

**Supporting the initiation of advance care planning in general practice:
the development of a complex intervention**

Aline De Vleminck

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Supporting the initiation of advance care planning in general practice: the development of a complex intervention

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Chapters 1-6 are based on the following publications

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Chapter 4

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Chapter 5

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Chapter 6

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PART I

General introduction

Introduction, background, research questions and methods

Introduction

One of the few certainties that life holds for us is the inevitability of death; it comes to us all. Despite its inevitability, many people do not prepare for their own death and do not discuss their preferences for care at the end of life, either with their families or with health care professionals. Advance care planning (ACP) is a process of discussion about future care between a capable patient, their professional carers, and their family and friends¹⁻³. The rationale behind ACP is that it provides information to health care professionals and relatives about a person's wishes and preferences in case the time comes when they are unable to express themselves. ACP is also a possible means by which people can exert greater control over their treatment, often but not exclusively relating to end-of-life issues⁴. While essentially simple in conception, the process of ACP encompasses many complexities in practice that hinder both patients and health care professionals from initiating such conversations^{5:6}. The initiation of ACP may be most appropriate with a health care professional who knows the patient well^{7:8} and in Belgium, as in many other countries, this is likely to be their general practitioner (GP). The present dissertation aims to contribute to the field by describing the Belgian public's involvement in ACP and their information preferences when facing a life-limiting illness, providing insights into the complexities of ACP for GPs and developing a complex intervention to support the initiation of ACP in general practice.

Firstly, we will provide a short background and guide the reader toward the objectives of this dissertation. The wider demographic developments, advances in medical technology and the increased value of personal autonomy and self-determinations that took place in modern society are broadly outlined. Secondly, a brief history of ACP is given along with the possible outcomes of the process of ACP in Belgium. Thirdly, an explanation is provided of why this dissertation aims to study public opinion on ACP on the one hand and gives particular attention to ACP in general practice on the other hand. Lastly, the research questions, the study design and methodologies used for this dissertation are discussed, and the outline of this dissertation is specified.

Background

Due to advances in medical knowledge and technological innovation, aiming care at prolonging life as much as possible has become more than ever a realisable option. The ability to keep people alive using potentially burdensome and invasive medical procedures has evolved, but there has also been an increasing realisation by patients and health care professionals that life-prolonging treatments are not always appropriate⁹. While evolving treatments have had enormous benefit, they are not infallible or without the potential for adverse outcomes. In many circumstances, treatments may prolong a person's life or merely the dying process at the expense of quality of life, in such a way that the person themselves may not have wished to receive that particular treatment if they had been given the choice. Understandably, many people want to be involved in these important decisions and the concept of recording wishes about medical treatment in advance has evolved as a result. In the past it was more common for doctors and other health care professionals to protect patients from bad news, such as the diagnosis or prognosis of a life-threatening disease (paternalism). But there has been a change in public attitudes and the deontology of physicians towards a growing openness about such issues and the involvement of patients in health care decisions^{10;11}, although this does not apply to everyone^{12;13}.

Increased value is being put on personal autonomy in modern societies – exercising one's own choices about treatment - and the right to self-determination, and these values are also increasingly being recognized at the end of life^{14;15}. One of the key aspects of good quality care at the end of life is that the care provided is in accordance with the patient's wishes^{16;17}. Internationally, there is consensus that to achieve this goal good communication and information is an important prerequisite¹⁸. Discussions about which care and treatments are desired at the end of life can take place at the moment when a patient's situation requires it. However, it may be difficult for relatives and/or physicians to make decisions when they are not sure what the patient would have wanted, especially in situations of high medical emergency when patients lack the capacity to make decisions or when their cognitive function is restricted.

Advance Care planning

Advance care planning (ACP) provides a means of increasing the congruence between a patient's wishes, values and needs and their future care¹⁹. ACP is a voluntary process of communication between the patient, their healthcare providers and their family and important others, regarding the kind of care that will be considered appropriate when the patient is unable to make decisions about care^{20;21}. It is a multistage communication process to achieve a shared understanding of the patient's current state of health, their goals of care and their values and preferences for future treatment and end-of-life care²².

Brief history: a shift from static documentation of specific treatment preferences towards an on-going process of communication about a patient's wishes

Advance care planning (ACP) initially began in the USA as a movement to establish advance directives (ADs) to refuse treatment, also known as living wills. Emphasis was mainly put on the documentation of an agreement regarding medical care between the physician and patient. It was considered necessary to jointly prepare and complete a document regarding the patient's wishes and to record this document, for example in the patient's medical file²³.

The concept of an AD or a living will was initially proposed in 1969 in the USA as a legal mechanism to guide the use of potentially life-prolonging medical treatments. It was embedded in US legislation following two high profile cases in the 1970s and 1980s which involved the withdrawal of life support from two young women left in persistent vegetative states, Karen Quinlan and Nancy Cruzan²⁴. In the Nancy Cruzan case, it took 7 years before her parents were authorized to withdraw her artificial life support. As a direct result of the Nancy Cruzan case, the Patient Self-Determination Act was passed in 1991, providing a legal basis for living wills and with the aim of encouraging competent adults to complete ADs²⁴. The Patient Self-Determination Act requires health care facilities receiving Medicare and Medicaid funding to ask incoming patients whether they have an AD and if not, to provide written information on treatment options, right-to-die information, and AD forms to adult patients^{25,26}.

As a result of developments in the USA, ADs have gradually been introduced in other countries, which for the first time allowed individuals to specify their choices regarding medical treatment before the loss of capacity. Yet, despite the legal and pragmatic utility of these documents, their uptake remains limited. Evidence also shows that there is no guarantee that these documents improve end-of-life care or correspond with future care preferences²⁷⁻³⁰. More recently, there has been growing recognition that the completion of documents alone is insufficient to ensure that patients receive care that is consistent with their values and preferences. ADs are too narrowly focused on the patient's right to refuse unwanted life sustaining treatment, they are often physically unavailable when needed, too vague to be useful in decision-making or at odds with the patient's current clinical circumstances.

Following the evidence regarding the limitations of ADs, a new model of ACP emerged in the mid-1990s in which emphasis is placed on the potential for discussions instead of documents³¹. While the traditional model of ACP was mainly focused on preparing for the incapacity of patients by having specific treatment choices on paper, the developing model of ACP also focuses on empowering competent patients to have a say about their care and treatments^{1,32}. ACP is now defined as a comprehensive, on-going process of communication by which patients discuss and reflect with their care providers upon topics such as wishes and goals for future care or treatment, quality of life, decision-making preferences, fears and anxieties, and also palliative care options, do-not-resuscitate orders, end-of-life decisions and surrogate decision-making in case of evolving disease stages^{33,34}. These discussions

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may or may not result into the documentation of a patient's preferences in ADs and are a potential outcome of the ACP process^{35;36}.

ACP allows health care providers and relatives to better assess what the patient's wishes would be in a given situation if they lose capacity. Therefore, ACP has the potential to improve end-of-life care by enabling patients to discuss and record their future health and care wishes and also to appoint someone as an advocate or surrogate, thus increasing the likelihood of these wishes being known and respected at the end of life³⁷.

In Belgium, the increased societal value of patient autonomy is reflected in the law on patient rights from 2002³⁸. The law on patient rights, together with the law on palliative care and law on euthanasia (2002), forms the legal framework of ACP in Belgium^{39;40}. The law on patient rights states that every patient has a right to quality care that meets their needs. In addition, each patient is entitled to all information that is needed to gain insight into their illness condition and its probable evolution. Patients have the right to be informed in advance about; and to consent to any intervention by the practitioner³⁸. Furthermore, patients are always entitled to good care and, more specifically towards the end of life, patients have a right to good palliative care.

Documentation of Advance Care Planning

The content of ACP discussions can be placed on record, if a patient chooses to do this. The exact form of implementation and the terms used, differ across states and countries⁴¹. For the purpose of documenting ACP discussions, a number of possibilities are available in Belgium:

Advance Directive (AD) to refuse treatment. Valid and applicable ADs are legally binding statements (written documents) that allow patients to refuse specific medical treatments if they lose capacity in the future. This may involve the refusal of cardiopulmonary resuscitation, mechanical ventilation, antibiotics, admission to the intensive care unit, etc. An AD to refuse treatment is basically indefinite and can always be withdrawn by the patient as long as they have capacity. This AD only comes into effect when the patient loses capacity.

Nomination of a surrogate decision-maker. The law also allow patients to appoint a specific surrogate decision maker via an advance directive, who has the authority to represent the patient if and as long as the patient lacks the capacity to exercise his or her rights. The designation of a surrogate decision-maker must be done in writing and is binding until the patient revokes this. The designated surrogate decision maker may, but does not need to, be a family member. The directive must be signed by the patient and the designate surrogate decision-maker with the date indicated. If the patients does not designated a specific surrogate decision maker, the following sequence is used: the (cohabiting) partner, an adult

child, a parent, an adult brother or sister. The highest in rank is the authorized surrogate decision-maker, even if family members lower in rank disagree with a decision taken. If nobody wants to perform this task, or if nobody is available to perform this task, a professional can take over the task of surrogate decision maker by means of multidisciplinary consultation, which is also the case when surrogate decision makers of the same rank disagree. In all cases where the surrogate decision-maker would take a decision that manifestly puts a patient's health at risk, a professional may overrule and make a decision in the best interest of the patient.

Advance statements. These are statements in which the patient can set out general wishes or personal values and views about future care and treatment. They can be about medical treatment or about social aspects of care, such as palliative sedation, admission to a care home, funeral arrangements, pain management, etc. These advance statements are also called "positive" ADs because they are about what patients would still want if they could no longer ask for it themselves, as opposed to ADs to refuse treatments or examinations. These advance statements are not legally binding for physicians.

Belgium is a specific case as it recognizes a type of positive AD that does not exist in most other countries. People in Belgium can draft an indicative **advance directive on euthanasia** in case they find themselves in specific situations of incapacity⁴². The law on euthanasia allows people with mental capacity to draw up a prior declaration of intent to request euthanasia should they be in an irreversible state of unconsciousness and no longer able to ask for euthanasia themselves. This AD must be recorded in writing and signed by two adult witnesses, of which one must not have any material interest regarding the patient's death. Patients can withdraw their AD on euthanasia at any time⁴⁰. The maximum period of validity for this AD is five years and must therefore be reconfirmed regularly. If not reconfirmed, it cannot legally come into effect. An AD for euthanasia is not legally binding and only acts as a guide for the treating physician. These statements may be officially registered (at the city hall), but this is not mandatory.

The evidence base of Advance Care Planning

Several intervention studies have identified benefits which result from ACP, although they report mixed results^{19;43}. Among the largest and most frequently cited is the US SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks and Treatments), in which nurse facilitators undertook discussions with seriously ill hospitalized patients and families to document their preferences⁴⁴. It was found that this intervention, based around the completion of AD forms which were then made available to patients' physicians, showed no improvement in patient control over their treatment. Moreover, this intervention had no impact on the style of communication between doctor and

patient, on the incidence or timing of do-not-resuscitate orders, or on the knowledge that doctors reported they had about a patient's preferences.

In the last years a number of studies have been published which shed light on the particular contribution that ACP, as a process of communication, can make to the quality of life of patients and families. A more recent randomised trial of ACP showed improved patient and family satisfaction and alleviation of anxiety in relatives of hospitalised patients⁴⁵, which was confirmed by an observational study⁴⁶. Other randomised trials and observational studies have shown that ACP increases the occurrence of discussions on prognosis, end-of-life issues and ADs^{47:48}, improves concordance between patient's preferences and end-of-life care received^{49:50} and improves quality of care at the end of life in different adult populations⁵¹. ACP is also often considered a means of making better use of healthcare resources at the end of life, however cost-effectiveness studies are still lacking⁵².

Qualitative studies indicated that many patients see ACP as having other important roles besides enhancing the patient's autonomy in healthcare decisions, such as lessening the burden on families and increasing trust and understanding between family members and with health professionals^{53:54}. Health professionals seem to have similar views, seeing the value of ACP not only in terms of allowing a patient's wishes to be honoured but also in giving peace of mind to patients and encouraging meaningful communication between family members about end-of-life issues⁵⁵. These studies show the importance of the process outcomes of ACP, illustrating how ACP may be a means for communication about the end of life through enhancing mutual understanding and openness, enabling discussion of concerns, relieving burden and fears about the burden of decision-making for surrogate decision-makers, and strengthening family ties⁵⁶.

Previous systematic reviews have shown that encouraging health professionals' involvement in ACP were most effective in increasing the uptake of ACP, whereas educational interventions directed at patients were least effective^{27:28:57}, hence the choice of developing an intervention to improve ACP directed at health care professionals.

The need to improve Advance Care Planning in general practice

Evidence based guidelines recommend that ACP discussions should ideally be initiated in primary care or in the outpatient setting before individuals become acutely unwell^{21:58}. In the Belgian health care system, GPs are core providers of medical care. The majority of people (95%) in Belgium also have a fixed GP with whom they have often built up a long-term relationship^{59:60}. They are likely to have good clinical and contextual knowledge of their patients and are therefore considered ideally placed to initiate an ACP discussion in a timely manner⁶¹.

However, research shows that the practice of ACP among GPs in Belgium remains limited^{16;62}. A cross-national mortality follow-back study was undertaken in 2009-2010 via representative nationwide Sentinel Networks of GPs in Belgium, the Netherlands, Italy and Spain to investigate the prevalence and characteristics of two aspects of ACP in the last three months of life in each country: 1) GP-patient discussion of treatment preferences and 2) the nomination of a surrogate decision-maker (verbally or in writing)⁶². This study showed that, in a population of patients who died non-suddenly (i.e. patients whose death could be expected by the GP), GP-patient discussion of treatment preferences occurred for 25% of patients in Belgium in the last three months of life. GP-patient discussion of treatment preferences had taken place with 47% of Dutch, 10% of Italian and 7% of Spanish patients. Furthermore, 16% of the Belgian patients had appointed a surrogate decision-maker, which was most frequently done verbally and not in writing. Of the Dutch, Italian and Spanish patients respectively 29%, 6% and 5% had appointed a surrogate decision-maker.

A discussion of the primary diagnosis between GPs and patients was strongly associated with both the discussion about treatment preferences and the appointment of a surrogate decision-maker, as well as more frequent contacts with the GP in the last months of life, GP provision of palliative care and the importance of palliative care as a treatment aim. Palliative care unit deaths and home deaths were also positively associated with discussions of preferences compared to hospital deaths. Furthermore, a dementia diagnosis was associated with less frequent discussion of treatment preferences. These findings show that the process of planning for the end of life often starts with the discussion of the primary diagnosis. So if avoided or delayed, opportunities for patient participation in decision-making may be missed⁶². Another key finding is that ACP relates strongly to the provision of palliative care. Although palliative care has much to offer from the early stages of a progressive disease, previous research demonstrated that palliative care is often initiated relatively close to death. This might suggest that ACP is initiated rather late in the illness trajectory, when death is imminent or end-of-life decision-making comes to the fore and that obstacles to early ACP discussions for patients in general practice still prevail¹⁶.

Public preferences on ACP

Because of the potentially beneficial outcomes of ACP for patients and their families, the area is becoming increasingly important for health care professionals and the public⁶³ and ACP is seen as a healthy and useful behaviour to promote among the general public⁶⁴. A number of studies have shown that the general population places a lot of importance on self-involvement in end-of-life care decision-making^{15;65}. Nonetheless, little information is available on their involvement in ACP and the extent to which people already plan their end-of-life care. Little is also known on the extent to which people want to be informed about their own end-of-life care, which is an important prerequisite for being involved

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in decision-making. A population-based cross-national survey in seven European countries revealed that a majority of people in all countries would always want to be informed about how much time they would have left in the scenario of having a serious illness with less than a year to live⁶³. But no population-based studies are available regarding information preferences on topics such as palliative care or end-of-life decisions and the extent to which people would like their relatives to be informed about these topics.

From a public health perspective, it is important to educate the public and raise awareness concerning the importance of communicating their preferences to their health care providers. Although more research is needed to confirm the positive effects of ACP as a process, ACP may be a potential contributor to end-of-life care. With an ageing population, the patterns of diseases and dying are also changing. Of the estimated 56 million people that die annually, the majority of deaths (66%) follow after a long period of chronic and degenerative diseases, predominantly cardiovascular diseases, cancers, respiratory diseases and diabetes⁶⁶. Work done in the USA describing patterns of physical decline at the end of life suggest that the clinical course of patients with eventually fatal chronic illnesses appears to follow three main patterns⁶⁷. The first trajectory is typified by cancer and generally follows a relatively predictable end-of-life course with maintenance of good function until a rapid decline in clinical status in the last weeks of life. The second trajectory, typically seen in patients with organ failure, is marked by a slow decline that is interrupted by acute deteriorations any of which might end in sudden death. The third trajectory, typically seen in frail older patients and patients suffering from dementia, follows a long term period of progressive decline in functional and mental capacity before death.

As part of these demographic evolutions and changing patterns of dying, people today often require long-term care during their illness trajectory⁶⁸. More people will die at an advanced age and physicians will be increasingly confronted with patients suffering from life-limiting conditions, for which ACP is particularly relevant^{20;69;70}. Information-giving is an essential aspect of clinical care, so understanding the public preferences for information in advanced disease and participation in ACP is not only necessary to promote communication about future treatment and end-of-life care, but also to support and train clinicians in responding appropriately.

Study objectives and research questions

The present dissertation has two main objectives: (1) to describe the experiences of the general population with regard to ACP and their information preferences when faced with life-limiting illness and (2) to develop an intervention to support the initiation of ACP in general practice.

Objective 1: To describe the experiences of the general population with ACP and information preferences when faced with life-limiting illness

The research questions are:

1. To what extent did members of the general population talk to a physician about their wishes regarding medical treatments at the end of life, what is the prevalence of an AD on euthanasia in the general population and which socio-demographic, health status and health service use characteristics are associated with these aspects of ACP?
2. To what extent do members of the general population want themselves and their relatives to be informed about diagnosis, chances of cure, life expectancy, treatment options, palliative care and the possibilities of prolonging or shortening life when faced with a life-limiting illness and which socio-demographic, health status and health service use characteristics are associated with these preferences?

Objective 2: To develop an intervention to support the initiation of ACP in general practice for patients with a serious progressive or life-limiting illness

The research questions are:

3. What are the perceived factors that hinder or facilitate GPs in engaging in ACP with their patients?
4. What are, from GPs' perspective, the differences between patients with cancer, heart failure and dementia in barriers to initiating ACP?
5. How do GPs conceptualise advance care planning, based on their experiences in practice?
6. What are the key components of a complex intervention to support the initiation of ACP in general practice in patients with a life-limiting illness?

Part II of this dissertation is concerned with monitoring the beliefs and preferences of the general population in relation to certain aspects of ACP (objective 1). Part III of this thesis focuses on the development of an intervention to support the initiation of ACP for a specific part of the population, i.e.

patients with serious progressive or life-threatening illnesses (objective 2). Current international guidelines suggest that ACP should be offered to all patients with a chronic life-limiting illness and in anticipation of deterioration, hence the focus of Part III in this dissertation.

Methods

I. Cross-sectional Health Interview Survey

To address research question 1 and 2, we used data from the national Health Interview Study (HIS) that was collected in 2008 from a large representative sample of the Belgian population. The HIS is organized by the Belgian Scientific Institute of Public Health (WIV-ISP) and was conducted for the fourth time in 2008-2009. Around 6000 private households were randomly selected from the National Population Register using a multistage stratified clustered sampling process. Of each selected household, a maximum of four members were eligible. The householder and partner were always selected, as well as two extra randomly selected members (or three if there is no partner). Data collection was performed via a self-administered questionnaire filled in by each selected person 15 years or older (N= 9651). The participation rate among the contacted households was 55% (around 6,000 households were contacted). More details on the methodology are described in PART II.

Several procedures were used to ensure data quality: the content of the HIS questionnaire was discussed in workgroup sessions with academic experts, health government agencies and fieldwork experts. The questionnaires were pre-tested: firstly, questions from other European surveys that were added to the HIS 2008 questionnaire benefited from a large scale pre-test[12] and secondly, the HIS questionnaire was pre-tested by the WIV-ISP in a small, diverse sample of people to evaluate the length, comprehension, readability etc. of questions.

Separate analyses were done for research question 1 and 2. Analyses were conducted with SPSS 22.0 software using the complex samples procedure to account for the complex survey design. The protocol of the Belgian HIS 2008 was approved by the Superior Council of Statistics⁷¹.

II. Medical Research Council (MRC) Framework for developing and evaluating complex interventions

Throughout the development of an intervention to support the initiation of ACP in general practice, the UK Medical Research Council's (MRC) Framework for Complex Interventions was used as a methodological guidance^{72;73}. The framework aims to help researchers identify the core components of interventions and adopt the appropriate evaluation methods. Since its publication, a number of

researchers in palliative care have applied the MRC framework to develop their interventions⁷⁴⁻⁷⁶. The MRC framework differentiates four different phases of 1) intervention development, 2) feasibility and piloting, 3) evaluation and 4) implementation, which take place as an iterative process (Figure 2)^{77:78}. These phases include exploring relevant theories and potential components and modelling the preliminary complex intervention by selecting the main components of the intervention (Phase 0-I), testing the feasibility of the intervention components and pilot-testing the preliminary intervention (Phase II), evaluating the intervention in a definitive randomised trial (Phase III), and implementing the intervention over the long term (Phase IV).

Each phase suggests the use of appropriate quantitative and/or qualitative methodologies depending on the specific objectives of the phase, and requires a specific study design taking into account the theoretical basis, any evidence on the issue and the context's specificity. According to the MRC framework, this dissertation is a Phase 0-I study comprising the development and modelling of a preliminary complex intervention⁷².

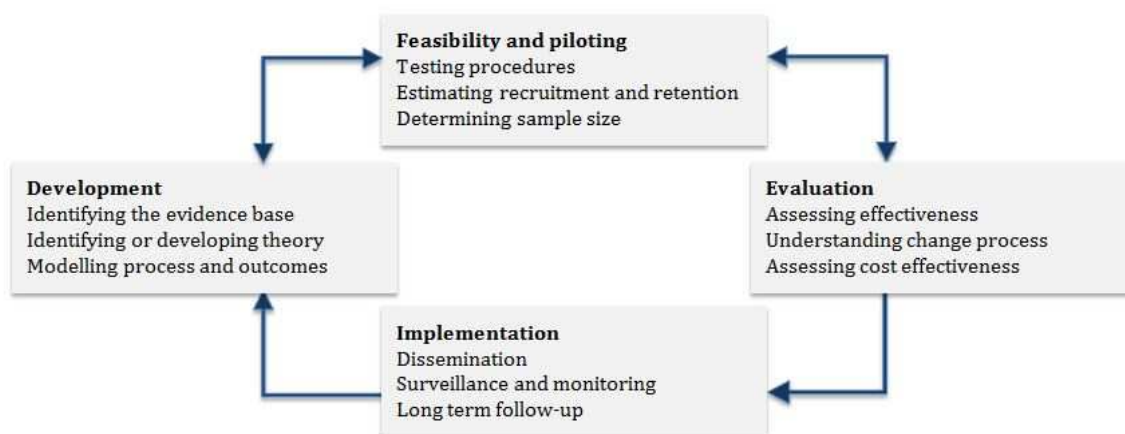


Figure 2 Medical Research Council Framework for complex interventions

Within this Phase 0-I study, different methodologies were used to address the research objectives. In phase 0, a mixed method approach was chosen, using a systematic literature review and qualitative focus groups with general practitioners to study the barriers and facilitators for GPs to initiating ACP and their perceived role in the process. In phase 1, the results of the previous studies were integrated to develop a preliminary intervention to improve the initiation of ACP in general practice that was reviewed and refined by two expert panels.

Phase 0: Exploring potential components of the intervention

Systematic literature review

A systematic literature review about the barriers and facilitators for GPs to engage in ACP was performed to address research question 3. Four electronic databases were searched for studies published in English, French or Dutch between 1990 and 2011: PubMed, CINAHL, EMBASE and PsycINFO. A search strategy was developed for Medline and adapted to each database separately. A combination of controlled vocabulary and free text words was used to search in titles and abstracts: advance care planning, advance directives, advance decision, advance statement, living will, general practice, primary health care, general practitioners, family physicians, primary care, primary practice and family practice.

The reference list of all identified studies was screened for additional relevant studies. The first author of each included study and known experts in the field of ACP were contacted for more studies. Furthermore, the most recent issues of 10 relevant journals were hand-searched for relevant papers. Studies were screened and included in the review on the basis of predefined inclusion- and exclusion criteria. Subsequently, the characteristics of the studies included were extracted to a standardized data-extraction form under the headings of general information, country, research question, design, participants, barriers and facilitators and quality assessment scores. The quality of studies was appraised and evaluated using critical appraisal tools according to the study design of the studies included^{79;80}. The studies were screened, analysed and graded for quality independently by two authors.

In addition, the body of evidence from the multiple studies was graded⁸¹. The individual studies were categorized as high quality studies (scores from 8 to 10), medium quality studies (scores from 6 to 8) and low quality studies (scores equal to or lower than 5).

Qualitative research: focus groups

In order to have an in-depth understanding of the barriers and facilitators for GPs to engage in ACP (research question 5) and GPs' perceptions regarding their role ACP (research question 6), a qualitative study design was considered the most suitable. Given the exploratory nature of the research questions in Phase 0 of this dissertation, focus groups were considered to be the best approach to obtain a wide range of experiences and opinions of GPs regarding ACP, given its meaningful process of sharing and comparing. The methodology of focus groups were used given the flexible approach that allows for opens discussion and interaction between the participants⁸². Five focus groups were conducted in Flanders, Belgium in 2012.

The participants were purposefully sampled by using several recruitment strategies in order to maximize the variation in their experience, age and practice location. Three focus groups were organized within

local peer-review GP groups by contacting the chairs of six of these groups. Local peer-review GP groups are geographically determined groups of GPs from both individual and group practices that meet four times a year to discuss their practice. Every GP who wants to be accredited in Belgium, needs to be affiliated to a peer-review group and is obliged to attend two out of four meetings per year. A report from 2005 showed that more than 90% of active GPs in Belgium are affiliated to a peer-review group⁸³. We chose to recruit via local peer-review groups to obtain a sample of GPs representing a wide range of experience related to the topic (maximum variation sampling)⁸⁴. Secondly, because research shows that advance care planning usually takes place with patients who are terminally ill and close to death¹⁶, we specifically also wanted to enrol GPs who presumably have more experience with palliative patients and possibly communication in the last phase of life. We contacted coordinators of the palliative care networks in Flanders with the request to disseminate our invitation to GPs active in palliative home care teams. Palliative home care teams consist of experts in palliative care (physicians, nurses, psychologists) who, in addition to their own practice, advise and support palliative patients in their last phase of life and work closely with the surrounding caregivers to organize optimal care for the patient. However, because not many GPs from the palliative home care teams responded to our invitation (n=2) we complemented this focus group with GPs not working in a palliative home care team. These other GPs were recruited through professional contacts of the palliative care coordinators and already participating GPs that referred us to these participants (snowball sampling). A fifth focus group was organized with members from a group practice that is located in an urban region as opposed to the rural and semirural regions where the other focus groups took place.

The focus groups lasted on average one and a half hours and were audiotaped, for which all participants gave their informed consent. The focus group discussions were transcribed verbatim. For analysing the data, constant comparative analysis was used^{85;86}. The qualitative analysis software QSR NVIVO 10 was used for this research. The Commission of Medical Ethics of the University Hospital of Brussels approved the research protocol. A signed informed consent was obtained from each participant before the focus group interview. Anonymity was assured by removing participant information that could lead to identification from the transcripts.

Literature scope of existing ACP interventions

A Medline search was conducted on systematic reviews with regard to ACP interventions. Journal articles were searched with the keywords “advance care planning” and publication type “systematic review”. Intervention studies were retrieved with a successful outcome on the occurrence of discussions, completion of advance directives, and improved patients’ end-of-life care and analysed for their components, to have a comprehensive overview of key features underpinning successful interventions and to identify potential components for the development of our intervention.

Phase I: Modelling the intervention to general practice with the help of expert panels

In Phase I, a first draft of a complex intervention to support the initiation of ACP in general practice was developed by the research team, by selecting appropriate intervention components. Subsequently, this draft of the complex intervention was presented in two expert panels who reviewed the key components and the possible and best course(s) of action to implement the intervention in practice. The two expert panels (n=4, n=5) were held in January 2015 and consisted of five GPs, one hospital geriatric, one palliative care consultant and two academic researchers in the field of ACP and health care communication. The expert panel discussions were audiotaped and transcribed verbatim. The research team analysed these discussions and used the results to refine the intervention and its components.

Dissertation outline

Following this general introduction, chapters 1 to 6 of the dissertation are based on scientific articles that have been published, accepted or submitted for publication. All of the chapters can be read independently.

Part II is concerned with the information preferences and involvement of the general population in Belgium regarding ACP. Chapter 1 is devoted to the prevalence in the general population of advance directives on euthanasia and discussions of wishes regarding medical care at the end of life. Chapter 2 examines the information preferences of the Belgian general population when faced with life-limiting illness.

Part III of this dissertation deals with the development of a complex intervention to support the initiation of ACP in general practice. Chapters 3 to 5 provide insight into the complexity of factors influencing the initiation of ACP in general practice. Chapter 3 describes the barriers and facilitators for GPs to engage in ACP with their patients according to the literature. In Chapter 4 the barriers to advance care planning in cancer, heart failure and dementia patients are explored, from GPs' perspectives in Belgium (Flanders). Chapter 5 is concerned with GPs' perspective on the concept of ACP and their role in ACP in Belgium (Flanders). The final Chapter 6 integrates the results of the previous studies, describes the development process and outlines the components of the complex intervention to support the initiation of ACP in general practice.

Part IV consists of a summary of the main findings of the study, a general discussion, reflections on its strengths and limitations, and the implications of the findings for health practice and future research.

Table 1: Overview of the aims and methods used in each chapter of the dissertation

Chapter	Research aims	Method
Chapter 1	To examine the information preferences of the Belgian general population when faced with life-limiting illness	Cross-sectional survey
Chapter 2	To describe the prevalence in the general population of advance directives on euthanasia and discussion of wishes regarding medical treatment at the end of life	Cross-sectional survey
Chapter 3	To identify the perceived factors that hinder or facilitate GPs in engaging in ACP with their patients	Systematic literature review
Chapter 4	To identify the barriers, from GPs' perspective, to initiating ACP and to gain insight into any differences in barriers between the trajectories of patients with cancer, heart failure and dementia.	Focus groups
Chapter 5	To explore how GPs conceptualise ACP, based on their experiences with ACP in their practice	Focus groups
Chapter 6	To develop an intervention to support the initiation of ACP by GPs in patients with a serious or life-limiting illnesses following Phase 0-I of the UK Medical Research Council's (MRC) guidance for developing complex interventions	Combined results of: <ul style="list-style-type: none"> ▪ Systematic literature review ▪ Focus groups ▪ Literature scope of existing ACP intervention ▪ Expert panels

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PART II

Involvement and information preferences of the general public regarding ACP

The prevalence in the general population of advance directives on euthanasia
and discussion of end-of-life wishes: a nationwide survey

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Submitted

Abstract

Background: To determine the extent to which members of the general population have talked to their physician about their wishes regarding medical treatment at the end of life, to describe the prevalence of advance directives on euthanasia, and to identify associated factors.

Method: This study used data from the cross-sectional Health Interview Study (HIS) 2008 that collected data from a representative sample of respondents aged 18 years or older (N=9324) of the Belgian population.

Results: Of all respondents, 4.4% had spoken to their physician about their wishes regarding medical treatment at the end of life, while 1.8% had an advance directive on euthanasia. Factors positively associated with discussions regarding wishes for medical treatment at the end of life were being female, being older in age, having poorer health status and having more GP contacts. People older than 55 years and living in Flanders or Brussels were more likely than the youngest age categories to have an advance directive on euthanasia.

Conclusion: Younger people, men, people living in the Walloon region of Belgium, people without a longstanding illness, chronic condition or disability and people with few GP contacts could represent a target group for education regarding advance care planning. Public information campaigns and education of physicians may help to enable the public and physicians to engage more in advance care planning.

Background

Advance care planning (ACP) has gained international attention for its perceived benefits in enhancing patient autonomy, ensuring better quality of care and improving quality of life in the final stages of life[1;2]. ACP is the process through which patients are able to express their preferences regarding end-of-life care [3;4]. ACP involves discussions about goals of care and preferences for treatment between patients and health professionals, which may involve family members or friends. ACP may include the designation of a surrogate decision-maker to make future health care decisions for the patient, or the completion of an advance directive (AD)[5].

A recently published systematic review showed that interventions including communication about ACP improved the quality of communication and concordance between patient preferences and end-of-life care received[2]. Because of these benefits, ACP is seen as a useful behaviour to promote among the general public and in several countries public health campaigns to encourage it have been put in place such as the Speak Up campaign in Canada or the Dying Matters initiative in the UK[6;7]. Nonetheless, little information is available on the involvement of the general public in ACP and the extent to which people actually plan their end-of-life care, which is the focus of this population-based study of the Belgian general population. Improved understanding of the public's involvement in ACP could help inform the development of public policy. Determining which subgroups of the population are engaged in ACP and which are not can help to define the communication and health campaigns about ACP within a context that is meaningful to the public[8].

In Belgium the Law on Patients' Rights (2002) gives people the right to reject any medical treatment and to appoint a surrogate decision-maker to advocate for their rights if they are unable to make decisions or speak for themselves[9]. Refusal of treatment can be documented in a legally binding negative AD, also known as a living will, which is similar to those in the Netherlands, the USA and Canada. Furthermore, people can document in advance specific wishes for end-of-life care in an advance statement, also called a positive AD, which is indicative but not legally binding on the physician. These advance statements are called "positive" ADs because they are about what patients would still want if they could no longer ask for themselves, as opposed to negative ADs to refuse treatments or examinations. Belgium is a specific case as it recognizes a type of positive AD that does not exist in most other countries. In 2002, the Belgian Parliament legalised euthanasia, i.e. the use of life-ending drugs by a physician on explicit patient request. People in Belgium can draft an AD on euthanasia in case they find themselves in specific situations of lack of capacity[10;11]. The law on euthanasia allows people with mental capacity to draw up a prior declaration of intent to request euthanasia should they be in an irreversible state of unconsciousness and no longer able to ask for euthanasia themselves. In practice, this means that an AD on euthanasia only applies to those in an irreversible coma. A request for euthanasia is not legally binding and acts as a guide for the treating physician. ADs on euthanasia

may be registered at the city hall, but this is not mandatory. In 2013, a total of 20,414 people in Belgium registered an AD on euthanasia, an increase compared with 12,728 people in 2012.

The aim of this study is firstly to determine to what extent members of the general population have talked to a physician about their wishes regarding medical treatments at the end of life and what the prevalence is of an AD on euthanasia in the general population and secondly to determine to what extent socio-demographic characteristics, health status and health service use are associated with the involvement in ACP.

Methods

Design and population

This study uses data from the cross-sectional Health Interview Study (HIS) that collects data from a large representative sample of the Belgian population. The HIS is organized by the Belgian Scientific Institute of Public Health (WIV-ISP) and was conducted for the fourth time in 2008-2009. Around 6000 private households are randomly selected from the National Population Register using a multistage stratified clustered sampling process. Of each selected household, a maximum of four members are eligible. The householder and partner are always selected, as well as two extra randomly selected members (or three if there is no partner). This study includes only participants older than 15 years.

Questionnaire

Involvement in ACP was analyzed based on two items: (1) Have you ever spoken to your physician about your wishes regarding medical treatments at the end of life? and (2) Do you have an advance directive requesting euthanasia?. Possible responses were Yes and No. Data collection is performed via a self-administered questionnaire filled in by each selected person aged 15 years or older. However, only respondents aged 18 years or older are included in the analysis, because an advance directive on euthanasia can only be drafted by people older than 18.

