

Towards Successful

ADVANCE CARE PLANNING IN NURSING HOMES

Joni Gilissen

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Towards Successful Advance Care Planning in Nursing Homes

Advance care planning (ACP) enables individuals to think ahead and define their goals and preferences for future treatment and care. Such a process has been shown to have a positive impact on both the individual and those close to them, and is widely considered to be an integral part of best practice long-term care. Implementation in daily nursing home practice however still seems to be a challenge, and research has failed to provide recommendations on how to implement ACP successfully in the complex setting of a nursing home. Effectiveness research has therefore been recommended to go beyond 'does it work?' to 'how and under what circumstances does it work?'.



Towards successful advance care planning in nursing homes was written as a Joint PhD dissertation and explores how to implement advance care planning successfully in nursing homes. Through the theory-based development and evaluation of a complex intervention, using qualitative and quantitative research methods, this work aims to contribute to improving advance care planning in routine nursing home care in Flanders, Belgium.

Joni Gilissen has a background in Social Work & Social Policy. She is a researcher at the End-of-Life Care Research Group (VUB-UGent) and an Atlantic Fellow for Equity in Brain Health at the Global Brain Health Institute (GBHI) in San Francisco.



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TOWARDS SUCCESSFUL IMPLEMENTATION OF ADVANCE
CARE PLANNING IN NURSING HOMES

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We are all but standing on the shoulders of giants

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Chapter 6

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My eternal cheerleaders, my **family**, in particular my sisters, parents, parents-in-law, grandparents and grandparents-in-law, who were always keen to know what I was doing and how I was proceeding. *Nonkel* Maurice Gilissen for being an inspiration to young palliative care advocates such as myself and for putting me in contact with the field in the very beginning. Rina and Pros for helping me out with getting to know the field of nursing homes as well as I know my own home.

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Finally, **I want to apologise to the environment**. We have printed out roughly 54,488 sheets of paper to distribute our questionnaires to professionals who do not have access to their own computer in their clinical practice. The rule of thumb is that a cord of hardwood (128 cubic feet) weighing two tons will produce 1,000 to 2,000 pounds of paper. So, to arrive at the number of trees needed for a ton, an average 8-inch diameter trunk to a usable height of about 45 feet. Applying the simple πr^2 formula to get the cross-sectional area and multiplying it by the height, we roughly used 10 cubic feet of wood. So, it would take about 8 of these trees to produce between 1,000 and 2,000 pounds of paper. Since a typical 500-sheet packet of the paper weighs five pounds, that's 10,000 to 20,000 sheets per tree. This means it took us three entire trees to conduct this

research. Of course, these are all fairly rough estimations, and I weighed things on the bathroom scales, but you do get the general idea. I can sincerely promise however that this vast amount was not wasted and was put to good use for science, and hence will hopefully improve future clinical practice. I have asked all those who would like to buy me a present to donate a small amount to a non-profit of their own choice focusing on global reforestation in areas that have been devastated by over-exploitation for commercial gain, or to cleaning oceans, ecological innovation, sustainable food, fashion or energy.

LIST OF ABBREVIATIONS

ACP Advance care planning

MRC Medical Research Council

ToC Theory of Change

GP General practitioner

AD advance directive

DNR Do-Not-Resuscitate

RCT Randomised controlled trial

TIDieR Template for Intervention Description and Replication

CAP Coordinating advisory physician

GCP Good Clinical Practice

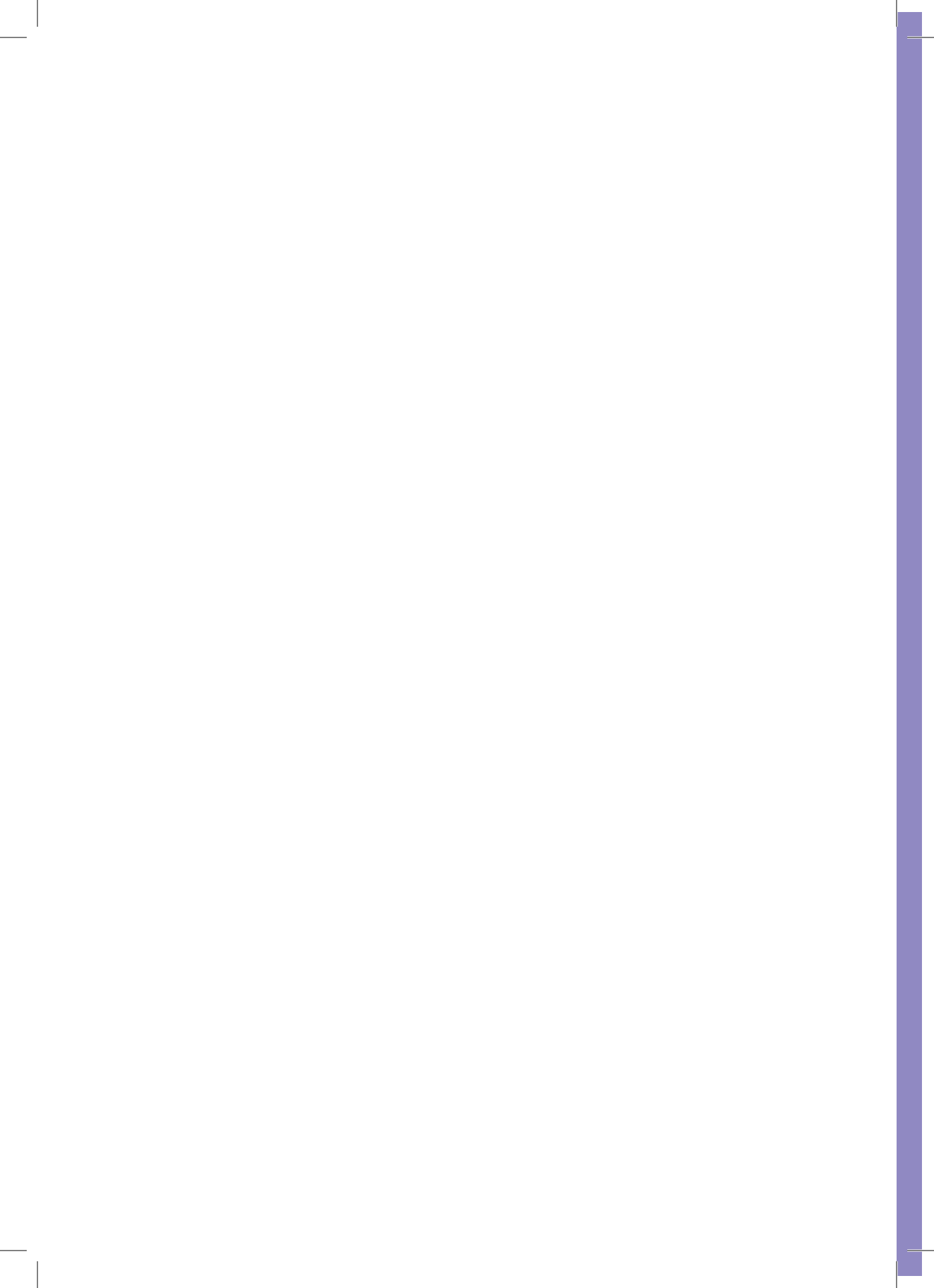
PREFACE

People tend to live longer and better than at any other time in history. Reaching an advanced age no longer has the value of rarity and life expectancy has climbed like never before due to improvements in nutrition, sanitation and medical care. Medicine and public health have transformed the trajectory of human life, and death is no longer a common and ever-present prospect; the trajectory of life in high-income countries is no longer a roll of the dice ending with a steep cliff but is more likely to be a hilly and bumpy road gradually leading downhill. The processes of aging and dying are turned into medical experiences and things that to a certain extent can be managed. As Peter Saul says: ‘there’s drugs now, and fluids, surgery, other intensive treatments, machines that say “ping” and other *wizardly* things to get people through and prolong, not save, life’.

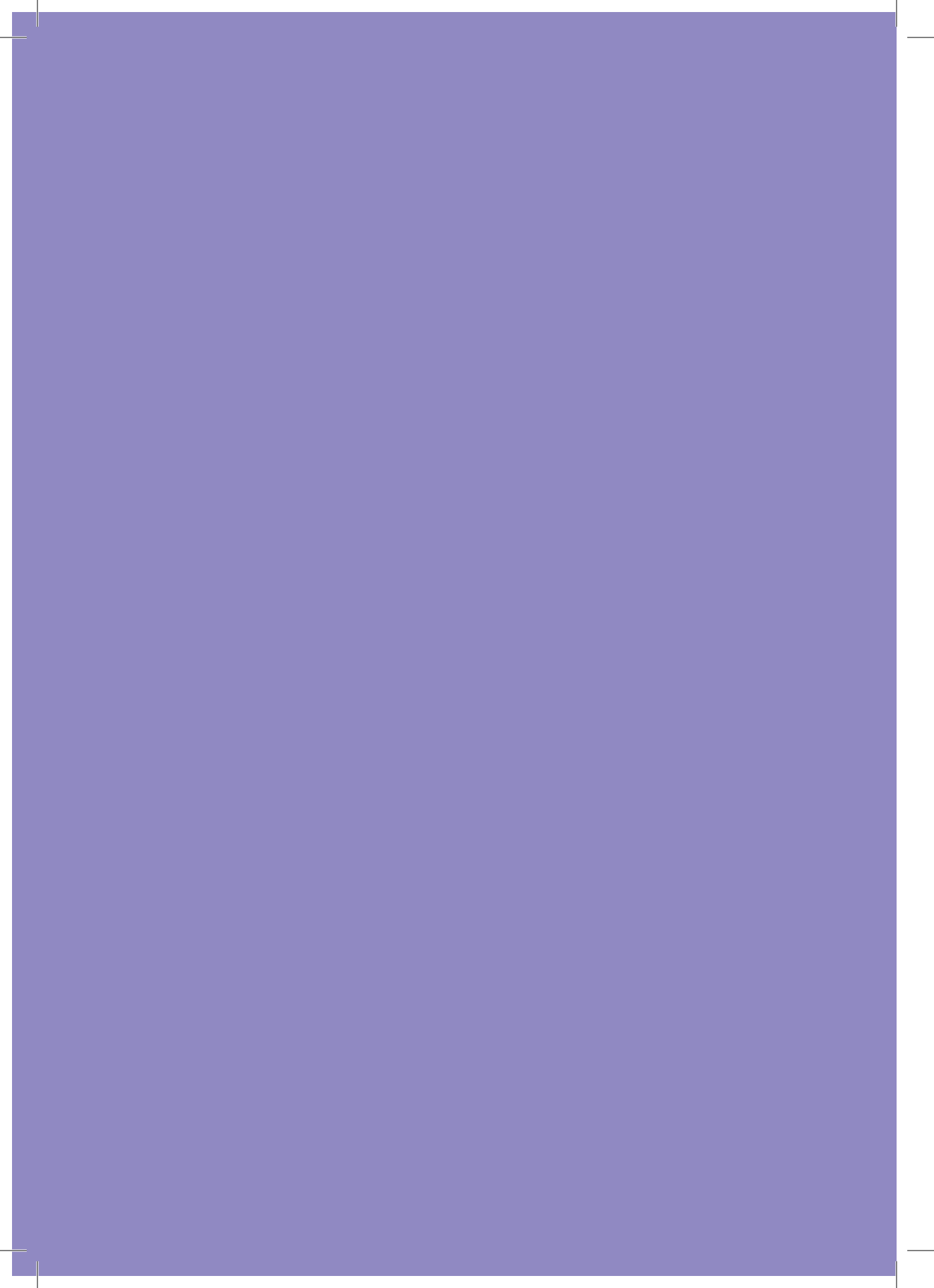
As people age, the curve of life can resemble a long and slow fade. We reduce the blood pressure here, beat back the osteoporosis there, control the vitamin levels, replace the failed joint, while watching the dwindling of capacity and perhaps the brain gradually giving out, until death is imminent and would not be unexpected. Sudden death just doesn’t happen to us anymore. At least six out of ten people reading this thesis will die non-suddenly, having become frail. Fortunately, though, we can prepare for it, as we prepare for things all our lives - which school do we want to go to, what kind of job do we want to do, will we marry or not - children, travel, sickness,... why not the end of life and death as well?

We will all die at some point; the statistics are undeniable. However, surveys show that apparently eight out of ten people do think they are immortal. And in fact, the human mind tends to avoid awareness of its own mortality or is perhaps incapable of really considering it. Our concern then is to find ways, without adopting a position of moral superiority, of asking people to consider their own forthcoming end of life and death in order to allow themselves more autonomy in decision-making when the time comes. I hope this work contributes to making the incredible more credible, if only temporarily, for the purposes of forward planning.

At the end, people find themselves asking new questions. Becoming older invites us to think about what would make life worth living and what might still make us happy. Before this happens, we should all at least be asked the question ‘if you are unwell and not able to communicate your preferences to others, who would you want to speak for you? What would you want them to say?’



PART I
GENERAL INTRODUCTION,
RESEACH AIMS AND METHODS



Background

1. PEOPLE ARE AGING, DISEASE AND DYING PATTERNS ARE CHANGING

1.1. Growth of the aging population

The population is aging and will continue to do so in rapid numbers in the upcoming years. Current population projections at international level generally assume that gains in life expectancy will continue in the future and births will continue to decline [1]. Under these assumptions, the number and share of the population reaching 65 and older in many OECD countries, will increase rapidly when the baby-boom generation (those born post-war) start reaching this age group. By 2050, the share of people that are on average 65 years and older will be more than one out of four people, or 26.5% of the total population in Belgium [2–4]. This is especially true for the ‘oldest old’ (people aged 85 and over) who will tend to grow the fastest [5]. For Belgium specifically, it is projected that by 2030 this share of people will double and will increase further to more than 5% in 2050, the year when the last of the baby-boom generation will reach the age of 85 [2].

1.2. Old age as most common predictor for serious illness

As people grow older, old age becomes the single most important common risk factor for developing serious chronic disease and dying from it. Modern death is nothing like what it was decades ago. The basic aspects – *the whys, wheres, whens, and hows* – are fundamentally different [6, 7]. During the nineteenth century, an increase of life expectancy was mainly driven by improvements in housing, education, sanitation; leading to decrease of infections and causing a steady decline in early and mid-life mortality. In the second half of the twentieth century however, the continuing increase of life expectancy was almost entirely due to decline in late-life mortality. The increases in life expectancy observed globally, and modern medicine saving more people from acute illness who now live longer with a heightened chance to have a chronic illness [8], have been accompanied or has led to substantial changes in death and dying [5]. In 2016, global health estimates by the World Health Organisation (WHO) listed the top causes of death (by number of deaths) as 1) ischaemic heart

disease, 2) stroke, 3) chronic obstructive pulmonary disease (COPD), 4) lower respiratory infections, 5) Alzheimer disease and other dementia types, 6) trachea, bronchus, lung cancers, 7) diabetes, 8) road injury, 9) diarrhoeal disease, and 10) tuberculosis [3]. In older people, the most common causes of death are cardiovascular diseases, cancer, and respiratory diseases (such as pneumonia, COPD...) [9]. Alzheimer's disease was in 2016 added to this list, and it is estimated that these numbers will grow substantially in the upcoming years [10, 11].

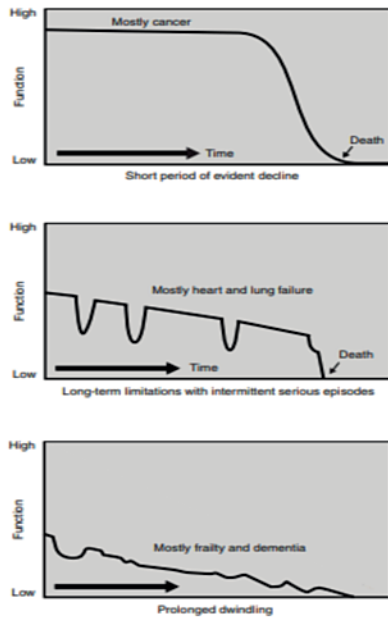
1.3. The trajectory of 'old age'

Although populations around the world are rapidly aging, evidence that aging is accompanied by an extended period of good health is scarce [12]. A recent WHO report identified the greatest causes of 'years living with disability' in people older than 60 years to be sensory impairments, back and neck pain, chronic obstructive respiratory disease, depressive disorders, falls, diabetes, dementia, and osteoarthritis [5]¹. However, the WHO suggests that, although severe disability in older people (that necessitates help from other people for basic activities such as eating and washing) might be decreasing slightly, no substantial change in less severe disability has been noted in the past 30 years [13].

An important aspect that distinguishes the disease status of the older persons from their younger counterparts, is the higher rate of having comorbidities [6]. Old age is strongly associated with an increased risk for multimorbidity, with prevalence ranging from 55 to 98% [5, 14]. Other authors argue that older people suffer from what is commonly known as 'geriatric syndromes', which is a term that describes the unique features of the health condition of elderly such as delirium, falls, incontinence and frailty. These are highly prevalent, multifactorial, and associated with substantial morbidity and poor health outcomes [5, 15–17]. These multifaceted dynamics between underlying physiological change, chronic disease, and multimorbidity in the older population may result in what is called 'a trajectory of old age' (Figure 1) that cannot be clearly categorised into one of the most common trajectories such as cancer or organ failure [18]. It has been argued that this often results in these people being disadvantaged when it comes to disease-based assessments of health status, clear prognostication and further or anticipatory planning of healthcare or treatment [19, 20].

¹For some of these disorders - but not for all - the burden per 100,000 older people is lower in middle-income countries than in low-income countries (Beard et al., 2016).

Figure 1. Most common dying trajectories (retrieved from Lynn and Adamson, 2003)



1.4. Increasing palliative care needs

Overall, this prolonged dwindling in functional status has led to people typically experiencing a wide range of complex needs and symptoms that are indicative of requiring palliative care [21]. Palliative care is defined by the WHO (2002) 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”* [22]. Pivodic et al. (2016) found that a large number of all registered deaths of 2008 in the Belgian population died from a disease indicative of palliative care needs (44%) [23], a number that is about to increase [24]. However, while the need for palliative care is projected to fall in younger age groups, the number of people aged 85 and older who need palliative care is projected to more than double between 2014 and 2040. Disease-specific projections show that dementia and cancer will be the main drivers [24].

2. DYING IN THE NURSING HOME AND THE NEED FOR PLANNING AHEAD

2.1. Nursing homes are increasingly becoming the place of care and death

Despite the sizeable portion of older people who would prefer to live and receive care at home for as long as possible [25–27], circumstances sometimes require them to move to a nursing home [28–31]. In 2017, 1 out of 3 people aged 80 or older lived in a nursing home in Flemish and Brussels region. And while up until the first quarter of the twentieth century, people tended to die in their own homes, unless death was sudden or violent [32], the process of dying has become more institutionalised in industrialised economies with increasing numbers of people dying in hospitals and in nursing homes [33, 34]. Based on numbers from the Flemish Agency of Care and Health, in 2016, 20% of men and 39% of women in Flanders died in a nursing home. Overall, two-thirds of people around the world die in institutions, with the proportion going up to about four out of five for people aged 65 and older [35]. Older adults most often die in nursing homes, especially if they are older than eighty years old [37]. In Belgium, of people dying with a palliative care need, 23% died in a nursing home [23]. Projections show that this demand for long-term care in high-income countries is expected to grow steadily [2, 5]. In recent years the proportion of deaths in hospitals has decreased slightly in contrast to nursing homes [26, 36]. It is estimated that by 2030 only one out of ten people in the UK will be able to die at home if no changes are made in care models [38]. Continuing this road, nursing homes are expected to be the most common place of death by 2040 [33].

2.2. Varying quality of end-of-life care in nursing homes

There is consistent evidence of significant variation in the quality of end-of-life care among nursing homes, with many nursing homes ill-prepared to provide optimal end-of-life care that is sensitive and respectful to the needs and preferences of its residents and their families [20, 39]. In a recent study across six European countries, poor quality of end-of-life care in nursing homes was specifically related to ‘preparatory tasks’ (e.g. ‘the resident having treatment preferences in writing’ or ‘the resident’s funeral having been planned’) and issues regarding ‘closure’ (e.g. residents indicating they were prepared to die) [20, 39]. In a recent study, where they interviewed 1212 family members (representing 4.8 million deceased people aged 65 and more), one in eight people found the care in

the last months of their life to be inconsistent with the patients' wishes. Such care was associated with worse ratings of care, pain management, and communication with professionals [40].

2.3. Need for planning ahead with nursing home residents and loved ones

Looking at what matters to people and what they would want to talk about, a recent study asking people with serious illnesses about what matters most near the end of life found that 44% of patients and their families stated they felt it is important "to complete things and prepare for life's end – review life, resolving conflicts, saying goodbye"; 56% wanted "not to be kept alive on a life support when it would be inappropriate"; and to have the information about their disease communicated to them in an honest manner [41]. A recent study looking at attitudes regarding death in the oldest-old showed that people perceived death as part of their life; most were ready to die and had concerns regarding quality of life. They were often not worried about death itself but concerned about the dying process and its impact on those that were left behind. They preferred to be made comfortable rather than have life-saving treatment if they became seriously ill, and they also wished to avoid the hospital. A "peaceful" and "pain-free" death was a common ideal [42]. These are all elements that can be part of an anticipatory advance care planning (ACP) process [43, 44].

While applying interventions to prolong life and postpone death in older adults might be possible from a medical point of view, it is not a preferred option by all and it has been found that medical care for nursing home residents is often more intensive than desired [20, 45]. Several studies found that people tend to prefer not to have potentially life-prolonging interventions if this requires hospitalisation, deprive them of their independence, or involve a high risk of side-effects that could be burdensome. They wish to "not be kept alive on life support if there is little hope for a meaningful recovery"[41]. There has been debate about appropriateness and particular relevance of interventions such as resuscitation, antibiotics, food, fluid, and hospital admissions for nursing home residents near the end of life – which might be futile and applying those might lead to outcomes that are even worse [46–53]. Authors also stipulate treatments should not be provided or withheld from elderly people without information or discussion [54].

Information and discussion regarding - but not limited to - specific future treatment is important because poor communication at the end of life can cause distress, both for the patient and their loved ones, and may adversely impact on post-bereavement outcomes in family [55, 56]. It has been shown that knowledge of possible outcomes of resuscitation in old age for example, can substantially

influence people’s decisions herein [57]. Surveys show that many older people in different parts of the world *want* to be resuscitated, but lack knowledge about its outcomes [58]. If the topic of do-not-reanimate has not been addressed with a nursing home resident, then resuscitation efforts – especially in the hospital settings - are often automatically performed when the person suffers from cardiopulmonary arrest. However, the evidence stated above might indicate these measures are sometimes medically inappropriate and might therefore cause undue harm. Given the poor health status of many people in nursing homes, they should get the opportunity to make those decisions, taking into account the assessment of the physician [59]. These physicians need to have an understanding of what is important to each individual and to advise them which outcomes are clinically possible [60]. This also relates to unavoidable hospital admissions that often result in aggressive treatments and high burden [61]. For example, it is important that nursing home residents can indicate whether they want to be admitted to a hospital. These decisions must consider the individual’s need and preference for hospital care (i.e. balancing admission risks with therapeutic opportunities) and cannot be placed outside the scope of staffing limitations and also the need for interventions that cannot be provided on the site of a nursing home, but can add to the quality of life of the person [62–64]. While evidence is limited to provide an unequivocal guidance to what constitutes an appropriate treatment and hospital admission [65], anticipatory care planning and most importantly, taking into account residents’ preferences are generally good references and key factors in determining these admissions [66]. Studies even show that the majority of these burdensome transfers can be avoided if there is better planning beforehand [67, 68].

3. ADVANCE CARE PLANNING (ACP)

3.1. The *process* of advance care planning (ACP)

Consensus definition

One way to define and discuss preferences of nursing home residents is ‘advance care planning’. Based on the results of a recent international Delphi study, it has been defined as follows:

“Advance care planning 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. The goal is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.” [69, 70].

ACP is rooted in the belief that patient involvement in end-of-life decisions is at the heart of a “good death” or “dying well” [71, 72]. ACP incorporates the importance of patient autonomy, and the idea that everyone should have the opportunity to make decisions about his/her own health, treatment and care as far as possible. ACP is often raised as one of the possibilities to respond to the challenges related to providing appropriate and high-quality end-of-life care to people [19]. While ACP is considered to be one of the core components of palliative care, it is generally important for everyone, including those who are healthy, those who are suffering from a life-limiting illness, and especially those who are in old age [69, 73].

While there used to be quite some emphasis on the documentation of wishes and preferences for medical treatment and care, the definition of ACP over recent years has been broadened [74, 75]. This broadened ACP paradigm, defined by international expert consensus, is a process, rather than a singular moment or document, 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 [69]. ACP enables individuals to define goals and preferences for future treatment and care, and to discuss these goals and preferences with family and healthcare providers. If a person chooses to, the contents of such conversations can be set down in writing, in the form of a positive or negative advance directive (AD). It may also include the appointment of a proxy decision-maker or lasting power of attorney in anticipation of future deterioration [76–78].

Discussing values, goals and preferences

During ACP conversations, people are prompted to “identify personal values, reflect on the meanings and consequences of anticipated illness scenarios, define goals and preferences of care for these situations, and issue appropriate documents and legal instruments that will help direct future healthcare decisions” [79]. Such conversations are usually held with a skilled healthcare professional, the resident, and a loved one [69]. Recently, there is increased emphasis in broadening ACP conversations to also incorporate non-medical preferences of older adults, because most residents found planning for practical issues – not related to treatment and care – most important and seemed particularly uninterested in making decisions about medical treatments [80, 81]. Outcomes deemed more important by older adults are mostly related to pain relief, natural death, and preserved quality of life and dignity at end of life [80]. This is in line with other evidence showing that older adults rather focus on outcomes than treatments when making decisions about future care [82].

Completing advance directives (AD) or 'living wills'

Advance directives can form one part of the comprehensive process of ACP [69]. These documents outline individual preferences, often in check-box fashion, for 1) withholding or withdrawing from life-sustaining treatments such as antibiotics and other treatments, or cardiopulmonary resuscitation and mechanical ventilation (cf. do-not-resuscitate or DNR orders); 2) do-not-intubate, 3) do-not-hospitalise decisions (cf. DNH orders) and 4) withholding or withdrawing artificial food and fluids. Negative ADs are legally binding in Belgium. Other decisions can be in the form of a positive living will, such as euthanasia or funeral arrangements, and are not [76, 83]. Physician or general practitioner (GP) orders are often mistakenly considered as ADs. These orders are usually documented in the resident's medical file by the physician. However, only when they have been discussed with the residents themselves can these be considered a result of patient-centred ACP [84].

Assigning a substitute, surrogate or proxy decision-maker

The ACP process and completion of an AD allows individuals to also designate a proxy decision-maker in case of decisional incapacity. Such a decision-maker can be: 1) chosen by the person; 2) assigned to the person by law in the absence of an appointed decision-maker (this is a 'default' proxy decision-maker designated by a legal cascade system in the following order: partner or cohabitant spouse, adult child, parent, adult sister or brother); or 3) appointed for the person (e.g. a legal guardian) [85]. A proxy decision-maker is called upon to make medical treatment decisions on behalf of a person who is unable to communicate their wishes. He or she is expected to make the decision they believe the person would have made in that particular situation. This decision should always be made in the best interest of the patient [85]. Designating a proxy decision-maker has been argued to be an essential part of ACP, because 50% to 76% of people will require proxy decision-making at the end of life [86, 87]. However, research shows that this role can be stressful and places intense moral, emotional, and cognitive demands on the surrogate [88]. Family, next-of-kin and others should therefore be informed of, and (emotionally) supported in, their role as proxy decision-maker [89]. In addition, decisions of such proxies may not always be consistent with the wishes of the person [90, 91]. Older adults might not inform their proxy correctly about their care preferences because they are convinced their loved ones would intuitively make the right decision [92]. The same may happen when ADs are vaguely constructed. In such cases it is difficult for both family members and professionals; they may not know or agree with what is stated in the document or they experience difficulties in how to understand or translate vague preferences into specific clinical care or practice [92]. Involving proxies from the start is consequently very important, especially in a population where chances on developing cognitive impairment are high [45].

3.2. Advance care planning in the nursing home as a ‘complex intervention’ in a ‘complex setting’

ACP is considered a complex intervention [93]. It typically targets or involves multiple groups or levels (resident, family, care providers, facility, or community) and is often delivered in a system which responds in (most often) unpredictable ways to a new intervention, and as such might be influenced by features of the organisation or wider context [93–95]. Rather than a large number of elements in the intervention package itself, ‘complex’ interventions contain several interacting components, that can operate at different levels, and may target a wide range of possible outcomes and vary to how they are, or should be, implemented in the target population [89, 93, 96]. Whereas ACP intervention programmes in nursing homes can be focused on implementing solely a new ACP document or advance directive, such as Physician Order for Life-Sustaining Treatment or ‘POLST’ [97], introducing an ACP conversation model or strategy [98], educating staff [99], residents or families, and in smaller amounts also GPs and emergency department staff [100]; such intervention programmes -especially those in nursing homes- have emergently been more extensive or complex [89]. In particular, nursing homes are additionally considered complex settings characterised by a large portion of differently skilled staff, understaffing and high staff turnover, scarce training opportunities, lack of time and financial resources, and provision of care to people that have complex needs [101–105]. Consequently, nursing homes are widely considered a particularly challenging environment to implement and organise ACP [106].

4. PREVALENCE OF ADVANCE CARE PANNING IN NURSING HOMES

Prevalence studies and complementary qualitative research into real-world settings, suggest the implementation of, and engagement among older adults in ACP is still rare [84, 107–110]. This despite the increasing interest in ACP, the general openness towards discussing wishes and preferences regarding future care [111–113], the increase in popular books [7, 114], Netflix documentaries [115], public policies [116] and widespread educational programmes [117, 118].

Whilst the prevalence of documentation is rather high, most documentation is still limited to GP orders², which are, in the majority, not discussed with the resident. A study from 2012 in Flemish nursing homes, found 62% of nursing home residents that died with dementia had some type of documented care plan, however, it was not clear what this plan entailed [119]. A written advance patient directive was present for 18% of nursing home residents with dementia and GP-orders for 57% [84]. Whilst the previous numbers are restricted to nursing home residents living or dying with dementia, recent European research (regarding both residents living with and without dementia) found that one out of three deceased residents in their study had a written AD, with great variety between countries. Having a DNR in place was most common [109].

Looking at the prevalence of ACP conversations, data is rather limited with regards to how many of these discussions are held, with whom and when. With regard to residents living with dementia, communication with family is more frequent. In a nation-wide study in nursing homes in France, one-third (approximately 33%) of cases showed that there were no discussions about end-of-life related topics, either with the resident or with the relative [120]. Also, in Flanders, professionals communicated infrequently with residents living with dementia (22% according to the GP and 9.7% according to a nurse) [84]. However, Vandervoort et al. also found that communication between professionals and relatives of nursing home residents with dementia appeared to be more frequent (71% according to the GP and 60% according to the nurse).

Awareness of resident's care preferences varies. A mortality follow-back study found that, according to GPs, 26% of their patients in nursing homes had expressed a preference for a proxy decision-maker at time of death. 51% of GPs indicated they were aware of their patient's preference about a medical end-of-life treatment [121]. However, nurses reported that relatives were not always aware of the existence of ADs for their relatives that died with dementia [84]. The latter study also showed a low level of congruence between nurses, GPs and relatives of the existence and content of ACP documentation [84].

² A General Practitioner (GP) order or 'treatment order', is defined by Vandervoort et al. [83] as "instructions from the GP placed in the resident's medical file governing (most often limiting) the use of specific treatments toward the end of life". These GP orders can be considered as part of the general care planning process in nursing homes, providing a plan for current and continuing healthcare (DNR – ACP code – DNH – etc.). They can be written in discussion with the individual or can be completed for an individual who lacks capacity in their best interest. The term GP order is especially used to differentiate between a treatment order made by the physician which is not necessarily discussed with the patient, and a patient advance directive with regards to future treatment and care, completed by the patient him or herself.

5. THE EFFECTIVENESS-IMPLEMENTATION CONUNDRUM OF ADVANCE CARE PLANNING IN NURSING HOMES

5.1. Evidence regarding effectiveness of existing advance care planning interventions in nursing homes is inconsistent

While only recently there has been international consensus regarding the outcomes that define successful ACP [122], which is to date still under debate, I list here the most frequently examined outcomes and associated effectiveness in nursing homes. Most studies regarding the effectiveness of ACP in nursing homes focused on the evaluation of effects on outcomes related to ACP practices (e.g. the number of ACP conversations or documents), outcomes related to healthcare use (e.g. the number of hospitalisations) or patient outcomes (e.g. satisfaction with care) [123, 124].

Studies reporting the effects of ACP in older adults or nursing homes consistently report an increase in actual ACP practices; including the number of ACP conversations reported, the rates of completing proxy decision-makers, and the documentation of end-of-life care preferences or standardised ADs [96]. However, increased documentation due to ACP is not surprising as ACP conversations and documents are generally part of the ACP process itself and are considered to be ‘ACP practices or actions’ [122].

ACP was found to reduce hospitalisation of nursing home residents, less use of unwanted treatments and hospital admissions, and residents having a higher chance of dying in their preferred place of death and being referred to palliative care. However, effects on symptom assessment and management differed between studies, and effects on treatment depended on the intervention used [124]. It was found that actions were more consistent with resident’s wishes [124]. In the trial from Hickman et al., which was mainly focused on the implementation of an AD form, they found that, with the exception of feeding tubes and antibiotic use, medical treatment for residents who had an AD for no antibiotics was almost always consistent with their wishes (or rather, their order) [97]. Although ‘care consistent with goals’ was ranked as the most important outcome of ACP by an international Delphi panel that listed the outcomes associated with successful ACP, it has been repeatedly cautioned that there are difficulties in defining and measuring this outcome [122, 125, 126].

Satisfaction with care and quality of life were outcomes that were rarely measured in nursing homes and results are therefore limited to a small amount of studies and varied across. In the study in older adults from Bischoff et al. based on a secondary analysis of U.S. Medicare and survey data, ACP was found to be associated with improved quality of care at the end of life [127]. Chan and Pang found significant improvements in quality of care [98] and van Soest-Poortvliet found that satisfaction with care was associated with their goals of care intervention in people living with dementia [128]. A more recent study found no positive effects on quality of life, satisfaction with care or patient activation [129].

To date no ‘real’ cost-effectiveness study has been carried out or analysed the societal cost perspective of ACP [89, 123]. Some well-conducted studies, however, did find ACP (or interventions involving ACP facilitation as a significant element) to be significantly associated with healthcare savings (mainly less and less long hospital admissions and stays), under some circumstances; these related to people living in nursing homes and for people living with dementia. ACP itself is expected to be limited in cost or is unlikely to be more expensive than standard care [89, 123, 130]. A recent randomised trial of ACP in Dutch nursing homes found no significant differences in average costs of medical care.

If we look at the outcomes on family and on staff level, we see that ACP has also been associated with better outcomes for family members, but staff outcomes are rarely investigated in a clinical trial design in nursing homes. Research in cancer and in hospitalised older people however shows ACP to have potentially good outcomes for family, such as: reduced decision-making burden, fewer anxiety and depressive symptoms, significant stress reduction [131, 132]. The same outcomes have been tested in an exploratory trial in dementia where only 7 family carers enrolled, hence no clear conclusions could be made [133]. While they found no significant effect of ACP intervention on relatives’ levels of satisfaction with healthcare, qualitative evidence shows bereaved relatives felt more adequately prepared for decision-making following the ACP conversations [129, 134] and felt these conversations had a positive influence on relationships between relatives and surrogate decision makers [43].

5.2. Multiple barriers inhibiting uptake and implementation of advance care planning

Despite its potential effects, implementation of ACP into daily practices of nursing homes, making sure people are routinely consulted about their wishes and preferences for future care,

seems to be a worldwide challenge, with many barriers still existing on multiple levels (resident, family, professional and organisational level) [102]. While ACP is a welcomed intervention for the majority of nursing home residents, some might find these conversations difficult and emotional [43] and prefer to live “one day at a time” [135]. Reduced mental capacity [136], a lack of preparedness in both resident and family [137], older adults fearing to be a burden for their family [138] and unwillingness or reluctance in residents and/or family to discuss future and related ACP issues [139], were reported in academic literature among the barriers on resident and family level. It has been highlighted frequently, that an individualized assessment should therefore be made of the person's receptiveness, readiness or reluctance to be involved in ACP and ACP should be tailored to different cultural values and backgrounds [140–142]. Not everyone needs to engage in ACP if they do not want to [143].

Health personnel and physicians are often reluctant or ambivalent to discuss ACP related issues [139, 144]. Common barriers include: lack of general knowledge about ACP [145] and uncertainty about the right timing and appropriate opportunities, which sometimes leads to avoidance and procrastination [146]; prognosis uncertainty [147] – for nursing home residents, this mainly involves the uncertainty regarding the prognosis of dementia [95, 148]; being unsure about what their role in ACP is [148]; being unsure about legal implementations of patient or family statements [139, 149]; and not feeling confident to introduce end-of-life care topics or discuss ACP related issues [150]. Interestingly, it has also been found that healthcare staff, as well as family, want to protect the resident from sensitive issues. However, it has been beautifully highlighted by Chan and Pang in their introduction, that “this conspiracy of silence does not necessarily prevent older people from thinking about these issues” [151]. Finally, whilst nursing home managers recognize the potential benefits of ACP, they are also shown to face intrinsic and extrinsic challenges related to the ascertaining of, and the implementation of ACP [152, 153]. This indicates a need to ensure that all levels of staff, including managers, are appropriately trained and supported to undertake this work. While lack of, or insufficient, knowledge and skills in ACP of healthcare professionals are reported to be the main and more consistent factors examined in the literature, potentially hindering the completion of ACP; associated outcomes as a result of an ACP intervention is to date not yet been evaluated in a cluster randomised trial design in nursing homes. It has however been shown that before changing outcomes on patient and family level (e.g. quality of life or receiving care that is consistent with one's preferences), targeting staff level outcomes first, can be considered an important prerequisite [122, 139].

Recently, there is a growing understanding of the importance of nursing home readiness to change practice and address barriers at institutional level [103, 104, 137, 139]. First, a lack of appropriate resources has been shown to form an important barrier for implementation of ACP – both financially and professionally. This includes the lack of time or suitable private locations to hold discussions which may be difficult and lengthy. Staff shortages, low educational levels and staff turnover are also often named in various papers [154, 155]. Internationally, staffing levels of certified nurses in nursing homes are reported to be often quite inadequate [155, 156], indicating they have little time to combine clinical care tasks with ACP [157]. With this comes a second category of barriers, which are often administrative or ‘procedural’. It includes the vast array of different ACP forms and documentation that often leads to confusion; not having enough administrative support; documents not being available when needed; lack of information flow between healthcare professionals (e.g. “important information regarding healthcare or wishes getting lost upon transfer between different care settings”) [139, 148, 149, 158–160] Third, cultural or system barriers are reported. Potential factors, among others, that influence this ability of a nursing home to changing its practice include: positive (senior) leadership, which is associated with more innovation; an “innovation-receptive culture” or “unconstructive culture” (i.e. flexibility/rigidity of policies and practices); staff that support one another; opportunities for professional development; how work is organised and the amount of control staff have over their day to day practice; logistics (e.g. time schedules) and infrastructure (e.g. appropriate software); innovation being aligned with other (existing) practices and guidelines in the facility; and (competing) priorities or lack of clarity in roles and responsibilities to carry out ACP [103, 104, 139, 149, 154, 161–164]. Finally, I would like to stipulate that the wider socio-political-economical context plays a significant role as well [95, 165, 166]. This is beyond the scope of this dissertation.

6. BEYOND ‘DOES IT WORK’ TO ‘HOW’ DOES IT WORK

A wide spectrum of ACP intervention models exist which are often poorly described and offer little guidance as to how they can be applied in clinical practice or translated into routine nursing home care. Previous evaluations of ACP interventions looked predominantly at *whether* or not they improve a variety of outcomes but were not able to outline *how* they did so (or did not), i.e. why their outcomes were different than others, which specific intervention components lead to

changes in outcomes, through which processes, and in which context. Recognition is growing that intervention research, from the start, should try to understand this complexity if they are to inform practitioners, policymakers and other researchers. Lack, thereof, hinders replicability, generalizability and implementation in real world practice. Achieving this will require researchers to move beyond a ‘does it work?’ focus, towards thinking about these elements early on, and combining outcome evaluations with process evaluations [167–172].

6.1. Interventions vary and detailed descriptions inhibit identification of effective components

Systematic reviews regarding the effectiveness of ACP are unsuccessful in identifying effective models, due to their variation in content, formation, duration, the contexts in which these are implemented, as well as the lack of detailed reporting [173, 174]. Since, to date, no study has compared different interventions directly, it is difficult to say which one is more effective than the other, and more specifically, which (combination of) component(s) is the most effective on desired outcomes. ACP models that were developed over recent years, both in general as in nursing homes, vary from completing a written advance directive to more comprehensive models that include facilitated reflections and communication, completion of documents, training professionals, and have been divided in several categories ranging from 1) the introduction and evaluation of new ACP documents, ADs or DNR/DNH orders; 2) communication strategies or conversation guides; 3) ACP programmes focused on information, including those that test decision aids, and/or education/training; 4) interventions that include ACP as part of a larger intervention that is aimed at improving palliative care and related outcomes; and 5) “complex or extensive ACP interventions” [89, 124].

Current evidence is hinting that documentation alone is not effective. Interventions that include both documentation of ACP next to communication about ACP, often lead to improved agreement between preferences and delivery of requested care and may also improve other outcomes, such as the overall quality of communication [175]. Consequently, recent systematic reviews suggest that only filling out a form that documents your wishes, in the form of an AD, might not be enough to significantly impact outcomes related to end-of-life care (such as place of death, hospitalization, intensive care unit care, life-sustaining treatments, and receipt of less aggressive medical treatment) [175, 176]. ACP interventions that focus on involving not only patients, but also family and professional caregivers at the same time, are also perceived to be more effective than others in

removing barriers to end-of-life communication [177]. Complex ACP interventions are argued to increase compliance with patients' end-of-life wishes and may improve communication about end-of-life care [178].

One of the reasons for the difficulty in comparing types of interventions, is the lack of detailed information about the interventions at hand. The absence of such detail, is a generally acknowledged phenomenon in ACP research and in intervention research in general [43, 173, 179]. Intervention components are most of the time vaguely described or defined, and though intervention manuals are usually developed, they are often not referenced properly, leaving readers with little insight into what the intervention actually was [179–181]. More transparency about the content of interventions is a first important step towards more insight into ACP implementation and what is needed for it to be successful [43, 182, 183]. Even in seemingly similar interventions there is still variation between studies in terms of how official or formalised the ACP conversation and documentation is, and how they were implemented [139, 180].

6.2. Lack of insight into what leads to (in)effectiveness

As outlined above, systematic reviews have shown that it is challenging to show the reasons why trials of ACP produced effective outcomes [89]. *Visa-versa*, when trials fail to show effectiveness regarding ACP, researchers find it challenging to understand the reasons for this lack of effectiveness on outcomes [129, 184]. The authors of the Dutch trial study were left to speculate about what could have caused their unexpected results. It can be due to implementation failure [185], genuine ineffectiveness, or lack of appropriate research design or measurements (e.g. choice of outcome measured, lack of appropriate measurement instrument, etc.) [93, 172]. Hence, currently, when ACP is implemented and evaluated, we often do not know what were important causal mechanisms through which the intervention led, or failed to lead, to its desired effect and what were contextual factors that were, or are, considered critical for optimal implementation³. Such complex interventions are more than just discrete packages of components which can be described in isolation from their

³The terms 'intervention component', 'implementation', 'causal mechanism', and 'context' are often used interchangeably in literature, and one can be part of the other. In this dissertation, intervention components are considered to be part of the intervention package itself and can include different activities (training, information sessions, etc.), which can be implemented in various ways. Implementation is the process through which intervention activities are delivered, and what is delivered in practice (e.g. dose, reach, fidelity). Intervention activities produce intended (or unintended) effects through causal mechanisms (responses and interactions from participants with the intervention components). This all occurs in a specific context which is usually external to the intervention package but might influence its implementation (De Silva et al., 2014; Moore et al., 2012).

contexts [103, 186], which in case of nursing homes, might be quite complex. As is demonstrated by the study of Overbeek et al., lack of such information is limiting the understanding - and, therefore, the value - of outcome research in this area [89, 123]. Authors have noted this “black box effect” as an explicit limitation that hinders translation and implementation of evidence in clinical practice [171, 187, 188].

6.3. Need for theory-based intervention development and process evaluations

There is a need to unravel the effective components and mechanisms of change through which an intervention leads, or fails to lead, to its desired effect and to outline the contextual factors critical to optimal implementation. To make sure practitioners and policymakers have access to at least minimal information about what is required to successfully integrate ACP into routine care practice, especially in complex settings such as nursing homes, important research bodies, such as the Medical Research Council (MRC) and the MORECare statement recognize that research, needs to move beyond a ‘does it work?’ focus to *how* and *why* an intervention has a particular effect in its context, and which specific elements of a complex intervention have the greatest impact on which outcomes [171, 189]. For this, a prospective, *theory-driven* process of intervention design and combining process evaluation with outcome evaluation, is said to be required [167, 172, 187]. Previous studies using theory-driven process evaluations in other domains, such as mental health research, concluded it makes interpretation of effectiveness data easier and it advances understanding of the implementation and functioning of the intervention in its specific context [190–192].

In the development phase of an intervention, an a-priori theoretical framework force researchers to carefully –and with a clear rationale- select components to include in the intervention programme, specify mechanisms that might explain outcomes and identify implementation barriers early on [167, 172, 187, 191, 193, 194]. Interventions developed through such close scrutiny are considered by the MRC as “more likely to be effective, sustainable and scalable”. To date, current ACP intervention research hardly ever explicitly reports a clear theoretical framework underpinning the intervention design. In some cases, a “logic model” is developed including a graphic illustration of programme components, but these are more the exception than the rule and merely descriptive and not explanatory-oriented [195, 196]. Others focus on behavioural change theories, e.g. Theory of Planned Behaviour [197, 198]. However, while these studies have made a substantial contribution to intervention research, they focus primarily, or exclusively, on psychological processes and fail to include the other levels to which the intervention applies [194, 199]. In exceptional cases,

interventions are modelled based on literature reviews and primary data collection and are also reported in detail [200, 201]; however, even then, the underlying theory remains descriptive or implicit.

Combining evaluations of intervention effectiveness with detailed process evaluations has been recommended by MRC. At best, such process evaluation is guided by some knowledge of the intervention theory, in terms of which components are expected to do what [172, 187]. Use of such a theoretical framework, can help in prioritizing key evaluation questions and guide the selection of data collection. Process evaluations, assessing implementation, causal mechanisms and contextual factors, are proven to be useful to highlight what is needed for the intervention to be successful or might provide information about why the intervention did not work in a particular setting [94, 202]. Though detailed process evaluations are becoming more widely used in trials, there are only a few studies specifically looking at ACP that combined an outcome evaluation to test effectiveness with a process evaluation. A minority of these studies were set in nursing homes. There are only a few published descriptions of the actual implementation processes of ACP interventions, combined with an outcome evaluation of the intervention's effectiveness, most conducted retrospectively [94, 161, 203], and to our knowledge, only one project is currently running which included a process evaluation alongside a cluster randomised clinical trial [204].

Study objectives

The first aim (Part II) is to explore which preconditions are hypothesised to be associated with successful advance care planning in nursing homes.

The second aim (Part III) is to develop an intervention programme to improve the implementation of advance care planning in nursing homes in Flanders, and to describe the design of a cluster randomised controlled trial and process evaluation to evaluate its effects and underlying processes of change.

The third aim (Part IV) is to describe the current state of art regarding advance care planning on staff level in nursing homes in Flanders.

Aim 1: To explore which preconditions are hypothesised to be associated with successful ACP in nursing homes

Objective 1: To identify the preconditions for successful ACP in the nursing home setting outlined in the academic literature (Chapter 1)

Objective 2: To develop a theory that outlines the hypothetical causal pathway of ACP in nursing homes, i.e. which changes are expected and how, through which processes and under which circumstances (Chapter 2)

Aim 2: To develop an intervention programme to improve the implementation of advance care planning in nursing homes in Flanders, and to describe the design of a cluster randomised controlled trial and process evaluation to evaluate its effects and underlying processes of change

Objective 3: To develop and test a theory-based ACP intervention programme to improve implementation of advance care planning in nursing homes in Flanders (Chapter 3)

Objective 4: To describe the study protocol of a cluster randomised controlled trial and mixed-methods process evaluation to evaluate the effects on professional level, the implementation, causal mechanisms and contextual factors of the ACP intervention in nursing homes (Chapter 4)

Aim 3: To describe the current state of affairs regarding advance care planning on staff level in nursing homes in Flanders.

Objective 5: To describe if and to what extent the level of knowledge of, self-efficacy and experience in ACP practices differ between nurses, care assistants and allied care staff in nursing homes (Chapter 5)

Objective 6: To explore relations between ACP knowledge, self-efficacy and practices in nurses working in nursing homes in Flanders (Chapter 6)

1. THE NURSING HOME SETTING IN FLANDERS, BELGIUM⁴

Long-term care is defined as a range of services required by persons with functional, physical or cognitive disability, who need help for an extended period of time with basic activities of daily living (ADL). This is often combined with basic medical services (such as nursing care), domestic help or help with instrumental ADL [205]. If such limitations in ADL and IADL become too severe and adequate support at home (both informal and professional) is unavailable or insufficient, the dependent person should have access to suitable and affordable residential care facilities. Residential facilities provide continuous nursing and personal care as well as living facilities for dependent older people. These facilities do not have on-site medical care and only some provide psychogeriatric care for people with dementia. Nursing home in Belgium are financed according to the dependency category of the residents whom are taken care for. Most nursing homes provide nursing and personal care to older people who are strongly dependent on care. In some of these nursing homes, a day care centre, short stay wards/beds or service flats are additionally provided. Each nursing home in Flanders is recognised by the Agency for Care and Health, after meeting certain criteria and norms. These are outlined by the Flemish government . As of the 1st of January 2020, these conditions have been changed. For most requirements of recognition, different types of nursing homes are required the same criteria.

On January 1 2019, there were 821 recognized nursing homes in Flanders, which equals a total of 81,851 beds. The medical responsibility for each nursing home residents rests with a GP that is linked to the resident [206]. Relevant to ACP, nursing homes are required to always have a functional link with a hospital and to cooperate with the acute geriatric ward of the hospital (G-service or SP-psychogeriatrics), or having an established partnership agreement with a palliative network or specialised service of palliative care, and developing a transfer procedure for residents from and to the nursing homes. In addition, there must be a coordinating and advisory physician (CAP) available who coordinates the continuity of care with GPs, and i.e. the medical record of each resident, the

⁴ This section has been reviewed and accepted by the Flemish Agency for Care and Health on December 2nd, 2019 [Dutch: *Vlaams Agentschap voor Zorg en Gezondheid*].

use of a pharmaceutical formulary and teaching activities for the personnel (hygiene, palliative care...). The average out-of-pocket price per day for staying in a nursing home in Flanders, in October 2017, was calculated at €52,23 (public), €54,85 (private non-profit) and €59,04 (private for-profit).

Palliative care in nursing homes in Belgium has been addressed in regulatory processes and policy documents and it has been shown that there is widespread direct palliative care provision to nursing home residents. While there is still room for improvement according to a recent study on quality of end-of-life care reported by Pivodic et al. [39], compared to other European countries, palliative care in nursing homes is well-developed [207]. At the end of 2006 around 95.1% of the nursing homes in Flanders had a policy regarding ACP. This number gradually increased starting in 1988, with an increase (of 17.8%) in 2002 when the laws on patient rights and law on euthanasia were enacted [85, 208]. Since January 2020, each nursing home is obliged to have available a policy with regards to dementia care, ACP, palliative care and end-of-life care, and is required to establish an interdisciplinary team (under which the CAP) with regards to ACP, palliative and end-of-life care.

A reference person for palliative care in a care home (0.10 FTE per 30 residents) is responsible for the establishment of a supportive palliative care culture, provision of training for personnel, making them aware of the facility's vision statement, coordinating palliative care and keeping records on palliative care initiation for all deceased residents. They also support the palliative residents, which may or may not involve bedside care. According to the Palliative Care Federation [Dutch: *Federatie Palliatieve Zorg*] this reference person should preferably have a bachelor's degree in Human Sciences or Nursing and experience with palliative care, but these are not legal requirements. In 2010, a reference person for palliative care was available in 41.4% of nursing homes [209]. As of July 2010, there is also financing for a 0.5 FTE 'reference person in dementia', which is a member of the nursing care staff. This function is not obligatory, but optional [210].

Nursing homes in Flanders are additionally required to measure and report several quality indicators twice a year, in which there are three quality indicators that are related to palliative care (e.g. place of death) and ACP (e.g. number of residents with "an up-to-date plan for end-of-life care"). Based on the results of a quality measurement of the Flemish government in 2018 (in 786 nursing homes), 51.4% of residents in nursing homes in Flanders had some sort of plan for end-of-life care. However, still in 20% of nursing homes, less than 1 out of four has an end-of-life care plan. Note there is uncertainty to how nursing homes examine the latter quality indicator and what they perceive to be "an up-to-date end-of-life care plan" [211, 212].

2. OVERALL DESIGN OF THE PHD DISSERTATION

This dissertation is constructed according to the conceptual framework outlined by the UK Medical Research Council (MRC) Framework to guide the development and evaluation of complex health interventions [93]. The MRC framework is well known and cited in academic literature and guides the process in making appropriate methodological and practical decisions in the development and evaluation of complex healthcare interventions. It consolidates many of the above-mentioned principles of challenging complex interventions in complex settings and provided an iterative model for the design and evaluation of the ACP intervention for nursing homes in this dissertation. We followed the first three phases of the 2008 update by Craig et al. and the extension from Moore et al. on process evaluations and De Silva et al. on the Theory of Change (ToC) approach [172, 187]. Together they provide a cyclical framework advising health researchers in answering a range of sequential questions regarding complex intervention theory, intervention development, feasibility and acceptability, effectiveness and implementation. We outline the methods that were used to answer all research aims below.

3. METHODS USED TO ANSWER RESEARCH AIM 1

3.1. Systematic literature review

To meet research objective 1, we performed a systematic literature review with the aim to identify the preconditions for implementing and organizing ACP in the nursing home setting to ultimately achieve desired outcomes. We searched four electronic databases: PubMed, PsycINFO, EMBASE and CINAHL. Two authors independently screened titles and abstracts first, then full-text publications. One author assessed methodological quality and extracted textual data, which was double-checked for a random sample. We extracted textual data and used thematic synthesis to identify "preconditions", defined as requirements, conditions and elements necessary to achieve the desired outcome of ACP.

3.2. A Theory of Change approach

To meet research objective 2, we first applied a Theory of Change approach with the aim to develop a theory that outlines the hypothetical causal pathway of ACP in nursing homes, i.e. what changes

are expected, by means of which processes and under what circumstances. Following the Aspen Institute and Centre for Theory of Change, a 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 hypothesised causal pathway to impact” [187]. This is visualised in a ‘ToC map’, which provides a comprehensive illustration of how long-term outcomes can be achieved in a specific context and under particular circumstances.

Using this approach, the results of a contextual analysis and the systematic literature review in Chapter 1 were integrated with the results of two workshops with stakeholders. Stakeholders were defined as people involved in the development, implementation or organisation of ACP in nursing homes. We purposively sampled and recruited stakeholders using a variety of criteria including: (i) affiliations with a Flemish nursing home OR having knowledge of the Flemish nursing home setting OR whose work in policymaking or research, influences care in Flemish nursing homes; AND (ii) being acquainted with ACP through their work. We conducted two half-day workshops, each with a structure that was determined from the outset, including a brief introduction of the project and the theory of change approach, the importance of ACP in nursing homes and a mapping exercise using structured group discussions and small group exercises. Each workshop was facilitated by trained facilitators and resulted in a draft theory of change map, which was then frequently discussed within the core research team and reviewed by a theory of change expert. This Theory of Change approach was both used and informed the selection of data as part of the systematic literature review (Chapter 1), in the development of the theoretical model (Chapter 2), the intervention components and activities (Chapter 3), and the process evaluation (Chapter 4).

4. METHODS USED TO ANSWER RESEARCH AIM 2

4.1. Intervention development and testing

To address research objective 3, we developed a new intervention programme that aims to improve implementation of ACP into routine nursing home care by 1) specifying how the intervention can be delivered, 2) evaluating feasibility (defined as “the extent to which the intervention can be delivered as intended” [93]) and acceptability (defined as “the extent to which people delivering or receiving the intervention consider it to be appropriate” [213]); 3) providing a standardized intervention description. We carried out:

- 1) Discussions with a multidisciplinary expert group that consisted of an ethicist, psychologists, GP, sociologist, social worker and nurse, all with expertise in ACP, end-of-life care and nursing home settings.
- 2) Review of available intervention materials from existing ACP programmes that were identified, based on two existing systematic reviews and literature selection by the expert group.
- 3) Three multidisciplinary semi-structured group interviews with 15 staff members and managers of three nursing homes, and two individual semi-structured interviews with healthcare professionals with extensive experience in ACP from two other nursing homes. The participants were paid nursing home employees. Trainees and interns were excluded from participation.
- 4) Revisions of materials by, and discussions with, a palliative care nurse who has a PhD in nursing and is specialized in providing training and implementing complex interventions in nursing homes.

We used Template for Intervention Description and Replication (TIDieR) checklist [214] to describe the ACP+ programme.

