Advance Care Planning In Frail Older People In The Netherlands

Advance Care Planning bij kwetsbare ouderen in Nederland

ANOUK OVERBEEK

Advance Care Planning In Frail Older People In The Netherlands

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General introduction

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1.1 BACKGROUND

Preferences for medical care

In Europe, the majority of deaths occur non-suddenly due to one or more chronic conditions [1]. Prior to their death, patients may have been receiving medical care for a longer period of time. During such long-lasting illness trajectories, knowing patients' preferences offers healthcare providers the opportunity *"to set priorities in their efforts to make health care more responsive to patient's wants and needs* [2]." Therefore, it is useful for individuals to timely define their preferences concerning their goals of medical treatment. This may prevent overtreatment (e.g. non-beneficial intensive care unit admissions) as well as undertreatment (e.g. suboptimal alleviation of symptoms such as pain) which are both quite common [3, 4]. Preferences can concern whether or not individuals want to undergo e.g. cardiopulmonary resuscitation, artificial ventilation or artificial hydration. Furthermore, individuals can indicate whether they want to be admitted to inpatient care facilities, such as a hospital, nursing home or hospice. Defining preferences for medical treatment and care seems especially useful for older people since the probability of developing multiple chronic conditions and the need of medical care is increasing with age [5]. One study from the Netherlands among relatives of deceased older people concluded that "*people who had a known preference for forgoing treatment had a much higher chance that treatment indeed would be foregone, compared to people in whom no preferences was known, and people who had a known preference for starting treatment had a much lower chance that treatment would be foregone compared to people in whom no preferences was known* [6]." One way to define and discuss preferences for medical treatment and care is Advance Care Planning (ACP).

Advance Care Planning

The aim of ACP is to prepare and to activate individuals to take a role in future healthcare decision-making. Originally, the focus of ACP was on the completion of advance directives (ADs), in which treatment preferences can be recorded. An AD can contain directions to forgo treatments ("negative directive") or preferences for treatment to be applied ("positive directive") [7, 8]. In the Netherlands, physicians have to follow a negative directive if it is sufficiently clear and detailed. However, physicians are not obliged to follow a positive directive since patients have no right to claim certain treatments without their physicians' agreement. A positive directive can, however, serve to support a physician in understanding patient's preferences [7, 8].

Nowadays, the focus of ACP has gradually shifted from solely the completion of an AD towards discussing preferences with relatives and healthcare providers [9], which seems to be more effective in improving health outcomes [10]. ACP is now defined as *"enabling individuals to define goals and* *preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate* [11].” ACP has the potential to enhance provision of care that is consistent with patients’ preferences, to improve the quality of patient-clinician communication and to increase hospice and palliative care among a variety of patient groups [10, 12]. For instance, a randomized controlled trial (RCT) among hospitalized older people from Australia found that preferences for medical treatment and care were much more likely to be known and followed in the ACP intervention group (86%) compared with the control group (30%). Another study among heart failure patients in the USA found that ACP participants were more likely to have used hospice care compared to nonparticipants (56% versus 37%) [13], indicating that ACP increases the likelihood of receiving comfort care above life-prolonging treatment.

Worldwide, interest in ACP continues to grow as e.g. indicated by a rising number of scientific publications [11]. In the Netherlands, interest in ACP is growing as well. A study conducted in 2009/2010 showed that a majority of the Dutch general public seems open to discussing end-of-life care [7]. Several associations such as the Royal Dutch Medical Association or the Dutch Association of Elderly Care Physicians and Social Geriatricians, recently released public awareness campaigns recommending ACP [3, 14]. In addition, the Dutch advisory group “LAEGO” (Landelijke Adviesgroep Eerstelijnsgeneeskunde voor Ouderen) published an ACP toolkit (revised in 2017) which serves as a guideline for physicians to implement ACP in their office or region [15]. Despite this growing interest and the beneficial effects of ACP, discussions about goals and preferences for treatment and care are not common [16]. Barriers preventing older people from engaging in ACP include not being ready for ACP and a lack of access to doctors willing to have ACP conversations [17]. To overcome such barriers, it is recommended that ACP is delivered by trained facilitators to support the process [11]. Such facilitators (e.g. trained nurses) assist individuals and their relatives in reflecting on goals, values and beliefs and in discussing healthcare preferences. ACP is not limited to specific patient groups and can be provided at any stage of life, however, the content of ACP “*should be more targeted when the individual’s health condition worsens or as they age* [11].”

Advance Care Planning in older people

A recent review on ACP in older people included nine RCTs, which were predominantly conducted in North America or Australia [18]. Most ACP programs resulted in increased completion rates of ADs and increased appointment of surrogate decision-makers [18]. Furthermore, we identified in total 22 studies on ACP and healthcare costs [19-40], of which six had a randomized controlled design [19, 25-27, 29, 31] and 16 were conducted in the United States [22, 24-29, 32-40]. The majority of studies (14/22, 64%) showed that ACP was associated with reduced healthcare costs [19, 20, 22, 24-26, 28, 30, 32, 33, 36, 38-40]. ACP has also been shown to improve relatives' satisfaction about the quality of death and to reduce levels of stress, anxiety and depression among relatives of hospitalized older people in Australia [41]. Other studies among relatives of older people found mixed results [42] or no positive results at all [19, 43] on health outcomes. It is unknown to which extent these results can be generalized to European countries including the Netherlands, given differences in healthcare systems and legal ACP regulations. ACP may be more familiar, accepted and effective in countries where ACP is supported by legislation, like in Australia, the United Kingdom and the United States [44-47]. Furthermore, previous studies did not necessarily focus on (bereaved relatives of) frail older people.

Advance Care Planning in frail older people

ACP may be especially relevant for frail older people since this population is most likely to develop physical and cognitive deficits in the near future and most likely to have to rely on others to communicate their treatment preferences. Frailty is defined as *"an accumulation of physical, psychological and/or social deficits in functioning which increase the chance of adverse health outcomes (functional disabilities, admissions to an institution, death*) [48]." Worldwide, an estimated 11% of community-dwelling people aged ≥65 years are frail and this proportion is increasing with age, up to an estimated 26% of people aged ≥85 years [49]. Also in the Netherlands, 11% of community-dwelling people aged ≥65 years are frail [50]. Frailty is associated with high needs for healthcare and increased costs of care. For instance, the difference in total costs of care during three months between frail and non-frail German people amounted to €1917 (when frail people had four or five symptoms) [51].

1.2 AIMS AND RESEARCH QUESTIONS

It is unknown to which extent ACP can support frail older people to take a more active role in their health and healthcare and how this in turn may affect their quality of life and other health outcomes, like the use of medical care. This thesis aims to investigate effects of an ACP program in frail older people in the Netherlands. The main research questions are:

1. Are frail older people able to self-manage their health and healthcare?
2. What are the effects of ACP in frail older people on patient activation, quality of life, advance directive completion and surrogate decision-maker appointment?
3. What are the effects of ACP in frail older people on use of medical care, costs of medical care and the concordance of care with preferences?
4. What are the effects of ACP in bereaved relatives of frail older people considering preparation for decision-making, anxiety and depression?

5. How many older people are admitted to inpatient care facilities in their last year of life across Europe?

1.3 OUTLINE OF THIS THESIS

Part 1: Patient activation in frail older people

In **Chapter 2**, we describe the study protocol of our RCT on ACP in frail older people. In **Chapter 3**, we use data from the baseline assessment of the RCT. We explore whether frail older people are able to self-manage their health and healthcare by measuring their level of activation as patients. Furthermore, we describe which characteristics of frail older people are associated with patient activation.

Part 2: Effects of Advance Care Planning in frail older people

In **Chapter 4**, we assess the feasibility of the ACP program in frail older people and describe the effects of ACP on patient activation, quality of life, satisfaction with healthcare, AD completion and surrogate decision-maker appointment. In addition, we explore how frail older people experience ACP conversations. **In Chapter 5**, we present the effects of ACP on use and costs of medical care, and the concordance of received care with preferences. We also discuss the costs of the ACP program.

Part 3: Effects of Advance Care Planning in bereaved relatives of frail older people

In **Chapter 6**, we explore how bereaved relatives of frail older people experience ACP conversations and whether ACP has an effect on relatives' satisfaction with healthcare, preparation for decision-making, satisfaction with quality of death and their levels of anxiety and depression.

Part 4: Admissions in Europe

In the last year of life, many older people rather avoid admissions to inpatient care facilities, such as a hospital, nursing home or hospice. In **Chapter 7**, we describe and compare such admissions in the last year of life of community-dwelling older people across Europe. Furthermore, we identify personal and contextual characteristics that are associated with hospitalizations in the last year of life.

Discussion

In **Chapter 8**, we provide a general discussion on our findings, with recommendations for clinical practice and future research.

1.4 RESEARCH METHODS

This thesis describes the Laurens study and the Survey of Health, Ageing and Retirement in Europe (SHARE). Data of the Laurens study were used for **Chapters 3 through 6.** SHARE data were used for **Chapter 7**.

Laurens study

The Laurens study aimed at determining the effectiveness of ACP in frail older people. The study was conducted by the Erasmus MC and care organization Laurens in 2013-2017 in Rotterdam, the Netherlands, among residential care home residents and community-dwelling older people. To be eligible for participation, individuals had to be ≥75 years old, frail and capable to consent to participation. The intervention group was offered standardized ACP based on the Respecting Choices ACP facilitator training, education materials and tools. The primary outcome was the change in patient activation between baseline and 12-months of follow-up. Secondary outcomes included the change in quality of life, the change in satisfaction with healthcare, AD completion and surrogate decision-maker appointment. Use and costs of medical care were assessed during 12 months after study inclusion. In addition, the concordance of received care with patients' preferences was assessed. If participants were no longer capable to participate or had died during the 12-month follow-up, a relative, assigned by the participant at the start of the study, was approached for a telephone interview.

The study was supported by The Netherlands Organization for Health Research and Development (ZonMw, project number 837001009), Foundation Theia (project number 2013204) and care organization Laurens in Rotterdam, the Netherlands.

SHARE study

SHARE is an ongoing longitudinal study on health, socio-economic status and social networks of community-dwelling older people aged ≥50 years from a number of European countries and Israel. Data are available at the SHARE Research Data Center to the entire research community free of charge. The first wave of data was collected in 2004, the fifth in 2013. We used data from after-death interviews that were conducted with proxy respondents of deceased SHARE participants. Proxy respondents provided information on the number and duration of admissions to inpatient care facilities in the last year of life of the deceased participant and on personal characteristics of the deceased.

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A cluster randomized controlled trial on the effects and costs of Advance Care Planning in elderly care: study protocol

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ABSTRACT

Background: Currently, healthcare and medical decision-making at the end of life for older people are often insufficiently patient-centered. In this trial we study the effects of Advance Care Planning (ACP), a formalized process of timely communication about care preferences at the end of life, for frail older people.

Methods/Design: We will conduct a cluster randomized controlled trial among older people residing in care homes or receiving home care in the Netherlands. The intervention group will receive the ACP program Respecting Choices® in addition to usual care. The control group will receive usual care only. Participants in both groups will fill out questionnaires at baseline and after 12 months. We hypothesize that ACP will lead to better patient activation in medical decision-making and quality of life, while reducing the number of medical interventions and thus healthcare costs. Multivariate analysis will be used to compare differences between the intervention group and the control group at baseline and to compare differences in changes after 12 months following the inclusion.

Discussion: Our study can contribute to more understanding of the effects of ACP on patient activation and quality of life in frail older people. Further, we will gain insight in the costs and cost-effectiveness of ACP. This study will facilitate ACP policy for older people in the Netherlands.

BACKGROUND

The number of Europeans over 65 years of age will double in the next 50 years. To enable countries to successfully manage the dynamics and healthcare costs of their ageing populations, the WHO has proposed an "active ageing approach", based on the United Nations Principles of independence, participation, dignity, care and self-fulfillment [1]. It targets government decision-makers at all levels, the nongovernmental sector and the private sector, all of whom are responsible for the formulation of policies and programs on ageing. It focuses on the activation of older people and is aimed at timely recognition and consideration of peoples' healthcare preferences and needs to enable strategic planning and decision-making by older people themselves. Communication about peoples' needs and preferences is typically postponed until acute events necessitate short-term medical decision-making. Sharp and colleagues showed that the majority of frail, older people would like to get the opportunity to timely discuss end-of-life care. However, most of them do not have this opportunity [2]. Advance Care Planning (ACP) is a formalized process of communication between patients, their relatives and professional caregivers about patients' health preferences, goals and choices [3]. Its central aim is to activate people to participate in decision-making about their healthcare and to raise awareness of the need to anticipate future deterioration of health. Patients are encouraged to appoint a surrogate decision-maker and to document their wishes about their preferred care in an advance directive. In this way, written advance directives extend the autonomy of patients to a phase when they are incompetent [4].

Several studies have assessed the outcomes of ACP programs. In der Schmitten and colleagues studied the effects of implementing a regional ACP program in German nursing homes and concluded that the implementation led in many cases to the completion of advance directives with potential relevance to medical decision-making [5]. Some reviews showed that ACP is associated with better patient outcomes. In a recent systematic review, Brinkman-Stoppelenburg and colleagues showed that some ACP programs are associated with a reduction in futile measures and unnecessary hospitalizations [6]. The programs contributed to better communication between patients and healthcare professionals and higher quality of life of both patients and their relatives. Furthermore, extensive ACP interventions seemed to increase compliance with patients' wishes and satisfaction with care more than just the completion of advance directives. According to the review of Brinkman-Stoppelenburg and colleagues, extended programs such as e.g. the Respecting Choices program are the most promising ACP programs [6]. In another systematic review, Houben and colleagues showed that ACP programs facilitated completion of advance directives and end-of-life discussions between patients and healthcare professionals. The programs improved concordance between preferred and delivered care and potentially improve other outcomes as well, such as quality of communication [7]. Overall, we can conclude that ACP programs have beneficial effects on several patient outcomes. However, evidence on the effects of ACP programs in care homes and in community-dwelling older people is scarce [6, 7]. Furthermore, few studies concerned a randomized controlled trial, although this is the most preferred method of studying effects of interventions in healthcare. Finally, most of the studies were performed in the US. Previous research showed that end-of-life decision-making varies largely between countries [8]. It is unknown to what extent results from the US can be generalized to European countries like the Netherlands, given the differences in healthcare systems.

Also, research on the costs of ACP is limited, although the cost-effectiveness of healthcare interventions at the end of life is an important issue due to the fact that end-of-life care is often expensive. While healthcare costs in an average life year have been found to amount to €1100 per person, costs per last year of life were 13.5 times higher and approximated €14,900 per person according to Polder and colleagues [9]. Molloy and colleagues assessed the costs of an ACP program in a randomized controlled trial in Ontario, Canada. Intervention nursing homes reported fewer hospitalizations per resident, a lower hospital length of stay ensuing reduced hospital care costs and lower total healthcare costs than control nursing homes [10]. We are not aware of any formal cost-effectiveness studies on ACP programs in care homes or nursing homes in Europe.

We will perform the first cluster randomized controlled trial on the effects of ACP in frail, older people in the Netherlands. The main objective of this project is to assess the effects, the costs and the cost-effectiveness of ACP. Participants in the intervention group will be offered the Respecting Choices program, one of the most promising ACP programs (see below for further information about the program) [6, 11]. We focus on older people living in care homes or living at home and receiving home care. We hypothesize that ACP will lead to better patient activation in medical decision-making and quality of life in the intervention group compared to the control group, while reducing futile interventions and thus healthcare costs.

METHODS/DESIGN

Study design

We will conduct a cluster randomized controlled trial among older people living in care homes or at home receiving home care, following the CONSORT guidelines. The clusters will consist of neighborhoods. In the Netherlands, standardized household incomes have been calculated per neighborhood. We will order neighborhoods according to these standardized incomes to control for differences in income per study arm, since income is related to health [12]. Neighborhoods will be randomized per set of two neighborhoods with comparable household incomes to either the control or intervention condition.

Study population

The study population consists of older people living at home and receiving home care or residing in one of 16 participating care homes of Laurens, a care organization in Rotterdam, the Netherlands. Residents of care homes generally suffer from one or more chronic conditions and 32% are totally dependent on others for daily care needs [13]. Their average life expectancy is 3.7 years and their health condition often involves important healthcare decisions in a relatively short time frame.

Inclusion criteria

In order to be eligible to participate in this study, an older person must meet all of the following criteria:

1. ≥75 years of age;
2. Mentally competent, as measured by judgement of caregiver and a Mini–Mental State Examination [14] (MMSE score >16);
3. Fluent in Dutch;
4. Being frail, as measured by the Tilburg Frailty Index [15] (TFI score ≥5).

These criteria apply for both people living in care homes and people living at home and receiving home care. Older people who move during the follow-up of the study can remain included in the study.

Intervention

Older people in the intervention group will be offered the Respecting Choices program in addition to their usual care. This program, developed in the US, involves trained nurse facilitators who, in collaboration with physicians, assist residents and their relatives in reflecting on the residents' goals, values and beliefs and in discussing their healthcare wishes [11, 16]. This discussion also supports people to identify specific activities and experiences that may contribute to, or detract from, their quality of life. Residents are encouraged to appoint a surrogate decision-maker and to document their wishes about the care they do or do not want to receive in an advance directive. These wishes can e.g. concern the (non)use of burdensome life-prolonging interventions such as hospitalization or cardiopulmonary resuscitation. For our study, a nurse practitioner followed the Respecting Choices train-the-trainer program in the US. She will deliver the training program for the facilitators. These are nursing staff members of Laurens, who will deliver the intervention to the study participants. The intervention concerns two meetings of a facilitator with a participant of 1 h. The content of the communication during these meetings will be structured by the use of interview cards.

Primary and secondary outcomes

The primary outcome measure is patient activation, which measures patient participation in medical decision-making [17]. Secondary outcome measures are quality of life, satisfaction with healthcare, cost-effectiveness, use of burdensome medical interventions, appointment of a surrogate decision-maker and documentation of care wishes in advance directives.

Assessment and data collection

At baseline, in personal structured interviews, patient activation will be measured (PAM-13) [17]. The PAM assesses patients' knowledge, skill and confidence in self-management. Also, generic health-related quality of life as measured by the SF-12 [18] and satisfaction with healthcare as measured by the PSQ-18-SF6 [19] will be assessed.

At 12-month follow-up, participants will be interviewed again and their competence will be assessed with an adapted version of the Mini-Cog [20]. If participants are competent, the questions of the SF-12 [18], PAM [17] and PSQ-18-SF6 [19] will be asked. We will also ask whether participants completed an advance directive and assigned a proxy decision-maker. In the intervention group, open questions will be asked about how the patient experienced the ACP program.

If the Mini-Cog indicates that participants are no longer competent, a proxy, assigned by the patient at the start of the study, will be approached for a telephone interview. This interview will include the PSQ-18-SF6 [19] and a caregiver activation measure (CAM) [21]. Completion of an advance directive and assignment of a proxy decision-maker by the participant will be assessed. In the intervention group, open questions will be asked about how the relative and the patient experienced the ACP program.

If people pass away during the 12-month follow-up, a proxy, assigned by the patient at the start of the study, will be approached for a telephone interview. This interview will address characteristics of the dying process, quality of dying [16], PSQ-18-SF6 [19] and feelings of anxiety and depression of the relative as measured by the HADS [22]. In the intervention group, open questions will be asked about how the relative and the patient experienced the ACP program.

In a medical file study, we will investigate whether people have an advance directive in their medical file (and study its content). Moreover, we will study the medical care people receive during 12 months after inclusion, such as hospitalizations (number, length of stay), use of home care, palliative care, diagnostic procedures and specific treatments (e.g. medication, mechanical ventilation, resuscitation, chemotherapy, artificial fluids or food, surgery or antibiotics).

Furthermore, an extensive economic evaluation of ACP will be performed from a healthcare perspective. For the calculation of the healthcare costs we will distinguish intramural and extramural medical costs. The unit price of the ACP program will be determined with the micro-costing method, which is based on a detailed assessment of all resources used [23]. Therefore, ACP facilitators will register their time investments per individual participant. Costs for inpatient days in care homes will be estimated as real, basic costs per day using detailed administrative information. For the calculation of other medical costs, we will use charges as published in Dutch guidelines as a proxy of real costs [24].

Sample Size

We aim at an overall power of 0.8 (alpha 0.05) to detect a difference of at least 0.5 SD in the Patient Activation Measure. We consider 0.5 SD to be a clinical relevant difference based on the article of Norman and colleagues [25]. To be able to detect such a difference we need 63 individuals in each arm in a non-clustered study. We used a multiplication factor of (1+(k-1)*ICC), with k indicating the average cluster size, which is 12, and ICC indicating the intraclass correlation, which is the fraction of total variation in the data that is accounted for by between-group variation. For an ICC of 0.05 this amounts to a multiplication factor of 1.55, and thus 98 (1.55*63) individuals in both the intervention and the control arm.

Study procedures

Staff of the care organization will use a checklist to assess whether participants - either living in care homes or at home - are potentially eligible for the study (see Figure 1: CONSORT flow chart). These people will be informed about the study and will be asked to participate by the research team. Furthermore, in the intervention group they will be invited to visit an informative meeting about the study and the intervention.

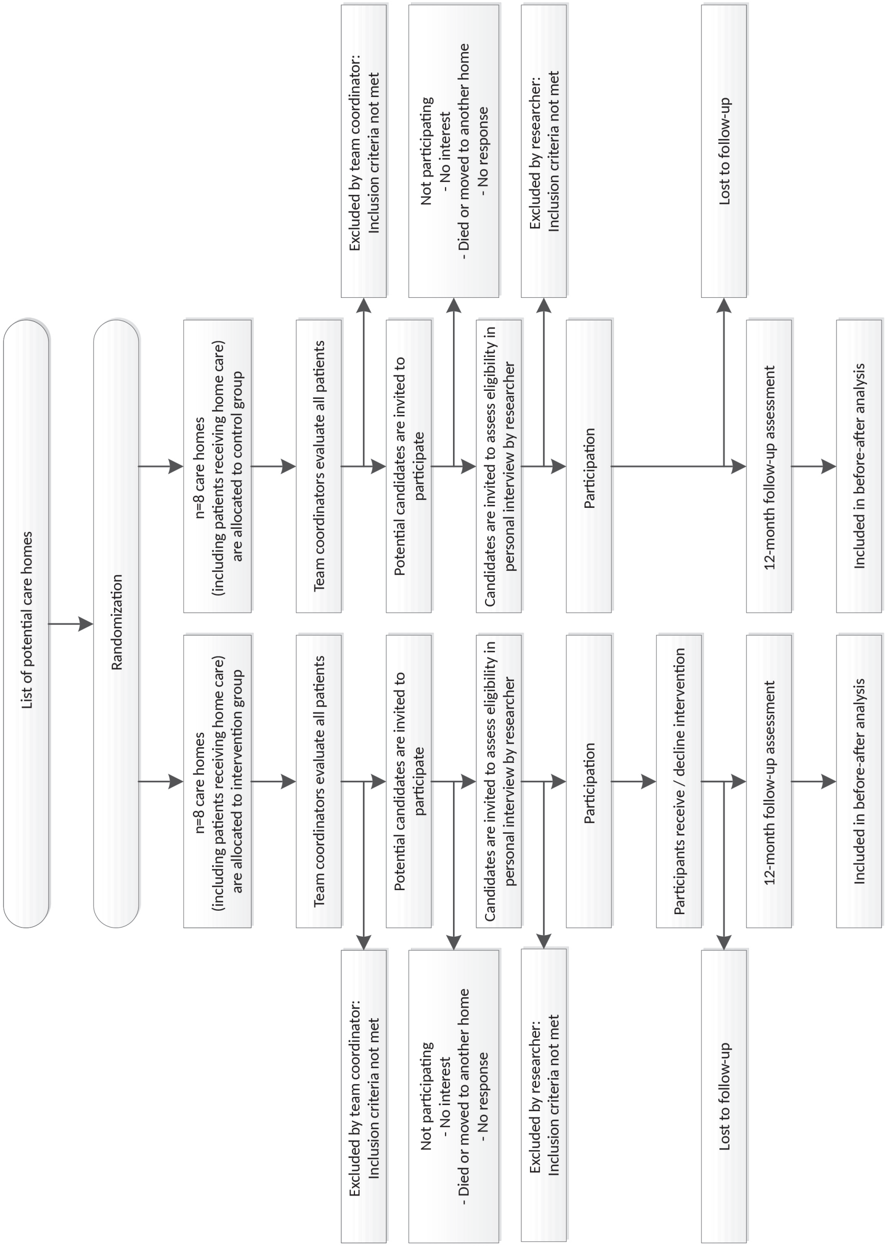

Figure 1 CONSORT flow chart

People who express an interest in the study, will be interviewed face-to-face by one of the researchers (AO, LJ). During this interview, they will receive additional information about the study. When individuals fulfil the inclusion criteria of the study and want to participate, written informed consent will be obtained. Subsequently, the baseline assessment will be completed and the intervention will be carried out in the intervention group. At 12 months after inclusion in the study, participants will be approached again by the researcher to complete a face-to face follow-up assessment. With written permission of the participants, data will be extracted from medical files with the use of a checklist, 12 months post-inclusion.

The independent Ethics committee of Rotterdam (Medisch Ethische Toetsingscommissie) has given approval for the study to be performed.

Statistical Analysis

Analyses will be performed following the intention-to-treat principle. Descriptive statistics will be used to summarize characteristics of the residents, the care homes and of people receiving home care. Characteristics of participating individuals (age, gender, socio-economic status, educational level) will be compared at baseline between the intervention and control (usual care) group using independent sample t tests and chi-square tests.

Multivariate analysis will be used to compare differences between the intervention group and the control group at baseline and to compare differences in changes after 12 months following the inclusion. Patient characteristics, TFI score, MMSE score and place of residence will be used as covariables. All statistical tests will be considered significant if $p<0.05$. Missing items will be imputed by the peoples' own average score if they have completed at least 50% of the items.

The cost-effectiveness of ACP will be assessed by calculating the incremental cost-effectiveness ratio (ICER), defined as the difference in costs of ACP compared to usual care, divided by the average change in effectiveness, with the patient activation as primary outcome measure [17]. We will perform a sensitivity analysis to assess the stability of the results to changes in costs and effectiveness parameters. Because of the short time horizon, costs and effects will not be discounted.

DISCUSSION

The presented study measures the costs and effects of ACP in elderly care. Until now, the costs and effects of ACP in Dutch care homes have not been studied in a randomized controlled trial. Currently, ACP is encouraged and several studies showed that ACP is associated with beneficial effects on patient outcomes [6, 7]. However, we do not know whether these beneficial effects apply to frail, older people residing in Dutch nursing homes or living at home and receiving home care. The presented study aims at studying whether offering ACP to older people will improve patient activation, quality of life and satisfaction with healthcare, while reducing futile medical interventions. Trained facilitators will talk with frail, older people about their wishes and preferences concerning medical treatment and care, facilitate timely conversations between participants and their appointed proxy decision-maker and support them in establishing an advance directive. This study will contribute to the implementation of an evidence-based ACP program for older people in The Netherlands. Below, some strengths and limitations of the study will be discussed.

Strengths and limitations

Strengths

First, older people will be offered standardized ACP using the Respecting Choices program [11]. According to Brinkman-Stoppelenburg and colleagues, complex interventions such as e.g. the Respecting Choices program are the most promising ACP programs [6]. Second, this study assesses costs. Until now no formal cost-effectiveness studies of ACP programs in care homes or nursing homes have been carried out. A methodological strength is that we will conduct a cluster randomized control trial which is the most preferred method of studying effects of ACP. Due to this design we will be able to draw conclusions on causal relationships.

Limitations

First, selection bias in identifying potential study participants cannot be ruled out. To prevent this as much as possible, we have prepared clear in- and exclusion criteria. These criteria are the same in both the intervention arm and the control arm.

Second, follow-up of the respondents is limited to 12 months after inclusion, while the average life expectancy of the study group is 3.7 years [13]. We expect that respondents may need to make important healthcare decisions within the timeframe of the study, given their frailty, but we may miss important decisions. However, the main goal of the study is to increase patient activation, and such activation is possible without major decisions taking place. Examples of this are conversations with relatives and healthcare professionals about preferences regarding future care.

Third, dropout will be an inevitable limitation of the study. Dropout can occur due to, for example, loss of contact. However, we ask staff members of Laurens to report participants moving house. If people move they can remain included in the study. Dropout can also take place because people are no longer interested in participation. However, we expect that the number of dropouts will be similar in both groups. If participants die during follow-up, one of their relatives will be asked to complete a bereaved carer questionnaire.

Fourth, the extent to which medical files reflect actual care can be questioned. We are not sure that all received treatments will be written down in medical files.

Opportunities

Realization of the study will contribute to more understanding of the effects of ACP in older, frail people in Europe. We will also gain insight in the costs and cost-effectiveness of ACP, which has rarely been studied until now. Positive outcomes of this study may facilitate the implementation of ACP in the target population of this study, but also in other populations and settings, such as younger people and/or people with advanced diseases. Future research could focus more on opinions and experiences of the patients' relatives. We hope that our results will encourage debates and discussions about optimal decision-making in the last phase of life and will lead to further studies, nationally and internationally.

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3

Low patient activation levels in frail older adults: a cross-sectional study

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ABSTRACT

Background: Frail older adults are increasingly expected to self-manage their health and healthcare. We assessed the extent to which this group is able to take up this responsibility by measuring their level of activation as patients (i.e. their knowledge, skills and confidence to self-manage their health and healthcare). Further, we studied which characteristics of older adults were associated with patient activation.

Methods: In this cross-sectional study 200 frail, competent adults (median age 87 years) participated. Participants were community-dwelling adults who received home care and residents of care homes. Data were collected via personal interviews in participants' homes. The main outcome measure was patient activation assessed by the short version of the Patient Activation Measure (PAM-13; range: 0-100). The PAM distinguishes four levels of increasing activation with level one indicating poor patient activation and level four adequate patient activation. Other studied variables were: multimorbidity, type of residency, frailty (Tilburg Frailty Index), mental competence (Mini-Mental State Examination), health-related quality of life (SF-12), satisfaction with healthcare (subscale Patient Satisfaction Questionnaire) and personal characteristics (age, gender, marital status, educational level). Regression analyses were performed to investigate which variables were associated with patient activation.

Results: Participants had a median PAM score of 51. Thirty-nine percent had level one activation, 31% level two, 26% level three and 5% level four. Fifty-nine percent of community-dwelling adults had level one or two activation versus 81% of care home residents (p=.007). Mental competence (Effect: 0.52, CI: 0.03–1.01, p=.04) and health-related quality of life (Effect: 0.15, CI: 0.01–0.30, p=.04 for physical health; Effect: 0.20, CI: 0.07–0.34, p=.003 for mental health) were positively associated with patient activation. Frailty (Effect: -1.06, CI: -1.75 – -0.36, p=.003) was negatively associated with patient activation.

Conclusions: The majority of this frail and very old study population, especially those with a lower health-related quality of life, may be unable to self-manage their health and healthcare to the level expected from them. The increasing population of frail older adults may need help in managing their health and healthcare.

BACKGROUND

"Frailty is a process of an accumulation of physical, psychological and/or social deficits in functioning which increase the chance of adverse health outcomes (functional disabilities, admission to an institution, death) [1]." In the Netherlands, around 27% of older adults aged 65 and over are frail. This percentage includes older adults living independently (of whom one quarter are frail) and older people living in an institution, e.g. a care home (of whom three-quarters are frail) [1].

Currently, governments in many Western countries including the Netherlands are reforming their healthcare sectors [2] and develop policies that aim to reduce institutional care, thereby encouraging frail older adults to remain community-dwelling [3, 4]. Since these efforts align with the preferences of many older adults [5], these policies may well be successful. However, their success relies on the degree of older adults' ability to manage their lives, health and healthcare by themselves while community-dwelling [6], where possible assisted by (informal) caregivers. The question is whether frail older adults have sufficient abilities to do so. Older adults often have lower health literacy skills than younger adults [7] and often find it difficult to take an active role in healthcare decision-making [8]. This suggests that the levels of patient activation in older adults may be relatively low.