Several procedures were used to ensure data quality: the content of the HIS questionnaire was discussed in workgroup sessions with academic experts, health government agencies and fieldwork experts. The questionnaires were pre-tested: firstly, questions from other European surveys that were added to the HIS 2008 questionnaire benefited from a large scale pre-test[12] and secondly, the HIS questionnaire was pre-tested by the WIV-ISP in a small, diverse sample of people to evaluate the length, comprehension, readability etc. of questions.

Analysis

The selection of the independent variables is based on their possible influence on involvement in ACP or the formulation of ADs, as shown in previous research[13-15]. Socio-demographic measurements include gender, age, educational level, marital status and region of residence. Health-related measurements include health status (having a longstanding illness, chronic condition or disability) and health service utilization (mean number of GP contacts in the past 12 months and mean number of specialist contacts in the past 12 months).

The sample is weighted according to the stratified clustered sampling design of the survey to be representative of the Belgian population. Involvement in ACP is described using frequencies. The independent characteristics were tested for significant association with involvement in ACP using Pearson chi2 test (not shown in paper) and, when found significant, entered in multivariate logistic regression models in order to control for confounding effects and investigate their association with the dependent variables. Confidence intervals are calculated at the 95% level. Analyses are conducted with SPSS 22.0 software using the complex samples procedure to account for the complex survey design.

Ethical considerations

The protocol of the Belgian HIS 2008 is approved by the Superior Council of Statistics[12] . Providing the data by the participants involved giving implied consent.

Results

The participation rate among the contacted households was 55% (around 6,000 households were contacted). Of the 9324 respondents, 52.1% were female, 26.2% were between the ages of 18 and 34, 37.5% were between the ages of 35 and 54, 25.6% between 55 and 74 and 10.7% 75 years or older (Table 1). For 38.7% of the respondents the highest educational level within the household was higher education (post-secondary). More than half of the respondents were married or had a registered civil relationship (56.6%) and lived in Flanders (58.3%). Of all respondents 32.7% suffered from a longstanding illness, chronic condition or disability. Around a quarter had seen their GP once every two months in the last year and the majority had not seen a specialist in the past 12 months (77.5%).

Involvement in advance care planning

Of all respondents, 4.4% indicated they had talked to a physician regarding medical treatments at the end of life and 1.8% said they had an AD on euthanasia (Table 1). Of all respondents who had discussed their wishes regarding medical treatment at the end of life with a physician, 22.2% had an AD on euthanasia. Vice versa, 55.4% of all respondents who had an AD on euthanasia, had discussed their wishes regarding medical treatment at the end of life with a physician. Women, older persons, the widowed and people who suffer from a longstanding illness, chronic condition or disability had spoken more often about their wishes regarding medical treatment at the end of life, as had those who saw a GP or specialist more than once a month. Having an AD on euthanasia was also more common among older respondents, the widowed and people with a longstanding illness, chronic condition or disability. Remarkably, people with a lower educational level had spoken more with a physician about medical treatments at the end of life and had more often an AD on euthanasia than people with a higher educational level. However, a cross tabulation between age and educational level showed that the majority of older people were represented in the lowest educational levels, while the majority of younger had a higher educational level (not shown in the paper).

Factors associated with involvement in advance care planning

The probability of having spoken to a physician about wishes regarding medical treatments at the end of life was higher for women (OR= 1.5) and those with a longstanding illness, chronic condition or disability (OR = 1.5) (Table 2). The probability of having discussed their wishes with a physician also significantly increased with age and with the number of GP contacts.

Compared with the youngest age category, people older than 55 years were more likely to have an AD on euthanasia. Those living in the Walloon region of Belgium were less likely to have an AD on euthanasia compared with those living in Flanders (OR= 0.5).

Table 1: Participant characteristics of the sample of the Belgian general population (N= 9324) and proportions having spoken about wishes regarding medical treatments at the end of life with their physician and having an AD on euthanasia

		Unweighted sample (Weighted %)	Has spoken about wishes regarding medical treatment at the EOL to their physician	Has an AD on euthanasia
		N (%)	%	%
Total respondents			4.4	1.8
Socio-demographic factors				
Gender	Man	4244 (47.9)	3.3*	1.7
	Woman	5080 (52.1)	5.4*	1.8
Age	18-34	2222 (26.2)	0.7*	0.5*
	35-54	2906 (37.5)	3.5*	0.9*
	55-74	2216 (25.6)	6.8*	3.3*
	75+	1980 (10.7)	12.0*	4.6*
Highest educational level within the household	≤ Primary education	1437 (12.2)	6.7*	2.7
	Lower secondary	1511 (15.9)	5.9*	1.8
	Higher secondary	2770 (33.2)	4.8*	2.0
	Higher education	3302 (38.7)	2.9*	1.4
Marital status	Single (never married)	2399 (26.4)	2.0*	1.1*
	Married or registered civil relationship	4672 (56.6)	3.9*	1.7*
	Widow/er (not remarried)	1428 (8.2)	13.0*	4.5*
	Divorced (not remarried)	804 (8.7)	7.3*	1.7*
Region of residence	Flemish region	3304 (58.3)	3.8*	2.0*
	Brussels' region	2750 (10.6)	4.8*	2.5*
	Walloon region	3270 (31.1)	5.5*	1.1*
Health status				
Longstanding illness, chronic condition or disability	Yes	3437 (32.7)	7.8*	2.6*
	No	5857 (67.3)	2.7*	1.4*
Health service use				
Number of GP contacts	Never	4502 (53.2)	2.1*	1.1*
	1x/2 months	2447 (26.9)	5.2*	2.0*
	1x/month	1412 (12.5)	8.5*	3.2*
	≥1x/month	811 (7.4)	11.8*	3.0*

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Number of specialist contacts	Never	6930 (77.5)	3.6*	1.6
	1x/2 months	1384 (14.4)	6.3*	1.8
	1x/month	496 (5.1)	7.3*	3.9
	≥1x/month	302 (3.0)	10.6*	2.4
Involvement in ACP				
Has spoken about wishes regarding medical treatments at the EOL to their physician		412 (4.4)	-	22.2*
Has an AD on euthanasia		167 (1.8)	55.4*	-

Abbreviations: GP = General practitioner; EOL = end of life

Sums may not always amount to the total sample number because of missing values on variables. Percentages may not always add up to 100 because of rounding. Percentages are row percentages.

Missing values: for gender n=0, age n=0, for highest educational level in the household n= 304 (3.3%); for marital status n=21 (0.2%); for region of residence n= 0; for having a longstanding illness, chronic condition or handicap n= 30 (0.3%); number of GP contacts n= 152 (1.6%); number of SP contacts n= 212 (2.3%); for having spoken about wishes regarding medical treatments at the EOL to their physician n= 2109 (22.6%); for having an AD on euthanasia n= 2128 (22.8%)

* Significant at p <0.05 using Pearsons Chi2 test

Table 2: Factors associated with involvement in ACP of a representative sample of the Belgian general population

		OR (95% CI) for yes vs. no*	
		Spoken about wishes regarding medical treatments at EOL to physician	Having an advance directive requesting euthanasia
Socio-demographic characteristics			
Gender	Man (ref)	Ref	
	Woman	1.5 [1.1 – 2.0]	
Age	18-34 (ref)	Ref	Ref
	35-54	5.1 [2.6 – 9.9]	2.1 [0.8 – 5.1]
	55-74	8.2 [4.1 – 16.4]	6.4 [2.7 – 14.9]
	75+	11.1 [5.2 – 24.0]	6.3 [2.1 – 18.4]
Region of residence	Flemish region (ref)		Ref
	Brussels' region		1.5 [0.9 – 2.4]
	Walloon region		0.5 [0.3 – 0.9]
Health status			
Having a longstanding illness, chronic condition or handicap	Yes	1.5 [1.1 – 2.0]	
	No (ref)	Ref	
Health care use			
Number of GP contacts	Never (ref)	Ref	
	1x/2 months	1.7 [1.1 – 2.6]	
	1x/month	2.2 [1.3 – 3.5]	
	≥1x/month	3.0 [1.7 – 5.2]	

Abbreviations: OR= Odds ratio; ref= reference category; Ns= not significant.

*Odds Ratio with 95% confidence interval from complex multivariate logistic regression analysis.

Bold denotes significant at $p < .05$.

Discussion

This study shows that 4.4% of a representative sample of the Belgian general public have spoken about their wishes regarding medical treatments at the end of life, while 1.8% have an AD on euthanasia. Discussions with a physician regarding wishes for medical treatment at the end of life were more likely to have taken place among women, as people get older, among people with a poorer health status and those having more GP contacts. Having an AD on euthanasia was more likely for people older than 55 years and living in Flanders or Brussels.

Discussions regarding wishes for medical treatment at the end of life with physicians are relatively rare among the Belgian general public. Even among those who have an AD on euthanasia only half of respondents (55.4%) had discussed their wishes regarding medical treatment with a physician. However, an AD on euthanasia does not need to be discussed with a physician, something about which some people might be hesitant. An AD on euthanasia must be drafted in the presence of two adult witnesses and they are responsible for notifying the treating physician of its existence should the patient fall into an irreversible coma. People can choose either to deliver copies of their AD on euthanasia to a number of people (of whom their physician might be one) or to register it at the city hall in a federal database, but this is not mandatory. It is however also possible that people do visit their physician with the intention of discussing the completion of an AD on euthanasia, but that the physician omits to take up the opportunity to elaborate on their wishes for medical treatment at the end of life.

A cross-sectional survey in the Netherlands (one of the three countries, with Belgium and Luxembourg, where euthanasia has been legal since 2002) showed that 13% of the general population had discussed issues related to medical decision-making at the end of life with a physician [13]. It is known that, especially in the Netherlands, patients prioritize autonomy and control during the dying process [16]. Cross-country studies also repeatedly found that Dutch physicians discuss end-of-life issues more frequently than their European counterparts [17-19]. Of the Dutch general population, 3% reported they have an AD on euthanasia compared with 1.8% in the present study. Internationally, the interest of people in making ADs refusing medical treatments has been shown to be low, ranging between 18% and 34% in the general population of the USA [20-23] and between 3% and 19% in the general population in Europe [14;24].

A number of characteristics associated with the public's engagement in ACP are consistent with earlier studies. Women and those with a serious illness or increased dependency have been shown to discuss their end-of-life care preferences more often with physicians or have higher AD completion rates [13;14;20;25]. As may be expected, older people were also more likely to have discussed or documented their end-of-life care wishes than those in the youngest age categories [13;26]. On the one hand, evidence suggests that people in general are unwilling to engage in ACP until they grow older or become ill; a

lack of information, procrastination or avoidance could be important reasons for the low completion rates among younger people [27;28]. Younger people in good health tend not to feel the need for ACP. On the other hand, physicians are also hesitant to initiate these discussions and often believe that ACP is unnecessary for young and healthy patients which compounds these barriers [29;30]. And although those who have been widowed are more involved in the process of ACP, marital status was surprisingly not a predictor of engagement in ACP in this study [31]. A population-based study on AD completion in Alberta showed that people who had looked after or given care to a dying person were more likely to complete an AD [32]. The authors argue that experience of death and dying are likely to have a greater impact on having an AD than socio-demographic characteristics. In our study, older age was a notable predictor of AD completion, but experiences with death and dying were not asked about. Older people, who are in general more likely to be widowed, could have experienced a death in their close environment. Also, the specific type of AD examined in this survey was an AD on euthanasia as opposed to an AD for medical treatment. Possibly, lived experiences could also greatly influence the level of involvement in ACP in Belgium. This is a focus for future research.

Remarkably, people living in the Walloon region of the country were less likely to have an AD on euthanasia compared to people living in the Flemish part of Belgium. Unfortunately, reasons for the identified differences between the regions in Belgium could not be explored. Previous research on end-of-life care in Belgium has suggested a difference in medical culture between the Dutch-speaking and French-speaking community, with a stronger appreciation of curative, technological and specialist medicine in the French-speaking community [33]. Perhaps, societal or culturally determined attitudes towards euthanasia might also differ between the regions in Belgium and influence the prevalence of an AD on euthanasia. However, these hypotheses need more research before solid conclusions can be drawn. This study also shows that having more contact with a GP was associated significantly with discussion of end-of-life care wishes. In the Belgian health care system a strong emphasis is put on primary care and most people have a long-lasting relationship with their GP whom they consult regularly (78% at least once a year) [34]. Moreover, the number of GP contacts increases exponentially with age (and probably health-related problems) and persons aged 75 or over are seen by their GP on an almost monthly basis. Future interventions might focus on stimulating GPs to initiate ACP discussions in good time as a sudden or serious chronic illness can render any adult incapable of decision-making. The aim of interventions should not only be to encourage the formulation of ADs on euthanasia, as such ADs only apply to very specific medical circumstances as described in the introduction, but to provide adequate information about the different types of ADs to those who are interested and to make the process of completing an AD an opportunity to have important conversations with physicians, family and friends.

Even though a previous study has shown that the majority of people in Belgium are open to discussions on end-of-life care [35], only a small percentage of the population had discussed their wishes regarding

medical treatment at the end of life with a physician. This suggests that the stimulation of both patients and physicians to engage in end-of-life care discussions would be useful to enhance ACP in practice. Public information campaigns can increase awareness among the Belgian general public regarding the importance of timely ACP discussions. This study shows that younger people, men, those living in the Walloon region of Belgium and those with few GP contacts are a target group for education. Nonetheless, older people represent another key target group, as they are at higher risk of needing end-of-life care [32]. Of those older than 75 years, only 12% had ever had a discussion with their physician about their wishes regarding medical treatment at the end of life. And although guidelines suggest that ACP should be initiated with people who suffer from a chronic, life-limiting illness, our results show that only 7.8% of people with a poorer health status had ever spoken with a physician about their wishes for medical treatment at the end of life. Public information campaigns can help to overcome important barriers to engagement in ACP, including the perception that ACP is irrelevant or the possession of insufficient information to engage in such discussions [5;28]. Secondly, a more active role for the physician in initiating such discussions could also enhance ACP. It has been suggested before that physicians have the responsibility to inform their patients and to initiate discussions in a timely manner [4;36;37]. However, they need to be trained and supported in how to do this, they often delay communication until the end of life or wait for patients to raise the topic [38-40].

This is the first study on the general public's involvement in ACP in Belgium. It is a population-based study founded on a representative sample of the Belgian population. Other important strengths include the large sample size, the robustness of the methodology and the quality of research procedures. We used data from the HIS, which has a long history of data collection in the Belgian population and is not based only on a specific interest in end-of-life care. However, this study also has some limitations. Firstly, the specific context of Belgium as one of the three countries where euthanasia is legal, might hamper the generalizability of our results to other settings. Secondly, because of the low response-rate (55%), non-response bias cannot be excluded. The missing values for the outcome variables are around 23% and non-response analysis showed that missing values were more likely to be male, older, have a lower educational level and live in Wallonia or Brussels. As a result, it is possible that some of our findings are biased because of non-response. Thirdly, because this study examined the respondent's own report of their involvement in ACP, the results may be subject to recall bias.

Conclusion

Few people in Belgium have discussed their wishes regarding medical treatment at the end of life with their physician or have completed an AD on euthanasia. Younger people, men, people living in the Walloon region of Belgium, people without a longstanding illness, chronic condition or disability and people with few GP contacts might represent a target group for education as they are less likely to engage in ACP. Public information campaigns and the education of physicians may encourage the public to engage in ACP and help to enable patients, families and physicians to have more conversations about care at the end of life.

List of abbreviations

ACP: Advance care planning

AD: Advance directive

GP: General practitioner

Competing Interest: The authors declare that they have no competing interests.

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Authors' contributions

ADV carried out the statistical analysis, the interpretation of the results and drafted the manuscript. LVD and LD were involved in the design of the study. KP, DH, LVD, RVS and LD critically revised the manuscript content. All authors read and approved the final manuscript.

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Information preferences of the general population when faced with life-limiting illness

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Abstract

Background: Giving the public and patients good information enables them to make effective choices about their care. This study describes public preferences for both themselves and their relatives on receiving information on end-of-life care topics when faced with a life-limiting illness and to identify associated factors.

Method: This study used data from the cross-sectional Health Interview Study (HIS) 2008 that collected data from a representative sample (N=9651) of the Belgian population.

Results: Around 82% of respondents wanted to be informed always about diagnosis, chances of cure and available treatments, 77% wanted to be informed on life expectancy, 72% on options regarding palliative care and 67% on possibilities of prolonging or shortening life. Around 55% wanted their relative to be informed always about diagnosis, chances of cure, life expectancy and different treatments available, while 50% wanted this in relation to the options regarding palliative care and 46% to the possibilities of prolonging or shortening life. Younger adults, people with more education and people with a regular GP were more likely to want to be informed always. Younger adults and women were less likely to want their relatives to be informed always.

Conclusion: The majority of the Belgian population wants to be informed always about end-of-life care topics when faced with a life-limiting illness. Physicians should be aware of the desired level of information and tailor information to individual patient preferences. Understanding population preferences may help to tailor patient education and health promotion programmes appropriately.

Introduction

In modern western societies, increased value is being put on personal autonomy, individualism, and the right to self-determination(1). With an aging population and rising numbers of deaths from chronic life-limiting illnesses, these values are increasingly being recognized at the end of life(2). These attitudinal changes have been incorporated into national legal codes in the past 20 years, e.g. as the Patient Self-Determination Act in the USA which is intended to promote awareness and discussion of health care issues in preparation for medical decisions at the end of life(3).

A number of studies have shown that the general population places a lot of importance on self-involvement in end-of-life care decision-making(2;4). Within Europe, four factors are associated with a preference for self-involvement: higher level of education, female gender, younger-middle age and valuing quantity over quality of life or valuing both equally. However little information is available on the extent to which people want to be informed about their own end-of-life care which is an important prerequisite of being involved in decision making. A population-based cross-national survey in seven European countries revealed that a majority of people in all countries would want always to be informed about how much time they would have left in the scenario of having a serious illness with less than a year to live(5). People younger than 70 years, men, those with personal experience of a serious illness such as cancer and those with higher educational attainment were more likely to want to know if they had limited time left. But to our knowledge, no population-based studies are available regarding information preferences on specific topics such as palliative care and end-of-life decisions or the extent to which people would like their relatives to be informed. For policy makers it is unclear what the preferences are in the general population and a population-based study can inform them on which steps to take, e.g. for the development of public health education campaigns to raise awareness of these matters in the population(6).

Most studies exploring information preferences have been focused on specific populations of patients, usually involving cancer patients or the terminally ill(7-9). This is the first cross-sectional study to describe variations in the information preferences of the general public with regard to themselves and their relatives for six specific end-of-life care topics in a hypothetical scenario of a life-limiting illness. The aims of this study are 1) to determine to what extent members of the general population would want to be informed about diagnosis, chances of cure, life expectancy, treatment options, palliative care and the possibilities of prolonging or shortening life when faced with a life-limiting illness; 2) to describe to what extent members of the general population would want their relatives to be informed about these six topics and 3) to study to what extent people's socio-demographic characteristics, health status and health service use is associated with their information preferences.

Methods

Design and population

This study uses data from the cross-sectional Health Interview Study (HIS) that collects data from a representative sample of the Belgian population. The HIS is organized by the Belgian Scientific Institute of Public Health (WIV-ISP) and was conducted for the fourth time in 2008-2009. Private households are randomly selected from the National Population Register using a multistage stratified clustered sampling process. Of the selected households, a maximum of four members per household are eligible. The householder and partner are always selected, as well as two extra randomly selected members of the household (or three if there is no partner). This study includes only participants older than 15 years.

Questionnaire

Two questions on information preferences in a scenario of a life-limiting illness were initially developed by KM, LVDB and LD and were incorporated into the HIS questionnaire of 2008. Data collection is performed via a self-administered questionnaire filled in by each selected person 15 years or older. The questions on information preferences (dependent variables) are formulated as a scenario imagining 'If you were to develop a life-limiting illness, would you want your doctor to inform you on the following topics': (1) diagnosis, (2) chances of curing the disease, (3) life expectancy with the disease, (4) the different types of treatments, their side effects and the expected outcome of each treatment, (5) options regarding palliative care, (6) possibilities of prolonging or shortening your life. Possible responses were 'Yes, in principle always', 'Yes, but only if I ask', 'No' and 'Don't know'. A second question is formulated as the hypothetical scenario 'If you were to develop a life-limiting illness, would you want your physician to inform your relative(s) on these six topics', for which the same response categories apply.

The selection of the independent variables is based on their possible influence on information preferences, as stated in previous research(5;8;10). Socio-demographic measurements include gender, age, highest educational level in the household, marital status, region and nationality. Health status is measured through the variables subjective health, severity of pain in the last four weeks, and having a longstanding illness, chronic condition or disability. Health service utilization measures include having a regular GP and inpatient hospitalizations in the past 12 months.

The content of the questions on information preferences was determined on the basis of existing validated questionnaires about the information preferences of people with advanced lung cancer (8). Several procedures were used to ensure data quality: each module of the HIS was discussed in workgroup sessions with academic experts, health government agencies and fieldwork experts. The

questionnaires were pre-tested. Firstly, the adjunction of European questions in the HIS 2008 questionnaires benefited from a large scale pre-test(11). Secondly, the HIS questionnaire was pre-tested by the WIV-ISP in a small, diversified sample of people to evaluate the length, comprehension and readability of questions, etc.

Analysis

The sample is weighted according to the stratified clustered sampling design of the survey to be representative of the Belgian population. The dependent variables are converted into a binary score: yes always = 1 vs. 'Yes, but only if I ask', 'No' and 'Don't know'= 0. Information preferences for the six topics are described. The bivariate associations between the independent and outcome variables are tested through cross-tabulations and binary logistic regression analysis (not shown in paper). Variables that are significantly associated (CI 95%) are included in multivariate logistic regression models in order to control for confounding effects and investigate their association with the dependent variables. Confidence intervals are calculated at the 95% level. Analyses are conducted with SPSS 22.0 software using the complex samples procedure to account for the complex survey design.

Ethical considerations

The protocol of the Belgian HIS 2008 is approved by the Superior Council of Statistics(11). Submission to the Ethical Committee of the WIV-ISP is not needed, because it is a recurrent project that had been approved in 2004.

Results

The participation rate among the contacted households was 55%. The characteristics of the sample (N= 9651) are displayed in Table 1.

Information preferences of the general population

When faced with a life-limiting illness, the majority of people would always want to be informed about their diagnosis (82.1%), the chances of cure of the disease (81.7%) and the different treatments available with their side effects and outcomes (82.1%). About three-fourths of people would always want to be informed about their life expectancy with the disease (76.7%) and the options regarding palliative care

(72.3%). The proportion of people wanting to be informed always about the possibilities of prolonging or shortening life was 67.3% (Table 2).

Information preferences for the relatives of the general population

When faced with a life-limiting illness, 55.4% would always want their relatives to be informed about their diagnosis (Table 2). A similar result was found for the specific topics of chances of cure of the disease (55.4%), life expectancy with the disease (53.3%) and the different treatments available with their side effects and the outcomes of every treatment (54%). Half of people would always want their relative to be informed about the options regarding palliative care (50.4%) and less than half about the possibilities of prolonging or shortening life (46.6%).

Factors associated with information preferences

Compared with the youngest age category, people aged 25 to 34, 35 to 44 and 45 to 54 were more likely always to want information about the six topics (Table 3). This was also significantly more likely among people with an educational level of 'higher secondary' and 'higher education'. People living in Wallonia were overall less likely to want information on these six specific topics always as opposed to people living in Flanders.

Always wanting to know about diagnosis (OR= 1.9), chances of cure (OR = 2.0), life expectancy (OR= 1.8) and different treatment options (OR= 1.8) was significantly related to having a regular GP. People who were divorced were more likely always to want information on palliative care, while those with of a non-Belgian and non-European nationality were less likely to want information on life expectancy. No significant association was found between subjective health status and information preferences.

Factors associated with information preferences for the relatives

Those who were married or legally cohabiting and those living in Flanders were more likely to have a preference for information to be provided to their relative(s) for all six topics (Table 4).

People aged 25 to 34 and 35 to 44 were less likely to want their relative to know about their diagnosis and chances of cure, as were people with an educational level of lower secondary. On the other hand, being older than 75 years was associated with wanting relatives to know about these topics (OR= 1.5 and OR= 1.5). Women were less likely to want their relative to know about their life expectancy, different treatment options, options regarding palliative care and possibilities of prolonging or

shortening life. No significant association was found between people's nationality, having a regular GP or being hospitalized in the past 12 months and wanting relatives to know about one of the six specific topics.

Discussion

Our study shows that, when faced with a life-limiting illness, the majority of a representative sample of the Belgian general public would always want to be informed about diagnosis, chances of cure and different treatments available, while more than 70% wanted always to be informed about life expectancy, options regarding palliative care and possibilities of prolonging or shortening life. Furthermore, important differences with the preferences regarding relatives being informed were identified: around 55% would want their relative to be informed always about diagnosis, chances of cure, life expectancy and different treatment options, while half wanted them always to be informed about the options regarding palliative care and fewer than half about the possibilities of prolonging or shortening life.

We found that most respondents want information on disease and treatment-related matters in a hypothetical scenario of a life-limiting illness. Nonetheless, respectively 72.3% and 67.3% of the respondents still indicated they would always want information on palliative care and the possibilities of prolonging or shortening life. This might be explained by the open public debate on end-of-life issues in Belgium since the enactment of the laws concerning euthanasia, palliative care and patient rights in 2002(12-14). A previous cross-country study showed strong variation in discussions of end-of-life preferences in patients who died non-suddenly from Italy, Spain, Belgium, and the Netherlands(15). The higher frequency of anticipatory decision-making in Belgium and the Netherlands as opposed to Spain and Italy was also considered to be related to the open public debate on end-of-life issues engendered by the process of legalization of euthanasia in both countries. A markedly high public acceptance of euthanasia was in 2008 also found in a small cluster of Western European countries, including the three countries that have legalized euthanasia, which strongly related to a belief in the right to self-determination(16). The importance of self-determination and open public debate on end-of-life issues has probably also contributed to an increased public preference to be informed about these topics.

The finding that younger adults and more highly educated respondents were overall more likely to want information always is in accordance with other studies indicating that these patients express more desire to receive detailed information with regard to their illness and to be involved in decision-making about care involving serious illness(4;6;7;17). We found that a shift in information preferences begins after the age of 54. This may be due to changing attitudes towards topics associated with aging or it may point to a cohort effect: possibly the younger generation will differ from the trend we found here and may want to receive more information when they get older. A European survey showed that besides people

younger than 70 years and those with a higher educational attainment, people with personal experience of a serious illness such as cancer were more likely to want to know about how much time they would have left, in the scenario of having a serious life-limiting illness(5). In our study, respondents with a poorer health status (measured in three different ways) did not have significantly different preferences as compared with those with a better health status. Several things might explain this difference. Firstly, this study did not specifically ask if the respondents wished to know that there was limited time left. Secondly, health status was measured as a broad concept and specific questions about e.g. the presence of a life-limiting illness such as cancer were not asked. However, a study on information preferences in advanced cancer patients regarding the same end-of-life care topics as used in this study revealed similar results(8). This points to a willingness in the general public to receive information on end-of-life care regardless of health status.

We also found that people with a regular GP were more likely to want information. As in many countries, GPs in Belgium have built up long-term relationships with their patients and they play a central role in providing continuous and comprehensive care, including at the end of life(15;18;19). General practice is highly accessible: 95% of the population have a regular GP whom they consult regularly. The importance of a good physician-patient relationship has been acknowledged to facilitate better information provision(20;21) and possibly people feel comfortable discussing these topics with their own GP. Lastly, differences in information preferences between the three different regions of Belgium, could mean that societal or cultural differences between the regions play a role. Previous studies have shown significant differences in type and prevalence of end-of-life decisions between the Dutch-speaking and French-speaking communities in Belgium(22). However, these factors need to be examined in more detail.

As a minority of the people in our study did not want to receive any information either at all or only if they requested it, our findings highlight the importance of physicians checking their patients' preferences in advance as to the extent and the specific topics about which they want to be informed. An examination of the role of relatives is also warranted, as only half of people want a relative to be informed always. Younger adults and women were less likely to want their relatives to be informed. An important concern of people when considering advanced cancer is being a burden on others(23) and these results may also reflect the importance to the general public of not wanting to worry their relatives by informing them on these topics(24). However, advance care planning guidelines emphasize the importance of involving relatives in discussions of end-of-life care(25;26). As relatives often play an important role in end-of-life care decisions(27), it follows that physicians should be adequately prepared to elicit both the patient's information preferences and the role they desire their relatives to play in order to enhance effective communication(28).

This is the first study on the information preferences of the general population for themselves and for their relatives and the first to describe variations in public information preferences for six different components of communication regarding illness and the end of life. Moreover, it is a population-based study founded on a representative sample of the Belgian population. Its other important strengths include the large sample size, the robustness of the methodology and the quality of the research procedures(11). We used data from the HIS which has a long history of data collection in the Belgian population and is not only based on a specific interest in end-of-life research, but obtains information about life style, health status, prevention and the use of health care facilities. However, this study also has some limitations. As the majority of the respondents considered their health to be good, it might have been difficult for them to imagine a scenario where they have a life-limiting illness and to foresee what their information preferences would be in that case. Secondly, because of the lower response rate (55%), non-response bias cannot be excluded. The missing values for the outcome variables are around 25% and non-response analysis of those missing values further shows that those missing values were more likely to be male, older, have a lower educational level and live in Wallonia or Brussels. As a result, it is possible that some of our findings are biased because of non-response. Finally, the cross-sectional nature of the HIS prevents the drawing of conclusions about causal relationships between information preferences and individual factors.

In conclusion, the majority of the Belgian population wants to be informed always about end-of-life care topics when faced with a life-limiting illness. However, people's preference for always wanting their relatives to be informed about these topics is less prevalent. The results of this study can inform policy makers on the role people would want to fulfil during end-of-life care and the understanding of public information preferences can help tailor public education and health promotion programmes appropriately.

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Conflict of interest: None declared

Key points:

- The general population places a lot of importance on self-involvement in end-of-life care decision-making; however little data is available on the extent to which people want to be informed about their own end-of-life care which is an important prerequisite of being involved in decision making. When faced with a life-limiting illness, around 82% of a representative sample of the Belgian general public would always want to be informed about diagnosis, chances of cure and different treatments available, while fewer wanted always to be informed about life expectancy (77%), options regarding palliative care (72%) and possibilities of prolonging or shortening life (67%).
- Preferences regarding relatives being informed always were less strong: around 55% would want their relative to be informed always about diagnosis, chances of cure, life expectancy and different treatment options, while fewer wanted them always to be informed about the options regarding palliative care (50%) and the possibilities of prolonging or shortening life (46%).
- Younger adults and more highly educated respondents were overall more likely to want information always. We found that a shift in information preferences begins after the age of 54. This may point to a cohort effect: possibly the younger generation may want to receive more information when they get older.
- For policy makers it is unclear what the preferences are in the general population and which steps to take to raise awareness of these matters in the population. The results of this study can inform them on the role people would want to fulfil during end-of-life care and the understanding of public information preferences can help tailor public education and health promotion programmes appropriately.

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Information preferences of the general population

Table 1: Socio-demographic characteristics, health status and health care utilization of the unweighted and weighted sample

		Unweighted sample (N = 9651)	Weighted sample	
		N	%	95% CI
Socio-demographic characteristics				
Gender	Man	4417	48.1	[47.2 – 49.1]
	Woman	5234	51.9	[50.9 – 52.8]
Age	15-24	1209	14.3	[13.2 – 15.4]
	25-34	1340	15.3	[14.1 – 16.5]
	35-44	1503	17.9	[16.7 – 19.2]
	45-54	1403	17.9	[16.8 – 19.1]
	55-64	1337	14.1	[13.0 – 15.2]
	65-74	879	10.3	[9.3 – 11.4]
	75+	1980	10.2	[9.4 – 11.1]
Highest educational level within the household	≤ Primary education	1459	11.9	[10.9 – 13.1]
	Lower secondary	1554	15.6	[14.3 – 17.1]
	Higher secondary	2883	33.3	[31.4 – 35.2]
	Higher education	3440	39.2	[37.2 – 41.2]
Marital status	Single (never married)	2725	29.8	[28.4 – 31.1]
	Married or legally cohabiting	4673	53.9	[52.5 – 55.6]
	Widow/er (not remarried)	1428	7.8	[7.2 – 8.5]
	Divorced (not remarried)	804	8.3	[7.5 – 9.2]
Region of residence	Flemish region	3411	58.2	[57.0 – 59.4]
	Brussels' region	2831	10.5	[10.1 – 10.9]
	Walloon region	3409	31.3	[30.2 – 32.4]
Nationality	Belgian	8440	91.2	[90.3 – 92.1]
	Non Belgian EU	792	5.8	[5.1 – 6.5]
	Non Belgian non EU	393	3.0	[2.5 – 3.6]
Health status				
Subjective health	Good to very good	5633	76.8	[75.3 – 78.1]
	Very bad to fair	2023	23.2	[21.9 – 24.7]
Severity pain in the last 4 weeks	None	3963	48.8	[47.2 – 50.4]
	Very mild - moderate	3340	39.2	[37.7 – 40.7]
	Severe to very severe	1048	12.0	[11.0 – 13.1]
Longstanding illness, chronic condition or disability	Yes	3470	31.5	[30.2 – 32.9]
	No	6150	68.5	[67.1 – 69.8]
Health service utilization				
Regular GP	Yes	8931	94.9	[94.2 – 95.5]
	No	687	5.1	[4.5 – 5.8]
Inpatient hospitalisations in the past 12 months	Yes	1222	11.8	[10.9 – 12.8]
	No	8364	88.2	[87.2 – 89.1]
Sums may not always amount to the total sample number because of missing values on variables. Percentages may not always add up to 100 because of rounding.				
Missing values: for highest educational level in the household n= 315 (3.3%); for subjective health n=1995(20.7%); for severity of pain the last 4 weeks n=1300 (13.5%).				
GP = General practitioner				

Table 2: Information preferences of the studied population if they are faced with a life-limiting illness, Belgium 2008 (N= 9,651)

	Information preferences (%)			Information preferences for relatives (%)		
	Yes, in principle always	Yes, only if I ask	No Don't know	Yes, in principle always	Yes, only if I ask	No Don't know
My diagnosis	82.1	11.1	2.5 4.3	55.4	32.0	8.3 4.3
The chances of curing the disease	81.7	11.7	2.9 3.7	55.4	32.0	8.3 4.3
My life expectancy with the disease	76.7	14.0	4.5 4.8	53.3	32.2	9.7 4.8
The different treatments, their side-effects and outcomes	82.1	10.9	2.6 4.4	54.0	32.6	8.4 5.0
Options regarding palliative care	72.3	17.1	4.2 6.5	50.4	34.2	9.4 6.0
Possibilities of prolonging or shortening my life	67.3	19.8	5.7 7.2	46.6	35.4	11.4 6.6

Figures are weighted percentages (95% confidence intervals). Percentages may not amount to 100 because of rounding.

Missing values Information preferences: for diagnosis n= 2280 (23.6%), for chances of cure n= 2324 (24.1%); for life expectancy n= 2372 (24.6%); for different treatments n= 2372 (24.6%); for options regarding palliative care n= 2386 (24.7%); for possibilities of prolonging or shortening life n= 2359 (24.4%)

Missing values Information preferences for relatives: for diagnosis n= 2308 (23.9%), for chances of cure n= 2363 (24.5%); for life expectancy n= 2398 (24.8%); for different treatments n= 2414 (25%); for options regarding palliative care n= 2423 (25.1%); for possibilities of prolonging or shortening life n= 2404 (24.9%)

Non-response analysis showed that non-respondents were more likely to be male, older, have a lower educational level and live in Wallonia and Brussels.

