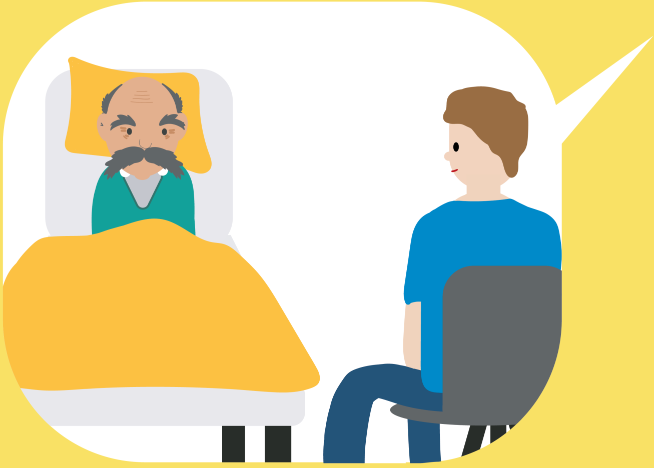
ADVANCE CARE PLANNING, DEMENTIA AND NURSING HOMES

Annelien E. Wendrich-van Dael



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Annelien Esther Wendrich-van Dael

Proefschrift ingediend met het oog op het behalen van de graad van doctor in de Medische Wetenschappen
Geneeskunde en Farmacie
Vrije Universiteit Brussel (VUB)
Maart 2021

The work presented here was carried out as part of the Marie Curie Innovative Training Network (ITN) action, H2020-MSCA-ITN-2015, under grant agreement number 676265.

Illustraties: Lotte Wendrich, www.papieravonturen.nl
Project logo ontwerp: Stijn Van Nuffelen

2021 Uitgeverij VUBPRESS Brussels University Press
VUBPRESS is an imprint of ASP nv (Academic & Scientific Publishers nv)
Keizerslaan 34
B-1000 Brussels
Tel. +32 (0)2 289 26 50
Fax +32 (0)2 289 26 59
E-mail: info@aspeditions.be
www.aspeditions.be
ISBN 978 94 6117 160 3
NUR 883
Legal deposit D/2021/11.161/075

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A. List of chapters

The chapters in this dissertation are based on the following articles.

Chapter 2.1

Wendrich-van Dael, A.E., Bunn, F., Lynch, J., Pivodic, L., Van den Block, L., & Goodman, C. (2020). *Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences.* International Journal of Nursing Studies, 107, 103576.
[2018 SCI impact factor 3.57; Ranking D1; ranking n°1 of 120 in NURSING in SCIE edition]

Chapter 2.2

Wendrich-van Dael, A.E., Pivodic, L., Cohen, J., Deliens, L., Van den Block, L. & Chambaere, K. (2019). *End-of-Life Decision Making for People Who Died of Dementia: A Mortality Follow-Back Study Comparing 1998, 2007, and 2013 in Flanders, Belgium.* J Am Med Dir Assoc, 20 (10), 1347-1349.
[2017 SCI impact factor 5.325; Ranking D1; ranking n°4 of 53 in GERIATRICS & GERONTOLOGY]

Chapter 2.3

Wendrich-van Dael, A.E., Pivodic, L., Smets, T., Deliens, L. & Van den Block, L.
Advance care planning among nursing home residents living with dementia: Results from two mortality follow-back studies (submitted)

Chapter 3.1

Wendrich-van Dael, A.E., Gilissen, J., Van Humbeeck, L., Deliens, L., Vander Stichele, R., Gastmans, C., Pivodic, L.* & Van den Block, L.*
Tools to support advance care planning conversations and documentation in nursing homes (submitted)

Chapter 3.2

Pivodic, L.*, Wendrich-van Dael, A.E.*., Gilissen,J., De Buyser, S., Deliens, L., Gastmans, C., Vander Stichele, R. & Van den Block, L.
Effects of a theory-based ACP intervention for nursing homes: a cluster randomized controlled trial (submitted)

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Wendrich-van Dael, A.E., Gilissen, J., Gastmans, C., Deliens, L., Vander Stichele, R., Pivodic, L.* & Van den Block, L.*
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*These authors contributed equally

B. Acknowledgements

Yes! Het is gelukt! Wat heerlijk dat er zoveel lieve mensen zijn die mij, op wat voor manier dan ook, hebben geholpen om deze rollercoaster heelhuids door te komen. Het was me het ritje wel!

Allereerst wil ik heel graag alle **woonzorgcentra** en hun bevlogen personeel bedanken voor deelname aan het VZP+ project! Bedankt om zo enthousiast met ons programma aan de slag te willen gaan en om jullie ervaringen met ons te delen. Een extra dikke merci aan **Harry** en **Katrien** om VZP+ handen en voeten te geven door er jullie aandacht en toewijding in te stoppen.

Lieve, bedankt voor het vertrouwen. Ik heb echt enorm veel van je geleerd en heb veel bewondering voor je passie voor onderzoek. Zoals ik schreef in de motivatie voor jouw VUB supervision award: 'Lieve is recht door zee en werkt hard. Ze legt de lat hoog en verwacht hetzelfde van haar studenten. Toch is er ruimte om fouten te maken en hiervan te leren en geeft Lieve complimenten, niet alleen als er dingen goed gaan, maar ook als ze ziet dat je hard werkt en je best doet.' Dat heb ik altijd zeer gewaardeerd. Naast inhoudelijke, heb ik je ook heel wat organisatorische hoofdbrekens bezorgd. Bedankt om je steeds weer in te zetten voor het optimaliseren van mijn work-life balance.

Lara, bedankt voor je oog voor detail, je kritische vragen en je scherpe pen. Ook jij merkte altijd op wat er nog beter kon, wat soms voelde als een stap achterwaarts, in plaats van voorwaarts, want 'weer terug naar de tekentafel', maar wat altijd leidde tot een veel beter eindproduct. Bedankt voor alle tips en trics die je me onderweg hebt meegegeven!

Joni, bedankt topper, zonder jou had ik het nooit gered! Ik heb enorm veel bewondering voor je enthousiasme en doorzettingsvermogen. Je was al bezig met het project toen ik om de hoek kwam piepen, maar je hebt me met open armen ontvangen en enthousiast je 'werkbaby' met mij gedeeld. Sorry dat ik jou en de werkbaby tot drie keer toe in de steek heb gelaten (twee keer voor mijn eigen babies en ook nog voor een 4mnd trip naar Engeland). Zalig dat we, ook toen je in de States zat, samen nog wat papers eruit konden knallen. Alle geluk met de glanzende carrière die zeker voor jou in het verschiet ligt, en natuurlijk ook als mama-to-be, je gaat dat fantastisch doen.

Aan alle **leden van de jury**, bedankt voor het kritisch doornemen van alle stukken in dit werk en voor de prikkelende vragen en discussie. Het was oprecht een genoegen!

Luc, Bob en Chris, bedankt voor het delen van jullie inzichten en de interessante discussies.

Kenneth, Joachim en Tinne, bedankt voor de samenwerking op 2 van de 6 papers uit dit doctoraat. Vooral aan Kenneth veel dank voor je geduld tijdens mij allereerste onzekere stapjes op het pad van artikels schrijven.

Frances, Jenni and Claire, and by extension the whole CRIPACC-team. Thank you for having me and for the most warm welcome you gave me.

A big thank you to all INDUCT members, for making this an unforgettable experience. Especially to **Frans, Marjolein, Inge and Fania** for organizing the INDUCT schools. All **INDUCT ESRs**, thank you for sharing this experience with me! Vooral **Rose** om mijn INDUCT maatje te zijn aan de VUB en samen met mij eens te diep zuchten over alle reports. En **Joeke**, omdat jij als mede mama-PhD als geen ander de struggles kent van het jongleren van alle taken.

Alle **ZrL-collega's**, bedankt voor de babbels, gezelligheid en support. **Geertje en Nadine**, bedankt om alles altijd gestroomlijnd te laten verlopen, en om ook te mogen komen aankloppen voor een babbeltje. In het bijzonder mijn roomies (**Kim DN, Else, Elisabeth, Rose, Romy, Julie, Veerle, Joni**

en Isabel) bedankt om te luisteren naar mijn gezucht en gesteun, mijn eindeloze verhalen over de kinderen en mijn onzekerheden. Ik heb jullie (en de dropjeskast) in het gekke corona-jaar echt gemist. Fijn dat jullie er waren!

Stefanie, bedankt voor je geduld en je fantastische uitleg over statistiek!

Alle **ZonMw collega's** binnen het cluster Palliatieve Zorg en binnen het cluster Ouderen, bedankt voor de support tijdens de laatste loodjes, die soms toch wel zwaar wogen. Ik hoop dat we elkaar in de toekomst wat vaker op kantoor kunnen treffen, in plaats van enkel vanachter een schermpje.

Alle **vrienden en vriendinnen**, soms wat dichterbij, soms wat verder weg, maar wat fijn dat jullie er zijn! In het bijzonder:

Lieve **Ysja**, dankjewel om altijd mijn hart bij je te mogen uitstorten, mijn beklag te mogen doen en te mogen opscheppen over de kindjes. Onze sauna-dates en de terrasjes hebben me er meer dan eens doorheen gesleept. **Marloes,** heerlijk dat jij ook nog steeds daarbij meewandelt.

Aisha & Daniël, Livia, Joëlle en Timeon, wanneer gaan we weer een weekendje met z'n allen op vakantie? Met jullie is het altijd feest ☺!

Dylan, Elena and Evert, thanks for all the support! As you all have been down this road, you know all about the ups and downs of PhD-life. Thank you for encouraging me not to give up.

Dames van de reisco (en natuurlijk ook **Arnaud, Elisa, Stef, Jim, Hannah en Thijs)**, hoe fijn dat we ondanks alle drukte en de afstand elkaar toch steeds weten te vinden. Heerlijk om te weten dat jullie er zijn om alle hoogte- en dieptepunten mee te beleven, om Disney-films te kijken en om nieuwe plaatsen te ontdekken. Ik kijk enorm uit naar ons volgende weekendje en alle weekendjes daarna!

Rianne (en Nico, Sofia en ook het kleine spruitje in ontwikkeling), hoe anders liepen de routes dan we in jaar 1 van de bachelor hadden bedacht. Hoe heerlijk dat we elkaar daarin toch steeds weer kunnen supporten.

Geke, bedankt om mijn voorbeeld te zijn. Ik heb een enorm bewondering voor je werkethos en je inzicht en inzet voor de mens achter de patiënt. Bedankt om me destijds te laten zien hoe leuk onderzoek kan zijn, zonder jou was ik hier nooit aan begonnen.

Liesbeth, merci om mijn vriendin te zijn in het Zeelse! Ik hoop echt dat we nog eens kunnen gaan lunchen alvorens we verhuizen.

Dames van de naailes, merci voor de babbels op donderdagavond. Naast nuttige naaitips heb ik ook een heleboel geleerd over de Vlaamse cultuur, over de flosj, hoe je Sinterklaas dient te vieren (zonder ingepakte cadeau's) en me zot hard geamuseerd met jullie!

Aan **alle familie**, het einde van de eindeloze ritjes naar België is eindelijk in zicht ☺. Wat fijn dat jullie bleven komen.

Lieve **Piet & Elly, Jose & Jan, Jeroen, Jelte, alle oma's (Lucia, Janna, Philothea)**, bedankt voor jullie meeleven tijdens alle ups en downs, lieve woorden, steun en gezelligheid.

Lieve **Gelda, Allard en Kim**, bedankt om onderdeel te zijn van 'het dorp' dat je nodig hebt om kleintjes groot te brengen. Bedankt voor alle support rondom dit proefschrift.

Lieve **papa en mama, Willem Jan, Evalinde en Janneke**, wat fijn dat jullie er altijd zijn! Bedankt voor alle fijne etentjes, weekendjes, oppasdagen en belletjes. Bedankt voor alle heerlijke insight-jokes die ik altijd met jullie zal delen. Mag ik nu ook pudding als ontbijt?

Lieve **Lotte**, lieve **Wilfried**, dank voor de gezelligheid tijdens de weekendjes weg en op alle andere momenten dat we jullie, fysiek of telefonisch, spreken. Dank voor de vele oppasuurtjes. Lotte, dankjewel ook voor de prachtige illustraties in dit proefschrift, zalig zo'n 'huisillustrator' ☺.

En dan, de drie allerliefste mannen van de hele wereld!
Liefste **Jos,** alleen jij weet hoeveel bloed (valt mee), zweet (aanzienlijk) en tranen (heel veel) dit proefschrift mij echt gekost hebben. Bedankt om altijd voor, naast en achter me te staan als ik val. Bedankt om samen met mij te vliegen bij successen. Met jou kan ik alles! Ik hou van jou!

Liefste **Gijs**, liefste **Olivier**. Speciaal voor jullie, hierbij de belangrijkste lessen die ik leerde tijdens het doen van dit doctoraat:

- Geef niet op, je kunt meer dan je denkt
- Vraag hulp, je hoeft het niet alleen te doen
- Trouw met iemand als je vader, liefde is het antwoord, altijd.

Ik hou van jullie, lieve aapies!

Zo, en nu op naar het volgende avontuur. 1^{e}, 2^{e} SPRING!

C. List of abbreviations

ACP	advance care planning
AD	advance directive
BPSD	behavioral and psychological symptoms of dementia
CAP	coordinating advisory physician
DNH	do-not-hospitalize
DNR	do-not-resuscitate
EAPC	European Association for Palliative Care
ELD	end-of-life decision
GP	general practitioner
NH	nursing home
NPS	neuropsychiatric symptoms
PwD	people with dementia
RCT	randomized controlled trial
WHO	World Health Organization

D. Preface

''It made me realize what a luxury it is to have a job like mine, to be able to ask the residents 'what makes you happy?'. This is such an existential question and we have to take it seriously. And that is what it's all about.''

This is a quote from one of the nurses who participated in the trial in which we evaluated the ACP+ program. This is a program we developed to help nursing home staff to embed advance care planning (ACP) in their daily practice. ACP is about communication, about listening to the nursing home residents, about values, about likes and dislikes, about goals, about future care, about what makes somebody happy.

The population is aging, and the extra years are often spend with one or more chronic health issues. Some are more serious than others, but inevitably, they will some day, lead to death. However, this also means that more and more, death is not going to happen unexpectedly. This sounds sad maybe, but it actually provides us with opportunities. Opportunities to talk to our loved ones and our health care professionals, regardless of whether we live in a nursing home or not, about what matters to us, what we fear and what we value, now and near the end of life. In other words, to engage in advance care planning.

This dissertation focusses on advance care planning, nursing homes and dementia, but in the end, it focusses on what makes people happy and how to communicate about that.

PART 1; GENERAL INTRODUCTION, RESEARCH AIMS AND METHODS

1.1 Background

1.1.1 The aging population & dementia

Facts and figures

The World Health Organization (WHO) predicted that by 2020 the number of people aged 60 years and over would outnumber children under 5 years of age worldwide[1]. Recent numbers from the United Nations are in line with this prediction, showing that roughly 300 million more people aged 60 years and over are alive today than people under 5 worldwide[2]. The number of older people is expected to grow even further, as there is a predicted increase from 12% to 22% by 2050 of the total global population who are aged 60 years and over[1]. So, worldwide the population is aging. However, there is little evidence that the last years of life are spent in good health[1]. Many older people may experience difficulties. The WHO states for example, sensory impairment (e.g., hearing loss), back and neck pain, chronic obstructive pulmonary disease (COPD), depressive disorders, falls, diabetes, osteoarthritis or dementia[1]. Moreover, as people age, it is common that they experience more than one condition at the same time[1]. Regardless of where in the world people live, the most common causes of death are noncommunicable diseases, with heart disease, stroke and COPD at first, second and third place, respectively[1,3]. In upper-middle-income and high-income countries, dementia can be found in the top 10 of causes of death, in the fifth and third places respectively[3].

Every three seconds there is a new case of someone with dementia. Today there are about 50 million people living with dementia, worldwide, and this number is expected to increase to 82 million in 2030 and 152 million in 2050[4,5]. In Europe, it is expected that the number of people living with dementia will be doubled by 2050[6]. For Belgium specifically, it is expected that almost 3% of the population (360.766 people) will be living with dementia in 2050[6]. An important factor influencing this increase appears to be the great growth in the number of people aged over 65, particularly those aged over 85, as prevalence rates of dementia increase tremendously with age[6].

Dementia is an umbrella term for a number of different diseases which all cause deterioration in cognitive function beyond what might be expected from normal aging[7,8]. Alzheimer's disease might be the best-known form, since it is the most common, contributing to 60% to 80% of all cases[7,9]. Other types of dementia include, among others, vascular dementia, Lewy body dementia and frontotemporal dementia. They all have their own pathologies, neurological changes and disease trajectories, however, the boundaries between different forms of dementia can be unclear in clinical practice and mixed-forms do occur[7].

Dementia follows a progressive course, meaning that, gradually, neurons in the brain are damaged and destroyed and do not regenerate. This can cause the characteristic symptoms of dementia, such as difficulties with memory and language, impaired motor skills, impaired vision and problem-solving and other cognitive skills that affect a person's ability to perform everyday activities, as well as disorientation in time, person and place and changes in mood and personality[7,9]. Furthermore, people with dementia can experience behavioral and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms (NPS), for example, apathy, depression, aggression, anxiety and trouble sleeping[10].

Dementia is currently irreversible and, eventually, fatal[9,11]. The speed at which symptoms develop differs per person and per disease type. However, as the disease progresses, the cognitive and functional abilities of a person living with dementia will decline. In the last stages of dementia, people will become dependent on other people to assist them with practically everything, including basic activities of daily living (e.g. bathing and eating). Additionally, people living with dementia will likely lose their ability to communicate[9]. Today, treatment mainly focuses on symptom control and psycho-social support[4,12]. Moreover, there are different initiatives worldwide on multidomain lifestyle interventions focusing on risk reduction and the prevention of dementia[13].

Palliative and end-of-life care

The WHO states that there is a large gap between the number of people in need of palliative care and the number actually receiving it[14,15]. Palliative care is defined as 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'[14]. Moreover, palliative care; '1) provides relief from pain and other distressing symptoms; 2) affirms life and regards dying as a normal process; 3) intends to neither hasten nor postpone death; 4) integrates the psychological and spiritual aspects of patient care; 5) offers a support system to help patients live as actively as possible until death; 6) offers a support system to help the family cope during the patient's illness and in their own bereavement; 7) uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; 8) will enhance quality of life, and may also positively influence the course of illness; 9) is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications'[14,16–18]. Since 2002, Belgium has had a law in place on palliative care, stating the right to palliative care for all citizens regardless of his/her life expectancy[19]. However, in 2014 a committee of experts reviewed the current status of palliative care in Belgium, finding a need to upscale specialist palliative care and funding thereof[20].

As stated above, palliative care also comprises of care delivered at the end of life, as it recognizes death as a normal outcome of life. Care at the end of life can involve medical end-of-life decisions (ELDs). ELDs have been defined as a range of medical decisions with potential life-shortening effects that can be categorized into three types: 1) withholding or withdrawing potentially life-prolonging treatment; 2) alleviating pain or symptoms pharmaceutically, in large enough doses to hasten death as a potential side effect; and 3) administration, prescription or supply of drugs to end life, either without or at the patient's explicit request, including euthanasia[21]. Since 2002, euthanasia is a legal option in Belgium for people who have the mental decision-making capacity[22]. This also applies to people living with dementia who still have the decision-making capacity, if they can meet the requisite of making a voluntary, well-considered and repeated request, although there have been societal debates on whether future projected suffering due to dementia fulfills the criteria intended by the law on euthanasia[22]. In case a patient is able to communicate near the end of life, the applicable ELDs can then be discussed. In case a patient is no longer able to communicate, the applicable ELDs -except for euthanasia- can be discussed with relatives or the health care team. In Belgium, it is also possible to state the wishes people might have concerning ELDs beforehand (e.g., by drafting an Advance Directive (AD)), to guide decision-making when people are no longer able to communicate these wishes. An AD for euthanasia is also a legal possibility but can only be applied when a patient is no longer conscious (i.e. in a coma) and this condition is irreversible[22]. Chambaere *et al*[23] found that in 2007 in Belgium, people dying with dementia were more likely than people dying with cancer to have life-prolonging treatment withheld or withdrawn. Moreover, they found that five people with dementia requested euthanasia, but did not receive it[23]. Unclarity remains about possible changes that might have occurred in the light of the installment of the laws on palliative care and euthanasia in Belgium, as well as the public debate about ELDs for people with dementia, for example triggered by the death of Hugo Claus in 2008[24].

Another important element of the palliative care approach is advance care planning (ACP)[16] defined as 'a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care'[25]. The main goal of ACP is to align care with the person's preferences and goals[26]. ACP and the challenges related to conducting ACP in general, and with people living with dementia specifically, are described further on in this dissertation.

Despite the fact that palliative care and care for people with dementia show an overlap in many areas (e.g., the person and relationship centeredness and acknowledgment of the life-limiting nature of the illness[27]), palliative care seems not to be the norm for people living with dementia**.** Dementia is often not seen as a terminal condition -a recent study among healthcare professionals in 155 countries showed that 62% of them considered dementia as a normal part of aging[28]-, and people with dementia are much less likely to receive palliative care[16,29]. In the UK, it was found that, compared to people with cancer and other diseases who died during an acute hospital admission, people with dementia receive remarkably less palliative care treatment, less palliative medication and fewer referrals to palliative care specialists (9% vs. 25%)[30]. This is perhaps not surprising as in most countries, palliative care has been developed focusing on cancer care. However, cancer has a very different disease trajectory, different symptoms and a different end-of-life process to dementia[12], and so typical or standard palliative cancer care might not be applicable as palliative dementia care. It is suggested by the Organization for Economic Co-operation and Development (OECD) Health Division that even when specialists have been trained in palliative care, they may be less familiar with the complexities of the end of life of people with dementia[12], for example, the communication difficulties regarding pain and other symptoms[31]. In line with this, the European Association for Palliative Care (EAPC) recently published a consensus paper on the definition of optimal palliative care for older people with dementia. Using Delphi consensus methods, they proposed 57 recommendations within 11 different domains (e.g., ACP), in order to optimize palliative care for people living with dementia[32] (see Box 1).

Domain 1. Applicability of palliative care
Domain 2. Person-centred care, communication and shared decision making
Domain 3. Setting care goals and advance planning
Domain 4. Continuity of care
Domain 5. Prognostication and timely recognition of dying
Domain 6. Avoiding overly aggressive, burdensome or futile treatment
Domain 7. Optimal treatment of symptoms and providing comfort
Domain 8. Psychosocial and spiritual support
Domain 9. Family care and involvement
Domain 10. Education of the health care team
Domain 11. Societal and ethical issues

Box 1. Domains of the EAPC recommendations to optimize palliative care for people living with dementia[32]

1.1.2 Nursing homes

A recent study in 45 countries found that 20% to 44% of deaths occur in long-term care facilities or nursing homes[33]. Long-term care facilities (called nursing homes, care homes, residential aged care homes and other terms) have been defined as, 'collective institutional settings where care, on-site provision of personal assistance in daily living, and on-site or off-site provision of nursing and medical care, is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time'[34–36]. In Belgium specifically, nursing homes are care facilities where older adults live who have problems with activities of daily living and/or physical and cognitive functioning. The nursing homes provide long-term care where continuous (24/7) nursing and personal care are available. Residents continue to receive medical care from their general practitioner (GP)[37]. Additionally, nursing homes can provide care in day care centers, short-stay wards or service flats[37]. In Flanders, the Flemish Agency for Care and Health [in Dutch: Vlaams Agentschap voor Zorg en Gezondheid] describes nursing homes as a permanent place for (nursing) care (see Box 2). In 2016 the agency ordered a study among nursing home residents without cognitive impairment, surveying their quality of life[38]. It was concluded that older people residing in Flemish nursing homes have a high quality of life with regard to privacy, feeling safe and being treated with respect. Themes related to personal relationships within the nursing home, for example connection with other residents, and leisure activities were however rated poorly.

Everyone aged 65 and over is welcome in a nursing home. A nursing home is set up for those who cannot live at home anymore. It is only after other options for care, for example home care, no longer offer a solution and you are in need of permanent care, that you would move into a nursing home.
As a resident in a nursing home, you have your own room and living space. Of course, you can come and go as you please and you can receive visits from friends and family as you wish.
Nursing homes offer extra support, ranging from assistance with cleaning activities to help with activities of daily living and nursing care.

Box 2. Description of nursing homes by the Flemish Agency for Care and Health[39]

Because of the high numbers of nursing home residents dying each year, palliative and end-of-life care, including ACP, are major themes in this setting. Palliative care has been advocated as the preferred approach to care[40], since the key features of palliative care correspond strongly with the key features of general, high-quality, person-centered care in this setting[41].

Nursing home residents

Nursing home residents are typically older adults who experience problems with activities in daily living. Furthermore, they might experience difficulties with cognitive functioning, as, for example, people living with dementia do. This subsequently leads to the vast majority (55% to 98%[42]) of nursing home residents to suffer from more than one progressive illness. Approximately 30% of nursing home residents die every year[43]. Factors associated with mortality are, among others, found to be higher age, higher comorbidity and more severe dementia[43].

The number of people with dementia dying in nursing homes, differs from 6% in South Korea, to 49% in The United States, to 93% in The Netherlands[44,45]. In Belgium specifically, it is estimated that more than 65% of the people with dementia die in nursing homes[44,46]. In light of the deterioration and symptoms described above, people living with dementia require 24/7 care and support, which often leads to them moving into a nursing home at some point in their disease trajectory. Since many people living with dementia wish to remain at home and in their communities for as long as possible[12], it makes the timing for moving to the nursing home a difficult decision for all parties involved. But with high rates of emotional caregiver burden due to behavioral and psychological symptoms[47,48] and the care provided at home being too fragmented, uncoordinated, and unresponsive to the needs of people living with dementia and their families[16], nursing homes might be the most suitable place to be at some point. Moreover, because of the company, the stimulation and the absence of having to worry about their own care, it has been suggested that people with dementia could thrive in nursing homes[4]. People with dementia can either be admitted to an open or a secure ward in the nursing home, depending on their cognitive status, the behavioral and psychological symptoms they experience or display and their need for assistance with activities of daily living.

Nursing home staff

Typically, in nursing homes, a large proportion of the care staff consists of nurses and nursing assistants. A recent study among several high-income countries found wide variations in staffing levels within and across countries. In the UK, for example, they found guidelines with a patient to staff ratio of 1:5 for early shifts, 1:6 for late shifts, and 1:10 for night shifts with an average of 35% nurses and 65% care assistants, whereas in Germany nurses must make up a minimum of 50% of all care staff on the ward[49]. In Flanders, (the Dutch-speaking and most densely populated region in Belgium), there are 819 nursing homes with 81.743 beds[50], with at least 40% nurses available at any time of day[51]. Moreover, the nursing home care staff includes care assistants, psychologists, physiotherapists, occupational therapists, social workers, animators, pastoral or spiritual caregivers and moral consultants. Additionally, nursing homes are required to have a reference person for palliative care, which is someone who provides support to palliative residents and is responsible for a supportive palliative care culture within the nursing home, provision of training for the staff on palliative care-related topics, coordinating palliative care and keeping records of palliative care initiation for all deceased residents[52]. Reference persons for dementia, i.e. the nursing staff with extra education in dementia, can also be available in Belgian nursing homes, but this is not obligatory[53].

Next to the care staff, a coordinating advisory physician (CAP) is available. This is a physician, who is usually also working as a GP, who participates in the management of the nursing home and coordinates the continuity of care with GPs, the use of pharmaceuticals and teaching activities for the nursing home staff and other GPs (e.g., hygiene, wound care, palliative care etc.). This physician could also be consulted in case of care-related conflicts or for a second opinion[54].

A recent memorandum from the Flemish parliament provides insight in the atmosphere for the staff in nursing homes, describing high levels of job satisfaction among staff, but also high workload and emotional and physical disstress[55].

Challenges in research in nursing homes – a complex setting

In essence, a nursing home can be seen as a complex system, with many interactions between many different players (e.g., management, staff, residents, family)[56]. These interactions are likely to be influenced by the different roles the players have, their relationships and the context, i.e. the formal and informal rules that apply. Moreover, this complex system both influences and is influenced by the behaviors of the players, such as their mood, motivation and goals[56]. This has implications for both the provision and the optimal delivery of care, as well as research in this setting. This dissertation distinguishes three key research challenges.

First, the characteristics of the nursing home complicate research and the implementation of research programs or interventions. The nursing home setting has been acknowledged to be a challenging field in which to conduct research[57,58]. Several reasons for this could be indicated, for example, lack of time, lack of financial resources, competing priorities of the staff, scarce training opportunities, understaffing and high rates of staff turnover, a large proportion of differently skilled staff, lack of incentives to engage in research and the reluctance of the staff and family to participate in interventions[57–62]. Additionally, Froggatt and colleagues identified three different levels on which palliative care interventions could be implemented in the nursing home setting: macro (e.g., national policy, legislation, financial incentives), meso (e.g., education, tools and frameworks and research) and micro (e.g., palliative care service delivery)[63]. Implementation of palliative care programs (e.g. an ACP intervention) at the meso- and micro-levels should be supported by macro-level engagement[63]. It is advised to take all these characteristics on different levels into account when developing interventions and to allow some flexibility in addressing the context to let the intervention succeed[64].

Second, **there are several methodological challenges when conducting research with the vulnerable nursing home population,** especially when the focus lies on end-of-life care-related research. There might be high levels of non-response, due to poor functional and/or cognitive status, or it might not be possible to include nursing home residents themselves, due to ethical concerns about burdening people who are very ill and for whom the end of their life is near[65,66]. Related to the latter is the concept of gatekeeping. This happens when healthcare professionals or other involved parties prevent residents who would be eligible to participate in research to do so. A recent review identified five groups of potential gatekeepers: healthcare professionals, research ethics committees, management, family and researchers and concluded that ‘gatekeeping is motivated by the general assumption of vulnerability of patients, coupled with an emphasis on the duty to protect patients’[67]. However, it was found that both residents and families value participating in research and it is ethically desirable to offer them the opportunity to do so[68]. Moreover, when only targeting the nursing home staff or family as respondents, problems related to recall bias or proxy bias can occur[57], as well as a lack of insight in to the experiences of the residents themselves.

Specifically, for nursing home residents living with dementia, these challenges in end-of-life care-related research are amplified. The uncertainty of the dementia disease trajectory makes it difficult to determine when people are near the end of life. Moreover, communication difficulties and memory problems might hinder the transferal of experiences and complicate data collection[69].

Thirdly, **determining the desired outcomes of interventions is difficult, as well as identifying accompanying valid and reliable outcome measures.** Outcomes of interventions can be determined on different levels, for example, on the level of the resident, the family, the healthcare professionals and even on the organizational-level. In 2013, the Methods Of Researching End of life Care (MORECare) project, provided a broad statement with best-practice solutions for end-of-life related research and the evaluation of complex intervention in this area[68]. They stated that the ‘outcome measures should be short, responsive to change and ideally used for both clinical practice and research’[68]. To provide further clarity the same research team undertook an international consensus workshop, concluding that the data collection time points need to be clear to establish a baseline[70]. Moreover, they underlined the importance of clear guidelines for family and healthcare professionals to enhance the validity of the outcome measures, in case these parties are requested to complete proxy-outcomes[70]. Specifically for nursing homes and nursing home residents, however, there is still a limited availability of appropriate measurement instruments[57]. Also, for evaluating the implementation of healthcare programs, quantitative instruments that have sound methodological and psychometric qualities are lacking[71]. In 2016, a review about the end-of-life care training in nursing homes found that the included studies generally used unvalidated measures[72]. For future research, the psychometric testing of existing instruments -if applicable- was recommended, rather than developing new instruments[71].

1.1.3 Advance care planning (ACP)

As described above, ACP can be defined as 'a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care'[25]. The main goal of ACP is to align care with the person's preferences and goals[26]. Therefore, ACP should be a process of reflection and dialogue between the person, those close to them and the healthcare professionals involved[73]. The importance of ACP being a process has been underlined by many[26,74,75] and different ways of structuring an ACP conversation have been proposed by several organizations, for example, the Royal College of Physicians of London, UK[76], and in Belgium, the Flemish Federation of Palliative Care[77,78].

The conclusions of an ACP conversation can be documented, for example, in the resident's file, or can be formalized in several ways. In Belgium, negative advance directives (ADs) are documents that outline the person's preferences for end-of-life treatment they would no longer like to receive in case s/he would become mentally incompetent, e.g., withholding or withdrawing life-sustaining treatments (e.g., antibiotics) or other treatments such as cardiopulmonary resuscitation and mechanical ventilation (also known as do-not-resuscitate (DNR) orders), do-not-intubate, do-not-hospitalize (DNH orders) and withholding or withdrawing artificial food and fluids. In Belgium, these negative ADs are legally binding[79–81].

ADs concerning euthanasia, which allow people to state a wish for euthanasia in advance are not legally binding in Belgium. Strict regulations do apply, the euthanasia AD needs to be drawn up with two adult witnesses and only applies to a situation in which the person is in an irreversible coma. All described ADs in Belgium are valid for life[79,82].

The appointment of a legal representative is also possible and legally binding in Belgium. A legal representative can be appointed by a person as part of his/her other ADs or can be appointed on a separate document too. A legal representative is someone who will make medical treatment decisions in case a person (the patient) is not (or no longer) able to communicate his/her wishes and has decisional incapacity. The legal representative is expected to always consider the best interest of the patient and to make the decision s/he believes the patient would have wanted. In case a legal representative is not appointed by the patient him/herself, Belgian law has foreseen a cascade of representatives, in descending order: a legal guardian (only if appointed for the patient), a person's partner or cohabitant spouse, and if not available or possible, an adult child, parent, adult sister or brother respectively[83].

The documents described above and the ACP conversation itself should always be considered as optional. If people in general, and nursing home residents specifically, do not want to talk about future preferences, for whatever reason, at a certain moment in time, it is their right not to continue ACP conversations[84]. Moreover, formalizing the ACP conversation in the form of filling out ADs or appointing a legal representative is never obligatory. This applies to both people with and without dementia.

Challenges regarding the implementation of ACP in nursing homes

Despite the increasing interest in ACP, the uptake is low[85]. Recently, Gilissen and colleagues[86] developed a theory of how ACP is expected to work in the nursing home context, highlighting important factors that could hinder or enable the implementation of ACP. For example, the availability of an external trainer responsible for implementation, and training for all types of staff involved in the nursing home were found to be crucial. Additionally, they suggest the engagement of the management is important to ensure buy-in into the project to help both implementation and sustainability[86]. Also, Batchelor *et al.*[87] identified several facilitators and barriers to conducting ACP in nursing homes, related to, 1) education and knowledge, 2) skills and training, 3) procedures and resources, 4) perceptions and culture, 5) legislation and 6) systems. They suggest the interplay between different healthcare providers is crucial and a comprehensive person-centered framework for ACP should be developed[87]. This is in line with other research, suggesting many barriers exist on the level of the healthcare professional, as well as on the level of the resident and their families[59]. Residents, as well as families, might not be ready to discuss ACP issues[59,62,88]. Furthermore, it was reported that residents do not want to burden their families[89], or feel their families will know what they would want, even without discussing this formally[90,91]. Some residents might feel ready to discuss ACP, but are unsure about how to start the conversation[85,92]. The latter is also true for healthcare professionals, as it is found they might not feel confident to start a conversation about ACP and end-of-life related issues[93], or they are unsure about what their role in ACP is[94–97], resulting in both the resident and the professional awaiting on each other to start the conversation. Moreover, on the level of the healthcare professional, barriers related to a lack of knowledge about ACP[98] and the fear of not being able to comply with future wishes have been identified[59,96]. Lastly, as stipulated by Batchelor *et al.*[87], several barriers exist on the nursing home level, in the form of a lack of time and resources, a lack of educated staff to conduct the ACP conversations, ACP not being embedded in routine care and a lack of flow of information between different healthcare professionals and settings[59–61,93,99,100]. A culture of openness around ACP, as well as organizational support for the nursing home staff, are recommended[101]. Moreover, the need for clear policies in nursing homes has been stipulated[102].

The identified challenges are reflected in the low numbers of composed ADs, a recent study in 6 European countries found only one in three deceased residents had a written AD in their nursing home file, with DNR and DNH orders being the most common[103]. This number varied greatly between countries, from 0.1% in Italy, to 76.9% in England. In Flanders specifically, 46% of the nursing home residents were found to have an AD in their file[103]. A factor possibly contributing to this might be the quality indicators for the nursing home sector introduced by the Flemish government in 2013[104]. Nursing homes need to report on this biannually and the results are reported online, in order to improve the quality of care. One of the quality indicators is the existence of an up-to-date end-of-life care plan for every resident[105]. The latest numbers (2019) show that 55.6% of all residents had such a plan in their nursing home file. This is an average increase of 4% per year between 2016 and 2019[106]. For Flemish nursing home residents with dementia these numbers remain unclear.

Challenges in the uptake of ACP for people living with dementia

Alzheimer's Disease International (ADI) stated in one of their recent reports that the palliative care approach may be appropriate across the dementia disease trajectory, with early ACP, and a continuing review of care preferences as one of the main courses of action[16]. This can empower people with dementia, as it enables them to exercise their autonomy regarding options for future care, consistent with their values and preferences[16]. However, currently in Western countries, less than 40% of people with dementia have the opportunity to participate in an ACP conversation and record their preferences[107,108].

The low uptake of ACP for people living with dementia could be aggravated by the lack of high-quality guidelines[73]. Many countries have some form of ACP document available to people living with dementia, it is however unclear what this exactly entails[12]. It could also be that the dementia disease itself makes it hard to conduct ACP. The barriers described above on the level of the nursing home resident, family and healthcare professional are also true for the conducting of ACP conversations with people with dementia. Moreover, several other barriers have been identified on multiple levels[75].

First and foremost **for people living with dementia,** the difficulties of talking about death and dying are intensified by the fact that they are planning care for a future unknown self[109]. Moreover, people with dementia might not know enough about the dementia disease trajectory or about the ACP process to participate[73,85,88,95,110–113]. Cultural factors, such as the stigma of cognitive impairment was also found to hinder ACP[114]. Additionally, difficult family dynamics were found to complicate ACP conversations for people living with dementia[115]. Higher age, being of the female sex, having received higher education and having a comorbid disease were found to be facilitators for people living with dementia to participate in ACP[88].

For family of people living with dementia, the main specific barrier was found to be a lack of knowledge about dementia and specifically the lack of understanding that dementia is a disease from which you can die[115]. Additionally, the family was found to lack knowledge about life-sustaining treatment, the role of a proxy decision-maker, ACP and palliative and end-of-life care[94,96,112,116–119]. Family not being close to the person living with dementia was also found to hinder ACP[88].

Despite evidence that **healthcare professionals** consider ACP as important for people with dementia[94], some barriers have been identified; lack of knowledge, high prognostic uncertainty, discomfort, lack of time, and language and communication difficulties[88,94,97,114,120]. Furthermore, it has been found that healthcare professionals fear to cause fear, anxiety and distress for people with dementia and their families when speaking about ACP and end-of-life related topics[88,94,96,97,110,121–123].

Notwithstanding these identified barriers, the evidence on the effectiveness of ACP for people with dementia and the experiences and views of ACP of people with dementia, their families and healthcare professionals is scattered and a clear overview is lacking.

Recently in Belgium, 32 recommendations for healthcare professionals on how to conduct ACP with people living with dementia have been developed by an expert panel, among which are recommendations about the initiation of ACP, how to conduct ACP conversations with people who experience difficulties with verbal communication, how to involve family and end-of-life decision-making[73]. In addition, a recent review proposed five important topics for conducting ACP conversations with cognitively impaired older people, also stating to address ACP early in the disease trajectory, repeat the conversation over time, assess his/her decision-making capacity, identify a proxy decision-maker, consider the use of structured tools and document the outcomes of the ACP discussions accurately in the electronic health record[114].

ACP for people living with dementia in nursing homes

Above mentioned difficulties for conducting ACP conversations with people with dementia are also applicable when these people are living in nursing homes, or may even be intensified by the fact that the person with dementia is living in a nursing home. For example, difficult family dynamics may increase when a person is admitted to a nursing home[124], further hindering ACP conversations. Moreover, the barriers hindering the uptake of ACP in nursing homes do also apply to the people with dementia living there (e.g., a lack of time and staff).

Additionally, specific barriers further complicating ACP for people living with dementia in nursing homes are identified. For example, the evaluation of the *Let Me Decide* program for nursing home residents with dementia in Canada revealed that out-of-hour doctors and the ambulance staff would fail to recognize the validity of the ADs that residents with dementia signed, sometimes resulting in transferals against a person's wish[96]. Moreover, they found it was not always clear which person in the nursing home should be responsible for conducting the ACP conversation, as the nursing staff would see ACP as a management role[96]. Additionally, a survey among nursing home nurses found that an emotional burden was more likely for those who have participated in conversations about end-of-life wishes with residents with dementia and family[125].

Lastly, it is important to keep in mind that nursing home residents could develop dementia while living in the nursing home, as currently large numbers of nursing home residents die with dementia[126]. It would therefore be important for the staff to be alert to the signs of cognitive deterioration of all nursing home residents and not only those admitted with a diagnosis of dementia, as a missed dementia diagnosis might unnecessarily trouble communication and by extension ACP conversations, as was found in primary care[127].

Challenges in designing and evaluating ACP – complex interventions

Designing ACP interventions and determining their effectiveness has proven difficult. ACP can be regarded as a complex intervention[56,84,128]. A complex intervention consists of many interacting components on multiple levels, can focus on a number of outcomes and often allows some degree of flexibility or tailoring when the intervention is implemented[128]. ACP typically involves different levels (e.g., the person him/herself, family, the healthcare professional and the nursing home), the outcomes are not always clear upfront and the health care systems in which it is implemented is rapidly changing in terms of demands and resources[37,129]. Hence, when designing and evaluating complex interventions, specifically those regarding ACP for nursing home residents, several issues need to be taken into account.

Designing and evaluating complex interventions – what is known?

With regard to the existing evidence, the effectiveness of ACP interventions shows mixed results and the quality of studies is often poor[69]. A recent review about the Respecting Choices® methodology and related ACP models showed mixed and inconclusive evidence about the change in, for example, congruence between stated wishes and care provided[130]. The review of Jimenez and colleagues from 2018 showed several positive effects of ACP such as improved end-of-life communication, documentation of care preferences, dying in a preferred place and health care savings. However, they also stated the included articles were of low quality and the evidence is compartmentalized, herewith hindering the gain in knowledge about what actual effects ACP can have[100]. A specific ACP intervention in the nursing home setting conducted in The Netherlands found increased completion of ADs and the appointment of proxy decision-makers, but the quality of life of the residents was not affected by the intervention[131]. Additionally, to the outcomes on the residential-level, the effect of ACP on family outcomes was evaluated in a paired cluster randomized controlled trial in Northern Ireland. This intervention found ACP to reduce the uncertainty about decision-making in the families of nursing home residents living with dementia, as well as improving their perceptions of quality of care in the nursing home[132]. A recent study from Norway found their ACP intervention in nursing homes to improve communication between the staff and the family[61]. Educational interventions to improve ACP skills in the nursing home staff can be implemented in the nursing home sector, but until now, this was also with mixed results[100,130,131,133,134]. A recent review found that training had a positive effect on the staff's knowledge, attitudes towards shared decision-making, perceived communication skills, confidence, comfort and experiences concerning discussing end-of-life issues[135]. The authors noted however that the quality of the included articles was only moderate and that high-quality randomized controlled trials were lacking.

In line with the above-mentioned research and reviews highlighting several approaches to ACP in different populations, the evidence about ACP in nursing homes focusing specifically on people with dementia is scarce, with reviews mostly either focusing on the nursing home population as a whole[59], or targeting people with dementia living in different settings (e.g., at home or in a nursing home)[107,136]. Although a significant part of the nursing home population consists of people living with dementia, this specific population warrants a specific approach to ACP, and therefore research -including reviews- targeting this population would be valuable.

The wide variance in the models of ACP -ranging from focusing on the completion of documents (e.g., ADs) to more complex interventions-, along with the sparse information about what the interventions precisely entail, make it difficult to compare different ACP interventions[59,84,137], and hinder designing ACP interventions that take into account the current state of the art.

For **evaluating complex interventions,** determining the right outcomes and concurrent outcome measures would be key. Also, research on ACP in nursing homes specifically, has been focusing on several different outcomes, either related to ACP practices (e.g., the number of ACP conversations or the number of ADs filled out), health care utilization (e.g., place of death, number of hospitalizations or specific treatments) or patient outcomes (e.g., satisfaction with care or concordance between stated wishes and care received)[136]. Recently, a Delphi panel has been undertaken to find consensus on which outcomes could define successful ACP[138]. The authors suggest future studies should focus on the five rated most important; 1) care received is consistent with goals, 2) patient decides on a proxy, 3) document the proxy decision-maker, 4) discuss values and care preferences with the proxy and 5) documents and recorded wishes accessible when needed[138].

For evaluating staff outcomes related to ACP, currently little guidance is available. Measures taking different roles and educational levels of the nursing home staff into account are lacking.

Designing and evaluating complex interventions - what is needed?

As can be concluded from the gaps identified above, further research should focus on a number of components. As Dixon and colleagues concluded from their systematic review on the effectiveness of ACP: 'There is a need for more high-quality outcome studies, particularly using randomized designs to control for confounding. These need to be underpinned by sufficient development work and process evaluation to clarify the appropriateness of outcome measures, explore implementation issues and identify active elements'[136]. Moreover, issues about the standardization of ACP outcomes across studies have been raised[138,139].

Additionally, it is often unclear why the interventions that report on positive ACP outcomes lead to the produced change. Therefore, it has been argued that besides a 'does it work' focus, we should also adopt a 'how does it work' attitude and untangle the so-called 'black box' of the interventions[69,75,140,141]. Since there is no single best way to design and carry out a process evaluation[140], it has been argued that developing an underlying theory about why and how the intervention could produce change is invaluable[86].

The ACP+ intervention

An example of a theory-based ACP intervention in nursing homes is the ACP+ intervention (using the Theory of Change[86] as well as the UK Medical Research Framework for developing and evaluating complex interventions[141]) of which the results of the randomized controlled trial and process evaluation are described further along in this dissertation (Chapter 3.2 and 3.3). The ACP+ intervention was developed using a Theory of Change approach, constructing a theoretical model and an appurtenant Theory of Change map[86]. The Theory of Change is 'a theory of how and why an initiative works which can be empirically tested by measuring indicators for every expected step on the hypothesized causal pathway to impact'[142]. The Theory of Change map is a visual representation of the drafted model (see Annex 1). For the development of the ACP+ intervention, a literature review, context analysis, stakeholder workshops and a feedback loop with the research team were organized, leading to the identification of two long-term outcomes, 13 preconditions and nine intervention components[86] (see Box 3). The ACP+ intervention has been evaluated for feasibility and acceptability in five Flemish nursing homes, by the nursing home management and staff (N=17) and expert discussions with a multidisciplinary expert group and a palliative care nurse-trainer[143]. This resulted in the final program, comprising of 10 intervention components, 22 activities and 17 materials to support the implementation of the program[143] They were described following the Template for Intervention Description and Replication (TIDieR) checklist[144]. This is a checklist developed to improve the completeness of reporting of interventions (see Annex 2).

The Theory of Change approach[142] was used to develop a theory that outlines the hypothetical causal pathway of ACP in Flemish nursing homes. This approach takes into consideration which changes are expected and how, through which processes and under what circumstances. The resulting Theory of Change map provides a comprehensive illustration of this pathway.

The Theory of Change approach uses a process of 'backwards outcome mapping' together with multiple stakeholders during Theory of Change workshops. This process starts by defining the ultimate impact and long-term outcomes that should be achieved. Subsequently all preceding 'intermediate outcomes or preconditions' necessary to reach these long-term outcomes are defined, and all intervention activities needed to reach the outcomes. Gilissen and colleagues[86] organized two half-day workshops with stakeholders (i.e. people involved in the development, implementation or organization of ACP in nursing homes) to create the Theory of Change. This resulted in two long-term outcomes, 13 preconditions and nine intervention components[86]

Long-term outcomes

1) To improve the correspondence between residents' wishes and the care/treatment they receive
2) To make sure residents and their family feel involved in planning their future care and are confident their care will be according to their wishes

Preconditions

1) Sufficiently skilled trainer available
2) Engagement of the nursing home management
3) Assigning staff to function as 'ACP reference person'
4) Trained nurses that are able to conduct ACP conversations
5) Trained staff that is able to signal triggers for ACP and knows how to pass on this information
6) Informed care professionals
7) Informed GPs
8) Informed residents and their families
9) Care professionals that have the intention to take the wishes and preferences of the nursing home residents into account and who are willing to engage in ACP
10) Wishes and preferences are known to ACP reference persons
11) All involved care professionals know these wishes and preferences
12) Availability of a written record
13) Ongoing monitoring to ensure high quality of ACP

Intervention components

1) Selection of external ACP trainer responsible for helping with gradual implementation of the intervention
2) Ensuring engagement and buy-in of the nursing home management
3) Selection and training of ACP reference persons
4) Information about ACP for staff, GPs, residents and their families
5) ACP conversations and ACP documentation
6) In-service education to nursing home staff and volunteers
7) Multidisciplinary meetings
8) Regular reflection sessions
9) Formal monitoring, including audit, feedback and action plans

Box 3. Summary of the Theory of Change and intervention components of the ACP+ intervention in Flemish nursing homes

1.2 Aims and objectives

This dissertation defined two aims, subdivided into six objectives described below.

Aim 1: To describe current evidence concerning advance care planning for people living with dementia and to examine to what extent advance care planning and end-of-life decision-making have changed over time among people with dementia.

Objective 1: To identify and summarize the evidence on how ACP is conceptualized by and for people with dementia, the effectiveness of ACP for people with dementia and the experiences and views of ACP of people with dementia, their families and professionals (Chapter 2.1).

Objective 2: To examine whether changes occurred in the frequencies of end-of-life decision-making for people who died of dementia between 1998, 2007, and 2013 and which people were involved in the decision-making process (Chapter 2.2).

Objective 3: To examine changes between 2010 and 2015 in verbal and written ACP for nursing home residents with dementia (Chapter 2.3).

Aim 2: To evaluate the ACP+ intervention, an intervention program to improve the implementation of advance care planning in nursing homes in Flanders.

Objective 4: To describe the ACP+ conversation and documentation tools that are part of the ACP+ intervention (Chapter 3.1).

Objective 5: To evaluate the effects of ACP+ on the knowledge and self-efficacy (confidence in own skills) of nursing home care staff concerning ACP (Chapter 3.2).

Objective 6: To evaluate implementation, mechanisms of impact and contextual factors affecting implementation and outcomes of ACP+ (Chapter 3.3).

1.3 Methods

To meet the research objectives of this dissertation, different methods were applied, and different types of data collection were used. To address how ACP and ELDs have changed over the years, we used a mortality follow-back design, surveying health care professionals about deceased people with dementia in different years. To describe current evidence concerning ACP for people with dementia, we performed an umbrella review, incorporating evidence from reviews and primary research. To improve the implementation of ACP in nursing homes, we evaluated the effects and the underlying processes of an intervention developed to support the nursing home staff with the implementation of ACP (ACP+ intervention), using a cluster randomized controlled trial with an embedded mixed-method process evaluation. The ACP+ tools were developed as part of the ACP+ intervention and refined during the feasibility study of the intervention. All methods are further explained in the following paragraphs.

1.3.1 Umbrella review (Aim 1)

To meet **objective 1,** we undertook an overview of the existing systematic reviews, also known as an umbrella review[145]. The electronic databases PubMed, CINAHL Plus, SCOPUS, Social Care Online and The Cochrane Library (CDSR & DARE) were systematically searched for review articles, using a predefined search string. Studies were included if they met the following criteria; 1) study design: systematic reviews of quantitative or qualitative evidence and relevant primary research not included in one of the reviews, 2) study population: people living with dementia, family or informal carers or health care professionals, 3) interventions: ACP with people living with dementia and/or carers, and 4) outcomes: effectiveness of ACP (e.g., care consistent with wishes, number of ACP conversations, number of ACP related written outputs, resource use) and experiences, understanding or perceptions of ACP. Primary research studies included in the reviews were tabulated to check for overlap between the reviews. Following this, PubMed, CINAHL Plus and SCOPUS were searched for recent primary studies on ACP for people with dementia that were not included in any of the reviews.

A quality appraisal was conducted using the AMSTAR-2 tool for reviews[146] and the Critical Appraisal Tools from the Joanna Briggs Institute for the primary studies[147–149]. No reviews or studies were excluded on the basis of the quality assessment score.

The effectiveness of ACP for people with dementia was investigated by categorizing the different outcomes reported and tabulating data including an indication of whether the effects of the intervention were positive, negative or not statistically significant. For qualitative data, a thematic synthesis was done using NVivo 12 software and comprised of three stages; 1) coding 'line-by-line', 2) developing 'descriptive themes' and 3) generating 'analytical themes'. To be as comprehensive as possible, the line-by-line coding included both the results and the discussion sections of the included articles.

The protocol of this review was registered on the PROSPERO website under the registration number: CRD42018107718.

1.3.2 Mortality follow-back studies – comparing differences between years (Aim 1)

To meet **objectives 2 and 3**, two different analyses were performed, comparing data from several years and studies, all using a mortality follow-back study design.

