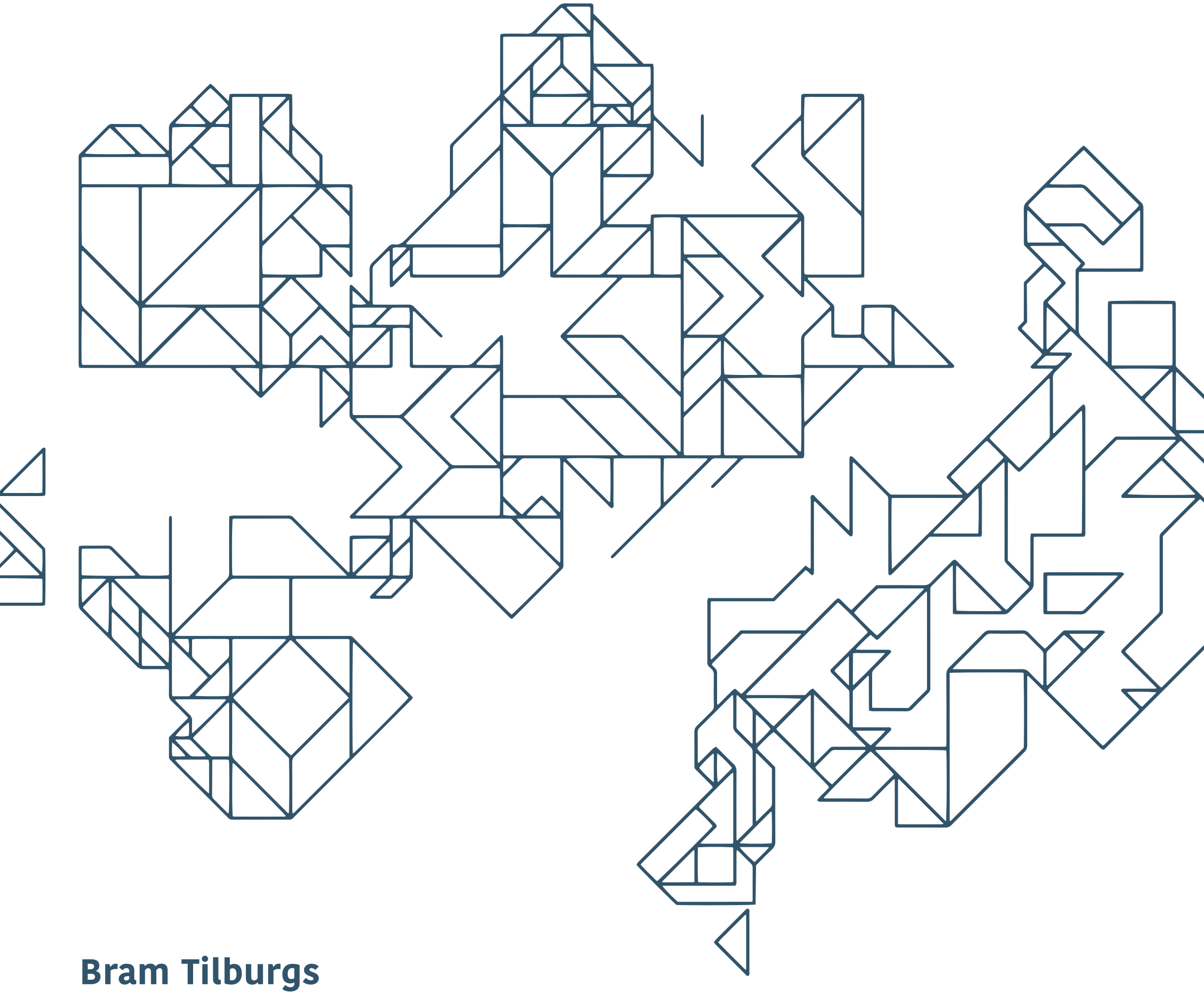
ADVANCE CARE PLANNING IN DEMENTIA

Development and evaluation of an educational intervention in primary care



Bram Tilburgs

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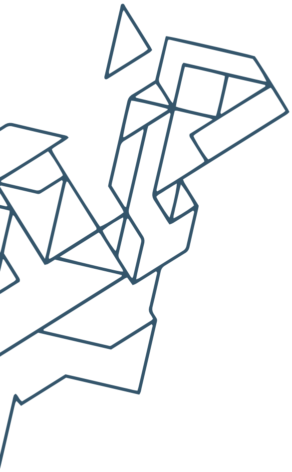

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Advance care planning in dementia

Development and evaluation of an educational intervention in primary care

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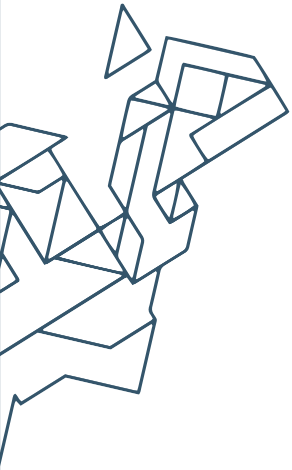
Table of contents

1

Chapter 1

General introduction and thesis outline



Prologue

Jan is 78 years old. He lives on the second floor of an apartment building together with his wife and their two dogs. They have been married for over 40 years and don't have any children. Jan has multiple health problems. He has obesity, diabetes, chronic heart failure and two years ago he was diagnosed with Alzheimer's disease/dementia. He is quickly out of breath, immobile, forgetful and has increasing trouble with activities of daily living.

Currently, Jan is not able to leave his apartment and he seldom participates in social activities, which is fine with him. He is satisfied with life's "small pleasures" like sitting in the sun on his balcony. There he looks at the birds and waters the plants if he has the energy. He often takes his wife's hand and says to her: "Sitting here with you makes me feel so happy, I wish I could stay here forever. As long as I have you by my side….., my life is meaningful.

Jan has a committed general practitioner who tries to visit him and his wife regularly. Because Jan receives daily home care, his general practitioner also maintains contact with Jan's community nurses. According to the nurses and Jan's wife, it becomes increasingly difficult to care for Jan at home. He has more memory problems, is bad tempered and sometimes verbally aggressive towards his wife. His general practitioner therefore wants to discuss different care and housing options. This makes Jan very upset and the conversation ends without having reached an agreement or an appointment to further talk about these issues.

And then, after she returns home from shopping, Jan's wife finds him lying on the floor of their apartment. He is out of breath and disorientated. Jan is acutely admitted to the hospital. Of course, his wife is very sad. She is afraid her husband will not be able to come home anymore and do the things he loves so much. She also doubts if this hospital admission is what he would have wanted, but is not sure because she never got the chance to further discuss this with him. Jan does not recover. After three weeks, he is transferred to a geriatric ward and four weeks later he dies during the night without his wife present.

Background

People with dementia are often unprepared for problems which may arise in the future, and fail to get access to timely palliative care. (1-4) A study on doctor-patient discussions in Italy, Spain, Belgium and the Netherlands showed that discussions on medical treatment preferences for the remaining phase of life had occurred in just 7% (Spain) to 47% (the Netherlands) of the patients who died non-suddenly and even less in people with dementia. (5) In addition, only a minority of the people with dementia in nursing homes have an advance directive, and palliative treatment is often lacking. (6-8) When cognitive decline progresses, people with dementia may no longer be able to discuss care and treatment preferences. In addition, family caregivers find it difficult to make healthcare decisions for people with dementia. (1, 2) Also, when preferences are unknown and decisions have to be made during an acute event, these may not always reflect the preferences of the person with dementia. (1, 2) Therefore, providing opportunities for a person with dementia and his/her family caregivers to make shared decisions on future health care preferences, may contribute to timely access of palliative care and improve their quality of life. (3, 9)

The societal impact of dementia

Dementia is a life limiting syndrome caused by degenerative brain diseases and characterized by a deterioration in memory, thinking, behaviour and the ability to perform every day activities. (10, 11) From diagnosis, the median survival of people with dementia reported in research is one to eight years. (12, 13) The most common early symptom is a decreased short-term memory. As dementia progresses, a wide range of other symptoms can emerge, such as disorientation, changes in mood, confusion, behavioural changes and difficulties in speaking, walking and swallowing. (10, 14) Although each person will experience dementia in his/her own way, most of those affected will eventually be unable to care for themselves and will need help with all aspects of daily life. (10, 14)

Advanced age is the most important risk factor for dementia. As life expectancy increases across the world, the number of people who are diagnosed with dementia is also expected to rise. In 2015, worldwide 47 million people were living with dementia and today, 9.9 million people are diagnosed each year. (15, 16) It is estimated that the number of people with dementia will rise to 75 million in 2030 with a global cost of 2 trillion US dollars. (15, 16) In the Netherlands in 2012, 245.000 people were living with dementia and it is expected that this number will increase to 500.000 in 2040. (17) It is also estimated that in 2025, the Dutch annual costs of dementia care will become 6.8 billion euro's. (17)

The impact of dementia on people's lives

Dementia has a significant impact on people's lives and is among the top 10 most burdensome conditions of older people worldwide. (15) Multiple personal and social aspects determine how people personally experience living with dementia.

(15, 18, 19) It is known that when people with dementia remain independent as much as possible, feel they are in control, participate in meaningful activities, are able to perform activities of daily living and live in a social environment which respects their dignity and personhood, the negative impact of dementia on quality of life is less. (20, 21) On the other hand, feelings of depression, anxiety and apathy of people with dementia increase the negative impact on quality of life. (18, 20, 21) There is no consensus on the impact of dementia severity on quality of life. Hessmann et al. (2016) showed that health-related quality of life of people with dementia decreased when dementia progressed. Banerjee et al. (2009) however concluded that convincing evidence for the influence of dementia severity on quality of life is missing. (19, 22)

Dementia also has a substantial impact on the lives of family caregivers. Those who care for a person with dementia who has more severe cognitive decline, less awareness of their disease, unmet medical needs, more functional impairment, more neuropsychiatric symptoms and less independence, have a decreased quality of life and experience their lives as more burdensome. (23-26) On the other hand, family caregivers' quality of life is better when they are confident, are able to care for the person with dementia and receive adequate support from friends and healthcare professionals. (23, 24)

Palliative care, advance care planning, shared decision making and positive health

As dementia is a chronic and life-limiting disease with a high burden for which no cure is foreseen in the near future, timely personalized palliative care is advised. (9) Palliative care aims to improve quality of life of patients who are frail and/or have a life threatening condition. Palliative care tries to timely identify, prevent and alleviate suffering caused by physical, psychological, social and spiritual problems. It thereby also aims to facilitate patients' autonomy, access to information, and to anticipate on wishes, needs and future scenario's. (27, 28)

In advance care planning, future care preferences are assessed in a timely and cyclic manner. In doing so, healthcare professionals help their patients to explore and share their needs and wishes and together decide on future care options. (2, 29-31) This closely relates to shared decision making where healthcare professionals and patients, each with their own 'expertise', share the best available evidence and together make informed decisions on treatment and options for care. (32, 33) In those situations where the personal circumstances and the context of the patient play a major role, as is the case in dementia, advance care planning, using the principles of shared decision making, is especially important. (32, 33) In addition, advance care planning is essential for respecting and stimulating autonomy of the person with dementia and their family caregiver in making decisions on future care. (34, 35)

Palliative care and advance care planning closely relate to positive Health as proposed by Huber et al. (2011). Positive health is defined as: “the ability to adapt and self-manage, in light of the physical, emotional and social challenges of life”. (36) This holistic concept includes six dimensions; bodily functions, mental functions and perceptions, spiritual/existential dimension, quality of life, social and societal participation and daily functioning. (37) In line with this, for people with dementia, advance care planning seems an important intervention as it facilitates making autonomous decisions aimed at timely access to palliative care and living healthy lives according to the definition of positive health. (9, 33, 34, 36, 38-41)

The primary care setting

In the Netherlands, two thirds of the people with dementia live at home and are registered at a primary care practice close to where they live. (42) Because of their gatekeeper’s role, Dutch general practitioners are almost always involved early in the dementia disease process and are in the position to timely start advance care planning. In dementia this is important because of the progressive cognitive decline. The often long-lasting relationship with their patients and familiarity with the personal situation of persons with dementia increases trust and facilitates discussing difficult subjects. (43-45) Patients are also positive about general practitioners’ availability and ability to take time to listen to their problems during the decision-making process. (43, 46) In addition, the general practitioners’ involvement results in patients’ perception of clearer treatment plans made and increased feelings of being helped forward. (44, 45) Also, community-dwelling people with dementia, as opposed to people living in nursing homes, are probably more able to actively participate in advance care planning. These aspects make the general practitioner suitable to timely initiate advance care planning. However, up to date, people with dementia and their family caregivers in primary care, seldom make timely shared decisions on future healthcare preferences. (3-5)

What is already known about advance care planning with people with dementia

Research, not specifically aimed at primary care, shows that people with dementia, their family caregivers and healthcare professionals are reluctant to engage in advance care planning because of their lack of knowledge with regard to the dementia disease trajectory or advance care planning. (1, 2) Moreover, when people with dementia or their family caregivers have not yet thought about possible future problems or have insufficient coping strategies, advance care planning is hampered too. (1) Anxiety, feelings of guilt, opposing assumptions on perspectives of people with dementia, religious beliefs and limited available time of healthcare professionals are other known barriers. (1, 2) Emotional support and providing information on dementia and advance care planning, help people with dementia and their family caregivers when decisions on future care have to be made. (2) Interventions aimed at educating healthcare professionals or relatives have been suggested to facilitate advance care planning initiation as well. (2)

Research on the effectiveness of interventions to improve advance care planning in dementia is scarce. (47, 48) In people with chronic diseases in a wide array of settings, interventions to stimulate advance care planning have shown to increase the occurrence of discussions on end-of-life preferences and the likelihood that advance directives are completed. These interventions also seem to lead to end-of-life care more in accordance with people's preferences and to enhance the quality of communication between patients and healthcare professionals. (47) Studies on advance care planning with people with dementia show that advance care planning interventions lead to increased advance care planning related outputs (e.g. advance directives), decreased hospitalisation rates and decreased healthcare costs. (48) The effects of advance care planning interventions on outcomes like quality of life, shared decision making and the experienced ability of the family caregiver to care for someone with dementia are unknown. (47, 48)

Improving advance care planning in primary care

With the expected future increase of the number of people diagnosed with dementia, the need for timely palliative care and advance care planning will further increase. (4, 15, 16) This is acknowledged by dementia experts and relevant civil society organisations. (9, 39, 49-51) Experts in shared decision making with frail elderly advise to start discussions on care preferences with the exploration of goals and values important for maintaining or improving quality of life. (32, 52, 53) In addition, people with dementia and their family caregivers stated they wanted to include topics like daily activities, mobility and social contacts when making decisions on future care. (54) To include these aspects into advance care planning with people with dementia, training general practitioners, and the involvement of practice nurses is needed. Such an approach has already proven to be effective in diagnosing dementia and the management of dementia in primary care. (55-57)

Thesis objective and research questions

The objective of this thesis is to develop and evaluate an educational intervention for general practitioners aimed at initiating and optimizing advance care planning with people with dementia. To reach our objective the following research questions will be answered:

1. What are the facilitators and barriers for initiating advance care planning with people with dementia by general practitioners?
2. What are the effects of an educational intervention aimed at initiating and optimizing advance care planning with people with dementia by their general practitioners?
3. What are the educational intervention's successful components and what could be improved?

Thesis outline

Chapter 2 presents an overview of prior qualitative and quantitative research on facilitators and barriers on the initiation of advance care planning by general practitioners with people with dementia.

In *chapter 3*, the knowledge gaps left after chapter 2 are filled and facilitators and barriers for people with dementia, their family caregivers, general practitioners and practice nurses related to advance care planning in primary care practice are further explored with the help of individual and focus group interviews. The knowledge gained from the first two chapters is used to develop an educational intervention to optimise advance care planning initiation with people with dementia by general practitioners.

Chapter 4 presents the effectiveness of this intervention on general practitioners' initiation of advance care planning conversations with people with dementia and the preferences discussed. The effects of the educational intervention on experienced level of shared decision making and quality of life of people with dementia, experienced competence of the family caregiver and cost effectiveness is presented as well. This is all studied in a cluster randomized controlled trial.

Chapter 5 presents the process evaluation of the educational intervention. A mixed methods approach is used to explore the intervention's successful components and what could be improved.

Finally, in *chapter 6*, the general discussion, the main findings of this thesis are presented in a broader theoretical and practical context. Recommendations and conclusions are presented as well.

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2

Chapter 2

Barriers and facilitators for GPs in dementia advance care planning: a systematic integrative review

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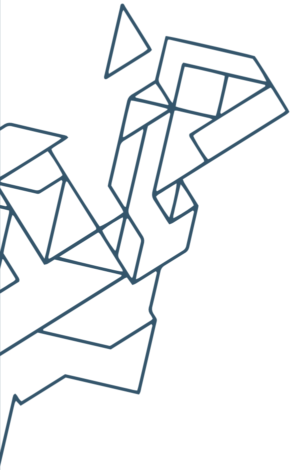

Abstract

Background
Due to the disease's progressive nature, advance care planning (ACP) is recommended for people with early stage dementia. General practitioners (GPs) should initiate ACP because of their longstanding relationships with their patients and their early involvement with the disease, however ACP is seldom applied.

Aim
To determine the barriers and facilitators faced by GPs related to ACP with people with dementia.

Data sources
We systematically searched the relevant databases for papers published between January 1995 and December 2016, using the terms: primary healthcare, GP, dementia, and ACP. We conducted a systematic integrative review following Whittemore and Knafl's method. Papers containing empirical data about GP barriers and/or facilitators regarding ACP for people with dementia were included. We evaluated quality using the Mixed-Method-Appraisal-Tool and analyzed data using qualitative content analysis.

Results
Ten qualitative, five quantitative, and one mixed-method paper revealed four themes: timely initiation of ACP, stakeholder engagement, important aspects of ACP the conversation, and prerequisites for ACP. Important barriers were: uncertainty about the timing of ACP, how to plan for an uncertain future, lack of knowledge about dementia, difficulties assessing people with dementia's decisional capacities, and changing preferences. Facilitators for ACP were: an early start when cognitive decline is still mild, inclusion of all stakeholders, and discussing social and medical issues aimed at maintaining normal life.

Conclusion

Discussing future care is difficult due to uncertainties about the future and the decisional capacities of people with dementia. Based on the facilitators, we recommend that GPs use a timely and goal-oriented approach and involve all stakeholders. ACP discussions should focus on the ability of people with dementia to maintain normal daily function as well as on their quality of life, instead of end-of-life-discussions only. GPs need training to acquire knowledge and skills to timely initiate collaborative ACP discussions.

Introduction

Dementia is a progressive and chronic condition with a median survival of 7 to 10 years (1). Worldwide, 50 million people suffer from dementia and this number is expected to increase to 152 million by 2050 (2). During the disease process, people with dementia undergo a declining cognitive capacity resulting in an increased dependency on others (3). It is estimated that in the USA and Europe, approximately 6% of the population aged over 60, and 45% aged over 90, have dementia (3). Above the age of 65, 10% of all deaths in men and 15% of all deaths in woman can be attributed to dementia (3). In addition, data from UK GP practices shows that 19% of people with dementia more commonly had five or more additional physical conditions than those without dementia (13,4%) (4).

Dementia care should be proactive, patient-centered, and focus on improving quality of life (QoL) and daily functioning (5-7). To accomplish this, advance care planning (ACP) is recommended (7, 8). ACP can be defined as 'a timely and cyclic assessment of future health issues by discussions between patients, their family and healthcare professionals, taking wishes and preferences for future care into account' (9-11). During ACP, medical, psychological, social and existential subjects can be addressed, and people are given the opportunity to discuss what they do and do not want regarding their future care (12). ACP may then result in the documentation of preferences for future care. Advance directives, decisions to refuse treatment, living wills and/or lasting power of attorney, are structured examples of this (10). Worthy of note is that most studies on the effectiveness of ACP primarily addressed medical, end-of-life related topics, which neither reflects the heterogeneity of the disease nor the broad definition advised (11).

ACP has been shown to improve the concordance between healthcare preferences and care delivered in different adult populations (13). It appears to increase the completion of advance directives, to enhance communication between patients, family carers and healthcare professionals, and to stimulate conversations about future wishes and preferences (13, 14). By registering these preferences the frail elderly undergo less aggressive treatment, less admittance to hospital, less anxiety, stress and depression, and increased death in a trusted environment (15). For people with dementia living in nursing homes, ACP reduces both hospital admissions and healthcare costs (16). However, because of the more common occurrence of advanced dementia in nursing homes, residents are often deemed less capable of making their own decisions and are therefore unlikely to be invited to actively participate in ACP (16). In contrast, most people with dementia who live at home have mild to moderate dementia (17) and therefore are able to express their preferences (18, 19).

Most home-dwelling people with dementia receive care from a general practitioner (GP). Because of GPs' longstanding relationships with their patients, they are the professionals most suited to initiate ACP in this group (20).

Research, however, has indicated that of the non-cancer patients who had non-sudden deaths, only 24% had an ACP conversation with their GP, and only 5.3% had a written plan (21). In addition, dementia is negatively associated with discussing treatment preferences, which indicates that ACP within dementia has its own specific challenges (22).

In order to gain a better understanding of these challenges, in this integrative review of the literature, we reviewed barriers and facilitators to the initiation of ACP by GPs for people with dementia.

Methods

We used the integrative review methodology described by Whittemore and Knafl (23). In contrast to traditional systematic reviews, this method allows the simultaneous inclusion of theoretical, quantitative, and qualitative studies. By systematically searching, evaluating, and analyzing relevant studies with different methodologies, were able to better integrate and understand all aspects related to our research question (23).

After having determined our research aim, we searched Embase, Psychinfo, Medline, Cinahl and the Cochrane Library databases using a combination of the following search terms: primary healthcare, general practitioner, dementia, and advance care planning as MeSH terms, free text words, and equivalent index terms (Table 1). The search was limited to English language peer reviewed journals published between January 1, 1995 and December 31, 2016. We chose 1995 as a starting point as literature on ACP in primary care prior to 1995 is scarce (24). Additionally, we hand-searched the reference lists of relevant studies.

Table 1.
Search strategies for Medline, Psychinfo, CINAHL

Medline	**Psychinfo**	**CINAHL**
(exp Primary Health Care/ OR exp General Practitioners/ OR exp Community Health Services/ OR ((primary adj3 care) OR (health adj3 care adj3 primary) OR (primary adj3 health adj3 care)).ti,kw,ab. OR (general adj3 practitioner?).ti,kw,ab. OR (community adj3 health adj services).ti,kw,ab. OR (family adj3 medicine).ti,kw,ab. OR exp Physicians, Family/ OR (physician? adj3 family).ab,kw,ti. OR (family adj 3 physician?).ab,ti,kw. OR (family adj3 doctor?).ab,kw,ti. OR (primary adj3 physician?).ti,ab,kw. OR (community adj3 health adj3 care).ti,ab,kw.) AND (exp Advance Care Planning/ OR exp Advance Directives/ OR (advance adj3 care adj3 planning).ti,kw,ab. OR ACP.ti,kw,ab. OR (advance adj3 medical adj3 plan?).ti,kw,ab. OR (advance adj3 health adj3 care adj3 plan?).ti,kw,ab. OR (advance adj3 healthcare adj3 plan?).ti,kw,ab. OR (advance adj3 health-care adj3 plan?).ti,kw,ab. OR (advance adj3 directive?).ti,kw,ab. OR (advance adj3 medical adj3 directive?).ti,kw,ab. OR (end adj3 life adj3 communicat*).ti,kw,ab. OR (end-of-life adj3 communicat*).ti,ab,kw. OR (life adj3 sustaining adj3 treat* adj3 preference?).ti,kw,ab. OR (life-sustaining adj3 treatment adj3 preference?).ti,kw,ab. OR (end adj3 life adj3 decision adj3 making).ti,kw,ab. OR (end-of-life adj3 decision adj3 making).ti,kw,ab. OR (living adj3 will?).ti,kw,ab. OR exp patient participation/ OR(patient adj3 participation).ti,kw,ab. OR (patient adj3 involvement).ti,kw,ab. OR (advance adj3 decision adj3 making).ti,kw,ab. OR (advance adj3 decision?).ti,kw,ab. OR (shared adj3 decision adj3 making).ti,kw,ab. OR exp Life support Care/ OR (life adj3 suppORt adj3 care).ti,kw,ab. OR (end adj3 life adj3 decision?).ti,ab,kw.) AND (exp Dementia/ OR (alzheimer* adj3 diseas*).ti,kw,ab. OR dement*.ti,kw,ab.)	(exp Primary Health Care/ OR exp General Practitioners/ OR ((primary adj3 care) or (health adj3 care adj3 primary) or (primary adj3 health adj3 care)).ti,id,ab. OR (general adj3 practitioner?).ti,id,ab OR (community adj3 health adj services).ti,id,ab OR (family adj3 medicine).ti,id,ab. OR exp Family Physicians/ OR (family adj3 physician?).ti,ab,id. OR (community adj health adj care).ti,id,ab. OR (family adj3 doctor?).ti,ab,id. OR (primary adj3 physician?).ab,ti,id.) AND (exp Advance Directives/ OR (advance adj3 care adj3 planning).ti,id,ab. OR ACP.ti,id,ab. OR (advance adj3 medical adj3 plan?).ti,id,ab. OR (advance adj3 health adj3 care adj3 plan?).ti,id,ab. OR (advance adj3 healthcare adj3 plan?).ti,id,ab. OR (advance adj3 health-care adj3 plan?).ti,id,ab. OR (advance adj3 directive?).ti,id,ab. OR (advance adj3 medical adj3 directive?).ti,id,ab. OR (end adj3 life adj3 communicat*).ti,id,ab. OR (end-of-life adj3 communicat*).ti,ab,id. OR (life adj3 sustaining adj3 treat* adj3 preference?).ti,id,ab OR (life-sustaining adj3 treatment adj3 preference?).ti,id,ab OR (end adj3 life adj3 decision adj3 making).ti,id,ab. OR (end-of-life adj3 decision adj3 making).ti,id,ab. OR (living adj3 will?).ti,id,ab. OR exp Client Participation/ OR (client adj3 participation).ti,id,ab. OR (patient adj3 participation).ti,id,ab. OR (client adj3 involvement).ti,id,ab. OR (patient adj3 involvement).ti,id,ab. OR (advance adj3 decision adj3 making).ti,id,ab. OR (advance adj3 decision?).ti,id,ab. OR (shared adj3 decision adj3 making).ti,id,ab. OR exp Palliative Care/ OR (palliative adj3 care).ti,id,ab. OR exp Life Sustaining Treatment/ OR (life adj3 sustaining adj3 treat*).ti,id,ab.) AND (exp Dementia/ OR (alzheimer* adj3 diseas*).ti,id,ab. OR dement*.ti,id,ab. OR exp Alzheimer’s Disease/)	(TI primary physician OR AB primary physician OR TI community health OR AB community health OR (MH “Community Health Services+”) OR TI family doctor OR AB family doctor OR TI family medicine OR AB family medicine OR TI primary health care OR AB primary health care OR TI primary healthcare OR AB primary healthcare OR (MH “Primary Health Care”) OR TI general practitioner OR AB general practitioner OR (MH “Physicians, Family”) OR TI family physician OR AB family physician) AND ((MH “Dementia+”) OR ((TI dementia) OR (AB dementia)) OR ((TI alzheimer’s disease) OR (AB alzheimer’s disease))) AND (TI end of life decisions OR AB end of life decisions OR TI life sustaining treatment preferences OR AB life sustaining treatment preferences OR TI palliative care OR AB palliative care OR (MH “Palliative Care”) OR TI end of life decision making OR AB end of life decision making OR TI shared decision making OR AB shared decision making OR TI advance decision OR AB advance decision OR TI patient involvement OR AB patient involvement OR TI patient participation OR AB patient participation OR TI living will OR AB living will OR TI end of life decisions OR AB end of life decisions OR TI life sustaining treatment OR AB life sustaining treatment OR TI end of life communication OR AB end of life communication OR (MH “Decision Making, Patient+”) OR (MH “Decision Making, Family”) OR TI advance medical directives OR AB advance medical directives OR TI advance health directive OR AB advance health directive OR (MH “Advance Care Planning”) OR ((TI advance care planning) OR (AB advance care planning)) OR (MH “Advance Directives+”) OR ((TI advance directives) OR (AB advance directives)))

We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for article selection (25, 26). Empirical papers containing quantitative and/or qualitative data about barriers and/or facilitators for ACP with people with dementia by GPs were included. After removing duplicate articles, three researchers (BT, AS, VH) independently excluded papers after reading the title and abstract. In a few cases, the title obviously showed that the paper did not address our research aim. Then the abstract was not read. The remaining articles were then read, full-text. Articles were excluded if they did not describe empirical research, were not about dementia, ACP, general practice, or were not written in English (Fig 1). After each step, we compared results and discussed any difference. In cases of disagreement, two other researchers (MP, YE) were consulted.