Patient activation refers to the motivation, knowledge, skills and confidence that equip adults to be actively engaged in their health and healthcare [9]. Hibbard and colleagues came up with the following conceptual definition of patient activation: *"Those who are activated believe patients have important roles to play in self-managing care, collaborating with providers, and maintaining their health. They know how to manage their condition and maintain functioning and prevent health declines; and they have the skills and behavioral repertoire to manage their condition, collaborate with their health providers, maintain their health functioning, and access appropriate and high-quality care* [9]." According to Hibbard and colleagues, activation is developmental in nature and involves four increasing levels [9]. Cross-sectional studies among populations with a range of conditions and economic backgrounds reported that adults' activation levels were positively related to their health status (e.g. health-related quality of life, which refers to the perceived well-being in physical, mental and social domains of life), healthy behaviors (e.g. physical activity, healthy diet), appropriate use of healthcare systems (e.g. not delaying doctor visits) and satisfaction with care services [10, 11]. Females, younger adults and those with higher education and income levels have been shown to have higher activation levels [12, 13]. Longitudinal studies suggest that the level of patient activation is also predictive of future health outcomes [14, 15]. For instance, Hibbard and colleagues assessed activation levels of adults with chronic conditions [15]. After four years of follow-up, less activated adults had "*significant worse levels of medication adherence, getting* *recommended care, health behaviors, functional health, emergency department use, and hospitalizations*" than the most activated adults [15].

Until now, only few studies have investigated patient activation among older adults [16-19]. The studied adults were not necessarily frail and their mean ages varied from 71 [17] to 77 [18]. Investigating patient activation among frail, very old adults is relevant because this population has high needs for healthcare and is more and more expected to manage their lives, health and healthcare by themselves. In this explorative study we determined the degree of patient activation in frail, very old adults. Furthermore, we aim to assess which personal (age, gender, marital status and education) and other characteristics (multimorbidity, type of residency, frailty level, mental competence, physical health, mental health and satisfaction with healthcare) are associated with patient activation in this population.

METHODS

Study design and population

This study had a cross-sectional design. We used data from the baseline assessment in a cluster randomized controlled trial on the effects of Advance Care Planning. Information on the study protocol of the trial can be found elsewhere [20]. The study population consisted of both community-dwelling older adults who received regular care from a home care organization, such as assistance with activities of daily living (ADL), self-care or domestic help, and older adults residing in one of 16 residential care homes of a large long term care organization in Rotterdam, the Netherlands. In the Netherlands, adults are admitted to residential care homes if they are no longer able to live on their own home due to illness, disabilities and/or old age. They can get assistance with ADL, self-care, medication use and/or domestic help 24 h a day. However, the medical care and treatment provided by residential care homes is very limited and residents are required to manage this by themselves (e.g. by consulting their general practitioner or other physicians). Dutch nursing homes on the other hand, employ their own medical, paramedical and psychosocial staff, including a specially trained nursing home physician. Their residents are often more disabled and need more help with ADL than residential care home residents [21].

To be eligible for participation, adults had to be ≥75 years, frail and mentally competent. Frailty was operationalized as a score of ≥5 on the Tilburg Frailty Index (TFI, range 0-15) [22]. The TFI consists of a physical (range: 0-8), psychological (range: 0-4) and a social domain (range: 0-3). Mental competency was based on the score of the Mini-Mental State Examination (MMSE, range 0-30) [23]. MMSE scores between zero and 16 are indicative of mental incapacity [24], therefore we used a score of ≥17 as criterion for inclusion. The care staff initially indicated which adults were likely eligible. Eligibility was subsequently confirmed by the research team using the instruments described above.

Measures

Personal interviews were conducted during the period March 2014 – April 2015. Through a subscale of the TFI, we collected socio-demographic data on age, gender, marital status, multimorbidity (≥2 diseases or chronic disorders) and education level. Education level was defined as the highest educational qualification achieved (low = none or primary education; middle = secondary education; high = higher professional or university education). To determine the degree of knowledge, skills and confidence for self-management of health and healthcare, we used the short version of the Patient Activation Measure (PAM-13) [9, 13]. The PAM consists of 13 statements, such as "I know how to prevent problems with my health" and "I am confident that I can tell a doctor my concerns, even when he or she does not ask." The four answer options range from "disagree strongly" to "agree strongly" and a fifth response option is "not applicable." We used a conversion table provided by the developers (Insignia Health) to calculate a standardized activation score ranging from zero to 100 (the PAM score). Besides the PAM score, with higher scores indicating more activation, the conversion table automatically calculates four levels of patient activation. At level one (PAM scores ≤47.0), adults "*tend to be overwhelmed with the task of managing their health and may not feel ready to take an active role*." At level two (PAM scores between ≥47.1 and ≤55.1), adults "*realize that they have a role to play in their healthcare, but may lack the knowledge and confidence to manage their health and healthcare*." At level three (PAM scores between ≥55.2 and ≤72.4), adults "*are beginning to take action, but may still lack some confidence to manage all aspects of their health*." At level four (PAM scores ≥72.5), adults can manage their health and care, but "*struggle with being able to maintain the behaviors they have already adopted* [25]." The PAM is a reliable and valid measure with good psychometric properties [9, 13] and has been shown to be valid in a study of multimorbid older adults with a mean age of 77 [18].

Further, we added outcome variables to the questionnaire that were found relevant for patient activation in previous research [10, 11]. Generic health-related quality of life was measured with the 12-Item Short Form Survey (SF-12) [26] which generates a physical component score (PCS) and a mental component score (MCS, range: 0-100). SF-12 scores of our frail and old study population were compared with the SF-12 scores of the general population aged ≥75 years, using data of "Statistics Netherlands [27]." General satisfaction with healthcare was measured by one subscale (two items) of the Patient Satisfaction Questionnaire (PSQ-18; range: 1-5) [28].

Statistical analysis

Since the scores of the TFI and MMSE were not normally distributed, we decided to report the median and interquartile range (IQR) for all continuous variables including the PAM score, which was normally distributed. A chi-square test investigated the association between type of residency and PAM levels. Further, we investigated associations between age, gender, marital status, education, multimorbidity, type of residency, frailty level, mental competence, physical health, mental health and satisfaction with healthcare on the one hand, and the PAM score on the other hand using univariate linear regression analysis. To assess whether each of our continuous variables was linearly related to the PAM score, we added a quadratic term of the continuous variable to each model. If continuous variables appeared to be non-linearly associated with the outcome we used a spline function to assess the association between that variable and the outcome (PAM). A multiple linear regression analysis was performed to investigate which variables were associated with the PAM score while controlling for personal characteristics (age, gender, marital status, education). In this multiple regression analysis, we only included variables that were significantly associated with patient activation in univariate analyses. We controlled the residual plot for each included variable. Analyses were performed using IBM SPSS statistics V.22 and using R.

Ethics

The independent Ethics committee of Rotterdam (Medisch Ethische Toetsingscommissie) proved approval for the study to be performed. Potential candidates received a letter with study information and had the possibility to ask questions in the first personal interview. If candidates were willing to participate and eligible, a second personal interview was arranged. During this interview, written informed consent was obtained.

RESULTS

Care staff evaluated 1881 individuals for possible participation in total, of whom 1006 were excluded because they did not fulfil the inclusion criteria. We approached the remaining 875 individuals. Six hundred ten out of 875 potential candidates did not participate (54 died or moved to another home, 452 indicated they were not interested and 104 did not respond). The remaining 265 candidates were willing to participate, of whom 201 were indeed eligible and participated (Figure 1).

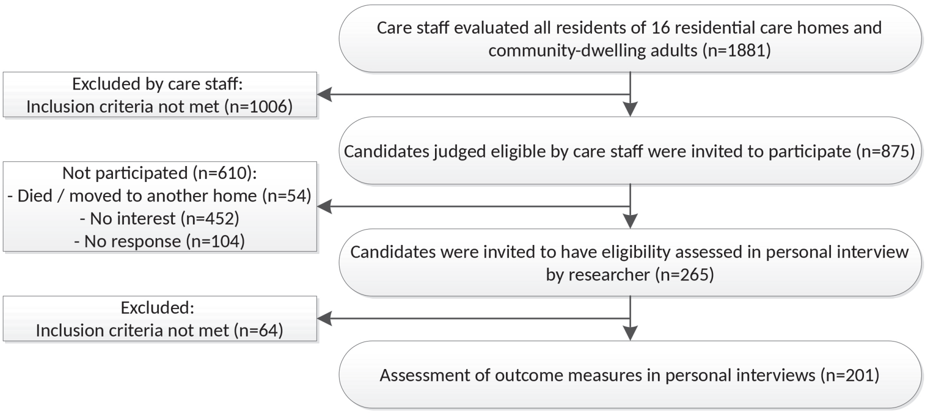

Figure 1 Flow chart

Data of one person were excluded due to responding “not applicable” too often (≥4 times) when completing the PAM. The median and mean age of participants was 87 years (Table 1). We found a median of 31 for the physical health (mean score = 32, compared to a mean score of 41 for the general older population [27]) and a median of 51 for the mental health (mean score = 51, compared to a mean score of 53 for the general older population [27]). Since the quadratic term of the PSQ score (subscale “General Satisfaction”) was significant, indicating a non-linear association between the PSQ score and the PAM score, we calculated a spline function (Figure 2), which showed a significant relationship of the PSQ and the PAM.

Table 1 Characteristics of the study population

Sample characteristic	**Sample description (n=200)**
Age, median (IQR, range)	87 (7.8, 73-102)
Gender, n (%)	
- female	140 (70)
Marital status, n (%)	
- married/cohabiting	39 (20)
- never married	16 (8)
- divorced	10 (5)
- widow(er)	135 (68)

Table 1 (continued) Characteristics of the study population

Sample characteristic	Sample description (n=200)
Education level, n (%)	
- high	21 (11)
- middle	104 (52)
- low	74 (37)
- *missing*	*1*
Multimorbidity, n (%)	
- yes	95 (48)
-missing	*1*
Type of residency, n (%)	
- community-dwelling	110 (55)
- care home	90 (45)
Frailty	
Tilburg Frailty Index (TFI), median (IQR, range)[a]	7 (3.0, 5-14)
- physical domain, median (IQR, range)[b]	5 (2.0, 1-8)
- psychological domain, median (IQR, range)[c]	1 (1.0, 0-4)
- social domain, median (IQR, range)[d]	2 (1.0, 0-3)
Competence	
Mini-Mental State Examination (MMSE), median (IQR, range)[e]	27 (4.0, 20-30)
Patient activation	
Patient Activation Measure (PAM), median (IQR, range)[f]	51 (10.3, 33-100)
Activation levels based on PAM score, n (%)[g]	
- level 1 (≤47.0)	77 (39)
- level 2 (≥47.1 and ≤ 55.1)	61 (31)
- level 3 (≥55.2 and ≤72.4)	52 (26)
- level 4 (≥72.5)	10 (5)
Generic health-related quality of life	
SF-12	
- physical health component score (PCS-12), median (IQR, range)[h]	31 (11.9, 10-68)
- mental health component score (MCS-12), median (IQR, range)[h]	51 (13.1, 22-75)

Table 1 (continued) Characteristics of the study population

Sample characteristic	**Sample description (n=200)**
Satisfaction with healthcare	
Subscale "General Satisfaction" of the Patient Satisfaction Questionnaire (PSQ-18), median (IQR, range)[i]	4 (1.0, 1.5-5)
- score 1.00- 2.00, *n* (%)	14 (7)
- score 2.50- 3.50, *n* (%)	79 (40)
- score 4.00- 5.00, *n* (%)	107 (54)

[a] TFI, normal range 0-15. Higher scores indicate worse functioning.
[b] TFI physical domain, normal range 0-8.
[c] TFI psychological domain, normal range 0-4.
[d] TFI social domain, normal range 0-3.
[e] MMSE, normal range 0-30. Higher scores indicate better functioning.
[f] PAM, normal range 0-100. Higher scores indicate a higher degree of engagement in health behavior.
[g] Higher levels indicate a higher degree of engagement in health behavior.
[h] SF-12, normal range 0-100. Higher scores indicate better functioning.
[i] Subscale PSQ-18, normal range 1-5. Higher scores indicate better functioning.

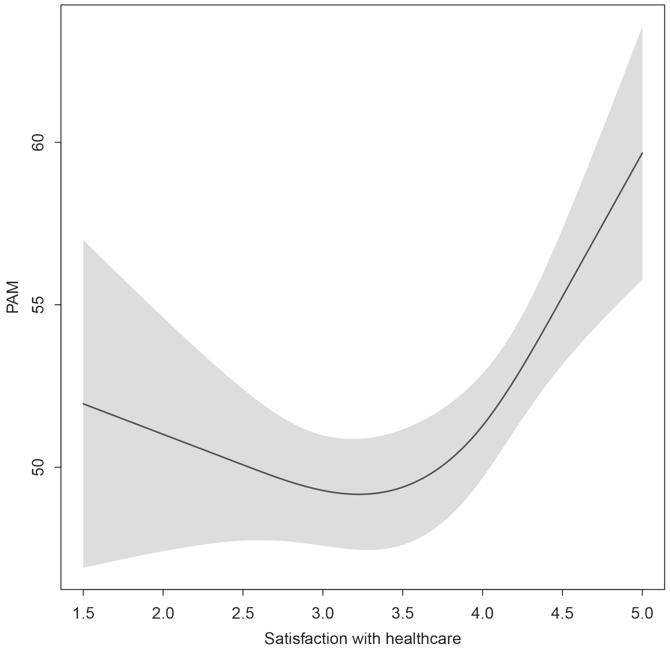

Figure 2 Spline plot of the association of satisfaction with healthcare (x-axis) with the score on the Patient Activation Measure (PAM, y-axis)

Patient activation

The median PAM score was 51 (IQR: 10.3, range: 33–100). Most adults reported activation level one (39%), followed by activation level two (31%), activation level three (26%) and activation level four (5%, Table 1). Care home residents more often reported lower activation levels (levels one and two; n = 73, 81%) than community-dwelling adults (n = 65, 59%, p=.007, Table 2).

Table 2 Activation levels by type of residency

Type of residency	**Activation levels, n (%)**			
	Level 1	**Level 2**	**Level 3**	**Level 4**
Community-dwelling, n=110	37 (34)	28 (26)	39 (36)	6 (6)
Care home, n=90	40 (44)	33 (37)	13 (14)	4 (4)

Being community-dwelling (compared to care home residents; Effect: 2.74, CI: 0.12–5.36, p=.04), the degree of mental capacity (Effect: 0.57, CI: 0.06–1.07, p=.03), physical health (Effect: 0.20, CI: 0.07–0.33, p=.004) and mental health (Effect: 0.27, CI: 0.15–0.40, p<.001) and satisfaction with healthcare (Effect: 1.99, CI: 0.37–3.62, p<.001) were positively associated with PAM scores. Education level (Effect: -4.74, CI: -9.28 – -0.21 for high educated adults compared to low educated adults, p=.05) and frailty (Effect: -1.64, CI: -2.24 – -1.04, p<.001) were negatively associated with PAM scores (Table 3).

Multiple regression analysis (Table 4) confirmed these findings, however, the association between satisfaction with healthcare and PAM scores was no longer significant.

Table 3 Univariate linear regression between personal and other characteristics of older adults, and patient activation

	Patient Activation Measure (PAM), n=200	
	Effect (95% CI)	**P-value**
Age (per year)	-0.05 (-0.28 – 0.19)	.71
Gender		.97
- female	-0.05 (-2.92 – 2.82)	
- male	Ref	
Marital status		.85
- married/cohabiting	1.35 (-2.02 – 4.73)	
- never married	-0.01 (-4.92 – 4.90)	
- divorced	-0.90 (-6.98 – 5.19)	
- widow(er)	Ref	

Table 3 (continued) Univariate linear regression between personal and other characteristics of older adults, and patient activation

	Patient Activation Measure (PAM), n=200	
	Effect (95% CI)	**P-value**
Education level[a]		.05
- high	-4.74 (-9.28 – -0.21)	
- middle	-2.93 (-5.72 – -0.14)	
- low	Ref	
Multimorbidity[a]		.11
- yes	2.14 (-0.49 – 4.77)	
- no	Ref	
Type of residency		.04
- community-dwelling	2.74 (0.12 – 5.36)	
- care home	Ref	
Frailty		
Tilburg Frailty Index (TFI, per point)	-1.64 (-2.24 – -1.04)	<.001
Competence		
Mini-Mental State Examination (MMSE, per point)	0.57 (0.06 – 1.07)	.03
Generic health-related quality of life		
SF-12		
- physical health component score (PCS-12, per point)	0.20 (0.07 – 0.33)	.004
- mental health component score (MCS-12, per point)	0.27 (0.15 – 0.40)	<.001
Satisfaction with healthcare		
Subscale "General Satisfaction" of the Patient Satisfaction Questionnaire (PSQ-18), interquartile distance (4 vs. 3)	1.99 (0.37 – 3.62)	<.001

[a] Missing n=1.

Table 4 Multiple linear regression between characteristics of older adults and patient activation[a]

	Patient Activation Measure (PAM), n=199	
	Effect (95% CI)	**P-value**
Type of residency		.009
- community-dwelling	3.49 (0.89 – 6.09)	
- care home	Ref	
Frailty		
Tilburg Frailty Index (TFI, per point)	-1.06 (-1.75 – -0.36)	.003
Competence		
Mini-Mental State Examination (MMSE, per point)	0.52 (0.03 – 1.01)	.04
Generic health-related quality of life		
SF-12		
- physical health component score (PCS-12, per point)	0.15 (0.01 – 0.30)	.04
- mental health component score (MCS-12, per point)	0.20 (0.07 – 0.34)	.003
Satisfaction with healthcare		
Subscale "General Satisfaction" of the Patient Satisfaction Questionnaire (PSQ-18), interquartile distance (4 vs. 3)	0.84 (-0.71 – 2.40)	.06

[a] The model is adjusted for age, gender, marital status and education.
Adjusted R squared=0.237.

DISCUSSION

This study describes a frail, very old population with lower levels of physical functioning than the general older population [27]. A majority of frail older adults in our study had low activation levels (levels one and two of the PAM). Low activation levels were in particular present among those with a lower health-related quality of life and among care home residents. However, more than half of community-dwelling adults had suboptimal activation levels (levels one and two) as well.

Compared to other study populations, such as younger adults with chronic physical disorders (mean PAM scores: 57 [14] - 69 [29] or community-dwelling older adults with lower mean ages (77, mean PAM score: 57 [18] and 74, mean PAM score: 66 [17]), the mean activation score of our participants (mean PAM score: 52) was rather low. This could be related to our participants' advanced age.

In accordance with previous findings [10, 11], health was positively associated with patient activation in our study. Unlike earlier studies, we found no significant association between age and patient activation [12, 13], which may not be surprising given the homogeneous age of our study population

(≥73 years). Unexpectedly, we found higher activation levels among those with low versus high education levels in univariate analyses. This finding could partly be due to a selection effect. In the Netherlands, life expectancy of adults with lower educational levels is 76.6 years for men and 80.2 years for women, while life expectancy for highly educated adults is 82.6 years for men and 86.9 years for women [30]. This boils down to a difference of 6 to 7 years. The mere fact that the low-educated participants in our study, with a median age of 87, were still alive, mentally competent and able and willing to engage in this research indicates that their health situation and everyday functioning was better than that of the majority of their lowly educated peers.

Due to healthcare reforms in the Netherlands, admission policies for residential care homes have become more restrictive. Adults who previously would have been admitted to residential care homes now have to remain community-dwelling, while receiving care at home. This results in an increasing number of community-dwelling frail older adults. For these healthcare reforms to be successful, frail older adults at least partly need to manage their lives, health and healthcare by themselves [6]. However, the low levels of patient activation as found in our study indicate that the majority of frail older adults may not have the abilities, knowledge, skills and confidence to adequately engage to this level of self-management. This may have several consequences for their health and healthcare. First of all, many older adults have multiple chronic conditions, often associated with disabilities, poor functional status and poor quality of life [31]. Their health and healthcare is further compromised if they also have low activation levels, as shown by Hibbard and colleagues [15].

A second possible consequence of older adults' limited self-management skills is a higher number of hospital (re-)admissions and an increasing use of complex emergency care. As shown by Hibbard and colleagues, less activated adults had higher rates of hospitalizations and emergency department visits than higher activated adults [10]. An increasing use of complex emergency care has been already observed in the Netherlands [32]. According to employees of emergency departments and ambulance control rooms of two Dutch provinces, this is due to higher numbers of community-dwelling frail older adults as a consequence of recent policy changes that aim to reduce institutional care [32]. Also, general practitioners from all over the country and the primary care branch association have reported to experience greater work burden due to more urgent care demands outside office hours from frail older adults, who now remain community-dwelling [33].

Third, limited self-management skills of older adults may result in a higher than expected need of (informal) caregiver assistance. Recent studies already demonstrated an increasing need for informal caregiver assistance [34]. This has been associated with high levels of caregiver burden and several health-related problems, such as sleep-disturbances and depressive symptoms [35, 36].

Previous studies have shown that patient activation can be improved by e.g. clinical-based or community-based interventions, which allow adults to be supported in the development of their self-management skills [10, 11]. However, as these studies were performed in young and middle-aged adults [10, 11], it is unknown whether patient activation is still modifiable in frail, older adults. It has been argued that efforts to promote patient activation are ethically justified because of two reasons. First, the right to self-determination of adults will be addressed by allowing them to set health goals and by promoting their ability to accomplish these goals [37]. The second justification is a consequentialist one: evidence shows that efforts to promote patient activation are likely to produce better health and health care outcomes [37]. However, expecting adults to actively promote their own health and healthcare is only justified when they have the capacity to do so and when others create a realistic opportunity for them to do so [37], e.g. by delivering healthcare tailored to their care needs and activation levels.

This study has several strengths. We conducted personal interviews assuring that participants understood the questions correctly and that we interpreted their answers appropriately. Furthermore, we were able to include study participants with the exceptionally high median age of 87 years. There are some limitations, which should be considered when interpreting the findings. The response rate of our study was modest. Therefore, our findings are not necessarily generalizable to all frail, older adults who receive care. Furthermore, our study population consisted of mentally competent older adults who were able and willing to engage in research and who were potentially more interested in conversations about health and healthcare than decliners. This may have resulted in an overestimation of the level of patient activation in this population. On the other hand, the TFI may be more likely to identify people who have lower levels of activation. Finally, this study had a cross-sectional design. We were not able to draw conclusions concerning the direction of associations between health characteristics and patient activation.

CONCLUSIONS

The majority of this frail and very old study-population, especially those with a lower health-related quality of life, may be unable to manage their health and healthcare to the level expected of them. The increasing population of frail older adults may need help in managing their health and healthcare.

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Advance Care Planning in frail older adults: a cluster randomized controlled trial

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ABSTRACT

Objectives: To determine the effectiveness of Advance Care Planning (ACP) in frail older adults.

Design: Cluster randomized controlled trial.

Setting: Residential care homes in the Netherlands (N=16).

Participants: Care home residents and community-dwelling adults receiving home care (N=201; n=101 intervention; n=100 control). Participants were 75 years and older, frail and capable of consenting to participation.

Intervention: Adjusted Respecting Choices ACP program.

Measurements: The primary outcome was change in patient activation (Patient Activation Measure, PAM-13) between baseline and 12-month follow-up. Secondary outcomes included change in quality of life (SF-12), advance directive (AD) completion and surrogate decision-maker appointment. Use of medical care in the 12 months after inclusion was also assessed. Multilevel analyses were performed, controlling for clustering effects and differences in demographics.

Results: Seventy-seven intervention participants and 83 controls completed the follow-up assessment. There were no statistically significant differences between the intervention (-0.26 ± 11.2) and control group (-1.43 ± 10.6) in change scores of the PAM (p=.43) or the SF-12. Of intervention group participants, 93% completed an AD and 94% appointed a decision-maker. Of control participants, 34% completed an AD and 67% appointed a decision-maker (p<.001). No differences in the use of medical care were found.

Conclusions: ACP did not increase levels of patient activation or quality of life but did increase completion of ADs and appointment of surrogate decision-makers. It did not affect use of medical care.

INTRODUCTION

Advance Care Planning (ACP) aims to prepare and to activate individuals to take a role in healthcare decision-making [1]. ACP is a process that enables individuals to define goals and preferences for future medical treatment and care, to discuss these with family and healthcare providers, and to record and review preferences if appropriate [1]. Individuals who have completed an advance directive (AD) are more likely to receive care that aligns with their preferences [2].

ACP may be especially relevant for frail older adults given the high prevalence of conditions that might affect communication about future healthcare decisions [3]. A recent review of ACP in older adults included nine randomized controlled trials predominantly conducted in nursing home populations in North America and Australia [4]. Most ACP programs resulted in higher AD completion rates and greater likelihood of appointment of surrogate decision-makers [4]. One of the nine studies reported significantly lower hospitalization rates in ACP participants [5]. It is unknown whether these results can be generalized to European countries or to frail, cognitively competent older adults.

The extent to which ACP can support frail older adults to become more active in their health and care, and how such activation may affect their quality of life and other health outcomes, is unknown. Patient activation refers to the knowledge, skills and confidence that equip individuals to be actively engaged in their healthcare [6]. Hibbard's conceptual model of patient activation postulates that modifiable social-environmental factors (e.g., support) can influence activation levels, which in turn can influence health outcomes [7]. Previous studies in younger adults have showed that community-based interventions can increase patient activation [8, 9].

We performed the first cluster randomized controlled trial on the effects of ACP in frail, older, cognitively competent adults in Europe. We assessed the feasibility of ACP in this population and hypothesized that ACP increases patient activation, quality of life, satisfaction with healthcare, completion of ADs and appointment of surrogate decision-makers while reducing the use of medical care.

METHODS

Trial design and participants

We conducted a cluster randomized controlled trial among frail older adults, following the Consolidated Standards Of Reporting Trials guidelines (Figure 1) [10]. To be eligible for participation, individuals had to be aged 75 and older, frail (Tilburg Frailty Index score ≥5, range 0-15) [11] and capable to consent to participation (Mini-Mental State Examination score ≥17, unadjusted for education level [12, 13]). Participants lived in residential care homes or in the immediate surroundings while receiving home care. In 2013, all residential care homes of a large care organization with potentially eligible residents were identified. Healthcare staff screened all residents of the participating 16 residential care homes and all community-dwelling adults who lived in the immediate surroundings and received home care for eligibility. The research team subsequently confirmed eligibility using the instruments described above.

Randomization

We used a cluster randomized design. Because income is an important indicator of socioeconomic status and is associated with patient activation [7], we controlled for differences in income between study groups. We ordered the 16 residential care homes according to standardized household incomes per neighbourhood, which ranged between €15,200 ($18,449) and €39,200 ($46,358) [14]. Then we randomized residential care homes per set of two with comparable household incomes using a computer-generated list of random numbers. Because of the study design and the nature of the intervention, participants, healthcare staff and researchers could not be masked to allocation status.

Intervention

The intervention group was offered facilitated planning conversations based on the Respecting Choices ACP facilitator training, education materials and tools. This US program [15], which involves trained facilitators who assist individuals in exploring the understanding of their illness; reflecting on goals, values and beliefs; discussing healthcare preferences and appointing a surrogate decision-maker, was modified for use in this Dutch context. Nurses who were employed by the care organization could apply for the role of facilitator. Eight nurses were selected based on criteria such as being able to talk about the end of life and having an open attitude toward individuals' preferences and were trained to deliver the intervention. The training lasted three days and included role plays and homework assignments. Our intervention had three core elements: information provision through leaflets; facilitated ACP conversations based on scripted interview cards and completion of an AD, including appointment of a surrogate decision-maker. See Supplementary Figure F1 and Supplementary Tables S1 and S2 for a detailed description of the ACP program. Intervention fidelity was assessed by determining whether participants received information leaflets, whether interview cards were used during ACP conversations and whether participants provided a copy of their study AD. Feasibility of the ACP intervention was determined as whether older adults wanted to participate in our study, whether participants engaged in the ACP program and whether participants in the intervention group provided a copy of their study AD.

Outcomes measures

Because ACP aims to prepare and to activate individuals to take a role in healthcare decision-making, we chose the 13-item Patient Activation Measure (PAM) as the primary outcome measure (range: 0-100) [16]. The PAM measures individuals' knowledge, skills and confidence to manage their health and healthcare. It consists of 13 items with five response options each: disagree strongly, disagree, agree, agree strongly, not applicable. We calculated a standardized activation score ranging from zero to 100. A change of at least four points is considered clinically meaningful [17]. The PAM is a reliable and valid measure with good psychometric properties [6, 16] and appeared to be valid in a study of older adults with multimorbidity [18].

Secondary outcome measures were quality of life, satisfaction with healthcare, documentation of care preferences in an AD, appointment of a surrogate decision-maker and use of medical care. Generic health-related quality of life was measured using the 12-Item Short-Form Health Survey (SF-12) [19] which generates a physical component score (PCS; range: 0-100) and a mental component score (MCS; range: 0-100). General satisfaction with healthcare was measured using one subscale of the Patient Satisfaction Questionnaire (PSQ-18; range: 1-5) [20]. Documentation of care preferences and appointment of a decision-maker were measured by asking: "Did you ever record the care or treatment you do or do not want to receive in writing?" (yes; no; I don't know) and "Have you appointed a surrogate-decision-maker?" (yes, orally; yes, in writing; no). We also asked participants in the intervention group who completed a study AD to provide us with a copy. We assessed whether the participants' general practitioner (GP) medical files contained an AD and registered the medical care that the participant received during the 12 months after inclusion.

Procedures

This trial was registered at the Netherlands Trial Registry (NTR4454). In 2014, potential candidates were sent a letter with study information. In the intervention clusters, this letter contained an invitation to attend an informative meeting about the intervention, which took place in each intervention care home before the interviews. Subsequently, we approached candidates in person or over the telephone to ask whether they were interested in participating in the study, unless they had already declared that they were not interested. During the first personal interview at the participants' home (either in a residential care home or in the community), researchers answered candidates' questions and assessed their eligibility. If candidates were willing to participate and were eligible, a second personal interview was arranged at the participants' home, during which written informed consent was obtained, the baseline assessment was completed and participants received information leaflets. Intervention participants subsequently engaged in the ACP program. After 12 months, the researcher approached participants to complete the follow-up assessment at the participants' home. If participants were no longer capable to participate (based on assessment using the Mini-Cog [21]), or had died, we approached a relative for a telephone interview.

Statistical analysis

We aimed at an overall power of 0.8 (alpha 0.05) to detect a difference of at least 0.5 standard deviations in PAM score. In a nonclustered study, this required 63 individuals per group. To adjust for the clustering effect, we used a multiplication factor of (1+(k-1)* intraclass correlation coefficient (ICC)), with k indicating the average cluster size (12 individuals). For an ICC of 0.05 we thus needed to include 98 (1.55*63) participants in each group.

Statistical analyses were according to intention-to-treat. Personal characteristics of the study groups at baseline were compared using chi-square tests and analysis of variance. Outcomes were compared using multilevel analyses, which were adjusted for clustering effects at residential care home level and differences in demographic characteristics between study groups. Differences were considered significant at p<0.05.

Ethics

The Research Ethics committee of Erasmus MC approved the study (MEC-2013-516, NL.46444.078.13).

RESULTS

Participation and Feasibility

The inclusion process is presented in Figure 1; 201 of 811 eligible older adults participated in our study. Reasons for nonparticipation were that people had died or moved (n=54), had no interest in the project (n=452) or did not reply to the invitation (n=104). The number of participants varied between one to 53 across the 16 participating clusters, with a mean cluster size of 12.5. A sensitivity analysis excluding the two n=1 clusters did not change the results. Mean age of participants was 87. Characteristics were balanced between study groups (Table 1), except for education level. Seventy-seven of 101 participants in the intervention group and 83 of 100 in the control group completed the PAM (primary outcome measure) at baseline and follow-up assessment. The corresponding attrition rates were 24% and 17%, respectively. Nineteen relatives of participants who had died or were no longer capable of participating at follow-up provided information on secondary outcome measures (e.g., AD completion). Therefore, follow-up assessments were conducted for 85 of 101 intervention participants, including interviews with relatives of participants who had died (n=7) or were no longer capable of participating (n=1). Follow-up assessments were conducted for 94 of 100 control participants, including interviews with relatives of participants who had died (n=9) or were no longer capable of participating (n=2, Figure 1). Finally, medical file analyses were conducted for 96 intervention participants and 92 control participants. Medical files for the remaining participants could not be accessed because participants (n=7) or their GPs (n=6) did not consent.