The study on ELDs (**objective 2**) used death certificates and surveyed physicians who registered deaths. The Flemish Agency for Care and Health (an agency of the Flemish Ministry of Health) registers all deaths through death certificates. In the years 1998, 2007 and 2013, the Agency drew random samples of all deaths of persons aged 1 year or over. These samples were stratified for place (the province in Flanders) and month of death. In 2007 and 2013 the samples were also stratified for the cause of death. This latter stratification was disproportionate and was done to increase the numbers, and thus statistical power and reliability of the incidence descriptions of the less common ELDs[150]. In the analysis, this stratification was weighed. For all sampled deaths the Agency sent out a questionnaire to the physician who had registered the death, including a letter with enough patient characteristics derived from the death certificates to enable the physician to identify their patient (e.g., sex, date of birth, date of death and municipality of death). Completed questionnaires were returned to an independent lawyer (Trusted Third Party, TTP), bound to professional confidentiality, to ensure anonymity. The TTP transmitted the questionnaires and the (anonymous) database with patient characteristics to the researchers.

The questionnaire the physicians received started with the question of whether the death of the patient had been sudden and unexpected. If the death was non-sudden, the physician was asked to answer more detailed questions about the actual medical practices s/he carried out. This was done using a three-step approach, asking 1) what act the physician initiated, 2) to which extent life-shortening was intended, and 3) if the patient explicitly requested the act. More than one end-of-life decision could have been made per patient. If this was the case, the end-of-life decision with the most explicit life-shortening intention was considered as being the most important. Hereafter, the physician was asked questions about the decision-making process for the most important end-of-life decision. These questions asked about involved parties in the decision-making process and the reasons for reaching the decision.

The sub-sample for this particular analysis consisted of people who died of dementia. We selected all decedents whose primary cause of death was registered as dementia using ICD-10 codes (either 'F01'=vascular dementia, 'F03'=non-specified dementia or 'G30'= Alzheimer’s disease) from the entire sample of deaths for the three years. Samples were corrected for disproportionate stratification (2007,2013) and non-response of the physicians (all years). For all variables, weighted percentages and frequencies were calculated. Statistical significance between years was calculated using chi-square tests.

To meet **objective 3**, data on nursing home residents who died with dementia from two cross-sectional mortality follow-back studies were used, the Dying Well with Dementia Study (data collected in 2010)[151] and the Palliative Care for Older People (PACE)-study (data collected in 2015)[152]. The first was a cross-sectional study of nursing home residents who died with dementia in nursing homes in Flanders. PACE was a European cross-sectional study of deceased nursing home residents. For this analysis, only the sample from Flanders was selected.

Three groups of respondents; the nursing home nurses most involved in the care, the GP of each deceased resident and a nursing home administrator, received a questionnaire about the residents who had died in the three months prior to the data collection. The resident was considered as a person with dementia if either the GP or the nurse, or both, indicated that the resident ‘had dementia’ or ‘was diagnosed with dementia’. Moreover, nurses were asked to fill out the Bedford Alzheimer Nursing Severity-Scale (BANS-S)[153], the Cognitive Performance Scale (CPS)[154] and the Global

Deterioration Scale (GDS)[155], as well as questions about ACP and end-of-life planning. Administrators were asked to report on the resident's length of stay and place of death.

Questionnaires were pseudonymized and distributed by the administrator, assisted by a researcher. All questionnaires were sent out accompanied with a study information sheet and a post-paid return envelope. Completed questionnaires were sent back directly to the research team.

Descriptive statistics were calculated for the sample characteristics of both years. Statistical tests were conducted using the generalized linear mixed models suitable to the respective dependent variable of interest (i.e. binomial or multinomial). To control for the clustering of the data on the nursing home-level, a random intercept was added for the nursing home. For the analyses of ACP and end-of-life care planning significant differences in sample characteristics between the years were controlled for by adding the respective characteristic as a fixed factor in the model.

1.3.3 ACP+ intervention – a complex intervention (Aim 2)

The ACP+ intervention is a multicomponent intervention aimed at training and supporting the staff with the implementation of ACP into daily nursing home care, with the help of an external trainer for eight months. It consists of 10 components, 22 activities and 17 materials, which are implemented in a step-wise manner[86,143,156]. A train-the-trainer model was used, with the trainers' support being more intensive in the beginning, but decreasing throughout the process as the nursing home staff became more autonomous in organizing ACP and consolidating the ACP+ intervention. A key aspect of ACP+ was the whole-setting approach, with the allocation of different roles to all staff members: ACP reference persons were responsible for implementing ACP within the nursing home; ACP conversation facilitators worked with the ACP reference persons and were responsible for planning and performing regular ACP conversations with nursing home residents and/or family; and all other staff, including the support staff (e.g. cleaning staff), were ACP antennas, who recognized and signaled triggers that could indicate a resident's readiness, need or willingness to engage in ACP.

The underlying Theory of Change, which describes how, why and under what circumstances ACP is expected to work in practice, was created after an extensive developmental process and is described in several publications[143,156,157]. The three ACP+ tools we developed to aid the care staff to elicit, discuss and document a resident's wishes and preferences for future treatment and care are described in Chapter 3.1.

ACP+ tools

The ACP+ tools were developed as part of the ACP+ intervention. Several steps have been taken in designing this intervention (as described above), starting with a literature review[60], discussions with a multidisciplinary expert group (consisting of an ethicist, three psychologists, a general practitioner, a sociologist and a social worker) and written feedback from an experienced palliative care nurse-trainer and a legal expert. Next, the ACP+ intervention and the ACP+ tools were tested in a feasibility study, using focus groups with the nursing home care staff and the management (N=17) of five different nursing homes[143]. For the qualitative analysis, these focus groups were transcribed verbatim and uploaded to NVivo 12 for coding. Adjustments to the ACP+ intervention and ACP+ tools were made in line with the feedback derived from the focus groups. The multidisciplinary expert group then reviewed the materials and tools again and finalized them.

Cluster-randomized controlled trial

From February 2018 (recruitment of the nursing homes) to March 2019 (end of the process evaluation data collection) we conducted a multi-facility cluster-randomized controlled trial in Flanders to compare the ACP+ intervention (intervention group) with the usual care (control group)[143,156]. The randomized controlled trial used a nested cohort pre-post design with randomization at the nursing home-level, because the intervention involved the training of all staff per nursing home. A paired-matched randomization strategy was executed by an independent statistician. The staff of the 14 included nursing homes (7 in the intervention arm, 7 in the control arm) filled out questionnaires on ACP knowledge and self-efficacy (primary outcomes) and ACP practices (secondary outcome). All outcomes were assessed at baseline (month 0) and after the intervention (month 8). Figure 1 shows an overview of all of these steps.

The questionnaire was developed by the research team, based on an English questionnaire by Detering *et al.*[158], and items from the Questionnaire Tool for Registered managers from Ulster University[159]. These items were translated into Dutch through forward-backward translation in collaboration with a translation agency and adapted to the Flemish nursing home context by the multidisciplinary research team. Furthermore, we added items developed by the research team. The new questionnaire was tested with six researchers who had clinical practice experience with older patients (three registered nurses, one GP, one psychologist, one nursing home volunteer), and through an online survey with 107 healthcare professionals and volunteers active in the Flemish nursing home setting. Moreover, questions related to legal issues were reviewed by an expert in medical law. The cluster randomized controlled trial was registered at ClinicalTrials.Gov on May 10th 2018 (no. NCT03521206).

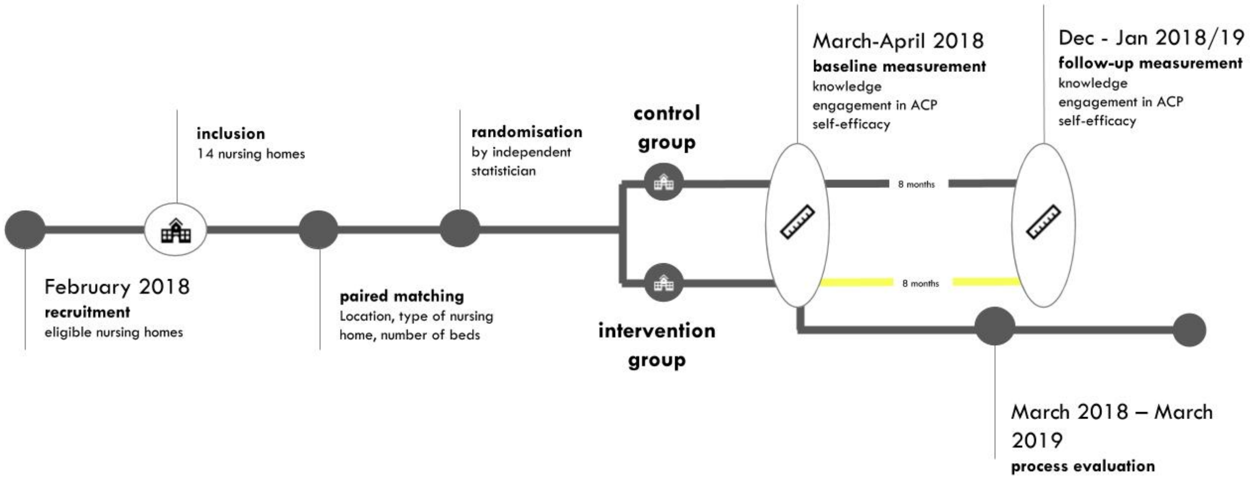

Figure 1. Overview of the ACP+ trial. Reprinted with permission[160].

Process evaluation

The cluster randomized controlled trial had an embedded mixed-methods process evaluation, using quantitative and qualitative research methods, collected throughout and after the intervention period[143,156]. Participants were the nursing home staff, nursing home managers and the ACP trainers. We distinguished two groups of staff: 1) nursing home 'care' staff, defined as nurses, care assistants, psychologists, physiotherapists, occupational therapists, social workers, animators, pastoral or spiritual caregivers, moral consultants, reference persons for dementia and reference persons for palliative care) and 2) nursing home 'support' staff, defined as the staff working in the nursing home but without having a role in care provision, i.e. cleaning, administrative, technical/logistical and the kitchen staff who have regular contact with residents or family but do not provide direct care to them. Quantitative measures included: 1) weekly structured diaries filled out by an ACP trainer, 2) attendance lists of all training activities, 3) observations forms of the training sessions, 4) post-training surveys and 5) facility-level data. Qualitative measures included interviews and focus groups with the care staff, the management and the ACP trainers, as well as field notes on the implementation of the ACP trainers. For the quantitative measures, we calculated descriptive statistics and frequencies per nursing home and across nursing homes. All qualitative data from interviews and focus groups were transcribed verbatim and were uploaded to NVivo 12 for coding. We used thematic analysis in a deductive way, hence, using a prespecified framework and template for analysis. This framework was built upon the research questions, using the dimensions (Implementation, Mechanisms of impact and Context) as main themes.

1.3.4 Ethical considerations

For all described studies in this dissertation, ethical approval was obtained from the Medical Ethical Committee of UZ Brussel (Brussels University Hospital). None of the studies carried risks for the participants.

In the study from Chapter 2.2, a stepwise procedure was in place to ensure anonymity. Each case was given a unique identification code, which was used to link the questionnaires to the socio-demographic information of the deceased person. The Trusted Third Party (TTP) safeguarded the anonymity of the physicians by removing any possible identifying information from the received questionnaires. To further ensure patient-anonymity, the TTP assigned a new code to every questionnaire. In order to still be able to link the questionnaire to the socio-demographic information on the patients' death certificate, s/he kept a database in which the new codes were linked to the original identifiers. This database was accessible to the TTP only. The Flemish Agency for Care and Health transmitted the database containing the socio-demographic characteristics of the patients to the TTP. The TTP assigned to these cases the new codes of the corresponding questionnaire which ensured linkage of the questionnaire data and the patients' socio-demographic information. After this procedure, the information in the database and questionnaires was anonymized. No links with physicians or patients could be made anymore.

In Chapter 2.3, all respondents participated on a voluntary basis. Extensive procedures guaranteed privacy for the nursing home staff, including using pseudonymized codes for questionnaires and asking respondents to return questionnaires directly to the researchers rather than to the administrator in the nursing home. The return of a questionnaire was taken as consent to participate in the study. Similar procedures were used for the study described in Chapter 3.2. Additionally, upon the start of the study, nursing home managers who agreed to participate were asked to sign an informed consent form. The participants of the studies described in Chapter 3.1 and Chapter 3.3 provided written and/or verbal informed consent to participate in the interviews and agreed with these being audio-recorded for analysis purposes. All names of people and places were changed in the transcribed recordings.

1.4 Outline

Following this introduction, chapters 2.1 to 3.3 of this dissertation are based on articles which have been published, accepted or submitted for publication in international peer-reviewed journals.

This dissertation consists of two parts, each answering specific research questions and aims.
Part 2 of this thesis describes the current evidence concerning ACP for people living with dementia and describes how ACP and ELDs for people with dementia have changed over the years. Chapter 2.1 presents the results of an umbrella review. Chapter 2.2 describes the evolution of ELDs made for people who died of dementia. Chapter 2.3 reports on the way people with dementia in nursing homes in Flanders have planned their care.
Part 3 focuses on the evaluation of the ACP+ intervention and the implementation of this intervention in nursing homes in Flanders. Chapter 3.1 provides insight into the materials used in the ACP+ intervention. Chapter 3.2 describes the randomized controlled trial. Chapter 3.3 reports on the process evaluation.

The final section of this dissertation, **Part 4**, consists of a summary of the main findings, reflections on its methodological strengths and limitations, a discussion of the findings in the context of the current evidence base and implications and recommendations for future research, practice and policy.

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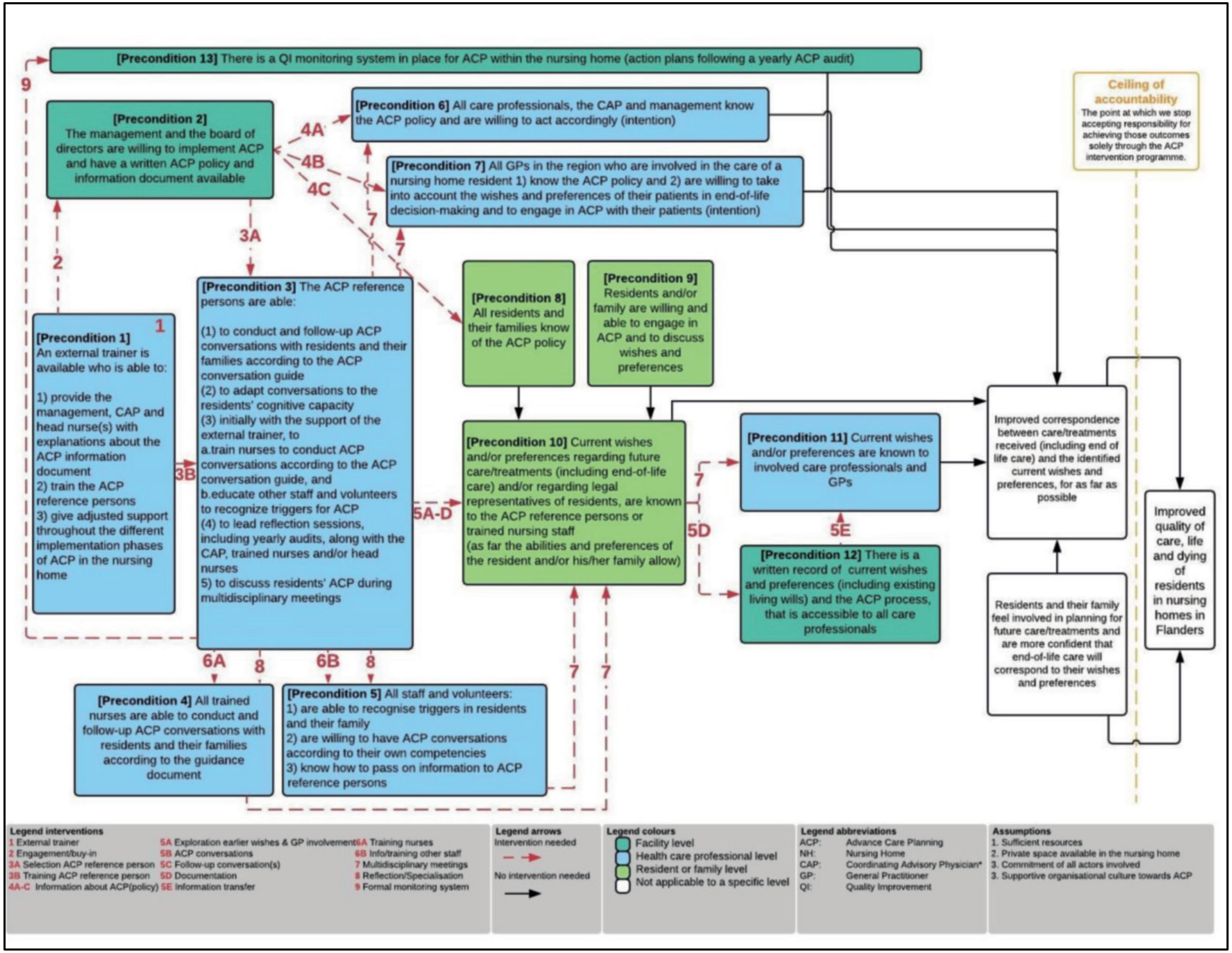
Annex 1. Theory of Change map

Theory of Change map, as was reported by Gilissen et al., 2018[86]



Theory of Change terminology (as was reported by Gilissen et al., 2018[86])

Terminology	**Definition** (Adapted from De Silva, 2015[142])
Impact	The real-world change we are trying to achieve in nursing homes.
Ceiling of accountability	The point at which we stop accepting responsibility for achieving those outcomes solely through the intervention.
Long-term outcomes	The outcome that the intervention is able to achieve on its own. This can inspire the choice for particular primary and secondary outcomes in the evaluation of the intervention.
Preconditions	A precondition or intermediate outcome is a necessary requirement, condition or element that needs to be realized for the desired outcome to be achieved. In the context of ACP, these preconditions are the precursors or requirements for accomplishing successful ACP.
Intervention	The different components of the complex intervention. They represent certain "actions" that need to be undertaken to bring about a certain result, intermediate outcome or precondition. These are "those things that the intervention must do to bring about the outcomes".
Assumptions	An external condition beyond the control of the project that must or is assumed to exist for the outcome to be achieved.
Rationales	The facts or reasons (based on evidence or experience) behind the choice of the intervention activities or strategies and each link of the causal pathway.

Annex 2. Template for Intervention Description and Replication (TIDieR) checklist

Short description of the final ACP+ intervention according to the Template for Intervention Description and Replication (TIDieR) checklist[144]. The full version was reported by Gilissen et al., 2019[143]

Timing	**Intervention component** (n=10)	**What (intervention activities, procedures and processes)** (n=22)	**How (mode of delivery)**	**Who (the intervention provider(s) and participants)**	**Materials (resources/tools that support the intervention activities)** (n=17)
3 months prior to start of program	**ACP Trainer**	Activity 1A: **Selection and preparation of two ACP (external) Trainers.**	NA	1) research team 2) ACP Trainer who is employed by the research team (50% FTE) and who is external to the nursing homes	1. **A list of necessary competencies** 2. **"Manual for ACP Trainer"**
month 1	**Buy-in and engagement of management**	Activity 2A: **Meeting(s) between the ACP Trainer and the nursing home management, representatives of the board of directors, head nurses and the Coordinating Advisory Physician.**	in a group	1) research team 2) ACP Trainer 3) management, board of directors, head nurses and coordinating advisory physician	3. **"ACP Information guide for the nursing home management".**
month 1 to 4	**ACP Trainer**	Activity 1B: **'Shadowing'.**	duo or in a group	1) ACP Trainer 2) ACP Reference Person(s)	None
month 1 to 4	**Tailoring**	Activity 3: **Tailoring-meeting(s) between ACP Reference Persons, management and important decision-makers**	in a group	1) Reference Persons with support of ACP Trainer 2) Management 3) Decision-makers (e.g. head residents' care, head nurses, quality coordinator)	4. **"Tailoring Checklist"**
month 1	**ACP Reference Persons**	Activity 4A: **Two-day interactive training (session 1) for the ACP Reference Persons**	in a group	1) ACP Trainer 2) Selected ACP Reference Persons from all participating nursing homes	5. **"Training manual for two-day training".** 6. **"ACP Manual for ACP Reference Persons".** 7. **"Summary list"**
month 2	**ACP Reference Persons**	Activity 4A: **Two-day interactive training (session 2) for the ACP Reference Persons.**	in a group	1) ACP Trainer 2) Selected ACP Reference Persons from all nursing homes	as above

month 3	**Information about ACP**	Activity 5A: **Information (session(s)) for all residents and their families**	individually or in a group (max 10 per group)	1) ACP Reference Persons, supported by ACP Trainer 2) all eligible, consented residents/proxies and their family	8. **"Invitation letter for residents and family"** 9. **"ACP information brochure for residents and family"**
month 3	**Information about ACP**	Activity 5B: **Information session(s) for all family physicians**	in a group	1) ACP Reference Persons supported by ACP Trainer 2) Coordinating advisory physician 3) Family physicians who have one (or several) patient(s) in the nursing home 4) research team to provide organizational support	10. **“Invitation letter for family physicians”** 11. **"ACP Information brochure for professionals"**
month 3	**In-house training**	Activity 6A: **In-house 2-hour training sessions (session 1) to train ‘ACP conversation facilitators’**	in a group (max 10)	1) ACP Reference Persons, supported by ACP Trainer 2) nurses in the nursing home that are willing (selected by important decision-makers 3) other healthcare staff (e.g. social worker, physiotherapist, psychologist, members of palliative support team) who are willing (selected by important decision-makers)	12. **"Training manual for ACP Reference Persons to train other staff".**
month 4	**In-house training**	Activity 6A: **In-house 2-hour training sessions (session 2) to train ‘ACP Conversation Facilitators’.**	as above	same as above	as above
month 4	**In-house training**	Activity 6B: **In-house 1.5-hour training session to train ‘ACP Antennas’**	as above	1) ACP Reference Persons supported by ACP Trainer 2) Staff and volunteers	as above
month 5 – 8	**Planned ACP conversations**	Activity 7A: **Exploration of earlier wishes and family physician involvement.**	duo (including the family physician)	1) One of the ACP Reference Persons or an ACP	13. **"ACP Conversation Guide" ∗**

		Activity 7B: **First planned advance care planning conversation**. Activity 7C: **Follow-up conversation(s)**. Activity 7D: **Documentation of wishes and preferences**		Conversation Facilitator, supported by ACP Trainer 2) Eligible (consenting) residents and/or their family	14. **"ACP Conversation Tool" ∗** 15. **"ACP Document" ∗** 16. **"Standardized advance directive documents"**
month 5-8 *(every month 1 MDO)*	**ACP information transfer**	Activity 8: **(Monthly) multidisciplinary meetings**.	in a group	1) ACP Reference Persons supported by ACP Trainer 2) Care professionals who are involved in the care of the resident (including volunteers and the family physician)	None
month 5-8	**Coaching**	Activity 9A: **One-to-one coaching**.	duo	1) ACP Reference Persons supported by ACP Trainer 2) all 'ACP Conversation Facilitators' (or others)	None
month 6	**ACP Reference Persons**	Activity 4B: **Come-back seminar**	in a group	1) ACP Trainer (supported by the research team) 2) ACP Reference Persons	None
month 6	**Coaching**	Activity 9B: **In-house specialization session 1: Dementia**.	in a group	1) ACP Trainer 2) ACP Reference Persons 3) ACP Conversation Facilitators	Extra: **"Guideline for healthcare professionals working with people living with dementia"**
month 6	**Buy-in and engagement of management**	Activity 2B: **Follow-up meetings between management, other decision-makers, ACP Reference Persons and the ACP Trainer**.	In a group	1) Quality coordinator or person responsible for quality-assurance in the nursing home 2) ACP Reference Persons, with support of ACP Trainer 3) Important decision-makers (e.g. head of residents' care, head nurses)	None
month 7	**Coaching**	Activity 9C: **In-house specialization session 2: Communication with other healthcare professionals (e.g. hospital, family physician).**	In a group	same as above	To be made by ACP Trainer

month 8	**Audit**	Activity 10A: **ACP audit meeting(s)**.	in a group	1) Quality coordinator or person responsible for quality-assurance 2) ACP Reference Persons, with support of ACP trainer 3) important decision-makers (e.g. head of residents’ care, head nurses) 4) Coordinating advisory physician	17. **"ACP audit instrument"**

∗ See Chapter 3.1 of this dissertation

PART 2; ADVANCE CARE PLANNING AND END-OF-LIFE DECISIONS IN DEMENTIA

Chapter 2.1

Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences

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Published: International Journal of Nursing Studies, 107, 103576 (2020).
[2018 SCI impact factor 3.57; Ranking D1; ranking n°1 of 120 in NURSING in SCIE edition]

Abstract

Background: End of life care is often inadequate for people with dementia. Advanced care planning (ACP) has the potential to improve outcomes for people with dementia. The aim of this review is to establish the strength of the evidence and provide decision makers with a clear understanding of what is known about ACP for people living with dementia.

Design: Evidence synthesis including systematic reviews and primary studies. PROSPERO registration: CRD42018107718.

Data sources: PubMed, CINAHL Plus, SCOPUS, Social Care Online and Cochrane Library were searched (July 2018). No year limit applied. To be included, reviews had to evaluate effectiveness of ACP for people with dementia or report on views and experiences of ACP from the perspective of people with dementia, carers, or health and care professionals. Additional searches (September 2018) were conducted to identify recent primary studies not included in the reviews.

Review methods: Data extraction was undertaken by one reviewer and checked by a second. Methodological quality was assessed using AMSTAR-2 and Joanna Briggs Institute instruments by two authors independently. Outcomes were categorized and tabulated to assess effectiveness. Qualitative data was analysed using thematic synthesis.

Results: Nineteen reviews (163 unique studies) and 11 primary articles with a range of advance care planning definitions and of variable quality were included. Advance care planning was associated with decreased hospitalizations, increased concordance between care received and prior wishes and increased completion of advance care planning documents but quality of primary research was variable. Views of ACP for people with dementia can be clustered around six themes; 1) timing and tailoring, 2) willingness to engage, 3) roles and responsibilities of healthcare professionals, 4) relationships, 5) training and 6) resources needed. Diminishing decision-making capacity over time is a key overarching feature.

Conclusions: Advance care planning is acceptable for people with dementia and their carers and is associated with improved outcomes. Guidelines on which outcomes and which definition to use are necessary, as is research to test different approaches to ACP. Education on topics related to diminishing decision-making capacity is key to optimize advance care planning for people with dementia and planning for people with dementia and their carers.

Keywords: Advance care planning, dementia, effectiveness, views and experiences, family carers, people with dementia

What is already known about the topic?

- Due to the neurodegenerative, terminal nature of dementia, advance care planning (ACP) is important for people with dementia and their carers.
- Less than half of people with dementia are involved in ACP conversations worldwide.

What this paper adds

- A range of ACP definitions and outcomes are used in the current literature. The research field would benefit from consensus on which ACP outcomes to use, as well as validating these constructs for people with dementia.
- Evidence of effectiveness of ACP for people with dementia is of variable quality. However, the associations with ACP and decreased hospitalizations, increased concordance between care received and prior wishes and increased completion of ACP documents were found in the majority of reviews and studies which evaluated effectiveness.
- Future research should go beyond descriptive accounts of what is thought to work and test different approaches in different settings that can ensure all parties benefit from involvement in these discussions.

Introduction

Worldwide there are about 50 million people living with dementia. This number is expected to increase to 131.5 million in 2050 (Prince et al., 2015). Characteristic symptoms of dementia are difficulties with memory and language, impaired problem-solving and other cognitive skills that affect a person's ability to perform everyday activities, and disorientation in time, person and place. Dementia is currently irreversible and is, eventually, fatal (Karlawish et al., 2017). People can either die from the dementia itself or from other illnessess, such as pneumonia, a chronic illness or another terminal condition. The likelihood of cognitive and functional decline as the dementia progresses means that individuals' priorities for health, and end-of-life care often need to be discussed before there is obvious deterioration in health (Dixon et al., 2018). This can be done in the form of advance care planning (ACP). A consensus paper from the European Association for Palliative Care (EAPC) describes ACP as care planning that: '*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.*'(R. Sudore et al., 2017).

End-of-life care for people with dementia is often inadequate, either unnecessarily prolonging life with (inappropriate) interventions, such as tube feeding (Sampson et al., 2009), or failing to address the fundamentals of care such as nutrition, pain control and social support (World Health Organization, 2011). ACP could create opportunities for people with dementia to participate in decision-making about their end-of-life care (Dixon et al., 2018). However, less than 40% of people with dementia worldwide currently have the opportunity to participate in an ACP conversation and record their preferences (Sellars et al., 2019). The well documented challenges of talking about death and dying are compounded for someone with dementia who is faced with the difficult task of planning for a future unknown self (Dixon et al., 2018). When decisions about end-of-life care for someone with dementia are left to healthcare professionals and family carers this can cause uncertainty (Brazil et al., 2018) and stress and guilt for carers (Carter et al., 2018). Furthermore, there is evidence that carers may not have a good understanding of the preferences of the person with dementia for end-of-life treatment (Harrison Dening et al., 2016).

There is an increasing literature on ACP for people with dementia, and the last decade has seen the publication of many systematic reviews on the topic. These reviews have covered a variety of aspects of ACP, included different types of studies, and reported a range of different outcomes. Finding and interpreting this evidence may be challenging for practitioners and decision makers. The aim of this review, therefore, is to provide an overall examination of all the available quantitative and qualitative evidence on ACP for people with dementia. We undertook an overview of existing systematic reviews (Smith et al., 2011), also known as an umbrella review (Aromataris et al., 2015). In order to provide a comprehensive and up-to-date overview we also included primary studies not identified by the systematic reviews. The advantage of this approach was that it allowed us to include diverse types of evidence and compare findings from relevant reviews. The objectives of the review were to identify and summarize the evidence on; 1) how ACP is conceptualized by and for people with dementia, 2) the effectiveness of ACP for people with dementia and 3) the experiences and views of ACP of people with dementia, their carers and professionals.

Methods

The review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA) (Moher et al., 2009). The PRISMA checklist can be found in the Supplementary file.

Protocol and registration

The protocol is registered on the PROSPERO website under the registration number: CRD42018107718.

Eligibility criteria

The inclusion criteria were as follows:

- Study design: systematic reviews of quantitative or qualitative evidence or primary research not included in one of the reviews
- Study population: people living with dementia, family or informal carers or healthcare professionals
- Interventions: ACP with people living with dementia and/or carers
- Outcomes: effectiveness of ACP (e.g. care consistent with wishes, number of ACP conversations, number of ACP related written outputs, resource use) and experiences, understanding, or perceptions of ACP.

Search strategy

The electronic databases PubMed, CINAHL Plus, SCOPUS, Social Care Online and The Cochrane Library (CDSR & DARE) were systematically searched for review articles, using a predefined search string composed with the help of a research librarian. In addition we checked reference lists and performed lateral searching using the 'related articles' option in PubMed and the 'cited by' option on Scopus. All searches were carried out on July 5th 2018. Experts within the ACP and dementia field were contacted (N=3, one from the UK, one from Australia, one from the Netherlands) and asked for possible additional studies which we might have overlooked.

Box 2. PubMed search string – Reviews

Search *((advance care planning[MeSH Terms]) OR (advance care plan* OR healthcare directive OR advance medical directive OR health care proxy OR durable power of attorney OR advance directive OR end-of-life decision OR future care plan*)) AND ((dementia[MeSH Terms]) OR dement* OR cognitive impair*) OR Alzheimer*) OR Lewy body disease) OR frontotemporal dementia)) AND ((review) OR realist review OR meta-analysis OR narrative review OR systematic review)*

Primary research studies included in the reviews were tabulated to check for overlap between the reviews. Following this, PubMed, CINAHL Plus and SCOPUS were searched (Jan 2016-18) for recent primary studies on ACP for people with dementia that were not included in any of the reviews. The search string was based upon the search string for the reviews but without the study type search terms.

Study selection

One author (AW-vD) removed duplicates, using Mendeley reference manager software, and screened the titles and abstracts for relevance. A second author (JL) independently screened twenty percent of records. No relevant records were missed by the first author (AW-vD). Full text of potentially relevant papers were screened against the eligibility criteria by one reviewer (AW-vD) and checked by a second author (JL and FB). Discrepancies were resolved by discussion.

Data extraction

The following data were collected using a piloted form: aim(s) and methods, search strategy, setting(s), participants, number of studies included, outcomes reported, ACP definition used, barriers and facilitators, quantitative and qualitative outcomes and main results of the study. Data were extracted by one author (AW-vD) and discussed with two other authors (JL and FB).

Quality appraisal

Included reviews were appraised using the AMSTAR-2 tool (Shea et al., 2017). Because the tool is focused on systematic reviews of randomized controlled trials we adapted it for the purpose of our review, which included reviews of studies of all designs. We omitted three questions concerning meta-analysis and adapted the questions about Risk of Bias (RoB). Critical Appraisal Tools from the Joanna Briggs Institute were used to appraise the quality of primary studies including randomized controlled trials (Tufanaru et al., 2017), qualitative research (Lockwood et al., 2015) and analytical cross-sectional studies (Moola et al., 2017). More details on the appraisal tools can be found in the supplementary file (Table 1e). All appraisal was done by two reviewers independently (AW-vD, FB, BE, NE). No reviews or studies were excluded on the basis of the quality assessment score.

Synthesis

Reviews and primary studies were classified as quantitative, qualitative or mixed methods. Primary studies in each review were tabulated to assess the overlap between reviews. Effectiveness was investigated by categorizing the different outcomes reported and tabulating data including an indication of whether the effects of the intervention were positive, negative or not statistically significant.

For qualitative data, a thematic synthesis (Thomas and Harden, 2008) was done using NVivo 12 software. Thematic synthesis had three stages; 1) coding ‘line-by-line’, 2) developing ‘descriptive themes’ and 3) generating ‘analytical themes’. To be as comprehensive as possible, the line-by-line coding included both the results and the discussion section of the included articles. Differences between groups of stakeholders (people with dementia, carers and healthcare professionals) and settings (home, care home, hospital) were explored. AW-vD performed the initial line-by-line coding of the text. This process was closely monitored by FB. Themes were synthesized by AW-vD and FB and refined after further discussion with JL.

Results

Study characteristics

Nineteen reviews and 11 primary studies met the inclusion criteria. A flow chart detailing the identification of the reviews and primary studies can be seen in Figure 1. A total of 329 primary articles were included in the reviews. When overlap was accounted for 163 unique articles were identified.

Systematic reviews.

The focus of the reviews was as follows:

- evaluations of the effectiveness of ACP n=4 (Bryant et al., 2019; Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014),
- facilitators and barriers for ACP n=9 (Arcand M., 2015; Brooke and Kirk, 2014; Dening et al., 2011; Jethwa and Onalaja, 2015; Petriwskyj et al., 2014a; Read et al., 2018; Tilburgs et al., 2018a; Van Der Steen et al., 2014b; Westenhaver et al., 2010),
- perspectives on and experiences of ACP for people with dementia n=5 (Beck et al., 2017a; Jones et al., 2016; Mignani et al., 2017; Petriwskyj et al., 2014b; Ryan et al., 2017).
- clinical recommendations as a support tool for healthcare professionals working with people with dementia n=1 (Piers et al., 2018).

The number of articles included in the reviews ranged from 4 to 67. Six reviews included only quantitative articles (Arcand M., 2015; Bryant et al., 2019; Dixon et al., 2018; Petriwskyj et al., 2014a; Robinson et al., 2012; Wickson-Griffiths et al., 2014). The rest included either qualitative or a mixture of quantaitve and qualitative articles (Beck et al., 2017a; Brooke and Kirk, 2014; Dening et al., 2011; Jethwa and Onalaja, 2015; Jones et al., 2016; Mignani et al., 2017; Petriwskyj et al., 2014b; Piers et al., 2018; Read et al., 2018; Ryan et al., 2017; Van Der Steen et al., 2014a; Westenhaver et al., 2010). Most reviews included either all settings (N=10), or the long-term care setting only (N=6). The views of people with dementia were incorporated in 13 reviews (Dening et al., 2011; Dixon et al., 2018; Jethwa and Onalaja, 2015; Jones et al., 2016; Mignani et al., 2017; Piers et al., 2018; Read et al., 2018; Robinson et al., 2012; Ryan et al., 2017; Tilburgs et al., 2018a; Van Der Steen et al., 2014b; Westenhaver et al., 2010; Wickson-Griffiths et al., 2014). Three reviews (Beck et al., 2017a; Brooke and Kirk, 2014; Piers et al., 2018) included reviews (Dening et al., 2011; Robinson et al., 2012; Van Der Steen et al., 2014b) that were also included as a source within this manuscript. Three reviews had no unique articles (Brooke and Kirk, 2014; Robinson et al., 2012; Ryan et al., 2017). In total 163 unique articles were incorporated, furthermore 33 studies were included in two reviews, 21 in three, 7 in four, 1 in five and 1 in six of the reviews. Tabulation of all reviews and their included articles can be be found in the supplementary file (Table 2e) as well as characteristics of included reviews (Table 3e).

Primary research articles.

The focus of the primary research was as follows

- effectiveness of an ACP programme n=1 (Mitchell et al., 2018)
- effectiveness of ACP training for healthcare professionals n=1 (Katwa et al., 2018)
- facilitators and barriers for ACP n=3 (Lo et al., 2017; McGlade et al., 2017; Tilburgs et al., 2018b)
- views, perspectives and experiences of ACP for people with dementia n=6 (Ashton et al., 2016; Beck et al., 2017b; de Vries and Drury-Ruddlesden, 2018; Givens et al., 2018; Jung et al., 2017; Sinclair et al., 2016).

Settings included long-term care (N=5), the community (N=3), hospital (N=2) or primary care (N=1). Three studies included the views of people with dementia, either using surveys (Jung et al., 2017) or via face-to-face encounters (Lo et al., 2017; Tilburgs et al., 2018b), but no studies reported the views of people with severe/advanced dementia. Healthcare professionals involved were general practitioners (GPs), physicians, nursing home managers, nursing home care staff and other professionals caring for people with dementia (e.g. practice nurses, case managers). Carers are family caregivers (e.g. spouses, children), healthcare proxies and surrogate decision makers. Characteristics of the included primary studies can be found in the supplementary file (Table 4e).

Quality appraisal

Quality scores for the included reviews (Supplementary file, Table 5e) ranged from two out of thirteen to 10/13. All but one explained the heteroginity of their findings and around half of the included reviews assessed and accounted for Risk of Bias in their manuscripts. Almost none of the included reviews published or drafted a study protocol before starting their studies. Of the primary studies the cluster RCT (Mitchell et al., 2018) fulfilled all but one of the criteria. The intervention was not delivered to blinded groups, however, this was due to the nature of the intervention. Scores for the qualitative studies ranged from 5-8 from a possible total of 10. All studies showed congruity between their chosen methodology and their research question, their methods used and the interpretation of their findings. However, none addressed the potential influence of the researcher on the research conducted. For the cross-sectional papers subjects, setting and statistical analysis were deemed appropriate, however the identification and inclusion of confounders was lacking in most of the studies.

ACP Definition

A wide range of ACP definitions was used. Some used definitions from national or international health organizations (e.g. WHO, 2011, N=2) or the EAPC white paper definition of Rietjens et al. (Rietjens et al., 2017)(N=3). Others used their own definition (N=7, of which 5 were reviews). None of the definitions used was specifically designed for ACP with people with dementia.

Most authors identified ACP as;

1) a multi-stage, voluntary, interactive, continuous, formalized process (Beck et al., 2017a, 2017b; Bryant et al., 2019; de Vries and Drury-Ruddlesden, 2018; Dening et al., 2011; Dixon et al., 2018; Jung et al., 2017; Lo et al., 2017; McGlade et al., 2017; Mignani et al., 2017; Piers et al., 2018; Robinson et al., 2012; Ryan et al., 2017; Tilburgs et al., 2018b, 2018a; Wickson-Griffiths et al., 2014)

2) being a discussion or conversation between either, individuals and healthcare professionals (Ashton et al., 2016; Brooke and Kirk, 2014; de Vries and Drury-Ruddlesden, 2018; Dening et al., 2011; Jones et al., 2016), patient and informal carer (Beck et al., 2017a, 2017b; Robinson et al., 2012; Ryan et al., 2017; Van Der Steen et al., 2014b; Westenhaver et al., 2010) or patient, carer and healthcare professional (Arcand M., 2015; McGlade et al., 2017; Mignani et al., 2017; Piers et al., 2018; Read et al., 2018; Ryan et al., 2017; Tilburgs et al., 2018a, 2018b; Wickson-Griffiths et al., 2014; Givens et al., 2018),

3) about goals and preferences for future care (Arcand M., 2015; Ashton et al., 2016; E. R. Beck et al., 2017b, 2017a; Brooke and Kirk, 2014; Dixon et al., 2018; Jones et al., 2016; Lo et al., 2017; McGlade et al., 2017; Piers et al., 2018; Read et al., 2018; Robinson et al., 2012; Ryan et al., 2017; Sinclair et al., 2016; Tilburgs et al., 2018b, 2018a; Van Der Steen et al., 2014b; Wickson-Griffiths et al., 2014; Givens et al., 2018), future wishes (Bryant et al., 2019; de Vries and Drury-Ruddlesden, 2018), or end-of-life decisions (Jethwa and Onalaja, 2015; Piers et al., 2018; Van Der Steen et al., 2014b),

4) in anticipation of future deterioration (Ashton et al., 2016; Brooke and Kirk, 2014; de Vries and Drury-Ruddlesden, 2018; Dening et al., 2011; Jones et al., 2016; Lo et al., 2017; Read et al., 2018; Sinclair et al., 2016) or awaiting reduced capacity or mental incompetence (Bryant et al., 2019; de Vries and Drury-Ruddlesden, 2018; Dixon et al., 2018; Jung et al., 2017; Mignani et al., 2017; Van Der Steen et al., 2014b).

Some advocated ongoing review of ACPs (Ryan et al., 2017; Tilburgs et al., 2018a, 2018b) or at least some continuing communication (Givens et al., 2018; Sinclair et al., 2016). The benefit of ACP was identified as creating a shared understanding between the person with dementia and their carers and healthcare professionals (Beck et al., 2017a, 2017b; Wickson-Griffiths et al., 2014) and promoting autonomy and choice for the person with dementia (Jethwa and Onalaja, 2015).

Effectiveness of ACP

Four reviews (Bryant et al., 2019; Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014) and one primary study (Mitchell et al., 2018), reported the effectiveness of ACP programs for people with dementia or cognitive impairment and their carers. The four reviews included 32 primary articles, of which 26 focussed solely on people with dementia and their carers. The included reviews reported on 25 unique primary studies, of which six used a (cluster) randomized controlled trial design, five used a cross-sectional study design, four a retrospective design, four a prospective design, three a before and after design, one a quasi-experimental design, one an evaluation without a control group and one was a feasibility study. Sixteen of these primary studies included in the reviews used patient notes or files as their main source of data-collection. Ten studies also included measures to collect data from the persons with dementia themselves.

Thirty-nine different outcomes were reported, with limited consensus on core outcomes. Outcome measures used in the reviews and the primary study (RCT), fell into five categories; 1) ACP and end-of-life outcomes, 2) healthcare utilisation, 3) patient outcomes, 4) carer outcomes and 5) resource use. All results are reported in Table 1. Either positive associations with ACP, or no change from the intervention was found for most outcomes for people with dementia and their carers. However, all reviews stated the quality of the included studies was of variable quality. Despite concerns that talking about dying and future wishes could be distressing, none of the reviews or the primary study identified any negative association with ACP. The most frequently reported outcomes are summarised in the text.

ACP and end of life outcomes

The completion of ACP documents was used as an outcome in three of the four included reviews and in the primary study (Bryant et al., 2019; Mitchell et al., 2018; Robinson et al., 2012b; Wickson-Griffiths et al., 2014). Most reported a significant association between ACP interventions and an increase in ACP documentation (Mitchell et al., 2018; Robinson et al., 2012b; Wickson-Griffiths et al., 2014). In three reviews, concordance between subsequent care and stated wishes was found to increase significantly where there had been an ACP intervention (Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014).

Healthcare utilisation

Hospitalisation rate was measured in all included reviews (Bryant et al., 2019; Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014), of which three showed a significant decrease in hospital use related to the presence of an advance care plan.

Patient and carer outcomes

People with dementia's satisfaction with care was measured in three reviews (Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014). One review, in the nursing home setting, showed significant positive associations with ACP (Wickson-Griffiths et al., 2014), the other two found no effect. Two of the three reviews that reported carer satisfaction with care found a significant increase post ACP interventions (Bryant et al., 2019; Dixon et al., 2018), the other found no effect (Robinson et al., 2012).

Experiences and views of ACP

We identified six discrete themes, with 19 different subthemes. Supporting evidence can be seen in Table 2. All themes were based upon input from people with dementia, carers and healthcare professionals. No differences were identified between different settings (home, nursing home, hospital).

Theme 1 'tailoring the approach and timing to the needs of people with dementia' The difficulties of knowing the best time to initiatie ACP discussions with the person with dementia and their family carer was a recurring theme and concerned, timing, initiation, communication, informal conversations and individualised approach. Recommendations for tailoring ACP to be suitable for people with dementia and their carers included, reflecting a commitment to personalized care, a recognition that ACP was likely to be an ongoing, repeated process over time, and communication approaches that fit with the style and level of the person with dementia. Some carers and healthcare professionals stated that immediately post diagnosis would be a suitable time to discuss ACP, others argued that a person should be given some time to become familiar with the dementia diagnosis and some felt that a decrease in the general health status of a person with dementia (e.g. pneumonia, broken hip) would be the right point to initiate ACP. Ryan et al., (Ryan et al., 2017) decribed finding the right moment as a balancing act between an individual's understanding of the implications of a dementia diagnosis and their diminishing decision-making capacity. As well as routine discussions as part of doctors' appointments ACP can involve informal, spontaneous conversations.

Theme 2 'variability in capacity and willingness to engage in ACP' highlights the differences between how people with dementia and their carers engage in ACP. People with dementia appeared to show little distress about engaging in ACP conversations whilst carers often found the decision-making tasks stressful and challenging. The diminishing decion-making capacity of people with dementia is a concern for both healthcare professionals and carers. However, studies found people with dementia are able to consistently express their future wishes and discuss values and healthcare decisions. Instances when people with dementia and carers were reluctant to engage in ACP related to a lack of familiarity with the process and the specific content of ACP and concerns about the future. Personal factors, such as strong religious beliefs, low social status and low IQ can also influence how people with dementia and carers engage in ACP.

Theme 3 'roles and responsibilities of healthcare professionals'. Healthcare professionals agreed that ACP is important for people with dementia, but consistently identified barriers including fear of causing stress and anxiety for people with dementia and carers, and not being able to comply with future wishes because of (possible) changes in the healthcare system. Healthcare professionals also identified a lack of clarity around whose role it is to initiate ACP. However, healthcare professionals are consistently identified by both themselves, as well as people with dementia and their carers, as the most appropriate party to initiate ACP conversations.

Theme 4 'impact of relationships on ACP' highlights that complex family dynamics can hinder ACP conversations, while a trusting relationship between carers and healthcare professionals can facilitate ACP conversations. The latter is especially important when the person with dementia is in the advanced stages of dementia. The quality of the healthcare professional-carer relationship depends on a range of interpersonal and contextual factors. How this can be assessed however, was not discussed in the evidence reviewed.

Theme 5 'the need to equip people with dementia, carers and professionals to engage in ACP'. Education and training were identified as important in preparing and enabling people to engage in ACP. For people with dementia an understanding of the dementia disease trajectory and of what ACP can achieve are facilitators. Carers of people with dementia could also benefit from training on these themes, as well as education on life-sustaining treatment, the role of a surrogate decision maker, ACP and palliative and end-of-life care. Training and education for healthcare professionals on ACP, the dementia disease trajectory, treatment options and communications skills were found to be facilitators when initiating conversations about ACP with people with dementia and their carers.

Theme 6 'lack of resources supporting ACP' captures the time, skills and access to training materials that staff often require to be confident in ACP and achieve quality conversations. More time for healthcare professionals to spend with individuals would facilitate ACP. Furthermore, financial resources for professionals would stimulate initiation of ACP conversations. Lastly, research has shown that decision-making tools and videos can be facilitators for ACP conversations with people with dementia and their carers.

Discussion

We identified 19 reviews including 163 unique studies, and an additional 11 primary studies on ACP for people with dementia. The results suggest that ACP can be implemented with and for people with dementia resulting in increased ACP documentation, greater concordance between care and an individuals' wishes, and increased satisfaction with care from both the point of view of people with dementia and their family carers. Furthermore, there is some evidence that the use of ACP is associated with decreased hospitalization rates of people with dementia. The effectiveness reviews and primary studies included in this review showed either positive associations with ACP, or no change from the interventions for people with dementia and their carers. What emerged from the thematic analysis was the variety of individual and organizational factors that impacted the way healthcare professionals and people with dementia and their carers engaged in ACP. Although there were many commonalities, for example positive relationships were a facilitator, views about the appropriate timing of ACP varied. There remains a lack of consensus on which ACP definition should be used for people with dementia. None of the current definitions focus specifically on people living with dementia (Van Der Steen et al., 2014a).

Outcome measures identified in this review could be clustered into five categories; 1) ACP and end-of-life outcomes, 2) healthcare utilization, 3) patient outcomes, 4) carer outcomes and 5) resource use. These categories are similar to those agreed in a recent international Delphi study on ACP (R. L. Sudore et al., 2017). This might suggest that outcomes of relevance to the general population are also likely to be relevant to people with dementia. However, it is also possible that researchers choose these outcomes based on previous research in populations of people without dementia or cognitive impairment. There is a need for outcome measures that specifically reflect the needs of people with dementia. This might include focusing more on people's sense of control and autonomy (Jimenez et al., 2018), or adjusting measures to closely match the impact of ACP conversations on feelings of security, mood and hope (Van den Block, 2019). Furthermore, both short and longer-term effects of ACP conversations on people with dementia and carers should be evaluated (Van den Block, 2019).

In terms of experiences and views of ACP for people with dementia, we found that there was a shared recognition that ACP conversations should be person-centered and communication and timing should be tailored to the level and wishes of the person with dementia. As with all conversations about death and dying, decisions about initiating ACP conversations were hampered by concerns about when to initiate and who should initiate (Goodman et al., 2015). The high likelihood of diminishing decision-making capacity for people with dementia exacerbated this feeling of uncertainty for both healthcare professionals and carers. However, our results suggest that people with dementia are able to express their future support needs and also find it important to do this.

The fear of causing stress and anxiety for people with dementia and carers is a persistent barrier that might be linked to the stigma and social dread associated with dementia (WHO, 2012). Evidence indicates that this can be mitigated by relationship continuity. When there are trusting and open relationships between carers and healthcare professionals, ACP conversations are more likely to occur. Recent research argued that these supporting relationships help overcome difficult emotions such as anxiety and stress for carers of people with dementia (Parkinson et al., 2017). The growing interest in initiatives to promote dementia awareness and community engagement with people with dementia (OECD, 2018) could also support conversations about living and dying with dementia that extend beyond the individual-professional encounter, for example during informal conversations and discussions within the family (de Vries and Drury-Ruddlesden, 2018) or a social (peer) group. However, few of the primary studies or reviews discussed how initiatives to promote community engagement and the inclusion of people with dementia could change how living and dying with dementia is discussed in wider society.

The lack of training for difficult conversations, awareness of the dementia trajectory and confidence in what services could be provided at the end of life were barriers repeatedly identified in this umbrella review. Therefore, training and education for all parties involved is recommended in many of the included papers. Research has shown that ACP training is associated with improved outcomes in nursing homes (Aasmul et al., 2018), confidence in undertaking ACP conversations with people with dementia (Katwa et al., 2018), and a reduction in uncertainty in decision-making (Brazil et al., 2018). However, merely educating healthcare professionals might not be sufficient to create real change for people with dementia. As Gilissen and colleagues showed in a recent paper (Gilissen et al., 2018), overall cultural change is needed to embed ACP conversations in standard care.

Strengths and limitations

The rapid increase in research on ACP for this population means that a review of reviews that synthesizes the evidence from qualitative, quantitative and mixed-methods reviews provides a resource of what is known and a platform for future work. Furthermore, by including a search on recent primary studies, this paper offers a comprehensive overview of the existing knowledge, methodological approaches and how people with dementia can be involved in research on ACP. Thirteen of the 19 included reviews used articles with direct data from people with dementia, as well as three of the primary studies.

We assessed the quality of included reviews using a modified version of the AMSTAR-2 (Shea et al., 2017). It is possible that these modification may have impacted the vailidity of the tool. However, since we did not exclude articles based on the quality appraisal, the results of this review have not been altered by these adjustments. Another limitation is the wide range of outcome measures found in the included studies. The lack of agreement on which primary outcome to use, ultimately leads to a lack of strong evidence on the effectiveness of ACP for people with dementia. Some outcome measures however, were found in multiple studies, increasing the likelihood of impact of these measures. Lastly, identifying differences in outcomes between different settings is difficult from reviews, therefore this could not be explored indepth. We would therefore recommend a focus on differences between context in future research.

There is no consensus about what ACP for people with dementia should include or the best outcomes to use when testing ACP effectiveness for people with dementia. Sudore and colleagues (R. L. Sudore et al., 2017), have advocated for further research to identify ACP outcome measures and validate them for use in research. We strongly underline the latter, since many of the theoretical assumptions in the included papers were implicit or not validated for people with dementia. Furthermore, the primary studies included in the reviews were of variable quality, leading to further difficulties in identifying the best outcomes for people living with dementia.