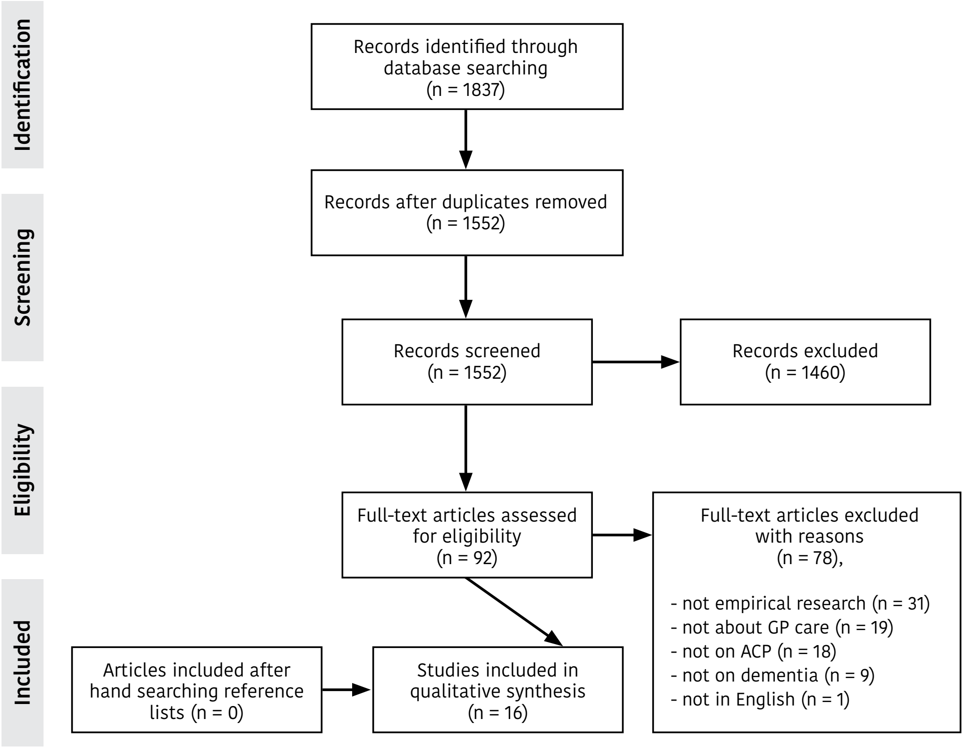

Figure 1. Preffered Reporting items for Systemetic Reviews and Meta-analyses (PIRISMA) flow diagram

To evaluate the data, we determined the methodological quality of the studies. Two researchers (BT, SK) independently used the Mixed Methods Appraisal Tool (MMAT), a tool designed for the appraisal of complex systematic reviews that include qualitative, quantitative and mixed methods studies (27). The MMAT consists of two screening questions for five different kinds of methodological research (qualitative research, randomized controlled quantitative research, non-randomized controlled quantitative research, observational descriptive quantitative research and mixed methods research). These questions address the clarity of the research question and whether the data collected are sufficient to answer the research questions. In addition, the MMAT consists of five specific sets with four quality criteria for each type of research. Each type of research is thus judged within its own methodological domain. Ratings vary between 0% (no quality criteria met) and 100% (all four quality criteria met) (27, 28).

We analyzed the data, aiming for a thorough interpretation of primary sources and synthesis of evidence (23). Since in qualitative research the emphasis is on exploration and classification and quantitative research focuses on enumeration, integration of data is complicated. Qualitative and quantitative results were therefore analyzed separately using qualitative content analysis. Thereto, the results sections of all the papers were transferred to ATLAS.ti. version 7. Using this software all passages in the result sections on ACP facilitators and barriers were given conceptual labels representing their underlying content. This coding process was performed independently by three researchers (BT, AW, SK), followed by several group sessions where researchers (YE, MP, MVD, HvG, BT) merged codes with similar meanings and categorized them. Using an affinity diagram, we combined these categories into themes representing the underlying codes and categories (29-31). The merged codes, categories and themes of all qualitative and quantitative studies were tabled, (Tables 2 and 3) enabling data comparison, interpretation and integration (23).

Table 2.
Themes, categories and codes of the included qualitative articles

Themes	Categories	Codes	
		Facilitators	Barriers
A timely initiation of ACP	*The start of ACP*	A timely start facilitates ACP (32, 34-36) (P,C,HP) The dementia diagnosis stimulates patients to think about the future(32, 35, 36) (P,C) Because of the cognitive decline, when ACP starts early more participation is possible(32, 34, 35, 37, 38) (C,HP) ACP gives patients time to think about the future(32) (P)	The right timing for ACP is difficult to determine(34, 37, 38) (P,C,HP) The patients denial/resistance of the dementia diagnosis hinders ACP(35, 36)(C) The denial of future problems hinders ACP (35)
	Initiating ACP	High impact events can prompt ACP(35) (C) The GP should take the initiative for ACP(32, 37) (C,HP) ACP stimulates discussions about the future(32) (C)	ACP is not initiated because it might cause stress or fear with the patient(34, 37) (C,HP) It is not always clear who should take the initiative for ACP(32, 37, 38) (HP)
Stakeholders engagement	*Relations between stakeholders* *Involving all stakeholders in ACP*	A good relationship between the patient/family and the GP facilitates ACP(32) (HP) If the patient is no longer capable of making decisions, others will(34, 36) (P,C) It is preferred to carry out ACP with all stakeholders(34, 36, 44, 45) (P,C)	Carers find that the difficult relationship between them and the patients hinders ACP(36) (C) The unawareness of the dementia diagnosis hinders ACP (37) (HP) The stakeholders assessment of the patients decisional capacity is limited in consisted and hinders ACP(38) (C) Carers find taking the responsibility for ACP decisions difficult (36) (C).

P: stated by the patient; C: stated by the carer; HP: stated by the GP/healthcare professional

Table 2.
Continued

Themes	Categories	Codes	
		Facilitators	Barriers
Important aspects of the ACP conversation	*Informing the patient*	Providing realistic information increases empowerment(47) (C)	Patients and carers are insufficiently informed about the diagnosis, disease trajectory, care and treatment options(32-34, 36, 37) (P,C,HP) Patients and carers lack knowledge about the purpose of ACP or are unaware of the existence (34, 45) (P,C) GPs provide information selectively because they feel patient/carers cannot cope(47) (C)
	Exploring the patient's wishes and needs	The GP must ask for the patients' needs directly(37) (C) The patients pursuit for a normal level of function influences ACP decision making (44) (P) Burdensome interventions take place when preferences are unknown(33) (C,HP)	
	Decision making in ACP	The carers previous experiences with other dementia patients influences ACP(36) (C) Financial matters and the power of attorney must be a topic in ACP(34-36, 38) (P,C,HP) Stakeholders prefer informal ACP discussions (34, 37) (P,C) The preservation of QOL influences ACP decisions (36) (C)	The limitations of healthcare can be a barrier for ACP(34, 36) (P,C) The costs of legal matters are high and limit ACP(38) (HP

P: stated by the patient; C: stated by the carer; HP: stated by the GP/healthcare professional

Table 2.
Continued

Themes	Categories	Codes	
		Facilitators	Barriers
Important aspects of the ACP conversation	*Decision making in ACP*	The use of decision aids can support ACP decision making(32, 47) (P,C)	
	Documentation of ACP	Documenting ACP makes patient wishes available to all stakeholders(32, 34, 35, 38) (P,C,HP) Trough ACP wishes are known by all stakeholders(32) (P,C)	ACP is not documented because future wishes/circumstances might change(34, 37) ACP decisions are not documented because of feelings of guilt/disloyalty(34) (C)
Prerequisites of ACP	*Abilities of the GP regarding ACP*	GP's knowledge about the diagnosis, disease trajectory, care and treatment options facilitate ACP(37) (HP) Training the GP is essential for ACP (32) (HP) Good communication skills of the GP facilitate ACP (32, 37) (HP)	GP's lack knowledge about the legal status of ACP(37, 38) (HP)
	Stakeholders attitudes towards ACP	ACP provides self-protection, feelings of relief and takes away concerns about the future (32) (P) ACP must be a cyclical process so decisions are regularly reviewed(34) (C) Previous experiences facilitate ACP (37) (HP)	Discussing the future can be dispiriting(32) (P) There are doubts about the added value of ACP (44) (C) The patients personality can hinder ACP(35) (C) ACP is not possible because patients preferences might change(33, 37, 38) (C, HP) ACP is difficult because the future is unpredictable (32, 34, 38, 45) (P,C,HP) Doubts if the decisions made in ACP are feasible (34, 38, 45) (P,C,HP) Patients/carers are not oriented on the future(32, 34-36, 45) (P,C)

P: stated by the patient; C: stated by the carer; HP: stated by the GP/healthcare professional

Table 2.
Continued

Themes	Categories	Codes	
		Facilitators	Barriers
Prerequisites of ACP	*Stakeholders attitudes towards ACP*		Stakeholders have doubts about the added value of ACP(38)(HP) A negative attitude towards ACP is a barrier for having these discussions(37) (HP) Some stakeholders feel that ACP is outside their professional remit(38) (HP)
	The continuous process of ACP	ACP must be a cyclical process so decisions are regularly reviewed (32, 34, 44) (P)	

P: stated by the patient; C: stated by the carer; HP: stated by the GP/healthcare professional

Table 3.
Themes, categories and codes of the quantitative articles

Themes	Categories	Codes	
		Facilitators	Barriers
A timely initiation of ACP	*The start of ACP*	Because of the cognitive decline, when ACP starts early more participation is possible(41-43) (P,HP) A timely start facilitates ACP(39) (HP)	The right timing of ACP is difficult to determine (39, 40) (HP) PWD's denial/resistance of the dementia diagnosis hinders ACP(39, 43) (HP)
	Initiating ACP	The GP should take the initiative for ACP(39, 40) (HP)	ACP is not initiated because it might cause stress or fear with PWD (39) (HP)
Stakeholder engagement	*Relations between stakeholders*		
	Involving all stakeholders in ACP	It is preferred to carry out ACP with all stakeholders(39, 46) (P,HP) PWD's participation is possible in all phases of dementia(41, 46) (P) PWD are able to participate about values longer(46) (P)	PWD are only limitary involved in ACP (41) (P) The assessment of the PWD's decisional capacity is limited, inconsistent and hinders ACP(41) (C,HP)
Key aspects of the ACP conversation	*Informing the patient*	PWD should be informed about the diagnosis, disease trajectory, care and treatment options (39) (HP)	
	Exploring the patient's wishes and needs	PWD's preferences for ACP depend on the domain of the topic discussed(41) (P)	
	Decision making in ACP	An advance directive is important in dementia (39) (HP)	
	Documentation of ACP		
Prerequisites of ACP	*Abilities of the GP regarding ACP*		
	Stakeholders attitudes towards ACP	A positive attitude towards ACP is a facilitator for having these discussions(43) (P)	
	The continuous process of ACP		

P: stated by the patient; C: stated by the carer; HP: stated by the GP/healthcare professional

Results

We selected 16 papers (Tables 4 and 5) published after 2004; most research was conducted in the UK (N=7) followed by the USA (N=4). Study populations consisted of people with dementia, family carers or GPs, sometimes in combination with other healthcare professionals. Ten were qualitative studies and five were quantitative studies with cross-sectional designs; one paper described an explorative mixed method study.

The overall quality of the papers was moderate, with MMAT ratings of 75% (5 papers), 50% (10 papers), and 25% (1 paper) (Tables 4 and 5). The qualitative papers often lacked a description of the relation between findings and the setting of the collected data. Some papers did not clearly describe the influence of the relation between the researcher and the participants. Several quantitative papers used an inappropriate sampling procedure or had a response rate below 60%.

Analysis resulted in the following four themes related to barriers and facilitators: 1. Timely initiation of ACP; 2. Stakeholder engagement; 3. Important aspects of the ACP conversation; 4. Prerequisites for ACP.

Table 4.
Description of the selected qualitative studies

Author	Design	Participants and settings	Main findings	Themes	MMAT*
Lawrence et al. United Kingdom, 2011	A qualitative design using in-depth interviews with healthcare professionals and family carers	27 bereaved FCs and 23 healthcare professionals from the community, care homes, general hospitals and continuing care units	The timing was considered crucial. ACP should not start too soon because this would cause distress and not to late because of the cognitive decline. PWD and FCs felt insufficiently informed about dementia and ACP. No one felt the responsibility to start ACP.	Timely initiation of ACP, Important aspects of the ACP conversation Prerequisites of ACP	50% of the criteria met
De Vleminck et al. Belgium, 2014	A qualitative exploratory design using focus group interviews	36 GPs from local peer-review groups	The lack of familiarity with the terminal phase of dementia, the lack of key moments to initiate ACP, the patients lack of awareness of their diagnosis and prognosis and the fact that patients do not initiate ACP themselves are barriers to conducting ACP. Familiarity with palliative care was considered a facilitator	Timely initiation of ACP Stakeholder engagement, Important aspects of the ACP conversation, Prerequisites of ACP	75% of the criteria met
Livingston et al. United Kingdom, 2010	A qualitative design using focus group and individual in-depth interviews	43 FCs for the focus group interviews. 46 family carers for the individual interviews. All respondents are recruited from 4 general practices, 3 memory clinics and 5 community clinics	Carers want support from other family members and healthcare professionals when making decisions. They want to receive information well timed. Relationships between stakeholders influence ACP. Remaining QoL is important when making ACP decisions	Timely initiation of ACP, Stakeholder engagement, Important aspects of the ACP conversation, Prerequisites of ACP	75% of the criteria met

ACP: advance care planning; PWD: people with dementia; FC: family carer; *Mixed Method Appraisal Tool

Table 4.
Continued

Author	Design	Participants and settings	Main findings	Themes	MMAT*
Stirling et al. Australia, 2012	A qualitative design using semi-structured, Individual, in-depth interviews and focus group interviews	13 carers of PWD. 4 community nurses, 4 community support workers and 4 counsellors from memory clinics.	Providing realistic information about dementia increases empowerment and facilitates ACP. Decision aids can support ACP. Healthcare professionals provide information selectively because they think PWD and FCs cannot cope with upsetting realities.	Important aspects of the ACP conversations	25% of the criteria met
Dening et al. United Kingdom, 2013	A qualitative design using interviews	6 PWD, 5 FCs, and 5 dyads of people with dementia and their carers from A memory service	ACP decisions have to be taken with all stakeholders. Wishes of people with dementia and their carers might differ. Information, independence and control are main themes in dementia care.	Stakeholder engagement, Important aspects of the ACP conversation, Prerequisites of ACP	50% of the criteria met
Poppe et al. United Kingdom, 2013	A qualitative design using semi-structured, in-depth, interviews	12 PWD living at home, 8 FCs and 6 staff members from memory clinics.	PWD and FCs lack knowledge about dementia and ACP. ACP should be initiated by a well-informed professional soon after the diagnosis. The outcome of ACP should be well documented and available for all health service providers. A decision aid can support ACP	Timely initiation of ACP, Stakeholder engagement, Important aspects of the ACP conversation, Prerequisites of ACP	50% of the criteria met

ACP: advance care planning; PWD: people with dementia; FC: family carer; *Mixed Method Appraisal Tool

Table 4.
Continued

Author	Design	Participants and settings	Main findings	Themes	MMAT*
van der Steen et al. the Netherlands, 2016	A cross sectional survey	133 GPs from Northern Ireland and 188 elderly care physicians from the Netherlands	39.8% of the GPs agreed that ACP should start at diagnosis and 45.9% strongly or moderately disagreed	Timely initiation of ACP	75% of the criteria met
Brazil et al. United Kingdom, 2015	A cross sectional survey	133 GPs from Northern Ireland	GPs moderately (45.5%) or strongly (23.5%) agree that early discussions facilitated decision making. 82.7% of the GPs agree that the GP should take the initiative for ACP. 56.4% of the GPs fear that taking the initiative increases PWD's and the family's anxiety. 96.3% of the GPs find including the patient and family caregiver in ACP as partners has to be a clinical practice goal.79% of the GPs agreed that PWD and their families should be informed about commonly occurring health problems in dementia. 60% of the GPs disagreed that informing PWD and their families about dementia not needed because families will witness the cognitive decline later which is sufficient	Timely initiation of ACP, Stakeholders engagement. Important aspects of the ACP conversation	50% of the criteria met
Karlawish et al. United States, 2005	A cross sectional design using semi-structured interviews, questionnaires and clinical evaluations	48 PWD and 102 FCs from a Alzheimer's Disease Centre	PWD were labelled by psychiatrists as non-competent for medical decision making ($Sn < 52\%$; $Sp > 79\%$) when MMSE scores were < 19	Timely initiation of ACP	75% of the criteria met

ACP: advance care planning; PWD: people with dementia; FC: family carer; *Mixed Method Appraisal Tool

Table 4.
Continued

Author	Design	Participants and settings	Main findings	Themes	MMAT*
Robinson et al. United Kingdom, 2013	A qualitative design using focus group and individual interviews	5 palliative care specialists, 10 general practitioners, 17 community nurses, 10 old-age psychiatrists, 22 mental health nurses, 6 social workers, 15 members of the ambulance services, 3 solicitors and 7 members of the voluntary sector	For the implementation of ACP concerns where expressed about the timing and initiation, the possibility to deliver the patients choice, the financial and legal aspects and the different forms of documentation.	Timely initiation of ACP, Stakeholder engagement, Important aspects of the ACP conversation, Prerequisites of ACP	50% of the criteria met
Dickinson et al. United Kingdom, 2013	A qualitative design using in-depth interviews	17 PWD and 29 FCs from local older peoples services	People with dementia undertake action for practical, financial and personal planning but have difficulties making plans for future healthcare. Barriers are: lack of awareness and knowledge of ACP, the right timing and constraints about choice of future care options	Timely initiation of ACP, Stakeholder engagement, Important aspects of the ACP conversation, Prerequisites of ACP	75% of the criteria met
Horton-Deutch et al. United States, 2007	A qualitative design using semi structured interviews	31 PWD and their FCs from a outpatient Alzheimer clinic	PWD want to make decisions with important others. PWD's pursuit of a normal level of function influences their decision making. The decisions made are not stable over time and FCs make different decisions compared to care receivers.	Stakeholder engagement, Important aspects of the ACP conversation	50% of the criteria met
Hirschmann et al. United States, 2008	A qualitative design, using semi-structured in-depth interviews	30 PWD and their FCs. 8 of these PWD lived at home, 3 used an assisted living facility and 19 lived in a long term facility	ACP discussions should be proactive and start early. Healthcare professionals should be educated to avoid a late start. Lawyers, financial workers can play a role in decision making.	Timely initiation of ACP, Engagement of all stakeholders. Important aspects of the ACP conversation, Prerequisites of ACP	50% of the criteria met

ACP: advance care planning; PWD: people with dementia; FC: family carer; *Mixed Method Appraisal Tool

Table 5.
Description of the selected quantitative studies

Author	Design	Participants and settings	Main findings	Themes	MMAT*
Hamann et al. Germany, 2011	A cross sectional survey	100 PWD, 99 FCs and their referring 93 physicians	MMSE correlates negatively with the understanding (r = -0.44) and reasoning (r = -0.27) sections of the MacCAT-T. PWD who are confident about their decisional capacities want to stay longer involved in the decision making (P = .02). There is no significant correlation between PWD's, their relatives' (r = 0.05) or their physicians' (r = 0.28) confidence in the decisional making capacities of PWD. The overall estimates of FCs en physicians of the decisional preferences of PWD by is poor (Kendall's tau, (b) rel-pat = 0.24, Kendall's tau (b) doc-pat = 0.07)	Timely initiation of ACP, Stakeholder engagement, Important aspects of the ACP conversation	50% of the criteria met
Tay et al. Singapore, 2015	A cross sectional design. A set of standard (clinical) evaluations were administered face to face	98 PWD from a tertiary hospital in Singapore	PWD scored higher on the FAB (t = -3.65, P < .0001) when they make ACP plans or intended to do so. PWD who do not feel the urge to make future plans were less willing to engage in ACP than PWD who used more active coping strategies (t = 2.83, p = .006). PWD who intended or already made future plans had less negative attitudes towards ACP (t=2.47, p=0,015)	Timely initiation of ACP, Stakeholder engagement, Prerequisites of ACP	50% of the criteria met

ACP: advance care planning; PWD: people with dementia; FC: family carer; *Mixed Method Appraisal Tool

Table 5.
Continued

Author	Design	Participants and settings	Main findings	Themes	MMAT*
van der Steen et al. the Netherlands, 2016	A cross sectional survey	133 GPs from Northern Ireland and 188 elderly care physicians from the Netherlands	39.8% of the GPs agreed that ACP should start at diagnosis and 45.9% strongly or moderately disagreed	Timely initiation of ACP	75% of the criteria met
Brazil et al. United Kingdom, 2015	A cross sectional survey	133 GPs from Northern Ireland	GPs moderately (45.5%) or strongly (23.5%) agree that early discussions facilitated decision making. 82.7% of the GPs agree that the GP should take the initiative for ACP. 56.4% of the GPs fear that taking the initiative increases PWD's and the family's anxiety. 96.3% of the GPs find including the patient and family caregiver in ACP as partners has to be a clinical practice goal.79% of the GPs agreed that PWD and their families should be informed about commonly occurring health problems in dementia. 60% of the GPs disagreed that informing PWD and their families about dementia not needed because families will witness the cognitive decline later which is sufficient	Timely initiation of ACP, Stakeholders engagement. Important aspects of the ACP conversation	50% of the criteria met

ACP: advance care planning; PWD: people with dementia; FC: family carer; *Mixed Method Appraisal Tool

Table 5.
Continued

Author	Design	Participants and settings	Main findings	Themes	MMAT*
Karlawish et al. United States, 2005	A cross sectional design using semi-structured interviews, questionnaires and clinical evaluations	48 PWD and 102 FCs from a Alzheimer's Disease Centre	PWD were labelled by psychiatrists as non-competent for medical decision making (Sn < 52%; Sp > 79%) when MMSE scores were < 19	Timely initiation of ACP	75% of the criteria met
Karel et al. United States, 2010	A mixed method study using cognitive, psychiatric capacity assessments alongside semi-structured, individual, interviews	20 PWD, 20 patients with schizophrenia and 19 cognitively healthy elderly from an outpatients clinic	PWD prefer collaborative decision making with their doctor and family. When they rate their collaboration preferences on a scale from 1 to 4, PWD prefer joined decision making with their doctor (mean 2.02) and their family (mean 1.55). For PWD it is more easy to justify their choices in terms of valued activities and relationships	Stakeholder engagement	50% of the criteria met

ACP: advance care planning; PWD: people with dementia; FC: family carer; *Mixed Method Appraisal Tool

1. Timely initiation of ACP

Facilitators of ACP addressed in qualitative research

People with dementia, their family carers, and GPs all noted that an early start facilitates ACP (32-36). Cognitive decline was frequently given as a reason (32-35, 37, 38). According to people with dementia and family carers, GPs should therefore timely initiate ACP (32, 37). They also indicated that diagnostic disclosure, high impact events like a hospital admission, and ACP itself stimulated them to think about future care (32, 35, 36).

Barriers of ACP addressed in qualitative research

People with dementia, family carers, and GPs all referred to having difficulties with determining an optimal timing for ACP (33, 34, 37, 38).

"The trouble with dementia is it can take a long time, it can take a short time. So I don't know what's the best time to do it, but personally I'd rather do it while I still have my wits about me" (carer, wife) (34).

Some family carers mentioned that people with dementia are in denial about their dementia diagnosis (35, 36) or about any possible future problems, and therefore are unwilling to participate in ACP (35). A number of family carers and GPs stated that stress or fear caused by ACP was a reason for them not to discuss future preferences (34, 37). The uncertainty about who should take the initiative for ACP was also mentioned as a barrier (33, 37, 38).

Facilitators of ACP addressed in quantitative research

The importance of early ACP initiation was noted in Brazil's survey among GPs in Northern Ireland (39). Here, most GPs moderately (45.5%) or strongly (23.5%) agreed that early initiation facilitated later decision making. Almost 83% of these GPs also strongly or moderately agreed that the GP should take the initiative to start ACP (39). Van der Steen et al. reported that 92% of Dutch GPs agreed that the GP should take the initiative for ACP (40).

The importance of an early start of ACP because of the cognitive decline was addressed in several studies. In their study on participation in medical and social aspects of decision making, Hamann et al. showed that Mini Mental State Examination (MMSE) scores correlated positively with the understanding ($r = 0.44$) and reasoning ($r = 0.27$) capacities of German people with dementia (41).

Karlawish's study on the ability of people with dementia from a memory clinic to decide on starting dementia medication, showed that those with MMSE scores below 19 were often unable to make these decisions (Sn < 52%; Sp > 79%) (42). People with dementia from a tertiary hospital in Singapore involved in ACP scored higher on the Frontal Assessment Battery (FAB) for frontal lobe functioning than those not involved ($t = -3.65$, $P < .0001$) (43).

Barriers addressed in quantitative research

The difficulty of the timing of ACP was reflected in Brazil's survey among Irish GPs: almost 40% strongly or moderately agreed that ACP should start at diagnosis, whereas 46% strongly or moderately disagreed with this statement (40). Van der Steen et al. note that 60% of Dutch GPs wanted ACP to start at diagnosis, but 25% did not (40). According to Tay & Davison, people with dementia who did not feel the urge to make future plans, were less willing to engage in ACP compared to those who used active coping strategies ($t = 2.83$, $p = .006$) (43). Brazil et al. reported that 56% of the participating GPs indicated they feared that initiating ACP would unnecessarily increase the family carer's anxiety (39).

2. Stakeholder engagement

Facilitators addressed in qualitative research

In interviews, people with dementia and family carers noted that ACP should take place with all stakeholders because of their involvement in the decision-making process. Several papers stated that regarding advance directives like living wills or lasting power of attorney, experts from outside the medical profession like lawyers or financial advisers may also need to participate (34, 36, 44, 45).

"Resuscitation was the biggest decision. . . I consulted with my children and my wife's sisters and they were all in agreement . . . she has gone through enough." (husband) (36).

According to GPs, a good relation between them, the people with dementia, and family carers eased ACP; when the relationship is good, people with dementia and family carers would be more open about discussing ACP (32). People with dementia also mentioned that if they were no longer capable of making decisions themselves, they would trust their family carers to do this for them and therefore wanted them involved. Family carers stated that they were able to fulfil this role (34, 36).

Barriers of ACP addressed in qualitative research

Four barriers to stakeholder engagement were mentioned. According to some family carers, a poor relation between stakeholders hampers ACP. Several family carers also stated that ACP is hindered by limited assessment of the decisional capacity of people with dementia, and because taking responsibility for ACP is difficult (36, 38). One study mentioned that people with dementia's unawareness of the dementia diagnosis also limits their engagement (37).

Facilitators of ACP addressed in quantitative research

Brazil et al. reported that 96% of the participating Irish GPs found that including people with dementia and family carers in ACP should be a goal of clinical practice (39). People with dementia from an American outpatient clinic who were asked to rate their collaboration preferences on a scale from 1 (I want to make the decision myself) to 4 (I want my doctor or family to make the decision), preferred shared decision-making with their doctor (mean 2.02) and their family (mean 1.55) (46). This study also showed that when ACP focused on the consequences of medical decisions and on the values of people with dementia instead of on complex treatment scenarios, people with dementia could participate longer (46). In addition, a survey among people with dementia or with mild cognitive impairment showed that confidence in their capacity to make medical decisions was an important factor in their willingness to be engaged in ACP. Those who were confident about their decision-making capacity wanted to stay involved longer (P=.02) as opposed to those lacking confidence (41).

Barriers addressed in quantitative research

A survey among people with dementia or mild cognitive impairment, their relatives and physicians, showed that people with dementia were more confident about their decisional capacities compared to their relatives or physicians. There was no significant correlation between people with dementia's confidence and their relatives (r = 0.05), between people with dementia and their physicians (r = 0.17) or between relatives and physicians (r = 0.28) regarding people with dementia's medical decision-making capacities (41). Relatives gave better estimates of the decisional preferences than physicians, but their overall estimation was poor (Kendall's tau, (b) rel-pat = 0.24, Kendall's tau (b) doc-pat = 0.07) (41).

3. Key aspects of the ACP conversations

Facilitators addressed in qualitative research

With respect to setting the goals they would like to achieve with ACP, people with dementia and family carers wanted to discuss a normal level of functioning and maintaining QoL (36, 44). In addition, people with dementia, family carers and GPs stated that financial matters and the power of attorney needed to be discussed (34-36, 38).

Family caregivers and healthcare professionals added that they felt that unwanted and burdensome interventions like hospital admissions took place if these preferences remained unknown (37). Family carers' earlier experiences with ACP therefore stimulated the decision-making process (36). Dickinson et al. showed that when goals are discussed, people with dementia and their family carers preferred informal discussions instead of written documents (34). The use of decision aids providing information and structure appeared to contribute to decision-making during ACP (32, 47). When ACP had taken place, documentation of preferences (for example in the medical file or a lasting power of attorney) was found essential, as it would make the preferences available to all stakeholders (32, 34, 35, 38).

"So she needed to make a decision whether she would be fed by a percutaneous endoscopic gastrostomy at some point, and by the time that was a reality, the family were left to make that decision for her. And she had said, anecdotally, that she wanted the least intervention possible, but then nothing was documented ... I suppose nobody took ownership or leadership of that process at all, and everyone was floundering a bit with it (social worker)" (38).

Family carers wanted realistic information during ACP because this increased their empowerment (37). They also felt that GPs should ask people with dementia directly about their preferences (37).

Barriers addressed in qualitative research

Several studies showed that family carers and people with dementia felt they were insufficiently informed about dementia, its consequences, and care and treatment options (32-34, 36, 37).