4.2. Cluster randomised controlled trial

To meet objective 4, we designed and planned a cluster randomised controlled trial (RCT) that aims to evaluate the effects of the ACP+ intervention programme on nursing home staff and volunteer level outcomes and an embedded mixed-methods process evaluation to evaluate its underlying processes of change (see 4.3). Eligible nursing homes were paired and one from each pair was randomised to either continue care and education as usual or to receive the ACP+ programme (a multicomponent intervention which is delivered stepwise over an eight-month period with the help of an external trainer). Primary outcomes were: nursing home care staff's knowledge of, and self-efficacy regarding ACP. Secondary outcomes were: 1) nursing home care staff's attitudes towards ACP and ACP practices; 2) support staff's and volunteer's ACP practices and 3) support staff's and volunteers' self-efficacy. Measurements were performed at baseline and eight-months-post-measurement, using structured self-reported questionnaires. Recruitment of nursing homes started in February 2018, baseline measurement was carried out in March 2018 and follow-up measurement in December 2018 and January 2019. The study protocol of this trial study can be found in Chapter 4. Results are not reported in the PhD dissertation.

4.3. Mixed-methods process evaluation

A process evaluation ran alongside the cluster RCT in nursing homes with the aim to explore the underlying process of change of the ACP+ intervention programme in the participating nursing homes. The design of the process evaluation is informed by the MRC framework for process evaluations of complex interventions [172] and a theory of change which was constructed in Chapter 2. We aim to assess:

- *Implementation*: defined as the process through which interventions are delivered, and what is delivered in practice. Outcomes involve: how delivery is achieved and what is delivered (dose, reach, fidelity, adaptations).
- *Mechanisms of impact*: the intermediate mechanisms through which intervention activities produce intended (or unintended) effects. This involves: responses and interactions from participants with the mediators that might explain changes in outcomes and unanticipated pathways or consequences.
- *Context*: factors external to the intervention that may influence its implementation or whether mechanisms of impact act as intended, including outcomes such as contextual moderators (barriers and facilitators) and participant's intention or commitment to continuing and maintaining the implemented intervention programme.

The process evaluation had a mixed-methods design combining quantitative and qualitative research methods (structured diaries, notes, semi-structured individual and group interviews and focus groups, attendance lists, surveys) collected regularly throughout and after the intervention period. Data collection of the process evaluation ended in March 2019. Results are not reported in this PhD dissertation.

5. METHODS USED TO ANSWER RESEARCH AIM 3

5.1. Cross-sectional survey study

To evaluate objectives 5 and 6 we carried out a cross-sectional survey study conducted from March 4th, 2018 to April 23th, 2018 that also served as baseline measurement of a cluster randomised controlled trial in 14 nursing homes in Flanders (outlined in Chapter 4). All care professionals working in these 14 nursing homes were invited to participate in the survey if they complied with the following eligibility criteria: (1) working as a nurse, care assistant, psychologist, physiotherapist,

occupational therapist, social worker, animator, pastoral or spiritual caregiver, moral consultant, reference person for dementia or reference person for palliative care; and (2) to be able to speak and understand Dutch. Students, interns or volunteers under 18 years old are excluded from participation. Eligible staff were invited to participate in the survey. Staff who were willing to participate were required to complete the questionnaire and to leave it in the closed envelope in a place indicated in each nursing home. We sent out two reminders, the first after two weeks, the second another two weeks later.

The survey instrument to evaluate knowledge, attitudes, self-efficacy and experiences in ACP practices was developed by a multidisciplinary research team from different research fields: ethics, psychology, family medicine, pharmacology, social work and sociology, with expertise in both ACP or end-of-life care, and care for older adults or the nursing home context, starting from two existing questionnaires in other research populations. We tested the questionnaire via cognitive testing and a pilot test in a representative sample of 107 professionals, volunteers and managers that were working or had recently worked in a nursing home in Flanders.

6. ETHICS

Ethics approval

The methods and research procedures in the development, modelling and feasibility stage were approved by the Medical Ethics Committee, University Hospital Brussels (Vrije Universiteit Brussels, 2017/31 B.U.N. 143201732133). The cluster RCT was approved by the Medical Ethics Committee of University Hospital Brussels (Vrije Universiteit Brussels, 22/02/2018, ref: 18-003 - B.U.N. 143201834759).

Informed consent

Consent to audiotape the interviews, group discussions and focus groups was given orally in Chapter 2 and in writing in Chapters 3 and 4. In Chapter 5 and 6 consent to participate was sought at cluster level. In addition, questionnaires were filled in voluntarily by respondents; by filling in the questionnaire, the participant consented to his/her data being used in the study.

Anonymity and confidentiality

We ensured pseudonymising and confidentiality of all participants throughout the studies. Regarding the qualitative research, all names of people and places were changed when transcribing recordings

of the interviews. To protect residents' and family's privacy during interviews planned in Chapter 4, they were interviewed separately from staff and a privacy sign hung at the door. In the cross-sectional survey study and trial, all staff was assigned an anonymous code that could be linked to names by a contact person in the nursing home facility but could not be accessed by the researchers.

Data management and protection

Consistent with Good Clinical Practice (GCP) guidelines, all paper forms, including written informed consent forms and questionnaires were consistently stored in a lockable filing cabinet in a room with restricted access on campus. Names and electronic data were stored in one file only and restricted to a few members of the research team and will be stored for 15 years.

Potential harms

The studies carried out had little to no risks for participants. Only in Chapter 4, a small sample of nursing home residents and family was planned to be approached for a short interview. While residents and family generally welcome the opportunity to engage in discussions regarding end-of-life care, others may feel uncomfortable discussing questions regarding quality of life or end-of-life care issues [43]. In all questionnaires and qualitative interviews, sensitive and potentially disturbing questions were avoided, however, it cannot be ignored that people may feel distressed by thinking or talking about issues related to ACP. Hence, with regard to the study outlined in Chapter 4, a series of procedures were put in place to identify and handle any significant distress in participants. In addition, as part of the process evaluation, we assessed unanticipated consequences of the ACP+ programme during interviews with staff and management.

7. TRIAL REGISTRY

The cluster randomised controlled trial is registered at ClinicalTrials.gov (no. [NCT03521206](https://clinicaltrials.gov/ct2/show/study/NCT03521206)).
Registration date: May 10, 2018.

Dissertation outline

PART I

Chapters 1 – 6 of the are based on articles which have been published, accepted or submitted for publication in academic peer-reviewed journals. All of the Chapters can be read independently.

The three main aims of this PhD project are addressed in three separate parts of the dissertation. Each part consists of different Chapters that answer the specific underlying objectives and research question. **PART I** describes the rationale for this PhD project as well as its aims and objectives. **PART II** focuses on the exploratory work to examine preconditions for successful ACP in nursing homes. **Chapter 1** presents the results of a systematic literature review. **Chapter 2** presents a theory of change model of ACP in nursing homes in Flanders. **PART III** focuses on the modelling and testing of an intervention to improve the implementation of ACP in nursing homes in Flanders. More specifically, **Chapter 3** describes how we developed the ACP+ programme and its materials, including how we evaluated its perceived feasibility and acceptability. **Chapter 4** outlines the study protocol for a cluster randomised controlled trial and embedded mixed-methods process evaluation. **PART IV** reports baseline data and state of current affairs regarding ACP in nursing homes, with a particular focus on nursing home staff. **Chapter 5** reports to what extent knowledge about, self-efficacy in and engagement in ACP practices, differs between nurses, care assistants and allied care staff in nursing home in Flanders. **Chapter 6** explores associations between ACP knowledge, self-efficacy and practices in nurses working in Flemish nursing homes. The final section of the dissertation, **PART V**, concludes the dissertation with a summary and discussion of the main findings, describes methodological reflections, strengths and limitations of the research methods used, and aims to suggest some useful practical implications, recommendations that might help policymakers, and what future research should focus on.

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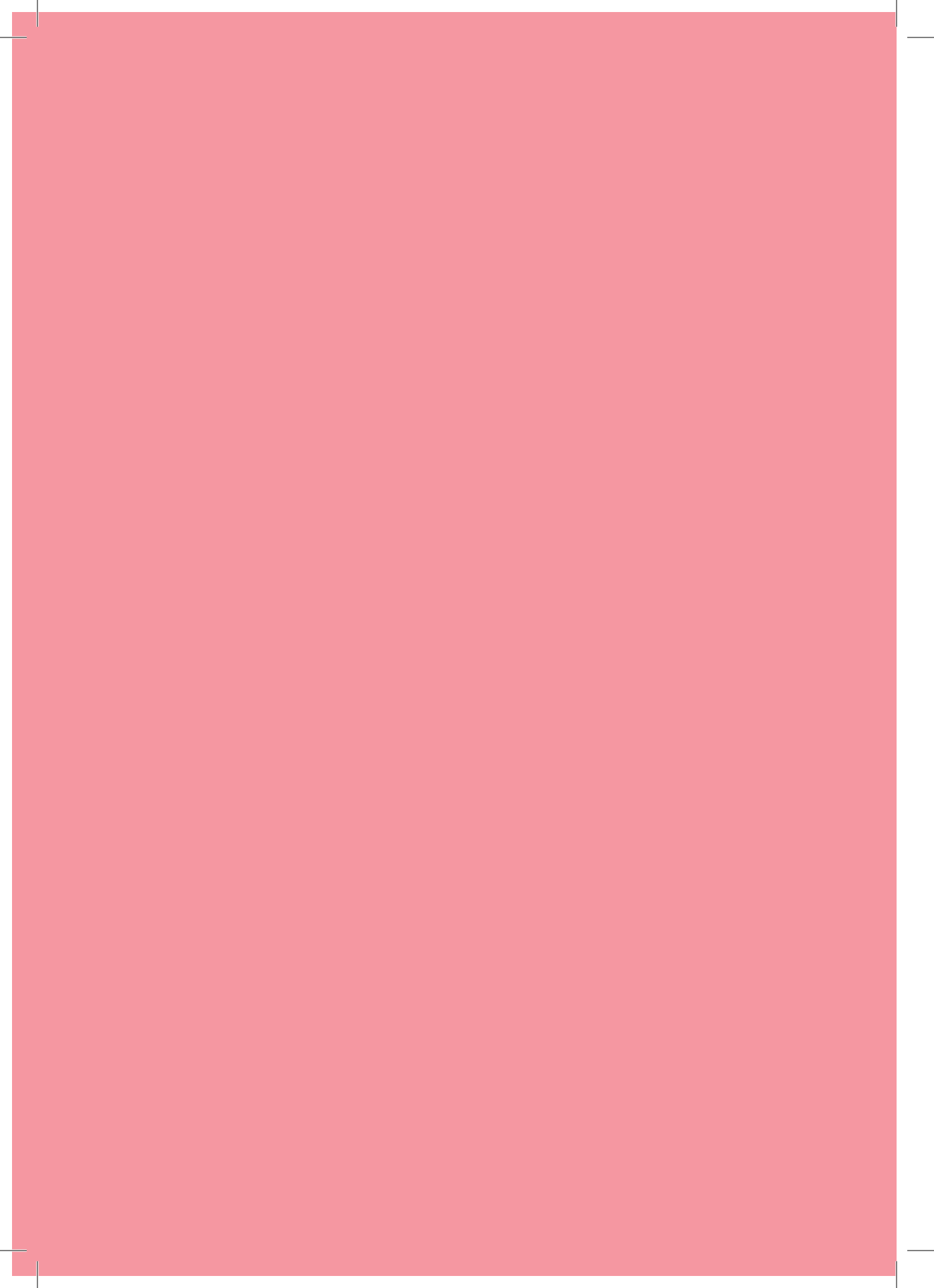
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PART II
PRECONDITIONS FOR
SUCCESSFUL ADVANCE CARE
PLANNING IN NURSING HOMES



*Chapter 1: Preconditions for successful advance care
planning in nursing homes: A systematic review*

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ABSTRACT

OBJECTIVES. There is growing evidence of the potential effectiveness of advance care planning. Yet important knowledge gaps remain regarding the preconditions for successful implementation of advance care planning in the nursing home setting. We aim to identify the preconditions related to successful advance care planning in the nursing home setting. By specifying those, we would be able to make well-founded choices for the future design and planning of advance care planning intervention programs.

DESIGN. A systematic review.

DATA SOURCES. PubMed, PsycINFO, EMBASE and CINAHL.

REVIEW METHODS. Two authors independently screened publications. One author assessed methodological quality and extracted textual data, which was double-checked for a random sample. We extracted textual data and used thematic synthesis to identify "preconditions", defined as requirements, conditions and elements necessary to achieve the desired outcome of advance care planning, i.e. attaining concordance between residents' preferences and actual care or treatment received at the end of life.

MAIN FINDINGS. Based on 38 publications, we identified 17 preconditions at five different levels: resident, family, health-care professional, facility and community. Most preconditions were situated on multiple levels but the majority addressed professionals and the nursing home itself. We summarized preconditions in five domains: to have sufficient knowledge and skills, to be willing and able to participate in advance care planning, to have good relationships, to have an administrative system in place, and contextual factors supporting advance care planning within the nursing home.

CONCLUSION. There are multiple preconditions related to successfully implementing advance care planning in the complex nursing home setting that operate at micro, meso and macro level. Future interventions need to address these multiple domains and levels in a whole-system approach in order to be better implementable and more sustainable, while simultaneously target the important role of the health-care professional and the facility itself.

BACKGROUND

Advance care planning (ACP) is a continual, dynamic process of reflection and dialogue between patients, family and care providers concerning preferences and values for future treatment and care including end-of-life care and is aimed at enhancing the concordance between preferences and actual care or treatments received¹⁻⁶. If a patient wishes, the contents of such conversations can be recorded in the form of a positive or negative advance directive, and may include the appointment of a proxy decision-maker or lasting power of attorney in anticipation of future deterioration^{7,8}. The process of advance care planning has been identified as particularly relevant for nursing home residents as they are a group with a high prevalence of frailty and multimorbidity and they often develop cognitive problems and become unable to take decisions about their end-of-life care^{9,10}. However, research shows that only a minority of older people actively engage in advance care planning, and that there is still a low prevalence of advance care planning in nursing homes¹¹⁻¹⁴. Nonetheless, a majority of this growing population would appreciate an opportunity for such a discussion¹⁵.

Advance care planning is a complex intervention¹⁰. It consists of multiple interacting components such as training professionals in their conversation skills, the actual discussions about end-of-life care and the documentation of wishes. All of these can operate at different levels in the nursing home (the level of the resident and family, the care providers, the care facility itself, or even the community), resulting in a variety of possible outcomes^{13,14}.

Despite growing evidence from randomized controlled trials regarding the efficacy of advance care planning interventions on patient and family outcomes¹⁷⁻²² (e.g. improved compliance between wishes and care received^{19,20,23}, higher quality of end-of-life care²⁴ and greater family satisfaction with care¹⁹), important knowledge gaps remain. Most importantly, we do not have a clear overview of all the important elements that contribute to optimally implementing and organizing advance care planning in the complex nursing home context^{17,25}. More specifically, it is unclear to care providers and policymakers what is needed to effectively carry out advance care planning in the nursing home setting so that its ultimate goals are attained. Understanding and mapping the most important elements is a prerequisite for an effective advance care planning intervention that is likely to be implementable in practice and sustainable in the long run²⁶. It is highly important knowledge given the time and human and financial resources that facilities invest when implementing advance care planning²⁷.

The aim of this study is to identify – through a systematic literature review – the preconditions for implementing and organizing advance care planning in the nursing home setting to ultimately achieve the desired outcome i.e. concordance between residents’ preferences and the actual care or treatments they receive at the end of life. This work is a first crucial step in a larger project that aims to develop and evaluate an advance care planning intervention program for nursing homes.

METHODS

We conducted a systematic review of published literature.

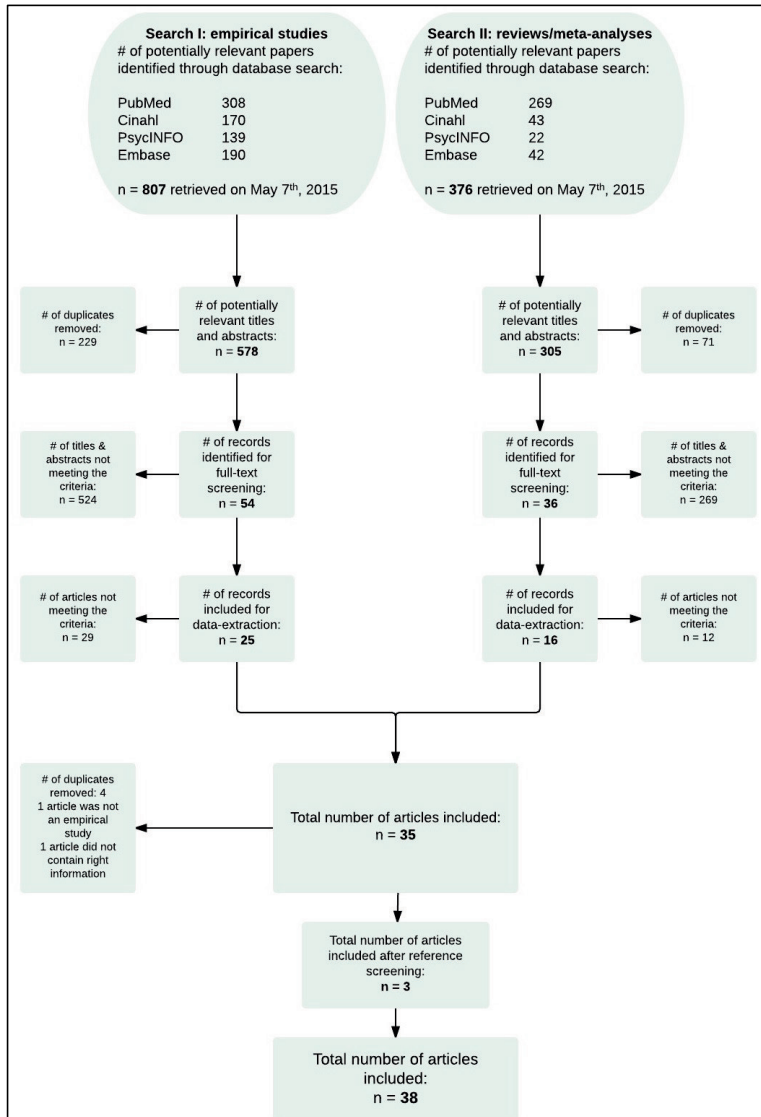
Search Strategy

Two systematic searches were conducted in four electronic databases: PubMed, PsycINFO, EMBASE and CINAHL. Articles were retrieved on May 7th, 2015. JG created a search string for PubMed and, with support from a university medical library advisor and Wolters Kluwer, translated it for use in other databases. In the first search, we extracted empirical articles on advance care planning specifically in nursing homes, published between 2004 and 2015. A second search identified reviews and meta-analyses concerning advance care planning in general with reference to the specific setting, published between 2004 and 2015. The electronic search strategy is provided as supplementary file 1.

Screening and Study Selection

Titles and abstracts were screened independently and in duplicate by two reviewers (JG and one other author, TS/LP/LVdB/CG or LD) for potential eligibility against inclusion and exclusion criteria (see supplementary file 2). In case of disagreement, consensus was reached through discussion with a third researcher. The articles selected for full text evaluation were acquired, if not electronically available, from the first author through e-mail, ResearchGate or inter-library lending, and were stored in a Zotero database. One reviewer (JG) assessed the full texts against the inclusion and exclusion criteria. In case of doubt, a second reviewer (LP) independently assessed the article. Disagreements were resolved by discussion and a third reviewer was available for arbitration (LVdB)²³. A flow diagram of the review process can be found in Figure 1.

Figure 1. PRISMA flow diagram of the study screening, eligibility, selection and inclusion process



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Theory of Change as theoretical framework

To identify the important preconditions for advance care planning from the reviewed literature, we used the Theory of Change framework as described by the Aspen Institute^{29,30}. A 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 the desired outcome’²⁹. A first and crucial step in building a Theory of Change is to identify all intermediate outcomes or “preconditions” that must be fulfilled in order for this long-term outcome to be achieved. Such preconditions are defined as all necessary requirements, conditions, elements or milestones that need to be in place for the long-term outcome to be achieved, including possible facilitators or barriers to be overcome. In a later phase of the project, these preconditions will be mapped chronologically in a causal pathway or Theory of Change map to be used in the development and evaluation of an advance care planning intervention program for nursing homes.

Data Items and Data Extraction

JG extracted data using the cutting technique, which involves identifying textual data (i.e. passages of the publication text) that are relevant for answering the research aim. Textual data, henceforth termed “excerpts”, were extracted line-by-line from the results and discussion sections. LP and LVdB each assessed the data extraction of four (10%) random articles to check the accuracy of the procedure³¹.

Quality Assessment

One author (JG) assessed the methodological quality of the research described in the included articles. The quality scores were not used to exclude articles from the review but to inform the reader about the quality of the research and to guide the interpretation of the findings. We assessed the quality of the empirical articles, using two different standardized scales: one for quantitative research (range from 0 or poor to 16 or good quality), and one for qualitative research (range from 0 or very poor to 30 or good quality)³². One article used mixed methods and was therefore evaluated using both scales. Articles were classified as having high, medium or low quality using the final scores of the scales (high >70%, medium 69-60%, low <60%)^{33,34}. The quality of the reviews was assessed using the standardized and validated Assessment of Multiple Systematic Reviews (AMSTAR) tool,

which resulted in summary scores from 0 to 11. A score of 0–4 is classified as low quality, 5–8 as medium quality and 9–11 as high quality^{35–37}.

Data Synthesis and Analysis: Identification of Preconditions

Analysis was guided by inductive thematic analysis^{38–40}, using the qualitative data analysis package QSR NVIVO 11. Each excerpt that we extracted from the articles was coded by its meaning and content as it emerged from the data. One researcher (JG) grouped excerpts with similar codes under main headings – the preconditions for successful ACP – and formulated them as outcomes i.e., as something to be achieved. All main headings were included for further analysis unless they were based on excerpts of three or fewer studies with a low quality rating. Figure 2 represents a flowchart of this coding process.

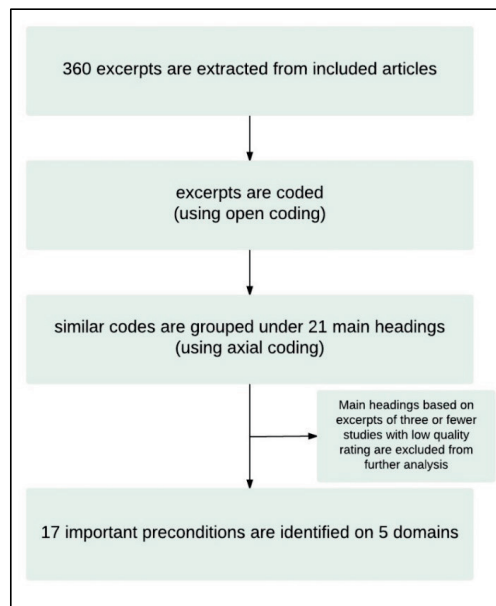


Figure 2. Flowchart of the coding process to identify preconditions (n=17) and domains (n=5) through the present review (using NVIVO)

We then described the levels to which these preconditions applied most: resident, staff (including health-care professionals in general, nurses or (family) physicians), family, nursing home facility or community level. Finally, we performed a narrative synthesis which is, unlike meta-analysis, typically used in cases

where the review's research question dictates the inclusion of a wide range of research designs, including qualitative and/or quantitative findings⁴¹.

RESULTS

Initial database searches yielded 807 references from our first search and 376 from the second. Reference list screening identified three papers⁴²⁻⁴⁴.

Article Range and Characteristics

A total of 38 articles were eligible: 14 articles describing studies using qualitative methods³⁷⁻⁴⁹ (of which 1 mixed-method article⁵⁸ that mainly employed qualitative methods), 6 articles describing studies using quantitative methods^{59,60} (of which 5 experimental designs^{20,61-63}), 7 reviews^{44,64-69} and 11 systematic reviews^{15,42,43,70-76} (of which one included a meta-analysis¹⁷). Characteristics of the included articles are described in Table 1.

Methodological quality of included articles

The median quality score of articles using qualitative methods was 16.5 (observed range: 12-20). None were of high quality. The median quality score of articles using quantitative methods, including four experimental studies, was 6 (observed range: 3-12). Three articles with an experimental design were of high quality⁶¹⁻⁶³. The median quality score of reviews was 4.5 (observed range 0-10). Two out of 11 reviews were of high quality^{17,70}.

Table 1. Characteristics of the included articles (n=38) about advance care planning

Observational qualitative studies (n=14)							
No.	First author, year of publication	Region	Methods	Sample (n)	Quality score* (range: 0-30)	Quality category†	Contributed to: Precondition x (no. of excerpts)‡
1	Addicott, 2011	Europe	Case study: interviews	Care homes (n=4)	12	low	2(0); 1(4); 6(2); 7(2); 10(1); 13(1)
2	Ashton et al., 2014	Europe	Semi-structured interviews	Family care givers within a specialist dementia unit (n=12)	16	low	14(1); 2(1); 3(2); 1(1); 6(2); 7(2); 5(2); 8(2); 10(2); 15(1); 17(1)
3	Black et al., 2009	USA	Semi-structured interviews	Surrogate decision-makers for hospice-eligible nursing home residents with dementia (n=34)	13	low	9(7); 5(2); 8(1)
4	Chan & Pang, 2011	Asia	Semi-structured interviews	Nursing home residents (n=42)	20	medium	3(0); 9(1); 5(1); 10(1)
5	Dickinson et al., 2013	Europe	Semi-structured interviews	People with mild to moderate dementia (n=17) and family carers (n=29)	19	medium	14(1); 2(5); 5(6); 8(1); 12(4)
6	Einterz et al., 2014	USA	Pre-post intervention design: chart reviews and interviews (mixed-methods)§	Nursing home residents with moderate to severe dementia and their surrogate decision-maker (n=18)	Qual: 13 Quant: 5	low	14(1); 5(1); 10(1)
7	Hall et al., 2011	Europe	Semi-structured interviews	Care home managers (n=9), nurses (n=8), care assistants (n=8), residents (n=11) and their family members (n=7)	19	medium	1(1); 6(1); 5(3); 11(1)
8	Jeong et al., 2010	Australia	Case study: participant observation, field notes, semi-structured interviews and document analysis	Residential sites (n=3)	17	low	14(2); 1(1); 6(6); 13(1)
9	Jeong et al., 2009	Australia	Case study: participant observation, field notes, semi-structured interviews and document analysis	Nursing home residents (n=3), family members (n=11) and nursing staff (n=13)	14	low	9(1)
10	Rhee et al., 2011	Australia	Semi-structured interviews	Expert clinicians, representatives of government organizations, professional societies, consumer groups and other organizations involved in aged care and end-of-life care (n=23)	17	low	2(4); 9(1)
11	Shanley et al., 2009	Australia	Semi-structured interviews	Aged care facility managers (n=44)	15	low	2(0); 4(1); 5(1); 12(1); 15(1)

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12	Stewart et al., 2011	Europe	Semi-structured interviews	Europe	Care home managers (n=33), 18 care home nurses (n=18), care home assistants (n=29), community nurses (n=10) and family members (n=15)	17	low	1(1); 5(5); 8(3); 10(5)	
13	Stone et al., 2013	Europe	Semi-structured interviews	Europe	Nursing home residents, family-members and nursing home staff (n=28)	16	low	2(4); 1(1); 9(1); 6(1); 7(3); 5(5); 10(2)	
14	van Eechoud et al., 2014	Europe	Semi-structured interviews	Europe	Family members (n=22)	19	medium	2(1); 4(0); 6(1); 5(5); 10(1); 11(6)	
Observational quantitative and experimental studies (n = 6)									
No.	First author, year of publication	Region	Methods	Sample (n)	Quality score* (0-16)	Quality category†	Contributed Precondition x (no. of excerpts)‡	to: Precondition x (no. of excerpts)‡	
15	Chan & Pang, 2010	Asia	Quasi-experimental randomized trial	non-nursing home residents (I: n=59; C: n=62)	12	high	14(1); 5(1); 15(1)		
16	Fernandes, 2008	Australia	Interrupted time series, situational analysis and audit	Aged care facility (n=1)	3	low	2(1); 9(2); 7(2); 13(1)		
17	in der Schmitt et al., 2014	Europe	Prospective non-randomized controlled trial	Nursing home residents (I: n=136; C: n=439)	12	high	14(1); 15(1)		
18	Morrison et al., 2005	USA	Non-randomized controlled trial	Nursing home residents (n=123)	6	low	9(1); 12(2)		
19	Reinhardt et al., 2014	USA	Prospective randomized trial	Family members of current nursing home residents with advanced dementia (I: n=47; C: n=40)	12	high	3(1); 9(1); 12(2)		
20	Silvester et al., 2012	Australia	Survey	Aged care organizations (n=12)	3	low	2(1); 1(3); 6(2); 7(4); 15(1)		
(Systematic) reviews and meta-analyses (n=18)									
No.	First author, year of publication	Review type	No. of studies included (n)	Quality score* (0-11)	Quality category†	Contributed Precondition x (no. of excerpts)‡	to: Precondition x (no. of excerpts)‡		
21	Bernaacki & Block, 2014	Narrative review	7	2	low	14(3); 1(2); 9(2); 6(2); 7(2); 13(4); 15(2); 17(1)			
22	Brinkman-Stoppelenburg et al., 2014	Systematic review	113	9	high	16(1)			
23	Brooke & Kirk, 2014	Literature review	4	2	low	14(1); 2(1); 1(2); 6(1); 7(3); 5(4)			
24	Butler et al., 2014	Review	16	4	low	2(1); 3(1); 9(1)			
25	Dening et al., 2011	Systematic review	17	8	medium	1(1); 9(2); 6(1); 5(2); 8(4)			

		Systematic review and meta-analysis	55	10	high	2(0); 1(0); 5(3); 12(1)
26	Houben et al., 2014					
27	Kc et al., 2015	Systematic review	18	4	low	14(4); 2(6); 4(1); 1(2); 9(3); 6(2); 7(4); 5(2); 8(1); 10(2); 11(2); 12(3); 13(1)
28	Lorenz et al., 2008	Systematic review	122	6	medium	1(2); 8(1)
29	Lovell & Yates, 2014	Systematic review	27	7	medium	14(4); 2(6); 3(2); 4(2); 1(2); 6(4); 7(3); 5(5); 8(1); 11(2); 17(1)
30	Lund et al., 2015	Systematic review	13	3	low	14(6); 1(3); 9(1); 12(2)
31	Oliver et al., 2004	Systematic review	43	4	low	7(1); 5(2)
32	Robinson et al., 2012	Systematic review	4	7	medium	9(0); 12(1); 13(1)
33	Séchaud et al., 2014	Integrative literature review	23	2	low	1(0); 6(2); 5(0); 11(1); 12(2)
34	Shalowitz et al., 2006	Systematic review	16	5	medium	9(1)
35	Sharp et al., 2013	Systematic review	26	7	medium	14(3); 4(1); 7(2); 5(13); 8(0); 11(2); 15(1)
36	Street & Ottmann, 2006	Review	85	5	medium	14(2); 12(1); 13(4); 15(1); 16(1)
37	Waldrop & Meeker, 2012	Focused literature review	86	0	low	14(1); 1(1); 5(1); 10(1)
38	Wickson-Griffiths et al., 2014	Review	4	4	low	9(1); 8(2); 12(4)

† Intervention group; C Control group

*Scoring of qualitative studies, based on Gomes et al.: Good (3pts), Fair (2pt), Poor (1pt), Very poor (0pt), final score: min=0; max=30. Scoring of quantitative and experimental studies³² Good (2pts), Fair (1pt), Poor (0pt), final score: min=0; max=16. One study used mixed methods and was therefore evaluated using both scales. Scoring of reviews, based on AMSTAR tool: “Yes” (1pt), “No”, “Can’t answer”, or “Not applicable” (0pt), final score: min=0; max=11.

‡Qualitative and quantitative studies were classified using final scores as high (>70%), medium (69-60%) or low (<60%) quality.³² Reviews were classified using final scores as high (9-11), medium (5-8) or low (0-4) quality.³⁷

‡Total n = 348

§This study mainly employed qualitative methods.

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Identified preconditions

We extracted 360 excerpts of which 348 contributed to the final preconditions. We identified 17 preconditions that were grouped into five overall domains. These are summarized below, accompanied by illustrative excerpts in Box 1. Table 2 indicates the number of articles and excerpts underlying each precondition and the level on which each precondition is located. Most preconditions were applicable to the level of the health-care professional (10 out of 17) and the facility (9 out of 17). Only a few were applicable to the community (3 out of 17).

DOMAIN 1: SUFFICIENT KNOWLEDGE AND SKILLS

1. An appropriately skilled health-care professional is available for advance care planning at the facility^{15,20,43,43,44,46,51,51,53,55,60,61,64,70,72–74}. It is important that a health-care professional (referred to as “professional”) who has the right skills initiates advance care planning.^{20,51,55,60,64,74} There was no consensus however, as to who has the responsibility to conduct advance care practice and who this appropriately skilled professional might be^{72,73}. Six articles named nursing staff,^{20,44,46,51,52,61,72} six named a physician^{15,44,53,64,72,73}, and several indicated that it had to be the general practitioner,^{53,64,72,73} nursing staff or that it could also be non-medical staff in collaboration with the treating physician.⁷⁰ Not having sufficient skills was found to be a barrier that inhibited professionals to initiate or engage in advance care planning^{17,20,45,46,50,56,60,65,67,68,71–74}. What exactly these “skills” entail was often not defined, although there was mainly specific emphasis on communication skills^{17,20,46,50,65,72,74}. Usually staff in general or social/health-care professionals were perceived to have such skills^{20,43,44,46,60,61,64,72–74}.

2. Residents, family and health-care professionals have knowledge of advance care planning^{17,43,45,46,48,53,54,56,57,59,60,63,65,68,71–73,76}. The lack of knowledge of advance care planning served as a barrier to engage in or successfully implement advance care planning. This included general knowledge or understanding of advance care planning or more specific knowledge as described in preconditions 3 and 4. Having sufficient knowledge mainly applied to the professional, resident, family or the community as a whole. Where it concerned the community, articles usually spoke of “understanding” or “awareness”, rather than “knowledge”^{54,72,73}. Reasons given for needing sufficient knowledge about advance care planning were: to accept why it is needed, to be adequately prepared, to make effective decisions,^{46,71} to counter reluctance from both professionals and residents and their families,^{49,65,72,73} and for residents to be able to share their care preferences adequately⁴⁸.

3. Residents and family have knowledge about the prognosis or illness/condition, its assumed trajectory and possible treatment options^{46,48,63,73}. It was highlighted that residents and their families often have limited understanding of the disease trajectory,^{46,66} the pros and cons of possible treatments and, if applicable, the poor prognosis^{66,73}. Residents who do understand the life-limiting nature of their illness are more likely to discuss end-of-life care or engage in advance care planning⁷³.

4. Residents, family and health-care professionals have knowledge about advance care planning-related legal issues^{15,54,57,72,73}. People are often confused about related legal issues,^{15,54,57,72,73} especially the paperwork that can have potential legal consequences^{15,54,57,72}. Professionals tend to be particularly uncertain about the legal status of directives as part of advance care planning⁵⁴. They are reluctant to discuss legal aspects with residents and their families,⁷¹ they worry about potential legal actions from family members, implementing such wishes in potentially legally inappropriate situations^{72,73} or the legal implications of not following documented wishes.

DOMAIN 2: WILLINGNESS AND ABILITY TO PARTICIPATE IN ADVANCE CARE PLANNING

5. Residents, family and professionals are willing to participate in advance care planning^{15,17,46–50,54–58,61,65,67,68,71–73,75}. While several articles state that residents are in fact willing to engage in advance care planning,^{15,51,56,58} certainly if they are informed⁷⁵ or have had previous experiences with illness and death among people close to them,^{49,57,73} reluctances to engage in advance care planning were often mentioned as a barrier. Specific, diverse reasons were named for this: residents often believe that others -family, medical staff or God- will decide for them;^{15,48,67,73} they do not want to plan ahead⁴⁹ or are not ready;^{15,48,49,73} residents, family and professionals in particular fear that advance care planning is potentially upsetting, distressing or burdensome;^{15,17,46,55–57,65} residents sometimes prefer informal over formal discussions;⁴⁹ residents experience a lack of choice;⁴⁹ residents and families are in denial and do not want to “give up”;⁷³ residents worry that professionals might abandon them too early, when they still have a chance of recovery⁷² and families feel guilty or feel they have failed their loved one^{65,71}.

6. There is a supportive culture for advance care planning in the facility and the community and health-care professionals have an open attitude towards talking about death and dying^{45,46,50,51,53,56,57,60,64,65,67,71–73}. It is important that professionals do see the benefits and importance

of advance care planning^{45,57,60,65,72,73} and that they have an open attitude towards talking about end-of-life issues^{45,50,51,72,73}. Additionally, advance care planning should be considered part of the person-centred culture and the associated care that should be provided in every nursing home^{46,51,67}. To implement and engage in advance care planning, there is a need for a change of culture in the facility or nursing home itself^{51,56,67,72}. At community level, there is ideally a common vision and conceptualization of advance care planning within the community that is reflected in the views and needs of the residents within nursing homes, their families and the professionals who are directly involved in their care^{44,53}.

7. Health-care professionals are confident and comfortable engaging in advance care planning^{15,45,46,56,59,60,64,65,72,73,75}. Lack of confidence or not feeling comfortable conducting advance care planning held professionals back from implementing advance care planning in their practice⁷⁷ or made them feel that it was not part of their role⁷³. Care professionals also often feel unconfident about addressing “emerging emotions from residents or their family”⁵⁶.

8. Residents have the cognitive capacity to discuss end-of-life care and engage in advance care planning^{15,43,46,47,49,55,69,73,77,77,78}. People with dementia are often a marginalized or disadvantaged group when it comes to timely invitations for care planning conversations and their low cognitive capacity is often seen as a barrier for initiation. Advance care planning should ideally take place before any cognitive decline,⁷² but in the case of dementia, in various stages of the condition, the person must be involved in decision-making as much as possible.^{69,71} One study even emphasizes that people with advanced dementia are also able to participate to some extent in end-of-life decisions^{46,49}. If not, surrogates can participate,⁴⁷ because their preferences might be more often concordant with those of the resident than those of the physician⁴³.

9. Wishes and preferences are known by the health-care professionals, the family and within the facility^{20,42,47,48,51,53,56,59,63,64,66,69,74,77–79}. In order to improve that care is consistent with residents’ wishes and preferences, knowing the residents’ wishes is an obvious precondition. However, research shows that this is often not the case^{47,51,63,77}. Knowing someone’s wishes concerning treatment and care can prevent unnecessary disputes over treatment decisions at the end of life and possible inappropriate care that is not in line with the residents’ wishes^{48,69}. Hence family or professionals are no longer forced to make decisions without any knowledge of what the resident might have preferred^{59,69}. As such, residents who engage in advance care planning are more likely to have their wishes respected^{20,42,53,63,64}.

DOMAIN 3: GOOD RELATIONSHIPS

10. There is a good relationship between staff and family and between staff and residents^{45,46,55–58,61,68,72}. Disputes between staff and family is often an important barrier to successful advance care planning.⁵⁵ Additionally, direct contact between physicians and families in the nursing home setting is found to be rare⁵⁸ and good relationships are frequently lacking⁶⁸. Conversely, prior familiarity among staff and residents, functions as a facilitator⁵⁵ and the importance for the resident of feeling trusted and in a “therapeutic” or “trusting” relationship with the physician and staff was highlighted^{45,46,55–57,61,72}. The importance of a good relationship between family and staff^{46,55–58,68,72} was accentuated more than the relationship between residents and nursing staff,^{45,55,56,61,72} although both are important.

11. Family dynamics are incorporated in the process^{15,50,57,67,73,77}. Family issues, dysfunctional family dynamics and disagreement within families can hinder advance care planning^{15,50,72,73}. Different family members also often take different positions in end-of-life care planning, depending on the degree of responsibility they want to take and the expectations of their family member⁵⁷. Professionals must be aware of such family dynamics⁶⁷.

DOMAIN 4: AVAILABILITY OF AN ADMINISTRATIVE SYSTEM FOR DOCUMENTING WISHES AND MONITORING CARE

12. There is a written record of the expressed wishes and preferences that is readable, accessible and clear^{20,44,49,54,63,67,69,74,77,79,80}. The outcome of advance care planning conversations is often measured by the increase in the number of standardized records or advance directives (ADs)^{17,49,51,54,62–64,67,69,74,76} and is additionally reported as one of the most important measures of the success of an advance care planning intervention^{17,62,69}. It is emphasized that, if recorded, related documents should be easily accessible when needed⁷⁷ and they should be clear and comprehensible so health-care professionals do not differ in interpretation and care can always be as consistent as possible with the residents’ hopes and choices^{44,80}.

13. Consistency between care and residents’ wishes is monitored regularly and feedback on performance is provided to the health-care professionals involved^{44,45,51,59,64,77}. To improve practice and ensure that care providers adhere to residents’ preferences, authors particularly

recommend real-time monitoring, feedback on performance and evaluative information for physicians,⁶⁴ external care providers in other settings⁴⁵ and health-care professionals in general^{59,77}.

DOMAIN 5: SUPPORTIVE CONTEXTUAL FACTORS

14. There are sufficient resources and time available for ACP^{15,44,46,49,51,58,61,62,64,65,68,73,74,77}.

Inadequate resources, additional costs, lack of time and specific tasks that conflict with other job demands are often mentioned as major barriers to implementing or organizing advance care planning^{15,49,58,61,64,65,72–74}. What these inadequate resources and additional costs specifically are is not defined. Only one article explicitly states: “payers should reimburse health-care providers for their time-investment in advance care planning”. Who these payers are, is not defined⁶⁸.

15. Advance care planning is embedded in routine or standard care in the facility^{15,44,46,54,60–}

^{62,64,76}. Advance care planning should be embedded in routine or standard care,^{62,76} integrated in the context of everyday practice and procedures^{44,46,61,74} and should ideally be a routine component of care and the care planning process in the facility^{15,54,60,64}.

16. Advance care planning also includes a community approach^{44,81}. Community involvement need to be addressed within advance care planning as well as educational, systematic and cultural concerns^{44,81}.

17. There is end-of-life or palliative care in place^{46,64,73}. Residents receiving and professionals working in specialized palliative care seem associated with greater uptake of advance care planning⁷³. Palliative care experts tend to explore nonmedical issues more often and are more patient-centred in their discussions with residents about goals of care and end-of-life care planning⁶⁴.

Box 1. Examples of excerpts underlying each precondition (n=17)

Precondition	Example excerpt	Article	Type of data	Level
1	"Good communication skills are necessary for staff to conduct discussions,..."	Hall et al., 2011	recommendation	health-care professional
2	"Five barriers to undertaking ACP were identified: lack of knowledge and awareness"	Dickinson et al., 2013	finding	resident, family, health-care professional and community
3	"... , thus understanding the risks and benefits of treatment options is essential"	Reinhardt et al., 2014	recommendation	resident
4	"Health professionals, patients and families all report being confused about the legal status of ACP"	Lovell & Yates, 2014	finding	resident, family and health-care professional
5	"the reason some patients did not develop an ACD was because they were reluctant to discuss such matters and preferred to leave the decision to others."	Black et al., 2008	finding	resident
6	"Ethos of the care home about ACP and EoL, that "dying is allowed" and "discussed", is highlighted to be a factor that they thought is associated with whether care homes carry out ACP effectively"	Addicott et al., 2011	finding	facility
7	"The reluctance of health professionals to initiate ACP discussions included personal discomfort..."	Brooke & Kirk, 2014	finding	health-care professional
8	"Staff and families identified residents who lacked cognitive capacity as a common barrier to ACP"	Stewart et al., 2011	finding	resident
9	"They experienced an ethical dilemma about whether they were doing more harm than good by delivering care without knowing what the residents would have wanted or the families would have wanted for their relatives."	Jeong et al., 2010	finding	health-care professional
10	"... quality of relationships of family with providers have been found to influence ACP"	Waldrop et al., 2012	finding	family and health-care professional
11	"Family issues could hinder the process of implementing ACP"	Ke et al., 2015	finding	family
12	"... formally recording wishes may be more important when people do not have close family or friends"	Dickinson et al., 2013	finding	facility
13	"... check a patient's ACP status for congruence between patients' stated wishes and actual care"	Street & Ottmann, 2006	recommendation	facility
14	"Health professionals also reported the pressure to see a large number of patients and difficulty of scheduling timely follow-up visits conflicts with the time needed for these conversations and so greatly reduced their ability to hold them."	Sharp et al., 2013	finding	health-care professional and facility
15	"ACP programmes should be integrated into nursing home care practice".	Chan & Pang, 2012	recommendation	facility
16	"ACP interventions should have a system-wide focus and address educational, systemic, and cultural concerns as well as community involvement issues."	Street & Ottmann, 2006	recommendation	no specific level
17	"System factors: life-sustaining care is the default, no systems for end-of-life care..."	Bernacki & Block, 2014	finding	facility

ACP Advance care planning; EoL end-of-life

*The level to which the excerpt is applicable: resident level, health-care professional (in general, nurse or primary physician), family, facility, community or not applicable to a specific level.

†The type of data of each excerpt: a *finding* from an article that was not named explicitly as a barrier or facilitator for ACP, as this was rather a current state, a fact or a problem; or a *recommendation* made by the author(s).

PART II

Table 2. Summary of the domains (n=8), the underlying preconditions (n=17) and the levels to which each precondition is applicable

N°	Preconditions	No. of articles	No. of excerpts	No. of articles high quality	No. of articles medium quality	Level*				
						Resident	Family	Health-care professional	Community	
Domain 1 Sufficient knowledge and skills										
1	An appropriately skilled health-care professional is available for ACP	16	29	1	4			X	X	
2	Residents, family and health-care professionals have knowledge of ACP	14	34	1	3	X	X	X		X
3	Residents and family have knowledge about the illness trajectory and prognosis	5	7	1	2	X	X			
4	Residents, family and health-care professionals have knowledge about ACP related legal issues	5	6	0	3	X	X	X		X
Domain 2 Willingness and ability to participate in ACP										
5	Residents, family and health-care professionals are willing to participate in ACP	20	65	1	8	X	X	X		
6	There is a supportive culture of ACP in the facility and the community and health-care professionals have an open attitude towards talking about death and dying	13	27	0	4			X	X	X
7	Health-care professionals are confident and comfortable to engage in ACP	11	28	0	2			X		
8	Residents have the cognitive capacity to discuss end-of-life care and engage in ACP	10	17	0	4	X				
9	Wishes and preferences are known by the health-care professionals, the family and within the facility	16	27	1	4	X	X	X	X	
Domain 3 A good relationship										
10	There is a good relationship between staff and family caregivers and residents	9	16	0	2	X	X	X		
11	There are good family dynamics	6	14	0	4		X			
Domain 4 Availability of an administrative system for documenting wishes and monitoring care										
12	There is a written record of the expressed residents' wishes and preferences available in the facility, that is readable, accessible and clear	11	20	3	2					X

13	Consistency between care and residents' wishes, is monitored regularly, and feedback regarding their performance is provided to the involved health-care professionals on their performance	7	13	0	1		X	X		
Domain 5 Supportive contextual factors within the nursing home										
14	There are sufficient resources and time available for ACP	14	31	1	5		X	X		
15	ACP is embedded in routine or standard care	8	9	1	4		X	X		
16	ACP also includes a community approach	2	2	1	1		X	X		
17	There is an end-of-life or palliative care system in place	3	3	0	1		X	X		
Total			348			7	7	10	9	3

ACP Advance care planning

X = The level to which most excerpts underlying this precondition were applicable.

PART III

DISCUSSION

Based on 38 publications with heterogeneous study designs and primarily moderate methodological quality, we have identified 17 preconditions in five domains. These domains are: 1) sufficient knowledge and skills, 2) willingness and ability to participate in advance care planning, 3) good relationships, 4) availability of an administrative system for documenting wishes and monitoring care, and 5) supportive contextual factors. We also identified the different levels to which each precondition is applicable, i.e. resident, family, health-care professional, facility and community level. There are multiple preconditions related to successfully implementing and organizing advance care planning in the complex nursing home context, and these preconditions operate at both ‘micro’, ‘meso’ and ‘macro’ level. This finding is in line with previous studies highlighting that successful implementation of initiatives to improve palliative and end-of-life care in health services requires a whole-system approach to bring about change^{76,78 43}. In particular, our findings indicate that health-care professionals and the facilities themselves appear to play an important role.

Other authors have found that a successful advance care planning intervention should combine effective communication with the completion of advance directives⁸³ or suggest that “complex interventions” are more effective⁸⁰ without really specifying what elements are actually needed to improve patient and family outcomes. Our review is the first to provide a summary of important preconditions that should especially be targeted by the programme. The results of our systematic review have important value for the future design and planning of advance care planning intervention programs in nursing homes. Interventions aimed at achieving sustainable effects in this complex setting cannot be limited to one intervention component (such as training health-care staff⁸⁴) but should address multiple domains and levels and take into account a multitude of factors in order to implement advance care planning optimally and provide care that is consistent with residents’ wishes and preferences. This summary of preconditions can subsequently be evaluated in the future to identify key features in advance care planning effectiveness.

Current internationally available advance care planning programs and interventions do not take an extensive whole-system approach as recommended here. While some focus primarily on the resident

and the family,⁶¹ others specifically emphasize training of health-care professionals to improve their skills and knowledge^{84,85}. In addition, many effective models use external advance care planning facilitators who conduct conversations with residents,^{19,62,86} a delivery model that is unlikely to be sustainable in the long run,^{74,87} and we doubt its cost-effectiveness. Current programs lack crucial elements for optimal implementation such as the need for an appropriate administrative system, a supportive culture for advance care planning and open attitude towards death and dying in the whole facility, a good monitoring system to evaluate facilities' and health-care professionals' performances, or the willingness of all staff to engage in such conversations, which were preconditions identified in this literature review.

Thus, the potentially effective elements of advance care planning programs might not only be the elements addressed by previous interventions but could also include and target the wider multi-level system in which advance care planning is implemented and organized. We found some advance care planning programs that did emphasize the importance of the wider context by including a formal review of advance care planning outcomes in multidisciplinary meetings or providing feedback on physicians' performance in providing patient-centred care^{20,88}. However, other preconditions, including the importance of a supportive culture and an open attitude, that we found to be important, were still lacking.

Strengths and limitations

To the best of our knowledge, this is the first systematic review that uses the Theory of Change framework to provide an evidence base that supports the suggestion that advance care planning should entail a whole-system approach, and additionally provides guidance as to the specific preconditions that interventions need to meet and the levels they need to address⁸⁹. The use of this established theoretical framework enabled us to identify and extract “preconditions” systematically. While we have used the Theory of Change approach, other attempts have been made to integrate theory into intervention development and evaluation, for example by using the Theoretical Domains Framework^{90,91}. Such approaches from implementation science are used to help apply theoretic approaches to model interventions aimed at behavioural change. The additional strength of using Theory of Change is that all identified preconditions will be integrated into one hypothetical causal pathway on how outcomes of advance care planning are to be achieved, that all intervention components are identified as activities to achieve that pathway, and that indicators will be developed

to measure to what extent all preconditions are achieved to use during the intervention's evaluation phase. This will allow us to understand *whether* but also *how, why* and *under what circumstances* the advance care planning programme works²⁶. Other studies about advance care planning did not use an approach such as ours to preliminary synthesize literature and process evidence to inform their hypothesis about what is needed early on, to enhance its effectiveness in the future. Another methodological strength is that we tried to mitigate the risk of error in the data extraction by selecting a random sample to check for accuracy. Additionally, we were able to integrate different types of data systematically by extracting (textual) data and performing data analysis in NVIVO. To safeguard the quality of the data, we excluded preconditions that were only based on three or fewer low-quality studies.

Our study has some limitations. Because the inclusion criteria used for the review were intentionally narrow, we may have missed potentially relevant studies. Due to the different study types we included, comparisons between methodological quality scores were not possible. Considerable human judgment was also involved in the analysis and coding of the preconditions, and this judgment is of course somewhat fallible³². Finally, while we identified a broad range of preconditions from the literature, not all studies included were of high quality. Hence we could not identify the relative strength of each of the preconditions in predicting the desired outcomes of advance care planning. Future intervention studies should evaluate the extent to which these preconditions are predictive, sufficient and/or necessary.

Deciding on which intervention components are needed to target the preconditions formulated in this review will be subject of our subsequent work in which these preconditions will be discussed during intensive stakeholder consultations, while examining existing ACP interventions that have been developed and evaluated in the past (and were proven to be efficacious)²².

CONCLUSION

This systematic review provides a considerable contribution to the evidence base of preconditions for optimal implementation of advance care planning in the nursing home context. Findings support efforts to improve advance care planning by giving particular attention to health-care professionals and the facility, stipulating that a whole-system approach must be taken. This paper also highlights that a theoretical framework such as the Theory of Change is useful to identify preconditions for

achieving desired outcomes for complex health-care interventions such as this one. By specifying these preconditions, we expect to be able to make well-founded choices among different components for the ACP intervention program that we will develop in the subsequent steps of our project.

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ADDITIONAL FILES CHAPTER 1

Table A1. Search String Pubmed*

Empirical studies		Reviews/meta-analyses	
ID#	Searches	ID#	Searches
1	advance care planning [Mesh] OR advance* care plan*[Title/Abstract]	1	advance care planning [Mesh] OR advance* care plan*[Title/Abstract]
2	Advance Directives [Mesh] OR advance* directive*[Title/Abstract]	2	systematic review [ti] OR meta-analysis [pt] OR meta-analysis [ti] OR systematic literature review [ti] OR this systematic review [tw] OR (systematic review [tiab] AND review [pt]) OR review [pt] OR meta synthesis [ti] OR integrative review [tw] OR integrative research review [tw] OR rapid review [tw] OR cochrane database syst rev [ta] OR evidence synthesis [tiab]
3	Living Wills [Mesh] OR "living will"[Title/Abstract] OR "living wills"[Title/Abstract]	3	#1 AND #2
4	#1 OR #2 OR #3	4	Filters activated: English
5	nursing home[Title/Abstract] OR "Nursing Homes" [Mesh] OR "long-term care facility"[Title/Abstract] OR "long-term care facilities" [tiab] OR "longterm care facility" [Title/Abstract] OR "long-term care facilities" [tiab] OR "care home"[Title/Abstract] OR "care homes" [tiab] OR "assisted living facility"[Title/Abstract] OR "assisted living facilities" [tiab] OR "residential care"[Title/Abstract] OR "Assisted Living Facilities" [Mesh] OR "Homes for the Aged" [Mesh] OR "elderly patient"[Title/Abstract] OR "older people"[Title/Abstract] OR "aged care"[Title/Abstract] OR "long term care home"[Title/Abstract] OR "long term care homes" [tiab] OR "long-term care home"[Title/Abstract] OR "long-term care homes"[tiab]		
6	#4 AND #5		
7	#6 AND Filters: Abstract; Publication date from 2004/01/01 to 2015/01/01; English		

*Translations to PsycINFO, CINAHL and Embase are available on request.

Table A2. Inclusion and exclusion criteria

Inclusion criteria Search I - All connected by 'AND'
Peer-reviewed article in English language
Publication date is between (1 January) 2004 – (1 January) 2015
Abstract available online
Subject: Article concerns ACP as stated in the MeSH-definition* OR in the study ACP is an important and substantial element of a wider palliative care, support or (quality) improvement programme OR the article concerns a discussion about end-of-life care issues as defined in the MeSH-definition*, but does not refer to it explicitly as “ACP” (e.g. “goals of care”)
Setting: The article includes information about the nursing home setting (or synonyms for this setting)†
Design: Empirical studies, RCTs and other quasi-experimental or interventional studies (comparison groups include usual care or other interventions) and observational studies
Exclusion criteria Search I - All connected by 'OR'
Duplicate
Subject
<ul style="list-style-type: none"> - Main focus on specific condition (e.g. cancer, renal disease, COPD, heart failure...), except dementia - Main focus on specific medical treatment or action (e.g. enteral nutrition, CPR, dialysis, amputation...) - Main focus on end-of-life decisions (ELDs; e.g. physician assisted suicide (PAS), euthanasia, withdrawing or withholding from possibly life-prolonging treatments (such as Do-Not-Resuscitate orders) and alleviation of pain and symptoms, Do-Not-Hospitalize orders (DNH's) or Advance Directives (AD's) <u>without</u> any reference to the communication/discussion process or other elements cited in the MeSH definition of ACP - If ACP is an outcome of another intervention rather than the intervention itself - Article concerning general care planning
Population: Population with a specific condition (except if the focus is on dementia and/or Alzheimers), racial, gender or cultural differences, psychiatric or paediatric population
Setting:
<ul style="list-style-type: none"> - Does not include information about the nursing home setting (or synonyms), only on other settings such as hospitals, ICU, primary care and home care. - Main focus only on transitions between different health care settings
Congress reports or –abstract, book or book chapter, opinion piece, editorial or discussion article, individual case report, evaluation of local programme, questionnaire or training session, or a PhD submission.
Inclusion criteria Search II - All connected by 'AND'
Peer-reviewed article in English language
Design: Systematic reviews, literature reviews and/or meta-analyses
Subject: Article concerns Advance Care Planning (ACP) as stated in the MeSH-definition*
Setting: Article includes information about the nursing home setting (or synonyms)† OR article is not setting-specific but is written in general terms without any reference to a specific setting
Population: Adult population OR the article is not population-specific but is written in general terms without any reference to a specific target group
Exclusion criteria Search II - All connected by 'OR'
Duplicate
Design: Not a systematic review, literature review or meta-analysis
Subject:
<ul style="list-style-type: none"> - Main focus on end-of-life decisions, do-not-Hospitalize orders (DNH's) or Advance Directives (AD's) <u>without</u> any reference to the communication/discussion process or other elements cited in the MeSH-definition* of ACP - Main focus on specific condition, medical treatment or action
Setting: Main focus on transitions or transfers between different health care settings, hospital, ICU or home-setting
Population: Population with a specific condition (except if the focus is on dementia and/or Alzheimers' disease), racial, gender or cultural differences, psychiatric or paediatric population

* MESH-definition ACP: “the discussion with patients and their representatives about the goals and desired direction of the patient’s care, particularly end-of-life care, in the event that the patient is or becomes incompetent to make decisions”.