Conclusions

This review of reviews found ACP interventions to be acceptable for people with dementia and their carers and to be associated with improved outcomes. The consistent findings across the reviews and the primary studies of the challenges faced by both healthcare professionals and carers would suggest that there is a limited need for further descriptive research on barriers and facilitators. Future studies should focus on how to involve people with dementia in decision making, the impacts of different approaches to ACP and the most appropriate timing for the initiation of ACP. To further align this research, we would advocate for the consistent use of an ACP definition, specifically targeting ACP for people with dementia. Furthermore, we believe future work could consider if ACP as a standalone activity reflects the experience and preferences of people with dementia or whether it could be integrated into ongoing decision making activities that recognize the intrinsic uncertainty of living (and dying) with dementia reflecting preferences and priorities for everyday care and service availability (Goodman, 2018).

Acknowledgements: Angela Dimond – information manager at UH, for the help with composing the search string. Babatunde Elugbaju & Nyemah Elnemr – nursing students, for the help with the quality appraisal.

Authorship:
Aims and search strategy: AW-vD, FB, JL, CG
Screening of the articles: AW-vD, FB, JL
Quality appraisal: Aw-vD, FB
All the authors contributed to drafting the review or revising it critically for important intellectual content. All the authors have approved the version to be published and have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Conflicts of interest: none

Funding: This work was supported Marie Sklodowska-Curie Innovative Training Network (ITN), H2020-MSCA-ITN-2015, under grant agreement number 676265. JL is a NIHR Knowledge Mobilisation Research Fellow. LP is a Postdoctoral Fellow of the Research Foundation Flanders (FWO). CG is NIHR Senior Investigator. The sponsors had no role in study design; in the collection, analysis and interpretation of data; in the writing of the report; or in the decision to submit the article for publication.

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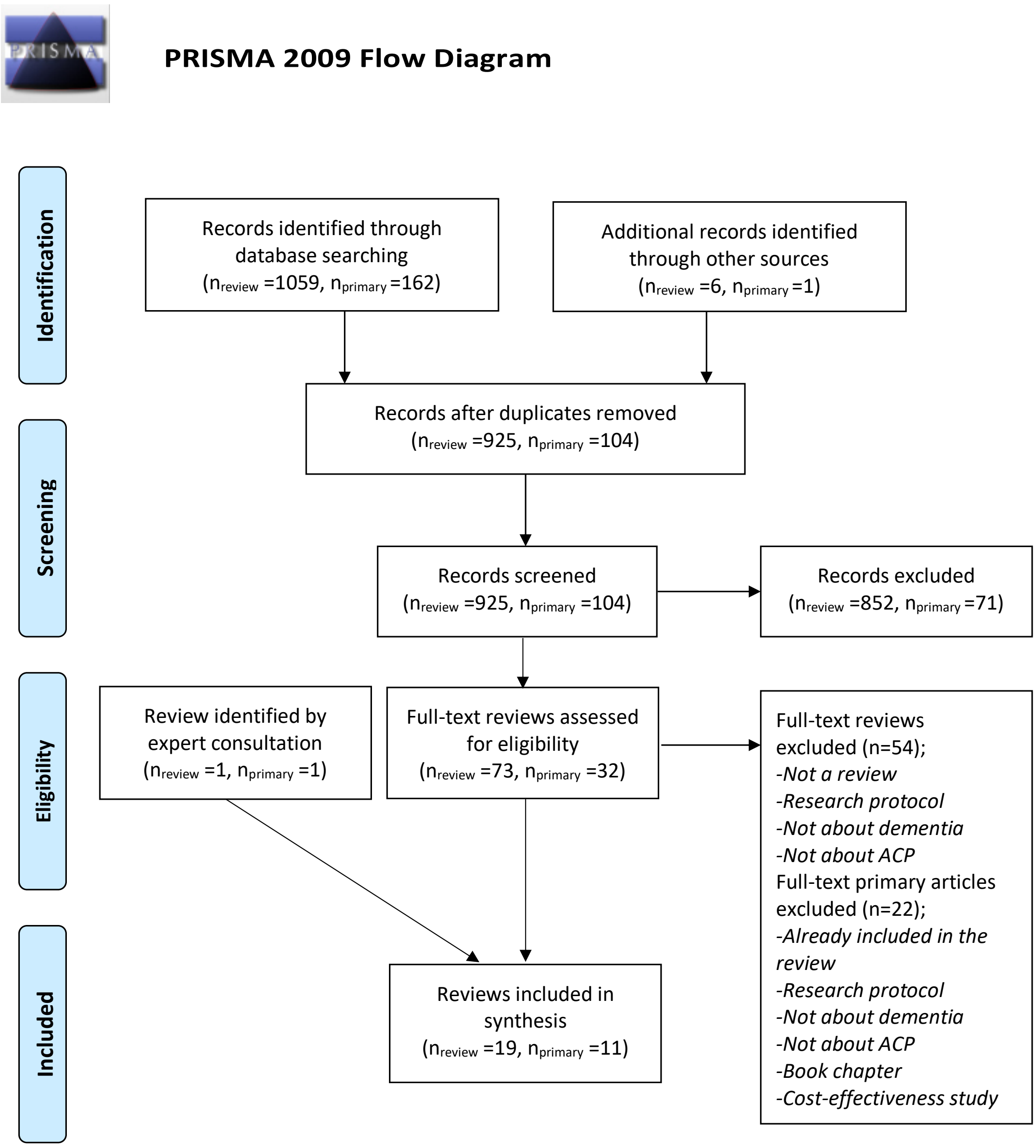

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Figure 1. PRISMA Flow Diagram of included reviews and primary articles

Table 1. Effectiveness of Advanced Care Planning
Outcome data provided by the reviews (n=3) and *primary study* (n=1)

Outcome measure	**Reviews and studie(s) reporting outcome (N)**	**Positive outcome (significant result reported)**	**No change**	**Study quality score (out of 13)**
ACP and end-of-life outcomes				
Concordance between care and wishes	Dixon, 2018; Robinson, 2012; Wickson-Griffiths, 2014 (N=3)	Increase (all primary studies in all reviews)		8.5 10 7.5
Burdensome transitions	Dixon, 2018 (N=1)	Decrease (all primary studies)		8.5
Place of death	Dixon, 2018 (N=1)	Increase in dying in preferred place (2/3 primary studies)	No effect found (1/3 primary studies)	8.5
Completion of ACP documents (incl. DNR)	Bryant, 2019; Robinson, 2012; Wickson-Griffiths, 2014; *Mitchell, 2018* (N=4)	Increase (1/2 primary studies in Wickson-Griffiths, 2014), increase (all primary studies in Robinson, 2012; *Mitchell, 2018*)	No effect found (1/4 primary studies in Bryant, 2019)	8.5 10 7.5 12
Number of ACP referrals	Robinson, 2012 (N=1)		No effect found (all primary studies)	10
Number of ACP discussions	Robinson, 2012; Wickson-Griffiths, 2014 (N=2)	Increase (1/6 primary studies in Wickson-Griffiths, 2014)	No effect found (all primary studies in Robinson, 2012)	10 7.5
Number of residents receiving palliative care and pain treatment	Robinson, 2012 (N=1)	Increase in pain assessment (all primary studies)	No difference found in use of pain medication (all primary studies)	10
Knowledge of residents wishes	Wickson-Griffiths, 2014 (N=1)	Increase (all primary studies)		7.5
Adherence to family's preferences	Wickson-Griffiths, 2014 (N=1)	Increase (all primary studies)		7.5
Burdensome treatments	*Mitchell, 2018 (N=1)*		No effect found	12
Level of care preferences	*Mitchell, 2018 (N=1)*		No effect found	12
Health utilization				
Hospitalization	Dixon, 2018; Robinson, 2012; Wickson-Griffiths, 2014; Bryant, 2019 (N=4)	Reduced hospitalization rates (all primary studies in Wickson-Griffiths, 2014; Robinson, 2012; Dixon, 2018)	No effect found (all primary studies in Bryant, 2019)	8.5 10 7.5 8.5

ICU use	Dixon, 2018 (N=1)	Reduction (all primary studies)		8.5
Tube feeding	Dixon, 2018 (N=1)	Reduction (1/2 primary studies)	No effect found (1/2 primary studies)	8.5
Days spend in hospital	Dixon, 2018; Robinson, 2012 (N=2)	Reduction (all primary studies in Robinson, 2012; 1/2 primary studies in Dixon, 2018)	No effect found (1/2 primary studies in Dixon, 2018)	8.5 10
Emergency ambulance calls	Dixon, 2018; Robinson, 2012 (N=2)	Reduction (all primary studies in all reviews)		8.5 10
Hospice use	Robinson, 2012 (N=1)	Increase (all primary studies)		10
Life-sustaining treatments	Dixon, 2018 (N=1)		No effect found (all primary studies)	8.5
Patient outcomes				
Anxiety	Dixon, 2018 (N=1)		No effect found (all primary studies)	8.5
Depression	Dixon, 2108 (N=1)	Reduction (all primary studies)		8.5
General health	Bryant, 2019 (N=1)		No effect found (all primary studies)	8.5
Quality of life	Dixon, 2018; Wickson-Griffiths, 2014 (N=2)	Significant increase (all primary studies in Wickson-Griffiths, 2014; 1/2 primary studies in Dixon, 2018)	No effect found (1/2 primary studies in Dixon, 2018)	8.5 7.5
Decisional conflict	Dixon, 2018 (N=1)	Reduction (all primary studies)		8.5
Stability of healthcare choices	Wickson-Griffiths, 2014 (N=1)	Increase (all primary studies)		7.5
Satisfaction with care	Robinson, 2012; Wickson-Griffiths, 2014; Dixon, 2018 (N=3)	Increase (all primary studies in Wickson-Griffiths, 2014)	No effect found (all primary studies in Robinson, 2012; Dixon, 2018)	10 7.5 8.5
Carer outcomes				
Decisional conflict	Bryant, 2019 (N=1)	Decrease (all primary studies)		8.5
Confidence in treatment decisions made	Bryant, 2019 (N=1)	Increase (all primary studies)		8.5
Knowledge of dementia	Bryant, 2019 (N=1)		No effect found (all primary studies)	8.5
Comfort with knowledge	Bryant, 2019 (N=1)		No effect found (all primary studies)	8.5

Emotional distress	Dixon, 2018 (N=1)	Decrease (all primary studies)		8.5
Physical distress	Dixon, 2018 (N=1)	Decrease (all primary studies)		8.5
Anxiety	Dixon, 2018 (N=1)		No effect found (all primary studies)	8.5
Depression	Dixon, 2018 (N=1)	Reduction (all primary studies)		8.5
Quality of life	Dixon, 2018 (N=1)	Increase (all primary studies)		8.5
Satisfaction with care	Dixon, 2018; Robinson, 2012; Bryant, 2019 (N=3)	Increase (all primary studies in Bryant, 2019; Dixon, 2018)	No effect found (all primary studies in Robinson, 2012)	8.5 10 8.5
ACP knowledge	Wickson-Griffiths, 2014 (N=1)	Increase (all primary studies)		7.5
Resource use				
Healthcare costs	Dixon, 2018 (N=1)	Reduction (all primary studies)		8.5
Hospital costs	Dixon, 2018; Robinson, 2012 (N=2)	Reduction (all primary studies in all reviews)		8.5 10
Cost per resident	Wickson-Griffiths, 2014 (N=1)	Reduction (all primary studies)		7.5

ACP; advance care planning, DNR; do not resuscitate, ICU; intensive care unit

Table 2. E

xperiences of and perspectives on ACP

Results of the thematic synthesis of reviews and primary studies

Themes	Subthemes	Reviews	Quality score reviews (all out of 13)	Primary studies	Quality score primary studies	Example
Tailoring the approach and timing to the needs of PwD	Communication	Piers, 2018;	10	Tilburgs, 2018	8/10	Adjust communication to the needs of the PwD (e.g. severity of dementia)
	Informal conversations	Tilburgs, 2018; Ryan, 2017; Petriwskyj, 2014 (qual); Brooke, 2014	9.5 7 6.5 2.5	de Vries, 2018; Asthon, 2016	8/10 8/10	Informal conversations between PwD, carers and/or HCP happen frequently and are preferred by PwD and carers
	Individual approach	Piers, 2018; Petriwskyj, 2014 (qual); Jones, 2016; Petriwskyj 2014 (quant)	10 6.5 10 5	Sinclair, 2016;	7/10	HCP should consider the specific situation of the PwD and carer
	Initiation	Brooke, 2014; Ryan, 2017; Jones, 2016; van der Steen, 2014; Mignani, 2017; Piers, 2018; Dening, 2011; Petriwskyj, 2014 (quant); Tilburgs, 2018; Beck, 2017	2.5 7 10 8.5 10 10 8 5 9.5 6.5	Jung, 2017; McGlade, 2017; Sinclair, 2016; Tilburgs, 2018; Beck, 2017	4/8 5/10 7/10 8/10 4/8	Concerns about when to initiate ACP is a barrier
	Timing	Piers, 2018; Dening, 2011; Petriwskyj, 2014 (qual); Jones, 2016; van der Steen, 2014	10 8 6.5 10 8.5	Sinclair, 2016; Tilburgs, 2018; McGlade, 2017; Beck, 2017	7/10 8/10 5/10 4/8 .	ACP conversations should be held on varies occasions

Variability in capacity and willingness to engage in ACP	Decision-making capacity	Beck, 2017; Read, 2018; Tilburgs, 2018; Jethwa, 2015; Dening, 2011; Brooke, 2014; Piers, 2018; Ryan, 2017; Westenhaver, 2010; Mignani, 2017	6.5 10 9.5 5 8 2.5 10 7 2.5 10	McGlade, 2017; Beck, 2017; Givens, 2018	5/10 4/8 6/8	Professionals worry about (diminishing) decision-making capacity and so do carers. PwD believe they are able to express their future support needs.
	Willingness to engage, carers	Petriwskyj, 2014 (quant); Petriwskyj, 2014 (qual); Mignani, 2017; van der Steen, 2014; Ryan, 2017; Dening, 2011; Westenhaver, 2010; Brooke, 2014; Arcand, 2015; Tilburgs, 2018; Jones, 2016	5 6.5 10 8.5 7 8 2.5 2.5 2 9.5 10	Ashton, 2016; Jung, 2017; de Vries, 2018; Lo, 2017; Sinclair, 2016; Tilburgs, 2018; Givens, 2018	8/10 4/8 8/10 8/8 7/10 8/10 6/8	For carers, decision making can be positive, but also a stressful and challenging task. Views of carers vary greatly. Low IQ, low social status, strong religious beliefs, ethnic minority status, carer burden and guilt are barriers for ACP. Earlier ACP experiences are facilitator for ACP.
	Willingness to engage, PwD	Dening, 2011; Petriwskyj, 2014 (quant); Petriwskyj, 2014 (qual); Westenhaver, 2010; Jethwa, 2015; Tilburgs, 2018; Read, 2018; Migani, 2017; Ryan, 2017; van der Steen, 2014	8 5 6.5 2.5 5 9.5 10 10 7 8.5	Lo, 2017; Jung, 2017; McGlade, 2017; Tilburgs, 2018	8/8 4/8 5/10 8/10	PwD show no distress before or after an ACP conversation, are not always keen on having a conversation, but find ACP important. Strong religious beliefs are a barrier to engage in ACP. Older age, higher education, being single and having an active coping strategy are facilitators to engage in ACP.
Roles & responsibilities	Healthcare system	Arcand, 2015; Beck, 2017; Jones, 2016; Petriwskyj,	2 6.5 10	Jung, 2017; McGlade, 2017;	4/8 5/10 8/10	HCP fear they cannot comply to future wishes because of

of healthcare professionals		2014 (quant); Piers, 2018; Ryan, 2017; van der Steen, 2014; Tilburgs, 2018; Wickson-Griffiths, 2014	5 10 7 8.5 9.5 7.5	Tilburgs, 2018; Beck, 2017	4/8	(changes in) the healthcare system
	HCP; professional views	Arcand, 2015; Beck, 2017; Dening, 2011; Jethwa, 2015; Ryan, 2017; Tilburgs, 2018	2 6.5 8 5 7 9.5	Lo, 2017; McGlade, 2017; Tilburgs, 2018; Beck, 2017	8/8 5/10 8/10 4/8	Being unsure who's role it is to initiate ACP is a barrier
	HCP; attitudes	Brooke, 2014; Beck, 2017; Tilburgs, 2018; Jones, 2016; Ryan, 2017	2.5 6.5 9.5 10 7	Beck, 2017; Tilburgs, 2018	4/8 8/10	Taking initiative, time and a positive attitude are facilitators. Fear of causing fear, anxiety or distress is barrier for ACP
The impact of relationships on ACP	Carers and PwD	Jethwa, 2015; Petriwskyj, 2014 (qual); Petriwskyj, 2014 (quant); Piers, 2018; Dening, 2011; Beck, 2017; Mignani, 2017; Arcand, 2015; van der Steen, 2014; Tilburgs, 2018	5 6.5 5 10 8 6.5 10 2 8.5 9.5	Givens, 2018; McGlade, 2017; Tilburgs, 2018; Beck, 2017	6/8 5/10 8/10 4/8	Complex family dynamics is a barrier
	Carers and HCP	Arcand, 2015; Dening, 2011; Piers, 2018; Tilburgs, 2018; Petriwskyj, 2014 (qual); Petriwskyl,	2 8 10 9.5 6.5 5	Ashton, 2016; McGlade, 2017; Beck, 2017; Tilburgs, 2018	8/10 5/10 4/8 8/10	Trusting relationship between carers and professionals is a facilitator for ACP

		2014 (quant) Ryan, 2017; van der Steen, 2014	7 8.5			
The need to equip PwD, carers and healthcare professionals to engage in ACP	HCP training and education	Brooke, 2014; Ryan, 2017; Dening, 2011; Jethwa, 2015; Arcand, 2015; Jones, 2016; Piers, 2018; Tilburgs, 2018; Beck, 2017	2.5 7 8 5 2 10 10 9.5 6.5	Katwa, 2018; McGlade, 2017; Givens, 2018; Tilburgs, 2018; Beck, 2017;	6/8 8/10 4/8	HCP need education about ACP in general and legal issues specifically; about the dementia disease trajectory; about treatment options, incl. withholding or withdrawing treatment; and about communication skills
	Carer training and education	Arcand, 2015; Dening, 2011, Petriwskyj, 2014 (quant); Brooke, 2014; Piers, 2018;	2 8 5 2.5 10	Beck, 2017; Tilburgs, 2018;	4/8 8/10	Carers need education about life-sustaining treatment, the role of a surrogate decision maker, ACP and palliative and end-of-life care.
	PwD training and education	Piers, 2018; van der Steen, 2014; Brooke, 2014; Mignani, 2017; Read, 2018	10 8.5 2.5 10 10	Jung, 2017; Givens, 2018; Lo, 2017;	4/8 6/8 8/8	PwD need training on the dementia disease trajectory and ACP
Lack of resources supporting ACP	Costs	Petriwskyj, 2014 (quant); Tilburgs, 2018;	5 9.5	Sinclair, 2016; Tilburgs, 2018	7/10 8/10	ACP consultation time should be reimbursed to HCP, possibly with a unique dossier code
	Tools	Petriwskyj, 2014 (quant); Tilburgs, 2018	5 9.5	Mitchell, 2018	12/13	Decision-making tools or videos are facilitators for ACP
	Time	van der Steen, 2014; Tilburgs, 2018	8.5 9.5	McGlade, 2017; Tilburgs, 2018; Beck, 2017;	5/10 8/10 4/8	Lack of time of HCP is a barrier for ACP

PwD; people with dementia, ACP; advance care planning, HCP; healthcare professional

Table 1e. Quality assessment criteria

Study type and tool used	Scoring criteria
Reviews – AMSTAR-2 *Yes, Partial Yes, No*	1. Did the research questions and inclusion criteria include the components of PICO? 2. Did the report of the review contain an explicit statement thet the review methods were established prior to the conduct of the review and did the report justify any significant deviations from the protocol? 3. Did the review authors explain their selection of the study designs for inclusion in the review? 4. Did the review authors use a comprehensive literature search strategy? 5. Did the review authors perform study selection in duplicate? 6. Did the review authors perform data extraction in duplicate? 7. Did the review authors provide a list of excluded studies and justify the exclusions? 8. Did the review authors describe the included studies in adequate detail? 9. Did the review authors use a satisfactory technique for assessing risk of bias (RoB) in individual studies that were included in the review? 10. Did the review authors report on the sources of funding for the studies included in the review? 13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review? 14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review? 16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?
Cluster randomized controlled trial – Joanna Briggs Institute *Yes, No, Unclear, Not Applicable*	1. Was true randomization used for assignment of participants to treatment groups? 2. Was allocation to groups concealed?

	3. Were treatment groups similar at the baseline? 4. Were participants blind to treatment assignment? 5. Were those delivering treatment blind to treatment assignment? 6. Were outcomes assessors blind to treatment assignment? 7. Were treatment groups treated identically other than the intervention of interest? 8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed? 9. Were participants analyzed in the groups to which they were randomized? 10. Were outcomes measured in the same way for treatment groups? 11. Were outcomes measured in a reliable way? 12. Was appropriate statistical analysis used? 13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?
Qualitative research – Joanna Briggs Institute *Yes, No, Unclear, Not Applicable*	1. Is there congruity between the stated philosophical perspective and the research methodology? 2. Is there congruity between the research methodology and the research question or objectives? 3. Is there congruity between the research methodology and the methods used to collect data? 4. Is there congruity between the research methodology and the representation and analysis of data? 5. Is there congruity between the research methodology and the interpretation of results? 6. Is there a statement locating the researcher culturally or theoretically? 7. Is the influence of the researcher on the research, and vice- versa, addressed? 8. Are participants, and their voices, adequately represented? 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? 10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Cross sectional studies – Joanna Briggs Institute *Yes, No, Unclear, Not Applicable*	1. Were the criteria for inclusion in the sample clearly defined? 2. Were the study subjects and the setting described in detail? 3. Was the exposure measured in a valid and reliable way? 4. Were objective, standard criteria used for measurement of the condition? 5. Were confounding factors identified? 6. Were strategies to deal with confounding factors stated? 7. Were the outcomes measured in a valid and reliable way? 8. Was appropriate statistical analysis used?

Table 2e. Tabulation of reviews and the included articles

	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson Griffiths, 2014**
Ahronheim, 2001						X													
Allen-Burge, 1997																		X	
Allen, 2003								X											
American Medical Ass, 1999												X							
Anquinet, 2013								X											
Arcand, 2005	X																		
Arcand, 2009	X																		
Ashton, 2014												X			X				
Awan, 2010							X												
Ayalon, 2012							X	X											
Baile, 2002												X							
Baranowski, 2012							X												
Benkendorf, 1997												X							
Berghmans, 2001												X							
Black, 2009								X			X						X		
Bollig, 2016									X										
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**

Bonner, 1999																		X	
Bonner, 2014				X															
Brazil, 2015												X				X			
Brazil, 2017				X															
Burla, 2014												X							
Cadigan, 2012							X												
Caplan, 2006					X	X								X					
Caprio, 2011							X												
Caron, Arcand, Griffth, 2005	X																		
Caron, Griffith & Arcand, 2005a											X								
Caron, Griffith & Arcand, 2005b	X										X						X		
Carpenter, 2007																		X	
Casarett, 2005																			X
Cavalieri, 2002		X			X		X	X									X		
Chan, 2010																			X
Chan, 2011												X							
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
Charles, 1997	X																		

Chen, 2002																		X	
Church, 2007												X							
Clare, 2011													X						
Clayton, 2007												X							
Cogen, 1992										X								X	
Conroy, 2009												X							
Cornege-Blokland, 2012										X									
Dautzenberg, 1996																		X	
de Boer, 2010												X							
de Boer, 2011										X	X	X							
de Boer, 2012												X	X						
De Gendt, 2010												X							
De Gendt, 2013							X	X				X					X		
De Vleminck, 2014			X													X			
Dening, 2011		X	X									X							
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver , 2010**	**Wickson-Griffiths , 2014**
Dening, 2012a								X				X							
Dening, 2012b								X				X							
Dening, 2013													X			X			

Detering, 2010												X							
Di Guillio, 2008								X											
Dickinson, 2013			X									X			X	X			
Ditto, 2003																		X	
Dobalian, 2006																		X	
Ebell, 1998	X																		
Elliott, 2009											X								
Engel, 2006						X	X											X	
Evans, 2009																	X		
Fazel, 1999					X														
Fazel, 2000					X														
Finucane, 1991					X														
Forbes, 2000					X			X			X						X		
Froggatt, 2009		X										X							
Gama, 2013							X												
Garand, 2011												X					X		
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
Garden, 2016						X													
Gessert, 2000	X					X											X		
Gessert, 2006											X								
Ghusn, 1995	X																		
Gillick, 2004												X							

Gillick, 2012												X							
Givens, 2009	X									X		X							
Givens, 2012							X				X						X		
Gjerberg, 2015									X										
Gjerdingen, 1999																		X	
Goldberg, 2008	X																		
Goodman, 2010												X							
Gozalo, 2011						X													
Gregory, 2007					X														
Griffith, 1995																		X	
Grisaffi, 2010																	X		
Grisso, 1997												X							
Hall, 2011	X																		
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
Hamann, 2011																X			
Hanson, 2005														X					X
Hanson, 2011										X							X		
Harle, 2008												X							
Harvey, 2006												X							
Haydar, 2004					X												X	X	

Helton, 2006										X						X		
Herrington, 2011							X											
Hertogh, 2010	X																	
Hertzberg, 2000										X								
Hilgeman, 2014						X							X					
Hirschman, 2004					X													
Hirschman, 2006					X							X					X	
Hirschman, 2008					X				X			X			X	X	X	
Hoe, 2007												X						
Hortin-Deutch, 2007																X		
Hurley, 1995																	X	
Jeong, 2011									X									
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
Johnston, 2014		X																	
Juthani-Mehta, 2015												X							
Karel, 2007					X								X						
Karel, 2010																X			
Karlawish, 1999																	X		
Karlawish, 2005																X			
Keirse, 2009												X							

Kellogg, 1995																		X	
Kiely, 2012						X													
Kim Suh, 2006												X							
Kim Suh, 2011												X							
Kruse, 2005	X																		
Kwok, 2007										X									
Lacey, 2006		X			X														
Lamberg, 2005	X						X												
Lamberg, 2011								X											
Lawrence, 2011																X			
Legault, 2009											X								
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
Lemmens, 2012												X							
Levi, 2010												X							
Lingler, 2008					X												X		
Liu, 2012							X												
Livingston, 2010																X	X		
Livingston, 2012		X					X										X		
Livingston, 2013						X		X											
Lopez, 2010											X								
Low, 2003																		X	

Malcomson, 2009									X										
Maust, 2008										X								
McGee, 2013							X											
McMahan, 2013												X						
Meier, 2001						X		X										
Messinger-Rapport, 2005																		X	
Mezey, 1996					X													X	
Mitchell, 2003a						X												
Mitchell, 2003b						X												
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
Mitchell, 2009	X																		
Mitchell, 2010	X																		
Mold, 1991												X							
Molloy, 2000						X								X					X
Monias, 1999																		X	
Monteleoni, 2004								X											
Morrison, 2005						X								X					X
Nakanishi, 2009								X											
Nicholas, 2014						X													
Norris, 2005																		X	

Owen, 2001																	X		
Pak, 2010							X												
Parsons, 2013								X											
Pasman, 2004										X							X		
Passmore, 2013							X												
Pearlman, 2000																		X	
Piers, 2013									X			X							
Poppe, 2013			X									X			X	X			
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
Potkins, 2000								X											
Powers, 2008																	X		
Raymond, 2014												X							
Reid, 2012																	X		
Reilly, 1994																		X	
Reinhardt, 2014				X				X											
Roberts, 2009													X						
Robertson, 1993																		X	
Robinson, 2000											X							X	
Robinson, 2001																	X		
Robinson, 2009							X												
Robinson, 2012		X						X				X			X				

Robinson, 2013			X				X									X			
Rurup, 2005					X														
Rurup, 2006		X						X		X									
Sachs, 2004	X																		
Sampson, 2010												X							
Sampson, 2011				X			X					X							
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
Schonwetter, 1996																		X	
Scott, 2012												X							
Seeber, 2012												X							
Shanley, 2009												X							
Sharp, 2013		X																	
Siegrist, 2008											X								
Silvester, 2012												X							
Sloane, 2008							X	X											
Smith, 2013												X							
Smucker, 2004							X												
Snyder, 2007													X						
Somogyi-Zalud, 2001										X									
St-Amant, 2012																	X		
Steeman, 2007												X							

Steeman, 2013												X							
Stewart, 2011		X						X	X								X		
Stirling, 2012																X			
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
Stone, 2013									X										
Strumpf, 2004																			X
Szafara, 2012												X							
Tay, 2015																X			
Teno, 2011										X							X		
The, 2002											X						X		
Thune-Boyle, 2010		X																	
Titler, 2008												X							
Triplett, 2008					X			X									X		
v/d Steen, 2005								X											
v/d Steen, 2007	X																		
v/d Steen, 2010	X						X					X							
v/d Steen, 2011	X											X							
v/d Steen, 2012	X											X							
v/d Steen, 2014		X	X									X							
v/d Steen, 2014 (NL)												X							
v/d Steen, 2016																X			

Van den Block, 2013							X												
	Arcand et al., 2015	**Beck et al., 2017**	**Brooke et al., 2014**	**Bryant et al., 2018**	**Dening et al., 2011**	**Dixon et al., 2018**	**Jethwa et al., 2015**	**Jones et al., 2016**	**Mignani et al., 2017**	**Petriwskyj (quant)**	**Petriwskyj (qual)**	**Piers et al., 2018**	**Read et al., 2018**	**Robinson et al., 2012**	**Ryan et al., 2017**	**Tilburgs et al., 2018**	**v/d Steen et al., 2014**	**Westenhaver, 2010**	**Wickson-Griffiths, 2014**
van Eechoud, 2014									X										
Van Mechelen, 2014												X							
Vandervoort, 2012						X	X					X					X		
Vandervoort, 2013												X							
Vandervoort, 2014		X				X		X											
Vellinga, 2006												X							
Volandes, 2007																		X	
Volandes, 2008							X												
Volicer, 2003						X													
Wackerbarth, 1999																	X		
Waddell, 1997																	X		
Ward-Griffin, 2003											X								
WHO, 2012												X							
Yeun-Sim Jeong, 2007		X																	
Zimmerman, 2015												X							

Columns are the included reviews, rows are the included primary articles included in those reviews.

Table 3e. Included studies – systematic reviews

Author	Year	Setting	Participants	Type and number (N) of articles included	Main aim	Outcomes	Main findings
Arcand	2015	Long-term care	Carers of PwD, HCP	Review of the literature composed of quantitative studies, total N=21	To review the issues with setting goals of care for PwD, describe the respective roles of the HCP and the family in the decision-making process, and suggest ways to support families who need more information about the care options.	Facilitators and barriers for setting goals of care and the role of the HCP and the family	HCP should consider advanced dementia as a terminal disease. Palliative care principles should guide communication about goals of care, and family education is important to avoid possibly unwanted, futile, and burdensome interventions.
Beck	2017	Long-term care	HCP	Narrative review. Quantitative and qualitative studies, total N=14	To synthesize the evidence on HCP's perspectives on ACP for PwD in LTC settings.	Perspectives on ACP	HCP need education on the dementia trajectory, the ACP process and how to communicate with PwD and their family.
Brooke	2014	Primary and community health care	HCP	Literature review. Qualitative primary research (N=4) and reviews (N=2), total N=6	To explore the barriers and facilitators that impact on HCP's engagement with ACP for PwD and their families.	Barriers to the initiation of ACP; experiences with ACP.	HCP lack the skills and knowledge to initiate ACP at an appropriate time. PwD and family often avoid ACP due to lack of knowledge about ACP and dementia.
Bryant	2018	All settings	Carers of PwD	Systematic review. Randomized controlled trials,	To determine 1) number of interventions published between	Discussion or completion of any type of medical planning instrument	Potential effectiveness of one intervention involving face-to face structured conversation

				cluster-randomized controlled trial, controlled before and after study, total N=4	1997 and July 2017 that aimed to increase ACP for PwD, 2) methodological quality of studies, 3) effectiveness of interventions in increasing ACP for PwD.	or a document outlining preferred place of care, goals of care or values.	about end-of-life care for increasing participation in ACP was found. Overall, studies examined a limited range of ACP outcomes.
Dening	2011	All settings	People with dementia or family members and HCP	Narrative review. Qualitative, quantitative and mixed-methods studies, total N=17	To examine the facilitators and inhibitors to ACP in people with dementia. We also aimed to identify key themes in the literature and critically review the methodologies used.	Facilitators and barriers for ACP.	Key facilitator to ACP is a dedicated professional educating families and HCP about ACP. HCP require more education and training in ACP and dementia. Key barrier is proxy decision-makers influencing EoLC that may not reflect the wishes of the PwD. Family carers need emotional support, information and education about dementia and issues around palliative and end-of-life care.
Dixon	2018	All settings	People with dementia and their informal carers	Systematic review composed of correlational and intervention studies, total N=18	To systematically identify, and critically assess, outcome studies indicating the potential effectiveness and	1) End-of-life outcomes, 2) Health utilization, 3) Patient outcomes, 4) Carer outcomes, 5)	ACP is relevant and applicable to PwD and associated with positive end-of-life outcomes, reduced healthcare utilization

					cost- effectiveness of ACP for people with dementia.	Economic outcomes	and improvements of patient/carer outcomes. It is unclear whether reduced healthcare utilization was achieved while improving, or not compromising, patient/carer outcomes.
Jethwa	2015	All settings	People with dementia, carers, HCP	Narrative review composed of quantitative and qualitative primary research and reviews, total N=26	To assess the factors that affect the clinical use of ACP and palliative care interventions in PwD. To identify key themes for future research and development and how they may relate to practice in the UK.	Facilitators and barriers for clinical use of ACP interventions	Many changes should be made in 1) identification of appropriate settings for ACP interventions, 2) educational interventions for HCP about ACP and palliative care in dementia, 3) improving access to ACP, 4) standardizing documentation and ensuring services can follow changes in patients’ wishes, 5) facilitating information transfer between primary and secondary care, 6) legal ACP issues.
Jones	2016	All settings	People with dementia, carers, HCP	Scoping review using the Levac et al. (2010) methodological	To synthesize the research evidence on decision-making	Experiences of ACP	ACP and EoLC decision making processes are complex, involving

				framework (=review including stakeholder consultations to inform or validate study findings). Qualitative and quantitative studies, total N=25	concerning EoLC for PwD		multiple factors. Decision making involves different individuals at different points of time of care and in various sites of care. ACP should include comfort care, as well as planning the withdrawal of treatment. Education and training can be an integral component of ACP.
Mignani	2017	Long-term care	Older people (age >65) living in long-term care facilities, their family members	Systematic review composed of qualitative research and thematic synthesis guided by Thomas & Harden (2008), total N=9	To search and synthesize qualitative studies exploring the perspectives of older people living in LTC facilities and of their family members about ACP discussions.	Perspectives on ACP	Despite their willingness to be involved in a shared decision-making process regarding EOL care, older residents of LTC settings across the globe and their family members still know and have little experience with ACP.
Petriwskyj	2014	Long-term care	Carers of PwD in LTC, HCP	Systematic review, narrative synthesis composed of experimental and descriptive studies, total N=11	To identify and appraise the existing quantitative evidence about family involvement in decision making for PwD living in LTC.	1) Decisions encountered by family surrogates, 2) Variables associated with treatment decisions, 3) Reasons or basis for decisions, 4) Collaborative decision making	Whilst the surrogate decision makers may be involved in discussion and decisions, the extent to which decisions are discussed with surrogates, and involve surrogates, varies considerably. Surrogates' level of

						process, 5) Outcomes of decision making.	satisfaction with the decision-making process can also vary.
Petriwskyj (qual)	2014	Long-term care	Carers of PwD in LTC, HCP	Thematic analysis. Phenomenology, grounded theory, ethnography, qualitative and mixed methods studies, total N=16	To identify and appraise existing knowledge about family involvement in decision making for PwD living in LTC.	1) Decisions encountered by family surrogates, 2) Variables associated with treatment decisions, 3) Families perceptions and preferences, 4) Outcomes for PwD.	Information, communication, and relationships between families and staff are important. Decision making can be a positive but also stressful, challenging, and emotionally straining. ACP and ADs should be provided as the need arises.
Piers	2018	All settings	People with dementia or family members and HCP	1) a literature search to identify what is already known about ACP in PwD, 2) the development of recommendations based on the existing evidence and expert opinion of the author group, 3) a validation process to provide feedback on the clarity, acceptability and importance and to discuss possible	To improve the prevalence, quality and consistency of ACP in PwD and to develop clinical recommendations for applying and conducting ACP in practice, to provide support for HCP who work with PwD in the community, residential and hospital settings.	Clincial recommendations on: 1) Initiation of ACP, 2) Evaluation of mental capacity, 3) Holding ACP conversations, 4) The role and importance of those close to the PwD, 5) ACP when it is difficult or no longer possible to communicate verbally, 6) Documentation of wishes and preferences, including information	Recommendations: 1) start ACP as early as possible and integrate in daily care, 2) HCP should initiate, 3) consider the person as an individual, 4) always assume full mental capacity, is fluctuating and task specific, 5) adjust communication style and content, 6) know the PwD, 7) explore current experiences and future wishes/fears, 8) family should be involved as early as possible in ACP and be informed about the role of a

				barriers to implement the recommendations. Qualitative, quantitative and mixed-methods studies, total N=67		transfer, 7) End-of-life decision-making, 8) Preconditions for optimal implementation.	surrogate decision-maker, 9) HCP should write down the outcomes of ACP in the medical files and communicate with the care team, 10) weigh earlier expressed wishes against the current best interest of the PwD, in consultation with the person's close circle and the HCP involved.
Read	2018	All settings	People with dementia participating in research	Integrative literature review composed of qualitative, quantitative and mixed-methods studies, total N=7	To identify, critique, and synthesize relevant research findings, to examine investigations of the participation of PwD in the planning of their care and support, when they have also provided study data.	3 approaches to include PwD in care planning: 1) Education and support programme, 2) Client directed goal setting in cognitive rehabilitation, 3) Advance care planning	Very limited evidence, but ACP studies so far provide promising indications of a PwD's capacity to identify how they wish to live their life into the future.
Robinson	2012	Long-term care & hospitals	Nursing home residents, their families, staff, GPs	Systematic review composed of quantitative studies, total N=4	To determine the effectiveness of ACP interventions in people with cognitive impairment and dementia and also to identify factors influencing the implementation of ACP in this area.	1) ACP outcomes, 2) patient health outcomes, 3) healthcare utilization outcomes	ACP has the potential to reduce inappropriate hospital admissions and healthcare costs for people with cognitive impairment and dementia. ACP has the potential to positively influence patient preferences for future care.

Ryan	2017	All settings	People with dementia or family members and HCP	Qualitative synthesis, approach of Thomas & Harden (2008), total N=5	To undertake a synthesis of the qualitative research undertaken within the field of ACP and dementia with an emphasis upon experiences, barriers and facilitators.	Experiences of ACP	Challenges for ACP with PwD are similar to general ACP challenges. However, timing and preference for informal approaches are specific for PwD. Skills of HCP should be given primacy.
Tilburgs	2018	All settings	People with dementia, carers, GP's	Systematic integrative review. Whittemore & Knafl method. Qualitative content analysis. Qualitative, quantitative and mixed-methods studies, total N=16	To determine the barriers and facilitators faced by GPs related to ACP with PwD.	Barriers and facilitators for ACP.	PwD should participate in ACP when future care is planned. GPs need to be aware of the consequences of dementia, including legal issues, and about the significance of informing PwD. Training GPs in the skills necessary to initiate ACP discussions is essential.
van der Steen	2014	Long-term care, hospice settings, ambulatory care settings.	People with dementia or family members and HCP	Systematic review composed of qualitative, quantitative and mixed-methods studies, total N=33	To identify factors associated with initiation of ACP regarding end-of-life issues in dementia.	Factors related to discussions, decision making, written advance directive. Distinguish between pre-specified factors (e.g. demographics) and factors abstracted	Initiation of ACP was associated with: 1) family's (lack of) initiative, 2) HCP (lack of) initiative, 3) PwDs health status, 4) continuity of care and healthcare system factors. HCP should initiate ACP and invest time in building up relationships, consider

						from explorative work.	timing and receptiveness, and work family- and patient-centered.
Westenhaver	2010	All settings	People with dementia, surrogate decision makers	Literature review composed of qualitative and quantitative studies, total N=24	To determine what is known about ACP in PwD concerning CPR and MV.	1) Preferences stability, 2) Patient characteristics, 3) Satisfaction with care.	Age, race, gender, education of the decision maker, and a depression diagnosis affect the decision-making process of CPR/MV in PwD. Stability and reliability of decisions over time is questionable and decisions need to be reverified over time.
Wickson-Griffiths	2014	Long-term care	People with dementia and their family members	Review, composed of quantitative studies, total N=6	To determine the impact of the ACP programs implemented in LTC. To evaluate the programs' inclusion of considering the important values of PwD according to the Dementia Policy Lens Toolkit.	Rigour & impact of ACP programs and values of LTC residents and their family members.	ACP programs demonstrated increased ACP discussion and documentation, adherence to wishes, reduced costs, increased staff and family knowledge about resident's wishes, improved resident QoL scores and stability of health care choices over time.

All settings; community, primary, secondary and tertiary care (GP, nursing home, hospital). Long-term care involves; nursing homes, (residential) care homes and all other long-term institutes for elderly people
ACP; advance care planning, ADs; advance directives, CPR; cardiopulmonary resuscitation, DNR; do-not-resuscitate, EoLC; end-of-life care, GP; general practitioner, HCP; healthcare professonial, LTC; long-term care, MV; mechanical ventilation, PwD; people with dementia, QoL; quality of life.

Table 4e. Includes studies – Primary studies

Author	Year	Setting	Participants	Number (N) of included participants	Type of study	Main aim	Outcomes	Main findings
Asthon	2016	Long-term care	Family carers	N=12	Descriptive qualitative study - semi structured interviews	To explore the experiences of ACP amongst family caregivers of PwD.	Experiences of ACP	Carers find ACP relevant but burdensome. It can be facilitated within everyday practice. Carers should feel ready for ACP conversations.
Beck	2017	Long-term care	LTC managers	N=116	Cross-sectional survey	To examine LTC managers' knowledge, attitudes, beliefs and current practice towards ACP for PwD in LTC settings.	Knowledge, attitudes, beliefs about ACP	LTC managers have a lack of knowledge and have reserve towards ACP for PwD. There is an overall lack of leadership and ownership with regard to ACP for PwD in this setting.
de Vries	2018	Community	Family carers	N=23	Exploratory qualitative study	To explore experiences of preparedness and support for family members of PwD, before, during and following the death of the PwD.	Experiences of preparedness and support for family members	Families can be well prepared for the time when they need to make decisions for the PwD based on ordinary everyday conversation that take place within families, throughout life.
Givens	2018	Community	Healthcare proxies	N=62	Cross-sectional	To describe aspects of ACP among PwD and	1) Care preferences, 2) Communication, 3)	There is a need for greater communication

					observational survey	examine the association between ACP and proxy acceptance of PwD' illness.	Proxy preparedness	between PwD and HCP regarding goals of care and preferences. Proxies have confidence to participate in shared decision making. Early and continued education for PwD and families over the course of the illness is needed.
Jung	2017	Psychiatric outpatient clinic	Elderly patients with memory complaints and their family	N=98 (PwD) N=62 (family)	Cross-sectional survey	To investigate the preferences on dementia disclosure and ACP in elderly outpatients with memory complaints and their families.	Attitudes towards ACP	Awareness of ACP was lower than in Western countries. Family was more likely to have heard of ACP and had a stronger wish to begin ACP. Having a family member with dementia is associated with stronger willingness to begin ACP.
Katwa	2018	Long-term care	HCP	N=78	Survey	To highlight the importance of timely ACP for LTC residents to HCP	Effectiveness of a simulation training	Simulation training is an effective way of training LTC staff on ACP. 89% strongly agrees they have a better understanding of early ACP discussions.

Lo	2017	Memory clinic	Patients with early cognitive impairment	N=158	Prospective study	To explore which factors are related to completion or non-completion of ACP in patients with early cognitive impairment.	Completion of ACP	There is a higher likelihood of PwD who never married completing ACP than married PwD. No association was found for age, gender, race, and education or cognitive status.
McGlade	2017	Long-term care	Long-term care staff	N=3 (facilities), N=290 (beds)	Feasibility study using surveys and monthly-feedback meetings	To identify challenges in implementing the 'Let Me Decide' ACP program in LTC	Barriers and facilitators when implementing an ACP program	While ACP in LTC can be challenging and laborious, it opens lines of communication and enhance peace of mind for all involved, while promoting residents' autonomy. The benefits outweigh the challenges to implementation. Barriers on staff, resident, carer and system level have been identified.
Mitchell	2018	Long-term care	Proxies of LTC residents	N=402	Cluster randomized controlled trial	To test whether an ACP video (vs usual care) has effect on documented ADs, level of care preferences, goals-of-care	1) Documented advance directives, 2) level of care preferences, 3) goals-of-care discussions, 4) burdensome treatments	An ACP video did not have an effect on preferences, DNH status, or burdensome treatments among residents with advanced dementia, but did increase

						discussions, and burdensome treatments among LTC residents with advanced dementia.		directives to withhold tube-feeding.
Sinclair	2016	Community	HCP, family	N=17	Delphi study in three rounds	To explore views of ACP for PwD. Reasons why uptake is low among PwD were also investigated.	Concensus views on ACP	Approval of autonomy and patient choice with regard to ACP is noted as most important.
Tilburgs	2018	Primary care	PwD, their family carers, GPs, practice nurses, case managers	N=20 (interviews) N=1 (focus group)	Semi-structured interviews, focus group meeting	To explore barriers and facilitators for ACP with community-dwelling PwD	Barriers and facilitators for ACP	Facilitators are: 1) having a relationship with the GP that is built on trust and mutual understanding, 2) discussing ACP in the comfort of PwD homes, 3) addressing non-medical issues, 4) involvement of case managers and practice nurse. GPs' lack of time is an important barrier for ACP. Availability of ACP documentation to all professionals is a concern.

								Collaborative care models might help to overcome these barriers.

All settings; community, primary, secondary and tertiary care (GP, nursing home, hospital). Long-term care involves; nursing homes, (residential) care homes and all other long-term institutes for elderly people

ACP; advance care planning, AD; advance directive, GP; general practitioner, HCP; healthcare professionals, LTC; long-term care, PwD; people with dementia.

Table 5e. Quality appraisal of the included reviews (AMSTAR-2 tool minus the questions about meta-analysis Q11, Q12, Q15) and included primary articles (Joanna Briggs Institute – Randomized Controlled Trial, Qualitative studies or Cross-sectional studies)

Review	YEAR	Q1; PICO used	Q2; prior protocol	Q3; selection of designs	Q4; compre hensive search strategy	Q5; duplicate study selection	Q6; duplicate data extraction	Q7; justified exclusions	Q8; details of included studies	Q9; RoB assessment	Q10; funding sources	Q13; RoB in interpretation	Q14; heteroginity explained	Q16; conflict of interest reported	Sum
Arcand	2015	Yes	no	no	no	no	no	no	no	no	no	no	no	Yes	2/13
Beck	2017	Yes	no	no	Partial yes	yes	no	yes	yes	no	no	no	Yes	Yes	6.5/13
Brooke	2014	Yes	no	no	Partial yes	no	no	no	no	no	no	no	Yes	No	2.5/13
Bryant	2019	Yes	no	yes	Partial yes	yes	no	yes	yes	yes	no	No	yes	Yes	8.5/13
Dening	2011	Yes	no	no	yes	yes	yes	no	yes	no	no	Yes	Yes	Yes	8/13
Dixon	2018	Yes	no	no	Partial yes	yes	no	yes	yes	yes	no	yes	Yes	Yes	8.5/13
Jethwa	2015	Yes	no	no	Partial yes	no	no	no	Partial yes	no	no	yes	Yes	Yes	5/13
Jones	2016	Yes	no	yes	Partial yes	yes	yes	yes	Partial yes	yes	no	yes	Yes	Yes	10/13
Mignani	2017	Yes	no	yes	Partial yes	yes	yes	no	Partial yes	yes	yes	yes	yes	Yes	10/13
Petriwskyj (quant)	2014	Yes	No	no	Partial yes	yes	no	no	Partial yes	yes	no	no	Yes	No	5/13
Petriwskyj (qual)	2014	Yes	No	no	Partial yes	yes	yes	no	Yes	yes	no	no	Yes	No	6.5/13
Piers	2018	Yes	No	yes	yes	yes	yes	yes	No	yes	no	yes	yes	Yes	10/13
Read	2018	Yes	No	yes	Partial yes	yes	yes	yes	Partial yes	yes	no	yes	yes	Yes	10/13
Robinson	2012	Yes	No	no	yes	yes	yes	yes	Yes	yes	no	yes	Yes	Yes	10/13
Ryan	2017	Yes	No	yes	Partial yes	no	no	yes	Partial yes	Yes	no	no	Yes	Yes	7/13
Tilburgs	2018	Yes	No	yes	Partial yes	yes	yes	yes	yes	yes	no	yes	Yes	No	9.5/13
van der Steen	2014	Yes	no	yes	Partial yes	yes	yes	yes	no	no	no	yes	yes	yes	8.5/13
Westenhaver	2010	Yes	no	no	Partial yes	no	no	no	no	no	no	no	yes	no	2.5/13

Wickson-Griffiths	2014	Yes	no	yes	Partial yes	no	no	yes	yes	yes	no	no	yes	Yes	7.5/13
Cluster Randomized Controlled Trial		Q1; true randomization	Q2; Allocation concealed	Q3; Similar treatment groups	Q4; Blind participants	Q5; Blind delivery of treatment	Q6; Blind outcome assessors	Q7; Identical treatment	Q8; Follow-up completed	Q9; Analysis in allocated group	Q10; Outcomes measured the same	Q11; Reliable outcomes	Q12; Appropriated statistical analysis	Q13; Appropriate trial design	
Mitchell	2018	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	12/13
Qualitative		Q1; congruity theory and method	Q2; congruity method and research question	Q3; congruity method-logy and method used	Q4; congruity method-logy and analysis	Q5; congruity methodology and interpretation	Q6; researchers cultural/ theoretical background	Q7; influence of researcher addressed	Q8; representation participants	Q9; ethical approval	Q10; link analysis and conclusion				
Asthon	2016	Yes	Yes	yes	Yes	yes	No	No	yes	Yes	yes				8/10
de Vries	2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes				8/10
McGlade	2017	NA	Yes	Yes	Unclear	Yes	No	No	unclear	Yes	Yes				5/10
Sinclair	2016	NA	yes	Yes	yes	Yes	no	No	Yes	yes	Yes				7/10
Tilburgs	2018	NA	yes	yes	yes	yes	yes	no	yes	yes	Yes				8/10
Cross sectional		Q1; inclusion criteria	Q2; subjects and setting	Q3; exposure valid and reliable	Q4; standard criteria	Q5; confounders idetified	Q6; dealing with confounders	Q7; valid and reliable outcomes	Q8; appropriate statistical analysis						
Beck	2017	Yes	yes	NA	NA	No	NA	Yes	Yes						4/8
Givens	2018	Yes	Yes	NA	Yes	Yes	No	Yes	Yes						6/8
Jung	2017	Yes	Yes	NA	Yes	Unclear	No	Unclear	Yes						4/8
Katwa	2018	no	Yes	yes	NA	no	No	yes	Yes						4/8
Lo	2017	yes	yes	yes	yes	yes	yes	yes	yes						8/8

RoB; risk of bias NA; not applicable Sum; sum score (times an item is graded ‘yes’ (=1) or ‘partial yes’ (=0.5)) on appraisal tool.

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Described as umbrella review
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	yes
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	yes
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	yes
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Yes – Prospero registration details given p4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	P4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	P4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	P4-5

Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	P5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	P5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	P4 and 5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	P5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	NA

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	NA
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	P6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	P7-8 and in supp file 1
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Table 1
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	NA
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	NA

Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	NA
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Yes - discussion
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	discussion
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Discussion
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Yes P23

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

Chapter 2.2

End-of-Life Decision Making for People Who Died of Dementia: A Mortality Follow-Back Study Comparing 1998, 2007, and 2013 in Flanders, Belgium

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Published: J Am Med Dir Assoc, 20, 10, 1347-1349 (2019)
[2017 SCI impact factor 5.325; Ranking D1; ranking n°4 of 53 in GERIATRICS & GERONTOLOGY]

Declining cognitive abilities in people with dementia (PwD) complicate communication and decision-making,[1] particularly at end of life. These circumstances lead to insecurity among physicians about end-of-life decisions (ELDs) and preferences of PwD. ELDs entail a range of medical decisions with potential life-shortening effects that can be categorized into three types: (1) withholding or withdrawing potentially life-prolonging treatment; (2) alleviating pain or symptoms pharmaceutically, in large enough doses to hasten death as a potential side effect; and (3) administration, prescription, or supply of drugs to end life at the patient's explicit request, including euthanasia (legally possible in Belgium for people with mental capacity).[2]

In the last two decades, Belgium has undergone important legal changes that may affect end-of-life care, i.e. laws on patient rights,[3] palliative care,[4] and euthanasia.[5] Furthermore, the importance of considering care preferences of PwD has been recognized in research and clinical practice.[6] To date, research has not studied whether and how frequencies of ELDs in PwD have changed in the context of these developments. We studied whether changes occurred in 1) frequencies of end-of-life decision-making for people who died of dementia between 1998, 2007 and 2013 and 2) people involved in the decision-making process.