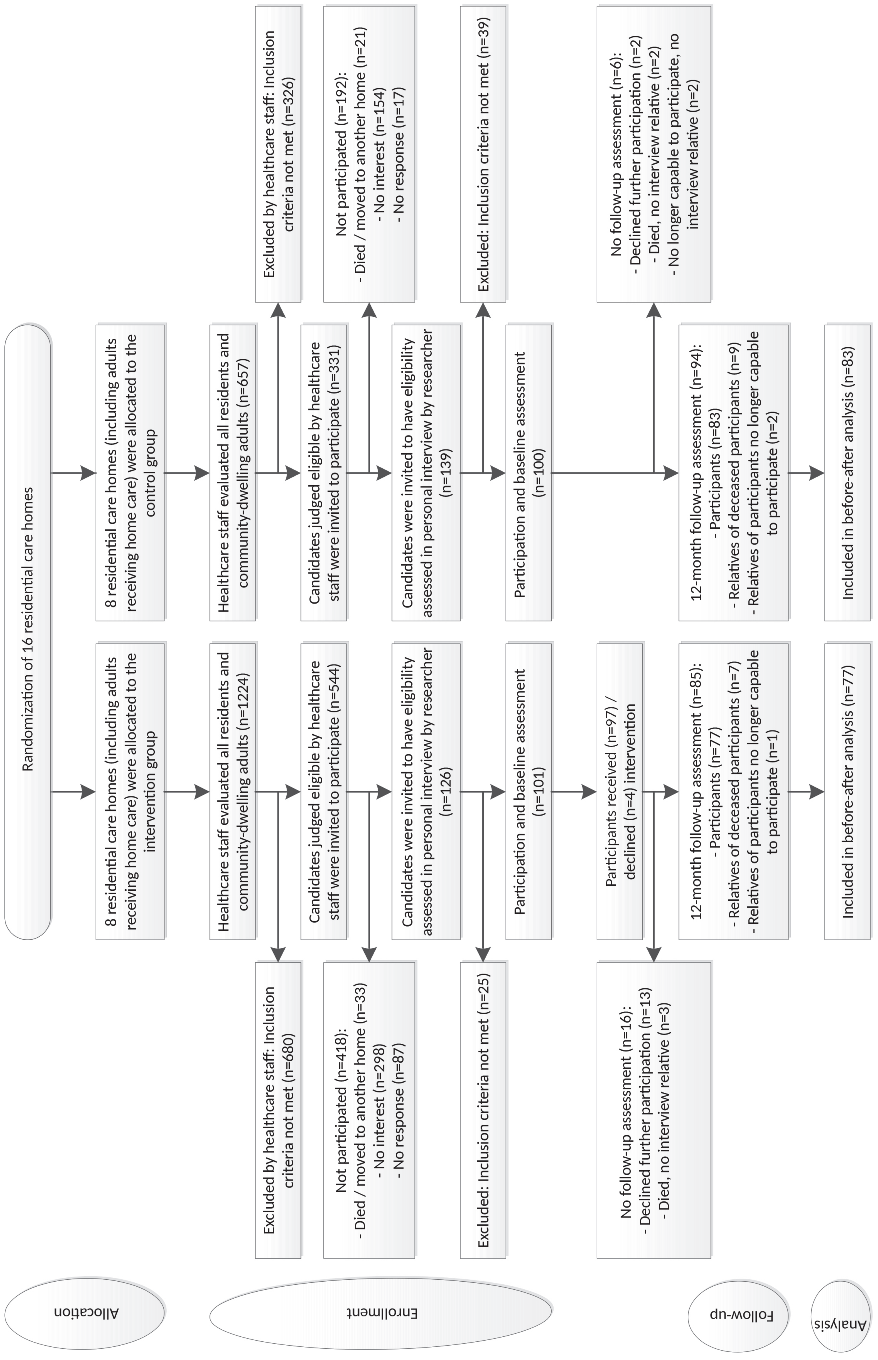

Figure 1 Consolidated Standards of Reporting Trials flow chart

Table 1 Baseline Characteristics of Study Population

Characteristics	Intervention Group, n=101	Control Group, n=100	P-Value
Age, mean ± SD (range)	86 ± 6.0 (75-102)	87 ± 5.2 (73-101)	.32
Female, n (%)	69 (68)	72 (72)	.57
Marital status, n (%)			.65
- married or cohabiting	19 (19)	20 (20)	
- not married	8 (8)	8 (8)	
- divorced	7 (7)	3 (3)	
- widowed	67 (66)	69 (69)	
Education level, n (%)			.002
- ≤ primary	26 (26)	48 (49)	
- high school	65 (65)	40 (40)	
- university	10 (10)	11 (11)	
- *missing*	*0*	*1*	
Residence, n (%)			.08
- care home	39 (39)	51 (51)	
- community	62 (61)	49 (49)	
Tilburg Frailty Index score, mean ± SD (range)[a]	7 ± 1.9 (5-13)	8 ± 2.2 (5-14)	.33
Mini-Mental State Examination score, mean ± SD (range)[b]	27 ± 2.5 (20-30)	26 ± 2.6 (20-30)	.19

[a] Normal range 0-15. Higher scores indicate worse functioning.
[b] Normal range 0-30. Higher scores indicate better functioning.
SD = standard deviation.

Intervention delivery and fidelity

All 97 (96%) intervention participants who received information leaflets received the ACP program, and interview cards were used with all 97 ACP participants, 80 of whom provided a copy of their study AD and 78 of whom appointed a surrogate decision-maker. The average number of facilitated conversations per participant was 1.6 (based on information provided for 90 participants); 40 (44%) had one facilitated conversation, 46 (51%) had two and 4 (4%) had three. The average conversation was 125 minutes long, including travel time of facilitators. The average time between the baseline assessment and completion of study ADs was 47 days (range: 5-185). In follow-up interviews, 54 of 75 (72%) surviving participants who engaged in the ACP program reported positive experiences, one (1%) reported a negative experience, 10 (13%) were ambivalent and 10 (13%) did not remember the facilitated conversations sufficiently; 59 (79%) considered the facilitated conversation useful (Supplementary Table S3).

Primary and secondary outcome measures

Overall PAM change scores did not differ significantly between the intervention (-0.26) and control group (-1.43) (p=.43, Table 2). The ICC for the PAM was 0. Differences between groups per item were insignificant (p>0.05, Supplementary Table S4).

Neither SF-12 change scores (PCS: 0.95 vs. 1.15, p=.98; MCS: -4.63 vs. -4.20, p=.71) nor PSQ-18 subscale change scores (-0.08 vs. 0.02, p=.90) differed between the intervention and control group (Table 2). In the intervention group, more participants had completed an AD at 12 months than in the control group (n=78, 93% vs. n=31, 34%; p<.001, Table 3). Some adults completed several ADs, for instance, the study AD and a do-not-resuscitate order. Seventy-five intervention group participants (89%) completed the study AD. Most control participants who had completed an AD had done this before the start of our study (n=25/31, 81%), and most often, they had completed a do-not-resuscitate order (n=23/31, 74%). For 37 of 96 (39%) intervention participants and 18 of 92 (20%) control participants, one or more ADs were identified in the medical file. These ADs included 32 study ADs in files of intervention participants. More participants in the intervention group than in the control group had appointed a surrogate decision-maker (n=80, 94% vs. n=62, 67%; p<.001). The majority of the intervention group (89%) appointed their decision-maker in writing, whereas the majority of the control group (63%) did so orally (p<.001). We found no effect of ACP on use of hospital care, diagnostic procedures or a selection of medical interventions (Supplementary Table S5).

Table 2 Outcome Measures of the Study Population

	Baseline score		**Follow-up score (12 months)**		**Change score**		
	Intervention, n=77	**Control, n=83**	**Intervention, n=77**	**Control, n=83**	**Intervention, n=77**	**Control, n=83**	**P-Value**[a]
Outcome	**Mean ± Standard Deviation**						
Patient Activation Measure[b]	52 ± 8.9	52 ± 10.2	52 ± 10.2	51 ± 8.9	-0.26 ± 11.20	-1.43 ± 10.61	.43
12-item Short-Form Health Survey[b]							
- physical component score	31 ± 10.0	33 ± 9.0	32 ± 10.1	34 ± 8.8	0.95 ± 10.98	1.15 ± 9.82	.98
- mental component score	52 ± 9.9	50 ± 10.3	48 ± 10.8	46 ± 12.1	-4.63 ± 11.75	-4.20 ± 11.25	.71
2 items (1 subscale) of Patient Satisfaction Questionnaire[c]	4 ± 0.8	4 ± 0.8	4 ± 0.8	4 ± 0.7	-0.08 ± 0.94	0.02 ± 0.95	.90

[a] Differences in change scores between study groups, adjusted for cluster, education level and residence.
[b] Normal range 0-100. Higher scores indicate better functioning. Missing for patient activation and generic quality of life n=1.
[c] Normal range 1-5. Higher scores indicate better functioning.

Table 3 Completion of Any Advance Directive (AD) at 12-Month Follow-Up

Outcome	Intervention, n=85	Control, n=94	P-Value[a]
Completed AD, n (%)[b]	78 (93)	31 (34)	<.001
Type of AD, n (%)[c]			
- study AD	75 (89)	Not applicable	
- other AD	5 (6)	8 (9)	
- do-not-resuscitate	11 (13)	23 (25)	
- do not treat	3 (4)	3 (3)	
Communicated about AD with (%)[d]:			
- family (partner, children)	67/78 (86)	24/29 (83)	.56
- other family and friends	13/78 (17)	4/29 (14)	.82
- general practitioner	64/78 (82)	20/29 (69)	.22
- other healthcare provider	40/78 (51)	14/29 (48)	.43
Appointed decision-maker, n (%)[e]	80 (94)	62 (67)	<.001
- orally	9 (11)	39 (63)	<.001
- in writing	71 (89)	23 (37)	

Data according to participants (intervention, n=77; control, n=83) and relatives of deceased (intervention, n=7; control, n=9) or incapable (intervention, n=1; control, n=2) participants.

[a] Differences between study groups, adjusted for cluster, education level and residence.

[b] Missing n=3. Sixty percent of intervention participants who completed an AD were community-dwelling; among controls who completed an AD, 65% lived in a residential care home.

[c] Missing n=3. More than 1 answer possible.

[d] Missing n=2. More than 1 answer possible.

[e] Missing n=1.

DISCUSSION

This is the first cluster randomized controlled trial on the effects of ACP in frail, cognitively competent older adults in Europe. No effect of ACP on the degree of patient activation, quality of life, satisfaction with healthcare or medical care use was found, although we found an effect on completion of ADs and appointment of surrogate decision-makers.

This study has several strengths. First, older adults were offered standardized ACP based on the Respecting Choices facilitation training, an internationally recognised ACP program [15]. The program was feasible in these frail older adults; approximately one-quarter of eligible older adults participated, and almost the entire intervention group engaged in the ACP program, completed an AD and appointed a surrogate decision-maker. Second, we conducted personal interviews, providing participants the opportunity to ask for clarification when needed. This study also has limitations. First, our power calculations did not account for expected loss to follow-up and attrition in the intervention group (24%) was somewhat higher than in the control group (17%). It is unclear whether this has affected the outcomes of our study, although it seems unlikely given the small size of the difference [22]. Second, two clusters contained only one participant. Third, our response rate was modest, although it was comparable with, or even higher than, response rates of similar studies [23, 24]. Fourth, outcome assessors could not be blinded to participant allocation because of the nature of the follow-up assessment. Fifth, the context of a randomized controlled trial, which requires several appointments and completion of questionnaires, differs from daily practice, where ACP could be more effective. Finally, our analyses of medical care use were limited to GP medical files, although hospital discharge letters were usually included in GP medical files, so the amount of information missed is probably limited.

At one-year follow-up, nearly all participants in the intervention group had completed an AD (93%) and had appointed a surrogate decision-maker (94% overall, 89% in writing). These numbers are higher than in most other trials [4]. The increased AD completion is important because ADs have been shown to increase the consistency of care with patients' goals and person-centered care [1]. ADs were identified more often in the medical files of intervention group participants (39%) than in those of the control group (20%). This is important because written ADs in the medical file may be more likely to influence care.

In our control group, rates of AD completion (34%) and surrogate decision-maker appointment (67% overall, 37% in writing) were rather high [4]. Studies in the Netherlands reported estimations of AD completion varying from 5% to 16% for different age groups [25-27]. Most ADs in the control group were do-not-resuscitate orders that care home residents had completed before the study. The relatively high AD completion rate in the control group may be related to recent societal debates concerning ACP. For instance, the Royal Dutch Medical Association released a public awareness campaign in 2015 recommending ACP [28]. We observed no significant differences between the intervention and control group in rate of communication about completed ADs, but because our study resulted in more adults completing ADs (93% intervention group, 34% control group), our study also resulted in more communication about ADs. It would have been difficult to achieve higher rates of communication about completed ADs in the intervention group than in the control group, because people in the control group with a completed AD communicated about their AD quite frequently.

We did not find an effect of the adapted Respecting Choices ACP facilitation on patient activation, quality of life, satisfaction with healthcare or use of medical care. This is striking, because several other studies have reported positive effects of standardized ACP programs on various outcomes.

For instance, the Respecting Choices program increased satisfaction of older hospitalised adults in Australia [23]. Respecting Choices also improved ACP knowledge and decreased willingness of older ambulatory U.S. adults to undergo life-sustaining treatments [24].

The lack of effect found in our study might have several explanations. The first possible explanation relates to implementation of our ACP program. We used the core part of the Respecting Choices ACP program but could not implement it system-wide. At 12-month follow-up, only 32 study ADs were included in GP medical files.

Our second explanation relates to the choice of outcome measurements and their timing. Given the high mean age (87) of participants, the low death rate (10%) during 12 months of follow-up was surprising. Healthcare use and related costs of care in the last year of life are 13.5 times as high as in an average life year [29]. It may be that not many important healthcare decisions had to be made within the study period and hence, we may have not been able to measure the full effect of ACP on medical care use. ACP covers many domains [30] and may have intermediate (e.g., completion of ADs) and downstream effects (e.g., use of medical care). Although many intervention participants appreciated ACP, the effects of our ACP program on patient activation, quality of life and satisfaction with healthcare might have been greater shortly after the intervention and diminished over time. Proper timing of ACP deserves further debate [31].

Thirdly, the specific Dutch healthcare context may explain our findings. Decisions to withhold or withdraw potentially life-prolonging treatment are more common in the Netherlands than in other European countries [32]. This has been partially attributed to the open public debate on end-of-life care and decision-making. In addition, Dutch healthcare has a history of avoiding overtreatment. For instance, Dutch nursing home residents are hospitalized less frequently and receive less aggressive care than US nursing home residents [33], which may mean that there is less to be gained from ACP.

Interest in ACP is growing [30] and current developments show that ACP is increasingly becoming part of usual care. Future ACP research should investigate the effects of ACP while considering the effect of culture, study population and study setting. In addition, more insight is needed into appropriate outcome measures of ACP and their timing. We also need to identify the effective components of ACP, as well the best way to integrate ACP into the healthcare system. ACP may not be a panacea [30]. To conclude, our study did not find positive effects of ACP on downstream outcome measures including levels of patient activation and quality of life, although we observed higher AD completion rates after ACP, including a significant increase in the written appointment of surrogate decision-makers, and did not find any harmful effects of ACP. In addition, many participants appreciated facilitated ACP conversations. Therefore, healthcare staff may consider providing ACP to frail older adults and their relatives.

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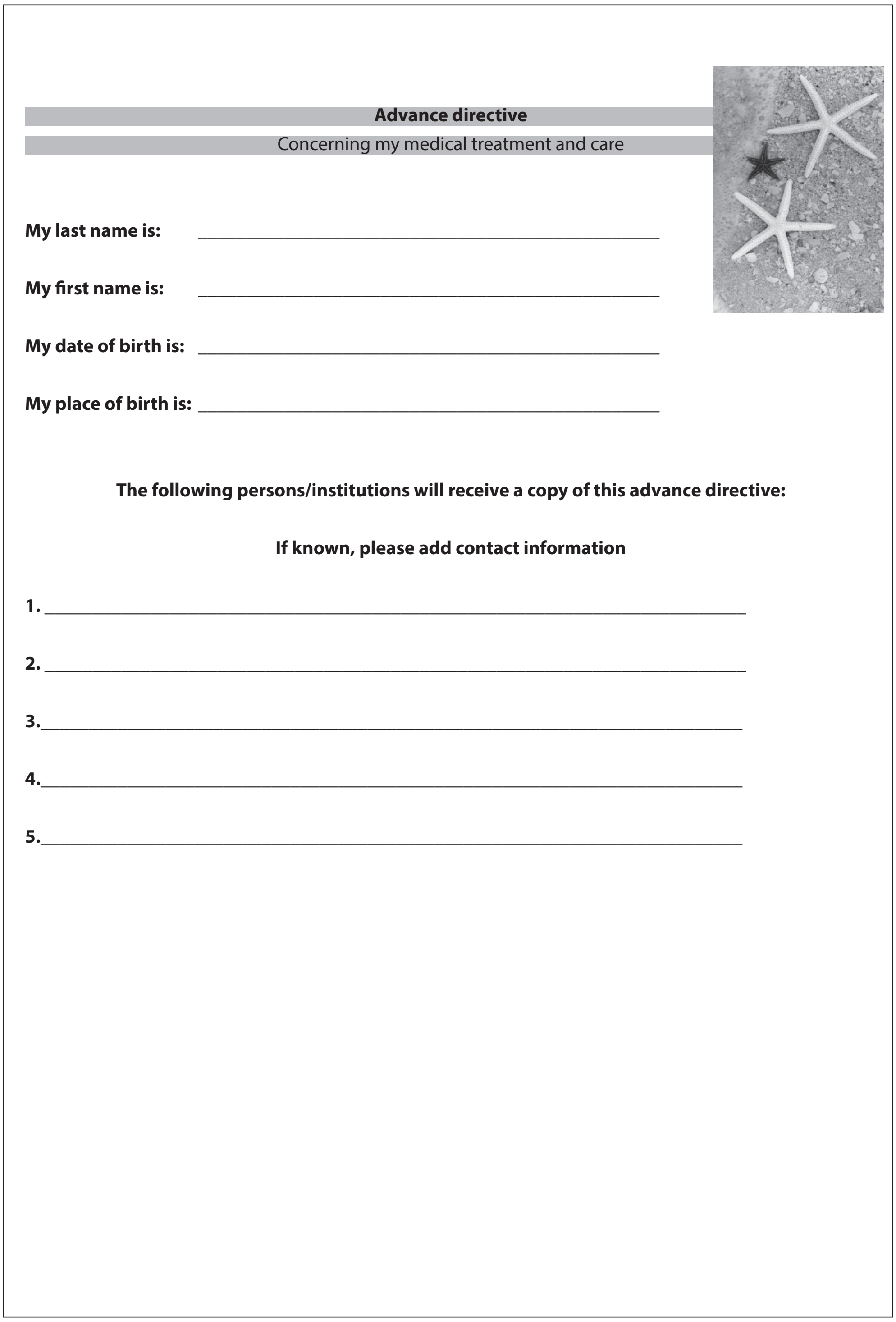
Supplementary Figure F1 Study advance directive



Advance directive

Concerning my medical treatment and care

My last name is: ______________________________

My first name is: ______________________________

My date of birth is: ______________________________

My place of birth is: ______________________________

The following persons/institutions will receive a copy of this advance directive:

If known, please add contact information

1. ______________________________

2. ______________________________

3.______________________________

4.______________________________

5.______________________________

Supplementary Figure F1 (continued) Study advance directive

Explanation

In an advance directive you record your preferences concerning medical treatment, e.g. concerning artificial feeding or cardiopulmonary resuscitation. The use of an advance directive is intended for situations in which you are no longer able to discuss these kind of preferences with your physician.

In this advance directive you can record which preferences are important to you. You can also appoint a person who is allowed to make decisions concerning your medical treatment in cases you are no longer able to do this yourself. This person is called a *surrogate decision-maker*.

<u>This advance directive only becomes valid when your physician has determined that you are no longer able to make decisions yourself.</u>
This advance directive does not permit your surrogate decision-maker to make decisions on your behalf about finances or about other issues. Before you complete this document, it is important that you first discuss with your intended surrogate decision-maker which decisions are important to you.

In principle, this advance directive always remains valid. To prevent misunderstandings, it is important that you discuss its content regularly, e.g. every year, with your physician. If you change your preferences, you can complete a new advance directive.

Completion of the advance directive

The advance directive is divided into four parts.

Part I - *Who makes decisions about my medical treatment when I am no longer able to do this myself.*
In this part you record the name of your surrogate decision-maker(s) to make clear who can make decisions on your behalf if necessary. The surrogate decision-maker also records that he or she is willing to accept this role.

Part II - *General authorities of my surrogate decision-maker.*
In this part you record the authorities of your surrogate decision-maker when making decisions. You sign the statement you agree with. You cross out the statement you do not agree with. You can add additional authorities.

Part III - *My preferences concerning future medical care.*
In this part you record which decisions are important to you. You sign each statement you agree with. You cross out each statement you do not agree with. In this part you can also describe specific conditions that you consider important.

Part IV – *Signature.*
The last part concerns signing the document, in addition to your name, date and place.

After the completion

When you have completed and signed the advance directive, it is important that you provide copies to your surrogate decision-maker(s), your physician and others for whom this information is important (e.g. the institution where you live). This will increase chances that the advance directive can be used as appropriate.

Supplementary Figure F1 (continued) Study advance directive

ADVANCE DIRECTIVE

Part I – Who makes decisions about my medical treatment in case I am no longer able to do this myself.

In this document I indicate who is allowed to make decisions about my medical treatment in case I am no longer able to do this myself. This person is my *surrogate decision-maker*.

My surrogate decision-maker is:

Name: ____
Phone number day: ______________ Phone number evening: ____________
Mobile phone number: ____________________________________
Address: ____
Postal code: _____________ Place: ____________________________

Acceptance:

_____________________ (first and last name) accepts the role as surrogate decision-maker and will act on behalf of __________________ (first and last name) to the best of his/her abilities by making decisions that are in line with the preferences and wishes of the person described above.

In case my surrogate decision-maker no longer will or can decide on my behalf,
my surrogate decision-maker will be:

First alternative surrogate decision-maker

Name: ____
Phone number day: ______________ Phone number evening: ____________
Mobile phone number: ____________________________________
Address: ____
Postal code: _____________ Place: ____________________________

Acceptance:

_____________________ (first and last name) accepts the role as surrogate decision-maker and will act on behalf of __________________ (first and last name) to the best of his/her abilities by making decisions that are in line with the preferences and wishes of the person described above.

Supplementary Figure F1 (continued) Study advance directive

In case this alternative surrogate decision-maker no longer will or can decide on my behalf, **my surrogate decision-maker will be:**

Second alternative surrogate decision-maker

Name: ____
Phone number day: ________________ Phone number evening: ______________
Mobile phone number: ____
Address: ____
Postal code: _______________ Place: ______________________________________

Acceptance:

________________________ (first and last name) accepts the role as surrogate decision-maker and will act on behalf of _____________________ (first and last name) to the best of his/her abilities by making decisions that are in line with the preferences and wishes of the person described above.

Part II – General authorities of my surrogate decision-maker

I give my surrogate decision-maker the following authorities:
(Sign each statement you agree with and cross out each statement you do not agree with)

_____ Make choices on my behalf concerning starting, continuing, or stopping medical treatment and procedures, such as tests, medication and surgeries.
_____ Discuss my preferences and wishes, as recorded in this document or indicated in conversations, with my medical practitioners.
_____ Give permission to disclose my medical records and other personal information, in case my physician considers it necessary for my medical treatment.
_____ Make decisions on my behalf about choosing a medical practitioner or place of care.

Part III – My preferences concerning future medical care

My surrogate decision-maker will make decisions that are in line with my preferences and wishes. In case it is unclear what I would have preferred in a specific situation, I want my surrogate decision-maker to make a decision, in consultation with my medical practitioners. In case my surrogate decision-maker cannot be reached, I want the following instructions to be followed.

Cardiopulmonary resuscitation

(Sign the statement you agree with and cross out the statement you do not agree with)

_____ I want to be resuscitated, unless my physician considers that medically futile
_____ I do not want to be resuscitated in case of a cardiac arrest

Supplementary Figure F1 (continued) Study advance directive

Medical treatments

(Sign the statement you agree with and cross out the statement you do not agree with)

When the doctor considers it likely, that I will no longer be capable of meaningful contact with my family, friends and others, I want:

_____ Full treatment as long as it makes sense
_____ Care that focuses on comfort, well-being and symptoms, not aimed at life-extension nor shortening of life.

In the situation as described above I want:

_____ Artificial feeding
_____ Hospital admission for medical treatment or surgeries
_____ Artificial ventilation

Specific conditions for the situation in which life-prolonging medical treatment is foregone

In this situation, I want further medical treatment and care focusing on comfort. The following aspects are important to me:

Specific conditions that apply when I choose the option "full treatment as long as it makes sense"

If I choose the option "full treatment as long as it makes sense", the following aspects are important to me:

Euthanasia, organ donation, body donation

Because there are separate regulations for euthanasia, organ donation and body donation, these items are excluded from this advance directive.

Part IV - Signature

I have completed this document voluntarily.

Name:
____

Date, place:
____

Signature:
____

Supplementary Table S1 Elements of our Advance Care Planning (ACP) program

Elements of ACP	Preparatory work	Fidelity
1. Information leaflets for participants and their relatives about the Respecting Choices program, resuscitation, artificial ventilation, artificial feeding and the surrogate decision-maker	Translating and adapting information leaflets to the Dutch context	Information leaflets were handed out to 97/101 (96%) participants in the intervention group
2. ACP conversations based on scripted interview cards	Attending the Respecting Choices facilitator and train-the trainer program in the US Translating training program Translating and adapting scripted interview cards to the Dutch context Conducting facilitator training in the Netherlands	The training program was delivered to eight nurses of the care organization 10 supervision meetings were arranged to give facilitators the opportunity to exchange insights and experiences and to check whether the intervention was conducted appropriately Interview cards were used with 97/97 (100%) ACP participants
3. Advance directives (ADs) based on the "Power of Attorney for Healthcare Document" for the La Crosse region including the following parts: - Part 1: Who makes decisions about my medical treatment when I am no longer able to do this myself - Part 2: General authorities of my surrogate decision-maker - Part 3: My preferences concerning future medical care - Part 4: Signature	Translating and adapting AD to the Dutch context	80/97 (82%) participants provided a copy of their study AD

Supplementary Table S2 Detailed information about the Advance Care Planning (ACP) program

For our study, a nurse practitioner attended the entire Respecting Choices facilitator and train-the-trainer program in the US. In addition, the nurse facilitator visited several locations in the US where Respecting Choices was conducted to study the use of the program in daily practice.

Subsequently, the nurse practitioner and other members of the research team translated the Respecting Choices program materials into Dutch and modified them to the Dutch context. The key modifications are described below.

The ACP program has the following core elements: Information leaflets for participants, facilitated ACP conversations based on scripted interview cards and an advance directive (AD). See Supplementary Table S1 for detailed information about these elements and for the assessment of intervention fidelity.

Key modifications to the Respecting Choices program were:

(1) Adaptation of materials to the Dutch context:

(1a) Information leaflets: We included evidence from the Netherlands describing the success rate of cardiopulmonary resuscitation (CPR).

(1b) Scripted interview cards: We extended the interview card for adults with chronic illness ("First Steps ACP for Adult/Patient with Chronic Illness", blue card) with some items of the sample scripts used in POLST ("Sample Scripts for Helping Individuals Make Specific End-of-Life Treatment Decisions Using the POLST form", see 1c for rationale). Further, we developed an additional interview card to be used when participants introduced the topic of euthanasia, which is legally regulated in the Netherlands, but subject to special regulations. This additional interview card clarified that the topic of euthanasia is not part of the ACP program and referred participants to their physicians if they wished to talk about euthanasia.

(1c) Study AD, based on the "Power of Attorney for Healthcare Document": In our study AD we excluded the authorities of the surrogate decision-maker concerning the admission to nursing homes/residential facilities, feeding tube and hydration and pregnancy. Since Dutch adults can express preferences for care, but cannot decide to receive that care without the physicians' agreement, we replaced the original option "I want CPR attempted if my heart stops" by the option "I want to be resuscitated, unless my physician considers that medically futile". Further, we did not include items concerning autopsy, organ/tissue or body donation since these items are subject to special regulations in the Netherlands. Finally, following local regulations, our study AD did not need to be signed by witnesses or a notary public, only by participants themselves (see Supplementary Figure F1 for our study AD).

Supplementary Table S2 (continued) Detailed information about the Advance Care Planning (ACP) program

(2) Given the study context, system-wide implementation of the program was not possible.

The adaption of the program to the study context in the Netherlands was conducted in close contact with the developers of Respecting Choices. Furthermore, we asked the client council of the care organization where the study was conducted for feedback on clarity of the intervention materials, information leaflets and our study AD. We also asked the client council whether they expected possible harms or unintended effects of the intervention. In addition, during the entire study period a multidisciplinary advisory board provided feedback on the acceptability and feasibility of intervention materials, information leaflets and the study AD. The advisory board consisted of 11 members, including an elderly care physician, a spiritual counsellor, an emergency-department doctor and the chair of the client council.

Nurses who were employed by the care organization could apply for the role of facilitator. Eight nurses were selected based on criteria such as being able to talk about the end of life and having an open attitude towards individuals' preferences. They were trained to deliver the intervention. The training lasted three days and included role plays and homework assignments (in line with the original Respecting Choices facilitator training program). In addition, a legal advisor explained the legal framework of Dutch ADs. All nurse facilitators received a certification after (1) completion of the program and (2) successful demonstration of skills associated with the program as assessed during a final role play on the last day of the training.

The face-to-face conversations between facilitators and participants were structured by scripted interview cards (in line with the original Respecting Choices program) and took place at the participants' home. Per participant, it was scheduled to use the green interview card used in the Respecting Choices program ("Introduction to First Steps ACP") and the extended blue interview card ("First Steps ACP for Adult/Patient with Chronic Illness"). We estimated that we would usually have to schedule two meetings per participant to apply both cards. If participants participated in two ACP conversations, these conversations were conducted by the same facilitator. Participants were encouraged to invite relatives to attend the meetings with the ACP facilitator. Participants were also encouraged to document their preferences in the study AD and to share copies of their study AD with relatives and healthcare providers. Facilitators registered their time investments and thereby provided information on the number and duration of ACP conversations.

Supplementary Table S3 Open questions about facilitated conversations at 12 months

	How did you experience the facilitated conversation? (n=75)	**In your opinion, was the facilitated conversation useful? (n=75)**
Positive answer	54 (72%)	59 (79%)
- answer example	- "Really good. She [the facilitator] explained everything in detail and she let me finish. My daughters were able to take part in the facilitated conversation and expressed their opinions. Very nice. In the beginning I was very scared, but in the end I was relieved."	- "Yes, it was useful. I am wiser now, I know more about the advance directive. It is pleasant when doctors know what you want."
Negative answer	1 (1%)	6 (8%)
- answer example	- "Worthless." (Participant had a strong faith and accepts life as it is)	- "No, I do not think that it [the facilitated conversation] changed me. It was not very useful."
Ambivalent answer	10 (13%)	7 (9%)
- answer example	- "Difficult topic, it was about death, it always remains difficult. It [the facilitated conversation] had to take place, now I do not have to put the pressure on my children, they do not have to decide."	- "I think I already knew most things. However, I started handing out my advance directive."
No memory of the intervention	10 (13%)	3 (4%)

Data are n (%).