† We refer to ‘nursing homes’ as ‘care homes’ defined in the review of Hall et al.(2013)⁵. ‘Care homes’ in this study were identified as “collective institutional settings where care is provided for older people 24 hours a day, 7 days a week. The care provided includes on-site provision of personal assistance with activities of daily living. Nursing and medical care may be provided on-site or provided by nursing and medical professionals from services external to the setting”. In line with Hall et al., we thus include nursing and residential homes, and aged care or long-term care facilities.

⁵ Hall S, Koliakou A, Petkova H, Froggatt K, Higginson IJ. Interventions for improving palliative care for older people living in nursing care homes. In: The Cochrane Collaboration, Cochrane Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd; 2011.

PART II

*Chapter 2: How to achieve the desired outcomes of
advance care planning in nursing homes: A Theory of
Change*

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ABSTRACT

BACKGROUND. Advance care planning (ACP) has been identified as particularly relevant for nursing home residents, but it remains unclear how or under what circumstances ACP works and can best be implemented in such settings. We aimed to develop a theory that outlines the hypothetical causal pathway of ACP in nursing homes, i.e. what changes are expected, by means of which processes and under what circumstances.

METHODS. The Theory of Change approach is a participatory method of programme design and evaluation whose underlying intention is to improve understanding of how and why a programme works. It results in a Theory of Change map that visually represents how, why and under what circumstances ACP is expected to work in nursing home settings in Belgium. Using this approach, we integrated the results of two workshops with stakeholders (n = 27) with the results of a contextual analysis and a systematic literature review.

RESULTS. We identified two long-term outcomes that ACP can achieve: to improve the correspondence between residents' wishes and the care/treatment they receive and 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. Besides willingness on the part of nursing home management to implement ACP, other necessary preconditions are identified and put in chronological order. These preconditions serve as precursors to, or requirements for, accomplishing successful ACP. Nine original key intervention components with specific rationales are identified at several levels (resident/family, staff or nursing home) to target the preconditions: selection of a trainer, ensuring engagement by management, training ACP reference persons, in-service education for healthcare staff, information for staff, general practitioners, residents and their family, ACP conversations and documentation, regular reflection sessions, multidisciplinary meetings, and formal monitoring.

CONCLUSIONS. The Theory of Change map presented here illustrates a theory of how ACP is expected to work in order to achieve its desired long-term outcomes while highlighting organisational factors that potentially facilitate the implementation and sustainability of ACP. We provide the first comprehensive rationale of how ACP is expected to work in nursing homes, something that has been called for repeatedly.

BACKGROUND

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^{1,2}. If a person chooses so, the contents of such conversations can be set down in writing^{3,4}. ACP is of particular relevance for frail older adults, considering their unpredictable and prolonged dying trajectories characterised by multiple cognitive and functional limitations⁵⁻⁷. Despite the sizeable portion of older people who remain at home until death^{8,9}, circumstances sometimes require them to move to a nursing home^{5,10,11}. In Belgium in 2013, 11% of people aged 75 and over and 26% of people aged 85 and over lived in a long-term care facility such as a nursing home¹². This makes the nursing home a particularly relevant setting for ACP.

However, the actual implementation of ACP in nursing home practice seems to be a worldwide challenge. Recent studies have shown that there is still a low prevalence of ACP engagement among older adults¹³⁻¹⁵ and that fewer than 11% of nursing home residents in Germany (2012) have completed an advance directive¹⁶. This is also the case in Flanders, Belgium. Although ACP policy documents are available in 95.1% of Flemish nursing homes¹⁷⁻¹⁹ and orders from general practitioners (GP orders) are relatively common among Flemish nursing home residents with dementia (59%), only three percent has an advance patient directive and eight percent has assigned a legal representative at time of death^{20,21}.

ACP is a complex intervention with multiple components operating at different levels of the healthcare system²², and until now it has been unclear what the effective elements of the intervention are and how or in what circumstances ACP can best be implemented in routine nursing home care^{15,23-25}. To provide a more detailed understanding of the effective elements and such circumstances, frameworks such as those from the Medical Research Council (MRC), the TIDieR checklist for better reporting of interventions, the MORECare statement or the multiphase optimization strategy (MOST) state that prior to modelling and evaluating an intervention, those developing them should specify the processes through which and the circumstances under which the intervention is expected to lead to the desired change^{22,26-30}. The MRC further articulates the importance of 'theory' and states that researchers should develop or report the logic model or theory behind the intervention early on, "to focus on the most important uncertainties that need to be addressed and hence advance

understanding of the implementation and functioning of the intervention”²². While there is literature outlining how interventions are supposed to be delivered, only a few reported their development, including the outline of an *a-priori* rationale, logic model or theory. It has been suggested that ACP can be informed by health behaviour models^{31,32} such as the Representational Approach to Patient Education, as described in a recent study from Song and Ward (2015)³³. However, except for the latter example, we have found no description of the development or use of such theory to inform intervention development for or evaluation of a comprehensive ACP programme in the nursing home setting. This is in fact a common problem identified in non-pharmacological (e.g. psychosocial and educational) intervention studies in general³⁴.

AIM

In this study, we aimed to develop a theory that outlines the hypothetical causal pathway of ACP in nursing homes, i.e. which changes are expected and how, through which processes and under what circumstances. This serves as a first step in the development of an ACP intervention for the nursing home setting.

METHODS

Design

A Theory of Change approach was used to develop a ‘theory of change’ for ACP using input from stakeholders from various backgrounds in two workshops. We integrated the results of these workshops with the results of a contextual analysis, a systematic literature review about preconditions for successful ACP in nursing homes (published elsewhere³⁵ and in Chapter 1), and relevant literature in the field.

Theory of Change approach

Following the Aspen Institute and Centre for Theory of Change, a Theory of Change (ToC) is “a theory of how and why an initiative works which can be empirically tested by measuring indicators

for every expected step on the hypothesised causal pathway to impact³⁶. This is visualised in a ‘ToC map’, which provides a comprehensive illustration of how long-term outcomes can be achieved in a specific context and under particular circumstances^{36,37}. Within this map specific terms are used (see Table 1).

Table 1. Theory of Change terminology

Terminology	Definition (Adapted from De Silva, 2015 ³⁶)
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 programme.
Long-term outcomes	The outcome that the programme 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 programme 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.

ACP Advance care planning

The process used to create a ToC map is ‘backwards outcome mapping’. This means that one starts by defining the ultimate impact and long-term outcomes that are to be achieved. From this point, ‘working backwards’ means that all preceding intermediate outcomes or ‘preconditions’ required to reach this envisioned impact are defined. Because this is different to the conventional ‘so-that’ reasoning, as it is called, it allows better reflection on the reality of how this intervention will achieve impact³⁸.

In this paper, we illustrate the process of developing a ToC map as part of the development phase of an ACP intervention. It is suggested by De Silva et al. (2014) that it has the potential to strengthen the MRC framework in all four of its phases: I) development, II) feasibility/piloting, III) evaluation and IV) implementation. During development, a ToC approach may enhance stakeholder engagement, improve the initial design of the intervention and help tailor the intervention to its specific context. During feasibility and pilot testing, it can highlight barriers to implementation and test the acceptability and applicability of the intervention in more detail. In the evaluation phase, the ToC map can enable a comprehensive evaluation of the implementation process to disentangle the key features of its effectiveness ³⁶. Combining the experience of implementation and evidence

gathered in the evaluation phase, this map can subsequently be revised to produce a ‘story’ of how ACP worked in a particular setting³⁶.

Setting

We performed this study in Flanders, where 60% of the Belgian population lives (approximately 6.5 million people out of a total of 11 million). Flemish nursing homes are facilities providing skilled nursing care for older adults who have problems with daily life activities and/or cognitive capacity. Medical care, including end-of-life care, is usually provided by external general practitioners (GPs) who are not part of the regular team of professionals in the nursing home³⁹. However, nursing homes are legally obliged to have at least one coordinating and advisory physician (CAP) (remunerated according to the number of beds), who coordinates medical care in the facility, as well as reference nurses for palliative care (0.10 FTE per 30 residents)⁴⁰. Together they are responsible for embedding a “palliative care culture”, sensitising staff about palliative care, providing GPs with advice, and organising specific training on palliative care³⁵. However, the training and accreditation of these physicians and nurses in palliative care is not legally regulated, which makes it unclear to what extent they can actually impact daily practice.

Steps to develop the Theory of Change map

We undertook six steps to develop the ToC map: **1)** context analysis, **2)** systematic literature review, **3)** first ToC workshop with stakeholders, **4)** meetings with core research team, **5)** second ToC workshop with stakeholders and **6)** finalizing meetings with core research team. Table 2 outlines the goals, methods and output of each of these steps. The results of the systematic review (step 2) are published elsewhere³⁵. In the following section, we describe in more detail which stakeholders were selected to take part in the workshops and how these were structured to develop the ToC map.

Table 2. Aim, methods and output of each step in developing Theory of Change map

Step	Aim	Methods	Output
1	To obtain full background information on ACP in Flanders and the nursing home context	Contextual analysis by means of: (literature) review of existing policies, national guidelines, national studies of ACP in the Flemish nursing home setting (e.g. PACE EU FP7 project) and local/national ACP initiatives for the nursing home setting	Background report listing possible barriers and facilitating factors† for ACP in nursing homes related to 1) the resident (e.g. average time of stay in a nursing home is 3 years), 2) family (e.g. family listed as contact person often not according to regulated cascade system±), 3) involved care professionals (e.g. GPs in Flanders are not employed by nursing home facilities), 4)

			facility (e.g. staff shortages), 5) Belgian/Flemish (healthcare) system (e.g. ACP policy not driven by law; existence of formal quality indicators)
2	To identify the preconditions related to successful ACP in the nursing home setting	Systematic review of empirical studies and reviews (2005-2015) about ACP in nursing homes, by the core research team ³⁵	List of preconditions for ACP in the nursing home setting to be used during workshop 1 to trigger discussion
3	To create a first draft of the ToC map	ToC stakeholder workshop 1 by ToC facilitators (LVDB and LP) and stakeholders	First draft of ToC map, including: <ul style="list-style-type: none"> ▪ Impact, ceiling of accountability and long-term outcomes ▪ Preconditions/intermediate outcomes, including their chronological order ▪ List of possible interventions, assumptions and rationales
4	To create a second draft of the ToC map based on integration of output from step 1, 2 and 3	Several meetings with core research group to construct a draft ToC map	Second draft of ToC map, including: <ul style="list-style-type: none"> ▪ Reformulated impact and long-term outcomes ▪ Preconditions chronologically ordered and coloured according to level to which they are applicable ▪ Precondition “support by an external trainer” (suggested by research team) ▪ Possible interventions (added by the research team) such as the availability of a trainer and a monitoring system
5	To refine the second draft ToC map, to fill in the gaps and to get consensus on the chronological order of the hypothesised causal pathway	ToC stakeholder workshop 2 by ToC facilitators and stakeholders in which second draft of ToC map (output of step 4) is presented	Refined draft of second ToC map, including: <ul style="list-style-type: none"> • Redefined secondary outcome to be measurable ▪ Additional elements, added in step 4, approved ▪ Details added by stakeholders (e.g. which healthcare professional is responsible for implementing ACP, re-named ACP facilitator as “ACP reference person”) ▪ Additional arrows added by stakeholders
6	To develop the final draft ToC map that outlines the hypothetical causal pathway of ACP in nursing homes based on integration of output from step 1 to 5	Several meetings with core research group to construct the ToC map, review by a ToC expert, comparison with existing ToC maps from other research projects and consultation of implementation science literature (in general and about ACP) and relevant theoretical models	Further integration of outputs of steps 1 - 5 into a final draft of a ToC map (presented in Figure 1) and narrative, including: <ul style="list-style-type: none"> ▪ Preconditions merged or reformulated and put in chronological order ▪ Numbers added to mark interventions ▪ Rationales and assumptions written up by the core researcher team in a separate document (narrative), based on stakeholders’ and researchers’ experience, literature and relevant theoretical models

ToC Theory of Change; ACP Advance Care Planning; GP General Practitioners

* The results of this systematic review are published elsewhere ³⁵.

† Barriers are defined as contextual elements that inhibit ACP in Flemish nursing homes; Facilitators are defined as contextual elements that can support ACP in nursing homes.

± A hierarchical system that regulates who functions as the legal representative/surrogate decision-maker if the person/patient has not assigned a legal representative him-/herself and lacks the mental capacity to make the decisions that have to be made: 1) the spouse or (legal) cohabiting partner, 2) an adult child of the patient, 3) a parent, 4) an adult sibling of the patient, 5) the professional carer representing the patient’s interests in multidisciplinary consultations.

Theory of Change stakeholder workshops

We organised two half-day ToC workshops with stakeholders (June 29th and July 13th 2015) following the methodology outlined in the available ToC manuals^{42,43}.

Stakeholders

Stakeholders were defined as people involved in the development, implementation or organisation of ACP in nursing homes. We purposively sampled and recruited stakeholders using a variety of criteria including: (i) affiliated with a Flemish nursing home OR having knowledge of the Flemish nursing home setting OR whose work in policymaking or research influences care in Flemish nursing homes; AND (ii) being acquainted with ACP through their work. All stakeholders were recruited by JG by means of e-mails and follow-up telephone calls, through contacts that were established in previous work regarding ACP and through the research group's network of experts in ACP practice. We sent out 30 invitations to potential stakeholders and 21 of those people participated. The stakeholders who attended the two workshops were not always the same people, but a key group of stakeholders (n=6) attended both to ensure continuity between the two workshops. Characteristics of the participating stakeholders can be found in Table 3.

Table 3. Characteristics of stakeholders in the Theory of Change workshops (n=2)

Characteristics	Workshop 1 (n=12)	Workshop 2 (n=15)†
Gender		
male	1	4
female	11	11
Primary profession		
<i>Care professional</i>		
general practitioner	1	1
coordinating and advisory physician	0	1
nurse (including public health nurses)	2	2
palliative care reference nurse	1	2
psychologist (one of whom is involved in research linked to ACP)	2	2
social worker	1	0
physiotherapist	1	1
dementia reference person	0	1
<i>Other</i>		
nursing home management	2	2
ethicist	1	1
health sociologist	0	1
representative of council for the elderly	1	1
Employer*		
nursing home	7	7
private practice	1	0
university	3	3
overarching organisation	1	1
national council for the elderly	1	1

*Multiple options are possible.

† The total number of unique participants was 21. Six participants attended both the first and the second workshop (1 nurse, 1 palliative care reference nurse, 2 psychologists, 1 social worker, 1 nursing home manager)

Procedure

Each workshop was structured to include a brief introduction of the project and the ToC approach, the importance of ACP in nursing homes and a mapping exercise using structured group discussions and small group exercises. These ToC workshops are characterised by their output, a ToC map (and gaining agreement on this among the involved stakeholders) rather than just giving views and opinions. In addition, the ToC facilitators generally have a more active role than those moderating focus groups, given that the aim was not only to obtain participants' views but to create a ToC map together. Table 4 shows the central themes and questions asked in each workshop.

Table 4. Central themes and questions asked in the Theory of Change stakeholder workshops

Workshop 1 and 2	
a)	Problem description
b)	Introduction to ToC method and ground rules (e.g. “Everyone’s input is equally valid”, “Think outside the box”, “Give the facilitator time to write things down”, “Nothing that is written down is definitive. We are following an iterative process”)
c)	The question to initiate reflection: “In an ideal world, what would need to happen for a successful implementation of ACP?”
Workshop 1	
a)	Agreement on impact: What is the fundamental change we want to see in the nursing home setting in Flanders? How will the Flemish nursing home community be different because of what we do?
b)	Ceiling of accountability
c)	The long-term outcomes of advance care planning in nursing homes
d)	What are the intermediate preconditions that are necessary to produce the long-term outcomes? Why do we think a given precondition will lead to (or is necessary to) reach the one that follows it?
e)	What contextual conditions or circumstances are necessary to achieve the preconditions?
f)	Consensus concerning the chronological order of preconditions
Workshop 2	
a)	Presentation and discussion of the ToC map developed in workshop 1
b)	Review and refinement of the ToC developed in workshop 1 and filling in the gaps: Is the ToC map presented here “feasible” (likely to work), “effective” and “sustainable”? Is the change logically displayed? Are there essential elements that are missing or that we should definitely consider or discuss?
c)	Which interventions should be initiated to achieve the preconditions and the long-term outcome?

ToC: Theory of Change; ACP: Advance Care Planning

LVDB and LP, trained in the use of ToC, facilitated both workshops. The results of the context analysis (**step 1**) and the systematic review (**step 2**)³⁵ were used to provoke discussion and prompt questions concerning the preconditions found most important in the literature to achieve the long-term outcome and to check whether all levels of change (the individual level (resident or family); the professional level (GP or nursing staff) and the facility level (nursing home)) were considered.

During the first ToC workshop (**step 3**), the impact and long-term outcome of ACP in nursing homes was defined, after which participants worked backwards to map all preconditions, using visual aids (post-it’s on a whiteboard). This process was repeated iteratively until consensus about the content and chronological position of the preconditions was reached. After this workshop, JG drafted a ToC map, which was then discussed during two meetings with the core research team to review the outcomes of the ToC workshops and the draft of the ToC map (**step 4**). The aim of the second workshop (**step 5**) was to reach consensus among all stakeholders about the preconditions, their positioning in the ToC map and to formulate intervention components and activities needed to attain the preconditions. The facilitators presented the draft ToC map created in step 4 in poster format, to make sure all participants shared a similar understanding of the causal pathway presented in the map. At both workshops, the participants were encouraged to reflect on their reasoning or rationales of how and why certain preconditions lead to the next, why certain interventions are

necessary for desired outcomes to be achieved and to make explicit their assumptions about possible implementation barriers in the local context.

After the second workshop, the core research team met four times (**step 6**) to discuss the formulation of the preconditions, their potential causal relationship, and the intervention components in the ToC map. During this step, a ToC expert (EB) reviewed the methods and terms used to ensure they were used correctly and to check the consistency of the causal pathway. The map was subsequently checked against relevant literature proposed by the core research group and the four attributes (plausible, doable, meaningful and testable) for a good theory of change⁴³.

Data analysis

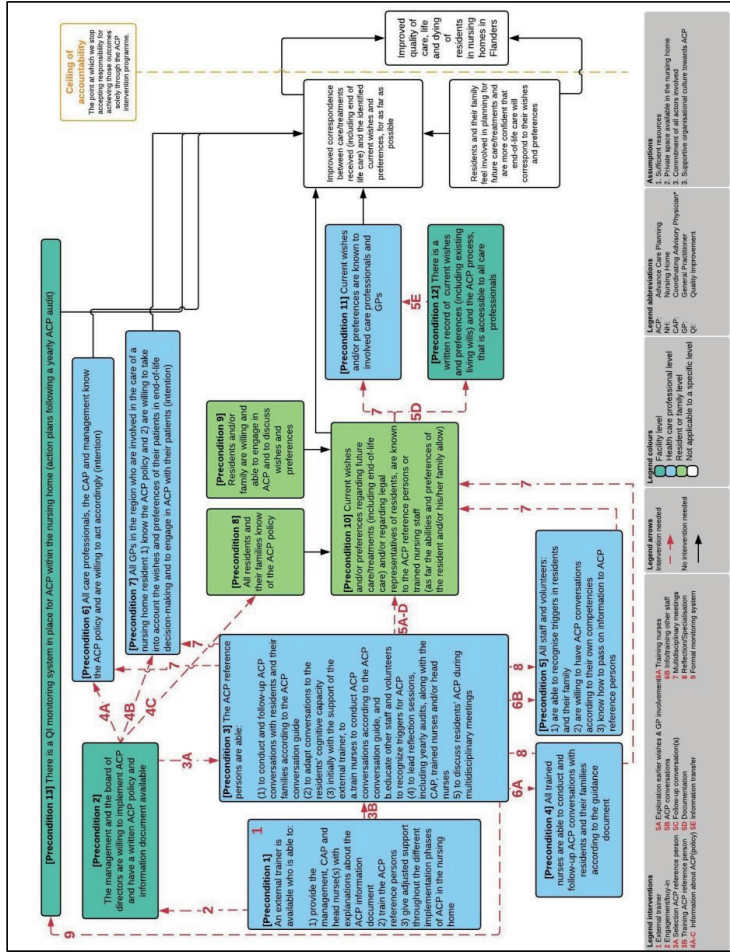
The first author transcribed video and audio recordings of the workshops (to which participants gave verbal consent) and took photographs of the ToC map at the end of each workshop to maintain a visual record. Points that were raised and perceived as important by the majority of stakeholders were included in the map. The first author constructed the ToC maps using Lucidchart (www.lucidchart.com).

RESULTS

As suggested in the Checklist for Reporting Theory of Change, we present i) impact, ii) ceiling of accountability, iii) long-term outcomes, iv) preconditions, v) interventions and vi) assumptions⁴⁴. These should be read in conjunction with the ToC map presented in Figure 1.

PART II

Figure 1. Theory of Change map



ACP advance care planning QI quality improvement; C:CAP coordinating advisory physician; GP general practitioner
 *Since 2000, each nursing home is legally bound to have a coordinating advisory physician (C:AP), a general practitioner, preferably trained in gerontology, whose tasks include some of those related to individual end-of-life care situations (consultancy, taking charge of care, or conflict mediation)^{81,82}.

Impact

The desired ultimate impact that should be achieved in nursing homes is identified as “improved quality of care, quality of life and quality of dying in nursing homes in Flanders”.

Ceiling of accountability

The threshold at which the ACP intervention is no longer directly accountable for the desired impact is delineated by the ‘ceiling of accountability’, which is situated between the impact ‘improving quality of care, life and dying’ and the long-term outcomes. ACP cannot achieve the formulated impact solely on its own (e.g. other personal factors and factors pertaining to the healthcare organisation, healthcare system, and the broader environment may also affect the quality of care of someone in the nursing home) though ACP may contribute to achieving the impact through its effect on the long-term outcomes, that are described below.

Long-term outcomes

We identified two long-term outcomes that are desired to be achieved by ACP:

- 1) “Correspondence between the care/treatments received (including end-of-life care) and the current wishes and preferences identified, as far as possible”. Care and/or treatments received do not always align with care/treatments preferred. However, a correspondence between the two is identified as the most important outcome for assessing the effects of ACP in nursing homes, and critical to improve care, quality of life and quality of dying⁴⁵. It is also reported as the primary or secondary outcome in a wide array of effectiveness studies^{15,23,46-48} and as a primary objective of ACP and in ACP definitions^{25,45,49,50}.
- 2) “Residents and/or their family feel involved in planning future care/treatments and are more confident that end-of-life care will correspond to their wishes and preferences”. Residents and families appreciate feeling prepared for the future and want their wishes and preferences regarding care and treatment to be considered seriously by the healthcare professionals involved^{51,52}.

Preconditions

Based on the results of the systematic review³⁵ and ToC workshops, we identified 13 important preconditions that need to be fulfilled for the desired long-term outcomes to be achieved. All preconditions are presented in the coloured boxes in Figure 1, which should be read from left to right. The distinct colours indicate the level to which each precondition is most applicable. Most preconditions are applicable to healthcare professionals within the nursing home.

The ToC map, as shown in Figure 1, first identifies the availability of a sufficiently skilled trainer [precondition 1], who is available for all participating nursing homes, as an essential first step in the implementation of an ACP intervention. Next to this trainer, who is external to the organisation, the engagement of the nursing home management is necessary [2] to ensure full integration into routine nursing home care provided by in-house staff, therefore this includes assigning staff that function as ‘ACP reference persons’ [3]; trained nurses that are able to conduct ACP conversations [4]; trained staff that is able to signal triggers for ACP and knows how to pass on this information [5]; informed care professionals [6], GPs [7] and residents and their families [8]; and care professionals that have the intention to take into account the wishes and preferences of nursing home residents and all to be willing to engage in ACP [9]. That wishes and preferences are known to the ACP reference persons or trained facilitators (through ACP conversations) is a key outcome in the ToC map [10]. This followed by the need for all involved care professionals to know these wishes [11] and the availability of a written record that is accessible [12]. To ensure quality of ACP is held high-standard, ongoing monitoring is necessary [13]. If all the preconditions described in the ToC map are achieved, nursing home residents that engaged in the ACP programme and their families, should feel more involved in planning for the future and should feel confident that care will correspond to their preferences, for them to eventually have improved correspondence between the care/treatment they are actually receiving and those wishes and preferences.

Interventions

Nine intervention components are required to fulfil each precondition. These are marked in Figure 1 with dotted red arrows and numbers. In this section, we describe these interventions and their rationales in more detail.

1. Selection of external ACP trainer responsible for helping with gradual implementation of the intervention

To carry out the tasks required in precondition 1, the stakeholders all agreed that an appropriately skilled external ACP trainer should be appointed to provide information, training and support, i.e. someone responsible for helping the staff throughout this change process of gradually implementing ACP into routine nursing home care. The intensity of the trainers' support should gradually decline as implementation progresses and the nursing homes and their healthcare staff become more skilled in organising and structuring ACP themselves.

Studies and models of change show that people and organisations progress through a series of stages or phases when modifying behaviour or organisational structures with the help of interventions⁵³⁻⁵⁵. Such stages usually contain a preparation phase, an action phase or implementation phase and a maintenance or consolidation phase. Therefore, all intervention components and activities should be implemented gradually in a step-by-step approach.

2. Ensuring engagement and buy-in by the nursing home management

To make sure the management and Board of Directors are willing to implement ACP (precondition 2), the external trainer has one or more meetings with them to establish their engagement and ensure buy-in into the project. The trainer also assesses the extent to which an ACP policy is already available within the nursing home and how it can be combined with the intervention and the ACP guidance document, which is part of the intervention. This guidance document provides detailed information about what ACP is, when and how it works and how ACP processes should be structured. The document is based on existing guidelines available in Belgium and internationally^{56,57}.

Ensuring management commitment is important in processes that aim to effect change in current practice^{55,58}. Research has shown that management support ensures that all staff has a good understanding of how to use the programme effectively and appropriately, with the result that it is more likely to be sustained^{58,59}. An institutional policy or guideline is shown to support the process of ACP and to promote its implementation⁶⁰.

3. Selection and training of ACP reference persons

ACP facilitators or "ACP reference persons" (healthcare professionals employed by the nursing home) should be appointed (3A) and receive training (3B) in order to have the skills necessary to accomplish the tasks highlighted in precondition 3, i.e. conducting conversations, training other staff, organising reflection sessions, performing monitoring and organising multidisciplinary meetings.

These reference persons should market the programme, communicate the high priority of ACP for nursing home residents, provide education to other nurses, healthcare staff and volunteers, and perform regular monitoring to audit ACP processes and outcomes within the nursing home. The ACP reference persons are the main persons responsible for ensuring ACP is implemented in the home (with the support of the external trainer) and for performing scheduled and manualised ACP conversations. They are chosen in consultation with the management of the nursing home. The management and reference persons subsequently identify an additional number of nurses (or other paramedic staff) who are also competent to do ACP conversations. Both ACP reference persons *and* a limited number of such carefully selected nurses (or other paramedic profiles) were identified in the workshops as responsible for performing scheduled and manualised ACP conversations, to increase feasibility (i.e. decrease workload per person) and sustainability. The ACP reference persons need somewhat different skills to the external ACP trainer, because the latter is mainly responsible for supporting the ACP reference persons by providing them with the necessary tools and training to gradually implement ACP and optimize the change process in their facility (e.g. resistance, coordination, providing a structure). The ACP trainer's support is intensive at the beginning of implementation but decreases throughout the process as the ACP reference persons become increasingly more autonomous.

Reference persons are identified as a successful factor in much implementation science literature and healthcare research^{59,61,62}. The reference persons are appointed among the professionals employed by the institution because evidence suggests that the use of 'external' facilitators does not enhance the sustainability of ACP, since they leave once the implementation period is over⁶⁰.

4. Information about ACP for staff, GPs, residents and their families

To achieve preconditions 6, 7 and 8, all care professionals, the CAP, management (4A), the GPs involved (4B) and the residents and their families (4C) should be informed about ACP and the ACP policy within the nursing home using brochures, letters, information sessions or resident/family councils.

Lack of knowledge of ACP has been shown to be a barrier to engage in or successfully implement ACP³⁵. Being fully informed about ACP helps people to accept why it is needed, be adequately prepared, make effective decisions, counter reluctance from both professionals and residents or families, and for residents to be able to share their care preferences adequately^{35,58}.

5. *ACP conversations and ACP documentation*

Precondition 10 requires the current wishes and preferences of the resident to be known. A guidance document based on existing guidelines^{56,57} is made available, outlining how conversations and documentation should be organised. After the resident is informed about the existence of the ACP policy in the nursing home and before they are invited for an initial ACP conversation, the ACP reference person or trained professionals (see intervention 6) explore whether the resident's wishes and preferences have been documented in the past and how the residents' GP wants to be involved in his/her patient's ACP process (5A). At least two months after admission and following an evaluation of mental capacity, every resident, who is able to participate and/or family members who are found to be significant (or their legal representative), are invited to participate in the first conversation (5B). Several follow-up ACP conversations are organised: when circumstances change, if nursing home staff signal any important triggers, and annually (5C). Outcomes of conversations are always documented (5D) in written records in the residents' files, where they are easily accessible to other care providers. In the event of a transfer to another care setting, the relevant information from the written record should accompany the resident (5E).

Regular follow-up is important as wishes and preferences can change with time, particularly if circumstances are different⁴⁵. For example, this could happen when the resident's health status changes (e.g. sudden deterioration or an additional diagnosis) or after a transition between hospital and the nursing home. Moreover, decisions take time and cannot be completed in one conversation⁶³. Documenting residents' preferences increases the likelihood that their wishes will be followed²³. In addition, to ensure that care is provided as preferred, these preferences must be clearly documented in a written format and must be rapidly accessible when clinically relevant³⁵.

6. *In-service education to nursing home staff and volunteers*

Two specific interventions are required to make sure that, besides the ACP reference persons, other nurses (or paramedic staff, as decided by the nursing home) are also able to conduct and follow up manualised ACP conversations (precondition 4), and that all other nursing home staff are involved and able to recognise meaningful triggers that signal that the resident or family wants to, is ready for or has a need to engage in an ACP conversation (precondition 5). Nurses receive regular in-service education about ACP conversations (6A). In addition, other nursing home staff (regardless of their age and specialism, including activity leaders, volunteers, night personnel, etc.) receive regular in-service training to help them recognise and signal triggers (6B). The training sessions for the latter

will focus on signalling triggers for ACP and engaging in spontaneous conversations about related topics, hence differ from those for staff performing manualised ACP conversations according to the guidance document. Both types of trainings should be organised regularly by the appointed ACP reference persons.

In-service staff education is shown to be essential to enable implementation and ensure that the programme remains an effective part of standard care, even after an external trainer's engagement period has ended^{58,59,61,64}. Nursing home residents usually have complex health trajectories where pending death and other triggers for ACP are not always recognised by the staff, who are often not trained in palliative care or similar areas^{56,65}. Because it is also important for residents and families to be able to have spontaneous ACP conversations as well as the ones that are scheduled, it is the responsibility of all professionals in the institution, including the hairdresser, to be able to engage in spontaneous conversations about such topics, according to their own competencies and within the bounds of their profession. For example, the resident may bring up the subject of future care and treatment while visiting the hairdresser⁶⁴. Finally, these training sessions should happen regularly, as staff turnover can be high⁶⁶.

7. Multidisciplinary meetings

To ensure the current wishes and preferences of the residents are known to all care professionals and GPs, as required in precondition 11, ACP conversations held with residents or their representatives and changes to ACP documentation should be regularly discussed in multidisciplinary meetings.

The importance of teamwork to achieve goals is supported by theories related to team effectiveness⁵⁵, scientific literature^{58,64} as well as the practical experience of the stakeholders.

8. Regular reflection sessions

To ensure nurses, care professionals and volunteers learn from, support and communicate with each other, the ACP reference persons facilitate regular reflective sessions held among nursing home staff, for example using significant event analysis, which enables staff to reflect on ACP and analyse significant events with the aim of improving ACP practice where possible.

Reflective debriefing is shown to help staff feel supported and valued, and enhance their ability to teach each other and to develop understanding and critical thinking⁶⁷. According to the stakeholders, these sessions can also function as 'post-training' support.

9. Formal monitoring, including audit, feedback and action plans

To ensure that long-term outcomes of ACP are achieved and high-quality ACP is provided, a formal monitoring system is put in place. A system of this kind is an assessment of practice to know if efforts to change are working or additional efforts are needed. It should integrate audit, feedback and, if necessary, action plans to improve practice and enable quality improvement⁶⁸.

To ensure that all care professionals adhere to residents' preferences, real-time monitoring through auditing and formal feedback on performance to the healthcare professionals involved are considered to be key drivers in implementing and sustaining new programmes⁵⁹.

Assumptions

Assumptions are defined as the contextual conditions that need to be in place for ACP to function successfully. A failure to provide these creates barriers that may hinder the achievement of the long-term outcomes. Based on the results of the systematic review³⁵, stakeholders' views and the contextual analysis, we identified the need for: sufficient resources (including funding, time and human capacity); a quiet private space where ACP conversations can be held; the commitment of everyone involved; a culture supportive of ACP in the nursing home so people feel free to reflect on and talk about death, dying and end-of-life issues; and an organisational culture that stimulates professionals to invest in ACP, despite the lack of financial incentives, staff shortages or staff turnover.

DISCUSSION

Using the Theory of Change approach, we have developed a theoretical framework for ACP in nursing homes that makes explicit what changes are expected as a result of ACP, how change can be achieved in long-term outcomes in nursing homes and under what circumstances. This is presented in a structured and logical 'ToC map'. This ToC map provides a summary of ACP as a complex intervention and makes explicit the hypothesised causal pathway through which all intervention components of ACP interact to achieve the intended long-term outcomes: 1) improved correspondence between care/treatments received and current wishes and preferences, and 2)

residents and family feeling more involved and confident that end-of-life care will correspond to their wishes. By achieving these long-term outcomes, we aim to improve the quality of care, quality of life and quality of dying among residents of nursing homes in Belgium (ultimate impact).

The approach used in this study has led us to the development of an ACP intervention programme that shares some key characteristics with those that have been developed before, such as an emphasis on in-service training for healthcare staff employed by the nursing home^{69,70}, providing standardized documentation, conducting structured conversations^{69,71-74} and promoting multidisciplinary awareness^{64,69}. Additionally, important elements were added compared to existing ACP intervention programmes. Firstly, unlike other interventions such as Let Me Talk⁷⁴ and the intervention by Morrison et al. in which social workers were trained to perform ACP⁴⁸, this intervention programme has a substantial focus on the role of the facility itself. The results of numerous (implementation) projects, including Respecting Choices^{58-60,64,75,76}, our systematic review³⁵ and the local experience of stakeholders indicate that a context that supports the implementation of ACP through institutional policy development, management engagement and quality improvement systems is highly valuable^{35,58,59,64,77}. Secondly, our ToC map highlights our hypothesis that a change in desired outcomes through ACP in a setting as complex as nursing homes is hypothesised to be achieved only by targeting multiple levels in a whole-setting approach. Hence ACP cannot be limited to one component (such as training healthcare staff or using a standardised advance directive) but should address multiple levels and domains and take into account a multitude of factors that can inhibit or facilitate its implementation in daily nursing home practice. These factors include high staff turnover (hence the need to continuously train staff), poorly educated staff and the limited number of staff trained in palliative care who are therefore able to recognize signals that it is time to raise subjects relating to ACP.

The main strength of this study is the application of a programme theory via a Theory of Change approach that requires the use of state-of-the-art evidence from research while integrating various stakeholder views in identifying all ToC components, which is different from using a 'off-the-shelf theory' such as the Representational Approach to Patient Education to inform the intervention you are developing^{33,78}. The participatory ToC workshops allowed the core research group and stakeholders to discuss in detail the hypothesised preconditions required along the causal pathway and to ensure the initial focus of the ACP intervention always remained on the long-term outcomes that could be achieved with ACP. This contributed to the development of a context-specific ACP

intervention whose feasibility is already been partly addressed in the development phase of the study, as recommended by a recent review^{42,79}. Additionally, this study is the first to present a rationale for the particular setup of an ACP intervention programme in nursing homes. It thereby answers a frequent call made by important research bodies to include the rationale, theory or goals that underpin the intervention^{26,28,79}. Not making explicit how interventions are expected to work makes it challenging for others to replicate and compare existing ACP interventions adequately. It also endangers efforts to scale up and their reliable implementation³⁰.

This research has several limitations. Firstly, because there is not enough information about the effectiveness of separate components of ACP in scientific literature, the stakeholders and core research group were the main contributors to the development of the overall structure of the ToC map and we were not able to provide high-quality scientific evidence for each link in the causal pathway. Secondly, the number of participants in the workshops was rather small and the heterogeneous composition of each workshop means that 'lower-level' staff may have been less vocal in the discussions due to existing hierarchies. However, we made attempts to mitigate these effects by calling participants without focusing on their profession or rank, and by organising rounds and smaller group discussions. Thirdly, the preconditions identified and the interventions that resulted from our developmental work (situational analysis, systematic review and stakeholder workshops) mainly concern the resident and family level, the staff level, the institutional/organizational level, and the GP collaboration. Other macro level preconditions (defined as "any outside condition or situation that influences the performance of the organization" [77]) such as the regional collaborations with hospitals, the existence of quality indicators or reimbursing providers for ACP conversations, have not been addressed in this work. Finally, the long-term outcomes presented in the ToC map, were chosen in consensus *as the most important long-term outcomes that ACP is directly accountable for* in the context of the Flemish nursing home setting, by the stakeholders involved in our panels and the evidence obtained from the systematic review. As has also been suggested by the EAPC Taskforce on Advance Care Planning, we are aware that there might also be additional outcomes of ACP which future evaluation studies might include ^{2,50}. In addition, this visual presentation is of course a simplification of a complex reality. The aim of the ToC approach is to identify the most important and necessary preconditions for implementing ACP successfully, rather than describing every specific element involved. This is hardly feasible, both in practical and financial terms.

Not all results of this study are directly generalizable to other countries. On the one hand, some preconditions are probably also applicable to other countries (i.e. the need for buy-in from management, communication and appropriate monitoring) while some are very specific to the context of Flanders (e.g. using the name ‘reference person’). Our in-depth investigation of the hypothesised process through which ACP can be successfully achieved, can provide researchers in other countries with guidance in developing similar interventions in their country. Within a recent mental health intervention, called PRIME (PRogramme for Improving Mental health carE)⁸⁰, the ToC approach proved to be a useful heuristic device for cross-country comparisons and the development and scaling up of mental health services in similar settings. Because the contextual conditions in each country vary significantly and ACP is influenced by a variety of social, political and health system changes, careful documentation and analysis of the context will be essential to interpret future results of ACP evaluations⁵⁸.

The results of this study provide the basis for the further design and evaluation of an ACP intervention programme for nursing homes. Developing a ToC is a continual process of reflection and adaptation as barriers to implementation arise and new evidence comes to light. This can require the pathway to be changed and strengthened throughout all phases of the MRC ³⁶. In the following phase, we will test and possibly further adapt the ToC map and the intervention components in terms of their acceptability and feasibility in the nursing home setting in Flanders. Subsequently, we will evaluate its effectiveness in a cluster randomised controlled trial including an in-depth process evaluation. Because we will develop indicators that will measure the achievement of each precondition, we will be able to gain a detailed understanding of whether an intervention is working, how it works and which components of the complex intervention are the most important in achieving the long-term outcomes. If the intervention does not influence the outcomes as expected, this ToC map will additionally help us to determine whether the lack of effectiveness of the intervention is due to sub-optimal intervention design, implementation failure or genuine ineffectiveness. This is something that past trials have often failed to detect or report⁷⁹.

CONCLUSION

Within this study, we created a Theory of Change map that describes how and in what circumstances ACP should be implemented and organised in nursing homes to achieve its desired long-term

outcomes. We also explicitly state which intervention components should be part of this ACP intervention. The Theory of Change map provides the first comprehensive rationale of how ACP is expected to work in nursing homes, something that has not been shown by research before but for which repeated calls have been made. We will use these insights in the further design of the ACP intervention and its evaluation to explore in greater depth how, why and in what circumstances ACP works best in routine nursing home care in Belgium.

DECLARATIONS

Ethics approval and consent to participate

No ethics committee approval was required. Local laws state that studies of this nature do not require ethical approval, see Belgian Law of 7 May 2004 on experiments on the human person. In Art. 3 (definitions and application) it states that only studies that have a direct intention to increase medical knowledge fall within the scope of the Law. Workshops such as those in the study do not have the direct intention to increase medical knowledge and cannot be considered as interventional research. They were expert consultations and served to gather expert opinion about elements needed to successfully implement ACP in nursing homes, rather than people's individual opinions, beliefs or experiences. Alongside the invitation to participate, all participants received an informational letter (one page explaining aim of each workshop, including a detailed script of each workshop [see Additional file 1]) prior to participation. They agreed to participate in writing (e-mail). The recording of the workshops was announced in the letter. After they provided their verbal consent to audio- and videotape the workshops, their consent was explicitly recorded on tape. Written consent was not necessary because no intervention was performed that could affect the physical or psychological integrity of the participants. This was approved by the Ethics Committee of University Hospital Brussels.

Consent for publication

Not applicable.

Availability of data and materials

Not applicable.

Competing interests

Deliens L. serves as a member of the BMC Geriatrics editorial board. The other authors declare that they have no competing interests.

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Authors' contributions

All authors made substantial contributions to the conception and design of the study. JG analysed and interpreted all data regarding the ToC map. LP, LVdB, CG and LD provided assistance in data analysis. JG drafted the article. All authors critically revised the manuscript and gave final approval of the version to be published. They all take responsibility for the integrity of the data and the accuracy of the data analysis.

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ADDITIONAL FILES CHAPTER 2

Script Stakeholder Workshop 1

Stakeholder workshop 1
 Development of an intervention concerning ACP in the Flemish nursing homes
 Monday 29th of June 2015 // Programme

Topic	Time
Registration and lunch <i>Lara Pivodic</i>	10 min
Getting acquainted (<i>starting when everyone is arrived</i>) <i>Lara Pivodic</i>	45 min
Introduction - Project and study - A new way of intervention development - Objectives stakeholder workshop 1 <i>Lieve Van den Block</i>	15 min
Problem analysis and current situation Ground rules and mutual expectations <i>Lara Pivodic</i>	10 min
Starting brainstorm 1/ The fundamental change we want to see in the nursing home setting in Flanders 2/ The long-term outcome of advance care planning in nursing homes (<i>small groups</i>) 3a/ What are the intermediate preconditions that are necessary to produce this fundamental change? <i>Lieve Van den Block</i>	1 h 05 min
<i>Coffee break</i>	15 min
Follow-up brainstorm 3b/ What are the intermediate preconditions that are necessary to produce this fundamental change? (follow-up) 4/ Consensus concerning chronological order of preconditions 5/ What interventions should be initiated to achieve preconditions and the long term outcome? 6/ Why do we think a given precondition will lead to (or is necessary to) reach the one above it? What contextual conditions are necessary to achieve the preconditions? <i>Lieve Van den Block</i>	1 h 30 min
<i>Coffee break</i>	15 min
End of brainstorm Feedback on methods workshop Conclusion	15 min

PART II

Script Stakeholder Workshop 2

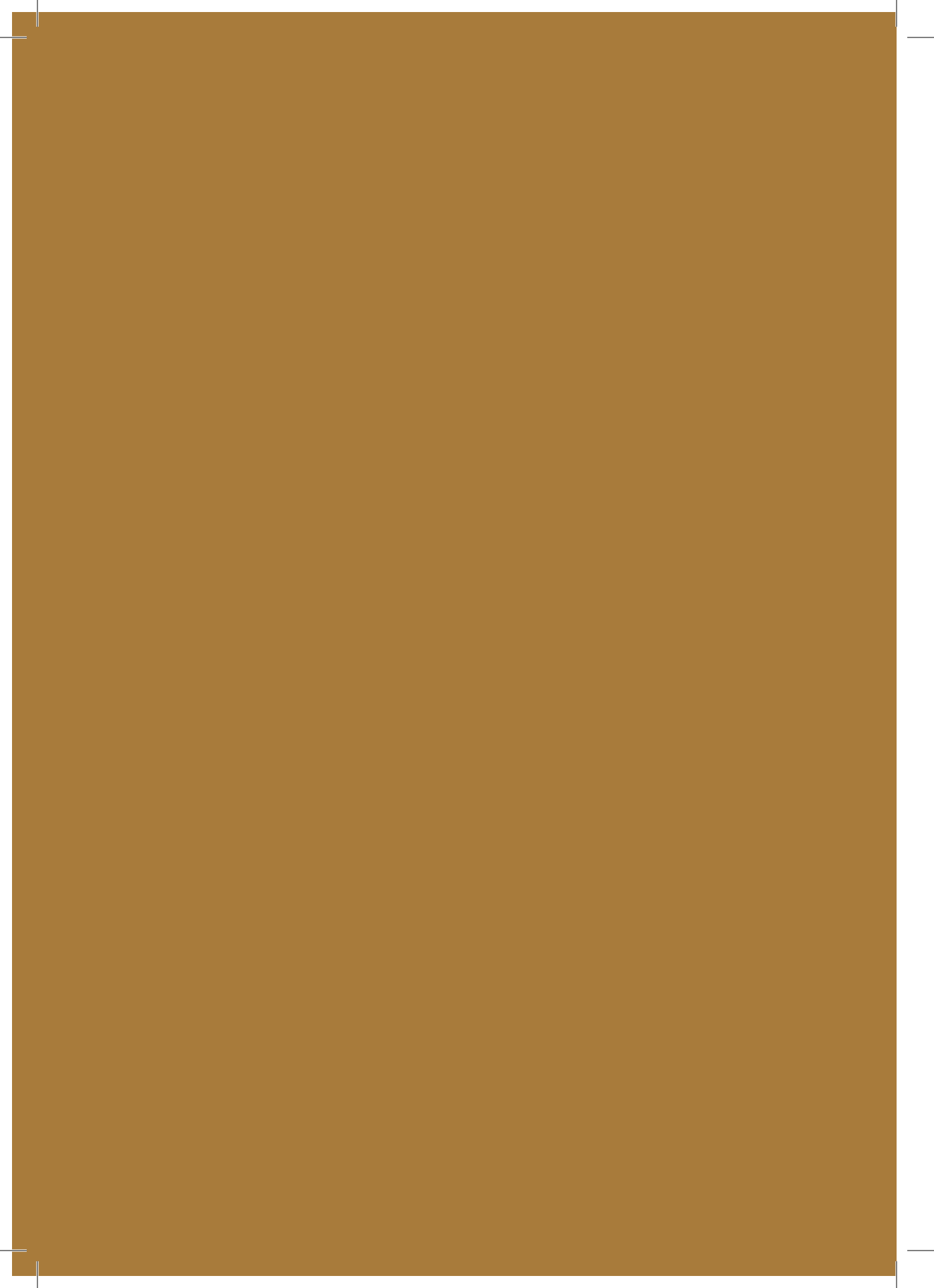
Stakeholder workshop 2

Development of an intervention concerning ACP in the Flemish nursing homes

Monday 13th of July 2015 // Programme

Topic	Time
Registration and lunch <i>Lara Prvodic</i>	15 min
Getting acquainted (<i>starting when everyone is arrived</i>) <i>Lara Prvodic</i>	15 min
Introduction <ul style="list-style-type: none"> - Project and study - A new way of intervention development - Objectives stakeholder workshop 2 <i>Lieve Van den Block</i>	15 min
Ground rules and mutual expectations Summary of results stakeholder workshop 1 <i>Lara Prvodic</i>	5 min
Start 1/ Presentation results stakeholder workshop 1 and preliminary "pathway to change" 2/ "Filling in the gaps" (<i>small groups</i>) <i>Lieve Van den Block</i>	1 h 20 min
<i>Coffee break</i>	15 min
Follow-up 3/ Feasibility and acceptability of the intermediate outcomes/ preconditions 4/ Feasibility and acceptability of the interventions with guiding questions such as; What contextual conditions are necessary to achieve the preconditions? Are there any major barriers to the precondition that need to be considered in our planning? What resources are required to implement the interventions? <i>Lieve Van den Block</i>	1 h 30 min
<i>Coffee break</i>	15 min
Conclusion <i>Lieve Van den Block</i> <i>Lara Prvodic</i> <i>Joni Gilissen</i>	15 min

PART III
DEVELOPMENT OF AN
INTERVENTION PROGRAMME
TO IMPROVE ADVANCE CARE
PLANNING IN NURSING HOMES



*Chapter 3: Development of a complex intervention to
improve advance care planning in nursing homes: the
ACP+ program*

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ABSTRACT

BACKGROUND While various initiatives have been taken to improve advance care planning in nursing homes, it is difficult to find enough details about interventions to allow comparison, replication and translation into practice.

OBJECTIVES We report on the development and description of the ACP+ program, a multi-component theory-based program that aims to implement advance care planning into routine nursing home care. We aimed to 1) specify how intervention components can be delivered; 2) evaluate the feasibility and acceptability of the program; 3) describe the final program.

DESIGN To develop and model the intervention, we applied multiple study methods including a literature review, expert discussions and individual and group interviews with nursing home staff and management. We recruited participants through convenience sampling.

Setting and participants Management and staff (n=17) from five nursing homes in Flanders (Belgium), a multidisciplinary expert group and a palliative care nurse-trainer.

METHODS The work was carried out by means of 1) operationalization of key intervention components – identified as part of a previously developed theory on how advance care planning is expected to lead to its desired outcomes in nursing homes – into specific activities and materials, through expert discussions and review of existing advance care planning programs; 2) evaluation of feasibility and acceptability of the program through interviews with nursing home management and staff and expert revisions; and 3) standardized description of the final program according to the TIDieR checklist. During step 2, we used thematic analysis.

RESULTS The original program with nine key components was expanded to include ten intervention components, 22 activities and 17 materials to support delivery into routine nursing home care. The final ACP+ program includes ongoing training and coaching, management engagement, different roles and responsibilities in organizing advance care planning, conversations, documentation and information transfer, integration of advance care planning into multidisciplinary meetings, auditing, and tailoring to the specific setting. These components are to be implemented stepwise throughout an intervention period. The program involves the entire nursing home workforce.

CONCLUSIONS The multicomponent ACP+ program involves residents, family, and the different groups of people working in the nursing home. It is deemed feasible and acceptable by nursing home staff and management. The findings presented in this paper, alongside results of the subsequent

randomized controlled cluster trial, can facilitate comparison, replicability and translation of the intervention into practice.

INTRODUCTION

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 [1,2]. If a person chooses, the contents of such conversations can be set down in writing [3].

ACP is particularly relevant for frail older adults residing in nursing homes, due to the high probability that they will develop cognitive impairment and loss of decision-making capacity towards the end of life [4,5]. However, despite widespread recognition of its importance, still only a minority engaged in advance care planning [6,7]. Findings suggest this is the case for over a quarter of older US Medicare beneficiaries and the majority of long-term care residents [8,9]. In Europe, recent numbers show 32.5% of deceased residents had had a written directive, the most common type being a ‘do not resuscitate (DNR) order’. Extensive differences were found between countries [10]. A survey carried out in Flanders (Belgium) showed that a minority of deceased nursing home residents (11.8%) had expressed their wishes regarding end-of-life care, and that only 13.8% had a patient-reported advance directive at time of death [11]. For the purpose of documenting advance care planning, a number of possibilities are available in Belgium: an advance directive to refuse treatment (e.g. Do-Not-Resuscitate), nomination of a surrogate decision-maker and an advance statement which sets out general wishes or personal values. Only advance directives refusing treatment are legally binding for healthcare staff. Belgium also recognizes a type of positive advance directive for euthanasia [12–14]. To date, healthcare professionals in Belgium are not legally obliged to initiate advance care planning conversations with their patients but are encouraged to by local governments.

Recent reviews show advance care planning interventions, especially those in nursing homes, are increasingly multicomponent programs involving different types of staff training, education for patients and family, and elements such as flagging advance care planning outcomes in charts and feedback on a resident’s advance care planning status to physicians [15–17]. Researchers have stated with regard to this that nursing homes must change at every level, from management to frontline staff, if they are to achieve meaningful change in advance care planning uptake, and that such change

should become and remain part of daily practice, not an on-off activity [18,19]. However, this is still what current advance care planning interventions often fail to do. They are mainly delivered by a ‘specialized group’ of expert facilitators [20], and training sessions are predominantly provided to nursing staff [21], social workers [22], and in rare cases, to healthcare professionals outside the facility (family physicians or emergency staff) [21]. Specific focus on engaging nursing home management and involving the entire nursing home workforce, including those that perform non-care tasks (e.g. cleaning staff or volunteers), has not been incorporated explicitly, although it is considered to be a crucial factor [23].

In previous work, we used a Theory of Change approach to develop a theoretical model of advance care planning for nursing homes [24]. This model is a ‘program theory’ rather than a ‘grand theory’ such as the Theory of Planned Behaviour [25,26]. It shows how or under what circumstances advance care planning is hypothesized to work and can best be implemented in nursing homes in Flanders, Belgium. It outlines nine possible intervention components necessary to achieve change in the desired outcomes. However, these components need to be operationalized further into specific activities and intervention materials, tested for feasibility and acceptability, and described in such a way that they allow for comparison with other programs, replication, and translation into practice.

This paper reports on the development and description of the ACP+ program, a multi-component theory-based program that aims to implement advance care planning into routine nursing home care. The objectives of the study were threefold: 1) to specify how each intervention component can be delivered into routine nursing home care; 2) to evaluate feasibility and acceptability of the program; 3) to describe the final program in a standardized manner. The program is currently being evaluated in a cluster randomized controlled trial (ClinicalTrials.gov, no. NCT03521206, May 10, 2018).

METHODS AND MATERIALS

The three objectives are achieved through three consecutive steps, outlined below. To develop and model our complex intervention according to the Medical Research Council (MRC) framework [27,28], we applied multiple study methods, including a literature review, discussions with a multidisciplinary expert group, semi-structured individual and group interviews with nursing home management and staff, and feedback from a palliative care nurse-trainer.

Step 1. Translation of key intervention components into specific intervention activities and materials

The nine key intervention components, identified as part of a previously developed theoretical model on how advance care planning is expected to lead to its desired outcomes in nursing homes [24], are converted into specific activities with accompanying materials. To do so, we performed discussions within a multidisciplinary expert group and a review of existing advance care planning programs published in academic literature. The expert group consisted of an ethicist, three psychologists, a family physician, a sociologist, a social worker and a palliative care nurse who has a PhD in nursing and is specialized in providing training to healthcare professionals and implementing complex interventions in nursing homes [38]. They convened once a month from April 2016 until March 2017. Available intervention materials from existing programs [21,22,29–39] were identified (e.g. training manuals, informational leaflets, conversation guide, documents), based on two existing systematic literature reviews and literature selection by the expert group [18,38,40]. The leading researchers in the two programs entailing a systematic, whole-setting approach and available in Dutch, were contacted to review the intervention materials they used for potential inclusion in our intervention [33,38]. For the intervention activities that we considered including in our intervention and for which no suitable materials could be identified in other existing programs, we used and adapted existing guidelines or informational materials, made available within the region (e.g. advance directives developed by the Belgian Federal Ministry of Health in 2017; www.leif.be) [29,41–43].

Step 2. Evaluation of the feasibility and acceptability of the implementation of the program

We conducted an evaluation of the perceived feasibility ('the extent to which the intervention can be delivered as intended' [27]) and acceptability ('the extent to which people delivering or receiving the intervention consider it to be appropriate' [44]) of the intervention activities, the materials and the program's implementation via interviews with nursing home management and staff, and revision of all intervention materials by the palliative care nurse-trainer.

1) Between April and November 2017, we carried out three semi-structured group interviews with 15 staff members and managers of three nursing homes, and two individual semi-structured interviews with healthcare professionals with extensive experience in advance care planning from two other nursing homes, because other team members in these nursing homes refused to participate due to busy work schedules. No additional interviews were carried out because we felt we had

reached data saturation. The participants were paid nursing home employees and were recruited through convenience sampling via regional palliative care, dementia and nursing home networks and newsletters. Trainees and interns were excluded from participation. Each interview lasted on average 120 minutes (range: 90–190 min). All participants were asked to fill out a short survey of their individual characteristics (sex, age, job position, number of years active, training) and facility characteristics (type, number of beds, average number of deaths, guidelines available regarding palliative care, advance care planning documents, multidisciplinary meetings), and were asked to sign an informed consent form to audiotape the interview. All interviews were facilitated by JG and AWvD, according to a pre-specified topic list. Participants were asked to evaluate: (i) informational leaflets, guidance documents and manuals that we intend to use in the intervention, including those provided to participants or used in intervention delivery; (ii) enabling or supportive intervention activities; (iii) the modes of delivery of each intervention activity; (iv) any infrastructure and resources perceived necessary to deliver each intervention activity; (v) timing (including number of training sessions, advance care planning conversations, meetings), their schedule, and their duration; and (vi) which parts of the intervention should be adapted to better fit nursing home routine care. All audio records were transcribed.

2) All intervention materials were additionally reviewed and revised by and discussed with the nurse-trainer. She previously worked with the research team and was contacted directly by the researchers.

We applied thematic analysis to structure the comments of all participants, according to the Template for Intervention Description and Replication (TIDieR) checklist. Suggested adaptations were discussed within multiple meetings with the expert group and nurse-trainer. Decisions about changes to the initial intervention were consensus-based. Suggested changes that were not included in the renewed intervention, mainly due to time and resource constraints, are reported in Table S2.

Step 3. Standardized description of the final program according to TIDieR

To describe the final ACP+ program, we used the TIDieR checklist describing the why, who, how, where, when, how much and elements of tailoring of the intervention program [45].

RESULTS

Translating ACP+ components into activities and materials (results of step 1)

Table 1 shows the original nine intervention components and the 16 intervention activities and materials underpinning them. The entire program and each of the activities should be implemented gradually, using a step-by-step approach. We distinguish a preparation phase and a follow-up phase. This phased implementation approach resulted from our previous work which built on theories highlighting that people and organizations progress through a series of stages or phases when modifying behavior or organizational structures with the help of interventions [24].