We analysed data from mortality follow-back studies[7] based on samples of death certificates of 1998, 2007 and 2013. For this analysis we selected deceased whose primary cause of death was registered as dementia using ICD-10 codes (either 'F01'=vascular dementia, 'F03'=non specified dementia, or 'G30'=Alzheimer's disease). The physician registering death was mailed a questionnaire on medical practices at the end of life. The questionnaire asked whether death was sudden and totally unexpected. If death was non-sudden, physicians were asked to further continue the questionnaire, as we presumed that sudden death precludes that ELDs are made. Regarding ELDs, the questionnaire asked (1) what act was initiated, (2) how far life-shortening was intended, and (3) if the patient had explicitly requested the act. More than one ELD could be indicated. Physicians were asked to consider the ELD with the most explicit life-shortening intention and to indicate with whom this ELD was discussed. Minor differences in wording existed in the questionnaires between years. Strict procedures guaranteed anonymity. Response rates were 48,1% (1998), 65,4% (2007) and 60,6% (2013).[7,8] All study protocols and questionnaires were approved by the Brussels University Hospital Ethics Committee. Statistically significant differences between years were calculated using chi-square tests.

Around 84% of PwD died non-suddenly. 80% were over 80 years old, around 70% were female. There were significantly more under-80s in 2007 (30%) and significantly fewer non-sudden deaths in 2013 (75%). Results (Table 1) show that the frequencies of ELDs varied little over the years. However, a significant shift over time was found in the frequency of withholding treatment, decreasing between 1998 and 2007, then increasing towards 2013 (p=.008). Maximum 10% of patients (1998) were involved in discussions of the ELD with the most explicit life-shortening intention, without significant differences between years.

Significantly increased involvement of relatives was found between 1998 and 2013 (12% vs. 67%; p<0.001). Involvement of other physicians and nurses did not differ significantly between years. In 2007, palliative care specialists were involved in 25.4% of decisions and 16% in 2013 (p=0.082). Almost all PwD were judged by the physician as lacking decision-making capacity (1998: 96.3%; 2007: 99.5%; 2013: 95.8%, not in table).

In conclusion, this study provides important epidemiological data on ELDs for PwD in Flanders over 15 years, supplementing the discussion of legal and societal changes affecting end-of-life care. We observed fluctuations in frequencies of ELDs, although few were statistically significant, perhaps owing to small sample sizes. Two findings stand out. Firstly: significant shifts in the frequency of withholding treatment over time. We have no immediate explanation for these shifts. Another remarkable result is the increase of ELDs preceded by discussions with relatives by 55.5 percentage points between 1998 and 2013. This increase seems to indicate inclusive end-of-life decision-making, concurrent with growing attention to shared decision-making for PwD and their relatives.[6] However, this research also shows that PwD are rarely included in decision-making. The low percentage of PwD with whom ELDs were discussed corresponds with physicians indicating that most PwD lack decision-making capacity at the end of life.

Overall, our study shows that ELDs are an important part of end-of-life care for people dying of dementia. Since most PwD no longer have decision-making capacity at the time of death, other parties have an important role in discussing ELDs. This research shows that relatives, rather than nurses or colleagues, increasingly take on this responsibility. However, earlier research showed that congruence between professionals and relatives about the content of care planning is low.[9] Educating physicians in appropriate care-planning conversations is therefore strongly recommended.[10]

All authors approved the manuscript and its submission to JAMDA. This research and Annelien Wendrich-van Dael was supported by the Marie Skłodowska-Curie Innovative Training Network (H2020-MSCA-ITN-2015I) INDUCT, under grant agreement number 676265. Lara Pivodic is a Postdoctoral Fellow of the Research Foundation Flanders (FWO). The authors have no conflicts of interest.

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Table 1. Frequency of ELDs in people who died non-suddenly of dementia and persons involved in the decision making process in 1998, 2007 and 2013 in Flanders, Belgium.

	1998 (N = 68) N (%)	2007 (N=165) N (%)	2013 (N=265) N (%)	p-value
Total end-of-life decisions[a]	36 (52.0)	89 (53.8)	151 (57.2)	0.72
Non-treatment decisions	31 (44.7)	65 (39.4)	120 (45.4)	0.45
Treatment withheld	30 (44.5)	39 (23.8)	82 (31.0)	**0.008**
with life shortening explicitly intended	9 (12.7)	14 (8.8)	35 (13.2)	0.30
Treatment withdrawn	14 (20.3)	43 (25.7)	88 (33.4)	0.06
with life shortening explicitly intended	5 (7.5)	9 (5.5)	30 (11.4)	0.11
Intensified alleviation of pain or symptoms	20 (29.2)	64 (38.6)	113 (42.9)	0.13
Life abbreviation without explicit patient request	2 (3.1)	1 (0.9)	8 (2.9)	0.23
Euthanasia/ physician-assisted suicide	1 (1.7)	0 (0)	3 (1.2)	[b]
If an ELD was made[a]	1998 (N=36) N (%)	2007 (N=89) N (%)	2013 (N=151) N (%)	p-value
Decision discussed with patient	4 (10.1)	3 (3.2)	13 (8.5)	0.20
Explicit request of patient	3 (8.4)	0 (0)	8 (5.5)	[b]
Wish previously stated by patient (orally or in writing)	4 (10.7)	11 (12.1)	30 (19.7)	0.21
Decision previously stated by patient (written will)	0 (0)	2 (1.9)	11 (7.2)	[b]
Decision discussed with relatives	4 (11.9)	54 (61.2)	102 (67.4)	**<0.001**
Decision discussed with colleague physician	8 (23.5)	15 (16.9)	30 (19.5)	0.75
Decision discussed with nurse	19 (54.5)	49 (55.4)	74 (48.8)	0.63
Decision discussed with palliative care specialist	[c]	23 (25.4)	25 (16.3)	0.08
Decision discussed with others	3 (8.7)	5 (5.1)	8 (5.4)	0.78

Note. Bold values are statistically significant (*P* < .05).
[a] More than one ELD/discussion per patient was possible.
[b] Could not be calculated due to empty cells.
[c] The question was not incorporated into this version of the questionnaire.
All % and N are weighted.

Chapter 2.3

Advance care planning among nursing home residents living with dementia: Results from two mortality follow-back studies

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Submitted

Abstract

Background: Advance care planning (ACP) is highly relevant for nursing home residents with dementia. Uptake is low, but awareness and related policymaking are growing. We examined changes between 2010 and 2015 in verbal and written ACP and GP orders.

Methods: We analyzed data from 198 deceased residents with dementia in 2010 and 183 in 2015, of proportional stratified random samples of Flemish nursing homes (64 and 43 respectively). A nurse, an administrator and the general practitioner filled out questionnaires concerning ACP and GP orders. We used generalized linear mixed models to calculate differences between years.

Results: Nurses' response rate was 88% in 2010 and 85% in 2015. Frequencies of GP orders did not change over time (58% vs 62%). Verbal ACP -expressed preferences concerning end-of-life treatment- increased from 8% in 2010 to 19% in 2015 (adjusted odds ratio (AOR) 2.80, 95% confidence interval (CI) 1.18 to 6.67). Written ACP -appointing a proxy decision-maker- increased from 5% to 32% (AOR 7.34, 95% CI 3.16 to 17.70), advance directives (e.g. do-not-resuscitate) increased from 13% to 41% (AOR 4.35, 95% CI 2.44 to 7.75).

Conclusion: We found significant growth in verbal and written ACP (2010-2015), GP orders remained stable. Though this suggests countries can swiftly and substantially increase ACP in nursing homes for residents with dementia, room for improvement remains as the majority of residents did not participate in conversations concerning end-of-life treatment. Several mechanisms (e.g. policies, education) could have triggered the increased uptake and should be studied further to evaluate their effect.

Keywords: Advance care planning, dementia, nursing homes, mortality follow-back study, advance directives

Introduction

Dementia is a neurodegenerative disease affecting a person's memory, ability to perform everyday activities and can cause disorientation in time, person and place[1]. Dementia is currently irreversible and nursing home residents' preferences for future treatments and care will need to be discussed as early as possible[2]. In Belgium, more than 65% of people with dementia die in nursing homes[3,4], and comparable percentages were reported in other countries such as England and the US[4]. These numbers highlight nursing homes as an important care setting in which to plan and document preferences for care and treatment towards the end of life of people with dementia.

Advance care planning is defined as 'a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care'[5]. These conversations are identified as verbal advance care planning. Outcomes of the advance care planning process can be documented, and these documents can be formalized as advance directives. Advance directives are patient-driven documents, meaning that they are always based on the patient's preferences. These documents are made when people still have their decision-making capacity; they specify a person's preferences concerning future care and medical treatment and indicate who should make decisions on their behalf when they are no longer able to do so themselves[6]. Another form of planning care that can be important for people with dementia are physician orders, i.e. documents written by a physician. These are kept in the resident's medical or nursing home file, stipulating end-of-life treatments and usually concern non-treatment decisions[6,7]. These decisions may have been discussed with the resident, their family or other professional caregivers, or can be completed for the resident on a best-interests basis[8]. Like in many other countries, physician orders for Belgian nursing home residents are usually written by their general practitioner (GP) and these orders are therefore also known as GP orders.

A Flemish study from 2006 showed that an advance directive was present in 10% of the files of nursing home residents with dementia[7]. This number increased to 14% in 2010[9]. Several initiatives on both policy and practice levels have been taken since to further increase the uptake of advance care planning and documentation for nursing home residents in Flanders. For example, the existence of an up-to-date end-of-life care plan for every resident was introduced in 2013, as a quality indicator for nursing home practice[10]. The official recognition by the Flemish government[11] of palliative care nurses (i.e. nurses with special education in palliative and end-of-life care) may also have influenced advance care planning practices.

In light of the growing awareness of the importance of advance care planning and related policy-making in the nursing home sector, this study aimed to examine changes between 2010 and 2015 in verbal and written advance care planning and GP orders for nursing home residents with dementia.

Methods

Study design

We used data on deceased nursing home residents with dementia from two cross-sectional mortality follow-back studies, the Dying Well with Dementia Study (data collected in 2010)[12] and the Palliative Care for Older People (PACE)-study (data collected in 2015)[13]. The first was a cross-sectional study of nursing home residents with dementia who died in nursing homes in Flanders. PACE was a European cross-sectional study of deceased nursing home residents. The methods of both studies are summarized here and described in-depth elsewhere[9,13]. Their design was identical in all aspects except for the following: the first screening procedure to identify the study population and the number of reminders sent to respondents (detailed further in this manuscript). The STROBE statement[14] was used to report this study.

Setting and sampling

Facility selection

In Flanders, a full list of all nursing homes in the country is available, which was used as our sampling frame to create a representative sample. In 2010, a random sample was drawn from this list and stratified by region (5 provinces), and subsequently by bed capacity (up to, or more than 90 beds) and ownership type (public, private/non-profit, private/profit). If a nursing home declined to participate, another was randomly selected until the targeted number per stratum was reached[12]. In 2015, nursing homes from Belgium (Flanders), Italy, Finland, the Netherlands, Poland and the United Kingdom were sampled. For this analysis, only the Belgian sample was selected using an identical stratified sampling frame[13].

Participant selection

We selected deceased residents with dementia in both studies. The data were reported by three groups of respondents: the nursing home nurse most involved in each resident's care (henceforth referred to as 'nurse'), each deceased resident's GP, and a nursing home administrator, manager or head nurse (henceforth referred to as 'administrator'). In both studies, the administrator identified residents who had died in the three months prior to data collection as well as the relevant respondents for each deceased resident.

In 2010, deceased residents with dementia were identified in two steps. In the first step, the administrator made a list of all the residents that died in the previous three months and consequently identified people who possibly could have had dementia using broad screening criteria; i.e. residents who either met 1) the Katz scale criterion for 'category C dementia' (i.e., 'being completely care-dependent or needing help with bathing, dressing, eating, toileting, continence and transferring plus being disoriented in time and space') or 2) the criterion of disorientation in time and space ('having almost daily a problem with disorientation in time and space'). In the second step, the selection of the study population was done by sending questionnaires to the GP and nurse. If either the GP or the nurse indicated that the resident 'had dementia' or 'was diagnosed with dementia', the person was considered to be a person with dementia.

In the 2015 study, questionnaires on all deceased residents were sent to respondents (without performing the first step pre-selection of 2010). Residents were further considered as a person with dementia following the same second step procedure i.e. if either the GP, nurse, or both, indicated that the resident 'had dementia' or 'was diagnosed with dementia'. The resident was judged not to have dementia if both the nurse and the GP indicated this. By using this method, we ensured no residents with dementia were missed.

Data collection procedures

In both studies, questionnaires were coded, pseudonymized, and distributed by the administrator with the assistance of a researcher. All questionnaires were sent out accompanied by a study information sheet and a post-paid return envelope. Completed questionnaires were sent back directly to the researcher. In case of non-response, one reminder was sent in 2010 after 3 weeks and two reminders (after 3 and 6 weeks) in 2015, creating a maximum response window of 4.5 months. Residents for whom the nurse did not return the questionnaire were excluded from the analysis.

Measurements

The completion of questionnaires was based on memory of the respondent, however respondents were free to check resident files.

Nurses' questionnaires surveyed the following:

- Resident's functional status one month before death *(Bedford Alzheimer Nursing Severity-Scale [BANS-S])*[15,16].
- Resident's cognitive performance and their stage of dementia *(Cognitive Performance Scale [CPS]*[17] and *Global Deterioration Scale [GDS]*[18]).
- Whether or not the resident had dementia; and whether s/he was diagnosed with dementia.
- Whether or not the resident had one or more GP orders in his/her file. More specifically: Did the GP recorded any of the following agreements in the resident's records about whether medical actions should or should not be taken in case a problem were to occur and the resident would be unable to decide: (do not resuscitate in case of a cardiac or respiratory arrest (DNR) – do not transfer to a hospital (DNH) – terminal sedation – euthanasia – request to try all life-prolonging treatments).
- Questions regarding advance care planning communication and documentation, more specifically:

1) Advance care planning communication (i.e. verbal advance care planning) with the resident:
    - Did the resident ever express specific preferences about a medical treatment he or she did or did not want during the last phase of life? (Yes – No – I don't know).
    - Did you ever speak with the resident about medical treatments he or she would or would not want in the last phase of life, or about the preferred course of care in the last phase of life? (Yes, only once – Yes, several times – No).
2) Advance care planning documentation:
    - Did the resident, in a prior living will, give power to a third party to take decisions for him or her in case he or she would no longer be competent to do so? (Yes – No).
    - Did the resident have a written living will concerning the following requests? (DNR – DNH – terminal sedation – euthanasia – request to try all life-prolonging treatments).

GPs were asked to indicate whether the resident had dementia/had been diagnosed with dementia. Administrators were asked to report on the resident's sex, age at time of death, length of stay and place of death.

Analysis

We calculated descriptive statistics for the sample characteristics of both years (e.g. age, sex). Statistical tests were conducted using the generalized linear mixed models suitable to the respective dependent variable of interest (i.e. binomial or multinomial). To control for the clustering of the data on the nursing home level, a random intercept was added for nursing home. For the analyses of advance care planning and GP orders, we controlled for significant differences in sample characteristics between the years by adding the respective characteristic as a fixed factor in the model. For all analyses, IBM SPSS for Macintosh version 25 was used. $P<0.05$ was considered statistically significant for all analyses.

Ethics

Ethical approval was obtained separately for both studies from the Medical Ethical Committee of UZ Brussel (Brussels University Hospital). All respondents participated voluntarily. Extensive procedures guaranteed the anonymity of the nurse, including the use of pseudonymized codes for questionnaires and asking respondents to return questionnaires directly to the researchers rather than to the administrator in the nursing home. The return of a questionnaire was taken as consent to participate in the study.

Results

Sample characteristics

In 2010 and 2015, 69 and 46 nursing homes participated respectively. Eight nursing homes were removed from the analysis (N=5 from 2010, N=3 from 2015) as no nurses from these homes returned a questionnaire, leading to a nurses' response rates of 88.4% in 2010 (198/224) and 85.1% in 2015 (183/215). Our sample included 198 deceased residents with dementia in 2010 and 183 in 2015 (Table 1). The samples were comparable over the years, with the majority being female (62% in 2010 vs 66% in 2015) and dying in the nursing home (90% in 2010 vs 86% in 2015). We also did not find any statistically significant differences between the samples of 2010 and 2015 regarding age at time of death, length of stay in the nursing home, functional status and stage of dementia. However, we found significantly and substantially fewer residents having (very) severe cognitive impairment (CPS score) in 2015 (66%) than in 2010 (77%) (p = 0.044).

Advance care planning

The number of residents with dementia who had expressed specific preferences for medical treatment increased significantly from 8% in 2010 to 19% in 2015, a difference that remained significant after correcting for the difference in CPS score across the years (adjusted p = 0.020, odds ratio (OR) 2.80, 95% confidence interval (CI) 1.18-6.67)(Table2). The percentage of nurses being unsure if the resident ever expressed wishes also increased; from 18% to 24% in 2015. In 2010, nurses spoke at least once (i.e. once or several times) with 10% of the residents about medical treatments s/he would or would not want in the last phase of life or about the preferred course of care in the last phase of life. This number increased to 21% in 2015 (p=0.008) but was no longer statistically significant after adjusting for the difference in CPS score between the years (adjusted OR 2.04, 95% CI 0.92 to 4.49).

In 2010, 5% of the residents with dementia gave power to a third party in a prior living will to make decisions on his or her behalf in case s/he would be no longer competent to do so. This number increased significantly to 32% in 2015 (adjusted p<0.001, OR 7.34, 95% CI 3.16 to 17.70). 13% of residents had a written advance directive in their file in 2010, which increased to 41% in 2015 (adjusted p <0.001, OR 4.35, 95% CI 2.44 to 7.75). More specifically, 11% of residents in 2010 versus 31% in 2015 had a written DNH advance directive in their file (adjusted p<0.001, OR 3.43, 95% CI 1.75 to 6.71) and a similar significant rise was found for residents with a DNR advance directive (12% in 2010 vs 38% in 2015, adjusted p<0.001, OR 4.10, 95% CI 2.22 to 7.58). All these differences remained significant in the adjusted analyses.

GP orders

58.1% and 62.3% of residents had a GP order in their file in 2010 and 2015 respectively (adjusted p 0.528, OR 1.19, 95% CI 0.69 to 2.07). No statistically significant changes were found for any of the individual GP orders.

Discussion

In the short time frame of five years, this study found a considerable increase in the proportion of residents with dementia who expressed specific preferences about medical treatment in the last phase of life (from 8 to 19%). A substantial rise was also found in the number of residents who had advance care planning documentation in their file, such as the appointment of a proxy decision-maker (from 5 to 32%), a DNH advance directive (from 11 to 31%) or a DNR advance directive (from 12 to 38%). Despite these increases, the absolute numbers of residents who engaged in advance care planning were still low in 2015; only one in five, and one in three residents with dementia, were engaged in communication and documentation of advance care planning respectively. Moreover, only 40% had an advance directive in their file. Interestingly, while advance care planning increased, we found no change in the use of GP orders regulating end-of-life treatments.

A possible explanation for the rise in verbal and written advance care planning could be the increased promotion of advance care planning in nursing homes in Belgium, resulting in a growing awareness of its importance for people with dementia on a societal and political level. In Flanders specifically, guidance on the legal statute of advance care planning and advance directives for people with dementia was made available for the healthcare sector in 2010[19], as well as broad reflections on the use of advance care planning in 2011[20]. In 2013, the Flemish government implemented quality indicators for the nursing home sector, one of which measures the existence of an up-to-date end-of-life care plan for every resident[10]. Nursing homes must report on this biannually and the results are reported online, to improve the quality of care. In 2018, on average 51.4% of all nursing home residents were reported to have a care plan for end-of-life treatment in their file[10], reflecting an increase of 7.6% since 2016 (43.8%)[21]. Hence, it is possible for countries to substantially increase advance care planning in nursing homes for people with dementia over a relatively short period.

Nevertheless, our data show that only one in five residents engaged in verbal advance care planning, that for one in four resident the nurse most involved in the care did not know if wishes were ever expressed and only 30-40% had a written advance care planning document in their file. There are several possible explanations of why these absolute numbers are still low.

First, the problems healthcare providers, including nursing home nurses, experience when initiating or conducting advance care planning conversations could hamper the uptake of advance care planning. For example, factors related to professionals' own ethical and moral concerns, communication difficulties both with residents with dementia and their relatives, and the lack of understanding and education about the advance care planning process were found to hinder advance care planning conversations[22–24].

Second, the low frequency of verbal and written advance care planning could be due to structural problems in the nursing home setting, such as a shortage of staff, a high staff turnover, the lack of time[24–27] or the lack of administrative support and regulations, and little support in the organizational culture[24,28,29] could lead to fewer advance care planning conversations.

Last, the low numbers of residents communicating their preferences could be related to unwillingness of these residents to participate, or the cognitive status of nursing home residents with dementia. It is possible that residents were no longer able to express preferences, and advance care planning conversations were too complex. This could also explain why the absolute number of GP orders was so much higher since they do not require direct input from residents[9].

Overall, the uptake of advance care planning is found to be a priority, but changing health care systems is a complex undertaking[27,30]. As it has been suggested that policy-related documents only constitute the starting point of change, their existence alone might not be sufficient to effectuate the desired transformation and knowledgeable and skilled professionals are needed to translate these policies into practice[31–33]. Hence, as a first step in improving the uptake of advance care planning in nursing homes for residents with dementia, nursing home staff (e.g. nurses) could benefit from both education on the dementia disease trajectory, as well as on advance care planning[22]. Internationally, several educational interventions on advance care planning for nursing home staff have already been evaluated. These studies have found increased patient participation[34], as well as improved communication[35], but also a lack of sustainable results[35] which suggests that ongoing staff support is needed. With continuously supporting professionals to initiate advance care planning conversations, the ultimate goal of advance care planning, providing care and treatment in concordance with the resident's wishes, might be reached[36].

Strengths and limitations

When using a retrospective study design, respondents' recall bias cannot be ruled out. However, the three-month timeframe of identifying deceased residents is rather narrow and a well-known approach in end-of-life care research[6,37]. Moreover, a retrospective design is recommended for the type of research questions used in this manuscript, as this is the most feasible way to identify the relevant and most representative sample of deceased residents[38,39]. Since we used data from 2010 and 2015, it would be interesting to examine if the described increases have persisted in the light of more recent initiatives, such as a national campaign about advance care planning which was launched in 2016[40].

By selecting the nurse most involved in each resident's care as a main respondent, we ensured reliable information on verbal ACP. However, the large proportion of nurses answering 'I don't know' regarding the resident ever expressing specific preferences about a medical treatment s/he did not want during the last phase of life, could have led to an underrepresentation of residents expressing their wishes verbally. Lastly, the participating nursing homes could have had a particular interest in advance care planning and palliative care, which forms another potential source of bias. This could lead to an overestimation of verbal and written advance care planning. The low absolute numbers found, however, provide an argument against this.

Conclusions

It is possible for countries to substantially increase advance care planning in nursing homes for people with dementia over a relatively short period of time. However, our study found that the majority of residents with dementia still did not participate in conversations or decision-making about their preferred course of care. The main priority for the future should be to evaluate the mechanisms that could trigger change (e.g. policies) and to provide ongoing support and training for nursing home staff in implementing and conducting advance care planning with residents living with dementia.

Funding: The study was funded by the Interdisciplinary Network for Dementia Using Current Technology (INDUCT, EU Horizon 2020). LP is a Postdoctoral Fellow of the Research Foundation Flanders. The funders have no role in the design of the study and collection, analysis, and interpretation of data, in writing the manuscript, or in the decision to submit the manuscript for publication.

Author contributions: Study conception: AW-vD, LVdB, LP; data acquisition: LVdB; data analysis: AW-vD, LP, TS; data interpretation: all authors; drafting of manuscript: AW-vD, LP, LVdB; revising manuscript critically for important intellectual content: all authors; final approval of the version to be published: all authors. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflict of interest: The authors have no conflict of interest.

Data availability: Data will be made available for non-commercial research purposes upon reasonable request to the authors (LVdB).

Acknowledgments: We would like to thank Rose Miranda and Isabel Vandenbogaerde for their support with the data analysis and Lindsay Jacobs for language editing.

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Table 1. Characteristics of all deceased residents with dementia in 2010 and 2015[a]

	2010 (N=198)		2015 (N=183)		p-value[b]
Age at time of death, mean (SD)	86.7	(7)	86.9	(7.3)	0.734
Sex, female n (%)	115	(61.5)	114	(65.5)	0.429
Length of stay in days[c], median (IQR)	893	(448-1694)	688	(283-1678)	0.278
Place of death, n (%)					0.327
Nursing home	171	(90.0)	152	(86.0)	
General hospital ward or intensive care unit	17	(9.0)	24	(14.0)	
Palliative care unit in hospital	2	(1.0)	0	(0.0)	
BANS-S, total score[d,] mean (SD)	20.9	(3.9)	20.3	(4.3)	0.193
CPS, n (%)					0.044
Intact, borderline intact, mild impairment	8	(4.3)	21	(12.7)	
Moderate impairment	27	(14.4)	20	(12.0)	
Moderately severe impairment	9	(4.8)	15	(9.0)	
Severe impairment	61	(32.6)	52	(31.3)	
Very severe impairment	82	(43.9)	58	(34.9)	
Stage of dementia[e, n] (%)					0.552
Non-advanced	95	(50.8)	75	(47.8)	
Advanced	92	(49.2)	82	(52.2)	

Generalized linear mixed models.

Abbreviations: SD; Standard Deviation, IQR; Inter Quartile Range, BANS; Bedford Alzheimer Nursing Severity Scale, CPS; Cognitive Performance Scale, GDS; Global Deterioration Scale.

[a] Table presents characteristics of deceased residents for whom nurses filled out a questionnaire. Missing data: age n_{2010}=12 (6.1%), n_{2015}=8 (4.4%); sex n_{2010}=11 (5.6%), n_{2015}=9 (4.9%); length of stay n_{2010}=13 (6.6%), n_{2015}=0 (0%); place of death n_{2010}=8 (4%), n_{2015}=7 (3.8%); BANS-S n_{2010}=4 (2%), n_{2015}=2 (1.1%); CPS n_{2010}=11 (5.6%), n_{2015}=17 (9.3%); Stage of dementia n_{2010}=11 (5.6%), n_{2015}=26 (14.2%).

[b] Differences between the years where calculated using generalized linear mixed models, $P<0.05$ was deemed significant.

[c] Calculated by subtracting date of admission from date of death.

[d] Total score is sum of individual item scores.

[e] Combination of CPS and GDS; CPS scores≥5 & GDS stage=7 advanced dementia, CPS scores <5 & GDS <7 non-advanced dementia

Table 2. Advance care planning communication and documentation, and GP orders in 2010 and 2015[a]

	2010 (N=198)		2015 (N=183)		OR (95% CI)	p-value	OR (95% CI)	p-value
	N	(%)	N	(%)	unadjusted	unadjusted	adjusted	adjusted (CPS)
Advance care planning communication								
Did the resident ever express specific preferences about a medical treatment he or she did not want during the last phase of life?					2.98 (1.46 to 6.07)	0.003[b]	2.80 (1.18 to 6.67)	0.020[b]
Yes	16	(8.2)	34	(18.9)				
I don't know	35	(17.9)	44	(24.4)				
Did you ever speak with the resident about medical treatments he or she would or would not want in the last phase of life or about the preferred course of care in the last phase of life?					2.37 (1.25 to 4.51)	0.008[c]	2.04 (0.92 to 4.49)	0.078[c]
Yes, only once	8	(4.1)	11	(6.1)				
Yes, several times	11	(5.6)	26	(14.5)				
Total yes	19	(9.7)	37	(20.6)				
Advance care planning documentation								
Resident appointed a proxy in a prior living will (yes)	10	(5.4)	56	(31.6)	7.70 (3.57 to 16.60)	<0.001	7.34 (3.16 to 17.70)	<0.001
Written advance directive in file								
Total[d]	25	(12.6)	75	(41.0)	4.90 (2.85 to 8.43)	<0.001	4.35 (2.44 to 7.75)	<0.001
Do-not-hospitalize	22	(11.1)	57	(31.1)	3.63 (1.89 to 6.97)	<0.001	3.43 (1.75 to 6.71)	<0.001
Do-not-resuscitate	23	(11.6)	69	(37.7)	4.81 (2.68 to 8.63)	<0.001	4.10 (2.22 to 7.58)	<0.001
Euthanasia	0	(0.0)	3	(1.6)	1.32 (0.43 to 4.10)	0.628	1.32 (0.40 to 4.33)	0.646
Terminal sedation	0	(0.0)	7	(3.8)	1.84 (0.64 to 5.33)	0.260	1.64 (0.53 to 5.05)	0.391
Try all life-prolonging treatments	0	(0.0)	2	(1.1)	1.21 (0.38 to 3.83)	0.747	1.25 (0.37 to 4.20)	0.714
GP orders								
GP orders in file								
Total[d]	115	(58.1)	114	(62.3)	1.27 (0.75 to 2.15)	0.366	1.19 (0.69 to 2.07)	0.528
Do-not-hospitalize	107	(54.0)	96	(52.5)	0.97 (0.57 to 1.63)	0.918	1.01 (0.59 to 1.73)	0.965
Do-not-resuscitate	93	(47.0)	104	(56.8)	1.75 (0.95 to 3.22)	0.073	1.68 (0.88 to 3.20)	0.116
Euthanasia advance directive	0	(0.0)	2	(1.1)	1.21 (0.38 to 3.83)	0.747	1.19 (0.35 to 4.01)	0.780
Terminal sedation	6	(3.0)	10	(5.5)	1.40 (0.57 to 3.42)	0.459	1.63 (0.64 to 4.16)	0.305
Try all life-prolonging treatments	5	(2.5)	3	(1.6)	0.87 (0.31 to 2.43)	0.790	0.88 (0.30 to 2.56)	0.810

OR; odds ratio, CI; confidence interval, GP; general practitioner

Generalized linear mixed models, adjusted for CPS.

[a] Missing data: specific preference n_{2010}=2 (1%), n_{2015}=3 (1.6%); speak with the resident n_{2010}=3 (1.5%), n_{2015}=4 (2.2%); proxy appointed n_{2010}=12 (6.1%), n_{2015}=6 (3.3%); written ADs n_{2010}=0 (0%), n_{2015}=0 (0%); GP orders n_{2010}=0 (0%), n_{2015}=0 (0%).

[b] The option 'I don't know' was not included in this analysis.

[c] The options 'spoke once' and 'spoke more than once' were combined as 'yes' for this analysis, due to low cell frequencies.

[d] Total N of people having one or more advance directives in their file.

PART 3; IMPROVING ADVANCE CARE PLANNING IN NURSING HOMES

Tools to support advance care planning conversations and documentation in nursing homes

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Abstract

Although advance care planning (ACP) is highly relevant for nursing home residents, its uptake in nursing homes is low. To meet the need for context-specific ACP tools to support nursing home staff in conducting ACP conversations, we developed the ACP+ intervention. At its core, we designed three ACP tools to aid care staff in discussing and documenting nursing home resident's wishes and preferences for future treatment and care: 1) an extensive ACP conversation guide, 2) a one-page conversation tool, and 3) an ACP document to record outcomes of conversations. These nursing home-specific ACP tools aim to avoid a purely document-driven or ''tick-box" approach to the ACP process and to involve residents, including those living with dementia according to their capacity, their families and healthcare professionals.

Advance care planning (ACP) is 'a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care'[1]. It usually involves several conversations with a person, family and healthcare professionals and can include appointing a legal representative[2]. Moreover, specific preferences can be formalized by completing legal documents such as Advance Directives (ADs).

Nursing home residents are among the most frail populations[3–7] and in the light of anticipated deterioration, discussing future care wishes and preferences is highly relevant. Nevertheless, the uptake of ACP in nursing homes seems low[8,9], with insufficient knowledge and skills of the care staff being one of the main reported barriers[10,11]. Especially for nursing homes, where different care staff (i.e. nurses, care assistants, allied health staff) can be involved in ACP[12], a clear need for context-specific ACP tools guiding ACP conversations has been reported.

To support the care staff in nursing homes to engage in ACP, we developed specific tools as part of a multi-component ACP intervention, called the ACP+ intervention[13]. The goal of this intervention was to support the implementation of ACP as part of the routine nursing home practice in Flanders, the Dutch-speaking part of Belgium, using an eight-month step-wise educational intervention[14]. We developed three ACP+ tools to aid the care staff in eliciting, discussing and documenting the residents' wishes and preferences for future treatment and care: 1) an ACP conversation guide, 2) a conversation tool, and 3) an ACP document.

Given that recent reviews have found great variance in the content of different ACP tools, and highlighted that detailed descriptions of intervention tools are often lacking[15,16], this report outlines the development and structure of the nursing-home specific ACP+ tools. The ACP+ tools aim to avoid a purely document-driven or 'tick-box' approach and, to involve residents, including those with dementia according to their capacity, their families and healthcare professionals in the ACP process.

Development of the ACP+ tools

In the first stage, we conducted a literature review of international research and grey literature to explore existing ACP tools used in older populations and nursing homes. The following tools were examined further for common themes: ACP tools from a European ACP trial[17], the ACP document of University Hospital Leuven[18], the 'Looking and thinking ahead document' of a European palliative care trial (PACE EUFP7[19]), the Advance Care Plan of Respecting Patient Choices[20], the ACP guideline no. 12 of the Royal College of Physicians of London, UK (2009)[21] and existing practice guidelines for ACP in Belgium (published by pallialine.be, the organization producing palliative care evidence-based guidelines under the Flemish Federation of Palliative Care[22,23]).

Together with a multidisciplinary expert group (consisting of an ethicist, three psychologists, a general practitioner, a sociologist and a social worker: CG, AW-vD, LP, LVdB, RVS, LD, JG, respectively), core themes for ACP conversations in nursing homes were selected, resulting in -among others- the **ACP+ conversation guide** and the **ACP+ document**. The preliminary tools were further reviewed by a legal expert and a palliative care nurse-trainer (LVH). All tools were tested in a feasibility study, involving two individual and three group-interviews with 17 management and staff members from five nursing homes[13]. Participants expressed the need for a user-friendly and practical summary of the ACP conversation guide to use during ACP conversations[13]. We therefore developed an additional **one-page ACP+ conversation tool** with prompts that could be used throughout the ACP conversation.

Structure and content of the ACP+ tools

Tool 1: The ACP+ conversation guide

The ACP+ conversation guide is a booklet including four chapters: 1) General information about ACP; 2) ACP conversations; 3) Documentation of ACP outcomes, including how to draft an AD within the legal context of Belgium; and 4) ACP with people with dementia and their families. An English translation of this guide can be found in the Appendix (1e).

In the first chapter, general information about ACP is given: with whom, when, how often, and which preparatory tasks are needed (Figure 1). For example, an estimation of the decision-making capacity of the resident is advised. This chapter also highlights the importance of recognizing that ACP is a process rather than a one-time event, that multiple conversations with the resident/family might be necessary and that preferences can be revisited regularly. It stresses that spontaneous conversations can occur but that planning conversations with all residents is important too.

The second chapter includes a template and communication tips to facilitate ACP conversations, comprising nine different sections, starting from broadly discussing what a good life entails for the resident and moving to more specific subjects about their preferences for future care, end-of-life care, death and dying. The order of the sections can be tailored to the residents'/families' preferences and readiness to engage in ACP. Not all sections need to be addressed in one conversation. Moreover, the care staff is encouraged to actively listen to residents (e.g., leave ample time for the residents/families to express themselves), and avoid having overly structured 'Q&A' conversations.

The third chapter provides information about how to document the outcomes of an ACP conversation using the ACP+ document (described below). Additionally, this chapter explains how to use the official (legal) documents to appoint a legal representative and to create ADs[24], if the resident wishes to do so.

In the fourth chapter, the care staff is offered advice on conducting ACP conversations with residents with dementia. In summary, we recommended to 1) prepare well and provide relevant information on dementia to the resident/family; 2) customize the conversation to the level of the resident with dementia; 3) draw the attention of the resident with dementia regularly by saying his/her name or with a gentle touch; 4) use supporting materials such as pictures to back up verbal communication; 5) involve all important parties (e.g. family) as early and as often as possible; and 6) observe the interaction between the resident with dementia and his/her family, as well as the interaction between the different family members.

Tool 2: The ACP+ conversation tool

The ACP+ conversation tool (Table 1) is an easy-to-use one-page document that is structured according to the nine sections of the second chapter of the ACP+ conversation guide. It includes prompts which the staff can use to conduct an ACP conversation, to summarize it and to plan a follow-up ACP conversation (if applicable). Lastly, it summarizes how and where the outcomes of the ACP conversation can be documented. This conversation tool helps the staff to guide conversations in a natural way and prevents forcing conversations into 'tick box exercises'.

Tool 3: The ACP+ document and summary

The ACP+ document (Appendix 2e) is meant to be filled in after an ACP conversation. It is structured according to the nine sections of the ACP+ conversation guide and conversation tool. For each section the care staff can write down what was discussed and which decisions, if any, were taken. Space is reserved to note who was present during the conversation, and to write down the observations of the care staff on the decision-making capacity of the resident.

Attached to the ACP+ document is the ACP+ summary, in which the care staff can highlight the most important decisions, i.e. who is appointed as the legal representative and which ADs were composed by the resident. It is advised to keep the official (legal) ADs forms together with this summary in case of an emergency or a transfer to another care setting.

Discussion

There is a worldwide call to create opportunities for ACP conversations among nursing home residents, discussing ACP over several sessions and revising decisions made[25]. In this paper, we discuss three tools that can be used to aid the nursing home care staff in discussing and documenting the resident's wishes and preferences for future treatment and care. These tools are part of the ACP+ intervention which aimed to support nursing homes with the implementation of ACP as part of the routine nursing home practice in Flanders, Belgium[26].

This paper serves as an important first step to provide practice with detailed tools to conduct ACP conversations with the vulnerable nursing home population and their families. Our tools are consistent with best practices for discussing care goals, as was outlined by Bernacki *et al.*[27] identifying a structured format to guide discussions and record information to hold promise in optimizing ACP conversations[27]. The absence of detailed intervention descriptions is a generally acknowledged phenomenon[15]. When developing the ACP+ tools, we therefore might have missed details of existing interventions or conversation guides, or tools described in the grey literature that might not have been covered by our search, but play an important role in daily nursing home care.

While the local legal context influences which advance end-of-life decisions people can make (e.g., euthanasia is a legal option in Belgium, but not in several other countries), the contextual barriers experienced by the nursing home staff to conduct ACP conversations are very similar across countries[28] (e.g., nursing home staff's lack of confidence to engage in ACP[29]), making the ACP+ tools widely applicable. However, integrating the residents' views and preferences in clinical practice, and ultimately aligning the residents' preferences and care, requires active and systematic integration of ACP conversations into the clinical care structures and processes, next to time and labor.

Acknowledgements: The research team would like to thank the nursing homes in which we tested all ACP+ related tools and procedures and Prof. Herman Nys (KU Leuven) for the advice concerning Belgian medical law.

Funding: The study was funded by the Research Foundation-Flanders (FWO) and the Interdisciplinary Network for Dementia Using Current Technology (INDUCT, EU Horizon 2020). Lara Pivodic was a Postdoctoral Fellow of the Research Foundation-Flanders (FWO, 2017-2020). Joni Gilissen is a postdoctoral fellow of the Belgian-American Educational Foundation (B.A.E.F.). The funders have no role in the design of the study and collection, analysis, and interpretation of data, in writing the manuscript, or in the decision to submit the manuscript for publication.

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Figure 1. ACP process as outlined in the ACP+ conversation guide

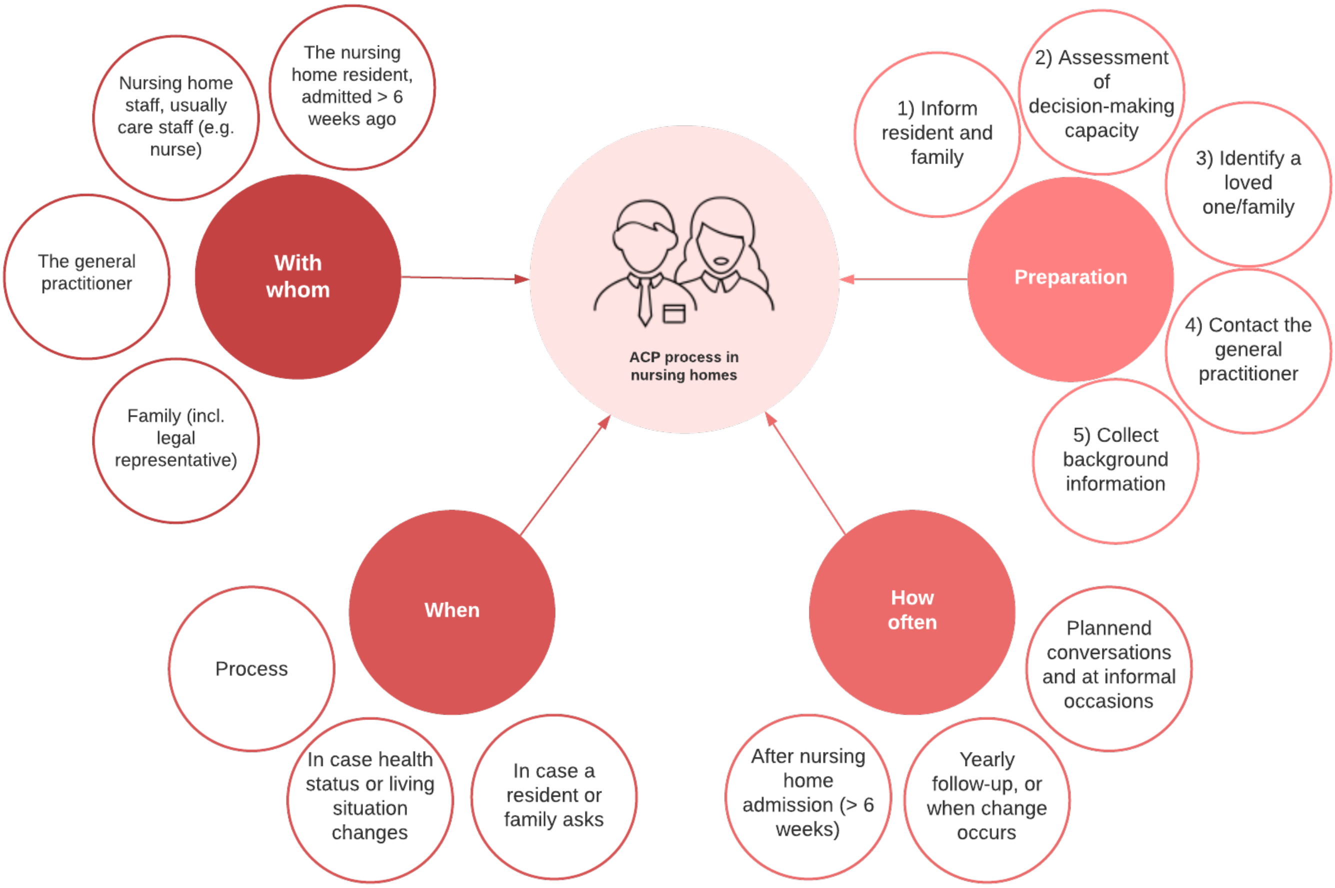

Table 1. Approach of ACP conversation as outlined in the ACP+ conversation guide

The ACP$^+$ conversation tool

Add sentences that are convenient for you

Section A and B	Section C and D	Section E, F, G, H and I	Summarize, document and follow-up
Section A: Ideas about a good life **(broadly asking about values)** "What is important to you?" "Which things make you feel joy?" "What are you proud of?" "What makes life worth living?" "Do you think you have had a good life?" "What do I need to know about you to give you the best possible care?" "How could we improve your care? "Which things give you strength?" "Do you have cultural, religious or spiritual beliefs? Would you like to talk about this with someone?" "At which point do you consider life not to be worth living anymore?" "What would you like your family, children and grandchildren to remember about you?" "What would you like to finish in your life?" "To which things would you still like to dedicate some time and energy?" "Is there something you are strongly looking forward to?" "Could you summarize for me what the doctors told you about your current health status?" "What do you expect to happen to you?" "What makes you happy? What is essential for your quality of life?" "Is there any business that you would like to finish?" **Section B: Preferences for *current* care and treatment** "How do you consider your current quality of life?" "Do you currently have a good life?" "How do you cope with your dementia/getting older?" "What is the hardest part for you about living with dementia?" "Do you find it hard to get older?" "What does aging mean to you?"	**Section C: Preferences for *future* care and care goals** **Ideas and worries about the future and the end of life** "When considering the future, what do you hope for/ are you worried about?" "When considering your illness, what would be the best or worst thing that could happen to you?" "Are you afraid to die?" "Did you ever witness someone getting very ill, becoming dependent, or dying?" "Did you ever witness someone else's death, good or bad? How did you experience this?" "Is there something you are afraid of? What would you rather avoid?" **The importance of ACP** "Have you ever considered the medical care you would like to receive when you are too ill to decide upon this? That is the goal of ACP, to guarantee you that you are cared for according to your wishes, even when you cannot convey these anymore." **Common goals of care** "Your health status could change in the future. Sometimes people can adjust or get used to this new situation, but not always. In the past you have told me that (e.g. not being hospitalized…) was important to you. Is this still the case?" "Would you like to consider your future health?" "Is it important to you to make your own decisions? If so, what are the things you would like to decide about?" "What is more important to you: suffering as little as possible/focusing on quality of life or living as long as possible?" **Section D: Appointing a legal representative** "In case you would become so ill, you could no longer make decision about you care for yourself, is there someone you trust enough to make these decisions for you?" "Would you like to appoint a legal representative?"	**Section E: Documenting end-of-life wishes** **Advance Directives** "There are several ways to document your wishes. Some people think it is useful to compose an Advance Directive. You don't have to do this if you don't want to, and you should certainly not rush into this. Shall we discuss all the options together?" "Have you ever heard about palliative care? What is your experience with this?" "Would you still like to go to the hospital if you are in a critical state?" "Do you have an Advance Directive? Would you like to compose an Advance Directive?" In case of questions posed by resident or family about euthanasia[1]: "What does euthanasia mean to you?" **Preference with regard to resuscitation** "There is a chance that you suddenly experience cardiac arrest, if this happens we can resuscitate you. Are you familiar with this? Have you ever thought about if you would want this?" "Would you like to be resuscitated?" **Section F: Place of care/death** "Where would you like to be cared for at the end of life?" **Section G: Other preferences** "Are there other preferences you would like to take us into account?" **Section H: Preferences with regard to dying** "Are there specific (religious) wishes that we should consider?" "Would you like to make funeral arrangements?" **Section I: Revising preferences and wishes** "Which circumstances would be a reason for you to revise your wishes and preferences about the care?"	**Summarize the conversation** "So today you told me about… Is that correct?" "Do I understand correctly that today we decide upon the following…?" **Document wishes and preferences** - ACP+ Document - ACP+ Summary - Advance Directives - Care codes (ABC, DNR) - Check if all documents correspond with each other **Planning a follow-up conversation (if wanted)** "A while ago we spoke about… You told me about… Is this still applicable?" "A year ago, we spoke about … I was just wondering how you feel about this now. Would that be alright for you to discuss this?" **Communication to other involved health care professionals** - Notes/copy in the (digital) nursing home file of the resident - Mention during the (monthly) multidisciplinary meetings to inform all healthcare staff - Inform the general practitioner

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[1] Euthanasia is a legal option in Flanders for people with decision-making capacity. This particular question should be considered in the light of this legal framework.

Appendix

This appendix belongs to the article, ‘Tools to support advance care planning conversations and documentation in nursing homes’, and includes the ACP+ conversation guide, as well as the ACP+ document.

1e: ACP+ conversation guide
2e: ACP+ document

ACP+
ADVANCE CARE PLANNING
IN NURSING HOMES

ACP$^+$ conversation guide

This conversation guide supports care professionals in nursing homes in conducting ACP conversations and documenting wishes and preferences of residents and their loved ones.

TO START

This conversation guide includes tips and tricks for preparing and conducting ACP conversations with residents and/or family. Moreover, the conversation guide will offer practical support while filling out ACP-documents and Advance Directives.

Please use this conversation guide as reference book and support tool when planning, preparing and conducting ACP conversations with residents and/or family. Do NOT use this conversation guide during an ACP conversation, as it is too extensive for that. Make sure you are familiar with all recommendations in this conversation guide before you start an ACP conversation or document wishes and preferences.

In the appendix of this conversation guide you can find several supporting materials that you can use during the ACP conversations and when documenting wishes and preferences of residents.

Whom is this conversation guide for?

The need for advance care planning (ACP) can be signaled by all team members (regardless of their specialty) in a nursing home setting and all team members can adhere to it, in line with their competences and function. The aims of this conversation guide are to facilitate (1) ACP conversations with residents and/or their family and (2) documenting wishes and preferences regarding future care and treatment.

CONTENT

With whom?

1 YOU AS CONVERSATION LEADER

As health care professional you can conduct ACP conversations. Throughout this document you will be referred to as the ‘conversation leader’. Make sure ACP conversation are not the responsibility of just one person in the nursing home. Signaling the need for an ACP conversation is explicitly the task of ALL nursing home staff. Every resident should have a chance to discuss ACP, especially when they request such a conversation themselves.

2 RESIDENT AND FAMILY

a. **Residents with decision-making capacity who were admitted more than six weeks ago**

All residents with decision-making capacity can be approached for an ACP conversation. Ideally, they will be informed about ACP on admission to the nursing home. The head nurse assesses the decision-making capacity. Residents and their loved ones can decide if they want an ACP conversation or not.

ACP can never be mandatory, but should be a right for all. In ideal circumstances no one should be left out. However, if you wait until a resident takes the initiative, there is a risk that a first step will never be taken. All opportunities to talk about the subject should be taken, but without being brutal or shocking residents. Therefore, it is necessary to create a climate of trust and open communication in the nursing home.

b. Family

For every resident, with or without decision-making capacity, it is recommended to involve the legal representative. It there is no legal representative, you can ask a loved one/family member of the resident’s choice or a trusted person to be present. Appointing a legal representative is an important part of the ACP conversation (see page 15).

3 THE GENERAL PRACTITIONER (GP)

When preparing the ACP conversation, you can check in what way the GP would like to be involved and how you should keep him/her up-to-date when a resident changes his/her wishes or preferences. Some GPs like to be present during the ACP conversation, some are happy to be updated over the phone. Always make sure to send the GP the ACP+ summary (see ACP$^+$ document).

ACP: when and how often?

Box. 1 Signals for the start or follow-up of an ACP conversation

When the resident's health status or living situation changes:

- On admission in the nursing home (or 6 to 12 weeks after admission)
- After a thorough health status check or yearly control visit of the GP
- Monitoring appointment of a (progressive) illness by the GP or hospital
- When discussing the diagnosis of a new or progressive illness
- On hospital admission (for a serious progressive illness)
- In case of severe suffering and a poor prognosis
- In case of signs of dementia or a life-threatening illness
- In case of signs of an illness which could lead to losing decision-making capacity
- Not having much longer to live
- The start of palliative care
- No family or disagreement between family members

When the resident or loved one asks for a conversation:

- Resident states wanting to die
- If the resident brings up ACP
- If the family of the resident brings up ACP
- Worries about the care a dying loved one of the resident has received
- Moments when speaking about hopes and fears
- Questions related to euthanasia or physician-assisted suicide

GENERAL GUIDELINES

Some general guidelines are provided:

- All **new residents** should ideally be offered an ACP conversation between 6 and 12 weeks after admission in the nursing home. We suggest to already mention ACP on admission. This way the resident and his/her family know they can expect the conversation.
- There might be **other moments** when a resident would like to speak about his/her preferences and wishes. Be alert and make use of every occasion to speak about ACP. Let all staff in the nursing home be alert on signs of residents and family wanting to speak about ACP.
- Make sure all documented preferences and wishes are always **up to date**. In case a situation occurs as described in **Box 1**, plan an ACP follow-up conversation with the resident and/or his/her family.

What to do before conducting an ACP conversation?

Every ACP conversation deserves a **proper preparation** and an adjusted setting, both in terms of time and space. Before you start the first conversation with a resident and/or his/her family it is recommended to take the steps described below.

Step 1: Inform resident and his/her family
Step 2: Assessment of decision-making capacity
Step 3: Identifying a loved one
Step 4: Contact with the GP
Step 5: Collecting background information

STEP 1: INFORM RESIDENT AND HIS/HER FAMILY

All residents and their family should be informed about ACP. Ideally, this happens on admission to the nursing home, but it can also happen on any other given moment. At first this should be a short information session, unless the resident (or his/her family) wants to know more immediately, aiming to encourage the resident to start thinking about wishes and preferences.

STEP 2: ASSESSMENT OF DECISION-MAKING CAPACITY

Before you start the ACP conversation it is important to assess a resident's decision-making capacity. This way you can determine if it would be possible to have the ACP conversation with the resident and his/her family, or only with the family.

Decision-making capacity reflects the individual ability to make independent decision. Decision-making capacity can be described as: Being able to correctly come to a reasonable appreciation of one's interests concerning a current specific decision or situation and arrive at a well-balanced decision.

This general assessment of decision-making capacity of residents is an essential element of the ACP conversations and should be done before you start the conversation. Of course, you can continuously pay attention to this: during the care you provide to the resident, throughout the conversation, on admission, when exploring the residents' insight in his/her illness, etc.