Table 3: Multivariate analysis: Characteristics of the general population associated with information preferences, HIS 2008, Belgium

	Information preferences						
	Diagnosis	Chances of curing the disease	Life expectancy with the disease	Different treatments	Options regarding palliative care	Possibilities of prolonging or shortening life	
	OR (95% CI) for wanting information vs. not wanting information						
Age	15-24 (ref)	Ref	Ref	Ref	Ref	Ref	
	25-34	2.0 [1.4 – 3.0]	1.6 [1.2 – 2.3]	1.9 [1.4 – 2.6]	1.6 [1.1 – 2.4]	1.9 [1.4 – 2.6]	1.5 [1.1 – 2.0]
	35-44	1.9 [1.4 – 2.8]	1.7 [1.2 – 2.4]	1.8 [1.3 – 2.5]	1.8 [1.2 – 2.6]	2.3 [1.7 – 3.1]	1.9 [1.4 – 2.5]
	45-54	1.6 [1.1 – 2.3]	1.7 [1.2 – 2.3]	1.9 [1.4 – 2.6]	1.8 [1.2 – 2.6]	2.1 [1.5 – 2.9]	1.7 [1.3 – 2.3]
	55-64	Ns	Ns	Ns	Ns	Ns	Ns
	65-74	Ns	Ns	Ns	Ns	Ns	Ns
	75+	Ns	Ns	Ns	Ns	Ns	Ns
Highest educational level of the household	≤ Primary school (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Lower secondary	Ns	Ns	Ns	Ns	Ns	Ns
	Higher secondary	1.5 [1.2 – 2.0]	1.5 [1.1 – 2.0]	1.4 [1.1 – 1.9]	1.4 [1.0 – 1.8]	1.4 [1.1 – 1.8]	1.3 [1.1 – 1.7]
	Higher education	2.2 [1.6 – 2.9]	1.7 [1.3 – 2.3]	1.9 [1.4 – 2.4]	2.0 [1.5 – 2.7]	1.6 [1.2 – 2.1]	1.6 [1.2 – 2.0]
Marital status	Single (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Married or legally cohabiting	Ns	Ns	Ns	Ns	Ns	Ns
	Widow(er)	Ns	Ns	Ns	Ns	Ns	Ns
	Divorced	Ns	Ns	Ns	Ns	1.5 [1.1 – 2.1]	Ns
Region of residence	Flemish region (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Brussels' region	Ns	Ns	Ns	Ns	Ns	Ns
	Walloon region	0.7 [0.6 – 0.8]	0.6 [0.5 – 0.7]	0.6 [0.5 – 0.8]	0.6 [0.5 – 0.8]	0.8 [0.7 – 0.9]	0.8 [0.7 – 0.9]
Nationality	Belgian (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Non Belgian EU	Ns	Ns	Ns	Ns	Ns	Ns
	Non-Belgian non-EU	Ns	Ns	0.6 [0.3 – 0.9]	Ns	Ns	Ns
Subjective health	Good to very good (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Very bad to fair	Ns	Ns	Ns	Ns	Ns	Ns
Regular GP	Yes	1.9 [1.2 – 2.8]	2.0 [1.4 – 3.0]	1.8 [1.3 – 2.6]	1.8 [1.2 – 2.8]	Ref	Ref
	No (ref)	Ref	Ref	Ref	Ref	Ref	Ref

OR= Odds Ratio; ref= reference category; Ns= not significant; CI= confidence interval

Odds Ratio with 95% confidence interval from multivariate logistic regression models

GP= General practitioner

Table 4: Multivariate analysis: Characteristics of the general population associated with information preferences for relatives, HIS 2008, Belgium

		Information preferences for relatives					
		OR (95% CI) for wanting information for relatives vs. not wanting information for relatives					
		Diagnosis	Chances of curing the disease	Life expectancy with the disease	Different treatments	Options regarding palliative care	Possibilities of prolonging or shortening life
Gender	Man (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Women			0.9 [0.8 – 1.0]	0.8 [0.7 – 1.0]	0.8 [0.7 – 1.0]	0.8 [0.7 – 0.9]
Age	15-24 (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	25-34	0.6 [0.4 – 0.7]	0.6 [0.4 – 0.8]	0.7 [0.5 – 0.9]	0.7 [0.5 – 0.9]	Ns	0.6 [0.5 – 0.9]
	35-44	0.7 [0.5 – 0.9]	0.7 [0.5 – 0.9]	Ns	Ns	Ns	Ns
	45-54	Ns	Ns	Ns	Ns	1.3 [1.0 – 1.8]	Ns
	55-64	Ns	Ns	Ns	Ns	1.4 [1.0 – 1.9]	Ns
	65-74	Ns	Ns	1.5 [1.1 – 2.1]	1.5 [1.1 – 2.1]	1.5 [1.1 – 2.1]	Ns
	75+	1.5 [1.0 – 2.1]	1.5 [1.1 – 2.2]	1.7 [1.2 – 2.4]	1.7 [1.2 – 2.5]	1.7 [1.2 – 2.5]	Ns
Highest educational level of the household	≤ Primary school (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Lower secondary	0.7 [0.5 – 0.9]	0.7 [0.5 – 0.9]	Ns	Ns	Ns	Ns
	Higher secondary	Ns	Ns	Ns	Ns	Ns	Ns
	Higher education	Ns	Ns	Ns	Ns	Ns	Ns
Marital status	Single (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Married or legally cohabiting	1.5 [1.2 – 1.8]	1.4 [1.1 – 1.7]	1.4 [1.1 – 1.7]	1.4 [1.1 – 1.7]	1.4 [1.1 – 1.7]	1.3 [1.0 – 1.5]
	Widow(er)	Ns	Ns	Ns	Ns	Ns	Ns
	Divorced	Ns	Ns	Ns	Ns	Ns	Ns
Region of residence	Flemish region (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Brussels' region	0.5 [0.4 – 0.6]	0.5 [0.4 – 0.5]	0.4 [0.4 – 0.6]	0.5 [0.4 – 0.6]	0.5 [0.4 – 0.6]	0.6 [0.5 – 0.7]
	Walloon region	0.4 [0.3 – 0.5]	0.4 [0.3 – 0.4]	0.4 [0.3 – 0.4]	0.4 [0.3 – 0.5]	0.4 [0.3 – 0.5]	0.5 [0.4 – 0.6]
Nationality	Belgian (ref)	Ref	Ref	Ref	Ref	Ref	Ref
	Non-Belgian EU	Ns	Ns	Ns	Ns	Ns	Ns
	Non-Belgian non-EU	Ns	Ns	Ns	Ns	Ns	Ns
Regular GP	Yes	Ns	Ns	Ns	Ns	Ns	Ns
	No (ref)	Ref	Ref	Ref	Ref	Ref	Ref
Hospitalisations	Yes	Ns	Ns	Ns	Ns	Ns	Ns
	No (ref)	Ref	Ref	Ref	Ref	Ref	Ref

OR= Odds Ratio; ref= reference category; Ns= not significant; CI= confidence interval

Odds Ratio with 95% confidence interval from multivariate logistic regression models

GP= General practitioner

PART III

Development of an intervention to support the initiation of ACP in general practice

**Barriers and facilitators for general practitioners to engage in advance care
planning: a systematic review**

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Chantal Van Audenhove, Robert Vander Stichele, Luc Deliens

Abstract

Objective: The aim of this systematic review is to identify the perceived factors hindering or facilitating GPs in engaging in ACP with their patients about care at the end of life.

Design: Studies (1990-2011) were searched in four electronic databases (PubMed, CINAHL, EMBASE, PsycINFO); by contacting first authors of included studies and key experts; and searching through relevant journals and reference lists. Studies were screened, graded for quality and analyzed independently by two authors; those reporting the perception by GPs of barriers and facilitators to engagement in ACP were included.

Results: Eight qualitative studies and seven cross-sectional studies were included for data-extraction. All barriers and facilitators identified were categorized as GP characteristics, perceived patient factors or health care system characteristics. Stronger evidence was found for the following barriers: lack of skills to deal with patients' vague requests, difficulties with defining the right moment, the attitude that it is patients who should initiate ACP, fear of depriving patients of hope. Stronger evidence was found for the following facilitators: accumulated skills, the ability to foresee health problems in the future, skills to respond to a patient's initiation of ACP, personal convictions about who to involve in ACP, a longstanding patient-GP relationship and the home setting.

Conclusion: Initiation of ACP in general practice may be improved by targeting the skills, attitudes and beliefs of GPs but changes in health care organization and financing could also contribute.

What is already known about this topic

GPs can easily engage themselves in advance care planning (ACP) but the incidence of GPs engaging their patients in ACP remains low

What this study adds

This review adds to the knowledge in this field by also including studies on ACP discussions, whether or not these discussions results in written advance directives.

Barriers and facilitators to engage in ACP were related to GP characteristics, perceived patient characteristics and health care system characteristics.

Stronger evidence was found for GP skills, GP attitudes and GP beliefs regarding patients as barriers to engage in ACP

Introduction

Consistency between a patient's wishes about end-of-life care and the actual care they receive at the end of life is considered an important aspect of both patient-centred care and quality end-of-life care [1-3]. This implies that the patient's preferences regarding end-of-life care must be known before they lose the capacity to make these decisions themselves [4].

ACP is defined as a voluntary process of discussion about future treatment and end-of-life care preferences between an individual, their family and their care providers should the individual become incapable of making decisions [5]. This process can result in three main outcomes, an 'advance statement' i.e. a documented statement of the patient's general values and views about future care and treatment and/or an 'advance directive'(AD), also known as a living will i.e. instructions regarding end of life care (e.g. the forgoing of specific treatment) and the appointment of a substitute decision-maker in the event of loss of capacity [6]. Internationally, different informal and legal documents related to ACP are used , depending on the specific jurisdiction in countries [7-10].

The advantages of the timely initiating of ACP are well known: it facilitates access to palliative care, stimulates communication between the patient, family and physicians and results in greater satisfaction for the patient and the bereaved [11]. In an ageing population, more people will die from serious progressive illnesses, making timely initiation of ACP important [12;13]. General practitioners (GPs) are well-placed to encourage and engage in ACP [14;15] and the long-term relationship many patients have with their GP may be a good basis for initiating timely discussion [16;17]. Yet, previous research

has shown that the incidence of ACP discussions and the completion rate of ADs remain low among the general public and in specific patient populations [18-22]. Only 8% of the general public in England and Wales have completed an ACP document of any kind [23]. Surveys conducted in the USA show that only one-third of adults have an AD expressing their wishes for end-of-life care [24] and even among severely or terminally ill patients, fewer than 50% have an AD in their medical record [25]. In Belgium and the Netherlands GPs discussed ACP with terminally ill patients in a third of all cases and documented the discussion in only 8% (Belgium) and 16% (Netherlands) [26]. Although both patients and physicians support the idea of ACP, these results suggest that certain obstacles still prevail [27-29].

The objective of this systematic literature review is to identify the perceived factors that hinder or facilitate GPs in engaging in ACP with their patients; this has not been studied before though understanding of these barriers and facilitators is important for the development of interventions and training programmes aimed at facilitating ACP in general practice.

Methods

Search strategy for the identification of studies

Four electronic databases were searched for studies published in English, French or Dutch between 1990 and 2011: PubMed, CINAHL, EMBASE and PsycINFO. A search strategy was developed by ADV and DH for Medline and adapted to each database separately. A combination of controlled vocabulary and free text words was used to search in titles and abstracts: advance care planning, advance directives, advance decision, advance statement, living will, general practice, primary health care, general practitioners, family physicians, primary care, primary practice and family practice.

The reference list of all identified studies was screened for additional relevant studies. The first author of each included study and known experts in the field of ACP were contacted for more studies. Furthermore, the most recent issues of 10 relevant journals were hand-searched for relevant papers.

Inclusion and exclusion criteria

An article was included if it reported (1) primary research (2) on barriers and facilitators (3) on GPs (4) on patient involvement in ACP. The inclusion criteria are defined as follows:

(1) Primary research: Both quantitative and qualitative studies reporting original data that contain a clearly formulated research question or study aim were included. Editorials, narrative reviews, comments and expert opinion were excluded.

(2) Barriers and facilitators are conceptualized as predisposing factors, reported by the GP, that hinder or facilitate their engagement in the process of ACP with their patients such as skills, beliefs and experiences [30].

(3) GPs: Articles reporting on general practitioners, family physicians or family doctors were included. Where a study reported on various types of health care professionals there must have been separate results for GPs.

(4) ACP is defined as a voluntary process of discussion about future treatment and end-of-life care preferences between an individual, their family and their care providers should the individual become incapable of making decisions [5]. Studies only reporting on discussions about future care without involvement of the patient were excluded.

Inclusion procedure

Duplicates of the retrieved records were removed. Titles and abstracts of all identified reports were screened independently by ADV and DH using a standardized study selection form. The eligibility of selected studies was independently assessed by ADV and DH. Disagreement was resolved by discussion and a third reviewer (KP) was available for arbitration.

Data extraction

Characteristics of the studies included were extracted to a standardized data-extraction form. ADV and DH independently extracted data under the headings of general information, country, research question, design, participants, barriers and facilitators and quality assessment scores.

Barriers and facilitators were extracted from the individual studies as mentioned in the article. Factors that were found as barriers and as facilitators in the same article were reported both as a barriers and facilitator. Factors only reported as barriers or only as facilitators in an article were also categorized only as barriers or facilitators. Discrepancies between reviewers were discussed and if consensus could not be reached, a third reviewer (KP) was consulted.

Quality assessment and grading evidence

The quality of studies was appraised and evaluated using the Critical Appraisal Skills Programme (CASP) [31]. Since no CASP tool is available for cross-sectional studies, an additional critical appraisal

tool developed by Crombie (21-items list) was used [32]. Total quality assessment scores for both qualitative and quantitative studies are presented as scores on a scale from 0 to 10.

In addition, the body of evidence from the multiple studies was graded using the three important elements for grading systems suggested by the Agency for Healthcare Research and Quality: quality, quantity and consistency [33]. The individual studies were categorized as high quality studies (scores from 8 to 10), medium quality studies (scores from 6 to 8) and low quality studies (scores equal to or lower than 5). Articles with low quality ratings were excluded from further data-extraction. Factors reported in two or more high quality studies were graded as stronger evidence. Factors reported in one high quality study or two medium quality studies were graded as medium evidence and factors reported in one medium quality study were graded as lower evidence. Consistency of the findings was achieved through the classification of all reported factors as barriers or facilitators, preceding the analysis of the results (Figure 1).

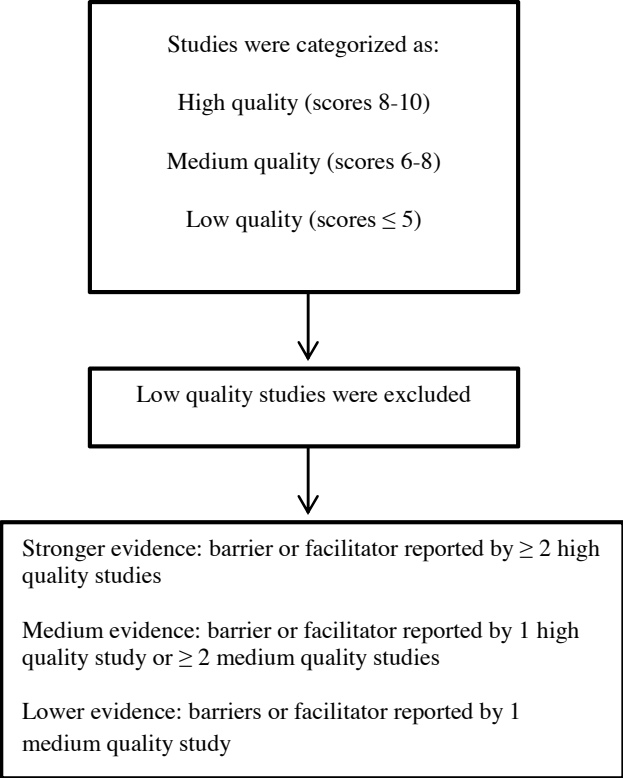


Figure 1: Quality assessment

Results

Identification of relevant studies (Figure 2)

From the electronic databases searches 442 records were identified. After removal of duplicates and irrelevant reports, the title and abstract of 320 records was screened and 61 full-text articles were retrieved for detailed evaluation. Contact with the first authors of included articles and known experts in the field, a search in reference lists and hand-searching through relevant journals yielded 42 records. Sixteen articles met all inclusion criteria and were included for data-extraction and quality assessment as were nine qualitative studies and seven cross-sectional studies.

Characteristics and quality assessment of relevant studies (Table I)

Of the sixteen included studies, four were conducted in the USA, four in the UK, two in the Netherlands, two in Australia and one in Belgium, Canada, Singapore and Israel. Of the nine qualitative studies, six studies used semi-structured interviews and three studies used both interviews and focus groups. Data in all quantitative studies were collected through questionnaires. Different types of ACP were addressed in the included studies: eight reported on communication about end-of-life care in general, eight others on more specific types of ACP (e.g. ADs).

Quality scores ranged from 4.5 to 8.5 for the qualitative studies and from 6.5 to 9 for the quantitative studies, both on a scale of 10. On the basis of these scores, four qualitative studies were considered as high quality, four as medium and one as low (excluded for further data extraction). Of the seven quantitative studies, we appraised five as high quality studies and two as medium quality studies.

Barriers and facilitators for GPs (Table II)

All reported barriers and facilitators were categorized as GP characteristics, perceived patient characteristics or health care system characteristics.

GP characteristics

Socio-demographic characteristics of GPs. There was medium evidence that the GP being younger was significantly and positively associated with the proportion of patients with whom they discussed end-of-life decisions [34].

Figure 2: Flow diagram of literature search and selection of articles

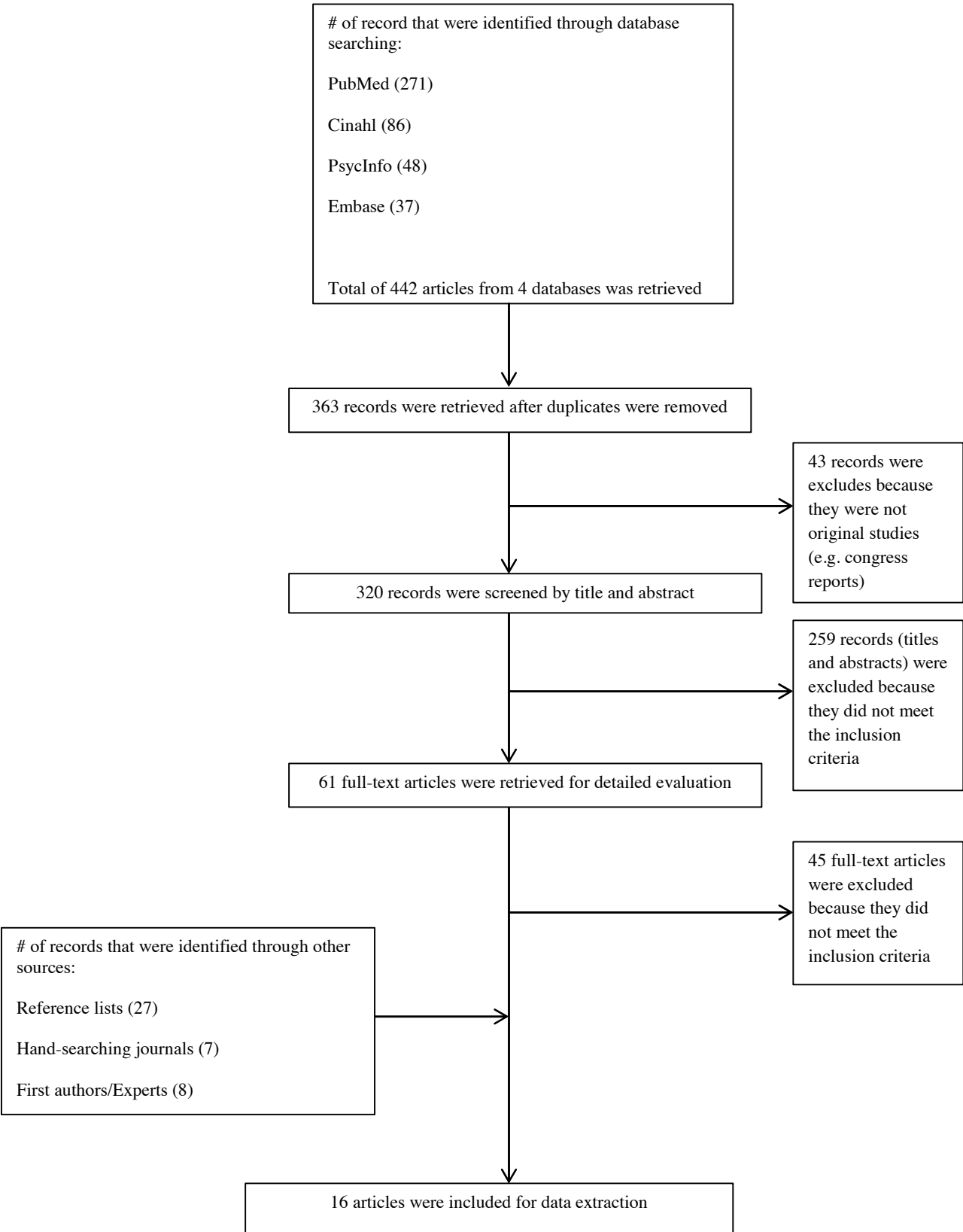


Table 1: Characteristics and quality assessment of studies included in the review¹

Study	Country	Research question	Design	Participants	Quality assessment ²
A. Qualitative studies					
1. Minto & Strickland (2011)[40]	UK	To explore the perceptions of GPs and district nurses (DNs) who have experience of ACP for their patients approaching the end of life.	Semi-structured interviews	Lead GP (n=1), GP (n=1), District nurse (n=3)	8
2. Boyd et al. (2010)[15]	UK	To explore the views of GPs and community nurses in 4 Scottish practices about ACP for cancer patients; to evaluate their learning objectives; and to see if a tailored educational intervention during continuing education would encourage greater involvement in ACP.	Mixed methods (including semi-structured interviews)	General practitioners (n=20) and community nurses (n=8)	7,5
3. Munday et al. (2009)[14]	UK	To explore the experiences and perceptions of general practitioners and community nurses in discussing preferences for place of death with terminally ill patients.	Semi-structured interviews	General practitioners (n=17) and nurses (n=19)	8,5

¹ Research question and study designs are presented as formulated in the articles.

² Qualitative studies were appraised by using the critical appraisal tool for qualitative research by CASP (10-item list). Quantitative studies were appraised using the critical appraisal tool for surveys developed by Crombie (21-items list). Both scales were converted to a 10-point scale.

4. Ostertag & Forman (2008)[64]	USA	To start a community inquiry into concerns at EOL by exploring the opinions and experiences of community members and health care workers.	Structured interviews and focus groups	Hospice medical directors (n=3), hospice nurse managers (n=4), primary care physicians (n=14), long-term care facility staff (n=18), hospice staff (n=12), community religious leaders (n=9), members of the volunteer hospice board (n=9) and family members of patients who died (n=19)	4,5
5. Bentur (2008)[44]	Israel	To determine what clinicians know about Israel's new "Dying Patient Act" and its recommendations, to examine their attitudes and perceptions about it, and to assess their willingness to increase their involvement in advance care planning.	In-depth face-to-face interviews and focus groups	Stakeholders and specialists in the health care system (n=10), senior family physicians and geriatricians (n=40)	6
6. Borgsteede et al. (2007)[38]	Netherlands	To investigate whether patients and their GPs talk about euthanasia, and if so, how they communicate about this.	Semi-structured interviews	General practitioners (n=20) and their patients (n=30)	8,5
7. Thompson et al. (2003)[42]	UK	To discover the views of health professionals on advance directives.	Semi-structured interviews and focus groups	Hospital doctors (n=4), GPs (n=4), nurses (n=4); Hospital nurses, hospice staff, GPs, consultant geriatricians, geriatrics in training grades and an interdisciplinary group (n=34)	7,5
8. Brown (2002)[41]	Australia	To explore the issues for GPs when introducing advance directives to their patients as a basis for further research into this process.	Interviews with GPs before and after the introduction of advance directives to patients during a normal consultation	General practitioners (n=5)	7

9. Pfeifer et al. (1994)[39]	USA	To identify primary care patients' and physicians' beliefs, attitudes, preferences, and expectations regarding discussions of EOL medical care, and to identify factors limiting the quality and frequency of these discussions.	Structured, qualitative interviews with open-ended questions	Primary care physicians (n=43) and ambulatory outpatients (n=47)	8
B. Quantitative studies					
1. Meecussen et al. (2011)[26]	Belgium	To investigate the prevalence and characteristics of ACP in two European countries and identify the associated factors.	Questionnaire, nationwide mortality follow-back study	Non-sudden deaths (n=1072) (Belgium (n=755); Netherlands (n=317))	9
2. James et al. (1998)[43]	USA	To assess the impact of traditionally unmeasured patient-centered factors on primary care physicians' decisions to adhere to an evidence-based clinical practice guideline for heart failure.	Questionnaires	Family physicians (n=459)	8,5
3. Steinberg et al. (1997)[35]	Australia	To examine health practitioner and community concerns, priorities and preferred options regarding patient self-determination in terminal care.	Postal questionnaire	General practitioners (n=229)	6,5
4. Tee et al. (1997)[36]	Singapore	To find out the attitudes and to assess the extent of knowledge regarding the AD among general practitioners in Singapore.	Cross-sectional, descriptive survey	General practitioners (n=199)	7

5. Pijnenborg et al. (1994)[34]	Netherlands	To gain insight into decisions made in general practice about the end of life.	Analysis of death certificates and questionnaires	Cases in which decisions about the end of life have been made (n=5197)	8
6. Hughes & Singer (1992)[45]	Canada	To examine the attitudes toward, the experience with and the knowledge of advance directives of family physicians in Ontario.	Questionnaire	Family physicians (n=643)	8,5
7. Doukas et al. (1991)[37]	USA	To determine the degree to which family physicians in the United States discuss and use the living will with their patients.	Questionnaire	Family physicians (n=494)	8,5

Table II: Barriers and facilitators to GPs engaging in ACP, as reported by the GP ³

	BARRIERS	FACILITATORS
GP CHARACTERISTICS	<p>Socio-demographic characteristics of GPs</p> <p>/</p> <p>Knowledge of GPs</p> <p>→ Lack of GP knowledge about ACP (e.g. about the legal status or time of execution of advance directives) [B3; B4; B7]**</p> <p>Skills of GPs</p> <p>→ Dealing with vague requests from patient [A3; A6]***</p> <p>→ Dealing with patients' changing preferences [A9]**</p> <p>→ Dealing with uncertainty of prognosis for cancer patients [A2]*</p> <p>→ Difficulties with defining the right moment [A6; B7]***</p> <p>→ Experiencing difficulties with advising patients in expressing their wishes [A8]*</p> <p>→ Dealing with emotional impact by the GP [A1]**</p> <p>→ Dealing with feeling uncomfortable by the GP [B7]**</p> <p>Experience of GPs</p> <p>/</p>	<p>Socio-demographic characteristics of GPs</p> <p>→ Younger age of the GP [B5]**</p> <p>Knowledge of GPs</p> <p>→ Good knowledge about ACP (e.g. regarding the use of advance directives or living wills) [B4; B7]**</p> <p>Skills of GPs</p> <p>→ Accumulated skills [A3; B6]**</p> <p>→ Defining the right timing for patients [A3]**</p> <p>→ Anticipating health problems in the future [A6; B2]***</p> <p>→ Dealing with patients initiating discussions [A2; A3; A8; A9; B7]***</p> <p>→ Dealing with explicit patient preferences [A3]**</p> <p>Experience of GPs</p> <p>→ Years of experience as GP [A1]**</p> <p>→ Positive experiences with end-of-life conversations in the past [A2]*</p> <p>→ GP personally signed living will [B7]**</p>

³ *** = Stronger evidence; ** = Medium evidence; * = Lower evidence

	<p>GP attitudes</p> <ul style="list-style-type: none"> → Thinking it is the GPs job to cure people [A9]** → Considering other healthcare professionals better positioned to initiate ACP [A3]** → Patients should initiate discussion [A6; B4; B7]** → The document of living wills itself is too legalistic and simplified for complicated medical scenarios [A9]** → Doubts about the pragmatic availability of living will documents [A9]** 	<p>GP attitudes</p> <ul style="list-style-type: none"> → Considering ACP as part of the job [A2; A8]** → Perceived usefulness of advance directives [A7; B3; B6]** → Physicians should initiate the discussion [B7]**
<p>PERCEIVED PATIENT CHARACTERISTICS</p>	<p>Patient-related obstacles to initiate ACP discussions</p> <ul style="list-style-type: none"> → Patient's denial of terminal illness [A3]** → Patients have fear of upsetting their families [B3]* → Patients are reluctant to think about future health care problems [B3]* → Patient lack knowledge of ACP <ul style="list-style-type: none"> - Lack of patient knowledge about the processes involved in making advance directives [B3]* - Patients not understanding or misinterpreting the GP [B7]** - Complexity and length of the advance directive form is too hard for patients to understand the instructions and complete it [A5]* 	<p>Patient-related facilitators to initiate ACP discussions</p> <ul style="list-style-type: none"> → Patient's acceptance of terminal illness [A3]** → Patient knowledge about ACP [B6]**

	<ul style="list-style-type: none"> - Patients misunderstanding about the sorts of health problems one will have in the future and the implications of treatment refusal [A7]* <p>Anticipated adverse outcomes as a result from ACP discussions</p> <ul style="list-style-type: none"> → Fear of depriving patients hope [A2; A9; B5]** → Fear of harming GP-patient relationship [A9]** <p>Personal convictions about which patients not to involve in ACP discussions</p> <ul style="list-style-type: none"> → Initiating communication with religious patients is difficult [A6]* → Medical condition patient as barrier for ACP discussions: <ul style="list-style-type: none"> - Incapacity of patient because of diminished consciousness or dementia [B5]** 	<p>Anticipated adverse outcomes as a result from ACP discussions</p> <p>/</p> <p>Personal convictions about which patients to involve in ACP discussions</p> <ul style="list-style-type: none"> → According to medical condition of patient: <ul style="list-style-type: none"> - Chronically ill patients or specific life-threatening diagnoses (e.g. cancer, end-stage heart disease) [B6]** - Short-term prognosis or terminally ill patients [B3; B4; B6]** - Cancer patients are more involved in ACP discussions as opposed to non-cancer patients [A6; B1]** - Patients who are competent of decision-making [B1; B5]** - Healthy patients (e.g. all adults, all patients over 65 years of age) [B4; B6]** → When do ACP discussions take place: <ul style="list-style-type: none"> - Admission or discharge from the hospital [A2; B6]** - End-of-life decisions that are estimated to shorten patients' life by more than one week [B5]** - Patients receiving palliative care [B1]**
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<p>HEALTH CARE SYSTEM CHARACTERISTICS</p> <p>Related to the GP practice</p> <ul style="list-style-type: none"> → Time limitations [A8]* → Limited resources available to honour patients' or families' expectations [A1]** 	<p>Related to the GP practice</p> <ul style="list-style-type: none"> → Long-term GP-patient relationship <ul style="list-style-type: none"> - Shared common history [A3; A6]** - Multiple contacts in the last week of life [B1]** → Time <ul style="list-style-type: none"> - Possibility to devote time [A3]** - Reimbursement of time spent on discussion [B6]** → Care setting <ul style="list-style-type: none"> - Home setting [A6; B1]** - GP office [B4]* <p>Related to other health care providers</p> <ul style="list-style-type: none"> → Collaboration with other healthcare professionals <ul style="list-style-type: none"> - Respect of advance directives by other healthcare professionals [B3]* - Consultation with other health care professionals about ELD's [B5]** → Hospital policy supporting or requiring the use of advance directives [B6]** <p>Related to legislation</p> <ul style="list-style-type: none"> → Legislation regarding advance directives <ul style="list-style-type: none"> - Legalization supporting the use of advance directives [B3; B6]** - Legalization protecting physicians when following advance directives [B6]**
<p>Related to the GP practice</p> <ul style="list-style-type: none"> → Lack of collaboration with secondary care: <ul style="list-style-type: none"> - Patients reaching the end of their lives leaving the care of their family physician [A5]* - Patients getting other messages from the hospital than the GP [A2]* <p>Related to other health care providers</p> <p>Related to legislation</p> <p>/</p>	

Knowledge. Medium evidence was found for the reported lack of GP knowledge about ACP as a barrier to involving patients in ACP [35-37].

Skills. There is stronger evidence that GPs perceive their own lack of skill in dealing with patients' vague requests, and their difficulties in defining the right moment for initiating discussion, as barriers to engaging in ACP [14;37;38]. Medium evidence was found that they perceive their lack of skill in dealing with a patient's changing preferences and with the emotional impact or discomfort of having ACP discussions as barriers [37;39;40]. Lower evidence supported the perceived lack of skill in advising patients on expressing their wishes, and the prognostic uncertainty for chronically ill patients as barriers [15;41]. Addressing patient initiation, accumulated skills and foreseeing health problems in the near future were factors reported as facilitators for which stronger evidence was found [14;15;39;41-43].

Experience. Medium evidence was found for the length of their experience as a GP and having a living will themselves as perceived facilitators [37;40]. Lower evidence supported positive experiences with end-of-life conversations in the past as a facilitator [15].

Attitudes. The attitude that GPs should initiate ACP was perceived a facilitator for which stronger evidence was found [37]. There is medium evidence that a conviction that it is their job to cure people whereas other healthcare professionals should initiate ACP prevents GPs engaging in ACP [14;39]. Doubts regarding the content and practical availability of living wills are hindering factors as well [39].

Perceived patient characteristics

Perceived patient-related obstacles can hinder GPs in initiating ACP. The GP holding the following beliefs is perceived as a barrier and supported by lower evidence: patients lack knowledge of ACP, patients have a fear of upsetting their families and patients are reluctant to think about future health care problems [35;37;42;44]. Medium evidence supports that a patient's denial of their terminal illness makes talking about preferences for end-of-life care very difficult [14].

Anticipated adverse outcomes. Fear of depriving a patient of hope or damaging the GP-patient relationship were cited as factors that keep GPs from engaging in the process of ACP, for which respectively stronger and medium evidence was found [15;34;39].

Personal convictions about who and who not to involve in ACP and when. When asked who should be approached about ACP, GPs designated terminally ill patients and healthy patients in medium quality studies [15;35;36;45]. GPs reporting that competent patients and cancer patients are more involved in ACP is supported by stronger evidence [26;34;38]. Medium evidence was found that three events trigger discussion between GPs and patients: admission or discharge of patients from the hospital, when end-

of-life decisions are estimated by the GP to shorten patients' life by more than one week and when patients receive treatment aimed at palliation in the last week of life [15;26;34;45].

Health care system characteristics

Related to the GP practice. Stronger evidence supported a longstanding patient-GP relationship as a perceived facilitator for ACP [14;38]. GPs also considered it advantageous if talking about ACP could take place in the home setting [26;38]. There is medium evidence for the time available, and the chances of reimbursement being facilitators [14;45]. The limited resources available in primary care were perceived as a barrier [40].

Related to other healthcare providers. There is lower evidence that lack of collaboration with secondary care is perceived as an impediment to the process of ACP [15;44]. Consultation with other healthcare professionals and hospital policy supporting or requiring the use of ADs was considered as a facilitator, supported by medium evidence [34;45].

Related to legislation. GPs reported that legislation supporting the use of ADs as well as protecting GPs who following them would encourage them to offer ADs to patients, which is supported by medium evidence [35;45].

Discussion

We found numerous perceived barriers and facilitators influencing GP engagement in ACP with patients. All reported factors were related to three groups: GP characteristics, perceived patient characteristics and health care system characteristics. Stronger evidence was found for lack of skills to deal with vague requests, difficulties with defining the right moment, the attitude that patients should initiate ACP and fear of depriving them of hope as perceived barriers. The perceived facilitators for which stronger evidence was found were accumulated skills, the ability to foresee health problems in the future, skills in addressing patient initiation of ACP, cancer patients, patients capable of decision-making, a longstanding patient-GP relationship and a home setting.

