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Advance Care Planning in Practice: Experiences of Patients and Healthcare Professionals

Vroegtijdige Zorgplanning in de Praktijk: Ervaringen van Patiënten en Zorgverleners

(met een samenvatting in het Nederlands)

Proefschrift

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Chapter 1

General Introduction

Everybody will be confronted with illness and death at some point in their life, either by becoming a patient, or by caring for a patient as a relative or a Healthcare Professional (HCP). However, how and when this will occur and which role one will have in such a situation is uncertain.

Recently, there has been an increased interest regarding the quality of the end of life. Quality of patients' end of life is closely related to appropriate care.[1,2] Such care is described as being patient oriented, safe and effective.[1] The term 'patient-oriented' highlights that appropriate care is individual and that what is appropriate differs between patients. To ensure that each patient receives the care that is appropriate for them, choices or decisions have to be made. These choices or decisions can be quite complex due to the fact that they can include initiating or withdrawing medical treatment that may prolong the patient's life. Making these decisions is also complicated by the multitude of technological developments in medical care and, consequently, the variety of treatments available. Patients, relatives and HCPs may question whether a specific treatment is useful and appropriate or whether the treatment is mainly harmful[1], and may therefore not be the best option.

In addition, patients might want to have a sense of control regarding decisions about their medical treatment and care throughout their lives.[3,4] This includes situations in which they cannot make decisions themselves.[3]

It is therefore important to consider how patients can be supported in the process of making choices or decisions in order to establish appropriate care for the patient.

As described above, what is appropriate care can differ between patients; therefore, an exploration of patients' values, goals and preferences is required. This exploration can be helpful for patients when they have to make in-the-moment decisions regarding medical treatment and care, and as a preparation for possible decisions that patients may face in times ahead. In addition, when patients discuss their thoughts in advance with someone who is closely involved, this person is better prepared to represent the patient and, where necessary, to make decisions that are concordant with the patients' goals and preferences when they can no longer make decisions themselves.

Originally, having a written form clarifying the patients' goals and preferences regarding medical treatment and care, such as an Advance Directive (AD), was seen as an appropriate approach to ensure that the medical team works in concordance with these goals and preferences.[3] An AD was described as an extension of personal control, particularly in a situation in which the person was not able to make decisions themselves.[3] Despite some years of recommending the use of ADs by healthcare organisations, in clinical practice it appeared that only a minority of patients completed an AD and shared it with relevant others.[5-9] This issue is related to barriers such as a lack of knowledge of patients or the perception that an AD is only necessary for someone with serious health problems.[3,7,8] Moreover, patients who complete an AD do not always share this document with family or relatives, because they do not want to burden them, nor with their HCP. As a result, ADs rarely affect the quality of end-of-life care, nor do they improve the HCP's or relative's knowledge of patient preferences.[5,10]

Advance care planning

It has been observed that the medical treatment and care patients received was not always in concordance with their goals and preferences and only a low number of ADs in clinical practice was seen.[1,5] In response, a strategy to support planning of future medical treatment and care was developed, referred to as Advance Care Planning (ACP). A recently developed definition states that:

Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.[11]

This definition underlines the importance of communication to understand the goals and preferences of the patients rather than completion of an AD only. In other words, the focus of planning for future care shifted from a product-oriented approach to a process of communication.[11]

All persons can engage in ACP at any stage of their life. This ability is reflected in studies investigating ACP in a variety of populations and ages, such as patients with cancer,[12-14] respiratory diseases,[15-18] kidney failure[19,20] or children.[21-23] Nevertheless, the ACP content may be more targeted when a person becomes older or when the illness progresses.[11] As such, ACP may be of particular relevance for patients with an advanced or progressive illness.[11,24,25]

Outcomes and perceptions of ACP

Recently, there has been an increase in the number of studies investigating ACP. Some studies focus on the effect of ACP, while others investigate perceptions and experiences regarding ACP.

In their systematic review, Brinkman-Stoppelenburg et al. (2014) concluded that there is some evidence that ACP positively impacts the quality of end-of-life care.[26] More specifically, evaluations of the included programs demonstrated that ACP has the potential to improve communication between patients and HCPs, increase the quality of life and well-being of patients and their relatives, reduce the use of possible futile treatments and unnecessary hospitalisations, enhance provision of care that is consistent with patient goals and increase patients' satisfaction with care.[26,27] In addition, research demonstrates that ACP positively influences the number of ADs and that ACP is more effective in promoting care that is consistent with patients' preferences compared to written documents alone.[26,27]

Although there is increased insight regarding the benefits of ACP, barriers that limit patient participation in ACP remain.[28-31] Patients may not want to be confronted with their own death, they may have concerns that their preferences will change over time or they do not want to burden their relatives.[28-30] In addition, patients expect HCPs to start an ACP conversation when appropriate and, consequently, do not start the conversation themselves.[13,31] However, it is known that HCPs are also hesitant to start an ACP conversation.[31-35] This problem is due to system-related barriers such as lack of time, but also fears of HCPs to introduce ACP too early or at a moment when a patient is not ready, to take away the patient's hope, and to cause unnecessary distress.[33,36] Consequently, HCPs often initiate ACP in a rather late stage during the course of the disease, even while it is recommended to discuss ACP-related topics proactively.[11,25] Therefore, HCPs require more training and experience in performing ACP conversations.[34,37]

As described above, not all patients and HCPs perceive ACP as being positive. However, current knowledge of barriers to ACP from patients' perspective is mainly derived from patients' responses to hypothetical scenarios.[20,29,38] Further, studies regarding HCPs' perspectives do not include an evaluation of a specific ACP program in combination with training.[31,34,35]

Experiences with ACP

Due to the increasing use of ACP programs in clinical practice, experiences with ACP are also increasing. This experience expansion offers the opportunity to shift from research into hypothetical use of ACP towards studying the experiences of patients, relatives and HCPs having real ACP conversations. These real experiences with ACP are helpful in understanding the process of ACP from the patients' perspective. The experiences of patients with a limited life expectancy (e.g. chronic respiratory diseases or advanced cancer) who participated in an ACP conversation are worthwhile because these patients are likely to be confronted with decisions about medical treatment and care in their near future.

Several programs have been developed to support HCPs to initiate an ACP conversation and to discuss goals and preferences for future medical care in daily practice. These programs aim to provide HCPs with guidance to the structure and content of ACP conversations with a script, a conversation guide or a less structured format.[26,39] There is no insight regarding the experiences of HCPs participating in ACP training and conducting structured ACP conversations.

To obtain a better understanding of the experiences of patients participating in ACP, an analysis of ACP conversations could be helpful, particularly regarding their readiness to participate in such a conversation. Patients' readiness for ACP is mentioned by both HCPs and patients as a precondition to participate in an ACP conversation.[11,25,40] Consequently, signs from patients that they are, possibly, not ready for these conversations are described by HCPs as a barrier to initiate such a conversation.[34,37] Insight into the manifestation of patients' readiness during an ACP conversation could provide a better understanding regarding patients' readiness for ACP, which may support HCPs to better anticipate what could happen during an ACP conversation and to better support patients.

Most ACP programs include the opportunity to document goals and preferences regarding future medical treatment and care in an AD. It may be helpful for relatives and HCPs if an AD includes more than only preferences, for example also beliefs and values. A completed AD prompted by an ACP conversation may reflect what patients understood and expressed during their ACP conversation. Investigating completed ADs will provide insight into the patients' thoughts after having participated in an ACP conversation.

The ACTION trial

The ACTION trial has been established to investigate an ACP intervention in a population of patients with a limited life expectancy (Supplementary material 1.).[41] It is a multi-centre cluster randomised controlled trial (RCT) evaluating an adapted version of the Respecting Choices (RC) ACP intervention, named the ACTION RC ACP intervention (Supplementary material 2.), in a European context. In the intervention group, adult patients with advanced lung or colorectal cancer (see Supplementary material 3. for the inclusion and exclusion criteria) are participating in an ACP conversation about their goals and preferences for future care and treatment with a trained facilitator (mostly nurses) and, if the patient wishes, a relative. This conversation is structured with the use of a scripted conversation guide.

The ACTION trial provides a context to investigate the experiences of HCPs conducting a structured ACP conversation after they participated in ACP training and to explore the experiences of patients with ACP.

Research questions of this thesis

The aim of this thesis is to obtain insight into the experiences of patients and HCPs with ACP and develop suggestions to improve ACP. To reach this aim, the following research questions will be answered:

- What is the current practice of ACP for patients with chronic respiratory diseases?
- How do patients with a life-threatening or life-limiting illness experience their participation in ACP?
- What are the experiences of HCPs delivering an ACP intervention?
- How does readiness of patients become manifest throughout an ACP conversation?
- What do patients document in an AD in the context of participation in an ACP intervention?

Besides these research questions related to the experiences of patients and HCPs with ACP, the following research question will be answered to enable performing a systematic review on a concept that is not yet clearly defined, such as experiences with ACP:

- How do we overcome the challenges of conducting a literature search for a review in a young and developing research domain?

Methods of this thesis

To answer the research questions of this thesis, a variety of methods were used. To start, two systematic reviews were performed to provide an overview of ACP in pulmonology and of patients' experiences with ACP. Simultaneously, in collaboration with Cochrane Netherlands, a coherent and transparent approach for conducting a literature search in a developing research domain was developed.

The answers to the remaining questions draw from qualitative studies performed along the ACTION trial. In the ACTION trial context, a qualitative study involving focus groups with RC facilitators was performed to gain insight into the experiences of trained facilitators with performing structured ACTION RC ACP conversations in Europe. These international data were analysed with the use of thematic analysis. Furthermore, a qualitative approach was used to describe patients' signs of readiness and of not being ready during the ACTION RC ACP conversations. Last, qualitative analysis and descriptive statistics were used to provide insight into the content of ADs developed for the ACTION study, the so-called My Preferences forms, completed by patients after having participated in ACTION RC ACP conversations.

Outline of this thesis

The study protocol of the ACTION trial is presented in **Chapter 2**.

An overview of ACP in pulmonology is provided in **Chapter 3**. In **Chapter 4**, a new iterative method for conducting a literature search in conceptually poorly developed fields is presented. **Chapter 5** provides an overview of the experiences of patients with a life-limiting or life-threatening disease with ACP.

In **Chapter 6,** the experiences of ACTION trained facilitators with performing structured ACP conversations are described. **Chapter 7** involves a content analysis of signs of readiness and of not being ready for ACP throughout ACP conversations. In **Chapter 8,** the content of completed My Preferences forms is described.

Finally, **Chapter 9** provides the general discussion and presents recommendations regarding ACP, based on insights gained from the different studies included in this thesis.

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Chapter 2

Advance Care Planning; an Innovative Palliative Care Intervention to Improve Quality of Life in Cancer patients – a Multi-Centre Cluster Randomised Clinical Trial: the Research Protocol of the ACTION study

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ABSTRACT

Background: Awareness of preferences regarding medical care should be a central component of the care of patients with advanced cancer. Open communication can facilitate this but can occur in an ad hoc or variable manner. Advance care planning (ACP) is a formalized process of communication between patients, relatives and professional caregivers about patients' values and care preferences. It raises awareness of the need to anticipate possible future deterioration of health. ACP has the potential to improve current and future healthcare decision-making, provide patients with a sense of control, and improve their quality of life.

Methods/ Design: We will study the effects of the ACP program Respecting Choices on the quality of life of patients with advanced lung or colorectal cancer. In a phase III multicenter cluster randomised controlled trial, 22 hospitals in 6 countries will be randomised. In the intervention sites, patients will be offered interviews with a trained facilitator. In the control sites, patients will receive care as usual. In total, 1360 patients will be included. All participating patients will be asked to complete questionnaires at inclusion, and again after 2.5 and 4.5 months. If a patient dies within a year after inclusion, a relative will be asked to complete a questionnaire on end-of-life care. Use of medical care will be assessed by checking medical files. The primary endpoint is patients' quality of life at 2.5 months post-inclusion. Secondary endpoints are the extent to which care as received is aligned with patients' preferences, patients' evaluation of decision-making processes, quality of end-of-life care and cost-effectiveness of the intervention. A complementary qualitative study will be carried out to explore the lived experience of engagement with the Respecting Choices program from the perspectives of patients, their Personal Representatives, healthcare providers and facilitators.

Discussion: Transferring the concept of ACP from care of the elderly to patients with advanced cancer, who on average are younger and retain their mental capacity for a larger part of their disease trajectory, is an important next step in an era of increased focus on patient centered healthcare and shared decision-making.

Trial Registration: International Standard Randomised Controlled Trial Number: ISRCTN63110516. Date of registration: 10/3/2014.

BACKGROUND

Despite progress in diagnosis and treatment, cancer remains a major life limiting disease, with 14.1 million new cases and 8.2 million deaths worldwide in 2012.[1] Patients with advanced cancer typically suffer from a reduced quality of life and multiple symptoms, such as pain, fatigue, and dyspnoea, due to their illness and/or its treatment.[2] A diagnosis of advanced cancer often has a tremendous impact on patients' emotional wellbeing and may result in depression, anxiety and a feeling of loss of control.[3,4] Ideally, these patients receive patient-centered care, addressing their needs concerning symptom control, psychosocial support, spiritual support, and practical issues. Patients' preferences regarding care and their wishes concerning their place of residence at the end of life should be central in the decision-making. Currently, treatment aimed at prolonging life has been found to often prevail over care aimed at relieving patients' suffering and enhancing their quality of life, which may not always be in accordance with patients' needs and preferences.[5]

Timely and efficient communication is an important prerequisite for care that adequately addresses patients' needs and preferences.[6] However, research findings consistently demonstrate that communication between physicians, patients with advanced cancer and their relatives is complex. Physicians tend to focus on treatment[7], patients may be overwhelmed and unaware of the possibility to opt for treatment aimed at relieving suffering, and relatives may feel stressed and uncertain to be involved in medical decisions without being aware of their beloved one's preferences.[8]

Advance care planning (ACP) has moved from being a process which aims to elicit specific instructions about medical treatment at the end of life, to being recognized as an opportunity to help patients and their families to prepare, in their own terms, for the changes wrought by serious progressive illness and work with them to plan nursing, social and medical care so that it better fits their needs, hopes and aspirations.[9] ACP is a formalized process of communication between patients, relatives and professional caregivers. It has been defined as "a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. […] It is recommended that with the individual's agreement this discussion is documented, regularly reviewed, and communicated to key persons involved in their care".[10] ACP promotes discussion of preferences and communication of these preferences to family, friends and healthcare professionals. Patients are encouraged to document their preferences in an advance directive and to review these preferences as circumstances change. Patients are also encouraged to appoint a personal representative, who can express their preferences if they are unable to do so themselves. However, the legal status of advance directives and personal representatives differs across countries. A review of the literature[11] shows that ACP programs have the potential to improve communication between patients and healthcare professionals, increase the quality of life and well-being of patients and their relatives, reduce the use of futile treatments and unnecessary hospitalisations, enhance provision of care that is consistent with patient goals, and increase patients' satisfaction with care. Other studies have shown that ACP can reduce healthcare costs.[12-14] The Respecting Choices program is one of the most promising ACP program. This program was developed in the US and successfully trialed in a geriatric setting in Australia, showing that patients' end of life care wishes were much more likely to be known and followed in the intervention group (86%) compared to the control group (30%).

Most ACP studies have been performed in the US, amongst nursing home patients with the main aim of establishing patients' preferences before they lose their competence. We will conduct our study in a European context and hypothesize that ACP can also be effective in improving the quality of life of patients with cancer who often remain competent until death or very close to death. ACP may support them in timely recognizing and continuously expressing their core values and preferences, and to communicate these with their loved ones and professional care givers, which will enable strategic and effective planning of care and decision-making. As a result, care may more adequately address patients' values and preferences, which may result in improved quality of life and more adequate symptom control, while patients feel more in control and receive less unwanted or futile interventions.

The overall hypothesis that will be studied in the ACTION project is that a formalized ACP program such as Respecting Choices significantly improves the quality of life and reduces the symptom burden of patients with advanced lung or colorectal cancer.

The primary objective is to assess the effect of the Respecting Choices ACP program on the quality of life and symptoms of patients with advanced lung or colorectal cancer.

The secondary objectives are:

1. To assess the effect of the Respecting Choices ACP program on the quality of life and symptoms of patients with advanced cancer in different subgroups (gender, age, education, ethnicity, country and type of cancer).
2. To assess the effect of the Respecting Choices ACP program on the extent to which care as received is in line with patients' documented preferences, on patients' evaluation of the quality of the decision-making process, and on how they cope with their illness.
3. To assess patient satisfaction with the Respecting Choices ACP program.
4. To assess the effect of the Respecting Choices ACP program on the quality of end of life care of patients with advanced cancer from the bereaved carers' perspective, and on the wellbeing of these carers.
5. To assess the cost effectiveness of the Respecting Choices ACP program.
6. To gain insight into how patients, patients' relatives and professional caregivers experience and respond to facilitated ACP.

METHODS/DESIGN

Study design and setting

We will perform a multicenter cluster-randomised clinical trial in 22 hospitals in six European countries (Belgium, Denmark, Italy, the Netherlands, Slovenia and the United Kingdom). Per country pairs of comparable hospitals (academic/non-academic) will be randomised to provide either 'care as usual' supplemented with ACP or 'care as usual'. Cluster-randomisation prevents healthcare providers from giving patients in the control group ('care as usual') more opportunity to discuss their preferences than usual due to their experience with providing the intervention in the intervention group ('care as usual' supplemented with ACP). The nature of the intervention makes blinding, for both healthcare professionals and patients and their relatives, impossible.

Study population

In total, 1,360 patients with advanced lung (N=680) or colorectal cancer (N=680) will be included. Lung and colorectal cancer patients are selected for this study because both types of cancer have high incidence and mortality rates in Europe and affect both sexes; see Supplementary material 3 for inclusion and exclusion criteria. At inclusion, the average life expectancy of these patients is about one year; their minimum estimated life expectancy to be eligible for the study is three months.

Intervention

In this study, we will evaluate the ACP Respecting Choices program. It involves trained healthcare professionals ("facilitators", mostly nurses) who assist patients and their relatives in reflecting on the patient's goals, values and beliefs and in discussing their healthcare wishes.[12, 15] The program also supports people to identify specific activities and experiences that may contribute to, or detract from, their quality of life. Patients are encouraged to appoint a patient representative who preferably also attends the Respecting Choices sessions, and to document their preferences for (future) medical treatment and care in an advance directive; the so-called My Preferences form. These wishes can e.g. concern the (non-)use of potentially burdensome life-prolonging interventions such as hospitalisations or cardio-pulmonary resuscitation. Patients are encouraged to discuss their preferences and questions they may encounter with their physician. The content of the communication during these meetings will be structured by the use of interview guides.

Study procedures

For each participating hospital, baseline background data will be collected, such as number of cancer patients attending annually, academic/nonacademic setting, number of beds and palliative care services, and a description of common practices regarding

ACP and decision-making at the end-of-life. In addition, background reports for each of the six participating countries will be created summarizing baseline national and local policies related to the provision of palliative care and ACP.

We will carefully translate the Respecting Choices program into the required European languages and adapt its content, in close collaboration with the US developers, to the specific legal, clinical, ethical, and cultural contexts of the participating European countries. To test the intervention and the process for acceptability and efficiency, a feasibility study will be conducted with five patients and potentially their family caregiver in each country. The patients will be offered the ACP program and will subsequently be interviewed. We will also test the questionnaires and have conversations with their healthcare providers.

Extensive training of the ACP facilitators is essential in this project. We will use the well-established structure of the training and implementation of the Respecting Choices program and will adopt a two-step education process. First, one representative per country will be trained in La Crosse, Wisconsin (USA) by the instructors of the Respecting Choices program. Subsequently, the country representative will train the local facilitators, who will be -where possible- selected among the healthcare workers of the hospitals, e.g. nurses. All together about 40 facilitators will be trained in the project.

Patients will be followed until one year after inclusion. During the inclusion period eligible patients in both intervention and control hospitals, will be approached for written informed consent. The information provided in the consent form for the intervention group and the control group will be as similar as possible to avoid selection bias with respect to interest in ACP. However, to minimize contamination, patients will be informed that the project aims at investigating the experiences of patients with different approaches towards medical decision-making in advanced stages of cancer, but no or limited details of the Respecting Choices program will be revealed in the control group. Patients will be given ample time to consider participation and they are free to withdraw from participating in the study without any effect on their care.

Patients in the intervention group will be offered the Respecting Choices program in addition to their usual care. Depending on the health status of the patient and the content of the conversations, a facilitated interview will last 45-60 minutes on average. We plan to have one or two sessions per patient. The facilitator will assist the patient in documenting preferences, including the assignment of a personal representative. For quality assurance, the interviews will be audio recorded by the facilitator.

By a standardized checklist a proportion of the interviews will be rated for intervention fidelity.[16]

Ethical committee procedures have been followed in all countries and institutions involved, and approval has been provided. The names of the main IRB's are:

The Netherlands: Medische Ethische Toetsings Commissie (METC) ErasmusMC;
Belgium: Universitair Ziekenhuis Brussel Commissie Medische Ethiek;
United Kingdom: NRES Committee North West - Liverpool East;
Italy: Comitato Etico Area Vasta Centro, Regione Toscana;
Denmark: De Videnskabsetiske Komiteer for Region Hovedstaden;
Slovenia: Komisija Republike Slovenije za medicinsko etiko (KME).
Approval was also obtained from the IRB's of all the remaining institutions.

The trial is registered in the International Standard Randomised Controlled Trial Number (ISRCTN63110516). A Data Steering Monitoring Board (DSMB) will be established.

Measurements

In ACTION, the following measurements will be performed (see Table 1):

a) Questionnaire study. Patients will be asked to complete a written questionnaire about quality of life, symptoms, the decision-making process, patient activation, coping, and satisfaction with care (and the intervention) at baseline (i.e., the moment of inclusion, before the ACP program is delivered in the intervention group), and at 2.5 and 4.5 months after inclusion. If a patient dies during follow up (i.e., within one year after inclusion), a relative identified by the patient as next of kin will receive a questionnaire to assess the patient's quality of end-of-life care and the relative's own wellbeing.
b) Medical file study. Data on patients' survival will be collected, as well as preferences as documented and care as received to assess whether patients' preferred care was congruent with received care. Data on care as received will also be used in the cost-effectiveness analysis. These medical files will be studied one year post-inclusion with a checklist.
c) Study of recorded ACP sessions. Data will be obtained from audio recorded facilitated interview sessions. Compliance with the intervention will be systematically evaluated with a predefined checklist.

Data management

Our data collection tool GemsTracker will be used to safely store data of all participating patients across hospitals and countries. GemsTracker enables restricted access to selected parts of its content. Legislation in the participating countries for research on humans, not involving medical products, will be taken into account.[17-22]

Power calculation, sample size and feasibility of recruitment

With at least 11 intervention and 11 control hospitals each recruiting 34 lung cancer patients and 34 colorectal cancer patients (of which 25 in each tumour type group are expected to remain in the study until at least month 2.5), this multicentre cluster-randomised clinical trial has an overall power of 90% to identify a minimum difference between intervention and control groups of half a standard deviation on the emotional functioning scale of the QLQ-C30 scale, assuming an intra-class correlation (ICC) of 0.1. On country level, these numbers give a power of 50% to show such a difference (assuming an ICC of 0.05).

The main outcomes are measured at 2.5 months post-inclusion. Although included patients have an average life expectancy of at least 3 months, we expect that a number of them will die within 2.5 months after inclusion. Based on Dutch colorectal and lung cancer survival statistics[23], we conservatively assume that this will be the case for 15% of included patients. Furthermore, we anticipate that around 10% of included patients may drop out of the study for other reasons, resulting in a total attrition rate of 25%. Based on this attrition rate and an estimated willingness of patients to participate of 33%, the total number of eligible patients per hospital per cancer type needs to be 101 in a 2-year period, which is feasible in the participating hospitals.

Table 1. Patient and bereaved carer endpoints of the project

I. Measured by questionnaire	Measure
Primary endpoints:	
- Quality of life	EORTC QLQ-C30 4-item emotional functioning scale[24]
	EORTC emotional functioning short-form based on CAT item bank
	EORTC QLQ-C15-PAL[25]
- Symptoms	
	APECC[26]
Secondary endpoints:	Self-constructed questions
- Shared decision-making	EORTC IN–PATSAT32[27]
- Patient involvement	COPE[28-30]
- Satisfaction with care	Self-constructed questions
- Coping with illness	Self-constructed questions
- Satisfaction with the intervention	VOICES-SF[31]*
- Socio demographic measures	HADS[32] IES[33]*
- Quality of end-of-life care	
- Bereaved carer wellbeing	
II. Obtained from medical files	
- Survival; date and place of death (if applicable)	
- Completion and content of advance directives; preferences for care; assignment of proxy decision-maker; physician orders	
- Diagnostic procedures and treatments received by the patient, hospitalisations and specialist palliative care input.	
III. Obtained from intervention sessions and qualitative interviews	
Systematic cross-cultural comparison of patient experiences, responses and concerns.	

* These endpoints are measured by the bereaved carer questionnaire and not by the patient questionnaire

Analyses

Analyses of the primary and secondary endpoints will be performed following the intention-to-treat principle. Descriptive statistics will be used to summarize characteristics of countries, hospitals and patients. Patient characteristics (age, gender, socio-economic class, educational level) will be compared at baseline between the intervention and control group. A multilevel modelling approach will be used to examine differences in the endpoints between the intervention and control groups, taking account of clustering effects at both hospital and country-level. All statistical tests will be two-sided and considered significant if $p<0.05$. Repeated-measures analyses of variance will be conducted to assess the development of endpoints over time.

Subgroup analysis will be conducted by means of formal interaction tests for intervention and those variables which are more likely to influence the effect of the intervention itself: gender, age class (<65, 65-74, 75+), educational status, and country.
Those conducting the data analysis will be blinded as to whether the patient was included in the intervention group or in the control group.

Qualitative study

A complementary qualitative study will be carried out in at least 3 of the 6 countries, to qualitatively explore the lived experience of engagement with the Respecting Choices intervention from the perspectives of patients, their Personal Representatives, healthcare providers and Respecting Choices facilitators. The patient and Personal Representative will undertake a facilitated advance care planning (ACP) conversation following the Respecting Choices program. Within two weeks of completing the ACP program they will be invited to take part in a baseline qualitative interview about their experiences. A follow up interview will occur 10-14 weeks after the initial intervention. At this second interview the patient will be asked whether he or she has discussed the Respecting Choices intervention with anyone from the healthcare team and for consent to contact this person. If the patient dies before the second interview, the Personal Representative will be contacted and invited for a qualitative interview. This will not be arranged until a minimum of six weeks after the patient's death. Healthcare professionals identified by the patient as being closely involved in the care will be invited to participate in a single face to face, Skype or telephone interview. Respecting Choices facilitators will be invited to participate in a single focus group discussion. In each of the participating countries, the qualitative study will involve between 6-10 cases including a patient and where appropriate a Personal Representative and healthcare professionals. All interviews and focus groups will be recorded and transcribed verbatim. Data will be thematically analysed using a pre-defined coding framework which will be developed through an iterative process of discussion and consensus among the research team.

Cost-effectiveness study
The economic evaluation will be performed from a healthcare perspective, for a period of one year post-inclusion per patient. Data on total in-hospital medical care will be obtained from medical files, using a standardized and piloted data extraction form. Medical costs will be calculated by multiplying the volumes of healthcare use with the corresponding unit prices. Unit prices will be calculated for all six countries separately. Costs for inpatient days in hospital will be estimated as real, basic costs per day using detailed administrative information. For other cost prices we will use charges. The unit price of the ACP intervention will be determined with the micro-costing method, which is based on a detailed assessment of all resources used. To compare the relative costs and outcomes of ACP versus 'care as usual' we will calculate the Incremental Cost Effectiveness Ratio (ICER); the average additional costs of ACP divided by the average change in emotional functioning measured with the EORTC-QLQ-C30 emotional functioning subscale (4 items). A sensitivity analysis will be performed to assess the stability of the results to changes in costs and effectiveness parameters (EORTC QLQ-C15-PAL quality of life subscale), and differences in healthcare systems between the European countries.

Dissemination
We have set up an Advisory Board of future international policy users of the project results. The role of the Advisory Board will be to provide a critical perspective throughout the life of the project. The project results will be disseminated through publications in scientific journals and conferences. To disseminate the knowledge to all stakeholders we will use the project website (www.action-acp.eu). A link of ACTION to the websites of the consortium and Advisory Board members will be featured.

DISCUSSION

This project aims to study the effects of the Respecting Choices program on quality of life and symptoms of patients with advanced lung or colorectal cancer. This study has several strengths. First, studies about Advance Care Planning have mainly been performed with older nursing home patients. Transferring the concept of ACP from care of the elderly to patients with advanced cancer, who on average are younger and remain competent for a larger part of their disease trajectory, is a highly relevant next step in an era of increasing focus on patient centered healthcare and shared decision-making. Second, a randomised controlled trial design will enable us to draw conclusions about the causal relations between ACP and the outcomes under study. The clustered design of this project prevents contamination between the control and intervention group. Third, the unique combination of quantitative and qualitative methods in this project will result in profound insights into the underlying working mechanisms of ACP.

In ACTION, we expect to encounter some challenges and possible limitations. First, patients may decline participation for different reasons. They may feel overwhelmed by the topics raised in the ACP intervention sessions and may not (yet) feel prepared to talk about these issues. We will use a patient-centered approach to facilitate study participation. Patients will receive information about the project through their treating specialist. Since patients may refuse because they do not want to engage in ACP conversations, non-response bias cannot be ruled out. Also selection bias cannot be ruled out, e.g. in intervention hospitals' where including physicians may be more likely to ask patients who they think are more 'open' to ACP to participate in the study. If such 'gatekeeping' comes into play, the effect of the intervention may be overestimated. However, our approach to systematically assess all lung and colorectal cancer patients for eligibility, and subsequently invite all who are eligible to participate in the study may reduce this risk. Attrition is another potential limitation to this project. Attrition may occur because the condition of the patient might worsen such that further participation becomes impossible, or patients might die during follow-up. We try to limit attrition by adding the inclusion criterion of a minimal anticipated life-expectancy of three months and to measure our main outcome measure at 2.5 months. Third, the international character of this project might be a challenge, as a balance needs to be found between on the one hand testing a uniform intervention in the six countries, that on the other hand is tailored to the specific cultural, ethical and legal context of each country. Fourth, the extent to which actual care will be reflected in medical files can be questioned. Potentially, not all treatments that patients receive will be documented in the hospital medical files.

CONCLUSION

Advanced cancer typically involves multiple symptoms and seriously affects patients' quality of life. Focusing care at patients' preferences and open and respectful communication are important values in end-of-life care, yet these have been found to be a challenge for healthcare professionals as well as for patients and relatives. Little is known about the outcomes of formal ACP, the effects of formal ACP on medical care and medical decision-making, costs and cost-effectiveness of formal ACP and country-specific factors that might influence ACP. Our project will fill these gaps in knowledge, based on an international multicenter cluster-randomised clinical trial to test the outcomes and effects of a formal ACP program, which is enriched by a qualitative study and a cost-effectiveness study.

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Chapter 3

Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices

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ABSTRACT

Background: Advance care planning (ACP) supports patients in identifying and documenting their preferences and timely discussing them with their relatives and healthcare professionals (HCPs). Since the British Thoracic Society encourages ACP in chronic respiratory disease, the objective was to systematically review ACP practice in chronic respiratory disease, attitudes of patients and HCPs and barriers and facilitators related to engagement in ACP.

Methods: We systematically searched 12 electronic databases for empirical studies on ACP in adults with chronic respiratory diseases. Identified studies underwent full review and data extraction.

Results: Of 2509 studies, 21 were eligible: 10 were quantitative studies. Although a majority of patients was interested in engaging in ACP, ACP was rarely carried out. Many HCPs acknowledged the importance of ACP, but were hesitant to initiate it. Barriers to engagement in ACP were the complex disease course of patients with chronic respiratory diseases, HCPs' concern of taking away patients' hopes and lack of continuity of care. The identification of trigger points and training of HCPs on how to communicate sensitive topics were identified as facilitators to engagement in ACP.

Conclusions: In conclusion, ACP is surprisingly uncommon in chronic respiratory disease, possibly due to the complex disease course of chronic respiratory diseases and ambivalence of both patients and HCPs to engage in ACP. Providing patients with information about their disease can help meeting their needs. Additionally, support of HCPs through identification of trigger points, training, and system-related changes can facilitate engagement in ACP.

Systematic review registration number: CRD42016039787

INTRODUCTION

Chronic respiratory diseases have grown in prevalence and are major causes of health burden and death.[1,2] Chronic pulmonary disease (COPD), for example, has become the fourth leading cause of death worldwide.[3] Patients with chronic respiratory diseases, such as COPD or pulmonary fibrosis, experience a complex and often unpredictable disease course,[4] which is characterized by a gradual decline, interrupted by sudden and life-threatening exacerbations.[5,6] As the disease progresses, complications may become more frequent and complex.[7] Disease progression may also lead to a variety of symptoms, such as dyspnea, and comorbidities, which can reduce the quality of life of patients substantially.[7] Patients, their relatives, and healthcare professionals (HCPs) are faced with treatment decisions throughout the disease course. Acute deterioration of health can,[7] for instance, result in respiratory failure requiring mechanical ventilation and the necessity of having to make ad hoc decisions on how to proceed.[8]

Since patient preferences for treatments such as mechanical ventilation vary,[9] patient centered discussions about goals of care are needed, while taking into account patients' preferences for content and timing of such discussions.[10] The British Thoracic Society and American College of Chest Physicians acknowledge advance care planning (ACP) as an integral part of cardiopulmonary medicine and encourage end-of-life discussions about goals of care.[11,12] ACP is a means to support patients in identifying their preferences of care, discussing these preferences timely with their relatives and HCPs and, if desired, documenting them in an advance directive (AD). In other disease groups, such as frail nursing home residents, ACP has been found to have beneficial effects on the communication between patients and HCPs and patients' quality of life.[13] ACP has also been found to have the potential to increase patients' satisfaction with care and care being delivered in accordance with patients' preferences.[13]

To date, there is no thorough overview of the use of ACP for patients with chronic respiratory diseases, of the attitudes towards ACP of those who may be involved in it, and of comprehensive ACP programmes in this context. This systematic review aims to describe ACP practice in chronic respiratory disease, summarizing findings on (1) how ACP is defined in chronic respiratory disease, (2) the experiences with and attitudes towards ACP of patients and HCPs, (3) the barriers and facilitators related to engagement in ACP, and (4) the effects of ACP programmes.

METHODS

Registration of the review

This systematic review was registered at the PROSPERO register (registration number: CRD42016039787). The full form can be accessed online at https://www.crd.york.ac.uk/PROSPERO/

Inclusion and exclusion criteria

Box 1. Inclusion and exclusion criteria for the current review

Inclusion criteria:

1. Original empirical research on the definitions of advance care planning (ACP), the experiences with and attitudes towards ACP of patients and healthcare professionals (HCPs), the barriers and facilitators related to engagement in ACP, and the effects of ACP programmes.
2. Research in the field of chronic respiratory disease.
3. Studies must address ACP, defined as:
    a. Interventions, programmes, or activities, which the authors label as 'advance care planning'.
    OR
    b. Studies addressing one or more core elements of ACP as defined by the National Academy of Medicine (NAM):[14]
        1) Discussing values and goals for future medical care and treatment with a healthcare professional
        2) clarifying values and goals for future medical care and treatment
        3) involving a personal representative
        4) documenting patients' wishes.
4. Studies published in English.

Exclusion criteria:

1. Studies in which ACP is only an element of a more complex care programme, such as palliative care, and specific content on ACP is not clearly described.
2. Studies involving children and adolescents.

We conceptualized ACP following the comprehensive definition of the National Academy of Medicine (NAM):

> *Advance care planning refers to the whole process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders. This process can start at any time and be*

> *revisited periodically, but it becomes more focused as health status changes. Ideally, these conversations (1) occur with a person's healthcare agent and primary clinician, along with other members of the clinical team; (2) are recorded and updated as needed; and (3) allow for flexible decision making in the context of the patient's current medical situation.*[14]

Based on this definition we identified four core elements of ACP (see Box. 1).

We included studies with interventions, programmes, or activities that were labelled as 'advanced care planning' by the authors or studies addressing one or more core elements of ACP as defined by the NAM.[14] This concerned standalone programmes or activities, as well as activities or programmes as part of a bigger (palliative care) intervention. However, if the ACP components in such a bigger intervention were not clearly described, we excluded the study.

Information sources and search

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist for reporting systematic reviews was used as the underlying structure of this review.[15] A systematic search strategy was developed with the aid of a biomedical information specialist of the Erasmus MC medical library. The following electronic databases were used: Embase, MEDLINE, Web of Science, Scopus, CINAHL EBSCO, PsycINFO, Cochrane, PubMed, LILACS, SciELO, ProQuest, and Google Scholar. The search was conducted on 26 June 2015. The search terms for the databases can be found in the supplementary file (S-box 1-11).

Study selection

Duplicates of the retrieved studies were removed. Based on the inclusion and exclusion criteria (Box 1.), two reviewers (LJJ and MZ) independently screened titles and abstracts for eligibility. Thereafter, they reviewed the full text of the remaining studies. Disagreements were discussed, if necessary including IJK and JACR, and solved. The reviewers used the web-based software platform Covidence (www.covidence.org) for screening and reviewing the studies.

Data extraction

We developed a data extraction form for this systematic review and used it to extract data on the study characteristics and results of the studies. We extracted the elements of ACP that were described in the conducted studies. Furthermore, we extracted data on the patients' as well as the HCPs' perspective on ACP, organizing the results into experiences with and attitudes towards ACP, barriers and facilitators related to engagement in ACP, and the effects of ACP programmes. We defined barriers and facilitators as predisposing factors reported by either patients, HCPs or both that hamper or facilitate engagement in ACP. We solely included those barriers and facilitators that were endorsed by at least 10% of the participants of the particular study. We chose for the cut-off point of 10% of participants to include as much information as possible, while at the same time keeping the information relevant and meaningful. The extraction was completed by one author (LJJ) and checked by another author (MZ). Disagreements were discussed and solved.

Risk of bias assessment and quality appraisal

Risk of bias assessment

The quantitative studies were assessed by two reviewers (LJJ and MZ) with a standardized form of seven items in a modified version of the guidelines for methodological quality assessment of the Dutch Cochrane Centre.[16] The checklist assesses the (1) research hypothesis, (2) study population, (3) selection bias, (4) exposure, (5) outcome, (6) confounding, and (7) a general opinion on the study's validity and applicability. A score of 1 was assigned when the criterion had been met sufficiently, a score of 0 when the criterion had not been met sufficiently and a question mark when the information for rating the criterion was lacking. The rating resulted in a total score from 0 to 7. A score of three or less was considered a study of low quality.