Supplementary Table S4 Effect of Advance Care Planning (ACP) on PAM items

	Baseline		Follow-up		Change		
	Intervention (n=77)	**Control (n=83)**	**Intervention (n=77)**	**Control (n=83)**	**Intervention (n=77)**	**Control (n=83)**	**P-value^a**
1. When all is said and done, I am the person who is responsible for taking care of my health	2.86 (0.85)	2.86 (0.75)	3.08 (0.70)	2.84 (0.67)	0.22 (0.93)	-0.01 (0.83)	.12
2. Taking an active role in my own health care is the most important thing that affects my health	2.91 (0.60)	2.94 (0.63)	2.92 (0.66)	2.81 (0.60)	0.01 (0.77)	-0.13 (0.91)	.29
3. I am confident I can help prevent or reduce problems associated with my health	2.68 (0.70)	2.82 (0.76)	2.79 (0.66)	2.78 (0.65)	0.11 (0.81)	-0.04 (0.85)	.18
4. I know what each of my prescribed medications do	2.93 (0.84)	2.80 (0.87)	2.82 (0.67)	2.92 (0.69)	-0.11 (0.91)	0.13 (0.98)	.15
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	3.14 (0.60)	3.01 (0.60)	3.00 (0.47)	2.94 (0.55)	-0.14 (0.73)	-0.07 (0.86)	.83
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask	3.13 (0.68)	3.14 (0.68)	3.18 (0.58)	2.99 (0.62)	0.05 (0.83)	-0.16 (0.71)	.23
7. I am confident that I can follow through on medical treatments I may need to do at home	3.08 (0.69)	3.21 (0.58)	2.80 (0.78)	2.95 (0.61)	-0.28 (0.97)	-0.26 (0.78)	.88
8. I understand my health problems and what causes them	3.11 (0.73)	2.94 (0.74)	3.04 (0.63)	3.07 (0.62)	-0.07 (0.93)	0.13 (0.78)	.29
9. I know what treatments are available for my health problems	2.74 (0.69)	2.88 (0.82)	2.86 (0.61)	2.80 (0.66)	0.12 (0.80)	-0.07 (0.86)	.24
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	2.97 (0.70)	2.87 (0.62)	2.86 (0.63)	2.83 (0.60)	-0.11 (0.87)	-0.04 (0.81)	.65
11. I know how to prevent problems with my health	2.51 (0.79)	2.60 (0.84)	2.58 (0.75)	2.63 (0.73)	0.08 (0.89)	0.02 (0.94)	.63
12. I am confident I can figure out solutions when new problems arise with my health	2.29 (0.78)	2.27 (0.80)	2.32 (0.70)	2.30 (0.70)	0.04 (0.80)	0.04 (0.88)	.88

Supplementary Table S4 (continued) Effect of Advance Care Planning (ACP) on PAM items

	Baseline		**Follow-up**		**Change**		
	Intervention (n=77)	**Control (n=83)**	**Intervention (n=77)**	**Control (n=83)**	**Intervention (n=77)**	**Control (n=83)**	**P-value**[a]
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	2.86 (0.67)	2.77 (0.70)	2.68 (0.68)	2.68 (0.69)	-0.17 (0.85)	-0.09 (0.89)	.41

Data are mean (SD).

Answer categories for PAM (= Patient Activation Measure) items: 1 = Disagree strongly, 2 = Disagree, 3 = Agree, 4 = Agree strongly.

[a] Differences in change scores between study groups, adjusted for cluster, education level and residence.

Supplementary Table S5 Use of medical care by study groups

Outcome	Intervention (n=96)	Control (n=92)	P-value[a]
Hospital care			
ED use	29 (30%)	28 (30%)	.81
If any, number of ED visits	1.3 (0.7)	1.4 (0.7)	.85
Hospitalisations	37 (39%)	31 (34%)	.29
If any, number of hospitalisations	1.4 (0.8)	1.4 (0.6)	.57
If any, number of days at general department	9.1 (10.8)	10.7 (8.0)	.97
ICU care	3 (3%)	2 (2%)	.85
If any, number of ICU days	4.7 (4.7)	1.5 (0.7)	-
Diagnostic procedures			
Blood transfusion	1 (1%)	1 (1%)	.99
If any, number of blood transfusions	2.0 (-)	4.0 (-)	-
CT scan	8 (8%)	12 (13%)	.25
If any, number of CT scans	1.3 (0.7)	1.0 (0)	-
Echography	6 (6%)	4 (4%)	.36
If any, number of echography's	1.0 (0)	1.3 (0.5)	-
MRI scan	2 (2%)	1 (1%)	.36
If any, number of MRI scans	1.0 (0)	1.0 (-)	-
X-ray	20 (21%)	15 (16%)	.37
If any, number of X-rays	1.6 (0.8)	1.5 (0.6)	.83
Biopsy	1 (1)	0 (0)	-
If any, number of biopsies	2.0 (-)	0 (-)	-
Medical interventions			
Chemotherapy	1 (1%)	0 (0%)	-
If any, number of chemotherapies	2.0 (-)	0 (-)	-
Radiotherapy	0 (0%)	0 (0%)	-
If any, number of radiotherapies	0 (-)	0 (-)	-
Surgery	10 (10%)	7 (8%)	.43
If any, number of surgeries	1.1 (0.3)	1.4 (0.8)	.34
Resuscitation	0 (0%)	1 (1%)	-
If any, number of resuscitations	0 (-)	1.0 (-)	-
Artificial ventilation	0 (0%)	0 (0%)	-
If any, days of artificial ventilation	0 (-)	0 (-)	-
Artificial feeding	2 (2%)	0 (0%)	-
If any, days of artificial feeding	20.5 (17.7)	0 (-)	-
Artificial hydration	4 (4%)	8 (8%)	.17
If any, days of artificial hydration	18.8 (23.3)	7.3 (8.9)	.44

Data are n (%) or mean (SD).

[a] Differences in use of medical care (during 12 months) between study groups, adjusted for cluster, education level and residence.

Advance Care Planning for frail older adults: Findings on costs in a cluster randomized controlled trial

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ABSTRACT

Background: Advance Care Planning aims at improving alignment of care with patients' preferences. This may affect costs of medical care.

Aim: To determine the costs of an Advance Care Planning program and its effects on the costs of medical care and on concordance of care with patients' preferences.

Design/settings/participants: In a cluster randomized trial, 16 residential care homes were randomly allocated to the intervention group, where frail, older participants were offered facilitated Advance Care Planning conversations or to the control group. We calculated variable costs of Advance Care Planning per participant including personnel and travel costs of facilitators. Furthermore, we assessed participants' healthcare use during 12 months applying a broad perspective (including medical care, inpatient days in residential care homes, home care) and calculated costs of care per participant. Finally, we investigated whether treatment goals were in accordance with preferences. Analyses were conducted for 97 participants per group. Trial registration number: NTR4454.

Results: Average variable Advance Care Planning costs were €76 per participant. The average costs of medical care were not significantly different between the intervention and control group (€2360 vs. €2235, respectively, p=.36). Costs of inpatient days in residential care homes (€41,551 vs. €46,533) and of home care (€14,091 vs. €17,361) were not significantly different either. Concordance of care with preferences could not be assessed since treatment goals were often not recorded.

Conclusions: The costs of an Advance Care Planning program were limited. Advance Care Planning did not significantly affect the costs of medical care for frail older adults.

INTRODUCTION

Advance Care Planning (ACP) is a communication process that "*enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate* [1]." The ultimate goal of ACP is to promote the alignment of care with patients' preferences [1, 2]. It is recommended that ACP is adapted to one's readiness and that trained facilitators support the process [1]. ACP is not limited to specific patient groups and can be provided at any stage of life; however, the content of ACP "*should be more targeted when the individual's health condition worsens or as they age* [1]."

In general, frailty is associated with high needs for healthcare use and increased costs [3]. Given this need and the related necessity for important future healthcare decisions, ACP may be especially relevant for frail older adults, also given the high prevalence of conditions that might affect their future communication about preferences [4].

We identified in total 22 studies on ACP and healthcare costs [5-26], of which six had a randomized controlled design and studied older adults with a mean age of ≥65 years [5, 11-13, 15, 17]. The majority of studies (14/22, 64%) showed that ACP was associated with reduced healthcare costs [5, 6, 8, 10-12, 14, 16, 18, 19, 22, 24-26]. Depending on the study period and type of cost measurement, cost savings per patient varied between €886 (US$1041) [22] and €55,190 (US$64,827) [25]. Such cost savings may be related to adults choosing less invasive medical interventions after having engaged in ACP [27].

Most studies (16/22, 73%) on ACP and healthcare costs were conducted in the United States [8, 10-15, 18-26]. It is unknown to what extent results from the United States can be generalized to other countries, given differences in healthcare systems and legal ACP regulations. For instance, general practitioners (GPs) may or may not act as gatekeepers to secondary and tertiary care [28, 29]. In many countries, adults have the right to refuse medical treatments and can indicate this, for instance, in an advance directive (AD) [28, 30]. However, adults from, for example, the Netherlands do not have the right to demand certain treatments without the physicians' agreement [28, 31]. They can indicate their preferences for treatment and care to be applied, for instance, in an AD, and this can serve to support their physicians in understanding their preferences [28, 31].

In their review on healthcare costs of ACP, Dixon and colleagues [32] emphasize a need to investigate detailed costs of ACP programs and to investigate the effect of ACP on healthcare costs in a broad perspective, including costs for both medical and nursing care. As previously reported, our ACP program increased the completion of ADs and the appointment of surrogate decision-makers in frail older adults in the Netherlands [33]. In addition, many participants positively evaluated facilitated ACP conversations. However, we found no effects of ACP on levels of patient activation, quality of life or healthcare use (narrow perspective) [33]. In the context of the same trial, we will now investigate the costs of our extensive ACP program, and, as recommended by Dixon and colleagues [32], the effects of ACP on costs of healthcare from a broad perspective, by focusing on the costs of medical care including medication as well as inpatient days in residential care homes and home care. In addition, we will determine concordance of care with patients' preferences.

METHODS

Setting

In a cluster randomized trial, 16 residential care homes were randomly allocated to the ACP intervention group (n=101) or the control group where adults received care as usual (n=100). Residential care homes, who offered both residential and non-residential care, were based in Rotterdam, the Netherlands. The trial followed the CONSORT guidelines. Data were collected between 2014 and 2016. Details of the study design, methods and main findings have been reported previously [33, 34].

Participants

Study participants lived either in one of the 16 residential care homes or at home, in the immediate surroundings of the care homes while receiving non-residential care from these care homes. To be eligible for participation, individuals had to be ≥75 years, frail (Tilburg Frailty Index score ≥5, range 0-15) [35] and capable to consent to participation (Mini-Mental State Examination Score ≥17, range 0-30) [36, 37]. Participants in the intervention group were offered facilitated planning conversations based on the Respecting Choices® ACP program [38]. For our study, a nurse practitioner attended the Respecting Choices facilitator and train-the-trainer programs in the United States. Following, she trained eight Dutch nurses to deliver the program, which consisted of three core elements: (1) information provision supported by leaflets, (2) facilitated ACP conversations based on scripted interview cards and (3) the completion of an AD, potentially including the appointment of a surrogate decision-maker. The study AD was based on the "Power of Attorney for Healthcare Document" as originally developed for the La Crosse region. Like the "Power of Attorney for Healthcare Document", our study AD included four parts: (1) Who makes decisions about my medical treatment when I am no longer able to do this myself, (2) General authorities of my surrogate decision-maker, (3) My preferences concerning future medical care and (4) Signature. The study AD included both check-boxes and open-text formats (Supplementary File S1).

We assessed fixed ACP program costs for the preparation phase including costs of the Respecting Choices facilitator and train-the trainer programs, the translation and adaptation of ACP materials, the translation and adaptation of the training program for facilitators and the training for facilitators. In addition, we assessed variable program costs for the ACP program per participant including average personnel costs and travel costs of facilitators.

Economic evaluation

We conducted a cost-minimization study, investigating the difference in healthcare costs between study groups from a healthcare perspective. To analyze the costs of healthcare use during 12 months after inclusion, we took a broad perspective focusing on the following categories: (1) costs of medical care including hospital care (emergency department (ED) visits, hospital stays, intensive care unit (ICU) care), diagnostic procedures (e.g. blood transfusion or computed tomographic (CT) scan), medical interventions (e.g. surgery or cardiopulmonary resuscitation) and medication, (2) costs of inpatient days in residential care homes including nursing and/or medical care, residential care housing and daytime activities and (3) costs of home care including nursing care and domestic help. To determine whether ACP enhances provision of care that is consistent with patients' preferences, we investigated whether goals of hospital stays, diagnostic procedures and medical interventions as described in medical files were in accordance with care preferences, as indicated by participants in their AD(s) (mostly study ADs). In addition, we compared the number of hospital stays, diagnostic procedures and medical interventions between study groups. Data from both participants' medical files of GPs and participants' files of the care organization were collected using a medical file checklist. This checklist was pilot-tested to verify whether relevant care items were accessible in files and to reduce inter-rater differences in interpretations between three researchers who collected these data.

The cost price of the ACP program was determined with the micro-costing method, which is based on a detailed assessment of all resources used [39]. Therefore, ACP facilitators registered their time investments per participant. Costs of medical care were calculated by multiplying the volumes of medical care use with the corresponding cost prices. For the calculation of hospital care, diagnostic procedures and medical interventions, we used charges as a proxy of real costs. In the Netherlands, a detailed "fee for service" system is available for the remuneration of diagnostic procedures and medical interventions. To calculate the costs of medication use, we used average cost prices per day. Only expensive medication, operationalized as a cost price of >€10 per day, was considered in the analysis. Costs of inpatient days in residential care homes and costs of home care were estimated as real, basic costs per day or per hour, respectively, using detailed administrative information from the care organization.

Statistical analysis

Statistical analyses were conducted according to the intention-to-treat principle. Personal characteristics were compared at baseline between study groups using chi-square tests and ANOVA. To compare costs of medical care between study groups, we used multilevel analyses, adjusting for clustering effects at residential care home level and differences in demographics. Differences were considered significant if $p<0.05$. Analyses were performed using IBM SPSS statistics V.23 and R V.3.2.3.

Ethics

The Research Ethics committee of Erasmus MC gave approval for the study on 14 January 2014 (MEC-2013-516, NL.46444.078.13). All participants gave written informed consent. The trial was registered on 22 January 2014 (NTR4454, www.trialregister.nl/trialreg/admin/rctview.asp?TC=4454).

RESULTS

Procedures

In total, 201 out of 1881 screened adults fulfilled the inclusion criteria and participated: 101 in the intervention group (of whom 97 received the ACP program) and 100 in the control group (Figure 1). In all, 80 out of 97 participants in the intervention group provided a copy of their study AD. In this AD, 78 out of 80 appointed a surrogate decision-maker. In all, 67 out of 80 (84%) participants indicated in their AD to prefer treatment that focuses on comfort in case being capable of meaningful contact with others would become unlikely. In all, three out of 80 participants (4%) indicated to prefer maximum care and 10 out of 80 (13%) participants did not indicate a preference (Supplementary File 2).

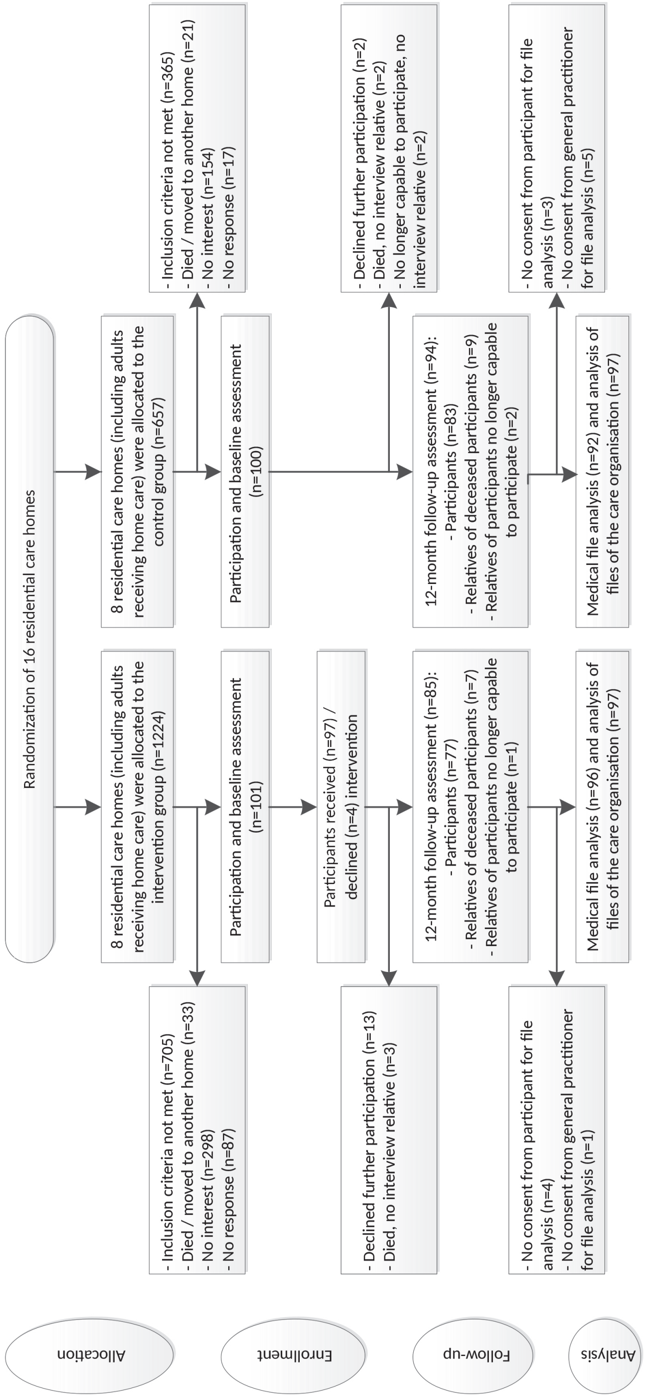

Figure 1 CONSORT flow chart

In all, 77 out of 101 intervention participants and 83 out of 100 controls completed the follow-up assessment after 12 months. In total, 21 participants died during the 12-month study period, of whom 10 in the intervention group and 11 in the control group. In both groups, most participants who lived in a residential care home died there (intervention: n=5/6; control: n=8/8). Of six deceased community-dwelling participants, three died at home (intervention: n=1/2; control: n=2/4), two in a hospital (intervention: n=1/2; control: n=1/4) and one participant from the control group died at a palliative care institution. Medical file analyses were conducted for 96 out of 101 adults in the intervention group and 92 out of 100 adults in the control group. Analyses for files of the care organization were conducted for 97 out of 101 adults in the intervention group and 97 out of 100 adults in the control group. Files of the remaining participants could not be accessed, because either the participants (n=7) or their GPs (n=6) did not consent (Figure 1).

Characteristics

Table 1 presents characteristics of 194 participants of whom data concerning use of medical care, inpatient days in residential care homes and/or home care were available. Their mean age was 86 years (standard deviation (SD): 5.5). Characteristics were comparable between study groups, except for education level, which was higher in the intervention group (p=.004).

Table 1 Characteristics of the study population (n=194)

Characteristic	**Intervention group (n=97)**	**Control group (n=97)**	**P-value**[a]
Age, mean (SD)	86 (5.8)	87 (5.2)	.26
Gender, n (%)			.53
- female	66 (68)	70 (72)	
Marital status, n (%)			.79
- married/ cohabiting	19 (20)	19 (20)	
- not married	8 (8)	8 (8)	
- divorced	6 (6)	3 (3)	
- widow(er)	64 (66)	67 (69)	
Education level[b], n (%)			.004
- low	25 (26)	46 (48)	
- middle	62 (64)	40 (42)	
- high	10 (10)	10 (10)	
- missing	-	*1*	

Table 1 (continued) Characteristics of the study population (n=194)

Characteristic	**Intervention group (n=97)**	**Control group (n=97)**	**P-value**[a]
Multimorbidity[c], n (%)			.95
- yes	46 (48)	46 (47)	
- missing	*1*	-	
Type of residence, n (%)			.06
- care home	38 (39)	51 (53)	
- community-dwelling	59 (61)	46 (47)	
Frailty			
Tilburg Frailty Index (TFI), mean (SD)[d]	7.4 (1.8)	7.5 (2.1)	.54
Competence			
Mini-Mental State Examination (MMSE), mean (SD)[e]	27 (2.4)	26 (2.7)	.13
Patient activation			
Patient Activation Measure (PAM-13)[e]			
- mean baseline (SD)[f]	52 (8.8)	52 (10.4)	.79
- mean follow-up (SD)[f]	52 (10.3)	51 (8.8)	.61
Generic quality of life, SF-12			
Physical component score[e]			
- mean baseline (SD)[f]	31 (10.1)	33 (9.1)	.22
- mean follow-up (SD)[f]	32 (10.1)	34 (8.8)	.16
Generic quality of life, SF-12			
Mental component score[e]			
- mean baseline (SD)[f]	52 (9.9)	50 (10.0)	.24
- mean follow-up (SD)[f]	48 (10.9)	46 (12.0)	.40

SD: standard deviation

[a] P-value based on chi-square test or ANOVA.

[b] Education level was defined as the highest educational qualification achieved (low = none or primary education; middle = secondary education; high = higher professional or university education).

[c] Multimorbidity: ≥2 diseases or chronic disorders.

[d] Higher scores indicate worse functioning.

[e] Higher scores indicate better functioning.

[f] Number of participants for whom this information is missing n=39.

ACP program costs

Fixed program costs for the preparation phase amounted to €21,754. The average number of facilitated conversations per participant was 1.6 (based on information provided for 90 participants). The variable costs for conducting these conversations were on average €76 per participant (Table 2).

Table 2 Costs of Advance Care Planning (ACP) program

	Total costs (€)	Costs per participant (€)
Preparation, fixed costs		
Respecting Choices facilitator and train-the-trainer programs:		
- Costs programs	1700	
- Travel and accommodation (14 days) costs Dutch trainer	2520	
- Working hours Dutch trainer	1600	
Translation and adaptation ACP materials[a]	4429	
Translation and adaptation training program for facilitators	5301	
Training for facilitators within the context of the study (n=8)	6204	
Total fixed costs	**21,754**	
ACP program, variable costs		
Average personnel costs of facilitators (3.3 h[b], * €19)		63
Average travel costs of facilitators for visiting participants at home[c]		13
Total average variable costs		**76**

[a] Materials included the captioning of an informative DVD about ACP for facilitators, scripted interview cards, the advance directive and information leaflets for participants.

[b] The average number of facilitated conversations was 1.6, while the average length per facilitated conversation was approximately two h (based on information provided for 90 participants) = 3,3 h per facilitated conversation per participant.

[c] Travelling costs of facilitators amounted to €0,27/km (on average, 29 km per facilitated conversation; * 1,6 facilitated conversations).

Healthcare use and costs

Table 3 gives an overview of the use and costs of medical care per participant in each study group. Total average costs of medical care during 12 months of follow-up did not differ significantly between intervention and control group (€2360 vs. €2235, respectively, p=.36).

Table 3 Use and costs of medical care per participant (n=194)

Cost by category	Cost price (€)	Intervention group (n=97) Average volume	Intervention group (n=97) Average costs (€)	Control group (n=97) Average volume	Control group (n=97) Average costs (€)	P-value[a]
Hospital care[b]						
ED visit	259	0.41 visits	105	0.43 visits	113	
Hospitalisation	476	3.50 days	1666	3.62 days	1723	
ICU care	1186	0.15 days	173	0.03 days	39	
Total hospital care			1944		1874	.38
Diagnostic procedures[b]						
Blood transfusion	308	0.02	6	0.04	13	
CT scan	138	0.10	14	0.13	18	
Echography	85	0.06	5	0.05	5	
MRI scan	217	0.02	5	0.01	2	
X-ray	58	0.33	19	0.24	14	
Biopsy	126	0.02	3	0.00	0	
Total diagnostics			53		52	.69
Medical interventions[b]						
Surgery	variable	0.11	349	0.11	503	
Cardiopulmonary resuscitation	65	0.00	0	0.01	1	
Total medical interventions			349		504	.55
Medication[c]	variable		134		7	. 21
Total costs medical care[d]			**2360**		**2235**	**.36**

[a] Adjusted for cluster, education level and residence.
[b] Number of participants for whom this information is missing n=6 (intervention group n=1, control group n=5). Radiotherapy and artificial ventilation were not applicable.
[c] Number of participants for whom this information is missing n=8 (intervention group n=2, control group n=6). Only costs of expensive medication (cost price of >€10 per day) have been calculated (applicable for n=8 participants in the intervention group and n=2 participants in the control group).
[d] Number of participants for whom this information is missing n=11 (intervention group n=5, control group n=6).

The average costs of medical care for residents of care homes were €2435 in the intervention group vs. €1651 in the control group (p=.33, Figure 2). In total 96 participants received care in a residential care home during 12 months of follow-up; the corresponding average costs of care were €41,551 in the intervention group and €46,533 in the control group (Table 4).

The average costs of medical care for community-dwelling adults were €2312 in the intervention group vs. €2947 in the control group (p=.16, Figure 2). The average costs of home care were €14,091 in the intervention group and €17,361 in the control group, based on 102 adults who received care at home (Table 4).

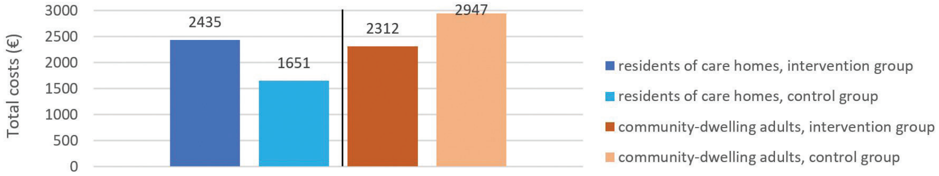

Figure 2 Costs of medical care per participant (n=194)

Table 4 Use and costs of inpatient days in residential care homes and home care (n=194)[a]

		Intervention group (n=97)		Control group (n=97)	
Cost by category	**Cost price (€)**	**Average volume**	**Average costs (€)**	**Average volume**	**Average costs (€)**
Care in residential care home/ nursing home (applicable for n=96 in total, of whom n=40 in intervention and n=56 in control group)	67-277[b] per day	334 days	41,551	341 days	46,533
Home care (applicable for n=102 in total, of whom n=57 in intervention and n=45 in control group)	50 per hour	282 h	14,091	347 h	17,361

[a] Number of participants for whom this information is missing n=4 (intervention group n=3, control group n=1).

[b] Adults residing in Dutch care homes/nursing homes have a care intensity package (ZZP). According to this package we calculated costs per day (Source: Nederlandse Zorgautoriteit). In our study population, costs varied between €67 (lowest care intensity package) and €277 (highest care intensity package) per day.

Whether goals of hospital stays, diagnostic procedures and medical interventions were curative or palliative was often not recorded in medical files. This complicated the assessment of the extent to which care as provided was concordant with the preferences on an individual level. Overall, the number of hospital stays, diagnostic procedures and medical interventions was low in both study groups. For instance, none of the participants in the intervention group received cardiopulmonary resuscitation vs. one participant in the control group. We found no differences on group level in the use of medical care.

DISCUSSION

Main findings

This is the first trial to investigate the costs of ACP and the effects of ACP on broad healthcare costs in frail older adults in a European country. We conclude that variable costs for the ACP program are limited. Average costs of medical care (including hospital care, diagnostic procedures, medical interventions and medication) did not differ significantly between study groups. Average costs of inpatient days in residential care homes and home care were not significantly different either. Concordance of received care with preferences could not be assessed on individual level since treatment goals (curative or palliative) were often not recorded in medical files.

Interpretation of results

An increasing number of scientific ACP publications worldwide, an increased number of ACP programs, initiatives to develop ACP laws and public awareness campaigns indicate that the interest in ACP is growing [40]. Despite this growing interest, we found limited literature on program costs for ACP. Studies that report on ACP program costs, show that costs of the ACP program per participant vary between €76 (US$89) in a nursing home setting [5] and €1676 (US$1968) in a primary care setting [14]. Corresponding cost savings were €1177 (US$1381) per participant over 12 months [5] and €9573 (US$11,239) per participant over six months [14], respectively. While we did not find cost savings in our study, we found that variables costs for an extensive ACP program were limited (€76).

ACP has previously been found to be associated with reduced healthcare costs [5,6,8,10-12,14,16,18,19,22,24-26], which may be related to adults choosing less invasive medical interventions after having engaged in ACP [27]. In our study population, many adults indeed preferred comfort care above maximum treatment (Supplementary File 2). Since no significant effect of ACP on the level of patient activation was found [33], we could not assess the cost-effectiveness of ACP. Instead, we conducted a cost-minimization study. Medical care costs were somewhat lower among community-dwelling adults in the intervention vs. the control group (€2312 vs. €2947, respectively). This may indicate that ACP especially affects costs of medical care while adults are community-dwelling. Overall, we did not find an effect of ACP on costs of medical care, which might be explained by several factors.

First, we might have studied a selective population of frail older adults. Costs of medical care in frail older adults are generally considered to be relatively high [3]. In the Netherlands, the average costs per year per person of hospital care as covered by standard healthcare insurance were €3059 in 2014 for adults aged ≥80 years [41]. Costs of hospital care in our study population were relatively low: €1910 per participant. This suggests that the health status of these frail study participants might have been better than that of the average frail older person. The mortality rate of 10% (n=21/201) during the 12-month study period is comparable to the average mortality rate of adults aged 86 years [42], but lower than we expected, as all study participants were frail and received care. ACP may affect costs of care especially during the last year of life, when costs are generally high [43].

Secondly, the Dutch healthcare context concerning life-prolonging interventions may partly explain our findings. Decisions to withhold or withdraw potentially life-prolonging intervention are more common in the Netherlands compared to other European countries [44]. This has been partially attributed to the open public debate on end-of-life decision-making. In addition, Dutch healthcare is often suggested to be characterized by a tendency of avoiding overtreatment for older adults [45]. This may explain the low numbers of invasive medical interventions and may indicate that there is less to be "gained" from ACP in terms of preventing overtreatment. This may also explain that healthcare costs mainly concerned costs of inpatient days in residential care homes and home care. Although ACP currently receives a lot of attention in the Netherlands, in education, clinical practice and in societal debates [46-48], ACP is not yet broadly implemented in the Netherlands and current ACP practices seem to mainly involve the completion of ADs rather than facilitated ACP conversations with trained healthcare providers.

Strengths and limitations of the study

Strengths of this study include its randomized controlled design, the use of standardized ACP involving facilitated planning conversations and the high rate of intervention group participants who completed the ACP program. In addition, we were able to calculate both fixed and variable costs of the ACP program and included core cost categories (hospital care, several diagnostic procedures, medical interventions and medication) in our economic evaluation. Our study has some limitations as well. Our analyses of medical care were limited to GP medical files. However, hospital discharge letters are usually included in GP medical files, so the amount of information missed is probably limited. Therefore, we do not expect that only having access to GP files largely impacted our findings on costs and on concordance levels of received care with preferences. In addition, we were not able to determine whether ACP enhances provision of care that is consistent with patients' preferences on individual level. Findings on group level have to be interpreted with caution, given the low number of hospital stays, diagnostic procedures and medical interventions. Several ACP experts raised caution about whether "care consistent with goals" can be reliably measured due to a lack of standardized methods and changing preferences for care [49].