IMPORTANT:

Always consider the general decision-making capacity of a resident as described below:

- Assume a maximum of decision-making capacity.
- Consider decision-making capacity as fluctuating and pay attention to signals of diminishing capacity. Consider the right moment to initiate ACP. For example, it might be hard for the resident to speak about preferences and wishes after a tiresome session with the physiotherapist. Pick a moment at which the resident is well rested.
- Assess decision-making capacity per task, so for a certain decision at a certain moment. The question is whether the resident would have sufficient decision-making capacity to think about the themes mentioned during the ACP conversation. So, when assessing a resident's decision-making capacity, you should not only consider the resident's cognitive capacity, but also the complexity of the themes you will discuss, the decisions that need to be made, the different options the resident has and the consequences of all options.
- Let the resident participate as much as possible. It is your task as a healthcare professional to adjust your approach and communication style to the resident and to ensure a loved one is present.
- Because of the fluctuating and task-specific nature of decision-making capacity, it could be helpful for you to reach out to other healthcare professionals, for example colleague-nurses who have a lot of experience caring for people with dementia, or the GP.

Assessment: *general assessment versus formal clinical assessment*

A **general assessment** of decision-making capacity of people living with dementia is a task of the GP, sometimes as part of ACP conversations. Other involved parties (e.g. healthcare professionals or family) can play an important role in this, especially because of the fluctuating and task-specific nature of decision-making capacity. According to the 'Mental Capacity Act', developed in the UK, a person is not capable of making his/her own decision when s/he cannot perform one or more of the following tasks:

- Understanding the information given to him/her,
- Remembering the information long enough to make a decision,
- Weighing different perspectives to make a decision,

- Communicating the decision made – either by verbal communication, using sign language or making small muscle movements (e.g. blinking the eyes or squeezing with a hand).

A **formal clinical assessment** of the decision-making capacity is not always necessary.

Make a formal clinical assessment of decision-making capacity when one of these situations apply:

- When in doubt or in case of a discussion (between healthcare professionals and/or loved ones)
- When the consequences of decisions can have high impact

A formal clinical assessment of decision-making capacity needs several conversations, observation and assessment by a well-informed healthcare professional. It is recommended to perform a careful clinical and neuropsychological assessment, with the expertise of an inter- or multidisciplinary team, consisting of a neurologist, a geriatrician, and a geronto-psychiatrist with expertise in dementia diagnostics. Decisions on decision-making capacity can never be based on screentest only. For example, only using the MMSE (Mini Mental State Examination) is insufficient to reach a decision.

STEP 3: IDENTIFYING A LOVED ONE

You identify which loved one(s) of the resident is/are able to be involved in the ACP process. If the resident is still capable of deciding upon this, then s/he should be involved.

- <u>In case the resident has already appointed a legal representative,</u>
  This person should be invited to be present during the ACP conversation.
- <u>In case the resident did not appoint a legal representative,</u>
  You check with the resident who s/he would want to be involved. You can ask the following questions:
  - "Who would you like to be involved in your future care?"
  - "Some people want their loved one(s) to be present during the ACP conversation. Is there someone you would like to be present?"

  The resident can also choose to go through the ACP process by him-/herself.
- <u>In case the resident cannot indicate a loved one (due to lack of decision making-capacity),</u> you can contact the contact person(s) noted in the resident's file to indicate which person would be willing to be involved. It is advised to involve the resident as much as possible. The person is ideally:
  - A person of age
  - A family member in the first degree
  - A person with a good and trusting relationship with the resident
  - A person who can serve the interests of the resident
  - A person who is independent relative to the residents' medical treatment

STEP 4: CONTACT WITH THE GP

It is important to check with the GP in what way s/he wants to be involved in the ACP process. This can either be done over the phone or face-to-face. Moreover:

- You inform the GP about ACP and the ACP-policy in the nursing home in case s/he is not up-to-date on this yet.
- Ask the GP if s/he wants to be present during the ACP conversation and if s/he wants to take the lead. In case the GP cannot be present, you can send written updates and invite him/her to the monthly multi-disciplinary meetings in the nursing home.
- Ask the GP about ACP conversation in the past and any filled out documents (e.g. ADs).
- Ask the GP about important family dynamics that should be considered.
- Ask the GP about other relevant information, for example the medical file, prognosis, general health status and an assessment of the decision-making capacity.

In case the resident received home care before admission to the nursing home, it is advised to contact this care organization and ask about any ACP conversations that might have happened, or any other relevant information you should know to prepare the ACP conversation.

STEP 5: COLLECTING BACKGROUND INFORMATION

Collect information about the residents' illness, comorbidities and treatment options and make sure you know which information has been given to the resident and his/her family. You can ask other healthcare professionals for this information, as well as information on family dynamics, religious beliefs etc.

Preparation checklist

- ✓ Have I made a proper estimation of the resident's decision-making capacity (keeping the fluctuating and task-specific nature in mind)?
- ✓ Are the resident and/or family aware of the planned ACP conversation? If not, make sure you can explain the purpose and main aims of ACP.
- ✓ Do I have sufficient knowledge about the resident's health status, treatment options and social network?
- ✓ Do I know whom to invite and how to involve the resident as much as possible?
- ✓ Is there a room available where we can have a private conversation? Have a put a sign up stating not to disturb?
- ✓ Do I have enough time?
- ✓ Have I contacted the GP to ask about in which way s/he wants to be involved?
- ✓ Have any ADs been drawn up in the past? If so, are they still relevant for the resident?
- ✓ Did the resident already appoint a legal representative?

How to conduct ACP conversations?

First ACP conversation

Plan the conversation in well in advance so the resident and/or the family are available. You can read about the content of this conversation further along in this conversation guide. If the resident wishes to do so, you can plan a follow-up conversation.

Follow-up ACP conversations

Preferably, you will conduct several conversations with the resident about the future. Some might be short, some long, depending on the time available and the resident's mood. Signals to follow-up on ACP conversations can be found in Box 1. Always bear the wishes of the resident in mind when planning a follow-up conversation.
You can also take the initiative to follow-up on the ACP conversation with the resident and/or family. It is advised to take the ACP+ documents of the last conversation with you and check with the resident is everything is still in line with his/her wishes and preferences.

Examples of questions of a follow-up conversation:

- "A while ago we were discussing… You spoke about… Is this still relevant/applicable to you?"
- "A year ago we spoke about… I would like to check with you if we are still on the same page, would that be alright with you?"

CONTENT OF ACP CONVERSATIONS

ACP conversations can be done according to the following **sections (Section A to I)**. A different order is also possible, depending on the topics the resident and/or wants to discuss first. It is also an option to discuss certain sections during one conversation and other sections during a follow-up conversation.

Section A: Ideas about a good life

Section B: Preferences for current care and treatment

Section C: Preferences for future care and care goals

Section D: Appointing a legal representative

Section E: Documenting end-of-life wishes

Section F: Preferences regarding place of care and place of death

Section G: Other preferences

Section H: Preferences with regard to dying

Section I: Revising preferences and wishes

To help you structure the ACP conversation you will find tips and guidance below. You can find a summary of this on the ACP+ conversation tool, which you can take with you to the conversation. To document the topics discussed you can make use of the ACP+ document and attached ACP+ summary.

Tips and tricks for communication with the resident and/or family

Below, you can find the different sections (section A to I) you can discuss during an ACP conversation. Per section you can find examples of questions you can ask the resident and/or family. You can use these questions as inspiration, there is no need to ask them all. They are meant as an example to help you conduct the conversation. Always pay attention to the verbal and non-verbal reactions of the resident and family.

It is also important to make sure you fully understand the resident. If this is not entirely the case, ask follow-up questions until you do. You can find some general communication tips on page 19.

SECTION A: IDEAS ABOUT A GOOD LIFE

Ask broad questions about values. Examples are:

1) What is important in life?

- What is important to you in your life?
- Do you think you have had a good life?
- What would you consider a "good life"? Did this change throughout the years and how?
- What are you proud of?
- What makes life worth living?
- Which things give you strength, or support you in life?
- What are things that make you feel happy?
- Is there something you are strongly looking forward to?
- Is there any business that you would like to finish?
- What would you like your family, children and grandchildren to remember about you?
- To which things would you still like to dedicate some time and energy?

2) Are there things that influence a resident's vision on healthcare?

- Cultural, religious or spiritual beliefs?
- Would the resident like a visit from a chaplain or priest?

SECTION B: PREFERENCES FOR CURRENT CARE AND TREATMENT

Ask the resident and/or family questions about:

1) Current quality of life

- How do you consider your current quality of life?
- Do you currently have a good life?
- Do you find it hard to get older?
- What does aging mean to you? What is the hardest part about this for you?
- What is your biggest worry or concern at the moment?
- How can we assist you with that?

Specific for residents living with dementia:

- How do you cope with your dementia and getting older?
- What is the hardest part about living with dementia?

2) Preferences for current care and treatment

- Would you currently like to receive care support for anything?
- What do you hope for when thinking about current treatments you receive?
- Can you share with me the things we should know about you so that we can provide you with the best possible care?
- How can we support you to live as well as possible here in the nursing home?
- How can we care for you in the best possible way?

SECTION C: PREFERENCES FOR FUTURE CARE AND CARE GOALS

1) Ideas and worries about the future and the end of life

You can speak with the resident and/or family about their ideas and expectations, as well as their worries and fears about the future and/or the end of life.

You can ask the resident about the extent to which s/he would like to be informed about illness-related matters and whether s/he has a correct representation of the future (e.g. does the resident have insight in his/her illness). **Some residents or family have unrealistic ideas about the future (either too positive or too negative); during this conversation you can adjust or correct these ideas.**

It is important to let the resident (partly) decide on the pace and the content of the ACP conversation. You adjust the conversation to the reactions of the resident and/or family. Not everyone would like to discuss everything, but everyone should be offered the option to speak about it.

Examples:

- What are you worried about?
- Is there something you are worried about, or something you fear might happen in case your health deteriorates?
- Would you like to think about your health in the future?
- When you think about the future, what do you hope for?
- When you think about the future, what are you worried about?
- In case the resident has an illness or disease:
    - When considering your illness, what would be the best thing that could happen to you?
    - When considering your illness, what would be the worst thing that could happen to you?
- Did you ever witness someone else's death, good or bad?
- Did you ever witness someone getting very ill, becoming dependent, or dying? How did you experience this?

- Is there something you are afraid of?
- Are you afraid to die?
- When would life no longer be worth living for you?
- What would be too little quality of life for you?
- **Always ask for clarification if answers are unclear. The way family considers these topics for the resident, often also tells you something about them.**

2) Preferences for future care and care goals

You can speak with the resident and/or family about the aims of ACP and check how important it is for the resident to make his/her own decisions in the future. Wishes of residents can be formalized in Advance Directives (ADs) (see section E and F), a legal representative can be appointed (see section D) and goals of care can be determined. Together with the resident and/or family you can speak about which concrete steps they wish to take. **Besides asking questions, it is important to provide information** (e.g. what is ACP, why is it important to speak about this, what are realistic options, which options are not possible, etc.).

Examples:

- Do you have wishes or preferences for the near future? What can we, as healthcare professionals, do to help you with this?
- Have you ever considered the medical care you would like to receive when you are too ill to decide upon this?

Examples for explaining ACP:

ACP is thinking about and planning care that you might need in the future, in case you become very ill or are no longer capable to make your own decision. Also, in case you can no longer speak, we would like to care for you in a way you would have liked. That is why it is important to already discuss you wishes and preferences with us.

- Did you ever speak with someone about ACP?
- What do you know about ACP?

Examples of questions about the importance of decision making:

- How important is it to you to be able to make your own decisions? About which things would you like to decide for yourself?
- How important is it to you to plan care together?

Examples of questions about determining goals of care together:

Everyone has personal goals and values influencing their plans for future care.

- I would like to know more about your goals concerning your health and future care and the things you value most in life. For some people their main goal is to live as long as possible; for others the main goal is to alleviate suffering, optimize quality of life, dying in a comfortable and peaceful way, etc. I suggest we go through several options together so it is easier for you to voice your goals.
- Your health status could change in the future. Sometimes people can adapt or adjust to the situation, and sometimes they cannot. In the past you told me (e.g. not getting hospitalized) was important to you. Is this still the case?
- As we age the chances of developing medical problems increase. Did you ever speak with a loved one about the types of (medical) treatment you would (no longer) want?
- What is more important to you: suffering as little as possible/focusing on quality of life, or living as long as possible?
- Based on everything you have told me so far, I would suggest … What do you think about this?

In clinical practice, healthcare professionals often use **ABC care codes** to capture residents' general goals of care. Ideally these are discussed thoroughly with the resident and/or family. We distinguish:

☐ A: **Try all life-prolonging treatments:** Main aim is to improve health status, try to treat complications, hospitalization is desired if this could prolong life.

☐ B: **Maintain function:** Main aim is a maximum of recovery with a minimum of burden. Hospitalizations should be in function of this, with a strong preference to remain in the nursing home.

☐ C: **Comfort care:** Main aim is offering as much comfort as possible. Hospitalization is no longer desired (only in function of optimizing comfort)

The table in the ACP+ document can be used to explain the different goals of care to residents and/or family. Moreover, you can ask the following questions:

In case a medical emergency occurs (e.g. heart attack) and you would not be able to speak, what would you prefer?

- Would you like to be transferred to a hospital?
- Would you like to receive life-saving treatments or surgery?
- If you would like to receive life-saving treatments or surgery, what extent should there be a realistic chance for you to recover onto your current level of functioning?
- To what extent would you like to receive life-saving treatments, even if chances of recovery are poor?
- Would you like for these decisions to be discussed with your legal representative?

SECTION D: APPOINTING A LEGAL REPRESENTATIVE

A person of age with decision-making capacity can appoint a **legal representative**. This person can make best-interest decisions on behalf of the resident, possibly informed by the completed ADs.

If the resident did not appoint a **legal representative**, it is determined by law who can make these decisions. Please check your local rules and regulations.

The role of a **trusted person** is, in the first place, to assist the resident (e.g. come to doctor's consultations). This leads to a trusted person often being aware of the health status of the resident. The resident can appoint one or more trusted persons. Usually these are captured in the resident's file as contact person. A trusted person always represents a person with decision-making capacity. In case the resident loses decision-making capacity, the legal representative takes over.

It is important to explain the roles of the trusted person and legal representative very clearly to the resident and family. Legal representatives often have a need for information about what this role entails, including the responsibilities and when it applies.

Examples for starting a conversation about trusted persons and legal representatives:

- Who is your trusted person? Who joins you on a doctor's consultation? Is this person aware of your health status? Who should we contact first in case something happens to you?
- In case you would become so ill you could no longer make decisions about your care for yourself, is there someone you trust enough to make these decisions for you?
- Would you like to appoint a legal representative?
- If you could no longer speak for yourself, who would you appoint as legal representative?
- If you could no longer participate in the decision-making process on your health, with whom should we speak? Would that be the right person for you?

Discuss the role of legal representative:

People differ in the extent they want others to decide for them. Some people put a lot of faith in the hands of their legal representative, others feel it is important that their stated wishes are followed as closely as possible. It is important to discuss this, both from the point of view of the resident and the legal representative:

- How important is it to you that your legal representative follows your stated wishes as closely as possible? Can you elaborate on this?
- Does the legal representative know what is expected of him/her? Does s/he have any questions about this?

SECTION E: DOCUMENTING END-OF-LIFE WISHES

ADVANCE DIRECTIVES AND PREFERENCES REGARDING EUTHANASIA

You can discuss with the resident if s/he would like to compose ADs or maybe already has done so in the past. The ACP+ document can be used to document this.

It is important to fully explain all ADs, when they apply and how they are used in practice. Please check your local rules and regulations! For example, euthanasia might not be a legal option in your country.

Examples on speaking about end-of-life wishes and ADs:

- You can document your wishes in several ways. Some people may find it useful to compose an AD. You don't have to do this if you don't want to, and you should certainly not rush into this. Shall we discuss all the options together?
- Have you ever heard of palliative care? What is your experience with this?
- Do you have an AD? Would you like to compose an AD?
- **The topic of euthanasia could come up, if the resident wishes to discuss this.** In case the resident has questions about this, you can ask: What does euthanasia mean to you? What would you like to know about it?

Speaking about preferences with regard to resuscitation:

Explain to the resident and/or family what resuscitation is and what could be the consequences of this:

In case of a heart attack or when your breathing stops, we could proceed to resuscitation (massage of the heart, mouth-to-mouth respiration or defibrillation/electro-shocks). Resuscitation is often less successful than people might think. There is only a small chance that you will survive the resuscitation. Out of 100 people older than 70 years of age, only 8 survive. The other 92 die of cardiac arrest. A recent study has shown that among the survivors 90% suffers from mild damage and 10% suffers from severe damage after resuscitation. The odds of dying of more severe damage increases with age. Elderly people living with dementia rarely survive resuscitation.

- There is a chance that you suddenly experience cardiac arrest, if this happens we can resuscitate you. Are you familiar with this? Do you know anything about this? Would you like to know more about this?
- Have you ever thought about if you would want this? Would you like to be resuscitated?
- Today I would like to speak with you about your wish not to be resuscitated.
- If the doctor or another healthcare professional would still find it worthwhile to start resuscitation, what would you like?

- Would you like to be resuscitated in case you breathing or your heart stops? 1) No, never; 2) Only if a doctor or other healthcare professional considers it worthwhile; 3) Yes, always, in any occasion.

SECTION F: PREFERENCES REGARDING PLACE OF CARE AND PLACE OF DEATH

Ask the resident where s/he would like to be cared for at the end of life and where s/he would like to die. Examples:

- Have you ever thought about where you would like to stay when you are getting severely ill/older? Where would you like to be cared for at the end of life?
- Some people have clear thoughts about where they would like to die. Some people prefer the nursing home, other people rather stay at a palliative care unit in the hospital. Do you have specific preferences for this? Could you share them with me?

SECTION G: OTHER PREFERENCES

Ask the resident about other preferences s/he might have. Examples:

- Are there any wishes you would like to share with us in case you are near the end of your life?
- What does religion or spirituality mean to you? Would you like to speak with someone about this?
- How would you like to be cared for in your final days? Do you have specific preferences or wishes?
- Are there other preferences you would like us, as your healthcare professionals, to take into account? Do you have any worries, fears or general remarks?

SECTION H: PREFERENCES WITH REGARD TO DYING

Check if the resident has specific wishes or preferences with regard to dying. Examples:

- Are there any specific (religious) wishes we should consider?
- It is hard for anyone to think about their own death. Are there any thoughts about your own death that bother you?
- Would you like to make funeral arrangements?
- Are there specific details about the funeral or cremation you would like to discuss?

SECTION I: REVISING PREFERENCES AND WISHES

Ask the resident in which circumstances s/he would like to revise his/her wishes and preferences.

A follow-up ACP conversation should be planned in any case, either when a situation occurs as described in **Box 1,** or with a predetermined interval (e.g. every year). In case the resident states specific occasions on which s/he would like to discuss ACP again, it can be recorded here.

EXTRA: HAVING A CONVERSATION WITH FAMILY OF A RESIDENT WITH DEMENTIA

Examples:

- Your loved one is living with dementia. What are you worried about when considering his/her future care?
- Your loved one is living with dementia. What would be important to him/her when considering his/her future care?
- It is very likely that your loved one's decision-making capacity diminishes. Therefore, we will turn to you for decision-making more often. How does this make you feel?
- Are there specific scenarios you know of which your loved one would absolutely want to avoid?
- We know that when the dementia process continues, your loved one will most likely experience difficulties eating and will have a high chance of getting infections. What are your thoughts on this?
- What is your estimation about your loved one's quality of life? How do you think s/he feels right now?

General communication tips

PREPARATION

- Try not to force ACP unto someone
- You should plan the ACP conversation at a time of day that is convenient for the resident (and family) and the GP (in case s/he wants to be involved).
- Make sure there is a quiet space available to conduct the ACP conversation (limit phones) and ensure privacy (e.g. by putting a sign on the door).
- There should be sufficient time to answer questions or repeat information that is unclear. If any of the participants experience time pressure, plan a new ACP conversation in the near future.
- Make sure the resident and/or family know they can always ask questions if anything in unclear to them: ‘’Please interrupt me if anything is unclear to you…”

DURING THE CONVERSATION

- Use an empathic patient-oriented communication style and listen actively.
- Try not to interrupt the resident and family. They might need some time to express themselves. Don’t be afraid to be silent in case someone becomes emotional.
- In case the resident and/or family is clearly upset, you can point out what you see: “I can see this is emotional for you, is that right?”, “Is it hard for you to speak about this?”, “It seems you are in doubt?”
- Always try to react to what the resident or family is saying. It is important to get to the underlying message: “When you say you do not want to suffer, what kind of suffering are you thinking about?”, “When you say you do not want to live like a vegetable, what exactually do you mean with that?”
- Ask regularly if you understood the resident and family correctly: “If I understand correctly, you are telling me that…”

SUMMARY AND FOLLOW-UP

- Summarize the conversation and ask if you understood everything correctly.
- Do not forget to check with the resident what s/he thought about the conversation: “How do you feel about everything we have just discussed?”, “Is there something you would like to hear again?”, “Is everything clear for you?”
- The results of the ACP conversation can be documented on the ACP+ document. Moreover, you should fill out the ACP+ Summary (and ADs and care codes) and add all relevant documents to the resident’s file. The ACP+ Summary can be found in the ACP+ Document.
- Plan a follow-up conversation.

HOW TO DOCUMENT?

1. The ACP⁺ document

2. Advance Directives - **Please check your local rules and regulations!**

3. Care and DNR-codes - **Please check your local rules and regulations!**

1. THE ACP⁺ DOCUMENT

What do you need to know about the ACP⁺ document?

The **ACP⁺ document** is green and meant for you to write down everything you spoke about with the resident and/or family AFTER the ACP conversation. The content can always be changed, based on new information from other/new ACP conversations. At the back of the ACP⁺ Document are also the following documents attached:

1) A red summary of ACP+ document; the ACP+ summary
2) Advance Directives
3) Care and DNR code sheets, summarizing the care goals of the resident

Make sure the most up-to-date version of all documents can always be found in the resident's file. They should be accessible to all healthcare professionals in the nursing home and be sent along in case the resident is admitted to the hospital (or elsewhere).

Make sure to send a copy of all relevant documents to the GP.

2. ADVANCE DIRECTIVES

PLEASE CHECK YOUR LOCAL RULES AND REGULATIONS!

3. CARE AND DNR-CODES

What do you need to know about ABC care codes and DNR codes?

Based on the ACP conversations with residents and/or family, nursing homes often use **ABC care codes.** You can document this in the ACP+ document. In a table you can note which care code is applicable to the resident and specify which concrete actions and decisions are linked to the care code. These codes should only be granted after consultation with the resident and/or family in an ACP conversation.

Explanation about the ABC care codes:

CARE CODE	A: try all life-prolonging treatments	B: maintain function	C; comfort care
AIM	Maintain and prolong life	Maintain life and treat any acute illnesses	Comfort care
PERSPECTIVES	Improvement of the health status	Improvement of the acute illness Stabilize health status	Slow decrease of health status. Rapid decrease of health status, dying on fairly short notice. Dying on short notice.
AGREEMENTS	Resuscitation Hospitalization Maximum medical treatment	No resuscitation No ICU No hemodialysis Hospitalization? (Only short visits, aiming to receive a diagnosis or non-invasive short therapy)	Only medication aimed at quality of life and comfort Symptom relief Palliative care

Every nursing home can use its own model. If this is the case, this document can be adjusted accordingly.

ABC care codes can be granted by healthcare professionals in the nursing home, in consultation with the resident and/or family. DNR codes however, can only be granted by a physician (e.g. the GP). DNR-codes are the results of a medical assessment about the usefulness of treatments in combination with the preferences of the resident. Moreover, it is advised that other healthcare professionals are involved in the consultation. Please check your local rules and regulations!

Explanation DNR-codes:

DNR 0	No limitations on therapy (resuscitation can be started, ambulance can be called)
DNR 1	Do not resuscitate (do not massage the heart, no defibrillation, do not call an ambulance), all other therapies are permitted
DNR 2	Do not resuscitate + limitations of therapy (do not start or expand certain life-saving treatments)
DNR 3	Do not resuscitate + only comfort care (withdraw or stop certain life-longing treatments)

IMPORTANT!

Always make sure all different ACP+ documents correspond with each other and are up-to-date!

SPECIFIC INFORMATION FOR RESIDENTS LIVING WITH DEMENTIA

ACP is important for people living with dementia, but can be difficult to initiate. The reasons for this are the typical disease characteristics; cognitive decline, a changed perspective of reality, behavioral symptoms and mood disorders can influence the ACP conversation. **A thorough preparation is key.**

Here we present a summary. For more information you can check (among others):

- Demaerschalk, M., Kindekens, D., Verraest, E., Hoste, V., Van Ooteghem, L., Nys, H., Pype, P., De Vleminck, A. & Gilissen, J., Draaiboek Vroegtijdige en vroegtijdige zorgplanning in woonzorgcentra. Vlaamse Vereniging voor Steden en Gemeenten, Brussel: Politea, 2016 [IN DUTCH]

Despite the cognitive decline of residents living with dementia, their changed perspective unto the world and reality and the influence of behavioural symptoms and mood disorders, an ACP conversation is still very often possible and is strongly encouraged. Described below you can find some tips and tricks for conducting an ACP conversation with a resident living with dementia.

1. PREPARE WELL – PROVIDE RELEVANT INFORMATION ON DEMENTIA

Before you initiate an ACP conversation, it is important to speak about dementia as an illness. Check what the resident knows about dementia and correct any misunderstandings. This is a delicate process and you should handle the situation carefully. It is important not to overwhelm the resident, or confront him/her with their mistakes. Be respectful. For example, you can ask the resident if s/he knows why s/he is here, in the presence of family. You can give examples of people you know, or the resident knows, who are forgetful often and who are unhappy about others making all their decisions for them. Based on examples provided by the resident, you can correct misunderstandings and explain which symptoms align with aging and which with the dementia disease trajectory.

By doing this, you help the resident with the process of acceptance and finding new ways of communication. A healthcare professional specialized in dementia care can help you. The process of acceptance will likely influence the way people engage in ACP.

2. STAY HONEST – CUSTOMIZE

Adjust to the reality of the resident, but do not tell lies. Even if the message is not hopeful, the resident is most likely to remember the way in which you explain this to them. You should not minimize the serious nature of the disease. The emotional pain, fear, sadness, anger… that people feel, have a right to be there. Acknowledgment and staying close contribute to a constructive grieving process.

3. DRAW THE ATTENTION

A resident with dementia has often trouble with focusing for a long time. A gentle touch or calling out his/her name can help to stay focused on the conversation. Repeat what you have said regularly. Repeat the name of the resident regularly. Maintain eye contact during the conversation.

4. ‘SUPPORTING’ COMMUNICATION

Supportive material can best be put in place before you start the conversation. The resident might experience trouble following the conversation due to diminishing concentration, too high a pace of the conversation, unclear word use, etc. What the resident hears, sees or thinks can often not be structured sufficiently anymore by the brain. Communication can then be supported by pictures, written language, signs etc. It is often easier to choose between two pictures than to formulate an answer verbally.

5. INVOLVE ALL IMPORTANT PARTIES AS EARLY AND AS OFTEN AS POSSIBLE

For residents with dementia the ACP process is very intensive. The specific disease characteristics may lead to the resident needing more time to consider all options. The (appointed) legal representative should be involved in the ACP process, as well as other healthcare professionals, especially when the resident no longer has decision-making capacity.

6. OBSERVE

You can obtain a lot of information when observing the interactions between different family members. For example, it can provide you with insight about how they see the resident and dementia (e.g. hesitating when being asked a question, stereotypical answers, emotional answers etc.).

MORE INFORMATION

This conversation guide is made by researchers of the End-of-Life Care Research Group of the Vrije Universiteit Brussels, Belgium. The conversation guide is based on the guidelines about advance care planning and advance care planning with people living with dementia ['Vroegtijdige zorgplanning' and 'Vroegtijdige zorgplanning bij mensen met dementie' (Pallialine, 2016) and 'Vroegtijdige zorgplanning bij mensen met dementie' (KBS, 2014) IN DUTCH], a brochure from the Federation Palliative Care Flanders ['Ook de laatste reis wil je samen bespreken…' (Federatie Palliatieve Zorg Vlaanderen, 2010) IN DUTCH], an adjusted conversation guide from 'Respecting Choices' (ACTION-ACP project financed by the European Commission, 2016) and the materials of the EUFP7 PACE project. The ACP+ conversation guide has been feasibility tested in collaboration with several health care professionals from the nursing home field.

For more information about the activities and projects of the End-of-Life Care Research Group you can visit the website: www.endoflifecare.be.

OTHER SUPPORTIVE MATERIALS FOR HEALTH CARE PROFESSIONALS [IN DUTCH]

1. **LEIF "Guide for health care professionals" [Wegwijs voor de zorgverlener]** – this can be used as extra support. It can be downloaded for free from the website: http://leif.be/home/.
2. Health care professionals searching for more information on ACP for people living with dementia can read a publication from Koning Boudewijnstichting: "Advance care planning for people living with dementia; how to do this?" [Vroegtijdige zorgplanning bij mensen met dementie: hoe pakt u dit aan?] (**freely** available from this website: https://www.kbs-frb.be/nl/.
3. If you are looking for more background information on ACP and ACP for people living with dementia we recommend the guidelines from Pallialine, available from this website: http://www.pallialine.be/.

OTHER SUPPORTIVE MATERIALS FOR RESIDENTS AND THEIR FAMILY [IN DUTCH]

1. **LEIF "Guide for the public" [Wegwijs voor de bevolking]** – this brochure can provide the resident and/or family with extra information. It can be downloaded for free from the website: http://leif.be/home/.
2. The publication of Manu Keirse et al. "The last journey" [De laatste reis] explains ACP very clearly. This publication is **freely** available from this website: http://www.delaatstereis.be/template.asp?f=index.htm.

ADVANCE CARE PLANNING
IN NURSING HOMES

ACP$^+$ document

When speaking about advance care planning (ACP) with a resident and/or their family or loved one, we recommend to use the **ACP$^+$ conversation tool** to guide the conversation. This **ACP$^+$ document** is meant to be used afterwards to take notes of everything that was discussed with the resident and/or family. The content of this document can always be altered, depending on what was discussed.

At the back/Attached are three important additional documents:

1) An extended **ACP$^+$ document** to take notes of the ACP conversation
2) An **ACP$^+$ summary** with information on Advance Directives of the resident
3) Care code forms (DNR or ABC code), summarizing the care goals for the residents

IMPORTANT

- ✓ **Always make sure that the most up-to-date version of the documents is used.** These documents need to be accessible to all relevant care providers and need to be **send along** in case the resident should transfer (to a hospital or other).
- ✓ **A copy of these documents needs to be delivered to the General Practitioner (GP).**
- ✓ **This ACP+ document was developed under Belgium law, please check your local rules and regulations on Advance Directives and Care codes.**

This is the ACP$^+$ Document of:

First and last name of the resident: ……………………………………………………………………………

Gender: Male ☐ Female ☐ Date of birth: ….…(*day*)/………………………..(*month*)/………..(*year*)

Nursing home (ward): ……………………………………… Room number: ……………………………….

Name of GP: …………………………………………………… Phone number of GP: ……………………

This ACP $^+$ Document was made on:

………...(*day*)/………………………...(*month*)/………...(*year*)

ACP conversations were conducted with:

(multiple options possible)

- ☐ Resident
- ☐ Spouse: ……….……………………………………………………………………… (name)
- ☐ Child(ren): ………………………………………………………………………………(name(s))
- ☐ Sibling: ………………………………………………………………………………………(name)
- ☐ Other: ………………..……………………………………………………(name and relation)

Date first conversation: ……(*day*)/…………………………(*month*)/………(*year*)

Date last conversation: ……(*day*)/…………………………(*month*)/………(*year*)

Total number of conversations: …………

Data and observations concerning the **decision-making capacity of the resident**

Decision-making capacity can be described as: Being able to correctly come to a reasonable appreciation of one's interests concerning a current specific decision or situation and arrive at a well-balanced decision.

Further explanation on how to estimate someone's decision making capacity can be found on page 6 of the ***ACP^{+} Conversation Tool.***

……………………………………………………………………………………………………

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……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

SECTION A

Ideas about a '**good life**' for the resident

For the resident, what is important in life?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Is there anything (religious, spiritual, cultural) that influences the resident's view on good health care?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

SECTION B

Preferences for **current care and treatment**

The current quality of life of the resident:

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Preferences for current care and treatment:

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

SECTION C

Preferences for **future care and care goals**

Important ideas, concerns or expectations about the future:

………..

……….

……….

Important wishes or preferences for future care:

………..

……….

……….

Care goals:

☐ A: Try all life-prolonging treatments: Main goal is to treat possible complications, hospitalization is desirable if this can prolong life

☐ B: Maintain function: maximum recovering with minimal burden, hospitalization is desirable in function of this, strong reference to stay in nursing home

☐ C: Comfort care: The main goal is to offer greatest comfort, hospitalization is no longer desirable (unless this would benefit overall comfort)

Additional remarks about care goals:

………..

……….

……….

SECTION D

Appointing a **legal representative**

Who is the **first contact person** in the residents' file?

………..

……….

……….

Who is/are the **trusted person(s)**?

………..

……….

……….

Does the resident wish to appoint a legal representative? If so, whom (name and relationship with the resident):

………………………………………………………………………………………………

………………………………………………………………………………………………

Please state this clearly on the ACP+ summary

SECTION E

Documenting end-of-life wishes **(Advance Directives)**

Advance Directives (filled out by the resident him-/herself, with assistance of healthcare provider) can be filled out on the attached forms, if the resident wishes to do so.

Document wishes with regard to resuscitation: **Would the resident liked to be resuscitated in case his/her breathing or heart stopped?**

☐ No, never

☐ Only if the physician or care provider would think it is worthwhile

☐ Yes, always, in any occasion

SECTION F

Preferences regarding **place of care** and **place of death**

Tick the box that is applicable:

☐ The residents' preferences with regard to the place s/he would like to be cared for until the end:

………………………………………………………… *(please fill this out)*

☐ The resident has no preferences with regard to the place s/he would like to be cared for until the end.

SECTION G

Other preferences all people caring for the resident should be informed about:

Other specific wishes or preferences:

………

………

………

………

………

………

SECTION H

Preferences with regard to **dying**

Specific wishes with regard to dying (e.g. funeral arrangements, religion):

……..

…….

…….

SECTION I

Revising preferences and wishes

Circumstances/reasons which would cause the resident to revise his/her wishes:

……..

…….

…….

Please fill out the ACP$^+$ summary and add this to the resident's file, together with the Advance Directives and the Care codes (ABC and DNR).

A follow-up ACP conversation is planned on:

……*(day)*/……..………..*(month)*/………..*(year)*

ACP$^+$
ADVANCE CARE PLANNING
IN NURSING HOMES

ACP$^+$ summary

This document provides a summary of the topics discussed during an ACP conversation with the resident and his/her family. This document can be added to the resident's nursing home file and be added when a resident is transferred (e.g. on hospital admission).

This is the ACP$^+$ summary of:

First and last name of the resident: ……………………………………………………………

Gender: Male ☐ Female ☐ Date of birth: …….*(day)*/……………………….*(month)*/………..*(year)*

Nursing home ward: ………………………………… Room number: ……………………………

Name of GP: ……………………………………………… Phone number of GP: ……………………

Information on the (first) <u>contact person</u> of the resident:

First and last name of the <u>contact person</u>: ……………………………………………………

Relation to the resident: ………………………………………………………………………

Address:

…………………………………………………………………………………………………

Postal code and city: ……………………………………………………………………………

Telephone number of the <u>contact person</u>: ………………………………………………………

Information about the <u>legal representative</u>:

Did the resident appoint a legal representative?
Yes ☐ No ☐
If 'yes', please specify on the next page and have it signed.

Information about <u>decision-making capacity</u> of the resident:

…………………………………………………………………………………………………

…………………………………………………………………………………………………

My legal representative

I, the one who signs, appoint this person as my legal representative in case I am unable to practice my rights as a patient:

First and last name of the person who is appointed as legal representative:

……

Relation to the resident: ………………………………………………………………………..………..

Address:

……………………………………………………………………………………………..…………..

Telephone number: ………………………………………………………………………………………

Social security number: …………………………………………………………………………………

Place …………………………………………… Date …………/……………/……………

Signature (resident):

Information on potential Advance Directives[1] of the resident

Did the resident compose an AD with personal wishes?

Yes ☐ No ☐

Did the resident compose a Euthanasia AD? *(only to be used in case of an irreversible coma)*

Yes ☐ No ☐

Did the resident compose an AD with regard to the manner of burial?

Yes ☐ No ☐

Did the resident compose an AD with regard to organ donation?

Yes ☐ No ☐

Please add all the composed ADs to this document.

---

[1] Based on the Belgian care system, please check your local rules and regulations!

Care & DNR code

CARE CODES[2]

Below you can indicate which care code (A, B, C) you would appoint to the resident and specify which concrete actions and agreements are linked to that. These codes are appointed after an ACP conversation with the resident and/or family. Please appoint these codes always in consultation with the GP or other specialized care providers.

Date of ACP conversation **dd/mm/yyyy**	**Care code (A, B, C)**	**Translation of the care code in concrete actions and agreements for all different disciplines + MOTIVATION**

---

[2] Based on the Belgian (Dutch-speaking) care system.

Explanation Care codes

CARE CODE	A: try all life-prolonging treatments	B: maintain function	C; comfort care
AIM	Maintain and prolong life	Maintain life and treat any acute illnesses	Comfort care
PERSPECTIVES	Improvement of the health status	Improvement of the acute illness Stabilize health status	Slow decrease of health status. Rapid decrease of health status, dying on fairly short notice. Dying on short notice.
AGREEMENTS	Resuscitation Hospitalization Maximum medical treatment	No resuscitation No ICU No hemodialysis Hospitalization? (Only short visits, aiming to receive a diagnosis or non-invasive short therapy)	Only medication aimed at quality of life and comfort Symptom relief Palliative care

Every nursing home can use its own model. If this is the case, this document can be adjusted accordingly.

DNR CODES[3]

DNR codes are the result of a medical assessment of the usefulness of treatment, combined with the preferences of the resident. DNR codes can only be allocated by a physician but are, in conformation with the legal and jurisdictional frameworks of informed consent, also in consultation with the resident or his/her legal representative.

DNR code ***(to be allocated by a physician)***	**Signature of the physician + date dd/mm/yyyy + stamp**	**Participants of the consultation:** **Name + role (resident, legal representative, GP,…) + signatures**

Explanation DNR codes

DNR 0	No limitations on therapy (resuscitation can be started, ambulance can be called)
DNR 1	Do not resuscitate (do not massage the heart, no defibrillation, do not call an ambulance), all other therapies are permitted
DNR 2	Do not resuscitate + limitations of therapy (do not start or expand certain life-saving treatments)
DNR 3	Do not resuscitate + only comfort care (withdraw or stop certain life-longing treatments)

---

[3] Please check your local rules and regulations!

Chapter 3.2

Effects of a theory-based ACP intervention for nursing homes: a cluster randomized controlled trial

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Luc Deliens Chris Gastmans, Robert Vander Stichele, Lieve Van den Block
*Shared first author

Submitted

Abstract

Background: Uptake of advance care planning (ACP) in routine nursing home care is low. Through extensive literature review, theoretical development, and stakeholder involvement, we developed the ACP+ intervention.
Aims: To evaluate the effects of ACP+ on the knowledge and self-efficacy (confidence in own skills) of nursing home care staff concerning ACP.
Design: Cluster randomized controlled trial, conducted between February 2018 and January 2019 (NCT03521206, clinicaltrials.gov). ACP+ is a multicomponent intervention aimed at training and supporting nursing home staff and management in implementing ACP in routine nursing home practice through a train-the-trainer approach over eight months. Fourteen nursing homes were randomized using a matched-pairing strategy, seven received ACP+, seven followed usual practice. We conducted intention-to-treat analyses using linear mixed models.
Setting/participants: Nursing homes in Flanders (Belgium).
Results: 694 of 1017 care staff (68% response rate) at baseline and 491 of 989 care staff (50%) post-intervention (at 8 months) returned questionnaires. Post-intervention, care staff's self-efficacy concerning ACP was significantly higher in the intervention than in the control group (baseline-adjusted mean difference 0.57; 95%CI 0.20 to 0.94; p=0.003; Cohen's d = 0.30). ACP knowledge (95%CI 0.95 to 1.15; p=0.339; ratio: 1.04) did not differ significantly between groups post-intervention.

Conclusions: The ACP+ intervention for nursing homes improved care staff's self-efficacy in performing ACP but not their ACP knowledge. Considering the comprehensive and multi-component training approach used, these effects were smaller than expected. Reasons for this may be related to the chosen follow-up period, outcomes and measurements, or to the intervention itself and its implementation.

Keywords: Advance care planning, nursing homes, dementia

Key statement

What is already known about the topic?

- Timely advance care planning (ACP) is recognized as an important part of routine nursing home care, but its uptake is low.
- Interventions aiming to improve ACP in nursing homes have led to inconsistent findings.

What this paper adds

- We tested the effects of the theory-based multicomponent ACP+ intervention that entailed a train-the-trainer approach to support and implement advance care planning in routine nursing home care.
- The ACP+ intervention improved nursing home care staff's self-efficacy (confidence in own skills) in performing ACP, albeit with an effect size that can be considered small to medium.
- The intervention did not improve care staff's knowledge concerning ACP.

Implications for practice, theory or policy

- An intensive training program such as the ACP+ intervention can positively impact nursing home care staff's confidence in discussing residents' preferences for care and aligning care with their preferences.
- Considering the comprehensive and multi-component training approach used, the intervention effects were smaller than expected.
- Reasons for this may be related to a too short follow-up period, outcomes and measurement instruments not being optimal to measure the effects of this intervention, or to implementation problems of the intervention.

Introduction

A growing number of older adults spend the last years or months of their life in nursing homes. In several high-income countries, up to one-third of people die there[1,2]. Timely advance care planning (ACP) is advocated as an important part of routine nursing home care[3]. ACP is defined as a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical, including end-of-life, care,[4]. If a person wishes, the contents of such conversations can be documented in the form of an advance directive (AD)[4,5]. Despite the great need for ACP in nursing homes[6], its uptake is low[7]. In a study of six European countries, only one in three deceased residents had a written AD, with large differences between countries.[8] In the United States, 65% of nursing home residents were estimated to have an AD[9].

Several trials have tested interventions to improve ACP in nursing homes, albeit largely with low-quality methods and inconsistent findings.[6,10–12] Lack of demonstrated effectiveness of ACP may be due to the fact that only few interventions pursued a broad and in-depth implementation of ACP within the nursing home setting.[13–17] We have therefore developed a multi-component ACP intervention targeting multiple levels of the nursing home (i.e. management, care staff, support staff, residents and family), that aims to integrate ACP in regular nursing home practice using a train-the-trainer approach. The ACP+ intervention was developed by integrating a theory of change approach within the steps of the UK Medical Research Council (MRC) framework for developing and evaluating complex interventions[17–21]. The theory of change is based on an extensive literature review, theoretical development and intensive stakeholder involvement[19] and postulates that nursing home care staff need to have sufficient knowledge of ACP and confidence in their own ACP skills to be able to increase the uptake of ACP in the nursing home context.

To evaluate this theory-based ACP+ intervention, we addressed the following research question: Does the ACP+ intervention improve nursing home care staff's knowledge and self-efficacy concerning ACP (primary outcomes) and their self-reported engagement in ACP communication and documentation (secondary outcome)?

Methods

Trial design

From February 2018 (start of recruitment) until January 2019 (end of data collection) we conducted a multi-facility cluster-randomized controlled trial in Belgium (Flanders, the Dutch-speaking part of Belgium) to compare the ACP+ intervention with usual care (control). The trial is registered at clinicaltrials.gov (NCT03521206). Ethics approval was granted by the relevant ethics committee (2017/31, (B.U.N. 143,201,732,133). We followed CONSORT guidelines to report study results[22]. The trial protocol has been published[18].

Participating nursing homes

Nursing homes in Belgium are care facilities where continuous (24/7) nursing care is available on-site, and residents receive medical care from their general practitioner (GP). Nursing homes whose management expressed interest in participating were added on a first come first serve basis to a list stratified by region, number of beds and facility type (non-profit and for-profit public/private). We then contacted the nursing homes consecutively, starting with the first per stratum, until the target number of clusters was recruited. Inclusion and exclusion criteria are presented in Table 1. Nursing home managers who agreed to participate were asked to sign an informed consent form.

Randomisation and blinding

A blinded statistician, not affiliated with this study, randomized the nursing homes using a matched-pairing strategy. All included nursing homes were ordered based on their facility type and, within each type, based on their geographic location. Each consecutive pair of nursing homes was then allocated randomly to either the intervention or control group, using a computer-generated random sequence. Owing to the nature of the study, allocation concealment (blinding) was not possible for participants or researchers.

The ACP+ intervention

The ACP+ intervention is a multicomponent intervention aimed at training and supporting nursing home staff and management with the implementation of ACP in routine nursing home practice through a train-the-trainer approach.[21] It combines ten intervention components and permits tailoring of several components to the existing nursing home context. Components were implemented step-wise, over a period of eight months, with the help of two external ACP trainers: a GP specialized in nursing home care and a nursing home nurse specialized in palliative care and dementia (assigned to 4 and 3 nursing homes in the intervention group, respectively). The ACP trainers' support was more intensive at the start of the intervention and progressively decreased.[21]

The ACP+ intervention defines several roles, assigned to nursing home care staff (henceforth termed 'care staff'; i.e nurses, care assistants, allied health staff (e.g. psychologists, physiotherapists, occupational therapists, social workers, animators, pastoral or spiritual caregivers, and moral consultants)) and support staff (i.e. staff working in the nursing home but without a role in care such as cleaning, administrative, technical/logistical or kitchen staff):

- ACP reference persons, who are trained specifically in ACP and subsequently train other staff and champion the implementation of ACP in their nursing home (at least two 0.10 FTE per 30 to 40 beds);
- ACP conversation facilitators, who plan and conduct ACP conversations with residents and family (number determined by the nursing home); and

- ACP antennas, whose task is to recognise and signal ‘triggers’ that indicate a resident’s readiness or need for ACP (all others).

All intervention components, activities and materials, as well as their development and feasibility-testing are described elsewhere, using the Template for Intervention Description and Replication (TIDieR)[17,19,21].

Outcomes

Primary outcomes

Primary outcomes were: 1) care staff’s knowledge concerning ACP and 2) care staff’s self-efficacy concerning ACP (confidence in own ACP skills). We measured these outcomes at baseline (T0) and post-intervention, i.e. after eight months (T1).

Secondary outcome

The secondary outcome was care staff’s self-reported engagement in ACP communication and documentation, measured at baseline and post-intervention. We had initially specified a further secondary outcome, i.e. care staff’s attitudes towards ACP. Due to the scale’s poor internal consistency at baseline, we did not include it in further analyses. This was decided after trial commencement but before the start of trial analysis.

Additional measurements

We collected data on the following care staff characteristics: age, sex, job experience in years, occupation, highest level of education, number of hours working in the nursing home per week, whether or not they received training in palliative care or ACP, and the mean number of residents for which they care on a regular working day. We also collected data on nursing home characteristics, i.e. facility type; location (region); availability of guidelines and documents concerning palliative care and ACP, number of staff and number of beds per nursing home.

To evaluate the overall implementation of the ACP+ intervention, we asked the ACP trainers to rate how well the intervention was implemented on a scale from 1 to 10, with 1 indicating ‘not at all implemented as intended’ and 10 indicating ‘entirely implemented as intended’.

Measurement instruments

When this study was designed, there were no validated measures available assessing ACP knowledge, self-efficacy and engagement in communication/documentation among care staff. We therefore developed new measures, based on adaptations of existing questionnaires[18]. We tested internal consistency and face validity through cognitive testing with several care professionals[18]. Cronbach’s alpha for the scales measuring ACP knowledge, self-efficacy and communication/documentation was 0.72, 0.97, and 0.81, respectively[18].

ACP knowledge was measured through 11 statements (e.g. concerning applicability of advance directives) with response options ‘true’, ‘false’ and ‘I don’t know’. The responses were scored as 0 (‘incorrect’; ‘I don’t know’) and 1 (‘correct’). The ACP self-efficacy scale measured confidence in own ACP skills (e.g. initiating an ACP conversation) with 12 items, rated on a 10-point Likert-type scale ranging from ‘not at all confident’ (scored as 0) to ‘very confident’ (scored as 10) or ‘not applicable’ (coded as missing). The scale measuring self-reported engagement in ACP communication/documentation assessed whether staff were engaged in six practices over the past six months (e.g. initiating an ACP conversation). Responses were scored as 0 (‘not performed) or 1 (‘performed’).

Data collection, procedures and respondents

In each nursing home, a contact person (i.e. head nurse, administrator or manager) was designated to identify all eligible care staff. We included care staff if they understood and spoke Dutch and were aged 18 years or over. Students and interns were excluded. Data were collected at month 0 (prior to randomization) and post-intervention (month 8). We collected nursing home characteristics through a questionnaire distributed among contact persons at baseline and post-intervention.

The return of a completed questionnaire was taken as consent to participate. Questionnaires were coded by the researchers to ensure pseudonymisation and distributed accompanied by an information leaflet and return envelope. Staff returned questionnaires to a locked mailbox in the nursing home accessible to the researchers only. Reminders were distributed twice (after two and four weeks).

Statistical analysis

We had estimated that a sample of 161 care staff for each study arm (approximately 30 to 35 per nursing home) would achieve at least 80% power to detect an effect size of 0,5 with an intra-cluster correlation coefficient (ICC) of 0,036, at significance level of 2,5%. To allow for 30% non-response as well as 10% staff turn-over[18], we recruited 7 nursing homes per arm.

ACP knowledge was treated as a rate of correct statements relative to the total number of statements responded to. For ACP self-efficacy, the mean score of all items was used. ACP communication/documentation was considered as a dichotomous variable (at least one activitiy performed versus none). Outcomes were set as missing if a respondent had not answered more than 25% of statements or items.

We fitted generalized linear mixed models to take the two levels of clustering in the data into account, i.e. care staff within nursing homes; measurements (baseline and post-intervention) within care staff. All final models included two random intercepts (one for nursing homes, one for care staff) and were fitted using the restricted maximum likelihood approach (REML). No random slope was used.

For ACP knowledge, a negative binomial mixed model was fitted. For ACP self-efficacy (mean score and scores on the individual items), linear mixed models were fitted. For ACP communication/documentation, a binairy logistic mixed model was fitted. For the individual items of ACP knowledge and ACP communication/documentation, binary logistic mixed models were fitted.

In two sets of exploratory subgroup analyses for the primary and secondary outcomes, we 1) compared intervention nursing homes with a high implementation score (>=) with the control group, and 2) tested whether the intervention effects of the intervention differed between staff with higher (i.e. nurses and allied health staff) versus lower (i.e. care assistants) educational levels.

All final models included the matching variables (i.e. facility type and location) timepoint (post-intervention vs. baseline), study arm (intervention vs. control) and the two-way interaction between timepoint and study arm. The ACP+ effect is reflected in the interaction between study arm and time point. Corresponding 95% confidence intervals (CIs) are reported. P-values for the two primary outcomes were considered statistically significant when <0,025 (Bonferroni correction for multiple testing). P-values for the secondary outcome were considered statistically significant when <0,05. All hypothesis testing was 2-sided. All analyses were on an intention-to-treat basis. We assumed missing outcome data was missing at random.

All presented intra-class correlation coefficients correspond to the proportion of variance in the respective outcome at baseline that can be explained at the level of the nursing home (i.e. null-model with one random intercept). We determined the Cohen's d effect size for ACP self-efficacy by calculating the standard deviation using the same null-model.

All analyses were performed using IBM SPSS Statistics Version 25 for Macintosh, except for the graphs, which were created using R version 3.6.1[23].

Results

Of 37 clusters assessed for eligibility, 14 were included and randomized to intervention or control after baseline data collection (Figure 1). All seven clusters received the intended intervention, none were lost to follow up, and all were included in all analyses, and analysed according to their originally assigned group. Nursing home characteristics are presented in Appendix 1-e.

Clusters and participants

Both study arms taken together, we received questionnaires from 694 of 1017 care staff (68% response rate) at baseline and 491 of 989 care staff (50% response rate) post-intervention. Characteristics of respondents are presented in Table 2. The proportion of nurses in the different groups and timepoints ranged from 27% to 31%, and from 42% to 48% for care assistants.

Outcomes

Post-intervention, care staff's mean ACP knowledge did not differ significantly between groups (ratio 1.04; 95%CI, 0.95 to 1.15; p=0.339). Care staff's mean self-efficacy in ACP was significantly higher in the intervention group than in the control group (baseline-adjusted mean difference, 0.57; 95%CI, 0,20 to 0,94; p=0.003; effect size (cohen's d) = 0.3) (Table 3, Figure 2). The ACP self-efficacy items that had significantly higher means in the intervention than in the control group were: discussing wishes and preferences for future care; explaining the role of a representative to residents/family, responding to residents'/family's questions regarding advance directives; aligning care with a resident's written wishes; knowing legislation regarding advance directives (Appendix, Table 5-e). The items of ACP knowledge and ACP communication/documentation are reported in the appendix (Table 4-e, 6-e).

We found no difference between the intervention and control group for staff's engagement in ACP communication/documentation (ratio 1.47; 95%CI 0.88 to 2.46; p=0.145) (Table 3).