Quality appraisal

For the quality appraisal of the qualitative studies two reviewers (LJJ and MZ) used the 'Consolidated criteria for reporting qualitative research' (COREQ) list,[17] which is recommended by Cochrane Netherlands. The COREQ is a 32-item checklist, developed to promote explicit and comprehensive reporting of qualitative studies. The checklist evaluates qualitative studies on three domains: (1) research team and reflexivity, (2) study design, (3) analysis and findings. A plus (+) was assigned when the criterion had been properly described (score 1), a minus (-) when it was described unclearly (score 0), and a plus-minus (+/-) when the description was incomplete (score 0.5). Points were added for a total score ranging from 0 to 32.

RESULTS

Study selection

Our systematic search identified 4031 studies as potentially eligible for this review. After removing duplicates, 2509 studies remained, which were screened based on title and abstract. 2264 studies were excluded, mostly because ACP was only an element of an overarching intervention, such as a palliative care programme, and the ACP-specific components were not clearly described. Full text of 245 studies was assessed for eligibility. In the end, 21 studies were included for the analysis (see figure 1).

Study characteristics

Of the 21 studies, 10 had a quantitative study design (Table 1).[18-27] Out of these 10 studies, eight were observational, cross-sectional, and retrospective.[19,20,22-27] Nine studies had been conducted in the USA.[18 20-23 25 26 28 29] Studies involved patients with COPD (n=13),[18,19,23-25,27,30-36] chronic lung diseases (n=5),[20-22,29,37], cystic fibrosis (n=2),[26,28] and progressive idiopathic fibrotic interstitial lung disease (n=1).[38] Sixteen studies described the patients' perspective on ACP,[18,21-26 28-30 33-38] nine described the perspective of HCPs.[19,20,24,25,27,29,31,32,38] Sixteen studies had been conducted in an outpatient setting.[18-26,29,30,32,33,35-37] Sample sizes varied from 17 to 513 in the studies with a quantitative design and from 7 to 67 in those with a qualitative design. Five studies evaluated an ACP programme.[18,21,33,35,37] Studies were published between 1996 and 2014.

Supplementary tables 1 and 2 (S-Table 1 and 2) present the results of the risk of bias assessment of the quantitative studies and the results of the quality appraisal of the qualitative studies, respectively. One study, that was described in a 'short communication', was of low quality (score of 2), due to concerns about the rationale of the study, study population, and selection bias, as well as potential confounding.[27] The quality scores of the remaining quantitative studies ranged from 4 to 7, indicating overall good quality of the studies. One study had the maximum score of 7.[24] Four studies had a score of 6. The results of these studies should be interpreted in the light of concerns about confounding[18,21] and selection bias.[23,25] These concerns were also the most prominent quality issues of the quantitative studies in general (risk of possible confounding in 6 out of 10 studies, concerns about selection bias in 4 out of 10 studies).

The mean quality appraisal score of the qualitative studies was 16.5 of 32 (range 12-26.5). Almost all studies had poor ratings on the first domain, 'Research team and reflexivity'. Studies with the lowest scores also provided insufficient information on the domains 'Study design' and 'Analysis and finings'. The first domain 'research team and reflexivity' was reported the poorest throughout all studies, which clearly had a detrimental impact on the overall quality of the studies.

Synthesis of results

Core elements of advance care planning studied in chronic respiratory disease

Our first aim was to summarize how ACP is defined in chronic respiratory disease. We therefore gathered which elements of ACP were described in the conducted studies (Table 2). The vast majority of studies investigated the discussion of end-of-life care in their studies. The documentation of patients' wishes was investigated in about half of the studies.

Table 1. Study characteristics of the included studies

1st author (year)	Study Design	Country	Setting	Type of disease	Sample size (response rate)
Quantitative study design					
Target group: patients					
Au (2012)[18]	Experimental Longitudinal Prospective	USA	Outpatient clinic	COPD	306 (81%)
Heffner (1997)[21]	Experimental Longitudinal Prospective	USA	Outpatient clinic	Chronic lung diseases	93 (% ns)
Heffner (1996)[22]	Observational Cross-sectional Retrospective	USA	Outpatient clinic	Chronic lung diseases	105 (100%)
Janssen (2011)[23] *	Observational Cross-sectional Retrospective	NL/ USA	Outpatient clinic	COPD	513 (% ns)
Sawicki (2008)[26]	Observational Cross-sectional Retrospective	USA	Outpatient clinic	Cystic fibrosis	234 (77%)
Target group: patients and healthcare professionals					
Janssen (2011)[24]	Observational Cross-sectional Retrospective	NL	Outpatient clinic	COPD	105 patients (63%), 101 HCPs (96%)
Knauft (2005)[25]	Observational Cross-sectional Retrospective	USA	Outpatient clinic	COPD	115 patients (40%), 56 HCPs (86%)
Target group: healthcare professionals					
Gaspar (2014)[19]	Observational Cross-sectional Retrospective	Portugal	In- and outpatient clinic	COPD	136 (29%)
Heffner (1996)[20]	Observational Cross-sectional Retrospective	USA	Outpatient clinic	Chronic lung diseases	218 (63%)
Smith (2014)[27]	Observational Cross-sectional Retrospective	Australia	Inpatient clinic	COPD	17 (41%)
Qualitative study design					
Target group: patients					
Brown (2012)[30]	Semi-structured interviews	Australia	Outpatient clinic	COPD	15
Dellon (2010)[28]	Semi-structured interviews	USA	Inpatient clinic	Cystic fibrosis	36
MacPherson (2012)[36]	Semi-structured interviews	United Kingdom	Inpatient clinic, GP practices	COPD	10
Seamark (2012)[34]	Semi-structured interviews	United Kingdom	Inpatient clinic	COPD	16

Table 1. continued

1st author (year)	Study Design	Country	Setting	Type of disease	Sample size (response rate)
Qualitative study design					
Target group: patients					
Nguyen (2013)[33]	Qualitative descriptive	Canada	Outpatient clinic	COPD	12
Burge (2013)[37]	Prospective semi-structured interviews	Australia	In- and outpatient clinic	Chronic lung diseases	67
Target group: patients and healthcare professionals					
Bajwah (2012)[38]	Semi-structured interviews	United Kingdom	Inpatient clinic	PIF-ILD	8 patients 6 HCPs
Hajizadeh (2014)[29]	Semi-structured interviews	USA	Outpatient clinic	Chronic lung diseases	11 patients 5 physicians
Target group: healthcare professionals					
Crawford (2010)[31]	Semi-structured interviews	United Kingdom	Inpatient clinic	COPD	7
Gott (2009)[32]	Focus group	United Kingdom	GP practices	COPD	39

NL = the Netherlands; USA = the United States of America; GP = general practitioner; COPD = chronic obstructive pulmonary disease; PIF-ILD = progressive idiopathic fibrotic interstitial lung disease
% ns = response rate not specified
** Data of a part of the included patients in this study were also used in the analysis of the study by Jansen et al. 2011[24].*

Table 2. Core elements of advance care planning studied in chronic respiratory disease (n=21)

	Specific core elements of advance care planning as addressed in studies in chronic respiratory disease (N=21)
Core elements of advance care planning	
1) Discussing end-of-life care	20[18-36,38]
2) Clarifying values and goals	7[18,19,23,24,27,29,33]
3) Involving a personal representative	7[18,26,27,29,30,35,37]
4) Documenting patients' wishes	11[19-22,26,29,30,33-36]

Experiences with and attitudes towards advance care planning in chronic respiratory disease from a patient perspective

Involvement in discussions about end-of-life care preferences was addressed in 11 articles. Six of these studies had a quantitative study design. Seven studies involved patients with COPD. Per study, 12 to 32% of patients could recall involvement in end-of-life care discussions.[18,23-26] The qualitative studies found that patients could rarely recall these discussions.[29,30,34,36]

Eight studies addressed patients' interest in discussing end-of-life care preference. Two quantitative studies, each of high-quality, involved patients with COPD and chronic lung diseases in an outpatient setting and found that 68% and 99% of the patients, respectively, were interested in discussing end-of-life care preferences (S-Table 3).[18,22] In five qualitative studies patients with a variety of chronic respiratory diseases expressed willingness to discuss end-of-life care preferences.[29,30,34,36,38] Two of these qualitative studies revealed some hesitation of patients to talk about end-of-life care preferences, mainly due to uncertainty about the stability of their preferences and the sensitive nature of the topic.[34,36]

Seven studies addressed the documentation of preferences. Two quantitative studies of high-quality, in an outpatient setting with patients with chronic lung diseases and cystic fibrosis, found that 30% and 42% of patients reported documentation of their wishes through an AD.[22,26] Documentation of patients' wishes however did not always result in those wishes being discussed with the HCP, merely 19% of the patients in this study discussed their ADs with their HCPs.[22] In four qualitative studies, involving patients with a variety of chronic respiratory diseases in inpatient as well as outpatient clinics, only a minority of the interviewed patients had heard of an AD.[29,30,34,38]

Experiences with and attitudes towards advance care planning in chronic respiratory disease from a healthcare professional perspective

Eight studies addressed the experiences with and attitudes towards ACP from the HCP perspective (S-Table 4). Four of these were quantitative studies, in both inpatient as well as outpatient settings, and addressed the engagement of HCPs in ACP discussions.[19,20,24,27] The percentage of self-reported engagement in ACP was 20-33% in the three high-quality studies[19 20 24] and 13% in a pilot study of low quality.[27]

Two of these high-quality studies and the pilot study of lower quality found that 42-77% of HCPs recognized the importance of discussing end-of-life care topics.[19,20,27]

The vast majority of HCPs in two qualitative studies with patients with COPD and chronic lung diseases in an outpatient setting endorsed the need of discussing end-of-life care.[29,32] HCPs in one of these studies stated that not discussing end-of-life care would limit patient choice.[32] The pilot study that was carried out in Australia found that 41% of HCPs thought that their patients would be willing to discuss their wishes.[27]

The same Australian study found that 77% of HCPs felt comfortable to talk about end-of-life care,[27] while a high-quality study from Portugal revealed that 89% of HCPs found it difficult to engage in discussions on end-of-life care preferences.[19] Two qualitative studies, that involved patients with COPD and Progressive Idiopathic Fibrotic Interstitial Lung Disease (PIF-ILD) in an inpatient clinic, showed that HCPs had doubts about the right moment to initiate these discussions on end-of-life care preferences[31,38] and felt uncomfortable to share prognostic estimates such as life expectancy.[29] In one qualitative study,[31] that involved

COPD inpatients, HCPs emphasized that the timing of engaging in these discussions was crucially dependent on the patients' disease pathway and highlighted a clear difference between diseases.[31]

Barriers and facilitators related to patient and HCPs' engagement in advance care planning
Table 3 shows the most frequently described barriers and facilitators related to patient and HCPs' engagement in ACP.[19,21,23,25,27-34,37,38] The barriers and facilitators described in these 13 studies were related to the level of the patient, the HCP, and the healthcare system.
Two high-quality quantitative studies and three qualitative studies, involving patients with COPD and PIF-ILD, and their HCPs described insufficient awareness of patients about the nature of their disease, especially about its severity, as a barrier to ACP.[23,25,29,32,38] Four studies, among which one high-quality quantitative study, found that the unpredictable disease course of these diseases, particularly COPD, makes it difficult for HCPs to define and communicate the prognostic estimates to patients.[19,27,31,32] The same four studies and an additional high-quality quantitative study found that the complex disease course of chronic respiratory diseases also makes it difficult for HCPs to identify trigger points for the initiation of ACP, especially in chronic lung diseases.[19,25,27,31,32] Besides, HCPs perceive patients to be hesitant to consider and discuss end-of-life care,[19,25,27] while patients perceived HCPs to be reluctant to initiate ACP discussions.[21,23] This impression by patients aligns with HCPs acknowledging their fear of taking away patients' hope. This might be related to an ethos of 'cure at all costs', as identified by three studies in the UK, USA, and Portugal involving patients with COPD.[19,25,32]
Seven studies reported system related barriers to ACP, among which time constraints,[23,25,27,29,32,34,38] a lack of structural support, such as a lack of continuity of care,[21,23,25,30,32,38] and a lack of formal training in communicating end-of-life care options.[19,22,32,37,38] Two quantitative and two qualitative studies found that both patients and HCPs perceived lack of continuity and coordination of care as a barrier,[23,25,30,38] resulting in uncertainty about whose responsibility it is to initiate ACP discussions and to follow-up on these discussions.[21,32]
Two qualitative studies, involving patients with COPD and cystic fibrosis, identified patient knowledge and understanding of the nature of their disease as a facilitator for engagement in ACP.[28,33] Patients' acceptance of their disease was mentioned as another facilitator.[27,31,33] Three studies with patients with COPD and cystic fibrosis found that patient acceptance might increase with disease progression.[23 25 28] Two high-quality quantitative studies suggested that with disease progression, patients' worries about becoming a burden for loved ones increased, which in turn was found to be a facilitator for engagement in ACP.[23,25] Engagement in ACP was more acceptable to patients who previously experienced loved ones having to decide about end-of-life care or who had experienced loved ones dying.[23,25,33]

Table 3. Barriers and facilitators related to engagement in ACP

	Patient-related	HCP-related	System-related
Barriers	Insufficient patient knowledge about their own disease.[23,25,29,32,38]	Perceived hesitance of HCPs to discuss preferences and engage in ACP.[21,23]	Ethos of 'cure at all costs' in.[32]
	Unpredictable disease course and difficult prognostication.[19,25,27,31,32]	HCP's perceived fear of taking away patients' hope.[19,25]	Perceived HCP's time constraints.[23,25,27,29,32,34,38]
	Perceived patient hesitation for considering and discussing treatment preferences.[19,25,27]		Lack of organisational support and formal training on communicating end of life care options.[19,22,32,37,38]
			Lack of continuity and coordination of care including uncertainty on whose responsibility it is to initiate and follow-up on ACP discussions.[21,23,25,30,32,38]
Facilitators	Increased patient knowledge on terminal nature of their disease.[28,33]	Advanced stage of disease.[23,25,27,29]	Patient initiation of ACP (as experienced by HCPs),[31] HCP initiation of ACP (as experienced by patients).[23,25,28]
	Patients accepting their disease, increasing readiness to discuss end of life care.[27,31,33]	Identification of the right moment and setting to engage in an ACP discussion.[28,31,32]	Implementation of trigger points to discuss ACP.[32]
	Patient worry to become a burden for the family.[23,25]	HCPs' experience with care for patients at the end of life/ with lung diseases.[23,25,34]	Continuity of care, including good HCP-patient relationship.[23,25,31,33,34]
	Patient experience with end of life.[23,25,33]		

Three quantitative studies, among which two of high-quality and one qualitative study found that patients as well as HCPs perceived talking about ACP to be easier when patients had an advance disease stage.[23,25,27,29] The identification of the right moment and setting to engage in ACP discussions was perceived as beneficial by both,[28,31,32] as well as the HCPs' expertise in caring for patients with lung disease or end-of-life care.[23,25,34] While patients with COPD and cystic fibrosis preferred ACP discussions to be initiated by HCPs,[23,25,28] one qualitative study with COPD patients in the UK found that HCPs preferred patients to start discussions on end-of-life care.[31] The implementation of trigger points to discuss ACP, such as the start of oxygen therapy, could help to overcome this dilemma.[32] Patients and HCPs experienced a good patient-HCP relationship, characterized by trust and continuity, as supportive for engagement in ACP.[23,25,31,33,34]

Effects of advance care planning programmes

Five studies, two quantitative and three qualitative, evaluated the effects of an ACP programme (S-Table 5).[18,21,33,35,37] Two high-quality quantitative studies evaluated a patient specific feedback form to stimulate ACP conversations in patients with COPD[18] and educational workshops on ADs and other end-of-life topics for patients with chronic lung diseases.[21] The interventions increased quality of end-of-life care communication[18] and resulted in an increased number of completed living wills.[21]

The three qualitative studies evaluated programmes ranging from delivering video material to patients with COPD,[33] to ACP conversations based on a conversation guide for patients with chronic lung diseases and COPD.[35,37] Some patients perceived the information presented as confrontational, nevertheless they agreed about the need to gain a thorough understanding of treatment options.[33,35,37] Considering the timing of the discussions, a study on the effects of a DVD movie covering information on end-of-life care options found that most patients wished their HCPs to mainly be sensitive to their individual needs.[33]

DISCUSSION

This is the first systematic review thoroughly describing ACP practice in chronic respiratory disease, summarizing findings on how ACP is defined in chronic respiratory disease, the experiences with and attitudes towards ACP of patients and HCPs, the barriers and facilitators related to engagement in ACP, and the effects of ACP programmes. We summarized the findings of 21 studies. Only five of these studies, mostly had a qualitative study design, evaluated an ACP programme, suggesting that ACP programmes are less commonly studied in chronic respiratory disease than in other disease groups such as motor neuron disease and with nursing home residents.[39,40] By looking at the definitions of ACP in chronic respiratory disease and the elements being investigated in the 21 studies themselves, we found that only 10 studies provided an explicit operationalization of ACP. The remaining studies did not mention the term ACP at all. This suggests that the concept of ACP is not widely known or used in chronic respiratory disease.

The assessment of elements of ACP described in the conducted studies revealed that in contrast to the NAM definition most of the studies did not include the clarification of patients' values and goals in their studies. According to the American Thoracic Society, comprehensive ACP however is a holistic approach, tailored to individual needs. Solely discussing treatment options without grounding these in the discussion about patients' values and goals lowers the chance that patient-centered treatment decisions are made.[8] We also found that the descriptions of ACP only rarely included the involvement of a personal representative in ACP. While traditionally ACP focused mainly on the completion of written documents, the American Thoracic Society[8] nowadays acknowledges the importance of patient-centered conversations about treatment decisions as well as the involvement of a personal representative. Involving family caregivers can ensure that patient preferences will still be taken into account, even if patients lose their decision-making capacity.[8]

ACP is widely embraced by professional bodies such as the British Thoracic Society, American Thoracic Society, and the American College of Chest Physicians.[8,11,12] Cumulative evidence, predominantly from studies in other disease groups, has established the positive effect of communication between patients and HCPs on patients' quality of life.[13] Our systematic review shows that many patients with chronic respiratory diseases and their HCPs are interested in engaging in ACP, while less patients reported to have had such conversations. The low uptake of these discussions seems to be comparable to other disease groups: 20% of general medicine patients and 29% of hospitalized cancer patients reported having had ACP discussions.[41,42] Apparently, there is a discrepancy between the expressed interest in ACP discussions and the extent to which ACP discussions take place. Our systematic review suggests three main explanations for this phenomenon.

First of all, chronic respiratory diseases are often characterized by a complex and unpredictable disease course.[4,5] Murray et al.[6] describe the illness trajectory of lung failure as long-term limitations with intermittent serious episodes. Patients with chronic respiratory diseases are usually ill for a longer period of time, interrupted by occasional acute and often severe exacerbations. As a result, it is difficult for HCPs to provide the patient with prognostic estimates,[6] hence complicating the choice of timing and content of ACP discussions.

Stapleton and Curtis[1] advise to engage in ACP in any case earlier than it is usually done. They advise to start when patients are still relatively well and able to participate in decision making[8] to prevent that the impact of their decisions on their (end-of-life) care is limited.[43] This advice might be of particular importance for patients with COPD, since Lau et al.[44] found 26.9% of patients having their first ACP discussions only 3 days before death. While indeed ACP discussions can start any time, they can become more targeted as the patient's health condition worsens.[45] To support HCPs in finding a good moment for ACP discussions Bernacki and Block[43] made an effort to identify trigger points for starting ACP discussions. Examples of such trigger points are ongoing oxygen requirement of COPD patients or lack of further treatment options. A negative response on the "surprise question" *('Would you be surprised if this patient died in the next year?')* could serve as an indication for HCPs to initiate ACP,[43] although further validation of this question is necessary in this population. Another way of enabling ACP discussions is to remain alert for patient-induced triggers. Patients reported that experiences with death and dying of family and friends facilitated their thinking about end-of-life care. Responding to and elaborating these experiences can help to initiate ACP discussions.

The second explanation for the low frequency of ACP in chronic respiratory disease is that despite of HCPs recognising the importance of engaging in ACP, they often fear taking away patients' hope. Related to this, HCPs also reported a lack of training on communicating sensitive topics such as end-of-life care options without threatening the patients' emotional well-being and feelings of hope. However, a qualitative study on the perspectives of nurses on meeting patients' needs for hope and illness information[46] and a review on hope in palliative care found that honest information about the patient's illness can contribute to patient hope.[47] Patients were, for example, hoping to live to the fullest in the time they have left.[47] In fact, being able to talk about death and dying gave patients a sense of control and made them less afraid of the process of decision making.[47] Our review also found that patients do not feel well informed and educated about their disease, and HCPs confirmed that patients lack knowledge particularly about the severity of their disease. Patients seem to appreciate information about their disease, if sensitively introduced. This also highlights the importance of good communication skills and training for HCPs. Providing information on the disease, possible disease course, and treatment options, can be the first step of ACP.

The third explanation for the low frequency of ACP discussions in chronic respiratory disease is that system-related barriers such as time constraints and lack of continuity of care limit the opportunity for both patients and HCPs to engage in ACP during medical encounters. Patients' care trajectory is often characterized by profound breaks in care settings and HCPs. These breaks in care make it a complex task for HCPs to assess patients' level of awareness and readiness to engage in ACP. Continuity of care can be strengthened by documenting discussions on diagnosis, prognosis, treatment, and care options in the medical file. A reliable system for storing written advance care documents can ensure that these documents can be retrieved and transferred easily. Besides, it can be valuable to look for settings in which patients with chronic respiratory diseases are treated throughout their disease trajectory, such as pulmonary rehabilitation.[21,22] Due to their long-term relationship with the patient, general practitioners might be in a good position to be involved in ACP as well.[48]

Limitations

This review however has some limitations. First, we aimed at a comprehensive search strategy by searching in 12 electronic databases and also including studies that addressed the core elements of ACP without explicitly mentioning the term 'advance care planning'. However, if ACP was part of a larger palliative care programme and it was not possible to answer our research questions regarding specific ACP elements of the programme, we had to exclude the respective paper. This may have affected our results to some extent. Second, since the studies were mainly descriptive, statements of causality cannot be made. Finally, our search was limited to published articles in English language, which creates the possibility of publication bias.

CONCLUSION

This systematic review, summarizing findings of 21 studies, provides, for the first time, an in-depth picture of ACP practice in chronic respiratory disease, summarizing findings on how ACP is defined in chronic respiratory disease, the experiences with and attitudes towards ACP of patients and HCPs, the barriers and facilitators related to engagement in ACP, and the effects of ACP programmes. ACP seems to be acceptable and desired, by both patients and HCPs, while the occurrence of ACP appears to be low. The complex disease course of chronic respiratory diseases and hesitance of both patients and HCPs to engage in ACP as well as system-related factors create barriers to engagement in ACP. These barriers could be overcome by, first, identifying trigger points throughout the disease course to discuss ACP and second, training HCPs on how to communicate sensitive topics such as end-of-life care. Finally, making system-related adjustments, such as enabling continuity of care, allowing the initiation of ACP in appropriate healthcare settings and taking away time pressure from HCPs, can help to take away barriers preventing engagement in ACP.

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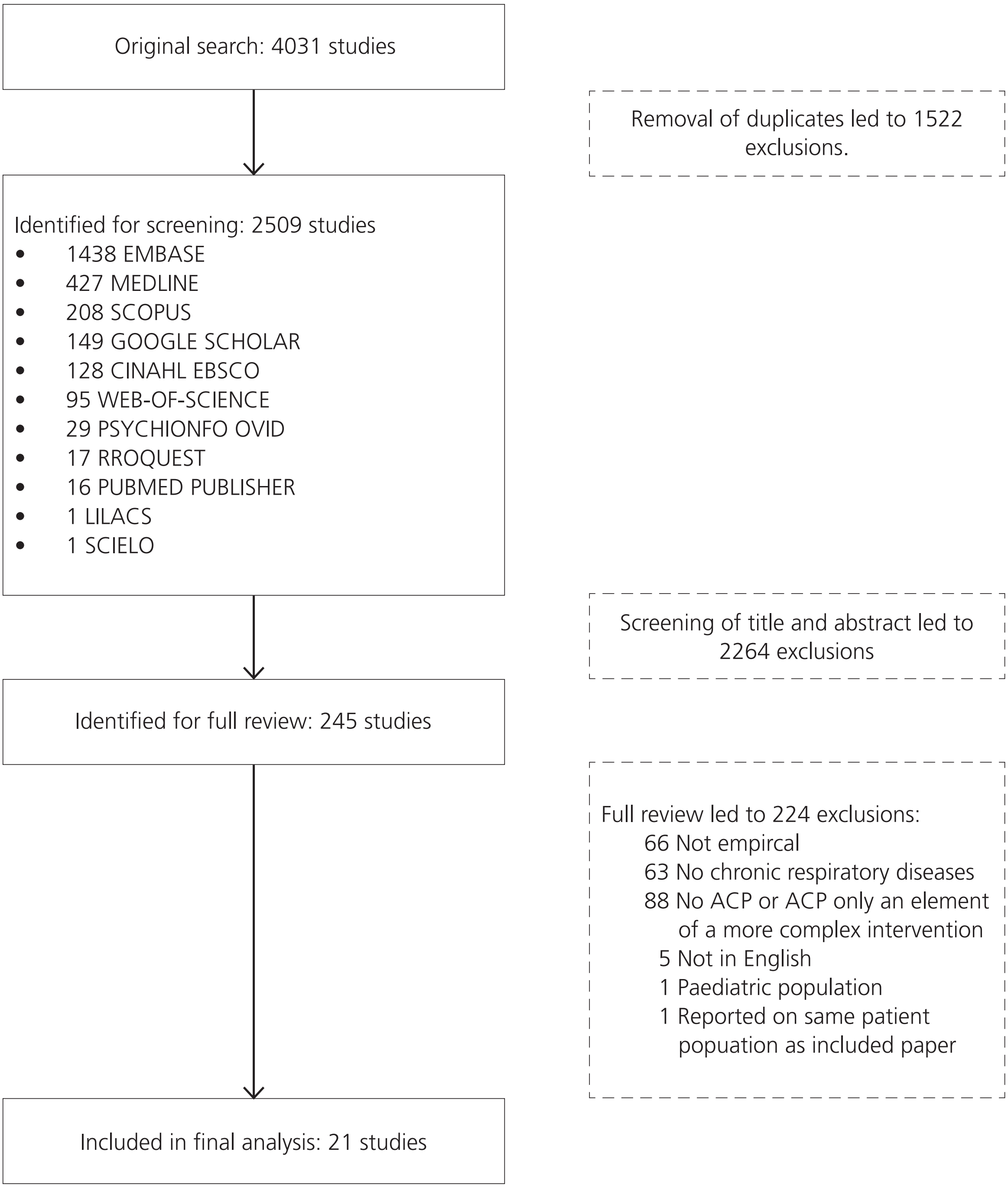
48. Michiels E DR, Van Der Kelen G, Bernheim JL, Mortier F, Vander Stichele R, Deliens L. The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin. Palliative Medicine 2007;**21**:409-15.

Figure 1. Flow diagram of article inclusion for this review



SUPPLEMENTARY FILE

S-BOX 1. Search strategy in Medline for the current systematic review

(exp “Advance Care Planning”/ OR (((“Decision Making”/ AND Patients/)) AND (“terminal care”/ OR “palliative care”/ OR “Terminally Ill”/)) OR (((Advance) ADJ3 (plan* OR directive*)) OR ((living) ADJ3 (will*)) OR (patient* AND (decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) ADJ6 (terminal* OR “end of life” OR palliativ* OR (life ADJ3 (saving OR saver* OR sustain* OR Prolong*))))).ab,ti.) AND (Pulmonary Medicine/ OR exp “Respiratory Tract Diseases”/ OR exp lung/ OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) ADJ3 (disease* OR disorder*))).ab,ti.) NOT ((exp child/ OR exp infant/ OR (child* OR infan* OR adolescen* OR pediatr* OR paediatr*).ab,ti.) NOT (exp adult/ OR (adult OR older OR elderl*).ab,ti.))

S-BOX 2. Search strategy in Embase for the current systematic review

(‘living will’/exp OR ((‘patient decision making’/exp) AND (‘terminal care’/exp OR ‘palliative therapy’/exp OR ‘terminally ill patient’/exp OR ‘terminal disease’/de)) OR (((Advance) NEAR/3 (plan* OR directive*)) OR ((living) NEAR/3 (will*)) OR (patient* AND (((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 (terminal* OR ‘end of life’ OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 life NEAR/3 (saving OR saver* OR sustain*))))):ab,ti) AND (pulmonology/exp OR ‘respiratory tract disease’/exp OR ‘lung surgery’/exp OR lung/exp OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) NEAR/3 (disease* OR disorder*))):ab,ti) NOT ((juvenile/exp OR (child* OR infan* OR adolescen* OR pediatr* OR paediatr*):ab,ti) NOT (adult/exp OR (adult OR older OR elderl*):ab,ti))

S-BOX 3. Search strategy in PsychINFO for the current systematic review

(exp “Advance Directives”/ OR (((“Decision Making”/ AND Patients/)) AND (“Terminally Ill Patients”/ OR “Palliative Care”/)) OR (((Advance) ADJ3 (plan* OR directive*)) OR ((living) ADJ3 (will*)) OR (patient* AND (decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) ADJ6 (terminal* OR “end of life” OR palliativ* OR (life ADJ3 (saving OR saver* OR sustain* OR Prolong*))))).ab,ti.) AND (exp “Lung Disorders”/ OR exp lung/ OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) ADJ3 (disease* OR disorder*))).ab,ti.) NOT ((100.ag. OR 200.ag. OR (child* OR infan* OR adolescen* OR pediatr* OR paediatr*).ab,ti.) NOT (300.ag. OR (adult OR older OR elderl*).ab,ti.))

S-BOX 4. Search strategy in Cochrane Library for the current systematic review

((((Advance) NEAR/3 (plan* OR directive*)) OR ((living) NEAR/3 (will*)) OR (patient* AND (((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 (terminal* OR ‘end of life’ OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish*OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 life NEAR/3 (saving OR saver* OR sustain*))))):ab,ti) AND ((copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) NEAR/3 (disease* OR disorder*))):ab,ti) NOT (((child* OR infan* OR adolescen* OR pediatr* OR paediatr*):ab,ti) NOT ((adult OR older OR elderl*):ab,ti))

S-BOX 5. Search strategy in Web-of-science for the current systematic review

TS=(((((Advance) NEAR/2 (plan* OR directive*)) OR ((living) NEAR/2 (will*)) OR (patient* AND (((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/5 (terminal* OR "end of life" OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/5 life NEAR/2 (saving OR saver* OR sustain*)))))) AND ((copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) NEAR/2 (disease* OR disorder*)))) NOT (((child* OR infan* OR adolescen* OR pediatr* OR paediatr*)) NOT ((adult OR older OR elderl*))))

S-BOX 6. Search strategy in Scopus for the current systematic review

TITLE-ABS-KEY(((((Advance) W/2 (plan* OR directive*)) OR ((living) W/2 (will*)) OR (patient* AND (((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) W/5 (terminal* OR "end of life" OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) W/5 life W/2 (saving OR saver* OR sustain*)))))) AND ((copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) W/2 (disease* OR disorder*)))) AND NOT (((child* OR infan* OR adolescen* OR pediatr* OR paediatr*)) AND NOT ((adult OR older OR elderl*))))

S-BOX 7. Search strategy in Cinahl for the current systematic review

(MH "Advance Care Planning+" OR (MH "Decision Making, Patient+" AND (MH "terminal Care" OR MH "Palliative Care" OR MH "Terminally Ill Patients+")) OR (((Advance) N3 (plan* OR directive*)) OR ((living) N3 (will*)) OR (patient* AND (decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) N6 (terminal* OR "end of life" OR palliativ* OR (life N3 (saving OR saver* OR sustain* OR Prolong*)))))) AND (MH "Respiratory Tract Diseases+" OR MH lung+ OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) N3 (disease* OR disorder*)))) NOT ((MH child+ OR MH infant+ OR (child* OR infan* OR adolescen* OR pediatr* OR paediatr*)) NOT (MH adult+ OR (adult OR older OR elderl*)))

S-BOX 8. Search strategy in PubMed publisher for the current systematic review

("Advance Care Planning"[mh] OR ((("Decision Making"[mh] AND Patients[mh])) AND ("terminal care"[mh] OR "palliative therapy"[mh] OR "Terminally Ill"[mh])) OR (Advance care plan*[tiab] OR Advance directive*[tiab] OR living will*[tiab] OR (patient*[tiab] AND (decision*[tiab] OR decid*[tiab] OR preference*[tiab] OR dilemma*[tiab] OR refus*[tiab] OR choos*[tiab] OR choice*[tiab]) AND (terminal*[tiab] OR "end of life" OR palliativ*[tiab] OR life saving*[tiab] OR life saver*[tiab] OR life sustain*[tiab] OR life Prolong*[tiab])))))) AND (Pulmonary Medicine[mh] OR "Respiratory Tract Diseases"[mh] OR lung[mh] OR (copd OR bronchi*[tiab] OR pulmon*[tiab] OR ((lung*[tiab] OR respirat*[tiab]) AND (disease*[tiab] OR disorder*[tiab])))) NOT ((child[mh] OR infant[mh] OR (child*[tiab] OR infan*[tiab] OR adolescen*[tiab] OR pediatr*[tiab] OR paediatr*[tiab])) NOT (adult[mh] OR (adult OR older OR elderl*[tiab]))) AND publisher[sb]

S-BOX 9. Search strategy in Google scholar for the current systematic review

“Advance directive|directives”|”advance * plan|planning”|”living will|wills” copd|pulmonary|lung|respiratory

S-BOX 10. Search strategy in Scielo for the current systematic review

(“Advance directive” OR “Advance directives” OR “advance care plan” OR “advance care planning” OR “living will” OR “living wills”) AND (copd OR pulmonary OR lung OR respiratory)

S-BOX 11. Search strategy in ProQuest for the current systematic review

(ti(“Advance directive” OR “Advance directives” OR “advance care plan” OR “advance care planning” OR “living will” OR “living wills”) OR ab(“Advance directive” OR “Advance directives” OR “advance care plan” OR “advance care planning” OR “living will” OR “living wills”)) AND (ti(copd OR pulmonary OR lung OR respiratory) OR ab(copd OR pulmonary OR lung OR respiratory))

S-TABLE 1. Results of the risk of bias assessment of the quantitative studies

1st author (year)	Au (2012)[18]	Heffner (1997)[21]	Heffner (1996)[22]	Janssen (2011)[23]	Sawicki (2008)[26]	Janssen (2011)[24]	Knauft (2005)[25]	Gaspar (2014)[19]	Heffner (1996)[20]	Smith (2014)[27]
Research hypothesis	1	1	1	1	1	1	1	0	1	0
Study population	1	1	1	1	1	1	1	1	1	0
Selection bias	1	1	1	?	1	1	0	0	1	0
Exposure assessment	1	1	1	1	1	1	1	1	1	1
Outcome	1	1	1	1	0	1	1	1	0	1
Confounding	0	?	?	1	0	1	1	1	?	0
General opinion	1	1	0	1	1	1	1	1	0	0
Total quality score	6	6	5	6	5	7	6	5	4	2

1 = Criterion has been met sufficiently
0 = Criterion had not been met sufficiently
? = Information for rating the criterion was lacking

S-TABLE 2. Quality evaluation of included studies according to the COREQ checklist

1st author (year)	Brown (2012)[30]	Dellon (2010)[28]	MacPherson (2012)[36]	Seamark (2012)[34]	Simpson (2011)[35]	Nguyen (2013)[33]	Burge (2013)[37]	Bajwah (2012)[38]	Hajizadeh (2014)[29]	Crawford (2010)[31]	Gott (2009)[32]
Domain 1: Research team and reflexivity											
Interviewer/ facilitator	+	+	+	-	-	-	-	-	-	-	-
Credentials	+	+	-	-	-	-	-	+ / -	-	-	-
Occupation	+	-	+	+	-	-	-	-	+ / -	-	-
Gender	+	+	+	-	-	-	-	-	-	-	-
Experience & training	+	-	+	+	-	-	-	-	+	-	-
Relationship established	-	-	+	-	-	-	-	-	-	-	-
Participants knowledge of the interviewer	-	-	+	-	-	-	-	-	-	-	-
Interviewer characteristics	-	-	+	-	-	-	-	-	-	-	-
Domain 2: Study design											
Methodological orientation and theory	+	-	+	+ / -	+	+	+	+ / -	+	+	+ / -
Sampling	+	+ / -	+	+ / -	+ / -	+ / -	+	+	-	+	+
Method of approach	+ / -	+	+	+	+	+	+	+	-	-	-
Sample size	+	+	+	+	+	+	+	+	+	+	+
Non-participation	-	+	+	+ / -	-	-	+	+	+	-	-
Setting of data collection	+	+	+	+	+	+	+	-	+	+	+
Presence of non-participants	-	+ / -	+	+	+	+	+ / -	+	-	+ / -	+
Description of sample	+	+	+	+	+	+	+	+	+	-	+
Interview guide	+ / -	+ / -	+ / -	+	+	+	+ / -	+	+ / -	+ / -	+ / -
Repeated interviews	+	-	-	-	+	+	-	-	-	-	-
Recording	+	+	+	+	+	+	+	+	+ / -	+	+
Field notes	+	-	+	+	+	+	-	-	-	-	+
Duration	-	+	+	-	-	-	-	-	+	+	-
Data saturation	-	-	+	-	-	-	+	-	-	-	-
Transcripts returned	-	-	-	-	-	-	-	-	-	-	-

S-TABLE 2. continued

1st author (year)	Brown (2012)[30]	Dellon (2010)[28]	MacPherson (2012)[36]	Seamark (2012)[34]	Simpson (2011)[35]	Nguyen (2013)[33]	Burge (2013)[37]	Bajwah (2012)[38]	Hajizadeh (2014)[29]	Crawford (2010)[31]	Gott (2009)[32]
Domain 3: Analysis and findings											
Number of data coders	+	-	+	+	-	-	+	+	-	-	+
Description of the coding tree	-	-	+ / -	-	-	-	+ / -	+ / -	+ / -	+ / -	+ / -
Derivation of themes	+	-	+	+ / -	+ / -	+ / -	+	+	+	+ / -	+
Software	-	-	+	-	-	-	-	+	+	+ / -	+
Participant checking	-	-	-	-	-	-	-	-	-	-	-
Quotations present	+ / -	+ / -	+ / -	+	+	+	+	+	+	+	+
Data and findings consistent	+	+	+	+	+	+	+	+	+	+	+
Clarity of major themes	+	+	+	+	+	+	+	+	+	+	+
Clarity of minor themes	+ / -	-	+	+	+	+	+	+ / -	+	+ / -	+ / -
Total +	17	12	25	15	14	14	15	14	13	9	13
Total + / -	4	4	3	4	2	2	3	4	4	6	4
Total -	11	16	4	13	16	16	14	14	15	17	15
Total score	19.0	14.0	26.5	17.0	15.0	16.0	16.5	16.0	15.0	12.0	15.0

+	= Criterion had been properly described
+ / -	= Description of the criterion was incomplete
-	= Description of the criterion was unclearly

S-TABLE 3. Incidence of and attitudes towards ACP: patient perspective

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
Au (2012)[18]	Discussing EOL care - 68% would like to discuss EOL care preferences with their HCPs.	Discussing EOL care 15% had EOL discussions.
Heffner (1996)[22]	Discussing EOL care - 69% wished to learn more explicit details about life-sustaining treatment options. - Most patients wished to actively participate in decisions about life support. Documenting patients' wishes - 89% were interested in learning more about ADs. - 78% found discussions about ADs informative. - 22% found discussions about ADs anxiety provoking but worthwhile. - 99% found discussions with HCPs about ADs acceptable. - 86% wanted to learn more about ADs, 12% had initiated these discussions. - 51% felt that physicians should initiate discussions about ADs. - 68% found that discussions about ADs and life-support should occur in the outpatient setting.	Discussing EOL care 15% had discussions about life-support. 14% believed physicians understood their wishes. Documenting patients' wishes - 95% heard of ADs. - 42 % completed ADs. - 19% had discussed ADs with HCPs.
Janssen (2011)[23]		Discussing EOL care - 12-18% discussed life-sustaining treatments with HCPs. - Quality of EOL care communication was rated very low (median score 1.1 (IQR 0.0-2.9) for patients with mild to moderate COPD and median score 1.4 (IQR 0.0-3.4) for patients with severe to very severe COPD). - HCPs did not ask about: • feelings about getting sicker (53-73%) • important things in life (85-80%) • what dying might be like (89-92%) • spiritual, religious beliefs (87-91%) - 69-84% reported no involvement in treatment discussion.