We also distinguish several roles. **ACP Trainers** will be available for nursing homes to support staff in implementing advance care planning. These trainers should be skilled and experienced in change management, have clinical practice experience in nursing homes and specifically in performing advance care planning conversations, and be able to train other professionals. The trainer's support is intensive at the beginning but decreases throughout the process as the ACP Reference Persons become increasingly autonomous. The nomination of several '**ACP Reference Persons**' is at the core of the program. These are professionals employed by the nursing home who have roles in daily resident care (e.g. head nurses, team coordinators, nurses, palliative care reference persons, reference persons for dementia, psychologists, members of the palliative care team). The ACP Reference Persons' main responsibility is to implement and sustain advance care planning within the nursing home. They market the program, communicate that it has a high priority, provide training to other staff, conduct advance care planning conversations, and perform regular monitoring of advance care planning procedures and outcomes within the nursing home. '**ACP Conversation Facilitators**' are healthcare staff, who are - along with ACP Reference Persons - responsible for planning and performing regular advance care planning conversations with residents and family. All other nursing home staff who do not *necessarily* provide resident care but do have daily contact with residents or family (e.g. care assistants, hairdressers, cleaning staff, administrative staff, volunteers), are called '**ACP Antennas**'. They recognize and signal triggers that are indicative of a person being ready or willing to engage in advance care planning.

All intervention materials, prepared to deliver the ACP+ program, their original source and adaptations made to the materials by the researchers, before testing in step 2, are provided in in the Supplementary Information Materials (Table S1).

Table 1. ACP+ intervention components, intervention activities and materials (results of step 1, prior to evaluation of feasibility and acceptability)

Intervention component (n=9)	Intervention activities (n=16)	Intervention materials (n=16)†
1 ACP (external) Trainer	1. Selection and preparation of an (external) ACP Trainer, who provides adjusted support throughout stepwise implementation	1. Manual for ACP Trainer
2 Engagement/ Buy-in of management	2. Meeting(s) between the ACP Trainer and the nursing home management, board of directors and coordinating advisory physician*	2. ACP Information guide for nursing home management
3 ACP Reference Persons	3. Selection of ACP Reference Persons 4. Two-day interactive training for the ACP Reference Persons, provided by the ACP Trainer	3. Training manual for two-day training 4. ACP Manual for the ACP Reference Persons
4 Information about ACP	5. Information (session(s)) for all care professionals, the coordinating advisory physician and the management 6. Information (session(s)) for all residents and their families about advance care planning and the policy/procedures in the nursing home 7. Information (session(s)) for all family physicians about advance care planning and the policy/procedures in the nursing home	5. Invitation letter for staff, coordinating advisory physician and management for information sessions 6. Invitation letter for family physicians 7. ACP Information brochure for nursing home staff and family physicians 8. Invitation letter for residents and families 9. ACP information brochure for residents and family
5 Planned ACP conversations	8. Exploration of previously recorded wishes and family physician involvement 9. First advance care planning conversation according to the ACP Conversation Guide, with resident and family or family alone, if resident is not able to participate 10. Follow-up advance care planning conversations (yearly or after trigger moments such as admission to hospital or death of a relative) 11. Documentation of wishes and preferences on a standardized form (of which a copy is saved in the resident's file), a summary sheet and ADs (if perceived necessary by the resident, or family if resident is not able to participate)	10. ACP Conversation Guide 11. ACP Document 12. Standardized Advance Directive documents
6 In-house training	12. In-house training sessions (session 1 and session 2) to train nurses (and others such as clerical workers, moral consultants, social workers, etc.) who are willing to conduct advance care planning conversations (called ACP Conversation Facilitators) 13. In-house training session to train other staff (care workers, hairdressers, cleaning	13. Training manual for training other staff

		staff, administrative staff etc.) and volunteers to train them to recognize triggers in residents and family (called ACP Antennas)	
7 Multi-disciplinary meetings	14.	Multidisciplinary meetings are held and the advance care planning process for each resident is discussed (the resident's most important decisions, possible triggers for initiating advance care planning with residents and/or family and discussions still planned)	14. Summary sheet
8 Reflection	15.	Reflective (debriefing) sessions among all care professionals at the nursing home in which they discuss the death and advance care planning process of every resident who died during that month	15. Reflection instrument
9 Formal monitoring system	16.	A formal monitoring system is put in place in which the nursing home evaluates advance care planning organization and procedures	16. Audit instrument

ACP advance care planning

*Nursing homes are legally obliged to have at least one coordinating and advisory physician (remunerated according to the number of beds), who coordinates medical care in the facility, as well as reference nurses for palliative care (0.10 FTE per 30 residents) [46].

†The source of and adaptations made to every intervention material is reported in the Supporting Information Materials (Table S1).

Revisions to enhance the feasibility and acceptability of the program (results of step 2)

The characteristics of the participants in step 2 can be found in Table S3. The majority of participants were female, had more than 15 years' work experience in their current position, and were trained in palliative care. Participants included nurses, care assistants, social workers, a coordinating advisory physician, a physical therapist, and management (i.e. quality coordinator and head of resident care). They were employed in public or private non-profit nursing homes, with numbers of beds ranging from 80 to 360.

Participants' perceptions of the feasibility and acceptability of the program's implementation did not vary extensively. All professional stakeholders and the nurse-trainer agreed with the suggested benefits of ACP+ for the nursing home and most thought the program was worthwhile. While maintaining the core principles of the program, their comments resulted in several adjustments to the components, activities and materials. Details of the identified issues and subsequent changes are provided in the Supporting Information Materials (Table 2S).

Important changes to intervention components and activities

Difficulty in involving family physicians

Involving family physicians in an intensive information session was deemed not feasible. In addition, participants felt the provision of general information via leaflets and posters very helpful and that sessions should be adapted to fit the physician's working schedules.

"Family physicians will come to your information session if it is organized late, after 5 p.m. and if you arrange accreditation" (quality coordinator)

"Make sure staff are trained to contact the physician to make sure he/she knows an ACP conversation is about to be organized but make sure staff does not wait before the physician takes the first step" (coordinating advisory physician)

In the final program, staff are asked to contact family physicians to inform them about the new advance care planning procedures and ask them how they would like to be involved in their patient's advance care planning. Family physicians should be invited for an accredited information session, organized by a trainer and the nursing home's coordinating advisory physician, after 5 p.m.

Lack of time and staff

Staff felt the program would be too time-intensive if several intervention activities were not combined into one activity. It was also recommended always to take lack of time and low staffing levels into account while organizing intervention activities.

"Make sure you combine the information session with the training of recognizing signals; and do this during lunch or at a time when it does not take up too much time. Split one session of 4 hours into 2 of 2 hours; otherwise care is interrupted." (nurse)

The activity aimed at informing staff, the nursing home's coordinating and advisory physician, and management was removed and replaced by word of mouth, internal meetings, folders/posters and training sessions to communicate information about advance care planning to personnel who are additionally trained in recognizing triggers. Moreover, management and the coordinating physician should be informed earlier, at the newly added 'management engagement meeting(s)'.

Insufficient management engagement

Participants voiced the need for activities that specifically encourage management engagement and support (called ‘buy-in’) and a clause in the written participation agreement stating that staff would be guaranteed enough time to carry out program-related tasks. For this reason, additional management meetings were added to the program. They will be specifically asked to give selected ACP Reference Persons the necessary time and mandate to carry out their tasks. Management was asked to select at least two reference persons in each ward who are guaranteed 0.10% FTE (full-time equivalent) to spend on activities of the ACP+ program. This excludes three full workdays of training (training and comeback seminar) and advance care planning conversations with residents and family.

Insufficient fit with existing procedures and work routines

All participants and the nurse-trainer felt the program could only be incorporated into usual care if it allowed for enough tailoring of details, in a way that is compatible with current practice. The same applies to multidisciplinary meetings which are ideally organized monthly, but there might be other forms and types of team meetings that may function as a platform to discuss advance care planning and changes in preferences of residents. In addition, it was recommended that nursing homes that are performing structural changes to their organization should not be included in the study. This was added to the exclusion criteria in the subsequent trial.

“Every nursing home has its own structure and it is important we have some freedom to for example arrange the information sessions according to the ways we know (e.g. family meetings, coffee gatherings, resident board...)” (nurse)

“If there are structural changes (e.g. renovations to the building) the implementation of such a new program is not compatible. In such times organizing advance care planning fades and primary attention of staff goes to daily nursing care.” (coordinating advisory physician)

We added ‘tailoring meetings’ as a separate intervention component. These meetings are carried out at the start of the implementation and are organized between facility manager, head nurses and staff responsible for implementing the program. The goal of these meetings is to determine which intervention aspects are to be tailored. As a result of this addition, the total number of intervention components changed from nine to ten.

Lack of profile description of ACP Reference Persons

Reference persons were thought to be needing some maturity and experience to carry out the tasks related to the function, to have regular contact with residents and family and be able to handle any resistance from staff. They should have a particular interest in end-of-life care and/or advance care planning and be sufficiently trained. They should be willing to carry out this function and have the mandate from the management to do so. Some participants argued they additionally should have some medical knowledge. Others felt that others, such as social workers, could function as ACP Reference Persons too.

“And even if you have had sufficient training, this is not something you can learn in one year with a short training. You need to practice and have experience.” (physical therapist)

Within the multidisciplinary expert group, we agreed on selection criteria which can be used to select ACP Reference Persons within the first management meetings, always in dialogue with the person him/herself. ACP Reference Persons are professionals employed by the nursing homes, who have responsibilities in daily nursing home care. They are preferably a nurse or head nurse, a member of the palliative care support team within the nursing home or another healthcare professional who is experienced or has some interest in advance care planning and communication about end-of-life care, who is enthusiastic and motivated, has sufficient organizational skills and is good at stimulating colleagues. A list for selecting ACP Reference Persons was added in the ‘ACP Information guide for the nursing home management’.

Importance of a specialized trainer who is familiar with the nursing home

All participants felt the trainer should be familiar with the specific context and working routines of the nursing home.

“Availability of a specialized trainer will motivate nursing homes to enrol in the subsequent study ...” (head of resident’s care)

“But he/she should know how we work.” (nurse)

A site visit/rotation at the start of the intervention was deemed by the nurse expert to be an important addition to the training component in order for him/her to become familiar with the way

of working in each nursing home. This was defined as a half-day site visit (called ‘shadowing’), preferably during a morning shift.

Lack of one-to-one coaching and specialization

Ongoing support, especially a ‘comeback seminar’ halfway through the implementation period of the program, was perceived to be necessary for trained staff to reflect on and present successes, challenges and overall experiences of the program along with staff from the other nursing homes. Staff also stipulated they would need additional information regarding advance care planning with people living with dementia. Also ‘continuity’ was frequently called upon and not knowing how to communicate wishes of residents to others to make sure all involved professionals are informed. Participants said they were worried that reflection sessions would take up too much time, although they were perceived as useful by all. It was suggested such reflection could also be integrated into other types of team meetings that already exist.

“I would like some more information regarding how to estimate cognitive capacity” (reference person palliative care)

“It is important that the staff know how to communicate with other professionals to make sure these wishes that we discussed are eventually followed, also in crisis situations” (nurse)

As a result, reflection sessions were broadened to encompass one-to-one coaching, a specialized training session about dementia and a specialization session focused on communication with and information transfer to other professionals (such as emergency staff or family physicians). Reflection sessions were made optional and the trainer will be instructed to stimulate staff to integrate this in existing meetings.

Important changes to the intervention materials

Revisions to the intervention materials included: 1) simplified language and better explanations of unfamiliar words, activities and learning points; and 2) clear descriptions of the objectives of the ACP+ program and its specific activities within each manual, leaflet or guidance document. The font in the ACP leaflet for residents and family was deemed to be too small, and some text was removed to improve readability. A short 1-page version (“The ACP Conversation Tool”), that can be used during advance care planning conversations (as communication guidance rather than a checklist),

was added, as well as a list where names of residents can be noted who are eligible for advance care planning and with whom conversations have been planned. In addition, a checklist was developed to inform trainers and management/staff about which procedures and materials cannot be tailored and should be standardized. All new materials were developed and reviewed by the research team and the nurse-trainer. The summary sheet to be used in multidisciplinary meetings was found to be redundant and was excluded, and materials to support reflection sessions were changed to optional. The total number of intervention delivery materials changed from 16 to 17.

Standardized description according to TIDieR (results of step 3)

Table 2 describes each intervention component, its timing, any supporting or enabling activities, the mode of delivery (whether it is provided in a group, duo or individually), intervention providers and participants involved during each activity, and materials to support the implementation or organization. Elements eligible for tailoring are highlighted.

The entire program is carried out over eight months and consists of a preparatory training phase (months 1 to 4) and a follow-up phase (months 5 to 8). Fig 1 provides an overview of the timing of each activity and who is responsible. This timeline however is how we intend to implement the intervention in the subsequent trial and is therefore not strict and can be adapted in the future.

Table 2. Description of final intervention according to TiDieR: The ACP+ program (results of step 3)

Timing	Intervention component (n=10)	What (intervention activities, procedures and processes) (n=22)	How (mode of delivery; individually or in a group)	Who (the intervention provider(s) and participants)	Materials (resources/tools that support the intervention activities) (n=17)
3 months prior to start of program	1 ACP Trainer	Activity 1A: Selection and preparation of two ACP (external) Trainers†. The research team provides the ACP Trainers with the necessary information and training regarding the ACP+ intervention.	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 will be made by the research team to use during the selection procedure and to assign a professional to become ACP Trainer. 2. "Manual for ACP Trainer" highlighting key issues of the ACP+ intervention program and guiding the ACP Trainer in performing their tasks (such as training the ACP Reference Persons and supporting them and the nursing home in implementing ACP).
month 1	2 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. At this meeting or series of meetings, the ACP Trainer explains the project and asks management for their (active) participation. This participation will include integrating ACP into the general policy of the nursing home and ensuring the ACP Reference Persons are appointed and able to spend time on their tasks to implement and organize the ACP+ intervention program and ACP in general, within the routine care. At this meeting, they put forward care professionals from among the nursing home staff as ACP Reference Persons‡ (preferably in consultation with the staff themselves)	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". This information guide highlights the key issues and challenges of ACP, how the ACP+ intervention works, how it should be implemented, what everyone's role is and how they should carry out all the steps within the ACP+ intervention program. It also includes what should be the profile, necessary competencies and selection criteria for selecting this ACP Reference Persons are described for the management §.
month 1 to 4*	1 ACP Trainer	Activity 1B: 'Shadowing'. During the first four months, the trainer follows the selected ACP reference persons in their daily job to become familiar with the aspects related to the nursing home, certain routines and ACP-related activities that are already in place.	duo or in a group	1) ACP Trainer 2) ACP Reference Person(s)	None
month 1 to 4*	3 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	4. "Tailoring Checklist"¶. A list which includes questions to guide

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	<p>about how to implement the ACP+ program in routine care (e.g. planning of training sessions, specialization sessions etc.). During these meetings, the Trainer specifically looks at intervention activities that should be 'tailored' to the specific setting and makes sure all intervention activities are planned per schedule within existing routine care. These meetings run parallel with the training session of the ACP Reference Persons (Activity 4A).</p>		<p>Trainer 2) Management 3) Decision-makers (e.g. head residents' care, head nurses, quality coordinators)*</p>	<p>the tailoring meetings (such as "Are their ACP documents already available at the nursing homes?") "Are there any ACP procedures already in place?" etc.). For each intervention component and activity, a list is provided with the minimum of elements that should be held constant over all nursing homes and which elements can be adapted to each nursing home routines (indicated in this table with an asterisk).</p>
<p>4 ACP Reference Persons month 1</p>	<p>Activity 4A: Two-day interactive training (session 1) for the ACP Reference Persons, provided by the ACP Trainer, to train ACP Reference Persons in performing their tasks and responsibilities. Session 1 includes: 1. Information about ACP, 2. How to conduct planned ACP conversations (according to the ACP guidance document), 3. How to document wishes and preferences, 4. How to inform residents and family about ACP, 5. The ACP+ program and the responsibilities and tasks of an ACP Reference Person and how to fit this into routine care ('tailoring').</p>	<p>in a group</p>	<p>1) ACP Trainer 2) Selected ACP Reference Persons from all participating nursing homes</p>	<p>5. "Training manual for two-day training": Training manual with educational materials for the ACP Trainer to use in the training for ACP Reference Persons "ACP Manual for ACP Reference Persons": This manual includes all the materials that are relevant for the ACP Reference Persons to use in the implementation and organization of all intervention activities in the program, and how each intervention component can be tailored to the nursing home's routine care. "Summary list" (first version): List on which the ACP Reference Persons note all residents and their loved ones who are eligible for an ACP conversation. This list provides an overview of who scheduled a planned ACP conversation and when. It is also used to follow up who has a conversation planned, who should be involved in this conversation and when it is planned.</p>

<p>4 ACP Reference Persons</p>	<p>Activity 4A: Two-day interactive training (session 2) for the ACP Reference Persons. Session 2 includes: 1. How to train other staff in performing planned ACP conversations (according to the guidance document), 2. How to educate other staff and volunteers in recognizing triggers for ACP, 3. How to integrate ACP in multidisciplinary meetings, 4. Problems and solutions with how to integrate ACP+ program in routine care.</p> <p>Activity 5A: Information (session(s)) for all residents and their families about ACP and the ACP policy/procedures in the nursing home in a format that is 'tailored' to routines in the specific nursing home setting (e.g. resident/family council, individually, exceptional information session)</p>	<p>in a group</p>	<p>1) ACP Trainer 2) Selected ACP Reference Persons from all nursing homes</p>	<p>as above</p>
<p>5 Information about ACP</p>	<p>Activity 5B: Information session(s) for all family physicians about ACP and the ACP policy within the nursing home, including motivating them to consider the wishes and preferences of their patients in (end-of-life) decision-making and to engage in ACP with their patients. They also get information about the ACP process and structure of ACP conversations, the ACP standardized document and the advance directive. Format: physicians are invited to an information session after 5 p.m., accreditation can be arranged.</p>	<p>individually or in a group (max 10 per group)*</p>	<p>1) ACP Reference Persons, supported by ACP Trainer 2) all eligible, consented residents/proxies and their family</p>	<p>8. "Invitation letter for residents and family"*, inviting them to participate in ACP information sessions. 9. "ACP information brochure for residents and family"*, including brief information about ACP and trigger questions for advance care planning</p>
<p>5 Information about ACP</p>	<p>Activity 6A: In-house 2-hour training sessions (session 1) to train 'ACP conversation facilitators' to conduct ACP conversations. Session 1 is to train them in: general conversation skills to engage in conversations about end-of-life care.</p>	<p>in a group*</p>	<p>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</p>	<p>10. "Invitation letter for family physicians"*, inviting them to participate in these ACP information sessions. 11. "ACP Information brochure for professionals"*, including brief information about ACP and example questions to start and engage in a conversation, that all staff and physicians can keep in their pockets to remind them what the signals are for the initiation of ACP and how they can indicate these signals to the ACP Reference Persons.</p>
<p>6 In-house training</p>	<p>Activity 6A: In-house 2-hour training sessions (session 1) to train 'ACP conversation facilitators' to conduct ACP conversations. Session 1 is to train them in: general conversation skills to engage in conversations about end-of-life care.</p>	<p>in a group (max 10)*</p>	<p>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</p>	<p>12. "Training manual for ACP Reference Persons to train other staff".</p>

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					team) who are willing (selected by important decision-makers)*	
month 4	6 In-house training	<p>Activity 6A: In-house 2-hour training sessions (session 2) to train 'ACP Conversation Facilitators'. Session 2 is to train them in: how to conduct ACP conversations with residents and/or their family according to the guidance document, and how to document such conversations.</p> <p>Activity 6B: In-house 1.5-hour training session to train 'ACP Antennas' to educate them in how to recognize triggers in residents and families, so they are more willing to have spontaneous ACP conversations according to their competencies and know how to pass on information to other staff.</p>	as above	as above	as above	as above
month 4	6 In-house training	<p>Activity 7A: Exploration of earlier wishes and family physician involvement. The person responsible for the conversation with the resident checks whether existing records of previous (documented) wishes are available and contacts the physician as to whether and how they want to be involved in the ACP process of the patient (eg. do they want to receive a call each time something changes in the ACP, do they want to be involved in the conversations, etc.). The family physician is also asked about their knowledge of existing records of previous (documented) wishes or if they had ever had an ACP conversation, and whether there are any family dynamics that the nursing home staff should be attentive to.</p> <p>Activity 7B: First planned advance care planning conversation according to the ACP conversation guide, with resident and family or family alone if resident is not able to participate.</p> <p>Activity 7C: Follow-up conversation(s).</p> <p>Activity 7D: Documentation of wishes and preferences on a standardized form (of which a copy is saved in the resident's file), a summary sheet and advance directives (if perceived necessary by the resident).</p>	as above	as above	1) ACP Reference Persons supported by ACP Trainer 2) Staff and volunteers	as above
month 5 – 8	7 Planned ACP conversations	<p>Activity 8: (Monthly*) multidisciplinary meetings. The ACP process of each resident (the most important decisions of the residents, possible signals for initiating ACP with residents and/or family and discussions still planned), are discussed during regular multidisciplinary meetings so that information is shared among professionals in the nursing home. Ideally the family physician of each resident is involved in these meetings.</p>	duo (including the family physician*)	1) One of the ACP Reference Persons or an ACP Conversation Facilitator, supported by ACP Trainer 2) Eligible (consenting) residents and/or their family	13. "ACP Conversation Guide" which provides information about initiating and preparing for ACP conversations. This conversation guide also includes a flash card that professionals can use during the conversation itself. 14. "ACP Conversation Tool"; short A4 document that ACP facilitators can use to guide the conversation. 15. "ACP Document"* 16. "Standardized advance directive documents"	13. "ACP Conversation Guide" which provides information about initiating and preparing for ACP conversations. This conversation guide also includes a flash card that professionals can use during the conversation itself. 14. "ACP Conversation Tool"; short A4 document that ACP facilitators can use to guide the conversation. 15. "ACP Document"* 16. "Standardized advance directive documents"
month 5-8 (every month 1 MDO)*	8 ACP information transfer		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	None

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	<p>identify problems and discuss action plans to improve current situations if necessary.</p>	<p>3) important decision-makers (e.g. head of residents' care, head nurses) 4) Coordinating advisory physician</p>
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ACP advance care planning. TIDieR template for intervention description and replication; N/A not applicable

*These activities can be tailored to the specific routine care at each nursing home (e.g. number of participants, number of sessions, who is involved, planning etc.).

†The ACP Trainer has the following necessary competencies: experience as a coach or trainer and preferably (work) experience in a nursing home or knowledge of the nursing home setting, knowledge of and/or experience in general principles of advance care planning and related conversations with patients/residents and/or family. Tasks: (1) To give explanations about the ACP+ program to management and staff members; (2) To facilitate the development of an advance care planning policy and to enhance 'tailoring' of specific elements of ACP+; (3) To facilitate the division of roles and responsibilities of staff members and ACP Reference Persons involved in the process within the nursing home; (4) To train the ACP Reference Person in the nursing homes; (5) To support ACP Reference Persons in training other staff members; (6) To give adjusted support throughout all phases of the stepwise implementation of ACP+ (e.g. support, providing a role model, feedback, advice etc.).

‡The ACP Reference Persons are professionals employed by the nursing homes and have roles/responsibilities in daily nursing home care. They are preferably a (head) nurse, a member of the palliative care support team within the nursing home or another healthcare professional who is experienced and has interest in advance care planning and communication about end-of-life care, who is enthusiastic and motivated, has sufficient organizational skills and is good at stimulating colleagues. These ACP Reference Persons will become responsible for implementing and sustaining the advance care planning culture in the nursing home (after training and support from the trainer). They are able to: (1) conduct and follow-up planned conversations with residents and their families according to the ACP Conversation Guide; (2) adapt conversations to the residents' cognitive capacity; (3) inform others about advance care planning; (4) (initially with the support of the ACP Trainer) a. train nursing colleagues (or other suitable clinical staff) to conduct planned conversations according to the ACP Conversation Guide, and b. educate other staff and volunteers to recognize triggers for advance care planning; (5) organize face-to-face reflection; (6) integrate advance care planning (outcomes) of residents/family during multidisciplinary meetings.

§The number of ACP Reference Persons per nursing home (at least two; 0.10 FTE's per 30 beds) depends on the number of beds in the nursing home. A minimum of two ACP Reference Persons will be assigned per 30 beds, which is the average number of beds in one ward.

Figure 1. Timeline of the final ACP+ program

INTERVENTION ACTIVITY	Selection and preparation ACP Trainers		Meeting(s) with ACP Trainer with management, BoD, head nurses and CAP* and CAP*		Training of ACP Ref Persons (session 1)		Training of ACP Ref Persons (session 2)		Information for residents and family		In-house training of ACP Conversation Facilitators (session 2)		Specialization session 1: Dementia		Specialization session 2: Communication with other healthcare professionals		ACP audit meeting		
	3 months before the start of the program	Before the start of the program	Research team	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8
TIMING	Tailoring-meetings with ACP Ref Person, management and decision-makers†																		
PHASE	ACP Trainer 'shadows' ACP Ref Persons																		
PERSON WITH MAIN RESPONSIBILITY	ACP Trainer takes the lead. As soon as ACP Ref Persons are trained they are involved in the organization of each activity.																		
	ACP advance care planning; BoD board of directors; CAP coordinating advisory physician; ACP Ref Person advance care planning reference person; IP family physician.																		
	The figure outlines the timeframe of the ACP+ program as how it will be evaluated in the subsequent trial.																		
	*Nursing homes are legally obliged to have at least one coordinating and advisory physician (C:AP) (remunerated according to the number of beds), who coordinates medical care in the facility, as well as reference nurses for palliative care (0.10 FTE, per 30 residents) [46].																		
	†Important decision-makers include head of nursing staff, head of residents' care, management; all those involved with decision-making tasks in the nursing home.																		

DISCUSSION

We present here the development and description of the ACP+ program, which is a comprehensive multicomponent and theory-based intervention that aims to implement advance care planning in nursing homes. The final program, which is described using the TIDieR checklist, consists of ten components ranging from training, coaching and management meetings, to planning advance care planning conversations, integration of advance care planning into multidisciplinary meetings and audit, all operationalized into 22 activities and 17 accompanying materials. These components are to be implemented stepwise over the course of at least eight months, with the help of an experienced trainer. Professional stakeholders perceived the ACP+ program to be feasible and acceptable for implementation in nursing homes in Flanders, if information sessions for family physicians were adapted, if enough tailoring was allowed, an experienced trainer who knows the nursing home context was available for coaching, comeback seminars and specialization sessions were organized (about dementia and communication with other healthcare professionals), and an additional specific focus on nursing home management's buy-in was added to the program. In addition, simplified language in all intervention materials was advised. The final program focuses on creating both the necessary knowledge and attitudes and the underlying care 'culture' for successful advance care planning in nursing homes.

While there are some comparisons with other existing advance care planning programs (such as the educational train-the-trainer approach [21,33], the assignment of facilitators [21,30], the use of conversation guidance [30,47], informational materials and a standardized ACP document [33]) important differences remain. This intervention targets different levels in the facility, thus ensuring that implementation is not dependent on one individual but is embedded at organizational level [23]. The program also differs from others because it explicitly follows a stepwise approach (separating 'preparation' from 'implementation'), in which the intensity of the trainer's support decreases. Volunteers and cleaning or administrative staff in other programs had no explicit or specific role, despite research showing their importance in signalling care wishes of residents [48,49], but function as ACP Antennas in ours. Additionally, while there has been much emphasis on tailoring the initiation of advance care planning to patient readiness and willingness [50,51], and as both a process measure of implementation [28,45,52,53], there has been no explicit focus on the opportunity to

tailor elements of advance care planning programs to suit local circumstances as part of the intervention itself. This is an important component of the ACP+ program.

Strengths and limitations

The primary methodological strength of the reported research is the thorough process undergone to develop the intervention. Starting from a theoretical model [24,54], we operationalized and tested all components, activities and materials for their perceived feasibility and acceptability in the field. This work is in line with recent recommendations to start from theory and include testing feasibility and acceptability as part of the development phase of a complex intervention [27,55]. Step 2 (evaluating feasibility and acceptability) of our work provided the opportunity to identify implementation issues early on and to formulate strategies for these. This may minimize the need for modifications and the chance of implementation failure when testing the effectiveness of the intervention in a subsequent trial [56]. Second, by describing all details of this development work here, we comply with growing calls for more detailed and transparent reporting of complex healthcare interventions [45,55]. Our method has allowed us to provide a robust rationale for each foreseen intervention component, activity and material. As such, we believe this will enable researchers to compare our intervention with others more effectively, and practitioners to convert it more easily into clinical practice.

This study also has limitations. Firstly, we did not include the perspective of nursing home residents and their families when evaluating the feasibility and acceptability of the program. Hence, while the program is supported by a wide range of professional stakeholders, caution must be applied. Secondly, while we have put forward definitions of both feasibility and acceptability, it remains difficult to agree upon a cut-off point to decide when the intervention can be considered feasible or acceptable. Thirdly, because the intervention is adapted to the Flanders, some intervention components may not be directly transferable to other countries. Other countries may work with on-site physicians [57], or have better implemented electronic health records or different legal and financing systems [58,59]. Our advance care planning model involves intensive support of a specialized trainer at the start of the implementation; such resources might not be available everywhere. Finally, because project funding was time-limited, we did not carry out a pilot study e.g. a reduced version of the eight-month intervention program to determine whether the intervention components can all function well together [60]. However, we do aim to assess whether implementation of the program is worthwhile, whether it should be developed further or should be

sent back to the drawing board [61], by using an in-depth process evaluation embedded in the subsequent trial.

CONCLUSION AND IMPLICATIONS

ACP+ is a theory-based intervention program that aims to implement advance care planning in routine nursing home care. It consists of multiple components, activities and materials that need to be implemented together in a stepwise manner over the course of eight months with the help of an external trainer. Its thorough development process and the standardized description in this paper aim to prevent implementation failure in real practice and increase transparency, comparison with other interventions and replication in the future. The program is currently under evaluation as part of a cluster randomized controlled trial.

DECLARATIONS

Ethics approval and consent to participate

This study was approved by the Ethical Committee of University Hospital Brussels (2017/31 B.U.N. 143201732133). Anonymity was assured by removing participant information that could lead to identification. All participants were asked verbally for their consent to the publication of anonymized data.

Availability of data and materials

The intervention materials generated from the current study are available from the corresponding author on reasonable request. They are only available in Dutch.

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Conflicts of interest

The authors declare that they have no competing interests.

Authors' contributions

Study concept and design: JG, LP, AWvD, LVH, LVDB, CG, RV, LD. Acquisition of data: JG and AWvD. Analysis and interpretation of data: JG, AWvD, LP and LVD. Drafting of the manuscript: JG. Critical revision of the manuscript for important intellectual content: All. All authors take responsibility for the integrity of the data and the accuracy of the intervention development.

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ADDITIONAL FILES CHAPTER 3

S1 Table. ACP+ intervention materials, their original source and adaptations made

Intervention materials (n=16)	Original source	Adaptations made compared to original source
17. Manual for ACP Trainer	Manual for Country Trainers (PACE*; GSF)	Content adapted to purpose of ACP+, keeping original structure
18. ACP Information guide for nursing home management	Information guide for nursing home management (PACE)	Adapted to purpose of ACP+ keeping original structure
19. Training manual for two-day training	Outline 2-day workshop (PACE) Content developed by research team	Adapted to purpose of ACP+, keeping original structure
20. ACP Manual for the ACP Reference Persons	Manual for Coordinators (PACE; GSF)	Content adapted to purpose of ACP+, keeping original structure
21. Invitation letter for staff, CAP and management for information sessions	Invitation letter (PACE)	Content adapted to purpose of ACP+, keeping original structure
22. Invitation letter for FP	Invitation letter (PACE)	Content adapted to purpose of ACP+, keeping original structure
23. Invitation letter for residents and families	Invitation letter (PACE)	Content adapted to purpose of ACP+, keeping original structure
24. ACP Information brochure for nursing home staff and FP	ACP brochure for professionals made available by LEIF†	Shortened and adjusted layout
25. ACP information brochure for residents and family	ACP brochure for population made available by LEIF†	Shortened and adjusted layout
26. ACP Conversation Guide	Guideline for ACP conversations' and 'Guideline for ACP with people with dementia' (Pallialine‡); ACP guideline, no. 12 (Royal College of Physicians, 2009); ACP guideline (KBS§)	Inspired by various sources and adjusted to purpose of ACP+
27. ACP Document	Korfage et al., 2015; ACP document (University Hospital Leuven); 'Looking and Thinking Ahead' document (PACE EUFP7); Advance Care Plan (Respecting Patient Choices, Silvester et al., 2013)	Inspired by various sources and adjusted to purpose of ACP+
28. Standardized Advance Directive documents	Nationally accepted advance directives approved by federal government (developed and distributed by LEIF†)	Not adjusted
29. Training manual for training other staff	Developed by research team	Not applicable
30. Summary sheet	Summary Sheet (PACE)	Adapted to purpose of ACP+, keeping original structure
31. Reflection instrument	Reflective Debriefing Instrument (PACE; Hockley et al., 2014)	Adapted to purpose of ACP+, keeping original structure
32. Audit instrument	Regional quality indicators made available by Flemish government; ACP audit tool (Ampe et al., 2015); ACP quality indicators (Sinuff et al., 2015); Audit data tool (PACE)	Inspired by various sources and adjusted to purpose of ACP+; regional quality indicators are kept the same but are supported by an example of how to calculate each quality indicator

ACP advance care planning; GSF Gold Standards Framework (www.goldstandardsframework.org)

*PACE is an EU-funded project (FP7) evaluating the PACE Steps to Success intervention to improve palliative care in nursing homes [33] (www.eupace.eu)

†LEIF “Belgisch LevensEinde InformatieForum” (Dutch) or “Belgian information forum for end-of-life care issues” (English) is an initiative by the Belgian federal government which is issued to provide information about end-of-life (care) issues to the public and professionals (www.leif.be). In 2017, they made several leaflets available to inform both the public and professionals about advance care planning. They have also developed and distribute advance directive forms, which are supported by the Belgian Federal Ministry of Health.

‡Pallialine is an initiative by the Flemish Federation for Palliative Care, assigned to develop evidence-based palliative care guidelines for practice.

§KBS King Baudouin Foundation Belgium is a public benefit organization (www.kbs-frb.be/eng). In 2011 they organized a nationwide campaign to promote “thinking earlier...about later”, which resulted in several publications available in Dutch and French about advance care planning, including a guideline for professionals which was developed by a multidisciplinary team of experts [36].

PART III

S2 Table. Changes, additions and removals made to the original intervention components (n=10), activities (n=22) and materials (n=17) of the ACP+ program (results of step 2)

Intervention component and underlying activities	Changes/deletions made (reasons)	Newly added (reasons)
1 ACP TRAINER Selection and preparation	The external ACP Trainer is made available for only 8 months; hence no consolidation phase is included in the project (because of limited funding); A list with criteria to select an appropriate trainer was made available; Two trainers will be selected, each responsible for training a certain number of nursing homes	Shadowing for at least half a day was added for the trainers to get acquainted with the activities related to routines and ACP at each NH. No supporting materials deemed necessary.
2 BUY-IN AND ENGAGEMENT OF MANAGEMENT Meetings with management, board of directors and coordinating advisory physician* Follow-up meetings	The meetings now include management, all members of palliative care team/working group and head nurses; board of directors will not participate in these meetings	Several meetings should be planned at the start and end of the study (Engagement of management is perceived as important step to guide implementation and sustainability)
3 TAILORING Tailoring meetings		This was added as a new intervention component (because 95.1% of nursing homes in Flanders have ACP procedures in place [60]); A tailoring checklist is made available to the trainers and ACP Reference Persons (to know which elements should and cannot be standardized)
4 TRAINING OF ACP REFERENCE PERSONS Training of ACP Reference Persons Come-back seminar	Necessary number of ACP Reference Persons changed from 0.50 FTEs per 30 beds to two 0.10 FTEs per 30 beds (more feasible and sustainable in the long run); Content of training was adapted (to fit new ACP+ program)	Added as new training activity (Perceived important by all professional stakeholders to add this activity)
5 INFORMATION Information about ACP for staff Information about ACP for family physicians	Removed (because the suggestion was made to focus primarily on word of mouth/internal meetings, folders/posters and training sessions to communicate information about ACP to personnel; management and coordinating advisory physician should already have been informed at the management engagement meetings) Timing changed from a session in the afternoon to a session in the evening (because patient visits are mainly before 5 p.m. which would guarantee more attendance); Accreditation must be guaranteed (to stimulate physicians to participate)	

Information about ACP for residents and family	Both information sessions and additional information channels (e.g. in-house newspaper or letter, family gatherings, posters in elevator) are put to use, depending on availability in nursing home (To reach all residents and family members)
6 IN-HOUSE TRAINING	
'In-house' training to perform ACP conversations	Not limited to nursing staff, but also including others those who are members of the palliative care team, reference persons for dementia/palliative care, experienced care assistants (unsustainable due to staff turnover and limited nursing staff; on average 1 FTE nurse for 30 beds in Flanders); Changed to two sessions of 2 hours instead of one session of 4 hours (because this would take them away from their care duties for less time during the day); People who are trained to perform ACP conversations are called 'ACP Conversation Facilitators'
Info/training for other staff to signal ACP triggers	These training sessions include all those who did not attend the previous training. Short sessions of 1.5 hours are enough. People trained to recognize signals are called 'ACP Antennas'
7 ACP CONVERSATION PROCESS	
ACP conversations	An "ACP Conversation Tool" was added to the list of supporting materials. It is a short A4 document that ACP facilitators can use to guide the conversation (The "ACP Conversation Guide" was too elaborate; all stakeholders felt they needed a tool they could use during ACP conversations)
Follow-up of ACP conversations	The team should discuss every 6 months (or after trigger) if follow-up is necessary (challenging to revise all conversations yearly or after each trigger); A list should be made available to provide a summary of who has planned a conversation with which resident and who is eligible to participate
8 INFORMATION TRANSFER	
Documentation	Tailoring is allowed (as it is bureaucratically and administratively challenging to implement new ACP documents; 4 out of 5 nursing homes have their own electronically available ACP documentation system); ABC codes are added to the ACP document (3 out of 5 nursing homes worked with this coding system)
Multidisciplinary meetings	Perceived as underlying activity for information transfer
9 COACHING	
Reflection sessions	We changed the name of this intervention component to 'coaching' and added 'one-to-one coaching' and two 'specialization sessions'; The reflective debriefing instrument was kept as 'optional'
One-to-one coaching	Perceived by the professional stakeholders to be necessary after a difficult ACP conversation
Specialization session on dementia	This specialization session has been added (because nearly 2/3 of residents in participating nursing homes have mild to severe dementia)
Specialization session on communicating with others	This specialization session is added (because this was found difficult by nursing home staff)
10 AUDIT	
Audit meetings	Changed from 'formal monitoring system' to the availability of an auditing tool (to guide a yearly meeting about ACP procedures); Because of the limited availability



PART III

of quality coordinators in nursing homes, this intervention component was believed to be unsustainable after the study period. To develop a large monitoring system requires an in-depth literature review and development work, which was not possible due to the constraints of the research project)

ACP advance care planning

*Nursing homes are legally obliged to have at least one coordinating and advisory physician (C/AP) (remunerated according to the number of beds), who coordinates medical care in the facility, as well as reference nurses for palliative care [40].

†ACP codes are A, B, C (in Dutch language): 'A' stands for 'to do everything', 'B' stands for 'preservation of functions', 'C' stands for 'comfort care'.

Changes that were suggested by the participants but were not integrated in the renewed intervention because of resource and time restraints, were: 1) more training capacity (one trainer that is available to the nursing home full-time); 2) longer period of implementation time; 8 months is perceived not to be enough to implement ACP in a nursing home; 3) new electronic system (or adaptations to the existing one) to integrate advance care planning more easily into medical file of the patient; 4) extra financial resources to make sure nursing staff has enough time to train others and meanwhile conduct advance care planning with residents.

S3 Table. Characteristics of participants in interviews regarding feasibility and acceptability of the program (step 2)

Characteristics of participants (n=17)					
Sex	Number				
Male	3				
Female	14				
Age (years)*					
≤ 29	1				
30 – 39	2				
40 – 49	4				
50 – 59	6				
Job position					
Social worker	1				
Nurse	3				
Head nurse/nursing unit manager	3				
Head of resident care	3				
Reference person for dementia	1				
Care assistant	2				
Reference person for palliative care	1				
Physical therapist	1				
Coordinating Advisory Physician	1				
Quality coordinator	1				
Number of years active in current position					
< 7 years	1				
7 – 9 years	2				
10 – 15 years	4				
≥ 15 years	10				
Received training in advance care planning					
Yes	15				
No	2				
Characteristics of participating nursing homes (n=5)	NH 1	NH 2†	NH 3	NH 4	NH 5‡
Organizing authority‡	Private non-profit	Public	Public	Public	Private non-profit
Number of nursing care beds§	80	306	120	150	170
Average number of residents who died in the past 12 months	33	NA	33	50	55
Specific guidelines regarding palliative care practice available (yes/ no)	yes	yes	yes	yes	yes
Patient-specific ACP documents available (yes/no)	yes	yes	yes	yes	yes
Multidisciplinary meetings regarding treatment and care plans of residents¶	monthly	monthly	monthly	yearly	other (every 5 weeks)

ACP advance care planning; NH nursing home; NA not available

*Missing n=4

†Nursing homes from which participants were recruited in individual semi-structured interviews

‡Organizing authority types: public, private commercial or private non-profit.

§Number of beds in the nursing home as acknowledged by RIZIV (Belgian national health insurance administration), excluding beds at daycare centers and beds for short stays.

||Information provided by one of the participants; residents who died between September 2016 and September 2017.

¶Response options: No or Yes; if yes, weekly, monthly or yearly.

PART III

*Chapter 4: Implementing the theory-based advance care
planning ACP+ programme for nursing homes: study
protocol for a cluster randomised controlled trial and
process evaluation*

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ABSTRACT

BACKGROUND Research has highlighted the need for improving the implementation of advance care planning (ACP) in nursing homes. We developed a theory-based multicomponent ACP intervention (the ACP+ programme) aimed at supporting nursing home staff with the implementation of ACP into routine nursing home care. We describe here the protocol of a cluster randomised controlled trial (RCT) that aims to evaluate the effects of ACP+ on nursing home staff and volunteer level outcomes and its underlying processes of change.

METHODS We will conduct a cluster RCT in Flanders, Belgium. Fourteen eligible nursing homes will be pair-matched and one from each pair will be randomised to either continue care and education as usual or to receive the ACP+ programme (a multicomponent programme which is delivered stepwise over an eight-month period with the help of an external trainer). Primary outcomes are: nursing home care staff's knowledge of, and self-efficacy regarding ACP. Secondary outcomes are: 1) nursing home care staff's attitudes towards ACP and ACP practices; 2) support staff's and volunteer's ACP practices and 3) support staff's and volunteers' self-efficacy. Measurements will be performed at baseline and eight months post-measurement, using structured self-reported questionnaires. A process evaluation will accompany the outcome evaluation in the intervention group, with measurements before, throughout and post-intervention to assess implementation, mechanisms of impact and context and will be carried out using a mixed-methods design.

DISCUSSION There is little high-quality evidence regarding the effectiveness and underlying processes of change of ACP in nursing homes. This combined outcome and process evaluation of the ACP+ programme aims to contribute to building the necessary evidence to improve ACP and its uptake for nursing home residents and their family.

TRIAL REGISTRATION The study is registered at ClinicalTrials.gov (no. NCT03521206).
Registration date: May 10, 2018.

Key words: *Advance care planning, Complex intervention, Nursing home, Process evaluation, Effectiveness, Care staff, Educational intervention, Implementation*

BACKGROUND

Timely advance care planning (ACP) is advocated as an important part of routine nursing home practice. A recent consensus definition defined ACP 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, including end-of-life care [1]. If a person wishes, the contents of such conversations can be recorded in the form of an advance directive (AD) and may include choosing a durable power of attorney or proxy decision-maker [1, 2].

A number of previous studies in nursing home populations have shown that, if ACP is actually conducted, it can effectively decrease hospitalisation rates and hospital deaths, decrease overall health costs and increase treatment concordant with people's wishes [3]. However, these findings usually do not come from studies using high-quality methodologies, as was identified in a recent systematic review using GRADE (Grading of Recommendations Assessment, Development, and Evaluation) criteria to assess the quality of the studies that had evaluated effects of ACP in nursing homes. In addition, very few randomised controlled trials (RCT) in this area have been published [3]. Moreover, the uptake of ACP in clinical practice remains limited and nursing home residents' wishes about their preferred medical treatment and care are often not, or not in time, explored [4–6]. Previous epidemiological studies have shown that uptake is also low in Belgium where only half of deceased nursing home residents had documented wishes or preferences [7] and 38% of residents never engaged in ACP during their two-year stay in a nursing home [6].

Healthcare professionals' lack of knowledge about ACP and their confidence in conducting ACP, are identified in the literature as prominent factors preventing them from engaging in ACP [8]. Improving this should be a first priority, given that two theoretical frameworks that describe successful ACP specify that sufficient knowledge and self-efficacy are necessary intermediate steps on the pathway to changing outcomes on the patient and family level [9, 10]. To improve the uptake of ACP in regular nursing home practice, we have developed the ACP+ programme for nursing homes in Flanders (Belgium). ACP+ is a theory-based multicomponent intervention focused on helping staff deliver ACP as part of routine nursing home care, implemented in a stepwise manner

over the course of eight months with the help of an external trainer. The underlying theoretical model can be found elsewhere [10]. However, the effectiveness of ACP+ and its theoretical assumptions have not yet been tested using a high-quality research design. This article describes the study protocol of a cluster RCT with an embedded process evaluation. The study aims to evaluate the effects of ACP+ on nursing home staff and volunteer level outcomes and its underlying processes of change. The protocol is outlined according to SPIRIT (Standard Protocol Items: Recommendations for Interventional Trials) guidelines [11].

METHODS

Trial design

We will perform a cluster randomised controlled trial (RCT) with embedded process evaluation. It is a superiority trial because it aims to establish whether the intervention is superior to usual practice in effectiveness [12]. The trial will be structured according to a nested cohort pretest-posttest design with a priori matching of clusters [13–15]. Clusters are nursing homes found eligible and willing to participate, which will be matched into pairs (1:1) by (in order) location (province in Flanders, type of facility (public, private non-profit or private for-profit) and number of beds. One of each pair will randomly be assigned to either intervention or control group. A cluster RCT is recommended for this type of study because most intervention components target the entire nursing home. Randomising staff within facilities was not an option as it would have been impossible to prevent contamination among staff on the same wards [16]. Figure 1 shows the flowchart of the RCT. Immediately after randomisation, baseline outcomes measures are performed (T0) and eight months later, outcome measurements (T1).

The outcome evaluation of the cluster RCT will be accompanied by an embedded process evaluation to evaluate processes of change (i.e. the implementation, mechanisms of impact and context) behind ACP in nursing homes. The design of the process evaluation is informed by the Medical Research Council (MRC) framework for process evaluations of complex interventions by Moore et al. [17] and a previously constructed theory of change [10]. The process evaluation has a mixed-methods design, collecting data before and throughout implementation of the intervention and post-intervention via structured diaries, notes, attendance lists, observation, post-training surveys and semi-structured interviews and focus groups. The study is registered at ClinicalTrials.gov (no. NCT03521206).

Participants, intervention and outcomes

Setting

The study will be carried out in nursing homes in Flanders, the Dutch-speaking part of Belgium.

Nursing homes are included if:

- they have at least 100 beds
- the facility manager 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)’.

Nursing homes are excluded if:

- they have taken or are taking part in another research study that is evaluating palliative care services or communication strategies, currently or in the past four years
- they have developed - or are planning to develop during the foreseen duration of the trial - an extensive ACP policy, meaning that (i) all nursing home residents, or their families, regularly receive ACP conversations (two conversations or more each 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).
- major organisational or physical changes to the facility (e.g. building activities or staff re-organisation) are planned or ongoing during the study period
- they were involved in the development of the intervention programme.

Study population and respondents

Nursing home staff and volunteers

Both the intervention and data collection methods are targeted at multiple staff members and volunteers working in the nursing home. Nursing home staff are people employed by the nursing home and include two groups:

- nursing home ‘care’ staff are nurses, care assistants, psychologists, physiotherapists, occupational therapists, social workers, animators, pastoral or spiritual caregivers, moral consultants, reference persons for dementia or reference persons for palliative care
- nursing home ‘support’ staff are staff working in the nursing home but without having a role in care provision i.e. cleaning, administrative, technical/logistical or kitchen staff who have regular contact with residents or family but do not provide direct care to them.

Nursing home staff are included if they are able to speak and understand Dutch. Volunteers are included if they are registered at the nursing home and able to speak and understand Dutch. Students, interns or volunteers under 18 years old are excluded from participation.

Nursing home residents and family

The intervention will not be directly targeted at nursing home residents or family, as ACP+ is a training and support programme directed at nursing home staff level. As part of the process evaluation, we will conduct semi-structured interviews with a small sample of residents and their families from the intervention nursing homes who have participated in ACP conversations. Family members are defined as relatives or friends of the resident and identified by the nursing home care staff. People younger than 18 years, unable to understand or speak Dutch or unable to provide written informed consent are excluded from participation.

Intervention: the ACP+ programme

The ACP+ programme is a multicomponent theory-based intervention aimed at training and supporting nursing home staff with the implementation of ACP into daily nursing home care and routine practice. It is focused around training and coaching, management buy-in, identifying roles and responsibilities in having ACP conversations with all residents and/or their families, documentation and information transfer, regular follow-up during multidisciplinary meetings and audit, and also includes possibilities of tailoring specific elements to the local context. The programme includes ten intervention components, 22 activities and 17 materials to support its delivery, detailed in Figure 2 and Table 1. The components are to be implemented stepwise over the course of eight months, with the help of one or two external trainer(s) whose support decreases as the nursing home becomes more autonomous in organising ACP. These trainers understand that coaching and communication are important to change practice, they have clinical practice experience in nursing homes, experience in delivering palliative care, and in performing ACP conversations. Ultimately, a family physician and a nurse were selected.

A key aspect of the programme is the imparting of different roles in the nursing home: ‘ACP Reference Persons’ will be responsible for implementing ongoing ACP within the nursing home; ‘ACP Conversation Facilitators’ work with ACP Reference Persons and are responsible for planning and performing regular ACP conversations with residents and/or family; all other staff, including

support staff (administrative, technical, cleaning staff) and volunteers, are ‘ACP Antennas’, who recognise and signal triggers that indicate a persons’ readiness, need or willingness to engage in ACP.

To develop the ACP+ programme, we first applied a Theory of Change approach to develop a theoretical model of all intermediate steps necessary to achieve desired long-term outcomes for nursing home residents and their families [10]. We constructed this model through 1) context analysis of facilitators/barriers that enhance or inhibit ACP, 2) systematic review of preconditions for ACP in nursing homes [8] and 3) two workshops with stakeholders to identify how ACP is expected to work in the local context in order to achieve its desired long-term outcomes [10]. We then operationalised key intervention components – identified as part of this theoretical model – into specific activities and materials, through expert discussions and review of existing ACP programmes, and we evaluated the programme (including the activities and materials) for perceived feasibility and acceptability of its implementation in nursing homes through interviews with nursing home management and staff of five nursing homes, and expert revisions; ethics approval was granted by the Ethics Committee of University Hospital Brussels (2017/31, (B.U.N. 143201732133). A standardised description of the final ACP+ programme, according to the TIDieR checklist can be found in Table 1.

Control group

In nursing homes that are randomized to the control condition, care will be provided as usual. In case nursing home staff in this group receives training regarding ACP and/or or initiate ACP with residents or families, these nursing homes will remain in the control group. We will perform baseline and follow-up measurement of primary and secondary outcomes in this group, but no process evaluation assessments as the intervention is not delivered there. After the study ends, the control nursing homes will have the possibility of discussing the results of the study with the research team, have access to all intervention materials and receive a one-day training from the external trainers.

Outcomes

Primary outcome

The two primary outcomes are: 1) nursing home care staff’s knowledge of ACP and 2) nursing home care staff’s confidence in their own skills regarding ACP (self-efficacy). These outcomes are measured at baseline (T0) and after eight months (T1). We assess knowledge and self-efficacy as these are

identified as necessary intermediate steps for healthcare professionals to be able to actually engage in ACP, according to both social cognitive theory and literature about successful ACP [9, 10, 18].

Secondary outcomes

The following secondary outcomes are measured at baseline (T0) and after eight months (T1): 1) nursing home care staff's attitudes towards ACP and ACP practices; 2) support staff's and volunteers' ACP practices; and 3) support staff's and volunteers' self-efficacy. Outcomes on support staff- and volunteer level were added because an important part of the ACP intervention is targeting these professional roles. The outcome measure was adapted to this population (See Supplementary Material).

Outcome measurements

To evaluate ACP knowledge, attitudes, self-efficacy and practices, we developed a questionnaire, based on the questionnaire in a study from Detering et al. [19], which was translated via forward-backward translation and adapted to fit the local context. Items were added based on the Questionnaire Tool for Registered managers from Ulster University [20] and expertise of the multidisciplinary author group. The adapted version of the questionnaire was tested with six researchers who have clinical practice experience with older patients (three registered nurses, one GP, one psychologist and a nursing home volunteer), and through an online survey with 107 healthcare professionals and volunteers active in the Flemish nursing home setting. All items were reviewed and discussed within the author group and questions related to legal issues were additionally reviewed by an expert in Medical Law. Results of this trial will be based on the final version of the questionnaire (Supplementary materials).

In the knowledge section of the final version of this questionnaire, respondents are asked to respond to 11 statements (e.g. 'a nursing home resident can only assign a family member to be his/her legal representative') 'true', 'false' or 'I don't know'. The self-efficacy section asks respondents to indicate how confident they feel (10-point Likert scale, ranging from 'little confidence'=0 to 'a lot of confidence'=10 and 'not applicable') regarding 12 items (e.g. 'how confident do you feel about: initiating ACP conversations?'). In the attitudes section respondents are asked to indicate how strongly they agree or disagree (5-point Likert scale ranging from 'completely disagree'= 0 to 'completely agree'=5) with 12 statements (e.g. 'in most cases nursing homes residents do not know enough about healthcare to construct an advance directive'). The construct ACP practices asks about

ACP activities in the past six months (e.g. initiating an ACP conversation, drafting of an advance directive, etc). For support staff and volunteers the ‘self-efficacy’ and ‘ACP practices’ sections are adapted to include three items evaluating ‘self-efficacy’ and two items to evaluate ‘ACP practices’. These items are all based on the main questionnaire. Table 2 provides a full overview of outcomes and measures.

Other measures

We additionally measure several structural facility-level characteristics of participating nursing homes, and demographic and background information in all participating staff and volunteers. These characteristics are described in Table 2.

Process evaluation

Via an in-depth process evaluation in the intervention group we will assess:

- implementation: defined as the process through which interventions are delivered, and what is delivered in practice [17]. Outcomes involve: how delivery is achieved and what is delivered (dose, reach, fidelity, adaptations).
- mechanisms of impact: the intermediate mechanisms through which intervention activities produce intended (or unintended) effects [17]. This involves: responses and interactions from participants with the mediators that might explain changes in outcomes and unanticipated pathways or consequences.
- context: factors external to the intervention that may influence its implementation or whether mechanisms of impact act as intended, including outcomes such as contextual moderators (barriers and facilitators) and participant’s intention for maintenance [17].

The process evaluation has a mixed-methods design combining quantitative and qualitative research methods, collected regularly before, throughout and after the intervention period. The results of this process evaluation will enable us to strengthen the links in the theoretical model we have developed in a previous phase [10]. An overview of the process evaluation outcomes (implementation, mechanisms of impact, context) and data collection methods can be found in Table 3.

Sample size

When we assume unequal cluster sizes with a coefficient of variation of 0.17 and mean size of 30 and an intra-cluster correlation coefficient of 0.036 [21, 22], the design effect for a completely randomised cluster randomised trial is estimated at 2.07, and a sample of 161 staff members for each group across

6 clusters will achieve 80.27% power to detect an effect size of 0.5 at a significance level of 2.5%. This number has been increased to 242 staff members per group (total sample size of 484) to allow for an initial response rate of 70% and a staff turn-over of 10%. Current sample size calculation is valid for a completely randomised RCT (hence assuming a matching correlation of zero and assuming the intervention effect is constant across pairs). To compensate for the loss of degrees of freedom introduced by matching, it is suggested to add two clusters per arm [15].

Recruitment

Umbrella organisations in the nursing home sector in Flanders will be asked to distribute a short informational form about the project and inclusion criteria among their members. If nursing homes express their interest, the researchers (JG and AWvD) will contact them by telephone to introduce the research, do a first check of eligibility, and plan a face-to-face introductory meeting on site. During this meeting, the researchers will inform facility management and head nurse(s) about the study procedures and formally evaluate all inclusion and exclusion criteria. Within two weeks the nursing home's management will be asked to confirm agreement to participate by signing an agreement form prior to randomisation. In case a facility manager declines to participate, another one fulfilling the eligibility criteria will be selected until a sufficient number of nursing homes are recruited. If this recruitment strategy delivers insufficient nursing homes, the researchers will randomly call a sample of eligible nursing homes from the list of formally acknowledged nursing homes by the national health insurance administration (National Institute for Health and Disability Insurance, in Dutch: Rijksinstituut voor Ziekte- en Invaliditeitsverzekering - RIZIV, in French: Institut National d'Assurance Maladie-Invalidité - INAMI).

