliative sedation), restlessness and misunderstood behaviour, incontinence, depressed feelings, fear and lack of initiative, feelings of loss and life questions, inflammation, shortness of breath and other illnesses.
    - Choice of place of care and change of environment: residence and care location and changes in the environment or in the care professionals involved
    - End-of-life wishes regarding medical and/or life-prolonging procedures: resuscitation, removals/admissions, artificial nutrition and fluids and respiration, administering antibiotics, operating, performing radiation treatments (such as chemotherapy), transfusions and dialysis and retaining devices such as ICD/pacemaker.
    - Active termination of life: euthanasia
    - Care for informal caregivers: collaboration between informal caregivers and healthcare professionals. You can use the conversation aid ‘Planning proactive care together’.
    - Dying phase (palliative sedation, place/environment of death, support with wakefulness and funeral wishes)
    - Aftercare (supporting of informal caregivers during the grieving process)
  - You can show the person with dementia and informal caregivers, for example, the guideline My wishes for my healthcare to indicate

    that it concerns communication and information needs, but also spiritual needs, which will give them a better picture of what advance care planning entails.

- After introducing or discussing advance care planning, give the person with dementia and his or her informal caregivers information documents- and brochures so that they can think about this subject.
- Take into account the fact that every person has their own ‘frame of reference’, which consists entirely of values, norms, beliefs and behaviours that they have internalized. This frame of reference influences the interpretation of the information received, and thus advance care planning.
    - That is why it is important, for example, to find out during the conversation about advance care planning how persons think about the end of life, so that you know which communication style suits the person best. Look at the different death styles in Five visions on dying or types of dying styles.
    - Individual, cultural and religious elements also play a role that may deviate from Western medical ethics. Medical ethics in Western society is based on four pillars: Autonomy, Benevolence, No Harm and Justice. Autonomy means the right to have one’s own vision, to make choices and to take actions. On the basis of autonomy, every person thus has the right to receive information about their diagnosis, prognosis and treatments. However, the definition of autonomy according to differ per culture or religion, and can also differ between individuals. In many Eastern cultures, autonomy is viewed as part a whole, in which informal caregivers can play an important decision-making role. Within many Eastern cultures, therefore, there are many decision-making models that are mostly family-centred with the aim of relieving the person suffering from the disease(s) of this responsibility. Regardless of cultural or religious beliefs, the person may also not wish to receive information and or be involved in making choices. In this way, the person also has the autonomy and the right to ‘not want to know and/or decide’. It is also important to clarify this.
    - After providing the information, it is essential to give the person with dementia and his or her informal caregivers sufficient time and space to think about this, and to come back to it in a subsequent meeting whether they would like to think about the care needs and care goals and want to discuss them. If they find it difficult to talk about it, ask them what exactly they find difficult, and how you, as a healthcare professional, can support them in this process.

3. Exploring (mapping wishes and preferences)
    - The next step is to discuss the various care needs in all health domains.
        - Determining spiritual/existential needs is important before working towards the care goals, because as a care professional you then know what the person with dementia and his or her informal caregivers experience meaningfully in life. The spiritual domain can also affect physical and psychosocial well-being, and it is therefore desirable, if the person with dementia and their informal caregivers wish it, to look at spiritual care according to the Attention, Guidance and Crisis Intervention (in Dutch: ABC) model whereby the roles of the healthcare professionals involved can also be mapped out. You can use the sample questions in the diamond model for this conversation. More information about the ABC model and the diamond model can be found in the guideline meaning and spirituality in the palliative phase (IKNL).
    - It is then important to translate the care needs into care goals and to indicate that the care goals can be chosen/selected on the basis of what persons with dementia and their informal caregivers see as high-quality care, that they can be adapted if the situation changes or someone's wishes change, and that these care goals guide decisions (in the next step). You can do this using the covenant model (ABC model). The ABC model describes these care goals: A for doing all, B for getting the functions maintained and C for comfort therapy. You can use the guideline adapting the care life plan in function of the care goal and care needs for more information about these care goals. You can use the information on the website care for better to provide the person with dementia and his or her informal caregivers with information about setting goals. During this conversation you can ask the questions that are listed in the information document My wishes for my healthcare.
    - You can relate these care goals to the four forms of medical action/ policy: 1. Curative policy, 2. Rehabilitation policy, 3. Palliative policy and 4. Symptomatic policy. More information can be found on page 36 of Concepts and due diligence requirements with regard to end-of-life decision-making in nursing home care.
    - Explain the care goals and describe which agreements can be made.
    - Provide the person with dementia and his or her informal caregivers with information about the decisions and the specific agreements that can be made.
4. Deciding
    - This involves discussing the pros and cons of each decision and providing

  recommendations for making choices.
  - In this step, the care goals are made concrete in the form of care agreements. You can use the contract model for this.
  - Joint decision-making is central to this, and this is further described in Core Element 5. Joint decision-making
5. Documenting
   - Documenting is the written recording of the specific care and treatment agreements.
     - It is important here that the agreements are incorporated in the care life plan and are recorded in the form of advance directives (such as a treatment ban, requests for euthanasia and appointment of a representative).
     - The agreements should be transparent to all parties involved (disciplines, informal caregivers and person with dementia). Note: The person with dementia and his or her family should have access to view the agreements and consultations made, and to view definitive diagnoses and medication lists, and should be given the opportunity to make suggestions or ask questions. When diagnosing or analysing problems for which no consensus has yet been reached among the disciplines, it is advisable to keep this information only among the disciplines and to store it in a location to which the person with dementia and his or her informal caregivers do not have access.
6. Maintaining
   - Reviewing the agreements made to check whether the choices remain stable, to reflect on any new changes, but also, above all, to continue the personal conversation about how the person with dementia and his or her informal caregivers feel and experience the care process.

- What are the points of attention when conducting early care planning interviews?
  1. Conversations do not follow fixed steps, and it is possible that several steps will be discussed during one conversation, so it is important to conduct the conversation dynamically.
  2. The main goal is to hold conversations and to explore wishes and preferences.
  3. Evaluation of the conversations (more about this is described in Core Element 7. Monitoring care together and looking back on it).

