End-of-life decisions and place of death in Belgium and Europe

Joachim Cohen

Studies presented in this thesis were supported by grants from:

- The Vrije Universiteit Research Council (GOA 27)
- The Fifth Framework Program of the European Commission (QLRT-1999-30859)
- Brussels Capital-Region (PRFB 2005)

Cover design: Joachim Cohen
Book design: Joachim Cohen
Print: Grafikon, Oostkamp

2007 VUBPRESS Brussels University Press
VUBPRESS is an imprint of ASP nv (Academic and Scientific Publishers nv)
Ravensteingalerij 28
B-1000 Brussels
Tel. 0032 (0)2 289 26 50
Fax 0032 (0)2 289 26 59
E-mail info@vubpress.be
www.vubpress.be

ISBN 978 5487 418 8
NUR 883
Wettelijk depot D/2007/11.161/008

End-of-life decisions and place of death in Belgium and Europe

Dissertation

Thesis, neergelegd ter verkrijging van de graad van Doctor in de Sociale
Gezondheidswetenschappen: Medisch Sociale Wetenschappen

Aan de Vrije Universiteit Brussel
Faculteit Geneeskunde en Farmacie
Richting Medisch Sociale Wetenschappen
Vakgroep Medische Sociologie
Onderzoeksgroep Zorg rond het Levenseinde
31 mei 2007

Joachim Cohen

Vrije Universiteit Brussel

RESEARCH GROUP
End-of-Life Care

Promotor:	**Prof. dr. Luc Deliens**
Co-promotoren:	**Prof. dr. Johan Bilsen**
	Prof. dr. Gerrit van der Wal

Examencommissie

Voorzitter:	Prof. dr. Anne Marie Depoorter
Overige leden:	Prof. dr. Wim Distelmans
	Prof. dr. Leon Kaufman
	Prof. dr. Freddy Mortier
	dr. Agnes van der Heide
	Prof. dr. Bob Vander Stichele
	Prof. dr. Dick Willems

CONTENTS

page

Part 1 Introduction 1
1.1 Shifting concerns: from the medicalisation and institutionalisation of death to the rising concept of 'good death' 4
1.2 Medical end-of-life decisions that possibly hasten death 8
1.3 The place of death 10
1.4 Research questions of this dissertation 15
1.5 Methodological issues 15
1.6 Outline of this dissertation 20

Part 2 End-of-life decisions 31
2 Trends in acceptance of euthanasia among the general public in 12 European countries, 1981-1999 *(European Journal of Public Health 2006)* 33

3 European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries *(Social Science & Medicine 2006)* 51

4 Physicians' attitudes towards end-of-life decisions and actual end-of-life decision making in six countries: the influence of life-stance. *(Journal of Medical Ethics, in press)* 75

Part 3 Place of death 93
5 End-of-life decision making in Belgium, Denmark, Sweden and Switzerland: Does place of death make a difference. *(Journal of Epidemiology and Community Health, in press)* 95

6 Using death certificate data to study place of death in 9 European countries: opportunities and weaknesses *(submitted)* 113

7 Dying at home or in an institution. Using death certificates to explore the factors associated with place of death *(Health Policy 2006)* 129

8 Hospital death rates in six European countries: a population-based cross national study of clinical, sociodemographic and health care system factors *(submitted)* 149

Part 4 Main findings and general discussion 167

List of abbreviations 219
Nederlandstalige samenvatting 221
Curriculum Vitae of Joachim Cohen 231
Figures in colour 235

PREFACE AND ACKNOWLEDGEMENTS

Primarily, this book is the dissertation submitted to obtain my PhD degree. However, with it I also hope to have made a sociological-epidemiological contribution to the contingent of knowledge about death and dying and provided some inspiration for the practical constitution of 'good' end-of-life; in other words a book of use for a wider audience than merely my examination committee.

The book fundamentally deals with two end-of-life issues: medical end-of-life decisions that possibly hasten death and the attitudes towards these decisions (part 2 of the book), and the place of death (part 3 of the book). Several of the chapters of these two parts have previously been published (or are in press) in international journals.

Before presenting you with the end product of my PhD-study, I am indebted to acknowledge the (direct and indirect) help and contribution of a number of persons.

My PhD could not have been realised without the help of my supervisors/promoters.

I am very much indebted to Johan Bilsen, Gerrit van der Wal, and Luc Deliens.

Johan, I enjoyed you as my direct supervisor (you always read and commented my work thoroughly, which was very reassuring), and even more so as a friend.

Gerrit, I very much appreciated how you managed to (usually timely) read my texts in detail and provide the most useful and to the point comments, despite your ridiculously full agenda. It has been a pleasure to work with you.

Luc, I want to thank you to give me the opportunity of writing my PhD in our Research Group. I have enjoyed working on the subject, and have much valued the working-method in the Research Group, in which a close supervising and guiding was balanced by enough freedom to work out my own ideas. Thanks for all critical but most useful remarks, and for the support and confidence you put in me.

I also wish to thank the thesis assessment commission for their comments and suggestions: Annemarie Depoorter, Wim Distelmans, Leon Kaufman, Freddy Mortier, Bob Vander Stichele, Agnes van der Heide, and Dick Willems.

A great deal of the success and satisfaction in a PhD trajectory depends on the valuable insights of cooperative colleague PhD-students. In this context, I am greatly indebted to Lieve van den Block, and Cindy De Gendt, who shared their knowledge on end-of-life care with me at the time I started working in the End-of-Life Care research group, and to Koen ‘criminal act’ Putman who initiated me into the world of advanced Excel. I also want to thank Greta and all other colleagues at the department of Medical Sociology who have not only been a great help, but were also fun to work with.

Several colleagues have contributed to the studies in this thesis. Isabelle Marcoux, Patrick Deboosere, Freddy Mortier, the late Peter Hooft, Guido Miccinesi, Cristina Canova, Julia Addington-Hall and Alison O’callaghan, Rurik Löfmark, Stein Kaasa and Finn Gutvik, Agnes van der Heide, Bregje Onwuteaka-Philipsen, Johannes van Delden, Colleen Cartwright, Michael Norup, Susanne Fisher, Karin Faisst,… I am indebted for all your assistance. It has been an enriching experience to work with all of you and you have all been extremely helpful in dotting the i’s and crossing the t’s.

Furthermore I hope to embarrass my friends by putting their names here: Dries, Kristof, Kris (x2), Maarten, Patrick, Roel, Roeland, Thomas, Katja, Sophie, Joke, … Thanks for all the fun and distraction from work.

Ma, Pa, Kristine, uiteraard horen jullie ook thuis in dit dankwoord. Waar zou ik staan zonder de steun die ik altijd van jullie heb gekregen? Ik dank ook mijn schoonfamilie die me altijd warm heeft ontvangen.

Ten slotte, en misschien meest belangrijk van al, gaat mijn oneindige dank uit naar Katja. Je hebt niet alleen altijd veel geduld en begrip gehad, ik vond bij jou ook altijd de nodige afleiding, emotionele steun, relativering, moed en strijdbaarheid om door te blijven gaan.

Joachim Cohen
Brussels, April 2007

End-of-life decisions and place of death in Belgium and Europe

Part 1

Introduction

> « *In every society the dominant image of death determines the prelevant concepts of health* »
>
> *(Ivan Illich, 1976, p.171)*

1

Introduction

page

1.1 Shifting concerns: from the medicalisation and institutionalisation of death to the rising concept of 'good death' 4
1.2 Medical end-of-life decisions that possibly hasten death 8
1.3 The place of death 10
1.4 Research questions of this dissertation 15
1.5 Methodological issues 15
  1.5.1 European Values Survey (1981, 1990, 1999-2000) 16
  1.5.2 European Study of End-of-life Decisions (Eureld 1 & Eureld 2) 16
  1.5.3 Death certificate data (Flanders 2001; Dying Well 2003) 19
1.6 Outline of this dissertation 20

1 Introduction

Can we put a degree of control to when, where, and how we die? Addressing this question has been one of the leitmotifs of the palliative care and right-to-die movements' efforts to ensure good quality of end-of-life. It put dying well on the agenda as an aspiration. The issues embedded in this question were also the stimulus for the two main aims of this dissertation on dying well in Belgium and Europe:

- describing attitudes towards and practice of euthanasia and other possibly life-shortening medical end-of-life decisions,
- describing who is dying in what setting, and for what reasons.

Before addressing these specific end-of-life issues, and in order to elucidate the relevance of these aims within a wider societal context, we will first give a brief description of how death and dying have altered in recent history, from an era of medicalisation and institutionalisation to an era where quality of death and dying became an issue of concern for a large societal basis. Within this framework we will sketch the issue and relevance of medical end-of-life decisions (and attitudes towards these decisions), and of place of death.

1.1 Shifting concerns: from the medicalisation and institutionalisation of death and dying to the rising concept of 'good death'

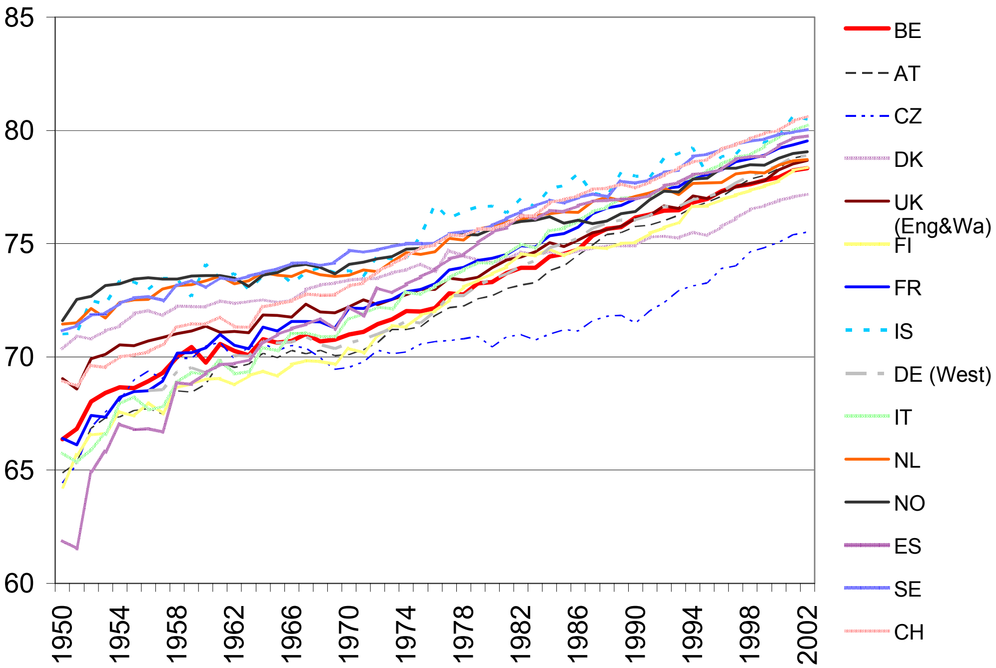
Medicalisation and institutionalisation of dying can be regarded an exponent of 'modernity'. Modernity allegedly led to a fading of experiences with existential and sacral things, to a formal technical-rational approach of reality, to a declining feeling of togetherness, and eventually to an imprisonment in an 'Iron cage' trivialising human action into a pursuit of interest and 'utility' [1-4]. Technical and economical rationality in healthcare also lead to health care 'enterprises' subordinate to this rationality, and altered the dealing with patients, causing a 'blindness' for their existential idiosyncrasies. As a consequence (the care of the) dying became something instrumentalist, impersonal, and the dying process a technical matter, bereaved of its existential and personal significance [5]. The controversial analysis of the medical system by Ivan Illich (1976) can be situated in the same line of thinking [6]. Illich believed the medical system to have proclaimed itself a heroic quasi-divine status and to have given rise to unrealistic expectations in the population it served, disguising the fact that suffering was an inevitable part of human life. This led to a situation where cultural and individual possibilities to deal with death, suffering and illness had vanished and where patients and their families lost their autonomy or ability to take care for themselves. Death and dying became ‘medicalised’ by the medical ‘enterprise’ and were transformed from a personal challenge into a technical medical problem. Death became something to be resisted, postponed or avoided, and patients seemed to have lost the autonomy to recognise when their time has come and to take their death into their own hands. One consequence was that all suffering had become hospitalised and home had become inhospitable to death. A hospitalisation of death can indeed be observed in much over the 20th century [7-11], and according to Illich this had inevitably imposed on society a new form of dying. The medicalisation and hospitalisation of death led to a loss of the capacity to accept death and suffering as meaningful existential aspects of life, but also led to a crippling of personal and family care and a devaluation of traditional rituals surrounding death and dying [6;12].

However, a number of developments have possibly started to cause a turnaround. According to authors like Beck and Giddens, a result of modernity’s collapse of family and tradition was also that it put the individual back in play [13]. Individuals, to speak with Beck, became the *planning agents* of their own life [13]; and consequently gained more autonomy and responsibility over their own life and death choices. Legal-political developments[a], like the passing of the Patient Self-Determination Act in the United States, the Oregon Death with Dignity Act, the Euthanasia laws in The Netherlands and Belgium, the laws on Palliative Care in various countries, and the laws on patients rights came (partly) as a result of this individualisation: patients should be able to decide for themselves what treatment they want and when they do not want any more treatment and choose to die peacefully.

Next to that, demographic and epidemiologic developments changed the circumstances of dying and contributed to an increased concern for death and dying in our contemporary society, both among the general public, health policy makers, as among (health) professionals. Achievements in public health throughout the last two centuries have incited a strong increase in life expectancy. Life expectancy at birth (which represents in fact the average age of all persons death in a certain year, and thus mostly born decades earlier) rose in Belgium from 65.8 in 1950 to 78.7 in 2002, and is still increasing by about a season per year. Several other European countries have undergone a similar shift (figure

1), with some countries having a life-expectancy of more than 80 years in 2002 (Switzerland, Iceland, Italy and Sweden). Ever more people pass the age of 80, contributing to an aged population. Along with that, our society has known a considerable alteration of its predominant epidemiological patterns, the so-called epidemiological transition [25;26]. Instead of from infectious diseases people now more often die from chronic diseases like cancer and chronic heart diseases and growing old is rather typified by a slow degenerative dying process than by a sudden or quick death. These developments not only put weight on public health policy --particularly through the increased emphasis on geriatric care and end-of-life care for elderly patients--, they also substantially confronted us with death and dying as an integral part of our life and of society [27].

Figure 1: Life expectancy in Europe 1950-2002



Source: own figure, based on data published by Human Mortality Database; web: http://www.mortality.org/ (accessed 23/06/2006). For West-Germany no data were recorded before 1957.
See p. 235 for colour version

Additionally, a new critical consciousness has started to question modern medicine's medical-technological approach of health problems. Improved life expectancy and expanded options for sustaining the life of terminally ill had also given way to a strong belief in progress in medicine, inciting the so-called technological imperative: a strictly technical-rational professional solution rather than a 'reflexive' one was sought for every medical problem [5]. However, the drawbacks to this progress have gradually become apparent, and criticism against futile medical (end-of-life) care and the vision that curative treatment is by definition beneficial have become more vocal. This criticism demanded a new approach to death and dying, one in which we realise that death is an inevitable aspect of life; and hence a good death an aspect of quality of life. The rising of palliative care, which can partly be regarded as a reaction towards how terminally ill people were being managed in highly medicalised settings in a highly medicalised manner, is exemplary for this awareness.

Thus, an attitude was shaped that reacted to the medicalisation of death and encouraged medicine to be gentler in its acceptance of death [12;28 29]. Illustrative for this changing general attitude towards death and dying is the rising concept of 'good death'[b]. The literature on (*what is* or *how to constitute)* the 'good death' presents us with an array of theories [29-40]. Most commonly a good death is described as dying in a way that heeds respect to the distinctive existential meaning this event can have for both the patient involved as well as his/her next of kin [5], or else as making the last weeks –not minutes- of life valuable and meaningful [30]. Attempts to describe the characteristics of a good death more into detail are for example found in an article by Clark[12] in the British Medical Journal: a pain-free death; open acknowledgment of the imminence of death; death at home, surrounded by family and friends; an «aware death», in which personal conflicts and unfinished business are resolved; death as personal growth; death according to personal preference and in a manner that resonates with the person's individuality. Similar components are found in several other articles [28 30-35;39;41]. Although conceptual models of 'the good death' are often overly simplistic, vague and difficult to translate into practical guidance [30], and it moreover remains the question whether a 'good death' can be generalised, there seem to be striking nearly universal ideals about a good death: death after a long and successful life; at home; without violence or pain; with the dying person being at peace with his environment and having at least some control over events [36].

1.2 Medical end-of-life decisions that possibly hasten death

Demographic changes (increasingly confronting us with dying), and general cultural and attitudinal changes (e.g. increased intolerance towards pain and suffering [6], increasing value put on personal autonomy, individualism, right to self-determination, and changed medical aspirations) [27;42] have thus incited our concerned attitudes towards death and dying. However, at the same time advances in medical diagnostic and therapeutic technologies have increased (and keep increasing) the possibilities to sustain life, sometimes for long periods. A patient loosing vital functions for instance can, due to the technological possibilities, still be kept alive for a long time [34]. These (conflicting) tendencies irrevocably raised, next to a policy-inspired question of financial costs, a number of ethical questions, especially the morally inspired question of comfort and dignity at the end of life. From this point of view, patients, families, physician and society as a whole may find it acceptable (or even necessary) that certain medical decisions are being made that do not futilely prolong the life of terminally ill. This may involve withholding of certain aggressive treatments and may (for some) go as far as hastening death. These kinds of decisions that potentially or certainly hasten death are usually referred to as medical end-of-life decisions, and are usually classified in five main categories (see Box 1).

Box 1: Overview of medical end-of-life decisions, and used definitions

1. Euthanasia: the administration of drugs with the explicit intention to end life at the explicit request of the patient
2. Physician assisted suicide (PAS): the prescription or supply of drugs with the explicit intention to enable the patient to end his or her own life at this patient's explicit request
3. Life-ending acts without an explicit request by the patient (LAWER): administration of drugs with the explicit intention to end life without an explicit request of the patient
4. Intensification of the alleviation of pain and symptoms (APS) by using drugs (e.g. morphine) taking into account a possible life-shortening side effect
5. Non-treatment decision (NTD): the withholding or withdrawing of treatment, taking into account the possibility or the certainty that this will hasten the patient's death

Several studies have demonstrated that euthanasia and other end-of-life decisions occur in medical practice in many European countries (as well as outside Europe) [43-50] (see Table 1, based on most recent incidence figures).

Table 1: End-of-life decisions in European and other countries (percentage of all deaths)

	BE [46]	CH [46]	DK [46]	IT [46]	NL [46]	SE [46]	UK [50]	AU [45]
Euthanasia	0.30	0.27	0.06	0.04	2.59	0.00	0.16	1.7
Physician assisted suicide	0.01	0.36	0.06	0.00	0.21	0.00	0.00	0.1
Life-ending acts without an explicit request by the patient	1.50	0.42	0.67	0.06	0.60	0.23	0.33	3.5
Intensification of the alleviation of pain and symptoms	22.0	22.1	25.9	18.9	20.2	21.2	32.8	28.6
Non-treatment decision	14.6	27.7	13.9	4.1	19.9	14.5	30.3	30.9

Source: own table, based on data from different studies (mentioned in column header)

These incidence studies have been extremely important, not only for ethical and legal discussions and debates, but also in contributing to a better understanding of how end-of-life decisions are performed and to ensuring a safe and prudent practice. For similar reasons it is however important to also study attitudes towards these decisions, and to evaluate how acceptable these practices are deemed, under certain circumstances, by both the potential requestors and subjects of end-of-life decision making and the primary actors in these decisions. Not only because they have an important influence on the legal and public debate but also because they can influence actual practice. Especially if we keep on struggling for a sense of control for patients over their dying trajectory, knowing the attitudes of all parties involved is important. The acceptance of various end-of-life decisions by the general public thereby rather illuminates the ethical and humane stances of potential requestors and subjects of these decisions. It reflects the extent to which people find it acceptable that an individual (not necessarily themselves), in certain circumstances, gets a certain degree of control over the timing and the manner of their death. Attitudes of physicians (or medical associations) rather illuminate ethical and realistic stances of those potentially taking end-of-life decisions in actual practice. It reflects a weighing of the extent to which they agree to the patient having control and the extent to which they will find it acceptable to make the decision if they were asked for it in practice. Examining these attitudes, of both the general public and the physicians, thus helps to further understand and interpret, but also to mould actual end-of-life practices [51;52]. It also helps to understand whether healthcare legislation and organisation meets the preferences of those involved [53].

This dissertation aims to make a contribution in this perspective, by researching the attitudes of both the general public and the physicians, as well as what influences these attitudes. It is often suggested that the acceptance of end-of-life decisions, in particular euthanasia, has increased over the last decades in several countries [54-61], that there is a relatively high acceptance and high support for the legalisation of euthanasia in several countries [54;62-67], that most people accept non-treatment decisions or decisions to intensify morphine dosages possibly hastening death in case of a severely suffering patient [54;55;68-70], and that physicians usually have a somewhat more reluctant attitude towards (the legalisation of) euthanasia than patients or the general public [67;70-74]. However, the existing research of attitudes towards end-of-life decisions has a number of limitations. No explanations for the changing attitudes have been examined, attitudes are often only studied among one party potentially involved in the decision-making process (usually only physicians), and there is an insufficient understanding of what influences physicians in their attitudes towards whether or not to make certain ELDs (especially with regard to the role of religious beliefs). Moreover all studies have usually been limited to one country, differ in study designs and questionnaires, hence, making results difficult to compare. An aim of this dissertation was therefore also to fill some of these gaps in the existing research.

1.3 The place of death

Next to controlling parameters of timing and circumstances of death, controlling the place of death has been proclaimed an important aspect of dying well in practice [35;36;41]. Like medical end-of-life decisions, place of death has become an issue of increasing clinical, ethical, and sociological importance in the context of the medicalised and institutionalised character of dying, the growing reaction against this and the desire to improve the quality of the dying process There are four main reasons suggested in the literature for why influencing and controlling the place of death, and hence studying it, might be important: because place of death is a parameter of quality of end-of-life, because of the strong preferences with regard to place of death, because of economical motives, and because of a sociological-historical interest.

First of all, the place of death is regarded as a quality parameter of dying and of end-of-life care. The place of death has frequently been named a parameter of a good death in the literature and in research [12;40;41]. Various authors and palliative care experts believe that home deaths are more natural, let people have more control over their quality of life and provide more psychological comfort [9;75]. Besides these arguments, there are also some empirical indications that the setting of end-of-life care affects the type and intensity of services, the interpersonal interactions, the caregivers skills, as well as patient outcomes [9;75-81]. Empirical studies have for example shown that dying at home alleviates the guilt of the bereaved, where in case of a hospital death family members often lack the ability to say goodbye [9;75;78;81]. In hospitals nurses were also shown to take longer to respond, doctors appeared to avoid patients once they have begun to die, and deaths moreover seemed frequently prolonged, painful and mechanically supported. This influence of setting on characteristics of care also lives forth in the perceptions of patients. Tang [82;83] demonstrated that terminally ill cancer patients preferred dying at home, because they believed it to provide a better quality of life, and because they valued the better availability and ability of family caregivers at home. Similar research by Choi (2005) indicated that many people feared to be lacking privacy, emotional comfort, safety, a sense of belonging, or being surrounded by beloved ones in a hospital [84].

In short, the setting seems to influence the (characteristics of) end-of-life care, and hence the quality of (end of) life for patients and their next-of-kin [9;75;78;83].

Of course, several authors have rightly questioned an a priori superiority of dying at home, especially since the degree to which dying at home is desirable and realistic depend greatly on the household situation of the patient, the care at hand, and the desirability or necessity of hospitalization depending on the condition of the patient[11;85]. Moreover, recent establishment and developments of palliative care initiatives in hospitals (palliative care units) and in care homes challenge the notion that home is always preferable.

Second**,** next to the alleged association with the quality of care, the place of death is an issue of importance because of the strong preferences with regard to place of death among the general population and terminal patients. While it is not a priori obvious that dying at home equates to a better death, there is clearly an overall preference for dying at home [85-90]. And with others [30;91-94], we want to assume that a 'good death' is one that is in general accord with patients' and families' wishes. Dying at the place of wish makes an important contribution to the sense of control over the own dying, which is key to dying with dignity and to delivering quality end-of-life care. Hence, the existing divergence between the desired and actual place of death is a substantial barrier to appropriate end-of-life care. Despite a distinct preference for home death (even just before death), the proportion actually dying at home is rather low [87;93]. Research shows that 32% of HIV patients [95], over more than 60% to 90% in the general population [88;96] up to 93.5% [89] of cancer patients prefer to die at home. A review of the research on preferences for place of death is presented in Table 2. While an expressed preference –a condition far from always present in the care for terminal patients- is indeed a factor determining the actual place of death [93;97-99], research also reveals that these preferences are far from always honoured [89;93;97-99]. In about a third to 78% of patients with an explicit preference, the preference was honoured (see Table 2)

Table 2: Preference for dying at home (and congruence with actual place of death) in different studies

Place	Population	N	% preferring home death	% congruence*	Reference
Italy	**Cancer patients**	**1900**	**94%**	**67%**	**Beccaro 2006 [89]**
UK	**Patients admitted to hospice home care team**	**77**	**90% (decreased to 50% right before death)**		**Hinton 1994 [90]**
USA	**General population**	**?**	**90%**		**Gallup 1997 [88]**
Israel	**Cancer patients**	**171**	**88.9%**		**Gilbar 1996 [100]**
USA(Connecticut)	**Terminal cancer patients**	**180**	**87%**	**30%**	**Tang 2003 [93]**
USA	**Terminally ill patients**	**479**	**82%**		**Pritchard 1998 [101]**
Ireland	**Patients admitted to hospice home care team**	**148**	**82%**	**47%**	**Tiernan 2002 [99]**
Australia (South)	**General population**	**2652**	**70%**		**Foreman 2006 [102]**
Italy	**General population**	**964**	**64%**		**Toscani 1991 [88]**
Scotland (South-west)	**General Practice attenders (compared to control group with close personal experience of death and dying)**	**4117 (control group = 100)**	**63% (52% in control group)**		**Charlton 1991 [103]**
Canada (south central/western Ontario)	**Terminally ill patients (via informal caregivers)**	**216**	**63%**	**78%**	**Brazil 2005 [98]**
Taiwan	**Cancer patients**	**559**	**61%**		**Tang 2005 [83]**
Australia (South Australia)	**General population**	**463**	**59%**		**Ashby 1993 [96]**
UK	**Cancer patients**	**84**	**58% (decreased to 49% right before death)**		**Townsend 1990 [87]**
Korea	**Cancer patients**	**371**	**47% (53% preferred home as place of terminal care)**		**Choi 2005 [84]**
Scotland (Edinburgh)	**HIV patients**	**139**	**32%**		**Brettle 1995 [95]**
USA	**Older persons (65+) with certain chronical diseases**	**246**	**43% (home as place of terminal care)**		**Fried 1999 [104]**

*: this is, among those patients who had an explicit preference for place of death, the percentage of patients who died in the preferred place of death; Source: own table, based on a review of existing research

Third, economical motives have also inspired public health policy's interest in the place of death**.** The costs of medical care seem increasingly to become a burden on society and therefore to become a political economical issue. This has especially also awakened interest in the costs of end-of-life care, in particular because the costs of medical care sharply increase towards the end-of-life [105]. Currently about 80% of a deceased persons medical care expenditures have occurred in the last year of life; 40% in the last month [105]. About 12% of total health care costs in UK [106] and about a quarter of total Medicare expenditures in the USA [107] are spent on the end of life. Most of the expenditures in the lasts months before death are for acute care hospitalisation and subsequent use of (sometimes futile) expensive treatments [107]. The demographic prospects in mind, this urges for a rational and cost-effective way to provide good end-of-life care. In this context research has suggested that a decrease of health care expenditures at the end of life might be realised, on the one hand by reducing the number of 'heroic' and futile medical interventions at the end of life of terminally ill patients and by promoting the adequate use of advance directives and palliative care alternatives [77;108-111]; on the other hand by limiting the number of (unnecessary) hospitalisations and letting patients more often die at home if they wish so [77;111-113]. Funds to increase the number of chronically ill patients dying at home (e.g. by fulfilling a number of preconditions like the availability of palliative home care) would not only comply with most patients' wishes [88] but would most likely eventually have substantial cost-saving effects as well [77;112;113]. Health economist David Taylor calculated that every million £ spent on home palliative cancer care releases 2 million £ from hospital funds[112]. Savings can thus be made if caregivers are more proactive about limiting people to get into hospital when this is not necessary. This has also inspired the House of Commons Health Committee in their recommendations to allow more people to die at home if they want to, explicitly referring to cost-saving effects of home deaths [114].

Although the cost-saving effects of a reduction of the proportion of hospital deaths remains a point of discussion [109;115], many countries have in fact in recent decades implemented policy measures to reduce the number of acute care hospitalisations as a means to restrict hospital expenditure [116;117].

Fourth, the interest in research about place of death also has a sociological-historical component. Much over the 20th century a hospitalisation-of-death has taken place [7-9;11;118] and this is one of the striking trends that marks the changes our society has undergone. In Canada the number of hospital deaths rose from 50.9% in 1950 to 80.5% in 1994 [10]. Basically everywhere, the proportion of deaths occurring at home decreased, in South Australia from 55.6% in 1910 to about a quarter in the 1980's [119], in Japan from 82% in 1951 to 13% in 2002 [120], in Korea from 72.9% in 1992 to 49.2% in 2001 [118].

Since these trends are so striking, and more or less universal in the western world, they have been of particular interest to sociologists (and historians), envisioning these trends as a very visible feature of medicalisation (and the reason for the described discrepancy in preference and practice), and seeking to describe consequences and causes. Social and demographic changes, but also of changes in the medical service in the community (e.g. the number of hospital beds) have to an important amount contributed to these trends [7;119;120].

For reasons mentioned above, it has also caught the attention of policy makers who now, in some way or another, want to reverse this hospitalisation-of-death trend. The slight rise in home deaths that can be observed in different countries since the 1990's is maybe an indication that this is already taking place [8;10;121-123].

The place of death is thus an issue of importance from various perspectives. Therefore it is essential to study (and monitor) where deaths are taking place and to gain a good understanding of the factors that determine why deaths occur in that place.

While place of death has frequently been studied, the previous research was often limited with regard to sample size [124-126], patient population [86;91;95;97;99;124;125;127-135] or setting [91;97;99;125;126;129;132;133;135;136]; did often not use appropriate multivariable statistical models allowing sufficient adjustment for confounders; and moreover made no (reliable) cross national comparisons. Nonetheless, systematic and comprehensive reliable epidemiological data have been proclaimed as crucial for the planning, organisation and implementation of (end-of-life) health care policies [137].

1.4 Research questions of this dissertation

Two main thematic aims guide this dissertation: first, describing the attitudes among the general public and among physicians towards euthanasia and other end-of-life decisions; second contributing to the knowledge of place of death and the influencing factors.

To the first aim the following specific research questions will be answered:

1. How has the acceptance of euthanasia among the general public changed over the last decades, and what factors have contributed to this change?
2. What is currently the degree to which euthanasia is accepted throughout Europe? Are there large differences between European countries, and, if so, how can these be explained?
3. What are the attitudes towards and the intended and actual behaviour of physicians in end-of-life decision making? What is the specific influence of religion?

To the second aim the following specific research questions will be answered:

4. Are different places of death associated with different end-of-life practices?
5. How appropriate are death certificates to study the place of death and associated factors? What are the opportunities and what are the weaknesses?
6. Where do people die in Belgium and in other European countries and what factors influence where they die? Are there striking inequalities?
7. What explanations can be given for (possible) differences in place of death between European countries, and can these explanations give suggestions for health policy makers?

1.5 Methodological issues

In order to answer these research questions, several data sources were used. These can however be grouped into three thematic categories: The European Values Studies, the Eureld Studies, and the Flanders 2001 death certificate data and the Dying Well in Europe death certificate data.

1.5.1 European Values Survey (1981, 1990, 1999-2000)

The European Values Studies (EVS) are studies exploring the patterns in cross-national differences and similarities in basic social, cultural, political, moral, and religious values in Europe and the changes in these patterns over time. Thus far, three surveys have been conducted: the first one in **1981** (in ten West European countries, Iceland and Sweden), the second in **1990 (**in 23 European countries), the third in **1999-2000 (**33 European countries, more than 40 000 respondents). All surveys were based on representative national samples of all adult citizens (quota sampling or random sampling with stratification by age, sex and region), interviewed through face-to-face interviews [138]. All three surveys yielded a satisfying response. Out of more than 300 questions, assessing attitudinal, cultural and socio-demographic information, the variable of our interest was the question on euthanasia, asked in the three surveys. The question, using a description of euthanasia dissimilar to the definition used in Box 1, was the following: "Please tell me whether you think 'euthanasia (terminating the life of the incurably sick)' can always be justified, never be justified, or something in between". The respondent was then asked to give a rating on a Likert scale from 1 to 10; 1 meaning 'never justified', and 10 expressing that euthanasia is 'always justified'.

1.5.2 The European Study of End-of-life Decisions (Eureld 1 & Eureld 2)

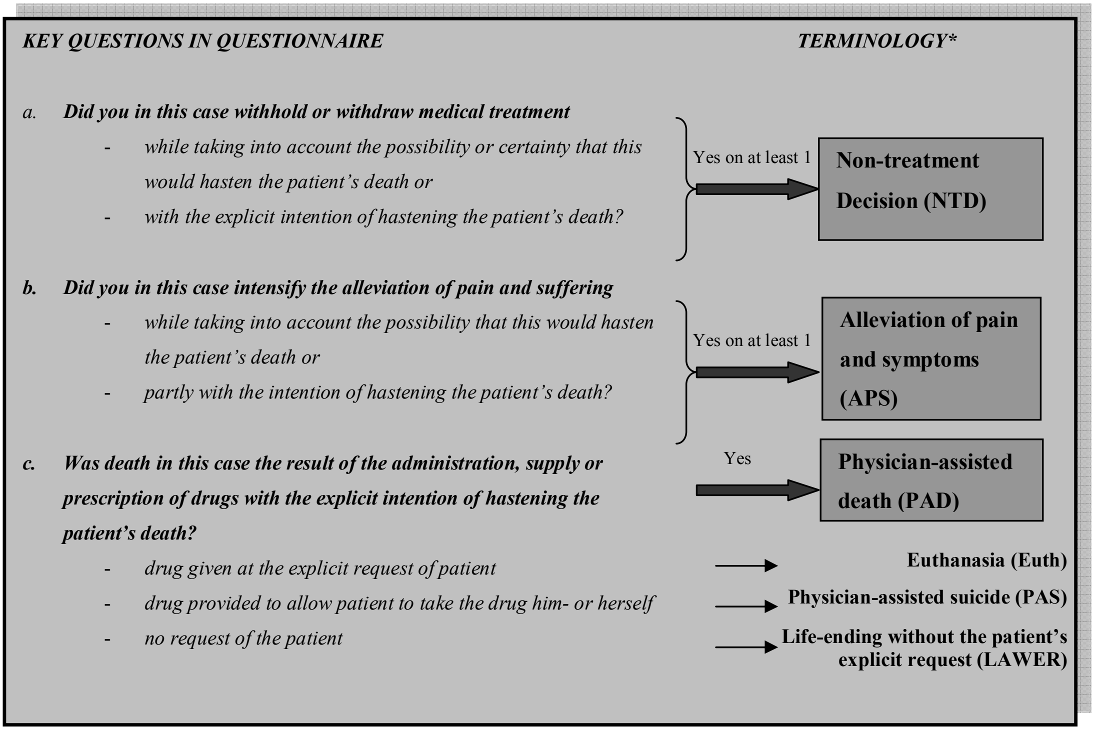
The European study of end-of-life decisions (Eureld) was an international collaborative research project between six European partners (Belgium, Denmark, Italy, Sweden, Switzerland, and The Netherlands), funded within the Fifth Framework Program of the European Union. The aim of this project was to explore the field of end-of-life decisions in six European countries, both the practice (i.e. the actual decisions being made) as the attitudes of physicians towards these decisions.

To classify the different kinds of end-of-life decisions, the Eureld study used a conceptual framework as the root of the questionnaires, based on at least two main dimensions [139]. One dimension describes the action of the physician (either withholding or withdrawing a potentially life-prolonging treatment, or using potentially life-shortening drugs). Another dimension describes the life-shortening intention of the physician when making the decision (either not intended but taken into account, co-intended, or explicitly intended) and the involvement of the patient, family and other caregivers in this decision (does the patient have an explicit request or not). The distinguished categories of end-of-life decisions are those listed in Box 1.

The project was split up into two separate studies.

The first study (**Eureld 1**), was a retrospective death certificate study aimed at making reliable population estimates of the number of deaths preceded by one or more end-of-life decisions. Data were gathered in the six European countries participating to the Eureld Study: Belgium (Flanders), Denmark, Italy (Emilia Romagna, Trento, Tuscany, and Veneto), Sweden, Switzerland (German-speaking part), and The Netherlands. In every country or region, random samples of death certificates were taken (with a stratification for causes of death with a high, medium, or low likelihood of end-of-life decisions being made) [46;140]. Standard questionnaires concerning the medical decision-making preceding death were sent to the physicians certifying the sampled deaths. An overview of the key questions in the questionnaire and the derived concepts from the answers on these questions (cfr. conceptual framework) is given in Box 2. Besides the questions in Box 2, also one question was asked about continuous deep sedation: “Did you use drugs such as barbiturates or benzodiazepines to keep the patient in continuous sedation until death?” A second section of the questionnaire asked for the characteristics of the decision-making process that preceded the end-of-life decision, and a third section obtained some more detailed information about which treatment was forgone and which drugs were used, if applicable. Follow-up mailings were used to optimise the response rate[46;140]. The response to the questionnaires was 74% in The Netherlands (n=5617), 67% in Switzerland (n=3355), 62% in Denmark (n=2939), 61% in Sweden (n=3248), 59% in Belgium (n=2950), and 44% in Italy (n=2604). In each country, specific information from the death certificate was linked to the information in the corresponding questionnaire, after complex anonymity-procedures to preclude identification of any of the doctors or patients. All country-specific databases were integrated into one common file to ensure exact identical coding and analysis procedures. Approval for the study was given in all countries by the relevant instances[140].

Box 2: Structure of key questions in Eureld 1 questionnaire and terminology derived from it



KEY QUESTIONS IN QUESTIONNAIRE ***TERMINOLOGY****

a. ***Did you in this case withhold or withdraw medical treatment***

- *while taking into account the possibility or certainty that this would hasten the patient's death or*
- *with the explicit intention of hastening the patient's death?*

Yes on at least 1 → **Non-treatment Decision (NTD)**

b. Did you in this case intensify the alleviation of pain and suffering

- *while taking into account the possibility that this would hasten the patient's death or*
- *partly with the intention of hastening the patient's death?*

Yes on at least 1 → **Alleviation of pain and symptoms (APS)**

c. ***Was death in this case the result of the administration, supply or prescription of drugs with the explicit intention of hastening the patient's death?***

Yes → **Physician-assisted death (PAD)**

- *drug given at the explicit request of patient* → **Euthanasia (Euth)**
- *drug provided to allow patient to take the drug him- or herself* → **Physician-assisted suicide (PAS)**
- *no request of the patient* → **Life-ending without the patient's explicit request (LAWER)**

* For cases where more than one of the questions in box 1 had been answered with 'yes', the decision with the most explicit intention was esteemed to be most important for our classification, whereby answer c prevailed over answer b, and answer b over answer a.

The second study **(Eureld 2)**, was a postal survey aimed at gaining more insight into the attitudes of physicians towards end-of-life decision making. In the six European countries participating to Eureld 1 and in Australia, written structured questionnaires were sent to practising physicians from 10 specialties frequently involved in the care of the dying (anaestheology, general practice, geriatrics, gynaecology, internal medicine, neurology, nursing home medicine (in NL), oncology, pulmonology and surgery)[141;142]. In all countries, random samples of 300 physicians were drawn in each specialty; or all physicians if less then 300 physicians were active in a specialty. Response rate was 68% in Denmark (n=1217), 64% in Switzerland (n=1397), 61% in The Netherlands (n=1275), 60% in Sweden (n=1514), 58% in Belgium (n=1750), 50% in Australia (n=1478), and 39% in Italy (n=1508). Questions were asked about attitudes, intended behaviour, and practices concerning end-of-life decisions and end-of-life care and on background characteristics of the physicians. The same conceptual framework (as listed in Box 1 and

Box 2) was used to define different end-of-life decisions. Questionnaires were processed anonymously[141;142].

1.5.3 Death certificate data (Flanders 2001; Dying Well 2003)

Death certificate data are typically gathered within the context of cause of death statistics. All deaths are usually declared via a death certificate. The physician completes (a part of) the death certificate, and in some countries a part of the death certificate is completed by the civil registrar. The certificate and the procedure of certification differs from country to country [143]. Before all information is processed, the causes of death on the death certificates are usually thoroughly checked by the responsible administration -if necessary by asking the attending physician for additional information - and coded (International Classification of Diseases). Additional error checks are performed to improve the data quality.

Two major sources of death certificate data were used.
The first **(Flanders 2001)** comprises all 55,772 deaths in 2001 of Flemish residents aged one year or older.
The second **(Dying Well 2003)** comprises a total of 1,102,642 deaths. These were gathered in the course of 2005 and 2006, as part of an international collaborative research project “Dying Well in Europe”. All partners of the study negotiated a database containing all deaths of the most recent available year for seven entire countries (Denmark, The Netherlands, Norway, Sweden, England, Wales, Scotland), two regions in Belgium (Flanders and Brussels), and three regions in Italy (Emilia Romagna, Tuscany, Milan). Besides place of death, inclusion was aimed of a limited number of clinical, socio-demographic, residential and health care system factors. Eventually we integrated into one common European database, all 10,108 deaths in 2003 in Brussels, all 57,156 deaths in 2003 in Flanders, all 141,936 deaths in 2003 in The Netherlands, all 58,473 deaths in 2003 in Scotland, all 505,341 deaths in 2003 in England, all 33,810 deaths in 2003 in Wales, all 42,550 deaths in 2003 in Norway, all 39,955 deaths in 2002 in Tuscany (Italy), all 45,647 deaths in 2002 in Emilia Romagna (Italy), all 14,247 deaths in 2002 in Milan (Italy), and all 95,064 deaths in 2002 in Sweden. The 58,355 deaths in 2001 in Denmark were not allowed to leave the country and be integrated into the

common database. An extensive methodological description of the Dying Well 2003 death certificate data study is given in Chapter 5.

In both data sources the variable “place of death” was directly available via the death certificates. Other clinical, socio-demographic and residence characteristics were available either directly via the death certificates or by individual linking with other population data files (e.g. census data). Finally, various ecological health care statistics were consulted and were linked to the municipality or local authority codes on the death certificate data file.

1.6 Outline of this dissertation

This dissertation is outlined in two main result parts, addressing the two main aims and research questions. Table 3 gives an overview of both parts, the chapters making up each part, and the data-collections used in each chapter.

Part 2, contains 3 chapters on end-of-life decisions. Chapter 2 examines how public attitudes towards euthanasia have changed over the last decades in Western-Europe, and what influenced this change. It will thereby answer to the first research question. Chapter 3 describes public acceptance of euthanasia in 33 European countries, and what factors contribute to a higher or lower acceptance, hence answering to the second research question. In Chapter 4, the attitudes of physicians from 5 European countries and Australia towards various end-of-life decisions (cfr Box 1) and their actual experiences in making these decisions are described. In particular the influence of the physicians’ religious beliefs will be examined. This will allow formulating an answer to the third research question.

Part 3 of this dissertation contains 4 chapters and explores the issue of place of death into greater depth. In Chapter 5, the end-of-life decision making is studied in relation to the place of death, thereby answering research question 4. In Chapter 6 a method is sought to overcome existing limitations in place of death research and the question is addressed whether death certificate data provide good opportunities to this purpose (research question 5). Chapter 7 and 8 then employ death certificate data to study the place of death and associated factors; in chapter 7 only for Flanders; in chapter 8 for six European countries, whereby possible explanations for country differences are also examined (research questions 6 and 7).

Finally, part 4 of this dissertation discusses (methodological) strengths and limitations of all presented studies, gives a summary and discussion of the most important findings, and aims to suggest some useful practical implications and recommendations that might eventually (in adding to the knowledge of all other aspects of good dying) help the practical constitution of a good death.

Table 3: chapters in this dissertation and the corresponding data-collection

	PART II End-of-life decisions			PART III Place of death			
	Trends in euthanasia acceptance in 12 countries	Euthanasia acceptance in 33 countries	Physician's religion and end-of-life decision making	Place of death via death certificates	Place of death in Flanders 2001	Hospital death rates in 6 European countries	Differences in ELD making at home, in a hospital or in a care home
EVS 1981 Face to face survey, N=14,281, 12 countries	2						
EVS 1990 Face to face survey, N= 17,134, 12 countries	2						
EVS 2000 Face to face survey, N=14,784 (12 countries) / N=41,125 (33 countries)	2	3					
Eureld 1 2001 retrospective death certificate study, N=12,493, 4 countries							5
Eureld 2 2002 postal survey, N= 8,631, 6 countries			4				
DC 2001 Flanders death certificate data, N= 55,772					7		
DW 2003, death certificate data, N= 1,102,642, 9 countries				6		8	

REFERENCES

1. Sloterdijk P. Eurotaoïsme. Over de kritiek van de politieke kinetiek. Amsterdam: Arbeiderspers, 1989.
2. Sloterdijk P. In hetzelfde schuitje. Proeve van een hyperpolitiek. Amsterdam: Arbeiderspers, 1997.
3. Weber M. The protestant ethic and the spirit of capitalism. London: Allen & Unwin, 1976.
4. Marcuse H. One dimensional man. London: Abacus, 1974.
5. Kunneman H. Van theemutscultuur naar walkman-ego. Amsterdam: Boom, 1996.
6. Illich I. Medical Nemisis. The expropriation of Health. New York: Bantam Books, 1979.
7. Wilson DM, Smith SL, Anderson MC et al. Twentieth-century social and health-care influences on location of death in Canada. Can.J.Nurs.Res. 2002;34(3):141-61.
8. Higginson IJ, Astin P, Dolan S. Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. Palliat.Med. 1998;12(5):353-63.
9. Bowling A. The hospitalisation of death: should more people die at home? J.Med.Ethics 1983;9(3):158-61.
10. Wilson DM, Northcott HC, Truman CD et al. Location of death in Canada. A comparison of 20th-century hospital and nonhospital locations of death and corresponding population trends. Eval.Health Prof. 2001;24(4):385-403.
11. Brown M, Colton T. Dying Epistemologies: an analysis of home death and its critique. Environment and Planning A 2001;33:799-821.
12. Clark D. Between hope and acceptance: the medicalisation of dying. BMJ 2002;324(7342):905-7.
13. Beck U. Risk society. Towards a New Modernity. London: Sage Publications, 1992.
14. Hoskins SA. Nurses and national socialism--a moral dilemma: one historical example of a route to euthanasia. Nurs.Ethics 2005;12(1):79-91.
15. Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. Lancet 1998;352(9134):1097-102.
16. Wise J. Australian euthanasia law throws up many difficulties. BMJ 1998;317(7164):969.
17. Ogilvie AD. Colombia is confused over legalisation of euthanasia. BMJ 1997;314(7098):1852.
18. Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. Lancet 2003;362(9391):1239-40.
19. Bosshard G, Fischer S, Bar W. Open regulation and practice in assisted dying. Swiss.Med.Wkly. 2002;132(37-38):527-34.
20. Giroud C, Augsburger M, Horisberger B, Lucchini P, Rivier L, Mangin P. Exit association-mediated suicide: toxicologic and forensic aspects. Am.J.Forensic Med.Pathol. 1999;20(1):40-44.
21. House of Lords Select Committee on the Assisted Dying for theTerminally Ill Bill. Assisted Dying for the Terminally Ill Bill [HL]. Volume 1: report. http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/86i.pdf . 4-4-2005. **House of Lords**. 6-7-2005.
    Ref Type: Electronic Citation
22. Huxtable R. Assisted suicide. BMJ 2004;328(7448):1088-89.

23. Bamgbose O. Euthanasia: another face of murder. Int.J.Offender.Ther.Comp Criminol. 2004;48(1):111-21.
24. Ozkara E, Civaner M, Oglak S, Mayda AS. Euthanasia education for health professionals in Turkey: students change their opinions. Nurs.Ethics 2004;11(3):290-297.
25. Mackenbach JP. [The epidemiological transition in The Netherlands]. Ned.Tijdschr.Geneeskd. 1993;137(3):132-38.
26. Wolleswinkel-van Den Bosch JH, Looman CW, Van Poppel FW, Mackenbach JP. Cause-specific mortality trends in The Netherlands, 1875-1992: a formal analysis of the epidemiologic transition. Int.J.Epidemiol. 1997;26(4):772-81.
27. Seale C. Changing patterns of death and dying. Soc Sci.Med 2000;51(6):917-30.
28. McNamara B. Good enough death: autonomy and choice in Australian palliative care. Soc.Sci.Med. 2004;58(5):929-38.
29. Walters G. Is there such a thing as a good death? Palliat.Med. 2004;18(5):404-8.
30. Emanuel EJ, Emanuel LL. The promise of a good death. Lancet 1998;351 Suppl 2:SII21-SII29.
31. DelVecchio Good MJ, Gadmer NM, Ruopp P et al. Narrative nuances on good and bad deaths: internists' tales from high-technology work places. Soc.Sci.Med. 2004;58(5):939-53.
32. Exley C. Review article: the sociology of dying, death and bereavement. Sociol.Health Illn. 2004;26(1):110-122.
33. McNamara B, Waddell C, Colvin M. The institutionalization of the good death. Soc.Sci.Med. 1994;39(11):1501-8.
34. Neuberger J. Dying Well, a guide to enabling a good death. 2 ed. Oxford: Radcliffe Publishing, 2004.
35. Payne SA, Langley-Evans A, Hillier R. Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. Palliat.Med. 1996;10(4):307-12.
36. Seale C, vander Geest S. Good and bad death: introduction. Soc.Sci.Med. 2004;58(5):883-85.
37. Van Hooff AJ. Ancient euthanasia: 'good death' and the doctor in the graeco-Roman world. Soc.Sci.Med. 2004;58(5):975-85.
38. Allen D. The right to a 'good death'. Nurs.Older.People. 2004;16(6):6.
39. Dobbins EH. Helping your patient to a "good death". Nursing. 2005;35(2):43-45.
40. Rietjens JA, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. Palliat.Med 2006;20(7):685-92.
41. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000;284(19):2476-82.
42. Baker ME. Economic, political and ethnic influences on end-of-life decision-making: a decade in review. J.Health Soc.Policy 2002;14(3):27-39.
43. Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000;356(9244):1806-11.
44. Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States: adherence to proposed safeguards and effects on physicians. JAMA 1998;280(6):507-13.
45. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med.J.Aust. 1997;166(4):191-96.

46. van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362(9381):345-50.
47. Cohen S, Sprung C, Sjokvist P et al. Communication of end-of-life decisions in European intensive care units. Intensive Care Med 2005;31(9):1215-21.
48. Onwuteaka-Philipsen BD, van der Heide A, Koper D et al. Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. Lancet 2003;362(9381):395-99.
49. Sprung CL, Cohen SL, Sjokvist P et al. End-of-life practices in European intensive care units: the Ethicus Study. JAMA 2003;290(6):790-797.
50. Seale C. National survey of end-of-life decisions made by UK medical practitioners. Palliat.Med 2006;20(1):3-10.
51. Mortier F, Bilsen J, Vander Stichele RH, Bernheim J, Deliens L. Attitudes, sociodemographic characteristics, and actual end-of-life decisions of physicians in Flanders, Belgium. Med.Decis.Making 2003;23(6):502-10.
52. Forde R, Aasland OG, Falkum E. The ethics of euthanasia--attitudes and practice among Norwegian physicians. Soc.Sci.Med. 1997;45(6):887-92.
53. Rietjens JA. Medical decision-making at the end of life Experiences and attitudes of physicians and the general public [dissertation]. Rotterdam: University Medical Center Rotterdam, 2006.
54. Benson JM. The polls-trends - End-of-life issues. Public Opinion Quarterly 1999;63(2):263-77.
55. Blendon RJ, Szalay US, Knox RA. Should physicians aid their patients in dying? The public perspective. JAMA 1992;267(19):2658-62.
56. Gallup Canada. The Gallup report. 1968. Toronto, Canadian Institute of Public Opinion.
    Ref Type: Report
57. Roy Morgan Research Centre. Morgan Polls on Medically Assisted Death. Finding No.2933. http://www.roymorgan.com/news/polls/polls.cfm. 1996. Roy Morgan Research Centre, Melbourne.
    Ref Type: Electronic Citation
58. van der Maas PJ, Pijnenborg L, van Delden JJ. Changes in Dutch opinions on active euthanasia, 1966 through 1991. JAMA 1995;273(18):1411-14.
59. Hamil-Luker J, Smith C. Religious authority and public opinion on the right to die. Sociology of Religion 1998;59(4):373-91.
60. Caddell DP, Newton RR. Euthanasia: American attitudes toward the physician's role. Soc.Sci.Med. 1995;40(12):1671-81.
61. Duncan OD, Parmelee LF. Trends in public approval of euthanasia and suicide in the US, 1947-2003. J.Med.Ethics 2006;32(5):266-72.
62. Helou A, Wende A, Hecke T, Rohrmann S, Buser K, Dierks ML. [Public opinion on active euthanasia. The results of a pilot project]. Dtsch.Med.Wochenschr. 2000;125(11):308-15.
63. Hurst SA, Mauron A. Assisted suicide and euthanasia in Switzerland: allowing a role for non-physicians. BMJ 2003;326(7383):271-73.
64. O'Neill C, Feenan D, Hughes C, McAlister DA. Physician and family assisted suicide: results from a study of public attitudes in Britain. Soc.Sci.Med. 2003;57(4):721-31.
65. Oehmichen M, Meissner C. Active euthanasia and physician-assisted suicide: the German discussion. Leg.Med.(Tokyo) 2003;5 Suppl 1:S20-S28.

66. Ryynanen OP, Myllykangas M, Viren M, Heino H. Attitudes towards euthanasia among physicians, nurses and the general public in Finland. Public Health 2002;116(6):322-31.
67. Teisseyre N, Mullet E, Sorum PC. Under what conditions is euthanasia acceptable to lay people and health professionals? Soc.Sci.Med. 2005;60(2):357-68.
68. Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. Soc.Sci.Med. 1999;48(12):1779-89.
69. Genuis SJ, Genuis SK, Chang WC. Public attitudes toward the right to die. CMAJ. 1994;150(5):701-8.
70. Rietjens JA, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. A comparison of attitudes towards end-of-life decisions: survey among the Dutch general public and physicians. Soc Sci.Med 2005;61(8):1723-32.
71. Cohen JS, Fihn SD, Boyko EJ, Jonsen AR, Wood RW. Attitudes toward assisted suicide and euthanasia among physicians in Washington State. N.Engl.J.Med. 1994;331(2):89-94.
72. Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. Lancet 1996;347(9018):1805-10.
73. Suarez-Almazor ME, Belzile M, Bruera E. Euthanasia and physician-assisted suicide: a comparative survey of physicians, terminally ill cancer patients, and the general population. J.Clin.Oncol. 1997;15(2):418-27.
74. Wolfe J, Fairclough DL, Clarridge BR, Daniels ER, Emanuel EJ. Stability of attitudes regarding physician-assisted suicide and euthanasia among oncology patients, physicians, and the general public. J.Clin.Oncol. 1999;17(4):1274.
75. Gallo WT, Baker MJ, Bradley EH. Factors associated with home versus institutional death among cancer patients in Connecticut. J.Am.Geriatr.Soc. 2001;49(6):771-77.
76. Mezey M, Dubler NN, Mitty E, Brody AA. What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? Gerontologist 2002;42 Spec No 3:54-67.
77. Finlay IG, Higginson IJ, Goodwin DM et al. Palliative care in hospital, hospice, at home: results from a systematic review. Ann.Oncol. 2002;13 Suppl 4:257-64.
78. Catalan-Fernandez JG, Pons-Sureda O, Recober-Martinez A et al. Dying of cancer. The place of death and family circumstances. Med.Care 1991;29(9):841-52.
79. Peters L, Sellick K. Quality of life of cancer patients receiving inpatient and home-based palliative care. J.Adv.Nurs. 2006;53(5):524-33.
80. Teno JM, Clarridge BR, Casey V et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004;291(1):88-93.
81. Grande GE, Farquhar MC, Barclay SI, Todd CJ. Caregiver bereavement outcome: relationship with hospice at home, satisfaction with care, and home death. J.Palliat.Care 2004;20(2):69-77.
82. Tang ST. When death is imminent: where terminally ill patients with cancer prefer to die and why. Cancer Nurs. 2003;26(3):245-51.
83. Tang ST, Liu TW, Lai MS, McCorkle R. Discrepancy in the preferences of place of death between terminally ill cancer patients and their primary family caregivers in Taiwan. Soc.Sci.Med. 2005;61(7):1560-1566.

84. Choi KS, Chae YM, Lee CG et al. Factors influencing preferences for place of terminal care and of death among cancer patients and their families in Korea. Support.Care Cancer 2005;13(8):565-72.
85. Thomas C, Morris SM, Clark D. Place of death: preferences among cancer patients and their carers. Soc.Sci.Med. 2004;58(12):2431-44.
86. Temkin-Greener H, Mukamel DB. Predicting place of death in the program of all-inclusive care for the elderly (PACE): participant versus program characteristics. J.Am.Geriatr.Soc. 2002;50(1):125-35.
87. Townsend J, Frank AO, Fermont D et al. Terminal cancer care and patients' preference for place of death: a prospective study. BMJ 1990;301(6749):415-17.
88. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. J.Palliat.Med. 2000;3(3):287-300.
89. Beccaro M, Costantini M, Rossi PG, Miccinesi G, Grimaldi M, Bruzzi P. Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). J.Epidemiol.Community Health 2006;60(5):412-16.
90. Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? Palliat.Med. 1994;8(3):183-96.
91. Bruera E, Sweeney C, Russell N, Willey JS, Palmer JL. Place of death of Houston area residents with cancer over a two-year period. J.Pain Symptom.Manage. 2003;26(1):637-43.
92. Evans N, Walsh H. The organisation of death and dying in today's society. Nurs.Stand. 2002;16(25):33-38.
93. Tang ST, McCorkle R. Determinants of congruence between the preferred and actual place of death for terminally ill cancer patients. J.Palliat.Care 2003;19(4):230-237.
94. Weitzen S, Teno JM, Fennell M, Mor V. Factors associated with site of death: a national study of where people die. Med.Care 2003;41(2):323-35.
95. Brettle RP, Morris S, Epton V. Patients with HIV dying in Edinburgh: an audit of preference and place of death. Int.J.STD AIDS 1995;6(3):221-22.
96. Ashby M, Wakefield M. Attitudes to some aspects of death and dying, living wills and substituted health care decision-making in South Australia: public opinion survey for a parliamentary select committee. Palliat.Med 1993;7(4):273-82.
97. Brazil K, Bedard M, Willison K. Factors associated with home death for individuals who receive home support services: a retrospective cohort study. BMC.Palliat.Care 2002;1(1):2.
98. Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C. Preferences for place of care and place of death among informal caregivers of the terminally ill. Palliat.Med 2005;19(6):492-99.
99. Tiernan E, O'Connor M, O'Siorain L, Kearney M. A prospective study of preferred versus actual place of death among patients referred to a palliative care home-care service. Ir.Med.J. 2002;95(8):232-35.
100. Gilbar O, Steiner M. When death comes: where should patients die? Hosp.J 1996;11(1):31-48.
101. Pritchard RS, Fisher ES, Teno JM et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. J.Am.Geriatr.Soc. 1998;46(10):1242-50.