S-TABLE 3. continued

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
Sawicki (2008)[26]	Discussing EOL care - 50% thought that the clinician should initiate the discussion on EOL care. - Patients felt necessity of considering their treatment options, vast majority considered treatment preferences.	Discussing EOL care - 74% spoke to someone about treatment preferences. - 13% talked with their CF clinician about treatment preferences. - 28% were asked by their CF clinicians if they would want to make decisions about their medical care if they became too ill to make their own decisions. - 79% felt comfortable talking to a CF clinician about EOL care preferences. Clarifying values & goals - 58% had specific wishes about medical treatment. Documenting patients' wishes - 30% completed an AD. Involving a personal representative - 65% thought about whom they would like to make their healthcare proxy.
Janssen (2011)[24]		Discussing EOL care - Quality of EOL care communication was rated very low (median score 0.0). Clarifying values and goals - Patients reported that HCPs did not address religious beliefs (93%) or important things in the patients' life (83%). - 85% of patients reported no involvement in treatment discussions.
Knauft (2005)[25]		Discussing EOL care 32% were involved in treatment discussions. Clarifying value sand goals 75% thought physicians probably/ definitely knew their treatment preferences.
Qualitative study design		
Brown (2012)[30]	Discussing EOL care - Patients would like to discuss EOL care preferences, if sensitively introduced by well-informed HCP.	Discussing EOL care - 2 out of 15 patients had conversations with HCPs about resuscitation. Documenting patients' wishes - 11 out of 15 patients had not seen ADs before.

S-TABLE 3. continued

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
MacPherson (2012)[36]	Documenting patients' wishes - Patients had doubts about documenting 'preferred priorities of care' due to uncertainty about stability of preferences. - Patients had doubts on usefulness of ADs.	Discussing EOL care - Most reported perceived lack of communication around time of diagnosis. - 2 out of 10 patients reported some discussion about future. - 1 out of 10 patients had discussed ACP with HCPs. - 14 out of 10 patients described consultations with HCPs being very focused on the present/ current problem; future/ treatment preferences were never discussed. - Participants had not discussed general care preferences with HCPs, but all stated they would be comfortable with doing so when asked.
Seamark (2012)[34]	Discussing EOL care - All patients were willing to discuss ACP and related issues such as resuscitation. - Discussing ACP was seen as a difficult but worthwhile. - Having to make concrete decisions about EOL care was perceived as being hard.	Discussing EOL care - No one recalled discussion in hospital about life prolonging treatment. - Patients recalled admission as being hurried with minimum of discussion with the ambulance crew or attending GP. - Actual inpatient stay was seen as chaotic by most patients with lack of recall about where care took place and by whom. Documenting patients' wishes - 1 out of 16 patients had a DNR order at home, however form did not accompany patient to hospital.
Bajwah (2012)[38]	Discussing EOL care - Patients would like to discuss EOL care preferences. - Patients felt a need for further information on e.g. prognosis. - All realised importance of discussions about EOL care preferences, but did not know how to initiate them. - Patients felt that HCPs should be able to best judge when discussions about EOL care preferences should take place.	Documenting patients' wishes - No patients had formulated EOL plans or considered EOL preferences.

S-TABLE 3. continued

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
Hajizadeh (2014)[29]	Discussing EOL care - Those who had not discussed EOL decisions with their physicians were willing to do it. - Most agreed that their physicians should be involved in the EOL decision-making process. - 8 out of 11 patients found that physicians should talk about their patient's chance of dying from their disease. - 10 out of 11 patients found that physicians should talk about patients' EOL treatment options . - Patients felt that conversations should take place in advance of acute disease. - Importance of EOL decision making mostly related to experience with a family member. Documenting patients' wishes - Most expressed desire to complete an AD. - 7 out of 11 patients found that physicians should help patients to make ADs.	Discussing EOL care - 8 out of 11 patients knew that they have the right to say no to a breathing machine. - 9 out of 11 patients knew that they have the right to say no to be taken to the hospital. - 1 out of 11 patients had ever talked with HCPs physician about chance of dying from the disease. - 4 out of 11 patients had ever talked about EOL decisions with HCP. Involving a personal representative - All patients had heard of a health-care proxy. Documenting patients' wishes - 3 out of 11 patients had heard of an AD.

ACP = advance care planning; AD = advance directive; EOL = end-of-life; HCP = healthcare professional; COPD = chronic obstructive pulmonary disease; CF = cystic fibrosis; GP = general practitioner; DNR = do-not-resuscitate

S-TABLE 4. Incidence of and attitudes towards ACP: healthcare professional perspective

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
Janssen (2011)[24]		Discussing EOL care - 6% of both patients and physicians reported having discussed preferences regarding life-sustaining treatment. - 20% talked about life-sustaining interventions with their patients.
Gaspar (2014)[19]	Discussing EOL care - 77% found it very important to discuss EOL care preferences with advanced COPD patients. - 89% found it (very) difficult to discuss EOL care preferences with their patients. - 99% would like EOL care preferences to be further discussed in scientific meetings.	Discussing EOL care - 62% rarely/ never initiated EOL communication. - 68% rarely/ never suggested patients to make decisions about invasive mechanical ventilation/ intubation. - 81% rarely/ never suggested patients to indicate preferences about cardio-pulmonary resuscitation. - 76% rarely/ never suggested patients to make decisions about place of death. Clarifying values and goals - 82% rarely/ never addressed spiritual/ religious beliefs. Documenting patients' wishes 80% never suggested ADs.
Heffner (1996)[20]	Discussing EOL care - 42% programmes affirmed obligation of HCPs to inform patients regarding all aspects of health care. Documenting patients' wishes - 86% would initiate educational sessions on ADs into their programmes if supplied with appropriate teaching materials.	Documenting patients' wishes: - 33% asked patients about ADs. - 33% presented educational sessions on ADs. - 42% gave written materials on ADs. - Most rehabilitation programmes had no knowledge of their patients' ADs.

S-TABLE 4. continued

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
Smith (2014)[27]	Discussing EOL care - 69% thought that most patients with advanced COPD wanted to know about their diagnosis, prognosis, and available care options - 41% thought that most patients with advanced COPD, if asked, wanted to discuss their wishes for EOL care. - 76% thought all adult patients with COPD should be offered the opportunity to discuss ACP. - 94% thought that ACP can improve patients' and families' satisfaction about EOL care. - 77% felt comfortable discussing issues related to death and dying with patients with advanced COPD and their families. - 71% thought it is appropriate to discuss ACP with seriously ill patients who may recover. - 35% felt that ACP could destroy a patients' sense of hope. - 12% were concerned that having ACP discussions with COPD patients would lead to them not returning for further follow up. - 18% felt that ACP conflicted with other chronic disease management goals. - 18% felt that discussing ACP conflicts with responsibility to advocate for ICU levels care/ intubation for COPD patients. - 81% felt comfortable discussing ACP with patients with advanced COPD. - 77% thought it is essential to discuss ACP after recovery in patients with respiratory failure requiring non-invasive ventilation. - 94% felt comfortable discussing DNR orders with patients. - 59% found that ACP should be discussed as a routine outpatient visit. - 71% thought that ACP is a specialist physician's responsibility. - 82% felt supported by colleagues in discussing ACP with patients and families. - 71% felt sufficiently knowledgeable about how to conduct ACP conversations with patients and their families. - 81% reported interest in further ACP education.	Discussing EOL care - 13% discussed ACP with most patients, 56% with few/ (almost) none. - >50% discussed most/ all of the time diagnosis, incurability of disease, purpose of medical treatment, symptom management options. - 47% preferred discussing ACP in outpatient setting, 80% discussed it in hospital. - 6% felt that ACP makes patients losing confidence in physicians' care. Clarifying values & goals and Involving a p - <30% discussed most/ all of the time appointment of health-care proxy, palliative care options, patients' goals, values and beliefs. - 65% had previous ACP education, 81% learnt ACP skills by adopting ACP skills from others.

S-TABLE 4. continued

First author (year)	Attitudes towards ACP	Experiences with ACP
Qualitative study design		
Bajwah (2012)[38]	Discussing EOL care - HCPs did not know when to best initiate discussions about EOL care preferences. - Recognized complexities of delivering information while preserving balance between hope and realism.	Discussing EOL care - Frustrations about poor communication among HCPs and recognition for needed improvement to ensure adequate coordination of end of life care.
Hajizadeh (2014)[29]	Discussing EOL care - All interviewees endorsed the need of having discussions about EOL care preferences, most expressed discomfort and/ or resistance discussing prognostic estimates such as life expectancy with their patients. - 4 out of 5 doctors found that physicians should be involved in decision making about EOL care preferences. - 3 out of 5 doctors found that physicians should be required to initiate discussions about EOL care preferences with their patients. - 3 out of 5 doctors believed that discussions about EOL care preferences should take place during outpatient clinic visits. Clarifying values and goals - EOL discussions should address the following topics: patients' possible outcomes and their impact on their quality of life, patients' treatment preferences in term of treatment, patients' preferences in the case of no reasonable chance of recovery, whether patients would like to identify a health-care proxy or surrogate, whether they have previous ADs and the option of not receiving treatment.	Discussing EOL care - All doctors had discussions about EOL care preferences with patients, mostly in the context of intensive care. - All doctors discussed decision-making or preparation for EOL with patients with severe chronic diseases.
Crawford (2010)[31]	Discussing EOL care - Timing of EOL discussions was crucially dependent on patients' disease pathway. - Language distinctions: 'cancer' has terminal associations; COPD is a medical label with little meaning to patients. - Avoidance of 'death' and 'dying' words from staff and tendency to soften impact of information given to COPD patients; when patients directly asked about death, physicians were unprepared and described anxiety and discomfort.	

S-TABLE 4. continued

First author (year)	Attitudes towards ACP	Experiences with ACP
Qualitative study design		
Crawford (2010)[31]	Discussing EOL care - continued - Lung cancer patients were usually prepared for discussing EOL care preferences by 'planting a seed in their mind'. - COPD patients were not provided with the opportunity for discussing/ to discuss EOL care preferences, rather HCPs look for 'cues' to start the discussion. - Patient-initiated discussions were perceived as easier. - Moral and ethical dilemmas were reported: what, who, how, when to tell, while maintaining balance between truth and hope.	
Gott (2009)[32]	Discussing EOL care - Not discussing EOL could limit patient choice. - No consensus on appropriateness of rarely discussing EOL. - Majority thought that whilst they might be the right person to initiate the discussion on EOL care preferences (due to long standing relationship with the patient), there were factors identified preventing them from fulfilling this role. - Practice nurses did not feel that it was their responsibility to start the discussions on EOL care preferences, some reporting that they did not see the very 'terminal' COPD patients because these patients received home visits from the GP, and that they had never received any training in breaking bad news and therefore were ill equipped to manage such discussions. - Respiratory nurses did identify that they often 'knew' patients well and acted as a more constant point of contact in secondary care than medical staff. - Acute admission was not seen as a good time for EOL issues to be discussed.	Discussing EOL care - Discussions about EOL care preferences were rare. - Small minority of GP participants initiate discussions about EOL care preferences earlier in the disease process; typically it was 'too late' for patient to be well enough to make care choices. - Most felt that people with COPD receive inadequate information about their condition. HCPs often use euphemisms when disclosing a diagnosis of COPD.

ACP = advance care planning; EOL = end-of-life; COPD = chronic obstructive pulmonary disease; AD = advance directive; ICU = intensive care unit; HCP = healthcare professional

S-TABLE 5. Effects of ACP programmes: Outcomes from the interventional studies (n=6)

First author (year)	ACP programme	Study groups (n=participants)	Behavioural outcome
Quantitative study design			
Au (2012)[18]	Based on a patients' questionnaire responses, the HCP and the patient received a one-page patient specific feedback form to stimulate an ACP conversation	Intervention group (n=151) vs control group (n=155)	- Intervention group: threefold rate of EOL discussions with physicians (absolute difference 18.6%, p<.001), higher quality of EOL communication (difference 5.7 points (scale 0-100), p=.03; Cohen effect size 0.21) - No significant effect on number of discussions about patients' feelings about getting sicker, prognosis, what dying might be like, family involvement, asking about things important to patient.
Heffner (1997)[21]	Educational workshop on ADs and other EOL topics	Patients receiving workshop vs care as usual	- Educational group: significant increase (p<0.05) in number of completed living wills (OR=3.6, 95%CI 1.1,12.9), AD discussions (OR = 2.9, 95% CI 1.1,8.3), discussions with physicians about life-support (OR=2.7, 95% 1.0,7.7) and assurance that physicians understand their preferences (OR=3.7, 95%CI 1.3,13.4).
Qualitative study design			
Simpson (2011)[35]	Two loosely structured sessions based on a conversation guide. Each family also got the local health district's brochure on ACP	n=8 (+ 7 informal caregivers)	- 1 patient expressed appreciation for the sessions in terms of social interaction and opportunity for learning. - 1 patient found that the AD template offered a way to ensure that her family member, spouse and very uncertain substitute decision-maker, would have a tangible guidance about the wishes. - Between study visits 1 patient used the template to develop an AD and planned to follow-up by talking about it with her children. - 1 patient pointed out the appreciation for the facilitator's approach.
Nguyen (2013)[33]	A DVD movie to help build patients' knowledge about EOL options and to facilitate patient-physician discussion	n=12	- Most felt DVD did a good job of fulfilling information needs. - Words as 'scary' and 'shocking' were used to describe the visual portrayal of the intubation and tracheostomy processes. Nevertheless most agreed that it was necessary to gain a thorough understanding of the reality of these treatments. - Those who struggled with their diagnosis and prognosis tended to dislike the DVD and not wanting to watch it at all. Generally, the further the participant had progressed in their stages of readiness, the more they expressed that the DVD met their needs.
Burge (2013)[37]	ACP sessions	"attendees" (n=44) vs "non-attendees" (n=23) of the ACP sessions	- 17 described PR&M programmes as appropriate to receive information about ACP and preferable to an acute hospital setting. - 38 patients found information valuable and gave 'peace of mind' in relation to future care. - 34 patients felt that information about ACP is best presented in a group. - No consensus on which health professional should present the ACP information. - 12 patients of the community-based group and 8 of the hospital-based group followed up with the ACP facilitators, 21 participants went on to complete documentation.

Chapter 4

Introducing PALETTE: an iterative method for conducting a literature search for a review in palliative care

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ABSTRACT

Background: In the rapidly developing specialty of palliative care, literature reviews have become increasingly important to inform and improve the field. When applying widely used methods for literature reviews developed for intervention studies onto palliative care, challenges are encountered such as the heterogeneity of palliative care in practice (wide range of domains in patient characteristics, stages of illness and stakeholders), the explorative character of review questions, and the poorly defined keywords and concepts. To overcome the challenges and to provide guidance for researchers to conduct a literature search for a review in palliative care, Palliative cAre Literature rEview iTeraTive mEthod (PALETTE), a pragmatic framework, was developed. We assessed PALETTE with a detailed description.

Methods: PALETTE consists of four phases; developing the review question, building the search strategy, validating the search strategy and performing the search. The framework incorporates different information retrieval techniques: contacting experts, pearl growing, citation tracking and Boolean searching in a transparent way to maximize the retrieval of literature relevant to the topic of interest. The different components and techniques are repeated until no new articles are qualified for inclusion. The phases within PALETTE are interconnected by a recurrent process of validation on 'golden bullets' (articles that undoubtedly should be part of the review), citation tracking and concept terminology reflecting the review question. To give insight in the value of PALETTE, we compared PALETTE with the recommended search method for reviews of intervention studies.

Results: By using PALETTE on two palliative care literature reviews, we were able to improve our review questions and search strategies. Moreover, in comparison with the recommended search for intervention reviews, the number of articles needed to be screened was decreased whereas more relevant articles were retrieved. Overall, PALETTE helped us in gaining a thorough understanding of the topic of interest and made us confident that the included studies comprehensively represented the topic.

Conclusions: PALETTE is a coherent and transparent pragmatic framework to overcome the challenges of performing a literature review in palliative care. The method enables researchers to improve question development and to maximise both sensitivity and precision in their search process.

BACKGROUND

Palliative care (PC), a relatively young specialty, is growing rapidly and will continue to do so over the next decades.[1,2] The values of PC, such as adequately controlling symptoms, alleviating the burden of patients and informal caregivers, and preventing unnecessary hospitalisations[3,4] have been presented in an increasing number of scientific publications.[5–7] Clinical practice is preferably guided by a sufficient body of high quality evidence from research in combination with clinical expertise and patients' preferences.[8] To inform evidence-based guidelines and protocols, the need for literature reviews in PC is pressing. Literature reviews summarise and appraise the best available evidence on a topic and are considered the highest quality of evidence for evidence-based medicine.[9,10]

Widely used methods for literature reviews are developed primarily for intervention studies and have been applied to other fields, including PC. However, there is a need for literature reviews in PC beyond those that seek to pool evidence from intervention studies. The methods used for reviews concerning evaluation of interventions may not be transferable to literature reviews on less clearly defined topics that involve different challenges.[11] One of the challenges in PC is to build review questions based on the four parts of the PICO framework (Patient-Intervention-Control-Outcome). The challenge for PC is characterised by the wide range of domains due to variations in patient characteristics, disease trajectories, stages of illness, management of treatments, and involved stakeholders, which leads to a variety of topics, such as symptom management, psychosocial care, decision-making, and health services.[1,6,7,12]

A developing discipline such as PC often uses explorative review questions to gain a better understanding of the topic of interest, for example: 'How do patients with chronic heart failure experience an exercise programme to reduce illness related fatigue?'. The heterogeneity in practice and the explorative nature of the questions have hampered the use of PICO, which should be considered by a researcher when developing the review plan. Different frameworks have been developed to handle this variation, such as SPICE (Setting, Perspective, Intervention, Comparison, Evaluation) or SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type), but the aforementioned challenges remain.[13–16]

After formulating a review question, the next stage of study identification has its own challenges. A young discipline such as PC often suffers from concepts and terms that are heterogeneous, poorly defined, indexed, or standardised, making term-based searching difficult. This is not unique for PC, as similar problems have been encountered in social sciences.[11,12,17] Consequently, indexing systems such as MeSH (Medical Subjects Headings, the controlled vocabulary thesaurus of MEDLINE) do not cover many key concepts within PC. Furthermore, most general bibliographical databases only publish the author written abstracts together with independently annotated indexing terms. However, relevant information for PC review questions is not always part of the original study objective or is only presented as a subtopic and not reflected in the abstract. In these cases, a perfect match search based on the elements of the review question will not be sufficient to retrieve relevant studies. Therefore, a different approach for identifying key representational features within abstracts to discover these articles needs to be employed. Taken together, poor indexing, and the heterogeneous use of terminology will result in an unbalance between specificity and sensitivity. To specify, either ineffective searches missing many relevant articles or inefficient search strategies resulting in very high numbers of search results, tens of thousands, that must be screened manually. To narrow down results in intervention studies, a component on study methodology is added to the search query. However, most research within PC cannot be answered by randomised controlled trials,[18–20] rather, it relies heavily on alternative study designs such as mixed methods and qualitative studies.[12,21] Since the preferred study design is not always clear at the start and most research papers poorly report the applied methodology, the use of methodological search filters has been contested.[22] Although some success using filters has been reported, the broad terms used will yield low-precision results and, therefore, a high number of needed-to-screen (NNS).[22] This phenomenon has also been seen in fields such as diagnostic accuracy.[23]

Although the Boolean search query is most widely used in literature reviews, it is not the only way of retrieving studies or finding information. Other retrieval methods, including berry picking (Table 1), pearl growing (Table 1), and snowballing, have their own strengths and weaknesses. Berry picking is difficult to reproduce and lacks transparency, but has the advantage of gaining knowledge and identifying knowledge gaps with each item (berry) found. Pearl growing can help in identifying the relevant phrases and indexing terms used within the field, but is highly dependent on the composition of the initial set. Using the knowledge of peers regarding the relevance of studies, can reveal information not available in the abstract, but runs the risk of bias towards the predominant view within the field. For literature reviews, transparency and reproducibility are key features and, therefore, the Boolean logic query is so popular, as it is transparent in what it does, all elements are visible, and it is reproducible.

To address the aforementioned issues, there is a need to combine several of the existing retrieval methods in a logical way to ensure transparency and provide guidance for researchers. To reflect the more iterative nature of searching for PC studies, we developed a pragmatic framework, Palliative cAre Literature rEview iTeraTive mEthod (PALETTE), to guide the fine-tuning of the review question, performing a literature search, and applying screening eligibility criteria. By introducing intermediate validation steps, the reasoning for going from one phase to the next within the framework becomes visible which increases the transparency. It is the combination of these iterative steps, the use of multiple retrieval methods, and the validation on evaluated suitable studies that will boost confidence by the researchers that all relevant studies are captured. The structured iterative manner also facilitates a better ability to trace-back decisions for re-evaluation in light of new discoveries and adjust when or where necessary.

In this paper, we assess the usability and performance of PALETTE on two literature reviews in PC. Furthermore, with a detailed description, we provide guidance on how to apply PALETTE for literature reviews in PC.

METHODS

In this section, we describe the phases of PALETTE and present the criteria for observation to provide insight into our initial experiences with the framework.

PALETTE

The iterative literature search, PALETTE, consists of four phases: (1) developing the review question, (2) building the search strategy, (3) validating the search strategy, and (4) performing the search. Each subsequent phase consists of sub-phases and is informed by what is previously learnt. Results from one phase could require the researcher to return to the previous phase. A detailed description of the phases, moments of decision-making, and techniques used is presented below and visualised in Figure 1.

(1) Developing the review question

At the beginning of a PC review, the researchers first explore the key elements of the question carefully by performing an initial literature search. This search will be explorative, covering (a combination of) various topics from the initial review question supplemented with searches for reviews and overview articles to enhance the understanding of the overall perception within the field. In addition to the initial search, experts in the domain of interest are contacted to provide valuable articles. When experts cannot be contacted, it can be helpful to scan publications by key authors within a field to identify key papers and find relevant phraseology. Moreover, to overcome bias in the article set and to increase the body of knowledge, the key articles from the initial search and experts are expanded by adapted pearl growing (Table 1) and by both forward and backward citation tracking (Table 1).

After having collected all the references from the initial search, experts, and expansion, the researchers discuss the found body of evidence and map it to the initial review question whereby all related concepts are envisioned. When necessary, they refine, based on the added knowledge about the topic of interest, the review question, or concepts and thus the search strategy. This fine-tuning of the review question helps to address the most important viewpoints on the topic and, therefore, ensures a rich evidence-base. Furthermore, clear eligibility criteria are developed. Based on the final review question and the eligibility criteria, the researchers, preferably two researchers to minimise subjectivity, will select those articles from the retrieved articles that are relevant to the review question and fit into the eligibility criteria. These articles are the so-called ‘golden bullets’ and will be used for both fine-tuning the search query as well as the validation of the searches (Table 1).

This iterative process of screening the articles, fine-tuning the review question, modifying and developing the search strategy, and defining the eligibility criteria for answering the review question should be carefully explored by the researchers. It is of utmost importance that this process is well documented so that decisions leading to the final review question, the eligibility criteria, and the 'golden bullets' are transparent for the reader.

(2) Building the search strategy

The 'golden bullets' are analysed using PubMed PubReMiner (an online software tool that performs a frequency analysis of text words, MeSH terms, etc. on returned results from a PubMed query, Table 1), swift review (a programme to search, categorise, and visualise patterns in literature search results, Table 1), and manual identification of frequently occurring terms, phrases, index keywords and concepts. This input is used to compose a search query and this search is run in the most appropriate medical electronic database for the topic.

(3) Validating the search strategy

To validate the search strategy built in phase 2, the researchers check whether all 'golden bullets' can be identified within the results of the new literature search. If not, the literature search must be adjusted and the process of searching should be repeated. For certain topics, a search query might even be composed of several parallel queries, a so-called multithreaded search query. Since concepts within the corpus are so dispersed, the only way to capture all references is to construct several queries consisting of different combinations of concepts which are run in parallel to reach optimal retrieval. When all 'golden bullets' are identified, the researchers can continue to the next phase of PALETTE with the built search strategy.

(4) Performing the search

The researchers adapted the final search strategy developed in the second phase of PALETTE to other relevant electronic databases and run the search in these databases. This is followed by screening and selection of the articles using the predefined eligibility criteria. The choice of additional databases depends on the topic, journals covered in the database, and the likelihood of containing relevant information. The resulting articles from this step will be included in the review. As a final check of completeness, both backward and forward citation tracking will be performed for potentially missed relevant studies (Table 1). Citation tracking aims to identify new potentially eligible studies and to determine whether highly specific and relevant terminology was missed. If so, the search query should be adapted. Based on the missed articles, the keywords must be adjusted, the literature search in all electronic databases must be repeated, relevant articles should be identified, and citation tracking must be performed (this step could be repeated several times). When no new articles are qualified for inclusion, the final set of relevant articles is reached and the iterative process is completed.

Figure 1. PALETTE: an iterative method for the search of a literature review

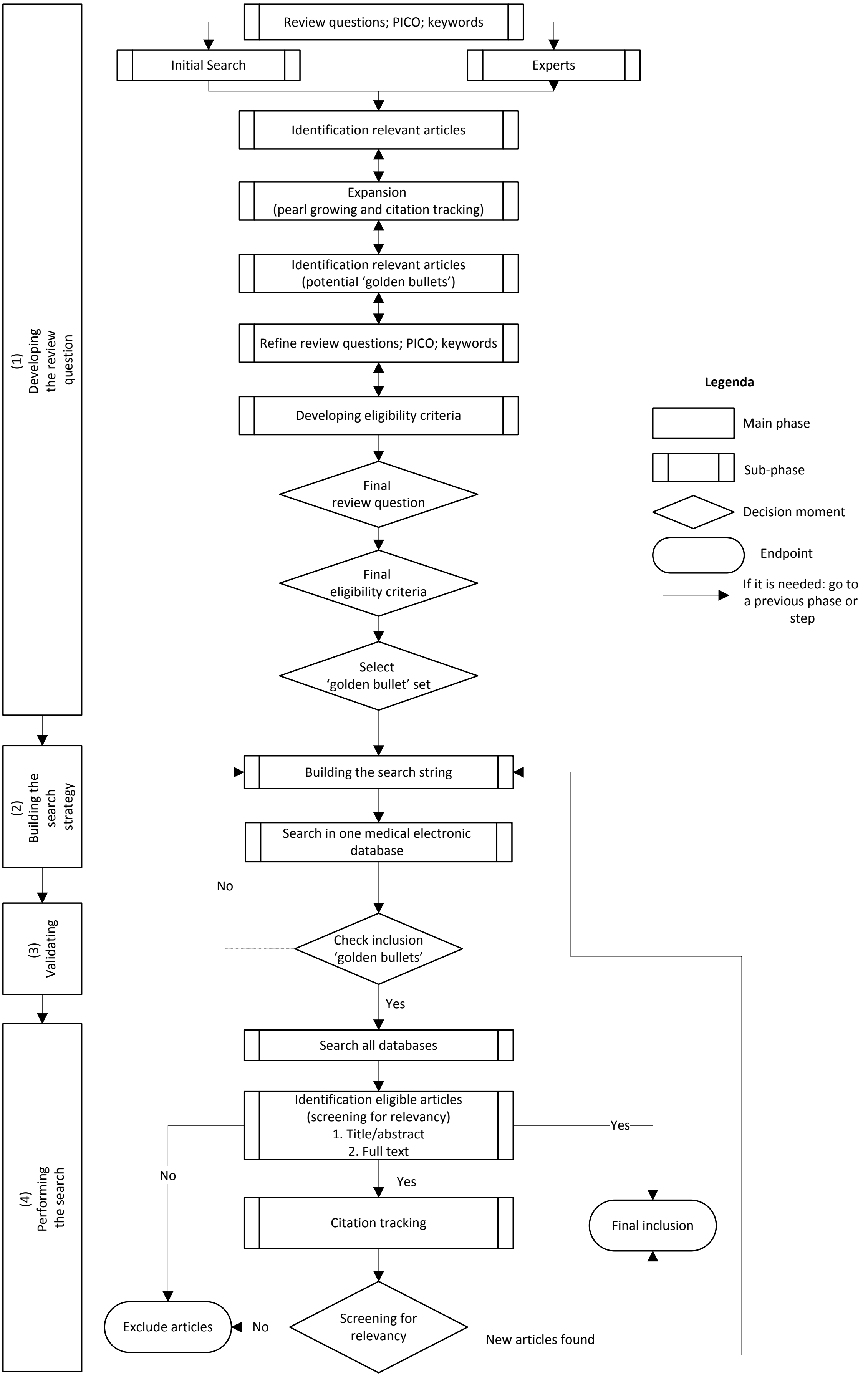

Table 1. Search techniques and analytic tools

Search techniques and analytic tools	Explanation
Berry Picking	Berry Picking is a retrieval model where obtaining evidence is not a linear path, but an iterative process where each newly identified piece of information can result in a modification of the information base required. Various techniques are used to identify the next piece of relevant information such as footnote chasing, journal browsing or database searching. Where it differs, is that information is not returned as a complete set, but in bits and pieces (the berries) informing the information base as one goes along.[24]
Pearl growing	In the process of pearl growing, relevant articles to the topic of interest are identified and they enable researchers to isolate keywords and index terms on which the researchers can base their search. By using these identified keywords and index terms to build the search, the corpus of relevant articles will grow. This process is repeated for all initial papers and newly identified relevant papers for either a predetermined number of times or until no new relevant papers are identified.[10,25]
Citation tracking	For citation tracking, researchers search for all articles which were cited by relevant articles (backward citation tracking) and for all articles which cite the relevant articles (forward citation tracking). Every found reference has been deemed relevant after careful consideration by the researchers. As such, researchers make use of the 'knowledgeable crowd'. That is, a corpus can grow through citation tracking based on the knowledge present within the literature by peers based on their knowledge and judgement of the content of the full article.[11,22]
'Golden bullets'	'Golden bullets' are articles that align with the inclusion criteria for the systematic literature review and, therefore, undoubtedly should be part of the review. The 'golden bullets' are used for feature extraction to inform the Boolean search strategy. Furthermore, the 'golden bullets' are used in the validation test of the search. During the validation, the reviewer is checking whether the 'golden bullets' are included in the outcome of the search, ensuring a suitable search strategy to identify relevant studies.
Software	During the iterative method, some text analysis tools can be used. For instance, during the analysis of the 'golden bullets' the analysis tools present in Eppi reviewer[26] can be used. A possible tool for word frequency is the TF*IDF option, which helps to identify relevant terms and PubReMiner (http://hgserver2.amc.nl/cgi-bin/miner/miner2.cgi). PubReMiner is an online resource to which PubMed search queries can be submitted to produce a list and frequency counts for all keywords (subheadings, title-words etc.) and MeSH-terms associated with the articles in that query. Swift-review is an interactive workbench that provides numerous tools to assist with literature prioritization. The software utilizes recently developed statistical modelling and machine learning methods that allow users to identify over-represented topics within the literature corpus and to rank-order titles and abstracts for manual screening.[27] To identify multi-word phrases, n-grams, the Termine tool can be used.[28] For identifying concepts within the 'golden bullet' set, it can be helpful to use cluster analysis[29] within Eppi reviewer, which is an application of the Lingo3 engine. Results of the search can be loaded in Endnote X7 (or any other suitable program for managing references) for deduplication. In the absence of Eppi reviewer a plethora of tools is available on the web like voyant-tools (https://voyant-tools.org) for term frequency analysis, termine on the web for n-grams (http://www.nactem.ac.uk/software/termine/) and vos-viewer for cluster analysis (http://www.vosviewer.com). For more information see http://systematicreviewtools.com.

Criteria to evaluate PALETTE

Our research team has recently performed two literature reviews in PC, which offers the opportunity to present practical experiences with applying PALETTE. The first review involved healthcare professionals' experiences in providing Paediatric Palliative Care (LR1). The second review concerned patients' experiences with Advance Care Planning (ACP) (LR2).

Firstly, we share user experiences to elicit relevant aspects of the process of PALETTE: use of experts, development of the review question, and understanding of the topic of interest. Secondly, the value of PALETTE was evaluated by comparing the PALETTE results for both LR1 and LR2 with results retrieved from a recommended search method for reviews of intervention studies (PICO). Criteria were number and value of identified 'golden bullets', NNS, and comprehensiveness of the search.

RESULTS

(1) Developing the review question

The input of experts in the phase of developing the review question was only applied in LR2 (Table 2). Thirty-three experts, identified as persons who were actively involved in ACP research and/or practice and, as such, were familiar with ACP literature, were asked to recommend relevant articles regarding the review question. This resulted in six potentially relevant articles. Although these six articles were helpful in fine-tuning the focus of the study, after close inspection and discussion within the research team, none of them became part of the 'golden bullets'.

The articles identified in this phase, were valuable for the research team in tuning between the information needed and the available information. Based on these articles in both LRs, the research question was refined, keywords were adapted and/or sharpened, and eligibility criteria were developed and tightened (Table 2).

(2) Building the search strategy

The identified 'golden bullets' of both LRs, were analysed both manually as well as with the use of software to identify frequently occurring terms, phrases, index keywords, and concepts. These words were subsequently used to build the search strategy in both LRs. This analysis appeared to be helpful for improving the search string, particularly to search more in-depth, which resulted in a more focussed search for both LRs.

(3) Validating the search strategy

For both LRs, not all 'golden bullets' could be identified in the results of the first search. Therefore, the reviewers returned to the previous phase and adjusted the search strategy. Once the 'golden bullets' were identified with the built search strategy and, consequently, the validation test was completed, the reviewers felt more certain that the final included articles represented a comprehensive set that covered the topic of interest.

Table 2. Description of initial observations and user experiences during the application of PALETTE

Topic	Experience LR1	Experience LR2
Developing the review question: Initial review question	'What are experienced barriers in practicing Paediatric Palliative Care from the perspective of professional caregivers?'	'How do patients experience and respond to ACP in palliative care?'
Developing the review question: experts	Approached: 0 experts.	Approached: 33 experts. Result: 6 potentially relevant studies of which none became a 'golden bullet'.
Developing the review question/ validation: 'golden bullets'	33 'golden bullets' were identified	7 'golden bullets' were identified.
Developing the review question: Adjusted review question	What barriers and facilitators in providing Paediatric Palliative Care are experienced by healthcare professionals?'	Not applicable
Developing the review question: PICO/keywords	'Barrier', 'facilitator' and, 'need' were removed from the search strategy.	The method of data collection was added to the search strategy.
Final review question	'What are the experiences of healthcare professionals when providing Paediatric Palliative Care?	'What are the experiences with ACP of patients with a life-threatening or life-limiting illness?'
Performing the search: number to screen	*Traditional search (Medline):* • 2815 articles • 31 relevant articles *PALETTE (Medline):* • 2600 articles • 42 relevant articles	*Traditional search I (Medline):* • 14746 articles • 20 relevant articles *PALETTE (Medline):* • 3555 articles • 20 relevant articles *Traditional search II (Medline)*: • 5153 articles • 14 relevant articles

(4) Performing the search

In comparison with the recommended search method for reviews of intervention studies (PICO), the NNS when applying PALETTE decreased in both LRs, whereas the number of relevant articles increased (Table 2). In LR1, the NNS decreased from 2815 (recommended search method) to 2600 (PALETTE) articles. At the same time, the number of relevant articles increased from 30 (recommended search method) to 42 (PALETTE). In LR2, the NNS decreased from 14746 (recommended search method) to 3550 (PALETTE) articles, and included the 20 studies that were identified by PALETTE. As a common step in the recommended search method, the search was developed further, resulting in 5153 NNS. Where the NNS had decreased, the number of relevant articles also decreased. Six relevant articles were missed out of the 20 relevant articles identified applying PALETTE.

DISCUSSION

Constructing relevant, focussed review questions in PC is a daunting task and requires an intricate knowledge of this field and all its actors. The same applies to the terminology used and the ability to identify all relevant studies. To address these issues and the shortcomings of the current literature review methodology, mainly developed for intervention studies, we present PALETTE as a pragmatic framework, which encompasses multiple retrieval methods applied in an iterative transparent way. Although the different techniques used within PALETTE have been around for some time, we provide a framework to use these in a transparent and coherent way with a clear decisional tree. As such, we provide guidance for researchers in the field of PC as well as in other specialties challenged by explorative questions, heterogeneity, and poorly defined keywords and concepts when conducting a review. Not every single technique will lead to a proportional number of relevant articles in every review; however, using PALETTE ensures a high likelihood of retrieving relevant articles with confidence.