"Patients are often sent home with a diagnosis. They know what's going on, but they didn't get very specific information from the specialists. They wonder, "What will happen to me? Is there really nothing they can do for me?" (Male GP) (37).

In one study, some family carers stated that GPs selectively provided information because, if too much information was given, people with dementia and family would not be able to process this (47). In two studies, family carers mentioned that they lacked knowledge about the purpose of ACP or that they were unaware of its existence (34, 45).

People with dementia, family carers, and GPs were all concerned that preferences for future care could not be met because of restrictions within the healthcare system (34, 36, 38, 45). In addition, GPs stated that when people with dementia or their family carers wanted to discuss financial matters and the power of attorney, the costs for actually settling these matters were considered to be too high (38).

In two studies, people with dementia, family carers, and GPs stated that wishes were not always registered in the patient's medical file or other formal documentation. The uncertain future and feelings of guilt or disloyalty made them reluctant to do so (34, 37).

Facilitators addressed in quantitative research

People with dementia emphasized they themselves want and are able to decide on social subjects within ACP. When people with dementia were asked who should have the greatest say on different subjects, (answers ranked from 1: this person should have the greatest say; to 3: this person should have the least say), people with dementia reported wanting to make their own social decisions e.g. about housing (mean rank 1.28; SD 0,6) or driving (mean rank 1.39; SD 0,63). With regard to drug related decisions, however, people with dementia wanted the physician to have the greatest say (mean rank 1.51; SD 0,7) (41).

In Brazil et al.'s study, the importance of informing people with dementia about dementia was stressed. Of all participants, 97% agreed with the statement: 'people with dementia and their families should be informed about commonly occurring health problems that might be expected in severe dementia' (39). Fifty-one percent of the GPs in this study also agreed that, when dealing with dementia, documenting preferences in an advance directive was essential (39).

4. Prerequisites for ACP

Facilitators addressed in qualitative research

GPs stated in interviews that they need sufficient knowledge about the dementia disease process and its life-limiting character, and that they need training to develop the skills to discuss difficult subjects and manage conflicts (32, 37). Some GPs added that positive previous experiences with people with dementia made them more willing to discuss ACP in the future (37).

People with dementia and family carers noted that after having had ACP consultations, they felt relieved and were more confident that their future wishes would be respected (32). They added that ACP discussions should be repeated to enable a review of decisions and/or documentation made (32, 34, 44). Horton Deutch et al's finding that half of the people with dementia who were asked to make a healthcare decision based on a vignette changed their initial preferences after four weeks, supports this view (44).

Barriers addressed in qualitative research

In several studies, part of the GPs, family carers, and people with dementia expressed negative attitudes towards ACP because of the unpredictable nature of the disease progression. This made them question the feasibility and added value of ACP, and therefore made them unwilling to discuss future care preferences (32, 34, 38, 45).

"You don't know what changes will happen, when they will happen . . . that's why it (ACP) is very difficult to define." (Carer) (45)

Some people with dementia and family carers added that 'living one day at a time' resulted in negative attitudes towards ACP, and some people with dementia found discussing the future dispiriting (32, 34-36, 45). Family carers also stated that the personality of people with dementia might impede ACP because, in general, they did not want to talk about difficult subjects (32, 34-36, 45).

A number of GPs felt that ACP was outside their professional remit (38). In addition, several GPs stated that ACP was not possible because preferences might change (33, 37, 38). They also noted barriers like their lack of knowledge regarding legal aspects in relation to ACP and the documentation of decisions in living wills, lasting power of attorney, or advance directives. This was especially true in relation to people with dementia (37, 38).

"I get confused about the terminology about advance care and advance directive and that and one's legal binding, and it all becomes a bit of a blur." (GP) (38)

Facilitators addressed in quantitative research

According to the Perceived Barriers Scale, people with dementia who already had or intended to make future plans, had less negative attitudes towards ACP than those who did not (t=2.47, p=0,015) (43).

Discussion

In this integrative review, we identified barriers and facilitators faced by GPs related to ACP for people with dementia, clustered in four themes: timely initiation of ACP; stakeholder engagement; important aspects of the ACP conversation; and prerequisites for ACP. After integrating the data, we noted slightly more facilitators than barriers. Interestingly, the selected quantitative papers mainly focused on the timely initiation of ACP and stakeholder engagement, while the qualitative papers addressed all four themes.

The most important facilitators mentioned were: an early start, when the person with dementia can still be actively involved, and the participation of all stakeholders. Diagnostic disclosure, providing information, a good relationship between all stakeholders, and discussions about social issues with a focus on people with dementia values, QoL and maintaining normal life also appeared relevant and important, as were regularly repeating ACP discussions and reviewing possible documentation, as preferences may change.

The most important barriers for ACP mentioned by all stakeholders included elements of uncertainty: the uncertainty of when to start, the uncertain future, and people with dementia's and family carers' lack of knowledge about dementia. GP-specific barriers were the difficulty of assessing the decisional capacity of people with dementia, the possibility that future preferences might change, and the uncertainty whether future care preferences eventually could be granted.

The reluctance to engage in ACP was also described in a systematic review by van der Steen et al. The barriers they found were mostly related to the unwillingness of people with dementia or their family carers to initiate ACP (48). In line with our results, this review suggests that, regarding the optimal timing for ACP, the healthcare professional should initiate ACP when people with dementia and their family carers are receptive and feel the urgency to start, but before a crisis develops (48). However, as our results show, GPs are also hesitant to initiate ACP. As stated in the review by De Vleminck et al., the dementia's uncertain disease process is one of the causes for this hesitation (32, 34, 38, 45, 49) which may lead to a prognostic paralysis: a situation where GPs avoid discussing future care preferences (50-52). Because GPs are used to providing reactive care, and ACP requires thinking ahead, ACP initiation becomes even more difficult (53).

Research on patients with chronic diseases shows that, even in cases where GPs want to start ACP early, patients first need time to cope with the idea of having a chronic, progressive disease (54, 55). GPs could stimulate timely ACP initiation by regularly checking people with dementia's readiness to start ACP, and by using cognitive or functional decline or a crisis situation as a motive (7, 48, 56-60).

Our results show that people with dementia and family carers feel insufficiently informed about dementia, which confirms the findings in the systematic reviews by Dening et al. and Gillissen et al., and in research on communication in dementia care (10, 52, 61, 62); only informed patients are able to reflect on which options they have or which problems may arise (63). If a person with dementia is unaware of or even denies the dementia diagnosis and therefore the possibility of future problems, the barrier to starting ACP becomes even more complex (35-37).

Initiation of ACP may also be postponed by the GPs' and family carers' doubts about the decisional capacities of people with dementia (37, 38). This was also shown in the review by Gillisen et al. about ACP in long term dementia care (52). However, the decisional capacity can differ between subjects and over time. GPs should therefore try to involve people with dementia and their family carers at every stage of the disease, and tailor ACP discussions to the specific abilities of the person with dementia in question (52, 55, 64). A goal-oriented approach is likely to help GPs overcome this problem (65). The use of this approach is supported by results from our review in which people with dementia emphasized the importance of maintaining normal lives, and their role in the present day where they mainly want to decide on (future) social issues (36, 44, 46). This approach is in line with the fact that patients in general want to articulate their life's values and use these to make decisions later on, or to have family carers decide for them (66).

ACP for people with dementia could therefore explore what is important in the present so that future care can then be planned according to these preferences (65). Using this approach corresponds with the broad definition of ACP used in our introduction.

Implications for practice

To improve the timely initiation of ACP, GPs need training (32, 67). As a key message, we suggest that people with dementia participate in ACP when future care is planned in light of their goals, life values, normal daily function, and their remaining QoL (41, 46, 67). A recently published dynamic model for shared decision making with frail elderly could be used for this purpose (65). In this model, the patient's near future goals are the starting point for discussing preferences for future care, and these are also regularly reviewed (65). By using this approach, barriers regarding an uncertain future and the decisional capacities of people with dementia may become less relevant. In addition, GPs need to be aware of the consequences of dementia, including legal issues, and about the significance of informing people with dementia. This may help GPs anticipate the illness process and recognize the people with dementia's and their carers' need for information (37, 38, 49, 68).

Using a collaborative care model, where case managers take on GP tasks, may also stimulate a timely initiation of ACP. Research shows that case managers have regular contact with people with dementia and have sufficient communication skills to discuss difficult subjects. They are also able to coordinate care and educate people with dementia and their family carers about dementia and the legal issues concerning ACP. This approach requires regular consultations between GPs and case managers (69, 70).

The use of an ACP workbook containing information and exercises on how to communicate choices in combination with a home visit of a social worker, increased the number of ACP discussions and documentation of preferences in people with a chronic illness. This may therefore also be useful for people with dementia (71). The Surprise Question or other tools used to identify patients in need of future care planning, may also help GPs to timely start ACP (71-73). Financial compensation for the time spent on ACP could possibly encourage GPs to embed ACP in regular care, however there is little evidence for this (49).

Strengths and limitations

The systematic and strong integration of qualitative and quantitative results is the main strength of this review. All the themes were covered by papers with differing methodologies, with only small differences noted. As a consequence, the themes resulting from our analysis are likely to reflect the most important barriers and facilitators for the initiation of ACP with people with dementia by GPs. As many of the selected studies were qualitative, we were able to collect additional in-depth information which may contribute to implementation of ACP solutions in primary dementia care.

One limitation of our study is that most of the articles were related to research conducted in western countries. Our results cannot therefore be generalized to non-western countries, as culture and ethnicity have a profound influence on ACP (74, 75). Several papers included other primary care professionals in addition to GPs, therefore it was not always clear if the given data concerned the GPs. Another limitation is reflected in the quality of the papers included. None of them had a maximum MMAT rating, and the overall quality was moderate. However, no contradictory findings were reported, and most were confirmed in more than one of the included papers.

Conclusion

Exploring people with dementia’s medical and social preferences for future care together with a focus on maintaining QoL and normal daily function may contribute to their better and longer involvement in ACP. ACP should therefore start with discussing what goals people with dementia have for the near future, which can then be used to make decisions about future care. Because of their position within the healthcare system, GPs have the opportunity to initiate ACP in primary care. Significant facilitators for this process are a timely start when cognitive decline is still mild, and the engagement of people with dementia and their family carers. To be successful, it is essential to train GPs in the skills necessary to initiate ACP discussions. This integrative review provides input for designing GP training programs, and facilitating future care planning for people with dementia in agreement with their wishes and preferences.

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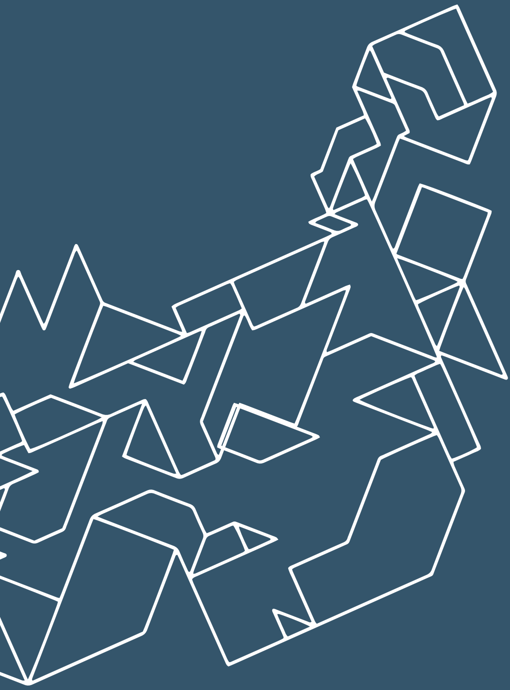

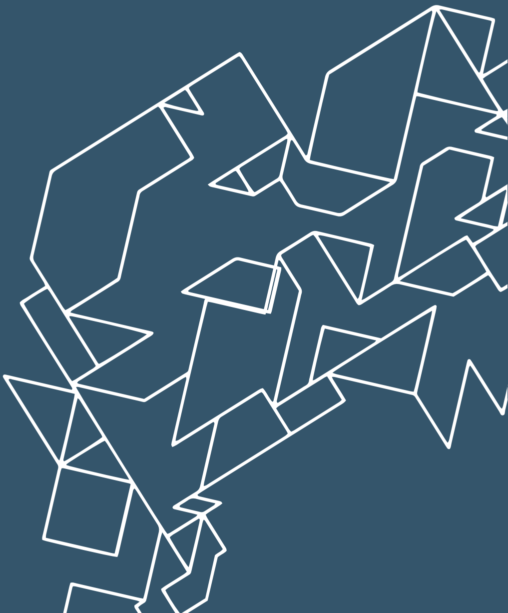

Chapter 3

The importance of trust-based relations and a holistic approach in advance care planning with people with dementia in primary care: a qualitative study

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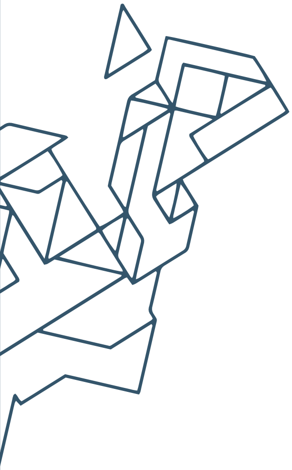

Abstract

Background

ACP enables individuals to define and discuss goals and preferences for future medical treatment and care with family and healthcare providers, and to record these goals and preferences if appropriate. Because general practitioners (GPs) often have long-lasting relationships with people with dementia, GPs seem most suited to initiate ACP. However, ACP with people with dementia in primary care is uncommon. Although several barriers and facilitators to ACP with people with dementia have already been identified in earlier research, evidence gaps still exist. We therefore aimed to further explore barriers and facilitators for ACP with community-dwelling people with dementia.

Methods

A qualitative design, involving all stakeholders in the care for community-dwelling people with dementia, was used. We conducted semi-structured interviews with community dwelling people with dementia and their family caregivers, semi structured interviews by telephone with GPs and a focus group meeting with practice nurses and case managers. Content analysis was used to define codes, categories and themes.

Results

Ten face to face interviews, 10 interviews by telephone and one focus group interview were conducted. From this data, three themes were derived: development of a trust-based relationship, characteristics of an ACP conversation and the primary care setting.

ACP is facilitated by a therapeutic relationship between the person with dementia/family caregiver and the GP built on trust, preferably in the context of home visits. Addressing not only medical but also non-medical issues soon after the dementia diagnosis is given is an important facilitator during conversation. Key barriers were: the wish of some participants to postpone ACP until problems arise, GPs' time restraints, concerns about the documentation of ACP outcomes and concerns about the availability of these outcomes to other healthcare providers.

Conclusions

ACP is facilitated by an open relationship based on trust between the GP, the person with dementia and his/her family caregiver, in which both medical and non-medical issues are addressed. GPs' availability and time restraints are barriers to ACP. Transferring ACP tasks to case managers or practice nurses may contribute to overcoming these barriers.

Background

People with dementia face a progressive decline in functional and mental capacity, with a median survival of 7 to 10 years from the first symptoms of the disease (1-3). Because of its chronic and life limiting nature and the expected cognitive decline, timely advance care planning (ACP) is advised (4).

A recently published international consensus statement from the European Association of Palliative Care defined ACP as the process which enables people to define goals and preferences for future medical treatment and care, to discuss these goals with family and healthcare providers, and to record and review these preferences if appropriate (5). Although ACP is recommended by dementia experts, for people with dementia it is uncommon in daily practice and futile medical treatments, avoidable hospitalisations and poor quality of life often occur (2, 4, 6-8).

Research on the effectiveness of ACP for people with dementia is scarce. However, in adult populations, ACP improved the concordance of preferred and delivered care and the communication between patients, their family and healthcare professionals (9, 10). In frail elderly, ACP reduced anxiety, depression and stress. When ACP was initiated, frail elderly also received less aggressive treatments, were less often admitted to the hospital and more often died in their trusted environment (11). Dementia-specific research in long-term care settings showed that ACP reduced healthcare costs and hospital admissions (12).

Compared to people with dementia who are institutionalized, community-dwelling people with dementia more often have the mental capacity to express their preferences for future care and to actively participate in ACP. In the Netherlands, over two third of the people with dementia live in the community with general practitioners (GP), often assisted by a practice nurse, as primary healthcare providers (13). In many cases, case managers are also involved to coordinate different aspects of care and provide emotional support (14). Because most people with dementia and their family caregivers have long-lasting relationships with their GPs, GPs seem suited and willing to initiate ACP (15, 16). In primary care however, ACP with people with dementia hardly takes place or takes place very late (12, 17, 18).

Previous research identified uncertainties about the timing, future, evaluation and decisional capacities of people with dementia to contribute to the limited initiation of ACP (19). A timely start, facilitates ACP, because in the beginning of the disease process when cognitive decline is still mild, participating in decision making is still possible. Involving people with dementia and family caregivers and regularly reviewing and documenting ACP outcomes facilitates ACP as well (19).

Because of the difficult subjects being discussed, it can be assumed that the communication and relationship with the GP are also important facilitators for ACP (20).

Dementia-specific knowledge about this topic is however limited (21, 22). Previous research also showed that people with dementia favour discussing non-medical issues within ACP (23). This holistic approach were the psychological, social and spiritual domains, next to the physical domain are included, fits the definition palliative care and the broad definition of ACP as proposed by Rietjens et al. (5, 24). Evidence on this potential facilitator is however also limited.

As ACP with people with dementia by GPs is still rarely practiced, we aimed to further explore barriers and facilitators concerning this subject. We thereby especially focused on the evidence gaps concerning the communication between the GP and people with dementia, the relationship of GPs with people with dementia and the inclusion of non-medical preferences within ACP.

Methods

Research design

A qualitative design was used in order to reach our research aim (25). We included people with dementia, living independently in the community or a in a residential home and receiving care from a GP, together with their family caregivers. GPs, practice nurses and case managers were included because they are important stakeholders in the care for people with dementia (26).

Case managers and practice nurses were interviewed during a focus group, which method is particularly useful to explore the participants' knowledge and experiences (27). Because of their busy time schedule, GPs were interviewed by telephone, as this facilitated flexibility in scheduling the interview. People with dementia, together with their family caregivers, were interviewed face to face in their own homes, as their cognitive decline might impede group discussions.

Recruitment of participants

We recruited GPs by contacting the GP peer review group of the department of primary and community care of the Radboudumc and through the professional contacts of the researchers involved in our study (MP, BT and YE). We strived for a sample of GPs which contained males and females and a variety of experience with dementia care, as both characteristics influence general practitioners' attitudes towards dementia (28).

People with dementia, their family caregivers, case managers and practice nurses were recruited during several community meetings for people with dementia and family caregivers (Alzheimer café's) in the region of Nijmegen and through the professional contacts of one of the researchers (MP). We decided to interview people with dementia accompanied by their family caregivers because earlier research showed that they prefer making decisions about future care together (23, 29).

Furthermore, we considered it very important for participating people with dementia to feel safe discussing such a delicate topic. GPs and case managers and practice nurses could participate if they were involved in the care for people with dementia. Potential participants were informed by letter about the study and were requested to sign an informed consent before the interview.

Data collection

The main researcher (BT), a male PhD candidate, psychologist and nurse, trained in conducting and analysing qualitative interviews, was present during all interviews. Two additional interviewers were: a female researcher in palliative care, trained in conducting and analysing qualitative interviews (YE) and a female medical student, with no prior experience in qualitative research (MW). No relationship existed with the respondents prior to the interviews.

The interviews with the GPs were conducted by one researcher (BT). The face to face interviews with people with dementia and family caregivers were conducted by two researchers (BT, MW) as was the focus group (BT, YE). Field notes were made during each interview and participants gave their consent to audio-tape the interviews.

A similar topic guide was used for all three forms of interviewing. This guide was developed during several sessions with the members of the research team (BT, MP, YE, MVD, RK) and pilot tested with a family caregiver and a person with dementia (additional file 1). All people with dementia and family caregivers received a written summary of their interview and were invited to give comments.

Data analysis

All interviews were transcribed verbatim. Data analysis started directly after the first interview using content analysis (30). After each interview had been coded, the topic list was adapted where required. Researchers independently open coded all interviews within each group of stakeholders (people with dementia/ family care givers: BT and MW; GPs/case managers and practice nurses: BT and EB or RT or PL). Results were compared until consensus was reached. In case of disagreement, this was discussed with a senior researcher (YE, MP). After the last interview within each group of stakeholders, the researchers made an affinity diagram to cluster codes and define categories and themes (30, 31). All data were then combined to create definitive categories and themes. Because we wanted to focus on new findings, codes already thoroughly described in earlier research were marked. The codes concerning new findings will be described in the results section. The codes already known from earlier research will only be presented in a table.

Ethical consent

The study was approved by the research ethics committee (CMO) of the region Arnhem-Nijmegen in accordance with the Medical Research Involving Human

Subjects Acts and the declaration of Helsinki (NL52613.091.15). Anonymity was assured by removing all participant information that could lead to identification from the transcripts.

Results

GPs aged 31 to 64 years and their work experience varied between one to 33 years. Sixty percent of the GPs was female. The number of patients within each practice ranged between 1700 and 7370 and the percentage of persons with dementia in their practice varied between 0.1% and 10%. One GP was trained as an expert GP elderly care. Case managers/practice nurses aged 46 to 63 years. Their work experience ranged between 5 and 25 years with a case load between 55 and 75 people with dementia. All were female and trained in dementia care. People with dementia aged 79 to 90 years and 70% was male. The time since diagnosis ranged from 6 months to 6 years. Family caregivers aged 24 to 85 years and 77% was female. Nine people with dementia lived in their own home with their family caregiver. One lived in a residential home, separately from her family caregiver.

One focus group of 90 min. with case managers and practice nurses was conducted. The interviews by telephone with GPs lasted 30 min. The interviews with people with dementia and family caregivers lasted 90 min. With the GPs, people with dementia and family caregivers, no new codes emerged after eight interviews. To confirm saturation two additional interviews were conducted. In three interviews with people with dementia and their family caregivers, an extra family caregiver was present. One person with dementia passed away after we already made the appointment for the interview. Because the widow of this person explicitly asked to participate and seemed capable to express her husband's view as well as her own, we decided to keep her included in this study. Field notes were made during each interview and participants gave their consent to audio-tape the interviews.

Content analysis revealed barriers and facilitators for initiating ACP by GPs with people with dementia in three themes: development of a trust based therapeutic relationship, characteristics of an ACP conversation, the primary care setting and eight categories: the relationship with the general practitioner, home visits, starting ACP, stakeholder involvement, discussing goals, evaluation and documentation, time availability, organisation of the general practice. These themes, categories and codes are displayed in Table 1.

Table 1.
Themes, categories and codes

Themes	Categories	Codes	
		Facilitators	Barriers
Development of a trust based therapeutic relationship	The relationship with the GP	The GP knows what PWD find important in life (PWD) The GP is easy to talk to (PWD) An open relationship with the GP is important (PWD) A trusting relationship with the GP is important (CM, FC, PWD, GP) The GP listens to the PWD (PWD, FC) The GP knows the PWD/FC personally (PWD, FC, GP) The GP provides empathic support (FC, PWD, GP) The GP understands the PWD (PWD) Providing information respectful is important (PWD, GP) *The GP provides the right information (PWD)** (52) *Good communication makes ACP easier (GP)** (21, 22) *A good relationship with the GP is important (PWD, FC)** (21)	The GP is to distant (FC,PWD) The GP does not listen to PWD (FC) The GP has little contact with PWD (PWD, FC,GP, CM) The GP trivialises the situation (PWD, FC)
	Home visits	ACP should take place at home (CM, FC, PWD) ACP should take place at a quiet moment (FC, PWD) More time available during home visits (FC)	The GP does not conduct home visits(FC, PWD) The GP does not know the living situation (CM, FC)

GP: stated by general practitioner; CM: stated by case manager/practice nurse; PWD: stated by person with dementia, FC: stated by family caregiver
* codes which already have been described in earlier research

Table 1.
Continued

Themes	Categories	Codes	
		Facilitators	Barriers
Development of a trust based therapeutic relationship	Home visits	By conducting home visits, the GP knows the living situation (CM, FC) ACP should be held at the PWD's preferred location (GP)	
Characteristics of an ACP conversation	Starting ACP	ACP starts after providing the diagnosis (GP) ACP should not start under stress (CM, GP) PWD/FC should first cope with the diagnosis before the start of ACP (GP) ACP should start when the PWD/FC states the need to do so (GP) FC takes the initiative to start ACP (FC) Because of a wish for euthanasia, ACP is started (PWD) PWD must be followed from diagnosis on (GP) Information from family and healthcare providers stimulates the start of ACP (GP) Surprise Question helps to start ACP (GP) *ACP should start early because of the cognitive decline (GP, FC, PWD, CM)** (21, 22, 45-47) *GPs should take the initiative for ACP (GP, CM, PWD, FC)** (16, 21, 22) *The GP's positive attitude stimulates the start of ACP (GP)** (22)	Not all PWD/FC want ACP (PWD, GP) GP's lack knowledge/experience of ACP (GP) The diagnosis is not always clear (GP) GP doesn't take the initiative to start ACP (CM, FC, PWD) Healthcare professionals find discussing end of life issues difficult (CM) Dementia does not give complaints (PWD) Start ACP when problems arise (CM, GP, PWD, FC) *The assessment of decisional competency is difficult** (46)

GP: stated by general practitioner; CM: stated by case manager/practice nurse; PWD: stated by person with dementia, FC: stated by family caregiver
* codes which already have been described in earlier research

Table 1.
Continued

Themes	Categories	Codes	
		Facilitators	Barriers
	Stakeholder involvement	Provide choices instead of open questions (GP) ACP should not be confronting (GP) ACP content must be adjusted to PWD level of understanding (FC, GP) End of life decisions are made together (FC, PWD)* (45, 53, 54) FC must present within ACP (CM, FC, PWD, GP)* (45, 53, 54) FC makes ACP decisions (PWD, FC)* (45, 53) PWD must be present when ACP is discussed (GP, FC, CM, PWD)* (45, 53-55)	Social status influences ACP (GP) Preferences of FC and PWD can differ (CM, GP) ACP is difficult to explain (GP) The assessment of decisional competency is difficult (GP)* (46)
Characteristics of the ACP conversation	Discussing goals	PWD's preferences are the starting point of ACP (GP CM) FC respects PWD choices (FC) PWD/FC want to be able to prepare ACP (CM, PWD, FC) ACP decisions provide clarity and peace (FC, PWD, GP) The GP sometimes must be authoritarian (GP) ACP should deal with current issues (GP) Supporting FCs should be discussed during ACP (FC) Medical subjects should be discussed during ACP (CM, PWD,FC)	Not all problems can be discussed upfront (GP)

GP: stated by general practitioner; CM: stated by case manager/practice nurse; PWD: stated by person with dementia, FC: stated by family caregiver
* codes which already have been described in earlier research

Table 1.
Continued

Themes	Categories	Codes	
		Facilitators	Barriers
Characteristics of the ACP conversation	Discussing goals	PWD know what they want for their future (FC, PWD) social subjects should be discussed during ACP (PWD,FC) ACP prevents moments of crisis and over treatment (GP) PWD know what they want for their future (FC, PWD) ACP prevents moments of crisis and over treatment (GP) ACP stimulates autonomy (GP)	
	Evaluation and documentation	ACP should not be evaluated to often (CM) ACP must be evaluated regularly (GP)* (45, 54) ACP outcomes must be documented and available for all stakeholders (GP, CM)* (21, 45-47) ACP must be a cyclical process (PWD,FC,CM, GP)* (45, 54) The GP should take enough time for ACP (FC)	ACP documentation not always available for all stakeholders (GP, FC, PWD, CM) ACP decisions are considered final (FC) The PWD's current will counts (CM, GP, FC) When to evaluate ACP is unclear (GP)* (54)
	Time availability	The GP is easily available (FC) ACP saves time in the long term (GP)	ACP consultations are often to short (GP, MC, PWD, FC) GP has limited time for ACP (FC) Because of limited time only medical subjects are discussed (PWD, FC, CM) The GP is rushed during ACP (FC)

GP: stated by general practitioner; CM: stated by case manager/practice nurse; PWD: stated by person with dementia, FC: stated by family caregiver
* codes which already have been described in earlier research

Table 1.
Continued

Themes	Categories	Codes	
		Facilitators	Barriers
The primary care setting	Time availability		ACP doesn't save time in the long term (GP) ACP takes time in the short term (GP)
	Organisation of the general practice	Regular appointments with GP/CM/PN facilitates ACP (FC, PWD, GP) CM/PN discusses medical and social subjects (FC) CM/PN has more knowledge of living situation compared to GP (FC,GP, PWD) CM/PN has more knowledge of dementia compared to GP (CM, PWD) The therapeutic relationship with the CM/PN facilitates ACP (PWD, FC) Special care programs for dementia facilitate ACP (GP) ACP should be structurally implemented (GP) ACP can also be provided by a CM/PN (FC) GPs and CMs/PNs should have regular contact (FC, GP) Specialized training in dementia/elderly care stimulates ACP (GP) PN/CM can support GP in ACP process (GP) GP should coordinate ACP (GP)	Case manager is often involved to late (GP, CM, PWD, FC) PWD have limited contact with their CM/PN (FC) PN/CM cannot discuss medical issues (GP) Inadequate reimbursement limits ACP (GP)

GP: stated by general practitioner; CM: stated by case manager/practice nurse; PWD: stated by person with dementia, FC: stated by family caregiver
* codes which already have been described in earlier research

Several codes within the categories of the relationship with the GP, starting ACP, stakeholder involvement and evaluation and documentation were identical to barriers and facilitators described in earlier research (Table 1) and were therefore not described in the result section.

