Place of death and circumstances of dying

Studies in a metropolitan, national and international context

Dirk Houttekier

Cover illustration: Constant Permeke, *Het afscheid (The farewell) 1948, oil paint/canvas, 163 x 178.5cm, Collection Mu.ZEE Oostende*

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Dood

Dood. Heb geen angst. Talm niet
voor mijn deur. Kom binnen.
Lees mijn boeken. In negen van de tien
kom je voor. Je bent geen onbekende.

Hou mij niet voor de gek met kwalen
waarvan niemand de namen durft te
noemen.
Leg mij niet in een bed tussen kwijlende
kinderen die van ouderdom niet weten wat
ze zeggen.
Klop mij geen geld uit de zak
voor nutteloze uren in chique klinieken.

Veeg je voeten en wees welkom.

Eddy Van Vliet

Uit: *Verzamelde gedichten*. De Bezige Bij, Amsterdam 2004

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Preface and acknowledgements

The place of care at the end of life and the place of death are inherent in the concept of a "good death", as depicted in Permeke's painting "The Farewell". If we could give orders to our own death, like Eddy Van Vliet does in his poem "Death", we would want it not to hesitate when the time is there, not to fool us with complicated and lingering diseases and not to force us to spend our last days in a care home or a hospital. Like Van Vliet we would want it to come to our home or where we feel comfortable and wipe its feet before coming in. Unfortunately, death is usually not that polite. Or is it rather our healthcare and social systems that are not always polite to dying people?

In this book, also my PhD-thesis, place of death is looked at as a way of considering the quality of end-of-life care and the extent to which health care systems are able to deliver "the good death" to the terminally ill. Place of death and the circumstances of dying are studied cross-nationally in specific disease groups such as cancer and dementia-related diseases, in metropolitan populations as compared to nonmetropolitan populations, and to evaluate health care strategies with respect to palliative care and care for the elderly.

For the realization of this book, I am indebted to many people: those who provided the data, the co-authors of the manuscripts, reviewers and editors and all my fantastic colleagues of the End-of-Life Care Research Group, the department of Medical Sociology and other departments of the Vrije Universiteit Brussel.

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My special thanks go to the promoter and co-promoter of my PhD, Prof. Dr. Luc Deliens and Dr. Joachim Cohen. Thank you for sharing your wisdom, for giving me strength during that difficult period, and for the beautiful cooperation.

Dirk Houttekier
Brussels, May 2011

Part I

Introduction

1 Introduction to this dissertation

1.1 Introduction

Place of death statistics became a symbol of the social movements for palliative care and dignified dying that emerged in the 1950s and 1960s in the UK and the USA criticizing the medicalization of terminal illness and death and the inhumane curative care approach at the end of many people's lives. These movements strived for a palliative and humane approach of end-of-life care relieving suffering and respecting the choices and increasing autonomy of the dying to guarantee a death in dignity.(1)

In this dissertation place of death is looked at as a way of considering the quality of end-of-life care and the circumstances of death and dying cross-nationally in specific disease groups such as cancer and dementia-related diseases, in metropolitan populations as compared with nonmetropolitan populations, and to evaluate health care policies with respect to palliative care services and care for the elderly.

Before addressing the concept of place of death we will situate this dissertation within the wider context of epidemiological, demographical and cultural changes in death and dying.

1.2 Changes in death and dying

Social changes such as improvements in standards of living, health habits, hygiene and nutrition and changes in medical and public health determinants such as improved public sanitation, immunization and the development of decisive therapies have resulted in an epidemiological transition. Pandemics of infection were gradually replaced by degenerative and man-made diseases, such as cancer, as the main form of morbidity and the primary cause of death.(1-4) This epidemiological transition resulted in increasing life expectancy and the ageing of populations.(2;5) Worldwide, the proportion of older persons (60 years or older) has grown progressively since the mid-twentieth century from 8% to 11% in 2009 and is expected to arrive at a global average of 22% in 2050.(6)

The population of older people is itself ageing. Within the aged population of those 60 years or older the age group of the oldest old, those 80 or more, is growing most rapidly. At present about one in seven older persons is aged 80 years or over; in 2050 this ratio is expected to increase to almost one in five.(6) The growing of the oldest age groups will lead to a sharp increase in the prevalence of age-related diseases such as Alzheimer’s and other dementia-related diseases.(7-11)

Because of longevity and gender differences in longevity with females outnumbering males in older ages, ageing of populations is accompanied by decreasing family sizes and an increase of elderly people living apart from their children, mostly elderly widows, who cannot rely on co-resident family caregivers when they become ill. In 1961, 7% of the households in the UK were single persons above pensionable age, while in 1996-97 this was 15%.(1) The proportion of men and women above 80 with cancer living alone was respectively 21.8% and 45.2% in 1981 against 27.5% and 55.1% in 1991.(12)

A consequence of the epidemiological transitions and the ageing of populations in many countries is that the time before death is characterized by longer periods of disability and longer dying trajectories with a higher prevalence of burdening symptoms. This results in longer and different care needs at the end of life such as management of pain and symptoms and psychosocial supportive care for patients and their caregivers.(1)

The emerging development of a self-identity and the aspiration for individual autonomy included the wish to plan for and control major life events such as the time and manner of death. The traditional model of medical autonomy and authority of physicians was increasingly questioned by patients and other medical professions such as nurses, seeking to play a more active role in making choices about health. Nurses obtained a significant degree of autonomy in end-of-life care by claiming specific psychosocial skills in caring for the dying.(1;13)

Compared with the sixties when relatives of terminally ill people were mostly aware of death being imminent but the dying person was often not, death and dying in the UK in the beginning of the nineties took place more in a context of awareness and openness with the dying person also being aware of death being imminent. Awareness and openness about death being imminent allows to a greater extent planning for end-of-life care, controlling time and place of death, and deciding about the involvement of palliative care services.(14) An indicator of the growing openness and awareness of terminal illness and death in Western societies is probably the growing acceptance in the past decades of euthanasia among the general population in Western-Europe as a way of termination the lives of the incurable sick and controlling the timing and place of death.(1;15)

The shift in needs, values and preferences about end-of-life care resulted to some extent in a shift of professional attitudes and practices.(1) In many countries such as the UK, Sweden, Italy, Germany, Spain, Belgium and the Netherlands, pioneering palliative care initiatives emerged from the late sixties onwards in different health care settings. By the late nineties, these services started to be integrated into the formal health care systems and were gradually funded by health care insurance mechanisms.(16;17) In 2006 there were more than 1,500 hospice and palliative care services in Europe.(3)

Palliative care services in Belgium have been developing since the early 1980s,(18) and the 2002 law on palliative care provides for access to palliative care at the end of life.(19)

The objectives of palliative care policy are to integrate palliative care into general health care (the care usually provided by professional caregivers in different health care settings), primary care in particular, rather than to replace that with care delivered by palliative care specialists, and to support out-of-hospital death.(16;17) Therefore, palliative care services have been set up to offer consultation and support for, and in principle only exceptionally to take over from, primary caregivers (ie GPs and home care nurses at home and GPs and care home nurses in care homes) in caring for the dying at home (known as multidisciplinary palliative home care teams) or in care homes (palliative care reference persons) and from medical and nursing staff in hospitals (multidisciplinary palliative support teams). In addition, small-scale (six or twelve beds) inpatient palliative care units in or near hospitals were established offering comprehensive care by multidisciplinary teams. The average stay is less than one month.(17)

To respond to the growing care needs of the growing elderly population, of which many suffer from chronic life-limiting conditions such as dementia, a substantial conversion of residential beds with limited nursing care in care homes to skilled nursing home beds with nursing care available on a daily basis has been taking place in Belgium since 1998. Between 1999 and 2010 the availability of skilled nursing beds in Flanders increased from 17,931 to 38,195.(20)

In addition, to guarantee respect for patient choices including end-of-life decisions, legal regulations were put in place such as the Patient Self-Determination Act in the US, the law on palliative care and on patients’ rights in Belgium and the law on euthanasia in the Netherlands and Belgium.(19;21-24)

Patterns in place of death in the previous century showed an increasing hospitalization of death. Concentration of health care in hospitals and the reduced availability of informal caregivers due to sociodemographic and economic developments resulted in a growing number of hospital deaths and the proportion of deaths occurring at home decreased from more than half to a quarter or less in many developed countries.(25;26) From the 1980s onwards a slight decrease in hospital deaths was observed both in cancer and non-cancer patients.(27-35) In many countries this trend was not balanced by an increase in home deaths,(32;36;37) not even in cancer patients,(27;29;30) but rather by an increase of deaths in other care settings such as hospices in some countries and care homes in others.(27;29;31-34)

In 2009 the global level of urbanization crossed the 50% mark and is expected to increase to 69% in 2050.(38) Although the percentage of the Belgian population living in urban areas was already very high in 2005 at 97.3%, it is expected to increase further to 98.4% in 2050. The Belgian urban agglomerations with 750,000 inhabitants or more, Brussels and Antwerp, are projected to grow very slightly until 2010 and from then onwards to remain stable. The urban agglomerations of the Netherlands and the UK are expected to grow slightly until 2025.(39) Death and dying in metropolitan populations might differ from that in nonmetropolitan populations given the differences in population characteristics and discrepancies in physical environment en healthcare provision between metropolitan en nonmetropolitan areas.(40-42)

1.3 Place of death

In end-of–life care research, home death is generally considered an outcome indicator of the quality of end-of-life care given the strong preference for home death among patients, caregivers and the general public observed in many studies.(43)

In the context of end-of-life care, home is associated with the presence of family and friends, comfort, privacy, autonomy and a feeling of control and is often considered the natural and the ideal place of death.(44;45) In a literature review in 2000, Higginson and colleagues found that between 49% and 100% of cancer patients, caregivers and the general population preferred to die at home, with inpatient hospice as second preference.(46) Results from studies in Belgium and other parts of the world since then seem to confirm that a majority of terminally ill cancer and non-cancer patients prefer to die at home.(47-56) In a systematic review Bell and colleagues found that congruence between the preferred and actual place of death was between 30% and 91%,(57) and dying in the place of choice was previously found to be a highly important for terminal cancer patients in the US.(45)

It seems that ’if anything would be possible’, ie if choice was not hindered by any obstacles, a large majority of patients would prefer to die at home. But end-of-life care and death in an institution (inpatient hospice, nursing home, palliative care unit or possibly an acute hospital ward) may be preferred by patients and their caregivers in cases where no family caregiver is available, where they are living in poor material conditions or in a house that is not suitable for providing end-of-life care (eg because of stairs or an upstairs toilet), when the burden of care would become too great for family caregivers, or in the case of loss of dignity or inadequate quality of care at home such as inadequate pain control or symptom relief.(44;45) In cases of dementia, a majority of patients may rather prefer long-term care facilities as the place of end-of-life care.(58) But even with ample social, emotional and material resources available to offer a ’good death’ at home, caring for a terminally ill person at home without involvement of specialist palliative care may be a harrowing experience both for the patient and his family, as was witnessed recently by Carolyn Cannuscio in the Journal of the American Medical Association.(59)

Preference for home death may therefore not be absolute and change depending on expectations about informal care resources, physical condition, professional services, and existential perspectives.(60;61) General practitioners reported that preferences for place of death sometimes change over time and are often not clear and stable choices.(62) Preferences for home as place of death may not be stable over time and preference for home death may decline as death becomes more imminent, although this is disputed by Higginson and colleagues.(63) The validity of the proportion of home deaths as an indicator of the quality of end-of-life care may therefore be debatable since a preference for home death may be less universal and stable, and outcomes of home death not always favorable.(61)

Hospital as place of end-of-life care and death on the other hand has been associated with unfavourable outcomes for patients and their caregivers and hence is an indicator of poor end-of-life care,(64) although in some cases hospital may be the only realistic option as place of terminal care and death. In the SUPPORT study in the US, the investigators found shortcomings in communication and awareness of patients' preferences in end-of-life care and pain treatment in hospitalized patients with life-threatening diagnoses, and more than a third of patients had spent at least ten days in an intensive care unit during the two year study period.(65) In a more recent study in the UK using the VOICES-questionnaire, bereaved relatives of cancer patients were less satisfied with care in hospitals than in inpatient hospices with respect to pain control, communication and medical, nursing and personal care.(66) Compared with cancer patients who died at home with hospice care, those who died in hospital or in an intensive care unit experienced a lower quality of life at the end of life and their bereaved caregivers had a higher risk of developing psychiatric illnesses, such as depression.(67)

Despite the negative outcomes of hospital deaths and the preference of only a small minority to die in hospital in Western societies, a recent comparative European study showed that in Europe a majority of patients still die in hospitals, ranging from 52% in Belgium to 63% in Wales, with the exception of the Netherlands (34%)(68). Similar hospital death rates were found in other parts of the world.(31;69-71)

Although the validity of home death as a measure of quality of end-of-life care may be questioned, the percentage of people dying in hospitals can be seen as a valid indicator for the quality of end-of-life care provided by health care systems on an aggregated level. Death in an acute hospital is preferred only by a small minority, although it was previously found to be slightly higher in ethnic minority groups in the US,(72) and end-of-life care in hospitals is associated with negative outcomes for both patients and their caregivers.(65;67) Cross-national research with respect to place of death could contribute to the evaluation of national health care systems in their ability to respect the preferences of dying persons and their relatives by measuring the proportion of deaths in hospitals or the hospital death risk of the terminally ill residing either at home or in a long-term care facility. Given the end-of-life care strategies in many countries to support home death,(17;73) the proportion of home deaths remains a most relevant research topic.

The place of terminal care and death also has a significant impact on health care costs. Health care expenditures tend to increase sharply during the last phase of life. About 10 to 12% of the total health care expenses in the US are related to care at the end of life and between 25% and 30% of Medicare expenditure for the elderly can be related to the 5% of Medicare beneficiaries who die each year. For persons aged 65 years and older, medical expenditure in the US during the last year of life was $37,581 during the last year of life versus $7,365 for other years.(74-76) About half of the Medicare expenditure in the last year of life was incurred in the final 60 days of life.(77) In the Netherlands, health care costs in the last year of life were 13.5 times higher compared with non-decedents (all ages). Most costs were related to hospital care (54%) and nursing home care (19%) and were higher for cancer patients.(78) The last finding corroborates the findings of Earle regarding the aggressiveness of treatment in cancer patients near the end of life.(79)

Since most health expenditures in the last phase of life are related to hospital care and hospital death,(80) avoiding hospitalization at the end of life and hospital death could decrease the health care expenses and improve quality of life at the end of life at the same time.(81) Palliative home care teams may increase satisfaction with care and deal more effectively with patients' and families' needs, while at the same time reducing the number of inpatient days and thus health care expenses.(82;83) For nursing home residents enrolled in hospice care in the US, Medicare spending was found to be less than for non-enrolees because of reduced hospitalizations, but the savings can vary by diagnosis and length of stay and diminish as hospice stays increase in length.(84;85) In hospitals, palliative care involvement in terminally ill patients in the US resulted in substantially lower admissions to an intensive care unit and lower costs compared with patients receiving usual care,(86;87) although home-based palliative care proved to be less expensive in the last week of life than hospital-based palliative care.(88) Advance care planning may also reduce health care costs between 25% and 40% in the last month of life, if implemented early in the disease course.(89;90)

The association of place of death with the quality of life of terminally ill, the quality of end-of-life care and health care costs make it interesting to study where people are dying in different countries. We studied it in cancer and dementia populations, two terminal conditions of which the prevalence is expected to raise substantially in the future,(3;4;7-10) and that pose specific challenges to end-of-life care.(91-96) Since substantial cross-national variation in place of death was found before in Europe,(68) we studied place of death of people with cancer and dementia cross-nationally to consider differences in distribution of place of death and factors associated with these differences.

Because we hypothesize that place of death differs in metropolitan populations compared with nonmetropolitan populations because of contrasts in population characteristics and the physical environment and healthcare provision in metropolitan areas, and because our university is situated in Brussels metropolitan region, we studied place of death in Brussels and compared it with metropolitan populations in England and the Netherlands. We also studied the circumstances of dying and death in Brussels. The association of palliative care services with place of death in Belgium and circumstances of death and dying in Brussels were studied because of the association between involvement of palliative care services and quality of life of terminally ill and their relatives, and health care costs, previously found elsewhere.(82;83;85)

Finally we studied trends in place of death in Belgium to examine factors associated with shifts, in particular the conversion from residential to nursing beds in care homes.

1.4 Research questions

There are three main thematic aims of this dissertation. The first is to study place of death in cancer and dementia cases and to describe whether and how place of death from cancer and dementia differs cross-nationally. The second is to examine whether place of death in metropolitan regions differs from that in nonmetropolitan regions across European countries and to examine place of death and related factors and circumstances at the end of life in Brussels metropolitan region. The third is to examine the association between place of death on the one hand and health care policies or care approaches on the other. More precisely, the influence of the involvement of palliative care services on place of death and the influence of shifts in care approaches on trends in the place of death over a ten year period are examined.

The following specific research questions will be answered with respect to the first thematic aim:

> 1. What is the proportion of cancer deaths occurring at home in Belgium, the Netherlands, Norway, England, Wales (2003) and in Italy (2002); and what factors are associated with dying at home in patients with cancer in these countries?
>
> 2. Where do older people with dementia-related diseases die in Belgium, the Netherlands, England, Scotland and Wales? In what respect does the place of death of older people who die from dementia differ from that of older people who die from cancer and the other most-prevalent chronic life-limiting conditions? Can differences in patient characteristics, social support and healthcare input explain country variation in place of death?

The following specific research questions will be addressed with respect to the second thematic aim:

3. Are there differences in place of death between metropolitan and nonmetropolitan residents with chronic life-limiting conditions in Belgium, the Netherlands, and England? What factors related to illness, personal characteristics, social support and health services can explain possible metropolitan/nonmetropolitan variation in place of death in Belgium, the Netherlands and England?

4. Where do people with chronic life-limiting illnesses die in Brussels Capital Region? Are there any important differences in patterns of place of death depending on illness, sociodemographic characteristics, or social support available to the patient?

5. What are the circumstances and characteristics of the death and dying of those dying non-suddenly in 2007 in the Brussels Capital Region? What is the association between involvement of specialist palliative care and these circumstances?

The following research questions will be addressed with respect to the third thematic aim:

6. Is involvement of palliative care services associated with place of death in Belgium?

7. How did place of death change in Belgium between 1998 and 2007 taking into account shifts in underlying cause of death, age, sex, living arrangement, educational attainment, urbanization level and availability of hospital and care home beds? Did place of death change differently for specific subpopulations regarding living arrangement? How would place of death change between now and 2040, based on trends between 1998 and 2007?

1.5 Methods

Three different types of data were used to address the research questions - death certificate data of Belgium (1998-2007) and other European countries (2002-2003), data collected by the Belgian sentinel network of GPs (2005-2006) and data collected by the post-mortem survey of 2007 on end-of-life decisions and circumstances at the end of life in Brussels Capital Region. For an overview of which dataset was used in the different chapters of this dissertation we refer to table 1.

1.5.1 Death certificates

In Belgium, death certificates contain information about the place and cause of death and the sociodemographic characteristics of the deceased. Information about the place and cause of death is completed by a physician who certifies the causal chain of diseases, starting with the underlying cause of death, which is used in our studies using death certificates. Information about the sociodemographic characteristics (eg educational attainment, nationality, marital status, and living arrangement) is provided by the municipal institutions, assisted by a relative of the deceased. Information from the death certificates is processed; the causes of death are coded in ICD-10 codes and both medical and sociodemographic information is checked by a government agency.(97;98)

For cross-national studies, we used a European database of death certificate data established by the partners of the European collaborative research project 'Dying well in Europe'. This database contains death certificate data of 2003 of the populations of seven European countries (Denmark, the Netherlands, Norway, Sweden, England, Wales and Scotland), two Belgian regions (Flanders and Brussels Capital Region), and three Italian regions (Emilia Romagna, Tuscany and the city of Milan. Data of 2002).(99;100)

The population studied consists of patients who died after chronic life-limiting conditions, the so-called palliative subset, as identified by Rosenwax et al.(101-103). These patients can be assumed to benefit most from receiving palliative care and to have had more chances to express their preferences about end-of-life care and place of death. This palliative subset consists of people who died from one or more of the following conditions: neoplasm, heart failure, renal failure, liver failure, respiratory disease, neurodegenerative disease and HIV/aids.(101-103) In the study on trends in place of death, a subpopulation of patients who died non-suddenly of one or more chronic life-limiting conditions as defined by van der Velden and colleagues (including cancer, cerebrovascular diseases, dementia, chronic obstructive pulmonary disorders, heart failure, diabetes, Parkinson's disease, chronic kidney disease, chronic liver disease, spinal muscular atrophy and related disorders, multiple sclerosis, neuromuscular disorders, and acquired immunodeficiency syndrome), and were thus eligible for palliative care was considered in multivariate analysis.(104)

1.5.2 Sentinel network of GPs

We used retrospective data from a nationwide mortality follow-back study about palliative care services involvement and general health care use delivered in the last three months of life to people who died in 2005 or 2006. Data were collected within the Senti-Melc study by the sentinel network of general practitioners, an epidemiologic surveillance network representative of all Belgian GPs, established in 1979 and covering 1.75% of the Belgian population. A sentinel network of GPs is a network of community-based physicians who monitor health problems on a continuing basis.(55;56;105-114) All GPs were asked to report weekly, on a standardized registration form, every patient in their practice who had died during that week. The study population consists of people aged one year or older who were part of the GP practice and who had died non-suddenly or expectedly as judged by the GP, ie those who can be considered potentially eligible for palliative care. For those patients the GPs registered the places of care and the caregivers involved in the final three months of life including palliative care services, the wishes regarding place of death, the goals of end-of-life care and the medical decision-making.(115)

1.5.3 ELD 3- study

The study about end-of-life care in Brussels Capital Region uses information from post-mortem questionnaires sent out to attending physicians as identified on the death certificate of a random representative sample of deaths drawn between June and September 2007 in the Brussels Capital Region.(116)

Every physician certifying a death certificate in the sample was sent a six-page questionnaire about the end-of-life care and end-of-life decision-making in the corresponding death. An accompanying letter explained the research and presented information about the decedent, so as to allow the physician to be able to recall the patient and look up the medical file. Where the physician certifying the death certificate was not the attending physician, he or she was asked to forward the questionnaire to the attending physician. The time lag between death and the sending out of the corresponding questionnaire was on average 1-2 months. Up to three reminders were sent in cases of non-response. After the data collection a one-page questionnaire was mailed to all non-responding physicians, asking for their reasons for not participating.

A lawyer acted as intermediary between responding physicians, researchers, and the administration authority for death certificates in the mailing procedure to guarantee that completed questionnaires could never be linked to a particular decedent or physician. This lawyer also anonymously linked the coded decedent information from the death certificates received from the administration authorities to the corresponding completed questionnaires received from the physicians, and further anonymized the databases. Positive recommendations for the anonymity procedure and study protocols were received from the Ethical Review Boards of the University Hospitals of the Vrije Universiteit Brussel and Ghent University, from the Belgian National Disciplinary Board of Physicians and the Belgian Federal Privacy Commission.

The questionnaire first asked whether death had been sudden and unexpected and whether the attending physician's first contact with the patient had been after death. If neither of these questions were answered affirmatively the physician was asked a number of questions about the care and treatment received by the patient at his end of life and the circumstances of his or her end of life: whether the physician was aware of the patient's preferred place of death; whether this preference was met and, if not, why; who was present at the moment of the patient's death; which care providers were involved in the end-of-life care of the patient; to what extent certain symptoms were present in the last 24 hours (using the Edmonton Symptom Assessment Scale(117)). A question about whether specialist palliative care providers were involved in the end-of-life care of the deceased was used to compare those deaths with and without specialist palliative care involvement. From the linked death certificate information, data on the patient’s sex, exact age, place of death (home, care home, hospital, or other) and underlying cause of death were available. The underlying cause of death was coded according to the International Classification of Diseases, 10th revision.

1.6 Dissertation outline

The findings of the studies that were undertaken are split into three parts. In part 2 of this dissertation the first two research questions will be addressed and the findings with respect to place of death in cancer patients (chapter 2) and dementia patients in Europe (chapter 3), using data from the death certificate database 'Dying well in Europe' will be reported. Part 3 addresses the influence of the metropolitan context on end-of-life care outcomes. Firstly metropolitan/nonmetropolitan variation in place of death in Belgium, the Netherlands and England will be addressed using death certificate data (chapter 4). Secondly, place of death in Brussels metropolitan region will be described and factors related to place of death will be examined using death certificates (chapter 5). Thirdly, findings about the circumstances at the end of life in Brussels Capital Region will be reported, using data collected by a post-mortem survey among attending physicians (chapter 6). In part 4 the association between involvement of specialist palliative care services and place of death will be considered based on information collected by the Belgian sentinel network of GPs (chapter 7). Finally the findings of the study concerning past (1998-2007) and future trends in place of death (2008-2040) will be presented, using death certificates and mortality projections (chapter 8).

In the last part of this dissertation (chapter 9), methodological strengths and weaknesses will be discussed, and the most important findings will be summarized and generally discussed. Finally, the implications of our findings will be addressed.

Table 1 Overview of parts, chapters and data that were used

	PART II Place of death in an international perspective		Part III Metropolitan perspectives in place of death and circumstances of dying			PART IV Place of death and health care policies	
	2. Place of death of people with cancer in 6 European countries	3. Place of death of people with dementia in 5 European countries	4. Place of death in metropolitan versus nonmetropolitan regions in 3 countries	5. Place of death in Brussels metropolitan region	6. Use of palliative care services and circumstances at the end of life in Brussels metropolitan region	7. Use of palliative care services and place of death in Belgium	8. Trends in place of death in Belgium
DW, 2003 Death certificate data 9 countries N=1 102 642	**X**	**X**	**X**	**X**			
ELD 3–study, 2007 Post-mortem study Brussels Capital Region N= 701					**X**		
Senti-Melc, 2005-2006 Sentinel network of GPs Belgium N=1690						**X**	
DC, 1998-2007 Death certificate data Flanders and Brussels Capital Region N= 661 773							**X**

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Part II

Place of death in an international perspective

2 Which cancer patients die at home? A study of six European countries using death certificate data

Cohen J, Houttekier D, Onwuteaka-Philipsen B, Miccinesi G, Addington-Hall J, Kaasa S, Bilsen J, Deliens L. Which patients with cancer die at home? A study of six European countries using death certificate data. J Clin Oncol 2010 May 1;28(13):2267-73.

ABSTRACT

Purpose

This study examines the proportion of cancer deaths occurring at home in six European countries in relation to illness and to demographic and healthcare factors.

Methods

Death certificate data of all cancer-related deaths in 2002 in Italy and 2003 in Belgium, the Netherlands, Norway, England, and Wales (N=231,276) were linked with regional healthcare and area statistics. Multivariate binomial logistic regressions were performed to examine factors associated with dying at home.

Findings

The percentage of all cancer deaths occurring at home was 12.8 in Norway, 22.1 in England, 22.7 in Wales, 27.9 in Belgium, 35.8 in Italy, and 45.4 in the Netherlands. Having solid cancers and being married increased the chances of dying at home in all countries. Being older and being female decreased the chances of dying at home, except in Italy where the opposite was the case. A higher educational attainment was associated with better chances of dying at home in Belgium, Italy, and Norway (countries where information on educational attainment was available). Better chances of dying at home was also associated with living in less urbanized areas in all countries but England. The number of hospital and care home beds seemed not to be universally strong predictors of dying at home.

Conclusion

There are large country-differences in the proportion of cancer patients dying at home, and these seem influenced by country-specific cultural, social, and health care factors. Alongside cross-national differences, country-specific aspects need to be considered in the development of policy strategies facilitating home death.

2.1 Background

Avoiding inappropriate hospital admissions and enabling patients to die at home have become important health policy issues.(1;2) Generally, terminally ill patients and their informal caregivers prefer death to occur at home,(3) and there are several indications that dying at home can contribute to a better death,(4;5) compared with dying in an institution. At the same time dying at home can have a potential cost-saving effect (both for the patient and for society).(6;7) However, 31% to 85% of cancer patients still die in hospital in European countries,(8) although mortality follow-back studies have shown that in Europe, from 73% (UK)(9) to 94% (Italy)(10) of terminal cancer patients express a preference to die at home.

It is inappropriate to focus health care policy strictly on organizing end-of-life care at home: limited possibilities for complex symptom control mean it is not suitable for every terminal cancer patient. Despite this, dying at home still remains an aspiration for many cancer patients.(3;10;11) Knowing which patients die where and what factors influence this is essential to developing rational and appropriate end-of-life care policies supporting this aspiration. This is especially true in cancer patients who have a more predictable course of dying allowing for better planning for end-of-life care and for dying in the place of choice.(12) Cross-national comparisons can be informative as they help to identify the factors facilitating home death.

A problem with existing research on place of death is the diversity of populations and methods used which hinders cross-national comparisons. This study, for the first time, examines home death in cancer patients in six European countries including all cancer deaths certified via death certificates over one year. The research questions are: what is the proportion of cancer deaths occurring at home in Belgium, the Netherlands, Norway, England, Wales (2003) and Italy (2002); and what factors are associated with dying at home in cancer patients in these countries?

2.2 Methods

Study design and data

The present study is an analysis of all death certificate data of one year.

In 2006, all partners of the international collaborative research project “Dying Well in Europe” established a database containing death certificate data from all deaths for a number of European countries and regions.

All included countries have a similar certification of death with the physician completing the part of the death certificate indicating the sex of the deceased, medical information and time and place of death (more details in Online Only appendix). A request to obtain an individual-level death certificate dataset of all deaths from 2003 (or the most recent available year) was submitted by all partners of the study to their national or regional administration of mortality statistics. The project lead coordinated all separate data requests in order to maximize the similarity of the variables provided. Besides place of death, we aimed to include a limited number of clinical, sociodemographic, residential and health care system factors, based on factors identified as relevant in the literature,(12) and on recommendations from all participants to the study.

After having obtained each national or regional dataset, all datasets were pooled into one common European database for analyses.(13)

The population included in this paper comprised 890,750 deaths, of which 67,264 were in Flanders and Brussels (Belgium) (2003), 141,936 in the Netherlands (2003), 42,550 in Norway (2003), 505,341 in England (2003), 33,810 in Wales (2003), and 99,849 in Tuscany, