



An overview of concluded, current and planned projects in the field of palliative care for people with dementia in the Netherlands

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Date: 06-07-2018

Abstract

Background: The increasing number of older people suffering from dementia imposes challenges on delivering the required support and care, which may be particularly complex at the end of life. Palliative care focuses hereby on comfort and the quality of life of people suffering from a disease such as dementia. To date, various Dutch initiatives exist aiming to increase the quality of palliative care for people with dementia. One of these initiatives is the research and implementation project DEDICATED. The board of the project DEDICATED noticed an overview of projects on palliative care for people with dementia is lacking and initiated this research.

Aim: To provide a clear overview of concluded, current and planned projects aimed at increasing the quality of palliative dementia care in the Netherlands.

Methods: The research started with a scoping review focussing on projects related to palliative care, dementia and/or end-of-life care. Academic and non-academic databases were used to search for projects. The scoping review led to an overview and infographic in which only projects related to dementia care and palliative care were included. Information about the content, the target group and setting, the related domains of palliative care were described for each project in the overview. The content of the concept versions of the overview and infographic were validated in a focus group by the advisory board of the project DEDICATED (which included experts in palliative care and dementia from organisations such as IKNL and Vilans).

Results: The scoping review resulted in 52 projects, of which 18 projects were eligible for inclusion. After a focus group with experts of the advisory board a total number of 22 projects were included. Of these 22 projects, the majority of projects has concluded. Eleven domains of palliative care are interconnected and need to be considered to provide optimal palliative care in dementia care. Most projects are related to domain three and domain ten. A total number of ten projects is solely focusing on people with dementia, a total number of eleven projects is related to healthcare providers, and eight projects are solely focusing on relatives. Only one project is focusing on the three target groups. The majority of projects is focusing on the intra and extramural care setting, as the minority is focusing on the transmurals care setting.

Conclusion: A comprehensive overview was lacking and is now developed including 22 Dutch projects and represents additional characteristics as the implementation phase, domains of palliative care, target group and setting. Overall, most projects are related to setting care goals and ACP and education of the healthcare team. However, to provide optimal palliative care for people with dementia, all domains of palliative care should be considered. The overview and infographic can be disseminated between stakeholders in the field of palliative care and dementia care to create awareness of the existence of various projects. Frequent adaptation of the overview is recommended.

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List of abbreviations

ACP	Advance Care Planning
IKNL	Integraal Kankercentrum Nederland
MUMC+	Maastricht Universitair Medisch Centrum +
SDM	Shared Decision Making
V&VN	Verpleegkundigen & Verzorgenden Nederland

1. Introduction

In the introduction chapter of this research, first the background of the study is discussed. Second, the relevance of the research will be elaborated. Third, the overall research approach is described.

1.1 Background

Dementia is a life-limiting disease with an unpredictable prognosis (Van der Steen et al., 2014; Badrakalimuthu & Barclay, 2013). In 2016, 4804 men and 10051 women died of dementia in the Netherlands and these numbers are continuously rising (Alzheimer Nederland, 2014; Van der Steen et al., 2014). The increasing number of older people suffering from dementia imposes challenges on delivering the required support and care, which can be particularly complex at the end of life (Badrakalimuthu & Barclay, 2013; Perrar, Schmidt, Eisenmann, Cremer & Voltz, 2015).

Palliative care focuses on comfort and the quality of life of people suffering from a disease leading to an imminent death, such as dementia (Boddaert, Douma, Dijxhoorn & Bijkerk, 2017; Mistiaen, Francke, Claessen & Onwuteaka-Philipsen, 2014). Palliative care involves managing burdensome symptoms (such as pain), as well as addressing social, psychological and spiritual problems. Palliative care neither rushes nor delays the actual death and sets out to preserve the best possible quality of life until death (Radbruch & Payne, 2009). Determining the initiation of the palliative phase for people with dementia is complex, as the course of decline associated with the disease is irregular and sudden aggravation of symptoms may occur at any stage (Dowling et al., 2015). Nevertheless, an early palliative approach to care is indicated by Van der Steen (2010). Moreover, due to the prognostic uncertainties, general practitioners may face difficulties in setting appropriate care goals (Carter et al., 2015). Throughout the course of dementia, care goals and the prioritizing of care goals are subject to change. Figure 1 demonstrates these care goals, plotted against the different stages of dementia. The visualization of care goals represents an abstraction of reality. In practice, this requires tailoring to the needs and preferences of people with dementia and their relatives (van der Steen et al., 2014).

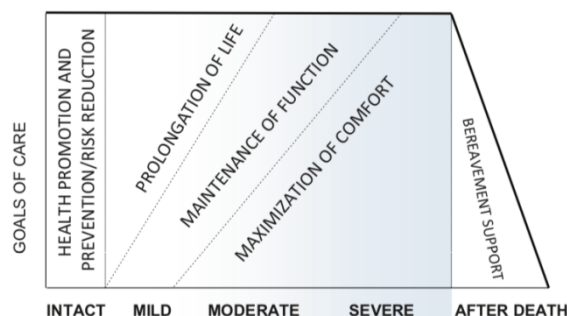


Figure 1: Dementia progression and suggested prioritizing of care goals

People with dementia may face difficulties when thinking about potential future problems due to cognitive impairments, which could obstruct the introduction of a palliative care approach. Timely provision of palliative care that is not limited to the terminal phase may prevent unnecessary hospitalizations and burdensome interventions in case of acute illness (Hertogh, 2006). Delaying palliative care may result in less effective and stressful treatments (Mistiaen et al., 2014). Advance Care Planning (ACP) is an essential element in palliative care for people with dementia (Dening et al., 2011). ACP increases the quality of care as it allows people with dementia in an earlier stage of their illness to state their preferences for (future) care. Ideally, people with dementia, their relatives, and the palliative care team should timely discuss the planning and delivery of palliative care. ACP is a continuous process in which the individuals' wishes, care preferences and medical treatment options should all be considered. Changes in the persons' condition or performance status will lead to adjustments in the treatment program. A continuous discussion and adaptation of the care program will result in an individual plan of care throughout the disease trajectory. Palliative care should integrate means for ACP, ensuring people with dementia to receive palliative care according to their desired preferences (Radbruch & Payne, 2010).

In the Netherlands, various efforts have already been made that are aimed at increasing the quality of palliative care. One of these efforts involves a quality framework for palliative care that was developed by Palliactief and the Integraal Kankercentrum Nederland (IKNL). The Dutch government wants to ensure that every citizen is assured of good palliative care in the right place and at the right time by the right caregivers. The quality framework was developed to clarify to patients, patients' relatives, and healthcare professionals what exactly 'good palliative care' entails. To create an unambiguous quality framework, a collaboration was established between national palliative care organizations, scientific associations, health insurers, and government parties. Although this quality framework assures that every citizen is provided with good palliative care, people with dementia and their relatives may need palliative care specific to dementia, as the disease trajectories differ compared to other types of patients (Van der Steen et al., 2014). In 2014, Van der Steen et al. (2014) developed a definition of palliative care specific for older people with dementia in a whitepaper. This definition entails eleven domains with recommendations to provide optimal palliative care. The different courses of patient deterioration warrant for dementia-specific palliative care strategies in which all the domains of palliative care should be applied (Van der Steen et al., 2014; Wanrooij, de Graeff, Koopmans, Prins & Leget, 2010).

With the goal of increasing the quality of palliative care for people with dementia, the research and implementation project DEDICATED (Desired Dementia Care Towards End of Life) was set up. This four-year project was established in 2017 in the Netherlands and receives funding from ZonMw. The overall goal of the DEDICATED project is to increase the quality of end of life care for people with dementia receiving long term care in the home setting or in the nursing home setting (DEDICATED, n.d.).

The board of the DEDICATED project noticed the existence of various other initiatives in the Netherlands also aiming to improve the quality of palliative care for people with dementia. Currently, a clear overview of these projects is lacking. Awareness of other initiatives existing in the field of palliative dementia care may support collaboration and effective dissemination of knowledge, thereby increasing efficiency. To map concluded, current, and planned Dutch projects in the field of palliative care for people with dementia, the following research question was formulated: *"What are concluded, current and planned projects in the field of palliative care for people with dementia in the Netherlands?"*

To answer the research question, different sub questions are formulated:

- *"What phase of development are the projects in?"*
- *"How do the projects relate to the suggested domains of palliative dementia care?"*
- *"What are the projects' setting and population of interest?"*

1.2 Relevance

This study is relevant from a societal, political and scientific point of view. The results from this study contribute to the awareness about different palliative care initiatives for people with dementia in the Netherlands. The identified projects will be mapped to provide a clear overview of projects aimed at increasing the quality of palliative dementia care in the Netherlands. This will enable stakeholders to easily identify projects that are relevant to their setting or context. From a scientific point of view, this research contributes to awareness of existing initiatives that may inform similar projects and aid knowledge transfer across projects. Researchers can share results of already examined aspects of palliative care, thereby disseminating knowledge. This may save time and effort as previous research findings can be re-used or elaborated on. Additionally, subsidy money can be used more efficiently as more researchers benefit from the performed research. This economic advantage can be utilized to target existing gaps in research concerning palliative care for people with dementia.

1.3 Overall research approach

The study will start with a scoping review to explore the existence of current projects in the Netherlands. The scoping review involves a literature search in which projects related

to palliative care and dementia will be included. Projects will be searched for using various sources. Websites of the key organizations of the DEDICATED project, PubMed, and Google Scholar will be used. Additionally, questions will be asked to the advisory board members of the project DEDICATED as well as to other stakeholders in the field of palliative care and dementia such as J. Meijers (project leader of the project DEDICATED) and J. van der Steen (researcher in the field of palliative care and dementia).

The overview will be presented to the advisory board of the DEDICATED project, using a focus group/ expert opinion approach. By discussing the different projects with the advisory board, additional recommendations can be made to complete and improve the overview. To present the results in a clear and visually attractive manner, the results will be translated into an infographic. An infographic improves the handiness of information, which in turn leads to easier use of the overview. Stakeholders can use the infographic as guidance to see which projects are relevant to their setting, so they can deepen themselves into that particular project. An infographic serves to simplify complex information and is therefore appropriate for comprehensively presenting the different projects (Meyer, 1997). Additionally, the advisory board will be asked to give their advice on how to distribute/disseminate the overview. Thereby, awareness that an overview of the projects is being developed, will be formed among stakeholders.

2. Theory and concept model

In this chapter, concepts related to the research objective will be elaborated on. Concepts of dementia, palliative care and the domains of palliative care will also be presented.

2.1 Theoretical framework

Dementia causes the brain to degenerate, leading to a decline in cognitive and physical functioning. Dementia is a progressive and incurable condition which follows a heterogeneous course (Alzheimer Nederland & Vilans, 2013). The most common form of dementia is Alzheimer's disease. 60-70% of all dementia cases are Alzheimer's. Currently, dementia is defined as an incurable disease and thus palliative care is required to address patients' and family concerns and needs (Van der Steen et al., 2014). IKNL developed an extensive quality framework for palliative care (Boddaert et al., 2017). The definition of palliative care is mentioned below:

"Palliative care is care that improves the quality of life of patients and their relatives who are confronted with a life-threatening condition or vulnerability, by preventing and alleviating suffering, through early signalling and careful assessment and treatment of physical, physical and mental problems, psychological, social and spiritual nature. During the course of the disease or vulnerability, palliative care has an eye for maintaining autonomy, access to information and decision possibilities. Palliative care has the following characteristics:

- *the care can be provided simultaneously with disease-oriented treatment;*
- *generalist caregivers and, where necessary, specialist caregivers and volunteers work together as an interdisciplinary team in close collaboration with the patient and their relatives and coordinate the treatment on values, wishes and needs set by the patient;*
- *the central care provider coordinates the care for continuity;*
- *the wishes of the patient and his relatives about dignity are recognized and supported during the course of the disease or vulnerability, during the dying process and after death" (Boddaert et al., 2017).*

The definition by Boddaert et al. (2017) includes important aspects of palliative care which focus on interdisciplinary collaboration, dignity, autonomy, information access and decision-possibilities. The definition can be used as a guideline for palliative care in general, but it is not specified for people with dementia. However, Van der Steen et al. (2014), in turn, describes a definition of palliative care specifically for people with dementia. In their white paper on optimal palliative care in older people with dementia', eleven domains with additional recommendations for each of them, form a framework for guiding clinical

practice, policy, and research. The eleven domains, with recommendations are presented below.

- Domain 1: Applicability of palliative care

Different aspects are important to fulfil the first domain. Recognition of the terminal nature of dementia is the basis for anticipating future problems and a drive to the provision of adequate palliative care. Also, goals of palliative care change over time and a palliative care approach for people with dementia should be available.

- Domain 2: Person-centred care, communication and shared decision making (SDM)

Problems should be viewed from a patient's perspective with application of person-centered care. On top of that, SDM should be aimed at and includes the patient and relatives as partners. The healthcare team should ask for information about needs on the course of dementia, and place of given care should be addressed and discussed on a regular basis.

- Domain 3: Setting care goals and ACP

ACP should start from the moment the diagnosis of dementia is made. In mild dementia, people need support in planning for the future, in severe dementia and when death approaches, the patient's best interest may be increasingly served with a primary goal of maximization of comfort. ACP should be seen as a process, and plans should be revisited with patient and family on a regular basis and following any significant change in health condition. Care plans should be documented and stored in a way that permits access to all disciplines involved in any stage and through transfers.

- Domain 4: Continuity of care

Continuity of care entails that care is continuous and has no interruption even with transfer. All patients should benefit from the early appointment of a central coordinator from within their care team. Transfers between settings require communication on care plans between former and new professional caregivers and patient and families.

- Domain 5: Prognostication and timely recognition of dying

A timely discussion of the terminal nature of the disease may enhance relatives' and patients' feelings of preparedness for the future. Prognostication in dementia is challenging and mortality cannot be predicted accurately. However, combining clinical judgement and tools for mortality predictions can provide an indication which may facilitate discussion of prognosis.

- Domain 6: Avoiding overly aggressive, burdensome or futile treatment

Domain six is related to avoiding overly aggressive, burdensome or futile treatment in which transfer to the hospital and the associated risks and benefits should be considered in relation to the care goals and taking into account also the stage of the dementia. Moreover, restraints should be avoided whenever possible.

- Domain 7: Optimal treatment for symptoms and providing comfort

A holistic approach to the treatment of symptoms is paramount. Distinguishing between sources of discomfort in severe dementia is facilitated by integrating views of more caregivers. Tools to assess pain, discomfort and behavior should be used for screening and monitoring of patients with moderate and severe dementia, evaluating effectiveness of interventions. Nursing care is hereby considered as very important to ensure comfort in patients near death.

- Domain 8: Psychosocial and spiritual support

A comfortable environment for people who are dying is desirable. In mild dementia, as also in the later stages, patients may be aware of their condition, and patients and families may need emotional support. Spiritual caregiving in dementia should include at least assessment of religious affiliation and involvement, sources of support and spiritual well-being; in addition, referral to experienced spiritual counsellors such as those working in nursing homes may be appropriate.

- Domain 9: Family care and involvement

Families may suffer from caregiver burden, may struggle to combine caring with their other duties and may need social support. Families may need support throughout the trajectory, but especially upon diagnosis, when dealing with challenging behavior. Families need education regarding the progressive course of the dementia and (palliative care) treatment options; this should be a continuous process addressing specific needs in different stages, examining family receptiveness.

- Domain 10: Education of the healthcare team

The health care team need to have adequate skills in applying a palliative care approach to dementia. Core competencies comprise all of the above listed domains (1 to 9). All competencies should be available within a health care team, and preferably all individual members of the team should be able to provide at least a baseline palliative care approach.

- Domain 11: Societal and ethical issues

People with dementia should have access to palliative care on the same footing as patients with other diseases which are unresponsive to curative treatment whereby collaboration between dementia and palliative care should be promoted. Economic and systemic incentives should encourage excellent end-of-life care for patients with dementia. National strategies for dementia, for palliative care, end-of-life care, and for long-term care should each include palliative care for dementia patients. Similarly, policy making on palliative care and long-term care settings should attend to dementia.

The domains can serve as a framework in which gaps in courses, programs, or in information provided to relatives can be identified. Moreover, the domains can be used in the development and implementation of policies in the development of quality indicators, or to make comparisons with (future) definitions or conceptualisations of palliative care in other progressive chronic diseases (Van der Steen et al., 2014). In this study, the domains of Van der Steen et al. (2014) will be used as framework to cluster projects according to their contents and correspondence with the domains.

Presently, there are various Dutch initiatives aiming to increase the quality of palliative care for people with dementia. The present research follows the design of the DEDICATED project, consisting of two interrelated subprojects.

The main focus of the first subproject is providing professional caregivers/nursing staff with basic knowledge and skills about palliative care for people with dementia. Additionally, the first subproject addresses timely and adequate end of life communication in the home care and nursing home setting. Within the first subproject, a competence toolkit will be developed, implemented, and evaluated. The toolkit will be established based on bottlenecks identified by professional caregivers as well as the needs and desires of people with dementia and their relatives. One part of the toolkit focuses on increasing the knowledge of nursing staff to help them with identifying and addressing palliative care needs in the physical, psychosocial and spiritual domain. The other part of the toolkit will be interdisciplinary and focuses on end of life communication, ACP, and making joint decisions. Innovative and feasible learning styles will be used in this part of the project.

The second subproject focuses on the interdisciplinary collaboration amongst the various stakeholders involved in the palliative care for people with dementia, within and between care settings. This subproject also focuses on transfers between the home care and nursing home setting, which should be pro-active as to prevent fragmentation of care. Both aspects of the second subproject are complementary and aim to guarantee the continuity of care. Existing collaboration models and tools will be inventoried. Based on

this inventory, a collaboration strategy for all the involved disciplines in palliative dementia care will be developed, implemented and evaluated.

2.2 Conceptual model of the study

In this study, the implementation of change model of Grol & Wensing (2005) will be used as a conceptual guideline. This model suggests different steps to support successful implementation of a project (Figure 2). This model will be used to assess in which phase of the implementation each project is allowing a division of different projects based on their implementation phase.