Assignment of interventions

Randomisation

After the purposive identification of all nursing homes taking part in the study, they will be matched into pairs (1:1) and one of each pair will then be randomly assigned to the control or intervention group. Facilities that expressed to be interested to participate, are ordered (on a first come first serve basis) on a list which described their region, number of beds and facility type (non-profit, for-profit public/private). We contacted the nursing homes consecutively, starting with the first of the list. After we visited the nursing home, the eligibility assessment was made (using the eligibility criteria). If the nursing home was included, the next on the list was contacted unless there were already

sufficient eligible nursing homes in a stratum, in which case the nursing home was skipped and another nursing home with different characteristics was contacted first. Paired randomisation will be performed by an independent and blinded statistician of Vrije Universiteit Brussel (VUB) via computer generated random numbers. The researchers will make a list of all included numbered, including information about facility status (public vs. private without profit objective vs. private with profit objective), location (province within Flanders) and number of beds. The nursing homes will be divided into groups; nursing homes from the same region are grouped. Within each group, nursing homes are subsequently subdivided to match in facility status and then number of beds. The randomisation procedure will be repeated if the numbers of beds are unbalanced i.e. if the difference between the control and intervention groups is greater than 15% of the largest group. Because we will include nursing homes with >100 beds the difference will not be very great. The randomisation procedure will be repeated a maximum of three times; if an imbalance persists, the last randomisation result will be used for the study. In cases where nursing home staff in the control facilities receive training regarding ACP and/or initiate ACP with residents or families during the study period, these nursing homes will remain part of the control group as this can be part of standard best practice nursing home care. However, to have an extensive ACP policy and practice is an exclusion criterion for nursing homes to be included in the study. This based on the judgement of the two researchers (JG and AWvD), using a list of 12 predefined criteria that define extensive policy and practice. This list is based on a list (of yes/no questions) which is used in a previous Flemish study [23]. Questions range from “The nursing home has a clear and written ACP policy”; “There is oral/written information made available to residents and family regarding ACP, ADs and the assignment of legal representatives” to “Wishes regarding the end-of-life for all nursing home residents (and/or their loved ones) are regularly discussed in team meetings, especially when there are changes”.

Blinding (masking)

The nature of the intervention makes it impossible to blind study participants because all those in the intervention group will receive additional training or information. During data collection, the researchers cannot be blinded because they will observe training sessions and conduct interviews with staff as part of the process evaluation, hence will know the staff who work in intervention facilities. The process evaluation will only be conducted in intervention facilities. During data analysis, researchers and statistician will be blinded for the unit of randomisation of each nursing home, using encrypted data.

Data collection, management and analysis

Data collection methods

In each facility, a key contact person (facility manager, head of care, head nurse or quality coordinator) will be identified. After randomisation, this key contact person will fill in the questionnaire concerning the baseline structural facility-level characteristics. In addition, the contact person lists *all* eligible nursing home staff and volunteers. Each eligible staff member/volunteer will be assigned an anonymous code, which will enable the research team to link T0 to T1 data. As part of baseline and post-assessment, they receive a structured self-report questionnaire with his/her personal code. They will put the questionnaire in sealed envelopes and deposit it in a locked letter box (only accessible to the researchers) in a central spot in the nursing home. As was done in a previous Flemish and EU study, two reminders will be sent [23, 24]. Using the anonymous codes, the researchers will register response. For non-responders, the contact person of the nursing homes will be asked to re-distribute the questionnaire to this professional and send out a general reminder. These procedures are repeated eight months after baseline measurement. Newly hired staff and new volunteers are added to the list of codes and will also receive a questionnaire.

Data collection procedures for the process evaluation, described in detail in Table 3, are the following:

- structured diary of ACP Trainers: the ACP Trainers keep track of all activities they perform regarding the ACP+ programme by filling in a structured diary on a weekly basis. The diary will be provided by JG via Google Forms, which will be password-protected and stored in a secured folder.
- notes of ACP Trainers: after each visit to a nursing home, trainers are asked to write a short report to the Trial Monitor (LP) via e-mail. These reports are held in a secured folder.
- semi-structured individual interviews with ACP Trainers: both trainers will be interviewed (60 to 180 minutes) by one of the researchers at four and eight months. They will be asked for verbal consent to audiotape the interview.
- attendance lists: at the beginning of every training or information session an attendance list will circulate among those attending and they will be asked to write down their name and signature. The key contact persons keep the lists in a secure place and will only hand over the total number of participants per session to the researchers.
- observation of training sessions: during the two-day training of ACP Reference Persons, the two researchers independently observe the training session using a structured observation checklist.

- post-training survey: all staff involved in a training session of the ACP+ programme receive an evaluation questionnaire about the quality of the training and trainer. The surveys will be handed out to the participants at the end of the training by the trainer. Participants will put the survey in a sealed envelope which is then put into the locked box, posted via mail or collected by the key contact person and handed over to one of the researchers. Surveys are anonymised.
- semi-structured post-ACP interviews with residents and family: via the key contact person and ACP Reference Persons of each intervention nursing home, at least three residents and their families are recruited to engage in a semi-structured interview with one of the researchers. After an ACP conversation the staff will ask the resident, family or dyad if they would be willing to participate in an interview. If they respond positively, a date will be planned (preferably shortly after the ACP conversation). At the start of the interview, the researcher will go over the informed consent procedure with the resident and/or their family member. Interviews will last approximately 30 minutes.
- semi-structured individual interview with management: after the intervention, one member of the nursing home management per intervention nursing home will be invited by the researchers for a 30-minute interview. The interview will be held in the nursing home and conducted by one of the researchers. Prior to the start of the interview informed consent will be asked and signed.
- semi-structured group interview with ACP Reference persons: after the intervention, at least two ACP Reference Persons per intervention nursing home will be invited by the researchers for a 60-minute group interview. The interview will be held in the nursing home and conducted by one of the researchers. Prior to the start of the interview informed consent will be requested and signed for.
- focus groups with nursing home staff: after the intervention, six to eight staff members per intervention nursing home will be recruited via the key contact person to participate in a 30 to 60-minute focus group, held in the nursing home and conducted by one of the researchers. Prior to the start of the interview informed consent will be requested and signed for.
- All interviews and focus groups are structured according to a prespecified topic list and audio-taped for analysis purposes. These will all be conducted by JG and AWvD.

Data management

Data will be entered as soon as possible after receipt of each questionnaire in a secure open source web-based survey application (Lime Survey). All paper forms, including written informed consent files and questionnaires, are stored in a lockable filing cabinet in a room with restricted access on

campus. The participating nursing homes' names, address and other identifying information will be stored in one file only. This file will be restricted to a few members of the research team (JG, LP, LVDB and AWvD). Consistent with the Good Clinical Practice (GCP) guidelines, the data (without information that is confidential, privacy-sensitive or that could identify individual people) and informed consent files will be stored for 15 years. Other documentation such as potential logbooks of the analyses, published papers, relevant e-mail correspondence etc. will be handed over in digital format to the project lead (LVDB). In case data is shared, a secure method will be used, to ensure it cannot be accessed by anyone outside the research team. This includes email using a suitable encryption programme, with the password sent by another method (usually telephone) or post in a secure envelope.

Analysis

OUTCOME ANALYSIS

We will calculate summative scale scores for both primary and secondary outcomes. The resulting scale score for an individual is the sum of the individual item scores. For the knowledge items instructions are provided to check correct answers. If people answered, 'I don't know', this will be scored as an incorrect item. The summative scale score of knowledge is sum correct knowledge items of 11 correct/incorrect answers. The summative scale score of 'self-efficacy' is the sum of self-efficacy items on a 10-point scale, ranging from 1 to 10, with 12 items. The primary statistical analyses will use an intention-to-treat (ITT) approach. In ITT the outcome data from all of the samples who were enrolled and randomised to the intervention or control group will be accounted for in the main analyses in the original groups to which they were randomised, regardless of whether or not they completed the ACP+ programme. We will fit a linear mixed model with condition, time and time*condition as fixed factors and with a random intercept for nursing home pair, random slope for time, condition and time*condition at the level of nursing home pair, random intercept for member, random slope for time at the level of member. The need for random slopes will be tested by comparing the difference between $-2 \log(\max)$ REML likelihoods with a $\chi^2_{1,2}$ distribution (using a mixture of chi-square distributions). In case of convergence issues, random slopes will also be left out of the model. Estimated cluster-adjusted means with corresponding 95% CI will be reported at T0 and T1, both for the intervention and control group. Differences in mean change (post-measurements minus baseline) between the intervention group and the control group (interaction group*time) will be calculated. All analyses will be two-tailed and considered significant if $\alpha = 0.025$. Data will be analysed in SAS, R and IBM SPSS.

ANALYSIS OF PROCESS EVALUATION DATA

We will calculate descriptive statistics for quantitative measures (attendance lists, structured diaries, post-training surveys). All qualitative data and transcripts from (group) interviews and focus groups will be analysed using thematic content analysis (via both inductive coding into themes [25] and deductive coding using the theory of change model [10]). The analysis will be carried out by at least two researchers, independently from each other; NVIVO (qualitative data analysis software) will be used for analysis.

Trial monitoring

The researchers will continuously monitor responses using MS Excel sheets. A Trial Monitor (LP), will be put in place to monitor, together with the research team, the course of the trial. She will act to oversee the progress of the trial and to ensure it will be conducted in accordance with the protocol and GCP [26]. She will also function as main contact person for participating nursing homes to report problems or to ask questions regarding the trial. All data entry will be performed by paid student(s) who are not involved in the research and hired to perform data entry alone. Data will be entered as soon as possible after receipt of each questionnaire in Lime Survey. The Trial Monitor will be responsible for checking and merging trial data. Independent double data entry will be required for 10% of the data to assess accuracy and to avoid data typing or editing errors. We will follow the guidelines of the EMGO's (Scientific Quality Committee Amsterdam) Quality Handbook regarding data entry accuracy [52]. After data entry, a second database will be created into which a random sample of questionnaires (selected by LP) can be re-entered. The data entry programme identifies double data entry when the second entry is completed correctly. In addition, the researchers (JG or AWvD) will check for and delete duplicate data entries after all data have been entered. If the number of errors on any given questionnaire exceeds 3%, the entire questionnaire must be re-entered. With regard to handling missing data, researchers will register the anonymous code (of eligible participants in the primary outcome measurement) for which no survey was received (MS Excel sheet). These codes will be signalled to the contact person who will be asked to send/present a reminder (i.e. the usual questionnaire). If forms have not been returned, up to two reminders are sent out.

ETHICAL CONSIDERATIONS

Harms

The entire team, including an ethicist involved in the research team (CG), is committed to minimize such risks of harm and maximize the benefits for potential participants. However, this study will carry little to no risk to the participating staff and volunteers. Participating staff and volunteers may feel uncomfortable discussing end-of-life care with residents/family and are only included in the training sessions if they are willing to participate. Sensitive and disturbing questions are avoided in the questionnaires and staff may at any point leave a training session or discontinue completing questionnaires, without stating reasons.

Participation in ACP by residents and their family has been considered highly beneficial with little or no burden associated with participation [3]. They may feel uncomfortable discussing questions about quality of life, or end-of-life care preferences about treatment or envisaging themselves as lacking cognitive capacity. Although sensitive and disturbing questions are avoided in the qualitative interviews, it cannot be fully excluded that some people may feel distressed in the process. Participants are free to withdraw their participation from interviews at any stage, and it will be stressed to staff in the training sessions that ACP should be adapted to the individual, considering his/her readiness and willingness to engage in ACP. ACP in this programme is considered a voluntary process for residents and family to engage in.

A series of procedures will be put in place to identify and handle any sign of distress in residents, relatives and nursing home staff/volunteers (e.g. where the participant contacts the researcher): 1) the contact details of the researchers are mentioned on all documents (including training materials for staff/volunteers and leaflets that can be distributed to residents/family) stating they can contact us in cases of distress; 2) if specific concerns arise, the researcher is advised to direct the participant to resources of help if appropriate (e.g. network for palliative care that is available within each region or a support telephone line for both general public and healthcare professionals; <http://leif.be/leiflijn/>). If we encounter bad practice in a participating nursing home, we will organise a meeting with the research team, followed by the possibility of an informal complaint to the nursing home management, or a formal complaint if this is deemed necessary. In addition, in the process evaluation, we will monitor unanticipated consequences.

Anonymity and confidentiality

We ensure anonymity and confidentiality of all participants throughout the study. The involved researchers will never be informed nor be able to be informed of the participating staffs and volunteer's identity, or other personal data that can reveal their identity. In each nursing home, a pseudonymising process will take place. Each eligible staff member/volunteer will be assigned an anonymous code, which will enable the research team to link T0 to T1 data. These lists linking names to codes are held by the contact person in the facilities. To have a spare in case the list gets lost, a duplicate will be kept by the Trial Monitor in a sealed envelope located in a locked space. This envelope can only be opened by the contact person in the facility. To preserve the anonymity of the resident and his/her family, no data will be collected from the administrative or medical files. If they agree to participate in interviews or recordings, their names (and nursing home) will be changed when transcribing the recordings. To protect residents' and relatives' privacy during the qualitative interviews, nursing home staff, management and volunteers shall be interviewed separately. When interviews are held, a privacy sign will hang at the door.

DISCUSSION

There is a lack of high quality trials to evaluate the effectiveness of ACP, especially in nursing homes [3]. This cluster randomised controlled trial (RCT), designed to evaluate the effects of the multicomponent theory-based ACP+ programme in Flanders, is unprecedented and will provide important evidence concerning the effectiveness of ACP on nursing home staff and volunteer level outcomes. With accompanying process evaluation, this project will contribute to providing evidence on the effectiveness of ACP in nursing homes and will enable us to provide insights into how and under what circumstances ACP is implemented in nursing homes and hence to develop better implementation strategies.

This study has several strengths. Firstly, while there are very few high-quality studies that evaluate the effects of ACP in nursing homes, and in particular very few cluster RCTs [3], we contribute to filling this gap by planning and designing this proposed study according to recent recommendations in the conduct of high-quality RCTs [27, 28]. The study design follows that of a previous trial conducted by members of the research team [23]. Therefore, the study protocol has been proved feasible and successful in this study population. Secondly, systematic reviews of ACP highlight that RCTs should be supported by process evaluations that explore implementation issues and identify 'active elements'

[29] which is an important element of this study. ACP is a complex intervention that ideally targets both organisational and behavioural aspects and is highly influenced by its context (e.g. staffing levels in nursing homes) [17]. Understanding these underlying processes of change can improve our understanding why ACP achieves or fails to achieve intended changes in residents, family or nursing home staff [17]. It can also facilitate the future comparison of similar interventions and the translation to clinical practices or other settings and contexts [17]. We were able to design and plan a process evaluation which is theory-based and structured according to recent guidance [10, 17], enabling us to answer the frequent calls for more transparency in trial results and provide reasons why the intervention did or did not lead to hypothesised effects. As such we will be able to limit something that happened in a recent trial in the Netherlands, where researchers were unable to explain why no effects were found on primary and secondary outcomes [30]. In addition, the results of this process evaluation will enable us to strengthen the links in the theoretical model we have developed in a previous phase [10]. Hence, we will be able to present a theory of how and under what circumstances ACP achieves or fails to achieve desired outcomes. Thirdly, all current trials regarding ACP in nursing homes evaluated outcomes on patient/family level or healthcare use alone (e.g. knowledge of ACP, satisfaction with care, hospitalisation admission rates, number of ADs) [3]. None evaluated the effects of ACP on the level of nursing home staff, while almost all current ACP interventions in nursing homes are educational programmes targeting the knowledge, attitudes or confidence in ACP of professionals [3, 29, 31]. Given that one of the main and most consistently reported factors potentially hindering the completion of ACP is in fact insufficient knowledge of and self-efficacy in ACP among healthcare professionals [8, 32], studying whether and how these educational ACP interventions affect staff outcomes is highly necessary. Considering that a summative evaluation of the effectiveness of our intervention cannot rely on one outcome measure, such as knowledge, we included self-efficacy as primary outcome. Self-efficacy has been identified in social cognitive theory as a mediator for translating knowledge into action (i.e. ACP practices). The results of this trial will be the first to provide evidence of the effects of a complex ACP intervention on staff level outcomes in nursing homes.

The study also has some limitations. Firstly, the most important shortcoming is the limited evaluation of outcomes on resident and family level. For several reasons we chose not to include a primary or secondary outcome for the evaluation of effectiveness of ACP+ at resident or family level. Based on previous research [10], we argue improving quality of care, life and dying is beyond the ceiling of accountability (cf. the point at which we stop accepting responsibility for achieving those outcomes solely through the intervention programme), and the likelihood of finding an effect is limited, as was shown in other trials [30]. Because improving staff level outcomes is a necessary precondition before

being able to change outcomes for residents and families, we feel this is an important first step in the effectiveness assessment of ACP+. Follow-up funding will enable us to also assess – retrospectively – whether the ACP+ programme had an effect on care concordance at the end of life, based on chart reviews and family interviews of nursing home residents who died during trial period [33, 34], and we will include residents and their families from intervention nursing homes in the process evaluation to evaluate their experiences. We do stipulate that this rationale underlying the study’s aim, generates an additional study limitation, given that changes in staff knowledge/self-efficacy may lead to changes in both behaviour as well resident outcomes. This is an assumption which might have face validity but is not yet supported by evidence about causal inference. We will also not assess economic outcomes simultaneously, which is recommended by recent reviews of ACP effectiveness in older adults [35]. Secondly, because the recruitment follows convenience sampling, there can be systematic differences between those who choose to participate in the ACP+ trial and those who do not. Thirdly, blinding participants (nursing homes and staff) and researchers will not be possible during the study period. During data analysis however, researchers will be blinded. A recent review which used the Oxford Quality Scale to assess methodological trial quality, showed this has not been possible in any of the past trials [35]. This might affect the answers of nursing home staff/volunteers who know they are in an intervention group. Fourthly, we adapted, developed and preliminarily tested a survey to measure knowledge, self-efficacy, attitudes and practices ourselves. However, the self-efficacy scale from Baughman et al., published in 2016, showed high internal consistency and some evidence of convergent, known groups, and predictive validity in family physicians and might be used in the future for similar research, after being tested in this particular population [36]. In addition, responses of staff and volunteers of intervention groups may be affected by their knowledge of their allocation because blinding will not be possible. Finally, because of the high staff turnover in nursing homes it will be unavoidable that throughout the study period of eight months, some staff will change jobs before follow-up data can be collected [37]. This also means that some nursing home staff will not have the possibility to provide baseline data but will be engaged in providing post-assessment at T1.

CONCLUSION

The ACP+ study will be the first cluster randomised controlled trial aimed at evaluating the effectiveness of the multicomponent, theory-based ACP+ programme to support implementation of ACP in nursing homes in Flanders (Belgium). Combined with an in-depth process evaluation, this study will add considerably to the evidence on the implementation of ACP in routine nursing home

care. Considering the expected large increase of older adults needing end-of-life care in a nursing home setting, such high-quality trials are urgently needed to provide essential knowledge to improve comparison between ACP programmes and translation into care practices.

LIST OF ABBREVIATIONS

ACP	advance care planning
AD	advance directive
GP	general practitioners
MRC	Medical Research Council
RCT	randomised controlled trial
FTE	full-time equivalent
ICC	intra-cluster correlation coefficient
GCP	Good Clinical Practice

DECLARATIONS

Ethics approval and consent to participate

The study and method of consent was approved by the Ethics Committee of University Hospital Brussels (Vrije Universiteit Brussels, 22/02/2018, ref: 18-003 - B.U.N. 143201834759). Important protocol modifications will be communicated to all relevant parties: investigators, trial participants, Ethics Committee and ClinicalTrials.gov. Consent to participate in the trial will be sought at cluster level. The researchers confirm the facility managers of the participating nursing homes gave permission for the researchers to interact with all staff, and the trainers to interact with both staff, involved GPs, residents and family. The researchers will not interact with any of the residents or family in the participating nursing homes. Research data collected via questionnaires that will be voluntarily filled in by respondents. By filling in the questionnaire, the participant consents to his/her data being used in the study. All persons participating in qualitative data collection methods must give their informed consent in writing and will be fully informed before participating by one of the researchers (JG or AWvD).

Consent to publish

Not applicable.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Conception and design of the work: JG, AWvD, LP, LVDB, CG, LD, RV; Ethics approval: JG, AWvD, LP, LVDB, CG, LD, RV; Drafting the work: JG; Critical revision for important intellectual content: JG, AWvD, LP, LVDB, CG, LD, RV, MVD, YE; All authors read and approved the final manuscript.

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Author's Information

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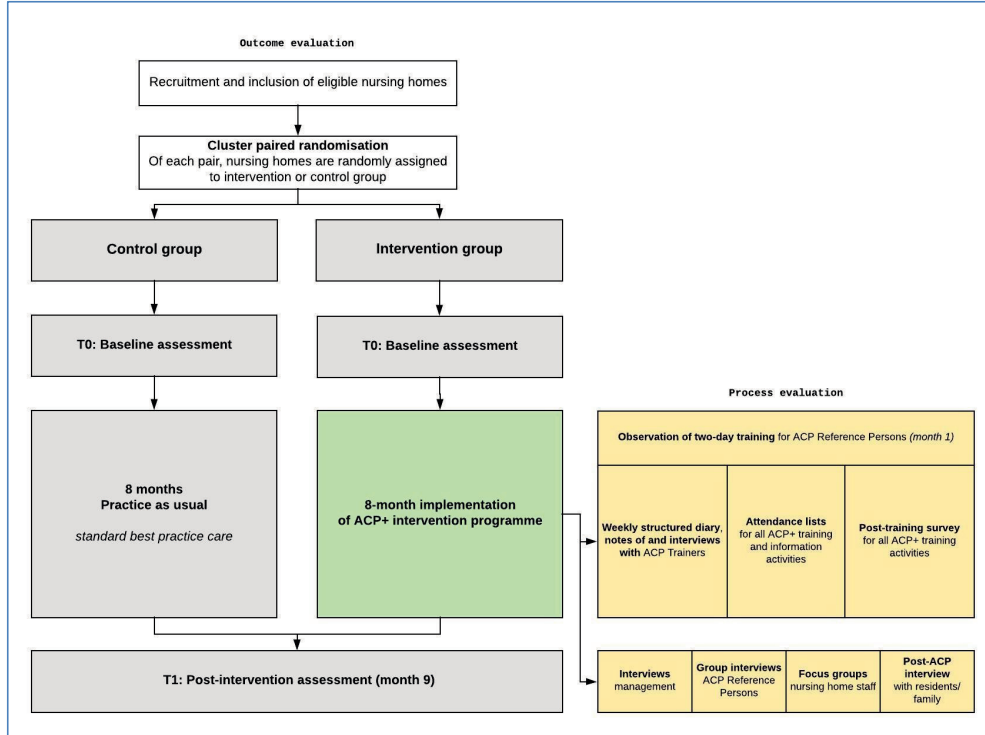
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FIGURES AND TABLES CHAPTER 4

Figure 1. Flow diagram of ACP+ trial



ACP advance care planning; T0 baseline assessment; T1 post-assessment

The yellow blocks indicate the process evaluation data collection methods. The green indicates the intervention

Figure 2: Schematic overview of the ACP + programme

INTERVENTION ACTIVITY	Selection and preparation ACP Trainers	Meeting(s) with ACP Trainer with management, BoD, head nurses and CAP		Training ACP Ref Persons (session 2)	Information for residents and family		In-house training ACP Conversation Facilitators (session 2)	Specialisation session 1: Dementia		Specialisation session 2: Communication with other healthcare professionals	Structured ACP audit meeting(s)	
		BoD, head nurses and CAP	Training ACP Ref Persons (session 1)		Information for GPs	In-house training ACP Conversation Facilitators (session 1)		Comeback seminar for ACP Ref Persons	Follow-up meeting(s) with management			
		Tailoring-meetings with ACP Ref Person, management and decision-makers* ACP Trainer 'shadows' ACP Ref Persons										
TIMING	3 months before start of the programme	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8			
PHASE	Before start programme	Preparation and training phase										
MAIN RESPONSIBLE PERSON	Research team	ACP Trainer takes the lead. As soon as ACP Ref Persons are trained, they are involved in the organisation of each activity.										
		ACP Ref Persons take the lead and are supported by the ACP Trainer										

ACP advance care planning; BoD board of directors; CAP coordinating advisory physician; ACP Ref Person advance care planning reference person; GP general practitioner

*Decision-makers are head of nursing staff, head of residents' care, nursing home management. All those involved with decision-making tasks in the nursing home.

Table 1. Summary of the ACP+ programme using the Template for intervention description and replication (TIDieR) checklist [38]

TIDieR nr*	TIDieR item	ACP+ intervention program
1	BRIEF NAME (name or a phrase that describes the intervention)	The intervention is called “The ACP+ programme” (Dutch: “ <i>Het VZP+ programma</i> ”) and has been developed to implement and improve advance care planning in routine care practice in nursing homes in Flanders, Belgium.
2	WHY (any rationale, theory, or goal of the elements essential to the intervention)	Research shows that only a minority of older people actively engage in ACP, and that there is still a low prevalence of ACP in Flemish nursing homes [6, 24]. Nonetheless, a majority of the growing population of older people would appreciate an opportunity for such discussions and planning [39, 40]. The overall aim of ACP is to improve quality of care, quality of life and quality of dying of residents in nursing homes in Flanders. The theoretical model which was developed in the first phase of intervention development additionally provides a rationale for the individual elements essential to the intervention. This Theory of Change map is reported elsewhere [10].
3	WHAT Materials (any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers)	17 intervention materials are provided to support delivery of the ACP+ programme: <ol style="list-style-type: none"> Manual for the ACP Trainer, highlighting key issues of the ACP+ programme and guidance for ACP Trainer to perform his/her tasks Information guide for nursing home management, highlighting key issues and challenges of ACP, explaining ACP+, how it should be implemented, what everyone's roles are and how they should carry out all the steps within the ACP+ programme Tailoring checklist, including information per intervention activity about the minimum of elements that should be held constant over all nursing homes and which elements can be adapted to each nursing home routines Training manual for two-day training of ACP Reference Persons including educational materials for the ACP Trainer to be used in training ACP manual for ACP Reference Persons including all materials that can be used in the implementation and organization of all intervention activities of the ACP+ program Summary list on which nursing home staff notes all residents and their loved ones, that are eligible for an ACP conversation. This list provides an overview of who scheduled a planned ACP conversation and when. Invitation letter for residents and family, inviting them to participate in information session about ACP ACP information brochure for residents and family Invitation letter for GPs, inviting them to participate in information session about ACP ACP information brochure for professionals Training manual for ACP Reference Persons to train other nursing home staff ACP Conversation Guide providing information about initiating and preparing ACP conversations. The guide is structured as follows: A) ideas about a good life and discussing broader views and values (e.g. “What makes your life meaningful?”); B) preferences for current care (“What makes you worry?”), C) the importance of ACP (“Have you ever thought about what kind of care you would want (or not) in case you would be too sick to tell it

		<p>yourself?"); D) shared care goals (e.g. "Do you feel it is important to make your own decisions with regards to your care? What do you feel is more important: quality of life or living as long as possible, not matter what?"); E) surrogate decision-maker/representative (e.g. in case you were too sick to make your own decisions regarding care, who do you trust to make medical decisions instead?"); F) documenting preferences, including advance directives; G) Place of death; H) other preferences (e.g. "Do you have other wishes that we can take into account?"); I) wishes regarding death (e.g. "Do you prefer to have specific rituals?"); J) revising preferences (e.g. "Under which circumstance would you like to definitely revisit your wishes?"). The conversation guide starts by exploring the broader views of the person and wishes regarding? Current care, and subsequently focuses on future care and end of life and dying.</p> <p>13. ACP Conversation Tool, a short A4 document that staff can use during ACP conversations. It includes probe questions and brief conversation guidelines following the same structure as the full conversation guide.</p> <p>14. ACP Document to document outcomes of ACP conversation(s); that can also be used as a transfer document to accompany the resident when transferring between care settings (e.g. ICU).</p> <p>15. Standardised advance directives</p> <p>16. Guideline about ACP in dementia for professionals working with people living with dementia [41]</p> <p>17. ACP audit instrument</p> <p>The ACP+ programme entails 10 intervention components that can be carried out via 22 intervention activities:</p> <p>As part of 'ACP Trainer' component (1)</p> <p><u>Activity 1: Selection and preparation of two ACP (external) Trainers</u></p> <p><u>Activity 2: 'Shadowing'</u>: During the first four months, the trainer follows the selected ACP Reference Persons in their daily job to get familiar with the aspects related to the nursing home, certain routines and ACP-related activities that are already in place</p> <p>As part of 'Buy-in management' component (2)</p> <p><u>Activity 3: Meeting(s) between the ACP Trainer and the nursing home management, representatives of the board of directors, head nurses and the coordinating advisory physician</u>† to explain the project and ask management for their (active) participation (including integrating ACP in the general policy of the nursing home and ensuring staff is able to spend time on their tasks to implement and organize the ACP+ programme and ACP in general, within the routine care). During this meeting they suggest nursing home staff eligible to function as ACP Reference Person‡ (in consultation with staff themselves)</p> <p><u>Activity 4: Follow-up meetings between management, other decision-makers, ACP Reference Persons and the ACP Trainer.</u></p> <p>As part of 'tailoring' component (3)</p> <p><u>Activity 5: Tailoring-meeting(s) between ACP Reference Persons, management and important decision-makers</u>‡ about how to fit the implementation of the ACP+ programme to routines</p>
4	Procedures (each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities)	

		<p><u>As part of 'ACP Reference Persons' component (4)</u> <u>Activity 6&7: Two-day interactive training (session 1 and 2) for the ACP Reference Persons</u> <u>Activity 8: Come-back seminar for all ACP Reference Persons</u></p> <p><u>As part of 'information about ACP' component (5)</u> <u>Activity 9: Information (session(s)) for all residents and their families about ACP in the nursing home during a format that is 'tailored' to routines in the specific nursing home setting (e.g. resident/family council, individually, exceptional information session)</u> <u>Activity 10: Information session(s) for all GPs about ACP in the nursing home, including motivating them to consider the wishes and preferences of their patients in (end-of-life) decision-making and to engage in ACP of their patients. GPs are invited to an information session after 5 p.m., accreditation can be arranged.</u></p> <p><u>As part of 'in-house training' component (6)</u> <u>Activity 11&12: In-house 2-hour training sessions (session 1 & 2) to train 'ACP Conversation Facilitators' in performing ACP conversations</u> <u>Activity 13: In-house 1,5-hour training session to train 'ACP Antennas' to educate them how to recognize triggers in residents and family, so they are more willing to have spontaneous ACP conversations according to their competencies and so they know how to pass on information to other staff</u></p> <p><u>As part of the ACP planned conversation(s) (7)</u> <u>Activity 14: Exploration of earlier wishes and GP involvement.</u> <u>Activity 15: First planned ACP conversation with resident and family</u> <u>Activity 16: ACP follow-up conversation(s)</u> <u>Activity 17: Documentation of wishes and preferences</u></p> <p><u>As part of 'information transfer' component (8)</u> <u>Activity 18: Integration of ACP into multidisciplinary meetings so information is shared across professionals in the nursing home</u></p> <p><u>As part of 'coaching' component (9)</u> <u>Activity 19: One-to-one coaching on request, by ACP Trainer to nursing home staff</u> <u>Activity 20: In-house specialization session 1: Dementia</u> <u>Activity 21: In-house specialization session 2: Communication with other healthcare professionals</u></p> <p><u>As part of 'audit' component (10)</u> <u>Activity 22: ACP audit meeting(s) to discuss ACP procedures with all involved healthcare professionals, the coordinating advisory physician and the management to identify problems and discuss action plans for improvement</u></p>
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5	<p>WHO PROVIDED (intervention provider, their expertise, background and any specific training given)</p>	<p>ACP Trainers will be available to support nursing homes in implementing ACP into routine care. These trainers are skilled and experienced in change management, have clinical practice experience in nursing homes and in performing ACP conversations. They are able to train other professionals. Their support decreases as nursing homes become more autonomous in organising ACP.</p> <p>'ACP Reference Persons' are professionals employed by the nursing home who have roles in daily resident care (e.g. head nurses, team coordinators, nurses, palliative care reference persons, reference persons for dementia, psychologists, members of the palliative (support or care) team/working group). The ACP Reference Persons' main responsibility is to implement and sustain ACP within the nursing home. They market the program, communicate the high priority for nursing home residents, provide education (to ACP Conversation Facilitators and ACP Antennas), conduct ACP conversations with residents and/or family, and perform regular monitoring to audit advance care planning processes, structures and outcomes within the nursing home.</p> <p>'ACP Conversation Facilitators' or other (head)nurses, palliative care reference persons, reference persons for dementia, psychologists, social workers, care assistants, pastoral or spiritual caregivers, moral consultants and members of the palliative (support or care) team/working group that are willing. These trained conversation facilitators are - together with ACP Reference Persons - responsible for planning and performing regular <i>manuëlgeel</i> ACP conversations with residents and/or family.</p> <p>'ACP Antennas' are all others. This is usually staff that do not necessarily provide resident care but do have daily contact with residents and/or family (e.g. care assistants, hair dressers, cleaning staff, administrative staff, volunteers, ...). They will receive a short training in a much easier formulae in recognizing and signalling triggers that can signal the person is ready or willing to engage in ACP.</p>
6	<p>HOW (modes of delivery)</p>	<p>All intervention activities are provided face-to-face, individually, in duo or in groups with a maximum of 15 participants.</p>
7	<p>WHERE (the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features)</p>	<p>The intervention is meant to improve ACP in nursing homes in Flanders (Belgium). These nursing homes are skilled nursing care facilities where older adults reside who have problems with activities of daily living and/or physical and cognitive functioning [42]. Most residents are still supervised by their GP but since 2000, each nursing home is legally obliged to have a coordinating advisory physician, a GP, preferably trained in gerontology whose tasks include among others, consultancy and conflict mediation in palliative care situations. In addition, nursing homes must cooperate with the geriatric service of the regional hospital and a specialized service of palliative care [43].</p> <p>The two-day training for the ACP Reference Persons is organised across all nursing homes in a geographically central location. The other training and information sessions are organised in-house. ACP conversations or meetings can be held in a private room in the nursing home.</p>
8	<p>WHEN and HOW MUCH (the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose)</p>	<p>ACP+ should be implemented over the course of 8 months and includes a thorough preparatory or training phase (month 1 to 4) and a follow-up phase (month 5 to 8). Information and training sessions vary from 1 hour to two days, depending on the type. ACP conversations are known to vary between 60 and 240 minutes [44].</p>
9	<p>TAILORING (if the intervention was planned to be personalized, titrated or adapted, then describe what, why, when, and how)</p>	<p>To maximize the fit between individual nursing home needs and ACP+, participating nursing homes have the opportunity, in consultation with the trainer, to choose how they operationalize some activities (e.g. how to fit intervention activities into existing work schedules (e.g. training during lunch, information session for GPs in the evening), how activities are routinely</p>

PART III

PART III

	discussed (formally and informally, e.g. through posters, meetings, family council), who needs to be involved in decision-making and how proposed materials can be entered into existing electronic systems).
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ACP advance care planning GP general practitioner

*IIDIER items 'modifications' and 'how well the intervention was implemented' cannot be reported here and can only be described after the study is complete.

†Nursing homes are legally obliged to have at least one coordinating and advisory physician (remunerated according to the number of beds), who coordinates medical care in the facility, as well as reference nurses for palliative care [45].

‡Decision-makers are head of nursing staff, head of residents' care, nursing home management. All those involved with decision-making tasks in the nursing home.

Table 2. Outcomes and outcome measures of ACP+ trial

Outcome	Respondent	No. of items	Item example(s)
Knowledge of ACP	Nursing home care staff (primary outcome)	11 items*	“A resident can only assign a family member as his/her legal representative?”
	Nursing home care staff (primary outcome)	12 items†	“Point out how much confidence you have in your own skills with regard to the following activities/roles: To explain the role of a legal representative to residents and family?”
Self-efficacy towards ACP	Support staff	3 items†	“Point out how much confidence you have in your own skills with regard to the following activities/roles: To talk about wishes regarding future care with family members and residents?”
	Volunteer	3 items†	Same as above
Attitudes towards ACP	Nursing home care staff	12 items‡	“GPs should be involved actively to help residents draft an advance directive?”
ACP practices	Nursing home care staff	8 items	“Did you start an ACP conversation the past six months?”
	Support staff	2 items	E.g. 1: “In the past six months, did you talk with a resident about the next themes: future care and his/her related wishes, dying and death, advance directives?” E.g. 2: “In the past six months, did you talk with a family member or next-of-kin of a residents, about the next themes: future care and his/her related wishes, dying and death, advance directives?”
Demographic and background information	Volunteer	2 items	Same as above
	Nursing home care staff		Age, gender, date of today, number of years working experience in direct patient care, number of years employment in nursing home sector, current function in the facility, highest education, number of hours working in the nursing home per week, whether or not they received training in palliative care or ACP, average number of residents for which they care on regular working day.
Structural characteristics	Support staff		Age, gender, date of today, number of years working experience in direct patient care, number of years employment in nursing home sector, current function in the facility, highest education, number of hours working in the nursing home per week, whether they received training regarding one of the following themes: vision and values of the nursing home, palliative care, communication skills, information transfer about resident to other care staff, ACP, other; if they had a personal conversation with a resident that has dementia or Alzheimer’s.
	Volunteer	7 items	Age, gender, date of today, employment status, highest education, number of years active as volunteer, number of years active as volunteer in this nursing home
Structural characteristics	facility-level	21 items	Type of facility, number of beds recognized by government, number of beds available, number of beds occupied, number of residents per KATZ scale category, umbrella organisation, with which electronic resident file system they work (e.g. GERAC, Care Solutions or others), number of residents died over past six months, average time of stay, availability of patient-specific forms regarding ACP, % of residents died care or ACP, availability of patient-specific forms regarding ACP, % of residents died in nursing home, % of residents that has an up-to-date plan regarding end-of-life care, number of residents with written AD, regular multidisciplinary team meetings, number of staff: FTE and heads, number of volunteers registered in nursing home,

PART III

number of hours per week the coordinating advisory physician is present in facility,
number of GPs involved with patients in nursing home

ACP advance care planning; GP general practitioner; FTE full-time equivalent; AD advance directive; KATZ index of independence in daily living; GHRACC software package for nursing homes in Belgium.

*Response categories: 'True', 'False' or 'I don't know'.

†Response categories: 10-point Likert scale, ranging from 'little confidence' (=0) to 'a lot of confidence' (=10) and 'not applicable'.

‡Response categories: 5-point Likert scale ranging from 'Completely disagree' (=0) to 'Completely agree' (=5).

§Response categories: 'Yes' or 'No'.

Table 3. Process evaluation methods based on UK MRC guidance on process evaluations of complex interventions (Moore et al. 2012)

Dimension (definition*)	Subdimension (definition*)	Measurements	Data collection method (qualitative or quantitative; timing)
Implementation** (the process through which interventions are delivered, and what is delivered in practice)	HOW delivery is achieved (implementation process: resources and mechanisms through which delivery is achieved)	<ul style="list-style-type: none"> - Resources: time spent by trainer on preparation and delivery of intervention - Resources: total trial cost associated with delivery of intervention (printing cost training materials, salary trainers, rent training locations and catering) - Implementation process of all ACP+ activities 	<ul style="list-style-type: none"> - Structured diary filled in by trainers (quantitative; weekly) - Expenses from researchers and trainers (quantitative; continuous) - Semi-structured interviews with trainers (qualitative; every 4 months) - Semi-structured group interviews with ACP reference persons per IF (qualitative; after T1)
WHAT is delivered (the quantity and quality of what is delivered)			
1) Dose (how much intervention is delivered)	is achieved through the quantity and quality of what is delivered	- Number and type of intervention activities; delivered in each IF	- Structured diary filled in by trainers (quantitative; weekly)
2) Reach† (the extent to which a target audience comes into contact with the intervention)	<ul style="list-style-type: none"> - Number of ACP Reference Persons of each IF attending two-day training /total number of staff in each IF - Attendance rate of staff during in-house training sessions (for ACP Conversation Facilitators and ACP Antennas) in each IF/ total number of staff in each IF 	<ul style="list-style-type: none"> - Number of residents informed about ACP in each IF/total number of residents at T0 in each IF - Number of residents for whom a family member is informed about ACP in each IF/total number of residents at T0 in each IF - Number of GPs informed about ACP in each IF/total number of GPs at T0 in each IF - Number of volunteers informed in each IF/total number of volunteers at T0 in each IF 	<ul style="list-style-type: none"> - Attendance lists (quantitative; before start of each training or information session) - Survey about number of residents, family and volunteers informed, to be filled in by key contact person in IF (quantitative; after month 6 and at the end)
3) Fidelity (the consistency of what is implemented with the planned intervention)	<ul style="list-style-type: none"> - Number of activities delivered as intended (dose delivered as intended) in each IF/total number of activities - Type of activities delivered, according to participating staff 	<ul style="list-style-type: none"> - Number of residents or family members of residents offered minimum one ACP conversation/total number of residents at T0 in each IF - Number of residents with an advance directive/total number of residents at T0 in each IF - Number of activities delivered as intended (dose delivered as intended) in each IF/total number of activities - Type of activities delivered, according to participating staff 	<ul style="list-style-type: none"> - Information provided by key contact person in IF, based on ACP+ registry document (quantitative; continuous) - Facility level data (quantitative; T1) - Structured diary filled in by trainers (weekly) - Semi-structured interview with trainers (qualitative; every 4 months)

<p>Context (factors external to the intervention which may influence its implementation, or whether its mechanisms of impact act as intended)</p>	<p>Contextual moderators† potentially inhibiting or facilitating the organisation, sustainability and outcomes of ACP practice)</p> <ul style="list-style-type: none"> - Contextual barriers and facilitators for 1) implementation ('the process through which interventions are delivered, and what is delivered in practice'), according to participants - Contextual barriers and facilitators for 2) sustainability ('the potential for an intervention to become part of routine practice'), according to participants - Contextual barriers and facilitators for 3) outcomes (knowledge, attitudes, self-efficacy and practice), according to participants 	<ul style="list-style-type: none"> - Semi-structured interview with one manager per IF (qualitative; after T1) - Two post-intervention focus groups with trained staff across IF (qualitative; after T1) - Semi-structured group interview with ACP Reference Persons in each IF (qualitative; after T1) - Semi-structured interviews trainers (qualitative; every 4 months)
<p>Intention for Maintenance‡ (extent to which the programme is intended to be part of routine organisational practice and policy)</p>	<ul style="list-style-type: none"> - Staff's intention for performing ACP+ activities in the future - Organisational intention for long-term implementation - Participants' recommendations for improving sustainability 	<ul style="list-style-type: none"> - Semi-structured interview with one manager per IF (qualitative; after T1) - Semi-structured group interview with ACP Reference Persons in each IF (qualitative; after T1)

ACP advance care planning; IF intervention facility; GPs general practitioners

†Types of training activities: 1) Two-day training for ACP Reference Persons (delivered by ACP Trainer), across all intervention nursing homes; 2) Two training sessions of each two hours for ACP Conversation Facilitators (delivered by ACP Reference Persons, supported by ACP Trainer), in-house; 2) One training session of 1,5 hour for ACP Antennas (delivered by ACP Reference Persons, supported by ACP Trainer), in-house.

*Definition by the MRC Framework by Moore et al. (2012)

**The term implementation is used within complex intervention literature to describe both post-evaluation scale-up (i.e. the 'development-evaluation-implementation' process) and intervention delivery during the evaluation period. Within this document, discussion of implementation relates primarily to the second of these definitions (i.e. the quality and quantity of what is actually delivered during the evaluation).

‡Added by the research team



ADDITIONALE FILE CHAPTER 1

Additional file 1. Overview of items in measures

ACP Knowledge

11 true/false items

Scale metrics: 'true' or 'false' or 'I don't know'

	Item included in questionnaire			
	Care staff	GP	Support staff	Volunteer
1. An AD allows a resident to communicate his will regarding healthcare in case he would lose his/her cognitive capacity in the future (<i>true</i>)	X	X		
2. A representative has the power to make decisions regarding healthcare in case the resident is no longer able to do this himself (<i>true</i>)	X	X		
3. A resident can only assign a family member as his representative. (<i>false</i>)	X	X		
4. A family member can refuse treatments instead of a resident that has no cognitive capacity (<i>true</i>)	X	X		
5. A physician is committed to perform all invasive treatments if a resident or family members asks, independent of potential advantages or disadvantages of those treatments (<i>false</i>)	X	X		
6. According to the law of Patient Rights both a positive and negative AD is binding (<i>false</i>)	X	X		
7. A residents living with dementia can change his/her AD. (<i>true</i>)	X	X		
8. Each family member of a resident living with dementia can change this person's AD (<i>false</i>)	X	X		
9. If a resident that has no cognitive capacity (e.g. someone with severe dementia) has not assigned a representative, it is established by law who will take his/her place in decision-making (<i>true</i>)	X	X		
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 (<i>true</i>)	X	X		
11. Residents that have no cognitive incapacity and are not terminally ill, have the right to refuse treatments, even if this decision can lead to death (<i>true</i>)	X	X		

ACP advance care planning; AD advance directive; GP general practitioner

ACP Self-efficacy

12 items to which participants indicated self-perceived confidence

Scale metrics: 10-point Likert scale with 1 'not at all confident' and 10 'very confident', including answer category to indicate 'not applicable'

	Item included in questionnaire			
	Care staff	GP	Support staff	Volunteer
1. Initiating ACP conversations	X	X		
2. Discussing disease and treatment options with a resident within the context of ACP	X	X		
3. Discussing wishes and preferences for future care	X	X	X	X
4. Explain the role of a representative to residents and family	X	X		

5. Respond to questions of residents regarding ADs	X	X		
6. Respond to questions of the family regarding ADs	X	X		
7. Correspond to a residents' written wishes	X	X		
8. Knowing legislation regarding ADs	X	X	X	X
9. Talking to family members about wishes for future care	X	X		
10. Talking about general issues regarding dying and death	X	X	X	X
11. Conduct a conversation regarding ACP with residents living with dementia	X	X		
12. Conduct a conversation regarding ACP with family members of residents living with dementia	X	X		

ACP advance care planning; AD advance directive; GP general practitioner

ACP Attitudes

12 items to which participants indicate to which degree they agree

Scale metrics: 5-point Likert scale with 1 'totally disagree' and 5 'totally agree'

	Care staff	GP	Support staff	Volunteer
1. In most cases residents know enough about healthcare to complete an AD.	X	X		
2. GPs must be actively involved to help residents to complete an AD.	X	X		
3. GPs are mostly informed about the wishes from their residents with regard to end of life care, without an AD or any other written document of ACP.	X	X		
4. The information in an AD is often sufficient to guide treatment.	X	X		
5. Family is often informed about the resident's wishes regarding end-of-life care.	X	X		
6. It is emotionally draining to help residents complete an AD.	X	X		
7. An ACP conversation should be held with every resident.	X	X		
8. ACP can facilitate the decision-making regarding the end of life for family members from residents living with dementia.	X	X		
9. Residents living with dementia can lose hope after an ACP conversation.	X	X		
10. For most residents with beginning dementia it is useful to receive information about their disease trajectory and possible options for future care and treatment.	X	X		
11. A resident with dementia should be involved in an ACP conversation.	X	X		
12. During an ACP conversation with a resident living with dementia, a family member should be present.	X	X		

ACP advance care planning; AD advance directive; GP general practitioner

ACP Practices

6 ACP practices to which participants must indicate their involvement in the last 6 months

Scale metrics: 'yes' or 'no' answer

	Included in questionnaire			
	Care staff	GP	Support staff	Volunteer
1. Started an ACP conversation	X	X		
2. Documented the outcomes of an ACP conversation in a resident's file	X	X		
3. Completed an AD with a resident	X	X		
4. Made an estimation if someone was capable of completing an AD	X	X		
5. Had an ACP conversation with a resident that has dementia	X	X		
6. Had an ACP conversation with family of a resident that has dementia	X	X		

6 additional questions related to ACP practices

Scale metrics are included in the questions

	Care staff	GP	Support staff	Volunteer
1. With how much residents have you started an ACP conversation over the past 6 months? <i>(numerical value)</i>	X	X		
2. With how many family members have you started an ACP conversation over the past 6 months? <i>(numerical value)</i>	X	X		
3. Who generally starts the ACP conversation in your nursing home? <i>(multiple choice)</i>	X			
4. When is an ACP conversation usually initiated? <i>(multiple choice)</i>	X			
5. Who usually participates in an ACP conversation in your nursing home? <i>(multiple choice)</i>	X			
6. Are ACP conversations documented? If yes, how? <i>(multiple choice)</i>	X	X	X	
Do you know if your nursing home has an ACP policy? <i>(yes/no)</i>	X	X	X	
7. Did you ever received information about ACP?			X	X
8. Did you talk to a resident in this nursing home about the following, in the last 6 months? <i>(multiple choice: future care and related wishes/ preferences, death and dying or advance directives)</i>			X	X
9. Did you talk to a resident in this nursing home about the following, in the last 6 months? <i>(multiple choice: future care and related wishes/ preferences, death and dying or advance directives)</i>			X	X
10. Do you sometimes function as an intermediary between resident and healthcare professional (e.g. signaling wishes from resident to healthcare professional)			X	X
10. Do you sometimes function as an intermediary between resident's family and healthcare professional			X	X

PART IV

**NURSING HOME STAFF'S
KNOWLEDGE ABOUT, SELF
EFFICACY REGARDING AND
ENGAGEMENT IN ADVANCE
CARE PLANNING IN NURSING
HOMES IN FLANDERS**



*Chapter 5: Comparing advance care planning practices,
knowledge and self-efficacy among nursing home care
staff: A survey study*

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Gilissen, J., Van Dael, A., Gastmans, C., Vander Stichele, R., Deliens L., Van den Block L. & Pivodic, L. *Comparing advance care planning practices, knowledge and self-efficacy among different nursing home care staff: A survey study* [submitted]

ABSTRACT

BACKGROUND AND OBJECTIVES To appropriately train nursing home staff and to delineate accurate responsibilities in advance care planning (ACP), we need to know if and to what extent staff members differ in the ACP practices they undertake, their knowledge and self-efficacy.

DESIGN Survey as part of baseline measurement of a cluster randomized controlled trial in a sample of 14 nursing homes.

METHODS Staff was asked to complete a survey, including 6 ACP practices (ranging from starting ACP conversations, helping with advance directives to initiating ACP with residents living with dementia), 11 items regarding knowledge and 12 items evaluating self-efficacy. Scores range from 0 to 1 (10 for self-efficacy).

RESULTS 169 nurses, 319 care assistants and 169 allied staff participated (67% response rate). After adjusting for confounders, two ACP practices, namely starting conversations (OR 4; 95%CI 1.73-9.82; $p < .001$) and documenting ACP (2.67; 1.29-5.56; $p < .005$) were carried out significantly more often by nurses than care assistants; differences not found between allied staff and care assistants. Knowledge differed significantly, with both nurses (estimated mean difference/EMD 0.13; 95% CI 0.08-0.17 with theoretical range 0 to 1; $p < .001$) and allied staff (0.07; 0.03-0.12; $p < .001$) scoring higher than care assistants, but differences were small. Self-efficacy did not differ.

DISCUSSION AND IMPLICATIONS While we report some differences between professions for ACP practices and knowledge, these were small and were not applicable to self-efficacy. Whereas nurses seem to be taking the lead, allied staff and care assistants might be an underused group in ACP, if they receive appropriate training.

BACKGROUND

Advance care planning (ACP) is defined as a process that supports adults at any age or in any stage of health in understanding and sharing their personal values, life goals and preferences regarding future care [1, 2]. In nursing homes specifically, there is an increased demand for a whole-setting approach to improve the implementation and organization of ACP [3]. Such approach requires a prolonged and substantial input of human resources and professional motivation [4].

A significant role has been laid out in ACP for healthcare staff in nursing homes and preliminary evidence is indeed supportive of involving skilled professionals [3, 5]. In recent theoretical frameworks, hypothesizing how ACP can be successful in these settings, staff knowledge and self-efficacy have been identified as important intermediate outcomes, before being able to change patient and family outcomes [6, 7]. Despite the fact that care professionals generally report a positive attitude towards being actively involved in ACP, lack of knowledge and skills limit this involvement [8–12].

Care in nursing homes is often conducted by a healthcare team, consisting of nurses, care assistants and allied care staff (e.g. social workers, pastoral caregivers, psychologists, physiotherapists), all with a direct responsibility for the care of the residing older adults and their families [13–15]. Previous studies have found significant differences between nurses and care assistants, in their levels of knowledge about palliative care [16], their self-perceived confidence in end-of-life communication [17, 18] and in the timing of communication with residents about death and dying [19]. These results suggest there might also be significant differences regarding their engagement in other ACP practices, their knowledge of and self-efficacy in ACP. If there are any differences, these should be taken into account when organizing training or deciding how to divide roles and responsibilities in ACP. To date, there is an absence of consensus as to which professional group in nursing homes has certain responsibilities, and most often the task lies mainly with nurses while other professionals may support them in this, or already does.

However, we do not know to what extent their involvement, knowledge and self-efficacy are comparable. With time constraints and inadequate staffing levels of nurses repeatedly being highlighted as an important barrier for ACP in nursing homes [10, 20, 21], involving other care staff might form a possible solution to respond to the high need for ACP in this population. In this study,

we aimed to evaluate whether and to what extent various professional groups of nursing home staff (nurses, care assistants and allied staff) differ in terms of ACP practices, their knowledge of and self-efficacy in ACP.

METHODS

Design

A survey study that served as baseline measurement of a cluster randomized controlled trial in nursing homes in Flanders, Belgium, carried out from March to April 2018 (ClinicalTrials.gov NCT03521206).

Setting and participants

We purposively recruited 14 nursing homes based on location (province in Flanders), type of facility (public, private non-profit or private for-profit) and number of beds. Nursing homes were eligible if they had at least 100 beds and if the facility manager expressed an explicit motivation to participate. Nursing homes were ineligible if they: 1) had taken part (in the past four years) or were currently taking part in a similar study; 2) had developed – or were planning to develop during the foreseen duration of the trial – an extensive ACP policy, as judged by the researchers; 3) were in the process of implementing or had planned organizational/physical changes; or 4) were involved in the development phase of the study. Care staff belonging to three professional roles in the nursing homes were included in the study: nurses (including head nurses), care assistants and allied care staff (i.e. physiotherapists, occupational therapists, social workers, psychologists, spiritual caregivers/pastoral clerks, reference persons for dementia or reference persons for palliative care). Participants were included if they were able to speak and understand Dutch. Students and interns were excluded from participation. We refer to “nursing home staff” or “staff” when we report results that are applicable to all staff, regardless of their profession. Differences between nurses, care assistants and allied staff are explained in [Box 1](#).

Box 1. Education and tasks of nurses, care assistants and allied staff in nursing homes in Flanders, Belgium

A **nurse** has a Nursing diploma or is entitled ‘nurse’ after having had at least four years of study (including 2300 hours’ clinical internship) in nursing [36]. Hence, in Flanders the nursing category can include both nurses whom have a college degree in nursing and nurses that have a secondary professional education (HBO/EQF 5). Both types of nurses can perform the same nurse-technical tasks [37, 38]; i.e. observing, recognizing and recording patient’s health status; describing nursing problems; assisting physicians with medical diagnosis and carrying out prescribed treatments; informing and advising patient and family; continuously assisting and carrying out treatments with the aim to sustain, improve or recover the health of both healthy and sick people or groups; end-of-life care; urgent life-saving measures in crisis situations; analysing quality of care; and technical-nursing tasks for which no prescription is necessary. To carry out the profession of nurse, the person should apply with the federal government for a license to practice. Nursing homes should have at least five FTE nurses or equivalent available, including one head nurse per 30 residents. [39].

A **care assistant** completed higher secondary (technical or professional) education, and followed an additional one year full-time education or equivalent (EQF 4); or has a certificate acknowledging his/her competencies as a care assistant as the result of successfully finalizing the first year of the Nurse higher college education, successfully succeeding for both theory and clinical parts of the education regarding elderly care (in the first year or later), or successfully finalizing 150 hours of internship (in the first year or later) [36, 40]. A care assistant assists a nurse, with care, health education and logistics under his/her supervision, within the scope of the nurse-coordinated activities, and in a structured healthcare team. To carry out the profession, the care assistant should register and be acknowledged by the Flemish Agency for Care and Health. Nursing homes should have at least five FTE care assistants per 30 residents available [41].

Allied staff is not a group of care professionals officially defined in the Belgian healthcare system but we use it in this study to group physio/occupational therapists, social workers, spiritual caregiver/pastoral clerks, psychologists, reference person for dementia or reference person for palliative care and ‘others’ (namely, “reference person wound care”, “reference person pain”, “reference person restraint use”, “speech language therapist”, “music therapist”, “psychological assistant”). It is a known group of professionals in academic literature. They are distinct from nursing, medicine, and pharmacy and work in healthcare teams providing a range of diagnostic, technical, therapeutic, direct patient care and support services. Most have at least three years of higher college education, or graduate education. The role of physiotherapists, and reference persons in palliative care and dementia are defined by Belgian/regional legislation [36]. A reference person for palliative care in a nursing home is responsible for the establishment of a supportive palliative care culture, provision of training for staff, making them aware of the facility’s vision statement, coordinating palliative care and keeping records on palliative care initiation for all deceased residents. They also support the palliative residents, which may or may not involve bedside care. This reference person should have a certain bachelor’s degree and have followed a specific training in ACP, palliative care and end-of-life care [42]. A reference person dementia is a professional caregiver who engages in improving the quality of care for people living with dementia. Required qualifications are described in Art 498. Nursing homes should have one FTE physio/occupational or speech therapist and 0.10 FTE reference person palliative care per 30 residents available.

EQF European Qualification Framework; FTE full-time equivalent. This overview was reviewed by representatives of the Flemish Agency for Care and Health and the Flemish umbrella organization for nurses in Belgium.

Data collection

In each nursing home, a contact person (manager, head of care, head nurse or quality coordinator) was designated to identify all eligible staff. The contact person decided how the survey (including an anonymized personal code linked to the specific staff member, only known by the contact person) was presented to the staff. This happened consistent with usual modes of communication to staff in

the nursing home (e.g. in person or via a personal mailbox in the facility). Staff members who agreed to participate, completed the survey and placed it in an anonymized envelope in a locked letter box, only accessible to the researchers. Researchers were able to identify non-responders using the anonymized codes. The contact person was then asked to redistribute the survey to the matching professional at two points in time, similar to previous studies, once after two weeks and again another two weeks later [22, 23].

