

Patient-physician communication at the end of life: a European perspective

The research presented in this thesis was conducted within the EMGO Institute for Health and Care Research, Department of Public and Occupational Health of the VU University Medical Center, Amsterdam, the Netherlands.

Financial support for the research included in this thesis:

Marie Curie PhD Fellowship

Funding for Natalie Evans' Marie Curie PhD Fellowship came via EUROIMPACT funded by the European Union Seventh Framework Programme (FP7/2007–2013, under grant agreement nu [264697]).

EURO SENTIMELC

Funding for the EURO SENTIMELC came from the Institute for the Promotion of Innovation by Science and Technology in Flanders as a Strategic Basic Research project (SBO) (contract SBO IWT 050158) (2006–2010), as part of the 'Monitoring Quality of End-of-Life Care (MELC) Study'. Funding also came from the Italian Ministry of Health through the 'Evaluation, testing and implementation of supportive care, care interventions, integrated programs and improving the quality of care for cancer patients' program 'Integrated Oncology Project n°6, years 2008–2011', from the annual budgets of the Autonomous Community of Castilla y León and Comunitat Valenciana.

LASA

Funding for the Longitudinal Ageing Study Amsterdam came from the Ministry of Health, Welfare and Sports, Directorate of Long Term Care.

Qualitative interview data

Funding for the primary studies was obtained from the following sources: The Belgian Science Policy and VUB (Belgium); The Centre for Development of Palliative Care Amsterdam, and the Dutch Ministry of Health, Welfare and Sports (The Netherlands); and Dimbleby Cancer Care (UK).

ISBN/EAN 9789461087669

Cover design:	Christopher Pell
Layout:	Natalie Evans
Printing:	Gildeprint, Enschede

Financial support for the printing of this thesis was provided by the VU University, the EMGO+ Institute and the Vrije Universiteit Brussel.

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VRIJE UNIVERSITEIT

**Patient-physician communication at the end of life:
a European perspective**

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. F.A. van der Duyn Schouten,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de Faculteit der Geneeskunde
op maandag 13 oktober 2014 om 13.45 uur
in de aula van de universiteit,
De Boelelaan 1105

door

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geboren te Londen, Verenigd Koninkrijk

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Chapter 1

General introduction

“Physicians must perform their [medical] duties calmly and adroitly, concealing most things from the patient...revealing nothing of the patient’s future or the present condition”

Hippocrates, Decorum (400 BC)

This chapter introduces the topic of patient-physician communication at the end of life and describes the ethical, historical and cultural factors that influence ideas about what constitutes good end-of-life communication and, indeed, a good death. The chapter begins with an outline of how respect for patient autonomy has replaced medical paternalism as the guiding medical ethic and the implications for patient communication.

The development of the modern hospice and palliative care movement in the United Kingdom, with its ideals of open and honest communication, is described and the attachment to such ideals in other European countries questioned. The chapter goes on to highlight the paucity, in spite of Europe's ageing population, of European cross-country research on end-of-life communication *practices* and research on older people's end-of-life communication experiences and preferences. Finally, how this thesis addresses the lacunae in research on end-of-life communication in Europe in cross-country perspective and for older people is outlined.

Autonomy and the patient-physician relationship

Over the last 50 years, the importance of patient autonomy and participation in decision-making has, to varying degrees, been recognised in all European countries[1]. This recognition has been heavily influenced by the emphasis on the rights of the individual and the dominance of autonomy in American bioethical discourse[2] and is exemplified in health care professionals' codes of conduct[3] and agreements precluding treatment without patients' informed consent[4]. This shift in the dominant ethical discourse, away from beneficent paternalism, towards a *prima facie* respect for autonomy, developed in response to calls for greater physician accountability and patients' right to self-determination[5,6]. It also provided the impetus for alternative, patient-centred¹ approaches, such as the informed and shared decision-making models[8].

These changes have wide ranging implications for health care in general, but particularly for care at the end of life. This is because assumptions underlying the paternalistic approach to decision-making are more easily questioned when curative options are no longer available. For example, the assumption that the physician has the expert knowledge to evaluate trade-offs between different treatment options and

¹ Patient-centered care is described as 'respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide clinical decisions' 7. Institute of Medicine (2001) Crossing the quality chasm: a new health system for the 21st century. Washington (DC): National Academies Press.

choose the *best* one is less valid when such decisions are based on improving patient-centred outcomes, such as quality of life – a subjective criteria of which the patient is the most appropriate adjudicator – rather than objective criteria, such as survival[5,9]. Respecting patient autonomy and facilitating participation in decision-making involves more advanced communication skills than those required for a more paternalistic approach. Systematic reviews of the literature also reveal that such skills are highly valued by patients and their caregivers, who, in general, prefer open and empathetic communication at the end of life[10] and emphasize the importance of good communication to their satisfaction with care[10,11].

Palliative and end-of-life care

Care provided at the end of life is often referred to as ‘palliative’ or ‘end-of-life’ care. The two terms are frequently used synonymously, although both have been variously defined[12,13]. In this thesis, however the two terms are used distinctly. ‘Palliative care’ takes the World Health Organisation (WHO) definition:

‘[An] approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems’[14].

‘End-of-life care’ is defined, in the context of this thesis, as care delivered at the end-of-life, which may or may not include a palliative approach. According to the British National Institute of Health (NIH), the ‘end of life’ is delimited as follows:

‘[T]here is no exact definition of end of life; however the evidence supports the following components: 1) the presence of a chronic disease(s) or symptoms or functional impairments that persist that may also fluctuate; and 2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death’[15].

End-of-life care, therefore, subsumes palliative care and is based on the presence of a life-threatening condition, unbounded by timeframe, rather than defined by aspects of care.

The modern hospice movement and the development of palliative care

Palliative care as we know it today developed out of the modern hospice movement² [16]^{Pp 2}. The modern hospice movement originated primarily through the efforts and leadership of Cicely Saunders and has been described as a reaction to the increasing institutionalization and medicalization of death within the newly developed National Health Service in post-war Britain[18]^{Pp 66}. Saunders, a physician who had previously worked as both a nurse and an almoner (a medical social worker), was exceptionally sensitive to the multiple and complex needs of dying patients and advocated evidence-based care combined with a holistic approach[16]^{Pp 1}. Working at a time when many questioned the appropriateness of disclosure of patients' terminal prognoses for fear of destroying hope[19], Saunders advocated open awareness of dying and encouraged good communication between patients and health care workers. Indeed, the dominant discourse surrounding the modern hospice and palliative care movement prioritizes a particular image of a 'good death', one characterised by 'truth-telling' and 'open awareness'[18]^{Pp 63}.

Saunders also emphasised the importance of patients' illness narratives in understanding their 'total suffering': physical, psycho-social and spiritual elements of pain[18]^{Pp 62}. A thorough assessment of total suffering requires excellent communication as health care workers must elicit enough information from the patient to identify his or her needs across diverse care domains[20].

Consequently, a strong emphasis has been placed on good patient-health care professional communication right from the inception of the palliative care movement and continues to this day. Palliative care is depicted as a patient-centred approach employing appropriate and sensitive communication for the discussion of bad news, care needs and preferences, including preferences for future care in case of loss of decision-making capacity[1,21]. End-of-life communication is therefore a rather broad area.

End-of-life communication practices in an ageing Europe

These ideals concerning end-of-life communication however are intimately associated with the cultural, historical and political context in which the modern hospice and palliative care movement originated in the UK. The attachment to such ideals in other

² The term palliative care was used by Canadian surgeon Balfour Mount to describe a hospital based initiative modelled on the care provided at St. Christopher's hospice (UK).

16. Clark D, Small N, Wright M, Winslow M, Hughes N (2005) A bit of heaven for the few? An oral history of the modern hospice movement in the United Kingdom
Lancaster: Observatory Publications.^{Pp2}

17. Woods S (2007) Death's dominion: ethics at the end of life: McGraw-Hill International.^{Pp51}

European countries following the spread and development of palliative care services is, however, less well understood. Europe is a small but extremely diverse continent, in which there is considerable variation in understandings of the concept of autonomy and the importance placed on it in relation to other bioethical principles, such as beneficence [17,22,23]^{Pp 94}, expectations regarding the patient-physician relationship and the role of the family in decision-making[23,24] and in the legal recognition given to advance directive (AD) documents[25-27]. This diversity potentially influences end-of-life communication practices.

There is however very little comparable, empirical evidence on the content and frequency of end-of-life communication *practice* in Europe. Previous European cross-country surveys, which revealed differences between countries, were either limited to physicians' attitudes to communication[28-31] or focused solely on the prevalence of medical end-of-life treatment discussions[32,33]. There remains, therefore, a distinct paucity of cross-country research on many aspects of end-of-life communication. International comparisons are valuable because they draw attention to factors that are universally important and those that are country specific and inform policy nationally and internationally.

An additional consideration when undertaking end-of-life care research in Europe is the changing demographic and epidemiological characteristics of the population. As a result of the increases in life expectancy and low birth rates, Europe's population is ageing and the region currently has the highest median age in the world[34]. Over the next 50 years, the percentage of people over 60 in Europe is projected to increase from 23.1% to 35.3%, whereas the percentage aged over 80, the 'oldest old', is projected to almost treble (from 4.7% to 12.1%)[35]. As a result, the patient population approaching the end of life is increasingly old, frail and suffering from cognitive decline[36]. Consequently, there is a particular need for research on the end-of-life communication experiences and preferences of people with these characteristics.

This thesis addresses the paucity of research on end-of-life communication in Europe, particularly in a cross-country perspective and for older people. The thesis focuses on patient-physician communication, to the exclusion of other health care professionals. This is because the ultimate legal responsibility for care and the onus of respecting patients' autonomy and gaining informed consent lies with the physician. In addition, whereas involvement of a physician in end-of-life care is standard in most European countries, there may be variation in the involvement of other health care professionals caused by differences in health care systems. There is also a particular focus in this

thesis on the GP-patient relationship due to the important role GPs play in the care given at the end of life for all patients, in all of the included countries[37,38]. To quantitatively measure aspects of end-of-life communication, this thesis examines specifically the discussion of end-of-life topics, elements of advance care planning; and ADs.

The discussion of end-of-life topics

Palliative care involves the ‘identification and impeccable assessment of physical, psychosocial and spiritual suffering’[1]. Such high quality assessment requires the discussion of a range of end-of-life issues, such as diagnosis, prognosis, treatment preferences, and psycho-social and spiritual issues. Within this thesis, the prevalence of ten specific topics spanning the various palliative care domains is examined in different populations. The choice of topics addressed during GP-patient conversations was made on the basis of relevant literature, and in dialogue with an expert panel, as integral to the provision of high quality end-of-life care[39]. These topics are: primary diagnosis; incurability of disease; life expectancy; possible medical complications; physical complaints; psychological problems; social problems; spiritual/existential problems; options for palliative treatment; and the possible burden of treatments.

Advance care planning

A high proportion of people lose the capacity to make decisions for themselves before they die[33,40,41]. To allow patients to participate in future care and treatment decisions, patients and health care staff are encouraged to discuss preferences in case of decision-making capacity loss beforehand. Often these preferences are described to family and health care professionals informally. A more standardized approach to discussing future care preferences is termed ‘advance care planning’. Advance care planning is a process of discussion about care goals and a means of placing on record the care preferences of patients whose ability to communicate may be impeded in the future[42]. Elements of advance care planning examined in this thesis include: general end-of-life care goals, medical end-of-life treatment preferences, appointment of surrogate decision-makers and preferred place of death. These aspects of advance care planning were also chosen on the basis of the literature and expert opinion[39].

Advance directives

A person may also wish to record his or her medical end-of-life treatment preferences more formally in an AD which outlines a person’s own treatment preferences in case of future loss of decision-making capacity[43]. ADs take two forms: instructional directives that detail an individual’s medical end-of-life treatment preferences; or surrogate decision-maker appointments that indicate who should make treatment

decisions on a person's behalf if his or her decision-making capacity is lost[44]. ADs are increasingly provided legal protection in Europe[25-27]. Although there is conflicting evidence concerning their effectiveness in improving end-of-life care[45-48], they remain an important tool for communicating end-of-life treatment preferences. In this thesis, two specific types of instructional ADs from the Netherlands are examined: 'euthanasia' ADs, which outline a desire for euthanasia under certain circumstances; and value-based 'care' ADs, which explicitly oppose euthanasia and state support for palliative care. These two AD types were chosen in order to study the impact of the 2002 Dutch euthanasia law on their possession.

Additionally, this thesis explores, qualitatively, the common themes and challenges in patient-physician communication at the end of life as described by patients in different European countries.

Research questions

The thesis is split into two parts. Part one consists of comparative research on end-of-life communication in Europe.

Research questions addressed in part one:

1. What proportion of people nearing death have end-of-life discussions with their GP and which factors influence their occurrence in different European countries?
2. For older patients, are there common themes and challenges in patient-physician communication at the end of life in different European countries?

Part two focuses exclusively on the situation in the Netherlands, allowing for an in-depth examination of the factors affecting various aspects of end-of-life communication in one European country with a focus on older people.

Research questions addressed in part two:

3. How does GP end-of-life communication and care provision differ by patient 'chronic illness trajectory group'?
4. What are older people's preferences for life-sustaining treatments in hypothetical cases of cancer and dementia and which socio-demographic,

social support, physical and mental health factors are associated with their preferences?

5. What is the relationship between older people's general end-of-life goals and specific life-sustaining treatment preferences?
6. Is there a trend in older people's euthanasia and care AD possession over time and which socio-demographic, social support, physical and mental health factors are associated with possession?

Methods

To address the research questions, a number of different studies were undertaken. A brief description of the methods employed in each are included below and described in more detail in subsequent chapters.

Cross-sectional, retrospective surveys of representative GP networks on end-of-life care in Belgium, the Netherlands, Spain and Italy

EURO SENTI-MELC is an ongoing study consisting of GPs from representative networks in Belgium, the Netherlands, Spain and Italy who record the demographic, health and care characteristics in the last three months of life of all practice patients who die. The Belgian and Dutch networks are nationwide, whereas the Spanish and Italian networks operate in specific regions.

Data from the four countries are used to answer the first research question 'what proportion of people nearing death have end-of-life discussions with their GP and which factors influence their occurrence in different European countries'? This question is addressed in chapters 2 and 3. In chapter 2, GP-patient discussion of ten physical, psycho-social or spiritual end-of-life topics is estimated and associations with patient and care characteristics are analysed using multivariable techniques for each country. In chapter 3, GP-patient discussion of medical end-of-life treatment preferences and patients' appointment of surrogate decision-makers are estimated and associations with patient and care characteristics are examined by country using multivariable analyses. These studies, although part of a larger and ongoing mortality follow-back study, take a cross-sectional approach and the sample size consists of 4,396 non-sudden deaths (Italy n=1,808, Spain n=379, Belgium n=1,556, the Netherlands n=653).

In chapter 5, SENTI-MELC data from the Netherlands are used to answer the third research question, 'how does GP end-of-life communication and care provision differ

by patient 'chronic illness trajectory group'? Differences in treatment aims, palliative care provision and end-of-life communication for 688 patients who died non-suddenly (453 cancer, 162 organ failure and 73 old-age/dementia patients) are analysed cross-sectionally using a multivariable approach.

Secondary analysis of older patients' interviews from the United Kingdom, Belgium and the Netherlands

In chapter 4, interviews from British, Dutch and Belgian patients over the age of 60 with a progressive terminal illness are used to address the second research question, 'for older patients, are there common themes and challenges in patient-physician communication at the end of life in different European countries?' A secondary analysis is conducted on purposefully selected sub-samples of interviews from three qualitative studies conducted in the United Kingdom (n=10), the Netherlands (n=11) and Belgium (n=17). Participants over the age of 60 with a range of socio-demographic characteristics, health statuses and care locations are included. Interviews are largely unstructured and aimed at generating patients' narratives[21]. Steps are taken to ensure sufficient contextual information is available to inform the analysis and to avoid decontextualization. Cross-cutting themes are identified using a thematic approach.

Cross-sectional and longitudinal studies of a representative, population-based, sample of older Dutch people

Data from the Longitudinal Aging Study Amsterdam (LASA) a population-based study[49] are used to answer the remaining research questions. The LASA study incorporates two nationally representative cohorts of older people, sampled from population registers of eleven Dutch municipalities[49]. Since 1992, data have been collected through face-to-face interviews, self-administered questionnaires and medical interviews every three years[49]. Data from 2008/09 are used to answer the research questions, 'what are older people's preferences for life-sustaining treatments in hypothetical cases of cancer and dementia and which socio-demographic, social support, physical and mental health factors are associated with their preferences?' in chapter 6 and, 'what is the relationship between older people's general end-of-life goals and specific life-sustaining treatment preferences?' in chapter 7. In chapter 6, older people's (n=1484) preferences for four life-sustaining treatments in hypothetical cases of cancer and dementia are described and factors associated with them examined using multivariable logistic regressions. In chapter 7, the agreement between older people's (n=1168) general goals and specific treatment preferences is estimated.

In chapter 8, LASA data from four collection rounds (1998/9, 2005/06, 2008/09, 2011/12) are used to answer the final research question, 'is there a trend in older people's euthanasia and care AD possession over time and which socio-demographic, social support, physical and mental health factors are associated with possession'? In this chapter, the prevalence, in each collection period, of older people's (1584 in 1998/99, 1207 in 2005/06, 1158 in 2008/09, and 1119 in 2011/12) possession of euthanasia and care ADs is described, any longitudinal trend in possession identified and associations between possession and socio-demographics, social support, physical and mental health analysed using logistic regressions with generalized estimating equations. The influence of the 2002 euthanasia law AD on possession is also considered.

Thesis structure

The chapters of this thesis are based on five published articles and two articles submitted for publication in international peer review journals. Chapter 9 provides an overarching discussion of the separate studies, summarizing the key findings and discussing implications for policy and practice and recommendations for future research.

Overview of chapters 2-9

Part I – End-of-life communication in Europe: cross-country comparisons

Chapter 2 The prevalence of GP-patient discussion of different end-of-life topics prior to patients' deaths in Italy, Spain, Belgium and the Netherlands is estimated and compared and associations between discussions and patient and care characteristics for each country are analysed.

Chapter 3 The prevalence of GP-patient medical end-of-life treatment preference discussions and patients' appointment of surrogate decision-makers in Italy, Spain, Belgium and the Netherlands is estimated and compared and country specific factors associated with treatment preference discussions and surrogate appointments are analysed.

Chapter 4 Common themes surrounding patient-physician end-of-life communication from British, Dutch and Belgian interviews with older patients on attitudes to death, dying and end-of-life care are examined and similarities and differences in attitudes and experiences within these common themes identified.

Part II – End-of-life communication for older people: the Dutch experience

Chapter 5 Dutch GPs' end-of-life care for patients who died from 'cancer', 'organ failure' and 'old-age or dementia' is described and compared. Aspects of care examined include: importance of cure, life prolongation and palliation in the last week

of life, two to four weeks before death, and two to three months before death; provision of palliative care by the GP and other services; prevalence of GP-patient discussion of ten end-of-life topics; and elements of advance care planning, specifically regarding preferred place of death, medical end-of-life treatment preferences and surrogate decision-makers.

Chapter 6 Dutch older people's preferences for artificial hydration and nutrition, antibiotics, cardio-pulmonary resuscitation and mechanical ventilation in hypothetical cases of cancer and dementia are described and associations between older people's preference to forgo one or more medical end-of-life treatments and socio-demographic characteristics, social support, physical and mental health analysed.

Chapter 7 The relationship between Dutch older people's general end-of-life goals and specific end-of-life treatment preferences is described: specifically, the relationship between general preferences for quantity vs. quality of life and preferences for artificial hydration and nutrition, antibiotics, cardio-pulmonary resuscitation and mechanical ventilation in hypothetical cancer and dementia scenarios.

Chapter 8 The trend in euthanasia and care AD possession amongst older people in the Netherlands (1998 - 2011) is described and associations between possession and socio-demographic characteristics, social support, physical and mental health analysed.

General discussion

Chapter 9 The key findings from the preceding chapters are discussed, methodological issues raised and implications for policy and practice and recommendations for future research outlined.

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Part I – End-of-life communication in Europe: cross-country comparisons

Chapter 2

End-of-life communication: a retrospective survey of representative GP networks in four countries

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Published in *Journal of Pain and Symptom Management* 2014, **47**(3): 604–619

Abstract

Context Effective communication is central to high quality end-of-life care.

Objectives This study examines the prevalence of general practitioner (GP)-patient discussion of end-of-life topics (according to the GP) in Italy, Spain, Belgium and the Netherlands and associated patient and care characteristics.

Methods This cross-sectional, retrospective survey was conducted with representative GP networks. Using a standardized form, GPs recorded the health and care characteristics in the last three months of life, and the discussion of ten end-of-life topics, of all patients who died under their care. The mean number of topics discussed, the prevalence of discussion of each topic and patient and care characteristics associated with discussions were estimated per country.

Results In total, 4396 non-sudden deaths were included. On average, more topics were discussed in the Netherlands (mean=6.37), followed by Belgium (4.45), Spain (3.32) and Italy (3.19). The topics most frequently discussed in all countries were 'physical complaints' and the 'primary diagnosis', whereas 'spiritual and existential issues' were the least frequently discussed. Discussions were most prevalent in the Netherlands, followed by Belgium. GPs from all countries tended to discuss fewer topics with older patients, non-cancer patients, patients with dementia, patients for whom palliative care was not an important treatment aim and patients for whom their GP had not provided palliative care.

Conclusions The prevalence of end-of-life discussions varied across the four countries. In all countries, training priorities should include the identification and discussion of spiritual and social problems and early end-of-life discussions with older patients, those with cognitive decline if possible, and those with non-malignant diseases.

Background

Palliative care involves the 'identification and impeccable assessment of physical, psychosocial and spiritual suffering'[1]. Such high quality assessment requires the discussion of a range of end-of-life topics, such as diagnosis, prognosis, treatment preferences, and psycho-social and spiritual issues. End-of-life discussions enable health care professionals to recognize their patients' values and preferences and are an important step in the provision of care commensurate with patients' wishes[2]. Good end-of-life communication enhances patients' understanding of their condition and care and treatment options[2], facilitates informed participation in decision-making[2] and is repeatedly identified as important for patient and caregiver satisfaction with end-of-life care[3,4]. Sub-optimal communication, in contrast, may result in poor pain and symptom management[5], psychological and spiritual distress[6,7] and a lack of knowledge concerning patients' preferences[6]. Considering the centrality of communication in high quality end-of-life care, it is important to understand how often physicians discuss different end-of-life issues with patients and the factors that influence discussions.

There is, however, little evidence concerning the topics that are discussed between physicians and patients at the end of life and even less from a cross-country perspective. International comparisons draw attention to factors that are universally important and those that are country specific, highlight examples of 'best practice' and inform policy nationally and internationally. Previous cross-national research has been mostly limited to attitudinal or prevalence studies focusing on diagnosis, prognosis and treatment discussions[8-11]. These studies revealed differences between countries: differences that were ascribed to cultural, social and institutional influences[8-11]. Furthermore, a study by Cartwright et al.[12], estimated the topics that, in principle, physicians from Australia and six European countries discuss with patients at the end of life[12]. However, Cartwright et al.[12] did not examine the topics that were actually discussed with individual patients. There is, therefore, no cross-country empirical research on the actual prevalence of physician-patient discussion of end-of-life topics in Europe.

This study examines the prevalence of general practitioner (GP)-patient discussion of different end-of-life topics in Italy, Spain, Belgium and the Netherlands. GPs were chosen because, although complex cases are often referred for a time to specialist care, much end-of-life care is provided in primary care settings[13,14]. GPs' role in end-of-life care provision, together with related laws, policy and training, in each country, is detailed in Table 1.

Table 1. General Practitioners' role in palliative care provision: law, policy and training.

	Spain		Belgium	The Netherlands
Italy				
Law	Access to palliative care has been recognised as a right under Italian law since 2010[15].	Access to palliative care in primary and secondary settings has been recognised as a basic right under Spanish law since 2003[16].	Access to palliative care has been recognised as a right under Belgian law since 2002[17,18].	There is no specific legislation in the Netherlands with regard to access to palliative care. Access to palliative care however is covered by general legislation on health care insurance[19].
Policy	Palliative care featured in the Italian National Health Plan for 2011-2013[20]. The Plan acts as a guideline for regional authorities health care provision[21]. Furthermore, the National Collective Agreement for GPs includes care for the dying at home[21].	Spain has had a comprehensive National Palliative Care Strategy since 2007[22,23] and clinical practice guidelines for palliative care[24]. The Strategy acts as a guideline for autonomous communities. Most communities have developed their own palliative care plans[25]. There is consensus across autonomous communities on an organisational model of care: a basic level of palliative care is provided in primary settings whereas specialist care is provided for those with complex needs[25].	Belgium has had a comprehensive national palliative care plan since 2005[26,27]. In Belgium there is a policy focus on the provision of multidisciplinary palliative home care under the supervision of the GP rather than care in specialist settings[26,27].	In 2011, the Ministry for Health, Welfare and Sport issued a policy brief that stated that palliative care should be accessible for all those who need it[28]. The brief from the Ministry for Health Welfare and Sport stated that palliative care should principally be provided by primary care professionals[28]. There are also guidelines available for generalist end-of-life care provision[29].
Practice	In Italy, local health authorities autonomously plan and provide services, leading to variation [30]. In general, GPs have a role in the co-ordination and provision of palliative care in primary and home care settings. GPs co-ordinate and participate in primary care based home care teams[30,31] but not hospital based home care teams[30]. The 2010 law on access to care makes specific reference to the need for GP palliative care[32].	In Spain, each autonomous community plans and provides its own health care, leading to variation[33]. In both the Valencian community and Castile and León, primary care is the first level of access to palliative care. Care is provided by GPs in the primary or home care settings. Home support teams are also co-ordinated by the GP.	Belgian GPs often share the provision of palliative care with a multi-disciplinary home team (physicians, pharmacists, nurses, physiotherapists, psychologists and social workers)[34]. The GP however remains entirely responsible for the care and supervision of the patient[26,27].	Dutch GPs have a high degree of personal responsibility for end-of-life care provision[35]. Care is often provided solely by the GP or in consultation with a mobile palliative care consultation team[36].

	Italy	Spain	Belgium	The Netherlands
Training	<p>Palliative care is not a medical specialty in Italy[37], but has recently been recognised as an autonomous medical discipline[38]. Palliative care is not an obligatory part of undergraduate medical training and until recently there were no official postgraduate courses in palliative care, although there were some unofficial ones[21,37]. The 2010 law on access to care however outlined the need for postgraduate courses in palliative care[39]. Proposed masters courses suitable for GPs included the master degrees "Pain" (1 year) and "Palliative Care" (2 years)[32].</p>	<p>Palliative care is not a recognised medical specialty in Spain[37]. The need for palliative care education in undergraduate curricula is however recognized[40]. The National Strategy describes three levels of training: basic (20-40 hours), intermediate (40-80 hours) and advanced (Masters courses or 3 months in a PCU). The 2012 evaluation report of the Strategy states that intermediate training courses have mostly been directed at primary health professionals[41].</p>	<p>Palliative care is not a recognised medical specialty[37]. Palliative care is not an obligatory part of undergraduate medical training, however, GPs can undertake optional advance postgraduate courses[42].</p>	<p>Palliative care is not recognised as a medical specialty in the Netherlands[37]. Dutch medical students receive a small amount of palliative care education during their medical training[43], however GPs can choose to undertake further specialist palliative care training (<i>palliatieve kaderopleiding</i>).</p>

The study draws on data collected by representative GP networks as part of the European Sentinel Network Monitoring End-of-Life Care (EURO SENTI-MELC) project which aims to describe and compare care provided to patients in the last three months of life. Specific objectives of this study are: to estimate and compare the prevalence of GP-patient discussion of different end-of-life topics prior to patients' deaths in four European countries; and to analyse associations between discussions and patient and care characteristics for each country.

Methods

Study design and procedure

The study followed a cross-sectional, retrospective design. GPs from representative networks in each of the four countries recorded the demographic, health and care characteristics in the last three months of life of all practice patients who died using a standardized registration form. GPs registered deaths weekly from January 1st, 2009 to December 31st, 2010 except for Spanish GPs who registered deaths from January 1st, 2010 to December 31st, 2010. Participants were asked to include information received from hospital physicians and patient records. Completed forms were sent to national co-ordinating institutions. Received forms were checked for missing data, which were retrieved via telephone, if possible. Researchers entered data into SPSS (SPSS, Inc. Chicago. IL), double entering 5% of data as a quality check.

Settings and study population

Existing Spanish, Belgian and Dutch GP sentinel networks participated[44-47]. A sentinel network is a monitoring system based on a representative sample of health care professionals reporting all cases of one or more conditions to study disease prevalence and associated factors[46]. In Italy, a representative network of GPs was created specifically for this end-of-life surveillance in nine health districts[48]. To avoid selection bias, Italian GPs were unaware of the aim of the surveillance when recruited[48].

The nationwide Belgian and Dutch networks covered 1.75% and 0.8% of the population respectively. The Spanish network operated in two autonomous communities: Castile and León and the Valencian Community, covering 3.8% and 2.2% of the respective regional populations. The Italian network operated in nine local health districts and covered 4% of each district's population.

GPs were instructed to record the deaths of all patients aged older than 18 years. To include only patients who could have received end-of-life care, deaths registered as sudden and totally unexpected, or for which this information was missing, were

excluded. As the study examines patient-GP end-of-life discussions, only patients who could have received care from a GP in the last year of life were included. This was determined from the patient's main place of residence in the last year of life; Dutch nursing home residents, cared for by a specially trained elderly care physician, were excluded, as were patients whose main place of residence was 'unknown' or 'other' (these were often institutions outside of the GP's remit e.g. hospitals or psychiatric institutions). Comparing the data with national place of death data (excluding Dutch nursing home deaths in the Netherlands) verified the representativeness of all deaths (except for a slight underrepresentation of non-sudden hospital deaths and people younger than 65 years in Belgium, and women in the Netherlands)[48].

Measurement instrument

The 22 item 2009/2010 EURO SENTIMELC registration form contained questions on patients' demographic, health, and end-of-life care characteristics in the last three months of life (Appendix). Specific aspects of care included the main place of care, place of death, communication, palliative care provision and symptoms in the last week of life.

A question on whether the following topics had ever been addressed during the GP's conversations with the patient was included (Question 11, Appendix), namely primary diagnosis, incurability of disease, life expectancy, possible medical complications, physical complaints, psychological problems, social problems, spiritual/existential problems, options for palliative treatment and the possible burden of treatments.

Independent variables collected were: age; sex; cause of death; dementia diagnosis; main place of residence in the last year of life; place of death; average monthly number of contacts with the patient (face to face) in the second and third months before death; provision of palliative care by the GP (as defined by the GP); and the importance of curative, life-prolonging and palliative care as treatment aims in the second and third months before death (rated on a five-point Likert scale).

Most questions had been piloted and used in previous studies[44,45,49-53]. New questions were agreed collaboratively by all partners. The questionnaire underwent forward and backward translations from Dutch into English, from English into Italian and Spanish, and from Dutch into French. The final form was piloted in each country (minimum 10 GPs)[48].

Data analysis

Patient characteristics in each country were assessed using descriptive statistics. Differences between countries were assessed using Pearson's Chi-squared test. Prevalence of discussion of each topic was assessed using descriptive statistics. Differences between countries were examined using logistic regression analyses (controlling for variables that differed significantly in the Pearson's Chi-squared tests). The mean number of topics discussed was estimated per country and differences between countries were assessed using a Kruskal-Wallis test.

Multiple ordinal regressions were conducted separately by country to explore associations between patient and care characteristics and the discussion of end-of-life topics. The dependent variable was a score of topics discussed between the GP and the patient (possible scores between zero and 10). Ordinal regression takes into account the rank ordering of the 11-level score. Odds ratios from ordinal regressions provide an estimate of the odds for a unit increase when changing levels on the dependent variable scale.

Continuous variables (age and number of GP contacts) were converted into categorical variables. Cause of death was re-categorized as cancer or non-cancer. Furthermore, treatment aims were dichotomized: "important" and "very important" were separated from other responses. All analysis was carried out in SPSS version 18.

Results

A total of 6858 deaths were recorded. After the removal of sudden and totally unexpected deaths (n=2243), deaths for which this information was missing (n=97), Dutch nursing home residents (n=22) and patients with an 'unknown' (n=28) or 'other' (n= 72) main place of residence, the final sample consisted of 4396 deaths (Italy n=1808, Spain n=379, Belgium n=1556, the Netherlands n=653).

Sample characteristics

Although characteristics varied between countries, most deaths occurred in those aged older than 85 years (32-44%) and the most common cause of death was cancer (37-52%). Just less than a third of patients in Italy, Spain and Belgium had dementia (29-31%), compared with 13% of Dutch patients (Table 2). Approximately half of Italian, Spanish and Dutch patients died at home (44-50%), compared with under a quarter of Belgian patients (24%). A quarter to one-third of patients (24-32%) in the last week of life, and 8-20% of patients in the second and third months before death, had no contact with their GP.

GP-patient discussion of end-of-life topics

The mean number of end-of-life topics discussed between patients and GPs differed significantly between countries ($p<0.001$). On average, more topics were discussed in the Netherlands (mean=6.37), followed by Belgium (4.45), Spain (3.32) and Italy (3.19) (Graph 1).

Table 2. Patients' personal and care characteristics (n=4,396)*.

		IT n=1808	ES n=379	BE n= 1556	NL n=653	p value †
		n (%)	n (%)	n (%)	n (%)	
Age	<= 64	227 (13)	43 (11)	214 (14)	119 (18)	<0.001
	65 - 74	293 (16)	47 (12)	212 (14)	125 (19)	
	75 - 84	556 (31)	124 (33)	516 (33)	198 (30)	
	85>	732 (40)	165 (44)	602 (39)	211 (32)	
	Mean	79.6	80.5	79.0	77.0	
Sex	male	844 (47)	202 (53)	712 (46)	304 (47)	0.075
	female	964 (53)	177 (47)	840 (54)	342 (53)	
Cause of death	Cancer	820 (46)	147 (39)	581 (37)	339 (52)	<0.001
	Cardiovascular disease	371 (21)	63 (17)	226 (15)	101 (16)	
	Respiratory disease	129 (7)	53 (14)	168 (11)	50 (8)	
	Diseases of the nervous system	104 (6)	17 (5)	113 (7)	20 (3)	
	Stroke	177(10)	40 (11)	103 (7)	28 (4)	
	Other	163 (9)	56 (15)	363 (23)	112 (17)	
Dementia diagnosed	Yes	520 (29)	112 (31)	478 (31)	84 (13)	<0.001
	No	1262 (71)	255 (69)	1050 (69)	544 (87)	
Place of death	Hospital	697 (39)	124 (33)	556 (36)	171 (28)	<0.001
	Residential or care home	163 (9)	46 (12)	479 (31)	112 (18)	
	Home (incl. service flat) or with family	842 (47)	186 (50)	365 (24)	273 (44)	
	Palliative care unit/hospice	100 (6)	16 (4)	147 (10)	65 (10)	
	(Other n=41) §					
Average GP-patient monthly contacts in the second and third months before death	0	145 (8)	73 (19)	127 (8)	130 (20)	<0.001
	1 or 2	972 (54)	222 (59)	1227 (79)	369 (57)	
	3>	691 (38)	84 (22)	202 (13)	154 (24)	
GP provision of palliative care	Yes	995 (55)	232 (65)	787 (51)	374 (60)	<0.001
	No	807 (45)	126 (35)	768 (49)	251 (40)	

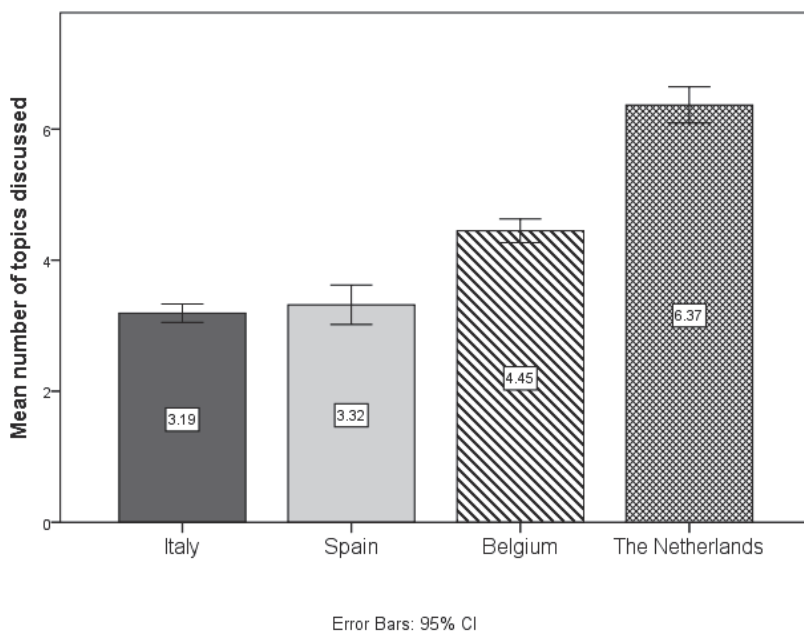
		IT n=1808	ES n=379	BE n= 1556	NL n=653	p value †
		n (%)	n (%)	n (%)	n (%)	
Curative treatment an important treatment aim	Yes	322 (18)	91 (24)	468 (31)	141 (24)	<0.001
	No	1449 (82)	288 (76)	1028 (69)	459 (76)	
Life prolongation an important treatment aim	Yes	747 (42)	91 (24)	573 (39)	165 (28)	<0.001
	No	1036 (58)	288 (76)	914 (61)	435 (72)	
Palliative care an important treatment aim	Yes	749 (42)	182 (48)	733 (51)	390 (65)	<0.001
	No	1022 (58)	197 (52)	714 (49)	212 (35)	

Valid percentage reported. Percentages have been rounded to whole numbers; therefore some totals are not exactly 100%.