102. Foreman LM, Hunt RW, Luke CG, Roder DM. Factors predictive of preferred place of death in the general population of South Australia. Palliat.Med 2006;20(4):447-53.
103. Charlton RC. Attitudes towards care of the dying: a questionnaire survey of general practice attenders. Fam.Pract. 1991;8(4):356-59.
104. Fried TR, van DC, O'Leary JR, Tinetti ME, Drickamer MA. Older persons' preferences for site of terminal care. Ann.Intern.Med 1999;131(2):109-12.
105. Luce JM, Rubenfeld GD. Can health care costs be reduced by limiting intensive care at the end of life? Am.J.Respir.Crit Care Med. 2002;165(6):750-754.
106. Higginson IJ, Koffman J. Public health and palliative care. Clin.Geriatr.Med. 2005;21(1):45-55, viii.
107. Miller SC, Intrator O, Gozalo P, Roy J, Barber J, Mor V. Government expenditures at the end of life for short- and long-stay nursing home residents: differences by hospice enrollment status. J.Am.Geriatr.Soc. 2004;52(8):1284-92.
108. Smith TJ, Coyne P, Cassel B, Penberthy L, Hopson A, Hager MA. A high-volume specialist palliative care unit and team may reduce in-hospital end-of-life care costs. J.Palliat.Med. 2003;6(5):699-705.
109. Campbell DE, Lynn J, Louis TA, Shugarman LR. Medicare program expenditures associated with hospice use. Ann.Intern.Med. 2004;140(4):269-77.
110. Pyenson B, Connor S, Fitch K, Kinzbrunner B. Medicare cost in matched hospice and non-hospice cohorts. J.Pain Symptom.Manage. 2004;28(3):200-210.
111. Chochinov HM, Kristjanson L. Dying to pay: the cost of end-of-life care. J.Palliat.Care 1998;14(4):5-15.
112. Burke K. Palliative care at home to get further funds if it saves money. BMJ 2004;328(7439):544.
113. Hearn LV, Tulak JA, Zimmerman SC. Performance improvement program for reducing home health care costs in hospice. J.Pain Symptom.Manage. 2004;28(4):417-19.
114. House of Commons Health Committee. Palliative Care. Fourth Report of Session 2003–04. Volume 1. 2004. London, House of Commons.
     Ref Type: Report
115. Emanuel EJ. Cost savings at the end of life. What do the data show? JAMA 1996;275(24):1907-14.
116. Kroneman M, Siegers JJ. The effect of hospital bed reduction on the use of beds: a comparative study of 10 European countries. Soc.Sci.Med. 2004;59(8):1731-40.
117. Dudgeon DJ, Kristjanson L. Home versus hospital death: assessment of preferences and clinical challenges. CMAJ. 1995;152(3):337-40.
118. Yun YH, Lim MK, Choi KS, Rhee YS. Predictors associated with the place of death in a country with increasing hospital deaths. Palliat.Med 2006;20(4):455-61.
119. Hunt RW, Bond MJ, Groth RK, King PM. Place of death in South Australia. Patterns from 1910 to 1987. Med.J.Aust. 1991;155(8):549-53.
120. Yang L, Sakamoto N, Marui E. A study of home deaths in Japan from 1951 to 2002. BMC.Palliat.Care 2006;5:2.
121. Burge F, Lawson B, Johnston G. Trends in the place of death of cancer patients, 1992-1997. CMAJ. 2003;168(3):265-70.
122. Buechner JS. Trends and patterns in place of death, 1989-2000. Med.Health R.I. 2002;85(9):289-90.
123. Flory J, Yinong YX, Gurol I, Levinsky N, Ash A, Emanuel E. Place of death: U.S. trends since 1980. Health Aff.(Millwood.) 2004;23(3):194-200.

124. Axelsson B, Christensen SB. Place of death correlated to sociodemographic factors. A study of 203 patients dying of cancer in a rural Swedish county in 1990. Palliat.Med. 1996;10(4):329-35.
125. Schrijvers D, Joosens E, Vandebroek J, Verhoeven A. The place of death of cancer patients in Antwerp. Palliat.Med. 1998;12(2):133-34.
126. Van den Eynden B, Hermann I, Schrijvers D et al. Factors determining the place of palliative care and death of cancer patients. Support.Care Cancer 2000;8(1):59-64.
127. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ 2006;332(7540):515-21.
128. Ahlner-Elmqvist M, Jordhoy MS, Jannert M, Fayers P, Kaasa S. Place of death: hospital-based advanced home care versus conventional care. A prospective study in palliative cancer care. Palliat.Med. 2004;18(7):585-93.
129. Bruera E, Russell N, Sweeney C, Fisch M, Palmer JL. Place of death and its predictors for local patients registered at a comprehensive cancer center. J.Clin.Oncol. 2002;20(8):2127-33.
130. Cardenas-Turanzas M, Grimes RM, Bruera E, Quill B, Tortolero-Luna G. Clinical, sociodemographic, and local system factors associated with a hospital death among cancer patients. Support.Care Cancer 2005.
131. Carroll DS. An audit of place of death of cancer patients in a semi-rural Scottish practice. Palliat.Med. 1998;12(1):51-53.
132. Fukui S, Kawagoe H, Masako S, Noriko N, Hiroko N, Toshie M. Determinants of the place of death among terminally ill cancer patients under home hospice care in Japan. Palliat.Med. 2003;17(5):445-53.
133. Fukui S, Fukui N, Kawagoe H. Predictors of place of death for Japanese patients with advanced-stage malignant disease in home care settings: a nationwide survey. Cancer 2004;101(2):421-29.
134. Grundy E, Mayer D, Young H, Sloggett A. Living arrangements and place of death of older people with cancer in England and Wales: a record linkage study. Br.J.Cancer 2004;91(5):907-12.
135. Izquierdo-Porrera AM, Trelis-Navarro J, Gomez-Batiste X. Predicting place of death of elderly cancer patients followed by a palliative care unit. J.Pain Symptom.Manage. 2001;21(6):481-90.
136. Tang ST. Influencing factors of place of death among home care patients with cancer in Taiwan. Cancer Nurs. 2002;25(2):158-66.
137. Singer PA, Wolfson M. "The best places to die". BMJ 2003;327(7408):173-74.
138. Halman, L. The European Values Study: a Third Wave. Source book of the 1999/2000 European Values Study Surveys. 2001. Tilburg, EVS, WORC, Tilburg University.
Ref Type: Report
139. Bilsen J. End-of-life decisions in medical practice in Flanders, Belgium. Gent: Academia Press Scientific Publishers, 2005.
140. Nilstun T, Cartwright C, Lofmark R et al. Access to death certificates: what should research ethics committees require for approval? Ann.Epidemiol. 2006;16(4):281-84.
141. Miccinesi G, Fischer S, Paci E et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. Soc Sci.Med 2005;60(9):1961-74.

142. Onwuteaka-Philipsen BD, Fisher S, Cartwright C et al. End-of-life decision making in Europe and Australia: a physician survey. Arch Intern.Med 2006;166(8):921-29.
143. Das C, van der Wal G. [The term 'cause of death': an international comparison]. Ned.Tijdschr.Geneeskd. 2002;146(43):2040-2043.

FOOTNOTES

---

[a] A number of legal-political developments have occurred within the context of this changing mentality. The number of laws on palliative care or on patients rights is - in international context- too extensive to describe. We can, to the purpose of illustrating the legal-political developments as a consequence of changing attitudes, limit ourselves to the legal initiatives on (active voluntary) euthanasia or physician assisted suicide. Opponents of euthanasia often refer to **Nazi-Germany** as the first state to legalise euthanasia. However, this is a misunderstanding. The so-called Aktion T-4 (named after the headquarters at Tiergartenstrasse 4, where the program was drafted) was aimed at destroying the ‘life unworthy of life’ and had little in common with the concept of euthanasia as perceived today [14]. Moreover, mainly because of religious and internal opposition, the euthanasia programme was never made official in any kind of law. The first country where a legalisation of euthanasia or assisted suicide was explicitly voted was the USA. The state of **Oregon** passed the "Death with Dignity Act" in November 1994 and the law went into effect in 1997. In 1995 the “Rigths of the Terminally Ill Act” was passed in **Australia’s Northern Territory** and went into effect in July 1996. Eight months (and four deaths under the act [15]) later, the law was repealed on 25 March 1997 because the national Parliament judged the Northern Territory Act to be in conflict with national views[16]. Although barely known, Japan also has a pseudo-law on euthanasia. In March 1995, a District Court in Yokahama sentenced a doctor for two-year imprisonment for ‘murdering’ a terminally ill cancer patient who was expected to die within a few days. However, the sentence was suspended, and the court then listed four conditions under which mercy killing would be permitted in Japan: 1)the patient is suffering in unbearable physical pain, 2) death is inevitable and imminent, 3) all possible measures have been taken to eliminate the pain with no other treatment left open, 4) the patient has clearly expressed his or her will to approve the shortening of his or her life. After Australia, **Colombia** was in fact the second country to vote a euthanasia law in May 1997 [17]. However, the legislation had been subject to confusion and never actually came into effect. In **The Netherlands** euthanasia is legal since 2002. However, the legislation knew a long history. The Dutch Supreme Court approved voluntary euthanasia under certain conditions as from 1984 and since then has a policy tolerating euthanasia. A law, permitting the voluntary ending of a patients life under a number of circumstances (e.g. a repeated request by the patient) was voted on 10 April 2001, and took effect on 1 April 2002 [18].

Unlike in the Netherlands, **Belgium** knew a quick legislation process of euthanasia. A law, similar to the one in The Netherlands was passed on 16 May 2002, coming into effect on 22 September 2002 [18]. In **Switzerland**, the development of assisted dying was based:1) on the non-penalisation of assistance in suicide without self-interest in the Swiss Penal Code in 1942 and 2) on the decision of the right-to-die organisation Exit Deutche Schweiz since 1990 to use this liberal legislation concerning assisted dying to offer assistance on request to severely ill people wishing to die. [19;20].

Many countries have thus adapted laws or procedural rules allowing patients to make their own 'death choices', and moreover this seems to be only a part of the developments that are still ongoing. There seem to be campaigns to follow in the mentioned countries' footsteps. At the moment of this writing, following the report of the Select Committee on Euthanasia, a debate on a draft of the Assisted Dying for the Terminally Ill Bill is being held in the UK parliament [21;22]. In Canada a similar bill (Bill C-407) has been introduced and is now being debated. Euthanasia/ assisted dying debate is also taking place in various US states and other states might possibly enter into the footsteps of Oregon. In most countries euthanasia remains illegal, However, sanctions are being downgraded and applied infrequently. In some countries amendments are also made to laws in order to distinguish death-hastening medical end-of-life decision in a patient with unbearable pain at the request of this patient from murder [23;24]. Other countries do not seem to make any initiatives to legalise euthanasia, but have adapted laws regulating other end-of-life decisions, such as non-treatment decisions (e.g. France).

[b] This 'art of death movement', as we could label it, revives the approach of death in the 15th and 16th century. At that time the general attitude towards death was that everyone faces his own and final death but that the dying process could be mastered by learning the 'art of dying'[6]. Handbooks about "Ars Moriendi", "how to die a good death" or "complete guides to the business of dying" were quite popular. Today, anew, (hand)books appear with certain regularity that try to spread the ideas (both among health care providers as among the general public) of 'how to ensure a good death' (e.g. Neubergers "Dying Well. A guide to enabling a good death' (2004).

Part 2

End-of-life decisions

2

Trends in acceptance of euthanasia among the general public in 12 European countries (1981-1999)

Joachim Cohen, Isabelle Marcoux, Johan Bilsen, Patrick Deboosere, Gerrit van der Wal, Luc Deliens

This paper is published in the European Journal of Public Health 2006; 16(6): 663–69

ABSTRACT:

Background: We wanted to examine how the acceptance of euthanasia among the general public in Western Europe has changed in the last decades, and we wanted to look for possible explanations.

Methods: We analysed data from the European Values Surveys, held in 1981, 1990 and 1999-2000 in 12 West European countries. In each country, representative samples of the general public were interviewed using the same structured questionnaire in all countries. Euthanasia was explained in the questionnaires as ‘terminating the life of the incurably sick’.

Results: A total of 46,199 respondents participated in the surveys. A significant increase in acceptance of euthanasia could be observed in all countries except (West) Germany. While the average increase in euthanasia acceptance was 22%, the increase was particularly obvious in Belgium, Italy, Spain, and Sweden. Although changes in several characteristics of respondents, such as decrease in religious beliefs, rising belief in the right to self-determination and (to a lesser extent) rise in levels of education, were associated with growing acceptance of euthanasia, they could only partly explain the increase of euthanasia acceptance over the years.

Conclusions: An increase of euthanasia acceptance among the general public took place over the last two decades in almost all West European countries, possibly indicating a growing support for personal autonomy regarding medical end-of-life decisions. If this trend continues, it is likely to increase the public and political debate about the (legal) regulation of euthanasia under certain conditions of careful medical practice in several West European countries.

INTRODUCTION

Increasing debate on the rights of terminally ill patients has marked the last 30 years in western society. The Netherlands and Belgium have adopted laws permitting euthanasia[1]. The state of Oregon and Switzerland permit or do not prosecute (physician-)assisted suicide under certain conditions, but euthanasia is not tolerated [2;3]. In most other western countries euthanasia remains illegal, but sanctions are often reduced and applied rarely and public debates about euthanasia legislation are not uncommon [4]. Following the report of the Select Committee on Euthanasia, a debate on a draft of an assisted suicide bill will be held in the UK parliament in the near future [5;6].

Among the general public empirical studies reveal an increased acceptance of euthanasia, e.g. in Australia [7], The Netherlands [8], in the United States of America [9;10], and in Canada.[11] The observed change in attitudes is explained by the secularisation and individualisation of society, which have influenced a movement away from traditional values to more liberal moral attitudes and with increased value being put on personal autonomy [8]. The association between these sociological developments and the trend in attitudes towards euthanasia has, however, never been investigated thoroughly.

Moreover, the studies describing the increasing acceptance of euthanasia are limited to a few countries, most of them with an ongoing and intense societal debate on the issue. Furthermore, the reported studies used different study designs and questionnaires. Hence, results cannot be generalised to other countries and are difficult to compare [12-14]. Using a model based on identical study designs and questionnaires in all participating countries, this article attempts to meet these shortcomings.

Firstly, we describe trends and differences in trends in the acceptance of euthanasia among the general public in 12 West European countries. Secondly, we look for explanations of the changes in attitudes by examining other possibly associated societal changes, based on factors found to be significantly associated in the literature. [12;15-27] Thirdly, we examine whether changes in the acceptance of euthanasia can be explained by other societal changes, such as increase in the more highly educated, secularisation, increase in general permissiveness, and/or whether there has been a specific change in euthanasia acceptance over the years. Finally, we investigate whether the change in the acceptance of euthanasia, in relation to other societal changes, is similar in all 12 countries or rather country-specific.

METHODS

Dataset

We used data from the European Values Study (EVS). The EVS study is based on a large-scale cross-national research programme, initiated in the late 1970s, with regularly repeated surveys on the social, cultural, political, moral, and religious values held by the populations of European countries. In 1981 a first survey was conducted in 10 West European countries (all EC countries plus Spain), soon after joined by Iceland and Sweden. In 1990, after the fall of the Iron Curtain, the second survey was held in 23 European countries, including six East European countries. The third survey was held in 1999-2000 among more than 41,000 residents in 33 countries in western, central, and eastern Europe.

In this study we use the data from the 12 countries that participated in all three surveys: Belgium, Denmark, France, Great Britain, Iceland, Ireland, Italy, The Netherlands, Spain, Sweden, Ulster, and West Germany.

Design

Each of the three surveys in these 12 countries involved representative national samples of all adult citizens (aged 18 years or older) who were interviewed face-to-face using the same structured questionnaires, enabling generalisations and comparisons. A total of 46,199 respondents were interviewed in the three surveys: 14,281 in 1980, 17,134 in 1990 and 14,784 in 1999-2000. The samples were obtained through quota sampling or random sampling with stratification by age, gender and geographical region (e.g. state, county). Depending on the representativeness of the national sample a weight factor was added to correct for gender, age, marital status, education, and region. To calculate the average acceptance of euthanasia over the 12 countries a weight factor accounting for population size of the countries was also used.

Detailed information on the questionnaires, sampling procedures, fieldwork, weighting, etc. can be found elsewhere [28-30].

Measurements

Dependent variable: acceptance of euthanasia

The three EVS surveys included one question that probed the attitude towards euthanasia: “Please tell me whether you think ‘euthanasia (terminating the life of the incurably sick)’ can always be justified, never be justified, or something in between”.

The respondent was asked to give a rating from 1 to 10, 1 meaning ‘never justified’, 10 meaning ‘always justified’. Respondents also had the possibility of answering ‘I don’t know’. Responses of ‘I don’t know’ were not considered in the analysis explaining the acceptance of euthanasia.

Independent variables

Only variables used in all three surveys, associated with acceptance of euthanasia as demonstrated in the literature and meaningful in the context of our analyses, were retained.

Socio-demographic variables include country of residence, gender, age, educational level (expressed in years of education), social class (manual or non-manual occupation) and finally an agricultural class variable (persons active in the agricultural sector versus others). The ‘religious belief’ variable, as an indicator of secularisation, was a factor constructed by means of principal component analyses (PCA) and describes whether or not someone belongs to a religious denomination, the frequency with which religious services are attended, as well as the measure in which someone believes, respectively, in God, life after death, hell, heaven, and sin. We also constructed a factor by means of PCA giving some indication of the belief in the right to self-determination. This factor, further in the text conveniently called ‘permissiveness’, is based on the acceptance of divorce, abortion, suicide, homosexuality, and adultery. Detailed information about the construction of both factors, their component loadings, and their internal consistency is not presented here, but is available from the authors.

Statistical analysis

Means and percentages were used to describe the changes in the acceptance of euthanasia over time. Because distribution of the dependent variable in all three surveys was not normal (confirmed by the Kolmogorov-Smirnov test), the non-parametric Jonckheere-

Terpstra test was used to determine statistical significance of associations between the dependent and the independent variables.

To test whether differences in euthanasia acceptance were related to the year of the survey independently from other significant correlates and possible confounders, corrected odds ratios were calculated by performing a multivariate ordinal logistic regression (cauchit link function). This method of analysis was considered to be the most appropriate one, given the non-normal distribution of our outcome variable. We expanded our model stepwise, by constructing five models. The first model describes the differences between the three survey years, controlling for country of residence; the second model adds age and gender as controlling variables; the third model adds educational level, social class, and the agricultural class variable; the fourth model adds the 'religious belief' factor; and the fifth model adds the 'permissiveness' factor.

SPSS (version 12.0) was used for all statistical computations and a probability level of 0.01 was set to determine statistical significance of associations.

RESULTS

For the first two surveys not all countries had documented complete information on the responses, but the number of cases obtained was higher than the targeted number of cases, and countries that did document response rates reported good figures (e.g. 71% average response rate in Scandinavian countries). The average response rate in 1999 was 56%. The characteristics of the samples of 1981, 1990 and 1999-2000 are described in table 1. The relative proportion of the countries within the total differs between the survey years. The mean age (in line with the ageing population), the number of the more highly educated, and the levels of general permissiveness have significantly increased. The number of persons employed in the agricultural sector, the number of manual workers and the general level of religious belief (most notably between 1981 and 1990) had significantly decreased. The missing values for the euthanasia question, mostly persons answering ‘I don’t know’, were stable over time.

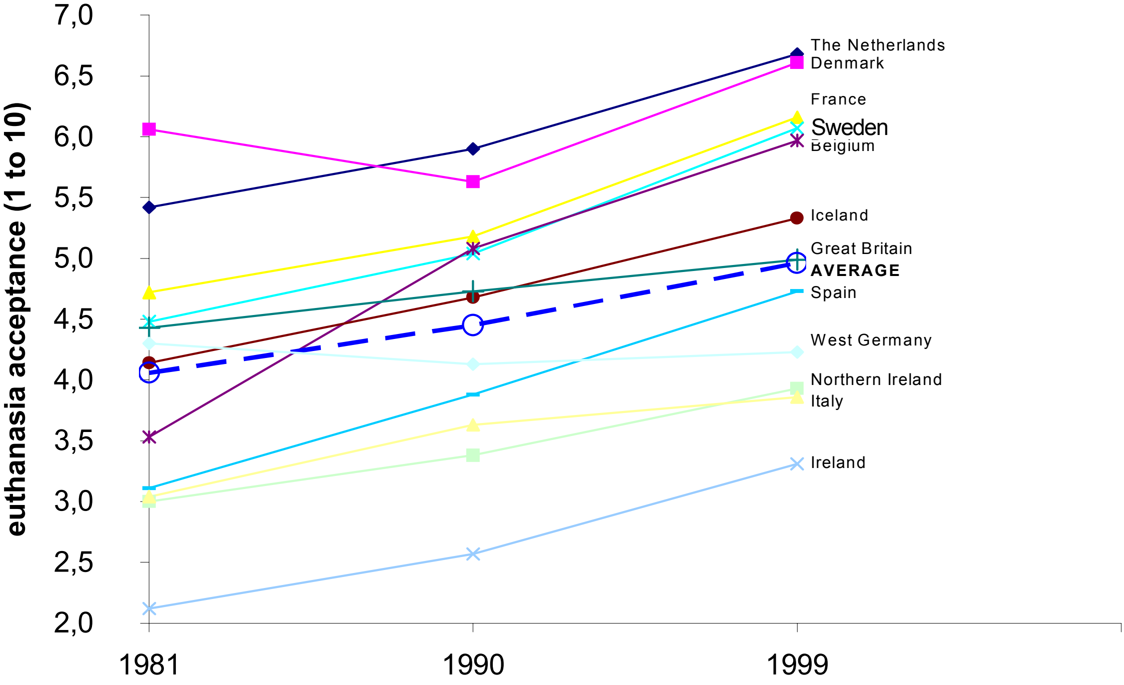
A significant increase in acceptance of euthanasia from 1981 over 1990 to 1999 can be observed in almost all countries (figure 1). The average increase was 22%. The increase was especially high in Belgium (69%), but also in Ireland (56%) and in Spain (52%). In Sweden, Northern Ireland and France, acceptance of euthanasia increased by about a third. The increase in Italy, Iceland and The Netherlands was in accordance with the average increase, while in Great Britain the increase was weaker (13%). The increase in Denmark was very weak (9%), with even a decrease in 1990 (in line with their decrease in general permissiveness). West Germany was the only country with no increase in euthanasia acceptance.

Table 1. Description of the sample of 12 countries from the European Values Study (1981, 1990, 1999)

	1981 (n=14281)	1990 (n=17234)	1999 (n=15784)	Total (n=46199)	p-value
Country					
Belgium	1145 (8.0%)	2792 (16.2%)	1912 (12.9%)	5849 (12.7%)	<0.001[a]
Denmark	1182 (8.3%)	1030 (6.0%)	1023 (6.9%)	3235 (7.0%)	
France	1200 (8.4%)	1102 (6.4%)	1615 (10.9%)	3817 (8.3%)	
Great Britain	1167 (8.2%)	1484 (8.6%)	1000 (6.8%)	3651 (7.9%)	
Iceland	927 (6.5%)	702 (4.1%)	968 (6.5%)	2597 (5.6%)	
Ireland	1217 (8.5%)	1000 (5.8%)	1012 (6.8%)	3229 (7.0%)	
Italy	1348 (9.4%)	2018 (11.7%)	2000 (13.5%)	5366 (11.6%)	
Netherlands	1221 (8.5%)	1017 (5.9%)	1003 (6.8%)	3241 (7.0%)	
Spain	2303 (16.1%)	2637 (15.3%)	1200 (8.1%)	6140 (13.3%)	
Sweden	954 (6.7%)	1047 (6.1%)	1015 (6.9%)	3016 (6.5%)	
Northern Ireland	312 (2.2%)	304 (1.8%)	1000 (6.8%)	1616 (3.5%)	
West Germany	1305 (9.1%)	2101 (12.2%)	1036 (7.0%)	4442 (9.6%)	
Age (in years)					
Mean (st.dev.)	44.41 (17.88)	44.44 (17.62)	45.45 (17.35)	44.75 (17.62)	<0.001[b]
Sex					
Women	7281(51.0%)	8841(51.7%)	7655(51.8%)	23777 (51.5%)	0.349[a]
Educational level (in years of education)					
<12	1527 (10.7%)	1314 (7.9%)	1271 (8.6%)	4112 (9.0%)	<0.001[c]
12 through 14	3138 (22.1%)	3277 (19.7%)	2158 (14.6%)	8573 (18.8%)	
15 through 18	5353 (37.6%)	6393 (38.4%)	5831 (39.4%)	17577 (38.5%)	
19 through 20	1405 (9.9%)	2096 (12.6%)	1770 (12.0%)	5271 (11.5%)	
21 or more	2796 (19.7%)	3576 (21.5%)	3753 (25.4%)	10125 (22.2%)	
Social class					
Manual class	6384 (48.1%)	6896 (42.2%)	4860 (38.3%)	18140 (42.9%)	<0.001[c]
Agricultural class					
Agricultural class	991 (7.5%)	908 (5.5%)	598 (4.7%)	2497 (5.9%)	<0.001[c]
Religiosity (factor scale, standardised scores) [d]					
Mean (st.dev.)	0.09 (0.97)	-0.04 (1.01)	-0.04 (1.01)	0.00 (1.00)	<0.001[b]
Permissiveness (factor scale. standardised scores) [d]					
Mean (st.dev.)	-0.18 (1.01)	-0.06 (0.94)	0.23 (1.01)	0.00 (1.00)	<0.001[b]
Missing values[e]					
N.a. or d.k.	*759 (5.3%)*	*923 (5.4%)*	*749 (5.0%)*	2431(5.3%)	0.487[a]

a: Pearson's chi² testing the independence between each row and the survey year.
b: One-way anova comparing means in the three survey years.
c: Kendal's tau-b testing the (ordinal) relationship between each row and the survey year.
d: The presented scores are standardised scores (factor-scale with mean=0 and standard deviation=1)
e: This is the number of missing values for the euthanasia variable, i.e. the number that gave no answer or answered with "do not know". The majority of the missing values however concerns people answering with do not know (4.4% of total in 1990 and 4.0% of total in 1999).

Figure 1: Acceptance of euthanasia in 12 countries (1981-1999)



		Mean in 1981	Mean in 1990	Mean in 1999	Difference 1999-1981 (in%)	p-value (Jonckheere-Terpstra)
◆	Netherlands	5.42	5.90	6.68	+ 23.2%	<0.001
■	Denmark	6.06	5.63	6.61	+ 09.1%	0.041
▲	France	4.72	5.18	6.16	+ 30.5%	<0.001
✱	Sweden	4.48	5.04	6.07	+ 35.5%	<0.001
✱	Belgium	3.53	5.08	5.97	+ 69.1%	<0.001
●	Iceland	4.14	4.68	5.33	+ 28.7%	<0.001
+	Great Britain	4.43	4.73	4.99	+ 12.6%	<0.001
▬	Spain	3.11	3.88	4.73	+ 52.1%	<0.001
◆	West Germany	4.30	4.13	4.23	- 02.6%	0.686
■	Northern Ireland	3.00	3.38	3.93	+ 31.0%	0.001
▲	Italy	3.04	3.63	3.86	+ 27.0%	<0.001
✱	Ireland	2.12	2.57	3.31	+ 56.1%	<0.001
○	**AVERAGE**	**4.06**	**4.45**	**4.96**	**+22.2%**	**<0.001**

The general increase in euthanasia acceptance remained after controlling for other factors (table 2). The increase of euthanasia acceptance was stronger when controlling for age and gender (model 2). The changes in social characteristics of respondents, i.e. decrease of persons active in the agricultural sector, the decrease of manual workers, and particularly the increase in numbers of the more highly educated explain part of the increase in acceptance of euthanasia (model 3). A much larger influence can be ascribed to the decrease of religious beliefs (model 4). However, even after controlling for these societal changes a significant increase in euthanasia acceptance could be observed. Finally, model 5 demonstrates that the increase in euthanasia acceptance is largely congruent with the increase in 'permissiveness' (towards abortion, divorce, homosexuality and adultery), but even taking this change into account the acceptance of euthanasia has still relatively increased.

Table 2: Trends in euthanasia acceptance 1981-1990-1999, multivariate ordinal logistic regression

		Model 1[a]	**Model 2[a]**	**Model 3[a]**	**Model 4[a]**	**Model 5[b]**
		(survey year & country of residence)	(+ gender and age)	(+ educational level, social class and agricultural class)	(+ religious beliefs)	(+ permissiveness)
1981 (reference year)	OR	*Reference*	*Reference*	*Reference*	*Reference*	*Reference*
1990	OR	1.41	1.43	1.40	1.36	1.20
	95% CI	1.36 - 1.46	1.38-1.48	1.35-1.45	1.31-1.40	1.15-1.24
1999	OR	1.90	1.98	1.91	1.84	1.38
	95% CI	1.83 - 1.97	1.91-2.05	1.84-1.98	1.77-1.91	1.33-1.44

a: All 9 thresholds statistically significant
b: All thresholds statistically significant, except between score 2 and 3.

Of course the influence of societal changes on the acceptance of euthanasia (but also, for example, the way in which the separate items of the 'permissiveness' factor loaded on the same dimension) varied between the countries. Therefore, an analysis per country was performed, which demonstrated that the trends in euthanasia acceptance, using this last model, are not the same in all countries (table 3). Belgium, Italy, Sweden, and Spain have a strong relative increase in euthanasia acceptance. France, Ireland, Iceland and The Netherlands experienced a somewhat weaker relative increasing acceptance. In The Netherlands the acceptance of euthanasia in 1990 was lower than would be expected from their general level of religious belief and 'permissiveness'. Great Britain, Denmark and Northern Ireland (confidence intervals include 1) experienced no relative increase in euthanasia acceptance and in Germany the acceptance of euthanasia has decreased relatively.

Table 3: Trends in euthanasia acceptance per country, based on model 5[a].

	1981	1990	1999
Country	(reference year)	OR (95%CI)	OR (95%CI)
Belgium	1.00	1.65 (1.47-1.85)	2.57 (2.26-2.92)
Italy	1.00	1.68 (1.48-1.91)	1.85 (1.62-2.11)
Sweden	1.00	1.60 (1.37-1.86)	1.75 (1.49-2.04)
Spain	1.00	1.43 (1.29-1.58)	1.72 (1.52-1.95)
France	1.00	1.19 (1.04-1.36)	1.61 (1.42-1.82)
Ireland	1.00	1.33 (1.12-1.58)	1.54 (1.29-1.82)
Iceland	1.00	1.07 (0.92-1.25)	1.37 (1.18-1.59)
Netherlands	1.00	0.79 (0.69-0.90)	1.18 (1.02-1.35)
Great Britain	1.00	1.08 (0.96-1.22)	1.13 (0.98-1.29)
Denmark	1.00	1.49 (1.28-1.73)	0.99 (0.86-1.14)
Northern Ireland	1.00	1.01 (0.77-1.32)	0.91 (0.73-1.15)
West Germany	1.00	0.83 (0.74-0.93)	0.78 (0.69-0.89)

a: Model 5: controlling for age, sex, educational level, proportion employed in agricultural sector, proportion belonging to manual social class, religious beliefs, and permissiveness.

DISCUSSION

We have presented clear empirical proof that the acceptance of euthanasia among the general public has increased in most West European countries throughout the last two decades. The only exception is West Germany. Our findings show that an increased acceptance of euthanasia can be related to the increase in educational attainment, secularisation and the increased value society puts on individual liberties, but the change in acceptance also differs strongly between countries.

This study is, to our knowledge, the first to examine trends in attitudes towards euthanasia linked to other relevant changes in society, and with a cross-national design comparing 12 countries.

An important limitation is that the EVS used only one question to measure acceptance of euthanasia, which makes it more difficult to gain a thorough understanding of public attitudes. Furthermore, the description used in the EVS for euthanasia misses an important condition (namely that the act is “at the explicit request of the patient” [31]), and does not specify any clinical circumstances (e.g. the degree of suffering, age of the patient, consciousness and mental alertness of the patient), which might have had an impact on the acceptability of this medical practice [26;32].

A number of striking and new insights are provided by our study.

First, the change in acceptance of euthanasia did not occur with the same speed in all countries. In particular, Belgium drastically changed its acceptance of euthanasia. In 1981 it was among the least accepting countries, but by 1999 the general public was clearly accepting euthanasia. This strong increase has probably been a major contribution to the Belgian euthanasia legislation of 2002 [1]. The increase is found to be strongly associated with the particularly strong decrease in religious beliefs in the 1980s and the increase of general permissiveness (i.e. the value society has put on an individual’s right to self-determination) in Belgium.

A second striking insight is that in Belgium, as well as in many other countries (France, Spain, Sweden, Ireland and The Netherlands) the increase in acceptance of euthanasia was stronger than the increase in permissiveness and the decrease of religious beliefs. This can possibly be ascribed to the intense debate and public discussions on terminal patients’ rights that were held in those countries, compared to the others. A public debate aimed at legalising euthanasia and exposure of dying patients in the mass media (e.g. the Ramon Sampedro case in Spain) may have led to a greater awareness of and sensibility towards the rights of terminally ill patients, and to an increase in the acceptance of euthanasia, faster than the increase in general permissiveness [33]. It seems that the rise in the acceptance of euthanasia reflects changing attitudes towards death and dying and a generalised desire to counter 'bad' ways of dying [34]. If these trends continue, and if more and more individuals (like Dianne Pretty in the UK) will be brought in the media, giving a face to suffering patients desiring to end their lives, it is plausible that the public acceptance of euthanasia will increase further.

A third new finding is that secularisation is strongly correlated with an increase of euthanasia acceptance, as could be expected from the previously reported association of religious beliefs and euthanasia acceptance, [12;17-21;24-26;35] but not necessarily coinciding with it. Countries with no change (e.g. Iceland) or with a weak decrease in religious beliefs still often experienced a strong increase in euthanasia acceptance. And while Italy has clearly increased its acceptance of euthanasia, it has also known an increase in religious beliefs according to the EVS data [36]. Based on these findings, we expect that further secularisation will not inevitably, as suggested by other authors, [15] bring about a further increase in euthanasia acceptance.

Finally, the case of Germany demonstrates that other, country-specific, factors are clearly important as well. While Germany has known an increase in permissiveness (towards abortion, divorce, homosexuality etc.) and a decrease in religious beliefs, it has not experienced any increase in euthanasia acceptance. Germany is, as has been reported elsewhere ,[37] an exception in Europe on attitudes towards euthanasia. It is very likely that Germany's Nazi history has a strong influence on their continued restrictive attitude towards euthanasia. The memory of the Nazi euthanasia programme (the T-4 programme), which functions as a dreaded example inspiring fear of possible abuse of euthanasia, possibly prevents Germans –both the medical community as well as the general public- from adopting a more positive attitude towards euthanasia.[37-41]

To summarize our findings, we can see that a marked increase of the acceptance of euthanasia has occurred during the last two decades in almost all West European countries. The decrease in religious beliefs and increase in permissiveness are obvious correlates of this increased acceptance. However, our findings seem to suggest that public sensibilities towards 'right-to-die' issues and public debates on euthanasia and terminal patients' rights have most probably also contributed to the increase in euthanasia acceptance. Changing attitudes towards pain and suffering [42] and an increased individualism reflected in a desire for individual control and choice over time, place and manner of death [33] have probably incited this attitude.

It is not unlikely that, if trends in public attitudes towards this sensitive issue continue as they have done in the last two decades, in most European countries it will be a question of when rather than whether euthanasia, under certain conditions of careful, medical practice will be regulated.

Acknowledgements

The data used in this paper are from the EVS 1999-2000 [43]; the EVS 1990 [44]; and the EVS 1981.[45] The authors wish to thank the Steinmetz-archief for providing the data.

The authors wish to acknowledge Johan Vanoverloop for his statistical advice.

REFERENCES

1. Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. Lancet 2003;362(9391):1239-40.
2. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. N.Engl.J.Med. 2000;342(8):557-63.
3. Bosshard G, Fischer S, Bar W. Open regulation and practice in assisted dying. Swiss.Med.Wkly. 2002;132(37-38):527-34.
4. Bamgbose O. Euthanasia: another face of murder. Int.J.Offender.Ther.Comp Criminol. 2004;48(1):111-21.
5. Huxtable R. Assisted suicide. BMJ 2004;328(7448):1088-89.
6. House of Lords Select Committee on the Assisted Dying for theTerminally Ill Bill. Assisted Dying for the Terminally Ill Bill [HL]. Volume 1: report. (http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/86i.pdf)
7. Roy Morgan Research Centre. Morgan Polls on Medically Assisted Death. Finding No.2933. (http://www.roymorgan.com/news/polls/polls.cfm. 1996). Roy Morgan Research Centre, Melbourne.
8. van der Maas PJ, Pijnenborg L, van Delden JJ. Changes in Dutch opinions on active euthanasia, 1966 through 1991. JAMA 1995;273(18):1411-14.
9. Benson JM. The polls-trends - End-of-life issues. Public Opinion Quarterly 1999;63(2):263-77.
10. Blendon RJ, Szalay US, Knox RA. Should physicians aid their patients in dying? The public perspective. JAMA 1992;267(19):2658-62.
11. Gallup Canada. The Gallup report. (1968-). Toronto, Canadian Institute of Public Opinion.
12. Suarez-Almazor ME, Belzile M, Bruera E. Euthanasia and physician-assisted suicide: a comparative survey of physicians, terminally ill cancer patients, and the general population. J.Clin.Oncol. 1997;15(2):418-27.
13. Holloway HD, Hayslip B, Murdock ME et al. Measuring attitudes toward euthanasia. Omega.(Westport.) 1994;30(1):53-65.
14. Nilstun T, Melltorp G, Hermeren G. Surveys on attitudes to active euthanasia and the difficulty of drawing normative conclusions. Scand.J.Public Health 2000;28(2):111-16.
15. O'Neill C, Feenan D, Hughes C, McAlister DA. Physician and family assisted suicide: results from a study of public attitudes in Britain. Soc.Sci.Med. 2003;57(4):721-31.
16. Ryynanen OP, Myllykangas M, Viren M, Heino H. Attitudes towards euthanasia among physicians, nurses and the general public in Finland. Public Health 2002;116(6):322-31.
17. De Moor R. Religion and Moral Values: The Case of Euthanasia. In: De Moor R, editor. Values in Western Societies. Tilburg: Tilburg University Press, 1995:31-50.
18. Hamil-Luker J, Smith C. Religious authority and public opinion on the right to die. Sociology of Religion 1998;59(4):373-91.
19. Finlay B. Right to life vs. the right to die: some correlates of euthanasia attitudes. Sociology and Social Research 1985;69(4):548-60.
20. Bachman JG, Alcser KH, Doukas DJ, Lichtenstein RL, Corning AD, Brody H. Attitudes of Michigan physicians and the public toward legalizing physician-assisted suicide and voluntary euthanasia. N.Engl.J.Med. 1996;334(5):303-9.

21. DeCesare MA. Public attitudes toward euthanasia and suicide for terminally ill persons: 1977 and 1996. Soc.Biol. 2000;47(3-4):264-76.
22. Caralis PV, Davis B, Wright K, Marcial E. The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. J.Clin.Ethics 1993;4(2):155-65.
23. MacDonald WL. The difference between blacks' and whites' attitudes toward voluntary euthanasia. J.Sci.Study Relig. 1998;37(3):411-26.
24. Caddell DP, Newton RR. Euthanasia: American attitudes toward the physician's role. Soc.Sci.Med. 1995;40(12):1671-81.
25. Hare J, Skinner D, Riley D. Why older age predicts lower acceptance of physician-assisted suicide. WMJ. 2000;99(7):20-7, 46.
26. Achille MA, Ogloff JR. When is a request for assisted suicide legitimate? Factors influencing public attitudes toward euthanasia. Can.J.Behav.Sci. 1997;29(1):19-27.
27. Loo R. Relationships between attitudes toward euthanasia and attitudes toward persons with disabilities. Social Science Journal 2004;41(2):295-99.
28. Halman, L. The European Values Study: a Third Wave. Source book of the 1999/2000 European Values Study Surveys. 2001. Tilburg, EVS, WORC, Tilburg University.
29. Halman L, Riis O, Pettersen T et al. Religion in Secularizing Society. The European's religion at the end of the 20th century. Tilburg: Tilburg University Press, 1999.
30. De Moor R., editor. Values in Western Societies. Tilburg: Tilburg University Press, 1995.
31. Materstvedt LJ. Palliative care on the 'slippery slope' towards euthanasia? Palliat.Med. 2003;17(5):387-92.
32. Hagelin J, Nilstun T, Hau J, Carlsson HE. Surveys on attitudes towards legalisation of euthanasia: importance of question phrasing. J.Med.Ethics 2004;30(6):521-23.
33. Baker ME. Economic, political and ethnic influences on end-of-life decision-making: a decade in review. J.Health Soc.Policy 2002;14(3):27-39.
34. Seale C, Addington-Hall J, McCarthy M. Awareness of dying: prevalence, causes and consequences. Soc.Sci.Med. 1997;45(3):477-84.
35. Suarez-Almazor ME, Newman C, Hanson J, Bruera E. Attitudes of terminally ill cancer patients about euthanasia and assisted suicide: predominance of psychosocial determinants and beliefs over symptom distress and subsequent survival. J.Clin.Oncol. 2002;20(8):2134-41.
36. Halman L, Riis O. Contemporary European Discourses on Religion and Morality. In: Halman L, Riis O, editors. Religion in Secularizing Society. The European's religion at the end of the 20th century. Tilburg: Tilburg University Press, 1999:2-18.
37. Sahm SW. Palliative care versus euthanasia. The German position: the German General Medical Council's principles for medical care of the terminally ill. J.Med.Philos. 2000;25(2):195-219.
38. Oehmichen M, Meissner C. Active euthanasia and physician-assisted suicide: the German discussion. Leg.Med.(Tokyo) 2003;5 Suppl 1S20-S28.
39. Kottow MH. Euthanasia after the holocaust--is it possible?: a report from the Federal Republic of Germany. Bioethics. 1988;2(1):58-59.
40. Hoskins SA. Nurses and national socialism--a moral dilemma: one historical example of a route to euthanasia. Nurs.Ethics 2005;12(1):79-91.

41. Wernstedt T, Mohr M, Kettler D. [Euthanasia in Europe--ten countries with special consideration of the Netherlands and Germany]. Anasthesiol.Intensivmed.Notfallmed.Schmerzther. 2000;35(4):220-231.
42. Illich I. Medical Nemisis. The expropriation of Health. New York: Bantam Books, 1979.
43. Halman, L.C.J.M.; Subfac. Sociale Wetenschappen; Universiteit van Tilburg; European Values Study 1999/2000, EVS ‘99/2000 (ZA Study 3811) [computer file]; Amsterdam, Steinmetz-archief (P1460)
44. European Values Study Group; n/a, n/a. Riffault, H.; Faits et Opinions, Paris, France. Barker, D.; Harding, S.; Heald, G.; Timms, N.; Gallup Poll, London, Great Britain. Kocher, R.; Institut fuer Demoskopie, Allensbach am Bodensee, West Germany. Capraro, G.; Gubert, R.; University of Trento, Italy. Orizo, F.; Elzo, J.; Data SA, Madrid, Spain. Halman, L.; Huenks, F.J.; Moor, R.A. de; Institute for Social Research, IVA, Tilburg, the Netherlands. Dobbelaere, K.; Kerkhofs, J; Dimarso, Brussels, Belgium. Gundelach, P.; Riis, O.; Danish National Institute of Social Research, Copenhagen, Denmark. Petterson, T.; SIFO, Stockholm, Sweden. Kennedy, K.; Whelan, C.; Economic and Social Research Institute, Dublin, Ireland. Johnsson, F. University of Iceland, Iceland. European Values Study, 1990 – EVS’90 [computer file], Amsterdam, Steinmetz-archief (P1217)
45. Moor, R.A. de; Katholieke Universiteit Brabant; Tilburg. Harding, S.D.; Nene College, Dept. of psychology; England. Kerkhofs, J.; Katholieke Universiteit Leuven; Leuven, Belgium. European Values Study, 1981 – EVS’81 [computer file], Amsterdam, Steinmetz-archief (P0830)

3

European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries

Joachim Cohen, Isabelle Marcoux, Johan Bilsen, Patrick Deboosere, Gerrit van der Wal, Luc Deliens.

This paper is published in Social Science & Medicine 2006; 63(3): 743-56.

ABSTRACT:

In many European countries the last decade has been marked by an increasing debate about the acceptability and regulation of euthanasia and other end-of-life decisions in medical practice. The growing public sensibility to a 'right to die' for terminally ill patients was one of the main constituents of these debates. Within this context we wanted to describe and compare the acceptance of euthanasia among the general public in 33 European countries. We used the European Values Study data of 1999-2000 with a total of 41 125 respondents (63% response rate) in 33 European countries. The main outcome measure of our study concerned the acceptance of euthanasia (defined as 'terminating the life of the incurably sick', rated on a scale from 1 to 10).

Results showed that the acceptance of euthanasia tended to be high in some countries (e.g. the Netherlands, Denmark, France, Sweden), while a markedly low acceptance was found in others (e.g. Romania, Malta and Turkey). A multivariate ordinal regression showed that weaker religious belief was the most important factor associated with a higher acceptance, but that there were also socio-demographic differences: younger cohorts, people from non-manual social classes, and people with a higher educational level tended to have a higher acceptance of euthanasia. While religious belief, socio-demographic factors, and also moral values (i.e. the belief in the right to self-determination) could largely explain the differences between countries, our findings suggest that perceptions regarding euthanasia are probably also influenced by national traditions and history (e.g. Germany). Thus we demonstrated clear cross-national differences with regard to the acceptance of euthanasia, which can serve as an important basis for further debate and research in the specific countries.

INTRODUCTION

New possibilities in health care technologies throughout the last decades have improved life expectancy and have expanded options for sustaining the life of the terminally ill. It has become apparent that there are also drawbacks to this progress: criticism against futile end-of-life care is becoming ever more vocal, questions are being raised over whether treatment aimed at cure is always beneficial or justified, and paradigms in medicine are shifting more and more from a 'quantity of life' to a 'quality of life approach', and from a paternalist approach to that of the patient's autonomy. A 'good death' is now being connected to choice and control over the time, manner and place of death [1-4]. All these developments have shaped discussion regarding terminally ill patients' rights to refuse or discontinue life-sustaining efforts or even to ask to actively end life.

As part of this discussion, in various European countries, the question whether the possibility of terminating the life of suffering, terminally ill patients in medical practice should be regulated or legalised has been publicly debated. In 2002, both the Netherlands and Belgium respectively legalised (active voluntary) euthanasia [5]. In Switzerland, (physician) assisted suicide (PAS) is not prosecuted when it is done without 'self-interest' [6;7]. Although in most countries euthanasia remains illegal, sanctions are also often being downgraded and applied infrequently and sometimes amendments in the law distinguish a medical decision that ends the life of a patient with unbearable pain at the request of the patient from murder [8;9]. In most European countries public debates on these issues are being held.

Two elements have been particularly important in this change, in the social and political debate and in the procedural rule-making. First, the evidence that euthanasia occurs in many European countries (as well as outside Europe) has increased concern about the necessity to better understand how euthanasia is performed and how to ensure safe practice [10-14]. Second, the growing support of the general public for a 'right to die' legislation has been an important influence for the euthanasia debate [15-17].

European studies of public attitudes towards euthanasia show that a majority of citizens think that euthanasia and/or PAS is acceptable or should be legalised: 80% to 93% in Germany [18;19]; 84% in Great Britain [20]; 82% in Switzerland [21]; 61% in France [22]; 50% in Finland [23]; 24% to 65% in Poland [24]. However, far from all European countries were studied (in particular the Eastern European countries were missed out) and the use of different instruments or questions limits comparability between countries. Many previous studies were also limited to health professionals' attitudes towards euthanasia (legislation), which is important because medical professionals will be the primary actors [25-27]. Awareness of public opinion is, however, also important since individuals and families would be initiators of the requests for euthanasia and subjects of the decision-making process [28].

Besides awareness of the public attitudes towards euthanasia, it is important to better understand how acceptance of euthanasia is influenced by socio-demographic and cultural factors. This might help in explaining different views of the public in different countries, but also in explaining differences in attitudes towards euthanasia between individuals or groups within a specific country. To date, there is a lack of clear understanding of what influences Europeans in their attitudes toward euthanasia.

In our study, we firstly examine and compare the degree to which euthanasia (in this study described as 'terminating the life of incurably ill') is accepted in 33 European countries. Second, based upon factors found to be significant in the literature, we examine the association of the following factors with the acceptance of euthanasia: age [20;23;29-31]; gender [23;32;33]; social factors [30;31;33-35]; educational level [31;36;37]; religious identity [29-31;33;36-39]; the strength of religious beliefs [29;32;36;37;40]; the degree to which religion is actively practised [29;33]; and (personal) moral attitudes [29;31]. Finally, we explore possible explanations for the differences between European countries, and discuss some implications of the findings.

METHODS

Sample and database

To compare the attitudes towards euthanasia in different European countries, we used the data from the 1999-2000 wave of the European Values Study (EVS) [41]. The EVS study provides unique data from national representative samples from almost all European countries, including Russia and Turkey. It gives insight into and allows comparison of the preferences and orientations of the populations of societies covering a wide range of economic, social, political, and cultural variation. The European Values project was designed to empirically explore the patterns and changes in cross-national differences and similarities in basic social values in Europe. To achieve this, surveys were carried out using uniformly structured questionnaires, enabling comparisons.

The data used in this paper are drawn from the third wave of surveys which was conducted in 1999-2000 in 33 countries in western, central, and eastern Europe, providing data about more than 41 000 European citizens (see Table 1). More information about the project design and the aim and purposes of the EVS can be found elsewhere [41].

Representative national samples of all adult citizens (aged 18 years and older) were interviewed in all countries through face-to-face interviews (except for a small number in Iceland who were interviewed by phone because of problems of accessibility). The samples were obtained through quota sampling or random sampling with stratification by age, sex and region.

Depending on the representativeness of the national sample, a weighting was added to correct for gender (in NL, IT, IR, GB, DE, FR); for age (in IR, NL;) for marital status (in FR); for education (in IT, IR) and for region (in DE, NL). To calculate averages throughout the 33 countries, an additional weighting was used to correct for the proportion of the population size within the total sample.

Detailed information on the translation of the questionnaire, the sampling procedures, fieldwork, weighting, etc. was provided in the methodological questionnaire of the EVS by the contributors in charge of the national surveys [41]. On the basis of this methodological questionnaire of EVS we calculated figures for non-response.

Measurements

Dependent variable: acceptance of euthanasia

Among a number of questions regarding tolerance, the EVS questionnaire included one question that probed the attitude towards euthanasia:

"Please tell me whether you think 'euthanasia (terminating the life of the incurably sick)' can always be justified, never be justified, or something in between".

The respondent was then asked to give a rating on a Likert scale from 1 to 10; 1 meaning 'never justified', and 10 expressing that euthanasia is 'always justified'. Respondents also had the possibility of answering 'I don't know'. Responses of 'I don't know' were not considered in the analysis explaining the acceptance of euthanasia.

Independent variables

The EVS questionnaire contains more than 300 questions, assessing a number of attitudinal, cultural and socio-demographic information. For the purpose of our analysis,

only variables associated with euthanasia acceptance as revealed in the literature or in previous research and meaningful in the context of our analyses were retained.
Socio-demographic variables included country of residence, sex, age, marital status, educational level, social class and an agricultural class variable. The educational level was measured as the highest level of educational degree achieved. Country-specific educational degrees were transformed into a standardised variable, based on the International Standard Classification of Education (ISCED) [41]. Social class was operationalised by means of the (last) exercised profession of the household's chief wage earner. It distinguished four social classes: 1) upper or upper-middle class; 2) middle class, non-manual workers; 3) skilled or semi-skilled manual workers and 4) unskilled manual workers or unemployed. On the basis of the last exercised profession of the household's chief wage earner we also distinguished persons active in the agricultural sector, as we thought it likely that the number of farmers in a country (as an indicator of urbanisation and the relative importance of the rural population within a country) might explain part of a country's higher or lower acceptance of euthanasia.

Two variables relating to religion were retained: religious identification (specific religious denomination or not religious) and strength of religious belief. The latter is a factor constructed by means of principal component analyses (PCA) and it describes whether or not someone belongs to a religious denomination and the frequency in which religious services are attended, as well as the degree to which someone believes respectively in God, life after death, hell, and heaven. By means of PCA a factor describing belief in the right to self-determination was also constructed. It measures the acceptance of divorce, abortion, homosexuality and having casual sex. We have labelled this factor 'permissiveness' further in the text.

Detailed information about the construction of these factors, their component loadings and their internal consistency is not presented here, but can be supplied by the authors on request.

Statistical analysis

The relatively large proportion of the respondents answering 1 'never justified' or 10 'always justified' resulted in a non-normal distribution of the dependent variable. The Kolmogorov-Smirnov test confirmed non-normality ($Z=33.63$; $p<0.001$). Hence, non-parametric tests and non-parametric multivariate analysis were performed.

In the bivariate analysis, we compared the mean scores among the different categories. Kruskal-Wallis or Jonckheere-Terpstra (if the independent variable was ordinal) tests were used to determine statistical significance.

Significant variables ($p<0.01$) and possible confounders were entered into a multivariate ordinal logistic regression (PoLitomous Universal Models; i.e. PLUM). Because of the high incidence of extreme scores (1 and 10) we chose the cauchit link function. To obtain a good final model and to get a clear view on how factors influence the acceptance of euthanasia we expanded our model stepwise, by constructing four models. The first model describes the country differences; the second model adds the educational level, social class (dichotomised into manual vs. non-manual), and the agricultural class variable; the third model adds age; the fourth model adds the religious belief factor. The identification with a religious group is not introduced in the model, because it is too country-specific. Differences in euthanasia acceptance between different religious groups were however described in a separate country-specific analysis. Eight countries were selected, as type examples of the large diversity of religious-historical backgrounds of all 33 countries. The selection was based on religious cultural backgrounds, history and patterns of secularisation, and similar composition in terms of the large religious denominations [42;42-44]. The Netherlands and Germany (being an exception), typify the Western, (more or less) pluralistic, secularised countries (BE, FR, LU, GB); Sweden typifies the Nordic, Protestant, secularised countries (DK, FI, IS); Latvia typifies the Eastern, Orthodox, secularised countries (CZ, BG, HU, EE, RU, UA, BY, SI), although Latvia is more pluralistic than the other countries; Italy typifies the Southern, Roman Catholic, religious countries (ES, PT, AT, MT, IE, incl. semi-Protestant Northern-Ireland); and Poland typifies the Eastern Roman Catholic religious countries (HR, LT, SK). Finally, Romania (as an Eastern, Orthodox, religious country) and Turkey (as the only Muslim country) are selected.

‘Permissiveness’ was not entered as a factor into the model, because it was too strongly correlated to euthanasia attitudes ($r=0.54$) (in a PCA the euthanasia attitude was found to be a component of the same dimension). It was however also used in an analysis to examine country-specific positions towards euthanasia.

SPSS (version 12.0) was used for all statistical computations.

RESULTS

Response rates varied from 31% in Spain to 95% in Slovakia, with an overall response rate of 63% (see Table 1), which is more than average for a social survey. For Turkey, no detailed data about the response were available. The total number of respondents was 41 125.

Table 1: description of sample and response rate of European Values Study 1999-2000

Country	Abbreviation*	Net response rate†	N of respondents
Slovakia	SK	95.1%	1331
Lithuania	LT	89.1%	1018
Bulgaria	BG	88.5%	1000
Italy	IT	83.0%	2000
Greece	EL	81.6%	1142
Hungary	HU	81.4%	1000
Austria	AT	81.0%	1522
Great Britain‡	GB	80.0%	1000
Malta	MT	79.5%	1002
Poland	PL	77.9%	1095
Latvia	LV	75.9%	1013
Belarus	BY	75.7%	1000
Russia	RU	75.4%	2500
Romania	RO	71.0%	1146
Ukraine	UA	70.3%	1195
Northern Ireland	NI	68.6%	1000
Iceland	IS	68.3%	968
Sweden	SE	63.4%	1015
Ireland	IE	62.2%	1012
Luxembourg	LU	61.6%	1211
Finland	FI	61.3%	1038
Denmark	DK	59.8%	1023
Germany	DE	57.8%	2036
Belgium	BE	56.8%	1912
Estonia	EE	55.6%	1005
Croatia	HR	54.4%	1003
Slovenia	SI	53.2%	1006
Czech Republic	CZ	53.1%	1908
France	FR	42.0%	1615
Portugal	PT	40.6%	1000
Netherlands	NL	39.5%	1003
Spain	ES	31.4%	1200
Turkey	TR	na§	1206
Total		63.4%	41 125

*: Abbreviations used in this paper are according to the rules proposed by the EU (see http://publications.eu.int/code/en/en-370101.htm (02-03-2005)); i.e. two-letter codes of the International Organisation for Standardization; ISO (ISO 3166 alpha-2 codes), except for Greece, for which the EU recommends the abbreviation EL

†: The net response rate is calculated as the number of productive interviews in relation to the total number of starting addresses, excluding inexistent or empty addresses, persons who had moved, were too sick or disabled or had deceased and also excluding the starting addresses where no-one met the sample requirements.