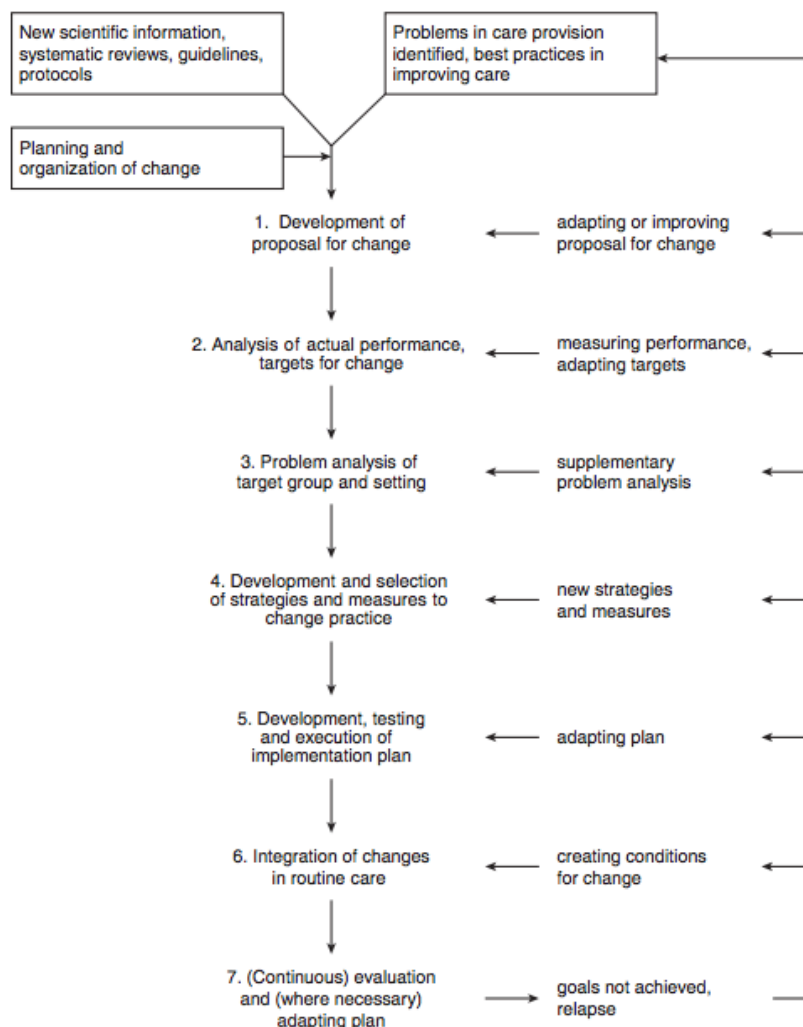


Figure 2: The Grol & Wensing implementation of change model

3. Methods

In this chapter, the methodology will be discussed. Therefore, in subchapter 3.1, the research design will be described. In subchapter 3.2 the method on data collection and sampling method will be shown. In the next subchapter, 3.3, the data analysis is represented. Finally, in subchapter 3.4, the validity and reliability of the study will be described.

3.1 Design of the research

In this research, a qualitative design was used to provide answers to the research question and sub questions comprising a scoping review and a focus group. The research has been conducted from April 2018 until July 2018 at Maastricht University as an element of the research and implementation project DEDICATED.

First, the research started with a scoping review which described key characteristics and concepts about current, previous and planned projects (Armstrong, Hal, Doyle & Waters, 2011). Second, the concept version of the overview and infographic were presented to the advisory board of the project DEDICATED for validation in a focus group setting. A focus group is useful for exploring people's knowledge and experiences. The group interaction was part of the method which encouraged members to contribute to the discussion and to come up with ideas to improve the overview (Kitzinger, 1995).

3.2 Study population

As the DEDICATED project focusses on increasing palliative care for people with dementia, solely projects involving a combination of both were considered. The project DEDICATED focusses only on the long-term care settings, therefore, projects focusing on short-term/acute care settings, such as acute (hospital) care or out-patient treatment, were not taken into account. Because the board of the DEDICATED project wanted to disseminate and transfer knowledge between different projects, only Dutch projects were included. The concluded projects contained only projects which have concluded but could still be used in today's practice.

The focus group consisted of the advisory board of the DEDICATED project including key persons (experts in palliative care and dementia care) from its partner organizations, which include: Vilans, CZ, Maastricht Universitair Medisch Centrum+ (MUMC+), Vivantes, Huis van de Zorg, Zuyderland, Thuiszorg Zuyderland, Envida, IKNL, Alzheimer NL and Verpleegkundigen & Verzorgenden Nederland (V&VN).

3.3 Data collection

A scoping review was conducted to identify projects aiming at increasing the quality of palliative care for people with dementia. To identify a broad range of projects, academic

and also non-academic databases were used such as PubMed, Google and websites of the organizations represented in the advisory board of the project DEDICATED. For example, the websites of IKNL and Alzheimer Nederland were searched for terms as: dementia, palliative care and palliative dementia care. Additionally, the website of ZonMw was used to collect data.

Another data collection method involved presenting the overview to the advisory board. One week prior to the focus group, the overview was sent to the members of the advisory board by e-mail, enabling every member to prepare questions and recommendations beforehand. During the focus group, the progress of the overarching project DEDICATED was presented. Additionally, the developed concept version of the overview and infographic were shown on screen and the advisory board members were given handouts. Every present member of the advisory board was asked to provide feedback on the overview and infographic one by one. After the focus group, an e-mail with the overview and infographic as attachments was sent to the absent members of the advisory board. In this e-mail, the researcher asked politely if the particular member of the advisory board missed projects or had additional recommendations.

3.4 Data analysis

The available information on different websites was analyzed by writing down characteristics of each projects, such as content of the project, year in which the project was, is or will be established, related organization, goal of the project and the place of development. To put all information together, an Excel overview was made containing the mentioned characteristics of each project. Additionally, the domains of palliative care described by Van der Steen et al. (2014), were used as guide to cluster projects in order to see which projects were related to which domains. At last, data was analyzed based on target groups by searching available data of the projects to find the group for who the project was initiated. The projects were initiated for people with dementia, healthcare providers, relatives, people with dementia and relatives or people with dementia, healthcare providers and relatives. The information about the target group of each project was added to the Excel sheet. Also, information about the care setting was searched for by writing down the setting for which the project was meant. Projects could be related to the trans, intra and/or extra mural setting of care. The distinction of projects was based on the phase of implementation, the domains of palliative care and target group and setting and was validated by the advisory board and other stakeholders in the field of palliative care for people with dementia. During the focus group, the researcher wrote down notes to document recommendations. These notes were analysed by searching for missed information in order to complement the overview.

3.5 Reliability and validity

A strength of this study was the use of both academic and non-academic resources for searching projects. The validity of the study was hereby increased since important projects would have been missed by using only academic resources. Another method that was used to increase the validity was member checking. With member checking the members of the advisory board were asked if they felt that the major findings of the focus group were accurate (Creswell, 2014). An e-mail was sent after the focus group to all the members of the advisory board. Thereby, both members that were present and those that were absent during the initial focus group were able to check the overview and provide the researcher with recommendations to improve it. Moreover, this enabled members of the advisory board that were absent during the physical meeting to get involved in evaluating and contributing to the overview.

To ensure the reliability of the study, a cross-analysis with other master students who were conducting research on the subject of palliative care has been performed. Four meetings were scheduled in with four master students, including the researcher and the supervisor of the study. During these meetings, feedback was provided on the research of other students and feedback has been received from other students. Prior to the meetings, the progress of the research was sent to the other students. In this way, other students had time to read the research and provide each other with recommendations for improvement. Triangulation was hereby established which increased the reliability of the study (Leung, 2015).

3.6 Ethical considerations

The research proposal of this study was examined by the ethical committee of the University of Maastricht and categorized the research as a low-risk thesis project since the project included an adult population, no vulnerable groups, non-sensitive topics, and non-invasive data collection instruments, and/or ready datasets and review methods.

4. Results

In this chapter, the main findings of the study will be presented. In subchapter 4.1, the literature search is elaborated. In subchapter 4.2, an overview of the included projects is shown. Subchapter 4.3 presents the project based on current status. The domains of palliative care related to the projects are elaborated in subchapter 4.4. In subchapter 4.5 the target group and setting are presented and at last, in subchapter 4.6, a comprehensive overview of different projects is provided.

4.1 Literature search

By searching the literature, various projects related to either dementia care, palliative care or both came forward. The literature search resulted in 52 projects, of which 38 projects were related to either palliative care, dementia, or both. Of the 38 projects, twelve projects concerned only palliative care and eight only concerned dementia care, which made 18 projects eligible for inclusion. After the focus group with the advisory board and stakeholders in the field of palliative care and dementia, four projects were added which resulted in a total number of 22 projects (Figure 3).

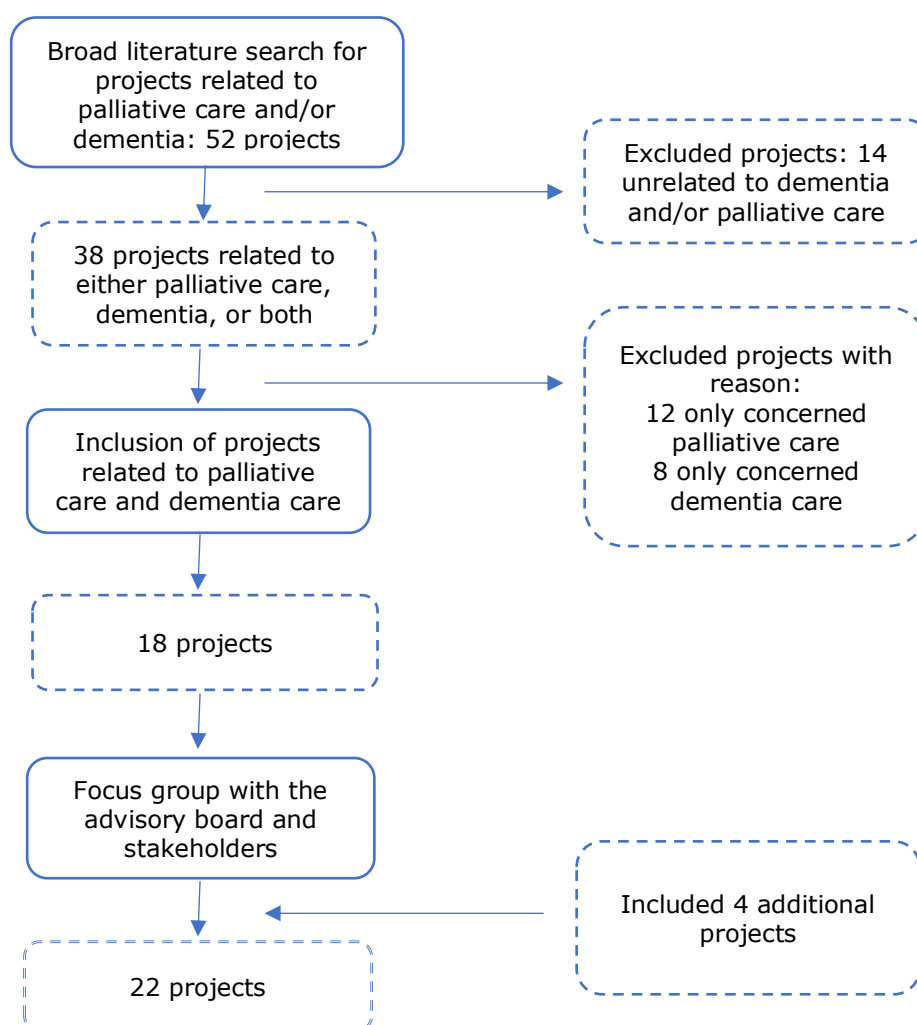


Figure 3: Overall flow diagram of the literature search

4.2 Overview of included projects

The 22 included projects are presented in an overview (Appendix I). In this overview, a short summary, together with additional information of the projects, can be found. Additionally, the included projects are presented in an infographic (Appendix II).