The introduced iterative method results in four main positive aspects. Firstly, because of the more qualitative nature and the poorly defined concepts, review questions in PC need preliminary exploration. If not, researchers run the risk of missing a related concept not envisioned at the beginning. When applying the more iterative approaches such as berry picking and pearl growing solely[24,25], it is difficult to maintain transparency concerning relevant article identification and introduces the possibility of bias. By having a clear framework, such as PALETTE with the precise reporting of each step, we overcome this problem and provide the researchers with an opportunity to evaluate the process. This is in line with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines, which underline the importance of transparent reporting.[30] In addition, the PRISMA flowchart can be complementary to PALETTE. To illustrate, once the final search string has been developed, the steps in PALETTE (phase 4) are comparable with PRISMA and can be reported according to the PRISMA flowchart.

Secondly, as compared with the search building methods in intervention studies, PALETTE enables the research team to provide input on opinions and views, which in-turn enables them to explain what works for whom, in what contexts, and why in a transparent manner.[31,32] This is necessary for an in-depth understanding of the content of the topic in the still poorly defined field of PC.[33]

Thirdly, the total body of evidence in an article on PC is not well captured in terms. Therefore, validation is required on an article level. By checking the 'golden bullets', PALETTE grants this opportunity and validates the literature search on content and not just on the presence of keywords. This technique within PALETTE results in a representative set of articles.

Lastly, PALETTE might offer greater proportionality between the efforts of the researchers and the results of the literature search. When using a Boolean logic search query based on the initial review question and using every conceivable terminology on its own, some of which are quite ambiguous, huge amounts of results (10s of thousands) have to be screened manually and highly relevant citations are still missed.[34] The literature search in PALETTE is guided by the keywords and the content of studies that undoubtedly should be part of the review ('golden bullets') to find an optimal balance between specificity and sensitivity to keep the NNS manageable. This became apparent in the comparison between the recommended search method for reviews of intervention studies and PALETTE for LR1 and LR2 in which the NNS decreased for both LRs whereas the number of relevant articles increased with the application of PALETTE. Additionally, the kind of evidence researchers are often looking for when performing a review in PC aims to discover the variety of experiences or all opinions. Therefore, it is less critical in comparison with studies about a specific intervention when not all studies are identified. A view does not necessarily gain importance with the number of studies found.[22]

Four limitations of PALETTE should be considered when applying PALETTE. Firstly, regular feedback within the research team is necessary to fine-tune the review question and to keep focussed on the aim of the review. Secondly, care should be taken when compiling the 'golden bullets'. The 'golden bullets' should reflect the topic well from multiple angles so as to not introduce a skewed data set. By combining wisely chosen experts with the initial literature search and the expansion of articles, the risk of a skewed data set can be avoided. Thirdly, the benefit of the involvement of experts was limited in our examples. In the literature, different opinions regarding the involvement of experts are evident.[22,33] We argue that although time-consuming, the involvement of experts should remain a component of PALETTE. Especially because the involvement of experts could be valuable due to the experts' intricate knowledge of their topic and their ability to identify key articles (potential 'golden bullets'). The value of the involvement of experts could however depend on the content of the review. Finally, to ensure the quality of the iterative literature search, researchers should preferably collaborate with an information specialist. In such a collaboration, researchers can provide the information and specialist experience of clinical practice to explain concepts whereas the information specialist can contribute to the literature search with his/her knowledge about the most optimal way of retrieving data from the sources, including which software to use to optimise the literature search (Table 1). Therefore, the collaboration provides the ultimate opportunity to combine knowledge of practice and knowledge of software and techniques used during the literature search, as also stated by Beverly et al.[35]

Some strengths and limitations should be taken into account. PALETTE is a new approach that can be helpful in performing literature reviews in PC. However, we still have limited experience with the application of PALETTE and compared minimal results between PALETTE and the recommended search method. We, for instance, did not measure the costs in terms of time needed for each phase of PALETTE. Regarding the time needed, we know from previous research that an experienced reviewer can screen an average of two abstracts per minute, but abstracts for complex topics may take several minutes each to evaluate.[36] Given the decrease of NNS when using PALETTE, we hypothesise, that a significant amount of time will be saved in the sub-phase of 'identification eligible articles'. Knowing these strengths and limitations of this study, we encourage researchers to use PALETTE and to evaluate the time needed for and the value of this method.

CONCLUSIONS

We presented PALETTE, a transparent and coherent pragmatic framework to overcome the challenges of conducting a literature search for a review in PC. This guidance enables the researchers in a relatively young and developing specialty to maximise both sensitivity and precision in their search process. PALETTE helps to improve question development and increase the understanding of the topic of interest and the development of a literature search. Compared with the recommended search method, PALETTE provided greater balance between the NNS and identified relevant articles. Whilst our initial results with PALETTE are promising, more research would provide valuable data about the applicability of PALETTE within the field of PC.

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Chapter 5

Advance Care Planning: a systematic review about experiences of patients with a life-threatening or life-limiting illness

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ABSTRACT

Background: Advance care planning is seen as an important strategy to improve end-of-life communication and the quality of life of patients and their relatives. However, the frequency of advance care planning conversations in practice remains low. In-depth understanding of patients' experiences with advance care planning might provide clues to optimize its value to patients and improve implementation.

Aim: To synthesise and describe the research findings on the experiences with advance care planning of patients with a life-threatening or life-limiting illness.

Design: A systematic literature review, using an iterative search strategy. A thematic synthesis was conducted and was supported by NVivo 11.

Data sources: The search was performed in Medline, Embase, PsychINFO and CINAHL on 7 November 2016.

Results: Of the 3,555 articles found, 20 were included. We identified three themes in patients' experiences with advance care planning. 'Ambivalence' refers to patients simultaneously experiencing benefits from advance care planning as well as unpleasant feelings. 'Readiness' for advance care planning is a necessary prerequisite for taking up its benefits, but can also be promoted by the process of advance care planning itself. 'Openness' refers to patients' need to feel comfortable in being open about their preferences for future care towards relevant others.

Conclusions: Although participation in advance care planning can be accompanied by unpleasant feelings, many patients reported benefits of advance care planning as well. This suggests a need for advance care planning to be personalised in a form which is both feasible and relevant at moments suitable for the individual patient.

BACKGROUND

The growing interest in Advance Care Planning (ACP) has resulted in a variety of ACP interventions and programmess.[1] Most definitions of ACP incorporate sharing values and preferences for medical care between the patient and health care professionals (HCPs), often supplemented with input from and involvement of family or informal carers. Differences are seen in whether ACP focuses only on decision-making about future medical care or also incorporates decision-making for current medical care. Furthermore, there are different interpretations about for whom ACP is valuable, ranging from the general population towards a more narrow focus on patients at the end of their lives.[2-5] A well-established definition of ACP is presented in Box 1.[3]

Box 1. Definition ACP

"ACP refers to the whole process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders. This process can start at any time and be revisited periodically, but it becomes more focused as health status changes. Ideally, these conversations occur with a person's health care agent and primary clinician, along with other members of the clinical team; are recorded and updated as needed; and allow for flexible decision making in the context of the patient's current medical situation". [3]

ACP is widely viewed as an important strategy to improve end-of-life communication between patients and their HCPs and to reach concordance between preferred and delivered care.[6-8] Moreover, there is a high expectation that ACP will improve the quality of life of patients as well as their relatives as it might decrease concerns about the future.[1] Other potential benefits, which have been reported, are that ACP allows patients to maintain a sense of control, that patients experience peace of mind, and that ACP enables patients to talk about end-of-life topics with family and friends.[9-13]

Despite evidence on the positive effects of ACP, the frequency of ACP conversations between patients and HCPs remains low in clinical practice.[14-18] This can partly be explained by patient related barriers.[9,11,13,19,20] Patients, for instance, indicate a reluctance to participate in ACP conversations because they fear being confronted with their approaching death; they worry about unnecessarily burdening their families; and they feel unable to plan for the future.[9,11,13,19,20] In addition, starting ACP too early may provoke fear and distress.[21] However, current knowledge of barriers to ACP is initially derived from patients' responses to hypothetical scenarios or from studies in which it remains unclear whether patients really had participated in such a conversation.[9,11,13,15,19,20] More recent research has shifted towards studies on the experiences of patients who actually took part in an ACP conversation. These studies can give a more realistic perspective and a better understanding of the patients' position when having these conversations.

To our knowledge, there is only one review that summarises the perceptions of stakeholders involved in ACP and which includes some patients' experiences. However, this review is limited to oncology.[21] Given the fact that ACP may be of particular value for patients with a progressive disease due to the unpredictable but evident risk of deterioration and dying[2,22,23], this study focusses on the experiences of the broader population of patients with a life-threatening or life-limiting disease with ACP.

We aim to perform a systematic literature review to synthesise and describe the research findings concerning the experiences of patients with a life-threatening or life-limiting illness who participated in ACP. Our analysis provides an in-depth understanding of ACP from the patients' perspective and might provide clues to optimize its value to patients.

METHOD

Design

A systematic literature search was conducted, the analysis relying on the method of thematic synthesis in a systematic review.[24]

Search strategy

In collaboration with the Dutch Cochrane centre we used a recently developed approach that is particularly suited to systematically review the literature in fields that are challenged by heterogeneity in daily practice and poorly defined concepts and keywords, such as the field of palliative care.[25] The literature search strategy consisted of an iterative method. This method has, like all systematic reviews, three components: formulating the review question; performing the literature search; and selecting eligible articles. The literature search, however, consists of combining different information retrieval techniques such as contacting experts, a focused initial search, pearl growing[26,27], and citation tracking.[25,27] These techniques are repeated throughout the process and are interconnected through a recurrent process of validation with the use of so-called 'golden bullets'. 'Golden bullets' are articles that undoubtedly should be part of the review and are identified by the research team in the first phase of the search (phase question formulating). These 'golden bullets' are used to guide the development of the search string and to validate the search.

Firstly, we undertook an initial search in PubMed and asked an internationally composed set of experts, who are actively involved in research and practice of ACP (*n*=33) to provide articles that in their opinion, should be part of this review. These articles were used to refine the eligibility criteria. Based on these refined criteria, the 'golden bullets' (*n*=7)[28-34] were selected from the articles identified from the initial search and by the experts. Secondly, the analysis of words used in the title, abstract and index terms of the 'golden bullets' were used to improve the search string. A new search was then conducted. The validation of this search was carried out by identifying whether all the 'golden bullets' were retrieved in this search. Not all 'golden bullets' could be identified in the retrieved citations after this first search. Therefore, the search string was adjusted several times and the process of searching and validation was repeated until the validation test was successful. Once the validation test was successful, the final search was carried out on 7 November 2016 using four databases namely Medline (Ovid), Embase Classic & Embase, PsychINFO (Ovid) and CINAHL (EBSCOhost) (see Table 1 for search terms). Finally, the reference list of all included articles was cross referenced in order to identify additional relevant articles.

Inclusion and exclusion criteria

Papers were included based on the following inclusion criteria: the study must be an original empirical study; published in English; it must concern patients diagnosed with a life-threatening (illnesses for which curative treatment may be feasible but can fail)[35] or a life-limiting illness (illnesses for which there is no reasonable hope of cure)[36]; and report experiences of patients who actually participated in ACP. We considered an activity to be ACP when it concerned a conversation which at least aimed at clarifying patients' preferences, values and/or goals for future medical care and treatment. This conversation could have been conducted either by a HCP irrespective of whether they were involved in the regular care for that particular patient or by persons who are not directly related to the patients' care setting.

Studies reporting the experiences of multiple actors were excluded when the patients' experiences could not be clearly distinguished. Studies in which only a part of the respondents had participated in ACP were also excluded when their experiences could not be distinguished from those patients who did not participate in ACP. Because of the difficulty of assessing the level of competence of the respondents, it was decided to exclude studies focussing on children aged under 18 and patients with dementia or a psychiatric illness.

Search outcomes

We identified 3,555 unique papers. Two researchers (MZ, LJJ) independently selected studies eligible for review based on the title and abstract using the inclusion criteria. Thereafter, the full text of the remaining studies (*n*=80) was reviewed (MZ, LJJ). The researchers discussed any disagreements until they achieved consensus. Remaining disagreements were resolved in consultation with a third researcher (MCK). Finally, 20 articles were found to meet the inclusion criteria (Figure I). The web-based software platform Covidence supported the selection process.[37]

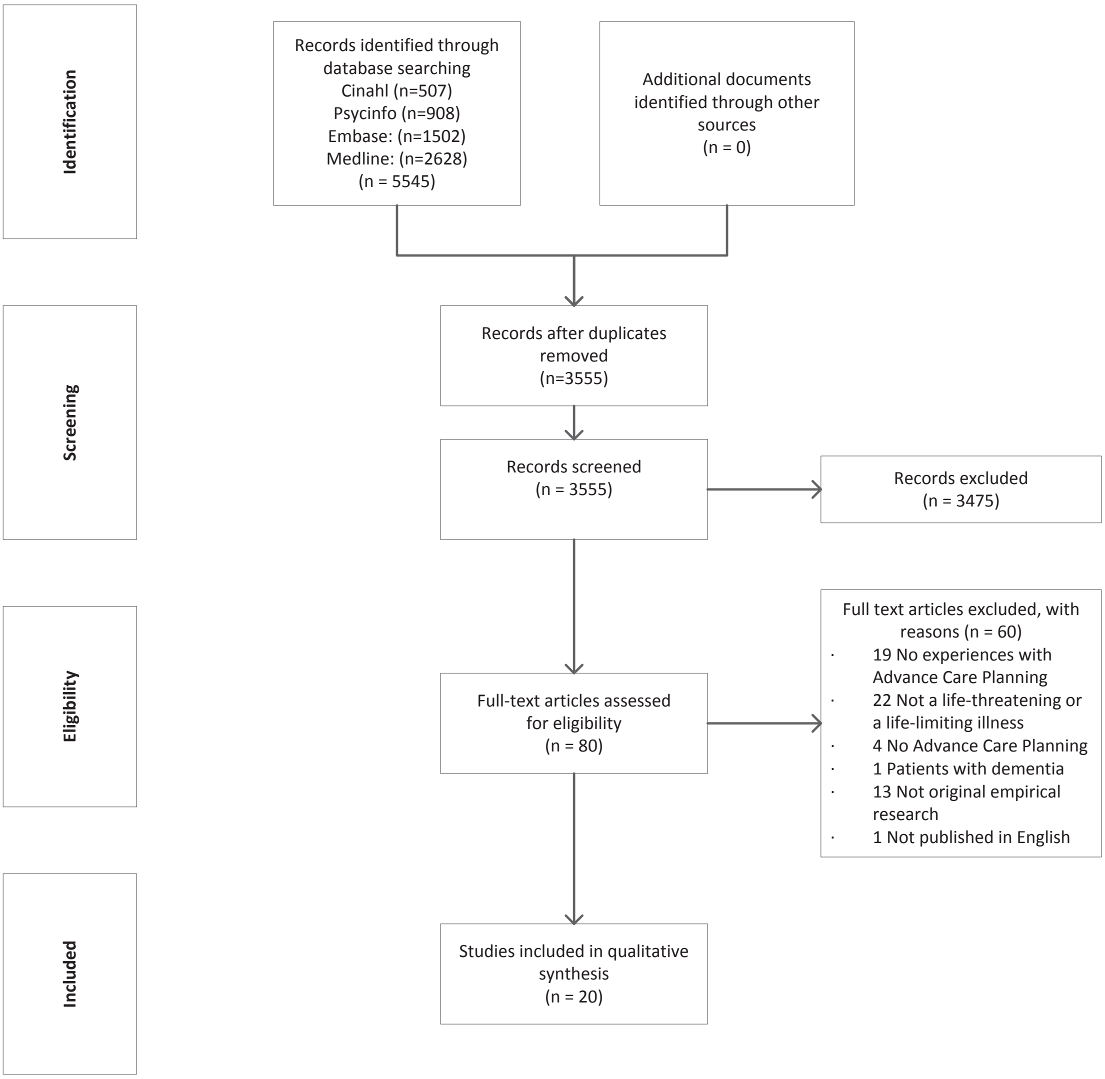
Quality assessment

The methodological quality of the qualitative studies was assessed using the Critical Appraisal Skills Programme (CASP) checklist[38], a commonly used tool in qualitative evidence syntheses.[39] The CASP checklist consists of ten questions covering the Aim, Methodology, Design, Recruitment strategy, Data collection, Relationship between researcher and participants, Ethical issues, Data analysis, Findings, and Value of the study.[38] A 'yes' was assigned when the criterion had been properly described (score 1), a 'no' when it was not described (score 0) and a 'can't tell' when the report was unclear or incomplete (score 0,5). Total scores were counted ranging from 0 to 10. We considered a score of at least 7 as indicating satisfying quality.

Table 1. Database search strategy

Database	Keywords
Medline (Ovid)	((qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or "participant observation" or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl* or "story telling" or (case adj (study or studies)) or "factor analysis" or "self-report").ti,ab,kf. OR (conversation adj2 analys*).ti,ab,kf. OR qualitative research/ or exp questionnaire/ or self report/ or health care survey/ or "nursing methodology research"/ or "Interviews as Topic"/) AND (exp advance care planning/ OR ((advance adj preferences) or "advance care planning" or advance directive* or living will* or end-of-life planning or (future care adj3 planning)).ti,ab,kf.)
Embase Classic & Embase	(qualitative or focus group$ or case stud$ or field stud$ or interview$ or questionnaire$ or survey$ or ethnograph$ or grounded theory or action research or "participant observation" or narrative$ or (life and (history or stor$)) or verbal interaction$ or discourse analysis or narrative analysis or social construct$ or purposive sampl$ or phenomenol$ or criterion sampl$ or "story telling" or (case adj (study or studies)) or "factor analysis" or "self-report" or (conversation adj2 analys*)).ti,ab,kw,hw. exp qualitative research/data collection method/ or exp interview/ or exp questionnaire/ health care survey/self-report/nursing methodology research/exp ethnography/discourse analysis/((advance adj preferences) or "advance care planning" or advance directive* or living will* or end-of-life planning or (future care adj3 planning)).ti,ab,kw,hw.
PsycINFO (Ovid)	(qualitative or focus group$ or case stud$ or field stud$ or interview$ or questionnaire$ or survey$ or ethnograph$ or grounded theory or action research or "participant observation" or narrative$ or (life and (history or stor$)) or verbal interaction$ or discourse analysis or narrative analysis or social construct$ or purposive sampl$ or phenomenol$ or criterion sampl$ or "story telling" or (case adj (study or studies)) or "factor analysis" or "self-report" or (conversation adj2 analys*)).ti,ab,id,hw. "Consumer Opinion & Attitude Testing".cw. exp Questionnaires/exp Self Report/exp Surveys/exp Ethnography/exp Grounded Theory/exp Phenomenology/qualitative research/ or exp interviews/ or observation methods/((advance adj preferences) or "advance care planning" or advance directive* or living will* or end-of-life planning or (future care adj3 planning)).ti,ab,hw,id.
Cinahl search (EBSCOhost)	SU((qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or "participant observation" or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl* or "story telling" or (case N1 (study or studies)) or "factor analysis" or "self-report") OR (conversation N2 analys*)) AB((qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or "participant observation" or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl* or "story telling" or (case N1 (study or studies)) or "factor analysis" or "self-report") OR (conversation N2 analys*)) TI((qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or "participant observation" or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl* or "story telling" or (case N1 (study or studies)) or "factor analysis" or "self-report") OR (conversation N2 analys*)) (MH "Qualitative Studies+")(MH "Clinical Assessment Tools+") OR (MH "Questionnaires+") OR (MH "Interview Guides+")(MH "Surveys")(MH "Interviews+")(MH "Self Report")(MH "Advance Care Planning") TI((advance adj preferences) or "advance care planning" or advance directive* or living will* or end-of-life planning or (future care N3 planning)) AB((advance adj preferences) or "advance care planning" or advance directive* or living will* or end-of-life planning or (future care N3 planning)) SU((advance adj preferences) or "advance care planning" or advance directive* or living will* or end-of-life planning or (future care N3 planning)) excluding medline records

Figure I. Flow diagram illustrating the inclusion of articles for this review.



The methodological quality of mixed-method studies was assessed using the multi-method assessment tool developed by Hawker et al.[40] This tool consists of nine categories; Abstract and title; Introduction and aims; Method and data; Sampling; Data analysis; Ethics and bias; Results; Transferability or generalizability; Implications. Each category was scored on a four-point scale, ranging from 1-4, resulting in a total score from nine (very poor) to 36 (good). We consider a score of at least 27 (= fair) as indicating satisfactory quality.

Two authors (MZ, LJJ) independently assessed all included articles. Discrepancies were encountered in 33 of the 190 items assessed with the CASP and in 3 of the 9 items assessed with the Hawker scale. These were resolved by discussion.

The mean score of the methodological quality of the qualitative studies [28-34,41-52], according to the CASP, was 8 out of 10 (range 6.5 – 9.5). Main issues concerned limitations describing ethical issues [30,33,34,41-45,47,49,51,52] and the lack of information concerning the relationship between researchers and respondents [28-30,32-34,41,42,44,46-50,52] (Table 2). The quality of the

Table 2. Quality assessment CASP

	Aim	Methodology	Design	Recruitment	Data collection	Relationship	Ethical	Data analysis	Finding	Values	Score
Abdul-Razzak et al.[28]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable	9
Almack et al. [29]	Yes	Yes	Yes	Yes	Can't tell	No	Yes	Can't tell	Yes	Valuable	8
Andreassen et al.[41]	Yes	Yes	Yes	Can't tell	Can't tell	No	Can't tell	Can't tell	Yes	Valuable	7
Bakitas et al.[42]	Yes	Yes	Yes	Can't tell	Can't tell	No	Can't tell	Yes	Yes	Valuable	7.5
Barness et al.[43]	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Valuable	8.5
Brown et al.[44]	Yes	Yes	Can't tell	Yes	Can't tell	No	Can't tell	Can't tell	Yes	Valuable	7
Burchardi et al.[45]	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Valuable	8.5
Burge et al.[30]	Yes	Yes	Yes	Can't tell	Can't tell	No	Can't tell	Yes	Yes	Valuable	7.5
Chen and Habermann [46]	Yes	Yes	Can't tell	Yes	Yes	No	No	Yes	Yes	Valuable	7.5
Epstein et al.[47]	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes	Valuable	8.5
Horne et al.[32]	Yes	Yes	Yes	Yes	Can't tell	No	Yes	Can't tell	Yes	Valuable	8
MacPherson et al.31)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Valuable	9.5
Martin et al.[34]	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes	Valuable	8.5
Metzger et al.[48]	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Can't tell	Yes	Valuable	8
Robinson, 2011 [49]	Yes	Yes	Can't tell	Can't tell	Can't tell	No	Can't tell	Can't tell	Yes	Valuable	6.5
Sanders et al.[50]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable	9
Simon et al.[51]	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Valuable	9
Simpson, 2011 [52]	Yes	Yes	Yes	Can't tell	Can't tell	No	Can't tell	No	Yes	Valuable	6.5
Singer et al.[33]	Yes	Yes	Yes	Yes	Can't tell	No	Can't tell	Yes	Yes	Valuable	8

mixed-method study [53] was 29 (out of 36) according to the scale of Hawker (Table 3).[40] Points were in particular lost in the categories 'method and data' and 'data analysis'.

The appraisal scores are meant to provide insight in the methodological quality of the included studies. They were not used to exclude articles from the systematic review because a qualitative article with a low score could still provide valuable insights and thus be highly relevant to the study aim.[54,55]

Table 3. Quality assessment Hawker

	Michael et al.[53]
Abstract and title	3
Introduction and aims	3
Method and data	3
Sampling	4
Data analysis	3
Ethics and bias	3
Results	3
Transferability or generalizability	4
Implications and usefulness	3
Total	29

Good; 4 points; Fair; 3 point; Poor; 2 points; Very poor 1 point

Data extraction and analysis

To achieve the aim of this systematic review, information was extracted on general study characteristics and the patients' experiences and responses (Table 4). To provide context and to facilitate the interpretation of the results, the number of patients refusing participation in the study and the number of drop outs were identified, as well as the underlying reasons. This process was undertaken and discussed by two authors (MZ, LJJ). Disagreements remained on three papers [28,31,46] and were resolved in discussion with a third author (MCK).

The thematic synthesis consisted of three stages.[24] By using the software program for qualitative analysis, NVivo 11, a transparent link between the text of the primary studies and the findings was created. Firstly, the relevant fragments, with respect to the focus of this systematic review, were identified and coded. Secondly, the initial codes were clustered into categories and the content of these clusters was described. Finally, the analytical themes were generated.[24] This analysis was performed by the first author (MZ) in collaboration with the last author (MCK).

Table 4. Extraction data form

Reference	Country	Aim	Method	Sample	Intervention/ setting	Data collection	Findings
Abdul-Razzak et al.[28]	CA	To understand patient perspectives on physician behaviours during EOL communication.	Qualitative study	Seriously ill hospitalized patients (cancer and non-cancer) with an estimated 6-12 month mortality risk of 50% (*n*=16)	Experiences with EOL communication in regular care, including ACP, in the moment decision-making and related information sharing processes.	Semi-structured face-to-face interviews	Two types of HCP behavior were felt to be beneficial during EOL communication. (1) 'Knowing me' relates to the importance of the family involvement during the EOL conversation by the HCP and the social relationship between the patient and the HCP. (2) 'Conditional candour', relates to the process of information sharing between the HCP and the patient including an assessment of the patients' readiness to participate in an EOL conversation.
Almack et al.[29]	UK	To explore the factors influencing if, when and how ACP takes place between HCP's, patients and family members from the perspectives of all parties involved and how such preferences are discussed and are recorded.	Qualitative study	Patients from palliative care register (cancer and non-cancer) and who were expected to die in the next year according to the HCP (*n*=18)	Experiences with ACP in regular care (focus on Preferred Place of Care tool).	Semi-structured face-to-face interviews	Nine out of 13 cancer patients had a degree of open awareness of which three patients had some preferences recorded in a written document. A few patients had initial conversations about future plans, but did not revisit these over time. When a HCP initiated an EOL conversation, patients wondered if they were close to dying. Patients who felt relatively better, were reluctant to participate in an ACP conversation.
Andreassen et al.[41]	DK	To explore nuances in long-term impact of ACP as experienced by patients and relatives.	Qualitative study	Patients with a life-limited disease (*n*=3) and relatives (*n*=7)	An ACP discussion in research context	Semi-structured face-to-face and phone interviews	ACP impacted patients and relatives in three ways. (1) Positive impact, such as better communication; awareness of dying and empowerment. (2) No impact, described as ACP being insignificant and not relevant yet. (3) Negative impact, less communication about the EOL.

Table 4. continued

Reference	Country	Aim	Method	Sample	Intervention/ setting	Data collection	Findings
Bakitas et al., [42]	USA	To elicit patient and caregiver participants' feedback on the clarity and overall usefulness of the commercially available PtDA when introduced soon after a new diagnosis of advanced cancer.	Qualitative study	Patients with an advanced solid tumor or hematological malignancy (prognosis between 6 and 24 months) (*n*=57 patients, *n*=20 caregivers)	Looking ahead: Choices for Medical Care When You're seriously Ill patient decision aid (PtDA).	Semi-structured phone interviews	Patients who participated in the programme 'Looking ahead' felt empowered, informed and 'in charge'. Patients needed to be ready to participate in this programme. Some patients had felt not ready before the start, but in hindsight mentioned that it was the right time. After the programme some patients started to talk with their healthcare proxy or their HCP.
Barness et al.[43]	UK	To inform the nature and timing of an ACP discussion intervention delivered by an independent trained mediator.	Qualitative study	Patients with clinically detectable, progressive disease (*n*=40)	An ACP intervention: ACP discussions with a trained planning mediator using a standardized topic guide. All patients received up to three sessions.	Verbatim transcripted audio-tapes of the face-to-face ACP intervention.	A third of the patients said the ACP discussion had been helpful and thought-provoking. Many patients found the information valuable and some found it challenging to think about dying. A few patients talked with their family about their future, some patients did not want to burden or upset their relatives and others were not yet ready to discuss this topic with family or the HCP. Over a third of the patients said their doctors were reluctant to introduce such topics.
Brown et al.[44]	AU	To explore issues relating to EOL decisions and ACP	Qualitative study	Patients with advance COPD (GOLD stage IV) (*n*=15)	Experiences in regular care with ADs and ACP in regular care.	Semi-structured face-to-face interviews	Two of the 15 patients had conversations with their HCP about CPR. One couple completed an AD and was well informed about future decision-making. Some patients talked with their family about their wishes and appointed a decision-maker. Others did not because of the feeling that the family would feel uncomfortable to make a decision.

Table 4. continued

Reference	Country	Aim	Method	Sample	Intervention/ setting	Data collection	Findings
Burchardi et al.[45]	DE	To investigate how neurologists provide information about LWs to ALS patients and to explore if their method of discussing it met the patients' needs and expectations.	Qualitative grounded theory study	ALS patients (*n*=15)	Experiences with LW in regular care.	Semi-structured face-to-face interviews	Six out of 15 ALS patients completed a LW, mostly after symptoms had worsened. Patients described ADs as important and necessary, but they also considered ADs as closely connected to forthcoming death. The patients preferred information given in a way that would minimise the anxiety. Some patients felt that a LW is contrary with the work of a HCPs. Family involvement was by some described as a process of discussion and coping, which led to completing a LW. Others only gave a copy of the LW.
Burge et al.[30]	AU	To evaluate the introduction of a structured ACP information session from the perspective of participants in PR&M programmes.	Qualitative study	Patients having chronic respiratory impairment, in PR&M (*n*=67).	A structured group ACP information session presented by two trained facilitators.	Semi-structured face-to-face Interviews	Seventeen patients described the PR&M programme as an appropriate place to receive information about ACP. Participants valued the received information and highlighted the importance of the educator. Twenty-four patients started to think about their personal decision-making and initiated a discussion with family members.
Chen and Habermann, 2013[46]	USA	To explore how couples living with advanced MS approach planning for future health changes together.	Qualitative study	Patients with advanced MS and their care-giver spouses (*n*=20)	Experiences with ACP among couples	Semi-structured face-to-face interviews	Three out of 10 couples with advanced MS had an AD or LW and communicated their wishes to their loved ones. These MS couples felt confident in knowing each other's wishes. Most couples had some thoughts about aspects of ACP, but had not a written AD. Expressed difficulties were to make a choice, communication and the hope for a cure.

Table 4. continued

Reference	Country	Aim	Method	Sample	Intervention/ setting	Data collection	Findings
Epstein et al.[47]	USA	To better understand the more general problem, and potential solutions to, barriers to communicate about EOL care.	Qualitative study	Patients with advanced hepatopancreaticobiliary cancers (*n*=54) (*n*=26 articulated questions or/and comments)	One-time educational video or narrative about CPR.	Face-to-face open interview following the intervention.	Video education was seen by patients as an appropriate means of starting an ACP conversation. ACP should start early because, it is better to discuss these topics when you are reasonably healthy. Patients found ACP sometimes difficult to discuss, but they considered it as important. The information was helpful and HCPs should be involved in ACP in order to realize life goals and to plan practically.
Horne et al.[32]	UK	To develop and pilot an ACP intervention for lung cancer nurses to use in discussing EOL preferences and choices for care with patients diagnosed with inoperable lung cancer.	Qualitative grounded theory study	Patients with inoperable lung cancer (*n*= 9) and their family members (*n*=6)	An ACP discussion with a trained lung cancer nurse using an ACP interview guide, an ACP record and an ACP checklist.	Semi-structured face-to-face Interviews	Most participants reported that they felt better after the ACP discussion. Nursing attributes enabled patients to talk about EOL issues. Some patients found it a 'personal thing' to discuss ACP with the nurse. Patients appreciated the information they received and accepted the recording of their preferences. These were shared with the HCP and sometimes with family.
MacPherson et al.[31]	UK	To answer whether people with COPD think that ACP could be a useful part of their care, and to explore their reasoning behind this view, as well as their thoughts about future and any discussions about future care that had taken place.	Qualitative grounded theory study	Patients with severe COPD (*n*=10) of these two respondents reported experiences with ACP	Experiences with ACP in regular care.	Semi-structured face-to-face interviews	2 out of 10 patients reported some discussion about future care. These discussions initially upset them. This was caused by being unfamiliar with ACP and the exploration of the patient's prognosis led the patient to think more about mortality. Patients felt uncomfortable documenting their wishes.

Table 4. continued

Reference	Country	Aim	Method	Sample	Intervention/ setting	Data collection	Findings
Martin et al.[34]	CA	To develop a conceptual model of ACP by examining the perspectives of individuals engaged in it.	Qualitative grounded theory study	Patients with HIV or AIDS (*n*=140)	An educational video with a generic Centre for bioethics LW or the disease-specific HIV LW or both ADs.	Semi-structured face-to-face Interviews	ACP was seen as confronting, but helpful. It helped patients to prepare to face death and helped them to confront and to accept the prospect of their death. Patients mentioned that they learned more about themselves and achieved feelings of "peace". Both ACP and an AD provided a language and framework that can help to organise patients' thoughts about their preferences for care, thus enabling a degree of control. ACP strengthened relationships with patients' loved ones.
Metzger et al.[48]	USA	To increase the understanding of patients' and surrogates' experiences of engaging in ACP discussions, specifically how and why these discussions may benefit patients with LVADs and their families.	Qualitative study	Patients with a LVAD (*n*=14) and their surrogates (*n*=14)	An ACP intervention: SPIRIT-HF	Semi-structured phone interviews	Three themes were identified. (1) Nearly all patients reported that sharing their Heart Failure stories was a positive and essential part of SPIRIT-HF. (2) SPIRIT-HF brought patients an increased peace of mind. It allowed patients to clarify their wishes which created a feeling of being more prepared for the future. (3) ACP discussions should be an individual approach, the best timing may vary.
Michael et al.[53]	AU	To assess the feasibility and acceptability of an ACP intervention.	Mixed methods study (Qualitative grounded theory study)	Patients with cancer stage III/IV (*n*=30)	A 5-step guided ACP intervention	Questionnaire and semi-structured face-to-face interviews	This ACP intervention may motivate participants to consider thoughts about their future health care. Many patients said that the intervention helped them to feel respected, heard, valued, empowered, and relieved. The intervention was both informative and distressing. Most patients welcomed the opportunity to involve their family during this conversation. A barrier to complete a written document was, e.g., not feeling ready.

Table 4. continued

Reference	Country	Aim	Method	Sample	Intervention/ setting	Data collection	Findings
Robinson, 2011[49]	CA	To explore the applicability and usefulness of a promising ACP intervention and examined the ACP process.	Qualitative study	Patients newly diagnosed with advanced lung cancer (*n*=18) and their loved one.	RC tool	Semi-structured face-to-face Interviews	The RC tool was addressed as difficult, but helpful. ACP is a family affair. Patients wanted to avoid burdening their family and they felt safe knowing that their wishes were clearly understood by a trusted loved one. ACP brought an enhanced sense of closeness. None of the patients had involved a HCP.
Sanders et al.[50]	UK	To examine the impact of incorporating the subject of planning for death and dying within self-management intervention.	Qualitative study	Patients with a long term health condition (*n*=31) and patients with HIV (*n*= 12)	Education group session about ACP within a much wider generic 'expert patient' course designed to teach people how to manage a long term health condition.	Semi-structured Interviews	A group educational session is a valuable form of social support. However, the session about LWs was disruptive and the introduction of the educational material was confrontational. One patient said it was traumatic, but relevant. Some patients thought that talking about LWs would be more acceptable for older people with chronic conditions or people with a terminal illness.
Simon et al.[51]	CA	To explore and understand what it is like to go through an ACP process as a patient.	Qualitative grounded theory study	Patients with end-stage renal disease who had completed a health region quality initiative, pilot project of facilitated ACP (*n*=6)	RC tool	Semi-structured face-to-face interviews	Patients addressed ACP as logical. One patient described an initial shock when being invited. One felt it was: "a positive thing: peace of mind" which contained three categories.(1) Witnessing an illness in oneself or in others and acknowledging mortality; (2) I don't want to live like that or to be a burden to oneself or others; and (3) the process. The awareness of the EOL allowed patients to participate in ACP, the workbook was viewed as central to discussions and the facilitator was seen as a paperwork reviewer. Some patients initiated a discussion with a HCP.

Table 4. continued

Reference	Country	Aim	Method	Sample	Intervention/ setting	Data collection	Findings
Simpson[52]	CA	To give insight in what is required for a meaningful, acceptable advance care planning in the context of advance COPD.	Qualitative research methodology	Patients with a primary diagnosis of COPD in an advance stage (n=8) and their informal caregivers (n=7)	Loosely structured conversations with the help of the brochure 'Patient and Family Education Document,: Let's Talk About ADs including an AD template.	An open interview	Despite the initial resistance of patients to participate in the ACP conversation positive outcomes of ACP occurred. ACP with a facilitator was an opportunity to learn about several factors. These included: the options for EOL care; considering or documenting EOL care preferences so the decision-maker would offer tangible guidance; countering the silence around the EOL through social interaction; and sharing concerns about their illness with the HCP.
Singer et al.[33]	CA	To examine the traditional academic assumptions by exploring ACP from the perspective of patients actively participating in the planning process.	Qualitative grounded theory study	Patients who are undergoing hemodialysis (n=48)	An educational video about ADs and patients receive an AD form.	Semi-structured face-to-face Interviews	Through the use of open communication, ACP is a helpful means of preparing for incapacity and death. Resulting in peace of mind. The awareness of life's frailty allowed patients to participate in ACP. ACP is based on autonomy, maintaining control and relieve of the burden on the loved ones. The result of ACP is not simply to complete an AD; the discussion about the patient's wishes is also meaningful in itself.