* % of missing observations ranged from 0.3-4.5%

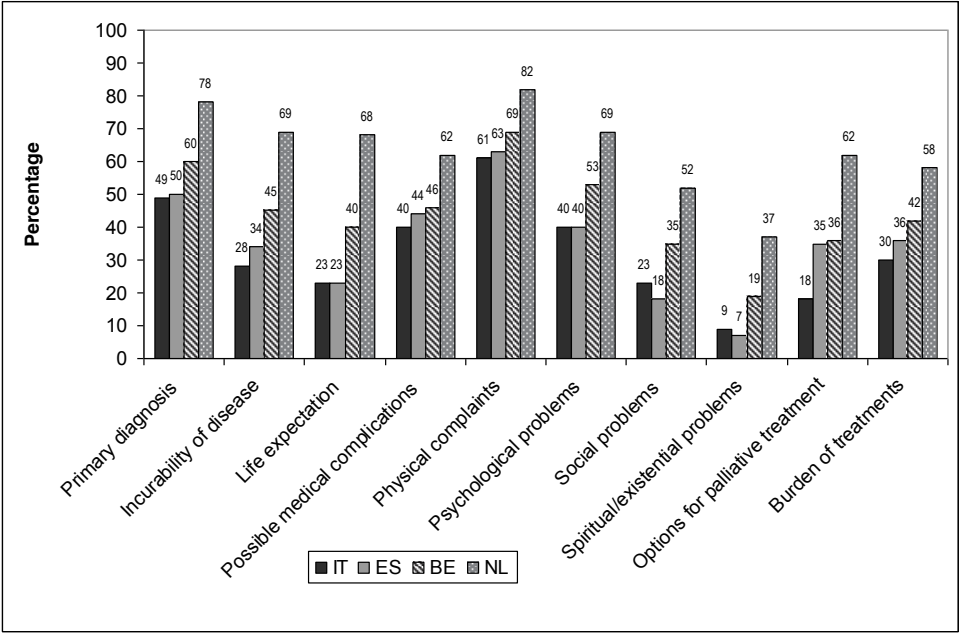
† test of association: Pearson's chi-sq

§ not included in statistical analyses



Graph 1. Mean number of topics discussed by country.

Discussion of all topics was most prevalent in the Netherlands, followed by Belgium then either Spain or Italy (depending on the topic; Graph 2). ‘Physical complaints’ was the most prevalent topic of discussion in all countries (61-82%). ‘Primary diagnosis’, the second most prevalent topic, was discussed with 49-78% of patients. The topic ‘spiritual and existential problems’ was least discussed (with 7-37% of patients). ‘Social problems’ was the second least frequently discussed topic in Spain, Belgium and the Netherlands (with 18%, 35% and 52% of patients respectively); whereas ‘options for palliative treatment’ was the second least frequent in Italy (with 18% of patients). Furthermore, the ‘incurability of disease’, ‘life expectation’, ‘medical complications’, ‘options for palliative treatment’ and the ‘burden of treatment’ were discussed with less than 50% of patients from all countries except for the Netherlands. In Italy and Spain, there was particularly low prevalence of GP-patient discussion about the ‘incurability of disease’ (28% and 34% respectively), ‘life expectation’ (23% in both countries) and ‘social problems’ (23% and 18% respectively) compared with the Netherlands and Belgium.



Graph 2. Prevalence of GP-patient discussion of end-of-life topics

Prevalence of discussion of each topic differed significantly between the four countries (Table 3). The odds of discussing each of the 10 topics were higher for Dutch and Belgian patients than Italian patients. There were no significant differences between Spain and Italy in the odds of discussion of four topics. The odds, however of

a Spanish patient having discussed the 'primary diagnosis', 'incurability of disease', 'medical complications', 'physical complaints', 'options for palliative treatment' and the 'burden of treatment' with their GP were significantly higher than those of an Italian patient.

Associations between the score of topics discussed and patient and care characteristics

Older age was negatively associated with the discussion of more end-of-life topics in Italy and Belgium. Also, in the Netherlands, the age groups 65-74 and 75-84 were associated with the discussion of more end-of-life topics compared with the group aged 85 years or older (Table 4).

Cancer as a cause of death was positively associated with the discussion of end-of-life topics compared with non-cancer deaths in all countries. Furthermore, diagnosis of dementia was negatively associated with the discussion of end-of-life topics compared to patients without dementia in all countries.

Place of death was associated with end-of-life discussions in Italy and Belgium. In Italy, dying at home was negatively associated with the discussion of end-of-life topics compared with hospital deaths, whereas, in Belgium, home and palliative care unit (PCU) deaths were positively associated with the discussion of end-of-life topics compared with hospital deaths. In addition, residential home deaths were negatively associated the discussion of end-of-life topics compared with hospital deaths in Belgium.

The personal provision of palliative care by the GP was positively associated with the discussion of end-of-life topics in Italy, Belgium and the Netherlands. Furthermore, more contact with the GP in the second and third months before death was positively associated with the discussion of end-of-life topics in Italy, Belgium and the Netherlands.

The identification of curative care as an important or very important treatment aim was positively associated with the discussion of end-of-life topics in Italy only. The identification of life prolongation as an important or very important treatment aim was positively associated with the discussion of end-of-life topics in Italy and the Netherlands. The recognition of palliative care as an important or very important treatment aim was positively associated with the discussion of end-of-life topics in all countries.

Table 3. GP-patient discussion of ten end-of-life topics (n=4,396)*.

End-of-life topic discussed	IT n=1808		ES n=379		BE n= 1556		NL n=653	
	n	Multivariable OR (CI) †	n	Multivariable OR (CI) †	n	Multivariable le OR (CI) †	n	Multivariable OR (CI) †
Primary diagnosis	880	1	172	1.38 (1.04, 1.84)	932	2.51 (2.01, 3.05)	498	5.11 (3.83, 6.80)
Incurability of disease	496	1	119	1.88 (1.40, 2.53)	701	3.62 (2.98, 4.40)	440	7.61 (5.85, 9.91)
Life expectation	422	1	77	1.18 (0.86, 1.63)	614	3.29 (2.70, 3.99)	431	8.96 (6.91, 11.62)
Possible medical complications	711	1	153	1.49 (1.13, 1.98)	712	1.75 (1.46, 2.10)	394	2.61 (2.05, 3.33)
Physical complaints	1087	1	222	1.41 (1.05, 1.89)	1065	2.27 (1.85, 2.79)	521	3.71 (2.73, 5.05)
Psychological problems	720	1	139	1.23 (0.94, 1.63)	822	2.30 (1.92, 2.75)	439	3.53 (2.76, 4.51)
Social problems	413	1	62	0.88 (0.63, 1.21)	550	2.47 (2.05, 2.97)	327	3.88 (3.08, 4.88)
Spiritual/existential problems	166	1	23	0.83 (0.52, 1.32)	299	2.80 (2.21, 3.56)	237	5.26 (4.03, 6.86)
Options for palliative treatment	326	1	119	4.65 (3.35, 6.46)	566	5.68 (4.51, 7.14)	394	12.44 (9.30, 16.63)
Burden of treatments	535	1	119	1.90 (1.41, 2.56)	647	2.54 (2.10, 3.07)	370	3.55 (2.78, 4.54)

Values for which p < 0.05 are highlighted in **bold**
 * % of missing observations ranged from 1.4-2.2%

† multivariable logistic regressions (forced enter). The dependent variable was if the topic had or had not been discussed.
 Independent variables included country (OR and CI shown), age, cause of death, dementia diagnosis, place of death, GP palliative care provision, the number of contacts with the GP in the last week and in the second and third months before death and the importance of curative, life-prolonging and palliative care as treatment aims. The results of the multivariable logistic regressions were compared with equivalent univariate analyses (not shown) to check for any major differences in the magnitude or direction of associations.

Table 4. Ordinal regression examining associations between patient and care characteristics and the discussion of more end-of-life topics.

		IT (n=1808)	ES (n=379)	BE (n= 1556)	NL (n=653)
		Multivariable OR (95% CI)†	Multivariable OR (95% CI)†	Multivariable OR (95% CI)†	Multivariable OR (95% CI)†
Age	<=64	1.96 (1.43, 2.68)	0.98 (0.47, 2.05)	1.89 (1.36, 2.65)	1.64 (0.96, 2.79)
	65-74	1.92 (1.45, 2.53)	0.91 (0.47, 1.79)	1.53 (1.11, 2.12)	2.45 (1.46, 4.12)
	75-84	1.23 (0.98, 1.53)	1.13 (0.70, 1.81)	1.33 (1.05, 1.68)	1.63 (1.07, 2.49)
	85+	1	1	1	1
Sex	Male	1.13 (0.94, 1.35)	1.05 (0.70, 1.57)	0.96 (0.79, 1.18)	0.87 (0.62, 1.20)
	Female	1	1	1	1
Cause of death	Cancer	1.46 (1.18, 1.81)	2.12 (1.31, 3.42)	2.03 (1.59, 2.58)	1.91 (1.31, 2.81)
	Non-cancer	1	1	1	1
Dementia diagnosed	Yes	0.16 (0.12, 0.20)	0.23 (0.14, 0.37)	0.20 (0.15, 0.25)	0.37 (0.22, 0.60)
	No	1	1	1	1
Place of death	Care home/ residential home	0.77 (0.54, 1.09)	0.66 (0.32, 1.37)	0.56 (0.42, 0.75)	0.62 (0.36, 1.08)
	Family or own home	0.71 (0.58, 0.87)	1.39 (0.87, 2.22)	1.25 (0.95, 1.65)	0.93 (0.57, 1.51)
	PCU or hospice	1.33 (0.90, 1.97)	1.17 (0.43, 3.16)	1.57 (1.10, 2.25)	1.64 (0.90, 2.97)
	Hospital	1	1	1	1
GP provided palliative care	Yes	1.67 (1.38, 2.02)	1.39 (0.89, 2.19)	1.75 (1.38, 2.21)	11.98 (7.68, 18.68)
	No	1	1	1	1
GP-patient 2nd- 3rd months before death	0	1	1	1	1
	1-2	1.36 (0.93, 1.98)	1.66 (0.96, 2.85)	2.64 (1.78, 3.90)	3.86 (2.43, 6.12)
	≥3	2.17 (1.48, 3.20)	1.39 (0.74, 2.63)	4.86 (3.06, 7.69)	6.43 (3.77, 10.96)
Importance of curative treatment	Likert scale 4-5	1.47 (1.15, 1.87)	1.33 (0.81, 2.18)	0.96 (0.76, 1.22)	0.89 (0.57, 1.38)
	Likert scale 1-3	1	1	1	1
Importance of life prolongation	Likert scale 4-5	1.37 (1.12, 1.66)	1.01 (0.61, 1.66)	1.36 (1.09, 1.69)	1.10 (0.73, 1.67)
	Likert scale 1-3	1	1	1	1
Importance of palliative care	Likert scale 4-5	1.50 (1.24, 1.81)	2.04 (1.35, 3.07)	1.28 (1.05, 1.57)	2.14 (1.50, 3.04)
	Likert scale 1-3	1	1	1	1

Values for which $p < 0.05$ are highlighted in **bold**

† multivariable ordinal regressions (forced enter). The dependent variable was a score of the number of topics discussed between the GP and the patient (possible scores between 0 and 10). Independent variables included: age; sex; cause of death; dementia diagnosis; place of death; GP provision of PC; the number of contacts with the GP in the second and third months before death; and the importance of curative, life-prolonging and palliative care as treatment aims. The results of the multivariable ordinal regressions were compared with equivalent univariate analyses (not shown) to check for any major differences in the magnitude or direction of associations. Results were also compared with univariate and multivariable logistic regressions for which dependent variables were “no topics discussed vs. any topic discussed” and “5 or less topics vs. more than 5 topics discussed” (analyses not shown) in order to check the robustness of the associations.

Discussion

This cross-national study maps the occurrence of end-of-life discussions related to 10 physical, psycho-social or spiritual issues and examines associated factors in the Netherlands, Belgium, Italy and Spain. The topics most frequently discussed in all countries were physical complaints and the primary diagnosis; spiritual and existential issues were the least frequently discussed. This is the first study to provide robust and comparable data on the prevalence of GP-patient end-of-life discussions with patients nearing death in the four countries.

Important between-country differences in the mean number of topics discussed and the prevalence of discussion of all topics were identified: a gradient from low prevalence in Italy to high prevalence in the Netherlands was revealed. However, despite these between-country differences, the overall associations between patient and care characteristics and the discussion of more end-of-life topics were remarkably similar across countries.

Topics discussed

The frequent discussion of 'physical complaints' and 'primary diagnosis' in all countries, compared with 'social problems' and 'spiritual and existential issues', reflects findings of cross-country attitudinal[12] and non-cross-country practice[44,45,54] surveys. Qualitative and survey studies examining patients' spiritual and psycho-social well-being at the end of life, however, report considerable unmet needs[55-58]. Physicians' avoidance of spiritual and social problems has been attributed to a lack of appropriate training, time pressure and difficulties identifying patients who wish to discuss spiritual issues[59-61].

Although some topics were more frequently discussed, most were still only discussed with less than half of patients from all countries except the Netherlands. Similarly, previous qualitative[62,63] and survey[64-66] studies have also found physician-patient end-of-life communication to be limited.

Between country differences

The greater discussion of end-of-life issues in the Netherlands, and to a lesser extent in Belgium, than other European countries has been partially attributed to the open public debate of all aspects of end-of-life care brought about by the process of legalization of euthanasia[67,68]. Dutch GPs are also said to have a discussion-led practice, prioritizing discussion of problems and associated psycho-social issues[69]. Less frequent end-of-life discussions in Italy and Spain, and to a lesser extent in Belgium, may also be partially explained by more limited diagnosis disclosure, hindering the discussion of other end-of-life topics[12,66,69-72]. Limited disclosure in Italy and Spain has been attributed to the greater importance given to beneficence than autonomy in clinical practice; physicians avoid discussions which cause patients distress and prioritise the maintenance of hope[71,73,74].

Between-country differences may also reflect country-specific differences in service organization. In the Netherlands, GPs have a high degree of personal responsibility for end-of-life care, which they provide alone or in consultation with a mobile palliative care team[28,36]. In Belgium and Spain however provision is more often shared with

palliative care home teams[30,33,34]. In Italy, multidisciplinary home teams provide most palliative care[30,75]. Italian GPs co-ordinate and provide palliative care in primary care-based home teams[30,31] but not in hospital-based teams[30] (Table 1). Access to and provision of end-of-life care is strongly supported by law or health care policy in the Netherlands, Belgium and Spain (Table 1). In contrast, access to palliative care only became a legal right in Italy in 2010[15] and, although palliative care is mentioned in the National Health Plan[20], there is no national strategy.

Finally, an additional explanation for the between country variation concerns physicians' training in palliative care. A survey of physicians from Belgium, Denmark, Italy, the Netherlands, Sweden and Switzerland revealed that 48%, 63% and 91% of Italian, Belgian and Dutch GPs, respectively, had ever had any specific palliative care training[76]. Training in palliative care is not, however, compulsory for GPs in any of the four countries, and the amount of training undertaken can vary greatly amongst GPs.

Patient and care characteristics

Although the frequency of end-of-life communication differed between countries, the overall significance, magnitude and direction of patient and care factors associated with discussions were remarkably similar. GPs from all countries tended to discuss fewer topics with older patients, non-cancer patients, patients diagnosed with dementia, patients for whom palliative care was not an important treatment aim and patients for whom the GP had not provided palliative care.

These findings resonate with those of previous studies: qualitative studies show that older patients receive less time and information during the patient-physician encounter[77,78]; survey studies reveal that dementia patients are less likely to receive timely end-of-life discussions[45,49]; and reviews of the literature highlight that patients suffering from non-malignant conditions receive less end-of-life information, primarily due to their less predictable illness trajectories and difficulties prognosticating the end-of-life phase[2,79].

The results also reflect broader problems of the recognition of palliative care needs and access to palliative care for older patients and those with non-malignant diseases[80,81]. Indeed, the most important care characteristics across the four countries associated with end-of-life discussions were GP palliative care provision and the importance of palliative care as a treatment aim. The effect of GP palliative care provision was particularly pronounced in the Netherlands and may reflect the greater individual responsibility Dutch GPs have in the provision of palliative care.

Strengths and limitations

More than 95% of the population in each of the four countries surveyed is registered with a GP[82,83] and registrations by representative GP networks provided a sample of non-sudden deaths. Furthermore, the retrospective, cross-sectional design enabled the identification of patients nearing the end of life, which is difficult if not infeasible in a prospective study[84]. The data were representative in terms of place of death when compared with national death certificate data. Cause of death was not compared because of concerns over the reliability of cause of death recording in death certificates[85,86]; place of death was considered a more objective measure. The use of an identical methodology in each country enabled direct comparison of data.

There are, however, several limitations. Although representative within those areas, the Spanish and Italian sentinel networks only covered specific regions. The Italian network was created especially for the end-of-life surveillance, therefore members were less familiar with the data collection procedure. The Spanish network collected data for one year only, resulting in a smaller sample and lower statistical power. Dutch nursing home residents were excluded from analyses and there was a slight underrepresentation of non-sudden hospital deaths and people aged younger than 65 in Belgium and women in the Netherlands. Some sudden deaths in hospitals may also have been missed by GPs in Spain and Italy. However, due to a lack of national data on place of death, this could not be tested.

Socially desirable answers may have been provided for items that reflect on GPs' care competencies; high levels of GP provision of palliative care were reported in all four countries. Furthermore, what is understood by 'palliative' care may differ not just between countries[87], but also amongst GPs[88]. It is not possible to discern whether the provision of 'palliative care' was, for example, understood as pain and symptom management or the holistic treatment of the patient's 'total pain', encompassing psycho-social and spiritual aspects of suffering. Other limitations include the lack of GPs' characteristics, possible recall bias and a reliance on GPs to report care in other settings (such as hospitals).

Moreover, the study only reports which topics were discussed, and, indeed, what constitutes a discussion, according to the GP. Patients and physicians may differ in their perception of what constitutes the 'discussion' of a certain topic. An issue reflected in previous research which has found that patients' and physicians' recall of topics discussed differs[89]. Patients may also have discussed some topics with other health, social or spiritual care professionals. This article does not, therefore, represent the totality of end-of-life communication with patients. The findings do, however,

support those of Cartwright et al[12] whose survey of physicians from a range of specialties (anaesthesiology, geriatrics, oncology, general practice etc.) found that all end-of-life topics were discussed, in principle, most by Dutch and least by Italian physicians.

Finally, the study only examines the prevalence of discussions and provides no information on the quality of discussions or patients' desire for such discussions. Surveys, such as this one, are appropriate tools for mapping large-scale variations between countries and over time. Such instruments can neither provide in-depth insights into the process of patient-physician communication, nor the expectations and experiences of the actors involved within the context of their social and cultural realities; this is the territory of qualitative rather than quantitative research. This epidemiological approach to the study of social phenomena can however reveal differences that deserve further investigation in future research of both a qualitative and quantitative nature.

Conclusions

Most end-of-life topics had been discussed with less than half of all patients in all countries, with the exception of the Netherlands. Dutch GPs discussed more topics on average and all topics more frequently than GPs from other countries. Across all four countries there was a particularly low prevalence of discussion of spiritual/existential and social problems. In order to improve the discussion of these topics it is essential that GPs are provided training on identifying and discussing spiritual and social problems.

GPs from all countries tended to discuss fewer topics with older patients, non-cancer patients, patients diagnosed with dementia, patients for whom palliative care was not an important treatment aim and patients for whom their GP had not provided palliative care. Due to cognitive decline in patients with dementia, and difficulties prognosticating the end-of-life phase for patients with non-malignant conditions, early and sensitive discussion of end-of-life issues is recommended.

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Appendix

REGISTRATION OF ALL DEATHS OF PATIENTS (aged 1 year or older) WHO <u>ARE PART</u> OF YOUR (GROUP) PRACTICE						
1. Your reference (e.g. initials) : 2. Date of birth : . . . / . . . / 3. Date of death : . . . / . . . / 2 0 1 0 4. Gender : <input type="checkbox"/> M <input type="checkbox"/> F 5. Postal code of patient's usual place of residence <input type="text"/> <input type="text"/> <input type="text"/>						
6. Where did the patient reside the longest in his/her last year of life? <input type="checkbox"/> at home or living with family <input type="checkbox"/> care home(nursing home/home for elderly persons) <input type="checkbox"/> other (namely)						
7. 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 only one cause per line. (a) Caused by : (b) Caused by : (c) Caused by : (d)						
<div style="border: 1px solid black; padding: 5px; display: inline-block;"> see instructions for examples </div>						
8. Did you or another doctor determine the diagnosis of dementia ? <input type="checkbox"/> yes, severe dementia <input type="checkbox"/> yes, mild dementia <input type="checkbox"/> no <input type="checkbox"/> unknown						
9a. 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.						
<div style="border: 1px solid black; padding: 2px;"> see instructions for examples </div> the last 3 months before death	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	elsewhere please specify	
	1 place of death and duration of stay	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days
	2 place of death and duration of stay	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days
	3 place of death and duration of stay	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days
	4 place of death and duration of stay	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days	<input type="checkbox"/> days
9b. To be filled in ONLY IF THE PATIENT WAS MOVED one or more times during the final three months of life: for what reason(s) was the patient moved to the place where s/he died? (More than one answer can be given) <input type="checkbox"/> it was the wish of the patient <input type="checkbox"/> it was the wish of the patient's family or significant other(s) <input type="checkbox"/> the patient needed (more) palliative care or palliative treatment(s) <input type="checkbox"/> the patient needed curative or life-prolonging treatment(s) <input type="checkbox"/> the patient did not need further treatment in that setting <input type="checkbox"/> other (please specify) :						
10. How often, on average, did you have contact (consultations, home visits, excl. telephone contact) with the patient or with significant others regarding the patient? <div style="display: flex; justify-content: space-around;"> <div style="text-align: center;"> last week before death . . . x per week </div> <div style="text-align: center;"> 2nd to 4th week before death . . . x per week </div> <div style="text-align: center;"> 2nd and 3rd month before death . . . x per month </div> </div>						
11. Were the following topics addressed during your conversations with the patient? yes no not applicable (1 answer per line) A primary diagnosis <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> B incurability of the illness <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> C life expectation <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> D possible medical complications <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> E physical complaints <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> F psychological problems (i.e., sadness, worry, fear) <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> G social problems (i.e., relationship problems, lack of social support from family/friends, family unable to accept situation, etc.) <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> H spiritual/existential problems (i.e., difficulty in accepting the situation, trouble with the meaning of life, angry at God, etc.) <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> I options for palliative care <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> J burden of treatments <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>						
12. How important do you think the following aspects were in the care of this patient? <div style="display: flex; justify-content: space-around; border: 1px solid black; padding: 2px;"> 1=not at all important 5=very important ?=unknown </div> <div style="display: flex; justify-content: space-around; margin-top: 5px;"> <div style="text-align: center;"> last week before death 1 2 3 4 5 ? </div> <div style="text-align: center;"> 2nd to 4th week before death 1 2 3 4 5 ? </div> <div style="text-align: center;"> 2nd and 3rd month before death 1 2 3 4 5 ? </div> </div> treatment aimed at cure 1 2 3 4 5 ? treatment aimed at prolonging life 1 2 3 4 5 ? treatment aimed at comfort/palliation 1 2 3 4 5 ?						
13. Within the last week of life, was the patient capable of making decisions? <input type="checkbox"/> yes <input type="checkbox"/> sometimes <input type="checkbox"/> no <input type="checkbox"/> unknown						

14a. Did **you** provide palliative care to this patient? ☐ yes, until death ☐ yes, but not until death ☐ no

14b. Which **palliative care initiatives** were involved in the last 3 months 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
☐ other (namely) :
☐ none
☐ unknown

14c. Estimate the number of days between the **first palliative intervention** and the moment of death days

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

15. How difficult was it for the **patient and his/her family** to cover the **costs** of the care in the last three months of the patient's life?
☐ very difficult ☐ somewhat difficult ☐ not difficult at all ☐ don't know ☐ patient did not need care

16. Did the **informal caregivers** feel **overburdened** (physically or emotionally) in the last three months of the patient's life?
☐ yes ☐ no ☐ don't know ☐ there were no informal caregivers

17. 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
☐ in hospital (excl. palliative care unit, and excl. nursing home unit in hospital)
☐ palliative care unit (hospital)
☐ elsewhere (namely) :
☐ NO

18. Did the **patient** ever express specific **wishes** about a 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

19. Did the **patient** ever express a **wish** about who was to make decisions regarding medical treatments or activities 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 ☐ unknown ☐ 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)

	Yes	No	Unknown	If YES, <u>how much</u> did that distress the patient?					
				not at all	a little bit	somewhat	quite a bit	very much	unknown
A lack of appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
B lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
C pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
D feeling drowsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
E constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
F dry mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
G difficulty breathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>

	Yes	No	Unknown	If YES, <u>how often</u> did the patient appear to feel this way?					unknown
				rarely	occasionally	frequently	almost constantly		
H feeling sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	<input type="checkbox"/>	<input type="checkbox"/>
I worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	<input type="checkbox"/>	<input type="checkbox"/>
J feeling irritable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	<input type="checkbox"/>	<input type="checkbox"/>
K feeling nervous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	<input type="checkbox"/>	<input type="checkbox"/>

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

22. Was the patient suffering from a life-threatening illness or condition (incl. coma) OR from serious health problems associated with old age?
☐ yes ☐ no

Chapter 3

End-of-life decisions: a cross-national study of treatment preference discussions and surrogate decision-maker appointments

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Published in *PLoS ONE* (2013), 8(3): e57965. doi:10.1371/journal.pone.0057965.

Abstract

Background Making treatment decisions in anticipation of possible future incapacity is an important part of patient participation in end-of-life decision-making. This study estimates and compares the prevalence of GP-patient end-of-life treatment discussions and patients' appointment of surrogate decision-makers in Italy, Spain, Belgium and the Netherlands and examines associated factors.

Methods A cross-sectional, retrospective survey was conducted with representative GP networks in four countries. GPs recorded the health and care characteristics in the last three months of life of 4,396 patients who died non-suddenly. Prevalences were estimated and logistic regressions were used to examine between country differences and country-specific associated patient and care factors.

Results GP-patient discussion of treatment preferences occurred for 10%, 7%, 25% and 47% of Italian, Spanish, Belgian and of Dutch patients respectively. Furthermore, 6%, 5%, 16% and 29% of Italian, Spanish, Belgian and Dutch patients had a surrogate decision-maker. Despite some country-specific differences, previous GP-patient discussion of primary diagnosis, more frequent GP contact, GP provision of palliative care, the importance of palliative care as a treatment aim and place of death were positively associated with preference discussions or surrogate appointments. A diagnosis of dementia was negatively associated with preference discussions and surrogate appointments.

Conclusions The study revealed a higher prevalence of treatment preference discussions and surrogate appointments in the two northern compared to the two southern European countries. Factors associated with preference discussions and surrogate appointments suggest that delaying diagnosis discussions impedes anticipatory planning, whereas early preference discussions, particularly for dementia patients, and the provision of palliative care encourage participation.

Introduction

The nature of the patient-physician relationship has changed considerably over the last forty years with patient autonomy and participation in decision-making increasingly recognised[1]. For patients receiving end-of-life (EoL) care, participation includes preparation for possible future incapacity.

The most well-known form of anticipatory decision-making is an advance directive. Advance directives are documents that outline treatments that a patient considers acceptable in the event that he or she can no longer communicate or that designate a surrogate decision-maker to make treatment choices on the patient's behalf[2]. Research indicates that, even in the US, where advance directives are actively promoted and legally binding, uptake amongst the general public remains low, at around 20%[3,4]. International studies and comparisons suggest even lower uptake[5,6].

Advance directives however are just one aspect of anticipatory decision-making. The cornerstone of this is rather the process of patient-physician discussion regarding EoL treatment decisions[7]. Therefore, measures of patient-physician discussions about treatment preferences or the informal and formal appointment of surrogate decision-makers may be more appropriate indicators of patients' involvement in treatment decisions than advance directive uptake[8,9]. Moreover, due to cross-country differences in legal status and use of advance directives, such measures are particularly appropriate for international comparisons[5,10].

Few studies have examined patient-physician EoL treatment preference discussions or patients' appointment of surrogate decision-makers (written and verbal). Furthermore, results of these studies are difficult to compare due to differences in study population and question formulation. Previous studies have focused on the discussion of specific treatments[11-13], formal surrogate appointments (legal guardians or power of attorney)[14,15] or on specific patient populations[11,14-16].

This study examines general practitioner (GP)-patient discussions of medical EoL treatment preferences and patients' appointment of surrogate decision-makers in Italy, Spain, Belgium and the Netherlands. The study draws on information from representative GP sentinel networks about patient care in the last three months of life. In the four countries, almost all patients are registered with a GP[17] and GPs are instrumental in the delivery and coordination of EoL care[18-22].

Specific objectives include: to estimate and compare the prevalence of GP-patient medical EoL treatment preference discussions and patients' appointment of surrogate decision-makers in four European countries; and to examine country specific factors associated with treatment preference discussions and surrogate appointments

Methods

Study design, setting and population

The study follows a cross-sectional, retrospective design. Participants from representative GP networks registered every patient death and described the patient and care characteristics using a standardised registration form.

In Spain, Belgium and the Netherlands, existing GP sentinel networks, used for epidemiological surveillance, took part in the study[18,20,23]. In Italy a network was created specifically for the study[24]. To avoid selecting GPs with a particular interest in EoL care, recruited GPs were not informed about the subject of the surveillance prior to participation[24].

In Belgium and the Netherlands the networks were nationwide and covered 1.75% and 0.8% of the population respectively. The Spanish network operated in two autonomous communities (Castile and León, and Valencia), covering 3.8% and 2.2% of the respective regional populations. The Italian network operated in nine local health districts and covered 4% of the population per health district. GPs registered deaths (aged 18 or older) from January 1st, 2009 to December 31st, 2010, apart from Spanish GPs who registered deaths from January 1st, 2010 to December 31st, 2010.

A total of 6,858 deaths were recorded. To include only patients who could have received EoL care, deaths registered as sudden and totally unexpected (n=2243), or for which this information was missing (n=97), were excluded. As the study concerns patient-GP discussions, only patients under their GP's care were included (patients resident in their own or a family member's home, or a care/residential home). Dutch nursing home patients, cared for by the nursing home physician, were excluded (n=22). Patients whose main place of residence was 'unknown' (n=28) or 'other' (often institutions outside the GP's care) (n= 72) were also excluded. The final sample consisted of 4,396 deaths (Italy n=1,808, Spain n=379, Belgium n=1,556, the Netherlands n=653). Comparing the data with national data on non-sudden deaths (excluding Dutch nursing home deaths in the Netherlands) verified representativeness of all deaths (except for a slight underrepresentation of non-sudden hospital deaths and people under the age of 65 in Belgium, and women in the Netherlands)[24].

Informed consent, patient anonymity and ethics approval

After being informed of the objectives and procedures of the study, participating GPs gave written informed consent at the beginning of each registration year. Strict procedures regarding patient anonymity were employed during data collection and entry; every patient received an anonymous reference code from their GP and any identifying patient and GP data (such as date of birth, postcode and GP identification number) were replaced with aggregate categories or anonymous codes.

In Belgium the protocol of the study was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (2004). In Italy, ethics approval for data collection was obtained from the Local Ethical Committee 'Comitato Etico della Azienda U.S.L. n. 9 di Grosseto', Tuscany (2008). Ethical approval was not required for posthumous collection of anonymous patient data in the Netherlands[25,26] or Spain[27-29].

Measurement instrument

The 2009/2010 EURO SENTI-MELC (European Sentinel Network Monitoring End-of-Life Care) form consisted of 22 structured questions about the patient's demographic, health, and care characteristics in the last three months of life. Participants were requested to include information from hospital physicians and patient records.

Discussion of treatment preferences was determined from the two-part question, "Did the patient ever express specific wishes about a medical treatment that he/she would or would not want in the final phase of life?" And, if yes, "Did you ever speak to the patient about these wishes?" The current article focuses on the second part of this question. With regard to surrogate decision-maker appointments, the registration form included the item, "Did the patient ever express a wish about who was to make decisions regarding medical treatments or activities in his/her place in the event he/she would no longer be able to speak for him/herself"?

The following independent variables, associated with anticipatory decision making in previous studies[20,30,31], were also collected: age; sex; cause of death; dementia diagnosis; residence in the last year of life; place of death; GP contacts; GP provision of palliative care (as defined by the GP); the importance of curative, life-prolonging and palliative care (on a 5-point Likert Scale); and whether the GP had discussed the primary diagnosis with the patient.

Most questions included in the registration form had been used in previous Dutch and Belgian studies[20,30,32] and had been subjected to extensive piloting[30,33]. New

questions were developed in collaboration with all partners. The final registration form underwent forward and backward translations from Dutch into English, from English into Italian and Spanish, and from Dutch into French and was piloted in each country (with 10 to 15 GPs)[24].

Data analysis

For each country, study population characteristics were assessed using descriptive statistics and differences between countries were assessed using Pearson's Chi-squared tests.

Prevalence of patient-GP treatment preference discussions and appointment of surrogate decision-makers were estimated per country using descriptive statistics. Differences between countries were examined using logistic regressions (controlling for study populations characteristics which differed significantly between countries).

Country specific factors associated with treatment preference discussions and surrogate appointments were examined through univariate and multivariable logistic regressions. Associations significant in univariate analyses were included in multivariable models. Stepwise backwards procedures were used (criteria for entry $p < 0.05$ and for removal $p > 0.1$) and residuals examined.

Continuous variables were transformed to be categorical (age, number of GP contacts). Cause of death was re-categorised as cancer or non-cancer. Furthermore, the treatment aims were dichotomised by combining "important" and "very important" in one category and other responses in another. All data analysis was carried out in SPSS version 18.

Results

Characteristics of the study population

Patient and care characteristics are shown in Table 1. The mean age of death was 80, 81, 79 and 77 for Italian, Spanish, Belgian and Dutch patients respectively. Although characteristics varied between countries, the most common cause of death was cancer (37-52%). Just under a third of patients in Italy, Spain and Belgium suffered from dementia (29-31%), compared with 13% of Dutch patients.

Table 1. Patients' personal and care characteristics (n=4,396)^a.

		IT	ES	BE	NL	p value ^b
		n=1808 n (%)	n=379 n (%)	n= 1556 n (%)	n=653 n (%)	
Age	<= 64	227 (13)	43 (11)	214 (14)	119 (18)	<0.001
	65 - 74	293 (16)	47 (12)	212 (14)	125 (19)	
	75 - 84	556 (31)	124 (33)	516 (33)	198 (30)	
	85>	732 (40)	165 (44)	602 (39)	211 (32)	
	Mean	79.6	80.5	79.0	77.0	
Sex	Male	844 (47)	202 (53)	712 (46)	304 (47)	0.075
	Female	964 (53)	177 (47)	840 (54)	342 (53)	
Cause of death	Cancer	820 (46)	147 (39)	581 (37)	339 (52)	<0.001
	Cardiovascular disease	371 (21)	63 (17)	226 (15)	101 (16)	
	Respiratory disease	129 (7)	53 (14)	168 (11)	50 (8)	
	Diseases of the nervous system	104 (6)	17 (5)	113 (7)	20 (3)	
	Stroke	177(10)	40 (11)	103 (7)	28 (4)	
	Other	163 (9)	56 (15)	363 (23)	112 (17)	
Patient diagnosed with dementia		520 (29)	112 (31)	478 (31)	84 (13)	<0.001
Place of death	Hospital	697 (39)	124 (33)	556 (36)	171 (28)	<0.001
	Residential or care home	163 (9)	46 (12)	479 (31)	112 (18)	
	Own or family home	842 (47)	186 (50)	365 (24)	273 (44)	
	PCU/hospice (Other n=41) ^c	100 (6)	16 (4)	147 (10)	65 (10)	
Number of GP-patient contacts in the week before death	0	475 (26)	123 (32)	366 (24)	162 (25)	<0.001
	1 or 2	786 (43)	149 (39)	768 (49)	173 (26)	
	3>	547 (30)	107 (28)	422 (27)	318 (49)	
Number of GP-patient contacts in the 2 nd and 3 rd month before death	0	145 (8)	73 (19)	127 (8)	130 (20)	<0.001
	1 or 2	972 (54)	222 (59)	1227 (79)	369 (57)	
	3>	691 (38)	84 (22)	202 (13)	154 (24)	
GP provided palliative care		995 (55)	232 (65)	787 (51)	374 (60)	<0.001
Treatment aim important or very important	Curative treatment	322 (18)	91 (24)	468 (31)	141 (24)	<0.001
	Life prolongation	747 (42)	91 (24)	573 (39)	165 (28)	<0.001
	Palliative care	749 (42)	182 (48)	733 (51)	390 (65)	<0.001
GP and patient had discussed the primary diagnosis		880 (49)	172 (50)	932 (60)	498 (78)	<0.001

^a % of missing observations ranged from 0.3-4.5%^b test of association: Pearson's chi-sq.^c not included in statistical analyses - Patients for whom the main place of care in the last year of life was reported as "other" and Dutch patients in nursing homes were excluded from the analysis for reasons described in the methods section.