To present the result chapter more comprehensive, the titles of the included projects are attached to a number in alphabetical order (Table 1). Throughout the result section of this research, the projects will be represented by the attached number as shown in table 2.

Table 1: Numbers and related project

	<i>Project Title</i>	<i>Reference</i>
1	Care4Youngdem	Pistorius, 2016
2	Comparing palliative care in care homes across Europe (PACE)	Van den Block et al., 2016
3	CONT-END	Leids Universitair Medisch Centrum, 2017
4	Decidem	Tilburgs, n.d.
5	DEDICATED: Desired dementia care towards end of life	DEDICATED, n.d.
6	Dementie en palliatieve zorg – scholing in de huisartsenpraktijk	Quartz, n.d.
7	Dementie, landelijke richtlijn versie 1.0	IKNL, 2010
8	Feedback op levenseindezorg bij dementie (FOLLOW up)	Vilans, n.d.
9	Gesprekshulp voor de laatste levensfase bij dementie	Van der Steen et al., n.d.
10	Goed voor elkaar	ZonMw, n.d.
11	Handreiking: zo verbindt u palliatieve zorg en dementie	Stapersma, n.d.
12	Handreiking: zorg rond het levenseinde	Van der Steen, Hertogh, & De Graas, 2011
13	Het plannen van zorg in de laatste levensfase bij dementie	Van Soest-Poortvliet, 2010
14	MAPRO: markering van de palliatieve fase en proactieve zorg planning bij dementie	Onderzoeksteam Saxion & Windesheim, 2017
15	Measuring the quality of dying and the quality of palliative care for patients dying with dementia: properties of Dutch versions of six new outcome measures	Van Soest-Poortvliet et al., 2012
16	Namaste Care family program	Simard, 2007
17	Palliatieve zorg Noord-Limburg: 'Een sterk vangnet ook voor mensen met dementie!'	ZonMw, 2013
18	Signaleren in de palliatieve fase	IKNL, n.d.

19	Verbeter palliatieve zorg bij dementie	Vilans, n.d.
20	Verdiepingsmodule palliatieve zorg bij mensen met dementie	Netwerk palliatieve zorg, 2014
21	Vroegtijdige inzet van palliatieve zorg bij demente verpleeghuisbewoners	ZonMw, n.d.
22	White paper defining optimal palliative care in older people with dementia for Palliative Care (Dutch Translation)	Van der Steen et al., 2014

4.3 Phases of implementation

The implementation of change model was used to assess in which phase of implementation each project is (Grol & Wensing, 2005). However, the collected data about the projects is lacking precise information about the phase of implementation which makes it hard to assign the projects to one of the phases. Nevertheless, based on the collected data, a rough distinction can be made whether a project has not yet started, is currently running or has concluded. Of the 22 included projects, 17 projects have concluded, four projects are currently running, and one project has not yet started (Table 2). The numbers mentioned in table 3 are related to the projects presented in table 1.

Table 2: Projects divided by status

<i>Status of the project:</i>	Not (yet) started	Currently running	Concluded
<i>Project number:</i>	3	1, 9, 5, 16	2, 4, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 17, 18, 19, 20, 21, 22

Overall, most projects have concluded and can therefore be used in practice.

4.4 Included projects related to the domains of palliative care

The included projects are divided by the domains of palliative care. By showing which projects are focused on the different domains, it becomes clear which domains are more fostered than other domains (Table 4). Domain 1: applicability of palliative care is touched upon by all projects as all projects aim to increase the palliative care for people with dementia. However, projects 14 and 21 are focusing on marking and signalling the palliative phase and have the tendency to be more related to the first domain than other projects. The majority of the projects is related to domain 3: Setting care goals and ACP, and/or 10: Education of the healthcare team. In general, there are seven projects which have an overall aim of increasing the discussion about needs and wishes of someone with dementia or their relatives and are therefore related to domain 3: Setting care goals and ACP. Domain 10: Education of the healthcare team, is also supported by seven projects,

which make domain three and ten the most supported domains of palliative care. It appears that there is no project which main objective is to avoid overly aggressive burdensome or futile treatment (Domain 6). However, various projects are related to multiple domains what does not allow for the projects to be assigned to a specific domain of palliative care. Project 13 focusses for instance on the education of the healthcare team (Domain 10) in order to increase the knowledge on how to set care goals (Domain 3). This shows that the domains of palliative care are intertwined in which all domains need to be touched upon to provide optimal palliative care. Yet, none of the projects is related to all the domains of palliative care.

The projects that are currently running (1, 9, 5, 16), are focussing on domains which are not directly supported by concluded projects. Moreover, project 3, which is planned, focusses on domain eleven which has not been covered by concluded projects.

Table 3: Projects related to the domains of palliative care in dementia

Domains:	Related project(s):	Total amount of projects:
1: Applicability of palliative care	14, 21	2
2: Person-centred care, communication, SDM	8, 9	2
3: Setting care goals and ACP	1, 3, 4, 5, 6, 13, 21	7
4: Continuity of care	10, 17, 18, 19	4
5: Prognostication and timely recognition of dying	14, 21	2
6: Avoiding overly aggressive, burdensome or futile treatment	n/a	n/a
7: Optimal treatment for symptoms and providing comfort	16	1
8: Psychosocial and spiritual support	16	1
9: Family care and involvement	12, 18	2
10: Education of the healthcare team	2, 5, 7, 10, 11, 20, 22	7
11: Societal and ethical issues	3	1

4.5 Target group and setting

The projects are aiming at different target groups. In this research, a target group can be seen as a specific group of people with the same shared characteristics, such as profession or illness. Overall, three target groups can be distinguished: people with dementia, healthcare providers and relatives (including family and informal caregivers) (Table 4). A total number of ten projects is solely focusing on people with dementia, a total number of eleven projects is related to healthcare providers, and eight projects are solely focusing on relatives. Some projects are focusing on multiple target groups. Five projects are focusing on both people with dementia and relatives. One project (project five) is focusing on people

with dementia, healthcare providers and relatives. The projects related to relatives have as primary goal to increase the quality of life for people with dementia.

Table 4: Projects related to target group

<i>Target group:</i>	People with dementia	Healthcare providers	Relatives	People with dementia and relatives	People with dementia, healthcare providers and relatives
<i>Projects:</i>	1, 3, 8, 9, 16	2, 4, 6, 7, 10, 11, 13, 14, 21	18, 20	9, 12, 15, 17, 22	5
<i>Percentage of total amount of projects:</i>	23%	41%	9%	23%	5%

Projects may be applicable to an intramural setting, extramural setting, or both. In Table 5, the care settings and related projects are presented including the percentage of one setting in comparison with the total amount of projects. Projects with the aim to make a connection between different organizations or networks to improve the quality of palliative care are assigned to the transmural setting. Ten projects are related to both the intra and extramural palliative care setting. Three projects are focused on the extramural palliative care setting. Four projects are focusing on the transmural setting of palliative care for people with dementia. Most projects are applicable to the intra/extramural care setting, but not specifically to either the intra, extra or transmural care setting.

Table 5: Projects related to care setting

<i>Care setting:</i>	Intramural	Extramural	Transmural	Intra/extramural
<i>Projects:</i>	2, 10, 16, 18, 21	4, 6, 12	5, 11, 17, 19	1, 3, 7, 8, 9, 13, 14, 15, 20, 22
<i>Percentage of total amount of projects:</i>	23%	14%	18%	45%

4.6 Comprehensive overview of included projects

The analyzed data, the responded e-mails and the written notes were used to complete the overview and the infographic (Appendix I & II). Additionally, to present a short summary of the projects in a comprehensive way, factsheets were made (Appendix III). The infographic, together with the factsheets, were translated into an interactive PDF. In this PDF, it is possible to press the title of a project which will automatically refer the reader to the related factsheet.

During the focus group with the advisory board, one member recommended to publish the overview on the Digi-platform of IKNL. Another member recommended to ask

the board of ZonMw to place the overview on the website of “The Palliantie Program” of ZonMw.

5. Discussion

In this chapter, the main findings of the study will be interpreted, limitations will be discussed, recommendations for further research will be provided, and a conclusion will be included.

Based on the literature search it appears that 22 projects are related to palliative care for people with dementia. Of these included projects, seventeen projects have already concluded, four projects are currently running, and one project has not yet started, which makes the majority of the projects concluded. Most projects touch upon domain three and domain ten of palliative care, while none of the projects is directly focussing on domain six. However, the domains of palliative care are intertwined. It was also found that most projects are applicable to the intra and extra mural care setting, and a minority of projects are related to only the transmural setting of care. Additionally, projects can be applicable for people with dementia, healthcare providers and/or relatives, or projects can be applicable to multiple domains. The majority of projects are focussing on healthcare providers, and only one project focusses on all three target groups.