‡: This includes England, Wales and Scotland. Northern Ireland is counted separately

§: For Turkey, no data about the response were available in the methodological information of EVS, but the response rate could be estimated separately for rural areas (90% or more), and urban or metropolitan areas (about 50%) (personal communication with the person responsible for the Turkish data-collection)

Attitudes towards euthanasia in 33 countries

The acceptance of euthanasia varied strongly between the different European countries (Table 2). The mean scores ranged from 6.68 in the Netherlands to 2.23 in Malta; a difference of 4.45. Italy (3.86), Portugal (3.50), Poland (3.37), Ireland (3.31) and most notably Romania (3.29), Turkey (2.78) and Malta (2.23) had a lower public acceptance of euthanasia. In Poland, Romania, Turkey and Malta, more than half of the population considered euthanasia to be justified under no circumstances. In the Netherlands (6.68), Denmark (6.61), France (6.16), Sweden (6.07) and Belgium (5.97), the public generally accepted euthanasia.

When asked whether euthanasia was justified, a lot of eastern Europeans responded that they did not know: about 14% in Lithuania and Romania, 13% in Bulgaria and Ukraine and 12% in Russia and Estonia. In the former Soviet countries, we also noticed a higher occurrence of extreme response categories. In Russia, 28.5% considered euthanasia to be almost always justified (score of 9 or 10) whereas also 28.4% said that it was almost never justified (score of 1 or 2). The same pattern prevailed for Latvia (26.5% vs. 34.5%) and Ukraine (26.2% vs. 35.5%). In most western European countries, the number of people with no opinion on euthanasia was lower (6.6% in Denmark, 4.1% in Italy and 0.6% in the Netherlands).

In all 33 European countries together, the mean score for the acceptance of euthanasia on a scale from 1 to 10 was just below 5.

Table 2: Acceptance of euthanasia (score from 1 to 10) in 33 European countries (from most accepting to least accepting); 1999-2000

	Mean*	Contras* (score 1 to 2)	Rather contra* (score 3 to 5)	Rather pro* (score 6 to 8)	Pros* (score 9 to 10)	**N answered on question***	*% of total don't know*	*% of total not answered*
Netherlands	**6.68**	*10.9*	*19.5*	*44.4*	*25.2*	**994**	0.6	0.2
Denmark	**6.61**	*15.7*	*21.3*	*28.8*	*34.1*	**949**	6.7	0.5
France	**6.16**	*16.1*	*27.0*	*33.1*	*23.8*	**1528**	3.5	1.9
Sweden	**6.07**	*16.1*	*25.8*	*35.8*	*22.3*	**975**	3.8	0.0
Belgium	**5.97**	*15.3*	*29.4*	*36.0*	*19.3*	**1878**	1.0	0.8
Luxembourg	**5.63**	*22.7*	*27.3*	*27.3*	*22.7*	**1145**	3.5	2.0
Russia	**5.60**	*28.4*	*22.3*	*20.7*	*28.5*	**2179**	12.4	0.4
Czech Republic	**5.50**	*26.1*	*24.2*	*27.8*	*21.9*	**1802**	4.6	0.9
Finland	**5.40**	*27.4*	*21.8*	*31.6*	*19.2*	**984**	3.4	1.8
Belarus	**5.38**	*26.5*	*26.3*	*25.7*	*21.6*	**904**	7.8	1.8
Lithuania	**5.38**	*30.2*	*22.2*	*24.7*	*22.8*	**867**	14.1	0.6
Slovenia	**5.37**	*32.7*	*11.9*	*28.7*	*26.7*	**950**	4.8	0.8
Iceland	**5.33**	*26.7*	*26.7*	*33.3*	*13.3*	**927**	3.6	0.6
Latvia	**5.24**	*34.5*	*19.5*	*19.5*	*26.5*	**892**	9.4	2.6
Ukraine	**5.20**	*35.5*	*17.9*	*20.3*	*26.2*	**1033**	13.4	0.9
Estonia	**5.16**	*30.2*	*25.4*	*23.8*	*20.6*	**860**	12.3	2.1
Great Britain	**4.99**	*26.9*	*33.0*	*24.4*	*15.7*	**966**	2.0	0.9
Slovakia	**4.96**	*34.1*	*24.2*	*23.1*	*18.6*	**1200**	9.6	0.0
Spain	**4.73**	*34.0*	*29.4*	*19.9*	*16.7*	**1094**	6.3	2.5
Austria	**4.37**	*40.5*	*25.0*	*20.4*	*14.1*	**1431**	5.6	0.5
Germany	**4.34**	*38.2*	*28.5*	*21.5*	*11.8*	**1888**	5.8	1.5
Greece	**4.20**	*39.1*	*28.6*	*23.7*	*8.7*	**1069**	2.0	4.1
Northern Ireland	**3.93**	*45.8*	*25.3*	*18.1*	*10.8*	**910**	7.9	1.2
Italy	**3.86**	*46.6*	*25.3*	*18.4*	*9.6*	**1898**	4.2	1.0
Hungary	**3.83**	*51.6*	*21.2*	*13.9*	*13.3*	**916**	7.1	1.3
Croatia	**3.82**	*52.8*	*21.0*	*11.2*	*15.0*	**975**	2.1	0.8
Bulgaria	**3.75**	*50.0*	*24.6*	*13.9*	*11.5*	**838**	13.4	2.8
Portugal	**3.50**	*50.5*	*27.6*	*14.6*	*7.3*	**883**	9.6	2.1
Poland	**3.37**	*57.0*	*20.4*	*13.1*	*9.5*	**1000**	8.6	0.0
Ireland	**3.31**	*55.8*	*22.6*	*14.7*	*6.8*	**936**	6.1	1.4
Romania	**3.29**	*62.3*	*13.9*	*11.2*	*12.6*	**918**	13.8	6.1
Turkey	**2.78**	*70.2*	*12.6*	*7.0*	*10.2*	**1184**	1.8	0.0
Malta	**2.23**	*72.7*	*18.2*	*4.5*	*4.5*	**1001**	0.0	0.0
Total	**4.71**	*37.5*	*23.6*	*20.9*	*18.0*	**37 976**	*6.4*	*1.3*

*: Presented figures are weighted means and weighted percentages, calculated on the basis of the total number of respondents that answered to the euthanasia question and did not answer with "don't know".

Bivariate analysis: socio-demographic factors associated with the acceptance of euthanasia. (Table 3)

When total mean scores were compared, results showed that men were slightly more accepting of euthanasia than women and that the acceptance decreased almost linearly with age. The acceptance of euthanasia was larger for the non-manual social classes, and was lower for persons in the agricultural sector, and increased with the educational level.

Table 3: Euthanasia acceptance by socio-demographic characteristics in 33 European countries (1999-2000) (weighted N=37976†)

	Mean score	p-value	% with score 1-2	% with score 3-8	% with score 9-10	N‡
Sex respondent		< 0.001*				
Male	**4.82**		*36.1*	*44.9*	*19.1*	18 039
Female	**4.60**		*38.8*	*44.2*	*17.0*	19 928
Age		< 0.001*				
18-29	**5.11**		*31.2*	*48.3*	*20.5*	8986
30-39	**5.10**		*32.3*	*46.8*	*21.0*	7530
40-49	**4.79**		*36.9*	*44.3*	*18.7*	7191
50-59	**4.58**		*39.3*	*43.2*	*17.4*	5586
60-69	**3.98**		*47.7*	*39.7*	*12.6*	4903
70 and more	**3.90**		*48.6*	*39.0*	*12.3*	3638
Social class (on basis of occupation chief wage earner)		< 0.001*				
Upper, upper-middle class	**5.00**		*33.1*	*47.6*	*19.3*	13 177
Middle, non-manual workers	**4.83**		*33.8*	*49.0*	*17.1*	4795
Manual workers - skilled, semi-skilled	**4.71**		*37.6*	*43.7*	*18.8*	11 072
Manual workers - unskilled, unemployed	**4.32**		*44.1*	*39.8*	*16.2*	4467
Agricultural sector		<0.001*				
Yes	**3.28**		*58.5*	*31.5*	*10.0*	2110
No	**4.89**		*34.7*	*46.3*	*18.9*	31 345
Education (degree(transformed))		<0.001*				
Elementary or inadequate	**3.61**		*52.5*	*36.5*	*11.0*	9593
Basic vocational or intermediate secondary	**5.09**		*32.6*	*46.7*	*20.6*	14 352
Full secondary or higher education	**5.17**		*30.7*	*48.5*	*20.8*	13766

Presented figures are weighted means and weighted percentages.
*: All significance tests with Kruskal-Wallis and Jonckheere Terpstra.
†: This is the total number of respondents that answered to the euthanasia question and did not answer with "don't know".
‡: Totals may not add up to 37 976, because of missing values. The number of missing values was relatively low except for Social Class (11%).

Multivariate analysis (Table 4)

All four multivariate (PLUM) models were based on nine thresholds for the dependent variable. In the first two models all nine of the thresholds were significant from a statistical point of view. In the third and fourth model the threshold between score 3 and 4 was not statistically significant.

Model 1 confirmed the large country differences.

In Model 2 we entered educational level, social class and agricultural class. People with a full secondary education (OR=1.62) or with only intermediate secondary education (OR=1.44) found euthanasia more acceptable than people with elementary or inadequate education. People from a non-manual social class found euthanasia to be more acceptable than those from a manual social class (OR=1.12), and people from outside the agricultural class tended to accept euthanasia more than those belonging to the agricultural class (OR=0.66). The higher educational level and the larger number of persons belonging to non-manual classes and non-agricultural classes explained a considerable part of the higher acceptance in several countries (e.g. NL, DK, SE, BE, IS, CZ, LT, LU).

Model 3 added age to the analysis. Older respondents tended to be less accepting. Adding age to the model explained part of the association found between euthanasia acceptance and educational level, and agricultural class, and also considerably explained lower or higher acceptance of euthanasia in some countries. A relatively young population explained the higher acceptance of euthanasia in e.g. Iceland. Given the older population, the acceptance of euthanasia was relatively high in the Netherlands.

Model 4, finally, also controlled for the level of religious belief. The acceptance of euthanasia decreased as the level of religious belief was increased (OR=0.72). After controlling for religious belief, the associations of educational level, social class and agricultural class changed moderately. Because the younger cohorts were less strongly religious, the association with age was weaker when controlling for religious belief. A lower level of religious belief also partly explained the higher acceptance of euthanasia in various countries (e.g NL, DK, FR, SE, BE, CZ), and *vice versa* where a higher level of religious belief partly explained lower acceptance of euthanasia (e.g. EL, NI, HR, IE, PL, RO, TR, MT). Controlling for all characteristics, country differences were maintained. Respectively respondents who were Dutch, Danish, French, Belgian, Finnish, Swedish, Icelandic or Lithuanian have a statistically significant higher acceptance of euthanasia than the British (which were chosen as the reference category because they had an average level of euthanasia acceptance). Respondents from Spain, Estonia, Northern Ireland, Austria, Greece, Germany, Italy, Portugal, Croatia, Eire, Poland, Bulgaria, Hungary, Romania, Malta and Turkey tended to accept euthanasia less than those from Britain.

A model was also tested by adding gender, marital status, and a factor “concern for other people”. These were barely significant factors, adding little to the prediction of euthanasia acceptance and lead to no meaningful conclusions. To achieve a parsimonious model, these factors are not retained.

Table 4: Multivariate ordinal regression on euthanasia acceptance

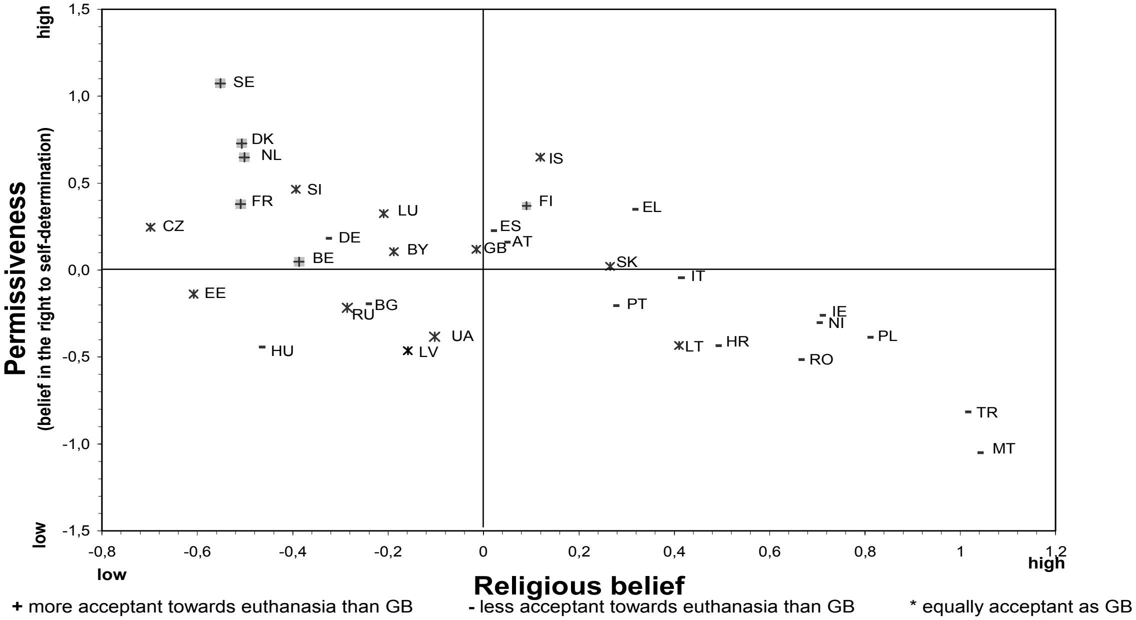
	MODEL 1		MODEL 2		MODEL 3		MODEL 4	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Country								
Netherlands	2.10	1.84-2.40	1.81	1.58-2.07	1.91	1.67-2.19	1.69	1.47-1.93
Denmark	1.95	1.71-2.23	1.79	1.56-2.06	1.74	1.51-1.99	1.55	1.35-1.78
France	1.60	1.42-1.80	1.54	1.36-1.74	1.58	1.40-1.79	1.39	1.23-1.58
Sweden	1.51	1.32-1.72	1.30	1.14-1.49	1.31	1.14-1.50	1.18	1.03-1.35
Belgium	1.49	1.33-1.67	1.29	1.15-1.46	1.34	1.19-1.51	1.24	1.10-1.39
Finland	1.27	1.11-1.44	1.22	1.06-1.39	1.20	1.05-1.38	1.24	1.08-1.42
Iceland	1.27	1.11-1.45	1.15	1.01-1.32	1.06	0.92-1.21	1.16	1.01-1.33
Czech Republic	1.22	1.09-1.37	1.09	0.97-1.23	1.10	0.97-1.24	0.91	0.80-1.02
Lithuania	1.22	1.07-1.40	1.06	0.92-1.22	1.04	0.91-1.20	1.22	1.06-1.41
Luxembourg	1.21	1.06-1.37	1.10	0.97-1.26	1.08	0.95-1.23	1.08	0.95-1.23
Russia	1.19	1.06-1.33	1.02	0.91-1.15	1.04	0.93-1.17	1.01	0.89-1.13
Slovenia	1.19	1.04-1.36	1.08	0.94-1.24	1.02	0.89-1.17	0.91	0.80-1.04
Belarus	1.17	1.02-1.34	1.08	0.94-1.23	1.09	0.95-1.25	1.07	0.93-1.23
Latvia	1.03	0.90-1.18	0.91	0.79-1.04	0.88	0.77-1.01	0.88	0.76-1.01
Ukraine	1.03	0.90-1.17	0.90	0.79-1.03	0.93	0.81-1.06	0.94	0.82-1.07
Estonia	1.01	0.88-1.15	0.90	0.78-1.03	0.89	0.78-1.03	0.74	0.64-0.85
Great Britain	1.00	1.00-1.00	1.00	1.00-1.00	1.00	1.00-1.00	1.00	1.00-1.00
Slovakia	0.99	0.88-1.13	0.90	0.79-1.03	0.89	0.78-1.02	0.98	0.86-1.12
Spain	0.85	0.74-0.96	0.88	0.77-1.00	0.84	0.73-0.95	0.85	0.75-0.97
Greece	0.77	0.68-0.88	0.62	0.54-0.71	0.57	0.50-0.65	0.67	0.58-0.76
Germany	0.75	0.66-0.84	0.73	0.65-0.82	0.70	0.62-0.79	0.65	0.58-0.73
Austria	0.72	0.64-0.81	0.73	0.65-0.83	0.69	0.61-0.78	0.72	0.64-0.82
Italy	0.62	0.56-0.70	0.55	0.49-0.62	0.55	0.49-0.62	0.63	0.56-0.71
Northern Ireland	0.62	0.54-0.71	0.61	0.53-0.70	0.57	0.50-0.66	0.73	0.63-0.83
Portugal	0.55	0.48-0.63	0.54	0.47-0.62	0.52	0.46-0.60	0.56	0.48-0.64
Bulgaria	0.53	0.46-0.61	0.48	0.41-0.55	0.50	0.43-0.58	0.47	0.41-0.54
Hungary	0.50	0.44-0.57	0.50	0.44-0.58	0.50	0.43-0.57	0.42	0.36-0.48
Croatia	0.48	0.42-0.54	0.46	0.40-0.53	0.44	0.38-0.50	0.54	0.47-0.62
Ireland	0.45	0.40-0.52	0.42	0.36-0.48	0.41	0.36-0.47	0.52	0.45-0.60
Poland	0.40	0.35-0.46	0.38	0.33-0.43	0.38	0.33-0.43	0.50	0.44-0.58
Romania	0.31	0.27-0.36	0.30	0.26-0.34	0.29	0.26-0.34	0.37	0.32-0.43
Turkey	0.23	0.20-0.26	0.25	0.21-0.29	0.20	0.17-0.23	0.28	0.24-0.32
Malta	0.22	0.19-0.26	0.21	0.18-0.25	0.20	0.18-0.24	0.29	0.25-0.33
Educational level								
Compulsory or inadequate			1.00	1.00-1.00	1.00	1.00-1.00	1.00	1.00-1.00
Basic vocational or interm secondary			1.44	1.38-1.50	1.21	1.16-1.26	1.18	1.13-1.23
Full secondary or higher education			1.62	1.55-1.69	1.30	1.24-1.36	1.26	1.20-1.32
Social Class								
Non manual (upper, upper-middle class)			1.12	1.08-1.16	1.15	1.11-1.19	1.13	1.09-1.17
Manual, unskilled,…			1.00	1.00-1.00	1.00	1.00-1.00	1.00	1.00-1.00
Agricultural class								
Agricultural class			0.66	0.62-0.71	0.71	0.66-0.76	0.76	0.71-0.82
Non-agricultural class			1.00	1.00-1.00	1.00	1.00-1.00	1.00	1.00-1.00
Age								
18-29					1.97	1.87-2.06	1.80	1.72-1.89
30-39					1.75	1.67-1.84	1.62	1.54-1.71
40-49					1.59	1.51-1.67	1.45	1.38-1.53
50-59					1.36	1.29-1.43	1.26	1.20-1.33
60 and more					1.00	1.00-1.00	1.00	1.00-1.00
Religious belief								
(factor scale)							0.72	0.70-0.73

Country-specific differences in euthanasia acceptance

Although a strongly associated factor, as suggested in model 4, religious belief could not entirely explain country differences. Two additional analyses were made that demonstrate country specificity.

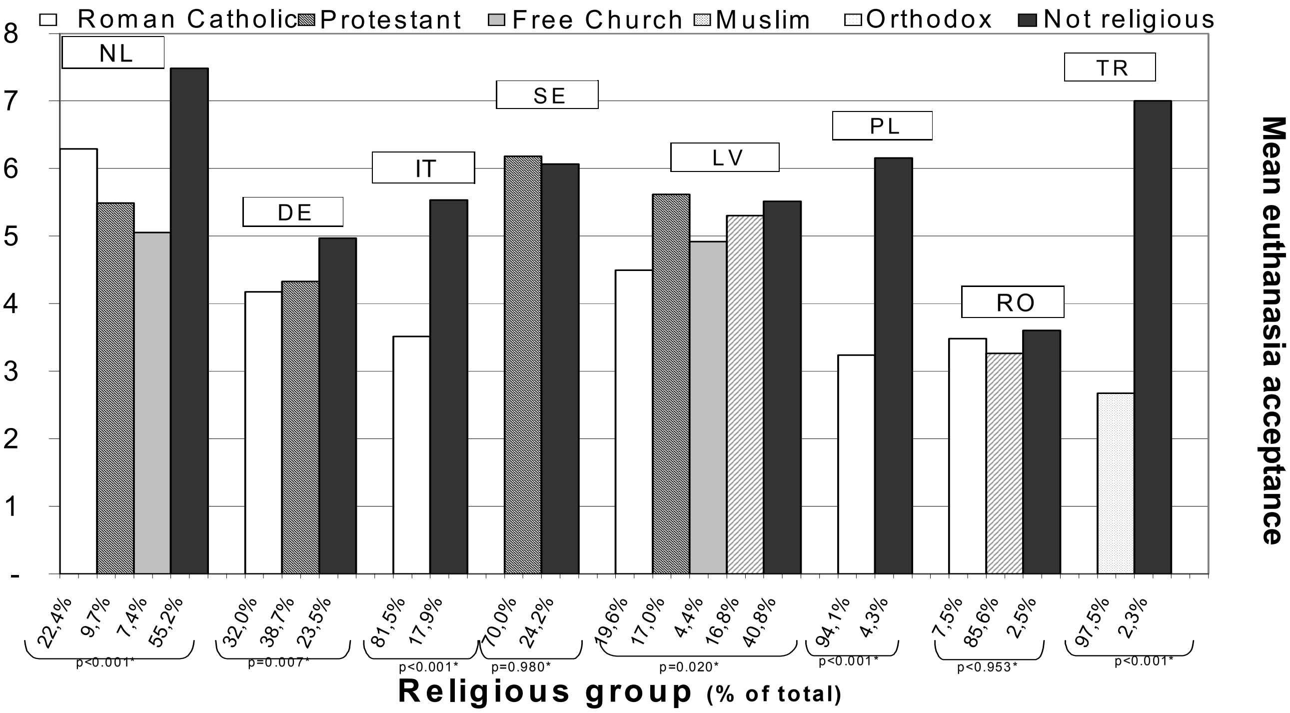
First, Figure 1 combines the factors 'religious belief' and 'permissiveness' in a co-ordinate system and demonstrates that both factors could largely predict a country's stance towards euthanasia, but that there were also exceptions. Highly-religious, less-permissive countries (bottom-right quadrant) were all less tolerant towards euthanasia than Great Britain (which was one of the most average countries on both axes together). The only exception was Lithuania. The countries with a higher acceptance of euthanasia than Great Britain were all less-religious, highly-permissive countries (top-left quadrant). We noticed a relatively low acceptance of euthanasia in relation to the generally secularised-personal liberal nature in Austria and Spain, but particularly so in Germany. Second, bivariate analyses describing the euthanasia acceptance among different religious groups per country (Figure 2), demonstrated that the influence of religious group membership on the acceptance of euthanasia differed strongly between countries. In Scandinavian countries like Sweden (but also in Denmark and Iceland) we noticed practically no difference in euthanasia acceptance between religious and non-religious persons. In the Netherlands (as well as in BE, FR, LU and GB) the acceptance of euthanasia was particularly high among non-religious persons, but was also relatively high among religious groups. In Germany and also in Romania differences were also small, but in the sense that non-religious persons also had a low acceptance. In Roman Catholic countries like Poland and Italy (as well as Austria and Spain) and in Muslim Turkey there were, on the contrary, large differences between non-accepting, typically religious persons and accepting, more often non-religious persons. In pluralistic Latvia, euthanasia acceptance varies little between most major religious groups and non-religious persons, although it is somewhat lower among Roman Catholics. Roman Catholics are generally less favourable towards euthanasia than other large Christian groups (i.e. Protestants and Orthodox), but in the Netherlands (as well as in Belgium and France) Catholics were more favourable.

Figure 1: Religious belief and permissiveness by country, related to the country's acceptance of euthanasia (compared with GB)†.



†: The country's acceptance of euthanasia compared with GB is based on Model 3 in Table 4 (i.e. controlling for age, social class, number of agricultural workers and educational level). Countries with a statistically significant higher acceptance than GB are indicated with a "+", countries with a statistically significant lower acceptance than GB are indicated with a "-"

Figure 2: Euthanasia by large religious (or non-religious) groups in 8 countries



Presented percentages are the percentages of the respective (religious) groups within the total population. They do not add up to 100%, because very small religious groups (i.e. <3% of total population) are not retained.

* p-values tested with Kruskall-Wallis, testing the differences in acceptance of euthanasia between religious and non-religious groups

DISCUSSION

Our results demonstrate that there is no common European attitude towards euthanasia. Broadly speaking, there are countries with a public opinion relatively accepting euthanasia (e.g. NL, DK, FR, SE, BE, LU, FI, IS); countries with certain reservations (e.g. GB, ES, SK, EL, UA, LV); and countries relatively rejecting euthanasia (e.g. PT, PL, IE, RO, TR, MT).

The study was performed on a large cross-national scale, using the same question in all countries and, to our knowledge, it is therefore the first study capable of making far-reaching cross-national comparisons. Previous studies regarding attitudes on euthanasia and the possible influencing factors were mostly limited to one country, and used a variation of questions, which makes it difficult to compare attitudes and beliefs of the public from different regions over the world or at different points in time [37;45;46].

This study also has some limitations. First, we did of course not dispose of information on all factors that might influence the acceptance of euthanasia (e.g. the health status of the respondent, satisfaction with the health care services). Second, attitudes are complex and therefore not easily captured by survey data [47]. It is difficult to gain a thorough understanding of public attitudes to euthanasia from a single question. Third, the question from the EVS study regarding the justification of euthanasia is not analogous to the definition used in a part of the medical literature today (i.e. administering a lethal dose of drugs with the explicit intention of ending the patient's life, at their explicit request) [48]. Especially the omission of the qualification 'at the explicit request of the patient' in the description of euthanasia used by the EVS study is a limitation, and has probably led to an underestimation of the degree of acceptance. Previous studies have demonstrated that interpretations of euthanasia can differ [26;36;45;46;49;50] and that acceptance of euthanasia can vary according to the interpretation, but also to the clinical conditions or circumstances (e.g. age of the patient, the degree of suffering, consciousness and mental alertness of the patient) [22;39;45;50;51]. However it is important to mention that, although the survey did not use a medical definition of euthanasia, the same description was used in questions asked in all countries.

Some characteristics of the question used may help to counteract its limitations. First, the Likert type answer between 1 and 10 gives a more nuanced picture of public attitudes on euthanasia than does a dichotomous yes-no answer. Second, instead of a question about the appropriateness of specific euthanasia legislation, a general question regarding the (moral) acceptability of euthanasia was used. This gives a good idea about the sensitivity of this theme in public opinion, which can be a basis for further exploration as to what degree of legislation/regulation the public is willing to discuss. As our study results clearly suggest a large differentiation between countries regarding euthanasia acceptance, this could be very different throughout Europe.

This study supports previous findings regarding religion as a major factor related to euthanasia attitudes. As people belong to a religious group, attend places of worship more often and tend to believe in God, life after death, heaven, hell, and sin they also tend to consider euthanasia as immoral. Religious belief influences the meaning given to life and death: it is connected with an absolutist moral orientation, a 'sanctity of life' ethic, that says it is wrong to kill, regardless of medical conditions or circumstances [28;31;49]. Persons who consider themselves as belonging to no religious group are the most accepting towards euthanasia. Their attitudes are possibly less directed by a religious authority but more influenced by intuitive relativistic arguments, whereby death is sometimes preferable to life [49]. Among the religious denominations, different religious traditions generally respond in different ways to the euthanasia debate and for some religious subgroups the voice of religious authority is still strong [30]. Protestants and Orthodox Christians were generally, not much less favourable towards euthanasia than non-religious persons, as frequently reported in previous research [29;30;37]. Roman Catholics were less accepting.

Religious beliefs thus still make a difference in attitudes towards euthanasia but these factors do not essentially coincide. Views are rather individual and diverse, both within and across religious groups. Among the large Christian denominations, even among Roman Catholics, there was a relatively high acceptance of euthanasia. Attitudes are moreover clearly influenced by the surrounding secular culture: to be Roman Catholic in a country with a liberal-secular environment has different consequences than to be Roman Catholic in a conservative-religious environment [29]. This is, for instance, demonstrated by the higher acceptance of euthanasia among Roman Catholics from the Netherlands, France and Belgium. Being a Roman Catholic, particularly in those countries, does not necessarily imply full commitment to the Vatican's complete rejection of euthanasia [30]. In Scandinavian countries people who considered themselves to be religious were as acceptant towards euthanasia as non-religious people. In countries such as Italy and Poland, on the other hand, there was a clear difference depending on whether respondents considered themselves Roman Catholic or not.

The question of life and death is the central theme of all religions, but the voice of religion is not equally strong in all countries. Specific historical events in some countries (e.g. the French Revolution) have sometimes altered the influence of, or even redefined, religious belief, liberalising the predominant thinking with regard to life and death. This declining influence of religious authority has made debates on controversial issues like euthanasia possible, practically independent of the religious denomination [20;29;30].

Religion is certainly not the only basis for attitudes towards euthanasia. While previous studies have explained the differences in attitudes between socio-demographic categories by stronger religious beliefs among older people, lower socio-economic groups, etc. [20;35;38], our results demonstrate apparent social, age, and educational differences, independent from the influence of religious belief. Older age is associated with a lower acceptance of euthanasia. Probably this is rather a cohort effect than an age effect [30]: rather than the ageing process leading to a reduced acceptance of euthanasia, it seems that younger generations, growing up in a more permissive society, have adopted more permissive attitudes towards euthanasia than previous generations. That the euthanasia acceptance is higher in younger cohorts could have important implications for the future of the euthanasia debate. A possible explanation for the lower acceptance of euthanasia among the less educated is that education increases the value felt for personal autonomy and individualism [36]. The lower acceptance of people from manual social classes can possibly be explained by a higher degree of mistrust, resulting from the different life experiences, or from previous structural conditions [35].

The sociodemographic differences and the influence of life stance point to the need for differentiation in planning of policy, as well as in dealing with patients by health care providers.

After controlling for socio-demographic factors and religious belief, large country differences in attitudes towards euthanasia persisted. Although we could not control for all possibly relevant factors which might explain differences between countries, we are inclined to believe that perceptions of euthanasia are sometimes country-specific, related to the countries' own tradition and history. The most striking illustrative example is Germany. Germans are relatively secular and have a relatively high tolerance in issues like divorce, abortion and sexual mores, but have a low acceptance of euthanasia in particular [19;52]. A possible explanation for this particular German attitude is the history of National Socialism [19]. The memory and the stigma of the Nazi 'euthanasia' plans may have resulted in a great reluctance among Germans today to approve of euthanasia [19;53-55]. The country differences must be interpreted with caution, as the use of the term 'euthanasia' might have lead to ambivalent and emotionally charged reactions. The countries' relative position in Europe towards the issue of euthanasia can however be an important element for a further debate. We expect that in the countries with a higher acceptance of euthanasia than in Great Britain, where a serious debate is now ongoing, public opinion is rather open to organising a legal debate.

As well as the large differences in euthanasia acceptance between different countries throughout Europe, there is sometimes also a polarisation within countries. A strong polarisation in the public attitudes regarding euthanasia was found particularly in former Soviet countries. Many respondents in those countries also answered with "I don't know" to the question about euthanasia. Possibly this is because, due to the nature of the Soviet regime, people in those countries were not supposed to think much about personal choices in life and death up until now. Perhaps serious public debates might further shape the attitudes towards euthanasia in these countries.

To summarise our findings we can say that there is no European consensus about the acceptability of euthanasia. Given the sometimes very country-specific character of attitudes towards euthanasia, each country will have its own debate, influenced by its cultural backgrounds. The outcome of these debates, even if a regulation of euthanasia is decided, will therefore not necessarily be similar to the Dutch or Belgian legal solutions towards euthanasia. Our findings with regard to cross-national differences can serve as a basis for further debate. However, further exploration of the public opinion by international and country-specific research, using more elaborate questions, about specific circumstances of euthanasia will be needed for a more thorough discussion.

Acknowledgements
The data used in this paper are from the European Values Study 1999-2000 (Halman, L.C.J.M.; Subfac. Sociale Wetenschappen; Universiteit van Tilburg; European Values Study 1999/2000, EVS '99/2000 (ZA Study 3811) (computer file); Amsterdam, Steinmetz-archief (P1460)). The authors wish to acknowledge the persons responsible for this study, and wish to thank the

Steinmetz-archief for providing the data. The authors thank Johan Vanoverloop for his statistical advice and Koen Putman for his assistance with this article.

REFERENCES

1. Emanuel EJ, Emanuel LL. The promise of a good death. Lancet 1998;351 Suppl 2:SII21-SII29.
2. DelVecchio Good MJ, Gadmer NM, Ruopp P et al. Narrative nuances on good and bad deaths: internists' tales from high-technology work places. Soc.Sci.Med. 2004;58(5):939-53.
3. McNamara B, Waddell C, Colvin M. The institutionalization of the good death. Soc.Sci.Med. 1994;39(11):1501-8.
4. Payne SA, Langley-Evans A, Hillier R. Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. Palliat.Med. 1996;10(4):307-12.
5. Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. Lancet 2003;362(9391):1239-40.
6. Bosshard G, Fischer S, Bar W. Open regulation and practice in assisted dying. Swiss.Med.Wkly. 2002;132(37-38):527-34.
7. Giroud C, Augsburger M, Horisberger B, Lucchini P, Rivier L, Mangin P. Exit association-mediated suicide: toxicologic and forensic aspects. Am.J.Forensic Med.Pathol. 1999;20(1):40-44.
8. Bamgbose O. Euthanasia: another face of murder. Int.J.Offender.Ther.Comp Criminol. 2004;48(1):111-21.
9. Ozkara E, Civaner M, Oglak S, Mayda AS. Euthanasia education for health professionals in Turkey: students change their opinions. Nurs.Ethics 2004;11(3):290-297.
10. van der Maas PJ, van der Wal G, Haverkate I, e.a. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in The Netherlands, 1990-1995. The New England Journal of Medicine 1996;335(22):1699-705.
11. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med.J.Aust. 1997;166(4):191-96.
12. Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States: adherence to proposed safeguards and effects on physicians. JAMA 1998;280(6):507-13.
13. Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000;356(9244):1806-11.
14. van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362(9381):345-50.
15. van der Maas PJ, Pijnenborg L, van Delden JJ. Changes in Dutch opinions on active euthanasia, 1966 through 1991. JAMA 1995;273(18):1411-14.
16. Benson JM. The polls-trends - End-of-life issues. Public Opinion Quarterly 1999;63(2):263-77.
17. Blendon RJ, Szalay US, Knox RA. Should physicians aid their patients in dying? The public perspective. JAMA 1992;267(19):2658-62.
18. Helou A, Wende A, Hecke T, Rohrmann S, Buser K, Dierks ML. [Public opinion on active euthanasia. The results of a pilot project]. Dtsch.Med.Wochenschr. 2000;125(11):308-15.
19. Oehmichen M, Meissner C. Active euthanasia and physician-assisted suicide: the German discussion. Leg.Med.(Tokyo) 2003;5 Suppl 1:S20-S28.

20. O'Neill C, Feenan D, Hughes C, McAlister DA. Physician and family assisted suicide: results from a study of public attitudes in Britain. Soc.Sci.Med. 2003;57(4):721-31.
21. Hurst SA, Mauron A. Assisted suicide and euthanasia in Switzerland: allowing a role for non-physicians. BMJ 2003;326(7383):271-73.
22. Teisseyre N, Mullet E, Sorum PC. Under what conditions is euthanasia acceptable to lay people and health professionals? Soc.Sci.Med. 2005;60(2):357-68.
23. Ryynanen OP, Myllykangas M, Viren M, Heino H. Attitudes towards euthanasia among physicians, nurses and the general public in Finland. Public Health 2002;116(6):322-31.
24. Domino G. Attitudes toward physician assisted suicide: Poland and the United States. Omega.(Westport.) 2002;46(2):105-15.
25. McGlade KJ, Slaney L, Bunting BP, Gallagher AG. Voluntary euthanasia in Northern Ireland: general practitioners' beliefs, experiences, and actions. Br.J.Gen.Pract. 2000;50(459):794-97.
26. Ben Diane MK, Peretti-Watel P, Lapiana JM et al. [Opinion of general and specialized physicians toward euthanasia. Results from the French survey on attitudes and practices against palliative care, 2002]. Ann.Med.Interne (Paris) 2003;154(7):441-47.
27. Grassi L, Magnani K, Ercolani M. Attitudes toward euthanasia and physician-assisted suicide among Italian primary care physicians. J.Pain Symptom.Manage. 1999;17(3):188-96.
28. Genuis SJ, Genuis SK, Chang WC. Public attitudes toward the right to die. CMAJ. 1994;150(5):701-8.
29. De Moor R. Religion and Moral Values: The Case of Euthanasia. In: De Moor R, editor. Values in Western Societies. Tilburg: Tilburg University Press, 1995:31-50.
30. Hamil-Luker J, Smith C. Religious authority and public opinion on the right to die. Sociology of Religion 1998;59(4):373-91.
31. Finlay B. Right to life vs. the right to die: some correlates of euthanasia attitudes. Sociology and Social Research 1985;69(4):548-60.
32. Bachman JG, Alcser KH, Doukas DJ, Lichtenstein RL, Corning AD, Brody H. Attitudes of Michigan physicians and the public toward legalizing physician-assisted suicide and voluntary euthanasia. N.Engl.J.Med. 1996;334(5):303-9.
33. DeCesare MA. Public attitudes toward euthanasia and suicide for terminally ill persons: 1977 and 1996. Soc.Biol. 2000;47(3-4):264-76.
34. Caralis PV, Davis B, Wright K, Marcial E. The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. J.Clin.Ethics 1993;4(2):155-65.
35. MacDonald WL. The difference between blacks' and whites' attitudes toward voluntary euthanasia. J.Sci.Study Relig. 1998;37(3):411-26.
36. Caddell DP, Newton RR. Euthanasia: American attitudes toward the physician's role. Soc.Sci.Med. 1995;40(12):1671-81.
37. Suarez-Almazor ME, Belzile M, Bruera E. Euthanasia and physician-assisted suicide: a comparative survey of physicians, terminally ill cancer patients, and the general population. J.Clin.Oncol. 1997;15(2):418-27.
38. Hare J, Skinner D, Riley D. Why older age predicts lower acceptance of physician-assisted suicide. WMJ. 2000;99(7):20-7, 46.

39. Achille MA, Ogloff JR. When is a request for assisted suicide legitimate? Factors influencing public attitudes toward euthanasia. Can.J.Behav.Sci. 1997;29(1):19-27.
40. Suarez-Almazor ME, Newman C, Hanson J, Bruera E. Attitudes of terminally ill cancer patients about euthanasia and assisted suicide: predominance of psychosocial determinants and beliefs over symptom distress and subsequent survival. J.Clin.Oncol. 2002;20(8):2134-41.
41. Halman, L. The European Values Study: a Third Wave. Source book of the 1999/2000 European Values Study Surveys. 2001. Tilburg, EVS, WORC, Tilburg University.
Ref Type: Report
42. Halman L, Riis O. Contemporary European Discourses on Religion and Morality. In: Halman L, Riis O, editors. Religion in Secularizing Society. The European's religion at the end of the 20th century. Tilburg: Tilburg University Press, 1999:2-18.
43. Agadjanian A. Revising Pandora's Gifts: Religious and National Identity in the Post-Soviet Societal Fabric. Europe-Asia Studies 2001;53(3):473-88.
44. Halman L, Petterson T. Differential Patterns of Secularization in Europe: Exploring the impact of Religion on Social Values. In: Halman L, Riis O, editors. Religion in Secularizing Society. The European's religion at the end of the 20th century. Tilburg: Tilburg University Press, 1999:41-65.
45. Holloway HD, Hayslip B, Murdock ME et al. Measuring attitudes toward euthanasia. Omega.(Westport.) 1994;30(1):53-65.
46. Nilstun T, Melltorp G, Hermeren G. Surveys on attitudes to active euthanasia and the difficulty of drawing normative conclusions. Scand.J.Public Health 2000;28(2):111-16.
47. Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. Soc.Sci.Med. 1999;48(12):1779-89.
48. Materstvedt LJ. Palliative care on the 'slippery slope' towards euthanasia? Palliat.Med. 2003;17(5):387-92.
49. Snelling PC. Consequences count: against absolutism at the end of life. J.Adv.Nurs. 2004;46(4):350-357.
50. Ho R. Assessing attitudes toward euthanasia: an analysis of the subcategorical approach to right to die issues. Pers.Individ.Dif. 1998;25(4):719-34.
51. Domino G. Community attitudes toward physician assisted suicide. Omega.(Westport.) 2002;46(3):199-214.
52. Muller-Busch HC, Oduncu FS, Woskanjan S, Klaschik E. Attitudes on euthanasia, physician-assisted suicide and terminal sedation--a survey of the members of the German Association for Palliative Medicine. Med.Health Care Philos. 2004;7(3):333-39.
53. Leichtentritt RD, Rettig KD, Miles SH. Holocaust survivors' perspectives on the euthanasia debate. Soc.Sci.Med. 1999;48(2):185-96.
54. Kottow MH. Euthanasia after the holocaust--is it possible?: a report from the Federal Republic of Germany. Bioethics. 1988;2(1):58-59.
55. Sahm SW. Palliative care versus euthanasia. The German position: the German General Medical Council's principles for medical care of the terminally ill. J.Med.Philos. 2000;25(2):195-219.

4

The influence of physicians' life-stance on attitudes towards end-of-life decisions and actual end-of-life decision-making in six countries.

Joachim Cohen, Johannes van Delden, Freddy Mortier, Rurik Löfmark, Michael Norup, Colleen Cartwright, Karin Faisst, Cristina Canova, Bregje Onwuteaka-Philipsen, Johan Bilsen, on behalf of the Eureld consortium

This paper has been accepted for publication by the Journal of Medical Ethics (in press)

ABSTRACT

Introduction

This study in Belgium, Denmark, The Netherlands, Sweden, Switzerland, and Australia examined how physicians' life-stance influences their attitudes towards end-of-life decisions and their actual end-of-life decision-making.

Methods

Practising physicians from various specialties involved in the care of dying patients received structured questionnaires concerning end-of-life care, which included questions about the physicians' life-stance. Response rates ranged from 53% in Australia to 68% in Denmark. General attitudes, intended behaviour for two hypothetical patients, and actual behaviour were compared between all large life-stance groups in each country.

Results

Only small differences by the physicians' life-stances were found in all countries in the general attitudes, the intended, and the actual behaviour with regard to various end-of-life decisions. However, with regard to the administration of drugs explicitly intended to hasten the patient's death (PAD), physicians with specific religious affiliations had significantly less accepting attitudes and lower willingness to perform it than non-religious physicians. They had also actually performed PAD less often. However, in most countries both Catholics (up to 15.7% in The Netherlands) and Protestants (up to 20.4% in the Netherlands) reported ever having made such a decision.

Discussion

Our results suggest that religious teachings to some extent influence end-of-life decision-making, but are certainly not blankly accepted by physicians, especially not when dealing with real patients and circumstances. Physicians seem to embrace religious belief in non-imperative ways, allowing for adaptation to particular situations.

INTRODUCTION

Physicians' attitudes towards life and death appear to orient their end-of-life decision-making.[1] It is important, therefore, both to assess their attitudes[2] and to understand exactly how these are related to end-of-life decision-making. Research has generally corroborated that (stronger) theistic religious beliefs are associated with a lower acceptance of various end-of-life decisions, particularly euthanasia.[3-9] Often this is explained by the traditional viewpoints of Judaism, Catholicism, Protestantism and Islam (or their religious authorities) regarding end-of-life issues, extensively described in the bioethical literature.[10-18] However, since these traditional religious doctrines are commonly balanced by considerations of due care and by general sentiments of humanity and compassion, that come into play in actually dealing with patients, there is some dispute over the decisiveness of statements of doctrine for physicians' actual decision-making.[19] A specific research question of this study is therefore: are viewpoints from different life-stances on different kinds of end-of-life decisions, as illustrated in the recent Lancet series,[11;16;18] also translated into attitudes and actual practices of the physicians who adhere to these life-stances? We will examine the impact of life-stance on physicians':

1) general attitudes towards different end-of-life decisions: non-treatment decisions; alleviation of pain and symptoms with a possible life-shortening effect; terminal sedation; and administration of lethal drugs (i.e. physician-assisted dying);
2) willingness to perform these ELDs, given certain circumstances;
3) actual decision-making.

We will also examine whether there are important differences depending on the country of residence, also making it possible to evaluate the influence of a surrounding (secular) culture.

METHOD

Design, sample and questionnaire

In six European countries, namely Belgium (Flanders), Denmark, Italy (Emilia-Romagna, Trento, Tuscany and Veneto), The Netherlands, Sweden, and Switzerland, and in Australia, a written structured questionnaire was sent to practising physicians from 10 specialties frequently involved in care of the dying: anaesthesiology, general practice, geriatrics, gynaecology, internal medicine, neurology, nursing home medicine (in The Netherlands), oncology, pulmonology and surgery.[4;20] For each country, a random sample of 300 physicians was drawn in each specialty, or all physicians if less then 300 physicians were active in a specialty. Questions were asked about general attitudes, intended behaviour, and actual practices concerning end-of-life care and background characteristics of the physicians. Questionnaires were sent in the second half of 2002 (after the euthanasia laws had come into effect in The Netherlands and Belgium) and were processed anonymously. More details can be found elsewhere.[4;20]

In the Italian version of the questionnaire the question on religious affiliation was omitted in order not to decrease the response rate, hence Italy is not included in the analyses for this paper.

Life-stance

The questionnaire asked: “What do you consider to be your religion or life-philosophy?”. Options were: ‘Roman-Catholic’, ‘Protestant’, ‘Other religion’, ‘Non-religious’, or ‘No specific philosophy’. If they answered ‘Other religion’ or ‘Non-religious’, they were asked to specify their religion or life-philosophy. All responses were classified into 11 categories of life-stance groups (see table 1). Non-religious physicians with a specific life-philosophy included those who attested to a (non-religious) value system (1) known to be shared groupwise and (2) known to offer some kind of guidance for life and death issues (e.g. “Humanism”).

Statistical analyses

First, principal component analyses was performed to uncover the underlying structure of a set of 14 statements [4] scored on a five point Likert scale from totally agree to totally disagree. It identified three factors of general attitudes towards end-of-life decisions. Items with a component loading higher than 0.5 were retained in the factors, and standardized scores were calculated by attributing a weight equal to the factor loading to each salient variable (see appendix). Physicians with higher standardized scores on a factor thus represent physician with higher agreement to the statements that define that factor. The mean standardised factor scores (and 95%CI) of the three factors were compared between the life-stance groups.

Second, to describe and compare the willingness to perform ELDs given certain (real life) circumstances, two hypothetical cases of a 71-year old cancer patient with extensive brain and bone metastases,[20] were considered.

For both cases, described in Box 1, percentages were compared (pearson chi²-tests) of physicians probably or certainly deciding (score one or two on a five-point Likert scale), and both at the request of the patient and without any request, to:

- intensify the alleviation of pain/symptoms by using drugs such as opioids, taking into account the probability or certainty that this would hasten the end of the patient's life (APS);
- administer drugs, such as benzodiazepines or barbiturates, to keep the patient in deep sedation until death, without giving hydration or nutrition (terminal sedation); and
- administer drugs with the explicit intention of hastening the patient's end of life (PAD).

A possible differential influence of certain circumstances on the willingness of the different life-stance groups to perform the respective ELDs was also checked by comparing the differences in scores for case 1 and case 2; and for presence or absence of an explicit patient request (tested with Kruskal-Wallis).

Box 1: Description of the two hypothetical patients

Both patients are 71-year old cancer patients with extensive brain and bone metastases. The patients underwent burdensome chemotherapy twice, and undergoing chemotherapy once more would give a limited chance of long-standing remission (<10%):

Case 1: The patient is **drowsy or subcomatose** and **communication is not possible**. You estimate the patient's life expectancy (without chemotherapy) to be no more than 2 weeks. **Pain can be adequately controlled**, but the patient is extremely tired, short of breath and bedridden.

Case 2: The patient is **clearheaded** and **can still communicate**. You estimate the patient's life expectancy (without chemotherapy) to be no more than 2 weeks. The patient had **pain that is difficult to control** despite the use of high doses of analgesics.

Third, the actual decision-making among different life-stance groups was compared by examining the percentages ever having actually performed APS, terminal sedation, and PAD. Pearson Chi² and Fisher exact were used to determine statistical significance of differences.

In all comparisons we retained only the larger life-stance groups, in view of the reliability of the results.

RESULTS

Response rates to the study ranged between 53% in Australia up to 68% in Denmark (table 1).

Table 1: Life-stance and importance of life-stance in end-of-life decision-making per country

	BE	DK	NL	SE	CH	AU
Response rate	**58%**	**68%**	**61%**	**60%**	**64%**	**53%**
Number of respondents	**1750**	**1217**	**1275**	**1514**	**1397**	**1478**
Life-stance						
Christian						
Roman Catholic	64.4	1.1	28.4	4.5	30.9	19.1
Protestant	0.8	56.9	22.1	50.6	34.7	29.2
Orthodox	0.0	0.1	0.0	1.4	0.5	1.3
Non-religious						
Specific philosophy*	8.8	3.1	3.3	3.8	2.1	2.6
No specific philosophy	23.9	37.6	43.9	36.0	27.0	36.5
Other religious						
Jewish	0.1	0.1	0.2	0.7	1.1	3.4
Muslim	0.1	0.1	0.1	1.6	0.5	0.3
Buddhist	0.2	0.1	0.2	0.1	0.5	1.9
Hindu	0.1	0.1	0.1	0.1	0.1	1.7
Other denomination	0.5	0.3	0.7	0.7	1.1	1.1
Religious without denomination	1.3	0.6	0.9	0.4	1.6	2.8
Self-reported importance of life-stance in end-of-life decision making						
% important or very important	*45.0*	*32.1*	*38.7*	*47.8*	*62.0*	*54.2*

*: This were usually humanists/existentialists: 94% in Belgium,79% in Denmark, 95% in the Netherlands, 91% in Sweden, 71% in Switzerland, 66% in Australia. The minority of other specific non-religious philosophies were mostly physicians indicating to be atheists but with Christian ethics (1.3%-18.4%), a small number of Taoists (0%-4%),…

Life-stances

Four large life-stance denominations appeared among physicians in all six countries (table 1): Roman Catholics (1.1% in Denmark to 64.4% in Belgium), Protestants (0.8% in Belgium to 56.9% in Denmark), non-religious people with a specific life-philosophy such as Humanism (2.1% in Switzerland to 8.8% in Belgium) and non-religious people without a specific life-philosophy (23.9% in Belgium to 43.9% in The Netherlands). From 32% of all physicians (both with theistic and with non-theistic life-stances) in Denmark to 62% in Switzerland indicated that their life-stance is important in their professional attitude towards end-of-life decision making.

Life-stance and general attitudes towards end-of-life decisions

Three dimensions of attitudes towards end-of-life decisions were distinguished via principal component analysis (appendix), for which significant differences were found between life-stance groups (table 2).

Table 2: physicians' attitudes towards end-of-life decisions by their life-stance

	BE	DK	NL	SE	CH	AU
Attitudes towards NTD & APS						
Roman Catholic	**-.40** (-.46;-.33)	*	**-.05** (-.14;.04)	**-.66** (-1.01;-.31)	**-.04** (-.14;.05)	**.08** (-.02;.18)
Protestant	*	**.32** (.26;.39)	**-.08** (-.18;.03)	**-.20** (-.28;-.12)	**.14** (.06;.22)	**.09** (.01;.18)
Non-religious (specific philosophy)	**.15** (.00;.30)	**.49** (.24;.75)	**.26** (.01;.50)	**-.15** (-.41;.10)	**.36** (.03;.69)	**.29** (-.07;.65)
Non-religious (no specific philosophy)	**-.03** (-.13;.07)	**.41** (.33;.49)	**.06** (-.01;.13)	**-.11** (-.20;-.02)	**.21** (.12;.30)	**.25** (.18;.32)
(p-value)	*(<.001)*	*(.102)*	*(.021)*	*(.002)*	*(<.001)*	*(.011)*
Attitudes towards use of lethal drugs						
Roman Catholic	**.21** (.16;.27)	*	**.20** (.12;.28)	**-.68** (-.95;-.40)	**-.17** (-.26;-.07)	**-.68** (-.80;-.56)
Protestant	*	**.01** (-.06;.08)	**.13** (.04;.23)	**-.75** (-.82;-.68)	**.03** (-.06;.11)	**-.20** (-.29;-.10)
Non-religious (specific philosophy)	**.77** (.65;.89)	**.44** (.15;.74)	**.60** (.37;.84)	**-.47** (-.77;-.17)	**.14** (-.27;.55)	**.02** (-.29;.32)
Non-religious (no specific philosophy)	**.67** (.60;.74)	**.18** (.09;.27)	**.35** (.29;.41)	**-.47** (-.56;-.39)	**.39** (.29;.49)	**.09** (.01;.17)
(p-value)	*(<.001)*	*(.001)*	*(<.001)*	*(<.001)*	*(<.001)*	*(<.001)*
Life preserving attitudes						
Roman Catholic	**-.08** (-.13;-.03)	*	**-.39** (-.47;-.32)	**.85** (.58;1.12)	**.04** (-.05;.12)	**.50** (.38;.61)
Protestant	*	**.39** (.31;.46)	**-.29** (-.38;-.19)	**.89** (.82;.96)	**-.23** (-.31;-.16)	**.07** (-.02;.16)
Non-religious (specific philosophy)	**-.77** (-.90;-.64)	**-.09** (-.43;.25)	**-.86** (-1.06;-.66)	**.67** (.36;.97)	**-.46** (-.80;-.11)	**-.29** (-.59;.02)
Non-religious (no specific philosophy)	**-.59** (-.66;-.52)	**.09** (.00;.18)	**-.65** (-.70;-.60)	**.52** (.44;.61)	**-.51** (-.59;-.42)	**-.34** (-.42;-.27)
(p-value)	*(<.001)*	*(<.001)*	*(<.001)*	*(<.001)*	*(<.001)*	*(<.001)*

mean standardized factor scores and 95%CI; higher scores signify respectively more acceptance of NTD & APS, more tolerance towards use of lethal drugs, more life preserving attitudes. The scores can be compared within and across countries.
* : Only life-stance groups with more than 2% of respondents in national sample were retained in the analyses

Apart from Denmark, the religious categories were significantly less accepting of NTD and APS than physicians with non-religious life-stances (especially in Belgium). In Sweden and in Switzerland Roman Catholic physicians were less accepting than Protestant physicians.

Differences between life-stances were much more pronounced for attitudes towards the use of lethal drugs (PAD). In all countries, and most notably in Belgium, non-religious physicians were more accepting than religious physicians. In Switzerland and in Australia Protestants were also more accepting than Catholics. Among non-religious physicians,

those with a specific life-philosophy tended to be more accepting than those without a specific life-philosophy in Belgium (p=0.165) and The Netherlands (p=0.032).
Similar but inversed patterns were found for life-preserving attitudes, which were particularly high for Swedish physicians.

Hypothetical decision-making by life-stance in different circumstances
For willingness to perform APS, no or barely significant differences were found between religious and non-religious physicians in most countries (Table 3). A significantly lower willingness was found among religious physicians in Switzerland for case 1 (with or without a request) and in Australia for case 1 (without a request).

Although differences were small, in Australia and Switzerland religious physicians tended to be less inclined than non-religious ones to perform terminal sedation when the patient requested it. In these countries Roman Catholics generally tended to be least inclined. In Sweden, however, Catholics were more inclined to perform terminal sedation than Protestant and non-religious physicians. In the absence of any request, no differences were found between the life-stance groups in their willingness to perform sedation, except in Sweden for case 1, where Catholic physicians were more inclined than physicians with any other life-stance to provide it, and in Belgium for case 2 where Catholics were more inclined to provide it than non-religious physicians without a specific life-philosophy (p=0.023).

Table 3: Life-stance and hypothetical decision-making in different circumstances

	BE		DK		NL		SE		CH		AU	
	Case 1	Case 2	Case 1	Case 2	Case 1	Case 2	Case 1	Case 2	Case 1	Case 2	Case 1	Case 2
APS on patient's request												
Roman Catholic	95	98	*	*	93	97	78	88	**82**	89	94	96
Protestant	*	*	87	98	93	99	88	93	**82**	89	95	98
Non-religious (specific philosophy)	98	99	95	100	95	100	84	98	**89**	96	97	97
Non-religious (no specific philosophy)	97	98	87	100	93	98	88	95	**89**	94	97	98
p-value	*.134*	*.670*	*.313*	*.055*	*.916*	*.218*	*.136*	*.058*	***.017***	*.063*	*.153*	*.130*
APS on own initiative												
Roman Catholic	83	79	*	*	63	45	68	71	**74**	69	**86**	71
Protestant	*	*	82	78	70	49	80	76	**69**	64	**80**	65
Non-religious (specific philosophy)	83	83	87	81	67	45	84	78	**74**	70	**92**	79
Non-religious (no specific philosophy)	81	76	78	77	67	47	78	74	**79**	72	**87**	65
p-value	*.692*	*.188*	*.215*	*.733*	*.342*	*.772*	*.092*	*.587*	***.019***	*.094*	***.013***	*.121*
Terminal sedation on patient's request												
Roman Catholic	81	78	*	*	74	**62**	**68**	**69**	**66**	74	**59**	**49**
Protestant	*	*	52	47	71	**70**	**50**	**50**	**70**	73	**67**	**55**
Non-religious (specific philosophy)	87	85	49	54	75	**80**	**62**	**61**	**78**	78	**70**	**54**
Non-religious (no specific philosophy)	84	80	56	52	71	**66**	**56**	**55**	**76**	76	**72**	**66**
p-value	*.121*	*.122*	*.297*	*.159*	*.823*	***.048***	***.010***	***.013***	***.037***	*.651*	***.002***	***<.001***
Terminal sedation on own initiative†												
Roman Catholic	60	**38**	*	*	38	10	**49**	33	54	33	46	22
Protestant	*	*	41	21	37	8	**34**	21	48	31	51	28
Non-religious (specific philosophy)	63	**43**	50	31	49	16	**36**	14	43	25	50	29
Non-religious (no specific philosophy)	57	**32**	42	26	36	11	**40**	21	56	35	53	26
p-value	*.295*	***.023***	*.566*	*.097*	*.485*	*.470*	***.045***	*.086*	*.072*	*.533*	*.324*	*.444*
PAD on patient's request												
Roman Catholic	**46**	**39**	*	*	**45**	47	6	**8**	**18**	**14**	**12**	**11**
Protestant	*	*	**20**	**19**	**42**	49	5	**3**	**24**	**23**	**22**	**18**
Non-religious (specific philosophy)	**81**	**79**	**38**	**35**	**65**	64	7	**4**	**29**	**43**	**30**	**27**
Non-religious (no specific philosophy)	**65**	**65**	**25**	**26**	**50**	61	9	**7**	**40**	**33**	**29**	**29**
p-value	***<.001***	***<.001***	***.012***	***.004***	***.019***	*<.001*	*.111*	***.011***	***<.001***	***<.001***	***<.001***	***<.001***
PAD on own initiative												
Roman Catholic	**22**	**9**	*	*	13	5	5	3	**10**	7	**8**	**4**
Protestant	*	*	**17**	**9**	13	3	5	2	**13**	9	**17**	**10**
Non-religious (specific philosophy)	**41**	**26**	**35**	**22**	15	5	4	2	**7**	4	**24**	**14**
Non-religious (no specific philosophy)	**33**	**15**	**21**	**14**	13	4	6	2	**18**	11	**19**	**10**
p-value	***<.001***	***<.001***	***.014***	***.002***	*.966*	*.622*	*.872*	*.819*	***.008***	*.285*	***<.001***	***.019***

Figures are the percentages **probably or certainly agreeing** to perform a given ELD; and p-values for Pearson Chi^2 Test

Case 1: the patient is drowsy or subcomatose and communication is not possible. You estimate the patient's life expectancy (without chemotherapy) to be no more than 2 weeks. Pain can be adequately controlled, but the patient is extremely tired, short of breath and bedridden.