Implications of our study and future research

Cost studies provide important additional information for health care organizations that plan to implement ACP. Given the limited costs of our extensive ACP program and earlier reported results of the ACP trial (higher completion rates of ADs, an increase in the appointment of surrogate decision-makers and positive evaluations of facilitated ACP conversations), healthcare providers may consider providing ACP to frail older adults. In our study context, facilitators on average delivered the ACP program to 13 patients. Outside a study context facilitators can obviously continue to deliver the ACP programs. Further research is needed to determine how to best define and assess the concordance of care with preferences, which is the most relevant ACP outcome according to ACP experts [49]. Furthermore, future research might incorporate a longer study period and ideally monitor use of care until death to be able to measure the full impact of ACP on costs of medical care. Future research might also investigate whether the use of trained ACP facilitators reduces the time investment of GPs to discuss preferences for medical care with their patients and of physicians to make medical decisions in the future.

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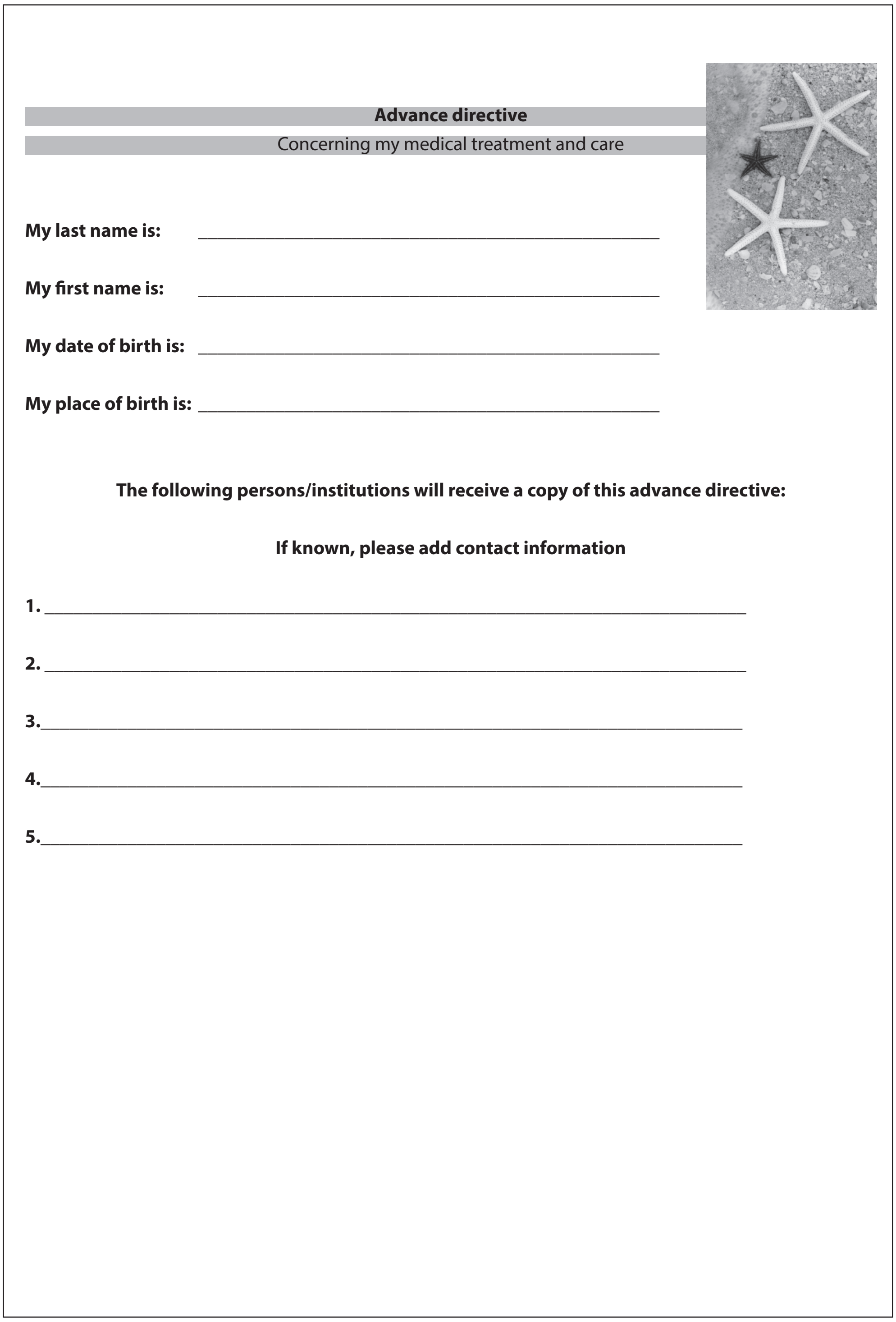
Supplementary Figure F1 Study advance directive



Advance directive

Concerning my medical treatment and care

My last name is: ______________________________

My first name is: ______________________________

My date of birth is: ______________________________

My place of birth is: ______________________________

The following persons/institutions will receive a copy of this advance directive:

If known, please add contact information

1. ____

2. ____

3.____

4.____

5.____

Supplementary Figure F1 (continued) Study advance directive

Explanation

In an advance directive you record your preferences concerning medical treatment, e.g. concerning artificial feeding or cardiopulmonary resuscitation. The use of an advance directive is intended for situations in which you are no longer able to discuss these kind of preferences with your physician.

In this advance directive you can record which preferences are important to you. You can also appoint a person who is allowed to make decisions concerning your medical treatment in cases you are no longer able to do this yourself. This person is called a *surrogate decision-maker*.

This advance directive only becomes valid when your physician has determined that you are no longer able to make decisions yourself.

This advance directive does not permit your surrogate decision-maker to make decisions on your behalf about finances or about other issues. Before you complete this document, it is important that you first discuss with your intended surrogate decision-maker which decisions are important to you.

In principle, this advance directive always remains valid. To prevent misunderstandings, it is important that you discuss its content regularly, e.g. every year, with your physician. If you change your preferences, you can complete a new advance directive.

Completion of the advance directive

The advance directive is divided into four parts.

Part I - *Who makes decisions about my medical treatment when I am no longer able to do this myself.*

In this part you record the name of your surrogate decision-maker(s) to make clear who can make decisions on your behalf if necessary. The surrogate decision-maker also records that he or she is willing to accept this role.

Part II - *General authorities of my surrogate decision-maker.*

In this part you record the authorities of your surrogate decision-maker when making decisions. You sign the statement you agree with. You cross out the statement you do not agree with. You can add additional authorities.

Part III - *My preferences concerning future medical care.*

In this part you record which decisions are important to you. You sign each statement you agree with. You cross out each statement you do not agree with. In this part you can also describe specific conditions that you consider important.

Part IV – *Signature.*

The last part concerns signing the document, in addition to your name, date and place.

After the completion

When you have completed and signed the advance directive, it is important that you provide copies to your surrogate decision-maker(s), your physician and others for whom this information is important (e.g. the institution where you live). This will increase chances that the advance directive can be used as appropriate.

Supplementary Figure F1 (continued) Study advance directive

ADVANCE DIRECTIVE

Part I – Who makes decisions about my medical treatment in case I am no longer able to do this myself.
In this document I indicate who is allowed to make decisions about my medical treatment in case I am no longer able to do this myself. This person is my *surrogate decision-maker*.

My surrogate decision-maker is:
Name: ____
Phone number day: ________________ Phone number evening: ______________
Mobile phone number: ____
Address: ____
Postal code: _______________ Place: _______________________________________

Acceptance:
_________________________ (first and last name) accepts the role as surrogate decision-maker and will act on behalf of _____________________ (first and last name) to the best of his/her abilities by making decisions that are in line with the preferences and wishes of the person described above.

In case my surrogate decision-maker no longer will or can decide on my behalf,
my surrogate decision-maker will be:

First alternative surrogate decision-maker
Name: ____
Phone number day: ________________ Phone number evening: ______________
Mobile phone number: ____
Address: ____
Postal code: _______________ Place: _______________________________________

Acceptance:
_________________________ (first and last name) accepts the role as surrogate decision-maker and will act on behalf of _____________________ (first and last name) to the best of his/her abilities by making decisions that are in line with the preferences and wishes of the person described above.

Supplementary Figure F1 (continued) Study advance directive

In case this alternative surrogate decision-maker no longer will or can decide on my behalf, **my surrogate decision-maker will be:**

Second alternative surrogate decision-maker

Name: ____
Phone number day: ________________ Phone number evening: ______________
Mobile phone number: ____
Address: ____
Postal code: _______________ Place: ______________________________________

Acceptance:

________________________ (first and last name) accepts the role as surrogate decision-maker and will act on behalf of _____________________ (first and last name) to the best of his/her abilities by making decisions that are in line with the preferences and wishes of the person described above.

Part II – General authorities of my surrogate decision-maker

I give my surrogate decision-maker the following authorities:
(Sign each statement you agree with and cross out each statement you do not agree with)

_____ Make choices on my behalf concerning starting, continuing, or stopping medical treatment and procedures, such as tests, medication and surgeries.
_____ Discuss my preferences and wishes, as recorded in this document or indicated in conversations, with my medical practitioners.
_____ Give permission to disclose my medical records and other personal information, in case my physician considers it necessary for my medical treatment.
_____ Make decisions on my behalf about choosing a medical practitioner or place of care.

Part III – My preferences concerning future medical care

My surrogate decision-maker will make decisions that are in line with my preferences and wishes. In case it is unclear what I would have preferred in a specific situation, I want my surrogate decision-maker to make a decision, in consultation with my medical practitioners. In case my surrogate decision-maker cannot be reached, I want the following instructions to be followed.

Cardiopulmonary resuscitation

(Sign the statement you agree with and cross out the statement you do not agree with)

_____ I want to be resuscitated, unless my physician considers that medically futile
_____ I do not want to be resuscitated in case of a cardiac arrest

Supplementary Figure F1 (continued) Study advance directive

Medical treatments

(Sign the statement you agree with and cross out the statement you do not agree with)

When the doctor considers it likely, that I will no longer be capable of meaningful contact with my family, friends and others, I want:

_____ Full treatment as long as it makes sense

_____ Care that focuses on comfort, well-being and symptoms, not aimed at life-extension nor shortening of life.

In the situation as described above I want:

_____ Artificial feeding

_____ Hospital admission for medical treatment or surgeries

_____ Artificial ventilation

Specific conditions for the situation in which life-prolonging medical treatment is foregone

In this situation, I want further medical treatment and care focusing on comfort. The following aspects are important to me:

Specific conditions that apply when I choose the option "full treatment as long as it makes sense"

If I choose the option "full treatment as long as it makes sense", the following aspects are important to me:

Euthanasia, organ donation, body donation

Because there are separate regulations for euthanasia, organ donation and body donation, these items are excluded from this advance directive.

Part IV - Signature

I have completed this document voluntarily.

Name:

Date, place:

Signature:

Supplementary File 2 Preferences as indicated in the study advance directive (AD) by 80/101 intervention participants. Values are numbers (percentages)

Outcomes	**Completed study AD (n=80)**
Appointed decision-maker	
- no	2 (3)
- yes, one	9 (11)
- yes, two or three	69 (86)
Cardiopulmonary resuscitation	
- I want to be resuscitated unless my doctor considers that medically futile	7 (9)
- I do not want to be resuscitated in case of a cardiac arrest	63 (79)
- no option or both options indicated	10 (13)
Medical treatments	
When the doctor considers it likely, that I will no longer be capable of meaningful contact with my family, friends and others, I want:	
- full treatment as long as it makes sense	3 (4)
- care that focuses on comfort, well-being and symptoms. My life will not be extended, but not shortened either	67 (84)
- no option or both options indicated	10 (13)
In the situation as described above I want:	
- artificial feeding	16 (20)
- hospital admissions for medical treatment and surgery	20 (25)
- artificial ventilation	16 (20)

Experiences with and outcomes of Advance Care Planning in bereaved relatives of frail older patients: a mixed methods study

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ABSTRACT

Background: Advance Care Planning (ACP) may prepare relatives of frail older patients for future decision-making.

Objective: To investigate (1) how bereaved relatives of frail older patients experience ACP conversations and (2) whether ACP has an effect on relatives' preparation for decision-making and on their levels of anxiety and depression.

Design: Cluster randomized controlled trial.

Setting: Residential care homes in the Netherlands and community setting.

Subjects: Bereaved relatives of care home residents and community-dwelling frail older patients.

Methods: We randomized 16 residential care homes to either the intervention group, where patient-participants were offered facilitated ACP, or the control group (n=201), where they received care as usual. If patient-participants died, we approached relatives for an interview. We asked relatives who had attended ACP conversations for their experience with ACP (open-ended questions). Furthermore, we compared relatives' preparation levels for decision-making and levels of anxiety and depression (HADS) between groups. This trial was registered (NTR4454).

Results: We conducted interviews with 39/51 (76%) bereaved relatives (intervention group: n=20, control group: n=19). Relatives appreciated the ACP conversations. A few considered ACP redundant since they were already aware of the patients' preferences. Nine of 10 relatives in the intervention group felt adequately prepared for decision-making as compared to five of 11 relatives in the control group (p=.03). Relatives' levels of anxiety and depression did not differ significantly between groups.

Conclusions: In our study, bereaved relatives of frail older patients appreciated ACP. ACP positively affected preparedness for decision-making. It did not significantly affect levels of anxiety or depression.

INTRODUCTION

As frail older patients may at some stage become unable to make healthcare decisions, their relatives may need to make decisions on their behalf [1]. However, relatives are often not aware of the preferences of patients, they often fail to predict patients' treatment preferences and may not feel adequately prepared to make such healthcare decisions [1-3]. This can be due to a lack of communication between patients and their relatives about goals and preferences for care [4]. It may result in complicated decision-making [5], patients not receiving their preferred care [4] and emotional stress, guilt and doubt in relatives regarding whether they made the right decisions [6, 7].

Advance Care Planning (ACP) is a formalized communication process that "*enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate* [8]." When relatives engage in ACP conversations, they can become familiar with patients' goals and preferences and their own potential role in the decision-making process [1, 4, 9]. This is especially useful for frail older patients given their high risk of conditions that might affect their capacity to make healthcare decisions [10]. Frailty is defined as "*an accumulation of physical, psychological and/or social deficits in functioning which increase the chance of adverse health outcomes (functional disabilities, admissions to an institution, death)* [11]." In the Netherlands, around 27% of people aged 65 and over are frail [11].

A recent systematic review about perspectives towards ACP showed that relatives of older patients may have ambivalent opinions and attitudes towards the initiation of ACP [4]. Until now, limited research is available on how relatives of deceased frail older patients experience involvement in ACP. Facilitated ACP by trained healthcare providers has been shown to improve relatives' satisfaction concerning the quality of death of patients, and to reduce levels of stress, anxiety and depression among relatives of hospitalized older patients in Australia [9]. Most studies in relatives of older patients were performed in North America or Australia, with only one trial focusing exclusively on bereaved relatives [9]. It is unknown to what extent the results of these studies can be generalized to European countries like the Netherlands, given the differences in culture, healthcare systems and legal ACP regulations. Dutch physicians are obliged to follow an advance directive (AD) with directions to forgo treatments ("negative directive") if it is sufficiently clear and detailed. They are not obliged to follow a directive with preferences for treatment to be applied ("positive directive"), since patients have no right to claim certain treatments [12, 13].

We conducted a randomized controlled trial to study the effects of ACP in frail older patients. We concluded that ACP increases the completion of ADs, but did not affect levels of patient activation or quality of life [14]. In the context of the same trial, we now address the following research questions:

1. How do relatives of deceased frail older patients experience facilitated ACP conversations?
2. What are the effects of ACP on bereaved relatives' satisfaction with healthcare, their preparation for decision-making, their satisfaction with the quality of death and their levels of anxiety and depression?

METHODS

Trial design/setting

Data for this study were collected in the context of a cluster randomized trial. We randomized 16 residential care homes per set of two with comparable average household incomes using a computer-generated list of random numbers. These residential care homes were randomly assigned to either the intervention group, in which residents and their relatives were offered ACP (n=101) or to the control group, in which residents received usual care (n=100). All residential care homes were based in Rotterdam, the Netherlands. Data were collected between 2014 and 2017. More details of the study design, methods and main findings can be found elsewhere [14, 15].

Participants

To be eligible for participation, individuals had to be ≥75 years, frail (Tilburg Frailty Index Score ≥5, range 0-15 [16]) and capable to consent to participation (Mini-Mental State Examination score ≥17, range 0-30 [17, 18]). At baseline, patient-participants were asked to identify a competent relative of at least 18 years of age who could be approached for an in-depth telephone interview. After the baseline assessment, patient-participants and their relatives in the intervention group were offered facilitated planning conversations based on the Respecting Choices® ACP facilitator training, education materials and tools, in addition to usual care. The program had three core elements: (1) information leaflets, (2) two facilitated ACP conversations by trained nurses based on scripted interview cards (we extended the interview card "First Steps ACP for Adult/Patient with Chronic Illness" with some items of the sample scripts from Last Steps used in POLST orders) and (3) the possibility to complete an AD or to appoint a surrogate decision-maker. Patient-participants and their relatives in the control group received care as usual.

Experiences with ACP: Qualitative study and analysis

Three months after the death of a patient-participant, appointed relatives were sent an invitation for an in-depth telephone interview. Approximately one week later, the researcher called the relative and explored his/her willingness to be interviewed. During these interviews, which were recorded, relatives were asked how they had experienced facilitated ACP conversations: (1) How did you experience the conversation?, (2) Did the conversation go as expected? Please explain., (3) In your opinion, was the conversation useful? Please explain., (4) Did the conversation facilitate potential healthcare decision making on behalf of the deceased patient? Please explain. Furthermore, relatives were asked about outcomes of the ACP conversation. We used a mixed sample scheme where qualitative and quantitative data were integrated in one interview.

The answers to open-ended questions were analyzed using a framework analysis approach which consists of five stages: (1) familiarization; (2) identifying a thematic framework; (3) indexing; (4) charting and (5) mapping and interpretation [19]. During the first stage, two researchers (AO & JR) became familiarized with the data and aware of key ideas and recurrent themes by reading and rereading the transcripts. During the second stage, the researchers identified a thematic framework with key issues, concepts and themes. Indexing means that the researchers identified sections of the interview texts that correspond to a particular theme. During the fourth stage (charting) pieces of data were rearranged in charts of themes, which means that data were lifted from their original textual context and placed in charts that consist of the headings and subheadings that were identified in step two. During the final stage (mapping and interpretation) we mapped and interpreted the data set as a whole [19].

Outcomes of ACP: Quantitative study and analysis

Outcomes of ACP in this study included relatives' satisfaction with healthcare, their preparedness for decision-making of the deceased patient, satisfaction with the quality of death and levels of anxiety and depression. Satisfaction with healthcare was measured by one subscale of the Patient Satisfaction Questionnaire (PSQ-18; range 1-5) [20]. We developed the following questions regarding decision-making: "Did you have to make (medical) decisions on behalf of the deceased patient?" and, if so, "Did you feel well prepared for making these decisions?". Satisfaction with quality of death was measured by asking [9]: "How satisfied are you about the way in which x died?". Finally, we used the Hospital Anxiety and Depression Scale (HADS; range 0-21 for each subscale) to measure symptoms of anxiety (subscale one) and depression (subscale two) [21].

Statistical analyses were by intention-to-treat. Personal characteristics of patients and their relatives, as well as outcomes of ACP were compared between groups, using chi-square tests for categorical data and ANOVA for continuous data. Differences were considered significant if p<.05. Analyses were performed using IBM SPSS statistics V.25.

RESULTS

Procedures

In total, 201 patients participated in our study (Figure 1). Fifty-six patients had died before or up to 14 months after the 12-month follow-up assessment (n=28 in both the intervention and the control group), with the maximum number of days between the follow-up assessment and the death of the patient being 453. Of the 56 deceased patients, 52 had assigned a relative at baseline. One relative turned out not to be mentally competent. We were able to conduct interviews with 39/51 (76%) bereaved relatives (intervention group: n=20, control group: n=19). Other bereaved relatives declined (n=5) or were uncontactable (n=7). The overall average time between the death of the patient and the interview was 221 days (range: 106-369). In the intervention group, the average time was 245 days (range: 123-359) and in the control group 195 days (range: 106-369, p=.07).

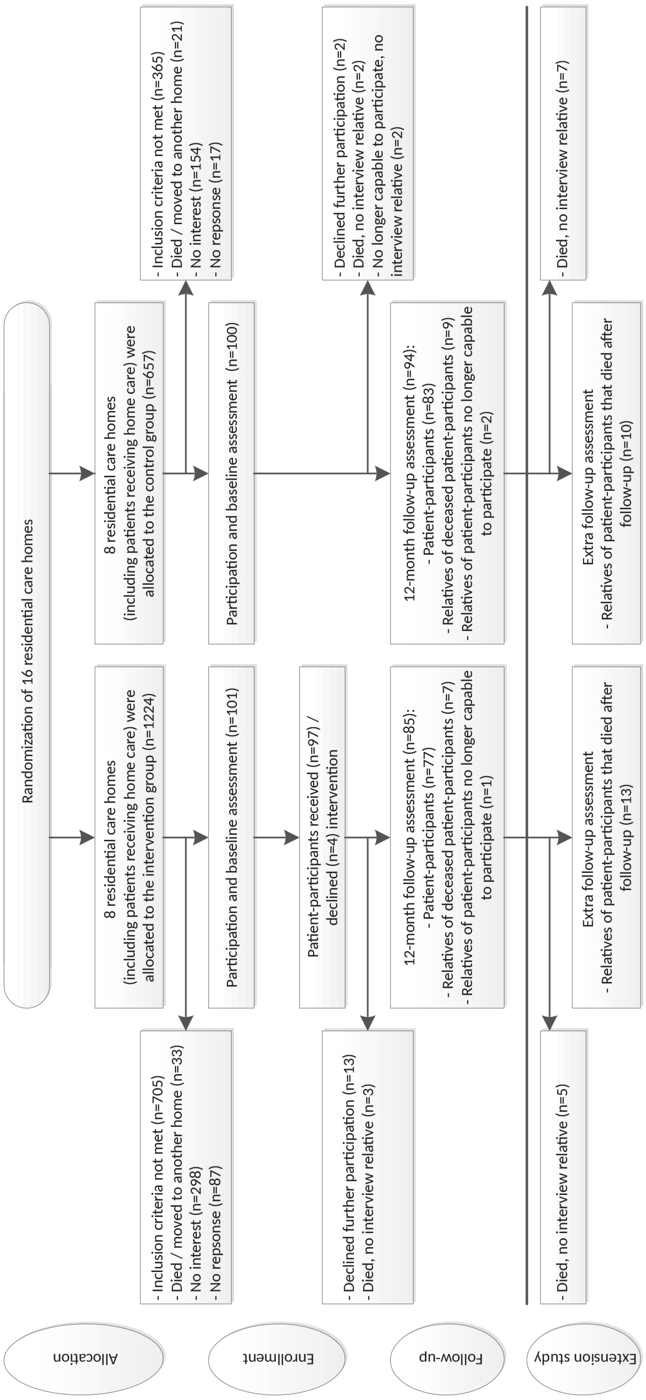

Figure 1 CONSORT flow chart

Characteristics of patients and relatives

In the intervention group, all 20 patients had completed an AD compared to eight out of 17 patients in the control group (p<.001, Table 1). In addition, the majority of patients in the intervention group (n=18/20) had appointed a surrogate decision-maker compared to 13/18 patients in the control group (p=.16). Most patients in the intervention group had appointed their decision-maker in writing (n=13/18), while most patients in the control group appointed their decision-maker verbally (n=10/13, p=.007).

The mean age of bereaved relatives was 62 years (SD: 5.2). The majority of relatives were female (n=29/39) and were adult children of the deceased patient (n=31/39). In the intervention group, approximately half of the relatives (n=11/20) had been present during one or more ACP conversations and 14 out of 20 were appointed as surrogate decision-maker by the patient. Among those who had been present during the ACP conversation, nine out of 11 relatives had discussed the content of the conversations with the patient afterwards vs. two out of nine relatives of those who were not present.

Table 1 Characteristics of deceased patients and their relatives

Characteristics	Intervention group n=20	Control group n=19	P-value
Patients			
Age, mean (SD)	89 (5.4)	89 (5.1)	.86
Gender, n (%)			.77
- female	15 (75)	15 (79)	
Residence, n (%)			.61
- care home	11 (55)	12 (63)	
- community-dwelling	9 (45)	7 (37)	
Tilburg Frailty Index score, mean (SD)[a]	7 (1.8)	8 (2.3)	.35
Mini-Mental State Examination score, mean (SD)[b]	26 (2.5)	26 (2.5)	.28
Completed advance directive according to relatives, n (%)[c]	20 (100)	8 (47)	<.001
Appointed surrogate decision-maker according to relatives, n (%)[d]	18 (90)	13 (72)	.16
- verbally	5 (28)	10 (77)	.007
- in writing	13 (72)	3 (23)	

Table 1 (continued) Characteristics of deceased patients and their relatives

Characteristics	Intervention group n=20	Control group n=19	P-value
Patients			
Location of death, n (%)			.52
- home	6 (30)	3 (16)	
- care home/nursing home	8 (40)	12 (63)	
- hospice	2 (10)	1 (5)	
- hospital	4 (20)	3 (16)	
Relatives			
Age, mean (SD)[d]	64 (7.6)	60 (8.6)	.18
Gender, n (%)			.52
- female	14 (70)	15 (79)	
Health status, n (%)[d]			.40
- very good	5 (26)	3 (16)	
- good	12 (63)	11 (58)	
- okay	2 (11)	5 (26)	
- bad	0 (0)	0 (0)	
Relationship with deceased patient, n (%)			1.00
- partner	1 (5)	1 (5)	
- child	16 (80)	15 (79)	
- other	3 (15)	3 (16)	
Relative attended Advance Care Planning conversation, n (%)[e]	11 (55)	-	-
Relative appointed as surrogate decision-maker by patient, n (%)[e,f]	14 (70)	-	-

[a] Normal range 0-15. Higher scores indicate worse functioning.
[b] Normal range 0-30. Higher scores indicate better functioning.
[c] Missing n=2.
[d] Missing n=1.
[e] Data only applicable for relatives in the intervention group.
[f] The appointed decision-maker is not necessarily the same person as the interviewed relative.

Circumstances of death according to relatives

Ten relatives in the intervention group and six relatives in the control group had been present during the patients' death (p=.24). According to relatives in the intervention group, 13 patients died at their preferred place of death vs. 11 patients in the control group, while two patients did not vs. four patients in the control group. Other relatives were not aware of the patients' preferred place of death (n=5 in intervention group vs. n=4 in the control group, p=.63). In the intervention group, 13 relatives thought that the patient was satisfied with the circumstances of death vs. 10 relatives in the control group, while seven relatives thought that the patient was more or less satisfied, or not satisfied at all, compared to nine relatives in the control group (p=.43).

Experiences with ACP of bereaved relatives

We explored two themes: (1) Experiences of relatives concerning facilitated ACP and (2) Beneficial elements of ACP according to relatives.

Experiences of relatives concerning facilitated ACP:

A substantial number of relatives (n=9/11) ***appreciated*** the facilitated ACP conversations:

"*It was a good and balanced conversation, during which my mother responded calmly and thoughtfully.*" *[Son, 69 years]*

Two relatives mentioned that ACP is ***important*** and that it facilitates reflecting on certain topics and situations which might come across:

"*[…] During the conversation about the advance directive a number of topics emerged […]. What to do in specific situations. So yes, it did help reflecting on certain topics. […] What needed to be done if my mother's health would worsen or if she would no longer able to make decisions herself […]. That was really important to me.*" *[Son, 73 years]*

According to several relatives, ACP ***provided clarity*** concerning the patients' preferences for medical treatment and care, and the decision that had to be made on behalf of the patient:

"*Yes, a lot of topics emerged during that conversation. My mother indicated clearly what she wanted to happen and what she did not want to happen. Especially what she did not want to happen. That was also documented in that advance directive, so it was really clear to me.*" *[Daughter, 64 years]*

Relatives also appreciated ACP because it ***facilitates healthcare decision-making***:

"[…] More insight and clarity concerning the necessary choices." [Son, 69 years]

Some relatives had ***no (good) memory*** of the conversation:

"*No, to be honest, I cannot say anything about that. But it undoubtedly went fine. Otherwise, if things had gone terribly wrong, or if I would have been angry about something, I would have remembered it.*" *[Niece, 61 years]*

In five cases, patients' ***preferences for medical treatment and care were already known*** and therefore relatives considered ACP redundant. However, the ACP conversation was also considered as a confirmation of preferences that had been formulated in the past:

"*[…] Maybe she was reassured that she had taken the right course.*" *[Daughter, 66 years]*

Some relatives mentioned that the ACP ***content did not fulfil expectations*** and/or that they did not feel well prepared for the conversations:

"*Well, I had no idea what would be discussed. So, I did not expect it, let me say it that way, because I had no idea.*" *[Daughter, 64 years]*

Beneficial elements of ACP according to relatives:

Some relatives reported that the ACP conversation was provided at the ***right moment***:

"*Earlier it was not the right moment for my father, it was too early. It was not yet relevant at that time, let me say it in that way […].*" *[Daughter, 60 years]*

The same relative appreciated that ACP was provided by an ***independent facilitator*** who did not influence her father or tried to persuade him in any way:

"[…] As people sometimes say: it takes a fresh pair of eyes to put things into proper perspective. Anyway, my father got a better understanding of the conversation and he did it (ACP) all by himself, so, without us. It was pleasant that another person, an independent one, asked the questions, otherwise it would seem that you are pushing him. […] I had the idea that this (ACP conversation) was really independent. Without our influence. It was nice that a "detached" person […] did it […]." [Daughter, 60 years]

Relatives also appreciated that facilitators provided ***clear explanations*** during the conversation:

"*Perfect. […] Everything was explained very well.*" *[Daughter, 67 years]*

Finally, ***openness of patients*** concerning their preferences is necessary, or at least facilitates ACP conversations according to three relatives:

"*It is clear for me that the person, in this case my mother, has to be open to having this kind of discussions. But this was the case, she has always been that way. Always discussing things.*" *[Son, 69 years]*

Outcomes of ACP of bereaved relatives

Satisfaction with healthcare did not differ significantly between relatives of intervention vs. control group patient-participants (Table 2) or between relatives of patient-participants in the intervention group who had or had not been present during ACP conversations. Relatives of patient-participants in the intervention group who had been involved in decision-making, more often had felt well prepared for decision-making than relatives of patient-participants in the control group (n=9/10 vs. n=5/11 respectively, p=.03). Relatives' satisfaction with the quality of death and levels of anxiety and depression did not differ significantly between study groups or between relatives of patient-participants in the intervention group who had or had not been present during ACP conversations. Furthermore, the study setting (residential care home vs. community) did not affect the outcomes.

Table 2 Outcomes of ACP

Outcomes	Intervention group n=20	Control group n=19	P-value
Relatives' satisfaction with healthcare, subscale PSQ-18, normal range: 1-5, mean (SD)[a,b]	3.6 (1.1)	3.5 (1.3)	.90
Decision-making, n (%)			.62
- relative was involved in decision-making	10 (50)	11 (58)	
- relative was not involved in decision making	10 (50)	8 (42)	
If involved:			.03
- relative felt well prepared	9 (90)	5 (46)	
- relative felt more or less/not prepared	1 (10)	6 (55)	
Relatives' satisfaction with quality of death, n (%)[c]			1.00
- very satisfied	7 (37)	7 (37)	
- satisfied	11 (58)	11 (58)	
- not satisfied	1 (5)	1 (5)	
Relatives' levels of anxiety and depression, Hospital Anxiety and Depression Scale, normal range per subscale: 1-21			
- anxiety, mean (SD)[a,d]	5.1 (4.1)	5.8 (4.5)	.63
- depression, mean (SD)[a,d]	1.9 (3.0)	2.9 (3.6)	.40

[a] Missing n=2.
[b] Higher scores indicating more satisfaction.
[c] Missing n=1.
[d] Higher scores indicating higher degree of anxiety/depression.

DISCUSSION

Main findings

Most bereaved relatives in our study appreciated the facilitated ACP conversations. According to several relatives, these conversations provided clarity concerning patients' preferences for medical treatment and care and facilitated healthcare decision-making. In five cases, patients' preferences were already known and therefore relatives considered ACP redundant. Among relatives who had been involved in decision-making, ACP had a positive effect on the perceived level of preparation for decision-making. ACP had no significant effect on levels of satisfaction, anxiety and depression.