Consulting with and providing feedback to colleagues about advance care planning[27]

- *Points of attention during formal meeting moments*
    1. Prepare the meeting
        - Create an agenda for the meeting and include advance care planning as a standard agenda item.
        - Make one or two care professionals from the care team (helpers, carers and nurses) present during the consultation with other care professionals responsible for thinking along, co-deciding, and writing down what has been decided, and the advice that arises from this, and passing on the advice and/or changes to others of the care team.
        - Important elements for preparing the interprofessional consultation are 1. Structure and division of tasks, 2. Group composition, 3. Purpose of the consultation, 4. Characteristics of the person with dementia and 5. Relationship between professionals, persons with dementia and their informal caregivers. These elements are described in the RICT (RIST) (Reflection framework interprofessional collaboration in teams) model for interprofessional consultations.
    2. Discuss the substantive points
        - These can be various input points, such as describing the problem or changing situation and what goal will be achieved with the input, anticipating a situation, making decisions, or venting about difficult collaboration processes and situations.
        - Share the necessary data/information with the interprofessional team
    3. Analyse the problem, situation, question or comment
        - It is important to check beforehand whether all team members understand what the meeting is about and what the goal is, so that everyone can respond and propose suggestions from their own frame of reference and field of expertise.
    4. Searching for solutions and formulating care strategies
        - Here, the suggestions that are approved by the entire team are assessed for necessity, desirability and feasibility.
        - If a solution is chosen, all healthcare professionals involved will mutually agree on what each will do for them in specific terms.
    5. Reporting
        - The roles, responsibilities and tasks are hereby documented in a way that it is visible to everyone.

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[27] Zaalen, Y. van, Mulderij, M., & Deckers, S. (2020). *Interprofessioneel communiceren in zorg en welzijn*. Uitgeverij Coutinho.

6. Closing
    - Briefly reflect on the agreements made, their follow-up and indicate the advantages and points for improving this consultation.

- *Communicating points of attention during interprofessional meetings/discussions*
  1. Before making agreements with each other or following up on advice/ assignments, it is important to be sure that your discussion partners and yourself have clearly understood what exactly has been agreed. For example, you can use closed-loop communication, which is a communication method in which the message is mutually heard, understood and fed back[28]. This method consists of six steps: 1. Sender formulates the message (advice/assignment), 2. Receiver receives the message, 3. Receiver gives feedback or other suggestions, 4. Sender and receiver discuss possible suggestions and their advantages and disadvantages, 5. Sender and receiver come to a joint conclusion (which may or may not differ from the initial message of the sender), and 6. Receiver repeats the message, indicates what and how they are
  2. going to do, and when and to whom they will feed this back.
  3. You can use the **ISBARR**-method to optimally provide input and clear communication during interprofessional meetings/conversations or during transfer moments.[29,30]
  4. An explanation of the SBARR-method can be found here. A checklist has also been developed for this, which is available on the website of the publisher Coutinho. The SBAR-technique can also be found at http://www.vvizvmail.be/Repository/Bijscholingsmodule/MichaelVerbiest-efficinteinformatieoverdracht.pdf

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[28] Härgestam, M., Lindkvist, M., Brulin, C., Jacobsson, M., & Hultin, M. (2013). Communication in interdisciplinary teams: exploring closed-loop communication during in situ trauma team training. *BMJ open*, *3*(10), e003525. https://doi.org/10.1136/bmjopen-2013-003525

[29] https://www.ahrq.gov/teamstepps/instructor/essentials/pocketguide.html

[30] Moi, E. B., Söderhamn Ulrika, Marthinsen, G. N., & Flateland, S. M. (2019). The isbar tool leads to conscious, structured communication by healthcare personnel. *Sykepleien Forskning*, *74699*(74699), 74699. https://doi.org/10.4220/Sykepleienf.2019.74699

Letter	Word	Description
I	Introduction	Introduce yourself (name and position), your location and department. Clearly indicate which client you are talking about (their name, date of birth, etc.).
S	Situation	Clearly state the reason you want to speak to the other healthcare professional, describe the current condition of the client, indicate what is going on and when something happened.
B	Background	Describe the problem/issue and the client's relevant medical background.
A	Assessment	State which analyses you have performed and the findings thereof. Explain clearly what your assessment is and what could be the underlying reason for the problem/issue.
R	Recommendation	Clearly describe your recommendation.
R	Readback	Briefly repeat what you have agreed upon and who will do what and record these agreements in the file.

- *Transferring points of attention information to colleagues in the care setting or between care settings*
    1. For example, to transfer information, you can use the **I PASS the BATON**-method.[31] Depending on the type of transfer (within the same department, within the same organisation, to another healthcare organisation, or to another healthcare setting), you can share general or specific information with the other healthcare professional.

Letter	Word	Description
I	Introduction	Introduce yourself
P	Patient	Introduce the person with dementia (name, age, gender, location, admission indication, examinations, procedures, etc.)
A	Assessment	The problem, status of an ongoing investigation, ambiguities, etc.
S	Situation	Current condition, circumstances, treatment limitations
S	Safety concerns	Lab/research results, allergies, threats, isolation and points of attention
B	Background	Co-morbidity, history, current medication and family history
A	Actions	What actions have been taken or have to be taken? Short argumentation here
T	Timing	Level of urgency, specific time schedule, prioritisation of actions
O	Ownership	Who is responsible for the person with dementia? Who represents the person with dementia?
N	Next	What's the plan? What must be done first? Questions or comments? Read back.

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[31] Starmer, A. J., Spector, N. D., Srivastava, R., Allen, A. D., Landrigan, C. P., Sectish, T. C., & I-PASS Study Group (2012). I-pass, a mnemonic to standardize verbal handoffs. *Pediatrics*, *129*(2), 201–204. https://doi.org/10.1542/peds.2011-2966

4.2 DO I/WE KNOW HOW WE CAN MAKE DECISIONS TOGETHER OPTIMALLY?

<u>Decision-making is a joint process between the person with dementia, his or her informal caregivers and the healthcare professionals involved.</u>

- What are the important steps in joint decision-making (both for persons with dementia and their informal caregivers separately and for care professionals themselves)?[32,33,34]
    - Invite the involved parties
        - Presence of the central point of contact for the person with dementia and informal caregivers
        - Avoid distractions such as noise (turning off radios and telephones)
    - Finding a suitable location
        - Find a quiet environment
        - Ensure it is suitable for a family conversation (a place where informal caregivers experience privacy and feel comfortable starting the conversation)
    - Choosing a suitable contact moment
        - If the person with dementia wishes only informal caregivers to participate, his or her informal caregivers can choose whether they want to discuss this with their central point of contact in family discussions and/or consult with other healthcare professionals.
        - If it concerns a consultation between various healthcare professionals, select or insert a consultation moment where all core healthcare professionals are present (this can be a physical or online consultation).
    - Identifying perceptions
        - Ask informal caregivers and involved healthcare professionals about their perceptions of advance care planning.
    - Checking what is already known
        - Ask informal caregivers and involved healthcare professionals whether they are familiar with the subject and check whether they have sufficient knowledge to make decisions.

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[32] Sieck, Cynthia & Johansen, Michael & Stewart, Jessica. (2015). Interprofessional shared decision making – increasing the “shared” in shared decision making. International Journal of Healthcare. 2. 10.5430/ijh.v2n1p1.

[33] Hanum, Chaina & Findyartini, Ardi. (2020). INTERPROFESSIONAL SHARED DECISION-MAKING: A LITERATURE REVIEW. Jurnal Pendidikan Kedokteran Indonesia: The Indonesian Journal of Medical Education. 9. 81-94. 10.22146/jpki.49207.