The results of the subgroup analysis regarding implementation score was similar to those of the main analyses in terms of statistical significance of baseline-adjusted differences between groups post-intervention, for occupational level no significant differences were found (Appendix, Table 2-e, 3-e).

Discussion

In this cluster RCT, the ACP+ intervention in nursing homes led to a statistically significant improvement on care staff's self-efficacy in ACP after 8 months, but did not improve their ACP knowledge. We did not detect any negative effects of the intervention. Although statistically significant, the effects on self-efficacy were smaller than expected.

This is the first cluster RCT testing the outcomes of an ACP intervention developed through in-depth theoretical modeling and targeting multiple levels of the nursing home.[18,19,21] Strengths include the trial's pragmatic nature permitting tailoring of several intervention components, absence of cluster drop-outs, and the focus on staff-level outcomes. While staff education has been the chief implementation strategy in ACP interventions in nursing homes,[24] no previous trials have evaluated their effect on staff outcomes. Limitations include that care staff could not be blinded due to the nature of the intervention. The response rate among care staff was only satisfactory and declined post-intervention. We could not assess potential non-response bias as we did not assess non-responder characteristics.

This study showed that we partially succeeded in reaching the aim of the ACP+ intervention, as care staff's self-efficay increased, but not their knowledge of ACP. This implies that an intensive training program such as the ACP+ intervention can positively impact staff's confidence in discussing residents' preferences for care and aligning care with preferences. However, we expected the effects to be larger (i.e. effect size for self-efficacy was small to medium-sized only and knowledge did not change), especially considering the comprehensive and multi-component training. While the medium range baseline scores for both primary and secondary outcomes might be part of the explanation, as improving a low baseline might be easier, we believe that there are additional possible reasons.

First, the choosen outcomes and measurement instruments might not have been optimal to detect improvements caused by the intervention[25]. Regarding ACP knowledge, there may have been a poor match between the contents of the intervention (i.e. focusing on communication and organizational embedment of ACP) and the constructs measured (i.e. knowledge of the legal framework concerning ACP). The intervention may have had a greater effect on constructs that we did not measure. We also needed to use newly developed scales, tested for face validity but not yet for content or construct validity. Although we determined internal consistency, the measure was not tested for sensitivity to change. Furthermore, there is no consensus on what is a clinically meaningful change in the tested outcomes[26].

Second, our follow-up period may have left too little time for the intervention to develop an impact on the outcomes. An additional consolidation phase following the implementation period -as was suggested in a recent white paper on guiding implementation of palliative care improvements in nursing homes- may have allowed ACP self-efficacy to grow further and engagement in ACP communication/documentation to increase.[27,28]

Third, we evaluated our outcomes in all groups of care staff (care assistants, allied health staff and nurses) while our intervention differentiated between several roles in terms of responsibilities within ACP. The effect on the outcomes was possibly greatest among the ACP reference persons, as they acted as champions of the intervention in their nursing homes and were responsible for training other staff. However, the analyses did not allow identification of these roles and the trial lacked power to perform sub-analyses per role.

Last, as three of seven intervention nursing homes did not receive a high implementation score from the ACP trainers, we must consider the possibility of insufficient implementation. Although we considered contextual barriers in the theory of change, risks for suboptimal implementation remain in such a complex context[17,29–32]. However, implementation problems alone cannot explain the absence of larger intervention effects seeing as our subgroup-analysis in nursing homes with high implementation scores led to similar findings as the main analysis. The process evaluation of this trial can shed further light on this.

Conclusions and Implications

The ACP+ intervention improved care staff's self-efficacy regarding ACP after eights months, albeit to a relatively limited extent. It did not improve care staff's ACP knowledge. The smaller than expected effects could be related to the chosen outcomes or measurements, or to the intervention itself and its implementation. Future research should prioritize development of relevant, reliable, valid and change-sensitive outcome measures of ACP specifically applicable in nursing homes.

Acknowledgments: The research team would like to thank all nursing home managers and staff for participating in this study, as well as Katrien Cordemans and Harry Sorgeloos. We additionally thank the experts who were involved in the development of the ACP+ intervention; Liesbeth Van Humbeeck (UZ Gent) for review of intervention materials; Naomi Dhollander (UGent), Marc Tange (UZ Gent), Kristel Paque (VUB), Charless Dupont (VUB) and Laura Neirinck (GP) for the pre-testing of our questionnaires, Prof. Herman Nys (KU Leuven) for checking that our questionnaire accurately represents Belgian medical law, Wilfried Cools (VUB) for conducting randomization, Zorgnet-Icuro, Ferubel, VLOZO/FOS and VVSG, Flanders Centre for expertise in Dementia, DeMens.Nu and the Flemish Palliative Care Federation for their support in recruiting nursing homes into our study.

Funding: The study was funded by the Research Foundation-Flanders (FWO) and the Interdisciplinary Network for Dementia Using Current Technology (INDUCT, EU Horizon 2020). LP is a Postdoctoral Fellow of the Research Foundation-Flanders (FWO; 2017-2020). The funders have no role in the design of the study and collection, analysis, and interpretation of data, in writing the manuscript, or in the decision to submit the manuscript for publication.

Author contributions: Study conception: LVdB, LP, JG, AW-vD, LD, RVS, CG; data acquisition: JG, AW-vD; data analysis: AW-vD, LP, SDB; data interpretation: all authors; drafting of manuscript: LP, AW-vD; revising manuscript critically for important intellectual content: all authors; final approval of the version to be published: all authors. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflict of interest: The authors have no conflict of interest.

Data availability: Data will be made available for non-commercial research purposes upon reasonable request to the authors (LP, LVdB).

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Table 1. In- and exclusion criteria for participating nursing homes

Inclusion criteria:

- have at least 100 beds
- nursing homes management expresses explicit motivation to participate in the study and agrees to allocate 0.10 FTE per week for at least two staff members per 30 to 40 nursing home beds to act as ‘ACP Reference Person(s)’.

Exclusion criteria:

- have taken or are taking part in another research study that is evaluating palliative care or advance care planning programs or communication strategies, currently or in the past four years
- have developed - or are planning to develop during the foreseen trial period - an extensive ACP policy, meaning that (i) all nursing home residents, or their families, regularly receive ACP conversations (two or more conversations per year) or (ii) the nursing home is judged by the researchers as having explicit and detailed ACP guidelines available (corresponding to high-quality ACP procedures and practices)
- planned or ongoing major organisational or physical changes to the facility (e.g. building activities or staff re-organisation) during the study period
- was involved in the development or pre-testing of the ACP+ intervention and materials[21]

Table 2. Characteristics of care staff included in the ACP+ trial, by group and time point[a]

	Baseline (T0) (N=694)				Post-intervention (T1) (N=491)			
	Control (N=355)		Intervention (N=339)		Control (N=254)		Intervention (N=237)	
Age, mean (SD)	39,8	(11,2)	40,4	(12,0)	40,1	(11,8)	41,6	(12,3)
Female gender, n (%)	323	(92,0)	298	(89,8)	229	(92,3)	204	(89,1)
Job experience in years, mean (SD)	13,9	(10,6)	15,4	(11,6)	14,0	(11,1)	16,5	(11,7)
Occupation, n (%)								
Nurse	95	(27,0)	101	(30,5)	75	(30,5)	68	(29,7)
Care assistant	159	(45,0)	160	(48,3)	104	(42,3)	102	(44,5)
Allied health staff	99	(28,0)	70	(21,1)	67	(27,2)	59	(25,8)
Highest level of education, n (%)								
Primary education	0	(0,0)	4	(1,2)	2	(0,8)	1	(0,4)
Secondary education	184	(52,6)	157	(48,0)	119	(48,4)	107	(46,5)
Higher college education	118	(33,7)	121	(37,0)	85	(34,6)	88	(38,3)
Graduate education (university)	48	(13,7)	45	(13,8)	40	(16,3)	34	(14,8)
Received training in palliative care, n(%)	256	(72,5)	235	(72,1)	193	(78,5)	172	(74,5)
Received training in ACP[b] , n (%)	100	(29,0)	72	(22,2)	78	(31,7)	102	(45,7)
Hours/week working in the nursing home, n (%)	29,1	(8,3)	30,6	(8,8)	29,5	(9,1)	30,7	(8,9)
Mean number of residents cared for per day, n (%)	26,1	(27,3)	23,8	(23,0)	26,0	(25,9)	19,2	(19,2)

SD; Standard Deviation, ACP; Advance Care Planning

[a] Missing data did not exceed 6%, except for 'number of residents cared for' at T1:14,6%.

[b] Prior to intervention (at T0) or in the previous 6 months (at T1).

Table 3. Cluster-adjusted mean scores and differences for the primary and secondary outcomes (T0: N=694, T1: N=491)

	Baseline (T0)		Post-intervention (T1)					
	Control	Intervention	Control	Intervention				
	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)	Baseline adjusted mean difference or ratio and 95% CI	ICC	Effect size: Cohen's d/ratio[d]	p-value[e]
Primary outcomes								
ACP Knowledge (rate)[a]	0,52 (0,48 to 0,56)	0,52 (0,48 to 0,56)	0,53 (0,49 to 0,58)	0,55 (0,51 to 0,60)	1,04 (0,95 to 1,15)	0,025	1,041	0,399
ACP Self-efficacy (mean score)[b]	5,99 (5,60 to 6,38)	5,76 (5,40 to 6,11)	5,89 (5,50 to 6,29)	6,23 (5,86 to 6,60)	0,57 (0,20 to 0,94)	0,015	0,301	**0,003**
Secondary outcome	EP (95% CI)	EP (95% CI)	EP (95% CI)	EP (95% CI)				
ACP communication and documentation (proportion)[c]	0,40 (0,33 to 0,48)	0,39 (0,32 to 0,47)	0,36 (0,28 to 0,44)	0,44 (0,35 to 0,53)	1,47 (0,88 to 2,46)	0,007	1,467	0,145

ACP; Advance care planning, CI; confidence interval, EMM; estimated marginal mean, EP; estimated proportions, ICC; intra-class correlation coefficient. Across scales: If more than 25% of items were not answered (missing or not applicable), the summary score was defined as missing. Excluded records in the models used: knowledge n=30 (2,5%); self-efficacy n=270 (22,8%)(approximately 16,3% of staff answered 'not applicable', range over all self-efficacy questions 12,1%-21,6%), ACP communication and documentation n=16 (1,4%).

[a] negative binomial mixed model for rate, random intercepts for clustering within nursing home and staff member, adjusted for nursing home type and location. Range 0-1, higher scores indicate more knowledge.

[b] linear mixed model, random intercept for clustering within nursing home, compound symmetry covariance matrix for clustering within staff member, adjusted for nursing home type and location. Range 0-10, higher scores indicate more self-efficacy.

[c] binary logistic mixed model, random intercepts for clustering within nursing home and staff member, adjusted for nursing home type and location. Proportion (%) of staff engaging in at least one ACP communication and documentation activity, higher scores indicate more staff.

[d] Ratio was calculated for negative binomial mixed model and binary logistic mixed model, Cohen's d for linear mixed model.

[e] Interaction effect of group (intervention vs. control) and timepoint (post-intervention vs. baseline).

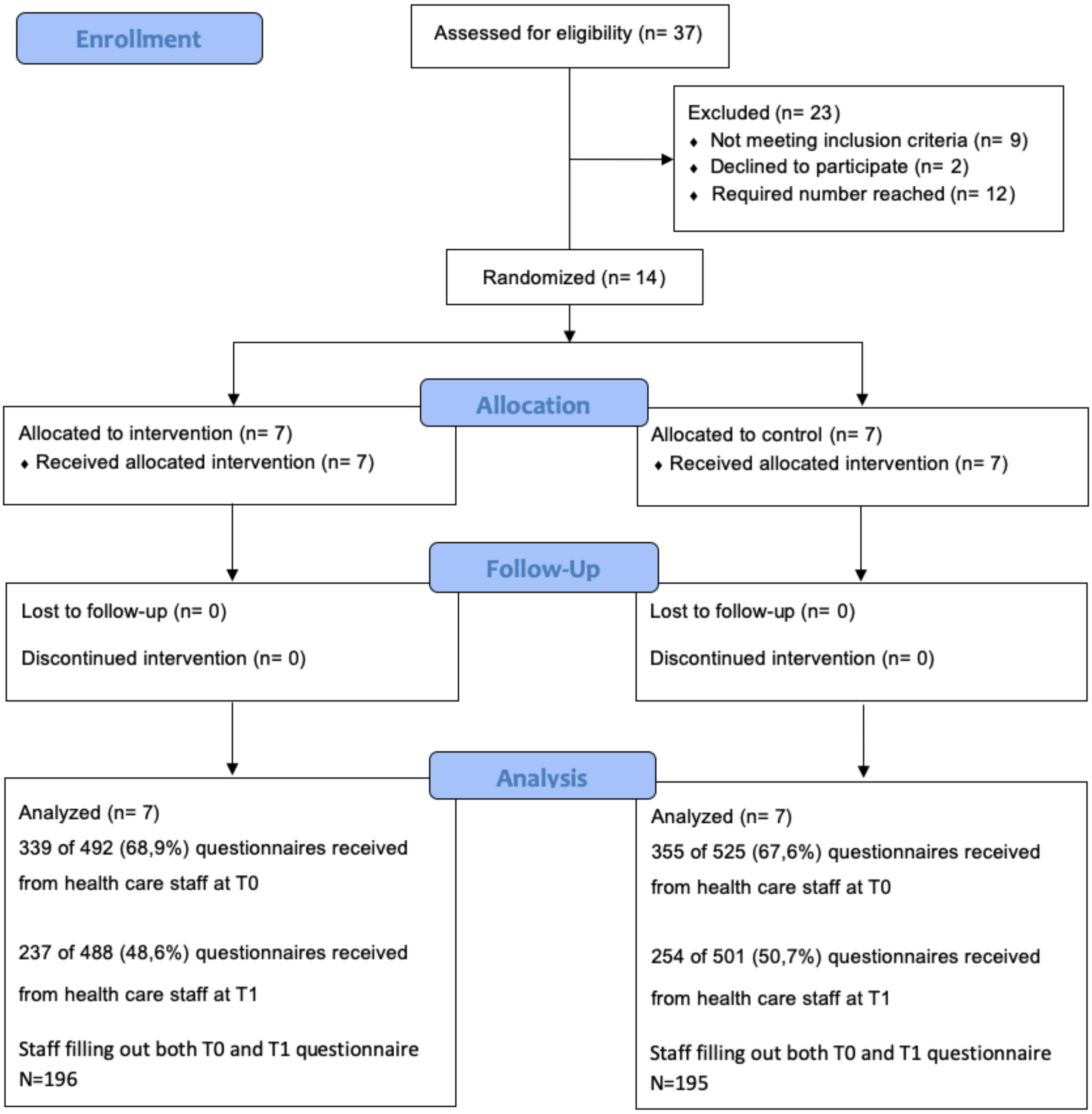
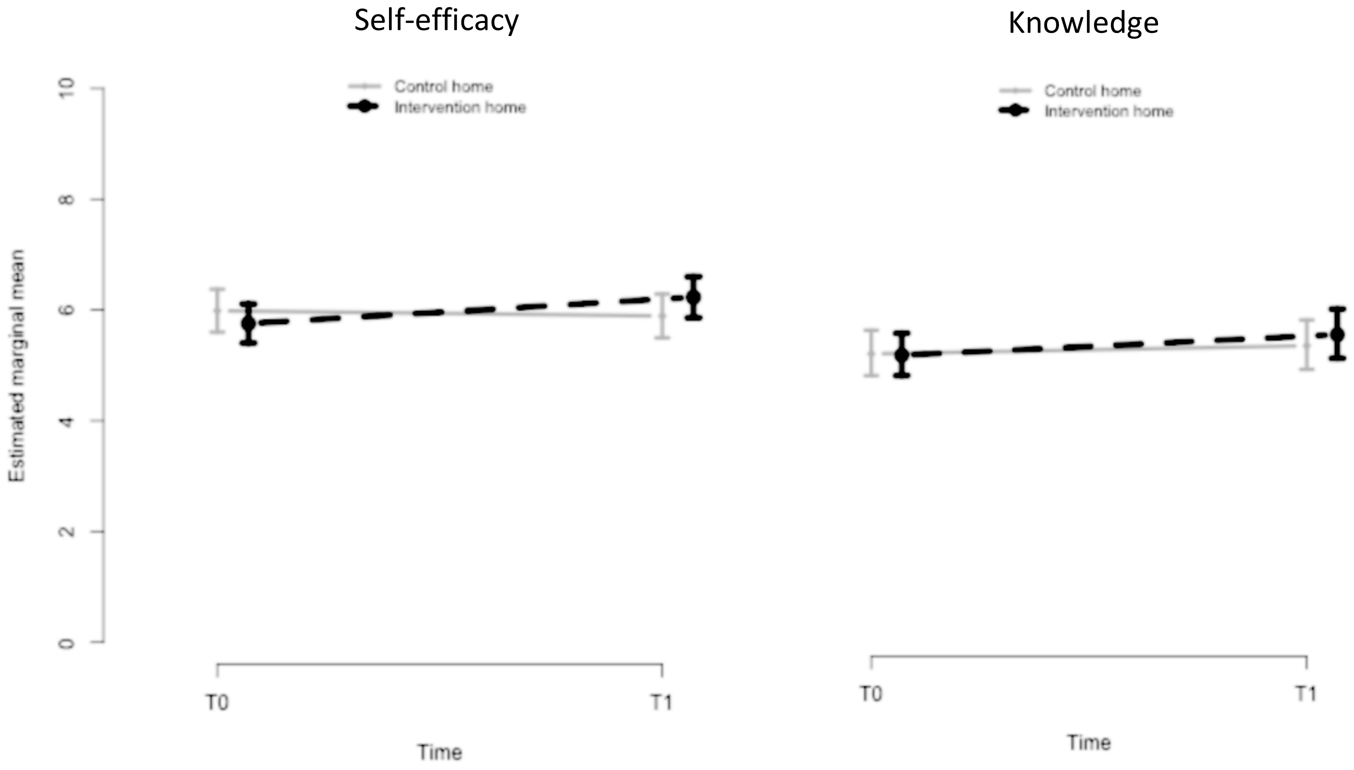


Figure 1. CONSORT Flow diagram of recruitment, randomization, and data collection

Figure 2. Estimated marginal means for ACP self-efficacy and ACP knowledge at T0 and T1 in intervention and control group



Effects of a theory-based ACP intervention for nursing homes: a cluster randomized controlled trial - Appendix

Table 1-e. Nursing home characteristics of nursing homes included in the ACP+ trial (N=14)
Table 2-e. Staff Outcomes – subgroup analysis: Cluster-adjusted mean scores and differences for the primary and secondary outcomes between control homes and homes with high intervention implementation score
Table 3-e. Staff Outcomes – subgroup analysis: Cluster-adjusted mean scores and differences between lower and higher educated care staff for the primary and secondary outcomes.
Table 4-e. Staff Outcomes: Cluster-adjusted mean scores and differences between groups for items of the ACP knowledge scale
Table 5-e. Staff Outcomes: Cluster-adjusted mean scores and differences between groups for items of the ACP self-efficacy scale
Table 6-e. Staff Outcomes: Cluster-adjusted mean scores and differences between groups for items of the ACP communication and documentation scale

This supplementary material has been provided by the authors to give readers additional information about their work.

It contains several tables providing further detail; two tables with subgroup analyses, as well as three tables with analysis on item-level for the primary and secondary outcomes.

The two subgroup analyses were performed for both primary outcomes and the secondary outcome. The first subgroup analysis only included nursing homes of the intervention group that had a high implementation score (i.e. 7 or higher) and compared to these to the nursing homes of the control group. The second subgroup analysis compared the effect of the intervention in lower educated staff (care assistants) with the effect in higher educated staff (nurses and allied health staff) using a three-way interaction between timepoint, study arm, and occupation. These subgroup analyses were exploratory and followed the same procedures as the main analysis.

Table 1-e. Nursing home characteristics of nursing homes included in the ACP+ trial at baseline (N=14)

Nursing home characteristic	T0
Type of facility, N	
Public	4
Private non-profit	9
Private for-profit	1
Location of facility, N	
Antwerp	5
East-Flanders	2
West-Flanders	1
Flemish-Brabant	2
Limburg	4
Availability of guidelines and documents, N	
Specific written guidelines for palliative care	14
Specific written guidelines for advance care planning	11
Patient-centered documents for advance care planning	14
Nursing home care staff per nursing home, median (range)	
Head nurse	3 (1-6)
Nurse	20 (11-56)
Care assistant	40 (20-106)
Physical therapist	3 (1-8)
Occupational therapist	3 (2-8)
Psychologist	0 (0-1)
Social worker or pastoral worker	1 (0-2)
Number of beds per nursing home, median (range)[a]	118 (90 – 264)

[a] One nursing home had 90 beds instead of 100, to secure distribution of location.

Table 2-e. Staff Outcomes – subgroup analysis: Cluster-adjusted mean scores and differences for the primary and secondary outcomes between control homes and homes with high intervention implementation score (T0: N=561, T1: N=393)

	Baseline (T0)		Post-intervention (T1)		Baseline adjusted mean difference or ratio and 95% CI	p-value[d]
	Control	High fidelity	Control	High fidelity		
	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)		
Primary outcomes						
ACP Knowledge (rate)[a]	0,50 (0,45 to 0,56)	0,54 (0,49 to 0,60)	0,52 (0,46 to 0,57)	0,59 (0,53 to 0,66)	1,06 (0,95 to 1,18)	0,330
ACP Self-efficacy (mean score)[b]	6,05 (5,11 to 7,00)	5,76 (4,79 to 6,73)	5,96 (5,03 to 6,88)	6,35 (5,40 to 7,29)	0,69 (0,24 to 1,13)	0,003
Secondary outcome	**EP (95% CI)**	**EP (95% CI)**	**EP (95% CI)**	**EP (95% CI)**		
ACP Communication and documentation (proportion)[c]	0,35 (0,26 to 0,45)	0,40 (0,31 to 0,55)	0,31 (0,22 to 0,41)	0,43 (0,31 to 0,55)	1,33 (0,74 to 2,40)	0,341

ACP; Advance care planning, CI; confidence interval, EMM; estimated marginal mean, EP; estimated proportion.

Across scales: If more than 25% of items were not answered (missing or not applicable), the summary score was defined as missing.

[a] negative binomial mixed model for rate, random intercepts for clustering within nursing home and staff member, adjusted for nursing home type and location. Range 0-1, higher scores indicate more knowledge.

[b] Linear mixed model, random intercept for clustering within nursing home, compound symmetry covariance model for clustering within staff member, adjusted for nursing home type and location. Range 1-10, higher scores indicate more self-efficacy.

[c] binary logistic mixed model, random intercepts for clustering within nursing home and staff member, adjusted for nursing home type and location. Proportion (%) of staff engaging in at least one ACP communication and documentation activity, higher scores indicate more staff.

[d] Interaction effect of group (intervention vs. control) and timepoint (post-intervention vs. baseline).

Table 3-e. Staff Outcomes – subgroup analysis: Cluster-adjusted mean scores and differences between lower and higher educated care staff[a] for the primary and secondary outcomes.

	Baseline (T0)		Post-intervention (T1)		Baseline adjusted mean difference or ratio and 95% CI	p-value
	Control	Intervention	Control	Intervention		
	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)		
Primary outcomes						
ACP Knowledge						0,044[e]
ACP Knowledge, lower educated staff (rate)[b]	0,46 (0,41 to 0,51)	0,47 (0,43 to 0,53)	0,50 (0,44 to 0,56)	0,47 (0,42 to 0,53)	0,92 (0,81 to 1,05)	
ACP Knowledge, higher educated staff (rate)[b]	0,56 (0,51 to 0,62)	0,55 (0,50 to 0,61)	0,56 (0,50 to 0,62)	0,62 (0,56 to 0,68)	1,13 (0,99 to 1,28)	
Self-efficacy in ACP						0,412[e]
Self-efficacy in ACP, lower educated staff (mean score)[c]	5,62 (5,13 to 6,12)	5,34 (4,87 to 5,81)	5,41 (4,89 to 5,94)	5,88 (5,37 to 6,39)	-0,21 (-0,76 to 0,35)	
Self-efficacy in ACP, higher educated staff (mean score)[c]	6,25 (5,77 to 6,74)	6,03 (5,59 to 6,46)	6,28 (5,78 to 6,77)	6,47 (6,01 to 6,93)	0,42 (-0,05 to 0,89)	
Secondary outcome	**EP (95% CI)**	**EP (95% CI)**	**EP (95% CI)**	**EP (95% CI)**		
ACP Communication and documentation						0,189[e]
ACP Communication and documentation, lower educated staff (proportion)[d]	0,31 (0,23 to 0,41)	0,29 (0,21 to 0,39)	0,30 (0,20 to 0,42)	0,28 (0,18 to 0,40)	1,06 (0,51 to 2,20)	
ACP Communication and documentation, higher educated staff (proportion)[d]	0,46 (0,36 to 0,56)	0,46 (0,37 to 0,56)	0,39 (0,29 to 0,50)	0,56 (0,45 to 0,67)	1,99 (1,01 to 3,94)	

ACP; Advance care planning, CI; confidence interval; EMM; estimated marginal mean, EP; estimated proportion.

Across scales: If more than 25% of items were not answered (missing or not applicable), the summary score was defined as missing.

[a] Lower educated care staff were care assistants, higher educated care staff included nurses and allied health staff.

[b] Negative binomial mixed model for rate, random intercepts for clustering within nursing home and staff member, adjusted for nursing home type and location. Range 0-1, higher scores indicate more knowledge.

[c] Linear mixed model, random intercept for clustering within nursing home, compound symmetry covariance model for clustering within staff member, adjusted for nursing home type and location. Range 1-10, higher scores indicate more self-efficacy.

[d] Binary logistic mixed model, random intercepts for clustering within nursing home and staff member, adjusted for nursing home type and location. Proportion (%) of staff engaging in at least one ACP communication and documentation activity, higher scores indicate more staff.

[e] Interaction effect of group (intervention vs control), timepoint (post-intervention vs baseline) and level of education (higher vs lower).

Table 4-e. Staff Outcomes: Cluster-adjusted mean scores and differences between groups for items of the ACP knowledge scale (T0: N=694, T1; N=491)[a]

	Baseline		Post-intervention			
	Control	Intervention	Control	Intervention		
Please indicate for each statement *'true'*, *'false'* or *'I don't know'*	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)	ratio and 95% CI	p-value interaction[b]
1. An AD allows a resident to communicate his/her will regarding healthcare in case s/he would lose decision-making capacity in the future *(true)*	0,89 (0,80 to 0,94)	0,88 (0,78 to 0,93)	0,86 (0,75 to 0,92)	0,89 (0,80 to 0,94)	1,60 (0,84 to 3,04)	0,149
2. A legal representative has the power to make decisions regarding healthcare in case the resident is no longer able to do this him-/herself *(true)*	0,63 (0,52 to 0,73)	0,62 (0,52 to 0,72)	0,68 (0,56 to 0,77)	0,64 (0,53 to 0,74)	0,90 (0,54 to 1,51)	0,686
3. A resident can only assign a family member as his/her legal representative *(false)*	0,69 (0,62 to 0,76)	0,69 (0,62 to 0,75)	0,76 (0,68 to 0,82)	0,75 (0,67 to 0,82)	1,02 (0,59 to 1,76)	0,943
4. A family member can refuse treatment instead of a resident who has no decision-making capacity *(true)*	0,32 (0,25 to 0,40)	0,28 (0,21 to 0,35)	0,34 (0,26 to 0,43)	0,30 (0,23 to 0,39)	1,02 (0,61 to 1,72)	0,933
5. A physician is obligated to perform all invasive treatments a resident/family asks for, independent of potential (dis)advantages of those treatments *(false)*	0,23 (0,17 to 0,31)	0,29 (0,23 to 0,37)	0,26 (0,19 to 0,35)	0,22 (0,15 to 0,30)	0,56 (0,32 to 0,98)	0,042
6. According to the Law on Patient Rights both a positive and negative AD are binding *(false)*	0,17 (0,11 to 0,24)	0,18 (0,13 to 0,25)	0,21 (0,14 to 0,30)	0,24 (0,17 to 0,33)	1,10 (0,60 to 2,04)	0,752
7. A resident living with dementia can change his/her AD *(true)*	0,11 (0,07 to 0,16)	0,10 (0,07 to 0,15)	0,11 (0,07 to 0,17)	0,20 (0,14 to 0,28)	2,17 (1,10 to 4,28)	0,025
8. Each family member of a resident living with dementia can change this person's AD *(false)*	0,69 (0,62 to 0,76)	0,73 (0,66 to 0,79)	0,72 (0,64 to 0,79)	0,71 (0,63 to 0,78)	0,82 (0,48 to 1,41)	0,474
9. If a resident that has no decision-making capacity (e.g. someone with severe dementia) has not assigned a legal representative, it is established by law who will take his/her place in decision-making *(true)*	0,48 (0,39 to 0,58)	0,45 (0,36 to 0,54)	0,45 (0,35 to 0,56)	0,56 (0,46 to 0,66)	1,81 (1,09 to 3,02)	0,022
10. According to the Law on Euthanasia a physician can perform euthanasia if a person is in an irreversible coma, in case that person has completed a written AD for euthanasia *(true)*	0,70 (0,60 to 0,78)	0,68 (0,59 to 0,76)	0,69 (0,59 to 0,78)	0,74 (0,65 to 0,82)	1,40 (0,83 to 2,35)	0,202
11. Residents that have no cognitive incapacity and are not terminally ill have the right to refuse treatment, even if this decision can lead to death *(true)*	0,81 (0,72 to 0,87)	0,83 (0,76 to 0,89)	0,80 (0,71 to 0,87)	0,85 (0,77 to 0,91)	1,24 (0,63 to 2,41)	0,534

ACP; Advance care planning, AD; advance directive, CI; confidence interval, EMM; estimated marginal means.

Missing data (highest N): T0-control N=12, 3,4%, T1-control N=17, 6,7%, T0-intervention N=11, 3,2%, T1-intervention N=9, 3,8%.

Answering 'true' to a true statement and 'false' to a false statement is counted as a correct answer. 'I don't know' is counted as an incorrect answer. All items are based upon Belgian law and checked by a certified lawyer.

[a] Binary logistic regression, random intercepts for clustering within nursing home and staff member, adjusted for nursing home type and location. Range 0-1, higher scores indicate more knowledge. [b] Interaction effect of group (intervention vs control) and timepoint (post-intervention vs baseline).

Table 5-e. Staff Outcomes: Cluster-adjusted mean scores and differences between groups for items of the ACP self-efficacy scale (T0: N=694 T1: N=491)[a]

	Baseline		Post-intervention			
	Control	Intervention	Control	Intervention	Baseline adjusted mean difference and 95% CI	p-value interaction[b]
Please indicate how confident you feel in performing the activities and roles below on a scale from 1-10, with higher scores indicating feeling more confident	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)	EMM (95% CI)		
1. Initiating ACP conversations	5,83 (5,27 to 6,39)	5,65 (5,14 to 6,15)	5,86 (5,29 to 6,43)	6,13 (5,60 to 6,65)	0,45 (-0,02 to 0,92)	0,059
2. Discussing disease and treatment options with a resident in the context of ACP	5,82 (5,36 to 6,28)	5,64 (5,22 to 6,06)	5,96 (5,49 to 6,43)	6,19 (5,74 to 6,63)	0,41 (-0,05 to 0,87)	0,079
3. Discussing wishes and preferences for future care	6,15 (5,71 to 6,60)	5,89 (5,48 to 6,31)	6,03 (5,56 to 6,49)	6,34 (5,90 to 6,77)	0,57 (0,13 to 1,01)	0,010
4. Explain the role of a legal representative to residents and family	5,90 (5,36 to 6,44)	5,70 (5,22 to 6,18)	5,82 (5,27 to 6,36)	6,21 (5,70 to 6,71)	0,59 (0,15 to 1,03)	0,009
5. Respond to questions of residents regarding ADs	5,78 (5,32 to 6,23)	5,40 (4,99 to 5,82)	5,52 (5,04 to 5,99)	5,94 (5,50 to 6,38)	0,80 (0,35 to 1,25)	0,001
6. Respond to questions of family regarding ADs	5,74 (5,23 to 6,24)	5,31 (4,86 to 5,77)	5,41 (4,90 to 5,93)	5,83 (5,36 to 6,31)	0,85 (0,40 to 1,29)	0,000
7. Align care with a residents' written wishes	6,96 (6,53 to 7,40)	6,67 (6,29 to 7,06)	6,81 (6,37 to 7,24)	7,01 (6,60 to 7,41)	0,49 (0,05 to 0,94)	0,031
8. Knowing legislation regarding ADs	4,85 (4,39 to 5,31)	4,66 (4,24 to 5,09)	4,77 (4,30 to 5,25)	5,43 (4,98 to 5,88)	0,84 (0,35 to 1,33)	0,001
9. Speaking to family members about wishes for future care	6,54 (6,15 to 6,93)	6,35 (5,98 to 6,71)	6,44 (6,03 to 6,85)	6,70 (6,31 to 7,08)	0,44 (0,03 to 0,86)	0,037
10. Speaking about general issues regarding death and dying	6,28 (5,96 to 6,60)	6,17 (5,86 to 6,49)	6,29 (5,94 to 6,64)	6,42 (6,07 to 6,77)	0,24 (-0,21 to 0,69)	0,302
11. Conduct an ACP conversation with residents living with dementia	5,52 (5,18 to 5,86)	5,31 (4,98 to 5,64)	5,58 (5,21 to 5,95)	5,65 (5,28 to 6,02)	0,27 (-0,20 to 0,75)	0,260
12. Conduct an ACP conversation with family of residents living with dementia	5,82 (5,48 to 6,17)	5,68 (5,34 to 6,02)	5,73 (5,35 to 6,11)	5,94 (5,56 to 6,32)	0,35 (-0,13 to 0,82)	0,154

ACP; Advance care planning, AD; advance directive, CI; confidence interval, EMM; estimated marginal means.

Missing data (highest N): T0-control N=92, 25,9%, T1-control N=71, 28%, T0-intervention N=74, 21,8%, T1-intervention N=42, 17,7%.

[a] Linear mixed model, random intercept for clustering within nursing home, compound symmetry covariance model for clustering within staff member, adjusted for nursing home type and location. Range 1-10, higher scores indicate more self-efficacy.

[b] Interaction effect of group (intervention vs control) and timepoint (post-intervention vs baseline).

Table 6-e. Staff Outcomes: Cluster-adjusted mean scores and differences between groups for items of the ACP communication and documentation scale (T0: N=694 T1: N=491)[a]

	Baseline		Post-intervention			
	Control	Intervention	Control	Intervention		
Please indicate if you were involved in each of these actions in the past six months (yes/no)	EP (95% CI)	EP (95% CI)	EP (95% CI)	EP (95% CI)	ratio and 95% CI	p-value interaction[b]
1. Started an ACP conversation	0,14 (0,10 to 0,20)	0,15 (0,10 to 0,21)	0,14 (0,09 to 0,20)	0,24 (0,17 to 0,33)	1,95 (1,01 to 3,76)	0,046
2. Documented the outcomes of an ACP conversation in a resident's file	0,15 (0,11 to 0,21)	0,20 (0,15 to 0,27)	0,17 (0,12 to 0,24)	0,27 (0,19 to 0,35)	1,26 (0,68 to 2,32)	0,464
3. Completed an AD with a resident	0,05 (0,02 to 0,10)	0,06 (0,03 to 0,11)	0,05 (0,02 to 0,10)	0,11 (0,06 to 0,21)	2,22 (0,88 to 5,64)	0,092
4. Made an estimation if someone was capable of completing an AD	0,22 (0,16 to 0,31)	0,24 (0,17 to 0,31)	0,20 (0,13 to 0,29)	0,28 (0,20 to 0,38)	1,45 (0,78 to 2,70)	0,240
5. Had an ACP conversation with a resident living with dementia	0,11 (0,07 to 0,17)	0,12 (0,08 to 0,18)	0,12 (0,07 to 0,19)	0,13 (0,08 to 0,20)	1,00 (0,46 to 2,18)	0,995
6. Had an ACP conversation with family of a resident living with dementia	0,20 (0,14 to 0,28)	0,19 (0,13 to 0,26)	0,16 (0,11 to 0,24)	0,19 (0,13 to 0,27)	1,28 (0,68 to 2,38)	0,445

ACP; Advance care planning, AD; advance directive, CI; confidence interval, EP; estimated proportions.

Missing data (highest N): T0-control N=10, 2,8%, T1-control N=7, 2,8% T0-intervention N=10, 2,9%, T1-intervention N=6, 2,5%.

[a] Binary logistic regression, random intercepts for clustering within nursing home and staff member, adjusted for nursing home type and location. Range 0-1, higher scores indicate more ACP communication and documentation.

[b] Interaction effect of group (intervention vs control) and timepoint (post-intervention vs baseline).

Chapter 3.3

A mixed- methods process evaluation of an advance care planning intervention in nursing homes

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Submitted

Abstract

Objectives: The ACP+ intervention aimed to implement advance care planning (ACP) in nursing homes. In a cluster randomized controlled trial (RCT), it showed to increase staff's ACP self-efficacy –to a smaller extent than expected– and did not increase staff's ACP knowledge. An embedded process evaluation enabled us to evaluate implementation, mechanisms of impact and contextual factors affecting implementation and outcomes of ACP+.

Design: Mixed-methods process evaluation alongside the RCT in 14 nursing homes (ClinicalTrials.gov NCT03521206).

Setting and Participants: Seven nursing homes in Flanders, Belgium receiving ACP+ (a theory-based 8-month multicomponent intervention aimed at training staff to implement ACP, supported by an external trainer). Management, staff and trainers participated in the process evaluation.

Methods: During implementation, weekly trainer diaries, post-training surveys and attendance lists were collected. Post-intervention (after month 8), facility-level data were obtained and interviews conducted (n=32).

Results: Concerning implementation, 33% of staff was trained on average (range 6%-69%, low to moderate reach); at least 13 of 17 intervention components were implemented as intended in each home (fidelity); 13 types of adaptations were made, mostly related to the staff's training sessions (adapted) and audit (removed). Micro- (e.g. motivation) and meso-level (e.g. coordination) mechanisms impacted implementation. Participants perceived ACP+ to: increase staff awareness about the importance of ACP, lead to more structured ACP procedures and, increase engagement in ACP. However, on-the-job learning experiences were too few. Most important contextual factors were lack of time and resources, staff turn-over and management buy-in.

Conclusions and implications: ACP+ was well received and participants highlighted positive effects of the intervention (e.g. increased ACP awareness) which were not reflected in the RCT analyses. The lack of large effects on ACP self-efficacy or knowledge may be explained by staff's low to moderate reach in trainings, too few on-the-job learning opportunities, and contextual difficulties. Based on these results, we propose to adapt ACP+ and its theoretical framework to optimize the intervention and its further evaluation.

Introduction

Advance care planning (ACP) is defined as ‘a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care’[1]. While ACP has been recommended to be an integral part of best practice nursing home care[2,3], its implementation in routine care has shown to be a challenge[4].

Incorporating evidence about the barriers that exist on multiple levels (resident, family, professional and organizational level) and stakeholders’ views on how to overcome these[5,6], we developed the ACP+ intervention for nursing homes in Flanders, Belgium. The ACP+ intervention is a multicomponent theory-based intervention program using a whole-setting approach, aimed at training and supporting nursing home staff with the implementation of ACP into daily nursing home care[2,7,8].

The effects of the ACP+ intervention on staff-level outcomes were evaluated in a cluster randomized controlled trial (RCT)[8]. Results showed that the program impacted the staff’s self-efficacy to engage in ACP positively, albeit to a relatively limited extent, while not impacting staff’s ACP knowledge. To understand these results better, process evaluations of clinical trials are indispensable. In 2015, the UK Medical Research Council (herein referred to as, “UK MRC”) updated its guidance on complex interventions and addressed the need for process evaluations accompanying RCTs to be able to interpret trial outcomes[9]. In line with this guidance, we conducted a mixed-methods process evaluation alongside our cluster RCT. More specifically, we aimed to answer the following research questions:

Implementation: How is the delivery of the ACP+ intervention achieved and what is delivered?

What is the dose, reach and fidelity of the intervention activities?

Which adaptations were made to the intervention activities?

Mechanisms of impact: How does the delivery produce change and to which degree do the different components of the ACP+ intervention affect the outcomes?

What are the participants’ responses to, and interactions with, the intervention activities?

What are the mediators & the unanticipated pathways or consequences for the intervention?

Context: How does the context affect the implementation of the ACP+ intervention and its outcomes?

What are the important contextual factors when implementing intervention activities?

What is the intention of maintenance among participants?

Methods

Design

The cluster RCT ran from February 2018 (recruitment of nursing homes) until March 2019 (end of data collection). It used a pre-post design to evaluate the effects of the ACP+ intervention on ACP knowledge and the self-efficacy of the nursing home care staff[8] over eight months, with seven nursing homes in the intervention arm and seven in the standard care arm. The process evaluation combined quantitative and qualitative research methods, collected throughout and until three months after the intervention implementation period in the intervention nursing homes only. The design of the process evaluation was informed by a Theory of Change map[2], which was made in the development phase of the intervention and outlined the most important intervention components, and the UK MRC framework guidance for process evaluations of complex interventions[9]. Results are reported according to the latter. The cluster RCT was registered at ClinicalTrials.gov (no. NCT03521206).

The ACP+ intervention

The ACP+ intervention and underlying Theory of Change, which describes how, why and under what circumstances ACP is expected to work in practice, was created after an extensive development process, described elsewhere[7,8]. ACP+ is a multicomponent intervention program aimed at training nursing home staff in the implementation of ACP into daily nursing home care, which consists of 10 components, 22 activities and 17 materials, implemented step-wise over a period of eight months[2,7,8].

ACP+ was delivered by two external trainers, who were responsible for three and four nursing homes, respectively. These ACP trainers had clinical practice experience in nursing homes (one as a general practitioner (GP) and Coordinating Advisory Physician (CAP), and one as a nurse and reference person for palliative care and dementia) and in performing ACP conversations. They trained nursing home staff through following a train-the-trainer model. Their support was intensive in the beginning, but decreased throughout the process as nursing home staff became more autonomous in organizing ACP and consolidating the ACP+ intervention.

A key aspect of ACP+ was the whole-setting approach, with the allocation of different roles to all staff members: ACP reference persons were responsible for implementing ACP within the nursing home; ACP conversation facilitators worked with the ACP reference persons and were responsible for planning and performing regular ACP conversations with residents and/or family; and all other staff, including support staff, were ACP antennas, who recognized and signaled triggers that could indicate a resident's readiness, need or willingness to engage in ACP.

Study setting and participants

The study was carried out in nursing homes in Flanders, Belgium. Nursing homes are care facilities where continuous (24/7) nursing and personal care is available[10] and medical care is provided by an external GP. Nursing homes participating in the cluster RCT needed at least 100 beds and the nursing home management needed to express explicit motivation to participate in the study[8].

A selection of staff and management in the seven nursing homes receiving the intervention were included in the process evaluation. Researchers invited one member of the management (i.e. member of the nursing home in a managerial position) for a 30-minute interview, as well as at least two ACP reference persons per intervention home for a 60-minute group interview. The key contact person in each nursing home (i.e. the head nurse, the administrator, or the manager responsible for the distribution of the questionnaires of the RCT[11]) was asked to recruit six to eight staff members who participated in either the training for ACP conversation facilitators or ACP antennas. The functions of staff assigned as ACP reference persons are described in the appendix (Table 1e). ACP conversation facilitators and ACP antennas could either be care staff (nurses, care assistants, allied health staff) or support staff (i.e. cleaning or administrative staff who have regular contact with residents or family but do not provide direct care to them). Those who were not able to speak and understand Dutch, students and interns under 18 years old were not included. Both ACP trainers were also invited by the researchers to participate in the process evaluation, in 60-minute interviews (month four) and post-intervention (month nine).

Outcomes and data collection of the process evaluation

Both quantitative and qualitative data were collected during and post-intervention. An overview of all operationalizations and data collection methods can be found in the appendix (Table 2e). We assessed:

- Implementation, comprising:
    - dose; i.e. how much intervention is delivered
    - reach; i.e. the extent to which a target audience comes into contact with the intervention
    - fidelity; i.e. the consistency of what is implemented with the planned intervention
    - adaptations; i.e. alterations made to the intervention in order to achieve a better contextual fit

  These were assessed via weekly ACP trainer diaries, attendance lists of training sessions, observation forms of training sessions and a facility-level data questionnaire per nursing home. Moreover, post-training surveys asked about the quality of the in-house training sessions delivered by the trainer, and the competencies of the trainer on a scale from 1-4, with higher scores indicating better quality. Post-intervention ACP trainers were asked to rate the overall implementation of each nursing home on a scale from 1 to 10, with higher scores indicating better implementation.
  Qualitative data collection included ACP trainer notes on the progress of implementation, short reports on the meetings they had in each nursing home, interviews with ACP trainers and management, interviews/focus groups with ACP reference persons, ACP conversation facilitators and ACP antennas groups (topic list added in appendix 3e).
- Mechanisms of impact i.e. how participants responded to and interacted with specific intervention activities were assessed via post-intervention interviews and focus groups.
- Context i.e. factors external to the intervention that were perceived by participants to affect implementation and/or outcomes were assessed via post-intervention interviews and focus groups.

Procedures

The researchers (JG and AW-vD) traveled to the nursing home for all interviews and focus groups. If face-to-face meetings were not possible for nursing home staff, telephone interviews were conducted.

The post-training surveys and a return envelope were distributed to attendants by the ACP trainer, or researcher, after each training session. Sealed envelopes with completed surveys were returned to the researchers. Trainers also kept a list of the attendance of the staff at the training sessions. These lists were kept in a secure place and only the total number of participants per session was handed to the researchers.

Data analysis

We report descriptive statistics and frequencies of dose, reach and fidelity measures per nursing home and across nursing homes (mean, median, range and proportions). All qualitative data from interviews and focus groups were transcribed verbatim and analyzed using NVIVO 12. Two independent coders (AW-vD, JG), who also conducted the interviews, deductively coded transcripts (AW-vD 80% and JG 20%) using a prespecified framework for analysis focusing on the research questions and the topics of implementation, mechanisms of impact and context (based on Moore et al.[9]). Subthemes were formed inductively in order to get a rich description of the overall data[12,13]. The initial coding structure was regularly discussed and refined by both researchers. When coding discrepancies occurred, a consensus was sought. After half of the interviews were coded, the coding tree was discussed with LVdB and LP. We then systematically applied the final codebook to all data. All coded data were double-checked by AW-vD and JG to assess whether each of the excerpts fitted the theme to which it was assigned.

Ethical considerations

Ethics approval was granted by the Ethics Committee of University Hospital Brussels (2017/31, (B.U.N. 143,201,732,133). This study carried little to no risk to the participants. Participants were free to withdraw their participation at any stage. The pseudonymization of all participants was ensured throughout the study. Questionnaires evaluating training sessions only included the nursing home code. Prior to each interview, written informed consent for audio-taping was asked of the participants. In case of a telephone interview, verbal informed consent was asked. To protect privacy during the interviews, the staff and management were interviewed separately. The names (and the nursing homes) of the participating staff were changed to numbers during the transcription.

Results

The majority of the participants (N=32) in the qualitative part of the process evaluation were female (81%, n=26 Table 1) and 66% were between 35 and 50 years old (n=21). Most were care staff (e.g., nurse or physical therapist); 13% were support staff (e.g., administrative, cleaning, technical staff, n=4) and 13% were management (n=4). Sixty-six percent of participants were trained as ACP reference persons (n=21) and 19% as ACP antennas (n=6); representing 10% of the total staff trained during the intervention (n=267).

Contact persons in all intervention homes indicated a preference for individual interviews over the planned focus groups with the staff, not to overburden the staff. Hence, face-to-face (n=3) and telephone (n=3) interviews replaced the focus groups in six facilities. One facility did not participate in interviews, feeling overburdened with all the data collection.

Figure 1 provides an overview of the results mapped according to the UK MRC framework for process evaluations[9], reporting factors relating to the implementation, the mechanisms of impact and the context. These are explained in detail below.

Implementation of the ACP+ intervention

All seven intervention nursing homes received the intended intervention, none were lost to follow up. The overall implementation score given by the trainers was 7.3 (on a scale from 1 to 10) across nursing homes. Because one nursing home (NH5) switched trainers due to personal difficulties, the implementation of the intervention for this nursing home was delayed (e.g., postponed in-house training sessions).

Dose, research and fidelity are reported in Table 2.

Dose: Over the study period (23 weeks), the trainers visited the nursing homes on average 11.4 times. Per visit, they spent on average two to five hours in the nursing home to deliver ACP+ components. Trainers also had contact over the phone, varying from one to eight calls per nursing home, with a median of one. The number of contacts via e-mail was not registered.

Reach: Across nursing homes, 32 ACP reference persons were appointed, ranging from three to seven in each nursing home (for characteristics see appendix Table 2e). They included nurses (n=15, including five palliative care reference persons), head nurses (n=9), occupational therapists (n=3), care assistants (n=2), a physical therapist, a chaplain and a social worker. All selected ACP reference persons were trained in a two-day workshop and a comeback seminar (100%) six months into the intervention. ACP conversation facilitators were social workers, head nurses, nurses, animators, physical therapists, care assistants and a chaplain. One nursing home (NH4) did not train any conversation facilitators. The ACP antennas were intended to be all other staff.

The reach of nursing home staff was low to medium (Figure 2), with a cross-facility average of 33% of the intended ACP conversation facilitators and ACP antennas receiving an ACP training session. In five of the seven nursing homes, the percentages of the staff reached with training were lower than 33%, with a minimum of 6%.

Fidelity: In one nursing home, 13 out of the foreseen 17 intervention activities were delivered as intended according to the researchers after the analysis of the interviews and focus groups; in three nursing homes 14/17, in two nursing homes 15/17 and in one nursing home 16/17 intervention activities were delivered as intended (Table 2). One nursing home (NH7) did not organize the information session for the GPs and one nursing home did not organize the training session for ACP conversation facilitators (NH4). The specialization session about dementia was organized by only two nursing homes (NH3 and NH6) and the specialization session about communication with other healthcare professionals only by NH2 and NH4. Moreover, the audit was only taken up by NH2 and NH3. Lastly, one nursing home (NH2) did not organize multi-disciplinary meetings. Post-training surveys (scale from 1 to 4) showed the average score of the quality of the in-house training sessions delivered by the trainer was 3.5; the average score of the competencies of the trainer was 3.9.

Adaptations: The most important adaptations to the ACP+ interventions, and the reasons for them, are reported in Table 3. We identified 13 types of adaptations. For example, all nursing homes developed an ACP protocol describing structured ways to conduct ACP, while this was not part of the intervention. Furthermore, different types of meetings were added (e.g., meeting between ACP reference persons). On the other hand, several planned training sessions were adapted or removed, mainly due to time restrictions. Also, the audit component was removed by five out of seven nursing homes, since they felt an audit would be more appropriate one or two years after the intervention implementation.

Mechanisms of impact

We identified several responses to and/or interactions with the intervention that might have served or could serve as potentially important mechanisms of impact: four were related to the individual staff (micro) level and four to the organizational (meso) level (quotes are reported in appendix Table 4e).

Confidence and intrinsic motivation of staff were mentioned by participants as important for successful implementation. All ACP reference persons experienced the 2-day training course as overwhelming, because of a lot of theoretical information. Nevertheless, they also reported this as a solid foundation from which they could start. ACP reference persons stated they lacked some confidence at the beginning of the intervention to start ACP conversations with residents, because of the delicacy of the topic. However, the experience of conducting ACP conversations has helped them gain confidence.

In-depth 'on-the-job' training to practice ACP conversations was perceived to be an important contributing factor to gaining more self-efficacy and confidence. ACP reference persons stated that they would have liked to gain more confidence in conducting ACP conversations before they needed to train their colleagues. Moreover, ACP reference persons stated their need for medical and legal knowledge to feel confident conducting ACP conversations.

Support from the trainers was predominantly perceived as helpful, especially because of their knowledge, either in legal or medical aspects, or in case the team did not know what to do and felt overwhelmed. It was appreciated that both trainers had experience in direct care provision and were motivated and energizing.

Trainers themselves experienced being outsiders. One trainer felt she was motivating staff but did not have the mandate to push the staff to engage more in implementing the intervention and carrying out the steps as intended. A good relationship with staff within the home (“a connection”), and support from management herein, were deemed essential by the trainers.

Almost all participants highlighted the need to clarify roles from the outset; especially between ACP reference persons, ACP conversation facilitators and GPs. Overall, ACP conversations were performed primarily by ACP reference persons who were generally also those who had the most experience in ACP before the study. This led one nursing home to reconsider whether additional training for conversation facilitators, next to ACP reference persons, was useful (see Table 3 - adaptations). A first necessary step after training ACP reference persons was found to be a meeting wherein mandates (e.g., who has the freedom to devote time to ACP tasks) and responsibilities were discussed and decided upon, preferably in collaboration with the management and the head nurses. This was believed to also enable others (including residents and family) to have more sense of with whom to talk. One manager argued the division of roles within ACP+ changed the perspective of the staff viewing the GP as mainly responsible (NH6) and awaiting until s/he would start ACP; as of now, staff would contact the GP proactively to align on how to proceed.

In most nursing homes (five of seven), at least one ACP reference person was not someone who provided direct resident care and was, therefore, able to devote some time to organizing trainings, information sessions, meetings with the trainer and planning ACP conversations. This coordinating role was perceived by all participants as very useful for implementation and many participants reported to be willing to keep this in place to maintain the organization of ACP.