Approximately half of the Italian, Spanish and Dutch patients died at home (44-50%), compared with under a quarter of Belgian patients (24%). 24-32% of patients in the last week of life, and 8-20% of patients in the second and third months before death had no contact with their GP. GPs however provided palliative care to 51-65% of patients.

Curative treatment was important in the care of 18-31% of patients, prolonging life in 24-49% of cases and palliative care in 42-65% of cases. GPs had discussed the primary diagnosis with 49% of Italian, 50% of Spanish, 60% of Belgian and 78% of Dutch patients.

Patient-GP discussion of medical EoL treatment preferences and patient appointment of a surrogate decision-maker

Table 2 shows the prevalence of treatment preference discussions and surrogate decision-maker appointments in the four countries.

A minority of patients from all countries (10-31%), except the Netherlands (52%), had either discussed treatment preferences or appointed a surrogate decision-maker. GP-patient discussion of treatment preferences had taken place with 10% of Italian, 7% of Spanish, 25% of Belgian and 47% of Dutch patients. Furthermore, 6% of Italian, 5% of Spanish, 16% of Belgian and 29% of Dutch patients had appointed (either verbally or in writing) a surrogate decision-maker.

Multivariable logistic regressions revealed a strong association between country and both treatment preference discussions and surrogate appointments. The odds of discussing treatment preferences with a GP were over six times higher for a Dutch patient, and almost four times higher for a Belgian patient, compared with an Italian patient. Similarly, the odds of appointing a surrogate decision-maker were over four times higher for a Dutch patient, and almost three times higher for a Belgian patient, than for an Italian patient. There were no significant differences in the odds of GP-patient discussion of treatment preferences or appointment of surrogate decision-makers between Italy and Spain. Surrogate appointment was entirely verbal in Italy and Spain and most frequently verbal in the Netherlands and Belgium.

Factors associated with discussion of a medical EoL treatment preference

Table 3 shows the factors associated with GP-patient discussion of EoL treatment preferences in univariate and multivariable analyses. The multivariable models revealed country specific associations. Diagnosis of dementia was negatively associated with treatment preference discussions in Belgium and the Netherlands.

Palliative care unit (PCU) deaths were positively associated with preference discussions compared with hospital deaths in Belgium. Furthermore, in Belgium, more frequent GP contact in the last week of life was positively associated with preference discussions, and in both Belgium and the Netherlands more frequent contact in the second and third months before death was positively associated with preference discussions. GP provision of palliative care was positively associated with preference discussions in all countries and the recognition of palliative care as an important/very important treatment aim was positively associated with preference discussions in Belgium. Previous GP-patient discussion of the primary diagnosis was positively associated with preference discussions in all countries.

Factors associated with patient appointment of a surrogate decision-maker

The factors associated with surrogate decision-maker appointments in univariate and multivariable analyses are presented in Table 4. Country specific associations were revealed in the multivariable models. Surrogate appointments were negatively associated with male patients in the Netherlands. In Spain PCU/hospice deaths were positively associated with surrogate appointments compared with hospital deaths.

More frequent patient-GP contact in the last week before death was positively associated with surrogate appointments for Belgium and the Netherlands. Furthermore, the importance of palliative care was positively associated with surrogate appointments in Belgium, the Netherlands and Spain. Previous discussion of the primary diagnosis between the patient and the GP was positively associated with surrogate appointments in all four countries.

Discussion

These data reveal that a minority of patients from all countries, with the exception of the Netherlands, had either discussed treatment preferences or appointed a surrogate decision-maker. Furthermore, there are important cross-country differences in prevalence of discussions and surrogate appointments, which were highest in the Netherlands, followed by Belgium, with no significant differences between Spain and Italy. Prior GP-patient discussion of the primary diagnosis was strongly associated with treatment preferences discussions and with surrogate appointments in all countries.

Table 2 The prevalence of patient-GP communication about medical EoL treatment preferences and patient appointment of a surrogate decision-maker (n=4,396)^a.

	IT n=1808		ES n=379		BE n=1556		NL n=653	
	n (%)	Multivariable OR (CI) ^b	n (%)	Multivariable OR (CI) ^b	n (%)	Multivariable OR (CI) ^b	n (%)	Multivariable OR (CI) ^b
Patient either discussed a treatment preference or appointed a surrogate	234 (13)	1	37 (10)	0.80 (0.54, 1.20)	487 (31)	3.53 (2.84, 4.39)	339 (52)	6.02 (4.64, 7.81)
Patient discussed a medical EoL treatment preference with their GP	173 (10)	1	26 (7)	0.83 (0.52, 1.33)	394 (25)	3.80 (2.99, 4.83)	304 (47)	6.44 (4.88, 8.50)
Patient appointed a surrogate decision-maker	110 (6)	1	20 (5)	0.93 (0.55, 1.57)	244 (16)	2.78 (2.12, 3.64)	187 (29)	4.48 (3.32, 6.05)
Manner of surrogate appointment	105 (6)	1	19 (5)	0.97 (0.57, 1.65)	191 (12)	2.15 (1.62, 2.86)	128 (20)	2.87 (2.08, 3.97)
In writing	4 (0)	c	1 (0)	c	53 (3)	c	53 (8)	c

^a % of missing observations ranged from 0.3-1.2%

^b multivariable logistic regressions (forced enter). Dependent variables were 'Patient did not discuss a medical EoL preference with GP or appoint a surrogate decision-maker'; 'Patient discussed a medical EoL preference'; 'Patient appointed a surrogate decision-maker'; 'Patient appointed a surrogate decision-maker in writing'; and 'Patient only appointed a surrogate decision-maker verbally'. Independent variables included country (OR and p-value shown), age, cause of death, dementia diagnosis; place of death; the number of contacts with the GP in the last week and in the second and third months before death; GP palliative care provision; the importance of curative, life-prolonging and palliative care as treatment aims and if the GP had discussed the primary diagnosis. The results of the multivariate logistic regressions were compared with equivalent univariate analyses (not shown) to check for any major differences in the magnitude or direction of associations.

^c Too few patients in this category to conduct a logistic regression

Table 3 Characteristics associated with a patient having discussed a medical EoL treatment preference with their physician in univariate and multivariable analyses (n=4,396)^a.

<i>Preference discussed</i>	IT (n=1808)			ES (n=379)			BE (n= 1556)			NL (n=653)		
	Logistic regression ^b			Logistic regression ^b			Logistic regression ^b			Logistic regression ^b		
	Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)	
<i>Age</i>												
<= 64	2.37 (1.48, 3.79)	d		4.32 (1.19, 15.71)	d		1.71 (1.22, 2.42)	d		1.14 (0.72, 1.79)	c	
65 - 74	2.27 (1.46, 3.52)			4.68 (1.36, 16.11)			1.44 (1.01, 2.04)			1.34 (0.86, 2.09)		
75 - 84	1.38 (0.92, 2.08)			2.81 (0.93, 8.43)			1.06 (0.80, 1.40)			1.03 (0.70, 1.53)		
85>	1			1			1			1		
<i>Sex</i>												
Male	1.24 (0.90, 1.69)	c		1.03 (0.46, 2.29)	c		1.10 (0.88, 1.39)	c		0.73 (0.54, 1.00)	c	
<i>Cause of death</i>												
Respiratory disease	1	d		1	c		1	d		1	d	
Cardiovascular disease	1.05 (0.50, 2.21)			0.83 (0.16, 4.31)			2.04 (1.23, 3.41)			1.31 (0.64, 2.68)		
Cancer	1.71 (0.87, 3.37)			1.91 (0.53, 6.88)			3.14 (2.00, 4.93)			2.42 (1.29, 4.53)		
Diseases of the nervous system	0.73 (0.26, 2.08)			1.04 (0.10, 10.73)			0.97 (0.50, 1.88)			0.98 (0.33, 2.93)		
Stroke	0.56 (0.22, 1.47)			0.43 (0.04, 4.27)			0.79 (0.39, 1.62)			0.32 (0.09, 1.07)		
Other	1.12 (0.48, 2.61)			0.94 (0.18, 4.89)			1.19 (0.73, 1.96)			1.14 (0.56, 2.32)		
<i>No dementia</i>	3.64 (2.23, 5.93)	d		3.62 (1.06, 12.31)	d		4.18 (3.03, 5.78)	d		3.04 (1.80, 5.13)	2.28 (1.18, 4.44)	
<i>Place of death</i>												
Hospital	1	c		1	c		1	1		1	d	
Residential or care home	0.82 (0.44, 1.52)			e			0.84 (0.61, 1.15)	0.96 (0.62, 1.49)		3.32 (1.98, 5.56)		
Own or family home	1.03 (0.73, 1.45)			2.69 (0.98, 7.39)			3.09 (2.30, 4.16)	1.71 (1.15, 2.53)		5.83 (3.77, 9.00)		
PCU/hospice	0.93 (0.45, 1.93)			1.57 (0.17, 14.39)			2.39 (1.61, 3.56)	1.93 (1.22, 3.04)		2.42 (1.32, 4.44)		

Preference discussed	IT (n=1808)			ES (n=379)			BE (n= 1556)			NL (n=653)		
	Logistic regression ^b			Logistic regression ^b			Logistic regression ^b			Logistic regression ^b		
	Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)	
Number of GP-patient contacts												
Last week before death												
0	1	1	1	1	d		1	1	1	1	1	
1 or 2	0.86 (0.55, 1.33)	0.80 (0.50, 1.26)		2.16 (0.66, 7.05)			1.67 (1.20, 2.32)	1.71 (1.14, 2.55)	2.28 (1.38, 3.77)	0.93 (0.47, 1.86)		
3>	2.12 (1.41, 3.19)	1.53 (0.97, 2.39)		3.76 (1.17, 12.03)			3.37 (2.38, 4.76)	2.93 (1.81, 4.75)	8.47 (5.36, 13.39)	1.88 (0.94, 3.75)		
Second and third months before death												
0	1	d		1	d		1	1	1	1	1	
1 or 2	1.79 (0.81, 3.96)			0.47 (0.16, 1.37)			1.89 (1.13, 3.17)	1.78 (0.90, 3.51)	2.25 (1.46, 3.47)	2.09 (1.13, 3.84)		
3>	2.77 (1.25, 6.11)			1.71 (0.60, 4.87)			4.10 (2.31, 7.27)	2.36 (1.13, 4.95)	3.38 (2.06, 5.56)	2.04 (1.04, 3.99)		
GP provided palliative care	2.59 (1.81, 3.69)	2.07 (1.40, 3.07)		4.53 (1.33, 15.41)	4.96 (1.43, 17.25)		2.27 (1.79, 2.88)	1.54 (1.11, 2.14)	8.81 (6.00, 12.93)	4.40 (2.57, 7.54)		
Care aim												
important or very important												
Curative treatment	0.84 (0.55, 1.30)		c	1.18 (0.48, 2.89)		c	0.64 (0.49, 0.83)		d	0.84 (0.57, 1.23)	c	
Life prolongation	0.80 (0.58, 1.10)		c	0.75 (0.27, 2.04)		c	0.88 (0.69, 1.12)		c	0.88 (0.61, 1.25)	c	
Palliative care	1.65 (1.20, 2.26)		d	2.17 (0.94, 4.99)		c	1.68 (1.32, 2.14)	1.45 (1.09, 1.93)	2.42 (1.71, 3.43)		d	
Diagnosis discussed	8.40 (5.31, 13.28)	7.47 (4.71, 11.87)		29.45 (3.94, 220.01)	28.59 (3.81, 214.63)		7.22 (5.22, 10.00)	4.66 (3.13, 6.94)	11.15 (6.33, 19.63)	5.66 (2.51, 12.75)		
Values for which p<0.05 are highlighted in bold .												
^a 0.3-4.5% of values for each characteristic were not provided by the GP (missing values)												
^b Backwards stepwise logistic regression - dependent variable 'Patient discussed a medical EoL preference with their GP'												
^c No patients in the category had discussed a medical EoL preference with their GP (odds ratio of 0)												
^d Removed during logistic regression												

Table 4 Characteristics associated with patients' appointment of a surrogate decision-maker by country in univariate and multivariable analyses (n=4,396)^a.

<i>Surrogate appointed</i>	IT (n=1808)			ES (n=379)			BE (n=1556)			NL (n=653)		
	Logistic regression ^b			Logistic regression ^b			Logistic regression ^b			Logistic regression ^b		
	Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)	
<i>Age</i>												
<= 64	1.20 (0.64, 2.25)	c		1.25 (0.24, 6.44)	c		1.12 (0.74, 1.68)	c		1.13 (0.69, 1.85)	c	
65 - 74	1.55 (0.91, 2.65)			3.13 (0.91, 10.77)			0.73 (0.46, 1.16)			1.11 (0.68, 1.80)		
75 - 84	1.22 (0.76, 1.96)			1.56 (0.51, 4.77)			0.86 (0.62, 1.19)			0.97 (0.63, 1.50)		
85>	1			1			1			1		
<i>Sex</i>												
Male	1.25 (0.85, 1.83)	c		1.30 (0.52, 3.26)	c		0.96 (0.73, 1.26)	c		0.54 (0.38, 0.77)	0.43 (0.28, 0.65)	
<i>Cause of death</i>												
Respiratory disease	1	c		1	c		1	d		1	c	
Cardiovascular disease	0.93 (0.35, 2.42)			1.37 (0.22, 8.51)			1.22 (0.71, 2.11)			1.19 (0.54, 2.62)		
Cancer	1.65 (0.70, 3.89)			1.89 (0.40, 8.92)	e		1.33 (0.83, 2.13)			1.61 (0.81, 3.21)		
Diseases of the nervous system	0.82 (0.23, 3.00)						0.87 (0.44, 1.73)			0.88 (0.24, 3.19)		
Stroke	1.34 (0.48, 3.74)				e		0.48 (0.21, 1.11)			0.56 (0.16, 1.95)		
Other	1.46 (0.53, 4.06)			2.55 (0.47, 13.76)			0.83 (0.49, 1.40)			0.89 (0.40, 1.97)		
<i>No dementia</i>	1.60 (1.00, 2.56)	c		1.32 (0.47, 3.73)	c		1.30 (0.96, 1.77)	c		1.85 (1.04, 3.29)	d	
<i>Place of death</i>												
Hospital	1	d		1	1		1	d		1	d	
Residential or care home	0.51 (0.20, 1.30)			e	e		1.19 (0.83, 1.70)			2.20 (1.23, 3.94)		
Own or family home	1.11 (0.73, 1.69)			1.52 (0.51, 4.48)			1.76 (1.23, 2.52)			3.34 (2.07, 5.40)		
PCU/hospice	1.41 (0.64, 3.11)			9.44 (2.18, 40.84)			1.96 (1.23, 3.12)			1.99 (1.00, 3.93)		
				12.49 (2.54, 61.49)								

Surrogate appointed	IT (n= 1808)			ES (n= 379)			BE (n= 1556)			NL (n= 653)		
	Logistic regression ^b			Logistic regression ^b			Logistic regression ^b			Logistic regression ^b		
	Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)		Univariate OR (95% CI)	Multivariable OR (95% CI)	
Number of GP-patient contacts												
Last week before death												
0	1	d		1	c		1	1		1	1	
1 or 2	1.03 (0.62, 1.73)			1.21 (0.42, 3.49)			1.90 (1.26, 2.87)	1.86 (1.20, 2.89)		1.22 (0.64, 2.36)	0.57 (0.26, 1.23)	
3>	1.69 (1.01, 2.82)			0.91 (0.27, 3.06)			2.99 (1.95, 4.59)	3.14 (1.99, 4.95)		6.43 (3.75, 11.02)	3.27 (1.74, 6.15)	
Second and third months before death												
0	1	c		1	c		1	d		1	d	
1 or 2	1.59 (0.63, 4.05)			1.06 (0.28, 3.96)			1.72 (0.93, 3.17)			2.77 (1.58, 4.84)		
3>	2.23 (0.88, 5.70)			2.00 (0.50, 8.05)			2.83 (1.43, 5.58)			4.28 (2.34, 7.84)		
GP provided palliative care	1.53 (1.02, 2.28)	d		2.11 (0.69, 6.50)	c		1.66 (1.25, 2.19)	d		3.93 (2.60, 5.95)	d	
Care aim												
important or very important												
Curative treatment	0.89 (0.53, 1.49)	c		1.03 (0.36, 2.91)	c		0.87 (0.64, 1.18)	c		0.75 (0.49, 1.15)	c	
Life prolongation	1.07 (0.72, 1.58)	c		1.71 (0.66, 4.43)	c		1.09 (0.82, 1.45)	c		0.72 (0.48, 1.08)	c	
Palliative care	1.78 (1.21, 2.63)	1.67 (1.12, 2.48)		1.60 (0.64, 4.00)	c		1.54 (1.15, 2.04)	1.49 (1.11, 2.01)		2.38 (1.60, 3.55)	1.62 (1.02, 2.57)	
Diagnosis discussed	2.15 (1.43, 3.23)	1.92 (1.27, 2.89)		5.74 (1.64, 20.09)	5.68 (1.58, 20.37)		2.69 (1.95, 3.71)	2.56 (1.83, 3.58)		5.98 (3.14, 11.38)	5.37 (2.31, 12.49)	
Values for which p < 0.05 are highlighted in bold .												
^a 0.3-4.5% of values for each characteristic were not provided by the GP (missing values)												
^b Backwards stepwise logistic regression - dependent variable 'Patient had appointed a surrogate decision-maker'												
^c Not entered into logistic regression												
^d Removed during logistic regression												
^e No patients in the category had appointed a surrogate decision-maker (odds ratio of 0)												

Differences between countries

There are notable differences between northern and southern European countries with a lower prevalence of treatment preference discussions and surrogate appointments in Italy and Spain. Considering the strong association between discussion of the primary diagnosis and both preference discussions and surrogate appointments, these cross-country differences are likely to be linked to lower levels of primary diagnosis discussion in Italy and Spain compared with the Netherlands and Belgium. Previous studies have also reported limited disclosure[9,31,34,35] and discussion of EoL treatment preferences[11,36] in the two southern European countries.

Meñaca et al[9], in a review of EoL care and culture in Italy, Spain and Portugal, highlighted the influence of Catholicism on disclosure of diagnoses and prognoses. Catholic teaching permits the gradual disclosure of “truth” to terminal patients in a way that does not destroy hope[37]. Meñaca[9] also found that although advance directives have a strong legal status in Spain (in contrast to Italy) in practice physicians are more guided by the principle of beneficence[9]. In Italy, it has been suggested that physicians’ concern about distress caused by EoL treatment discussions leads them to delay or avoid such discussions[37].

Belgium, in contrast, although nominally Catholic, has more in common with the Netherlands. The process of legalization of euthanasia in both countries engendered open public debate on EoL issues[5,38]. A higher frequency of anticipatory decision-making in the Netherlands and Belgium may therefore be expected considering the importance of self-determination and the open discussion of death and dying. This is especially true in the Netherlands, where patients prioritize autonomy and control in the dying process[39,40]. Cross-country studies have repeatedly found that Dutch physicians’ more frequently discuss EoL issues than their European counterparts[13,41,42].

Family members’ opposition to full-disclosure of primary diagnosis, the so called “conspiracy of silence”, has also been said to contribute to low levels of disclosure in both Italy and Spain[9]. A lack of disclosure and subsequent EoL discussions may also impact patients’ appointment of surrogate decision-makers. Equally, such appointments may be deemed unnecessary if family members are considered *de facto* proxies. This may contribute to the lower prevalence of surrogate appointments compared with preference discussions in all countries, particularly in Spain and Italy, which are often seen as more family orientated.

An additional consideration concerns patients' wishes for information. A systematic review of EoL communication reported that studies from northern European countries report higher levels of desired information amongst patients than studies from the south of Europe[43]. Although the desire for diagnosis and prognosis information may not be as common amongst patients and the general public in Italy and Spain compared to northern European countries; in general, the proportion reported to prefer full disclosure is still greater than the proportion that receives full disclosure in clinical practice[9,44].

A GP's responsibility for EoL care also varies between the four countries. In the Netherlands there is a strong focus on GP EoL care provision: GPs are primarily responsible for generalist EoL care provision and have easy access to palliative care guidelines and consultation[45,46]. In Belgium, Spain and Italy however provision is more often shared with palliative care home teams[21,47,48]. Furthermore GPs have a 'gatekeeper' role (coordinating all referrals to specialist services) in the Netherlands and Spain, but not in Belgium and Italy.

A further explanation for the strong cross-country differences lies in the amount of palliative care training physicians receive. A survey of physicians from Belgium, Denmark, Italy, the Netherlands, Sweden and Switzerland revealed that the percentage of physicians who had undertaken formal palliative care training was lowest in Italy and highest in the Netherlands[49]. Palliative care training may improve EoL communication skills and may contain specific EoL communication training.

Country specific factors associated with treatment preference discussions and surrogate appointments

A number of patient and care characteristics were associated with treatment preferences discussions. As mentioned previously GP-patient discussion of the primary diagnosis was strongly associated with both treatment preferences and surrogate appointments. In addition, dementia diagnosis was associated with less frequent discussion of treatment preferences in Belgium and the Netherlands. Timely discussions are a priority for patients with dementia. A related issue is the early diagnosis of dementia. Research shows that 50-66% of patients with dementia are not diagnosed with the condition by primary care physicians[50]. GPs are recommended to begin preference discussions as soon as mental capacity decline is detected.

Frequency of contact with GPs, GP provision of palliative care and the importance of palliative care as a treatment aim were also associated with preference discussions and surrogate appointments.

Palliative care unit and home deaths were associated with treatment preference discussions in Belgium. This may reflect an emphasis on palliative home care in Belgium[5] and discussion of preferences in the palliative care sector. In Spain, surrogate appointment was associated with PCU and hospice deaths. Indeed, for Spain, 'place of death' was strongly associated with surrogate appointments in the multivariable model; suggesting that, for Spanish patients, surrogate appointment is specifically related to specialist inpatient palliative care.

Interestingly, in the Netherlands patient surrogate appointment was more frequent amongst female patients. This may indicate a greater reluctance amongst GPs to discuss surrogate appointments with male patients or of male patients to assign decision-making responsibilities. Men are also more likely to have a living partner, so may feel less need to appoint a surrogate decision-maker[51]. Why this should only be significant in the Netherlands and not the other countries is, however, unclear.

Strengths and limitations

This is the first study to estimate the prevalence of medical EoL treatment discussions and patients' appointment of surrogates in the Netherlands, Belgium, Italy and Spain. The use of the same study design amongst representative GP sentinel networks in each country provided robust and comparable data. Bias was avoided by selecting GPs with no specific interest in EoL care. Most people in each country are registered with a GP, and the sentinel networks aim to be representative for age, gender and population density. The retrospective, cross-sectional design enabled the identification of patients nearing death.

The study was, however, subject to a number of limitations. Although GPs completed registration forms on a weekly basis, there may have been some recall bias. In addition, GPs may have provided socially desirable answers especially concerning items that reflect on their own care competencies; particularly high levels of GP provision of palliative care for example were reported in all four countries. Furthermore, the study reports the discussion of treatment preferences according to the GP. Patients and physicians may differ in their perception of what constitutes the "discussion" of treatment preferences and patients may have discussed preferences with other health professionals.

The Spanish and Italian sentinel networks were not nationwide, although they were representative of the areas they covered (Italy was representative for the largest statistical regions). Dutch nursing home residents were excluded from analyses and there was a slight underrepresentation of non-sudden hospital deaths and people under the age of 65 in Belgium and a slight underrepresentation of females in the Netherlands. Some sudden deaths in hospitals may also have been missed by GPs in Spain and Italy. However, due to a lack of national data on place of death, this could not be tested. The survey also relied on GPs to report care in other settings, although GPs were asked to maximize information from other sources. In addition, GPs' characteristics were unavailable; preventing examination of associations with GP characteristics.

Finally, the study only examines the prevalence of treatment preference discussions and surrogate appointments and some associated factors. Further qualitative research on the patient-physician communication process may help in understanding the complex reasons for between country differences.

Conclusions

Discussion of both medical EoL treatment preferences and surrogate appointments were highest in the Netherlands, followed by Belgium, with no significant differences between Spain and Italy. A number of factors related to the discussion of the primary diagnosis, patient's mental capacity and specialist or generalist palliative care were associated with treatment discussions and surrogate appointments.

These findings suggest that the process of planning for the EoL often starts with the discussion of the primary diagnosis: if avoided or delayed, opportunities for patient participation in decision-making may be missed. Communication training for physicians can help change attitudes towards diagnosis disclosure[52,53]. Ideally training would also highlight the right of a patient not to receive such information if he or she so wishes; such a preference however must be stated by the patient and not assumed *a priori* by the physician.

Furthermore, early preference discussions for all patients, particularly those with dementia or cognitive decline, and the provision of palliative care support patients' participation in EoL decision-making.

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Chapter 4

Older patients' attitudes towards and experiences of patient-physician end-of-life communication: a secondary analysis of interviews from British, Dutch and Belgian patients

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Published in *BMC Palliative Care* (2013), **11**:24.

Abstract

Background: Older patients often experience sub-standard communication in the palliative phase of illness. Due to the importance of good communication in patient-centred end-of-life care, it is essential to understand the factors that influence older patients' communication with physicians. This study examines older patients' attitudes towards, and experiences of, patient-physician end-of-life (EoL) communication in three European countries.

Methods: A secondary analysis of interviews from British, Dutch and Belgian patients over the age of 60 with a progressive terminal illness was conducted. Cross-cutting themes were identified using a thematic approach.

Results: Themes from 30 interviews (Male n=20, Median age 78.5) included: confidence and trust; disclosure and awareness; and participation in decision-making. Confidence and trust were reinforced by physicians' availability, time and genuine attention and hindered by misdiagnoses and poor communication style. Most participants preferred full disclosure, though some remained deliberately ill-informed to avoid distress. Patients expressed a variety of preferences for and experiences of involvement in medical EoL decision-making and a few complained that information was only provided about the physician's preferred treatment.

Conclusions: A variety of experiences and attitudes regarding disclosure and participation in decision-making were reported from each country, suggesting that communication preferences are highly individual. It is important that physicians are sensitive to this diversity and avoid stereotyping. In regard to communication style, physicians are advised to provide clear explanations, avoid jargon, and continually check understanding. Both the 'informed' and the 'shared' patient-physician decision-making models assume patients make rational choices based on a clear understanding of treatment options. This idealized situation was often not reflected in patients' experiences.

Background

The majority of deaths in Europe occur over the age of 65. However, the needs of older patients are often neglected during end-of-life (EoL) care[1]. Older patients have less access to specialist palliative care services than younger patients and are more likely to have their treatment needs under-assessed[1, 2]. Patients and carers frequently identify communication as one of the most important aspects of good EoL care[3, 4]. There is however evidence that older patients are given less time during the physician-patient interview[5], are provided less information on their diagnoses and prognoses[2, 6] and are less likely to discuss their EoL preferences[2, 7].

Sub-standard communication is both a cause and an outcome of poor EoL care. Poor communication affects physicians' ability to recognize patients' palliative care needs and make referrals to specialist services[2]. Furthermore, poor patient-physician communication influences patients' understanding of their advanced condition, participation in treatment decisions and satisfaction with services[3, 4, 8]. These issues might be pertinent for all patients however they are particularly relevant for older patients whose characteristics suggest specific communication needs. For example, generational differences in communication style mean that older patients may afford physicians more respect and be less likely to question their judgments than other patient groups[5]. Older patients also suffer more multiple morbidities, leading to greater health care needs[1], and are more likely to suffer from impaired cognitive functioning.

Due to the importance of good patient-physician communication in EoL care, it is essential to understand the factors that influence communication between older patients and physicians. European surveys that explore patient-physician communication and participation in decision-making at the EoL have revealed that country of residence is a strong determinant of practices and attitudes[9-12]. For instance, surveys mapping physicians' actual and intended discussion with patients on a number of EoL issues have found significant cross-country differences, such as more frequent discussions in the Netherlands and less frequent discussions in Italy than other European countries[9-11] (the United Kingdom (UK) was not included in these surveys). These between country differences were attributed to cultural factors[9-11]. Culture, a term which has been variously defined but which the authors understand as 'a system of shared ideas and meanings that underlie, influence and structure the ways in which people think and act in practical situations'[13], influences both the content and the process of patient-physician communication. Culture shapes patients' and physicians' expectations concerning accepted patterns of communication, defined roles of the physician and the patient and topics discussed[14].

Although surveys are excellent for mapping differences in practices and attitudes across Europe, a deeper understanding of patients' and physicians' experiences, attitudes and preferences surrounding EoL communication is most readily achieved through qualitative rather than quantitative research[15, 16]. Unfortunately, the growth in cross-country quantitative EoL research in Europe in recent years has not been accompanied by a comparable increase in qualitative research. This paucity is undoubtedly influenced by the relatively high-cost and time-consuming nature of qualitative approaches[17], as well as the challenges of multi-lingual and trans-cultural research[18, 19]. Since cross-country qualitative research is still in its infancy there is currently no study available with a specific focus on EoL communication issues comparing data from different European countries.

By reporting the results of an exploratory secondary analysis of older patients' interviews from three northern European countries, this paper begins to address the paucity of cross-country qualitative research on EoL communication in Europe. The interviews analyzed were conducted as part of studies that explored terminally ill patients' attitudes towards, and experiences of, death, dying and EoL care. As the primary studies varied in their specific foci, this cross-country comparison only examines common themes surrounding patient-physician EoL communication. In light of calls to implement European-wide EoL care policies and for best practice models to be used across Europe[1, 20], such an approach assists the identification of common issues in patient-physician EoL communication throughout Europe and potentially contributes to the formulation of Europe-wide policy recommendations.

This study therefore aims to examine older patients' attitudes towards, and experiences of, patient-physician EoL communication in the United Kingdom, the Netherlands and Belgium. Specific objectives include: 1) to examine common themes surrounding patient-physician EoL communication from British, Dutch and Belgian interviews with older patients on attitudes to death, dying and EoL care; and 2) to identify similarities and differences in attitudes and experiences within these common themes.

Methods

Secondary analysis

Selection of studies and participant interviews

This study is part of a two part project. The first part consisted of a detailed reflection on ethical and methodological challenges in interviewing older adults about EoL

issues, comparing experiences from six qualitative studies in four European countries[21]. This article however focuses more narrowly on older patient-physician EoL communication. As such it was necessary to assess the nature of the studies and the quality of the interviews included in the methodological reflection, to ensure the phenomenon of interest was sufficiently represented and the interviews and related documents were complete[22, 23]. Interviews from one of the studies were no longer available[24]. A number of transcripts (minimum three) and associated field notes from each of the remaining five studies were critically reviewed by the first and second authors (NE and RP). Two studies were excluded as they either did not cover patient-physician communication[25] or did not involve a palliative care population[26]. Interviews from the remaining studies were deemed to provide sufficient depth and detail concerning older patients' experiences of, and attitudes towards, patient-physician EoL communication.

This secondary analysis therefore draws upon data from these three qualitative studies conducted in the United Kingdom, the Netherlands and Belgium (Table 1). Participants from all studies had been diagnosed with a progressive terminal illness and were receiving EoL care. Whilst the primary aims of the studies ranged from exploring patient-GP EoL communication[27], identifying aspects of EoL care valued by the patient[28] and understanding cultural constructs of loss, transition and adaptation, all the interviews were largely unstructured and aimed at generating patients' narratives[21] (Table 1). The interviews from all studies had been transcribed verbatim for the purposes of conducting thematic analysis. Details of the primary studies' aims, informed consent, and funding sources can be found in Table 1.

A sub-sample of available interviews was purposively selected from each study: participants over the age of 60 with a range of socio-demographic characteristics, health statuses and care locations were included. One of the studies (Ethnicity and Cancer) compared the views of older Chinese and white patients resident in the UK. From this study Chinese participants (n=24) were excluded, leaving only white older patients (n=47), in order to make the sample's ethnic composition comparable to the samples from the Netherlands and Belgium. A final sub-sample of 30 interviews (United Kingdom=10, the Netherlands=11, Belgium=9) was selected from 94 interviews (United Kingdom=47, the Netherlands=30, Belgium=17).

Table 1. Details of primary studies

Country	Primary study title	Aim	Participants	Patient consent	Funding
Belgium	Medical and ethical quality of care when talking EoL decisions.	To develop a guideline for general practitioners (GPs) on EoL communication with patients who wish to die at home.	Patients with terminal illnesses (n=17).	Informed consent was obtained verbally.	Belgian Science Policy.
The Netherlands	End-of-life care in general practice in the Netherlands.	To explore the aspects valued by both patients and GPs in EoL care at home.	Patients with terminal illnesses in the care of a GP (n=30).	Written informed consent obtained.	Centre for Development of Palliative Care Amsterdam, and the Ministry of Health, Welfare and Sports.
United Kingdom	Ethnicity and cancer: examining psychosocial transitions for older people.	To investigate the cultural constructs of loss, transition, and adaptation when encountering a diagnosis of a life threatening illness; to elicit narratives from older adults about their experiences of cancer diagnosis.	Chinese (n=24) and white (n=47) hospice day centre patients.	Written informed consent obtained.	Dimbleby Cancer Care.

Thematic analysis

The selection and construction of data are intertwined with the assumptions and procedures of the intended analytical approach[29]. Thematic approaches had been used to identify key themes in all three included studies. Thematic analysis was also, therefore, appropriate for the secondary analysis and key cross-cutting themes were identified using a constant comparison approach[30].

After a reading of the English language interview transcripts by the first author (NE), and of the Dutch and Flemish interview transcripts by the second author (RP), a preliminary coding scheme was developed. Both researchers used this coding scheme to code all interviews. Interview segments from the non-English language transcripts that dealt with patient-physician interactions were identified by the second author (RP) and translated into English by professional translators. The language expertise provided by the professional translators, combined with the authors' language skills

and understanding of the research topic enabled a sensitive and nuanced translation of the interview data[18]. The preliminary coding scheme also provided the basis for an iterative process of coding and identification of emergent themes conducted by the first author (NE) using the full English language transcripts and the translated sections of the non-English language transcripts. Codes and emergent categories were compared and contrasted until a number of key cross-cutting themes were identified from the data[30]. Interview transcripts and field notes were managed and coded using Atlas ti qualitative data analysis software[31].

Ethics approval and informed consent

Ethics approval was obtained for all of the primary studies (Table 1). Either verbal or written informed consent was gained from all primary study participants. The conditions of the primary studies' ethics approval were reviewed to ensure that secondary analysis of interview data was in line with the aims of the informed consent obtained from the participants[25]. Furthermore, the researchers involved in the primary research thoroughly anonymized the data[32].

Theoretical considerations and methodological issues

Although the secondary analysis of datasets is most readily associated with quantitative research, there is increasing interest in the secondary analysis of qualitative data[32]. There are a number of theoretical and methodological issues involved in applying such approaches to qualitative data. Quantitative research is often described as being based on a positivist paradigm whereas qualitative research is based on a constructivist paradigm[33]. Although this dichotomy is somewhat simplistic[34], it is useful for understanding the epistemological issues involved in the secondary analysis of qualitative data. Within a constructivist paradigm reality is created between the observer and the observed and qualitative inquiry does not aim to reveal a single objective, measurable reality[33]. As such the context in which qualitative data are created is central to their interpretation. The secondary analysis of qualitative data is often criticized because this vital understanding of context is lost[35].

Van den Berg[29] however argues that secondary analysis of qualitative data is feasible when the contextual information most relevant for the interpretation of the text is provided. Attempts to provide sufficient contextual information for the current secondary analysis are described in Table 2. Furthermore, measures taken to ensure the rigor of the secondary analysis, as recommended by Heaton[36] and Van den Berg[29], are detailed in Table 2.

Table 2. Recommendations for the reporting of secondary analyses of qualitative data and measures taken.