Abbreviations

ACP: Advance Care Planning; AD: Advance Directive; AIDS: acquired immunodeficiency syndrome; ALS: Amyotrophic Lateral Sclerosis; AU: Australia; CA: Canada; COPD: Chronic Obstructive Pulmonary Disease; CPR: Cardiopulmonary resuscitation; DE: Germany; DK; Denmark; EOL: end-of-life; GOLD: Global Initiative for Obstructive Lung Disease; HCP: Health Care Professional; HIV: Human immunodeficiency virus; PtDA: Patient Decision Aid; LVAD: a Left Ventricular Assist Devices; LW: Living Wills; MS: multiple sclerosis; PR&M: Pulmonary Rehabilitation and Maintenance; PtDA: Looking Ahead Patient Decision Aids; RC: Respecting Choices; SPIRIT-HF: 'Sharing the Patient's Illness Representations to Increase Trust in Heart Failure'; UK: United Kingdom

RESULTS

Study characteristics

Of the 20 articles selected,[28-34,41-53] 19 had a qualitative study design [28-34,41-52] and one a mixed-methods design.[53] All included studies were conducted in Western countries, mostly in Canada (*n*=6) (Table 4).[28,33,34,49,51,52] The studies included patients with cancer [28,29,32,42,43,47,49,53] as well as patients with other life-threatening or life-limiting illnesses (e.g. Chronic Obstructive Pulmonary Disease (COPD)[31,44,52], Human Immunodeficiency Virus (HIV)[34,50], Amyotrophic Lateral Sclerosis (ALS))[45] (Table 4).[28-31,33,34,41,43,44,46,48-52] Most studies reported the experiences of patients in an advanced stage of their illness.[28,29,32,41-44,46-49,51-53] A total of 14 studies reported patients' experiences with an ACP intervention in a research context,[30,32-34,41-43,47-53] the remaining six articles focused on ACP experiences in daily practice (Table 4).[28,29,31,44-46] The studies labelled the conversations as ACP conversations [29-34,41-53] (*n*=19) or as end-of-life conversations (*n*=1).[28]

Eight studies reported the number of refusals and/or the reasons why patients refused to participate in the study.[30,31,33,34,42,45,51,53] The total number of eligible patients in these eight studies was 579 of which 206 patients refused to participate. Patients refused for 'practical' reasons (*n*=44)[30,42] or felt too ill to participate (*n*=42).[33,34,53] Other reasons concerned logistics (e.g. could not be reached by phone) (*n*=42)[33,42,45,51,53] and some patients (*n*=25) died during the period of recruitment.[33,34,45] Eleven patients (5%) were reported to have refused because they felt not ready to participate or were too upset by the word "palliative".[31,53] The number of drop-out remained unclear. Three studies reported reasons for drop-out [29,33,41] showing that some patients were too disturbed by the topic to proceed with ACP.[33] One patient reported feeling better and was, therefore, reluctant to follow-up the end-of-life conversation.[29]

Synthesis of results

Three different, but closely related, main themes were identified which reflected the experiences of patients with ACP conversations namely: 'ambivalence', 'readiness' and 'openness'. Themes, subordinated themes and subthemes, are presented in Table 5. 'Ambivalence' was identified in 18 studies [28-34,41-43,45,47-53] and 'readiness' in 18 studies.[28-34,42-48,50-53] The theme 'openness' was found in all studies.

AMBIVALENCE

Several studies reported the patients' ambivalence when involved in ACP. From the invitation to participate in an ACP conversation to the completion of a written ACP document, patients simultaneously experienced positive as well as unpleasant feelings. Such ambivalence was identified as a key issue in five studies.[34,43,47,49,53] Irrespective of whether the illness was in advanced stage, patients reported ACP to be informative and helpful in the trajectory of

Table 5. Themes

Main theme	Subordinate theme	Subtheme
Ambivalence		
	Positive aspects	
		Receiving information
		Being in control
		Thinking about end of life
		Learning
		Confrontation
	Unpleasant feelings	
		It's not easy to talk about
		Confrontation
	Possible solution	
		Group session
Readiness		
	Being ready	
		Readiness is needed for ACP to be useful
	Not being ready	
		Invitation
		Resistance in advance
		In hindsight pleased
	Documentation	
	Timing of ACP	
		Assess readiness
Openness		
	Positive aspects	
		Relatives: Enables to become a surrogate decision-maker
		Relatives: Actively engage family in the ACP process
	Difficulties	
		Relatives: Feeling uncomfortable to be open
		HCP: Feeling uncomfortable to be open
	Overcoming difficulties	
		Attitude facilitator

ACP: advance care planning; HCP: healthcare professional.

their illness, while participation in ACP was also felt to be distressing and difficult.[47,49,53] *"It's not easy to talk about these things at all, but...information is power."* [43] Thirteen studies showed that patients who participated in ACP were positive about participation or felt it was necessary for them to participate in ACP also described negative experiences. However, the nature of these was not specified further.[28-33,41,42,45,48,50-52]

Positive aspects

Looking at why patients experienced ACP as positive, studies mentioned the information patients received during the ACP conversation and the way it was provided.[28,29,32,42,43,47,52,53] Information that made patients feel empowered was clear, tailored towards the individual patient's situation, and framed in such a way that patients felt it was delivered with compassion and with space for them to express accompanying feelings and emotions.[28,45] Another positive aspect of ACP was that it provided patients a feeling of control. This was derived from their increased ability to make informed healthcare decisions [28,32,47] and to undertake personal planning.[28,32,42] Patients also mentioned that the ACP process offered them an opportunity to think about the end of their life. This helped them to learn more about themselves and their situation, such as what kind of care they would prefer in the future. Additionally, participating in ACP made them feel respected and heard.[32-34,41-43,48,49,51-53] One patient summarised it by saying that ACP allowed him to feel that "everything was in place".[34]

Unpleasant feelings

Turning to the unpleasant feelings evoked during the process of ACP, these were often caused by the difficulty to talk about ACP, especially because of the confrontation with the end of life. Patients particularly experienced this confrontation at the moment of invitation and during the ACP conversation. Eleven studies[29,31,33,34,43,45,47,49-51,53], of which eight concerned an ACP intervention in a research context[33,34,43,47,49-51,53], reported that being invited and involved in ACP made patients realise that they were close to the end of their lives and this had forced them to face their imminent death.[29,31,33,34,43,45,47,49-51,53] Four of these studies found that this resulted in patients feeling disrupted.[31,33,50,53] In particular, an increased awareness of the seriousness of their illness and that the end-of-life could really occur to them, was distressing.[31,33,50,53] A notable finding was that some patients in five studies,[34,43,47,52,53] labelled the confrontation with their end-of-life as positive, because it had helped them to cope with their progressive illness.

Possible solution

In order to overcome, or to soften, the confrontation with their approaching death, some patients offered the solution of a more general preparation. These patients had received general information on ACP through participation in a group ACP session with trained facilitators.[30,50] They believed that the introduction of ACP in a more general group approach or by presenting it more as routine information was less directly linked with the message that they themselves had a life-threatening disease.[30,50] In addition, patients who participated in a group setting mentioned that questions from other patients had been helpful to them.[30] Particularly those that they had not thought of themselves, but of which the answers proved to be useful.[30]

Readiness

During our analysis we noticed how influential the patients' ability and willingness to face the life-threatening character of the disease and to think about future care was during this process. Patients, both in earlier and advanced stages of their disease, refer to this as their readiness to participate in an ACP conversation.[28,29,42,43,45,48,50,51,53]

Being ready

One study involving seriously ill patients looked at their preferences regarding the behaviour of the physician during end-of-life communication.[28] In response to their own ACP experience, several patients in this study suggested that an ACP conversation is only useful and beneficial when patients are ready for it.[28]

Not being ready

Of the patients in the studies which addressed 'readiness', some had not yet felt ready to discuss end-of-life topics at the moment they were invited for an ACP conversation.[29,31,42,43,45,50-53] This was true both for an ACP intervention in a research context or an ACP conversation in daily practice, irrespective of the stage of illness. These patients reported either an initial shock when first being invited [31,50,51] or their initial resistance to participate in an ACP conversation.[29,43,45,51-53] This was particularly true because of their being confronted with the life-threatening nature of their disease.[29,31,33,42,45,50-53] In addition, some patients were worried about the possible relationship between the process of ACP and their forthcoming death.[29,31,42,45,53] The patients in one study reported that introducing ACP at the wrong moment could both harm the patient's well-being and the relationship between the patient and the HCP.[28]

In spite of the initial resistance of some patients to participate in an ACP conversation, most patients completed the conversation and in hindsight felt pleased about it.[42,43,50-53] In two studies, a few patients felt too distressed by the topic and, as a consequence, had not continued the ACP conversation.[29,33]

Documentation

In nine studies patients' experiences in writing down their values and choices for future medical care were reported.[32-34,44-46,51-53] Patients who participated in an ACP conversation and did not write a document about their wishes and preferences did not do so because they felt uncomfortable about completing such a document.[45,51,53] This was particularly due to their sense of not feeling ready to do so.[45,51,53] In addition, they mentioned their difficulty with planning their care ahead and their need for more information. Some patients felt reluctant to complete a document about their wishes and preferences due to their uncertainty about the stability of their end-of-life preferences in combination with their fear of no longer having an opportunity to change these.[31,45,51,53] However, the patients who completed a document indicated it as a helpful way to organise their thoughts and experienced it as a means of protecting their autonomy.[32-34,44-46,51,52] In a study about the experiences of ALS patients with a living will, a few said that they had waited until they felt ready to complete their living will. This occurred when they had accepted the hopelessness of the disease or when they experienced increasingly severe symptoms.[45]

Timing of ACP

In addition, in three studies investigating patients' experiences with an ACP intervention in a research context, patients emphasised that an ACP conversation should take place sooner rather than later.[42,47,51] In a study among cancer patients about a video intervention as part of ACP, patients mentioned that "It is better to deal with these things when you are reasonably healthy".[47] In two studies, patients suggested that it would be desirable to assess the patient's readiness for an ACP conversation by just asking patients how much information they would like to receive.[28,48]

OPENNESS

In all included studies, it appeared that besides sharing information with their HCP or the facilitator who conducted the ACP conversation, patients were also stimulated to share personal information and thoughts with relatives, friends or informal carers.[28-34,41-53] 'Openness' in the context of ACP refers to the degree to which patients are willing to or feel comfortable about sharing their health status and personal information, including their values and preferences for future care, with relevant others.

Positive aspects

Some patients, including a number who were not yet in an advanced stage of the illness, positively valued being open towards the HCP about their options and wishes. An open dialogue enabled them to ask questions related to ACP and to plan for both current and future medical care.[28,29,32,44,45,47,51] Openness towards relatives was also labelled as positive by many patients.[28,30,33,34,42-44,46,48,49,52,53] Patients appreciated the relatives' awareness of their wishes and preferences, which enabled them to adopt the role of surrogate decision-maker in future, should the patient become too ill to do so his or herself.[28,30,33,34,42-44,46,48,49,52,53] Most patients thought their openness would reduce the burden on their loved ones.[28,33,34,46,47,49,51,52] In two studies, patients described a discussion with family members that led to the completion of the patients' living wills.[45,53] Because of these positive aspects of involving a relative in the ACP process, some patients emphasised that the facilitator should encourage patients to involve relatives in the ACP process and to discuss their preferences and wishes openly.[28,43]

Difficulties

On the other hand, openness did not always occur. Eight studies reported patients' difficulties being open about their wishes and preferences towards others.[32,33,41,43-45,49,53] Some patients had felt uncomfortable about discussing ACP with their HCP because they considered their wishes and preferences to be personal.[32,33,49] Others felt that an ACP conversation concerned refusing treatment and, as such, was in conflict with the work of a doctor.[43,45]

The difficulties reported about involving relatives derived from patients' discomfort in being open about their thoughts.[32,33,44,53] Some patients consciously decided not to share these. For instance, patients felt the family would not listen or did not want to cause them upset.[32,33,43,44] The ACP conversation did occasionally expose family tensions such as feelings of being disrespected or about the conflicting views and wishes of those involved.[41,53]

Overcoming difficulties

According to the patients, the facilitator who conducted the ACP conversation had the opportunity to support patients to overcome some of these difficulties.[28,30,32,48,52] Patients highlighted that when the facilitator showed a degree of informality towards the patient during the conversation, was supportive and sensitive - which in this context meant addressing difficult issues without 'going too far' - they felt comfortable and respected.[28,30,32,48] This enabled them to be open about their wishes and thoughts.[28,30,32,48]

DISCUSSION

Main findings

This systematic review of research findings relating to the actual experiences with ACP of patients with a life-threatening or life-limiting illness shows that 'ambivalence', 'readiness' and 'openness' play an important role in the willingness and ability to participate in ACP. Previous studies involving hypothetical scenarios for ACP indicate that it can have both positive and negative aspects for patients.[9,11,13,19,20] This systematic review now takes this further showing that individual patients can experience these positive and unpleasant feelings simultaneously throughout the whole ACP process. However, aspects of the ACP conversation that initially are felt to be unpleasant can later be evaluated as helpful. Albeit that patients need to feel some readiness to start with ACP, this systematic review shows that the ACP process itself can have a positive influence upon the patient's readiness. Finally, consistent with the literature concerning perceptions of ACP[9,11,13,19,20], sharing thoughts with other people of significance to the patient was found to be helpful. However, this systematic review reveals that openness is also challenging and patients need to feel comfortable in order to be open when discussing their goals and plans for future care with those around them.

What this study adds

All three identified themes hold challenges for patients during the ACP process. Patients can appraise these challenges as unpleasant and this might evoke distress.[56-58] For example, the confrontation with being seriously ill and/or facing death, which comes along with the invitation and participation in an ACP conversation, can be a major source of stress. In addition, stress factors such as sharing personal information and wishes with significant others or, fearing the consequences of written documents which they feel they may not be able to change at a later date, may also occur later in the ACP process. All these stress factors pose challenges to coping throughout the ACP process.

The fact that the process of ACP in itself may help patients to discuss end-of-life issues more readily, might be related to aspects of the ACP process which patients experience as being meaningful to their specific situation. It is known from the literature on coping with stress that situational meaning influences appraisal thereby diminishing the distress.[58] Participation in the ACP process suggests that several perceived stress factors can be overcome by the patient. Although ACP probably does not take away the stress of death and dying, participation in ACP, as our results show, may bring patients new insights, a feeling of control, a comforting or trusting relationship with a relative, or other experiences that are meaningful to them.

Patients use a variety of coping strategies to respond to their life-threatening or life-limiting illness and, since coping is a highly dynamic and individual process, the degree to which patients' cope with stress can fluctuate during their illness.[59-61]

ACP takes place within this context. Whereas from the patients' perspective ACP may be helpful, HCPs should take each individual patients' barriers and coping styles into account to help them pass through the difficult aspects of ACP in order to experience ACP as meaningful and helpful to their individual situation.

The findings of this systematic review suggest that the uptake and experience of ACP may be improved through the adoption of a personalised approach, reflectively tailored to the individual patient's needs, concerns and coping strategies.

While it is widely considered to be desirable that all patients approaching the end of life should be offered the opportunity to engage in the process of ACP, a strong theme of this systematic review is the need for 'readiness' and the variability both in personal responses to ACP and the point in each personal trajectory that patients may be receptive to such an offer. Judging patients' readiness', as a regular part of care, is clearly a key skill for HCPs to cultivate in successfully engaging patients in ACP. An aspect of judging patients' 'readiness' is being sensitive to patients' oscillation between being receptive to ACP and then wishing to block this out. Some patients may never wish to confront their imminent mortality. However, it is evident that ACP may be of great value, even for patients who were initially reluctant to engage, or who found the experience distressing. Therefore, HCPs could provide information about the value of participation in ACP given the patient's individual situation.

If patients remain unaware of ACP, they are denied the opportunity to benefit. Consequently, it is important that information about the various ACP options should be readily available in a variety of formats in each local setting. Given the challenges of ACP and the patient's need to feel comfortable in sharing and discussing their preferences, HCPs should be sensitive , and willing to openly discuss the difficulties involved.

Several additional strategies can be helpful. First, ACP interventions can include a variety of activities, for example choosing a surrogate decision-maker, having the opportunity to reflect on goals, values and beliefs, or to document one's wishes. Separate aspects can be more or less relevant for patients at different times. Therefore, HCPs could monitor patients' willingness to participate in ACP throughout their illness, before starting a conversation about ACP or discussing any aspect of it. Second, the option of participating in a group ACP intervention could be a helpful means of introducing the topic in a more 'hypothetical' and non-threatening way, especially for patients who are reluctant to participate in an individual ACP conversation. An initial group discussion could lower the barriers to subsequently introducing and discussing personal ACP with the HCP.[30,50]

The reality remains that discussing ACP with patients requires initiative and effort from HCPs. Even skilled staff in specialist palliative care roles experience reluctance to broach the topic and difficulty in judging how and when to do so.[29,62,63] Therefore, it is important that HCPs are provided with adequate knowledge and training about all aspects of ACP (e.g. appointment of proxy decision makers as well as techniques for sensitive discussion of difficult topics). It may be helpful for HCPs to have access to different practical tools or ACP interventions which they can use in the care of patients during their end-of-life trajectory. For example, an interview guide with questions that have been established to be helpful could offer guidance to HCPs when asking potentially difficult questions. For that reason, it is important for future research to study the benefits of (different aspects of) ACP interventions in order to improve the care and decision-making processes of patients with a life-threatening or life-limiting illness.

Limitations of the study

Some limitations of this systematic review should be taken into account. First, the articles included were research studies offering an ACP intervention in a research context or studies evaluating daily practice with ACP. It is likely that the patients included here were self-selected for participation in these studies because they felt ready to discuss ACP. This would represent a selection bias, influencing patients' experiences with ACP positively. However, from the studies that reported patients' refusals to participate, we learnt that part of the patients felt initial resistance to ACP and a small number of patients refused participation because they felt not ready. Second, our search was limited to articles published in English.

CONCLUSION

This systematic review of the evidence of patients' experiences of ACP showed that patients' 'ambivalence', 'readiness' and 'openness' play an important role in their willingness and ability of patients to participate in an ACP conversation. We recommend the development of a more personalised ACP, an approach which is reflectively tailored to the individual patient's needs, concerns and coping strategies. Future research should provide insight into the potential for ACP interventions in order to benefit the patient's experience of end–of-life care.

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Chapter 6

Trained Facilitators' Experiences with Advance Care Planning Conversations in Oncology: An International Focus Group Study within the ACTION trial

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ABSTRACT

Background: In oncology, Health Care Professionals experience conducting Advance Care Planning (ACP) conversations often as difficult and are hesitant to start them. A structured approach by trained facilitators could help to overcome this. In the ACTION trial, a Phase III multi-center cluster-randomized clinical trial in six European countries (Belgium, Denmark, Italy, the Netherlands, Slovenia, United Kingdom), patients with advanced lung or colorectal cancer are invited to have one or two structured ACP conversations with a trained facilitator. It is unclear how trained facilitators experience conducting structured ACP conversations.

Aim: To understand how facilitators experience delivering the ACTION Respecting Choices (RC) ACP conversation.

Methods: A qualitative study involving focus groups with RC facilitators. Focus group interviews were recorded, transcribed, anonymized, translated into English, and thematically analysed, supported by NVivo 11. The international research team was involved in data analysis from initial coding and discussion towards final themes.

Results: Seven focus groups were conducted, involving 28 of in total 39 trained facilitators, with different professional backgrounds from all participating countries. Alongside some cultural differences, six themes were identified. These reflect that most facilitators welcomed the opportunity to participate in the ACTION trial, seeing it as a means of learning new skills in an important area. The RC script was seen as supportive to ask questions, including those perceived as difficult to ask, but was also experienced as a barrier to a spontaneous conversation. Facilitators noticed that most patients were positive about their ACTION RC ACP conversation, which had prompted them to become aware of their wishes and to share these with others. The facilitators observed that it took patients substantial effort to have these conversations. In response, facilitators took responsibility for enabling patients to experience a conversation from which they could benefit. Facilitators emphasized the need for training, support and advanced communication skills to be able to work with the script.

Conclusions: Facilitators experienced benefits and challenges in conducting scripted ACP conversations. They mentioned the importance of being skilled and experienced in carrying out ACP conversations in order to be able to explore the patients' preferences while staying attuned to patients' needs.

Trial registration: ISRCTN63110516

BACKGROUND

Advance Care Planning (ACP) is a process of conversations with patients about their values, goals and preferences for future medical treatment and care and has the potential to improve the quality of end of life care.[1-3]

Previous studies report that, due to a lack of knowledge and experience in how to initiate and facilitate ACP conversations, many health care professionals (HCPs) have difficulty conducting ACP conversations.[4-10] The fear of harming the patient's coping strategies or damaging their professional relationship with the patient are also important barriers to HCPs initiating an ACP conversation.[4-8,10] A structured approach and delivery by trained facilitators could be strategies to overcome these barriers, thus facilitating ACP in clinical practice.[11,12] However, it has not been investigated yet how trained facilitators experience the use of a structured approach and whether this could, in their view, resolve some of the reported barriers to carrying out ACP conversations.

Currently, there are many different approaches to carrying out ACP in different settings.[1] One of the most well-known ACP programmes is the Respecting Choices (RC) ACP programme.[13,14] Since its initiation in 1993 in the USA, the RC ACP programme has developed towards a structured and widely used programme, particularly in the USA.[15-17] An adapted version of the RC ACP programme is being tested in the ACTION trial.[18] The ACTION trial is a Phase III multi-centre cluster-randomised clinical trial which is being carried out in six European countries (Belgium (BE), Denmark (DK), Italy (IT), the Netherlands (NL), Slovenia (SI) and the United Kingdom (UK)) (see supplementary material 1.). The ACTION RC ACP intervention involves one or two scripted conversations between an ACTION RC ACP trained facilitator, the patient (advanced lung- or colorectal cancer patients) and, if the patient wishes, a person nominated as their personal representative (PR). The facilitators assist patients during the ACTION ACP RC conversations in exploring their understanding of their illness, reflecting on their goals, values and beliefs, and to consider their future treatment preferences and decisions. Facilitators also inform patients about the opportunity to document their preferences for (future) medical treatment and care in the so-called My Preferences form (see supplementary material 2 and 4.).[18]

This paper presents findings from a qualitative study which was part of the ACTION trial. The study aimed at exploring the ACTION RC facilitators experiences with carrying out the structured RC ACP conversations with patients and their relatives and whether this could overcome barriers to conduct an ACP conversation.

METHOD

Research Design

To get insight into the ACTION RC ACP facilitators' experiences, focus groups were performed in each of the participating countries and thematically analysed.[19] The study is reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) Guidelines.[20]

Participants

Facilitators were eligible for participation in the focus group if they had undertaken an ACTION RC ACP conversation with at least three patients, to ensure that the participating facilitators had gained some experience with the delivery of the ACTION RC ACP conversations. Eligible facilitators were invited by email.

Table 1. Facilitator focus group aide memoire

Main topics	Prompts
Understanding of ACP before ACTION	
	What was your experience of ACP before the ACTION trial?
Experience of ACTION and RC ACP intervention	
	What were your initial thoughts about the ACTION RC ACP intervention?
Experience of RC ACP intervention training	
	- How would you assess the training you received about the ACTION RC ACP intervention and how to discuss this with patients? - How helpful was the training in enabling you to feel confident about delivering the ACTION RC ACP intervention?
Experience of delivering the ACTION RC ACP conversations	
	- Can you tell us about your experience of delivering the ACTION RC ACP intervention? Was having a standard script helpful/unhelpful? - How did you feel about the support you received? - How did patients and Personal representatives respond? - Will you/have you used the RC approach, or aspects of it, in your normal practice (outside the ACTION trial)? - Were there any things you found difficult or challenging? - Do you think patients found it helpful or distressing?

Data Collection

In the summer of 2016 we conducted one focus group in each participating country. Each focus group lasted approximately 1.5 hours, and was carried out in a private room in the hospital where the facilitators worked. Personal background information was collected before the start of the focus group. An aide memoire, consisting of open-ended questions and a set of prompts for each question, was used to guide the focus groups. This aide memoire, based on literature and expert knowledge of the multidisciplinary international ACTION research team, covered four main topics: (1) prior experience with conducting ACP conversations, (2) prior thoughts about the ACTION RC ACP intervention, (3) experiences with the ACTION RC ACP training and (4) experiences with conducting the ACTION RC ACP conversations (Table 1). All focus groups were moderated and observed by one or two male and female researchers involved in the ACTION trial with a background either in health science, psychology, psychiatry, anthropology or nursing. They ensured that all predefined topics were discussed and made field notes during the focus group. Some moderators knew the participants before the start of the focus group. All focus groups were recorded and transcribed verbatim.

Data Analysis

The thematic analysis was based on the stepwise approach of the Qualitative Analysis Guide of Leuven (QUAGOL).[19] This guide was adjusted by the international qualitative research team (MZ, MK, AT, FB, GM, GC, KP) to accommodate the international scope of this study. A detailed description of the steps taken is visualised in Figure 1.

During the first stage, the transcriptions were anonymized, translated into English and uploaded to NVivo 11. In stage two, each member of the international qualitative research team wrote a summary of the key storylines of all focus group interviews. Based on these summaries, a preliminary coding framework including a description of the content of each code was developed (MZ). The members of the qualitative research team tested and developed the coding framework by independently coding the same focus group transcript. The team discussed the coded transcripts during several meetings until arriving at a consensus on definitions and application of codes and sub codes (Table 2).

The first researcher (MZ) coded all transcripts in the third stage. To ensure the validity of the coding process, each transcript was also independently coded by a second researcher of the qualitative research team. After each coded transcript, discrepancies regarding coding were solved during telephone meetings and the content of the transcript was discussed. Subsequently, codes were categorised and themes were identified. This process was supported by the development of mind maps (MZ, MK) and validated by the qualitative research team. Saturation was achieved, meaning that the analysis of the last two focus group interviews did not uncover ideas that could not be assigned to already existing themes.[21]

In stage four, all researchers who had attended one of the focus groups checked and approved the identified themes.

In the final stage, relevant quotes to illustrate the identified themes were extracted by MZ and approved by the qualitative research team.

Figure 1. Process data analysis

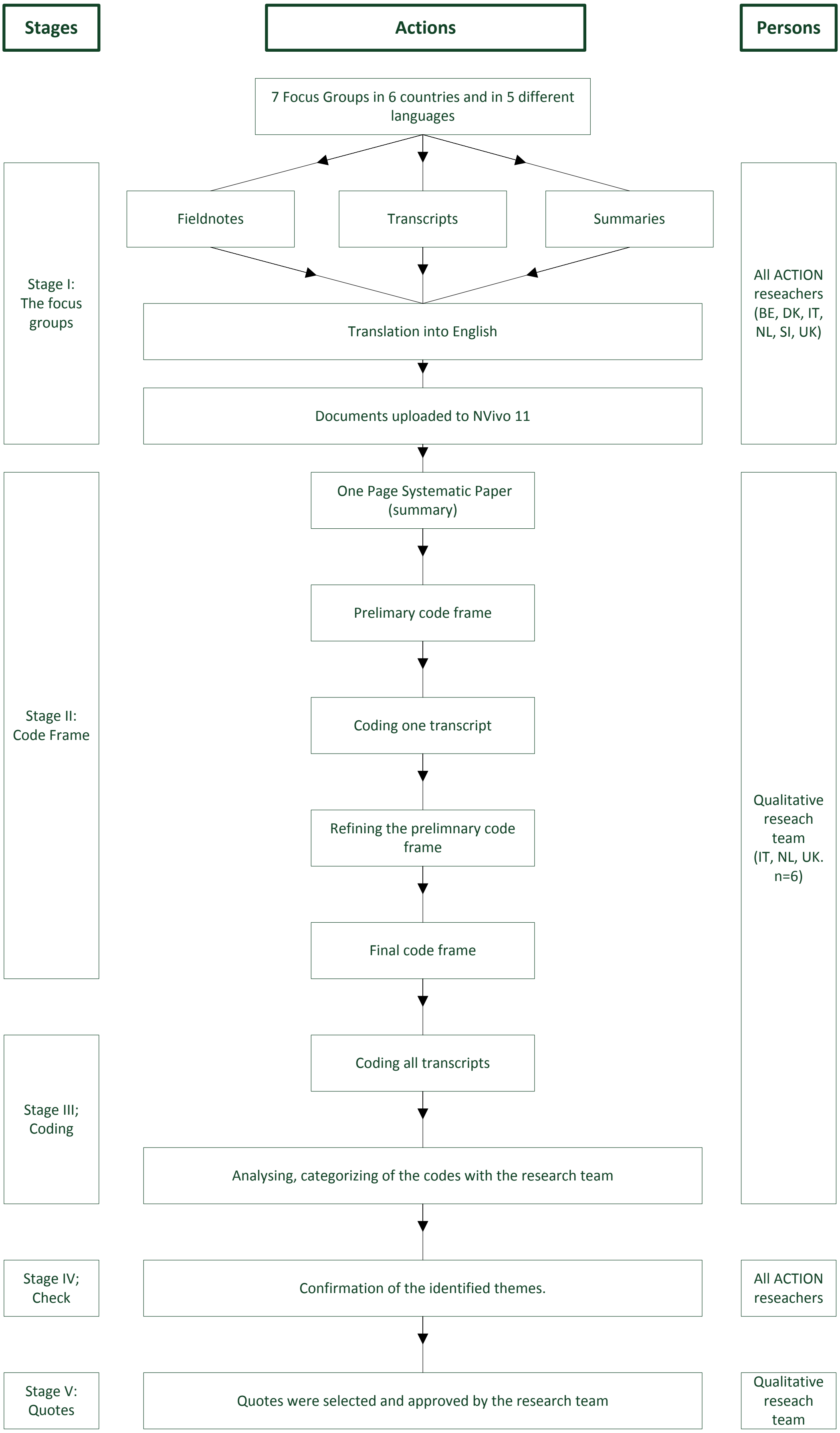

Table 2. Coding framework

Main codes	Subcodes
Prior experiences with ACP	
Thoughts about ACTION	
Reasons to participate in ACTION	
Becoming a facilitator	The RC training Support during the study Learning by doing Personal and professional growth Becoming aware of RC
Cultural issues	During the training During the conversations
Aspects RC	Structure Script_positive Script_helpful questions Script_negative Script_difficult questions Script_lay-out My preferences form
Preconditions RC	Timing Place of the conversation
Being a facilitator	Needed skills Dual role facilitator Be involved in the regular care Not involved in the regular care Out of their comfort zone Workload Uncertainty Responsibility
Impressions concerning patients	Reasons for patients to participate Investment Preparation Difficulties Patients responses The fit between RC and the patient
Personal representative	Awareness of their role Influence on the conversation
The value of ACTION RC ACP conversations	Opportunity to reflect and talk Empowerment of patients Quality of life Relationship patient-facilitator Communication patient-PR Patients undertake actions Have the time to conduct an ACP conversation Helpful
Impact on current practice	Using the intervention Managing study and daily practice
ACP in the future	Fit RC intervention to patients Setting Script Part of routine job Risks for the future Improvements Implementation of the intervention
Being part of a research	The feeling of being watched by the researcher Wanted to do it right Patients should benefit from it Use as an excuse to the questions they ask

Ethical Consideration

Ethical approval for the ACTION trial, including the qualitative work package, was obtained from the locally responsible Research Ethics Committees in all countries and institutions. Written informed consent was obtained from all participating facilitators.

RESULTS

Participant demographics

We conducted seven facilitator focus groups in six participating countries (for logistic reasons Dutch facilitators were split into two focus groups). Of the 39 facilitators involved in the ACTION trial, 28 participated in the focus group interviews. One facilitator (SI) had conducted only one conversation and was erroneously included (Table 3). In total, eleven facilitators were excluded, mainly because they performed less than three ACTION RC ACP conversations (*n*=8). The included facilitators had conducted ACTION RC ACP conversations with six patients on average, ranging from one to 14 patients.

Most facilitators were female (*n*=24), HCP (*n*=22), mostly a nurse (*n*=18) and 18 facilitators had during their career participated in a palliative care course. Thirteen of the 22 HCP-facilitators were involved in clinical care for patients to whom they had delivered the ACTION RC ACP conversations (Table 3 and Table 4). For each citation below it is indicated whether the facilitator was involved in the care for the patient or not.

Table 3. Facilitators per country

Country	Number of trained facilitators within the ACTION trial	Respondents n (%)	Reasons to not included	The number of respondents involved in the clinical care for some of the patient's n (%)
BE	10	4 (40%)	n= 5: performed less than 3 ACTION RC ACP conversations n= 1: not able to participate in the FG	1 (25%)
DK	4	4 (100%)	n.a.	3 (75%)
IT	7	4 (57,1%)	n=3: performed less than 3 ACTION RC ACP conversations	4 (100%)
NL	8	7 (87,5%)	n= 1: Logistic reasons (time and availably)	5 (71,4%)
SI	5	5 (100%)	n.a.	0 (0%)
UK	5	4 (87,5%)	n=1: Logistic reasons (time and availably)	0 (0%)
Total	**39**	**28 (71,8%)**		**13 (46,4%)**

Table 4. Facilitator background information

		Facilitator n (%) or mean (range) n=28
Age		
		44 years (28 – 58)
Gender		
	Male	4 (14.3%)
	Female	24 (85.7%)
Highest educational qualification		
	Doctoral or equivalent	4 (14.3%)
	Master degree or equivalent	9 (32.1%)
	University degree or equivalent	8 (28.6%)
	Post-secondary, non-tertiary	6 (17.9%)
	Not elsewhere classified; finishing a master degree	1 (3.6%)
Education: palliative care course		
	Yes	18 (64.3%)
	no	10 (35.7%)
Current professional role		
Health Care professional		**22 (78.6%)**
	Nurse	8 (28.6%)
	Nurse coordinator	1 (3.6%)
	Nurse specialist (in training)	9 (32.1%)
	Oncologist	1 (3.6%)
	Social worker	1 (3.6%)
	Clinical psychologist	2 (7.2%)
No Health Care professional		**6 (21.4%)**
	Researcher	3 (10.7%)
	Senior consultant	1 (3.6%)
	Lead hospital unit	2 (7.2%)
Involvement in the care for ACTION patients		
	Yes	8 (28.6%)
	For some patients	5 (17.9%)
	No	15 (53.6%)
Work experience		
		20.2 years (4 – 36)

Themes

From the experiences of facilitators delivering the ACTION RC ACP conversations six themes could be identified; (1) A welcomed opportunity, but challenging, (2) Experiences with using the script, (3) Helpful and difficult, (4) Feeling uncertain and responsible, (5) Learning process, and (6) Thoughts about implementation. Below we will describe these themes in detail.

A welcomed opportunity, but challenging

The facilitators' experiences with ACP, prior to their participation in the ACTION trial, were diverse. Four facilitators appeared to be skilled and clinically experienced in a more comprehensive type of ACP conversations, the so-called 'family conversations'. Three facilitators were familiar with the concept of ACP, but had no clinical experience with it. However, the majority of facilitators (*n*=21) were involved in clinical practice and were used to discuss particular aspects of ACP, such as the preferred place of care, cardiopulmonary resuscitation or palliative sedation. Most described discussing these topics in an ad hoc and unstructured manner, usually in response to patient cues and fine-tuned to the patient's coping style. Consequently, if these topics are discussed, this usually occurs in an advanced stage of illness.

Based on clinical experience and their understanding of ACP, many facilitators had a positive disposition towards ACP. They believed that ACP conversations are a suitable answer to the needs they perceive among patients with advanced cancer.

> *'I personally think that it is a very important thing [ACP] and I am very aware of its importance, working with our patients. Being able to speak about how to deal with care and also the end, in essence, of life, is a fundamental aspect'* (IT, HCP, involved).

In anticipation of their participation in the ACTION study, most facilitators welcomed the opportunity to become a facilitator. They considered participation in the ACTION trial to be an opportunity to learn new skills. They expected that the ACTION trial could contribute to the normalisation of ACP as a routine part of care and could support them to discuss difficult topics.

Besides the positive stance towards becoming a facilitator, some challenges were anticipated. The majority of the facilitators expected the conversations to be difficult. In particular, facilitators without medical expertise feared being confronted with medical questions. Others thought that working with a script would require great changes to their normal ways of communicating with patients, and as such would be demanding. Lastly, some facilitators had doubts about the appropriateness of the ACTION ACP RC conversations for some of the patients, because the treatment of lung cancer stage 3a and 3b is often aimed to be curative.

> *'I had this feeling [of wrong timing] in advance, I thought: then we are going to say to those people [patients with lung cancer stage 3a and 3b] that we will give a treatment aimed at cure, and then we come up with this ACTION study'* (NL, HCP, involved).

Experiences with using the script

In the ACTION trial, facilitators had dedicated time to schedule ACTION appointments with patients and were asked to carry out the RC ACP conversations according to a script. Facilitators who positively valued the scripted approach mentioned that it enabled them to conduct ACP in a more structured and comprehensive manner than they were used to. The script also offered support in which topics could be addressed in ACP and helped them to ask questions they perceived to be difficult for patients to cope with. Some questions of the script were especially positively valued. For example, the question 'If you were having a good day, what would happen on that day?' was experienced as a key topic that revealed a lot of relevant information about how patients lived and coped with their illness. Because of this, several facilitators had already started to use their experiences from involvement in the ACTION study in their wider practice.

> *'…and it [the script] is helpful with questions about hope and… about pushing through, asking for prior experiences, these are points that the script covers very well'* (NL, HCP, involved).

Although facilitators evaluated the script as helpful at times, most facilitators also felt frustrated by the scripted approach of the conversation. This was caused by their sense of being forced to follow the script even when they thought that topics were not presented in what they believed to be the right order, or to ask questions that they considered inappropriate for the category of patients under study, particularly in relation to patients' illness process and well-being. Consequently, facilitators felt they risked losing rapport and becoming less aligned with patients.

> '*That heart and mind clash at such a moment'* (NL, HCP, not involved).
>
> *'The topics are not impossible… but the guide is impossible'* (DK, no HCP, involved).

In particular, facilitators who were not involved in regular patient care and, consequently, did not have a prior relationship with patients, found that the formality and structure of the script could hamper creating a trusting relationship with patients during the ACTION RC ACP conversation. Facilitators who worked in clinical practice had already developed their own style of communication with severely ill patients. Working in accordance with the script forced them to use different (e.g. more medically-orientated) language compared to what they were used to and to ask ACP-related questions they would not otherwise have asked. This took many facilitators outside their comfort zone. They described it as a major challenge to balance working with the script and having a meaningful and sensitive discussion with the patients and their PRs.

Some variance between the six participating countries in terms of facilitators' experiences with specific questions was encountered. For some facilitators the questions about hope ('*What do you hope for with your current medical plan of care*?' followed by '*If all these hopes do not come true, what else would you hope for?*') were difficult to ask because they did not want to distress patients. The Italian facilitators in particular felt uncomfortable asking what patients would hope in case the hopes for current medical treatment would not come true, because, from their perspective, this involved a risk of taking away the patients' hope. In contrast, several facilitators from other countries felt positive about the questions regarding hope. They mentioned that, although challenging, these questions led to an in-depth understanding of patients' ideas and views regarding their future in relation to the expected course of their illness.

> *'I think it [hope question] sometimes turns out to be crucial, to get people to open up'* (SI, HCP, not involved).

Helpful and difficult

When undertaking ACTION RC ACP conversations, facilitators did not only experience what it was like to conduct these conversations, but also observed the responses of the patients and PRs involved in the conversations. Facilitators concluded that most patients were positive about having had an ACTION RC ACP conversation, which was encouraging to them. Facilitators reported that some patients spontaneously shared their positive feelings subsequent to the conversation. Patients told them they appreciated the information received or were grateful for being given the opportunity to discuss perspectives and preferences for future care and treatment they had not thought about before. One patient for instance, after having been transferred to a hospice, contacted the facilitator to say, 'thank you'. '*It was where she wanted to be, thanks to the interview'* (IT, HCP, involved).
Facilitators observed that some questions prompted patients to think deeply about their wishes. These included questions about understanding the nature of their illness and about what, at this point in their lives, constituted a good day. Others saw value in the ACTION RC ACP conversations because they noticed how it created an opportunity for patients to make decisions about their own care and encouraged them to share those wishes with their HCP. Facilitators considered the involvement of PRs in the ACTION RC ACP conversations as a key benefit. It provided an opportunity for an open and valuable discussion between the patient and the PR. It could be the first time that a PR became aware of their role and of the wishes of the patient. Facilitators often noticed that PRs experienced a myriad of emotions and a feeling of responsibility, which also became apparent to the patient.