Case 2: the patient is clearheaded and can still communicate. You estimate the patient's life expectancy (without chemotherapy) to be no more than 2 weeks. The patient had pain that is difficult to control despite the use of high doses of analgesics.

* : Only life-stance groups with more than 2% of respondents in national sample were retained in the analyses

†: For Case 1 (communication not possible) 'on patient request' was defined as a request stated in an advance directive

In all countries, religious physicians were clearly less inclined than non-religious physicians to perform PAD on the patient's request (except in Sweden for case 1 and for Swedish Catholics in case 2). Among non-religious physicians in Belgium, Denmark (case 1), and The Netherlands (case 1), those with a specific life-philosophy were more inclined to do so than those without such a life-stance. A differentiation was also found among religious physicians: Roman Catholics were less inclined than Protestants to perform PAD on the patient's request in both cases in Switzerland and in Australia. When no request was present the willingness to perform PAD decreased considerably (most strongly in The Netherlands). It was lowest among Swedish Protestant physicians in case 2 (1.7%) and highest among Belgian non-religious physicians with a specific life-philosophy in case 1 (41.4%). Differences between life-stances in The Netherlands, Sweden and Switzerland were no longer significant (case 2).

A differential influence by circumstances was found (not presented in table). A patient request influenced religious physicians less than non-religious physicians to perform PAD. The effect was comparable for terminal sedation (Belgium and Sweden) and for APS (Australia and Belgium). In Switzerland and Australia the patient's request also tended to be more important for Protestants than for Catholics. There was only a marginal difference in the influence of clinical circumstances (case 2 vs. case 1) on the willingness to perform any ELD.

Life-stance and actual decision-making

Differences between life-stances in actual decision-making of APS and terminal sedation were small (table 4). APS had been performed more frequently by non-religious than by religious physicians and more by Protestants than by Catholics in Sweden and in Switzerland. Terminal sedation had been performed significantly more often by non-religious physicians with a specific life-philosophy in Sweden and Belgium; however, it was a practice also relatively frequent among religious physicians, and particularly among Catholics (23.9% in Switzerland to 40.4% in The Netherlands).

For PAD differences were more marked. Non-religious physicians and (in BE, DK, NL, CH) particularly those with a specific philosophy such as Humanism had more frequently performed a PAD. In Sweden the proportion ever having done so was very low, with no Roman Catholic or non-religious physician without a specific life-philosophy ever having performed a PAD and only 2.5% of the non-religious physicians with a specific life-philosophy having done so. In comparison, in The Netherlands 15.7% of Catholic and 20.4% of Protestant physicians had ever performed a PAD.

Table 4: physicians' life-stance and actual end-of-life decision-making

	BE	DK	NL	SE	CH	AU
Ever performed APS?						
Roman Catholic	84.0	*	91.6	55.6	64.8	86.2
Protestant	*	94.6	90.5	66.0	70.7	85.4
Non-religious (specific philosophy)	85.0	97.3	97.5	78.4	85.2	92.1
Non-religious (no specific philosophy)	81.1	96.1	92.8	70.1	73.6	89.4
p-value	*.550*	*.580*	*.383*	*.026*	*.016*	*.222*
Ever performed terminal sedation?						
Roman Catholic	30.7	*	40.4	30.8	23.9	31.8
Protestant	*	29.4	36.2	22.2	27.4	30.5
Non-religious (specific philosophy)	35.5	24.3	45.0	37.0	39.3	24.3
Non-religious (no specific philosophy)	27.2	32.0	44.8	27.6	28.4	35.1
p-value	*.020*	*.658*	*.127*	*.017*	*.216*	*.313*
Ever performed PAD on patient's request[‡]?						
Roman Catholic	6.1	*	15.7	0.0	3.4	2.9
Protestant	*	4.9	20.4	0.4	5.1	2.4
Non-religious (specific philosophy)	14.5	16.2	34.1	0.0	14.8	5.3
Non-religious (no specific philosophy)	11.1	6.4	22.9	2.5	7.2	6.3
p-value	*<.001*	*.036*	*.009*	*.009*[†]	*.021*	*.018*

Figures are the percentages ever performed the ELD mentioned; and p-values for Pearson Chi² or †: Fisher Exact.
* : Only life-stance groups with more than 2% of respondents in national sample were retained in the analyses
†: Tested with Fisher Exact
‡: this includes prescribing or supplying drugs to allow the patient to end his or her life (physician-assisted suicide) and administering the drugs

DISCUSSION

Our findings demonstrate that physician life-stance may result in different end-of-life decision-making, as suggested by Wenger and Carmel.[3] Whereas moderate differences were found between life-stances in attitudes towards, and actual decision-making of non-treatment decisions, as well as of intensification of alleviation of pain/symptoms with a possible life-shortening effect, or terminal sedation, these differences were very strong for the use of drugs with the explicit intention of hastening the patient's end-of-life (i.e. physician-assisted dying). While life-stance seems indeed to have an influence on attitudes and actual behaviour, there seems to be an even larger influence by country of residence, possibly indicating that the (country specific) surrounding culture is a more relevant determinant of behaviour than (theoretical) differences in the teachings of various life-stances.

Our study had a large-scale, cross-national design to allow investigation of the relationship between life-stance and end-of-life decisions, and also to take account of variation in religious cultural backgrounds (e.g. history and patterns of secularisation). A major strength is that the study describes attitudes, as well as intended and actual behaviour. The study had certain limitations. First, the life-stance variable was solely based on self-declared denomination. The question also used a general category of 'Protestant', which did not allow distinguishing patent differences with respect to end-of-life decision-making between liberal, moderate and conservative Protestant Churches.[21] Second, in order not to decrease the response rate, the life-stance question was omitted in Italy. Therefore we could not include this country with a Roman Catholic cultural background.

Differences identified between physicians with different life-stances in attitudes, hypothetical behaviour, and actual decision-making can be discussed in the framework of viewpoints and teachings of different life-stances on respectively non-treatment decisions, possibly life-shortening pain and symptom alleviation, terminal sedation, and physician-assisted dying.

The finding of generally small differences between Christian (Protestant and Roman Catholic) life-stances and non-religious life-stances in the acceptance as well as the actual practice of non-treatment decisions and possibly life-shortening intensification of the alleviation of pain/ symptoms can be seen in accordance with these religions' acceptance of the human condition[16] and inevitability of death,[10;13;16;22-24] considerations of compassion, the doctrine of double effect,[13] or rather the psychological difference between "doing" and "allowing". The fact that the use of opioids rarely involves a shortening of life [25] may be an additional explanation for both religious and non-religious physicians' relatively positive attitude and frequent practice.

The minor differences between religious and non-religious physicians in the approval of terminal sedation might be explained in a similar way. However, sedation has a particular position in Christian doctrine, as the use of drugs is regarded as wrong (particularly in Catholicism[13;24]) when it deprives the dying person of consciousness, thus taking away the final opportunity for repentance and for meeting Christ in full consciousness.[26] Yet our findings demonstrated that, in the absence of any request, Catholics, Protestants and non-religious physicians were almost equally willing to perform sedation. In Sweden, Catholics even tended to be more willing to perform it. Furthermore, relatively small differences were found in practice. In some countries (e.g. in Belgium) it was relatively common among Catholics. Terminal sedation thus seems to be morally acceptable to Catholics (and to Protestants), whereas the 'doctrinal teachings' do not accept this unconditionally.[17;27]

Official viewpoints on physician-assisted dying (including euthanasia and physician-assisted suicide) are very clear. Not only in traditional doctrines, but also among contemporary official Christian viewpoints it is considered morally wrong.[28] This is reflected in our results, showing a considerably lower acceptance of, and willingness to perform physician-assisted dying, as well as a lower frequency of actually performing it among religious physicians. Rejection of divine authority explains both why self-determination is considered as a prime right and why euthanasia is more willingly accepted by non-religious physicians, in particular by those with specific life-philosophies like Humanism.[13] Secular culture has put relatively high value on self-determination in life- (and death-)choices. Moderate and liberal Protestantism's appraisal of individual conscience and responsibility (in life-choices) possibly explains their tendency to accept euthanasia more than Catholics. In Catholicism (and in conservative Protestantism) the individual is neither the author of his own life nor the arbiter of his own death, but a steward of God's sacred gift of life[10;24] Therefore, the Roman-Catholic central authority uniformly declares euthanasia as immoral and equal to killing (e.g. in the official declaration on euthanasia).[29] Our results demonstrated that Catholics were indeed generally much less inclined to accept (or to perform) physician-assisted dying (including euthanasia and physician-assisted suicide) than non-Catholic physicians.

However, notwithstanding the Roman Catholic Church's blank rejection of euthanasia, relatively high percentages of Catholics seemed to be open to the practice of euthanasia: in the Netherlands up to 47.3% of Roman Catholics said that they would consider performing euthanasia (i.e. physician-assisted dying on the patient's request) on a hypothetical patient, and a non-negligible percentage of Roman Catholics admitted to ever having performed physician-assisted dying (2.9% in Australia, 3.4% in Switzerland, 6.1% in Belgium, and 15.7% in The Netherlands). Moreover, physicians with a life-stance seemingly connected with an absolutist moral orientation[16] are sensitive to the peculiarity of circumstances. Our data demonstrate that a considerably higher proportion of religious physicians are willing to administer lethal drugs at the patients' request than in the absence of any request. Religious physicians are thus to some extent willing to comply with patients' explicit requests.

While relatively strong differences were found depending on the physician's life-stance, much stronger differences were found depending on the country of residence. For physician-assisted dying, a high acceptance and a high frequency of physicians ever performing these actions was found in Belgium and The Netherlands, but in Sweden it was very low. Circumstances of the decision-making, such as the presence of a patient request, also appeared to play a larger role in some countries than in others (e.g. it appeared to be a more important factor in the acceptability of physician-assisted dying for Dutch physicians than for Belgian physicians). Moreover, the country of residence was also related to the way in which physicians with different life-stances framed their oppositions. Belgian and Dutch Catholics were relatively accepting of the use of lethal drugs, and were even more accepting than non-religious physicians from the other studied countries (most notably Sweden). This is also translated in actual behaviour: Dutch Catholic physicians more often performed physician-assisted dying than the non-religious ones in any other studied country. Being a Roman Catholic in countries like Belgium and The Netherlands implies even less commitment to the Vatican's rejection of euthanasia than in the other countries.[30] Moreover, in Sweden and the Netherlands

Roman Catholics were more tolerant of physician-assisted suicide than Protestants, although in other countries the converse was the case.

Part of these differences can be explained by the surrounding secular culture (and the strength of the voice of religious authorities).[15;28;30] Physicians in a society that values individual choice and self-determination regarding ways of life are more likely to also value individual choice and self-determination regarding (ways of) death, even if they are religious.[31] It is also possible, however, that other factors contribute to the tolerance by physicians of physician-assisted dying (e.g. low or high participation of patients in decision-making). It can be safely hypothesized that the actual or imminent achievement of legal status, as is the case in the Netherlands, Switzerland and Belgium, is a major cultural factor determining attitudes and practice.

General conclusion

We have demonstrated that teachings of religious bodies indeed have an influence on end-of-life decision-making, but are certainly not blankly accepted by physicians. The influence of doctrinal teachings is somewhat clearer on general attitudes towards end-of-life decisions. However, it tends to be smaller when dealing with more realistic cases and specific circumstances. There is thus incongruence between official doctrinal views towards end-of-life decisions and the actual stances of the followers of those doctrines in concrete situations. It can perhaps be explained by the fact that most people embrace (theistic) belief not in strict metaphysical terms, but in non-imperative ways, allowing for adaptation to particular situations, for instance to the needs and wishes of the dying and to considerations of humaneness.

ACKNOWLEDGEMENTS

We want to acknowledge all physicians providing the data, all research assistants on the Eureld Project, all national and regional medical associations and other authoritative bodies that supported the study, and to the national advisory boards for their support.

We also thank Johan Vanoverloop for his Statistical assistance with this article. This study was supported by a grant from the Fifth Framework Program of the European Commission, Brussels, Belgium (contract QLRT-1999-30859). The Australian part of the study was supported by a grant from the National Health & Medical Research Council of the Australian Government.

REFERENCES

1. Mortier F, Bilsen J, Vander Stichele RH, Bernheim J, Deliens L. Attitudes, sociodemographic characteristics, and actual end-of-life decisions of physicians in Flanders, Belgium. Med.Decis.Making 2003;23(6):502-10.

2. Forde R, Aasland OG, Falkum E. The ethics of euthanasia--attitudes and practice among Norwegian physicians. Soc.Sci.Med. 1997;45(6):887-92.

3. Wenger NS, Carmel S. Physicians' religiosity and end-of-life care attitudes and behaviors. Mt.Sinai J.Med. 2004;71(5):335-43.

4. Miccinesi G, Fischer S, Paci E et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. Soc Sci.Med 2005;60(9):1961-74.

5. Neumann JK, Olive KE. Physician values and medical decisions. South.Med J. 2004;97(8):793.

6. Baume P, O'Malley E, Bauman A. Professed religious affiliation and the practice of euthanasia. J.Med Ethics 1995;21(1):49-54.

7. Kaldjian LC, Jekel JF, Bernene JL, Rosenthal GE, Vaughan-Sarrazin M, Duffy TP. Internists' attitudes towards terminal sedation in end of life care. J.Med.Ethics 2004;30(5):499-503.

8. Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, Deliens L. Trends in acceptance of euthanasia among the general public in 12 European countries (1981-1999). Eur.J.Public Health 2006;16:663-69.

9. Fischer S, Bosshard G, Faisst K et al. Swiss doctors' attitudes towards end-of-life decisions and their determinants: a comparison of three language regions. Swiss.Med.Wkly. 2006;136(23-24):370-376.

10. Larue GA. Euthanasia and religion. A survey of the attitudes of world religions to the right-to-die. Los Angeles: The Hemlock Society, 1985.

11. Baggini J, Pym M. End of life: the humanist view. Lancet 2005;366(9492):1235-37.

12. Coleson RE. Contemporary religious viewpoints on suicide, physician-assisted suicide, and voluntary active euthanasia. Duquesne.Law Rev. 1996;35(1):43-80.

13. Donovan GK. Decisions at the end of life: Catholic tradition. Christ.Bioeth. 1997;3(3):188-203.

14. Engelhardt HT. Physician-assisted death: doctrinal develoment vs. Christian tradition. Christ.Bioeth. 1998;4(2):115-21.

15. Engelhardt HT. Physician-assisted suicide reconsidered: dying as a Christian in a post-Christian age. Christ.Bioeth. 1998;4(2):143-67.

16. Engelhardt HT, Jr., Iltis AS. End-of-life: the traditional Christian view. Lancet 2005;366(9490):1045-49.

17. Pauls M, Hutchinson RC. Bioethics for clinicians: 28. Protestant bioethics. CMAJ. 2002;166(3):339-43.

18. Markwell H. End-of-life: a catholic view. Lancet 2005;366(9491):1132-35.

19. Mahawar KK. End-of-life issues. Lancet 2005;366(9500):1848.

20. Onwuteaka-Philipsen BD, Fisher S, Cartwright C et al. End-of-life decision making in Europe and Australia: a physician survey. Arch Intern.Med 2006;166(8):921-29.

21. Burdette AM, Hill TD, Moulton BE. Religion and attitudes toward physician-assisted suicide and terminal palliative care. Journal for the Scientific Study of Religion 2005;44(1):79-93.

22. Childress, JF. Religious viewpoints. In: Emanuel LL, editor. Regulating how we die the ethical, medical, and legal issues surrounding physician-assisted suicide. Cambridge, Mass: Harvard University Press, 1998:120-147.

23. Cozby D. Prolonging life: an Orthodox Christian perspective. Christ.Bioeth. 1997;3(3):204-21.

24. Kopfensteiner TR. Death with dignity: a Roman Catholic perspective. Linacre.Q. 1996;63(4):64-75.

25. Sykes N, Thorns A. The use of opioids and sedatives at the end of life. Lancet Oncol. 2003;4(5):312-18.

26. Melton J, Manning C. The Churches Speak on Euthanasia: Official Statements from Religious Bodies and Ecumenical Organizations. Detroit: Gale Research, 1991.

27. Walter JJ. Terminal sedation: a Catholic perspective. Update. 2002;18(2):6-8, 12.

28. Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, Deliens L. European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. Soc Sci.Med 2006;63(3):743-56.

29. Snelling PC. Consequences count: against absolutism at the end of life. J.Adv.Nurs. 2004;46(4):350-357.

30. Hamil-Luker J, Smith C. Religious authority and public opinion on the right to die. Sociology of Religion 1998;59(4):373-91.

31. Kasachkoff T. Euthanasia and religious belief: the importance of how we frame the questions. Int.J.Appl.Philos. 1991;6(1):37-44.

APPENDIX

Principal component analysis: retained items and their component loadings.

		Attitude towards NTD & APS	Attitudes towards using lethal drugs	Life preserving attitude
1.	Physicians should comply with a patient's request to withhold or withdraw life-sustaining treatment	0,79		
2.	If necessary, a terminally ill patient should receive drugs to relieve pain and suffering, even if these drugs may hasten the end of the patient's life	0,65		
3.	A person should have the right to decide whether or not to hasten the end of his or her life		0,70	-0,78
4.	In all circumstances physicians should aim at preserving the lives of their patients, even if patients ask for the hastening of the end of their lives			0,75
5.	The use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain or other distress		0,87	
6.	If a terminally ill patient is suffering unbearably and is not capable of making decisions, the physician should be allowed to administer drugs in lethal doses		0,81	
7.	Permitting the use of drugs in lethal doses on the explicit request of the patient will harm the relationship between patients and physicians			0,77
8.	Clear wishes on withholding or withdrawing life-sustaining treatment of an incompetent patient as expressed in an advance directive must always be respected, even if this could hasten the end of the patient's life	0,74		

Note: only items with component loading higher than 0.50 were retained in the factors.

End-of-life decisions and place of death
in Belgium and Europe

Part 3

Place of death

5

End-of-life decision-making in Belgium, Denmark, Sweden and Switzerland: Does place of death make a difference?

Joachim Cohen, Johan Bilsen, Susanne Fischer, Rurik Löfmark, Michael Norup, Agnes van der Heide, Guido Miccinesi, and Luc Deliens, on behalf of the Eureld Consortium

This paper has been accepted for publication by the the Journal of Epidemiology and Community Health (in press).

ABSTRACT

Objective: To examine differences in end-of-life decision-making in patients dying at home, in a hospital or in a care home.

Design: Death certificate study: certifying physicians from representative samples of death certificates, taken between June 2001 and February 2002, were sent questionnaires on the end-of-life decision-making preceding the patient's death.

Setting: Four European countries: Belgium (Flanders), Denmark, Sweden, and Switzerland (German-speaking part).

Main outcome measures: Incidence of and communication in different end-of-life decisions (ELDs): physician-assisted death, alleviation of pain/symptoms with a possible life-shortening effect, and non-treatment decisions.

Results: Response rates ranged from 59% in Belgium to 69% in Switzerland. Total number of deaths studied was 12492. Among all non-sudden deaths the incidence of several ELDs varied by place of death. Physician-assisted death occurred relatively more often at home (0.3%-5.1%); non-treatment decisions generally more often in hospitals (22.4%-41.3%), although they were also frequently taken in care homes in Belgium (26.0%) and Switzerland (43.1%). Continuous deep sedation, in particular without administration of food and fluids was more likely to occur in hospitals. At home, ELDs were usually more often discussed with the patients. Discussion with other caregivers was generally relatively low at home compared to in hospitals or care homes.

Conclusion: Our results suggest the possibility that end-of-life decision-making is related to the care setting where people die. The study results seem to call for the development of good end-of-life care options and end-of-life communication guidelines in all settings.

INTRODUCTION

The place of death has, for some time now, been an issue of interest to public health policy and in particular to palliative care. Interest in this issue has risen with the observation that patients often prefer to die at home, whereas only a low number actually does so.[1-6] More recently, economical motives have also incited attention for the place of death.[7;8] However, it has clearly also received attention in health care research because of an association between the place of dying and the type and quality of end-of-life care: [9-18] the setting of end-of-life care seems to involve a particular 'care-culture'.[9-15] In this perspective it is plausible that the place of dying also influences the end-of-life decision-making. However, empirical evidence is lacking. While studies on the practice of end-of-life decisions have occasionally been undertaken,[19-25] few or no of these studies make focussed evaluations for different settings of care (hospital, care home, home).

The research questions of this article are therefore: first, are there differences in the incidence and type of end-of-life decisions in patients dying at home, in a hospital or in a care home; second, are there differences by these settings in the discussion between the physician and the patient, relatives, or other healthcare professionals preceding these end-of-life decisions; and third, do these differences occur in all studied countries?

METHOD:

Study Design

Data used in this article are from the European study of end-of-life decisions (Eureld), studying six European countries: Belgium (Flanders), Denmark, Italy (four areas), The Netherlands, Sweden, and Switzerland (German-speaking part). The main results of this study were presented in 2003.[22] Because it was not possible to distinguish between home, hospital or care home as place of death in The Netherlands and in Italy, these countries were not included in our analyses.

In every participating country or region, random samples of death certificates were taken, stratified for cause of death (indicating the likelihood that an end-of-life decision had preceded the death).[22;26] The stratification procedure, applied to make more reliable estimates for end-of-life decisions, was not possible in Switzerland because of its delay in cause of death registration.

Questionnaires were sent to the physicians certifying the sampled deaths. In case they were not the treating physician, they were asked to pass the questionnaire to the treating physician.[22;26] Follow-up mailings were used to optimise the response rate.[22;26] In each country, specific information from the death certificate was linked to the information in the corresponding questionnaire, after complex anonymity-procedures to preclude identification of any of the doctors or patients. All country-specific databases were integrated into one common file. Depending on the sampling procedure and the representativeness of the obtained national or regional sample, a weight factor correcting for stratification and for patient characteristics (e.g. sex, age, cause of death) was added in order to make reliable estimates of end-of-life decisions.

Approval for the study was given in all countries by the relevant instances (e.g. research ethics committees).[26]

Measures

Place of death and patient characteristics

Place of death, cause of death (aggregated into five major categories: cardiovascular diseases, malignant neoplasms, neurological diseases, respiratory diseases, and other diseases), sex, and age (aggregated into 4 categories: less than 18, 18-64, 65-79, 80 or older) of the deceased were available from the death certificate.

End-of-life decisions (ELDs)

On the basis of a combination of answers to the questions (that only needed to be answered when the death was not totally sudden and unexpected) ELDs were classified as indicated in Box 1.

Box 1: classification of end-of-life decisions

1. **Physician-assisted death (PAD):** the administration, prescription or supply of drugs with the explicit intention of hastening the patient's death, further subdivided into:
    - *Euthanasia (EUTH)* or *physician-assisted suicide (PAS)* if drugs were respectively administered or prescribed or supplied at the patient's explicit request;
    - *Life-ending acts without the patient's explicit request (LAWER)* if drugs were administered without an explicit request of the patient.

2. **Possibly life-shortening alleviation of pain and symptoms (APS)** by using drugs (e.g. morphine), taking into account the possibility to hasten the patient's death (APS1), or partly with the intention of hastening the patient's death (APS2).

3. **Non-treatment decision (NTD):** the withholding or withdrawing of (potentially life-prolonging) treatment, taking into account the possibility of hastening the patient's death (NTD1) or explicitly intending the hastening of the patient's death (NTD2).

To describe the end-of-life decision (if any) preceding each death, a decision with an explicit life-shortening intention prevailed over a decision with partly a life-shortening intention, which on its turn prevailed over a decision taking into account the life-shortening possibility. More information on the classification of the end-of-life decisions can be found elsewhere.[22]

Continuous deep sedation until death (CDS) was measured by asking the physician to indicate whether the patient received drugs, such as barbiturates or benzodiazepines, to keep him/her continuously in deep sedation or coma until death. A distinction is made between cases of with or without the administration of artificial nutrition or hydration (ANH). More information can be found elsewhere.[27]

Next to these questions, the questionnaire inquired about whether or not the patient was competent (i.e. capable of making a decision) when the decision was made, and whether or not the ELD had been discussed with the patient, with the patient's relatives, and with other caregivers (i.e. one or more physicians, nursing staff, or other caregivers).

Statistical analyses

For the different places of death (hospital, home, care home), the percentage of deaths preceded by different types of ELDs were presented and Fisher exact tests were used to test for statistically significant differences. Because the probability to die suddenly and unexpectedly strongly varies between the three settings, the analyses are limited to the non-sudden deaths, where an ELD was possible.

A multivariate logistic regression was performed on all non-sudden deaths to test the relation between all ELDs and the place of death, controlling for age and cause of death. Finally, Fisher exact tests were used to examine differences between the three places of dying in whether or not (the life-shortening potential of) the ELD had been discussed with the patient, relatives and other caregivers.

RESULTS

A response rate ranging from 59% in Belgium to 67% in Switzerland resulted in a total of 2950 deaths in Belgium; 2939 in Denmark; 3248 in Sweden and 3355 in Switzerland.

Place of death

The proportion of people dying in a hospital varied from 37.3% in Switzerland to 50.0% in Belgium, at home from 21.2% in Sweden to 26.5% in Belgium, and in a care home from 21% in Belgium to 33.7% in Switzerland (Table 1).

Table 1: characteristics of the sampled deaths in Belgium, Denmark, Sweden and Switzerland

	Belgium	Denmark	Sweden	Switzerland
Total number	**2950**	**2939**	**3248**	**3355**
Response percentage	**59**	**62**	**61**	**67**
sex				
male	50.5	48.0	47.5	49.3
female	49.5	52.0	52.5	50.7
Age				
1-17	0.3	0.3	0.2	0.4
18-64	17.0	19.1	11.8	17.3
65-79	33.9	34.3	31.8	29.3
80+	48.8	46.3	56.3	53.0
Cause of death				
cardiovascular diseases	30.1	26.2	50.6*	36.1
malignant neoplasms	26.5	27.0	27.2	24.5
respiratory diseases	10.4	11.7	4.3	8.4
diseases of the nervous system	11.2	10.2	1.0*	10.7
other/unknown	21.8	24.9	16.8	20.2
Place of death				
hospital	50.0	39.8	43.9	37.3
home	26.5	25.4	21.2	22.7
care home†	21.0	30.6	33.6	33.7
other	2.5	4.1	1.4	6.3

*: In Sweden stroke was not categorized under diseases of the nervous system, but under cardiovascular diseases †: care homes include nursing homes and residential homes for older people

Place of death and end-of-life decisions

Of all deaths 65.7% to 68.0% were not sudden and unexpected. Of these non-sudden deaths 0.4% in Sweden to 2.8% in Belgium were preceded by physician-assisted death, 21.4% in Sweden to 39.0% in Denmark were preceded by possibly life-shortening pain and symptom alleviation, and 20.9% in Denmark to 40.8% were preceded by non-treatment decisions (Table 2).

The probability that a death was not sudden and unexpected, and thus the possibility that death was preceded by an end-of-life decision, varied between the settings. The proportion of non-sudden deaths was generally lowest at home (46.6%-56.2%) and higher in hospitals (63.9%-83.7%) and care homes (73.8%-86.0%).

Among the non-sudden deaths, the incidence of several end-of-life decisions varied by the place of death. In Denmark and Switzerland, the incidence of physician-assisted death was higher at home than in a hospital or a care home. In these countries as well as in

Belgium, especially euthanasia or physician-assisted suicide more often occurred at home. In Switzerland, a quarter of all assisted suicides occurred in the apartments of a right-to-die organisation (other place of death). The incidence of life-ending acts without an explicit request from the patient also tended to be higher at home, but only in Switzerland significantly. Small setting differences were found in the incidence of alleviation of pain and symptoms with a possible life-shortening effect. It tended to be higher at home in Denmark and lower in care homes in Belgium. However, no significant differences were found for the incidence of these decisions with partly a life-shortening intention (APS2). Non-treatment decisions occurred generally less frequently at home, and in Denmark and Sweden also less frequently in a care home. However, in Belgium and Switzerland the incidence of non-treatment decisions where the life-shortening was not the explicit intention was even highest in care homes.

Multivariate logistic regression confirmed several differences between the three settings in the probability of end-of-life decisions, independent from (confounding) differences in age, sex and cause of death. A higher probability of physician-assisted death at home was confirmed in Denmark, Belgium, and Switzerland. Euthanasia or physician-assisted suicide was also more likely to take place at home in Belgium and Switzerland and a life-ending act without an explicit request from the patient was more likely to take place at home in Switzerland. No significant differences were found between the settings of care for the probability of alleviation of pain and symptoms, except in Denmark where the probability of these kinds of decisions with only a foreseen life-shortening was lower in hospitals. The lower probability of death being preceded by a non-treatment decision (and in particular one where hastening death was the explicit intention) was confirmed for home deaths in Switzerland, and for home deaths as well as care homes deaths in Sweden and Denmark.

Table 2: Incidence of end-of-life decisions by place of death in non-sudden deaths in Belgium, Denmark, Sweden, and Switzerland *

	Hospital	Home	Care home	p-value[†]	Total [‡]
Belgium, nr. of non-sudden deaths[§] (% of all deaths)	1054 (71.5%)	417 (53.3%)	457 (73.8%)	<0.001	1938 (65.7%)
Physician-assisted death (PAD)	**2.6**	**4.3**[**]	**2.0**	0.101	**2.8**
euthanasia or physician-assisted suicide	*0.3*	*1.4*[**]	*0.0*	***0.005***	*0.5*
life-ending without explicit patient request	*2.3*	*2.6*	*2.0*	*0.804*	*2.3*
Alleviation of pain/symptoms (APS)	**34.4**	**38.3**	**26.0**	**<0.001**	**33.3**
taking into account life-shortening	*30.0*	*32.5*	*23.2*	***0.005***	*28.9*
partly intending life-shortening	*4.5*	*5.8*	*2.8*	*0.099*	*4.3*
Non-treatment decision (NTD)	**22.4**	**17.7**[**]	**26.0**	**0.012**	**22.2**
taking into account life-shortening)	*9.9*	*6.5*[**]	*10.7*	*0.060*	*9.3*
explicitly intending life-shortening	*12.5*	*11.3*	*15.3*	*0.179*	*12.9*
Denmark, nr. of non-sudden deaths[§] (% of all deaths)	736 (63.9%)	413 (56.2%)	762 (86.0%)	<0.001	1954 (66.5%)
Physician-assisted death (PAD)	**0.7**	**2.7**[**]	**0.9**	**0.015**	**1.2**
euthanasia or physician-assisted suicide	*0.0*	*0.7*	*0.1*	***0.034***	*0.2*
life-ending without explicit patient request	*0.7*	*1.9*	*0.9*	*0.131*	*1.0*
Alleviation of pain/symptoms (APS)	**37.1**	**46.2**	**37.5**	**0.005**	**39.0**
taking into account life-shortening	*33.3*	*42.1*[**]	*35.3*[**]	***0.011***	*35.7*
partly intending life-shortening	*3.8*	*4.1*	*2.2*	*0.110*	*3.3*
Non-treatment decision (NTD)	**27.0**	**14.5**[**]	**18.9**[**]	**<0.001**	**20.9**
taking into account life-shortening	*11.7*	*6.1*[**]	*9.4*[**]	***0.007***	*9.5*
explicitly intending life-shortening	*15.4*	*8.5*[**]	*9.4*[**]	***<0.001***	*11.4*
Sweden, nr. of non-sudden deaths[§] (% of all deaths)	948 (67.9%)	315 (46.7%)	842 (78.8%)	<0.001	2145 (66.0%)
Physician-assisted death (PAD)	**0.4**	**0.3**	**0.4**	0.999	**0.4**
euthanasia or physician-assisted suicide	*0.0*	*0.0*	*0.0*	*/*	*0.0*
life-ending without explicit patient request	*0.4*	*0.3*	*0.4*	*0.999*	*0.4*
Alleviation of pain/symptoms (APS)	**29.2**	**29.8**	**33.3**	0.168	**30.8**
taking into account life-shortening	*28.6*	*29.8*	*32.5*	*0.189*	*30.2*
partly intending life-shortening	*0.6*	*0.0*	*0.7*	*0.387*	*0.6*
Non-treatment decision (NTD)	**27.2**	**17.5**[**]	**16.0**[**]	**<0.001**	**21.4**
taking into account life-shortening	*8.6*	*5.4*	*6.3*[**]	*0.069*	*7.3*
explicitly intending life-shortening	*18.5*	*12.1*[**]	*9.7*[**]	***<0.001***	*14.1*
Switzerland, nr. of non-sudden deaths[§] (% of all deaths)	1044 (83.7%)	354 (46.6%)	867 (77.0%)	<0.001	2283 (68.0%)
Physician-assisted death (PAD)	**0.4**	**5.1**[**]	**1.2**[**]	**<0.001**	**1.5**
euthanasia or physician-assisted suicide	*0.1*	*3.4*[**]	*0.6*[**]	***<0.001***	*0.9*
life-ending without explicit patient request	*0.3*	*1.7*[**]	*0.6*	***0.018***	*0.6*
Alleviation of pain/symptoms (APS)	**34.3**	**33.3**	**30.3**	0.158	**32.4**
taking into account life-shortening	*31.1*	*28.0*	*26.6*	*0.081*	*28.7*
partly intending life-shortening	*3.2*	*5.4*	*3.7*	*0.170*	*3.7*
Non-treatment decision (NTD)	**41.3**	**32.8**[**]	**43.1**	**0.003**	**40.8**
taking into account life-shortening	*8.8*	*7.3*	*13.2*	***0.001***	*10.3*
explicitly intending life-shortening	*32.6*	*25.4*[**]	*29.9*	***0.038***	*30.5*

* All data are weighted (i.e. adjusted for stratification and sociodemographic characteristics)

†: Fisher exact test for differences between home, hospital and care home

‡: this includes a small number of deaths in other places. Totals might not add up.

§: number of deaths (and percentage within total number of deaths in hospital, at home, etc.) where an ELD was possible (i.e. not sudden or unexpected, and where physician first saw the patient before the patient's death)

****:** the probability remained statistically higher or lower than for hospitals (reference category) in a logistic regression controlling for age, sex and cause of death.

Continuous deep sedation until death occurred in 3.9% to 12.8% of all non-sudden deaths and was more likely found in hospital deaths in Belgium and Sweden (Table 3). However, there was a varying picture depending on whether or not artificial nutrition/hydration was withdrawn. In all countries continuous deep sedation without artificial nutrition/hydration was (also after controlling for age, sex and cause of death) more likely in hospitals than in care homes or at home. Continuous deep sedation with artificial nutrition/hydration was more likely in Denmark and less likely in Sweden to precede a death at home.

Table 3: Incidence of continuous deep sedation by place of death in non-sudden deaths in Belgium, Denmark, Sweden, and Switzerland

	Hospital	Home	Care home	p-value*	Total
Belgium					
Continuous deep sedation (total)	18.9	7.1[†]	4.3[†]	**<0.001**	12.8
with ANH[‡]	*5.6*	*5.7*	*2.9*	*0.078*	*4.9*
without ANH[‡]	*13.4*	*1.5[†]*	*1.3[†]*	***<0.001***	*7.9*
Denmark					
Continuous deep sedation (total)	4.7	4.7	2.6	0.063	3.9
with ANH[‡]	*1.4*	*4.5[†]*	*2.6*	***0.007***	*2.6*
without ANH[‡]	*3.3*	*0.2[†]*	*0.0*	***<0.001***	*1.3*
Sweden					
Continuous deep sedation (total)	7.9	2.1[†]	3.0[†]	**<0.001**	5.2
with ANH[‡]	*3.8*	*0.7[†]*	*3.0*	***0.028***	*3.0*
without ANH[‡]	*4.1*	*1.4[†]*	*0.1[†]*	***<0.001***	*2.2*
Switzerland					
Continuous deep sedation (total)	9.2	7.0	5.4	**0.009**	7.4
with ANH[‡]	*4.1*	*6.1*	*4.2*	*0.289*	*4.4*
without ANH[‡]	*5.1*	*0.9[†]*	*1.2[†]*	***<0.001***	*3.0*

All data are weighted (i.e. adjusted for stratification and sociodemographic characteristics)
*: Fisher exact test for differences between home, hospital and care home
†: The probability remained statistically higher or lower than for hospitals (reference category) in a logistic regression controlling for age, sex and cause of death.
‡: ANH: administration of (artificial) nutrition and hydration

Place of death and communication of end-of-life decisions

In Switzerland and Belgium physician-assisted death was most often discussed with other caregivers in hospitals (100%), and least often at home (42.9%-73.0%). This tendency was also found in the other countries but was, because of a limited number of cases, not statistically significant (Table 4).

Cases of alleviation of pain and symptoms and non-treatment decisions were generally also more discussed with other caregivers in a hospital or in a care home than at home (except in Sweden).

Relatives tended to be more involved in discussion about (the life-shortening potential of) alleviation of pain and symptoms or a non-treatment decision at home than in a hospital or care home (in Belgium and in Denmark), and more at home or in a hospital than in a care home (in Sweden and Switzerland).

Discussion with the patient of alleviation of pain and symptoms or non-treatment decisions was relatively low (4.7% of APS in care homes in Sweden to 55.8% of NTD at home in Switzerland), but was generally higher at home than in a hospital (except for Sweden), and lowest in care homes. A physician-assisted death tended to be discussed more often with the patient at home than in a hospital (or a care home), but this was only statistically significant in Belgium. The reason why the end-of-life decision was not discussed with the patient was mostly, especially in hospitals and in care homes, that the patient was no longer capable to participate in end-of-life decision-making. Further exploration of the end-of-life decisions discussed with the patient learned that in home deaths the discussion was (except in Sweden) significantly more often initiated by the patient and/or (except in Switzerland) by the patient's relatives than in hospital deaths, where the discussion was more often initiated by the physician (not shown in tables).

Table 4: Discussions in end-of-life decisions by place of death in Belgium, Denmark, Sweden, and Switzerland

	Physician assisted death			Alleviation of Pain/Symptoms			Non-Treatment Decision		
	Hospital	Home	Care home	Hospital	Home	Care home	Hospital	Home	Care home
BELGIUM, nr. of cases	**26**	**38**	**10**	**374**	**324**	**144**	**202**	**106**	**121**
not discussed with patient, patient incompetent	50,0	26.3	90.0 †	50.5	44.4	65.3 †	66.3	63.4	67.2
discussed with patient	50,0	65,8	0,0 †	34,0	36,5	19,8 †	27,5	26,7	20,7
discussed with relatives	92,3	94,7	90,0	70,2	72,5	66,9	82,0	93,0	77,4 †
discussed with other professionals	100,0	73,0	80,0 †	81,8	59,5	84,2 †	92,2	70,4	92,9 †
DENMARK, nr. of cases	**6**	**17**	**8**	**342**	**273**	**281**	**200**	**76**	**123**
not discussed with patient, patient incompetent	16.7	29.4	62.5	60.5	44.8	67.0 †	68.8	41.1	68.7 †
discussed with patient	50,0	58,8	37,5	19,6	25,1	12,9 †	23,7	47,9	27,0 †
discussed with relatives	83,3	88,2	62,5	39,9	50,8	39,3 †	62,5	74,0	58,3 ††
discussed with other professionals	80,0	62,5	71,4	41,0	32,8	55,9 †	76,0	56,9	71,4 †
SWEDEN, nr. of cases	**5**	**1**	**2**	**370**	**111**	**336**	**280**	**58**	**144**
not discussed with patient, patient incompetent	75.0	0.0	100.0	62.4	52.1	73.3 †	67.7	66.1	80.3 †
discussed with patient	0,0	0,0	0,0	10,0	9,6	4,7 ††	22,3	19,6	14,4
discussed with relatives	75,0	0,0	100,0	25,7	22,2	16,5 †	65,1	58,9	51,1 †
discussed with other professionals	75,0	0,0	100,0	28,1	27,8	18,8 †	70,4	66,1	61,1
SWITZERLAND, nr. of cases	**4**	**18**	**10**	**358**	**118**	**262**	**431**	**116**	**373**
not discussed with patient, patient incompetent	25.0	26.7	30.0	46.9	30.7	57.8 †	54.6	35.4	58.4 †
discussed with patient	50,0	66,7	70,0	40,0	41,6	27,0 †	38,1	55,8	29,9 †
discussed with relatives	75,0	86,7	70,0	68,6	65,0	53,2 †	79,7	80,5	65,6 †
discussed with other professionals	100,0	42,9	90,0 †	77,2	49,5	74,0 †	87,2	53,1	87,3 †

†: $p<0.05$ (Fisher exact test); ††: $p<0.1$ (Fisher exact test)

DISCUSSION

Our study revealed some clear differences in end-of-life decisions and in the communication about these decisions according to the place of dying. End-of-life decision-making differed by where patients died, even after controlling for cause of death, sex, and age of the patient, factors found to be correlated to end-of-life decisions in several previous studies.[19;22;27]

This study compares, probably for the first time, the end-of-life decisions that are made in hospital, at home, or in a care home, using a large-scale cross national death certificate study. It thereby contributes to the knowledge of how people die. The death certificate method used allowed to make reliable epidemiological estimates per setting. Other methodological strengths are the large and representative nation- or region-wide sample sizes and relatively good response percentages. However, next to a possible bias by nonresponse, it is uncertain whether the results can be extrapolated to the other regions in Belgium and Switzerland. Possible bias might also occur in the self-reported end-of-life decision-making of physicians for instance as a consequence of fear for legal consequences. A more important limitation is that we did not dispose over all relevant patient information, allowing to control for all possible confounders. For example, we cannot exclude that differences in decision-making between settings might be due to differences in patient characteristics such as symptom severity.

Physician-assisted death was rare, but although at the time of the study physician-assisted suicide was only legal in Switzerland and euthanasia was illegal in all countries (it became legal in The Netherlands and Belgium in 2002), it occurred in all four countries. Physician-assisted death took more often place at home than in the other settings in Belgium, Denmark and in Switzerland. This difference is especially caused by the higher incidence of euthanasia or physician-assisted suicide at home. Next to the Swiss “Exit” association[28] usually offering assistance in suicide in the domestic setting of the patient as partial explanation for Switzerland, possible explanations for the higher euthanasia/PAS incidence at home than in other settings can be sought in the degree of intimacy, privacy, and concealment, characteristics of the relation with the professional caregiver, different (palliative) care and treatment options, or institutional policies to restrict euthanasia.[29] An evident explanation might also be that both dying at home and euthanasia/PAS characterize those patients (and their families) with (a desire for) a higher degree of autonomy.

Apart from Belgium, non-treatment decisions were more often performed in hospitals, possibly due to the fact that the greater availability of possible (technically advanced) treatments that are part of (standard) medical practice in hospitals also contribute to more decisions to withhold or withdraw them.

Continuous deep sedation occurs less at home or in care homes than in hospitals, possibly due to differences in (technical) palliative medicine possibilities (e.g. constant monitoring of the doses). However, particularly continuous and deep sedation combined with the withholding of food and fluid administration, which can be considered to demonstrate an intention of hastening or not prolonging the patient's death,[27] was more likely in hospitals. Whether this can be ascribed to hospital policies, considering continuous deep sedation an acceptable 'palliative filter'[29] for euthanasia, still needs to be researched further.

The probability of similar patients to receive alleviation of pain and symptoms with a possible life-shortening effect was basically the same at home, in a hospital, or in a care home. The use of analgesics is thus probably a part of standard practice of specialists in hospitals as well as of GPs at home, less influenced by the surrounding (setting specific) 'care-culture'.

Another important finding is that communication about and involvement of others in the decision-making process are, as indicated in previous studies,[24;30] far from perfect. Decisions that may have involved life-shortening like intensification of pain and symptom management and non-treatment decisions, which were taken in about half or more of non-suddenly dying patients, were for instance discussed with a minority of these patients. Moreover, there is also a differentiation by the setting of end-of-life care. The discussion with other professional caregivers, which is a safeguard of prudent end-of-life practice, is shown to be low at home. The reason for this is probably that general practitioners operate more isolated, whereas physicians in institutions have more formal (and informal) consultations and discussion with other physicians or nurses.

The discussion with patients however, was in most countries more frequent at home than in institutions. The main explanation from the data is that patients dying in hospital were more often incompetent at the moment of decision-making, a finding confirming previous research.[24] Possibly this is an indication that specialists wait too long before discussing end-of-life decisions. Many acutely ill patients lose the ability to make medical care decisions around the time of hospital admission, but often it seems that discussion and exploration of patient and family wishes could have been initiated beforehand (or via advance directives).[31] Indications of a greater control over care and situation of patients receiving palliative care at home compared to those in hospitals,[14] and of more paternalistic attitudes among specialists[24;32] (also reflected in our finding that discussion was less often initiated by the patient and more often by the physician in hospital deaths) are other possible explanations.

Finally, a marked finding of our study is that the differences in end-of-life decisions between settings are similar in all countries, but that there are at the same time some clear country differences. While previous research demonstrated more discussion with patients and families in northern, than in central or southern European countries, [24] our results indicate a strikingly lower patient involvement in end-of-life decisions in Sweden and Denmark than in the others countries. Probably some cultural and country-specific factors (e.g. stronger paternalism among Swedish physicians[32]) play a role. Further research can give more insight into these factors.

In summary, our results do not preclude the possibility that end-of-life decision-making practices are related to the care setting where people die. Our findings may suggest a number of focal points to eradicate some differences between settings, and guarantee good end-of-life care in all settings, based on patient preferences and clinical circumstances.[33;34] At home, especially if we aim to let more people die there, the usually solo-acting general practitioners might benefit from having possibilities to consult other professional caregivers so that they do not need to make difficult decisions on their own. In institutional care settings physicians should particularly avoid waiting before discussing end-of-life decisions with the patient until the latter becomes incompetent. If possible, discussions should be made in an early stage. Involving the patients in timely discussion with regard to their treatment and care can probably not only ameliorate medical decision-making, but also increase the likelihood of dying at the place of wish.[1] Further research should examine more into depth the factors that explain differences in end-of-life decision-making between settings. In order to make more qualitative interpretations about the decision-making in each setting, attention should also be paid to information on the course of dying.

Acknowledgements

We wish to thank all physicians in the participating countries providing the study data, all authoritative bodies supporting the Eureld Study, and all project assistants in the participating countries. We also wish to acknowledge Johan Vanoverloop for his statistical advice.

This study was supported by a grant from the Fifth Framework Program of the European Commission, Brussels, Belgium (contract QLRT-1999-30859). The Swiss part of the project was funded by the Swiss Federal Office for Education and Research, Berne (contract BBW 99.0889).

The members of the EURELD consortium (apart from the authors) are:

Freddy Mortier, Julie van Geluwe, Ghent University, Ghent, Belgium; Annemarie Dencker, Anna Paldam Folker, University of Copenhagen, Copenhagen, Denmark; Riccardo Cecioni, Eugenio Paci, Center for Study and Prevention of Cancer, Florence, Italy; L. Simonato, University of Padua, Padua, Italy; S. Franchini, Local Health Authority, Trento, Italy; A.C. Finarelli, Regional Department of Health, Bologna, Italy; Tore Nilstun, University of Lund, Lund, Sweden; Georg Bosshard, Karin Faisst, Ueli Zellweger, University of Zurich, Zurich, Switzerland; and Paul J. van der Maas, Erasmus University Medical Center Rotterdam, Rotterdam, The Netherlands; Bregje Onwuteaka-Philipsen, Gerrit van der Wal, VU University Medical Center, Amsterdam, The Netherlands; and Johannes J.M. van Delden, University Medical Center Utrecht, Utrecht, The Netherlands.

REFERENCES

1. Beccaro M, Costantini M, Rossi PG, Miccinesi G, Grimaldi M, Bruzzi P. Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). J.Epidemiol.Community Health 2006;60(5):412-16.
2. Cohen J, Bilsen J, Hooft P, Deboosere P, Wal G, Deliens L. Dying at home or in an institution Using death certificates to explore the factors associated with place of death. Health Policy 2006;78(2-3):319-29.
3. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ 2006;332(7540):515-21.
4. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. J.Palliat.Med. 2000;3(3):287-300.
5. Tang ST, Liu TW, Lai MS, McCorkle R. Discrepancy in the preferences of place of death between terminally ill cancer patients and their primary family caregivers in Taiwan. Soc.Sci.Med. 2005;61(7):1560-1566.
6. Townsend J, Frank AO, Fermont D et al. Terminal cancer care and patients' preference for place of death: a prospective study. BMJ 1990;301(6749):415-17.
7. Kroneman M, Siegers JJ. The effect of hospital bed reduction on the use of beds: a comparative study of 10 European countries. Soc.Sci.Med. 2004;59(8):1731-40.
8. Dudgeon DJ, Kristjanson L. Home versus hospital death: assessment of preferences and clinical challenges. CMAJ. 1995;152(3):337-40.
9. Mezey M, Dubler NN, Mitty E, Brody AA. What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? Gerontologist 2002;42 Spec No 3:54-67.
10. Finlay IG, Higginson IJ, Goodwin DM et al. Palliative care in hospital, hospice, at home: results from a systematic review. Ann.Oncol. 2002;13 Suppl 4:257-64.
11. Catalan-Fernandez JG, Pons-Sureda O, Recober-Martinez A et al. Dying of cancer. The place of death and family circumstances. Med.Care 1991;29(9):841-52.
12. Bowling A. The hospitalisation of death: should more people die at home? J.Med.Ethics 1983;9(3):158-61.
13. Gallo WT, Baker MJ, Bradley EH. Factors associated with home versus institutional death among cancer patients in Connecticut. J.Am.Geriatr.Soc. 2001;49(6):771-77.
14. Peters L, Sellick K. Quality of life of cancer patients receiving inpatient and home-based palliative care. J.Adv.Nurs. 2006;53(5):524-33.
15. Teno JM, Clarridge BR, Casey V et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004;291(1):88-93.
16. Evans N, Walsh H. The organisation of death and dying in today's society. Nurs.Stand. 2002;16(25):33-38.
17. Grande GE, Farquhar MC, Barclay SI, Todd CJ. Caregiver bereavement outcome: relationship with hospice at home, satisfaction with care, and home death. J.Palliat.Care 2004;20(2):69-77.
18. Tang ST, McCorkle R. Determinants of place of death for terminal cancer patients. Cancer Invest 2001;19(2):165-80.
19. Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000;356(9244):1806-11.

20. Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States: adherence to proposed safeguards and effects on physicians. JAMA 1998;280(6):507-13.
21. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med.J.Aust. 1997;166(4):191-96.
22. van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362(9381):345-50.
23. van der Maas PJ, van der Wal G, Haverkate I, e.a. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in The Netherlands, 1990-1995. The New England Journal of Medicine 1996;335(22):1699-705.
24. Cohen S, Sprung C, Sjokvist P et al. Communication of end-of-life decisions in European intensive care units. Intensive Care Med 2005;31(9):1215-21.
25. Sprung CL, Cohen SL, Sjokvist P et al. End-of-life practices in European intensive care units: the Ethicus Study. JAMA 2003;290(6):790-797.
26. Nilstun T, Cartwright C, Lofmark R et al. Access to death certificates: what should research ethics committees require for approval? Ann.Epidemiol. 2006;16(4):281-84.
27. Miccinesi G, Rietjens JA, Deliens L et al. Continuous deep sedation: physicians' experiences in six European countries. J.Pain Symptom.Manage. 2006;31(2):122-29.
28. Bosshard G, Ulrich E, Bar W. 748 cases of suicide assisted by a Swiss right-to-die organisation. Swiss.Med Wkly. 2003;133(21-22):310-317.
29. Gastmans C, Lemiengre J, van der Wal G, Schotsmans P, Dierckx dC. Prevalence and content of written ethics policies on euthanasia in Catholic healthcare institutions in Belgium (Flanders). Health Policy 2006;76(2):169-78.
30. Bilsen J, vander Stichele R, Mortier F, Bernheim J, Deliens L. The incidence and characteristics of end-of-life decisions by GPs in Belgium. Fam.Pract. 2004;21(3):282-89.
31. Wenger NS, Oye RK, Bellamy PE et al. Prior capacity of patients lacking decision making ability early in hospitalization: implications for advance directive administration. The SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. J.Gen.Intern.Med 1994;9(10):539-43.
32. Sjokvist P, Nilstun T, Svantesson M, Berggren L. Withdrawal of life support--who should decide? Differences in attitudes among the general public, nurses and physicians. Intensive Care Med 1999;25(9):949-54.
33. Christakis NA, Asch DA. Physician characteristics associated with decisions to withdraw life support. Am.J.Public Health 1995;85(3):367-72.
34. Hinkka H, Kosunen E, Metsanoja R, Lammi UK, Kellokumpu-Lehtinen P. Factors affecting physicians' decisions to forgo life-sustaining treatments in terminal care. J.Med Ethics 2002;28(2):109-14.

6

Using death certificate data to study place of death in 9 European countries: opportunities and weaknesses.

Joachim Cohen, Johan Bilsen, Guido Miccinesi, Rurik Löfmark, Julia Addington-Hall, Stein Kaasa, Michael Norup, Gerrit van der Wal, Luc Deliens

This paper has been submitted

ABSTRACT

Background

This study illustrates opportunities and weaknesses of death certificate data to study place of death and associated factors in nine European countries (seven entire countries and five regions).

Methods

We investigated the possibility and modality of all partners in this international comparative study (BE, DK, IT, NL, NO, SE, UK) to negotiate a dataset containing all deaths of one year with their national/regional administration of mortality statistics, and analysed the availability of information about place of death as well as a number of clinical, socio-demographic, residential and healthcare system factors.

Results

All countries negotiated a dataset, but rules, procedures, and cost price to get the data varied strongly between countries. In total, about 1.1 million deaths were included. For seven countries/regions not all desired categories for place of death were available. Most desired clinical and socio-demographic information was available, be it sometimes via linkages with other population databases. Healthcare system factors could be made available by linking existing healthcare statistics to the residence of the deceased.

Conclusions

Death certificate data provide a unique opportunity for cross-national studying and monitoring of place of death. However, modifications of certain aspects of death certificate registration and rules of data-protection are perhaps required.

BACKGROUND

There are several reasons why it is important for public health policy to study place of death and to gain a better understanding of the reasons why people die where they die. The place of death is often regarded as an important parameter for the quality of the end-of-life [1-11], and there seems to be a large discrepancy between the preferred and actual place of death [12-18]. Moreover, as allocation of means is becoming increasingly important in healthcare organisation, and as healthcare costs are particularly high at the end-of-life [19-21], there can be economical motives. The UK for instance has made policy incentives to allow more people to die at home if they want to, explicitly referring to cost-saving effects of home deaths [22]. Many other countries implemented policy measures to reduce the number of acute care hospitalisations as a means to restrict hospital expenditure [23;24].

However, there are a number of deficiencies of place of death research which make it difficult to compare results and to draw meaningful conclusions. Previous research has often been limited with regard to sample size [25-27], patient population [16;25;26;28-40] (e.g. only cancer patients, or only patients in a palliative care program) or setting [26;27;30;32;33;36;37;39-41] (e.g. only in a home situation), and often did not use appropriate multivariable statistical models allowing sufficient adjustment for confounders. Because reliable epidemiological data are necessary for planning, organisation and implementation of (end-of-life) health care policies, the challenge is to develop systematic and comprehensive information at population level [42], eventually serving for cross-national comparisons.

Although employed for studies in USA [33;43-49], UK [50;51], Japan [52], Italy [53], Denmark [54], and Belgium [13], death certificate data remain underexplored and underexploited in this context. We wanted to examine these opportunities on the basis of national/regional death certificate data in nine European countries (Belgium, Denmark, Italy, The Netherlands, Norway, Sweden, England, Scotland, Wales), collected within the framework of a collaborative end-of-life care research project ("Dying Well in Europe") among seven European partners (BE, DK, IT, NL, NO, SE, UK). The research questions we tried to answer in this article were:

First, what procedure is required to obtain a database of all deaths of one year containing place of death information as well as a number of possibly associated factors, and are there rules that limit the use of the data?

Second, how well do the death certificate data allow describing place of death, and possibly associated factors, indicated as relevant in the literature?
Finally, we will make some recommendations.

METHODS

Design

In the course of 2005 and 2006 a database was collected containing all deaths of the most recent year for seven entire countries (Denmark, The Netherlands, Norway, Sweden, England, Wales, Scotland), two regions in Belgium (Flanders and Brussels, the Walloon region being left out due to a serious lacking behind in death certificate registration), and three regions in Italy (Emilia Romagna, Tuscany, Milan). All these regions have an autonomous public health policy and authority over the death certificate data.
Besides the place of death, we aimed to include a limited number of clinical, socio-demographic, residential and health care system factors, based on factors identified as relevant in the literature. We therefore drafted a typical database (box 1), based on recommendations from all participants to the study. All partners of the study negotiated a dataset maximally resembling this typical database with their national or regional administration of mortality statistics, which was to be integrated in one common European database on deaths. In case variables of the typical database were not available directly via the mortality statistics, partners needed to inquire for possibilities to combine the data register with other registers.

Analysis

Characteristics of the data collection and the collected data will be described:

- procedure to obtain the data
- most recent year available and total number of deaths in the data file
- place of death information
- other variables, potentially associated with place of death, available on the death certificate data, or included via linkage of the death certificate data with other data files.