Interpretation of results

According to bereaved relatives in our study, positive experiences of ACP were related to e.g. clear explanations and examples of facilitators, and the fact that facilitators were open-minded concerning the patients' preferences for medical treatment and care. More than half of the relatives had been present during the ACP conversations, suggesting that they were open to being involved in the ACP process. This finding confirms results of other studies [4]. In our study, patients' preferences concerning medical treatment and care were already known in some cases. Therefore, a small number of relatives considered ACP as not relevant. However, it can still be useful to repeat or confirm earlier ACP conversations, since ACP is a process and patients' preferences concerning future medical treatment and care may change [22]. Even if preferences are stable, ACP can be useful since it allows preferences to be confirmed, as reported by one relative in this study.

Among relatives who were involved in decision-making, ACP had a positive effect on preparation for decision-making. This is in line with findings of Bravo and colleagues, who found that relatives' rating of their own ability to make concordant decisions for patients increased following ACP [23]. These are important findings, since many relatives of frail older patients have to make healthcare decisions on behalf of the patient, for instance if he/she develops dementia [1]. In addition, preparation for decision-making among relatives is important to enable patients to receive care that aligns with their preferences. Detering and colleagues actively involved relatives in the ACP process of hospitalized older patients and found that patients' preferences concerning medical treatment and care were much more likely to be known and followed in the ACP intervention group compared with the control group [9]. The positive effect of ACP on preparation for decision-making as found in our study may be due to ACP providing clarity concerning patients' preferences and facilitating healthcare decision-making, as described by relatives in the qualitative study. The positive effect may also be due to the finding that significantly more patient-participants in the intervention group completed an AD, despite rather high AD completion rates in the control group [14]. The content of these ADs could have been an important guide for relatives during the decision-making process.

In contrast to the study of Detering and colleagues [9] we did not find significant effects of ACP on levels of satisfaction, anxiety and depression in bereaved relatives. This may be related to (1) the timing of the interview and (2) the number of relatives who had been present during ACP conversations. In the study of Detering and colleagues [9] relatives were interviewed a median of 104 days after the patients' death, while we conducted the interview after 221 days on average. Due to late communication of the patients' death or relatives' preference to postpone the interview, the average time between the death of some patients and the interview was relatively long. Possibly, the effects of ACP on satisfaction, anxiety and depression were larger shortly after the death of the patient and have diminished over time. While, in our study, bereaved relatives were present during 55% of ACP conversations, this percentage was even higher in the study of Detering and colleagues (72%) [9]. As a result, a higher number of relatives in the study of Detering and colleagues [9] may have been familiar with the goals and preferences of the patients than relatives in our study, leading to a better alignment of medical care with preferences and, in turn, higher levels of satisfaction with healthcare and quality of death. Among relatives who had been present during our ACP conversations, the mean score for satisfaction with healthcare was indeed somewhat higher (however, not significantly) than the score of relatives who had not been present.

Strengths and limitations

Strengths of this study include the randomized controlled trial design, the mixed methods design, the use of standardized ACP based on the internationally recognized Respecting Choices facilitation training and the high rate of patient-participants in the intervention group who completed the ACP program. This study has limitations as well. First of all, we did not conduct a power analysis for this sub-study. The number of bereaved relatives was small which may reduce internal and external validity. Secondly, recall bias may have influenced our findings concerning levels of satisfaction especially among relatives in the intervention group, with the average time between the death of the patient and the interview being 245 days (vs. 195 days in the control group). However, research suggests that important emotional events (such as the death of a patient) and their characteristics (such as satisfaction with the quality of death) can be recalled better than neutral ones [24]. Recall bias may also have influenced our findings concerning relatives' experiences of ACP. While relatives' views of the ACP program were usually positive, some comments indicate the limitations of recall of details of the circumstances and relationships. Thirdly, social desirability may have affected our findings concerning the preparedness for decision-making, with relatives potentially reporting higher than actual preparation levels. This may have occurred especially in the intervention group where relatives may have wanted to "please" the researcher by reporting positive effects following ACP. However, both the interview and the interview protocol were aimed at limiting social desirable answers as much as possible. Fourthly, the qualitative study focused on the intervention group only. It might have been interesting to understand the views of relatives of patient-participants from the control group as well. This may have captured views of difficulties with existing arrangements, that may be addressed by an extensive ACP program.

Implications for clinical practice and future research

This study highlights that many relatives of frail older patients were open to being involved in ACP. In our study, most relatives had positive experiences with ACP and felt adequately prepared for decision-making following ACP. Being better prepared is an important advantage and can prevent difficult decision-making among relatives. We recommend that future studies among bereaved relatives include a larger sample size to allow for more power. In addition, researchers in future studies are recommended to conduct interviews with relatives as soon as possible after the death of the patient-participant, to measure short-term effects of ACP on levels of anxiety and depression. On the other hand, bereaved relatives should be beyond the state of acute grief when conducting the interview. Finding the right window for interviewing bereaved relatives on ACP deserves further attention.

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Admissions to inpatient care facilities in the last year of life of community-dwelling older people in Europe

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ABSTRACT

Background: In the last year of life, many older people rather avoid admissions to inpatient care facilities. We describe and compare such admissions in the last year of life of 5092 community-dwelling older people in 15 European countries (+Israel).

Methods: Proxy-respondents of the older people, who participated in the longitudinal SHARE study, reported on admissions to inpatient care facilities (hospital, nursing home or hospice) during the last year of their life. Multivariable regression analyses assessed associations between hospitalizations and personal/contextual characteristics.

Results: The proportion of people who had been admitted at least once to an inpatient care facility in the last year of life ranged from 54% (France) to 76% (Austria, Israel, Slovenia). Admissions mostly concerned hospitalizations. Multivariable analyses showed that especially Austrians, Israelis and Poles had higher chances of being hospitalized. Further, hospitalizations were more likely for those being ill for six months or more (OR:1.67, CI:1.39-2.01) and less likely for persons aged 80+ (OR:0.54, CI:0.39-0.74; compared with 48-65 years), females (OR:0.74, CI:0.63-0.89) and those dying of cardiovascular diseases (OR:0.66, CI:0.51-0.86; compared to those dying of cancer).

Conclusions: Although healthcare policies increasingly stress the importance that people reside at home as long as possible, admissions to inpatient care facilities in the last year of life are relatively common across all countries. Furthermore, we found a striking variation concerning the proportion of admissions across countries which cannot only be explained by patient needs. It suggests that such admissions are at least partly driven by system-level or cultural factors.

INTRODUCTION

Most people prefer to receive care and to die at home [1, 2]. However, many people are admitted to inpatient care facilities at the end of their life, such as a hospital, nursing home or hospice [3-7]. A study conducted in Belgium, the Netherlands, Italy and Spain (2009-11) showed that transitions between care sites are rather common in the last three months of life, with 55% (the Netherlands) to 60% (Italy) of patients having been transferred at least once [6]. Especially transitions to a hospital occurred rather frequently in the last phase of life in all studied countries (Belgium, the Netherlands, Italy and Spain) [5]. In line with these findings, several studies showed that the majority of people dies in a hospital [8-10]. Pivodic and colleagues [8] compared the place of death of people dying from diseases indicative of palliative care need in 14 countries and concluded that between 25% (the Netherlands) and 85% (South Korea) of people died in a hospital. In a study among older patients who died with cancer, a higher proportion of decedents (38-52%) died in acute care hospitals in Canada, Belgium, England, Germany and Norway than in the USA (22%) and the Netherlands (29%) [11]. Hospitalizations in the last three months of life have been found to be associated with male gender and residing at home rather than in a care home [5]. Further, being aged less than 85 years, having an infection and the absence of a palliative treatment goal were associated with hospitalization in the last week of life [4].

Hospitalizations do not always align with the wishes of patients at the end of their life [1] and carry the risk of patients receiving poor quality of end-of-life care and of poor coordination or planning of follow-up care after discharge from the inpatient care facility [5, 12-15]. Currently, in many countries health policy is aiming at reducing hospitalizations at the end of life and encouraging end-of-life care in the community for as long as possible [16].

Cross-country comparisons of admissions to inpatient care facilities in the last phase of life can help to identify similarities and differences concerning the frequencies and duration of admissions and its causes. Previous international comparative research on such admissions is mainly limited to place of death studies based on restricted and sometimes inaccurate or incomplete death certificate data [8-10]. Further, most of these studies focused on the last three months of life and incorporated just a few countries [4-7]. This is the first cross-national study to describe and compare admissions of community-dwelling older people to inpatient care facilities in 15 European countries (+Israel), focusing on the last year of their life. We will address the following research questions:

1. How often and how long do community-dwelling older people spend time in inpatient care facilities in the last year of life of and does this vary between the studied countries?

2. Which personal and contextual characteristics are associated with hospitalizations in the last year of life of community-dwelling older people and do these associations vary between the studied countries?

METHODS

Study design and sample

We used data from the Survey of Health, Ageing and Retirement in Europe (SHARE). SHARE is an ongoing longitudinal study in which data are collected on health, socio-economic status and social and family networks of community-dwelling older people (aged 50 years or over) from a number of European countries and Israel. People are excluded if they are incarcerated, hospitalized or out of the country during the entire survey period, unable to speak the country's language(s) or have moved to an unknown address. The first wave of data was collected in 2004; the fifth in 2013. The weighted average of household response rates in 2004 was 62% (38% in Switzerland and 74% in France). The corresponding participation rate was 39% (17% in Switzerland and 60% in Denmark). The weighted average of individual response rates in 2004 was 48% (33% in Switzerland and 69% in France). Analyses revealed only small differences in the patterns of survey participation by gender and age group [17]. Survey continuation in wave two was higher among participants aged 59-74, those having a good health and those living in free standing homes [18]. More information on SHARE can be found elsewhere [18-25].

We used data from 16 countries: Austria, Belgium, the Czech Republic, Denmark, Estonia, France, Germany, Greece, Israel, Italy, the Netherlands, Poland, Spain, Sweden, Slovenia and Switzerland. If a SHARE participant died, interviewers conducted a structured end-of-life interview with a proxy-respondent (n=5095). Proxy-respondents were mostly relatives, but also neighbors or friends [18]. For three deceased people, two interviews were available of which one of them was excluded from the analyses. This leads to a final sample of 5092. A total of 716 interviews were held in wave two [26], 1137 in wave three [27], 1110 in wave four [28] and 2129 in wave five [29]. The average time between the participants' death and the interview varied between 14 months (wave three) and 18 months (wave four) across waves. In wave two, end-of-life interviews were conducted in somewhat more than 60% of the cases of deceased persons [18]. In wave three, the lowest participation rate for end-of-life interviews was 41% in Austria, followed by 51% in the Netherlands, 52% in Sweden, 56% in France, 64% in Germany, 65% in Denmark and Belgium (Dutch), 67% in Switzerland, 73% in Belgium (French), 75% in the Czech Republic, 82% in Italy, 85% in Poland and 86% in Spain and Greece [21]. For wave four and five, no information on the participation rates for end-of-life questionnaires is available.

Procedures and measurements

Data were collected in computer assisted personal- or telephone interviews conducted by professional interviewers. Proxy-respondents were asked to provide information on:

1. the number and the duration of admissions to inpatient care facilities in the last year of life of the deceased person;
2. whether or not the deceased had been admitted to a hospital, a nursing home and/or a hospice in the last year of life;
3. personal characteristics of the deceased, the following of which were selected for this study as they were found relevant for admissions to inpatients care facilities in previous research [4, 8-10, 30]: age, gender, education level (International Standard Classification of Education, ISCED-97) [31], living alone, main cause of death, place of dying, duration of the illness before death, number of difficulties with activities in daily living (ADL) in the last year of life for at least three months, help with ADL during the last year of life and the overall time the deceased received help by relatives and/or professional helpers during the last 12 months (Supplementary Table).

Analyses

We compared the characteristics of the deceased and the time spent in inpatient care facilities across countries using Pearson's chi-square tests and ANOVA. Furthermore, we calculated percentages of hospitalizations for subgroups. To determine which personal characteristics were associated with hospitalizations in the last year of life we conducted a multivariable binary logistic regression analysis with the dependent variable being: hospitalized in the last year of life vs. not hospitalized. Independent variables were simultaneously entered. Analyses were conducted for each country separately and for the whole study population altogether (n=5092). Moreover we performed a "test for interaction" to study whether the odds ratios differed across countries. We did this for every characteristic separately by including all countries and adding an interaction term for country*characteristic. Finally we conducted a multivariable binary logistic regression analysis for all countries together, with country as an independent variable. All statistical tests were performed with a significance level of $\alpha<.05$.

Ethics

Until July 2011, SHARE has been reviewed and approved by the Ethics Committee of the University of Mannheim. Since then, the Ethics Council of the Max-Planck-Society for the Advancement of Science (MPG) is responsible for ethical reviews and the approval of the study.

RESULTS

Characteristics

The mean age at death (Table 1) ranged from 74 years in Poland to 81 years in Sweden. Between 40% (the Netherlands, Poland) and 54% (Austria) of deceased people were female. Concerning the level of education we observed much variation between countries (25% in Germany and 94% in Spain had a low education). This also holds for the percentage of people who lived alone (14% in Poland and 50% in Denmark). In all countries, cancer (ranging between 23% in Estonia and Greece and 38% in the Netherlands) or cardiovascular diseases (ranging between 17% in Belgium, Denmark and the Netherlands and 35% in Greece) were the most common cause of death, as reported by the proxy. The percentage of people dying in the hospital ranged from 31% in the Netherlands up to 67% in Slovenia. In total 57% of people had been ill for six months or more before they died, 43% had had difficulties with more than two ADL in the last 12 months of life and 57% received assistance with ADL a full year before death.

Table 1 Characteristics of the study population (n, %), n=5092

Characteristic	**AT**	**BE**	**CH**	**CZ**	**DE**	**DK**	**EE**	**ES**	**FR**	**GR**	**IT**	**IL**	**NL**	**PL**	**SE**	**SI**
	n=293	**n=377**	**n=139**	**n=371**	**n=193**	**n=388**	**n=329**	**n=577**	**n=405**	**n=197**	**n=386**	**n=356**	**n=272**	**n=250**	**n=507**	**n=52**
Age, mean (SD)[a]	76(11)	78(11)	80(12)	76(10)	76(10)	78(11)	76(10)	80(10)	79(12)	79(12)	78(10)	77(10)	76(11)	74(10)	81(10)	77(10)
48-65	52(19)	61(16)	17(12)	75(21)	28(15)	57(15)	60(18)	57(10)	67(17)	27(14)	53(14)	50(16)	54(20)	51(21)	38(8)	7(14)
66-80	124(44)	128(34)	51(37)	144(40)	97(51)	151(39)	145(45)	216(38)	129(33)	76(39)	167(44)	132(43)	122(45)	125(51)	173(35)	26(51)
81-104	103(37)	185(50)	71(51)	143(40)	66(35)	177(46)	121(37)	293(52)	200(51)	90(47)	162(42)	127(41)	93(35)	71(29)	287(58)	18(35)
Gender, female[b]	157(54)	164(44)	57(41)	171(46)	89(46)	204(53)	145(44)	272(47)	195(48)	90(46)	168(44)	162(46)	109(40)	100(40)	237(47)	20(39)
Education[b]																
Low	108(38)	217(59)	55(42)	228(64)	48(25)	148(39)	168(51)	523(94)	301(76)	160(83)	331(87)	172(49)	167(63)	160(69)	356(72)	28(55)
Middle	137(48)	81(22)	72(55)	102(29)	99(52)	144(38)	126(38)	16(3)	70(18)	20(10)	40(11)	116(33)	56(21)	61(26)	88(18)	20(39)
High	39(14)	73(20)	5(4)	28(8)	44(23)	87(23)	35(11)	18(3)	27(7)	12(6)	10(3)	62(18)	43(16)	11(5)	54(11)	3(6)
Living alone[b]	116(40)	120(32)	59(42)	130(35)	61(32)	193(50)	83(25)	107(19)	148(37)	86(44)	61(16)	87(25)	74(27)	34(14)	215(43)	13(25)
Cause death[b]																
Cancer	66(24)	115(31)	46(33)	90(25)	64(34)	117(31)	74(23)	135(24)	119(31)	45(23)	138(36)	98(31)	102(38)	65(26)	145(29)	17(33)
Cardiovascular	66(24)	63(17)	32(23)	104(29)	62(33)	65(17)	95(30)	150(26)	69(18)	68(35)	94(25)	56(18)	45(17)	84(34)	108(22)	13(25)
Stroke	40(14)	32(9)	7(5)	53(15)	12(6)	27(7)	59(18)	51(9)	44(11)	30(16)	42(11)	36(12)	19(7)	36(15)	38(8)	5(10)
Respiratory	7(3)	11(3)	4(3)	15(4)	4(2)	21(6)	13(4)	45(8)	22(6)	10(5)	21(6)	4(1)	5(2)	10(4)	14(3)	0(0)
Infectious	20(7)	22(6)	9(7)	16(4)	9(5)	22(6)	5(2)	23(4)	12(3)	1(1)	12(3)	11(4)	14(5)	4(2)	30(6)	3(6)
Other	79(28)	130(35)	41(30)	84(23)	40(21)	129(34)	75(23)	169(30)	121(31)	39(20)	76(20)	107(34)	84(31)	50(20)	164(33)	14(27)

Table 1 (continued) Characteristics of the study population (n, %), n=5092

Characteristic	**AT**	**BE**	**CH**	**CZ**	**DE**	**DK**	**EE**	**ES**	**FR**	**GR**	**IT**	**IL**	**NL**	**PL**	**SE**	**SI**
	n=293	**n=377**	**n=139**	**n=371**	**n=193**	**n=388**	**n=329**	**n=577**	**n=405**	**n=197**	**n=386**	**n=356**	**n=272**	**n=250**	**n=507**	**n=52**
Place of dying[b]																
Hospital	139(50)	172(47)	58(42)	231(64)	90(48)	158(42)	155(49)	306(54)	210(55)	77(43)	169(44)	210(62)	83(31)	127(52)	191(39)	33(67)
Home	100(36)	118(32)	33(24)	85(23)	64(34)	98(26)	123(39)	220(39)	105(28)	96(54)	189(50)	104(31)	101(38)	108(44)	113(23)	14(29)
Nursing home	23(8)	59(16)	36(26)	21(6)	23(12)	107(28)	24(8)	31(6)	45(12)	2(1)	12(3)	22(7)	64(24)	1(0)	161(33)	2(4)
Hospice	6(2)	12(3)	6(4)	16(4)	5(3)	9(2)	4(1)	2(0)	8(2)	0(0)	2(1)	1(0)	12(5)	6(2)	22(5)	0(0)
Other	8(3)	7(2)	4(3)	10(3)	6(3)	8(2)	13(4)	8(1)	13(3)	3(2)	9(2)	1(0)	5(2)	4(2)	6(1)	0(0)
Ill before death[b]																
< 6 months	110(40)	161(45)	78(57)	153(42)	73(39)	157(42)	133(43)	265(47)	158(42)	103(59)	169(45)	94(29)	127(48)	116(47)	202(42)	18(36)
≥ 6 months	162(60)	200(55)	59(43)	209(58)	115(61)	220(58)	179(57)	298(53)	218(58)	73(42)	210(55)	228(71)	138(52)	129(53)	281(58)	32(64)
Difficulties ADL[bc]																
None	138(50)	134(36)	67(49)	162(45)	82(43)	153(40)	149(47)	206(36)	156(41)	102(53)	128(34)	136(41)	110(41)	119(48)	187(38)	22(42)
1-2	35(13)	71(19)	37(27)	75(21)	24(13)	71(19)	49(15)	75(13)	47(12)	23(12)	49(13)	42(13)	46(17)	39(16)	105(21)	4(8)
> 2	105(38)	169(45)	34(25)	121(34)	84(44)	159(42)	121(38)	293(51)	179(47)	68(35)	205(54)	155(47)	111(42)	91(37)	203(41)	26(50)
Assistance ADL[bc]																
No	14(10)	8(3)	8(11)	8(4)	5(4)	9(4)	14(8)	8(2)	6(3)	3(3)	13(5)	12(6)	7(4)	8(5)	28(8)	3(10)
Yes, < 3 months	11(8)	27(11)	4(5)	33(16)	11(9)	39(16)	15(8)	48(13)	25(10)	21(19)	36(14)	21(10)	33(20)	24(16)	34(10)	7(24)
Yes, ≥ 3 months	36(25)	59(23)	26(35)	65(32)	32(27)	59(24)	64(34)	95(25)	62(26)	34(31)	86(33)	49(23)	42(26)	32(21)	64(19)	6(21)
Yes, a full year	81(57)	162(63)	37(49)	99(48)	69 (59)	144(57)	93(50)	230(60)	149(62)	52(47)	129(49)	130(61)	83(50)	88(58)	212(63)	13(45)
Any hospital care[bc]	196(71)	219(59)	76(55)	221(61)	127(67)	244(64)	181(56)	360(63)	201(52)	104(54)	253(66)	242(73)	158(59)	173(70)	301(61)	31(61)
Any nursing home care[bc]	35(13)	61(16)	34(25)	37(10)	29(15)	88(23)	30(9)	47(8)	67(17)	3(2)	19(5)	38(12)	42(16)	2(1)	110(22)	2(4)

Table 1 (continued) Characteristics of the study population (n, %), n=5092

Characteristic	**AT**	**BE**	**CH**	**CZ**	**DE**	**DK**	**EE**	**ES**	**FR**	**GR**	**IT**	**IL**	**NL**	**PL**	**SE**	**SI**
	n=293	**n=377**	**n=139**	**n=371**	**n=193**	**n=388**	**n=329**	**n=577**	**n=405**	**n=197**	**n=386**	**n=356**	**n=272**	**n=250**	**n=507**	**n=52**
Any hospice care[bc]	10(4)	45(12)	12(9)	31(9)	6(3)	14(4)	12(4)	8(1)	62(16)	0(0)	4(1)	8(3)	12(5)	8(3)	72(15)	1(2)

Missing data on age n=125, gender n=12, education n=123, living alone n=23, main cause of death n=130, place of dying n=74, how long been ill before death n=135, difficulties with activities of daily living (ADL) n=125, anyone helped with activities of daily living (ADL) n=150, hospital care n=122, nursing home care n=116, hospice care n=135.
AT, Austria; BE, Belgium; CH, Switzerland; CZ, Czech Republic; DE, Germany; DK, Denmark; EE, Estonia; ES, Spain; FR, France; GR, Greece; IT, Italy; IL, Israel; NL, the Netherlands; PL, Poland; SE, Sweden; SI, Slovenia.
P–value ≤0.05 based on [a] Anova or [b] Chi-square test on difference between countries.
[c] In last 12 months.

Admissions in the last year of life

Between 52% (France) and 73% (Israel) of people had at least one hospital admission in the last year of life, between 1% (Poland) and 25% (Switzerland) had received any care in a nursing home and between 0% (Greece) and 16% (France) stayed in a hospice at least once (Table 1). The proportion of people with any admission to an inpatient care facility in the last year of life ranged from 54% (France) to 76% (Austria, Israel, Slovenia) (Supplementary Figure). Overall, 42% were admitted for one month or more (ranging from 27% in Estonia and Greece to 48% in Austria), with considerable variation in the total duration of admissions among the countries ($p<.001$).

Hospitalizations

Table 2 shows that, overall, the oldest age group was admitted less often to hospitals in the last year of life (58% for ≥81 years vs. 66% for 66-80 years and 62% for 48-65 years). In total 63% of males vs. 62% of females were hospitalized. Of people living alone, 60% were hospitalized vs. 63% of people living together. 78% of people who died from cancer were hospitalized in the last year of life, followed by 60% of those who died from a stroke. Furthermore, 73% of people who had been ill for six months or more were hospitalized vs. 50% for having been ill for less than six months. People with more than two ADL difficulties in the last year of life were admitted more often to hospital (70%) compared with people with one or two ADL difficulties (65%) or no difficulties (53%). People who received assistance with ADL for three months or more in the last year of life were hospitalized more often (78%) than people who received assistance for a full year (64%), assistance for less than three months (74%) or no assistance (56%). Finally, people who had received care in a nursing home were more often admitted to a hospital (82%) than people who did not receive nursing home care (59%). This also applies to people who stayed in a hospice (88% vs. 60% respectively).

Multivariable binary logistic regression analyses were performed for each country to assess the independent association between personal characteristics and hospitalizations (Table 3). The analyses confirmed that hospitalizations were less likely for persons aged 80 or over (overall OR: 0.56, CI: 0.41-0.76) compared with persons aged 48-65 years. However, in Switzerland, France, Greece and Israel the reverse pattern was observed. Furthermore, females had lower chances of being hospitalized (overall OR: 0.77, CI: 0.65-0.91) except in France and Israel. Those dying of cardiovascular diseases (OR: 0.70, CI: 0.54-0.90) and "other" diseases (OR: 0.55, CI: 0.44-0.69) also had lower chances of being hospitalized compared to those dying of cancer. Hospitalizations were more likely for those who had been ill for six months or more (OR: 1.70, CI: 1.42-2.05). People who received assistance with ADL for three months or more had higher chances of being hospitalized compared with people who received no assistance or assistance a full year (OR:2 .52, CI: 1.70-3.74 and OR: 1.77, CI: 1.43-2.19 respectively).

Furthermore, hospitalizations were more likely for people who stayed in a nursing home (OR: 2.51, CI: 1.95-3.22) and for people who stayed in a hospice (OR: 2.24, CI: 1.48-3.41). We found an interaction between some characteristics (age, ill before death and difficulties with ADL) and country (p<.05). For instance, hospitalizations were especially common for Greece people aged 66-80 (OR: 4.55, CI: 1.45-14.31) or 80 or over (OR: 4.05, CI: 1.34-12.24) and Israeli people aged 80 or over (OR: 2.50, CI: 1.02-6.11). Finally, we performed a multivariable binary logistic regression analysis for all countries together to assess whether there is an association between country of residence and hospitalization while taking into account personal characteristics (age, gender, education, living alone, main cause of death, duration of illness, difficulties with ADL, assistance with ADL, nursing home care and hospice stays, Table 4). People from France (reference) and the Netherlands (OR: 1.12, CI: 0.72-1.77) had the lowest probability of being hospitalized. People from Slovenia (OR: 2.31, CI: 0.93-5.73), Poland (OR: 2.61, CI: 1.59-4.30), Israel (OR: 2.65, CI: 1.65-4.26) and Austria (OR: 3.46, CI: 2.03-5.90) had the highest probability of being hospitalized.

Table 2 Unadjusted hospitalization rates in the last year of life by country, n=5092

Characteristic	**AT**	**BE**	**CH**	**CZ**	**DE**	**DK**	**EE**	**ES**	**FR**	**GR**	**IT**	**IL**	**NL**	**PL**	**SE**	**SI**	**Total**
	n=293	**n=377**	**n=139**	**n=371**	**n=193**	**n=388**	**n=329**	**n=577**	**n=405**	**n=197**	**n=386**	**n=356**	**n=272**	**n=250**	**n=507**	**n=52**	**n=5092**
	%	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**n (%)**
Age																	
48-65	65	62	65	49	64	**82**[a]	57	65	54	**26**[a]	72	**55**[a]	**76**[a]	67	66	86	465(62)
66-80	74	**67**[a]	56	65	73	69	57	60	56	**63**[a]	**73**[a]	75	63	73	66	58	**1312(66)**[a]
81-104	70	**53**[a]	52	64	58	**55**[a]	55	64	50	54	**57**[a]	72	**45**[a]	63	57	56	**1261(58)**[a]
Gender																	
Male	70	60	54	58	68	65	58	64	53	49	70	71	63	71	62	55	1676(63)
Female	71	58	56	65	65	64	55	62	52	60	61	76	53	67	59	70	1409(62)
Education																	
Low	76	59	47	63	57	63	56	63	51	**58**[a]	64	70	56	69	62	67	1898(61)
Middle	65	59	59	64	72	62	57	81	55	**30**[a]	83	78	64	72	62	60	783(64)
High	73	60	60	46	67	70	57	50	63	36	70	73	63	55	53	33	331(62)
Living alone																	
No	72	59	58	59	64	68	56	63	53	56	67	71	**63**[a]	69	64	56	**2164(63)**[a]
Yes	68	57	51	67	72	60	57	60	50	52	60	82	**49**[a]	74	57	75	**908(60)**[a]
Cause death																	
Cancer	**86**[a]	**73**[a]	**84**[a]	72	**86**[a]	**79**[a]	**72**[a]	**75**[a]	**71**[a]	**82**[a]	**77**[a]	**83**[a]	**80**[a]	**91**[a]	**78**[a]	77	**1112(78)**[a]
Cardiovascular	**59**[a]	49	**22**[a]	57	**55**[a]	59	51	59	**39**[a]	**34**[a]	60	**59**[a]	**38**[a]	**60**[a]	**48**[a]	69	**608(52)**[a]
Stroke	**67**[a]	**34**[a]	29	66	50	59	62	61	50	**77**[a]	62	82	**37**[a]	67	61	**0**[a]	315(60)
Other	71	58	54	55	60	**57**[a]	**46**[a]	59	**44**[a]	**42**[a]	59	65	52	63	**55**[a]	53	**1008(56)**[a]

Table 2 (continued) Unadjusted hospitalization rates in the last year of life by country, n=5092

Characteristic	AT n=293 %	BE n=377 %	CH n=139 %	CZ n=371 %	DE n=193 %	DK n=388 %	EE n=329 %	ES n=577 %	FR n=405 %	GR n=197 %	IT n=386 %	IL n=356 %	NL n=272 %	PL n=250 %	SE n=507 %	SI n=52 %	Total n=5092 n (%)
Ill before death																	
< 6 months	**52**[a]	**42**[a]	**39**[a]	**48**[a]	**52**[a]	**53**[a]	**46**[a]	**58**[a]	**33**[a]	**46**[a]	**52**[a]	**58**[a]	**46**[a]	65	**50**[a]	**39**[a]	**1039(50)**[a]
≥ 6 months	**83**[a]	**73**[a]	**76**[a]	**72**[a]	**76**[a]	**73**[a]	**67**[a]	**68**[a]	**66**[a]	**71**[a]	**78**[a]	**80**[a]	**70**[a]	73	**70**[a]	**74**[a]	**1979(73)**[a]
Difficulties ADL																	
None	**60**[a]	**47**[a]	**39**[a]	**48**[a]	60	63	**44**[a]	**55**[a]	**40**[a]	**39**[a]	**58**[a]	**61**[a]	53	64	57	**46**[a]	**1066(53)**[a]
1-2	77	55	**78**[a]	62	83	63	**71**[a]	67	49	52	61	71	59	**85**[a]	66	50	**515(65)**[a]
> 2	**81**[a]	**70**[a]	62	**77**[a]	68	66	**66**[a]	**67**[a]	**64**[a]	**77**[a]	**72**[a]	**82**[a]	65	70	62	**76**[a]	**1469(70)**[a]
Assistance ADL																	
No	79	50	63	71	40	44	50	63	50	33	**31**[a]	67	43	75	54	100	**86(56)**[a]
Yes, < 3 months	91	78	50	70	82	77	67	63	68	76	75	81	70	83	77	100	**288(74)**[a]
Yes, ≥ 3 months	92	68	73	78	81	71	73	**79**[a]	69	77	**80**[a]	89	**83**[a]	84	**78**[a]	67	**628(78)**[a]
Yes, a full year	74	65	68	69	68	62	65	**61**[a]	55	58	65	75	**53**[a]	72	**59**[a]	54	**1122(64)**[a]
Any nursing home care																	
No	69	**55**[a]	**48**[a]	**59**[a]	65	**59**[a]	55	**61**[a]	**43**[a]	54	65	**70**[a]	57	70	**55**[a]	59	**2252(59)**[a]
Yes	80	**82**[a]	**77**[a]	**83**[a]	76	**83**[a]	68	**83**[a]	**93**[a]	67	84	**91**[a]	71	50	**81**[a]	100	**516(82)**[a]
Any hospice care																	
No	**69**[a]	**55**[a]	**51**[a]	60	65	64	55	**62**[a]	**43**[a]	54	66	72	**58**[a]	69	**56**[a]	60	**2787(60)**[a]
Yes	**100**[a]	**89**[a]	**100**[a]	74	100	79	82	**100**[a]	**97**[a]	0	50	71	**100**[a]	75	**86**[a]	100	**267(88)**[a]

AT, Austria; BE, Belgium; CH, Switzerland; CZ, Czech Republic; DE, Germany; DK, Denmark; EE, Estonia; ES, Spain; FR, France; GR, Greece; IT, Italy; IL, Israel; NL, the Netherlands; PL, Poland; SE, Sweden; SI, Slovenia.