[34] Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: a model for clinical practice. *Journal of general internal medicine*, *27*(10), 1361–1367. https://doi.org/10.1007/s11606-012-2077-6

  - Inform informal caregivers about advance care planning before discussing care goals, future scenarios and treatment options.
    - Refer informal caregivers, for example, to existing aids:
      - My wishes about my healthcare (https://websites.mijndokter.be/muysbroek/wp-content/uploads/sites/89/2017/12/mijn_wensen.pdf)
      - The last care in nursing homes (https://www.wzh.nl/sites/default/files/brochure_wzh_hoge_veld_laatste_zorg_verpleeghuis_terminale-fase.pdf)
      - Booklet talking about forgetting (https://palliaweb.nl/overzichtspagina-hulpmiddelen/spreken-over-vergeten)
      - Talking about your end of life in time (https://www.knmg.nl/advies-richtlijnen/dossiers/praten-over-het-levenseinde-1)
      - Talk about your end of life in time (https://meidoorn.info/wp-content/uploads/2017/02/KNMG-Publieksbrochure.pdf)
    - When providing information about advance care planning, think about the way you speak and approach informal caregivers positively. For example: Instead of saying, *"We will prevent your informal caregiver's suffering."* Say, *"Our priority is your informal caregiver's comfort and dignity."*
- Checking what the expectations are
  - Ask informal caregivers and involved healthcare professionals about their expectations regarding advance care planning.
- Discussing future care goals and treatments
  - Propose care goals and discuss them with informal caregivers and involved core care professionals.
    - Examples of care goals are maintaining and/or improving function, and providing comfort care.
  - Discuss the future scenarios you want to anticipate and why it is important to anticipate them (explain the consequences if they are not anticipated)
- Showing empathy (this especially applies when you are talking to informal caregivers)
  - Name the kinds of emotions you see in informal caregivers.
  - Show understanding for their situation.
  - Show respect for their collaboration with healthcare professionals and for all they have done for their informal caregiver.
  - Offer support and indicate what you can do for informal caregivers.
  - Identify the challenges that informal caregivers experience in talking or thinking about advance care planning.
- Discuss the decisions that can be made for the future scenarios

    - Explain the outcomes of all decisions, the pros and cons, the effect that it has on the person with dementia, and whether it is feasible (make a balance sheet)
    - Indicate what the healthcare professionals involved propose and explain why
    - Ask informal caregivers what they think about this, what their preference is and why
- Summarise what has been discussed
    - Document what has been discussed and/or the agreements made
    - If it involves a family conversation, also report what has been discussed to the other healthcare professionals
- Regularly reviewing decisions
    - Have regular conversations about this subject and the agreements made

4.3 DO I/ WE KNOW HOW WE CAN HANDLE DIFFERENT PERSPECTIVES AND CONFLICTS?

Handling different perspectives on ethical issues

- When handling ethical issues, it is not only about ethical values, but also about the care organisation (practice and policy) and legislation.
- If informal caregivers do not agree with each other or with healthcare professionals, a moral deliberation can be organised look more deeply into the reasoning and thus arrive at a shared decision-making process. For more information about conducting a moral deliberation see:https://www.zorgvoorbeter.nl/zorgvoorbeter/media/documents/thema/welbevinden-levensvragen/5-handvatten-ethiek-levensvragen.pdf

Handling conflicts[35]

- The existence of a team conflict or conflict with an informal caregiver, if handled in a constructive way, can lead to improvements in quality and creativity, because then optimal use is made of team diversity. Team diversity (having different opinions, skills and knowledge) is therefore essential for improving the quality of care. Nevertheless, if not handled responsibly, team conflicts do not lead to the best possible joint solutions, and if they occur too often or have no objective basis, can be destructive to the team climate, team effectiveness and interpersonal relationships between collaboration partners.
- Three types of conflicts can be described:
  1. Task-oriented conflicts: Conflicts that arise when team members do not agree on substantive issues/tasks (e.g. deciding which step to take or which product to use).
  2. Process-oriented conflicts: Conflicts that arise when team members do not agree on how a task should be performed (e.g., division of labour).
  3. Inter-personal conflicts: Conflicts that arise when there is irritation between team members when they have various personal preferences, styles, values and other non-work-related aspects (e.g. personal negative comments).
- You can use the following four steps to deal with task-oriented or process-oriented conflicts:
  1. Focus on the problem/issue/action and not the persons involved
  2. Focus on the interests/underlying reasons and not the positions (for or against) of the persons
  3. Look for a joint solution with the highest 'win-win' outcome. Look at underlying wishes and needs

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[35] West, M. A. (1994). *Effective teamwork: Practical lessons from organisational research.* Blackwell Publishing.

4. Clearly describe (with objective reasons) why a certain solution was chosen

- You can use the **CUS** approach to dealing with task-oriented or process-oriented conflicts:[36,37,38]

Letter	Word	Description
C	Concern	Describe your concerns
U	Uncomfortable	State why you feel insecure
S	Safety	State why your concerns and uncertainties are related to client safety

- You can use the **DESC** approach to deal with interpersonal conflicts:[36,39]

Letter	Word	Description
D	Describe	Describe the specific situation or behaviour of the other team member
E	Express	Explain how you feel and/or the concerns you have because of the situation or the behaviour of the other team member
S	Suggest	Come up with suggestions or recommendations to come to a joint agreement or solution
C	Consequences	Check the consequences of the agreement or solution and the effect it has on the team goals

- Engage a mediator/intermediary
  - Our research has shown that the team leader can act as a mediator in team conflicts, because the team leader is connected to various disciplines and plays an important role in safeguarding the common starting point and thus also joint solutions.
  - You can also engage mediators who work within or outside your organisation. Consonant is an external organisation that specializes in (for a fee) mediation in the last phase of life.

What tools can I use, as an individual healthcare professional, to contribute to joint communication, decision-making and documentation?

What can I use as an individual to prepare the interprofessional consultation?

1. You can use the Timekeeping worksheet (page 43) of the team development workbook

What can I use as an individual to increase my knowledge of collaborative decision-making?

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[36] https://www.ahrq.gov/teamstepps/instructor/essentials/pocketguide.html#descscript

[37] McCoy, L., Lewis, J. H., Simon, H., Sackett, D., Dajani, T., Morgan, C., & Hunt, A. (2020). Learning to Speak Up for Patient Safety: Interprofessional Scenarios for Training Future Healthcare Professionals. *Journal of medical education and curricular development*, *7*, 2382120520935469. https://doi.org/10.1177/2382120520935469

[38] http://icontracts.com/wp-content/uploads/2017/11/Conflict-Resolution.pdf

[39] https://your.yale.edu/sites/default/files/adviformanagers_usingdesctomakeyourdifficultconversations.pdf

1. You can use the Toolbox deciding together in dementia
2. You can use the Efficient Decision Making Worksheet (page 37) of the team development workbook
3. You can use the Steps of joint decision-making

How can I, as an individual, increase ***my*** *knowledge on handling different perspectives in ethical issues?*

1. You can use the Ethical toolkit and the Step-by-step plan for moral deliberation
2. You can watch the video Handling conflicts

How can I, as an individual, stimulate the ***team*** *to work on an interprofessional moral deliberation?*

1. You can use the agenda for a moral deliberation meeting on page 17 of the Guideline interprofessional moral deliberation
2. You can use the "vizier model" that describes eight steps on pages 53 to 56 or the step-by-step plan on page 56 of the workbook End-of-life. Towards an ethical framework.