To our knowledge, this is the first study to provide a systematic overview of the perceived barriers to and facilitators for GPs engaging in ACP. All required methodological steps to complete a systematic review were implemented and performed separately by two reviewers. This review adds to the knowledge in this field by also including studies on ACP discussions, whether or not these discussions result in written advance directives [46]. This review also has limitations. Given the variation in how ACP is implemented and documented and the variation in GP practice, our findings may not be

generalizable to all countries and health care systems. Second, only barriers and facilitators reported by GPs were considered although understanding the barriers and facilitators for patients is equally important and deserves research. Third, we retrieved only qualitative research and observational studies though in our opinion such research designs provide the best way of addressing the research question. As the studies used different methods, it was not appropriate to combine data across the studies for meta-analysis [47;48]. However, the methodological quality was assessed and in addition, the body of evidence was graded. This approach allows to provide a conclusion that incorporates both the results and quality of the studies [49].

Stronger evidence was found for the GP attitude that patients should initiate discussions being a barrier and for having the skill to address a patient's initiation of discussion as a facilitator. Remarkably, many studies show that patients believe it is the physician's responsibility to initiate ACP which suggests that there is a gap in expectation between patients and GPs. This difference has been pointed out in previous studies and may explain why ACP consultations are often initiated tardily when end-of-life decisions need to be made [50-53].

Most of the perceived barriers for GPs were classified as a lack of skills; it is recognized that physicians are less likely to initiate ACP when they believe they lack the skills required [54]. The perceived lack of skills to deal with a patient's changing preferences and to address vague requests and difficulties with defining the right moment to initiate ACP were also found in other health care settings [28;55]. Many of the same barriers could also be found in the literature on communication at the end of life in general and may cover the same ground, since ACP is often initiated at the end of life [56-58].

According to GPs, cancer patients are more involved in the process of ACP than non-cancer patients. As they often have a more predictable disease course, defining the right moment to initiate ACP might be easier. Research has shown that one of the reasons ACP was not initiated with patients with chronic obstructive pulmonary disease (COPD) was because of physicians' lack of understanding that COPD is a life-threatening disease [21]. Not only physicians, but also chronically ill non-cancer patients often have a poor understanding of their illness [59;60]. It is possible that non-cancer patients initiate ACP less often because of a reduced awareness of their diagnosis and prognosis. Most patients and professionals agree that talking about ACP should take place around the time of diagnosis of a life-threatening illness, but fear of depriving patients of hope is a barrier preventing GPs from initiating ACP for which stronger evidence was found [61;62].

The facilitators identified were often related to health care system characteristics. Previous research showed that conversations about ADs averaged 5.6 minutes and physicians spoke for two thirds of this time, making patient's values and preferences rarely explored [63]. Financial compensation for the time spent on ACP could possibly encourage GPs to make ACP a current practice but it could also acknowledge the importance of this aspect of care.

Conclusion

Understanding the barriers and facilitators is important for the development of interventions aimed at facilitating ACP in general practice. Initiation of ACP in general practice may be improved by targeting GP-related barriers and facilitators, but changes in health care organization and finances could also contribute. Training programmes are necessary to change skills, attitudes and beliefs preventing GPs from initiating ACP and to provide good role models for the difficult task of initiating communication about end of life in a helpful and empathetic way.

Conflict of Interests Statement

The authors declare that they have no competing interests.

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**Barriers to advance care planning in cancer, heart failure and dementia patients:
a focus group study on general practitioners' views and experiences**

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Abstract

Background: The long-term and often lifelong relationship of general practitioners (GPs) with their patients is considered to make them the ideal initiators of advance care planning (ACP). However, in general the incidence of ACP discussions is low and ACP seems to occur more often for cancer patients than for those with dementia or heart failure.

Objective: To identify the barriers, from GPs' perspective, to initiating ACP and to gain insight into any differences in barriers between the trajectories of patients with cancer, heart failure and dementia.

Method: Five focus groups were held with GPs (n=36) in Flanders, Belgium. The focus group discussions were transcribed verbatim and analyzed using the method of constant comparative analysis.

Results: Three types of barriers were distinguished: barriers relating to the GP, to the patient and family and to the health care system. In cancer patients, a GP's lack of knowledge about treatment options and the lack of structural collaboration between the GP and specialist were expressed as barriers. Barriers that occurred more often with heart failure and dementia were the lack of GP familiarity with the terminal phase, the lack of key moments to initiate ACP, the patient's lack of awareness of their diagnosis and prognosis and the fact that patients did not often initiate such discussions themselves. The future lack of decision-making capacity of dementia patients was reported by the GPs as a specific barrier for the initiation of ACP.

Conclusion: The results of our study contribute to a better understanding of the factors hindering GPs in initiating ACP. Multiple barriers need to be overcome, of which many can be addressed through the development of practical guidelines and educational interventions.

Introduction

The expected increase in numbers of people developing dementia, the growing number of old people suffering and dying from serious chronic diseases and the rising costs of health care as a result of an aging population have focused attention on advance care planning [1]. Advance care planning (ACP) is the voluntary process by which patients discuss their future treatment and end-of-life care preferences with their care providers in case they lose the capacity to make decisions or communicate their wishes in the future. If a patient chooses to, the contents of such a discussion can be placed on record in the form of an advance statement (of wishes and preferences), or an advance decision to refuse treatment in specific circumstances and may include the appointment of a proxy decision-maker or lasting power of attorney [2;3] .

The long-term relationship between general practitioners (GPs) and their patients is considered an ideal context for introducing the subject and starting the process of ACP before the patient becomes seriously ill [4-6]. Evidence shows that patients are comfortable discussing ACP with their GP when their condition is stable in anticipation of future ill-health [7]. In Belgium, as in many European countries, GPs have mostly built up long-term relationships with their patients [8]. However, a cross-national retrospective study showed that, in a population of patients who died non-suddenly, GP-patient discussion of treatment preferences occurred for 25% of patients in Belgium [9]. Cancer patients are also more often involved in the process of ACP than non-cancer patients, suggesting that initiation of ACP with other patient groups has its own challenges [10].

Current international guidelines suggest that all patients with a chronic life-limiting illness should be offered ACP before time-critical situations occur [3;11], but discussions about end-of-life care often takes place with those who are terminally ill and are relatively close to death [12-14]. However, an understanding of the three main illness trajectories of patients with chronic life-limiting diseases indicate that these patients may benefit from the timely initiation of ACP [15;16]. The first trajectory is typified by cancer and generally follows a relatively predictable end-of-life course with a maintenance of good function until a rapid decline in clinical status in the last weeks of life. Heart failure is typical of the second trajectory, marked by a slow decline that is interrupted by acute deteriorations any of which might end in sudden death. For these individuals there is considerable uncertainty about when death is likely to occur. The third trajectory, typically seen in patients suffering from dementia, follows a long term period of progressive decline in functional and mental capacity before death [17]. When patients are hospitalized for health crises resulting from their chronic incurable disease, the patient may be close to death, yet there often is no clearly recognizable starting point between being very ill and actually dying [18]. Reserving ACP discussions for the end-of-life may thus deny patients the chance to adequately prepare for and plan their future care while having the decision-making capacity to do so [19].

Previous qualitative studies conducted in the UK and Australia identified a lack of time, a desire to maintain hope, prognostic uncertainty and the belief that patients are not willing or able to face discussions around death and dying as barriers to initiating ACP in primary care [20-22]. However, most of these studies have been focused on single patient groups (e.g. cancer patients) or on the initiation of ACP with terminally ill patients. The aim of this study is to identify the barriers, from GPs' perspective, to initiating ACP and to gain insight into any differences in barriers between the trajectories of patients with cancer, heart failure and dementia.

Methods

Research design

This exploratory study used the qualitative methodology of focus groups. The focus group approach was chosen because it is flexible in that it allows for open discussion and interaction in order to obtain in-depth insight into the range of views and experiences of GPs regarding barriers to initiating ACP [23].

Recruitment of participants

Five focus group interviews with GPs were held in Flanders (Belgium) during March 2012. The participants were purposefully sampled by using several recruitment strategies in order to maximize the variation in their experience, age and practice location. Three focus groups were organized within local peer-review GP groups by contacting the chairs of six of these groups. Local peer-review GP groups are geographically determined groups of GPs from both individual and group practices that meet four times a year to discuss their practice. Every GP who wants to be accredited in Belgium, needs to be affiliated to a peer-review group and is obliged to attend two out of four meetings per year. A report from 2005 showed that more than 90% of active GPs in Belgium are affiliated to a peer-review group [24]. We chose to recruit via local peer-review groups to obtain a sample of GPs representing a wide range of experience related to the topic (maximum variation sampling) [25]. Secondly, because research shows that advance care planning usually takes place with patients who are terminally ill and close to death [26], we specifically also wanted to enroll GPs who have experience with palliative patients and communication in the last phase of life. We contacted coordinators of the palliative care networks in Flanders with the request to disseminate our invitation to GPs active in palliative home care teams. Palliative home care teams consist of experts in palliative care (physicians, nurses, psychologists) who, in addition to their own practice, advise and support palliative patients in their last phase of life and work closely with the surrounding caregivers to organize optimal care for the patient. However, because not many GPs from the palliative home care teams responded to our invitation (n=2) we complemented

this focus group with GPs not working in a palliative home care team. These other GPs were recruited through professional contacts of the palliative care coordinators that referred us to these participants (snowball sampling). A fifth focus group was organized with members from a group practice that is located in an urban region as opposed to the rural and semirural regions where the other focus groups took place.

Data collection

A topic guide, consisting of open questions and a set of prompts for each question, was developed and reviewed within a multidisciplinary research team of sociologists (ADV, DH, LD), psychologists (KP, KB, CVA), a GP (RVS) and an anthropologist (RD), and covered four general themes: (1) experiences of GPs with ACP in their current practice (2) attitudes regarding ACP (3) perceived barriers to and facilitators for initiating ACP and (4) possible interventions to improve initiation of ACP in general practice (Figure 1). A definition of ACP was introduced at the beginning of each focus group and participants were asked whether they were familiar with this definition and the term 'ACP'. ACP was defined as a voluntary process by which patients discuss their future treatment and end-of-life care preferences with their care providers in case they lose the capacity to make decisions or communicate their wishes for the future [2;3].

At the start of each focus group, the participants were informed about some important 'ground rules' of a focus group discussion, e.g. no talking across each other, keeping the information discussed confidential, etc. Each focus group was moderated and observed by two researchers (ADV, KP, RVS or LD) and took place in a quiet meeting room. The focus groups were conducted in Flemish and were translated by the first author. The focus groups lasted on average one and a half hours and were audiotaped, for which all participants gave their informed consent. Before the interview the participants also filled in a short questionnaire regarding their own characteristics. After conducting the first two focus groups, that focused on discussing the differences between the initiating of ACP with patients with cancer, dementia and heart failure, the research team decided to explore these differences further by focusing on one of the specific patients groups in each of the three following focus groups. To improve data collection the topic guide was slightly modified after the first two focus groups, without compromising consistency. However, during these focus groups the participants drew comparisons themselves between the trajectory chosen for discussion and the other trajectories. After five focus groups, the researchers evaluated that saturation had been reached.

Figure 1: Topic guide of the focus groups with general practitioners

<p>Introduction + Definition of ACP</p> <p>Theme 1: Experiences of GPs with ACP in practice</p> <ol style="list-style-type: none">1. Do you know the concept of ACP?2. Do you have any experience with ACP in your practice? <p>Theme 2: Attitudes regarding ACP</p> <ol style="list-style-type: none">1. Can you describe your attitude regarding ACP? Do you feel that ACP can be useful?2. What are the main advantages and disadvantages of ACP for you? <p>Theme 3: Perceived barriers and facilitators for initiating ACP</p> <ol style="list-style-type: none">1. Are there situations when the initiation of ACP is perceived as more difficult or easy for you?2. Do you think that the (one of the three) specific disease trajectory of patients has an influence on the initiation of ACP for you? <p>Theme 4: Interventions to improve the initiation of ACP in general practice</p> <ol style="list-style-type: none">1. What do you think could contribute to the improvement of initiating ACP for general practitioners?
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Data analysis

The focus group discussions were transcribed verbatim. For analyzing the data, constant comparative analysis was used [27;28]. Firstly, two researchers (ADV & KB) independently read and coded two full focus group transcripts. The codes were discussed and mutually compared for similarities and differences until a primary coding framework was constructed. Subsequently, the five focus group transcripts were independently read and compared with the primary coding framework by all the members of the research team. Codes were added, modified or merged where necessary. Notes were taken about the decisions that had been made during the coding process to ensure consistency of results. ADV coded the remaining transcripts by applying the final coding framework, which was additionally checked by KB and KP for agreement on interpretation. Once coding was completed, ADV & KP revised the transcripts and the coding framework. An ongoing refinement of the coding framework, by grouping the codes that had common elements, eventually resulted in categories that related to the research questions. Finally, quotes were selected (ADV & KP) and approved by the research team to illustrate the results. The qualitative analysis software QSR NVIVO 10 was used for this research.

Ethical aspects

The research protocol was approved by the Commission of Medical Ethics of the University Hospital of Brussels. A signed informed consent was obtained from each participant before the focus group interview. Anonymity was assured by removing participant information that could lead to identification from the transcripts.

Results

A total of 36 GPs (n= 9, n= 11, n= 4, n= 5, n= 7) attended one of the five focus groups. Participants' characteristics are presented in Table 1.

Although the GPs identified end-of-life care conversations as an important aspect of general practice, many of them were not familiar with the term ACP. Once a general definition was introduced, most GPs indicated that they had some experience with end-of-life care discussions but stated that they were mostly conducted in an informal way.

It [ACP] does not have to be anything formal, it may also be just a little chat in response to...I think it is very important that that is monitored. That [ACP] does not become a formality, a consensus on paper with a hierarchical structure and a number of conditions which must be complied with. (Female GP, 40 years, FG 1)

Is ACP also not something that is often discussed between the lines? (Female GP, 41 years, FG 1)

GPs with more experience and expertise in palliative care were generally more familiar with the concept and process of ACP. Positive experiences with previous ACP discussions was, according to most GPs, also considered to be an important facilitator for the initiation of ACP.

Barriers to initiating ACP according to GPs

An overview of all the barriers that were mentioned in the focus groups is presented in Table 2. The perceived barriers were interpreted as barriers relating to the GP, to the patient and family and to the health care system (e.g. lack of time to discuss ACP in general practice). Most of the barriers identified related to the GP and could be classified as lack of GP communication skills, lack of GP knowledge regarding illness trajectories or GP attitudes and beliefs regarding ACP. There were barriers for which no differences between the trajectories of cancer, heart failure and dementia were perceived, e.g. lack

Table 1: Characteristics of participating GPs (N = 36)

Characteristics	FG 1 (n= 9)	FG 2 (n=11)	FG 3 (n= 4)	FG 4 (n= 5)	FG 5 (n= 7)	Total
Sex						
Male	5	7	4	5	6	27
Female	4	4	0	0	1	9
Age (years)						
≤ 29	1	0	0	0	0	1
30-39	1	2	0	1	1	5
40-49	5	3	1	2	2	13
50-59	1	5	1	1	1	9
60-69	1	1	2	1	3	8
≥ 70	0	0	0	0	0	0
Practice location						
Urban	9	0	0	0	0	9
(Semi-)Rural	0	11	4	5	7	27
Number of terminal patients in their practice in the last year						
None	2	1	1	0	0	4
1-3	3	3	1	2	1	10
4-6	3	1	2	2	3	11
7-9	0	1	0	0	1	2
≥ 10	1	5	0	1	2	9
Active in a palliative home care team						
Yes	0	0	0	0	2	2
No	9	11	4	5	5	34
Clinical work experience (years)						
1-9	2	2	0	0	0	4
10-19	2	1	0	2	2	7
20-29	3	4	2	1	2	12
≥30	2	4	2	2	3	13

Table 2: Barriers according to GPs to initiate ACP

<p>Barriers related to the GP</p> <p><i>Lack of communication & interpersonal skills of GPs:</i> Difficulties for the GP with addressing non-specific patient issues GPs not feeling comfortable in talking about death and dying Lack of GP education about ACP Lack of GP experience with ACP Lack of GP experience with palliative patients</p> <p><i>Lack of GP knowledge regarding illness trajectories in order to initiate ACP:</i> Lack of GP knowledge about treatments options in order to discuss ACP Lack of GP familiarity with the terminal phase of illness Difficulties for the GP with making accurate predictions of life expectancy Difficulties for the GP to define key moments to timely initiate ACP Lack of GP knowledge about the legal status of advance directives</p> <p><i>GP attitudes & beliefs concerning ACP:</i> Fear of legal proceedings by implementing ADs Fear of losing the patient as a client by discussing end-of-life care Fear of destroying hope in the patient by initiating ACP Fear of creating anxiety by initiating ACP Uncertainty over appropriateness of ACP for non-chronically ill patients Lack of trust in the value of ACP to comply with patient wishes at the end of life Believing that patients will initiate ACP themselves if they are ready to discuss it Believing patients do not like to discuss end-of-life care</p>
<p>Barriers related to the patient and family</p> <p>Lack of patient initiation Patients changing end-of-life care preferences Patients' unawareness about the diagnosis and prognosis Patients' and/or family members' denial about imminent death Patients misinterpreting disease information Future lack of decision-making capacity Patients' family hindering end-of-life care discussions Lack of a longstanding relationship with the patient</p>
<p>Barriers related to the health care system</p> <p>Lack of structural collaboration with secondary care or other health care professionals Lack of time to discuss ACP in general practice</p>

of time. The barriers for which differences were indicated between these trajectories are explored in depth below.

Differences in barriers to initiating ACP between cancer, heart failure and dementia (Table 3)

Lack of GP knowledge about cancer treatment options. Several GPs reported a lack of knowledge about existing treatments for different cancer types and their possible effects as a barrier, which they considered essential to the discussion of treatment decisions and end-of-life care preferences.

For a good planning you need to be well informed, you need to know what are the possibilities and what aren't the possibilities and I do feel that... that I often know too little. That might be because... maybe I should inquire about it more often, that may well be so, but I often get the feeling: I can't assess this anymore, what benefits does it have, or doesn't it have. I find it hard. (Female GP, 60 years, FG 5)

This problem existed far less with regard to heart failure and dementia because of the perception by the GPs of the limited treatment options they offer.

Heart failure is a pretty aggressive condition. Once you've got it, you can't do anything about it anymore. (Male GP, 60 years, FG 4)

Lack of GP familiarity with the terminal phases of heart failure and dementia. During the focus groups, it became clear that several GPs were less familiar with the terminal phases of heart failure and dementia; not only is the terminal phase less clear than with cancer but for some GPs the life-limiting nature of heart failure and especially dementia is not always apparent. Consequently, for some GPs the recognition of the need to discuss end-of-life care does not always arise.

Do you die from dementia? (Male GP, 58 years, FG 4)

Yeah, but in that case it's from age? Well yeah, you have to die once. I mean... (Male GP, 45 years, FG 4)

However, during the focus groups, some GPs came to recognize the importance of timely initiation of ACP for heart failure and dementia patients:

Yes, [for cancer patients] you can feel or sense that better as a GP. But for heart failure... I myself am actually a little stunned. It is true, there should actually be a discussion about it. (Male GP, FG 4, 38 years)

On the other hand, for a patient that is becoming demented, you may have to provide care for more than 5 years, without him knowing. So actually it is important to know what they really care about and what not. (Female GP, 35 years, FG 2)

Table 3: Differences in barriers to initiate ACP between the trajectories patients with cancer, heart failure and dementia according to the GP

	Cancer	Heart failure	Dementia	Mentioned in FG
Barriers related to the GP:				
Lack of GP knowledge about treatment options	↑			4, 5
Lack of GP familiarity with the terminal phase of illness		↑	↑	3, 4
Difficulties for the GP to define key moments to timely initiate ACP		↑	↑	2, 3, 4, 5
Barriers related to the patient and family:				
Patients' unawareness about diagnosis and prognosis		↑	↑	3, 4, 5
Future lack of decision-making capacity			↑	1, 3, 5
Lack of patient initiation		↑	↑	1, 2, 3, 4, 5
Barriers related to the health care system:				
Lack of structural collaboration between primary and secondary care	↑			1, 2, 3, 4, 5

↑: barrier according to GPs for the initiation of ACP with a specific patient group in comparison to the other patient groups

Lack of key moments for the initiating of ACP in the trajectories of heart failure and dementia.

Although a number of key moments suitable for initiating ACP with cancer patients were raised during the focus groups (at diagnosis, when patients experience negative effects from medical treatment, when treatment is withdrawn and when patients are deteriorating at the end of life), the point when curative treatment is exhausted was considered the most appropriate according to most GPs. The majority of GPs acknowledged that the stage of advanced illness was too late to initiate ACP with heart failure patients but end-of-life care issues were generally raised when the patient's condition was obviously declining after numerous acute hospital admissions. For dementia patients, no key moments were identified for the initiation of ACP.

Because it's obvious, they [cancer patients] have been diagnosed, for the time being I'm assuming most people have been informed of this diagnosis as well, and otherwise I'll deliver it myself. And so I think it's way easier to, sooner or later, start a conversation in response to that diagnosis, while it's a lot harder in case of dementia, because there's already some cognitive impairment. And it's also very difficult in case of organ failure huh, because those people are doing well, there's no sudden diagnosis, they've already been hospitalized for this before... and a patient with organ failure does get worse, but there isn't always a facilitating moment. Therefore it's not always easy to [talk to] such a person, who despite having for example lung problems, doesn't always realize he's just as terminal as a cancer patient. And I find that much harder, ... (Male GP, 42 years, FG 5)

Only a few GPs with considerable experience in end-of-life care believed that ACP should be initiated as early as possible:

I start [ACP] with my patients as early as possible. Even if they come to me on a consultation for the first time and I see the opportunity to bring it up, I will. Because I like to know those things before it happens. I like people to give their advice before anything happens to them. It also allows for a more open and free discussion. So for me it is: the earlier, the better. And I mean, I do not snub people and ask them “what’s your name and what is your vision on the end-of-life?”. But still, if an opportunity arises, I will grab it as soon as possible. I like to know how the patients sees things. (Female GP, 35 years, FG 2)

A patient’s lack of awareness of diagnosis and prognosis in heart failure and dementia was expressed as a barrier to the initiation of ACP compared with cancer patients. Although most heart failure patients are informed that they are suffering from a heart condition, the prognosis is not always communicated because GPs can have difficulty in explaining potential events such as the risk of sudden death without creating anxiety. The fear of creating anxiety or depression for dementia patients by explaining the expected deterioration of their mental capacity was similarly mentioned as a barrier. GPs considered it too difficult to initiate ACP at any point with patients who are unaware of their diagnosis or prognosis.

I think we’ve got quite a lot of patients with dementia, but you won’t immediately start telling these people: soon you won’t know what you’re doing anymore. It’s time that you do something about it, that you start planning this, I think it’s a bit of a taboo to start discussing this, to tell someone with Alzheimer’s, in a year you won’t know what you’re doing anymore. (Male GP, 44 years, FG 3)

According to the GPs in our focus group, cancer patients were more aware of their diagnosis as opposed to patients with heart failure and dementia, which can create an opening for the discussion of prognosis and types of treatment:

Patients are often sent home with a diagnosis. They know what is going on, but they haven’t received very specific information from the specialists. They wonder: “What will happen to me? Is there really nothing they can do for me?”. (Male GP, 60 years, FG 2)

Lack of patient initiation of ACP in heart failure and dementia was mentioned as a barrier in all focus groups. The GPs described cancer patients as the easiest group with whom to initiate ACP, because they spontaneously make the association with death and dying when hearing their diagnosis.

But it’s different, because in this case the question won’t come from the patient that often, I think. For cancer it’s known, “cancer – death”, people do make that association. While heart failure is like, yeah, he’s got heart problems. (Male GP, 38 years, FG 4)

Because patients with dementia and heart failure are often unaware of or in denial about the life-threatening nature of their disease according to most GPs, they rarely initiate ACP themselves.

It has never happened [that a patient with dementia starts discussing ACP on his/her own initiative] (Male GP, 69 years, FG 3)

Cancer patients do however. (Male GP, 65 years, FG 3)

Future lack of decision-making capacity of dementia patients was given great weight as a barrier to initiating ACP. Many GPs felt uncomfortable about discussing and planning end-of-life care with patients who are losing the capacity to express a change in preference or confirm their wishes at the end of life. As patient's wishes and circumstances may change over time, some GPs were also reluctant to make formal documentation of decisions expressed by dementia patients.

Because I think for the category of people with a deteriorating level of consciousness it's a different story than for people with cancer or kidney failure, with whom you can hold conversations until the very end sometimes... I think this is a really difficult category of people compared to a person who can still talk to you about what he wants or doesn't want. (Female GP, 44 years, FG 1)

I think in the really early stages of dementia we actually don't discuss this with the patient because it's often diagnosed very late. At that moment, discussing it is actually no longer possible. (Male GP, 44 years, FG 3)

On the other hand, some GPs considered the future loss of a patient's decision-making capacity the very reason for initiating ACP:

It is much better that you discuss this in advance, rather than to discuss it with the patient's family because the patients has dementia. If you previously haven't talked about it, than you actually have missed your chance. So yes, I believe that ACP discussions should start early with the patient instead of talking to the family, the nurse, or the care team around a patient that is not able to communicate anymore. (Male GP, 65 years, FG 5)

In some focus groups, doubts about the legality of advance directives (ADs) drafted by dementia patients and anxieties about possible legal proceedings that may follow their implementation were also mentioned as a barrier to initiate ACP discussions:

If the patient signs, and he has been diagnosed with dementia, where do you stand, is it still legal? He signed while, according to the court of justice, he no longer knew what he was doing. (Male GP, 44 years, FG 3)

Lack of structural collaboration between primary and secondary care for cancer patients was mentioned in all focus groups as a barrier to initiating ACP. In the case of cancer particularly, limited

contact with patients and lack of information from specialists during treatment phases were considered as factors that hinder the initiation of ACP.

The patient used to be able to report back to you once in a while about what had or hadn't been decided. But nowadays they [the hospital] actually keep them to themselves for a very long time, even in a palliative situation I think. Well, at certain wards this is definitely the case. You don't have to draw their blood anymore, they don't have to come and talk to you. They do that at the hospital for a really long time, even the moment they say, now we can't do anything anymore, maybe you should go to the palliative unit now, while the patient actually won't hear a lot about dying at home if we don't come and explain it, I think. (Female GP, 49 years, FG 1)

Some GPs evaluated the collaboration between GPs and specialist more positively, but acknowledged that was mostly due to a longer relationship or a past experience between the GP and specialist:

I feel that you almost need to have a personal relationship with a specialist before you can have any impact. (Male GP, 30 years, FG 1)

Yes, there is indeed a big difference. I also hear that from colleagues who work in a completely different area, where there is a smaller local hospital. They have a much closer relationship with the specialist than here. I think here some older colleagues who have some experience have much more direct contact with the specialists, so a lot more things are possible. (Male GP, 29 years, FG 1)

The tendency of specialists to persist with curative treatment even when patients are deteriorating appeared to be an obstacle to initiating ACP for many GPs.

You do tell the family, just keep him here because he's dying, he only has a couple of weeks left, whereas the oncologist told them 2 days before 'you really need to come, because this will still make you feel good'. So there you are then. (Male GP, 65 years, FG 5)

As a GP, you really can't go against this. (Male GP, 46 years, FG 5)

Discussion

Summary of main findings

The GPs in our study reported multiple barriers to initiating ACP relating to their own characteristics, the characteristics of the patients and their families and the structure and organization of the health care system. They also perceived certain of these barriers to relate more to the specific trajectories of cancer, heart failure or dementia. In cancer patients, a GP's lack of knowledge about treatment options and the lack of structural collaboration between the GP and specialist were expressed as barriers. Barriers that occurred more often with heart failure and dementia patients were the lack of GP familiarity with the terminal phase, the lack of key moments to initiate ACP, the patient's lack of awareness of their

diagnosis and prognosis and the fact that patients did not often initiate such discussions themselves. The future lack of decision-making capacity of dementia patients was reported by the GPs as a specific barrier for the initiation of ACP.

Strengths and limitations of the study

To our knowledge, this is the first qualitative study providing in-depth insight into the similarities and differences in the barriers to initiation of ACP between cancer, heart failure and dementia patients, as perceived by the GP. By using different sampling strategies we gained insight into the complex range of views and experiences regarding ACP in daily practice from GPs with diverse backgrounds, experience and interest in ACP. This study provides a better understanding of the problems that need to be overcome when developing interventions or training programmes to enhance the initiation of ACP in general practice [29]. Our description of the barriers remained as close as possible to the phrasing used in the focus groups and we divided them into three main categories as relating to the GP, to the patient and family and to the health care system; however many barriers are interrelated and should not be interpreted as isolated factors. The focus group composition may have presented a limitation. Most of the participating GPs were male (n= 27), so female GPs (n= 9) were underrepresented, as were GPs younger than 39 years (n= 6 vs. n= 30). Secondly, the perspective of the GPs themselves is valuable in obtaining the information essential for making changes in education and innovation in practice. However, other perspectives such as those of patients and family members, and of specialists, could provide additional insights that could also contribute to a better understanding of the problems of ACP and to the formation of useful educational approaches.

Comparison with existing literature

The findings of this qualitative study confirm many barriers to GP initiation of ACP found in previous studies [1;5;30], but are here placed in the context of the three illness trajectories of cancer, heart failure or dementia. Four of the seven barriers for which a difference was identified, pertained to heart failure and dementia patients. The barriers pertaining to both heart failure and dementia patients seem mainly to be consequences of the less predictable disease course of these conditions, leading to GPs experiencing difficulty with predicting the terminal phase of disease [31;32]. The clearer demarcation between curative and palliative care in cancer patients, often used as a trigger and also considered as the most appropriate moment by the GPs in our focus groups to initiate ACP, is less distinct in heart failure and dementia. This challenges GPs to identify other key moments to initiate ACP, one of the main problems for GPs that needs to be addressed according to previous studies [33;34]. Previous research also shows that GPs find diagnosing heart failure and giving a prognosis particularly challenging,

making it difficult for them to relay information back to patients [31]. Many patients are never actually told that they have heart failure because doctors are reluctant to use the term [35] and similar concerns have been raised for dementia [36]. Communicating a diagnosis and prognosis is however an important element in informing patients of treatment and end-of-life care choices. Recently, experiential skills-building communication training in cancer has been shown to improve clinicians' skills in communication about end-of-life care [37;38]. As GPs' experience with ACP was also considered to be a facilitator in this study, offering GPs such training may improve their confidence and skills with initiating ACP for all patients in relation to chronic life-limiting conditions.

The barriers pertaining to cancer patients (lack of knowledge about treatment options and lack of structural collaboration between primary and secondary care) seem to be related to the increasing specialization and complexity of cancer treatments. While heart failure and dementia are largely managed in primary care, most follow-up and surveillance of cancer patients remains in the hands of specialists [39]. As a consequence, GPs often lose touch with their patients during active treatment, which is not countered by effective collaboration or information transmission between GPs and specialists [40]. Although GPs are generally identified, including by specialists, as the most appropriate professionals to initiate ACP, GPs themselves have reported a lack of clarity about whose role it is [41]. Addressing a GP's need for detailed and timely information regarding their patient's care by improving the standard communication procedures between GPs and specialists could facilitate the initiation of ACP for GPs. It is however also important for GPs to acknowledge that the discussion of treatment options is only a part of ACP and the difficult subject of end-of-life care should not be disregarded.

The future lack of decision-making capacity was the only specific barrier reported to the initiation of ACP with dementia patients. Previous research has pointed out that diagnosing dementia is a complex task and usually when diagnoses are formally assessed, patients are already suffering from some form of cognitive impairment [36;42]. However, in the early stage of dementia there is a time span when patients can talk about their values and goals in a way that could inform end-of-life care decisions when they have lost the capacity to make decisions [43]. A number of explanations are possible for the reservations GPs express about assessing such patients' capacity to participate in ACP discussion. Firstly, as this study also shows, GPs have doubts about the relevance or the value of ACP in the context of future loss of capacity to confirm previously planned decisions and they perhaps adopt the attitude that advance care planning for dementia patients is invalid [44]. Secondly, physicians don't always recognize that dementia can be a terminal illness, which may explain why patients with dementia are less likely than those with cancer to have advance directives [45]. Finally, a lack of knowledge about the extent to which advance statements or decisions should be followed and to which extent they are legally binding, which was reported as a barrier by the GPs in our study, may further strengthen their negative attitudes or beliefs.

Conclusion and implications for practice, policy and research

Because GPs in Belgium, as in many other countries, have a central role in the coordination of patients' care, they are considered to be ideally placed to initiate ACP with their patients. To put this into practice, a broad range of barriers relating to the GPs, to the patients and family and to the health care system needs to be overcome. Educational training and the development of guidelines adapted to the Belgian context can play an important role in achieving this goal [46], as most of the perceived barriers identified in this study were related to skills, knowledge and attitudes. Future large scale studies may contribute to a more complete picture of the prevalence and importance of the barriers encountered by GPs when initiating ACP. Future research is also necessary on when GPs can elicit patients' wishes for future end-of-life care before time-critical situations occur, especially for patients with heart failure and dementia (two conditions with a less predictable end-of-life trajectory than cancer patients [47]). Introducing the concept of ACP in advance of illness and as part of standard care may be a realistic strategy and requires further research.

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How do general practitioners conceptualise advance care planning in their practice? A qualitative study.

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Submitted

Abstract

Objectives

To explore how GPs conceptualise ACP, based on their experiences with ACP in their practice.

Methods

Five focus groups were held with 36 GPs. Discussions were analysed using a constant comparative method.

Results

Five overarching themes in the conceptualisations of ACP were discerned: (1) the organisation of professional care required to meet patients' needs, (2) the bad news conversation, (3) choices of treatment and goals of care for the patient, (4) the completion of documents regarding patient preferences and (5) the exploration and understanding of patients' preferences. Within these themes, ACP was both conceptualised in terms of content of ACP and in terms of tasks for the GP (establishing consensus about the appropriate care and coordinating patient's care, providing comfort and reassurance, providing information about ADs, and initiating conversations).

Conclusions

This study illustrates that GPs have varying conceptualisations of ACP, of which some are more limited to specific aspects of ACP. A shared conceptualisation of the key elements of ACP and agreement on the purpose and goals of ACP is needed to ensure successful implementation, as well as a systematic integration of ACP in routine practice that could lead to a better uptake of all the important elements of ACP.

Introduction

Good quality communication between patients and health care professionals is essential in enabling patients with a life-limiting illness to understand their diagnosis, prognosis, treatment options and end-of-life care options in order to help them prepare and plan for their future care if they so desire [1]. Advance care planning (ACP) is a process of discussions with a patient about their wishes for future healthcare, in preparation for a time when they might lose capacity [2;3]. This process, involving healthcare professionals and family members or others, may be formally documented in an advance directive (AD) [4]. ACP is gaining attention worldwide for its perceived benefits in improving patient autonomy [5], concordance between patients' preferences and end-of-life care received [6-8] and the quality of end-of-life care [9].

The traditional purpose of ACP has been to have patients prepare for incapacity and make treatment decisions in advance so that clinicians can attempt to provide care consistent with their goals at the end of life [10]. Emphasis was mainly put on the documentation of an agreement regarding medical care between the physician and patient through ADs. Yet, internationally their uptake remains limited [11;12]. Evidence also shows that there is no guarantee that these documents as such improve end-of-life care or correspond with future care preferences [13;14]. ADs are too narrowly focused on the patient's right to refuse unwanted life sustaining treatment, they are often physically unavailable when needed, too vague to be useful in decision-making or at odds with the patient's current clinical circumstances. In response to these concerns, there has been a shift from ACP as a static documentation of specific treatment preferences to an ongoing process of discussion and communication about a patient's wishes [15]. It is expected that these changes in how ACP is operationalised can address these previously described concerns and increase the uptake and implementation of ACP [6].