Theme 1: Development of a trust based therapeutic relationship

The relationship with the general practitioner

Facilitators

GPs, people with dementia and family caregivers stated that it is important that the GP knows the person with dementia personally, is empathic, supportive and provides information respectfully. People with dementia and their family caregivers added that, when discussing preferences for the future, they want their GP to listen to them, is easy to talk to and knows what they find important in life.

"A connection, an invisible connection, but that is a feeling, a feeling you have that you are at ease because she (GP) is there. He (person with dementia) did not have to be afraid anymore. He did not have to worry. He did not have to be nervous If he couldn't remember something, well… he could get his thoughts of his mind so to speak….. There was a trusting relationship which was beautiful to see" (family caregiver, interview 2).

Barriers

Several family caregivers and people with dementia stated that their GP trivialized their situation, was too distant and did not listen to them. This made them hesitant to discuss sensitive topics. GPs, people with dementia, family caregivers and case managers and practice nurses also found that GPs had too little contact with people with dementia and their family caregivers. According to some GPs, having infrequent contacts was due to either a capable family caregiver or the person with dementia living in a residential home.

Home visits

Facilitators

People with dementia, family caregivers, case managers and practice nurses preferred to have ACP at the home of the person with dementia. In this trusted environment, people with dementia are more at ease to talk about sensitive topics and feel less hurried by the GP's time schedule.

People with dementia, family caregivers, case managers and practice nurses found that during such home visits, GPs get more insight in the person with dementia's living situation.

"I would prefer to have the conversation here (at home) and not at an impersonal office. The home environment is different; than you can sit in your own chair and communicate about personal topics. (family caregivers, interview 9)

According to the GPs, ACP conversations ideally should take place at the location preferred by the person with dementia and family caregiver.

Barriers

Case managers and practice nurses and GPs doubted if home visits for ACP would be feasible because of the GP's busy schedule. This corresponded with the fact that, according to most people with dementia and family caregivers their GPs rarely conduct home visits.

Theme 2: Characteristics of an ACP conversation

Starting ACP

Facilitators

Some GPs, people with dementia, family caregivers and all case managers and practice nurses wanted to start ACP immediately after the diagnosis was given. Starting early has the advantage of being able to choose the moment of initiation and ACP under stressful circumstances can be avoided

" Yes, uh.... it also depends on the co-morbidities but for me pretty soon... That is difficult because what is pretty soon... But I would say that from diagnosis, you want to start to discuss what peoples wishes are.....". (general practitioner, interview 2)

Other GPs also stated that dyads should first be given time after the disclosure of the diagnosis, because this is often a difficult experience. Case managers and practice nurses, people with dementia and family caregivers added that people with dementia and family caregivers should be given time before an ACP conversation to think about what they want to discuss.

According to several GPs, some types of information received from other healthcare professionals or family caregivers could trigger them to start ACP. According to some people with dementia, ACP is initiated sooner when a wish for euthanasia was expressed.

One GP added that using the Surprise Question (a question the general practitioner asks himself in silence to identify those patients with an increased chance to die or deteriorate within a year) stimulated his proactive behaviour.

Barriers

Part of the GPs, people with dementia and family carers only wanted to discuss preferences for the future when problems actually arise. Some GPs said to postpone ACP until the cognitive deterioration becomes problematic, and for that reason monitored the person with dementia after the diagnosis had been provided. A lack of knowledge and experience with ACP, an unclear diagnosis and the fact that ACP is a difficult concept to explain were other reasons to postpone ACP, as mentioned by GPs. Finally, according to case managers and practice nurses, GPs do not initiate ACP as they fear talking about difficult subjects.

Stakeholder involvement

Facilitators

Some GPs wanted all healthcare professionals involved in the care for a person with dementia to participate in ACP so that all knew what had been discussed and decided. Some GPs also stated that, if the person with dementia approved, ACP consultations sometimes took place without the person with dementia. For example, when the person with dementia denied or did not accept the dementia diagnosis. Family caregivers and GPs found that, in order to stimulate involvement of people with dementia, the GP should tailor ACP to the cognitive level of the person with dementia and make sure that the conversation is not confronting. When GPs asked closed instead of open questions, participation of people with dementia within ACP also becomes easier.

Barriers

Some GPs mentioned that people with dementia’s and family caregivers’ low social status, low IQ, limited self-knowledge or strong religious beliefs sometimes made involving dyads in ACP difficult. According to some GPs, the presence of multiple family caregivers during ACP was a disturbance and therefore only wanted ACP with the person with dementia and their family caregiver.

Discussing goals

Facilitators

According to GPs, case managers and practice nurses, people with dementia's life values, wishes and goals must be the starting point of ACP and such a conversation should therefore begin with what they find important in life. People with dementia, family caregivers, case managers and practice nurses explicitly mentioned that during ACP not only medical (e.g. do not resuscitate statements, hospital admissions) but also non-medical subjects (e.g. daytime activities, social contacts, what bothers him or her at this moment) should be discussed. Case managers and practice nurses, people with dementia and family caregivers agreed that if people with dementia express a wish for euthanasia, this topic should be addressed as well.

" We discussed the human aspect..........but also if we can still keep on living in this house and if more care has to be provided. He (person with dementia) doesn't want to move........ He himself is the driving force behind this (ACP). He wants to anticipate..." (family caregiver, interview 8).

The discussion of goals had additional advantages. According to GPs, it gave them the opportunity to explain possible care options and in addition provide clarity, peace, stimulate mourning and prevent overtreatment, which often happened when decisions had to be made all of a sudden in moments of crisis. Some GPs added that discussing goals fostered autonomy. However, sometimes a paternalistic approach was found necessary.

Barriers

If the preferences of people with dementia and family carers differed, GPs, case managers and practice nurses found the discussion of goals more difficult. GPs also expressed that it is not always possible to openly discuss all potential future problems.

Evaluation and documentation

Facilitators

In the opinion of case managers and practice nurses, reviewing ACP too often made it seem artificial. In their opinion, reviewing ACP every 6 to 12 months was sufficient.

Barriers
Most family caregivers and GPs agreed that the current wishes of people with dementia should be leading, even if this would contradict earlier decisions. One family caregiver considered ACP decisions to be binding and therefore found ACP evaluation unnecessary.

People with dementia, family caregivers, GPs and case managers and practice nurses doubted if important ACP outcomes are documented in a structured way by GPs and raised concerns about the availability of such outcomes for other healthcare professionals.

Theme 3: The primary care setting

Time availability

Facilitators
According to family caregivers, the GP should be easily available and should take enough time for ACP consultations. According to part of the GPs, although ACP requires short term time investments, it saves time in the long run.

Barriers
All interviewees found the usual duration of a consultation too short for ACP. Consequently, according to people with dementia, family caregivers and case managers and practice nurses, GPs mainly address medical subjects and are rushed during ACP.

"When we came in, the first thing she (the GP) said was; I don't have much time and then she said: good afternoon. She sat down and started to fire all sorts of questions at my mother. My mother didn't know what was going on... At a certain moment I said; stop!.... This doesn't make her happy at all." (family caregiver, interview 9).

According to part of the GPs, ACP demands short term time investments while time is scarce and they were not convinced that ACP would save time in the long term. Moreover, some GPs stated that they do not have time to plan and regularly review ACP decisions.

Organisation of the general practice

Facilitators

GPs found guidelines and the use of specialised care programs for dementia useful. These helped them to initiate ACP in a structured manner.

The involvement of a case manager and practice nurse could further accommodate ACP. According to case managers and practice nurses and family caregivers, case managers and practice nurses have more knowledge of dementia. They also have more time to plan, prepare and carry out ACP than GPs do. Case managers and practice nurses, compared to GPs, also have more opportunities to monitor people with dementia and family caregivers and thereby identify problems early.

Quote: "We use a certain score and when somebody is frail,......our practice nurse visits them at home.... more in a general sense.... to see...... how are you doing? What are the problems now, but also what do you expect in the future?" (general practitioner, interview 6).

People with dementia and family caregivers confirmed this and added that regular contact and the therapeutic relationship they develop with a case manager and practice nurse helped them to discuss preferences for future care.

Barriers

Some GPs stated that case managers and practice nurses cannot make medical decisions and therefore can only partly conduct ACP. Some GPs stated that they occasionally forgot to make use of a case manager and practice nurse. This was confirmed by case managers and practice nurses who as a result were often involved late.

Difficulties with reimbursing ACP within the Dutch healthcare system were also mentioned as a problem by GPs. Solving this would stimulate them to initiate ACP, also because some believe that ACP will reduce healthcare costs.

Discussion

In this study we aimed to further explore barriers and facilitators for ACP with people with dementia by GPs, with a focus on the evidence gaps concerning the communication between the GP and people with dementia, the relationship of GPs with people with dementia and the inclusion of non-medical preferences within ACP. Newly found facilitators are: having a relationship with the GP that is built on trust and mutual understanding, and the discussion of ACP in the comfort of people with dementia's homes. Explicitly addressing non-medical issues in ACP discussions, with a focus on discussing people with dementia's current and short-term goals was considered a facilitator by all stakeholders. The involvement of a case managers and practice nurse also facilitates ACP. GPs' lack of time is an important barrier for ACP. To two other barriers known from earlier research nuances could be added:

Some participants wanted ACP to start early, while others wanted to wait until problems actuality arise. Stakeholders raised concerns about the availability of ACP documentation to all professionals involved. They were willing to review ACP but not often.

The importance of the relationship with the GP, as stressed by the participants in this study, is in line with earlier research in primary care (32). Patients who suffer from more severe diseases or who have problems with psychosocial or existential impact, such as people with dementia, appraise their relationship with the GP as more important (33). Unfortunately, the focus during consultations still seems to be on treatment compliance with little attention to social, psychological or spiritual issues, even when advance directives are discussed (34, 35). Particularly in dementia, with its high psychosocial and existential burden and specific relational and communicational needs, this can be considered an omission (3, 36, 37).

As shown in our results and in a systematic review on GP communication, home visits and taking time are important when difficult subjects are discussed (38). When GPs take more time, more psychosocial problems are attended and patient satisfaction rises (39). However, it is also known that GPs are busy, and time per consultation is limited. This time restraints seems an important reason for the limited number of home visits, for the GPs' main focus on medical problems and for the inadequate assessment of care needs (40-42). The lack of ACP by GPs therefore seems, at least partly, caused by how GPs are organized.

Recommendations for future practice

Participants in our study mentioned the use of case managers or practice nurses as a possible solution for overcoming problems concerning the development of a therapeutic relationship and the available time. Case managers and practice nurses have more opportunities to visit people with dementia and thereby develop a therapeutic relation which seems so important (43). When using collaborative care models, in which case managers or practice nurses take on certain tasks of the GP, regular consultations between GPs and case managers and practice nurses are advised and division of tasks regarding ACP should be explicitly addressed (44). This facilitates a combined medical, psychosocial and spiritual and thus holistic approach. Also, when multiple disciplines are involved, it is essential that preferences for future care are clearly documented and made available to all (21, 45-47). Because case managers and practice nurses also have time constraints their caseload must be monitored (43).

In recent years ACP has shifted from a document driven conversation where mainly options for medical treatments and end-of-life preferences were discussed, to a broader scope where the physical, psychosocial and spiritual domains are all included (5, 48).

Previous research and this paper showed that a broad approach to ACP including non-medical issues is a facilitator for people with dementia. When their valued abilities or activities are used to justify their choices, their participation in ACP can be established despite of their cognitive decline (29). This holistic approach which starts with the person's with dementia current wishes and concerns, therefore contributes to their autonomy and can also be used to guide further decision making about future care (49, 50). ACP then is extended to something more than just a 'checkbox' for medical decisions. It becomes an open encounter between people with dementia, family caregivers and healthcare professionals during which a wide array of preferences concerning future care can be discussed that may contribute to living well with dementia (51).

Strengths and limitations

The inclusion of all important stakeholders involved in ACP with people with dementia in primary care is the main strength of this study. By integrating the findings from different perspectives, robust and all-embracing insights were built (25). As we chose to interview people with dementia and family caregiver dyads in their own homes, we were able to discuss delicate topics in their trusted environment without any rush or disturbance. This gave the participants the opportunity to provide in depth information which enriched our data and conclusions.

The study also has some limitations. Because of recruitment difficulties, the number of case managers and practice nurses participating in this is study was limited and we were not able to conduct ideal purposive sampling. As a result, some beliefs or experiences may not be represented in our data (25). However, as we reached saturation in the interviews with people with dementia, family caregiver dyads and GPs, and no new themes emerged within the focus group with case managers and practice nurses, we assume that all themes concerning our research aim were exposed.

The fact that we choose to conduct the interviews with people with dementia accompanied by their family caregiver may have influenced our study outcomes. As our results show, their preferences for future care sometimes differ. For that reason both parties may possibly have expressed some different views when interviewed alone. This therefore might be addressed during future research. However, our interview strategy is similar to the situation in daily practice, in which GPs usually discuss future care with patients and informal caregivers together.

Our study outcomes may also be influenced by the specific region in which we conducted our research. This may therefore also be addressed during future research.

Conclusion

When people with dementia and family caregivers discuss preferences for future care with their GP, home visits, an open relation built on trust and addressing non-medical issues, particularly those in the near future, are key facilitators to ACP.

GPs' busy time schedule is an important barrier. Case managers and practice nurses have more opportunities to regularly conduct home visits, gain insight in the living situation and to start an open trust-build relationship with people with dementia and their family caregivers. This provides them with the opportunity to use a goal-oriented approach and discuss a broad range of topics. Collaborative care models might therefore help to overcome the time barrier and contribute to exploiting the newly found facilitators to ACP and contribute to living well with dementia.

Declarations

Ethics approval and consent to participate

The study was approved by the research ethics committee (CMO) of the region Arnhem-Nijmegen in accordance with the Medical Research Involving Human Subjects Acts and the declaration of Helsinki (NL52613.091.15). Anonymity was assured by removing all participant information that could lead to identification from the transcripts. Written consent was obtained from all participants.

The family caregiver gave consent on behalf of the person with dementia.

Consent for publication

Not applicable

Availability of data and material:

Not applicable

Competing interests

The authors declare that they have no competing interests.

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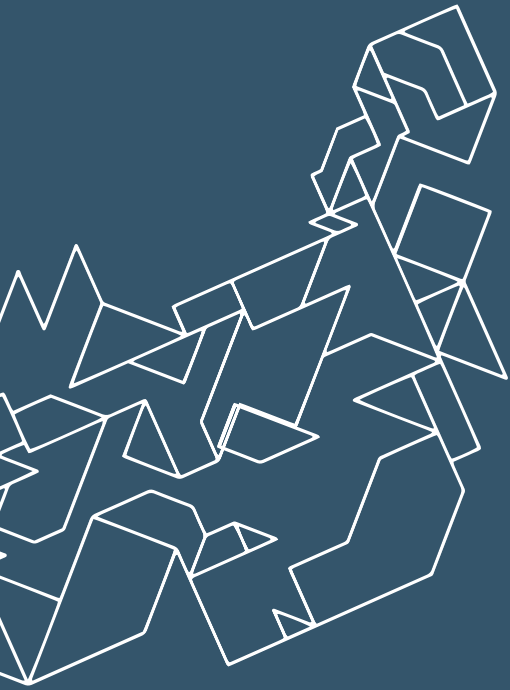
Additional file 1: Topic guide, barriers and facilitators for GPs when discussing ACP with people with dementia.

Can you tell something about an advance care planning conversation you had?
- What went well, what could be improved?

What, in your opinion, should the role of the GPs be when preferences for future care are discussed?
- Who should take the initiative?
- Who should be present during ACP?
- When should such an conversation take place?
- Do other disciplines, besides the GP, have a role in ACP as well?
- Are there important (relational)-aspects when discussing ACP?

Which subjects should be discussed during advance care planning?
- Are there specific subjects you do or do not want to discuss?
- How do you think ACP conversations should be documented?
- When and how often, do you think ACP should be reviewed?



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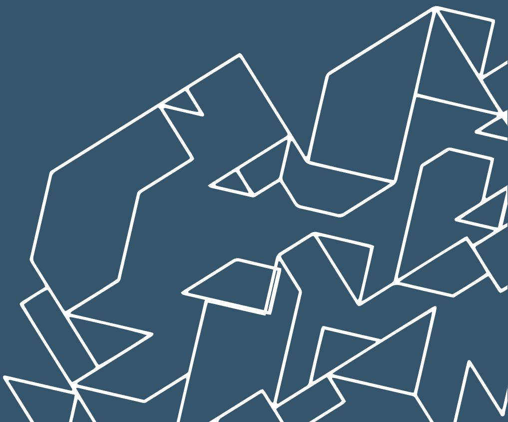

Chapter 4

Educating Dutch general practitioners in dementia advance care planning: a cluster randomised controlled trial

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Abstract

Objectives

Advance care planning (ACP) is seldom initiated with people with dementia (PWD) and mainly focuses on medical end-of-life decisions. We studied the effects of an educational intervention for general practitioners (GPs) aimed at initiating and optimizing ACP, with a focus on discussing medical and non-medical preferences of future care.

Design

A single-blinded cluster randomised controlled trial.

Setting and participants

In 2016, 38 Dutch GPs (all from different practices) completed the study. They recruited 140 PWD, aged ≥ 65 at any stage and with any type of dementia, from their practice.

Methods

Intervention group GPs were trained in ACP, including shared decision making and role-playing exercises. Control group GPs provided usual care. The primary outcome was ACP initiation: the proportion of PWD that had at least one ACP conversation documented in their medical file. Key secondary outcomes were the number of medical (i.e. resuscitation, hospital admission) and non-medical (i.e. activities, social contacts) preferences discussed. At six months follow-up, subjects' medical records were analysed using random effect logistics and linear models with correction for GP clustering.

Results

38 GP clusters (19 intervention; 19 control) included 140 PWD (intervention 73; control 67). Four PWD (2.9%) dropped out on the primary and key secondary outcomes. After six months, intervention group GPs initiated ACP with 35 PWD (49.3%), control group GPs initiated ACP with 9 PWD (13.9%) (OR=1.99; p=0.002). Intervention group GPs discussed 0.8 more medical (95% CI = 0.3-1.3, p=0.003) and 1.5 more non-medical (95% CI = 0.8-2.3, p<0.001) preferences per person with dementia than control group GPs.

Conclusions and implications

Our educational intervention increased ACP initiation, and the number of non-medical and medical preferences discussed. This intervention has the potential to better align future care of PWD with their preferences but, because of the short follow-up, the GPs long-term adoption remains unknown.

Introduction

Dementia is a syndrome characterized by progressive deterioration in memory and thinking, changes in behaviour, decreasing ability to perform daily activities, and increasing dependency on others.(1, 2) It affects not only people with dementia (PWD), but also their family caregivers (FCs).(2) Worldwide, 50 million people are currently diagnosed with dementia, and their number is expected to rise to 152 million by 2050.(1)

Care for PWD should be proactive, focus on living and dying well and include advance care planning (ACP).(3, 4) Traditionally ACP addressed end-of-life preferences.(5) Recently, ACP was redefined as 'a process which enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate'. By this means, ACP includes the physical, the social, spiritual and psychological domains.(6)

Important features of a complex and delicate process like ACP are familiarity with and trust in healthcare professionals.(7, 8) Although these are primary care core values, general practitioners (GPs) rarely initiate ACP with PWD.(9) Most important barriers GPs report are uncertainties concerning the right timing of ACP, PWD's decisional capacities, changing preferences, and the uncertain disease trajectory.(10) Most of these barriers might be resolved by training GPs in initiating ACP using the broader definition, which allows for discussion of both medical and non-medical issues.(6, 10)

A systematic review and meta-analysis showed that ACP interventions in various populations and settings, increased the initiation of end-of-life discussions and the concordance between preferences and care delivered.(11) ACP interventions with PWD, reduced healthcare utilization and costs and increased documentation of future care preferences.(12, 13) Additionally, ACP interventions are expected to cause positive effects on PWD's quality of life (QoL), involvement in care and FCs' burden. However, results of systematic reviews on these outcomes are inconclusive.(11-13)

We developed a GP educational intervention aimed at initiating and optimizing ACP with a focus on discussing both medical and non-medical preferences for future care . We assessed the effects of this intervention on the initiation of ACP and the number of medical and non-medical preferences discussed. Additionally, we performed a cost effectiveness analysis and studied the intervention's effects on PWD's QoL, experienced involvement in care decisions, and FCs' sense of competence.

Methods

Trial design

We performed a single-blinded cluster-randomised controlled trial (RCT) with six months follow-up in the Netherlands (Dutch trial register no: NTR5773). The Dutch primary healthcare system and the role of the PNs in GP practices, is explained in additional file 1. The study was approved by the research ethics committee of the region Arnhem-Nijmegen in accordance with the Medical Research Involving Human Subjects Acts and the declaration of Helsinki (NL52613.091.15). All participants gave written informed consent. Extended Consort guidelines for reporting cluster RCTs were followed.

Inclusion of participants

Between January and June 2016, 38 GPs, all from different practices, were included. We invited a representative, regional sample from the database of the Dutch institute for health services research (NIVEL), containing the majority of the Dutch GPs. We also used the Practice Based Research Network of the Radboud university medical center for recruitment, containing affiliated GPs. (N=1313) GPs were included if they committed to recruiting five PWD from their practice. GPs were excluded if they were unable to include at least one person with dementia.

GPs were requested to include PWD aged ≥65 years, at any stage and with any type of dementia. GPs briefly explained the research project to both the person with dementia and the FC, and asked permission to share their contact information with the research team. PWD and FCs who agreed were first informed about the research project by mail and received a phone call from a researcher (BT) one week later. After oral consent, the researcher performed a home-visit to sign the informed consent form and collect baseline data. PWD were not included if they (or their legal representatives) did not provide informed consent, did not speak Dutch, or were unwilling to participate in baseline data collection.

The intervention

The educational intervention consisted of two 3-hour interactive workshops. GPs randomised to the intervention group were trained between March and June 2016. As practice nurses can play an important role in dementia care and ACP, GPs were invited to bring their practice nurse.(8, 10)

The intervention was developed according to the adapted framework of the Medical Research Council Guidance for the development and evaluation of complex interventions.(14) Half of both workshops was used to practice ACP conversations with training actors.

To structure ACP conversations, a model for shared decision-making (SDM) with frail elderly was introduced. In SDM, professionals and patients share their respective knowledge, values and preferences about healthcare choices and together explore beneficial solutions.(15) (16) We chose this model as it explicitly starts with the discussion of personal goals of care and values and thereby includes the PWD's physical, social, spiritual and psychological domains.(6) The SDM model used consists of six steps including the traditional steps of choice talk, option talk and decision talk. During step one (preparation) previously discussed and/or documented future care preferences are explored and the primary informal caregiver is identified. During step two (goal talk) the discussion partner is identified and the person with dementia's values and personal goals of care are explored. During step three (choice talk) the previous steps are summarized and the person's care goals are formulated. During step four (option talk) personalized care goals are discussed after which (decision talk; step five) decisions can be made. Finally, the ACP process is evaluated (step six).(16) (additional file 2) By including the person with dementia's values and care goals, including non-medical preferences (i.e. activities, housing), the SDM model addresses the principles of social health and includes the influence of the social environment and the dynamic balance between capabilities and limitations.(17) The use of the SDM model was not yet evaluated with people with dementia.(16)

During the workshop important barriers and facilitators, known from previous research, were emphasized discussing real-life case descriptions.(8, 10) (additional file 2)

Intervention group GPs and PNs also received a booklet containing background information on ACP.

An experienced GP/researcher/expert in dementia care, who also acted as the expert in the second workshop (MP), had two-monthly telephone consultations with the GP practices in the intervention group. These telephone consultations were not protocolled. GPs were asked if they had any questions or needed support in any way. The control group received information about the rationale, aim and design of the study and provided usual care during the six months follow-up.

Outcome measures and data collection

The primary outcome was the proportion of PWD for whom ACP was initiated during the six months following the intervention. This was defined as the number of included PWD that had at least one ACP conversation documented in their medical file divided by the total number of included PWD in each study arm. PWD who had ACP were registered with a "1" and PWD who did not have ACP were registered with a "0". Only consultations in which preferences for future treatments and care were actually discussed were considered as ACP conversations.(6)

Key secondary outcomes were the number of medical and non-medical preferences discussed during all ACP conversations as documented in the PWD's medical files during the six months following the intervention. Medical items were: resuscitation, mechanical ventilation, use of antibiotics, hospital admissions, life prolonging treatments (e.g. tube feeding), and palliative treatments (e.g. pain relief).(18) Non-medical items were: social contacts, activities, housing, safety, care needs, mobility and finances.(19) Remaining preferences were categorized as not specified. These key secondary outcomes were based on earlier research and several discussions with the authors.(18, 19)

To retrieve data on primary and key secondary outcomes, GPs were asked to upload a pdf-file containing the PWD's medical records to a secure digital environment. Three researchers (BT, TdW, VH), blinded to the GPs' allocations, registered all documented ACP conversations one year prior and in the six months after the intervention on a case report form. To increase reliability, the first 20 medical files were analysed independently by two researchers (BT, TdW or VH) and then compared. In case of disagreement, two researchers were consulted (YE, MP) using anonymized data. The remaining medical files were analysed by one researcher (TdW or VH). Doubts were discussed, using anonymized data, with three researchers (BT, MP, YE).

Other secondary outcomes were: QoL (Dementia quality of Life questionnaire and EuroQol 5D questionnaire), experienced level of SDM of the person with dementia (Collaborate questionnaire), experienced level of competence of the FC (Sense of Competence Questionnaire), and healthcare costs (Recourse Utilization in Dementia questionnaire).(20-24) (additional file 3) This data was collected at baseline and six months after the intervention by seven researchers (BT, TdW, VH, LvD, LR, SvH, FW). QoL and the experienced level of SDM questionnaires were administered at the PWD's homes. As the FC's experienced level of competence addresses delicate subjects (e.g. "I wish that my .... and I had a better relationship"), this questionnaire was completed during a telephone interview, without the person with dementia present. The questionnaire about healthcare costs was completed independently by the FC.

Characteristics of GPs, PWD and FC's were collected at baseline and included age and gender, and whether PWD lived with their FC. Dementia severity was assessed by the GPs at baseline using the Clinical Dementia Rating scale (CDR).(25) (additional file 3)

Sample size and power calculation

On the primary outcome, we expected a difference between the intervention and control group of 25%, which was based on a study on ACP with frail elderly during hospital admission. (26) They found a difference of 50% on their primary outcome (end-of-life wishes known and respected). We expected a smaller difference, as our intervention lacked a marked moment to start ACP and as ACP with PWD is more complex.

Cluster randomisation was taken into account when calculating the sample size. Clusters were expected to include five PWD, and intra-class correlation (ICC) to be 0.05 or lower.(27) For a power of 0.8 and two-sided testing at 0.05, 26 GPs were required. In a recent RCT with people with mild to moderate dementia and one-year follow-up, study drop-out was 8.5%. (28) We therefore aimed to recruit 30 GPs.

Randomisation and masking

To minimize selection bias, cluster-randomisation of GPs (all from different practices) took place after inclusion of PWD and FCs. To minimize imbalance between the study groups and limit researchers' selection bias, study-wise minimization was applied.(29) A statistician used a computerized algorithm to calculate the imbalance of all possible allocations, including the following characteristics: gender; age; total number of patients aged ≥ 65; urbanisation level; if the GP was specialized in geriatric care; and the GP's intention to bring a practice nurse to the training. Finally, from all allocations with the fewest imbalance, one allocation was randomly selected.(29). All researchers involved in the outcome assessment were masked to the allocation.

Statistical analyses

Prior to the start of the trial a statistical analysis plan was documented. A random effects logistic model was applied to analyse the effects of the intervention on the primary dichotomous outcome, taking clustering at GP level into account. The effects on the (key) secondary continuous outcomes were analysed using a random effects linear model taking clustering on GP level into account. We performed a cost effectiveness analysis (CEA), adhering to the Dutch manual for costing research.(30) (additional file 4) All analyses were performed on an intention to treat basis, included GP as random effects and used two-sided alpha's of 0.05 to test statistical significance. The intervention effects were expressed as odds ratios or adjusted mean differences with 95% confidence intervals. We did not use multiple imputation of missing values since this is not necessary when random effect models are used (31) Variables for which differences in baseline characteristics between the intervention and control group were observed, were added as confounders. Baseline data were presented using descriptive statistics. For all analyses, SPSS version 22 was used.

Results

A total of 38 GPs (all from different practices) participated in the study. 33 were included through the NIVEL database and three were included though the Practice Based Research Network of the Radboud university medical centre database. Two GPs contacted the research team themselves. GPs' mean age was 48.5 years, 55% was female, and one GP was an expert in geriatric care. (Table 1)

Table 1.
Baseline characteristics of general practitioners and their practices

	Control group (N=19)		Intervention group (N=19)	
Variable	Mean (SD) or N (%)	Range (min-max)	Mean (SD) or N (%)	Range (min-max)
Female GP's	11 (57.9%)		10 (52.6%)	
Age GPs (in years)	48.4 (10.5)	31 (31-62)	48.7 (8.5)	27 (27-63)
GPs who intended to take a PN to the educational intervention	15 (78.9%)		14 (73.7%)	
Number of patients in GP's practice	3544 (1807.6)	7518 (1368-8886)	3442 (1871.8)	6628 (1900-8528)
Patients ≥ 65 years in GP's practice	639 (371.8	1389 (125-1514)	526 (166.1)*	633 (285-918)
GPs trained as expert GP elderly care	1 (5.3%)		0 (0%)	
Practices with a care programme for older adults	14 (73.7%)		14 (73.7%)	

**Data missing for one practice*
GP: general practitioner; PN: practice nurse

Of the 182 PWD/FC dyads approached, 140 (77%) agreed to participate. Thirty-five dyads (19.2%) refused, six moved or died (3.3%) before baseline measurements could take place, and one person was excluded because he did not have dementia.