How can I, as an individual, best prepare ***the person with dementia, his or her informal caregivers*** *to discuss different perspectives and avoid conflicts?*

1. You can explain to the person with dementia and his or her informal caregivers why it is important to discuss sensitive issues with each other in advance by recommending the video Otherwise your mother will die or the video What could we have done differently

You can support decision-making by the person with dementia and his or her informal caregivers by using the Before I Forget app. Here you can find more information about the app.

Core question 5. Do I/we know what and how to coordinate?

Below are two sub-questions:

Do I/we know………

5.1 What requires anticipation, coordination and follow-up?

5.2 What joint leadership is?

5.1 DO I/ WE KNOW WHAT REQUIRES ANTICIPATION, COORDINATION AND FOLLOW-UP?

Coordination[40,41]

- Coordination is performing actions to achieve a task and to convert team input into team results.
- Central to this is the orchestration of the sequence and duration of interdependent actions.
- In interprofessional collaboration, one often speaks of relational coordination (coordination through interactions/relationships) involving common goals, shared knowledge and mutual respect.

Anticipating, coordinating and following up in advance care planning

- At the client level, the following points for attention are discussed:
    - Identify the central point of contact for the person with dementia and his/her informal caregivers.
    - Find connection/documentation between home and nursing home.
        - Referring back to end-of-life conversations in the home setting is essential in order to continue efficiently with advance care planning in the nursing home (part of the information transfer during the nursing home transition). In this way, the repetition of conversations can be avoided.
    - Preferably initiate the advance care planning conversation before the move and do not wait until after the introductory conversation, which is usually only held after six weeks.
    - Take the time together to create an optimal overview of the person with dementia as regards advance care planning
        - Since all disciplines have their own role in advance care planning and have separate conversations with the person with dementia and his or her informal caregivers, it is essential to document these agreements in the file (which is accessible to all disciplines) and to briefly communicate these orally to each other.
    - Clearly define the roles of various disciplines in a joint plan
        - It is important to draw up a joint plan of action with each other about how you will carry out advance care planning together.
            - For example: For Mrs Pieters, the primary care provider (Evelien)

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[40] Jody Hoffer Gittell, Marjorie Godfrey & Jill Thistlethwaite (2013) Interprofessional collaborative practice and relational coordination: Improving healthcare through relationships, Journal of Interprofessional Care, 27:3, 210-213, DOI: 10.3109/13561820.2012.730564

[41] Reeves, S., Xyrichis, A., & Zwarenstein, M. (2018). Teamwork, collaboration, coordination, and networking: Why we need to distinguish between different types of interprofessional practice. *Journal of interprofessional care*, *32*(1), 1–3. https://doi.org/10.1080/13561820.2017.1400150

is the central point of contact. Evelien will conduct the first end-of-life conversation and will focus in particular on 1) identifying the representative, 2) determining whether Mrs Pieters would like to participate in the conversation or would prefer it if the representative takes on this responsibility, 3) what the representative's communication and information wishes are, 4) who, besides the representative, participates in the decision-making process, 5) informing Mrs Pieters about advance care planning, 6) examining what is important for Mrs Pieters in all health domains, 7) what role the representative and other informal caregivers want to play in the daily life of the person with dementia, 8) explaining what care goals there are, 9) what the wishes and preferences of Mrs Pieters are (physical, social, emotional, psychological and spiritual) in daily life, 10) which end-of-life wishes have already been recorded, and so on. After that Evelien can discuss her findings with the geriatric specialist (Mark) and they can conduct a second conversation with the person with dementia and his or her informal caregivers, during which Mark will go into more detail about the medical treatments, the active termination of life and care arrangements. Other disciplines can then also have separate end-of-life conversations, each with its own focus area, and in this way monitor this process together and keep each other informed of new developments (describe the role and task of each discipline).

  - Draw up an anticipatory policy
    - Discuss how best to act in future scenarios.
      - For example: Discuss the most common (life-prolonging) actions in the last phase of life (e.g. whether or not antibiotics are administered). If it is decided to perform this action, immediately agree on the best way in which this action can be performed (e.g. antibiotics orally, intravenously or intramuscularly). If the previous treatment is not effective, which alternative can be chosen (e.g. if antibiotics orally do not work, and antibiotics intramuscularly are chosen, subcutaneous fluid administration will take place at the same time).

- The following points for attention are discussed at team level:
  - Engage, advise and listen to each other
    - After the division of roles and tasks has been clarified and discussed with each other, the next step is actually making use of each other's expertise and knowing when other disciplines should be involved.
  - Ensure that the information that is discussed during consultations (such as contact consultations, behavioural visits and MDM) is not lost during information transfer

        - During consultations with practitioners, one or two care workers from the care team are usually appointed to provide information about the clients, but also to receive information from practitioners in the form of advice and the care actions based on it. It is up to these two care workers to inform the entire care team of the agreements made.
        - Do not use written transfer only, but combine this with oral (briefing or short consultation) or/and visual transfer (for example with videos).
    - Inform your colleagues or other employees who are filling in for you temporarily about the care agreements made in order to prevent miscommunication or other ambiguities. Ensure that team members are held accountable for communicating changes/new points of attention to their colleagues. If the services (morning, afternoon and evening) overlap, it is advisable to write down these changes/new points for attention as briefly and clearly as possible in the file.
        - For example: Write down the agreements made (current care and during moments of crisis) as a permanent ward physician in the file so that the physician on duty who comes in at the weekend knows how to act.
    - During consultations, always immediately translate advice into task-oriented actions.
    - During consultations, agree clearly about what the agreements are, why they are made and how they are evaluated (also document this immediately).
    - As a practitioner, ask for input from the care team about the given advice (translated into task-oriented actions): are they workable, what effects do they have and are any adjustments required?
    - Discuss workload and responsibilities
    - Set up leaders/attention fielders/attention officers, such as palliative care nurses and palliative care consultants to support the team in advance care planning
- The following points for attention are discussed at the organisational level,:
    - Support employees in the workplace with the performance of care tasks (after agreements have been made and coordination has taken place). This involves not only making materials/resources available (such as antibiotics or morphine pumps), but also, for example, making available an employee who arranges administrative and practical matters regarding the materials, so that the care employees on duty do not do this within their work time and can perform their care tasks one after the other.
    - Ensure secure and shared information systems
        - Do not make a distinction between the care and medical records (all disciplines should use the same system)
        - Keep concerns and discussions in the identification or discussion phase of new symptoms or diagnoses separate from the record that the informal

caregivers have access to (which can lead to frustration and distress for the informal caregivers) until the final results and decisions emerge.

