END-OF-LIFE CARE IN BELGIUM

A NATIONWIDE STUDY
VIA THE REPRESENTATIVE SENTINEL NETWORK
OF GENERAL PRACTITIONERS

KOEN MEEUSSEN

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DOCTORAL DISSERTATION

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CHAPTER 2

Meeussen K, Van den Block L, Echteld M, Boffin N, Bilsen J, Van Casteren V, Abarshi E, Donker G, Onwuteaka-Philipsen B, Deliens L. End-of-life care and circumstances of death in patients dying of cancer in Belgium and the Netherlands. A nationwide retrospective study. (submitted)

CHAPTER 3

Meeussen K, Van den Block L, Echteld M, Boffin N, Bilsen J, Van Casteren V, Deliens L. Older people dying with dementia: a nationwide study. (submitted)

CHAPTER 4

Meeussen K, Van den Block L, Echteld M, Bossuyt N, Bilsen J, Van Casteren V, Abarshi E, Donker G, Onwuteaka-Philipsen B, Deliens L. Advance care planning in Belgium and the Netherlands: a nationwide retrospective study via sentinel networks of general practitioners. Journal of Pain and Symptom Management (accepted for publication).

CHAPTER 5

Meeussen K, Van den Block L, Bossuyt N, Bilsen J, Echteld M, Van Casteren V, Deliens L. GPs' awareness of patients' preference for place of death. British Journal of General Practice 2009;566(59):665-670.

CHAPTER 6

Meeussen K, Van den Block L, Bossuyt N, Echteld M, Bilsen J, Deliens L. Dealing with requests for euthanasia. Interview study among general practitioners in Belgium. Journal of Pain and Symptom Management (accepted for publication).

CHAPTER 7

Meeussen K, Van den Block L, Bossuyt N, Echteld M, Bilsen J, Deliens L. Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium. BMC Public Health 2010;10(186).

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PART I

INTRODUCTION
&
RESEARCH
QUESTIONS

CHAPTER 1:
INTRODUCTION AND RESEARCH QUESTIONS

APPROACHING DEATH: A TOPIC OF GROWING INTEREST

INTRODUCTION

Death and dying is of all time and ever will be. Eventually, it will happen to all of us although in different moments, places, and circumstances. Epidemiologic shifts in mortality and developments in demography and medicine have led to a sharp rise in the attention being paid to end-of-life care as an important clinical and public health concern. Without doubt it will remain one of the major and urgent societal challenges of the 21st century [1;2].

Nationwide insights into how people die within a country can provide valuable information for policy makers in pursuit of better end-of-life care for everyone. This dissertation hopes to make a contribution by giving a broad overview of important aspects of quality of care at the end of a patient's life in Belgium. Some of these aspects will be studied in more depth than others, and special attention is given to vulnerable patient groups and far-reaching medical end-of-life practices.
At some points, we will simultaneously gather data on the end-of-life care received by patients dying in the Netherlands. Cross-national research studying differences between health care systems, and estimating their impact on the care provided could contribute to a better understanding and improvement of how patients are cared for in our country.

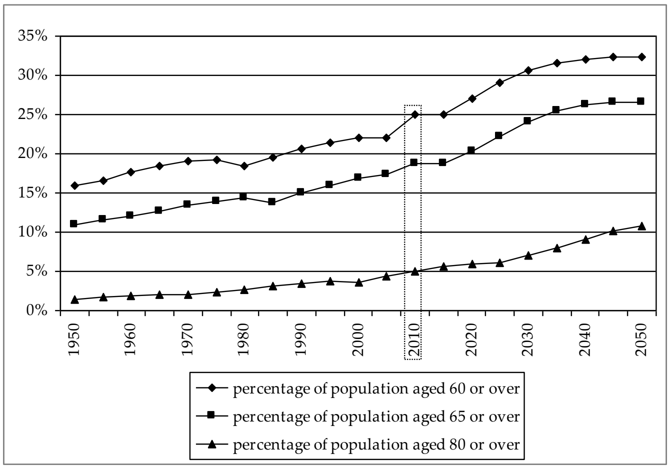
The following paragraphs will provide some background and guide the reader towards the aims of this dissertation. Firstly, the value of palliative care is described in broad outline. Secondly, we will pay attention to the need for nationwide research in end-of-life care. Thirdly, several important domains in measuring quality of end-of-life care are described. Fourthly, we will focus on the specific vulnerable groups and exceptional medical practices in which some of these domains will be studied.

In a subsequent part the research questions are given, the methodology, study design and setting are discussed, and the outline of this dissertation is specified.

BACKGROUND

Populations are ageing and this phenomenon is global and unprecedented, without parallel in human history. Worldwide the number of persons aged 60 or more has tripled over the last 50 years (1950-2000); it will more than triple again over the next 50 (2000-2050) [3]. According to the United Nations 2008 biennial population forecast, the median age is projected to increase between 2009 and 2050 from 29 to 38 years worldwide and from 40 to 47 years within Europe [4].
In Belgium today, 5% of the population is aged 80 or over, and this is expected to more than double by 2050 (figure 1).

FIGURE 1. DEMOGRAPHIC PROFILE FOR BELGIUM 1950-2050



SOURCE: OWN FIGURE, BASED ON DATA PUBLISHED BY THE POPULATION DIVISION OF THE DEPARTMENT OF ECONOMIC AND SOCIAL AFFAIRS OF THE UNITED NATIONS SECRETARIAT, WORLD POPULATION PROSPECTS: THE 2008 REVISION, HTTP://ESA.UN.ORG/UNPP (ACCESSED 18/08/2010).

As part of population ageing, most of the burden of illness and use of health-care services now falls in the last phase of life, when people generally experience established, serious, eventually fatal chronic illnesses for a few years, such as cancer or cardiovascular disease [5;6]. As a result, about two thirds of all deaths in present Western society do not occur totally unexpectedly [7;8]. Formerly, death was more often caused by acute infectious diseases early in life whereby death was rarely apparent even a week or two beforehand.

As a result, people today often require long-term care at the end of their lives. This care might be aimed at prolonging life as much as possible, which has become a realistic option due to advances in medical knowledge in diagnostics and therapeutic techniques. Alternatively, there is an increasing awareness that care aimed at cure or at the prolongation of life might not always be in the best interests of the patient; quality of life may be considered a priority, even at the expense of survival time. New priorities such as symptom relief, plans and preferences for future care, support of family members and dying with dignity may then come to the fore [1]. This approach had been embodied by a strong development of palliative care as a new discipline within medicine and nursing. Palliative care was defined by the World Health Organization in 2002 as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual [9]. Palliative care strives to achieve, to support, to preserve and to enhance the best possible quality of care and quality of life, determined by each patient individually for themselves [10]. This aim is to be pursued by all organised efforts of society.

THE NEED FOR RESEARCH

It was not until relatively recently that the issue of end-of-life care has achieved a position of great significance in the field of empirical scientific research. This is clearly illustrated by the yearly number of peer reviewed publications on palliative care, which has more than doubled over the last fifteen years (up to 1,774 publications in 2009) . These efforts have been – and are – significantly contributing to a better understanding of the circumstances of people's lives as they approach death. The challenges however remain urgent, and are not just about the demographic characteristics and health conditions of those who die, but also about their quality of care as they cope with declining health, and about the quality of their death.

A fundamental barrier to improving quality of care at the end of life is the lack of information about the current state of end-of-life care among populations [11;12]. Therefore, large-scale population-based nationwide studies are essential to allow us to benchmark where we are today as a society. Thus far, the vast majority of end-of-life research refers to fragmentary aspects of care, to selected groups of patients in terms of diagnosis and care settings, or are limited to relatively small geographical areas.

In Belgium, end-of-life care research is increasingly gaining attention. Recent work has addressed issues like the place of death, medical end-of-life

practices and decision-making in Flanders and Brussels [13-17]. Where nationwide data on the care patients receive in their last phase of life is concerned, research remains relatively scarce [18;19]. These studies have extended our knowledge of – all during the last phase of life – the time spent in different care settings and the number of transitions, hospitalisation rates, the use of multidisciplinary specialist palliative care, and the type and content of care among a terminally ill patient population.
However, there remain several important gaps to bridge in order to develop a broad public health policy on improving end-of-life care in Belgium. The following paragraphs will enter at length into important domains to be studied.

END-OF-LIFE CARE PROVISION AND ITS QUALITY

What constitutes a good death? It may seem unfeasible to answer this question in a general way as every individual is unique and each one brings a set of unique expectations, values, fears and hopes to the care setting [20]. Additionally, one must always take into account the patient's personal and environmental context (eg financial means, diagnosis, severity, history and trajectory of the illness, personal support network, time, space and resource constraints, and cultural influences) within which end-of-life care is received [21;22].

Quality of care for dying patients can be perceived as a more general descriptor of the process of care rather than the intrinsic experience of the patient [23]. Defining key components of what patients, families and health care practitioners view as important at the end of life is considered integral to the success of the improvement of care of dying patients, and may affect the patient's dying experience [24].

Almost two decades ago, the Ethics Committee of the American Geriatrics Society proposed ten main areas in measuring end-of-life care and its quality [25], ie physical and emotional symptoms; support of function and autonomy; advance care planning; aggressiveness of care near death; patient and family satisfaction; global quality of life; family burden; survival time; provider continuity and skill; and bereavement. Over the years, several generic models of care at the end of life have been published internationally [22;24;26-35].

The approach from Stewart, Teno et al. for example concerns an overall conceptual model of factors affecting the quality of life of dying patients and their families in which the following aspects were considered important in the delivery of care: access to care (eg availability of hospice and palliative services); organisation of care (eg time allowed for care); availability of formal support services (eg home care); physical environment of care (eg location of death, transfers); technical process with patient (eg continuity and coordination of care); decision-making process with patient and family (eg preferences, advance care planning); counseling (eg what to expect); and communication style (eg attention to spiritual needs) [22]. These factors can influence, together with the patient's personal and social environment, satisfaction with care (eg preferences honoured) and quality of life (eg physical, psychological, social, spiritual, cognitive functioning and well-being).
Casarett et al. stated that even the most basic administrative data can provide important insights into the quality of end-of-life care within a nation [26]. For instance, death certificate studies can reveal general information on the place of death. Retrospective studies may be suitable to assess pain and symptom management, psychosocial and spiritual well-being, information and communication, decision-making and future planning, continuity of care, family support, financial burden on family, information about palliative care services, availability, and timely access.

On the basis of these models, we identified three main domains in measuring end-of-life care that will be addressed throughout this dissertation (Table 1). In the methodology section of this introduction a detailed overview of the topics inquired within our study is given.

Medical care processes

Firstly, enabling patients to spend the last phase of their life at home until death would meet the wish of many [1;36-38]. There are several indications that dying at home and out-of-hospital may contribute to a more favourable dying experience [33;39], and to cost-saving for both patients and society [40;41]. This does not mean however that hospital admission may not be wanted, needed, or feasible in some cases [42].

Secondly, the provision of palliative care should be initiated early in the disease trajectory and can involve both health care professionals and informal caregivers [1].

TABLE 1. KEY DOMAINS IN MEASURING END-OF-LIFE CARE IN THIS DISSERTATION

I.	MEDICAL CARE PROCESSES
	- Place of care and death
	- Palliative care services (information, availability, use, and timely access)
	- Continuity and co-ordination of care
II.	COMMUNICATION PROCESSES
	- Information and communication with patient and family (concerning all important care and treatment decisions)
	- Advance care planning (including exploration of preferences, planning and advance decision-making with patient and family)
	- Actual decision-making process
III.	DYING PROCESS
	- Physical, psychological, cognitive, spiritual, social, and emotional comfort and functioning
	- End-of-life preferences honoured

During this process, specialist palliative care services may be very supportive. However, recent research shows that less than half of all non-sudden deaths in Belgium received specialist palliative care, and that access to these services is much lower for non-cancer compared to cancer patients [43]. Also, timely referral to specialist palliative care services often failed to occur [44].

Thirdly, terminally ill patients attach great value to relational continuity with their GP [45;46]. Maintaining close contact with the patient when death becomes imminent might be of particular importance in the dying experience. It is believed that high GP involvement is associated with improved end-of-life care and out-of-hospital death [47;48].

Communication processes

From its inception, one of the core values of palliative care has been in enabling people to make genuine choices about their own care, and to provide care that is in accordance with a patient's wishes [2;30]. Whereas only a few decades ago the principle of medical paternalism was highly valued, today more liberal moral attitudes which place value on personal autonomy and self-determination come to the fore [49]. As a result, there is an increasing recognition of the importance of focusing on patient-centered care rather than on the disease itself [49;50].

One way to put patients at the centre of their own care trajectory up to the very end of life is by engaging in a process of continuous communication between patients, their family, and health care providers aimed at exploring end-of-life care preferences and wishes so that they can be taken into account at a future time when the patient has lost capacity [51;52]. This approach is often referred to as ‘advance care planning’ [53].

Dying process

One of the aims of palliative care is to give relief to patients from pain and other distressing symptoms, and to make the last phase of life as comfortable as possible [1]. The failure to attend to a patient’s well-being is often an important indicator of inadequate quality of care that patients receive at the end of life [22]. Notwithstanding the dying process is a highly idiosyncratic experience, insights into the symptom burden of patients at the end of life, the physical and cognitive functioning in the last days before death, and whether or not patients’ advance stated preferences could be honoured, might be indicative of the circumstances of death in a country.

END-OF-LIFE CARE IN CANCER AND DEMENTIA

Two noticeable subpopulations that can be considered potentially eligible for palliative care receive particular attention in studying different aspects of end-of-life care throughout this dissertation.

Dying of cancer

Almost everyone knows someone who has become very sick from or died of cancer. In 2004 in Europe, there were an estimated 2.9 million incident cases of cancer diagnosed and approximately 1.7 million cancer deaths [54]. These figures provide a good indication of the burden of cancer incidence and death throughout Europe.

From the very outset, the management of cancer pain has been conceived as the spearhead for a comprehensive and integrated palliative care approach [49]. Today, the vast majority of patients currently treated in specialist palliative care services suffer from cancer [10]. Notwithstanding the provision of access to high-quality palliative care for non-cancer patients is considered to be a priority of national and European health policy development, there is broad agreement that there is still a great need for further improvement in the provision of good end-of-life care for patients suffering and dying from cancer [55;56]. Nationwide epidemiological data gathered irrespective of care setting or type of cancer might be considered as an important first step.

Dying with dementia

One of the major challenges facing older people all over the world is dementia [57-59]. In present Western society, prevalence figures double about every five years after age 65 and it is expected that in the near future numbers will continue to increase owing to the rapid growth of the oldest age groups, from approximately 1.3 million a year across Europe in 2000 to more than 4 million in 2050 [60-62].
The median length of survival from diagnosis to death in dementia is eight years, and during this time there is a prolonged decline in ability and awareness [2]. At the end, most patients with dementia are not able to communicate their preferences, leaving them at an increased risk of prolonged suffering.

Although there is growing recognition that people with dementia are entitled to appropriate palliative care, end-of-life care often remains suboptimal for these patients and their families [59;63;64]. Large-scale nationwide data – across care settings – mapping out the care delivered at the end of life and the circumstances in which patients with dementia die are lacking, but urgently needed.

END-OF-LIFE CARE: A CLOSER LOOK INTO PREFERENCES, ADVANCE CARE PLANNING AND END-OF-LIFE DECISION-MAKING

This dissertation puts particular focus on the communication processes at the end of life as a key domain in measuring end-of-life care.

A general focus on preferences and advance care planning at the end of life

In Belgium, but also in the Netherlands, the increased emphasis on personal autonomy and patient-centered communication has been reflected in recent legal-political developments not only in a law on patient rights [65;66], but also in a law on euthanasia [67;68], the first two countries worldwide to do this. Organisations like the Belgian Life End Information Forum or the Dutch Association for Voluntary Euthanasia are providing patient-orientated documents for people who want to state their wishes, on euthanasia and other aspects of end-of-life care [69;70]. Initiatives have been undertaken to develop guidelines for health and social care professionals on how best to manage end-of-life communication in clinical practice [71;72], and also healthcare organisations, such as hospitals or care homes, are more frequently outlining their own specific advance care planning (often including euthanasia) policies and conventions, designed to guide doctors and nursing staff in their institutions [73-79].

Little is known however about the prevalence, content and timing of communication at the end of life in Belgium, neither about the patient's preferences for end-of-life care and the caregiver's acquaintance with these preferences, nor about end-of-life agreements made about treatments or medical decision-making. For these issues, our attention goes beyond a specific target group approach and addresses a general population of the dying who can be considered potentially eligible for palliative care.

A particular focus on preferences and decision-making in life-ending medical practices

Prior recent work shows that about half of all deaths in Flanders (Belgium) are preceded by a medical end-of-life practice that possibly or certainly hastened death. Administration of medication use with the explicit intention of ending a patient's life is more exceptional, but does occur in a significant minority though (3.8% of all deaths)[7]. As death is explicitly intended, it goes without saying that the practice of physician-assisted dying is the subject of intense medical, societal, and legal debate. Apart from physician-assisted suicide which hardly ever occurs, two main subcategories can be distinguished, depending on the absence or presence of the patient's explicit request for life to be ended (table 2).

TABLE 2. PREVALENCE OF PHYSICIAN-ASSISTED DEATH, PERCENTAGE OF ALL DEATHS IN 2007, BELGIUM (FLANDERS)

PHYSICIAN-ASSISTED DYING	3.8%
Euthanasia: The administration of drugs with the explicit intention to end life at the explicit request of the patient	1.9%
Physician-assisted suicide: The prescription or supply of drugs with the explicit intention to enable the patient to end his or her own life at the explicit request of the patient	0.07%
Life-ending drug use without the patient's explicit request: The administration of drugs with the explicit intention of hastening the patient's death, without explicit request from the patient	1.8%

Since 2002, the practice of euthanasia is legal in Belgium if practiced under strict conditions of careful practice [67]. Crucial requirements are that the patient is suffering continuously and unbearably without prospect of improvement, and that he or she makes an explicit and repeated request for death to be hastened.

Can euthanasia be part of good palliative care? It may be clear this remains a highly controversial issue [80]. In an official position paper, the European Association for Palliative Care states that ‘the provision of euthanasia should not be part of the responsibility of palliative care’[10]. In Belgium, the Flemish Organisation of Palliative Care carries out a much more balanced judgement, endorsing the view point that pal¬liative care and euthanasia are neither alternatives nor antagonistic [81]. Recently, epidemiological data have reinforced this conclusion, demonstrating that euthanasia is not related to a lower use of palliative care and often occurs within the context of multidisciplinary care [82]. Still, also in Belgium the debate is continuing … [83-85].

Despite a divergence of views on euthanasia as a justifiable medical practice of good care, the subject deserves to be studied thoroughly if only because of its impact on a patient’s life. Research in Belgium has predominantly focused on incidence figures of euthanasia [7;8;86;87], and only recently addressed the practice itself [88;89] and its relationship with the delivery of end-of-life care [82]. However, it is known that after a patient has requested euthanasia, this does not always lead to euthanasia being performed [90;91]. Insights into how euthanasia requests are dealt with could contribute to a better understanding of this complex and delicate medical practice in Belgium.

Opinions polarise much less often when physician-assisted death is concerned without the patient explicitly requesting the hastening of the end of life. Such practice is legally prohibited in all countries whatever the circumstances, and it is often viewed as being equivalent to murder. Nevertheless, as table 2 shows, a small but substantial proportion of annual deaths in Belgium occur following life-ending drug use without the patient’s explicit request. In-depth empirical research on this controversial practice is lacking, though.

RESEARCH QUESTIONS

Previous work has successfully investigated several aspects of how people die in Belgium [18;43;82;87;92-96]. The introduction of this dissertation however clearly indicates that the work is anything but over.

This dissertation aims at extending the knowledge of the dying process and the care received at the end of life in terms of medical care and communication processes, and clinical status and symptom distress at the very end of life.

Some chapters specifically focus on specific patient populations:

1. What are the characteristics of patients dying of cancer in Belgium and the Netherlands, their dying process and the care delivered at the end of life?
2. What are the characteristics of elderly patients dying with dementia in Belgium, their dying process and the care delivered at the end of life?

Some chapters examine aspects of end-of-life communication as a key domain of good care at the end of life in more depth:

3. What is the prevalence and characteristics of advance care planning in Belgium and the Netherlands?
4. What is the GP awareness of the preferred place of a patient’s death in Belgium, and how often did death occur in the place of choice?

Some chapters approach aspects of end-of-life communication about emotionally charged medical care practices which explicitly hasten the end of a patient’s life.

5. Which patients dying at home in Belgium express a request for euthanasia, what are the characteristics of the request and how they are dealt with?
6. Which patients die following the use of life-ending drugs without explicit patient request at home or in a care home in Belgium, what are the characteristics of the decision-making process, and how was this practice performed?

METHODOLOGY

To get a better insight into the end-of-life care patients receive in a country, making cross-national comparison could be highly instructive. However, comparisons are often made post-hoc, creating many difficulties in comparing population, setting, instruments, and design. To answer some of our research questions we were able to use the same research instrument with similar research procedures in Belgium and the Netherlands. We will first give some country-specific aspects of where, how and by whom the care for the terminally ill is organised and delivered as this can facilitate interpretation of the data. Afterwards, the methodology of the SENTIMELC study on which this dissertation builds to answer the research questions is briefly addressed.

COMPARING BELGIAN AND DUTCH END-OF-LIFE CARE SERVICES

Places of care and death

In both Belgium and the Netherlands places for receiving terminal care and dying include patients' own homes or with family members, care homes, hospitals, and hospices or palliative care units in which a multidisciplinary team predominantly aims to offer patients and their next-of-kin as much quality of life as possible and as much autonomy as possible. There is a notable difference between countries, though.

In Belgium, care homes are the place of residence both for the elderly who need care because of a long-term illness but do not require permanent medical hospital care, and for the elderly who are still in good medical condition but not able to manage life on their own at home. In the Netherlands, there is a structural distinction between care homes or so-called residential homes and nursing homes. Although both provide long-term home-replacement care, the former provide basic formal assistance to older people who can no longer live independently, and the latter organise more specialised geriatric care provided by specialist nursing-home physicians.

Palliative care provision

In both countries palliative care has been well-developed and integrated within the national health system with a general awareness of both the population and the health authorities on the subject [97;98]. The emphasis of palliative care policy is on integration in general rather than specialist care, particularly primary care, and on supporting out-of-hospital death [99-101].

On a recently published Quality of Death Index which measures the current end-of-life healthcare environment, availability, cost , and quality across 40 countries, Belgium and the Netherlands ranked respectively fifth and seventh [102].

In Belgium, specialist palliative care services have been organised and implemented in the different care settings to support regular care. This was partly instigated by a law on palliative care in 2002 positing the right to palliative care for every patient and substantially increasing its funding [65]. Terminally ill patients residing at home may benefit from a specialist multidisciplinary palliative home care team whose mission is to advise caregivers, to provide psychological and spiritual support, to give information to patients and their families, to organise and coordinate the provision of palliative care, and only exceptionally to perform specific care tasks. As a continuation of home care, palliative day care centres are established to provide ambulatory palliative support. Also institutional care settings have specialist palliative services at their disposal. Belgian hospitals and most care homes have adopted a palliative care function to introduce a palliative care culture into the institution, to make the staff sensitive to it, to formulate advice, and to organise training. In addition, many hospitals also have a specialist small-scale inpatient palliative care unit which can best be seen as a distinctive health care setting where patients in need of palliative care can reside and where they are cared for, surrounded, and supported, often until death [99;103].

Also in the Netherlands several specialist palliative care initiatives have been set up that are accessible to end-of-life patients in different care settings, ie a GP with palliative care training; a hospital-based palliative care consultation team (trained nurse or physician); a bijna-thuis-huis (a dying home or low care hospice); a palliative unit (in hospital / nursing home / residential home for older people); and care provided in a hospice.

The role of the general practitioner at the end of life

In Belgium and the Netherlands there is a strong emphasis on primary care, also and especially in the provision and coordination of end-of-life care [99;104;105]. General practitioners (GPs) often have built up an established and close relationship with their patients that also makes them arguably the most appropriate caregivers to initiate discussions about the end of life, using a sensitive approach and providing ongoing relational continuity [45;106].

In Belgium, the GP does not act as a formal gate-keeper for referral to more specialist care. Recent findings from the 2008 Belgian Health Interview Study indicate that in 49% of all contacts with a specialist, this is at the patient's initiative, in 35% the patient is referred by a GP, and in 10% by another specialist [107]. The GP's key role in healthcare cannot be underestimated though. Data from the same study demonstrate that almost 95% of the population, including care home residents, have a regular GP whom they consult regularly (78% of the population have at least one encounter per year). Moreover, the number of GP contacts exponentially increases with age: persons aged 75 or over four times more often make an appeal to their GP compared with persons younger than 45, and they are seen by their GP on an almost monthly basis. Also, the majority of patients in the final months of life live at home or in a care home where GPs are their primary professional caregivers [43]. Those patients who reside in a palliative care unit usually continually maintain contact with their GP as well. Notwithstanding that hospital transfer increases exponentially as patients get closer to death [96] resulting in clinical specialists take over the care from GPs once patients are admitted, it is recommended that GPs stay informed about the patient's condition and treatment, including notification of a their death.

In the Netherlands, primary medical care has three major system characteristics: 'listing', 'gatekeeping', and 'family orientation' [108]. Listing means that, in principle, all inhabitants have a GP. GPs are gatekeepers to most specialised services. The impact of this is reflected in a low referral rate: the majority of all complaints are treated by GPs. The third characteristic, family orientation, refers to the fact that a Dutch GP generally serves as the personal physician for a patient's entire family. The role of the GP as professional with regard to places of care of the dying patient in the Netherlands is rather similar compared with the Belgium situation, with one exception. The provision and coordination of medical care including palliative care, in Dutch nursing homes is the competence of specialised nursing home doctors instead of GPs. As such, care trajectories that involve long-term stay in nursing homes are essentially outside the purview of the GPs [101;109].

THE SENTIMELC REGISTRATION STUDY

Since 2005, a nationwide mortality follow-back study has been set up in Belgium and the Netherlands aimed at monitoring care patients receive during the last phase of life. To measure on a population-based level across patient groups and care settings, we collaborated with the nationwide Sentinel Network of General Practitioners in both countries. These networks have proved to be a reliable surveillance system for a wide variety of health-related epidemiological data for several decades [95;110-114]. As general practice is highly accessible for patients often until the very end of life in both Belgium and the Netherlands, the GP can provide a good public health perspective on end-of-life care and dying.

In both countries, the Sentinel Network of GPs yearly covers between 1% and 2% of the total patient population and is representative of all GPs in the country in terms of age, sex and geographical distribution [115-118]. The Belgian Scientific Institute of Public Health (IPH) and NIVEL (the Netherlands Institute of Health Services Research) acted as coordinators of the respective national Sentinel Networks.

All participating Sentinel GPs were asked to fill in a short registration form on the care the deceased received in the last phase of life. This was done for all patients of the GP's practice aged one year or more at the time of death. Over the subsequent registration years different aspects of end-of-life care and the dying process were covered. For the purposes of this dissertation, we selected these components in measuring end-of-life care for which GPs were expected to provide valid information about. Table 3 gives an overview of the topics involved.

The study design was identical in Belgium and the Netherlands and several procedures were used to ensure data quality. Table 4 shows the differences and similarities in the methodology in both countries.
The SENTIMELC registration study was used to answer research question 1 to 4.

THE SENTIMELC INTERVIEW STUDY

In 2005 and 2006 a face-to-face semi-structured interview study was conducted in Belgium in order to provide more in-depth information about the care received at the end of life and the circumstances surrounding death for some of the patients deceased within the SENTIMELC registra-

TABLE 3. COMPONENTS OF KEY DOMAINS IN MEASURING END-OF-LIFE CARE, COVERED BY THE SENTI-MELC REGISTRATION STUDY

I.	MEDICAL CARE PROCESSES
	- place of care and death
	- number of GP-patient encounters in the final three months of life
	- number of transitions, if any, between care settings in the final three months of life
	- in case of hospital death, the moment of admission
	- the patient’s main treatment goal in the last week of life (cure, prolonging life, palliation)
	- involvement of specialist palliative care services (and in case of involvement, moment of admission)
II.	COMMUNICATION PROCESSES
	- content of the GP-patient conversations in the last month of life and before
	- whether the patient had ever expressed wishes about any medical treatment that he/she would or would not want in the final phase of life, the place of death, and about who was to make decisions regarding medical treatments/acts in his/her place in the event the patient would no longer be able to speak for him/herself (proxy decision-maker).
	- whether or not GPs were aware of a previous agreement, with the patient or his/her family, to take certain end-of-life decisions, or not to initiate or to stop several potentially life-prolonging treatments under certain circumstances; and whether these agreements had been made in writing and or in consultation with the patient
III.	DYING PROCESS
	- physical symptom prevalence and distress during last week of life (lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, difficulty breathing)
	- psychological symptom prevalence and distress during last week of life (feeling sad, worrying, feeling irritable, feeling nervous)
	- patient’s decision-making capability in the last week of life
	- patient’s performance status in the last week of life (fully active, restricted, ambulatory, capable of only limited selfcare, completely disabled)
	- period of being in a coma or unconscious immediately before death
	- whether the patient died in their place of choice

tion study. Two types of interviews were conducted, each with specific criteria for inclusion.

Firstly, the so-called regular interview was conducted for all registered patients who died at home between January 2005 and March 2006 (14-month period), aged one year or older at the time of death, and whose death did not occur suddenly or totally unexpectedly as judged by the GP.

A physician-assisted-death interview was conducted if – in addition to the inclusion criteria of the regular interview – death was preceded by a medical end-of-life decision with the explicit intention of shortening the patient’s life. In order to increase the number of cases eligible for interview inclusion, those patients dying in a care home were included and the period of inclusion was extended to 24 months.

Every two months, the registration forms were screened for interview inclusion criteria. The GPs in cases meeting these criteria were contacted

TABLE 4. DIFFERENCES AND SIMILARITIES IN THE SENTIMELC METHODOLOGY IN BELGIUM AND THE NETHERLANDS

	BELGIUM	THE NETHERLANDS
Observational unit	Sentinel GP Network, coordinated by IPH; GPs not enrolled because of specific interest in end-of-life care	Sentinel GP Network, coordinated by NIVEL; GPs not enrolled because of specific interest in end-of-life care
Representativeness of network in country	Nationwide (Flanders, Wallonia and Brussels)	Nationwide
Patient population coverage	Between 1% and 2%	Approximately 1%
Number of GP practices participating	N (2005) = 181 N (2006) = 174 N (2007) = 154 N (2008) = 172	N (2005-2008) = 45
Denominator of the study	All deaths of patients within GP practice +1y	All deaths of patients within GP practice +1y
Data collection procedures	Weekly reporting Selection of regular participating GPs (registered 26 weeks or more of one year) Data entry by the IPH Double data entry by researchers, between 50% and 100% Anonymisation of patient data upon data entry; anonymisation of physician data when closing database Automatic follow-up forms to prevent missing data for key variables; telephone contact with GP also possible	Weekly reporting Selection of regular participating GPs (reminders by NIVEL) Data entry by researchers Double data entry by researchers, about 5% Anonymisation of patient data upon data entry; anonymisation of physician data when closing database Check by NIVEL for missing data on key variables; if necessary telephone contact with GP
Training for GPs	Registration instructions each year Yearly individualized feedback on basic parameters	Registration instructions each year Yearly presenting of results on meeting of participating GPs
Ethical approval	Approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel	No approval required due to the nature of the data collection (post mortem)

by telephone by an independent person to request their participation in a face-to-face interview. The interview took place at a time and place of the GP's choice. The length of the regular and physician assisted death interview was estimated at a maximum of 30 minutes and 1 hour respectively.

Strict procedures were used to preserve patient anonymity and physician confidentiality.

Research questions 5 and 6 were approached by the SENTIMELC interview study.

An overview of the research questions of this dissertation and the corresponding data collection is given in table 5.

TABLE 5. RESEARCH QUESTIONS OF THIS DISSERTATION AND THE CORRESPONDING DATA COLLECTION

Research question	Data collection	Year	Inclusion criteria	Country
1	Reg	2008	sudden and non-sudden death ≥ 65y at time of death	Be
2	Reg	2008	patients dying from cancer non-sudden death >1y at time of death	Be + Neth
3	Reg	2007	non-sudden death >1y at time of death	Be + Neth
4	Reg	2006	non-sudden death >1y at time of death	Be
5	Int	Jan 2005 / Mar 2006	patients dying at home non-sudden death >1y at time of death	Be
6	Int	2005-06	patients dying at home or in care home death preceded by end-of-life decision with explicit intention to hasten death, without explicit patient request non-sudden death >1y at time of death	Be

Reg = registration study; Int = interview study
Be = Belgium; Neth = the Netherlands

OUTLINE OF THIS DISSERTATION

Part II of this dissertation provides a substantial overview of characteristics of the dying process and the care received at the end of life for two specific patient groups. Chapter 2 sheds lights on patients dying of cancer and investigates both Belgium and the Netherlands. Chapter 3 focuses on how patients suffering from dementia die in Belgium and makes a comparison with the last phase of life of other elderly people.

Part III is concerned with a more profound description of one of the key domains of good end-of-life care, i.e. processes of communication during or with regard to the last phase of life. Chapter 4 is devoted to the prevalence and characteristics of advance care planning with respect to the kind of care that will be considered appropriate when the patient can no longer make decisions. This study was performed in Belgium and the Netherlands. Chapter 5 examines where patients prefer to die in Belgium and how often this wish can be fulfilled.

Part IV enters at length into preferences and decision-making about two medical end-of-life practices in which the hastening of death was explicitly intended. It goes without saying that when life or death is considered the importance of the patient's preferences, a deliberate decision-making process, and intensive communication cannot be overestimated. Chapter 6 expands upon how many and which patients expressed a wish for euthanasia, the characteristics of these wishes, how many and which were not granted, what the reasons for not granting them were, and how patients whose euthanasia wish was not granted eventually died. Finally, Chapter 7 examines the use of life-ending drugs by GPs without explicit patient request, and tries to gain insights into how, why and for which patients GPs decide to end a life in this manner, and into the circumstances of death.

Part V entails a summary of the most salient findings of the study, followed by a general discussion. Also, reflections will be made on some strengths and limitations of the study, and attention will be given to implications for health policy and practice.

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PART II

END-OF-LIFE CARE IN CANCER AND DEMENTIA

CHAPTER 2:

END-OF-LIFE CARE AND CIRCUMSTANCES OF DEATH IN PATIENTS DYING OF CANCER IN BELGIUM AND THE NETHERLANDS

A NATIONWIDE RETROSPECTIVE STUDY

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Submitted

ABSTRACT

PURPOSE

To examine and compare characteristics of end-of-life care and dying in cancer patients in Belgium (Be) and the Netherlands (Nl).

METHODS

General Practitioners of the nationwide representative sentinel GP networks in both countries reported weekly on end-of-life care and circumstances of death of all cancer patients who died non-suddenly in their practices in 2008, using standardised forms.

RESULTS

Of the 422 reported cancer patients, most resided at home during the last year of life (Be:91%; Nl:95%). Death occurred at home in 34% (Be) and 59% (Nl), and in hospital in 29% (Be) and 19% (Nl). In the last month of life end-of-life issues were more often discussed in Nl (88%) than in Be (68%). In both countries, physical problems (Be:49%; Nl:78%) were discussed most often, and spiritual issues (Be:20%; Nl:32%) least often. Certain end-of-life treatment preferences were known for 43% (Be) and 67% (Nl) of patients. In the last week of life, treatment was most often (Be:94%; Nl:91%) focused on palliation and not on life-prolonging or cure. Physical distress was reported in 84% of Belgian, and in 76% of Dutch patients; psychological distress in 59% and 36% respectively. Most distressing symptoms were lack of energy (Be:73%; Nl:71%) and lack of appetite (Be:61%; Nl:53%). Two-thirds of patients were bedridden (Be:67%; Nl:69%).

CONCLUSION

While place of death and communication about end-of-life issues differs substantially, a palliative care philosophy is strongly embedded in cancer care in both countries. However, GPs reported that many did experience symptom distress at the end of life.

INTRODUCTION

Cancer therapy is successful for many cancer patients. However, in advanced cancer, cure or life-prolonging may no longer be possible, and palliative care becomes the only realistic treatment option. Palliative care is aimed at improving the quality of life of patients and their families by providing relief from physical, psychological and spiritual problems [1]. Although palliative care is well developed for patients suffering from cancer [2], there is consensus that further improvement is still possible and needed [3;4].

Although large-scale studies demonstrated that many cancer patients die at home [5;6], thus far information on end-of-life care and circumstances of dying for cancer patients is often gathered from studies focusing on specific institutional care settings [7-13]. To gain better insight into how the total cancer patient population is cared for and dies, nationwide studies irrespective of care setting or type of cancer are needed.

In both Belgium and the Netherlands, the existence of a nationwide representative network of general practitioners (GPs) can be used to meet these goals since the provision of palliative care in both countries is often coordinated by the GP; almost all inhabitants have their own GP [14;15] and GPs are involved in end-of-life care in virtually all cancer patients [16]. This sentinel GP network has been used successfully in the past to study aspects of end-of-life care in both countries [17-23], but studies have never focused specifically on patients dying of cancer.

Because an identical study design was used in both countries, this methodology provides an important opportunity to perform cross-national comparisons. While in both Belgium and the Netherlands there is high accessibility of general health care services and integration of palliative care into the national health system [24], there are also important differences, which makes comparisons particularly relevant. While Belgium has chosen to place multidisciplinary teams into different care settings, the Netherlands focuses more on the promotion of palliative care skills among regular caregivers, supported by consultation teams [25]. Also, there are specialized nursing homes facilities and an absolute GP gatekeeping system in the Netherlands but not in Belgium [26].

In this study, the following questions are addressed for both countries:

1. What care patients dying of cancer do receive at the end of life?
2. Where and how do they eventually die?
3. What are the differences and similarities between the two countries?

METHODS

STUDY DESIGN

This study is an analysis of a one-year (2008) data collection within the Senti-Melc study, a study designed to monitor retrospectively the end of life of patients via existing national Sentinel Networks of General Practitioners in Belgium and the Netherlands [27]. In both countries, these GP networks are reliable surveillance systems with a long history of nationwide surveillance of a wide variety of health-related topics using similar standardised procedures of data collection [27-33]. In 2008, the Belgian network comprised 172 regularly participating practices compared with 45 in the Netherlands, both covering approximately one to two percent of the total registered patient population in the country and being representative of GPs nationwide by gender, age and geographic distribution [34;35].

Within one week of a patient's death, participating GPs were asked to fill in a standardised registration form for all deaths at age one year or more in their practice. This form gathered information about the dying process and the care received during the last months of life of patients. Patients dying of cancer were identified by asking the GP about the underlying cause of death (encoded into ICD-10 classification). Those who had died 'totally unexpectedly and suddenly' as judged by the GP were excluded from further analysis since our focus was on those cancer patients for whom the provision of end-of-life care was a relevant consideration [20;21;23].

END-OF-LIFE CARE SETTING AND THE GP

In both countries the main settings for receiving end-of-life care and for dying are home, hospital, hospice or palliative care unit and care home. In the Netherlands, there is a structural distinction between care homes or so-called residential homes and nursing homes. Although both provide long-term home-replacement care, the former provide basic formal assistance to older people who can no longer live independently under the care of the GP, while the latter organize more specialized geriatric care provided by specialist nursing-home physicians [36]. In Belgium, the GP is responsible for the care of both kinds of care home residents [21] .

MEASUREMENTS

Several comprehensive conceptual frameworks on quality of end-of-life care exist, some of them specifically for patients with cancer [3;37-48]. On the basis of these models we identified the following key domains of end-of-life care: medical care processes, communication processes and circumstances of dying (see Table 1 for a full overview of the topics surveyed in these domains).

We also surveyed important patient characteristics such as age, gender, place of longest residence during the last year of life and place of death. Most questions had been developed and pretested in previous research [20-22;27;49-53].

Several procedures were used to ensure data quality: collective development of the registration form in both countries with attention to semantic differences in language; pretesting of the questionnaire; automatic follow-up (in Belgium) and telephone contact with the GPs to prevent missing data; data-entry with consistency, range and skip checks. Full methodological details are described elsewhere [27].

DATA ANALYSIS

Palliative care services were considered to have been used if at least one service had been used during the last three months of life. Psychological symptoms were considered to have caused distress if patients appeared to feel this way ‘frequently’ or “almost constantly” during the last week of life. Physical symptoms were considered to have caused distress if symptoms distressed the patient ‘quite a bit’ or ‘very much’. Symptoms that were not present were considered to have caused no distress. The Global Distress Index was calculated as the mean of the item scores for all physical and psychological symptoms; patients for whom no answer was given on more than three symptom items were not included in this calculation [50].

Percentages were used to describe the proportion of cancer patients for whom different aspects of end-of-life care were provided. Fisher’s Exact Tests were used to determine which aspects of the dying process or the received care at the end-of-life were associated with residing in either Belgium or the Netherlands ($p<.05$). Associations were further explored in multivariate logistic regression analyses while adjusting for differences in place of death – because of the relationship with GP involvement and country – and age and gender, unless stated otherwise. Possible interaction effects were determined between these patient characteristics and the

TABLE 1. IMPORTANT DOMAINS IN END-OF-LIFE CARE ASSESSED IN THIS STUDY

Medical care processes at the end of life:

- number of GP-patient encounters in the final three months of life
  (or encounters between GP and patient's relatives, regarding the patient)
- transitions, if any, between care settings in the final three months of life
- in case of hospital death, the moment of admission
- patients' main treatment goal in the last week of life (cure, prolonging life, palliation)
- involvement of specialist palliative care services:
  in the Netherlands: a GP with palliative care training, team with a palliative care consultant (trained nurse or physician), hospital-based palliative units, nursing-home-based palliative care units, and hospice day care facility;
  in Belgium: multidisciplinary palliative support home-care teams, hospital-based mobile support teams, hospital-based palliative care units, palliative day-care centres, and care home-based palliative care reference nurses

Communication processes at the end of life:

- content of the GP-patient conversations in the last month of life and before
- whether the patient had ever expressed wishes about any medical treatment that he/she would or would not want in the final phase of life, and about the place of death

Circumstances of dying:

- functional status during the last week of life using the Eastern Cooperative Oncology Group Performance Status Scale (ECOG)
- whether the patient was in a coma or unconscious until death and if so, for how long
- physical and psychological symptom distress during the last week of life measured by the Memorial Symptom Assessment Scale Global Distress Index (MSAS-GDI)
- whether the patient died at the place of wish

patient's country. In the tables, we display the odds-ratios in case a main effect of country was found.

To investigate the representativeness of the data for all non-sudden cancer deaths in Belgium and the Netherlands, we compared age, gender and place of death of our sample with figures identified in previous nationwide representative death-certificate studies in both Belgium (Flanders) [54] and the Netherlands [55]. In Belgium, no significant differences for these characteristics between studies were found (multinomial 95% confidence interval). In the Dutch part of the sample nursing home deaths were underrepresented. This was to be expected since nursing home physicians take over care from the GP. After leaving out these deaths, representativeness was reached.

We used SPSS 17 (Chicago, Illinois) and StatXact6 (Cytel Studio, Cambridge, MA) for statistical computations.

RESULTS

PATIENT CHARACTERISTICS

The Belgian and Dutch GPs reported 1,354 and 405 deaths respectively. We excluded all patients who died suddenly (n=616; 35%) leaving 1,143 patients. For 422 of these, 37% in each country, cancer was reported as the underlying cause of death. The mean age of the sample was 72 years in Be versus 70 years in Nl, 46% were female in Be versus 48% in Nl, 91% mostly resided at home during the last year of life in Be versus 95% in Nl, and 34% died at home in Be versus 59% in Nl, 29% in the hospital in Be versus 19% in Be, 24% in a palliative care unit in Be versus 9% in Nl, and 12% in the care home in Be versus 10% in Nl (table 2). Place of death was strongly associated with the patient's country, with more hospital deaths in Belgium and more deaths at home in the Netherlands; all other patient characteristics did not significantly differ between the two countries.

TABLE 2. CHARACTERISTICS OF THE STUDY POPULATION

	All cancer deaths n=422		Belgium n=321		The Netherlands n=101		p-value *
	n	%	n	%	n	%	
Age at death							
≤ 64 y	120	28.7	87	27.4	33	32.7	0.381
65–79y	156	37.3	117	36.9	39	38.6	
80y +	142	34.0	113	35.6	29	28.7	
mean	71.7		72.2		70.4		0.247
Gender							
male	226	53.7	173	54.1	53	52.5	0.819
female	195	46.3	147	45.9	48	47.5	
Educational level							
elementary or lower	129	33.7	92	32.1	37	38.5	0.465
lower/higher secondary	202	52.7	156	54.4	46	47.9	
higher education	52	13.6	39	13.6	13	13.5	
Longest place of residence in last year							
home or with family	382	92.0	287	91.1	95	95.0	0.289
care home	33	8.0	28	8.9	5	5.0	
(elsewhere n=6) †							
Place of death							
home or with family	169	40.0	109	34.0	60	59.4	<0.001
care home ‡	48	11.4	38	11.8	10	10.0	
hospital	113	26.8	94	29.3	19	18.8	
hospice/palliative care unit	87	20.6	78	24.3	8	8.9	
(elsewhere) †	5	1.2	2	0.6	3	3.0	

Missing values age n=4; gender n=1; level of education n=39; longest place of residence n=1

* Fisher's Exact Test or T-test for equality of means to test differences between cancer patients dying in Belgium and the Netherlands

† not included in statistical analysis

‡ care homes / residential homes for older people (n=43) ; nursing homes (n=5)

MEDICAL CARE PROCESSES AT THE END OF LIFE

During the last three months of life, 38% of Belgian and 56% of Dutch patients had more than eight contacts with their GP; 66% of Belgian and 44% of Dutch patients were transferred to another care setting, and for 72% of Belgian and 34% of Dutch patients palliative care services were used (table 3). Multivariate analyses controlling for age, gender and place of death showed that these services were more often used in Belgium than in the Netherlands.

During the last week of life, GP contact was maintained in 71% of Belgian and 87% of Dutch cases, 35% of Belgian and Dutch patients who died in hospital were admitted in the last week of life and in 94% of Belgian and 91% of Dutch patients the treatment goal was palliation and not cure or life prolonging. Variations in the proportion of patient-GP encounters (more in the Netherlands) and hospital deaths (more in Belgium) remained significant after controlling for differences in patient characteristics.

COMMUNICATION PROCESSES AT THE END OF LIFE

Prior to the last month of life 74% (Belgium) and 71% (the Netherlands) of patients who died of cancer had discussed one or more end-of-life care issues with their GP (table 4). Primary diagnosis, incurability of the illness and physical symptoms were discussed most frequently in both countries, spiritual issues least frequently. No country-differences were found.

During the last month of life, 68% (Belgium) and 88% (the Netherlands) of patients who died of cancer had discussed one or more end-of-life care issues with their GP. Less than a third of the patients in Belgium had talked about spiritual issues, social problems, the burden of treatments, primary diagnosis, possible medical complications or life expectation. The incurability of illness, psychological problems, options for palliative care and physical symptoms were discussed more often but never in more than half of cases. In the Netherlands, only communication about spiritual issues was uncommon, whereas all other topics were discussed in at least half of patients, and most frequently concerned life expectation, options for palliative care and physical problems. All differences between countries – except for spiritual issues – remained significant in the multivariate analyses, also after additional adjustment for patient contacts during the last month of life.

TABLE 3. CHARACTERISTICS OF MEDICAL CARE PROCESSES AT THE END OF LIFE

	All cancer deaths n=422		**Belgium n=321**		**The Netherlands n=101**		**p-value ***	**Odds-ratio [95% Confidence Interval] †**
	n	**%**	**n**	**%**	**n**	**%**		
During the last 3 months of life								
More than 8 GP-patient contacts ‡	179	42.4	122	38.0	57	56.4	**0.001**	ns
Transferred at least once between care settings	250	61.1	209	66.3	41	43.6	**<0.001**	ns
Palliative care services initiated	265	62.9	231	72.0	34	34.0	**<0.001**	**6.73 [3.86-11.75]**
During last week of life								
One or more GP-patient contacts	316	74.9	228	71.0	88	87.1	**0.001**	**0.48 [0.23-0.996]**
Transferred at least once between care settings	82	20.0	70	22.2	12	12.8	0.056	ns
Terminal hospital admission	113	26.8	94	29.3	19	18.8	**0.040**	**1.89 [1.08-3.30]** §
admission in last week (vs. before last week)	38	34.9	32	34.8	6	35.3	1.000	ns
Palliative treatment goal (vs. curative/life prolonging)	385	93.0	294	93.6	91	91.0	0.372	ns

Missing values for transfer between care setting n=13; timing of terminal hospital admission n=9; treatment goal n=8; specialist palliative care services involved n=1

* Fisher's Exact Test to test differences between cancer patients dying in Belgium and the Netherlands

† Odds ratio with 95% confidence intervals from multivariate logistic regression models.
For these analyses we compared end-of-life care between cancer patients from Belgium (0) and the Netherlands (1)

‡ Dichotomised at its median value

§ Not controlled for place of death in multivariate analysis

ns = not significant

TABLE 4. CHARACTERISTICS OF COMMUNICATION PROCESSES AT THE END OF LIFE

	All cancer deaths n=422		Belgium n=321		The Netherlands n=101		p-value *	Odds-ratio [95% Confidence Interval] †
	n	%	n	%	n	%		
GP-PATIENT CONVERSATIONS								
During last month of life, about								
primary diagnosis	155	37.9	98	31.0	57	61.3	**< 0.001**	**0.33 [0.20-0.54]**
incurability of illness	174	42.2	107	33.9	67	69.8	**< 0.001**	**0.27 [0.16-0.45]**
life expectation	169	41.2	100	31.7	69	72.6	**< 0.001**	**0.21 [0.13-0.36]**
possible medical complications	151	36.9	98	31.2	53	55.8	**< 0.001**	**0.42 [0.26-0.68]**
physical symptoms	231	56.1	156	49.4	75	78.1	**< 0.001**	**0.34 [0.20-0.58]**
psychological problems	207	50.6	140	44.7	67	69.8	**< 0.001**	**0.41 [0.25-0.68]**
social problems	139	34.2	90	28.8	49	51.6	**< 0.001**	**0.45 [0.27-0.73]**
spiritual problems	91	22.6	61	19.8	30	31.9	**0.017**	ns
options for palliative care	215	52.3	144	45.9	71	73.2	**< 0.001**	**0.38 [0.23-0.63]**
burden of treatments	153	37.1	98	31.0	55	57.3	**< 0.001**	**0.34 [0.24-0.63]**
One or more of these topics was discussed	299	72.2	214	67.5	85	87.6	**<0.001**	**0.37 [0.19-0.72]**
Prior to last month of life, about								
primary diagnosis	239	58.4	192	60.8	47	50.5	0.094	ns
incurability of illness	213	51.7	157	49.7	56	58.3	0.162	ns
life expectation	170	41.5	127	40.3	43	45.3	0.407	ns
possible medical complications	178	43.5	136	43.3	42	44.2	0.906	ns
physical symptoms	240	58.3	187	59.2	53	55.2	0.555	ns
psychological problems	175	42.8	134	42.8	41	42.7	1.000	ns
social problems	128	31.4	101	32.4	27	28.4	0.529	ns
spiritual problems	77	19.2	61	19.8	16	17.0	0.654	ns
options for palliative care	147	35.8	106	33.8	41	42.3	0.146	ns
burden of treatments	179	43.4	143	45.3	36	37.5	0.197	ns
One or more of these topics was discussed	302	72.9	233	73.5	69	71.1	0.695	ns
END-OF-LIFE PREFERENCES								
Patient ever expressed preference								
about a medical end-of-life treatment	184	48.8	119	42.5	65	67.0	**<0.001**	**0.38 [0.23-0.63]**
for place of death	219	59.0	150	54.2	69	73.4	**0.001**	ns

Missing values on communication <5%; Missing values or indicated by the GP as unknown, for treatment preferences n=45, for preference for place of death n=51

* Fisher's Exact Test to test differences between cancer patients dying in Belgium and the Netherlands

† Odds ratio with 95% confidence intervals from multivariate logistic regression models. For these analyses we compared end-of-life care between cancer patients from Belgium (0) and the Netherlands (1)

ns = not significant

About half (54%) of Belgian and 73% of Dutch patients expressed a preference for place of death and 43% of Belgian and 67% of Dutch patients had at some point expressed a wish concerning medical end-of-life treatment. After adjustment for differences in age, gender and place of death, country remained associated with the prevalence of a preference for end-of-life treatment (more in the Netherlands).

CIRCUMSTANCES OF DYING

During the last week, about two thirds of cancer patients in Belgium (67%) and the Netherlands (69%) were physically completely disabled and bedridden (table 5). Physical distress was reported in 84% in Belgium and in 76% in the Netherlands, psychological distress in 59% and 36% respectively. As judged by the GP, most distressing symptoms were a lack of energy (in 73% of Belgian and 71% of Dutch cases) and lack of appetite (in 61% of Belgian and 53% of Dutch cases). Psychological distress was more often experienced among cancer patients in Belgium compared with the Netherlands as reported by the GP, remaining after adjustment for differences in gender, age and place of death. We additionally controlled for the occurrences of patient contact in the last week of life and prevalence of communication about psychological problems in the last month of life as possible confounders, but this did not alter the results. Congruence between the preferred and actual place of death was reached in 71% of Belgian and in 88% of Dutch cases. The chances of dying in the place of choice were three times higher in the Netherlands than in Belgium.

TABLE 5. CHARACTERISTICS OF THE DYING PROCESS

	All cancer deaths n=422		Belgium n=321		The Netherlands n=101		p-value *	Odds-ratio [95% Confidence Interval] †
	n	%	n	%	n	%		
Clinical status in last week of life								
Physically completely disabled and bedridden ‡	275	67.1	209	66.6	66	68.8	0.712	ns
One or more days unconsciousness until death	214	56.0	171	58.0	43	49.4	0.177	ns
Physical symptom distress in last week of life								
GP could make estimation §	362	85.8	282	87.9	80	79.2	**0.034**	**2.95 [1.48-5.85]**
Distress from at least one symptom	297	82.0	236	83.7	61	76.3	0.138	ns
lack of appetite	207	59.3	165	61.1	42	53.2	0.241	ns
lack of energy	254	72.8	197	73.2	57	71.3	0.775	ns
pain	80	23.2	61	23.0	19	23.8	0.881	ns
feeling drowsy	98	28.9	82	31.7	16	20.0	**0.049**	ns
constipation	34	11.0	29	12.7	5	6.3	0.147	ns
dry mouth	63	20.4	52	22.5	11	14.1	0.143	ns
difficulty breathing	86	25.3	74	28.5	12	15.0	**0.018**	ns
Psychological symptom distress in last week of life								
GP could make estimation §	322	76.3	244	76.0	78	77.2	0.893	ns
Distress from at least one symptom	172	53.4	144	59.0	28	35.9	**<0.001**	**2.90 [1.63-5.15]**
feeling sad	102	34.1	88	38.9	14	19.2	**0.002**	**2.83 [1.43-5.60]**
worrying	121	39.9	101	44.3	20	26.7	**0.007**	**2.19 [1.17-4.07]**
feeling irritable	41	13.4	37	15.9	4	5.3	**0.019**	**3.90 [1.30-11.66]**
feeling nervous	61	20.3	56	24.7	5	6.8	**0.001**	**4.53 [1.69-12.10]**
Global Distress Index (mean)	1.25		1.32		1.04		**0.001**	**2.86 [1.56-5.26]**
Preferences honoured								
Died at the place of wish ‖	167	76.3	106	70.7	61	88.4	0.004	0.31 [0.12-0.71]

Additional missing values on symptom distress vary between n=13 up to n=54; missing values for performance status n=12; for unconsciousness n=40

* Fisher's Exact Test or T-test for equality of means to test differences between cancer patients dying in Belgium and the Netherlands

† Odds ratio with 95% confidence intervals from multivariate logistic regression models.

For these analyses we compared end-of-life care between cancer patients from Belgium (0) and the Netherlands (1)

‡ Performance Status Scale (ECOG) 0-Fully active; 1-Ambulatory, capable of work of a light nature; 2-Capable of self-care but not work; 3-In bed ≥50% of the time, capable of only limited self-care; 4-Completely bedridden, incapable of self-care; figures in table are % of patients for whom a grade 4 (vs. 0 to 3) was assigned

§ For at least one symptom

‖ For patients the GP was informed about the preferred place of death; variables controlled for in multivariate analysis: age, sex, longest place of residence

DISCUSSION

This nationwide study examined the end-of-life characteristics and circumstances of cancer patients dying in Belgium and the Netherlands. Patients were recruited via existing representative national GP networks to obtain a nationwide general practice cancer population irrespective of care setting. Strengths of both networks include a nationwide representativeness of GPs not specifically selected for research in end-of-life care, the long history of performing research and the quality of the data collection procedures [27]. The 2008 registration form used in this study was developed simultaneously and in close collaboration for the purpose of cross-national comparability.

A number of limitations can be stated. Firstly, a retrospective study design may always induce some recall bias. Secondly, GPs reported on the care they had provided themselves. Although this has benefits, it may have led to some bias as well, eg an underestimation of the symptom distress experienced. However, GPs also report on care that is provided by other caregivers (eg clinical specialists are supposed to inform the GP regarding a hospitalized patient’s condition and treatment). Thirdly, full nationwide representativity could not be guaranteed in the Netherlands for nursing home deaths because GPs are not involved in care in these settings. However, given the high involvement of the GP in end-of-life care in both countries [14-16], the largely non-cancer population in Dutch nursing homes [36;56-58], the adjustment for place of death in our analyses and the representativeness of the sample if excluded from nursing home deaths, the results provide valuable insights into how the general population of cancer patients dies in Belgium and the Netherlands. Fourthly, the broad overview of end-of-life care topics precludes entering at length into all issues separately and more in-depth information is needed for a better understanding and interpretation of country differences.

The results of this study show similarities as well as differences in the end of life of cancer patients in Belgium and the Netherlands. Notwithstanding that more than 90% of patients were able to live at home for most of the time during the last year of life in both countries, a substantial proportion of cancer patients in Belgium (29%) and the Netherlands (19%) dies in the hospital. As is known, terminally ill cancer patients prefer not only to be cared for but also to die at home [59-61], hence the latter result might be a cause for practice and policy concerns. However, the problem of hospital deaths seems most obvious in Belgium and might be related to government and palliative care policies more strongly directed at home care in the Netherlands [5;57] but also to differences in primary care culture. In both, GPs occupy a prominent position in the provision of palliative care [26;62] but their specific roles at the end of life might be perceived differently. Being gatekeepers to the health care system, Dutch GPs take on most care tasks themselves while Belgian GPs seem more often to pursue a coordinating role only [25;26;63]. This hypothesis is further supported by the finding that palliative care services are more likely to be used in Belgian than in Dutch general practice, and by the difference in patient contacts in the last phase of life, especially during the last week.

The higher prevalence of end-of-life patient-GP conversations during the last month of life in the Netherlands compared with Belgium might also be related to the differences in medical culture. Ideas of candour and open communication might be valued more highly in the Netherlands [26], which might also partly explain the variation in the GPs' knowledge of patients' preferences about medical end-of-life treatment (43% in Be vs. 67% in Ne).

Notwithstanding these differences, there are several analogies across the countries as well. In both, GPs focus more on physical and psychological than on spiritual or social issues; it may be that GPs feel less comfortable in introducing these topics, other professionals may fulfill this task or these issues did not concern patients very much. Options for palliative care were principally discussed during conversations held in the last month of life rather than earlier when the subject was addressed in fewer than half of patients. The late onset of these discussions was somewhat surprising given the strong emphasis the palliative care movement places on advocating early communication and advance care planning and the relatively predictable disease trajectory of cancer patients [2;64;65].

From its beginnings, palliative care has predominantly focused on cancer care and our results show a large penetration of palliative care into end-of-life care for cancer patients in the two countries studied [1]. Notwithstanding that a palliative care approach was present for most patients, many experienced symptom distress at the very end of life. Lack of energy and lack of appetite occur as the most distressing physical symptoms in a majority of patients. Pain was reported far less often as having caused distress, which might indicate that pain is a symptom that can be alleviated by palliative care while others are far more challenging. However, pain was still a distressing symptom in more than 20% of cancer patients in both countries, also suggesting that there is potential for improvement in alleviating pain at the end of life.

In conclusion, the use of nationwide sentinel networks of general practitioners creates important opportunities to provide insights into how cancer patients in general are dying in a country, and can serve as a valuable instrument in monitoring end-of-life conditions. While place of death and communication at and about the end of life differs substantially, a palliative care philosophy is strongly embedded in cancer care in both Belgium and the Netherlands. However, GPs reported that many did experience symptom distress at the end of life.

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CHAPTER 3:
OLDER PEOPLE DYING WITH DEMENTIA

A NATIONWIDE STUDY

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Submitted

ABSTRACT

BACKGROUND

Large-scale nationwide data describing the end of life of older people with dementia is lacking

OBJECTIVES

To describe how people die with mild or severe dementia in Belgium, and to compare with patients dying without dementia.

DESIGN, SETTING, PARTICIPANTS

Nationwide retrospective mortality study, via representative network of GPs, 2008, Belgium; weekly registration of all deaths (aged ≥ 65) using a standardized form

MEASUREMENTS

GPs reported on diagnosis and severity of dementia, aspects of end-of-life care and communication, and on the last week of life in terms of symptoms that caused distress as judged by the GP using the MSAS-GDI, and the patients' physical and cognitive abilities.

RESULTS

31% of our sample (1,108 deaths) suffered from dementia (43% mildly, 57% severely). Of those, 26% died suddenly, 59% in care home, and 74% received treatment aimed at palliation, versus 37%, 19%, and 55% of non-dementia elderly. GP-patient conversations were less frequent among those with (45%) than those without (73%) dementia, and 11% of both groups had assigned a proxy decision-maker. During the last week of life, 66% of dementia patients were judged to have experienced physical and 32% psychological distress, 83% were incapable of decision-making and 83% were bed-ridden; significantly higher percentages than among the non-dementia group.

CONCLUSION

Considering that a substantial minority of patients with dementia are judged to have died suddenly, and in view of the physical and psychological problems they experience, this study might underscore the importance of considering dementia as a trigger for a timely palliative care approach.

INTRODUCTION

Dementia is a major health care challenge worldwide. A growing number of people are dying with dementia in western society [1;2] and research suggests that palliative care delivered to these patients is not always optimal [3-5]. However, large-scale nationwide data are lacking on how and in what circumstances older people with dementia die. Previous studies have focused on patients in hospitals or nursing homes, or those with advanced dementia only, and are limited in terms of national representativity [5-8]. One recent large-scale study of nursing home residents dying with advanced dementia (the CASCADE-study) addressed the clinical course and the characteristics of the final stages of advanced dementia using prospective data gathered in 22 nursing homes in the Boston area of the US [5]. However, not all patients develop an advanced form of dementia, and in many countries a substantial proportion of patients with dementia live and die at home [9;10]. Additionally, comparisons between those dying with and those without dementia might provide important insights into the differences in clinical challenges at the end of life of both patient groups.

Carried out in 2008, we report the results of a nationwide study on dying with dementia in Belgium across different care settings, using the Belgian Network of General Practitioners (GPs). This network, like other European Sentinel Networks, has a long history in surveillance of health-related epidemiological data eg on diabetes, stroke, cancer, accidents [11;12], and several years of experience in surveillance of end-of-life issues [13-15]. Because detailed information concerning a patient's conditions and the care provided cannot always be automatically extracted from the patients' medical records, a registration directly with GPs has an important surplus value. In the past, several of the registrations (eg stroke mortality, suicide incidences) have been compared with data from external resources and have resulted in a good validity of the sentinel network's registrations [16;17]. Comparisons of death certificate data and health insurance data with the network's results on place of death and care setting trajectories in Belgium also point at high validity [18;19].

The main objective of this study is to describe how older people die with mild or severe dementia in Belgium and to compare with patients dying without dementia.

METHODS

STUDY DESIGN, SETTING AND SELECTION OF STUDY SUBJECTS

In Belgium, almost everyone, including residents of care homes, has a GP whom they contact regularly. Although GPs may not have a legally sustained gatekeeper's role for referral to more specialist care, in practice the coverage of primary care is almost universal. Given this pivotal position, the GP is a good source of information about the care patients receive. In 2008, the sentinel network of GPs included 172 practices, together representative of all practising GPs for age, sex and geographic distribution, recorded all deaths of their practice patients older than one year of age within a week of occurrence, using a standardized registration form. A detailed description of the study's methodology is described elsewhere [20]. Patients suffering from dementia were identified by asking the GP: 'Did you or another doctor determine the diagnosis of dementia? No / Yes, mild Dementia / Yes, severe dementia'. Previous work in Belgium and the Netherlands has shown that the diagnostic accuracy of GPs in dementia was found acceptable compared with clinical experts [21;22]. Additionally the long-lasting relationship and regular contacts with patients, makes them arguably a reliable source to provide this information. For sixteen cases this information was missing. Valid information was gathered for 1,108 cases. Age, sex and place of death for the Dutch-speaking part of our sample (n=664) could be compared with corresponding official mortality rates of 2007, provided by the Flemish Agency for Care and Health (n=45940). Our sample was representative for sex and age, but hospital deaths (44.3%, 95%CI 40.5-48.2 vs. 52.3%; 95%CI 51.7-52.8) were slightly underrepresented (multinomial 95% CI exact method).

MEASUREMENTS

Several comprehensive conceptual frameworks of end-of-life care exist, some of which are specifically for older patients and patients with dementia [23-25]. On the basis of these models we identified three broad key domains in measuring the end-of-life.

- medical care processes: number of GP-patient encounters in the final three months of life (and/or encounters between GP and patient's relatives regarding the patient); occurrence of at least one transition between care settings in the final three months of life; in case of hospital death, the moment of admission (in last week vs. before last week); the patient's main treatment goal in the last week of life (cure, prolonging life, palliation); involvement of specialist palliative care services during the last three months of life (homecare or care home team, mobile hospital team, palliative care unit, or palliative day care).

- communication processes: content of the GP-patient conversations in the last month of life and before; whether the patient had ever expressed wishes about any medical treatment that he/she would or would not want in the final phase of life, the place of death, and about who was to make decisions regarding medical treatments/acts in his/her place in the event the patient would no longer be able to speak for him/herself (proxy decision-maker).
- dying process (last week of life): patient's decision-making capability in the last week of life: (fully capable, sometimes capable sometimes not, not capable at all); functional status using the ECOG-Performance Status Scale (0-Fully active; 1-Ambulatory, capable of work of a light nature; 2-Capable of self-care but not work; 3-In bed ≥50% of the time, capable of only limited self-care; 4-Completely bedridden, incapable of self-care); whether the patient was in a coma or unconscious immediately before death and if so, for how long; symptom distress using the Memorial Symptom Assessment Scale; A symptom is labeled as causing distress if it was present and distressed the patient 'quite a bit' or 'very much' (physical symptoms), or if it was present and the patient 'frequently' or 'almost constantly' felt this way (psychological symptoms), as reported and judged by the GP [26]; whether the patient died in their place of choice.

We also surveyed patient characteristics and whether or not death had occurred "suddenly and totally unexpectedly" as judged by the GP. Most questions were developed and pretested in previous research [13;14;20;26;27], and several have been used in end-of-life care research conducted via the sentinel network of GPs [14;15].

ANALYSES

Fishers' Exact Tests were used to test differences between patients with and without dementia, and between patients with mild and severe dementia. Statistical significance was set at p≤0.05. Associations were further explored in multivariate logistic regression analyses investigating the independent effect of dementia (yes/no, and mild/severe) on all care and outcome measure separately while adjusting for age, gender, cause of death, and whether death could be foreseen. We also controlled for place of death except in the models examining the association between diagnosis of dementia and terminal hospital admission, because of multicollinearity problems. We additionally investigated possible interaction effects between these patient characteristics and dementia. In the tables, we display the odds-ratios in cases where a main effect of dementia was found. We used SPSS-17 and StatXact6 for all statistical computations.

RESULTS

PATIENT CHARACTERISTICS

One third (31%) of the study population had dementia according to their GP (Table 1). Of these, 57% suffered from severe and 43% from mild dementia at the time of death. Fifty-six percent of all patients with dementia were aged 85 or older and 66% were women. Death occurred in a care home in 59% of cases and was non-sudden in 74%.

Compared with the rest of the sample, those dying with dementia were older, more often female and their deaths were more often non-sudden. They were more likely to reside in a care home rather than at home in their last year of life and to die in a care home. Compared with patients with mild dementia, patients with severe dementia more often died non-suddenly, and more often resided and died in a care home.

TABLE 1. OLDER PEOPLE DYING WITH AND WITHOUT DEMENTIA

	patients **with** dementia		patients **without** dementia		**p-value** *	patients with **mild** dementia		patients with **severe** dementia		**p-value** *
	n=338		**n=770**			**n = 146**		**n=192**		
	n	%	**n**	%		**n**	%	**n**	%	
Age at death										
65-79y	65	19.2	308	40.0	**<0.001**	32	21.9	33	17.2	0.551
80–84y	83	24.6	173	22.5		34	23.3	49	25.5	
85y +	190	56.2	289	37.5		80	54.8	110	57.3	
mean	*85.4*		*81.3*		***<0.001***	*84.9*		*85.8*		*0.195*
Gender										
male	116	34.3	412	53.6	**<0.001**	59	40.4	57	29.7	**0.049**
female	222	65.7	356	46.4		87	59.6	135	70.3	
Longest place of residence in last year										
home	132	39.3	616	80.0	**<0.001**	72	49.7	60	31.4	**0.001**
care home	198	58.9	146	19.0		72	49.7	126	66.0	
(elsewhere n=14) †	6	1.8	8	1.0		1	0.7	5	2.6	
Place of death										
care home	196	58.2	146	19.0	**<0.001**	60	41.4	136	70.8	**<0.001**
home	45	13.4	232	30.1		22	15.2	23	12.0	
palliative care unit	10	3.0	61	7.9		8	5.5	2	1.0	
hospital	83	24.6	323	41.9		52	35.9	31	16.1	
(elsewhere n=11) †	3	0.9	8	1.0		3	2.1	0	0.0	
Cause of death										
cardiovascular disease	60	17.8	194	25.2	**<0.001**	34	23.3	26	13.5	**<0.001**
malignancies	30	8.9	237	30.8		18	12.3	12	6.3	
respiratory disease	33	9.8	77	10.0		18	12.3	15	7.8	
disease nervous system	42	12.4	14	1.8		3	2.1	39	20.3	
stroke (CVA)	37	10.9	58	7.5		18	12.3	19	9.9	
other	136	40.2	190	24.7		55	37.7	81	42.2	
Foreseeability of death										
sudden death	87	25.7	286	37.1	**<0.001**	54	37.0	33	17.2	**<0.001**
non-sudden death	251	74.3	484	62.9		92	63.0	159	82.8	

Missing values for gender n=2; longest place of residence n=2; place of death =1

* Fisher's Exact Test or T-test for equality of means to test differences between patients with and without dementia, and between patients with mild and severe dementia

† not included in statistical analysis

MEDICAL CARE PROCESSES AT THE END OF LIFE

During the last three months of life patients with dementia had on average seven contacts with their GP, 41% experienced at least one transition between care settings and 32% received specialist palliative care (Table 2). During the last week of life, 77% had contact with their GP, 74% received treatment aimed at palliation and 14% were transferred at least once; a quarter died in hospital.

Compared with other older people, those with dementia were twice as likely to have a palliative treatment goal during the last week of life, and half as likely to die in hospital.

Compared with patients with mild dementia, patients with severe dementia were half as likely to be transferred in the last three months of life, two and a half times more likely to receive treatment aimed at palliation and three times less likely to die in a hospital.

COMMUNICATION PROCESSES AT THE END OF LIFE

Of all issues, physical problems were the most common topic of conversation between patients with dementia and their GP before (26%) and during (24%) the last month of life, followed by psychological problems (14% and 19% respectively) (Table 3). Options for palliative care were rarely addressed. Overall, communication on end-of-life care was reported for 45% of patients. GPs reported that their patient had ever expressed a preference about the place of death (16%), a proxy decision-maker in the event he or she would no longer be able to speak for him or herself (11%) or about any medical treatment that he or she would or would not want in the last phase of life (11%).

Comparisons with the patients without dementia showed that several end-of-life care issues and preferences were significantly less often discussed with dementia patients, but also were less often aware of these patients' ever expressed end-of-life care treatment preferences. By contrast, the proportion of patients who had ever expressed a preference for a proxy decision-maker to make decisions on their behalf was independent of patient group. The severity of dementia was of particular importance in communication processes at the end of life: compared with mild dementia, severe dementia was related to fewer end-of-life care discussions in the last month of life and before.

TABLE 2. CHARACTERISTICS OF MEDICAL CARE PROCESSES AT THE END OF LIFE

	patients **with** dementia		patients **without** dementia		p-value	OR [95% CI]	patients with **mild** dementia		patients with **severe** dementia		p-value	OR [95% CI]
	n=338		n=770		*	†	n = 146		n=192		*	†
	n	%	**n**	%			**n**	%	**n**	%		
MEDICAL CARE PROCESSES												
During the last 3 months of life												
Seven or more GP-patient encounters ‡	173	52.2	351	45.6	0.090	ns	70	47.9	103	53.6	0.324	ns
Transferred at least once between care settings	135	40.7	457	60.5	**<0.001**	ns	82	56.2	53	28.5	**<0.001**	**0.48 [0.24-0.98]**
Specialist palliative care service used	108	32.0	236	30.7	0.672	ns	33	22.6	75	39.3	**<0.001**	ns
During the last week of life												
One or more GP-patient encounters	259	76.6	490	63.6	**<0.001**	ns	104	71.2	155	80.7	0.051	ns
Palliative treatment goal (vs. curative/life prolonging)	242	73.8	406	54.6	**<0.001**	**2.29 [1.53-3.43]**	84	59.6	158	84.5	**0.001**	**2.61 [1.35-5.07]**
Transferred at least once between care settings	47	14.2	189	25.0	**<0.001**	ns	28	19.2	19	10.2	**0.026**	ns
Death occurred in hospital	83	24.6	323	41.9	**<0.001**	**0.44 [0.33-0.60]**	52	36.6	31	16.1	**<0.001**	**0.34 [0.20-0.59]**
Admission in last week (vs. before last week)	37	45.7	139	44.0	0.803	ns	21	40.4	16	55.2	0.248	ns

Missing values for timing of terminal hospital admission n=10; treatment goal n=37; use of specialist palliative care services n=3;

* Fisher's Exact Test to test differences between patients with and without dementia, and between patients with mild and severe dementia

† Odds ratio with 95% confidence intervals from multivariate logistic regression models comparing patients with (1) and without dementia (0), and comparing patients with severe (1) and mild dementia (0)

‡ Dichotomised at its median value

TABLE 3. CHARACTERISTICS OF COMMUNICATION PROCESSES AT THE END OF LIFE

	patients **with** dementia		patients **without** dementia		p-value *	OR [95% CI] †	patients with **mild** dementia		patients with **severe** dementia		p-value *	OR [95% CI] †
	n=338		**n=770**				**n = 146**		**n=192**			
	n	%	**n**	%			**n**	%	**n**	%		
GP-PATIENT COMMUNICATION												
During last month of life, on												
primary diagnosis	27	8.2	194	25.5	**<0.001**	**0.27 [0.17-0.43]**	22	15.5	5	2.7	**<0.001**	ns
incurability of illness	15	4.6	129	17.0	**<0.001**	**0.29 [0.16-0.52]**	11	7.7	4	2.1	**0.029**	ns
life expectation	20	6.1	133	17.5	**<0.001**	ns	14	9.9	6	3.2	**0.018**	ns
burden of treatments	24	7.3	145	19.2	**<0.001**	**0.32 [0.20-0.53]**	14	9.9	10	5.3	0.136	ns
physical symptoms	78	23.8	281	37.3	**<0.001**	ns	43	30.3	35	18.8	**0.018**	**0.55 [0.31-0.97]**
psychological problems	44	13.5	232	30.8	**<0.001**	ns	29	20.6	15	8.1	**0.002**	**0.39 [0.19-0.81]**
social problems	26	8.0	124	16.5	**<0.001**	ns	16	11.4	10	5.4	0.062	ns
spiritual problems	11	3.4	68	9.1	**0.001**	**0.41 [0.20-0.85]**	8	5.7	3	1.6	**0.060**	ns
options for palliative care	21	6.4	158	20.9	**<0.001**	**0.27 [0.12-0.46]**	15	10.6	6	3.2	**0.011**	**0.22 [0.07-0.66]**
Prior to last month of life, on												
primary diagnosis	51	15.5	285	37.5	**<0.001**	ns	30	21.1	21	11.2	**0.020**	ns
incurability of illness	33	10.0	194	25.6	**<0.001**	ns	20	14.1	13	7.0	**0.041**	ns
life expectation	25	7.6	172	22.7	**<0.001**	**0.45 [0.28-0.72]**	18	12.7	7	3.7	**0.003**	**0.35 [0.13-0.91]**
burden of treatments	23	7.0	192	25.4	**<0.001**	ns	16	11.3	7	3.7	**0.009**	**0.32 [0.12-0.87]**
physical symptoms	84	25.6	308	40.8	**<0.001**	**0.59 [0.43-0.82]**	46	32.4	38	20.4	**0.016**	ns
psychological problems	63	19.3	222	29.5	**<0.001**	ns	39	27.7	24	12.9	**0.001**	**0.40 [0.21-0.75]**
social problems	40	12.3	164	21.8	**<0.001**	ns	25	17.9	15	8.1	**0.010**	**0.47 [0.22-0.98]**
spiritual problems	21	6.4	90	12.0	**0.006**	ns	12	8.6	9	4.8	0.180	ns
options for palliative care	12	3.7	118	15.6	**<0.001**	ns	9	6.3	3	1.6	**0.035**	**0.21 [0.05-0.85]**
Overall end-of-life communication ‡	148	45.1	554	72.9	**<0.001**	ns	83	58.8	65	34.9	**<0.001**	**0.43 [0.26-0.71]**
END-OF-LIFE PREFERENCES												
Patient ever expressed preference												
about a medical end-of-life treatment	24	7.8	181	25.8	**<0.001**	**0.26 [0.16-0.43]**	15	11.1	9	5.3	0.085	ns
for place of death	46	15.7	232	34.3	**<0.001**	ns	33	25.2	13	8.0	**<0.001**	**0.22 [0.10-0.50]**
for proxy decision-maker	32	10.8	75	10.9	1.000	ns	18	13.8	14	8.4	0.186	ns

Missing values for conversations between patient and GP < 3%; missing values or indicated by the GP as unknown, for treatment preferences n=100, for preference for place of death n=138; for preference for proxy decision-maker n=132

* Fisher's Exact to test differences between patients with and without dementia, and between patients with mild and severe dementia

† Odds ratio with 95% confidence intervals from multivariate logistic regression models comparing patients with (1) and without dementia (0) and comparing patients with severe (1) and mild dementia (0)

‡ Whether patient-GP conversations were occurring about one or more issues within or prior to the last month of life

THE DYING PHASE

During the last week of life, the majority of dementia patients were no longer capable of making decisions (83%), completely bedridden and incapable of self-care (83%) and unconscious or in a coma for one or more days until death (59%) (Table 4). According to their GP's estimations, 66% experienced physical distress from at least one symptom during the last week, mostly in terms of a lack of appetite (47%), lack of energy (55%) and drowsiness (36%). Distress from psychological symptoms was judged to occur in 32% of patients, mostly related to feeling sad (20%) or feeling nervous (19%). Finally, 67% of dementia patients with an expressed preference for place of death actually died in their place of choice.

Compared with other older people, those with dementia were 13 times more likely to be incapable of making decisions in the last week of life, more than three and a half times more likely to be completely disabled and twice as likely to be distressed by drowsiness as perceived by their GP.

Compared with patients with mild dementia, patients with severe dementia were 15 times less likely to be capable of decision-making during the last week of life, three times less likely to suffer from psychological distress, and more than two times more likely to feel distressed from drowsiness according to the GP.

TABLE 4. CHARACTERISTICS OF THE DYING PROCESS (LAST WEEK OF LIFE)

	patients **with** dementia		patients **without** dementia		p-value *	OR [95% CI] †	patients with **mild** dementia		patients with **severe** dementia		p-value *	OR [95% CI] †
	n=338		n=770				n = 146		n=192			
	n	%	n	%			n	%	n	%		
THE DYING PROCESS												
Clinical status in last week of life												
Not capable at all to make decisions	269	82.8	172	23.9	**<0.001**	**13.01 [8.75-19.36]**	87	63.5	182	96.8	**<0.001**	**15.40 [5.81-40.78]**
Physically completely disabled and bedridden ‡	280	83.1	398	52.0	**<0.001**	**3.52 [2.41-5.15]**	108	74.5	172	89.6	**<0.001**	ns
One or more days unconsciousness until death	183	58.5	350	48.7	**0.004**	ns	74	54.8	109	61.2	0.297	ns
Physical symptom distress in last week of life §												
GP could make estimation for at least one symptom	296	87.6	640	83.1	0.071	ns	128	87.7	168	87.5	1.000	ns
Distress for at least one symptom	196	66.2	411	64.2	0.606	ns	78	60.9	118	70.2	0.107	ns
lack of appetite	128	46.9	233	38.4	**0.022**	ns	42	35.9	86	55.1	**0.002**	ns
lack of energy	144	55.2	311	50.6	0.237	ns	55	47.0	89	61.8	**0.018**	ns
pain	34	12.8	77	12.7	1.000	ns	11	8.9	23	16.1	0.098	ns
feeling drowsy	95	36.3	124	20.5	**<0.001**	**1.78 [1.21-2.62]**	29	24.0	66	46.8	**<0.001**	**2.38 [1.24-4.55]**
constipation	20	8.1	35	6.3	0.366	ns	9	8.0	11	8.1	1.000	ns
dry mouth	31	13.1	53	9.4	0.129	ns	8	7.3	23	18.3	**0.019**	ns
difficulty breathing	58	20.5	161	26.5	0.055	ns	25	20.2	33	20.8	1.000	ns
Psychological symptom distress in last week of life §												
GP could make estimation for at least one symptom	213	63.0	575	74.7	**<0.001**	**0.52 [0.38-0.72]**	109	74.7	104	54.2	**<0.001**	**0.35 [0.21-0.59]**
Distress from at least one symptom	69	32.4	237	41.2	**0.026**	ns	48	44.4	21	20.2	**<0.001**	**0.31 [0.16-0.62]**
feeling sad	37	19.7	138	25.4	0.137	ns	26	27.1	11	12.0	**0.010**	**0.29 [0.12-0.70]**
worrying	26	13.7	148	27.7	**<0.001**	ns	21	21.0	5	5.6	**0.003**	**0.30 [0.10-0.90]**
feeling irritable	23	11.4	67	12.3	0.801	ns	14	13.3	9	9.3	0.386	ns
feeling nervous	39	19.1	105	19.2	1.000	ns	27	25.2	12	12.4	**0.021**	**0.40 [0.18-0.90]**
Preferences honoured												
Died at the place of wish ▯	31	67.4	166	71.6	0.596	ns	22	66.7	9	69.2	1.000	ns

Missing values for decision-making capability n=62; performance status n=6; consciousness n=77

Additional missing values on symptom distress vary between n=38 (feeling nervous) up to n=135 (dry mouth)

* Fisher's Exact Test to test differences between patients with and without dementia, and between patients with mild and severe dementia

† Odds ratio with 95% confidence intervals from multivariate logistic regression models comparing patients with (1) and without dementia (0), and comparing patients with severe (1) and mild dementia (0)

‡ Performance Status Scale (ECOG) 0-Fully active; 1-Ambulatory, capable of work of a light nature; 2-Capable of self-care but not work; 3-In bed ≥50% of the time, capable of only limited self-care; 4-Completely bedridden, incapable of self-care; figures in table are % of patients for whom a grade 4 (vs. 0 to 3) was assigned

§ MSAS-GDI; Psychological symptoms caused distress if patient "frequently" or "almost constantly" felt this way, according to the GP. Physical symptoms caused distress if symptom distressed the patient "quite a bit" or "very much", according to the GP.

▯ For patients the GP was informed about the preferred place of death

DISCUSSION

To our knowledge this study is the first to describe the circumstances of death for a nationwide population of patients suffering from dementia, irrespective of care setting. It also compares patients with and without dementia and those with mild versus severe dementia. Other strengths of the study include the use of a nationwide and representative network of GPs not selected on the basis of a specific interest in end-of-life care research [12], the representativeness of the identified sample of deaths with the exception of hospital deaths, the research methodology and design which have been used since 2005 to monitor care received at the end of life [13;14;20] and several control mechanisms used to ensure reporting quality [20]: we pretested the questionnaire in 20 GPs for comprehensibility; and performed an automatic follow-up and telephone contact with the GPs to prevent missing data. Upon data-entry, the registration forms were closely scrutinized for errors and data were entered with consistency, range and skip checks).

Several limitations of this study also deserve comment. Firstly, we needed to rely on the GP's judgment of diagnoses and severity of dementia which might have resulted in a limited number of misclassifications. Secondly, notwithstanding end-of-life care registrations made by the Belgian sentinel network of GPs have been found to be valid in previous research [18;19], we were not able to validate the GPs' self-reports against external sources in this particular study. Thirdly, although being a limitation of all investigation using self-reports, we cannot exclude a retrospective recall bias. GPs are asked to make retrospective judgments of their own behavior at that time, and they might have provided socially desirable answers. Also, by using a retrospective data collection approach a possible recall bias about the care provided in the final months of life cannot be excluded. This was partly minimized by collecting data on a weekly basis, leaving little time between death and registration, and by instructing the GP to use patient files as much as possible. Finally, although an extensive set of domains of end-of-life care was taken into account, several aspects could not be covered eg the specific care setting trajectories of dementia patients at the end of life, the support given to the patient's family, the co-ordination of care across providers and care settings, etc.

While dementia research mostly focuses on patients with advanced dementia [5;6], this study shows that in four out of ten dementia patients death occurs before the disease has progressed to an advanced form, and that there is a strong association between the severity of dementia and the location of death. Patients with dementia more often die in a care home than other older patients, a finding that appears to be particularly true for those with severe dementia. That percentages vary greatly depending on the severity of the dementia diagnosis might indicate that efforts are being undertaken to prevent transferring patients with severe dementia to the hospital. This might be related to the growth in anticipatory do-not-hospitalize decisions in Flemish care homes within the last years [28]. However, 25% of patients with dementia (and 16% of those with advanced dementia) still die in hospital in Belgium. Other studies also show that hospital deaths are not uncommon in this population eg a US study reported 15.6% of deaths from dementia take place in hospital [10]. These results highlight the importance of studying dementia across different care settings, but more importantly they pose questions concerning the quality of dying of those experiencing such late-stage hospital transitions [7;13].

A striking result is that dementia patients' end-of-life treatment preferences often remain unknown and that proxy decision-makers are rarely appointed. However, a timely exploration of these preferences is especially recommended for patients with dementia [4], which is stressed by our finding that many patients lack decision-making capacity at the very end of life. Recent work conducted among care home residents in Belgium also showed that few patients suffering from dementia had formally assigned a proxy decision-maker (11% of residents diagnosed with moderate dementia, and 7% of these with severe dementia) [29] On the contrary, in the US almost all nursing home residents with advanced dementia have a designated substitute decision-maker [30], possibly due to the enactment of the Patient Self-Determination Act two decades ago mandating the discussion of advance directives. Our results may stimulate health care professionals to initiate advance care planning timely, to effectively explore preferences of patients for palliative care and end-of-life treatment decisions, and to designate a proxy decision maker more often.

Corresponding with prior work [3], our results also suggest that dementia is not always recognized as a trigger for a palliative care approach. Notwithstanding it might in itself be reassuring that GPs more often anticipate death in case of severe compared with mild dementia, still one out of six patients with severe dementia died suddenly and totally unexpectedly according to the GP, and one out of four dementia patients (16% of severe and 40% of mild dementia patients) still received treatment principally aimed at cure or prolonging life until the very end of life. Also, palliative care was rarely discussed and specialist palliative care services (homecare or care home team, mobile hospital team, palliative care unit, or palliative day care) were involved not more often among those with dementia than among other older people.

In conclusion, considering that a substantial minority of patients with dementia are judged to have died suddenly, and in view of the physical and psychological problems they are judged to experience at the very end of life, our findings might underscore the importance of considering dementia as a trigger for a timely advance care planning and palliative care approach even when life-prolonging treatments are still necessary or needed.

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PART III

END-OF-LIFE CARE: PREFERENCES AND ADVANCE CARE PLANNING

CHAPTER 4:
ADVANCE CARE PLANNING IN BELGIUM AND THE NETHERLANDS

A NATIONWIDE RETROSPECTIVE STUDY VIA SENTINEL NETWORKS OF GENERAL PRACTITIONERS

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ABSTRACT

CONTEXT

Advance care planning (ACP) is an important part of patient-centered palliative care. However, there is a lack of nationwide investigation, especially in Europe.

OBJECTIVES

To investigate the prevalence and characteristics of ACP in two European countries and identify the associated factors

METHODS

A mortality follow-back study was undertaken in 2007 via representative nationwide Sentinel Networks of GPs in Belgium and the Netherlands using similar standardized procedures. All GPs reported on each non-suddenly deceased patient in their practice. Our main outcome measure was whether or not ACP, i.e. an agreement for medical treatment and/or medical decisions in the last phase of life in the case of the patient losing competence, was present.

RESULTS

Among 1072 non-sudden deaths, ACP was made with 34% of patients, and most often related to the forgoing of potential life-prolonging treatments in general (24%). In 8% of all cases ACP was made in consultation with the patient and documented. In 23% of cases care was planned with the patient's family only.

After multivariate analysis, ACP was more often made with patients if they were capable of decision-making during last three days of life [OR 3.86; 95%CI 2.4-6.1]; received treatment aimed at palliation in last week [OR 2.57; 95%CI 1.6-4.2], had contact with GP in the last week [OR 2.71; 95%CI 1.7-4.1]; died of cancer [OR 1.46; 95%CI 1.1-2.0]; or died at home [OR 2.16; 95%CI 1.5-3.0].

CONCLUSION

ACP has been made with a third of the studied terminally ill patient population. The majority of the agreements are made only verbally and care is also often planned with family only. ACP relates strongly both to patient factors as to health care measures performed at the very end of life.

INTRODUCTION

An important aspect of the quality of end-of-life care is the congruence between the care and the patient's wishes. A patient's inability to participate in decision-making could hinder the provision of good quality end-of-life care if their exact preferences remained unknown. One way of shaping future clinical care to fit each patient's wishes and values is by engaging in Advance Care Planning (ACP), a process of communication among patients, their health-care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient is unable to make decisions about his or her care [1].

With the implementation of the Patient Self-Determination Act [2] in the US in 1991, much attention has been given to the right of patients to be involved in decision-making, resulting in the formalization of advance directives such as living wills and the durable power of attorney. Research shows that more than a decade after the enactment, a majority (71%) of those US citizens who experienced a non-traumatic death had completed an advance directive and this was perceived by family members as being associated with better quality of end-of-life care [3;4]. However, most of the literature suggests that merely between 18% and 30% of the US general population have completed an advance directive which may be considered as a low percentage in view of the widespread support for ACP [5].

Comparing with the amount of research conducted in the USA, relatively little studies have addressed the topic of advance care planning in Europe [6]. However, within recent decades the patient's right to self-determination concerning the end of life has increasingly received attention in Western Europe as well.

In this study the prevalence and characteristics of ACP in both Belgium and the Netherlands were investigated. These neighboring countries are situated in the centre of Western Europe and have between 100.000 (Belgium) and 135.000 (the Netherlands) deaths annually which is approximately 1% of the total population [7;8]. Both countries place high value on patient autonomy in their legal frameworks concerning end-of-life issues, eg both have specific laws on patient rights [9;10], and both have a law on euthanasia [11;12] as the first worldwide. In both countries palliative care has been well-developed and integrated within the national health care system [13;14], and on a recently published Quality of Death Index which measures the current end-of-life healthcare environment, availability, cost, and quality across 40 countries, Belgium and the Netherlands ranked respectively fifth and seventh [15].

Using an identical study design, we aim to address the following research questions among a representative sample of terminally ill patients:

1. What is the prevalence and characteristics of advance care planning within a non-suddenly deceased population in Belgium and the Netherlands?
2. Which patient and healthcare characteristics are associated with the occurrence of ACP?

METHODS

STUDY DESIGN, SETTING AND PARTICIPANTS

In Belgium and the Netherlands, we set up a nationwide mortality follow-back study in 2007 aimed at monitoring end-of-life care in collaboration with the national Sentinel Networks of General Practitioners (SENTI-MELC Study). Both networks have a long history of nationwide surveillance of a wide variety of health-related topics [16-22], with a turnover rate that, from year to year, remains low. This means that participating GPs did not enroll because of specific interest in the field of end-of-life care.

The Belgian network covers 1.6% of the total patient population and is representative of all GPs in the country in terms of age, sex and geographical distribution [19;23]. The coverage in the Netherlands approximates to 1% of the registered patient population and the network is nationally representative by gender, age, geographical distribution and population density [24;25]. The Belgian Scientific Institute of Public Health (IPH) and NIVEL (the Netherlands Institute of Health Services Research) acted as coordinators of the respective national Sentinel Networks. In 2007 the Belgian network comprised 156 regularly participating practices, compared to 45 in the Netherlands.

Participating GPs register each death in their practice of anyone aged one year or older on a standardised form within a week of its occurrence [21]. The GP certifies the death of his/her patients him/herself or is notified by the certifying GP or hospital colleague after death.

In order to identify a sample of terminally ill patients who could benefit the most from having an advance care plan, we asked the GP ”Was this death sudden and totally unexpected?”. Only those patients whose death was non-sudden and expected, as judged by the GP, were included in this study.

The design has been used previously in several other studies on end-of-life care and decision-making [21;26-29].

DATA COLLECTION

The registration form comprised structured closed-ended questions surveying socio-demographic patient information, the patient’s place of longest residence during the last year of life, the place and cause of death, and the GP's appraisal whether or not the patient was capable of making decisions in the last three days of life.

A major part was aimed at measuring the existence and content of an advance care plan. Definitions of ACP vary between countries and studies. We based our question on Teno and colleagues who defined ACP as a process of communication among patients, their health-care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient is unable to make decisions about his or her care [1]. ACP in this article covers a range of preferences – without being exhaustive–, both related to the withholding or withdrawal of potentially life-prolonging procedures that are common in end-of-life care decision-making, as to preferences to receive certain care or treatment rather than to have it withheld. We furthermore not only focus on advance care planning made with patients themselves, but also on agreements about the patient's situation that are made with the patient's family only.

In a first set of questions, GPs were asked to indicate whether or not they were aware of "a previous agreement, with the patient or his/her family, not to initiate or to stop one of the following potentially life-prolonging treatments under certain circumstances: chemotherapy, artificial food administration, artificial fluid administration, blood transfusion, artificial respiration, cardiopulmonary resuscitation, dialysis, antibiotics, vasopressors, and hospital transfer". If yes, then GPs were asked to indicate whether or not the agreement was also "made in writing" (advance directive) and/or "made in consultation with the patient". A second group of questions measured the GP's knowledge of any previous agreement with patient or family to perform under certain circumstances the following medical practice: 1) an overall agreement to forgo any potential life-prolonging treatments; (when testing the questionnaire, some GPs indicated that patients do not always plan for specific treatments but use more general statements) 2) intensifying the alleviation of pain and/or symptoms with a possible life-shortening effect; 3) keeping the patient unconscious until death using medication with/without artificial feeding or hydration (continuous deep sedation); 4) prescribing, supplying or administering a drug with the explicit intention of hastening the end of life (physician assisted death). If yes, GPs were asked to indicate whether or not the agreement was "made in writing" and/or "in consultation with the patient".

Other care characteristics measured included: whether or not GP contacts with the patient or with relatives concerning the patient had occurred during the last week of life; whether or not a specialist palliative care service had been involved within the last three months of life; and the main treatment goal in the last week of life (cure, prolonging life, or comfort/palliation; in cases in which the treatment goal had changed during the last week, we relied on the GP's judgment to indicate the most important goal). The wording of these questions was identical to that used in previous research [26;29]. The selection of patient and healthcare characteristics was based on their possible influence on end-of-life care and communication in both countries, as stated in previous research [6;28].

Several procedures were used to ensure data quality: the registration form was originally developed in Dutch, then translated via a forward-backward procedure into French, as the study covered both language regions of Belgium; the study design has been subject to an extensive pilot-study in 2004 [30] and has been used in previous registration years (2005 and 2006) [21;26-29;31];The 2007 questionnaire was pre-tested by ten GPs from each country for readability and comprehensibility; an automatic follow-up and telephone contact with the GPs was used to prevent missing data; upon data-entry, the registration forms were closely scrutinised for errors and several quality control measures were used to ensure optimal data quality (a.o. data-entry checking for consistency and whether GPs followed the correct route in the questionnaire).

ANALYSES

We calculated the proportion of patients for whom the GPs indicated that – for at least one particular medical practice– there was
(1) an advance care plan made in consultation with patient;
(2) an advance care plan made both in consultation with patient and in writing;
(3) care plan made with the patient's family without consulting the patient.

With StatXact6 95% confidence intervals were calculated on the percentages shown. SPSS 17.0 & STATA 10 was used for other statistical computations: logistic regression analysis was used to explore bivariate associations between patient/health care characteristics and the binary outcome measures. Variables that were significantly associated were included in multivariate logistic regression models in order to investigate their independent predictive value. Multilevel analyses (by means of a marginal Generalized Estimating Equations model) accounted for clustering of the data by physician practices. If missing data for an independent variable were higher than 5% of cases these were also entered as a separate category in the multivariate analyses to increase statistical power of the model.

RESULTS

The Belgian and Dutch Sentinel GPs reported 1191 and 520 deaths respectively. Of these 1711 deaths, 20 cases were excluded because too much data was missing. Of all remaining deaths, 63.4% were non-sudden (n=1072). In both countries, the characteristics of the non-sudden deaths were compared with those of a group of non-sudden deaths identified in a nationwide representative large-scale death-certificate study (for Belgium this covered only the Dutch-speaking part). The Belgian sample was representative for age, gender and place of death (n=2128) [32]. In the Netherlands, representativeness was reached for age and gender. However, nursing home deaths were underrepresented (n=9965) [33] (analyses not shown). The characteristics of the study population are presented in Table 1.

An overview of the types and characteristics of ACP within the total sample of terminally ill patients is shown in Table 2. Advance agreements about a medical practice were made with 34% of patients. More specifically, percentages of ACP concerning the withholding or withdrawing of a particular life-prolonging treatment varied between 4% (about vasopressors) and 20% (about hospital transfer). Prevalence figures of ACP to perform a medical decision at the end of the patient's life varied much between the different types of decisions. The highest proportion was found for an agreement made with patients about forgoing any potentially life-prolonging treatment (24% of patients) followed by the decision to intensify pain or symptom alleviation despite a possible life-shortening effect (16%).

The GPs indicated that in 8% of all non-sudden deaths a written advance agreement was made with the patient. As such, the outcomes of the advance care planning were committed to paper in 23% of patients with whom an ACP had been discussed (not shown in table). About most of the treatments and decisions a written advance agreement was made with 1% or 2% of cases. Comparatively speaking, ACP about forgoing potential life-prolonging treatments in general (5%) and about the use of drugs with the explicit intention of shortening the patient's life (3%) was most often documented.

TABLE 1. CHARACTERISTICS OF THE NON-SUDDEN DEATHS STUDIED IN BELGIUM AND THE NETHERLANDS

	All non-sudden deaths * n=1072			Belgium n=755	The Netherlands n=317
	n	%	95% CI †	%	%
Age at death					
< 65 y	176	16.8	[14.2 - 19.7]	15.9	19.0
65–79y	313	29.9	[26.5 - 33.4]	29.2	31.6
≥80y +	559	53.3	[49.6 - 57.1]	54.9	49.3
Gender					
male	489	46.5	[43.1 - 50.0]	45.3	49.7
female	562	53.5	[50.0 - 46.9]	54.7	50.3
Level of education ‡					
elementary or lower	419	44.5	[40.6 - 48.4]	42.2	50.4
lower / higher secondary	427	45.4	[41.5 - 49.3]	48.6	37.3
higher education / university	95	10.1	[7.9 - 12.6]	9.2	12.3
Capacity for decision making 3 days before death ‡ §					
totally incapable	310	36.1	[32.2-40.1]	42.1	20.6
not entirely capable	281	32.8	[29.0-36.7]	30.3	39.1
capable of making decisions	267	31.1	[27.4-35.0]	27.6	40.3
Main treatment goal in last week of life ‡					
cure / prolonging life	188	18.8	[16.1-21.7]	22.7	8.6
comfort / palliation	812	81.2	[78.3-83.9]	77.3	91.4
Specialist palliative care services used ‡					
yes	348	33.2	[30.0-36.5]	38.3	21.2
no	700	66.8	[63.5-70.0]	61.7	78.8
Patient-GP contact in last week of life					
none	290	27.1	[24.1-30.2]	27.8	25.2
at least one	782	72.9	[69.8-76.0]	72.2	74.8
Cause of death					
malignancies	449	42.0	[38.0 - 46.0]	40.2	46.3
cardiovascular disease	189	17.7	[14.7 - 20.9]	17.2	18.7
respiratory disease	89	8.3	[6.3 - 10.8]	8.6	7.6
disease of nervous system	50	4.7	[3.2 - 6.6]	4.5	5.1
stroke	74	6.9	[5.0 - 9.2]	6.6	7.6
other	218	20.4	[17.2 - 23.8]	22.8	14.6
Longest place of residence in last year					
home	750	72.5	[69.7 - 76.0]	71.5	75.2
institution ‖	272	27.5	[24.0 - 30.3]	28.0	24.8
elsewhere (n=6) ¶					
Place of death ‡					
home	298	28.5	[25.1 - 32.1]	24.5	38.6
hospital	382	36.5	[32.8 - 40.3]	39.0	30.2
care home	271	25.9	[22.6 - 29.4]	25.3	27.4 **
palliative care unit / hospice	95	9.1	[7.0 - 11.5]	11.2	3.7

* missing values <5% for age at death, gender, specialist palliative care services, patient-GP contact, cause of death, longest place of residence; place of death; <10% for treatment goal; <15% for level of education; 20% for decision-making capacity

† multinomial confidence intervals (CI), exact method

‡ difference between countries was significant at alpha 0.05 (Fisher's Exact Test)

§ scores could range from 0 to 10: capable of making decisions (score 0 to 4); not entirely capable (score 5 to 9); totally incapable (score 10)

‖ for Belgium: care homes (28.0%); for the Netherlands: residential homes for older people (22.9%) and nursing homes (1.9%)

¶ not included in analysis

** residential homes for older people (19.3%), nursing homes (8.1%)

TABLE 2. PREVALENCE OF ADVANCE CARE PLANNING (N=1072) *

	ACP with **patient**		ACP with **patient and in writing**		Care planning with **family only**	
	%	**95% CI †**	**%**	**95% CI †**	**%**	**95% CI †**
Any type of advance care planning	**33.6**	**[30.7 - 36.6]**	**7.7**	**[6.1-9.5]**	**22.7**	**[20.2-25.4]**
Advance care planning to withhold/withdraw a potentially life-prolonging treatment	**26.2**	**[23.6 - 29.0]**	**3.6**	**[2.6-5.0]**	**18.4**	**[16.1-20.9]**
chemotherapy / radiotherapy	13.4	[11.4 - 15.7]	1.2	[0.6-2.0]	8.1	[6.5-9.9]
artificial food administration	10.5	[8.7 - 12.5]	1.3	[0.7-2.2]	11.6	[9.7-13.7]
artificial fluid administration	9.6	[7.9 - 11.6]	1.5	[0.9-2.5]	12.2	[10.3-14.3]
blood transfusion	7.0	[5.5 - 8.7]	0.9	[0.4-1.6]	6.2	[4.9-7.9]
artificial respiration	9.8	[8.1 - 11.8]	1.4	[0.8-2.4]	9.9	[8.1-11.9]
cardiopulmonary resuscitation	13.0	[11.0 - 15.2]	1.7	[1.0-2.7]	13.3	[11.3-15.6]
dialysis	6.8	[5.4 - 8.5]	0.8	[0.3-1.5]	6.9	[5.5-8.6]
antibiotics	4.9	[3.7 - 6.4]	0.5	[0.2-1.1]	6.4	[5.0-8.1]
vasopressors	3.6	[2.5 - 4.9]	0.6	[0.2-1.3]	6.0	[4.6-7.6]
hospital transfer	19.7	[17.3 - 22.2]	2.2	[1.4-3.3]	12.9	[10.9-15.1]
Advance care planning to perform a medical end-of-life decision	27.2	[24.5 - 30.0]	6.3	[4.9-8.0]	20.6	[18.2-23.2]
forgoing potential life-prolonging treatments in general	24.3	[21.7 - 27.0]	4.7	[3.5-6.2]	18.0	[15.8-20.5]
intensifying pain / symptoms alleviation with a possible life-shortening effect	16.4	[14.2 - 18.8]	2.3	[1.5-3.4]	14.5	[12.4-16.8]
continuous sedation with artificial feeding or hydration	1.8	[1.1 - 2.8]	0.6	[0.2-1.3]	3.1	[2.1-4.3]
continuous sedation without artificial feeding and hydration	3.9	[2.8 - 5.3]	0.9	[0.4-1.6]	3.6	[2.6-5.0]
administration, prescription or supply of drugs with the explicit intention of shortening the patient's life	5.5	[4.2 - 7.0]	3.4	[2.4-4.6]	1.2	[0.6-2.0]

* denominator is all non-sudden deaths; 30 cases (2.8%) were excluded from all analyses on ACP as all of the involved questions were left unanswered

† binomial confidence interval; exact method

In 23% of cases, a care planning was made with the patient's family without involvement of the patients themselves. Most agreements concerned forgoing potential life-prolonging treatments in general (18%), intensifying of pain or other symptoms despite a possible life-shortening effect (15%), CPR (13%), hospital transfer (13%), and artificial food or fluid administration (12%). Agreements about the use of drugs with the explicit intention of shortening the patient's life that were made with the family occurred in 1% of cases.

Multivariate analyses indicated that advance care planning was more often made when patients had had contact with their GP in the last week of life (3 times more often)(table 3), when patients were capable to some extent to make decisions in the last 3 days of life as opposed to totally incompetent patients (2 to 4 times), when treatment was aimed at palliation as opposed to cure or the prolongation of life during the last week of life (2.5 times), when patients died from cancer as opposed to non-cancer disease (1.5 times), and when patients died at home as opposed to in an institution (2 times).

Multivariate analyses also showed that patients in Belgium were half as likely to have an ACP made in writing compared with those in the Netherlands. Additionally, patients had about five times more chance of having a documented ACP when treatment was aimed at palliation or when they had had contact with their GP during the last week of life, and double the chance when specialist palliative care initiatives had been delivered over the last three months of life of when they were still fully capable of making decisions in the last three days of life.

Results of the multivariate analyses further indicated that patient care was three times more likely to be planned with the patient's family only (without consulting the patient) in case treatment was aimed at palliation in the last week of life, and respectively three times and two times less likely if patients remained competent until the end of life or died of a non-cancer disease.

TABLE 3. FACTORS ASSOCIATED WITH THE PREVALENCE OF ADVANCE CARE PLANNING (N=1072)

	ACP with **patient**		ACP with **patient and in writing**		Care planning with **family only**	
	%	95% CI †	%	95% CI †	%	95% CI †
Any type of advance care planning	**33.6**	**[30.7 - 36.6]**	**7.7**	**[6.1-9.5]**	**22.7**	**[20.2-25.4]**
Advance care planning to withhold/withdraw a potentially life-prolonging treatment	**26.2**	**[23.6 - 29.0]**	**3.6**	**[2.6-5.0]**	**18.4**	**[16.1-20.9]**
chemotherapy / radiotherapy	13.4	[11.4 - 15.7]	1.2	[0.6-2.0]	8.1	[6.5-9.9]
artificial food administration	10.5	[8.7 - 12.5]	1.3	[0.7-2.2]	11.6	[9.7-13.7]
artificial fluid administration	9.6	[7.9 - 11.6]	1.5	[0.9-2.5]	12.2	[10.3-14.3]
blood transfusion	7.0	[5.5 - 8.7]	0.9	[0.4-1.6]	6.2	[4.9-7.9]
artificial respiration	9.8	[8.1 - 11.8]	1.4	[0.8-2.4]	9.9	[8.1-11.9]
cardiopulmonary resuscitation	13.0	[11.0 - 15.2]	1.7	[1.0-2.7]	13.3	[11.3-15.6]
dialysis	6.8	[5.4 - 8.5]	0.8	[0.3-1.5]	6.9	[5.5-8.6]
antibiotics	4.9	[3.7 - 6.4]	0.5	[0.2-1.1]	6.4	[5.0-8.1]
vasopressors	3.6	[2.5 - 4.9]	0.6	[0.2-1.3]	6.0	[4.6-7.6]
hospital transfer	19.7	[17.3 - 22.2]	2.2	[1.4-3.3]	12.9	[10.9-15.1]
Advance care planning to perform a medical end-of-life decision	27.2	[24.5 - 30.0]	6.3	[4.9-8.0]	20.6	[18.2-23.2]
forgoing potential life-prolonging treatments in general	24.3	[21.7 - 27.0]	4.7	[3.5-6.2]	18.0	[15.8-20.5]
intensifying pain / symptoms alleviation with a possible life-shortening effect	16.4	[14.2 - 18.8]	2.3	[1.5-3.4]	14.5	[12.4-16.8]
continuous sedation with artificial feeding or hydration	1.8	[1.1 - 2.8]	0.6	[0.2-1.3]	3.1	[2.1-4.3]
continuous sedation without artificial feeding and hydration	3.9	[2.8 - 5.3]	0.9	[0.4-1.6]	3.6	[2.6-5.0]
administration, prescription or supply of drugs with the explicit intention of shortening the patient's life	5.5	[4.2 - 7.0]	3.4	[2.4-4.6]	1.2	[0.6-2.0]

* denominator is all non-sudden deaths; 30 cases (2.8%) were excluded from all analyses on ACP as all of the involved questions were left unanswered

† binomial confidence interval; exact method

DISCUSSION

In general, advance care planning on at least one medical practice concerning the end of life occurred with about a third of all non-suddenly deceased patients in Belgium and the Netherlands, and most often related to the forgoing of potential life-prolonging treatments in general. Only in a small part of the sample an advance care plan was made in writing. For a quarter of all patients, care had been planned with the family without patient involvement. The factors associated with the outcome measures but varying according to type of care planning were: country, dying at home, dying of cancer, having GP contacts within the last week of life, being capable of decision-making in the last three days of life, having a palliative treatment aim during the last week of life, the involvement of specialist palliative care services within the last three months of life.

To our knowledge, this study is the first to provide European data on the prevalence of ACP within a robust terminally ill population, irrespective of setting, country or diagnosis. This has been made possible by the use of an identical and dependable methodology across countries: a nationwide representative Sentinel Network of GPs, each with a long history of registration research not selected on the basis of a specific interest in end-of-life research. Because the observation unit of this study was the GP, knowledge of whether the patient had an advance care plan was based on the report of the GP only. However, several control mechanisms were used to ensure reporting quality. Registrations were made within a week after death to limit recall bias as much as possible, and GPs were generally instructed to use the patient's records while completing the form. However, since detailed information concerning the care provided is not always available from the patient's medical files (e.g. verbal agreements), surveying GPs directly has an important surplus value. We also took several measures that contributed to the reliability of data: the use of an identical jointly-developed and pre-tested questionnaire, and strict research procedures such as data-entry with consistency, range and skip checks. The surveyed sample of non-sudden deaths is well representative of the national population of non-sudden deaths by age, gender, and place of death in the Dutch-speaking part of Belgium and by age and gender in the Netherlands. The lack of representativity for place of death in the Netherlands is a limitation resulting from an underrepresentation of nursing home patients due to the fact that nursing home physicians take over the care from GPs once patients are admitted for long-term care [34;35]. Additionally, since our reports were limited to the perceptions of GPs, ACP made within a hospital might not always have been fully communicated to GPs. Consequently, although representativity is reached for the general practice population in both Belgium and the Netherlands, there might be some underestimation of the prevalence of ACP for all non-sudden deaths in both countries. This study has other limitations as well. Due to the retrospective design of the study a possible memory bias could never be excluded. It was also not possible to explore cause and effect relationships, only associations between characteristics and the prevalence of ACP. Additionally, definitions of ACP may vary between countries which makes comparison of results with previous studies difficult. Finally, the timing of the agreement was not measured.

ACP is documented only in a small part of patients, but verbally occurs with many more. This finding is in line with the prevailing consensus in present literature, that ACP may not be narrowed to the formulation of a written advance directive, but must be regarded as a continuous process of communication of which a written declaration may be an outcome [36]. Nevertheless, in order to provide care in correspondence with the patient's wishes, a written advance directive may be very important when the decision-making is urgent without time for consultation, to use as a foundation for future updating and reviewing, or to ensure continuity of care – end-of-life care transitions occur rather frequently in Belgium and the Netherlands [27;37]. In addition, ACP only has a legal status when it is made in writing. Possible reasons for the low prevalence are that preferences may change, that physicians prefer to remain free to act according to their own medical judgment at the moment of decision-making [38], or that ACP is seen as a social process between physician and patient and documenting it formally is regarded as unnecessary [39].

Remarkably, advance care planning is documented considerably more often in the Netherlands than in Belgium, even after controlling for country differences in patient or care characteristics. This country-specific effect might be rooted in a general difference in medical culture between the two countries, as physicians in the Netherlands tend more towards the formalization of practices [40;41]. Also, the political and societal debate concerning euthanasia and other end-of-life decisions has a longer history in the Netherlands than in Belgium and the Dutch Medical Treatment Contracts Act [10] in which the importance of the patient's written authority for medical treatments has to be made explicit to them, has been in place several years longer than the Belgian Law on Patient Rights [10]. As a result, advance directive forms in the Netherlands (widely promoted by the Dutch Association for Voluntary Euthanasia) are more widespread compared with Belgium, which may also be part of the explanation.

However, compared with findings from the US (71% of non-traumatic deaths) the prevalence of advance directives in both our study samples remains very low [3]. Also in the UK, a study concluded that discussions related to ACP are very rarely initiated among a group of chronically ill patients [42]. It seems safe to suggest that advance directives are still more prevalent in the US than in Europe. A reason for this may be that advance directives have a much longer tradition in the US, and the fact that advance directives, which usually limit treatment, are considered more necessary in the US because American physicians are more inclined to more aggressive treatment options than their European colleagues [43]. Also, in most European countries it is not compulsory for hospitals or nursing homes to inform admitted patients of their right to draft a treatment directive, in contrast to the US where studies have shown that the prevalence of advance directives documentation in nursing home medical records has increased significantly since the implementation of the Patient Self-Determination Act [44]. The relatively high rate of care planning with the family of the patients without the latter's involvement in our study might also reflect these differences in legislation. This finding was particularly surprising since in both Belgium and the Netherlands, a great value is being placed on patient autonomy in health care, as is the case in most Western countries.

Our results further show that cancer patients are more often involved in the process of advance care planning than non-cancer patients, as the opposite is true for patient care planning that occurs with family only. It is known that cancer patients have a relatively more predictable dying course with often a short period of evident decline at the very end compared with other chronic diseases [45]. This might also mean that cancer patients may be more aware of the life-threatening consequences of their disease, and thus possibly engage in advance care planning more proactively compared to others.

Another key finding is that ACP relates strongly to the provision of palliative care. A core value of the palliative care philosophy from its inception has been in enabling people to make genuine choices about their own care [46]; this is very reconcilable with what is intended by ACP. Although palliative care has much to offer from the early stages of a progressive disease [47], previous research demonstrated that palliative care is often initiated relatively close to death [28;48]. This might suggest that also end-of-life care planning is initiated rather late in the dying process, when death is imminent and end-of-life decision-making comes to the fore.

That end-of-life care agreements are relatively often made without consulting the patient supports this thought as it possibly means that discussions about future medical care take place at a time when the patient has already become incompetent or is unable to express his/her wishes and advice from family members is needed, which is in line with our results. The finding that many patients are unable to make decisions at the very end of life points at the importance of exploring patient wishes beforehand so that physicians can take them into account when making end-of-life decisions. Also, the strong relationship between having one or more GP consultations within the last week of life and the chance of having made an ACP might further suggest that ACP is initiated and discussed at, rather than before, these late contacts. This may be because some GPs feel constrained time-wise, or are uncertain about when to initiate end-of-life discussions [49-51]. Previous studies have shown that patients are more satisfied with their GP when advance directives are discussed [51]. And moreover, it could be a satisfactory experience for the physician as well [52]. Altogether, the extent to which advance care planning truly occurs in advance of future medical decision-making is questionable.

In conclusion, advance care planning is present in one third of the studied terminally-ill patient population, but these end-of-life care agreements are very often left undocumented. This study supports the idea that advance directives are more widespread and prevalent in the US than in European countries, although differences did occur between Belgium and the Netherlands as well. Our results further suggest that ACP strongly relates to the provision of palliative care and that it is often made ad hoc in the patient’s terminal phase of life, rather than earlier in the course of the illness. The high rate of care planning with the family without patient involvement further supports this thought. Initiatives to encourage GPs to document the ACP discussions and agreed outcomes, and to do this timely, could assist to ensure that a person's wishes are followed.

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CHAPTER 5:

GPS’ AWARENESS OF PATIENTS’ PREFERENCE FOR PLACE OF DEATH

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ABSTRACT

BACKGROUND

Being able to die in one's place of choice is an indicator of the quality of end-of-life care. GPs may play a key role in exploring and honouring patients' preferences for place of death.

AIM

To examine how often GPs are informed about patients' preferred place of death, by whom and for which patients, and to study the expressed preferred place of death and how often patients die at their preferred place.

DESIGN OF STUDY

One-year nationwide mortality retrospective study.

SETTING

Sentinel Network of GPs in Belgium, 2006.

METHOD

GPs' weekly registration of all deaths (patients aged ≥1 year).

RESULTS

A total of 798 non-sudden deaths were reported. GPs were informed of patients' preferred place of death in 46% of cases. GPs obtained this information directly from patients in 63%. GP awareness was positively associated with patients not being hospitalised in the last 3 months of life (odds ratio [OR] = 3.9; 95% confidence interval [CI] = 2.8 to 5.6), involvement of informal caregivers (OR = 3.3; 95% CI = 1.8 to 6.1), use of a multidisciplinary palliative care team (OR = 2.5; 95% CI = 1.8 to 3.5), and with presence of more than seven contacts between GP and patient or family in the last 3 months of life (OR = 3.0; 95% CI = 2.2 to 4.3). In instances where GPs were informed, more than half of patients (58%) preferred to die at home. Overall, 80% of patients died at their preferred place.

CONCLUSION

GPs are often unaware of their patients' preference for place of death. However, if GPs are informed, patients often die at their preferred location. Several healthcare characteristics might contribute to this and to a higher level of GP awareness.

INTRODUCTION

InWestern society, the importance of patient-centered care is increasingly recognised, [1] and personal autonomy and respect for patients' preferences at the end of life have become increasingly important [2;3]. More specifically, being able to die in one's place of choice is considered a key indicator of the quality of end-of-life care and of a good death [4;5].

GPs may play a key role in exploring and honouring a patient's preference for place of death. In many countries, including Belgium, GPs have built up long-term relationships with their patients over the course of many years [6;7]. They also play a central role at the end of life, as patients spend most of their time at home or in care homes in the final months before death, where GPs are their primary professional caregivers [8]. As a result of their pivotal position, GPs can be the expert caregivers, initiating advance care planning, identifying where people would prefer to die, and coordinating care in accordance with the patient's preference [9]. As many patients might lack the competence to make decisions at the end of life, [10] timely communication between the GP and patient is of particular importance [11].

Empirical data on how often GPs are informed about such preferences are lacking. Previous research has focused mainly on studying how many patients would like to die at home, [12-14] but has not explored how often GPs are informed of this and about which patients they are informed. Also, it is unknown how often GPs are informed about patients' preferences by patients themselves or by proxies, which can also provide insights regarding patient autonomy. In addition, many previous studies have shown large variations in the proportion of patients preferring home death, or the proportion of patients dying at their place of choice. This is mostly due to differences in design or methodology, where studies have focused only on specific patient groups or care settings; for example, cancer patients or hospitalised patients [12]. Studies measuring across settings and patient groups are lacking.

This study focuses on the following research questions:

1. How often and by whom are GPs informed about their patients' wish for place of death, and what are the associated patient, disease, and healthcare characteristics?
2. What are the preferences of those patients about whom GPs are informed?
3. How often do those patients die in their place of choice and what are the associated patient, disease, and healthcare characteristics?

METHODS

STUDY DESIGN

A 1-year nationwide retrospective mortality study was carried out in 2006 in Belgium. Data were collected within the SENTI-MELC study [15] "the Study on Monitoring End-of-Life Care via the nationwide Sentinel Network of General Practitioners" in Belgium. This GP network has been operational since 1979 and proved to be a reliable surveillance system for health-related epidemiological data [15-19]. It covers 1.75% of the total Belgian population and is representative of all GPs in the country in terms of age, sex, and geographical distribution [19;20]. In 2006, the network counted 174 regularly participating GP practices.

DATA COLLECTION

Each week all participating GPs reported, on a standardised registration form, every deceased patient in their practice aged 1 year or older. For each patient, GPs were asked whether the death had occurred 'suddenly and totally unexpectedly'; those deaths were excluded in order to identify a sample of dying persons for whom the provision of end-of-life care is a relevant consideration [10;15;21]. Several quality control measures (such as data entry with consistency, range, and skip checks, possibility of contacting GPs by phone, double data entry) were used to ensure optimal data quality.

REGISTRATION FORM

For all deaths, the registration form surveyed: age at death, sex, region of Belgium where the patient resided, living status (for example; living with regular partner at time of death), level of education, cause of death, and place of death. For all non-sudden deaths it further measured:

- whether the GP was informed, verbally or in writing, of the patient's preference regarding place of death. If yes, by whom the GP was informed (patient him/herself, patient's family or significant other, someone else) and where the patient preferred to die: at home or living with family, in a care home (home for older people or nursing home), in a hospital (excluding palliative care unit), in an inpatient palliative care unit, or elsewhere;

- main treatment goal in the last 3 months of life: cure, prolonging life, comfort/palliation;
- presence of a multidisciplinary palliative care service in the last 3 months of life (multidisciplinary home care or care home teams, mobile hospital teams, inpatient palliative care units, or palliative day care centre);
- involvement of informal caregivers during the last 3 months of life: not/sometimes/often;
- extent to which physical, psychosocial, and spiritual (existential/religious) care was provided in the last 3 months of life (1 = not/to a very small extent, to 5 = to a very large extent);
- number of contacts (consultations, home visits, excluding telephone contact) with the patient or with significant others regarding the patient in the last 3 months of life;
- whether or not the patient was hospitalised during the last 3 months of life.

The number of GP contacts, the main treatment goal, and the extent to which physical, psychosocial, and spiritual care was provided were measured in three separate time frames: final week of life, second to fourth week, and second to third month before death.

The registration form was originally developed in Dutch and translated via a forward–backward procedure into French, as the study covered both language regions of Belgium. The full registration form and more details on the SENTI-MELC study's methodology have already been published [15].

ANALYSES

Fisher's exact tests were conducted to explore bivariate associations between patient, disease, and healthcare characteristics, and whether or not: (1) the GP was informed about the preference for place of death; and (2) there was congruence between the preferred and actual place of death. A multivariate logistic regression analysis was also used to further investigate these associations. All analyses were performed using SPSS (version 16.0).

RESULTS

STUDY POPULATION

In total, 1305 deceased patients were registered, of which 20 cases were excluded from further analysis because of too many missing data. Of the remaining 1285 patients, 62.1% (n = 798) died non-suddenly; these are described in Table 1. Age, sex, and place of death of those who died in the Dutch-speaking part of Belgium were compared with the non-sudden deaths identified in another study representative of all deaths in the same part of the country (n = 2128) [22]. There were no significant differences for these characteristics between studies (binomial 95%confidence interval [CI], exact method). No comparison data were available for the French speaking part of Belgium.

TABLE 1. PATIENT CHARACTERISTICS OF THE STUDY POPULATION OF NON-SUDDEN DEATHS (N=798) *

	n	(%)
Age at death		
≤ 64 years	99	(12.5)
65-79 years	275	(34.6)
≥ 80 years	421	(53.0)
Sex		
male	404	(50.6)
female	394	(49.4)
Level of education		
elementary or lower	313	(43.5)
lower secondary	221	(30.7)
higher secondary	124	(17.2)
higher education / university	62	(8.6)
Cause of death †		
cancer	362	(45.8)
non-cancer	428	(54.2)
Place of death		
home	187	(23.4)
care home ‡	220	(27.6)
hospital	308	(38.6)
palliative care unit	83	(10.4)

* missing values for age n=3; level of education n=78; and cause of death n=8

† encoded into ICD-10 codes (coding by International Statistical Classification of Diseases and Related Health Problems)

‡ care homes include homes for older people and nursing homes

GPS' AWARENESS OF PATIENTS' PREFERRED PLACE OF DEATH

GPs knew patients' preferred place of death in 363 (46%) of all 798 non-sudden deaths. They were informed directly by the patient in about 63% of cases: 40% (40.4%) by the patient only and 22% (22.2%) by both the

TABLE 2. FACTORS ASSOCIATED WITH GP AWARENESS OF THE PATIENT'S PREFERRED PLACE OF DEATH (N=796)

	Total n *	% Being informed	Bivariate p-value †	Multivariate OR (95%CI) ‡
Patient and disease characteristics				
Age at death, years				
≤ 64 years	99	53.5	0.18	ns
65-79 years	274	42.7		
≥ 80 years	420	45.7		
Sex				
male	403	43.9	0.36	ns
female	393	47.3		
Level of education				
elementary of lower	313	44.1	0.48	ns
lower secondary	221	46.2		
higher secondary	124	50.0		
higher education / university	62	53.2		
Cause of death				
cancer	362	53.6	**<0.001**	**ns**
non-cancer	426	39.0		
Residence characteristics				
Place of death				
home	186	81.2	**<0.001**	§
care home	219	50.7		
hospital	308	18.5		
palliative care unit	83	53.0		
Hospitalized ¶				
not	314	69.1	**<0.001**	**3.91[2.78-5.56]**
at least once	474	30.2		**ref**
Region of Belgium				
Dutch-speaking	499	44.5	0.71	ns
French-speaking	225	47.6		
Brussels capital	72	47.2		
Degree of urbanisation				
core of large city	433	48.7	0.14	ns
average	214	40.7		
low or rural	148	43.9		
Living with regular partner				
yes	370	47.8	0.28	ns
no	420	43.8		

patient and a family member or a significant other. Thirty-six per cent were informed by the patient's family or significant other only, and less than 2% by someone else.

Bivariate analyses showed that GPs were more often informed about preferred place of death for patients who died of cancer, for home deaths, and for patients who had never been hospitalised in the final 3 months of life (Table 2). GPs were also more often informed if they had had more than seven contacts with the patient or family over the last 3 months of life, if informal care was given, or if treatment had a palliative aim. The in-

TABLE 2. FACTORS ASSOCIATED WITH GP AWARENESS OF THE PATIENT'S PREFERRED PLACE OF DEATH (N=796) (CONTINUED)

	Total n *	% Being informed	Bivariate p-value †	Multivariate OR (95%CI) ‡
Health care variables				
Number of GP contacts ‖ ¶				
0-7	402	27.9	**<0.001**	**ref**
> 7	394	63.7		**3.04[2.16-4.28]**
Informal care ¶				
none or very little	78	25.6	**< 0.001**	**ref**
sometimes / often	676	49.4		**3.30[1.78-6.12]**
Treatment goal ¶				
curative / life-prolonging	121	24.8	**< 0.001**	**ns**
palliative	230	61.3		
from curative/life-prolonging to palliative in last month	361	46.3		
other combinations	37	27.0		
Multidisciplinary palliative care services ¶				
yes	317	62.1	**<0.001**	**2.50[1.78-3.52]**
no	439	35.8		**ref**
Physical care ¶				
not or to a (very) small extent	9	33.3	0.51	ns
average / to a (very) large extent	702	47.3		
Psychosocial care ¶				
not or to a (very) small extent	122	33.6	**<0.001**	**ns**
average / to a (very) large extent	533	52.7		
Spiritual care ¶				
not or to a (very) small extent	276	45.3	**<0.001**	**
average / to a (very) large extent	229	62.9		

* missing values for being informed n=2; age at death n=3; level of education n=76; cause of death n=8; hospitalised in last three months of life n=8; degree of urbanisation n=1; living with regular partner at time of death n=6; informal care n=42; treatment goal n=47; specialist palliative care initiative delivered n=40; physical care n=85; psychosocial care n=141; and spiritual care n=291

† Fisher's Exact Test

‡ odds ratio (OR)with 95% Confidence Intervals from multivariate regression analysis (not informed as reference category), performed for all bivariately tested significant associations

§ not taken into account in multivariate analysis because of potential multicollinearity problems with being hospitalised in last 3 months of life

‖ total number of contacts dichotomized at its median value

¶ over the last three months of life

** not taken into account in multivariate analysis because of potential multicollinearity problems with psychosocial care

ns = not significant; ref = reference category

volvement of multidisciplinary palliative care services and the provision of psychosocial or spiritual care also contributed to a greater awareness by the GPs.

After multivariate logistic regression analysis (Table 2), four factors remained significant: GPs were almost four times more likely to be informed if patients were never hospitalised, more than three times more likely if informal care was provided, two and a half times more likely if a multidisciplinary palliative care initiative was involved, and three times more likely if they had had more than seven contacts with the patient or family, all in the last 3 months of life.

PREFERRED AND ACTUAL PLACE OF DEATH

If the GP was informed, then in more than half of cases (58%) the patient preferred to die at home (Table 3): 31%in a care home, and far less in other settings. For 72% of all patients who preferred to die at home, their preference was fulfilled. Patients who preferred to die elsewhere died at their place of choice in 83%or more of cases. Overall, for 80% of patients, congruence between the actual and the preferred place of death was attained.

TABLE 3. PREFERRED AND ACTUAL PLACE OF DEATH OF PATIENTS FOR WHOM THE GP IS INFORMED OF THE PREFERENCE (N=363) *

Home	209	57.7	**71.8 †**	3.3	14.4	10.5
Care home	112	30.9	0	**92.9 †**	6.3	0.9
Hospital	17	4.7	0	0	**94.1 †**	5.9
Palliative care unit	24	6.6	0	0	16.7	**83.3 †**

* missing values preferred place of death n=1

† percentages of patients who eventually died at the expressed preferred place of death (of which the percentages are shown in the left part of the table)

FACTORS ASSOCIATED WITH CONGRUENCE BETWEEN THE PREFERRED AND ACTUAL PLACE OF DEATH

For those patients who wished to die at home, congruence was more often achieved if patients were not hospitalised in the last 3 months of life (86% compared with 49% for those hospitalised at least once) and for those with whom the GP had more than seven contacts over the last 3 months of life (78% compared with 58% of those with seven contacts or fewer). Both factors remained significant when tested multivariately (odds ratio [OR] 5.65; 95% CI = 2.9 to 11.1 and OR 2.35; 95% CI = 1.2 to 4.7 respectively). Significance was reached for none of the other patient, disease, residence, or healthcare characteristics included in the registration form. Because the number of patients choosing to die in places other than home but not doing so was small, no factors were associated with the congruence between these preferred and actual places of death.

DISCUSSION

SUMMARY OF MAIN FINDINGS

In Belgium, less than half of GPs had been aware of their deceased patients' preferred place of death. In cases where they were aware, they had been informed mostly by the patients themselves but also often by proxies. GP awareness was higher if, during the last 3 months of life, the patient was not hospitalised, if informal caregivers were involved, if a specialist multidisciplinary palliative care team was consulted, or if there were more than seven contacts between the GP and the patient or family. The majority of patients expressed a wish to die at home or in a care home, although a minority preferred to die in a hospital or a palliative care unit. Most incongruence between the actual and preferred place of death occurred for those patients wishing to die at home.

STRENGTHS AND LIMITATIONS OF THE STUDY

As far as the authors know, this is the first study investigating GP awareness of preference of place of death on a nationwide and population-based level. An important strength of the study is the use of a representative sample of non-sudden deaths, not restricted to a specific setting, age group, or disease, due to the fact that most of the Belgian population (95%), including care home residents, have their own GP who is easily accessible and consulted on a regular basis (79%of the population have contact with their GP at least once a year) [23]. Another strength is the use of the representative, [19;20] nationwide Sentinel Network of GPs, which is a highly reliable surveillance system for a wide variety of health-related epidemiological data, including end-of-life care provision [15;16;18;22;24;25]. Consequently, the high quality of the network's research procedures (for example, weekly registrations which may limit memory bias, leaving little time between death and registration) guarantees data of high scientific quality.

There are also some limitations to this study. First, due to the retrospective approach, a possible memory bias cannot be excluded entirely; for example, a patient's wishes might not always be registered in their records. Second, by measuring preference for place of death only if GPs had been informed, these results cannot be generalised to all deaths. Third, it was not possible to explore cause and effect relationships, only associations between GP awareness and patient/healthcare factors. Finally, the timing of or changes in expressed preferences were not measured, which could have provided more in-depth interpretation.

COMPARISON WITH EXISTING LITERATURE

In cases where patients are hospitalised within the last 3 months of life, GPs appear to be less often informed of their wishes. This might mean that GPs, once informed, may actively contribute to preventing hospitalisations at the end of life, or that GPs more often set out to explore the patient's preference if the patient's situation allows the possibility of dying at home. However, it is more likely that GPs either lose track of their patient once hospitalised, or that it becomes much more difficult to communicate and to explore where these patients want to die. It probably also means that exploration or expression of wishes occurs relatively late in the dying process, as most hospitalisations take place close to the time of death [25]. This suggests that end-of-life care communication might best be started early in the progress of the illness, prior to the moment of possible hospitalisation. The Belgian guideline for GPs on end-of-life care communication ('Zorgzaam thuis sterven; een zorgleidraad voor huisartsen') could be a very useful instrument to deal with feelings of uncertainty and to initiate timely advance-care planning [26].

The positive association between the involvement of a multidisciplinary palliative care team and GP awareness might suggest that an expressed preference triggers GPs to get such a team involved so that the patient can die more easily at a preferred place, which is often at home. However, the association could also be explained conversely: involving such palliative care teams might also indicate that GPs recognise that the patient is in a terminal phase of life, making the exploration regarding their end-of-life care automatically more relevant.

Besides professional palliative care, the involvement of informal caregivers also increases the possibility of GPs being informed. Loved ones surrounding the patient may act as facilitators so that patients can more easily express their end-of-life wishes to their GP. Or GPs may discuss the patient's situation directly with the family, which is supported by the present results (58%informed by proxy). Studies have likewise shown that the presence of informal caregivers itself is strongly related to the possibility of staying at home (which is often the preferred place) until death [27].

The present finding that the majority of patients prefer to die at home in the presence of their loved ones fits well with other studies [12;13;28]. Overall, the number of patients dying in their place of choice in Belgium is quite high compared with other studies, in which percentages between 30%and 94%are found, depending on the methodology used [12;13;29-37]. Since congruence could only be measured for those patients whom GPs were informed about, it can be assumed that the high congruence found in the present study is probably an overestimation. The fact that patients died in hospital more often when GPs were not informed (58% as opposed to 16% where GPs were informed) confirms this hypothesis. Additionally, congruence may also be obtained less often in societies where the relationship between a GP and his/her patient is less stable, or where out-of-hours arrangements are not necessarily manned by local GPs, or are manned by teams in whom patients do not confide their hopes.

IMPLICATIONS FOR FUTURE RESEARCH OR CLINICAL PRACTICE

Awareness by GPs of where their patients want to die is an important prerequisite if GPs aim to coordinate care in accordance with their patients' wishes. The relatively low figure found in this study leaves room for improvement for many GPs. Timely communication and involvement of palliative care teams and informal caregivers might contribute to a higher GP awareness.

Congruence between the actual and preferred place of death is allied not only to the patient's choice, but also to social and structural healthcare availability as well, and may therefore not always be realistic to attain [38]. However, results of this study showing that the high positive association between GPs being aware and patients dying in their place of choice, might suggest that GPs, if aware, actively contribute to making it possible for patients to die where they want to. Care might be coordinated and directed by the GP in such a way that fulfilment of the patient's end-of-life wishes is maximally enhanced.

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PART IV

PREFERENCES AND DECISION-MAKING ABOUT LIFE-ENDING PRACTICES

CHAPTER 6:
DEALING WITH REQUESTS FOR EUTHANASIA

INTERVIEW STUDY AMONG GENERAL PRACTITIONERS IN BELGIUM

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ABSTRACT

CONTEXT

In many countries physicians are confronted with requests for euthanasia. Notwithstanding euthanasia is legally permitted in Belgium, it remains the subject of intense debate.

OBJECTIVE

To gather in-depth empirical data on how GPs deal with these requests in Belgium.

METHODS

Mortality follow-back study in 2005-2006 via the nationwide Sentinel Network of General Practitioners. Standardised face-to-face interviews were conducted with GPs for all reported patients who did not die suddenly or totally unexpectedly at home, as judged by the GP.

RESULTS

We conducted 205 interviews. Of these, 27 patients had at some point expressed a wish to receive a drug administered by a physician with the explicit intention to end life, i.e. euthanasia. Thirteen of these formulated their request explicitly and repeatedly, according to their GP. Compared with patients who expressed a wish but not an explicit/repeated request for euthanasia, those patients' request was more often documented (8/13 vs. 2/14;p=0.01), and reiterated until their final days of life (6/13 vs. 0/14;p=0.02). Five patients received euthanasia. For the other 22 patients, GPs gave different reasons for not acceding to the request, often related to criteria stipulated in the Belgian law on euthanasia, and sometimes related to personal reasons.

CONCLUSIONS

It is not uncommon for patients to ask their GP for euthanasia, although explicit requests remain relatively rare. Requests tend to vary widely in form and content, and far more are expressed than complied with. For many GPs the Belgian law on euthanasia serves as a guiding principle in this decision-making process, although in a minority of the cases a GP's personal opinion towards euthanasia seems to be decisive.

INTRODUCTION

Many studies in several countries have shown that physicians are confronted with patients who explicitly request them to end their lives [1-11]. Notwithstanding that it is illegal in most countries to grant these requests, robust incidence studies have shown that euthanasia occurs in many countries [1;5;7;10;11] and is the subject of intense societal, legal, and medico-ethical debate. Belgium, the Netherlands and recently Luxembourg are the only countries in the world where euthanasia is legally permitted if practiced under strict conditions of careful practice [12-14].

General practitioners (GPs) are the physicians most often confronted with requests for euthanasia [2;6;9]. However, their long-term relationship with patients and their intimate involvement in the patient's situation often make it very challenging for them to deal with these far-reaching requests [15;16]. A Dutch study among GPs has shown that many are confronted with far more requests than they actually comply with. Fifty-six percent remained ungranted because the patient died before euthanasia was carried out (13%) or before decision-making was finalized (13%), because the physician refused the request (12%) or because the patient withdrew the request themselves (13%) [4]. Unfortunately, in-depth information on the desire or request for euthanasia and the way they are handled is very limited.

One recent Dutch study focused on the concept of unbearable suffering in the context of ungranted euthanasia requests, but did not address in detail the nature, timing and characteristics of such requests, and did not study the actual dying process of patients with ungranted requests [17]. In Belgium, only prevalence data are available while no study has ever explicitly focused on euthanasia requests [18-20].

For this study, we conducted in-depth interviews with GPs in Belgium, focusing on patients who died at home under the GP's care. We investigated how many and which patients expressed a wish for euthanasia, the characteristics of these wishes, how many and which were not granted, what the reasons for not granting them were, and how patients whose euthanasia wish was not granted eventually died.

METHODS

STUDY DESIGN, SETTING AND PARTICIPANTS

We performed a large-scale mortality follow-back study in 2005-2006 to monitor end-of-life care and decision-making in Belgium using the Sentinel Network of General Practitioners (SENTI-MELC study) [21]. This network, founded in 1979, has proved to be a reliable surveillance system for a wide variety of health-related epidemiological data [21-24]. In 2005 and 2006, it consisted of 181 and 174 practices respectively, representative of all Belgian GPs in terms of age, sex and region [23;25].

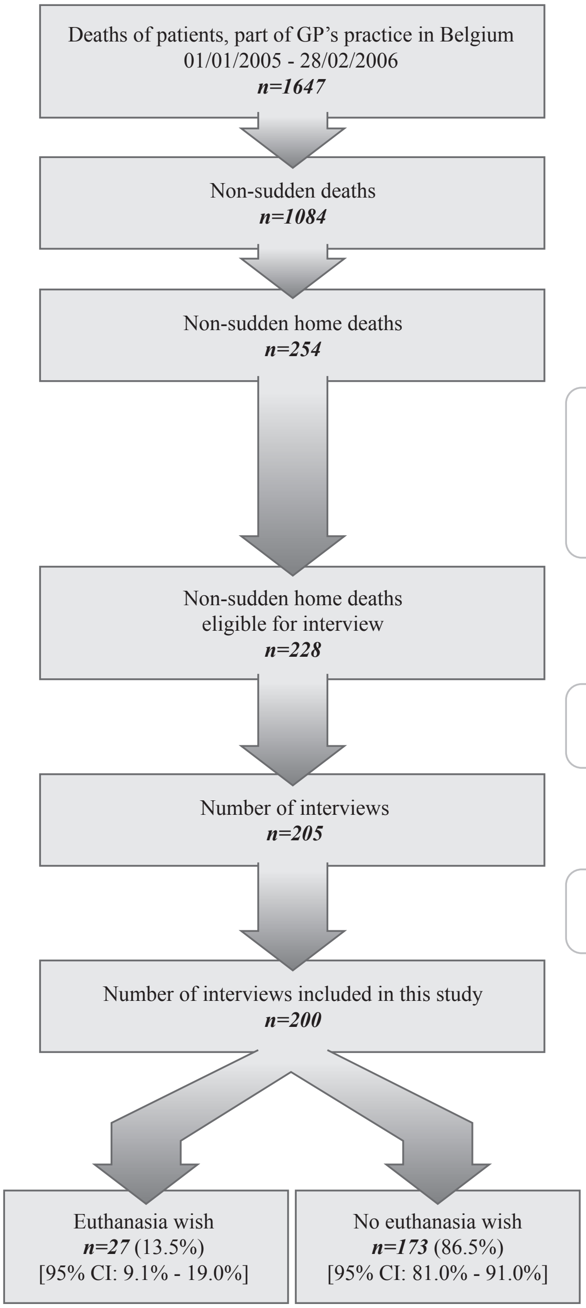
The sentinel GPs registered each week all deaths of patients in their practice older than one year, using a standardised registration form. On the basis of this registration, deaths that did not occur ‘suddenly or totally unexpectedly’ as judged by the GPs were identified. This resulted in a robust representative sample of non-sudden deaths (n=1690) [20] not restricted to a specific setting, age group or disease. The study protocol has been published elsewhere [21].

For this interview study, we identified those patients who had died non-suddenly at home during the first 14 months of the registration period (January 2005 - March 2006), resulting in 254 cases. An interview could not be conducted in 49 cases because of reasons related to procedural requirements or refusal by the GP to participate (Figure 1).

PROCEDURE

Every two months, all registration forms were automatically screened for interview inclusion criteria. In order to prevent recall bias, the interview was arranged as soon as possible, ranging between one and four months after death. GPs were contacted by telephone by an independent intermediary to request their participation in a face-to-face interview to take place at a time and place of the GP’s choice. If the interview did not concern a case of euthanasia, it was undertaken by students of psychology or medicine who had been trained for this study by the researchers. If euthanasia was performed, two researchers attended the interviews because in these sensitive and often complex cases, we thought it would be difficult for an interviewer to ask questions as well as write down all answers. One researcher conducted the interview, the other made detailed notes of the interviewee's responses, and intervened only in case clarification of a GP response was needed.

FIGURE 1 SELECTION OF CASES



Strict procedures were used to preserve patient anonymity and physician confidentiality. Patient names were never identifiable to the interviewers or to the other members of the research group: GPs used anonymous codes in the registration form to refer to their patients and the interviewers were given closed envelopes to give to the GP before starting the interview to make sure that the GP would give information about the right patient. After the study, the identity of the GP was permanently deleted from all files. The Ethical Review Board of Brussels University Hospital approved the study protocol.
Data-entry was done with consistency, range and skip checks, and the data were entered twice.

MEASUREMENTS

The interview was semi-structured and included both closed-ended questions for which multiple responses were often allowed to be given, and open-ended questions for which responses were written down verbatim. For all questions there was room to note additional qualitative information given by the GP. Requests for euthanasia were identified by asking the GP whether or not 'the patient expressed a wish to receive a drug administered by a physician with the explicit intention of hastening the end of life'. If yes, the GP was asked whether or not this wish concerned an 'explicit and repeated request'. Cases of actual euthanasia were identified via the question "was death the result of the administration of a drug by a physician with the explicit intention to hasten death or to end life, on the explicit request of the patient?". Other interview questions were largely based on existing questionnaires [10;26-30] and concerned the patient's medical situation during the final months of life, the characteristics of the patient's wish for euthanasia and the reasons for not granting the euthanasia request; questions were also asked about medical end-of-life decision-making (see box 1 for details).

ANALYSES

All closed-ended questions were descriptively analyzed using PASW Statistics (SPSS Inc, Chicago, Ill). Results of the study are presented both on an aggregate and on an individual case level. Answers to open-ended questions and additional information given by the GPs were encoded into categories by two researchers and/or registered as quotes. The GP's reasons for not granting a patient's request were compared with the substantive legal due care requirements for euthanasia in Belgium [12],

BOX 1. INTERVIEW TOPICS ASSESSED IN THIS STUDY

Questions on the **patient's medical situation** during the final months of life, assessing

- patient's main diagnosis [30]
- time before death patient had started feeling ill and time before death patient was diagnosed [26;28;30]
- functional status during the last three months of life using the
- Eastern Cooperative Oncology Group Performance Status Scale (ECOG) [29]
- patient's capability to communicate during the last week of life [26;28;30]
- patient's capability to make decisions during the last week of life [26;28;30]
- symptom burden in the last week of life using an adapted version of
- the Memorial Symptom Assessment Scale Global Distress Index (MSAS-GDI) [27]
- number of GP contacts with the patient or with family regarding the patient
- during the last 3 months of life
- the involvement of informal caregivers and/or clinical specialists in providing care for this patient
- during the last 3 months of life
- extent to which care in last 3 months of life was focused on physical, psychological, and spiritual
- problems
- main treatment goal during the last 3 months of life
- whether or not multidisciplinary palliative care services were involved
- during the last 3 months of life
- GP's estimation of the quality of the patient's death (peacefulness) measured on a scale
- from -5 (not peaceful) to 5 (peaceful)

Questions on the **characteristics of the patient's request** for euthanasia [10;30]

- time before death the wish(es) were expressed
- to what extent the final wish was explicit and repeated (i.e. a euthanasia request)
- whether or not the wish was made in writing
- whether or not the wish was granted
- patient's exact way of formulating the wish for euthanasia

namely: the patient must be 18 years or above, the request must be voluntary and not the result of any external pressure, the request must be well-considered and repeated and must be made in writing; the patient must be in a medically futile state of constant and unbearable physical or psychological suffering which cannot be alleviated, resulting from a serious and incurable condition caused by illness or accident.

Socio-demographic patient information was retrieved from the registration study. Fisher's Exact Tests and logistic regression analysis were used to bivariately explore differences between patients who made, and those who did not make, a request for euthanasia. To explore the extent to which patients who requested euthanasia experienced symptom burden –as judged by the GP– during their final days of life in proportion to other deaths, we compared their level of distress to the mean score of all 200 included patients who died non-suddenly at home. Distress levels were

BOX 1. INTERVIEW TOPICS ASSESSED IN THIS STUDY (CONTINUED)

Question on the **reasons for not granting** the euthanasia request

Reasons for not granting the patient's request for euthanasia

- GP never grants a euthanasia request
- it did not involve a severe illness
- patient was depressed
- suffering was not unbearable and persistent
- request was not repeated and explicit
- situation was not medically futile
- request was not voluntary
- request was pressured by family
- patient was insufficiently capable of making own decisions
- patient withdrew euthanasia request
- patient is too close to death
- patient died before decision-making was finalised
- patient died after decision-making but before administration
- family explicitly requested not to grant request
- patient uttered request never directly to GP
- fear of judicial consequences
- legally forbidden
- other, namely …

Questions on **medical decision-making** [1;10;11;31]

Whether or not four types of medical end-of-life decisions were made at the end of the patient's life:

(1) non-treatment decisions taking into account a possible hastening of death or with the explicit intent to hasten death;
(2) intensifying alleviation of pain or other symptoms taking into account or co-intending the hastening of death;
(3) using drugs to continuously sedate the patient until death
(4) administering drugs explicitly intending to hasten a patient's death on his/her explicit request (i.e. euthanasia)

calculated using the Global Distress Index Score [27], except for patients who were in a state of unconsciousness during the entire last week of life.

RESULTS

STUDY POPULATION

For five out of 205 patients no information could be provided on whether or not a euthanasia request had been formulated (Figure 1). Of the remaining 200 cases (registered by 103 GP practices), 27 (registered by 19 GP practices) had at some point expressed a wish to receive a drug administered by a physician with the explicit intention of hastening the end of life (13.5%, CI 9.1%-19.0%).

The majority of these patients suffered from cancer (77.8%) and had been feeling ill for more than 6 months (63.0%) (Table 1). In the last week of life, all but one patient needed help with self-care or was completely bedridden, and all but one were capable of communicating although often with restrictions. Lack of energy (73.1%) and feeling sad (60.0%) were most frequently reported to have caused distress in the last week of life. The treatment of all patients was aimed at palliation and more than half (55.6%) received multidisciplinary specialist palliative care in the last phase of life.

Compared with those who died non-suddenly at home and had never expressed a wish for euthanasia according to the GP, patients who had expressed a wish for euthanasia were relatively younger (p=0.01), more often male (p=0.03) and more often competent during the last week of life (p=0.02). They had more contact with their GP during the final three months of life (p=0.01), and were twice as likely to experience symptom distress in the last week (Odds Ratio: 2.27 with 95% Confidence Interval: 1.21-4.25) (not shown in table).

CHARACTERISTICS OF EUTHANASIA WISHES

Requests for euthanasia were judged by the GP to be explicit and repeated in half of cases (13 out of 27) (Table 2). Based on qualitative information we discerned different types of requests: of the 13 cases, some patients (case n° 2, 3, 11, 12, 13) formulated an urgent and actual preference to end their life (eg “Now, I can’t cope with it anymore”, case n° 2) while other requests were expressed in advance (eg “when the time comes, give me something and make sure it is over”, case n°10). We further discerned four patients (case n° 1, 2, 3, 9) who explicitly referred to the unbearableness of experienced pain as a reason for euthanasia (eg “If the moment comes

TABLE 1: PATIENTS DYING AT HOME WITH A EUTHANASIA REQUEST (N=27)

Sociodemographic and clinical characteristics	n*	%
Age at death		
<18 years	0	0.0
18-64 years	11	40.7
65-79 years	9	33.3
≥ 80 years	7	25.9
Sex		
male	22	81.5
female	5	18.5
Educational level		
≤ lower secondary	17	63.0
higher secondary or more	10	37.0
Fixed partner at time of death		
yes	21	77.8
no	6	22.2
Main diagnosis		
cancer	21	77.8
cardiovascular disease	3	11.1
global deterioration after CVA	2	7.4
disease of the nervous system	1	3.7
Time before death patient was diagnosed		
≤ 1 month	2	7.4
between 1 and 6 months	6	22.2
> 6 months	19	70.4
Time before death patient started feeling ill		
≤ 1 month	1	3.7
between 1 and 6 months	9	33.3
> 6 months	17	63.0
Performance status within last three months of life †		
needed help for self-care and/or bedridden		
2nd and 3rd month before death	12	44.4
2nd to 4th week before death	22	81.5
last week of life	26	96.3
Capacity to communicate during last week		
fully capable	11	40.7
capable with restrictions	15	55.6
not capable at all	1	3.7
Competence during last week		
competent	20	76.9
intermittent	4	15.4
not competent	2	7.7
Symptoms that caused distress during the last week of life ‡		
physical distress		
lack of energy	19	73.1
lack of appetite	12	46.2
difficulty breathing	10	38.5
dry mouth	4	16.0
drowsy	4	16.0
constipation	3	13.0
pain	3	12.0
psychological distress		
feeling sad	15	60.0
worried	12	48.0
nervous	8	30.8
irritated	6	23.1

TABLE 1: PATIENTS DYING AT HOME WITH A EUTHANASIA REQUEST (N=27) (CONTINUED)

End-of-life care provision	**n***	**%**
GP contacts in last week of life		
never	1	3.7
once or more	26	96.3
GP contacts in last 3 months of life		
up to 10	7	25.9
more than 10	20	74.1
Clinical specialist involved in care over last 3 months of life		
none or sometimes	11	42.3
often	15	57.7
Informal care over last 3 months of life		
none or sometimes	2	7.4
often	25	92.6
Treatment goal over last 3 months of life		
curative/life prolonging	0	0.0
comfort/palliation or transition to comfort/palliation	27	100
Multidisciplinary palliative care services delivered over last 3 months of life		
no	12	44.4
yes	15	55.6
Physical care in the last three months of life		
none to (very) small extent	0	0.0
average to (very) large extent	26	100
Psychosocial care in the last three months of life		
none to (very) small extent	2	8.0
average to (very) large extent	23	92.0
Spiritual care in the last three months of life		
none to (very) small extent	8	33.3
average to (very) large extent	16	66.7

* Numbers may not always add up to 27 due to missing values;

† Performance Status Scale (ECOG) 0-Fully active; 1-Ambulatory, capable of work of a light nature; 2-Capable of self-care but not work; 3-In bed ≥50% of the time, capable of only limited self-care; 4-Completely bedridden, incapable of self-care; figures in table are % of patients for whom a grade 3 or 4 was assigned;

‡ Symptoms which caused the patient distress during the last week before death, despite possible treatment. Distress levels were measured using the Memorial Symptom Assessment Scale-GDI, except for patients who were in a state of unconsciousness during the entire last week of life (n=1). Psychological symptoms were considered to have caused distress if answer was “frequently” or “almost constantly”. Physical symptoms were considered to have caused distress if answer was “quite a bit” or “very much”

that I am in that much pain, then I want to be put to sleep", case n°9) as for others non-physical aspects of suffering seemed to be more central to their request (case n°4, 6, 11) (eg "You will help me when I can no longer cope, won't you? I want life to be valuable; if it's no longer valuable, then I want you to end it", case n° 6); other requests were less specific.

In the 14 out of 27 cases where the wish for euthanasia was judged not to be both explicit and repeated, most requests (n=8) were considered to be quite vague (eg "Do not let me suffer needlessly; I do not want to be on the decline", case n°14), but varied between patients in their nature, formulation, and timing. Nevertheless, formulations were quite strong in six of these cases (case n° 15, 17, 19, 22, 26, 27) (eg "Could you give me an injection to end it quickly", case n°19; "I want euthanasia, when could it be performed?", case n°27).

Compared with patients who expressed a wish but not an explicit/repeated request for euthanasia, those considered to have made an explicit/repeated request had drawn up a written advance directive about euthanasia more often or had documented their request in another way (8 out of 13 vs. 2 out of 14; p=0.01). Also, these patients more often reiterated their wish for euthanasia until their final days of life (6 out of 13 vs. 0 out of 14; p=0.02) (Fisher's Exact Tests, statistics not shown in table). Wishes that were not judged to be explicit and repeated had often been expressed several months before death and not repeated.

GRANTED AND NOT GRANTED WISHES

Granted

In total 19% of all euthanasia wishes were granted (5 out of 27 cases) (Table 2). These patients had all expressed an explicit and repeated request for euthanasia, and all but one had requested euthanasia over a longer period including during the last week of life. For four out of five, the request was also made in writing.

Not granted although expressed explicitly and repeatedly

Twenty-two patients did not receive euthanasia notwithstanding eight of them having expressed an explicit and repeated request. For these eight patients, the reasons given by the GP for not acceding to the request were the following: [a] three patients (case n° 6, 8, 13) changed their mind at the very end of life, one of which (case n°6) was influenced by his wife and child whereupon he no longer requested euthanasia but wished to

TABLE 2. CHARACTERISTICS OF EUTHANASIA REQUESTS OF PATIENTS DYING AT HOME (N=27)

	nature of request *		moment of request in relation to death *				outcome				
								wish/request not granted *			
Case n°	explicit and repeated request	made in writing	month >3	month 2-3	week 2-4	last week	wish/request granted	legal due care requirements not fulfilled ‡	patient withdrew wish/request §	illness progressed too quickly	other reason according to GP
1	x	x	x	x			x				
2	x				x	x	x				
3	x	x	x	x		x	x				
4	x	x	x	x	x	x	x				
5	x	x	x	x	x	x	x				
6	x	x		x					x		
7	x	x		x	x						x
8	x	x		x					x		
9	x	x	x							x	
10	x		x								x
11	x					x				x	
12	x					x					x
13	x		x					x	x		
14			x					x			
15	unknown	x		x					x		
16					x			x			x
17 †								x	x		
18				x				x			
19					x			x	x		x
20					x					x	
21			x						x		
22			x					x			
23		x			x					x	
24			x					x			
25			x					x	x		
26			x					x			
27	unknown	unknown	x								x
In total	**n=13**	**n=10**	**n=12**	**n=9**	**n=8**	**n=6**	**n=5**	**n=10**	**n=8**	**n=4**	**n=6**

* More than one answer possible;

† Exact timing of wish/request unknown;

‡ The patient’s request must be voluntary and well-considered; it must be repeated, and may not be the result of any external pressure; the patient must be in a medically futile state of constant and unbearable physical or psychological suffering which cannot be alleviated, resulting from a serious and incurable condition caused by illness or accident [12]. Reasons expressed by the GP were compared with these requirements and interpreted as such by the research team.

§ Or the patient had made a conditional euthanasia request but died earlier be sedated while accepting and desiring death as a side effect. One patient (case n° 13) did not want to hurt his family by persevering with his request since they did not want it, and one (case n°8) no longer wanted euthanasia if he lapsed into a coma, which was eventually the case; [b] For two patients the illness had proceeded too quickly to perform euthanasia as they died before the end of the decision-making process (case n° 9 and 11); [c] In one case (case n° 13), one of the mandatory criteria for due care, namely that the patient's suffering must be unbearable and persistent, was not met; [d] in other cases the GP named other reasons (case 7, 10, 12), eg one GP declared he/she never granted a request for euthanasia because it involved extra paperwork and procedural requirements (case n° 10). Also, one GP (case n° 7) preferred to administer continuous deep sedation until death and asked the patient to rewrite his advance directive. This GP stated he/she did not consider the request as a request for euthanasia since the patient did not explicitly use the wording "euthanasia", but "the wish to receive an injection to hasten death when being in a state of coma". Finally, one GP judged that the patient (case n°12) thought he was a burden to his children and therefore asked for euthanasia; this was not considered a valid reason.

Not granted and not expressed explicitly and repeatedly

For the fourteen remaining cases the GP did not judge the patient's wish to be an explicit and repeated request. This was considered as a reason not to grant euthanasia in seven of these cases (n° 14, 16, 18, 19, 24, 25, 26). For three cases the patient's suffering was not unbearable and persistent (case n° 17, 18, 22). Both reasons can be seen as fulfilling the mandatory due care requirements underpinning the legality of euthanasia in Belgium.

THE FINAL PHASE OF LIFE

Medical decision-making

No medical end-of-life decisions with a possible or certain life-ending effect were made for seven out of the 22 patients who did not receive euthanasia but had previously requested it (table 3). For 14 of the other 15 patients, the GP decided to intensify the alleviation of pain or other symptoms while co-intending or taking into account the hastening of death. Three were brought into continuous deep sedation or coma preceding death, in one case (case n°6) with and in two cases (case n° 7, 26) without the artificial administration of nutrition or hydration. For ten patients, a

TABLE 3. MEDICAL END-OF-LIFE DECISION-MAKING AND THE LAST WEEK OF LIFE IN PATIENTS WITH A EUTHANASIA REQUEST (N=27)

	medical decisions made at the end of life								
Case n°	no end-of-life decision	euthanasia	continuous deep sedation until death *	intensified alleviation of pain or other symptoms†	non-treatment decision ‡	fully capable to communicate without restrictions during last week	fully capable to take decisions during last week	no or little symptom burden in last week of life §	patient died a peaceful death ‖
1		x		x					x
2		x		x		x	x	x	x
3		x		x	x	x	x	x	x
4		x				x	x		x
5		x			x	x	x	x	x
6			x_1	x			x		
7			x_2	x	x_3		x		
8				x		NA	NA	NA	
9				x			x		x
10				x	x		x	x	x
11	x					x	x		x
12				x	x	x	x		x
13	x					x	x		x
14				x	x_3				x
15	x						x	x	x
16	x								x
17	x					x	x	x	x
18					x		x		x
19				x	x_3		x		x
20				x			x		x
21	x					x	x	x	x
22				x			x		x
23				x		x	x		x
24				x	x			x	x
25	x					x	x		x
26			x_2	x	x				x
27				x					x
In total	**n=7**	**n=5**	**n=3**	**n=17**	**n=10**	**n=11**	**n=20**	**n=8**	**n=24**

* x_1 = with administering nutrition and hydration; x_2 = without administering nutrition and hydration

† taking into account or co-intending the hastening of death

‡ taking into account the hastening of death, with x_3 = explicitly intending the hastening of death

§ Global Distress Index Score for all 200 patients who died at home dichotomised at its mean value (1.58), x = score below the mean

‖ measured on a scale from -5 (not peaceful) to 5 (peaceful) with x = a score higher or equal to 1

NA = not applicable because patients was unconscious during entire last week of life decision had been taken to withhold or withdraw treatment, in three of which the hastening of death was explicitly intended (case n° 7, 14, 19).

Clinical characteristics

Three out of five patients whose request for euthanasia was granted scored below the mean value for general symptom distress, as was the case for five of the twenty-two who did not receive euthanasia. Four of out five patients who died from euthanasia remained fully capable of communicating without restrictions and of making their own decisions during the last week of life. Far fewer (seven out of 22) who expressed a wish but did not receive euthanasia remained fully able to communicate. According to the GP, the majority died a peaceful death whether or not they had received euthanasia.

DISCUSSION

We conducted face-to-face interviews with GPs in relation to 200 patients who died at home in Belgium and identified 27 (13.5%) patients who had at some time expressed a wish to receive a drug administered by a physician with the explicit intention of hastening the end of life, i.e. euthanasia. These wishes varied widely between patients in their nature, formulation, and timing. Thirteen patients with a wish for euthanasia formulated their request explicitly and repeatedly, according to their GP. Compared with other euthanasia wishes, these patients had both repeated their request more often up to the final days of life and had more often made it in writing. Five of them received euthanasia. For the other 22 patients, GPs gave different reasons for not acceding to the request, often related to criteria stipulated in the Belgian law on euthanasia. Sometimes the patient was too close to death or reconsidered his/her wish. In a minority of cases the GP did not comply with the request for personal reasons. All patients with a request for euthanasia received treatment at the end of life aimed at palliation and many died following a possibly life-shortening decision in the last week of their life.

Our study is the first in Belgium to provide detailed information on patients dying at home under the care of their GP who expressed a wish for euthanasia. Rather than on the practice of euthanasia itself, these face-to-face interviews focus on the characteristics of the euthanasia requests and how they were handled. Cases were identified via a nationwide mortality registration study which has been found to be representative of all non-sudden deaths in the country [20]. Other strengths include the reliability and representativity of the surveillance network from which the interviewed GPs were selected [23;25], the strict procedures followed and the quality control measures practiced during the study eg interviewers were trained in general interview techniques and end-of-life care in particular, interviews were conducted as soon as possible after inclusion, and data were entered twice.

Our study also has limitations. Firstly, although 200 interviews were conducted for this study, conclusions about requests for euthanasia are based on small samples. Secondly, our study is limited to GPs and to home deaths and can therefore not claim to be representative for other settings or for how other caregivers deal with such requests. Finally, GPs were asked to call a case to mind retrospectively, including the verbatim formulation of their patient's euthanasia wish, therefore a possible memory bias cannot be excluded.

A first major finding is that in Belgium, approximately one out of seven terminally ill patients dying at home under the care of a GP expresses a euthanasia request in the last phase of life, according to their GP. This means that it is not uncommon for patient to ask for euthanasia. Since euthanasia was legalized in 2002 [12], the issue has been brought to the attention of the general public and media coverage has increased enormously. It must be taken into account however that the proportion of explicit and repeated requests remains relatively rare. In addition, our results suggest that these requests often not relate to a patient's current wish to die, but rather reflect advance concerns about the dying process.

Due to the long-term relationship they have often had with patients dying at home, GPs have the opportunity to address the patient's last wishes and possibly formalize them when death approaches [32]. During our 14-month study period, almost one out of five GPs who cared for a terminally ill patient dying at home was confronted with at least one patient requesting euthanasia. Dealing with these wishes is thus not part of their daily routine practice. Still, these figures indicate it is most likely that a GP will be confronted with a euthanasia request at least once in their career. Studies have shown that that moment could have a major emotional impact on the GP [33], therefore, training and consultation for GPs in these sensitive matters seems necessary. Initiatives are being undertaken to achieve this in Belgium and the Netherlands [34].

Clearly, the process of decision-making for this life-ending act requires serious reflection, and not all euthanasia requests that GPs are confronted with will be granted [4]. This is clearly demonstrated by our results. On top of the possible emotional burden, dealing with a patient's request for euthanasia may be complicated by the fact that such requests are often unique and vary widely between patients in form and content. Not only differences in the nature of the request, its wording, the kind of suffering or values in a patient's life it relates to, but also in the moment of expression, and how often it is repeated afterwards at different time points make a case by case approach indispensable in the process of decision-making.

The strict conditions for careful practice regulated by the Belgian Law on Euthanasia [12] seem to be an aid to GPs in this difficult decision-making: patients who died following euthanasia had all repeatedly and explicitly formulated their request, often in the last days of life and mostly in writing, while none of the inexplicit or unrepeated euthanasia requests were granted. This statutory requirement, together with that of unbearable suffering, was often mentioned as a reason for a GP's reluctance to perform euthanasia. Thus, it seems that GPs in Belgium adhere to the substantive requirements for due care both in approving and rejecting euthanasia requests. However, our results also suggest that the way GPs deal with requests may in some cases depend on a personal opinion towards euthanasia. In some cases for example the request appears to have been formulated strongly and explicitly, although it was not described by the GP as 'explicit and repeated' and was not taken into account in the later decision-making. Some GPs also explicitly mentioned personal reasons for not granting a patient's euthanasia request. These GPs however felt committed to alleviating the patient's suffering but chose to make a different medical end-of-life decision. Other research also indicates that some GPs want to avoid euthanasia but strive to find a balance between lessening the suffering of a terminally ill patient and being able to remain faithful to their own opinions and values [15].

Overall, patients with a request for euthanasia seemed twice as likely to have experienced considerable symptom burden during the last week compared with other non-sudden home deaths, despite palliative treatment. Notably, most distress was related to a patient's state of mind (such as feeling sad, lack of energy, worry) rather than to physical pain. This is comparable to a large-scale study of euthanasia requests in the Netherlands in which the three highest ranking symptoms patients experienced were feeling bad, tiredness, and not being active [4]. Similarly, another Dutch study found that long-term deterioration had become more important in requesting euthanasia than the experience of pain [6].

CONCLUSION

Patients dying at home relatively often express a wish to receive euthanasia to their GPs. These wishes tend to vary highly in form and content. Far more euthanasia wishes are expressed than are complied with. For many GPs the Belgian law on euthanasia serves as a guiding principle in this decision-making process, although in a minority of the cases a GP's personal opinion towards euthanasia seems to be decisive.

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CHAPTER 7:
PHYSICIAN REPORTS OF MEDICATION USE WITH EXPLICIT INTENTION OF HASTENING THE END OF LIFE IN THE ABSENCE OF EXPLICIT PATIENT REQUEST IN GENERAL PRACTICE IN BELGIUM

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ABSTRACT

BACKGROUND

Although the incidence of the use of life-ending drugs without explicit patient request has been estimated in several studies, in-depth empirical research on this controversial practice is nonexistent. Based on face-to-face interviews with the clinicians involved in cases where patients died following such a decision in general practice in Belgium, we investigated the clinical characteristics of the patients, the decision-making process, and the way the practice was conducted.

METHODS

Mortality follow-back study in 2005-2006 using the nationwide Sentinel Network of General Practitioners, a surveillance instrument representative of all GPs in Belgium. Standardised face-to-face interviews were conducted with all GPs who reported a non-sudden death in their practice, at home or in a care home, which was preceded by the use of a drug prescribed, supplied or administered by a physician without an explicit patient request.

RESULTS

Of the 2690 deaths registered by the GPs, 17 were eligible to be included in the study. Thirteen interviews were conducted. GPs indicated that at the time of the decision all patients were without prospect of improvement, with persistent and unbearable suffering to a (very) high degree in nine cases. Twelve patients were judged to lack the competence to make decisions. GPs were unaware of their patient's end-of-life wishes in nine cases, but always discussed the practice with other caregivers and/or the patient's relatives. All but one patient received opioids to hasten death. All GPs believed that end-of-life quality had been "improved considerably".

CONCLUSIONS

The practice of using life-ending drugs without explicit patient request in general practice in Belgium mainly involves non-competent patients experiencing persistent and unbearable suffering whose end-of-life wishes can no longer be ascertained. GPs do not act as isolated decision-makers and they believe they act in the best interests of the patient. Advance care planning could help to inform GPs about patients' wishes prior to their loss of competence.

INTRODUCTION

Studies in several European countries have consistently reported that a number of patients die following end-of-life decisions which may, or are intended to, shorten life. The use of drugs by physicians with the intention of ending a patient's life without his or her explicit request is a practice that has evoked considerable political, ethical and public debate [1-3]. Although legally prohibited all over the world, this practice seems to take place everywhere in modern healthcare, albeit with differences between countries. Incidence estimates within Europe range between 0.06% and 1.50% of all deaths with the highest prevalence being reported in Flanders, Belgium [4-6].

However, despite extensive debate about this practice little is known about its conduct. In Belgium, for instance, it is performed relatively more often among those younger than 80, and those who were judged cognitively incompetent [7-10], and occurs in the home and care home setting under the care of the general practitioner (GP) in about half of all cases in 2001 [8;11;12].

In order to get a comprehensive picture of the last phase of life in these cases, it is indispensable to gain additional insight into the clinical characteristics of the patients, the decision-making process and the performance of the practice. Setting-specific information is also valuable because GP-patient relationships formed over a long period can differ notably from specialist-patient relationships which are often short-term and take place in acute circumstances [13].

This study will focus on the use of life-ending drugs by GPs without explicit patient request, to gain insights into how, why and for which patients GPs decide to end a life in this manner.
This study focuses on the following research questions:

1. What are the socio-demographical and clinical characteristics of patients dying following the use of life-ending drugs without explicit patient request in general practice in Belgium?
2. Was the decision discussed with patients, family and/or other professional caregivers?

3. Were other end-of-life decisions made and did they precede, follow or take place jointly with the decision to use life-ending drugs?
4. How was the practice performed?

METHODS

STUDY DESIGN, SETTING AND PARTICIPANTS

In 2005 and 2006, a large-scale mortality follow-back study was conducted to monitor end-of-life care and decision-making in Belgium using the Sentinel Network of General Practitioners (SENTI-MELC) study [14]. It involved a quantitative registration study of deaths in the practices of GPs within the Belgian Sentinel Network which, since it was founded in 1979, has proved to be a reliable surveillance system for a wide variety of health-related epidemiological data [14-18] and which is representative of all Belgian GPs in terms of age, sex and region [17;19]. The study resulted in a robust representative sample of non-sudden deaths (n = 1690) [10] not restricted to a specific setting, age group or disease. The study protocol and the first set of results are published elsewhere [10;13;14;20;21].

During this registration study, we identified deceased patients meeting the following inclusion criteria:

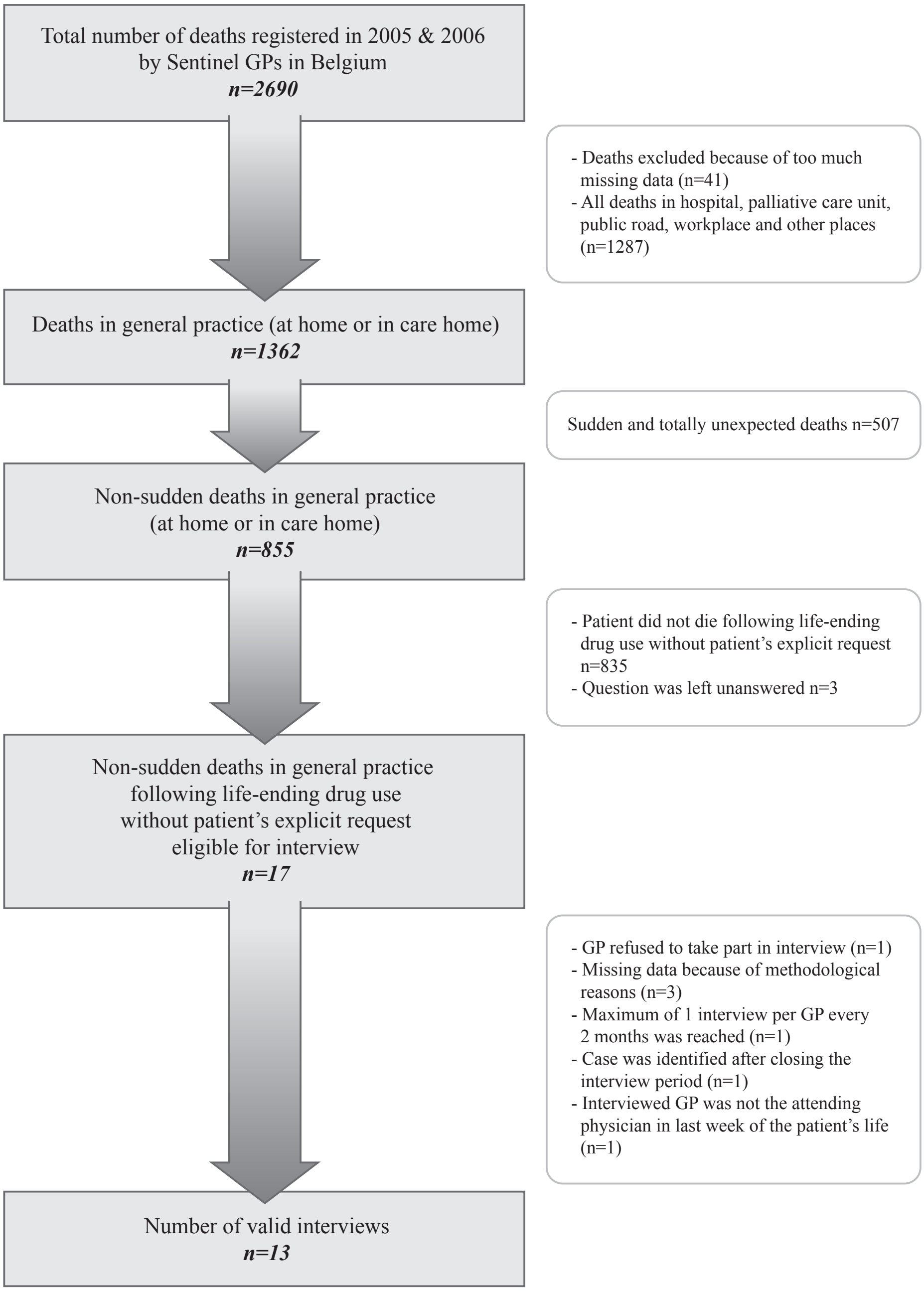
- aged one year or older at time of death
- death did not occur "suddenly or totally unexpectedly"
- as judged by the GP
- death occurred at home or in a care home

Based on these criteria 225 such patients were identified and a large interview study involving them was performed. For the current study, patients were included if the GP registered that, in addition:

- death followed the use of 'a drug prescribed, supplied or administered by the GP or a colleague physician with the explicit intention of hastening the end of life'
- the decision concerning this act was made without an explicit request from the patient.

For 17 (1.3%) out of 1362 patients who died at home or in a care home in Belgium (Figure 1), life-ending drugs without explicit patient request preceded death (binomial 95% CI, exact method: [0.7-2.0]), which is 2.0% of all patients who died in these settings non-suddenly (binomial 95% CI, exact method: [1.2-3.2]). In four cases which met the criteria for inclusion

FIGURE 1 PROCESS OF INTERVIEW INCLUSION



interviews did not take place; in only one of these was the GP unwilling to participate. In total thirteen interviews were conducted.

MEASUREMENTS

The interview with each GP was face-to-face and semi-structured and included both closed-ended and open-ended questions. Answers to open-ended questions were written down verbatim. For all questions, there was room to note additional information given by the GP.

Interview questions were based largely on existing questionnaires [1;22-27](see Table 1 for all interview topics). Information about each patient's socio-demographics such as age at death, sex, level of education, and place of death was retrieved from the SENTI-MELC registration study.

TABLE 1. INTERVIEW TOPICS ASSESSED IN THIS STUDY

Questions on the patient's **clinical and care characteristics** during the last phase of life, assessing:

- patient's main diagnosis [27]
- other diseases for which the patient received treatment during the last three months of life [22;23;25]
- patient's level of consciousness during the last week of life (not unconscious; unconscious one or more hours before death; unconscious one or more days before death; unconscious during whole week) [22;23;25]
- time before death patient had started feeling ill and time before death patient was diagnosed [22;23;25]
- number of GP contacts with the patient or with family regarding the patient during the last 3 months of life
- the involvement of informal caregivers and/or clinical specialist in providing care for this patient during the last 3 months of life
- symptom burden in the last week of life using an adapted version of the Memorial Symptom Assessment Scale Global Distress Index (MSAS-GDI) [24]
- functional status during the last three months of life using the Eastern Cooperative Oncology Group Performance Status Scale (ECOG) [26]
- whether or not multidisciplinary palliative care services were involved
- whether or not curative, life-prolonging or alternative palliative treatments could be considered that were not applied, and what the reasons were for not applying them [28]
- to what extent the patient's suffering was persistent and unbearable and how GPs came to their judgment [28]
- to what extent physical and/or psychological suffering was present that could not be alleviated [28]
- to what extent the patient's medical situation was without prospect of improvement [28]

TABLE 1. INTERVIEW TOPICS ASSESSED IN THIS STUDY (CONTINUED)

Questions on the **process of the decision-making**, assessing [1;3;5;6;22;23;25;29]:

The content and timing of the decision-making process:

- whether or not the hastening of death was discussed with the patient (and reason for not discussing)
- whether or not the patient was competent to make decisions (and reasons for incompetence)
- wishes expressed by the patient concerning the termination of life, prior to the decision-making
- involvement in the decision-making of patient's relatives and other caregivers
- time before death the decision was made and GP's main considerations for doing so

Whether or not three other types of medical end-of-life decisions were made at the end of the patient's life and their sequence in time in relation to the decision to end life without explicit patient request:

- non-treatment decisions taking into account a possible hastening of death or with the explicit intent to hasten death;
- intensifying alleviation of pain or other symptoms taking into account or co-intending the hastening of death;
- using drugs to continuously sedate the patient until death

Questions on the **performance of the practice**, assessing [3;5]:

- moment of drug administration and the circumstances surrounding death
- drugs used to end life, time between administration of life-ending drugs and coma, and death
- persons involved in the drug administration and GP's presence during the period until death
- estimated life shortening effect of the drugs

PROCEDURE

In the SENTI-MELC registration study GPs registered deaths weekly, using a standardised form [14]. Every two months, the registration forms were screened for interview inclusion criteria. The GPs in cases meeting these criteria were contacted by telephone by an independent person to request their participation in a face-to-face interview. The interview took place at a time and place of the GP's choice. Each interview was undertaken by two researchers, one conducting the interview; the other making detailed notes of the interviewees' responses.

Strict procedures were used to preserve patient anonymity and physician confidentiality. Patient names were never identifiable to the interviewers or to other members of the research group: GPs used anonymous codes to refer to their patients in the registration form and the interviewers were given closed envelopes (prepared by the independent telephone operator) to give to the GP before each interview to make sure they referred to the correct patient. After closing the interview study, the GP's identity was permanently deleted from all files. The Ethical Review Board of Brussels University Hospital approved the study protocol.

Several procedures were used to ensure data quality and prevent missing data. If the question to identify patients who died following a life-ending act without explicit request was left unanswered on the registration form, a follow-up letter was sent to the GP. Also, to preclude overburdening the GP, each had no more than one interview per two months and the length of an interview was estimated at a maximum of one hour. In order to prevent recall bias, the interview was arranged as soon as possible after inclusion. Data-entry was done with consistency, range and skip checks, and the data were entered twice.

ANALYSES

All closed-ended questions were descriptively analyzed using SPSS 16.0 (SPSS Inc, Chicago, Ill). Results of the study are presented both on an aggregate and on an individual case level. Both answers to open-ended questions and to questions for which additional information was provided by the GPs were encoded into categories by two researchers and/or registered as quotes.

RESULTS

Table 2 and Table 3 give an overview of the socio-demographic, care and clinical characteristics of patients dying following life-ending drug use without their explicit request. Of all thirteen patients three were aged 65 or younger at the time of death, eight died at home and five in the care home. Six out of the thirteen patients had been diagnosed with cancer and eleven had suffered from at least one co-morbidity within the last three months of life. In the last week of life, all patients were completely bedridden and incapable of self-care, all but one were unconscious or in a coma for one or more hours or days before death, and all experienced symptoms. In general, physical symptoms were reported more often than psychological ones. The most frequently reported physical symptoms were: lack of energy, lack of appetite, feeling drowsy, and pain. The psychological symptoms most frequently reported were feeling nervous and feeling sad. For all but one patient (case n°12) the symptoms also caused serious distress.

For six patients, GPs judged curative or life-prolonging treatments to be available which were not applied for reasons such as affording little chance of improvement or risking additional suffering. In three cases it was considered that palliative treatment options were available but they were not applied because the patient refused further treatment or the physician judged it preferable not to prolong treatment or the life of the patient. Multidisciplinary palliative home care was involved in four cases.

At the time of decision-making, the GP judged the medical situation of all thirteen patients as without any prospect of improvement (Table 4). Nine were considered to suffer persistently and unbearably to a high or very high degree. All patients suffered physically and/or psychologically to some degree, in ways which could not be alleviated otherwise though one GP deemed the patient's suffering not persistent and unbearable (case n°13). According to this GP 'the suffering was kept under control by medication'; though any attempts at improving the patient's medical situation had been futile and ending life was 'clearly the best for him' (qualitative additional information). In all cases GPs based their judgments on observation and compassion; and in ten cases also after conferring with patients themselves (before they lost competence), their loved ones, or with other professional caregivers (not shown in table).

DECISION-MAKING PROCESS

All but one patient had lost the capacity to assess their situation and to make an informed decision about it (Figure 2). Reasons for incompetence cited were: the patient could no longer communicate, or was severely demented, unconscious, mentally disabled or considered too young (not shown in figure). One patient was considered competent but not able to express himself well (case n°9) and had earlier expressed a wish not to suffer anymore although this wish was not an explicit request to hasten death. In this case the medical situation was judged futile to the extent

TABLE 2. LIFE-ENDING DRUG USE IN GENERAL PRACTICE WITHOUT PATIENT'S EXPLICIT REQUEST- AGGREGATED (N=13)

Sociodemographic characteristics *	**n**	
Age at death		
1-64 years	3	
65-79 years	6	
≥80 years	4	
Sex		
male	8	
female	5	
Educational level*		
elementary or lower	2	
lower secondary	6	
higher secondary or more	4	
Community of Belgium		
Dutch community	6	
French community	7	
Fixed partner at time of death		
yes	6	
no	7	
Place of death		
home	8	
care home	5	
Symptom burden in the last week of life †		
Physical symptoms		
lack of energy	12	(6)
pain	9	(5)
dry mouth	8	(5)
difficulty breathing	8	(4)
feeling drowsy	10	(3)
constipation	7	(2)
lack of appetite	11	(1)
Psychological symptoms		
feeling sad	7	(5)
feeling nervous	9	(4)
worrying	6	(4)
feeling irritable	5	(3)

TABLE 2. LIFE-ENDING DRUG USE IN GENERAL PRACTICE WITHOUT PATIENT'S EXPLICIT REQUEST- AGGREGATED (N=13) (CONTINUED)

End-of-life care provision	n
Patient-GP encounters	
in last week of life (range)	1-15
in last 3 months of life (range)	6-42
Clinical specialist involved in care in last 3 months of life	
none	4
sometimes or often	9
Informal care over last 3 months of life	
none	1
sometimes or often	12
Treatment goal over last 3 months of life	
comfort/palliation	5
transition to comfort/palliation	8
Consideration of curative or life-prolonging treatments by GP ‡	
not possible anymore	7
still possible but not applied	6
reason: § physician deemed chance for improvement too small	4
physician wanted to end further suffering	4
patient refused treatment (verbally or non-verbally)	2
proxies wanted to end further suffering	1
proxies were psychologically and physically exhausted	1
Consideration of alternative palliative treatments by GP ‡	
not possible anymore	10
still possible but not applied	3
reason: § physician did not want to prolong patient's life	1
physician wanted to end further suffering	2
patient refused treatment	1
Multidisciplinary palliative home care team involved in last three months of life	
yes	4
no	9

* Missing values for level of education n=1

† Symptoms that were present during the last week before death, despite possible treatment. Between brackets: symptoms that distressed the patient, if present. Distress levels were measured for all but one case (patient comatose during last week) using the MSAS-GDI. Psychological symptoms were considered to have caused distress if answer was "frequently" or "almost constantly". Physical symptoms were considered to have caused distress if answer was "quite a bit" or "very much"

‡ At the time of the decision making

§ Multiple answers were possible

TABLE 3. LIFE-ENDING DRUG USE IN GENERAL PRACTICE WITHOUT PATIENT'S EXPLICIT REQUEST: PATIENTS' CLINICAL CHARACTERISTICS DURING THE LAST PHASE OF LIFE – CASE LEVEL

Case n°	main diagnosis	time before death patient started feeling ill	performance status in 2nd and 3rd month before death ‡	performance status during last week	number of symptoms that caused distress during last week §	symptom that caused most distress during last week	unconscious or in a coma during last week
1	COPD *	> 6 months	4	4	8	difficulty breathing	last hours
2	cancer †	5 months	1	4	7	lack of energy	last hours
3	dementia *	> 6 months	4	4	1	dry mouth	never
4	cancer *	3 months	3	4	4	feeling irritable	last day(s)
5	dementia *	> 6 months	1	4	5	pain	last hours
6	pneumonia *	2 weeks	0	4	1	difficulty breathing	last day(s)
7	cardiovascular *	4 months	3	4	6	pain	last day(s)
8	CVA *	4 weeks	2	4	1	dry mouth	last hours
9	cancer * †	> 6 months	1	4	4	worrying	last hours
10	encephalitis *	5 months	4	4	not applicable	not applicable	entire week
11	cancer * †	> 6 months	2	4	3	lack of energy	last hours
12	cancer	> 6 months	4	4	0	not applicable	last day(s)
13	cancer * †	5 months	1	4	2	lack of energy	last hours

* With long-lasting co-morbidities within the last three months of life;

† With metastases

‡ Performance Status Scale (ECOG) 0-Fully active; 1-Ambulatory, capable of work of a light nature; 2-Capable of self-care but not work; 3-In bed ≥50% of the time, capable of only limited self-care; 4-Completely bedridden, incapable of self-care

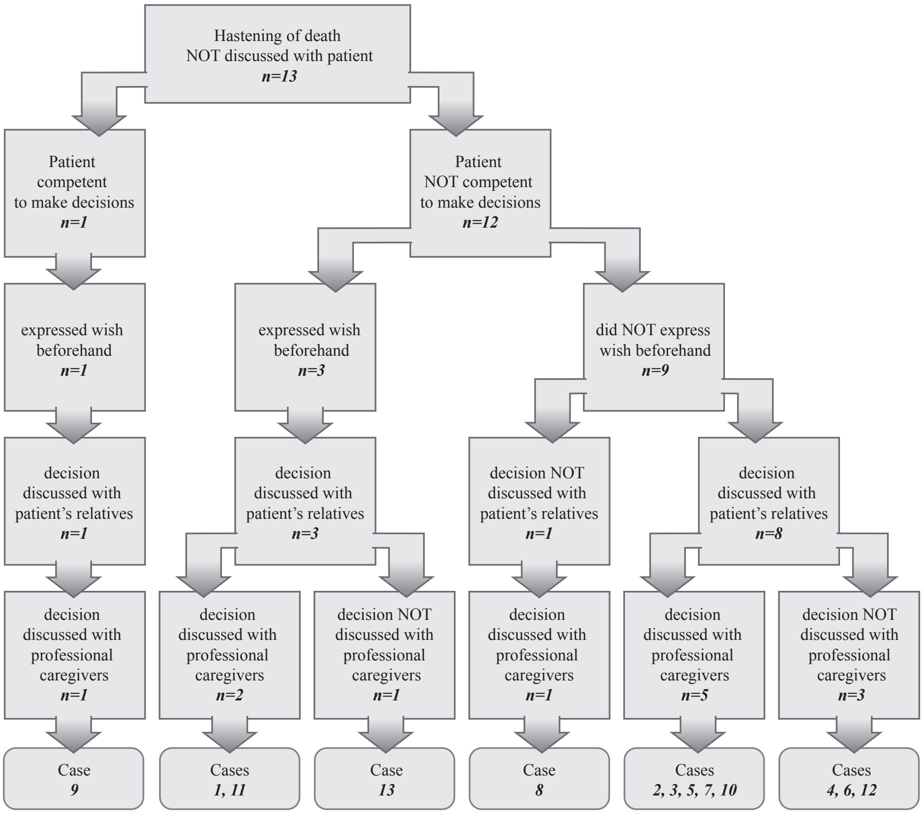
§ Despite possible treatment. Distress levels were measured using the Memorial Symptom Assessment Scale-GDI (measuring 11 possible symptoms) except for patients who were in a state of unconsciousness during the entire last week of life (n=1). Psychological symptoms were considered to have caused distress if patient did appear to feel this way "frequently" or "almost constantly". Physical symptoms were considered to have caused distress if symptom distressed the patient "quite a bit" or "very much"

TABLE 4. LIFE-ENDING DRUG USE IN GENERAL PRACTICE WITHOUT PATIENT'S EXPLICIT REQUEST: PATIENT'S SUFFERING AT THE TIME OF THE DECISION-MAKING (N=13)

Case n°	suffering was persistent and unbearable	unbearable physical suffering that could not be alleviated	unbearable psychological suffering that could not be alleviated	medical situation was without prospect of improvement	Total number of (+++ or ++) within each case
1	+++	+++	+++	+++	**4**
2	+++	+++	++	+++	**4**
3	+++	+++	+++	+++	**4**
4	++	+++	++	+++	**4**
5	++	++	++	+++	**4**
6	+++	+++	+	+++	**3**
7	+++	+++	+	+++	**3**
8	++	+	+++	+++	**3**
9	++	+	+	+++	**2**
10	+	+	+++	++	**2**
11	+	++	+	+++	**2**
12	+	+	+++	+++	**2**
13	0	+	0	+++	**1**
Total number of cases with (+++ or ++)	**9**	**8**	**8**	**13**	

Key to symbols: +++ (to a very high degree); ++ (to a high degree); + (to a lesser degree); 0 (no suffering)

FIGURE 2. LIFE-ENDING DRUG USE WITHOUT PATIENT EXPLICIT REQUEST AND PROCESS OF DECISION-MAKING: THE DISCUSSION OF THE DECISION (N=13)



that, in the GP's view, the decision was in the patient's best interest. The GP made the decision in collaboration with a colleague physician and after several discussions with the patient's children.

Nine patients were not competent to make decisions and had not expressed an advance wish about the termination of life. Within this group, the decision to end life was always discussed with either the relatives or a professional caregiver, and mostly with both. In one case no relatives were involved because the patient no longer had family.

In three cases the GP indicated that a wish had been expressed on various occasions while the patient was still competent which, although according to the GP not explicit, bore upon life-ending e.g. 'I do not want to suffer at the end of life' (qualitative additional information).

Nurses were involved in the decision-making in seven cases for the purpose of exchange of information, joint decision-making, support, or the arrangement of practicalities. Colleague physicians were involved in three cases when they were asked for information, advice, support, or to make the decision jointly. A frequent reason for lack of discussion with a colleague physician was that there was no need or that the situation was clear (not shown in figure).

In seven cases the GP felt influenced by the patient's relatives when making the decision: in five the family was supportive: 'we were on the same wavelength', 'it counts that the family indicates it is taking too long', 'they asked me: can't you do anything?'. In two cases the GP indicated that the family was initially not ready to consider such a decision, until they were confronted with the increasingly unbearable pain and suffering of their relative (qualitative additional information).

Table 5 displays other end-of-life decisions made in each case in a chronological manner. In all cases the decision to end life without explicit patient request was preceded by or made jointly with the decision to intensify symptom alleviation. Decisions to withhold or withdraw treatment were also made for ten patients, often at different times. The following treatments were decided to be withheld or withdrawn: the administration of medication (n = 8); artificial hydration or nutrition (n = 7); chemotherapy or radiotherapy (n = 3); reanimation (n = 2); a blood transfusion (n = 1); the performance of an operation (n = 1).

In seven cases the GP decided to sedate the patient continuously and deeply until death, and in five of these this decision was made at the same time as the use of life-ending drugs. While for most patients the decision to end life was made within the last weeks or days, two GPs – in collaboration with the patient's relatives - made it more than one month before death. For one patient (case n°12), the relevant drugs (morphine and dormicum) were made available seven months prior to administration in the event that the brain tumour made suffering unbearable without possible alleviation which was the case in the end. For one other patient (case n°9), the drugs were available for several weeks before death and kept in the patient's house, in case the relatives agreed upon on ending the patient's life; the GP told them: 'it is you who has to decide' (qualitative additional information).

TABLE 5. LIFE-ENDING DRUG USE WITHOUT PATIENT'S EXPLICIT REQUEST AND THE PROCESS OF DECISION-MAKING: TIMING AND INVOLVEMENT OF OTHER END-OF-LIFE DECISIONS (N=13)

Case n°	Time before death the decision to use life-ending drugs without explicit patient request was made	Other end-of-life decision(s) *preceding* the decision to use life-ending drugs without explicit patient request				Other end-of-life decision(s) *made jointly with* the decision to use life-ending drugs without explicit patient request				Other end-of-life decision(s) *following* the decision to use life-ending drugs without explicit patient request				At least one other end-of-life decision was made
		withholding / withdrawing treatment †	intensified symptom alleviation ‡	continuous deep sedation until death	**In total**	withholding / withdrawing treatment †	intensified symptom alleviation ‡	continuous deep sedation until death	**In total**	withholding / withdrawing treatment †	intensified symptom alleviation ‡	continuous deep sedation until death	**In total**	
1	**≤ 1 day**						+		**+**					**+**
6	**≤ 1 day**	+			**+**		+		**+**					**+**
13*	**≤ 1 day**		+	+	**+**									**+**
4	**2-7 days**	+			**+**		+		**+**					**+**
2	**2-7 days**	+			**+**	+	+	+	**+**	+			**+**	**+**
3	**2-7 days**	+			**+**	+	+	+	**+**					**+**
8	**2-7 days**	+	+		**+**									**+**
10	**1-4 weeks**		+	+	**+**					+			**+**	**+**
7	**1-4 weeks**	+			**+**		+	+	**+**	+			**+**	**+**
11	**1-4 weeks**	+			**+**	+	+	+	**+**	+			**+**	**+**
5	**1-4 weeks**					+	+		**+**					**+**
9	**1-2 months**						+		**+**					**+**
12	**> 6 months**						+	+	**+**					**+**
	In total	n=7	n=3	n=2	**n=9**	n=4	n=10	n=5	**n=10**	n=4	n=0	n=0	**n=4**	**n=13**

* A decision to withhold/withdraw treatment was made but moment of decision-making unknown;

† Taking into account or explicitly intending hastening of death

‡ Taking into account or co-intending hastening of death

CHARACTERISTICS OF THE PERFORMANCE OF THE PRACTICE

None of the patients was competent at the time of the administration of the drugs (Table 6). The hastening of death involved the administration of opioids in all but one case; seven patients received no other drug but opioids, and opioids were combined with a benzodiazepine in five other cases. A barbiturate induced death for one patient (case n°10). Neuromuscular relaxants were not used at all.

In three quarters of cases where the GP indicated opioids were used to end life, they had already been administered previously to alleviate pain or other symptoms. In six cases, patients were already in a coma at the time the first drug was administered and most others lapsed into a coma within the following hours. All patients died within three days of the first drug being administered. Three GPs reported having technical problems during the administration: one reported the occurrence of unexpected spasms (case n°7), one expected death to occur more rapidly (case n°3), and one expected it to occur more slowly (case n°6) (not shown in table).

In seven cases the final drug was given by the GP and in six by a nurse (case n°3/4/5/6/7/8). For all patients for whom death occurred in a care home a nurse administered the drug without presence of the GP although the GP was on call in four out of five of these cases (not shown in table). Relatives of the patient were present during the administering of the drug in nine cases. The estimated life-shortening effect was for all but one patient less than one month. This one patient (case n°10) had lost all brain function several months before death and had been held in a coma ever since (qualitative additional information).

All GPs said that the instigation of life-ending had improved their patients' end-of-life quality to some or to a considerable extent.

TABLE 6. LIFE-ENDING DRUG USE WITHOUT PATIENT'S EXPLICIT REQUEST: PERFORMANCE OF THE PRACTICE (N=13)

		n
Patient was competent at time of drug administration		0
Drugs used to end life	Opioids only	7
	Opioids in combination with a benzodiazepine	5
	Barbiturate	1
In case opioids were used to end life (n=12)	Opioids already administered previous to life-ending practice to alleviate pain or other symptoms	9
Time between administration of (first) life-ending drug and coma	Patient was already in a coma at time of administration	6
	Patient never lapsed into a complete coma (awoke now and then)	1
	15 minutes	1
	2 hours	1
	8 hours	1
	1 day	1
	2 days	2
Time between administration of (first) life-ending drug and death	instantly	1
	20 minutes	1
	90 minutes	2
	3 hours	1
	4 hours	1
	12 hours	1
	13 hours	1
	1-2 days	3
	2-3 days	2
Persons involved in administration		
Person who administered the (last) life-ending drug	GP	7
	Nurse	6
GP's presence during the administration of life-ending drugs until the time of death	Continuously	2
	With short interruptions	3
	Not present, but on call	6
	Not present	2
Other persons present during the administration of life-ending drug	Professional caregivers & patient's relatives	2
	Professional caregivers only	3
	Patient's relatives only	7
	No other persons present	1
GP's estimation of life-shortening effect of administration of life-ending drugs	< 1 day	2
	1-7 days	8
	1-4 weeks	2
	> 6 months	1

DISCUSSION

In this interview study, we examined the practice of life-ending drug use without explicit patient request in thirteen cases in general practices in Belgium. The GPs involved indicated that at the time of making the decision there was no realistic prospect of improvement in the condition of any of these patients, most of whom who were suffering persistent and unbearable pain. Almost all patients had lost the capacity to assess their situation and to make decisions. In all cases the life-ending decision was discussed with other caregivers and/or those close to the patient and had preceded, accompanied or was followed by at least one other end-of-life decision. All but one patient received opioids with the explicit intention of hastening the end of life. GPs believed without exception that the patient's end-of-life quality had been improved considerably by their actions.

This is the first study to report on the practice of life-ending drug use without explicit patient request and to provide detailed information on an individual level on clinical characteristics during the last phase of life, on the decision-making process and on the performance of the practice. One major strength is that the thirteen cases were selected from a large two-year registration study, representative of all non-sudden deaths in the country [10], and gathered via a nationwide Sentinel Network representative of all GPs in Belgium. As such, the number of patients dying non-suddenly following life-ending drug use without explicit request in general practice (2.0%) was very similar to estimated incidence figures described in other studies in Belgium in 2001 (2.3%) [12]. Furthermore, the collected data are considered to be of high quality because the cooperation of the GPs in the network is optimal, because all interviews were conducted face to face by two researchers and as soon as possible after inclusion, and because quality control measures were used in both the registration and the interview study. Finally, since the incidence of life-ending drug use has been shown to be relatively high compared with other countries [4-6] this study of Belgium is of particular interest.

However, because of the small sample of cases the results have to be interpreted cautiously. Notwithstanding that 13 interviews out of a possible 17 were conducted, the four additional interviews could probably have provided even more insight into the nature of this delicate practice. Also, due to the retrospective design of the study a possible recall bias could not be excluded entirely, or some decisions might have been interpreted differently a posteriori. Finally, our findings remain limited to the experiences of GPs. Views of patients, their family, and other caregivers were not studied.

The current study shows that patients who die following the practice of life-ending drug use without explicit request are those who suffer from incurable lingering diseases and whose quality of life dwindles drastically in the last phase. Although some patients were still fully active and ambulatory during the third month before death, they were all completely bedridden and incapable of self-care in the last week of life. Their medical situation within the final days was characterized mainly by unbearable and persistent suffering, characterized by physical as well as psychological symptom burden or by intermittent or permanent unconsciousness. That being in a coma is seen as a kind of suffering might seem inconsistent, but this might be explained by a subjective, compassionate interpretation GPs make at this very end of their long-lasting relationship with the patient. As the GPs believed without exception that their patient's end-of-life quality had been improved considerably by taking this step, it appears that they acted out of compassion and chose what they believed to be the least bad option in a medically futile situation. Whether compassion alone may in some cases justify this practice remains subject to intense debate however [30].

Another important finding of the study is that, even though patients did not or were not able to make an explicit life-ending request, GPs were in many cases unaware of their patient's wishes. This is remarkable since 95% of the population has a regular GP in Belgium [31] and have often built up a long-lasting relationship over the course of many years [32;33]. An explanation may be found in previous research that indicated that GPs experience uncertainty about initiating end-of-life discussions with their patients [34-36] which could mean that they wait for the moment at which decision-making becomes relevant, by which time patients may no longer have the capacity to express their wishes themselves. Therefore, advance care planning, i.e. communication with patients to explore their wishes in the case that they become unable to participate in decision-making [37], remains a matter of great concern in current general practice as GPs are in a key position to initiate and facilitate such discussions [38-41].

Although consultation rarely takes place with patients themselves, it does occur frequently with others: GPs do not appear to act surreptitiously or as isolated decision-makers but to involve both other professional caregivers and the patient's close circle in the decision-making process. This might suggest that GPs have a need for the exchanging of information, for consultation and advice, and for making these decisions jointly with others. However, it should be noted that in some cases the GP felt no need to discuss the decision with other professional caregivers. Furthermore, it is remarkable that multidisciplinary palliative home care teams are not consulted more often within the last months of these patients' lives, even though in Belgium they are available to all GPs in the country. The question however remains as to whether the involvement of such teams would have led to a different end-of-life decision.

Several of our findings further suggest that this end-of-life practice is quite complex and that for the GPs involved it resembles the process of intensified symptom alleviation with a possible life-shortening effect or the process of continuous deep sedation until death rather than a separate and lethal act such as euthanasia. Firstly, such decisions (symptom alleviation/sedation) were made in all cases in addition to the explicit decision to end the patient's life, and often at the same time. Therefore it seems that these medications were often given with a dual purpose: alleviating symptoms and hastening the end of life. Secondly, death did not occur immediately after the administration of the drugs. In a substantial number of cases several hours or days passed by before the patient died. This is in contradiction to what could be expected where a practice such as euthanasia was intended. Thirdly, even though there is strong evidence that the lethal potential of opioids and sedatives is doubtful and they therefore considered unsuitable agents where the hastening of death is explicitly intended [42-44], opioids, whether or not in combination with a benzodiazepine, were the predominant drug used. In addition, opioids were often already being administered to alleviate pain and symptoms prior to the life-ending action. The use of a neuromuscular relaxant which is noted in literature as an efficient euthanaticum with immediate life-shortening effect [45] was not administered in any of the reported cases. Other studies confirm that opioids are commonly in this practice [6;46].

CONCLUSION

In conclusion, this study shows that the practice of life-ending drug use without explicit patient request in general practice often seems to be an act of compassion to end the unbearable suffering of patients who can no longer decide for themselves. Our study provides various indications that the line between different end-of-life decisions is not always easy to define as the clinical context of this practice leans towards the process of intensified symptom alleviation or of continuous deep sedation until death. Although GPs are often not aware of their patient's end-of-life wishes, they do not act as isolated decision-makers and involve other professional caregivers and the patient's close circle in the decision. Advance care planning could inform GPs about their patient's wishes before the patient becomes incompetent.

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PART V

GENERAL DISCUSSION & CONCLUSION

CHAPTER 8:
GENERAL DISCUSSION AND CONCLUSION

INTRODUCTION

The main objective of this dissertation was to extend the knowledge of the care patients receive at the end of life in Belgium, and the circumstances of death and dying. In this part, the main results of the study will be discussed. Paragraph 8.2. briefly summarises the earlier chapters. Paragraph 8.3. addresses some methodological reflections. Paragraph 8.4. provides an overall discussion of the most important findings and paragraph 8.5. proposes some challenges for practice and policy and further directions for research.

SUMMARY OF THE MAIN FINDINGS

In the following paragraph, the results of the previous chapters are summarised in three separate themes, namely (1) investigation of several aspects of end-of-life care for two important patient groups, ie patients dying of cancer and patients dying with dementia; (2) investigation of several aspects of end-of-life communication in a terminally ill patient population ie the extent to which preferences for place of death are discussed with GPs and the prevalence of advance care planning; and (3) the provision of more in-depth insights into medical end-of-life practices that occur in Belgium with the explicit intention to hasten death - results of the interview study.

END-OF-LIFE CARE IN CANCER AND DEMENTIA

Dying of cancer

In chapter 2, the 2008 SENTIMELC study supplied an overview on the end-of-life of 321 patients who died non-suddenly of cancer in Belgium. More than nine out of ten patients resided most of the time at home during the last year of life. Eventually, 34% died at home, 29% in a hospital, 24% in a palliative care unit, and 12% in a care home. Overall, specialist palliative care services were used in 72% of cases, and 94% were treated with a palliative-centered goal. GPs reported that conversations that were held with the patient during the last month of life chiefly addressed physical symptoms (49%), psychological problems (45%), and options for palliative care (46%). The GP was aware of a patient's preferences with regard to medical treatment and place of death in 43% and 54% of cases respectively. Two thirds of cancer patients were completely physically disabled during the last week of life, 58% had lapsed into a coma until the moment of death, and many suffered from physical (84%) or psychological (59%) symptom distress.

Data were simultaneously gathered in the Netherlands using an identical methodology. The results showed that several aspects of care and dying were found to be country-related. Cancer patients more often died in the hospital, more often received specialist palliative care, and more often suffered from at least one psychological symptom in Belgium than in the Netherlands. Also, in Belgium communication about end-of-life issues in the last month of life was less likely, end-of-life preferences were less often known and patients less often died in the place of choice.

Dying with dementia

In chapter 3, the Belgian sentinel network of general practitioners reported the death of 1,108 patients aged 65 or more. One third (31%) of this sample was suffering from dementia, according to the GP. Of these cases, dementia was still in an early phase in 43% whereas for the remaining 57% the disease had progressed to a more advanced stage. Of all patients dying with dementia, 66% were female, 56% were aged 85 or more at the time of death, 26% died unexpectedly, 59% died in a care home, and 25% died after hospitalisation. Three out of four patients were in touch with their GP during the last week of life, 74% received treatment aimed at palliation, and 14% were transferred to another care setting during these final days. During the last three months of life, specialist palliative care services were used in 32% of cases. During the last month of life, patient-GP communication on end-of-life care most often concerned physical (24%) and psychological problems (14%) but rarely addressed options for palliative care (6%). The same was true for conversations held prior to the last month of life. The GP knew who was to take decisions in case the patient became incompetent in 11% of patients dying with dementia. For the majority of patients the dying phase was characterised by decision-making incapacity (83%), advanced physical restrictions (83%), and distressing symptoms such as a lack of energy (55%) and a lack of appetite (47%).

Several aspects of care and dying were found to vary greatly between patients suffering from mild compared with severe dementia, and between patients suffering from dementia compared with other elderly people.

END-OF-LIFE CARE: PREFERENCES AND ADVANCE CARE PLANNING

Advance care planning

In chapter 4, the 2007 SENTIMELC study reported on 1,072 patients who had died non-suddenly in Belgium or the Netherlands. With about a third of all patients an advance agreement had been made about at least one medical practice, and most often related to the foregoing of potentially life-prolonging treatment (24% of patients), or concerned an agreement about the intensification of pain and symptom alleviation despite a possible life-shortening effect (16%), or about being transferred to the hospital setting (20%). Overall, in eight percent of all cases, a written advance directive was made with the patient, but with great differences between countries: 13% in the Netherlands, and 5% in Belgium.

Interestingly, GPs indicated that in 23% of cases as care planning was made with the patient's family without involvement of the patients themselves. The factors associated with the outcome measures but varying according to type of care planning were: country, dying at home, dying of cancer, having GP contacts within the last week of life, being capable of decision-making in the last three days of life, having a palliative treatment aim during the last week of life, the involvement of specialist palliative care services within the last three months of life.

GP awareness and preference for place of death

In chapter 5, 46% of a total of 798 reported non-sudden deaths in 2006 involved a GP who was aware of the preferred place of death. GPs were informed directly by the patient in 63% of these cases. Of those whose GPs were aware, 58% had preferred to die at home, 31% in a care home, 7% in a palliative care unit, and 5% in a hospital. Not being hospitalised in the last three months of life, the involvement of informal caregivers, using specialist palliative care services, and the maintenance of a regular patient-GP contact over the final phase of life were associated with higher GP-awareness odds. Overall, four-fifths of patients with a known preferred place of death died there.

PREFERENCES AND DECISION-MAKING ABOUT LIFE-ENDING MEDICAL PRACTICES

Requests for euthanasia

In chapter 6, 200 interviews were included that were conducted with GPs about patients who died at home and for whom death was non-sudden.

Of these, 27 patients (14%) had at some point in their disease trajectory expressed a euthanasia request. The results showed that these requests varied widely between patients in nature, formulation and timing. In thirteen cases the request had been formulated in an explicit and repeated manner. Of these, five patients eventually died following euthanasia. In the remaining fourteen patients for whom the GP did not consider the request to be explicit and repeated, euthanasia was not performed. Overall, several reasons were given for not acceding to a patient's euthanasia request. Sometimes the patient reconsidered his or her wish or died during the decision-making process. More often, reasons were related to criteria stipulated in the Belgian law on euthanasia that apparently served as a guiding principle in the decision-making process for many GPs. In a minority of cases the GP did not comply with the request for personal reasons. In the last week of life, all patients received treatment aimed at palliation and comfort.

Life ending drug use without explicit patient request

In chapter 7, physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium are given. Thirteen interviews were conducted. At the time of the decision-making, the GP judged the medical situation of all thirteen patients as without any prospect of improvement, with persistent and unbearable suffering to a (very) high degree in nine cases. One patient was considered competent but not able to express himself well. All other patients had lost the capacity to assess their situation and to make an informed decision about it. In four cases the GP indicated that a wish had been expressed on various occasions while the patient was still competent which, although according to the GP not explicitly, bore upon life-ending. For the remaining nine cases, GPs were unaware of their patient's end-of-life wishes. The decision-making was always discussed with other caregivers and/or the patient's relatives.

During the last week of life, all patients were completely bedridden, all but one were unconscious, and all but one had suffered from serious symptom distress. All patients were incompetent to make their own decisions at the time of administration of the life-ending drugs. The hastening of death involved the administration of opioids in all but one cases, sometimes in combination with benzodiazepine. All GPs believed that end-of-life quality had been "improved considerably".

METHODOLOGICAL CONSIDERATIONS

In the earlier chapters, the main strengths and limitations of the SENTIMELC study have been briefly described. This section focuses on some general methodological considerations of the study.

A RETROSPECTIVE APPROACH IN STUDYING END-OF-LIFE CARE

In this dissertation we used a retrospective or mortality follow-back study design, ie general practitioners were requested to provide information on care the deceased had received in the last phase of life. It has been suggested however that studying care rendered to patients prior to their death may be biased by subject selection and time periods that are examined, and therefore lead to invalid conclusions [3]. It is argued that some patients who are perceived to be dying and therefore treated as if they are expected to die, may recover and thus will not be included, although being of interest. Also, the period of time leading up to death that is studied in retrospective designs (eg last three months of life) may for some patients exclude parts of the disease trajectory (eg diagnosis was made formerly) and for others include time irrelevant to the study (eg diagnosis was made just before death). Other concerns with the use of retrospective assessment are a possible recall bias, and the use and selection of proxies, especially a patient's close relative, as responses may be affected by grief or reflect own emotional states rather than experiences of the dying persons [4].

However there are several reasons why we used a retrospective rather than a prospective design to study end-of-life care [4-6].

Firstly, prospectively identifying patients who are approaching the end of life is often not feasible. Prognostication of death is especially difficult in cases of rather unpredictable dying trajectories, and may depend on the patient's individual and environmental context as well as on the physician's ability and experience in the estimation of survival time. Looking back over the time leading up to death more easily allows for identifying and obtaining a sample of dying persons. In our studies patients whose death was judged non-sudden and expected by their GP were selected as a result of which we were able to study care that was truly delivered in the context of a dying process.

Secondly, patients often experience transitions between care settings at the end of their lives through which prospectively studying these patients is hampered to a great extent. Since we aimed at gathering population-based data on a nationwide level irrespective of patient group, care setting, and geographical region, a retrospective design best meets these challenges.
Thirdly, although it is true that using proxies may impede the validity of the results, inquiries among terminally ill patients may cause difficulties as well. Patients may become overburdened at the very end of life and therefore drop out or become unable to provide all information needed (nonresponse bias). Because in our study most attention is put on an objective description of the care received in the last phase of life rather than on a patient's personal feelings or experiences, we believed the use of a professional caregiver as proxy may be justifiable. Some items however appeared to be especially difficult to judge, eg symptom prevalence and distress during the last week of life, resulting in a high proportion of missing data. Concerning the possible recall bias caused by a retrospective design, this was minimised by collecting data on a weekly basis, leaving little time between death and registration. Additional research procedures were undertaken to enhance the quality of the data [6]: registration forms were scrutinised for missing data and errors, a consistency check during the first and second data-entry, and an automatic follow-up on key variables with the possibility of contacting GPs by phone.

THE GENERAL PRACTITIONER AS OBSERVATIONAL UNIT

There were several reasons to opt for the general practitioner as a proxy in providing useful and representative information on end-of-life care in the general population in Belgium and the Netherlands. In both countries general practice is highly accessible and frequently used, and GPs hold a key position in the provision and coordination of end-of-life care [7-10]. GPs often build up long-lasting relationships with patients which not only results in a great knowledge of their clinical and personal history, but also in a reciprocal respect and trust which lays solid foundations for being the caregivers par excellence to explore and become acquainted with a patient's end-of-life care preferences. Also, both countries provide a representative network of general practitioners with a nationwide coverage and a long history in surveillance of health-related topics [6;10-18]. Participation by GPs is voluntary, turnover rates from year to year are low, and GPs are not specifically selected for research on end-of-life care, hence limiting response bias which contributes to the collection of data of high scientific quality.

Nevertheless, the use of a GP has also some limitations. First, some recall bias could never be entirely excluded. GPs are asked to provide information on aspects of care delivered over a period of time, some of which may not have been previously recorded and fully depend on the GP's abilities to remember certain details. For patients dying in hospital or in the Dutch nursing home missing data are more likely to occur because GPs often lose track of these patients. Also, some outcomes of care (eg symptoms) that require interpretation from the GP may be over or underestimated.
Also, some information might be open to self-reporting bias. This is especially true for the interview studies in which GPs are asked to report in a face-to-face conversation on ethically controversial practices such as the process of decision-making and performance of administering life-ending drugs without explicit patient request. As a possible result, some decisions might have been interpreted differently a posteriori. Registering personal characteristics of GPs of their attitudes to end-of-life practice could have provided valuable additional information, but were however not possible in the scope of this study. Full physician anonymity was preserved though, due to the sensitivity of the information and the relatively small number of interviews.

REPRESENTATIVENESS OF THE SAMPLE OF DEATHS

All data in the SENTIMELC study were gathered via the sentinel network of general practitioners of which the nationwide representativeness is conscientiously monitored. Considering the high involvement of the GP at the end of a patient's life, it was evaluated whether the deaths registered by the GPs were comparable in terms of age, sex, and place of death to the deaths occurring within the general population identified in corresponding official mortality data or in other published death certificate studies on end-of-life care. For Dutch nursing home residents only, representativeness was not expected as these settings provide long-term home-replacement care where GPs hand-over the care of these residents to specialised nursing home physicians.
Table 1 summarises the results on the representativeness of the study populations used throughout this dissertation as presented in the previous chapters. For the French-speaking part of Belgium no recent death

certificate data were on hand which limited our comparisons to the Northern part of the country only.

TABLE 1. REPRESENTATIVENESS (IN TERMS OF SEX, AGE, AND PLACE OF DEATH) OF THE STUDY POPULATIONS USED IN THIS DISSERTATION

Chapter (registration year used)	Study population Selected	Country	Reference database	Representativeness reached
chapter 2 (2008)	non-sudden death >1y by cancer	Be	2007 death certificate study [19]	yes
		Ne	2005 death certificate study [20]	nursing home deaths underrepresented
chapter 3 (2008)	all deaths ≥ 65y	Be	2007 official mortality rates[1]	hospital deaths underrepresented
chapter 4 (2007)	non-sudden death >1y	Be	2001 death certificate study [21]	yes
		Ne	2005 death certificate study [20]	nursing home deaths underrepresented
chapter 5 (2006)	non-sudden death >1y	Be	2001 death certificate study [21]	yes
chapter 6 (2005-2006)	non-sudden death >1y	Be	2001 death certificate study [21]	yes
chapter 7 (2005-2006)	non-sudden death >1y	Be	2001 death certificate study [21]	yes

For Belgium, the representativeness of the 2005, 2006, 2007 and 2008 non-sudden death sample regarding sex, age, and place of death was proved. However, there were two main problems. Firstly, hospital deaths were slightly underrepresented in the 2008 sample of older Belgian patients who died either suddenly or non-suddenly. This could be explained by the higher proportion of deaths in the hospital among those elderly whose death was considered sudden (43%) compared to those whose death was considered non-sudden (34%) which might suggest that GPs more easily lose track of some suddenly deceased patients once they are hospitalised than of non-suddenly deceased patients. Consequently, it might also be more difficult for GPs to make a judgment about the care and especially about experienced outcomes of care during the last days of life if their patient dies in the hospital. Data analysis indeed confirmed that missing data were most frequent in the case of hospital death.

Secondly, nationwide representativeness could not be guaranteed in the Netherlands for patients dying in the nursing home. This was expected, but should be considered as a limitation of cross-country research via general practitioners in the Netherlands.

MEASURING AND EVALUATING END-OF-LIFE CARE

A major strength of the SENTI-MELC registration study is the robust research methodology and design which have been used continuously since 2005 to monitor care received at the end of life [6;22-25]. Due to the fact that registration is continuous from weekly forms, the length of the questionnaires was limited to a maximum of two pages. However, as there was a possibility to annually adjust or alter the themes and the items on the registration form, the study design allowed for investigating an extensive set of domains of end-of-life care over the years.

A drawback of the quantitative study design however is that several aspects of end-of-life care were not fully covered or explored in depth. The interview study allowed for more depth and detail, but had a quantitative design as well.

While the studies in this dissertation mainly focused on providing basic descriptions of important domains of end-of-life care, both in processes and outcomes of care, a thoroughgoing evaluation of the quality of end-of-life care is not possible. However, our data might serve as a starting point to provide some indications on the quality of care, hence contributing to the development of "quality indicators" for end-of-life care. Quality indicators are measurable elements of practice performance of which there is evidence or consensus that it can be used to assess and monitor quality and hence promote a higher quality of care provision [26]. Quality indicators are usually described with a numerator (eg all terminally ill patients with a preference for home death and actually dying at home), a denominator (eg all terminally ill patients with a preference for home death), and a performance standard (eg for how many of these patients home death can be realistically pursued). Our results, for instance, provide insights into how many patients actually died at the place of choice, if the GP was aware of the preferred place of death.

The development of quality indicators for palliative care is ongoing in Belgium and the Netherlands, and is expected to improve quality assessment and monitoring within the coming years [27]. In a current research project, the End-of-Life Care Research Group Ghent University & Vrije Universiteit Brussel has identified several key aspects of quality end-of-life care on which the SENTIMELC registration study may provide valuable information, eg maintaining sufficient contact with the patient during the last three months of life; informing the patient about their diagnosis, the prospect of the disease, and the options for palliative care; exploring end-of-life preferences, and meeting these preferences in cases where the situation does arise; measuring symptom burden that patients might have experienced in the last week of life; whether care is no longer aimed at cure at the very end of life etc.

GENERAL DISCUSSION

The following paragraphs provide some reflections on the main results of this study. Three main domains that were identified in the introduction of this dissertation as highly valuable in describing and evaluating end-of-life care will be taken as a guide, ie medical care processes (8.4.1.), communication processes (8.4.2.), and the aspects of the dying process (8.4.3.). Also, for some discussion points specific recommendations and challenges for practice and policy are given.

MEDICAL CARE PROCESSES

Places of care and death

The GPs in our study reported that approximately seven out of ten patients whose deaths were expected or non-sudden were able to live at home for most of the time during the last year of life. Among patients dying of cancer this was the case for almost all (>90%) compared to four out of ten elderly people with a diagnosis of dementia. Results on the actual place of death showed that residing at home can often not be maintained until the very end of life. The proportion of patients dying at home is about one quarter of non-sudden deaths, one third of non-sudden cancer deaths, and one out of seven of elderly patients diagnosed with dementia. These figures are congruent with corresponding data from large-scale published death certificate studies in Flanders, Belgium [28-30] . Previous research that was conducted among a general patient population of terminally ill already showed that transitions between care settings often occur at the end of life in Belgium [22].

It should be noticed however that for a substantial part (two thirds) of patients dying with severe dementia the care home is the longest place of residence during the last year of life, where most of these patients also die (71% of cases). It is known that people with dementia are likely to enter institutional care [31] because of the relatively high age, the increasing clinical needs [32] and the great burden the disease puts on the patient's surroundings [33;34]. As such, the low proportion of patients with severe dementia dying at home is related to the high rate of residential care and does not need to cause concern. It is on the contrary encouraging that many of these patients can die at the place where they reside for most of the time during the last year. After all, late transfers at the end of a patient's life are often questionable [35], especially to a hospital in cases of

dementia where continuity of care is of great importance as disorientation in time and place is usually prominent and hospital-related health risks are often prevalent [36;37].
In this view it is worth mentioning that patients with severe dementia are three times less likely to die in a hospital (16%) compared with patients with mild dementia (37%), after adjusting for patient characteristics such as age and sex. That percentages vary greatly depending on the severity of dementia might indicate that efforts are being undertaken to prevent transferring severe dementia patients to the hospital. Perhaps this means that institutional guidelines regarding do-not-hospitalise decisions, which have grown in prevalence in Flemish care homes within the last decade [38], are often used and respected for these vulnerable patients. Research (2006) showed that a physician's order not to hospitalise was the most common (37%) anticipatory documented decision in Flemish deceased care home residents [39].
However, our results showed that at least a minority of dementia patients still die in the hospital and admission takes place during the last week of life in almost half of the cases, which might leave some room for improvement. Also in other Western countries, hospital admission and hospital death among dementia patients is prevalent, except for the Netherlands due to well-developed long-term care nursing homes and a great availability of nursing home beds [30;32;40].

A specific advantage of the SENTIMELC study is the ability to differentiate between patients dying in a hospital and patients dying in a palliative care unit, contrary to studies that make use of death certificates in which the response category hospital covers both settings. This is an important distinction as hospitals primarily intend to cure whereas palliative care units focus on comfort care. Our data show that a final admission to a palliative care unit occurs frequently among cancer patients, ie in a quarter of non-sudden deaths. In the case of severe dementia, these units were used in 1% of patients.

GP-patient contacts in last phase of life

During the last three months of life. GPs often remain in close contact with their patients during the final phase of life. In the last three months before death, half of all terminally ill patients, half of all elderly with dementia, and half of all non-sudden cancer deaths had contact (consultations, home visits) with their GP on respectively at least eight, seven, and nine occasions. Three out of four patients in the euthanasia request study had more than ten contacts, and none of the patients whose death was preceded by life-ending drug use without explicit request had less than six contacts during these final months.

During the last week of life. Contact was often preserved until the very end of life. The majority (72%) of terminally ill patients had at least one encounter with their GP during the last seven days of life. During this period, the mean number of GP visits to patients at home was 3.2 for home deaths and 2.3 for care home deaths with respectively 6% and 9% of patients who had no contact with their GP in these settings [41]. In the last week of life, contacts occurred in four out of five elderly persons suffering from severe dementia, and in seven out of ten patients dying of cancer. A home visit or consultation also occurred for all but one patient with a request for euthanasia. All thirteen patients for whom death was preceded by life-ending drug use without explicit request received a GP visit at least once – one GP reported to have visited the patient fifteen times– in the last seven days prior to death.

It is estimated that approximately five non-sudden death cases occur per GP per year in Belgium [42]. This means that caring for patients for whom death becomes imminent is not part of a GP's daily routine practice notwithstanding that visiting these patients may be very time-consuming and emotionally burdening. Our results suggest that GPs invest time and effort in ensuring relational continuity with their patients, especially in case life-shortening decisions are requested or made.

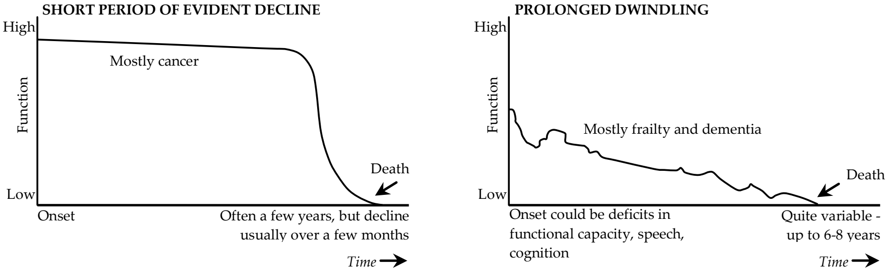
Palliative care provision in the last phase of life

Traditionally, palliative care was regarded as relevant only in the very last weeks of life with a clear shift from curative or life-prolonging care to palliative care. In the past decades however, a new palliative care concept emerged focusing on an initiation of comfort care from the early stages of the disease [1;43]. Nevertheless, previous work within the SENTIMELC study has shown that focussing treatment on comfort often occurs relatively late (not before the last month of life) for many patients in Belgium and that for approximately one out of five terminally ill patients a palliative treatment goal is lacking at the very end of life [24]. These findings are corroborated in this study. Additionally, we have shown that 85% of patients dying with severe dementia received palliative-centred care during the last week of life, compared with 60% of patients dying with mild dementia. This appears to be different from a population of patients dying of cancer, in which 94% of cases received treatment aimed at palliation. The data on the use of specialist palliative care services in the last three months of life showed a very similar variation across patient groups. These services were involved in 39% of patients with severe dementia, in 23% of patients with mild dementia, and in 72% of patients dying non-suddenly of cancer in 2008 in Belgium.

That the differences between patient groups are so apparent, even at the very end of a patient's life, is interesting but understandable. We know that from its origin, palliative care has predominantly focused on cancer patients. Also, the onset of a palliative care philosophy in the care of a patient with a noncancer disease is more difficult due to the different illness trajectories. In figure 8.1 the trajectory of cancer patients and most frail elderly, such as patients with advanced dementia, is outlined [44;45]. Patients suffering from dementia may live for a long time – the median length of survival from diagnosis to death is eight years [46] – but become increasingly dependent and cognitively impaired. Cancer patients have a more predictable dying course with a short period of evident decline which might make it easier to plan the initiation of specialist palliative care services. Our results indicate that this correlation between cancer and palliative care is still very prevalent in Belgium at the beginning of the 21st century.

On the contrary, our results suggest that suffering from dementia might be not enough of a trigger to be recognised as being eligible for palliative care, which has also been put forward by previous research [37;47;48]. However, patients with a diagnosis other than cancer – in particular patients with dementia, have been identified as being at risk of suboptimal care [43;46]. As the WHO states that palliative care should be aimed at enhancing the quality of life of all patients suffering from life-threatening conditions – which dementia is – and might be initiated early in the disease course [43;44;46], this might argue in favour of adopting a palliative care philosophy for people with dementia from diagnosis to death. As such, palliative care might well go hand in hand with life-prolonging treatment in the early stages of the disease and more and more comes to the fore when death becomes imminent. Palliative care then acts as supportive care rather than terminal care only.

FIGURE 8.1. TYPICAL ILLNESS TRAJECTORIES FOR PEOPLE WITH PROGRESSIVE CHRONIC ILLNESS



SOURCE: ADAPTED FROM LYNN AND ADAMSON, 2003 [1]; MURRAY ET AL., 2005 [2]

In this view, also specialist palliative care services might be consulted earlier in the disease trajectory of patients with dementia, perhaps not from the moment of diagnosis, but rather according to the needs of the patient. As access for non-cancer patients to these services is generally rather low [24;49], it might be a challenge to better equip services to deal more easily with patients who experience other than typical cancer trajectories and to enhance access when necessary.

Important to mention is that a palliative treatment goal was always present at the end of life in our studies on patients who had requested euthanasia, and for whom life-ending drugs were used without their explicit request.

Comparison with Dutch data from the SENTIMELC study

Our data show large differences between Belgium and the Netherlands concerning various aspects of end-of-life care provision. Firstly, cancer patients more often die at home in the Netherlands compared to Belgium. This was found in a large-scale death certificate study as well [50]. Secondly, cancer patients dying in the Netherlands were twice as likely to have contact with their GP during the last week of life compared to Belgian patients, even when differences in place of death were taken into account. Prior work that studied GP contacts in the home and care home separately in both countries among a non-suddenly dying patient population had already found higher prevalence figures for the Netherlands in both settings [41]. It seems that although Belgian GPs highly engage in maintaining patient contact in the last phase of life, they do not seem to have as many contacts as their Dutch colleagues. Thirdly, data on the provision of palliative care yielded some interesting results.

In chapter 4 – the 2007 database of all non-sudden deaths – it is shown that during the last week of life, treatment was more often aimed at palliation in the Netherlands (91% vs 77%) whereas specialist palliative care services were more often used during the last three months of life in Belgium (38% vs. 21%), and recent research in the home and care home setting showed that this country-difference regarding the use of specialist palliative care services remained consistent despite correcting for possible confounders [41]. For cancer patients (chapter 2), data on treatment goal at the end of life did not reveal any cross-national differences as care was aimed at palliation in almost all cases in both countries (>90%). However, the involvement of palliative care services depends very much on the patient's country as it was shown that cancer patients were seven times more likely to have received specialist palliative care in Belgium compared to the Netherlands (72% vs 34%).

Several aspects might contribute to the explanation of these results and differences.

Whereas in Belgium cancer care seems more oriented towards hospital and palliative care units, a clear home-care approach seems to be followed in Dutch policy. As most cancer patients prefer to die at home [51], this indicates room for improvement in Belgian health care. Also, the role of the GP at the end of life might be perceived differently in both countries. Being gatekeepers to the health care system, Dutch GPs take on more care giving tasks themselves [52] while Belgian GPs seem to more often pursue a coordinating role only. GPs in the Netherlands are more often formally trained in palliative care than in Belgium (91% vs 63%) [53] which might make them more perceptive for detecting palliative care needs of non-cancer patients. Finally, because most geriatric and dementia patients die in a nursing home in the Netherlands outside the purview of GPs, the end-of-life population that is being cared for by GPs is more heterogonous in Belgium making the delivery of palliative care by GPs themselves possibly more complex .

COMMUNICATION PROCESSES

At the end of life, sensitive communication between patients, their families and caregivers is considered an important aspect of good palliative care and may relate to a range of positive health outcomes [43]. Discussing end-of-life issues may also give occasion for exploring a patient's end-of-life preferences, values, and goals which contributes to the process of advance care planning [54]. Several aspects of end-of-life communication were examined throughout this study: 1) the prevalence of conversations between cancer / dementia patients and their GP about primary diagnosis, incurability of illness, life expectation, possible medical complications, physical, psychological, social, and spiritual issues, options for palliative care, and burden of treatments; 2) advance care planning, ie preferences for place of death, medical treatments, and a proxy decision-maker, and agreements on end-of-life treatment and care.

Advance care planning or general care planning

The findings presented in chapter 4 might suggest that advance care planning is often performed ad hoc or late in the illness trajectory, rather than early and in advance of decision-making incompetence. In 23% of all terminally ill patients advance agreements had been made without their involvement. Perhaps the patient was mentally incapacitated, and agreements were made with family members to make plans for current and continuing health and social care that contains achievable goals and the actions required. Advance care planning was also found to relate strongly to palliative care, and it is known that palliative care is often initiated relatively close to death [24;55]. Also, patients who were capable to make decisions in the last three days of life, or these with whom the GP had contact during the last week of life were far more likely to be involved in the process of advance care planning compared with other patients.

In the UK, the National End of Life Care Programme distinguishes between 'advance care planning' on the one hand from 'general care planning' on the other [56;57]. Both stem from the desire for an ongoing, continuing and effective dialogue between the patients, carers, partners and relatives, in which the latter focuses on the current situation and can also be made by the family in the patient's best interest whereas the former requires patient involvement and aims at directing future care in the event of patient decision-making incapacity.

From this viewpoint, our data suggest that the discussing of end-of-life issues, the exploration of end-of-life preferences and the formulation of end-of-life agreements comprise aspects of both advance and general care planning. A recent study conducted in all nursing homes in Flanders also concludes that true advance care planning still occurs rather sporadically [39].

Advance directives

In chapter 4 it was found that, according to the GP, a previous agreement made with the patient and in writing for medical treatment and/or medical decisions in the last phase of life was present in 8% of terminally ill patients. Results from a study in Flemish nursing homes also indicated that the percentage of residents who have written an advance directive is very low (5% of all residents, 2% of all residents with severe dementia) [58]. Also in other European countries, prevalence figures are low. In the Netherlands, an interview study was conducted among relatives of a representative sample of deceased older persons (age 59-96) as part of the Longitudinal Aging Study Amsterdam [59]. Results showed that few older people had died with a written advance directive regarding medical end-of-life decisions (10%). In the UK, a study among the general public showed that only 8% in England and Wales had completed an ACP document of any kind [60;61]. Studies carried out in Japan and Australia also show a generally low percentage of actual formal planning [62;63].

On the contrary, advance directives are more often embedded in American general health care and society. With the implementation of the Federal Patient Self-Determination Act in the USA in 1990, it was mandatory for all patients to be informed of their rights regarding decisions on their own medical care [64]. Since then advance directives have been widely promoted in the US [54]. Literature suggests that between 18% and 30% of Americans have completed an advance directive [65]. Teno and colleagues showed that among a national sample of non-traumatic deaths this was the case for 71% of patients [66].

Advance directives however are subject of much controversy. The following paragraphs present some concerns and some positive and negative aspects that arise with advance directives.

In several studies advance directives have shown to be associated with positive outcomes for both patients and their families. A Canadian study conducted in the nursing home setting demonstrated that a systematic implementation of a program to increase the use of advance directives reduced use of health care services without affecting satisfaction or mortality [67]. Data from the Asset and Health Dynamics Among the Oldest Old (AHEAD) study showed a lesser likelihood of dying in an acute hospital if an advance directive was in existence [68]. Teno and colleagues examined whether or not advance directives were positively associated with the quality of end-of-life care as perceived by family members at all sites of medical care [66]. Their study showed that a bereaved family member report of the completion of an advance directive was related to fewer concerns about physician communication and with more information about what to expect during the dying process.

However, many other studies question the benefit of written advance directives. A patient's preferences may change with time, age, and health status which leads us to be wary of its apparently resolute character [69-71]. Sometimes preferences may be unclear and vague which can be misleading [72], and questions are raised about the future applicability of an advance directive or about the way certain concepts should be interpreted in clinical practice, such as 'unbearable suffering', 'not competent to make own decisions' [73]. Also, some health professionals might be unwilling to follow the patient's previously expressed preferences; they may assume they know what is in the advance directive without reading it [72].

Notwithstanding these limitations, there is a growing consensus that advance directives provide an important opportunity to improve the quality of end-of-life care for older people if the emphasis is being put on the process of communication and interaction rather than on a legal document [74;75]. Written advanced directives are still acknowledged to be important but not sufficient to improve end-of-life care. Their added value may lie in the understanding that they serve as a guiding principle for following discussions, but also in their availability to inform later care. It is shown that end-of-life care in Belgium is characterised by a high prevalence of transitions between care settings, especially to hospitals, in the last weeks of life [22]. Ensuring continuous, well-organised care may be facilitated by a document containing information about a patient's preferences which can be passed on to different health care providers. It goes without saying that it is burdensome for patients to have to explain their wishes all over again to different health care professionals in cases of a transfer to different care settings [76;77].

Appointing a proxy decision-maker in cases of dementia

Our results show that only in 8% of severe and in 14% of mild dementia patients the GP was aware of a preference for a proxy decision-maker to make decisions on the patients' behalf. This finding was particularly remarkable since it is known that many dementia patients become incompetent at the end of their life which makes an anticipated exploration of the patient's preferences highly recommended. This finding corroborates a Belgian study among care home residents in which 11% of residents diagnosed with moderate dementia had formally assigned a surrogate decision-maker, and 7% of these with severe dementia [39]. However, the importance of advance care planning is highly valued in these settings as almost all Flemish care homes have implemented a policy regarding

advance care planning nowadays in terms of guidelines or patient-specific planning forms [38]. An institutional guideline or a standardised document on the appointment of a patient's representative was present in respectively one fourth and one third of care homes in 2006 [38].
Recent large-scale research in the US additionally demonstrated that appointing a proxy decision-maker can prevent burdensome treatments, and might account for unforeseen factors [78]. It is good to mention that since 2002, Belgium has a law concerning Patient Rights [79] in which the status of the proxy-decisionmaker is legally regulated. If we want more dementia patients to assign a surrogate decision-maker, then these wishes should be addressed timely, and more initiatives should be taken to get both patients and caregivers acquainted with this legal initiative, and to put policy into practice.

Of course, health professionals can best proceed with caution when relying on these proxy decision-makers to make end-of-life treatment decisions for incapacitated patients as the accuracy with which surrogates can predict patients' preferences is often questioned. Surrogates may project their own views and hopes onto what they predict the patient's preferences are as a result of which preferences of a patient and his/her family are often not in concordance [80-83]. Therefore, effective patient-proxy communication before medical decision-making incompetence occurs is of utmost importance to act for the patient in the best possible way, with a correct knowledge about the true wishes of the dying person [84]. In addition, drawing a patient's family into these end-of-life discussions is reassuring for both patients and family caregivers. Being a patient, it is a comforting thought to know that someone you love will take decisions on your behalf if you lose capacity. Being a patient's family, you may feel less stressed, anxious, or depressed the moment end-of-life decisions are required [85].

Dementia and cancer patients are approached differently

The surveillance of the prevalence of end-of-life discussions in cancer patients (chapter 2) and patients suffering from dementia (chapter 3) via the 2008 registration form divulges substantial differences between both patient groups. Our results are indicative for a much higher rate of GP-conversations in cancer patients compared to dementia patients, both in the last month of life and before.

Whereas at least one of the issues was discussed in nine out of ten cancer patients, this was true in 59% and 35% of elderly patients dying with mild and severe dementia respectively. Interestingly, the prevalence of discussions with dementia patients up to the last month of life was found to be very low as well. In less than 5% of patients suffering from severe dementia at the time of death a conversation about possible options for palliative care (1.6%), life expectation (3.7%), burden of treatments (3.7%), or existential problems (4.8%) was held prior to the last month of life. With regard to the patient's preferred place of death, GPs reported to be informed directly by the patient in 28% of all non-sudden deaths, in 54% of all non-sudden cancer deaths, and in 16% of all elderly who died with dementia (8% of severe and 25% of mild dementia patients). The data also indicated that dementia and cancer patients had expressed specific wishes about any medical treatment that he or she would or would not want in the final phase of life in 8% and 43% of cases respectively.

It can be argued that having cancer still more easily triggers a palliative care approach, in which end-of-life communication is highly valued, than being diagnosed with dementia. The differences in palliative care provision between both groups that are presented earlier in this chapter are in line with this finding. Considering the typical disease trajectory of cancer patients, there is generally time to anticipate needs, and make plans for future care (also see figure 8.1). Being diagnosed with cancer might also open up people (patients and caregivers) for discussing end-of-life issues [1;2;86]. Dementia, on the other hand, is characterised by a more prolonged dwindling and progressive disability from an already low baseline of functioning. As such, many dementia patients lack the ability to make their own decisions at the end and their communication capabilities may have been hampered for several months or years already. With this in mind, caregivers might be encouraged to initiate end-of-life discussions and to explore preferences for future care and treatment early in the process of the disease. Yet, our results suggest that this is often not the case and that both patients and caregivers are rather reticent about discussing the end of life timely enough. As being aware of a patient's end-of-life preferences is a prerequisite for GPs and other caregivers to be able to organise future care that meets the patient's values and expectations – eg considering our finding that GP awareness can truly help improve someone's chances of dying in the place of choice –, it can be suggested that there is still great room for improvement in both groups, but especially in dementia patients.

Content of end-of-life discussions

GPs clearly discuss some end-of-life issues more than others. Both physical and psychological problems rank among the most frequently discussed issues, whereas the opposite is true for social and especially spiritual problems. This result was found among all studied patient groups (cancer patients – chapter 2, dementia patients, non-dementia elderly – chapter 3), which makes it likely to be a general trend in how GPs deal with the discussion of end-of-life issues with their patients. In our study, spiritual/ existential problems were specified as difficulties in accepting the situation, trouble with the meaning of life, anger at God, etc.

Physicians might feel uncomfortable about discussing these matters with patients, either because it is considered as falling outside their professional expertise, or because they feel it would be an intrusion into the patient's private life [87]. Also, a lack of sufficient time might be considered a barrier [88].

Still, as we did not measure individual wishes for this type of care, it cannot be concluded that patients' needs had been left unsatisfied. Previous research however indicates that patients put great value on their GP inquiring about their spiritual needs in particular when confronted with a life-threatening illness or serious medical condition [87;89-91]. Among the most important reasons were the desire for understanding and the encouragement of hope [91]. Also, the World Health Organisation increasingly promotes palliative care as holistic ie integrating physical, psychological, spiritual, and social aspects of patient care [43;44].

Requests for and decision-making in explicitly intended life-ending practices

Having knowledge of a patient's preferences is a factor that cannot be underrated in the actual decision-making process, especially if the explicit hastening of death is concerned. Our data have shown that, while a relatively large proportion of patients dying at home formulate a wish for euthanasia (1 out of 7 patients) – some more explicit than others – only a minority die following euthanasia. Our interview data also provide insights into how requests for euthanasia are dealt with and demonstrate that the request's specific characteristics – mainly whether or not the substantive requirements as stated in the Belgian law on euthanasia were met – are pondered carefully before a decision has been made. In some cases, GPs did not comply with the request for personal reasons, but however felt committed to alleviating the patient's suffering in another way.

Sometimes however, no explicit request is present nor could the patient's wishes be ascertained due to a lack of decision-making capacity, but the GP judges suffering to be unbearable and persistent in such a way that putting life to an end is believed to be in the patient's best interest. GPs may be on the horns of a dilemma here as the decision-making needs very delicate deliberation. Our study shows that GPs then sometimes proceed to the administration of drugs with the explicit intention of hastening the end of life, but not before consulting the patient's relatives or other professional caregivers, and mostly both. Notwithstanding that not acting as an isolated decision-maker may be reassuring for GPs, more timely discussion with patients themselves before incompetence occurs would be most recommendable to get acquainted with a patient's preferences, values, and priorities which might facilitate the decision-making process for all caregivers involved.

Comparison with Dutch data from the SENTIMELC study

On several issues, communication is more often prevalent in the last phase of life in Dutch compared to Belgian general practice. Dutch terminally ill patients had informed their GP about the preferred place of death themselves in 49% of cases [92] (vs. 28% in Belgium), and in 73% in case cancer had caused death (vs. 54% in Belgium). Cancer patients in the Netherlands were three times more likely to have expressed a preference for treatment at the end of life, and discussions on end-of-life issues during the last month of life were much more likely to have occurred compared to patients dying of cancer in Belgium. Agreements on end-of-life treatments and decision-making were made in consultation with patients in 37% of Dutch non-sudden deaths (vs. 32% in Belgium), and documented in 13% (vs. 5% in Belgium). It could be argued that at least some part of the variation could be due to the underrepresentation of nursing home deaths in the Dutch sample. As such, relatively more deaths from settings with high GP involvement are included with a possible effect on end-of-life communication. Nevertheless, in the analyses the effect of differences in place of death between countries had been kept under control. Also in a cross-national attitude study it was shown that Dutch physicians were in principle far more inclined to always discuss end-of-life topics with competent terminally ill patients compared to their Belgian colleagues [93].

Other explanations then come to the fore; the difference between countries in the way the GP's role at the end of a patient's life is perceived may be one. The Dutch gatekeeping system and the higher personal involvement of Dutch GPs in the provision of palliative care may contribute to a different end-of-life care communication pattern. Other reasons might be more culturally-related and may refer to ideas of candour and open communication which are highly valued in the Netherlands [52]. As a result, Dutch GPs might be less paternalistic in how they provide care than Belgian GPs, but also patients in the Netherlands might be more articulate or more often take the first step towards discussing end-of-life issues than in Belgium. As physicians in the Netherlands tend more towards the formalisation of practices than in Belgium, the difference in documented advance directives can be partly explained as well [94;95]. However, more in depth research needed.

THE DYING PROCESS

Functional and cognitive status during the last week of life

Four out of five elderly with dementia and two out of three cancer patients were completely physically disabled and bedridden at the end of their life, as were all patients who died following the use of life-ending drugs without explicit request and most of patients with a euthanasia request. In addition, many patients lapsed into a coma in the last hours or days before death (59% of elderly with dementia; 49% of elderly without dementia; 58% of cancer patients). Six out of thirteen patients for whom death was explicitly intended without request had been in a coma at the time the life-ending drugs were administered, and also none of the other patients were still competent at that moment. The capability to participate in the decision-making at the end of life was completely lacking as well for almost all of the patients with a diagnosis of severe dementia. These results suggest that for many patients a comprehensive palliative care approach and early onset of advance care planning is pivotal. This might also include an approach in which attention is being paid to the wellbeing and support of a patient’s family, as a relative but also as an informal caregiver.

Symptom distress during the last week of life

By definition, one of the main aims of palliative care is the relief of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms, physical, psychosocial and spiritual [44]. For as far as GPs were able to judge the patient’s symptoms in the last week of life, symptom distress was found to be prevalent at the very end of life in the majority of cases in all patient groups.

At least one of the following symptoms – lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, and difficulty breathing – were quite a bit or very much distressing in 66% of dementia, and in 82% of cancer patients. One out of three dementia patients, and 59% of cancer patients was frequently or almost constantly worried or feeling sad, irritable, or nervous during the last week of life.

Also in cases where physician-assisted death was requested or performed, symptoms of distress were commonly reported at the end of life.

Some symptoms distressed patients more than others. A lack of energy ranked highest in all studied samples whereas pain was judged to cause distress in a relatively small minority of patients. It is important to mention that this concerns the perceived burdening upon patients rather than whether of not the symptom had been present– other studies found pain to be ranked among the most prevalent symptoms at the very end of a patient's life [96]. Possibly the distressing effects of pain can be managed more easily compared to relieving the distress caused by a lack of energy. Perhaps this relates to the great attention to pain relief in medicine in general health care and in palliative care in particular, and points to the need for research in how to effectively manage and cope with symptoms other than pain.

From research we know that symptoms are often underestimated and consequently undertreated especially among non-cancer patients [46;97]. Also in our study distressing symptoms were more often reported in cancer than in dementia patients. In this view it is notable that GPs experienced much more difficulty to make an estimation of psychological distress symptoms for severe than for mild dementia patients. This might suggest that particularly psychological problems remain underdetected and therefore undertreated rather than being not present. Perhaps this is because this distress is perceived no longer to exist once a patient's self-awareness has drastically declined. Also, although less prevalent than physical distress, psychological problems are shown to be an important issue to deal with in end-of-life care provision. This is in line with a holistic palliative care approach not to limit care to pain and other physical symptoms.

Dying at the place of wish

Honouring a patient's end-of-life preferences contributes to satisfaction with health care and experienced quality of life [98]. Our study investigated the relationship between preferred and actual place of death in different patient populations. Overall, death occurred in the place of choice in 80% of non-sudden deaths, in 71% of cancer patients, and in 67% of older people suffering from dementia, but only in cases where the GP was aware of the patient's preferred place of death. Notwithstanding that a substantial amount of patients finally died at the place of wish, incongruence between the preferred and actual place of death was rather common. However, considering the fact that relatively few people prefer death in hospital and patients more often died in hospital when GPs were not informed of the preference, it can be assumed that these percentages are an overestimation. When taking into account that these studies include patients who suffered from life-threatening diseases and whose death was in most cases expected, questions could be raised as to why congruence could not be reached to a greater extent.

Disagreement between preference and outcome has been found in many other studies albeit with great variation between studies [99]. In Italy, for instance, 67% of a sample of cancer deaths that was representative of the whole country took place in the place of choice [51] whereas a prospective study among terminally ill cancer patients in the US reported 30% of congruence [100]. Differences in defining the patient population, methodology, moment of exploration of preferences in view of disease trajectory or in view of death, using the patient or using a professional caregiver or a next-of-kin as a proxy, can all account for some part of the variance. The 2006 non-sudden death study revealed some additional information per care setting, and showed that the congruence between preferred and actual place of death was lowest for those patients who wished to die at home; a finding that should not cause any surprise given the aspiration of many to die at home and the high prevalence of end-of-life transitions, especially from the home setting to the hospital [22].

Dying in the place of choice may be hampered by several factors that may be identified as illness-related, environmental, or individual-related [68;99-104]. Illness-related factors can refer to an inability to control symptoms, a need for 24-hour care, an unclear prognosis, and death before admission. Environmental aspects include a lack of availability of continuous professional care in the home care setting, hospitalisation, proximity to hospital, and the burdening of the informal support network. Individual related factors may concern the preference to die at home, and a patient's change of mind. Our own data additionally suggest that a preference for home death was more often achieved if patients were never hospitalised in the last months of life and if a regular contact with the GP was maintained. More important still, our study suggests that GPs, if aware, may actively contribute to dying at the place of wish. Care might be coordinated and directed by the GP in such a way that fulfilment of the patient's end-of-life wishes is maximally enhanced.

Comparison with Dutch data from the SENTIMELC study

Data gathered in the Dutch part of the study show some similarities as well as differences with the Belgian sample. Although patients dying of cancer experience a relatively comparable dying process in both countries in terms of functional status and loss of consciousness close to death, Belgian patients are perceived to have more psychological distress than the Dutch ones. The difference was striking and concerned all investigated symptoms ie worrying, feeling sad, irritable and nervous. In chapter 4 we hypothesise that Dutch GPs feel more comfortable or experienced in dealing with these issues, or interpret the patient's situation differently. Further research however should address these issues in more depth.

Figures on the congruence between the preferred and actual place of death in a non-sudden death sample indicate that 80% and 84% of patients in Belgium and the Netherlands respectively were able to die in the place of choice in both countries, which is very comparable [92]. In cases where home was the preferred place of death congruence however was more often reached in the Netherlands than in Belgium (83% vs 72%). Perhaps some of the Dutch nursing home deaths that were excluded from the sample may have had the aspiration to die at home. However the question remains if the GP would be aware of these patient's preferences as they do not act as the responsible caregiver in this setting. That there are more frequent GP visits at the end of life in the Netherlands than in Belgium is more likely to serve as an explanation [41].

CHALLENGES FOR PRACTICE AND POLICY AND RECOMMENDATIONS FOR FUTURE RESEARCH

PRACTICE AND POLICY

Invest in end-of-life communication

In general, our findings suggest that there is room for improvement in the content, modalities, and timing of communication processes at and about the end of life. Preferences are often not explored or elicited and also advance care planning is often not implemented, or rather late in the disease process. However, it can be questioned whether such communication should be promoted at all times. One of the key principles of end-of-life communication is that it is a voluntary process without pressure to take part in it [56]. Patients may feel uncomfortable addressing issues related to death, illness and the end of life. While some patients openly acknowledge that they are dying, others will deny the imminence of death and avoid talking about it [105]. However, caregivers do not need to stand back but they can sensitively and proactively explore whether the patient is ready and willing to discuss their future care. For example, even though a patient does not want to discuss his or her prognosis, it may still be important to start up a conversation about other aspects or possibilities of care and treatment [106].

Alternately, health care providers may also struggle to bring up conversations about end-of-life care and treatment preferences with their patient [107;108]. This may be because some feel constrained time-wise, or are uncertain about when to initiate end-of-life discussions [109;110]. Therefore the process of advance care planning should be time-effective by targeting its content in relation to the patient's disease trajectory or with the patient's daily environment [111].

Our results exemplify the complexity of providing care in accordance with the patient's preferences at any given moment, but at the same time plead for investing time and efforts in a trustful and transparent relationship between the patient and his or her caregivers.

In spite of all possible barriers, it can be recommended to use this relationship to involve both the patient and the family in the process of end-of-life communication as early as possible on both current and future aspects of health and social care, to engage in documenting these outcomes, and to continue close consultation with family members the moment the patients becomes incapacitated. Completing an advance directive form should be encouraged but always be seen as a means to effective advance care planning, and not as an end in itself.

Appoint a proxy decision-maker in case of dementia

In light of the disease trajectory many dementia patients might experience, an early onset of advance care planning is especially recommended in these patients. The low prevalence figures considered, assigning a surrogate decision-maker in case of future incompetence can best receive ample attention in end-of-life care discussions. As such, care-giving will not only more often fit the patient's wishes, but family members might also feel more comfortable in taking decisions on behalf of the patient.

Invest in education, training, guidelines and information campaigns

For professional carers: Many organisations have been engaging in the development of guidelines, providing practical guidance for caregivers on core questions about when and with whom discussions should be considered, how to raise delicate subjects, how to involve patients and proxies in difficult medical decision-making, how to deal with patients who lose competence etc. [56;57;61;110]. In Belgium, for instance, The Belgian guideline for GPs on end-of-life care communication ('Zorgleidraad') could be a very useful instrument to deal with feelings of uncertainty and to initiate timely advance-care planning [110]. Although such guidelines might be very useful, they may not be sufficient and interactive courses on palliative care and communication strategies to educate health and social care staff in medical and nursing schools may provide an additional step forward. Such training skills could be further maintained and developed by regular workplace-based education led by experts and expert patients [61]. A commendable initiative in this regard is taken by the "Life End Information Forum" (LEIF) which not only offers a wide information and support forum for professional caregivers, but also organises training sessions on end-of-life care and communication [112;113].

For the general public: Along with the growing awareness among health care organisations and professionals of the importance of end-of-life care communication, an important role in providing information with regard to the end of life and in promoting advance care planning among the general public also lies with policy makers, who can set up or support information campaigns indicating the importance of these initiatives for all people, especially the elderly. The initiatives that have been taken by several organisations, eg LEIF – offering an elaborate leaflet with information and legal documents about the end of life [112] –, The Flemish Federation of Palliative Care – offering a guide aimed at the promotion of advance care planning [106]– should be further encouraged and circulated.

An important challenge may also lie in the dissemination of scientific study results on a wide scale, both to professional target groups as to the general public, through press communiqués, accessible websites, approachable conferences, presentations and Dutch-language publications.

A concerted engagement of all professional actors involved

Encouraging patients and caregivers to start up advance care planning and to document their preferences, wishes, values, and decisions may be a first great step forward, yet this may not be sufficient. It is known that there might be several barriers that may prevent advance directives from affecting care.

Notwithstanding that it might require a great deal of effort, health care settings and professional caregivers should enter into close consultation with each other to develop a joint approach on how to formulate advance directives, and how these could best be managed and handed over the moment a patient is transferred, eg from home to the hospital. Initiatives that may contribute are informing health care professionals about the value of discussing and documenting a patient's preferences, and promoting close communication between first-line and second-line care. Also, an electronically-managed patient record which is used uniformly throughout the different care settings with the patient's consent might be one practical step to take.

A target group specific approach in palliative care?

Insights into how people with cancer or dementia are dying in Belgium revealed important differences with regard to place of care and death, and actual end-of-life care provision and communication. As a result, one could suggest that the provision and organisation of palliative care preferably depends on the specific disease a person is confronted with.

When dementia is concerned, studies most often focus on severe dementia patients only. Our study shows many older people with dementia die before the disease had progressed to an advanced phase. As it seemed that for several of the studied care and clinical characteristics mild dementia patients bear resemblance to patients who died without dementia rather than to severe dementia patients, this makes them an important patient group to pay attention to while organising end-of-life care. The differences in palliative care approach between cancer and dementia patients that clearly emerged from our results indicate that more efforts are needed to alert both practice and policy in meeting the palliative needs of non-cancer patients – a recommendation that has also being made by the World Health Organization [43;46].

On the other hand, advocating a target-group specific approach to palliative care might pigeon-hole patients whereas it should be taken into account that many elderly people have comorbidities, and that the general objectives of palliative care (patient-centred care, providing comfort and relieve, respect values, choices, and preferences) apply to every patient, irrespective of diagnosis.

Adopting a palliative care (considered as supportive rather than merely terminal care) philosophy for all persons suffering from life-threatening conditions early in the course of the disease and access to specialist palliative care services according to the needs of the person while bearing the typical disease trajectories in mind, will be an important challenge for the decades to come.

FUTURE RESEARCH

First, the use of a stable and nationwide Sentinel GP Network can provide opportunities to monitor aspects of end-of-life care within a country over several years. The information gathered in the previous registration years of the SENTIMELC study could be used as a reference point for future research. As such, possible improvements in the end-of-life care received by patients in Belgium can be assessed and evaluated more easily in the coming decades. Also, this study was able to compare with several data from the Dutch part of the SENTIMELC study. As many other European countries have at least one sentinel network of GPs, extending the international collaboration in setting up a comparable SENTIMELC methodology may provide very valuable insights.

The SENTIMELC consortium has been joined by Italy in 2009 and by Spain in 2010. The first comparative results of this European study are expected to be available in 2011 and provide cross-country comparisons concerning the continuity of care at the end of life in terms of care setting transitions; information and communication processes concerning the end of life; specialist palliative care provision; symptoms in the last week of life; and costs and burden of end-of-life care.

Secondly, while this dissertation focuses on gathering basic information on several broad domains in measuring end-of-life care, we were not able to thoroughly evaluate this care in terms of quality. Therefore, a set of quality indicators should be developed and implemented in actual palliative care practice and their applicability studied in future research.

Thirdly, one of the main conclusions of this dissertation is that end-of-life communication and advance care planning could improve considerably. Besides the necessity for additional epidemiological studies describing and monitoring the prevalence and content of these important domains in end-of-life care across different patient populations and settings, it remains unclear to what extent and how they influence patient and family satisfaction and quality of life. Controlled intervention studies might contribute greatly to achieving this aim. Interventions might comprise workshops and training modules for professional caregivers and performing structured advance care planning discussions. Both a between-subjects (comparing intervention and control group) and within-subjects design (comparing outcomes before and after the intervention) may be combined.

Fourthly, as a palliative care philosophy is not equally adopted in cancer and dementia patients, studies should be undertaken to provide insights into how and when GPs recognise the palliative phase for these different disease-types, and into possible facilitators and barriers that GPs might experience. Such research could evaluate whether there is a clear-cut transition from cure to palliation in these different patient groups, or whether there is a care continuum characterised by a gradual transition, and might as well concern the timing between the first palliative intervention and death, and whether or not the GP had made the prognosis that the patient would die (and if so, when).

Fifthly, the burdening of a patient’s family members and their satisfaction with care is considered an important aspect in measuring quality of end-of-life care [46;98]. This dissertation briefly addressed the involvement of family in the process of advance care planning, and in the decision-making of cases where death followed the administration of life-ending drugs without explicit patient request. There is a need for large-scale research conducted among bereaved family members and directed at the physical and emotional distress they experience, their experiences with caring for a terminally ill loved one, the financial burden this care possibly causes, after-death bereavement and dealing with grief.

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SAMENVATTING VAN DE BELANGRIJKSTE BEVINDINGEN

INLEIDING

Dood gaan zullen we uiteindelijk allemaal. Maar de omstandigheden, de plaats en het tijdstip kunnen erg verschillend zijn van mens tot mens. Een aantal belangrijke evoluties op het gebied van demografie, morbiditeit en mortaliteit hebben samen met een aantal veranderende ontwikkelingen en attitudes in de geneeskunde geleid tot een toenemende aandacht voor een goede zorg aan het levenseinde. Zonder enige twijfel wordt dit een van de grootste en belangrijkste uitdagingen die ons de komende jaren als maatschappij te wachten staan.

Landelijke gegevens over hoe mensen sterven kunnen beleidsmakers en zorgverleners waardevolle inzichten verschaffen om levenseindezorg zo goed mogelijk te organiseren en te verbeteren. Deze studie hoopt hieraan een bijdrage te leveren door betrouwbare epidemiologische gegevens aan te reiken over de laatste levensmaanden en omstandigheden van het overlijden in België. We hopen hierbij een mooi overzicht aan te leveren van een heel aantal domeinen waarvan algemeen wordt aangenomen dat ze erg waardevol zijn bij het meten van goede levenseindezorg, en schenken hierbij specifieke aandacht aan mensen die sterven aan kanker of met de diagnose van dementie, aan wensen, voorkeuren en vroegtijdige zorgplanning met betrekking tot de laatste levensfase, en aan de communicatie en besluitvorming van verreikende medische praktijken die de intentie hebben het leven te beëindigen. Waar mogelijk maken we ook crossnationale vergelijkingen met gegevens uit Nederland, gelijktijdig verzameld via een identieke methodiek.

ONDERZOEKSVRAGEN

1. Wat zijn de kenmerken van mensen die aan kanker sterven in België en Nederland, welke zorg verkrijgen ze in de laatste levensmaanden en wat zijn de omstandigheden van het overlijden?
2. Wat zijn de kenmerken van oudere mensen die sterven met dementie in België, welke zorg verkrijgen ze in de laatste levensmaanden en wat zijn de omstandigheden van het overlijden?
3. Wat zijn de kenmerken en de prevalentie van vroegtijdige zorgplanning in België en Nederland?
4. Hoe vaak zijn huisartsen op de hoogte van waar hun patiënt het liefst zou willen sterven, en hoe vaak kan deze wens worden ingewilligd?
5. Binnen de groep van zij die thuis sterven in België, welke mensen uiten een euthanasieverzoek, wat zijn de kenmerken van dit verzoek en hoe wordt hier mee omgegaan?
6. Welke mensen sterven thuis of in het rusthuis in België na het toedienen van levensbeëindigende middelen zonder diens uitdrukkelijk verzoek, en wat zijn de kenmerken van het besluitvormingsproces en van de praktijk zelf?

METHODE

REGISTRATIESTUDIE (ONDERZOEKSVRAAG 1 -4)

Doordat in België de huisarts als een belangrijk spilfiguur in de zorg voor patiënten fungeert– zo goed als iedereen (95%), ook rusthuisbewoners, geeft aan een vaste huisarts te hebben die ze regelmatig consulteren, werd een samenwerking opgestart met een bestaand netwerk van huisartsen, de Huisartsenpeilpraktijken, met als doel een beter zicht te krijgen op het sterfbed in België.

Deze Huisartsenpeilpraktijken zijn representatief voor alle Belgische huisartsen voor wat betreft leeftijd en geslacht, en met een goede spreiding over het hele land. Het netwerk is opgericht in 1979 en heeft onder meer als doel de aanpak en opvolging in de huisartspraktijk van bepaalde gezondheidsproblemen te onderzoeken. Over de jaren heen heeft het zich als een gevestigde waarde weten te positioneren om gezondheidsgerelateerde epidemiologische gegevens (waaronder zorg aan het levenseinde) op een betrouwbare manier te vergaren. Het netwerk valt onder de coördinatie van het Wetenschappelijk Instituut Volksgezondheid.

De studie is een retrospectieve mortaliteitsstudie. Deelnemende huisartsen werd gevraagd om alle sterfgevallen (ouder dan 1 jaar bij overlijden) uit hun praktijk wekelijks te registreren, en dit zowel voor gestorven patiënten voor wie de arts zelf het overlijdensattest opstelde als voor overlijdens die door een andere arts geattesteerd werden, maar waarvan men achteraf op de hoogte werd gesteld. Naast algemene gegevens van de patiënt zoals leeftijd, geslacht, opleidingsniveau, en of het overlijden al dan niet plots en geheel onverwacht kwam volgens de beoordeling van de huisarts, bevroeg een gestandaardiseerd registratieformulier een heleboel aspecten over de zorg die de patiënt verkreeg in de laatste maanden van zijn of haar leven, en over de omstandigheden van het overlijden. De inhoud van de vragenlijst werd jaarlijks herbekeken en aangepast om een zo breed mogelijke waaier aan onderwerpen te kunnen aankaarten.

Volgende tabel geeft de voornaamste thema's weer die bevraagd werden in deze studie.

In Nederland werd een vergelijkbaar onderzoek opgezet dat ook kan stoelen op een representatief surveillancenetwerk van huisartsen met

TABEL. VOORNAAMSTE THEMA'S BEVRAAGD IN STUDIE

I.	Aspecten van medische zorg
	- plaats van zorg en overlijden
	- contacten tussen arts en patient
	- transfers tussen zorgsettings
	- voornaamste behandeldoel
	- betrokkenheid van gespecialiseerde palliatieve zorg
II.	Communicatie
	- inhoud van gesprekken tussen arts en patiënt
	- wensen en voorkeuren t.o.v. plaats overlijden, behandelingen en medische beslissingen
	- wensen t.o.v. wettelijk vertegenwoordiger om beslissingen te nemen in plaats van patiënt
	- voorafgaande zorgplanning (aanwezigheid, schriftelijk of mondeling)
	- zorgplanning met familie
III.	Omstandigheden van overlijden
	- aanwezigheid en hinder van fysieke symptomen
	- aanwezigheid en hinder van psychologische symptomen
	- bekwaamheid om zelf beslissingen te nemen
	- functionele status
	- coma of bewusteloos tot aan het overlijden
	- sterven op de plaats van wens

een lange ervaring. De vragenlijsten werden in beide landen zo identiek mogelijk gehouden om zo de mogelijkheden tot het vergelijken te optimaliseren. Het NIVEL, het Nederlands Instituut voor Onderzoek van de Gezondheidszorg geldt er als coördinator van het project.

De studie kreeg de naam SENTI-MELC studie mee, wat staat voor 'Sentinel Network of General Practitioners Monitoring End-of-Life Care Study'.

INTERVIEWSTUDIE (ONDERZOEKSVRAAG 5-6)

In 2005 en 2006 werd een semigestructureerde interviewstudie uitgevoerd om wat dieper in te kunnen gaan op een aantal aspecten van de zorg en de omstandigheden rond het levenseinde bij een aantal sterfgevallen uit de registratiestudie. Twee types van interview werden hierbij afgenomen.

Het standaardinterview werd afgenomen voor alle geregistreerde niet-plotse overlijdens die thuis stierven tussen januari 2005 en maart 2006 (periode van 14 maanden). Een 'physician-assisted-death' interview vond plaats als het overlijden was voorafgegaan door een medische beslissing om het leven van de patiënt uitdrukkelijk te beëindigen. Hiervoor werden niet alleen thuisoverlijdens maar ook sterfgevallen uit het rusthuis geïncludeerd, en dit gedurende een periode van 24 maanden.

Voor zowel de registratie- als de interviewstudie hanteerden we verschillende procedures om datakwaliteit te optimaliseren (bv nauwkeurige dubbele data-entry) en om de anonimiteit van zowel arts als patiënt te waarborgen.

BELANGRIJKSTE BEVINDINGEN

LEVENSEINDEZORG BIJ PERSONEN DIE STIERVEN AAN KANKER

In 2008 verzamelden de Huisartsenpeilpraktijken via de SENTIMELC studie gegevens over 321 personen die stierven ten gevolge van kanker in België en waarbij het overlijden verwacht was gekomen, als zodanig ingeschat door de arts.

Van deze sterfgevallen kon meer dan 90% thuis verblijven voor het grootste gedeelte van de tijd gedurende het laatste levensjaar. Uiteindelijk stierf 34% thuis, 29% in het ziekenhuis, 24% in een palliatieve zorgeenheid en 12% in het rusthuis. Een gespecialiseerd palliatief zorginitiatief werd ingezet voor 72% van de patiënten in de loop van de laatste drie levensmaanden, en 94% kreeg zorg die voornamelijk gericht was op palliatie en comfort gedurende de laatste zeven dagen voor overlijden.

De deelnemende huisartsen gaven aan dat de gesprekken die ze voerden met hun patiënt in de laatste maand voornamelijk gingen over fysieke problemen (49%), psychologische problemen (45%), en opties in verband met palliatieve zorg (46%). Spirituele aspecten werden het minst vaak aangekaart (20%). De arts was voor respectievelijk 43% en 54% van de gevallen op de hoogte van de behandelingswensen van de patiënt en van zijn of haar voorkeur voor waar men het liefst wilde sterven.

In de laatste week voor overlijden was twee derde volledig bedlegerig en niet meer in staat tot zelfzorg, 58% verkeerde in een coma een of meer dagen tot aan de dood, en velen ondervonden hinder van fysieke (84%) en/of psychologische (59%) symptomen. Uiteindelijk kon iets meer dan 70% sterven op de plaats van wens.

Voor deze studie beschikken we over gegevens uit Nederland die we gelijktijdig verzamelden via een identieke onderzoeksmethode. Uit de resultaten bleek dat een aantal aspecten van de zorg en de omstandigheden van overlijden verschilden van land tot land. Zo merkten we dat patiënten met kanker als doodsoorzaak in België vaker in het ziekenhuis stierven, vaker gespecialiseerde palliatieve zorg verkregen in de laatste levensfase, en vaker hinder leken te ondervinden van psychologische symptomen op het einde van het leven. Ook voerden Belgische huisartsen, in vergelijking met Nederland, minder vaak gesprekken met hun patiënt over een aantal problemen en aspecten van de ziekte gedurende de laatste levensmaand, waren ze minder vaak op de hoogte van een patiënt zijn of haar wensen en voorkeuren, en uiteindelijk stierven patiënten ook minder vaak op de plaats waar men had aangegeven te willen sterven.

LEVENSEINDEZORG BIJ PERSONEN DIE STIERVEN MET DE DIAGNOSE VAN DEMENTIE

In het derde hoofdstuk van dit proefschrift maakten we melding van 1108 sterfgevallen (ouder dan 65 bij overlijden), in het jaar 2008. Bij ongeveer een op drie (31%) van deze groep had de peilarts de diagnose van dementie gesteld. Hiervan werd de dementie op het moment van overlijden geacht zich nog in een vroeg stadium te bevinden bij 43% van de ouderen, en werd ze als ernstig (gevorderd) beschouwd bij 57%.

Van zij die stierven met de diagnose van dementie was twee derde vrouw, en 56% ouder of gelijk aan 85 jaar. Voor 26% kwam het overlijden plots en geheel onverwacht – volgens de arts; 59% stierf in het rusthuis en een kwart in het ziekenhuis. In de laatste week voor overlijden bleef het contact met de huisarts bewaard bij drie op de vier patiënten, 74% had een palliatief behandeldoel en 14% onderging nog een transfer naar een andere zorgsetting in die periode. Voor ongeveer een op drie patiënten met dementie werd een gespecialiseerd palliatief zorginitiatief ingeschakeld in de loop van de laatste drie levensmaanden, en in de laatste maand handelden de gesprekken tussen arts en patiënt voornamelijk over fysieke (24%) en psychologische (14%) problemen en slechts zelden (14%) over opties in verband met palliatieve zorg. Ook voor de laatste maand was palliatieve zorg slechts sporadisch onderwerp van gesprek. Voor ongeveer een op de tien personen met dementie wist de huisarts wie aan te spreken als wettelijk aangesteld vertegenwoordiger om beslissingen te nemen in naam van de patiënt in geval hij of zij wilsonbekwaam zou zijn. De omstandigheden van overlijden werden erg vaak gekenmerkt door wilsonbekwaamheid (83% van de dementiepatiënten), door zeer ernstige restricties in functioneren (83%), en door symptomen die als hinderlijk werden ervaren zoals een gebrek aan energie (55%) of een gebrek aan eetlust (47%).

In vergelijking met andere sterfgevallen hadden zij die gediagnosticeerd waren met dementie twee maal zo veel kans om in de laatste week van het leven een behandeldoel te hebben dat gericht was op comfortzorg, en twee keer minder kans om uiteindelijk in het ziekenhuis te overlijden. Ook waren er minder gesprekken tussen arts en patiënt aan het levenseinde, en was de arts minder vaak op de hoogte van een patiënt zijn of haar behandelingswensen. Opvallend, het percentage waarbij een wettelijk vertegenwoordiger was aangesteld bleek onafhankelijk te zijn van patiëntgroep, en kwam dus niet vaker voor bij patiënten met dementie in vergelijking met de groep van overige ouderen. We vonden wel markante verschillen tussen beide groepen wanneer we de omstandigheden van overlijden bekeken: dementiepatiënten hadden 13 keer zoveel kans om volledig wilsonbekwaam te zijn aan het eind van hun leven, meer dan 3,5 keer zoveel kans om volledig bedlegerig te zijn, en twee maal zoveel kans om zich suf te voelen en daar last van te ondervinden.

We konden ook een aantal verschillen optekenen tussen personen die gestorven waren met een milde vorm van dementie en zij die als ernstige dement waren gediagnosticeerd. Een ernstigere vorm van dementie bij overlijden was geassocieerd met een kleinere kans op een transfer tussen zorgsettings in de laatste drie maanden van het leven of om in het ziekenhuis te sterven, en met een grotere kans op een behandeldoel gericht op palliatie en comfort. Met patiënten met milde dementie werden nog vaker gesprekken aangeknoopt, niet alleen in de laatste maand maar ook voordien. Personen waarbij de ziekte ver gevorderd was, waren ook veel vaker niet langer meer in staat om zelf beslissingen te nemen, en deze mensen hadden volgens de arts ook veel minder last van psychologische symptomen in laatste levensweek, al was de inschatting ervan wel moeilijker.

VROEGTIJDIGE ZORGPLANNING

In hoofdstuk vier gaan we dieper in op een erg actueel thema binnen de palliatieve zorg: vroegtijdige of voorafgaande zorgplanning wat men kan omschrijven als het bespreken en plannen van aspecten van mogelijke toekomstige zorg voor het geval men zelf niet meer in staat zou zijn om beslissingen te nemen.

De SENTIMELC studie rapporteerde in 2007 over 1072 niet-plotse sterfgevallen uit België en Nederland. Voor bijna een derde was er een of andere voorafgaande zorgplanning besproken met de patiënt over het stopzetten of niet opstarten van mogelijk levensverlengende behandelingen of over het uitvoeren van medische beslissingen in de laatste levensfase van de patiënt. Over sommige behandelingen of beslissingen werd veel vaker een vroegtijdige afspraak gemaakt dan over andere. De meest voorkomende afspraken betroffen het afzien van potentieel levensverlengende behandelingen in het algemeen (24%), het opdrijven van pijn- en/of symptoombestrijding met een mogelijk levensverkortend effect (16%), en de afspraak om niet langer naar een ziekenhuis getransfereerd te worden (20%). Een vroegtijdige zorgplanning over continue sedatie tot aan het overlijden of over het expliciet bespoedigen van het overlijden kwam relatief weinig voor.

Wanneer enkel naar schriftelijke afspraken werd gepeild, gaf de huisarts in slechts een kleine minderheid van de gevallen (8%) aan weet te hebben van een gedocumenteerde wilsverklaring, zonder echte uitschieters naargelang het type (be)handeling dat besproken werd.

Een interessante bevinding: huisartsen gaven aan dat er in bijna een kwart van alle geregistreerde niet-plotse overlijdens een voorafgaande zorgplanning werd besproken met de familie van de patiënt zonder de patiënt daarbij betrokken te hebben.

Tot slot is gezocht naar factoren die samenhangen met het al dan niet aanwezig zijn van een vroegtijdige zorgplanning met de patiënt. Hieruit bleek dat sterven ten gevolge van kanker, een palliatief behandeldoel in de laatste week, een zekere mate van beslissingsbekwaamheid gedurende de laatste drie dagen van het leven, het behoud van contact met de huisarts en de mogelijkheid om thuis te sterven en niet in een geïnstitutionaliseerde setting, samenhangen met een verhoogde kans op de aanwezigheid van zo een zorgplanning. Of de patiënt uit België dan wel uit Nederland afkomstig is, was niet van invloed.

De factor land bleek wel van invloed bij schriftelijke zorgplanning. Gedocumenteerde wilsverklaringen kwamen veel vaker voor in Nederland (13%) in vergelijking met België (5%), zelfs wanneer men de analyse voor andere beïnvloedende factoren corrigeerde. Andere elementen geassocieerd aan een hogere kans op een wilsverklaring waren palliatief behandeldoel in de laatste week, wilsbekwaam in de laatste dagen, en de inzet van een gespecialiseerd palliatief zorginitiatief gedurende de laatste drie maanden voor het overlijden.

Sterven aan een ziekte anders dan kanker, het krijgen van behandeling in de laatste week die gericht is op comfort, en geheel niet meer in staat zijn om zelf beslissingen te nemen in de laatste drie dagen van het leven, bleken goede voorspellers voor de aanwezigheid van een zorgplan dat is opgesteld met alleen de familie zonder betrokkenheid van de patiënt.

VOORKEUR PLAATS OVERLIJDEN

In 2006 werd melding gemaakt van 798 niet-plotse overlijdens. In 46% van de gevallen waren de huisartsen op de hoogte van waar de patiënt graag wilde sterven. In 63% van deze overlijdens hadden ze dat rechtstreeks van de patiënt zelf vernomen: in 40,4% enkel door de patiënt, in 22,2% via de patiënt en zijn/haar familie of naaste. Zesendertig procent werd alleen door de familie of naaste op de hoogte gesteld en minder dan 2% nog door iemand anders.

Analyses toonden aan dat huisartsen een hogere kans hadden om weet te hebben van waar de patiënt wenste te sterven als deze in de laatste drie maanden nooit gehospitaliseerd was geweest, als er mantelzorg aanwezig was in die periode, als een gespecialiseerd palliatief zorginitiatief werd ingezet en indien ze gedurende de laatste drie maanden meer dan zeven keer contact hadden met de patiënt of zijn/haar familie over de patiënt.

Als de huisarts op de hoogte was van de gewenste plaats, verkoos meer dan de helft (58%) van de patiënten om thuis te sterven, 31% in het rusthuis en een kleine minderheid koos voor een andere setting. Voor 72% van hen die graag thuis wilden sterven, ging deze wens in vervulling. Van degenen die een andere plaats verkozen, stierf 83% of meer ook op die gewenste plaats. In totaal werd voor 80% van de patiënten overeenstemming bereikt tussen de gewenste en uiteindelijke plaats van sterven.

EUTHANASIEVERZOEKEN

Het zesde hoofdstuk van deze dissertatie maakt gebruik van de SENTI-MELC interviewstudie. Van de 200 interviews die werden afgenomen met de huisarts over een patiënt die thuis was gestorven en waarvan het overlijden niet geheel onverwacht was, waren er 27 waarbij de patiënt ooit in de loop van hun ziekteproces een wens tot euthanasie hadden geuit (14%). Onze resultaten tonen aan dat deze wensen erg verschilden in aard, formulering, en het tijdstip waarop ze geuit waren. In dertien gevallen bleek het om een herhaaldelijk en expliciet gesteld euthanasieverzoek te gaan. Vergeleken met de andere euthanasieverzoeken, waren degene die herhaaldelijk en expliciet waren geuit ook vaker op schrift gesteld, en bovendien vaker herhaald tot in de laatste dagen voor overlijden. Uiteindelijk stierven vijf patiënten na euthanasie, allen waarvan de vraag expliciet en terugkerend was gesteld.

Voor de anderen haalden de huisartsen verscheidene redenen aan waarom de wens of het verzoek niet was ingewilligd. In een aantal gevallen veranderde de patiënt zelf van mening en soms stierf de patiënt vooraleer het besluitvormingsproces volledig afgerond kon worden. Vaker echter leken de noodzakelijke voorwaarden waaraan voldaan moet worden zoals gesteld in de wet inzake euthanasie de doorslag te hebben gegeven, zoals dat er sprake moet zijn van een aanhoudend en ondraaglijk lijden, en dat het verzoek herhaaldelijk en expliciet moet zijn. In een minderheid van de gevallen werd het verzoek niet ingewilligd door de arts om persoonlijke redenen.

LEVENSBEËINDIGEND HANDELEN ZONDER EEN EXPLICIET VERZOEK VAN DE PATIËNT ZELF

Tenslotte wilden we ook meer inzicht verkrijgen in een wel erg controversiële medische praktijk, namelijk het toedienen van middelen met het expliciete doel het levenseinde te bespoedigen, zonder dat de patiënt hierom uitdrukkelijk had verzocht. Niet minder dan dertien uitgebreide interviews werden afgenomen met huisartsen waarvan hun patiënt op deze manier was gestorven, thuis of in het rusthuis. Huisartsen gaven voor alle patiënten aan dat ten tijde van de besluitvorming hun situatie compleet medisch uitzichtloos was, en voor velen onder hen was er ook sprake van een groot fysiek en/of psychisch lijden dat niet langer gelenigd kon worden. Een enkele patiënt was op dat moment, in zekere mate althans, nog wilsbekwaam zonder zichzelf nog goed uit te kunnen drukken. De overigen waren niet meer in staat hun situatie te overzien en daarover op adequate wijze een besluit te nemen. In vier gevallen verklaarde de arts dat er voorafgaand aan de besluitvorming ooit iets over levensbeëindiging was kenbaar gemaakt, al betrof dit nooit een expliciet verzoek. Voor de andere negen patiënten had de huisarts geen weet over wensen of voorkeuren met betrekking tot het levenseinde. Belangrijk om te vermelden is dat het besluitvormingsproces steeds gekenmerkt werd door een overleg tussen de huisarts en andere zorgverstrekkers en/of de familie van de patiënt.

Op het eind van het leven waren alle patiënten volkomen geïnvalideerd, niet meer in staat zichzelf te verzorgen en volledig bedlegerig. Met uitzondering van een iemand, was iedereen een of meerdere dagen voor overlijden buiten bewustzijn of in coma, en was er sprake van symptomen die de patiënt hinder bezorgden. Op het ogenblik dat er levensbeëindigende medicatie werd toegediend, waren allen volkomen wilsonbekwaam. Bijna altijd maakte men gebruik van opioïden, soms in combinatie met een benzodiazepine. Spierverslappers werden in geen van de gevallen toegediend.

Zonder uitzondering waren alle geïnterviewde huisartsen ervan overtuigd dat hun handelwijze de kwaliteit van het levenseinde van de patiënt aanzienlijk had verbeterd.

BEKNOPTE DISCUSSIE

PLAATS VAN ZORG EN OVERLIJDEN

Onze resultaten tonen grote verschillen tussen de onderzochte patiëntgroepen op het gebied van plaats van zorg en overlijden. Zo is het rusthuis de setting bij uitstek waar oudere personen met dementie verblijven gedurende het laatste jaar van het leven, en ook sterven. Dit hoeft niet te verbazen gezien de intensiteit van zorg die deze mensen behoeven, en de enorme draagkracht die deze aandoening vergt van de naaste omgeving van de patiënt. Daar voorgaand onderzoek heeft uitgewezen dat er bij heel veel patiënten nog zorgtransfers plaatsvinden aan het einde van het leven – die vanzelfsprekend een grote impact hebben op de persoon met dementie gezien de desoriëntatie in tijd en plaats, lijkt het juist bemoedigend dat het rusthuis zorg kan bieden voor deze mensen tot aan het overlijden. Mogelijk heeft het groeiend aantal artscodes waarin verklaard wordt niet meer getransfereerd te willen worden naar het ziekenhuis een positieve invloed op het kunnen sterven in het rusthuis, waar men wordt verzorgd.

Wat dan weer opvalt bij patiënten met kanker als doodsoorzaak, is het hoge percentage dat sterft in een palliatieve zorgeenheid (ongeveer een op vier), waarbij dit slechts het geval is voor ongeveer 1% zij die sterven met ernstige dementie. Dit versterkt alvast de indruk dat kanker en het gebruik van palliatieve zorgvoorzieningen in België nog erg nauw verweven zijn met elkaar.

CONTINUÏTEIT VAN ZORG: ARTS-PATIËNT CONTACTEN

Uit ons onderzoek blijkt dat huisartsen zich in het algemeen erg engageren om het contact met hun patiënt te bewaren gedurende de laatste maanden van het leven, en zeker in de laatste dagen voor overlijden. Wanneer het een situatie betreft waarbij een ingrijpende medische handeling gewenst of verricht wordt met het doel het leven te beëindigen, blijkt het aantal contacten nog toe te nemen. Men zou dus kunnen besluiten dat er vaak tot aan de dood een hoge mate van relationele continuïteit blijft bestaan tussen huisartsen en hun patiënten. Hierbij mag toch niet vergeten worden dat dit soort van zorgverlening niet tot de standaarddagtaken van een huisarts behoort, en dat het vaak erg tijdsintensief en ook emotioneel belastend kan zijn.

PALLIATIEVE ZORG – BEHANDELDOEL EN GESPECIALISEERDE ZORGINITIATIEVEN

De traditionele visie op palliatieve zorg gaat uit van een duidelijk te onderscheiden overgang van zorg gericht op levensverlenging of genezing naar comfortzorg waarbij palliatie vaak pas in de laatste dagen of weken van het leven van belang wordt. De laatste jaren echter groeit de consensus dat palliatieve zorg ook al veel te bieden heeft in een vroeg stadium van de ziekte, en niet alleen voor patiënten die getroffen worden door kanker, maar ook voor zij die lijden aan een andere levensbedreigende aandoening zoals dementie.

De resultaten uit onze studie geven duidelijk aan dat zowel het hebben van een palliatief behandeldoel, maar zeker het gebruik van een palliatief zorginitiatief veel vaker voorkomt bij kankerpatiënten dan bij personen die lijden aan dementie.

Deze bevindingen onderschrijven des te meer de sterke heersende relatie tussen kanker en palliatieve zorg. Het is gekend dat kankerpatiënten een beter te voorspellen ziektetraject volgen waardoor men beter kan inschatten wanneer bepaalde zorg best kan worden ingezet. Dementie is dan weer een progressieve degeneratieve aandoening waarbij dit minder duidelijk blijkt.

Het lijkt dan ook gepast aan te bevelen reeds veel vroeger in het ziekteproces van dementie een palliatieve zorgbenadering op te starten, als een soort supportieve zorg niet alleen tijdens, maar ook vóór de terminale stadia van een ziekte. De behoefte van de patiënt zou hierbij moeten primeren op het criterium van ingeschatte levensverwachting, dat nog te vaak wordt gehanteerd bij het inzetten van palliatieve zorg. Daarbij ligt er ook nog heel wat werk op de plank wat betreft de organisatie, opstart, en ondersteuning van palliatieve zorgvoorzieningen voor een niet-kanker patiëntpopulatie, en hun naaste omgeving.

VROEGTIJDIGE ZORGPLANNING OF ALGEMENE ZORGPLANNING?

Opvallend is dat in bijna een kwart van de mensen met een sterfbed afspraken gemaakt worden met de familie zonder dat de patiënt daarin gekend wordt. De sterke relatie met de mate van wilsbekwaamheid in de laatste drie dagen voor overlijden, en met bepaalde aspecten van de zorg uitgevoerd in de laatste levensweek, doen vermoeden dat het proces van vroegtijdig plannen van zorg vaak pas kort voor het overlijden wordt opgestart.

Daar veel chronisch zieke patiënten een hogere kans hebben om op het eind van hun leven niet meer in staat te zijn om volledig zelf beslissingen te nemen, is het op zulke momenten aangewezen om de familie of naasten van de patiënt te consulteren, wat een verklaring kan bieden dat zo weinig patiënten betrokken worden. Het is dus nog maar de vraag in hoeverre het vroegtijdig plannen van zorg niet eerder ad hoc dan echt vroegtijdig gebeurt. Mogelijk voelen artsen zich erg onzeker om gesprekken over een zo een delicaat onderwerp zoals het levenseinde aan te gaan, en stellen ze dit uit tot op het moment dat het echt nodig blijkt.

WILSVERKLARINGEN

Voorts is het zeer opvallend dat slechts zeer weinig patiënten op schriftelijke wijze hun wensen voor behandelingen of beslissingen te kennen hebben gegeven. Enerzijds past dit in de huidige internationale opvatting dat een vroegtijdige zorgplanning niet verengd mag worden tot een schriftelijke wilsverklaring, maar dat het gekaderd dient in een continu proces van communicatie waarvan een schriftelijke neerslag een mogelijke uitkomst vormt. Anderzijds kan een schriftelijke neerslag van wat je nog wilt of niet meer wilt een erg belangrijk hulpmiddel blijken om de zorg tegemoet te doen komen aan de vooropgestelde wensen. Zo kunnen dergelijke schriftelijke documenten bijvoorbeeld erg belangrijk zijn wanneer mensen tussen verschillende zorgsettings verhuizen in de laatste levensmaanden, hetgeen in België relatief vaak gebeurt (bijvoorbeeld van en naar ziekenhuizen). Door het doorgeven van het dossier bijvoorbeeld kunnen andere zorgverleners gemakkelijk op de hoogte gesteld worden van de wensen van de patiënt.

Niettegenstaande het grote enthousiasme in de ouderenzorg om schriftelijke voorafgaande wilsverklaringen in rusthuizen of ziekenhuizen te organiseren, zijn er toch een aantal kanttekeningen te maken bij de het gebruik ervan. Zo bestaat bezorgdheid over de wijze waarop bepaalde begrippen (bijvoorbeeld “uitzichtloos lijden”, “onomkeerbare aandoening”, “wilsonbekwaamheid”) worden geïnterpreteerd in een klinische situatie. Ook de geldigheid en duurzaamheid van de neergeschreven wensen en behandelvoorkeuren die vooraf worden geformuleerd voor een onbekende en onzekere toekomst, kunnen in vraag gesteld worden. Verder blijkt uit onderzoek dat wilsverklaringen niet steeds in de dossiers opgenomen zijn en dat ze bij hospitalisatie zelden worden getransfereerd van rust- en verzorgingshuizen naar het ziekenhuis. Nog meer zorgwekkend is de zeer beperkte mate waarin artsen en patiënten met elkaar spreken over een voorafgaande wilsverklaring. Artsen zijn vaak niet op de hoogte van het bestaan van een voorafgaande wilsverklaring, zelfs als het staat genoteerd in het medische dossier.

Het is daarom van groot belang te benadrukken dat het opstellen van een schriftelijke wilsverklaring maar een deel van het verhaal is. Het is belangrijk ze te beschouwen als een middel, eerder dan een doel op zich. Zorgplanning moet gezien worden als een continu proces van overleg en communicatie waarbij men in voortdurende dialoog treedt met elkaar, zonder zich te laten verleiden tot het louter opstellen van een document. Het zou goed zijn dat er gewerkt wordt aan uniforme richtlijnen, afspraken tussen zorgverstrekkers uit de eerste en tweede lijn, tussen organisaties, en aan een toegankelijk maar toch veilig e-dossier, om de continuïteit van de wensen en voorkeuren van de patiënt te waarborgen bij een transfer naar een andere zorgsetting.

Aanstellen van een wettelijk vertegenwoordiger bij dementie

Een opmerkelijk resultaat is toch dat slechts in een erg beperkt aantal gevallen een wettelijk vertegenwoordiger is aangesteld die in de plaats van de patiënt beslissingen mag nemen, en dat er geen verschil is in vergelijking met andere oudere patiënten die niet geconfronteerd waren met dementie.

Iemand met dementie gaat gradueel steeds verder achteruit. Soms langzamer, soms sneller. Uiteindelijk raakt de persoon met dementie zo onthecht van de realiteit in tijd en ruimte, dat hij of zij niet meer in staat is zelf beslissingen te nemen over de zorg die men wilt, laat staan om deze wensen te communiceren aan de directe verzorgers. Dementie is daarom ook des te meer een aandoening waarbij een tijdig voorafgaandelijk overleg erg aangewezen is om de zorg in de laatste levensmaanden zo goed mogelijk volgens de wensen van de patiënt georganiseerd te krijgen, en waarbij een wettelijk vertegenwoordiger dus een grote rol kan spelen.

Een mogelijke verklaring voor de lage prevalentie kan zijn dat men zich vragen kan stellen over de wijze waarop een wettelijk vertegenwoordiger namens de patiënt keuzes kan maken wanneer deze laatste wilsonbekwaam is. Kunnen wettelijk vertegenwoordigers of zorgverleners wel überhaupt namens de patiënt oordelen? Ook het moment van transitie van patiëntenautonomie naar de vertegenwoordiging ervan door een “proxy” is niet altijd helder vast te stellen. Daarom lijkt het essentieel ook tijdens het proces van voorafgaande zorgplanning met de patiënt tijdig de familie, waar mogelijk en gewenst, te betrekken zodat men inzicht krijgt in de wensen, waarden, voorkeuren, en doelen van de patiënt deze dan ook in een mogelijke toekomstige besluitvorming centraal kan stellen.

VERZOEKEN VOOR EN BESLUITVORMING BIJ MEDISCH GEASSISTEERD LEVENSBEËINDIGEND HANDELEN

Zeker wanneer een beslissing om het overlijden te bespoediging aan de orde is, is het erg aangewezen om over informatie te beschikken die inzicht biedt in de patiënt zijn of haar voorkeuren met betrekking tot het levenseinde. Uit onze resultaten blijkt dat een relatief groot aandeel (1 op 7) van personen die niet-plots thuis sterven een wens tot euthanasie uiten, maar dat deze wens slechts in een heel beperkte minderheid wordt ingewilligd.

Soms is de arts niet op de hoogte van de wensen van de patiënt en kunnen deze ook niet meer worden bevraagd omdat de patiënt niet meer in staat is zijn wil te uiten of beslissingen te nemen. In een aantal gevallen achtte de arts het lijden zo ondraaglijk en aanhoudend, en de situatie zo medisch uitzichtloos, dat hij of zij ervan overtuigd was dat het in het belang van de patiënt was aan diens leven een einde te stellen. Vanzelfsprekend is dit een erg moeilijke afweging die de arts dient te maken, en behoeft dit een nauwgezette besluitvorming en overleg. Soms besliste men dan letale middelen toe te dienen om het overlijden van de patiënt expliciet te bespoedigen. Echter, altijd werden ofwel de familie ofwel andere zorgverstrekkers geraadpleegd bij deze beslissingen, en vaak beide partijen. Ook hier geldt dat een vroeg opgestarte zorgplanning de zorgverstrekker heel wat informatie zou kunnen bieden over wat de patiënt zelf nog zou willen of niet meer willen, wat het besluitvormingsproces in zulke situaties mogelijk wat makkelijker maakt.

OMSTANDIGHEDEN VAN OVERLIJDEN

Het moge duidelijk zijn dat de laatste levensweek van vele patiënten met een sterfbed gekenmerkt wordt door ernstige fysieke, cognitieve, psychologische en functionele beperkingen, wat een palliatieve zorgbenadering des te belangrijker maakt. Velen zijn volledig geïnvalideerd, niet meer in staat zichzelf te verzorgen en bedlegerig. Meer dan pijn, blijkt vooral het gevoel een gebrek aan energie te hebben door huisartsen als erg belastend te worden ingeschat voor de patiënt, en dit in alle onderzochte groepen. Mogelijk is pijn als symptoom beter behandelbaar, misschien ook omdat dit in het verleden vaak, en terecht, erg veel aandacht kreeg toebedeeld. Ook vermoeden we dat psychologische problemen vaak nog niet voldoende erkend en daardoor onderkend worden, en dusdanig ook niet voldoende behandeld. In het kader van een holistische visie op palliatieve zorg, pleiten we ervoor dat zowel fysieke als psychologische, sociale, en spirituele problemen voldoende aandacht krijgen in de zorg die mensen mogen krijgen in hun ziekteproces en zeker in de laatste fase van hun leven.

De mogelijkheid om te sterven op de plaats van wens kan een belangrijke indicator zijn voor de kwaliteit van de zorg aan het levenseinde en van een goede dood. Een sleutelrol hierbij is weggelegd voor huisartsen die in vele landen, waaronder België, duurzame relaties met hun patiënten opbouwen en onderhouden. Door hun speciale positie in de zorg kunnen huisartsen de spilfiguur zijn om vroegtijdige zorgplanning te initiëren, om te weten te komen waar patiënten willen sterven en om de zorg te coördineren volgens de wensen van de patiënt.

Algemeen genomen kunnen we stellen dat het aantal patiënten dat in België op de plaats van wens kan sterven relatief hoog is. Wij konden enkel de congruentie nagaan voor die patiënten van wie de huisarts de voorkeur kende. De hoge congruentie uit ons onderzoek is dus waarschijnlijk een overschatting. Het feit dat patiënten vaker in een ziekenhuis overleden wanneer de huisarts niet op de hoogte was van hun voorkeur, bevestigt deze hypothese. Congruentie is bovendien minder vaak te realiseren in landen waar de relatie tussen de huisartsen en hun patiënten minder duurzaam is, of waar de wachtdiensten niet bemand zijn door de lokale huisartsen, of bemand door teams waaraan de patiënten hun verwachtingen niet willen toevertrouwen.
Toch kan me zich afvragen of er toch niet gestreefd kan worden om nog meer mensen te laten sterven op de plaats van wens. Er kunnen verscheidene valkuilen en hindernissen geïdentificeerd worden die dit kunnen bemoeilijken. Zo kan het zijn dat de toestand van de ziekte dusdanig verslechterd is dat symptomen niet meer in de thuissetting onder controle kunnen worden gehouden, of kan het zijn dat er een continu dag-en-nacht zorgtoezicht nodig is dat niet iedere setting kan aanbieden. Ook de omgeving kan een rol spelen, bv de familie van de patiënt die de zorg niet meer kan dragen. En natuurlijk de wensen van de persoon zelf zijn ook beïnvloedend. Zo is het vaak moeilijker om een wens om thuis te sterven

in vervulling te doen gaan, dan een wens om in het ziekenhuis te sterven. En wensen kunnen ook wijzigen naar gelang de evolutie van de ziekte of de setting waar men verblijft.

Toch tonen de resultaten van dit onderzoek aan dat als de arts wel weet heeft van de wens van plaats van overlijden, deze patiënten dan ook vaak kunnen sterven op de plaats van hun voorkeur. Dit zou kunnen betekenen dat huisartsen, indien ze het weten, actief meewerken om het de patiënten mogelijk te maken te sterven op de plaats van wens. De zorg zou zodanig door de huisarts kunnen worden gecoördineerd en gestuurd dat deze wensen beter kunnen worden vervuld.