Nineteen GPs were allocated to the intervention group. They recruited 73 PWD/FC dyads. Sixteen GPs (84.2%) attended both workshops and three GPs (15.8%) attended one workshop. Eighteen GPs (95%) brought their PN. Fifteen PNs (83.3%) attended both workshops. The 19 GPs allocated to the control group recruited 67 PWD/FC dyads. (additional file 5)

PWD's mean age was 81.9 years and 58% was female. FCs' mean age was 69 years, 65% was female and 66% lived with the person with dementia. (Table 2) All GP's, PWD's and FC's characteristics, the number of initiated ACP conversations and the (non) medical issues discussed one year before the inclusion of PWD were well balanced between the study groups, apart from the FCs' gender. (Table 1 and Table 2) Only FCs' gender was therefore included as a confounder in all analyses. After six months, two medical files (2.7%) from the intervention and two from the control group (2.9%) and approximately 25% of all questionnaires on the secondary outcomes (QoL, level of SDM and healthcare costs) could not be retrieved. (additional file 5)

We investigated for each variable with missing data whether this was related to the level (magnitude) of other variables, and found no pattern. Therefore, we considered missingness completely at random (MCAR) plausible.

During the six-month follow-up, ACP was initiated in 35 (49.3%) of the 71 PWD in the intervention group and in 9 (13.9%) of the 65 PWD in the control group (ICC 0.4; OR=1.99; p=0.002). Sixteen of the 19 GPs in the intervention group and 7 of the 19 GPs in the control group had an ACP discussion with at least one of the PWD.

In the intervention group, a total of 165 ACP preferences (58 medical, and 107 non-medical) compared to 15 (8 medical and 7 non-medical) in the control group were documented. Of the 58 medical preferences documented in the intervention group, resuscitation (43% of the 58 medical preferences) and hospital admission (31% of the 58 medical preferences) were most often discussed, whereas of the 107 non-medical preferences, activities (29% of the 107 non-medical preferences), housing (21% of the 107 non-medical preferences), and care (i.e. informal care) (16% of the 107 non-medical preferences) were most often discussed. (additional file 6)

In the intervention group, 35 ACP conversations took place including an average of 1.7 medical preferences and 3.1 non-medical preferences. In the control group, nine ACP conversations took place including an average of 0.9 medical preferences and 0.8 non-medical preferences.

Table 2.
Baseline characteristics of people with dementia and family caregivers

	Control group (N=67)		Intervention group (N=73)	
Variable	Mean (SD) or N (%)	Range (min-max)	Mean (SD) or N (%)	Range (min-max)
Female PWD	36 (53.7%)		45 (61.6%)	
Female FCs	48 (71.6%)		42 (57.5%)	
PWD's mean age	82.1 (SD 7.1)	39 (65-104)	81.7 (SD 5.9)	29 (67-96)
FCs' mean age	68.7 (SD 14.3)	59 (33-92)	69.6 (SD 13.6)	52 (39-91)
FCs living with PWD	44 (66.7 %)		48 (65.8 %)	
PWD who died between T0 and T1	6 (9 %)		6 (8.2 %)	
Clinical Dementia Rating scale	1.6 (SD 0.8)	2.5 (0.5-3)	1.6 (SD 0.9)	2.5 (0.5-3)
Dementia Quality of Life questionnaire	59.1 (SD 6.6)	39 (38-77)	57.6 (SD 6.6)	35 (37-72)
PWD's EQ5D	73.3 (SD 18.1)	80 (29-109)	74.6 (SD13.7)	70 (31-101)
Collaborate questionnaire	21.3 (SD 4.8)	27 (0-27)	21.2 (SD 4.1)	17 (10-27)
Sense of Competence Questionnaire	93.9 (SD 12.8)	64 (61-125)	92.4 (SD 12.0)	59 (59-118)
Number of ACP preferences discussed with PWD	0.51 (SD 1.3)	6 (0-6)	0.68 (SD 2.3)	17 (0-17)
Number of medical ACP preferences discussed with PWD	0.22 (SD 0.8)	5 (0-5)	0.23 (SD 0.8)	4 (0-4)
Number of non-medical ACP preferences discussed with PWD	0.29 (SD 0.8)	4 (0-4)	0.45 (SD 1.8)	13 (0-13)
PWD who had ACP conversation	14 (20 %)		12 (16.9 %)	
PWD/FCs' mean healthcare costs	9892 (SD 3642)	17859 (0-17859)	9885 (SD 3951.4)	27460 (0-27460)

Data are missing with no more than two individuals in the control group and no more than two individuals in the intervention group
GP: general practitioner; PN: practice nurse; PWD: people with dementia; FC: family caregiver; ACP: advance care planning; SD: standard deviation

Overall, GPs in the intervention group documented significantly more ACP preferences per patient (mean 2.3 and ; SD 2.99) than in the control group (mean 0.2; SD 0.7) (adjusted mean difference 2.4; 95% CI 1.2 to 3.5). Both more medical preferences (intervention: mean 0.8 (SD 1.2); control: mean 0.1 (SD 0.5); adjusted mean difference 0.8; 95% CI 0.3 to 1.3) and more non-medical preferences (intervention: mean 1.5 (SD 2.1); control: mean 0.1 (SD 0.4); adjusted mean difference 1.5; 95% CI 0.8 to 2.3) were documented. (Table 3)

Table 3.
Observed means and estimated effects of the total number of ACP preferences, the number of medical preferences, and the number of non-medical preferences discussed per person with dementia.

Primary and Key Secondary Outcomes	Intervention (n=71)		Control (n=65)			
	Mean (SD) or N (%)	Range (min-max)	Mean (SD) or N (%)	Range (min-max)	Adjusted mean difference (95% CI)	p value
Total ACP preferences discussed**	2.3 (2.99)	15 (0-15)	0.2 (0.7)	4 (0-4)	2.4 (1.2 to 3.5)	<0.001
Mean medical ACP preferences discussed (SD)**	0.8 (1.2)	5 (0-5)	0.1 (0.5)	3 (0-3)	0.8 (0.3 to 1.3)	0.003
Mean non-medical ACP preferences discussed (SD)**	1.5 (2.1)	10 (0-10)	0.1 (0.4)	2 (0-2)	1.5 (0.8 to 2.3)	<0.001

** medical files missing; 2 of 73 in the intervention group and 2 of 67 in the control group*
***A random effect multi-level analysis, with correction for GP clustering and FCs' gender was used for estimation.*
FC: family caregiver, ACP: advance care planning, CI: confidence interval; SD standard deviation

PWD's QoL, PWD's experienced level of SDM, and the FCs' sense of competence did not differ between study groups. The cost analysis shows that PWD's and FCs' healthcare costs and PWD's QALY's did not differ between study groups, therefore there seem to be no economic restrictions for implementing our educational intervention. (Table 4)

Table 4.
Observed means and estimated effect of the total number of people with dementia's quality of life and experienced level of shared decision making; family caregivers' experienced level of competence, quality adjusted life years and healthcare costs.

Secondary Outcomes	Intervention		Control			
	Mean (SD) or N (%)	Range (min-max)	Mean (SD) or N (%)	Range (min-max)	Adjusted mean difference (95% CI)	p value
PWD's QoL (DEMQOL) Number of cases	58.1 (6.9) 56	36 (45-81)	57.8 (7.1) 56	48-34-82)	0.4 (-2.7 to 3.4)	0.8
PWD's Experienced level of shared decision making (Collaborate) Number of cases	21.7 (2.9) 56	13 (14-27)	22.1 (3.4) 56	15 (12-27)	-0.4 (-1.8 to 9.5)	0.53
FCs' Experienced level of competence (SCQ) Number of cases	94.3(11.9) 52	60 (61-121)	97.8 (13.3) 52	61 (61-122)	-3.5 (-8.5 to 1.6)	0.17
PWD's QALY's Number of cases	0.3 (0.1) 56	0.39 (0.11-0.5)	0.3 (0.1) 56	0.55 (−0.05 to 0.5)	0.02 (-0.03 to 0.6)	0.43
PWD/FCs' Healthcare costs in euros (RUD) Number of cases	10111.7 (4505.6) 52	29418.2 (132.54-29550.8)	10412.6 (3344.7) 55	17816.1 (18056.5-10412.6)	-349.1 (-1903.5 to 1205.3)	0.66

A random effect multi-level analysis, with correction for GP clustering and FCs' gender was used for estimation.
QoL: quality of life; DEMQOL: dementia quality of life questionnaire; SCQ: sense of competence questionnaire; EQ-5D; Euroqol 5D questionnaire; RUD: recourses in dementia questionnaire; QALY's: quality adjusted life years
PWD: people with dementia, FC: family caregiver, ACP: advance care planning

Discussion

After participating in the educational intervention, GPs initiated ACP with 49.3% of the PWD compared to 13.9% in the control group. The number of medical and non-medical preferences discussed during these ACP consultations also significantly differed. Our intervention therefore relevantly changed daily practice. No differences between the two groups on PWD's QoL, PWD's experienced level of SDM, the FCs' competence, PWD's QALY's and PWD's and family carers' healthcare costs were found.

With our intervention we trained GPs to start ACP with discussing care goals important to PWD's current and remaining phase of life. As a result, ACP was initiated three times more often and both medical and non-medical preferences discussed increased.

These findings support the recently proposed conceptual shift of ACP from mainly discussing future medical treatments and end-of-life preferences, to discussing all domains of palliative care.(5, 6)

The fact that non-medical preferences were more often discussed supports earlier findings that PWD consider discussions of these non-medical care goals important for their current and remaining phase of life (8, 10). This suggests that starting ACP with discussing non-medical issues may be a successful strategy for involving PWD in conversations on future medical and end-of-life preferences.(10)

PWD's preferences for discussing non-medical issues may indicate that living well with their condition is their aim and that they find a focus on maintaining their capabilities at least as important as discussing medical issues. This reflects the importance of integrating the principles of social health, with its emphasis on the use of people's remaining capacities in making shared decisions in ACP.(17) Hereby, our study contributes to the body of knowledge on social health, as an aspect of positive health, and patient centred approaches in the context of dementia.(17)

The 49% implementation rate of ACP in the intervention group may however indicate that GPs and PNs still experience barriers to initiate ACP with people with dementia and/or that ACP was not carried out or documented as addressed during our educational intervention. This will be explored more in-depth in a thorough process evaluation which is expected to be published at the end of 2019.

This study has several strengths. Up to now, most studies on the effects of ACP suffered from methodological limitations like insufficient sample sizes, allocation bias and lack of intention to treat analysis. (11) In this RCT on the effects of an educational intervention for GPs on ACP with PWD we succeeded in minimizing bias to influence the trial results. We reached the planned sample size, which is often challenging regarding GPs and PWD.(32, 33) We minimized risk of study group imbalance by using study-wise minimization.(29) We also minimized GP's selection bias by including PWD and FCs before GP's were randomized. Few data were missing on the primary outcome measure and the assessors of all outcomes were blinded to the participants' allocation.

Our study has some limitations. Our primary outcome depended on GPs' medical files and was therefore sensitive to registration bias, as health records data are often incomplete, and do not always reflect medical performance.(34) However, ACP initiation and future care preferences discussed are of limited value without their documentation, especially in acute situations and involvement of other GPs or healthcare professionals.(35) Therefore one could argue that this phenomenon can be considered a positive intervention effect instead of a study limitation.

The intervention had a relatively short follow-up of six months. Evaluating whether ACP discussions result in preferred treatment of care likely takes more time, especially when these decisions concern long-term end-of-life preferences (e.g. hospital admission, resuscitation). This could explain why we did not find a positive effect on PWD's QoL and healthcare costs.

Another possible explanation is that QoL in PWD is difficult to measure and its sensitivity to change is limited.(36) The lack of effects on PWD's experienced level of SDM or FCs' experienced level of competence could be explained by the fact that, as described in earlier research, some PWD and FCs do not want to make shared decisions on future care.(8, 10) Moreover, these measures were already valuated high at baseline (Table 2) and suffered from a dropout of approximately 25%. Future research could resolve these shortcomings by identifying more relevant and specific patient reported outcomes in the context of ACP, investigating the effects of an educational intervention for GPs with these measures as primary outcome with accompanying power calculation and a longer follow-up.

As participation in this study was voluntary it probably attracted early adopters, i.e. GPs with an increased interest in ACP with PWD. (37) This may negatively influence the external validity of our results but is an adequate way to initiate quality improvement. (37) However, the participating GPs were representative with regard to age and gender to the Dutch national GP database, which suggests eligibility of the intervention to a broader GP population.(38) An additional process evaluation could reveal the intervention's successful components and elements for improvement. (39)

Conclusions and implications

GPs can be effectively trained to initiate ACP and thereby discuss non-medical and medical preferences with PWD. This study is an important step towards improving future care for community-dwelling PWD and their FCs, and the implementation of a more holistic approach to ACP. There seem to be no economic restrictions for implementing this innovative way of discussing health care preferences. We recommend a process evaluation to further improve ACP initiation and research with long-term follow up to explore the effects of ACP on patient reported outcomes.

Conflict of interest statement

The authors have no conflicts of interest.

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Additional file 1: Description of the Dutch primary health care system

In the Netherlands, most general practitioners (GPs) work in a general practice together with colleague GPs. In most GP practices, a practice nurse (PN) is available. PNs are registered nurses who independently provide care for primary care patients under the GPs supervision. Patients in their caseloads include people with chronic conditions such as diabetes, cardiovascular disease and chronic obstructive pulmonary disease. To be able to provide holistic care for frail older people in including people with dementia, PNs must follow a short additional training. Almost all non-institutionalized inhabitants of the Netherlands are registered at a primary care practice close to where they live. GPs see patients with a large range of diseases in different stages without any selection regarding age, gender, socio-economic status, or ethnicity. They form a gatekeeper's role to specialist medical care. Most GPs have long-lasting relationships with their patients, and as a result know the patients' personal situations.

Additional file 2: Description of the educational intervention

The educational intervention consisted of two protocolized workshops, each lasting three hours. The workshops took place in a small theatre and started with a personal welcome by the course leader following a meal with all participants and trainers. We used a variety of didactic interactive strategies, as these proved to be the most effective. (1)

The first workshop started with a communication exercise to "warm up" the participants and get them acquainted with the trainers. This was followed by the presentation of a model for shared decision making (SDM) with frail elderly.2 This presentation was given by an experienced GP/researcher who was also specialised in medical education and SDM with frail elderly and who developed the SDM used in the intervention. The SDM model presented consists of 6 steps, including the traditional steps of choice talk, option talk and decision talk. During step one (preparation) previously discussed and/or documented future care preferences are explored and the primary informal caregiver is identified. During step two (goal talk) the discussion partner is identified and the person with dementia's values and personal goals of care are explored. During step three (choice talk) the previous steps are summarized and the person's care goals are formulated. During step four (option talk) personalized care goals are discussed after which (decision talk; step five) decisions can be made. Finally, the ACP process is evaluated (step six). (2)

After the presentation, the expert showed, the different steps which could be taken in an ACP conversation with the use of training actors. In addition, the importance of starting ACP and discussing non-medical preferences (e.g. daily activities, housing, social contacts), aimed at living the remaining phase of life as well as possible, rather than on end-of-life preferences, was emphasized and demonstrated.

After a short break, participants received a list of examples of sentences to start an ACP discussion on how to start an ACP conversation (e.g. could you tell me what is most important to your current situation?) and the expert explained how these examples could help them focus on addressing near-future preferences. Groups were formed with one training actor and a maximum of five participants. One of the participants was asked to introduce a real-life case description, which was then used to practice an ACP conversation. Participants were invited to stimulate the use of capacities and autonomy of PWD. (3) The training actor played the person with dementia and other roles (e.g. GP, FC) were played by the course participants. The remaining participants in each group observed.

The group evaluated and discussed each ACP conversation, paying special attention to the patient's expressed concerns or wishes. The first workshop ended with a summary by the course leader.

The second workshop started with a presentation of a real-life case in which the following important aspects of advance care planning (ACP) with persons with dementia (PWD) were integrated: a trust-based relationship between the general practitioner (GP), the person with dementia and the family caregiver (FC); home visits; an early start; regular reviewing and documenting ACP outcomes; and a proactive attitude from the GP. (4,5) The importance of timely discussing both medical and non-medical preferences and the involvement of FCs within ACP was also emphasized. (4,5) This presentation was given by an experienced GP/researcher specialized in dementia care. Some participants were then invited to summarize the key points of the presentation in a one-minute elevator pitch. By doing so, we wanted to show that different participants find different aspects important, and therefore documentation may vary.

A former FC then told the participants about her father's disease process and her own view on the role of the GP and the FC in ACP. Course participants were invited to react and ask questions.

After a short break, groups were formed with one training actor and a maximum of five participants. Each group was given several case descriptions in order to practice an ACP conversation. Each case contained multiple opportunities to discuss medical and non-medical preferences. An FC was deliberately included in the case description. This enabled participants to practice interacting with an FC and showed that conflicting interests sometimes occur during ACP. The training actor played the person with dementia, other roles (e.g. GP, FC) were played by the course participants. The remaining participants and trainers observed. Each ACP conversation was evaluated and discussed.

Finally, trainers and the participants discussed how goals and decisions formulated in ACP conversations could be documented in the medical files. The workshop ended with a summary of both workshops, and the invitation to contact one of the trainers if any questions remained or help was needed.

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Additional file 3: Measurement of other secondary outcomes and dementia severity

Quality of life of the person with dementia

To assess the QoL of PWD, we used the Dutch version of the Dementia Quality of Life (DEMQOL) questionnaire (28 items, 4-point Likert scales, a minimum score of 28 representing a low QoL, a maximum score of 112 representing a high QoL) and the EuroQol 5D (EQ-5D) questionnaire (5 items, 3 options per item, a minimum score of 5 representing a low QoL, a maximum score of 15 representing a high QoL). (1, 2) The EQ-5D was also used to facilitate the cost-effectiveness analysis.

Experienced level of shared decision making of the person with dementia

The experienced level of shared decision making of PWD was assessed with the Dutch version of the Collaborate (3 items, 10 point numeric scale, a minimum score of 0 representing low experienced level of shared decision making, a maximum score of 27 representing high experienced level of shared decision making). (3)

Experienced sense of competence of the family caregiver

The FC's experienced sense of competence was measured with the Dutch version of the Sense of Competence Questionnaire (SCQ) (27 items, 3 and 5 point Likert scales, a minimum score of 27 representing a low level of experienced competence, a maximum score of 129 representing a high level of experienced competence). (4)

Healthcare costs of the person with dementia and family caregiver

Healthcare costs were measured with the Dutch version of the Resource Utilization in Dementia (RUD). The RUD measures the FCs and person with dementia's healthcare usage in the previous month. (5)

The Clinical dementia rating scale

The Clinical Dementia Rating scale (CDR), a 5-point scale used to characterize six domains (memory, orientation, judgement and problem solving, community affairs, home and hobbies, personal care) of cognitive and functional performance applicable to dementia which measures the severity of dementia, was assessed by the GPs. (6)

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Additional file 4: Description of the cost effectiveness analysis

We performed a cost effectiveness analysis (CEA), adhering to the Dutch manual for costing research.1 Outcome measures were quality adjusted life years (QALYs), based on combining the EQ5D utility scores with survival. (1) Productivity losses of FCs were measured using the friction cost approach. (1)To determine robust confidence intervals surrounding the Incremental Cost-Effectiveness Ratio, we used (non)parametric bootstrapping. At patient level, volumes of care (e.g. medical home care, hospital visits) were determined on a per person with dementia and FC basis using the Resource Utilization in Dementia (RUD) questionnaire at baseline and after six months. The volume of each registered healthcare consumption was multiplied by its corresponding prices as presented in the Dutch manual of costing research. (1) If no guideline or standard prices were available, real prices were determined. Intervention costs (e.g. training bureau costs; participants' traveling expenses) were also included. In absence of substantiated information on the intervention's sustainability, the current GP practice PWD population was used to determine these costs.

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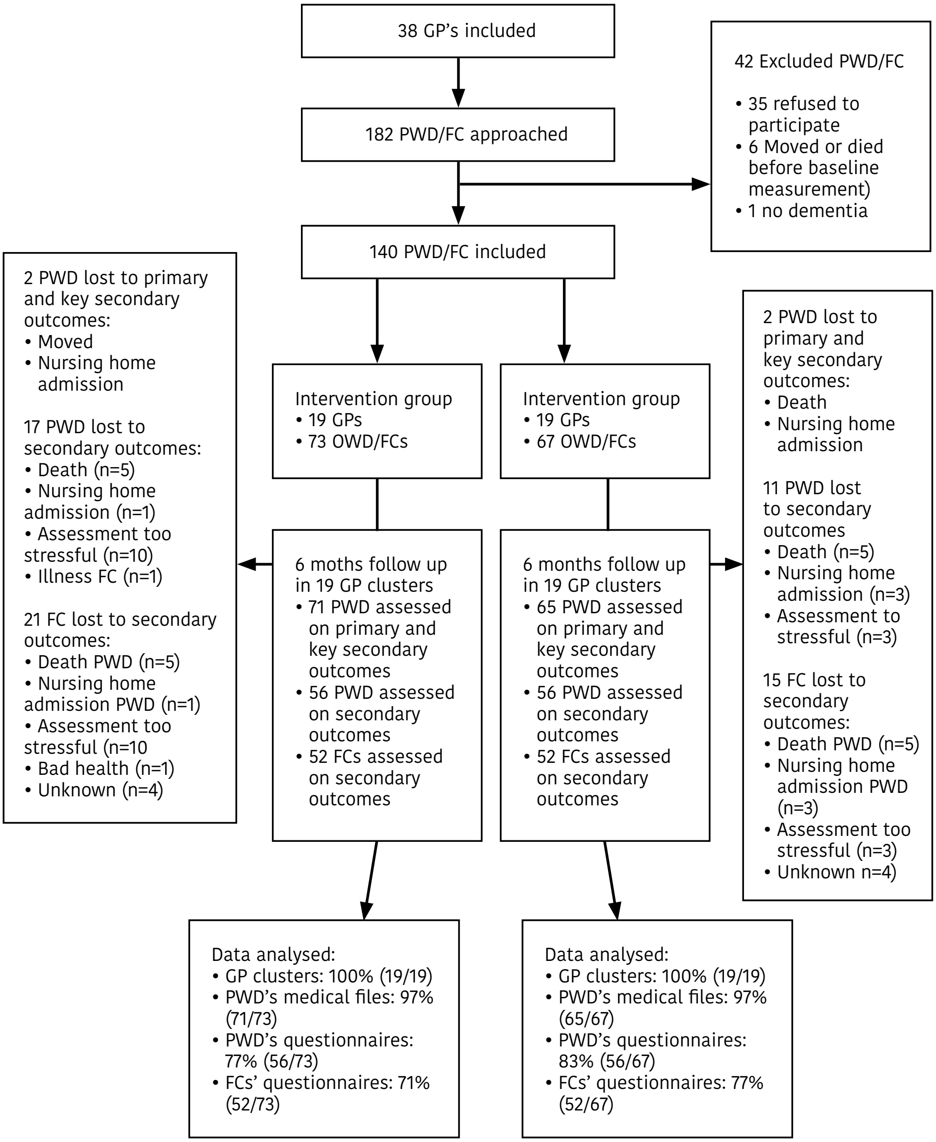
Additional file 5: Inclusion of participants



GP: general practitioner; PWD: people with dementia; FC: family caregiver

Figure 1. Inclusion of participants

Additional file 6: Observed means and estimated effects

Table 4.
Observed means and estimated effect of the total number of people with dementia's quality of life and experienced level of shared decision making; family caregivers' experienced level of competence, quality adjusted life years and healthcare costs.

Medical preferences documented	Number of preferences documented in the control group	Number of preferences documented in the intervention group
- Resuscitation	3 (37.5 %)	25 (43.1 %)
- Hospital admission	1 (12.5 %)	18 (31 %)
- Mechanical ventilation	0	3 (5.2 %)
- Use of antibiotics	1 (12.5 %)	4 (6.9 %)
- Interventions to prolong life	1 (12.5 %)	8 (13.8 %)
- Palliative care	2 (25.%)	0
Total	8	58
Non-medical preferences documented		
- Social contacts	1 (14.3 %)	10 (9.3 %)
- Activities	1 (14.3 %)	31 (28.9. %)
- Housing	0	23 (21.5 %)
- Safety	1 (14.3 %)	4 (3.7 %)
- Care needs	1 (14.3 %)	17 (15.9 %)
- Mobility	0	2 (1.9 %)
- Finances	0	2 (1.9%)
- Other	3 (42.9 %)	18 (16.8 %)
Total	7	107
Total of medical and non- medical preferences documented	15	165

PWD: people with dementia; ACP: advance care planning
% are from the total medical or non-medical items documented

5

Chapter 5

Advance care planning with people with dementia: a process evaluation of an educational intervention for general practitioners

Submitted

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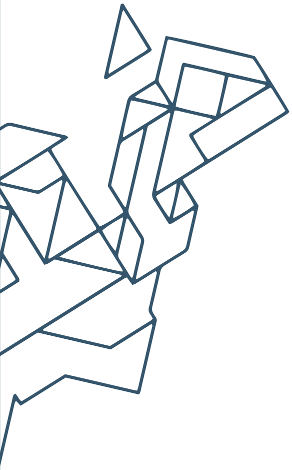

Abstract

Background

General practitioners (GPs) are advised to offer advance care planning (ACP) to people with dementia (PWD). In a randomized controlled trial, an educational intervention for GPs, aimed at initiating and optimizing ACP, proved to be effective. During the intervention most GPs were accompanied by their practice nurse (PN). To provide insights into the intervention's successful components and what could be improved, we conducted a process evaluation and explored implementation, mechanisms of impact and contextual factors.

Methods

We used the Medical Research Council guidance for process evaluations. Implementation was explored identifying reach and acceptability. We performed descriptive analyses of participants' characteristics; selection, inclusion and intervention attendance; a GP post-intervention survey on initiating ACP; a post intervention focus group with trainers of the intervention.

Mechanisms of impact were explored identifying adoption and appropriateness. We used: participants' intervention ratings; a GP post-intervention survey on conducting ACP; ACP documentation in PWD's medical files; post-intervention interviews with PWD/FC dyads. All data was used to identify contextual factors.

Results

The intervention was implemented by a small percentage of the total Dutch GP population invited, who mostly included motivated PWD/FC dyads with relatively little burden, and PWD with limited cognitive decline. The mechanisms of impact for GPs were: interactively learning to initiate ACP with training actors with a heterogeneous group of GPs and PNs. For PWD/FCs dyads, discussing non-medical preferences was most essential to their SDM experience and QoL. Some dyads however found ACP stressful and not feasible. Younger female GPs more often initiated ACP. Male PWD and persons with mild dementia more often had had ACP. These characteristics and the safe and intimate training setting, were important contextual facilitators.

Conclusion

We recommend Interventions aimed at improving ACP initiation with PWD by GPs to include interactive components and the discussion of non-medical preferences. A safe environment and a heterogeneous group of participants facilitates such interventions. However, in practice not all FC/PWD dyads will be ready to start. Therefore, it is necessary to check their willingness when ACP is offered.

Background

Dementia is a life limiting syndrome with a worldwide rising number of people being diagnosed per year. (1, 2) Earlier research advised dementia care to be proactive, person-centred and focus on living and dying well. (3, 4) All these aspects of care can be improved with advance care planning (ACP). (5, 6) ACP has recently been defined as: "the process which enables individuals to define goals and preferences for future care with family and healthcare professionals and to record and review these preferences when appropriate". (7) ACP thereby focuses on medical and non-medical care preferences, and should not be restricted to end of life care. (7-9) Particularly in dementia, because of the deteriorating cognition, it is advised to start ACP timely. As most people with dementia (PWD) live in the community, ACP initiation by general practitioners (GPs) is most appropriate. (2, 10, 11) However, this hardly takes place.

To train GPs in timely initiating ACP with PWD, we developed an interactive educational intervention, which we evaluated in a cluster randomised controlled trial (RCT) with 38 GPs. The 19 intervention group GPs initiated ACP significantly more often and discussed a statistically significant larger number of medical and non-medical preferences. No effects were found on patient-related secondary outcome measures, such as quality of life (QoL), shared decision making (SDM), and family caregivers' (FCs) competence. (12)

The educational intervention under study consisted of multiple components. (13) For such a complex intervention, a process evaluation can help healthcare professionals, researchers and policy makers to understand what contributes to the intervention's success, and what can be improved. In addition, a process evaluation can provide insights into the intervention's mechanisms of impact on everyday life by exploring if study participants adopted the trained skills in daily practice and if all stakeholders found these skills appropriate. (14, 15)

Also, recruiting GPs, PWD and FCs for research is challenging and often has low GPs' participation rates and high PWD/FC dropout rates. (16, 17)
It is therefore essential to identify the population reached by the educational intervention and investigate if the intervention was found acceptable for both GPs and PWD/FC dyads. (18-20)

For those reasons, we aimed to explore the implementation of the educational intervention by focussing on reach and acceptability. We also aimed to explore the intervention's mechanisms' impact on everyday life by focussing on the adoption and appropriateness of ACP in daily practice, including the experiences of GPs, PWD and their FCs. We also defined contextual factors important to both implementation and the mechanisms of impact.