Recommendation to ensure rigour in secondary analysis of qualitative data	Measure taken
Information about the discursive context of interviewee's responses. Information about the discursive history of interviewee's responses.	Detailed transcriptions, transcribed verbatim, were available. Whole interviews were available to at least one of the researchers involved in the secondary analysis rather than just the relevant sections.
Information about background characteristics of interviewer and interviewee.	Field note summaries (interview 'pen portraits'), included information about the participant's gender, age, socio-economic status, residence, family situation, key life events and the context in which each interview took place were provided.
Information about the place, time and setting of the interview, such as presence of third persons.	Information included in detailed field note summaries.
Information about the composition of the secondary dataset.	Sampling frameworks of the primary studies and the selection of the subset used in the secondary analysis are described in the methods section.
Funding of the primary and secondary work.	Funding information for the primary studies is included in Table 1. Additional funding sources for the secondary analysis are included in the acknowledgements.
The relationship of each of the authors to the data.	At least one researcher from the original study was available to provide further information on any contextual queries (ShP, BP, RD). The original researchers were not however involved in the re-coding of the data (conducted by NE and RP).
Information about informed consent.	Ethics and informed consent are described in the methods section.
Rationale for approach used in secondary analysis and a description of analysis procedure.	Rationale for the thematic analysis is described in the methods section.
Information about how the data were managed.	Data were managed using Atlas ti qualitative data analysis software.
Information about how the rigour of the analysis was established.	Details provided in this table.
Information about how the 'fit' of the data was ascertained.	At least one researcher from the original study confirmed the fit of the resulting themes.
Details of limitations.	Limitations are outlined in the limitations section.

Results

The majority of participants had cancer, whereas just under a quarter suffered from non-malignant conditions (Table 3). The median age was 78.5 and the majority of participants were male (67%) (Table 3).

The analysis provided insight into the nature of the patient-physician interaction for older patients receiving EoL care. Cross-cutting themes included: confidence and trust; disclosure and awareness; and participation in decision-making.

Table 3. Characteristics of participants included in the purposive sub-sample

		Belgium	The Netherlands	The United Kingdom	Total	
		Medical and ethical quality of care when talking end-of-life decisions	End-of-life care in general practice in the Netherlands	Ethnicity and cancer		
		n=9	n=11	n=10	n=30	%
		n	n	n	n	%
Age	60 - 64	2	0	1	3	10
	65 - 74	5	1	1	7	23
	75 - 84	1	8	6	15	50
	85>	1	2	2	5	17
Sex	male	7	7	6	20	67
	female	2	4	4	10	33
Condition	Cancer	9	5	9	23	77
	Non-cancer	0	6	1	7	23

Confidence and trust

The physician-patient encounter is affected by patients' expectations, which are shaped in part by their past experiences with physicians and other healthcare professionals. Factors that reinforced older patients' trust and confidence in their physician included availability, time and genuine concern.

Participant's wife: But if we call him, he's there for us. It's true. He doesn't count it. He says, "I'm getting up and I'm there," and ten minutes later there he is. He doesn't live far away, but he still has to come here.

Participant 8, Male, 65 – 74 years, Belgium

Interviewer (I): Are there any things regarding the doctor about which you are less satisfied?

Participant (P): No, not at all. Nothing with regard to the general practitioner or with regard to the lung specialist. That's a really nice woman. I can call her at any time of the day. Even in the middle of the night, at her home number!

Participant 10, Male, 75 – 84 years, the Netherlands

P: [...] I think in general principle, this place [the hospice] has been superb. The ordinary hospital sort of stuff that you get is in and out, flash, bang, wallop and really has nothing, there's nothing humane about it whatsoever.

Participant 21, Male, 75 – 84 years, United Kingdom

Participants frequently commented on their physician's availability, the amount of time the physician dedicated to them and if the physician appeared to be in a hurry. Furthermore, older patients emphasized how important it was that their physician gave them their full attention and, even if they had only a little time to spare, that their concern was genuine.

Negative experiences also greatly impacted older patients' trust and confidence in their physician. Some participants specifically criticized the manner in which physicians spoke to them, describing a lack of empathy and sensitivity. Whereas others criticized physicians' use of medical jargon and expressed satisfaction with physicians who were prepared to explain difficult to understand medical terms.

I: [...] did you still trust that general practitioner?

P: No, I had asked for a walker then. And then he said, 'that's not worth the trouble anymore.'

Participant 12, Male, 75 – 84 years, the Netherlands.

P: I said "he's [the physician] a Canadian and he's as cold as a bloody fish that they pull out of the sea in Canada" [...] So he is a cold fish and I mean that sincerely, but what does he deal with? Death constantly. And all he's ever got to say to some poor bugger is "I'm afraid that you're on the way out". [...] [b]ut I do wish that he'd sort of look at me as if to say "well, I do appreciate how you feel", but I understand how he has to cope with it and that's it. So we beg to differ at times, you know. If he says something I don't agree with, I'll bloody tell him so. Because I've got nothing to lose, have I?

Participant 21, Male, 75 – 84 years, United Kingdom

P: But you'd prefer a doctor to speak to you as a human being, and not use all these formal terms.

I: They use too many formal words?

P: Yes, when my daughter was here too, she even said so to the specialist.

Participant 5, Male, 65 – 74 years, Belgium

Older patients' confidence in physicians and the efficacy of biomedicine were also negatively affected by experiences of misdiagnoses and inappropriate treatments.

I: Yes, you were on the wrong track really weren't you [in reference to a misdiagnosis by Dr. Smith]?

[...] So that's the difficult one is the fact it wasn't picked up.

P: That's the difficult one yes.

Participant 22, Male, 60 – 64 years, United Kingdom

Disclosure and awareness

Older patients frequently expressed a preference for open and honest disclosure of diagnoses and prognoses. Indeed, the one woman who knew that she had not received a prompt disclosure of her diagnosis stated that she would have preferred full disclosure.

P: My GP, when he'd got the letter [from the specialist]...He said, "Look, Denise, I've had this letter a while. I'll give it to you now," he said, "but Denise, I should have told you in January; that you needed another scan... but it would've been the same. We couldn't do anything about it anyway." And he said that my morale was still so good that he didn't want to... because that's what he said, this doctor, that you can't do anything about it. If I'd been three months earlier, then yes. And so I asked my GP why he hadn't done anything with the letter for so long...

I: And you think your doctor should tell you?

P: (hesitantly) Yes, I do think so... although to be honest, Dr R. did do it in a gentle way.

Participant 1, Female, 60 – 64 years, Belgium

Patients also expressed dissatisfaction with the amount of information provided by their physician about their illness and treatment options. A common complaint was that information was something that needed to be sought and was not routinely provided.

In contrast, other patients preferred to remain deliberately unaware about their illness and treatment options in an attempt to avoid distress.

I: Did they [the GP] discuss it with you?

P: Not much. Those doctors don't say much.

I'd prefer not to know. Otherwise it breaks my heart.

I: Did they tell you what to expect?

P: No. I prefer not to know; it would make me sick.

I've already had a fever for three days. I don't want to know.

I: Have you talked about what you want to say or decide?

P: There's no point in asking me anything, I can't answer you. Unfortunately. I don't know...

I: Is there a doctor who has explained things when you've asked anything?

P: No. They don't say anything.

I: Have you ever asked anything or would you like to have asked anything?

P: No, if they don't say anything, then I don't ask. I don't say anything. They definitely don't say anything.

Participant 2, Female, 75 – 84 years, Belgium

P: Yes, well when I came here I saw the doctor the same day. And the doctor said, 'Now I'm going to...' I was in an hour. 'Now I said when you've gone I shall be writing to your GP', and he said, 'you've got every right to ask to see the letter. Now what do you want to do?' So I said, 'I don't. Whatever you say to him, I don't want to read... hear about it you see.'

Participant 29, Female, 85≥ years, United Kingdom

When asked if a physician should provide full information about diagnosis and prognosis, some older patients were pragmatic and stated that a physician should know when and for whom full information is appropriate. Others stated that a physician should always be open and direct in communication.

An additional complaint was that, when information on treatments was given, the physician only provided information concerning the treatment option they recommended and did not discuss the consequences of other actions.

P: Yes convinced, he didn't leave me any choice, they don't leave you any choice. My reward is that I'm not given any choice [...] So there were two possibilities: chemotherapy or not. And I already knew that chemotherapy could also have physical consequences and stuff, vomiting and feeling bad and everything. But what actually happened if I refused chemotherapy. I didn't actually hear anything about that. So I think that was missing. So I didn't actually make a decision, err, with any conviction. Yes. Correct me if I'm wrong.

Participant 6, Male, 65 – 74 years, Belgium

P: And I regret that. That they pushed me [to get started with a treatment]. You just grasp at a straw. So when they tell you: 'You are terminally ill; you have cancer and the only possibility is surgery' than you want to seize that possibility, right? However, afterwards, it turned out that it was so radical. When I had to go to the hospital and that they first told me that: first with that doctor, then with that internist, to the surgeon, and that only then I found out that it was way too radical [...] Every time I make a phone call, I have to recover my breath. At those times, I'm jealous that I was not told about the possibility of being 'taped' [an alternative procedure] from the start [instead of surgery] [...] Then I went to the lung specialist and I said: 'I changed my mind, I'm not going to do it'. And she said: 'I'm glad you didn't go through with it.' Because they push you to do it! [to become a study subject] However, they just need people. Because, in twenty years, there will be an explosion of asbestos victims who have all worked there.

Participant 10, Male, 75 – 84 years, the Netherlands

Participation in decision-making

In each country older patients expressed a variety of preferences for and experiences of involvement in medical EoL decision making. Levels of involvement included: active involvement in decisions; involvement with family support; and no involvement in decisions. Many older patients described joint discussions about treatment options, including non-treatment decisions, with their physician.

I: Did you talk with the doctor about you not wanting euthanasia or resuscitation? Did this take place on your initiative or on the doctor's initiative?

P: Yes, on my own initiative. I've witnessed a resuscitation in the hospital and I thought it was horrible. And I do not want surgery either any more

Participant 12, Male, 75 - 84, the Netherlands

Some participants believed that patients should make decisions in collaboration with, or with the support of, their family and saw the physician as having more of an advisory role. The presence of a spouse or adult child at the physician-patient interview who provided emotional support or aided the understanding of options available was often mentioned.

P: [...] I said, 'Would you mind if my son came. Can you explain everything to him?' 'Oh no that's a good idea.' So my son came and they told him what's what.

Participant 26, Male, 75 - 84, United Kingdom

Wife: No, no, it's us who decides that [treatment], together with the specialist. But if you don't want to, you don't have to continue. They'd continue. They say it makes no difference anymore, but they want to continue anyway.

Participant 5, Male, 65 - 74, Belgium

Family involvement in decision-making was not however universally positive or supportive. Family members have their own hopes and expectations, which may differ from those of an older patient. The presence of family members was described by one participant as having a coercive effect on his decision to choose a more aggressive, experimental treatment, which he later regretted.

P: All my children were there. So you are anxious all the time. Normally, you have a meeting with the general practitioner, but when all the children also have to be present, and they are going to make a decision and are all enthusiastic: "Dad, you have to get surgery" [...] So, looking back, I actually regret this.

Participant 10, Male, 75 - 84, the Netherlands

In some cases the participant deferred decision-making responsibilities to the physician, whereas others were simply told what their treatment would be rather than being included in treatment (or non-treatment) decisions. This lack of involvement often went unchallenged and was treated fatalistically by participants.

P: So I was told in my case that they weren't going to operate. And I accept that. OK? Yes, I can run from one hospital to the next and... err... to Aalst [Belgian city] or what's it called?

Participant 6, Male, 65 - 74, Belgium

Discussion

This exploratory secondary analysis of older patients' interviews from three northern European countries highlights some common issues in patient-physician EoL communication. Furthermore, it represents the first step in addressing the paucity of qualitative cross-country research on patient-physician EoL communication in Europe. The identification of the common themes of 'confidence and trust', 'disclosure

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and awareness' and 'participation in decision-making' from Dutch, Belgian and British older patients' interviews implies that they are relevant across diverse social and cultural settings.

Within each of these common themes, a diversity of participant experiences and attitudes were reported from each of the three countries. This suggests that attitudes and preferences of older people regarding EoL patient-physician communication are highly individual. The variety of preferences for information provision and decision-making (including the involvement of family members), revealed in the findings, highlights the lack of an 'idealized' preference for older patients. For example, although older patients frequently expressed a preference for open disclosure of their diagnosis and prognosis, others remained deliberately unaware by rejecting information offered by their physician. These patients can be considered in a state of self imposed 'partial awareness' of dying. Partial awareness, according the typology of Glaser and Strauss, includes the suspicion of dying or the pretence of not dying[37]. This finding underlines the importance of denial or partial knowledge as a coping mechanism for some patients. It is important that information should be frequently and sensitively offered, but never be forced upon such patients.

Whereas more quantitative approaches reveal that country of residence is a strong determinant of practices and attitudes [9-12], this qualitative secondary analysis emphasizes that, even though the proportions of people with a particular attitude or preference might vary between countries, each attitude or preference type is still represented in each country. Calls for cultural sensitivity in regard to communication in EoL care in Europe should therefore be interpreted as a need for a sensitive understanding and flexible inclusion of all preferences rather than the modification of recommendations and policy for different European countries[38]. It is not advisable to modify recommendations regarding participation in decision-making, disclosure and communication as such an approach runs the risk of reifying culture and neglects diversity in patient preferences. It is instead essential that physicians throughout Europe recognize the importance of ascertaining individual patients' EoL communication preferences, which whilst influenced by culture are not determined by culture alone. Indeed culture is only one amongst a variety of factors that affect older patients' EoL communication preferences. There remains a need to better understand the relations between different factors and how they depend on and influence each other.

Patients reported a variety of experiences of communication with physicians, ranging from caring to coercive. Trust and confidence were reinforced by physicians'

availability, time and genuine concern, and negatively impacted by previous negative experiences such as misdiagnoses and poor communication style (lack of sensitivity and empathy) in all three countries. These findings highlight the importance of continued EoL communication training for physicians.

The themes revealed by the secondary analysis are supported by the findings of international research on patient-physician EoL communication. Nolan et al.[39] described American patients' diverse preferences for participation of physicians and family in decision making, whereas Pardon et al.[40] described similar results amongst Flemish patients. Aldred et al.[41] described older British heart failure patients' dissatisfaction with physicians' availability and information provision concerning their condition. Misunderstanding of some medical terms was also reported[41]. Heyland et al.[3] found that the majority of Canadian patients with advanced cancer considered trust and confidence in their physician as extremely important and that just under half considered the honest communication of information extremely important. It should be noted that all of the countries included in these studies, like those included in this study, are developed, high-income countries.

Strengths and limitations

The studies, from which the interviews were derived, varied in their foci (though all explored older patients' attitudes towards, and experiences of, death, dying and EoL care). As such the secondary analysis only looked at common themes on patient-physician EoL communication in three northern European countries. The variation found in the primary studies' main foci does however make the identification of common themes even more remarkable.

Decontextualization is a major risk in secondary analysis of qualitative data. A number of steps, therefore, were taken to ensure sufficient contextual information was available to inform the analysis. These steps are outlined in Table 2.

Further research

This secondary analysis only begins to address the paucity of cross-country qualitative research on patient-physician EoL communication in Europe. Furthermore, in Europe, EoL attitudes and practices are often discussed in terms of northern/southern, Protestant/Catholic, or Anglo-Saxon/Mediterranean dichotomies. However, all the interviews included in this secondary analysis come from northern European countries. Further research is required to ascertain whether the themes identified in this study are applicable in other European countries. There remains a

need for primary cross-country research to better understand both the similarities and differences in attitudes, preferences, physicians' practices and patients' experiences across the continent, as well as the role of socio-economic characteristics and past experiences of illness, death or bereavement, to ensure the flexibility of patient care and the accommodation of a variety of patient preferences.

Conclusion

This study highlights that older patients' attitudes and preferences concerning patient-physician EoL communication are highly individual and that there is no 'idealized' preference for disclosure or participation in decision-making. Physicians must therefore be sensitive to a diversity of preferences amongst older patients and avoid stereotyping. In regard to communication style physicians are advised to be mindful to provide patients with clear explanations, avoid jargon, and continually check patients' understanding. Physicians must also be careful to avoid partial information provision or any other attempt to manipulate older patients' treatment choices as such actions can compromise patient autonomy and trust.

The findings have implications for the dominant patient-physician decision-making models. In both the 'shared' and the 'informed' decision-making models the doctor informs the patient of the benefits and risks of all treatment options[42]. In the 'shared decision-making model' the doctor and patient discuss their own treatment preferences and decision-making is shared. In the 'informed decision-making model', in contrast, the decision-making process is the sole responsibility of the patient. Both models require that all the relevant treatment options and associated risks and benefits have been explained to the patient. However, findings from older patients' interviews from three northern European countries reveal that this idealized situation does not always reflect the reality of patients' experiences.

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Part II – End-of-life communication for older people: the Dutch experience

Chapter 5

End-of-life care in general practice: a cross-sectional, retrospective survey of ‘cancer’, ‘organ failure’ and ‘old-age/dementia’ patients

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Published in *Palliative Medicine* [Epub ahead of print March 2014]

Abstract

Background: End-of-life care is often provided in primary care settings.

Aim: To describe and compare GP end-of-life care for Dutch patients who died from 'cancer', 'organ failure' and 'old-age or dementia'.

Design: A cross-sectional, retrospective survey was conducted within a sentinel network of GPs. GPs recorded the end-of-life care of all patients who died (01/01/2009 to 31/12/2011). Differences in care between patient groups were analysed using multivariable logistic regressions performed with generalized linear mixed models.

Setting/participants: Up to 63 GPs, covering 0.8% of the population, recorded the care of 1491 patients.

Results: GPs personally provided palliative care for 75% of cancer, 38% of organ failure patients and 64% of old-age/dementia [adjusted OR (CI): cancer (reference category); organ failure 0.28 (0.17, 0.47); old-age/dementia 0.31 (0.15, 0.63)]. In the week before death, 89% of cancer, 77% of organ failure and 86% of old-age/dementia patients received palliative treatments: [adjusted OR (CI): cancer (reference category); old-age/dementia 0.54 (0.29, 1.00); organ failure 0.38 (0.16, 0.92)]. Options for palliative care were discussed with 81% of cancer, 44% of organ failure patients and 39% of old-age/dementia [adjusted OR (CI): cancer (reference category); old-age/dementia 0.34 (0.21, 0.57); organ failure 0.17 (0.08, 0.36)]

Conclusion: The results highlight the need to integrate palliative care with optimal disease management in primary practice and to initiate advance care planning early in the chronic disease trajectory to enable all patients to live as well as possible with progressive illness and die with dignity and comfort.

Introduction

During the last year of life, many people receive care within primary practice[1,2] and General Practitioners (GPs) are central to the co-ordination and provision of this care.[3] In the Netherlands, emphasis is placed on GPs providing palliative care.[4] A 2011 policy brief from the Dutch Ministry for Health, Welfare and Sport stipulated that primary care professionals principally provide palliative care and address patients' and relatives' physical, psychosocial and spiritual needs.[5] Important aspects of GP palliative care include recognising palliative care needs, referrals to specialist palliative care, effective communication regarding end-of-life issues and advance care planning (ACP).

Primary care is an appropriate setting for much palliative care, particularly for non-cancer patients.[6,7] However, with non-cancer patients, GPs are less likely to know when to initiate palliative care,[8] provide timely referrals to specialist services[9] and discuss end-of-life issues and ACP.[10,11] Nonetheless, non-cancer patients experience high levels of physical[12-14] and psycho-social distress,[15-17] which may benefit from a palliative approach. Differences in care between cancer and non-cancer patients are often attributed to non-cancer patients' less predictable illness trajectories.[8-10] Non-cancer patients, however, are a diverse group with distinct illness trajectories. It is, therefore, crucial to compare patients' end-of-life care by trajectory group rather than the usual cancer and non-cancer dichotomy. The term 'end-of-life care' has been variously defined,[18,19] however, it is used herein to describe the GP-reported care patients received before death,[20] which may or may not have included a palliative approach.

Inspired by observations that 'perceived course of dying' strongly influenced patients' care,[21] Lunney et al[22] described three archetypal trajectories for progressive chronic illnesses: cancer patients experience rapid predictable decline; organ failure patients (e.g. heart disease, chronic obstructive pulmonary disease) experience a more gradual decline with serious intermittent episodes; and frail/dementia patients experience gradual prolonged decline. Illness trajectory can affect treatment aims (to cure, prolong life, or palliate symptoms), use of palliative care services and end-of-life communication. Subsequent research has examined the trajectories of physical, psycho-social and spiritual suffering at the end-of-life in various patient populations.[14,16,23-26] Only two studies however have directly and

quantitatively compared aspects of end-of-life *care* between illness trajectory groups: Lunney et al[27] studied US patients' Medicare expenditure, whereas Beernaert et al[28] investigated referrals to specialist palliative care services. No studies have examined different aspects of GPs' end-of-life care provision by trajectory group. Based on GPs' reports, this study describes and compares GP end-of-life care for patients who died from 'cancer', 'organ failure' and 'old-age or dementia' in the Netherlands. Specific objectives include estimating and comparing:

- importance of cure, life prolongation and palliation in the last week of life, two to four weeks before death, and two to three months before death;
- provision of palliative care by the GP and other services;
- prevalence of GP-patient discussion of ten end-of-life topics; and
- elements of ACP, specifically regarding preferred place of death, medical end-of-life treatment preferences and surrogate decision-makers.

Methods

Study design and procedure

The study design was cross-sectional and retrospective, with a clustered sample. GPs from The Dutch Sentinel General Practice Network recorded demographic, health, and care characteristics for all deaths of practice patients (aged one or over) using a standardised registration form after death (01/01/2009 to 31/12/2011). Components of care recorded included treatment aims and palliative care provision, which GPs recorded for the last three months of life. This timeframe was identified as relevant to study on the basis of other literature.[29-31] GPs were also asked about the discussion of end-of-life topics and ACP. No timeframe was put on these questions because illness can affect timing.

The Netherlands Institute of Health Services Research (NIVEL) coordinated the sentinel GP network, which is based on a representative sample of healthcare professionals that report all cases of particular conditions to study disease prevalence and associated factors.[32] Participating GPs completed the registration form by hand within a week of the patient's death, including any information from medical records and hospital physicians. Forms were sent to NIVEL.

Informed consent, patient anonymity and ethics approval

After being informed of the study objectives and procedures, participating GPs gave written informed consent at the beginning of each registration year. Strict procedures regarding patient anonymity were employed during data collection and entry; GPs gave every patient an anonymous reference and any identifying patient and GP data (such as date of birth, postcode and GP identification number) were replaced with aggregate categories or anonymous codes. Ethical approval is not required for posthumous collection of anonymous patient data in the Netherlands.[33,34]

Settings and study population

The Dutch Sentinel GP Network has been operating since 1970. The Network is designed and managed to be representative for the Dutch population (for age, sex, and population density) through stratified random sampling and aims to cover 1% of the population. Registered GPs (National General Practitioner Register held by NIVEL) are invited to participate on the basis of their practice population characteristics, keeping in mind the need to manage the representativeness of the network. GPs who accept the invitation to participate undergo a two-month trial period to assess their motivation and reporting accuracy. The same procedure is used when replacing a GP who leaves the network.

To include only data from patients who could, in theory, have received palliative care, deaths registered as 'sudden and totally unexpected', or for whom suddenness of death information was missing, were excluded. Furthermore, only patients who were under their GP's care in the last year of life were included. This was determined from the patient's main place of residence in the last year of life; nursing home residents, cared for by an elderly-care physician were excluded, as were patients whose main residence was 'unknown' or 'other' (often institutions outside of the GP's care).

GPs recorded the primary cause of death: cancer, cardiovascular disease, pulmonary disease, neurological disease, cerebrovascular accident, old-age or 'other' (specified). Dementia was not a specific cause of death category but dementia diagnosis (mild or severe), as reported by the GP, was recorded. To compare patients' end-of-life care, three groups were created: 'cancer', 'organ failure' and 'old-age/dementia'. The 'cancer' group included patients whose cause of death was any cancer; the 'organ failure' group included patients

whose cause of death was cardiovascular or pulmonary disease; and the 'old-age/dementia group' included patients whose cause of death was 'old-age', patients reported to have severe dementia whose cause of death was 'neurological disease' and patients for whom the 'other' cause of death category was specified as 'dementia'. Neurological diseases other than dementia, cerebrovascular accidents and 'other' causes of death (apart from those specified as 'dementia') were excluded (Figure 1). Elderly patients whose primary cause of death was organ failure or cancer were categorised in those groups rather than the 'old age' group. Disease trajectory groups were therefore based on the primary cause of death as reported by the GP and co-morbidities were not considered.

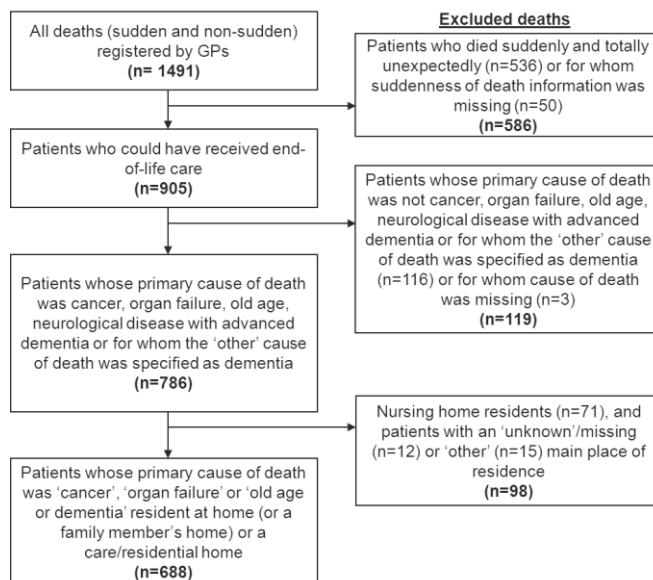


Figure 1. Selection of patients who died non-suddenly from 'cancer', 'organ failure' and 'old-age/dementia' who were under their GP's care in the last year of life.

Measurement instrument

Patient and care characteristics collected included: age; sex; cause of death; dementia diagnosis; main place of residence in the last year of life; and place of death.

Treatment aims

GPs were asked to rate the importance of cure, life-prolongation and palliation as treatment aims on a five-point Likert scale during: the last week of life; two

to four weeks before death; and two to three months before death. The scale ranged from one (totally unimportant) to five (very important). As the importance of each treatment aim was rated separately for each time period, multiple aims were possible within the same period.

Palliative care

GPs recorded if they had personally provided palliative care. To capture all care considered to be of a palliative nature for this diverse patient group, GPs self-defined 'palliative care'. GPs were also asked if the patient had received care from any other palliative care service (palliative care consultant; hospital palliative care unit (PCU); nursing home PCU; hospice; or 'other') in the last three months of life.

Discussion of end-of-life topics and advance care planning

GPs were asked if they had ever discussed ten end-of-life topics (see Table 3 for list) with the patient. In addition, GPs were asked about their knowledge of, and discussion with the patient about, preferred place of death, medical end-of-life treatment preferences and surrogate decision-maker appointment.

Data analysis

The personal and care characteristics of patients who died from cancer, organ failure and old-age/dementia were assessed using descriptive statistics. Differences between groups were assessed using Pearson's Chi-squared or Kruskal-Wallis tests. Treatment aims were dichotomised: 'important' and 'very important' (collectively referred to as 'important') were combined and separated from other responses. A new variable 'palliative care only important treatment aim' was created, indicating whether palliation was the only aim considered important for the patient at a given time interval.

Multivariable logistic regression was performed with generalized linear mixed models (GLMM) to analyse the association between patient group and binary outcome measures. Multi-level analyses accounted for the clustering of patient data by GP. For each separate GLMM analysis, age, sex, longest place of residence, place of death and dementia status were held constant. A variance component covariance structure was assumed and robust covariances specified. Analysis was carried out in SPSS20.

Results

During the study, a maximum of 42 GP practices (employing up to 63 GPs) in any given year, providing GP services to 0.8% of the Dutch population (16,600,000[35]), participated and GP turn-over was low.[36,37] GPs recorded a total of 1491 deaths. Of these, 688 patients were under their GP's care in the last year of life and died non-suddenly from cancer (n=453), organ failure (n=162) or old-age/dementia (n=73) (Figure 1). The characteristics of these patient groups are shown in Table 1.

Table 1 Patient characteristics n=688

		Cancer	Organ failure	Old-age /dementia	P value †
		n=453	n=162	n=73	
Patient characteristics		n (%)	n (%)	n (%)	
Age	<= 64	121 (27)	10 (6)	1 (1)	<0.001
	65 - 84	269 (59)	71 (44)	18 (25)	
	85>	63 (14)	80 (50)	54 (74)	
Sex	Mean (SD)*	71.67 (12.13)	82.23 (10.09)	87.70 (6.74)	<0.001
	male	248 (55)	81 (51)	20 (28)	<0.001
	female	201 (45)	78 (49)	52 (72)	
Longest place of residence in the last year of life	Home/with family	428 (95)	133 (82)	41 (56)	<0.001
	Care/Residential home	25 (6)	29 (18)	32 (44)	
Place of death	Home/with family	278 (62)	45 (29)	29 (40)	<0.001
	Residential or care home	22 (5)	27 (18)	31 (43)	
	Nursing home	29 (7)	42 (27)	4 (6)	
	Hospital	73 (16)	35 (23)	5 (7)	
	PCU/hospice	44 (10)	5 (3)	3 (4)	
	(Elsewhere n=15) ^a				
Dementia diagnosis	Severe	4 (1)	4 (3)	23 (33)	<0.001
	Mild	12 (3)	22 (14)	10 (14)	
	None	420 (96)	130 (83)	37 (53)	

Valid Percentage reported. Missing values n (%): age, 0; sex 8 (1.2); longest place of residence 0; place of death 16 (2.3); and dementia diagnosis 26 (3.8)

† Test for differences Pearson's Chi-squared (**Test for difference Kruskal-Wallis (non-parametric)*).

^aNot included in analysis

Treatment aims

The proportion of patients receiving palliative treatments increased, whereas curative and life prolonging treatments decreased closer to death for all patient groups. For organ failure patients, palliative treatments were less common,

whereas life prolonging and curative treatments were more common, at each time interval compared with other patient groups (Table 2, Figure 2). Two to three months before death, cancer patients more commonly received curative (21%) and life-prolonging care (28%) than old-age/dementia patients (13% and 9% respectively). One week before death, however, the treatment aims of cancer and old-age/dementia patients were remarkably similar: 89% of cancer and 86% of old-age/dementia patients received palliative treatments, whereas 4% and 6% respectively received curative treatments (Table 2, Figure 2). Controlling for differences in patient characteristics between groups (age, sex, longest place of residence, place of death and dementia status), two to three months before death, the odds of receiving palliative care were significantly lower for organ failure compared with cancer patients. Two to four weeks before death, the odds of receiving palliative, or only palliative, treatments were significantly lower for organ failure and old-age/dementia patients compared with cancer patients (Table 2). In the week before death, the odds of receiving curative treatment were significantly higher for organ failure patients compared with cancer patients, whereas the odds of receiving palliative treatment were significantly lower for old-age/dementia patients compared with cancer patients, but comparable between organ failure and cancer patients (Table 2). The odds of receiving only treatments aimed at palliation in the last week of life were however significantly lower for organ failure and old-age/dementia patients than cancer patients (Table 2).

Palliative care

More cancer patients received palliative care (either from their GP or another palliative care service) (81%) than old-age/dementia (68%) and organ failure (47%) patients. Controlling for patient characteristics, the odds of receiving palliative care were significantly lower for organ failure and old-age/dementia patients than cancer patients (Table 2). Because most palliative care was GP-provided, results were similar when solely examining GP palliative care provision: more cancer patients received palliative care from their GP (75%) than old-age/dementia (64%) and organ failure (38%) patients. Controlling for patient characteristics, the odds of receiving GP-palliative care were significantly lower for organ failure and old-age/dementia patients than cancer patients (Table 2).

Around a quarter (26%) of cancer, 11% of organ failure and 10% of old-age/dementia patients received care from other palliative care services (such

as a palliative care consultant; hospital PCU; nursing home PCU; hospice; or 'other'). Controlling for patient characteristics, the odds of accessing such a palliative care service were significantly lower for organ failure than cancer patients; differences between cancer and old-age/dementia patients were not significant (Table 2).

Discussion of end-of-life topics and advance care planning

The prevalence of discussion of each end-of-life topic was highest for cancer, then organ failure and old-age/dementia patients. 'Physical complaints' were frequently discussed (with 92% of cancer, 77% of organ failure and 61% of old-age/dementia patients), whereas 'spiritual and existential problems' were infrequently discussed (with 46% of cancer, 27% of organ failure and 25% of old-age/dementia patients). (Figure 3, Table 3). The odds of discussing each topic (except 'primary diagnosis' and 'spiritual/existential problems') were significantly lower for organ failure and old-age/dementia patients compared with cancer patients (Table 3). GPs were more frequently aware of cancer patients' preferred place of death, end-of-life treatment preferences, and surrogate decision-makers, followed by organ failure and old-age/dementia patients (Table 3). Controlling for patient characteristics, the odds of the GP knowing the patient's preferred place of death were significantly lower for an organ failure patient and an old-age/dementia patient compared with a cancer patient (Table 3). Furthermore, the odds of the GP knowing the patient's end-of-life treatment preferences were significantly lower for an old-age/dementia patient compared with a cancer patient. The odds of appointing a surrogate decision-maker were also significantly lower for an old-age/dementia patient compared with a cancer patient (Table 3).

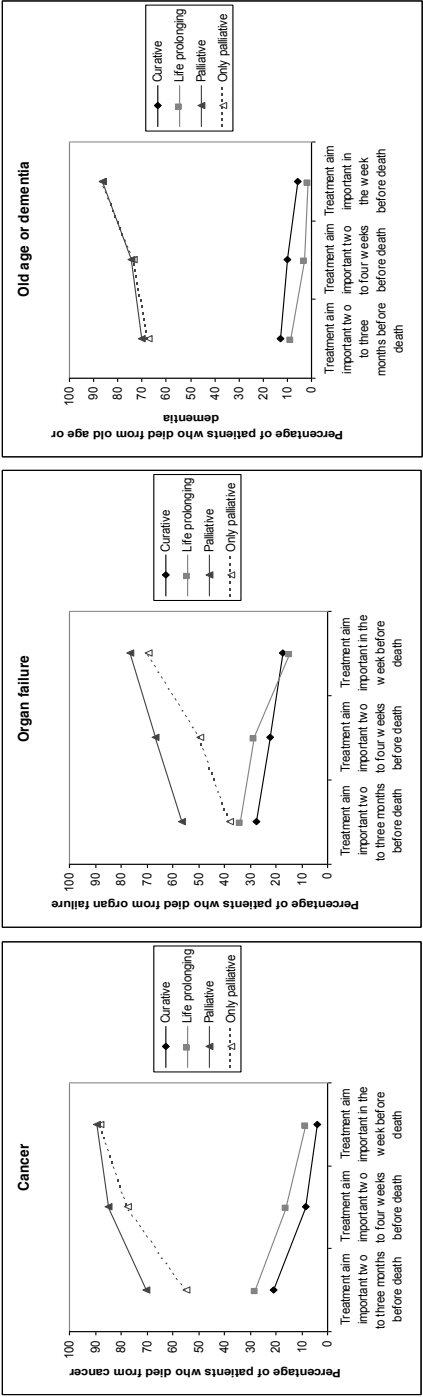


Figure 2. Treatment aims important at three time periods before death n=688

Table 2 Importance of treatment aims and palliative care use n=688

	Cancer n=453		Organ failure n= 162		Old-age/dementia n=73	
	n (%)	OR ref	n (%)	OR (CI) †	n (%)	OR (CI) †
Treatment aims important two to three months before death						
Curative	89 (21)	1	41 (28)	0.83 (0.48, 1.43)	9 (13)	0.55 (0.24, 1.28)
Life prolonging	119 (28)	1	50 (34)	1.44 (0.88, 2.37)	6 (9)	0.44 (0.13, 1.45)
Palliative	307 (70)	1	83 (57)	0.60 (0.36, 0.99)*	49 (70)	0.58 (0.24, 1.41)
Only palliative	221 (55)	1	50 (38)	0.59 (0.34, 1.03)	41 (67)	0.86 (0.36, 2.05)
Treatment aims important two to four weeks before death						
Curative	37 (9)	1	34 (22)	1.12 (0.64, 1.95)	7 (10)	1.52 (0.66, 3.54)
Life prolonging	69 (16)	1	43 (29)	1.71 (0.94, 3.09)	2 (3)	0.33 (0.07, 1.65)
Palliative	374 (85)	1	100 (67)	0.42 (0.26, 0.68)***	53 (75)	0.37 (0.18, 0.77)**
Only palliative	321 (77)	1	66 (49)	0.41 (0.25, 0.68)***	47 (73)	0.39 (0.17, 0.89)*
Treatment aims important in the week before death						
Curative	17 (4)	1	27 (17)	2.40 (1.19, 4.85)*	4 (6)	2.83 (0.99, 8.07)
Life prolonging	36 (8)	1	23 (15)	1.26 (0.58, 2.73)	1 (1)	0.80 (0.29, 2.21)
Palliative	398 (89)	1	121 (77)	0.54 (0.29, 1.00 ^a)	62 (86)	0.38 (0.16, 0.92)*
Only palliative	372 (88)	1	98 (70)	0.49 (0.27, 0.87)*	57 (86)	0.35 (0.14, 0.86)*
Palliative care received from the GP or another palliative care service	355 (81)	1	68 (47)	0.29 (0.17, 0.49)***	47 (68)	0.25 (0.11, 0.56)***
Palliative care received from the GP	331 (75)	1	59 (38)	0.28 (0.17, 0.47)***	45 (64)	0.31 (0.15, 0.63)***
Involvement of other palliative care service §	110 (26)	1	15 (11)	0.37 (0.15, 0.91)*	7 (10)	0.43 (0.15, 1.25)
Valid and unadjusted percentage reported						
Missing values n (%): treatment aims two to three months before death - curative 41 (6), life prolonging 43 (6.3), palliative 35 (5.1), palliative only 91 (13.2); treatment aims two to four weeks before death - curative 34 (4.9), life prolonging 38 (5.5), palliative 27 (3.9), palliative only 75 (10.9); treatment aims in the week before death - curative 27 (3.9), life prolonging 28 (4.1), palliative 13 (1.9), palliative only 58 (8.4); palliative care received from the GP or another palliative care service 36 (5.2); palliative care received from the GP 17 (2.5); and involvement of other palliative care service 58 (8.4).						
† multivariable logistic regressions performed using generalized linear mixed models. Fixed effects included illness trajectory group (OR and CI shown), age, sex, longest place of residence, place of death and dementia status.						
* **, and *** indicate significance at the p < .05, p < .01, and the p < .001 levels, respectively.						
^a (52) less than 1.00 at 3 decimal places.						
§ Palliative care services available in the Netherlands: hospice care; palliative care consultation; palliative care unit (based in a hospital, nursing home or residential home); other (but only included if it is a palliative care service).						