> *'…actually, it was still kind of quite challenging, painful, emotional, to talk through some of those experiences again and revisit. But, but equally, she [the mother] wanted to do it for her daughter, and she did it but it wasn't easy for her'* (UK, HCP, not involved).

> *'You saw that they, that was often the very first time that they had thought about it and were so open about it and… so I had a couple like that and well, I found that very rewarding'* (BE, no HCP, not involved).

While facilitators emphasized the importance of the PR's involvement, some reported that this involvement sometimes complicated the ACTION RC ACP conversation due to the strong influence of the PR. They had to talk to two individuals with different perspectives and emotions and, as such, facilitators concluded that the ACTION RC ACP conversation was an intervention for the PR as well.

Facilitators observed that patients also experienced difficulties with some parts of the ACTION RC ACP conversations. Some patients found it difficult to express themselves or to explore what might happen in the future. Other patients or PRs became emotional. There were also patients who did not seem to understand some of the questions, had difficulty making decisions, or expressed being afraid that they could not change preferences once they were documented. These observations led facilitators to think that participation in an ACTION RC ACP conversation required quite an effort from patients because of the time invested, the emotional effort involved, and the energy required in combination with the time and efforts already needed to undergo their current treatment. Therefore, some facilitators thought that having two ACP conversations on top of patients' normal care and treatment was too much. Nevertheless, facilitators felt that being challenged to openly and honestly discuss all topics at once could be overwhelming or upsetting for some patients.

> *'I get the impression that in part, it is difficult to understand it [the questions], but I don't know if it is difficult to understand because it is formulated in a certain way, or the patient is put in a very complicated position emotionally.'* (IT, HCP, involved).

Feeling uncertain and responsible

Despite their observation that many patients positively evaluated the ACTION RC ACP conversation, many facilitators remained uncertain about whether these conversations were the right thing for patients. This feeling was caused by the discomfort facilitators experienced in relation to some parts of the script, the observation that having an ACTION RC ACP conversation was emotionally challenging for both the patient and the PR, and the time and energy it took from patients who were already considerably burdened by their treatment, symptoms and side-effects. In particular HCPs worried about the patients' wellbeing. In light of this uncertainty, facilitators reported an increased sense of responsibility for ensuring that the patient derived benefits from the ACTION RC ACP conversation and to safeguard their well-being and coping strategies in dealing with their illness. As one facilitator said:

> *'Time must have meaning, that's what you feel. So there I feel… I always have patients in that phase, but here I'm more aware of what that conversation is supposed to mean, it must be productive in some way'* (NL, HCP, not involved).

Feeling responsible led facilitators to check on patients' well-being, also after the ACTION RC ACP conversation had finished, and whether they needed any additional support. Facilitators who were not involved in the regular care of patients missed this opportunity.

> *'And I think that hard bit is, we're used to being able to follow up our patients, and we're worried and we're thinking they are distressed, (we can) see them again, you know, it's very easy to pick up the phone. But, with these patients, you are leaving them potentially quite vulnerable and I think that's really hard, really hard'* (UK, HCP, not involved).

Facilitators' feeling of responsibility made them develop goals for themselves. These included the need to keep the patient and the PR emotionally in balance, to safeguard the beneficial effects of the ACTION RC ACP conversations for the patient and to create and maintain a trusting relationship throughout the conversation. The need for working with these goals was reinforced, but made more difficult, by the necessity of following the study protocol, including the script, which could be felt as conflicting with the need to respond sensitively to the perceived needs and preferences of patients.

Learning process

Over time, many facilitators felt better capable of conducting ACP conversations. They referred to this as a learning process during which they had gained skills and had grown more confident to conduct the ACTION RC ACP conversations

> *'It gets better in time. You have to put in some effort, but eventually it gets easier'* (SI, HCP, not involved).

The initial ACTION RC training constituted the foundation of this learning process. All facilitators highlighted the ACTION RC training as essential to understand and become familiar with the scripts and to improve their communication skills. Facilitators mentioned this had helped them to stay attuned to patients' needs while performing the ACTION RC ACP conversation according to the script.

> *'I did find it [the training] intensive but, I am really grateful that we received it, this training'* (BE, HCP, involved).

In addition to the training, 'learning by doing' was also important. Practising the conversations in conjunction with ongoing coaching on the job by the research team, feedback and reflective conversations with colleague facilitators and members of the research team, and feedback of patients and PRs was mentioned to be indispensable.

Reflective conversations, in particular, addressed difficulties that arose during the conversations and the facilitators' doubts and uncertainties concerning the balance between the beneficence of the conversation and the – emotional- efforts that were required from patient and PR. This was particularly important because of the facilitators' increased sense of responsibility for the patients' coping and well-being and their eagerness to make the conversations valuable for patients.

> *'Yes, I still think the feedback moments are the most important of all, to discuss the difficult cases and find a solution together and to… learn from each other'* (BE, no HCP, not involved).

In addition, facilitators felt more comfortable and confident to continue conducting ACTION RC ACP conversations when patients positively valued aspects of the conversation or when the facilitators themselves identified worthwhile aspects from the patients' perspective. In addition, 'learning by doing' taught facilitators the value of certain communication skills such as the teach-back method (in which patients are asked to repeat in their own words what they understood about the discussed topic). Many facilitators also experienced benefits to their personal and professional development by performing ACTION ACP RC conversations. For example, facilitators became key figures for the patients.

> *'I see this as a very good learning experience for myself as a health care professional. And in a personal sense as well. To be a facilitator is basically a privilege'* (SI, HCP, not involved).

Thoughts about implementation

A number of facilitators worried about the use of scripted conversations in clinical practice. Some facilitators, in particular those from the UK, stressed that the ACTION RC ACP conversations should not simply become a kind of tick box exercise after being implemented. They emphasised the importance of skilled communication and underlined the need for advanced communication skills to deliver ACTION RC ACP conversations effectively and safely and the need to practice in order to become skilled in the art of these conversations. Refining their skills had enabled them to work with the script, and concurrently to reflect upon the non-verbal communication of the patient and the PR:

> *'And that's my worry, I think, is that the risk is with the guide and the script, that people will just follow it, maybe not pick up on those cues'* (UK, HCP, not involved).

The question whether HCPs who are already involved in patient care should also take up the role of facilitator set the facilitators thinking. Some indicated that it might be better if facilitators were a part of the medical team enabling them to be informed about the patients' situation and to build on existing relationships.

> *'An existing relationship of trust allows them [patients] to open up about certain subjects and I don't know if they would do this or how they could do this with a stranger in an unfamiliar environment'* (IT, HCP, involved).

In contrast, others felt that it was desirable not to have prior knowledge of the patient to safeguard the openness of the conversation, and that not having a pre-existing relationship also meant that no dilemmas would arise as a result of their other roles as nurses or doctors.

> *'Well you can say, at least you wouldn't have any preconceived opinions. No, you don't have any'* (DK, HCP, not involved).

DISCUSSION

This study of facilitators delivering an ACP intervention revealed that the intervention was supportive to conduct ACP conversations as well as challenging. Facilitators learned that addressing topics that made patients think and discuss their current and future situation and preferences often resulted in meaningful moments during the conversation. In addition, they felt that patients and PRs often positively evaluated the conversation. Concurrently, the use of a scripted approach in a study context forced them to address topics and to ask questions in a way that was very different to their usual approach. Facilitators felt uncomfortable because this scripted approach threatened rapport with the patient and PR and required considerable –emotional– engagement from patients already managing the considerable demands imposed by serious illness and its treatment. Driven by some uncertainty about whether these conversations are experienced as beneficial by the patient as well as doable, facilitators felt responsible for ensuring that this was the case. Facilitators emphasized this was a matter of 'learning by doing', supported by reflective conversations and coaching on the job.

Previous studies on HCPs' perspectives about carrying out ACP conversations show that HCPs fear taking away the patients' hope or that the conversations will leave the patient in an emotionally unbalanced state even knowing the potential benefits of ACP.[4-8] Facilitators in our study also felt the ethical dilemma between beneficence and non-maleficence. To illustrate, HCPs initiated ACP and promoted the benefits of ACP, but at the same time they felt a duty not to harm the patient and to protect potentially vulnerable patients. The findings suggest three aspects that encouraged facilitators in performing the conversations.

Firstly, our study revealed that facilitators went through a learning process during which they noticed that patients actually responded well to questions that they had anticipated would prove difficult. In addition, they learned how to work with the script. These findings indicate that becoming experienced gave HCPs self-confidence in conducting ACP conversations and to asked ACP-related topics they would usually not have asked to prevent emotional disruption or harming the patients' coping strategy.

Secondly, the participants in this focus group study mentioned that facilitators need to be highly skilled and stressed in particular the need for good communication skills in order to balance working with the script and attune to the patient's needs. This is in line with earlier studies that described a lack of communication techniques as a barrier to undertaking ACP conversations [4-9] and that a skilled facilitator might be the critical link to an effective ACP conversation.[22-24] It is interesting that despite the variation in the facilitators' professional roles and background, none considered themselves to be lacking competence as a facilitator, though some were more experienced and confident to conduct the ACTION RC ACP conversations than others. The combination of the training, 'learning by doing' and reflective conversations (including discussing the ethical problems) seems thus critical to become a skilled facilitator. Still, more research is needed, especially from patients' perspectives, on whether facilitators need clinical or palliative care skills.

Lastly, facilitators in this focus group study described that patients appeared to be grateful for the opportunity to talk about their preferences for future care despite moments of emotional distress. Based on this, it could be argued that emotions expressed during an ACP conversation are a part of the patients' process of coping with illness. Therefore, HCPs need not label expressed emotions directly as negative and need not consider these emotions as an expression of burden for the patient. To be able to respond carefully to the emotions expressed by patients, facilitators need advanced communications skills.[25]

The facilitators thought differently about whether a facilitator should be involved in regular patient care to perform high quality ACP conversations. Although Briggs (2004) reported that facilitators should have an understanding of the patient's disease and its progression, it is not specified whether they should also be involved in regular care for the patient.[26] In the current study, 13 facilitators were involved in the care for patients with whom they had the ACTION RC ACP conversation. Some facilitators argued that being able to build on an existing trusting relationship made them feel more comfortable in asking ACP-related questions. In addition, they stressed the possibility of following-up the patient after the ACP conversation. In contrast, other facilitators mentioned the importance of having a conversation without any knowledge or preconceptions in advance, which may open up the opportunity to really explore the patient's perspective. Our results showed pros and cons regarding the involvement of facilitators in the regular care for patients. The optimal way forward might also be influenced by the patients' personal preference to know or not know the facilitator. Therefore, more research is needed to understand in which situation it is helpful for the conversation to be conducted by a facilitator who is already involved in the care for patients or by an independent person.

Strengths and limitations

Some strengths and limitations of this study have to be taken into account. Firstly, when implementing a new complex intervention, time and experience are necessary to ensure that it is delivered effectively. Although on average facilitators in the study had completed ACP conversations with six patients, this might not have been sufficient for them to achieve proficiency. Secondly, this study was undertaken across six countries. For purpose of analysis, the focus group transcripts were translated into English as a common language. Some information or nuance might have been lost in translation, which is an issue in all international studies. However, by using the summaries made by each local team and by validating the results with the researchers of each country, we believe that we took sufficient measures to mitigate these losses. Finally, it should be noted that patients who were willing to be included in the ACTION trial might have self-selected as being receptive to, and ready to discuss, ACP. This might well have influenced the nature of the RC ACP conversations, thus leading the facilitators to have evaluated the conversations more positively.

CONCLUSION

Facilitators experienced positive aspects of the ACTION RC ACP conversation as well as challenges. They indicated the importance of support and training them to build confidence and becoming skilled in delivering ACP conversations. In particular support is needed in addressing difficult topics and asking confronting questions that proved to be of value for patients, but they would usually not have asked. Facilitators felt that aspects of the conversations were of meaning to patients and PRs, but also questioned the efforts it took from patients and PRs.

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Chapter 7

Patients' Readiness for Advance Care Planning Conversations: a Qualitative Study as part of the ACTION Study

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Submitted

ABSTRACT

Objective: Patients' readiness for advance care planning (ACP) is considered a prerequisite to initiate ACP conversations. This study explores patients' readiness throughout an ACP conversation.

Methods: A qualitative content analysis of recorded structured ACP conversations of a trained facilitator, a patient with advanced cancer and a relative. Conversations were conducted in the Netherlands, as part of the international ACTION trial. The analysis was supported by NVivo 11.

Results: All patients (*n*=13) expressed both signs of not being ready and of being ready within one conversation. Signs of being ready included answering questions on a personal level or demonstrating understanding of one's disease. Signs of not being ready included limiting one's perspective to the here and now or indicating a preference not to talk about an ACP-related topic. These signs were especially seen when future oriented topics such as 'complications' and 'hope' were discussed. Despite signs of not being ready, patients were able to continue the conversation.

Conclusion: Patients do not have to be ready for all elements of ACP to be able to participate in an ACP conversation.

Practice implications: Healthcare professionals should be aware of patients' ability to alternate in readiness depending on the topic that is discussed.

INTRODUCTION

During the last two decades, the focus of Advance Care Planning (ACP) has evolved from the completion of a written advance directive alone to a communication process between the patient, his/her relatives and a Health Care Professional (HCP), aimed at identifying and discussing goals and preferences for future medical treatment and care.[1-3] This altered perspective is reflected in recently published definitions of ACP.[4,5]

ACP has the potential to improve the wellbeing of patients and their relatives and the communication between patients and HCPs.[6] Most ACP conversations consist of four phases. The first two phases include the practical arrangement of the ACP conversation (preparation) and the actual start of the conversation (initiation). The third and core phase includes sharing thoughts on topics such as the patient's illness, hopes, worries and personal beliefs (exploration). In this phase, preferences regarding future medical treatment and care (e.g. cardiopulmonary resuscitation, final place of care, or general goals of care) are also discussed. The final phase of an ACP conversation consists of summarizing the topics discussed and can include documenting and/ or providing patient specific recommendations (action).[7]

Patients' readiness to participate in an ACP conversation is often described as a predictor of their engagement in ACP,[8-11] as an indicator for HCPs to initiate an ACP conversation,[12] and as an essential prerequisite for patients to experience an added value of ACP.[4,5,13] Therefore, recent studies have recommended assessing the patients' readiness before starting an ACP conversation.[4,5] The assessment of readiness for ACP typically focuses on a patient's state-of-mind prior to the start of the ACP conversation (during the preparation phase). However, readiness is also described as a process outcome of successful ACP,[14] and patients have reported that the ACP process itself can have a positive influence on their readiness.[15] Until now, the literature sheds little light on the manifestations of patients' readiness during an ACP conversation. In this study, we aim to gain a nuanced understanding of patients' readiness for ACP throughout the ACP conversation itself.

METHODS

Research Design

A qualitative study of audio recordings of ACP conversations was conducted using content analysis. This study is a sub-study of the ACTION trial, a Phase III multicentre cluster-randomised clinical trial that evaluates the ACTION Respecting Choices (RC) ACP intervention in six European countries (Belgium, Denmark, Italy, the Netherlands, Slovenia and the United Kingdom).[16] The ACTION RC ACP intervention consists of one or two conversations about the patient's values, goals and preferences for future care and treatment with a trained facilitator (mostly nurses) and, if the patient wishes, a relative (see Supplementary material 2.).[16] The facilitator's primary purpose and goal in the ACTION RC

ACP conversation is to listen to and help clarify the patient's perspective. This conversation is structured with the use of a guide; Table 1 includes a list of the topics discussed and an example of a question per topic.

Table 1. Topics ACTION RC ACP conversation

Topic	Example question
Understanding of role of the PR	What do you understand about the role of the Personal representative?
Patient's and PR's understanding of ACP	Have you done any Advance Care Planning before?
Understanding of illness	Tell me what you understand about your illness
Complications	What do you understand about the possible complications of your illness and what might happen in the future?
Experiences	What did you learn from that experience [experiences with family or friends who became ill or injured and were not able to communicate]?
'Living well'	What does living well mean to you?
Worries and fears	Do you have worries about your illness or medical care? If so, what worries do you have?
Possible personal, cultural, religious, or spiritual beliefs	Do you have any personal or cultural beliefs that might influence your preferences for future care and treatment?
Patient's hopes for current medical plan of care (part 1) Patient's hopes for current medical plan of care (part 2)	What do you hope for with your current medical plan of care? I understand these hopes. If all these hopes do not come true, what else would you hope for?
Help making an informed decision regarding CPR	What do you understand about resuscitation?
Discuss goals, values and preferences for future complications	Tell me in your own words what you understand about this option [Selective Treatment plus Comfort-Focused Care]?
Preferences relating to final place of care	Do you have preferences relating to the final place of your care?

Population

Patients with advanced lung or colorectal cancer were recruited to participate in the ACTION trial between May 2015 and December 2017.[16] For this sub-study, we purposively sampled patients in the Netherlands who received the intervention in one of the Dutch intervention arms. Of the 67 patients included in the intervention arm of the ACTION trial, 62 patients actually participated in an ACTION RC ACP conversation, four patients changed their mind regarding participation and one patient could not participate due to illness progression.

Data Collection

Audio recordings of the ACTION RC ACP conversations were eligible for this study when (1) a facilitator who conducted at least three ACTION RC ACP conversations was involved and (2) it concerned a completed ACTION RC ACP intervention, irrespective of whether this took one or two ACP conversations.

To achieve a maximum variation sample, we purposively selected an initial sample of four patient conversations with different facilitators, diseases and patient characteristics. We then selected nine additional audio recordings to achieve a variation in the level of readiness, based on a rough first assessment of the patients' readiness. The corresponding background data were collected from the patients' medical files; the location of the ACP conversation and the number of conversations per patient were extracted from the facilitators' reports of the ACTION RC ACP conversations.

The included conversations were transcribed verbatim by a professional transcription service.

Data analysis

The data analysis team, with professional backgrounds in nursing (MZ, MK) and comparative literature (MM), and experienced in narrative theory and qualitative research, performed a content analysis to gain insight into the signs of readiness and the development of readiness throughout the course of the ACP conversations.

The data analysis consisted of three stages. In the first stage, manifestations of being ready and of not being ready were identified. In stage two, an in-depth analysis was performed regarding readiness in relation to discussing the past, current and future situation and stage three included an analysis of manifestations of readiness in relation to the topics discussed.

In stage one, all three members of the analysis team individually listened to all audio recordings and read the corresponding transcripts to gain a broad impression of what patients' readiness in the context of ACP conversations entailed. Subsequently, they independently wrote a summary regarding patients' readiness for ACP throughout the ACTION RC ACP conversation and within each ACP topic discussed. In particular, they looked for (1) signs that indicated some degree of readiness of the patient or signs of not being ready, (2) whether and how the conversation was continued after such signs and (3) what was underlying the identified signs. These summaries were discussed, resulting in a preliminary overview of signs of being ready and of not being ready. Following this, MZ coded a full transcript, developed a draft code tree and categorized common codes. To ensure inter-observer agreement, MZ and MM independently coded three of the thirteen transcripts. Differences in coding were discussed until consensus was reached. MZ coded the remaining transcripts.

During the second stage, the three authors performed an in-depth analysis of the

patients' readiness while answering questions about the past, the present and the future. Questions about the past (past-oriented questions) included asking the patient to reflect upon the progression of their illness or discuss previous experiences with a family or friend's illness. Questions about the present (present-oriented questions) asked about the patient's current health status and perspectives. Future-oriented questions were aimed at stimulating a discussion of possible scenarios and preferences regarding patients' future medical treatment and care.
With this 'orientation' of the questions in mind, the three authors each coded the transcripts by focusing on whether the patients' utterances were in line with the orientation of a question. In addition, they focused on utterances of the facilitator and the PR that potentially influenced the patient's signs of readiness. Including how the conversation continued. The three authors discussed the different interpretation of the utterances until agreement was reached.

The third stage included a categorisation of the topics discussed during the ACTION RC ACP conversations into three levels of difficulty. This categorisation was based upon the earlier identified signs of being ready and not being ready. More identified signs of not being ready was interpreted as a higher level of difficulty to discuss a topic.
Finally, we validated our results by going backwards and checking whether the identified codes were coherent to the final list of signs of readiness and signs of not being ready.
The software program Nvivo11 supported the data analysis.

Ethical considerations

Ethical approval for the ACTION trial, including the qualitative work package, was obtained from the Research Ethics Committee (REC) of Erasmus MC, University Medical Center Rotterdam. Written informed consent was obtained from all participating patients. Verbal informed consent was obtained and recorded from the relatives presented at the ACP conversation. To ensure the confidentiality, all transcripts were coded and any identifying information was removed.

RESULTS

Thirteen of the forty-seven eligible audio recordings were included for analysis (28%). The mean age of the involved patients was 64 years (range 51-77 years of age) and most patients were female (*n*=8). Nine patients were diagnosed with lung cancer and almost all patients' current treatment had a palliative aim (*n*=12) (Table 2). Most patients had one ACTION RC ACP conversation with the facilitator (*n*=9); ten conversations took place in a hospital.

All patients appeared to be able to participate in the ACTION RC ACP conversation, but we found a great variation in their readiness and willingness to talk about the scripted questions. Our analysis of the transcripts showed that patients could display *both* signs of not being ready and of being ready for ACP within one conversation and even within one topic. Table 3 provides a summary of the ACP conversations of two patients to illustrate that, even if a patient showed to have difficulties with one topic, this did not imply the patient would also have difficulties discussing the subsequent topic in the script. For example, Patient 9, who was unwilling or unable to talk about topics such as his diagnosis and potential future complications, and who openly struggled emotionally at multiple points throughout the conversation, could nevertheless clearly and resolutely articulate his preferences regarding resuscitation and his final place of care.

Table 2. Background characteristics

	N (%)
N patients	13 (100%)
Male	5 (38,5%)
Age	64,2 years (range: 51-77 years of age)
Marital status	
Married/civil partnership	12 (92,3%)
Living with a spouse/partner	13 (100%)
Living in a private household	13 (100%)
Having children	11 (84,6%)
Number of children living at home	0
Being religious	7 (53,8%)
WHO	
0	4 (30,8%)
1	9 (69,2%)
Diagnosis	
Lung cancer (stage III or IV)	9 (69,2%)
Colorectal cancer (stage IV or metachronous metastases)	4 (30,8%)
Current treatment*	
Chemotherapy	4
Radiation therapy	4
Immunotherapy	5
Targeted therapy	2
Current cancer-directed treatment	
Palliative	12 (92,3%)
Curative	1 (7,7%)

*Some patients received more than one treatment at the same time.

Table 3. Samples of shifts in readiness during the ACTION RC ACP conversation

<table>
<tr><th>TOPIC</th><th colspan="2">PATIENT 2
(male, 67 years of age, PR is his wife)</th><th colspan="2">PATIENT 9
(male, 77 years of age, PR is his wife)</th></tr>
<tr><td>1. The role of the PR</td><td colspan="2">**Ready:** Has read the folder about the role of the PR prior to the conversation, presumes and expects that his wife will carry out the tasks required by a PR.</td><td colspan="2">**Ready:** PR can describe her role and function as representative if her husband can no longer speak for himself, namely that she will communicate his preferences and decisions. Patient is confident she will be able to do this even in difficult situations.</td></tr>
<tr><td>2. Practice and understanding of ACP</td><td colspan="2">**Not ready:** No previous experience with or knowledge of ACP, patient and PR both admit that patient is “not a talker.”</td><td>**Ready:** Has thought about resuscitation (does not want CPR); has discussed this preference with HCP.</td><td>**Not ready:** Has purposefully delayed talking about other preferences until the future, or when it is necessary.</td></tr>
<tr><td>3. Understanding of illness</td><td>**Ready:** Can state diagnosis: colon cancer with metastasis in the liver.</td><td>**Not ready:** Stresses the positive aspects of treatment, minimizes the side-effects of chemotherapy to pain in his fingers.</td><td>**Ready:** Can state diagnosis: lung cancer with four metastases.</td><td>**Not ready:** Knows very little about illness (i.e. location of lung tumor, purpose of chemotherapy).</td></tr>
<tr><td>4. Complications</td><td colspan="2">**Not ready:** Does not want to think about complications, prefers to delay such a conversation until it’s necessary, to avoid worrying.</td><td colspan="2">**Not ready:** Clearly states that he does not know about complications, does not want information about complications, and does not want to think about his own death.</td></tr>
<tr><td>5. Experiences with family or friends who became ill</td><td>**Unclear:** Patient answers “no” to the question, so PR tells about an illness experience in the family.</td><td>**Ready:** At a later point in the conversation, the patient spontaneously describes his own previous illness experience 40 years prior and links his previous coping strategy to his current coping strategy.</td><td>**Ready:** Can tell about illness experience of family member.</td><td>**Not Ready:** Cannot think of any links to his own situation.</td></tr>
<tr><td>6. ‘Living well’</td><td>**Ready:** Describes what living well means to him: living without physical hindrances or constraints.</td><td>**Not ready:** When asked to consider what “living well” would mean in the future with a deteriorated state of health, patient says he can’t think of or give an answer. PR says this is because he’s not the type to think ahead.</td><td colspan="2">**Ready:** Describes what living well means to him: to wake up healthy, to be together with his family, children, and grandchildren.</td></tr>
</table>

7. Worries about illness or medical care	**Ready:** Admits to be scared that the current treatment will eventually stop being effective.	**Not ready:** Pronominal shift to second-person perspective, wants to keep the future uncertain and “make the best of it.”	**Not ready:** Only wants to talk about positive aspects of treatment, does not want to think about future. Additional information: Becomes emotional when answering.	
8. Possible personal, cultural, religious, or spiritual beliefs	**Ready:** Patient says that he used to go to church and for that reason could be considered a believer.	**Not ready:** When asked to describe the most important aspects of his belief for him personally, patient responds that he “can’t put it into words.”	**Ready:** Talks about Roman Catholic faith.	**Not ready**: Repeats “I don’t want [to think about] it yet” when conversation turns to topic of his own religious funeral service.
			Additional information: Becomes emotional when answering.	
9. Hopes for current medical plan of care	**Ready:** Can clearly articulate his hopes: to stay alive for a long period of time and to be cured .	**Not ready:** Pronominal shift from ‘I’ to ‘we’ when discussing hopes.	**Ready:** Can clearly articulate his hopes: to feel better every day, that the illness will disappear, that he will leave the hospital cured.	
10. Hope should other hopes go unfulfilled	**Not ready:** Does not want to think or talk about it.		**Ready:** Can answer the question with an alternative hope: that he can live as long as possible.	
11. Preferences for resuscitation	**Ready:** Expresses a clear preference to be reanimated in current physical state. Anticipates future scenarios and admits that this preference may change. Adds that at a certain point in the future he would rather not be reanimated.		**Ready:** Expresses a clear wish not to be in a vegetative state and has already communicated this wish to his HCP and family. Mentions this preference spontaneously multiple times in the conversation.	
12. Care during final phase of life	**Ready:** Describes various possible scenarios that are related to his own illness.	**Not ready:** Delays making a choice because of uncertainty about the future and the variety of possible scenarios.	**Ready:** Expresses a clear preference for treatment of all future possible complications.	
13. Final place of care	**Ready**: Would like to die at home, but realizes this will depend on the situation. PR adds that she will do her best to honor his wish and names people who can help her care for him if necessary.		**Ready**: Expresses a clear preference to die at home where his wife can help care for him.	**Not ready:** Pronominal shift to third-person when talking about the end of life.
			Additional information: Becomes emotional when answering.	

Signs of not being ready

Patients' reluctance or inability to discuss ACP topics were most apparent at moments in the conversation when topics were discussed that made them face or imagine their own deterioration or death, to relate a past experience to their current circumstances, or to consider the significance of an ACP prompt for them personally. The patients in this study signaled their reluctance to consider these aspects of ACP in a variety of ways. Identified signs of not being ready included indicating a preference not to talk about an ACP-related topic and/or refusing more information or limiting one's perspective to the here and now (Table 4). These signs indicated that a patient's inability or unwillingness to talk about certain ACP topics was not just a reflection of the patient's state of mind at that moment in the conversation. Many of the signs of not being ready also revealed that a patient was delaying or avoiding having to think about his/her own deterioration of health or death.

Signs of being ready

Conversely, showing willingness and ability to discuss an ACP topic or to consider the personal relevance and impact of an ACP topic constituted important indications that a patient was ready for a topic of ACP. Identified signs of being ready included, demonstrating an understanding of one's diagnosis and current state of health or spontaneously mentioning ACP-related topics (Table 5). Although patients indicated their readiness to discuss an ACP topic in a variety of ways, each sign of readiness essentially revealed that a patient could face and talk about an aspect of ACP and/or could link his/her thoughts to future scenarios related to the end of life.

Synthesis

The role of perspective in a patient's readiness for ACP

While the ACTION RC ACP script encouraged patients to reflect upon the past, the present and the future at certain moments during the conversation, patients who were more ready to discuss ACP topics were able to shift between the past, present, and future spontaneously and independently of the script.

Most patients were ready to say something about the present. Most patients were also ready to reflect upon the past. But when asked to link the past to the present or to think about the future–be it possible future complications or preferences regarding end-of-life care–we noticed more diversity in patients' states of readiness. As can be seen in Table 4, patients who were not ready to think about a future deterioration in health and death employed a variety of strategies to delay or avoid the topic, such as refusing to answer a question, keeping the future vague, and actively choosing to focus on the present. And as Table 5 illustrates, those patients who were ready and willing to think about the future could consider their own deterioration in health from the past, the present and the future position. They could anticipate future scenarios, and demonstrated a more informed and pragmatic view of their own prognosis.

Table 4. Signs that a patient is not ready for aspects of ACP

Action	Description and rationale	Sample
Keeping things out of sight	When asked to consider future scenarios and articulate a clear preference about end-of-life care, the patient avoids taking a definitive stance by either stressing the unpredictability of the future or postponing a decision until an unspecified later moment. *The patient tries to:* • Actively avoid facing the end of life • Avoid an emotionally painful topic • Cultivate or preserve a sense of uncertainty • Delay having to make difficult decisions or indicate a preference • Keep the possibility open for an improvement or cure • Maintain a sense of control over the current situation • Manage worries and anxieties or prevent unnecessary worrying	I: I understand the hope that you've just mentioned, but what if this hope can't be realized, that you reach a point where you decide to stop with the treatments, what would you hope for then? R: I don't dare think about that right now. I: That's too far away, eh. R: We're pushing that away with a big bulldozer. *(Pat 2. Male, 67 years of age)*
Indicating a preference not to talk about an ACP-related topic and/or refusing more information	The patient actively puts a stop to the exploration of the topic by declining the facilitator's offer to provide more information or by simply refusing to discuss the topic any further. *The patient tries to:* • Avoid facing the prospect of a physical deterioration or end of life • Avoid unnecessary worrying • Delay having to learn about negative outcomes • Maintain a curative or 'fighting' stance • Maintain a feeling of control over his/her life and emotions • Protect him/herself from unnecessary or emotionally painful information	I: Then is the question what do you know about the possible complications of your illness, what in the future may possibly happen. Do you know anything about this? R: Now, I understood that to mean that if your liver stops working you poison yourself. For the rest I don't want to know how sick I may eventually feel or which functions I may lose, all the things I won't be able to do anymore. Because that is one of my fears, that I'll only be lying in bed waiting until I die. R2: That's not for you. R: No, I need to be able to go outside and I need to be able to do things (laughs). I: Yes, in that respect it could be helpful if Doctor K could talk to you [about the complications] so that you know whether or not you have to adjust your expectations. R: Yes, at some point. I: At some point. R:For me it's not necessary yet. *(Pat 3. Female, 60 years of age)*

Table 4. continued

Action	Description and rationale	Sample
Limiting one's perspective to the here and now	The patient refuses to consider the future when asked to do so in the ACTION ACP RC script and chooses instead to remain present-centered. *The patient tries to:* • Delay having to think about him/herself in a deteriorated condition • Maintain a curative or 'fighting' stance • Maintain a positive outlook • Protect him/herself from negative or confrontational information	I: Let's say that your wife has to make the decision at certain moment about whether or not to resuscitate. What would your advice for her be? R: As it is now, yes [resuscitate]. I: No, but if you can't speak anymore, eh? That would mean something has happened. R: Yes, but I'm pretty good now, so I would definitely say try to resuscitate me. *(Pat 2. Male, 67 years of age)*
Minimizing the seriousness or significance of one's symptoms	When asked about the progression of the illness, the patient avoids having to consider the seriousness of the situation and chooses instead to focus on the positive aspects of the treatment or a small improvement in health, downplay the symptom burden, or mention unrelated illness symptoms. *The patient tries to:* • Actively steer the conversation in a positive direction to cope with the situation • Avoid facing the prospect of a physical deterioration or death • Maintain a curative or 'fighting' stance • Maintain a sense of control over the situation • Suppress, fragment, or avoid signals of deterioration by focusing instead on details that can be managed or easily explained • Purposively stay positive	I: Has your illness changed in the last months? R: No, I have to say with the deteriorated liver function that I really felt a new dip and that you immediately also think: I'm more tired, is my condition going to get worse, and is there something wrong, do I have more pain now? And I actually have that every time for 1 or 2 days after I get bad news, of if it sounds like bad news to me, and then it gets better. I switch that button again, then I think: how bad is it if you can't eat candy anymore and have to drink more water? You just have to keep swallowing the hormone pills, period. And these are the consequences, deal with it. *(Pat 7. Female, 52 years of age)*
Shifting pronominally and/or from personal to generalized descriptions	When discussing various ramifications of a deterioration in quality of life or death, the patient can provide an answer but distances him/herself from the topic by switching from the first- to second- or third-person perspective or by making her observations more general and less personal. *The patient tries to:* • Emotionally distance him/herself from the topic being discussed • Maintain control over her emotions • Make it easier to articulate his/her stance • Make it seem like the decision or stance is not merely his/her own	R: Yes, I'll talk about it with her [HCP] again, I'll say: now explain to me what is your image, idea, about when will die, and what are the symptoms that that will go along with that. And what is for me acceptable, what isn't? Now there is a limit, and that I need to get clear. […] R: Yes, because the limit may change, every time different. I think that's how it is with a lot of people. I: Yes. It is difficult to establish a limit, because maybe it doesn't work that way. R: No, you can't just determine the limit. You only realize it when you experience it, then you say: it's finished. *(pat 12. Male, 71 years of age)*

Table 5. Signs that a patient is ready for aspects of ACP

Action	Description and rationale	Sample
Providing an answer to the scripted question	The patient shows a willingness and ability to discuss an ACP topic and links the answer to his/her own experiences or personal situation. *The patient:* • Is capable of making links between the ACP topic and his/her personal situation • Takes the ACP question seriously	I: Do you have any worries about your illness or treatment? R: No. Yes, you are going to die, but you knew that already. Even if I hadn't gotten sick. Look, I'm 73, I have nothing to complain about. *(Pat 8. Male, 73 years of age)*
Spontaneously mentioning ACP-related topics independently of the script prompts	The patient independently brings up an ACP-related topic and indication that he/she has previously considered the topic and is therefore ready to discuss this topic with the facilitator. *The patient:* • Has a strong preference or wish regarding a certain aspect of ACP • Has considered possible steps that will need to be taken in the future • Has reflected upon his/her present situation • Has already made decisions regarding his/her future care • Has proactively arranged for his/her future care and discussed this with his/her HCP	I: Are there other personal beliefs that matter in regards to your future care and treatment? R: No, well in regards to resuscitation, then of course it would be: do not resuscitate. *(Pat 7. Female, 52 years of age)*
Learning from past illness experiences	When considering a previous personal illness experience or that of a family or friend, the patient can not only describe the experience, but can also draw lessons from the experience, thus linking the past to his/her present state and stance. *The patient:* • Can relate a previous experience with illness to his/her own thoughts, feelings, and preferences • Can us an illness experience to help formulate and articulate his/her own values, goals and preferences • Has thought about the significance and meaning of another person's suffering and death and can transfer it to his/her own life and situation	R2: So that means that you don't endlessly treat, treat, treat. R: Because that would be treatment for treatment's sake. R2: If the results are dubious, and the chance of a positive result are really small, and that it has a negative influence on the quality of life, then you would choose not to be treated and to enjoy the last few months. We experienced this with friends in France, where the situation is different, the doctor-patient interaction, too. And there they kept treating and treating, and we said afterwards, he would have been a lot happier if he had died six months earlier, then he would have been happier than with the year and a half he had to endure. R: Yes. R2. So that's the difference. […] R: Yes, if you keep treating for sake of it, or if you are treating to reduce symptoms, even if the man is getting worse and worse. No. *(Pat 4. Female, 67 years of age)*

Table 5. continued

Action	Description and rationale	Sample
Demonstrating an understanding of one's diagnosis and current state of health	The patient can clearly and realistically articulate a realistic view of his/her situation and can describe what medical information means to him/her personally. *The patient:* • Can describe the situation for what it is • Can describe why and how information related to his/her illness is personally significant • Can provide a nuanced description of the diagnosis and current state of health • Can provide a realistic explanation for changes in his/her symptom burden	I: What do you know about your illness? R: I know that I have stomach cancer, that is the primary cancer, and it's metastasized to my peritoneum and my liver. And that it can't be cured because the tumors in the liver, they're located on inoperable spots, they're tiny. On the CT scan you can't even see all of them, but you can on the MRI. Nevertheless, the surgeons can't find them, so it's inoperable. And because the liver is inoperable it doesn't make sense to operate on the other tumors. It makes more sense to talk about the quality of life you have, according to Doctor X, to try to keep it under control for as long as possible *(Pat 10. Female, 56 years of age)*
Demonstrating and understanding of one's disease and prognosis	The patient demonstrates a clear understanding of the seriousness of the situation and what this may entail in the future. *The patient:* • Has considered that his/her illness may be incurable • Is not avoiding the prospect of a deterioration in quality of life and death • Can imagine what a future deterioration of health might entail	I: You say that this is the third time in two years [that you've had long cancer]. You had it earlier and it has returned. R: Yes, limited. A half long has been removed, and a half year later there were metastases in the lung and chest glands. And now a year later the cancer is in both longs and the liver. So that means end of story. It's finished. *(Pat 13. Female, 61 years of age)*
Considering the topic from various sides	The patient demonstrates that he/she can weigh the pros and cons of various decisions, consider the last phase of life from different angles or perspectives, and can reflect upon a previous experience with illness by considering various actors and effects. *The patient:* • Can imagine what a future deterioration of health might entail • Can reflect upon his/her own situation or experiences • Can see his/her own illness in broader context • Has previously thought about ACP-related topics • Is willing to ask for more information to get a clear view regarding his/her situation and possibilities for his/her future care and treatment • Can reflect upon his/her good and bad feelings or worries in his/her daily life • Is willing and capable of linking the topic to his/her emotions	[In regards to choosing complete treatment or comfort treatment] R: I would choose for comfort. I think that comfort is the priority for me. It's not like I want to live a few more months at all costs, no. I: No. R: But if it yields something, if it yields real quality. If I have a bladder infection and it's simple to treat with antibiotics, great. But if they say, now it's in your lungs, and you know that treating a lung infection would mean that you would then have to remain on an oxygen machine, then no. *(Pat 2. Male, 67 years of age)*

Table 5. continued

Action	Description and rationale	Sample
Anticipating possible future scenarios	The patient can face and talk about end-of-life topics such as future complications, reanimation, and place of final care and has thought about and can anticipate a deterioration in quality of life and death. *The patient:* • Has actively considered the last phase of life • Is capable of thinking and talking about death • Has a pragmatic or realistic view of the future • Is prepared to consider the steps that may need to be taken to ensure that his/her goals and preferences are honored • Is sensitive to his/her own future needs as his/her disease progresses • Can articulate his/her emotions regarding a future deterioration of health • Actively searches for a realistic description and understanding of his/her future symptoms	R: I've made it completely clear to my children that I don't want to live in a vegetative state in bed waiting until I stop breathing, that there may be a moment when euthanasia becomes a desired option. And my GP told me that this wouldn't be a problem in my case, it's clear my suffering is hopeless and unbearable. When I talked with him about the things I might be scared about, things that might happen, he told me that I didn't need to be scared because he would sedate me. We talked about that sort of things. *(Pat 6. Female, 64 years of age)*
Accepting one's disease and deterioration of health	The patient demonstrates an acceptance of the seriousness of the disease and demonstrates that he/she has previously thought about and come to terms with a deterioration of health and death. *The patient:* • Can face and talk about the gravity of the situation • Is willing and able to talk about his/her end of life as a given fact • Actively reflects upon his/her life and relates these reflections to the topic being discussed • Spontaneously anticipates and mentions his/her own death	I: Wat does a good life mean for you, what, for instance, does a good day look like to you? R: You mean right now, not in the past? I: I would hope that your answers would be similar, but… R: Now, the answers are quite far apart, depending on what you make of it. A good life is wat we've done, what I've done, at the moment that you realize that it's going to end, then you look back at your life. *(Pat 12. Male, 71 years of age)*

Rational versus experiential perspective-taking

We noticed a further differentiation in the manner in which patients articulated their stance: via *rational* and *experiential* perspective taking. Most patients spoke without discernible emotional distress about past- and present-focused topics. They could, for instance, describe practical matters related to the future, such as funeral arrangements, financial arrangements, or the eventual reallocation of household tasks. While these future matters pertained to them directly, patients only discussed these matters in an abstract or generalizing manner. To illustrate, one patient answered the question regarding completed advance directives as: ‘my non-resuscitation wishes and the euthanasia form [living will], signed and all, are here [in a folder] and [also] with my doctor’ *(patient 12)*. This patient shared only the technical side of euthanasia without giving any impression of what it meant to him personally.