BOX 1 : typical aimed data base, to be negotiated with national or regional administration of mortality statistics

1. Year of registration	2003
2. Population	all deaths (except stillborns) in the whole country/region
3. Variables	- Place of death (hospital, care home, home, other, unknown) - Natural vs. non-natural death - Underlying cause of death (ICD-coded) - Age - Sex - Civil status - Living situation/family type - Level of education - Place (country) of birth / Nationality - Municipality of death - Municipality of residence (ZIP code) (area statistics to be linked to place of residence)

RESULTS

Procedure to obtain the data

There were considerable variations in the procedure to obtain the requested data in the different countries (table 1). Approval of the project, based on a provided project description, by the agencies responsible for the death certificate data was sufficient to get the data files in Italy, Belgium, and Scotland. In the Netherlands this was also the case, but the office's data protection policy to prevent possible identification of individuals implied some restrictions in the use of the data, so that some variables could not be provided (e.g. marital status, place of residence), while aggregations needed to be made for others (e.g. age, cause of death). Data were provided relatively fast in these countries.

In other countries additional approvals were required next to those by the agencies responsible for the death certificate data: in Sweden by the National Board of Health and Welfare; in Denmark by the Danish Data Protection Agency (including an additional approval of access to micro data with a restriction to use the data only within Denmark); in England/Wales by the Micro release panel; and in Norway by the data protection agency and by the Social- and Public Health Department of the Ministry of Health.

In Denmark, Sweden, England/Wales and Norway, the time from the order of the data to the delivery exceeded (sometimes considerably) 6 months. No charges were asked for the datasets in Belgium (Flanders and Brussels), and Italy (all three regions). In the Netherlands, England/Wales and in Scotland the cost price was less than 1,000 euros, in Sweden over 2,500 euros and in Denmark over 3,500 euros.

Table 1: Procedure to obtain the databases

	approval data agency	approval data protections agency	other approval/license	restrictions in use
Belgium*	X			
Denmark	X	X	X	X‡
Italy*	X			
Sweden	X		X	X†
The Netherlands	X			X
Scotland (UK)	X			
England/Wales (UK)	X	X		
Norway	X	X	X	X

*: comprises all separate regions for Italy, and Belgium
†: data cannot leave European Union
‡: Danish data could initially only be used on-site. After an additional approval of access to micro data, the data could be accessed via internet on one personal computer in Denmark, with the data staying on the server of Statistics Denmark.

Most recent year available and total number of deaths on the data file

The most recent year of the available full and error-checked databases –at the time of the initiation of the study (September 2004)– was 2003 for Flanders(BE), Brussels(BE), The Netherlands, Norway , Scotland (UK), and England/Wales (UK); 2002 for Tuscany (IT), Emilia Romagna (IT), the city of Milan (IT), and Sweden, and 2001 for Denmark.
Total number of deaths ranged from 10,108 in Brussels to 505,341 in England (table 2).

Table 2: total number of deaths on the datafile and year of registration

	year	total number of deaths*
Brussels (Belgium)	2003	10 108
Flanders (Belgium)	2003	57 156
The Netherlands	2003	141 936
Scotland (UK)	2003	58 473
England (UK)	2003	505 341
Wales (UK)	2003	33 810
Norway	2003	42 550
Tuscany (Italy)	2002	39 955
Emilia Romagna (Italy)	2002	45 647
Milan (Italy)	2002	14 247
Sweden	2002	95 064
Denmark	2001	58 355

*: these are all deaths on the datafile, excluding stillbirths

Place of death information

The categories of the place of death variable on the death certificate data file corresponded in most countries with the categories that could be marked on the actual death certificates (table 3). In the Netherlands it was most comprehensive, comprising the categories: hospital, psychiatric hospital, nursing home, home for older people, other institute, own home, and other. On the Belgian file, the place of death was divided in hospital, care home (which covers both nursing homes and homes for older people), home and other (subdivided in workplace, public road, or a textual specification by the physician). The Scotland data file comprised hospital (hospital, and joint user), care homes (residential homes, nursing homes, and contracturals), own home, other institution (prison, and homes), and other. The England and the Wales file distinguished hospitals, psychiatric hospitals, care homes (residential homes, and nursing homes), own home, and independent hospices.

Table 3: Available categories of the variable 'place of death' on the death statistics database

	Hospital	Psychiatric hospital	Nursing home	Home for older people	Other institutes	Home	Other
Belgium‡	X		X*			X	X
Denmark	X		X†			/	X
Italy‡	/					X	X
Sweden	X¶	X				/	X
The Netherlands	X	X	X	X	X	X	X
England & Wales (UK)	X	X	X	X	X	X	X
Scotland (UK)	X	X	X	X	X	X	X
Norway	X**	X	X**			X	X

An X indicates categories on the death certificate and on the data file; an / indicates categories on the death certificate but not coded on the datafile

*: One category of ‘care home’ is given, comprising both nursing homes and homes for older people

†: This is a category ‘institution’ (comprising all institution, except hospitals)

‡: Comprises all separate regions for Italy and Belgium

¶: not recorded on the death certificate data file, but could be deduced from the postcodes

**: care homes and hospitals are lumped together in one category

However, in four countries the place of death variable on the dataset did not contain all categories that could be marked by certifying physicians on the death certificate. The Italian datasets only made a distinction between ‘home’ and ‘other’, while the category ‘hospital’ from the death certificate was not recorded. The Danish data file only distinguished ‘hospitals’, ‘institutions (but not hospitals)’, and ‘other’, while ‘home’ could also be marked on the death certificate. In Norway hospitals and care homes were grouped in the same category. In Sweden, place of death, while a certified variable, was not even recorded at all on the death certificate data file. However, ‘hospital’, ‘psychiatric hospital’ or ‘other’ could be deduced from the postcodes of the parish of death, as these institutions have their own postcodes.

Other variables, potentially associated with place of death

In Belgium and in Italy most desired clinical and socio-demographic information was directly available via the countries’ death certificate data (table 4). In other countries the clinical and socio-demographic information directly available via the death certificate data was more limited, but in several countries linkages could be made (via unique identifiers) with other population databases. The living environment of the deceased was however not available in Norway, Sweden, and Scotland. In England and Wales the living environment and the civil status of the deceased, recorded in census data, were not linked to the death certificate data due to privacy rules. The level of education could not be retrieved in The Netherlands and in the UK, but in England, Wales and Scotland the social class based on the last occupation (i.e. NS-SEC code) was available for all deaths below 75 years.

In all countries, the cause of death variable was provided as an ICD-10 (3 digits) coded variable, except in The Netherlands and in Italy, where the data protection policies called for certain aggregation. In these countries we negotiated to have 27 pre-determined aggregated cause of death categories, for which we in broad outlines followed the instruction manual by the U.S. Department of Health and Human Services [55].

Besides socio-demographic and clinical variables we also aimed to include a number of residence and healthcare system characteristics. As the municipality (or the parish, council, or local authority) of residence was available on the data files, the variables urbanisation, contextual SES-measures, and number of hospital beds per 1,000 inhabitants were operationalized by linking existing statistics to this place of residence of the deceased.

The Dutch data protection policy, however, did not allow providing us a database containing the municipality of residence of the deceased. At our request the inclusion of the residence characteristics was therefore done in advance by the Dutch Central Bureau of Statistics.

Table 4: variables potentially associated with place of death on the data-file

	BE*	DK	IT*	SE	NL	Engl./Wales (UK)*	Scotland (UK)	NO
Sociodemographic variables								
age	X	X	X	X	X	X	X	X
sex	X	X	X	X	X	X	X	X
civil status	X	L	X	X	†		X	X
living environment/family type of deceased (alone, institute,…)	X	L			L			
level of education	X	L	X	L				L
nationality	X	L	X	X	L	X‡		L
Clinical characteristics								
natural vs. non-natural death	X	X	X	X	X	X	X	X
cause of death	X	X	X	X	X	X	X	X
Residence characteristics								
municipality of death	X	X	X	X	†		X	X
municipality of residence	X	X	X	X	†	X	X	X
urbanisation	L	X	L	L	L	L	L	X
contextual SES	L	L	L	L	L	L	L	L
hospital bed rate	L	L	L	L	L	L	L	L

An X indicates that the variable is on the death certificate and on the death statistics file, an L indicates that the variable was available via linkage with other databases

*: Comprises all separate regions for Italy, Belgium, and England/Wales

†: the variable was available, but was not provided to us because of data protection policy

‡: country of birth

DISCUSSION

Previous research has demonstrated that death certificates can be a very useful basis to study and monitor the place of death in society [13;43;45;47-50;52;54], and can therefore be a useful public health tool. This study demonstrates that it is feasible to conduct cross-national research on the place of death using death certificate data. However, the suitability of the data files seems to differ between countries, and there are country variations in the difficulty to obtain the necessary data.

This study is, to our knowledge, the first to make a cross-national evaluation of the suitability of death certificate data regarding place of death. The study only involved seven entire countries and five regions, and can therefore not necessarily be generalized to other countries or regions. Nevertheless the information is ample enough to give some insights into the opportunities and the limitations of using death certificate data to study and monitor the place of death.

Opportunities

Death certificates have a long tradition as a monitoring tool for public health policy. A major strength is that of completeness: death certificates allow describing patterns within a whole population and not just for a sample. The issue of place of death can be studied across patient populations and across settings, which has been indicated as one of the limitations in many of the previous place of death studies[16]. Our study in nine countries covers more than 1.1 million deaths. This provides more statistical power, potentially leading to more reliable results, and making it is possible to use multivariable statistical models with many associated factors, or to generate meaningful results for specific subpopulations (e.g. lung-cancer or HIV patients, low educated people, specific regions) [13]. As our study demonstrates, most variables on the death certificate data are available for researchers. Especially the Italian and Belgian death certificate data provided many variables besides the place of death. Fewer variables were available directly via the death certificates in other countries, but linkage with other databases made it possible to include several variables, indicated in the literature as relevant to studying place of death [4;16;29;33;38;46;47;49;56-59]. Linkage could be made with unique identification numbers to include a number of important socio-demographic variables, or via the residence of the deceased to include variables such as health care system statistics or contextual socio-economic status. In principle there is an even larger potential, via linkages with other databases, to include additional relevant information (e.g. hospitalisation and individual healthcare use). This could eventually move us further beyond place of death towards researching care at the end-of-life, and might shape good opportunities for health policy to monitor on how health care resources are allocated within each country and between countries within Europe. However, this possibility and the implications this will have on the procedure to use the data for research, needs further investigation.

Because of the comparability of death certificate data as a study method throughout time and across different countries, they facilitate reliable comparison of results. Comparison of temporal trends of place of death across nations, and placed against other mortality trends (e.g. cause of death, age, living conditions) can for example potentially allow us to

monitor the impact of public health policy (e.g. implementation of palliative care services, reorganization of home care).
Finally, an advantage is that the data are relatively easy to obtain and at a relatively low cost price (range of 0 to +/-3500 € in our study).

Weaknesses

Our study shows that there is considerable variation between countries in the quality and type of information on the death certificate data. The place of death variable, while certified in all countries, was in several countries not or only in a limited way coded on the death certificate data files. Therefore several countries only allowed making rough distinctions between dying at home vs. other, or dying in a hospital vs. other. In The Netherlands the variable did not appear on the database before 2003; in Italy only since 2003 in more than 2 categories.

Additionally, procedures to obtain the data and the rules of data-protection were sometimes a barrier to easily get and use the data. The required permissions from different instances often complicated getting the data and integrating them into one data file, resulting in long waiting periods. The privacy and data-protection rules also limited the use of the data.
Finally, next to well known weaknesses of death certificates concerning cause of death miscoding and misclassification [60;61] and possible country and time variation in (mis)classifications (which might be a potential impediment for comparisons between countries and over time), another weakness for studying place of death is that death certificate data do not contain all variables regarded as relevant in predicting the place of death [4;30;56;62], such as information about patients' preferred place of death, or qualitative information about the dying process (e.g. characteristics of the course of the disease, the predictability of death, the use or need of a specific therapy). Death certificate data --if not linked to other information (e.g. on the quality of end of life care)-- remain not well designed for non-etiological purposes, like monitoring 'good death' or quality of dying [42]. The use of death certificate data can reveal statistical patterns, but does not allow us to draw conclusions on the choices, behaviours, attitudes, processes, or feelings that underlie or precede these patterns [43].

Conclusions

Based on our findings, we believe that death certificate data are certainly a useful tool to give good insight in place of death in relation to other factors in a cross-national perspective and an ideal basis to interpret complementary qualitative and epidemiological studies. However, in order to make international monitoring of place of death more feasible and accurate, improvements are recommended:

1. A minimum set of variables should be (made) available [13]. Next to the place of death variable (with at least the categories hospital, care home, and own home), age, sex, cause of death (in ICD10 codes, or in detailed aggregations), and living situation (e.g. single, in household, in institution) and/or marital status should be minimally available to construct an appropriate statistical model (controlling satisfactory for confounders). This set can be elaborated with other variables (e.g. socio-economic status, hospital bed rate) that are highly relevant to monitor specific target populations and specific associated factors.
2. We suggest therefore to make modifications on aspects of the death certificates, for example by striving for more standardization in the ‘place of death’ variable, and by regularly modifying the place of death variable according to developments in the patterns of dying in our society (e.g. providing a category of ‘hospice’). In the light of monitoring how health care resources are allocated distinguishing patients dying in a regular inpatient facility or in a highly equipped intensive care unit might be opportune. Also modifications in the coding of the death certificates can be considered, for example by the coding of all certified information on place of death, and by more standardisation in cause of death coding.
3. Quality assurance programs that safeguard the reliability of the data for research purposes (next to administrative purposes), might need to be implemented. Benefit might be gained in this context from more training of death certificate completion for physicians [63]. Well-thought-out procedures to link death certificate information with other databases might also preclude duplicate registration of certain variables, and possibly increase the quality of the data.
4. Finally, we also suggest some modifications in the procedures to get permission to use the death certificate data for research purposes. Although a thorough scrutinising of an application is surely required in order to protect confidentiality, additional protective requirements should be proportional to the possible harm individuals might

suffer from a possible (ab)use of the data [64]. More standardisation in the procedures to get permission to use death certificate data is required, and ideally one (centralised) authorisation should be sufficient. However, if the useful opportunity to include information via linkage with other data sources (e.g. discharge records) will be increasingly employed, a good balance will have to be sought between the protection of personal data (and safeguarding of anonymity) on the one hand, and the difficulty of the procedure to get permission for the data on the other hand.

Acknowledgements

The contents of this article were part of the Dying Well in Europe project. The following persons contributed to the preparations for this study:
Italy: Antonio Russo (Local Health Authority of Milan), Alessia Furini (Servizio Sanità Pubblica Assessorato alla Sanità Regione Emilia-Romagna), Lucia Giovannetti (Regional Mortality Register Regione Toscana); United Kingdom: Alison O'Callaghan (School of Nursing and Midwifery, Southampton University), Geoffrey Hanks (Department of Palliative Medicine, University of Bristol); Norway: Finn Guttvik (Norwegian University of Science and Technology Trondheim); The Netherlands: Bregje Onwuteaka-Philipsen (VU University medical centre Amsterdam).
We also want to acknowledge the offices providing the data files: Belgium: Preventive and Social Heath Care Division of the Ministry of Flanders (Flanders); Observatory of Health and Well-being (Brussels); Denmark: Statistics Denmark; Italy: Local Health Authority of Milan (city of Milan); Local Health Authority of Region Emilia-Romagna (Emilia-Romagna); Regional Mortality Register of Region Tuscany (Tuscany); Sweden: Statistics Sweden; The Netherlands: Statistics Netherlands, UK: Statistics Scotland (Scotland), Office for National Statistics (England and Wales); Norway: Statistics Norway.
This study was supported by a grant of Brussels Capital-Region

REFERENCES

1. Bowling A. The hospitalisation of death: should more people die at home? J.Med.Ethics 1983;9(3):158-61.
2. Catalan-Fernandez JG, Pons-Sureda O, Recober-Martinez A et al. Dying of cancer. The place of death and family circumstances. Med.Care 1991;29(9):841-52.
3. Evans N, Walsh H. The organisation of death and dying in today's society. Nurs.Stand. 2002;16(25):33-38.
4. Gallo WT, Baker MJ, Bradley EH. Factors associated with home versus institutional death among cancer patients in Connecticut. J.Am.Geriatr.Soc. 2001;49(6):771-77.
5. Grande GE, Farquhar MC, Barclay SI, Todd CJ. Caregiver bereavement outcome: relationship with hospice at home, satisfaction with care, and home death. J.Palliat.Care 2004;20(2):69-77.
6. Mezey M, Dubler NN, Mitty E, Brody AA. What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? Gerontologist 2002;42 Spec No 3:54-67.
7. Tang ST, McCorkle R. Determinants of place of death for terminal cancer patients. Cancer Invest 2001;19(2):165-80.
8. Teno JM, Clarridge BR, Casey V et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004;291(1):88-93.
9. Wilson DM, Smith SL, Anderson MC et al. Twentieth-century social and health-care influences on location of death in Canada. Can.J.Nurs.Res. 2002;34(3):141-61.
10. Clark D. Between hope and acceptance: the medicalisation of dying. BMJ 2002;324(7342):905-7.
11. Payne SA, Langley-Evans A, Hillier R. Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. Palliat.Med. 1996;10(4):307-12.
12. Beccaro M, Costantini M, Rossi PG, Miccinesi G, Grimaldi M, Bruzzi P. Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). J.Epidemiol.Community Health 2006;60(5):412-16.
13. Cohen J, Bilsen J, Hooft P, Deboosere P, Wal G, Deliens L. Dying at home or in an institution Using death certificates to explore the factors associated with place of death. Health Policy 2006;78(2-3):319-29.
14. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. J.Palliat.Med. 2000;3(3):287-300.
15. Tang ST, McCorkle R. Determinants of congruence between the preferred and actual place of death for terminally ill cancer patients. J.Palliat.Care 2003;19(4):230-237.
16. Temkin-Greener H, Mukamel DB. Predicting place of death in the program of all-inclusive care for the elderly (PACE): participant versus program characteristics. J.Am.Geriatr.Soc. 2002;50(1):125-35.
17. Thomas C, Morris SM, Clark D. Place of death: preferences among cancer patients and their carers. Soc.Sci.Med. 2004;58(12):2431-44.
18. Townsend J, Frank AO, Fermont D et al. Terminal cancer care and patients' preference for place of death: a prospective study. BMJ 1990;301(6749):415-17.
19. Luce JM, Rubenfeld GD. Can health care costs be reduced by limiting intensive care at the end of life? Am.J.Respir.Crit Care Med. 2002;165(6):750-754.
20. Higginson IJ, Koffman J. Public health and palliative care. Clin.Geriatr.Med. 2005;21(1):45-55, viii.
21. Miller SC, Intrator O, Gozalo P, Roy J, Barber J, Mor V. Government expenditures at the end of life for short- and long-stay nursing home residents: differences by hospice enrollment status. J.Am.Geriatr.Soc. 2004;52(8):1284-92.
22. House of Commons Health Committee. Palliative Care. Fourth Report of Session 2003–04. Volume 1. 2004. London, House of Commons.
    Ref Type: Report
23. Kroneman M, Siegers JJ. The effect of hospital bed reduction on the use of beds: a comparative study of 10 European countries. Soc.Sci.Med. 2004;59(8):1731-40.

24. Dudgeon DJ, Kristjanson L. Home versus hospital death: assessment of preferences and clinical challenges. CMAJ. 1995;152(3):337-40.
25. Axelsson B, Christensen SB. Place of death correlated to sociodemographic factors. A study of 203 patients dying of cancer in a rural Swedish county in 1990. Palliat.Med. 1996;10(4):329-35.
26. Schrijvers D, Joosens E, Vandebroek J, Verhoeven A. The place of death of cancer patients in Antwerp. Palliat.Med. 1998;12(2):133-34.
27. Van den Eynden B, Hermann I, Schrijvers D et al. Factors determining the place of palliative care and death of cancer patients. Support.Care Cancer 2000;8(1):59-64.
28. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ 2006;332(7540):515-21.
29. Ahlner-Elmqvist M, Jordhoy MS, Jannert M, Fayers P, Kaasa S. Place of death: hospital-based advanced home care versus conventional care. A prospective study in palliative cancer care. Palliat.Med. 2004;18(7):585-93.
30. Brazil K, Bedard M, Willison K. Factors associated with home death for individuals who receive home support services: a retrospective cohort study. BMC.Palliat.Care 2002;1(1):2.
31. Brettle RP, Morris S, Epton V. Patients with HIV dying in Edinburgh: an audit of preference and place of death. Int.J.STD AIDS 1995;6(3):221-22.
32. Bruera E, Russell N, Sweeney C, Fisch M, Palmer JL. Place of death and its predictors for local patients registered at a comprehensive cancer center. J.Clin.Oncol. 2002;20(8):2127-33.
33. Bruera E, Sweeney C, Russell N, Willey JS, Palmer JL. Place of death of Houston area residents with cancer over a two-year period. J.Pain Symptom.Manage. 2003;26(1):637-43.
34. Cardenas-Turanzas M, Grimes RM, Bruera E, Quill B, Tortolero-Luna G. Clinical, sociodemographic, and local system factors associated with a hospital death among cancer patients. Support.Care Cancer 2005.
35. Carroll DS. An audit of place of death of cancer patients in a semi-rural Scottish practice. Palliat.Med. 1998;12(1):51-53.
36. Fukui S, Kawagoe H, Masako S, Noriko N, Hiroko N, Toshie M. Determinants of the place of death among terminally ill cancer patients under home hospice care in Japan. Palliat.Med. 2003;17(5):445-53.
37. Fukui S, Fukui N, Kawagoe H. Predictors of place of death for Japanese patients with advanced-stage malignant disease in home care settings: a nationwide survey. Cancer 2004;101(2):421-29.
38. Grundy E, Mayer D, Young H, Sloggett A. Living arrangements and place of death of older people with cancer in England and Wales: a record linkage study. Br.J.Cancer 2004;91(5):907-12.
39. Izquierdo-Porrera AM, Trelis-Navarro J, Gomez-Batiste X. Predicting place of death of elderly cancer patients followed by a palliative care unit. J.Pain Symptom.Manage. 2001;21(6):481-90.
40. Tiernan E, O'Connor M, O'Siorain L, Kearney M. A prospective study of preferred versus actual place of death among patients referred to a palliative care home-care service. Ir.Med.J. 2002;95(8):232-35.
41. Tang ST. Influencing factors of place of death among home care patients with cancer in Taiwan. Cancer Nurs. 2002;25(2):158-66.
42. Singer PA, Wolfson M. "The best places to die". BMJ 2003;327(7408):173-74.
43. Brown M, Colton T. Dying Epistemologies: an analysis of home death and its critique. Environment and Planning A 2001;33:799-821.
44. Buechner JS. Trends and patterns in place of death, 1989-2000. Med.Health R.I. 2002;85(9):289-90.
45. Flory J, Yinong YX, Gurol I, Levinsky N, Ash A, Emanuel E. Place of death: U.S. trends since 1980. Health Aff.(Millwood.) 2004;23(3):194-200.

46. Hansen SM, Tolle SW, Martin DP. Factors associated with lower rates of in-hospital death. J.Palliat.Med. 2002;5(5):677-85.
47. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J.Am.Geriatr.Soc. 2005;53(2):299-305.
48. Polissar L, Severson RK, Brown NK. Factors affecting place of death in Washington State, 1968-1981. J.Community Health 1987;12(1):40-55.
49. Weitzen S, Teno JM, Fennell M, Mor V. Factors associated with site of death: a national study of where people die. Med.Care 2003;41(2):323-35.
50. Lock A, Higginson I. Patterns and predictors of place of cancer death for the oldest old. BMC.Palliat.Care 2005;4:6.
51. Higginson IJ, Astin P, Dolan S. Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. Palliat.Med. 1998;12(5):353-63.
52. Yang L, Sakamoto N, Marui E. A study of home deaths in Japan from 1951 to 2002. BMC.Palliat.Care 2006;5:2.
53. Costantini M, Balzi D, Garronec E et al. Geographical variations of place of death among Italian communities suggest an inappropriate hospital use in the terminal phase of cancer disease. Public Health 2000;114(1):15-20.
54. Aabom B, Kragstrup J, Vondeling H, Bakketeig LS, Stovring H. Population-based study of place of death of patients with cancer: implications for GPs. Br.J.Gen.Pract. 2005;55(518):684-89.
55. Instruction Manual. Part 9. ICD-10 Cause-of-Death Lists for Tabulating Mortality Statistics (Updated October 2002 to include ICD codes for Terrorism Deaths for data year 2001 and WHO updates to ICD-10 for data year 2003). U.S.Department of Health and Human Services, Centers for Disease Control and Prevention National Center for Health Statistics. 2002. Hyattsville, Maryland.
    Ref Type: Generic
56. Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? Soc.Sci.Med. 1998;47(5):565-79.
57. Mor V, Hiris J. Determinants of site of death among hospice cancer patients. J.Health Soc.Behav. 1983;24(4):375-85.
58. Pritchard RS, Fisher ES, Teno JM et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. J.Am.Geriatr.Soc. 1998;46(10):1242-50.
59. Tolle SW, Rosenfeld AG, Tilden VP, Park Y. Oregon's low in-hospital death rates: what determines where people die and satisfaction with decisions on place of death? Ann.Intern.Med. 1999;130(8):681-85.
60. McKelvie PA. Medical certification of causes of death in an Australian metropolitan hospital. Comparison with autopsy findings and a critical review. Med J.Aust. 1993;158(12):816-1.
61. Nielsen GP, Bjornsson J, Jonasson JG. The accuracy of death certificates. Implications for health statistics. Virchows Arch A Pathol.Anat.Histopathol. 1991;419(2):143-46.
62. Higginson IJ, Jarman B, Astin P, Dolan S. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. J.Public Health Med. 1999;21(1):22-28.
63. Messite J, Stellman SD. Accuracy of death certificate completion: the need for formalized physician training. JAMA 1996;275(10):794-96.
64. Nilstun T, Cartwright C, Lofmark R et al. Access to Death Certificates: What Should Research Ethics Committees Require for Approval? Ann.Epidemiol. 2006;16(4):281-84.

7

Dying at home or in an institution. Using death certificates to explore the factors associated with place of death

Joachim Cohen; Johan Bilsen; Peter Hooft; Patrick Deboosere; Gerrit van der Wal; Luc Deliens

This Chapter is also published as an article in: Health Policy *2006;78(2-3):319-29*.

ABSTRACT:

Introduction : The knowledge of determinants of place of death is important for public health policy aimed at improving the quality of end-of-life care.

Methods : We investigated the influence of clinical, socio-demographic, residential and health care system factors on the place of death, using data from all 55,759 deaths in 2001 in Flanders (Belgium), gathered via official death certificates and data from anonymously linked health care statistics. A multivariate logistic regression was used to examine the associated factors (home versus hospital as dependent categories).

Results : Of all deaths in Flanders, 53.7% took place in hospital, 24.3% at home and 19.8% in a care home. The probability of home deaths varied by region, by rural or urban residence and by the hospital bed availability in the region and dying at home was less likely among those suffering from certain non-malignant chronic diseases, the less educated and those living alone.

Conclusion : Although most people wish to die at home, most deaths in Flanders (Belgium) in 2001 did not take place there. The clinical, socio-demographic and residential factors found to be associated with the place of death could serve as focal points for a policy to facilitate dying in the place of choice, including at home.

INTRODUCTION

The place of death is presumed to be an important parameter of the quality of end-of-life care [1-5]. Interest in research about place of death often ensues from beliefs [3;6-8] and proof [6;9-11] of better overall end-of-life care for patients dying at home as well as better support for their next of kin. Some authors, however, dispute the a priori superiority of home death. Dying at home might not always be the best option and in some situations it might also be very stressful for others involved [12;13]. Nevertheless, most authors agree that a "good death" may be one which is as much as possible in accordance with the patient's and family's wishes [3;14-16]. Because, as is shown in research in other countries, there is an overall preference for dying at home [12;17-21], it is striking that few deaths occur there [18;22]. In this context it seems important for a public health policy that envisions the "good death" to study the place of death, but also to gain a better understanding of the reasons why people die where they do. Previous worldwide research highlighted a number of important determinants of place of death, but most of these studies focused on the death experience of cancer patients, were limited to specific settings of care or lacked robust statistical models [17]. In Belgium, very few and only rather limited studies of place of death have so far been conducted [23;24].

In this study we include the whole population of deceased inhabitants in 2001in Flanders, the northern Dutch-speaking region of Belgium where approximately 60 % of the population lives. Due to the use of death certificates we can use large numbers (i.e. more statistical power) which gives good insight into the issue of place of death in relation to other factors and gives a good basis on which to interpret more qualitative studies. We investigate where deaths occurred, and investigate the associations with the place of death, to be expected from the literature [7;14;16;17;25-32], of clinical (e.g cause of death), socio-demographic (e.g. age, presence of an informal caregiver, level of education), residential (e.g. degree of urbanization) and health care system factors (e.g. the number of available hospital beds in the region). Finally, we will formulate some research and policy implications of our findings.

MATERIALS AND METHODS

Study design and data

In this study we performed analyses on data gathered within the context of cause of death statistics and health care statistics in Flanders (the largest region in Belgium, with six million inhabitants and approximately 55,000 deaths per year). The analyses presented here are based on all 55,772 deaths in 2001 of Flemish residents aged 1 year or older.

Death statistics.

In Belgium, declaration of death is made via a death certificate issued by the civil registrar of the municipality where the death takes place. The physician completes the first part of the death certificate, indicating the sex of the deceased, medical information and time and place of death. The second part of the death certificate is completed by the civil registrar. This part contains information about the residence, age, education, occupation, nationality, civil status and living situation of the deceased. Before all information is processed, the causes of death on the death certificates are thoroughly checked by the regional health administration -if necessary by asking the attending physician for additional information - and coded (International Classification of Diseases, 10th ed., ICD-10). In some occasions the underlying cause of death, as indicated by the physician, is revised on the basis of this information. A number of additional error checks (e.g. via control for unlike information on record level, via sampled controls of the civil registrar, via a thorough control of the database) guarantee a good quality of data.

Health care statistics

Various ecological health care statistics (number of general practitioners, number of available hospital beds and number of available care homes) on the level of municipalities, districts and provinces were consulted and were linked to the municipality or province codes on the death statistics file.

Data analysis

As dependent variable we used the variable “place of death” from the death statistics. The physicians could mark six options on the death certificate: home, hospital, care home, public road, workplace or “other”. The specifications they needed to make if they marked “other” (n=1615) were thoroughly checked and could often be recoded as home (43%), hospital (26%) or care home deaths (2%). For example, deaths at the home of a relative, friend or acquaintance were considered home deaths. Specifications that could not be considered as home, hospital or care home death (29%) as well as the options “workplace” and “public road” on the death certificates were grouped into a remaining category.

For the choice of independent variables we included four types of factors that were found to be relevant in the literature [8;26;28]: socio-demographic, clinical, residence and health care characteristics. Socio-demographic variables, all directly obtained from the death statistics, comprised age at death, sex, nationality, educational level (according to highest graduation, grouped into four categories), marital status (married, unmarried, widowed, divorced or separated) and living environment (living alone, in a household or in an institution). For the clinical data, we used the ICD-10 codes on the death statistics file to make a classification of underlying causes of death, in broad outlines following the instruction manual by the U.S. Department of Health and Human Services [33] (e.g. C00-C14 were coded as head and neck malignancies; I20-I25 were coded as ischemic heart diseases). The residence-related factors we included in this study were the residential province of the deceased person and an additional distinction between urban or rural residence. The province was directly available in the death statistics. The urban-rural residence variable was created by combining the codes of the municipality of residence of the death statistics with an index made by the National Institute of Statistics. Finally, combining municipality codes on the death certificates with national health care statistics for the year 2001, we created a number of health care system variables: the density of general practitioners in the province (i.e. rate per 1,000 inhabitants), the rate (per 100,000 inhabitants) of care homes in the province and the rate (per 1,000 inhabitants) of hospital beds in the health region (i.e. a cluster of municipalities in which the majority of the people use the same health institutions).

Statistical analysis

Since the data presented here are population data, differences encountered cannot be due to sample hazards and tests for statistical significance are therefore not required. Nevertheless, significance tests can be useful to determine whether observations might be liable to hazardous fluctuations from year to year and thus not necessarily systematic. For the bivariate analysis Pearson χ^2-tests were used to determine which of the patient characteristics were associated with place of death.

All variables significant at $p<0.01$ in the bivariate analysis were entered into a multivariate logistic regression analysis comparing home deaths and hospital deaths. In order to simultaneously control for multiple factors associated with place of death and for possible confounding elements (e.g. cause of death is strongly related to age and sex) we considered it necessary to obtain a homogeneous risk population . Care home residents and care home deaths were left out of this analysis for two reasons [7]. A first reason is the appropriateness of comparison. Care homes are quasi-institutions: they often have a home-like character and in fact are the actual and only "home" for many residents, and can hence be considered neither home nor institutional. A second reason is the confounding due to differences in populations. Care home residents are significantly more likely to be older, female, less educated and are more likely to die from degenerative diseases. Leaving care home residents and care home deaths out thus eliminates plural confounding elements. Additionally we chose to retain only the deaths aged 45-79 years. For all deaths aged 80 years or more a separate analysis was made. Finally, because the association between diagnosis and place of death is likely to be confounded by disease-specific characteristics, we performed separate analyses for all chronic diseases (i.e. all deaths from natural causes excluding acute cardiovascular deaths) on the one hand, and only for cancers on the other.

SPSS version 12.0 was used for all statistical computations.

RESULTS

Place of death according to cause of death

Approximately half of all deaths occurred in hospital, one fifth in a care home and a quarter at home. A small remaining group (2.2%) died elsewhere (e.g. public road, at work) (table 1).

Deaths from natural causes occurred less often at home than deaths from external causes. The occurrence of home death was highest among patients with cardiovascular diseases (30.8%) or malignancies (29.1%). Ischemic heart disease patients had the highest home death rate (35.5%) compared to any other condition. Patients suffering from hematologic malignancies more often died in hospital and less often at home than patients suffering from other malignancies. Care home deaths were often found among congestive heart failures, acute lower respiratory infections, Parkinson's, Alzheimer's and cerebrovascular diseases.

Place of death according to patient characteristics

Men died at home more frequently than women, and less frequently in a care home (table 2). With increasing age more patients died in care homes and fewer at home. Persons with higher education died more often at home than lower educated persons. A higher proportion of married people than unmarried people died at home. People living alone more often died at the hospital. One third of the people living in a private household died at home. Of those living in an institution (mostly care homes) 69% died in the care home. It must be noted that the educational level and the living environment were also strongly associated with age and sex, which consequently confounds the association.

TABLE 1. Place of death by underlying cause of death in Belgium (Flanders) 2001

	No. of deaths (% of total)	% occurring at home	% occurring in hospital	% occurring in care home	% occurring elsewhere
ALL DEATHS*	**55759**	**24.3**	**53.7**	**19.8**	**2.2**
Deaths from external causes [†]	**3324 (6.0%)**	**32.7**	**36.3**	**5.0**	**26.0**
Deaths from natural causes[*]	**52435 (94.0%)**	**23.8**	**54.8**	**20.7**	**0.7**
Cardiovascular diseases[*]	***15846 (28.4%)***	***30.8***	***45.3***	***22.0***	***1.9***
Ischemic heart diseases	7245 (13.0%)	35.5	48.3	13.9	2.3
Heart failures	2909 (5.2%)	23.2	36.0	40.4	0.4
Other diseases of heart	4551 (8.2%)	29.9	43.9	23.9	2.3
Other cardiovascular diseases	1141 (2.0%)	23.7	56.5	19.1	0.7
Malignancies[*]	***15008 (26.9%)***	***29.1***	***61.9***	***8.9***	***0.1***
Gastrointestinal	3960 (7.1%)	31.8	58.4	9.7	0.1
Respiratory	3787 (6.8%)	31.6	63.7	4.6	0.1
Breast cancer	1403 (2.5%)	27.4	59.5	12.9	0.2
Genitourinary	2622 (4.7%)	28.0	59.9	12.1	0.0
Hematologic	1109 (2.0%)	17.4	75.1	7.3	0.2
Other malignancies	2128 (3.8%)	28.4	62.5	9.0	0.1
Respiratory diseases [*]	***6393 (11.5%)***	***14.4***	***60.6***	***24.7***	***0.3***
Acute lower respiratory infections	2517 (4.5%)	7.1	62.5	30.4	0.0
Chronic lower respiratory infections	2606 (4.7%)	22.8	55.3	21.5	0.4
Other respiratory diseases	1270 (2.3%)	11.7	67.7	20.2	0.4
Cerebrovascular diseases	***5018 (9.0%)***	***13.5***	***60.4***	***26.0***	***0.1***
Diseases of the nervous system [*]	***1258 (2.3%)***	***20.8***	***37.7***	***40.9***	***0.6***
Parkinson's disease	252 (0.5%)	16.3	34.1	49.6	0.0
Alzheimer's disease	486 (0.9%)	17.7	19.3	62.8	0.2
Other diseases of nervous system	520 (0.9%)	25.8	56.7	16.3	1.2
Other diseases[*]	***8912 (16.0%)***	***15.5***	***54.4***	***29.6***	***0.5***
HIV	28 (0.1%)	7.1	92.9	0.0	0.0
Non-malignant neoplasms	375 (0.7%)	12.0	60.8	27.2	0.0
Diseases of blood (-forming organs)	108 (0.2%)	14.8	64.8	20.4	0.0
Residual	8401 (15.1%)	15.7	53.9	30.0	0.4

Presented percentages are row percentages except percentages in brackets (column percentages).

*: p-values for natural vs. non-natural, among and within all major disease groups <0.001 (Pearson χ^2-test for differences in proportion between all place of death categories).

†: Deaths from external causes comprise accidents, suicides and homicides (excl. euthanasia, which is in the Belgian registration considered a natural cause of death).

TABLE 2. Place of death by socio-demographic characteristics in Belgium (Flanders) 2001 (N= 55759†)

	No. of deaths (% of total)	% occurring at home	% occurring in hospital	% occurring in care home
Sex*				
Men	28248 (50.7%)	28.2	56.8	11.7
Women	27511 (49.3%)	20.3	50.5	28.1
Age*				
<65	9487 (17.0%)	35.8	53.7	1.2
65-80	19430 (34.8%)	27.7	62.0	8.8
+80	26841 (48.1%)	17.8	47.7	34.3
Education*‡				
None / elementary	25324 (57.5%)	20.4	54.3	24.4
Lower secondary	10982 (25.0%)	26.6	57.7	13.0
Higher secondary	5469 (12.4%)	28.8	56.0	9.7
Higher education	2233 (5.1%)	34.2	49.2	11.3
Civil status*				
Unmarried	5984 (10.7%)	25.0	47.9	20.2
Married	23751 (42.6%)	31.4	59.5	6.8
Widow/Widower	23217 (41.6%)	16.5	48.9	34.0
Divorced	2797 (5.0%)	27.9	56.4	10.5
Living environment*				
Alone	10161 (18.4%)	28.1	65.3	4.1
Private household	31131 (56.3%)	32.6	61.4	3.1
Institution	13756 (24.9%)	2.1	28.4	69.1
Other	289 (0.5%)	50.9	33.6	12.5

Presented percentages are row percentages except percentages in brackets (column percentages).

*: p-values for all variables <0.001 (Pearson χ^2-test for differences in proportion between all variable categories and all place of death categories).

†: The remaining category for place of death (2.2%) is not presented in the table.

‡: In 21,1% of the cases, the educational level was unknown.

Place of death according to residence and health care characteristics

Geographical variation by province was found in the proportion of home deaths (22.6 - 29.1%), hospital deaths (52.0-56.1%) and care home deaths (11.7-21.2%) (table 3). The proportion of home deaths increased and the proportion of hospital deaths decreased as municipalities were less urbanized.

The proportion dying at home, in hospital or in a care home differed little by health care variables such as hospital bed rate and rate of care homes. The density of general practitioners in the region was not at all related to the place of death (not shown in table).

TABLE 3. Place of death by residence and health care characteristics in Belgium (Flanders) 2001 (N= 55759†)

	No. of deaths (% of total)	% occurring at home	% occurring in hospital	% occurring in care home
Residence				
Province of residence*				
Antwerpen	15644 (28.1%)	22.6	54.8	20.6
Limburg	5952 (10.7%)	29.1	56.1	11.7
Oost-Vlaanderen	13700 (24.6%)	24.6	52.0	21.2
Vlaams Brabant	9218 (16.5%)	26.0	52.4	19.7
West-Vlaanderen	11245 (20.2%)	22.6	53.8	21.2
Degree of urbanisation*				
Core of large city	15395 (27.6%)	21.6	57.0	19.7
High	18391 (33.0%)	23.6	52.7	21.6
Average	19056 (34.2%)	26.9	52.3	18.3
Low or rural	2914 (5.2%)	27.4	51.0	18.7
Health care characteristics				
Hospital beds in health care area*‡				
<6,75 per 1000	28874 (51.8%)	24.8	53.8	19.2
>6,75 per 1000	26884 (48.2%)	23.9	53.5	20.4
Care homes in province*‡				
<13,5 per 100000	32841 (58.9%)	24.4	55.2	18.1
>13,5 per 100000	22918 (41.1%)	25.2	52.1	20.6

Presented percentages are row percentages except percentages in brackets (column percentages).

*: p-values for all variables <0.001 (Pearson χ^2-test for differences in proportion between all place of death categories).

†: The remaining category for place of death is not presented in the table.

‡: These health care system resource variables are dichotomised at their median values.

Multivariate analysis

For all deaths from natural causes, excluding acute cardiovascular deaths, we found seven factors associated with dying at home (table 4). The probability of dying at home strongly depended on the cause of death. The probability of dying at home was relatively high (compared to acute lower respiratory infections) for heart failures (odds ratio (OR)=7.63), non-ischemic chronic heart diseases (OR=7.40), diseases of the nervous system (OR=5.91), gastrointestinal malignancies (OR=5.69), and respiratory malignancies (OR=5.03). Patients with acute lower and other respiratory infections (OR=2.60), hematologic malignancies (OR=2.60) and cerebrovascular diseases (OR=2.15) had a relatively high probability of dying in hospital. Men and women had almost equal probabilities of dying at home, however women had a slightly lower probability. Controlling for all other influences, age had very little impact, but younger patients still had somewhat higher odds of dying at home. People who received a higher education were more likely to die at home than lower educated people (OR=1.41). People living in a private household had a higher probability of dying at home than people living alone (OR=1.29). Finally, residence played a role. Living in rural or slightly urbanized municipalities gave the highest odds for a home death. Dying at home became less likely when living in a health care region with a higher hospital bed rate.

The logistic regression for only the cancer deaths largely confirmed and strengthened the above reported findings. The analysis confirmed higher odds for a home death for gastrointestinal malignancies (OR=2.76) and lower odds for hematologic malignancies. Compared to hematologic malignancies, every type of malignancy had higher odds of dying at home. The differences between people with higher and no higher education (OR=1.61) and the differences between people living in a private household and people living alone (OR=2.50) were higher than for all chronic diseases together. Residence was also a higher factor for cancer patients. Not only the degree of urbanization and the hospital bed rate in the region influenced the place of death, but also the province of residence. Residing in the province of Limburg resulted in slightly higher odds of dying at home (OR=1.21).

Because of plural confounding elements (as mentioned in Section “Statistical analysis”) we chose to perform a separate analysis for the deaths aged 80 years or more, for natural causes as well as for cancers only. These analyses gave very similar results (not shown). The difference between Limburg and the other provinces and the influence of hospital bed availability were more pronounced than for those aged 45 -79 years.

TABLE 4. Logistic regression for home (1) vs. hospital death (0) for all cancer deaths only, and for all deaths (excl. sudden cardiac deaths) in Belgium (Flanders) 2001, aged 45-79

	Cancer deaths		All deaths (not acute cardiac deaths)	
	OR	95% CI	OR	95% CI
Cause of death				
Acute lower respiratory infections			1.00	1.00, 1.00
Other respiratory diseases			2.60	1.72, 3.91
Chronic lower respiratory infections			4.56	3.22, 6.46
Cerebrovascular disease (stroke)			2.15	1.52, 3.06
Diseases of the nervous system			5.91	4.02, 8.70
Heart failure			7.63	5.26, 11.09
Chronic ischemic heart disease			5.12	3.60, 7.28
Other heart disease			7.40	5.11, 10.73
Other cardiovascular diseases			4.49	3.05, 6.61
Hematologic malignancies	1.00	1.00, 1.00	2.13	1.45, 3.11
Genitourinary malignancies	2.35	1.87, 2.95	4.90	3.48, 6.90
Breast cancer	2.38	1.86, 3.04	4.87	3.41, 6.97
Respiratory malignancies	2.49	2.01, 3.09	5.03	3.60, 7.03
Gastrointestinal malignancies	2.76	2.22, 3.44	5.69	4.07, 7.97
Other malignancies	2.33	1.85, 2.94	4.64	3.29, 6.56
Residual (all other diseases)			3.36	2.40, 4.70
Sex				
Man *(vs. Woman)*	*	*	1.07	1.02, 1.17
Age				
Continuous (45-79)	*	*	0.99	0.99, 0.99
Education				
Higher education *(vs. no higher education)*	1.61	1.36, 1.92	1.41	1.23, 1.62
Living environment†				
Private household *(vs. Alone)*	2.50	2.19, 2.88	1.29	1.18, 1.41
Province of residence				
Limburg *(vs. other regions)*	1.21	1.05, 1.40	*	*
Urbanisation				
Core of large city	1.00	1.00, 1.00	1.00	1.00, 1.00
High	1.58	1.40, 1.78	1.27	1.16, 1.38
Average	2.04	1.81, 2.30	1.45	1.33, 1.58
Low or rural	2.21	1.80, 2.72	1.50	1.29, 1.74
Hospital bed availability				
<6.75 per 1000 *(vs. more)*	1.13	1.02,1.34	1.12	1.05, 1.20

Presented figures are odds ratios and 95% confidence intervals.

*: entered in the regression. but not significant and consequently eliminated by the stepwise procedure.

†: A problem of multi-collinearity between living environment and marital status made us omit the latter, as the living environment is a more important factor than marriage because it estimates in a much better way the extent of support from children or other relatives and friends [34]

DISCUSSION

Our results show that despite the fact that a large majority of dying people wish to die at home [8;17-22;35], only a quarter of all deceased in our country actually did. We found that mainly disease related characteristics determine dying at home. Most cardiovascular patients, most cancer patients, but also patients suffering from chronic lower respiratory diseases have a higher probability of dying at home than other patients. However, we also found important discrepancies in the chances of dying at home between certain categories (e.g. between higher and lower educated) that are less evident and need further attention. In contrast to previous studies about place of death, this study was not limited to a certain subgroup of deceased persons or a particular setting in health care, but involved the whole population [17]. We found only one other study about the place of death that used individual (and not ecological) death certificate data for all deaths in one year in a nation [29]. This study established for the first time in Belgium (Flanders) reliable information about the place of death, associated with clinical, socio-demographic and health care factors, especially by using multivariate statistical analyses.

Nevertheless there are some limitations to this study. First, the death certificates did not contain all data regarded as relevant in predicting the place of death [7;26;36;37], such as information about the income of patients or their household, qualitative information about the dying process, such as characteristics of the course of the disease and the predictability of death, or the use or need of a specific therapy. The lack of patient preferences in the place of dying is perhaps an even more important limitation. Second, the reliance on death certificates for the cause of death is a potential limitation, as there is evidence that the cause of death reported on death certificates can differ from the cause of death recorded from autopsy or medical records. The use of larger categories for the underlying cause of death and the use of large national data is a counterweight to this limitation. Third, the type of quantitative research we performed here reveals statistical patterns, but does not allow us to make any conclusive remarks about the choices, behaviors, attitudes or social processes that really underlie the patterns we found [13].

Dying at home might not always be the ultimate goal or the "good death" for everyone but indeed depends upon the need, the desirability, even the necessity of hospitalization or therapy. For example, for a person living alone and suffering from a severe respiratory infection requiring a specific therapy, dying at home might not be preferable and hospitalization might be more logical. It can thus be questioned whether the general wish to die at home is always "realistic". The alleged discrepancy between wishes and practice can largely be ascribed to the specificity of certain diseases and the implications they have for the possibility of "choice".

Cancer patients, for example, have other "patterns of dying" than most other chronically terminally ill [38;39]. In general, cancer patients have a longer survival after diagnosis and a somewhat more predictable course of disease, which allows them to better prepare for death and to plan for the needs of patients and their families [14;40]. The place of death is much more an issue of choice among cancer patients than among other patients. The use and need that individuals with specific diseases have for more complex, acute and aggressive treatments before the end of life will also be more likely to involve hospitalization and are sometimes associated with considerably higher mortality. This might hold for hematologic malignancies and cerebrovascular diseases (stroke). On the other hand, acute cardiovascular deaths often take place at home, which can logically be explained by the fact that they are sudden and unexpected [41].

However, despite these rather obvious reasons, some factors seem to limit dying at home without evident reasons. A striking discrepancy in the place of death seems to occur between different social groups. People without higher education more often die in hospital and less often at home. Among cancer patients, where choice is a stronger aspect, the effect is even larger. This is in line with previous findings [29]. Explanations can possibly be found in differing treatment or care preferences, but also in differing capabilities to express those preferences [42]. Because of cultural differences, communication and advance planning between lower educated people and physicians might be more difficult than for higher educated people, who have cultural resources more similar to those of their physicians. Another possibility is that the lower educated have less access to home-based care because of fewer financial resources. In Belgium, because of the particular way public health care is organized, home care is generally more expensive for the patient and his/her family than institutional care. It is also plausible that social class culture, with a greater value on autonomy among higher social classes, may cause differences in the degree to which people plan their dying trajectories together with their caregivers[43].

Chances of dying at home are also markedly lower for someone living alone than for someone living in a private household, especially among cancer patients. Although this might be due to differences in (financial) resources, it probably denotes the effect of the absence of informal caregivers. In many studies it was found that patients who did not reside with a spouse or another potential (healthy) informal caregiver and consequently did not dispose of social support had lower odds of dying at home [17;26;27;35;37]. Apart from being less realistic, it can also be frightening when dying at home means dying alone [44]. Another marked, but not so evident finding is the influence of geographical attributes on the place of death. The proportion of hospital deaths is indisputably higher in urban areas than in rural or slightly urbanized areas. This is in line with previous findings [6;13]. Next to the influence of the degree of urbanization of the municipality of residence there seem to be modest regional differences (depending on the province of residence) in the probability of a home death. These differences do not appear to be explained primarily by accessibility to a formal care facility. Despite our expectations based on previous research [28-31], health care characteristics had a modest effect. The differences between the provinces (for the cancer patients) and the rural and urban municipalities also remained after controlling for the hospital bed availability in the health region. It is also unlikely that access to public transportation or the distance to care settings plays a role in a densely populated region like Flanders. The regional differences might of course be due to policy effects. The supply of care facilities or services and resources to support dying patients and their families influences circumstances to manage the care at home [25]. Perhaps a possible explanation can better be found in the way the available health care facilities are used: the so-called "medical culture" [31;45]. The regional development of home based (palliative) care and the degree to which it is used (the "home-care culture"), as well as the professionals' ideas of 'best practice' and of a 'good death' might play an important role [45;46]. In Belgium palliative care originates from home care, with a naturally strong focus on dying at home. The (further) development of palliative care, both specialist and non-specialist and the extension of palliative care culture to hospitals and care homes might contribute to a different medical culture, allowing a greater percentage to die in their place of choice.

The regional and urban-rural differences are to some extent also likely to be explained by cultural-attitudinal factors, such as differences in "family culture" and interpersonal relationships, and the will and ability of the family unit to provide care inside the home [1;20;21].

CONCLUSIONS

Of all deaths in Flanders, more than half took place in a hospital, approximately a quarter at home and a fifth in a care home. The probability of home deaths varied by region, by rural or urban residence and by hospital bed availability in the region and was smaller among several non-malignant chronic diseases, lower educated people and people living alone. Although people often wish to die at home, most people in Flanders (Belgium) in 2001 did not die at home. The clinical, socio-demographic and residential factors that were found to be associated with the place of death could serve as focal points for a policy to facilitate dying in the desired place, including home death. For several categories shown to be less likely to die at home (lower educated, people living alone, many non-malignant patients, and people living in urban municipalities) further in-depth research needs to clarify whether they really are the “disadvantaged dying” (i.e. patients less likely to have their choices and preferences respected) and investigate the real reasons and social processes causing the observed differences. In doing so, nuanced and focused policy interventions can be suggested. Another question that needs to be addressed in future research is which part of the discrepancy between desire and reality is caused by elements that are amenable to policy intervention, so that a greater number of people may be able to die in their desired place.

REFERENCES

1. Wilson DM, Smith SL, Anderson MC et al. Twentieth-century social and health-care influences on location of death in Canada. Can.J.Nurs.Res. 2002;34(3):141-61.
2. Mezey M, Dubler NN, Mitty E, Brody AA. What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? Gerontologist 2002;42 Spec No 3:54-67.
3. Evans N, Walsh H. The organisation of death and dying in today's society. Nurs.Stand. 2002;16(25):33-38.
4. Payne SA, Langley-Evans A, Hillier R. Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. Palliat.Med. 1996;10(4):307-12.
5. Clark D. Between hope and acceptance: the medicalisation of dying. BMJ 2002;324(7342):905-7.
6. Bowling A. The hospitalisation of death: should more people die at home? J.Med.Ethics 1983;9(3):158-61.
7. Gallo WT, Baker MJ, Bradley EH. Factors associated with home versus institutional death among cancer patients in Connecticut. J.Am.Geriatr.Soc. 2001;49(6):771-77.
8. Tang ST, McCorkle R. Determinants of place of death for terminal cancer patients. Cancer Invest 2001;19(2):165-80.
9. Teno JM, Clarridge BR, Casey V et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004;291(1):88-93.
10. Catalan-Fernandez JG, Pons-Sureda O, Recober-Martinez A et al. Dying of cancer. The place of death and family circumstances. Med.Care 1991;29(9):841-52.
11. Grande GE, Farquhar MC, Barclay SI, Todd CJ. Caregiver bereavement outcome: relationship with hospice at home, satisfaction with care, and home death. J.Palliat.Care 2004;20(2):69-77.
12. Thomas C, Morris SM, Clark D. Place of death: preferences among cancer patients and their carers. Soc.Sci.Med. 2004;58(12):2431-44.
13. Brown M, Colton T. Dying Epistemologies: an analysis of home death and its critique. Environment and Planning A 2001;33:799-821.
14. Weitzen S, Teno JM, Fennell M, Mor V. Factors associated with site of death: a national study of where people die. Med.Care 2003;41(2):323-35.
15. Emanuel EJ, Emanuel LL. The promise of a good death. Lancet 1998;351 Suppl 2:SII21-SII29.
16. Bruera E, Sweeney C, Russell N, Willey JS, Palmer JL. Place of death of Houston area residents with cancer over a two-year period. J.Pain Symptom.Manage. 2003;26(1):637-43.
17. Temkin-Greener H, Mukamel DB. Predicting place of death in the program of all-inclusive care for the elderly (PACE): participant versus program characteristics. J.Am.Geriatr.Soc. 2002;50(1):125-35.
18. Townsend J, Frank AO, Fermont D et al. Terminal cancer care and patients' preference for place of death: a prospective study. BMJ 1990;301(6749):415-17.
19. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. J.Palliat.Med. 2000;3(3):287-300.
20. Choi KS, Chae YM, Lee CG et al. Factors influencing preferences for place of terminal care and of death among cancer patients and their families in Korea. Support.Care Cancer 2005.
21. Tang ST, Liu TW, Lai MS, McCorkle R. Discrepancy in the preferences of place of death between terminally ill cancer patients and their primary family caregivers in Taiwan. Soc.Sci.Med. 2005;61(7):1560-1566.
22. Tang ST, McCorkle R. Determinants of congruence between the preferred and actual place of death for terminally ill cancer patients. J.Palliat.Care 2003;19(4):230-237.

23. Schrijvers D, Joosens E, Vandebroek J, Verhoeven A. The place of death of cancer patients in Antwerp. Palliat.Med. 1998;12(2):133-34.
24. Van den Eynden B, Hermann I, Schrijvers D et al. Factors determining the place of palliative care and death of cancer patients. Support.Care Cancer 2000;8(1):59-64.
25. Ahlner-Elmqvist M, Jordhoy MS, Jannert M, Fayers P, Kaasa S. Place of death: hospital-based advanced home care versus conventional care. A prospective study in palliative cancer care. Palliat.Med. 2004;18(7):585-93.
26. Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? Soc.Sci.Med. 1998;47(5):565-79.
27. Grundy E, Mayer D, Young H, Sloggett A. Living arrangements and place of death of older people with cancer in England and Wales: a record linkage study. Br.J.Cancer 2004;91(5):907-12.
28. Mor V, Hiris J. Determinants of site of death among hospice cancer patients. J.Health Soc.Behav. 1983;24(4):375-85.
29. Hansen SM, Tolle SW, Martin DP. Factors associated with lower rates of in-hospital death. J.Palliat.Med. 2002;5(5):677-85.
30. Pritchard RS, Fisher ES, Teno JM et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. J.Am.Geriatr.Soc. 1998;46(10):1242-50.
31. Tolle SW, Rosenfeld AG, Tilden VP, Park Y. Oregon's low in-hospital death rates: what determines where people die and satisfaction with decisions on place of death? Ann.Intern.Med. 1999;130(8):681-85.
32. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J.Am.Geriatr.Soc. 2005;53(2):299-305.
33. Instruction Manual. Part 9. ICD-10 Cause-of-Death Lists for Tabulating Mortality Statistics (Updated October 2002 to include ICD codes for Terrorism Deaths for data year 2001 and WHO updates to ICD-10 for data year 2003). U.S.Department of Health and Human Services, Centers for Disease Control and Prevention National Center for Health Statistics. 2002. Hyattsville, Maryland.
    Ref Type: Generic
34. Axelsson B, Christensen SB. Place of death correlated to sociodemographic factors. A study of 203 patients dying of cancer in a rural Swedish county in 1990. Palliat.Med. 1996;10(4):329-35.
35. Karlsen S, Addington-Hall J. How do cancer patients who die at home differ from those who die elsewhere? Palliat.Med. 1998;12(4):279-86.
36. Higginson IJ, Jarman B, Astin P, Dolan S. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. J.Public Health Med. 1999;21(1):22-28.
37. Brazil K, Bedard M, Willison K. Factors associated with home death for individuals who receive home support services: a retrospective cohort study. BMC.Palliat.Care 2002;1(1):2.
38. Murtagh FE, Preston M, Higginson I. Patterns of dying: palliative care for non-malignant disease. Clin.Med. 2004;4(1):39-44.
39. Davies, E. and Higginson, I. J. Better Palliative Care for Older People. Davies, E. and Higginson, I. J. 2004. World Health Organisation Europe.
    Ref Type: Report
40. Burge F, Lawson B, Johnston G. Trends in the place of death of cancer patients, 1992-1997. CMAJ. 2003;168(3):265-70.
41. Brettle RP, Morris S, Epton V. Patients with HIV dying in Edinburgh: an audit of preference and place of death. Int.J.STD AIDS 1995;6(3):221-22.
42. Oliviere D, Monroe B. Death, dying and social differences. Oxford: Oxford University Press, 2004.
43. Seale C, Addington-Hall J, McCarthy M. Awareness of dying: prevalence, causes and consequences. Soc.Sci.Med. 1997;45(3):477-84.
44. Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older people's views about home as a place of care at the end of life. Palliat.Med. 2004;18(5):460-467.