Instrument

Since no validated instrument for nursing home care staff was available to investigate ACP practices, knowledge, and self-efficacy, we developed a survey. Items were developed based on items from a 26-item questionnaire for physicians from Detering et al. [24]; 35 items from a tool developed for nursing home managers by researchers at Ulster University [25]; questionnaires used in another study in Flemish nursing homes [22, 26]; and input from the multidisciplinary team for this project, including an ethicist (CG), three psychologists (AWvD, LP, LVDB), a family physician (RVS), a social worker (JG) and a sociologist (LD), who all have expertise in ACP and the nursing home setting. The instrument was tested by way of individual cognitive interviews, using the ‘think aloud’ method [28], with three registered nurses, one family physician, one psychologist and a volunteer. During completion of the questionnaire, all were additionally asked to verbally elaborate on their thoughts about each item and what their corresponding answers meant. They were also invited to make suggestions regarding how the measure could be improved. In a next phase, the instrument was distributed to a sample of professionals (e.g. administrative staff, care assistants, nurses, family physicians, volunteers, management) who were working or had worked in a nursing home and were at least 18 years old (n=107). They completed either the online version of the survey via the research group’s newsletter and several umbrella organizations for nursing professions and healthcare organizations; or a paper version that was distributed on a regional conference and in a course for nursing students. Items were excluded if they showed a large number of missing data or floor/ceiling effects, as these were considered not clear, too difficult or too easy. Knowledge items and answers were reviewed by a professor in Medical Law. The resulting instrument includes one section assessing participants’ characteristics (age, gender, years of employment in residential care sector, current professional role, educational level, training in palliative care, training in ACP, number of hours working in nursing home/week, number of residents cared for on an average working day), and three sections on ACP practices, knowledge and self-efficacy. In these sections, respondents were

asked if they performed any of the six listed activities in the past six months ('yes'=1 or 'no'=0). Total scores for ACP practices range from 0 to 1, with higher scores indicating staff carried out more ACP practices. Cronbach's alpha (α) was .807. In the knowledge section respondents indicate 'true', 'false' or 'I don't know' for 11 statements. A 'true' answer to a true statement and 'false' to a false statement were counted as a correct answer. Total scores range from 0 to 1, with higher scores indicating better knowledge. Cronbach's α for this subscale was .724. In the self-efficacy section staff indicated their self-perceived confidence in 12 roles and tasks on a 10-point Likert scale, ranging from 'little confidence' (1) to 'a lot of confidence' (10), or 'not applicable'. Total scores for self-efficacy range from 0 to 10, with higher scores indicating better self-efficacy. Cronbach's α was .970.

Statistical analysis

All analyses were performed with SPSS 23. Characteristics of the sample are presented as n (%), mean (standard deviation, SD) or median (interquartile range). Total scores for ACP practices, knowledge and self-efficacy are means per whole subscale. Cases with missing data in >25% of items on a scale were excluded from total score calculations for that particular scale. In order to take the clustering of staff within nursing homes into account, mixed models were fitted with a random intercept for nursing home. Depending on whether the dependent variable was continuous, binary or categorical, generalized linear mixed-models were fitted with normal, binomial or multinomial distribution and with identity, logit or generalized logit link respectively. Unadjusted analyses included professional role (nurse, care assistant or allied staff) as fixed effect. Adjusted analyses also included gender, educational level, training in ACP, years working in the sector and average hours working per week as fixed effects. We checked for multicollinearity between variables by looking at Pearson correlations and Variance Inflation Factors (VIF). None of the VIFs was higher than 2. After a missing data pattern analysis (using the "mice" package in R), we deleted 'number of residents cared for' from the model because of a low proportion of usable cases (missing data >5%). All other covariates with <5% missing values were retained in the model. Results are presented as unadjusted and adjusted estimated means and estimated mean differences (EMD) with 95% confidence intervals (CI) for continuous dependent variables and as odds ratio (OR) with 95% CI for binomial or multinomial dependent variables. An alpha level of <.05 defines statistical significance. The total mean score of ACP practices is a count variable with excess zeros, and because it included data generation that produces event counts, a log transformation of this variable was not possible [29]. We were therefore not able to test differences between nurses, care assistants and allied staff, using

linear mixed models, reporting estimated means and EMD. Hence, for this subscale, we only show differences on item level. Total score for self-efficacy generated a lot of missing data because the 'not applicable' answer category was counted as missing. Results of the linear mixed model are however valid under the assumption that the data is missing at random, meaning that it did not depend on covariates in the model, such as staff member's profession.

RESULTS

We received 694 questionnaires (response rate of 67%) and included 684 in the analysis, since in 10 cases staff members did not indicate his/her professional role. Response rates varied among nursing homes ranging from 46% to 85%. Characteristics of the participating nursing homes can be found in Table 2A.

Characteristics of the sample

From a total of 684 participants, 196 were nurses, 319 were care assistants and 169 were allied staff. Staff were on average 40 years old, the majority were female (90% in nurses, 94% in care assistants and 86% in allied staff). Significantly more nurses (88%; $p < .001$; Table 1) and allied staff (72.6%; $p < .001$) were highly educated than care assistants. More than half of all staff were trained in palliative care; nurses significantly more often than others (82.7%; $p < .001$). Less than half of all staff had some training in ACP. Median years working in the sector varied from 12 years in nurses to 7.5 in care assistants. Nurses worked significantly more hours per week than other professional roles in the nursing home, with a median of 38 ($p < .001$) and provided care to a median of 14 residents on an average working day.

Table 1. Demographic and professional characteristics of participants (N=684)

Characteristics	Nurses* (n=196)	Care assistants (n=319)	Allied staff* (n=169)	P value†	Missing, n (%)
Age, mean (SD)	42.1 (10.9)	38.5 (12.1)	40.6 (11.1)	0.005	29 (4.2)
Gender, female, n (%)	173 (89.6)	297 (94)	146 (86.4)	0.018	11 (1.6)
Educational level, n (%)				<0.001	12 (1.8)
Primary education	0	4 (1.3)	0		
Secondary education	23 (11.9)‡	274 (88.4)	46 (27.4)		
Higher college education	131 (67.5)	32 (10.3)‡	75 (44.6)		
Graduate education (university)	40 (20.6)	0	47 (28)		
Training in palliative care as part of degree, additional education after degree or other§, n (%)	162 (82.7)	224 (72.3)	103 (60.9)	<0.001	9 (1.3)
Training in advance care planning, n (%)	66 (34.4)	59 (19.2)	47 (28.1)	<0.001	24 (3.5)
Years since working in sector, median (IQR)	12 (5-20.3)	7.5 (3-18.8)	11 (5-19)	0.002	21 (3.1)
Average hours working in nursing home per week, median (IQR)	38 (30-38)	30 (20-38)	30 (19-38)	<0.001	36 (5.3)
Average number of nursing home residents cared for on average working day, median (IQR)	14 (10-24)	20 (10-36)	15 (9-24)	0.002	122 (17.8)

IQR Interquartile range

*Allied care staff includes different types of care staff.

†Calculated with mixed binary logistic regression analysis for dichotomous variables and mixed multinomial logistic regression analysis for categorical variables with more than 2 categories.

‡A person in Belgium can also function as care assistant as the result of successfully finalizing the first year of the Nurse higher college education, successfully succeeding for both theory and clinical parts of the education regarding elderly care (in the first year or later), or successfully finalizing 150 hours of internship (in the first year or later). Nursing staff can also have a secondary educational level. Care assistants can have college education because people that succeed first year of higher college education for Nursing but do not finish the study can receive recognition as care assistant from the federal government of Belgium (see Box 1).

§Category 'other' includes "on the job", "at work", "from in-house palliative care working group".

Advance care planning practices

The unadjusted analysis showed that nurses were more likely to have carried out most of the ACP practices; they were more likely than care assistants to having performed ACP conversations (OR 6.33; 95%CI 4-9.99; $p < .001$; Table 2), documented outcomes of such conversations (4.88; 3.31-7.21; $p < .001$), estimated a resident's cognitive capacity to complete an AD (3.56; 2.41-5.28; $p < .001$) and having had a conversation with family (2.67; 1.75- 4.06; $p < .001$). After controlling for potential confounders, the odds of starting an ACP conversation for nurses were 4 times higher than for care assistants (4.12; 1.73-9.82; $p < .001$), and their odds to have documented the outcomes of such conversation were 2.7 times higher (2.67; 1.29-5.56; $p = .008$). No significant differences for separate ACP practices were found between allied staff and care assistants.

Table 2. Differences between nurses, care assistants and allied staff regarding ACP practices (N=684)

Missing per item	Nurses (n=196)		Care assistants; Ref (n=319)		Allied staff (n=169)	
	n (%)†	unadjusted OR (95% CI)‡	n (%)†	adjusted OR (95% CI)§	n (%)†	unadjusted OR (95% CI)‡
1. Started an ACP conversation	14 (2)	6.33 (4 to 9.99)**	19 (6.1)	4.12 (1.73 to 9.82)**	24 (14.5)	2.3 (1.27 to 4.19)
2. Documented the outcomes of an ACP conversation in a resident's file	13 (1.9)	4.88 (3.31 to 7.21)**	31 (10)	2.67 (1.29 to 5.56)*	25 (15.1)	1.60 (.95 to 2.69)
3. Completed an AD with a resident	9 (1.3)	2.57 (1.27 to 5.17)	14 (4.5)	1.28 (0.37 to 4.40)	10 (6.1)	1.43 (.61 to 3.33)
4. Made an estimation if someone was capable of completing an AD	20 (2.9)	3.56 (2.41 to 5.28)**	39 (12.8)	1.91 (0.85 to 4.30)	29 (17.7)	1.44 (.80 to 2.57)
5. Had an ACP conversation with a resident living with dementia	14 (2)	1.60 (.87 to 2.96)	26 (8.4)	0.84 (0.38 to 1.86)	14 (8.6)	1.03 (.61 to 1.72)
6. Had an ACP conversation with family of a resident living with dementia	16 (2.3)	2.67 (1.75 to 4.06)**	45 (14.5)	1.47 (0.67 to 3.26)	31 (18.9)	1.38 (.86 to 2.20)

ACP advance care planning; OR odds ratio; AD advance directive; CI confidence interval; Ref reference category

Staff was asked to indicate 'yes' if they were involved in the ACP practice over the past 6 months.

*Statistically significant $p < .05$; ** $p < .001$.

†Observed absolute and relative frequency, not estimated from a model.

‡Binary logistic mixed-model unadjusted analyses with nursing home as random effect and professional role (nurse, care assistant or allied staff) as fixed effect. Care assistants are the reference. Missing data: item 1 (n=14; 2%), item 2 (n=13; 1.9%), item 3 (n=9; 1.3%), item 4 (n=20; 2.9%), item 5 (n=14; 2%), item 6 (n=16; 2.3%).

§Binary logistic mixed-model adjusted analyses with nursing home as random effect and professional role, gender, educational level, training in ACP, years since working in sector and average hours working in nursing home per week as fixed effects. Care assistants are the reference. Missing data in adjusted analysis, including missing in covariates: item 1 (n=82; 12%), item 2 (n=81; 11.8%), item 3 (n=79; 11.5%), item 4 (n=87; 12.7%); item 5 (n=84; 12.3%); item 6 (n=86; 12.6%). Missing in unadjusted analysis: item 1 (n=14; 2%), item 2 (n=13; 1.9%), item 3 (n=9; 1.3%), item 4 (n=20; 2.9%), item 5 (n=14; 2%), item 6 (n=16; 2.3%).

Knowledge of advance care planning

Nurses were significantly more likely to answer most of the knowledge questions correctly, in comparison to care assistants. After controlling for potential confounders, nurses were still more likely than care assistants to answer almost half of the questions correctly: they were more likely to answer correctly that an AD (in Belgium) allows a resident to communicate his or her will in case he or she lost cognitive capacity (OR 4.10; 95%CI 1.82-9.24; $p < .001$; Table 3); that a family member can refuse treatments on behalf of a resident that no longer has cognitive capacity (2.68; 1.57-4.58; $p < .001$); that according to the Belgian Law on Patient Rights only a negative AD is legally binding for professionals (2.07; 1.29-3.31; $p = .003$); and that residents who have no cognitive incapacity and are not terminally ill, have the right to refuse treatment, even if that would lead to death (3.79; 1.59-9.41; $p = .004$). Allied staff and care assistants only differed significantly on this latter item with the odds of allied staff answering correctly being 4 times higher than care assistants (4.12; 2.43-6.99; $p < .001$).

Both the unadjusted and adjusted estimated mean of total scores on knowledge differed significantly between staff, with nurses scoring on average 0.13 points higher than care assistants (0.08-0.17; $p < .001$; theoretical range 0 to 1), and allied staff scoring 0.07 points higher than care assistants (0.03-0.12; $p < .001$).

Table 3. Differences in ACP knowledge by type of nursing home care staff (N=684)

	Missing data		Nurse (n=196)		Care assistant; Ref (n=319)		Allied staff (n=169)	
	n (%)	Correct, n (%)†	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Correct, n (%)†	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	
1. An AD allows a resident to communicate his will regarding healthcare in case he would lose his/her cognitive capacity in the future (true)	20 (2.9)	171 (89.5)	2.50 (1.32 to 4.75)**	4.10 (1.82 to 9.24)***	239 (78.1)	1.54 (.81 to 2.91)	1.85 (1.06 to 3.22)*	
2. A representative has the power to make decisions regarding healthcare in case the resident is no longer able to do this himself (true)	20 (2.9)	142 (74.3)	2.34 (1.48 to 3.69)***	2.23 (1.13 to 4.39)*	171 (55.9)	1.34 (.93 to 1.94)	1.17 (0.63 to 2.16)	
3. A resident can only assign a family member as his representative (false)	18 (2.6)	159 (81.5)	3.15 (1.70 to 5.87)***	2.37 (1.07 to 5.22)	178 (58.4)	1.98 (1.25 to 3.14)***	1.57 (0.87 to 2.83)	
4. A family member can refuse treatments instead of a resident that has no cognitive capacity (true)	22 (3.2)	75 (39.1)	1.61 (1.09 to 2.37)*	2.68 (1.57 to 4.58)***	87 (28.4)	.95 (.66 to 1.38)	1.23 (0.69 to 2.18)	
5. A physician is committed to perform all invasive treatments if a resident or family members asks, independent of potential advantages or disadvantages of those treatments (false)	10 (1.5)	101 (52.3)	1.01 (.72 to 1.41)	1.02 (0.69 to 1.50)	102 (63)	.53 (.29 to .94)	0.65 (0.36 to 1.18)	
6. According to the law of Patient Rights both a positive and negative AD is binding (false)	16 (2.3)	49 (25.4)	2.50 (1.96 to 3.19)***	2.07 (1.29 to 3.31)**	37 (11.9)	1.43 (.94 to 2.17)	1.13 (0.68 to 1.88)	
7. A residents living with dementia can change his/her AD (true)	15 (2.2)	28 (14.6)	1.61 (.83 to 3.09)	1.24 (0.58 to 2.64)	29 (9.4)	1.43 (1.04 to 1.97)	1.49 (0.82 to 2.60)	
8. Each family member of a resident living with dementia can change this person's AD (false)	12 (1.8)	155 (79.5)	1.93 (1.21 to 3.09)*	1.57 (0.80 to 3.04)	207 (66.8)	1.44 (.91 to 2.27)	1.23 (0.73 to 2.06)	
9. If a resident that has no cognitive capacity (eg. someone with severe dementia) has not assigned a representative, it is established by law who will take his/her place in decision-making (true)	9 (1.3)	98 (50.3)	2.19 (1.38 to 3.50)**	1.47 (0.68 to 3.19)	100 (32.1)	1.44 (.92 to 2.28)	1.12 (0.58 to 2.19)	
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)	11 (1.6)	131 (67.5)	1.28 (.93 to 1.76)	1.34 (0.97 to 1.86)	192 (61.7)	1.06 (.76 to 1.47)	1.05 (0.74 to 1.50)	
11. Residents that have no cognitive incapacity and are not terminally ill, have the right to refuse treatments, even if this decision can lead to death (true)	10 (1.5)	176 (89.8)	2.77 (1.53 to 5.02)**	3.79 (1.53 to 9.41)**	237 (76.2)	2.65 (1.88 to 3.74)***	4.12 (2.43 to 6.99)***	
Unadjusted estimated means (95% CI)¶	--		0.62 (0.59 to 0.64)	0.48 (0.46 to 0.50)		0.56 (0.52 to 0.59)		
Adjusted estimated means (95% CI)¶	--		0.58 (0.51 to 0.64)	0.44 (0.38 to 0.51)		0.52 (0.45 to 0.59)		
Unadjusted estimated mean difference (95% CI)¶	--		0.14 (0.10 to 0.17)***	Ref		0.08 (0.04 to 0.11)***		
Adjusted estimated mean difference (95% CI)¶	--		0.13 (0.08 to 0.17)***	Ref		0.07 (0.03 to 0.12)***		

ACP advance care planning; AD advance directive; Ref reference category

Staff was asked to indicate 'true', 'false' or 'I do not know' to each of the 11 items. Answering 'true' to a true statement and 'false' to a false statement is counted as a correct answer.

*Statistically significant $p < .05$; ** $p < .005$; *** $p < .001$.

†Observed absolute and relative frequency, not estimated from a model.

‡Multiple adjusted logistic mixed-model analysis (N=647) with nursing home as random effect and with professional role, age, gender, educational level, training in ACP, years since working in sector and average hours working in nursing home per week as fixed effects. Care assistants are the reference category. Missing per item for logistic mixed models, including missing values in covariates: item 1 (n=82; 12%); item 2 (n=83; 12.1%); item 3 (n=12.1%); item 4 (n=84; 12.3%); item 5 (n=75; 11%); item 6 (n=80; 11.7%); item 7 (n=81; 11.8%); item 8 (n=78; 11.4%); item 9 (n=74; 10.8%); item 10 (n=75; 11%); item 11 (n=75; 11%).

§Multiple unadjusted logistic mixed-model analysis (N=647) with nursing home as random effect and with professional role as fixed effect. Care assistants are the reference category. Missing data: item 1 (n=20; 2.9%); item 2 (n=20; 2.9%); item 3 (n=18; 2.6%); item 4 (n=22; 3.2%); item 5 (n=10; 1.5%); item 6 (n=16; 2.3%); item 7 (n=15; 2.2%); item 8 (n=12; 1.8%); item 9 (n=9; 1.3%); item 10 (n=11; 1.6%); item 11 (n=10; 1.5%).

¶Total scores on the items range between 0 and 1 with higher scores indicating greater knowledge. Estimated means and estimated mean differences (with care assistants as reference category) were calculated using a multiple linear mixed-model analysis with nursing home as random effect and professional role as fixed effects in the unadjusted analysis. In the adjusted analysis we added age, gender, educational level, training in ACP, years since working in sector and average hours working in nursing home per week as fixed effects. Missing unadjusted analysis: n=7 (1%). Missing adjusted analysis: n=37 (5.4%).

Self-efficacy in advance care planning

The unadjusted estimated means for self-efficacy in ACP in nurses differed significantly from those of care assistants on all separate self-efficacy items in the same direction, with nurses reporting on average significantly more confidence than care assistants in almost all ACP practices, ranging from an EMD of 0.59 (95% CI 0.17- 1.02; $p=.007$; Table 4) in performing ACP conversations with people living with dementia, to an EMD of 1.35 (0.94-1.76; $p<.001$) in discussing disease and treatment options with a resident. After controlling for potential confounders, these differences were no longer statistically significant. All staff reported lowest confidence levels in their knowledge of legislation related to ACP (5.41 \pm 2.34 in nurses, 4.26 \pm 2.39 in care assistants and 4.42 \pm 2.46 in allied staff; theoretical scores 0 to 10 with higher scores indicating more self-efficacy). This item did not differ significantly in both unadjusted and adjusted analyses. Allied staff reported lower confidence levels than care assistants in almost all items. However, these differences were not significant in both unadjusted and adjusted analyses.

Total unadjusted estimated means only differed significantly between nurses and care assistants (EMD 0.97; 0.61-1.33; $p<.001$). However, these differences were no longer significant when we adjusted for potential confounders.

Table 4. Differences in ACP self-efficacy by type of nursing home care staff (N=684)

	Missing data		Nurses (n=196)		Care assistants; Ref (n=319)		Allied staff (n=169)	
	n (%)†	Mean score (SD)‡	Unadjusted EMD (95% CI)§	Adjusted EMD (95% CI)§	Mean score (SD)‡	Mean score (SD)‡	Unadjusted EMD (95% CI)§	Adjusted EMD (95% CI)§
1. Initiating ACP conversations	9 (1.3)	6.30 (2.10)	1.28 (0.85 to 1.71)***	0.42 (-0.20 to 1.05)	5.30 (2.28)	5.21 (2.85)	0.14 (-0.35 to 0.64)	-0.54 (-1.15 to 0.08)
2. Discussing disease and treatment options with a resident within the context of ACP	11 (1.6)	6.27 (1.90)	1.35 (0.94 to 1.76)**	0.48 (-0.11 to 1.07)	4.95 (2.19)	5.07 (2.25)	0.12 (-0.35 to 0.58)	-0.54 (-1.12 to 0.04)
3. Discussing ACP	14 (2)	6.26 (2.00)	1.24 (0.83 to 1.64)***	0.58 (-0.01 to 1.17)	5.35 (2.11)	5.50 (2.24)	0.13 (-0.34 to 0.59)	-0.39 (-0.97 to 0.19)
4. Explain the role of a representative to residents and family	11 (1.6)	6.28 (2.19)	1.06 (0.62 to 1.49)***	0.28 (-0.32 to 0.89)	5.22 (2.26)	5.52 (2.40)	0.28 (-0.21 to 0.77)	-0.25 (-0.85 to 0.34)
5. Respond to questions of residents regarding ADs	13 (1.9)	6.18 (2.09)	0.99 (0.58 to 1.41)**	0.43 (-0.17 to 1.03)	5.20 (2.19)	5.26 (2.33)	0.04 (-0.42 to 0.51)	-0.37 (-0.95 to 0.22)
6. Respond to questions of the family regarding ADs	14 (2)	6.15 (2.14)	1.05 (0.63 to 1.47)**	0.44 (-0.17 to 1.04)	5.12 (2.18)	5.16 (2.34)	0.03 (-0.43 to 0.49)	-0.39 (-0.98 to 0.19)
7. Correspond to a residents' written wishes	14 (2.5)	7.05 (1.82)	0.37 (-0.03 to 0.77)	-0.26 (-.82 to 0.29)	6.68 (2.23)	6.60 (2.27)	-0.9 (-0.54 to 0.35)	-0.56 (-1.1 to -0.02)
8. Knowing legislation regarding ADs	11 (1.6)	5.41 (2.34)	1.15 (0.70 to 1.60)*	0.65 (0.1 to 1.30)*	4.26 (2.39)	4.42 (2.46)	0.16 (-0.35 to 0.65)	-0.112 (-0.75 to 0.5)
9. Talking to family members about wishes for future care	12 (1.8)	6.90 (1.91)	0.88 (0.48 to 1.28)***	0.35 (-0.23 to 0.93)	6.04 (2.16)	6.15 (2.43)	0.11 (-0.34 to 0.55)	-0.17 (-0.73 to 0.39)
10. Talking about general issues regarding dying and death	13 (1.9)	6.83 (1.88)	0.96 (0.54 to 1.37)***	0.45 (-0.16 to 1.05)	5.88 (2.29)	6.07 (2.47)	0.18 (-0.28 to 0.65)	-0.10 (-0.69 to 0.48)
11. Conduct a conversation regarding ACP with residents living with dementia	15 (2.2)	5.54 (2.13)	0.59 (0.17 to 1.02)**	0.04 (-0.59 to 0.66)	4.95 (2.19)	4 (2.37)	0.06 (-0.44 to 0.55)	-0.35 (-0.96 to 0.27)
12. Conduct a conversation regarding ACP with family members of residents living with dementia	12 (1.8)	6.22 (2.18)	0.93 (0.49 to 1.37)***	0.36 (-0.28 to 0.99)	5.30 (2.25)	5.39 (2.40)	0.99 (-0.39 to 0.59)	-0.29 (-0.90 to 0.33)
Unadjusted estimated means total score (95% CI)¶	--		6.33 (6.02 to 6.63)		5.35 (5.08 to 5.63)		5.52 (5.16 to 5.88)	
Adjusted estimated means total score (95% CI)¶	--		6.43 (5.98 to 7.44)		6.43 (5.71 to 7.15)		6.09 (5.35 to 6.83)	
Unadjusted EMD in total score (95% CI)¶	--		0.97 (0.61 to 1.33)***		Ref		0.17 (-0.25 to 0.58)	
Adjusted EMD in total score (95% CI)¶	--		0.28 (-0.22 to 0.79)		Ref		-0.34 (-0.84 to 0.16)	

ACP advance care planning; AD advance directive; SD standard deviation; EMD estimated mean difference; CI confidence interval; Ref reference category

Staff was asked to indicate per activity or role how confident they felt in performing the activity or role on a scale from 1 to 10 with higher scores indicating greater self-efficacy in the ACP activities or roles.

†They were also given the opportunity to answer 'not applicable' to all the items. Frequencies for the latter are reported in the Supplementary materials.

*Statistically significant p<.05; **p<.005; ***p<.001.

‡Missing values were significantly higher in care assistants (see Table 1A).



PART IV

‡Observed absolute and relative frequency, not estimated from a model.

§Supporting on the central limit theory the mean score on item level was considered a continuous variable. Differences between staff on item level are therefore calculated using an unadjusted and adjusted multiple linear mixed-model analysis with nursing home as random effect and with professional role as fixed effect. In the adjusted analysis, we added age, gender, educational level, training in ACP, years since working in sector and average hours working in nursing home per week as fixed effects. We report unadjusted and adjusted estimated mean difference (EMD) and 95% CI with care assistants as reference category.

¶Total scores on the items range between 0 and 10 with higher scores indicating more self-efficacy. Differences were calculated using a multiple linear mixed-model analysis (N=475) with nursing home as random effect and with professional role, age, gender, educational level, training in ACP, years since working in sector and average hours working in nursing home per week as fixed effects. We also the report estimated means and EMD from adjusted and unadjusted analysis. Missing in adjusted analysis: item 1 (n=209; 31%), item 2 (n=211; 31%), item 3 (n=200; 29.2%), item 4 (n=195; 28.5%), item 5 (n=168; 24.6%), item 6 (n=166; 24.3), item 7 (n=155; 22.7%), item 8 (n=156; 22.8%), item 9 (n=152; 22.2%), item 10 (n=153; n=22.4%), item 11 (n=200; 29.2%), item 12 (n=190; 27.8%). Analysis with mean score of self-efficacy excluded 162 of 684 cases (24%) because of missing data on >25% of items (see Table 1A).

DISCUSSION

This is the first survey study that compared nurses, care assistants and allied nursing home care staff with regard to ACP practices, knowledge and self-efficacy. We found small differences between staff in terms of their engagement in ACP practices and knowledge about ACP, with nurses generally having carried out more ACP and having more knowledge than did care assistants. We found no differences in staff's self-efficacy in ACP.

Our finding that nurses are more likely to carry out both ACP conversations and documentation, and that they are considerably more knowledgeable than others, is not surprising, given that nurses (besides physicians) are still considered the leading profession within ACP [30–34]. In addition, this result also corresponds to another study which found that nurses' knowledge in palliative care is generally higher than that of other staff [16]. This, together with nurses being considered the leading role in ACP (and hence assumedly having more access to training in ACP), might explain their higher knowledge scores in ACP. In addition, it might also lead to nurses receiving a clear mandate to carry out ACP in practice, which potentially explains their higher engagement in ACP conversations and documentation.

However, we also found that a considerable number of nurses still did not engage in ACP, and allied staff and care assistants engaged in ACP considerably more than we initially expected. In fact, allied staff, such as social workers and chaplains, have been shown to be increasingly involved in ACP across settings [13, 31]. The finding that knowledge also differed to only a small extent between staff and our results showing professional roles of staff might not be associated with self-efficacy over and above other confounders (such as previous training in ACP), indicates that allied staff and care assistants are a potential group to carry out ACP too. Considering time constraints and inadequate staffing levels of nurses, with nurses indicating they have little time to combine ACP with clinical care tasks [13, 20, 21], involving care assistants and allied staff might actually be a good option to respond to the high need for ACP in this population [6, 13]. To this extent, there has been increasing work looking at defining different professional roles in ACP and carrying out ACP as a team-approach [13]. In a recent study, Arnett et al. found that 85% of a wide range of healthcare staff felt that non-physicians (including social workers) could have ACP conversations, after having had appropriate training [31]. Given the fact that multi-professional teamwork already is an essential

component of long-term care, team-based ACP interventions should be acknowledged and expanded across all professional groups in the nursing home [31].

Limitations and strengths

This study specifically examines differences among nursing home staff. Existing studies in this area are often restricted to one professional group, only compared nurses to care assistants, or did not analyse allied staff separately but under the header of healthcare professionals together with care assistants [16, 17]. While the study has a large sample size and fair response rate [11], it also has some limitations. First, there is a non-response bias involved in this study. Second, while the survey instrument has been tested to a limited extent, it requires additional testing (e.g. validity, sensibility to change and other psychometric properties) [35]. Third, delineation of discrete cut-off points for high and low levels of knowledge and self-efficacy was not possible. Fourth, a self-administered survey to assess knowledge may lead to overestimation as the respondents have the opportunity to look up the correct answers or to discuss questions amongst each other. Finally, because of the excess zeros in the total score of practices (i.e. many staff members who completed none of the practices), we were not able to report differences between staff on total scores of ACP practices.

Conclusion and implications

While we did find some differences between nurses, care assistants and allied nursing home care staff with regard to their engagement in ACP practices and knowledge therein, differences were rather small and were not reflected in staff differences regarding self-efficacy in ACP, which were no longer significant after controlling for confounders. Hence, whereas nurses seem to be taking the lead in performing ACP conversations and documentation, allied staff and care assistants might be an underused group that could support nurses, if they receive appropriate training. Given nurses' time constraints and limited staffing levels, this can be considered a more sustainable option to meet the high need for ACP in the nursing home population.

DECLARATIONS

Ethics approval and consent to participate

This study was submitted as part of a larger trial and was approved by the Commission of Medical Ethics of the University Hospital of Brussels (B.U.N. 143201834759).

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Conception and design of the work: JG, AWvD, LP, LVDB, CG, LD, RV, KD; Ethics approval: JG, AWvD, LP, LVDB; Development and testing of questionnaire: AWvD, LP, LVDB, JG, CG, LD, RV, KD; Statistical data analysis: JG, in close collaboration with professional statistician; Interpretation of data analysis: JG, LP, LVDB. Drafting of the manuscript: JG; Critical revision for important intellectual content: all. All authors have read and approved the final manuscript.

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ADDITIONAL FILES CHAPTER 5

Table 1A. Staff answering ‘not applicable’ and missing data in self-efficacy items (N=684)

	Nurses (n=196)		Care assistants (n=319)		Allied staff (n=319)	
	NA, n (%)	Missing, n (%)	NA, n (%)	Missing, n (%)	NA, n (%)	Missing, n (%)
1. Initiating ACP conversations	18 (9.2)	0	83 (26.6)	7 (1)	50 (29.9)	2 (0.3)
2. Discussing the disease and treatment options with a resident within the context of ACP	14 (7.2)	1 (0.1)	85 (27.3)	8 (1.2)	51 (30.5)	2 (0.3)
3. Discussing ACP	12 (6.2)	1 (0.1)	77 (24.9)	10 (1.4)	47 (28.3)	3 (0.4)
4. Explain the role of a representative to residents and family	14 (7.2)	1 (0.1)	73 (23.5)	8 (1.2)	45 (26.9)	2 (0.3)
5. Respond to questions of residents regarding ADs	11 (5.7)	2 (0.3)	54 (17.4)	9 (1.3)	38 (22.8)	2 (0.3)
6. Respond to questions of the family regarding ADs	11 (5.6)	1 (0.1)	54 (14.5)	11 (1.6)	38 (22.8)	2 (0.3)
7. Correspond to a residents’ written wishes	6 (3.1)	3 (0.4)	45 (14.7)	12 (1.7)	36 (21.6)	2 (0.3)
8. Knowing legislation regarding ADs	9 (4.6)	1 (0.1)	53 (17.0)	8 (1.2)	33 (19.8)	3 (0.4)
9. Talking to family members about wishes for future care	8 (4.1)	2 (0.3)	43 (13.8)	8 (1.2)	34 (20.4)	2 (0.3)
10. Talking about general issues regarding dying and death	5 (2.6)	1 (0.1)	46 (14.9)	10 (1.4)	35 (21.0)	2 (0.3)
11. Conduct a conversation regarding ACP with residents living with dementia	13 (6.7)	1 (0.1)	76 (24.7)	11 (1.6)	49 (29.5)	3 (0.4)
12. Conduct a conversation regarding ACP with family members of residents living with dementia	12 (6.2)	1 (0.1)	70 (22.6)	9 (1.3)	45 (26.9)	2 (0.3)

ACP advance care planning; NA not applicable; AD advance directive

Table 2A. Nursing home characteristics (N=15)*

CHARACTERISTICS	Frequencies/descriptive
Type of facility, n	
Public	5
Private non-profit	9
Private for-profit	1
Availability of guidelines and documents*, yes, n	
Specific written guidelines for palliative care	14
Specific written guidelines for advance care planning	11
Patient-centered documents for advance care planning	15
Nursing home healthcare staff, 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 clerk	1 (0-2)
Number of beds, median (range)	
Total number of beds	118 (90 – 264)
Number of beds currently occupied by a resident	111 (92 – 270)

*We report the characteristics of one nursing home separately for two different campuses (N=15).



PART IV

Chapter 6: Nurses' self-efficacy, rather than their knowledge, is associated with their engagement in advance care planning in nursing homes: a survey study
(Short report)

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ABSTRACT

BACKGROUND Considering social cognitive theory and current literature about successful advance care planning in nursing homes, sufficient knowledge and self-efficacy are important preconditions for staff to be able to carry out advance care planning in practice.

AIM Exploring to what extent nurses' knowledge about and self-efficacy is associated with their engagement in advance care planning in nursing homes.

DESIGN Survey study as part of a baseline measurement of a randomised controlled cluster trial (NCT03521206).

SETTING/PARTICIPANTS Nurses in a purposive sample of 14 nursing homes in Belgium.

METHODS A survey was distributed among nurses, evaluating knowledge (11 true/false items), self-efficacy (12 roles and activities on 10-point Likert scale) and six advance care planning practices (yes/no), ranging from performing advance care planning conversations to completing advance directives.

RESULTS 196 nurses participated (66% response rate). While knowledge was not significantly associated with ACP practices, self-efficacy was. One unit's increase in self-efficacy was statistically associated with an estimated 32% increase ($\log \beta=1.32$) in the number of practices having carried out.

CONCLUSIONS Nurses' engagement in advance care planning practices is associated with their self-efficacy rather than their knowledge. Further research is necessary to improve the evidence regarding the causal relationship between constructs. However, these results suggest that educational programmes that focus solely on knowledge might not lead to increasing uptake of advance care planning in nurses.

BACKGROUND

The voluntary process of advance care planning (ACP) [1], has been repeatedly voiced as especially valuable for people living in nursing homes [2]. While a wide range of factors can influence healthcare professionals' engagement in ACP, having sufficient knowledge and skills have been identified as important intermediate steps towards successful ACP [3, 4]. However, nursing home staff often initiate ACP too late or infrequently [5, 6]. It has been found that prominent factors inhibiting them to do so are lack of knowledge and low self-efficacy [7, 8].

Social cognitive theory, that aims to explain determinants for behaviour, proposes that there is a relationship between knowledge and skills, which translates into action by raising self-efficacy to overcome barriers [9, 10]. Based on this theory, we might for example hypothesise that nurses who have similar knowledge may still perform differently, depending on fluctuations in self-efficacy [11]. Bandura's theory has been used as a model to evaluate relationships between knowledge, self-efficacy, and behaviour in research regarding health promotion, palliative care, and recently in research regarding patients' readiness to engage in ACP [12–16].

We know that knowledge about ACP is associated with self-efficacy in ACP and vice versa [8, 17]. However, our understanding whether and to what extent these constructs also relate to professionals' engagement in actual ACP practices, is incomplete. To date only a small amount of studies evaluated associations between knowledge *or* self-efficacy, and its relation to the amount of conversations carried out [18, 19]. The purpose of this exploratory study is to better understand the relationship between nurses' knowledge and self-efficacy with their engagement in ACP practices (ranging from ACP conversations to completing ADs and performing ACP in people living with dementia) in nursing homes.

METHODS

Study design

This cross-sectional survey study is part of a cluster randomised controlled trial (NCT03521206) that aims to evaluate a structured ACP implementation programme in nursing homes. As a baseline

measure, staff's knowledge, self-efficacy and engagement in ACP practices were measured (March–April 2018).

Setting and participants

We purposively recruited 14 nursing homes in Flanders, Belgium. These were eligible if they had at least 100 beds and if the facility manager expressed explicit motivation to participate. Nursing homes were ineligible if they had or were currently taking part in a similar study, if they had an extensive ACP policy or if organisational changes were planned. All nurses on staff were invited upon condition that they speak and understand Dutch. Students and interns were excluded.

Data collection

In each nursing home, a contact person was designated to identify all eligible nurses. Surveys were distributed, consistent with regular ways of communicating to staff. Nurses who agreed to participate, completed the survey and were asked to post it in a locked box only accessible to the researchers, using an anonymised envelope. Reminders were sent twice (after two and four weeks).

Instrument

We developed a survey instrument to investigate ACP knowledge, self-efficacy and practices. Items were based on existing surveys [20–22] and input from the multidisciplinary research team. The instrument was tested with healthcare professionals that were working or had worked in a nursing home via individual cognitive interviews (n=6) [24] and through distributing a paper version of the survey (n=107). Participant's characteristics included age, gender, years of employment in aged care sector, educational level, previous education in ACP, number of hours working/week and average number of residents caring for. Respondents were asked to indicate 'true', 'false' or 'I don't know' for 11 knowledge statements. To assess self-efficacy, nurses had to indicate their confidence regarding 12 ACP roles/tasks, on a 10-point Likert scale, ranging from 'little' (1) to 'a lot of confidence' (10), or 'not applicable'. Respondents were also asked if they had performed any of six listed ACP practices in the past six months ('yes' or 'no').

Statistical analyses

Total scores of the subscales were means, ranging from 0 to 1 for knowledge and practices, and 0 to 10 for self-efficacy, with higher scores indicating better knowledge, having carried out more ACP practices or higher self-efficacy respectively. Cases with missing data on >25% of items were excluded from this calculation. Strong multicollinearity between covariates (age, gender, years of employment, education, education in ACP, hours working/week) was not found. Because of excess zero count data in the total score of ACP practices (43%), a Zero-Inflated Poisson model was applied, combining a count model and a logistic zero model [22], with total ACP practices as target variable, and total knowledge and self-efficacy scores as interacting independent variables. We included 'previous education in ACP' and 'hours working/week' as covariates, after forward-backward manual selection. Non-significant results led to the removal of other covariates from the model, evaluated with a Wald test and Akaike Information Criterion. A mixed model was not applied because it showed a near zero intra-class correlation within nursing homes. Results are statistically significant if $p < .05$ on a two-sided test.

RESULTS

A total of 196 nurses participated (66%). The majority was female (90%; Table 1), with a sample mean age of 42 (± 11), and highly educated (21%). 64% was not trained in ACP. Nurses worked on average 30 hours/week and had worked a median of 12 years in the sector. They cared for a median of 20 residents/day.

Table 1. Demographic and professional characteristics of participating nurses* (N=196)

NURSE CHARACTERISTICS	
Age, mean (SD)	42.1 (10.9)
Gender, female, n (%)	173 (89.6)
Educational level, n (%)	
Secondary education	23 (11.9)
Higher education (college)	131 (67.5)
Higher education (university)	40 (20.6)
Previous training in advance care planning, 'no', n (%)	126 (64.3)
Average hours working in nursing home per week, median (25-75% IQR)	30 (30-38)
Years since working in residential care/sector, median (25-75% IQR)	12 (5-20.3)
Average number of residents taking care of (daily), median (25-75% IQR)	20 (10-35.5)

SD standard deviation; IQR interquartile range

*A nurse (as stated in the coordinated Belgian Law on Care Professions, Chapter 4, 2015) has a Nursing diploma or is entitled 'nurse' after having had at least three years of study (of at least 4600 hours theoretical and clinical education) in nursing.

Missing: age (n=8; 4.1%), gender (n=3; 1.5%), educational level (n=2; 1%), previous training in ACP (n=4; 2%), average hours working/week (n=8; 4.1%), years in sector (n=8; 4.1%), average number of residents taking care of (n=30; 15.3%).

Knowledge was on average 0.58 (± 0.15 ; Table 2), ranging from 0 to 1. Self-efficacy was on average 6.59 (± 1.78), with 10 indicating highest self-efficacy. 43% of nurses participated in none of the ACP practices; the mean total score was 0.26 (± 0.31), with scores ranging from 0 and 1. Self-efficacy was significantly associated with ACP practices ($p < .001$). Each score increase in self-efficacy, increased the expected log count in ACP practices by 1.32 (95%CI 0.77-2.25; $p < .001$), which equals an estimated 32% increase in the number of practices. Knowledge was not statistically associated with practices. The zero inflation is suggested to be partly due to nurses who had no previous education in ACP (log odds 0.25; 95%CI 0.08-0.72; $p < .01$; Table 2A).

Table 2. ACP knowledge, self-efficacy and relationship with ACP practices in nurses (N=196)

ACP KNOWLEDGE (CORRECT 'Y' VS INCORRECT '0')	n (%)†	mean (SD)‡	median (25-75% IQR)‡	Coefficient β (95% CI)‡	Exp β (95% CI)‡	P-value‡
Total score ACP knowledge (ranging from 0 to 1)*	-	-	-	-	-	-
Association between knowledge and ACP practices						
1. An AD allows a resident to communicate his will regarding healthcare in case he would lose his/her cognitive capacity in the future (<i>true</i>)	171 (89.5)	0.58 (0.15)	0.62 (0.45-0.73)	0.59 (-0.28 to 1.46)	1.80 (0.76 to 4.29)	0.18
2. A representative has the power to make decisions regarding healthcare in case the resident is no longer able to do this himself (<i>true</i>)	142 (74.3)	0.74 (0.44)	1 (0-1)			
3. A resident can only assign a family member as his representative (<i>false</i>)	159 (81.5)	0.82 (0.39)	1 (1-1)			
4. A family member can refuse treatments instead of a resident that has no cognitive capacity (<i>true</i>)	75 (39.1)	0.39 (0.49)	0 (0-1)			
5. A physician is committed to perform all invasive treatments if a resident/family asks, independent of potential (dis)advantages of those treatments (<i>false</i>)	59 (30.1)	0.3 (0.46)	0 (0-1)			
6. According to the law of Patient Rights both a positive and negative AD is binding (<i>false</i>)	49 (25.4)	0.25 (0.44)	0 (0-1)			
7. A residents living with dementia can change his/her AD (<i>true</i>)	28 (14.3)	0.15 (0.35)	0 (0-1)			
8. Each family member of a resident living with dementia can change this person's AD (<i>false</i>)	155 (79.5)	0.79 (0.41)	0 (0-1)			
9. If a resident that has no cognitive capacity (e.g. someone with severe dementia) has not assigned a representative, it is established by law who will take his/her place in decision-making (<i>true</i>)	98 (50.3)	0.50 (0.50)	1 (0-1)			
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 a written AD for euthanasia (<i>true</i>)	131 (67.5)	0.68 (0.47)	1 (0-1)			
11. Residents that have no cognitive incapacity and are not terminally ill, have the right to refuse treatments, even if this decision can lead to death (<i>true</i>)	176 (89.8)	0.90 (0.30)	1 (1-1)			
ACP SELF-EFFICACY (RANGING FROM 0 TO 10)						
Total score ACP self-efficacy (ranging from 0 to 10)*	-	-	-	-	-	-
Association between self-efficacy and ACP practices						
1. Initiating ACP conversations	131 (73.6)	6.29 (1.78)	6.83 (5.2-7.5)	0.27 (-0.26 to 0.81)	1.32 (0.77 to 2.25)	<0.001
2. Discussing disease and treatment options with a resident within the context of ACP	132 (72.9)	6.30 (2.10)	7 (5-8)			
3. Discussing ACP	139 (75.9)	6.27 (1.9)	7 (5-8)			
4. Explain the role of a representative to residents and family	125 (69.1)	6.56 (2)	7 (6-8)			
5. Respond to questions of residents regarding ADs	127 (69.4)	6.28 (2.19)	7 (5-8)			
6. Respond to questions of the family regarding ADs	127 (69.0)	6.18 (2.09)	7 (5-8)			
7. Correspond to a residents' written wishes	155 (82.9)	6.45 (2.14)	7 (5-8)			
8. Knowing legislation regarding ADs	100 (53.8)	7.05 (1.82)	7 (6-8)			
9. Talking to family members about wishes for future care	152 (81.7)	2.41 (2.34)	6 (4-7)			
10. Talking about general issues regarding dying and death	146 (76.8)	6.90 (1.91)	7 (6-8)			
11. Conduct a conversation regarding ACP with residents living with dementia	104 (57.1)	6.83 (1.88)	7 (6-8)			
12. Conduct a conversation regarding ACP with family members of residents living with dementia	131 (71.6)	5.54 (2.13)	6 (5-7)			
131 (71.6)	6.22 (2.18)	7 (5-8)				
ACP PRACTICES (YES 'Y' VS NO '0')						

PART IV

Total score ACP practices (ranging from 0 to 1)*

		0.26 (0.31)	0.17 (0-0.5)	
1. Started an ACP conversation	62 (31.8)	0.32 (0.47)	0 (0-1)	-
2. Documented the outcomes of ACP in a resident's file	69 (35.2)	0.35 (0.48)	0 (0-1)	-
3. Completed an AD with a resident	20 (10.2)	0.34 (0.30)	0 (0-0)	-
4. Made an estimation if someone was capable of completing an AD	66 (33.8)	0.34 (0.47)	0 (0-1)	-
5. Had an ACP conversation with a resident living with dementia	26 (13.3)	0.13 (0.34)	0 (0-0)	-
6. Had an ACP conversation with family of a resident living with dementia	60 (30.9)	0.31 (0.46)	0 (0-1)	-
ACP advance care planning; AD advance directive; SD standard deviation; IQR inter-quartile range; Exp exponential				

*Total scores are means per whole subscale and range from 0 to 1 (10 in self-efficacy). Cases with missing data on more than 25% of items were excluded from total score calculations for that particular scale. Missing total score knowledge and ACP practices: n=0. Missing total score self-efficacy: n=15. For the self-efficacy subscale, respondents were also given the opportunity to answer 'not applicable' to all the items. These were not counted in the total mean score.

†Observed absolute and relative frequency, not estimated from a model. For self-efficacy we report n (%) for all those reporting self-efficacy levels >5 (on 10-point Likert scale). Missing data ACP practices: item 1, 4 (n=1; 0.5%), item 2, 3, 5 (n=0), item 6 (n=2; 1%). Missing data knowledge: item 1, 2 (n=5; 2.6%), item 3, 8, 9 (n=1; 0.5%), item 4, 7 (n=4; 2%), item 5, 11 (n=0), item 6 (n=3; 1.5%), item 10 (n=2; 1%). Missing data self-efficacy, including those that answered 'not applicable': item 1 (n=18; 9.2%), item 2, 4 (n=15; 7.7%), item 3, 5, 12 (n=13; 6.6%), item 6 (n=12; 6.1%), item 7 (n=9; 4.6%), item 8, 9 (n=10; 5.1%), item 10 (n=6; 3.1%), item 11 (n=14; 7.1%).

‡Coefficients, 95%CI and adjusted p-values were calculated using the Zero-Inflated Poisson count model. Because 15 cases showed a missing on the total score of ACP practices, and this was the dependent variable, they were eliminated from this analysis, resulting in a total N of 181 for the analysis of associations. Results of the logistic zero model that shows which variables are statistically significantly associated with nurses having structurally carried out none of the ACP practices, are shown in the supplementary materials (Table 2A)

DISCUSSION

This study showed that, whereas having carried out ACP practices not associated with nurses' knowledge, they were estimated to carry out 32% more practices per unit increase in self-efficacy. Consistent with this finding, another recent study also found self-efficacy to be positively associated with the frequency nurses carried out ACP [19]. While in both our study and a similar Italian study [18] no association was found between knowledge and ACP, it is a rather surprising result since both knowledge *and* self-efficacy are considered necessary for nurses to be able to actually engage in ACP [3, 4, 26].

Our results comply with social cognitive theory that assumes an individual's knowledge translates through self-efficacy into action [10]. Hence, while both constructs are important, raising self-efficacy can be considered essential to increase nurses' uptake of ACP. Our study therefore implies that existing educational programmes should focus primarily on improving self-efficacy rather than solely increasing knowledge about ACP. As we cannot conclude causation from this cross-sectional study, the results might also suggest that carrying out a variety of ACP practices leads to having more confidence in doing so. Similarly, a path analysis by Bandura and a recent review by Godin et al. showed that self-efficacy is influenced by prior experiences of the action that is required [10, 11, 27].

A large share of nurses in our sample did not carry out any of the ACP practices (43%), and zero-inflation results show this was significantly associated with having had previous education in ACP. Nurses' previous education in ACP might therefore function as a predictor of whether nurses engage in ACP *at all*. The latter is consistent with a wide range of literature showing limited ACP education is a prominent barrier to engage in ACP [28, 29].

Several limitations of this study caution consideration. This was a cross-sectional study with a small sample, conducted in purposively recruited regional nursing homes. Results cannot serve as long-term predictions or inferences about causality, and findings certainly warrant further research to establish causal relationships and to explore other determinants that shape nurses' involvement in ACP. In addition, the survey instrument should undergo additional reliability and validity testing [30]. And finally, the resulting estimate for knowledge had a broad CI, which reveals the sample size might

be too small. Larger sample sizes are generally recommended when applying Zero-Inflation models [31].

CONCLUSIONS

We found no statistically significant association between knowledge in ACP and ACP practices carried out by nurses, ranging from starting ACP conversations, helping nursing home residents complete their ADs, to performing ACP with people living with dementia. Higher self-efficacy however was statistically associated with having carried out more ACP practices. While these results warrant future research, educational programmes might consider focusing primarily on raising self-efficacy rather than increasing knowledge alone, as self-efficacy might be an important precursor in actually improving nurses' uptake of ACP in nursing homes.

DECLARATIONS

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Authors' contributions

Conception and design: All authors; Provision of study materials: A.W-VD.; J.G.; Collection and assembly of data: J.G.; A.W-VD.; Data analysis: W.C., in close collaboration with J.G.; Interpretation of data: All authors; Manuscript writing: J.G., L.P., L.VDB., C.G.; Final approval of manuscript: All authors; Accountable for all aspects of the work: All authors.

Availability of data

The datasets generated and/or analysed during the current study are not made public to protect confidentiality but are available from the corresponding author upon reasonable request.

Declaration of conflicting interests

The authors have no conflicts of interest.

Ethics and consent

This study was submitted as part of a larger trial study and was approved by the Commission of Medical Ethics of the University Hospital of Brussels (ref. B.U.N. 143201834759). All participants gave written consent, including consent for publication of anonymised findings. Trial procedures are described and registered under ClinicalTrials.gov NCT03521206.

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Table 1A. Nursing home characteristics (N=15, of which one nursing home as two campi)

NURSING HOME CHARACTERISTICS	
Type of facility, n	
Public	5
Private non-profit	9
Private for-profit	1
Availability of guidelines and documents*, 'yes', n	
Specific written guidelines for palliative care	14
Specific written guidelines for advance care planning	11
Patient-centred documents for advance care planning	15
Nursing home healthcare staff, median per facility (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 clerk	1 (0-2)
Number of beds, median (range)	
Total number of beds	118 (90 – 264)
Number of beds currently occupied by a resident	111 (92 – 270)

Table 2A. Zero-Inflated Poisson model to examine associations between knowledge, self-efficacy and ACP practices

PREDICTORS	COEFFICIENT B (95% CI)	EXP B (95% CI)†	P-VALUE‡
Zero-Inflated Poisson model: predicting number of ACP practices in nurses not in the “certain zero” group			
<i>Intercept</i>	-8.21 (-9.30 to -7.13)	0.00 (0.00 to 0.00)	<0.001
Knowledge	0.59 (-0.28 to 1.46)	1.80 (0.76 to 4.29)	0.18
Self-efficacy	0.27 (-0.26 to 0.81)	1.32 (0.77 to 2.25)	<0.001
Logistic zero model: predicting membership of nurses in the “certain zero” group of ACP practices			
<i>Intercept</i>	-0.41 (-0.90 to 0.08)	0.66 (0.41 to 1.08)	0.1
Previous education in ACP	-1.40 (-2.47 to -0.33)	0.25 (0.08 to 0.72)	0.01

ACP advance care planning; CI confidence interval; Exp Exponential

*15 cases showed a missing on the total score of practices, and this was the dependent variable, they were eliminated from further analysis, resulting in a total N of 181 for the main analysis.

†To show the multiplicative effect of the predictors on ACP practices, we exponentiated the estimates.

‡Coefficients, 95% CI and adjusted p-values were calculated using a zero-inflated Poisson model, combining a count model generating counts and a zero model, with in both model a total ACP practices score as target variable and total knowledge and self-efficacy scores as independent variables. After backward-forward manual selection covariates ‘previous education in ACP’ and ‘average number of hours working the nursing home per week’ were retained in the model.

PART V
GENERAL DISCUSSION



Summary of main results

In **Chapter 1**, we report the results of a systematic review regarding the preconditions for advance care planning (ACP) in nursing homes. Preconditions are defined as requirements, conditions and elements necessary to achieve the desired outcome(s) of ACP. We searched 4 electronic databases and included 38 publications with heterogeneous study designs (6 quantitative studies (one RCT), 14 qualitative studies, 11 systematic reviews, and 7 literature reviews) and moderated them for methodological quality. Based on our inductive thematic analysis and narrative synthesis, we identified 17 preconditions in five domains: 1) sufficient knowledge and skills, 2) willingness and ability to participate in ACP, 3) good relationships, 4) availability of an administrative system for documenting wishes and monitoring care, and 5) supportive contextual factors. We also identified different levels to which each precondition is applicable, i.e. resident, family, healthcare professional, facility and community level. Most preconditions are applicable to the professional level. This systematic review supports the claim that ACP should entail a whole-setting approach.

In **Chapter 2**, we report a programme theory that outlines the hypothetical causal pathway of ACP in nursing homes i.e. what changes are expected, by means of which processes and under what circumstances. This theoretical model was developed following a Theory of Change approach, which is a participatory method of programme design and evaluation whose underlying intention is to improve understanding of how and why a programme works. We integrated the results of two workshops with stakeholders (n=27) with the results of a contextual analysis and the systematic review. We identified two long-term outcomes that ACP aims to achieve: to improve the correspondence between residents' wishes and the care/treatment they receive; and to make sure residents and their families feel involved in planning their future care and are confident that care will be provided according to their wishes. Necessary preconditions were put in chronological order in a theory of change map: a sufficiently skilled trainer [precondition 1], engagement of the nursing home management [2], assignment of 'ACP reference persons' [3]; nurse training to make sure they are able to conduct ACP conversations [4]; trained staff that are able to signal triggers for ACP and know how to pass on this information [5]; informed care professionals [6], GPs [7] and residents/families [8, 9]; and care professionals that intend to take into account the wishes and preferences of nursing home residents and who are willing to engage in ACP. That wishes and preferences are known to

the ACP reference persons or trained facilitators (through ACP conversations) is a key outcome in the map [10]. This is followed by the need for all involved care professionals to know these wishes [11] and the availability of a written record that is accessible to all professionals involved in the care of the resident [12]. To ensure that the quality of ACP is consistently high, ongoing monitoring is necessary [13]. Nine intervention components with specific rationales were identified at the same levels as in Chapter 1, most of which were applicable to the professional level. These intervention components are hypothesised to be required to move from one step to another are: selection of a trainer; ensuring engagement of management; training ACP reference persons; in-service education for healthcare staff; information for staff, GPs, residents and their family; ACP conversations and documentation; regular reflection sessions; multidisciplinary meetings; and formal monitoring.

In **Chapter 3**, we developed and tested our intervention for acceptability and feasibility. This involved a qualitative study, including a literature review, expert discussions, and individual and group interviews with nursing home staff and management. The work resulted in the ACP+ intervention, a multicomponent programme which is delivered stepwise over an eight-month period with the help of an external trainer. The final ACP+ programme includes 10 intervention components, 22 activities and 17 materials to support delivery into routine nursing home care. The key components are: ongoing training and coaching; management engagement; different roles and responsibilities for organizing ACP; conversation; documentation and information transfer; integration of ACP into multidisciplinary meetings; auditing; and tailoring it to the specific setting. Challenges identified were: difficulties involving GPs; lack of time and staffing; insufficient management support; insufficient fit with existing procedures and work routines; lack of profile description of ACP Reference Persons; involvement of a trainer who is unfamiliar with the nursing home; lack of information regarding ACP in dementia and need for one-to-one coaching. Consequently, several adjustments were made to the ACP+ programme to make sure it would be more acceptable and feasible to implement: involvement of GPs in information sessions that are accredited and organised after 5 p.m.; limiting the amount and length of training sessions; organising buy-in meetings for management; allowing tailoring of details of procedures and timing of several components and activities; adding extra guidance to select ACP Reference Persons; arranging for a site visit for the trainer to become acquainted with the routines in each nursing home; a comeback seminar for trained staff, and additional coaching (including one-to-one coaching and specialised training sessions regarding dementia and information transfer). A key aspect of the final programme is the diffusion of different roles in the nursing home: ‘ACP Trainers’ will be available to support

nursing homes; ‘ACP Reference Persons’ will be responsible for implementing ongoing ACP within the nursing home; ‘ACP Conversation Facilitators’ work with ACP Reference Persons and are responsible for planning and performing regular ACP conversations with residents and/or family; and all others are ‘ACP Antennas’, who recognise and signal triggers that indicate a persons’ readiness, need or willingness to engage in ACP.