- Offer health care workers the opportunity to participate in education or training about interprofessional collaboration and advance care planning
- Deploy working groups, steering groups or affiliated hospices to support the care organisation in advance care planning
- Confirm agreements regarding advance care planning in annual and quarterly plans and discuss these with external healthcare professionals. Record agreements regarding advance care planning in annual or quality plans and discuss these clearly with external treatment services or care workers.
- Ensure that materials are available for optimal end-of-life care. This concerns not only medicines and equipment, but also information leaflets and watch cases, for example. You can, for example, use the procedure and materials regarding warm farewells described by the care organisation Vivantes.

5.2 DO I/ WE KNOW WHAT JOINT LEADERSHIP IS?

Joint leadership[42,43]

- Joint leadership is about having mutual task dependence, having joint responsibility for outcomes and maintaining a cohesive group and relationships between the collaborating partners. Joint leadership can go hand in hand with vertical/hierarchical leadership (more focused on coaching, supporting, providing preconditions, encouraging and facilitating) and complement each other.
- The following steps are essential to contribute to effective leadership:[44]
  - Create the right climate for change
    - Reinforce sense of importance/necessity
    - Form a leading team
  - Involve and equip the entire organisation
    - Develop an appropriate vision and strategy
    - Communicate and enthuse vision
    - Ensure support, and motivate and enable employees to change
  - Implement and maintain
    - Identify short- and long-term effects and celebrate successes/progress
    - Perseverance: mapping obstacles or barriers and looking for (intermediate) solutions
- Most common leadership styles[45]
  - Transformational leadership: focused on the process of 'transformation', in which the persons and relationships between collaboration partners and a shared vision are central.
  - Transactional leadership: focused on performing tasks (manager transfers task 'transaction' to an employee).

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[42] Contractor, N. S., DeChurch, L. A., Carson, J., Carter, D. R., & Keegan, B. (2012). The topology of collective leadership. *Leadership Quarterly*, *23*(6), 994-1011. https://doi.org/10.1016/j.leaqua.2012.10.010

[43] Zaccaro, S. J., Heinen, B., & Shuffler, M. (2009). Team leadership and team effectiveness. In E. Salas, G. F. Goodwin, & C. S. Burke (Eds.), *Team effectiveness in complex organisations: Cross-disciplinary perspectives and approaches* (pp. 83–111).

[44] https://docplayer.nl/1080171-Effectief-leiderschap-in-de-nederlandse-gezondheidszorg-een-kwestie-van-hard-werken.html

[45] West, M. A. (1994). *Effective teamwork: Practical lessons from organisational research.* Blackwell Publishing

What tools can I use as an individual healthcare professional to contribute to joint leadership?

How can I as an individual increase ***my*** *knowledge about joint leadership?*

1. You can use the following resources to learn more about what joint leadership entails:
   a. Shared leadership: does your facility worker already participate in the decision-making process?
   b. This is how you put shared leadership into practice
   c. Spot on: shared leadership
   d. Seven characteristics of effective leadership
2. You can use tools that describe leadership for doctors, carers and nurses:
   a. Medical leaderschip (e.g. meant for specialists geriatrics)
   b. Caring leadership (meant for carers)
   c. Nursing leadership and strengthening nursing leadership (meant for nurses)
3. You can use the document Leadership styles in long-term care to gain more insight into the different leadership styles.

How can I, as an individual, give the ***team*** *more insight about joint leadership?*

1. You can suggest that your team members use the document Leadership, self-management and team collaboration in nursing home care for persons with dementia from Trimbos.

Core question 6. Do I/we know what and how to guard, monitor and evaluate?

Below are three sub-questions:

Do I/we know………

6.1 How we can contribute to an optimal collaboration context?

6.2 How we can monitor optimally?

6.3 How we can reflect and evaluate optimally?

6.1 DO I / WE KNOW HOW WE CAN CONTRIBUTE TO AN OPTIMAL COLLABORATION CONTEXT?

Interpersonal issues such as getting to know each other, having respect for each other, creating an equal, safe and open atmosphere, trusting each other and supporting each other are indispensable basic elements for interprofessional collaboration.

Offer support to each other:[46]

- Emotional support: Being an active and open listener, caring and showing empathy for the emotions of another team member (this concerns work-related matters).
- Instrumental support: Performing a task for another team member.
- Informational support: Giving information to another team member.
- Appreciative support: Providing an overview of the current/problem situation (and possibly suggesting alternative options) to another team member.

Creating an equal, open and safe atmosphere

- All disciplines should be given an equal opportunity to share their perspectives and to express themselves openly.
    - Although the physician is in charge, it is important that decisions are taken together and that all collaborating partners have a voice. This often means that team members who are in a superior position/function (such as for example team leader and doctor) should radiate a positive and open attitude to the other team members and make them feel that they are part of the team.[47] The team members with an inferior position/function will have to show more assertiveness, daring and courage, and create and take the opportunities to express their voice.

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[46] West, M. A. (1994). *Effective teamwork: Practical lessons from organisational research.* Blackwell Publishing

[47] Fox, S., & Comeau-Vallée, M. (2020). The negotiation of sharing leadership in the context of professional hierarchy: Interactions on interprofessional teams. *Leadership, 16*(5), 568-591. doi:10.1177/1742715020917817

6.2 DO I/ WE KNOW HOW WE CAN MONITOR OPTIMALLY?

Joint monitoring:

- Joint monitoring is the process whereby:[48]
    - The client is monitored: the client is actively scanned and assessed to identify changes and understand and map the evolving health situation.
    - The situation is monitored: here you check for yourself whether you are aware of the new/changing situation and everything that is happening around you.
    - The team functioning is monitored: the aim is to check whether all team members are on the same page and to maintain/guarantee awareness of the joint functioning and the joint approach.
- You can apply the **STEP**-approach to joint monitoring:[49]

Letter	Word	Description
S	Status	Describe the client's status (all health domains).
T	Team	Discuss the way in which current tasks are performed (what is going well and what could be done differently/ better), task skills, work pressure, fatigue and stress.
E	Environment	Discuss environmental aspects that affect the efficiency of care delivery. This includes information provision, administrative support, working conditions and materials.
P	Progress towards goal	Discuss progress as a team with regard to the client's established care goals (for example, tasks that have already been performed and tasks that still need to be performed, updating the care plan, etc.)

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[48] West, M. A. (1994). *Effective teamwork: Practical lessons from organisational research.* Blackwell Publishing.