45. Thomas C. The place of death of cancer patients: can qualitative data add to known factors? Soc.Sci.Med. 2005;60(11):2597-607.

46. Demarest, S., Van der Heyden, J., Gisle, L., Buziarsist, J., Miermans, PJ., Sartor, F., Van Oyen, H., and Tafforeau, J. Gezondheidsenquête door middel van Interview, België, 2001. Afdeling Epidemiologie. IPH/EPI REPORTS N° 2002 - 25. 2002. Brussel, Wetenschappelijk Instituut Volksgezondheid.
Ref Type: Report

8

Hospital deaths in six European countries: population-based cross national study of factors associated with dying in hospital

Joachim Cohen, Johan Bilsen, Julia Addington-Hall, Rurik Löfmark, Guido Miccinesi, Stein Kaasa, Bregje Onwuteaka-Philipsen, Luc Deliens

This paper has been submitted

ABSTRACT

PURPOSE

This population-based study examined the proportion of hospital deaths in six European countries (Belgium, England, Scotland, Sweden, The Netherlands, Wales), and to what extent country-variation in proportion of hospital deaths is related to demographic, epidemiologic, and health care factors.

METHODS

Data of all deaths in 2003 of the studied countries (2002 in Sweden) were gathered via official death certificate data, linkage with other population data files, and linkage with regional healthcare statistics, and were integrated into one common database (N=891,780) for analyses.

RESULTS

Of all deaths, 33.9% in The Netherlands to 62.8% in Wales occurred in hospital. The large country differences in hospital death rate were only partly explained by availability of care home beds and (to a lesser extent) availability of hospital beds. Country differences were strikingly large in older patients and cancer patients. Older patients had a higher probability to die in hospital in Sweden, Scotland, England, and Wales than in Flanders and (in particular) The Netherlands. Cancer patients often died in hospitals in Sweden (OR of dying in hospital versus outside hospital=4.07), but less frequently so in The Netherlands (OR =0.60), and England (OR=0.67).

CONCLUSION

Country differences in proportion of patients dying in hospital are only in part the result of differences in health care provision, and are in particular large for certain patient populations, suggesting country-specific end-of-life practices in these populations. Our findings can contribute to a rational planning of policy aimed at reducing hospital death rates for specific patient populations in the studied countries.

BACKGROUND

Within the context of end-of-life care hospital deaths are sometimes considered less ‘good deaths’ [1-3], in particular because they are often incongruent with people’s wishes [4;5]. These considerations have been challenged lately with the establishment of palliative care programs and units in many hospitals with an integrated caring pathway, including both hospital, nursing home, and home care as options to the patients[6]. Place of death and in particular reversing the hospitalisation-of-death [2;7-9] have also become a topic of wider interest for public health policy makers because of fiscal pressure, since dying in hospitals would be associated with higher health care expenditures [10]. A House of Commons Health Committee report (UK) has called for more care to allow people to die at home if they want to, explicitly referring to a cost-saving effect [11]. Many other European countries have implemented policy measures to reduce the number of (acute care) hospital beds as a means to restrict hospital expenditure [12;13]. Concerns of healthcare costs and the need to curtail long-term stay of an increasing number of older patients have stimulated some countries to develop specialised nursing homes providing continuous long-term and palliative care for dying people, while others have developed a combined approach with an addition of ‘acute’ palliative care beds in nursing homes [14].

Existing research on hospital deaths has been limited with regard to population, and a lack of standardization in study materials and methods makes cross national comparisons unreliable. No study has to our knowledge examined country-variation in hospital deaths, and the relative influence of demographic and health care policy factors in these country-differences. For a rational planning of policy to reduce hospital deaths, cross-national systematic and comprehensive information at population level is a major challenge [15].
In this study hospital deaths in six European countries were compared for a period of one year. The research questions of the study were:
What is the number of deaths occurring in a hospital?
Which factors contribute to explaining possible country differences in the proportion of hospital deaths?

METHODS

Study design and data

In the course of 2005 and 2006, all partners of the international collaborative research project "Dying Well in Europe" negotiated a database containing all deaths of the most recent available year for seven entire countries (Denmark, The Netherlands, Norway, Sweden, England, Wales, Scotland), two regions in Belgium (Flanders and Brussels), and three regions in Italy (Emilia Romagna, Tuscany, Milan). All databases were integrated in one common European database (except for Denmark where this was not allowed). Besides place of death, inclusion was aimed of a limited number of clinical, socio-demographic, residential and health care system factors, based on factors identified as relevant predictors of place of death in the literature [16-18].

Data analysis

Place of death was derived from patients' death certificate, and was dichotomized into hospital versus outside hospital for analyses. Analyses are limited to the countries in the common database where this dichotomization could be made. This comprises all 57,156 deaths in 2003 in Belgium (Flanders); all 141,936 in 2003 in The Netherlands; all 95,064 deaths in 2002 in Sweden; all 58,473 deaths in 2003 in Scotland; all 505,341 deaths in 2003 in England; and all 33,810 deaths in 2003 in Wales.

Independent variables included clinical, demographic and area of residence factors. For the clinical data, a classification of causes of death was made based on the ICD-10 codes on the death certificate data, in broad outlines following the instruction manual by the U.S. Department of Health and Human Services [19]. A 'palliative care subset' of causes of death was created by selecting all ICD-10 codes indicated by Rosenwax et al [20] to distinguish a population potentially benefiting from palliative care. Demographic information, sex and age at death, was obtained via the death certificate data of all countries. Codes for the place of residence of the deceased were either directly available via the death certificate data, or in the Netherlands by linking unique identifiers with another population database. For each place of residence, the rate (i.e. per 1,000 inhabitants) of available hospital beds (excluding psychiatric hospitals) and care home beds per health region (i.e. a region in which the majority of the people use the same health institutions and, in most countries, regions with certain autonomy for organization and expenditures in public health policy) were created, based on official health care statistics. To the care home beds we counted all beds in nursing homes and in residential homes for older people.

Statistical analysis

Percentages were used to describe country-differences in hospital deaths.

In order to identify factors possibly explaining country differences in proportion of hospital beds, a stepwise expanded multivariate logistic regression analysis compared the probability of dying in- or outside a hospital in all countries, controlling for confounding effects of age, sex, cause of death, and for the number of available hospital and care home beds. Three separate regressions were performed for all natural deaths (0-39 years, 40-79 years, 80 years and older) in order to create more homogeneous populations in terms of etiologic patterns.

Additionally, separate multivariate logistic regression analysis was performed for all deaths from natural causes in each country in order to estimate the associations of various factors with dying in hospital in the studied countries.

FINDINGS

Of all deaths, 3.2% (England) to 5.0% (Flanders) were accidents, suicides and homicides (external causes) (table 1). Cardiovascular diseases, in particular ischemic heart diseases were a more common cause of death in Sweden than in the other countries. Cancer was the cause of death in 22.4% (Sweden) to 26.9% (The Netherlands) of all deaths. Respiratory diseases occurred less often as a cause of death in Sweden than in other countries. Stroke was however a more common cause of death in Sweden, Scotland, England, and Wales. Diseases of the Nervous system were the cause of death in 2.2% (Scotland) to 3.0% (Wales) of all deaths. Some country differences were also found in the age at death (with more people over 80 dying in Sweden).

Considerable country variation was also noticed in the average number of available hospital beds (2.50 in Sweden, 3.03 in England, 3.67 in The Netherlands, 3.98 in Wales, 4.62 in Scotland, and 5.53 in Flanders) and care home beds (4.16 in Wales, 4.49 in Flanders, 7.75 in Scotland, 8.15 in England, 10.6 in The Netherlands, and 12.35 in Sweden) per 1000 inhabitants (not shown in tables).

Hospital deaths

The proportion of all deaths occurring in hospital ranged from 33.9% in The Netherlands to 62.8% in Wales (table 2). Additionally, of all deaths, 33.5% in The Netherlands, 22.2% in Flanders, 18.1% in Scotland, 17.2% in England, and 14.1% in Wales died in a care home (i.e. nursing home or residential home for older people). The Swedish data set did not register this information.

Country differences in hospital deaths were more or less manifested in practically all causes of death (table 2). However, there were in particular large country differences for cancer deaths. In Sweden 85.1% of all cancer deaths (and 90.8% of hematologic cancer deaths) occurred in hospital compared to 30.8% of all cancer deaths (and 46.8% of hematologic cancer deaths) in The Netherlands. As compared to most other patients, acute lower respiratory patients died relatively less often in hospitals in Sweden than in most other countries. Nervous system patients died relatively more often in a hospital in Wales.

No striking country-variation was found in differences between the sexes. However, some varying age-patterns seemed to emerge. Compared to the other countries (and relative to the general hospital death rate) hospital death was frequent in the older cohorts (70 to 89 years) in Sweden and Wales. After the age of 79 the proportion of people dying in a hospital dropped steadily in most countries, but remained quite elaborate in Wales. In particular for the oldest old (aged 90 and over) large country differences manifested: 16.3% of them died in a hospital in The Netherlands compared to about 50% or more in England and in Wales.

Table 1: Deaths in 2003* by cause of death, sex and age

	Belgium (Flanders)	The Netherlands	Sweden*	Scotland	England	Wales
Total nr of DEATHS	57 156	141 936	95 064	58 473	505341	33810
Cause of death†						
Deaths from external causes ‡	5.0	3.8	4.4	4.0	3.2	3.3
Cardiovascular diseases	27.7	25.0	34.1	26.7	27.3	28.9
Ischemic heart diseases	12.0	10.9	20.8	19.5	18.4	19.9
Heart failures	5.4	4.1	3.5	1.1	2.0	1.8
Other heart/ cardiovascular diseases	10.3	10.0	9.8	6.0	6.9	7.2
Malignancies	25.6	26.9	22.4	25.9	25.2	24.9
Gastrointestinal	6.9	7.7	7.0	7.2	6.9	7.1
Respiratory	6.7	6.5	3.4	6.9	5.5	5.2
Breast cancer	2.2	2.4	1.6	2.0	2.1	2.1
Genitourinary	4.2	4.4	5.3	4.0	4.4	4.4
Hematologic malignancies	2.0	2.1	2.1	1.8	2.0	1.7
Other malignancies	3.6	3.8	3.0	4.0	4.4	4.4
Respiratory diseases	12.6	10.0	6.9	12.7	13.9	13.8
Acute lower respiratory infections	5.2	4.4	3.3	5.2	6.6	6.1
Chronic lower respiratory infections	4.9	4.6	2.9	5.4	5.1	5.6
Other respiratory diseases	2.6	1.0	0.8	2.1	2.2	2.0
Cerebrovascular diseases (stroke)	8.6	8.1	10.5	11.1	10.7	11.0
Diseases of the nervous system	2.8	2.6	2.4	2.2	2.9	3.0
Other diseases	17.7	19.9	19.3	17.4	16.7	15.2
Sex (Women) †	50.1	51.4	51.8	52.4	52.8	52.5
Age †						
<69	23.6	26.9	19.5	28.8	23.8	23.8
70-79	27.2	25.8	22.8	27.2	25.3	26.8
80+	49.2	47.4	57.8	44.0	50.8	49.3

*: in Sweden, all deaths of 2002 were included

†: p-values for external vs. natural, among and within all major disease groups, for men vs. women, and for age groups <0.001 (Pearson χ^2-test for differences in proportion between all countries)

‡: deaths from external causes comprise accidents, suicides and homicides

Table 2: Percentage of deaths occurring in care homes and percentage of deaths occurring in hospital by cause of death, age and sex in 6 countries

	Belgium (Flanders)	The Netherlands	Sweden	Scotland[*]	England[*]	Wales[*]
Proportion of all deaths in care homes	22.2	33.5	†	18.1	17.2	14.1
Proportion of all deaths in hospital	51.6	33.9	62.5	58.5	58.1	62.8
Hospital deaths by cause of death						
Cardiovascular diseases[‡]	43.5	36.3	56.1	55.0	58.7	59.7
Ischemic heart diseases[‡]	*47.4*	*37.2*	*55.4*	*51.1*	*56.6*	*57.8*
Heart failures[‡]	*35.3*	*29.9*	*54.0*	*66.5*	*66.7*	*67.4*
Other heart/cardiovascular diseases[‡]	*43.2*	*38.0*	*58.3*	*65.6*	*61.9*	*63.0*
Malignancies[‡]	59.5	30.8	85.1	57.4	49.5	59.8
Hematologic malignancies[‡]	*70.9*	*46.8*	*90.8*	*73.7*	*70.0*	*77.6*
Other malignancies[‡]	*58.5*	*29.4*	*84.6*	*56.2*	*47.7*	*58.5*
Respiratory diseases[‡]	59.2	38.4	64.0	65.9	66.0	69.6
Acute lower respiratory infections[‡]	*60.9*	*30.2*	*55.9*	*62.1*	*63.4*	*66.8*
Chronic lower respiratory infections[‡]	*54.2*	*42.8*	*71.6*	*67.3*	*67.9*	*72.3*
Other respiratory diseases[‡]	*65.2*	*54.1*	*70.0*	*71.6*	*69.5*	*70.4*
Cerebrovascular diseases (stroke)[‡]	59.3	42.2	61.4	60.2	64.8	68.0
Diseases of the nervous system[‡]	32.9	18.1	42.3	44.6	45.0	54.4
Other deaths from natural causes[‡]	51.7	31.0	52.3	63.4	63.3	68.4
Deaths from external causes[‡][§]	33.5	37.3	52.1	45.9	50.0	47.5
Hospital deaths by age[‡]						
0-39	46.5	50.0	43.3	49.2	58.9	51.8
40-69	56.2	40.1	67.4	57.0	56.2	62.0
70-79	60.2	40.3	70.9	62.3	61.7	66.6
80-89	50.9	30.5	63.6	61.7	60.4	65.4
90+	33.5	16.3	47.0	48.1	49.8	53.0
Hospital deaths by sex[‡]						
Men	55.1	37.6	65.0	59.0	60.2	64.9
Women	48.1	30.5	60.1	57.9	56.3	60.8

*: In England and Wales, ‘hospital’ includes all NHS and non-NHS hospitals and excludes all NHS and non-NHS hospices. In Scotland ‘hospital’ comprises all hospitals and joint user hospitals

†: Care home was not registered as a category for the place of death on the Swedish data set

‡: p-values among and within all major disease groups, for men vs. women, and for age groups <0.001 (Pearson χ^2-test for differences in proportion of hospital deaths between all countries)

§:. Deaths from external causes comprise accidents, suicides and homicides

Multivariate regression to explain country-variation

A multivariate regression estimated country differences, controlling for differences in sex, age, cause of death, and number of available hospital beds (age group 0 to 39 years), and additionally for number of available care home beds (age group 40 to 79 years and 80 and older)

In the age group 0 to 39 years the probability to die in a hospital was almost 2 times more likely in Sweden than in The Netherlands (table 3).

Of those dying between 40 and 79 years, hospital death was more than two times more likely in England and Wales and more than four times more likely in Sweden.

In patients aged 80 and more, the hospital death probability was slightly higher in Flanders (OR=1.34), but considerably higher in Wales (OR=2.89), Scotland (OR=3.00), England (OR=3.49), and especially in Sweden (OR=5.17) than in The Netherlands.

In the three regression models, stepwise addition of sex, age and cause of death only modestly changed the differences between countries (not shown in table). Number of hospital beds also explained a small part of the country differences. However, addition of the number of care home beds (in model 2 and 3) explained a considerable part of the country differences, except for Sweden.

Table 3: Multivariate logistic regression estimating country differences in probability of hospital death*

	Age 0-39		Age 40-79		Age 80 and more	
	OR	95% CI	OR	95% CI	OR	95% CI
Country						
The Netherlands	1.00	1.00-1.00	1.00	1.00-1.00	1.00	1.00-1.00
Belgium (Flanders)	1.42	1.18-1.71	1.54	1.47-1.61	1.34	1.28-1.40
Sweden	1.98	1.67-2.35	4.52	4.37-4.67	5.17	5.01-5.32
Scotland	1.13	0.98-1.31	1.91	1.84-1.97	3.00	2.90-3.11
England	1.52	1.38-1.67	2.09	2.05-2.14	3.49	3.41-3.57
Wales	1.39	1.14-1.71	2.10	2.01-2.20	2.89	2.77-3.02

*: The multivariate logistic regression included country of residence, controlling for sex, age at death, cause of death, hospital bed availability, and care home bed availability. In the model for age 0-39 care home bed availability was not included in the regression. Due to some considerable interaction effects with the country of residence the odds ratio's for the other factors are not shown and can best be viewed for each country separately in table 4.

Associated factors per country

Multivariate logistic regressions per country showed that, in all countries, men had a higher probability to die in hospital than women (table 4). Most notably in The Netherlands, but also in Flanders, the probability of a hospital death is much lower at an older age (80+) than at a younger age. In Sweden, Scotland, England, and Wales these age differences are less pronounced. The manner in which causes of death, in particular malignancies, influence dying in hospital varied per country. Compared to ischemic heart diseases (reference category) cancers (not hematologic) were less likely as a cause of death to occur in a hospital in The Netherlands (OR=0.60), and England (OR=0.67), but more likely in Scotland (OR=1.19), Flanders (OR=1.40), and especially Sweden (OR=4.07). For hematologic malignancies hospital death was even 7.49 times more likely in Sweden, compared to 1.28 in The Netherlands. The palliative care diseases subset also less probably than non-palliative care diseases lead to hospital death in England, Scotland, and Wales, and more likely in Flanders, and Sweden.

DISCUSSION

Relatively large country differences exist in the proportion of deaths occurring in hospital, and these seemed not or hardly related to differences in cause of death, sex, age, and even availability of hospital beds. Availability of alternatives to hospital for older people (i.e. care home beds) explained to a more considerable amount why more people die in hospitals in some countries than in others. Considerable country differences were found in the probability to die in hospital of certain patient populations, in particular cancer patients and older patients.

This robust study including almost 900,000 deaths in six countries is, to our knowledge, the first to examine European country-variation in hospital deaths, the relative influence of demographic and health care policy factors on this, as well as differences in patterns for specific patient populations. It thereby adds to the knowledge of cross-national differences in place of death, which has been subject to misleading speculation. A major strength of this study was that of reliability and completeness: patterns are described within whole populations and not just for samples, and moreover across patient populations and across settings [21]. The demonstrated possibility of linking several data sources points to good opportunities of using death certificate data for similar purposes.

Table 4: Clinical and demographic factors associated with hospital death (multivariate logistic regression on all natural deaths)

	Belgium (Flanders)	The Netherlands	Sweden*	Scotland	England	Wales
Sex*						
men (vs. women)	1.17 (1.13-1.21)	1.18 (1.15-1.21)	1.15 (1.11-1.18)	1.07 (1.03-1.11)	1.19 (1.18-1.21)	1.22 (1.16-1.28)
Age†						
1—39	4.21 (3.58-4.94)	10.83 (9.91-11.83)	1.40 (1.23-1.60)	1.62 (1.43-1.83)	2.49 (2.38-2.60)	1.59 (1.32-1.91)
40-69	2.76 (2.59-2.94)	4.51 (4.30-4.74)	1.93 (1.83-2.03)	1.71 (1.61-1.82)	1.74 (1.71-1.78)	1.77 (1.63-1.91)
70-79	2.93 (2.76-3.10)	3.98 (3.80-4.17)	2.23 (2.13-2.33)	2.00 (1.88-2.12)	1.97 (1.93-2.01)	1.98 (1.84-2.13)
80-89	2.06 (1.95-2.17)	2.41 (2.30-2.52)	1.83 (1.76-1.90)	1.86 (1.76-1.97)	1.70 (1.67-1.72)	1.78 (1.66-1.91)
90+	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Cause of death‡						
ischemic heart disease	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
heart failure	0.78 (0.71-0.85)	1.00 (0.94-1.07)	1.12 (1.04-1.21)	2.25 (1.90-2.66)	1.82 (1.74-1.90)	1.80 (1.50-2.15)
other hearth & cardiovascular diseases	0.92 (0.86-0.99)	1.11 (1.05-1.16)	1.19 (1.14-1.26)	1.88 (1.73-2.03)	1.29 (1.26-1.32)	1.29 (1.17-1.42)
cerebrovascular disease	1.83 (1.70-1.98)	1.49 (1.41-1.56)	1.34 (1.28-1.41)	1.54 (1.45-1.64)	1.55 (1.52-1.59)	1.69 (1.55-1.84)
diseases of nervous system	0.52 (0.47-0.59)	0.36 (0.32-0.39)	0.57 (0.52-0.62)	0.79 (0.70-0.88)	0.63 (0.60-0.65)	0.90 (0.79-1.03)
respiratory infections	1.82 (1.70-1.95)	1.25 (1.19-1.31)	1.50 (1.41-1.59)	1.95 (1.83-2.07)	1.63 (1.59-1.66)	1.81 (1.67-1.96)
haematologic malignancies	2.46 (2.14-2.83)	1.28 (1.18-1.39)	7.49 (6.41-8.76)	2.63 (2.28-3.04)	1.69 (1.62-1.77)	2.42 (1.97-2.96)
other malignancies	1.40 (1.31-1.48)	0.60 (0.58-0.63)	4.07 (3.88-4.28)	1.19 (1.13-1.25)	0.67 (0.66-0.68)	0.99 (0.92-1.06)
residual	1.33 (1.25-1.42)	0.88 (0.84-0.92)	0.96 (0.92-1.00)	1.76 (1.67-1.87)	1.45 (1.43-1.48)	1.77 (1.64-1.92)
Palliative care subset‡§						
subset vs. other causes of death	1.24 (1.19-1.29)	/§	3.92 (3.77-4.09)	0.88 (0.84-0.91)	0.57 (0.57-0.58)	0.77 (0.73-0.81)

*: Odds ratios, controlling for age and cause of death

†: Odds ratios controlling for sex and cause of death;

‡: Odds ratios controlling for sex and age;

§: palliative care subset includes neoplasms, heart failure, renal failure, COPD, alzheimer, liver failure, Parkinson, motor neuron disease, Huntington, HIV/AIDS. In The Netherlands NL ICD10-codes were not present on the database, hence the subset could not be created

A number of limitations can be stated. First, due to the place of death variable being coded incompletely in some countries, not allowing distinguishing hospital versus out-of-hospital, only six of nine countries of which we collected data for this international study could be included in the analyses in this article. Second, a well known weakness of death certificates concerns cause of death miscoding and misclassification, although our use of large cause of death categories partly counters this. Possible country variation in (mis)classifications can not be excluded. Third, death certificates' use for non-etiological purposes is still not ideal. Information about patients' preferred place of death, or qualitative information about the dying process was not available for our study. Finally, some marginal drawings also need to be made as to the interpretation of cross national differences in place of death, in the sense that the character of settings might be country specific. Our analyses could for instance not take into account that care homes in The Netherlands possibly have a more medicalised character than in other countries.

Based on our study results, three interrelated possible explanations for cross national differences in proportion of hospital beds are plausible: availability of care, practice with regard to admitting certain patients, and societal expectations.

Availability of care

Previous research in the USA has indicated health-resource factors as the most important factors associated with place of death [3;22;23]. Variation between states in available hospital beds in large amount explained variation between states in place of death [22], and trends in available health resources explained trends in place of death [7;9]. Our research in Europe seems to indicate that the availability of hospital beds only plays a minor role in explaining European country-differences. Availability of alternatives for older people to hospitals (i.e. number of care home beds) explained differences between countries to larger amount. The relatively low availability of care home beds in Wales, and Flanders, compared to The Netherlands, could to a considerable part explain the higher probability of hospital death. However, the case of Sweden, with a low number of hospital beds and a high number of care home beds but a high probability of hospital death, illustrated that this factor can not fully explain country-variation. Possibly, other factors such as cross national differences in reimbursement policies [24], or possibilities for complex home care [6;17] play a role, but this can not be answered by our data. Another factor may be the national guidelines on medical treatment of advanced disease. One may speculate whether treatment policy for malignant diseases in Sweden is different from the other countries. If that is the case, such differences may have a major impact on utilization of health care resources at a national level

Admittance practice

However, a number of striking patterns in our data suggest differences in admittance practices in different countries, and possibly provide additional partial explanations for the large country differences.

First, country differences were specifically large for older patients. In Scotland, England, Wales, and Sweden, compared to Flanders and The Netherlands, in particular older people (aged 80 and over) relatively more often died in a hospital. While in Wales this was partly related to the lower availability of care alternatives for older people, this was less in Scotland, and England and certainly not in Sweden the case. An explanation can likely be found in different countries or regions having different practices with regard to transferring older people from the care home to the hospital right before their death[25]. In this line of thinking we can possibly explain why, whereas many live in sheltered homes for older people in Sweden, hospital is often the place of death for them. Of course, the type and quality of care facilities at hand in care homes will also play an important role. The specific character of Dutch nursing homes as long term care institutions, with explicit non-transfer policies likely explains the lower hospital death rates in the Netherlands [14]. In this context it can be noted that care homes are different in content in different countries, and that this probably explains some of the cross-national differences. Additionally, cross-country variation in social inequalities or ageism in end-of-life care can play a role here. Research in the UK and other countries for instance indicated worse access to specialist palliative care or hospice services for older people [16;26].

Second, large country differences in hospital deaths were found depending on the nature of the terminal illness, most obviously so in cancer patients. In Sweden cancer patients very likely died in a hospital (more than four times more likely than ischemic heart patients). However, in The Netherlands and in England (and somewhat less in Wales) cancer patients had good chances of dying outside a hospital. This probably reflects an influence of both availability of care (i.e. offering of care alternatives to hospitals for cancer patients like palliative home care or hospices) and admittance practice (admission of cancer patients to palliative care). In this context, the fact that specifically cancer patients and patients in the palliative care subset had good odds of dying outside a hospital in England could be related to the long tradition and development of palliative care and hospice care for these patients (including the provision of a large number of hospice beds [27]). However, our data also seem to render some support for indications in the literature that England's palliative and hospice care focuses predominantly on cancer patients and not so much on non-malignant patients potentially benefiting from palliative care[28]. Patients suffering from heart failure were for example relatively likely to die in a hospital in England compared to those in The Netherlands, or Flanders.

Societal expectations

Of course, cultural factors, like differences in medical culture and in avoidance of death, resulting in country specific attitudes towards hospital as an appropriate place of death for older people possibly play a role [7;29]. Societal expectations towards caring for (frail) older people or provision of palliative care for certain patient groups probably influenced the patterns we found.

In summary, our study demonstrates that large country differences exist in the proportion of patients dying in hospitals, and that these differences are accounted for in part by provision of health care services and resources but also in part by differing practices surrounding death in specific patient populations like cancer patients or older patients. These also illuminate broader cultural values [29]. Keeping in mind that a lower hospital death rate is not a priori better, these findings can contribute to a rational planning of policy aimed at reducing hospital death rates in the studied countries. Next to the provision of care alternatives to hospital for older people and cancer patients, which are likely to have some effect, attention will have to be paid in each country to those factors and mechanisms contributing to specific patient populations markedly more often dying in hospital than in other countries.

Identification of patients at higher risk of hospital mortality should also be acknowledged by appropriate planning and implementation of palliative care services in hospitals [30;31]. Future research will therefore have to focus on shortcomings in these end-of-life services for specific patient groups in specific locations in different countries. A major challenge of future research is also to better map out the actual cost-saving effect of a reduction of the proportion dying in hospital, and simultaneously expand specialized and non-specialized palliative care services, both in hospital and in care homes.

ACKNOWLEDGEMENTS

The contents of this article are part of the Dying Well in Europe project. The following persons contributed to the preparations for this study:

Italy: Antonio Russo (Local Health Authority of Milan), Alessia Furini (Servizio Sanità Pubblica Assessorato alla Sanità Regione Emilia-Romagna), Lucia Giovannetti (Regional Mortality Register Regione Toscana); United Kingdom: Alison O'Callaghan (School of Nursing and Midwifery, Southampton University), Geoffrey Hanks (Department of Palliative Medicine, University of Bristol); Norway: Finn Guttvik (Norwegian University of Science and Technology Trondheim); The Netherlands: Gerrit van der Wal (VU University medical centre Amsterdam).

We also want to acknowledge the offices providing the data files: Belgium: Preventive and Social Heath Care Division of the Ministry of Flanders (Flanders); Sweden: Statistics Sweden; The Netherlands: Statistics Netherlands, Scotland: Statistics Scotland, England and Wales: Office for National Statistics.

This study was supported by a grant from the Research Council of the Vrije Universiteit Brussel (GOA 27).

REFERENCES

1. Barbera L, Paszat L, Chartier C. Death in hospital for cancer patients: an indicator of quality of end-of-life care. Palliat.Med. 2005;19(5):435-36.

2. Bowling A. The hospitalisation of death: should more people die at home? J.Med.Ethics 1983;9(3):158-61.

3. Gallo WT, Baker MJ, Bradley EH. Factors associated with home versus institutional death among cancer patients in Connecticut. J.Am.Geriatr.Soc. 2001;49(6):771-77.

4. Tang ST, McCorkle R. Determinants of congruence between the preferred and actual place of death for terminally ill cancer patients. J.Palliat.Care 2003;19(4):230-237.

5. Beccaro M, Costantini M, Rossi PG, Miccinesi G, Grimaldi M, Bruzzi P. Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). J.Epidemiol.Community Health 2006;60(5):412-16.

6. Jordhoy MS, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, Kaasa S. A palliative-care intervention and death at home: a cluster randomised trial. Lancet 2000;356(9233):888-93.

7. Wilson DM, Smith SL, Anderson MC et al. Twentieth-century social and health-care influences on location of death in Canada. Can.J.Nurs.Res. 2002;34(3):141-61.

8. Yun YH, Lim MK, Choi KS, Rhee YS. Predictors associated with the place of death in a country with increasing hospital deaths. Palliat.Med 2006;20(4):455-61.

9. Davies E, Linklater KM, Jack RH, Clark L, Moller H. How is place of death from cancer changing and what affects it? Analysis of cancer registration and service data. Br.J.Cancer 2006;95(5):593-600.

10. Burke K. Palliative care at home to get further funds if it saves money. BMJ 2004;328(7439):544.

11. House of Commons Health Committee. Palliative Care. Fourth Report of Session 2003–04. Volume 1. 2004. London, House of Commons.
    Ref Type: Report

12. Kroneman M, Siegers JJ. The effect of hospital bed reduction on the use of beds: a comparative study of 10 European countries. Soc.Sci.Med. 2004;59(8):1731-40.

13. Dudgeon DJ, Kristjanson L. Home versus hospital death: assessment of preferences and clinical challenges. CMAJ. 1995;152(3):337-40.

14. Schols JMGA, Grebolder HFJM, van Weel C. Nursing Home and Nursing Home Physician: The Dutch Experience. J Am Med Dir Assoc 2006;5:207-12.

15. Singer PA, Wolfson M. "The best places to die". BMJ 2003;327(7408):173-74.

16. Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? Soc.Sci.Med. 1998;47(5):565-79.

17. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ 2006;332(7540):515-21.

18. Cohen J, Bilsen J, Hooft P, Deboosere P, Wal G, Deliens L. Dying at home or in an institution Using death certificates to explore the factors associated with place of death. Health Policy 2006;78(2-3):319-29.

19. Instruction Manual. Part 9. ICD-10 Cause-of-Death Lists for Tabulating Mortality Statistics (Updated October 2002 to include ICD codes for Terrorism Deaths for data year 2001 and WHO updates to ICD-10 for data year 2003). U.S.Department of Health and Human Services, Centers for Disease Control and Prevention National Center for Health Statistics. 2002. Hyattsville, Maryland.
    Ref Type: Generic

20. Rosenwax LK, McNamara B, Blackmore AM, Holman CD. Estimating the size of a potential palliative care population. Palliat.Med 2005;19(7):556-62.

21. Temkin-Greener H, Mukamel DB. Predicting place of death in the program of all-inclusive care for the elderly (PACE): participant versus program characteristics. J.Am.Geriatr.Soc. 2002;50(1):125-35.

22. Hansen SM, Tolle SW, Martin DP. Factors associated with lower rates of in-hospital death. J.Palliat.Med. 2002;5(5):677-85.

23. Pritchard RS, Fisher ES, Teno JM et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. J.Am.Geriatr.Soc. 1998;46(10):1242-50.

24. Intrator O, Mor V. Effect of state Medicaid reimbursement rates on hospitalizations from nursing homes. J.Am.Geriatr.Soc. 2004;52(3):393-98.

25. Mor V. Hospitalization of Nursing Home Residents: A Review of Clinical, Organizational and Policy Determinants. Providence: Brown University, 1998.

26. Burt J, Raine R. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. Age and Ageing 2006;35(5):469-76.

27. The National Council for Palliative Care. National Survey of Patient Activity Data for Specialist Palliative Care Services. MDS Full Report for the year 2005–2006. http://www.ncpc.org.uk/download/mds/MDS_Full_Report_2006.pdf . 2006.
    Ref Type: Electronic Citation

28. Addington-Hall J, Fakhoury W, McCarthy M. Specialist palliative care in nonmalignant disease. Palliat.Med. 1998;12(6):417-27.

29. Lloyd L. Mortality and morality: ageing and the ethics of care. Ageing & Society 2004;24(2):235-56.

30. Pantilat SZ, Billings JA. Prevalence and structure of palliative care services in California hospitals. Arch.Intern.Med. 2003;163(9):1084-88.

31. Cardenas-Turanzas M, Grimes RM, Bruera E, Quill B, Tortolero-Luna G. Clinical, sociodemographic, and local system factors associated with a hospital death among cancer patients. Support.Care Cancer 2005.

Part 4

Main findings and general discussion

> « “(…) *‘making’ a death good or bad is an active process in which both dying people and those around them participate, showing some elements that appear to be shared across many cultures, and others that appear to be less widespread”* »
>
> *(Seale & van der Geest, 2004)*[1]

9

Main findings and general discussion

Page

9.1 Introduction 170

9.2 Methodological considerations, strengths and limitations 170

9.3 Main findings 174

9.4 General discussion 181

  9.4.2 End-of-life decisions: attitudes and behaviour 181

  9.4.3 Place of death 188

  9.4.4 Place of death and end-of-life practice 193

9.5 Implications and recommendations for policy and practice 194

  9.5.1 Healthcare policy 194

  9.5.2 Healthcare professionals 203

9.6 Further research 206

9.1 Introduction

Although the aim of this dissertation was not to map out all end-of-life problems possibly impeding the accomplishment of a ‘good death’, or to prescribe how a ‘good death’ can be achieved, this dissertation highlighted three highly relevant public health issues in this context. First, it explored views of the public towards euthanasia, and physicians’ views towards euthanasia and other end-of-life decisions, as well as their actual end-of-life decision-making (in relation to physicians’ life-stances). Second, we also examined how different places of death are associated with a different end-of-life practice. Third, the dissertation contributed to answering a central question in end-of-life care, why many people tend to die in hospitals and outside home, whereas home is mostly the desired place of death. All three issues are highlighted in a wide (cross-national) European context.

In this discussion section, we will first consider some methodological strengths and limitations of the studies used in this dissertation. Second, keeping these in mind, we will briefly recapitulate our main findings in answer to the research questions posed in the introduction of this thesis. Third, we will further discuss some of the striking findings (and their interpretation) more into depth and in relation to each other. Fourth, we will formulate some implications and recommendations for public health policy and for health care practice. Finally, heeding the limitations of our own study results, we will formulate a number of recommendations for future research.

9.2 Methodological considerations, strengths and limitations

A. European Values Studies

The findings with regard to public attitudes towards euthanasia in chapter 2 and chapter 3 are based on the European Values Studies (EVS). Major strengths of these studies are a relatively good overall response, large sample sizes, and especially the large cross national design with standardised research protocols and questionnaires in several European countries. The latter allowed us to make reliable cross-national comparisons, where previous studies were mostly limited to one country and lacked standardisation in questions used, impeding the comparison of attitudes and beliefs of the public from different regions over the world or at different points in time [2-4]. Another major strength was the study's (pseudo) longitudinal design. Repetition of the surveys with regular time intervals allowed us to, for the first time, examine trends in euthanasia attitudes in several countries simultaneously and relate these trends to other relevant changes in society.

Also, several limitations must be stipulated before interpreting the results. First, the EVS used only one question to measure acceptance of euthanasia, whereas in reality these attitudes are of course complex. Public attitudes towards euthanasia embrace legal attitudes, personal permissiveness, aspects of humaneness, personal experiences, religious concerns… Survey data, and especially a single question, cannot fully capture the understanding of these complex public attitudes to euthanasia[5]. Attitudes towards euthanasia will moreover clearly also vary according to (differing) interpretations [3;4;6-9] and according to several clinical conditions or circumstances (e.g. age of the patient, the degree of suffering, consciousness and mental alertness of the patient) [3;9-14]. Second, the euthanasia question in EVS differs from the definition used in medical literature today, defining euthanasia as the administering of a lethal dose of drugs with the explicit intention of ending the patient's life, at his/her explicit request [15]. The EVS description of euthanasia ("terminating the life of incurably ill"), especially the omission of the qualification 'at the explicit request of the patient', could have affected the degree of acceptance. Finally, while we investigated many factors associated with euthanasia acceptance and possible confounders, several factors possibly influencing it could not be examined, such as health status of the respondent or satisfaction with health care services.

B. European End-of-life Decisions Study II (Eureld 2)

A first strength of the Eureld 2 physician survey is that it is not only limited to attitudes, but also inquires about intended behaviour in hypothetical cases, as well as about actual behaviour. This allowed not only to indicate possible differences between attitudes and behaviour, but also to examine how certain factors, in our case life-stance, influence attitudes and behaviour in a different way. Other methodological strengths of the Eureld 2 physician survey were the good response, the relatively large sample size, and the systematic cross national comparison.

A limitation is that non-responders bias can not be excluded. A non-response study for the Eureld 2 data in Denmark, The Netherlands, Sweden, and Switzerland found a small participation bias [16;17].

C. European End-of-life Decisions Study I (Eureld 1)

The strengths of physicians' death certificate studies to examine end-of-life decision making have repeatedly been demonstrated [18-22]. The death certificate method employed in Eureld 1 is probably the most reliable method to make epidemiological estimates, as it allowed taking representative samples from all death certificates in each country or region participating to the study, during a certain period. Other studies have tried to map out end-of-life decision making by interviewing a sample of physicians about the last recalled case [19;23;24]. However, this method is more susceptible to recall bias and still does not allow making reliable epidemiological estimates [25]. An additional advantage of the death certificate method is that all information gathered via the physician questionnaire (which is of course kept reasonably short), can be linked to the information on the death certificates for the respective death. A particular major strength and contribution of Eureld 1 was that it, in employing standardised research protocols and questionnaires, compared end-of-life decision making in several European countries. Before the study reliable estimates had only been made for The Netherlands [26] and Belgium [22]. Finally, the Eureld 1 study generated large sample sizes and relatively good response.

A number of limitations are intrinsic to the death certificate method: a possible bias by nonresponse, a possible recall bias due to the retrospective design, a possible rater bias since we rely on the physician and not on the patient perspective, and a possible bias in giving socially desirable answers. A more specific limitation, pertinent to the study in Chapter 5 is that neither the physician questionnaire (since it had to be short in order not to overburden the physicians) nor the death certificates gave us all relevant information about the patient or about the complex end-of-life decision making process. The decision making could therefore not be situated within a broader process of end-of-life care, and – more importantly- we could not assess the influence of the changing clinical situation, competence, and preferences of the patient throughout the process.

D. Death certificate data

The major strengths and limitations of using death certificate data to study the place of death (as in Chapter 5,7, and 8) are extensively described in the methodological chapter 6, completely devoted to this subject. We limit ourselves here to a summary of these strengths and weaknesses.

Major strengths are that death certificate data allow describing total populations instead of samples, and hence allow using large numbers (i.e. statistical power). This also makes it possible to study many associated factors and various subpopulations. Also, analyses from death certificate data are not (necessarily) limited to specific patient populations and settings. Other strengths are the possibility of linking death certificate data with other relevant data files (e.g. health care data), and the possibility to make cross national comparisons and to study trends. Finally, death certificate data are relatively cheap and easy to obtain.

There are also several weaknesses. First, variation between countries occurred in the quality and the type of information on certificates and on death certificate data files (e.g. in categories listed in the 'place of death' variable). Second, possible miscodings and misclassifications, especially with regard to cause of death, are inherent to death certificates. Finally, they do not give all relevant information in predicting place of death.

9.3 Main findings

The following research questions were posed in the introduction of this dissertation:

End-of-life decisions: attitudes and behaviour:

1. How has the acceptance of euthanasia among the general pubic changed over the last decades, and what factors have contributed to this change?
2. What is currently the degree to which euthanasia is accepted throughout Europe? Are there large differences between European countries, and, if so, how can these be explained?
3. What are the attitudes towards and the intended and actual behaviour of physicians in end-of-life decision making? What is the specific influence of religion?

End-of-life decisions and place of death:

4. Are different places of death associated with different end-of-life practices?

Place of death:

5. How appropriate are death certificates to study the place of death and associated factors? What are the opportunities and what are the weaknesses?
6. Where do people die in Belgium and in other European countries and what factors influence where they die? Are there striking inequalities?
7. What explanations can be given for (possible) differences in place of death between European countries, and can these explanations give suggestions for health policy makers?

1. Trends in public acceptance of euthanasia and factors contributing to these trends

Our study of 46,199 respondents in 1981, 1990 and 1999-2000 in 12 West European countries demonstrated in all countries but West-Germany a significant increase in acceptance of euthanasia among the general public. The countries with the strongest increase of euthanasia acceptance were respectively Belgium (69%), Ireland (56%) and Spain (52%). The increase was less strong (but still strong) in Sweden (36%), Northern Ireland (31%) and France (31%). In Northern Ireland, it must be noted, the acceptance nevertheless remained very low despite this strong increase. A moderate increase was noticed in Iceland (29%), Italy (27%), and the Netherlands (23%). Great Britain (13%) and Denmark (9%) had the weakest increase in public acceptance of euthanasia in the studied period. West Germany was the only country with no increase in euthanasia acceptance.

As to the factors that contributed to this change, we demonstrated an influence of the decrease in religious beliefs (~secularisation), the rising belief in the right to self-determination, and (to a lesser extent) the rise in educational attainment. However, our results also clearly demonstrated that these changes did not contribute to the change in euthanasia acceptance in the same manner in all countries. Other, country-specific, factors seem important as well.

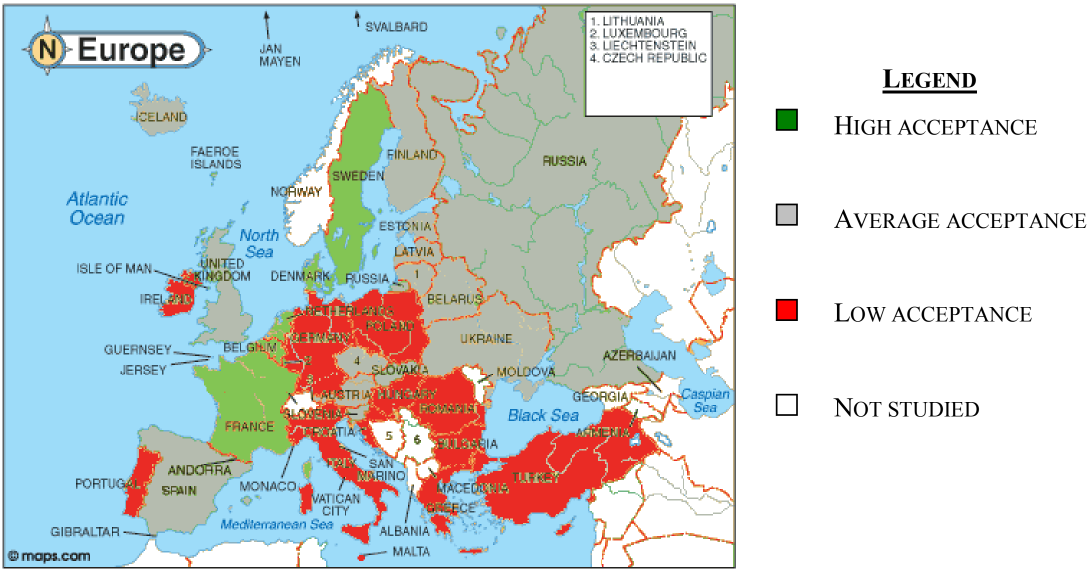
2. Euthanasia acceptance throughout Europe and cross national differences

There is not one common acceptance of euthanasia throughout Europe. Acceptance was high in The Netherlands but very low in Malta. Generally, we could say that there are three clusters of countries (see Figure 1):

- countries with a high acceptance, respectively The Netherlands, Denmark, France, Sweden, Belgium, and Luxembourg
- countries with an average acceptance, respectively Russia, Czech Republic, Finland, Belarus, Lithuania, Slovenia, Iceland, Latvia, Ukraine, Estonia, Great Britain, Slovakia, Spain, and Austria
- countries with a low acceptance, respectively Germany, Greece, Northern Ireland, Italy, Hungary, Croatia, Bulgaria, Portugal, Poland, Ireland, Romania, Turkey, and Malta

Several factors were identified as explanations for the large country differences. Demographic differences (e.g. age and educational attainment) accounted for a very small part of the differences between countries. Religious beliefs were a much better predictor of countries' stances towards euthanasia. However, our results also indicated that the effect of (differences in) religious beliefs should not be overestimated and that certain countries seemed to have a very idiosyncratic stance towards euthanasia. While highly-religious, less-permissive countries were generally less, and highly-permissive, low-religious countries generally more tolerant towards euthanasia, a number of countries did not fit in this logic. This led us to believe that attitudes seemed sometimes very country-specific, related to the countries' own tradition and history.

Figure 1: Map of Europe, coloured according to degree of acceptance of euthanasia



Source: maps.com, coloured according to our own results (see page 237 for colour version)

3. Attitudes and (intended) behaviour of physicians in end-of-life decisions: the influence of life-stance

Acceptance of a possible life-shortening due to pain and symptom alleviation and acceptance of withdrawing possibly life-prolonging treatment were generally high among physicians, and usually almost as high among Protestant or Catholic physicians as among non-religious physicians. Using lethal drugs (e.g. in euthanasia) was clearly less accepted by religious than by non-religious physicians, most obviously so in Belgium.

Similar patterns and differences were found in the intended behaviour (i.e. in hypothetical patients), however differences tended to be less significant. Both religious and non-religious physicians indicated a high inclination to alleviate pain and symptoms even if a life-shortening of the (hypothetical) terminally ill patient can be foreseen (78% to 100% if the patient requests this). The willingness to terminally sedate the patient also differed little in religious and non-religious physicians. However, very large variation was found between religious and non-religious physicians (and across countries) in the reluctance to administer lethal drugs. About 3% to 49% of religious physicians and 4% to 82% of non-religious physicians were willing to do this if the patient requests it; and respectively 2% to 22% and 2% to 42% if the patient does not request it (e.g. compassionate assisting in dying).

In the actual decision-making, differences between life-stances were again smaller. Possibly life-shortening pain and symptom alleviation and terminal sedation had been performed almost as frequently by religious as by non-religious physicians. Only the reported actual administration of lethal drugs showed marked differences between non-religious and religious physicians. Nevertheless, in most countries both Catholics (up to 15.7% in The Netherlands) and Protestants (up to 20.4% in the Netherlands) reported ever having made such a decision.

Thus, religious beliefs influence physicians' views on end-of-life decision-making, but less the actual decision-making, when dealing with real patients and circumstances. Our results indicated that religious physicians are also susceptible to circumstances (e.g. the degree of suffering of the patient, a request of the patient), and hence allowed for adaptation to particular situations.

Finally, a marked finding was that stronger differences were found depending on the country of residence than depending on the physicians' life-stances, which seemed to suggest a pertinent influence of the surrounding (secular) culture, also on the manner in which religious physicians frame their opposition to certain end-of-life decisions.

4. End-of-life decisions and place of death

Of all non-sudden deaths from 0.4% in Sweden to 2.8% in Belgium were preceded by physician-assisted death, 21.4% in Sweden to 39.0% in Denmark were preceded by possibly life-shortening pain and symptom alleviation, and 20.9% in Denmark to 40.8% were preceded by non-treatment decisions. However, in all countries clear variation was found in the incidence (and type) of end-of-life decisions by the place of death, even after controlling for cause of death, sex, and age of the patient. Physician-assisted dying tended more often to take place at home; terminal sedation (especially in combination with the withdrawal of food and fluid administration) occurred less often at home or in care homes than in hospitals; and non-treatment decisions mostly occurred in hospitals (but also very frequently in care homes in Belgium and Switzerland). Possibly life-shortening pain and symptoms alleviation occurred more or less in the same degree in all settings.

A number of striking differences in the decision-making process were also found between the different places of death. Discussion with other caregivers (e.g. other physician, nurse) occurred much less frequent at home. Discussions with patients, however, usually occurred more often at home than in institutions. Relatives, finally, tended to be more involved in discussions on end-of-life decisions at home than in a hospital, and in Belgium and Denmark (but not in Sweden and Switzerland) also clearly more often in care homes than in hospitals.

5. Studying place of death and associated factors: appropriateness of death certificate data

Next to well known general weaknesses of cause of death miscoding and possible country and time variation in (mis)classifications in death certificates [27;28], our study in nine European countries (Chapter 6) demonstrated considerable variation between countries and regions in the quality and type of information on death certificate data, resulting in a differential suitability of death certificate data (place of death variable and other variables). Perhaps a more important limitation in the specific context of studying place of death is that a lot of relevant information in the context of place of death could not be known from death certificate data [29-32].

The primary identified strength was that death certificate data can describe patterns within a whole population and not just for a sample. Therefore it was also not limited to certain patient populations or settings, which is a problem in many previous research [33]. The good statistical power associated with this can lead to more reliable results. Additionally, the availability of several variables on the death certificate data make it possible to construct good multivariable statistical models, or to generate meaningful results for specific subpopulations (e.g. lung-cancer or HIV patients, low educated people, specific regions) [34]. The possibilities of linkage with information from other databases even enhanced these opportunities. Another major strength is that death certificate data can be used to make relatively reliable comparisons of temporal trends of place of death across nations, and placed against other mortality trends (e.g. cause of death, age, living conditions).

6. Place of death and associated factors in Belgium and Europe

In 2001, the Belgian (Flemish) proportion of hospital deaths was at 53.7% (Chapter 7). At that time, 19.8% died in a care home and 24.3% died at home.
In 2003 the proportion of hospital deaths in Belgium had dropped to 51.5% (Chapter 8). Relatively large country differences were found in the place of death in 2003. In the Netherlands only 33.9% of all deaths occurred in a hospital. In England (58.1%) and Scotland (58.5%) this proportion was considerably larger, and it was almost twice as large in Sweden (62.5%) and Wales (62.8%).
Looking at the place of death for cancer patients only, we saw that in 2001 (in Belgium, Flanders) 29.1% of them died at home, 8.9% in a care home, and 61.9% in a hospital (Chapter 7). In 2003 the percentage of cancer deaths in a hospital in Belgium (Flanders) had decreased to 59.5% (Chapter 8). Focusing only on cancer patients also demonstrated even more profound country differences in place of death. The percentage of hospital deaths in this population ranged from 30.8% in The Netherlands and 49.5% in England, to 85.1% in Sweden.

We found four types of associated factors: clinical, socio-demographic, social support, and health system characteristics.

Clinical

The type of (terminal) disease influenced the probability to die at home, in a hospital or in a care home (Chapters 7 and 8). (Acute) cardiovascular deaths often took place at home, and cancer (not haematological) patients usually also had a good probability to die at home (or outside a hospital). However, the latter seemed to vary strongly between countries (Chapter 8). In Sweden cancer patients had a very high probability to die in hospital, whereas in particular in The Netherlands and in England this probability was relatively low. Belgium (Flanders) was somewhere in between.

Socio-demographic

Striking discrepancies in the place of death were found between different social groups. First, age differences in the place of death were found. In Belgium, the probability to die at home (compared to in a hospital) slightly decreased with age (Chapter 7). Age differences occurred in several countries and the magnitude of these differences proved to be country specific (Chapter 8).

Second, people without higher education more often died in hospital and less often at home. Among cancer patients this difference was even more manifest.

Finally, the people residing in urban areas usually had higher odds of dying in hospital than people in rural or slightly urbanized areas.

Social support/Family

Dying at home proved to be markedly less likely for someone living alone than for someone living in a private household (i.e. with a potential informal caregiver).

Health resources

Greater availability of hospital beds in a healthcare region increased the probability of hospital deaths. However the effect was smaller than in previous (American) research. Greater availability of care home beds decreased the probability of hospital deaths. However, this was especially true for all countries in the UK, and did much less explain regional differences in Belgium and The Netherlands.

7. Cross-national differences in place of death: some explanations

The clear country differences in hospital deaths were barely related to the (small) etiological and demographic differences between the studied countries. The availability of hospital beds, contrary to our expectations based on the literature, explained only a relatively small part of the country-differences. However, the number of care home beds explained country differences in hospital death to a larger amount. Nevertheless care home beds did neither fully explain country-variation in hospital or out-of-hospital death. Sweden, for instance had a great number of care home beds but also a large proportion of hospital deaths. Clearly, other factors also play a role.

In this context our data suggested two particularly striking patterns.

First, country differences were especially large when we only considered older patients, suggesting a country-differential care policy and (admittance) practice in older people.

Additional analyses on Belgian and Dutch data for instance pointed to different practices with regard to the transferral of older people from the care home to the hospital right before their death: about one seventh of older people living in Dutch care homes died in a hospital compared to one quarter in Belgian (Flemish) care homes.
Second, country differences were particularly large for certain types of terminal illness, most obviously cancer. Whereas in Sweden cancer patients very likely died in a hospital, they had good chances of dying outside a hospital in The Netherlands and in England.

9.4 General discussion

9.4.1 End-of-life decisions: attitudes and behaviour

Several points of and throughout the main findings on end-of-life decisions deserve further discussion and interpretation. First, a noticeable point was that in several countries there seemed to be a large difference, even opposition, between the general public and physicians as regards attitudes towards euthanasia. Second, a number of important socio-demographic differences were found in the acceptance of euthanasia. Third, religiosity and secularization were identified as strong explanations of the large country variation in euthanasia acceptance and the speed in which euthanasia acceptance increased in different countries. However, both factors could only to a certain amount serve as explanations, and certainly to a lesser amount than could be expected from propositions in the literature. This suggested that clearly other factors play a role, and we suggested that debate on rights of terminally ill patients might strongly influence attitudes. Of course, on their turn, attitudes likely further influence debate. This will be a fourth discussion point. Fifth, as a country's stance could not always well be predicted on the basis of all identified determinants, we will further discuss (and illustrate) country specificity in attitudes towards end-of-life decisions.

A. Attitudes towards euthanasia: general public versus physicians

A noticeable finding, throughout the main results in Chapter 2-4, is the difference in attitudes towards euthanasia between the general public and physicians in some countries. If we compare the percentage in the total population being rather pro or pro euthanasia (score of 6 or higher on 10, see Chapter 3) and the percentage of physicians admitting to the statement that "a person should have the right to decide whether or not to hasten the end of his or her life" (see Chapter 4 and Miccinesi et al. 2005[16]) we notice a considerably lower acceptance among physicians than among the general public in Denmark (42% vs. 63%) and in Sweden (31% vs. 58%) (although it should be repeated here that the 'euthanasia' description used to examine the public attitudes allows for a somewhat wider interpretation). In Belgium and The Netherlands no strong discrepancy was found. However, also in the Netherlands there are indications of such a discrepancy [35], for instance in the fact that while the public acceptance of euthanasia had increased between 1990 and 2000, that of physicians rather decreased [36].

The seeming discrepancy between public and physicians has been reported several times in previous studies in various countries [2;12;37-41]. It has often, plausibly, been explained from the different roles and responsibilities physicians and the public have in end-of-life decision-making [35]. Physicians possibly project decision-making more directly on themselves (i.e. they risk to be confronted with requests from patients) whereas the public is not necessarily involved. Others claim that the lower euthanasia acceptance of physicians might be related to the greater knowledge and appreciation of palliative care alternatives in physicians compared to the general public [35]. Whatever the case may be, it is also clear that the physician-public discrepancy is strongly country-dependent. In The Netherlands and Belgium for instance such discrepancy was smaller or non-existent and perhaps this was also a crucial prerequisite of euthanasia legalization.

B. Sociodemographic differences in attitudes

Unlike propositions put forth in previous research [42-44], our results showed that a number of socio-demographic differences exist in the acceptance of euthanasia, independent from differences in the degree of religious beliefs.

Older age (or cohort(cfr.[14;44;45])), lower education (cfr. [2;7;46]), and manual social class were associated with a lower acceptance of euthanasia. These sociodemographic differences stipulate that actors from different socio-demographic backgrounds need to be involved in the planning of policy or legislation, since they might have their specific concerns.

