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

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2014

### **document version**

Publisher's PDF, also known as Version of record

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### **citation for published version (APA)**

Evans, N. C. (2014). *Patient-physician communication at the end of life: a European perspective*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

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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-centred<sup>1</sup> 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

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<sup>1</sup> 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 movement<sup>2</sup> [16]<sup>Pp 2</sup>. 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]<sup>Pp 66</sup>. 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]<sup>Pp 1</sup>. 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]<sup>Pp 63</sup>.

Saunders also emphasised the importance of patients' illness narratives in understanding their 'total suffering': physical, psycho-social and spiritual elements of pain[18]<sup>Pp 62</sup>. 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

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<sup>2</sup> 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.<sup>Pp2</sup>

17. Woods S (2007) *Death's dominion: ethics at the end of life*: McGraw-Hill International.<sup>Pp51</sup>

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]<sup>Pp 94</sup>, 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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