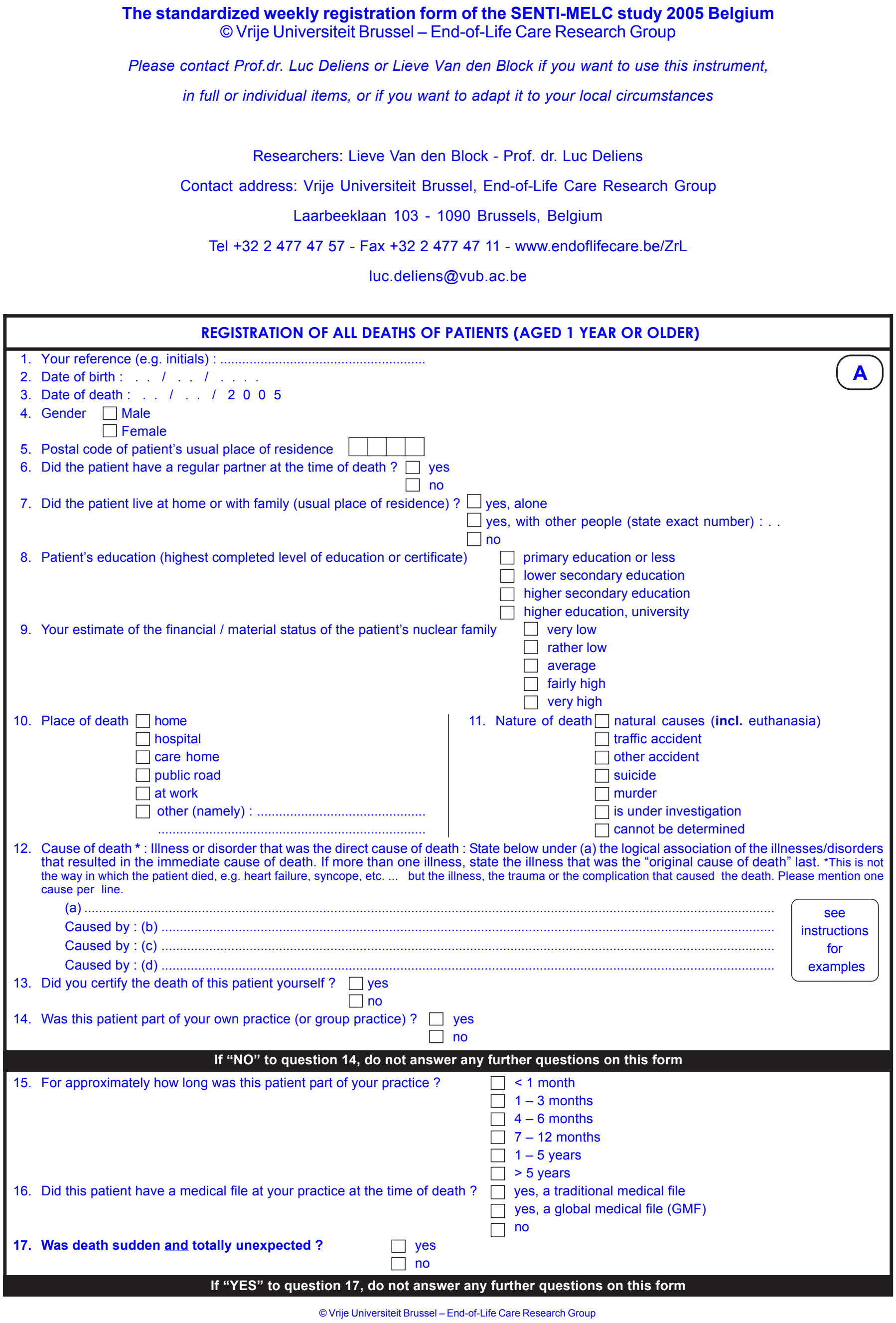
APPENDIX

I

THE SENTIMELC REGISTRATION FORMS

THE SENTIMELC REGISTRATION FORM

2005



The standardized weekly registration form of the SENTI-MELC study 2005 Belgium

Please contact Prof.dr. Luc Deliens or Lieve Van den Block if you want to use this instrument, in full or individual items, or if you want to adapt it to your local circumstances

Researchers: Lieve Van den Block - Prof. dr. Luc Deliens
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Tel +32 2 477 47 57 - Fax +32 2 477 47 11 - www.endoflifecare.be/ZrL
luc.deliens@vub.ac.be

REGISTRATION OF ALL DEATHS OF PATIENTS (AGED 1 YEAR OR OLDER)

A

1. Your reference (e.g. initials) : ....
2. Date of birth : . . / . . / . . . .
3. Date of death : . . / . . / 2 0 0 5
4. Gender ☐ Male
   ☐ Female
5. Postal code of patient's usual place of residence ☐☐☐☐
6. Did the patient have a regular partner at the time of death ? ☐ yes
   ☐ no
7. Did the patient live at home or with family (usual place of residence) ? ☐ yes, alone
   ☐ yes, with other people (state exact number) : . .
   ☐ no
8. Patient's education (highest completed level of education or certificate) ☐ primary education or less
   ☐ lower secondary education
   ☐ higher secondary education
   ☐ higher education, university
9. Your estimate of the financial / material status of the patient's nuclear family ☐ very low
   ☐ rather low
   ☐ average
   ☐ fairly high
   ☐ very high
10. Place of death ☐ home
    ☐ hospital
    ☐ care home
    ☐ public road
    ☐ at work
    ☐ other (namely) : ....
    ....
11. Nature of death ☐ natural causes (**incl.** euthanasia)
    ☐ traffic accident
    ☐ other accident
    ☐ suicide
    ☐ murder
    ☐ is under investigation
    ☐ cannot be determined
12. Cause of death * : Illness or disorder that was the direct cause of death : State below under (a) the logical association of the illnesses/disorders that resulted in the immediate cause of death. If more than one illness, state the illness that was the "original cause of death" last. *This is not the way in which the patient died, e.g. heart failure, syncope, etc. ... but the illness, the trauma or the complication that caused the death. Please mention one cause per line.
    (a) ....
    Caused by : (b) ....
    Caused by : (c) ....
    Caused by : (d) ....
    see instructions for examples
13. Did you certify the death of this patient yourself ? ☐ yes
    ☐ no
14. Was this patient part of your own practice (or group practice) ? ☐ yes
    ☐ no

If "NO" to question 14, do not answer any further questions on this form

15. For approximately how long was this patient part of your practice ? ☐ < 1 month
    ☐ 1 – 3 months
    ☐ 4 – 6 months
    ☐ 7 – 12 months
    ☐ 1 – 5 years
    ☐ > 5 years
16. Did this patient have a medical file at your practice at the time of death ? ☐ yes, a traditional medical file
    ☐ yes, a global medical file (GMF)
    ☐ no
17. **Was death sudden <u>and</u> totally unexpected ?** ☐ yes
    ☐ no

If "YES" to question 17, do not answer any further questions on this form

B

1. The **place of death** of the patient and **place(s) of residence** during the **last 3 months (=90 days) before death**, as well as the duration of stay in **days** (approximately if not precisely known). If the patient remained in the same place until death, only fill in Place 1.

see instructions for examples	at home or living with familly (incl. service flat)	care home: home for the elderly / nursing home	hospital (**excl.** pall care unit and **excl.** nursing home unit in hospital)	palliative care unit (hospital)	elsewhere **(please specify)**
last 3 months before death **1** place of **death** and duration of stay	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days
2 previous place of **residence** and duration of stay	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days
3 previous place of **residence** and duration of stay	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days
4 previous place of **residence** and duration of stay	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days

2. Were you informed (verbally or in writing) of the patient's preference regarding place of death ?

(More than one answer can be given)

☐ yes
- ☐ by the patient him/herself
- ☐ by the patient's family or significant other
- ☐ by a colleague physician
- ☐ by a (member of a) specialist palliative care team
- ☐ the information was written in the patient's medical file
- ☐ other (namely) : ....

If **YES**, where did this patient prefer to die ?
- ☐ at home or living with family (incl. service flat)
- ☐ in a care home: home for elderly persons / nursing home
- ☐ in hospital (**excl.** palliative care unit, and **excl.** nursing home unit in hospital)
- ☐ palliative care unit (hospital)
- ☐ elsewhere (namely) : ....

☐ no

3. How often (on average) did you have **contact** (consultations, home visits, **excl**. telephone contact) with the patient or with significant others regarding the patient ?

last week before death	**2nd to 4th week before death**	**2nd and 3rd month before death**
. . . x per **week**	. . . x per **week**	. . . x per **month**

4. What was the **main goal** of this patient's treatment ?

(More than one answer can be given)	**last week before death**	**2nd to 4th week before death**	**2nd and 3rd month before death**
cure	☐	☐	☐
prolonging life	☐	☐	☐
comfort / palliation	☐	☐	☐
unknown	☐	☐	☐

5. Indicate what treatment/aids the patient received

(More than one answer can be given)	**last week before death**	**2nd to 4th week before death**	**2nd and 3rd month before death**
A unknown	☐	☐	☐
B chemotherapy or radiotherapy (curative or life-prolonging)	☐	☐	☐
C artificial food administration	☐	☐	☐
D artificial fluid administration	☐	☐	☐
E blood transfusion	☐	☐	☐
F artificial respiration	☐	☐	☐
G cardiopulmonary resuscitation (CPR)	☐	☐	☐
H dialysis	☐	☐	☐
I antibiotics	☐	☐	☐
J vasopressors	☐	☐	☐
K specific palliative medication (e.g. analgesics, anti-depressants, sedatives, corticoids, anti-emetics, laxatives, anti-hiccough/ anti-irritation, ...)	☐	☐	☐
L comfort care materials (e.g. for incontinence or wound/stoma care,...)	☐	☐	☐
M general comfort aids (e.g. mattresses, hospital bed, commode,...)	☐	☐	☐
N none of the above	☐	☐	☐

6. Circle the extent to which the care provided (by you and/or other caregivers) was directed at :

1=not or to a very small extent **5**=to a very large extent **?**=unknown

	last week before death	**2nd to 4th week before death**	**2nd and 3rd month before death**
treatment / care for physical problems	1 2 3 4 5 ?	1 2 3 4 5 ?	1 2 3 4 5 ?
psychosocial care	1 2 3 4 5 ?	1 2 3 4 5 ?	1 2 3 4 5 ?
spiritual care (existential, religious, etc)	1 2 3 4 5 ?	1 2 3 4 5 ?	1 2 3 4 5 ?

7. How often were the following persons/disciplines actively involved in providing care for this patient during the last 3 months of life?

	not at all	**sometimes**	**often**	**unknown**
you yourself	☐	☐	☐	☐
clinical specialist	☐	☐	☐	☐
informal caregiver (e.g. partner, child, sister, friend, …)	☐	☐	☐	☐
nurse	☐	☐	☐	☐
carer / home carer / geriatric assistant (**excl.** nurse)	☐	☐	☐	☐
chaplain / pastor / non-religuous counsellor	☐	☐	☐	☐
physiotherapist / occupational therapist / speech therapist	☐	☐	☐	☐
other (namely) : …………………………………………	☐	☐	☐	☐

8. Which **specialist palliative care initiatives** were adopted in the last 3 months of this patient's life?
(More than one answer can be given)
☐ 1 palliative homecare team
☐ 2 mobile palliative care support team in a hospital
☐ 3 palliative care unit (hospital)
☐ 4 reference persons for palliative care in a care home (co-ordinating and advisory physician and/or reference nurse)
☐ 5 LEIF or EOL- physician (End-of life Information Forum) (LEIF or EOL physicians provide support and advice to colleague physicians concerning issues related to euthanasia, medical end-of-life decisions, and the possibilities of palliative care in Belgium)
☐ 6 palliative day care centre
☐ 7 other (namely) : ……………………………………………………………………………………
☐ 8 none
☐ 9 unknown

9. Was the patient kept continuously in deep sedation or coma until death by means of e.g. benzodiazepines or barbiturates?
☐ yes, and food and fluids were not artificially administered
☐ yes, and food and fluids were artificially administered
☐ no

The following questions concern medical decisions, with a (potentially) life-shortening effect for the patients

10. Did you or a colleague physician take one or more of the following acts (or ensure that one of them was taken), taking into account the probability or certainty that this act would hasten the end of the patient's life? (**Please answer both questions 10a and 10b**):

10a. withholding a treatment or withdrawing a treatment (incl. artificial administration of food and/or fluids) ? ☐ yes
☐ no

10b. intensifying the alleviation of pain and/or symptoms using a drug? ☐ yes, ➔**go to question 11**
☐ non, ➔**go to question 12**

11. Was hastening the end of life partly the intention of the act indicated in question **10b** ? ☐ yes
☐ no

12. Was death caused by withholding a treatment or withdrawing a treatment (incl. artificial administration of food and/or fluids), which you or a colleague physician decided to take with the explicit intention of hastening the end of life ?
☐ yes
☐ no

13. Was death caused by the use of a drug prescribed, supplied or administered by you or a colleague physican with the explicit intention of hastening the end of life (or of enabling the patient to end his or her own life) ?
☐ yes
☐ no
If yes, who administered this drug (= introduced it into the body) ?
(More than one answer can be given)
☐ the patient
☐ you or a colleague physician
☐ nursing staff/other caregivers
☐ other (namely) : ……………………………………………………………………………………

The following questions relate to the LAST "YES" in answer to questions 10a to 13

If you answered "no" to all parts of these questions, do not answer any further questions on this form

14. Did you or a colleague physician discuss with the patient the (possible) hastening of the end of life as a result of the (last-mentioned) act?
☐ yes, at the time of performing the act or shortly before
☐ yes, some time beforehand
☐ no, no discussion

15. Was the decision concerning the (last-mentioned) act made upon an explicit request of the patient?
☐ yes
☐ no, but the patient had expressed a wish
☐ no, and the patient had never expressed a wish

16. Did you consider the patient capable to assess his/her situation and to make a decision about it adequately ?
☐ yes
☐ no, not fully capable
☐ no, not capable at all

THE SENTIMELC REGISTRATION FORM

2006

The standardized weekly registration form of the SENTI-MELC study 2006 Belgium

Please contact Prof.dr. Luc Deliens or Lieve Van den Block if you want to use this instrument,

in full or individual items, or if you want to adapt it to your local circumstances

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REGISTRATION OF ALL DEATHS OF PATIENTS (AGED 1 YEAR OR OLDER)

A

1. Your reference (e.g. initials) : ....
2. Date of birth : . . / . . / . . . .
3. Date of death : . . / . . / 2 0 0 6
4. Gender ☐ Male
   ☐ Female
5. Postal code of patient's usual place of residence ☐☐☐☐
6. Did the patient have a regular partner at the time of death ? ☐ yes
   ☐ no
7. Did the patient live at home or with family (usual place of residence) ? ☐ yes, alone
   ☐ yes, with other people (state exact number) : . .
   ☐ no
8. Patient's education (highest completed level of education or certificate) ☐ primary education or less
   ☐ lower secondary education
   ☐ higher secondary education
   ☐ higher education, university
9. Your estimate of the financial / material status of the patient's nuclear family ☐ very low
   ☐ rather low
   ☐ average
   ☐ fairly high
   ☐ very high
10. Place of death ☐ home
    ☐ hospital
    ☐ care home
    ☐ public road
    ☐ at work
    ☐ other (namely) : ....
    ....
11. Nature of death ☐ natural causes (**incl.** euthanasia)
    ☐ traffic accident
    ☐ other accident
    ☐ suicide
    ☐ murder
    ☐ is under investigation
    ☐ cannot be determined
12. Cause of death * : Illness or disorder that was the direct cause of death : State below under (a) the logical association of the illnesses/ disorders that resulted in the immediate cause of death. If more than one illness, state the illness that was the "original cause of death" last.
    *This is not the way in which the patient died, e.g. heart failure, syncope, etc. ... but the illness, the trauma or the complication that caused the death. Please mention one cause per line.
    (a) ....
    Caused by : (b) ....
    Caused by : (c) ....
    Caused by : (d) ....
    see instructions for examples
13. Was this patient part of your own practice (or group practice) ? ☐ yes
    ☐ no

If "NO" to question 13, do not answer any further questions on this form

14. **Was death sudden <u>and</u> totally unexpected ?** ☐ yes
    ☐ no

If "YES" to question 14, do not answer any further questions on this form

1. The **place of death** of the patient and **place(s) of residence** during the **last 3 months (=90 days) before death**, as well as the duration of stay in **days** (approximately if not precisely known). If the patient remained in the same place until death, only fill in Place 1.

B

last 3 months before death

see instructions for examples	at home or living with familly (incl. service flat)	care home: home for the elderly / nursing home	hospital (**excl.** pall care unit and **excl.** nursing home unit in hospital)	palliative care unit (hospital)	elsewhere **(please specify)**
1 place of **death** and duration of stay	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days
2 previous place of **residence** and duration of stay	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days
3 previous place of **residence** and duration of stay	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days
4 previous place of **residence** and duration of stay	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days

2. Were you informed (verbally or in writing) of the patient's preference regarding place of death ?

(More than one answer can be given)

☐ yes ☐ by the patient him/herself
☐ by the patient's family or significant other
☐ other (namely) : ....

If **YES**, where did this patient prefer to die ?
☐ at home or living with family (incl. service flat)
☐ in a care home: home for elderly persons / nursing home
☐ in hospital (**excl.** palliative care unit, and **excl.** nursing home unit in hospital)
☐ palliative care unit (hospital)
☐ elsewhere (namely) : ....

☐ no

3. How often (on average) did you have **contact** (consultations, home visits, **excl**. telephone contact) with the patient or with significant others regarding the patient ?

last week before death	**2nd to 4th week before death**	**2nd and 3rd month before death**
. . . x per **week**	. . . x per **week**	. . . x per **month**

4. What was the **main goal** of this patient's treatment ?

(More than one answer can be given)

	last week before death	**2nd to 4th week before death**	**2nd and 3rd month before death**
cure	☐	☐	☐
prolonging life	☐	☐	☐
comfort / palliation	☐	☐	☐
unknown	☐	☐	☐

5. Please indicate the extent to which the following signs or symptoms were present during **the last week** of this patient's life, despite any treatment? Please circle the most appropriate number

no pain	0	1	2	3	4	5	6	7	8	9	10	worst possible pain
not tired	0	1	2	3	4	5	6	7	8	9	10	worst possible tiredness
not nauseated	0	1	2	3	4	5	6	7	8	9	10	worst possible nausea
not depressed	0	1	2	3	4	5	6	7	8	9	10	worst possible depression
not anxious	0	1	2	3	4	5	6	7	8	9	10	worst possible anxiety
not drowsy	0	1	2	3	4	5	6	7	8	9	10	worst possible drowsiness
best appetite	0	1	2	3	4	5	6	7	8	9	10	worst possible appetite
best feeling of well-being	0	1	2	3	4	5	6	7	8	9	10	worst possible feeling of wellbeing
no shortness of breath	0	1	2	3	4	5	6	7	8	9	10	worst possible shortness of breath

Additional remarks for question 5 : . ...

....

6. Please indicate how you rate this patient's death. Please circle the most appropriate number.

mild death	0	1	2	3	4	5	6	7	8	9	10	no mild death

7. Circle the extent to which the care provided (by you and/or other caregivers) was directed at :

1=not or to a very small extent **5**=to a very large extent **?**=unknown

	last week before death	**2nd to 4th week before death**	**2nd and 3rd month before death**
treatment / care for physical problems	1 2 3 4 5 ?	1 2 3 4 5 ?	1 2 3 4 5 ?
psychosocial care	1 2 3 4 5 ?	1 2 3 4 5 ?	1 2 3 4 5 ?
spiritual care (existential, religious, etc)	1 2 3 4 5 ?	1 2 3 4 5 ?	1 2 3 4 5 ?

8.How often were the following persons/disciplines actively involved in providing care for this patient during the last 3 months of life?

	not at all	**sometimes**	**often**	**unknown**
you yourself	☐	☐	☐	☐
clinical specialist	☐	☐	☐	☐
informal caregiver (e.g. partner, child, sister, friend, …)	☐	☐	☐	☐
nurse	☐	☐	☐	☐
carer / home carer / geriatric assistant (**excl.** nurse)	☐	☐	☐	☐
chaplain / pastor / non-religuous counsellor	☐	☐	☐	☐
physiotherapist / occupational therapist / speech therapist	☐	☐	☐	☐
other (namely) :	☐	☐	☐	☐

9. Which **specialist palliative care initiatives** were adopted in the last 3 months of this patient's life?
(More than one answer can be given)
☐ 1 palliative homecare team
☐ 2 mobile palliative care support team in a hospital
☐ 3 palliative care unit (hospital)
☐ 4 reference persons for palliative care in a care home (co-ordinating and advisory physician and/or reference nurse)
☐ 5 LEIF or EOL- physician (End-of life Information Forum) (LEIF or EOL physicians provide support and advice to colleague physicians concerning issues related to euthanasia, medical end-of-life decisions, and the possibilities of palliative care in Belgium)
☐ 6 palliative day care centre
☐ 7 other (namely) : ....
☐ 8 none
☐ 9 unknown

10. Was the patient kept continuously in deep sedation or coma until death by means of e.g. benzodiazepines or barbiturates?
☐ yes, and food and fluids were not artificially administered
☐ yes, and food and fluids were artificially administered
☐ no

The following questions concern medical decisions, with a (potentially) life-shortening effect for the patients

11. Did you or a colleague physician take one or more of the following acts (or ensure that one of them was taken), taking into account the probability or certainty that this act would hasten the end of the patient's life? (**Please answer both questions 11a and 11b**):

11a. withholding a treatment or withdrawing a treatment (incl. artificial administration of food and/or fluids) ? ☐ yes
☐ no

11b. intensifying the alleviation of pain and/or symptoms using a drug? ☐ yes, ➔**go to question 12**
☐ non, ➔**go to question 13**

12. Was hastening the end of life partly the intention of the act indicated in question **11b** ? ☐ yes
☐ no

13. Was death caused by withholding a treatment or withdrawing a treatment (incl. artificial administration of food and/or fluids), which you or a colleague physician decided to take with the explicit intention of hastening the end of life ?
☐ yes
☐ no

14. Was death caused by the use of a drug prescribed, supplied or administered by you or a colleague physcian with the explicit intention of hastening the end of life (or of enabling the patient to end his or her own life) ?
☐ yes
☐ no
If yes, who administered this drug (= introduced it into the body) ?
(More than one answer can be given)
☐ the patient
☐ you or a colleague physician
☐ nursing staff/other caregivers
☐ other (namely) : ....

The following questions relate to the LAST "YES" in answer to questions 11a to 14

If you answered "no" to all parts of these questions, do not answer any further questions on this form

15. Did you or a colleague physician discuss with the patient the (possible) hastening of the end of life as a result of the (last-mentioned) act?
☐ yes, at the time of performing the act or shortly before
☐ yes, some time beforehand
☐ no, no discussion

16. Was the decision concerning the (last-mentioned) act made upon an explicit request of the patient?
☐ yes
☐ no, but the patient had expressed a wish
☐ no, and the patient had never expressed a wish

17. Did you consider the patient capable to assess his/her situation and to make a decision about it adequately ?
☐ yes
☐ no, not fully capable
☐ no, not capable at all

THE SENTIMELC REGISTRATION FORM

2007

APPENDIX I

REGISTRATION OF ALL DEATHS OF PATIENTS (AGED 1 YEAR OF OLDER) PART OF YOUR (GROUP) PRACTICE

1. Your reference (e.g. initials) : ....

2. Date of birth : . . / . . / . . . .

3. Date of death : . . / . . / 2 0 0 7

4. Gender : ☐ Male ☐ Female

5. Postal code of patient's usual place of residence ☐☐☐☐

6. Patient's education(highest completed level of education or certificate)
   - ☐ primary education or less
   - ☐ lower secondary education
   - ☐ higher secondary education
   - ☐ higher education / university

7. Nature of death
   - ☐ natural causes (**incl.** euthanasia)
   - ☐ traffic accident
   - ☐ other accident
   - ☐ suicide
   - ☐ murder
   - ☐ is under investigation
   - ☐ cannot be determined

8. Where did the patient reside most of the time in his/her **last year** of life?
☐ at home or living with family (incl. service flat) ☐ care home ☐ other (namely) ....

9. Place of patient's death and length of stay in this place (**max. of 90days** – if length of stay > 90d, please enter 90)

	at home or living with family (incl.service flat)	care home: home for the elderly / nursing home	hospital (**excl.** pall care unit, and **excl.** nursing home unit in hospital)	palliative care unit (hospital)	elsewhere **(please specify)**
place of **death** and lenght of stay	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ . . . . days	☐ .... days

10. Cause of death * : Illness or disorder that was the direct cause of death : State below under (a) the logical association of the illnesses/ disorders that resulted in the immediate cause of death. If more than one illness, state the illness that was the "original cause of death" last.
*This is not the way in which the patient died, e.g. heart failure, syncope, etc. ... but the illness, the trauma or the complication that caused the death. Please mention one cause per line.
(a) ....
Caused by : (b) ....
Caused by : (c) ....
Caused by : (d) ....
see instructions for examples

11. How often (on average) did you have **contact (**consultations, home visits, **excl**. telephone contact) with the patient or with significant others regarding the patient ?

last week before death	**2nd to 4th week before death**	**2nd and 3rd month before death**
. . . x per **week**	. . . x per **week**	. . . x per **month**

12. What was the main goal of this patient's treatment in the last week of life?
☐ cure ☐ prolonging life ☐ comfort/palliation ☐ unknown/not applicable

13. Which **specialist palliative care initiatives** were adopted in the last 3 months of the patient's life?
(More than one answer can be given)
   - ☐ palliative homecare team
   - ☐ mobile palliative care support team in a hospital
   - ☐ palliative care unit (hospital)
   - ☐ palliative day (care) centre
   - ☐ reference persons[1] for palliative care in a care home
   - ☐ LEIF or EOL - physician (End-of-life Information Forum)[2]
   - ☐ none
   - ☐ unknown

[1] (coordinating and advisory physician and/or reference nurse)
[2] (LEIF or EOL physicians provide support and advice to physician colleagues concerning issues related to euthanasia, medical end-of-life decisions, and the possibilities of palliative care in Belgium)

14. Were you informed (verbally or in writing) of the patient's preference regarding place of death? *(More than one answer can be given)*
☐ yes ☐ by the patient him/herself
☐ by the patient's family or significant other
☐ other (namely) : ....
If **YES**, where did this patient prefer to die ?
   - ☐ at home or living with family (incl. service flat)
   - ☐ in a care home: home for elderly persons / nursing home
   - ☐ in hospital (**excl.** palliative care unit, and **excl.** nursing home unit in hospital)
   - ☐ palliative care unit (hospital)
   - ☐ elsewhere (namely) : ....

☐ no

15. Did the patient ever express specific **wishes** about any medical treatment that he/she would or would not want in the final phase of life?
☐ yes ☐ no ☐ unknown
If **YES,**
a) Did you ever speak to the patient about these wishes? ☐ yes ☐ no
b) Within the last week of life, was there any medical procedure or treatment that was inconsistent with previously stated wishes?
☐ yes ☐ no ☐ unknown
c) Did these wishes include any of the following medical treatments/decisions? *(More than one answer can be given)*

- to forgo or not to forgo further life-prolonging treatment	☐ yes, in writing	☐ yes, verbally	☐ no
- to keep or not to keep the patient continuously under deep sedation by means of medication until death	☐ yes, in writing	☐ yes, verbally	☐ no
- prescribe, supply or administer, or not, medication with the explicit intention of hastening the end of life	☐ yes, in writing	☐ yes, verbally	☐ no

16. The following table concerns the advance care planning of possible treatments/medical decisions in the final phase of the life of the patient in case he/she becomes incapable of making such decisions.
Please work per column and circle what applies to this patient Y=yes N=no ?=unknown

potentially life-prolonging treatment	As far as you know, was there a **previous agreement,** with patient or his/her family, not to initiate or to stop this treatment under certain circumstances?	If **YES**, Was this agreement also made in writing?	Was this agreement made with the patient him/herself?	In the final three months of life, was there an illness or condition for which this treatment could have been considered?	If **YES**, Has this **prior agreement** been followed at the end of life?
chemotherapy or radiotherapy	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
artificial food administration	Y / N / ?	y / N	Y / N / ?	Y / N / ?	Y / N / ?
artificial fluid administration	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
blood transfusion	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
artificial respiration	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
cardiopulmonary resuscitation (CPR)	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
dialysis	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
antibiotics	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
vasopressors	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
hospital transfer	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?

medical end-of-life decisions	As far as you know, was there a **previous agreement** with patient or family to make this medical decision under certain circumstances?	If **YES**, Was this agreement also made in writing?	Was this agreement made with the patient him/herself?	In the final three months, was there an illness or condition for which this medical decision could have been considered?	Was this **medical decision** made at the end of the patient's life?
forgoing potential life-prolonging treatments in general	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
intensifying the alleviation of pain and/or symptoms with a possible life-shortening effect	Y / N / ?	Y/ N	Y / N / ?	Y / N / ?	Y / N / ?
keeping the patient unconscious until death through medication					
- with artificial feeding or hydration	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
- without artificial feeding and hydration	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?
prescribing, supplying or administering a drug with the **explicit intention** of hastening the end of life	Y / N / ?	Y / N	Y / N / ?	Y / N / ?	Y / N / ?

If **YES**

16.a) Was the decision concerning this act made upon an explicit request of the patient? ☐ yes ☐ no
16.b) Who administered this drug? ☐ patient ☐ you or another physician
☐ nursing staff ☐ someone else (*namely*) : ....

17. Please indicate, as far as you know, the extent to which the following signs or symptoms were present during **the three days** of this patient's life, despite any treatment. Please circle the most appropriate number.

no pain	0	1	2	3	4	5	6	7	8	9	10	worst possible pain
not tired	0	1	2	3	4	5	6	7	8	9	10	worst possible tiredness
not nauseated	0	1	2	3	4	5	6	7	8	9	10	worst possible nausea
not depressed	0	1	2	3	4	5	6	7	8	9	10	worst possible depression
not anxious	0	1	2	3	4	5	6	7	8	9	10	worst possible anxiety
not drowsy	0	1	2	3	4	5	6	7	8	9	10	worst possible drowsiness
best appetite	0	1	2	3	4	5	6	7	8	9	10	worst possible appetite
best feeling of well-being	0	1	2	3	4	5	6	7	8	9	10	worst possible feeling of wellbeing
no shortness of breath	0	1	2	3	4	5	6	7	8	9	10	worst possible shortness of breath
conscious	0	1	2	3	4	5	6	7	8	9	10	comatose
not confused	0	1	2	3	4	5	6	7	8	9	10	worst possible confusion
fully capable to take decisions	0	1	2	3	4	5	6	7	8	9	10	not capable to all of taking decisions

18. Please indicate how you rate the death of the patient. Please circle the most appropriate number.

mild death	0	1	2	3	4	5	6	7	8	9	10	no mild death

19. **Was death sudden and totally unexpected ?** ☐ yes ☐ no

THE SENTIMELC REGISTRATION FORM

2008

REGISTRATION OF ALL DEATHS OF PATIENTS (AGED 1 YEAR OR OLDER) WHO ARE PART OF YOUR (GROUP)PRACTICE

1. Your reference (e.g. initials) : ....

2. Date of birth : . . / . . / . . . .

3. Date of death : . . / . . / 2 0 0 8

4. Gender : ☐ Male ☐ Female

5. Postal code of patient's usual place of residence ☐☐☐☐

6. Patient's education(highest completed level of education or certificate)
   - ☐ primary education or less
   - ☐ lower secondary education
   - ☐ higher secondary education
   - ☐ higher education / university

7. Nature of death
   - ☐ natural causes (**incl**. euthanasia)
   - ☐ traffic accident
   - ☐ other accident
   - ☐ suicide
   - ☐ murder
   - ☐ is under investigation
   - ☐ cannot be determined

8. Where did the patient reside most of the time in his/her **last <u>year</u>** of life?
   ☐ at home or living with family (incl. service flat) ☐ care home ☐ other (namely) ....

9a. Place of **death**
   - ☐ at home or living with family (incl. service flat)
   - ☐ care home: home for elderly persons / nursing home
   - ☐ hospital (**excl**. pall care unit, and **excl**. nursing home unit in hospital)
   - ☐ palliative care unit (hospital)
   - ☐ elsewhere (please specify) : ....

9b. **Length of stay** at this place of death? ...... days
(**max. of 90days** – if length of stay > 90d, please enter 90)

10. Cause of death ***** : Illness or disorder that was the direct cause of death : State below under (a) the logical association of the illnesses/ disorders that resulted in the immediate cause of death. If more than one illness, state the illness that was the "original cause of death" last.
*This is not the way in which the patient died, e.g. heart failure, syncope, etc. ... but the illness, the trauma or the complication that caused the death. Please mention one cause per line.

(a) ....

Caused by : (b) ....

Caused by : (c) ....

Caused by : (d) ....

see instructions for examples

11. How long prior to death was the prognosis made that the patient would die within a certain amount of time?
   ☐ not ☐ ≤ 3 days ☐ 4-7 days ☐ 1-4 weeks ☐ 1-3 months ☐ 4-6 months ☐ > 6 months

12. Did you or another doctor determine a diagnosis of dementia?
   ☐ yes, severe dementia ☐ yes, mild dementia ☐ no ☐ unknown

13. How often (on average) did you have **contact (**consultations, home visits, **excl**. telephone contact) with the patient or with significant others regarding the patient ?

last week before death	**2nd to 4th week before death**	**2nd and 3rd month before death**
. . . x per **week**	. . . x per **week**	. . . x per **<u>month</u>**

14. Which of the following topics were addressed during **your conversations** with the **patient**? (*minimum 1 answer per line*)

	never	**laast week** before death	**2nd to 4th week** before death	**prior to the last month** before death	not applicable
A primary diagnosis	☐	☐	☐	☐	☐
B incurability of the illness	☐	☐	☐	☐	☐
C life expectation	☐	☐	☐	☐	☐
D possible medical complications	☐	☐	☐	☐	☐
E physical symptoms	☐	☐	☐	☐	☐
F psychological problems (i.e., sadness, worry, fear)	☐	☐	☐	☐	☐
G social problems (i.e., relationship problems, lack of social support from family/friends, family not accepting the situation, etc.)	☐	☐	☐	☐	☐
H spiritual/existential problems (i.e., difficulty in accepting the situation, trouble with the meaning of life, angry at God, etc.)	☐	☐	☐	☐	☐
I options for palliative care	☐	☐	☐	☐	☐
J burden of treatments	☐	☐	☐	☐	☐

15. What was the main goal of this patient's treatment in the <u>last week</u> of life?
   ☐ cure ☐ prolonging life ☐ comfort/palliation ☐ unknown ☐ not applicable

16a. Which specialist palliative care initiatives were adopted <u>in the last 3 months</u> of this patient's life?
(More than one answer can be given)
   - ☐ palliative homecare team
   - ☐ mobile palliative care support team in a hospital
   - ☐ palliative care unit (hospital)
   - ☐ reference persons* for palliative care in a care home
   - ☐ palliative day care centre
   - ☐ none
   - ☐ unknown

16b. Estimate the number of days between the first palliative intervention and the moment of death ...... days

*(coordinating and advisory physician and/or reference nurse)

17. Did the patient ever express a wish regarding the place of death? *(More than one answer can be given)*
☐ yes, in writing ☐ yes, verbally ☐ no ☐ unknown

If **YES**,

where did this patient prefer to die?
☐ at home or living with family (incl. service flat)
☐ in a care home: home for elderly persons / nursing home
☐ in hospital (**excl.** palliative care unit, and **excl.** nursing home unit in hospital)
☐ palliative care unit (hospital)
☐ elsewhere (namely) : ....

18. Did the patient ever express specific **wishes** about any medical treatment that he/she would or would not want in the final phase of life?
☐ yes ☐ no ☐ unknown

If **YES,**

a) Did **you** ever speak to the patient about these wishes? ☐ yes ☐ no
b) Within the last week of life, was there any medical procedure or treatment that was inconsistent with previously stated wishes?
☐ yes ☐ no ☐ unknown
c) Did these wishes include any of the following medical treatments/decisions? *(More than one answer can be given)*

- to forgo or not to forgo further life-prolonging treatment	☐ yes, in writing	☐ yes, verbally	☐ no
- to keep or not to keep the patient continuously under deep sedation by means of medication until death	☐ yes, in writing	☐ yes, verbally	☐ no
- to prescribe, supply or administer, or not, medication with the explicit intention of hastening the end of life	☐ yes, in writing	☐ yes, verbally	☐ no

19. Did the patient ever express a **wish** about who was to make decisions regarding medical treatments/acts **in his/her place, in the event he/she would no longer be able to speak for him/herself?** (*More than one answer can be given*)
☐ yes, in writing ☐ yes, verbally ☐ no ☐ unknown

If **YES,**

a) Did **you** ever speak to the patient about these wishes? ☐ yes ☐ no
b) If the situation did arise, was this person consulted? ☐ yes ☐ no ☐ unknwown ☐ situation did not arise

20. Did the patient have the following symptoms during the **last week** prior to death? *(Please circle the most appropriate answer)*

				If **YES,** how much did that **distress** the patient?					
	Yes	**No**	**Unknown**	not at all	a little bit	somewhat	quite a bit	very much	unknown
A lack of appetite	☐	☐	☐	1	2	3	4	5	☐
B lack of energy	☐	☐	☐	1	2	3	4	5	☐
C pain	☐	☐	☐	1	2	3	4	5	☐
D feeling drowsy	☐	☐	☐	1	2	3	4	5	☐
E constipation	☐	☐	☐	1	2	3	4	5	☐
F dry mouth	☐	☐	☐	1	2	3	4	5	☐
G difficulty breathing	☐	☐	☐	1	2	3	4	5	☐
				Ifi **YES**, **how often** did the patient appear to feel this way?					
				rarely	occasionally	frequently	almost constantly		unknown
H feeling sad	☐	☐	☐	1	2	3	4		☐
I worrying	☐	☐	☐	1	2	3	4		☐
J feeling irritable	☐	☐	☐	1	2	3	4		☐
K feeling nervous	☐	☐	☐	1	2	3	4		☐

21. What was the performance status of the patient during the **last week** prior to death?
☐ fully active, without restriction (able to carry on all pre-disease performance)
☐ restricted to work of a light or sedentary nature, e.g., light house work, office work
☐ ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
☐ capable of only limited selfcare, confined to bed or a chair more than 50% of waking hours
☐ completely disabled. Cannot carry on any self-care. Totally confined to bed or chair

22. Was the patient capable of making decisions during the **last week** prior to death?
☐ yes ☐ sometimes ☐ no ☐ unknown

23. Was the patient **in a coma or unconscious** until death and if so, for how long?
☐ never unconscious ☐ ≤ 1 day ☐ 2-7 days ☐ 1-4 weeks ☐ > 4 weeks ☐ unknown

24. **Was death sudden and totally unexpected ?** ☐ yes ☐ no

APPENDIX
II

CV
&
LIST OF
PUBLICATIONS

CURRICULUM VITAE

Koen Meeussen, born September 5, 1981, studied Latin-Mathematics in high school, Personnel management, Work and Organizational Psychology at Ghent University (2004), and obtained a postgraduate certificate in neuropsychology at K.U.Leuven (2005). He started working half-time as a psychology teacher in high school, and half-time at a General Hospital Psychiatric Department performing screening, testing and psychodiagnostic evaluation for patients with a variety of problems. In 2006, he started his academic research career at the End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel. Currently he is appointed part-time Valorization Manager of the IWT SBO project Flanders Study to Improve End-of-life Care and Evaluation, and part-time Project Manager of the EU 7th Framework Programme Marie Curie ITN Research Project EURO IMPACT, both under the lead of the End-of-Life Care Research Group.

Koen lives in a *verrienaaishuizeken* with a *verrienaaisvrouwken*, Caroline, in the one and only City of Belgium.

LIST OF PUBLICATIONS AND PRESENTATIONS

ARTICLES IN INTERNATIONAL PEER-REVIEWED JOURNALS

Meeussen K, Van den Block L, Bossuyt N, Echteld M, Bilsen J, Deliens L. Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium. BMC Public Health 2010;10(186). (2009 impact factor: 2.223)

Meeussen K, Van den Block L, Bossuyt N, Bilsen J, Echteld M, Van Casteren V, Deliens L. GPs' awareness of patients' preference for place of death. British Journal of General Practice 2009;566(59):665-670. (2009 impact factor: 2.442)

Meeussen K, Van den Block L, Bossuyt N, Echteld M, Bilsen J, Deliens L. Dealing with requests for euthanasia. Interview study among general practitioners in Belgium. Journal of Pain and Symptom Management 2011 (accepted for publication). (2009 impact factor: 2.423)

Meeussen K, Van den Block L, Echteld M, Bossuyt N, Bilsen J, Van Casteren V, Abarshi E, Donker G, Onwuteaka-Philipsen B, Deliens L. Advance care planning in Belgium and the Netherlands: a nationwide retrospective study via sentinel networks of general practitioners. Journal of Pain and Symptom Management 2011 (accepted for publication). (2009 impact factor: 2.423)

Abarshi E, Echteld M, Van den Block L, Donker G, Bossuyt N, Meeussen K, Bilsen J, Onwuteaka-Philipsen B, Deliens L. Use of palliative care services and end-of-life GP visits in the Netherlands and Belgium. Journal of Pain and Symptom Management 2011 Feb;41(2):436-78. (2009 impact factor: 2.423)

ARTICLES IN NATIONAL PEER-REVIEWED JOURNALS

Meeussen K, Van den Block L, Bossuyt N, Bilsen J, Echteld M, Van Casteren V, Deliens L. Weet de huisarts waar zijn patiënt wil sterven? Huisarts Nu 2010;39(4):159-164.

BOOKS

Meeussen K, Van den Block L, Deliens L. ADVANCE CARE PLANNING: international perspectives. Chapter in Living and Dying Well: palliative and End of Life Care for Older People. Oxford University Press. In press.

Chapter in: Palliatieve zorg en euthanasia in België. Het MELC consortium. VUB Press. In press.

REPORT

Deliens L, Van den Block L, Meeussen K, De Gendt D, D'Haene I, Vander Stichele R. ADVANCE CARE PLANNING EN DEMENTIE; Onderzoeksrapport in opdracht van de Koning Boudewijnstichting, Vrije Universiteit Brussel, Onderzoekgroep Zorg rond het Levenseinde
In samenwerking met de Universiteit Gent, Heymans Instituut. September 2008

PRESENTATIONS - INTERNATIONAL

Meeussen K. Advance care planning in Belgium and the Netherlands. 6th Research Forum of the European Association for Palliative Care, Glasgow, 10/06/2010.

Meeussen K. EUROSENTIMELC. AGORA: internationaal onderzoek naar levenseindezorg, Rotterdam, 26/03/2009.

Meeussen K. Dying at the place of wish. Results from the Senti-Melc study. 5th Research Forum of the European Association of Palliative Care, Trondheim, Norway, 29/05/2008.
Meeussen K. Monitoring end-of-life care via general practice in Europe: a study with the Sentinel Surveillance Networks of General Practitioners. Dying at the place of wish. 13e WONCA EUROPE Congres, Parijs, 17/10/2007.

PRESENTATIONS - NATIONAL

Meeussen K. De organisatie van het permanent overleg tussen zorgverlener, patiënten met dementie en/of diens vertegenwoordiger. Symposium Advance care planning Lessius Mechelen, 4/02/2011.

Meeussen K. Een stand van zaken van de levenseindezorg in België. Eindcongres MELC-study, Brussel, 2/12/2010.

Meeussen K. Sterven met dementie. Gebruikerscommissie, Brussel, 16/09/2010.

Meeussen K. Voorafgaande zorgplanning en dementie. Dementiecafé, Antwerpen, 10/05/2010.

Meeussen K. Advance care planning en dementie. Studiedag Euthanasie, pijnbestrijding en levensmoeheid: juridische en sociologische aspecten, Wilrijk, 18/12/2009.

Meeussen K. Advance care planning: een voorstelling van het Koning Boudewijnrapport. Gebruikerscommissie Melc Project, Brussel, 3/12/2009.

Meeussen K. Advance care planning in België. Nederlands-Vlaams Onderzoeksforum Palliatieve Zorg, Rotterdam, 20/03/2009.

Meeussen K. Advance care planning in België. Wintermeeting Geriatrie, Oostende, 6/02/2009.

Meeussen K. Advance care planning in België. Federatie Palliatieve Zorg Vlaanderen: Studiedag Voorafgaande zorgplanning, Brussel, België, 17/01/2009.

Meeussen K. Advance care planning in Vlaamstalig en Franstalig België. ZrL Seminarie, VUB, Brussel, 11/09/2008.

Meeussen K. Het sterfbed in België. Tuesday Seminar, Wetenschappelijk Instituut Volksgezondheid, 8/04/2008.

Meeussen K. Dying at the place of wish. Results from the Senti-Melc Study. 9th Public Health Symposium: Public Health at the End of Life, Brussels, 14/12/2007.

Meeussen K. Weet de huisarts waar zijn patiënt wenst te sterven: resultaten van de Senti-Melc studie. Wetenschap in de palliatieve zorg, Onderzoeksforum Nederland-Vlaanderen, Antwerpen, België, Antwerpen, 17/11/2007.

Meeussen K. Weet de huisarts waar zijn/haar patiënt wenst te sterven. Achtste eerstelijnssymposium, Gasthuisberg, Leuven, 22/09/2007.