Some patients could imagine themselves in various situations or consider the significance of a specific topic for them personally. This experiential perspective was most apparent in patients’ answers to the future-oriented ACP prompts. To illustrate, one patient answered the question regarding personal beliefs: ‘Yes I do have these, I think it would be very unpleasant not to be able to do anything, just lying in bed and needing a lot of care. That’s why we have talked about a euthanasia form [living will]’ *(patient 3)*. This patient shows to imagine herself in a future situation of deterioration and suffering. Patients who could relate the scripted questions to what it meant to their own life and experiences also gave signs that they were ready and able to face the future including the real and imminent prospect of their own death.

Easy and difficult ACP topics

The topics discussed during an ACTION RC ACP conversation can broadly be categorized into three levels of difficulty (see Table 6), which correspond to the signs of being ready and of not being ready we identified per topic. The predominantly easy topics were ones that patients could discuss rationally or from an emotional distance. The most difficult questions were the ones that explicitly challenged patients to imagine themselves in specific situations, to shift from a present- to future-oriented stance, or to link their answer to their own lives, thoughts, and feelings.

Table 6. Easy and difficult topics in the ACTION ACP conversations*

Predominantly easy topics	Somewhat difficult topics	Predominantly difficult topics
• Designation of a personal representative • Previous knowledge or practice of ACP • Earlier experiences with illness in their social or familial circle • Personal definition and description of ‘a good life’ • Hopes (part one of two-part question)	• Religious or spiritual beliefs • Diagnosis • Preferences regarding resuscitation • Goals of future care (complete treatment or comfort-oriented treatment) • Final place of care	• Knowledge of potential future complications • Worries and questions about illness • Hope should other hopes go unfulfilled (part two of two-part question)

** Listed in the order they appear in the ACTION RC script.*

DISCUSSION AND CONCLUSION

Discussion

In this qualitative study, we analyzed ACP conversations led by trained facilitators and guided by a script. This study revealed that patients could express various signs of readiness during the course of one ACP conversation and could display both signs of readiness as well as signs of not being ready to discuss or think about a certain ACP-related topic. We noticed that signs of not being ready most frequently occurred when patients discussed future-oriented topics related to a deterioration of health and the end of life. We also identified a variety of expressed emotions and ways of talking about these future-oriented topics. For example, when asked to talk about potential complications, most patients were not able to provide an answer and indicated not wanting to be informed about this topic. These patients seemed to want to protect themselves from being confronted with the possibility of their own suffering and death. Morse and Carter (1996) relate the expression of emotions to a patient's shifting between a state of enduring and a state of suffering during their illness process.[17] Morse and Penrod (1999) further nuance this finding by adding that these shifts are related to an individual's corresponding level of knowing (e.g. awareness, recognition, acknowledgment or acceptance).[18] Similarly, Stroebe and Schut (1999) have argued that a person frequently "oscillates" between avoiding and confronting the possibility of death.[19] Taking these points into consideration, readiness should not be seen as a unequivocal prerequisite for starting an ACP conversation, but rather as a state of mind that fluctuates throughout an ACP conversation.

Based on our findings, we developed the following description of readiness for ACP. It is necessary to note that most patients in our study were *partially* ready for ACP, meaning that they could talk about some, but not all ACP topics.

Readiness for ACP is the *willingness* and *ability* to engage in a discussion about the progression of one's illness, one's current physical and/or mental state, and possible future scenarios related to the end of life; one is also ultimately ready for ACP when one can both rationally articulate one's stance toward end-of-life topics, can articulate one's corresponding emotions, and can imagine oneself in future situations.

This study has strengths and limitations that should be taken into account when interpreting the results. A strength of this study was that investigator triangulation was applied by including three researchers with different professional backgrounds and expertise in the data analysis team. This lead to in-depth discussions and a search for agreement about how to interpret and categorize the signs of readiness and of not being ready. It is worth noting that we studied facilitated conversations that were structured by a conversation guide. The facilitators were trained to bring up and to explore all topics. As a consequence, the topics discussed were the same in all conversations. This enabled us to study readiness in relation to a broad range of ACP topics. However, facilitated and structured conversations can have a unique influence on the patients' readiness to be discerned from other ACP approaches, for example, ACP conversations conducted by the patient's physician or nurse using an open approach that is more aligned to the patient. This could influence the patient's readiness, although it is difficult to hypothesize in what way.

Only 13 conversations were included for analysis and all concerned Dutch respondents. Although there is a variety between patients, it should be investigated whether patients participating in an unstructured ACP conversation or patients from other countries express the same signs of readiness and not being ready. Lastly, it should be noted that patients who were willing to participate in the ACTION trial might have self-selected as being receptive to and ready to discuss ACP.

Conclusion

Patients do not have to be ready for all elements of ACP to participate in an ACP conversation. During ACP conversations, patients are able to discuss ACP-related topics and respond to questions they feel ready to discuss. However, patients may not be ready to discuss all topics. Nevertheless, an exposure to topics that might trigger signs of not being ready can at least make a patient aware. Moreover, a patient might be able to answer such questions even when they are emotionally difficult.

Practice implications

HCPs should not use the patient's readiness before an ACP conversation as an indicator whether or not to initiate or to postpone an ACP conversation. Instead, HCPs should initiate a person tailored ACP conversation by being aware of the patient's signs of being ready and of not being ready and of potential triggers of signs of not being ready. In addition, knowing the patient's ability to alternate in readiness depending on the topic that is being discussed, HCPs can guide the patients through the conversation accordingly.

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Chapter 8

Content analysis of Advance Directives completed by patients with advanced cancer as part of an Advance Care Planning intervention: insights gained from the ACTION trial

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Under Review

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ABSTRACT

Purpose: Writing an Advance Directive (AD) is often seen as a part of Advance Care Planning (ACP). ADs may include specific preferences regarding future care and treatment and information that provides a context for healthcare professionals and relatives in case they have to make decisions for the patient. The aim of this study was to get insight into the content of ADs as completed by patients
with advanced cancer who participated in ACP conversations.

Methods: A content analysis and descriptive statistics were conducted to describe the content of the completed My Preferences Forms, an AD used in the intervention arm of the ACTION trial, testing the effectiveness of the ACTION Respecting Choices ACP intervention.

Results: In total, 33% of 439 patients who received the ACTION RC ACP intervention completed a My Preferences Form. Document completion varied per country: 9.6% (United Kingdom), 21% (Denmark), 27.6% (Belgium), 43.8% (the Netherlands), 61.3% (Italy) and 64.3% (Slovenia). Content analysis showed that 'maintaining normal life' and 'experiencing meaningful relationships' were important for patients to live well. Fears and worries mainly concerned disease progression, pain or becoming dependent. Patients hoped for prolongation of life and to be looked after by healthcare professionals. Most patients preferred to be resuscitated and 44% of the patients expressed maximizing comfort as their goal of future care. Most patients preferred 'home' as final place of care.

Conclusions: My Preferences Forms provide some insights into patients' perspectives and preferences. However, understanding the reasoning behind preferences requires conversations with patients.

INTRODUCTION

An Advance Directive (AD) provides a framework for patients to document thoughts regarding future medical care and treatment, to ensure that their wishes and preferences can be followed if they become unable to make their own decisions.[1] Although ADs can be helpful in maintaining the quality of a patient's end of life,[2,3] the majority of people do not have an AD, mainly due to a lack of knowledge of ADs or because an AD is considered unnecessary now.[4,5] Consequently, the use of ADs in clinical practice remains low.[4-10] Advance Care Planning (ACP) conversations can be effective to increase the rate of completed Ads.[11-13] Therefore, the completion of ADs is no longer seen as self-contained, but rather as a component of ACP. This perspective is reflected in recently developed definitions of ACP that include the opportunity to document wishes for future care and treatment as part of the ACP process.[14,15]

Currently, most ADs concern do-not-resuscitate orders, advance euthanasia directives, or a durable power of attorney for healthcare, and they often involve expressions of concrete treatment preferences.[16-18] However, if ADs are part of the ACP process, it may be helpful if they also include information on patients' values, beliefs and more general wishes. This provides a context for understanding the patient whenever healthcare professionals and relatives are to make decisions on behalf of patients who are not able to speak for themselves. To our knowledge, there is only one study that has investigated the content of ADs covering a broader range of topics.[19] This study showed that patients with haematological malignancies described aspects related to medical treatments or actions, effective pain treatment and personal messages for their family in their ADs. What patients describe in a more comprehensive AD in the context of a guided ACP conversation, has not yet been investigated. Consequently, we do not know whether patients provide in-depth information on their preferences in their ADs after having participated in a guided ACP conversation. An analyses of ADs made following or during an ACP conversation may provide insight into the various factors that are important to seriously ill patients. An analysis may also show whether relatives and healthcare professionals can use the information if they have to make decisions for the patient.

The aim of this study was to get insight into the content of ADs completed by patients with advanced cancer who participated in a structured ACP conversation.

METHODS

Research Design

We analysed the content of ADs of patients using content analysis[20] and descriptive statistics. This study represents a sub-study of the ACTION trial, a phase III multicentre cluster randomised controlled trial that evaluates the ACTION Respecting Choices (RC) ACP intervention in six European countries (United Kingdom (UK), Denmark (DK), Belgium (BE), the Netherlands (NL), Slovenia (SI) and Italy (IT)) (Supplementary material 1 and 2.)[21]

Population

Patients with advanced lung- or colorectal cancer were recruited to participate in the ACTION trial between May 2015 and December 2017 (see Supplementary material 3. for inclusion and exclusion criteria). For this sub-study, we included all patients participating in the intervention arm of the ACTION trial who completed and returned an AD as part of this intervention.

Data collection

During the ACTION RC ACP conversations, a facilitator who had been trained in delivering the ACTION RC ACP intervention, encouraged patients to document their goals and preferences for future medical treatment and care in a My Preferences Form (MPF) (Supplementary material 4.). The MPF was developed for the ACTION trial and can be used –depending on local regulations– as an AD. This comprehensive form consists of information about the patient's Personal Representative (PR), explorative sections regarding 'Living well' (section A1), 'Worries and fears' (section A2), 'Beliefs' (section A3) and 'Hopes' (section B), and preferences sections concerning Cardio-Pulmonary Resuscitation (CPR) (section C), goals of future care (section D), final place of care (section E) and other preferences (section F) (Supplementary material 4.). MPFs where at least one of the six sections of the form were filled in were included for analysis. Data collection continued until 1 October 2017. At that time, five of the six participating countries had finished their inclusion for the ACTION trial.

Background data (demographic characteristics and medical conditions) were retrieved from the patients' medical files and the facilitators' report of the ACP conversation.

Data analysis

The ACTION research team of each country collected and anonymised the MPFs. The answers to the closed questions (sections C, D and E) were extracted and converted into an Excel document. The open questions (sections A, B and F) were translated into English by the local ACTION researchers of DK, IT and SI. The content of all forms was merged into a single document, ordered per section.

Descriptive analyses of the answers to the closed questions of the MPF were performed using the Statistical Package for the Social Sciences (SPSS version V21.0).

We began the content analysis by (re)reading the answers of the open sections to become familiar with the data.[20] Subsequently, two authors (MZ and MK) independently started with open coding of the first three MPFs of each country (15% of included MPFs). During several meetings, MZ and MK discussed the initial codes per section of the MPF, working towards intersubjective agreement. Related codes were then clustered into categories (Table 4. Code tree). MZ continued the process of coding and categorizing. The content analysis was supported by the use of NVivo 11.

Table 4. Code tree

Category	Code	Subcode
Section A: living well		
Maintaining normal life		
	Keeping the daily routine	
	Feeling healthy	
	Enjoying life	
Undertaking activities		
	Daily activities	
		Gardening
		Walking
		Shopping
		Hobby
		Eating & drinking
	Special activities	
Being independent		Holiday
	Being able to communicate	
	Remain mentally competent	
	Remain physically independent	
Experiencing meaningful relationships		
	Family	
	Friends	
	Being of meaning	
		To other people
		Work
Being free from pain		
Additional aspects of living well		
	Nature	
	No worries, peace, no stress	
Section A: Worries and fears		
Patient worries		
	Disease progression	
		Physical decline
		A fear of frightening moments
		Hopeless suffering
		Being dependent
		Being in a vegetative state
	Unpredictability	
		Effect treatment
		Time left
	Final place of care	
	Unable to maintain normal life	
Worries about loved ones		
	Worries about relatives	
	Being a burden	
No worries		

Table 4. continued

Category	Code	Subcode
Additional worries/fears		
Section A: Beliefs		
Religious beliefs		
	Value	
	Take into account	
	Atheist	
Personal beliefs		
Spiritual beliefs		
No beliefs		
Additional information		
Section B: Hopes		
Prolonging life		
	Cure	
	Miracle	
	Shrink of the tumor	
	Being stable	
	Maintain/improve physical condition	
	Being able to be present at a special moment	
	Benefit from new treatment	
Burden of disease		
	Relieve symptoms	
	No suffering	
Preserving independency		
	Staying mentally competent	
	Being able to communicate	
Being looked after		
	Communication with health care professionals	
	Appointments with health care professionals	
In case of deterioration		
	Goals of care	
	Place of care	
	Dying with dignity	
Quality of life		
	Maintaining normal life	
	Enjoying life	
	Family	
State of mind		
	Trust in doctors	
	Staying positive	
	Fighting	
No hope		
Additional hopes		

Table 4. continued

Category	Code	Subcode
Section F: My other preferences that I consider important to be known by those who care for me		
Additional information to section A, B, C, D or E		
Treatment		
	No endless treatment	
	Alternative medicine	
	Euthanasia	
Stage of deterioration and dying		
	Visits	
	Family	
	Dignity	
After-death arrangements		
	Funeral	
		Giving substance to the funeral
		Decision about the location of the funeral
	Organ donation	
No other preferences		
Additional preferences		

One researcher of each local team checked whether the reported outcomes were in line with the content of the MPFs of their country. No significant adjustments to the categories were made. Finally, relevant quotes were extracted from the MPFs to fully convey the essence of the categories.

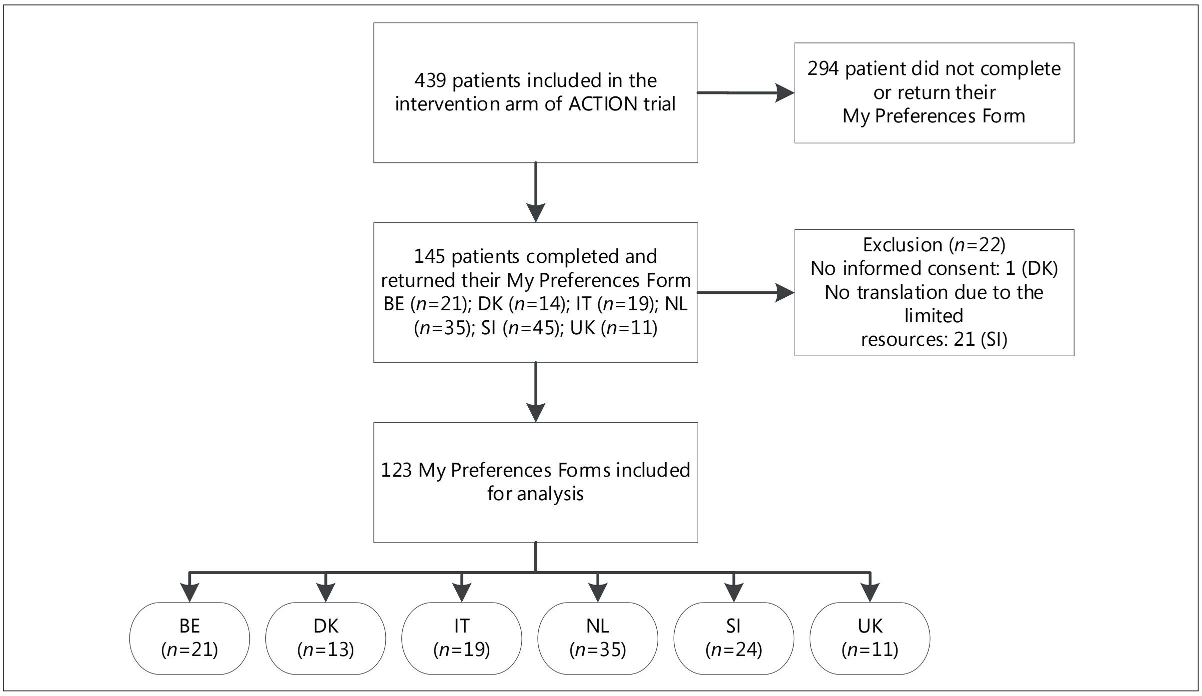
Ethical considerations

Ethical committee procedures have been followed in all countries and institutions involved, and approval has been provided. Informed consent was obtained from all individual participants in the study.

RESULTS

Of the 439 patients who participated in the intervention arm of the ACTION trial, 145 had returned the MPF by 1 October 2017. Document completion varied per country: 9.6% (UK), 21.0% (DK), 27.6% (BE), 43.8% (NL) 64.3% (SI) and 61.3% (IT). Of the 145 MPFs, 123 forms were included for analysis (Figure I). In total, 22 MPFs were excluded, mainly due to limited resources for translation (*n*=21). One patient did not give consent. Background characteristics of patients are shown in Table 2. Many patients (*n*=94) completed the MPF during the ACTION RC ACP conversation. Most patients completed at least four of the six sections (*n*=113), including 21 patients who completed all sections. Below, each section of the MPFs will be discussed separately and the number of patients who completed this section is provided.

Figure I. Inclusion My Preferences Forms for analysis



Explorative sections

Section A1: Activities or experiences that are important for me to live well (n=116)

‘Maintaining normal life’, ‘undertaking activities’, ‘being independent’ and ‘experiencing meaningful relationships’ were categories that appeared to be essential to live well for many patients from all participating countries.

Patients often described in their MPF ‘maintaining normal life’, for example: *‘To live a normal life, to maintain the everyday life’* (DK). It appeared that maintaining normal life enabled some patients to enjoy life.

The variety of described activities was captured in the category ‘undertaking activities’. Daily activities such as walking, gardening and engaging in hobbies were mentioned as well as

Table 2. Background characteristics of patients who completed a MPF

	N (%)
N patients	123 (100%)
Male	77 (62,3%)
Age	Mean 66,9 (range 40 – 86)
Marital status	
Married/civil partnership	80 (65,6%)
Unmarried	10 (8,1%)
Divorced/separated	16 (13%)
Widowed	15 (12,2%)
Living with a spouse/partner	85 (69,1%)
Living in a private household	116 (94,3%)
Having children	112 (91,1%)
Number of children living at home	Mean 2 (range 1 – 3)
Total number of years of education	Mean 12.9 (Range 5 - 26)
Being religious	51 (41,5%)
Member of a minority ethnic group in your country	1 (0,8%)
Type of cancer	
Small cell – extensive disease lung cancer	18 (14,6%)
Non-small cell lung cancer	
Colon cancer	49 (39,8%)
Rectal cancer	41 (33,3%)
	13 (10,6 %)
Stage of cancer	
Stage III, lung cancer	16 (13%)
Stage IV, lung cancer	51 (41,5%)
Colorectal cancer stage IV	42 (34,1%)
Colorectal cancer - metachronous metastases	11 (8,9%)
WHO	
0	40 (32,5%)
1	66 (53,7%
2	13 (10,6%)
3	1 (0.8%)
Current treatment*	
Chemotherapy	82 (66,7%)
Radiation therapy	18 (14,6%)
Immunotherapy	4 (3,3%)
Targeted therapy	12 (9,8%)

Data are means ± range or n (%) of total number of patients of whom information was available, this could be differ from the total n of 123.
** Some patients received more than one treatment at the same time.*

special activities, such as going on holidays or activities with beloved persons.

'A day at the sea with my loved ones' (IT).

'Being independent' was described by patients in different ways. Some patients used the word 'independent' as such, others described for example being able to communicate, being physically independent and remaining mentally competent. '*To be able to take care of myself'* (DK), '*When I can do things autonomously'* (IT) and *'Being able to think clearly'* (SI).

'Experiencing meaningful relationships' was by some patients described as having a '*family life'* (DK) or '*friendship*' (NL). Other patients elaborated on their relationships, describing visits to family and friends or engaging in activities with them, in particular with children and grandchildren. Some patients described the importance of their life having meaning, writing down for whom and how they wanted to be of meaning. For instance, by contributing to their organization as an employee or helping their children by taking care of grandchildren.

Some patients, from NL, IT and the UK specifically, described being free from pain in this section, mainly as a precondition of living well.

Section A2: I have the following fears or worries (n=92)

Patients from all participating countries feared the consequences of disease progression. Some patients expressed this in a general way, '*Fears and worries about the complications of the illness'* (IT), while others were more concrete in their worries and fears regarding disease progression. For example: having less energy, physical decline, hopelessness suffering and frightening experiences (e.g. *'to be in pain'* [SI]). Several patients described their fear of becoming dependent or being in a vegetative state. As one patient expressed: '*My greatest fear is being trapped in an unresponsive body'* (UK).

Patients also struggled with unpredictability, worrying about the outcomes of their treatment and how much time they had left. '*Naturally, I am worried about whether the treatment will work on me'* (DK).

Becoming unable to maintain their normal life was a fear expressed by a few patients as well as the worry or fear of being taken to a final place of care they disliked.

Several patients from IT, NL and the UK worried about being or becoming a burden or causing distress to their relatives. Some patients worried about how their loved ones would recover after they had passed away. For example, one patient mentioned being married for 50 years and was worried about his spouse.

Several patients wrote that they had no worries or not yet. Others mentioned they actively avoided thinking about worries and described living one day at the time or trying not to think about worries and fears: '*Of course I have fears and worries, but I will not let my life be influenced by it. 'It goes the way it comes'* (NL).

Section A3: I have the following cultural, religious or spiritual beliefs (n=68)

Religion was described by most patients. Fifteen patients specified their religion (e.g. Church of England, Catholic or Christian). The same number of patients elaborated on the role their religion played in their lives regarding their disease or described preferences based on their religion. For example, '*I have no fear of dying, I know He is waiting for me*' (NL) or *'Church of England. I would want to see the vicar if I was very poorly'* (UK*).*

Regarding personal beliefs, a few patients described living day-by-day, not giving up and being positive. One patient described: '*I believe in faith, that the course of life and experiences are predestined'* (SI). Some patients addressed their belief in science and the health system. Not having any beliefs that affected their wishes was also described by a number of patients.

Section B: My hopes for my current medical plan of care include (n=118)

The majority of patients hoped for prolongation of life. Several patients expressed this as hope for a cure, remaining stable or the hope that their tumour would shrink. Other patients described prolongation of life in terms of being able to reach a special moment. '*I hope to await my daughter´s graduation*' (BE). A few patients wanted to prolong their lives in the hope that science would make progress on treatment that improved their chance for survival.

Hope to diminish the burden of the disease was also described and included being free from suffering as well as symptom relief. Patients mentioned in particular the hope of being free from pain.

Patients from all participating countries described their hope to remain independent and expressed the hope that they would remain able to take care of themselves.

Another hope expressed by patients was being looked after by healthcare professionals. This was specified as the hope for frequent appointments and good collaboration with the healthcare professional, which included receiving clear and honest information.

Some patients shared their goals of care in the case of deterioration (NL, SI, UK). For example, '*To a certain limit (treatment) as long as tolerant and humane to me*' (NL). Others hoped to stay at home as long as possible (BE, NL, UK) or to die with dignity (BE, IT, UK): '*When it comes to the end, I want to go in peace and not to keep me hanging on*.' (UK).

Described hopes also included maintaining a normal life and enjoying life: '*Hope chemo will maintain my current quality of life*' (UK). Some patients from NL, IT and SI described their state of mind in the section of hope. These patients wanted to stay positive, were willing to fight or trusted their healthcare professionals. Only one patient described not having any hopes because of the advanced stage of the disease.

Preferences sections

Personal Representative (n=111)

Of the 123 patients, 111 patients had chosen someone to make decisions on their behalf if they would become unable to make decisions themselves.

Section C: My preferences regarding resuscitation (n=118)

Two thirds of the patients (*n*=77) indicated their preference to receive CPR if their physician considered it medically appropriate in their actual situation (Table 3). This option was

Table 3. Indicated preferences

	BE (n=21)	DK (n=13)	IT (n=19)	NL (n=35)	SI (n=24)	UK (n=11)	Total (n=123)
Cardio Pulmonary Resuscitation (CPR) (Section C)							
I wish to have CPR attempted if my physician considers it medically appropriate in my actual situation.	11 (52,4%)	10 (76,9%)	17 (89,5%)	20 (57,1%)	12 (50%)	7 (63,6%)	77 (62,6%)
I do not wish CPR attempted if my heart or breathing stops.	9 (42,9%)	3 (23,1%)	2 (10,5%)	14 (40%)	7 (29,2%)	4 (36,4%)	39 (31,7%)
Added sentences*	1	4	0	1	2	0	8
Left open	1 (4,8%)	0	0	0	4 (16,7%)	0	5 (4,1%)
Goals of Care (Section D)							
Selective Treatment plus Comfort-Focused care	3 (14,3%)	6 (46,2%)	17 (89,5%)	12 (36,3%)	11 (45,8%)	7 (63,6%)	56 (45,5%)
Comfort-Focused Care	13 (61,9%)	5 (38,5%)	2 (10,5%)	22 (63%)	9 (37,5%)	3 (27,3%)	54 (43,9%)
Added sentences*	1	3	0	8	4	2	18
Left open	5 (23,8%)	2 (15,4%)	0	0	3 (12,5%)	0	10 (8,1%)
Final Place of Care (Section E)							
I have a preferred final place of care	16 (76,2%)	11 (84,6%)	14 (73,7%)	28 (80%)	24 (100%)	10 (90,9%)	103 (83,7%)
This place is†:							
Home	10	6	7	24	19	7	73
Hospice	3	6	3	6	0	2	20
Hospital	5	1	2	0	0	2	10
Other	0	2	3	0	5	0	9
I do not have a preferred final place of care.	4 (19,0%)	2 (15,4%	3 (15,8%)	6 (17,1%)	0	0	15 (12,2%)
Left open	1 (4,8%)	0	2 (14,3%)	1 (2,9%)	0	1 (9,1%)	5 (4%)

**Either added sentences to the choice made or only described information without making a choice; †Patients could write more than 1 preferred final place of care.*

chosen most often in IT and DK (respectively 89,5% and 76,9%). Eight patients explained their choice by referring to the circumstances in which they did or did not want CPR. *'If after CPR I will return in a condition I am right now, I would choose CPR. Otherwise not'* (SI).

Section D: My goals of future care (n=113)

Preferences regarding goals of future care were almost equally divided between 'Comfort-Focused Care' and 'Selective Treatment plus Comfort-Focused Care' (Table 3). In NL and BE, the majority of the patients preferred 'Comfort-Focused Care'. In other countries, the majority of the patients chose 'Selective Treatment plus Comfort-Focused Care', where the primary goal is treating a complication. All Italian respondents, except for two, chose the latter option.

A few patients precisely clearly articulated what they meant by their preferences. For example: '*Would like to have for example IV antibiotics, if it seems to have an effect and it is only for a short period of time. Do not wish to be treated for infections if the illness is much progressed and it is futile*' (DK).

Section E: My preferences regarding final place of care (n=118)

In all six countries, the vast majority of patients reported a preferred final place of care (*n*=103), most often 'home' (*n*=73) (Table 3). Others preferred a hospice (*n*=20) or hospital (*n*=10). Patients who added specific information (*n*=24) mainly specified personal aspects of quality *'[living] at home with family'* (IT), '*[living] as long as possible and in a good condition'* (BE) or '*with a view to my garden'* (NL). A few patients added what they did not want. '*Hospice/hospital. Not home'* (UK).

*Section F: My other preferences that I consider important to be known by those who care for me (n=*50*)*

Most patients used this section to add explanations following the information provided in one of the previous sections of the MPF. To illustrate: *'If causing distress to family or if unable to be treated at home, I would like my personal representative to decide if a nursing home, hospital or hospice is the best alternative*' (UK).

A few patients wrote down preferences regarding their wish for alternative treatment, or to prevent futile treatment. A wish for euthanasia in the case of unbearable suffering was reported by a few patients from NL and BE.

Preferences regarding the stage of deterioration and dying were also mentioned, including wishes about visitors and family (*'I wish that not too many people will visit at one time'* [DK]) and being free from pain.

After-death arrangements were also described by several patients. Some patients shared their preferences regarding their funeral (e.g. cremation and pictures on the coffin) or organ donation.

DISCUSSION

We found that a third of patients participating in an ACP intervention completed an AD. The degree of completion varied substantially between countries. Analysis of ADs showed that the topics described by patients in the explorative sections mainly concerned maintaining a normal life, hope for prolonging life and experiencing meaningful relationships. Also the fear of suffering from disease progression and becoming dependent was often described. Most patients chose a personal representative and preferred 'home' as their final place of care. Preferences regarding CPR and goals of future care varied between patients and countries.

In the explorative sections, many patients described their values, wishes and hopes, as well as their fears or worries in a rather concrete way. Similar to a study by Trarieux-Signol et al. (2018)[19], who predominantly analysed blank sheet ADs, we found that preventing functional and mental dependency, effective symptom treatment and after-death arrangements were considered important.[19] However, it seemed that patients in our study provided more information regarding worries, fears and hopes. To illustrate, patients not only formulated their hope to prolong life, but also their hope that science would make progress to improve their chances. It is likely that patients provided more information because they were asked specifically about this during the ACP conversation. Studies investigating hope in palliative care confirm this variety in objectives, meanings and functions of hope.[22-24]

A completed AD with such broad information might provide healthcare professionals and relatives with a better insight in the patients' perspectives and might improve the guidance of the professionals throughout the end of life process when applying the AD. However, previous studies described the importance of ADs being as precise as possible and that ADs should include relevant information for HCPs to make decisions.[19,25,26] Other ADs often prompt patients to indicate preferences concerning specific life-prolonging treatments.[4,17,18] It is known that patients may find it difficult to complete such ADs.[16,19,27] In contrast, the preferences sections of the MPF in our study contained two sections that formulated preferences in a broader way, e.g. 'goals of future care' and 'other preferences'. These sections shed light on the patients' goals and intentions with respect to the medical treatment and care. Although less specific, it might be easier for patients to indicate their perspectives and preferences this way, which could result in an increased completion of ADs.

It would seem desirable that HCP discuss the content of ADs with patients in order to better understand their expressed preferences in light of the described thoughts in the explorative sections. ADs should provide for input in a conversation and should not prevent such conversation to happen at all.

It is important to be aware of some limitations of this study. We included forms of patients who might be more open to completing a form or who completed the form during the conversation. This might have influenced the results of this study. Additionally, although translated carefully, some information or nuances may have been lost in translation. However, by validating the results with native speaking researchers of each participating country, we believe that we took sufficient measure to mitigate this limitation.

In conclusion, this study provides the insight that being independent, maintaining a normal life, having meaningful relations and being free from pain are important topics in ADs for patients with advanced cancer in Europe. A more comprehensive AD, meaning an AD that includes explorative sections and preferences, provides healthcare professionals and relatives a better perspective of the most important values of patients at the end of their life, and, therefore, offers an opportunity to improve the guidance of the healthcare professionals. Having a conversation to understand the reasoning behind indicated preferences remains essential for relatives and HCP to make decisions that are in line with the preferences of the patient.

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Chapter 9

General Discussion

In the last two decades, Advance Care Planning (ACP) has been increasingly investigated. Studies have shown that ACP can positively influence the quality of the last phase of life.[1,2] Other research has given insight in how healthcare professionals (HCPs)[3-5] and patients think about ACP[4,6-8] and what kind of facilitators and barriers are present.[4,6,8-10] The main focus of this thesis was the experiences of patients and HCPs with structured ACP conversations. ACP may be beneficial for patients with chronic respiratory diseases due to the fact that these patients experience an uncertain future with possibly difficult decisions to be made. However, in our systematic review regarding the current practice of ACP for patients with chronic respiratory diseases (Chapter 3), it was noted that ACP was rarely carried out, while a majority of patients were interested in engaging in ACP.

While starting the systematic review regarding patient experiences with ACP, it became apparent that specific challenges needed to be overcome. A young and developing research domain, such as ACP, often suffers from poorly defined keywords and concepts and uses explorative review questions. Therefore, we developed PALETTE, a transparent and coherent pragmatic framework to overcome the challenges of conducting a literature search for a review in a developing research domain or in other domains that recognize the aforementioned challenges (Chapter 4).

We applied PALETTE to enable a literature search of the experiences of patients with a life-threatening or life-limiting illness with ACP (Chapter 5). Our results demonstrate that patients' ambivalence, readiness and openness play an important role in their willingness and ability to participate in ACP.

Earlier research has demonstrated that HCPs experience a variety of barriers to both begin and conduct ACP resulting in ACP still being relatively uncommon.[3,4,11] For this reason, we investigated how facilitators experienced delivering a structured ACP intervention (Chapter 6). It was observed that facilitators felt that aspects of the conversations were meaningful to the patients and their personal representative, but that they also questioned the emotional and practical efforts it took from patients and their personal representative. Hence, there is an ethical dilemma that facilitators feel between doing what is best for the patient and not harming them. Facilitators mentioned the importance of training and support to become experienced and feel sufficiently competent to conduct ACP conversations.

While patients' readiness for ACP is often described as a required condition for them to participate in ACP, a content analysis of structured ACP conversations regarding patient readiness showed that patients could display both signs of being and not being ready for ACP within one conversation and even within the discussion of one topic (Chapter 7).

One element of ACP is that patients are encouraged to document their goals and preferences in an advance directive (AD). Our analysis of the written document used in the RC ACTION ACP intervention, the so-called My Preferences form, revealed that being independent, maintaining a normal life, having meaningful relations and being free from pain are important topics in ADs for patients with advanced cancer in Europe (Chapter 8).

These findings suggest that a comprehensive AD provides HCPs and relatives with a better perspective of important values of patients at the end of their life. Having a conversation about the reasoning behind the indicated goals and preferences of the patient remains essential for relatives and HCPs to make decisions that are in line with these goals and preferences.

Considerations

The results from our studies lead to at least three insights regarding ACP.

Role of the facilitator

The results of our studies provide significant insight into the person who might conduct ACP conversations. In earlier research, a variety of views concerning this issue were noted.[9,10,12-16] Two aspects need to be discussed regarding the role of the facilitator: (1) whether the facilitator should be an HCP (e.g. nurse, doctor) and, (2) whether the facilitator, when being an HCP, should be involved in the regular care of patients.