[49] https://www.ahrq.gov/teamstepps/instructor/essentials/pocketguide.html

6.3 DO I / WE HOW WE CAN REFLECT AND EVALUATE OPTIMALLY?

Reflecting:[50]

- Describe the current situation regarding advance care planning
- Examine your own and the team's actions regarding advance care planning
- Examine your own and the team's skills in advance care planning
- Find out your (and the team's) motivation for, and beliefs about advance care planning
- Consider your own identity regarding advance care planning (what does advance care planning mean to you?)
- Have an eye for your deeper motives regarding advance care planning

Evaluating:[48]

- Assess the results of the implemented actions regarding advance care planning
- Look at confounding factors that have affected advance care planning
- Draw conclusions for the method used with regard to advance care planning
- Assess whether expectations have been met regarding advance care planning

What tools can I use as an individual healthcare professional to contribute to the joint monitoring of the collaboration process?

What can I use to reflect on my own or others' actions?

1. You can use the fill-in document from the book Interprofessional collaboration in health care by Giannoula Taskitzidis and Paul van Royen. Each role is given a score based on the assessment criteria. You can then enter all the scores of all team members in the score form and discuss these scores with each other.
2. You can use the document Good conversation: Simple working methods for reflections within long-term care.
3. You can find various methods on the website Zorg en beter to provide optimal feedback to team members.

What can I use to reflect and evaluate together with my team?

1. You can use the reflection questions for teams from Dignity and pride.
2. You can use the reflection framework interprofessional collaboration in teams (RIST). You can find more information about RIST on this website: Improvement strategy for interprofessional collaboration

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[50] Zaalen, Y. van, Mulderij, M., & Deckers, S. (2020). *Interprofessioneel communiceren in zorg en welzijn*. Uitgeverij Coutinho.

[48] West, M. A. (1994). *Effective teamwork: Practical lessons from organisational research.* Blackwell Publishing.

3. You can use the Questionnaire about the functioning of a team to map out team effectiveness.
4. You can use the Assessment of Interprofessional Team Collaboration Scale (AITCS) to evaluate interprofessional collaboration.[51]

What can I use to evaluate care together with persons with dementia and/or their informal caregivers?

1. You can use the Checklist from Sting the National Professional Association, the Team scan from V&CN and OPTION observation list.

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[51] https://www.signnow.com/fill-and-sign-pdf-form/38021-assessment-of-interprofessional-team-collaboration-scale-aitcs

Colophon

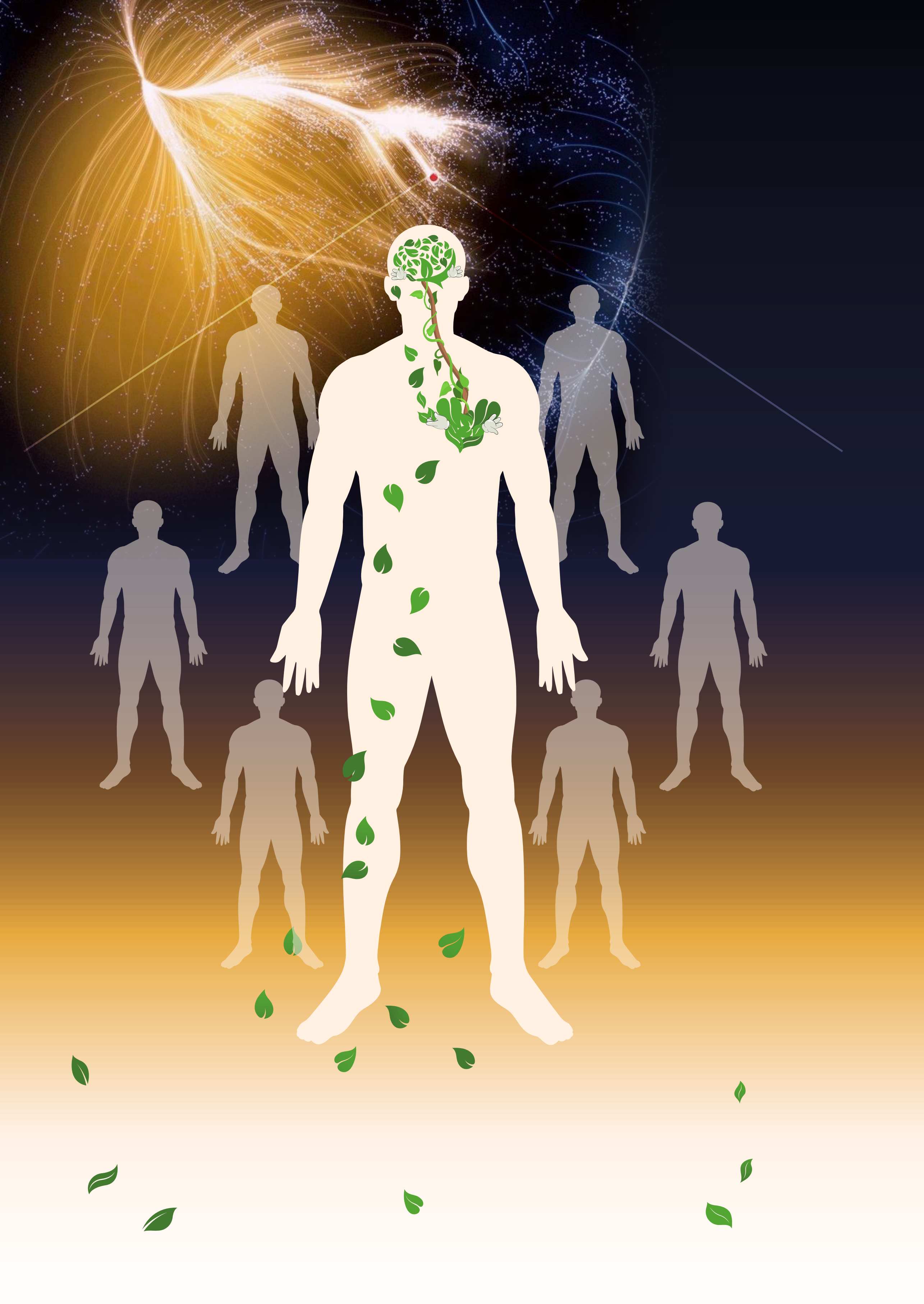
The *Moving together DEDICATED and DEDICATED collaboration in advance care planning* are two guidance documents of the *DEDICATED* project. The DEDICATED project is financed by ZonMw within the *Palliance. More than Care* program. This guidance document and the *DEDICATED – collaboration in advance care planning* infographic based on it, were developed by Chandni Khemai (first author), the promotion team (Judith Meijers, Daisy Janssen and Jos Schols) and the daily board team of DEDICATED (Lara Dijkstra, Els Knapen, Sascha Bolt, Saskia Wolters and Jesper Biesmans). This guidance document and the *DEDICATED-collaboration in advance care planning* infographic were designed by Gielen (press print web media). This guidance document and the *DEDICATED – collaboration in advance care planning* infographic were translated into English by Irma Mujezinović.