Methods

We used a mixed methods approach and followed the Medical Research Council (MRC) guidance for process evaluations. (19) We addressed the intervention's implementation, mechanisms of impact on everyday life and relevant contextual factors. With regard to implementation, we focussed on reach and acceptability. Reach was defined as whether intended stakeholders came into contact with the intervention. For GPs this meant that they participated in the training. For PWD/FC dyads this meant that they participated in an ACP conversation with their GP. Acceptability was defined as whether stakeholders found the educational intervention acceptable. (19-21) With regard to the intervention's mechanisms of impact in daily practice we focussed on adoption and appropriateness. Adoption was defined as the participants' intention or initial decision to employ ACP in practice. Appropriateness was defined as the perceived relevance of ACP in primary care. (19-21) As for contextual factors we focussed on the setting of the intervention and the characteristics of the study participants. Contextual factors can influence both implementation and mechanisms of impact. (19)

Ethical consent

The study was approved by the medical ethics committee (CMO) of the region Arnhem-Nijmegen in accordance with the Medical Research Involving Human Subjects Acts and the declaration of Helsinki (NL52613.091.15). Anonymity was assured by removing all participant information that could lead to identification from this manuscript.

The educational intervention

Between March and June 2016, we trained 19 GPs in initiating ACP with PWD during two workshops in a small theatre. We hypothesised that first discussing near future non-medical preferences (e.g. housing, daily activities) before preferences on medical scenarios (e.g. hospital admission, or resuscitation) were discussed, would facilitate PWD's engagement in ACP. (8, 9, 22) Discussing such preferences was therefore included in the training.

We used role playing exercises with training actors, combined with other didactic and interactive, proven effective strategies. (23) A model for shared decision making (SDM) with frail elderly was introduced by a GP specialised in this topic and was used to guide the ACP conversations. (24) Barriers and facilitators (e.g. a trust-based relationship with the GP, engaging all stakeholders, GPs' proactive attitude, starting timely and regularly reviewing ACP) were addressed by a GP specialized in elderly care. (8, 9) Participating GPs were invited to bring a practice nurse (PN), as PNs have an important role in dementia care communication in primary care. (8, 9) A full description of the intervention is published elsewhere. (12)

Process evaluation participants

The study population consisted of GPs, PNs and PWD/FCs dyads who participated in the RCT and all trainers who provided the educational intervention. We purposefully selected dyads from different GP practices in order to include participants with characteristics that allowed answering our research questions. We wanted to include female and male PWD and female and male FCs who had had at least one ACP conversation after their GP was trained.

Data collection on reach and acceptability

With regard to the intervention's reach we used the following information. Regarding GPs we registered numbers of those invited to the cluster RCT and characteristics of those who decided to participate. We documented which GP included a PN as well as GPs' and PNs' workshop attendance. Six months after the intervention, all intervention group GPs were invited to complete an 8-item survey. The first item explored reach as it addressed barriers to include PWD and FCs in the study, using a five-point Likert-scale (totally disagree (1) – totally agree (5)). From PWD and FCs we registered numbers of those invited to the cluster RCT and characteristics of those who decided to participate. When PWD and FCs decided not to participate they were asked for their reasons.

With regard to exploring the acceptability of the educational intervention we used the following information. GPs and PNs were asked to complete an evaluation form after each of both workshops. This evaluation form consisted of 10 items. Nine items used a five-point Likert-scale (totally disagree (1) - totally agree (5)), rating separate training elements (e.g. the use of training actors; the heterogeneity of the group, meaning that the group consisted of GPs and PNs with different levels of experience). We considered a rating positive when participants agreed or totally agreed with an item. With the last item of the evaluation form, participants were asked to rate the complete workshop (1-10). From all trainers who provided the educational intervention we gathered qualitative data. They took part in a focus group interview, nine months after the intervention. All were asked for written informed consent. The topic list used was established during several meetings with the research team (BT, MP, YE, RK, MVD) (additional file 1). A researcher (YE), trained in interviewing, chaired the focus group.

Data collection on adoption and appropriateness

With respect to adoption we used the following information. From GPs we used documented ACP conversations in the medical files of included PWD to determine per GP whether they did or did not initiate ACP discussions. The medical files were analysed retrospectively, six months after the intervention by two researchers who were blinded to study allocation. (12) We also used item 2 of the GP survey. This item addressed barriers to initiate ACP with PWD.

With respect to appropriateness we used items 3 to 8 of the GP survey and qualitative data from PWD and FCs. (25-27) We invited PWD/FCs dyads from the intervention condition to participate in a semi-structured interview. All participants were asked for written informed consent. A researcher (BT) trained in interviewing, conducted each interview at PWD's homes, assisted by a research assistant. To guide the interviews, a topic list, constructed during several meetings with the research team (BT, MP, YE, RK, MVD) was used. (additional file 2). Data collected are shown in Table 1.

Additional data

From all participants, demographic characteristics were collected at baseline.

Data analyses

For all quantitative data we used descriptive statistics. With regard to reach we compared the characteristics of PWD, FCs, PNs and GPs who participated in the RCT or who declined. In addition, we analysed the first item of the GP survey on barriers for the inclusion of PWD/FC dyads.

For acceptability, we analysed PNs' and GPs' workshop attendance and evaluation. We used content analyses to analyse the focus group. (28) The focus group was audio taped, transcribed verbatim and analysed separately by at least two researchers using Atlas.Ti version 7 software. Pieces of text from the transcripts related to our research aim were coded. After each interview, codes from both researchers were compared and merged and a codebook was created. As a next step, the codes were combined into categories and eventually themes. Disagreements during this process were discussed with other members of the research team (MP, YE). (28)

Table 1.
Data used to answer our research questions

Research aim		Operationalization	Data collected	Data source
To explore the implementation of the educational intervention	Reach	The percentage and characteristics of persons who receive or are affected by the educational intervention	1. Numbers and descriptives on GPs', PWD's and FCs' cluster-RCT invitation and participation 2. Selection procedure used by GPs 3. Numbers on educational intervention attendance of GPs and PNs 4. Reasons why PWD/ FC declined study participation 5. GPs' barriers on cluster- RCT inclusion of PWD/FCs	1. Electronic database 2. Mail from GPs 3. Educational intervention attendance form 4. Telephone call 5. Electronic survey completed by GPs (item 1)
	Acceptability	The perception among stakeholders that the intervention is agreeable	1. GPs' and PNs' educational intervention evaluation 2. Trainers' educational intervention experiences	1. Educational intervention evaluation form 2. Focus group interviews with trainers
To explore the intervention's mechanisms impact on everyday life	Adoption	The intention or initial decision to try to employ the intervention	1. Descriptives on GPs, PWD and FCs who did or did not had ACP 2. GPs' barriers on ACP initiation with PWD/ FCs 3. Documented ACP conversations with PWD	1. Electronic database 2. Electronic survey completed by GPs (item 2) 3. PWD's medical files
	Appropriateness	The perceived fit or relevance of the intervention in a particular setting	1. Experiences of GPs with ACP in daily practice 2. ACP experiences of PWD and FCs with ACP in daily practice	1. Electronic survey completed by GPs (item3- 8), 2. Interviews with PWD and FCs

PWD: people with dementia; FCs; family caregivers; GPs: general practitioners; ACP: advance care planning; cluster-RCT: cluster randomized controlled trail

With regard to adoption we compared GPs who did or did not conduct ACP with PWD and FCs. ACP conversations documented in the PWD's medical file and item 2 of the GP survey were used as our source of data.

For appropriateness, we analysed items 3 to 8 of the GP survey. To analyse the interviews with PWD and FCs, we used content analyses as described above. (28)

Results

Implementation of the educational intervention

Reach:

We invited 1313 GPs by mail of whom 36 GPs (2.7%) agreed to participate. Characteristics of GPs who declined are unknown. Before randomisation, participating GPs contacted 182 PWD/FCs dyads. Of those, 140 dyads, (78%) gave informed consent (mean age PWD 82y, 58% female; mean age FC 69y, 65% female). For those who declined (n=42; 22 %; mean age PWD 84y, 56% female; mean age FC 76y, 65% female) the expected burden of participation was the most frequently mentioned reason (n=10).

Item 1 of the survey was completed by 16 of the 19 GPs from the intervention group. Thirteen GPs stated they did not invite all PWD who met the inclusion criteria (age ≥65, any stage of dementia, FC also participated in the study) to participate. (additional file 3)

Several reasons were mentioned: dementia severity (n=4); PWD's/FCs' lack of motivation to discuss ACP (n=11), PWD/ FCs not being aware or accepting the dementia diagnosis (n=5), PWD/FCs denying possible future problems (n=4).

Acceptability

Of the 19 GPs in the intervention group (range age 36-63y, 8 females), 16 attended both workshops, and three attended one workshop. Reasons for non-attendance were: lack of time (n=2) and illness (n=1). Of the 18 practice nurses, 15 attended both workshops. Three attended only one workshop due to time constraints.

Twenty-six participants (GPs and PNs) completed the workshop's evaluation form. All 26 participants were positive about practicing ACP with training actors. All but one (96%) were positive about the workshops relevance and the alignment with daily practice. Twenty-one (81%) were positive about the presentations on ACP and the SDM model with frail elderly. Twenty-two (85%) were positive about the location of the workshops. Fifteen (58%) were positive about the presentation given by a FC. The workshops received a mean overall rating of 8.1 (out of 10).

The focus group interview with the seven trainers (range age 40-66y, 4 women) took place in November 2017 at the Radboud University Medical Centre. Data analyses resulted in two themes (the workshops' successful elements and elements which could be improved; contextual factors) and five categories (communicating goals during ACP; from theory to practice; workshop components which could be improved; the heterogeneity of the workshop participants; the workshop environment). (Table 2)

Table 2.
Categories and codes from the focus group interviews with trainers and training actors

Themes	Categories	Codes
The workshop's successful elements and elements which could be improved	Communicating goals during ACP	ACP should start with what is currently important in life Talking about life values is the essence of ACP Trough ACP keeping a dignified life should be discussed Workshops focuses on communication Workshop is about making contact during ACP A personal relation is important during ACP The workshops focuses on talking about remaining QoL
	From theory to practice	Addressing Some theory is necessary Experiencing ACP is most important Experiencing ACP deepens the theory Workshops focus on practicing ACP A demonstration helps to understand theory
	Workshop components which could be improved	Family caregiver presentation lacked a clear focus Family caregiver presentation was to personal The family caregiver presentation did not focus on complexity of the situation
Contextual factors	The heterogeneity of the workshop participants	Every group is different Participants had different levels of experience with ACP Participants had different levels of experience with dementia Not all participants have the same learning curve Heterogeneous groups enrich the workshops Participants learn from each other Participants have their own communication preferences
	The workshop environment	Small groups are important Maximum of five participants per training actor Fifteen is the maximum group size The intimate setting facilitates learning The theatre contributed to the intimate setting the intimate setting facilitated involvement

ACP: advance care planning; Qol: quality of life

Theme 1: the workshops' successful elements and elements which could be improved

The trainers found practicing ACP with training actors and starting ACP with non-medical preferences currently important to the PWD's QoL, the most successful workshop elements.

In addition, the trainers stated that they demonstrated that for ACP it is important to establish a personal relationship with the person with dementia and FC.

Such relationships create an atmosphere where difficult issues concerning care preferences and maintaining a dignified remaining phase of life with optimal quality can be discussed. Balancing theoretical and interactive exercises was also considered a successful element.

"When there was more tranquillity during an ACP conversation, and we (trainers who acted as PWD) were given the time to tell things, we actually won time and were able to discuss difficult subjects...... When a GP was rushed, you (training actor) became restless or confused. When there is tranquillity and time is taken, you get a completely different conversation which is also more pleasant."

Trainers stated that the participants (GPs and PNs) had different learning curves and that their experiences with PWD and ACP prior to the training differed. This heterogeneity made the workshops challenging. Nevertheless, trainers preferred such a heterogeneous group because participants then also learned from each other.

"I (trainer) have to say... when a group is more diverse, it gets more interesting, especially when a group is not that big, diversity is nice. To me it is not that interesting whether the participants are PNs or GPs. I just see 15 people who want to learn from each other."

According to the trainers, the presentation given by a FC left room for improvement as this did not fully address the complexity of caring for a person with dementia. Looking back, the trainers found that they had not discussed the aims of her presentation thoroughly enough with the FC.

Theme 2: contextual factors

According to the trainers, the workshop location (a small theatre) and the limited number of participants (maximum of 15 GPs/PNs with 4 trainers), created an intimate and safe setting. As a result, trainers were able to give sufficient personal attention and feedback and participants dared to experiment when practicing ACP conversations.

Mechanisms of impact on everyday life

Adoption

The medical records' reviews showed that 16 of the 19 GPs in the intervention group, had had at least one ACP conversation with at least one person with dementia during the six months after the intervention. Nine GPs had had at least one ACP conversation with more than half of the included PWD from their practice. These GPs were younger (45.1 vs. 51.7 years) and more often female (7 out of 9 vs. 3 out of 10) compared to the 10 GPs who had had ACP conversations with less than half of the PWD from their practice. (additional file 3)

In the GP-survey, thirteen GPs stated they had initiated ACP with all included PWD. (additional file 3) Those who did not, stated that a lack of time and dementia severity were the main reasons for not having initiated ACP.

PWD who had ACP during the six months after the intervention were more often male (25/35 male vs. 10/35 female) compared to those who had not had ACP (19/36 male vs. 17/36 female). In addition PWD who had ACP more often had very mild dementia (5/35) compared to those who had not had ACP (1/36). (Table 3)

Table 3.
Characteristics of PWD and FCs who had ACP or had no ACP

Characteristics	PWD who had ACP (n=35)	PWD who had no ACP (n=36)
Mean age PWD (sd)	81 (6.8)	82 (5.1)
Gender PWD	25 male	19 male
Mean age FC (sd)	70 (13.8)	69 (13.8)
Gender FC	19 male	21 male
Dementia rating scale		
Very mild	5	1
Mild	14	18
Moderate	9	9
Severe	7	8

PWD: people with dementia; FC: family caregiver; ACP: advance care planning

Appropriateness

Most GPs (n=11) found it important to start ACP with discussing non-medical preferences of PWD. All GPs stated that continuing ACP about medical scenarios became easier when these non-medical preferences were known. Fifteen GPs wanted to start ACP early in the disease trajectory and found engaging FCs not difficult. Nine GPs found engaging PWD not difficult. (Additional file 3)

Ten FCs (range age 70-84y, 6 females) and two PWD (range age 70-84y, 2 females) were interviewed between January and June 2017. The first two interviews showed that PWD had trouble remembering ACP conversations and were not able to provide information concerning our research aims. We therefore decided to conduct the remaining eight interviews by telephone with only the FC. After eight interviews no new codes emerged and two more interviews were conducted to confirm saturation. Two themes (experiences with discussing goals, making timely shared decisions) including four categories (discussing medical and non-medical issues, additional ACP outcomes, shared decision making, proactive behavior) were derived. (Table 4)

Table 4.
Appropriateness: Categories and codes from the interviews with family caregivers and people with dementia

Themes	Categories	Codes
Experiences with discussing preferences	Discussing medical and non-medical issues	Choices within ACP depend on the present situation ACP focused on medical and non-medical issues ACP also focused on the here and now ACP mostly focused on health related issues
	Additional ACP outcomes	ACP stimulates to think about the future ACP provides peace ACP provides clarity ACP increases trust in the healthcare provider ACP increases contact with the healthcare provider ACP increases the knowledge about dementia ACP makes sure their wishes are known ACP was not confronting ACP had not been useful ACP was confronting ACP was stressful
Making timely shared decisions	Shared decision making	ACP should be decided upon together Healthcare professional should also listen to family caregiver FC could co-decide during ACP FC discussed ACP with person with dementia FC makes ACP decisions if necessary FC felt equal to the GP during ACP Engaging PWD is difficult because cognitive decline PWD keep aloof during ACP Making decisions for PWD is sometimes difficult SDM did not take place Taking responsibility for ACP decisions is difficult FC doubts if person with dementia can co-decide PWD's insight in their situation is limited ACP is not feasible because of cognition
	Proactive behaviour	ACP has to be repeated twice a year ACP has to be repeated annually FC had not thought about the future Proactive behaviour stimulates ACP GP has to take the initiative FC does not take the initiative Regular contact is important for ACP Discuss ACP when problems arise Has not thought about the future Does not want to think about the future FC does not contact the GP herself for ACP

ACP: advance care planning; GP: general practitioner; FC; family caregiver; PWD: people with dementia; SDM; shared decisions making

Theme 1: experiences with discussing preferences

Most FCs indicated that starting ACP with near future non-medical care preferences suited the PWD's needs as these preferences importantly influenced their current situation and QoL.

> *"I really liked the fact that not only medical issues were discussed. I always say: when discussing well-being, all aspects of the person have to be discussed".*

Some FCs however stated that ACP had mostly focused on the PWD's illness and medical preferences. According to them, this was a missed opportunity. Capabilities of PWD and non-medical issues should have been addressed as well.

Most FCs found ACP important as it provided tranquility, clarity, increased their knowledge about dementia, improved the contact with their GP and increased trust in healthcare professionals. FCs also stated that the GP gained more insight in their living situation. Some FCs however found discussing future preferences confronting, stressful and not useful. These FCs only wanted to discuss care when a problem actually arose.

Theme 2: Making timely shared decisions

FCs appreciated that they, with the person with dementia, were engaged in ACP conversations. They could both participate and co-decide. FCs felt no hierarchy between them and the GP.

> *"I really felt we could co-decide. She (GP) would put it on the table, so to speak and then we start talking about it……"*

Most FCs appreciated the GPs' proactive behaviour as FCs would not have initiated ACP themselves.

Some FCs doubted if engaging PWD in ACP was possible because of their memory problems or limited insights. If PWD were unable to make decisions themselves, FCs decided for them, which they found difficult. Most FCs found an annual evaluation of ACP sufficient, while others wanted this at least twice a year. One FC stated that during ACP, the GP gave little opportunity for SDM.

Discussion

In this process evaluation we aimed to explore the implementation of the educational intervention and the intervention's mechanisms' impact including important contextual factors.

The intervention was implemented by a small part of the invited GPs. The participating GPs mostly reached PWD/FC dyads who were motivated and experienced relatively little burden. The intervention's most successful elements were practicing and experiencing timely ACP with training actors in a heterogeneous group, with near future non-medical preferences and improving QoL as the starting point. The highly appreciated training was acceptable to all stakeholders. The intimate and safe environment was an important contextual factor.

Most GPs adopted ACP in daily practice. With regard to appropriateness, GPs stated that an early start of ACP including non-medical preferences facilitated ACP. PWD/FCs dyads stated that ACP, including non-medical preferences, improved SDM and was important to PWD's current QoL Some FCs doubted the feasibility of ACP. ACP was more often applied by younger female GPs. male PWD and persons with mild dementia more often had ACP. We therefore consider gender of professionals, PWD and FCs, and dementia severity important contextual factors.

Interpretation of the study in comparison with other literature

Training healthcare professionals in communication skills regarding future care has been shown effective before. (29-31) Using role models, simulations and mixed interactive and didactic education in a small and safe environment, as we did, are thereby the most effective approaches. (23, 32-36) Although a Cochrane review concluded that the overall effects of training healthcare professionals are limited, (23) our study showed that education on professional behaviour in performing ACP in daily primary care practice can be substantial. Nevertheless, a maximum implementation degree was not reached. (12, 23)

It is not surprising that GPs included PWD/FC dyads of whom they thought to be capable and willing to participate in ACP. (7, 37) ACP and SDM, when aimed at deciding on future medical preferences, require the ability to imagine future scenario's, which is difficult for PWD, especially when dementia is severe. In addition, willingness and motivation depend on the right timing, perceived barriers and subjects discussed, and are therefore not fixed states assessable at one time point. (8, 38, 39) Regularly checking PWD/FCs dyads' willingness and motivation, and customizing ACP to the needs and capabilities of those involved, leads to more dyads being engaged and prevents that ACP is experienced as stressful or not feasible. (40-44) In addition, taking in account the role of FCs, as cognitive decline progresses and FCs are deemed to decide for PWD, is thus important. (43) As shown in our results and earlier research, including non-medical preferences in ACP facilitates ACP as these are important to PWD's current QoL and SDM. (8, 9, 45) To provide appropriate ACP in primary care we recommend to include such non-medical aspects in future educational interventions.

Our research showed that gender of GPs and PWD are important contextual factors. Younger female GPs more often initiated ACP compared to their male and older colleagues. This is congruent with previous studies which showed that younger female GPs have more knowledge and more positive attitudes towards dementia care management. (46) We also showed that male PWD more often had had ACP compared to female PWD. This contrasts with earlier research which found that females are more active in decision making, are more inclined to discuss a wider variety of preferences for future care, feel more empowered by discussing care preferences and believe preferences will be granted when documented. (47, 48) On the other hand, as these characteristics also apply to FCs, the mostly female FCs of the male PWD in our study will have had an important role in initiating ACP in dementia.

In contrast to the secondary outcomes of the cluster RCT, this process evaluation shows that ACP, in which discussing nearby non-medical preferences has a central role, has an impact on experienced involvement in decision making and is important to QoL. This contrast can be explained by the fact that quantitative measurements of QoL do not properly reflect those aspects of daily life individuals find important and appraise for their QoL (50-53). Also, earlier research indicated that PWD and FCs find qualitative research methods more appropriate to assess important aspects related to their QoL. (54) Given the above, we emphasize the importance of future research on PWD's, FCs' and GPs' gender, GPs' age, and relevant more personalised measurements of QoL for PWD.

Study strengths and limitations

This study has several strengths. With the MRC guidance for the process evaluation of complex interventions we were able to provide insights into the effective working mechanisms of the multiple components of the educational intervention and the experiences of stakeholders when gained skills were applied in daily practice. (19) We used a mixed-methods approach, included the views of PWD, FC and GPs and included researchers with a wide range of expertise. As a result, triangulation and in-depth understanding of our research findings was achieved. (55)

Our study also has some limitations. Recruiting GPs for palliative care education research is known to be difficult and in this study only a small percentage decided to participate. (17) It is known that GPs mainly participate in research they personally find important or valuable for the medical profession as a whole. (56, 57) In addition, GPs doubt the feasibility of ACP in daily practice and are uncertain about how to discuss end-of-life preferences. (8, 9) This can explain GPs' low participation rate. However, interventions aimed at relatively new and complex skills are often implemented first in a small group of motivated professionals and from there on spread to the rest of the target population. (58)

We were not able to retrieve characteristics of GPs who did not respond or declined to participate. Hence, we were not able to determine if these GPs differed from the participating GPs and could not further explore possible consequences for the intervention's external validity.

As we did not confront GPs with the difference between the mentioned and documented ACP conversations, we were not able to explain why this discrepancy was found. This can be caused by incomplete medical records which do not reflect actual medical performance. (59) It can also be caused by GPs' giving socially desirable answers in the survey.

As PWD were not able to remember ACP conversations, we may not have a complete view of how ACP was applied and experienced in daily practice.

Conclusion

We recommend to include interactive and didactic elements in future educational interventions on ACP with PWD in primary care, and focus on practicing ACP with non-medical preferences aimed at remaining QoL as a starting point. A safe learning environment and heterogeneous groups will increase learning effects. GPs' younger age and female gender, and PWD's male gender may positively influence ACP initiation.

In daily practice, ACP can be experienced as stressful and not feasible by PWD. GPs should therefore check PWD/FC dyads' willingness to be engaged and only start when they are ready. Future research on interventions to increase engagement of PWD and FCs in ACP is recommended.

We also advise future research to include a broad sample of GPs, PWD and FCs and to take into account how gender of both the professional and patient, and age of healthcare professionals, influences ACP application in daily practice. To improve further initiation of ACP in dementia, we suggest a wider implementation of our educational intervention.

Declarations

Ethics approval and consent to participate

The study was approved by the research ethics committee (CMO) of the region Arnhem-Nijmegen in accordance with the Medical Research Involving Human Subjects Acts and the declaration of Helsinki (NL52613.091.15). Anonymity was assured by removing all participant information that could lead to identification from the transcripts. Written consent was obtained from all participants. The family caregiver gave consent on behalf of the person with dementia.

Consent for publication

Not applicable

Availability of data and material

Data are available at reasonable request.

Competing interests

The authors declare that they have no competing interests.

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MP: contributed to the design, data analysis, data interpretation and writing of the manuscript.

Abbreviations

ACP: advance care planning
SDM: shared decision making
PWD: people with dementia
FC: family caregiver
GP: general practitioners
MRC: medical research council
QoL: quality of life

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Additional file 1: Topic list focus group interview with workshop trainers

Start with a description of the workshop components and with both workshop aims

Aim of workshop 1:
At the end of workshop 1, general practitioners and practice nurses are able to complete the steps of the model of shared decision making with frail elderly with a person with dementia and his/her family caregiver.

Aim of workshop 2:
At the end of workshop 2, general practitioners and practice nurses are able to discuss and report medical and non-medical issues, important to the person with dementia's and his/her family caregiver's quality of life, during an ACP conversation.

Questions:

- What did general practitioners and practice nurses learn during the workshops and how did you notice?
- Did you see differences between practice nurses and general practitioners and what were these differences?
- Were the different workshop components executed as planned?
- Which workshop components contributed most to reaching the workshop's aims?
- Which workshop components did not contribute to the workshop's aims or what should be improved?
- What should be added to the workshops?
- Did general practitioners and practice nurses appreciate the workshops and how could you notice?
- What are the advantages or disadvantages of using multidisciplinary groups?
- What was the influence of the workshop setting and the number of participants?

Additional file 2: Topic list interviews with people with dementia and family care givers

- How did the advance care planning conversation with your general practitioner and or practice nurse go (what went well and what could be improved)?

- Were you engaged in the conversation and could you able to co-decide?

- What did the advance care planning conversation yield?

- Do you think advance care planning is a good addition to the care delivered by your general practitioner or practice nurse and why do you think so?