The overview of projects shows which domains of palliative care, described by van der Steen et al. (2014), are covered by previous and existing projects. Assigning the projects to the domains of palliative care shows that most projects are related to education of healthcare providers and to setting care goals and ACP. Due to the increased prevalence of people with dementia, palliative care and end-of-life care gained more importance in medical and nursing school curricula. End-of-life care competencies are increasingly attached to requirements and exams of residency review bodies and specialty boards. Therefore, the special skills required for caring for people with dementia should be recognized and the continuity of education is needed to reach professionals who are already in practice (Sachs, Shega & Cox-Hayley, 2004). This could be an explanation of the presence of various projects related to education of the healthcare team.

Also, domain three is related to a high number of projects, which indicates the need for ACP in palliative dementia care. Moreover, the domains are interconnected with each other. By providing for instance optimal treatment for symptoms and providing comfort, aggressive burdensome or futile treatment will be avoided (Stacpoole, Hockley, Thompsell, Simard & Volicer, 2015). Also, ACP can be used as an example to indicate the interconnection of the domains. It indicates an improvement in satisfaction of the provided care and reduces feelings of stress, anxiety and depression in both patients and family members (Song, 2004). Therefore, the domains are related to each other and projects need to touch upon all domains in order to aim for optimal palliative care.

Three projects are focusing on the extramural palliative care setting and five projects are focused on the intramural palliative care setting and four projects are focusing on the transmurial setting of palliative care for people with dementia. It is remarkable that a minority of projects is related to the transmurial setting of care, as chronic complex care, such as dementia care, asks for interprofessional collaboration including transmurial care (Van Royen, 2009).

Five projects are focusing on both people with dementia and relatives. Project five is focusing on all three of the target groups. Projects related to relatives have as main focus to improve the palliative care for people with dementia, not focusing on the impact providing care has on relatives. Although, palliative care for people with dementia is extremely demanding of relatives (Schulz et al., 2003).

5.1 Limitations

For this research, information about existing projects, to develop a clear and comprehensive overview, was gathered within three months. Over time, researchers frequently develop new projects with the aim to improve the quality of palliative care for people with dementia. On this basis it can be stated that in case of reproduction of the research, the results concerning existing projects may differ from the results in this research which could result in a different outcome. However, the overview is intended to be a dynamic product. Frequent adaption as well as maintenance of the overview is desired to provide an accurate reflection of previous and existing projects. This can be done by the board of the DEDICATED project as the overview is part of the project DEDICATED.

5.2 Recommendations

It is recommended to disseminate the overview in order to create awareness of the existence of other projects. This can be done by publishing the overview on the Digi-platform of IKNL or by placing the overview on the website of "The Palliantie Program" of ZonMw. Also, frequent adaptation of the overview is advised to keep the overview up to date with current projects.

Recommendations for further research need to be considered. First, as most included projects are finished, it is recommended to thoroughly search at available evidence of the effectiveness of the finished projects. In this way, an extra aspect of the projects can be added to the overview. Second, in this research, only projects related to palliative care were taken into account. It is recommended to also include projects which use different terms for palliative care, so all related projects will be included, even though another term was used for palliative care. Third, in this research, only projects in the Netherlands are included, it is possible that other countries are focussing on different

domains of palliative care. To develop a more extended overview, international projects need to be included.

5.3. Conclusion

In conclusion, various projects in the Netherlands exist aiming to improve the quality of palliative care for people with dementia. A comprehensive overview was lacking and is now developed including 22 projects and represents additional characteristics as the implementation phase, domains of palliative care, target group and setting. This overview is translated into an interactive PDF in which an overall view of the existence of projects is given. Overall, most projects are related to setting care goals and ACP and education of the healthcare team. However, to provide optimal palliative care, all domains of palliative care should be considered. Although dementia care asks for interprofessional collaboration including transmural care, the minority of projects is focusing on transmural care. The overview can be disseminated between stakeholders in the field of palliative care and dementia to create awareness of the existence of various projects. Frequent adaptation of the overview is advised.

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Appendix I: Excell overview of projects focusing on palliative care for people with dementia

Naam project	Organisatie	Domein	Doelgroep	Inhoud	Plaats	Datum
Dementie en palliatieve zorg – scholing in de huisartsenpraktijk	QUARTZ-scholing	ACP	Huisartsen, ouderen zorg verleners, specialist ouderengeneeskunde, wijkverpleegkundigen, casemanager dementie	Vergroten van de discussie over de zorgwensen en behoeften van patiënten en de mantelzorger op een proactieve en tijdige manier. Een uur durende cursus om meer bewustzijn te creëren over dementie bij zorgverleners.	Helmond	2016
Decidem	Universitair Kennisnetwerk Ouderenzorg Nijmegen (Memorabel)	ACP	Huisartsen en praktijkondersteuners	Opleiding bestaande uit workshops om ACP te stimuleren voor personen met dementie. Onderzoek heeft aangetoond dat huisartsen (en praktijkassistenten) die de training volgden een significante toename laten zien in het bespreken en documenteren van ACP.	Nijmegen	
Verdiepings module palliatieve zorg bij mensen met dementie	Zorg voor beter	Educatie van zorgverleners	Verzorgenden die het programma 'palliatieve zorg' hebben gevolgd	Scholing (/bijeenkomsten) waarin wordt ingegaan op palliatieve zorg bij mensen met dementie.	Waardenland en Rotterdam	
richtlijnen						
Dementie, landelijke richtlijn versie 1.0	Pallialine	Educatie van zorgverleners	Zorgverleners	In de richtlijn worden aanbevelingen gedaan voor de verlening van dementiezorg.		2009
Handreiking zorg rond het levenseinde	VU medisch centrum, EMGO, afdeling Verpleeghuisgeneeskunde.	Familie zorg en betrokkenheid	Familie en naasten van iemand met dementie	De handreiking geeft inzicht in de ontwikkeling van dementie naar het einde van het leven en geeft mogelijke problemen en behandelmethoden weer. De nadruk ligt op palliatieve zorg.	Amsterdam	2011
Het plannen van zorg in de laatste levensfase bij dementie	ZonMw, Verenso, V&VN, Nederlnds Huisartsen Genootschap (NHG)	ACP	Zorgverleners	Het project resulteerde in een handleiding voor zorgaanbieders: 'Het plannen van de zorg in de laatste levensfase bij dementie' waarin gezamenlijk behandeldoelen worden vastgesteld.	Amsterdam	2013
Vrmechtijde Inzet van Palliatieve Zorg bij Dementie Verpleeghuisbewoners	Vu Medisch Centrum (Palliantie, meer dan zorg)	Signaleren en markeren palliatieve fase, ACP	Zorgverleners (verpleeghuis)	Handreiking met informatie over vroege start van palliatieve zorg bij personen met dementie in het verpleeghuis.		2009-2014
Signaleren in de palliatieve fase	IKNL	Familie zorg en betrokkenheid	Verzorgenden	Methode waarin stapsgewijs zorgproblemen worden gesignaleerd om te komen tot concrete handvaten op het gebied van signaleren, uitvoeren en evalueren van palliatieve zorg.		2016
MAPRO: Markering van de palliatieve fase en proactieve zorgplanning bij dementie	Saxion & Windesheim ism netwerken PZ en dementie (Palliantie, meer dan zorg)	Signaleren en markeren palliatieve fase, ACP	Zorgverleners (eerstelijin)	Gesprekswijzer waarbij zorgverleners worden ondersteund bij het tijdig bespreken van de palliatieve fase en het vormgeven van proactieve zorgplanning bij mensen met dementie.	Overijssel en Drenthe	2016-2017
Gesprekshulp voor de laatste levensfase bij dementie	LUMC, VUmc, Radboud UMC	Communicatie/SDM	Mensen met dementie en hun naasten	Het ontwikkelen van een gesprekshulp voor mensen met dementie en hun naasten, om gesprekken onderling en met zorgverleners over de laatste levensfase en palliatieve zorg te stimuleren en te structureren. De gesprekshulp geeft informatie en voorbeeldvragen.		2017-2019
Handreiking zo verbindt u palliatieve zorg en dementie	Vilans	Educatie van zorgverleners	Zorgverleners en professionals	De handreiking biedt zorgverleners en professionals praktische hulpmiddelen om dementiezorg en palliatieve zorg met elkaar te verbinden.		
Instruments						
Measuring the quality of dying and the quality of palliative care for patients dying with dementia: properties of Dutch versions of six new outcome measures	VU Medisch Centrum (Palliantie, meer dan zorg)	Metten van QoD/ palliatieve zorg	Nederlanders die zijn overleden aan dementie (in verschillende settings)	De 'End-Of-Life in Dementia-Satisfaction With Care' (EOLD-SWC) is het meest geschikt voor familie om de kwaliteit van zorg rond het levenseinde te meten. De 'End-Of-Life in Dementia-Comfort Assessment in Dying' (EOLD-CAD) is het meest geschikt voor het meten van de kwaliteit van sterven (vanuit het perspectief van een naaste en/ of zorgverlener).		2007-2010
Research						
Feedback op levenseindezorg bij dementie. (FOL low up)	VU Medisch Centrum (Palliantie, meer dan zorg)	Communicatie/SDM	Personen met dementie	Onderzoek naar de effecten van generieke en patiënt specifieke feedback op de kwaliteit van sterven en de kwaliteit van zorg van het levenseinde bij personen met dementie.		2012-2014
White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care (Dutch Translation)	European Association for Palliative Care	Educatie van zorgverleners	Beleidsmakers, mensen met dementie, naasten	In deze studie is op basis van bewijs en consensus een definitie gegeven van palliatieve zorg bij dementie. Ook is een kader met richtlijnen voor de klinische praktijk, beleid en onderzoek ontwikkeld.		2014
Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a Cross-sectional Study of Deceased Residents in 6 EU Countries.	European Union's Seventh Framework Programme	Educatie van zorgverleners	Zorgverleners (verpleeghuis)	Onderzoeksprotocol dat onderzoekers in zorginstellingen informeert over het uitvoeren van zorg aan het levenseinde. Ontwikkelt een internationale vergelijkende evidence-base die de palliatieve zorg in verzorgingstehuizen kan verbeteren.		2016
Care4Youngdem	UKON	ACP	Dementie bij personen <65 jaar	Het doel van dit onderzoek is om de zorg bij jonge mensen met dementie in kaart te brengen en te optimaliseren. Er zullen specifieke aanbevelingen geformuleerd worden voor de optimale (palliatieve) zorg.		2016-2021
CONT-FND	LUMC	ACP, sociale en ethische dilemma's	Mensen met dementie	In dit project, bestaande uit drie delen, wordt antwoord gegeven op de vraag welke mate van controle passend is voor iemand met dementie.		Nog niet gestart
Programma's						
Namaste Care Family program	VU Medisch Centrum (Memorabel)	Optimale behandeling van symptomen en comfort bieden	Personen met gevorderde dementie of personen die andere fysieke of mentale beperkingen hebben	Programma dat helpt bij het creëren van een veilige en geruststellende omgeving voor mensen met dementie.	Amsterdam	2014-2019
DEDICATED: Desired Dementia Care Towards End of Life	Academische Werkplaats Ouderenzorg Universiteit Maastricht (Palliantie, meer dan zorg)	Educatie van zorgverleners, continuïteit van zorg, ACP	Zorgverleners, personen met dementie, naasten	Verhogen van competenties bij het bieden van palliatieve zorg en het verbeteren van interprofessionele en transmurale samenwerking.	Maastricht	2017-2021
Verbeter palliatieve zorg bij dementie	Vilans	Continuïteit van zorg	Organisaties en netwerken	Het verbetertraject helpt bij het tot stand brengen van een samenwerking tussen dementiezorg en palliatieve zorg.	Zeeland	
Netwerken						
Goed voor elkaar	AxionContinu (Palliantie, meer dan zorg)	Continuïteit van zorg, educatie van zorgverleners	Zorgverleners (eerstelijin, hospices en intramurale ouderen zorg)	Dit project heeft oa geresulteerd in de inzet van vrijwilligers in de intramurale zorg voor ouderen en de beschrijving van een procedure hiervoor. Ook is een Modelrichtlijn voor hospices ten behoeven van personen met dementie en uitwisseling van kennis en ervaring tussen de verschillende deelnemers ontwikkeld.	Utrecht	2013-2014
Palliatieve zorg Noord-Limburg: 'Een sterk vangnet ook voor mensen met dementie!'	Proteion Thuiszorg Noord-Limburg (Palliantie, meer dan zorg)	Continuïteit van zorg	Personen met dementie en mantelzorgers	Verbindingen opzetten tussen ketenzorg dementie en het netwerk palliatieve zorg wat uiteindelijk resulteert in een aangepaste handleiding.	Haelen	2013-2015