In the Belgian health care system, as in many other countries, general practitioners (GPs) are core providers of medical care and the majority of people (95%) have a fixed GP with whom they have often built up a long-term relationship [16;17]. The GP is likely to have good clinical and contextual knowledge of each patient and is probably best placed to initiate an ACP discussion in a timely manner [18-20]. GPs play an important role in providing and coordinating end-of-life care in primary care, often in consultation with palliative home care teams [21;22]. Nonetheless, studies show that the practice of ACP in GPs remains limited [23-25]. It has been suggested before that differences in the conceptualisation of ACP have implications on how ACP is delivered and promoted in practice [15]. However, it remains unclear how ACP is conceptualised by GPs and how they perceive their role in it. Previous studies have focused mainly on the factors impeding GPs and patients in raising the topic of end-of-life care, but the way in which GPs already engage in ACP has not been studied [26-29], and would be an important step towards improving the standard of practice by delineating how GPs currently understand and conceive ACP in their practice.

Conceptualisations are an abstract or general idea derived from specific events or situations. The aim of this qualitative study is to explore how GPs conceptualise ACP, by asking the participants about their experiences with ACP in practice. The aim of this qualitative study is to explore how GPs conceptualise ACP, by asking participants to describe their experiences with ACP in their practice. The goal of understanding the range of conceptualisations circulating among GPs is to provide new insights into how GPs can be helped to engage in the full and complex process of ACP.

Methods

Research design

In order to have an in-depth understanding of GPs' perceptions and experiences regarding ACP, a qualitative study design was considered the most suitable. This study used the methodology of focus groups given the flexible approach this allows for opens discussion and interaction between the participants [30]. The focus groups were conducted in Flanders, Belgium in 2012.

Recruitment of participants

Participants in three focus groups were recruited by using existing peer-review groups for GPs, contacted via email. Nearly 97% of all full-time practicing GPs in Belgium are affiliated to such peer-review groups, where practice-related aspects are discussed four times per year [31]. Every GP who wants to be accredited in Belgium needs to be affiliated to such a group and attendance at two out of four meetings per year is mandatory. A fourth focus group was organised by contacting the coordinators of the palliative care networks in Flanders with the request to disseminate our invitation to participate in a focus group to the GPs active in palliative home care teams. Because of lower response, this focus group was complemented with other GPs recruited via the professional contacts of the network coordinators. A fifth focus group was organized with members from a large practice located in an urban region.

Data collection

Each focus group was moderated and observed by two researchers (ADV, KP, RVS or LD) and lasted on average one and a half hours. At the start of each group the participants were informed that the discussions would be audiotaped, to which they all gave written informed consent. A topic guide, consisting of open questions and a set of prompts for each question, was used to generate the discussion.

This topic guide was developed and reviewed within a multidisciplinary team of sociologists (ADV, DH, LD), psychologists (KP, KB) and one GP (RVS) and covered four themes: (1) experiences of GPs with ACP in their current practice, (2) attitudes regarding ACP, (3) perceived barriers to and facilitators for initiating ACP and (4) ways to improve initiation of ACP in general practice. At the beginning of each focus group, participants were asked whether they knew or were familiar with the term ACP. After this question, a theoretical definition of ACP as stated in the literature was introduced in the focus group. ACP was defined as the voluntary process by which patients discuss their future treatment and end-of-life care preferences with their care providers, in case they lose capacity to make decisions or communicate their wishes for the future [3].

Data analysis

The focus group discussions were transcribed verbatim. Analysis of the data was guided by a constant comparative method [32;33]. Firstly, ADV & KB independently read and openly coded two full focus group transcripts. The codes were discussed and mutually compared for similarities and differences until they could be grouped into categories related to the research questions. Subsequently, the five focus group transcripts were independently read and compared with the primary coding framework by all the members of the research team. Codes were added, modified or merged where necessary. ADV coded the remaining transcripts by applying the final coding framework, which was additionally checked by KB and KP for agreement on interpretation. After this, coding saturation was judged to be achieved by the research team as no new categories emerged. An ongoing refinement of the coding framework resulted in overarching themes deduced from the categories. Finally, quotes were selected and approved by the research team to illustrate the results. The qualitative analysis software QSR NVIVO 10 was used for this research.

Ethical aspects

Ethics approval for this study was given by the Commission of Medical Ethics of the University Hospital of Brussels.

Results

Five focus groups were held with a total of 36 GPs (n=9, n=11, n=4, n=5, n=7). The participants' demographic characteristics are presented in Table 1.

The GPs' conceptualisation of ACP was explored by asking the participants to describe their experiences with ACP. At the beginning of each focus group, participants were asked whether they knew or were familiar with a definition of ACP. Not many GPs knew the specific term, but once a general definition was introduced in the focus groups, the GPs could describe a range of experiences in this area. After analysis, GPs' conceptualisation of ACP could be categorized in 5 overarching themes. Within these themes, the GPs conceptualised ACP both in terms of the content of ACP and in terms of tasks for the GP. Some GPs had several conceptualisations of ACP in their narrative. Others only used one conceptualisation to describe ACP in their practice.

(1) Organisation of professional care to meet patients' and families' needs

Firstly, ACP was sometimes conceptualised as the process and discussions surrounding the organisation of professional care to meet patients' and families' needs, e.g. initiating (palliative) home care or moving to a nursing home. Planning care to address patients' and families' changing care needs often comprises collaboration between different informal and formal caregivers. A first important task in the organisational preparation for care is to establish a consensus between the patient's preferences and the perspectives of the GP and of family members regarding adequate care (the initiation of palliative home care, moving to a nursing home, community nurse visits), which could sometimes require many discussions according to the GPs. The GPs indicated that it is not always an easy task to mediate between different perspectives about patients' future care, especially if different distressed family members are involved.

"It can be very difficult. For example, I am taking care of patient now that is really not doing well. Since a few days, he can't get out of bed anymore. I tried to have a conversation with that man and his wife about the end of life, but on my way out his wife said to me: 'He does not like to talk about that, we are not going to do that anymore.' So it is very difficult for me to organize palliative home care for them. They do not want to hear about it." (Male GP, 44 years, FG 3)

The coordination of care often involves communication and collaboration with other health care professionals (e.g. specialists, community nurses or palliative home care teams). Although this

Table 1: Characteristics of participating GPs (n=36)

Characteristics	N
Sex	
Male	27
Female	9
Age (years)	
≤ 29	1
30-39	5
40-49	13
50-59	9
60-69	8
Practice location	
Urban	9
(Semi-)Rural	27
Number of terminal patients in the last year	
None	4
1-3	9
4-6	11
7-9	3
≥ 10	9
Number of participants	
Focus group 1	9
Focus group 2	11
Focus group 3	4
Focus group 4	5
Focus group 5	7

communication and collaboration was not always judged as optimal, several GPs saw an important task for themselves in these contacts:

“A very important point for me, is the contact with the social services in the hospital, which does not happen enough. You [the GP] have to make time for that and pick up the phone. That is important.”
(Male GP, 65 years, FG 5)

(2) Bad news conversations

Secondly, ACP was also conceptualised in terms of “bad news conversations”. The GPs construed ACP discussion then as the process of communicating a terminal diagnosis to patients and their families. In this context, ACP was also described as the process of patients and their family preparing for death (psychologically, financially, etc). Although many participants felt it is also the treating specialist’s responsibility to explain the diagnosis and prognosis or discuss future treatment options with their patients, most GPs saw an important task in discussing palliative care options, comforting patients and reassuring terminal patients that they will be available and provide support until the end of life:

“I believe that’s when you’ve got to tell them about what is available in palliative care, that they won’t be in any pain, that you’ll be there for them, that you’ll be able to... give them all the peace they need and a bit of assurance that you’ll walk that bit of road with them.” (Male GP, 42 years, FG 5)

“Nowadays, they [the hospital] actually keep patients to themselves for a very long time, even at the point when nothing can be done for them anymore I think. Well, at certain wards this is definitely the case. They do that at the hospital for a really long time, even the moment they say, now we can’t do anything anymore, maybe you should go to the palliative unit now, while the patient actually won’t hear a lot about dying at home if we don’t come and explain it, I think.” (Female GP, 49 years, FG 1)

(3) Choices of treatment and goals of care

Thirdly, the discussion and reflection on choices of cancer treatments, the experience of a hospital admission and the possibility of future admissions were mostly mentioned by the GPs when discussing goals and types of care and treatment with patients. However, this conceptualisation was mostly linked to patients suffering from serious chronic or progressive illnesses such as cancer or organ failure, but not patients with dementia. No specific tasks for the GP were mentioned within this theme during the focus groups.

(4) ACP documents

Fourthly, some participants talked specifically about the completion of documents regarding patient preferences in their conceptualisation of ACP. This was often in reference to the written plans about future care for their patients in nursing homes (either ADs or GP treatment orders) or the AD on euthanasia that was brought up by patients in their practice.

“Something that we often see are ADs on euthanasia, when patients come by and say ‘look, this is in case if something happens to me, if I get a terminal illness’. They then want to sign a document in which they choose euthanasia and then don’t want to think about any more. That happens very often.” (Male GP, 45 years, FG 4)

The GPs explained that patients often have misunderstandings regarding ADs and it was considered an important task of the GP to inform their patients about ACP, the limitations of ADs, and ensure that ADs are valid and accurate.

“Many patients say ‘if I am suffering dementia, I want euthanasia’, only there is no legal standing on that yet”. (Female GP, 48 years, FG 2)

“Yes, I also often have to explain that.” (Female GP, 35 years, FG 2)

(5) Exploring and understanding patients’ preferences

The participants explained that ACP discussions are also initiated by patients expressing vague end-of-life care wishes. A number of participants considered actively initiating ACP discussions as an important task for GPs, but acknowledged that this often depends on the competencies and attitudes of the GP regarding ACP. Others were more reluctant to actively initiate ACP and commented that patients need to take initiative for these discussions, but it is the GP’s task at that moment to elaborate on the topic.

Being aware of trigger moments, listening to patient cues for initiating ACP, and making the right judgment of a patient’s willingness to discuss the topic were considered important skills for the initiation of ACP. However, a number of younger GPs indicated that experience with or expertise in ACP discussions is an important factor in actively initiating these discussions.

“I think there are many different ways about it, as was said just before. Sometimes it’s because of a sudden diagnosis and you can talk to them [the patients] about it actively. Or sometimes you notice that patients try talks to you about it if you are a good listener.” (Female GP, 41 years, FG 1)

“Also, many elderly people you visit quite often before they get ill and you know these people, so if you have a certain talent for it, there are many occasions to speak to them about it.” (Female GP, 60 years, FG 5)

However, it was also noted that not all GPs further explored patients’ vague preferences such as *“when needed, you [the GP] will help me”*. Especially in cases of terminally ill or very old patients, a few GPs stated to know their patients well enough to know it means not to prolong life unnecessary. However, most of the GPs responded to feel uncertain when patients expressed such vague wishes and preferred to explore these.

Discussion and conclusion

Summary of main findings

Our study identified a diversity of conceptualisations of ACP in general practitioners (GP)s. Five overarching themes in the conceptualisations of ACP were discerned: (1) the organisation of professional care required to meet patients’ needs, (2) the bad news conversation, (3) choices of treatment and goals of care for the patient, (4) the completion of documents regarding patient preferences and (5) the exploration and understanding of patients’ preferences. Within these themes, ACP was both conceptualised in terms of content of ACP and in terms of tasks for the GP.

Strengths and limitations

To our knowledge, this is the first qualitative study to explore GPs’ conceptualisation of ACP on the basis of their experiences when engaging in ACP with their patients. The qualitative design, using different recruitment strategies [26], allowed us to gain insight into the complex range of views and experiences regarding ACP in daily practice from GPs with diverse backgrounds, experience and levels of interest in ACP. The multidisciplinary composition of the research team guaranteed interpretation of the data from a range of perspectives. However, the focus group composition may have presented a limitation. Most of the participant GPs were male (n= 27), so female GPs were underrepresented, as were GPs younger than 39 years (n= 6 vs. n=30) although the national average age of GPs is 49 years in Belgium. Secondly, although our study is aimed at theoretical rather than statistical generalization, the findings may not necessarily be generalizable to other countries where euthanasia is not legalized or countries that may have a very different context in which ACP is (partly) structurally embedded in national health care strategies [34].

Comparison with existing literature

While ACP is suggested in the relevant literature as a comprehensive and multifaceted process of care planning that should be initiated at an early stage of a serious illness, the conceptualisations circulating among GPs tend to be more limited sometimes. For example, the conceptualisation of ACP as a process that is to be initiated very late in the disease trajectory when death is imminent in order for patients and family to prepare for death seems to be prevailing among some GPs. Based on the narratives about how they perform ACP in their own practice, the results of this study also suggest that the conceptualisation of ACP sometimes implies an engaging in specific aspects of ACP rather than engaging in multiple discussions that address all key elements as recommended in the literature [4;10;35-37]. These are ascertaining patients' information and decision-making preferences, wishes for family involvement, understanding patients' values, quality of life, fears and goals, explaining the nature and trajectory of serious illnesses, but also discussing disease outcomes, eliciting patients' preferences for care and encouraging them to document their preferences and/or choose an appropriate surrogate decision maker. Previous studies have argued that time constraints and the fact that GP consultations are mostly focused on a patient's acute care needs restrict the possibilities of initiating these sensitive and time-consuming discussions [38;39]. However, implementing ACP as an iterative and multifaceted process of discussion throughout the illness course can help GPs in introducing difficult subjects gradually without having to find a single 'perfect' moment to introduce ACP. It is noticeable that GPs consider experience as an important factor in actively initiating ACP. Communication skills can be learned and retained and do not reliably improve with experience alone. Offering GPs practical guidance on the content of ACP discussions might thus increase their use of it [40;41].

Conclusion and implications for policy and practice

It has been recognized before that health care professionals have an important role in the promotion of ACP. They have a responsibility to initiate ACP in a timely way, by informing and educating patients [42]. However, our findings highlight significant differences in how ACP is conceptualised among GPs, which can cause confusion and conflict because the practice of individual GPs may vary according to how ACP is conceptualized [15]. Therefore, differences in the conceptualisation of ACP have important implications on how ACP should be promoted among GPs. A shared conceptualisation of the key elements as described above and agreement on the purpose and goals of ACP is needed to ensure successful implementation. Recently, the first guideline on ACP for health care professionals in Flanders was published, which can help in promoting a common view on ACP [43].

Nonetheless, previous studies have shown that the barriers to initiating ACP for GPs are complex and multifaceted [39;44]. It has been suggested that the combination of several interventions hold promise in implementing and systematizing the initiation of ACP with patients: education of physicians, systems to identify and trigger early discussions for eligible patients, patient and family education, structured formats to guide the discussions, dedicated sections in the electronic health record for recording information and continuous measurement [18;35].

Postponing ACP discussions until the end of life or waiting for patients to raise the subject may result in withholding from patients the right to receive information and plan their future care accordingly. This study illustrates that GPs have considerably varying conceptualisations of ACP in terms of the content of ACP discussions and in terms of tasks for the GP, of which some are more limited to only specific aspects of ACP. This can lead to confusion as the role of GPs may vary according to how ACP is conceptualised. A shared conceptualisation on the goals and key elements of ACP is needed to ensure a successful implementation of ACP.

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Conflict of interests

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Author contribution

Conceived and designed the study: ADV, KP, KB, DH, LD and RVS. Analysed the data: ADV and KB. Wrote the paper: ADV and KP. Contributed to the planning of the data collection and the actual collection of data: ADV, KP, LD and RVS. Contributed to the writing of the article and approved the final version of the manuscript: ADV, KP, KB, DH, LD and RVS.

We confirm that all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story.

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CHAPTER 6

Development of a complex intervention to support the initiation of advance care planning by general practitioners in patients with a serious or life-limiting illnesses: a phase 0-I study.

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Submitted

Abstract

Background: Most patients with life-limiting illnesses are treated and cared for over a long period of time in primary care and guidelines suggest that Advance Care Planning (ACP) discussions should be initiated in primary care. However, a practical model to implement ACP in general practice is lacking. Therefore, the objective of this study is to develop an intervention to support the initiation of ACP in general practice.

Methods: We conducted a Phase 0-I study according to the Medical Research Council (MRC) Framework. Phase 0 consisted of a systematic literature review about the barriers and facilitators for general practitioners (GPs) to engage in ACP, focus groups with GPs were held about their experiences, attitudes and concerns regarding initiating ACP in general practice and a review of ACP interventions to identify potential components for the development of our intervention. In Phase 1, we developed a complex intervention to support the initiation of ACP in general practice in patients at risk of deteriorating or dying, based on the results of Phase 0. The complex intervention and its components were reviewed and refined by two expert panels.

Results: Phase 0 resulted in the identification of the factors inhibiting or enabling GPs' initiation of ACP and important components underpinning existing ACP interventions. Based on these findings, an intervention was developed in Phase 1 consisting of: (1) a training for GPs in initiating and conducting ACP discussions, (2) a register of patients eligible for ACP discussions, (3) an educational booklet on ACP for patients to prepare the ACP discussions that includes general information on ACP, a section on the role of GPs in the process of ACP and a prompt list, (4) a conversation guide to support GPs in the ACP discussions and (5) a structured documentation template to record the outcomes of discussions.

Conclusion: Taking into account the barriers and facilitators for GPs to initiate ACP as well as the key factors underpinning successful ACP intervention in other health care settings, a complex intervention for general practice was developed, after gaining feedback from two expert panels. The feasibility and acceptability of the intervention will subsequently be tested in a Phase II study.

Background

Many patients receive inappropriate or futile care at the end of life and this mostly results from a mismatch between the needs of patients and the norms of current practice(1). A possible response to this concern is advance care planning, as it is a means to discuss patients' potential needs and care preferences during their illness trajectory. Advance care planning (ACP) is the voluntary process by which patients discuss and reflect with their care providers upon topics such as goals and preferences for future care, quality of life, decision-making preferences, fears or anxieties, and also palliative care options, do-not-resuscitate orders, end-of-life decisions and surrogate decision-making in future disease stages(2;3). These discussions may or may not result in the documentation of these decisions in an advance directive (AD)(4).

ACP discussions can play a major role in facilitating adaptation to illness realities by providing patients with information about diagnosis and prognosis, by leading to appropriate decision-making, by alleviating anxiety and by improving quality of life throughout the trajectory of the illness(5;6). Previous studies have shown that ACP interventions stimulate discussions about goals of care between patients and their care providers(7;8), improve concordance between a patient's preferences and the end-of-life care they receive(9-11) and improve the quality of care at the end of life(12) and they are also associated with positive family outcomes such as improved satisfaction with care and reduced stress and anxiety(9). Effective ACP discussions support not only end-of-life care but quality of life throughout the illness trajectory, including the period before death is imminent.

Most patients with serious chronic illnesses are treated and cared for over a long period of time in primary care(13) and guidelines suggest that ACP discussions should be initiated in there(4). Initiating ACP optimally requires a proactive approach by a health care professional who is likely to have a good knowledge of the patient in terms of medical, psychosocial and social background(14). Given their often longstanding and trusting relationship with patients, including in Belgium, it is assumed that general practitioners (GPs) have good knowledge of the patient and family context. They are also according to other health care professionals(15) in an ideal position to initiate and facilitate timely a structured discussion about the patient's wishes for future care(1;16-18).

However, a practical model to implement ACP in general practice is lacking and a cross-national survey showed that only a minority of patients in Belgium had discussed treatment preferences with their GP(19). Therefore, our study aims to develop an intervention to support the initiation of ACP in general practice following the UK Medical Research Council's (MRC) guidance for developing complex interventions(20).

Methods

Study design

The development of this intervention was conducted following the Medical Research Council's (MRC) framework on complex intervention design(21;22). The MRC framework addresses strategies for developing and evaluating complex interventions and proposes a phased approach going from Phase 0 to Phase IV, which take place as an iterative process (Figure 1)(20). This study entails a Phase 0-I, comprising the development and modelling of a preliminary complex intervention.

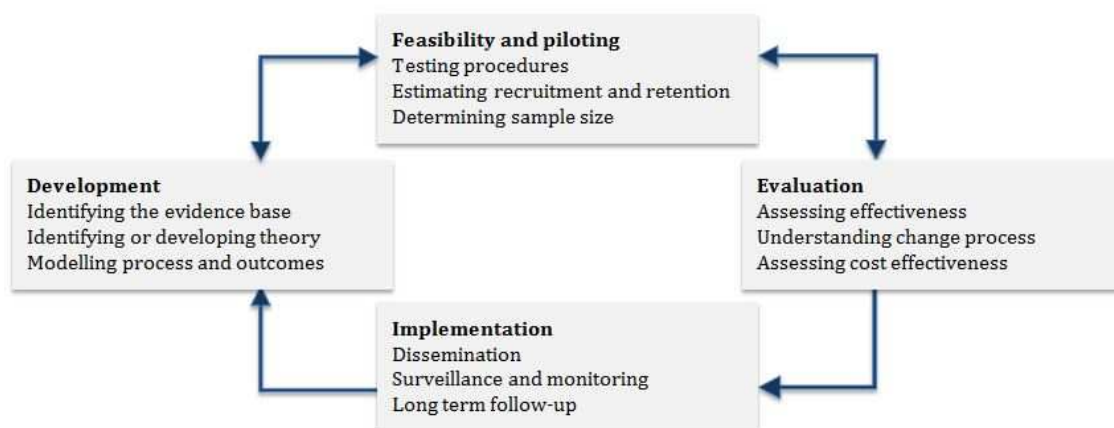


Figure 1 MRC framework for design and evaluation of complex interventions to improve health

Phase 0: Exploring potential components of the intervention

Three methods were applied to provide information and evidence for the key components of the intervention. The key components of an intervention refer to the features (i.e. building blocks) of a program that are judged necessary and most effective to produce the desired outcomes(23). Key components are intended to be, or have been, demonstrated through research to be positively associated with the outcomes that address the identified needs.

First, we performed a systematic literature review about the barriers to and facilitators for GPs to engage in ACP, to identify the relevant factors inhibiting or enabling their initiation of ACP in practice and to guide the choice of intervention components that could overcome the modifiable barriers and enhance the facilitators(24).

Second, focus groups with GPs were held covering their experiences, attitudes and concerns regarding initiating ACP in general practice and investigating their reasons for initiating or not initiating ACP discussions(25). Five focus groups were held with a purposefully sampled group of GPs to maximize variation in experience, age and practice (n=36). GPs' experiences and perceptions were used for further delineating the key components of the intervention that would target the specific barriers and facilitators for GPs in Belgium.

Third, a focused literature search was conducted to identify systematic reviews with regard to ACP interventions. We searched journal articles with the keywords 'advance care planning' and publication type 'systematic review'. From the systematic reviews, we retrieved the randomized controlled trials with a successful outcome on at least one of their intended outcome measurements. The included studies were read in full and analysed for their components, in order to inductively obtain a comprehensive overview of key features underpinning successful interventions and to identify potential components for the development of our intervention.

Phase I: Modelling the intervention to general practice

Based on the results of Phase 0, a first draft of a preliminary complex intervention to support the initiation of ACP in general practice was developed by the research team, by selecting appropriate intervention components. Subsequently, the first draft of the complex intervention was presented to expert panels which reviewed the key components and the possible and best course of action to implement the intervention in practice. For the composition of the expert panels, we purposefully sampled either GPs, persons with considerable experience in conducting ACP conversations, academics in the field of ACP or patient-physician communication and/or persons experienced in giving communication trainings to physicians. Most participants in the expert panels had experience in a number of these fields. The two expert panels (n=4, n=5) were held in January 2015 and consisted of five GPs, one hospital geriatric, one palliative care consultant and two academic researchers (psychologists) with expertise in the field of ACP and health care communication. During the panels, the experts were asked to evaluate the completeness of the intervention's components, to review the components on feasibility and acceptability and to identify the implementation barriers for each component. The expert panels were both consulted in a two-hour long meeting. The panel discussions were audiotaped (for which the participants gave verbal consent) and transcribed verbatim by ADV. The results were categorized for each component and further analysed within the research team to refine the intervention.

Ethical aspects

The research protocol for the qualitative focus group study was approved by the Commission of Medical Ethics of the University Hospital of Brussels. A signed informed consent was obtained from each participant before the focus group interview. Anonymity was assured by removing participant information that could lead to identification from the transcripts.

Results

Phase 0: Exploring potential components of the intervention

Identification of the factors inhibiting or enabling GP initiation of ACP

Both the systematic review and the focus groups showed that GP, patient and healthcare system factors all influence the initiation of ACP.

1) GP factors influencing the initiation of ACP

A lack of confidence, skills and knowledge about ACP and how to initiate it were identified as important barriers inhibiting GPs from holding ACP discussions. Many GPs felt poorly prepared to conduct ACP discussions and a lack of awareness of the different components of ACP was shown through their varying conceptualisations of it. Some GPs had a comprehensive view of what constitutes ACP, while others had a limited conception. The difficulty of defining the right time to initiate ACP was also reported as an important barrier for the GPs. They indicated that, especially in patients with a less predictable disease course such as dementia or chronic heart failure, they lacked awareness of the key moments to initiate discussions. ACP discussions were more easily initiated with cancer patients, who have a relatively more predictable illness trajectory and clearer key moments. Difficulties with judging a patient's mental capacity to participate in ACP and concerns about the legal implications of following their documented wishes were also reported as barriers. Being aware of the potentially positive outcomes of ACP and having positive attitudes towards anticipating future scenarios were identified as important facilitating factors to initiating ACP. Positive experiences with ACP in the past also encouraged GPs to initiate ACP with their patients.

2) Perceived patient factors influencing the initiation of ACP

Most GPs in the focus groups considered patients suffering from a life-limiting illness such as cancer to be most eligible for initiating discussions with. However, a barrier that was often mentioned was the concern that initiating ACP discussions too early might deprive patients of hope or create anxiety. Both

the patient's denial and lack of awareness about the prognosis of a serious illness were identified as patient-related factors that contribute to the challenges of GPs initiating ACP. Many GPs also expressed concerns about patients' lack of understanding regarding ACP. Knowing that patients are prepared to participate in ACP or patients initiating ACP discussions themselves were perceived as important facilitators for GPs to engage in these discussions.

3) Healthcare system factors influencing the initiation of ACP

Knowing and caring for the patient for a long time was identified as an important facilitating factor for engaging in ACP discussions while a lack of time discourages GPs from initiating them during routine consultations. Poor communication and collaboration between GPs and specialists was also perceived as a barrier for ACP. Especially where patients are mainly being treated by a specialist, it may not be clear whose role it is to discuss ACP. The lack of a central system for recording the patient's wishes across different health care settings also contributed to the perceived irrelevance of ACP and was perceived as a challenge to initiating it. Many GPs expressed uncertainty about the usefulness of ADs as these are not always readily available in a patient's medical records or consistently recorded across the health care system.

Key components underpinning ACP interventions

The examination of ACP interventions identified four common features underpinning successful ACP interventions: A) the involvement of a trained or experienced facilitator, B) a selection process to identify patients eligible for ACP, C) the use of ACP tools to support the discussions D) structured and patient-centred ACP discussions and E) the opportunity to complete ACP documents (Box 1).

Box 1. Summary of key features underpinning ACP interventions

A) Trained or experienced facilitators

In all interventions the ACP discussions were facilitated by a trained health care professional (mostly nurses or allied health workers)(9-11;26-29) or by health care professionals already experienced in counselling and communicating with patients about ACP, such as social workers or palliative care physicians(7;30). The facilitator trainings ranged from half a day to two days and used a competency-based educational approach, comprising interactive discussions about the key components of ACP, role play exercises, reading materials, and learning to assess a person's capacity to engage in ACP(9-11;26;28;29). A minority of studies did not provide training to the health care professionals involved(31) (8;32).

B) Identification of patients

In most interventions, patient selection was focused on those with a serious advanced life-limiting illness, such as advanced cancer, COPD, end-stage renal disease or end-stage congestive heart failure(7;8;10;26;27;30;33;34). Other indicators used to select patients with whom ACP was initiated were age (e.g. all patients ≥ 65 years)(9;28;30;31;33;34), admission to a health care facility (hospital or nursing home)(9;27-29;31) and the expectation of serious complications or death within the next year(10;26;27).

C) Tools

A number of interventions used specific tools such as individualized patient-specific questionnaires about the patient's preferences for discussing ACP(8), a question prompt list about end-of-life care provided to patients before their consultation to stimulate conversations(7), or educational material about ACP mailed to patients in advance(30;34) to prepare them and to facilitate patient-centred discussions. Structured preference-elicitation and decision aids for ACP to help patients consider their health care options were also implemented as tools during the ACP discussions(9;10).

D) Structured discussions

All interventions included structured discussion of the patient's values, goals and beliefs(9;27), an assessment of their understanding of their illness(10;26;27;29), discussion of their future treatment preferences(9-11;26;27;29), the assessment of their surrogates' understanding of their illness and treatment preferences and their role as health care agents(9-11;26-28;31) and the opportunity to complete ADs(9;10;26;28-31). The discussions reportedly lasted between one and one and a half hours(9;10;28). In all studies, the patient was encouraged to include their family.

E) Completion of ACP documents

Most ACP interventions provided the opportunity to complete ACP documents (e.g. documentation of treatment preferences, appointment of a health care proxy, appointment of a surrogate decision-maker)(9-11;27-34). A number of studies reported that the completed documents were filed in the patient's medical records or charts(9;11;29). In two studies conducted in an inpatient setting, extra time was dedicated during the interdisciplinary team meeting after the ACP intervention to discussion of the care wishes of the patient (11;27).

Phase I: Modelling phase

Table 1 indicates how we linked specific barriers and facilitators to the selection of intervention components. This was informed by the features underpinning successful ACP interventions (Box 1). The final selection of intervention components was further informed by what was considered by the research team as relevant for the context in Belgium, was likely to be feasible and could be implemented as a cohesive intervention. The components of the intervention are: 1) a training program for GPs, 2) an register of patients eligible for ACP, 3) an educational booklet for patients about ACP, 4) a conversation

guide to support GPs during discussions and 5) a structured documentation template to record the outcomes of the discussions. The components of the intervention were reviewed by two expert panels to refine and improved the intervention.

1) The training session is based on a two hour educational programme about ACP specifically developed for GPs that has been shown to improve their confidence and ability to undertake ACP conversations with patients(35). It includes active, practice-oriented strategies such as role-play exercises, feedback, the use of video role modelling, group discussions and feedback during the session as these are educational strategies which have shown to be most effective in improving communication skills(36). Pre-reading material and information provision will also be a part of the training programme as lack of knowledge about the potentially positive outcomes of ACP and about its legal implications were identified as important barriers. A previous study also showed that improved clinician knowledge about decision-making capacity legislation positively correlated with ACP participation(37). The experts perceived two hours as too short to complete all training elements and recommended spreading the training over two sessions which would permit reinforcement and allow for home work exercises in between.

2) Standardised triggers for the timely identification of all patients who are at risk of deteriorating or dying in the near future was considered essential to support GPs in defining a key moment and prompting them to initiate ACP discussions. While the timing of ACP must be sensitive to patients' readiness to enter into such conversations, a pragmatic three-step guide that has been proposed for physicians is to consider ACP if: (a) No is the answer to the surprise question "Would you be surprised if this patient died within the next year?", (b) The patient's general health is poor (eg limitations in self-care or multiple hospitalisations), and (c) If disease-specific indicators indicate a poor prognosis (eg advanced organ failure, dementia, progressive malignancies)(1). Identified eligible patients will be documented in a register. These patients should be invited to consider ACP.

3) To overcome the patient-related barriers to GPs in initiating ACP, an educational booklet for assisting patients and their caregivers and improving their knowledge about ACP was considered helpful to increase patient and family engagement(1;38). This booklet was based on an already existing booklet 'Planning your future care' developed by the University of Nottingham and published by the NHS as part of the Dying Matters campaign in the UK(39). This booklet was deemed suitable by the expert panels as it includes general information on ACP and a section on the role of GPs in the process of ACP. However, most experts considered this booklet as too long and suggested to shorten it and slightly adapt its content to our target group of patients. A prompt list was also included as research showed that a prompt list helped patients to ask questions about prognosis and end-of-life care, and discuss more issues

Table 1: Description of the components within a complex intervention to support the initiation of ACP in general practice

Components of a complex intervention to support the initiation of ACP in general practice (evidence based key feature described in Box 1)	
Component 1: A training program for GPs (A)	
<p>Content of the component to overcome the barriers and enhance the facilitators:</p> <ul style="list-style-type: none"> • Prior to the training, participants will receive reading materials to ensure baseline knowledge on ACP and the relevant law and to limit the time of the training • The training consists of information provision, case studies addressing the identified barriers to initiating ACP, facilitated group discussion and video demonstration of how to conduct ACP discussions and how to incorporate the initiation of ACP into standard consultations, and role play exercises with feedback from an expert instructor to practice the taught skills, which have been shown to be the best strategies to improve communication skills • GPs will learn about the key elements that should be addressed with patients, including exploring prognostic understanding and acceptance of diagnosis and providing patients with information about prognosis to the degree desired by the patient • Instructions are provided for GPs during the training to collect all information regarding the patient's health status and treatment options, and to contact other health care professionals when necessary for this. • Training will be led by an expert instructor • After the training sessions, GPs will be able to practice their skills at home through e-simulation exercises with fictive patients 	<p>Barriers and facilitators that are addressed by the component:</p> <ul style="list-style-type: none"> ➤ Lack of skills, knowledge about ACP and confidence to discussions ➤ Lack of awareness about the different elements of ACP ➤ Lack of knowledge about decision-making capacity legislation ➤ Recognizing the relevance of ACP ➤ Positive attitudes towards anticipating future scenarios and initiating ACP ➤ Patients' denial and lack of awareness about prognosis ➤ Lack of adequate communication between GPs and the multiple clinicians involved in the patient's care

Component 2: Establishing a register of patients eligible for ACP discussions (B)	
<p>Content of the component to overcome the barriers and enhance the facilitators:</p> <ul style="list-style-type: none"> • Systematic and selective identification of patients at risk of deteriorating or dying will be done using a pragmatic three-step guide of triggers for when to initiate ACP • During the training, GPs will be taught how to identify eligible patients using these triggers and to set up an ACP register, which is a constantly updated list of patients for whom ACP should be initiated at upcoming appointments 	<p>Barriers and facilitators that are addressed by the component:</p> <ul style="list-style-type: none"> ➤ Most GPs in the focus groups considered patients suffering from a life-limiting illness to be most eligible for initiating ACP with ➤ Difficulties with defining a key moment to initiate ACP ➤ Cancer patients are more easily involved in ACP as opposed to non-cancer patients (eg dementia, advanced organ failure, etc)
Component 3: Educational booklet about ACP for patients (C)	
<p>Content of the component to overcome the barriers and enhance the facilitators:</p> <ul style="list-style-type: none"> • The goal of an educational booklet is to provide patients with appropriate information on ACP in advance and to prepare them for a patient-centred discussion adapted to their individual information needs • This educational booklet includes a question prompt list for patients and family • Patients are encouraged to reflect on and clarify their wishes together with their relatives through discussion 	<p>Barriers and facilitators that are addressed by the component:</p> <ul style="list-style-type: none"> ➤ Patients' lack of understanding regarding ACP ➤ Patients are prepared to participate in ACP
Component 4: Patient-centred ACP discussions with the help of a conversation guide (D)	
<p>Content of the component to overcome the barriers and enhance the facilitators:</p> <ul style="list-style-type: none"> • The conversation guide includes the following topics: understanding of prognosis, information preferences, prognostic information, patient's previous experiences with ACP, patient goals and quality of life, fears, acceptable function, family involvement and contains examples of questions and communication tips 	<p>Barriers and facilitators that are addressed by the component:</p> <ul style="list-style-type: none"> ➤ Lack of awareness about the different elements of ACP ➤ Varying conceptualisations of ACP among GPs

Component 5: A structured template for documenting the outcomes of the ACP discussions (E)

Content of the component to overcome the barriers and enhance the facilitators:

- A structured template will provide the opportunity for recording patient preferences, values and goals of care
- Instructions are provided for GPs during the training to communicate this document to other involved health care professionals (with patient permission). These instructions are also included on the templates.
- Patients are encouraged by the GP to make this document available for other care providers

Barriers and facilitators that are addressed by the component:

- Difficulties in sharing information across the health care system when patients are cared for by (multiple) specialists
- Uncertainty regarding the transferability of ACP information as there is no consistent standard for location

For more information on the content of components, we refer to the Appendix of this dissertation

covered by the question prompt list with their physician(7). The educational booklet would be given to patients during a routine visit and would facilitate subsequent patient-centred ACP discussions.

4) A conversation guide was developed to support GPs and to assure a better uptake of all the key elements of ACP discussions(38). A draft was made based of a conversation guide for communication about serious illness care goals that was developed on the basis of a review and synthesis of best practice and afterwards validated in the expert panels. The key elements addressed in the conversation guide are: 1) understanding of prognosis, 2) decision making and information preferences, 3) prognostic disclosure, 4) patient goals and quality of life, 5) fears, 6) level of functioning acceptable to the patient, 7) trade-offs that might be necessary to achieve different outcomes and 8) family involvement and choosing an appropriate surrogate decision-maker. The experts suggested shortening the conversation guide to a one-page topic list. Most experts found a structured conversation guide useful to assure the completion of key steps in the conversations, but emphasized that it should be made clear in the training sessions that the conversation guide should not be used as a checklist or static script.

5) A documentation template was developed that is standardised, simple and patient-friendly and that allows the opportunity to record and document the outcomes of ACP conversations. In the expert panels consensus was reached that the document should be complementary to an AD and record key information such as the patient's values and goals, quality of life, fears and anxieties, etc. to help guide complex decisions. It was decided that this template could follow the same structure as the conversation guide. To improve the exchange of information about patient values and goals, instructions are also provided for GPs to communicate this document to other involved health care professionals with the patient's permission, and patients will be encouraged by the GP to make this document available to other care providers.

Discussion

This article describes in detail the development process of an intervention to support the initiation of ACP in general practice consisting of five key components: 1) a training program for GPs in initiating and conducting ACP, 2) a register of patients who should be invited for ACP, 3) an educational booklet for patients to prepare them for ACP discussions, 4) a conversation guide to support GPs in ACP discussions and 5) a structured documentation template to record the discussions.

An important strength of the study is that it was systematically developed using the MRC framework for the development and evaluation of complex interventions. To our knowledge, this is the first development of a complex intervention aiming to support the initiation of ACP for patients at risk of deteriorating or dying in general practice. It has been recognized that the development of interventions

calls for a systematic approach with a strong rationale for design and for the explicit reporting of the development process(40). The framework aims to help researchers identify the core components of interventions and adopt the appropriate evaluation methods. Since its publication, a number of researchers in palliative care have applied the MRC framework to develop their interventions(41-43).

Some limitations have to be acknowledged. Firstly, our search strategy was limited to systematic reviews about the effect of ACP interventions, which were screened for successful intervention studies that were then analysed by the research team for their key components. Observational studies as well as studies in which ACP was one component of a larger intervention were not included in our scope. Including different study designs such as qualitative studies could have provided additional insights. Second, the composition of the expert panels might have presented a limitation. Although the panels were purposively sampled, not all relevant disciplines, such as patient representatives, were represented. Nonetheless, academic researchers and experts in the field of health care communication and the development of booklets and decision aids were attending. Third, a key component mentioned in a recently published clinical review on ACP could not be included in the intervention. It was found that not only a structured template for documenting the discussions should be provided, but also that a specific page in the electronic medical record (EMR) should be designated that can be easily accessed by all health care professionals involved(38). A small study recently examined the quality of ACP documentation templates in the EMR. This study found a great potential for making ACP documentation standardized and easily accessible in EMRs. The vast majority of notes in patients' EMR contained important information regarding desired surrogate decision-makers and care preferences. In Belgium, cross-setting electronic health records do not exist yet and can thus not be used as a tool for communication across the health care system. Therefore, GPs are given the instruction to notify all involved health care professionals by communicating the documentation template that records the outcomes of the ACP discussions (with patients' approval).

The key components of our intervention largely correspond with the key factors identified in a recent narrative review on the enhancement of patient-professional communication about end-of-life issues. This narrative review did include intervention studies as well as observational studies and qualitative studies(44). Important features of a successful ACP model are shown to be focused participant-led training, the use of effective communication to improve patient understanding and flexible patient-led ACP discussions. The authors argue that the development of an ACP intervention for patients with life-limiting conditions should include careful consideration of these features. Findings also showed that ACP should ideally take place over a number of meetings, with a trained professional with sufficient time to answer questions. ACP discussions should focus more on the goals of care than specific treatments and discussions should be tailored to the individual patient. Lastly, discussions should be supported with written documentation. A number of recently published systematic reviews on the effects of ACP on end-of-life care confirmed that complex ACP interventions may be more effective in meeting

patients' preferences than written documents alone(45;46). Interventions focusing on ADs as well as those that also included communication about end-of-life care increased the chances of an AD being completed and the occurrence of end-of-life care discussions between patients and healthcare professionals. But interventions that also included communication about ACP improved concordance between preferences for care and delivered care(46).

The developed ACP intervention differs from other interventions, most of which tend to be delivered by a trained facilitator who is not always knowledgeable about the clinical profile and social context of individual patients. This study took as the point of departure the proposition that ACP discussions should be initiated and facilitated by a health care professional with whom the patient feels comfortable about discussing their wishes and goals of care. The evidence suggests that other health care professionals can successfully conduct ACP, yet patients continue to state that they expect their primary care physician to initiate such conversations(47). In the Belgian health care system GPs are core providers of primary care and the majority of people have a GP with whom they often have a long-term relationship. GPs are usually cognisant of both the physical and non-physical domains of the patient's health. So by targeting GPs, the time consuming nature of ACP conversations can possibly be limited (in contrast to the reported discussions of 1.5h in Box 1) because GPs in Belgium mostly know and care for their patients and their families over a long period time.

A study on the implementation and embedding of ACP interventions in routine clinical practice showed that the factors that promote implementation in practice are largely concerned with structural mechanisms(48). These include prescheduled interventions and administrative procedures applied to selected patients, dedicated teams to organize the interventions, specifically trained facilitators to deliver the interventions and a dedicated document and organisational policies or guidelines to support the process. This intervention takes into account these factors by training GPs to manage the interactional processes with their patients, equipping them with simple tools such as a register for patients eligible for ACP discussions, a conversation guide, and documentation templates to record the ACP discussions. A patient brochure that will assist and increase the knowledge of patients and their caregivers of the potentially positive outcomes of ACP will also increase their willingness to engage in it with their GP. Educating patients on ACP and letting them prepare for the discussions with the educational booklet can also possibly contribute to limiting the time involved in conducting ACP discussions. It is however crucial that such tools are not considered as a replacement for meaningful communication between the GP, their patients and their families; they should rather precede, facilitate and support ACP discussions(49).

Further research should focus on testing the feasibility and acceptability to patients and GPs of the intervention's components and on explaining how the various components work together in a Phase II study(50;51). When trials have shown to be effective, it is usually difficult to understand how the

intervention caused its effect or what the critical components were in achieving success. In Phase II study, a combination of quantitative and qualitative research methods is recommended to identify the barriers for implementation and participation, to understand the best way to implement the components in standard care, to explain how the intervention works and to revise the results of Phase 0-I accordingly(22), which will greatly improve the intervention design and evaluation. Having developed and modelled this intervention to support the initiation of ACP in general practice, it will be important to evaluate its effectiveness thoroughly.

Conclusion

Performing a phase 0-I study according to the MRC framework helped us to develop a complex intervention to support the initiation of ACP in general practice for patients at risk of deteriorating or dying. Taking into account the barriers to and facilitators for GPs to initiate ACP as well as the key factors underpinning successful ACP interventions in other health care settings, we developed and modelled a complex intervention for general practice in patients with serious or life-limiting illnesses, after gaining feedback from two expert panels.

List of abbreviations

ACP: Advance Care Planning

AD: Advance Directive

GP: General Practitioner

MRC: Medical Research Council

Competing interests

The authors declare that there is no conflict of interest. This study is supported by a grant from the Flemish government agency for Innovation by Science and Technology (Agentschap voor Innovatie door Wetenschap en Technologie) (SBO IWT nr. 100036).

Authors' contributions

ADV had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. For the systematic review on barriers and facilitators for GPs to engage in ACP with their patients, ADV and DH developed a search strategy, independently screened all titles and abstracts as well as the eligibility of the selected studies, extracted the data from the included studies and assessed their quality. The focus groups were moderated by ADV, KP, LD and RVS. Data analysis was carried out by ADV and KP. All authors were involved in the interpretation of the results and the design of the study. This manuscript was drafted by ADV. KP, DH, RVS and LD critically revised the manuscript content. All authors read and approved the final manuscript.

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Figure legends

Figure 1: MRC framework for design and evaluation of complex interventions to improve health

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PART IV

General discussion

Introduction

The research objectives of this dissertation were two-fold: (1) to describe the information preferences and experiences of the general public regarding advance care planning and (2) to develop an intervention to support the initiation of advance care planning in general practice.

In this part, the main results of the studies undertaken to meet the objectives of this dissertation will be discussed. First, the main findings of the studies will be summarized, followed by a discussion on the methodological strengths and limitations of the studies and a general discussion of the most important findings. Finally we propose some implications for policy, practice and future research.

Summary of the main findings

I. Experiences of the general population regarding advance care planning and their information preferences when faced with a life-limiting illness

In Chapter 1 and 2, we reported the results of the 2008 cross-sectional Health Interview Study on the involvement in advance care planning (ACP) and the information preference when faced with a life-limiting illness of a representative sample of 9651 respondents of the Belgian population.

Of all respondents, around 4.4% had spoken to their physician about their wishes regarding medical treatment at the end of life, while 1.8% reported to have an advance directive (AD) on euthanasia. Of the respondents who had discussed their wishes regarding medical treatment at the end of life with a physician, 22.2% had an AD on euthanasia. Vice versa, 55.4% of the respondents who had an AD on euthanasia, had discussed their wishes regarding medical treatment at the end of life with a physician. The probability of having discussed their wishes with a physician significantly increased with age, was higher for women compared to men, and for those respondents with a poorer health status compared to a good health status. This study also showed that having more contact with a GP was associated significantly with discussion of end-of-life care wishes. People older than 55 years were more likely to have an AD on euthanasia compared with the youngest age category. Those living in the Walloon region of Belgium were less likely to have an AD on euthanasia compared with those living in Flanders.

Around 82% of respondents wanted to be informed always about diagnosis, chances of cure and available treatments, 77% wanted to be informed on life expectancy, 72% on options regarding palliative care and 67% on possibilities of prolonging or shortening life. Around 55% wanted their relative to be informed always about diagnosis, chances of cure, life expectancy and different treatments available, while 50% wanted this in relation to the options regarding palliative care and 46% to the possibilities of prolonging or shortening life. A minority of the respondents did not want to receive any information

either at all or only if they requested it. Compared with the youngest age category, people aged 25 to 34, 35 to 44 and 45 to 54 were more likely always to want information, as well as more highly educated respondents. People living in Wallonia were overall less likely to want information on these six specific topics always as opposed to people living in Flanders. Women were less likely to want their relative to know about their life expectancy, different treatment options, options regarding palliative care and possibilities of prolonging or shortening life. People aged 25 to 34 and 35 to 44 were less likely to want their relative to know about their diagnosis and chances of cure, as were people with an educational level of lower secondary. In contrast, being 75 years and older was associated with wanting relatives to know about these topics.

II. The development of an intervention to support the initiation of ACP in general practice

Phase 0: Exploring potential components of the intervention

To develop this intervention, a Phase 0-I study according to the Medical Research Council (MRC) Framework was conducted. Phase 0 consisted of 1) a systematic literature review about the barriers and facilitators for GPs to engage in ACP, 2) focus groups with GPs that were held about their experiences, attitudes and concerns regarding initiating ACP in general practice, and 3) a review of ACP interventions to identify potential components for the development of our intervention. In Phase 1, we developed a complex intervention to support the initiation of ACP in general practice for patients at risk of deteriorating or dying, based on the results of Phase 0. The complex intervention and its components were reviewed and refined by two expert panels.

Systematic review

For the systematic literature review studies were searched in four electronic databases (PubMed, CINAHL, EMBASE, PsycINFO). All reported factors hindering or facilitating GPs to engage in ACP were related to three groups: GP characteristics, perceived patient characteristics and health care system characteristics. Stronger evidence (factors reported in two or more high quality studies) was found for the following barriers: a lack of skills to act in response to vague patient requests to discuss ACP, difficulties with defining a right moment to initiate ACP discussions, the attitude that patients should initiate ACP discussions and the fear of depriving patients of hope when initiating ACP. A lack of GP knowledge, the emotional impact of ACP discussions, patients' denial of death and a lack of resources were barriers for which medium evidence was found (factors reported in one high quality study or two medium quality studies). The perceived facilitators for which stronger evidence was found were previous gathered skills by conducting ACP discussions, the willingness or awareness to foresee and

discuss future health problems, and the skills to react to and address patient initiation of ACP. Cancer patients are also more involved in ACP discussions., as well as patients capable of decision-making. A longstanding patient-GP relationship and being able to conduct discussion in the home setting were also perceived as important facilitators for GPs to engage in ACP. Sufficient time and financial reimbursement to conduct ACP discussions were facilitators for which medium evidence was found.

Qualitative focus groups

Five focus groups were held with 36 GPs in Flanders, Belgium. In this qualitative study, the GPs reported multiple barriers to initiating ACP relating to their own characteristics, the characteristics of the patients and their families and the structure and organization of the health care system. Certain of these barriers were perceived to relate more to the specific trajectories of patients with cancer, heart failure or dementia. In cancer patients, a lack of knowledge about treatment options for all different cancer types and their possible effects and the lack of structural collaboration between the GP and specialist were expressed as barriers by a number of GPs. More specifically, the limited contact with patients and a lack of information from specialists during curative treatment phase were considered as factors that hinder the initiation of ACP for GPs. Barriers that occurred more often with heart failure and dementia patients were the lack of GP familiarity with the terminal phase and a lack of key moments to initiate ACP as opposed to the trajectory of cancer patients for which a number of key moments were identified. Not only was the terminal phase described less clear than with cancer but for some GPs the life-limiting nature of heart failure and especially dementia was also not always apparent or recognised. Consequently, the need to discuss end-of-life care does not always arise. Patients' lack of awareness of diagnosis and prognosis as compared to cancer patients and the fact that patients did not often initiate such discussions themselves were also reported as barriers to discuss ACP. Prognosis is not always communicated because GPs can have difficulty in explaining potential events such as the risk of sudden death without creating anxiety. Consequently, these patients rarely initiate ACP themselves. The possible lack of decision-making capacity of dementia patients was reported by the GPs as a specific barrier for the initiation of ACP. Although, some GPs considered the future loss of a patient's decision-making capacity the very reason for initiating ACP, many felt also uncomfortable about discussing and planning end-of-life care with patients who are losing the capacity to express a change in preference or confirm their wishes at a certain point. Concerns were also expressed regarding the legal implications of implementing the documented wishes of patients with dementia who may lack decision-making capacity.

In this qualitative study, participants were also asked at the beginning of each focus group whether they knew or were familiar with a definition of ACP. Not many GPs knew the specific term, but once a general definition was introduced in the focus groups, the GPs could describe a range of experiences in

this area. After analysis, GPs' conceptualisation of ACP could be categorized in terms of the content of ACP and in terms of tasks for the GP. With regard to content of discussions, ACP was firstly conceptualised as the organisation of professional care required to meet patients' needs. Secondly ACP discussions were also described as bad news conversations. In this context, ACP was also conceptualised as a process of preparing for death. Thirdly, ACP was conceptualised as the discussion and reflection on choices of treatment and types of care for the patient, and fourthly by some participants as the completion of documents regarding patients' preferences. These conceptualisations could occur simultaneously in the narrative of a GP, however some GPs used only one of the conceptualisations to present ACP in their practice. With regard to the tasks for the GP, ACP was considered in terms of exploring and understanding patients' preferences, also when patients mention the completion of an AD on euthanasia during a consultation. The GPs explained that patients often have misunderstandings regarding this AD. Coordinating care to address patients' and families' needs was also described as a task for the GP with regard to ACP, which often comprises collaboration between different informal and formal caregivers. It was however not always perceived as an easy task to mediate between different perspectives involved in patients' care. While some participants were reluctant, a number of participants considered actively initiating ACP discussions as an important task for GPs, but acknowledged that this often depends on the competencies and attitudes of the GP regarding ACP. Finally, most GPs found that discussing palliative care options, comforting patients and reassuring terminal patients that they will be available and provide support until the end of life are important tasks for the GP related to ACP discussions.

Key components underpinning ACP interventions

A Medline search was conducted to identify systematic reviews with regard to ACP interventions. From these systematic reviews, we retrieved the intervention studies with a successful outcome regarding the occurrence of discussions, completion of advance directives, and improved end-of-life care and these were read in full and analysed for their components, in order to obtain a comprehensive overview of key features underpinning successful interventions and to identify potential components for the development of our intervention. This scope of ACP interventions identified four key features underpinning successful ACP interventions: 1) the involvement of a trained or experienced facilitator, 2) a selection process to identify patients eligible for ACP, 3) structured and patient-centred ACP discussions and 4) the opportunity to complete ACP documents (for a more detailed description of these key features, see Box 1 in Chapter 6).

Phase I: Modelling a complex intervention to support the initiation of ACP in general practice

Phase 0 resulted in the identification of the factors inhibiting or enabling GPs' initiation of ACP and important components underpinning existing ACP interventions. Based on these findings, an intervention was developed in Phase 1 consisting of five components: (1) A training program for GPs in initiating and conducting ACP discussions. The training is based on an educational programme about ACP specifically developed for GPs that has shown to improve their confidence and ability to undertake ACP conversations with patients. (2) A register of patients eligible for ACP discussions. A standardised tool for the timely identification of people who are at risk of deteriorating or dying was considered essential to support GPs in defining a key moment and prompting them to initiate ACP discussions. (3) An educational booklet on ACP for patients to prepare the ACP discussions that includes general information on ACP, a section on the role of GPs in the process of ACP and a prompt list about ACP. (4) A conversation guide to support GPs in the ACP discussions. The key elements that are addressed in the conversation guide are: understanding of prognosis, decision making and information preferences, prognostic disclosure, patient goals and quality of life, patient's fears, acceptable function for the patient, trade-offs that might be necessary to achieve different outcomes, family involvement and appropriate surrogate decision-maker. (5) A structured documentation template to record the outcomes of discussions. A documentation template was developed that is standardised, simple and patient-friendly that allow the opportunity to record and document the outcomes of the ACP conversations. A detailed description of these five components can be found in Chapter 6 and appendix I of this dissertation. The key components of this intervention are available in a preliminary version and will be tested and finalised in a subsequent feasibility and pilot study (Phase II).

Methodological strengths and limitations

This doctoral thesis has made use of several research methods to address the specific research aims, each having their own strengths and limitations.

Cross-sectional Health Interview Survey

To describe the experiences of the general population with regard to ACP and their information preferences when faced with life-limiting illness and (objective 1), data was used from a population-based study founded on a representative sample of the Belgian population. Other important strengths include the large sample size (N= 9651), the robustness of the methodology and the quality of research procedures. We used data from the Health Interview Survey (HIS), which has a long history of data collection in the Belgian population and is not based only on a specific interest in end-of-life care, but

obtains information about life style, health status, prevention and the use of health care facilities¹. Several procedures were used to ensure data quality: the content of the HIS questionnaire was discussed in workgroup sessions with academic experts, health government agencies and fieldwork experts. The questionnaires were pre-tested: firstly, questions from other European surveys that were added to the HIS 2008 questionnaire benefited from a large scale pre-test and secondly, the HIS questionnaire was pre-tested by the WIV-ISP in a small, diverse sample of people to evaluate the length, comprehension, readability etc. of questions¹. However, this population-based study also has some limitations. Because of the lower response-rate among the contacted households (55%), non-response bias cannot be excluded. The missing values for the outcome variables on ACP are around 23% and around 25% for the outcome variables on information preferences. Non-response analysis of those missing values showed that those missing values were more likely to be male, older, have a lower educational level and live in Wallonia or Brussels. As a result, it is possible that some of our findings are biased because of non-response. Because this population-based study examined the respondent's own report of their involvement in ACP, the results may be subject to recall bias. Finally, as the majority of the respondents considered their health to be good, it might have been difficult for them to imagine a scenario where they have a life-limiting illness and to foresee what their information preferences would be in that case.

Systematic literature review

To identify the perceived factors that hinder or facilitate GPs in engaging in ACP with their patients, a systematic literature review was carried out. Four electronic databases were searched for studies published between 1990 and 2011: PubMed, CINAHL, EMBASE and PsycINFO. A search strategy was developed for Medline and adapted to each database separately. A combination of controlled vocabulary and free text words was used to search in titles and abstracts. An important strength of the study is that all required methodological steps to complete a systematic review were implemented and performed separately by two reviewers (ADV & DH). The titles and abstracts of all identified reports were screened independently these two reviewers using a standardized study selection form, as well as the eligibility of selected studies. Disagreement was resolved by discussion and a third reviewer (KP) was available for arbitration. The characteristics of the studies included were extracted to a standardized data-extraction form under the headings of general information, country, research question, design, participants, barriers and facilitators and quality assessment scores.

The quality of studies was appraised and evaluated using the Critical Appraisal Skills Programme (CASP)². However, since no CASP tool is available for cross-sectional studies, an additional critical appraisal tool developed by Crombie (21-items list) had to be used³. In addition, the body of evidence from the multiple studies was graded using the three important elements for grading systems suggested by the Agency for Healthcare Research and Quality: quality, quantity and consistency⁴. This is a less

common approach, but it allows to provide a conclusion that incorporates both the results and quality of the studies and has been used successfully in other systematic reviews⁵. Given the variation in how ACP was defined in the included studies and the variation in GP practice, our findings may not be generalizable to all countries and health care systems. Also, we retrieved only qualitative research and observational studies though in our opinion such research designs provided the best way of addressing the research question. Moreover, we believe that the combination of qualitative and quantitative research methods within this study contributed to stronger validation of the results (data triangulation).

Focus groups

A qualitative research design was used in Chapter 4 and 5, which was considered to be most suitable to explore the perspectives of GPs regarding ACP. We chose focus group discussions as the best approach to explore the opinions and experiences of GP, given the flexible approach that allows for open discussion and interaction between the participants^{6,7}. Focus groups have proven to be a useful methodology to gain insights into a wide range of views^{8,9}.

Participants in three focus groups were recruited by using existing peer-review groups for GPs, contacted via email. Nearly 97% of all full-time practicing GPs in Belgium are affiliated to such peer-review groups, where practice-related aspects are discussed four times per year¹⁰. Every GP who wants to be accredited in Belgium needs to be affiliated to such a group and attendance at two out of four meetings per year is mandatory. Using such pre-existing groups has proven to be beneficial, as group discussions are naturally occurring during these meetings¹¹. However, it is also possible that some GPs might have felt restricted to report on their practice or experiences with ACP. A fourth focus group was organized by contacting the coordinators of the palliative care networks in Flanders with the request to disseminate our invitation to participate in a focus group to the GPs active in palliative home care teams. Because research shows that ACP usually takes place with patients who are terminally ill and close to death, we specifically also wanted to enroll GPs who supposedly have more experience with palliative patients. The indirect recruiting strategy, via the coordinators of the palliative networks, was probably the reason for the lower participation rate of these GPs (n=2). Because of lower response, this focus group was complemented with other GPs recruited via the professional contacts of the network coordinators (snowball sampling)¹². Nonetheless, during the focus groups, it became clear that the nurses, who are also part of a palliative home care teams, are the ones who are mainly in contact with the patients at home. During the focus groups, the GPs active in a palliative home care team also mostly shared experiences from their own practice. Therefore, we believe this has not biased the results. A fifth focus group was organized with some members from a large practice located in an urban region as opposed to the rural and semirural regions where the other focus groups took place. As a result of the recruitment procedure for the fourth and fifth focus groups, these participants might have had an increased interest

in the topic, which we believe was not necessarily the case for the focus groups that were organized using peer-review groups. Nonetheless, by using different sampling strategies we gained insight into the complex range of views and experiences regarding ACP in daily practice from GPs with diverse backgrounds, experience and interest in ACP⁷. The focus group composition may have presented a limitation. Most of the participating GPs were male (n= 27), so female GPs (n= 9) were underrepresented, as were GPs younger than 39 years (n= 6 vs. n= 30).

The focus group discussions were transcribed verbatim. For analyzing the data, constant comparative analysis was used^{13;14}. In this approach, analysis is usually done in several stages of coding and interpreting the data. Firstly, two researchers (ADV & KB) independently read and openly coded two full focus group transcripts. The codes were discussed and mutually compared for similarities and differences until they could be grouped into categories related to the research questions. Subsequently, the focus group transcripts were independently read and compared with the primary coding framework by all the members of the research team. Codes were added, modified or merged where necessary. The remaining transcripts were coded by applying the final coding framework, which was additionally checked by the research team for agreement on interpretation. After this, coding saturation was judged to be achieved by the research team as no new categories emerged. An ongoing refinement of the coding framework resulted in overarching themes deduced from the categories. This approach allowed us to refine the results while focusing on the research questions. Moreover, the results were discussed in each stage of the data analysis within the research team to further improve consistency of the results. The multidisciplinary composition of the research team (consisting of medical sociologists, psychologists, a GP and an anthropologist, all with experience in qualitative research), guaranteed interpretation of the data from a range of perspectives.

Medical Research Council Framework (Phase 0-I)

We adopted the Medical Research Council (MRC) Framework to develop an intervention to support the initiation of ACP in general practice^{15;16}. The MRC framework was published in 2000 and subsequently revised in 2008 to reflect the experience that had accumulated since the initial publication. Although the version published in 2000 proposed a stepwise, linear approach to designing and evaluating complex interventions (following a structure analogous to the development of pharmaceutical therapies)¹⁵, the 2008 framework proposed a nonlinear approach that emphasizes both piloting and implementation studies; integrates process and outcome evaluation; acknowledges the importance of alternative, non-experimental research methods and highlights the importance of understanding the intervention's context¹⁶.

Phase 0-I of the MRC framework encompasses the “development” phase which includes 2 sub-phases: (1) theory and evidence identification and (2) intervention modelling¹⁷. In this phase, it is suggested that

evidence is accumulated through systematic literature reviews, epidemiological research, qualitative research and expert opinion. For our Phase 0-I study, we used robust research methods: 1) a systematic review about the barriers and facilitators indicated by GPs to engage in ACP, 2) focus groups with GPs covering their experiences, attitudes and concerns regarding the initiation of ACP in general practice, 3) a literature search in order to obtain a comprehensive overview of key features that underpin successful ACP interventions and 4) a review of the preliminary complex intervention by an expert panel consisting of five GPs, one hospital geriatric, one palliative care consultant and two academic researchers in the field of ACP and health care communication. By using these research methods, we gained insight into the barriers and facilitators for GPs to initiate ACP with their patients, the conceptualisations of GPs regarding ACP in terms of the content of ACP discussions and the tasks for GPs in the process of ACP, and the potential components of an intervention to support the initiation of ACP in general practice. By using different research methods, data-triangulation was achieved, which we believe is an important strength of our Phase 0-I study. Moreover, the expert panel helped to identify the possible and best course of action to implement the intervention in practice.

It has been recognized that the development of interventions calls for a systematic approach with a strong rationale for design and for the explicit reporting of the development process¹⁸, which we provided in Chapter 6. However, some limitations have to be acknowledged. Other perspectives such as those of patients and family members could have provided additional insights that could have contributed to a better understanding of the underlying problems of initiating ACP in general practice. Furthermore, when exploring the key components underlying existing ACP interventions, our search strategy was limited to systematic reviews about the effect of ACP interventions. These reviews were screened for successful intervention studies that were then analysed by the research team for their key components. Observational studies as well as studies in which ACP was one component of a larger intervention were not included in our scope. Including different study designs could have provided additional insights into the barriers and facilitators for implementation of the intervention. Despite these perceived limitations, we believe to have succeeded to thoroughly and correctly perform a Phase 0-I study according to the MRC framework.

Discussion of the findings

The participation of the general population in ACP

Our results show that only a small proportion of people have in fact discussed their wishes for medical treatment at the end of life with a physician (Chapter 1). A cross-sectional survey in the Netherlands indicated that 13% of the general population had discussed issues related to medical decision-making at the end of life with a physician, as opposed to 4% of the general public in Belgium¹⁹. These figures

suggest that the involvement of the Belgian general population in ACP could be further stimulated. ACP is increasingly being viewed as a public health issue given its potential to prevent unnecessary suffering and to support individuals' decisions and preferences related to future care and the end of life²⁰. When ACP is implemented as an ongoing process of communication, it promotes the communication of patients' preferences to family and friends, and it can improve concordance between a patient's preferences and the end-of-life care received, as well as improve patient and carer satisfaction and quality of life²¹⁻²⁴. It is thus important to raise public's awareness concerning the importance of communicating their values and preferences for future care to their family members, surrogate decision-makers and health care providers, such as the Speak Up initiative in Canada or Dying Matters in the United Kingdom^{25;26}. However, our study also showed that among those who have an AD on euthanasia, only half had discussed their wishes regarding medical treatment at the end of life with a physician. A reason for this is that, in general, ADs do not have to be discussed with, drafted in the presence of or signed by a physician. However, a recent study of ACP in primary care showed that ADs were perceived by GPs as an instrument towards further communication between physicians, patients and their relatives²⁷. It was also stated in our focus group study that ACP discussions are initiated by patients mentioning or asking about the completion of an AD on euthanasia during a consultation, but also that patients often have misunderstandings regarding this AD (Chapter 5). Most GPs considered it an important task to correctly inform their patients about the benefits and limitations of ADs, and to ensure that their patients' ADs are valid and accurate. It is however also possible that people do visit their physician with the intention of discussing the completion of an AD on euthanasia and actually more broadly their wishes for care at the end of life, but that the physician omits to take up the opportunity to elaborate on this^{28;29}.

It is known that the formulation of documents should ideally be framed within a process of communication and consultation and that ADs should be seen as a potential outcome of the process of ACP³⁰. The willingness of physicians to adhere to directives has also been shown to be dependent on whether or not the directive was coupled with physician-patient discussions³¹. Fried & Drickamer (2010) have recommended before that people should be made aware of the importance of ACP as a communication process through the development of a public health message by providing accurate information about the benefits of timely engaging in ACP and the potential negative consequences of failing to engage³².

Information preferences of the general population

The results presented in Chapter 2 revealed that a majority of people in Belgium would always want to be informed about their diagnosis, their chances of being cured, the available treatments, and their life expectancy in the scenario of having a serious life-limiting illness³³. These results were also found in a

European population survey that revealed a wide-spread public preference to always be informed in the scenario of having a serious illness with less than a year to live³⁴. Additionally, our study showed that in Belgium around 70% of the respondents also indicated to always want information on palliative care and the possibilities of prolonging or shortening life. The results of this cross-sectional survey can be placed within the context of an increased societal importance of patient autonomy and participation in decision-making on the one hand (as discussed in the introduction of this dissertation) and the open public debate on end-of-life issues engendered by the process of legalization of euthanasia in Belgium on the other hand³⁵⁻³⁷. The Belgian general public is regularly confronted with reports on euthanasia as an end-of-life decision in the media³⁸, which might have influenced the public preferences to be informed about these topics. Previous studies have already shown that a markedly high public acceptance of euthanasia was found in a small cluster of Western European countries, including the three countries that have legalized euthanasia (Belgium, the Netherlands and Luxembourg), which is strongly related to a belief in the right to self-determination^{39;40}.

It is important to note that these questions were asked in the general population in the hypothetical scenario of having a life-limiting illness, which might have been difficult for respondents to imagine. However, the preferences for information on all of these specific topics were previously also studied in newly diagnosed advanced lung cancer patients³⁶. In comparison to our study in the general population, the preference of these patients to always want to be fully informed were higher on the specific topics of diagnosis, treatment and cure rate and life expectancy, while fewer wanted to have always information about palliative care and end-of-life decisions. This shows that the willingness to receive information on specific topics such as diagnosis and treatment options is generally high, but also that patients' preferences for information may shift when their health changes. Remarkably, it was found that only half of the respondents wanted their relatives to always be informed about these topics. Previous research has shown that patients vary in how involved they want family members to be and how much they want their own values as opposed to those of family members, to determine care at the end of life⁴¹. Nonetheless, most would opt for shared decision-making with loved ones and physicians. Sudore et al. (2010) indicated that the main objective of ACP is to prepare patients and their surrogates to participate with physicians in making the best in-the-moment decision⁴². In doing so, a first important step for patients is choosing a surrogate decision-maker. Physicians should explore these issues and patients should be stimulated to think about who they would consider appropriate to make medical decisions for them if they would lack the capacity to do so.

These data provide evidence that, as part of a patient-centred approach, physicians might do well to inquire patients up front about their preferences for information. Exploring patients' preferences for information is one of the first elements that should be addressed when engaging in ACP with patients⁴³⁻⁴⁵. Physicians should be alert to patients' specific information preferences depending on the topic and verify whether they want their relatives to be informed or not. They should anticipate most patients

wanting full knowledge on disease and treatment-related matters (although a minority of respondents indicated to not want to know at all or unless they were asked first). This will require the appropriate skills from physicians to elicit information preferences and knowledge to provide the desired information⁴⁶.

Barriers to and facilitators for the initiation of ACP

Findings from the 2008 Belgian Health Interview Survey in Chapter 1 & 2 demonstrate that almost 95% of the population, including care home residents, have a fixed GP whom they consult regularly (78% of the population have at least one encounter per year). Moreover, the number of GP contacts increases with age: persons aged 75 or over make an appeal four times more often to their GP compared with persons younger than 45, and they are seen by their GP on an almost monthly basis⁴⁷. Evidence-based guidelines suggest that ACP is preferably initiated by a health care professional when patients are in a stable state of health and in anticipation of future ill-health, before crisis situations occur^{48;49}. Primary care settings remain a critical setting to engage these patients in ACP^{50;51}. Given their longstanding and trusted relationship with patients, GPs are likely to have good clinical and contextual knowledge of their patients and explore patients' and families' willingness to engage in ACP⁵². Our study showed that patients who have been in frequent contact with their GP had discussed their wishes for medical treatments at the end of life more than patients who had no contact with their GP (Chapter 1), which might suggest that GPs can play a special role in empowering patients to participate in ACP.

Nonetheless, GPs face significant barriers to engage in ACP with their patients. Many barriers found throughout this dissertation were either related to GPs' lack of skills, knowledge or attitudes towards ACP (Chapter 3 & 4). Some GPs are reluctant to discuss end-of-life issues and tend to wait until the patient raises the topic. Remarkably, studies show that patients would appreciate the chance to discuss ACP but they wait for their doctor to broach the subject, which suggests that there is a gap in expectation between patients and GPs⁵³⁻⁵⁵. During the focus groups, the GPs explained that ACP discussions are sometimes initiated by patients by either expressing vague end-of-life care wishes or asking about the AD on euthanasia during a consultation. These moments may provide opportunities for GPs to initiate ACP, but a lack of skills to address patients' initiation or patients' vague requests about end-of-life care were reported as barriers for GPs (Chapter 3). As the GPs recognized themselves during the focus groups, actively initiating ACP often depended on their experience with initiating ACP, their perceived competencies (good communication skills) and positive attitudes of the GP regarding ACP (Chapter 5), which is confirmed by other research⁵⁶.

Although the literature provides common terms and definitions used in ACP^{48;57}, many GPs found it difficult to define ACP in a consistent way. As a consequence, their conceptualisations of ACP ranged

from a comprehensive and multifaceted process of planning to completing specific documents or the process of preparing for death (Chapter 5). The conceptualisations sometimes also implied an engaging in specific aspects of ACP rather than engaging in multiple discussions that address all key elements as recommended in the literature^{58;59}. During the focus groups, it was also stated that ACP discussions were mostly conducted in an informal way and sometimes perceived as something that is already discussed with patients between the lines. Previous research already showed that health care professionals perceived no difference between day-to-day care planning and ACP^{60;61}. However, the National Health Service in the UK makes a clear distinction in their National End of Life Care Programme between ‘general care planning’ on the one hand and ‘advance care planning’ on the other^{57;62}. General care planning encompasses the care of people both with and without capacity to make their own decisions, whereas ACP always requires the involvement of patients who have the mental capacity to establish and express their preferences. ACP is always about patients with capacity expressing preferences with the aim to aid decision-making and direct future care in the event when patients’ decision-making capacity is later lost⁶². General care planning indeed involves a process of assessment and patient-centred dialogue to establish a person’s needs, preferences and goals of care and making decisions about how to meet these in the context of available resources, but it focuses on the current situation.

Recently, the first guideline on ACP was published for GPs in Flanders⁶³. This guideline is currently being endorsed among GPs via two hour workshops in local peer review GP groups. Local peer-review GP groups are geographically determined groups of GPs that meet four times a year to discuss their practice. The workshops consist of a presentation on the content of ACP and an evaluation of patient case reports in terms of the need for ACP. The development of guidelines and training programmes can be helpful to change the skills, attitudes, and beliefs of GPs, and to provide good role models for the difficult task of initiating communication about end of life. It is also important that a training programme for GPs is time efficient because it will lead to greater access and completion by these physicians⁶⁴. However, a training programme on ACP also needs to include active, practice-oriented strategies such as role-play exercises, feedback, the use of video role modelling, group discussions and feedback during the training session as these are educational strategies which have shown to be most effective in improving physicians’ competencies⁶⁵⁻⁶⁸.

Moreover, the findings of this dissertation show that the barriers to ACP are more complex than a lack of skills and knowledge but instead extend to entire health systems, which is confirmed by other studies⁶⁹. A number of barriers and facilitators identified for GPs to initiate ACP were related to health care system characteristics (Chapter 3 -5). Ineffective communication between health care providers across settings, as well as difficulties with sharing the outcomes of ACP discussions across the health care system were perceived by GPs as important reasons for not initiating ACP. The GPs in our study indicated that they often lose touch with their patients when they are mainly being cared for by the specialist. According to them, this is not countered by effective collaboration or information transmission across health care

settings (Chapter 4). Furthermore, personalized and comprehensive ACP discussions can be time consuming and the GPs in our focus groups also argued that during regular consultations time constraints restricted them from initiating ACP discussions⁷⁰. A financial reimbursement was in the systematic literature review also identified as a structural factor that could facilitate GPs' engagement in ACP. Financial incentives have already been suggested by other research as needed to stimulate clinicians to engage in ACP⁶⁹. However, a financial reimbursement as such does not guarantee that ACP will be carried out properly and safeguards will need to be built in. Concerns have already been raised by health care professionals that otherwise ACP may be reduced to merely a check-box exercise⁶⁹.

It has been indicated before that to systematically implement ACP in practice, an intervention may not rest solely on improving communication skills⁷¹. Few health care systems have developed structures and processes that systematically address ACP⁵⁹. As other authors have suggested, to embed ACP into routine practice, it is necessary that all health care organisations (including general practices) need to become "conversation ready"; this means systematically eliciting, documenting and enacting patients' preferences⁷²⁻⁷⁴.

The development of an ACP intervention for general practice

A systematic, multicomponent intervention holds the greatest potential for improving ACP and is aligned with existing evidence^{44;69}. The barriers and facilitators indicated by GPs to initiate ACP found in this dissertation are complex and multifaceted. Therefore, a complex intervention was deemed necessary to support the initiation of ACP in general practice. Complex interventions are defined as interventions comprising a number of components that may act both independently and inter-dependently^{15;75}. A recently published systematic review regarding the effects of ACP on end-of-life care showed that complex or multicomponent ACP interventions may be more effective in meeting patients' preferences than written documents alone⁷⁶. These interventions were found to result in an increased frequency of out-of-hospital and out-of-ICU care and in increased compliance with patient's end-of-life wishes and satisfaction with care. Moreover, patients and families who participated in ACP did not report more stress, anxiety or depression compared to patients or families who did not participate.

With the development of a complex intervention to support the initiation of ACP in general practice, we aim to improve communication between patients and their GP, increase quality of life and well-being of patients and their relatives, enhance provision of care consistent with patient goals and preferences, and increase satisfaction with care^{21-23;77}. Research has shown that system-wide processes are needed that will consistently 1) invite all eligible patients to consider ACP for future care relevant to their stages of illness, 2) provide competent assistance by trained and accountable personnel and 3) ensure written and documented plans⁷⁸. Recent research on successful ACP programmes identified a number of elements

that are shared by these programmes: a facilitated, clinician-initiated discussion process to develop individualized care plans, standardized documentation and forms, proactive yet appropriately staged timing of discussions, systems and processes that ensure planning occurs, ongoing evaluation of the programme and quality improvement⁷⁹. Other elements that were shown to be promising facilitators of ACP include the use of easy-to-understand ACP educational materials, systematic clinician training in communication skills and extensive clinician-led discussions over time about patient values^{71;79}.

Following phase 0-I of the UK Medical Research Council's (MRC) guidance for developing complex interventions^{80;81}, we developed a complex intervention to support the initiation of ACP in general practice in Flanders, Belgium (Chapter 6 & Appendix 1). Our intervention is somewhat different from existing ACP programmes such as the Respecting Choices Program⁸², as it will be delivered by patients' GP instead of a trained non-medical facilitator. We aimed for the initiation of ACP to occur with a health care professional who is likely to have good clinical and contextual knowledge of the individual patient, is aware of both the physical and non-physical domains of health and is in a trusting relationship with patients, or able to develop such a relationship^{78;83}. By targeting GPs, we considered that the time consuming nature of ACP could possibly be limited to some extent because GPs in Belgium, as in many other countries, mostly know and care for their patients and their families over a long period time. A study on the implementation and embedding of existing ACP initiatives in routine clinical practice showed that the factors that promote the implementation are largely related to following procedures⁸⁴: prescheduled interventions applied to selected patients, a dedicated team to organize the interventions, specifically trained facilitators to deliver the interventions and a dedicated document and organisational policies or guidelines to support the process. Our intervention takes these factors into account by training GPs in managing the interactional processes with their patients, equipping them with simple tools such as a register for patients eligible for ACP discussions, a conversation guide, and a standardized template to document the ACP discussions. An additional challenge to address in this intervention was the lack of communication between the different health care providers involved in patients' care. In Belgium, cross-setting electronic health records to disseminate and access patients' medical files by different health care providers does not exist yet and can thus not be used as a tool for communication across health care settings⁸⁵. Therefore, specific guidelines were linked to the standardized documentation template for the GPs. Patients need to be encouraged by their GP to talk about this documentation template to their other care providers. But GPs are also given the instruction to notify other involved health care professionals about the outcomes of the ACP discussions (of course with patients' approval), for example by sending a copy of the standardized documentation template together with patients' referral letter to the involved specialist.

Another important barrier identified by the GPs was the uncertainty about when to initiate ACP. As the findings presented in Chapter 5 show, ACP was conceptualised by some GPs as discussions in terms of communicating a terminal diagnosis or as discussions about the initiation of palliative home care, which

suggests that in actual practice ACP is sometimes initiated rather late in the course of disease. A literature review on ACP in primary care confirmed that most physicians only initiate ACP conversations when patients are terminally ill or suffering from potentially fatal illnesses²⁷. Previous research already showed that ACP is strongly related to the provision of palliative care^{35;56;86}, but also that palliative care is still often associated with terminal care which is mostly initiated relatively close to death^{9;87;88}. When developing our intervention, it was considered to be an important aspect of implementation to take into account when or with whom GPs feel most comfortable with initiating ACP. Most GPs in the focus groups considered patients suffering from a life-limiting illness to be most eligible for initiating ACP with. However, the initiation of ACP in patients with non-cancer conditions such as heart failure or dementia also proved to be more challenging (Chapter 4). These diseases were often perceived as non-terminal and therefore not as relevant to the principles of ACP (Chapter 4). According to the GPs, cancer patients were more easily involved in ACP. It was therefore considered important to standardize the timing of ACP discussions by identifying in general patients at risk of deteriorating or dying (and documenting these patients in a register). A number of triggers have been proposed in the literature as a guide for health care professions to initiate ACP^{72;89}. GPs can make use of general triggers such as a poor general health of the patient (limitations in self-care or multiple hospitalization) or age (e.g. all patients older than 80 years), prognosis-related triggers such as the surprise question “*Would you be surprised if this patient died in the next year?*” or condition-based criteria by using the Supportive and Palliative Care Indicators Tool (SPICT) which is a simple, one page format that contains general indicators of deteriorating health commonly present in advanced conditions^{44;83;90-92}.

Lastly, an educational booklet that will assist and increase the knowledge of patients and their caregivers of the potentially positive outcomes of ACP will also increase their willingness to engage in it with their GP. Moreover, educating patients on ACP and preparing them for the discussions could also contribute to limiting the time involved in conducting ACP discussions, which was perceived as a barrier by the GPs. Because ACP can be a time-intensive process, helping patients and families begin this process on their own is useful^{59;93}. The challenge that awaits us now, is to test this complex intervention in a Phase 2 study, in order to determine the feasibility and acceptability of the intervention in a sample of patients and GPs^{16;94} (see recommendations for future research).

Implications for policy, practice and future research

This dissertation reveals a number of issues concerning the initiation of ACP in general practice. This section contains several recommendations for policy makers and GPs (although we believe many of these recommendations may apply to or profit other caregivers) regarding the initiation of ACP in clinical practice. Lastly, several important points for future research are identified.

Policy recommendations

Despite the potential advantages of ACP, it is initiated rarely or rather late in the disease trajectory of patients. This suggests that stimulation of both patients and physicians to engage in ACP discussions would be useful as part of efforts to enhance ACP in practice.

Public information campaigns can increase the public's awareness on the importance of having timely ACP discussions. Public health campaigns may have a strong impact on the population and they could also lower the barriers for physicians to address ACP with their patients. As the GPs in our study indicated, many of their patients lack knowledge about ACP and ADs. Public health messages can increase people's knowledge by providing accurate information about the benefits of engaging in ACP and the potential negative consequences of failing to do so. Our study showed that younger people, men, those living in the Walloon region of Belgium, those with poorer health and those with few GP contacts are target groups for education because of their lower uptake of ACP. Younger people in good health tend not to feel the need for ACP because they are less confronted with the consequences of a life-limiting illness than older adults and do not want to think about the end of life. Nonetheless, they can also be stimulated to engage in ACP or to appoint a surrogate decision-maker because sudden serious illness or injury can quickly render adults of all ages incapable of decision-making⁹⁵. A strategy that has been proposed by other authors would be to encourage them first to identify a surrogate decision-maker, which may eventually lead them to initiate discussions about their preferences and goals of care, which may be possibly followed by an AD⁹⁶. Older people are another key target group for ACP, as they are at higher risk of needing end-of-life care. Of those older than 75 years, our study showed that only a minority has ever had a discussion with their physician about their wishes regarding medical treatment at the end of life. Public information campaigns may help to overcome important barriers for patients to engage in ACP, including the perception that ACP is irrelevant or that they have to wait for their physician to initiate these discussions. A study on the impact of the Terri Schiavo media coverage in the US found that her story motivated the majority of participating adults to define their own goals for medical care and to talk to their family and friends about ACP⁹⁷. Terri Schiavo was a 41-year-old woman who was in a persistent vegetative state after suffering a cardiac arrest in 1991. After a prolonged legal battle, her feeding tube was finally removed in 2005.

GPs can also have an important role in the promotion and initiation of ACP^{98,99}. However, a lack of time, experience and training to discuss ACP often discourages them from initiating such conversations with their patients. As this dissertation showed, one of the problems is that the skills, knowledge and attitudes of GPs can strongly influence whether or not ACP is (timely) initiated. **Policy should therefore aim to motivate and support GPs to introduce ACP to their patients.** Barriers caused by lack of training and experience in ACP could be addressed by education or training programmes. **It is important that**

GPs are trained in conducting ACP discussions so they feel less hindered when confronted with situations that require these discussions. GPs should better understand what ACP is, what its significance and goals are, and improve their communication skills so they can talk effectively to their patients about their values and goals for future care. This can be done by ensuring that formal education on ACP is included in the medical curricula for GPs and by stimulating further postgraduate training on ACP.

ACP is a complex and time consuming task, which can lead physicians avoiding the initiation of ACP or shifting the responsibility for it towards other professionals. **An appropriate financial recognition for the time invested has been suggested as a way to further encourage physicians to have such conversations with their patients**⁶⁹. It has also been suggested by the International Society of Advance Care Planning and End of Life Care to establish formal credentials for those health care professionals providing ACP. These credentials could assist in legitimizing the role of the ACP facilitator within healthcare, provide a consistent approach to training, and facilitate reimbursement for activities related to ACP¹⁰⁰.

Lastly, **a central electronic register that holds information about patients' advance care planning** could improve communication and facilitate health care professionals' access to this information. This central register must be accessible for all relevant health care professionals. Today, a central register that stores patients' ACP-related information has not been implemented in Belgium, hence alternative ways must be found to share a written record of the ACP process quickly and efficiently between the different health care settings. Since 2012, patient-held wallet cards have been introduced in Belgium to flag the existence of ADs (i.e. LEIF card)¹⁰¹. This card does not replace the paper version of an AD but indicates whether a patient has an AD.

Recommendations for practice

We recommend for GPs to participate in adequate training programmes in order to enhance their competencies in conducting ACP discussions and improve their knowledge on the process, benefits and outcomes of ACP. Many GPs find these conversations difficult and as this dissertation showed, whether or not GPs are willing to initiate ACP greatly depends on their attitudes, knowledge and skills. Based on evidence from the literature, a training programme on ACP was developed as part of our complex intervention to support the initiation of ACP in general practice. This training programme will include active, practice-oriented strategies such as role-play exercises, feedback, the use of video role modelling, group discussions and feedback during the session.

Standardizing the timing and conduct of ACP discussions by identifying patients eligible for ACP discussions can also be helpful for timely initiating ACP. This study indicated that many GPs experience

difficulties with defining a key moment to initiate ACP, especially in patients with organ failure and dementia as opposed to cancer patients. There is no agreed standard on when to initiate ACP, but a pragmatic three-step guide that can be used by GPs is to consider ACP if: 1) ‘no’ is the answer to the question “*Would you be surprised if this patient died within the next year?*”, 2) the patient’s general health is poor (e.g. multiple hospitalisations, limitations in self-care) and 3) disease-specific indicators point to a poor prognosis (e.g. progressive malignancies, dementia, advanced organ failure, disabling neurological conditions). Specific triggers to discuss ACP might include: patients initiating the conversation, the diagnosis of a progressive life-limiting illness, change in a patient’s personal circumstances such as moving into a care home or loss of a family member⁸³.

Another possible measure to facilitate ACP for GPs is to make use of tools such as brochures or information leaflets for patients. In that way patients can already consider ACP before talking to their doctor. A preliminary version of a patient brochure on ACP was developed as part of our complex intervention to support the initiation of ACP. To address ACP in a more systematic way, it is important that patients are informed about ACP and the benefits of engaging in it, and that these information resources are widely available. GPs can hand out brochures or information leaflets to their patients who are interested or in need of ACP discussions. The use of a conversation guide could also support GPs during ACP discussions by providing an overview of the key elements that should be addressed with patients. Our findings highlight the importance of checking patients’ preferences in advance as to the extent and the specific topics about which they want to be informed. An examination of the role of relatives is also warranted (as only half of the people want a relative to always be informed). By exploring these issues with the patient, GPs can help them to develop a plan to engage relatives in these discussions and choose an appropriate surrogate decision-maker. As part of our intervention to support the initiation of ACP in general practice, a draft of a conversation guide was developed and approved by an expert panel, consisting of the following key elements: understanding of prognosis, decision making and information preferences, prognostic disclosure, patient goals and quality of life, fears, level of functioning acceptable to the patient, trade-offs that might be necessary to achieve different outcomes, family involvement and a surrogate decision-maker.

Lastly, it is recommended that patients’ wishes, preferences, goals of care and decisions are documented in their medical record. This information must be timely, accurate, relevant and understandable, but also easily retrievable and transferable wherever the patient is being treated. As part of our intervention, we developed a structured template that can be used to document the outcomes of ACP discussions. It is important that the outcomes of ACP discussions are communicated to all health care providers involved in the patient’s care.

Recommendations for future research

In this dissertation, a cross-sectional survey was performed to quantify the information preferences of the general population when faced with a life-limiting illness and their involvement in ACP. However, several study findings are in need of further clarification. We for instance observed that although the majority of people in Belgium wants to be informed about different topics related to their illness when faced with a life-limiting illness, people's preference for always wanting their relatives to be informed about these topics is less prevalent. Reasons for this are however not clear. Similarly, it was observed that there are differences in information preferences or the involvement in ACP of the general population between the different regions in Belgium. Qualitative research with patients could lead to additional insights and to new suggestions for how to address ACP with patients and their relatives, especially in patients with non-malignant life limiting diagnoses as they continue to achieve lower rates of ACP compared to patients with cancer diagnoses. In addition, as health care professionals will increasingly be faced with a growing number of immigrants with whom ACP discussions can be conducted, research on the experiences and attitudes, barriers and facilitators for ACP of people with different racial and cultural backgrounds is warranted, which is today still underexposed in research regarding ACP^{63;102}.

Performing a Phase 0-I study according to the MRC framework helped us to develop a complex intervention to support the initiation of ACP in general practice. However, it is known that evaluations of complex interventions are often accompanied by problems because researchers have not fully defined and developed the intervention through an iterative phased approach. Future research should therefore aim to reveal the effectiveness of the intervention's components we developed. It should also focus on the best way to implement the components in standard care procedures by testing the feasibility of the intervention's components and on explaining how the various components can work together to achieve the desired outcomes⁹⁴. The Phase II study serves to establish the probable active components of the intervention so that they can be delivered effectively during a subsequent large-scale randomized controlled trial that evaluates the effectiveness of the intervention (Phase III study).

In Phase II, the information gathered in Phase 0-I is used to develop the optimum intervention and study design. Firstly, this involves testing the feasibility of delivering the intervention and its acceptability to providers and patients. This means that the intervention may have to be adapted to achieve optimal feasibility¹⁶. For example, the patient brochure developed for our intervention can be tested through qualitative interviews with a number of patients in which they are asked for their feedback. A focus group interview with GPs may provide insights into the feasibility and acceptability of the conversation guide and the template for documenting the outcomes of the ACP discussions. This study should also focus on how triggers to identify eligible patients for ACP can be embedded in routine care. The training for GPs may be tested with a small group of participants that can complete an evaluation before and

after the training programme. The content and educational materials can also be evaluated by the GPs following the education. If it is found that certain components of the intervention are unacceptable to potential recipients, these components may have to be re-examined.

Secondly, in Phase II, appropriate outcome measures for the main trial have to be carefully selected and piloted during the exploratory study. Recently, a number of systematic reviews on the effects of ACP were conducted^{77;103}. However, the authors concluded that a meta-analysis to define which ACP approach is the most effective, was not possible because of the variability in the definitions and measurements of the outcomes⁷⁷. Therefore other researchers have recommended to use validated instruments in future intervention studies to make the comparison of outcomes across different studies possible. Nonetheless, it has also been recognized that ACP interventions may turn out to be unsuccessful because they are based on the narrow outcome of AD document completion and the assumption that the value of ACP depends on whether the plans are followed, and that the intervention was unsuccessful if they are not⁹⁸. However, the completion and adherence to ADs may not necessarily be the main reasons why patients, their families and health care professionals engage in ACP (as is discussed in the introduction of this dissertation)^{104;105}. With this complex intervention, we aim to ultimately improve the initiation of ACP in general practice. In doing so the following goals can be achieved, i.e. enhance provision of care consistent with patient goals and preferences, increase patients' and relatives' satisfaction with care and contribute to the quality of life and well-being of patients and their relatives.

Thirdly, as part of Phase II, the complex intervention is evaluated in an exploratory pilot trial that ideally should be randomised so effect size and variability of the effect can be estimated and potential problems in the implementation of the trial detected (such as the feasibility of the recruitment process and measurement, randomization, adherence and drop out, etc).

To perform Phase II, a combination of quantitative and qualitative research methods are recommended to evaluate the intervention^{106;107}. This is necessary to understand the barriers for participation and implementation, to clarify why the intervention works or not and accordingly revise and improve the intervention design and evaluation. Phase II provides an understanding of which components of the intervention are probably essential and should be retained and which ones can be modified without jeopardizing outcomes. This approach ensures that when the intervention is ready to be rolled out and evaluated in a large-scale Phase III study, it is feasible within the target context and that the processes of its implementation are understood.

Conclusion

This doctoral thesis reveals that few people of the general population in Belgium have discussed their wishes regarding medical treatment at the end of life with their physician or have completed an AD on euthanasia. Younger people, men, inhabitants of the Walloon region of Belgium, people with a poorer health status and people with fewer GP were less likely to engage in ACP. However, the majority of the Belgian population indicated the preference to always be informed concerning disease-related topics and end-of-life care topics when faced with a life-limiting illness. Younger adults, people with a higher education and people with a regular GP were more likely to always want to be informed on these topics. Younger adults and women were less likely to want their relatives to be always informed. Information-giving is an essential aspect of clinical care, so understanding the public preferences for information in advanced disease and participation in ACP is not only necessary to promote communication about future treatment and end-of-life care, but also to support and train clinicians in responding appropriately.

In the Belgian health care system, GPs were considered ideally placed to initiate an ACP discussion in a timely manner. However, in this thesis we found multiple reasons of why GPs do not initiate ACP with their patients that could be allocated to either their own characteristics, the characteristics of the patients and their families, or the structure and organization of the health care system. We also gained insight into the specific barriers for GPs to initiate ACP placed in the context of the three illness trajectories of cancer, heart failure and dementia. Key barriers and facilitators were not only related to GPs' skills knowledge and attitudes about ACP, but also to structural elements such as the lack of collaboration and communication between the involved care providers in different health care settings. Additionally, we found varying conceptualisations of ACP among GPs in terms of the content of ACP discussions and the task for GPs in the process of ACP, of which some are more limited to only specific aspects of ACP. This can lead to confusion as the role of GPs may vary according to how ACP is conceptualised. A shared conceptualization is needed to ensure a successful implementation of ACP.

The barriers and facilitators found in this dissertation are complex and multifaceted. Therefore, the development of a complex intervention is needed to support the initiation of ACP in general practice. The construction of this complex intervention was based on the results of 1) a systematic review about the barriers and facilitators indicated by GPs to engage in ACP, 2) focus groups with GPs covering their experiences, attitudes and concerns regarding the initiation of ACP in general practice, 3) a literature search in order to obtain a comprehensive overview of key features that underpin successful ACP interventions and 4) a review of the preliminary complex intervention by an expert panel. The intervention consists of five key components: 1) training for GPs in initiating and conducting ACP discussions, 2) a register of patients eligible for ACP discussions, 3) an educational booklet for patients to prepare them for ACP discussions, 4) a conversation guide to support GPs in ACP discussions and 5) a structured template to document the outcomes of the discussions. A future challenge will be to test and

finalize the intervention in a subsequent feasibility and pilot study (Phase II). With this complex intervention, we aim to ultimately improve the initiation of ACP in general practice. In doing so the following goals can be achieved, i.e. enhance provision of care consistent with patient goals and preferences, increase patients' and relatives' satisfaction with care and in the long run contribute to the quality of life and well-being of patients and their relatives.

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Samenvatting van de belangrijkste bevindingen

Inleiding

Een belangrijk aspect van kwaliteitsvolle en patiëntgerichte levenseindezorg is de mate waarin de zorg overeenstemt met de wensen van de patiënt. Dit veronderstelt dat de wensen en voorkeuren van patiënten m.b.t. hun levenseindezorg gekend zijn alvorens ze wilsonbekwaam worden om zelf hun voorkeuren te uiten en beslissingen te nemen. Voorafgaande zorgplanning (VZP) kan daartoe een belangrijke bijdrage leveren. VZP is een proces dat mensen de mogelijkheid biedt om, in overleg met hun naasten en verzorgers, op voorhand doelstellingen en keuzes te formuleren in verband met de manier waarop zij willen dat er voor hen wordt gezorgd wanneer zij niet langer in staat zullen zijn om voor zichzelf in te staan. Dit communicatieproces kan uitmonden in een aantal beslissingen die schriftelijk kunnen worden vastgelegd. In een positieve wilsverklaring kunnen patiënten toestemmen in een medische tussenkomst of een uitdrukkelijk verzoek doen tot medische tussenkomst (bv. een voorafgaand verzoek tot euthanasie). Positieve wilsverklaringen zijn juridisch niet afdwingbaar. Een voorafgaande wilsverklaring inzake euthanasie is een voorbeeld van een positieve wilsverklaring. In een negatieve wilsverklaring kunnen patiënten preciseren welke behandelingen en onderzoeken ze al dan niet nog wensen wanneer ze zelf niet meer in staat zijn te oordelen. Een negatieve wilsverklaring is juridisch wel afdwingbaar. Tenslotte kan ook een wettelijke vertegenwoordiger worden aangeduid, die erover waakt dat de wensen van de patiënt nageleefd worden wanneer een patiënt zijn wil niet meer kan uiten.

De voordelen van VZP zijn uitgebreid beschreven en worden door zorgverleners van verschillende disciplines erkend. VZP leidt tot een betere overeenstemming tussen de wensen van de patiënt en de zorg aan het levenseinde, het stimuleert communicatie tussen patiënten, hun naasten en zorgverleners en leidt tot een grotere tevredenheid over de zorg bij patiënt en nabestaanden. Daarenboven toont onderzoek aan dat VZP geen aanleiding geeft tot verhoogde angst of depressie bij patiënten. Een sleutelfiguur in het VZP-proces is de huisarts: hij kent zijn patiënten meestal goed en heeft met hen vaak een vertrouwensband. Toch blijkt uit (inter)nationale studies dat dergelijke gesprekken niet zo frequent worden aangegaan, wat erop wijst dat huisartsen bepaalde remmingen ervaren om over VZP te spreken. Omwille van de positieve uitkomsten van VZP voor de patiënt en zijn naasten, wordt VZP ook steeds meer als een belangrijk domein van volksgezondheid beschouwd. Niet alleen het aantal mensen dat zorg rond het levenseinde nodig heeft, is drastisch gestegen maar ook de wijze waarop zorg rond het levenseinde wordt aangeboden, is veranderd. In onze samenleving werd overgegaan van traditionele naar meer liberale waarden, waarbij meer belang wordt gehecht aan de autonomie van de persoon en rekening wordt gehouden met een groeiende steun voor een 'recht op sterven' wetgeving. De tendens naar een meer patiënt-georiënteerde benadering van het levenseinde legt de nadruk op de rol van de voorkeuren en wensen van mensen in het nemen van medische beslissingen. Een kwaliteitsvolle zorg bij het levenseinde dient daarom duidelijk geënt te zijn op de houdingen en voorkeuren hieromtrent van de bevolking. Voor België ontbrak echter elke informatie hieromtrent.

Doelstellingen en onderzoeksvragen

Dit proefschrift heeft twee algemene doelstellingen: (1) beschrijven in welke mate het Belgische publiek betrokken is bij VZP en wat de informatievoorkeuren zijn van de Belgische bevolking in het geval van een levensbedreigende ziekte en (2) ontwikkelen van een complexe interventie om de initiatie van VZP te verbeteren in de huisartsenpraktijk bij patiënten met een ernstige chronische of levensbedreigende aandoening.

Binnen de eerste doelstelling hebben we getracht volgende onderzoeksvragen te beantwoorden:

1. In welke mate hebben personen uit de algemene bevolking ooit al met een arts gesproken over hun wensen met betrekking tot medische behandelingen aan het levenseinde, in welke mate beschikken mensen uit de algemene bevolking over een voorafgaande wilsverklaring inzake euthanasie en welke factoren of kenmerken zijn hieraan verbonden?
2. In welke mate willen personen uit de algemene bevolking dat ze zelf geïnformeerd worden en dat hun naasten geïnformeerd worden over diagnose, kans op genezing, levensverwachting, behandelingsmogelijkheden, opties op het vlak van palliatieve zorg en mogelijkheden om het leven te verlengen of verkorten, en welke factoren of kenmerken zijn hieraan verbonden?

Binnen de tweede doelstelling hebben we getracht volgende onderzoeksvragen te beantwoorden:

3. Wat zijn de belemmerende en bevorderende factoren voor huisartsen om VZP ter sprake te brengen bij hun patiënten?
4. Is er een verschil voor huisartsen in belemmerende factoren om VZP te initiëren bij patiënten met kanker, hartfalen of dementie?
5. Op welke manier wordt VZP geconceptualiseerd door huisartsen, op basis van hun ervaringen in de praktijk?
6. Wat zijn de componenten van een complexe interventie om de initiatie van VZP in de huisartsenpraktijk te bevorderen bij patiënten met een ernstige chronische of levensbedreigende aandoening?

Methoden

1) Gezondheidsenquête 2008 (hoofdstuk 1 & 2)

Om de eerste twee onderzoeksvragen te beantwoorden, gebruikten we data van de nationale gezondheidsenquête verzameld in 2008 bij een representatieve steekproef van de Belgische bevolking. De nationale gezondheidsenquête wordt georganiseerd door het Wetenschappelijk Instituut voor Volksgezondheid (WIV-ISP) en werd in 2008-2009 voor de vierde maal uitgevoerd. Aan de hand van een meertrapse, gestratificeerd geclusterde steekproeftrekking worden ongeveer 6000 private

huishoudens willekeurig geselecteerd uit het nationale bevolkingsregister. Van deze geselecteerde huishoudens wordt telkens een maximum van vier personen bevraagd (het gezinshoofd en de partner, en twee extra willekeurige leden behorend tot het huishouden). De datacollectie werd uitgevoerd via een vragenlijst dat ingevuld werd door alle geselecteerde personen van 15 jaar of ouder (N= 9651). De participatiegraad onder de geselecteerde huishoudens was 55% (ongeveer 6000 huishoudens werden gecontacteerd). De gegevensverzameling via de gezondheidsenquête heeft betrekking op de gezondheidstoestand, medische consumptie, leefstijl, socio-economische status en andere gezondheidsdeterminanten en heeft als doel informatie in te winnen over de algemene gezondheidstoestand van de bevolking en hun gezondheidsbehoeften. In de gezondheidsenquête van 2008 werd voor de eerste en enige maal een specifieke module rond houdingen ten aanzien van het levensende opgenomen.

2) Medical Research Council Framework voor de ontwikkeling en evaluatie van complexe interventies (hoofdstuk 4 - 6)

Bij de ontwikkeling van deze interventie werd als methode gebruik gemaakt van de internationaal erkende richtlijn van het Medical Research Council (MRC) voor de ontwikkeling en evaluatie van complexe interventies (*MRC Guidance for Developing and Evaluating Complex Interventions*). Deze richtlijn stelt onderzoekers in staat de juiste methoden te herkennen en toe te passen en is reeds zeer invloedrijk geweest in de ontwikkeling van interventies binnen de gezondheidszorg. De MRC richtlijn gaat uit van een procesmatige aanpak, gaande van Fase 0 t.e.m. Fase IV. Fase 0-I omvat de ontwikkeling van de interventie. Fase 0-I werd uitgevoerd op basis van verschillende methoden die hierna kort beschreven worden.

Fase 0: Exploreren van de potentiële componenten van een interventie

Systematische literatuurstudie (hoofdstuk 3)

Voor het beantwoorden van de derde onderzoeksvraag werd een systematische literatuurstudie uitgevoerd naar belemmerende en bevorderende factoren voor huisartsen om VZP ter sprake te brengen bij hun patiënten. Er werd op zoek gegaan naar wetenschappelijke studies gepubliceerd tussen 1990 en 2011 over drempels en faciliterende factoren in vier databases: PubMed, Cinahl, Embase en PsycInfo. Daarenboven werden de literatuurlijsten van de geïdentificeerde studies gescreend op mogelijk relevante studies en werden de eerste auteur van de geïncludeerde studies en experts op het vlak van VZP gecontacteerd voor mogelijke bijkomende studies. Tenslotte werden ook de recentste uitgaven van de 10 meest relevante wetenschappelijke tijdschriften doorzocht.

Studies werden gescreend en geïncludeerd volgens vooropgestelde inclusie- en exclusiecriteria. De geïncludeerde studies werden beoordeeld op hun kwaliteit aan de hand van specifieke instrumenten die ontwikkeld werden voor de kwaliteitsbeoordeling van bepaalde types van studies (in dit geval kwalitatieve studies en cross-sectionele studies). De totale kwaliteitsscores voor de studies werden

uitgedrukt op een schaal van 0 tot 10. Op basis van de kwaliteitsscores konden de studies opgedeeld worden in studies met een lage kwaliteit (score ≤ 5), een middelmatig kwaliteit (score 6 of 7) of studies met een hoge kwaliteit (scores 8-10). Wanneer drempels of faciliterende factoren gerapporteerd werden in 2 of meer studies met een hoge kwaliteit, dan werden deze factoren beschouwd als factoren waarvoor sterkere evidentie werd teruggevonden in de literatuur.

Kwalitatieve focusgroepstudie (hoofdstuk 4 & 5)

In 2012 werden in Vlaanderen vijf focusgroepen met huisartsen georganiseerd om dieper in te kunnen gaan op de belemmerende factoren voor huisartsen om VZP te initiëren en het verschil tussen de initiatie van VZP bij patiënten met kanker, hartfalen en dementie, alsook om een beter inzicht te krijgen in de ervaringen van huisartsen met VZP in de praktijk. In totaal namen 36 huisartsen deel aan deze focusgroepstudie (n= 9, n= 11, n= 4, n= 5, n= 7). De deelnemers aan deze focusgroepen werden op verschillende manieren gerekruteerd om voldoende variatie te bekomen in de ervaring, leeftijd, en de locatie van de huisartsen. Tijdens de focusgroepgesprekken werd gebruik gemaakt van een gesprekshandleiding (topiclijst) waarbij de volgende onderwerpen bevroegd werden: 1) ervaringen met VZP in de praktijk, 2) attitudes omtrent VZP, 3) ervaren drempels en faciliterende factoren om VZP aan te snijden, 4) mogelijke hulpmiddelen of interventies om VZP te verbeteren in de huisartsenpraktijk. De data van de focusgroepen werd geanalyseerd volgens de constante vergelijkingsmethode.

Fase 1: Modelleren van de interventie naar de huisartsenpraktijk met behulp van een expertenpanel (hoofdstuk 6)

Een eerste ontwerp van een interventie om de initiatie van VZP te verbeteren in de huisartsenpraktijk werd ontwikkeld door het onderzoeksteam door de resultaten uit Fase 0 te combineren en te integreren. Dit ontwerp werd vervolgens voorgelegd aan twee expertenpanels (n= 4, n= 5) in januari 2015. Voor de samenstelling van de expertenpanels werd doelbewust op zoek gegaan naar huisartsen, personen met ervaring in het voeren van VZP-gesprekken, academici met expertise op het gebied van VZP of patiënt-arts communicatie en/of personen die ervaringen hadden met het geven van communicatietrainingen aan artsen. De meeste deelnemers hadden ervaring op meerdere vlakken. Tijdens de expertenpanels werd gevraagd de volledigheid van de interventie en de haalbaarheid en aanvaardbaarheid van de componenten te beoordelen en de drempels voor de implementatie van de componenten te identificeren.

Belangrijkste bevindingen

De prevalentie in de algemene bevolking van een voorafgaande wilsverklaring inzake euthanasie en de bespreking van wensen met betrekking tot het levenseinde (hoofdstuk 1)

In deze studie werd bij een representatieve steekproef van de Belgische bevolking nagegaan in welke mate mensen communiceren over de wijze waarop ze wensen te sterven. In het licht van de sinds 2002 goedgekeurde wet op euthanasie wordt nagegaan in welke mate mensen al beschikken over een voorafgaande schriftelijke wilsverklaring inzake euthanasie. In deze studie werden enkel de gegevens van respondenten ouder dan 18 jaar geanalyseerd (N = 9324).

De resultaten van deze studie tonen aan dat 4.4% van de bevolking ooit met een arts heeft gesproken over de medische behandeling die toegepast zou moeten worden tijdens de laatste fase van hun leven en nauwelijks 1.8% van de bevolking geeft aan over een schriftelijke wilsverklaring inzake euthanasie te beschikken. Vooral ouderen (12% van de personen van 75 jaar en ouder) hebben het ooit met hun arts gehad over de medische behandelingen aan het levenseinde; bij jongeren is dit percentage verwaarloosbaar. Hetzelfde geldt voor het beschikken over een schriftelijke voorafgaande wilsverklaring inzake euthanasie; pas vanaf de leeftijd van 55 jaar is deze praktijk iets meer courant. Vrouwen, oudere respondenten, mensen met een slechtere gezondheidsstatus en respondenten met veel huisartscontacten hebben een statistisch significant hogere kans om ooit met hun arts gesproken te hebben over medische behandelingen aan het levenseinde. Wat een voorafgaande wilsverklaring inzake euthanasia betreft, is de kans groter dat respondenten ouder dan 55 jaar en inwoners van het Vlaams of Brussels gewest hierover te beschikken.

Informatievoorkeuren van de algemene bevolking in geval van een levensbedreigende ziekte (hoofdstuk 2)

Aan de hand van de gegevens van de nationale gezondheidsenquête uit 2008 werd nagegaan wat de informatievoorkeuren van de algemene bevolking in België zijn indien men geconfronteerd zou worden met een levensbedreigende aandoening, of levensbedreigend ziek zou worden. In deze studie namen in totaal 9651 respondenten deel.

De resultaten tonen aan dat een meerderheid van de Belgische bevolking altijd geïnformeerd wil worden door de arts indien een levensbedreigend ziek zou vastgesteld worden. Ongeveer 82% wil altijd geïnformeerd worden over de diagnose, de kans op genezing en mogelijke behandelingen, terwijl 77% van de respondenten altijd geïnformeerd wil worden over de levensverwachting. Uit de resultaten blijkt tevens dat 72% altijd geïnformeerd wil worden over de opties op het vlak van palliatieve zorg en 67% over de mogelijkheden van verlenging of verkorting van het leven. Een andere belangrijke bevinding is dat maar ongeveer de helft van de respondenten wenst dat hun naasten altijd geïnformeerd zouden worden over diagnose, kans op genezing, mogelijke behandelingen,

levensverwachting, opties op het vlak van palliatieve zorg en mogelijkheden om het leven te verlengen of te verkorten.

Vooraf jongvolwassenen (jonger dan 54), mensen met een hoger opleidingsniveau en mensen met een vaste huisarts hebben een significant hogere kans om zelf altijd informatie te wensen van hun arts wanneer ze levensbedreigend ziek zouden worden. Jongvolwassenen en vrouwen hebben minder kans om hun naasten altijd te informeren in het geval van een levensbedreigende ziekte.

Drempels en faciliterende factoren voor huisartsen bij het ter sprake brengen van voorafgaande zorgplanning: een systematisch literatuuronderzoek (hoofdstuk 3)

In de hierbij besproken studie werd de internationale literatuur nageplozen op de factoren die huisartsen als een drempel of als faciliterend ervaren wanneer ze het gesprek over VZP willen aangaan. Op basis van 16 artikels identificeerden de auteurs drempels en faciliterende factoren op het vlak van (1) kenmerken van de huisartsen, (2) kenmerken van de patiënt of (3) kenmerken van het gezondheidssysteem. Sterke evidentie werd gevonden voor volgende drempels bij huisartsen om VZP te bespreken: een gebrek aan vaardigheden om met vage wensen en voorkeuren om te gaan, het moeilijk kunnen bepalen van het juiste moment om VZP aan te snijden, het idee dat patiënten zelf over VZP moeten beginnen en de angst om patiënten hoop te ontnemen. Faciliterende aspecten met sterke evidentie waren opgebouwde communicatievaardigheden m.b.t. VZP-gesprekken, de bekwaamheid om toekomstige gezondheidsproblemen in te schatten, vaardigheden om in te gaan op het initiatief van de patiënt inzake VZP, wilsbekwame patiënten, een lange relatie met de patiënt en een thuissetting. Voor faciliterende factoren en drempels met een matige tot zwakke evidentie verwijzen we naar het volledige artikel in dit proefschrift.

Drempels voor voorafgaande zorgplanning bij patiënten met kanker, hartfalen en dementie: ervaringen en visies van huisartsen (hoofdstuk 4)

Om zicht te krijgen op de drempels bij huisartsen en hoe deze mogelijk verschillen naargelang het ziekte-traject (m.n. kanker, dementie of hartfalen) werden in Vlaanderen 5 focusgroepen (n= 9, n= 11, n= 4, n= 5, n= 7) met huisartsen samengesteld. Huisartsen rapporteerden verscheidene drempels om VZP op te starten en brachten die in verband met zichzelf (bv. gebrek aan opleiding in VZP), kenmerken van de patiënt en zijn familie (bv. veranderende voorkeuren van de patiënt m.b.t. levenseindezorg) en de structuur en organisatie van de gezondheidszorg (bv. gebrek aan tijd om VZP te bespreken in de huisartsenpraktijk) (voor de gedetailleerde opsomming verwijzen we naar de originele paper). Sommige van de drempels waren specifiek voor een van de drie ziekte-trajecten. Bij kankerpatiënten gaven huisartsen aan dat onvoldoende kennis van behandelingsopties en het gebrek aan structurele samenwerking tussen huisarts en specialist belangrijke drempels vormden. Drempels die vaker voorkwamen bij patiënten met hartfalen en dementie bleken een te geringe vertrouwdheid met de terminale fase, het ontbreken van sleutelmomenten om VZP op te starten, te weinig kennis bij

de patiënt over zijn diagnose en prognose en het feit dat deze patiënten niet vaak zelf dergelijke gesprekken begonnen. Een specifieke drempel om bij dementiepatiënten over VZP te praten, was het feit dat deze patiënten hierover in de toekomst zelf geen beslissing meer zouden kunnen nemen.

Hoe wordt voorafgaande zorgplanning geconceptualiseerd door huisartsen in de praktijk? Een kwalitatieve studie (hoofdstuk 5)

Aan de hand van vijf focusgroepen met huisartsen gingen we na op welke manier huisartsen voorafgaande zorgplanning (VZP) conceptualiseren, op basis van hun ervaringen in de praktijk. Deze conceptualisaties konden ingedeeld worden in vijf thema's: (1) de organisatie van professionele zorg die nodig is om tegemoet te komen aan de noden van de patiënt, (2) het slecht-nieuwsgesprek, (3) keuzes van behandeling en zorgdoelen voor de patiënt, (4) invullen van VZP documenten met betrekking tot voorkeuren en wensen van de patiënt, (5) het exploreren en begrijpen van de wensen van de patiënt.

Binnen deze thema's werd VZP zowel geconceptualiseerd in termen van inhoud van VZP als in termen van taken voor de huisarts. Binnen de organisatie van de zorg om tegemoet te komen aan veranderende zorgnoden van patiënt en familie zagen huisartsen twee belangrijke taken voor zichzelf. Enerzijds de communicatie en het overleg met informele zorgverleners zoals de familie en mantelzorgers van de patiënt en anderzijds de samenwerking en communicatie met andere professionele zorgverleners zoals specialisten, thuisverpleegkundigen of verpleegkundigen van de palliatieve thuiszorgequipes. Bij het voeren van slecht-nieuwsgesprekken werd het inlichten van de patiënt over opties op het vlak van palliatieve zorg ook als een belangrijke taak voor de huisarts vermeld. Huisartsen worden in de praktijk ook vaak geconfronteerd met patiënten die een wilsverklaring (meestal een voorafgaande wilsverklaring inzake euthanasie) hebben ingevuld (of patiënten die van plan zijn om deze in te vullen). Volgens de huisartsen bestaan er echter veel misverstanden bij patiënten over wilsverklaringen en de meeste huisartsen beschouwden het dan ook als een belangrijke taak om patiënten hierover goed te informeren. Tenslotte waren een aantal artsen ook van mening dat het een belangrijke taak was voor de huisarts om VZP zelf te initiëren. Andere huisartsen waren eerder van mening dat de patiënt het initiatief hiervoor moet nemen, maar dat huisartsen wel de taak hebben om steeds goed te luisteren naar signalen van de patiënt en hierop in te gaan. Een belangrijke bevinding in deze studie is dat de verschillende conceptualisering van VZP bij sommige huisartsen allemaal aan bod kwamen bij het beschrijven van VZP in hun praktijk. Maar sommige huisartsen gebruikten slechts een van de conceptualisering om hun praktijk te beschrijven.

De ontwikkeling van een complexe interventie om de initiatie van voorafgaande zorgplanning in de huisartsenpraktijk te verbeteren: een Fase 0-I studie (hoofdstuk 6)

VZP is een complex proces dat gaat over meer dan een interventie of een moment. Een complexe interventie is dan ook aangewezen om VZP structureel te verbeteren in de huisartsenpraktijk. In deze

Fase 0-I studie werd een complexe interventie ontwikkeld om de initiatie van VZP in de huisartsenpraktijk te verbeteren voor patiënten met een ernstige of levensbedreigende aandoening. In Fase 0 werden relevante theorieën en mogelijke componenten van de interventie geëxploreerd. Fase 0 werd uitgevoerd op basis van 3 verschillende methoden: 1) ten eerste werd een overzicht van systematische literatuurstudies over interventies om VZP te bevorderen opgesteld met als doel de belangrijkste componenten van succesvolle interventies te identificeren. De gemeenschappelijke componenten van succesvolle VZP interventies betreffen getrainde facilitators voor het voeren van de VZP-gesprekken, een specifieke doelgroep die aanmerking komt voor VZP, het gebruik van tools zoals bv. brochures, gestructureerde gesprekken, de mogelijkheid tot het invullen van documenten. 2) ten tweede werd een systematische literatuurstudie over de drempels en bevorderende factoren voor huisartsen om VZP op te starten uitgevoerd met als doel de relevante factoren te begrijpen die het ter sprake brengen van VZP voor huisartsen bevorderen of faciliteren en waar rekening mee moet worden gehouden in de interventie (de resultaten van deze studie staan beschreven in hoofdstuk 3 van dit proefschrift), 3) ten derde werden 5 focusgroepen met huisartsen uit verschillende regio's in Vlaanderen georganiseerd om te peilen naar hun ervaringen, opvattingen en bezorgdheden met betrekking tot VZP in de dagelijkse praktijk, met het oog op het verder afbakenen van de belangrijkste componenten die moeten opgenomen worden in de interventie. Vervolgens werd in Fase I de interventie gemodelleerd voor de huisartsenpraktijk door het selecteren van de belangrijkste componenten van de interventie op basis van Fase 0. Een eerste ontwerp van de interventie werd vervolgens voorgelegd aan een expertenpanel om de verschillende componenten, de haalbaarheid en de aanvaardbaarheid van de interventie te beoordelen.

De uiteindelijk ontwikkelde interventie om de initiatie van VZP te verbeteren in de huisartsenpraktijk bestaat uit vijf componenten: 1) een interactieve training voor huisartsen, 2) een register van patiënten die in aanmerking komen voor VZP, 3) een patiëntenbrochure over VZP bestaande uit educatieve informatie en een gerichte vragenlijst, 4) een gesprekshandleiding voor de huisarts, 5) formulieren voor het documenteren van het overleg tussen de patiënt en de huisarts.

Bespreking van de resultaten

De deelname van de algemene bevolking in VZP

De resultaten in hoofdstuk 1 tonen aan dat slechts een klein percentage van de algemene bevolking ooit heeft gesproken met een arts over hun wensen voor medische behandelingen aan het levenseinde (hoofdstuk 1). Een gelijkaardige studie in Nederland toonde aan dat ongeveer 13% van de algemene bevolking met een arts heeft gesproken over de medische besluitvorming aan het levenseinde, dit in tegenstelling tot 4.4% in België. Deze cijfers suggereren dat de betrokkenheid van de Belgische bevolking in VZP nog verder gestimuleerd kan worden. VZP wordt steeds meer gezien als een publiek

domein van volksgezondheid omwille van de potentiële gezondheidsvoordelen zoals het voorkomen van onnodige hospitalisaties aan het levenseinde, een betere overeenstemming tussen de wensen van de patiënt en de effectief verkregen zorg aan het levenseinde en grotere tevredenheid bij patiënt en naasten. Het is dus belangrijk om het bewustzijn bij de algemene bevolking te verhogen omtrent het tijdig communiceren van hun wensen en voorkeuren m.b.t. toekomstige zorg voor het geval patiënten in een situatie komen waarin ze hun wil niet meer kunnen uiten. Hierbij kan gedacht worden aan publieke voorlichtingscampagnes zoals het Speak Up-initiatief in Canada of de Dying Matters-campagne in het Verenigd Koninkrijk. Onze studie toonde aan dat van diegenen die beschikken over een voorafgaande wilsverklaring inzake euthanasie, slechts de helft ooit met een arts had gesproken over de medische behandelingen die ze wensen aan het levenseinde. Een belangrijke reden hiervoor is dat het voor patiënten niet verplicht is om een wilsverklaring op te stellen, te bespreken of te laten ondertekenen door een arts. Een recente gepubliceerde studie over ACP in de eerstelijnszorg toonde nochtans aan dat artsen een wilsverklaring beschouwen als een bruikbaar instrument om verdere communicatie te stimuleren tussen arts, patiënt en hun naasten. Idealiter zou het opstellen van een wilsverklaring gekaderd worden binnen een continu proces van communicatie en overleg, waarbij het opstellen van een wilsverklaring de mogelijke uitkomst is. Studies hebben reeds aangetoond dat de bereidheid van artsen om een wilsverklaring te volgen ook groter is naarmate de wilsverklaring gekoppeld was aan gesprekken tussen de arts en patiënt.

Informatievoorkeuren van de Belgische bevolking

De resultaten van Hoofdstuk 2 tonen aan dat een overweldigende meerderheid van de bevolking wenst dat de arts hun medische informatie verstrekt in geval ze met een levensbedreigende ziekte geconfronteerd zouden worden. Deze resultaten kunnen enerzijds geïnterpreteerd worden binnen de context van het toegenomen maatschappelijk belang van autonomie van de patiënt en patiëntendeelname in de medische besluitvorming, maar anderzijds ook binnen de context van het publieke open debat in België over levenseindebeslissingen veroorzaakt door de legalisering van euthanasie sinds 2002. De Belgische bevolking wordt regelmatig geconfronteerd met berichten in de media over euthanasie (en andere levenseindebeslissingen), wat de publieke voorkeuren om geïnformeerd te worden over deze onderwerpen misschien ook wel beïnvloed heeft. Voorgaande studies toonden reeds een opvallend hoge publieke aanvaarding van euthanasie aan in een aantal West-Europese landen. Deze hoge aanvaardingsgraad was steeds sterk gerelateerd aan de overtuiging van het recht op zelfbeschikking; dit geldt ook in de drie landen waar euthanasie reeds gelegaliseerd is (België, Nederland en Luxemburg). Deze studie toont aan dat, als onderdeel van een patiëntgerichte aanpak, artsen er goed aan doen om de specifieke informatievoorkeuren (ook steeds per onderwerp) van patiënten op voorhand te bevragen. Het exploreren van de informatievoorkeuren van de patiënt is een van de eerste elementen die aangekaart zouden moeten worden binnen het proces van VZP.

Drempels en faciliterende factoren voor huisartsen om VZP ter sprake te brengen

In hoofdstuk 3 werd in de resultaten terug gevonden dat zowel de attitude van huisartsen die van mening zijn dat patiënten zelf VZP ter sprake moeten brengen ervaren wordt als drempel, als voor het feit dat huisartsen het initiatief van de patiënt zelf inzake VZP ervaren als een faciliterend aspect. Dit is een opmerkelijk resultaat aangezien veel studies aantonen dat patiënten ervan uitgaan dat het de verantwoordelijkheid is van artsen om VZP ter sprake te brengen. Dit suggereert dat er een onevenwicht is tussen de verwachtingen van patiënten en van artsen over wie VZP best initieert. Dit verschil in verwachtingen werd in eerdere studies beschreven en kan mogelijk verklaren waarom gesprekken over VZP vaak pas laattijdig worden opgestart wanneer levenseindebeslissingen effectief moeten genomen worden.

Nog een opmerkelijk resultaat is dat volgens huisartsen patiënten met kanker sneller betrokken worden in VZP. Het ziekteverloop van patiënten kent een meer voorspelbaar verloop, waardoor het voor artsen makkelijker is om een goed moment te bepalen om VZP ter sprake te brengen (Hoofdstuk 4). De focusgroepstudie toonde ook aan dat een van de redenen waarom VZP niet werd geïnitieerd bij bijvoorbeeld patiënten die lijden aan hartfalen of dementie precies het onbegrip is bij zowel patiënten als artsen dat deze aandoening een levensbedreigende aandoening zijn. Het is ook zo dat niet-kankerpatiënten omwille van een slecht begrip van de diagnose en de prognose zelf minder vaak VZP ter sprake brengen, wat een drempel is voor huisartsen. Artsen en patiënten zijn het erover eens dat VZP best ter sprake wordt gebracht rond het tijdstip van de diagnose van een levensbedreigende ziekte, maar de angst om patiënten hoop te ontnemen houdt artsen vaak tegen (zeker bij dementiepatiënten); een drempel waarvoor ook in de systematische literatuurstudie sterkere evidentie werd teruggevonden.

Toch tonen de bevindingen van dit proefschrift aan dat het niet initiëren van VZP meer complex is dan een gebrek aan vaardigheden of kennis over VZP bij de huisarts (hoofdstuk 5). Structurele of organisatorische factoren, zoals het gebrek aan een systeem in België om informatie overheen de verschillende zorgsettings te delen en de soms beperkte samenwerking tussen de eerste- en tweedelijnszorg, spelen ook een belangrijke rol. Zo werd een financiële compensatie voor de huisarts voor het voeren van VZP-gesprekken ook aangehaald als een structurele verandering die de initiatie van VZP zou kunnen stimuleren. Opdat VZP optimaal, goed en effectief geïmplementeerd kan worden, is het dus noodzakelijk voldoende aandacht te besteden aan het verbeteren van factoren zowel op het niveau van de huisarts, de patiënt als het gezondheidszorgsysteem (en niet enkel te investeren in bv. een opleiding voor artsen).

De ontwikkeling van een VZP interventie voor de huisartsenpraktijk

Met het ontwikkelen van een complexe interventie om de initiatie van VZP in de huisartsenpraktijk te verbeteren, hopen we op termijn bij te dragen tot de verbetering van de communicatie tussen huisartsen en patiënten, de kwaliteit van leven en het welzijn van patiënten en hun familie en een

verbeterde overeenkomst tussen de wensen van de patiënt en de verkregen zorg aan het levenseinde, alsook de tevredenheid van de patiënt en zijn naasten te verhogen. Onderzoek heeft aangetoond dat interventies (of aanpassingen) op verschillende niveaus van het gezondheidszorgsysteem nodig zijn om VZP succesvol in de praktijk te implementeren. Dit houdt concreet in 1) dat patiënten die in aanmerking komen voor VZP of hier nood aan hebben, tijdig uitgenodigd worden voor deze gesprekken, 2) dat deze patiënten tijdens deze gesprekken bijgestaan kunnen worden door competente en opgeleide zorgverleners met voldoende kennis en de juiste communicatievaardigheden en 3) dat de uitkomsten van deze gesprekken gedocumenteerd en gedeeld kunnen worden (bv. door middel van een elektronisch patiëntendossier). Recent onderzoek toonde ook aan dat de gemeenschappelijke elementen van succesvolle VZP-programma's de volgende zijn: VZP-gesprekken geïnitieerd door de arts, gestandaardiseerde documenten om het resultaat van VZP-gesprekken te documenteren, een correcte timing van deze gesprekken (afhankelijk van de individuele bereidheid van patiënten) en het implementeren van systemen die ervoor zorgen dat de planning uitgevoerd kan worden, dat het VZP programma geëvalueerd kan worden en dat daardoor aan kwaliteitsverbetering wordt gedaan. Andere veelbelovende elementen van succesvolle VZP-programma's zijn het gebruik van eenvoudig te begrijpen educatief materiaal voor patiënten, interactieve communicatietrainingen voor artsen en het organiseren van meerdere gesprekken doorheen het ziekteverloop van de patiënt. Deze elementen werden geïntegreerd in de ontwikkeling van onze VZP-interventie voor de huisartsenpraktijk. Toekomstig onderzoek moet er zich nu op richten om de haalbaarheid en aanvaardbaarheid van de componenten van deze complexe interventie te testen in een Fase II pilotstudie.

Appendix I

Detailed description of the intervention's components

Component 1: A training program for GPs (A)

Content of the component to overcome the barriers and enhance the facilitators:

- Prior to the training, participants will receive reading materials to ensure baseline knowledge on ACP and the relevant law and to limit the time of the training
- The training consists of information provision, case studies addressing the identified barriers to initiating ACP, facilitated group discussion and video demonstration of how to conduct ACP discussions and how to incorporate the initiation of ACP into standard consultations, and role play exercises with feedback from an expert instructor to practice the taught skills, which have been shown to be the best strategies to improve communication skills
- GPs will learn about the key elements that should be addressed with patients, including exploring prognostic understanding and acceptance of diagnosis and providing patients with information about prognosis to the degree desired by the patient
- Instructions are provided for GPs during the training to collect all information regarding the patient's health status and treatment options, and to contact other health care professionals when necessary for this.
- Training will be led by an expert instructor
- After the training sessions, GPs will be able to practice their skills at home through e-simulation exercises with fictive patients

Barriers and facilitators that are addressed by the component:

- Lack of skills, knowledge about ACP and confidence to discussions
- Lack of awareness about the different elements of ACP
- Lack of knowledge about decision-making capacity legislation
- Recognizing the relevance of ACP
- Positive attitudes towards anticipating future scenarios and initiating ACP
- Patients' denial and lack of awareness about prognosis
- Lack of adequate communication between GPs and the multiple clinicians involved in the patient's care

The training session were originally based on a two hour educational programme about ACP specifically developed for GPs that has been shown to improve their confidence and ability to undertake ACP conversations with patients. It includes active, practice-oriented strategies such as role-play exercises, feedback, the use of video role modelling, group discussions and feedback during the session as these are educational strategies which have shown to be most effective in improving communication skills. Pre-reading material and information provision will also be a part of the training programme as lack of knowledge about

the potentially positive outcomes of ACP and about its legal implications were identified as important barriers. A previous study also showed that improved clinician knowledge about decision-making capacity legislation positively correlated with ACP participation. The experts perceived two hours as too short to complete all training elements and recommended spreading the training over two sessions which would permit reinforcement and allow for home work exercises in between.

Component 2: Establishing a register of patients eligible for ACP discussions (B)

Content of the component to overcome the barriers and enhance the facilitators:

- Systematic and selective identification of patients at risk of deteriorating or dying will be done using a pragmatic three-step guide of triggers for when to initiate ACP
- During the training, GPs will be taught how to identify eligible patients using these triggers and to set up an ACP register, which is a constantly updated list of patients for whom ACP should be initiated at upcoming appointments

Barriers and facilitators that are addressed by the component:

- Most GPs in the focus groups considered patients suffering from a life-limiting illness to be most eligible for initiating ACP with
- Difficulties with defining a key moment to initiate ACP
- Cancer patients are more easily involved in ACP as opposed to non-cancer patients (eg dementia, advanced organ failure, etc)

It was considered important to standardize the timing of ACP discussions to support GPs in defining a key moment and prompting them to initiate ACP discussions. While the timing of ACP must be sensitive to patients' readiness to enter into such conversations, a pragmatic three-step guide that has been proposed in the literature for physicians is to consider ACP if: (a) No is the answer to the surprise question "Would you be surprised if this patient died within the next year?", (b) the patient's general health is poor (eg limitations in self-care or multiple hospitalizations), and (c) if disease-specific indicators indicate a poor prognosis (eg advanced organ failure, dementia, progressive malignancies). Identified eligible patients will be documented in a register. These patients should be invited to consider ACP.

Component 3: Educational booklet about ACP for patients (C)

Content of the component to overcome the barriers and enhance the facilitators:

- The goal of an educational booklet is to provide patients with appropriate information on ACP in advance and to prepare them for a patient-centred discussion adapted to their individual information needs
- This educational booklet includes a prompt list
- Patients are encouraged to reflect on and clarify their wishes together with their relatives through discussion

Barriers and facilitators that are addressed by the component:

- Patients' lack of understanding regarding ACP
- Patients are prepared to participate in ACP

To overcome the patient-related barriers to GPs in initiating ACP, an educational booklet for assisting patients and their caregivers and improving their knowledge about ACP was considered helpful to increase patient and family engagement. This booklet was based on an already existing booklet 'Planning your future care' developed by the University of Nottingham and published by the NHS as part of the Dying Matters campaign in the UK, which was also deemed suitable by the expert panels as it includes general information on ACP and a section on the role of GPs in the process of ACP. However, most experts considered this booklet as too long and suggested to shorten it and slightly adapt its content to our target group of patients. A prompt list was also included as research showed that a prompt list helped patients to ask questions about prognosis and end-of-life care, and discuss more issues covered by the question prompt list with their physician. The educational booklet would be given to patients during a routine visit and would facilitate subsequent patient-centred ACP discussions.

Component 4: Patient-centred ACP discussions with the help of a conversation guide (D)

Content of the component to overcome the barriers and enhance the facilitators:

- The conversation guide includes the following topics: understanding of prognosis, information preferences, prognostic information, patient's previous experiences with ACP, patient goals and quality of life, fears, acceptable function, family involvement and contains examples of questions and communication tips

Barriers and facilitators that are addressed by the component:

- Lack of awareness about the different elements of ACP
- Varying conceptualisations of ACP among GPs

A conversation guide was developed to support GPs and to assure a better uptake of all the key elements of ACP discussions. A draft was made based of a conversation guide for communication about serious illness care goals that was developed on the basis of a review and synthesis of best practice and afterwards validated in the expert panels. The key elements addressed in the conversation guide are: 1) understanding of prognosis, 2) decision making and information preferences, 3) prognostic disclosure, 4) patient goals and quality of life, 5) fears, 6) level of functioning acceptable to the patient, 7) trade-offs that might be necessary to achieve different outcomes and 8) family involvement/choosing an appropriate surrogate decision-maker. The experts suggested shortening the conversation guide to a one-page topic list. Most experts found a structured conversation guide useful to assure the completion of key steps in the conversations, but emphasized that it should be made clear in the training sessions that the conversation guide should not be used as a checklist or static script.

Component 5: A structured template for documenting the outcomes of the ACP discussions (E)

Content of the component to overcome the barriers and enhance the facilitators:

- A structured template will provide the opportunity for recording patient preferences, values and goals of care
- Instructions are provided for GPs during the training to communicate this document to other involved health care professionals (with patient permission). These instructions are also included on the templates.
- Patients are encouraged by the GP to make this document available for other care providers

Barriers and facilitators that are addressed by the component:

- Difficulties in sharing information across the health care system when patients are cared for by (multiple) specialists
- Uncertainty regarding the transferability of ACP information as there is no consistent standard for location

Documentation templates were developed that are standardised, simple and patient-friendly and allow the opportunity to record and document the outcomes of ACP conversations. In the expert panels consensus was reached that the document should be complementary to an AD and record key information such as the patient's values and goals, quality of life, fears and anxieties, etc. to help guide complex decisions. It was decided that these documentation templates could follow the same structure as the conversation guide. To improve the exchange of information about patient values and goals, instructions are also provided for GPs to communicate these documents to other involved health care professionals with the patient's permission, and patients will be encouraged by the GP to make these documents available to other care providers.

CV & List of publications of Aline De Vleminck

Curriculum Vitae

Aline De Vleminck was born on the 9th of October 1986 in Tienen, Belgium. She studied Sociology at the Vrije Universiteit Brussel (VUB) and obtained her Master's degree in 2010. In 2011, Aline started to work as a junior researcher at the End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel (VUB). Supported by a grant from the Flemish government agency for Innovation by Science and Technology (IWT), Aline conducted research on advance care planning in general practice, supervised by Prof. dr. Robert Vanderstichele, Prof. dr. Luc Deliens, Prof. dr. Koen Pardon and Prof. dr. Dirk Houttekier.

Aline De Vleminck currently works at the End-of-Life Care Research Group as a senior researcher on a follow-up project of this dissertation regarding the initiation of advance care planning in general practice. This project is supported by Kom op Tegen Kanker.

List of Publications

Articles in international peer-reviewed journals

De Vleminck A, Houttekier D, Pardon K, Deschepper R, Van Audenhove C, Vander Stichele R, Deliens L. *Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review*. Scandinavian Journal of Primary Health Care. 2013 Dec;31(4):215-26.

De Vleminck A, Pardon K, Beernaert K, Deschepper R, Houttekier D, Van Audenhove C, Deliens L, Vander Stichele R. *Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences*. PLoS One. 2014 Jan 21;9(1):e84905.

Beernaert K, Deliens L, De Vleminck A, Devroey D, Pardon K, Van den Block L, Cohen J. *Early identification of palliative care needs by family physicians: A qualitative study of barriers and facilitators from the perspective of family physicians, community nurses, and patients*. Palliative Medicine. 2014 Feb 17;28(6):480-490.

De Vleminck A, Pardon K, Roelands M, Houttekier D, Van den Block L, Vander Stichele R, Deliens L. *Information preferences of the general population when faced with life-limiting illness*. European Journal of Public Health. 2015 Jun;25(3):532-8.

Beernaert K, Deliens L, De Vleminck A, Devroey D, Pardon K, Van den Block L, Cohen J. *Is There a Need for Early Palliative Care in Patients With Life-Limiting Illnesses? Interview Study With Patients About Experienced Care Needs From Diagnosis Onward*. American Journal of Hospice and Palliative Care. 2015. [Epub ahead of print]

Vleminck A, Pardon K, Houttekier D, Van den Block L, Vander Stichele R, Deliens L. *The prevalence in the general population of advance directives on euthanasia and discussion of end-of-life wishes: a nationwide survey*. Submitted

De Vleminck A, Pardon K, Beernaert K, Houttekier D, Vander Stichele R, Deliens L. *How do general practitioners conceptualise advance care planning in their practice? A qualitative study*. Submitted

De Vleminck A, Houttekier D, Deliens L, Vander Stichele R, Pardon K. *Development of a complex intervention to support the initiation of advance care planning by general practitioners: a phase 0-I study*. Submitted

Articles in national journals

De Vleminck A, Houttekier D, Pardon K, Deschepper R, Van Audenhove C, Vander Stichele R, Deliëns L. *Drempels en faciliterende factoren voor huisartsen bij het ter sprake brengen van voorafgaande zorgplanning: een systematisch literatuuronderzoek*. Nederlands-Vlaams Tijdschrift voor Palliatieve Zorg, 2015; 14 (1): 13-29.

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Book chapters

De Vleminck A & Pardon K. 2015. *Voorafgaande zorgplanning in de thuissituatie*. In: Cohen J, Smets T, Pardon K, Deliëns L. Palliatieve zorg, meer dan stervensbegeleiding. Nood aan integratie en verbetering. Leuven, Lannoo, 232p.

De Vleminck A & Deliëns L. 2015. *Advance Care Planning for older people*. In: Oxford Textbook of Geriatric Medicine, 3rd edition, Chapter 162. (in print)

Presentations at international and national conferences

Improving advance care planning in primary care: a research design for the development of a complex intervention, 7th World Research Congress of the European Association Palliative Care (EAPC) 2012 – 31 May-2 June 2012, Trondheim, Norway (poster presentation)

Improving advance care planning in primary care: a research design for the development of a complex intervention, 2nd International Collaboration on End-of-life Care Research-day – 20 September 2012, VUmc, Amsterdam, The Netherlands (poster presentation)

Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review, 2nd International Seminar Palliative Care Research Centre & EAPC Research Network, 18-19 October 2012, Ghent, Belgium (poster presentation)

Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review, First Care Congress of the FLIECE Consortium [Eerste FLIECE- zorgcongres – zorgen voor morgen? Goede palliatieve zorg in woonzorgcentra begint vandaag!] (18 April 2013, Leuven, Belgium) (poster presentation)

Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review, the 8th World Research Congress of the EAPC 2013 – 20 May-2 June 2013, Prague, Czech Republic (poster presentation)

Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review, 3th International Collaboration of End-of-life Care Research-day, 13 November 2013, Erasmus MC, Rotterdam, The Netherlands (oral presentation)

Improving the initiation of ACP in general practice: the development of a complex intervention, pre-congress seminar organized by the European Palliative Care Research Centre (PRC) and the European Association for Palliative Care Research Network (EAPC RN), 2-3 June 2014, Lleida, Spain. (oral presentation, presented by Dirk Houttekier)

Barriers to advance care planning in cancer, heart failure and dementia patients: A focus group study on general practitioners' views and experiences, 8th World Research Congress of the EAPC 2014, 5-7 June 2014, Lleida, Spain. (poster presentation, presented by Koen Pardon)

Barriers to advance care planning in cancer, heart failure and dementia patients: A focus group study on family physicians' views and experiences, 20th International Congress on Palliative Care, Montreal, Canada. 9-12 September, 2014. (oral presentation)

Barriers to advance care planning in cancer, heart failure and dementia patients: A focus group study on general practitioners' views and experiences, 20th International Congress on Palliative Care 2014, 9-12 September 2014, Montreal, Canada (poster presentation)

Barriers to advance care planning in cancer, heart failure and dementia patients: A focus group study on family physicians' views and experiences, 12th International Conference on Communication in Healthcare (ICCH) , Amsterdam, the Netherlands. September 28 – October 1, 2014. (oral presentation)

Early identification of palliative care needs by family physicians: a qualitative study of barriers and facilitators from the perspective of family physicians, community nurses and patients, 12th International Conference on Communication in Healthcare (ICCH), Amsterdam, the Netherlands. September 28 – October 1, 2014. (oral presentation, presented for Kim Beernaert)

Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review, 12th International Conference on Communication in Healthcare (ICCH) September 28, 2014 - October 1, 2014, Amsterdam, The Netherlands. (poster presentation)

Early identification or palliative care needs by the family physician, 12th International Conference on Communication in Healthcare (ICCH) September 28, 2014 - October 1, 2014, Amsterdam, the Netherlands. (oral presentation)

Verbeteren van Vroegtijdige Zorgplanning in de eerstelijnszorg, Vlaams congres voor Palliatieve Zorg Rouw in zicht? Inzicht in rouw! September 23, 2014, Turnhout, Belgium. (oral presentation)

Tijdig starten van palliatieve zorg en voorafgaande zorgplanning in de thuissetting, FLIECE congres 'Hoe de palliatieve zorg verbeteren in Vlaanderen', January 29 & 30 in Brussels, Belgium. (oral presentation)

How do general practitioners conceptualise advance care planning in their practice? A qualitative study, 5th International Conference on Advance Care Planning and End of Life Care in Munich, Germany, from September 9-12, 2015 (oral presentation, presented by Luc Deliens)