C. Influence of secularization and religion?

The change in attitudes towards euthanasia has very often been ascribed to the secularization of society [7;44;47]. O'Neil (2003), for instance, suggests that secularization has lead to a willingness to accommodate pluralism, hence making it possible for differing euthanasia opinions to be espoused[44]. Cadell & Newton (1995) put forward that changes in American religion are very likely to affect the euthanasia debate[7]. Our results partly support these assertions, but also suggest that secularization is not the only (and perhaps not the most important) factor contributing to an increased acceptance (for instance in Italy the euthanasia acceptance as well as religiosity increased). Van der Maas et al (1995) suggest that the increased acceptance of euthanasia in The Netherlands and in the US occurred during a time of change in attitudes towards not only religious practices, but also sexual morals, divorce, and abortion[47]. Our results indeed confirm that the increase in euthanasia acceptance is largely congruent with the increase in 'permissiveness' towards abortion, divorce, homosexuality and adultery. However, even taking this into account can not fully explain the increase in acceptance of euthanasia. Clearly, there are also other factors that can be held responsible for the increased euthanasia acceptance. As we have demonstrated in the introduction of this dissertation, our society has undergone a general changing attitude specifically towards death and dying, for instance reflected in a growing desire for individual control and choice over time, place and manner of death [48] and in a changing attitude towards pain (to speak with Illich (1979) a growing belief that pain ought not to be suffered, alleviated, and interpreted by the affected person, but that it should be destroyed through the intervention of a priest or a physician [49]). The rise in acceptance of euthanasia in that perspective perhaps reflects changing attitudes towards death and dying and a generalised desire to counter 'bad' forms of dying[50]. Thus, rather than being a result of secularization, the rising support for euthanasia seems to be a reflection of the same force that has driven the palliative care or the hospice movement: that of planning, control and self-identity in dying (even though the hospice movements and euthanasia movements seem to clash because of religious differences and because of a 'symbolic' struggle to acquire a place within general medicine) [51].

Like secularization is viewed as the determinant of the change in euthanasia attitudes in society, people’s religious beliefs are often viewed as the determinant of their stances towards end-of-life decisions. Suarez-Almazor (1997) for instance suggested that regional differences in acceptance of euthanasia are due to predominant religious beliefs in each region[2].

Among the general public, we indeed found, as in previous research[2;45;52], clear differences between non-religious and religious persons, and differences by religious affiliation (Protestants and Orthodox Christians were only slightly less favourable towards euthanasia than non-religious persons, Roman Catholics were less accepting). However, an important conclusion of the research presented in Chapter 3 was that religion and religious authorities do not necessarily determine the stances of their followers, especially not in some countries. In several countries a relatively high acceptance of euthanasia was found in Christian denominations, even among Roman Catholics. It was suggested that the surrounding (secular) culture plays a role here [52].

Among physicians, we also found differences by life-stance in attitudes (and actual behaviour) towards various end-of-life decisions. However, while doctrinal teachings repeatedly serve as explanation for these differences in the literature, our results seem to nuance this. The small differences between religious and non-religious physicians in the acceptability of non-treatment decisions or possibly life-shortening pain/symptoms alleviation, as in previous research[53] , were not in conflict with the doctrinal positions. While in Christian (bio)ethics, life is the gift of God, and a natural reaction is to postpone death and to prolong life[54;55], there is at the same time a realisation that death is inevitable, and that life needs not be maintained at all costs or by all technological means available[54-57]. Withholding and withdrawing a potentially life-prolonging therapy, on the request of a competent patient and --particularly so in Catholicism and conservative Protestantism-- on the premise that it had not as its intention the death of the patient, are therefore justified as an acceptance of the human condition [55;57;58]. Out of considerations of compassion (and in Roman Catholicism also under the doctrine of double effect), the use of analgesia is deemed appropriate to avoid terminal suffering[55]. However, the minor differences between religious and non-religious physicians in the approval of and actual behaviour in terminal sedation is less in line with the doctrinal teachings. Officially, sedation after all has a particular position in Christian doctrine, as the use of drugs is regarded as wrong (particularly in Catholicism[58]) when it deprives the dying person of consciousness, thus taking away the final opportunity for repentance and barring the individual from meeting Christ in full consciousness[56;58]. Of course, whereas the moral acceptance of continuous deep sedation by Catholics (and Protestants) somewhat conflicts with the 'doctrinal teachings'[59], it is on the other hand understandable from a religious point of view as it is –contrary to euthanasia- in a way still God, and not the physician, who decides when the patient dies[60;61]. As in previous research[62], the finding of considerably lower acceptance of, and lower intended and actual behaviour in physician-assisted dying (including euthanasia) among religious physicians is thus in line with the very clear official doctrinal viewpoints on euthanasia. After all, there is a large consensus, not only in traditional doctrines, but also among contemporary official Christian viewpoints –including the Roman Catholic Church's blank rejection of euthanasia-- that euthanasia and PAS are considered morally wrong[45;63]. Nevertheless, our results also indicated that relatively high percentages of Catholics and Protestants were open to the practice of euthanasia, and a non-negligible percentage admitted to ever having performed euthanasia or PAS.

Our findings with regard to both the general public and the physicians thus indicate that the voice of communal tradition, religion and religious authority still echo in the stances towards end-of-life decisions like euthanasia, and this proofs that society has not completely become individualized. The individual is only to a certain extent accepted as autonomous actor[64]. On the other hand our findings proof that religious authority is no longer absolute regarding ethical issues like euthanasia and other end-of-life decisions, neither for the general public nor for physicians. The latter is for instance also clearly illustrated in the policy of Catholic hospitals and care homes, who no longer necessarily seem to be following the Magisterium on euthanasia [65] (although the religious identity of these institutions does incite them to restrict euthanasia and promote the so-called palliative filter). Religious people's thinking with regard to life and death has to a certain amount been liberalised and tends to be susceptible for intuitive arguments of compassion and humaneness[44;45;52]. The latter is all the more true for physicians, as they deal with more concrete and real cases in specific (real-life) circumstances. Physicians in such cases likely embrace (theistic) belief in non-imperative ways, allowing for adaptation to particular situations, for instance to the needs and wishes of the dying [55;66;67]. Our findings that physicians with a religious life-stance -- connected with an absolutist moral orientation[55]-- are sensitive to the idiosyncrasy of circumstances (e.g. a patient request, clinical circumstances), render support to this assertion.

D. Influence of and on the euthanasia debate

It is likely that, next to secularisation, in several countries intense debate and public discussions on terminal patients' rights as well as exposure of dying patients in the mass media have contributed to an increase in euthanasia acceptance. Mediatisation of and debate on specific individuals, who give a face to suffering patients desiring to hasten or not to postpone their death (e.g. Ramon Sampedro in Spain, Dianne Pretty in UK, Mario Verstraete in Belgium) possibly contribute to an increase in the public acceptance of euthanasia (although the inverse might be true is certain cases).

Of course, the influence also works the other way round. The particularly strong increase in public acceptance of euthanasia in Belgium has for example very likely been a major contribution to the euthanasia legislation in 2002[68]. In several other countries (e.g. France, UK) it has likely also fuelled the debate [69]. As concluded in our Chapter 2, further increase of public acceptance will possibly increase pressure on the public and political debate about the (legal) regulation of euthanasia under certain conditions of careful medical practice in several countries.

It is of course difficult to draw conclusions from our figures [4;13], but following this presumption that public acceptance of euthanasia can fuel the debate, we can assume that (as far as the general public concerns) the societal basis for a legalisation of euthanasia is sufficiently large in the countries with a high acceptance. The countries with an average acceptance will very likely hold debates much like the debate taking place in Great Britain at this moment, although much of course depends on a country's political and public debate tradition (e.g. former Soviet countries are clearly different from Western European countries in this respect). The outcome of these debates is unpredictable, and subject to various other actors and factors. While debates, often initiated by individual initiative, are not excluded in the countries with a low acceptance, the low societal basis in those countries makes a long and profound debate on euthanasia, let alone a legalisation of euthanasia, less likely.

E. End-of-life decisions: a European stance?

Most European countries knew a clear and strong increase in euthanasia acceptance, and this is in contrast with that in the USA, where euthanasia acceptance only increased weakly between 1977 and 2002 (a rise between 1978 and 1991, was followed by a drop between 1991 and 2000) [14]. Nevertheless, there is certainly not a common European attitude towards euthanasia and other end-of-life decisions (Chapter 2,3,4). On the contrary, attitudes often seemed to be rather country specific, probably influenced by national tradition and history. Belgium, Germany and Sweden, according to us, are some of the most noticeable examples of how country specific factors could influence attitudes towards end-of-life decisions.

Belgium knew a particularly fast increase in the public acceptance of euthanasia. This increase was stronger than any other Western European country and has also been much stronger than its decline in religious beliefs and its increase in acceptance of various other moral issues (e.g. abortion, divorce, adultery). Relative to its other characteristics (Belgium was in 2000 for instance more religious and less permissive than Slovakia) it had a very high public acceptance of euthanasia. Chapter 4 demonstrated that the acceptance of euthanasia is moreover also relatively strong among physicians, and even – despite Belgium's strong pillarisation (i.e. denominational segregation of society) - relatively high in all life stances. The legalisation of euthanasia, which was likely incited by these tendencies, was also quite peculiar, since Belgium did not, like The Netherlands, have a tradition of euthanasia or a long public debate. It is difficult to speculate on the factors that may have contributed to the specific Belgian stance towards euthanasia. Amongst other possible influences are the strong role of the right-to-die societies, the interconnectedness of the latter with the palliative care movement, the independence from the Vatican of certain Catholic actors, the role of the media,…

A noticeable fact in Sweden is that a high acceptance of euthanasia of the general public (in line with their secular and permissive nature and high valuing of self-determination [70;71]) is in sharp contrast with the very reluctant attitude towards euthanasia of the medical class. Of all 6 countries studied in Chapter 4, Swedish physicians were least inclined to accept or to perform euthanasia. This reluctant attitude was moreover found in both religious and non-religious physicians. Although we can speculate about the influence of the high “hypocratism” or paternalism in Swedish physicians it remains unclear what factors underlie this pattern.

Germany is the most striking example of country-specificity. Whereas Germany knew a secularisation and an increased permissiveness it did not change it’s stance towards euthanasia. In 2000 Germans were relatively secular and had a relatively high tolerance in issues like divorce, abortion and sexual mores, but clearly had a low acceptance of euthanasia in particular [72;73]. An evident explanation for this particular German attitude is the history of euthanasia under National Socialism [73]. Although in contrast with those who lived it through from first hand (Israeli holocaust survivors were shown to see profound differences between euthanasia in Nazi-Germany and in the contemporary context of socially assisted dying, and even got frustrated about philosophers making such parallels [74]), the memory and stigma as ‘offenders’ of the Nazi ‘euthanasia’ plans (‘Aktion T4’) may have resulted in a great reluctance among Germans today to approve of euthanasia [73-76]. This is for instance also reflected in the principles adapted by the German General Medical Council. Especially because of fear for slippery slope (with Aktion T4 in mind), this medical association has formulated a rejection in principle of ‘active’ euthanasia [76]. The German fear has even lead the medical association to judge artificial feeding for patient in a persistent vegetative state obligatory, and has lead to physicians being prosecuted for stopping life-sustaining treatments [76]. Next to the German history of National Socialism, a number of scandals discrediting the German right-to-die organisation possibly also play a role [76].

9.4.2 End-of-life practice by places of death

Different places of death or terminal care seem to involve different end-of-life decision making. These differences very likely relate to characteristics of the care settings, the care at hand in these settings, the (expertise and knowledge) of the caregivers operating in that setting, patient characteristics,…

The intimacy, privacy, and concealment of the home setting, the possibly lower (palliative) care and treatment options at home, characteristics of the interpersonal relations with general practitioners, and characteristics of the patients themselves (e.g.

both dying at home as euthanasia/PAS characterize patients who aim for choice and autonomy) can explain why physician-assisted dying (and especially euthanasia) more often occur at home. These factors likely also explain why patients and their families are more involved in the decision-making process. Since general practitioners usually operate more isolated, there is however less consultation of other professionals.

Physicians in institutions have more formal (and informal) consultations and discussion with other physicians or nurses. However, research suggests that specialists tend to wait (too) long before discussing end-of-life decisions with patients[77-80]. Our findings for instance also indicated that patients dying in hospital were more often no longer competent at the moment of decision making. Some characteristics of hospital settings likely also determine the specific end-of-life decision making in hospitals. Greater availability of possible (technically advanced) treatments that are integrated in (standard) medical practice in hospitals, can explain the higher number of reported non-treatment decisions. Differences in (technical) palliative medicine possibilities like a constant monitoring of the doses can explain the higher incidence of terminal sedation.

Since alleviation of pain and symptoms with a possible life-shortening effect occurred more or less to the same degree in all settings, we deemed it possible that the use of analgesics (also in higher doses) is part of standard practice of specialists in hospitals as well as of GPs at home or in care homes.

Both involvement of the patient and the discussion with other physicians is regarded as a safeguard of prudent end-of-life practice. Previous studies[79;81] already demonstrated a serious margin of improvement in this context. Our results thus add to these studies that it can not be precluded that (characteristics of) end-of-life decisions are also differentiated by the setting of end-of-life care.

9.4.3 Place of death

Before interpreting and discussing some of the major findings with regard to place of death, we want to put into perspective the significance of place of death as a parameter of good dying. After that, we will elaborate on possible explanations for the large cross national variation in places of death, and discuss more into depth on the factors that contribute to dying in a certain place (home, hospital, of care home).

A. Place of death: an appraisal

Whereas dying at home is often perceived as a good outcome, this is not necessarily true for all patients. The degree to which dying at home is desirable and realistic, will depend on the household situation of the patient (and the care at hand) as well as on the desirability or necessity of hospitalization. Although often the case in palliative care literature and research, it is thus treacherous to regard place of death as a parameter of good death and to attach a quality of care interpretation to it. Research by Steinhauser et al has moreover indicated that dying at home is not regarded as the most important attribute of a good death [82]. Judged more important is freedom from pain, the feeling that life was meaningful, the presence of family, respect for treatment choices, affordability, etcetera. The meaning of a home death in absence of all these characteristics is thus very relative (and we thereby do not even address the question of whether the location of home is actually experienced as 'home' by the patient[83;84]).

On the other hand it is very clear that home death is still an attribute of great value to many people [82;85], and it has also been suggested that dying at home leads to better outcomes in the other attributes (e.g. presence of family, comfort, discussion about preferences) judged more importantly than dying at home in itself [86]. Although the quality of dying can not be read from the place of death, place of death clearly is an important aspect of quality of dying. We therefore believe that it is important to pay attention to place of death within the framework of the 'good death'. Place of death is moreover something on which health policy can (easily) have an influence. Highlighting the importance of place of death will influence health care policies' efforts to improve the care of the dying [82], e.g. by addressing why most people die –against their wishes- in a hospital, alone and in pain [87]. Research on a large sample of cancer deaths in Italy for instance indicated that in 98% of patients dying at home, the preference was met, compared to 15% of those dying in hospital [88]. Irrespective of questions like whether all home deaths can be considered good, it is relevant to map out the striking patterns in place of death and to search for explanations. Found patterns can provide very relevant and focussed starting points for further research and policy[84] (see paragraph 9.5).

B. Cross national differences in place of death: some explanations

Our results indicated a possibly declining hospital death trend (between 2001 and 2003) in Belgium (Flanders), in particular for cancer patients (as opposed to the increasing hospital death trend in England reported in other research[89]). Nevertheless, despite the fact that a majority of (dying) people wish to die at home, still only about a quarter of all people in Flanders does so. Even if we consider care home deaths as home deaths, which is an issue of dispute, the proportion dying at home is less than half.

However, in cross-national (European) perspective the Belgian proportion of hospital deaths (more than half) is not even an exceedingly high proportion. Cross national variation in proportion of hospital deaths was surprisingly large, and several explanations were sought for this: provision of care possibilities, policy differences, and (medical) cultural and attitudinal differences.

The influence of hospital bed availability is mentioned in part of the literature as an (if not the most) important factor associated with place of death [30;31;90-92]. Research in Canada[93] and UK[89] indicated that trends in availability of hospital beds (and other health resources) explained trends in place of death. Research in the USA indicated that variation between states in available hospital beds in large amount explained the variation between states in place of death [91]. We therefore expected that hospital bed availability would explain cross national differences in hospital deaths but this seemed not to be the case.

Availability of alternatives for older people to hospitals, so we concluded, much more influences out-of-hospital death. The high number of care home beds in The Netherlands explained the low number of hospital deaths, in particular in older people, and the low number of care home beds in Wales was in line with the high hospital death rate (in older people) in that country.

A striking finding and additional explanation for cross national variation in place of death was that older people tend to end up in different places in different countries. Compared to in Flanders and (in particular) in The Netherlands older people (aged 80 and over) more likely died in a hospital in Scotland, England, Wales, and Sweden, although the number of care home beds for older people (and the number of older people residing there) was high in some of these countries. We related this to the transferral practice in older dying patients in different countries. Several causes can be suggested for these differences. First, country specific attitudes towards hospital as an appropriate (and home but also care home as an inappropriate) place of death for older people probably influence this [94]. Second, the type and quality of the care facilities at hand in care homes also plays an important role (i.e. whether good end-of-life care is possible in the care home). In some countries they are relatively medicalised and provide continuous and good care opportunities, whereas in other countries the organization of (palliative) care is inadequate. Third, cross-country variation in ageism in palliative or end-of-life care can play a role. Research for instance indicated worse access to specialist palliative care or hospice services for older people in certain countries [31;95-97]. While this is often explained by more complex and unpredictable shape and duration of dying trajectories of older people, the largely differing patterns in the studied countries suggests that this can not be the only explanation. Perhaps there is indeed, in some countries more than in others, a lack of attention to older people's needs in palliative care [95].

Like older people, cancer patients also seem to end up in different places in different countries. Several explanations can be suggested for this very large country variation in place of death for cancer patients. First, as a result of differences in (medical) culture (and in avoidance of death), hospital possibly remains more predominantly regarded as a place of death in some countries [93]. Second, the offering of care alternatives to hospitals for cancer patients like palliative home care or hospices likely play a role. In this context it did not surprise us that specifically the English cancer patients (and patients in the palliative care subset) were likely to die outside a hospital. We believed this to be related to England's long tradition and development of a palliative care and hospice culture for these patients, the provision of a large number of hospice beds [98], and the tradition in end-of-life care for this specific patient population (especially as compared to non-malignant patients potentially benefiting from palliative care [99;100]).

Finally, cultural factors are also suggested in previous studies as a likely influence of geographic variation in place of death [88;89;101]. Costantini et al. however found differences in place of death between two neighbouring Italian regions, too large to be caused solely by cultural differences[102], and believed it to suggests an inappropriate (and little rational) use of hospital. We would not go as far as stating that the cross national variation in hospital deaths indeed implies this. However, our results do indicate margins for most countries for a rational planning of policy aimed at reducing proportion of hospital deaths for specific patient populations.

C. Place of death in Belgium and Europe and associated factors.

In our examination of possible reasons of why people die where they do, we distinguished four types of factors associated with place of death, as also indicated in a pioneer article by Mor and Hiris in 1983 [103]. These include clinical, socio-demographic, social support, and health system characteristics. We will here discuss possible interpretations as to the manners in which these associated factors influence where people die.

The influence of the type of terminal disease on the place of death was seen as rather logic. The sudden and unexpected nature of cardiovascular deaths for instance often does not allow for hospitalization before death [104]. An advantage of cancer patients to die out of hospital/at home was indicated in the proceedings of the First International Symposium on Places of Death as one of the (scarce) common patterns in Western countries [105], and was (Chapter 7) also deemed rather logical, since cancer patients die according to other “patterns of dying” than most other chronically ill [96;106], in general, with a longer survival after diagnosis, a more predictable course of disease, and a gradual preparation for (and planning of) death [107]. However, the cross national comparison in Chapter 8 indicated that cancer patients having a higher probability to die at home or outside a hospital is less universal and less logic than assumed, but also the result of (national) medical culture, the offering of care alternatives to hospitals for cancer patients (e.g. palliative home care, hospices), public health care policy, …

Several socio-demographic differences were found in the probability to die at home or in a hospital.

For the differences by age, indications of a lower likelihood for older people to be referred to home care [31;108;109], mainly because of fewer care resources at home [31], lower likeliness of having a suitable primary carer, higher additional care needs, and even poorer access to home palliative care [31;95] could serve as possible explanations.

The differences by educational attainment confirm findings in other countries in previous studies[31;90;91] and indicate a social inequality or a socio-economic gradient of access to end-of-life care.
Finally, strong (intra-country) regional geographical differences were found (e.g. between rural and urban regions). Availability and use of care facilities, services and resources [110-112], but also cultural differences in ideas of best practice and 'good death' and in the role of family as a care-providing unit [31-33;93;113-116] were stated as possible explanations.

As indicated in previous research, the higher likelihood of people living in a household with others, very likely stipulates the role and the effect of informal caregivers. Patients not residing with a spouse or other potential (healthy) informal caregiver have a lower social support and hence lower odds of dying at home [31;90;117]. In cancer patients, where informal care support might be most pertinent, this difference was even larger. Our findings thus clearly seem to confirm the importance of informal care and social support in end-of-life care [118]. Although we were not able to examine this, it is likely that characteristics of the support network (e.g. health status, occupational duties, financial resources,…) play a role too.

A final type of factors influencing place of death relates to the healthcare system, as indicated in many previous research [31;90;103;119]. Our results indicated an effect of bed availability in a region (within a country), but also suggested that this effect should not be overestimated (at least for several European countries). Of course, several other healthcare system factors like the availability of and access to palliative care, home care, hospices, etcetera likely also play a role. We were not able to examine this.

9.5 Implications and recommendations for policy and practice

9.5.1 Healthcare policy

a) Euthanasia debate and regulation

Our research showed that the public acceptance of euthanasia is very high in some countries and that this acceptance has increased strongly during the last decades in these countries. However, up to now only Belgium and The Netherlands have regulated euthanasia, Switzerland, Oregon and the Netherlands have regulated assisted suicide, and only a number of countries have held wide public and political debates on the issues [68;69;120;121]. A conclusion of our research was that, especially if trends in public attitudes keep proceeding in the same way, the pressure will increase for several countries to debate (and possibly eventually regulate) euthanasia under certain conditions. Not 'if' but 'when' is the relevant question, especially if we also consider the proof that hastening of death with lethal doses of drugs occurs in practice in many countries and that the ethical and legal circumstances surrounding these decisions are not always ideal [25;62;79;122]. Thus, both in the benefit of concurring policy with expectations and aspirations among the public, as for safeguarding a practise for those potentially involved, several countries will likely put it on the political agenda. Opinions of several actors should then determine the outcome of these debates.

In this context some recommendations can be extracted from our findings.

First, since attitudes towards euthanasia sometimes have a very country specific character and countries will have their own concerns, countries should have their own debate, rather than implementing the Dutch, Belgian, or Swiss legislation. And if a certain regulation of euthanasia is the outcome of the debate, this will therefore not necessarily match (the conditions in) the Dutch or Belgian law. Our findings with regard to cross-national differences can serve as a basis for further debate. Second, it is thereby also of utmost importance that the political or legal debate involve all relevant actors. Of course, given the demonstrated differences that often manifest between the public and the physicians and the different concern both can have, it is important to integrate the opinions of both actors [47]. Third, since our findings demonstrated some considerable socio-demographic differences in attitudes, which might point to differentiated worries and concerns, people from different backgrounds should be involved (e.g. via civil society). It is important that, in an ever more diversifying society, policy makers try to guarantee that health care policy is culturally inclusive and not only representative of the values of the dominant culture [48]. Since doctrinal teachings of religions seemed somewhat remote from the actual stances held by religious subjects (and somewhat alienated from realistic sentiments of compassion and humaneness), persons belonging to different religious groups need to be involved, rather than persons representing the doctrinal religious authorities.

It should be added here that public opinion can not be the arbiter of what is ethically correct[4;14]. However knowledge of it helps to address the issues in a way that will best benefit the public discourse, and our findings create a good starting point in this perspective.

b) Debate on other end-of-life decisions

Healthcare debate and policy (but not necessarily healthcare law) should not focus uniquely on euthanasia.

First, Chapter 4, Chapter 5, as well as several other research demonstrate clearly that euthanasia is far from the only (or most important) end-of-life decision [25;62;122-124]. Possibly life-shortening end-of-life decisions are reported in about one to two thirds of all non-sudden deaths and Euthanasia/PAS only represent about six per cent of all end-of-life decisions (ELDs) in The Netherlands and about one per cent or less in other studied countries (Chapter 5). However, about fifteen to thirty percent of all end-of-life decisions were taken with an explicit intention to end the patient's life. Moreover, the relatively often occurring practice of terminal sedation as a means to control refractory symptoms cannot a priory be regarded as unproblematic (Chapter 4 and 5). This in itself seems to suggest that health care policy should not solely focus on the administration of life-ending drugs, but (in particular) also on other forms of decision-making that may affect patients' life expectancy.

Second, the need for a wider focus manifests from the finding that the making of other end-of-life decisions (besides euthanasia or PAS) is far from unproblematic in different healthcare settings. Conditions of good and careful practice seem not always to be met and are surely susceptible to improvement. Even in decisions with explicit life-shortening intention, especially in hospital settings, patient or family members were not always involved in the decision-making process, and, especially in a home care setting, other healthcare workers were not always previously consulted (Chapter 5).

Finally, while these other end-of-life decisions may not be unproblematic, they are more willingly accepted by physicians, religious or not, as part of standard medical practice (Chapter 4).

Overall, since our findings (Chapter 5) seemed to suggest that safeguards and conditions of prudent practice were better met in countries with an imminent or current legal regulation on certain end-of-life decisions (e.g. Switzerland, The Netherlands, Belgium), we are inclined to believe that debating several types of end-of-life decisions, and organising safeguards of and guidelines for good practice in different healthcare settings, can also improve the carefulness of the decision-making process and performing of these decisions. This debate should include policy makers, healthcare professionals from different healthcare settings, education centres, and (potential) patients and next of kin.

c) Place of death as an important health policy concern

We can safely assume that where death takes place is easier to control than when and how. Place of death is more susceptible to (policy) interventions as compared to various other, often abstract parameters of 'good death' (e.g. life completion, being at peace with self, sense of meaning of life) [82;125]. At the same time there is proof that most people die, against their wishes, in a hospital, alone and in pain[87], which is in sharp contrast with a predominant vision of 'good death' as death at home, free from pain or distressing symptoms, and surrounded by loved ones. One of the responsibilities of a public health care policy is to endeavor a good quality of end-of-life, and this includes the facilitation of dying in the place of choice. There is evidence that, currently, we are not doing enough[90]. Our results can make a considerable contribution in this context. Policy recommendations can be formulated with regard to manners to facilitate monitoring of place of death (i.e. assessment), possible measures to reduce the number of hospital deaths and allow more people to die where they want to (i.e. interventions), specific risk populations (i.e. focus), and a setting-specific development of good end-of-life care (i.e. prevention).

d) Good monitoring of place of death

We can not even envision a health policy aimed at the 'good death' without knowing where death is taking place and for whom[84]. One of the central recommendations in this dissertation is that healthcare policy needs to create the conditions to organize good cross national and monitoring of place of death. To increase the feasibility and accuracy of using death certificate data as a basis for international and monitoring of place of death several recommendations can be made, with regard to the status of information on the death certificate and the quality of certification, the coding into data files, and the procedures to get access to data. Because the type and quality of information on the death certificates differs from country to country we should aim at more (European) standardisation in the forms, for instance in the 'place of death' variable. We should thereby also consider (in each country) whether developments in the patterns of dying in our society are covered by the categories of the place of death variable (which could for instance imply that we need to distinct between nursing homes and homes for the elderly, or provide a category of 'hospice' or 'palliative unit'). Standardisation in forms is useless without certain assurances as to the quality of certification. Therefore we believe that quality assurance programs safeguarding the reliability of data for research purposes (next to administrative purposes), might need to be implemented. More training of death certificate completion for physicians could be useful [126].

Death certificate forms are not always translated in the same way into data files. This should improve, for example by coding all certified information (on place of death as well as on other variables), and by standardisation in cause of death coding.

Finally, access to the data for research or monitoring purposes should be organised in acceptable ways. We consider a thorough scrutinising of any research application as required in order to protect confidentiality, however protective requirements should be proportional to the possible harm individuals might suffer from a possible (ab)use of the data [127]. Chapter 6 clearly demonstrated a variation in the procedures to get permission to use death certificate data, and something needs to be done about this. Better (centralised) organisation and authorisation of data could help (although the opposite might be true). If a good balance can be found between the protection of personal data (and safeguarding of anonymity) on the one hand, and the difficulty of the procedure to get permission for the data on the other hand, we think that it might be opportune to allow for well-thought-out procedures to link death certificate information with other databases. This might preclude duplicate registration of certain variables and possibly increase the quality of the data, but might also (e.g. via linkage with discharge records) considerably enlarge the potential of death certificate data to study the end-of-life (beyond merely describing place of death). In combination with the other proposed modifications this will for example also allow us to monitor how health care resources are allocated.

e) Organize good (end-of-life) care alternatives for hospital care …

The high percentage wishing to die at home and the low percentage actually doing so indicate that more efforts are needed to increase the number of people dying at the preferred place of death.

Our findings do not essentially favour a continued hospital bed reduction as a strategy to reduce the number of hospital deaths. Those countries and regions with a (particularly) lower number of available hospital beds were not necessarily those with a lower number of hospital deaths. Policies of hospital bed reduction will not necessarily achieve the aimed effect. Moreover it remains the question whether such policies, inspired by economical motives, will not (indirectly) affect the quality of care (e.g. by forced and inappropriate discharges from hospital). However, Chapter 8 suggested that availability of care alternatives to hospital might more effectively reduce the number of hospital deaths and increase the number of people dying in the place of wish. Increasing the number of available care home beds (and developing good long-term and palliative care opportunities in care homes or nursing homes) could for instance decrease the number of (older) patients dying in a hospital. Care home could in this case, for many older people, be considered a home death. However, it will remain the question, if a health care policy results in more older people living their last years of lives in care homes, whether these older people actually experience the care home as their home and as a place were they prefer to die. A rational policy will, therefore, also need to develop and guarantee a good quality of care and life in care homes, and timely evaluate this. A potential danger is for instance that nursing homes replace hospitals as settings for intensive care, which will have implications for the quality of life of patients and for the costs at the end-of-life.

Not only the access and use of (palliative) healthcare resources but also the circumstances in which people live and need to be cared for can be an important policy focus. Chapter 7 indicated the importance of having potential informal caregivers to (be able to) die at home. A possible policy to allow people to die at home if they and their families want to is therefore to support families in the care of the dying. Expanding palliative leaves and providing medical and paramedical support for people caring for their loved ones at home could increase possibilities of informal caregivers. In this context the organisation of flexible and anticipatory home health care, so that more intensive care can be organised in short notice, is also important[90;118]. Expanding and improving and promoting the networks of services to support dying patients and their families and ameliorate their accessibility will be effective strategies to increase the chances of dying at home if this is preferred by patients and their families.

f) … and implement (the principles of) palliative care in general medicine

Next to the availability of care alternatives to hospital it is probably equally important to stimulate a palliative care culture. Increasing end-of-life care possibilities by expanding the availability of good palliative care facilities (outside hospitals), and at the same time stimulating the use of these facilities (e.g. via mandatory palliative care training of physicians, and by implementing systematic risk assessment and care planning strategies[90]) is likely to successfully influence where people die. Our results for instance suggested that in England the development of palliative and hospice care (and the good availability) as well as the tradition and culture of palliative and hospice care contributed to out-of-hospital deaths. Not only influencing the availability of palliative care but also influencing the mentality towards it (i.e. integrating palliative care in general care and medicine) is important in this context. The way we deal with older people at the end-of-their life and the way we deal with patients suffering from certain terminal diseases, after all, strongly influence patterns in place of death.

Additionally, there is also a need to raise public awareness of palliative care (as well as of possibilities of surrogate decision-making, advance directives)[90] and influence the mentality towards death and dying.

g) Focus on specific patient populations and disadvantaged groups

Our results show that less educated people, single people, people suffering from other chronic diseases than malignancies, and older people are possibly at a disadvantage when it comes to dying in the place of wish. Policy needs to get a good understanding of the reasons behind the apparent disadvantages, and on this basis try to develop a strategy that meets the specific needs and preferences of these specific populations.

The apparent disadvantage of lower educated people to die at home, which confirms the disadvantage of people with a lower socio-economic status in previous research [31;90;128;129], likely reflects both financial as cultural aspects and a policy aimed at social inclusion will have to anticipate on these factors[130]. This will probably also require a wider policy of social inclusion, since social differences in the place of death likely also reflect wider social inequalities in the access to and use of end-of-life care[129;131], in receiving the adequate care and treatment [132], as well as in the quality of life in the year before death[130]. Reducing all these social inequalities at the end-of-life can engender an overall improvement of quality of end-of-life. Good understanding of the social barriers to an optimal end-of-life care for the disadvantaged is a prerequisite for working out programs and rational interventions to eliminate existing discrimination. For instance, knowledge training programs for practitioners (perhaps integrated in the standard training) can consequently be made, which emphasise focal points with regard to their interaction and communication with patients from different social backgrounds[133].

The lower likelihood of dying at home for patients living single is of course to a certain amount logic, since dying alone is perhaps less preferable. However, it is also likely that situational factors play a role here. It is very well possible that well co-ordinated home care and supporting informal care by relatives and friends may increase the likelihood of single persons to die in a home (not necessarily their own).

Patients suffering from certain non-malignant diseases also deserve some attention in this context. For most countries cancer patients had relatively good chances of dying at home (or outside hospital), which can perhaps be framed in the repeatedly demonstrated finding that end-of-life and palliative care predominantly focus on cancer patients. This is of course related to the disease trajectories and prognostic aspects, however, Rosenwax et al. demonstrated that several non-malignant patients potentially benefit from palliative care[134]. There is thus some margin of work in the development of end-of-life care for non-malignant chronic diseases. This could probably also lead to more home end-of-life care and more deaths at the place of wish for, for instance, heart failure patients, renal failure patients, COPD patients, Alzheimer patients, …

Finally, health care policy should also specifically focus on older people. Not only by monitoring the quality of end-of-life care in care homes, but also by creating good possibilities for older people to be cared for inside their household or that of relatives and by increasing the access to palliative and end-of-life care for older people as well as stimulating a palliative and end-of-life care approach in older people. For several countries there has after all been proof of and age differential or even an age bias in access to end-of-life care services [31;97]. While arguments as ‘fair innings’ prioritising health care resources to young people might be justified for life-saving interventions, this is not justified for palliative and end-of-life care. Good access to effective symptom control and psychosocial support therefore needs to be guaranteed if we aim to decrease the risk for older people of dying in hospital. This could possibly also be provided in care homes (e.g. the Dutch nursing homes).

h) A setting specific end-of-life care focus?

Next to a number of demonstrated associated outcomes [30;78;135;136], place of death is also associated with a different patient- and family-involvement and discussion with other healthcare professionals in end-of-life decision-making (Chapter 5). Our findings can suggest a number of focal points in this context. First, there is a need to organise good palliative care options in all settings and develop clear guidelines for different kind of decisions in different kind of circumstances. Second, general practitioners might benefit from possibilities of consultation with (or even participation of) other professional caregivers in order to co-ordinate difficult decisions. Healthcare policy could aim to develop initiatives thereto (e.g. the LEIF-physicians in Belgium, palliative support and information networks for GPs) and incorporate them in general practice. Such co-ordinated decisions could eventually increase continuity of care and facilitate dying at home and could increase the quality of end-of-life decision-making.

Third, the culture of discussions in institutions should improve. Particularly in hospitals, but also in care homes there is less discussion about end-of-life decisions with patients and their relatives, in particular because physicians seem to be waiting too long before discussing end-of-life decisions with patients until the latter becomes incompetent. This can perhaps be viewed in the light of the assertion that medical (hospital) culture values technology over communication with patients[118]. Of course, certain patients (still believing in cure) might prefer (a safer) environment with high technological resources in stead of communication, but it is possible that this precisely results in intensive strategies, not always in the patient's best interest. The Dutch guidelines for palliative care distinguish three phases of palliative care: a first phase of supportive care aimed at maintaining the quality of life, a second phase of symptom-oriented palliation, and a third terminal phase where preserving the cognitive functions of the patient is no longer a priority[137]. We can safely hypothesize that specialists often consider important end-of-life decisions and options of end-of-life care only in this last phase, at a stage where patients have become incompetent to participate. For example the development of clear communication guidelines and communication training for specialist might contribute to timely discussion on (palliative) care and treatment options (although the factors time and money might be the key impediments).

In summary, as a patient may assume that decisions are made objectively, depending on their situation and not on characteristics of the care setting[138], we should aim to develop quality end-of-life care and decision-making, independently from the setting. This will both require a setting specific focus (to improve those aspects pertinent for a certain setting) as well as an integrated (cross-setting) approach.

i) Towards a European approach?

Several countries could reduce their number of hospital deaths and increase their number of home deaths, as well as increase the quality of end-of-life decision-making in different care settings. Each country can look at its position relative to other studied countries and determine policy priorities.

In this context, our mapping out of the cross national differences highlights the need and can be an impulse for initiating a European policy agenda on end-of-life care. The latter requires both research and policy (evaluation) on a cross national scale. Creating cross national collaborative research groups/actions could aim to develop a continuous monitoring of end-of-life care (including place of death research) with certain standardization in study methods and results. This would allow indicating (e.g. via comparative rankings) where one country stands compared to others, and would also much enable the evaluation of which policy actions work (and in which countries). Accordingly, European policy makers could determine the most functional actions in each country.

9.5.2 Healthcare professionals

a) Understanding ones own commitments and those of patients

Our results have suggested that most physicians (religious or not) are not insensitive to the interplay of the physician, the patient and the family, making it less likely that religion based ethics impede on clinical decision-making (as often suggested). Nevertheless, there are a number of points of attention in this context. Life-stance traditions can, and do, provide a framework for end-of-life decision making, and therefore physicians treating persons with another life-stance should develop an understanding of their own commitments and of the spiritual needs of their patients. Physicians should maintain their integrity and not act in conflict with their own religious views, but at the same time they should respect the patient's views, even if the patient's religious concerns demand medical decisions not corresponding with the physicians perception of best possible decisions. Good communication about existential values can avoid that physicians make medical decisions based on religious or spiritual or other concerns or customs, without discussing these concerns[51]. Not only discussing preferences and values of patients is important. Systematic consultation and involvement of other caregivers can be a kind of training and evaluation of decision-making.

b) Timely discussions, exploration of preferences and permitting choice

Physicians, particularly specialists in institutional care settings, should avoid waiting before discussing end-of-life decisions with the patient until the latter becomes incompetent. If possible discussions should be made in an early stage (possibly in an outpatient setting or possibly also, but preferably not solely[139], via advance care directives). Involving the patients in timely discussion with regard to their treatment and care can probably not only ameliorate medical decision-making, but can perhaps also increase the likelihood of dying at the place of wish[88] and improve the general quality of life. Ideally, only the patient preferences and clinical circumstances (and for example not the physician or the setting of terminal care) should influence decision-making[140].

In this context it is also important to explore preferences of patients and to present them with choice. As repeated several times, congruence between actual and preferred place of death gives an indication of the quality of death. Therefore patient choice needs to be facilitated. This will require eliciting patient preferences, which on its turn requires communication skills. An attitude generally found among physicians is one of beneficence (i.e. making decisions without involving the patient for his/her own good) and paternalism. There is, however, good evidence that the majority of palliative care patients do want full information about their condition and want to be involved in decision-making. Improving end-of-life care thus means improving patient-family-physician communication and assessment of preference. It is not the aim of this dissertation to draft guidelines on how to achieve this. However, useful guidelines can be found elsewhere [141;142].

Of course, the issues of patient choice and autonomy are not unproblematic. There is a particular difficulty for instance with regard to preferences (or advance directives) in demented patients. In order to be considered 'good' a death should usually also not only satisfy needs and wishes of the person who is dying, but also meet those from the next of kin, as well as social and cultural expectations (e.g. a suicide is therefore not by definition considered a good death). It will therefore not always be easy for a physician to decide what's right. Several developed guidelines can, however, be useful[142].

c) Develop good communication with people from different social backgrounds

Our results suggested that special attention should be paid to the physician's approach of and communication with less educated people. Different cultural background of physician and patient can make communication and assessment of preferences more difficult. Moreover, the patient's social context will influence the patient's experiences, preferences and perceptions of care [143]. Communication with patients and presentation of care and treatment options will therefore not be as simple as merely objectively offering options. Physicians need to make further efforts in order to give equal opportunities for good end-of-life care. Integrating more difficult communication with patients from different cultural backgrounds in training of physicians can possibly be useful[133]. In order to give the best possible care, health care workers should be aware of and heed respect to background of patients. Good practical guidelines in this context can be found in David Oliviere's book 'Death, dying, and social differences'[129].

e) An integrated care model

To provide good continuity of long-term care all professional caregivers involved in the care for a dying person (specialists, palliative care providers, GPs,…), should aim at some form of cooperation and coordination of decisions in the benefit of the patient. Bad coordination can result in opposing strategies. This needs to be avoided.

In this context we want to advocate that simply defining a period of 'end-of-life', or calling for the introduction of palliative care from a defined stadium is not always beneficial. Caregivers need to pay attention to fluctuating needs and dependency. Process- assessment and–evaluation are thus prerequisite to organising quality care, especially since it is so difficult to predict dying trajectories (physically, as well as spiritually, socially en psychologically). Care models, constantly assessing and evaluating important patient parameters such as attentiveness, responsibility, competence, responsiveness, etcetera need to be employed. Healthcare institutions could implement such care models to timely engage palliative care actions.

9.6 Further research

a) Further and better understand attitudes towards different ELDs

We related trends in euthanasia acceptance to several other trends in society and did not preclude the possibility that trends will proceed and will increase pressure on the legalization debate in several countries. However, our study on trends in public acceptance of euthanasia was limited up to the year 1999. Therefore, trends in euthanasia acceptance have to be studied further, also in relation to other trends, in order to monitor further evolutions in euthanasia acceptance and to observe how certain factors affect thinking with regard to euthanasia in several countries.

In order to get a better view on what influences attitudes towards euthanasia more thorough studies of euthanasia are required than the studies we presented. First of all, these future studies should present several well defined questions and also inquire about acceptance in different circumstances in order to better capture the complex attitudes towards euthanasia (and to distinct between moral attitudes, legal attitudes,…). Second, better definitions or descriptions of euthanasia, in accordance with the predominant contemporary medical and ethical literature, should be used. Third, other possibly highly relevant independent factors should be examined in relation to euthanasia (e.g. health status, attitudes towards and trust in the health care system,…). Qualitative studies could to a large extent complement these studies. Since our studies indicated some clear differences depending on the socio-demographic backgrounds of respondents, qualitative studies might better explore and capture their possible specific concerns.

While our studies on public attitudes were limited to euthanasia, there is also a need to study attitudes towards several other (not a priori unproblematic) end-of-life decisions. Currently little is known about how the public sees (and defines) decisions like terminal sedation and how the public frames its opposition towards them. Since we proclaimed, in our policy recommendations, that health care policy and debate should also focus on other forms of decision-making that considerably affect patients' life expectancy, a better knowledge and understanding of attitudes towards these decisions (and possibly the studying of trends) might guide this debate.

As it seemed that other considerations can determine attitudes of physicians than those of the public and because we believed that discrepancy in attitudes of both importantly influences debate and legislation, future research will have to employ methods to study both physicians and general public at the same time, with similar questions. This could further examine and compare the complex attitudes of both parties as well as the factors influencing their attitudes, and accordingly examine reasons for their opposition towards end-of-life decisions or towards the legalization of decisions. In particular in those countries without any legislation, this could contribute to better debate involving arguments from both parties.

It might be opportune to also examine the views and concerns of terminal patients in end-of-life decisions, although research has demonstrated that their attitudes differ little from those of the general public[2]. Examining this population (e.g. in prospective studies) could perhaps also allow to acquire insight into how attitudes and personal requests or wishes differ and/or relate to each other.

With regard to the role of religion as a determinant of attitudes towards end-of-life decisions, we concluded in our studies that admitting to a theistic life-stance did not imply admitting to this life-stance's doctrinal views on end-of-life decisions. However, future studies should perhaps aim measuring religious beliefs more into detail, distinguishing merely denominated from professing believers. Including more countries could better inform on how the (cultural) background of a country influences thinking with regard to end-of-life decisions (both in religious as in non-religious subjects).

b) Further explore opportunities of death certificate data in more countries

In order to get a better view on how death certificates can be used in a world-wide monitoring and studying of place of death, a thorough scrutinizing of death certificates and of possibilities to use death certificate data needs to be performed in all continents. In this context we can mention that an effort has been undertaken to this purpose: a collaborative research (USA, Belgium, The Netherlands, Italy) was initiated to collect information on more than 100 countries in all continents. Furthermore, our presented study was limited to examining a few linking possibilities. However, linking possibilities with other types of data (e.g. hospital admission data, data from health care insurance agencies, etc.) and the implications this will have on permissions to use data could be examined further.

c) Elaborate analyses of place of death: attention for transitions and trajectory during last months of life

This linking with other data could increase possibilities to include more relevant predictors and determinants of place of death and could also make it possible to study not only place of death, but the whole dying trajectory (including how clinical circumstances and preferences change). While such studies, examining not only place of death, but also the preceding dying trajectory, have been undertaken in some countries[87;88;144], there is certainly a need to have these data on a population level[145]. This could better examine the reasons why people with similar care needs (and preferences) die in different places and consequently instruct place of death policies. Prospective studies complementing these large-scale retrospective designs might inform us even more precisely on factors that impede dying at the place of wish. All these studies might enable us to indicate which part of the discrepancy between desire and reality is caused by elements that are amenable to policy intervention, and hence concretely map out policy directives. Additionally, the research focus should be elaborated from a mere place of death focus to the (type and number of) transfers to and from different places of end-of-life care during the last two or three months of life, the reasons for these transfers, and the impact on the quality of life and quality of care.

d) Towards more evidence-based policy research for place of death

If the latter could be organized in a cross-national design, this would allow to a higher extent than in our presented cross-national study to examine what factors can explain cross national differences in patterns of place of death. Research questions that need to be answered in this context are for instance to what extent cross national differences in the organization of health care (e.g. reimbursement policies [146], or possibilities for complex home care[32]) or cross national differences in medical practice (e.g. communicational aspects [147]) influence place of death. An important aspect is moreover to evaluate policy interventions and programs. This could lead to a more evidence-based foundation for health care policy towards place of death and dying.

e) Answer the question of financial effects of place of death

An additional important potential of extensive cross national study designs, as described above, is that it could better answer questions of financial concern. Policies to allow more people die at home are said to have cost-saving effects, but whether this is effectively so is still an issue of discussion. Most studies do not (enough) account for patient mix (i.e. patients in hospital often also need more intensive and hence more expensive treatments). Some authors have claimed that hospice care can even have an add-on effect [148]. The actual cost-effects (sufficiently accounting for patient mix) need to be mapped out better.

f) Look for quality/performance indicators to measure quality of end-of-life care and to compare between settings and countries

Since many people die in hospital and in care homes and since –the demographical changes in mind- this will probably remain so in the near future, it is important that we examine and monitor quality of end-of-life care in all settings. Therefore, primordially, patient needs need to be mapped out and monitored on a population level. End-of-life care can be planned accordingly (on an aggregate level). For instance, the identification of patients at higher risk of dying in hospital could be acknowledged by appropriate planning and implementation of quality end-of-life services in hospitals for these patients [149;150]. Future research will therefore also have to monitor these end-of-life services for specific patient groups in specific locations in different countries. Similarly, the quality of end-of-life care in care homes in different countries need to be examined and compared. A challenge will be to look for appropriate and standardized assessment tools and study methods in similar settings, but also across settings. A difficulty that has to be considered is not only that the different settings of care need to be covered, but also the large variation in health care system organisation in different countries.

g) Study social inequalities in end-of-life care

Several of our studies found patterns possibly suggesting a socio-economic gradient or social inequalities in place of death (e.g. lower educated people, older people). Previous studies also indicated that, next to substantial educational and socioeconomic inequalities in prevalence of and mortality from various diseases[151-153], use of and access to various treatments and health care services [153-155], and quality of care [153;155], there are also social inequalities in access to the best possible care at the end of life [129-132;143]. However, while social inequalities have been a major research issue within public health care and medicine in general [156], very little is known –especially in certain countries, including Belgium-- about social inequalities in the way people die and are cared for at the end of life. Future research will therefore have to answer three particular questions: first, what patterns of social inequality emerge in the whole complex of end-of-life care, second, what are the precise mechanisms or pathways by which these social inequalities in end-of-life care are generated in particular contexts, and third, what effective actions can be taken to reduce, or ameliorate the effects of social inequalities in end-of-life care? Answering these questions could result in a better palliative care and better access to palliative care for all [96;129;157;158].

h) Further explore differences in end-of-life decision making by place of death

Finally, further research should examine more into depth the factors that explain differences in end-of-life decision-making between settings. We observed such differences in Chapter 5, but were not able to conclusively state whether they are caused by differences in clinical characteristics or preferences of patients. Therefore end-of-life decision making should be more related to information on the course of dying, in order to make more qualitative interpretations about the decision-making in each setting.

REFERENCES

1. Seale C, vander Geest S. Good and bad death: introduction. Soc.Sci.Med. 2004;58(5):883-85.
2. Suarez-Almazor ME, Belzile M, Bruera E. Euthanasia and physician-assisted suicide: a comparative survey of physicians, terminally ill cancer patients, and the general population. J.Clin.Oncol. 1997;15(2):418-27.
3. Holloway HD, Hayslip B, Murdock ME et al. Measuring attitudes toward euthanasia. Omega.(Westport.) 1994;30(1):53-65.
4. Nilstun T, Melltorp G, Hermeren G. Surveys on attitudes to active euthanasia and the difficulty of drawing normative conclusions. Scand.J.Public Health 2000;28(2):111-16.
5. Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. Soc.Sci.Med. 1999;48(12):1779-89.
6. Ben Diane MK, Peretti-Watel P, Lapiana JM et al. [Opinion of general and specialized physicians toward euthanasia. Results from the French survey on attitudes and practices against palliative care, 2002]. Ann.Med.Interne (Paris) 2003;154(7):441-47.
7. Caddell DP, Newton RR. Euthanasia: American attitudes toward the physician's role. Soc.Sci.Med. 1995;40(12):1671-81.
8. Snelling PC. Consequences count: against absolutism at the end of life. J.Adv.Nurs. 2004;46(4):350-357.
9. Ho R. Assessing attitudes toward euthanasia: an analysis of the subcategorical approach to right to die issues. Pers.Individ.Dif. 1998;25(4):719-34.
10. Domino G. Community attitudes toward physician assisted suicide. Omega.(Westport.) 2002;46(3):199-214.
11. Achille MA, Ogloff JR. When is a request for assisted suicide legitimate? Factors influencing public attitudes toward euthanasia. Can.J.Behav.Sci. 1997;29(1):19-27.
12. Teisseyre N, Mullet E, Sorum PC. Under what conditions is euthanasia acceptable to lay people and health professionals? Soc.Sci.Med. 2005;60(2):357-68.
13. Hagelin J, Nilstun T, Hau J, Carlsson HE. Surveys on attitudes towards legalisation of euthanasia: importance of question phrasing. J.Med.Ethics 2004;30(6):521-23.
14. Duncan OD, Parmelee LF. Trends in public approval of euthanasia and suicide in the US, 1947-2003. J.Med.Ethics 2006;32(5):266-72.
15. Materstvedt LJ. Palliative care on the 'slippery slope' towards euthanasia? Palliat.Med. 2003;17(5):387-92.
16. Miccinesi G, Fischer S, Paci E et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. Soc Sci.Med 2005;60(9):1961-74.
17. Fischer S, Miccinesi G, Hornung R et al. Responders and non-responders in a study on medical end-of-life decisions in Denmark, the Netherlands, Sweden and Switzerland. Soz.Praventivmed. 2006;51(1):24-33.
18. van der Maas PJ, van der Wal G, Haverkate I, e.a. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in The Netherlands, 1990-1995. The New England Journal of Medicine 1996;335(22):1699-705.
19. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med.J.Aust. 1997;166(4):191-96.
20. Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States: adherence to proposed safeguards and effects on physicians. JAMA 1998;280(6):507-13.
21. van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362(9381):345-50.
22. Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000;356(9244):1806-11.
23. Seale C. National survey of end-of-life decisions made by UK medical practitioners. Palliat.Med 2006;20(1):3-10.

24. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N.Engl.J.Med. 1998;338(17):1193-201.
25. Bilsen J. End-of-life decisions in medical practice in Flanders, Belgium. Gent: Academia Press Scientific Publishers, 2005.
26. van der Maas PJ, van der Wal G, Haverkate I et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. N.Engl.J.Med 1996;335(22):1699-705.
27. McKelvie PA. Medical certification of causes of death in an Australian metropolitan hospital. Comparison with autopsy findings and a critical review. Med J.Aust. 1993;158(12):816-1.
28. Nielsen GP, Bjornsson J, Jonasson JG. The accuracy of death certificates. Implications for health statistics. Virchows Arch A Pathol.Anat.Histopathol. 1991;419(2):143-46.
29. Higginson IJ, Jarman B, Astin P, Dolan S. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. J.Public Health Med. 1999;21(1):22-28.
30. Gallo WT, Baker MJ, Bradley EH. Factors associated with home versus institutional death among cancer patients in Connecticut. J.Am.Geriatr.Soc. 2001;49(6):771-77.
31. Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? Soc.Sci.Med. 1998;47(5):565-79.
32. Brazil K, Bedard M, Willison K. Factors associated with home death for individuals who receive home support services: a retrospective cohort study. BMC.Palliat.Care 2002;1(1):2.
33. Temkin-Greener H, Mukamel DB. Predicting place of death in the program of all-inclusive care for the elderly (PACE): participant versus program characteristics. J.Am.Geriatr.Soc. 2002;50(1):125-35.
34. Cohen J, Bilsen J, Hooft P, Deboosere P, van der Wal G, Deliens L. Dying at home or in an institution. Using death certificates to explore the factors associated with place of death. Health Policy (In Press) 2005.
35. Rietjens JA. Medical decision-making at the end of life Experiences and attitudes of physicians and the general public [dissertation]. Rotterdam: University Medical Center Rotterdam, 2006.
36. Onwuteaka-Philipsen BD, van der Heide A, Koper D et al. Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. Lancet 2003;362(9381):395-99.
37. Cohen JS, Fihn SD, Boyko EJ, Jonsen AR, Wood RW. Attitudes toward assisted suicide and euthanasia among physicians in Washington State. N.Engl.J.Med. 1994;331(2):89-94.
38. Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. Lancet 1996;347(9018):1805-10.
39. Wolfe J, Fairclough DL, Clarridge BR, Daniels ER, Emanuel EJ. Stability of attitudes regarding physician-assisted suicide and euthanasia among oncology patients, physicians, and the general public. J.Clin.Oncol. 1999;17(4):1274.
40. Rietjens JA, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. A comparison of attitudes towards end-of-life decisions: survey among the Dutch general public and physicians. Soc Sci.Med 2005;61(8):1723-32.
41. Ryynanen OP, Myllykangas M, Viren M, Heino H. Attitudes towards euthanasia among physicians, nurses and the general public in Finland. Public Health 2002;116(6):322-31.
42. Hare J, Skinner D, Riley D. Why older age predicts lower acceptance of physician-assisted suicide. WMJ. 2000;99(7):20-7, 46.
43. MacDonald WL. The difference between blacks' and whites' attitudes toward voluntary euthanasia. J.Sci.Study Relig. 1998;37(3):411-26.
44. O'Neill C, Feenan D, Hughes C, McAlister DA. Physician and family assisted suicide: results from a study of public attitudes in Britain. Soc.Sci.Med. 2003;57(4):721-31.
45. Hamil-Luker J, Smith C. Religious authority and public opinion on the right to die. Sociology of Religion 1998;59(4):373-91.

46. Finlay B. Right to life vs. the right to die: some correlates of euthanasia attitudes. Sociology and Social Research 1985;69(4):548-60.
47. van der Maas PJ, Pijnenborg L, van Delden JJ. Changes in Dutch opinions on active euthanasia, 1966 through 1991. JAMA 1995;273(18):1411-14.
48. Baker ME. Economic, political and ethnic influences on end-of-life decision-making: a decade in review. J.Health Soc.Policy 2002;14(3):27-39.
49. Illich I. Medical Nemisis. The expropriation of Health. New York: Bantam Books, 1979.
50. Seale C, Addington-Hall J, McCarthy M. Awareness of dying: prevalence, causes and consequences. Soc.Sci.Med. 1997;45(3):477-84.
51. Seale C. Changing patterns of death and dying. Soc Sci.Med 2000;51(6):917-30.
52. De Moor R. Religion and Moral Values: The Case of Euthanasia. In: De Moor R, editor. Values in Western Societies. Tilburg: Tilburg University Press, 1995:31-50.
53. Giannini A, Pessina A, Tacchi EM. End-of-life decisions in intensive care units: attitudes of physicians in an Italian urban setting. Intensive Care Med. 2003;29(11):1902-10.
54. Cozby D. Prolonging life: an Orthodox Christian perspective. Christ.Bioeth. 1997;3(3):204-21.
55. Engelhardt HT, Jr., Iltis AS. End-of-life: the traditional Christian view. Lancet 2005;366(9490):1045-49.
56. Kopfensteiner TR. Death with dignity: a Roman Catholic perspective. Linacre.Q. 1996;63(4):64-75.
57. Larue GA. Euthanasia and religion. A survey of the attitudes of world religions to the right-to-die. Los Angeles: The Hemlock Society, 1985.
58. Donovan GK. Decisions at the end of life: Catholic tradition. Christ.Bioeth. 1997;3(3):188-203.
59. Melton J, Manning C. The Churches Speak on Euthanasia: Official Statements from Religious Bodies and Ecumenical Organizations. Detroit: Gale Research, 1991.
60. Pauls M, Hutchinson RC. Bioethics for clinicians: 28. Protestant bioethics. CMAJ. 2002;166(3):339-43.
61. Walter JJ. Terminal sedation: a Catholic perspective. Update. 2002;18(2):6-8, 12.
62. Sprung CL, Cohen SL, Sjokvist P et al. End-of-life practices in European intensive care units: the Ethicus Study. JAMA 2003;290(6):790-797.
63. Coleson RE. Contemporary religious viewpoints on suicide, physician-assisted suicide, and voluntary active euthanasia. Duquesne.Law Rev. 1996;35(1):43-80.
64. McNamara B. Good enough death: autonomy and choice in Australian palliative care. Soc.Sci.Med. 2004;58(5):929-38.
65. Gastmans C, Lemiengre J, van der Wal G, Schotsmans P, Dierckx dC. Prevalence and content of written ethics policies on euthanasia in Catholic healthcare institutions in Belgium (Flanders). Health Policy 2006;76(2):169-78.
66. Engelhardt HT. Physician-assisted death: doctrinal develoment vs. Christian tradition. Christ.Bioeth. 1998;4(2):115-21.
67. Engelhardt HT. Physician-assisted suicide reconsidered: dying as a Christian in a post-Christian age. Christ.Bioeth. 1998;4(2):143-67.
68. Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. Lancet 2003;362(9391):1239-40.
69. Burgermeister J. French parliamentary committee advocates passive euthanasia. BMJ 2004;329(7464):474.
70. Forde R, Aasland OG, Falkum E. The ethics of euthanasia--attitudes and practice among Norwegian physicians. Soc.Sci.Med. 1997;45(6):887-92.
71. Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, Deliens L. European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. Soc Sci.Med 2006;63(3):743-56.
72. Muller-Busch HC, Oduncu FS, Woskanjan S, Klaschik E. Attitudes on euthanasia, physician-assisted suicide and terminal sedation--a survey of the members of the German Association for Palliative Medicine. Med.Health Care Philos. 2004;7(3):333-39.