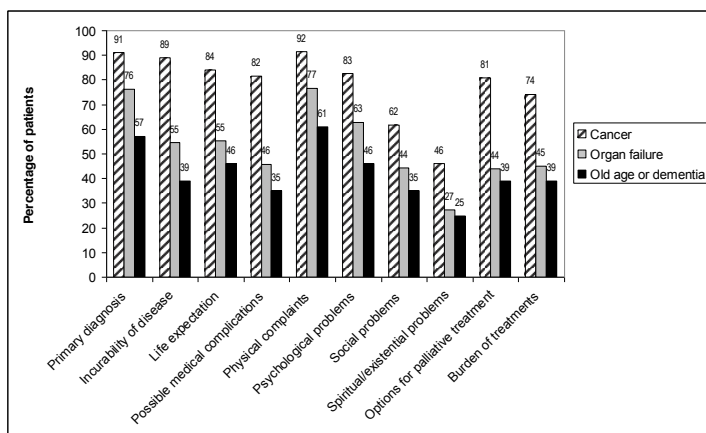
Table 3 Patient-GP communication and advance care planning n=688

	Cancer n=453			Organ failure n= 162		Old-age/dementia n=73	
	n (%)	OR ref	n (%)	OR (CI) †	n (%)	OR (CI) †	
End-of-life topics discussed							
Primary diagnosis	411 (91)	1	121 (76)	0.72 (0.41, 1.26)	41 (57)	0.23 (0.09, 0.59)**	
Incurability of disease	401 (89)	1	87 (55)	0.30 (0.18, 0.48)***	28 (39)	0.12 (0.05, 0.29)***	
Life expectation	379 (84)	1	88 (55)	0.41 (0.26, 0.64)***	33 (46)	0.19 (0.08, 0.43)***	
Possible medical complications	367 (82)	1	72 (46)	0.30 (0.18, 0.52)***	25 (35)	0.26 (0.13, 0.51)***	
Physical complaints	413 (92)	1	122 (77)	0.40 (0.21, 0.73)**	44 (61)	0.22 (0.10, 0.53)***	
Psychological problems	373 (83)	1	99 (63)	0.50 (0.31, 0.81)**	33 (46)	0.23 (0.12, 0.45)***	
Social problems	278 (62)	1	70 (44)	0.63 (0.41, 0.98)**	25 (35)	0.44 (0.22, 0.88)**	
Spiritual/existential problems	208 (46)	1	43 (27)	0.70 (0.40, 1.23)	18 (25)	0.52 (0.25, 1.08)	
Options for palliative treatment	365 (81)	1	70 (44)	0.34 (0.21, 0.57)***	28 (39)	0.17 (0.08, 0.36)***	
Burden of treatments	333 (74)	1	71 (45)	0.42 (0.26, 0.66)***	28 (39)	0.36 (0.18, 0.70)**	
Advance care planning							
Preferred place of death known	331 (74)	1	76 (48)	0.54 (0.32, 0.90)*	43 (59)	0.32 (0.15, 0.70)**	
Treatment preferences known	271 (61)	1	70 (44)	0.71 (0.40, 1.25)	28 (38)	0.44 (0.20, 0.96)**	
Surrogate decision-maker appointed	159 (36)	1	42 (26)	0.83 (0.49, 1.39)	13 (18)	0.42 (0.20, 0.89)**	

Valid and unadjusted percentage reported. Missing values n (%): primary diagnosis 6 (0.9); incurability of disease 6 (0.9); life expectation 7 (1.0); possible medical complications 8 (1.2); physical complaints 6 (0.9); psychological problems 7 (1.0); social problems 7 (1.0); spiritual/existential problems 7 (1.0); options for palliative treatment 6 (0.9); burden of treatments 8 (1.2); preferred place of death known 7 (1.0); end-of-life treatment preference known 7 (1.0); surrogate decision-maker appointed 9 (1.3).

† multivariable logistic regressions performed using generalized linear mixed models. Fixed effects included illness trajectory group (OR and CI shown), age, sex, longest place of residence, place of death and dementia status.

*, **, and *** indicate significance at the $p < .05$, $p < .01$, and the $p < .001$ levels, respectively.

**Figure 3** Prevalence of GP-patient discussion of end-of-life topics

Discussion

This study, the first to directly compare different aspects of GP palliative care by trajectory group, reveals less frequent palliative treatments, palliative care use, end-of-life discussions and ACP amongst organ failure and old-age/dementia patients than cancer patients. Comparing illness trajectory groups revealed that organ failure patients received the least palliative care, whereas old-age/dementia patients, the group most likely to lose decision-making capacity, had the least end-of-life discussions and ACP. Differences often remained after controlling for patient characteristic differences. GPs' seemingly limited recognition and discussion of the end of life for organ failure and old-age/dementia patients impedes palliative care provision, needs assessment, management of physical, psychosocial and spiritual suffering, and identification of end-of-life preferences.

The particularly infrequent provision of (GP or any other) palliative care to organ failure patients suggests that GPs have difficulty recognising that organ failure patients are at high risk of death, identifying their palliative care needs and referring them to other services. Results from a qualitative interview study of Dutch GPs,[38] indicated that palliative care is rarely started early in the disease course for organ failure patients: GPs recognised organ failure patients' palliative care needs gradually, and late in the illness trajectory. The high prevalence of curative and life prolonging treatments and low prevalence of palliative treatments for this group suggests that disease management is prioritised when setting treatment aims. Because organ failure patients might recover from acute episodes, life-prolonging measures may be appropriate right until death. Nonetheless, treatments with a palliative aim are also appropriate alongside optimal chronic disease management and have been recommended for kidney failure,[39,40] heart failure,[7] and COPD.[29,41] GPs, however, appear to find this difficult to implement. Organ failure patients may also have received more curative treatments for secondary diseases; it is not, however, possible to discern this from the data.

Although most old-age/dementia patients received palliative care from their GP (64%), end-of-life topic discussions and ACP were not common. Although GPs seemed to recognize a need for palliative care amongst old-age/dementia patients in the last three months of life, by this point, frailty or cognitive decline may prevent end-of-life discussions and ACP. The findings raise doubts about the 'palliative care' provided for these patients: is patient-centred palliative care feasible without an understanding of patient preferences? It is imperative that ACP, which is feasible with elderly[42] and

dementia patients,[43] is started early to give patients an opportunity to take part in end-of-life decision making.[44]

Cancer patients had the most palliative care, palliative treatments, discussion of end-of-life topics and ACP. The relative predictability of cancer patients' decline should enable physicians to anticipate palliative care needs and initiate end-of-life conversations and ACP.[29] Claessen et al.[38] revealed, however, that the main impetus for Dutch GPs to initiate a palliative approach with cancer patients is a letter from the oncologist stating that curative options are no longer available. This highlights the difficulties GPs face combining disease management and palliative approaches even for the patient group with the most predictable illness trajectory.

As individual illness trajectories can vary widely, questions remain about the appropriateness of using population-based approaches to guide individual care.[26,45] Expectations based on the common disease course, however, do strongly influence patient care. This care, and its underlying assumptions, deserve further attention to develop models of palliative care with an emphasis on need rather than predicted life expectancy.

Strengths and limitations

Nearly 100% of the Dutch population is registered with a GP,[46] and the Dutch Sentinel GP Network aims to be representative of the Dutch population for age, gender and population density, and covered up to 0.8% of the population. The retrospective, cross-sectional design enabled identification of patients nearing death. The retrospective nature of data collection was however subject to recall bias. Although this was minimised by weekly registration of deaths, GPs recalled aspects of care that may have occurred long before death (e.g. discussion of primary diagnosis).

Nursing home residents were excluded from analyses. In the Netherlands, these patients receive multidisciplinary care coordinated by the nursing home physician[47] and a small number of Dutch nursing homes even have their own PCUs.[48,49] In contrast, nursing home residents in other countries may be cared for by their GP or have limited access to palliative care.[47,50] Nursing home residents are characteristically disabled with chronic diseases or progressive dementia and need complex care and support.[51] Therefore, the old-age/dementia group was relatively small in our study, leading to lower statistical power, with the most complex cases and older participants missing from analyses. This may have led to an overestimation of communication items and an under-estimation of palliative care for the group; this however would not have weakened the main findings. The trajectory

groups were created from primary cause of death only, so co-morbidities were not considered.

Other limitations include: absent GP characteristics, possible desirability bias and incomplete medical records. The aims of care provided in other settings (e.g. hospitals) were also open to GPs' interpretation. Furthermore, the study reports GP-defined communication; patients and physicians may differ in their perception of a 'discussion' and patients may have discussed end-of-life issues with other health, social or spiritual care professionals.

Finally, differences in end-of-life care do not necessarily imply that inequities exist. Equity in healthcare implies equal access to available care for equal need, equal utilisation for equal need and equal quality of care for all.[52] This study does not examine care need. Previous research amongst non-cancer populations has, however, revealed high prevalence of distressing symptoms (amongst organ failure,[12,13,53] frail older and dementia[14,54] patients) and psycho-social and spiritual distress at the end-of-life (organ failure patients[15-17]); indicating considerable palliative care needs.

Conclusion

The study highlights a particular need in primary practice to integrate palliative care with optimal disease management for organ failure patients and to initiate ACP early in the chronic illness trajectory for old-age/dementia patients to enable patients to live as well as possible with progressive illness and die with dignity and comfort in line with their own preferences.

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Chapter 6

Life-sustaining treatment preferences: social support more important than health?

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Submitted

Abstract

This study examines Dutch older people's preferences for life-sustaining treatments and factors associated with a preference to forgo treatments. Participants from the Longitudinal Aging Study Amsterdam identified preferences for four life-sustaining treatments in hypothetical cases of cancer and dementia in a cross-sectional survey (n=1484). Preferences were described and associations examined using multivariable logistic regressions. A majority preferred to forgo a treatment in both cancer (78%) and dementia (85%) scenarios. Different elements of the multidimensional variable 'social support' influenced preferences in distinct ways: larger social networks were associated with forgoing treatment in the dementia scenario, whereas, in the cancer scenario, a live-in partner and greater emotional support were associated with preferring all treatments. Current health was not associated with preferences (except anxiety - associated with a preference for treatment in dementia). Understanding social support influences may encourage professionals to explore patients' expectations and fears about social support during advance care planning.

Introduction

At the end of life, physicians and family members are frequently required to make decisions for patients who have lost decision-making capacity. Often these decisions are made without the benefit of prior knowledge of patients' end-of-life treatment preferences[1,2]. These situations can however be avoided by discussing medical end-of-life treatment preferences in a timely manner. Understanding life-sustaining treatment preferences and the factors that influence them can inform and facilitate end-of-life discussions.

Several studies, primarily from the United States, have examined attitudes towards medical end-of-life treatments, typically by ascertaining preferences for life-sustaining treatments in different end-of-life scenarios and the factors associated with these preferences. These studies have revealed that, in the case of terminal illness, people often do not want aggressive life-sustaining treatments[3-7]. Preferences, however, depend on the treatment in question: more invasive procedures, such as cardio-pulmonary resuscitation (CPR) and mechanical ventilation, are, in general, less acceptable than non-invasive treatments, such as antibiotics[3-5,8,9]. A number of personal characteristics associated with preferences for life-prolonging treatment have also been identified. For example, younger[5,8,10], male[9,11-14], less educated[3,14], more religious[3,14,15] and African American[12,14,16] participants more frequently prefer life-sustaining treatments compared with older, female, better educated, less religious and white American participants.

Aspects of individuals' physical and mental health have also been associated with treatment preferences: in hypothetical scenarios, the terminal condition influences treatment preferences[8,16-18] whereby treatments are less acceptable in the case of coma and dementia[18]. In addition, participants' current health has been associated with life-sustaining treatment preferences. Health-related associations with treatment preferences are of interest because health deteriorates towards the end of life and it is important to understand whether participants' preferences when they experience reasonable health remain the same if their health declines. Some studies that participants in worse health are *less* likely to forgo treatments [3,10]. The Prospect Theory of decision-making has been used to explain this apparent 'response shift'[10,19]: the process by which preferences change as they adapt to deteriorating health[20]. Prospect Theory postulates that pairs of distant prospects are less distinguishable than closer ones[21]. To people with poor health/functional limitations the difference between death and living in poor health would seem greater than to healthy people and acceptance of worse health outcomes, therefore, might be more acceptable in comparison to death. Other studies however suggest that

participants in worse health are *more* likely to forgo treatments[5,22]. The relationship between physical and mental health and preferences for life-sustaining treatment, therefore, remains unclear.

As well as health, social relationships and available social support can change towards the end of life. Social network size, for example, has been shown to decrease in old age[23]. ‘Fundamental Cause Theory’, posits that social conditions, including social support, mediate access to resources that can be used to enhance health[24]. Whereas the influence of social conditions such as gender and education level on life-sustaining treatment preferences have been well described, the influence of social support remains almost entirely unexplored. Expectations of informal practical and emotional support, or indeed the burden of such support on loved-ones, may influence participants’ preferences. Social support factors have been found to influence the management of chronic disease[25], advance care planning and surrogate decision-maker appointments[26]. However, as far as the authors are aware, just one study has touched upon the relationship between social support and medical end-of-life treatment preferences: Barnato *et al.*[14] found that participants with less-than-weekly contact with family or friends were less likely to want potentially life-shortening palliative drugs. In the same study, however, living alone was associated with not wanting mechanical ventilation.

No study has provided a thorough examination of the influence of socio-demographic characteristics, social support, physical and mental health on preferences for different life-sustaining treatments. To obtain a comprehensive understanding of preferences and associated factors it is important to examine preferences for multiple life-sustaining treatments and in different end-of-life scenarios (such as cancer or dementia).

This study examines medical end-of-life treatment preferences amongst participants of the Longitudinal Aging Study Amsterdam (LASA): a population-based study[27]. The specific objectives are:

- To determine Dutch older people’s preferences for artificial hydration and nutrition, antibiotics, cardio-pulmonary resuscitation (CPR) and mechanical ventilation in hypothetical cases of cancer and dementia.
- To examine the associations between older people’s preference to forgo one or more medical end-of-life treatments and socio-demographic characteristics, social support, physical and mental health.

Data and methods

In 2008/9, older people participating in LASA identified preferences for four life-sustaining treatments in a self-administered questionnaire. This study, therefore, although part of a larger longitudinal study, takes a cross-sectional approach.

Sample

To date, two nationally representative cohorts of older people have been included in LASA. The cohorts were selected via random stratified sampling from population registers of eleven Dutch municipalities (chosen to represent Protestant, Catholic and secular areas and different levels of urbanisation)[27]. The samples were stratified for age and sex and there was a deliberate oversampling of men and older participants (in order to maintain some members from these high mortality groups throughout the study)[27]. The first cohort, aged 55-85, was recruited in 1992/93 and the second, aged 55-64, in 2002/03. Data were collected from both cohorts at three-year intervals through a face-to-face interview, medical interview and self-administered questionnaire[27]. The LASA study has a low drop-out rate and most attrition is due to mortality, with much lower attrition due to frailty, refusal to participate and loss of contact[27]. In the 2008/09 data collection cycle 1818 people were still participating (985 people from the first and 833 from the second cohort)[27], of these 1484 (82%) completed the self-administered questionnaire.

Measurement instrument

In the 2008/09 self-administered questionnaire, participants were asked to indicate their preferences for four medical end-of-life treatments in two end-of-life scenarios (cancer and dementia), Box 1. Vignettes concerning both cancer and dementia were chosen as previous research has shown distinct life-sustaining treatment preferences in cases of physical and cognitive decline[8,16-18].

Socio-demographics, social support and health characteristics were ascertained from population registries, face-to-face interview and medical interviews. Full details of the study have been published elsewhere[27]. The study was approved by the Medical Ethics Committee of the VU University Medical Center and all participants gave written informed consent.

Factors associated with treatment preferences

Socio-demographic characteristics collected included: age; sex; ethnicity (self-defined by participants and categorized as 'white Dutch' or 'other'); membership of a religious organisation (Protestant, Roman Catholic or other); education level (low [≤ 6 years], medium [7–11 years] or high [≥ 11 years]); and monthly net household income.

Household income was multiplied by 0.7 if participants lived with a partner to make it comparable to that of a single person household, income was then categorized into tertiles: low (≤ 1248 euros), medium (1248-1929 euros) or high (> 1929 euros).

Scenario 1. You are diagnosed with cancer, which has spread throughout your body. The disease is incurable. For some days you have not been responsive to any form of communication. You show clear signs of severe pain and agitation.				
Scenario 2. You suffer from dementia and no longer recognize your family or friends. You refuse to eat and drink and you are becoming increasingly withdrawn. It is no longer possible to discuss treatment options with you.				
Preferences for four medical end-of-life treatments				
	Yes	Probably yes	Probably not	No
Would you, in the above situation, wish to receive artificial hydration and nutrition (through a nasal gastric tube).	1	2	3	4
Would you, in the above situation, wish to be given antibiotics if you got pneumonia?	1	2	3	4
Would you, in the above situation, want cardiopulmonary resuscitation in the event of a cardiac arrest?	1	2	3	4
Would you, in the above situation, want mechanical respiration?	1	2	3	4

Box 1. End-of-life scenarios and questions on medical end-of-life treatment preferences.

Three dimensions of social support were measured. The first, ‘structural characteristics’, consisted of the partner status (co-residing with a partner or not) and the personal network size (the number of named people aged 18 or over with whom the participant had an important and regular contact [maximum 80])[28]. The second, ‘functional characteristics of support’, consisted of the practical and emotional support received from the nine most frequently contacted members of the participant’s personal network. Participants were asked how often they received practical or emotional support from the nine members of the participant’s personal network with whom they had most contact in the previous year. Possible responses were: never (0), rarely (1), sometimes (2), and often (3). The mean practical and emotional support received from the nine relationships was calculated (ranging from 0-3). The final dimension of social support, ‘perceived support’, was a measure of

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participants' sense of loneliness. Loneliness was defined as the discrepancy between what one wants and what one has in terms of interpersonal affection and intimacy. This was measured using De Jong Gierveld's loneliness scale (scores range from 0 to 11 with higher scores indicative of more intense loneliness)[29].

Aspects of physical health measured included: chronic disease; perception of own health; experience of pain; and physical limitations. Chronic disease was determined by asking participants if they had one or more of seven common chronic diseases (chronic non-specific lung disease; cardiac disease; peripheral arterial disease; diabetes mellitus; cerebrovascular accident (CVA)/stroke; osteoarthritis or rheumatoid arthritis; and cancer). Participants were also asked to rate their own health (very good (1), good (2), fair (3), sometimes good/sometimes poor (4) and poor (5)). Experience of pain was measured using Hunt *et al.*'s[30] pain scale abbreviated to five items. Scores were dichotomized, resulting in the categories 'no pain' (score 0) and 'any pain' (scores 1–5). Finally, physical limitations were measured by asking participants if they had difficulty carrying out seven simple tasks (e.g. dress and undress yourself, sit down and stand up from a chair and walk outside during five minutes without stopping) (scores 0 [no difficulties] to 7 [all with difficulty]).

Mental health measures included cognitive functioning, anxiety and depressive symptoms. Cognitive functioning was measured with the Mini-Mental State Examination (MMSE) (scores range from 0 to 30, with scores of 23 or under indicating lower cognitive functioning)[31]; Anxiety was measured with the Hospital Anxiety and Depression Scale-Anxiety (HADS-A) (scores range from 0 to 21, with higher scores indicating more anxiety symptoms)[32]. Depressive symptoms were measured with the 20 item Centre for Epidemiologic Studies Depression (CESD) Scale (scores range from 0 to 60, with higher scores indicating more depressive symptoms)[33].

Analysis

Sample characteristics and preferences for life-sustaining treatments were analysed using descriptive statistics. Percentages, means and standard deviations weighted for sex and age (standard: Dutch 1st January 2009 population[34]) in order to adjust for the over sampling of older and male participants. The relationships between participants' desire to forgo pairs of different life-sustaining treatments (nasal and gastric tubes, antibiotics, CPR and mechanical respiration) were determined using Spearman's rho correlations.

A factor analysis revealed that responses concerning the four medical end-of-life treatments formed one component in both the cancer and dementia scenarios

(analysis not shown). It was therefore possible to create one dichotomous variable from the four variables for each scenario: preference for all four life-sustaining treatments vs. preference to forgo one or more end-of-life treatments. Associations between preference to forgo one or more medical end-of-life treatment and socio-demographic characteristics, social support, physical and mental health were examined through univariate and multivariable logistic regressions. A forced enter procedure was used for the multivariable regressions. Residuals were examined and multicollinearity tests conducted.

Non-responders and missing data

The 334 participants who did not complete the self-administered questionnaire were older (Pearson's chi-square, $p < 0.001$), more frequently female ($p < 0.001$), and had lower educational attainment ($p < 0.001$) than those who completed the questionnaire. Ethnicity and religious group membership did not differ significantly between responders and non-responders; however few participants identified as non-white Dutch (1%).

In addition to non-participation in the questionnaire, there was a relatively high proportion of missing data regarding treatment preferences (ranging from 8.2-10.9%). Furthermore, missing values for the variable 'all four treatments', a combination of individual preference responses, were 11.9% cancer and 13.5% dementia scenario. In the cancer scenario, participants for who the variable 'all four treatments' was missing were older (Pearson's chi-square, $p < 0.001$), more frequently female ($p < 0.05$) and had lower education ($p < 0.001$). Similarly, in the dementia scenario, participants for who the variable 'all four treatments' was missing were older (Pearson's chi-square, $p < 0.001$), more frequently female ($p < 0.05$), had lower education ($p < 0.001$), and were church members ($p < 0.001$).

Results

Sample characteristics

Participants, aged between 61 and 101, had a mean age of 70.85 (SD 7.88). Just over half were female (53%) and the vast majority identified as white Dutch (99%) (Table 1).

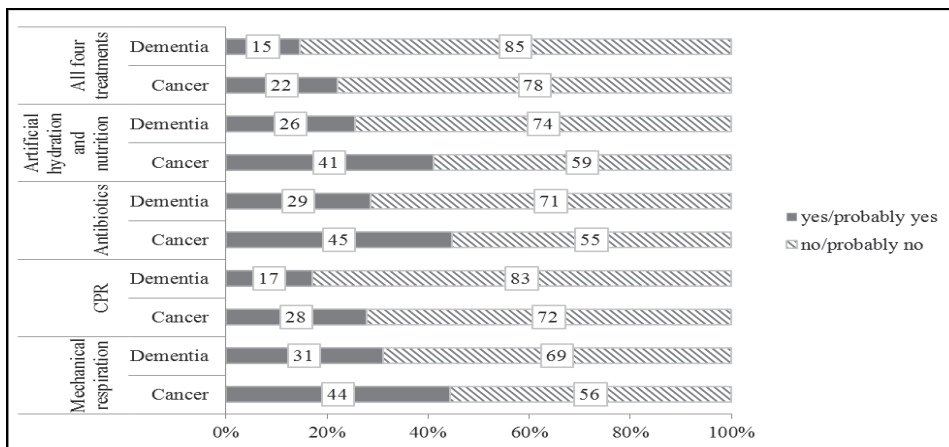
Table 1. Sample characteristics (n=1484).

		n	Adjusted mean (SD) or %
Socio-demographics			
Age (range 61-101)		1484	70.85 (7.88)
Gender	Male	670	47
	Female	814	53
Ethnicity	Dutch/Netherlands	1468	99
	Other	16	1
Religious affiliation	None	626	43
	Protestant	436	29
	Catholic	398	26
	Other	24	2
Education	Low	367	23
	Medium	542	37
	High	575	40
Household income	Low	454	32
	Medium	451	34
	High	415	34
Social support characteristics			
<i>Structural network</i>			
Partner status	Partner co-residing	961	69
	No partner co-residing	522	31
Total network size		1405	16.69 (9.66)
<i>Functional receipt of support</i>			
Practical support		1405	0.85 (0.66)
Emotional support		1402	1.72 (0.71)
<i>Perceived receipt of support</i>			
Loneliness score		1454	1.81 (2.41)
Physical health			
Chronic disease and co-morbidity	No chronic disease	334	25
	Has one or more chronic diseases	1149	75
Own perception of health		1481	2.31 (0.90)
Experience of pain	Yes	466	30
	No	1000	70
Physical limitations		1483	1.34 (1.93)
Mental health			
Cognitive functioning	Low cognitive functioning	89	5
	Normal cognitive functioning	1394	95
Anxiety		1482	2.69 (3.02)
Depressive symptoms		1479	7.29 (6.81)
True n, adjusted valid percentages and adjusted mean and standard deviation reported (SD) reported (adjusted = weighted for age and sex). Percentages have been rounded to whole numbers; therefore some totals are not exactly 100%. Missing values 0-11.1%. Variables with missing values >5%: household income (11.1%), network size (5.3%), practical support (5.3%) and emotional support (5.5%)			

Participants who claimed membership of a Protestant church made up 29% of the sample; 26% were members of the Catholic church, whereas just under half (43%) were non-church members. Just under a quarter of the sample had no more than primary school education (23%), whereas 37% had achieved a high level (11 years or more) of education. As participants' monthly household income was categorized into tertiles, there was an even distribution over the income categories. Participants resided with a partner made up 69% of the sample and the mean number of people in participants' personal network was 16.69 (SD 9.66). The mean support received was 0.85 (SD 0.66) for practical and 1.72 (SD 0.71) for emotional support. Loneliness was, on average, low (mean 1.81, SD 2.41). Although the majority of participants reported one or more chronic conditions (75%), mean self-perceived health (2.31, SD 0.90) was good to fair. The vast majority demonstrated normal cognitive functioning (95%). The mean anxiety score was 2.69 (SD 3.02) (indicating low anxiety) and the mean depressive symptom score was 7.29 (SD 6.81) (indicating few depressive symptoms) (Table 1).

Treatment preferences

The majority of participants preferred to forgo one or more life-sustaining treatments: 78% and 85% in the cancer and dementia scenario respectively. Treatment preferences, however, depended on the end-of-life scenario and the specific treatment in question: in the dementia scenario, more participants wanted to forgo all treatments. In the cancer scenario, a similar proportion of people desired antibiotics (45%), mechanical respiration (44%) and artificial hydration and nutrition (41%). The least frequently desired treatment was CPR, preferred by 29% of participants. Likewise, in the dementia scenario, similar proportions of people desired antibiotics (29%), mechanical respiration (31%) and artificial hydration and nutrition (26%). The least frequently desired treatment was CPR, preferred by 17% of participants (Graph 1). Responses for life-sustaining treatment preferences correlated highly with each other. Correlation coefficients were lower in the cancer scenario (ranging from 0.55 to 0.73), however, compared with the dementia scenario (ranging from 0.66 to 0.79) (data not shown).



Graph 1. Older people's preferences for each life-sustaining treatments (n=1484). Adjusted valid percentages reported (weighted for age and sex). Missing values for treatment preferences were 8.2-9.4% cancer and 9.2-10.9% dementia scenario. Missing values for the variable "all four treatments", a combination of individual preference responses, were 11.9% cancer and 13.5% dementia scenario.

Factors associated with forgoing treatment

Factors associated with the desire to forgo one or more end-of-life treatments in univariate and multivariable analyses are shown in Table 2 for the cancer scenario and Table 3 for the dementia scenario. Factors significant in multivariable analysis are discussed below.

Socio-demographic characteristics

Increasing age was negatively associated with the desire to forgo one or more end-of-life treatments in multivariable analysis in the cancer scenario only (OR 0.97).

Although gender was not significantly associated with the desire to forgo in univariate analysis in either scenario, female gender was positively associated with forgoing in the multivariable analysis in the cancer scenario (OR 1.76), indicating a possible suppressor effect. Entering other independent variables individually into a forced enter regression with gender (analysis not shown) revealed that female gender was significantly positively associated with forgoing in the case of cancer when any of the following were controlled for: church membership; education; income; and emotional support.

Table 2. Associations between participant characteristics and the desire to forgo one or more end-of-life treatments in case of cancer.

		Cancer		
		Prefer to forgo treatments n (%)§	Univariate OR (95% CI)	Multivariable† OR (95% CI)
Socio-demographics				
Age		1005 (78)	0.97 (0.95, 0.98)***	0.97 (0.94, 0.99)**
Gender	Male	454 (77)	1	1
	Female	551 (79)	1.19 (0.92, 1.54)	1.76 (1.23, 2.51)**
Ethnicity	Dutch/ Netherlands	999 (78)	1	1
	Other	6 (38)	0.22 (0.08, 0.64)**	0.09 (0.02, 0.34)***
Religious affiliation	None	493 (88)	1	1
	Protestant	241 (66)	0.26 (0.19, 0.36)***	0.23 (0.16, 0.34)***
	Catholic	257 (74)	0.39 (0.28, 0.55)***	0.38 (0.26, 0.57)***
	Other	14 (81)	0.50 (0.16, 1.57)	0.44 (0.12, 1.57)
Education	Low	210 (70)	1	1
	Medium	344 (75)	1.28 (0.93, 1.75)	1.09 (0.73, 1.62)
	High	451 (85)	2.37 (1.70, 3.32)***	1.58 (1.01, 2.48)*
Household income	Low	257 (66)	1	1
	Medium	318 (81)	2.00 (1.44, 2.76)***	1.85 (1.27, 2.67)**
	High	330 (87)	3.07 (2.15, 4.38)***	2.46 (1.59, 3.81)***
Social support				
<i>Structural network</i>				
Partner status	Partner co-residing	661 (78)	0.91 (0.69, 1.19)	0.61 (0.42, 0.90)*
	No partner co-residing	343 (78)	1	1
Total network size		963 (78)	1.01 (1.00 ^a , 1.03)	1.02 (1.00 ^a , 1.04)
<i>Functional receipt of support</i>				
Practical support		805 (78)	0.79 (0.65, 0.96)*	0.90 (0.70, 1.15)
Emotional support		928 (78)	0.83 (0.69, 1.01)	0.75 (0.59, 0.96)*
<i>Perceived support</i>				
Loneliness score (scores >3)		555 (77)	0.97 (0.92, 1.02)	0.98 (0.91, 1.05)
Physical health				
Chronic disease	No chronic disease	228 (78)	1.06 (0.77, 1.44)	0.67 (0.45, 1.01)
	Has one or more chronic diseases	776 (78)	1	1
Perception of health		1004 (78)	0.85 (0.73, 0.97)*	0.93 (0.75, 1.15)
Pain	Yes	307 (77)	0.94 (0.71, 1.24)	1.28 (0.86, 1.92)
	No	693 (78)	1	1
Physical limitations		541 (75)	0.94 (0.88, 1.00^a)*	0.99 (0.89, 1.10)
Mental health				
Cognitive functioning (MMSE, cut off 23/24)	Low functioning (<24)	40 (59)	1	1
	Normal functioning	964 (79)	2.45 (1.49, 4.05)***	1.38 (0.69, 2.75)
Anxiety (HADS-A, cut-off 7/8)		708 (76)	0.97 (0.93, 1.01)	0.94 (0.87, 1.01)
Depressive symptoms (CESD, cut-off 15/16)		897 (77)	0.99 (0.97, 1.01)	1.03 (0.99, 1.07)

§ True n and adjusted valid percentages reported (adjusted = weighted for age and sex).
† Multivariable logistic regressions (forced enter – two tailed). Dependent variable: 0 – desire to have all four life-sustaining treatments, 1 - desire to forgo one or more end-of-life treatments desire to forgo one or more end-of-life treatments.
*, **, and *** indicate significance at the p < .05, p < .01, and the p < .001 levels, respectively.
^a Value less than 1.00 at 3dp.
Multicollinearity tests – no tolerance values less than 0.1 and no VIF values greater than 10, no big difference in eigenvalues or variables with high proportion loadings on the same eigenvalue.

Table 3. Associations between participant characteristics and the desire to forgo one or more end-of-life treatments in case of dementia.

		Dementia		
		Prefer to forgo treatments n (%)§	Univariate OR (95% CI)	Multivariable† OR (95% CI)
Socio-demographics				
Age		1088 (85)	0.97 (0.96, 0.99)**	0.98 (0.96, 1.01)
Gender	Male	504 (85)	1	1
	Female	584 (86)	1.07 (0.79, 1.45)	1.40 (0.93, 2.10)
Ethnicity	Dutch/Netherlands	1080 (86)	1	1
	Other	8 (56)	0.28 (0.09, 0.87)*	0.18 (0.04, 0.74)*
Religious affiliation	None	523 (93)	1	1
	Protestant	266 (74)	0.21 (0.14, 0.31)***	0.17 (0.10, 0.26)***
	Catholic	284 (84)	0.37 (0.24, 0.56)***	0.39 (0.24, 0.63)***
	Other	15 (85)	0.37 (0.10, 1.34)	0.32 (0.08, 1.30)
Education	Low	237 (81)	1	1
	Medium	379 (82)	1.08 (0.75, 1.56)	0.88 (0.56, 1.39)
	High	472 (91)	2.22 (1.48, 3.33)***	1.32 (0.77, 2.24)
Household income	Low	286 (77)	1	1
	Medium	346 (87)	1.84 (1.27, 2.66)**	1.69 (1.11, 2.58)*
	High	346 (91)	3.02 (1.97, 4.64)***	2.32 (1.39, 3.88)**
Social support				
<i>Structural network</i>				
Partner status	Partner co-residing	721 (85)	1.00 (0.73, 1.38)	0.73 (0.47, 1.12)
	No partner co-residing	366 (85)	1	1
Total network size		1035 (85)	1.02 (1.00, 1.04)*	1.02 (1.00, 1.05)*
<i>Functional receipt of support</i>				
Practical support		869 (85)	0.71 (0.56, 0.89)**	0.82 (0.61, 1.09)
Emotional support		1000 (86)	0.83 (0.66, 1.04)	0.83 (0.63, 1.10)
<i>Perceived support</i>				
Loneliness score (scores >3)		591 (84)	0.94 (0.89, 1.00^a)*	0.97 (0.89, 1.05)
Physical health				
Chronic disease	No chronic disease	251 (87)	1.17 (0.81, 1.70)	0.72 (0.44, 1.17)
	Has one or more chronic diseases	836 (85)	1	1
Perception of health		1087 (85)	0.82 (0.70, 0.97)*	1.04 (0.81, 1.33)
Pain	Yes	322 (82)	0.75 (0.55, 1.03)	1.08 (0.68, 1.71)
	No	760 (87)	1	1
Physical limitations		580 (82)	0.87 (0.81, 0.93)***	0.90 (0.80, 1.01)
Mental health				
Cognitive functioning (MMSE, cut off 23/24)	Low functioning (<24)	44 (72)	1	1
	Normal functioning	1043 (86)	2.40 (1.35, 4.24)**	1.67 (0.80, 3.51)
Anxiety (HADS-A, cut-off 7/8)		765 (84)	0.93 (0.89, 0.97)**	0.91 (0.83, 0.99)*
Depressive symptoms (CESD, cut-off 15/16)		971 (85)	0.98 (0.96, 1.00^a)*	1.04 (1.00 ^a , 1.09)
§ True n and adjusted valid percentages reported (adjusted = weighted for age and sex).				
† Multivariable logistic regressions (forced enter – two tailed). Dependent variable: 0 – desire to have all four life-sustaining treatments, 1 - desire to forgo one or more end-of-life treatments.				
*, **, and *** indicate significance at the p < .05, p < .01, and the p < .001 levels, respectively.				
^a Value less than 1.00 at 3dp.				
Multicollinearity tests – no tolerance values less than 0.1 and no VIF values greater than 10, no big difference in eigenvalues or variables with high proportion loadings on the same eigenvalue.				