Based on the analyses of audio recorded ACP conversations between facilitators and patients and on the experiences of facilitators within the ACTION study, it seems to be an advantage when the facilitator has knowledge about the disease and processes in the setting where the patient is treated. Facilitators with an HCP background are able to give patients more and realistic information about the diagnosis, relevant medical treatment and care. In addition, an HCP is better informed about the level of detail required to be able to respond to patient preferences for medical treatment and care. Clear written preferences will make it less difficult for an HCP to make a decision in line with patient preferences in a later stage. However, it can be argued that HCPs have certain patterns in their way of thinking and, consequently, do not ask sufficient questions to fully explore the patients' thoughts. To conduct ACP conversations, HCPs need other communication skills than those required for the usual conversations within their role as an HCP. Still, we recommend that ACP conversations are conducted by HCPs. To be more precise, a patient might feel better able to be open and honest about his or her goals and preferences regarding their future treatment and care to a HCP they experience as easy accessible and understanding. Such an attitude can be derived from characteristics as being able to focus at discovering what is important for the patient (patient perspective), being supportive with trust and equality and attributes of empathy and understanding. These characteristics are, generally speaking, more seen in nursing than among physicians.[13,17] However, in some medical specialisms the aforementioned characteristics are more available than in others. For example, general practitioners care known for their accessibility and a patient centered approach. When doctors will indeed conduct ACP conversations, they should be aware that patients might feel limited to discuss their goals and preferences with them. This can be explained due to the fact that doctors are often more focused on treating patients (disease orientated) and are responsible for making the medical decisions.[10,15]

The second issue is whether the HCP should be involved in regular care of the patient. There are a number of pros and cons to be mentioned in this regard. First, being able to continue the care for the patient after the ACP conversation may be an advantage of facilitators being involved. When involved, the HCP has the opportunity to check whether the patient has any questions after the conversation and whether that patient is feeling fine after having discussed difficult topics. The results of our focus group study regarding the experiences of facilitators demonstrated that indeed facilitators who were not involved in the care for the patient missed the opportunity of follow-up. Second, from the results of our focus group study, it became apparent that facilitators add information during the ACP conversation, for example, they provided realistic information about the patient's diagnosis to fill in gaps in patients' understanding. This result underlines the value of an HCP who is involved in the patient's care. Such an HCP knows the diagnosis and prognosis of the patient and, consequently, is able to tune the conversation to the patient's understanding of the disease and could provide additional information. Lastly, an involved HCP can directly incorporate the indicated preferences into the patient's care (e.g. preference regarding resuscitation). This incorporation is an advantage, particularly because patients may have difficulties in initiating a discussion of such topics with their HCP, as demonstrated in our systematic literature review. A disadvantage of being involved in the regular care for the patient, as illustrated in the focus group study, could be that having knowledge about the patient's situation negatively influences the explorative nature of the conversation. To illustrate, HCPs may consider that they already know patients' preferences and, consequently, do not ask any further to explore patients' perspectives. An additional disadvantage could be that patients do not openly discuss all topics because they think that this might influence, in a negative way, the course of the medical treatment and care or the cooperation with their HCP. This issue could possibly be influenced by the difficulty for the facilitator to distinguish the role of facilitator and HCP during the ACP conversation.

Although being involved in regular care as a facilitator may influence the exploration of patients' thoughts and their openness, we think that the benefits outweigh the negative factors. Therefore, being involved as an HCP in regular care for the patient is our recommended procedure, particularly, because an involved HCP knows the current situation of the patient and can share medical information when necessary. Moreover, an involved HCP is able to continue care for the patient after the ACP conversation.

Independently of the role the facilitator might have, the importance of being skilled and experienced in performing ACP conversations needs to be emphasized. Facilitators should know the goal of ACP, the aim of reflection during an ACP conversation, how to encourage patients to share their thoughts and that they should feel comfortable to ask potentially difficult questions to conduct a high-quality ACP conversation. Based on these factors, it is advisable that HCPs participate in ACP training and receive support; for example, by participating in group sessions to reflect on their experiences and discuss ethical dilemmas. In addition, we suggest that HCPs have access to various practical tools or ACP interventions that they could use in the care of patients.

Working with a script

That HCPs need access to tools or interventions to conduct an ACP conversation, leads directly to the second insight derived from this thesis concerning the value and challenges of working with a script. It can be discussed whether facilitators need to use a script when performing an ACP conversation. In the focus group study, it was observed that the facilitators who worked with the ACTION ACP Respecting Choices (RC) script experienced the added value of the script, but also encountered some challenges. Positive aspects of the script were that it enabled facilitators to conduct an ACP conversation in a structured manner and that the script offered them support in introducing important topics to be addressed in an ACP conversation. Moreover, the script was supportive for facilitators in asking potentially difficult questions and, by doing so, they experienced that many patients were able to answer these questions. The challenges were particularly related to the fact that working with a script was new to them and forced them to ask questions they normally would not have asked. Based on the insights into the experiences with using a script, we recommend using a script or conversation guide when a facilitator begins conducting ACP conversations. For relatively inexperienced facilitators, a tool to structure the ACP conversation is supportive. In addition, the script can be used as a tool to ask questions that are considered to be difficult for patients. When a facilitator is familiar with the words and questions and has experienced the benefits of some ‘new’ questions, the script can potentially be used as a guide. Although the script can be helpful in the beginning, advanced communication skills are definitely necessary to adequately implement the script, so that it is not used as a tick-box, and in order to respond well to individual patient needs.

Timing of an ACP conversation

The third insight concerns the moment of initiating ACP. Our systematic review regarding ACP in pulmonology showed that HCPs have difficulties initiating an ACP conversation. This issue is confirmed by other studies that found that starting ACP is difficult for HCPs[3,5,9,16,18], for example due to the fact that they are not sure about the right time to start ACP.[3,18]

Whether a certain moment is the right time, is often linked to the readiness of patients to talk about ACP-related topics.[9] This thesis provides insight into the concept of readiness. In the systematic review about patients’ experiences with ACP, we found that patients mention readiness as necessary to experience the benefits of ACP and at the same time that the conversation can increase the patients’ readiness. Still, readiness was seen by these patients as a state of being. Based on these results, we investigated signs of readiness throughout an ACP conversation. In contrast to the results of the systematic review, we found that patients are not simply ready (or not ready) for ACP, but that readiness is a more nuanced concept. To be precise, readiness is not static, but fluctuates throughout the conversation. All patients show signs of readiness as well as of not being ready when discussing a certain topic during an ACP conversation. In addition, despite signs of not being ready, patients were able and willing to continue the ACP conversation. Based on these observations, we recommend seeing readiness not as a condition to begin ACP, or as a 'yes' or 'no' concept. Readiness should rather be viewed as a dynamic concept with different levels (e.g. ready to talk about the past, present and/or future) and ACP as such can influence the patients' readiness. Therefore, HCPs should be sensitive to the readiness of patients, but should not discontinue the conversation after a difficult moment. This is particularly the case because the content analysis of the audio recordings of structured ACP conversations demonstrated that patients are able to respond, either by answering questions or by declining to think about a certain topic, and are not directly confused.

Lastly, emotions are often labelled as being an indicator of not being ready to discuss a certain topic. In our analysis, it was noted that patients expressed emotions in response to some topics but were also able to share their thoughts and/ or preferences. It can be stated that emotions are a normal response to facing end of life issues and should not directly be seen as a sign of not being ready to discuss a certain ACP-related topic.

To conclude, HCPs do not have to be afraid to initiate an ACP conversation or to ask questions to patients expressing signs of not being ready. HCPs need to be aware of patients' ability to alternate in readiness depending on the topic being discussed. Nevertheless, when patients do not want to participate in ACP, even after an explanation of its aims and potential benefits, patients still obviously have the right to refuse ACP.

Limitations and strengths

Some strengths and limitations of this thesis should be taken into account. A strength of this thesis is that the studies have been performed in the context of the ACTION study, a collaboration of six European countries.[19] This collaboration including the discussions of the findings and sharing views was very valuable, but at the same time sometimes challenging, particularly regarding the different languages involved. To specify, we evaluated an intervention that was first created in the USA and needed to be translated into the different languages of participating countries while considering cultural variance. In addition, focus group transcripts had to be translated into English. Although the transcripts were carefully translated, some information or nuances may have been lost in translation. However, by validating the results of all empirical international manuscripts with native speaking researchers of each participating country, we believe that we took sufficient measures to mitigate this limitation.

A strength of this thesis is that we included experiences of patients as well as HCPs. However, including patients' experiences with the ACTION RC ACP conversation would have made this thesis more complete. Due to limited time and resources, we were not able to include such data in this thesis.

Conclusion

This thesis provides insight into the experiences of patients and HCPs with ACP. It demonstrates that patients and HCPs experience positive elements as well as challenges related to ACP. Positive elements are that ACP conversations are informative and helpful and provide the opportunity to talk about important topics in a structured manner. The challenges derive from the fact that talking about ACP-related topics can be confrontational and that HCPs feel uncertain to conduct ACP conversations. Based on insights from experiences of patients as well as facilitators, it can be concluded that ACP has the potential to improve the quality of end-of-life communication. Recommendations to improve ACP are that it should preferably be implemented by trained HCPs who are involved in the regular care for patients, that exploration of patients' interest in ACP conversations should not solely be dependent on perceived readiness of patients, and that, finally, tools, training and support for HCPs are required to bring out the best of ACP.

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Chapter 10

Appendices

Supplementary material 1. The ACTION trial

The primary objective of the ACTION trial is to test the effectiveness of an adapted version of the Respecting Choices (RC) ACP programme among patients affected by advanced lung (small cell – extensive disease/ stage III of IV and non-small cell – stage III of IV) and colorectal cancer (stage IV of metachronous metastases) in a cluster randomised design. Twenty-two hospitals in six European countries —Belgium (BE), Denmark (DK), Italy (IT), the Netherlands (NL), Slovenia (SI) and the United Kingdom (UK)— were randomised in the intervention arm (ACTION RC ACP programme) or control arm (care as usual). In total, 1360 patients will be included (Trial Number: ISRCTN63110516).

Supplementary material 2. The ACTION Respecting Choice Advance Care Planning intervention

In the ACTION trial, we evaluate the ACTION Respecting Choices (RC) Advance Care Planning (ACP) intervention. The ACTION RC ACP intervention is an adapted and integrated version of the RC ® First Steps and Advanced Steps RC facilitated ACP conversation. The RC facilitated ACP conversation is one component of the more comprehensive RC ACP programme that was developed and implemented in La Crosse, Wisconsin, and also includes health care system redesign; the education of the whole health care team; patient and community engagement; and ongoing management with quality improvement. More details can be found at www.respectingchoices.org.

Translation

ACTION RC ACP intervention materials were drafted in English and were translated into the languages of the countries participating in the ACTION trial, in close collaboration with the RC programme developers. In this translation process, materials were, where necessary, adapted to local cultural and ethical nuances, whilst not losing the content, structure and integrity of the RC ACP facilitated conversation. In addition, we developed the so-called My Preferences form. The My Preferences form can be used to document the patient’s goals, values, and preferences. Depending on local legal regulations, the My Preferences form can be used as an Advance Directive.

Education and Certification

The ACTION RC ACP intervention consists of one or two conversations between the patient and, if he or she wishes, a relative, and a certified facilitator (mostly a nurse). In each country, 4-10 facilitators, in total 39, participated in a two-day RC First and Advanced Steps training programme given by a certified RC teacher. The training programme included role plays, videos demonstrating RC ACP conversations, and one additional day homework assignments. Trained facilitators were certified using competency based criteria. During the ACTION trial, facilitators received regular support and feedback from the RC teacher, based on audio-recorded conversations. Furthermore, facilitators had the opportunity to share their experiences or to discuss difficulties with the RC teachers.

Main elements of the ACTION RC ACP intervention

1. ACP CONVERSATION GUIDES

The ACTION RC ACP conversations are structured by the use of conversation guides that include scripted questions, information and the integration of general interview (communication) skills. Based on these guides, facilitators support patients and their relatives in exploring the understanding of their illness, in reflecting on their goals, values and beliefs, and in discussing their preferences for future treatment and care. The intervention also supports patients in identifying specific activities and experiences that may contribute to, or detract from, their quality of life and future care planning.

There are three conversation guides that facilitators select for different situations:

- The blue guide: for the first conversation with the patient and a personal representative (PR).
- The green guide: for the first conversation with the patient, but without a PR.
- The yellow guide: for a follow-up conversation with the patient and a PR.

These conversation guides include a variety of topics. To start, patients are supported in identifying a PR, who preferably also attends the follow-up ACTION RC ACP conversation. This enables the PR to become familiar with the patient's views and wishes and encourages an open dialogue between the patient and the PR. Next, the script continues with the following key topics: what is the patient's understanding of their disease and possible complications, what did the patient learn from previous experiences with family or friends who became ill and were not able to communicate, what are the patients' beliefs, what are the patients' fears and worries, what is the patient hoping for, and what is important for the patient to live well. In addition, the patient's preferences concerning resuscitation, goals of care, and final place of care are discussed. Finally, patients are informed by the facilitator that they can document their preferences for future medical treatment and care in the My Preferences form. Patients are encouraged to discuss their preferences and questions with their attending physician.

2. MY PREFERENCES FORM

The My Preferences form is partly based on the RC Power of Attorney for Healthcare and the Physicians Orders for Life-Sustaining Treatment (POLST) program in the U.S. (www.polst.org). The My Preferences form aligns with topics in the conversation guides and consists of open sections regarding 'Living well', 'Worries and fears', 'Beliefs', and 'Hopes', and a structured section in which patients can indicate their preferences regarding Cardio-Pulmonary Resuscitation (CPR), goals of future care, and final place of care as well as other preferences.

3. INFORMATION LEAFLETS

The facilitators provide leaflets with information regarding ACP and the role of the Personal Representative (PR) to all participants. Where relevant, facilitators also provide leaflets about resuscitation, artificial ventilation and/or artificial feeding. The content of these leaflets was informed by the original RC patient educational materials.

Fidelity

For each facilitator, fidelity assessments were conducted twice. In these assessments, the ACTION RC teachers evaluated to what extent the facilitators adhered to the ACTION RC ACP intervention by assessing:

A. To what extent the content of the facilitator's conversation with patient and, when present, the PR, was in accordance with the ACP Conversation Guide;
B. The facilitator's general interview (communication) skills;
C. The overall quality of the ACP conversation.

Supplementary material 3. Inclusion and exclusion criteria ACTION trial

Inclusion Criteria	Exclusion Criteria
Histologically confirmed diagnosis of: ✓ Lung cancer stage III or IV ✓ small cell – extensive disease/ stadium III of IV* ✓ non-small cell – stadium III of IV* ✓ Colorectal cancer ✓ stadium IV or metachronous metastases And ✓ WHO performance status 0 – 3 ✓ Written informed consent to participate	✗ Age < 18 jaar ✗ Unable to provide informed consent ✗ Unable to complete questionnaire in country's language ✗ Less than 3 months anticipated life expectancy ✗ Taking part in a research study that is evaluating palliative care services or communication strategies.

*according to 7th edition of TNM classification and staging system

Supplementary material 4. The My Preferences Form

The My Preferences form was developed by the ACTION research team for the purposes of the ACTION trial. The form can be seen and used –depending on local regulations– as an Advance Directive. Aside from the legal status of the My Preferences form, it can provide useful information for both healthcare professionals and family members when they have to make a decision on behalf of the patient.

The My Preferences form consists of six sections with open and closed questions concerning patients' wishes and preferences in relation to their future medical treatment and care. The first two sections (section A and B) are open sections and explorative. In these two sections, the patients can describe their thoughts regarding 'Living well' (section A), 'Worries and fears' (section A), 'Beliefs' (section A), and 'Hopes' (section B).

The next three sections (section C, D, and E) are multiple choice questions and consist of decisions regarding the (non-)use of potentially burdensome life-prolonging interventions. In section C, Cardio-Pulmonary Resuscitation (CPR), the patient can choose between (1) 'I wish to have CPR attempted if my physician considers it medically appropriate in my actual situation' or (2) 'I do not wish CPR attempted if my heart or breathing stops'. In section D, goals of future care, the patient can choose between 'Selective Treatment plus Comfort-Focused Care' (Primary goal of attempting to treat the complication) and 'Comfort-Focused Care' (Primary goal of maximizing comfort). Both sections are closed, but patients are able to included additional information regarding their preference. In section E, the patients can write whether they have a preferred final place of care. If yes, they are able to describe which place (more answers are possible).

In the last section (section F) there is space for patients to include other information which the patients consider as important to share with relevant others.

Patients have the opportunity to complete this form during the ACTION RC ACP conversation with the facilitator, but may also complete the form at home, at their own convenience.

Advance Care Planning conversation: An open or a scripted conversation?

M Zwakman, MC Kars, JJM van Delden
February 8, 2017

Continuing a series of posts from members of the ACTION Consortium about their European study that aims to investigate how to support people with advanced cancer to have a conversation about preferences and wishes.

Marieke Zwakman, Marijke Kars and Hans van Delden, Team Utrecht, discuss whether Health Care Professionals should use an open or structured approach when performing an Advance Care Planning conversation.

There is a growing interest in Advance Care Planning (ACP). ACP involves a process of conversations between patients and their relatives about patients' goals and wishes for future care and treatment to prepare for events in which patients may not be able to make decisions for themselves. Although ACP is viewed as an important strategy to improve the communication between patients and Health Care Professionals (HCPs) (Brinkman, 2014), in practice the frequency of conversations remains low.

In the Netherlands, there is no accepted standard on how to perform an ACP conversation. From our experience, HCPs typically conduct these conversations intuitively. They tend to use an open and flexible approach (open strategy). By applying an open strategy, they maximally follow the patient, which means that they reply to patients' questions and signals in a very individualized and sensitive way. In line with this, HCPs are inclined not to mention topics the patient might not want to talk about or topics they consider to be potentially stressful for the patient. An important goal for HCPs who engage in ACP is to prevent confrontations that could unbalance the patient (Mullick, 2013). However, as a result of this approach patients might miss out on the opportunity to think and talk about aspects of ACP that they themselves do not mention.

Currently, there is an increase in initiatives that provide more guidance to HCPs to conduct an ACP conversation. With the open strategy at one end, the other end of the continuum consists of a completely scripted approach. When HCPs use a scripted ACP conversation guide, discussing all topics that are addressed in the guide may pose a challenge given the barriers for engaging in ACP that have been reported by HCPs (e.g. the fear of upsetting the patient by destroying hope) (Mullick, 2013). However, a script could be a strategy that provides guidance and which enables HCPs to ask potentially difficult questions. Consequently, patients and their relatives will have the opportunity to become aware of the patient's wishes and preferences and will probably even discuss topics they did not think about before.

It seems that both strategies have a number of advantages as well as disadvantages. Using a scripted intervention enables researchers to safeguard the fidelity of the intervention. Consequently, this will improve the quality of the research. In the ACTION study (a cluster randomised controlled trial in six European countries), a structured ACP script that is a modified version of the 'Respecting Choices' programme is tested (Rietjens, 2016). In an embedded qualitative study, we investigate the experiences of the patients, their relatives and their HCPs with this programme. This qualitative study will increase our understanding of conducting, and participating in a scripted ACP conversation and will contribute to the improvement of ACP interventions.

Links

- ACTION: https://www.action-acp.eu/
- Follow us on Twitter @ACPinScience
- Read more posts from the ACTION Consortium on the EAPC Blog.

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Chapter 11

Summary

Samenvatting

Everybody will be confronted with illness and death at some point in their life. The medical treatment and care that patients receive at the end of their life should be appropriate and in concordance with the patients' goals and preferences. To achieve this concordance, an exploration of the goals and preferences of the patient is required. Therefore, Advance Care Planning (ACP), a strategy to support planning for future medical treatment and care, was developed. ACP has potential benefits for patients and healthcare professionals; however, some barriers remain. Investigating real experiences of patients and healthcare professionals with ACP is needed to understand the process of ACP and to develop suggestions to improve ACP.

In **Chapter 2**, we describe the protocol of the ACTION trial. The ACTION trial is a European multi-centre cluster Randomised Control Trial (RCT) that evaluated an adapted version of the Respecting Choices (RC) ACP intervention, named the ACTION RC ACP intervention. This trial was conducted in a population of adult patients with advanced lung or colorectal cancer. This intervention includes an ACP conversation about the patients' goals and preferences for future medical treatment and care with a trained facilitator (mostly nurses) and, if the patient wishes, a relative. This conversation is structured with the use of a scripted conversation guide. The ACTION trial enabled us to investigate experiences of patients and healthcare professionals with a structured ACP conversation.

In **Chapter 3**, we give an overview regarding the current practice of ACP for patients with chronic respiratory diseases. This systematic literature review showed that ACP is uncommon in chronic respiratory disease, which could be caused by the complex disease course of chronic respiratory diseases and ambivalence of both patients and healthcare professionals to engage in ACP. Additionally, system related factors (e.g. time and formal training) created barriers. These barriers could be overcome with improvements, such as triggers point throughout the disease course to discuss ACP, and second, training healthcare professionals on how to communicate about sensitive topics such as end-of-life care.

In **Chapter 4**, we present the iterative method PALETTE (Palliative cAre Literature rEview iTeraTive mEthod). We developed this transparent framework to overcome the challenges of conducting a literature search for a review in less conceptually developed fields. PALETTE consists of four phases: developing the review question, building the search strategy, validating the search strategy and performing the search. The phases within PALETTE are interconnected by a recurrent process of validation on 'golden bullets' (articles that align with the inclusion criteria and undoubtedly should be part of the review) and citation tracking. The comparison of PALETTE with the recommended search method for reviews of intervention studies showed that PALETTE helps to improve question development, increase the understanding of the topic of interest and supports the development of a literature search. Additionally, PALETTE provided greater balance between the Number Need to Screen and identified relevant articles. Although the different techniques used within PALETTE already exist on their own, we provide a framework to use these in a transparent and coherent way with a clear decisional tree. As such, PALETTE is a promising framework and provides guidance for researchers in performing systematic literature searches.

In **Chapter 5**, we give an overview regarding the experiences of patients with a life-threatening or life-limited disease with ACP. This review showed that patients are ambivalence about being involved in ACP, as they simultaneously experienced positive as well as unpleasant feelings throughout the whole ACP process. Additionally, patients indicated they needed a degree of readiness to face their own end of life and, consequently, to discuss preferences for future care. It was also seen that the ACP process itself positively influenced the patient's readiness. Lastly, patients needed to feel comfortable to be open about their wishes and thoughts with relevant others (openness). Therefore, we propose to adopt personalised ACP: a form of ACP that is in line with evidence from the literature, the patients' readiness and their current coping strategies.

In **Chapter 6**, we investigated trained facilitators experiences conducting a structured ACP conversation with patients with advanced lung or colorectal cancer. This study gave insight that the intervention was supportive to conducting ACP conversations as well as challenging. Facilitators learned that addressing topics that made patients think and discuss their current and future situation and preferences often resulted in meaningful moments. Although facilitators evaluated the script as helpful at times, most experienced it as a barrier to a spontaneous conversation. In addition, the facilitators observed that it took patients substantial effort to have these conversations. Consequently, facilitators took responsibility for enabling patients to experience a conversation from which they could benefit. Based on this insight, we could say that training and coaching on the job is important for facilitators to build confidence and becoming skilled in delivering ACP conversations.

In **Chapter 7,** we explored patients' readiness during the course of an ACP conversation. This study lead to the insight that all patients expressed both signs of not being ready and of being ready within one conversation. Signs of being ready included answering questions on a personal level or demonstrating an understanding of one's disease. Signs of not being ready included limiting one's perspective to the here and now or indicating a preference not to talk about an ACP-related topic. These signs were occurred most frequently when future oriented topics such as ‘complications’ and ‘hope’ were discussed. Despite showing signs of not being ready, patients were able to continue the ACP conversation. In addition, we noticed a differentiation in patients’ readiness and willingness to discuss topics related to the past, the present or the future, as well as a differentiation in the manner in which patients articulated their stance (via rational perspective taking or experimental perspective taking). Based on these results, we conclude that patients do not have to be ready for all elements of ACP to be able to participate in an ACP conversation. Therefore, we recommend that healthcare professionals should initiate a person tailored ACP conversation by being aware of the patient’s shifting state of readiness during the conversation and of potential triggers of signs of not being ready.

In **Chapter 8,** we gave insight into the content of Advance Directives as completed by patients with advanced lung or colorectal cancer who participated in ACP conversations within the ACTION trial. Of the in total 439 patients who received the ACTION RC ACP intervention, 33% completed a My Preferences Form (a form developed for the ACTION trial that can be seen and used as an Advance Directive). The explorative sections showed that ‘maintaining normal life’ and ‘experiencing meaningful relationships’ were important for patients to live well. Fears and worries mainly concerned disease progression, pain or becoming dependent. Patients hoped for prolongation of life, diminish the burden of the disease and to be looked after by healthcare professionals.

In the preferences section it was seen that most patients preferred to be resuscitated (62,6%) and 44% of the patients expressed maximizing comfort as their goal of future care. Most patients preferred ‘home’ as their final place of care. Thus, a comprehensive Advance Directive provides healthcare professionals and relatives a better perspective of the most important values of patients at the end of their life, and, therefore, offers an opportunity to improve the guidance of the healthcare professionals. Having a conversation remains essential to understanding the reasoning behind the indicated preferences.

Finally, in **Chapter 9,** we describe three insights based on the results of our studies. First, the role of the facilitator. Our recommended procedure is an ACP conversation conducted by a healthcare professional who is involved in the regular care of the patient. This healthcare professional should have characteristics including being able to focus on what is important for the patient and being supportive with trust and equality. Independently of the role the facilitator might have, the importance of being skilled and experienced in performing an ACP conversation needs to be emphasized.

Our second insight includes working with a script. We recommend using a script during an ACP conversation, especially for a facilitator with less experience because the script offers them support. The last insight concerned the timing of an ACP conversation. The timing of an ACP conversation is often linked to the readiness of patients. We suggest seeing readiness not as a condition to begin ACP, or as a ‘yes’ or ‘no’ concept. Instead, healthcare professionals should be sensitive for the readiness of patients and should not discontinue after a difficult moment. Finally, tools, training and support for healthcare professionals are required to bring out the best of ACP.

Samenvatting

Iedereen wordt op enig moment in zijn leven geconfronteerd met ziekte en de dood. De medische behandeling en de zorg die patiënten ontvangen aan het einde van hun leven, moet passend zijn en moet in overeenstemming zijn met de doelen en voorkeuren van de patiënt. Om deze overeenstemming te bereiken, is een verkenning van de doelen en voorkeuren van de patiënt nodig. Om deze reden is vroegtijdige zorgplanning ontwikkeld, een strategie die ondersteunend is in het plannen van toekomstige medische behandeling en zorg. Vroegtijdige zorgplanning heeft potentiële voordelen voor zowel patiënten als zorgverleners. Echter, er blijven een aantal barrières bestaan. Het onderzoeken van echte ervaringen van patiënten en zorgverleners met vroegtijdige zorgplanning is nodig om het proces van vroegtijdige zorgplanning te begrijpen en om suggesties ter verbetering van vroegtijdige zorgplanning te ontwikkelen.

In **Hoofdstuk 2** beschrijven we het protocol betreffende de ACTION studie. De ACTION studie is een multicenter cluster gerandomiseerde studie. In deze studie wordt een aangepaste versie van de Respecting Choices (RC) interventie, genaamd de ACTION RC Advance Care Planning (ACP) interventie, geëvalueerd in een populatie van volwassen patiënten met gevorderde longkanker of colorectaal kanker. Deze interventie bestaat uit een vroegtijdige zorgplanningsgesprek over de doelen en voorkeuren van de patiënt betreffende toekomstige medische behandeling en zorg met een getrainde gespreksondersteuner (meestal verpleegkundigen) en, als de patiënt dit wil, een naaste. Dit gesprek is gestructureerd door middel van een script.

In **Hoofdstuk 3** geven we een overzicht van de huidige praktijk van vroegtijdige zorgplanning bij patiënten met chronisch longaandoeningen. Deze systematisch literatuurstudie laat zien dat ondanks het feit dat zowel patiënten als zorgverleners geïnteresseerd waren in vroegtijdige zorgplanning en de toegevoegde waarde ervan zagen, deze gesprekken weinig plaatsvonden. Een oorzaak hiervan kan de complexe loop zijn van chronisch longaandoeningen en de ambivalente gevoelens van zowel patiënten als zorgverleners om deel te nemen aan vroegtijdige zorgplanning. Bovendien creëren systeem relateerde factoren (zoals tijd en training) barrières. Deze barrières kunnen overwonnen worden door verbeteringen zoals *trigger points* gedurende de ziekte om vroegtijdige zorgplanning te bespreken. Daarnaast zouden zorgverleners training moeten krijgen om te communiceren over gevoelige onderwerpen zoals het einde van het leven.

In **Hoofdstuk 4** presenteren we de iteratieve methode PALETTE (Palliative cAre Literature rEview iTeraTive mEthod). We hebben deze nieuwe methode ontwikkeld om literatuur te kunnen zoeken in minder conceptueel ontwikkelde velden. PALETTE bestaat uit vier fasen: de ontwikkeling van de vraagstelling, het bouwen van de zoekstrategie, het valideren van de zoekstrategie en het uitvoeren van de zoekstrategie. De fasen van PALETTE zijn met elkaar verbonden door een terugkerend validatieproces met de hulp van de zogenoemde *golden bullets* (artikelen die voldoen aan de inclusiecriteria en die beslist deel uit moeten maken van het review) en *citation tracking*.

De vergelijking van PALETTE met de aanbevolen methode voor het zoeken van literatuur over interventie studies laat zien dat PALETTE helpt bij de verbetering van de vraagstelling, het vergroot het begrip van het betreffende onderwerp en het ondersteunt de ontwikkeling van de zoekstrategie. Bovendien geeft PALETTE een betere balans tussen het aantal te screenen artikelen en het aantal geïdentificeerde relevante artikelen.

Hoewel de technieken die gebruikt worden in PALETTE al op zichzelf bestaan, bieden wij een kader om deze verschillende technieken op een transparante manier met een duidelijke beslisboom te gebruiken. PALETTE is een veelbelovende methode die adequate begeleiding biedt aan onderzoekers.

In **Hoofdstuk 5** geven we een overzicht van de ervaringen van patiënten met een levensverkortende of levensbedreigende ziekte met vroegtijdige zorgplanning. Dit review laat zien dat patiënten ambivalent zijn over vroegtijdige zorgplanning: patiënten ervaren op hetzelfde moment zowel positieve als onprettige gevoelens gedurende het gehele proces van vroegtijdige zorgplanning. Daarnaast geven de patiënten aan dat ze een zekere mate van *readiness* (in de betekenis van er klaar voor zijn) nodig hebben om het einde van hun eigen leven onder ogen te zien. De patiënten gaven ook aan dat het proces van vroegtijdige zorgplanning hun *readiness* positief beïnvloed. Als laatste gaven patiënten aan zich comfortabel te moeten voelen om open te zijn over hun wensen met relevante anderen (openheid). Daarom stellen wij gepersonaliseerde vroegtijdige zorgplanning voor: een vorm van vroegtijdige zorgplanning die aansluit op de literatuur, de mate van *readiness* van de patiënt en diens coping strategie.

In **Hoofdstuk 6** hebben we onderzocht hoe getrainde gespreksondersteuners het hebben ervaren om gestructureerde vroegtijdige zorgplanningsgesprekken te voeren met patiënten met gevorderde longkanker of colorectaal kanker. Deze studie maakte inzichtelijk dat de ACTION RC ACP interventie ondersteunend was om vroegtijdige zorgplanningsgesprekken te voeren en tegelijk een uitdaging. Gespreksondersteuners leerden dat het adresseren van onderwerpen die patiënten aanzetten tot het kijken naar en bespreken van hun huidige en toekomstige situatie vaak resulteerden in betekenisvolle momenten. Hoewel de gespreksondersteuners het script als helpend hebben geëvalueerd op bepaalde momenten, hebben zij het script ook als een barrière ervaren om een spontaan gesprek te voeren. Daarnaast

merkten de gespreksondersteuners dat de gesprekken aanzienlijke inspanningen vergde van patiënten naast het hebben van de ziekte en het ondergaan van de bijbehorende behandelingen. Als gevolg hiervan namen de gespreksondersteuners de verantwoordelijkheid om te zorgen dat patiënten hun voordeel hadden van hun deelname aan het gesprek.
Op basis van deze inzichten kunnen we zeggen dat training en coaching in de praktijk belangrijk is voor gespreksondersteuners om vertrouwen op te bouwen en om ervaring te krijgen in het voeren van vroegtijdig zorgplanningsgesprekken.

In **hoofdstuk 7** hebben we de *readiness* van de patiënt gedurende het vroegtijdige zorgplanningsgesprek onderzocht. Deze studie liet zien dat patiënten zowel signalen van *being ready* (in de betekenis van er klaar voor zijn), als *not being ready* (in de betekenis van er niet klaar voor zijn) uitten tijdens een gesprek. Signalen van *being ready* bestaan uit antwoord geven op vragen op een persoonlijk niveau of zichtbaar maken dat dat ze kennis hebben van hun ziekte. Signalen van *not being ready* bestaan uit het perspectief beperken tot het hier en nu of aangeven niet te willen praten over een bepaald onderwerp gerelateerd aan vroegtijdige zorgplanning. Deze signalen werden voornamelijk gezien wanneer toekomst georiënteerde onderwerpen werden besproken zoals complicaties en hoop. Ondanks signalen van *not being ready* waren patiënten in staat om het vroegtijdig zorgplanningsgesprek voort te zetten. Daarnaast viel een verschil op in de *readiness* en bereidheid van patiënten om te praten over onderwerpen vanuit het verleden, het heden en de toekomst en een verschil in de manier waarop patiënten hun standpunt uitten (op een rationale manier of met meer inleving). Op basis van deze resultaten, concluderen wij dat patiënten niet *ready* hoeven te zijn voor alle elementen van vroegtijdige zorgplanning om hieraan deel te nemen. Om deze reden raden wij aan dat zorgverleners een op de persoon aangepaste vroegtijdige zorgplanningsgesprek moeten initiëren door alert te zijn op de *readiness* van de patiënt en op potentiele prikkels voor signalen van *not being ready*.

In **hoofdstuk 8** geven we inzicht in de inhoud van de wilsverklaringen van patiënten met gevorderde longkanker of colorectaal kanker die hebben deelgenomen aan vroegtijdige zorgplanningsgesprekken binnen de ACTION studie. Van de in totaal 439 patiënten die de ACTION RC ACP interventie hebben ontvangen, heeft 33% een Mijn Voorkeuren Formulier (een door de ACTION studie ontwikkeld formulier die gebruikt kan worden als een wilsverklaring) ingevuld. Content analyse van de verkennende secties laat zien dat een normaal leven behouden en het ervaren van waardevolle relaties belangrijk zijn voor patiënt om goed te leven. Angsten en zorgen betroffen meestal progressie van de ziekte, pijn of afhankelijk worden. Patiënten hoopten op verlenging van leven,

verminderen van de last van de ziekte en begeleiding door de zorgverleners. In de voorkeuren secties zagen we dat de meeste patiënten (62,6%) de voorkeur hadden voor reanimatie en 44% van de patiënten koos voor maximale comfort als het doel van de toekomstige zorg. De meeste patiënten gaven 'thuis' aan als de plaats om de laatste zorg te ontvangen.
Een uitgebreidere wilsverklaring geeft zorgverleners en naasten een beter beeld van de belangrijkste waarden van de patiënt aan het einde van diens leven, wat een mogelijkheid biedt om de begeleiding van zorgverleners te verbeteren. Een gesprek blijft essentieel om de redenatie achter de beschreven voorkeuren te begrijpen.

Als laatste, in **hoofdstuk 9**, beschrijven we drie inzichten gebaseerd op de resultaten van onze studies. Als eerste raden aan om een vroegtijdig zorgplanningsgesprek te laten voeren door een in de zorg betrokken zorgverlener van de patiënt. Deze zorgverlener zou moeten focussen op wat belangrijk is voor de patiënt en ondersteuning bieden met vertrouwen en gelijkwaardigheid. Los van de rol die een gespreksondersteuner heeft, moet de gespreksondersteuner vaardig zijn en ervaring hebben. Ons tweede inzicht betreft het werken met een script. We bevelen aan om een script te gebruiken tijdens een vroegtijdig zorgplanningsgesprek. Dit geldt in het bijzonder voor gespreksondersteuners met minder ervaring omdat het script ondersteuning biedt. Het laatste inzicht betreft het moment van het vroegtijdig zorgplanningsgesprek. Het moment wordt vaak gelinkt aan de *readiness* van patiënten. We raden aan om *readiness* niet te zien als een voorwaarde om een vroegtijdig zorgplanningsgesprek te starten of als een 'ja' of 'nee' concept. In plaats daarvan moeten zorgverleners sensitief zijn voor de *readiness* van patiënten en na een moeilijk moment niet het gesprek beëindigen. Als laatste, hulpmiddelen, training en support voor zorgverleners is nodig om het beste te halen uit vroegtijdige zorgplanning.

Chapter 12

List of publications

Curriculum Vitae

Dankwoord

JAC Rietjens, IJ Korfage, L Dunleavy, NJ Preston, LJ Jabbarian, C Arnfeldt Christensen, M de Brito, F Bulli, G Caswell, B Červ, JJM van Delden, L Deliens, G Gorini, M Groenvold, D Houttekier, F Ingravallo, MC Kars, U Lunder, G Miccinesi, A Mimić, E Paci, S Payne, S Polinder, K Pollock, J Seymour, A Simonič, A Thit Johnsen, MN Verkissen, E de Vries, A Wilcock, **M Zwakman** and A van der HeideAdvance care planning – a multi-centre cluster randomised clinical trial: the research protocol of the ACTION study. *(BMC Cancer, 2016, 264-016-2298-x.)*

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On behalf of the ACTION consortium Content analysis of Advance Directives completed by patients with advanced cancer as part of an ACP intervention: insights gained from the ACTION trial *(Under review)*

M Zwakman, K Pollock, F Bulli, G Caswell, B Červ, JJM van Delden, L Deliens, A van der Heide, LJ Jabbarian, H Koba-Čeh, U Lunder, G Miccinesi, CA Møller Arnfeldt, J Seymour, A Toccafondi, MN Verkissen, MC Kars *On behalf of the ACTION consortium*
Facilitators' Experiences with Conducting Respecting Choices Advance Care Planning Conversations in Oncology: An International Focus Group Study within the ACTION trial *(Under review)*

M Zwakman*, SWM Weldam*, SCJM Vervoort, JWJ Lammers, MJ Schuurmans Patients' perspectives on the COPD-GRIP intervention, a new nursing care intervention for COPD *(Under review)*

M Zwakman, M Milota, A van der Heide, LJ Jabbarian, IJ Korfage, J Rietjens, JJM van Delden, MC Kars Patients' Readiness for Advance Care Planning Conversations: a Qualitative Study as part of the ACTION Study *(Submitted)*

Curriculum Vitae

Marieke Zwakman was born on 20 July 1985 in Soest, the Netherlands. After graduating from secondary school at the Baarnsch Lyceum in Baarn, she studied nursing at the University of Applied Sciences in Utrecht. After obtaining her bachelor degree in nursing in 2006, she worked as a registered nurse and then as a senior nurse at the lung department of the University Medical Center Utrecht for six years. In 2008 she started the master in Nursing Science at Utrecht University and she obtained her Master of Science degree in 2011.

In 2012, she started working as a nurse staff member at the departments for neurology and neurosurgery at the University Medical Center Utrecht, where she focused on patient satisfaction and the development of care pathways. After one year, she returned to the lung department as a clinical nurse leader, focusing on coaching the senior nurses, nursing research and the development of protocols. Additionally, she worked as a research nurse in the COPD-GRIP study for which she collected data and performed, in collaboration with the research team, a qualitative study.

Between 2010 and 2015, she was a member and, subsequently, the chair of the Nurse Platform (‘verpleegkundig podium’) of the University Medical Center Utrecht.

In 2015 she started her PhD project within the department of Medical Humanities at the Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht.

Currently, Marieke holds a position as a lecturer in Nursing at the University of Applied Sciences Utrecht (HU).

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