It was deemed important by all participants that there was a sense of support by the team, especially by other staff trained in ACP conversations, to function as a back-up when a conversation was planned but an emergency occurred, or when they had questions or needed to share their feelings about distressing subjects which they discussed during ACP conversations.

Lastly, a structured way of working and having guidelines/a protocol in place, including a clear mission and vision of the managers, on how to integrate ACP in the daily care structures or on how and when to conduct ACP conversations was perceived as helpful. All nursing homes drafted such a document, notwithstanding that this was not a part of the intervention (Table 3-added adaptations).

When asked about how ACP+ had influenced daily practice in the nursing home, several ACP reference persons reported an increase in their self-efficacy and knowledge. Also, the interviewed ACP antennas felt more confident in knowing what to do and whom to refer to in case a resident had questions about end-of-life related topics. They perceived this to be true for their colleagues as well. Additionally, some participants stated that ACP+ led to an increase in the mental well-being of the residents, due to speaking more freely about their end-of-life preferences.

Most participants stated an increase in awareness about the importance of ACP of all colleagues throughout the nursing home. They mentioned colleagues passing on signals of residents that could need an ACP conversation to the reference persons. Some also mentioned an increase in their family asking for an ACP conversation. In one nursing home (NH4), initiatives were taken to speak about existential questions with the residents during the social activities (e.g., weekly discussion group meeting). On the other hand, however, in one nursing home (NH3), staff reported that ACP+ and ACP in general ‘belonged’ to the reference persons.

Furthermore, the implementation of ACP+ led to a more structured way of working around ACP for all involved nursing homes. Many participants stated an improvement of the processes and clearer distinction of the roles and responsibilities between staff, as well as a clearer view on how to handle the ACP conversations and conduct these in an appropriate manner.

Lastly, various participants mentioned an increase in ACP conversations and documentation, and a more in-depth documentation about residents' preferences in the nursing home file, instead of only advance directives.

Context

We identified several contextual factors affecting the implementation of ACP+ and conducting ACP conversations. All respondents mentioned a lack of time and resources. Trainers, management and ACP reference persons reported having trouble organizing all the required training sessions within the proposed timeframe, as well as having ACP conversations with the residents and documenting these conversations. Primary care processes were always prioritized over ACP conversations and even when ACP conversations were planned incidents (e.g., a resident falling) often hindered these plans. Furthermore, factors also included high staff turn-over, not having enough (head) nurses available and staff getting sick, occasionally for extended periods of time. During the summer holidays (July and August), these factors were intensified, further complicating implementation.

The close involvement of the management was perceived to be a facilitator for the implementation of ACP+ by all participants. Management with a clear sense of direction of where the project needed to go and who stressed the importance of ACP were perceived by the staff as supportive, which motivated them to work on the project. The management also contributed to the organizational culture of the nursing home, which involved the implicit rules about the tasks the staff could or could not perform.

The collaboration with parties outside the nursing home that affected ACP+ the most was with the residents' GPs. Staff stated the importance of involving a physician in the ACP conversations, especially for the medical advance decisions and the jurisdictions accompanying those. However, not all GPs were open to participating in ACP conversations, or were up to date on the legislations regarding end-of-life decisions. Also, staff sometimes had trouble finding family willing to be involved in ACP, and occasionally were confronted with disagreement within the family about which course of action would be appropriate for the resident. Nevertheless, involving the social context of the resident in ACP conversations was mentioned as important.

All nursing homes struggled with integrating the ACP information in their electronic system. Specifically, on how to get a quick overview of how to react in cases of emergency (e.g., do-not-resuscitate). Additionally, not all staff had equal access to the electronic system and therefore information was not always transferred to the right person.

All nursing homes made plans for sustaining the implemented processes, for example, by creating a protocol in which the procedures for ACP conversations are explained, as well as the vision and mission of the nursing home concerning ACP. Various participants talked about the integration of ACP in existing palliative care workgroups or the creation of new workgroups focusing specifically on ACP. Moreover, many participants mentioned the intention of repeating ACP training sessions for (new) staff and information sessions for (new) residents and their families.

Discussion

The aim of this process evaluation was to provide a more detailed understanding of the implementation, the mechanisms of impact and the context of the ACP+ intervention in nursing homes. This study sheds light on areas for improving the intervention and several potential explanations for why the effects of the ACP+ intervention on staff's ACP self-efficacy and knowledge were lower than expected. Overall, the process evaluation showed that ACP+ was well received. Key implementation issues concerned the low to moderate reach of the staff with training activities, and the many adaptations made to the intervention components. Participants perceived several factors as important mechanisms of impact: staff-level factors (e.g., motivation); management-level factors (e.g., coordination); as well as trainer support. They highlighted that the intervention had mostly impacted staff awareness of the importance of ACP and the organizational aspects of ACP. A number of contextual difficulties were found to influence implementation.

A striking first result of the process evaluation –which might be a major factor in explaining the trial effects we found– is the low to moderate reach of the staff with the intervention's training activities. The aim of ACP+ was to provide all staff with ACP training. The intervention assigned several roles, and the trainings were adapted for each role. However, while all ACP reference persons (between three and seven identified in each home) were reached, which probably led to trainers indicating high scores on overall implementation, on average across nursing homes only 33% of the other staff received an ACP training session. In five of the seven nursing homes, the percentages of staff reached with training activities were even lower, suggesting the intervention did not adopt the whole-setting approach sufficiently. It is also possible that more time was needed to ensure all trainings would be delivered to all staff, or that we underestimated the amount of time and energy ACP reference persons needed to adopt ACP+ and change their behavior before they could train others. This then hampered the implementation of ACP conversation facilitators and ACP antennas, as ACP reference persons could not sufficiently take on their role of trainer.

Difficulties in reaching all staff in nursing home educational interventions have been recognized before, for example when implementing palliative care practices in nursing homes in different EU countries[14,15]. Since the RCT investigated the effect on all staff in terms of improving ACP self-efficacy and knowledge, the lack of reach of the training sessions seems to be a plausible explanation for finding the smaller than expected effects. This hypothesis is further supported by the finding that the majority of the adaptations made to the intervention by the nursing homes concerned training sessions for ACP conversation facilitators and ACP antennas. Implementation science literature highlights the importance of allowing flexibility in the implementation. However, when adaptations are made, they should still be aligned with the major parts of its underlying theory. This might not have been the case in our study as the trainings for all staff were an essential element of the whole-setting approach of ACP+[16,17].

More on-the-job learning might lead to higher self-efficacy and an increase in ACP knowledge, leading to more ACP communication and documentation. Specifically related to the trainings provided, the support from the ACP trainers was perceived to be essential by ACP reference persons and managers, but participants also reported the training to be too short or found it missed emphasizing on-the-job learning. This is in line with several educational and social behavioral theories. The theory of progressive education of Dewey[18] emphasizes, for example, 'learning by doing' and proposes that people gain new skills by interacting with their environment. Bandura's social cognitive theory[19] suggests that there is a relationship between knowledge and skills, and it is through self-efficacy that people undertake action. Self-efficacy is also influenced by prior experiences of that particular action[20,21]. Michie's behavior change framework COM-B additionally states that behavior is an interplay between capability, motivation and opportunity[22], suggesting that, in order to increase ACP communication and documentation, staff should be allowed the necessary time to gradually adopt ACP+.

Importantly, our analyses of the mechanisms of impact also revealed that we might have missed relevant outcomes in our outcome evaluation. Participants indicated that ACP+ led to a more structured way of working around ACP and an increase in the number of ACP conversations and documentation. They also highlighted that there was increased awareness throughout the nursing home about the need for ACP, and the increase in staff and volunteers passing on signals of residents to the ACP reference persons. An outcome focusing more on this awareness, as was done in recent community research in Australia[24] and Canada[25], might have led to other effectiveness results.

Lastly, some important contextual factors hampered the optimal implementation of the intervention in all nursing homes. These were related to staff availability (especially during the summertime), time and resources, and workforce challenges -which are well-known barriers in the nursing home context[6,26,27]-and led mainly to the adaptation of the training sessions for ACP conversations facilitators and ACP antennas. However, despite these time-related issues, some components were added to the intervention, such as meetings between all ACP reference persons. This suggests that ACP reference persons were allowed to spend time to implement ACP+ -in line with our Theory of Change precondition[2]- but all other staff were insufficiently involved to be able to shape their role in the ACP+ intervention, herewith undermining the whole-setting approach.

Strengths and limitations

A major strength of this study is the extensive data collection procedure with both qualitative and quantitative measures, based on the underlying Theory of Change map[2] and the UK MRC framework for complex interventions[9], leading to a broad overview of factors and themes hindering or facilitating implementation processes. Furthermore, data collection running alongside the intervention, and not only post-hoc, led to less recall bias and strengthened the insights gained.

A limitation is the inclusion of only those who participated in (at least one) ACP+ training and the large amount of ACP reference persons in our sample. Herewith we could have created a selection bias, leading to an overly positive evaluation of ACP+. Another limitation is that the qualitative data was collected, analyzed and interpreted by the same researchers as those developing the ACP+ intervention. Social desirability bias might have influenced the responses of participants, even though researchers emphasized the need to identify both barriers and facilitators and prompted the participants to speak about difficulties along the implementation trajectory.

Recommendations

Based on these results, we propose a longer implementation or consolidation period when implementing ACP. This will provide chances for ACP reference persons to gain experience with ACP conversations on-the-job and to grow in their role as trainers. This might consequently lead to a higher reach of staff with training sessions and a more thorough adoption of the whole-setting approach. Such a recommendation is also consistent with a recent European position paper highlighting the importance of building confidence through on-the-job training, in order to effectively implement palliative care practices[23] and stressing the need for the ongoing support of staff to sustain positive effects of educational interventions. As such, this recommendation is supported by several learning and social theories[18,20–22]. We also recommend, for future studies, to integrate these existing theories better into the Theory of Change underling the intervention[2].

Another recommendation concerns the need for long-term structural investments in the nursing home sector in many countries[28,29]. The contextual factors we found to hinder implementation are those that are often outside of the control of an intervention, e.g., workforce and time constraints. They underline that adequate staffing and resources for nursing homes might be essential before new quality improvement initiatives can be implemented.

Finally, further research is urgently needed for the selection of the appropriate outcomes to comprehensively evaluate ACP interventions. In addition, valid and reliable instruments to measure these outcomes need to be developed. In this process evaluation, we learned that, despite the thorough development, the proposed outcome measures might not have captured the created change entirely.

Conclusion

Overall, ACP+ was well-received among participating nursing home staff and management. They highlighted positive effects of the intervention which were not reflected in the RCT analyses, such as an increase in awareness about the importance of ACP throughout the nursing home. Probably, the trial effects can be explained by the low to moderate reach of the staff with the provided trainings, too few on-the-job learning opportunities for all staff and contextual difficulties undermining the whole-setting approach. Adaptations to the ACP+ intervention, its evaluation and its theoretical framework are proposed to optimize future interventions and research concerning ACP training in nursing homes.

Acknowledgments: The research team would like to thank all nursing home managers and staff for participating in this study, as well as Katrien Cordemans and Harry Sorgeloos. We additionally thank the experts who were involved in the development of the ACP+ intervention; Liesbeth Van Humbeeck (UZ Gent) for review of intervention materials; Naomi Dhollander (UGent), Marc Tange (UZ Gent), Kristel Paque (VUB), Charless Dupont (VUB) and Laura Neirinck (GP) for the pre-testing of our questionnaires, Prof. Herman Nys (KU Leuven) for checking that our questionnaire accurately represents Belgian medical law, Zorgnet-Icuro, Ferubel, VLOZO/FOS and VVSG, Flanders Centre for expertise in Dementia, DeMens.Nu and the Flemish Palliative Care Federation for their support in recruiting nursing homes into our study.

Funding: The study was funded by the Research Foundation-Flanders (FWO) and the Interdisciplinary Network for Dementia Using Current Technology (INDUCT, EU Horizon 2020). LP is a Postdoctoral Fellow of the Research Foundation-Flanders (FWO; 2017-2020). The funders have no role in the design of the study and collection, analysis, and interpretation of data, in writing the manuscript, or in the decision to submit the manuscript for publication.

Author contributions: Study conception: LVdB, LP, JG, AW-vD, LD, RVS, CG; data acquisition: JG, AW-vD; data analysis: AW-vD, JG; data interpretation: all authors; drafting of manuscript: AW-vD, JG, LP, LVdB; revising manuscript critically for important intellectual content: all authors; final approval of the version to be published: all authors. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflict of interest: The authors have no conflict of interest.

Data availability: Data will be made available for non-commercial research purposes upon reasonable request to the authors (LVdB).

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Table 1. Participant characteristics (N=32)

Demographics	n	(%)
Age		
less than 35	3	9%
35 - 50	21	66%
50+	8	25%
Gender, *female*	26	81%
Professional background		
Nursing home manager	4	13%
Head nurse	2	6%
Nurse	13	41%
Allied health staff[a]	4	13%
Support staff	4	13%
Care assistant	2	6%
Head care	3	9%
Role in ACP+ intervention, *n*		
ACP+ Trainer	2	6%
ACP Reference Person	21	66%
ACP Antenna	6	19%
Manager (no role in ACP+)	3	9%

ACP advance care planning

[a] Allied health staff includes social worker, two physical therapists and a chaplai

Table 2. Implementation (dose, reach and fidelity) of ACP+ in intervention nursing homes

Dimension	Indicator	NH 1	NH 2	NH 3	NH 4	NH 5	NH 6	NH 7	Weighted average across NHs[a]	Median across NHs
OVERALL	**Overall implementation score** given by trainers (score ranges from 1 to 10, with 10 resembling the highest score)	9,5	6,5	7,5	4,5	6,5	8,5	8	**7,3**	**7,5**
DOSE & REACH	**Median duration of each visit spent by trainer on actual ACP+ delivery on site** (hours)	2-5	5-10	5-10	2-5	2-5	2-5	2-5	**/**	**2-5 hrs.**
	Number of times the trainer visited the nursing home on site (in a total of 23 weeks)	7	11	17	14	12	8	11	**11,4**	**11**
	Number of times trainer provided consultation via telephone (at least 30 min, in 23 weeks)	1	1	1	8	1	1	4	**2,4**	**1**
	Proportion of nursing home residents with up-to-date end-of-life care plan at end of implementation period (%)	65	49	65	NA	77	60	85	**59,5%**	**65%**
	Proportion of nursing home residents with advance directive at end of implementation period (%)	13	27	NA	NA	7	64	80	**27,9%**	**27%**
	Proportion of ACP reference persons trained (number of ACP reference persons attending two-day training/total number of reference persons assigned) (%)	100	100	100	100	100	100	100	**100%**	**100%**
	Proportion of ACP reference persons attending comeback seminar (number of ACP reference persons attended 'comeback seminar'/total number of reference persons assigned) (%)	100	100	86	20	100	100	100	**84,4%**	**100%**
	Proportion of nursing home staff trained to perform conversations or recognize signals of ACP[b] (attendance rate of nursing home staff during in-house training sessions (for ACP conversation facilitators and ACP antennas)/ total number of nursing home staff that would be eligible for training) (%)	25	69	60	15	6	23	22	**33,3%**	**23%**
	Proportion of GPs informed about ACP (number of GPs informed/total number of GPs at baseline) (%)	50	39	NA	6	0	NA	16	**12,0%**	**16%**
FIDELITY	**Number of activities delivered as intended** out of total activities (n=17)[c]	14	15	16	14	14	15	13	**14,4**	**14**
	Score of quality of in-house training sessions provided by trainer (range: min-max) (score ranges from 1 to 4, with 4 indicating the highest score)	3,83 (2,75-4)	3,33 (2,5-4)	3,67 (2,83-4)	3,67 (2,83-4)	3,25 (3-3,83)	3,6 (2,83-4)	3,67 (3-4)	**3,5**	**3,7** **(2,50 - 4)**
	Score of trainer competencies for each in-house training provided by trainer (range: min-max) (score ranges from 1 to 4, with 4 indicating the highest score)	4 (3-4)	3,88 (2,5-4)	4 (3-4)	3,5 (3-4)	3,75 (3-4)	4 (2,75-4)	4 (3-4)	**3,9**	**4** **(2,50 - 4)**

ACP advance care planning; NH nursing home; NA no data available/not reported by the nursing home; GP general practitioner

[a] Weighted for sample size.

[b] This includes both care staff (e.g. nurse, care assistants, physical therapists, social workers) and support staff (eg. administrative, technical and cleaning staff).

[c] Determined by researchers after analysis of qualitative data (interviews and focus groups), compared to intervention protocol[7]. Excluded activities were; GP information session (n=1), training for ACP conversation facilitators (n=1), specialization session ‘dementia’ (n=5), specialization session ‘communication with other healthcare professionals’ (n=5), audit (n=5), multidisciplinary meetings (n=1).

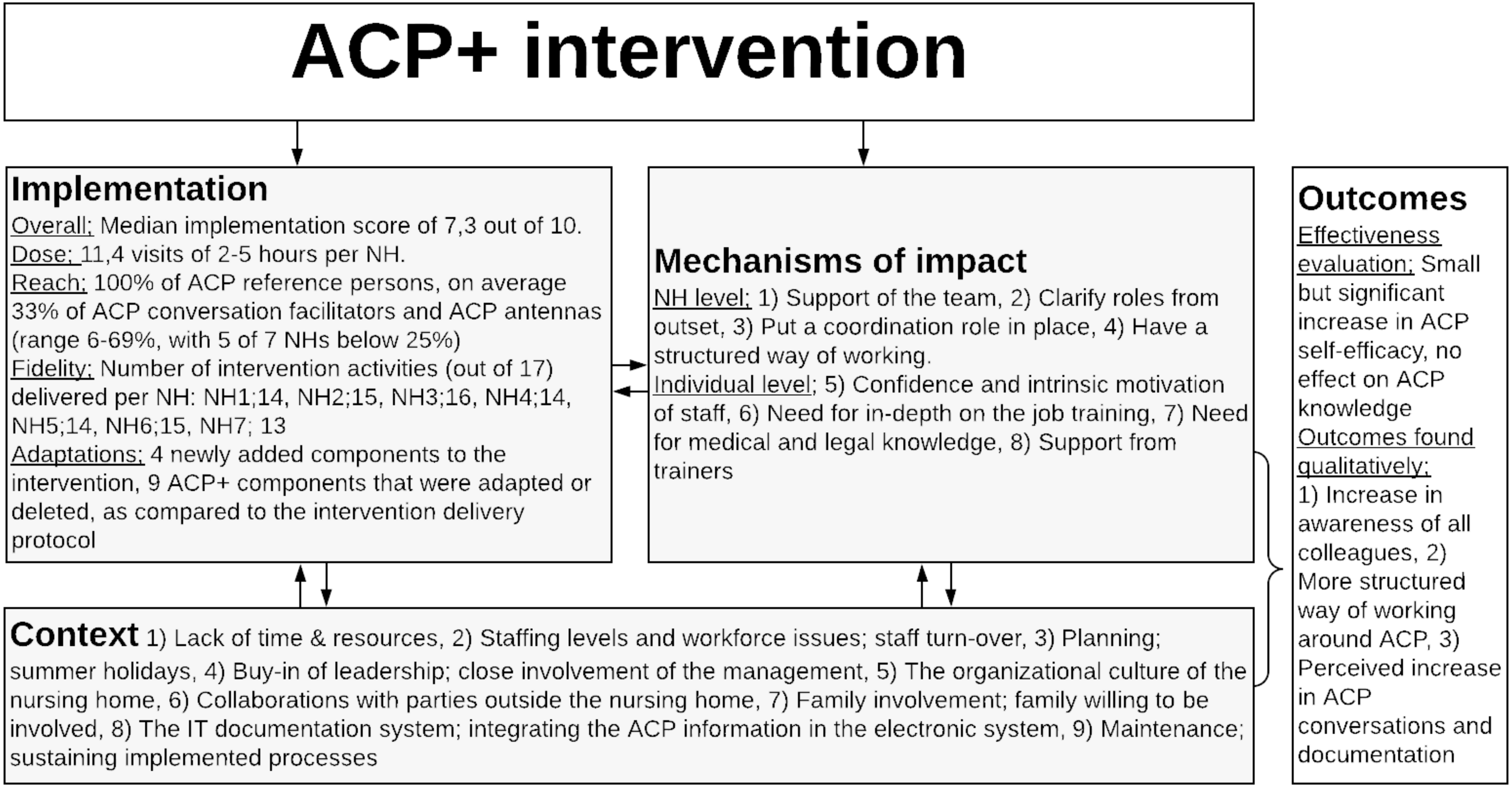
Table 3. Most important adaptations made to the ACP+ intervention components during implementation

Intervention component	Removed, added or changed, n (number of Nursing Homes (NH))	Description of adaptation, including general reasoning behind change
A. Newly added components to the intervention		
1. **Meeting between coordinating advisory physician and the trainer**	Added by 1 NH	Extra meeting with the coordinating advisory physician to facilitate buy-in
2. **ACP working group** with all ACP Reference Persons	Added by 4 NH	Several nursing homes put in place specific 'ACP working group', which mostly comprised the ACP Reference Persons and - if available - head care or coordinator, to facilitate collaboration between the ACP reference persons (and the management)
3. ACP **coordinator**	Added by 4 NH	The role of coordinator was added to streamline the implementation and engage in the practical side of organization of different components, including organizing trainings (e.g. send out invitations, facilities, logistics) and ACP conversations (eg. inviting families, arranging private space)
4. Development of an **ACP protocol** that describes a structured way of working	Added by *all NH*	Composing a protocol was not an intervention activity, however all NHs did this to facilitate sustainability. In this protocol they outlined procedures about: 1) with whom and when ACP conversations would be organized; 2) how ACP conversations were to be planned and who would be responsible; 3) how to document ACP conversations, and where; 4) how to communicate ACP outcomes to other involved staff (GPs, internally and externally); 5) how to continue training and educating new staff
B. ACP+ components that were adapted or deleted, as compared to the intervention delivery protocol		
1. Training for ACP Reference Persons	Adapted by 1 NH	New ACP reference persons were appointed and trained separately by the trainer, due to staff turn-over
2. Training for staff, including cleaning, technical and administrative staff and volunteers, either to become 'ACP conversation facilitators' i.e. have ACP conversations with residents, or 'ACP antennas', i.e. to be able to recognize signals that function as triggers to engage in ACP conversations.	Adapted by *all NH* Removed by 1 NH	*Adapted:* - A separate training was not feasible due to busy work schemes, so information was provided via leaflets/posters and/or during existing work meetings and/or Facebook group - The training was integrated in a large monthly meeting in which the nursing home (NH1) chose to inform all staff (including non-care staff) about ACP and signals for ACP, instead of training - In one nursing home (NH7), non-care staff were not informed because of "language and culture barriers". - In one nursing home (NH1), volunteers were invited to the info session of family instead of staff, given the volunteers were most often also family members; in another (NH2), this resulted in a separate session for volunteers - In one nursing home (NH3) training sessions were organized per ward instead of across wards, due to differences in wards in the NH *Removed*: In one nursing home (NH4) training conversation facilitators was not done, due to lack of staff able to take-up this role

3.	Audit to formally monitor ACP organization and procedures	Adapted by 1 NH Removed by 5 NH	*Adapted:* ACP audit papers were integrated in existing audit of the NH *Removed:* Not perceived as useful directly after the intervention
4.	Information session for involved GPs	Adapted by 1 NH Removed by 1 NH	*Adapted:* The coordinating advisory physician discussed the ACP project with GPs via telephone due to low attendance rates *Removed:* Coordinating advisory physician is GP of most residents and the work-relation between the GPs and the NH is troubled
5.	Discussing ACP in team meetings, instead of multidisciplinary meetings	Adapted by 4 NH	Instead of organizing separate multidisciplinary meetings, ACP was discussed during existing meetings
6.	Information session for residents to inform about ACP	Adapted by 3 NH	Residents were most often divided in two groups of which those who were still mentally competent were informed via leaflets and posters and/or resident-newspaper and/or combined with information session for family; while those who had cognitive impairment or hearing problems were informed individually and/or in small group sessions (e.g. two nursing homes integrated this in an interactive animator session)
7.	Specialization sessions about dementia and communication with other involved healthcare workers	Adapted by 4 NH Removed by 3 NH	*Adapted: T*he trainers integrated the information in other training (e.g. training for conversation facilitators) or coaching sessions; or combined both specialization session about dementia and communication with external partners in one session (given on several occasions with different small groups) due to too many training sessions in a short period of time *Removed:* This intervention component was not organized due to lack of time
8.	Availability of one-to-one coaching between trainer and nursing home staff	Adapted by 4 NH	Most nursing homes conducted group coaching in sessions or meetings because coaching in group was found to be more feasible within work schedules
9.	ACP+ document to register wishes and preferences of nursing home residents	Adapted by 4 NH	ACP+ document was found to be too extensive or was found redundant because the nursing home had their own. Several nursing homes combined the ACP+ document with the document which was already available in the nursing home.

ACP advance care planning; GP general practitioner

Figure 1. Results related to implementation, responses & interactions (mechanisms of impact) and context of the ACP+ intervention



ACP+ intervention

Implementation
Overall; Median implementation score of 7,3 out of 10.
Dose; 11,4 visits of 2-5 hours per NH.
Reach; 100% of ACP reference persons, on average 33% of ACP conversation facilitators and ACP antennas (range 6-69%, with 5 of 7 NHs below 25%)
Fidelity; Number of intervention activities (out of 17) delivered per NH: NH1;14, NH2;15, NH3;16, NH4;14, NH5;14, NH6;15, NH7; 13
Adaptations; 4 newly added components to the intervention, 9 ACP+ components that were adapted or deleted, as compared to the intervention delivery protocol

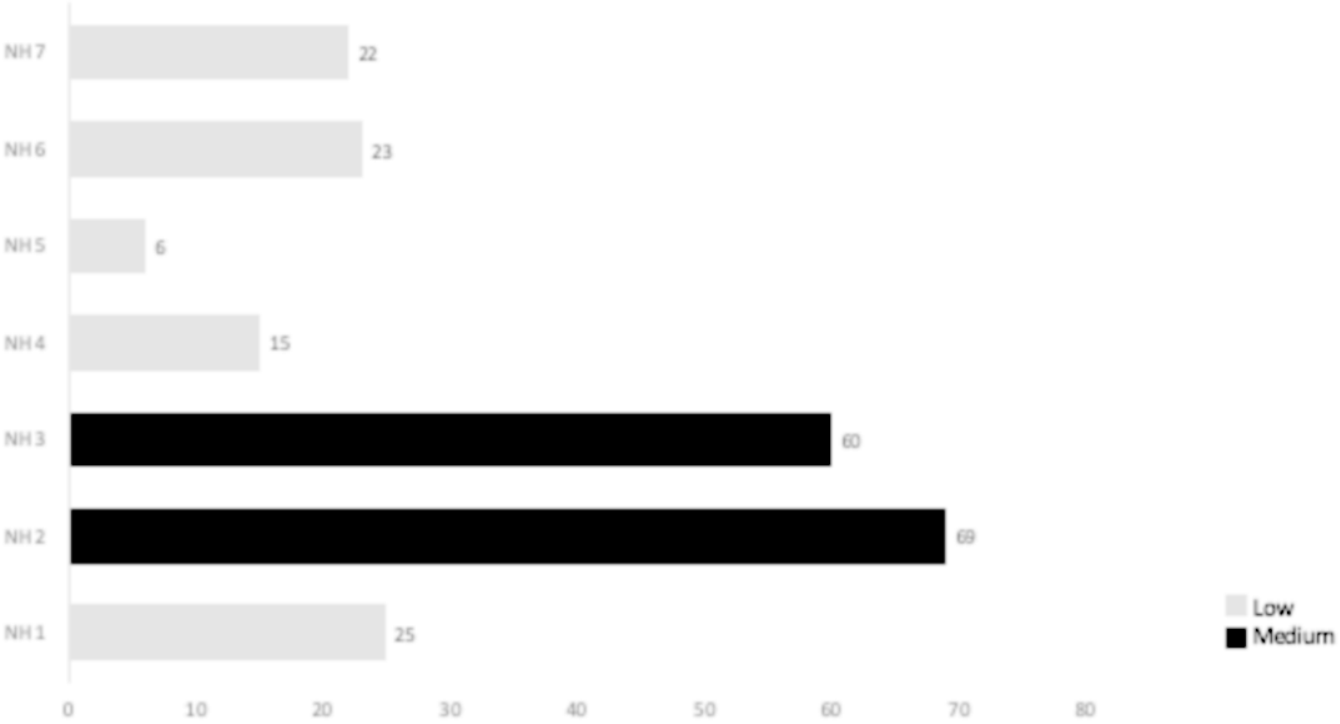
Mechanisms of impact
NH level; 1) Support of the team, 2) Clarify roles from outset, 3) Put a coordination role in place, 4) Have a structured way of working.
Individual level; 5) Confidence and intrinsic motivation of staff, 6) Need for in-depth on the job training, 7) Need for medical and legal knowledge, 8) Support from trainers

Outcomes
Effectiveness evaluation; Small but significant increase in ACP self-efficacy, no effect on ACP knowledge
Outcomes found qualitatively;
1) Increase in awareness of all colleagues, 2) More structured way of working around ACP, 3) Perceived increase in ACP conversations and documentation

Context 1) Lack of time & resources, 2) Staffing levels and workforce issues; staff turn-over, 3) Planning; summer holidays, 4) Buy-in of leadership; close involvement of the management, 5) The organizational culture of the nursing home, 6) Collaborations with parties outside the nursing home, 7) Family involvement; family willing to be involved, 8) The IT documentation system; integrating the ACP information in the electronic system, 9) Maintenance; sustaining implemented processes

ACP; Advance care planning, NH; Nursing home

Figure 2. Level of reach of nursing home staff (ACP conversation facilitators and ACP antennas) trained as part of ACP+ intervention per nursing home



Percentage of nursing home staff trained as ACP conversation facilitator or ACP antenna per nursing home (< 30% = low; 30–69% = medium; ≥ 70% = high)[30]; based on the number of staff that engaged in in-house training out of all staff that would have been eligible to participate in the trainings (e.g. Dutch-speaking).

Table 1e. Number of ACP reference persons* per nursing home with particular function

	NH 1	NH 2	NH 3	NH 4	NH 5	NH 6	NH 7
Total	4	4	7	5	5	3	4
Physical therapist						1	
Palliative care reference person^	1			1		3	
Nurse	2	3	4	1	1	2	2
Care assistant							2
Occupational therapist	1		1	1			
Head nurse	1		2	3	3		
Chaplain					1		
Social worker		1					

NH nursing home, ACP advance care planning

*ACP reference person is a member of the nursing home care staff responsible for implementing ongoing ACP within the nursing home.

^Palliative care reference persons are mostly nurses. Hence, this counts double.

Table 2e. Operationalization and indicators for all process evaluation components according to Moore et al. [9]

Dimension	Operationalization			Method used
	Quantitative, per NH	Quantitative, across NHs	Qualitative, across NHs	
1. IMPLEMENTATION **What is implemented and how**				
1.1. **How delivery is achieved** Structure, resources and mechanisms through which delivery is achieved	--	Time spend by trainer in nursing home to deliver intervention Overall implementation score	Implementation process of all ACP+ activities	1. Structured weekly diaries for trainers 2. Interview trainers 3. Post-intervention interviews and focus groups
1.2. **What is delivered** The quantity and quality of what is delivered				
1.2.a. Dose How much intervention is delivered	Number and type of intervention activities delivered	--	--	1. Structured weekly diaries for trainers 2. Interview trainers 3. Post-intervention interviews and focus groups
1.2.b. Reach The extent to which a target audience comes into contact with the intervention	- Proportion of staff trained - Proportion of GPs informed - Proportion of volunteers informed - Proportion of nursing home residents with up-to-date end-of-life care plan at end of implementation period	--	--	1. Proof of participation documents that were sent out to all staff that attended the training session & attendance lists 2. Intermediate reports from trainers 3. Post-intervention interviews and focus groups 4. Post-training surveys 5. Post-intervention facility level data questionnaire to be filled out by manager
1.2.c. Fidelity The consistency of what is implemented with the planned intervention	Number of activities delivered as intended	- Content and quality of training sessions - Quality of trainer competencies	--	1. Post-intervention interviews and focus groups 2. Interview trainers 3. Post-training surveys 4. Observation training sessions by researchers
1.2.d. Adaptations Alterations made to the intervention in order to achieve better contextual fit	--	--	- Type of adaptations made to activities of the ACP+ intervention - Reasons behind adaptations made	1. Post-intervention interviews and focus groups 2. Interview trainers
2. MECHANISMS OF IMPACT **The intermediate mechanisms through which intervention activities produce intended (or unintended) effects**				
2.1. Responses and interactions How participants interact with the intervention	--	-	Staff and management experiences with the ACP+ intervention and activities	1. Post-intervention interviews and focus groups 2. Interview trainers
2.1. Mediators & unanticipated pathways or consequences			Observed changes due to ACP+ intervention	1. Post-intervention interviews and focus groups 2. Interview trainers

Intermediate processes which explain subsequent changes in outcomes				
3. CONTEXT **Factors external to the intervention which may influence its implementation, or whether its mechanisms of impact act as intended**				
3.1 Context	--	--	- Factors external to ACP+ that inhibit/challenge organization/implementation ACP in the nursing home - Factors external to ACP+ that inhibit/challenge sustainability and outcomes (knowledge, attitudes, self-efficacy and practice) of ACP+	1. Post-intervention interviews and focus groups 2. Interview trainers
3.2 Intention for maintenance Extent to which the intervention is intended to be part of routine organizational practice and policy	--	Number of nursing homes that created a protocol*	Organizational intention for long- term implementation of ACP activities Recommendations for improving sustainability	1. Post-intervention interviews and focus groups 2. Interview trainers

ACP advance care planning; NH nursing home
*Structured guidelines describing how ACP should be practiced within the nursing home, to create a uniform way of working

Appendix 3e. Topic list interviews with staff and management of intervention nursing homes

General question

1) Could you please describe your own role in implementing the ACP+ program?

Implementation

The interviewer and interviewee can go over all the activities that took place within the ACP+ program. This will refresh the interviewees' memory.

1) Did you have to adjust or tailor some of the activities, to make them suitable for your nursing home? If so, how did you adjust the activities? (please consider duration, timing, location, content, participants etc.)

Mechanisms of impact

1) In general, what was your experience with the ACP+ program?
2) What did you think about the activities that where organized within the ACP+ program?
3) Which of the activities were perceived to be…
    …useful to execute in daily practice?
    …hard to execute in daily practice?
    …unnecessary to execute in daily practice?
4) Did the ACP+ program lead to change in your nursing home and the way ACP is organized?
5) Did the ACP+ program lead to changes in the ways of working? If so, what has changed? If not, what could be the reason for this?
    - Did 'the willingness of the management' play a role in this?
    - Did 'the trainer' play a role in this?
    - Did 'having a policy' play a role in this?
    - Did 'having had training' play a role in this?
    - Did 'involving other staff than care staff' play a role in this?
    - Did 'information sessions for residents, family, general practitioners and volunteers' play a role in this?
6) Did the ACP+ program meet your expectations? Why or why not?
7) Did anything go differently than expected? Are there things that went wrong?

Context

1) Which factors would have helped to execute the ACP+ program? What are factors that make it difficult to implement or organize the ACP+ program?
2) Can you tell me if factors like; the change of staff, leadership, having a policy about ACP or other things, influenced implementation of the ACP+ program?
3) Are you still working according to the ACP+ program? Why or why not?
4) Would you like to continue with the ACP+ program? Which components would you like to keep?
5) Are there any plans made to continue with the ACP+ program?

Closing

Is there anything you would like to add or discuss more in-depth?

Table 4e. Quotes of the qualitative data analysis regarding mechanisms of impact and context

Theme	Quote	Respondent
Mechanisms of impact		
Confidence and intrinsic motivation of staff	*Motivation was always there I think. People want to deliver good care. What I noticed, right from the start, is that you don't need to convince people of the need of ACP. […] they feel the need of the residents, families, they are mainly very happy they received some tools and some theory.'*	ACP trainer
	'Well, even the normal ACP conversation is hard for many people. And actually, only after that, you can explain the theory of all the choices people can make and also patient rights and regulations needed to be explained more. For example, filling out a do-not-resuscitate order, you can have a wonderful conversation with a resident, but if you do not know which boxes to tick on the legal files, your document is worth nothing'	ACP reference person, NH1
In-depth 'on-the-job' training	*'I am a nurse, but I did not have the feeling of knowing everything. So, I wanted to conduct some ACP conversations first, before I could train others'*	ACP reference person NH2
	'It [..] was mainly by conducting the ACP conversations that I gained confidence'	ACP reference person, NH4
Need for medical and legal knowledge	*'Interviewer: 'so what you are saying is that medical knowledge is very essential?' Reference person: 'Yes, absolutely, absolutely.'*	ACP reference person NH2
Support from the trainers	*'His enthusiasm, his education as a nurse, but mainly his excellent knowledge of the law of euthanasia, of proxy-decision makers, and his examples from the […] nursing home work field, and also the way he transferred all his knowledge to us. It was all very helpful for me.'*	ACP reference person, NH2
Clarifying roles from the outset	*'It is a feeling of being allowed to take up these issues when they occur […]. The fact that ACP automatically integrates within the care is being perceived as very positive.'*	Management, NH6
Coordinating role	*'It is the go-to person in the nursing home, the one to contact when a meeting needs to be scheduled'*	ACP trainer
Support by the team	*'I have to say, some moments to ventilate are very important to have. When you have had a conversation, sometimes that can really stick with you. And especially when you have multiple [ACP] conversations in a short period of time, then it's important to get some feedback and just sit down and share your experiences'*	Reference person, NH1
Structured way of working	*'The director has made a leaflet about ACP years ago, so the nursing home already had a vision around ACP, but taking part in the project really gave us a kick-start to continue and that was very much appreciated'*	ACP reference person, NH5
Influence of ACP+ -Increase in awareness about the importance of ACP of all colleagues	*'Me and my colleagues from the cleaning staff, I think we are much more aware of questions and needs of residents now, […] we have an idea now of how much more in-depth we can speak with a resident'*	ACP antenna, NH2
	Reference person 1: 'I notice, for example, colleagues of the physiotherapy, when I step into their office, they tell me stuff they picked up from their ACP antenna-function. I feel that it is a very spontaneous attitude here within the nursing home. Also, from the cleaning staff, or other paramedics.' Reference person 2:' And from the volunteers as well.'	ACP reference persons, NH5
Influence of ACP+ -More structured way of working around ACP	*'There is more structure with the new protocol, more systematism'*	Management, NH3

	‘We have always delivered best possible care, but now I can state more clearly why I came to discuss these topics with them and why it’s important’	ACP reference persons, NH6
Influence of ACP+ -Increase in ACP conversations and documentation	*‘It [ACP] is more discussed, both with the staff, and with the residents’*	ACP reference person, NH7
Context		
Lack of time and resources	*‘The main stumbling stone was planning the ACP conversations, there is always too little time’*	ACP reference person, NH5
Staff turn-over	*‘Interviewer: ‘Is that [not being able to spend time on ACP] also due to staff turn-over?’* *‘Management: ‘Yes, that really complicates things. You have to ensure the basic care processes, you want enough care staff to be available so you can ensure the quality of the care. When staff leaves and doesn’t return it complicates projects as ACP+’*	Management, NH4
Summer holidays	*‘The timing of activities within the summer holidays was awful’*	ACP reference person, NH7
Close involvement of the management	*‘Interviewer: what makes you so committed?’, Reference person 1: ‘our bosses mostly’. Reference person 2: ‘yes, the support we receive from the management’*	ACP reference person, NH5
Organizational culture of the nursing home	*‘The context starts with the type of manager. The vision of this manager is key in how things are done. They can be supportive or strict, but the good ones let the staff discover their own intrinsic motivation for ACP and ACP+’*	ACP trainer
Collaboration with parties outside the nursing home	*‘ACP reference person: ‘Well you see, here [GP information session] is where the seed for the whole project is planted. If the GP is not on board, and you can only discuss medical stuff with them, but not the real ACP…’ Interviewer: ‘It is interesting you say that, so you mean the GP is essential and the GP should be up-to-date?’ ACP reference person: ‘Not only up-to-date on legislations, but they should participate in the project [ACP+]. It is important they see the bigger picture. And the CAP can play a very important role in that.’*	ACP reference person, NH1
Family willing to be involved in ACP	*‘You have to be sensitive to the issues that are happening within the family and hope they are open to have a conversation’*	ACP reference person NH3
Integrating the ACP information in electronic systems	*‘We are still working on making it [ICT system] as practical as possible, so we do not have to do the work twice, once on paper and once on the computer, that is just waste of time’*	Management, NH4
Sustaining the implemented processes	*‘I think, if we really want to be the project to be sustainable, that we need to continue the training for new staff and also actively remind current staff, otherwise the knowledge will disappear’*	Management, NH3
	‘Once the trainer is gone and the project finishes, the palliative care working group will take over to sustain the changes within the nursing home’	ACP reference person, NH7

ACP advance care planning; GP general practitioner; CAP coordinating advising physician; NH nursing home

PART 4; GENERAL DISCUSSION

4.1 Main findings

The research aims of this dissertation were two-fold: 1) to describe the current evidence concerning ACP for people living with dementia and to examine to what extent ACP and end-of-life decision-making have changed over time among people with dementia, and 2) to evaluate the ACP+ intervention, an intervention program to improve the implementation of ACP in nursing homes in Flanders.

To identify and summarize the evidence on how ACP is conceptualized by and for people with dementia, the effectiveness of ACP for people with dementia, and the experiences and views of ACP of people with dementia, their families and professionals, we undertook an umbrella review of which the results were described in Chapter 2.1. We searched electronic databases for quantitative and qualitative reviews evaluating this. Additional searches were conducted to identify recent primary studies not included in the reviews, to get a comprehensive overview of all existing evidence. We found evidence that ACP is acceptable for people with dementia and their families and could be associated with improved outcomes, for example, increased concordance between subsequent care and stated wishes, decreased hospitalization use and an increase in ACP documentation. However, our results suggested that there is a need for guidelines on which outcomes and which definition of ACP to use, as well as research to test different approaches to ACP. Additionally, we suggested that education on topics related to a diminishing decision-making capacity is key to optimizing ACP for people with dementia and their families.

In Chapter 2.2 and Chapter 2.3, we used mortality follow-back studies as research designs. In Chapter 2.2, we focused on end-of-life decision-making for people with dementia between 1998 and 2013 showing that ELDs were prevalent for people dying of dementia and varied little over the years. In 1998 for 52% of people dying of dementia and ELD was made, in 2007 for 54%, and in 2013 for 57%. Almost all people with dementia were judged by the physician as lacking the decision-making capacity (1998: 96%; 2007: 100%; 2013: 96%). This could be the main reason why other parties played an important role in discussing ELDs. About one in 10 patients in our samples were involved in these decisions, without significant differences between the years. In 1998 the ELD was discussed with 10% of the people dying of dementia, in 2007 with 3%, and in 2013 with 9%. Importantly, this research showed that family, rather than nurses or colleague physicians, were increasingly involved in the discussion regarding end-of-life decision-making, with significantly increased involvement of family found between 1998 and 2013 (12% vs 67%; $P < .001$).

In Chapter 2.3, we examined changes between 2010 and 2015 in verbal and written ACP and end-of-life care planning in nursing homes in a sample of deceased nursing home residents with dementia in Flanders. Although the use of general end-of-life care planning in the form of GP orders did not change between the years (58% vs 62%), residents who had expressed preferences concerning end-of-life treatments increased from 8% in 2010 to 19% in 2015 (adjusted odds ratio (OR) 2.80, 95% confidence interval (CI) 1.18 to 6.67). The appointment of a proxy decision-maker increased from 5% to 32% (adjusted OR 7.34, 95% CI 3.16 to 17.70). Having a written advance directive increased from 13% to 41% (adjusted OR 4.35, 95% CI 2.44 to 7.75) in this population. However, despite this growth in verbal and written ACP, the majority of people living with dementia in nursing homes still did not participate in conversations about their preferences for end-of-life treatments.

As the current state of the art shows the need to better embed ACP in nursing home practice, a second part of this dissertation investigated whether a comprehensive training intervention (ACP+) could achieve this. Using a cluster randomized controlled trial with an embedded process evaluation we aimed to evaluate the effectiveness of the ACP+ intervention on the knowledge, self-efficacy and self-reported ACP communication and documentation of the nursing home care staff (Chapter 3.2) and the implementation, mechanisms of impact and the context of the ACP+ intervention in nursing homes in Flanders (Chapter 3.3). The ACP+ intervention is a multicomponent intervention aimed at training and supporting the staff with the implementation of ACP into daily care, with the help of an external trainer for eight months. It was developed via an extensive and participatory development including the development of a Theory of Change highlighting how the intervention was supposed to work in practice[1–4]. In Chapter 3.1 the main tools that were developed for the ACP+ intervention are described, aiming to be of use for future research and in clinical practice in nursing homes.

Collecting data from 14 nursing homes in Flanders, Belgium, we found that the ACP+ intervention significantly improved the nursing home staff's self-efficacy, albeit to a small to medium extent (baseline-adjusted mean difference 0.57; 95% CI 0.20 to 0.94; p=0.003). ACP staff knowledge (95% CI, 0.95 to 1.15; p=0.339; ratio: 1.04) and staff-reported ACP communication and documentation did not differ significantly post-intervention between intervention and control group (0.88 to 2.46; p=0.145; ratio 1.47) (Chapter 3.2). Due to the corrections for multiple primary outcomes, we can claim the superiority of the ACP+ intervention over care as usual, but the effects are less than expected, especially considering the extensive training approach, backed up by thorough and theory-based intervention development.

The process evaluation described in Chapter 3.3 provided insight into the implementation, the mechanisms of impact and contextual factors and helped to explain these intervention effects. Overall, the ACP+ intervention was well received according to the participants. On average, overall implementation was rated by the trainers 7.3 on a scale from 1-10, with higher scores indicating better implementation. Participants perceived the ACP+ intervention to have led to increased awareness about the importance of ACP throughout the nursing home. Moreover, they perceived the ACP+ intervention led to more structured ACP procedures and increased engagement in ACP conversations and documentation. However, only about 33% of the staff was trained across nursing homes (low to moderate reach), with 5 of the 7 intervention homes reporting even lower numbers of the staff reached. Furthermore, insufficient on-the-job learning opportunities and contextual difficulties were apparent.

4.2 Methodological considerations

Several methods and study designs were used to answer the research questions in this dissertation, each having their own strengths and limitations.

4.2.1 Umbrella review

To identify and summarize the evidence of ACP on dementia (Objective 1), we carried out an umbrella review[5], i.e. an overview of existing systematic reviews[6]. In order to do this, a search strategy was developed for PubMed and adapted to the other electronic databases (CINAHL Plus, SCOPUS, Social Care Online and The Cochrane Library (CDSR & DARE)). Additionally, we checked reference lists, performed lateral searches and contacted experts within the field. Moreover, we searched for recent primary studies on ACP for people with dementia that were not included in any of the reviews. This comprehensive approach is one of the strengths of this study. To add to this, the qualitative line-by-line coding to understand the views of people, included both the results and the discussion section of the included articles. Moreover, the combination of qualitative and quantitative research methods within this study has likely contributed to a stronger validation of the results, so-called data triangulation[7]. Another strength is that we published the protocol of our study in The International Prospective Register of Systematic Reviews (PROSPERO), which enhances the transparency of systematic reviews[8].

A limitation is the wide range of outcome measures found in the included studies, which leads to a lack of strong evidence on the effectiveness of ACP for people with dementia. Some outcome measures, however, were found in multiple studies, increasing the likelihood of the impact of these measures. Moreover, it could be argued that, instead of a limitation, this could be considered a key finding of the study, providing insight in the difficulties of choosing appropriate outcomes and concurrent outcome measures when researching ACP for people with dementia.

Another limitation of the umbrella review is the variable quality of the included studies. Risk of Bias assessment is seen as a key concept for reviews[9], and therefore we assessed this for all included reviews and primary research with the most appropriate tools (e.g., AMSTAR-2[10] for the reviews and the instruments of the Joanna Briggs Institute for the primary research articles[11–13]). However, in our analyses, we also included low-quality studies since we wanted to be as comprehensive as possible.

4.2.2 Mortality follow-back studies – comparing differences between years

To examine whether changes occurred in the frequencies of end-of-life decision-making for people who died of dementia between 1998, 2007 and 2013 (Objective 2), we used mortality follow-back studies based on samples of death certificates from 1998, 2007 and 2013[14]. Using death certificates facilitates rigorous data collection of the entire population, as a population-based sample of deaths can be drawn across care settings and all causes of death[14–16], which is considered a major strength of this study design. Since the used sample was stratified, the inclusion of less prevalent ELDs (e.g., euthanasia)[14] was also ensured. Another strength of this retrospective study design is that it does not create a burden for patients who are very ill, nor attrition nor non-response of the sickest patients[15,17]. Furthermore, the risk of influencing the ELDs is avoided by using this design[14].

However, there are a few limitations to consider. The rigorous procedure, involving a lawyer as an intermediary between responding physicians and researchers, was in place to ensure the anonymity of both the patient and the physician. This prevents social desirability bias, but could potentially increase recall bias, since there was a delay of up to 4 months before the questionnaire reached the physician[14,18]. Another limitation of this study is that no information was collected on the initiation, content and the outcomes of the discussions that took place between the physicians and the patient and/or his/her family[19], which prevents us from knowing what happened precisely and how the decision was ultimately made. Lastly, as dementia might be underreported on death certificates, both as main and contributory causes of death (i.e. dementia was found to appear on only 69% of death certificates of people with Alzheimer's disease)[20], our study might also involve an underestimation of all people dying of dementia.

To examine changes between 2010 and 2015 in verbal and written ACP and end-of-life care planning in nursing homes (Objective 3), we compared data of the Dying Well With Dementia Study (data collected in 2010)[21] and the Palliative Care for Older People (PACE)-study (data collected in 2015)[22]. The first was a cross-sectional study of nursing home residents who died with dementia in nursing homes in Flanders. PACE was a European cross-sectional study of deceased nursing home residents, of which the sample from Flanders was used for this analysis. Both studies used the same designs.

The strengths of this study were the use of validated questionnaires (e.g., Bedford Alzheimer Nursing Severity-Scale [BANS-S][23,24], Cognitive Performance Scale [CPS][25] and Global Deterioration Scale [GDS][26]), which led to a standardized data collection. Furthermore, response rates of the nurses most involved in the care were 88.4% for the data collected in 2010 and 85.1% for the data collected in 2015, which is much higher than the average response rate of health care professionals[27] and exceeds the acceptable minimum standard of 75%[28].

As with any retrospective design, as described above, recall bias cannot be ruled out. In these studies, we tried to minimize this by having a timeframe of a maximum of three months between identifying a nursing home resident's death and providing the staff with the questionnaire, as recommended in other retrospective end-of-life care research[15,17,29–31]. Another limitation was that only two-time points were used to observe changes over time, and the last measurement was in 2015. After 2015, several initiatives have been taken in Flanders to increase the uptake of ACP (e.g., a national campaign about ACP[32]) and these changes might have improved ACP in nursing homes even further. Hence our study results might not show the most up-to-date situation for people living with dementia in nursing homes in Flanders.

4.2.3. Cluster randomized controlled trial with an embedded process evaluation

To evaluate the effects of the ACP+ intervention (Objective 5) and to evaluate the implementation, mechanisms of impact and the context of the ACP+ intervention in nursing homes in Flanders (Objective 6), we carried out a cluster randomized controlled trial in 14 nursing homes with an embedded process evaluation in the seven intervention homes.

Strengths of the intervention include the thorough development, following the UK Medical Research Council (MRC) in their framework for complex interventions and the Theory of Change methodology from Aspen Institute[2,33,34], including a literature review[2], a contextual analysis and the input of experts from the field[1]. These were reported in earlier publications. Additionally, the intervention was examined for feasibility and acceptability in five nursing homes[3]. This led to the expansion of the original program of nine key components to 10 key intervention components, 22 activities and 17 materials to support delivery into routine nursing home care[3]. Next to these strengths, a strength related to the trial design is the pragmatic nature of the cluster-randomized trial we undertook to evaluate the ACP+ intervention. The pragmatic nature is reflected in the possibility for nursing homes to tailor some of the intervention components, in order to fit the intervention to the existing context[35]. For example, ACP+ forms could be adjusted to ACP forms already in use in the nursing home.

Furthermore, there was no attrition in both arms and sufficient statistical power. The embedded process evaluation as recommended by Moore *et al.* is another major strength in our evaluation of the ACP+ intervention as this can provide insight into the implementation process, the mechanisms of impact and the contextual factors behind the found outcomes[36]. The research questions of the process evaluation were developed prospectively[37], allowing us to collect data both during and after intervention implementation, to provide a broad perspective and prevent recall bias.

A major limitation of the trial is not having used validated outcome measures. Since there was a lack of existing validated measurement instruments to assess the primary (ACP self-efficacy and ACP knowledge) and secondary outcomes (self-reported ACP communication and documentation), questionnaires were developed by the research team. Although based upon existing questionnaires[38,39] and tested for reliability (Cronbach's alpha for the scales measuring knowledge, self-efficacy and ACP communication and documentation were 0.72, 0.97 and 0.81, respectively and cognitive testing with six people who have clinical practice experience with older patients[40]) it could be that the instruments were not sensitive enough to detect a change, or that they did not capture the change we intended with our intervention. However, so far there is no consensus on what would be a clinically meaningful change in the outcomes measured[41]. Moreover, we measured the staff's attitudes towards ACP, but we did not include this measure in our analysis, due to poor internal consistency of the scale at baseline.