Membership of a minority ethnic group was negatively associated with the desire to forgo treatments in multivariable analysis in case of cancer (OR 0.09) and dementia (OR 0.17). Religious affiliation was also significant: multivariable analysis showed membership of the Catholic or a Protestant church to be negatively associated with the desire to forgo treatments, compared with no religious affiliation in the cancer (Protestant OR 0.23, Catholic OR 0.38) and dementia scenario (Protestant OR 0.17; Catholic OR 0.39).

Multivariable analysis indicated that, in the cancer scenario, a high level of education (11 years or more) was positively associated with the desire to forgo, compared with a low level of education, (OR 1.60). Also in the cancer scenario, higher monthly household income categories were positively associated with the desire to forgo, compared with the low income category, in the case of cancer (medium OR 1.84, high OR 2.45) and dementia (medium OR 1.69, high OR 2.30).

Social support

Partner status was not significantly associated with forgoing treatments in univariate analysis. However, multivariable analysis indicated that living with a partner, compared with living without a partner, was negatively associated with the desire to forgo treatments in the cancer scenario (OR 0.61) – again, a potential suppressor effect. Further analysis (not shown) revealed that living with a partner was significant when either age or personal network size was controlled for.

Personal network size was positively associated with the desire to forgo treatments in multivariable analysis in case of dementia (OR 1.02).

Emotional support was not significantly associated with forgoing treatments in univariate analysis. However, it showed a protective effect in multivariable analysis for the cancer scenario (OR 0.75) (Table 2). Further analysis (not shown) demonstrated that when age, sex, ethnicity, education or network size was controlled for, emotional support was significant.

Health

In multivariable analysis, only one health related factor was significantly associated with a desire to forgo treatments once other factors had been controlled for: anxiety was negatively associated with the desire to forgo treatments for the dementia scenario only (OR 0.91).

Discussion

The findings illustrate that, when faced with end-of-life scenarios involving cancer and dementia, the majority of older people prefer to forgo a life-sustaining treatment. Treatments were desired less frequently in the dementia compared to the cancer scenario and participants' preferences to forgo treatments were also most consistent in the dementia scenario. This suggests that older people find cognitive impairment less acceptable than physical cancer pain, even when such pain is accompanied with an inability to communicate.

Although previous research has found that more invasive procedures are, in general, less acceptable than non-invasive treatments, such as antibiotics, that was not the case in this study. Mechanical ventilation, an intensive and invasive intervention, was the second most frequently preferred treatment in the cancer scenario and the most frequently preferred treatment in the dementia scenario. This may reflect specific fears surrounding suffocating or choking to death[35-37] or participants' understanding of what the treatment entails, which may have been influenced, for example, by media representations that depict ventilation as part of a 'controlled death' in which family members are able to say goodbye before ventilation is withdrawn. Cardio-pulmonary resuscitation, the burdens of which are perhaps more commonly understood, was however the least preferred treatment.

Preferences for forgoing treatments differed in relation to participants' characteristics. The complex relationship between the multidimensional 'social support' variable and treatment preferences was perhaps the most novel finding. Personal network size was positively associated with forgoing treatments in the dementia scenario. A potential explanation is linked to the greater possibility of encountering end-of-life situations involving friends, family or acquaintances that a larger social network brings. These encounters and the resultant awareness of the suffering experienced at the end of life may engender negative attitudes towards life-sustaining treatments, particularly in the case of cognitive decline. Living with a partner and receipt of higher levels of emotional support from one's personal network, in contrast, were associated with a preference to have all four treatments in the cancer scenario. A live-in partner is commonly the most important source of practical and emotional support, and an emotionally supportive and close network may damper any desire to hasten death when faced with cancer. In contrast, mental deterioration might be perceived as damaging to close personal relationships, which may prove less acceptable. Within a Fundamental Cause Theory framework, the findings suggest that those with more immediate or emotionally supportive social

resources are more likely to wish to extend their lives in poor physical, but not mental, health.

In contrast, participants' physical and mental health – often considered important determinants of treatment preferences – were not associated with end-of-life treatment preferences once other factors had been controlled for (with the exception of anxiety and a preference for all four treatments in dementia). This suggests that, contrary to the predictions of Prospect Theory, in general, they are of limited importance to people's preference choices. Moreover, it is possible that participants suffering from anxiety have exaggerated fears about the withholding of treatments in the case of cognitive decline.

Older age was negatively associated with the desire to forgo treatments in the cancer scenario. In contrast, previous studies amongst older people from the United States have found age to be positively associated with a desire to forgo treatments[4,5,10]. In addition to an age effect, however, a cohort effect may be considered. The younger old in the current study may have been particularly influenced by the intense public debate concerning end-of-life care that occurred six years prior to data collection, around the time of the legalization of euthanasia[38,39]. To date, the item regarding life-sustaining treatment preferences has only been included in one round of LASA data collection, future use of this item would provide the longitudinal data necessary to determine if this finding is a result of a specific cohort effect or the effect of ageing on preferences.

Other socio-demographic characteristics were associated with end-of-life treatment preferences in ways that, in general, supported previous research. Women were more likely to express a preference to forgo treatments in the cancer scenario and this finding is consistent with those of other studies that have found women to prefer less aggressive end-of-life care[3,8,9,13,17,22]. Arber *et al.*[7], in a qualitative study of older people's attitudes towards life-prolonging technology, related women's preference to forgo life-sustaining treatments to their greater life-time involvement in caring for others and putting the concerns of others before their own.

Membership of a minority ethnic group was strongly associated with a preference for all four life-sustaining treatments. Although the Netherlands is a multicultural society, mass immigration only began in the late 1960s and the age structure of the minority ethnic population is younger than that of the Dutch white population[40]. Due to the age of the LASA participants, few participants were members of a minority ethnic group; this makes the magnitude and significance of the association even more

remarkable. De Graaff *et al.*[41], in a qualitative study amongst patients and carers of Turkish and Moroccan descent (two of the largest minority ethnic groups in the Netherlands), revealed that patients and families prefer starting life-sustaining treatments to maintain hope of recovery.

Another important socio-demographic variable was church affiliation. Protestant and Catholic affiliations were negatively associated with forgoing life-sustaining treatments. Although neither the Catholic nor the major Dutch Protestant churches oppose forgoing 'extraordinary' life-sustaining measures[42-44], the churches' vitalist rhetoric in connection to the euthanasia debate may have created ambiguity regarding their position amongst their members.

Forgoing treatments was also associated with a high level of education (11 years or more). Garrett *et al.*[3], in a survey of older patients concerning treatment preferences, observed a similar association. Better-educated participants may be more informed about the burden of life-sustaining treatments and, therefore, choose to forgo them.

Higher monthly household income was positively associated with the desire to forgo treatments. The importance of income, even when education and other socio-demographic variables were controlled for, is striking. Carr *et al.*[45] found a similar association between net worth and advance directive possession and hypothesized that those with greater financial resources may be more inclined to write a will and, in doing so, be encouraged to carry out health care planning.

Strengths and limitations

This is the first study to examine older Dutch people's preferences for different life-sustaining treatments within a representative sample of the older population. Moreover, it is the first to comprehensively examine the influence of social support next to socio-demographic, physical and mental health factors on preferences for life-sustaining treatments.

There were, however, some limitations. Participants were asked about treatment preferences but were not provided with detailed descriptions of the treatments or associated burdens. It is, therefore, unclear how informed preferences were. Furthermore, preferences in hypothetical scenarios may not reflect decisions in situations of actual illness. Advance directive documents, however, often require people to identify preferences regarding specific treatments in hypothetical situations.

There was a relatively high proportion of missing data regarding treatment preferences. Non-responders and participants for whom the main outcome variable was missing also had statistically different characteristics to those who did complete the items. These findings may reflect the challenges older and less educated participants faced answering a self-administered questionnaire or indeed the difficulty many people have thinking about end-of-life preferences. As responders and non-responders differed on variables found to be associated with treatment preferences (age, sex, church membership and education), this may have led to a slight underestimation in the preference for each life sustaining treatment.

Conclusions

In light of findings that many older people would prefer to forgo life-sustaining treatments at the end of life, particularly in the case of dementia, it is imperative that preferences are discussed with relatives and healthcare professionals in a timely manner to avoid unwanted interventions.

In this population, social support had a greater influence on preferences than participants' current physical, cognitive and emotional health. As social structures continue to change, it is important to understand how social support might influence medical end-of-life treatment preferences. This, together with awareness of the more commonly recognized influences of socio-demographic characteristics and health, may enhance the advance care planning process by encouraging healthcare professionals to explore patients' expectations and fears about social support at the end of life.

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Chapter 7

How do general end-of-life goals and values relate to specific treatment preferences? A population-based study

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Published in *Palliative Medicine* [Epub ahead of print June 2014]

Abstract

Background: There is a lack of research on the relationship between general end-of-life goals and values and preferences for specific life-sustaining treatments.

Aim: To examine agreement between Dutch older people's general end-of-life goals and specific life-sustaining treatment preferences.

Design: Participants identified general end-of-life goals in an interview and preferences for four life-sustaining treatments in hypothetical cancer and dementia scenarios in a separate questionnaire. Agreement between general goals and specific treatment preferences was calculated.

Setting/participants: In total, 1818 older people from 11 representative Dutch municipalities participated in the study.

Results: In total, 1168 answered questions on general end-of-life and specific treatment preferences. Agreement between a desire to live as long as possible, irrespective of health problems, and a preference for life-sustaining treatments ranged from 51 to 76% in cancer and 41 to 60% in dementia scenarios, depending on the treatment. Agreement between a desire for a shorter life, if without major health problems, and a preference to forgo treatments ranged from 61 to 79% in cancer and 75 to 88% in dementia scenarios.

Conclusion: For a sizable minority of participants, specific treatment preferences did not agree with their general end-of-life goals. The more frequent desire to forgo treatments in case of dementia than cancer suggests that physical deterioration is more acceptable than cognitive decline. The findings underline the importance of discussing general care goals, different end-of-life scenarios and the risks and burdens of treatments to frame discussions of more specific treatment preferences.

Introduction

End-of-life treatment preferences have typically been examined in two ways: determining specific life-sustaining treatments preferences[1-3] and identifying general goals or outcomes of care[4-6], such as maintaining quality of life.

Determining treatment preferences involves people in decisions about future care, strengthening autonomy. However, people may not thoroughly understand the risks and burdens of treatments. Moreover, because it is impossible to foresee all potential circumstances and treatments, knowledge of specific treatment preferences is often insufficient to guide all end-of-life decisions[7]. Questions also remain about people's ability, when relatively healthy, to predict preferred treatments during future incapacity[8-10]. In light of these shortcomings, some authors recommend that determining general end-of-life values and goals may be as, or more, useful in guiding decisions[6,11,12]; such information could orientate health care practitioners, who are perhaps better able to judge the potential outcomes of interventions.

Few studies, however, have investigated the relationship between general end-of-life goals and values and specific life-sustaining treatments preferences. Two studies that did found general care goals to be poor predictors of treatment preferences[13,14]. Schneiderman *et al.*[13] examined the relationship between choice of three brief care instructions (general care goals) and specific life-sustaining treatment preferences. However, 45 participants chose the first care instruction, 11 the second and just two the third: limiting comparison and statistical power[13]. Fischer *et al.*[14] compared general care goals along with specific treatment preferences in different health scenarios. This study, however, was only conducted amongst physicians[14].

Drawing on data from the Longitudinal Ageing Study Amsterdam (LASA) – a population based study[15] – this article examines the relationship between older people's general end-of-life goals and specific end-of-life treatment preferences: specifically, the relationship between general preferences for quantity vs. quality of life and preferences for artificial hydration and nutrition, antibiotics, cardio-pulmonary resuscitation (CPR) and mechanical respiration in hypothetical cancer and dementia scenarios. If general goals agree with specific treatment preferences, participants who preferred to have a longer life, irrespective of health problems, would be expected to prefer life-sustaining treatments, whereas those who prefer a shorter life, if without major health problems, would be expected to favor forgoing treatments.

Methods

2.1 Sample

To date, the LASA study incorporates two nationally representative cohorts of older people, selected via random stratified sampling from 11 Dutch municipality registers[15]. Men and older participants were deliberately oversampled (to maintain members of these high mortality groups throughout the study)[15]. The first cohort (aged 55-85) was recruited in 1992/93, and the second (aged 55-64) in 2002/03. Data were collected at three-year intervals through a face-to-face interview, self-administered questionnaire and medical interview[15]. Described in more detail elsewhere, the study has a low drop-out rate, most of which is due to mortality[15]. The Medical Ethics Committee of the VU University Medical Center approved the study and participants gave written informed consent.

Measurement instruments

Socio-demographics (age, gender, religious affiliation and education) and health characteristics (presence of chronic disease) were ascertained from population registries and face-to-face interviews, respectively. General end-of-life goals were measured during the face-to-face interview via a question on quantity vs. quality of life (Box 1). During this interview, a self-administered questionnaire was left for participants to complete and hand-in during a subsequent medical interview. In the questionnaire, participants were asked to indicate preferences for artificial hydration and nutrition, antibiotics, CPR and mechanical respiration in case of cancer and dementia (Box 1). Vignettes concerning cancer and dementia were chosen because previous research has shown distinct life-sustaining treatment preferences if faced with physical or cognitive decline[16-19]. Questions were piloted with ten older people looking at whether the questions were understandable and acceptable for the respondent group. For this, the 'think aloud' method was used[20]. Where necessary questions were adjusted.

Analysis

Sample characteristics, treatment preferences and agreement with general goals were described using true numbers and adjusted percentages or means (weighted for sex and age, standard: Dutch population 01/01/2009[21]). Differences in treatment preferences between participants with different general end-of-life goals were assessed using Pearson's chi-squared.

Question on general care goals (asked during the main face to face interview)

When you think about the future, which do you prefer?

- A. To live as old as possible, irrespective health problems
- B. To have a shorter life, if without major health problems

Question on specific end-of-life treatment preferences (asked in the self-administered questionnaire)

Scenario 1.

You are diagnosed with cancer, which has spread throughout your body. The disease is incurable. For some days you have not been responsive to any form of communication. You show clear signs of severe pain and agitation.

Scenario 2.

You suffer from dementia and no longer recognize your family or friends. You refuse to eat and drink and you are becoming increasingly withdrawn. It is no longer possible to discuss treatment options with you.

Preferences regarding four medical end-of-life treatments

	Yes	Probably yes	Probably not	No
Would you, in the above situation, wish to receive artificial hydration and nutrition (through a nasal gastric tube)?	1	2	3	4
Would you, in the above situation, wish to be given antibiotics if you got pneumonia?	1	2	3	4
Would you, in the above situation, want cardiopulmonary resuscitation in the event of a cardiac arrest?	1	2	3	4
Would you, in the above situation, want mechanical respiration?	1	2	3	4

Box 1. Questions on quality vs. quantity of life and medical end-of-life treatment preferences.

Results

In the 2008/09 data collection cycle, there were 1818 participants (985 from the first and 833 from the second cohort) and 1601 participants participated in a face-to-face interview and were subsequently invited to participate in the self-administered questionnaire. Of these, 1168 (73%) answered questions on specific treatment preferences in the questionnaire and a question about general end-of-life goals during the interview. Participants who did not answer the questionnaire ($n=118$), or who did not respond to end-of-life preferences questions ($n=315$), were older ($p<0.001$), more frequently female ($p<0.001$), church members ($p<0.001$) and had lower education ($p<0.001$). Ethnicity did not differ between the two groups, however, only 1% were non-white Dutch. Participants' socio-demographic and health characteristics are shown in Table 1.

Table 1. Sample characteristics (n=1168)

Socio-demographic characteristic		n	Adjusted sample mean and 95% CI or proportion of sample
Age (range 61-99)		1168	70.21 (7.49)
Gender	Male	560	50
	Female	608	50
Ethnicity	Dutch/Netherlands	1158	99
	Other	10	1
Religious affiliation	None	519	46
	Protestant	317	26
	Catholic	316	27
	Other	16	2
Education	Low	254	21
	Medium	416	36
	High	498	44
Chronic disease	No chronic disease	266	25
	Has one or more chronic diseases	902	75

No missing values. True n, adjusted valid percentages and adjusted mean reported (adjusted = weighted for age and sex). Percentages have been rounded to whole numbers, therefore some totals are not exactly 100%.

End-of-life preferences

In total, 13.5% (n=156) of participants wanted to live as long as possible, irrespective of health problems, whereas 86.5% (n=1012) preferred a shorter life, if without major health problems. There were significant differences ($p<0.001$) in preferences for artificial hydration and nutrition, antibiotics, CPR and mechanical respiration in hypothetical cases of cancer and dementia between participants who sought to extend life and who sought to maximize quality of life (Tables 2 and 3).

Agreement between a preference for a longer life and the desire for a treatment ranged from 51% (CPR) to 76% (antibiotics) in the cancer scenario (Table 2), and from 41% (CPR) to 60% (antibiotics and mechanical respiration) in the dementia scenario (Table 3). Of those who preferred a longer life, 46% wanted all life-sustaining treatments, 38% preferred one to three treatments, and 17% wanted no treatments in the case of cancer (Table 2). In the case of dementia, of those who preferred a longer life, 38% wanted all treatments, 32% wanted one to three treatments, and 30% wanted no treatments (Table 3).

Table 2. Relationship between preferences for four life-sustaining treatments and longevity/health preferences in case of cancer (n=1168).

Cancer scenario		All participants		Preference for quality vs. quantity of life				P value*
				As old as possible, irrespective of health problems		Shorter life, if without major health problems		
Medical end-of-life treatment	Preference for treatment	n	% ^a	n	% ^a	n	% ^a	
Artificial hydration and nutrition	Yes/probably yes	481	40	107	69	374	36	<i>P</i> <0.001
	No/probably no	687	60	49	31	638	64	
Antibiotics	Yes/probably yes	514	43	120	76	394	38	<i>P</i> <0.001
	No/probably no	654	57	36	24	618	62	
Cardiopulmonary resuscitation	Yes/probably yes	311	25	83	51	228	21	<i>P</i> <0.001
	No/probably no	857	75	73	49	784	79	
Mechanical respiration	Yes/probably yes	507	43	109	69	398	39	<i>P</i> <0.001
	No/probably no	661	57	47	31	614	61	
Preference for all treatments	Wants all treatments	254	21	73	46	181	17	<i>P</i> <0.001
	Wants 1, 2 or 3 treatments	399	35	59	38	340	34	
	Wants no treatments	515	45	24	17	491	49	

^a Percentages are weighted to population age and sex distribution.

* Test for differences Pearson's chi-sq.

Table 3. Relationship between preferences for four life-sustaining treatments and longevity/health preferences in case of dementia (n=1168).

Dementia scenario		All participant s		Preference for quality vs. quantity of life				
				As old as possible, irrespective of health problems		Shorter life, if without major health problems		P value*
Medical end-of-life treatment	Preference for treatment	n	% ^a	n	% ^a	n	% ^a	
Artificial hydration and nutrition	Yes/probably yes	290	25	86	56	204	20	<i>P</i> <0.001
	No/probably no	878	75	70	44	808	80	
Antibiotics	Yes/probably yes	325	27	95	60	230	22	<i>P</i> <0.001
	No/probably no	843	73	61	40	782	78	
Cardiopulmonary resuscitation	Yes/probably yes	197	16	66	41	131	12	<i>P</i> <0.001
	No/probably no	971	84	90	59	881	88	
Mechanical respiration	Yes/probably yes	355	30	94	60	261	25	<i>P</i> <0.001
	No/probably no	813	70	62	40	751	75	
Preference for all treatments	Wants all treatments	175	14	60	38	115	11	<i>P</i> <0.001
	Wants 1, 2 or 3 treatments	257	22	50	32	207	21	
	Wants no treatments	736	64	46	30	690	69	

^a Percentages are weighted to population age and sex distribution.

* Test for differences Pearson's chi-sq.

Agreement between a preference for a shorter, better quality life, and the desire to forgo treatments ranged from 61% (mechanical respiration) to 79% (CPR) in the cancer scenario (Table 2), and from 75% (mechanical respiration) to 88% (CPR) in the dementia scenario (Table 3). Of those who preferred a shorter life, 17% wanted all life-sustaining treatments, 34% preferred one to three treatments, and 49% wanted no treatments in the cancer scenario (Table 2). In the dementia scenario, of those who preferred a shorter life, 11% wanted all treatments, 21% wanted one to three treatments, and 69% wanted no treatments (Table 3).

Discussion

The study reveals a majority agreement between general end-of-life goals and specific treatment preferences. For a sizable minority of participants, however, general goals did not agree with specific life-sustaining treatment preferences. Poor understanding of the risks and burdens of life-sustaining treatments or different understandings of their purpose may cause disagreement between general and specific end-of-life preferences. For example, a qualitative study[22], revealed that patients often perceived life-sustaining treatments differently than their physicians – as acceptable to meet short-term goals (e.g. to reassess their medical condition or to say goodbye to loved ones) but not long-term dependence.

Regardless of general end-of-life goals, more participants preferred forgoing treatments in case of dementia compared with cancer. This suggests that physical deterioration is more acceptable than cognitive decline and supports findings from previous research[16-19,23]. It also supports the interpretation that patients may view treatments as acceptable for meeting short-term goals, which are easier to make in physical than cognitive decline.

In the dementia scenario, agreement between general care goals and specific treatment preferences was highest amongst those who preferred a shorter, better quality, life. This finding resonates with longitudinal research showing preferences for refusing life-sustaining treatments to be more stable over time than preferences for accepting treatments[24-26].

Strengths of the study include the use of a large population-based representative sample and the separate measurement of general end-of-life goals and specific treatment preferences (minimizing question order[27] and item context effects[28]). There were, however, limitations. Participants were not provided descriptions of treatments or associated burdens, therefore it is unclear how informed preference choices were. The study also reports the preferences of older people, rather than

people nearing death. Future research might recruit participants according to specific end-of-life illness trajectories[29,30], and explore participants' experiences of treatments, to differentiate between hypothetical and personal end-of-life scenarios.

Non-responders' and respondents' characteristics differed, reflecting the challenges older and less-educated participants face answering self-administered questionnaires or the confronting nature of the questions. Patients with these characteristics frequently receive substandard patient-physician communication[31,32], future research examining reasons for non-response might help identify patient-based barriers to end-of-life communication.

Conclusion

Although general end-of-life goals were predictive of specific life-sustaining treatment preferences for the majority of participants, for a sizable minority general goals and specific treatment preferences did not agree. Advance care planning involves patients, families and health care practitioners considering end-of-life values and goals and articulating preferences[33]. This study underlines the importance of promoting a stepwise process of discussing general care goals before specific treatment preferences to frame discussions within the context of general goals, different end-of-life scenarios and the risks and burdens of treatments. A Dutch initiative "Guide to timely talk about the end of life", for example, promotes and provides practical tips on GP-patient end-of-life discussions for anyone who would like them, including older people and those with life limiting illnesses and covering both general and personal end-of-life scenarios, in GP[34] and patient[35] leaflets.

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Chapter 8

Older Dutch people's advance directive possession before and after the enactment of the euthanasia law: a time trend study (1998- 2011)

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Submitted

Abstract

This time trend study describes 'euthanasia' and 'care' advance directive (AD) possession amongst representative samples of Dutch older people from 1998 to 2011 and factors associated with possession. Euthanasia ADs represent a request for euthanasia under specific circumstances, whereas care ADs outline an opposition to euthanasia. The data can provide insight into the influence of the 2002 Dutch euthanasia law on 'euthanasia' and 'care' AD possession. A total of 2576 participants were asked about AD possession in face-to-face interviews during one or more data collection cycle (1998, 2005, 2008 and 2011). Possession of 'euthanasia' and 'care' ADs in each collection cycle was described and associations with personal characteristics analysed with multivariable logistic regression using generalized estimating equations. 'Euthanasia' AD prevalence was 6.8%, 4.3%, 6.4% and 6.2%, and 'care' AD prevalence was 1.3%, 0.2%, 0.1% and 0.4% in 1998, 2005, 2008 and 2011 respectively. The odds of possession 'euthanasia' and 'care' ADs were significantly lower in 2005 and 2008 compared with 1998. There were, however, no significant differences in the odds of possessing a 'euthanasia' or a 'care' AD between 1998 and 2011. Health factors had little or no influence on AD possession. This suggests a stability of preferences in various states of health and supports the legitimacy of ADs. The findings also suggest that the 2002 euthanasia law negatively influenced the possession of euthanasia and care ADs in the period directly following its enactment.

Introduction

Advance directives (ADs), documents that outline end-of-life preferences in case of future loss of decision-making capacity, are frequently promoted as a way to extend patient participation and autonomy at the end of life. Despite a general strengthening of their legal status in Europe[1-3], surveys reveal low uptake in general and older populations across Europe (between 2 and 10%[4-10]). Compared with the United States, these figures are low (uptake from American studies range from 20 to 55%, depending on the population)[11-13].

Attempts to understand the factors that influence AD possession have often focussed on the influence of personal characteristics[7,9,14-20], the effect of (macro-level) societal influences, such as the legal and policy context, are however less well understood. For example, in the US, the implementation of the 1991 Patient Self-Determination Act, which required health care institutions to inform patients about ADs, led to increased documentation of people's ADs, although not actual AD possession[11,21,22].

Advance directives can be instructional directives, which outline end-of-life treatment preferences, or proxy directives, which name a surrogate decision-maker[1]. Broadly, three types of instructional ADs are available in the Netherlands: non-treatment ADs, which detail unwanted treatments, such as cardio-pulmonary resuscitation; euthanasia ADs, which outline a desire for euthanasia under certain circumstances; and value-based 'care' ADs, which explicitly oppose euthanasia and state support for palliative care. Non-treatment ADs are legally binding under the 1995 Medical Treatment Contract Act[1]. Euthanasia ADs are covered by the 2002 Law on Euthanasia and Assisted Suicide and are not legally binding[1]. Euthanasia ADs first received legal recognition in the 2002 euthanasia law, they were however encountered in clinical practice before that date because euthanasia and assisted suicide had been tolerated and exempt from prosecution since the early 1990s, if conducted by a physician within prescribed standards of care[23]. These standards required an explicit request for euthanasia from the patient; the 2002 law however clarified that this request could also be made in the form of a euthanasia AD[24]. Stating an opposition to euthanasia in a care AD is, judicially, unnecessary as euthanasia is only legal with an explicit request, but reflects a desire never to request euthanasia.

This study describes the trend over time in AD possession amongst older Dutch people, participants of the Longitudinal Aging Study Amsterdam (LASA), and identifies the socio-demographic, social support, physical and mental health factors associated

with possession. The data, spanning from 1998 to 2011, are well-suited to study the impact the 2002 euthanasia law had on AD possession. As such the article focuses on the two ADs related to this law: euthanasia and care ADs. Time trend research can shed light on the effect of ageing, participants' personal characteristics and macro-level influences. Specific objectives include: to describe any trend in the possession of 'euthanasia' and 'care' ADs amongst older people in the Netherlands using data collected in 1998, 2005, 2008 and 2011; and to analyse and compare associations between older peoples' socio-demographic, social support and health characteristics and possession of 'euthanasia' and 'care' ADs.

Methods

LASA is a population based, longitudinal cohort study examining 'predictors and consequences of changes in physical, emotional, and social functioning in older people'[25].

Sample

To date, two nationally representative cohorts of older people have been included in LASA. The cohorts were selected via random stratified sampling from population registers of eleven Dutch municipalities, chosen to represent Protestant, Catholic and secular areas and different levels of urbanisation[25]. The samples were stratified for age and sex and there was a deliberate oversampling of men and older participants to maintain some members from these high mortality groups throughout the study[25]. The first cohort, aged 55-85, was recruited in 1992/93 and the second, aged 55-64, in 2002/03. Data were collected from both cohorts at three year intervals through a face-to-face interview, followed, 2-6 weeks later, by a medical interview and a self-administered questionnaire[25]. The LASA study has a low drop-out rate: most attrition is due to mortality and much lower attrition results from frailty, refusal to participant and loss of contact[25]. The Medical Ethics Committee of the VU University Medical Center approved LASA and all participants gave written informed consent.

Although the missing values for the question regarding AD possession were low (between 0.3 and 3.6%, depending on the year), across the collection years, non-responders were found to be significantly older (Pearson's chi-square, $p < 0.001$), more frequently female ($p < 0.05$) and more frequently non-church members ($p < 0.001$).

Measurement instrument

A question on AD possession was asked during face-to-face interviews in 1998, 2005, 2008 and 2011. Participants' ADs were categorized as 'non-treatment', 'euthanasia', 'care' or 'other' (a diffused group including, where specified, proxy ADs, instructions

for leaving the body to medical science and financial wills amongst others). 'Non-treatment' and 'other' ADs were not included in analyses.

Socio-demographics, social support and health characteristics were ascertained from population registries, face-to-face interviews and medical interviews, respectively. Socio-demographic characteristics included: age; gender; membership of a church/religious organisation (Protestant, Roman Catholic or other); education level (low [≤ 6 years], medium [7–11 years] or high [≥ 11 years]); and monthly net household income. Household income was multiplied by 0.7 if participants lived with a partner to make it comparable to that of a single person household. Using the data collection year's modal income, household income was categorized into 'below modal' and 'above modal' income.

Three dimensions of social support were measured. The first, 'structural characteristics', consisted of the partner status (co-residing with a partner or not) and personal network size. Personal network size was defined as the number of named persons aged 18 or over with whom the participant had important and regular contact [maximum 80][26]. The second, 'functional characteristics of support', consisted of the practical and emotional support received from frequently contacted personal network members. Participants were asked how often they received practical or emotional support from the nine members of the participant's personal network with whom they had most contact in the previous year. Possible responses were: never (0), rarely (1), sometimes (2), and often (3). The mean practical and emotional support received from the nine relationships was calculated (ranging from 0-3). The final dimension of social support, 'perceived support', was a measure of participants' sense of loneliness. Loneliness was defined as the discrepancy between what one wants and what one has in terms of interpersonal affection and intimacy. This was measured using De Jong Gierveld's loneliness scale, with scores ranging from 0 to 11 and higher scores indicative of more intense loneliness[27].

Aspects of physical health measured included: chronic disease; perception of own health; experience of pain; and physical limitations. Chronic disease was determined by asking participants if they had one or more of seven common chronic diseases (chronic non-specific lung disease; cardiac disease; peripheral arterial disease; diabetes mellitus; cerebrovascular accident (CVA)/stroke; osteoarthritis/rheumatoid arthritis; and cancer). Participants were also asked to rate their own health as very good (1), good (2), fair (3), sometimes good/sometimes poor (4) and poor (5). Experience of pain was measured using Hunt *et al.*'s[28] pain scale abbreviated to five items. Scores were dichotomized, resulting in the categories 'no pain' (score 0) and

'any pain' (scores 1–5). Finally, physical limitations were measured by asking participants if they had difficulty carrying out six activities of daily living, e.g. dress and undress oneself, sit down and stand up from a chair and walk outside during five minutes without stopping (scores 0 [no difficulties] to 6 [all with difficulty]). Mental health measures included cognitive functioning and depressive symptoms. Cognitive functioning was measured with the Mini-Mental State Examination (MMSE), with scores ranging from 0 to 30 and scores of 23 or under indicating lower cognitive functioning[29]. Depressive symptoms were measured with the 20-item Center for Epidemiologic Studies Depression (CESD) Scale, with scores ranging from 0 to 60, with higher scores indicating more depressive symptoms[30]. Independent continuous variables (such as the MMSE) were used as nominal variables if they violated the assumption of linearity of the logit.

Analysis

To ensure that in all four data collection years the age range of participants was comparable, those under the age of 65 and over the age of 91 (the age of the oldest participant in 1998) were excluded from analyses.

Sample characteristics were analysed separately for each of the four data collection cycles using descriptive statistics. The percentages of participants in possession of a 'euthanasia' or 'care AD' in each of the four collection cycles were described. Due to the over-sampling of older and male participants and to aid interpretation, true values were reported but percentages were adjusted for sex and age (weighting standards: the Dutch population on January 1st of 1999, 2006, 2009 and 2012[31]).

Differences in possession of 'euthanasia' and 'care' ADs over time were examined with logistic regressions using generalised estimating equations (GEE) with time as the main independent variable. This accounted for intra-personal correlation in responses as measurement occasions were nested within individuals[32]. Because a non-linear relationship between data collection year and AD possession was observed, and due to the uneven time intervals between sampling, time was included as a discrete variable in the analysis [32]. The variables age and sex (used to create the weights), as well as the interaction between them, were included as main effects in the GEE to control for the over-sampling of male and older participants but still giving unbiased estimates and standard errors. Model specifications included a logit link function, exchangeable correlation matrix and a robust covariance matrix estimator [32].

Associations between possession of a 'euthanasia' or 'care' AD, and socio-demographic, social support, physical and mental health factors were estimated with multivariable logistic regression using GEE (using the same model specifications as above)[32]. Multicollinearity tests were conducted and interactions between age and the data collection year examined. Analyses were carried out in SPSS20 (IBM Software).

Results

A total of 2576 individual participants were asked about their AD possession between one and four times over the fourteen year study period, corresponding to the question being asked 5068 times and responded to on 4988 (98%) occasions. The characteristics of people participating in each data collection cycle are shown in Table 1.

Advance directive possession over time

Possession of a 'euthanasia AD' declined from 6.8% in 1998 to 4.3% in 2005 before increasing to 6.4% in 2008 and remaining at a similar proportion (6.2%) in 2011. The odds of possession were significantly lower in 2005 compared with 1998, although there were no significant differences in 2008 and 2011 compared with 1998 (Table 2, Graph 1).

Possession of a 'care AD' declined from 1.3% in 1998 to 0.2% in 2005 and 0.1% in 2008 before increasing slightly to 0.4% in 2011. The odds of possession were significantly lower in both 2005 and 2008 when compared with 1998. There were no significant differences in the odds of possessing a 'care AD' in 2011 compared with 1998 (Table 2, Graph 1).

Table 1. Participant characteristics during each of the four data collection cycles.

		1998-1999 N=1584	2005-2006 N=1207	2008-2009 N=1158	2011-2012 N=1119
		n (adjusted %) <i>Adjusted mean (SD)</i>	n (adjusted %) <i>Adjusted mean (SD)</i>	n (adjusted %) <i>Adjusted mean (SD)</i>	n (adjusted %) <i>Adjusted mean (SD)</i>
Age	Youngest old (65-74)	765 (59.3)	650 (59.5)	632 (59.1)	633 (67.9)
	Middle old (75-84)	576 (32.5)	430 (33.4)	421 (33.5)	376 (25.0)
	Oldest old (85-91)	243 (8.2)	127 (7.0)	105 (7.5)	110 (7.0)
	Mean (SD)	74.38 (6.61)	74.10 (6.42)	74.31 (6.57)	72.76 (6.76)
Gender	Male	698 (40.6)	530 (44.3)	515 (45.2)	501 (46.8)
	Female	886 (59.4)	677 (55.7)	643 (54.8)	614 (53.2)
Religious affiliation	None	579 (37.2)	472 (39.1)	469 (40.8)	454 (41.8)
	Protestant	517 (32.2)	365 (30.0)	353 (30.3)	332 (29.2)
	Catholic	467 (29.2)	356 (29.7)	321 (27.6)	310 (27.2)
	Other	21 (1.4)	14 (1.1)	15 (1.3)	19 (1.9)
Education	Low	651 (40.3)	367 (29.7)	303 (25.4)	255 (21.7)
	Medium	502 (31.9)	411 (34.1)	407 (35.1)	420 (38.6)
	High	431 (27.7)	429 (36.2)	448 (39.5)	440 (39.8)
Household income	Below average	1037 (74.3)	701 (65.6)	664 (63.8)	625 (60.7)
	Above average	346 (25.7)	357 (34.4)	365 (36.2)	367 (39.3)
Partner status	Partner co- residing	820 (54.5)	730 (62.4)	703 (62.4)	707 (66.8)
	No partner co- residing	764 (45.5)	477 (37.6)	455 (37.6)	412 (33.2)
Total network size		14.63 (8.76)	16.41 (9.30)	16.47 (9.75)	16.25 (9.69)
Practical support		0.82 (0.70)	0.88 (0.69)	0.90 (0.67)	0.84 (0.64)
Emotional support		1.62 (0.76)	1.67 (0.74)	1.71 (0.72)	1.69 (0.68)
Loneliness score		2.36 (2.66)	1.96 (2.51)	1.98 (2.52)	1.94 (2.53)
Chronic disease	None	350 (23.3)	245 (21.3)	226 (20.2)	226 (22.5)
	One or more	1224 (76.7)	962 (78.7)	932 (79.8)	893 (77.5)
Own perception of health		2.40 (0.86)	2.46 (0.91)	2.40 (0.89)	2.36 (0.89)
Experience of pain	Yes	515 (36.0)	433 (37.0)	373 (33.7)	386 (33.4)
	No	871 (64.0)	718 (63.0)	717 (66.3)	666 (66.6)
Physical limitations		1.59 (1.88)	1.69 (1.89)	1.57 (1.86)	1.43 (1.78)
Cognitive functioning	Low	200 (9.8)	104 (7.6)	84 (6.6)	68 (5.0)
	Normal	1384 (90.2)	1103 (92.4)	1074 (93.4)	1051 (95.0)
Depressive symptoms		8.69 (7.65)	8.51 (7.30)	7.63 (6.72)	7.83 (7.05)

True n, adjusted valid percentages and adjusted mean and standard deviation reported (SD) reported (adjusted = weighted for age and sex).