73. Oehmichen M, Meissner C. Active euthanasia and physician-assisted suicide: the German discussion. Leg.Med.(Tokyo) 2003;5 Suppl 1:S20-S28.
74. Leichtentritt RD, Rettig KD, Miles SH. Holocaust survivors' perspectives on the euthanasia debate. Soc.Sci.Med. 1999;48(2):185-96.
75. Kottow MH. Euthanasia after the holocaust--is it possible?: a report from the Federal Republic of Germany. Bioethics. 1988;2(1):58-59.
76. Sahm SW. Palliative care versus euthanasia. The German position: the German General Medical Council's principles for medical care of the terminally ill. J.Med.Philos. 2000;25(2):195-219.
77. Wenger NS, Oye RK, Bellamy PE et al. Prior capacity of patients lacking decision making ability early in hospitalization: implications for advance directive administration. The SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. J.Gen.Intern.Med 1994;9(10):539-43.
78. Peters L, Sellick K. Quality of life of cancer patients receiving inpatient and home-based palliative care. J.Adv.Nurs. 2006;53(5):524-33.
79. Cohen S, Sprung C, Sjokvist P et al. Communication of end-of-life decisions in European intensive care units. Intensive Care Med 2005;31(9):1215-21.
80. Sjokvist P, Nilstun T, Svantesson M, Berggren L. Withdrawal of life support--who should decide? Differences in attitudes among the general public, nurses and physicians. Intensive Care Med 1999;25(9):949-54.
81. Bilsen J, vander Stichele R, Mortier F, Bernheim J, Deliens L. The incidence and characteristics of end-of-life decisions by GPs in Belgium. Fam.Pract. 2004;21(3):282-89.
82. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000;284(19):2476-82.
83. Angus J, Kontos P, Dyck I, McKeever P, Poland B. The personal significance of home: habitus and the experience of receiving long-term home care. Sociology of Health and Illness 2005;27(2):161-87.
84. Brown M, Colton T. Dying Epistemologies: an analysis of home death and its critique. Environment and Planning A 2001;33:799-821.
85. Tang ST. When death is imminent: where terminally ill patients with cancer prefer to die and why. Cancer Nurs. 2003;26(3):245-51.
86. Teno JM, Clarridge BR, Casey V et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004;291(1):88-93.
87. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. JAMA 1995;274(20):1591-98.
88. Beccaro M, Costantini M, Rossi PG, Miccinesi G, Grimaldi M, Bruzzi P. Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). J.Epidemiol.Community Health 2006;60(5):412-16.
89. Davies E, Linklater KM, Jack RH, Clark L, Moller H. How is place of death from cancer changing and what affects it? Analysis of cancer registration and service data. Br.J.Cancer 2006;95(5):593-600.
90. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ 2006;332(7540):515-21.
91. Hansen SM, Tolle SW, Martin DP. Factors associated with lower rates of in-hospital death. J.Palliat.Med. 2002;5(5):677-85.
92. Pritchard RS, Fisher ES, Teno JM et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. J.Am.Geriatr.Soc. 1998;46(10):1242-50.
93. Wilson DM, Smith SL, Anderson MC et al. Twentieth-century social and health-care influences on location of death in Canada. Can.J.Nurs.Res. 2002;34(3):141-61.

94. Lloyd L. Mortality and morality: ageing and the ethics of care. Ageing & Society 2004;24(2):235-56.
95. Addington-Hall J, Altmann D, McCarthy M. Which terminally ill cancer patients receive hospice in-patient care? Soc.Sci.Med. 1998;46(8):1011-16.
96. Davies, E. and Higginson, I. J. Better Palliative Care for Older People. Davies, E. and Higginson, I. J. 2004. World Health Organisation Europe.
Ref Type: Report
97. Burt J, Raine R. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. Age and Ageing 2006;35(5):469-76.
98. The National Council for Palliative Care. National Survey of Patient Activity Data for Specialist Palliative Care Services. MDS Full Report for the year 2005–2006. http://www.ncpc.org.uk/download/mds/MDS_Full_Report_2006.pdf . 2006.
Ref Type: Electronic Citation
99. Murtagh FE, Preston M, Higginson I. Patterns of dying: palliative care for non-malignant disease. Clin.Med. 2004;4(1):39-44.
100. Murray SA, Boyd K, Sheikh A, Thomas K, Higginson IJ. Developing primary palliative care. BMJ 2004;329(7474):1056-57.
101. Foreman LM, Hunt RW, Luke CG, Roder DM. Factors predictive of preferred place of death in the general population of South Australia. Palliat.Med 2006;20(4):447-53.
102. Costantini M, Balzi D, Garronec E et al. Geographical variations of place of death among Italian communities suggest an inappropriate hospital use in the terminal phase of cancer disease. Public Health 2000;114(1):15-20.
103. Mor V, Hiris J. Determinants of site of death among hospice cancer patients. J.Health Soc.Behav. 1983;24(4):375-85.
104. Brettle RP, Morris S, Epton V. Patients with HIV dying in Edinburgh: an audit of preference and place of death. Int.J.STD AIDS 1995;6(3):221-22.
105. Kabengele Mpinga E, Pennec S, Gomes B et al. First International Symposium on Places of Death: An Agenda for the 21st century. J.Palliat.Care, in press.
106. Murtagh FE, Preston M, Higginson I. Patterns of dying: palliative care for non-malignant disease. Clin.Med. 2004;4(1):39-44.
107. Burge F, Lawson B, Johnston G. Trends in the place of death of cancer patients, 1992-1997. CMAJ. 2003;168(3):265-70.
108. Costantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative home care and place of death among cancer patients: a population-based study. Palliat.Med. 1993;7(4):323-31.
109. Grande GE, McKerral A, Todd CJ. Which cancer patients are referred to Hospital at Home for palliative care? Palliat.Med. 2002;16(2):115-23.
110. Ahlner-Elmqvist M, Jordhoy MS, Jannert M, Fayers P, Kaasa S. Place of death: hospital-based advanced home care versus conventional care. A prospective study in palliative cancer care. Palliat.Med. 2004;18(7):585-93.
111. Tolle SW, Rosenfeld AG, Tilden VP, Park Y. Oregon's low in-hospital death rates: what determines where people die and satisfaction with decisions on place of death? Ann.Intern.Med. 1999;130(8):681-85.
112. Thomas C. The place of death of cancer patients: can qualitative data add to known factors? Soc.Sci.Med. 2005;60(11):2597-607.
113. Karlsen S, Addington-Hall J. How do cancer patients who die at home differ from those who die elsewhere? Palliat.Med. 1998;12(4):279-86.
114. Grundy E, Mayer D, Young H, Sloggett A. Living arrangements and place of death of older people with cancer in England and Wales: a record linkage study. Br.J.Cancer 2004;91(5):907-12.
115. Choi KS, Chae YM, Lee CG et al. Factors influencing preferences for place of terminal care and of death among cancer patients and their families in Korea. Support.Care Cancer 2005.

116. Tang ST, Liu TW, Lai MS, McCorkle R. Discrepancy in the preferences of place of death between terminally ill cancer patients and their primary family caregivers in Taiwan. Soc.Sci.Med. 2005;61(7):1560-1566.
117. Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older people's views about home as a place of care at the end of life. Palliat.Med. 2004;18(5):460-467.
118. Klinkenberg M. The last phase of life of older people: health, preferences and care. A proxy report study [dissertation].EMGO institute, VU Amsterdam, 2004.
119. Tang ST, McCorkle R. Determinants of place of death for terminal cancer patients. Cancer Invest 2001;19(2):165-80.
120. Guerra MJ. Euthanasia in Spain: the public debate after Ramon Sampedro's case. Bioethics. 1999;13(5):426-32.
121. House of Lords Select Committee on the Assisted Dying for theTerminally Ill Bill. Assisted Dying for the Terminally Ill Bill [HL]. Volume 1: report. http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/86i.pdf . 4-4-2005. **House of Lords**. 6-7-2005.
Ref Type: Electronic Citation
122. van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362(9381):345-50.
123. Bilsen J, Norup M, Deliens L et al. Drugs used to alleviate symptoms with life shortening as a possible side effect: end-of-life care in six European countries. J.Pain Symptom.Manage. 2006;31(2):111-21.
124. Miccinesi G, Rietjens JA, Deliens L et al. Continuous deep sedation: physicians' experiences in six European countries. J.Pain Symptom.Manage. 2006;31(2):122-29.
125. Teno JM. Measuring end-of-life care outcomes retrospectively. J.Palliat.Med 2005;8 Suppl 1:S42-S49.
126. Messite J, Stellman SD. Accuracy of death certificate completion: the need for formalized physician training. JAMA 1996;275(10):794-96.
127. Nilstun T, Cartwright C, Lofmark R et al. Access to Death Certificates: What Should Research Ethics Committees Require for Approval? Ann.Epidemiol. 2006;16(4):281-84.
128. Kessler D, Peters TJ, Lee L, Parr S. Social class and access to specialist palliative care services. Palliat.Med. 2005;19(2):105-10.
129. Oliviere D, Monroe B. Death, dying and social differences. Oxford: Oxford University Press, 2004.
130. Cartwright A. Social class differences in health and care in the year before death. J.Epidemiol.Community Health 1992;46(1):54-57.
131. Greiner KA, Perera S, Ahluwalia JS. Hospice usage by minorities in the last year of life: results from the National Mortality Followback Survey. J.Am.Geriatr.Soc. 2003;51(7):970-978.
132. Cleeland CS, Gonin R, Hatfield AK et al. Pain and its treatment in outpatients with metastatic cancer. N.Engl.J.Med. 1994;330(9):592-96.
133. Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. Soc.Sci.Med. 1999;48(12):1779-89.
134. Rosenwax LK, McNamara B, Blackmore AM, Holman CD. Estimating the size of a potential palliative care population. Palliat.Med 2005;19(7):556-62.
135. Catalan-Fernandez JG, Pons-Sureda O, Recober-Martinez A et al. Dying of cancer. The place of death and family circumstances. Med.Care 1991;29(9):841-52.
136. Bowling A. The hospitalisation of death: should more people die at home? J.Med.Ethics 1983;9(3):158-61.
137. Palliatieve zorg, richtlijnen voor de praktijk. Utrecht: Vereniging van Integrale Kankercentra, 2006.
138. Hinkka H, Kosunen E, Metsanoja R, Lammi UK, Kellokumpu-Lehtinen P. Factors affecting physicians' decisions to forgo life-sustaining treatments in terminal care. J.Med Ethics 2002;28(2):109-14.
139. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern.Med 2006;166(5):493-97.

140. Christakis NA, Asch DA. Physician characteristics associated with decisions to withdraw life support. Am.J.Public Health 1995;85(3):367-72.
141. Deschepper R, Vander Stichele RH, Mortier F, Deliens L. Zorgzaam thuis sterven. Een zorgleidraad voor huisartsen. 1st ed. Gent (B): Academia Press, 20043.
142. von Gunten CF, Ferris FD, Emanuel LL. The patient-physician relationship. Ensuring competency in end-of-life care: communication and relational skills. JAMA 2000;284(23):3051-57.
143. Karim K, Bailey M, Tunna K. Nonwhite ethnicity and the provision of specialist palliative care services: factors affecting doctors' referral patterns. Palliat.Med. 2000;14(6):471-78.
144. Addington-Hall J, McCarthy M. Regional Study of Care for the Dying: methods and sample characteristics. Palliat.Med. 1995;9(1):27-35.
145. Singer PA, Wolfson M. "The best places to die". BMJ 2003;327(7408):173-74.
146. Intrator O, Mor V. Effect of state Medicaid reimbursement rates on hospitalizations from nursing homes. J.Am.Geriatr.Soc. 2004;52(3):393-98.
147. Mor V. Hospitalization of Nursing Home Residents: A Review of Clinical, Organizational and Policy Determinants. Providence: Brown University, 1998.
148. Campbell DE, Lynn J, Louis TA, Shugarman LR. Medicare program expenditures associated with hospice use. Ann.Intern.Med. 2004;140(4):269-77.
149. Pantilat SZ, Billings JA. Prevalence and structure of palliative care services in California hospitals. Arch.Intern.Med. 2003;163(9):1084-88.
150. Cardenas-Turanzas M, Grimes RM, Bruera E, Quill B, Tortolero-Luna G. Clinical, sociodemographic, and local system factors associated with a hospital death among cancer patients. Support.Care Cancer 2005.
151. Huisman M, Kunst AE, Bopp M et al. Educational inequalities in cause-specific mortality in middle-aged and older men and women in eight western European populations. Lancet 2005;365(9458):493-500.
152. Mackenbach JP, Huisman M, Andersen O et al. Inequalities in lung cancer mortality by the educational level in 10 European populations. Eur.J.Cancer 2004;40(1):126-35.
153. Ward E, Jemal A, Cokkinides V et al. Cancer disparities by race/ethnicity and socioeconomic status. CA Cancer J.Clin. 2004;54(2):78-93.
154. Pappas G, Hadden WC, Kozak LJ, Fisher GF. Potentially avoidable hospitalizations: inequalities in rates between US socioeconomic groups. Am.J.Public Health 1997;87(5):811-16.
155. Navarro V. The "Black Report" of Spain--the Commission on Social Inequalities in Health. Am.J.Public Health 1997;87(3):334-35.
156. Macintyre S. The Black Report and beyond: what are the issues? Soc.Sci.Med. 1997;44(6):723-45.
157. Exley C. Review article: the sociology of dying, death and bereavement. Sociol.Health Illn. 2004;26(1):110-122.
158. Better Palliative Care for Older People. Davies, E. and Higginson, I. J. 2004. World Health Organisation Europe.
    Ref Type: Report

LIST OF ABBREVIATIONS AND ACRONYMS USED

APS	alleviation of pain and symptoms with a possible life-shortening effect
AT	Austria
AU	Australia
ANH	Artificial nutrition and hydration
BE	Belgium
BG	Bulgaria
BY	Belarus
CDS	continuous deep sedation until death
CH	Switzerland
CI	confidence interval
CZ	Czech Republic
DE	Germany
DK	Denmark
EE	Estonia
EL	Greece
ELD	end-of-life decision
ES	Spain
EURELD	European End-of-life Decisions
EVS	European Values Studies
FI	Finland
FR	France
GB	Great Britain[‡]
GP	General practitioner
HR	Croatia
HU	Hungary
IE	Ireland
IS	Iceland
IT	Italy
LAWER	administration of lethal drugs without an explicit request by the patient
LT	Lithuania
LU	Luxembourg
LV	Latvia
MT	Malta
N	Number
NI	Northern Ireland
NL	The Netherlands
NO	Norway
NTD	non-treatment decisions
OR	odds ratio
P	probability
PAD	physician-assisted dying (this includes euthanasia, physician-assisted suicide, and administration of lethal drugs without an explicit request by the patient)
PAS	physician-assisted suicide
PCA	principal component analysis
PL	Poland
PT	Portugal
RO	Romania
RU	Russia
SD	standard deviation
SE	Sweden
SES	Socio-economic status
SI	Slovenia
SK	Slovakia
TR	Turkey
UA	Ukraine
UK	United Kingdom

Medische beslissingen aan het levenseinde en plaats van overlijden in België en Europa.

Samenvatting van de belangrijkste bevindingen

ACHTERGROND

Demografische, epidemiologische, en medisch-technologische ontwikkelingen en een toenemend credo van het individu als planner van zijn eigen leven en dood hebben bijgedragen tot een verhoogde aandacht voor omstandigheden en kwaliteit van het overlijden (vb. autonomie, inspraak, goede pijnbestrijding, sterven in een vertrouwde omgeving).
Dit proefschrift belicht in hoofdzaak drie relevante thema's in deze context:

1. publieke opinies over euthanasie,
2. opinies en gedrag van artsen inzake euthanasie en andere mogelijk levensverkortende medische beslissingen aan het levenseinde
3. plaats van overlijden (i.e. ziekenhuis, thuis, rusthuis)

ONDERZOEKSVRAGEN

De volgende onderzoeksvragen werden gesteld:

1. Hoe is de publieke aanvaarding van euthanasie door het algemeen publiek veranderd doorheen de laatste decennia, en welke factoren hebben bijgedragen tot deze veranderingen?
2. Wat is heden ten dage de mate waarin euthanasie wordt aanvaard in Europa? Zijn er grote verschillen tussen Europese landen en hoe kunnen deze worden verklaard?
3. Wat zijn de houdingen, en het gedrag van artsen inzake medische besluitvoering aan het levenseinde van patiënten? Wat is de specifieke invloed van religie?
4. Zijn verschillende plaatsen van overlijden geassocieerd met verschillende medische praktijken aan het levenseinde?
5. Hoe geschikt zijn overlijdenscertificaten om de plaats van overlijden en geassocieerde factoren te bestuderen? Wat zijn de mogelijkheden en wat zijn de zwaktes?
6. Waar sterven mensen in België en in andere Europese landen en welke factoren beïnvloeden waar ze sterven? Zijn er opvallende verschillen?
7. Welke verklaringen kunnen naar voren worden gedragen voor (mogelijke) verschillen in plaats van overlijden tussen Europese landen, en kunnen deze verklaringen suggesties bieden voor beleidsmakers?

ONDERZOEKEN

Om deze onderzoeksvragen te beantwoorden werd gebruik gemaakt van data verzameld in verschillende onderzoeken.

1. European Values Survey (EVS) 1981, 1990, 1999-2000 (Hoofdstuk 2 en 3)
In de EVS-studies werden representatieve steekproeven van respondenten uit verschillende Europese landen bevraagd (van 12 landen in 1981 tot 33 in 1999-2000) over hun sociodemografische achtergrondkenmerken, maar ook over hun sociale, culturele, politieke, morele, en religieuze waarden en houdingen. De surveys stelden ook een vraag naar de aanvaardbaarheid van euthanasie.

2. Europese studie over 'end-of-life decisions' (Eureld 1 en 2) (Hoofdstuk 4 en 5)
Deze studie omvatte twee grote dataverzamelingen: een overlijdenscertificatenstudie in zes Europese landen naar de feitelijke praktijk van medische beslissingen (Eureld 1), en een survey naar de houdingen van artsen ten opzichte van die beslissingen in zes Europese landen en Australië (Eureld 2). In de eerste studie werd naar de certificerende artsen van een representatieve steekproef van overlijdenscertificaten een vragenlijst opgestuurd over de medische besluitvoering aan het levenseinde van de betrokken overledenen. In de tweede studie werd een steekproef van artsen, gestratificeerd naargelang specialisme, schriftelijk bevraagd over hun houdingen en ervaringen rond medische besluitvoering aan het levenseinde van patiënten. Beide studies vertrokken van een conceptueel kader bestaande uit verschillende soorten medische beslissingen aan het levenseinde (met een mogelijk of zeker levensverkortend effect):

- Het toedienen van middelen met de uitdrukkelijke bedoeling het levenseinde van de patiënt te bespoedigen, op expliciet verzoek van deze patiënt *(euthanasie)* of zonder diens expliciet verzoek *(levensbeëindiging zonder expliciet verzoek)*; of het verstrekken van dergelijke middelen om de patiënt in staat te stellen zijn eigen leven te beëindigen (*arts-geassisteerde zelfdoding*)
- Het intensiveren van *pijn- en symptoombestrijding* met een mogelijk levensverkortend neveneffect
- Het niet opstarten of stopzetten van behandelingen waardoor het levenseinde (mogelijk) wordt bespoedigd (*niet-behandel beslissingen*)

3. Overlijdenscertificaten data (Vlaanderen 2001; Dying Well 2003) (Hoofdstuk 5, 6, 7)
Overlijdenscertificaten worden typisch verzameld in functie van doodsoorzakenstatistiek, maar verschaffen ook overige relevante informatie, bijvoorbeeld over plaats van overlijden. Daarom werden twee databases van overlijdenscertificatendata aangelegd. Een eerste bevat alle 55 772 overlijdens uit 2001 in Vlaanderen. Een tweede bevat meer dan 1,1 miljoen overlijdens en integreert de overlijdenscertificatendata van 2003 uit negen Europese landen (zie hoofdstuk 5 voor meer uitleg).

RESULTATEN

De resultaten van alle onderzoeken (en antwoorden op de onderzoeksvragen) zijn verwerkt in twee delen (medische beslissingen aan het levenseinde, en plaats van overlijden), onderverdeeld in zeven hoofdstukken. De nummering van de resultaten hieronder verwijst naar de corresponderende onderzoeksvragen hierboven.

Medische beslissingen aan het levenseinde

1. Trends in publieke aanvaarding van euthanasie en beïnvloedende factoren(Hoofdstuk 2)

De studie van 46,199 respondenten in 1981, 1990 en 1999-2000 in 12 West-Europese landen toonde een significante stijging aan van de publieke aanvaarding van euthanasie in alle landen behalve (West-)Duitsland. België (69%), Ierland (56%) en Spanje (52%) waren de landen met de sterkste stijging in euthanasie-aanvaarding, gevolgd door Zweden (36%), Noord Ierland (31%, waarbij wel kan worden opgemerkt dat de aanvaarding laag blijft) en Frankrijk (31%). IJsland (29%), Italië (27%), en Nederland (23%) kenden een iets meer gematigde stijging, terwijl in Groot-Britanië (13%) en Denemarken (9%) slechts een zwakke stijging kon worden vastgesteld in deze periode van ongeveer 2 decennia.

Er werden verschillende factoren geïdentificeerd die deze trends in euthanasie-aanvaarding kunnen verklaren. Zo toonden we een invloed aan van de daling van religiositeit (~secularisatie), het groeiend geloof in het recht op zelfbeschikking, en (in iets mindere mate) de stijgende scholingsgraad. Desalniettemin toonden onze resultaten ook duidelijk aan dat deze (maatschappelijke veranderingen) niet in alle landen in dezelfde mate bijdroegen tot de verandering in euthanasie aanvaarding. Andere, landenspecifieke factoren leken eveneens belangrijk.

2. Euthanasie aanvaarding in Europa en crossnationale verschillen (Hoofdstuk 3)

Analyse van EVS data (1999 - 2000) van 33 landen toonde aan dat er geen gemeenschappelijke Europese publieke aanvaarding is van euthanasie. Aanvaarding was aanzienlijk in Nederland, maar zeer laag in Malta. Over het algemeen kunnen we stellen dat er 3 clusters van landen zijn:

- landen met een hoge aanvaarding, respectievelijk Nederland, Denemarken, Frankrijk, Zweden, België, en Luxemburg
- landen met een matige aanvaarding, respectievelijk Rusland, Tsjechië, Finland, Wit-Rusland, Litouwen, Slovenië, IJsland, Letland, Oekraïne, Estland, Groot-Brittannië, Slowakije, Spanje, en Oostenrijk
- landen met een lage aanvaarding, respectievelijk Duitsland, Griekenland, Noord-Ierland, Italië, Hongarije, Kroatië, Bulgarije, Portugal, Polen, Ierland, Roemenië, Turkije, en Malta

Verschillende factoren konden de grote verschillen tussen landen gedeeltelijk verklaren. Demografische verschillen (vb. leeftijd en opleidingsniveau) verklaarden slechts een klein gedeelte van de crossnationale verschillen. De mate van religiositeit was al een betere voorspeller van de houding ten opzichte van euthanasie in een land. Toch bleek dat het effect van (verschillen in) religiositeit niet moet worden overschat en dat sommige landen een sterk idiosyncratische houding hebben ten opzichte van euthanasie. Terwijl sterk-religieuze, weinig permissieve landen over het algemeen minder tolerant, en weinig-religieuze, sterk permissieve landen meer tolerant waren ten opzichte van euthanasie, waren er verschillende landen die niet in deze logica pasten. Dit deed ons besluiten dat attitudes soms zeer landspecifiek zijn, gerelateerd aan de traditie en geschiedenis van een land.

3. Attitudes en gedrag van artsen in mogelijk levensverkortende medische beslissingen aan het levenseinde: de invloed van levensbeschouwing (Hoofdstuk 4)

Deze studie, die gebruikt maakt van de Eureld 2 gegevens, toonde aan dat een mogelijk levenverkortend effect van pijn- en symptoombestrijding, alsook de eventuele levensverkorting door het stopzetting of niet opstarten van behandelingen sterk wordt aanvaard door artsen, en over het algemeen even sterk door Protestantse of Katholieke als door niet religieuze artsen. Het gebruik van letale middelen (vb. bij euthanasie) werd duidelijk minder aanvaard bij religieuze artsen, en dit verschil naar levensbeschouwing was nog het duidelijkst in België.

We vonden gelijkaardige patronen en verschillen voor het *intentionele* gedrag (i.e. bij hypothetische patiënten), hoewel de verschillen iets minder significant neigden te zijn. Zowel religieuze als niet-religieuze artsen gaven in hoge mate aan pijn en andere symptomen te bestrijden, ook al kan een levensverkortend effect van de (hypothetische) patiënt worden voorzien (78% tot 100% zou dit uitvoeren indien de patiënt daarom verzoekt). De bereidheid om een patiënt terminaal te sederen (i.e. door middelen in een diepe slaap of subcomateuze toestand brengen en houden) verschilde ook weinig tussen religieuze en niet-religieuze artsen, hoewel deze praktijk niet zomaar wordt aanvaard door de religieuze doctrines. Zeer grote variatie werd echter gevonden tussen religieuze en niet-religieuze artsen in de bereidheid om letale middelen toe te dienen. Ongeveer 3% tot 49% van de religieuze artsen en 4% tot 82% van de niet-religieuze artsen was bereid dit te doen indien de patiënt erom verzoekt; en respectievelijk 2% tot 22% en 2% tot 42% indien de patiënt er niet om verzoekt (vb. uit redenen van compassie).

In het *feitelijke* gedrag, tenslotte, waren de verschillen naargelang levensbeschouwing kleiner. Mogelijk levensverkortende pijn- en symptoombestijding en terminale sedatie werden bijna even vaak ooit uitgevoerd door religieuze artsen als door niet-religieuze. Enkel voor de toediening van letale middelen zagen we een duidelijk verschil. Toch rapporteerden in de meeste landen zowel Katholieken (tot 16% in Nederland) en Protestanten (tot 20% in Nederland) dat ze ooit zo een beslissing hadden uitgevoerd.

Dus, religie beïnvloedt de visies van artsen op medische besluitvoering aan het levenseinde van patiënten, maar in mindere mate de feitelijke besluitvoering, wanneer echte patiënten en omstandigheden in het spel komen. De resultaten in Hoofdstuk 4 toonden aan dat religieuze artsen ook vatbaar zijn voor omstandigheden (vb. mate van lijden van de patiënt, verzoek van de patiënt), en bijgevolg hun houdingen en gedrag ook aanpassen aan specifieke situaties. Zij volgen met andere woorden zeker niet per definitie de religieuze doctrines over beslissingen aan het levenseinde.

Tot slot, was een opvallende bevinding in Hoofdstuk 4 dat er sterkere verschillen waren afhankelijk van het land van residentie dan van de levensbeschouwing van de arts. Dit suggereert een duidelijke invloed van de omgevende cultuur.

Plaats van overlijden

4. Medische beslissingen aan het levenseinde en plaats van overlijden (Hoofdstuk 5)

Het proefschrift onderzocht de relatie tussen medische besluitvoering aan het levenseinde van patiënten en de plaats van overlijden in België, Denemarken, Zweden, en Zwitserland, aan de hand van gegevens van de Eureld 1 studie. Van alle niet plotse overlijdens werd 0.4% in Zweden tot 2.8% in België viirafgegaan door het toedienen of verstrekkken van middelen met de uitdrukkelijke bedoeling het levenseinde van de patiënt te bespoedigen, 21% in Zweden to 39% in Denemarken door mogelijk levensverkortende pijn- en symptoombestrijding, en 21% in Denemarken tot 41% in Zwitserland door niet behandelingsbeslissingen. In alle landen werd echter ook een duidelijke variatie aangetroffen in de incidentie (en het type) van medische beslissingen aan het levenseinde naargelang de plaats van overlijden van de patiënt, zelfs indien we rekening houden met de verschillen in doodsoorzaak, geslacht en leeftijd. Gebruik van letale middelen kwam wat vaker voor bij thuisoverlijdens; terminale sedatie (vooral in combinatie met het weerhouden van vocht en voeding) kwam minder vaak thuis of in rusthuizen voor dan in ziekenhuizen; en niet-behandelingsbeslissingen werden het vaakst genomen in ziekenhuizen (maar ook relatief vaak in rusthuizen in België en Zwitserland). Mogelijk levensverkortende pijn- en symptoombestrijding kwam min of meer in gelijke mate voor in alle settings.

Er werden ook een aantal opvallende verschillen gevonden in het besluitvormingsproces naargelang de plaats van overlijden. Thuis werd er veel minder vaak overlegd met andere professionele zorgverstrekkers, hoewel dit een belangrijke toets kan zijn voor goed medisch handelen. Met de patiënt werd er echter vaker overlegd in de thuissituatie dan in ziekenhuizen en rusthuizen, en ook familieleden werden thuis over het algemeen meer betrokken in het overleg.

5. Geschiktheid van overlijdenscertificaten data om de plaats van overlijden en geassocieerde factoren te bestuderen (Hoofdstuk 6)

Dit is in hoofdzaak een methodologisch artikel dat de sterktes en zwaktes van overlijdenscertificaten gegevens bespreekt en illustreert aan de hand van een verzameling van zulke gegevens in negen Europese landen. Naast de welgekende algemene zwaktes van verkeerde coderingen in doodsoorzaken en mogelijke nationale en temporele variatie hierin, toonde onze studie aanzienlijke variatie aan tussen de landen en regio's in de kwaliteit, kwantiteit, en het soort informatie beschikbaar via overlijdenscertificaten data (plaats van overlijden en andere variabelen), wat resulteerde in een differentiële geschiktheid van deze data voor het vooropgestelde doel. Een nog belangrijkere beperking in de specifieke context van het bestuderen van plaats van overlijden was waarschijnlijk dat veel relevante informatie niet gekend is via overlijdenscertificaten (vb. preferentie voor plaats van overlijden van de patiënt).

De belangrijkste geïdentificeerde sterkte van overlijdenscertificaten data was dat ze toelaten om patronen te beschrijven voor een hele populatie en niet enkel voor een steekproef. Daardoor is men ook niet noodzakelijk beperkt tot het bestuderen van specifieke patiëntenpopulaties of settings, zoals vaak het probleem in bestaand onderzoek. De grotere statistische 'power' voortkomend uit de grote aantallen kan leiden tot meer betrouwbare resultaten. Bovendien maakt de beschikbaarheid van verschillende relevante variabelen het mogelijk om vrij goede multivariate statistische modellen te maken (i.e. waarbij gecontroleerd wordt voor verschillende zgn. verstorende effecten), maar ook om zinvolle resultaten te genereren voor zeer specifieke subpopulaties (vb. longkankerpatiënten, HIV patiënten, laag opgeleiden, specifieke regio's). De mogelijkheid van het linken van de overlijdenscertificaten data met informatie uit andere databases vergrootte deze mogelijkheden bovendien. Een andere belangrijke geïdentificeerde sterkte, ten slotte, was dat overlijdenscertificaten gebruikt kunnen worden om vrij betrouwbare vergelijkingen voor plaats van overlijden te maken overheen de tijd en tussen landen, en deze te plaatsen ten opzichte van andere trends (vb. doodsoorzaken, leeftijd, leefsituatie).

6. Plaats van overlijden en geassocieerde factoren in België en Europa (Hoofdstuk 7 en 8)

In 2001 vond 54% van alle overlijdens in Vlaanderen plaats in het ziekenhuis; 20% stierf in een rusthuis (rob of rvt) en 24% stierf thuis (Hoofdstuk 7).
In 2003 was het aandeel overlijdens in een ziekenhuis in Vlaanderen gedaald tot 51.5% (Hoofdstuk 8).Er werden relatief grote verschillen gevonden tussen landen. In Nederland vond maar 34% van alle overlijdens plaats in het ziekenhuis, in Engeland (58%) en Schotland (58.5%) was dit aanzienlijk hoger, en het aandeel was bijna dubbel zo groot in Zweden en Wales (beiden 63%).

De plaats van overlijden werd eveneens onderzocht voor enkel de kankerpatiënten. In 2001 stierf 29% van deze patiënten in Vlaanderen thuis, 9% in een rusthuis, en 62% in een ziekenhuis (Hoofdstuk 7). In 2003 was het percentage kanker overlijdens in een ziekenhuis in Vlaanderen gedaald tot 59.5% (Hoofdstuk 8). Het bekijken van plaats van overlijden voor enkel de kankerpatiënten toonde ook nog grotere verschillen tussen landen aan dan de algemene verschillen. Het percentage overlijdens in ziekenhuizen binnen deze populatie varieerde van 31% in Nederland, en 49.5% in Engeland, tot 85% in Zweden.

We vonden vier types van factoren geassocieerd met de plaats van overlijden: klinische, socio-demografische, sociale ondersteuning, en kenmerken van gezondheidszorg.

Klinische
De onderliggende (terminale) ziekte beïnvloedde de kans om thuis, in een ziekenhuis, of in een rusthuis te sterven (Hoofdstuk 7 en 8). Cardiovasculaire overlijdens vonden vaak

thuis plaats, en kankerpatiënten (niet hematologisch) hadden meestal ook een goede kans om thuis te sterven (of buiten het ziekenhuis). Dit bleek echter wel sterk te variëren tussen de bestudeerde landen.

Socio-demografisch
Opvallende verschillen in plaats van overlijden werden gevonden tussen verschillende sociale groepen. Ten eerste bleek de kans om in Vlaanderen thuis te sterven (vergeleken met in een ziekenhuis) lichtjes af te nemen met leeftijd. Leeftijdsverschillen kwamen voor in de verschillende bestudeerde landen, maar de grootte van deze verschillen bleek nogal landenspecifiek (Hoofdstuk 8). Ten tweede bleken mensen zonder hogere opleiding vaker in een ziekenhuis te sterven en minder vaak thuis. Bij de kankerpatiënten was dit scholingseffect nog sterker. Tot slot, bleken mensen woonachtig in verstedelijkte gebieden een hogere kans te hebben om in een ziekenhuis te sterven dan mensen in rurale of licht verstedelijkte gebieden.

Sociale ondersteuning/familie
Thuis sterven bleek veel minder waarschijnlijk voor iemand die alleen woont dan voor iemand die in een privé huishouden woont (i.e. met een potentiële mantelzorger).

Kenmerken gezondheidszorg
Een relatief groter aanbod van ziekenhuisbedden in een gezondheidsregio bleek de probabiliteit van ziekenhuisoverlijdens te verhogen. Toch was het gevonden effect heel wat kleiner dan in eerder (Amerikaans) onderzoek. Een relatief groter aanbod van rusthuisbedden deed de kans op ziekenhuisoverlijdens dalen.

7. Crossnationale verschillen in plaats van overlijden: enige verklaring (Hoofdstuk 8)

De zeer duidelijke crossnationale verschillen in aandeel ziekenhuisoverlijdens tussen Vlaanderen, Nederland, Zweden, Schotland, Engeland en Wales waren nauwelijks te wijten aan (kleine) demografische verschillen of verschillen in doodsoorzaken tussen de bestudeerde landen.

Het aanbod van ziekenhuisbedden verklaarde, tegen onze verwachtingen gebaseerd op de literatuur, slechts een relatief klein gedeelte van crossnationale verschillen. Het aanbod rusthuisbedden verklaarde de crossnationale verschillen in grotere mate. Toch konden we ook hiermee niet volledig de crossnationale variatie in ziekenhuis- of niet-ziekenhuisoverlijdens verklaren. Andere factoren spelen duidelijk een rol en onze data suggereerden twee aanvullende verklaringen in deze context.

Ten eerste waren verschillen tussen landen bijzonder groot als we enkel naar de oudere patiënten keken. Dit suggereerde een landen-gedifferentieerd zorgbeleid en (doorverwijs) praktijk bij ouderen. Aanvullende analyses op Belgische en Nederlandse data wezen bijvoorbeeld duidelijk verschillende praktijken uit met betrekking tot het transfereren van ouderen van het rusthuis naar het ziekenhuis voor het overlijden: ongeveer een zevende van de ouderen wonend in een Nederlands rusthuis stierf in een ziekenhuis tegen een vijfde van de ouderen wonend in een Vlaams rusthuis.

Ten tweede waren de crossnationale verschillen bijzonder groot als we keken naar specifieke ziektegroepen, vooral kankerpatiënten. Terwijl in Zweden kankerpatiënten zeer waarschijnlijk in een ziekenhuis stierven, hadden zij goede kansen om buiten het ziekenhuis te sterven in Nederland en Engeland. Ook m.b.t. deze patiëntengroep gelden dus andere zorg-, behandelings-, en doorverwijspraktijken in verschillende landen

DISCUSSIE/AANBEVELINGEN

In Hoofdstuk 9 worden eerst alle sterktes en zwaktes van de studies uit dit proefschrift kritisch geanalyseerd. Daarna worden de voornaamste resultaten samengevat en hun interpretatie bediscussieerd. Tot slot worden ook een aantal aanbevelingen voor gezondheidszorgbeleid, gezondheidszorgprofessionals, en voor toekomstig onderzoek gedistilleerd uit de onderzoeksresultaten. Wij zullen ons in deze samenvatting enkel op dit laatste focussen.

Aanbevelingen voor beleid

Gezien de snelle stijging van publieke euthanasie-aanvaarding is het waarschijnlijk dat de regulering van euthanasie publiek zal worden gedebatteerd in verschillende landen (zoals nu o.m. het geval in het Verenigd Koninkrijk). Hierbij kunnen een aantal aanbevelingen worden gemaakt gebaseerd op de resultaten. Landen moeten hun eigen debat houden, eerder dan de Belgische of Nederlandse wet te willen overnemen, zodat er voldoende rekening kan worden gehouden met landenspecifieke traditie, geschiedenis,… Daarbij is het van belang verschillende actoren die elk hun specifieke bezorgdheden kunnen hebben te betrekken: zowel publiek als artsen, mensen met verschillende sociale achtergrond, …

Bovendien dient het debat binnen de gezondheidzorg zich niet uitsluitend te focussen op euthanasie. Andere mogelijk levensverkortende medische beslissingen aan het levenseinde zijn niet a priori probleemloos (ook al worden ze algemeen aanvaard als onderdeel van de standaard praktijk), en er wordt bij deze handelingen niet altijd voldaan aan de voorwaarden van goede en veilige praktijk. Ook deze handelingen zouden misschien gebaat zijn bij duidelijkere afspraken en/of protocollen om zo de kwaliteit van besluitvorming te verbeteren.

Er is bewijs dat er momenteel niet voldoende wordt gedaan om mensen in staat te stellen te overlijden waar ze verkiezen. Velen verkiezen thuis te sterven maar belanden in het ziekenhuis. Uit onze onderzoeksresultaten haalden we vier types van concrete beleidssuggesties: evaluatie, interventie, focus, en preventie.
Een eerste concrete aanbeveling is dat er een betere en crossnationale monitoring moet worden voorzien van plaats van overlijden, zodat niet alleen kan vergeleken worden met andere landen (waaruit concrete beleidsacties kunnen worden gesuggereerd) en een focus op specifieke groepen kan worden bijgesteld, maar ook concrete beleidsacties kunnen worden geëvalueerd (*evaluatie*).
Om het aandeel mensen dat in ziekenhuizen overlijdt te beperken en meer mensen te laten sterven op de plaats van voorkeur moeten er goede alternatieven voor het ziekenhuis worden georganiseerd met goede levenseindezorg (vb. rusthuizen met voldoende palliatieve zorg, uitbouw en ondersteuning van palliatieve thuiszorg en

ondersteuning van mantelzorg, hospices,…). Even belangrijk als het uitbouwen van goede alternatieven voor het ziekenhuis is het ontwikkelen van een palliatieve zorgcultuur, zodat o.m. ziekenhuisspecialisten ook effectief tijdig doorverwijzen naar deze alternatieven. Trainingen in palliatieve zorg en in communicatie, en betere implementatie van strategieën van zorgplanning kunnen hier heil brengen. (*interventie*)
Aangezien er duidelijke sociale verschillen zijn in waar mensen sterven, is het belangrijk dat er een specifieke beleidsfocus wordt gericht op mogelijk benadeelde groepen. Zo kan een beter inzicht worden verworven in achterliggende redenen en kunnen strategieën worden ontwikkeld om tegemoet te komen aan noden en voorkeuren van specifieke populaties. (*focus*)
Tot slot, gezien de grote verschillen in medische besluitvorming aan het levenseinde naargelang de setting van levenseindezorg, lijkt het ons ook raadzaam een setting-specifieke ontwikkeling van goede zorg rond het levenseinde na te streven. (*preventie*)

Aanbevelingen voor zorgverstrekkers

Voor artsen en andere professionele zorgverstrekkers formuleerden we volgende aanbevelingen:
- streven naar een reflexiviteit over de eigen bindingen en overtuigingen via duidelijke communicatie met patiënten over hun existentiële (en eventueel spirituele) bezorgdheden en noden
- tijdige, duidelijke, en gelijkwaardige communicatie met patiënten en een duidelijk verkennen van preferenties van patiënten, om op die manier keuzemogelijkheden te geven.
- goede communicatie ontwikkelen met mensen met verschillende sociale en culturele achtergronden (vb. via bijkomende training) om sociale inclusie na te streven in kwalitatieve levenseindezorg
- streven naar maximale coöperatie en coördinatie tussen alle zorgvertrekkers betrokken bij de zorg voor een stervende persoon (zowel thuis als in het ziekenhuis als in het rusthuis), zodat goede continuïteit wordt gewaarborgd.

Aanbevelingen voor verder onderzoek

Tot slot kunnen we stellen dat een aantal onderzoeksnoden onbeantwoord blijven na dit proefschrift. Zo is er nood een beter en verder begrip van attitudes (van zowel publiek als artsen) ten opzichte van verschillende medische beslissingen rond het levenseinde. Om beter de vraag te kunnen beantwoorden wat de determinanten zijn van de plaats van overlijden zijn analyses nodig die ook aandacht hebben voor transities (of transfers) en die het overlijdensproces gedurende de laatste levensmaanden bekijken. Bovendien zou de effectiviteit van beleidsinterventies om de plaats van overlijden te beïnvloeden moeten worden nagegaan. Een belangrijk, nauwelijks verkend terrein in het levenseinde onderzoek is dat van sociale ongelijkheden. Aangezien er duidelijke aanwijzingen zijn van het bestaan van sociale ongelijkheden aan het levenseinde, is het van groot belang dat deze goed in kaart worden gebracht.

CURRICULUM VITAE

Joachim Cohen, spawn of Yves Cohen and Martine Haesendonckx, first saw light on March 3, 1979 in Bree, Belgium.
In 1997 he graduated from secondary school in Koninklijk Atheneum Overpelt, and four years later finished his Master degree in Sociology at the Vrije Universiteit Brussel. In the meanwhile he built worldwide reputation being the drummer of the best ever Belgian melodic metal band Infernal Beauty and the keyboard player of Belgian's cult wave band De Brassers.
In 2002 he started his academic research career, being employed as a junior researcher for the Tempus Omnia Revelat study group at the Sociology department of the Vrije Universiteit Brussels, where he worked 15 months on a research project on end-of-career issues. Then, indeed, time revealed it was time for something new, so from October 2003 he started working as a PhD-student in the End-of-Life Care Research Group, Department of Medical Sociology, Faculty of Medicine at the Vrije Universiteit Brussel. Since that time he conducts research on end-of-life care issues.
Joachim is currently working at the End-of-Life Care research group as a senior researcher, supervising research on place of death and on consultation of other physicians in end-of-life decision-making.

List of publications by Joachim Cohen

A. Articles in international peer-reviewed journals

1. Cohen J, Bilsen J, Hooft P, Deboosere P, van der Wal G, Deliens L. Dying at home or in an institution. Using death certificates to explore the factors associated with place of death. Health Policy, 2006, **78**:319-29.
2. Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, Deliens L. European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. Social Science & Medicine, 2006, **63**:743-56.
3. Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, Deliens L. Trends in acceptance of euthanasia among the general public in 12 European countries (1981-1999). European Journal of Public Health, 2006 **16**: 663–69..
4. Kabengele Mpinga E, Pennec S, Gomes B, Cohen J, Higginson I, Wilson D, Rapin C-H (2006) Places of Death: Agenda for the 21st century. Journal of Palliative Care, 2006, **22**:293-297
5. Cohen J, Bilsen J, Fischer S, Löfmark R, Norup M, van der Heide A, Miccinesi G, Deliens L, on behalf of the Eureld consortium. End-of-life decision-making in Belgium, Denmark, Sweden and Switzerland: Does place of death make a difference? Journal of Epidemiology and Community Health *(In press)*
6. Cohen J, van Delden J, Mortier F, Löfmark R, Norup M, Cartwright C, Faisst K, Canova C, Onwuteaka-Philipsen B, Johan Bilsen, on behalf of the Eureld consortium. The influence of physicians' life-stance on attitudes towards end-of-life decisions and actual end-of-life decision-making in six countries? Journal of Medical Ethics (in press).

B. Articles in national journals

1. Bilsen J, Cohen J, Deliens L. La fin de vie en Europe: la point sur les pratiques médicales. Population & Sociétés, 2007, **430**:1-4
2. Bilsen J, Cohen J, Deliens L. End-of-life in Europe : an overview of medical practices. Population and Societies, 2007, **430**, online publication: http://www.ined.fr/fichier/t_publication/1223/publi_pdf2_pop.soc.english.430.pdf
3. Cohen J, Van Der Wal G (2005). Boekaankondiging: Death, dying, and social differences. Oliviere, D. en Moore, B. Nederlands Tijdschrift voor Geneeskunde; **149**: 1307.
4. Elchardus M & Cohen J. De uittrede uit de arbeidsmarkt in België. Onderzoek naar de determinanten van het einde van de loopbaan. Over.Werk. Tijdschriift van het Steunpunt WAV, 2003, **13**: 214-217.

C. Chapters in books

1. Elchardus M & Cohen J. Retirement as the Future of Work. An Empirical Analysis of Early Exit from the Labour Market in Belgium. In: P. Littlewood, I. Glorieux & I. Jönsson (eds.), The Future of Work in Europe, Asghate, Aldershot, 2004: 221-240
2. Elchardus M & Cohen J. [Early exit from the labour market: exploration of the factors contributing to an early exit] In Dutch: De vroege uittrede uit de arbeidsmarkt. Exploratie van de factoren die bijdragen tot een vroege arbeidsmarktexit. In: De arbeidsmarkt in Vlaanderen. Jaarboek Editie 2003, Garant, Antwerpen, 2003: 149-161

D. Abstracts in international peer-reviewed journals

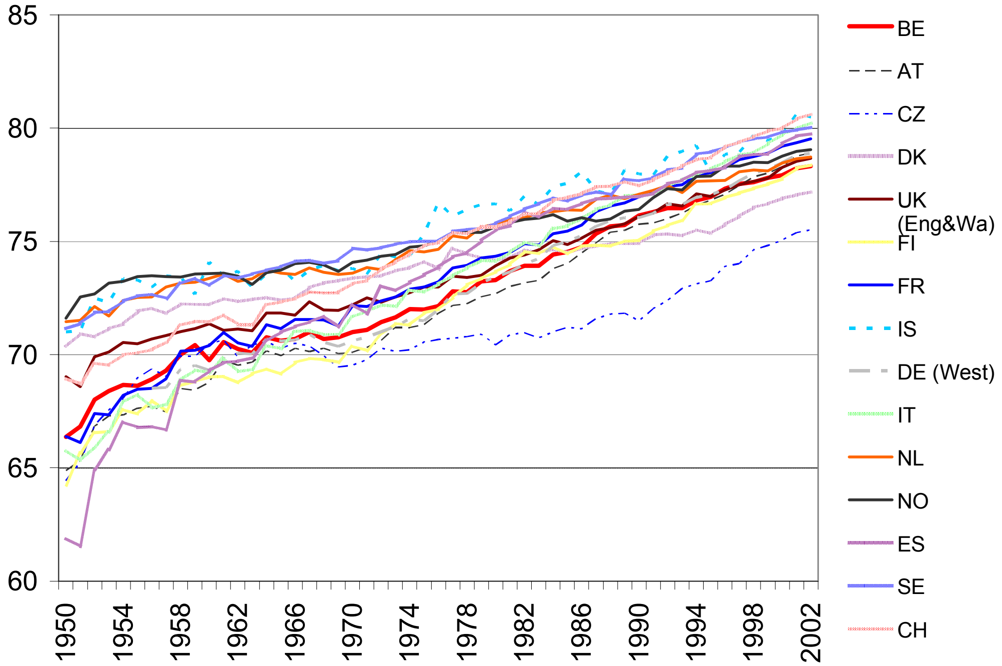
1. Cohen J, Marcoux I, Bilsen J, van der Wal G, Deliens L. Trends in acceptance of euthanasia among the general public in 12 European countries (1981-1999). Palliative Medicine, 2006, **20**: 112
2. Cohen J, Miccinesi G, Löfmark R, Addington-Hall J, Deliens L. Studying place of death via death certificates. An overview of the Dying Well in Europe Death Certificate Study (DW-DCS) in 7 European countries. Palliative Medicine, **20**: 294
3. Cohen J, Bilsen J, Van der Wal G, Hooft P, Deliens L. Which patients die at home in Flanders, Belgium? Analysis of the determinants of dying at home, in hospital or in a nursing home. European Journal Of Palliative Care, 9th Congress of the European Association for Palliative Care, Aachen, 8-10 April 2005, p.19
4. Cohen J, Marcoux I, Bilsen J, van der Wal G, Deliens L. Public attitudes towards euthanasia in 33 European countries. Socio-demographic and cultural factors associated with the justification of euthanasia. European Journal Of Palliative Care, 9th Congress of the European Association for Palliative Care, Aachen, 8-10 April 2005, p.13

E. Thesis to obtain MA degree in Sociology

1. Cohen J. [Modernity, individualism, and politics: on the influence of individualism on political culture]. In Dutch: Moderniteit, individualisme en politiek: over de invloed van het individualisme op de politieke cultuur. Brussel, Vrije Universiteit Brussel, 2001.

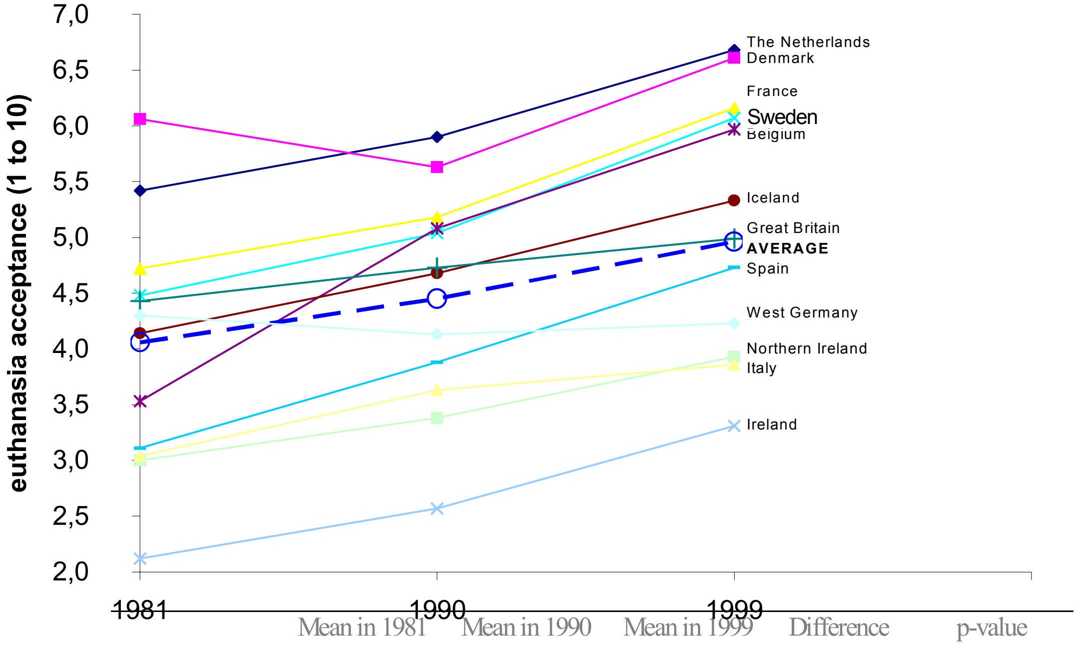
Figures in color

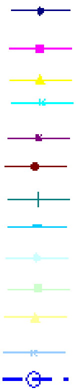
Figure 1: Life expectancy in Europe 1950-2002 (Chapter 1 page 6)



Source: own figure, based on data published by Human Mortality Database; web: http://www.mortality.org/ (accessed 23/06/2006). For West-Germany no data were recorded before 1957.

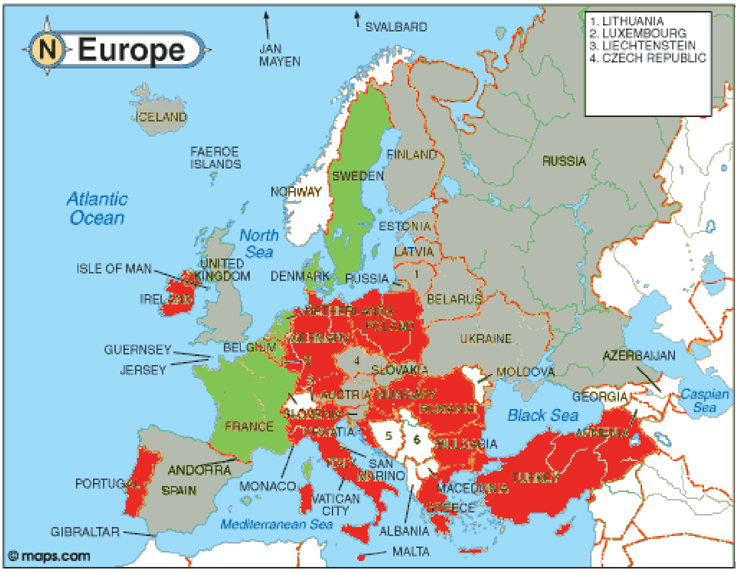
Figure 1: Acceptance of euthanasia in 12 countries (1981-1999) (Chapter 2, page 41)





	Mean in 1981	Mean in 1990	Mean in 1999	Difference 1999-1981 (in%)	p-value (Jonckheere-Terpstra)
Netherlands	5.42	5.90	6.68	+ 23.2%	<0.001
Denmark	6.06	5.63	6.61	+ 09.1%	0.041
France	4.72	5.18	6.16	+ 30.5%	<0.001
Sweden	4.48	5.04	6.07	+ 35.5%	<0.001
Belgium	3.53	5.08	5.97	+ 69.1%	<0.001
Iceland	4.14	4.68	5.33	+ 28.7%	<0.001
Great Britain	4.43	4.73	4.99	+ 12.6%	<0.001
Spain	3.11	3.88	4.73	+ 52.1%	<0.001
West Germany	4.30	4.13	4.23	- 02.6%	0.686
Northern Ireland	3.00	3.38	3.93	+ 31.0%	0.001
Italy	3.04	3.63	3.86	+ 27.0%	<0.001
Ireland	2.12	2.57	3.31	+ 56.1%	<0.001
AVERAGE	**4.06**	**4.45**	**4.96**	**+22.2%**	**<0.001**

Figure 1: Map of Europe, coloured according to degree of acceptance of euthanasia (Chapter 9, page 176)



Source: maps.com, coloured according to our own results

<u>LEGEND</u>

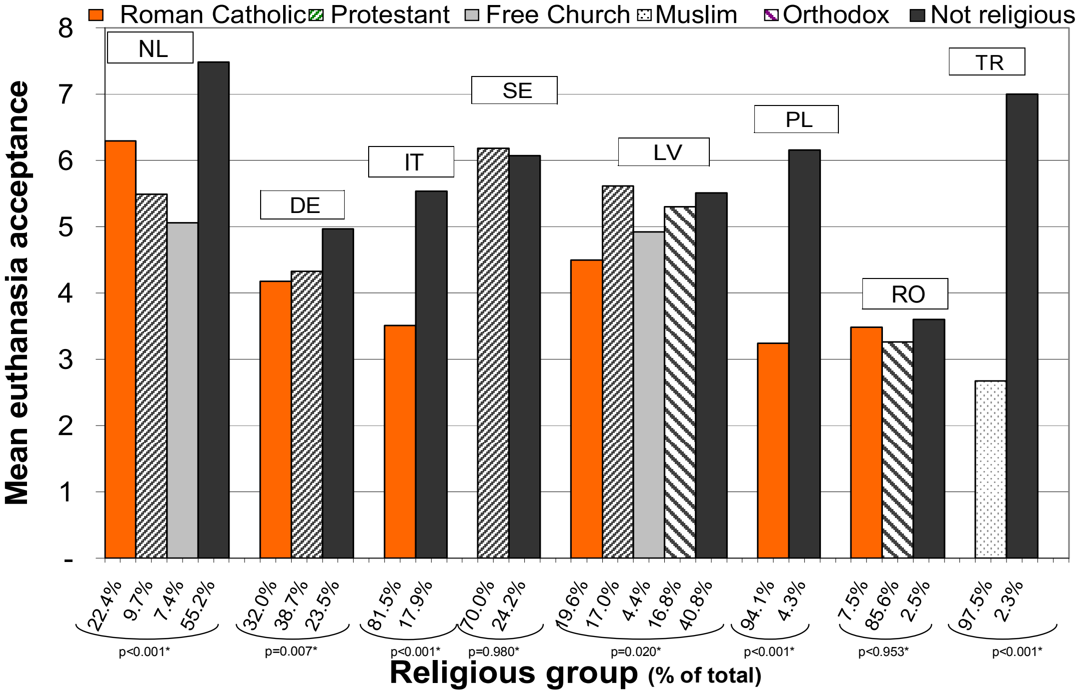
🟩 HIGH ACCEPTANCE

⬜ AVERAGE ACCEPTANCE

🟥 LOW ACCEPTANCE

☐ NOT STUDIED

Figure 2: Euthanasia by large religious (or non-religious) groups in 8 countries (Chapter 3, page 67)



Presented percentages are the percentages of the respective (religious) groups within the total population. They do not add up to 100%, because very small religious groups (i.e. <3% of total population) are not retained.

* p-values tested with Kruskall-Wallis, testing the differences in acceptance of euthanasia between religious and non-religious groups