Additional file 3: Characteristics of GPs who did or did not have ACP and the items of the GP survey

Additional table. Characteristics of GPs who did or did not have ACP and items of the GP survey

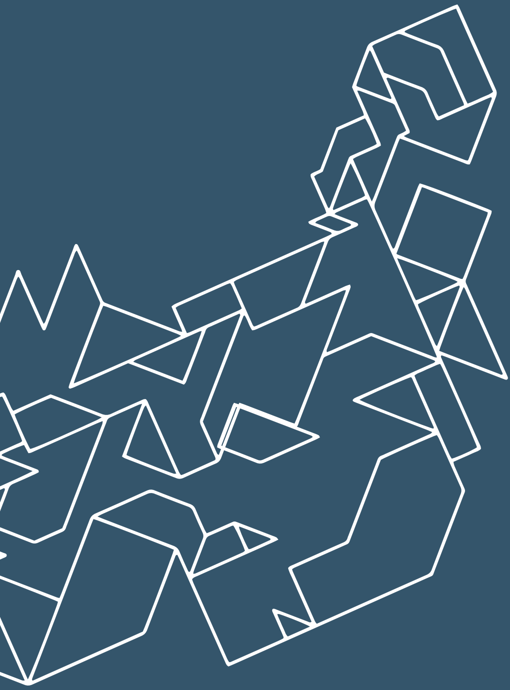
ID number of GPs who had ACP with > 50% PWD	PWD who had ACP	GP gender	GP age in years	% elderly patients in GP practice	Items 1-8 of the GP survey**							
					1	2	3	4	5	6	7	8
554	3/3 (100%)	v	38	8	No	Yes	4	3	2	5	4	5
28	2/2 (100%)	v	45	10	Yes	Yes	4	5	2	2	4	4
233	2/2 (100%)	v	36	16	Yes	Yes	5	4	2	4	5	4
234	3/3 (100%)	m	58	25	No	Yes	4	4	2	4	4	4
552*#	1/1 (100%)	m	51	11	-	-	-	-	-	-	-	-
314	4/4 (100%)	v	39	18	No	Yes	4	4	2	4	5	4
368	5/5 (100%)	v	41	23	No	Yes	5	2	2	4	4	4
235	3/4 (75%)	v	39	16	Yes	Yes	4	4	5	4	5	4
511	3/4 (75%)	v	59	20	No	Yes	4	4	2	4	4	4
Totals of GPs who had ACP with >50% PWD ***	26/28 (93%)	77% female	Mean 45	16 %	n/a	100% yes	4(4)	4(4)	2(2)	4(4)	4(4)	4(4)

GP: general practitioner; PWD: people with dementia; ACP: advance care planning
**1 medical file missing*
 # GP survey missing
*** 1: totally disagree; 2: not agree; 3: not disagree/agree; 4: agree; 5: totally agree*
- Item 1: I have nominated all PWD who met the inclusion criteria for study participation
- Item 2: I have had one or more advance care planning conversations with all included people with dementia from my practice

Additional table. Continued

ID number of GPs who had ACP with < 50% PWD	PWD who had ACP	GP gender	GP age in years	% elderly patients in GP practice	Items 1-8 of the GP survey**							
					1	2	3	4	5	6	7	8
502*	2/5 (40%)	m	43	19	No	Yes	5	5	2	3	4	4
14	2/5 (40%)	m	63	10	No	No	4	4	2	3	4	4
450	1/3 (33%)	m	59	20	No	No	5	3	2	4	4	4
389	1/5 (20%)	v	49	26	No	No	3	3	2	4	4	4
646	1/5 (20%)	v	45	12	No	Yes	5	4	2	4	4	4
397	1/5 (20%)	m	46	28	No	Yes	5	2	2	4	5	5
394	1/5 (20%)	v	52	24	No	Yes	5	2	2	3	4	5
459*	0/2 (0%)	m	43	15	No	Yes	5	2	2	2	4	4
244#	0/4 (0%)	m	57	12	-	-	-	-	-	-	-	-
405#	0/4 (0%)	m	60	12	-	-	-	-	-	-	-	-
Totals of GPs who had ACP with ≤50% PWD ***	9/43 (21%)	33% female	Mean 52	18%	n/a	62.5% Yes	5(5)	3(2)	2(2)	3.5(4)	4(4)	4(4)

GP: general practitioner; PWD: people with dementia; ACP: advance care planning
**1 medical file missing*
 # GP survey missing
*** 1: totally disagree; 2: not agree; 3: not disagree/agree; 4: agree; 5: totally agree*
- Item 1: I have nominated all PWD who met the inclusion criteria for study participation
- Item 2: I have had one or more advance care planning conversations with all included people with dementia from my practice



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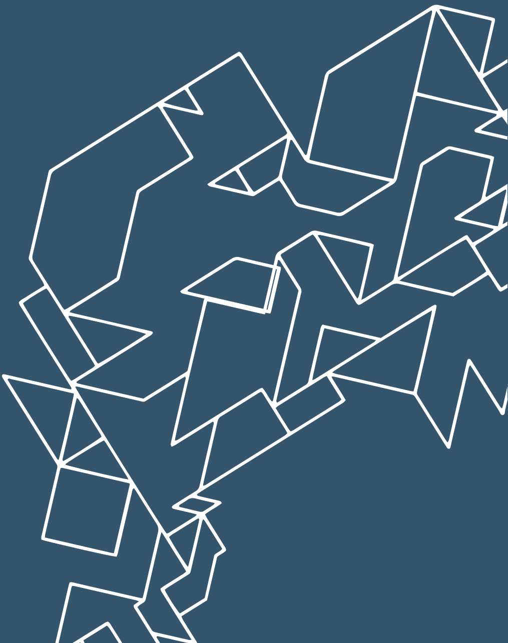
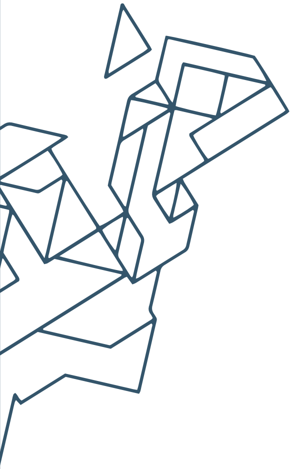


Chapter 6

General discussion



General discussion

Epilogue

As described in the prologue, Jan's general practitioner was highly motivated to discuss Jan's care preferences for his remaining phase of life. However, engaging Jan in such a conversation was challenging and did not take place. So, what if Jan´s general practitioner had participated in our educational intervention?

Jan's general practitioner then would have learned to timely start advance care planning and begin the conversation with non-medical preferences important to Jan's current and near future's quality of life. From there on, preferences for future care and medical treatment could have been discussed. During such conversations Jan could have expressed that staying at home as long as possible, where he could sit on his balcony and have his wife and dogs around, were the things which mattered most to him. Jan, his wife and the general practitioner then could have discussed what was necessary to facilitate this. For example, increasing daily care or going to a day care centre during several days a week to relieve his wife. As a next step, Jan, his wife and his general practitioner could have discussed the long-term consequences of Jan's preferences. They might have decided that, if Jan would further deteriorate, he would receive palliative care at home. These preferences then could have been documented in his medical file and shared with other healthcare professionals. This might have prevented Jan from being admitted to a hospital and he could have died at home with his wife and dogs around him.

Main research findings

In this thesis we described the development and evaluation of an intervention for general practitioners aimed at initiating and optimizing advance care planning with people with dementia. Here the main findings per research questions are listed:

What are the facilitators and barriers for initiating advance care planning with people with dementia by general practitioners? (chapters 2 and 3):

- Proactive behaviour of the general practitioner facilitates timely advance care planning. People with dementia and their family caregivers want the general practitioner to initiate advance care planning. On the other hand, general practitioners are uncertain about who should take the initiative.
- Advance care planning is facilitated by general practitioners and practice

nurses who know the person with dementia and their family caregiver and have a trusted, warm relationship. Conducting home visits also facilitates advance care planning.
- Advance care planning is facilitated by including medical (e.g. hospital admission, resuscitation) and non-medical (e.g. housing, social contacts) preferences, aimed at remaining and improving quality of life.
- Barriers of people with dementia and their family caregivers are related to their denial of the diagnosis, the uncertain disease trajectory or the preference to “live one day at a time”.
- Barriers of general practitioners are related to uncertainties about the feasibility of advance care planning, the decisional capacity of people with dementia, the fear to talk about difficult topics and the fear to cause stress in people with dementia and their family caregivers.

What are the effects of an educational intervention aimed at initiating and optimizing advance care planning with people with dementia by their general practitioners? (chapter 4):
- General practitioners who received the educational intervention significantly initiated more advance care planning conversations and discussed significantly more medical and non-medical preferences with people with dementia.
- Advance care planning did not affect quality of life or the experienced level of shared decision making of people with dementia.
- Advance care planning did not affect healthcare costs or family caregiver’s experienced level of competence.

What are the educational intervention’s successful components and what could be improved? (Chapter 5):
- Including non-medical preferences to maintain or increase current quality of life, and using training actors in a safe and multidisciplinary setting are successful strategies to train general practitioners to initiate and engage people with dementia and family caregivers in advance care planning.
- Family caregivers of the intervention group appreciated the fact that people with dementia were actively engaged in advance care planning, the general practitioner’s proactive behaviour and the inclusion of medical and non-medical preferences in advance care planning.
- The inclusion of participants by general practitioners could be improved. General practitioners mainly included motivated people with dementia and

family caregivers who experienced relatively little burden and people with dementia with limited cognitive decline.
- The general practitioners' person centred approach could be improved even more. In some cases, people with dementia and their family caregivers from the intervention group found advance care planning stressful and not feasible.

Discussion of the main findings

In this thesis we showed that in dementia care, general practitioners' proactive approach facilitates advance care planning. People with dementia and their family caregivers wanted to talk about their preferences for future care but would not initiate these discussions themselves. (1, 2) Therefore, if the general practitioner does not take the initiative, advance care planning may start too late or not at all. When starting too late, because of the cognitive decline, it becomes increasingly difficult to engage people with dementia.

Despite the need for a proactive approach and an early start, preferences for future care can only be discussed when people with dementia and their family caregivers are ready. They first have to be well informed about the dementia diagnosis, the disease trajectory and the process of advance care planning. (1-5) Also, people with dementia and their family caregivers should be given time to cope with the idea of having a chronic terminal disease before discussions about their preferences for future care can take place. (6, 7) Starting directly after the dementia diagnosis is given may therefore be too soon. It seems more appropriate to first assess the readiness of people with dementia and family caregivers before advance care planning is initiated. (3, 8-10)

This thesis supports our assumption that general practitioners are suited to initiate advance care planning. As shown in chapter 5, 49% of the general practitioners and practice nurses from the intervention group had had an advance care planning conversation with more than half of the included people with dementia from their practice. It is thereby known that general practitioners only adhere to complex recommendations or guidelines when they feel self-confident to perform the recommendations in daily practice, agree with its contents, believe the benefits outweigh the harms and believe that the recommendations match the patient's preferences. (11, 12) In addition, we showed that the person with dementia and his or her family caregiver preferably have a trusting, personal relationship with the healthcare professional who initiates advance care planning. (2) General practitioners and practice nurses are often involved from diagnosis on, know their patients well and have such relationships with their patients. (13)

Traditionally, advance care planning focussed mainly on medical and end of life preferences (e.g. resuscitation, hospital admission). (14-17) In this thesis we showed however that in dementia, a broad and patient centred approach is more appropriate. Including non-medical preferences in advance care planning is important as it supports the need of people with dementia to stay as autonomous as possible. It also supports their ability to self-manage, to adapt to living with dementia, be engaged in social activities and live meaningful lives. These preferences are aspects of positive and social health and directly influence someone's current quality of life. (1, 2, 18-25) Medical preferences on the other hand are also more abstract and often linked to the end of life. As a result, discussing these topics could be more stressful, difficult and confronting and people with dementia and their family caregivers may be less willing to be engaged in advance care planning. Non-medical preferences should therefore be the starting point and from thereon, when people are ready, medical preferences can be discussed. (1, 2, 4, 5, 26, 27) The results of our randomized controlled trial and process evaluation further underlined the importance of including non-medical preferences. We showed that people with dementia, when given the change, discuss more non-medical (n=107) preferences compared to medical preferences (n=58). (28)

This broad view on advance care planning, which includes a shift to specifically address the patient's preferences and goals of care, has also been described in other studies. (4, 5, 26) For example, Rietjens et al. (2017) proposed a new definition for advance care planning. According to this definition, the physical, psychological, social and spiritual domains related to preferences for medical treatment and care should all be part of planning future care. (26) In addition, in the model for shared decision making with frail elderly of van der Pol et al. (2015), discussing the patients values and goals of care are included in the model's second step "goal talk". (5) Also, Elwyn et al. (2017) adapted their model for shared decision making. In the revised model, during "team talk", the physician is advised to specifically discuss the patient's goals of care. (4) In both models the patients' goals are then used to make patient centred decisions on future medical treatment and care.

Including medical and non-medical preferences in advance care planning is also consistent with Huber et al.'s (2011) definition of positive health: the ability to self-manage and adapt to (chronic) illness. (18) Since the introduction of this definition, further research has been conducted. In Huber et al.'s (2011) first analysis, positive health included three dimensions: physical health, mental health and social health. (18) Since 2016, Huber et al. included six dimensions of positive health: bodily functions, mental functions and perceptions, spiritual/existential dimension, quality of life, social and societal participation, and daily functioning. Our educational intervention and broad concept of advance care planning thereby even more closely relates to Huber et al.'s latest view on positive health. (19) In addition, Vernooij-Dassen and Jeon. (2016) and Dröes et al. (2017) related positive health to dementia and more specifically described the social health dimension. According to them social health includes: 1) having the capacity to fulfil ones potential and obligations, 2) the ability to manage one's life to some degree of independence and 3) participation in social activities. (20, 29) By participating in advance care planning, people with dementia are given the opportunity to plan their care according to what is important to them.

They also provide information and thereby prevent their family to be uncertain about people's with dementia values and wishes and about making the right decision. Social health thus does not only relate to receiving support,
but also to giving to others, to contribute and to reciprocity. It is thereby also important that the family caregiver stimulates the person with dementia to stay socially healthy.

Positive health and social health seem much more productive in dementia compared to the definition of health from the World Health Organisation (WHO): a state of total physical, mental and social well-being. (18, 30) According to the WHO's definition, people with dementia can never be healthy. We showed however that advance care planning can become more person centred and thereby support people with dementia in living healthy lives according to the definition of positive health including social heath. (9, 20, 28, 29, 31-34).

In recent years the broad interpretation of advance care planning has also been integrated in several Dutch guidelines and healthcare policies. (35, 36) According to the dementia guideline of the Dutch College of General Practitioners, general practitioners should, together with the person with dementia and their family caregiver, discuss goals based on someone's personality, background, way of living, needs and possibilities. (35) The care standard dementia ("zorgstandaard dementie"), written on behalf of the Dutch government by leading societal organisations to guarantee good quality dementia care, advises to discuss and plan care according to the person with dementia´s wishes and possibilities and stimulate people with dementia to stay in control as long as possible. (36) Even though general practitioners state they find such guidelines and healthcare policies helpful to initiate advance care planning in a structured manner (chapter

3), solely providing guidelines is insufficient to change everyday practice. (12) General practitioners also need training. (1, 2) We showed that training general practitioners interactively, in a heterogeneous setting, with the use of training actors is effective and can support people with dementia too in planning their future care according to their preferences. (28, 34)

Reflections on the outcome measures for advance care planning interventions

There is a lack of consensus on the most appropriate outcomes to determine if advance care planning interventions are successful. (15, 37-40) In our cluster randomized controlled trial, we used documented advance care planning conversations in the patients' medical file to determine our primary outcome: the number of initiated advance care planning conversations, and the key secondary outcomes: medical and non-medical preferences discussed. However, other outcomes may have been appropriate as well.

In a Delphi study, Sudore et al. (2018) concluded that the most important outcome to define successful advance care planning is care provided consistent with someone's goals. (41)

This outcome was also found important by Rietjens et al. (2017) although the participants in their Delphi study rated the identification, communication, documentation and satisfaction with advance care planning even higher. (26) We agree that advance care planning should eventually lead to care consistent with goals.

However, in our study we were only able to follow participants for six months. The multiple step process of first discussing care preferences and then providing care consistent with goals undoubtedly takes longer. (3-5) In addition, general practitioners probably don't directly initiate advance care planning after being trained. Also, not all goals discussed during advance care planning will apply to someone's future (e.g. not everybody who decides that they don't want to be admitted to an intensive care unit will eventually need that kind of care). Also, to provide care consistent with goals, all healthcare providers involved in the care of a person with dementia should have access to someone's documented preferences. As shown in chapter two, in practice this still is difficult to arrange. (1) For all these reasons it was not feasible to use care consistent with goals as an outcome in our randomized controlled trail.

To our opinion, in accordance with Sudore et al's. (2018) and Rietjens et al. (2017), the initiation of advance care planning is an important indicator for the effectiveness of advance care planning. Before care consistent with goals can be provided, someone's preferences must first be discussed and documented. (4, 5, 9, 26, 41) It is thereby noteworthy that Sudore et al. (2018), rated discussing and documenting who the proxy decision maker will be when someone is no longer able to express one's preferences, higher than the documentation and discussion of values and preferences for care. (41) We believe however that our primary and key secondary outcomes have a more direct link with care consistent with goals than deciding on the proxy decisionmaker. Discussing what brings value to a person's life provides essential information to deal with difficult situations which may arise in the future. We therefore consider documented advance care planning initiation and preferences discussed more relevant outcome measures than deciding on the proxy decision maker, especially in early dementia.

One could argue that the ultimate reason for undertaking an intervention in healthcare is the enhancement or maintenance of health related quality of life. (42) Measuring health related quality of life in dementia is however difficult. Earlier research concluded that health related quality of life of people in dementia hardly changes within a year. (43-45) Also, with each person, dementia is expressed in different ways. Because of this, it is difficult to capture dementia specific health related quality of life in a questionnaire. (46, 47) In addition, most measurements of health related quality of life have a heavy emphasis on physical and mental functioning where people with dementia themselves have identified a wider range of areas of life they find important. (1, 2, 23, 27, 48).

Even though the DEMQOL (the measurement of health related quality of life we used), is among the best available assessment instruments in dementia, it mainly focuses on mood and memory. (49, 50) Elements like self-efficacy, autonomy and meaningful activities, receive less attention even though these are important to quality of life in dementia. In addition, these are aspect of positive and social health which are important for a person-centred approach to being healthy. (1, 2, 18-20, 27, 29, 49-51). On the other hand, it may be difficult to capture these aspect in a questionnaire (e.g. how do you measure meaningful activities?). It may be even more difficult for people with dementia to answer those questions since dementia inhibits the ability to remember recent events. The fact that DEMQOL refers to feelings and events of the previous week, which people with dementia may not be able to remember, thus complicates matters even further.

We used the CollaboRATE to assess the experienced level of shared decision making of people with dementia. This questionnaire relates to whether a healthcare professional helped to explain health issues and made efforts to listen to and include what matters most to a person when making decisions. (52) We were unable to show any effect on this outcome.

Earlier research found that Dutch patients almost always positively evaluate their general practitioner on elements of shared decision making (e.g. listening to you, explaining the purpose of test and treatments). (53) Moreover, the participating general practitioners in our study were probably already interested in shared decision making and in dementia care. As a result they may already have spent more time with people with dementia and their family caregivers before our intervention took place. This may be the reason why at baseline people with dementia rated their level of shared decision making quite high (mean 21.3; SD 4,5; max score 27). Because of this ceiling effect there was little room for improvement.

Patient-related outcome measures which focus specifically on the decisions made during advance care planning and the consequences of those decisions, might have been more suitable. The decisional regret and decisional conflict scales are reliable and valid examples of such assessment instruments (54, 55) On the other hand, these measurements require the ability to remember and reflect on decisions and events. Since we showed that for people with dementia it was difficult to remember their advance care planning conversation, using these measurements in dementia may also not be feasible. (34)

We used the Sense of Competence Questionnaire to assess the caregiver's feeling of being capable to manage the caregiving role. (56) We were not able to show any effect on this outcome. There are several factors which relate to sense of competence, such as situational, demographic and personality characteristics of the family caregiver, behavioural and psychological symptoms, and dementia severity.

In addition, family caregivers who are able to identify positive aspects of caregiving experience fewer negative outcomes on sense of competence. Summarized, it seems that those family caregivers who experience relatively little burden from dementia, experience a greater sense of competence. (57)
Our process evaluation showed that general practitioners mostly included dyads who experienced relatively little burden. In addition, as mentioned above, the participating general practitioners were probably already interested in advance care planning and dementia care in general.

This may have resulted in the high baseline scores of the sense of competence in our randomized controlled trial (mean 93,2; SD 12,4; max score 129) which left little room for improvement. In addition, for those family caregivers who did experience a high burden at baseline, it is expected that it may take some time for the effects of advance care planning to take place. As a result we were unable to capture the effect of our intervention during the six-month intervention period. However, we still believe that sense of competence is an important outcome in advance care planning. Especially given its close relation to social health and the uncertainties caused to family caregivers about their role when care needs and wishes are not discussed. (20, 29)

Strengths and limitations

The main strength of this study is that we used input from existing research and all stakeholder to develop and evaluate an educational intervention consistent with the needs of general practitioners and people with dementia and family caregivers. We used a mixed methods approach based on the Medical Research Council guidance for the development and evaluation of complex interventions. (58-60) We systematically searched and integrated existing qualitative and quantitative literature. (1, 61) Knowledge gaps left were then filled with qualitative research including general practitioners, practice nurses, case managers, people with dementia and family caregivers. (2) This knowledge was then combined with expert opinions of all members of our research group, including a family caregiver, general practitioners, experts in palliative care, dementia care, elderly care, shared decision making and medical education, to develop the educational intervention. We specifically choose an interactive training method as solely providing information and tools for advance care planning (e.g. forms, question prompts) is ineffective. (5, 62-64) In addition, we allowed general practitioners to adapt the intervention to their practice as a too strict standardisation of the intervention may be inappropriate. (60) Finally, we conducted a process evaluation to identify the intervention's successful components and what could be improved. (34, 59, 60)

Another strength is that we were able to reach our planned sample size. This was not easy and took a lot of effort. Several rounds of approaching general practitioners, people with dementia and their family caregivers were needed.

Because we reached our sample size, we could conduct a cluster randomised controlled trial with sufficient power to determine the effects of the intervention on our primary outcome and reach a high level of evidence. (65, 66) We also choose primary and key secondary outcomes closely linked to the educational intervention. In addition, as already mentioned above, the initiation and documentation of advance care planning conversations are also important prerequisites to provide care according to one's preferences. (26, 41)

We choose to include people with dementia and their family caregivers before general practitioners were randomized and trained. We did this to prevent bias, as general practitioners were then unable to include people with dementia and their family caregivers of whom they thought to match our intervention. On the other hand, in chapter five we showed that general practitioners mainly included people with dementia and family caregivers who experienced relatively little burden from dementia and people with dementia with limited cognitive decline. They probably did this because they thought these people were best suited to participate. Including people with dementia after training general practitioners might have shown general practitioners that proactive person centred advance care planning, including medical and non-medical preferences, is also suitable for people with dementia with more severe cognitive decline and people with dementia and family carer which are burdened. As a result our study would have reached a wider population. Including a wider population may also have prevented the ceiling effect we observed with respect to shared decision making of people with dementia and competence of the family caregiver.

We did not completely follow the medical research council guidance for the development and evaluation of complex interventions which is a limitation of our research. This guidance advises to conduct a pilot testing phase after an intervention has been developed. (59, 60) A pilot test might have shown us for example that the presentation of a former family caregiver, which was part of the educational intervention, did not provide sufficient information on the complexity of caring for someone with dementia. We then could have adapted the intervention accordingly.

The medical research guidance also advises to combine qualitative and quantitative data when evaluating a complex intervention. (59, 60) Although we collected qualitative and quantitative data with respect to people with dementia and their family caregivers, no qualitative data was collected from general practitioners. We did not collect qualitative data because we did not want to burden general practitioners.

However, interviewing a selective sample could have provided information on: 1) The discrepancy between advance care planning conversations documented in the medical files and reported by general practitioners in the questionnaire used in the process evaluation. 2) Why some general practitioners did not conduct or document advance care planning. 3) Why some advance care planning conversations were stressful for some people with dementia and their family caregivers according to the general practitioners.

Implications for daily practice

In daily practice there should be a shift from reactive to proactive care. In an early disease stage, general practitioners should take the initiative and focus on meeting those care needs which matter most, try to anticipate on future problems and allow people with dementia and their family caregivers to participate in planning future care. (1, 2, 67-69)

General practitioners however experience barriers to advance care planning. (1, 2, 70) To overcome these barriers and achieve the shift mentioned above, we advise to structurally train more general practitioners. (1, 28, 34, 67, 71-73). However, our training was time consuming and expensive which may limit a wide implementation. We do believe however that the interactive components and the small group of participants are imperative to the educational intervention's effects. (28) Larger groups, less opportunities to practice conversations and the exclusion of training actors is therefore undesirable. Hence we advise to also include dementia specific advance care planning in the general practitioners curriculum. As general advance care planning is already included, this seems feasible and cost-effective. (74) A collaboration with the nurses curriculum would thereby even better align with the needs of daily practice.

Although training general practitioners in advance care planning is an important step, it is probably insufficient to reach a sustainable change in daily practice. Some general practitioners consider advance care planning too time consuming and outside their professional remit. (1, 2) Reallocation of tasks between the practice nurses and general practitioners may, at least partly, solve this problem. Practice nurses are able to have regular face to face contact, develop trusting relationships, identify healthcare needs, discuss and review care plans and coordinate care. (1, 2, 9, 71, 72, 75-77) We therefore believe that, especially during those stages of advance care planning where the psychological, existential and social care needs are discussed, the practice nurse can play an important role. Medical decisions however still have to be discussed and decided upon by the general practitioner. In addition, discussing palliative care in dementia can be emotionally burdensome for healthcare professionals. (78)

Shared decision making and thereby advance care planning should thus be a team effort by which the general practitioner and practice nurse share responsibilities, support each other and reallocate tasks in such a manner that it complies with daily practice. (62, 63) Given the above, we disagree with other studies which suggest that healthcare professionals solely trained in advance care planning and not having a long-standing relationship with the patient should conduct advance care planning conversations. (10, 26, 79).

Lastly, advance care planning should be documented and at least evaluated annually. (1, 2) In those cases where the condition of the person with dementia changes or when a crisis occurs, more frequent evaluation may be necessary. Using specific care plans which contain goals and describe how and when these goals are met could help in this regard. (80)

Implications for future research

The process of advance care planning probably takes more than six months to have any effect on goal concordant care, quality of life and family caregiver's competence. Also, advance are planning mostly affects the level of competence of those family caregiver's who feel most burdened. (57) Therefore longitudinal research, including a large, broad sample of people with dementia and family caregivers is needed.

With respect to measuring health related quality of life, new questionnaires should be developed which include non-medical aspects related to positive and social health. In these questionnaires it should be possible for people with dementia to indicate which aspects of quality of life are most important to them personally. As a result an individualized weighing system can be created which allows for a more accurate and person centred assessment. (47) Because it is difficult for people with dementia to remember recent events and feelings, it would be beneficial to administer several questionnaires during a certain time period. This opposed to using a measurement at one point in time which refers to a preceding period.

More research is also needed on the right timing to starts advance care planning. It would thereby be useful to gain more knowledge on variables (e.g. readiness to engage in planning, time since diagnosis, cultural differences, age, gender, comorbidity) which may affect the right timing. (81, 82) The use of "tools", for example: the conversation help (de Gesprekshulp); the conversation guide dementia (Gesprekswijzer dementie); Talk about forgetting (Spreken over vergeten), which may help people with dementia and their family caregivers to initiate advance care planning and prepare them for such conversations should also be researched further. (83-85) This could help to initiate advance care planning with as many people with dementia and their family caregivers, as person centred as possible.

In future research other methods to determine if advance care planning took place and how and which preferences were discussed, as opposed to or in combination with using medical file documentation, should be considered.

Medical performance does not always comply with medical record data. (86, 87) This was also illustrated in chapter 5 where we showed a discrepancy between the number of documented and self-reported advance care planning conversations. (34)

For general practitioners it is challenging to covert details of such advance care planning onto paper and they prefer to verbally communicate advance care planning discussions to their co-workers. (87) In addition, according to some family carers advance care planning was stressful, not feasible and provided no opportunity for shared decision making. (34) This may be caused by general practitioners who did not tailor advance care planning to the needs of the person with dementia and family caregiver (e.g. building a good relation, taking time, a timely start etc.). (1, 2)

In future research, using specific advance care planning registrations forms and interviewing general practitioners, people with dementia and their family caregivers soon after a consultation where preferences for future care were discussed, could help to determine more precisely if and how advance care planning interventions occurred. When using registration forms these should, as advised by Mariana et al. (2018), adhere to international standards and address medical, physical and psychological needs; include a problem statement and goals of care; include specific interventions; specify the measurements and a time table; be developed and implemented with respect to the values of the person with dementia and their family caregiver. (80) This aligns with a project recently started by the Dutch integral cancer centre (Integraal Kankercentrum Nederland) were personalized plans are developed and updated with patients and healthcare professionals. (88)

Using video recordings, audio recordings or interviews could thereby provide additional information on actual medical performance as opposed to documented data and might provide insights on why advance care planning was sometimes negatively experienced. (89, 90) Since these are rigorous and time consuming research methods, the feasibility is however of some concern.

Longitudinal research is also needed to determine if advance care planning indeed leads to more care consistent with goals. Properly measuring goals concordant care is only possible if healthcare professionals register all advance care planning outcomes and when these outcomes are available to all healthcare professionals working in primary and secondary healthcare. Moreover, as advance care planning is a cyclic process in which care preferences change, longitudinal studies should incorporate updated preferences. (41)

If preferences change when time passes, all involved healthcare professionals should be notified. Furthermore, the time frame should be considered as goal concordant care does not only pertain end of life preferences. (41)

Using survey's with family caregivers of people with dementia may also be a possibility to assess if care provided aligned with someone's preferences. However after death of the person with dementia, the right timing to obtain reliable data without causing stress is unknown and should be researched further. (41, 91)

Conclusions

Advance care planning by general practitioners is an important step to engage people with dementia and family caregivers in shaping future care. The research presented in this thesis aimed to determine the effectiveness of training general practitioners in initiating advance care planning. Here we present the main conclusions for each research question:

What are the facilitators and barriers for initiating advance care planning with people with dementia by general practitioners?

- In primary care, there should be a shift form reactive to proactive person centred care. Initiating advance care planning is an important step in providing such care. Advance care planning should start timely. People with dementia and their family caregivers should be given time to get used to the dementia diagnosis and be ready before preferences for future care can be discussed. However, advance care planning should not start too late in the disease trajectory, because then the capacity of the person with dementia will hamper active involvement in decision making.
- Including medical and non-medical preferences in advance care planning is consistent with the needs of people with dementia and their family caregivers. This approach is consistent with recent models of shared decision making, the concept of positive health (including social health), health care policies aimed to maintain quality of life and the broad view on advance care planning which includes the physical, psychosocial and spiritual domains.

What are the effects of an educational intervention aimed at initiating and optimizing advance care planning with people with dementia by their general practitioners?

- Our educational intervention stimulates and improves advance care planning by general practitioners and their practice nurses. Training general practitioners seems an important first step to provide timely proactive person centred care.
- Longitudinal research including a large and broad sample of participants and innovative research methods are needed to determine if advance care planning with people with dementia leads to: care provided consistent with preferences; the effects on quality of life; the effects on shared decision making; the effects on experienced level of competence of family caregivers.

What are the educational intervention's successful components and what could be improved?

- The educational intervention is consistent with the needs of general practitioners, people with dementia and family caregivers. Pilot testing and using qualitative data of general practitioners to evaluate the educational intervention may have provided information to further enhance the intervention.
- More general practitioners have to be trained in proactively engaging people with dementia and their family caregivers in advance care planning including the discussion of medical and non-medical preferences.