In **Chapter 4** we describe how we conducted a cluster randomised controlled trial (RCT) and embedded process evaluation to study the effects, implementation, causal mechanisms and context of the ACP+ programme in 14 nursing homes in Flanders. Eligible nursing homes were pair-matched, and one from each pair was randomised to either continued care and education as usual, or to receive the ACP+ programme. The primary outcome was nursing home care staff’s knowledge of and self-efficacy in ACP. Secondary outcomes were: 1) nursing home care staff’s attitudes towards ACP and ACP practices; 2) support staff and volunteer engagement in ACP practices and 3) support staff’s and volunteers’ self-efficacy. Measurements were performed at baseline and eight-month post-measurement, using structured self-reported questionnaires. A process evaluation accompanied the outcomes evaluation in the intervention group, with measurements during and after the intervention, using a mixed-methods design (including structured diaries, notes, attendance lists, observation, post-training surveys, semi-structured interviews and focus groups).

Chapter 5 reports differences between nurses, care assistants and allied care staff in nursing homes, using data from the baseline measurement of the cluster RCT presented in Chapter 4. The study is carried out in 14 nursing homes; a total of 196 nurses, 319 care assistants and 169 allied staff completed the questionnaire ($n=684$, overall response rate 67%). ACP conversations (OR 4; 95%CI 1.73-9.82; $p<.001$) and ACP documentation (2.67; 1.29-5.56; $p<.005$) were carried out significantly more by nurses than care assistants. Such differences were not found between allied staff and care assistants. Knowledge differed significantly, with both nurses (estimated mean difference (EMD) 0.14; 95%CI 0.10-0.17; $p<.001$) and allied staff (EMD 0.08; 0.04-0.11; $p<.001$) scoring higher than did care assistants, with estimated means ranging from 0 to 1. Self-efficacy did no longer differ after controlling for confounders.

In **Chapter 6** we explored whether and to what extent nurses’ knowledge about and self-efficacy in ACP is associated with their involvement in actual ACP practices in 14 nursing homes. A total of 196 nurses participated (response rate 66%). This study shows that, whereas nurses’ knowledge about

ACP was not associated with the number of ACP practices they carried out (ranging from performing ACP conversations to completing an advance directive), having more self-efficacy was shown to be significantly associated with having carried out more ACP practices. Nurses' total score of ACP practices was estimated increase by 32% (log β or multiplicative effect of 1.32), per unit increase in self-efficacy ($p < .001$). Structurally carrying out none of the ACP practices was associated with the nurses' previous education in ACP, typically the nurses with no previous ACP education, never carried out ACP practices. Results show that the odds of structurally performing none of the ACP practices, decrease by 75% (OR=0.25) in case the nurse per unit increase in previous ACP education ($p < .001$).

*Methodological considerations, strengths and
limitations*

To answer the research questions of this dissertation, several methods and different study designs were used. Chapters 1 and 2 were based on a systematic review, a context analysis and stakeholder workshops, using the Theory of Change approach. In Chapter 3, we performed a literature search, reviewed existing intervention guidance documents, performed expert consultations and semi-structured interviews for the development of the intervention and modelling of the intervention materials. In Chapter 4, we outlined the design of the cluster RCT in 14 nursing homes, including a process evaluation. The last two chapters, Chapters 5 and 6, present data from the baseline measurement of the trial presented in Chapter 4. In the following paragraphs, key methodological considerations, strengths and limitations are discussed. These are categorised under the following headings:

- 1) Use of a Theory of Change approach throughout the development of a complex intervention;
- 2) A cluster randomised controlled trial to study effectiveness;
- 3) Embedding a process evaluation into a cluster randomised controlled trial to evaluate underlying processes of change.

1. USE OF A THEORY OF CHANGE APPROACH THROUGHOUT THE
DEVELOPMENT OF A COMPLEX INTERVENTION

Chapters 1 to 3 comprise the development of a complex intervention and can be considered as a phase 0-1 study, as defined by the Medical Research Council's (MRC) framework [1]. These first two phases of the MRC framework outline the steps that researchers should take when developing a complex intervention: identifying the evidence base, identifying or developing theory (including the rationale for the intervention, i.e. what changes are expected, and how change is to be achieved), refining the intervention, and testing its feasibility. In the three paragraphs below, the most important strengths and limitations of the key steps undertaken to develop the ACP+ programme are highlighted.

We first identified necessary preconditions for the successful implementation of ACP in nursing homes via a systematic literature review, reported in Chapter 1.

Systematic reviews in particular are recommended by both the MRC framework and others to inform intervention development [1, 2]. A precondition in our review is defined as ‘a requirement, condition or element that is needed to be realized for the desired outcome to be achieved’. The identification of such preconditions is considered an important step in the construction of a theory of change map as they represent the intended outcomes or results of the intervention and its separate components, and therefore serve as a rationale for why each of the intervention components is part of the programme [3]. These preconditions need to exist in order for the logical causal pathway not to be broken and the desired outcome(s) to be achieved. By performing this review, we were able to make a list of the most important elements that need to be part of ACP in nursing homes. This is important knowledge given the temporal, human and financial resources that facilities invest when implementing ACP [4, 5]. Rather than focusing solely on outcome data, which has usually been achieved through meta-analysis of literature [6], we included different types of study designs and therefore also report preconditions that are deemed important by the researchers themselves, those that implemented ACP (e.g. trained healthcare professionals/researchers/trainers), residents, family, and healthcare professionals.

Our systematic review has some limitations. Although the review is carried out according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) principles, we did not publish our study protocol in the International Prospective Register of Systematic Reviews (PROSPERO) database prior to carrying it out, which has been widely recommended [7, 8]. In addition, we did not carry out an explicit Risk of Bias Assessment, leading Jimenez et al. to grade our systematic review with a quality score of 6 on a scale from 1 – 10 (based on a modified version of the AMSTAR tool⁶) [9]. None of the included studies were of high quality, and comparisons between methodological quality scores was not possible due to the difference in study designs among included studies. In addition, we examined textual data or “excerpts”, extracted line-by-line from both the results and discussion sections. It can be argued that a discussion section of a paper often goes beyond the strict results of the study, and includes hypotheses made by the authors. Finally, we

⁶ AMSTAR scores ranging from 5 to 8 represent medium quality (Seo and Kim, 2012).

identified preconditions for successful ACP, but we fell short of defining what we considered ‘successful’. Over the range of included papers, ACP was perceived successful if it was “easier to implement”, if a certain ACP component “had a positive effect” on measured outcome(s) (of any type), or if “it would have been better to organise ACP, if ‘x’ was in place”. In Chapter 2 however, we asked stakeholders how they would define ‘success’ of ACP in nursing homes, which is outlined in the resulting ToC map.

*Secondly, in Chapter 2, a **Theory of Change approach** was used to set up a theoretical model of how ACP is hypothesised to work in the nursing home setting in Flanders, incorporating results of the systematic review in Chapter 1, a context analysis, and two **participatory stakeholder workshops**, which were attended by a multidisciplinary group of professionals.*

Both the MRC guidance and newly developed guidelines to optimise the MRC framework’s development phase, articulate the importance of ‘theory’ and state that researchers should develop or report the logic model or theory behind the intervention early on [4, 10]. We used the Theory of Change approach, as was developed first by Weiss et al. and is outlined more recently by De Silva and the Aspen Institute [3, 10]. The value of this approach in our study lies first of all largely in the extent to which we as intervention developers were forced to focus carefully on constructing a clear understanding of what we wanted to achieve with every intervention component and why certain intervention components are actually needed to impact the desired outcomes [4]. Such rationales underlying an intervention are often not made explicit in the literature [11]. In addition, as we engaged in theory development, the feasibility of the intervention was already partially addressed during this phase of the project [12]. The map was constructed based on consensus amongst professional stakeholders, and a context analysis provided insight into the specific situation of Flanders, ensuring the map’s contextual fit. This process led to the identification of key intervention components that already had a high chance of being perceived as acceptable and feasible to implement, without major revisions in the test phase, reported in Chapter 3. Including a wide variety of stakeholders in the workshops allowed us to co-develop the theory of change with potential end-users [13]. Because implementers, researchers and policy-makers each have their own implicit understanding of how and why ACP works, and what outcome it will or should achieve, stakeholders contributed different types of information to the map, ensuring potentially more buy-in from all those that ought to be involved during the actual implementation [14]. It has been argued that a stakeholder approach enhances feasibility, and even the effectiveness of the intervention [3, 4, 15].

In the future, this map might help to enhance improvement of the programme after evaluation, to enhance replication in same or other settings, and to pursue implementation in daily practice [3]. The provision an ‘implementation plan’ within a specific context, such as our map, has been considered extremely valuable for practice [15].

There are however some key limitations to consider. The main contributors of the map were professionals and the core research team. We did not include nursing home residents and their family, because it would have increased the complexity of the workshops, which were also rather new to us. In addition, we felt the elements to be discussed as part of the theory of change might have included too much jargon. Recent literature however has shown that it is feasible to include older people, including those with dementia and their family caregivers, when co-designing an intervention regarding end-of-life care [16–19]. Because the workshops were rather time intensive and included a lot more human and financial resources than we anticipated, we limited the number to two. With regard to the content of the map, it focuses mainly on the resident, family, professional and organisational level, and discarded any macro level preconditions, such as regional collaborations with hospitals, the existing regional quality indicators, etc. Even though it has been shown that a variety of social, political and health system changes are essential in understanding ACP in the wider context [20]. In addition, the theory of change map can be considered rather linear [21, 22], and might be an oversimplification of a complex reality. It would have been hardly feasible to provide a detailed description of every element involved in the entire ACP process in one map and our current knowledge is arguably still too limited to grasp every influencing factor. In addition, even though linear models may not reflect complexity as accurately, they still provide a useful model for designing the intervention [23]. In addition, the Theory of Change approach is perceived to be superior to logic models or logical frameworks, which tend to be more rigid and are even more linear in outlining the inputs, processes, outputs and outcomes of an intervention [3, 24]. Finally, the map is not directly generalizable to other countries, because some elements are specific to the context of Flanders (e.g. the use of the term ‘reference persons’, or the fact that GPs are not part of the regular care team in the nursing home). However, a recent project in mental health has shown that a theory of change map can serve as a heuristic device to adapt programmes for other contexts, e.g. their research found that preconditions in the map are generally the same in different regions, but the way they are achieved can differ [25, 26].

*Thirdly, in Chapter 3, we further developed the **ACP+ programme**, and modelled activities and materials using existing tools and multidisciplinary expert meetings. We examined the **feasibility and acceptability** of the implementation of the ACP+ programme, as perceived by professionals.*

This work has some important strengths. Throughout Chapters 2 and 3, we continuously prioritised, reduced, selected and refined components of the ACP+ programme. Such an iterative development approach has been considered important to optimise intervention design and, as such, reduce research waste [1, 4, 27, 28]. Non-profit, patient and governmental organisations increasingly respond to the growing attention and need for ACP with initiatives such as the development of ACP guidelines and tools [29–32], which were argued by stakeholders to already play an important role in existing daily nursing home care. The fact that we mainly used these existing tools to form the basis of our intervention materials, can both be a strength (as we used/adapted what was already available and therefore did not contribute to research waste or overabundance) and a limitation (because existing tools are practice- rather than evidence-based). Finally, the use of the TIDieR (Template for Intervention Description and Replication) checklist enabled us to systematically describe our intervention in Chapter 3 [33]. This has been identified by the EQUATOR (Enhancing QUALity and Transparency Of Health Research) network to represent best practice. Insufficient intervention descriptions make it hard for practitioners and other researchers to build on findings and translate them into practice, to compare interventions, to adapt and replicate them elsewhere, and to increase their scale to entire regions [11, 34, 35].

A first limitation is that we lacked a predefined cut-off criterion to decide at what point our intervention would be feasible/acceptable. We primarily listed all remarks made by the participants in the test phase and discussed this within the multidisciplinary research group, in which we then decided which of the intervention activities or materials to adapt. This is a common critique in feasibility studies and it has been recommended to move towards pre-specified objective progression criteria in these stages of research [36]. It can be said that without such criteria and using only professional's views and subsequent multidisciplinary consensus dialogue as definite evidence, does not adhere to the highest standard of rigour for feasibility studies. Participants' remarks however did not contradict each other's. Second, we did not formally test the waters in a pilot study (e.g. a smaller version of the main trial, often with smaller samples or with a shorter follow-up phase [37]). We carried out a small-scale feasibility study, testing the intervention using the perceptions of several professionals, rather than testing the envisaged trial procedures and methods. We chose to only test

the elements around which there was particular uncertainty (i.e. the selected intervention), because the recruitment phase and the evaluation methods at hand were quite similar to another Belgian cross-sectional survey study and subsequent trial carried out in nursing homes (cf. PACE study 1 and 2) [38, 39]. While the exact distinction between a feasibility and pilot study has been the subject of debate [40], some argue that a pilot study prior to a powered trial is necessary to estimate sample size and calculate statistical power, while others argue that powering a trial on pilot data might be unreliable in itself, partly because the sample size is too small, and the time span of implementation of the intervention is too short [40–43]. In addition, recruitment and retention rates might not be transferrable from a small pilot to a large trial [42]. Because of the in-depth development phase of our intervention and the fact that we only included staff, we decided to go along with a powered trial. Taking into account that piloting every subsequent envisaged step of the trial, might lead to an evaluation period being spread out over multiple years, chances are high the context has already changed once you are ready for the roll-out of a full-scale trial [44].

2. A CLUSTER RANDOMISED CONTROLLED TRIAL TO EVALUATE THE EFFECTIVENESS OF ACP IN NURSING HOMES

In Chapter 4, we report the study protocol for a cluster randomised controlled trial to study the effects of the ACP+ programme. The primary methodological considerations are related to the study's **research design**. RCTs are considered the most internally valid means of establishing how much change occurred after an intervention (relative to its comparator) and, as such, draw conclusions on causal relationships [45, 46]. RCTs are recommended to examine the effectiveness of the intervention [1]. Recent literature discriminates however between a) 'effectiveness' or 'pragmatic' trials (trials that usually take place in the 'real-world' context, with all its dynamic features, and differentiate between the intervention group and a group with usual or standard care as the comparison group), b) 'efficacy' trial designs (in which a treatment is compared to a placebo and in which elements can, to a large extent, be controlled), or c) 'hybrid' trials, which combine both a and b. A hybrid design is intended to assess both effectiveness and implementation, usually via mixed-methods, combining elements of effectiveness with observations and gathering information about implementation [47]. Our trial would most probably be considered hybrid [48]. Such a hybrid design has been carried out before in palliative care by Husebo et al. [49]. However, 'pure' hybrid designs are considered to refine and improve the intervention and implementation process while under study [50]. This is done neither in our study or that of Husebo et al. (2015).

With regard to the **allocation to intervention and control group**, we randomised participants at cluster level – the nursing home [51, 52]. In a nursing home, physical proximity of staff and administrative arrangements make it difficult to deliver an intervention to individual people in the same nursing home; the use of clustered designs is therefore considered appropriate [48, 51]. As a result, contamination between the intervention and control group is limited. Random allocation also ensures all people who are involved in the recruitment process cannot predict their group assignment and it prevents nursing homes with specific characteristics from being assigned to one or the other group, possibly resulting in misbalance or biased results [46]. The paired randomisation enabled us to perform an a-priori stratification to reduce the risk of misbalanced groups due to large differences in size or type of facility [46]. However, using paired randomisation cannot rule out the possibility of potential selection bias of nursing homes enrolled in our study. However, while participation was voluntary, we did apply strict inclusion criteria and we ensured there was sufficient diversity among included homes (e.g. one from each province in Flanders, number of beds >100, and at least two nursing homes of each type, i.e. non-profit, private, public) via purposive sampling.

Another methodological consideration relates to the **study's duration**. The intervention's implementation period is 8 months, and T1 measurement is at month 9. Although we recommend in Chapter 1 that ACP needs to entail a whole-setting approach, it can be argued that 8 months is not enough time. The length of time required to implement whole-setting changes of attitudes or cultures is recognised to be an often-underestimated issue in research [53]. However, we were confronted with a trade-off between attrition, length of funding, and time for the intervention to show effect.

In our **sample size** and power calculation, we accounted for 10% of staff to be dropping out of the study. However, annual turnover rates of nurses are reported to range from 10% in Canada and New Zealand, to up to 62% in the US [54–56]. Turnover rates amongst care assistants are shown to be even higher [57]. Considering the low staffing levels of nurses in Belgium, our estimation might be too low. In addition, considering the difficulty of recruiting and retaining staff in a study, a target sample size of 484 can be considered large for a nursing home study. However, based on our baseline response rates (Chapter 5 and 6), reaching the minimum sample size might be feasible. Finally, the intention-to-treat (ITT) analysis that we aim to apply during analysis, might control for attrition bias.

In the ITT, all participants that have been randomised will be included in the final analysis, regardless of whether they completed the study or dropped out [58, 59].

The **outcomes of the trial** are limited to staff level outcomes, because those are identified as important preconditions in the theory of change map presented in Chapter 2, and because our intervention mainly entails educational components targeting staff. As staff outcomes need to change first, before embarking on ACP outcomes for patient and family, this can be considered our first priority. Not evaluating any patient or family outcomes is an important limitation of the study. Within the process evaluation (discussed below), we did however plan to conduct interviews with patients and family. Finally, we did not assess costs or cost-effectiveness [60]. Using the trainer's diaries however, we will be able to assess the amount of time they spent in supporting the nursing homes. Additional Bonferroni corrections in final analysis might be necessary to correct for multiple primary outcomes and adjust for multiplicity.

The survey instrument that served as the **outcome measurement instrument to evaluate primary and secondary outcomes** of the trial, and which is used to present baseline data in Chapters 5 and 6, is not validated and was only subject to limited testing. Looking at the MORECare consensus workshop regarding properties of the best primary outcome measures in evaluations of end-of-life care, our study does not score highly [61]. In its development, we used items from existing questionnaires, translated via forward-backward translation, and adjusted, removed and added items to fit our specific multidisciplinary group setting. The instrument was tested in cognitive interviews and via self-administration in a representative sample of 107 professionals. Cronbach's α 's of knowledge, self-efficacy and practices subscales (ranging from .724 for knowledge to .970 for self-efficacy) are generally considered sufficient. However, a Cronbach's alpha reaching the somewhat arbitrary value of .70 cannot be considered as a sole measure of reliability or internal consistency of an instrument, and it is recommended to do more than simply present this statistic without further explanation. Complementary statistical measures (such as factor analyses) might be additionally applied, where appropriate [62, 63], and additional testing - to evaluate reliability (internal consistency, test-retest reliability, interrater reliability) and validity (e.g. construct, content and face) - is advisable [64]. This might have limited the issues we faced while using the scale and the data it yielded. For example, as is shown in Chapter 5, the self-efficacy subscale has a category 'not applicable', for answers. This would have been better phrased 'not my responsibility', as a large share of care assistants indicated 'not applicable', without us being able to conclude if they meant it was

not their responsibility. This made it difficult to interpret the data. Also, excess of zeros in the total ACP practices score might suggest the survey was not developed appropriately. However, in healthcare research, the outcome of interest is often relatively infrequent behaviours, especially when specific events are counted [65]. In Chapter 6, we used a statistical strategy to account for the overabundance of zeros in our data, which is perceived a rigorous approach in biomedical and healthcare applications [65–67].

It might be considered to be a limitation of this work that the **final results of the trial** are not yet included in this PhD thesis. However, the extensive development phase of both the intervention and the study design of the trial is innovative in its own and has the potential to provide insights to other researchers into how theory can be included within the development of an intervention and how this enables researchers to form a clear rationale for every choice made along the way.

3. AN EMBEDDED PROCESS EVALUATION TO STUDY UNDERLYING PROCESSES OF CHANGE

By combining outcome and process evaluation, we adhere to recommendations made by Moore et al. (2012) that ‘effect sizes’ alone are insufficient, and that it is necessary to also understand implementation (how is delivery achieved, and what/how much is actually delivered?), causal mechanisms (how does the delivered intervention produce change?) and contextual factors (how does context affect implementation and outcomes?). In ACP research, this is an often-missed opportunity by researchers, who might have carried out a well-designed cluster RCT but lacked to carry out a process evaluation during the implementation of the intervention itself [68–70]. ACP implementation can be a particular challenge in a RCT, especially in nursing homes, as protocol compliance relies on usual healthcare providers rather than a research team. Limited intervention uptake by these providers - for example due to constraints of intensive, competing demands of routine care or other factors - can translate into ‘implementation error’, rather than genuine ineffectiveness of ACP itself [71]. This is important to investigate given the high need of ACP for the nursing home population and the risk of interpreting negative or insignificant results of ACP trials as ACP being not helpful or positive of the particular population. We applied a mixed-methods design, which is consistent with recent recommendations made by various authors in the field [23, 72–74].

In planning a process evaluation, it is considered essential to start by carefully considering what the underlying assumptions are about how your intervention is supposed to change desired outcomes [23]. We comply to this recommendation by our use of a specific theory of change map. By explicitly stating the causal assumptions underlying the implementation of ACP+, we were able to prioritise which aspects to evaluate in our process evaluation [3, 23]. As such, we specified prospectively a set of process research questions [75]. The Theory of Change approach guaranteed our process evaluation appropriately matched the proposed implementation of our intervention because at least one indicator was linked to each intervention and precondition outlined in the map in Chapter 2. These indicators will enable us to evaluate whether each of the preconditions perceived necessary to reach long-term goals had been reached [3, 76]. However, we failed to determine what is defined 'success' in each indicator. For example, we did not determine up front how many staff had to be trained minimally to define success of that specific precondition. We will only describe how many staff is trained in comparison to how many staff is eligible to be trained. An important limitation is that, by using our theoretical model for the design of the process evaluation, there is a danger of becoming receptive to facts that confirm our theory and to easily ignore facts that disprove our theory, or those that we cannot explain. In addition, we also gather only limited information on the resident and family perspective and unintended consequences. Finally, although our envisaged monitoring will give a first impression/description about the implementation of our programme, it does not give any solid explanations for its success or failure.

*Discussion of findings in the light of current challenges
and state of affairs*

In this dissertation, the aim was to evaluate how to implement advance care planning (ACP) successfully in nursing homes in Flanders, by the development and evaluation of an intervention model to support nursing home staff herein. In the following section, we discuss what is hypothesised to contribute to successful implementation of ACP in nursing homes and what might be the underlying causal pathway, based on existing literature and knowledge and insights gained from professional stakeholders. In addition, the importance of sufficiently knowledgeable and skilled nursing home staff is highlighted and discussed.

1. SUCCESSFUL ADVANCE CARE PLANNING IN NURSING HOMES

Need for a whole-setting approach

That the implementation and organisation of ACP is hypothesised to be successful when it entails a setting-wide or whole-setting approach, is considered a key finding of this dissertation. Findings presented in both Chapter 1, 2 and 3, support the idea that ACP interventions must consist of a broad approach, targeting multiple levels within the nursing home facility.

What's in a name? While we conclude our systematic review in Chapter 1 by arguing that successful ACP requires a whole-*systems* approach, we changed this in Chapter 2 to a whole-*setting* approach, because we wanted the key focus to be on the nursing home. Using the term '*system*' focuses more on the wider public healthcare system in which we interact but which we are not targeting directly with our intervention [77]. Concepts such as 'whole-system' and 'whole-setting' have been used interchangeably throughout healthcare research, particularly in health promotion and wider public health [77–80]. Also in end-of-life care, there has been a growing emphasis on whole-systems oriented end-of-life care in the form of e.g. compassionate communities, in which improving health is actioned throughout whole communities and across a diverse range of sectors, including workplaces, recreational sites and events, schools and universities, nursing homes and hospitals,

churches, local government, and voluntary organizations [81]. The definition of a ‘whole-setting approach’, based on the findings in this dissertation, is: an approach to ACP that 1) includes interventions targeting multiple stakeholders concurrently (as is shown in Chapter 2, change should be actioned at both the level of the resident and the family, as well as by professionals and the organisation); and 2) that focuses on different components in the organisation, such as policy, documentation, organisation of conversations, and delineation of roles and responsibilities (also shown in Chapters 2 and 3). The term ‘whole-setting approach’ is believed to contradict a process that tends to be solely top-down and that is primarily focused on a single level, e.g. on individual-level behavioural change. It is rather an approach that is endorsed or explicitly supported by the management, enshrined by a supporting policy and that permeates the whole nursing home [80]. ‘Whole-setting’ therefore refers to the organisational context in implementation research⁷, mainly covering organisation-related factors such as culture, available resources, integration with existing processes, relationships, skill mix and staff involvement, and is not the same but can be influenced by the macro level in which it operates; often also referred to as the ‘external context’ (involving policies, incentivisation structures, dominant paradigms, infrastructure and advances in technology) [82]. In ACP, other terms have also been used to describe the involvement of the whole organisation. Saevereid et al., for example, speak of a ‘whole-ward’ approach in their ACP trial study, because their intervention was “focusing on wards specifically, targeting staff and transcending the individual level the resident” [83]. The necessity of involving the whole setting was also shown in a Flemish intervention study by Ampe et al., which applied an educational ACP intervention to staff from nursing homes and found no increase in the frequency of discussions. According to staff, the involvement of the whole organisation might have acted as a facilitator for organising ACP [84]. Such ‘whole organisation involvement’ entailed -amongst other things- involving all disciplines/functions, support of direct supervisors, peers, and the nursing home management. This is consistent with what we found in our systematic review and theory of change.

But how does this focus on the wider organisational setting relates to a focus on the micro level, and on individual behaviour? While we do support the idea that ACP incorporates behavioural change at micro level [85–88], we highlight that ACP should additionally incorporate the wider (organisational) context in which the resident’s or family’s behavioural change takes place. As reviews

⁷ Implementation research, the study of methods to promote the integration of research into routine practice (Eccles and Mittman, 2006).

by Lau et al. also show, changes at the organisational level of a nursing home (policy, organisational (in)stability, exigencies of routines or everyday work) all affect implementation [82, 89]. Incorporating health behaviour approaches into ACP interventions, such as newly developed interventions like STAMP (Sharing and Talking about My Preferences study) [90], are crucial. In the STAMP interventions, ACP is considered a set of inter-related health behaviours. It builds on prior research that has demonstrated that participants have variable readiness to engage in ACP [88] and that this readiness can be represented and explained by constructs from the Transtheoretical Model, including different stages and processes of change [86]. The focus on behaviour change within interventions is indubitably an attribution to interventions that mainly focus on changing the context with which they interfere, but we doubt both can exist without one another. This has been highlighted in previous literature; ACP - especially in the complex nursing home context - should include both organisational and behavioural changes amongst all involved, including changing organisational systems and structures, individual knowledge, skills and attitudes [91–93].

Is such whole-setting approach more effective? A whole-setting approach has been consistently raised as essential in the recent ACP literature [84, 94, 95]. However, there is no evidence that directly supports the use of a whole-setting intervention over an intervention that is not, because they never have been compared head-to-head in a comparison trial that measures the same outcomes in both groups. Nevertheless, if we consider the guidance from Moore et al., a ‘complex’ intervention almost always adopts a whole-setting approach [42], and therefore there is some evidence available that might be supportive of such complex interventions compared to interventions that only comprise one component of ACP. More specifically, two systematic reviews regarding the effectiveness of ACP conclude that complex interventions are potentially more effective than those that only focus on completion of ADs [96, 97]. In addition, Overbeek et al. considered the lack of a ‘system-wide’ approach in the entire nursing home to be one possible explanation for the lack of effect that was found in their study, as they only used core elements of the Respecting Choices ACP program to implement in The Netherlands [70]. Interventions are considered to be more effective when they involve patients, family caregivers, and healthcare providers simultaneously [98], and multicomponent ACP interventions are found to lead to improved concordance of surrogate and patient wishes, improved concordance of wishes and received care (in nursing homes specifically), higher incidence for preferred place of death (in nursing homes specifically), increased ACP-related documentation, increased occurrence of discussions, decreased use of unwanted life-sustaining treatments and lower use of resources and hospitalization rates [99].

The importance of nursing home management support or buy-in

Management ‘buy-in’ in the form of providing staff the opportunity to engage in training; making sure there’s a written policy available and making sure those who are responsible to carry out ACP have the mandate to do so, are key findings of Chapter 1, 2 and 3. Indeed, according to our theoretical model, presented in Chapter 2, this buy-in is required for nursing home staff to actually engage in ACP. This is consistent with other findings [84, 100–102]. In order to successfully implement a demanding intervention, the nursing home needs to put its support behind the intervention.

Not surprisingly, good and consistent management was identified as an important facilitator in a review by Flo et al., who studied implementation strategies for ACP in nursing homes [103]. Also, in a recent interview study by Dixon and Knapp with 12 international healthcare organisations conducting system-wide ACP, it was found that, within these organisations, senior managers were actively involved in helping to sustain ACP by giving it organisational priority and supporting those leading ACP [104]. After implementing a multicomponent intervention in long-term care settings in the US, Hickman et al. also suggested that management buy-in was essential [105]. Prior to launching their ACP initiative, they spent considerable time planning for implementation, reaching out to corporate and facility leadership to identify deficits in current protocols and processes that could undermine ACP efforts. In the process evaluation from Aasmul et al., which was carried out after they had implemented the COSMOS ACP intervention, nursing home staff also suggested that the involvement of managers and unit leaders was crucial, and if managers were motivated to send their employees to intervention training, this could facilitate effective implementation [100]. In both studies, they recruited nursing homes by motivating the management and ensuring they allocated resources to adequately implement the programme [100, 105]. Similarly, we included explicit motivation of management as one of our inclusion criteria to participate in the trial. However, it can be argued that management buy-in and support could be considered a key component of the intervention itself. While other researchers did focus on management support in the beginning of their studies, it was not explicitly incorporated in their ACP interventions [84, 105, 106], making it unclear for readers what might have been essential for the success of it.

After testing the feasibility and acceptability of the ACP+ programme in Chapter 3, ‘management buy-in meetings’ were integrated as a separate intervention activity in ACP+. During management buy-in meetings, the ACP Trainer and the management, representatives of the board of directors, head

nurses and the Coordinating Advisory Physician ideally come together in one or a series of meetings in which the ACP Trainer explains the project and asks management for their (active) participation. This participation will include the integration of ACP into the general policy of the nursing home and ensuring the ACP Reference Persons are appointed and able to spend time on their tasks to implement and organise ACP within routine care. However, we only assess the management's motivation via a qualitative interview during the process evaluation (Chapter 4). A recent study from Goossens et al. (2019) also assessed the support of management via a self-constructed S-ACP questionnaire.

Need for tailoring? Why, how and to what extent?

In Chapter 3, we found a sufficient amount of tailoring of intervention components might allow for greater acceptability and feasibility of the ACP+ programme in nursing homes. The fact that ACP conversations should be tailored to the individual's needs and readiness is nothing new [86, 107]. Drawing upon the growing field of knowledge translation, we know that interventions need to be tailored according to both individual needs and the attributes of the environment in which they are implemented [108]. The type of tailoring in our study can be considered 'tailoring to the specific needs of a facility setting' [109]. Tailoring implementation to a local context was specifically addressed in other studies outside the field of palliative care and most often included strategies such as a pre-implementation phase to plan for adaptations needed for the local setting or site-specific adjustments to implementation during implementation [109]. A Cochrane Review in this area found that strategies tailored to address identified barriers to change were more likely to improve professional practice [110, 111]. Tailoring of interventions to specific needs has been a widely encouraged strategy in implementation research to encourage the contextual fit of the intervention (e.g. in-person trainings may be difficult to scale-up in community settings because they require substantial expenditures of time and money; thus, the training may need to be delivered as a web-based module) [111]. Adjusting some of the intervention's components to the local setting has been found to encourage managers to engage in the study from Hickman et al. [105]. In other research areas, even in surgery trials, which are assumed to be applied rigorously, some flexibility is often allowed [112].

We did not use a prescribed method to decide what should be tailored in the intervention, which has been a common critique in implementation research [110, 113, 114]. However recently, progress to

establish some guidance has been made [111]. In the planning of our study, we tried to apply some rigour to our tailoring method. Together with the professional stakeholders in the test phase and the nurses themselves (Chapter 3), we considered which parts of each intervention activity could be amenable to change, resulting in a list of intervention elements that should minimally be kept standardised during implementation in Chapter 4. Elements that could not be tailored included the overall timing of intervention components to make sure the order was standardised across participating nursing homes (e.g. tailoring meetings were encouraged to be organised after ACP Reference Persons were selected and trained, but nursing homes were free to determine when exactly); who should be present in the management meetings; the duration of training sessions; whether they would use the ACP+ leaflets or whether they would use their own (if the latter was the case, the quality of the document would ideally have been reviewed by the trainers, in close collaboration with the Trial Coordinator).

The hypothesised causal pathway to successful change in ACP in nursing homes

The theory of change map in Chapter 2 provides a summary of ACP as a complex intervention and makes explicit through which intervention components ACP is hypothesised to achieve the intended long-term outcomes. Based on consensus derived within the stakeholder panels, the desired outcomes of ACP to change in this map are considered to be: 1) improved correspondence between care/treatments received and current wishes and preferences, and 2) residents and family feeling more involved and confident that end-of-life care will correspond to their wishes. At the time we constructed this map, there was no international consensus about what should be the outcomes that define success of ACP, and outcomes that were measured in trials up to that point, varied considerably (Houben et al., 2014). Recently, a new outcomes framework was constructed by an international Delphi panel, including clinicians, researchers, and policy-makers [93]. In this framework, ‘care consistent with wishes’ was also defined as one of the primary outcomes for successful ACP. This outcome has been measured in several trials and potential positive effects were illustrated [97, 115]. Residents and family feeling involved in their future care is a secondary outcome defined in our theory of change map, which has not been explored in a trial yet and was also not defined explicitly in the Delphi’s outcomes framework. This despite the fact that patient involvement is a primary goal of ACP and considered by dying patients and their family to be a core component of end-of-life decision-making [116, 117]. A review from Song et al. [118] however did investigate effects on ‘affective outcomes’ (outcomes perceived by patients as important) after end-of-life

communication, including, amongst other things, involvement in decision-making. The little evidence that is available, suggests no negative effects [118].

The causal pathway outlined in Chapter 2 is similar to the outcomes framework presented by Sudore et al. in the way that it also emphasises process outcomes, such as ‘being able and willing’ (knowledge, attitudes and self-efficacy) first (cf. preconditions 3-8 in our map), before engaging in ACP conversations or other ACP related “actions” (cf. intervention 5A-D in our map) [93]. Our theory of change is more an implementation programme, programme theory or implementation theory, rather than a ‘grand or off-the-self theory’ [44]. Such as another logic model for ACP in cancer, based on the results of a systematic review [87], our theoretical model differs from those that are commonly used to inform intervention development in ACP (e.g. Representational Approach to Patient Education, Leventhal’s Common Sense Model, Hewson’s Model of Conceptual Change, Transtheoretical model of Behaviour Change, and The Theory of Planned Behaviour [119–122]). While the latter tend to focus primarily, or exclusively, on psychological processes, and hence address the most proximal surface influences on behaviour, we rather aimed to describe how our programme is intended to work, through which steps and pathways. Adopting a well-established ‘off-the-shelf’ social science or behavioural theory is considered by Moore and Evans to be a common response among intervention researchers seeking to satisfy the heightened call for theory-based interventions, while many such ‘formalised’ theories have only demonstrated limited utility in improving intervention effectiveness [44, 123]. Our theory of change map is primarily considered a dynamic tool, rather than an established theory, and will be adapted as new knowledge comes along. The map was already adapted after the test phase in Chapter 3 (*not published*, see Supplementary Materials, page 256) and will be adapted again, after results of the trial and process evaluation are reported.

2. NURSING HOME CARE STAFF AS AN IMPORTANT ASSET FOR ACP IN NURSING HOMES

Importance of staff being able and willing to engage in ACP

That healthcare professionals should be *willing* and *able* to engage in ACP is a precondition that spans throughout our work in Chapter 1, 2 and has been the main focus of the intervention developed in Chapter 3. In line with most recommendations [124, 125], and results of Chapter 1 and consequently

Chapter 2, we found that ACP requires ‘skilled providers’ to navigate the ACP process in the nursing home. In Chapter 1, we found that most preconditions (10 out of 17) were related to the professional level. More specifically, we found that healthcare professionals need to have appropriate knowledge (domain 1, precondition 4), be willing and have an open attitude towards talking about death and dying (domain 2, preconditions 5 and 6), and to be confident and comfortable in engaging in ACP (domain 2, precondition 7). Consistent with these findings, knowledge and self-efficacy in healthcare professionals, amongst other things, are considered important process outcomes of ACP, necessary to be acquired before being able to conduct ACP [93]. A vast number of studies consistently report that staff is often reluctant to take ownership of delivering ACP, mainly because of lack of confidence, knowledge or experience in ACP [84, 125–127]. While both knowledge and self-efficacy are important for staff to be able to carry out ACP in practice, we only found a significant association between nurses’ self-efficacy and them carrying out practices, with higher scores in self-efficacy corresponding to a higher count of ACP practices in nurses ($p < .001$). Higher self-efficacy in nurses is associated with a 32% increase in the total score (total number) of ACP practices they carry out. Analysis of this study however, only included a small sample of nurses ($n=196$).

Nursing home care staff’s involvement in ACP practices, their knowledge and self-efficacy

In Chapter 5, we found that all staff, despite their profession, generally engaged only to a limited extent in different **ACP practices**, with nurses being more likely to carry out ACP conversations. It is remarkable however that a large amount of staff members however did not carry out any of the listed ACP practices. Both having conversations about ACP and documenting ACP outcomes in the resident’s file were ACP practices that were carried out the most, with the highest percentages reported for having carried out ACP documentation. The latter finding might suggest that there is still much emphasis on documenting ACP. Completion of an AD however seemed to have been carried out the least (10% in nurses, 5% in care assistants and 6% in allied staff). This is consistent with another study that also reported very low rates of AD completion in nurses [128]. Looking at ACP conversations, a similar Italian study found that 16% of nursing home staff discussed ACP at least sometimes [129]. In Chapter 5, this was 32% in nurses, 6% in care assistants and 15% in allied staff. Taking into account that Italian law regarding ACP was implemented only a few years ago, it is surprising that, in Flanders, where supporting law has existed from 2002, related nursing home policies are common, and several initiatives have been undertaken, staff engagement is still this low.

Note that these results are based on baseline data, and results might be linked back to the purposive sampling of nursing homes for the trial.

In Chapter 5, the estimated means in **ACP knowledge** were shown to vary from 0.44 in care assistants to 0.52 in allied staff and 0.58 in nurses. Given the total mean score of knowledge ranges from 0 to 1 (with 1 indicating a correct answer on all items), this knowledge score might be considered moderate to low. Much like in Ottoboni et al., staff in our study also showed most uncertainty in AD specifications which very much relate to the legal status of ACP in particular [129]. All staff in our study generally scored lowest on the item “Residents living with dementia can change his/her AD (true)” (25% in nurses and 11.9% in care assistants) and “According to the law of Patient Rights both a positive and negative AD is binding (false)” (15% in nurses and 9.4% in care assistants). In our subscale regarding self-efficacy, staff also reported the lowest self-efficacy scores on the item “Knowing legislation regarding ADs”. These results are consistent with previous surveys, which show that knowledge of legislation is poor [130, 131].

That healthcare professionals should feel **confident and comfortable to engage in ACP** was found to be an important precondition in Chapter 1. Lack of confidence, or not feeling comfortable conducting ACP, previously held professionals back from implementing ACP in their practice, or made them feel as though it was not part of their role [132–134]. We found consistent results in Chapter 6. Nurses’ self-efficacy is strongly associated with the ACP practices they had carried out. This relation between self-efficacy and actual behaviour or action taken has also been stressed by social cognitive theory [135]. However, vice versa, the importance of previous encounters with the desired behaviour to increase self-efficacy is also stressed [136], and “more experienced” healthcare professional have been found to have more self-efficacy in performing end-of-life care communication and documentation [137–139]. Self-efficacy was the only construct in Chapter 5 on which staff, despite their profession, generally reported scores above the midpoint of the score range (0 to 10), with estimated means very close to each other across groups (6.43 in nurses and care assistants and 6.09 in allied staff). This is a little lower than findings reported by Evenblij et al., who reported “high” self-efficacy regarding end-of-life communication in care staff (across mental health, nursing and care homes in Europe) and an overall mean score of 5.47 out of 7 (± 1.25) [138]. In Chapter 5, we also found no significant differences in self-efficacy between staff after adjusting for potential confounders, while we would expect that nurses would have more self-efficacy, as was found in another study comparing staff on self-efficacy regarding end-of-life communication [139],

and as was reflected by the differences in knowledge among staff in our study. In comparison to the other groups, nurses also received significantly more education in ACP (30%; $p < .001$). A possible explanation for not finding a significant difference in self-efficacy between these groups might be that staff's self-efficacy is dependent on other elements rather than their professional role (e.g. previous ACP education). Another explanation might be that almost all participants received some training in palliative care, which is known to be a potential determinant for higher self-efficacy in end-of-life communication [139]. While nurses do seem to be more engaged in ACP practices, one would intuitively expect their self-efficacy to therefore be much higher than that of others. However, following Maslow's four Stages of Learning/Competence Model [140], we might assume that care assistants who did not engage in ACP at all ($n = 225$; 70%) might still report higher self-efficacy scores than expected. Maslow's model describes the four phases a person goes through when a new skill is acquired, moving from unconsciously incompetent to consciously incompetent, then to consciously competent, to finally become unconsciously competent. Given that care assistants who had no experience in ACP might be in the first stage - not knowing what they actually need to know or should be able to do - can explain why they report a higher self-efficacy; they have never engaged in ACP and therefore might not even know how hard it actually is. To my knowledge, this assumption has not yet been investigated.

Importance of staff education in ACP to increase their engagement in ACP practices

The importance of ACP education has been stressed throughout every chapter of this dissertation and, because it comprised a large part of the ACP+ programme that has been tested, we will be able to also provide insight into how it changed staff's knowledge, self-efficacy and ACP practices. In Chapter 6, ACP education was shown to be a potential predictor for having carried out at least one ACP practice. In other words, nurses that were not previously trained (64% of the sample) were significantly ($p < .001$) more likely to have carried out none of the listed ACP practices. These findings therefore suggest the need for more education to enhance staff's engagement in ACP to begin with.

Training is a key part of the ACP+ programme. It is aimed at improving staff knowledge and self-efficacy regarding ACP (primary outcome of trial). Skill development/staff training was consistently reported to be a facilitator in the implementation of ACP [103, 105, 125, 132]. Lack of competence or previous training even led in a particular study to untrained staff not being able understand the significance of the ACP intervention at hand, and therefore unmotivated to read guidelines or engage

in training [106]. Evidence also shows that staff training in ACP is associated with feeling more comfortable with engaging in conversations regarding death, and some training programmes specifically targeting ACP did increase knowledge and attitudes towards shared decision-making, perceived communication skills, confidence, comfort and experiences concerned with discussing end-of-life issues [141, 142]. Chung et al. conclude in their review that of 20 studies (6 RCTs, 14 observational) including educational interventions to train healthcare professionals in end-of-life communication skills, trainings were associated with i.e. greater self-efficacy (8 studies, standardised mean difference 0.57; 95% CI 0.40–0.75; $p < .00$; considered very low quality evidence) and more knowledge (4 studies, 0.76; 95% CI 0.40–1.12; $p < .00$; low quality evidence) [143].

Need for clear roles and responsibilities

In Chapter 1, we also found that a potential barrier preventing staff from engaging in ACP is feeling as though it is not their responsibility. In Chapter 5, we consistently report a large amount of care assistants (and allied staff – in lesser amounts) answering ‘not applicable’ when we asked about their confidence in 12 roles and tasks involved in ACP. These results might suggest that they feel as though ACP is not part of their responsibilities. Lacking insight into roles and responsibilities has been consistently shown in the literature to be a barrier for healthcare professionals, and while the emphasis has largely been on care assistants [144, 145], other literature confirms that it is also a barrier faced by nurses. Nurses sometimes see it as the primarily a role of management, and feel they lack ownership of the process because there is no clarity in who’s role it actually is [125, 146, 147]. This led various authors in the field to conclude that there is a strong need for greater clarity on the roles and responsibilities of different professional groups, both across and within settings [104, 147, 148]. As a result, we distinguished particular roles of staff in both the theory of change map, and the ACP+ programme. Delineating roles ensures there is a certain structure to the ACP process in the nursing home, and such standardisation is consistently called upon in nursing home literature [103, 105, 125, 132]. Aasmul et al., for example, reported after the implementation of their ACP intervention, that the focus on clearly defined roles and responsibility, was deemed helpful by staff in anchoring ACP at the organisational level [106].

Including all staff in a tiered roles system

But who to involve? While we found in Chapter 1 that there is no clear consensus about who should take the leading role in ACP, we consistently found in subsequent Chapters that a **knowledgeable or skilled person, acting as a leader or ‘champion’ is needed**. Such a ‘champion’, who focuses on processes and procedures, is also consistently called upon in nursing home literature [103, 125, 132, 149]. In our ACP+ programme, we have named them ‘ACP Reference Persons’. These persons comply with Aasmul’s notion of “ACP Ambassadors”[106]. While ACP+ Reference Persons in the should ideally be supported by ACP Conversation Facilitators to carry out the ACP conversations with residents, they have to deliver a range of tasks. After a while, ACP Reference Persons are also required to train colleagues, following the train-the-trainer principle. Especially for a larger scale roll-out, such a train-the-trainer model is perceived most beneficial [150]. However, to this extent, other authors highlighted it might be useful to also make sure some staff members have specialist skills, as those may be required to deliver more complex aspects of ACP, such as issues involving the legal aspects of an advance directive, or ACP with people living with dementia [106, 147, 151].

Nurses are most often put forward as the leading agents in ACP [152–155], which is also shown in Chapter 5. In Cornally et al.’s ‘Let Me Decide’ study, they found that in most of the homes that participated in their intervention study, senior nurses took ownership over the role [150]. In this particular study they also perceived that core aspects of ACP should be led by senior nursing staff [150]. ACP Reference Persons in our study however are not necessarily nurses. Because we found in almost all Chapters that **all staff (including volunteers) might play a role in ACP**, we elicited roles including a wide range of staff. We consider this to be a particular strength compared to previous research. Such a multidisciplinary team-approach or involvement has been shown beneficial in other studies [104, 127, 150, 156]. However, it does need to be a team approach that includes a clear role for management and senior nurses, care assistants, GPs, “involving everyone”, including junior staff, care assistants and even household (cleaning/catering) staff [150]. This might be covered by distinct roles: ACP Reference Persons, ACP Conversation Facilitators and ACP Antennas.

Our research and the ACP+ programme highlights the importance of providing support when implementation is carried out [124]. In the ACP+ programme an external **trainer provides extensive support** in the beginning, which decreases after a while, with the intend to facilitate sustainability. However, such a temporary position of an external trainer might also be

disadvantageous for the sustainable adoption of ACP in the facility because support is only limited in time. However, we do argue ACP has more chance to be sustainable if it is carried out by in-house staff. This contradicts other intervention studies that have mainly worked with external conversation facilitators to carry out ACP [95]. Such studies might have responded to operational or resource problems by using a specially prepared facilitator to ensure that ACPs could be delivered and integrated into a particular context without making demands on the clinical practice and workflow of others. While this might simplify carrying out the research, it may not be a practical proposition once an evaluation comes to an end [145]. However, a current new German model is currently being set up to evaluate such external specialist ACP facilitation that is sustainably build into the healthcare system (In der Schmitt et al. – not published). Hence such facilitation model cannot be ruled out or dismissed.

*Recommendations for practice, policy and future
research*

1. RECOMMENDATIONS FOR CLINICAL PRACTICE

Based on the results of this dissertation, nursing homes are recommended to integrate ACP in daily practice, by putting forward a whole-setting approach (taking into account that such approach is currently under evaluation and results are not yet finalised). Making sure there is a written policy available and providing standardised documentation for ACP, which has primarily been the status quo, might not be enough. Nursing home management is encouraged to additionally be supportive of ACP and to make sure staff feels *mandated/responsible/supported* to engage in ACP. This can be done by delineating clear roles, not solely depending on staff's professional title.

Involving the multi-professional team which is already available in nursing homes, and that had access to appropriate training in ACP, is important. Findings indicate it might be feasible to have at least one ACP Reference Person or an ACP 'leader' available per ward (given a ward often includes 30 beds), who champions ACP throughout the facility. Such ACP Reference Person can be made responsible for organising ACP in the nursing home, helping to develop policy, promoting the high priority of ACP by informing staff, residents and family, training staff in performing conversations or signalling triggers⁸, performing ACP conversations and communicating ACP needs and outcomes in multidisciplinary team meetings. Other staff can take on other roles, according to their willingness and ability. To this extent continuous training of (new) staff is important. It might enhance feasibility by first seeking support from an (external) expert for training, until staff is skilled enough and feels comfortable to provide in-house ACP and training themselves. ACP tools (such as leaflets and guidelines [30, 151]) that can support staff in performing ACP conversations and documentation are available in Flanders and can be made easily accessible to staff. Given that knowledge about and self-efficacy in ACP, particular in dementia, could still be improved, and given the rise of prevalence of

⁸ There are several key triggers for (starting or revising) ACP conversations identified in the ACP Conversation Guide and training sessions, as part of the ACP+ programme – which were based on previous literature and professionals' perspectives: admission to the nursing home, admission to a hospital/emergency, initiation of palliative care, deterioration of the condition, upon request, diagnosis of illness (e.g. dementia), while discussing the overall general care plan and/or when changes occur in health status, financial or family situation, etc.

dementia in nursing homes, managers can best be aware the population of nursing homes might change dramatically over the upcoming years and staff might need to be appropriately prepared to engage in ACP with residents living with dementia and additionally support their families. We found that only a minority of staff is trained in ACP and given that education is both a precondition for successful ACP and a potentially important predictor for engagement in the first place, ACP should be implemented in the educational curriculum of all health-related occupations in general.

2. RECOMMENDATIONS FOR POLICYMAKERS

Given the recommendations outlined here are mainly based on stakeholder perspectives and literature, and trial results are not yet finalised, policymakers are warranted to carefully interpret the results and conclusions that are outlined here. This research however does encourage policymakers to advise and support nursing homes to implement ACP via a whole-setting approach. The establishment of quality indicators (that mainly focus on the number of nursing home residents that have an up-to-date end-of-life care plan), and the provision of standardised ADs, is found not to be enough to change desired outcomes in the care of residents and their family. If policy in Belgium and Flanders is to a large extent focused on the documentation of ACP alone, rather than incorporating change and action on other levels of the healthcare system, it might not lead to a larger uptake of ACP. Policymakers are specifically recommended to stimulate nursing home management to provide a clear structure to carry out ACP in their settings and to make sure staff has a clear role in ACP for which they receive a mandate and explicit support. Including such elements into the quality indicators, might be a good way to start.

Structural support (in the form of sufficiently trained staff and volunteers, space, appropriate tools, and time) is found to be necessary to make sure the uptake of ACP in nursing homes can increase and desired outcomes can be achieved. We found all care staff is required to be knowledgeable and confident to deliver ACP in a sensitive, patient-centred and supportive way, and therefore time and resources should be available to them to follow training. Of course, additional time is not easy to provide, given the difficulty in staffing levels in nursing homes. To date, it seems there is an expectation in current policy that care professionals engage in ACP within their existing roles and limited worktime [104, 116]. Problems such as the allocation of staff time however might possibly be minimised by the appointment of one (or several) ACP champion(s) with specialist training within the nursing home. Additional *external* help from umbrella organisations might also be of value (e.g.

assigning regional ACP experts, via the networks of Palliative Care in Flanders, or DeMens.Nu) because there is already a lot of expertise available within these organisations. In addition, we found administrative challenges often inhibit staff to incorporate ACP documents into existing documentation systems (e.g. Care Solutions or GERACC), which might highlight the need for improvement of (electronic) standardised resources (e.g. apps, electronic patient files) that more easily incorporate ACP into existing systems. This cannot be left to the discretion of teams or of individuals. Policymakers can provide help by encouraging market leaders in the provision of documentation systems for nursing homes to also incorporate ACP documentation in their patient filing systems, in an evidence-based manner.

A reimbursement rule for time devoted to ACP for physicians is currently under development by the Belgian federal government. However, this rule is not covering the variety of care professions that are carrying out ACP in nursing homes and a similar GP reimbursement system in the US has been found not to be affecting actual practice [157]. At the other hand, there might be a symbolic role to this reimbursement rule, and such policy initiative could have more impact as its existence becomes more widely known. Given the latter, we might consider exploring ways on how to expand the reimbursement rule from reimbursing physicians to also reimbursing other healthcare professionals for their time invested in ACP, after having evaluated the effects, as was done in the US; cf. one year after implementation. We encourage however to – at least - provide additional support in other non-financial ways (e.g. training) for those that are mainly carrying out ACP in nursing homes.

Finally, research funding bodies are encouraged to not only focus on research with large potential effect sizes but to guard that intervention research is developed carefully with refined techniques to also provide enough knowledge to translate findings into practice. It is additionally recommended to heighten the focus on implementation science that explicitly aims to translate evidence into practice.

3. IMPLICATIONS AND SUGGESTIONS FOR FURTHER RESEARCH

The ACP+ trial results are currently being analysed and will enable us to better understand the effects and underlying process of ACP in nursing homes, according to the design that is outlined in Chapter 4. The theory of change map should be updated according to these results, and as new knowledge comes along. Future researchers are also strongly encouraged to further test the survey instrument

that was developed for the purposes of the ACP+ trial. Supported by a structured approach, we suggest them to apply strategies to demonstrate the reliability and validity of the measure [158].

If the effects of the ACP+ programme on staff outcomes are positive, a subsequent study in which the effects of the ACP+ programme on patient and family outcomes are evaluated, might be possible. One of the desired outcomes of ACP defined in our theory of change map is ‘care consistent with goals’. To date however, there is no standardised, valid or reliable method to measure this outcome [10] and future research might consider to first evaluate how this can be measured best. To this extent, we encourage colleagues in the field to simultaneously invest in finding out what are ‘key’ desired outcomes for ACP, from the perspective of the older population and their family. As this might be an important first step before even being able to actually demonstrate effectiveness of ACP. Given two recent ACP trials found no effect on their primary outcomes (e.g. patient activation, quality of life, end-of-life care received, patient satisfaction with care, or well-being) [68, 70], it can be hypothesised we are currently not evaluating the right outcomes. Future researchers might therefore consider evaluating the effect of ACP on other outcomes, or even focus their research on providing a list of outcomes (and measures) for ACP studies to enable us to better define what successful ACP in nursing homes really means, and how to evaluate short- and longer-term effects. To this respect the Core Outcome Set (COS) approach, suggested by the COMET initiative, is an interesting future research area [98]. A core outcome set is an agreed standardised set of outcomes that should be measured and reported as a minimum, to support outcome choices in clinical trials, routine care and systematic reviews.

Our TOC map and associated methods might encourage other researchers to also engage in a (type of) Theory of Change approach when developing their intervention. In general, we encourage researchers to make explicit their theories and assumptions underlying the interventions that they developed and plan to evaluate; and to make explicit what exactly happened during implementation. To this respect we also especially advocate putting more effort into providing more detailed intervention descriptions. Detailed descriptions of ACP interventions are often lacking, which is a common problem identified in non-pharmacological intervention studies in general [11]. Not making explicit what are the underpinnings of the intervention and what are the details, makes it challenging for others to replicate and compare existing ACP interventions adequately, and endangers efforts for reliable implementation and scaling-up [33, 159]. Using the TIDieR checklist proved us very helpful. Taking into account limitations of journals and trial registration databases that sometimes preclude

inclusion of all intervention information or have space restrictions that prevent publication of details of interventions, this is also a call to journal editors to provide enough space to describe interventions sufficiently or making it possible to add web hyperlinks to other documentation. Eventually, even a registry for interventions, such as those for RCT methods might be helpful. Finally, researchers might also consider using innovative communication methods to explain their intervention models. A variety of graphic, video and audio techniques have already been used by The BMJ and Elsevier.

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NEDERLANDSE SAMENVATTING

DEEL 1 Introductie en onderzoeksdoelen

Mensen worden ouder, ziekte en het overlijden veranderen

De levensverwachting van de bevolking stijgt op internationaal niveau en zal dit blijven doen in de toekomst. Mede door het dalen van het aantal geboortes, de technologische, geneeskundige, maar ook algemene maatschappelijke veranderingen in de samenleving, is de bevolking sterk aan het verouderen. Projecties tonen dat in 2050 het aandeel mensen boven 65 jaar zal stijgen tot 1 op 4, of 26.5% van de totale populatie in België. Oudere leeftijd is een risicofactor voor het ontwikkelen van chronische aandoeningen. Mensen sterven tegenwoordig niet meer plots, zoals dat was in de negentiende eeuw. De fundamentele elementen van sterven – waarom, waar, wanneer en hoe – zijn volledig veranderd. De top 10 doodsoorzaken volgens de Wereldgezondheidsorganisatie (WHO) – internationaal – in 2016 waren: 1) ischemische hartziekte, 2) beroerte, 3) chronische obstructieve longaandoeningen (COPD), 4) infecties van de lage luchtwegen, 5) Alzheimer en andere dementie types, 6) luchtpijp-, bronchus- en longkanker, 7) diabetes, 8) verkeersongevallen, 9) diarreeziekten en 10) tuberculose. Niet-overdraagbare ziekten namen de afgelopen jaren sterk toe. Noteer hier dat er heel wat verschillen zijn tussen lage, middel en hoge inkomenslanden. Niet-overdraagbare ziekten veroorzaakten 71% van alle overlijdens globaal, van 37% in lage-inkomenslanden tot 88% in hoge-inkomenslanden. In hoge-inkomenslanden staan slechts vier overdraagbare ziekten in de lijst van de top 10 doodsoorzaken, terwijl in lage inkomenslanden het merendeel van de doodsoorzaken nog steeds overdraagbare ziekten zijn. Sinds 2016 staat ook Alzheimer hoog op deze lijst. Er wordt voorspeld dat deze snel zal stijgen naar de top, zeker wat ouderen betreft.