Appendix II: Projects presented in infographic

Project:

15

Meet-

Instrument

Projecten:

1- 2- 3- 8- 22

Onderzoek

Projecten:

7- 9- 11- 12- 13- 14-

Middelen

Projecten:

5- 16- 19

Programma's

Projecten:

4- 6- 20

Educatie

Projecten:

10- 17

Netwerken

- 1:** Care4Youngdem
- 2:** Comparing palliative care in homes across Europe (PACE)
- 3:** CONT-END
- 4:** Decidem
- 5:** DEDICATED: Desired dementia care towards end of life
- 6:** Dementie en palliatieve zorg-

- scholing in de huisartsenpraktijk
- 7:** Dementie, landelijke richtlijn versie 1.0
- 8:** Feedback op levenseinde zorg bij dementie (FOLLOW up)
- 9:** Gesprekshulp voor de laatste levensfase bij dementie
- 10:** Goed voor elkaar
- 11:** Handreiking: zo verbindt u

- 12:** Handreiking: zorg rond het levenseinde
- 13:** Het plannen van zorg in de laatste levensfase bij dementie
- 14:** MAPRO
- 15:** Measuring the quality of dying and the quality of palliative

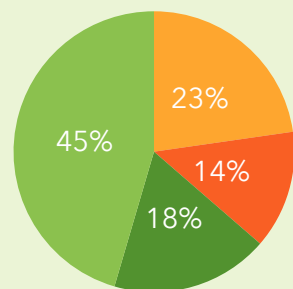
care for patients dying with dementia

- 18:** Signaleren in de palliatieve zorg bij dementie
- 19:** Verbeter palliatieve zorg bij dementie
- 20:** Verdiepingsmodule palliatieve zorg bij mensen met dementie

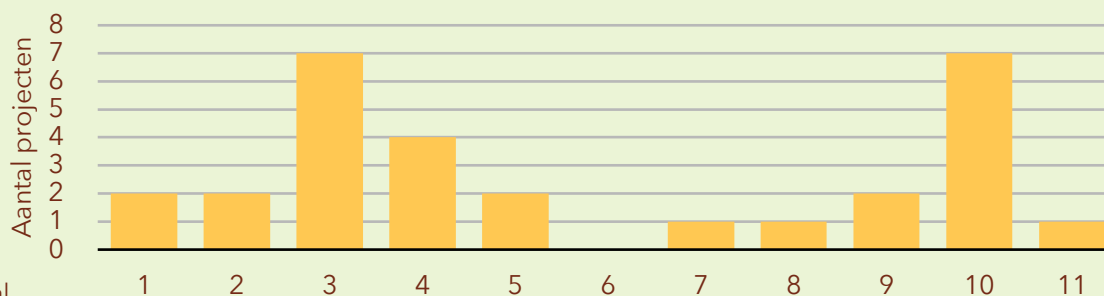
- 16:** Namaste Care family program
- 17:** Palliatieve zorg Noord-Limburg

21: Vroegtijdige inzet van

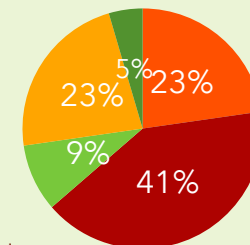
Zorgsetting



palliatieve zorg en dementie
Domeinen van palliatieve zorg (White paper: Defining optimal palliative care, Van der Steen et al., 2014)



Doelgroep



- Mensen met dementie
- Zorgverleners
- Naasten
- Mensen met dementie en naasten
- Mensen met dementie, zorgverleners, naasten

30

Appendix III: Factsheets of included projects

The factsheets are presented on the next pages.

Het doel van het onderzoek 'Care4Youngdem' is om de zorg voor jongeren met dementie in kaart te brengen en te optimaliseren. Artsen, verzorgers en familieleden van jongeren met dementie die zijn opgenomen in een gespecialiseerde afdeling, worden gevraagd een vragenlijst in te vullen. De vragen hebben onder andere betrekking op de kwaliteit van het leven, gedeelde besluitvorming, symptomen en behandelingen van dementie. Daarnaast zullen (focusgroep-) interviews worden gehouden met een aantal artsen, mantelzorgers, thuiswonende jongeren met dementie en hun gezinsleden. Dit wordt gedaan om een beter inzicht te krijgen in de resultaten van de vragenlijsten. Op basis van de behaalde resultaten zullen aanbevelingen worden geformuleerd voor optimale palliatieve zorg bij jongeren met dementie. Uiteindelijk zal hierover consensus worden bereikt via zogenaamde Delphi-rondes. Het onderzoek begon in 2016 en zal in 2021 worden afgerond. Momenteel bevinden de onderzoekers van het project zich in de fase van gegevensverzameling.

Contactpersoon:

B. Pistorius

ACP



Personen
(<65jaar) met
dementie

Intra/
extramuraal



Comparing palliative care in care homes across Europe (PACE)



Contactpersoon:

L. van den Block

Educatie van
zorgverleners



Zorgverleners

Intramuraal



Het onderzoeksprotocol 'PACE' informeert internationaal onderzoek in verzorgingstehuizen over hoe representatief onderzoek naar de levenseindezorg in deze instellingen kan worden uitgevoerd en geeft een beter inzicht in welke systemen worden geassocieerd met betere resultaten. De PACE-studie bestaat uit verschillende deelonderzoeken. Om een representatief landelijke populatie te verkrijgen, zal een grootschalige cross-sectionele studie van overleden bewoners in verzorgingshuizen in België, Finland, Italië, Nederland, Polen en het Verenigd Koninkrijk worden uitgevoerd. In elk land rapporteren alle deelnemende verpleegtehuizen achteraf alle sterfgevallen van bewoners in en buiten de voorzieningen in de afgelopen periode van drie maanden. Om een representatief beeld te krijgen van de kennis en attitudes van het personeel met betrekking tot palliatieve zorg, zal PACE een cross-sectionele studie uitvoeren van het personeel dat in de deelnemende verpleegtehuizen werkt. De PACE-studie is gepubliceerd in 2016.