Bold text indicate significant differences.

[a] p≤.05 based on chi-square test; adjusted residuals are used to identify the categories responsible for a significant chi-square statistic.

Table 3 Associations between personal characteristics and hospitalizations in the last year of life by country (adjusted odds ratios), n=5092

Characteristic	**AT**	**BE**	**CH**	**CZ**	**DE**	**DK**	**EE**	**ES**	**FR**	**GR**	**IT**	**IL**	**NL**	**PL**	**SE**	**SI**	**Total**	**Test for interaction, P-value; n=5092[e]**
	n=293	**n=377**	**n=139**	**n=371**	**n=193**	**n=388**	**n=329**	**n=577**	**n=405**	**n=197**	**n=386**	**n=356**	**n=272**	**n=250**	**n=507**	**n=52[d]**	**n=5092**	
Age																		**.001**
48-65	Ref	Ref	Ref	Ref	-	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	
66-80	3.20	.54	.46	1.31	-	.52	.89	.88	1.10	8.38	.58	**6.61[b]**	.46	.06	.72	-	.95	
81-104	.87	**.20[b]**	1.17	.91	-	**.23[a]**	.52	.92	1.05	1.16	.29	2.38	**.14[b]**	.05	.36	-	**.56[c]**	
Gender																		.50
Male	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	
Female	.84	.80	.70	.99	.28	.69	.66	.78	1.17	.98	**.48[a]**	1.52	**.37[a]**	**.22[b]**	.61	-	**.77[b]**	
Education																		.24
Low	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	
Middle	**.24[a]**	.47	3.19	1.28	1.00	.98	.96	.98	1.00	.35	.98	1.45	.47	2.16	.58	-	.92	
High	1.65	.50	3.52	.55	4.05	.88	1.33	.64	.36	1.55	1.10	1.35	1.25	.15	.49	-	.89	
Living alone																		.17
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	
Yes	1.16	1.09	1.43	1.24	**5.27[a]**	.48	.94	1.29	1.36	**5.98[a]**	1.33	1.82	.87	1.06	1.31	-	1.06	
Cause death																		.06
Cancer	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	
Cardiovascular	1.18	1.80	**.07[a]**	.65	.64	.61	1.03	.77	.79	**.08[a]**	1.73	1.57	**.11[b]**	**.16[a]**	**.41[a]**	-	**.70[b]**	
Stroke	1.27	.28	.25	.70	1.68	.74	.81	.95	1.21	29.70	.86	1.24	**.15[a]**	.23	.75	-	.82	
Other	1.04	.72	.27	**.34[a]**	1.02	.54	.40	.80	.88	**.09[a]**	.84	.62	**.18[b]**	**.09[b]**	.59	-	**.55[c]**	

Table 3 (continued) Associations between personal characteristics and hospitalizations in the last year of life by country (adjusted odds ratios), n=5092

Characteristic	AT n=293	BE n=377	CH n=139	CZ n=371	DE n=193	DK n=388	EE n=329	ES n=577	FR n=405	GR n=197	IT n=386	IL n=356	NL n=272	PL n=250	SE n=507	SI n=52^d	Total n=5092	Test for interaction, P-value; n=5092^e
Ill before death																		**.02**
< 6 months	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	
≥ 6 months	2.40	1.90	3.61	1.17	3.31	1.15	1.32	1.38	**3.21^b**	**6.03^a**	**2.73^b**	1.45	.48	.83	**2.19^b**	-	**1.70^c**	
Difficulties ADL																		**.002**
None	-	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	
1-2	-	.66	**35.31^a**	1.08	.13	.49	1.68	1.32	.69	1.53	1.12	1.58	.74	.68	.71	-	.92	
> 2	-	.68	9.70	2.50	.12	.41	1.27	1.34	.75	3.76	1.70	**6.25^a**	1.21	.25	.48	-	.97	
Assistance ADL																		.99
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	
Yes, < 3 months	1.73	5.31	.22	1.62	2.01	3.81	1.61	1.43	1.78	**>100^b**	**6.91^a**	6.24	1.75	9.30	2.34	-	**2.32^c**	
Yes, ≥ 3 months	2.44	2.23	1.46	2.36	12.42	5.12	2.06	2.90	1.64	24.44	**6.42^a**	**6.97^a**	7.66	10.61	2.63	-	**2.52^c**	
Yes, a full year	.45	2.33	1.43	1.44	2.03	4.44	2.03	1.09	.94	26.13	2.78	1.77	2.86	10.90	1.39	-	1.42	
Any nursing home care																		.11
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	
Yes	1.16	**5.26^b**	1.88	1.67	3.05	**6.37^c**	1.16	2.32	**9.94^c**	**.003^a**	2.75	1.77	**2.85^a**	.10	**2.26^a**	-	**2.51^c**	

Table 3 (continued) Associations between personal characteristics and hospitalizations in the last year of life by country (adjusted odds ratios), n=5092

Characteristic	**AT n=293**	**BE n=377**	**CH n=139**	**CZ n=371**	**DE n=193**	**DK n=388**	**EE n=329**	**ES n=577**	**FR n=405**	**GR n=197**	**IT n=386**	**IL n=356**	**NL n=272**	**PL n=250**	**SE n=507**	**SI n=52[d]**	**Total n=5092**	**Test for interaction, P-value; n=5092[e]**
Any hospice care																		.054
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	-	Ref	Ref	Ref	Ref	Ref	-	Ref	
Yes	>100	**2.96[a]**	>100	.45	>100	.39	1.83	>100	**42.00[b]**	-	.39	.20	>100	10.41	**4.16[b]**	-	**2.24[c]**	

AT, Austria; BE, Belgium; CH, Switzerland; CZ, Czech Republic; DE, Germany; DK, Denmark; EE, Estonia; ES, Spain; FR, France; GR, Greece; IT, Italy; IL, Israel; NL, the Netherlands; PL, Poland; SE, Sweden; SI, Slovenia.

Bold text indicate significant differences.

[a] p≤.05,

[b] p<.01,

[c] p<.001.

[d] Analysis for Slovenia not possible due to a low number of included participants.

[e] We performed a "test for interaction" to study whether the odds ratios differed significantly across countries. We did this for every characteristic separately by including all the countries and adding an interaction term for country*characteristic.

Table 4 Associations between personal characteristics and hospitalizations in the last year of life (adjusted odds ratios), n=5092

Characteristic	**Total population, n=5092** **OR (CI)**
Age	
48-65	Ref
66-80	.90 (.66-1.24)
81-104	**.54^{c} (.39-.74)**
Gender	
Male	Ref
Female	**.74^{b} (.63-.89)**
Education	
Low	Ref
Middle	.88 (.70-1.10)
High	.90 (.67-1.22)
Living alone	
No	Ref
Yes	1.13 (.92-1.38)
Cause death	
Cancer	Ref
Cardiovascular	**.66^{b} (.51-.86)**
Stroke	.79 (.58-1.10)
Other	**.55^{c} (.44-.70)**
Ill before death	
< 6 months	Ref
≥ 6 months	**1.67^{c} (1.39-2.01)**
Difficulties ADL	
None	Ref
1-2	.93 (.65-1.32)
> 2	.95 (.68-1.33)
Assistance ADL	
No	Ref
Yes, < 3 months	**2.44^{c} (1.57-3.77)**
Yes, ≥ 3 months	**2.64^{c} (1.77-3.95)**
Yes, a full year	**1.49^{a} (1.02-2.17)**
Any nursing home care	
No	Ref
Yes	**2.69^{c} (2.08-3.48)**

Table 4 (continued) Associations between personal characteristics and hospitalizations in the last year of life (adjusted odds ratios), n=5092

Characteristic	Total population, n=5092 OR (CI)
Any hospice care	
No	Ref
Yes	**2.55[c] (1.66-3.91)**
Country	
FR	Ref
NL	1.12 (.72-1.77)
DK	1.50 (.99-2.29)
BE	**1.52[a] (1.01-2.29)**
EE	1.53 (.98-2.39)
SE	**1.55[a] (1.05-2.27)**
CH	1.58 (.86-2.92)
GR	**1.84[a] (1.09-3.12)**
ES	**1.93[b] (1.33-2.82)**
IT	**1.99[b] (1.32-2.99)**
CZ	**2.15[b] (1.37-3.37)**
DE	**2.15[b] (1.26-3.68)**
SI	2.31 (.93-5.73)
PL	**2.61[c] (1.59-4.30)**
IL	**2.65[c] (1.65-4.26)**
AT	**3.46[c] (2.03-5.90)**

FR, France; NL, the Netherlands; DK, Denmark; BE, Belgium; EE, Estonia; SE, Sweden; CH, Switzerland; GR, Greece; ES, Spain; IT, Italy; CZ, Czech Republic; DE, Germany; SI, Slovenia; PL, Poland; IL, Israel; AT, Austria.
Bold text indicate significant differences.
[a] p≤.05.
[b] p<.01.
[c] p<.001.

DISCUSSION

In all studied countries, between half and three quarters of all older people were at least once admitted to an inpatient care facility in their last year of life. The average duration of the total time spent in care facilities varied considerably between countries with 42% of all older people spending one month or more in an inpatient care facility (ranging from 27% in Estonia and Greece to 48% in Austria). The large majority of admissions concerned hospitalizations. People from eastern and southern European countries (especially Slovenia, Poland and Israel) had higher chances of hospitalizations in the last year of life compared with northern and western European countries (like France, the Netherlands, Estonia, Belgium, Denmark and Sweden).

Our study confirms findings of previous studies showing that many countries face the challenge that a high number of older people are admitted to inpatient care facilities in the last phase of life, even though healthcare policies are more and more focused on residing at home as long as possible [4-7]. The large variance in the occurrence of hospitalizations between countries in our study suggests that non-medical factors affect the decision to hospitalize a person, especially since this variance cannot be fully explained by the differences in peoples' illness-related factors. First of all, differences in the organization of care for older community-dwelling people may play a role. In some countries, like the Netherlands and Estonia, general practitioners (GPs) work as gatekeepers to secondary and tertiary care [32]. It has been suggested that a gatekeeping system could contribute to a lower proportion of hospitalizations at the end of life [33]. Indeed, the Netherlands and Estonia had relatively low hospitalization rates in our study. However, other study countries with full gatekeeping systems (Spain, Italy and Slovenia) [32] had relatively high hospitalization rates. This needs further investigation. Second, medical decision-making in the last phase of life could be affected by cultural issues. Bosshard and colleagues concluded that cultural factors affect non-treatment decisions (=decisions to withhold or withdraw treatment) and that important cultural differences can have country-specific effects on end-of-life practices. The authors found that Swiss physicians reported more non-treatment decisions than Dutch, Belgian, Danish and Swedish physicians, while Italian physicians reported the lowest occurrence of non-treatment decisions [34]. Likewise, we found that Italians had higher hospitalization rates than people from the other countries. Third, the availability of long-term care services may be an important factor. The number of residential facilities and formal home care services is still relatively limited in southern European countries. For example, Italy has the lowest number of long-term care beds of all OECD-countries [35]. Southern European countries are often considered to be "strong-family-ties countries" [36], however, the availability and expectation of informal support may actually hinder the organization of residential facilities and formal home care [5, 37]. In our study, we indeed observed higher hospitalization rates among southern European countries compared with hospitalization rates of northern and western European countries.

In all countries except Switzerland, France, Greece and Israel, the oldest age group was less likely to be hospitalized in the last year of life compared with younger people (48-65 years). Some hospital-based medical or surgical interventions may be considered less appropriate for the oldest old due to frailty or comorbidities [38]. In most countries, hospitalizations were more likely for those being ill for a longer period of time and those receiving assistance with ADL. However, overall, people who received assistance a full year, had a lower probability of being hospitalized than people who received assistance for a shorter period of time. Maybe these people relied on regular, professional help, making a hospitalization unnecessary in case of illness. In addition, hospitalizations were more likely for people receiving nursing home or hospice care in most countries. The process of institutionalization itself may promote continued institutionalization [39]. For instance, it could be easier for older patients to get access to other care organizations while hospitalized. Based on other study findings [3], we can indeed assume that hospital care often preceded nursing home care. However, in our study, we miss information on whether the hospital use was before or after the use of nursing home- or hospice care.

The study has other limitations as well. In some countries, the participation rate for end-of-life interviews was rather low (e.g. 41% in Austria). This may have resulted in some overestimation of the number of hospitalizations. Another limitation is the recall bias of proxy-respondents: the average time between the participants' death and the end-of-life interview was relatively long. However, research suggests that hospitalizations can usually be recalled quite accurately as they are often salient events with large impact [40]. Finally, we miss information on people without close relatives or friends nearby who could report on end-of-life circumstances of the deceased. This study has several strengths. We were able to study many European countries and included many participants leading to a representative sample. The 16 selected countries are a balanced representation of countries on several parameters; they cover e.g. countries with different healthcare systems and varying histories of economic growth.

CONCLUSION

Admissions to hospitals of older people in their last year of life are rather common throughout Europe. The large variation in admissions of older people across the 16 studied countries is striking and suggests that admissions are at least partly driven by system-level or cultural factors rather than by patient needs only.

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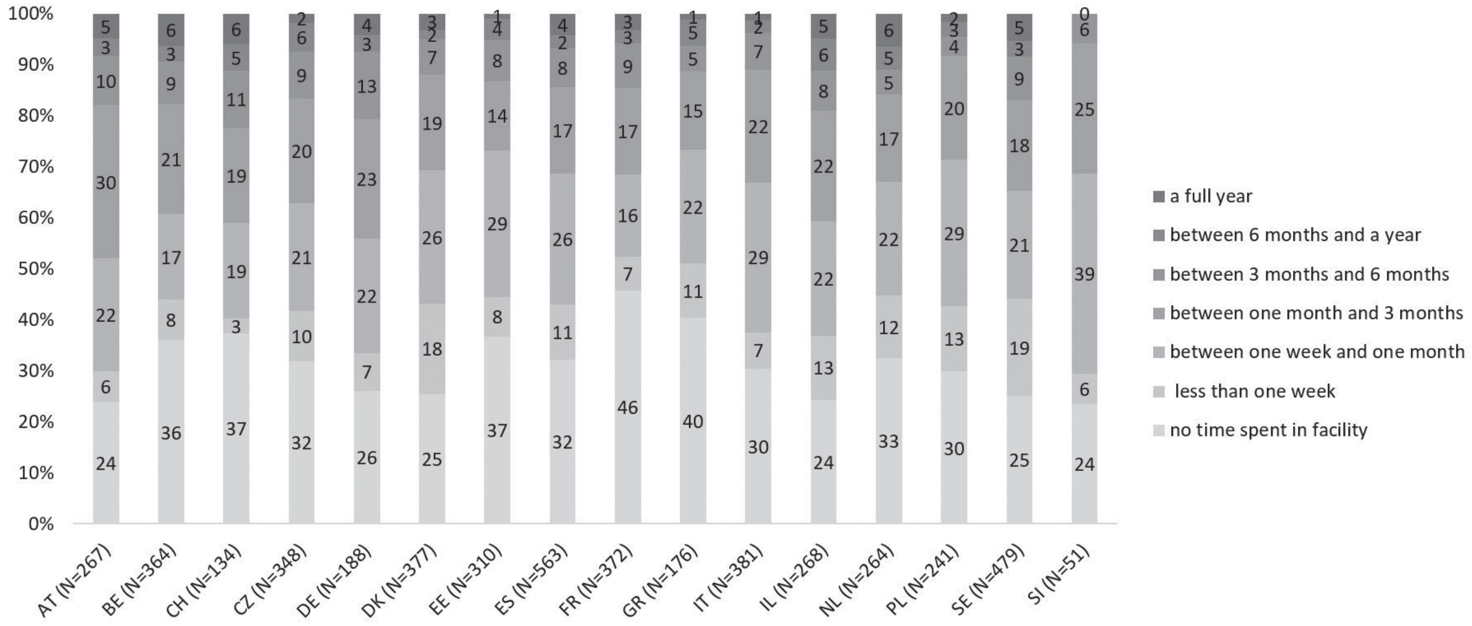

Supplementary Figure Total time spent in inpatient care facilities in the last year of life (% per country), n=5092

Missing values n=309 and <10% for all cells except for Greece (10,7%) and Israel (24,7%). Range of missing values: 1,3% (Italy) - 24,7% (Israel).
P–value <.001.
AT, Austria; BE, Belgium; CH, Switzerland; CZ, Czech Republic; DE, Germany; DK, Denmark; EE, Estonia; ES, Spain; FR, France; GR, Greece; IT, Italy; IL, Israel; NL, the Netherlands; PL, Poland; SE, Sweden; SI, Slovenia.

Supplementary Table Questions and answering options

Question	Answering options
In the last year before he/she died, on how many different occasions did (name of deceased) stay in a hospital, hospice or nursing home?	(1) not at all (2) 1 to 2 times (3) 3 to 5 times (4) more than 5 times
During the last year of his/her life, for how long altogether did (name of deceased) stay at hospitals, hospices or nursing homes?	(1) less than one week (2) between one week and one month (3) between one month and 3 months (4) between 3 months and 6 months (5) between 6 months and a year (6) a full year
Has (name of deceased) had any hospital stays in the last 12 months of his/her life?	(1) yes (2) no
Has (name of deceased) had any care in a nursing home in the last 12 months of his/her life?	(1) yes (2) no
Has (name of deceased) had any hospice stays in the last 12 months of his/her life?	(1) yes (2) no
How old was (name of deceased) when he/she passed away?	(1) 48-65 (2) 66-80 (3) 81-104
Sex of decedent	(1) Male (2) Female
What is the highest school leaving certificate or school degree that you have obtained? (question was answered in earlier wave by participants themselves)	(1) low (= ISCED[a] 0-2) (2) middle (= ISCED 3-4) (3) high (= ISCED 5-6)
Houshold size (provided in earlier wave by participants themselves)	(1) 1 (= living alone) (2) > 1 (= not living alone)
What was the main cause of his/her death?	(1) cancer (2) cardiovascular illness (= heart attack or other cardiovascular illness) (3) stroke (4) other (= disease of the digestive system, respiratory disease, infectious disease, accident or other cause)

Supplementary Table (continued) Questions and answering options

Question	**Answering options**
Did he/she die ..	(1) in a hospital (2) at home (= at his/her home or at another person's home) (3) in a nursing home (4) in a hospice (5) at some other place
How long had (name of deceased) been ill before he/she died?[b]	(1) < 6 months (2) ≥ 6 months
Because of a physical, mental, emotional, or memory problem, did (name of the deceased) have difficulty doing any of the following activities during the last 12 months of his/her life? Please name only difficulties that lasted at least three months. Activities: dressing, walking across a room, bathing or showering, eating, getting in or out of bed, using the toilet	(1) none (2) 1-2 (3) > 2
Thinking about the activities that the deceased had problems with during the last 12 months of his/her life, has anyone helped regularly with these activities? Overall, during the last 12 months of his/her life, for how long did the deceased receive help?	(1) no (2) yes, < 3 months (3) yes, ≥ 3 months (4) yes, a full year

[a] ISCED = International Standard Classification of Education. Classification in SHARE is based on the ISCED-97 which divides educational programs into seven broad ordinal levels: 0 = pre-primary education, 1 = primary education or first stage of basic education, 2 = lower secondary education or the second stage of basic education, 3 = upper secondary education, 4 = post-secondary non-tertiary education, 5 = first stage of tertiary education, 6 = second stage of tertiary education.

[b] If the main cause of death was not an accident, the question "How long had (name of deceased) been ill before he/she died?" was asked.

General discussion

8

The main aim of this thesis was to investigate effects of an Advance Care Planning (ACP) program in frail older people. ACP is defined as *"enabling individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate* [1]." This chapter includes a summary of the main findings, an interpretation of the findings, methodological considerations and recommendations for clinical practice and future research.

MAIN FINDINGS

In the introduction of this thesis, five research questions were formulated. The main answers to each of these research questions are summarized below.

Research question 1: Are frail older people able to self-manage their health and healthcare?

To answer this research question, we investigated the level of patient activation of frail older people, defined as the knowledge, skills and confidence to self-manage health and healthcare **(Chapter 3)**. We found that 70% of frail older people had low levels of patient activation. Low activation levels were in particular present among those with a lower health-related quality of life and among care home residents. However, more than half of community-dwelling people had low activation levels as well. The low levels of patient activation as found in our study indicate that the majority of frail older people may be unable to self-manage their health and healthcare to the level expected from them.

Research question 2: What are the effects of ACP in frail older people on patient activation, quality of life, advance directive completion and surrogate decision-maker appointment?

We conducted a cluster randomized controlled trial (RCT) among residential care home residents and community-dwelling people who received home care. The intervention group was offered facilitated planning conversations based on the Respecting Choices ACP program. This program was developed in the United States and involves trained facilitators who assist individuals in exploring the understanding of their illness, reflecting on goals, values and beliefs, discussing healthcare preferences and appointing a surrogate decision-maker. The control group received care as usual. We found no significant differences between the intervention and control group considering the extent in which patient activation changed in the course of one year follow-up **(Chapter 4)**. Change scores for health-related quality of life did not differ either between groups. Of intervention group participants, 93%

completed an advance directive (AD) and 94% appointed a decision-maker. Of control participants, 34% completed an AD and 67% appointed a decision-maker. The majority of the intervention group (89%) appointed their decision-maker in writing, whereas the majority of the control group (63%) did so orally.

Research question 3: What are the effects of ACP in frail older people on use of medical care, costs of medical care and the concordance of care with preferences?

We found no differences in the use of medical care between the ACP intervention group and the control group **(Chapter 5)**. Accordingly, the average costs of medical care did not differ between the study groups (€2360 vs. €2235, respectively). Whether goals of hospital stays, diagnostic procedures and medical interventions were curative or palliative was often not recorded in medical files. This complicated the assessment of the extent to which care as provided was concordant with the preferences on individual level.

Research question 4: What are the effects of ACP in bereaved relatives of frail older people considering preparation for decision-making, anxiety and depression?

We conducted interviews with 39 bereaved relatives of frail older people, of whom 20 in the intervention group and 19 in the control group **(Chapter 6)**. Nine of 10 bereaved relatives in the intervention group who had been involved in decision-making on behalf of the deceased felt adequately prepared for this process, as compared to five of 11 bereaved relatives in the control group. Relatives' levels of anxiety and depression did not differ significantly between groups.

Research question 5: How many older people are admitted to inpatient care facilities in their last year of life across Europe?

Between 54% (France) and 76% (Austria, Israel, Slovenia) of people aged ≥50 years were at least once admitted to an inpatient care facility in their last year of life **(Chapter 7)**. The average duration of the total time spent in care facilities varied considerably between countries. Forty-two percent of all older people spent one month or more in an inpatient care facility (ranging from 27% in Estonia and Greece to 48% in Austria). The large majority of admissions concerned hospitalizations.

INTERPRETATION OF FINDINGS

Patient activation in frail older people

Due to healthcare reforms in the Netherlands, admission policies for residential care homes have become more restrictive. Frail older people who previously would have been admitted to residential care homes now have to remain community-dwelling, while receiving care at home. This results in an increasing number of community-dwelling frail older people. For these healthcare reforms to be successful in reducing institutional care, frail older people at least partly need to manage their lives, health and healthcare themselves. The low levels of patient activation as described in **Chapter 3** indicate that the majority of frail older people may not have the abilities, knowledge, skills and confidence to adequately engage to the level of self-management as needed for living independently at home. Therefore, the increasing population of frail older people may need support in managing their health and healthcare, for example through programs that aim at developing and maintaining self-management skills. One element of self-management support can be ACP, which aims to prepare and to activate individuals to take a role in future healthcare decision-making.

Advance Care Planning in frail older people

As shown in **Chapter 4**, nearly all participants in the intervention group in our RCT on the effects of ACP had completed an AD (93%) and had appointed a surrogate decision-maker (94% overall, 89% in writing) after one year follow-up. These numbers are higher than in most other trials [2]. Also in the control group, rates of AD completion (34%) and surrogate decision-maker appointment (67% overall, 37% in writing) were rather high. Estimations of AD completion in the Netherlands as reported earlier varied between 5-16% for different age groups [3-5]. We found that most ADs in the control group had been completed before the start of the study by residential care home residents. They mostly concerned a do-not-resuscitate order, probably completed as part of the intake policy in residential care homes. In addition, the relatively high AD completion rate in the control group may be related to recent societal debates concerning ACP. Several associations, such as the Royal Dutch Medical Association and the Dutch Association of Elderly Care Physicians and Social Geriatricians recently released public awareness campaigns recommending ACP [6,7]. Furthermore, the Dutch advisory group "LAEGO" (Landelijke Adviesgroep Eerstelijnsgeneeskunde voor Ouderen) published an ACP toolkit that had been revised in 2017 and could serve as a guideline for physicians to implement ACP in their office or region [8].

We did not find an effect of the Respecting Choices ACP program on participants' activation level, quality of life, satisfaction with healthcare, use and costs of medical care (**Chapters 4 and 5**).

Several other RCTs among older people with a mean age of ≥65 years reported positive effects of standardized ACP programs on these outcome measures [9-15]. ACP has been shown to improve other outcomes as well among older people, such as the concordance of care with patients' preferences [10, 16] and the quality of patient-clinician communication [17].

The lack of effects as found in our study might have several explanations. The first possible explanation relates to the content of our ACP program and the way it was conducted. We used the core part of the Respecting Choices ACP program, including the training program, the structure of the facilitated conversations and the involvement of relatives. However, due to the study context, we could not conduct a system-wide implementation of the program. A systematic inclusion of ADs in medical files and, in general, a system-wide implementation of ACP practices and community engagement might be more effective.

Secondly, ACP facilitation may not be effective in a population of frail, very old people. In general, people have a lower preference for involvement in the decision-making process with advancing age [18-21]. Accordingly, the level of participation in the decision-making process was low among very old people (aged ≥80 years) [22]. As reported by Bynum and colleagues, "*accepting an active role in decision-making may require entirely new skills for an older population who has grown up in the paternalistic era of medicine and who may be less savvy about information technology* [22]." On the other hand, Sharp and colleagues concluded in their review that many frail older people would appreciate the chance to discuss end-of-life care [23]. In addition, the majority of participants who engaged in our ACP program reported positive experiences and considered the facilitated conversation useful.

Our third explanation for the lack of effect of the ACP program concerns the choice of outcome measurements and their timing. Both are challenging as ACP covers many domains [24] and may have intermediate effects (like the completion of ADs) and more downstream effects (like the use and costs of medical care). Possibly, the effects of our ACP program on patient activation, quality of life and satisfaction with healthcare were greater shortly after the intervention and diminished over time. We indeed found that 13% of the intervention participants did not remember the facilitated conversations sufficiently after 12 months, strengthening the idea that potential effects of the ACP program could have diminished over time. On the other hand, effects on use and costs of medical care may have not taken place yet. Medical care use and related costs of care in the last year of life are 13.5 times as high as in an average life year [25]. It may be that not many important healthcare decisions had to be made within the study period, and hence, we may have not been able to measure the full effect of ACP on use and costs of medical care.

Fourthly, the Dutch healthcare context may explain our findings. Dutch healthcare is often suggested to be characterized by a tendency of avoiding overtreatment for older people [26]. This may explain the rather low numbers of invasive medical treatments among our participants, and may indicate that there is less to be "gained" from ACP in terms of preventing overtreatment. This may also explain that healthcare costs in our study population mainly concerned costs for inpatient days in residential care homes and home care.

Whether goals of hospital stays, diagnostic procedures and medical interventions were curative or palliative was often not recorded in medical files. Therefore, the concordance of received care with preferences could not be assessed on the individual level. In general, literature on concordance of care with preferences is scarce. A Dutch mortality follow-back study among relatives of deceased older people found that 90% of people who preferred life-prolonging treatment to be applied received care in accordance with their preferences [27]. Among people who preferred no life-prolonging treatment, 54% received care in accordance with their preferences [27], suggesting that there is room for improving (effective) communication between frail older people and healthcare providers about preferences for medical care.

The extent to which ACP can contribute to better alignment of care with preferences and therefore appropriate care for frail older people in the Netherlands remains unclear. According to Dutch patients and relatives, appropriate care is a wide-ranging term and can be interpreted in different ways. It can refer to supportive care (*"care directed at support, helping the patient and relatives to cope with the situation and supporting him in his (everyday) needs"*), treatment decisions (*"decisions made on treatment or other medical interventions, involving a physician"*), location of care, the role of the patients' wish in decision-making and patient-physician communication [28]. During ACP conversations, patients' preferences concerning medical treatment and care are discussed which can include preferences for treatment location. In addition, individuals are encouraged to discuss their preferences with their physicians and other healthcare providers. Therefore, it seems that ACP can contribute to appropriate medical care. In our RCT on the effects of ACP, we also encouraged participants to inform their GP and other healthcare providers about their preferences concerning future treatment and care. However, we did not actively involve healthcare providers in the ACP process which might have been more effective in improving health outcomes and decreasing use and costs of invasive medical care.

Advance Care Planning in bereaved relatives of frail older people

Approximately half of the interviewed relatives of participants in the intervention group had been present during one or more ACP conversations, suggesting that they were open to being involved in the ACP process **(Chapter 6)**. Many bereaved relatives of frail older people reported positive experiences of ACP. One relative spontaneously mentioned that the ACP conversation was provided at the right moment. In general, finding the right time window for ACP is challenging. While some older people prefer ACP discussions rather sooner than later, others prefer to postpone such discussions as long as possible [23]. An individualized approach of ACP is recommended, considering patients' readiness to engage in ACP, the disease stage and local legal and cultural circumstances [1].

Among relatives who had been involved in decision-making on behalf of the deceased, ACP had a positive effect on the perceived level of preparation for decision-making. This is in line with findings of Bravo and colleagues, who found that relatives' rating of their own ability to make concordant decisions for patients increased following ACP [29]. These are important findings, since many relatives of frail older people have to make healthcare decisions on behalf of the frail individual, for instance when he/she develops dementia [30]. Currently, around 258.000 people aged ≥65 years have dementia in the Netherlands and this number is expected to increase rapidly [31].

In our study, ACP had no significant effect on relatives' levels of satisfaction, anxiety and depression. This is in contrast to the findings of Detering and colleagues, who concluded that facilitated ACP improves relatives' satisfaction concerning the quality of death and reduces levels of stress, anxiety and depression among relatives of hospitalized older patients in Australia [10]. These different findings may be related to the timing of the interview. In the study of Detering and colleagues [10], relatives were interviewed a median of 104 days after the patients' death, while we conducted the interview after 221 days on average (range: 106-369 days). We contacted relatives at least three months after the death of the participant, however, due to particular reasons (e.g. late communication of the participant's death or relatives' preference to postpone the interview) the average time between the death of some participants and the interview was relatively long. Possibly, the effects of ACP on relatives' satisfaction, anxiety and depression were larger shortly after the death of the frail participant and have diminished over time.