Hoewel we steeds ouder worden is er slechts weinig evidentie waaruit blijkt dat de toegevoegde jaren ook in goede gezondheid kunnen doorgebracht worden. En, hoewel ernstige invaliditeit licht aan het dalen is naarmate mensen ouder worden, werd er de laatste 30 jaar nog steeds geen substantiële verandering aangetoond. Ouder worden gaat gepaard met een vermindering van functies. Volgens een recent rapport van de WHO zijn de meest voorkomende oorzaken bij mensen ouder dan 60 jaar, voor wat ze ‘jaren van invaliditeit’ noemen: sensorische stoornissen (bijv. gehoor of zicht), rug- en

neklachten, chronisch obstructieve respiratoire ziekte, depressieve symptomen, valincidenten, diabetes, dementie en osteoartritis. Ouder worden is een traject dat zich onderscheidt van dat van kanker of andere chronische aandoeningen. Het wordt gekenmerkt door de veelzijdige dynamiek tussen onderliggende fysiologische veranderingen, chronische ziekten en multimorbiditeit. Er wordt daarom in de literatuur vaak verwezen naar ‘een ouderdomstraject’ of ‘a trajectory of old age’. In alle trajecten van chronische aandoeningen (bijv. kanker, COPD en dementie) – en absoluut in het langdurig traject van ouder worden - ervaren mensen een reeks van complexe noden en symptomen die vaak indicatief zijn voor het opstarten van palliatieve zorg. Palliatieve zorg is daarbij niet gelimiteerd tot enkel terminale zorg. Het is veel meer een benadering die de kwaliteit van het leven verbetert van zowel patiënten alsook hun naasten 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. Nadenken en praten over toekomstige zorg, het overlijden en de dood, is hierbij een belangrijk onderdeel.

Ondanks het grote aandeel mensen dat thuis zou willen sterven, overlijden ouderen vaak in een ziekenhuis of woonzorgcentrum (WZC). Een studie van 2013 toont aan dat over heel de wereld tweederde in een zorginstelling sterft, een proportie die rechtevenredig stijgt met leeftijd; vier op vijf mensen ouder dan 65 jaar sterft in een ziekenhuis of woonzorgcentrum. Daarnaast toont recent onderzoek dat het aandeel dat sterft in een ziekenhuis de laatste jaren ook daalt in het voordeel van woonzorgcentra. In 2017, stierf 20% van alle Vlaamse mannen in een woonzorgcentrum, 39% van de vrouwen. Mensen van 80 jaar en ouder, sterven het vaakst in woonzorgcentra in België.

Er is consistent bewijs dat er een grote variatie is in levenseindezorg tussen verschillende woonzorgcentra in Europese landen. Gelijklopende domeinen voor verbetering die overheen studies worden gerapporteerd zijn 1) het belang van ‘voorbereiding’ (woonzorgcentra bewoners geven bijvoorbeeld aan dat ze graag de kans willen om hun begrafenis te regelen, of hun levenseindewensen kenbaar te maken) en 2) ‘closure’ of ‘afronding’. Onderzoek bij ouderen en mensen met een chronische aandoening, naar wat ze belangrijk vinden en waarover ze het (nog) graag willen hebben, toont het volgende: de meerderheid vindt het belangrijk “to complete things and prepare for life’s end – review life, resolve conflicts and say goodbye”; “not to be kept alive on a life support when it would be inappropriate”; en, om alle informatie te krijgen over hun ziekte, gecommuniceerd op een eerlijke manier.

Advance care planning (ACP) in woonzorgcentra

Waar in het Engels gesproken wordt over advance care planning (ACP), worden in Vlaanderen de termen ‘vroegtijdige zorgplanning’ en ‘voorafgaande zorgplanning’ (VZP) als synoniemen gebruikt. In deze samenvatting spreken we van de term advance care planning en zal verder de afkorting ACP gebruikt worden. ACP is een **continu en dynamisch proces waarin reflectie en dialoog tussen de resident, zijn 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**. Dit kan de besluitvorming bevorderen op een later ogenblik indien er belangrijke beslissingen over zorg of behandeling moeten genomen worden, of indien het individu (of patiënt/resident/bewoner) niet meer in staat is zijn wil te uiten. Het is een continu proces van communicatie waarbij het individu aangeeft hoe hij zijn toekomstige zorg ziet, alsook welke zorg hij aan het einde van zijn leven wenst te ontvangen. Het doel van ACP is om hoogstaande kwalitatieve zorg te bieden die voor zover als mogelijk in overeenstemming is met de wensen en voorkeuren van de patiënt. De belangrijkste juridische omkadering van ACP in België zijn: de wet betreffende de rechten van de patiënt (22 augustus 2002), de wet betreffende het recht op palliatieve zorg (14 juli 2002) en de euthanasiewetgeving (28 mei 2002).

ACP bestaat uit herhaaldelijke gesprekken met de bewoner of – indien dit niet mogelijk is – met zijn naasten (vertegenwoordiger, familie of vrienden). Gedurende deze gesprekken wordt er een kader gecreëerd waarin iedere bewoner de kans krijgt om over verschillende onderwerpen na te denken en te reflecteren. Tijdens dergelijke gesprekken kunnen o.a. de volgende onderwerpen besproken worden: de voorkeuren van de resident en/of zijn familie m.b.t. toekomstige zorg, zijn of haar wensen, kwaliteit van leven, waarden, gevoelens en overtuigingen over persoonlijke doelstellingen en de verwachtingen over het verloop van de ziekte, prognose, de mogelijke behandelingen met hun uitkomsten, en de verschillende soorten beslissingen die ze zullen moeten maken over hun toekomstige zorg en behandeling.

Het is belangrijk dat de resultaten van ACP-gesprekken op een eenvoudige, eenduidige en schematische manier in het dossier samengevat worden, en - idealiter - gecommuniceerd naar (huis)arts en ander personeel via een multidisciplinair overleg. Dit kan o.a. via de wilsverklaring, die de resident al dan niet heeft opgesteld, en of aan de hand van algemene zorgdoelen die als referentiekader of leidraad kunnen dienen voor de betrokken zorgverstrekkers. Schriftelijke wilsverklaringen zijn alle documenten waarmee iemand zijn wil te kennen geeft omtrent zijn toekomstige (gezondheids)zorg voor de situatie waarin hij/zijn zijn/haar wil niet meer kan

uitdrukken. Deze wilsverklaringen kunnen negatief (behandeling weigeren - zoals chemotherapie, reanimatie, beademing, antibiotica, CT-scan, MRI, biopsie) dan wel positief (bijv. voorafgaande wilsverklaring euthanasie – enkel van toepassing bij onomkeerbare coma) geformuleerd zijn. De negatieve wilsverklaring is wettelijk bindend als alle voorwaarden zijn vervuld en blijft ‘onbeperkt/altijd’ van kracht totdat deze herroepen wordt. In een positieve wilsverklaring kan een patiënt aangeven welk zorgdoel hij nastreeft. Deze is niet wettelijk afdwingbaar.

Een belangrijk onderdeel van ACP en de schriftelijke wilsverklaring is het aanduiden van een wettelijke vertegenwoordiger. Deze zal de rechten van de patiënt uitoefenen wanneer deze niet meer in staat is om zelf zijn rechten als patiënt uit te oefenen⁹. Indien er geen wettelijke vertegenwoordiger werd aangeduid, geldt de wettelijke cascade, volgens de Wet op Patiëntenrechten (samenwonende echtgenoot of de wettelijk of feitelijk samenwonende - meerderjarig kind – ouder - meerderjarige broer of zus van de patiënt - de betrokken beroepsbeoefenaar, in voorkomend geval in multidisciplinair overleg).

Advance care planning als een complexe interventie in de complexe setting van het woonzorgcentrum

ACP is een complexe interventie. Het vereist verandering of actie op verschillende niveaus. Het individu en zijn familie doorlopen heel wat stadia van gedragsverandering vooraleer ze 'klaar' zijn om beslissingen te nemen; zorgverleners moet voldoende kennis en vaardigheden hebben vooraleer ze zich comfortabel genoeg voelen om een ACP-gesprek te initiëren bij een patiënt of bewoner en zijn familie; en de organisatie moet de juiste basis bieden om dit allemaal mogelijk te maken (de juiste cultuur, structuur, ondersteunend beleid, etc.). Ondanks de toenemende mate aan wetenschappelijk bewijs van de effectiviteit van ACP programma's, blijft het voor zorgverleners vaak onduidelijk hoe ACP nu precies optimaal georganiseerd kan worden in de praktijk. Het praktisch implementeren van een ACP programma in een WZC is van veel meer afhankelijk dan enkel het trainen van het zorgpersoneel en het voorzien van een gestandaardiseerd document. Daarnaast zorgt een drukke en onderbezette setting, zoals het woonzorgcentrum, voor extra uitdaging. Een effectieve en duurzame benadering voor organisatie van ACP in woonzorgcentra vereist niet alleen een fundamentele verandering in de attitude van zorgpersoneel én bewoners/familie - om het levenseinde te bespreken en erop te anticiperen, maar ook de betrokkenheid van management, en zelfs beleidsmakers en politici om woonzorgcentra hierin te ondersteunen.

⁹ In dit document verwijst vertegenwoordiger steeds naar een wettelijke vertegenwoordiger, een persoon die op grond van wettelijke bepalingen is aangewezen om op te treden in plaats van patiënt.

Prevalentie van advance care planning in woonzorgcentra in Vlaanderen, de effecten ervan en de barrières die implementatie verhinderen

De laatste jaren is er maatschappelijk steeds meer aandacht voor ACP, en wordt het proces van ACP steeds vaker beschouwd als een essentieel element van kwaliteitsvolle (levenseinde)zorg, ook binnen het woonzorgcentrum. Onderzoek toont aan dat het merendeel van de ouderen graag betrokken wil worden bij beslissingen over later. De meerderheid van Vlaamse WZC (95%) blijkt dan ook een beleid of patiëntgerichte documenten (waaronder vooral niet-reanimeren of niet-hospitaliseren) ter beschikking te hebben, een aandeel dat sterk is toegenomen sinds 2000. Toch blijkt uit de meest recente metingen op basis van de Vlaamse kwaliteitsindicatoren, dat nog steeds in het overgrote deel van de woonzorgcentra die hierover cijfers rapporteren, slechts de helft van de bewoners (51.4%) een 'up-to-date plan voor zorg rond het levenseinde' heeft. Hetzelfde zien we in andere Europese landen. Zo blijkt uit de recente Europese PACE-studie dat slechts 32.5% van de rusthuisbewoners een wilsverklaring heeft bij overlijden. Voor Vlaanderen is dat 48% - wat in vergelijking met Finland (76.9%) niet al te hoog is.

Maar het hebben van een wilsverklaring betekent niet noodzakelijkerwijs dat er ook werd gesproken met de bewoners, en dat heeft toch de voorkeur op het louter documenteren ervan. ACP-gesprekken, in combinatie met het documenteren van voorkeuren, zijn vermoedelijk veel effectiever dan het louter documenteren. Helaas is er voor woonzorgcentra weinig cijfermateriaal beschikbaar over de mate waarin er ACP-gesprekken gehouden worden. Tot dusver is onderzoek eerder gericht op het rapporteren van het aantal documenten omdat dit simpelweg gemakkelijker te meten is. We weten wel dat de prevalentie van ACP-gesprekken bij mensen met dementie nog lager ligt, en dat er in dat geval vaker gesproken wordt met de familie dan met de bewoner. Daarnaast tonen studies ook aan dat bij overlijden personen met dementie vaker niet-behandelcodes in hun dossier hebben (die overigens slechts in een klein percentage werden afgetoetst met de bewoner zelf).

Er zijn aanwijzingen dat ACP de tevredenheid over de geleverde zorg kan verbeteren en dat ACP gevoelens van stress, angst en depressie kan verminderen, zowel bij patiënten als familieleden. ACP geeft geen aanleiding tot toegenomen stress of angst bij personen met dementie. Daarnaast kan ACP de vertegenwoordiger helpen om zowel de doelstellingen van de toekomstige medische zorg, als de wensen van de patiënt beter te begrijpen en/of nauwkeuriger in te schatten. Patiënten goed informeren over ACP (lieft gecombineerd: schriftelijk en mondeling) resulteert daarbij in een toename van het aantal geschreven wilsverklaringen door de patiënt en een toename van de

gedocumenteerde zorgvoorkeuren in het dossier. ACP kan het risico op onnodige of ongewenste ziekenhuisopnames en de verblijfsduur in het ziekenhuis alsook de hospitalisatiekosten en gezondheidsuitgaven beperken. Het vroegtijdig starten van palliatieve zorg met speciale aandacht voor zorgplanning vermindert het aantal belastende behandelingen aan het levenseinde.

Kwalitatieve studies over barrières die zorgpersoneel verhinderen om ACP te initiëren, wijzen vooral op een gebrek aan kennis en zelfvertrouwen en, bij uitbreiding, training. Zorgpersoneel vreest met ACP de hoop van de bewoners weg te nemen, ondanks het feit dat meerdere studies tonen dat ACP niet leidt tot verhoogde stress, angst of depressieve gevoelens. Dit neemt natuurlijk niet weg dat dergelijke gesprekken voeren gewoonweg moeilijk is. De omgeving van een WZC is dan ook extra uitdagend voor de organisatie van ACP. Denk aan tijdsdruk door personeelstekorten, zware zorgprofielen, kort verloop en veel bewoners met dementie. Daarnaast blijkt het in de context van woonzorgcentra vaak onduidelijk wie welke rol opneemt. Toch biedt het kader van een WZC waardevolle en unieke mogelijkheden. Er wordt vaker multidisciplinair samengewerkt, het personeel staat in nauw contact met de bewoners en hun naasten en er wordt gebruik gemaakt van gemeenschappelijke patiëntendossiers.

Voorbij ‘werkt het’ naar ‘hoe’ werkt het

Er is een breed spectrum aan bestaande interventies, programma's of modellen die werden getest in verscheidene settings (ziekenhuis, thuis, woonzorgcentrum) en bij verschillende populaties (ouderen, mensen met kanker, mensen met dementie,...) om ACP te verbeteren. De meeste van deze interventies werden tot dusver niet of nauwelijks via systematische wijze en in detail beschreven in de wetenschappelijke literatuur. Daarnaast ontbreken onderzoekers vaak de juiste methoden om in hun trials of effectiviteitsstudies na te gaan hoe, waarom en in welke omstandigheden er een effect werd behaald op gemeten uitkomsten, of waarom net niet. Dit wordt ook wel eens een 'black box' probleem genoemd: zelfs als we effect vaststellen, weten we niet hoe of waarom dit tot stand komt. Door gebrek aan deze informatie is het voor de praktijk, beleidsmakers en andere onderzoekers vaak moeilijk om onderzoek en verschillende ACP modellen te vergelijken, om bevindingen te vertalen naar de reële praktijk of te generaliseren naar andere contexten of zorgsettingen. Meer transparantie van zowel de interventie zelf, alsook de manier waarop het al dan niet effectief was, geeft mogelijk meer inzicht in de manier waarop ACP kan geïmplementeerd worden, en wat daarbij dan nodig is om dit succesvol te kunnen doen.

Om dit te verbeteren is er toenemende oproep naar gedetailleerde beschrijvingen van interventies en het combineren van effectiviteitsstudies met diepgaande procesevaluaties. In dergelijke procesevaluatie gaat men niet alleen na of een programma werkt, maar eveneens op welke manier, in welke mate en door wie het geïmplementeerd werd, wat belangrijke causale mechanismen en wat kritische contextfactoren zijn. Het gebruik van een apriori opgesteld theoretisch model wordt geopperd hierbij van hulp te kunnen zijn. Dit theoretisch model is idealiter “...a theory of how and why an initiative works” (Carroll Weiss). Dergelijk theoretisch model kan de planning en uitvoering van een interventie aanscherpen (bijv. Kijken alle neuzen in dezelfde richting? Is het haalbaar in de specifieke context van Vlaanderen? Kloppen onze assumpties?). Dergelijk model heeft ook het potentieel om verdere dataverzameling van de evaluatie te sturen (bijv. Wat willen we precies weten?), en helpt bij het expliciteren van de onderliggende veranderingstheorie – die er eigenlijk altijd is maar vaak niet expliciet wordt gemaakt. Het geeft een beeld van het onderliggende idee van beoogde causaliteit (“Waarom denkt men door A te doen, B te kunnen bereiken?”).

Onderzoeksdoelen

Het **eerste doel** van dit doctoraatsproefschrift was te exploreren wat mogelijke voorwaarden kunnen zijn voor succesvolle implementatie en organisatie van advance care planning in woonzorgcentra.

Het **tweede doel** was een interventieprogramma te ontwikkelen om advance care planning in woonzorgcentra in Vlaanderen te verbeteren; en te evalueren wat effecten, implementatie, causale mechanismen en kritische contextfactoren zijn, via een cluster gerandomiseerde gecontroleerde studie en mixed-methods procesevaluatie.

Het **derde doel** was de huidige toestand te beschrijven m.b.t. de kennis, het zelfvertrouwen en betrokkenheid in advance care planning van verschillende types zorgverleners in de woonzorgcentra die deelnamen aan de gerandomiseerde studie.

Methoden

Het algemene design van het gehele PhD project is gebaseerd op de eerste twee fasen van de UK *Medical Research Council's Framework* voor de ontwikkeling en evaluatie van complexe interventies door Craig et al. (2008), de extensie voor de ontwikkeling van procesevaluaties door Moore et al. (2012) en de extensie voor de ontwikkeling van een theoretisch model van complexe interventies via de *Theory of Change Approach* door De Silva et al. (2014). ***In wat volgt, wordt steeds per hoofdstuk de gehanteerde methoden en belangrijkste resultaten beschreven.***

*DEEL 2 Voorwaarden voor het succesvol organiseren en
implementeren van advance care planning in
woonzorgcentra*

In **Hoofdstuk 1** voerden we een systematische literatuurstudie uit in elektronische databases voor wetenschappelijke literatuur (PubMed, PsycINFO, EMBASE en CINAHL). We includeerden wetenschappelijke studies over ACP bij ouderen en/of in WZC, van verschillende studiedesigns van de voorbije 10 jaar. Uit 1183 studies, includeerden we 38 studies voor verdere analyses na systematische titel-, abstract- en *full-text* screening. Relevante passages (“excerpten”) uit elke studie werden thematisch (inductief) geanalyseerd en narratief gesynthetiseerd. Op basis van 38 publicaties, identificeerden we 17 belangrijke voorwaarden (of ‘preconditions’) voor ACP in WZC - op vijf verschillende niveaus: bewoner, familie, zorgverlener, de instelling/het WZC en de brede gemeenschap (m.a.w. een bepaalde verandering of actie is noodzakelijk op één of meerdere van deze niveaus). De meeste voorwaarden zijn gerelateerd aan de zorgverlener of het woonzorgcentrum zelf. Voorwaarden werden gecategoriseerd onder vijf overkoepelende domeinen: 1) het belang van voldoende kennis en vaardigheden; 2) willen en kunnen participeren in ACP; 3) het hebben van een goede relatie; 4) een administratief systeem; 5) kritische contextfactoren. Om ACP succesvol te implementeren in een woonzorgcentrum is er dus verandering nodig op *micro*, *meso* en *macrolevel*. Noteer dat dit een samenvatting is van de ‘preconditions’ gerapporteerd in de Engelstalige wetenschappelijke paper in Hoofdstuk 1.

In **Hoofdstuk 2**, gingen we op basis van het literatuuronderzoek uit Hoofdstuk 1, een contextanalyse van Vlaanderen, en verschillende Theory of Change stakeholderspanels/workshops (met verpleegkundigen, vertegenwoordigers van de ouderenraad, maatschappelijk assistenten, huisartsen, coördinerende en raadgevende artsen (CRA), directie en beleid) na wat belangrijke voorwaarden zijn voor het succesvol implementeren van ACP in WZC. De centrale vragen in deze Theory of Change workshops waren: “Wat zijn de doelen op korte, middellange en lange termijn?; “Welke voorwaarden (‘preconditions’) zijn nodig om doelen te bereiken? (‘backward reasoning’ techniek); “Welke interventies moeten worden uitgevoerd om deze voorwaarden te bewerkstelligen?”. Dit werk resulteerde in een context-specifiek veranderingsmodel (*Theory of Change map*), ‘programmatheorie’ of implementatiestrategie voor ACP in een woonzorgcentrum in

Vlaanderen. Dit model toont dat het belangrijk is om de verschillende niveaus in het WZC hierbij te betrekken (bewoner, familie, zorgverleners en organisatie) in een ‘whole-setting approach’. Daarnaast is de allereerste stap die gezet moet worden ‘de bereidheid en het engagement van de directie om een effectief beleid rond ACP te voeren’. Andere belangrijke stappen bij het implementeren van ACP zijn chronologisch weergegeven in **Tabel 1**. Dit is een samenvatting van de ‘precondities’ gerapporteerd in de Engelstalige wetenschappelijke paper in Hoofdstuk 2.

Tabel 1. Theoretisch veranderingsmodel voor het implementeren van ACP in WZC, zoals momenteel geëvalueerd binnen het ACP+ programma
1. Een trainer/expert ondersteunt de directie en de CRA bij het maken van een beleid rond ACP, traint personeel tot ACP Referentiepersoon, en helpt bij de implementatie.
2. De directie en de raad van bestuur schrijven een beleid uit rond ACP en maken dit bekend bij het personeel.
3. ACP Referentiepersonen zijn aangesteld, om naast het voeren van ACP-gesprekken met bewoners en familie, gradueel de taken van de trainer over te nemen.
4. Het overgrote deel van de verpleegkundigen en andere zorgverleners zijn in staat om ACP-gesprekken te voeren met bewoners en familieleden of naasten, volgens opgestelde richtlijnen.
5. Al het personeel en vrijwilligers zijn in staat om triggers op te pikken die door bewoners of familieleden worden gegeven rond toekomstige zorg.
6. De zorgverleners, CRA en het management kennen het beleid rond ACP en handelen ernaar.
7. De huisartsen zijn op de hoogte van dit beleid en zijn bereid om rekening te houden met de wensen en voorkeuren van hun eigen bewoners-patiënten.
8. De bewoners en hun familieleden worden op de hoogte gebracht van (het beleid rond) ACP.
9. Bewoners en naasten zijn bereid deel te nemen aan ACP.
10. De huidige voorkeuren en afspraken over toekomstige zorg (inclusief levenseindezorg) van bewoners/familie zijn bekend bij een van de referentiepersonen. Ook de (aangeduide) vertegenwoordiger is bekend.
11. De huidige wensen en voorkeuren van een bewoner zijn daarna bekend gemaakt bij betrokken de zorgverleners en de behandelende huisarts.
12. De resultaten van het ACP overleg zijn neergeschreven en bevatten de <i>huidige</i> wensen en voorkeuren (en wilsverklaringen). Deze zijn (elektronisch) toegankelijk voor de zorgverleners die het aanbelangt.
13. Er is een monitoringsysteem voor het correct uitvoeren van ACP en er worden regelmatig (jaarlijks) actieplannen voor verbetering opgesteld.

DEEL 3 *Ontwikkeling van een interventieprogramma om advance care planning in woonzorgcentra te verbeteren*

In **Hoofdstuk 3** werd het ‘VZP+ of ACP+ programma’ ontwikkeld en afgetoetst bij personeel en management uit vijf Vlaamse WZC, alsook bij experts. Het resulterende ACP+ programma beoogt specifiek ACP in de dagelijkse zorg van Vlaamse WZC te integreren via een gestructureerd kader. Gedurende de evaluatiestudie ervan (Hoofdstuk 4) werd het ingevoerd over een tijdsspanne van 8 maanden. De onderliggende visie van dit programma is dat het praktisch inzetten van ACP in WZC van veel meer afhankelijk is dan enkel een training of het voorzien van een gestandaardiseerd document of een ‘zorgcode’. Het vereist niet alleen een fundamentele verandering in de attitude van personeel én bewoners en hun naasten, maar ook de betrokkenheid van leidinggevenden. Cruciaal is een top-down ondersteuning, naast een bottom-up verantwoordelijkheid van alle personeelsleden en vrijwilligers, en een verankering in de dagelijkse werking. Gedurende het onderzoek werd initieel en voornamelijk ingezet op het informeren/trainen van personeel. Twee externe trainers werden aangesteld om de WZC hierbij te begeleiden en ondersteunende materialen werden aangeboden. In werkelijkheid kan de implementatie van ACP een natuurlijkere gang van zaken volgen. Het volledige programma werd beschreven via de *Template for Intervention Description and Replication* (TIDieR) checklist en is volledig gerapporteerd in Hoofdstuk 3.

Box 1. Belangrijke rollen binnen het ACP+ programma

- Twee **ACP Referentiepersonen** per afdeling (minimum 1 per 30 bewoners) zijn verantwoordelijk voor het implementeren, organiseren en behouden van ACP en zullen in de toekomst en op regelmatige basis ook andere zorgverleners opleiden.
- **ACP Gespreksleiders** zijn teamleden uit het sociale -/zorgteam die samen met de ACP Referentiepersonen de gesprekken met de bewoners en hun naasten plannen en uitvoeren.
- Alle andere personeelsleden zijn in principe **ACP Signaleerders** (ook het technisch, administratief en onderhoudspersoneel en de vrijwilligers). Zij zijn cruciaal in het detecteren van signalen bij zowel de bewoners als hun naasten.

Figuur 1. Nederlandstalig overzicht van ACP+ programma gedurende implementatie tijdens gerandomiseerde studie

Meeting met ACP Trainer, management, directie, leidinggevenden en CRA	Training van ACP Referentiepersonen (sessie 2)	Informatie voor bewoners en familie	Training van ACP Gespreksleiders (sessie 2)	Specialisatie- sessie 1: Dementie	Specialisatie- sessie 2: Communicatie met andere zorgverleners	ACP interne evaluatie / audit
Training van ACP Referentiepersonen (sessie 1)	Training van ACP Gespreksleiders (sessie 1)	Informatie voor huisartsen	Training van ACP Signaleers	Terugkomdag voor ACP Referentiepersonen		
ACP GESPREKKEN						
Maandelijks multidisciplinair overleg & One-to-one coaching						
Maand 1	Maand 2	Maand 3	Maand 4	Maand 5	Maand 6	Maand 7
Voorbereidingsfase						
ACP Trainer neemt de leiding. Zodra de ACP Referentiepersonen zijn getraind nemen zij deel aan de organisatie van alle ACP+ activiteiten						
Uitvoerings- en follow-up fase						
ACP Referentiepersonen nemen de leiding en krijgen hierbij ondersteuning van de ACP Trainer						

In **Hoofdstuk 4** werd dit programma voor evaluatiedoeleinden, gedurende acht maanden, uitgerold bij de helft van **veertien Vlaamse WZC**, in een cluster gerandomiseerde gecontroleerde studie. Na inclusie werden WZC gepaard aan een soortgelijk WZC (even groot, dezelfde regio en hetzelfde type: privaat non-profit, privaat for-profit of publiek). Door een onafhankelijke statisticus werd vervolgens *at random* één WZC van elk paar bij de interventiegroep ingedeeld (n=7), en het andere bij de controlegroep (n=7). Vervolgens werd er *aan de start van de studie*, via vragenlijsten in beide groepen, **de kennis, het zelfvertrouwen in eigen kunnen (*self-efficacy*) en de betrokkenheid van personeel en management in ACP**, geëvalueerd. Deze vragenlijsten werden afgenomen bij zorgpersoneel (waaronder verpleegkundigen, zorgkundigen, kinesisten, sociaal en pastoraal werkers, ergotherapeuten), ondersteunend personeel (administratief, onderhouds- en technisch personeel), betrokken vrijwilligers, management en huisartsen. Na deze 'baselinemeting' werd er in de interventie-groep gestart met het ACP+ programma, zoals beschreven in Hoofdstuk 3. In de controlegroep werd er geen interventie uitgevoerd. *Acht maanden na baseline*, volgde een opvolgingsmeting waarbij dezelfde uitkomsten worden gemeten, om zo een effect te detecteren. In de WZC uit de interventiegroep werd gedurende de implementatie van het ACP+ programma en erna, bijkomend een diepgaande procesevaluatie uitgevoerd. Via dagboeken, interviews en focusgroepen werden 1) implementatie, 2) causale mechanismen en 3) kritische contextfactoren geëvalueerd. In Hoofdstuk 5 en 6 worden er twee aparte analyses gerapporteerd die werden uitgevoerd op basis van de baselinemeting van deze gerandomiseerde studie. De finale resultaten van de gerandomiseerde studie – effectiviteitsmeting en procesevaluatie – zijn geen onderdeel van deze PhD thesis.

*DEEL 4 Kennis over, zelfvertrouwen in en betrokken
in advance care planning van zorgpersoneel in
woonzorgcentra in Vlaanderen*

Zowel **Hoofdstuk 5** en **Hoofdstuk 6** bevatten analyses op basis van de baselinedata – eerste vragenlijstenronde - uit de gerandomiseerde studie uit Hoofdstuk 4. Bij baseline, *aan de start van de studie*, werden verschillende types zorgpersoneel gevraagd om:

- 1) voor zes **'ACP-praktijken'** te antwoorden of ze dit wel of niet hadden gedaan, de laatste zes maanden voorafgaand aan het invullen van de vragenlijst (bijv. "Heeft u in de afgelopen 6 maanden een ACP-gesprek opgestart met een bewoner?" (ja/nee); "Heeft u in de afgelopen 6 maanden een bewoner geholpen bij het opstellen van een wilsverklaring?" (ja/nee));
- 2) voor 11 juist-fout stellingen te antwoorden, om hun **kennis over ACP** te evalueren (bijv. "Een bewoner kan alleen een familielid aanduiden als zijn vertegenwoordiger (juist of fout)"; "Volgens de Wet Patiëntenrechten is zowel een positieve als een negatieve wilsverklaring bindend (juist of fout)");
- 3) voor 12 rollen en taken m.b.t. ACP te antwoorden in welke mate ze hierin **'zelfvertrouwen in eigen kunnen'** hadden, via een 10-puntenschaal met 1 'geen zelfvertrouwen' en 10 'veel zelfvertrouwen' (bijv. "Geef aan hoeveel zelfvertrouwen u heeft in uw eigen kunnen bij: "De rol van vertegenwoordiger uitleggen aan bewoners en familie"; "... bij: Het beantwoorden van vragen van een bewoner over wilsverklaringen").

In **Hoofdstuk 5** gingen we na *of en in welke mate* kennis, zelfvertrouwen en betrokkenheid in ACP verschilt tussen verschillende types zorgverleners in het WZC, m.n. verpleegkundigen, zorgkundigen en 'andere zorgverleners' tewerkgesteld in het woonzorgcentrum (zoals kinesisten, ergotherapeuten, animatoren, pastoraal of sociaal werkers, etc.). We ontvingen 694 ingevulde vragenlijsten (response rate 67%), waarvan 684 bruikbaar voor analyses (196 verpleegkundigen, 319 zorgkundigen en 169 andere zorgverleners). Meer dan de helft van alle zorgverleners kreeg enige vorm van training in palliatieve zorg, verpleegkundigen meer dan de anderen (82.7%; $p < .001$). De helft van alle zorgverleners kreeg enige vorm van training in ACP. Uit statistische analyses blijkt dat de kans dat een verpleegkundige een ACP-gesprek start, 4 keer hoger is dan dat een zorgkundige dat doet (odds ratio 4.12; 95% BI¹⁰ 1.73-9.82; $p < .001$); de kans dat een verpleegkundige de uitkomsten van dergelijk gesprek documenteerde is 2.7 keer hoger dan dat zorgkundigen dat deden (2.67; 1.29-5.56; $p = .008$). Geen significante verschillen werden gevonden tussen zorgkundigen en 'andere zorgverleners' in de mate waarin ze verschillende ACP-praktijken uitvoerden in de afgelopen zes maanden. Uit deze resultaten blijkt dat verpleegkundigen nog steeds de leidende rol nemen of krijgen in het uitvoeren van ACP in het WZC. Kennis over ACP was het hoogst bij verpleegkundigen en is ook significant verschillend dan de kennis die zorgkundigen of 'andere zorgverleners' hebben over ACP. De kennis is over alle groepen heen niet erg hoog. Verpleegkundigen scoren 0.13 punten hoger dan zorgkundigen, op een schaal van 0 tot 1 met 1 veel kennis (0.08-0.17; $p < .001$); andere zorgverleners

¹⁰ BI = betrouwbaarheidsinterval.

scoren 0.07 punten hoger dan zorgkundigen (0.03-0.12; $p < .001$). Verschillen zijn klein, wat mogelijks wijst op een ondergebruik van zorgverleners die potentieel evenveel kennis bezitten over ACP dan verpleegkundigen. Zelfvertrouwen is gemiddeld over de groepen heen, met scores rond de middelste waarde van de schaal (0=geen zelfvertrouwen tot 10=veel zelfvertrouwen). Verschillen tussen groepen zijn niet significant. Over alle groepen heen situeert het laagst gerapporteerde zelfvertrouwen zich rond items gerelateerd aan wettelijke bepalingen omtrent ACP (*estimated mean* van 5.41 ± 2.34 ¹¹ bij verpleegkundigen, 4.26 ± 2.39 in zorgkundigen en 4.42 ± 2.46 in andere zorgverleners; met scores van 0 tot 10). ‘Andere zorgverleners’ rapporteren het laagste zelfvertrouwen, lager dan zorgkundigen. Deze verschillen zijn echter niet statistisch significant.

In **Hoofdstuk 6** gingen we specifiek voor verpleegkundigen na in welke mate hun kennis en zelfvertrouwen in eigen kunnen m.b.t. ACP geassocieerd is met hun betrokkenheid in ACP. We kijken hier niet naar een oorzakelijk verband maar naar een negatieve of positieve associatie (m.a.w. “Als kennis/zelfvertrouwen hoger is, zijn verpleegkundigen dan meer betrokken bij ACP/voeren zij dan meer ACP-praktijken uit?”). In deze studie analyseerden we de data van 196 verpleegkundigen uit de baselinemeting (66% response). Uit deze studie bleek dat kennis niet statistisch geassocieerd is met het uitvoeren van (en de hoeveelheid) ACP-praktijken; zelfvertrouwen was dat wel. We vonden dat bij elke ‘unit’ stijging in zelfvertrouwen, de hoeveelheid ACP-praktijken (tussen 0 en 1) statistisch geassocieerd is met een stijging van 32% (of een multiplicatief effect van 1.32). Bijkomende analyses op het grote aandeel verpleegkundigen dat geen enkele ACP-praktijk uitvoerde toont een statistisch significante associatie met het al dan niet getraind zijn in ACP, wat doet vermoeden dat verpleegkundigen die geen enkele opleiding in ACP kregen meer geneigd zijn om geen ACP-praktijken uit te voeren. Analyses in deze studie zijn wel gebaseerd op een kleine steekproef. Bijkomend geldt voor zowel Hoofdstuk 5 en 6 dat dit analyses zijn op een *purposive sample*, m.a.w. een steekproef die als primair doel is gerekruteerd voor de gerandomiseerde studie in Hoofdstuk 4.

¹¹ Standaarddeviatie.

DEEL 5 Algemene discussie en aanbevelingen voor onderzoek, praktijk en beleid

Algemene discussie

In dit PhD project werd nagegaan hoe ACP succesvol in woonzorgcentra kan geïmplementeerd en georganiseerd worden. Bevindingen uit Hoofdstuk 1, 2 en 3 ondersteunen het idee dat ACP een whole-setting benadering vereist, waarbij er actie en verandering moet plaatsvinden op verschillende niveaus in het woonzorgcentrum. ‘Whole-setting’ -in het kader van interventies- op basis van dit PhD werk kan als volgt worden geïnterpreteerd: Het is een benadering waarbij 1) interventie-activiteiten verschillende stakeholders tezelfdertijd *impacteren*; 2) dat focust op verschillende componenten in de organisatie (zoals beleid, administratieve systemen, organisatie, rolverdeling en verdeling van verantwoordelijkheden); 3) dat verschillende uitkomsten kan hebben, op verschillende niveaus. Neem in rekening dat een whole-setting benadering de noodzaak van macrolevel veranderingen en ondersteuning (bijv. kwaliteitsindicatoren geëvalueerd door Vlaamse overheid, ondersteunende wettelijke bepalingen, interregionale samenwerking tussen verschillende zorgsettings, etc.) niet afschrijven; dit valt buiten de scope van het PhD project. De term ‘whole-setting’ sluit daarom de nood aan een bredere maatschappelijke benadering niet uit, noch distantieert zich ervan (de twee -afhankelijk van hun gehanteerde definitie kunnen namelijk op hetzelfde wijzen). We benoemen de benadering als ‘whole-setting’ om een proces dat enkel top-down en primair gefocust op één niveau is (bijv. gedragsverandering bij de bewoner of familie) te weerleggen. Het is eerder een benadering waarbij het management expliciet ondersteuning geeft, waarbij ACP verankerd is in een geschreven beleid en doorgedrongen in het gehele woonzorgcentrum. Dergelijke whole-setting benadering is weerspiegeld in het VZP+ programma in Hoofdstuk 3. Na het testen ervan bleek immers dat zorgpersoneel het niet haalbaar zag ACP te implementeren zonder ‘buy-in’ van het management. Deze bevinding is consistent met andere wetenschappelijke literatuur maar werd tot dusver niet expliciet opgenomen als een interventiecomponent als onderdeel van een interventieprogramma.

Het theoretische model gerapporteerd in Hoofdstuk 2 is tot zeker hoogte nieuw in het onderzoeksveld van palliatieve zorg en ACP. Om tegemoet te komen aan de steeds groter wordende *call* van de onderzoeksgemeenschap, voor het gebruik van theorie in de ontwikkeling en evaluatie

van complexe interventies, werd er door andere onderzoekers veelal gegrepen naar ‘grand theory’ of ‘off-the-self-theory’ (bijv. Representational Approach to Patient Education, Leventhal’s Common Sense Model, Hewson’s Model of Conceptual Change, Transtheoretical model of Behaviour Change, and The Theory of Planned Behaviour). Dergelijke theorieën focussen voornamelijk op psychologische processen en gedrag. Ondanks het feit dat deze zeker nuttig zijn, is het noodzakelijk om – daarnaast of met hulp van bovenstaande theorieën- ook een programmatheorie of implementatiestrategie te ontwikkelen zoals de Theory of Change map in Hoofdstuk 2. Dergelijk model gaat voorbij aan wat onderzoekers recent in kankeronderzoek gebruikten, m.n. een logic model. Een Theory of Change maakt immers expliciet hoe een programma bedoeld is om te werken, via welke stappen. Het is een dynamische tool dat steeds wordt aangepast naarmate er nieuwe evidentie of kennis is. De map uit Hoofdstuk 2 werd reeds aangepast op basis van nieuwe inzichten uit Hoofdstuk 3 en zal opnieuw veranderen eens we nieuwe kennis hebben op basis van Hoofdstuk 4. De map kon additioneel ondersteuning bieden bij het identificeren van belangrijke onderzoeksvragen voor verdere evaluatie van het causale veranderingsmodel (door bijvoorbeeld aan elke stap van de map, indicatoren voor ‘succes’ te bepalen).

Doorheen de gehele PhD thesis, komen ‘*being able*’ en ‘*being skilled*’ sterk op de voorgrond. In zowel Hoofdstuk 1 en 2 werd ‘voldoende kennis en vaardigheden’ beschouwd als noodzakelijke voorwaarden voor succes. In Hoofdstuk 3 werd dit vertaald naar specifieke interventiecomponenten gericht op het verhogen van kennis en vaardigheden van personeel in WZC, evenals dat van bewoners en familie. Personeel blijkt uit dit onderzoek een belangrijke asset te zijn bij het leveren van ACP. Wij kozen er daarom ook voor om effectiviteit van het programma vooral te meten op het niveau van het personeel. Het is met name belangrijk dat zorgverleners voldoende betrokken zijn in ACP, en om dat te doen blijkt kennis - maar vooral (op basis van Hoofdstuk 6) – een zeker mate van zelfvertrouwen, uiterst belangrijk. Ook het theoretisch model in Hoofdstuk 2 en de literatuurstudie in Hoofdstuk 1 tonen dat ‘*skilled*’ zorgverleners essentieel zijn. Maar eerst training. Zo tonen bijkomende analyses in Hoofdstuk 6 dat het gebrek aan enige vorm van training of educatie in of over ACP, een potentiële predictor is voor het *niet* uitvoeren van ACP. Verpleegkundigen zonder enige vorm van training in ACP (64% van de steekproef) zijn meer waarschijnlijk om geen enkele ACP-praktijk uit te voeren; m.n. één ‘unit’ stijging in ACP educatie (gaande van ‘geen’ naar ‘enige’ training in ACP) doet de kans dat je meer dan nul (of minstens één – van de 6) ACP-praktijken uitvoert, stijgen met 75% ($p < .001$).

Op basis van Hoofdstuk 5 weten we dat de kennis van zorgpersoneel over het algemeen gemiddeld tot laag is, evenals hun zelfvertrouwen. Deze bevindingen zijn consistent met andere literatuur. Vooral hun betrokkenheid in verschillende ACP-praktijken is over alle types zorgverleners laag. Het grote aandeel personeel dat geen enkele ACP-praktijk uitvoerde, en het grote aandeel personeel dat bij de *self-efficacy* of zelfvertrouwen geen antwoord gaf maar in de plaats daarvan ‘niet van toepassing’ invulde, kan wijzen op een diffusie van verantwoordelijkheid. Zij die hiertoe geen duidelijk mandaat hebben of voelen zich hiervoor niet verantwoordelijk. Op basis van Hoofdstuk 1 en 5 kunnen we daarom concluderen dat een duidelijkheid in rolverdeling en verantwoordelijkheden belangrijk is. Dit steunt ook op vorige wetenschappelijke studies waaruit blijkt dat het gebrek hieraan, verschillende zorgverleners ervan weerhoudt om ACP op te nemen.

Gegeven dat zelfvertrouwen niet verschilt tussen verpleegkundigen, ‘andere zorgverleners’ en zorgkundigen in het WZC, en hun kennis slechts in kleine mate, kan dit wijzen op de mogelijkheid om ook personeel, anders dan verpleegkundigen, te betrekken in het uitvoeren van ACP in het woonzorgcentrum; zeker in het licht van toenemende personeelsdruk en het tekort aan verpleegkundigen. In deze PhD thesis en het resulterende ACP+ programma, werd er gekozen voor een ‘tiered’ of gelaagde *rolstructuur* – ACP Trainer, ACP Referentiepersoon, ACP Gespreksleider en ACP Signaleerder. Een structuur die tot dusver niet expliciet werd gehanteerd in bestaande ACP programma’s. Het gegeven van een leider of ‘champion’ werd meermaals in de academische literatuur aangeraden. Daarnaast werd er meermaals in - vooral kwalitatieve - literatuur aangehaald dat personeelsleden, anders dan zij die instaan voor de ‘directe’ zorg van de bewoner – zoals vrijwilligers, administratief, technisch en onderhoudspersoneel – vaak over het hoofd worden gezien maar net een belangrijke intermediaire rol kunnen opnemen tussen bewoner, familie en zorgpersoneel en daarom potentieel zouden kunnen functioneren in het observeren en doorgeven van bepaalde signalen voor ACP. We kozen voor bijkomende ondersteuning van een expert-trainer voor de eerste fase van implementatie van ACP, mede door verscheidene theoretische veranderingsmodellen, alsook bevindingen uit Hoofdstuk 2 en 3. De haalbaarheid van dit programma en dit specifieke model van rolverdeling werd reeds afgetoetst bij personeel en management in Hoofdstuk 2. Finale resultaten uit de gerandomiseerde studie (Hoofdstuk 4) moeten nog uitwijzen of er in de toekomst bijkomende aanpassingen moeten gebeuren, of verdere toetsing of brede implementatie wenselijk is.

Aanbevelingen

Praktijk

Integreer ACP in de dagelijkse routine en hanteer hiervoor een whole-setting benadering. Een geschreven beleid en gestandaardiseerde documentatie is vermoedelijk niet voldoende om ACP effectief en duurzaam te integreren in de dagelijkse zorg in het woonzorgcentrum. Management wordt hierbij aangemoedigd expliciete ondersteuning te bieden aan verschillende types zorgpersoneel, door ze de tijd en mogelijkheid te geven training te volgen, gesprekken te voeren en ACP te organiseren, en hen hierin aan te moedigen door het installeren van een duidelijk mandaat. Daarnaast is een multidisciplinaire teambenadering aangeraden en kan een leider (of ACP Referentiepersoon) mogelijks bevorderend werken. Continue training om kennis en -vooral- zelfvertrouwen van personeel te verhogen is sterk aangeraden.

Beleid

Het beleid kan woonzorgcentra en hun managers bijkomend aanmoedigen tot het uitbouwen van een whole-setting benadering bij het implementeren en organiseren van ACP. Denk hierbij aan het uitbreiden van de kwaliteitsindicatoren die jaarlijks gemeten in Vlaamse WZC (verder dan “de proportie bewoners met een levenseinde plan”). Denk aan structurele ondersteuning (door het vrijmaken van nieuwe middelen bijv. voor ACP Referentiepersonen per 30 bedden, het installeren van specifieke ACP mandaten, het voorzien van specifieke en gratis trainingsmodules, aangepaste ruimtes, tools en tijd); het ondersteunen van externe organisaties die reeds veel expertise hebben, om bijkomende ondersteuning te kunnen bieden aan WZC die trachten ACP te implementeren of verder uit te bouwen; en het uitbreiden van de terugbetalingsmaatregel voor ACP naar ander zorgpersoneel dan enkel (huis)artsen.

Toekomstig onderzoek

Analyses van de finale resultaten van de trial moeten uitwijzen of het ACP+ programma in zijn huidige hoedanigheid nuttig kan zijn voor bredere implementatie. Op basis van de procesevaluatie kunnen aanbevelingen gedaan worden naar bevordering van implementatie (bijv. nood aan trainer met expertise voor het zetten van eerste stappen in ACP), noodzakelijke causale mechanismen (bijv. indien geen ‘buy-in’ van management geen mogelijkheid tot implementatie), en kritische contextfactoren (bijv. turnover van personeel zorgt voor discontinuatie van trainingen). Toekomstige onderzoekers worden daarnaast ook aangemoedigd het survey instrument dat werd ontwikkeld voor

de gerandomiseerde studie (en Hoofdstuk 5 en 6) verder te ontwikkelen en te testen; de *Theory of Change* map aan te passen n.a.v. finale resultaten en bijkomende evidentie; en -indien effectief- het ACP+ programma verder te evalueren op gewenste (klinische) uitkomsten voor bewoners en hun naasten.

Curriculum Vitae

About the author

Joni Gilissen (°1990) obtained her bachelor's degree in Social Work in 2011 and her master's degree in Social Policy (KULeuven) in 2013. After she completed a Postgraduate degree in Social Profit and Public Management (Universiteit Gent) in 2014, she started as a junior PhD researcher at the End-of-Life Care Research Group (VUB-UGent), working on a project funded by Fonds Wetenschappelijk Onderzoek (FWO). Her PhD project entailed the development and evaluation of a cluster randomised controlled trial to improve advance care planning in nursing homes, a joint PhD between VUB as main institution and the Centre for Biomedical Ethics and Law (KULeuven) as partner institute. The project was carried out in close collaboration with Annelien van Dael (INDUCT, Interdisciplinary Network for Dementia Using Current Technology), and was supervised by Dr. Lara Pivodic, Prof. Dr. Lieve Van den Block, Prof. Dr. Chris Gastmans, Prof. Dr. Luc Deliens and Prof. Dr. Robert Vander Stichele. In 2017, Joni was awarded the Academy Fellowship by INTERDEM, a pan-European network of researchers collaborating in research on dissemination of early, timely, psychosocial interventions in dementia, and had the opportunity to work at the IQ Healthcare department at Radboud UMC Nijmegen, The Netherlands. In August 2019, Joni started a 12-month research training at the Global Brain Health Institute (GBHI), UCSF as one of the selected Atlantic Fellows for Equity in Brain Health. She is awarded a postdoctoral grant from the Belgian American Educational Foundation (BAEF) and the Fulbright Commission to carry out a subsequent study regarding early palliative care at Boston Massachusetts General Hospital and Harvard Medical School, under the supervision of Prof. Jennifer Temel, Prof Christine Ritchie and Prof. Van den Block, starting September 2020.

List of publications

Articles in international peer-reviewed journals

- Gilissen, J., Pivodic, L., Smets, T., Gastmans, C., Vander Stichele, R., Deliens, L., & Van den Block, L. Preconditions for Successful Advance Care Planning in Nursing Homes: A Systematic Review. *International Journal of Nursing Studies* 66, 2017, 47–59. [2015 SCI impact factor: 3.561; ranking D1]
- Penders, Y.W.H., Gilissen, J., Moreels, S., Deliens, L. & Van den Block, L. Palliative care service use by older people: time trends in representative samples in Belgium between 2005 and 2014. *Palliative Medicine*, p1-10, 2017. [2016 SCI impact factor 4.22; journal ranking Q1]
- Gilissen, J., Pivodic, L., Smets, T., Gastmans, C., Vander Stichele, R., Deliens, L., Breuer, E. & Van den Block, L. How to Achieve the Desired Outcomes of Advance Care Planning in Nursing Homes: A Theory of Change. *BMC Geriatrics*, 18, no. 1, 2018. [2016 SCI impact factor: 2.611; ranking Q2]
- Piers R., Albers G., Gilissen J., De Lepeleire J., Steyaert J., Van Mechelen W., Steeman E., Dillen L., Vanden Berghe P., Van den Block L. Advance care planning in dementia: recommendations for healthcare professionals. *BMC Palliative Care*. 2018; 17:88. [2016 SCI impact factor 1.602; ranking Q1]
- Gilissen, J., Pivodic, L., Van Dael, A., Van Humbeek, L., Gastmans, C., Vander Stichele, R., Deliens L. & L. Van den Block. Development of a complex intervention to improve advance care planning in nursing homes: the ACP+ program. *PLoS ONE*, 14(10), e0223586. [2018 SCI impact factor 2.776; ranking Q1]
- Gilissen, J., Van Dael, A., Pivodic, L., Gastmans, C., Vander Stichele R., Deliens L., Vernooij-Dassen, M., Engels Y. & Van den Block, L. Effects and implementation of advance care planning in nursing homes: study protocol for a cluster randomized controlled trial and process evaluation. [submitted]
- Gilissen, J., Van Dael, A., Gastmans, C., Vander Stichele, R., Deliens L., Van den Block L. & Pivodic, L. Comparing advance care planning practices, knowledge and self-efficacy among different nursing home care staff: A survey study [submitted]
- Gilissen, J., Pivodic, L. Van Dael, A., Vander Stichele, R., Deliens, L., Cools, W., Van den Block L. & Gastmans, C. Nurses' self-efficacy, rather than their knowledge, is associated with their engagement in advance care planning in nursing homes: a survey study [submitted]

Books

- Demaerschalk, M., Kindekens, D., Verraest, E., Hoste, V., Van Ooteghem, L., Nys, H., Pype, P., De Vleminck, A. & Gilissen, J., Draaiboek Vroegtijdige en voorafgaande zorgplanning in woonzorgcentra. [Implementation guidance for advance care planning in nursing homes]. *Vlaamse Vereniging voor Steden en Gemeenten [Flemish Federation for Cities and Municipalities]*. Brussel, 2016.

Non-academic publications

- Gilissen, J. & Van den Block, L. Het VZP+ programma: implementeren van VZP in WZC [The ACP+ programme: implementing ACP in nursing homes]. *GERON*, 2019.
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- Van Rickstal, R., De Vleminck, A., Gilissen, J., Wendrich-van Dael, A. & Van den Block, L. Voorafgaande Zorgplanning bij Dementie. Denken onderzoekers tijdig na over de toekomst van hun onderzoek? *Peiler*, 10, 12-13, 2019.
- Vanderstichelen, S., Gilissen, J., Vermorgen, M., Vandenbogaerde, I., Werrebrouck, B. & Robijn, L. Tijd voor een echte vermaatschappelijking van palliatieve zorg? *INFO PHA* 25:1, 22-25, 2019.
- Honinx, E., Gilissen, J., Smets, T. & Van den Block, L. Hoe ver staat het met palliatieve zorg in onze woonzorgcentra? Een overzicht op basis van recente onderzoeksgegevens. [Current state of affairs regarding palliative care in nursing homes? An overview], *Peiler*, 9, 14-15, 2019.
- Beernaert, K., Dierickx, S., Gilissen, J., Penders, Y.W. Hoe de palliatieve zorg in Vlaanderen verbeteren? Aanbevelingen voor beleid en praktijk van de acht doctoraatstudies en het eindcongres van het FLIECE-onderzoeksproject. [How to improve palliative care in Flanders? Recommendations for policy and practice based on 8 doctoral theses and the final conference of the FLIECE-research project], *Tijdschrift voor Palliatieve Zorg [Magazine of Palliative Care]*, 11, 2015.

Other media and press

- Gilissen, J. & De Vleminck, A., *Waarom nu praten over de dood belangrijk is [Why now talking about death is important]*. Magazine, De Knack, July 2019.
- Gilissen, J. & Van den Block, L., *Over je levenseinde praten is moeilijk, ook voor je arts [Talking about the end-of-life is hard, also for your physician]*. Newspaper, De Standaard, January 2019.
- Gilissen, J., *I am Joni, and this is how I work*. Online blogpost, PhD Talk, December 2018.
- Gilissen, J., De Schreye, R., Maetens, A., Robijn, L., Vanderstichelen, S., Van Rickstal, R. & Vermorgen, M., *From well-equipped cohort to future research leaders: Preparing the next generation palliative care researchers*. Online blogpost, European Association Palliative Care (EAPC), September 2018.
- Gilissen, J., *Paper of the month: A theory of change approach*, Cicely Saunders Institute, King's College London, February 2018.
- Werrebrouck, B. & Gilissen, J., *Februari 2017, in het teken van palliatieve zorg [February 2017 in the light of palliative care]*. Online blogpost, Wetenschap in en uit Brussel, WTNSCHP, 2017.
- Gilissen, J. & Verkissen, M., *Preconditions for successful implementation of advance care planning in nursing homes*. Online blogpost, European Association Palliative Care (EAPC), 2017.
- Gilissen, J., *INTERDEM Academy Fellowship 2016-2017: Final report on research exchange by Joni Gilissen*. Online blogpost, INTERDEM (Early detection and timely INTERvention in DEMentia), 2017.

Presentations at international and national conferences and seminars

2020

Alzheimer's Disease International (ADI), Singapore – *Uptake of, knowledge about and self-efficacy in advance care planning in general and in dementia in different types of nursing home staff* (oral presentation)

2019

Recht op Waardig Sterven, Antwerp – *Het VZP+ project: implementatie van VZP in de woonzorgcentra [The ACP+ project: implementation of ACP in nursing homes]* (invited speaker)

ACP-I Advance Care Planning International, Rotterdam – *Finding the “right” outcomes of ACP* (themed session, oral presentation, together with Dr De Vleminck)

2018

International Alzheimer Conference, Barcelona - *Advance care planning in nursing homes: a Theory of Change* (oral presentation)

International seminar Public Health Research in Palliative Care: Shifting the Paradigm, Brussels – *Stakeholder engagement in the development of complex interventions* (oral presentation)

Training for family physicians, Lier – *Vroegtijdige zorgplanning en hoe VZP te integreren in MDO [Advance care planning and how to integrate ACP in multidisciplinary team meeting]* (invited speaker)

Zin in Zorg Congres, DeMens.nu, Brussels – *Vroegtijdige zorgplanning: inzichten uit de wetenschap [Advance care planning: insights from science]* (invited speaker)

Community Center Halle, Brussels – *Wat is vroegtijdige zorgplanning en hoe vul ik mijn papieren in? [What is advance care planning and how to manage my advance care planning documents]* (invited speaker)

2017

Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg, Amsterdam - *Hoe de praktijk betrekken bij de ontwikkeling van een complexe interventie? Voorafgaande zorgplanning in woonzorgcentra als voorbeeld [How to involve clinical practice in the development of a complex intervention]* (invited speaker)

Post-EAPC-symposium, Palliatief, University Medical Center, Utrecht - *Nieuwe ontwikkelingen in onderzoek over advance care planning: een samenvatting [New developments in science regarding advance care planning]* (invited speaker)

1st INDUCT Winter School, Interdisciplinary Network for Dementia using Current Technology, Maastricht – *Collaborative masterclass: Raising the standard again: MRC Framework and Theory of Change* (invited speaker, in collaboration with Rose-Marie Dröes, Graham Moore, Lieve van den Block and Lara Pivodic)

15th World Congress of the European Association for Palliative Care, EAPC, Madrid - *Advance Care Planning in Dementia: Recommendations for Healthcare Professionals Working with People Living with Dementia* (oral presentation)

2016

9th World Research Congress of the European Association for Palliative Care, EAPC, Dublin - *Successful Advance Care Planning in nursing homes: a systematic review* (poster)

VUB PhD Research Day, VUB, Brussels - *Successful advance care planning in the nursing home setting* (poster presentation)

31th International Conference of Alzheimer's Disease International, ADI, Budapest - *Dying according to wishes: A rapid review to identify the steps towards successful Advance Care Planning* (poster presentation)

2015

5th International Conference of Advance Care Planning and End of Life Care, ACPEL, Munich - *Meet-the-expert workshop II: Randomized Controlled Trials. Presentation and (small) group discussion of 4 currently ongoing RCTs to study the effect of ACP* (oral presentation)

Awards, Grants and Fellowships

Postdoctoral Fellowship by *Fulbright Commission*, 2019

Postdoctoral Research Visit Fellowship by *BAEF (Belgian American Educational Foundation)*, 2019

Wetenschappelijk Fonds Willy Gepts (WFWG) by *University Medical Center VUB*, 2018

INTERDEM Academy Award by *INTERDEM network*, 2017

Certificates

U.S. Privacy Rules Certification by HIPAA

Good Clinical Practice (GCP) by IQVIA

Advance Care Planning Facilitator by ACTION (<https://www.action-acp.eu/>)

Theory of Change Facilitator by London School of Hygiene and Tropical Health