CONT-END

Het onderzoek CONT-END bestaat uit drie delen. In het eerste deel van het onderzoek zal de aanvaardbaarheid van verschillende niveaus van controle voor artsen, patiënten en familieleden in zes landen worden onderzocht. Onderzoekers proberen een antwoord te vinden op de volgende vraag: 'In hoeverre is de culturele interpretatie van autonomie belangrijk voor beslissingen over het levenseinde?' In het tweede deel van het onderzoek worden twee soorten ACP vergeleken. Eén type ACP waarin elke stap, elk gesprek en elke afspraak in detail wordt vastgelegd en één type ACP waarin meer aandacht wordt besteed aan wereldwijde zorg doelen en acceptatie van deze ziekte en de bijbehorende onzekerheden rond het beloop ervan. Het laatste deel van het project gaat over het verhogen van de kwaliteit van levenseinde-onderzoek. Antropologen zullen meelopen met onderzoekers om te meten wat de invloed van bijv. de persoonlijkheid van de onderzoeker is op de uitkomsten van een onderzoek.

Contactpersoon:

J. Van der Steen

ACP, sociale
en ethische
dilemma's



Personen met
dementie

Intra/
extramuraal



Decidem



Contactpersoon:

B. Tilburgs

ACP



Zorgverleners

Extramuraal



Het doel van Decidem is om een interventie te ontwikkelen ter bevordering van ACP voor personen met dementie en hun naasten door de huisarts. De interventie, bestaande uit twee workshops voor huisartsen, zal naar verwachting resulteren in een betere discussie over wensen en behoeften van personen met dementie en om afspraken te maken over de wensen en behoeften in het medisch dossier. Bovendien wil Decidem de kwaliteit van leven verbeteren en de tevredenheid over de zorg van de patiënt verbeteren. Dit zal uiteindelijk resulteren in een verminderde last van mantelzorgers. Begin 2017 is het verzamelen van gegevens voltooid. Resultaten zijn echter (nog) niet beschikbaar. Dit programma maakt deel uit van het programma Memorabel en wordt gefinancierd door ZonMw.



DEDICATED: Desired Dementia Care Towards End-of-Life

Het project DEDICATED is een onderzoeks- en implementatieproject dat bestaat uit twee onderling verbonden delen. Het eerste deelproject geeft inzicht in de barrières en behoeften op het gebied van kennis en end-of-life communicatie op het gebied van palliatieve zorg voor professionele zorgverleners, mensen met dementie en hun naasten en heeft als doel de competenties en kennis over palliatieve zorg voor mensen met dementie te vergroten en tijdige en adequate communicatie rond het levenseinde in de thuissituatie te bevorderen. Het tweede deel gaat over interdisciplinaire samenwerking. Er wordt een samenvatting gemaakt van bestaande samenwerkingsmodellen en hulpmiddelen. De (elementen van de) meest toepasbare strategieën worden geselecteerd en wetenschappelijk geëvalueerd om een geschikte samenwerkingsstrategie voor implementatie in de deelnemende organisaties verder te ontwikkelen. Het project maakt deel uit van het ZonMw-programma 'Palliatie, meer dan zorg'. Het project is gestart in 2017 en is gepland in 2021.

Contactpersoon:

J. Meijers

Educatie van
zorgverleners,
continuïteit van
zorg, ACP



Zorgverleners,
personen met
dementie, naasten

Transmuraal



Dementie en palliatieve zorg - scholing in de huisartsenpraktijk



Contactpersoon:

M. Trompper

ACP



Zorgverleners

Extramuraal



Quartz heeft een training ontwikkeld om meer bewustzijn bij zorgverleners te creëren over het feit dat dementie een progressieve ziekte is, waarbij de patiënt zich in de palliatieve fase van de diagnose bevindt. Deelnemers kunnen onderzoeken hoe ze het bewustzijn van personen met dementie en hun mantelzorgers kunnen bevorderen. Daarnaast zal ook het ontwerp van ACP in deze patiëntengroep worden besproken. De training vindt plaats in de huisartsenpraktijk en duurt een uur. Het is wenselijk dat naast huisartsen ook de praktijkondersteuner ouderenzorg, de specialist ouderengeneeskunde, wijkverpleegkundige en casemanager dementie worden uitgenodigd. Andere zorgverleners en welzijnswerkers die in de praktijk betrokken zijn bij de zorg voor dementie, kunnen een rol spelen bij verdere training.

Dementie, landelijke richtlijn versie 1.0

IKNL heeft in 2010 de richtlijn 'Dementie, landelijke richtlijn 1.0' gepubliceerd. De gids beschrijft hoe de integrale palliatieve zorg voor personen met dementie kan verbeteren door het verbinden van twee zorgketens.

Contactpersonen:
R. Koopmans, J. van der Steen, S.
Zuidema, J. Hobbelen

Educatie van
zorgverleners



Zorgverleners

Intra/
extramuraal



Feedback op levenseinde zorg bij dementie - FOLlow up



Contactpersoon:
J. van der Steen

Communicatie
SDM



Personen met
dementie en
naasten

Intra/
extramuraal



'FOLlow up' is een onderzoeksproject dat als doel heeft de effecten te bepalen van generieke en patiënt specifieke feedback op de kwaliteit van sterven en de kwaliteit van end-of-life care bij dementie. Het onderzoek biedt inzicht in de praktische implicaties van het gebruik van feedback in een verpleeghuis setting. Het verpleeghuispersoneel nodigt families uit om een vragenlijst in te vullen over de kwaliteit van sterven en kwaliteit van zorg nadat een bewoner met dementie overleden is. In een gerandomiseerde, gecontroleerde studie met voor en na metingen, wordt het effect gemeten van de twee manieren om feedback te geven over de kwaliteit van leven en sterven. De resultaten van dit onderzoek bieden inzicht in het effectieve gebruik van feedback om de kwaliteit van levenseinde te verbeteren voor personen met dementie. FOLlow up is onderdeel van het ZonMw-programma 'Palliantie, meer dan zorg' en werd uitgevoerd van 2012 tot 2014. Informatie over de implementatiefase van dit project is niet (online) beschikbaar.

In het project 'Gesprekshulp voor de laatste levensfase bij dementie' zal een gesprekstool voor personen met dementie en hun naasten worden ontwikkeld. De gesprekstool stimuleert en structureert gesprekken tussen personen met dementie, familieleden en zorgverleners over palliatieve zorg en de laatste fase van het leven. De gesprekstool biedt informatie over communicatie en biedt voorbeeldvragen. De ontwikkeling van de gesprekstool is gestart in 2017 en beoogd klaar te zijn in 2019. Momenteel bevindt het project zich in de fase van gegevensverzameling.

Contactpersoon:

J. Van der Steen

Communicatie SDM



Personen met
dementie en
naasten

Intra/
extramuraal



Goed voor elkaar



Contactpersoon:

M. Wanders

Continuïteit van
zorg, educatie
van
zorgverleners



Zorgverleners

Intramuraal



Het netwerk 'Goed voor elkaar' beoogd structurele verbanden te leggen tussen palliatieve zorg en dementie zorg in de stad en de westelijke regio van Utrecht. Het richt zich op eerstelijnszorg, hospices en intramurale ouderenzorg. Een kennisverspreiding heeft plaatsgevonden tussen twee zorgsectoren (palliatieve zorg en zorg voor dementie) door; deskundigheidsbevordering, multidisciplinair overleg, onderling overleg en een grotere betrokkenheid van vrijwilligers. Op deze manier hebben zorgverleners in beide zorgsectoren van elkaar geleerd en kregen ze inzicht in dementie zorg, inzicht in palliatieve zorg. Vilans heeft hierbij uitwisselingsbijeenkomsten en werkbijeenkomsten met andere netwerken georganiseerd en heeft een digitaal platform ontwikkeld. Het project liep van 2013 tot 2014 en was onderdeel van het programma 'Palliatie, meer dan zorg' van ZonMw.



Handreiking zo verbindt u palliatieve zorg en dementie

Vilans heeft een handreiking ontwikkeld voor projectleiders die palliatieve zorg en dementie zorg willen verbinden (in een specifieke regio). De gids biedt zorgverleners en professionals praktische hulpmiddelen om dementie zorg en palliatieve zorg met elkaar te verbinden. Hierdoor zijn zorgaanbieders beter in staat om een optimale dialoog te bieden op basis van de beschrijving van belemmerende factoren, zoals de vraag stellen in hoeverre deze factoren ook een rol spelen bij de betrokkenen en hoe zij elkaar kunnen helpen.

Contactpersoon:

E. Stapersma

Educatie van
zorgverleners



Zorgverleners

Transmuraal



Handreiking zorg rond het levenseinde



Contactpersonen:

J. van der Steen, C. Hertogh,
T. De Graas

Familie zorg en
betrokkenheid



Personen met
dementie en
naasten

Extramuraal



De handreiking 'Zorg rond het levenseinde' geeft algemene informatie over de progressie van dementie naar het einde van de levenscyclus. Op deze manier kan meer inzicht worden verkregen in mogelijke zorg problemen (bijvoorbeeld spraakstoornissen en onbegrip van de omgeving) in de laatste levensfase. Bovendien wordt informatie over behandelingsopties verstrekt. Deze handreiking richt zich op palliatieve zorg en houdt zich voornamelijk bezig met de medische aspecten van palliatieve zorg. Onderwerpen zoals begeleiding en communicatie met personen met dementie en andere aspecten van zorgverlening in eerdere fasen worden slechts kort besproken. De originele gids werd uitgebracht in 2005. In 2011 werd een herziene versie van de gids ontwikkeld door het VUmc en EMGO.

De handleiding 'Het plannen van zorg in de laatste levensfase bij dementie' is ontwikkeld door het VUmc samen met vertegenwoordigers van Verenso, V & VN, de geriatrische afdeling van V & VN en de NHG. De gids is een informatiebron voor zorgverleners om de laatste levensfase voor personen met dementie te plannen en te combineren met hun eigen wensen. Deze handleiding is in eerste instantie bedoeld voor personen met dementie, maar kan ook relevant zijn voor andere patiënten met cognitieve stoornissen.