Admissions in Europe

In **Chapter 5**, we concluded that ACP had no effect on the use and costs of medical care. A minority of frail, older people in both the intervention and control group had received hospital care during 12 months after study inclusion. In **Chapter 7**, however, we concluded that between half and three quarters of older people across Europe were at least once admitted to an inpatient care facility in their last year of life. Admissions mostly concerned hospitalizations. This may indicate that hospitalizations are more likely in the last months of life. Accordingly, it has been found that between 49% (the Netherlands) and 56% (Belgium) of people in Europe were hospitalized at least once in the last three months of their life [32]. Another study from Belgium found similar results and concluded that hospitalizations increased considerably when patients were closer to death [33]. Preferences concerning medical treatment and care may change and patients may increasingly prefer to receive hospital care when nearing death. Indeed, the preference of the patient for hospital care was often a reason for hospitalizations at the very end of life according to Van den Block and colleagues [33]. Other reasons for hospitalizations in the last months of life may be that patients and GPs see no alternatives because of exacerbating symptoms and/or a high burden on caregivers [33]. Given these findings, it may be useful to monitor the effect of ACP on the use and costs of medical care until death.

METHODOLOGICAL CONSIDERATIONS

The study in **Chapter 3** used baseline data from a RCT and therefore had a cross-sectional design. **Chapters 4 through 6** described both baseline- and follow-up data from the RCT. Study findings from **Chapters 6 and 7** were based on after-death interviews with bereaved relatives. Cross-sectional designs, RCT designs and after-death interviews incorporate methodological challenges which should be considered when interpreting study findings.

Cross-sectional design

A major challenge of cross-sectional designs concerns the interpretation of study findings. It may be possible to generate hypotheses about cause-and-effect relationships, but causality cannot be proven. Based on baseline data from our RCT, we concluded that being community-dwelling, the degree of mental capacity, physical health, mental health and satisfaction with healthcare were positively associated with patient activation, while education level and the degree of frailty were negatively associated with patient activation. However, we were not able to draw conclusions concerning the direction of associations between participants' characteristics and patient activation.

Randomized controlled trial design

RCTs are considered to be the gold standard in medical research. However, RCTs have at least two major challenges. The first concerns gatekeeping of healthcare providers and others involved in the inclusion process. This kind of gatekeeping is defined as "*the process whereby actors involved in the research process prevent participation of eligible patients in clinical research* [34]." According to a systematic review, the most important reason for gatekeeping in palliative care research is the fear of burdening potentially vulnerable candidates [34]. This may result in selection bias when some groups (e.g. very frail people) are excluded from participation. In our study on the effects of ACP, healthcare staff screened all residents of the participating residential care homes and all community-dwelling people who lived in the immediate surroundings for eligibility, using clear in- and exclusion criteria that we provided to prevent selection bias as much as possible. Nevertheless, it cannot be ruled out that healthcare staff prevented participation of some eligible candidates, e.g. very frail and old people.

A second challenge of the RCT design concerns drop-out, especially in case of a frail, older study population. Frail, older participants often have a relatively large chance of dying during the study period or of withdrawing from the study because of deteriorating health. Generally, this can lead to over- or underestimations of intervention effects, especially when attrition rates differ between study groups. In our ACP study, power calculations did not account for expected loss to follow-up and the attrition rate in the intervention group was somewhat higher than the one in the control group (24% vs. 17%). However, whereas this difference is quite small, it seems unlikely that the difference in attrition between the study groups has affected our outcomes [35].

After-death interviews

Like RCTs, after-death interviews have at least two major challenges as well. The first concerns participation rates. Generally, after-death interviews among bereaved relatives can provide important information on the circumstances and quality of end-of-life care, and on experiences with end-of-life care [36]. However, bereaved relatives are a vulnerable group, associated with high levels of stress and an increased risk of developing physical and mental health problems. They may not feel comfortable talking about the end-of-life of the deceased and may choose not to participate in an interview. This can lead to low participation rates, which may undermine internal and external validity. In our ACP study, we conducted interviews with 39/51 (76%) bereaved relatives which is an acceptable participation rate. In the SHARE study on admissions in Europe, 5092 bereaved relatives participated in after-death interviews. However, the participation rate for after-death interviews was rather low in some countries (e.g. 41% in Austria) which means that study findings may not be representative for all deceased people in these countries.

A second challenge concerns the timing of after-death interviews. Generally, the shorter the period between death and interview, the easier it may be for relatives to recall what has happened [36]. Due to ethical concerns, however, we did not want to approach relatives too soon after the participants' death. In our ACP study, the average time between the death of the participant and the interview was 221 days (range: 106-369 days). In the SHARE study, the average time between the participants' death and the interview varied between 14 and 18 months across waves. Because of the relatively long period between the participants' death and the interview in both the ACP study and the SHARE study, participants may have not been able to recall information accurately. On the other hand, research on autobiographical memory suggests that information on healthcare visits and hospital admissions can be recalled more accurately than e.g. dietary information [36, 37]. Overall, important emotional events (such as the death of a patient) and their characteristics (such as satisfaction with the quality of death) can be recalled better than neutral ones [36, 37], suggesting that recall bias did not have a huge impact on our study findings.

IMPLICATIONS FOR CLINICAL PRACTICE AND FUTURE RESEARCH

Currently, interest in ACP is growing, as indicated by an increasing number of scientific publications, an increased number of ACP programs, initiatives to develop ACP laws and public awareness campaigns [24]. In the future, the concept of ACP may be even more relevant given the increasing emphasis on participatory medical decision-making. Reasons for this increasing emphasis include the "*rise of healthcare consumerism and the notion of the patient/consumer sovereignty in healthcare decision-making* [38]." Participatory medical decision-making has been shown to improve several affective-cognitive patient outcomes, such as satisfaction and decisional conflict [39]. To improve such patient outcomes, it is crucial that individuals share their goals, values and preferences concerning medical treatment and care with their healthcare providers. During ACP, individuals are prepared for this process.

Our structured Respecting Choices ACP program turned out to be feasible among frail older people: almost all participants from the intervention group engaged in the ACP program, completed an AD and appointed a surrogate decision-maker. However, approximately three quarters of eligible people did not participate in our study, mostly due to a lack of interest. These people may not have felt ready or able to engage in ACP. An individualized approach of ACP is recommended, considering patients' readiness to participate. In practice, several triggers can help healthcare providers for determining whether patients are ready to start the ACP process [40]. These triggers include a diagnosis of a progressive life-limiting illness, a change or deterioration of a condition, or a change in the patients' personal situation, such as moving to a residential care home or loss of a loved one [40]. An "Advance Care Planning Readiness Scale" (ACPRS) has been developed and validated to assess the readiness of gynecologic cancer patients to engage in ACP [41]. The validated "Advance Care Planning Engagement Survey" can be used to assess the patients' readiness to engage in ACP as well [42].

More insight is needed into appropriate outcome measures of ACP and their timing. A highly rated ACP outcome according to ACP experts from all over the world is the concordance of received care with preferences [43]. However, several ACP experts raised caution about whether "care consistent with goals" can be reliably measured due to a lack of standardized methods and changing preferences for care [43]. Future research is needed to determine how to best define and assess the concordance of care with preferences [43]. To measure preferences, it is recommended to use ADs with both a structured format to allow for easy and fast identification of specific goals and preferences in emergency situations, and an open-text format where individuals can describe their overall goals, values and preferences [1]. Since most medical treatments are carried out in the last year of life [25], studies ideally monitor the ACP process and the use of care until death to be able to measure the full impact of ACP on concordance of care with preferences.

In addition, more insight is needed into effective components of ACP. In general, extensive ACP programs with trained facilitators and several structured ACP conversations seem to be more effective than the completion of ADs alone [44]. Most extensive ACP programs have been shown to increase out-of-hospital and out-of-ICU care, compliance with patients' preferences and satisfaction with care among different patient populations [44]. Engaging relatives in the ACP process seems helpful to prepare for the decision-making process on behalf of the dying person. Besides, ACP seems helpful to resolve family conflicts and to help with bereavement [40]. To determine effective elements of ACP, participants and their relatives could be asked for elements that they thought were valuable and important, and be asked for feedback to improve the overall ACP process.

Despite the lack of effect of our Respecting Choices ACP program on several outcomes measures, ACP may be beneficial for some people who are able and willing to engage in facilitated conversations. In addition, our Respecting Choices ACP program may be effective in other settings and/or cultures. Therefore, more insight is needed on how to best integrate ACP into care practice. Healthcare providers often struggle with identifying patients most likely to benefit from ACP [45]. As already mentioned, ACP may be especially relevant for frail older people. Several instruments can help to assess the level of frailty, such as the Tilburg Frailty Index (TFI) which consists of a physical, psychological and a social domain [46]. Other barriers to ACP often include a lack of time and discomfort with emotions of the patient [45]. Therefore, it may be necessary for healthcare providers to gain experience in ACP conversations [45]. In the United States, two "Current Procedural Terminology" (CPT) codes have been introduced by the Centers for Medicare & Medicaid Services (CMS) which are intended to encourage healthcare providers to engage in ACP discussions with their patients earlier and more frequently [45, 47]. Research is needed on whether these CPT codes are successful in increasing the timely initiation of the ACP process.

In general, the translation of research into practice is challenging. In many healthcare areas, the gap between research and practice is large and troubling [48]. This may be due to characteristics of the program (e.g. intensive and demanding), the target setting (e.g. limited resources, staff time or expertise) or the research design (e.g. the lack of important outcome measures such as cost-effectiveness) [49]. It is recommended by Glasgow and Emmons to *"develop and evaluate research programs with greater attention to context and external validity and in partnership with relevant decision makers and target audiences"*, which makes it easier for practitioners and policy makers to appreciate program relevance [49]. When evaluating ACP programs, it is therefore useful to measure the time investment of trained facilitators for conducting ACP conversations and to measure ACP program costs among other outcome measures (such as e.g. health-related outcomes).

To conclude, we did not find an effect of our Respecting Choices ACP program on downstream outcome measures including the level of patient activation, quality of life and costs of medical care. However, our ACP program positively affected the completion of ADs and the appointment of surrogate decision-makers. In addition, we observed limited costs of our ACP program and found that many (relatives of) frail older people appreciated the facilitated ACP conversations. Finally, our ACP program positively affected preparedness for decision-making in relatives. Given the increasing interest in ACP and the increasing emphasis in policy and practice on patient-centered care and participatory medical decision-making, further research on ACP strategies is desirable.

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Summary

Samenvatting

9

SUMMARY

Chapter 1 provides an introduction on this thesis about Advance Care Planning (ACP). ACP enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers and to record and review these preferences if appropriate. ACP has the potential to enhance provision of care that is consistent with patients' preferences, to improve the quality of patient-clinician communication and to increase hospice and palliative care among a variety of patient groups. ACP may be especially relevant for frail older people since this population is most likely to develop physical and cognitive deficits in the near future and to have to rely on others to communicate their treatment preferences. It is unknown to what extent ACP can support frail older people to take a more active role in their health and healthcare and how this in turn may affect their quality of life and other health outcomes, like the use of medical care. Therefore, the main aim of this thesis was to investigate effects of an ACP program on patient activation, quality of life, advance directive (AD) completion, surrogate decision-maker appointment, use of medical care, costs of medical care and the concordance of care with preferences in a randomized controlled trial (RCT) among frail older people in the Netherlands. The study protocol is described in **Chapter 2**.

In **Chapter 3**, we used data from the baseline assessment of the RCT. We investigated the level of patient activation of frail older people, defined as the knowledge, skills and confidence to self-manage health and healthcare. The level of patient activation was assessed by the short version of the Patient Activation Measure (PAM-13) which distinguishes four levels of increasing activation. We found that 39% of participants had level one activation (indicating poor patient activation), 31% level two, 26% level three and 5% level four (indicating adequate patient activation). Low activation levels (= levels one and two) were in particular present among those with a lower health-related quality of life and among care home residents. However, more than half of community-dwelling people had low activation levels as well. The low levels of patient activation as found in our study indicate that the majority of frail older people may be unable to self-manage their health and healthcare to the level expected from them.

In **Chapter 4**, we determined the feasibility and effectiveness of ACP in frail older people in the Netherlands. Participants in the intervention group were offered standardized ACP based on the Respecting Choices ACP program. This US program involves trained facilitators who assist individuals in exploring the understanding of their illness, reflecting on goals, values and beliefs, discussing healthcare preferences and appointing a surrogate decision-maker. The primary outcome was change in patient activation (PAM-13) between baseline and 12-month follow-up. The ACP program

turned out to be feasible among frail older people: almost all participants from the intervention group engaged in the ACP program, completed an AD and appointed a surrogate decision-maker. The majority of participants who engaged in the ACP program reported positive experiences and considered the program useful (72% and 79%, respectively). We found no significant differences between the intervention and control group considering the extent in which patient activation changed in the course of one year follow-up. Change scores for health-related quality of life and for satisfaction with healthcare did not differ either between groups. Of intervention group participants, 93% completed an AD and 94% appointed a decision-maker. Of control participants, 34% completed an AD and 67% appointed a decision-maker. The majority of the intervention group (89%) appointed their decision-maker in writing, whereas the majority of the control group (63%) did so orally.

We found no differences in the use of medical care between the ACP intervention group and the control group during 12 months **(Chapter 5)**. Accordingly, the average costs of medical care did not differ between the study groups (€2360 versus €2235, respectively). Whether goals of hospital stays, diagnostic procedures and medical interventions were curative or palliative was often not recorded in medical files. This complicated the assessment of the extent to which care as provided was concordant with the preferences on individual level. Mean variable costs for carrying out the ACP conversations were rather limited (€76 per participant).

In addition, we investigated experiences with and outcomes of ACP in 39 bereaved relatives of frail older people **(Chapter 6)**. In the intervention group approximately half of the interviewed relatives (n=11/20) had been present during one or more ACP conversations, suggesting that they were open to being involved in the ACP process. These relatives appreciated the facilitated ACP conversations, which provided clarity concerning patients' preferences for medical treatment and care and facilitated healthcare decision-making. A minority of relatives considered ACP redundant since they were already aware of patients' preferences. Nine of 10 bereaved relatives in the intervention group who had been involved in decision-making on behalf of the deceased felt adequately prepared for this process as compared to five of 11 bereaved relatives in the control group. Relatives' levels of anxiety and depression did not differ significantly between groups.

Studies show that many older people rather avoid admissions to inpatient care facilities (such as a hospital, nursing home or hospice) in the last year of life. In **Chapter 7**, we described and compared such admissions in the last year of life of 5092 community-dwelling people across Europe. We found that between 54% (France) and 76% (Austria, Israel, Slovenia) of people aged ≥50 years were at least once admitted to an inpatient care facility in their last year of life. The average duration of the total time spent in care facilities varied considerably between countries. Forty-two percent of all older people spent one month or more in an inpatient care facility (ranging from 27% in Estonia and

Greece to 48% in Austria). The large majority of admissions concerned hospitalizations. People from eastern and southern European countries had higher chances of hospitalizations in the last year of life compared to people from northern and western European countries. Furthermore, hospitalizations were more likely for those being ill for six months or more and less likely for people older than 80 years of age, females and those dying of cardiovascular diseases.

In **Chapter 8**, we provide a general discussion on our findings, with recommendations for clinical practice and future research. We conclude that our study did not find an effect of our Respecting Choices ACP program on downstream outcome measures including the level of patient activation, quality of life and costs of medical care. However, our ACP program positively affected the completion of ADs and the appointment of surrogate decision-makers. Furthermore, we observed limited costs of our ACP program and found that many (relatives of) frail older people appreciated the facilitated ACP conversations. Finally, our ACP program positively affected preparedness for decision-making in relatives. Given the increasing interest in ACP and the increasing emphasis in policy and practice on patient-centered care and participatory medical decision-making, further research on ACP strategies is desirable.

SAMENVATTING

Hoofdstuk 1 bevat een inleiding van dit proefschrift over Advance Care Planning (ACP). ACP stelt individuen in staat om doelen en voorkeuren voor toekomstige medische behandeling en zorg te definiëren, om deze doelen en voorkeuren te bespreken met familie en zorgaanbieders en om deze voorkeuren vast te leggen en indien nodig te herzien. ACP heeft de potentie om de geleverde zorg beter te laten aansluiten op de voorkeuren van patiënten, om de kwaliteit van de communicatie tussen patiënt en arts te verbeteren en om meer betere palliatieve zorg bij verschillende patiëntengroepen te bewerkstelligen. ACP is relevant voor kwetsbare ouderen, omdat deze populatie in de nabije toekomst hoogstwaarschijnlijk fysieke en cognitieve beperkingen zal ontwikkelen en afhankelijk zal zijn van anderen om hun behandelingsvoorkeuren aan te geven. Het is onbekend in hoeverre ACP kwetsbare ouderen kan ondersteunen om een meer actieve rol op zich te nemen in de zorg voor hun eigen gezondheid en hoe dit de kwaliteit van leven en andere gezondheidsgerelateerde uitkomsten (zoals het gebruik van medische zorg) kan beïnvloeden. Daarom was het belangrijkste doel van het in dit proefschrift beschreven onderzoek om de effecten van een ACP-programma te meten op de betrokkenheid van kwetsbare ouderen bij de medische zorg, de kwaliteit van leven, het opstellen van wilsverklaringen, het aanwijzen van zorgvertegenwoordigers, het gebruik van medische zorg, de kosten van medische zorg en de mate van overeenstemming van geleverde zorg met voorkeuren. Het studieprotocol van deze cluster gerandomiseerde studie (RCT) is opgenomen in **Hoofdstuk 2**.

In **Hoofdstuk 3** hebben wij gebruik gemaakt van baseline data van de RCT. Wij onderzochten de mate van betrokkenheid bij de medische zorg bij kwetsbare ouderen, oftewel de kennis, vaardigheden en het vertrouwen om de eigen gezondheid te managen. De betrokkenheid bij de medische zorg werd gemeten middels de korte versie van de Patient Activation Measure (PAM-13), die vier niveaus van toenemende betrokkenheid onderscheidt. We vonden dat 39% van de deelnemers niveau één had (wijst op een lage betrokkenheid bij de medische zorg), 31% niveau twee, 26% niveau drie en 5% niveau vier (wijst op voldoende betrokkenheid bij de medische zorg). Lage niveaus (= niveaus één en twee) werden vooral geconstateerd bij ouderen met een lagere gezondheidsgerelateerde kwaliteit van leven en bij bewoners van verzorgingshuizen. Echter, meer dan de helft van de thuiswonende ouderen had ook lage niveaus. Deze lage niveaus duiden erop dat de meerderheid van de kwetsbare ouderen mogelijk niet voldoende in staat is om hun eigen gezondheid te managen.

In **Hoofdstuk 4** hebben we de haalbaarheid en effectiviteit van ACP onder kwetsbare ouderen in Nederland bepaald. Deelnemers in de interventiegroep kregen gestandaardiseerde ACP op basis van het Respecting Choices ACP-programma aangeboden. Dit Amerikaanse programma houdt in dat opgeleide gespreksondersteuners individuen ondersteunen om hun gezondheidssituatie te begrijpen, om over doelen, waarden en overtuigingen na te denken, om behandelingsvoorkeuren te bespreken en om zorgvertegenwoordigers aan te wijzen. De primaire uitkomstmaat was de verandering in de betrokkenheid bij de medische zorg (PAM-13) tussen baseline en 12 maanden follow-up. Het ACP-programma bleek haalbaar bij kwetsbare ouderen: bijna alle deelnemers in de interventiegroep namen aan het ACP-programma deel. De meerderheid van de deelnemers was positief over het programma en vond het programma nuttig (respectievelijk 72% en 79%). We vonden geen significante verschillen tussen de interventie- en controlegroep in de mate waarin de betrokkenheid bij de medische zorg veranderde gedurende de follow-up periode van een jaar. Ook vonden wij geen verschil in de gezondheidsgerelateerde kwaliteit van leven en de tevredenheid met de medische zorg tussen studiegroepen. Van deelnemers in de interventiegroep stelde 93% een wilsverklaring op en wees 94% een zorgvertegenwoordiger aan. Van deelnemers in de controlegroep stelde 34% een wilsverklaring op en wees 67% een zorgvertegenwoordiger aan. De meerderheid van de interventiegroep (89%) wees hun zorgvertegenwoordiger schriftelijk aan, terwijl de meerderheid van de controlegroep (63%) dit mondeling deed.

We vonden geen verschil in het gebruik van medische zorg tussen de ACP-interventiegroep en de controlegroep gedurende 12 maanden **(Hoofdstuk 5)**. Ook de gemiddelde kosten van medische zorg verschilden niet significant tussen de studiegroepen (respectievelijk €2360 versus €2235). Of intenties van ziekenhuisverblijven, diagnostische procedures en medische interventies curatief of palliatief waren, werd vaak niet vastgelegd in medische dossiers. Dit compliceerde de beoordeling van de mate waarin de geleverde zorg overeenstemde met de voorkeuren op individueel niveau. De gemiddelde variabele kosten voor het uitvoeren van de ACP-gesprekken waren beperkt (€76 per deelnemer).

Daarnaast onderzochten wij ervaringen met en uitkomsten van ACP bij 39 nabestaanden van overleden kwetsbare ouderen **(Hoofdstuk 6)**. In de interventiegroep was ongeveer de helft van de geïnterviewde nabestaanden (n=11/20) aanwezig tijdens één of meer ACP-gesprekken. De nabestaanden waardeerden de ACP-gesprekken. Volgens hen leverden de ACP-gesprekken duidelijkheid op ten aanzien van de voorkeuren van patiënten voor medische behandeling en zorg, en vergemakkelijkten de gesprekken de medische besluitvorming. Een minderheid van de nabestaanden vond ACP overbodig, omdat zij al op de hoogte waren van de voorkeuren van patiënten. Negen van de 10 nabestaanden in de interventiegroep, die namens de overledenen betrokken waren geweest bij de medische besluitvorming, waren voldoende voorbereid op dit proces vergeleken met vijf van de 11 nabestaanden in de controlegroep. De mate van angst en depressie van nabestaanden verschilde niet significant tussen studiegroepen.

Studies laten zien dat veel oudere mensen opnames in het laatste levensjaar liever vermijden (zoals bijvoorbeeld een opname in een ziekenhuis, verpleeghuis of hospice). In **Hoofdstuk 7** onderzochten en vergeleken wij dergelijke opnames in het laatste levensjaar van thuiswonende ouderen in heel Europa. Wij maakten daarbij gebruik van gegevens over 5092 personen die hadden deelgenomen aan de SHARE studie. Wij constateerden dat tussen 54% (Frankrijk) en 76% (Oostenrijk, Israël, Slovenië) van de mensen van 50 jaar of ouder minstens één keer waren opgenomen in hun laatste levensjaar. De gemiddelde totale opnameduur varieerde aanzienlijk van land tot land. Tweeënveertig procent van alle ouderen bracht één maand of langer door in een instelling (variërend van 27% in Estland en Griekenland tot 48% in Oostenrijk). De grote meerderheid van de opnames betrof ziekenhuisopnames. Mensen uit Oost- en Zuid-Europese landen hadden in het laatste levensjaar hogere kansen op ziekenhuisopnames vergeleken met mensen uit Noord- en West-Europese landen. Bovendien was de kans op ziekenhuisopnames groter voor mensen die zes maanden of langer ziek waren en kleiner voor mensen ouder dan 80 jaar, voor vrouwen en voor mensen die aan hart- en vaatziekten overleden.

Hoofdstuk 8 bevat een algemene discussie over onze bevindingen, met aanbevelingen voor de klinische praktijk en toekomstig onderzoek. We concluderen dat wij in onze studie geen effect vonden van het Respecting Choices ACP-programma op de betrokkenheid van de deelnemers bij de medische zorg, de kwaliteit van leven en de kosten van medische zorg. Echter, ons ACP-programma had een positief effect op het opstellen van wilsverklaringen en het aanwijzen van zorgvertegenwoordigers. Bovendien waren de kosten van ons ACP-programma beperkt en vonden wij dat veel (nabestaanden van) kwetsbare ouderen de gefaciliteerde ACP-gesprekken waardeerden. Ten slotte had ons ACP-programma een positieve invloed op de voorbereiding van de medische besluitvorming van nabestaanden. Verder onderzoek naar ACP-strategieën is wenselijk gezien de toenemende belangstelling voor ACP en de toenemende nadruk in beleid en praktijk op patiëntgerichte zorg en participatieve medische besluitvorming.

Dankwoord
About the author
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PhD Portfolio

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DANKWOORD

Allereerst wil ik graag mijn begeleiders Agnes van der Heide, Judith Rietjens en Ida Korfage bedanken. Agnes, veel dank voor jouw kritische blik op de wetenschappelijke artikelen die ik de afgelopen jaren heb geschreven. Ondanks jouw drukke agenda kan ik altijd met mijn vragen bij jou terecht en straal je veel rust uit. Hier heb ik, naast je kennis van zaken en efficiënte manier van werken, veel bewondering voor. Judith, jouw enthousiasme en torenhoge ambities zijn zeer aanstekelijk. Veel dank voor het delen van al jouw kennis op het gebied van onderzoek doen en het schrijven van wetenschappelijke artikelen. Ik heb veel van je geleerd! Ida, ook jou wil ik heel erg bedanken voor het enthousiasme waarmee jij mij de afgelopen jaren hebt begeleid. Ik bewonder jouw efficiëntie en nauwkeurigheid. Dank ook voor de gezellige gesprekken tussendoor en je persoonlijke belangstelling. Agnes, Ida en Judith, ik heb de samenwerking met jullie als zeer prettig ervaren en ben enorm trots op ons gezamenlijk resultaat: dit proefschrift!

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ABOUT THE AUTHOR

Anouk Overbeek was born on June 20th, 1990 in Nijmegen, the Netherlands. In 2009, she completed secondary school at the Freiherr-vom-Stein Gymnasium in Kleve, Germany. Subsequently, she started studying Psychology at the Radboud University Nijmegen, the Netherlands. She wrote her graduation thesis about the visuospatial and verbal working memory in patients with Alzheimer's disease compared to cognitively healthy older people. In 2013, she obtained her Master of Science degree (cum laude). In that same year, she started as a PhD candidate at the Department of Public Health of Erasmus MC, the Netherlands. She conducted a study on the effects of Advance Care Planning in frail older people. Her PhD research resulted in this thesis. In 2018, she started as a postdoctoral researcher at the Erasmus School of Law, the Netherlands, where she is involved in an interdisciplinary project entitled "Doctors and criminal lawyers dealing with death and dying".

Anouk Overbeek werd geboren op 20 juni 1990 in Nijmegen. In 2009 behaalde zij haar gymnasiumdiploma aan de Freiherr-vom-Stein Gymnasium in Kleve, Duitsland. Hierna startte zij de studie Psychologie aan de Radboud Universiteit Nijmegen. Haar afstudeeronderzoek richtte zich op het visuele en verbale werkgeheugen van patiënten met de ziekte van Alzheimer in vergelijking met cognitief gezonde ouderen. In 2013 behaalde zij de titel "Master of Science" (cum laude). In datzelfde jaar is zij begonnen als PhD kandidaat op de afdeling Maatschappelijke Gezondheidszorg van het Erasmus MC te Rotterdam. Ze voerde een studie uit naar de effecten van Advance Care Planning bij kwetsbare ouderen. Haar promotieonderzoek resulteerde in dit proefschrift. In 2018 is zij begonnen als postdoctoraal onderzoeker bij de afdeling Strafrecht van de Erasmus School of Law te Rotterdam. Sindsdien is zij betrokken bij een interdisciplinaire studie met als titel "Doctors and criminal lawyers dealing with death and dying".

LIST OF PUBLICATIONS

This thesis

Korfage IJ, Rietjens JA, **Overbeek A**, Jabbarian LJ, Billekens P, Hammes BJ, Hansen-van der Meer E, Polinder S, Severijnen J, Swart SJ, Witkamp FE, van der Heide A. A cluster randomized controlled trial on the effects and costs of advance care planning in elderly care: study protocol. BMC Geriatr. 2015 Jul 22;15:87.

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PHD PORTFOLIO

Summary of PhD training and teaching

Name PhD student:	Anouk Overbeek
Erasmus MC Department:	Public Health
PhD period:	October 2013 – April 2019
Promotor:	Prof. dr. A. van der Heide
Supervisors:	Dr. J.A.C. Rietjens, Dr. I.J. Korfage

1. PhD training				
		Year	**Workload**	
			Hours	**ECTS**
General academic skills				
-	CPO course "Patient Oriented Research"	2014	8	
-	Research Integrity	2015	8	
-	Systematic literature retrieval in PubMed	2014	6	
-	EndNote	2014	3	
-	Introduction R	2016	1.5	
-	Time management	2016	3.5	
NIHES courses				
-	Analysis of Public Health	2014		1.9
-	Intervention development and education	2014		1.9
-	International comparison of Health Care Systems	2014		1.4
-	Quality of Life Measurement	2015		0.9
-	From Problem to solution in Public Health	2015		1.1
In depth courses				
-	Suffering, Death and Palliative Care	2015		1
Seminars and workshops				
-	Research meetings, Department of Public Health, Erasmus MC, Rotterdam	2013-16		2
-	Symposium "Kwaliteit en Implementatie: Durf de uitdaging aan!", Rotterdam	2013	3.5	
-	International Collaborative for End-of-Life Research (ICER), Rotterdam	2013	6.5	
-	Symposium junior onderzoekers proactieve palliatieve zorg, Nijmegen	2014	5.5	

1. PhD training (continued)				
		Year	**Workload**	
			Hours	**ECTS**
Seminars and workshops (continued)				
-	Pre-conference workshop "Research on ACP and EOLC", International Conference on Advance Care Planning and End-of-Life Care, München, Germany	2015	3	
-	International Collaborative for End-of-Life Research (ICER), Brussels, Belgium	2015	6.5	
-	GENERO-symposium "Preventie en ouderen", Rotterdam	2015	4.5	
-	Workshop Landelijke Consulentendag palliatieve zorg, Lunteren	2016	3	
Presentations - International				
-	Oral presentation: International Conference on Advance Care Planning and End-of-Life Care, München, Germany	2015		1
-	Oral presentation: World Research Congress of the European Association of Palliative Care, Dublin, Ireland	2016		1
-	Poster-presentation: World Research Congress of the European Association of Palliative Care, Dublin, Ireland	2016		1
-	Oral presentation: International Conference on Communication in Healthcare, Heidelberg, Germany	2016		1
-	Oral presentation: World Research Congress of the European Association of Palliative Care, Bern, Switzerland	2018		1
-	Poster presentation: World Research Congress of the European Association of Palliative Care, Bern, Switzerland	2018		1
Presentations - National				
-	Oral presentation: Symposium junior onderzoekers proactieve palliatieve zorg, Nijmegen	2014		1
-	Poster-presentation: Nationaal Congres Palliatieve Zorg, Lunteren	2014		1
-	Oral presentation: Nederlands Congres voor Volksgezondheid, Rotterdam	2014		1
-	Oral presentation: Research meeting Public Health, Erasmus MC, Rotterdam	2015		1
-	Oral presentation: Domeindag Laurens, Rotterdam	2015		1

1. PhD training (continued)	Year	Workload	
		Hours	ECTS
Presentations - National (continued)			
- Poster presentation: Nederlands Congres voor Volksgezondheid, Rotterdam	2016		1
- Oral presentation: Kenniscafé universitair netwerk voor de care sector Zuid Holland, Rotterdam	2016		1
- Oral presentation: Workshop Landelijke Consulentendag palliatieve zorg, Lunteren	2016		1
(Inter)national conferences			
- Nationaal Congres Palliatieve Zorg, Lunteren	2014		1
- Nederlands Congres voor Volksgezondheid, Rotterdam	2014		1
- International Conference on Advance Care Planning and End-of-Life Care, München, Germany	2015		1
- Nederlands Congres voor Volksgezondheid, Rotterdam	2016		1
- World Research Congress of the European Association of Palliative Care, Dublin, Ireland	2016		1
- International Conference on Communication in Healthcare, Heidelberg, Germany	2016		1
- World Research Congress of the European Association of Palliative Care, Bern, Switzerland	2018		1

2. Teaching activities	Year	Workload	
		Hours	ECTS
- Correcting Bachelor essays (3rd year medical students)	2015-16		2
- Supervising medical students theme 3.C.4 (community project)	2016		0.6

3. Awards	Year
- Jaarprijs Palliatieve Zorg Onderzoek voor het artikel “Advance Care Planning in Frail Older Adults: A Cluster Randomized Controlled Trial”	2018