Missing value 0-12.7%. Variables with missing values over 5% for years 1998/99, 2005/06, 2008/09 and 2011/12 - n (%):

Household income 201 (12.7), 149 (12.3), 129 (11.1), 127 (11.3);

Network size 135 (8.5), 79 (6.5), 58 (5.0), 6 (5.5);

Practical support 139 (8.8), 79 (6.5), 58 (5.0), 61 (5.5);

Emotional support 141 (8.9), 56 (4.6), 68 (5.9), 67 (6.0);

Pain 198 (12.5), 60 (4.9), 75 (6.3), 71 (6.2).

Table 2. Trends in older people's advance directive possession over time.

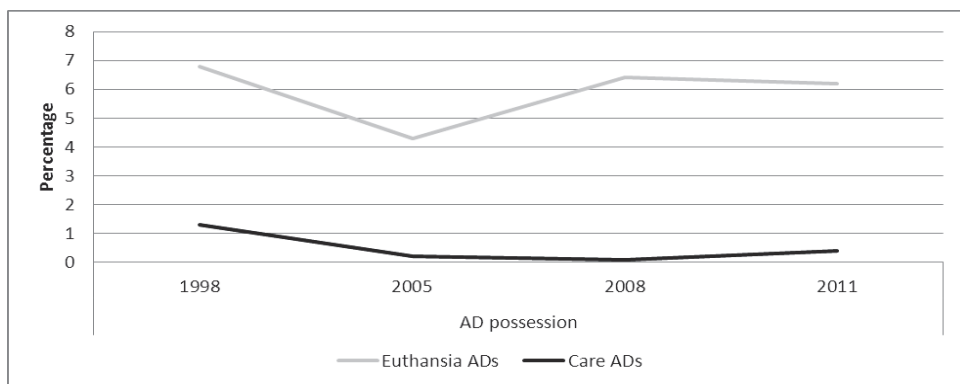
		AD possession			
		1998-1999 N=1584	2005-2006 N=1207	2008-2009 N=1158	2011-2012 N=1119
Euthanasia AD	n unadjusted	106	54	74	80
	Adjusted %	6.8	4.3	6.4	6.2
	OR (CI) †	1	0.71 (0.55, 0.92)*	0.95 (0.74, 1.24)	1.11 (0.85, 1.46)
Care AD	n unadjusted	20	2	1	6
	Adjusted %	1.3	0.2	0.1	0.4
	OR (CI) †	1	0.13 (0.02, 0.66)*	0.08 (0.01, 0.52)**	0.46 (0.19, 1.10)

Unadjusted numbers and adjusted valid percentages reported (adjusted = weighted for age and sex).

Missing values: 1998-1999 - 16 (1%); 2005-2006 - 44 (3.6%); 2008-2009 - 17 (1.5%); 2011-2012 - 3 (0.3%).

†Logistic regression using generalised estimating equations (GEE). The variables age, sex and age*sex were included as main effects in the GEE (ORs not shown) to control for the over-sampling of male and older participants.

*, **, and *** indicate significance at the $p < .05$, $p < .01$, and the $p < .001$ levels, respectively.

**Graph 1.** Trend in older people's possession of euthanasia and care advance directives over time (adjusted percentages).

Factors associated with AD possession

Revisiting the time trend, and controlling for all sample characteristics, the odds of possessing a 'euthanasia AD' were significantly lower in 2005/06 and 2008/09 compared with 1998/99 (Table 3). There were still no significant differences in the odds of 'euthanasia AD' possession in 2011 compared with 1998. 'Euthanasia AD' possession was positively associated with increasing age, female gender, higher educational attainment and higher household income (Table 3); possession was negatively associated with membership of the Catholic or a Protestant church compared with no religious affiliation (Table 3).

Table 3. Associations between participant characteristics and possession.

		Euthanasia ADs	Care ADs
		Multivariable	Multivariable
		OR (95% CI)†	OR (95% CI)†
Study period §	1998-99	1	1
	2005-06	0.50 (0.36, 0.69)***	0.17 (0.03, 0.82)*
	2008-09	0.72 (0.52, 0.99)*	0.11 (0.01, 0.79)*
	2011-2012	0.78 (0.57, 1.07)	0.56 (0.23, 1.34)
Age category §	Youngest old (65-74)	1	1
	Middle old (75-79)	1.71 (1.29, 2.28)***	1.36 (0.53, 3.51)
	Oldest old (80+)	2.53 (1.57, 4.09)***	4.69 (1.51, 14.56)**
Gender	Male	1	1
	Female	2.09 (1.45, 3.00)***	1.41 (0.52, 3.84)
Religious affiliation	None	1	1
	Protestant	0.16 (0.10, 0.28)***	0.93 (0.33, 2.64)
	Catholic	0.10 (0.05, 0.17)***	0.94 (0.32, 2.78)
	Other	0.26 (0.04, 1.63)	2.65 (0.42, 16.89)
Education §	Low	1	1
	Medium	2.36 (1.45, 3.83)***	1.20 (0.53, 2.73)
	High	3.05 (1.86, 4.98)***	0.54 (0.15, 1.91)
Household income §	Below average	1	1
	Above average	1.41 (1.01, 1.97)*	0.34 (0.09, 1.34)
Partner status	Partner co-residing	1	1
	No partner co-residing	1.32 (0.94, 1.85)	1.27 (0.50, 3.28)
Total network size		1.00a (0.98, 1.01)	1.00a (0.96, 1.04)
Practical support		0.83 (0.67, 1.03)	0.93 (0.45, 1.92)
Emotional support		1.12 (0.92, 1.36)	0.90 (0.47, 1.73)
Loneliness score		1.02 (0.96, 1.09)	1.06 (0.88, 1.29)
Chronic disease	None	1	1
	One or more	1.24 (0.82, 1.88)	1.24 (0.42, 3.67)
Own perception of health		1.15 (0.96, 1.37)	0.87 (0.48, 1.57)
Experience of pain	Yes	1	1
	No	0.80 (0.59, 1.08)	0.67 (0.32, 1.40)
Physical limitations		0.92 (0.83, 1.02)	0.73 (0.56, 0.95)*
Cognitive functioning	Low	1	1
	Normal	5.76 (0.83, 40.27)	2.34 (0.29, 19.21)
Depressive symptoms		0.99 (0.97, 1.02)	1.02 (0.95, 1.10)

†Logistic regression using generalised estimating equations: Dependent variable: 0 – does not possess AD, 1 – possesses AD.

^aValue less than 1.00 at 3dp.

*, **, and *** indicate significance at the $p < .05$, $p < .01$, and the $p < .001$ levels, respectively.

Tests for multicollinearity revealed no tolerance values less than 0.1 and no VIF values greater than 10, no big difference in eigenvalues or variables with high proportion loadings on the same eigenvalue. No significant interactions were found between participants' age and the data collection year (analysis not shown) therefore interaction terms were not included in the multivariable analysis.

Controlling for all sample characteristics, the odds of possessing a care AD were significantly lower in 2005/06 and 2008/09 compared with 1998/99. There was no significant difference in the odds of possessing a 'care AD' in 2011 compared with 1998. The odds of possessing a 'care AD' were higher amongst the oldest old compared with the youngest old, and lower with increasing physical limitations (Table 3).

Discussion

This study is the first to assess AD possession over time in a representative sample of older people from a European country. The findings illustrate that in the two data collection cycles following the enactment of the 2002 Dutch euthanasia law, there was a significant decrease in possession of 'euthanasia' and 'care' ADs. In the third data collection cycle following the euthanasia law's enactment, however, possession of 'euthanasia' or 'care' ADs had increased so that there were no significant differences with pre-law levels. These findings suggest that legal changes in the status of euthanasia ADs actually negatively affected possession in the first instance. This decrease in euthanasia AD possession mirrors decreases in both euthanasia requests and incidence that occurred shortly after the enactment of the euthanasia law[33,34] and that have been ascribed to uncertainty regarding the functioning of the new law[33]. A parallel decline in AD possession suggests that older people, undoubtedly aware of the widely debated new law, may have been unsure about how a euthanasia AD might be interpreted in this new legal context. The subsequent increase in euthanasia AD possession to a level not significantly different from pre-euthanasia law levels suggests increasing public confidence in their use and interpretation by physicians.

Surprisingly, possession of care ADs also declined after the enactment of the 2002 euthanasia law. A Dutch mixed-methods study amongst AD holders found that those who had drafted a care AD did so mainly due to fear that physicians might hasten their death against their wishes[35]. The intense public debate surrounding the new law may have convinced some people that such fears were unfounded and that, in particular, the patient must actively request euthanasia. This may also explain why the prevalence of care ADs remains low and does not experience an increase of the same magnitude as euthanasia directives in the years following the initial decline.

The characteristics of participants in possession of 'euthanasia' or 'care' ADs also differed. Euthanasia AD possession was associated with increasing age, female gender, higher education and higher household income, and negatively associated with Catholic or Protestant church membership. The association with increasing age may reflect an increasing relevance and experience of death and dying, both motivating factors in drafting an AD[35]. A lack of interaction between age and data collection year indicates all age groups were affected equally by time factors. Women's greater direct involvement in caring roles[36] and awareness of the burden of care, or more proactive approach to health care[37], may explain their more frequent possession of euthanasia ADs. The negative association with Catholic or Protestant affiliation and euthanasia AD possession reflects the opposition to euthanasia from the Catholic and

many Protestant churches. A higher level of education may be related to greater awareness of ADs and end-of-life options. Independent of educational attainment, higher household income was associated with euthanasia AD possession. In the US, higher income or net worth has also been linked with AD possession[14,18,38,39] and has been explained by wealthier participants' greater need to organise financial end-of-life affairs that might motivate end-of-life care planning[18]. Possession of a care AD was higher amongst the oldest old compared with the youngest old. Older people with more physical limitations were also less likely to possess a care AD.

Previous studies have associated indicators of poor health, such as hospital admittance, number of illnesses, functional limitations, experience of pain and use of prescription medicines with AD possession[9,14,16-18,38-40]. In contrast, health factors had no influence on possession of a euthanasia AD, and limited influence on possession of a care AD, in this study.

Strengths and limitations

The findings are strengthened by the use of data on AD possession and a range of socio-demographic, social support and physical and mental health factors from a representative sample of older people spanning fourteen years. There are, however, also limitations. The first measurement sampled only the first cohort, whereas subsequent measurements sampled both the first and second cohorts. Some degree of cohort effect is therefore possible. Also, although there was, in general, a low level of attrition and missing data, missing values for some independent variables often considered sensitive topics, such as household income, social support (network size, practical and emotional support) and experience of pain were relatively common. Although the missing values for AD possession were low, non-responders were significantly older, more frequently female and non-church members. Because these characteristics are associated with possessing an AD, possession estimates may have been slightly underestimated.

Conclusions

This time trend study suggests an influence of the legal context on AD possession. Whereas legal changes had no significant effect on the possession of ADs in the US, the Dutch 2002 euthanasia law, which clarified the use of euthanasia ADs was actually followed by a decline in euthanasia and care ADs in the Netherlands. Strengthening the legal status of ADs may not, therefore, result in an increase in AD possession. Health factors' lack of influence on euthanasia AD possession, and very limited influence on care AD possession suggests that preferences remain stable in different health states and supports the legitimacy of ADs.

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Chapter 9

General discussion

“The single biggest problem in communication is the illusion that it has taken place.”

George Bernard Shaw, 1856-1950.

This thesis addresses – at least in part - the paucity of research on end-of-life communication in Europe, particularly in a cross-country perspective and for older people. This chapter begins with a comprehensive description of methodological strengths and limitations, and the approaches taken to minimise the impact of limitations. This is followed by some epistemological reflections on the study of social phenomena through primarily quantitative means. The key findings from the preceding chapters, and their interpretations, are then described in the context of the original research questions. Finally, the implications of this thesis for policy and practice, and recommendations for future research, are outlined.

Methodological strengths and limitations

The data included in this thesis come from a variety of sources across Europe (see Box 1). Although this strengthens the overall findings, the different data sources have various limitations. Some of these stem from practical or feasibility issues, whereas others are inherent to cross-country research, secondary data analysis, or using data collected with a broad aim to answer more focused research questions.

<p style="text-align: center;">Quantitative data and their sources</p> <p><u>Ten end-of-life topics:</u> primary diagnosis; incurability of disease; life expectancy; possible medical complications; physical complaints; psychological problems; social problems; spiritual/existential problems; options for palliative treatment; and the possible burden of treatments.</p> <p>Data sources: EURO SENTI-MELC (Spain, Italy, Belgium, the Netherlands).</p> <p><u>Elements of advance care planning:</u> general end-of-life care goals, medical end-of-life treatment preferences, appointment of surrogate decision-makers and preferred place of death.</p> <p>Data sources: LASA (the Netherlands) and EURO SENTI-MELC (Spain, Italy, Belgium, the Netherlands).</p> <p><u>Advance directives:</u> possession of euthanasia and care directives.</p> <p>Data source: LASA (the Netherlands).</p> <p style="text-align: center;">Qualitative data and their sources</p> <p><u>Older patients' attitudes towards and experiences of patient-physician end-of-life communication:</u> patient interviews.</p> <p>Data sources (primary studies): 'Medical and ethical quality of care when taking end-of-life decision' (Belgium); 'End-of-life care in general practice in the Netherlands' (the Netherlands); 'Ethnicity and cancer: examining psychosocial transitions for older people' (UK).</p>
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Box 1. Aspects of end-of-life communication examined.

Cross-sectional, retrospective surveys of representative general practitioner networks on end-of-life care in Belgium, the Netherlands, Spain and Italy

The EURO SENTI-MELC data was collected to describe end-of-life care provided in general practice. The analyses included in this thesis fall within that remit and are not secondary analyses; the research questions were however more focused than the

general aim. The strengths and limitations of this approach, already touched upon in previous chapters, are elaborated on below.

Strengths

In EURO SENTI-MELC, representative networks of general practitioners (GPs) in four European countries recorded the care received before death of all practice patients who died and this yielded comprehensive and comparable data. The GP networks were representative in terms of GPs' age, sex and geographical distribution for the whole country in the case of the Netherlands and Belgium, and for particular regions for Italy and Spain[1]. The retrospective nature of the research, and the exclusion of sudden and unexpected deaths from analyses, enabled the identification of patients nearing the end of life for whom palliative care may have been appropriate which is a challenge in prospective studies due to difficulties prognosticating dying[2].

In the Netherlands, Belgium and Spain, data were collected by existing sentinel networks and their co-ordinating institutes. This conferred a number of advantages: GPs did not participate due to a particular interest in death and dying or palliative care, reducing selection bias, and GPs received a high level of training and support and were familiar with reporting procedures. In Italy, a sentinel network was created specifically for the study, GPs were not however aware of the topic under surveillance when recruited, minimising selection bias. Recall bias was minimised through weekly death registrations. These measures contributed to the high level of reporting and low yearly turn-over of GPs[1].

The standardized registration form used for recording patients' end-of-life care underwent a thorough development procedure. Where possible, questions from previous Belgian and Dutch studies were used[3-9]. New questions were developed, after a review of the relevant literature, in collaboration with a multidisciplinary expert panel and approved by all research partners[1]. This process enhanced the validity of the measure, ensuring that items included covered all domains considered important to high quality end-of-life care. The form underwent forward and backward translation, allowing for adjustments aimed at providing equivalence of concepts and services[10]. The final form was piloted in each country (minimum ten GPs)[10]. Co-ordination of data collection, entry and cleaning by experienced research institutes also resulted in data of a high quality: missing data were retrieved via telephone if possible and 5% of data were double entered as a quality check.

Limitations

Limitations with the use of GP sentinel networks included the voluntary nature of participation, which may have biased selection towards GPs interested in research. Furthermore, the Italian network was created especially for the end-of-life surveillance; participants were therefore less familiar with the data collection procedure. The Spanish and Italian sentinel networks also only covered specific regions, though they were representative of the GPs within those areas.

For reasons of feasibility and practicality, the GP (and not patient) population is sampled. Because over 95% of the population in each of the four countries surveyed is registered with a GP[11,12], it was hypothesized at the beginning of EURO SENTI-MELC that such an approach could provide a representative sample of patients nearing the end of life. Additional analyses revealed that deaths registered by the networks were fairly representative of deaths in the four countries, with a few notable exceptions. The percentage of deaths recorded as 'non-sudden' by the networks[1] were comparable to those of reported in a previous European death certificate study[13]. Some deaths were however excluded or under-reported. Firstly, Dutch nursing home residents were excluded from analyses as they receive multidisciplinary care coordinated by the nursing home physician rather than their GP. Secondly, comparison of the Dutch and Belgian non-sudden death data with data from death certificate studies (excluding Dutch nursing home deaths) confirmed the representativeness of deaths recorded apart from a slight underrepresentation of women in the Netherlands and of non-sudden hospital deaths and people under the age of 65 in Belgium[1]. Comparison of all deaths recorded in Italy and Spain with death rates for the country or reference population confirmed their representativeness[1]. Due to a lack of national data on place of death, some sudden deaths in hospitals may have been missed by GPs in Spain and Italy; however, this could not be confirmed.

There are also a number of limitations associated with the measurement instrument. EURO SENTI-MELC GPs report on different aspects of patients' end-of-life care. The breadth of information however is, at times, at the expense of detail about any one item. The EURO SENTI-MELC items analysed in this thesis primarily concern patient-physician end-of-life communication, specifically the discussion of ten end-of-life topics between the patient and the GP and aspects of advance care planning, such as medical end-of-life treatment preferences, appointment of surrogate decision-makers and preferred place of death (Box 1). No information however was available concerning the timing, duration, frequency or quality of discussions or patients' desire for such discussions. In addition, Dutch SENTI-MELC data were used to compare GPs'

end-of-life care for patients who died from 'cancer', 'organ failure' and 'old-age or dementia'. There was however no separate category for cause of death from dementia, which had to be constructed later and may have resulted in an underestimation of dementia deaths. The under-reporting of deaths from dementia is however also a problem in death certificate studies[14]. The exclusion of nursing home residents further reduced the size of the old-age or dementia group, resulting in relatively few deaths in this category.

There are also limitations associated with GPs' reporting. Although the weekly reporting of deaths ensured recall bias was minimized, the reporting of certain aspects of end-of-life care, such as communication, which could have taken place considerably earlier, may have been subject to recall bias. Socially desirable responses may also have been provided for items that reflected particularly on GPs' care competencies, such as advance care planning and GP palliative care provision. Although the registration form underwent forward and backward translation and attempts were made to provide cultural equivalence of concepts and services[10], understanding of some concepts, such as 'palliative care', which differ across countries, specialities and individuals[15,16], may have varied. As well as GPs' potentially varied understanding of such terms, GPs and patients may have had different interpretations of what was and was not discussed during the patient-physician interview. Patients and physicians may have differed in their perception of what constitutes the 'discussion' of a certain topic; an issue reflected in previous research which has found that patients' and physicians' recall of topics discussed differs[17]. EURO SENTI-MELC also relied on GPs to report care in other settings, although they were asked to maximize information from other sources.

Analysing the data presented further challenges. The Spanish network collected data for one year only, resulting in a smaller sample, fewer deaths per GP and lower statistical power. Furthermore, sampling in all countries occurred at the level of the GP; patient data were therefore clustered by GP. Multi-level analysis may therefore have been appropriate in order to take into account the dependence among patients nested within the same GP. This analysis strategy was not, however, advocated for the cross-country papers because, due to the process of anonymization in Belgian, it was not possible to determine the GP but only the group practice. It was not, therefore, possible to ascertain which patients were treated by which GPs in those practices. This hampers multi-level effects analyses because they can only correct for differences between GP practices and not individuals, and the hypothesis that patient-physician communication behaviour or care is clustered around practices is less valid than the clustering around individual GPs. There were also few observations per cluster (153

GPs/practices from the participating countries supplied less than two registration forms during the period 2009-2010) and multi-level models with an average of less than five observations per cluster, as was the case for the Spanish data (mean 3, median 2), have been found to be unreliable[18]. Moreover, all previous analyses carried out on SENTI-MELC data found that accounting for group level clustering had no or little effect on the results[4,19]. As such, when choosing between two sub-optimal analysis strategies, the simplest approach - to treat the data as unclustered - was taken to aid interpretability of results. In chapter 5, only Dutch EURO SENTI-MELC data were used, and the problems with the identification of Belgian GPs and the small number of observations per cluster from Spain were no longer applicable. Furthermore, three years of data rather than two were included, resulting in larger cluster sizes. Multi-level analysis was therefore appropriate for these data.

Secondary analysis of qualitative interview data

Secondary analysis involves 'further analysis of an existing data set which presents interpretations, conclusions or knowledge additional to, or different from, those presented in the first report on the enquiry as a whole and its main results'[20]. Such analyses are most readily associated with quantitative data within a positivist research paradigm. The secondary analysis of qualitative data however raises a number of theoretical and methodological considerations: primarily, the concern that an understanding of the context in which qualitative data are created, vital to the interpretation of such data within a constructivist research paradigm, may be lost. The analysis carried out in chapter 4 represents a supplementary secondary analysis of qualitative data: the emergent theme of patient-physician communication was examined in studies that looked more broadly at terminally ill patients' attitudes towards and experiences of death, dying and end-of-life care.

Strengths

To ensure that the theme of patient-physician communication was sufficiently represented, interviews from available studies were subject to a thorough quality assessment before their inclusion for secondary analysis. The efforts made to maintain sufficient context in order to interpret the data was the major strength of this analysis. Context was deemed sufficient if it provided the 'conditions of discursive production'[21]. This level of contextual information was elicited from full interview transcripts, transcribed verbatim and from detailed field notes. A sensitive and nuanced translation of Dutch and Flemish transcripts into English was achieved through the language expertise of the researchers undertaking the secondary analysis and the use of professional translators[22]. Furthermore, at least one researcher from each of the primary studies was available to provide further information on any

contextual queries. Rigour of reporting of the secondary analysis process was achieved through following recommended guidelines[21,23]. A further strength of the study was the use of the same analytical approach (thematic analysis) for the primary studies and the secondary analysis and checking the 'fit' of resultant themes with at least one researcher from each of the primary studies.

Limitations

The study was framed as an exploratory secondary analysis to begin to address the paucity of cross-country qualitative research on end-of-life communication in Europe. Ideally, cross-country qualitative research would be carried out by the same research team, with the interview guides translated sensitively for equivalency of terms and meanings, and with an ongoing data collection process until a saturation of themes had been achieved. Such research was, unfortunately, beyond the scope of this thesis.

Within the context of a secondary analysis, however, the main limitation was the varied foci of the primary studies. As such, only common themes on patient-physician end-of-life communication in three northern European countries could be examined because any between-country differences may have been the result of different interview guides. This also meant that it was not possible to achieve a saturation of themes in any traditional sense, but rather all themes that were present in all three countries were identified. A further weakness of the study was the lack of interviews from southern European countries, particularly in light of the differences between northern and southern Europe reported in chapters 2 and 3.

Longitudinal Ageing Study Amsterdam (LASA)

The Longitudinal Ageing Study Amsterdam's main aim is to study the determinants, trajectories and consequences of physical, cognitive, emotional and social functioning in relation to ageing[24]. One aspect of ageing covered by the study is end-of-life preferences and care. Therefore, in a similar fashion to the analyses undertaken of EURO SENTI-MELC data, the analyses conducted of LASA data were not considered secondary analyses.

Strengths

The main strength of LASA is its nationally representative sample of older adults. Men and the oldest old were over-sampled in the stratified random sampling scheme to maintain representation of these high mortality groups throughout the study[24]. This over-sampling was taken into account in analyses. LASA also has a low drop-out rate and most attrition is due to mortality, with much lower attrition due to frailty, refusal to participant and loss of contact[24]. The second major strength is the wide range of

data available on participants' socio-demographic characteristics, social support, physical and mental health in each data collection cycle and over time.

Limitations

The outcomes analysed, specifically general end-of-life care goals, preferences for life-sustaining treatments and possession of advance directives (ADs), were measured via participant self-report. Self-report may be subject to greater desirability bias than more objective measurements. The independent measures used in analyses also included a mix of validated, self-report (subjective) and measured (objective) variables. Some self-reported measures however, such as self-perceived health, physical limitations and experience of pain, might be considered particularly subject to variances of 'mood state', the propensity to view the world in negative or positive terms[25]. As the analyses sought to find factors that influence end-of-life preferences however it was precisely the subjective experience of the participant that was most important.

There was a relatively high proportion of missing values for end-of-life general goals and treatment preferences. Non-responders were, in general, older, more frequently female, had lower educational attainment and were church members. The difference in the personal characteristics of responders and non-responders affects the external validity of findings: their generalizability to the wider population. Because responders and non-responders differed on variables found to be associated with treatment preferences (age, sex, church membership and education), preferences for life-sustaining treatments may be slightly underestimated. Although the missing values for AD possession were very low, across the collection years, non-responders were found to be significantly older, more frequently female and to be non-church members. Because these characteristics are all associated with possessing an AD, estimates of AD possession may also be slightly underestimated.

In general, missing values for independent variables were rare. There were however more missing values for some variables that are often considered to be sensitive topics, such as household income, social support (network size, practical and emotional support) and experience of pain.

Depth of information about specific LASA items sometimes had to be sacrificed to achieve the breadth of items measured. For example, participants were not provided with detailed descriptions of life-sustaining treatments or their associated burdens. It is, therefore, unclear how informed preferences were.

Also, unfortunately, some measures were not recorded at every data collection cycle. This affects the ability to trace time trends. AD possession was not, for example, measured in the 2001 data collection cycle. In addition, the trend in possession of euthanasia and care ADs described in chapter 8 may have been subject to some degree of cohort effect: the first measurement sampled only the first cohort, whereas subsequent measurements sampled both the first and second cohorts. Finally, the interval between data collection cycles may be too long for end-of-life monitoring. If ADs are drafted close to death their prevalence may be underestimated because of the three-year interval between measurements.

Epistemological reflections

This thesis takes, primarily, an epidemiological approach to the study of social phenomena: large-scale survey data are used to examine social processes such as patient-GP communication, to elicit people's preferences for medical end-of-life treatments and to ascertain the extent of their end-of-life planning through the discussion of medical end-of-life treatment preferences, appointment of surrogate decision makers and AD possession. The scale of analysis –mapping variations between countries, over time and between different population groups – meant that surveys were the most appropriate methodology. This quantitative approach however is open to critique. Firstly, it might be considered reductionist: to quantitatively measure 'end-of-life communication', this broad topic had to be reduced to a number of comparable, measurable items that could feasibly be collected and examined (see Box 1). This thesis however does not claim to represent the entirety of end-of-life communication but instead concerns itself with aspects of end-of-life communication identified as important to the delivery of high quality end-of-life care in the research literature and by palliative care experts to provide the most clinically relevant evidence[1].

Secondly, the approach might be considered 'atomistic' in that it treats a society or culture as a sum of individual behaviours and neglects the cultural context within which these behaviours take place[26]. This criticism itself, however, removes quantitative approaches from the wider body of research and underestimates the importance of qualitative research – which explores not just people's behaviour, but the meaning of actions within the context of social and cultural realities – in survey design and interpretation of results. Findings from large-scale surveys can also generate hypotheses to be tested in subsequent qualitative research and confirm (or challenge) the generalizability of associations identified in small context-specific qualitative studies. The knowledge generated from quantitative and qualitative research can, therefore, be complementary and jointly contribute to the

understanding of social phenomena[27]. Differences between countries revealed in this thesis have been interpreted by highlighting differences in certain aspects of culture, such as the open discussion of death and dying, the importance of beneficence and autonomy, and (viewing health systems as specific cultural systems) palliative care service organization. Nonetheless, simply ascribing cross-country variation to 'cultural differences' has been avoided. This was a conscious attempt to unpack some of these culturally influenced differences in behaviour yet acknowledge that 'cultural' differences cannot be truly understood unless a 'culture' is studied as a whole and understood on its own terms. Therefore evaluations of the quality of care provided in the four countries compared have also been avoided; not only because of the lack of information on patients' desire for, or the quality of, end-of-life communication but also because such value based judgments would be ethnocentric.

In addition to the primarily epidemiological approach taken, this thesis also incorporated a secondary analysis of qualitative interview data in chapter 4. This analysis provided a contrast to the cross-country differences reported in chapters 2 and 3, by emphasizing similarities in patients' preferences and experiences across different European countries. The secondary analysis also highlighted the paucity of cross-country qualitative research, particularly in light of the increasing popularity of cross-country quantitative research.

Key findings and their interpretation

Six research questions were originally posed. The first two concerned comparative end-of-life communication research in Europe, whereas the final four focused on various aspects of end-of-life communication in the Netherlands with a focus on older people.

Part I - End-of-life communication in Europe

The first research question was, 'what proportion of people nearing death have end-of-life discussions with their GP and which factors influence their occurrence in different European countries?' To answer this question, the concept of 'end-of-life discussions' was operationalized by mapping the prevalence of discussion of ten end-of-life topics and aspects of advance care planning in Italy, Spain, Belgium and the Netherlands. The prevalence of GP-patient discussion of ten end-of-life topics prior to patients' deaths was estimated and compared in chapter 2, whereas GP-patient medical end-of-life treatment preference discussions and patients' appointment of surrogate decision-makers in the four countries was estimated and compared in chapter 3. Chapter 2 reveals that all topics except primary diagnosis and physical complaints were discussed with less than half of patients from Italy, Spain and

Belgium. In contrast, most topics were discussed with more than half of patients in the Netherlands. In all four countries, the primary diagnosis and physical complaints were the most frequently discussed topics, whereas 'spiritual and existential issues' was the least frequently discussed topic. In addition, more topics, on average, were discussed with each patient in the Netherlands (mean=6.37), followed by Belgium (4.45), Spain (3.32) and Italy (3.19). Chapter 3 reveals a higher prevalence of GP-patient end-of-life treatment preference discussions and surrogate appointments in Belgium and the Netherlands compared to Spain and Italy. GP-patient discussion of treatment preferences occurred for 10%, 7%, 25% and 47% of Italian, Spanish, Belgian and Dutch patients respectively. Furthermore, 6%, 5%, 16% and 29% of Italian, Spanish, Belgian and Dutch patients appointed (either verbally or in writing) a surrogate decision-maker. As surrogate appointments were made known to the GP almost entirely verbally, they were considered an important aspect of end-of-life communication.

These findings reveal the limited discussion of end-of-life topics that have been identified as important for the provision of high quality end-of-life care in general practice. They also highlight some important cross-country differences. Patient-GP discussion of end-of-life topics and aspects of advance care planning was most frequent in the Netherlands, followed by Belgium. There were few differences between Italy and Spain, although the odds of a Spanish patient having discussed the 'primary diagnosis', 'incurability of disease', 'medical complications', 'physical complaints', 'options for palliative treatment' and the 'burden of treatment' with their GP were significantly higher than those of an Italian patient. These cross-country differences are discussed extensively in chapters 2 and 3: they are most likely linked to variation in the priority given to the principles of beneficence and autonomy in clinical practice, GPs' responsibility for and training in end-of-life care, the social acceptability of discussing death and dying, involvement of family members in decision making, and legal and policy contexts. The cross-country differences do not represent country 'rankings' because what is considered 'good' end-of-life communication, 'good' care and, indeed, a 'good' death, may vary between countries. It is however possible to use the results to identify specific factors which may encourage end-of-life communication and those which may limit it. GP-patient communication on all items measured was found to be most frequent in the Netherlands, where there is a strong emphasis on end-of-life care in primary care settings and GPs have greater personal responsibility for palliative care provision. Dutch GPs have also been found to receive more training in palliative care than GPs from other European countries[28] and Dutch health care policy places a strong emphasis on palliative care provision in primary settings[29].

Despite cross-country differences in the prevalence of discussions, the personal and care characteristics of patients for whom patient-GP discussion of end-of-life topics and aspects of advance care planning occurred were remarkably similar across countries. Both the discussion of more end-of-life topics and aspects of advance care planning were, overall, more frequent with patients for whom palliative care was an important treatment aim and patients for whom their GP had provided palliative care, and less frequent with patients diagnosed with dementia. In addition, GPs tended to discuss more end-of-life topics with younger patients and cancer patients and report more discussions of treatment preferences or surrogate appointments for patients with whom they had previously discussed the primary diagnosis and had more frequent contact. The associations between GP-patient end-of-life discussions and GP care factors underline the importance of the GP-patient relationship and GPs' competencies in identifying the need for palliative care. A coherent picture also emerges of the characteristics of patients for whom limited GP-patient end-of-life discussions take place, exposing relatively less frequent engagement in discussions with older patients, non-cancer patients and those with cognitive decline in general practice. The strong relationship between aspects of advance care planning and GP-patient discussion of the primary diagnosis suggests that the foundations of good end-of-life communication are laid in the early stages of the illness trajectory. Although patient-GP non-discussion of the primary diagnosis does not automatically equate to non-disclosure of the diagnosis or prognosis, high proportions of patients dying of cancer have been reported to be unaware of their diagnoses in both Italy and Spain[30,31].

The second research question was: 'for older patients, are there common themes and challenges in patient-physician communication at the end of life in different European countries?' Common themes were identified from British, Dutch and Belgian older patients' interviews on attitudes to death, dying and end-of-life care in chapter 4. Whereas chapters 2 and 3 tend to highlight between country differences in the prevalence of end-of-life discussions if not in the characteristics of the patients engaged in discussions, chapter 4 highlights similarities across countries in older patients' attitudes towards and experiences of patient-physician end-of-life communication. Common themes from patients' interviews included: confidence and trust; disclosure and awareness; and participation in decision-making. Confidence and trust were reinforced by physicians' availability, time and genuine attention and hindered by misdiagnoses and poor communication style. Most participants preferred full disclosure, though some remained deliberately ill-informed to avoid distress. These patients can be considered as being in a state of 'partial awareness' of dying,

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which includes the suspicion of, or pretence of not, dying. Patient-centred care does not dictate that a patient must be aware of dying but rather requires working with all levels of death awareness. Indeed, for some patients, denial is an important coping mechanism[32]. It is important that prognosis information should be frequently and sensitively offered, but never forced upon such patients. Patients from all three countries also expressed a variety of preferences for and experiences of personal and family involvement in medical end-of-life decision-making. A few patients complained that information was only provided about the physician's preferred treatment. This represents a 'framing effect', when information is presented in a way as to bias the patient towards the physician's preferred outcome[33], and limits informed decision-making. Framing effects are difficult to avoid, especially if patients appeal to physicians to tell them 'what they would do', however when describing treatment options physicians should discuss both their possible risks and benefits and the consequences of limiting treatment to provide patients with complete information.

Within each of the common themes identified across the three countries, participants from each country reported diverse experiences and attitudes. This diversity demonstrates that there is no 'idealized' model for older patients, or for end-of-life communication in any one country, and highlights the importance of assessing individual patients' preferences for end-of-life communication and participation in decision making.

Part II - End-of-life communication for older people: the Dutch experience

Limited end-of-life communication and palliative care for non-cancer patients is often attributed to their less predictable illness trajectories. Non-cancer patients are however often studied as a group and compared with cancer patients. Although physical, psycho-social and spiritual suffering at the end of life has been increasingly described for archetypal illness trajectory groups, such as cancer, organ failure and frailty/dementia, there remains a paucity of research comparing end-of-life *care* between illness trajectory groups. The third research question, 'how does GP end-of-life communication and care provision differ by patient 'chronic illness trajectory group?' sort to address this lacuna. This was addressed in chapter 5 by describing and comparing the end-of-life care and communication received by cancer, organ failure and old age and dementia patients in the Netherlands.

The study revealed less frequent palliative treatments, palliative care use, end-of-life discussions and advance care planning amongst organ failure and old-age/dementia patients than cancer patients. Comparing illness trajectory groups revealed that organ failure patients received the least palliative care, whereas old-age/dementia patients,

the group most likely to lose decision-making capacity, experienced the least end-of-life discussions and advance care planning of the three patient groups.

It has been suggested that primary care is perhaps the most appropriate setting for most of non-cancer patients' end-of-life care[34,35]. In the Netherlands, where there is already a strong emphasis on end-of-life care in primary care settings, differences in GPs' end-of-life care provision associated with illness trajectory group remain. These results highlight the need to further integrate palliative care with optimal disease management in primary practice and to initiate advance care planning early in the chronic illness trajectory to enable all patients to live as well as possible with progressive illness and die with dignity and comfort in line with their own preferences.