Contactpersoon:

M. van Soest-Poortvliet

ACP



Zorgverleners

Intra/
extramuraal



MAPRO: Markering van de palliatieve fase en proactieve zorg planning bij dementie

Contactpersonen:

M. Uitdehaag, M. Keurhorst

Signaleren en
markeren in de
palliatieve fase



Zorgverleners

Intra/
extramuraal



In het MAPRO-onderzoek wordt een Gesprekswijzer Dementie ontwikkeld voor zorgverleners in de eerstelijns, waaronder ook casemanagers dementie. Deze gesprekswijzer ondersteunt zorgverleners bij het tijdig bespreken van de palliatieve fase en het vormgeven van proactieve zorg planning bij personen met dementie. Tijdige discussie kan leiden tot minder 'over'- behandeling bij complicaties als palliatieve 'onder'-behandeling. Het project beoogt een bijdrage te leveren aan het verbeteren van de levenskwaliteit van personen met dementie en hun naasten en de kwaliteit van de zorg rondom het sterven. Het MAPRO-project is gestart in maart 2016 en wordt uitgevoerd door Saxion en Windesheim, die beide onderwijsinstellingen zijn. Het project wordt uitgevoerd in nauwe samenwerking met de netwerken Dementie Drenthe en IJssel-Vecht. Tot het begin van 2018 zullen semi-gestructureerde interviews worden afgenomen onder de betrokken professionals en personen met dementie en hun familieleden.

Het (onderzoeks-) project is onderdeel van het ZonMw-programma 'Palliatie, meer dan zorg' en werd uitgevoerd vanuit 2007 tot 2010. Het project heeft onderzocht welke meetinstrumenten het meest geschikt zijn om met terugwerkende kracht de kwaliteit van sterven en de kwaliteit van de zorg aan het levenseinde te meten van Nederlandse patiënten die in verschillende settings zijn overleden aan dementie. Vervolgens werden de voorwaarden voor een optimale implementatie van de meest geschikte instrumenten onderzocht. De EOLD-SWC lijkt het meest geschikt voor familieleden om de kwaliteit van zorg aan het levenseinde te meten. De EOLD-CAD is het meest geschikt voor het meten van de kwaliteit van stervend vanuit het perspectief van een familie en/ of zorgverlener.

Contactpersoon:

J. van der Steen

Metten van kwaliteit
van sterven en
palliatieve zorg



Personen met
dementie en
naasten

Intra/
extramuraal



Namaste Care family program



Contactpersoon:

J. van der Steen

Optimale behandeling
van symptomen en
comfort bieden,
psychosociaal
welbevinden



Personen met
dementie

Intramuraal



In het Amerikaanse programma Namaste Care staat contact tussen de patiënt in een verpleeghuis en een naaste centraal, bijvoorbeeld door aanraking of door iets samen te doen. De onderzoekers testen het programma in zestien Nederlandse verpleeghuizen. Zij willen familie en vrijwilligers betrekken en nog duidelijker maken wat zij kunnen doen in de laatste dagen van het leven van iemand met dementie. De effectiviteit van het Namaste Care Familieprogramma wordt onderzocht via vragenlijsten, interviews, gegevens van artsen en het observeren van de verpleeghuisbewoners. De verwachting is dat de extra tijdsinvestering van familie en vrijwilligers in hun naaste met dementie direct ten goede komt aan hen allemaal. Als deze verwachtingen uitkomen, wordt het Namaste Care Familieprogramma verder ingevoerd in het verpleeghuis en zo mogelijk ook bij families thuis.

Palliatieve zorg Noord-Limburg: 'Een sterk vangnet ook voor personen met dementie!'

Het netwerk 'Palliatieve zorg Noord-Limburg' beoogde aansluiting te vinden tussen dementie en het palliatieve zorgnetwerk. Door verbindingen tot stand te brengen, wordt gezorgd voor een betere coördinatie van ondersteuning en zorg voor personen met dementie en hun zorgverleners. Dit had als doel te zorgen voor bewustzijn van het bespreekbaar maken van palliatieve zorg in een vroeg stadium van dementie en leidde daarom tot een effectievere ondersteuning van de zorg. De verschillende betrokken professionals hadden wederzijdse voordelen in deze interactie, wat kon resulteren in meer kennis en vaardigheden. Uiteindelijk is een gedeelde visie geformuleerd en is een samenwerkingsovereenkomst ontwikkeld die wordt ondersteund door de besturen van beide netwerken. Het project liep van 2013 tot 2015 en was onderdeel van het programma 'Palliatie, meer dan zorg' van ZonMw.

Contactpersoon:
E. Dickhoff-Evers

Continuïteit van
zorg



Personen met
dementie en
naasten

Transmuraal



Signaleren in de palliatieve fase

Contactpersoon:
M. Verkammen

Familie zorg en
betrokkenheid



Zorgverleners

Intramuraal



IKNL heeft een methode ontwikkeld die zorgaanbieders concrete handvatten biedt voor signalering, implementatie en evaluatie van palliatieve zorg. De methode kent vijf fasen om stapsgewijs gezondheidsproblemen te signaleren en om op dit moment de huidige problemen op te lossen. De deelnemer wordt begeleid door de fasen met behulp van signaleringskaarten en bijbehorende achtergrondinformatie. De zorgprofessional registreert de resultaten stapsgewijs op een werkblad. De methode kan binnen organisaties worden gebruikt door deel te nemen aan de IKNL train-the-trainer-cursus, op elke gewenste locatie, regionaal of zorg wensen van de patiënt. Het project ondersteunt de zorgverlener bij het identificeren, in kaart brengen en uiten van zorg problemen, versterkt de samenwerking met collega's en draagt bij aan het vergroten in de kennis van symptomen van de palliatieve fase.



Verbeter palliatieve zorg bij personen met dementie

'Verbeter palliatieve zorg bij personen met dementie' is een verbetertraject dat is ontwikkeld door Vilans. In dit proces worden verschillende stappen gevolgd. Het proces begint met een startvergadering, waarbij netwerken en organisaties in de regio zijn verbonden om de zorg voor personen met dementie te optimaliseren. Samen met partners en het projectteam zal een effectief actieplan worden ontwikkeld om de palliatieve zorg in de regio te verbeteren. Het projectteam zal werken aan de implementatie en op zoek gaan naar belangrijke aspecten van verbetering. Continue ondersteuning zal worden gegeven door deelnemers te informeren over ontwikkelingen en innovatie van dementie en palliatieve zorg gedurende het hele project. De startdatum van dit verbeteringstraject is onbekend, het project loopt tot op heden.

Contactpersoon:

E. Stapersma

Continuïteit van
zorg



Zorgverleners

Transmuraal



Verdiepingsmodule palliatieve zorg bij personen met dementie



Contactpersoon:

Onbekend

Educatie van
zorgverleners



Verzorgenden

Intra/
extramuraal



In 2014 werd de 'Verdiepingsmodule palliatieve zorg bij personen met dementie' geïntroduceerd. De Verdiepingsmodule is bedoeld voor verzorgenden en verpleegkundigen die recent de basisopleiding palliatieve zorg hebben gevolgd. In de primaire cursus wordt aandacht besteed aan het concept van palliatieve zorg en aan de fysieke, psychosociale en spirituele aspecten van palliatieve zorg. Tijdens de vervolgcursus blijkt vaak hoe verschillend het is om palliatieve zorg te bieden aan personen met dementie. Kennis over het verlenen van palliatieve zorg aan personen met dementie zal toenemen.

In dit project is een multidisciplinaire richtlijn ontwikkeld voor palliatieve zorg bij verpleeghuisbewoners met dementie. Belangrijke aspecten die werden onderzocht zijn de effecten van zorg en de factoren die samenhangen met vroege planning en het bieden van deze zorg. De kwalitatieve gegevens van het onderzoek 'Zorg bij Dementie' zullen als uitgangspunt worden gebruikt. Het project omvat literatuuronderzoek om een brede basis van de richtlijn vast te stellen. Daarnaast werden interviews gehouden onder familieleden, verzorgers en artsen van verpleeghuisbewoners met dementie die zijn overleden. Het project geeft inzicht in de mate waarin palliatieve zorg wordt gegeven aan personen met dementie en hoe palliatieve zorg de kwaliteit van sterven en de tevredenheid van het gezin met zorg rond het levenseinde beïnvloedt. Ook is een multidisciplinaire richtlijn ontwikkeld voor vroege planning en inzet van palliatieve zorg bij dementie. Het project startte in 2009 en eindigde in 2014 als onderdeel van het ZonMw-programma 'Palliantie, meer dan zorg'.

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Signaleren en markeren
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Zorgverleners

Intramuraal



White paper defining optimal palliative care in older people with dementia (Dutch Translation)



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Beleidsmakers,
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Zorgverleners

Intra/
extramuraal



In dit onderzoek wordt optimale palliatieve zorg voor personen met dementie gedefinieerd. Op basis van literatuur stelde een groep van twaalf experts uit zes landen een reeks kerndomeinen op met aanbevelingen voor elk domein. In totaal is een set van elf domeinen en 57 aanbevelingen ontwikkeld. Negen domeinen bereikten volledige consensus: persoonsgerichte zorg, communicatie en gedeelde besluitvorming; optimale behandeling van symptomen en comfort; het stellen van zorg doelen en planning vooraf; continuïteit van zorg; psychosociale en spirituele ondersteuning; familie zorg en betrokkenheid; opvoeding van het gezondheidsteam; maatschappelijke en ethische kwesties; en prognosticeren en tijdige herkenning van sterven. Aanbevelingen over voeding en uitdroging en over dementie stadia in relatie tot zorg doelen bereikten een gematigde consensus, maar worden niettemin als kerndomeinen beschouwd.