4.3 Discussion in the context of the current evidence base

In this discussion, the insights gained from this research will be discussed in two cross-cutting themes: i.e. the challenges related to the uptake of ACP for people living with dementia, and the challenge of changing ACP practices in nursing homes.

4.3.1 Challenges in the uptake of ACP for people living with dementia

In Part two of this dissertation, the research related specifically to people living with dementia, we found that, based on a representative sample of deaths due to dementia, a maximum of 10% of people dying of dementia were involved in the decision-making process concerning the ELDs made (Chapter 2.2). Physicians indicated that people with dementia no longer had the decision-making capacity at the time the decision was taken, which inevitably points to the need to discuss wishes and preferences early on, especially for people with dementia. ACP has been highlighted as particularly relevant in dementia. Chapter 2.1 provided an overview of ACP in dementia and showed that, while high-quality evidence is not prevalent, there are clear indications that ACP is feasible in dementia and might lead to increasing concordance between care received and stated wishes, increasing ACP documentation and decreasing hospitalizations. The results of Chapter 2.3 further underline the need for ACP in the nursing home context for people with dementia. These data showed that preferences are increasingly being discussed with people living with dementia in nursing homes (8% in 2010 vs 19% in 2015 among nursing home residents who had died with dementia) but are still relatively low. Interestingly, we also observed an increase in this study of nursing home residents with dementia who had appointed a proxy decision-maker (up to 32% in 2015), findings which are in line with the increase of 55 percentage points of relatives who were involved in the ELDs (12% in 1998 to 67% in 2013) as was found in Chapter 2.2.

From this review and the data collected over the years, we can conclude that ACP is highly relevant for people living with dementia and is practiced more often over the years. However, despite the observed trends of increasing ACP conversations and documentation for people living with dementia, the majority of this population seems not to be involved in decision-making nor in discussions about preferences of care, leaving considerable room for improvement in this population.

Within the international literature, many explanations and barriers have been identified to explain our findings. The uncertainties that people living with dementia and their families experience when making treatment decisions in the context of ACP and end-of-life care[42], especially because people with dementia are planning their care for a future unknown self[43], is one possible explanation why uptake of ACP has been low in this population. Other patient-level barriers hindering the uptake of ACP for people living with dementia, found both in this dissertation (Chapter 2.1) and in other research, are the lack of knowledge about the dementia disease trajectory or about the ACP process[44–51], difficult family dynamics[52] and the fear of the family 'giving up' on their loved one[43]. Several barriers for the uptake and initiation of ACP also relate to the healthcare professionals. For example, healthcare professionals fear causing stress and anxiety[53,54], herewith possibly harming the professional–patient relationship, as patients may feel the healthcare professional is giving up on them by starting a conversation about end-of-life related topics[55]. Moreover, we found (Chapter 2.1) that healthcare professionals struggle with the timing of initiation of ACP, with opinions ranging from having to discuss ACP directly following a dementia diagnosis, to when a serious physical health condition occurs (e.g., pneumonia). Ryan *et al.*[56] describe this struggle very clearly, stating: 'Striking a balance between gaining insight into one's diagnosis of dementia and losing capacity to be involved in the process is at the heart of this challenge'. Lastly, healthcare professionals are unsure whose role it is to initiate ACP

(Chapter 2.1), therewith postponing and sometimes even failing to take up this role themselves. Training and education for healthcare professionals are proposed as a solution to encounter these barriers and increase the uptake of ACP communication and documentation (Chapter 2.1, 2.2) and is the focus of the second part of this discussion, specifically the ACP+ educational intervention we evaluated in nursing homes in Flanders.

4.3.2 Changing ACP practices in nursing homes – a complex intervention in a complex setting

The ACP+ intervention is a multicomponent theory-based intervention program using a whole-setting approach, aimed at training and supporting the nursing home staff with the implementation of ACP into daily nursing home care[1,3,40]. Hence, a complex intervention to change practice in a complex setting. More specifically, a nursing home can be seen as a complex setting, with many interactions between many different players (e.g., management, staff, residents and family). ACP is recognized to be a complex process[57], with many interacting components on multiple levels and not one, but many steps to be achieved and documented, and therefore warrants being evaluated as a complex intervention[33,58–60]. Recent reviews found that the most promising and sustainable ACP interventions target multiple levels (individual, interpersonal, provider, system), with each level and component reinforcing the other, and take into account known barriers to, and facilitators of, uptake[61,62].

Prior to the research described in this dissertation, the ACP+ intervention underwent a thorough developmental process[1,2]. As a first step in evaluating the hypothesized causal pathway (i.e. Theory of Change), we focused on the precondition of the staff being ‘willing and able to engage in ACP’ as the most important aspect to improve, in order to ultimately increase ACP communication and documentation practices with residents[1,4]. We operationalized this precondition as the care staff’s knowledge of ACP and self-efficacy in ACP (i.e. confidence in own ACP skills, such as initiating an ACP conversation).

From February 2018 (recruitment of the nursing homes) to March 2019 (end of the process evaluation data collection) we conducted a multi-facility cluster-randomized controlled trial in Flanders to compare the ACP+ intervention (intervention group) with the usual care (control group)[3,40]. We found the ACP+ intervention leads to a statistically significant -however with a small to medium effect size- improvement in self-efficacy in ACP of the care staff, but no improvements of their ACP knowledge (Chapter 3.2). Moreover, we did not find a significant increase in the care staff’s reports of the extent to which they engaged in ACP communication and documentation in the intervention homes. We hypothesized several potential explanations.

As a first, there could have been a poor match between the intervention and all new skills and knowledge gained by the staff, and the measurement instruments. Since the instruments were not tested for content or construct validity, they might not have captured the change accomplished by the intervention[63].

Second, it could be that the intervention did not leave sufficient time for the staff to internalize all new knowledge and skills, in line with Bandura’s social cognitive theory[64], suggesting that self-efficacy is a first step in the relationship between knowledge and skills, and self-efficacy is influenced by prior experiences[65,66]. A recent white paper on guiding implementation of palliative care improvements in nursing homes also suggested a consolidation phase in addition to an implementation period to increase uptake of the newly gained skills or knowledge[67,68].

A third possible explanation for this could be that we did not pick up on the effects on the outcomes, as these were possibly greatest among the ACP reference persons -since they acted as champions of the intervention in their nursing homes- but we evaluated our outcomes in all groups of care staff (care assistants, allied health staff and nurses) with all types of roles (ACP reference persons, ACP conversation facilitators and ACP antennas).

Our RCT results underline the difficulties of changing ACP practices in the complex setting of nursing homes, as was also found in an earlier review[69]. Using a process-evaluation embedded in the effectiveness evaluation -as was recommended by the UK Medical Research Council[36]- has provided us with some insights into what happened during the implementation of ACP+ concerning implementation, mechanisms of impact and the context (Chapter 3.3). Based on this, we hypothesized several additional explanations for our RCT results. These are further discussed in terms of implementation, mechanisms of impact and outcomes and the context.

Implementation

As a first possible explanation for the smaller than expected results, it could be that the **implementation of the intervention was hampered**. The process evaluation (Chapter 3.3) provided us with insights about the **reach** of the intervention, showing we only reached 33% of the staff on average across nursing homes to receive an ACP training session. This can be linked to the ACP reference persons stating that they needed more time to feel secure about conducting ACP conversations, as well as more time to transferring these newly gained skills to their co-workers, as we used a train-the-trainer methodology and so ACP reference persons were designated to take the lead to implement ACP further throughout their nursing home. In past research in nursing homes, the same model (i.e. train-the-trainer) was used and the ACP intervention was found to lead to improved communication, and family and staff satisfaction as well as reduced staff distress[70]. However, in Chapter 3.3 we found the ACP reference person not feeling fully equipped to organize training sessions, stating they needed more time to prepare for these tasks.

It also might be that there was **insufficient time** for the intervention to be implemented and sustained. This is in line with the statement of Hickman *et al.*[71] that the time- and resource-intensive nature of robust ACP must be anticipated when systematically implementing ACP in nursing homes. In Chapter 3.3, we found that the staff experienced barriers implementing ACP+, due to a lack of time and resources (i.e. workforce) and that these barriers were intensified during the summer holidays. Since the summer holidays (i.e. July and August) account for two out of the eight months of the implementation, the implementation period might have been perceived by the staff as only six months and possibly should have been extended.

Mechanisms of impact and outcomes

In the qualitative part of the process evaluation (Chapter 3.3) we identified eight important mechanisms of impact: four at the micro-level (i.e. need for on-the-job learning opportunities, confidence and motivation, a need for medical and legal knowledge and trainer support) and four at the meso-level (i.e. having a coordinator in place, team support, having a structured way of working and clarifying roles from the outset). Especially, the **presence of the ACP trainer** was identified to be very valuable for the implementation. These trainers had specific knowledge, both in legal and medical aspects, which was perceived as helpful. Moreover, they could coach the team in case they did not know what to do or when the implementation process was overwhelming, herewith supporting the staff to, at least partly, overcome some of the organizational barriers.

Another possible explanation we found in the results of the process evaluation (Chapter 3.3) is that the **outcomes** used in the RCT might not have entirely matched the intervention and were therefore not optimal to detect improvements caused by the intervention[63]. In the interviews and focus groups, we found participants indicating that the ACP+ intervention led to a more structured way of working around ACP and an increase in ACP conversations. The latter was not reflected in our quantitative data, when measuring staffs' self-reported engagement in ACP communication and documentation. However, as we did not use any outcomes on the residential-level and therefore did not measure the number of ACP conversations that had happened per resident, overarching insight into this is currently still lacking.

Additionally, the process evaluation participants highlighted that there was increased awareness throughout the nursing home about the need for ACP, and the increase in the staff and the volunteers passing on signals of residents to the ACP reference persons. If we would have used outcomes focusing more on this awareness, as was done in recent community research in Australia[72] and Canada[73], this might have led to other RCT results. In line with this is a recent review on ACP outcomes, stating a need for appropriate expectations of ACP outcomes, as well as standardized outcomes across studies[74].

Context

A recent review suggested that incorporating an implementation strategy when developing a palliative care intervention for nursing homes is essential[62], suggesting to incorporate the known facilitators of the setting into the intervention. Despite the contextual barriers that were identified in the developmental phase of the ACP+ intervention[1,2], the qualitative results described in Chapter 3.3 are in line with the barriers of the nursing home context identified in many studies, for example, -among others- a lack of time, a lack of financial resources, the competing priorities of the staff, scarce training opportunities, understaffing and high rates of staff turnover and a large proportion of variably skilled staff [2,70,75–79]. In Chapter 3.3, similar barriers were identified, with a lack of time -especially during the summer holidays- named by all participants in the process evaluation. We tried to overcome these barriers, by allowing for the intervention to be -to some extent- **tailored**, meaning several components could be adjusted to fit with existing nursing home structures, or the capabilities of all nursing home staff[35,80,81]. The, presumed, benefit of this is that the implementation process will be easier for the staff in the nursing home since the newly gained knowledge and skills comply with structures with which they are familiar. Moreover, it was found that interventions are most likely to be successful when they make elements of ACP workable within the complex and time-pressured workflows[78]. A major disadvantage is that it compromises the standardization of the intervention, so when applied too rigorously, the intervention implemented in one nursing home will differ greatly from the intervention implemented in another[82], herewith hindering or at least complicating effectiveness evaluations. Despite the tailoring options, however, implementation of ACP+ was suboptimal, for example because we overlooked the summer holidays as an extremely busy period for nursing home care staff. This points to the need of very precise mapping of possible contextual barriers[78].

A facilitating contextual factor, **support of the management,** was identified both in Chapter 3.3 as in other recent studies[39,75,83]. This support was both material (e.g., the manager agreeing with the staff to spend time on this project, or freeing them up for training) as well as immaterial (e.g., supporting staff by recognizing their efforts). Within the ACP+ intervention, this was incorporated into the whole-setting approach we used, aiming to incorporate both the managers as well as the team. More specifically, within ACP+ we applied the whole-setting approach by the **appointment of different roles to the participating staff**: ACP reference persons were trained specifically in ACP and then used their knowledge and skills to train the other staff and implement ACP practice in their nursing home; ACP conversation facilitators worked with ACP reference persons and were responsible for planning and performing planned ACP conversations with residents and family; ACP antennas were responsible for recognizing and signaling 'triggers' that indicate a resident's readiness, need or willingness to engage in ACP. This corresponds to appointing 'champions' to guide the intervention, as has been done by other complex interventions, and was recommended in the literature[84–86]. By doing so, it creates a shared responsibility of all staff for the intervention, making it more likely to be successfully adopted. Nursing home managers were strongly encouraged to participate and had planned meetings with ACP reference persons and the external trainer. A recent Norwegian study using the whole-setting approach to implement ACP in nursing homes found positive effects of their intervention, i.e. more residents participated in ACP conversations[87]. A recent study from The Netherlands found no effect of their ACP intervention and concluded that this was because of the lack of a whole-setting approach, since they targeted both nursing homes and home care[88].

With regard to the ACP+ intervention, as well as ACP interventions in general, many gaps in our knowledge still exist and further steps are warranted. Recommendations about which steps to take next are described in-depth below.

4.4 Recommendations for future research, practice and policy

Our findings suggest that there is room for improvement in the uptake of ACP for people living with dementia in general and for those residing in nursing homes specifically. Based on the studies in this dissertation, there are some important recommendations for future research, practice and policy regarding -adjustments of- the ACP+ intervention, outcome measures, educational strategies, a whole-setting approach and the involvement of trainers.

4.4.1 Recommendation for future research

Despite the findings outlined in this dissertation, many gaps still exist. Since it was not feasible to focus on the entire Theory-of-Change map -with all preconditions, interventions and assumptions[1] related to the ACP+ intervention- we focused on evaluating how the ACP+ intervention changed the nursing home care staff's ACP knowledge and self-efficacy in ACP. However, using this approach means we do not know if and how the ACP+ intervention ultimately benefitted the nursing home residents, or their families, as was the intended long-term outcome identified in the Theory-of-Change map[1]. Additionally, we lack insight into the effectiveness of ACP+ on other involved professional parties, such as the management or the cleaning staff in the nursing home. Since data of these groups have been collected at both time points of the ACP+ trial, we recommend **to analyze and evaluate the effects of ACP+ on other nursing home staff (e.g., cleaning staff)**. Moreover, it is unclear how the ACP+ intervention affected the nursing home volunteers and the GPs who are responsible for the resident's medical care during the last days of life. Their involvement in creating a positive ACP-environment within the nursing home were considered important preconditions of the theoretical framework and the Theory-of-Change map drafted in preparation of the ACP+ program[1]. Therefore, additional data-analysis of the data collected during the ACP+ intervention of these groups would be important too. This was however beyond the scope of this dissertation.

Additionally**, the ACP+ intervention as well as the underlying Theory of Change should be adjusted to the findings of this dissertation**. More concretely, we recommend to either **prolong the implementation period** of ACP+ in the nursing homes, or include a consolidation phase after implementation, to allow the staff to move the lessons learned from intervention to routine practice[62,68]. This extra time may allow the ACP reference persons to gain more experience with ACP conversations with the residents, as well as allowing them to grow into their roles as trainers for their colleagues. Linked to this is the theory of progressive education of Dewey[89] which emphasizes, 'learning by doing' and could be integrated into the underlying Theory of Change as rationale, in order to link as closely as possible to the processes of change going on in the nursing home. The further selection and inclusion of other behavioral change theories could also be considered to further build the Theory of Change and accompanying intervention components, to increase effectiveness and implementation. For example the behavior change framework 'COM-B', which states that behavior is an interplay between capability, motivation and opportunity[90], suggesting that, in order to increase the uptake of ACP conversations, staff should be allowed the necessary time to gradually adopt ACP+ and acquire the necessary skills.

More generally, researchers evaluating interventions to increase the uptake of ACP in nursing homes could benefit greatly from **standardized outcomes, and accompanying reliable and valid instruments should be established on different levels.** Defining the desired outcomes of an ACP intervention beforehand -including establishing a 'ceiling of accountability' (a point after which the intervention can no longer solely be responsible for change)- as proposed by Gilissen, Van den Block and Pivodic[91], would be a valuable first step. Moreover, thorough validation of the questionnaires matched to these outcomes could benefit future research in order to establish reliable and valid outcome measures on the staff-level concerning ACP knowledge, self-efficacy regarding ACP and ACP communication and documentation. Moreover, research in nursing homes could benefit from a consensus on what would be a clinically meaningful change with regard to these outcomes, as such a consensus is currently lacking[41]. On the level of the nursing home residents, it would be interesting to explore what outcomes residents themselves would consider important concerning ACP and to design and/or validate questionnaires related to those outcomes. Ultimately, such a 'core set' of ACP outcomes used throughout the research field would facilitate reviews and meta-reviews evaluating the effectiveness of ACP and provide insight into which ACP interventions could establish change on which outcomes.

4.4.2 Recommendations for practice

Results of this dissertation showed that it is important to let people living with dementia engage in future medical end-of-life decision-making for them and that the process of ACP could be an option for this, since the majority of people living with dementia will not be fully able to participate in the decision-making process when they are near the end of life. However, we identified many barriers on different levels hindering the initiation of ACP conversations. Focusing on clinical practice, we found a lack of knowledge about the dementia disease trajectory and about ACP of people living with dementia, their families and healthcare professionals (Chapter 2.1). Therefore, our first recommendation for practice would be to **educate and train all stakeholders involved in ACP**. The need for education is highlighted by many throughout Europe and Australia, as well as by *Alzheimer's Disease International*[38,54,56,92,93]. Piers *et al.*[44] recently developed guidelines for health care professionals to engage in ACP conversations with people living with dementia, despite the stage of the dementia trajectory they are in, which is considered an important first step in the education of professionals. Moreover, it might be important to specifically provide healthcare professionals with **on-the-job training**, as we did with the ACP+ intervention (Chapter 3.2 and Chapter 3.3). Trained professionals could then educate both people living with dementia and their families.

With regard to implementing the ACP+ intervention in the nursing home, several recommendations can be made, mainly related to the **whole-setting approach** of the intervention. The implementation process will have a higher chance of succeeding when multiple levels (e.g., management, nurses, care staff, volunteers, physicians, families, cleaning or other support staff) are targeted within the nursing home[2,87,94]. Colleagues in the nursing home can provide support when implementing the intervention, creating a positive and open environment to learn and develop new skills and deliver the best care possible. In this way, the intervention can produce a shift in the working culture and attitudes, and deliver sustainable change (Chapter 3.2 and Chapter 3.3). Concretely, **management engagement** should be ensured, meaning commitment of the nursing home management to the project's success will help to ensure that the staff have sufficient time and other resources to participate in the new way of working. An important task would be to **ensure a clear distinction of the roles and responsibilities of the staff.** This helps for every staff member to know exactly what is expected of him/her and for colleagues, not directly involved in the intervention, to know what they can ask and expect of the staff involved in the implementation. Moreover, the nursing home management can then determine how much time would be needed for the staff to implement the intervention in an appropriate manner (Chapter 3.3).

4.4.3 Policy recommendations

A major barrier for the uptake of ACP in nursing homes is the lack of time and resources, as was found during the development of the ACP+ intervention in Flanders[2,3], as well as in many other ACP studies throughout the world[2,70,75–78,95,96]. Moreover, the same barriers of understaffing, high staff turnover and a lack of time were mentioned by the participants in the process evaluation (Chapter 3.3). To overcome this, **structural changes in the organization of the nursing homes and the financing of the nursing home sector are necessary.** As a first step, the Belgian federal government is currently developing a reimbursement rule for the time spent on ACP for physicians, as was suggested in some research from The Netherlands[97]. However, since ACP is not always initiated or conducted by the GP, this should explicitly be considered as a starting point and financial compensation for other healthcare professionals should be considered.

The process evaluation of the ACP+ intervention (Chapter 3.3) also highlighted the difficulties of transferring ACP-related documents and information between different settings, for example, from the nursing home to the hospital. The nursing home staff reported that ACP documents are often overlooked in case a resident gets admitted, or are not used at all in the hospital. **Nation-wide guidelines on ACP and standardized documents, which can be easily transferred from the nursing home to the hospital, could potentially benefit residents greatly.** This was also suggested in other recent research, especially in light of the current Covid-19 pandemic[61,98], however, the discrepancy between IT systems in healthcare has been identified as one of the key barriers in enabling the exchange of ACP documentation[99].

To implement the ACP+ intervention in nursing homes, results of this dissertation show that the involvement of a **dedicated trainer throughout the entire implementation period** was crucial (Chapter 3.3). Therefore, when implementing ACP+ in nursing homes throughout Flanders, we recommend that trainers should be able to spend dedicated time to deliver the trainings in the nursing home. Ensuring the long-term involvement of such trainers could facilitate better implementation of complex interventions such as ACP+, as the timing of the trainings can then be tailored to the learning needs of the nursing home staff[100,101]. With this in mind we would recommend for policy-makers to focus on **financing sustainable regional partnerships**, for example, cooperations between the nursing homes, palliative care networks, as well as home care organizations. Not only could this ensure that the trainers could provide all healthcare professionals with education about ACP, most importantly it could help ensure the timely initiation of ACP for vulnerable groups -such as people living with dementia- as the whole chain of care around a person with dementia would be knowledgeable and confident in performing ACP conversations. Recent studies[102,103] found especially the latter to be particularly important for the uptake of ACP of nurses in nursing homes, so a focus on increasing self-efficacy in these trainings seems to be important.

Additionally, public awareness campaigns might be needed to sustain **ACP awareness throughout society**[104]. It has been proposed that the recent Covid-19 pandemic has led to a shift in public awareness about ACP and made people realize the importance of planning ahead[61]. The hopes are that this awareness is sustainable, but Selman *et al.* recommend consistent and coordinated public health messaging to ensure this change[61]. Public awareness campaigns, such as 'forget dementia, remember the person' [vergeet dementia, onthou mens] of the Flanders Centre for Expertise in Dementia[105], might be a good possibility if links with ACP can be made. This would help to familiarize the general public with dementia and ACP.

4.5 References (Part 4)

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E. Nederlandse samenvatting

Introductie

Wereldwijd neemt de levensverwachting en het aantal ouderen toe. Met het ouder worden, neemt ook de kans op één of meerdere, vaak chronische, aandoeningen toe. Dit maakt dat de dood meestal niet meer onverwacht komt. De meest voorkomende doodsoorzaken zijn dan ook niet-overdraagbare ziekten, met hartfalen, beroertes en COPD (chronic obstructive pulmonary disease, in het Nederlands Chronische Obstructieve Long Ziekte) op de respectievelijke eerste, tweede en derde plaats wereldwijd. In geïndustrialiseerde landen en landen met een hoog inkomen staat ook dementie in de top 10.

Wereldwijd komt er elke 3 seconden iemand bij met dementie. Vandaag de dag zijn er ongeveer 50 miljoen mensen die leven met dementie en de verwachting is dat dit in 2050 ongeveer 152 miljoen mensen zullen zijn. Voor België is de verwachting dat in 2050 ongeveer 3% van de bevolking (360766 mensen) zal leven met dementie.

Dementie

Dementie is een overkoepelende term voor een heel aantal ziektes die hersenschade veroorzaken. De ziekte van Alzheimer is de bekendste, 60 tot 80% van de mensen met dementie hebben de ziekte van Alzheimer. Andere vormen zijn, onder andere, vasculaire dementie, Lewy body dementie en frontotemporale dementie[2]. Al deze vormen hebben verschillende symptomen en ziektetrajecten. De overeenkomst is echter dat er een progressief traject gevolgd wordt. Dit betekent dat de neuronen in de hersenen beschadigd raken en niet zullen herstellen. Dit lijdt tot de karakteristieke symptomen van dementie, zoals problemen met het geheugen en taal, een verstoord probleemoplossend vermogen en andere vaardigheden die ervoor zorgen dat dagelijkse taken (zoals boodschappen doen of autorijden) niet meer uitgevoerd kunnen worden. Daarnaast kan dementie lijden tot disoriëntatie in plaats, tijd en persoon en veranderingen in stemming en persoonlijkheid teweegbrengen. Tot op heden is er geen genezing mogelijk. Behandeling richt zich op symptoomcontrole en psychosociale ondersteuning. Gezien de achteruitgang die veel mensen met dementie op een zeker moment zullen meemaken, is opname in een woonzorgcentrum vaak noodzakelijk. In België sterft meer dan 65% van de mensen met dementie in een woonzorgcentrum.

Woonzorgcentra

Een woonzorgcentrum in België is een centrum waar ouderen wonen die problemen ervaren met dagelijkse activiteiten en/of fysiek en cognitief functioneren. Er is 24 uur per dag verpleegkundige en persoonlijke zorg aanwezig. Voor medische zorg kunnen bewoners zich tot hun eigen huisarts wenden. Mensen met dementie kunnen op een open of een gesloten afdeling opgenomen worden, afhankelijk van de hoeveelheid zorg die ze nodig hebben.

In Vlaanderen (de dichtstbevolkte regio van België) zijn 819 woonzorgcentra met 81.743 bedden. Naast verplegend personeel (verpleegkundigen en zorgkundigen), is er paramedisch personeel in dienst, bijvoorbeeld psychologen, fysiotherapeuten en ergotherapeuten. Daarnaast zijn er vaak sociaal werkers, animatoren en pastoraal werkers in dienst. Tevens moeten woonzorgcentra in Vlaanderen

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[2] Op de website van Alzheimer Nederland (www.alzheimer-nederland.nl) staat veel informatie over dementie en de verschillende soorten dementie.

een referentiepersoon palliatieve zorg in dienst hebben. Dit is iemand die gespecialiseerd is in palliatieve zorg en die verantwoordelijk is voor het palliatieve beleid in een woonzorgcentrum. Hij/zij kan ondersteuning bieden aan bewoners met een palliatief statuut, verzorgt trainingen over palliatieve zorg aan het personeel en coördineert de palliatieve dossiers. Een referentiepersoon dementie, dat wil zeggen iemand die extra geschoold is in dementie, kan ook aanwezig zijn in een woonzorgcentrum, maar dit is niet verplicht vanuit de overheid. De medische zorg wordt gecoördineerd door een coördinerend raadgevend arts (CRA). Dit is een arts, meestal tevens werkzaam als huisarts, die samen met het managementteam in staat voor continuïteit van zorg, bijscholing verzorgd voor het personeel en andere huisartsen en geconsulteerd kan worden voor een second opinion.

Palliatieve zorg

Een recent onderzoek in 45 landen toont aan dat 20 tot 44% van de overlijdens plaats vinden in een woonzorgcentrum. Zo'n 55 tot 98% van de bewoners heeft meer dan één progressieve ziekte, en per jaar overlijdt dan ook gemiddeld 30% van de bewoners. Het is dan ook niet verwonderlijk dat palliatieve zorg en levenseindezorg terugkerende thema's zijn binnen de zorg in woonzorgcentra.

Palliatieve zorg[3] wordt door de wereldgezondheidszorgorganisatie (WGO, ook gekend als World Health Organization; WHO) gedefinieerd als: 'een benadering die de kwaliteit van het leven verbetert van patiënten en hun naasten die te maken hebben met een levensbedreigende aandoening, door het voorkomen en verlichten van lijden, door middel van vroegtijdige signalering en zorgvuldige beoordeling en behandeling van pijn en andere problemen van lichamelijke, psychosociale en spirituele aard.'. De WHO geeft aan dat er een grote discrepantie is tussen het aantal mensen dat nood heeft aan palliatieve zorg en het aantal mensen dat deze zorg ook daadwerkelijk ontvangt. In België is er sinds 2002 een wet die stelt dat elke inwoner recht heeft op palliatieve zorg, ongeacht zijn of haar levensverwachting.

Palliatieve zorg komt op veel fronten overeen met kwaliteitsvolle patiëntgerichte zorg in woonzorgcentra. Onderzoek heeft echter aangetoond dat de kwaliteit van de palliatieve zorg in woonzorgcentra achterblijft. Ook specifiek voor mensen met dementie, is er overlap tussen patiëntgerichte zorg en palliatieve zorg.

Advance care planning

Een belangrijk onderdeel van palliatieve zorg is het reflecteren op toekomstige (zorg)wensen. Dit wordt ook wel advance care planning (ACP), vroegtijdige of voorafgaande zorgplanning (VZP) genoemd. ACP wordt gedefinieerd als: 'een continu en dynamisch proces waarin reflectie en dialoog tussen een persoon, zijn/haar naaste(n) en zorgverlener(s) centraal staat en waarin waarden en voorkeuren geëxpliciteerd worden en toekomstige zorgdoelen of -beslissingen rond het levenseinde worden besproken en/of gepland. Het doel van ACP is om de zorg af te stemmen op de wensen en doelen van de betreffende persoon. Het is belangrijk om ACP als een proces te zien, waarbij de bewoner in samenspraak met naasten en zorgverleners blijft reflecteren op wensen en voorkeuren. Zeker voor bewoners met dementie is het van belang om ACP als een proces te zien, gezien de wilsbekwaamheid van deze bewoners kan fluctueren van moment tot moment.

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[3] Op de website van de Federatie Palliatieve Zorg Vlaanderen (www.palliatief.be) staat veel informatie over palliatieve zorg in Vlaanderen.

De conclusies van een ACP gesprek kunnen op verschillende manieren gedocumenteerd worden, 1) het aanwijzen van een wettelijk vertegenwoordiger, 2) negatieve wilsverklaringen (voorkeuren voor behandelingen die men niet meer wil, bijvoorbeeld naar het ziekenhuis gaan) en 3) positieve wilsverklaringen (bijvoorbeeld voorkeuren over teraardebestelling). Ook kunnen mensen kiezen om een zorgvolmacht aan te duiden om hun financiële zaken te regelen.

ACP moet altijd aangeboden worden als optie en niet als verplichting. Indien een bewoner niet over zijn/haar voorkeuren wenst te spreken, dan dient dit gerespecteerd te worden. Dit geldt zowel voor mensen met, als zonder dementie.

Onderzoeksdoelen

Het eerste doel (Deel 2 van dit proefschrift) is om te onderzoeken welke veranderingen er hebben plaats gevonden wat betreft ACP en levenseindebeslissingen voor mensen met dementie en wat de huidige stand van zaken is aangaande ACP voor mensen met dementie.

Het tweede doel (Deel 3 van dit proefschrift) is om de ACP+ interventie te evalueren. Deze interventie is ontwikkeld om de implementatie van ACP in woonzorgcentra in Vlaanderen te verbeteren.

Bevindingen

In hoofdstuk 2.1 werd een review van reviews, ook wel een paraplu-review uitgevoerd. Er is in elektronische databases gezocht naar kwalitatieve en kwantitatieve reviews die betrekking hadden op hoe ACP geconceptualiseerd wordt voor en door mensen met dementie, de effectiviteit van ACP voor mensen met dementie en de ervaringen met ACP van mensen met dementie, hun familie en zorgverleners. Daarnaast hebben we gezocht naar recente artikelen die nog niet in de reviews waren opgenomen om een zo volledig mogelijk beeld te krijgen van alle beschikbare evidence. We vonden dat ACP als acceptabel wordt gezien door mensen met dementie en hun familie en dat ACP geassocieerd kan worden met verbeterde uitkomsten, zoals bijvoorbeeld, een toename in de overeenstemming tussen de zorg die mensen ontvangen en de wensen die ze hebben geuit, minder ziekenhuisopnames en een toename van ACP documentatie. Onze resultaten suggereren echter ook dat er nood is aan richtlijnen met betrekking tot welke uitkomstmaten en welke definitie van ACP er het beste gebruikt kan worden, als ook onderzoek dat meer inzicht geeft in verschillende benaderingen van ACP. Daarnaast stellen we dat educatie over onderwerpen gerelateerd aan de verminderde wilsbekwaamheid van mensen met dementie noodzakelijk zijn om ACP te optimaliseren voor mensen met dementie en hun familie.

In hoofdstuk 2.2 lag de focus op levenseindebeslissingen van mensen die overleden aan dementie in de jaren 1998, 2007 en 2013. Het onderzoek toonde aan dat er weinig variatie was over de jaren, waarbij voor iets meer dan de helft van de mensen die overleden aan dementie een levenseindebeslissing werd gemaakt. Het feit dat bijna alle mensen die overleden aan dementie door de arts beoordeeld werden als wilsonbekwaam, zou een verklaring kunnen zijn waarom andere partijen een belangrijke rol speelden in het bespreken van de levenseindebeslissingen. Slechts 1 op de 10 mensen met dementie in onze steekproef was zelf betrokken in deze besluitvorming. Dit onderzoek toont aan dat familie over de jaren wel steeds meer betrokken werd in het besluitvormingsproces (van 12% in 1998 naar 67% in 2013).

In hoofdstuk 2.3 hebben we onderzocht welke veranderingen er plaats vonden tussen 2010 en 2015 in ACP communicatie en documentatie en zorgplanning rond het levenseinde voor bewoners met dementie in Vlaamse woonzorgcentra. We vonden dat algemene zorgplanning, in de vorm van voorafgaande afspraken genoteerd door de huisarts, stabiel bleef over de jaren. Wel steeg het aantal bewoners met dementie die; 1) voorkeuren voor behandelingen aan het levenseinde hadden uitgesproken (van 8% in 2010 naar 19% in 2015), 2) in een schriftelijke voorafgaande wilsverklaring een derde persoon de volmacht gegeven had om beslissingen te nemen voor hem/haar in het geval hij/zij incompetent zou worden (van 5% in 2010 naar 32% in 2015) en 3) een schriftelijke wilsverklaring hadden (van 13% in 2010 naar 41% in 2015). Ondanks deze statistisch significante toenames is het grootste deel van bewoners met dementie in Vlaamse woonzorgcentra niet betrokken bij gesprekken over hun wensen rond het levenseinde.

Bovengenoemde hoofdstukken geven inzicht in de huidige stand van zaken en tonen aan dat ACP beter ingebed moet worden de dagelijkse praktijk van de woonzorgcentra. Hiervoor werd de ACP+ interventie ontwikkeld en onderzocht in 14 Vlaamse woonzorgcentra.

In hoofdstuk 3.1 worden de drie belangrijkste tools van de ACP+ interventie beschreven, zodat deze gebruikt kunnen worden in toekomstig onderzoek en in de dagelijkse praktijk van woonzorgcentra.

In hoofdstuk 3.2 en 3.3 werd de ACP+ interventie geëvalueerd. De ACP+ interventie bevat 10 interventiecomponenten, 22 activiteiten en 17 materialen om implementatie in de dagelijkse praktijk te ondersteunen. Met behulp van een externe trainer werd het programma in acht maanden uitgerold. Hierbij werden verschillende rollen toebedeeld aan al het personeel in de deelnemende woonzorgcentra: ACP referentiepersonen werden intensief getraind om de interventie verder te brengen in het woonzorgcentrum, ACP gespreksleiders werden opgeleid om ACP gesprekken te voeren met bewoners en ACP signaleerders ontvingen training over wat te doen als bewoners signalen gaven nood te hebben aan een ACP gesprek.

De analyses in hoofdstuk 3.2 tonen aan dat zorgpersoneel in de interventiegroep significant meer vertrouwen kreeg in eigen kunnen door de ACP+ interventie, maar dat hun kennis over ACP niet verbeterde ten opzichte van de controlegroep. Ook toonde het onderzoek geen verschil op de door het zorgpersoneel gerapporteerde ACP communicatie en documentatie tussen de interventie- en de controlegroep.

De procesevaluatie beschreven in hoofdstuk 3.3 gaf inzicht in de implementatie, de impactmechanismen en contextuele factoren en daarmee ook in de effecten van de interventie, zoals beschreven in hoofdstuk 3.2. Over het algemeen werd de ACP+ interventie goed ontvangen door de participanten. Zij gaven aan dat de ACP+ interventie heeft geleid tot meer aandacht voor het belang van ACP in het gehele woonzorgcentrum. Daarnaast ervoeren zij dat de ACP+ interventie leidde tot beter gestructureerde ACP procedures en meer inzet op ACP gesprekken en documentatie. Echter, resultaten van de procesevaluatie laten zien dat overheen alle woonzorgcentra slechts 33% van al het personeel getraind was volgens ACP+. Ook vonden we dat het zorgpersoneel onvoldoende leerervaringen had gehad op de werkvloer en dat er contextuele hindernissen werden ervaren, bijvoorbeeld een hoge werkdruk en hoge doorloop van personeel.

Aanbevelingen

Op basis van de resultaten beschreven in dit proefschrift zijn verschillende aanbevelingen geformuleerd.

Voor **toekomstig onderzoek** zou het aangewezen zijn om de verzamelde data van het ondersteunend personeel, huisartsen en vrijwilligers te analyseren om meer inzicht te krijgen in de effecten van de ACP+ interventie bij deze groepen. Daarnaast zou de Theory of Change, die onderliggende is aan de ACP+ interventie, aangepast moeten worden aan de bevindingen uit dit proefschrift. Concreet zou dit bijvoorbeeld zijn om de implementatieperiode van de ACP+ interventie te verlengen, of een consolidatieperiode in te bouwen, zodat het personeel meer tijd en ruimte krijgt om zich de geleerde lessen en vaardigheden eigen te maken.

Meer in het algemeen, zouden onderzoekers die ACP interventies in woonzorgcentra evalueren baad kunnen hebben bij gestandaardiseerde uitkomstmaten, met bijbehorende betrouwbare en valide meetinstrumenten op verschillende niveaus.

Voor de **praktijk** blijkt gebrek aan kennis een belangrijke hindernis te zijn om ACP gesprekken te voeren. Daarom is het aangewezen om in te zetten op het onderwijzen en trainen van alle betrokken partijen. Dit start bij goede educatie voor zorgverleners, waarbij het belangrijk is om ook voldoende tijd te voorzien voor voldoende leerervaringen op de werkvloer.

Met betrekking tot de implementatie van de ACP+ interventie in woonzorgcentra zijn de volgende zaken belangrijk:

- Zorg voor een duidelijk onderscheid in rollen en verantwoordelijkheden van het personeel.
- Waarborg de betrokkenheid van het management.
- Richt je op verschillende niveaus, betrek iedereen.

Voor het **beleid**, zijn de aanbevelingen drieledig. Ten eerste is het aangeraden om structurele veranderingen in de organisatie en de financiering van de woonzorgcentra aan te brengen. Ten tweede zouden bewoners van woonzorgcentra veel baat kunnen hebben bij uniforme richtlijnen, met bijbehorende uniforme documenten, die gemakkelijk kunnen worden gedeeld indien de bewoner opgenomen wordt in het ziekenhuis. Ten derde zou het aangewezen zijn om met bewustmakingscampagnes ACP en dementie meer bekendheid te geven bij het grote publiek.

Specifiek voor het implementeren van de ACP+ interventie is het aangewezen om een trainer aan te stellen voor de gehele duur van de interventie. De financiering van deze trainers zou bijvoorbeeld ondergebracht kunnen worden in duurzame regionale partnerschappen om zo alle zorgverleners van voldoende training en ondersteuning te kunnen voorzien en daarmee tijdige initiatie van ACP voor kwetsbare groepen te kunnen borgen.

F. Summary

Introduction

Dementia

Every three seconds there is a new case of someone with dementia. Today there are about 50 million people living with dementia, worldwide, and this number is expected to increase to 82 million in 2030 and 152 million in 2050. In Europe, it is expected that the number of people living with dementia will be doubled by 2050. For Belgium specifically, it is expected that almost 3% of the population (360.766 people) will be living with dementia in 2050.

Dementia is an umbrella term for a number of different diseases which all cause deterioration in cognitive function beyond what might be expected from normal aging. Alzheimer's disease might be the best-known form, since it is the most common, contributing to 60% to 80% of all cases. Other types of dementia include, among others, vascular dementia, Lewy body dementia and frontotemporal dementia.

Dementia follows a progressive course, meaning that, gradually, neurons in the brain are damaged and destroyed and do not regenerate. This can cause the characteristic symptoms of dementia, such as difficulties with memory and language, impaired motor skills, impaired vision and problem-solving and other cognitive skills that affect a person's ability to perform everyday activities, as well as disorientation in time, person and place and changes in mood and personality. Dementia is currently irreversible and, eventually, fatal.

Nursing homes

Long-term care facilities (called nursing homes, care homes, residential aged care homes and other terms) have been defined as, 'collective institutional settings where care, on-site provision of personal assistance in daily living, and on-site or off-site provision of nursing and medical care, is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time'. In Belgium specifically, nursing homes are care facilities where older adults live who have problems with activities of daily living and/or physical and cognitive functioning. The nursing homes provide long-term care where continuous (24/7) nursing and personal care are available. Residents continue to receive medical care from their general practitioner (GP).

Because of the high numbers of nursing home residents dying each year, palliative and end-of-life care, including advance care planning, are major themes in this setting. Palliative care has been advocated as the preferred approach to care, since the key features of palliative care correspond strongly with the key features of general, high-quality, person-centered care in this setting.

Advance care planning

An important element of the palliative care approach is advance care planning (ACP) defined as 'a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care'. The main goal of ACP is to align care with the person's preferences and goals.

ACP conversations should always be considered as optional. If people in general, and nursing home residents specifically, do not want to talk about future preferences, for whatever reason, at a certain moment in time, it is their right not to continue ACP conversations. Moreover, formalizing the ACP conversation in the form of filling out ADs or appointing a legal representative is never obligatory. This applies to both people with and without dementia.

Research aims

This dissertation defined two aims, subdivided into six objectives described below.

Aim 1: To describe current evidence concerning advance care planning for people living with dementia and to examine to what extent advance care planning and end-of-life decision-making have changed over time among people with dementia.
Objective 1: To identify and summarize the evidence on how ACP is conceptualized by and for people with dementia, the effectiveness of ACP for people with dementia and the experiences and views of ACP of people with dementia, their families and professionals (Chapter 2.1).
Objective 2: To examine whether changes occurred in the frequencies of end-of-life decision-making for people who died of dementia between 1998, 2007, and 2013 and which people were involved in the decision-making process (Chapter 2.2).
Objective 3: To examine changes between 2010 and 2015 in verbal and written ACP for nursing home residents with dementia (Chapter 2.3).

Aim 2: To evaluate the ACP+ intervention, an intervention program to improve the implementation of advance care planning in nursing homes in Flanders.
Objective 4: To describe the ACP+ conversation and documentation tools that are part of the ACP+ intervention (Chapter 3.1).
Objective 5: To evaluate the effects of ACP+ on the knowledge and self-efficacy (confidence in own skills) of nursing home care staff concerning ACP (Chapter 3.2).
Objective 6: To evaluate implementation, mechanisms of impact and contextual factors affecting implementation and outcomes of ACP+ (Chapter 3.3).

Main findings

To identify and summarize the evidence on how ACP is conceptualized by and for people with dementia, the effectiveness of ACP for people with dementia, and the experiences and views of ACP of people with dementia, their families and professionals, we undertook an umbrella review of which the results were described in Chapter 2.1. We found evidence that ACP is acceptable for people with dementia and their families and could be associated with improved outcomes, for example, increased concordance between subsequent care and stated wishes, decreased hospitalization use and an increase in ACP documentation. However, our results suggested that there is a need for guidelines on which outcomes and which definition of ACP to use, as well as research to test different approaches to ACP. Additionally, we suggested that education on topics related to a diminishing decision-making capacity is key to optimizing ACP for people with dementia and their families.

In Chapter 2.2 and Chapter 2.3, we used mortality follow-back studies as research designs. In Chapter 2.2, we focused on end-of-life decision-making for people with dementia between 1998 and 2013 showing that ELDs were prevalent for people dying of dementia and varied little over the years. Almost all people with dementia were judged by the physician as lacking the decision-making capacity (1998: 96%; 2007: 100%; 2013: 96%). This could be the main reason why other parties played an important role in discussing ELDs. Importantly, this research showed that family, rather than nurses or colleague physicians, were increasingly involved in the discussion regarding end-of-life decision-making, with significantly increased involvement of family found between 1998 and 2013 (12% vs 67%; P < .001).

In Chapter 2.3, we examined changes between 2010 and 2015 in verbal and written ACP and end-of-life care planning in nursing homes in a sample of deceased nursing home residents with dementia in Flanders. Although the use of general end-of-life care planning in the form of GP orders did not change between the years (58% vs 62%), residents who had expressed preferences concerning end-of-life treatments increased from 8% in 2010 to 19% in 2015 (adjusted odds ratio (OR) 2.80, 95% confidence interval (CI) 1.18 to 6.67). The appointment of a proxy decision-maker increased from 5% to 32% (adjusted OR 7.34, 95% CI 3.16 to 17.70). Having a written advance directive increased from 13% to 41% (adjusted OR 4.35, 95% CI 2.44 to 7.75) in this population. However, despite this growth in verbal and written ACP, the majority of people living with dementia in nursing homes still did not participate in conversations about their preferences for end-of-life treatments.

In the second part of this dissertation we aimed to evaluate the effectiveness of the ACP+ intervention on the knowledge, self-efficacy and self-reported ACP communication and documentation of the nursing home care staff (Chapter 3.2) and the implementation, mechanisms of impact and the context of the ACP+ intervention in nursing homes in Flanders (Chapter 3.3).

The ACP+ intervention is a multicomponent intervention aimed at training and supporting the staff with the implementation of ACP into daily care, with the help of an external trainer for eight months. It was developed via an extensive and participatory development including the development of a Theory of Change highlighting how the intervention was supposed to work in practice. In Chapter 3.1 the main tools that were developed for the ACP+ intervention are described, aiming to be of use for future research and in clinical practice in nursing homes.

Collecting data from 14 nursing homes in Flanders, Belgium, we found that the ACP+ intervention significantly improved the nursing home staff's self-efficacy, albeit to a small to medium extent (baseline-adjusted mean difference 0.57; 95% CI 0.20 to 0.94; p=0.003). ACP staff knowledge (95% CI, 0.95 to 1.15; p=0.339; ratio: 1.04) and staff-reported ACP communication and documentation did not differ significantly post-intervention between intervention and control group (0.88 to 2.46; p=0.145; ratio 1.47) (Chapter 3.2).

The process evaluation described in Chapter 3.3 provided insight into the implementation, the mechanisms of impact and contextual factors and helped to explain these intervention effects. Overall, the ACP+ intervention was well received according to the participants. Participants perceived the ACP+ intervention to have led to increased awareness about the importance of ACP throughout the nursing home. Moreover, they perceived the ACP+ intervention led to more structured ACP procedures and increased engagement in ACP conversations and documentation. However, only about 33% of the staff was trained across nursing homes (low to moderate reach), with 5 of the 7 intervention homes reporting even lower numbers of the staff reached. Furthermore, insufficient on-the-job learning opportunities and contextual difficulties were apparent.

G. Curriculum Vitae

About the author

Annelien was born on the 17th of May 1990 in Rotterdam, the Netherlands. She obtained her high school diploma (VWO at Lek & Linge in Culemborg) in 2007. Being unsure about the next step, she chose adventure and spend half a year in Australia and half a year working at the cardiology ward of the Rivierenland hospital in Tiel. The latter is where she found her interest in the care for older people. While obtaining her bachelor's (2011) and master's degree in Clinical and Health Psychology (2013) from Utrecht University, she worked as a care assistant at a nursing home for blind older people in Wolfheze. In 2013 she started as a research assistant at the geriatrics department of the Radboud University Medical Centre in Nijmegen, further exploring her interest for older people, dementia and quality of care. In September 2016 Annelien started as an Early Stage Researcher (ESR) at the End-of-Life Care Research group (VUB), within the Marie-Curie funded INDUCT-project (Interdisciplinairy Network for Dementia Using Current Technology), focusing on advance care planning. She was supervised by Prof. Dr. Lieve Van den Block and Prof. Dr. Lara Pivodic and worked in close collaboration with Dr. Joni Gilissen, Prof. Dr. Luc Deliens, Prof. Dr. Robert Vander Stichele and Prof. Dr. Chris Gastmans. During her PhD-trajectory, Annelien also had the opportunity to work with Prof. Dr. Claire Goodman, Prof. Dr. Frances Bunn and Dr. Jennifer Lynch of CRIPACC research group of the University of Hertfordshire (UK).

Currently, Annelien works at ZonMw, the Dutch organization to promote quality and innovation of healthcare research.

Annelien is married to Jos and the proud mother of Gijs (~2017) and Olivier (~2019).

List of publications

Wendrich-van Dael, A., Pivodic, L., Cohen, J., Deliens, L., & Van den Block, L. (2019). End-of-Life Decision Making for People Who Died of Dementia: A Mortality Follow-Back Study Comparing 1998, 2007, and 2013 in Flanders, Belgium. *Journal of the American Medical Directors Association*, *20*(10), 1347-1349. https://doi.org/10.1016/j.jamda.2019.04.004

Gilissen, J., Pivodic, L., Wendrich-van Dael, A., Gastmans, C., Vander Stichele, R., Van Humbeeck, L., ... Van den Block, L. (2019). Implementing advance care planning in routine nursing home care: The development of the theory-based ACP+ program. *PLoS ONE*, *14*(10), [e0223586]. https://doi.org/10.1371/journal.pone.0223586

Van Rickstal, R., De Vleminck, A., Gilissen, J., Wendrich-van Dael, A., & Van den Block, L. (2019). Voorafgaande Zorgplanning bij Dementie: Denken onderzoekers tijdig na over de toekomst van hun onderzoek? *Peiler*, *10*(april-mei-juni), 12-13.

Wendrich-van Dael, A., Bunn, F., Lynch, J., Pivodic, L., Van den Block, L., & Goodman, C. (2020). Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. *International Journal of Nursing Studies*, *107*, [103576]. https://doi.org/10.1016/j.ijnurstu.2020.103576

Gilissen, J., Pivodic, L., Wendrich-van Dael, A., Gastmans, C., Vander Stichele, R., Engels, Y., ... Van den Block, L. (2020). Implementing the theory-based advance care planning ACP+ programme for nursing homes: study protocol for a cluster randomised controlled trial and process evaluation. *BMC Palliative Care*, *19*(1), 5. https://doi.org/10.1186/s12904-019-0505-7

Gilissen, J., Pivodic, L., Wendrich-van Dael, A., Cools, W., Vander Stichele, R., Van den Block, L., ... Gastmans, C. (2020). Nurses' self-efficacy, rather than their knowledge, is associated with their engagement in advance care planning in nursing homes: A survey study. *Palliative Medicine*, *34*(7), 917-924. https://doi.org/10.1177/0269216320916158

Gilissen J., Wendrich-van Dael A., Gastmans C., Vander Stichele R., Deliens L., Detering K., Van den Block L.* & Pivodic L.*. Should we rethink the roles of nursing home staff in advance care planning? Survey study comparing practices, knowledge and self-efficacy among nurses, care assistants and allied staff. [submitted]

Wendrich-van Dael A., Pivodic L., Smets T., Deliens L. & Van den Block L. Advance care planning among nursing home residents living with dementia: Results from two mortality follow-back studies. [submitted]

Wendrich-van Dael A., Gilissen J., Gastmans C., Deliens L., Vander Stichele R., Pivodic L.* & Van den Block L.*. A mixed- methods process evaluation of an advance care planning intervention in nursing homes [submitted]

Pivodic L.*, Wendrich-van Dael A.*, Gilissen J., De Buyser S., Deliens L., Gastmans C., Vander Stichele R. & Van den Block L. Effects of a theory-based ACP intervention for nursing homes: a cluster randomized controlled trial [submitted]

Wendrich-van Dael, A., Gilissen, J., Van Humbeeck, L., Deliens, L., Vander Stichele, R., Gastmans, C., Pivodic, L.* & Van den Block, L.* Tools to support advance care planning conversations and documentation in nursing homes. [submitted]

*These authors contributed equally

Presentations at national and international conferences

2017

Levenseindebeslissingen bij mensen die sterven aan dementia: een grootschalige survey in Vlaanderen [End-of-life decisions of people who died of dementia: a survey in Flanders]. Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg, Amsterdam, the Netherlands (poster presentation)

2018

End-of-life decisions of people who died of dementia, trend-analysis in Flanders, Belgium. 10th World Research Congress of the European Association for Palliative Care, Bern, Switzerland (oral presentation)

An Advance Care Planning intervention for nursing home staff in Flanders: A feasibility study. 10th World Research Congress of the European Association for Palliative Care, Bern, Switzerland (poster presentation)

2019

Understanding advance care planning for people living with dementia: a review of reviews. ACP-I congress, Rotterdam, the Netherlands (oral presentation)

Understanding advance care planning for people living with dementia, a review of reviews. 29th Alzheimer Europe conference, Den Haag, the Netherlands (poster presentation)

Recommendations of the INDUCT project. 29th Alzheimer Europe conference, Den Haag, the Netherlands (oral presentation)

Vroegtijdige zorgplanning voor mensen met dementie; een review van reviews [advance care planning for people living with dementia; a review of reviews]. Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg, Antwerp, Belgium (oral presentation)

2020

Comparing advance care planning practices, knowledge and self-efficacy among different nursing home care staff: A survey study. 11th World Research Congress of the European Association for Palliative Care, online (poster presentation)

Courses

Course	Year	Institution	Credits
Introduction to scientific integrity	2016	VUB	1
Publishing and registering your ouput	2016	VUB	1
POSADEM, e-learning	2016	Maastricht University	6
Developing and evaluating complex interventions in palliative and end-of-life care (MOREcare)	2017	King’s College London	9
1st INDUCT school	2017	Maastricht University	6
2nd INDUCT school	2017	Maastricht University	6
3rd INDUCT school	2018	Maastricht University	6
4th INDUCT school	2018	Maastricht University	6
Writing papers for peer reviewed medical journals	2019	Ghent University	1
Statistische analyse van geclusterde en longitudinale data in SPSS	2020	Ghent University	3