The fourth research question was: 'what are older people's preferences for life-sustaining treatments in hypothetical cases of cancer and dementia and which socio-demographic, social support, physical and mental health factors are associated with their preferences'? Chapter 6 reports Dutch older people's life sustaining treatment preferences and factors associated with their desire to forgo one or more treatments. The majority of older people preferred to forgo at least one life-sustaining treatment in both the hypothetical cancer (78%) and dementia (85%) scenarios, indicating that treatments are desired less in the case of cognitive compared with physical decline. In light of findings that many older people would prefer to forgo life-sustaining treatments at the end of life, particularly in the case of dementia, it is imperative that preferences are discussed with relatives and healthcare professionals in a timely manner to avoid unwanted interventions. Although in previous studies current health state had been associated with life sustaining treatment preferences[36-39], current health factors had limited influence on treatment preferences. Indeed, social support factors were more influential. Different elements of the multidimensional variable 'social support' influenced preferences in distinct ways: larger social networks were associated with forgoing treatment in the dementia scenario, whereas, in the cancer scenario, a live-in partner and greater emotional support were associated with preferring all treatments. Social support, therefore, made forgoing less likely in hypothetical scenarios of poor physical, but not mental, health. The lack of significant association between health state and treatment preference suggests that preferences remain stable in different health states. Furthermore, an understanding of social support influences may encourage professionals to explore patients' expectations and fears about such support during advance care planning.

Some authors have suggested that determining general end-of-life values and goals may be more useful in guiding clinical decisions than knowing specific life sustaining treatment preferences[40-42]. The fifth research question, therefore, was: ‘what is the relationship between older people’s general end-of-life goals and specific life-sustaining treatment preferences?’ The agreement between Dutch older people’s general preferences for quantity vs. quality of life and specific end-of-life treatment preferences is described in chapter 7. For a substantial proportion of Dutch older people, specific life-sustaining treatment preferences did not agree with their general end-of-life goals. Agreement ranged from 51-76% in a hypothetical scenario of cancer and 41-60% in a hypothetical scenario of dementia scenarios, depending on the treatment. Poor understanding of the risks and burdens of life-sustaining treatments or different understandings of their purpose (such as to meet short-term goals rather than to be dependent on long-term) may lead to disagreement between general and specific end-of-life preferences. A stepwise process of discussing general care goals, followed by specific treatment preferences is therefore recommended to frame discussions within the context of general goals, different end-of-life scenarios and the risks and burdens of treatments.

Finally, the sixth and last research question was: ‘Is there a trend in older people’s euthanasia and care AD possession over time and which socio-demographic, social support, physical and mental health factors are associated with possession?’ Trends in ‘euthanasia’ and ‘care’ AD possession amongst Dutch older people from 1998 to 2011 are described in chapter 8. Data, collected before and after the implementation of the 2002 Law on Euthanasia and Assisted Suicide, were also appropriate for studying the impact of the law on AD possession. This is particularly relevant because few studies have examined societal influences, such as legal and policy changes, on AD uptake. The findings revealed significant decreases in possession of ‘euthanasia’ and ‘care’ ADs following the enactment of the 2002 euthanasia law. The decline in euthanasia ADs mirrors declines in euthanasia requests and incidence after the enactment of the euthanasia law and may reflect uncertainty regarding the functioning of the new law[43]. By 2011, however, there were no significant differences in possession of ‘euthanasia’ or ‘care’ ADs compared with pre-law levels, perhaps indicating increasing public confidence in ADs use and interpretation by physicians.

The characteristics of participants in possession of ‘euthanasia’ and ‘care’ ADs also differed. Few factors were associated with the possession of care ADs. Care AD possession was associated with the oldest old compared with the youngest old age category and fewer physical limitations. Factors associated with euthanasia AD possession (positive association with increasing age, female gender, higher education

and higher household income, and negative association with Catholic or Protestant church membership) however were similar to factors associated with AD possession in previous studies[44-53]. In contrast to previous studies, however, health factors had no influence on possession of a euthanasia AD, and limited influence on possession of a care AD. The limited influence of health factors on AD possession suggests stability of preferences in various states of health and supports the legitimacy of ADs.

Recommendations for policy and practice

Taken together, the findings from this thesis lead to a number of recommendations for policy and practice based around strengthening the provision of palliative care in primary care settings and improving end-of-life communication and advance care planning.

Strengthening the provision of palliative care in primary care settings

1. GP training in palliative care

Currently, palliative care is not an obligatory part of GP training in any of the countries from which data for this thesis were collected[54,55]. Dutch GPs, who, in general, benefit from more palliative care training, more frequently discussed all end-of-life communication items measured. Including palliative care as an obligatory element of the GP training curriculum and ensuring continuous training and participation in initiatives aimed at strengthening palliative care provision in primary care settings, such as the British Gold Standards Framework (GSF)[56] or the Dutch 'Palliatieve Thuiszorg' (Palliative homecare – PaTz)[57] is, therefore, highly recommended (see Box 2).

2. Recognizing palliative care needs

Dutch GPs' seemingly had difficulties recognising, and discussing, the end-of-life for organ failure and old-age/dementia patients compared with cancer patients. There are a number of different models for prognosticating the end of life: some are based on the probable amount of time remaining before death[58] and others are based on health and care characteristics[59,60]. These models, however, tend to show poor discrimination for non-cancer patients[59] and physicians have a tendency to over-estimate their patients' life expectancy[61]. Difficulties in prognosticating the dying phase highlight the need to deliver palliative care based on patients' psycho-social, physical and spiritual needs rather than on prognostication of 'dying'. Recognizing these needs and integrating palliative care and optimal disease management is, therefore, a priority for GP training.

The Gold Standards Framework (United Kingdom)

Within the primary care setting, the GSF aims to support GPs and district nurses to: identify patients in the last years of life; assess patients' symptoms, needs and preferences; and to plan care commensurate with patients wishes.[56] The GSF achieves this through the provision of training, tools, outcome measures and local support (<http://www.goldstandardsframework.org.uk/>).

Palliatieve Thuiszorg (Palliative Homecare – PaTz) (the Netherlands)

The PaTz project, based on the British GSF, focuses on developing and supporting partnerships between GPs and nurses in palliative home care in the Netherlands. PaTz has three main aims: better cooperation between GPs and nurses; the early identification and registration of patients with palliative care needs; and the creation of patient-centred palliative care plans[57].

Box 2. Initiatives for strengthening palliative care provision in primary care settings

Improving end-of-life communication and advance care planning

1. Timely initiation of end-of-life discussions and advance care planning

Timely end-of-life discussions and advance care planning facilitate symptom assessment and encourage patient participation in decision-making. Due to difficulties prognosticating dying, especially for non-cancer patients (see above), and indications that the foundations of good end-of-life communication are laid early in the illness trajectory, it is advisable to broach sensitively end-of-life issues soon after diagnosis of any life-limiting illness. For patients with dementia, for example, 'timely', due to necessity, equates to 'early'. Indeed, the recent EAPC white paper on palliative care for older people with dementia recommends that advance care planning starts at diagnosis, when the patient 'can still be actively involved and patient preferences, values, needs and beliefs can be elicited'[62].

2. Effective communication

End-of-life communication training should encourage physicians to develop effective communication skills, particularly when communicating with older patients. Such skills include determining patients' preferences for participation in decision-making (including non-involvement), providing clear explanations, avoiding jargon and partial information provision and continually checking patients' understanding.

3. The process of advance care planning

This thesis reveals that, for a substantial minority of older people, general goals and specific life sustaining treatment preferences did not agree. Life-sustaining treatments were also more frequently desired in hypothetical scenarios of cancer than dementia. These findings underline the importance of a stepwise process of eliciting preferences for care prior to possible future incapacity. Specific treatment preferences should be discussed within the context of general goals, different end-of-life scenarios and the risks and burdens of treatments. These preferences should also be revisited regularly.

This process of considering end-of-life values and goals and articulating preferences typifies advance care planning[63], which may or may not lead to the formal recording of preferences in an AD.

The findings that current health factors had very limited influence on older patients' life-sustaining treatment preferences and possession of euthanasia and care directives, suggests a stability of preferences in various health states and supports the legitimacy of discussing treatment preferences for future hypothetical states of health. The less frequently studied influence of social support factors was, in contrast, found to be highly influential on life-sustaining treatment preferences. Healthcare professionals are, therefore, also encouraged to explore patients' expectations and fears about social support at the end of life.

4. Macro-level initiatives to strengthen patient autonomy at the end of life Finally, attempts to encourage AD possession through the strengthening of their legal status may not have the intended effect. If the impetus for legal changes and policy initiatives is to strengthen patient autonomy at the end of life, encouraging advance care planning and informal end-of-life discussions may be more effective.

Recommendations for further research

The findings also lend themselves to recommendations for further research, of both a quantitative and qualitative nature, to improve the mapping of variations between countries, over time and between different population groups and to develop an in-depth understanding of variations.

End-of-life communication in Europe

The four countries included in the EURO SENTI-MELC study exemplify a typical northern-southern Europe dichotomy. The addition of countries that do not conform so readily to these stereotypes, such as Ireland (where the Catholic church is still highly influential in medical decision-making[64]) or Norway (where physician-patient relationships have been described as relatively paternalistic[65]) would benefit the understanding of cross-country differences.

It would also be beneficial to employ a mixed methods approach to future EURO SENTI-MELC studies to attempt to understand the social processes underlying these cross-country differences. A related recommendation is the need for primary qualitative research to understand what is considered 'good' end-of-life care and communication amongst patients, physicians, carers and members of the general public in different European countries.

End-of-life communication for older people

The Dutch SENTI-MELC data were used to compare the care and end-of-life communication received in general practice by 'cancer', 'organ failure' and 'old-age or dementia' patients. The study, however, did not examine palliative care needs. To identify inequities in service provision, future studies might examine palliative care needs alongside access to services[66]. Although comparing the care 'needs' of different patient groups across the multiple palliative care domains (physical, psycho-social and spiritual) is challenging, past approaches include comparing symptom burden[67,68] and scores on standardized physical and mental health assessment scales[68] as well as qualitative approaches[69]. Qualitative research should also explore physicians' reasons for initiating palliative care and treatments, discussion of the end of life and advance care planning with different patients.

LASA data were used to examine the influence of social support next to socio-demographic, physical and mental health factors on preferences for life-sustaining treatments and possession of euthanasia and care ADs. Social support factors, other than marital status, are rarely taken into account in research on medical end-of-life preferences. They were, however, found to be highly influential, at least with regard to life-sustaining treatment preferences. Future qualitative research should explore the influence of social support on older people's life sustaining treatment preferences, whereas quantitative research might aim to examine these associations in other populations and countries.

Finally, examining the time trend in euthanasia and care AD possession in the Netherlands suggested that macro-level, legal changes negatively affected their possession, at least in the period immediately following the euthanasia law's enactment. Similarly, the implementation of the 1991 Patient Self-Determination Act in the United States did not lead to a subsequent increase in AD possession[70-72]. It would therefore be worthwhile to examine the effect on AD possession of recent legal changes in other European countries, such as Germany[73], Switzerland[74] and Portugal[75], if indeed data on AD possession before the implementation of legal changes are available.

Final remarks

This thesis reveals marked differences between European countries in the topics that patients and GPs discuss before death. At the same time, it highlights the similar characteristics of those patients for whom end-of-life communication is limited: non-cancer patients, older patients, and those suffering cognitive decline. These patients, however, will characterise Europe's future palliative care population and the findings

therefore have important implications for the delivery of patient-centred palliative care. As well as identifying the patient groups that are neglected with regard to communication at the end of life, the thesis also highlights priorities for how this communication could be improved. For example, the importance of eliciting older people's end-of-life treatment preferences and framing preference discussions within the context of general care goals, different end-of-life scenarios, the risks and burdens of treatments and any personal concerns, such as the presence or otherwise of social support. Finally, the thesis provides suggestions for strengthening palliative care in primary care settings and improving physicians' communication skills and suggests that these measures may be more effective in encouraging patient participation in end-of-life decision-making than legally strengthening ADs.

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Summary

Throughout Europe, researchers and practitioners increasingly recognise the ethical basis of including the patient in end-of-life medical treatment decisions and the benefits of good end-of-life communication on patient-centred outcomes. There remains however a paucity of European cross-country research on end-of-life communication *practices*. End-of-life communication is also complicated by the changing characteristics of the population reaching the end of life; the population in need of palliative care is increasingly old, frail and suffering from multiple morbidities. However, people with these characteristics are often neglected in research on end-of-life communication.

This thesis addresses the lacunae in research on end-of-life communication in Europe in cross-country perspective and for older people. The thesis begins by introducing the topic of patient-physician communication at the end of life and the rationale for researching specific aspects of end-of-life communication. The research section is split into two parts: part one consists of comparative research on end-of-life communication in Europe; part two focuses exclusively on the situation in the Netherlands with a particular focus on older people.

Part One - End-of-life communication in Europe: cross-country comparisons

Chapter two draws on EURO SENTI-MELC data. EURO SENTI-MELC involves representative GP networks in Italy, Spain, Belgium and the Netherlands collecting data on the care provided to patients in the last three months of life of all patients who died under their care. Chapter two reveals that, on average, more end-of-life topics were discussed between the patient and the GP in the Netherlands, followed by Belgium, Spain and Italy. Discussions of each one of the end-of-life topics measured in the survey were most prevalent in the Netherlands, followed by Belgium. GPs from all countries tended to discuss fewer topics with older patients, non-cancer patients, patients with dementia, patients for whom palliative care was not an important treatment aim and patients for whom their GP had not provided palliative care. The chapter concludes by recommending early end-of-life discussions with older patients, those with cognitive decline if possible, and those with non-malignant diseases.

Chapter 3 also draws on EURO SENTI-MELC data, but looks at the prevalence of two aspects of advance care planning: GP-patient end-of-life treatment discussions and patients' appointment of surrogate decision-makers. There was a higher prevalence of GP-patient end-of-life treatment preference discussions and surrogate appointments in Belgium and the Netherlands compared to Spain and Italy. Despite some country-specific differences, previous GP-patient discussion of the primary diagnosis, more frequent GP contact, GP provision of palliative care, the importance of palliative care

as a treatment aim and deaths in the patient's own home or a hospice/palliative care unit were positively associated with preference discussions or surrogate appointments. A diagnosis of dementia was negatively associated with preference discussions and surrogate appointments. In line with the recommendations of the previous chapter, early preference discussions, particularly for patients with cognitive decline, and the provision of palliative care encouraged anticipatory decision making.

Chapter 4 consists of a secondary analysis of qualitative interview data from older British, Dutch and Belgian patients. The study focuses on patients' attitudes towards and experiences of patient-physician end-of-life communication and provided a contrast to the cross-country differences reported in Chapters 2 and 3 by emphasizing similarities in patients' preferences and experiences across different European countries. Themes identified from patients' interviews in all three countries were 'confidence and trust', 'disclosure and awareness' and 'participation in decision-making'. Confidence and trust were reinforced by physicians' availability, time and genuine attention and hindered by misdiagnoses and poor communication style. Most participants preferred full disclosure, though some remained deliberately ill-informed to avoid distress. Patients expressed a variety of preferences for, and experiences of, involvement in medical end-of-life decision-making and a few complained that information was only provided about the physician's preferred treatment. A variety of experiences and attitudes regarding disclosure and participation in decision-making were reported from each country, suggesting that people's communication preferences are highly individual. Physicians are advised to be sensitive to this diversity and avoid stereotyping. In regard to communication style, physicians should provide clear explanations, avoid jargon, and continually check understanding.

Part two - End-of-life communication for older people: the Dutch experience

Chapter 5 draws exclusively on three years of Dutch SENTI-MELC data. In this chapter, GP end-of-life care for patients who died from 'cancer', 'organ failure' and 'old-age or dementia' is described and compared. This study reveals that organ failure patients receive less palliative care from their GPs than cancer and old-age/dementia patients, whereas old-age/dementia patients, the group most likely to lose decision-making capacity, have the least end-of-life discussions and advance care planning of the three patient groups. These results highlight the need to integrate palliative care with optimal disease management in primary practice and to initiate advance care planning early in the chronic illness trajectory.

Chapter 6 draws on data from the Longitudinal Aging Study Amsterdam (LASA) to examine participants' preferences for four life-sustaining treatments in hypothetical

cases of cancer and dementia and the factors associated with a preference to forgo treatments. A majority preferred to forgo a treatment in both cancer and dementia scenarios. Different elements of the multidimensional variable 'social support' influenced preferences in distinct ways: larger social networks were associated with forgoing treatment in the dementia scenario, whereas, in the cancer scenario, a live-in partner and greater emotional support were associated with preferring all treatments. Current health was not associated with preferences (except anxiety - associated with a preference for treatment in dementia). Understanding social support influences may encourage professionals to explore patients' expectations and fears about social support during advance care planning.

Chapter 7 also draws on data from LASA, but looks at how participants' general treatment goals and values relate to their specific treatment preferences in hypothetical cancer and dementia scenarios. Treatments were desired less in the case of cognitive compared with physical decline and for a sizable proportion of participants, specific treatment preferences did not agree with their general end-of-life goals. Poor understanding of the risks and burdens of life-sustaining treatments or different understandings of their purpose (such as to meet short-term goals rather than to be dependent long-term) may lead to disagreement between general and specific end-of-life preferences.

Chapter 8 draws on LASA data collected in 1998, 2005, 2008 and 2011. This study describes 'euthanasia' and 'care' advance directive (AD) possession over time and factors associated with their possession. The data provide insight into the influence of the 2002 Dutch euthanasia law on 'euthanasia' and 'care' AD possession. In the two data collection cycles following the enactment of the 2002 Dutch euthanasia law (2005 and 2008), there was a significant decrease in possession of 'euthanasia' and 'care' ADs. In the third data collection cycle following the euthanasia law's enactment (2011), however, possession of 'euthanasia' and 'care' ADs had increased so that there were no significant differences with pre-law levels. These findings suggest that legal changes recognizing euthanasia ADs actually negatively affected possession in the first instance. Health factors had little or no influence on AD possession. This suggests a stability of preferences in various states of health and supports the legitimacy of ADs.

General discussion

Chapter 9 begins with a comprehensive description of methodological strengths and limitations. Strengths stemmed primarily from the use of large data sets from different European countries, representative for populations of GPs or older people, containing measurements on participants' demographics, physical and psychological health and

their available social support. Limitations were largely due to issues of feasibility or were inherent to cross-country research, secondary data analysis, or using data collected with a broad aim to answer more focused research questions. The chapter also includes an epistemological reflection that argues that surveys were the most appropriate methodology for mapping variations between countries, over time and between different population groups. The key findings from the preceding chapters, and their interpretations, are then described in the context of the original research questions. In particular, the findings reveal marked differences between European countries in the occurrence of end-of-life discussions between patients and GPs. These findings reflect differences in the open discussion of death and dying, priority given to beneficence or autonomy in clinical practice, and palliative care service organisation (particularly GPs' training in, and responsibility for, palliative care). The similar characteristics of those patients for whom end-of-life communication is limited is also highlighted: non-cancer patients, older patients, and those suffering cognitive decline. Such patients, however, will characterise Europe's future palliative care population and the findings have important implications for the delivery of patient-centred palliative care. Finally, recommendations for policy and practice are also given. The thesis provides suggestions for strengthening palliative care in primary care settings and improving physicians' communication skills and suggests that these measures may be more effective in encouraging patient participation in end-of-life decision-making than legally strengthening ADs.

Samenvatting

De ethische grondslag om patiënten te betrekken bij beslissingen over de medische behandelingen aan hun levenseinde wordt in Europa in toenemende mate erkend, net als de voordelen van goede communicatie over het levenseinde waarbij de patiënt centraal staat. Er is echter een gebrek aan vergelijkend onderzoek naar de manier waarop de communicatie over het levenseinde wordt uitgevoerd in de verschillende Europese landen. Communicatie over het levenseinde wordt bemoeilijkt, doordat mensen die dit aangaat in toenemende mate oud en fragiel zijn, en lijden aan meerdere aandoeningen. Ouderen met deze kenmerken worden daardoor vaak over het hoofd gezien in onderzoek naar communicatie over het levenseinde.

Dit proefschrift richt zich op de hiaten in het onderzoek naar communicatie over het levenseinde in verschillende Europese landen. Dit proefschrift begint met de introductie van het onderwerp arts-patiënt communicatie over het levenseinde en de beweegredenen om specifieke aspecten van levenseinde communicatie te onderzoeken. Het proefschrift is opgesplitst in twee delen: deel één betreft een vergelijkend onderzoek naar communicatie over het levenseinde in Europa; deel twee gaat exclusief over de situatie in Nederland, met een specifieke focus op ouderen.

Deel één – communicatie over het levenseinde in Europa: een vergelijkend onderzoek.

Hoofdstuk twee is gebaseerd op EURO SENTI-MELC data. EURO SENTI-MELC is gebaseerd op een representatief huisartsen netwerk in Italië, Spanje, België en Nederland dat data verzamelt over de zorg die is geleverd door huisartsen in de laatste drie maanden van het leven van alle patiënten die zijn overleden onder de zorg van de huisartsen in dit netwerk. Dit hoofdstuk toont aan dat tussen patiënt en huisarts, gemiddeld genomen, meer onderwerpen over het levenseinde worden besproken in Nederland, gevolgd door België, Spanje en Italië. De prevalentie van discussies per levenseinde onderwerp dat is gemeten in het onderzoek is hoger in Nederland, gevolgd door België. Huisartsen uit alle landen bespraken minder onderwerpen met oudere patiënten, niet-kankerpatiënten, patiënten met dementie, patiënten waar palliatieve zorg geen belangrijk behandeldoel was en met patiënten waar de huisarts geen palliatieve zorg had gegeven. Dit hoofdstuk sluit af met de aanbeveling om op tijd te starten met het bespreken van het levenseinde met oudere patiënten, waaronder vaak mensen met cognitieve achteruitgang, en met mensen met niet maligne aandoeningen.

Hoofdstuk drie is ook gebaseerd op EURO SENTI-MELC data, maar kijkt naar de prevalentie van twee aspecten van *advance care planning*, namelijk naar de arts-patiënt bespreking over voorkeuren ten aanzien van het wel niet krijgen van

behandelingen aan het levenseinde en naar het aanwijzen van een wettelijk vertegenwoordiger (volmacht) door patiënten. In België en Nederland werden de behandelingsvoorkeuren en het aanwijzen van een vertegenwoordiger vaker besproken tussen arts-patiënt dan in Spanje en Italië. Ondanks enkele land-specifieke verschillen is er in alle landen een positieve associatie gevonden tussen het bespreken van voorkeuren en het benoemen van een vertegenwoordigers aan de ene kant, en het eerder bespreken van de primaire diagnose tussen huisarts en patiënt, een frequenter huisarts contact, het verlenen van palliatieve zorg door de huisarts, het belang van palliatieve zorg als behandeldoel en sterfgevallen in het eigen huis van de patiënt, of in een hospice/palliatieve zorg-unit aan de andere kant. Een dementiediagnose was aan de andere kant negatief geassocieerd met bespreken van voorkeuren en het benoemen van een vertegenwoordigers. In het verlengde van de aanbevelingen in het vorige hoofdstuk, worden artsen en patiënten gestimuleerd om vroegtijdig voorkeuren voor behandelingen te bespreken, in het bijzonder voor patiënten met cognitieve achteruitgang.

Hoofdstuk vier bestaat uit een secundaire analyse van kwalitatieve interview data van oudere Britse, Nederlandse en Belgische patiënten. Deze studie richtte zich op de houding van patiënten ten opzichte van, en hun ervaringen met, arts-patiënt communicatie over het levenseinde. De analyse is, in tegenstelling tot de analyses in hoofdstuk 2 en 3, gericht op overeenkomsten tussen de Europese landen als het gaat om voorkeuren en ervaringen van patiënten. Op basis van de interviews met patiënten in de drie landen zijn de volgende thema's vastgesteld: 'geloof en vertrouwen', 'bekendmaking van diagnose en prognose en bewustzijn' en 'deelname in besluitvorming'. Het geloof en vertrouwen werd versterkt door de beschikbaarheid, tijd en oprechte aandacht van de artsen en belemmerd door verkeerde diagnoses en een slechte communicatiestijl. De meeste deelnemers gaven aan een voorkeur te hebben voor volledig open communicatie, hoewel sommigen ook bewust slecht geïnformeerd wilden blijven om stress te voorkomen. Patiënten uitten een verscheidenheid aan voorkeuren voor, en ervaringen met, de betrokkenheid in medische besluitvorming over het levenseinde. Een aantal vond het lastig dat de arts alleen informatie verstreekte over de voorkeursbehandeling van de arts. In elk land werd een verscheidenheid aan ervaringen en opvattingen met betrekking tot open communicatie en deelname aan besluitvorming gerapporteerd, hetgeen suggereert dat de voorkeuren in communicatie zeer individueel zijn. Artsen wordt daarom aangeraden aandacht te hebben voor deze diversiteit en om stereotypering te vermijden. Met betrekking tot de communicatie stijl moeten artsen duidelijk uitleg geven, jargon vermijden en voortdurend controleren op begrip.

Deel twee –Communicatie aan het levenseinde voor ouderen in Nederland

Hoofdstuk vijf is uitsluitend gebaseerd op gegevens van drie jaar uit de Nederlandse SENTI-MELC dataset. In dit hoofdstuk wordt de geleverde zorg van huisartsen bij het levenseinde van patiënten die overleden zijn aan 'kanker', 'orgaanfalen' en 'ouderdom of dementie' beschreven en vergeleken. Dit onderzoek toont aan dat patiënten met orgaanfalen minder vaak palliatieve zorg ontvangen van hun huisarts dan patiënten met kanker of ouderdom/dementie. Hoewel van de drie groepen de groep met de patiënten ouderdom/dementie de groep is die het meest waarschijnlijk de capaciteit tot besluitvorming verliest, wordt er in deze groep het minst gesproken over het levenseinde en advance care planning. Deze bevindingen onderstrepen de noodzaak om palliatieve zorg te integreren in de eerstelijns geneeskunde en om te starten met advance care planning aan het begin van een chronisch ziekte-traject.

Hoofdstuk zes is gebaseerd op gegevens uit de Longitudinal Aging Study Amsterdam (LASA). In dit onderzoek is de voorkeur van deelnemers onderzocht voor vier levensverlengende behandelingen aan het levenseinde aan de hand van hypothetische gevallen van kanker en dementie. Ook is gekeken naar de factoren die meespelen bij het hebben van een voorkeur om af te zien van een behandeling. Een meerderheid gaf aan af te willen zien van levensverlengende behandeling in het geval van kanker en dementie. Verschillende elementen van de multidimensionale variabele 'sociale steun' beïnvloedden de voorkeuren op verschillende manieren: een groter sociaal netwerk was geassocieerd met de wens om levenseinvrengende behandelingen te starten of mee door te gaan in het geval van dementie, terwijl in het geval van kanker een inwonende partner en krijgen van grotere emotionele steun waren geassocieerd met een voorkeur voor het starten of doorgaan met alle behandelingen. De huidige gezondheidstoestand was niet geassocieerd met een voorkeur voor een behandeling (behalve angst – geassocieerd met een voorkeur voor behandeling bij dementie). Inzicht in de invloed van sociale steun kan artsen stimuleren om de verwachtingen en angsten van patiënten over de sociale steun te exploreren tijdens advance care planning.

Hoofdstuk zeven is ook gebaseerd op LASA data, en vergelijkt uitspraken van mensen over hun voorkeur voor de toekomst (zo oud mogelijk worden onafhankelijk van gezondheidsproblemen versus korter te leven, maar zonder grote gezondheidsproblemen) met voorkeuren voor specifieke behandelingen (zoals reanimatie) in de hypothetische gevallen van kanker en dementie. Behandelingen waren in het geval van cognitieve achteruitgang in mindere mate gewenst dan in het geval van fysieke achteruitgang. Voor een aanzienlijk deel van de deelnemers kwamen specifieke behandelingsvoorkeuren niet overeen met hun algemene voorkeur voor het

levenseinde. Een slecht begrip van de risico's en nadelen van levensverlengende behandelingen, of verschillende voorstellingen van hun voorkeur (zoals het bereiken van korte termijn doelen in plaats van een focus op lange termijn) leiden waarschijnlijk tot een discrepantie tussen de algemene en specifieke voorkeuren met betrekking tot het levenseinde.

Hoofdstuk acht is gebaseerd op LASA gegevens verzameld in 1998, 2005, 2008 en in 2011. Dit onderzoek beschrijft zowel het hebben van een euthanasieverklaring en een levenswensverklaring, als de factoren die geassocieerd worden met het bezit hiervan, in een longitudinale analyse. De data geven inzicht in de invloed van het aannemen van de Nederlandse Euthanasiewet in 2002 op het bezit van een deze wilsverklaringen. Tijdens de twee cycli van dataverzameling (2005 en 2008) na de inwerkingtreding van de Nederlandse euthanasiewet in 2002 was er een significante daling van zowel de euthanasieverklaring als de levenswensverklaring. Bij de derde dataverzamelingscyclus, na de invoering van de euthanasiewet (2011), is echter het bezit van een euthanasieverklaring en een levenswensverklaring toegenomen, waardoor er uiteindelijk geen significante verschillen zijn met de aantallen van de periode voordat de wet werd ingevoerd. Deze bevindingen suggereren dat veranderingen in de wetgeving in eerste instantie een negatieve invloed hadden op het hebben van een euthanasieverklaring. Gezondheidsfactoren hadden geen invloed op het bezit van een wilsverklaring. Dit suggereert een stabiliteit van voorkeuren in verschillende gezondheidstoestanden en ondersteunt de legitimiteit van wilsverklaringen.

Algemene discussie

Hoofdstuk negen begint met een uitvoerige beschrijving van de methodologische sterke punten en beperkingen van het onderzoek beschreven in dit proefschrift. Sterke punten zijn het gebruik van een grote dataset uit verschillende Europese landen, representatief voor de populatie van huisartsen of de ouderenpopulatie, met metingen over de demografie, lichamelijke en psychische gezondheid en de beschikbare sociale steun van deelnemers. Beperkingen van deze studie zijn grotendeels te wijten aan problemen van haalbaarheid, of waren inherent aan een vergelijking tussen landen, het gebruik van secundaire data analyse, of aan het gebruik van gegevens die verzameld zijn voor een groter doel om meer gerichte onderzoeksvragen te beantwoorden. Hoofdstuk negen bevat daarnaast een epistemologische reflectie die stelt dat survey onderzoek de meest geschikte methode is voor het in kaart brengen van verschillen tussen landen, gedurende een bepaalde tijd en tussen verschillende bevolkingsgroepen. De belangrijkste resultaten uit de

voorgaande hoofdstukken en de interpretaties hiervan worden vervolgens beschreven in de context van de oorspronkelijke onderzoeksvragen.

In het bijzonder laten de bevindingen in dit proefschrift de opmerkelijke verschillen tussen de Europese landen zien ten aanzien van het voorkomen van gesprekken tussen patiënt en huisarts over het levenseinde. Het geeft de verschillen aan in het open bespreken van de dood en sterven, in prioriteit geven aan welzijn en autonomie in de klinische praktijk, en in de organisatie van het verstrekken van palliatieve zorg (met name de training van huisartsen in, en de verantwoordelijkheid voor, palliatieve zorg). Ook worden in dit proefschrift de overeenkomende kenmerken benadrukt van die patiënten voor wie communicatie over het levenseinde beperkt is, namelijk voor niet-kankerpatiënten, oudere patiënten, en voor diegenen die lijden aan cognitieve achteruitgang. Deze patiënten karakteriseren echter de toekomstige palliatieve zorgpopulatie. Ten slotte worden daarom aanbevelingen gegeven voor zowel praktijk als beleid. Dit proefschrift geeft suggesties voor het versterken van palliatieve zorg in de eerstelijns en het verbeteren van de communicatieve vaardigheden van artsen. Dit zal waarschijnlijk meer invloed hebben op het laten deelnemen van patiënten aan de besluitvorming over het levenseinde, dan het wettelijk versterken van de wilsverklaringen.

Kindly translated by Marije de Groot

Thanks

Dankwoord

First and foremost, I thank my supervisors and co-supervisor. Bregje Onwuteaka-Philipsen, Luc Deliens and Roeline Pasman. I was fortunate to have worked with you as part of PRISMA and then more closely as one of your Euro Impact PhD fellows. Thank you for sharing your expertise, providing encouragement and excellent banter and for making everything seem possible. Working with you all has been a pleasure. I'd also like to thank Massimo Costantini who acted as my supervisor during my 6 month secondment at the Ospedale San Martino in Genova, Italy. I was lucky to have had such an expert share his insights with me. Thanks also to all co-authors, especially Lieve van den Block and Dorly Deeg for the help and advice on working with EURO SENTI-MELC and LASA data respectively.

Special thanks go to Marjolein Gysels and Robert Pool. Thank you for giving me the opportunity to work at the Barcelona Centre for International Health Research (CRESIB) on the PRISMA project and for initiating me into the world of palliative care research. Your tradition of opening a bottle of fizz upon publication of an article greatly contributed to my productivity.

Thanks go to my colleagues at the Vrije Universiteit. In particular, my roomies Gwenda, Ria, Susanne, Martijn, Anita, Sacha and Emily. I was extremely lucky to have had such lovely people to share tea and cake with (and we all know how much I love cake). I'll thank Emily twice as my roommate in both Genova and Amsterdam; Emily, you have been a great friend. My thanks also extend to the other members of the department: Isis, Pam, Linda, Mariska, Eva, Maaïke, Sandra, Mattijs, Annicka, and Jon. You were all wonderful colleagues and inspiring researchers. Thanks also go to all of my colleagues from Euro Impact, both the fellows and the collaborators. Thank you for your excellent company and for sharing your diverse experiences.

I'd like to say a special thank you to my parents, for dragging me up right, for believing in me, for tolerating my perpetual nomadism and, Dad, for acting as last minute proofreader throughout my university career.

My most heartfelt thanks go to my husband, Christopher. Thank you for your unwavering love and support. For the past ten years, your approach to life and strong work ethic have inspired me. Thank you for moving with me to Amsterdam, I know how much you had to give up. You are, and always will be, my love and my home. Finally, thank you to our baby daughter Beatrix, born two-weeks after I handed in this thesis, you were with me during much of this journey and, most importantly, provided a very definite submission deadline.

About the author

Natalie Evans was born on January 12th, 1981 in London, England. After completing her A-levels she taught English for a year in Thailand. Natalie obtained her BSc (hons) in Biological Sciences from the University of Edinburgh and MSc in the Anthropology and Ecology of Development from University College London. After university she worked on a number of projects, including conducting research on livelihoods, poverty and social vulnerability in Karen villages in Mae Hong Son province, Thailand for the Karen Hilltribes Trust. From 2008 to 2011 Natalie worked as a Social Science Research Fellow for the Medical Anthropology Team at the Barcelona Centre for International Health Research (CRESIB). Here she had the opportunity to work on the FP7 funded PRISMA programme. PRISMA aimed to inform best practice and harmonise research in end-of-life care for cancer patients across Europe. Natalie was involved in the PRISMA work package on cultural issues in end-of-life care and authored and co-authored nine academic articles during the course of the project. In April 2011, Natalie started working as a Marie Curie PhD Fellow at the EMGO Institute for Health and Care Research as part of the FP7 funded EURO IMPACT project. EURO IMPACT aimed to develop a multi-disciplinary, multi-professional and intersectorial educational and research training network to monitor and improve palliative care in Europe. During this time Natalie completed her PhD thesis and undertook a total of 14 MSc and PhD level courses on aspects of research and palliative care coordinated by EURO IMPACT partners such as Lancaster University, the Norwegian University of Science and Technology, King's College London. As part of the EURO IMPACT project Natalie also completed a six month secondment to the National Cancer Research Institute in Genoa, Italy.

Natalie is married to Christopher Pell, with whom she has a beautiful daughter, Beatrix.

Publications

Publications

1. **Evans N, et al.** on behalf of EURO IMPACT. How do general end-of-life goals and values relate to specific treatment preferences? A population-based study. *Palliative Medicine* [Epub ahead of print June 2014]
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14. Meñaca A, **Evans N, et al.** on behalf of Project PRISMA (2012) "End-of-life care across Southern Europe: a critical review of cultural similarities and differences between Italy, Spain and Portugal". *Critical Reviews in Oncology/Hematology* **82**: 387–401

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1. **Evans N et al.** on behalf of PRISMA. Research on culture and values in palliative care – the experience of PRISMA. 8th Research Congress of the European Association for Palliative Care. *Palliative Medicine*, 2014; 28 (6): 547 [Invited Speaker]
2. **Evans N, et al.** on behalf of EURO IMPACT. Life-sustaining treatment preferences: social support more important than health? 8th Research Congress of the European Association for Palliative Care. *Palliative Medicine*, 2014; 28 (6): 558
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7. **Evans N, et al.** on behalf of PRISMA. Physician Assisted Suicide, Euthanasia and Palliative Sedation: Attitudes and Incidence in Germany. 11th Congress of the European Association for Palliative Care 18th-21st May 2011
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9. **Evans N, et al.** Making culture relevant to end-of-life care practice: an overview of approaches to cultural competency. 10th Congress of the European Association for Palliative Care 7th-10th May 2009