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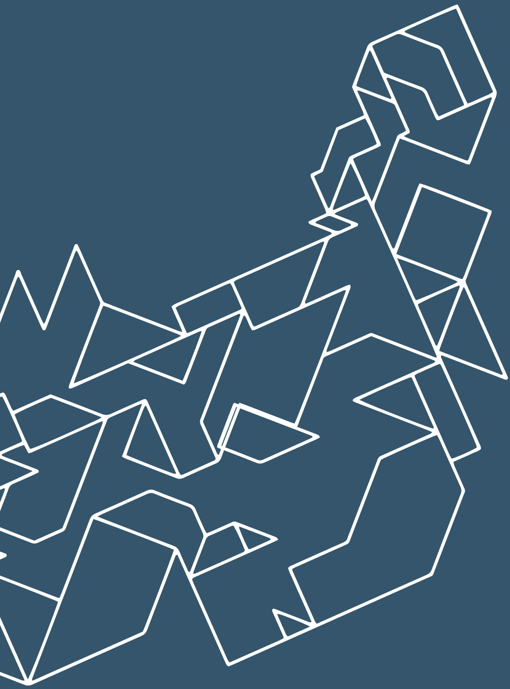

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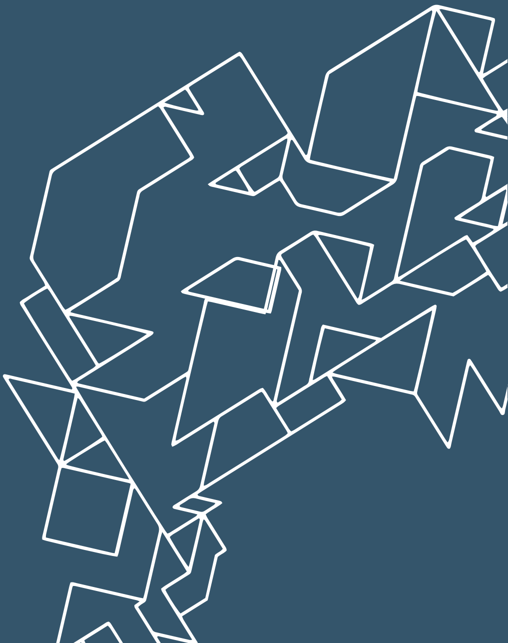
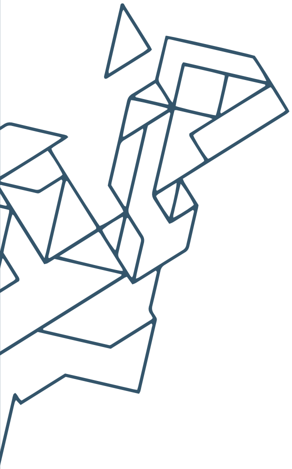


Chapter 7

Summary, Samenvatting, Data management, Portfolio, Curriculum vitae, Publication list, Proefschriftenlijst RAC, Dankwoord



Summary

In *chapter 1*, the background and aims of this thesis are described. Dementia is a chronic, life limiting disease with a high burden. The most common symptoms are related to a progressive decline in memory and thinking. For dementia no cure is foreseen in the near future and personalized palliative care is advised. Hence, people with dementia should be offered to discuss preferences for future care.

In advance care planning, future care preferences are assessed in a timely and cyclic manner with patients, loved ones and healthcare professionals. Together they decide on options for future treatment and care and document these if necessary. General practitioners seem best suited to initiate advance care planning since they are mostly involved early in the disease process and know their patients and context well. In primary care however, advance care planning with people with dementia seldom takes place.

Therefore the aim of this thesis was to develop and evaluate an educational intervention aimed to stimulate and optimize advance care planning by general practitioners with people with dementia. To reach our aim the following research questions were answered:

4. What are the facilitators and barriers for initiating advance care planning with people with dementia by general practitioners?
5. What are the effects of an educational intervention aimed at initiating and optimizing advance care planning with people with dementia by their general practitioners?
6. What are the educational intervention's successful components and what could be improved?

In *chapter 2* we identified facilitators and barriers for general practitioners for advance care planning with people with dementia. To reach this aim we conducted an integrative review. We searched Medline, Embase, Psychinfo, Cinahl and the Cochrane library databases and used the mixed methods appraisal tool for quality assessment. Data was analysed using qualitative content analysis.

Four themes were derived: timely initiation of advance care planning, stakeholder engagement, important aspects of advance care planning, and prerequisites for advance care planning. Barriers were: uncertainty about the right timing, how to plan for an uncertain future, lack of knowledge about dementia, difficulties assessing people with dementia's decisional capacities, and changing preferences. Facilitators were: an early start when cognitive decline is still mild, inclusion of all stakeholders, and discussing social and medical issues aimed at maintaining normal life.

We concluded that advance care planning in dementia should focus on improving and maintaining quality of life people with dementia, instead of end-of-life-discussions only. Training general practitioners to timely initiate advance care planning is needed.

In *chapter 3* we focussed on the knowledge gaps left by the integrative review. For this we conducted a qualitative study on barriers and facilitators for advance care planning with people with dementia.

Face to face interviews with community dwelling people with dementia and their family caregivers, interviews by telephone with general practitioners, and a focus group with case managers and practice nurses, were conducted. All interviews were analysed using qualitative content analysis.

Three themes were derived: development of a trust-based relationship, characteristics of advance care planning and the primary care setting. Facilitators were: a trustful relationship between the person with dementia/family caregiver and the general practitioner, home visits, and addressing medical and non-medical issues. Barriers were: postponing advance care planning until problems arise, general practitioners' time restraints, concerns about the documentation and availability of advance care planning outcomes.

We concluded that a trustful relationship, discussing both medical and non-medical issues, and reallocation of tasks between the case manager or practice nurse and the general practitioner may help to overcome the main barriers.

In *chapter 4*, using a single blinded cluster randomized controlled trail, we aimed to determine the effects of an educational intervention for training general practitioners in timely advance care planning with people with dementia.

The participating general practitioners included persons with dementia before randomisation took place. 19 general practitioners were trained using role-playing exercises. 19 general practitioners provided usual care and did not receive training. The primary outcome was: the proportion of people with dementia that had at least one advance care planning conversation documented in their medical file. Key secondary outcomes were the number of medical (i.e. resuscitation, hospital admission) and non-medical (i.e. activities, social contacts) preferences discussed. We also assessed: quality of life and shared decision making of people with dementia, healthcare costs and competence of the family caregiver. At six months follow up, intervention effects were determined using random effect logistics and linear models with correction for general practitioners clustering.

General practitioners in the intervention group initiated advance care planning with 35 people with dementia (49.3%). General practitioners in the control group initiated advance care planning with 9 people with dementia (13.9%) (OR=1.99; p=0.002). General practitioners in the intervention group discussed 0.8 more medical (95% CI = 0.3-1.3, p=0.003) and 1.5 more non-medical (95% CI = 0.8-2.3, p<0.001) preferences per person with dementia than general practitioners in the control group. The educational intervention showed no effect on quality of life and shared decision making of people with dementia, healthcare costs or the competence of the family caregiver.

We concluded that the educational intervention has the potential to better align future care of people with dementia with their preferences. Because of the relatively short follow-up, the general practitioners' long-term adoption remains unknown.

In *chapter 5* we conducted a process evaluation according to the Medical Research Council guidance and aimed to determine the educational intervention's successful components and what could be improved. We focussed on educational intervention's implementation and mechanisms of impact.

For implementation we focussed on reach and acceptability and used the following data: descriptive analyses of participant‘s characteristics; selection, inclusion and intervention attendance; intervention's valuation; a general practitioner post-intervention survey on initiating advance care planning; content analyses of a post intervention focus group with trainers of the intervention.

For the mechanisms of impact we focussed on adoption and appropriateness. For this the following data was used: a general practitioner post-intervention survey on conducting advance care planning; advance care planning documented in the medical files of people with dementia; questionnaires on quality of life and shared decision making of people with dementia, and family caregivers' competence; content analysis of post-intervention interviews with people with dementia/ family caregivers dyads. All data was used to identify contextual factors.

We showed that the intervention was implemented with a small percentage of Dutch general practitioners. They mostly included people with dementia and family caregiver dyads who were motivated and experienced relatively little burden, and people with dementia with limited cognitive decline. The mechanisms of impact were: interactively learning to initiate ACP with training actors with a heterogeneous group of participants. Dyads stated that discussing non-medical preferences was essential for their quality of life and improved shared decision making. Some dyads however found advance care planning stressful and not feasible. Younger female general practitioners more often initiated advance care planning and men with mild dementia more often had advance care planning. These characteristics and the safe and intimate setting were important contextual factors.

We concluded that interventions aimed at improving advance care planning should include interactive components and the discussion of non-medical preferences, in a heterogeneous group and safe environment. However, in daily practice not all dyads seemed ready to participate. Therefore it is necessary to regularly check their willingness before advance care planning is started.

Chapter 6 provides the discussion of the main findings against the background of recent literature and daily practice. The research done in this thesis showed that a proactive approach regarding advance care planning, in which medical and non-medical preferences are discussed, is consistent with the needs of most people with dementia and their family caregivers, recent research on this topic, the concept of positive health, and Dutch healthcare policies and guidelines.

We discussed our outcome measures for effective advance care planning and concluded that, although preferences discussed and documented are important for the process of advance care planning, these discussions should eventually lead to care provided in accordance to someone's preferences and an improvement of quality of life. However, to measure such effects, more research, including a broader and larger sample of participants with longer follow up, is needed. With regard to measuring quality of life, more research on how assessments can be made more person-centred is needed as well.

For daily practice we advised to train more general practitioners in proactive person-centred advance care planning including medical and non-medical preferences. To make this approach sustainable, tasks related to advance care planning can be reallocated between the general practitioner and the practice nurse. Since some people with dementia found advance care planning stressful, their willingness and capabilities to engage in this process should be checked before discussions on future care can start.

Samenvatting

In *hoofdstuk 1* worden de achtergrond en doelstellingen van dit proefschrift beschreven. Dementie is een chronische en levensbedreigende ziekte met een grote ziektelast. De meest voorkomende symptomen zijn gerelateerd aan een progressieve achteruitgang van het geheugen en het denkvermogen. Omdat dementie nog niet te genezen is, wordt gepersonaliseerde palliatieve zorg geadviseerd.

Door middel van advance care planning worden voorkeuren voor toekomstige zorg tijdig en cyclisch besproken met patiënten, naasten en gezondheidzorgprofessionals. Zij beslissen samen welke zorg het beste bij hen past. Deze beslissingen worden, in dien nodig, gedocumenteerd. Omdat huisartsen meestal vroeg betrokken zijn bij het ziekteproces van de patiënt en de persoonlijke situatie goed kenen, lijken zij geschikte zorgprofessionals om advance care planning te initiëren. In de eerste lijn vindt advance care planning met mensen met dementie echter zelden plaats. Daarom is het doel van dit proefschrift het ontwikkelen en evalueren van een educatieve interventie gericht op het stimuleren en optimaliseren van advance care planning met mensen met dementie. Om dit doel te bereiken zullen de volgende onderzoeksvragen worden beantwoord:

1. Wat zijn de belemmerende en bevorderende factoren voor huisartsen met betrekking tot advance care planning met mensen met dementie?
2. Wat zijn de effecten van een educatieve interventie voor huisartsen gericht op het initiëren en optimaliseren van advance care planning met mensen met dementie?
3. Wat zijn succesvolle componenten van de educatieve interventie en wat kan er worden verbeterd?

In *hoofdstuk 2* worden de door huisartsen ervaren belemmerende en bevorderende factoren van advance care planning met mensen met dementie beschreven. Hiervoor hebben we een integratieve review uitgevoerd. De Medline, Embase, Psychinfo, Cinahl en de Cochrane databases werden doorzocht en de kwaliteit van de geselecteerde artikelen werd bepaald met behulp van de Mixed Method Appraisal Tool. Vervolgens werden de artikelen geanalyseerd met kwalitatieve content analyse.

Uit de analyse kwamen vier thema’s naar voren: het tijdig initiëren van advance care planning, het betrekken van alle stakeholders, belangrijke aspecten van advance care planning en randvoorwaarden voor advance care planning. De belangrijkste belemmerende factoren waren: onzekerheid over de juiste timing, het maken van een plan ondanks een onzekere toekomst, een gebrek aan kennis over dementie, het bepalen van de wilsbekwaamheid en veranderende voorkeuren van mensen met dementie.

De belangrijkste bevorderende factoren waren: een vroege start van advance care planning, een goede relatie met alle stakeholders, het bespreken van medische en niet-medische onderwerpen gericht op het behoud van een normaal leven.

We hebben geconcludeerd dat advance care planning zich moet richten op het verbeteren of behouden van de kwaliteit van leven van mensen met dementie en niet alleen op onderwerpen gerelateerd aan het einde van het leven. Het is noodzakelijk om huisartsen te trainen in het tijdig initiëren van advance care planning.

In *hoofdstuk 3* worden de door huisartsen ervaren belemmerende en bevorderende factoren van advance care planning met mensen met dementie beschreven. We hebben ons specifiek gericht op die factoren die nog niet geheel duidelijk waren of ontbraken na het uitvoeren van de integratieve review. We hebben interviews met mensen met dementie en hun naasten, interviews met huisartsen en een focusgroep met casemanagers en praktijkondersteuners gehouden. Alle interviews werden geanalyseerd met kwalitatieve content analyse.

Uit de analyse kwamen drie thema’s naar voren: het belang van relaties gebaseerd op vertrouwen, kenmerken van advance care planning, en de eerste lijns-gezondheidszorg. De belangrijkste bevorderende factoren waren: relaties gebaseerd op vertrouwen tussen de persoon met dementie, de naaste en de huisarts, het houden van huisbezoeken door de huisarts en het bespreken van medische en niet-medische onderwerpen. De belangrijkste belemmerende factoren waren: het uitstellen van advance care planning totdat problemen zich voordoen, de beperkte beschikbare tijd van huisartsen, zorgen over het documenteren en de beschikbaarheid van uitkomsten van advance care planning.

We hebben geconcludeerd dat relaties gebaseerd op vertrouwen, het bespreken van medische en niet-medische onderwerpen, en het herverdelen van taken tussen de huisarts en de praktijkondersteuner of casemanager, kan helpen om de belemmerende factoren te overwinnen.

In *hoofdstuk 4* wordt een enkel blind cluster gerandomiseerd onderzoek beschreven. Dit onderzoek had als doel de effecten te bepalen van de educatieve interventie gericht op het trainen van huisartsen in het tijdig initiëren en optimaliseren van advance care planning met mensen met dementie.

De deelnemende huisartsen hebben mensen met dementie voor de randomisatie geïncludeerd. Negentien huisartsen werden interactief getraind in a5vance care planning met behulp van acteurs en rollenspellen. Negentien huisartsen werden niet getraind. De primaire uitkomstmaat was: de proportie mensen met dementie waarbij ten minste één advance care planningsgesprek was gedocumenteerd in het medisch dossier. De belangrijkste secundaire uitkomstmaten waren: de aantallen gedocumenteerde medische (b.v. reanimatie, ziekenhuisopname) en niet-medische (b.v. activiteiten, sociale contacten) voorkeuren in de medische dossiers van mensen met dementie. We hebben ook kwaliteit van leven, gezamenlijke besluitvorming zoals ervaren door de persoon met dementie, de competentie zoals ervaren door de naaste, en de kosten van het gezondheidszorggebruik gemeten. Na zes maanden werden de effecten van de interventie op deze uitkomstmaten bepaald door logistische en lineaire regressie analyses met correcties voor clustering.
Huisartsen uit de interventie groep initieerden advance care planning met 35 mensen met dementie (49,3%). Huisartsen uit de controle groep initieerde advance care planning met 9 mensen met dementie (13,9%) (OR=1.99; p=0.002). Huisartsen uit de interventie groep bespraken 0,8 medische voorkeuren meer (95% CI = 0.3-1.3, p=0.003) en 1,5 niet-medische voorkeuren meer met mensen met dementie (95% CI = 0.8-2.3, p<0.001). De interventie had geen effect op de kwaliteit van leven, de gezamenlijke besluitvorming zoals ervaren door de persoon met dementie, de competentie zoals ervaren door de naaste en de kosten van de gezondheidszorg.

We hebben geconcludeerd dat de educatieve interventie toekomstige zorg voor mensen met dementie meer in overeenstemming kan brengen met hun voorkeuren. Vanwege de relatief korte follow-up zijn de lange termijn uitkomsten van onze interventie onbekend.

In *hoofdstuk 5* wordt een procesevaluatie, uitgevoerd volgens de richtlijnen van de Medische Onderzoeksraad (Medical Research Council guidance), beschreven. Het doel van deze evaluatie was het bepalen van succesvolle elementen en verbeterpunten van de interventie. We hebben ons specifiek gericht op de implementatie en mechanismen met impact.

Met betrekking tot de implementatie hebben we ons gericht op het bereik van de interventie en of deze acceptabel werd gevonden. Hiervoor werd de volgende data gebruikt: karakteristieken van de deelnemers; gegevens over selectie, inclusie en aanwezigheid bij de educatieve interventie; de evaluatie van de interventie door huisartsen en praktijkondersteuners; een vragenlijst over het initiëren van advance care planning afgenomen bij huisartsen na de interventie, een focusgroep met trainers van de interventie.

Met betrekking tot de mechanismen met impact hebben we ons gericht op de geschiktheid en de toepassing van de interventie. Hiervoor werd de volgende data gebruikt: een vragenlijst over het toepassen van advance care planning in de dagelijkse praktijk afgenomen bij huisartsen na de interventie; advance care planning zoals gedocumenteerd in het medisch dossier van de persoon met dementie; vragenlijsten over kwaliteit van leven en gezamenlijke besluitvorming van mensen met dementie; een vragenlijst over de competentie zoals ervaren door de mantelzorger; interviews met mensen met dementie en hun naasten afgenomen na de interventie. Alle data werd ook gebruikt voor het bepalen van belangrijke contextuele factoren van de interventie.

De resultaten van de procesevaluatie lieten zien dat de interventie is geïmplementeerd bij een klein percentage van de Nederlandse huisartsen. Zij hebben met name mensen met dementie en naasten geïncludeerd die gemotiveerd waren en relatief weinig last ervaarden van de dementie. Ook hebben zij met name mensen met dementie met beperkte cognitieve achteruitgang geïncludeerd. De elementen met de grootste impact waren het interactief leren hoe advance care planning kan worden geïnitieerd in een heterogene groep met trainingsacteurs. Mensen met dementie en hun naasten gaven aan dat het bespreken van niet medische voorkeuren essentieel was voor hun kwaliteit van leven en dat dit de gezamenlijke besluitvorming bevorderde. Sommige mensen met dementie en hun naasten vonden echter dat advance care planning stressvol en niet haalbaar was. Daarnaast bleken leeftijd en geslacht belangrijke contextuele factoren. Jonge vrouwelijke huisartsen initieerde advance care planning vaker en mannen met milde dementie namen vaker deel aan advance care planning.

We hebben geconcludeerd dat educatieve interventies, met als doel het bevorderen van advance care planning, interactieve componenten moeten bevatten. Deze kunnen het beste plaats vinden in een heterogene groep en een veilige omgeving. In de dagelijkse praktijk blijken niet alle mensen met dementie en hun mantelzorgers klaar voor advance care planning. Hulpverleners moeten daarom regelmatig controleren of zij hier aan toe zijn.

In *hoofdstuk 6* worden de belangrijkste bevindingen van dit proefschrift bediscussieerd in het licht van de meest recente literatuur en de dagelijkse praktijk. Dit proefschrift laat zien dat dat een proactieve benadering met betrekking tot advance care planning, waarbij zowel medische als niet medische voorkeuren worden besproken, in overeenstemming is met de behoeften van mensen met dementie en hun naasten, recente literatuur, het concept sociale gezondheid en het Nederlandse gezondheidszorgbeleid.

Met betrekking tot de gebruikte uitkomstmaten voor advance care planning concludeerden wij het volgende. Hoewel gedocumenteerde voorkeuren in het medisch dossier belangrijk zijn voor het proces van advance care planning, moeten deze gesprekken uiteindelijk ook leiden tot een verbetering van de kwaliteit van leven en zorg die in overeenstemming is met iemands voorkeuren. Voor het adequaat meten van dergelijke effecten is echter meer onderzoek met een bredere onderzoekspopulatie en een langere follow-up nodig. Daarnaast is voor het adequaat meten van het effect van advance care planning op de kwaliteit van leven aanvullend onderzoek nodig naar meer gepersonaliseerde meetinstrumenten.

Voor de dagelijkse praktijk adviseren wij om meer huisartsen te trainen in proactieve gepersonaliseerde advance care planning waarbij zowel medische als niet medische voorkeuren worden besproken. Om een dergelijke benadering toekomstbestendig te maken, is het noodzakelijk om taken te verdelen tussen de huisarts en de praktijkondersteuner. Omdat mensen met dementie advance care planning soms stressvol vinden moeten hun capaciteiten en motivatie om aan dit proces deel te nemen worden besproken voordat gesprekken over toekomstige zorg kunnen worden gestart.

Data management

This study involves human participants and is conducted in accordance with the principles of the Declaration of Helsinki. The medical and ethical review board committee on research involving human subjects form the region Arnhem and Nijmegen, the Netherlands, has approved to conduct this study. The data management plan was approved by the Radboudumc Clinical Research Centre Nijmegen.

All data concerning this project is stored on the Radboudumc server: (\\Umcfs006\iqhdata$\Sectie2_HIC\Decidem_Data). This protected folder can only be accessed by the investigator (Bram Tilburgs) and a research assistant of IQ Healthcare. The paper data is stored in locked closet in room M245-1.030B of the Radboudumc.

We used paper teleform questionnaires of people with dementia and family caregivers, medical files of people with dementia and interviews with stakeholder to collect data. After validation, data from the teleform questionnaires was transferred to SPSS. Data from the patient medical files was entered into Microsoft Access, validated and then transferred to SPSS. The interviews were audiotaped and transcribed verbatim. The privacy of all study participants was assured by using unique individual subject codes. Name and address data was stored separately from the study data.

With regard to the quantitative data: alterations to the raw data files were registered, including the reason for altering the data. These altered files were then stored under a different file name on the protected Radboudumc server. After data cleaning, the audit trail was locked as an PDF file and stored on the protected Radboudumc server.

All data will be stored for 15 years after termination of the study (December 31, 2018). Patient data can only be used in future research after renewed permission by the study participants as recorded in the informed consent. The data sets are only available from the corresponding author on reasonable request.

Institute for Health Sciences
Radboudumc

PHD Portfolio

Name PhD candidate: B. Tilburgs
Department: IQ Healthcare
Graduate School: Radboud Institute for Health Sciences

PhD period: 01-01-2015 – 02-07-2020
Promotors: Prof. M.J.F.J. Vernooij-Dassen; Prof. R.T.C.M. Koopmans; Prof. Y.M.P. Engels
Co-promotor(s): Dr M. Perry

TRAINING ACTIVITIES

a) Courses & Workshops	Year(s)	ECTS
- RIHS Introduction Course for PhD candidates, Radboudumc, Nijmegen	2015	1.5
- Kwalitatief interviewen, Evers Research & Trainingen, Erasmus Universiteit, Rotterdam,	2015	1.5
- Basiscursus regelgeving en Organisatie voor klinisch onderzoekers, Dutch Federation of University Medical Centres	2015	1.5
- Atlas.Ti, IQ Healthcare, Radboudumc, Nijmegen	2015	0.5
- Qualitative Research Methods in Healthcare (CARE), IQ Healthcare, Radboudumc, Nijmegen	2015	1.5
- Academic writing for PhD candidates, Radboud University, Nijmegen	2015	1.5
- Opfriscursus statistiek voor promovendi, Radboud University, Nijmegen	2016	1.5
- MRC framework and theory of change, Interdem Academy, Maastricht (2016)	2016	1.5
- Advanced conversation, Radboud University, Nijmegen	2017	1.5
- Scientific integrity, Radboud University, Nijmegen	2017	1.5
- Implementatie in de gezondheidszorg, IQ Healthcare, Radboudumc, Nijmegen	2017	1.5
- Presentation Skills, Radboud University, Nijmegen	2017	1.5
- Multilevel analyse, EpidM, VU medisch centrum, Amsterdam	2017	1.5
- Economische evaluaties van medische interventies, META, Leuven	2017	1.5
- Evidence Based Practice, Cochrane Netherlands, Utrecht	2018	1.5
- Herregistratie Basiscursus Regelgeving en Organisatie voor klinisch onderzoekers, Dutch Federation of University Medical Centres	2018	0.2

b) Symposia & congresses		
- ACPEL Conference, “Key to Patient-Centred Care”, Munich, Germany	2015	0.5
- Alzheimer Europe Conference “Excellence in dementia research and care”, Copenhagen, Denmark	2016	0.5
- Alzheimer Europe Conference “Care today, cure tomorrow”, Berlin, Germany	2017	0.5
- World Congress of the EAPC, Berlin, Germany	2018	0.5
- Nederlands-Vlaamse Wetenschapsdagen Palliatieve zorg, Amsterdam, The Netherlands	2018	0.5
- Alzheimer Europe Conference “Making valuable connections”, The Hague, The Netherlands	2019	0.5

Radboud Universiteit Radboudumc

c) Oral and poster presentation at International events	Year(s)	ECTS
- "Advance care planning for persons with dementia in primary care: an integrative review", Alzheimer Europe, Copenhagen, Denmark	2016	0.5
- "Identifying barriers and facilitators for the implementation of Advanced Care Planning regarding people with dementia in primary care: a qualitative study." Alzheimer Europe, Copenhagen, Denmark	2016	0.5
- "Barriers and Facilitators for general practitioners Dementia Advance Care Planning: A Systematic Integrative Review" EAPC, Bern, Switzerland	2018	0.5
- "Training General Practitioners in Initiating Advance Care Planning in Dementia Care, Results of a Randomized Controlled Trail" EAPC, Bern, Switzerland	2018	0.5
- "Training General Practitioners in Initiating Advance Care Planning in Dementia Care, Results of a Randomized Controlled Trail" Interdem, Alzheimer Europe, The Hague, The Netherlands	2019	0.5
d) Oral and poster presentation at national events		
- "Het bevorderen van anticiperende zorgplanning met mensen met dementie door de huisarts: resultaten van een gerandomiseerd onderzoek met een controlegroep", Nederlandse-Vlaamse wetenschapsdagen, Amsterdam	2018	0.25
- "Anticiperende zorgplanning met mensen met dementie door de huisarts: een integratieve review naar de bevorderende en belemmerende factoren", Vlaams Nederlandse wetenschapsdagen, Amsterdam	2018	0.25
e) Other		
- Palliatieve zorg en dementie, IQ Healthcare, Radboudumc, Nijmegen	2015 - 2018	1,0
- Guest editor, BMC palliative care	2018	0.1
TEACHING ACTIVITIES		
f) Lecturing		
- "Euthanasia in dementia patients", Honours Academy, Radboud University, Nijmegen	2018	2.0
- "Professionaliteit en coaching", 1st and 2nd year medical students", Radboud Health Academy, Nijmegen	2016 - 2019	20
g) Supervision of internships / other		
- 4 medical master students, Radboud Health Academy, Nijmegen	2016 - 2017	2.0
TOTAL		**55,7**

Curriculum vitae

Bram Tilburgs was born on the 22nd of December 1977 in Arnhem, the Netherlands. In 1995 he graduated from the HAVO at the Thomas a Kempis College in Arnhem and started a study in Nursing at the University of Applied Sciences of Arnhem and Nijmegen.

After his graduation in 1999, Bram worked as a nurse on a surgical ward in the Canisius Wilhelmina Hospital in Nijmegen, the Netherlands. In 2001 he started his intensive care training in the Radboudumc in Nijmegen, the Netherlands. In 2003 he completed this training and worked as an intensive care nurse in the Radboudumc in NIjmegen until the end of 2018.

In 2005, while working as an intensive care nurse, Bram started studying health psychology at the Open University in Heerlen, the Netherlands. His master's thesis was about the relation between social support, anxiety, post-traumatic stress and quality of life of former intensive care patients. He was supervised by dr. M. Nijkamp and dr. E. Bakker. In 2013 he completed his masters in health psychology.

Bram began as a PhD student at the department of IQ healthcare of the Radboudumc in 2015. His research project was about advance care planning with people with dementia by general practitioners. During his PhD, he was supervised by prof. dr. M.J.F.J. Vernooij-Dassen, prof. dr. R.T.C.M. Koopmans, prof. dr. Y.M.P. Engels and dr. M. Perry.

In 2019, while finishing his PhD, he started working as researcher at the department of Public Health and Primary Care (PHEG) of the Leiden University Medical Centre, the Netherlands. There he studies different approaches to advance care planning for people with dementia in primary care under the supervision of dr. ir. J.T. van der Steen and prof. dr. W.P. Achterberg. In the same year he also started working at the department of Process Improvement and Innovation of the Radboudumc, the Netherlands. Here he worked in the support team person centred care until the end of 2019.

Since January 2020, Bram is working as a researcher at the intensive care department of the Radboudumc, the Netherlands. There, under the supervision of dr. M. van den Boogaard, his research focusses on delirium, long term consequences of an intensive care admission and the work environment of intensive care nurses.

Bram lives together with his lovely wife (Inge) and children (Sam and Romijn) in Arnhem, The Netherlands.

Publication list

Thesis:

Tilburgs B, Vernooij-Dassen M, Koopmans R, van Gennip H, Engels Y, Perry M. Barriers and facilitators for GPs in dementia advance care planning: A systematic integrative review. PLOS ONE. 2018;13(6):e0198535.

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