This guidance document was established based upon literature research, existing practical materials, and practical research involving meetings with various parties (carers, nurses, nurse specialists, team leaders, psychologists and specialists geriatrics) from three care organisations (Vivantes, Zuyderland en Envida).

Participants at the meetings:

- Carers: Rick Janssen (Zuyderland) and Helga Claessens (Envida)
- Nurses: Angelique Fraussen (Vivantes), Anita Kessen (Envida) and Luca Welbergen (Vivantes)
- Quality nurse: Marie-Lou Vanhautem (Envida)
- Nurse specialists: Els Stouten (Vivantes) and Ina Schutgens (Zuyderland)
- Team leaders: Diana Kill (Envida), Mara Boshuis-Ritt (Zuyderland) and Nelleke Tinbergen (Vivantes)
- Psychologists: Anouk Hermans (Vivantes), Caroline Steins (Zuyderland) and Lisanne Janssen (Envida)
- Physician specialized in old age medicine: Wendy Beks (Envida), Elian Gorissen (independent geriatrics specialist and teacher of geriatrics at the University of Maastricht) and Dre Knols (former physician specialized in old age medicine)
- Teacher/Researcher: Jerome van Dongen (Zuyd University of Applied Sciences and University of Maastricht)

For more information or questions about this guidance document and the *DEDICATED-collaboration in advance care planning* infographic, please contact the first author: Chandni Khemai (c.khemai@maastrichtuniversity.nl, or ckhemai@hotmail.com or chandnni94@hotmail.nl).



ADDENDA

LIVING LAB IN AGEING AND LONG-TERM CARE

PUBLICATIONS

AUBOUT THE AUTHOR

ACKNOWLEDGEMENT

LIVING LAB IN AGEING AND LONG-TERM CARE

LIVING LAB IN AGEING AND LONG-TERM CARE

This thesis is part of the Living Lab in Ageing and Long-Term Care, a formal and structural multidisciplinary network consisting of Maastricht University, nine long-term care organizations (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Intermediate Vocational Training Institutes Gilde and VISTA college and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands. In the Living Lab we aim to improve quality of care and life for older people and quality of work for staff employed in long-term care via a structural multidisciplinary collaboration between research, policy, education and practice. Practitioners (such as nurses, physicians, psychologists, physio- and occupational therapists), work together with managers, researchers, students, teachers and older people themselves to develop and test innovations in long-term care.

ACADEMISCHE WERKPLAATS OUDERENZORG LIMBURG

Dit proefschrift is onderdeel van de Academische Werkplaats Ouderenzorg Limburg, een structureel, multidisciplinair samenwerkingsverband tussen de Universiteit Maastricht, negen zorgorganisaties (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Gilde Zorgcollege, VISTA college en Zuyd Hogeschool. In de werkplaats draait het om het verbeteren van de kwaliteit van leven en zorg voor ouderen en de kwaliteit van werk voor iedereen die in de ouderenzorg werkt. Zorgverleners (zoals verpleegkundigen, verzorgenden, artsen, psychologen, fysio- en ergotherapeuten), beleidsmakers, onderzoekers, studenten en ouderen zelf wisselen kennis en ervaring uit. Daarnaast evalueren we vernieuwingen in de dagelijkse zorg. Praktijk, beleid, onderzoek en onderwijs gaan hierbij hand in hand.

PHD-THESES LIVING LAB IN AGEING AND LONG-TERM CARE / PROEFSCHRIFTEN ACADEMISCHE WERKPLAATS OUDERENZORG LIMBURG

Chandni Khemai. THERE IS AN I IN WE. Collaborative awareness in the DEDICATED palliative care approach for persons with dementia. 2023

Priscilla Attafuah. Quality of life, health, and social needs of slum-dwelling older adults in Ghana. 2023

Ron Warnier. Frailty screening in older hospitalized patients. 2023

Megan Davies. Tri-national ethnographic multi-case study of person-centred care and quality of life in long-term residential care. 2023

Christoph Golz. Technostress among health professionals: The blame game between health professionals and technology. 2023

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Anne van den Bulk. Differences that matter: Understanding case-mix and quality for prospective payment of home care. 2022

Marlot Kruisbrink. Towards enhanced management of fear of falling in older people. Unravelling interventions and measuring related avoidance of activity. 2022

Ruth Vogel. Nurses in the Lead: empowering community nurse leaders to implement evidence into practice. 2022

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Roy Haex. Take a look through my eyes: The development of an experienced quality measure with clients, informal, and formal caregivers in Dutch home care. 2021

Sascha Bolt. The fundamentals of a DEDICATED palliative approach to care for people with dementia. 2021

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Donja Mijnarends. Sarcopenia: a rising geriatric giant. Health and economic outcomes of community-dwelling older adults with sarcopenia. 2016

Tanja Dorresteijn. A home-based program to manage concerns about falls. Feasibility, effects and costs of a cognitive behavioral approach in community-dwelling, frail older people. 2016

Basema Afram. From home towards the nursing home in dementia. Informal caregivers' perspectives on why admission happens and what they need. 2015

Noemi Van Nie-Visser. Malnutrition in nursing home residents in the Netherlands, Germany and Austria. Exploring and comparing influencing factors. 2014

Esther Meesterberends. Pressure ulcer care in the Netherlands versus Germany 0-1. What makes the difference? 2013

Math Gulpers. EXBELT: expelling belt restraints from psychogeriatric nursing homes. 2013

Hilde Verbeek. Redesigning dementia care. An evaluation of small-scale homelike care environments. 2011

Judith Meijers. Awareness of malnutrition in health care, the Dutch perspective. 2009

Ans Bouman. A home visiting program for older people with poor health. 2009

Monique Du Moulin. Urinary incontinence in primary care, diagnosis and interventions. 2008

Anna Huizing. Towards restraint free care for psychogeriatric nursing home residents. 2008

Pascalle Van Bilsen. Care for the elderly, an exploration of perceived needs, demands and service use. 2008

Rixt Zijlstra. Managing concerns about falls. Fear of falling and avoidance of activity in older people. 2007

Sandra Zwakhalen. Pain assessment in nursing home residents with dementia. 2007

PUBLICATIONS

PUBLISHED CHAPTERS OF THIS THESIS

Khemai, C., Janssen, D. J. A., Schols, J. M. G. A., Naus, L., Kemper, S., Jole, I., Bolt, S. R., & Meijers, J. M. M. (2020). Nurses' needs when collaborating with other healthcare professionals in palliative dementia care. Nurse education in practice, 48, 102866. https://doi.org/10.1016/j.nepr.2020.102866

Khemai, C., Meijers, J. M., Mujezinovic, I., Bolt, S. R., Pieters, S., Moser, A., Schols, J. M. G. A., & Janssen, D. J. A. (2022). Interprofessional collaboration in palliative dementia care through the eyes of informal caregivers. Dementia (London, England), 21(6), 1890–1913. https://doi.org/10.1177/14713012221098259

Khemai, C., Meijers, J. M., Bolt, S. R., Pieters, S., Janssen, D. J. A., & Schols, J. M. G. A. (2023). I want to be seen as myself: needs and perspectives of persons with dementia concerning collaboration and a possible future move to the nursing home in palliative dementia care. Aging & mental health, 1–10. Advance online publication. https://doi.org/10.1080/13607863.2023.2226079

OTHER PUBLISHED ARTICLES

Mujezinović, I., Khemai, C. & Meijers, J. Een vredige dood bij mensen met dementie. TVZ verpleegkd prakt wet 131, 28–31 (2021). https://doi.org/10.1007/s41184-020-0903-6

Rossell L, Khemai C, Meijers J. Het ontwikkelen en evalueren van een gespreksshulp om de samenwerking te bevorderen tussen naasten van mensen met dementie en zorgprofessionals omtrent vroegtijdige zorgplanning in het verpleeghuis. Nederlands-Vlaams Tijdschrift voor Palliatieve Zorg. 2021;17(2):81-87.

Bolt, S. R., van der Steen, J. T., Khemai, C., Schols, J., Zwakhalen, S., & Meijers, J. (2021). The perspectives of people with dementia on their future, end of life and on being cared for by others: A qualitative study. Journal of clinical nursing, 10.1111/jocn.15644. Advance online publication. https://doi.org/10.1111/jocn.15644

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dementia living in long-term care facilities during the COVID-19 pandemic: A rapid scoping review. International journal of nursing studies, 113, 103781. https://doi.org/10.1016/j.ijnurstu.2020.103781

Groenvynck, L., Khemai, C., de Boer, B., Beaulen, A., Hamers, J. P. H., van Achterberg, T., van Rossum, E., Meijers, J. M. M., & Verbeek, H. (2023). The perspectives of older people living with dementia regarding a possible move to a nursing home. Aging & mental health, 1–9. Advance online publication. https://doi.org/10.1080/13607863.2023.2203693

ABOUT THE AUTHOR

Chandni Khemai was born on March 23, 1994 in Amsterdam, the Netherlands. She completed grammar school at International Edith Stein college (2012). Chandni was 17 years when she first conducted survey research for her school research project involving older adults living in the nursing home Vrederust-West in The Hague. During college years, she acquired her Bachelor degree in Biomedical Science (2016) and Master degree in Vitality and Ageing at Leiden University (2017). In her bachelor thesis, she investigated the risk factors associated with one-year mortality within the emergency department patients aged 70 years and older (*Department of Geriatrics and Gerontology*). In her master thesis, she explored the needs regarding knowledge transfer and distilled recommendations to improve knowledge transfer (*Department of Public Health and Primary Care*). During her master, she additionally performed a case study about the appropriate timing to conduct advance care planning for older adults. After university graduation, she worked for one and a half year at the Netherlands Organisation for Health Research and Development (ZonMw) as a programme assistant for the Joint Programming Initiative More Years Better Lives (JPI MYBL). JPI MYBL focusses on coordinating and collaborating with national and European research programs investigating demographic changes, and healthy and active ageing. As programme assistant, she conducted organisational tasks such as organising meetings, workshops and conferences, supported in writing reports and strategical documents, and aided in monitoring the progression of the programme. She additionally contributed to communicating the experiences and needs of the participating organisations after international congresses via vlogs and/or newsletters.

In January 2019, Chandni started her PhD trajectory at the Department of Health Services Research Maastricht University. This PhD trajectory was part of the Desired Dementia Care Towards End of Life (DEDICATED) within the Living Lab of Ageing and Long-Term Care. DEDICATED aims to improve palliative care for persons with dementia living at home and in nursing homes. Between 2021 and 2022, she developed the two guidance documents, two infographics and one video together with healthcare professionals and educational professionals, and thereby contributed to the overall DEDICATED approach. During her PhD trajectory, she collaborated with the TRANS-SENIOR project to deliver her input for the development of the moving scan, attended international and national (digital) conferences, followed diverse courses, and co-supervised several BSc and MSc students. After her PhD, Chandni strives to continue to work in the healthcare sector for the elderly and aims to develop herself in the area of implementation science, or other fields related to achieving impact in practice.

Chandni is currently working as an implementation specialist at ZonMw, and focuses on the implementation of knowledge derived from research conducted within the care sector for older and chronically ill persons. Chandni will start soon with her upcoming new profession as senior policymaker at the Ministry of Health, Welfare and Sport (VWS). In her profession as policymaker, she will focus on key aspects of quality of care such as shared decision-making and advance care planning.

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My PhD trajectory had some bright but unfortunately also many dark moments. It is in those dark moments that teach a person who is really there for you and what is really important in life, and life is fortunately not about whether you get knocked down but whether you get up (*Vince Lombardi*). All you need to get up is yourself. The most beautiful moments I will always remember were those moments when I interviewed persons with dementia. I enjoyed every conversation with them. Apart from conducting conversations with them to extract results for this thesis, I learned a lot about their perspective on life and lessons learned in life. I also vividly embodied the moments of writing my articles and this thesis. To me writing feels like a work of art by putting the puzzle pieces together until your voice is expressed on the paper the way you want it to be heard by the reader.

I would like to thank the following persons for their support during my PhD trajectory:

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THE EXECUTIVE COMMITTEE OF THE DEDICATED TEAM

I want to thank **Els Knapen**, **Lara Dijkstra**, **Saskia Wolters**, **Jesper Biesmans** and **Sascha Bolt** as members of the executive committee of the DEDICATED team for their input on the products derived from this trajectory. Every Thursday was the (online) DB-meeting in which we did not only discuss the progression of the research project, but also conducted several discussions on how to reach the target group. Together we came up with ways to improve the products and the method to deliver these products. Thank you for all those discussion moments and creative brainstorms that led to the introduction of Charlotte Grün and Ruud Lenssen into the DEDICATED project, and enriched my products.

MY PHD COLLEAGUES

I want to thank Sascha Bolt for sharing her experience, advice and working together with me in the DEDICATED project. From outside of the DEDICATED project, I especially want to thank **Lindsay Groenvynck** and **Nannan Li** for connecting with them. We did not only share PhD stories, but were also able to talk about other things in life. Even after my PhD trajectory, I received warm and supporting words from both of you.

MY PARANYMPHS

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IMPORTANT CONTRIBUTORS

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THE ASSESSMENT AND OPPOSITION COMMITTEE

I want to thank **Prof. dr. S. M.G. Zwakhalen**, **Prof. dr. G.D.E.M. van der Weijden**, **Prof. dr. M.E. de Vugt**, **Prof. dr. D. Gerritsen** and **Dr. M. Engel** for assessing my thesis, and providing me the opportunity to defend my thesis. I additionally want to thank **Prof. Dr. A. Swinnen** and **Dr. M. Klapwijk** as part of the opposition committee.

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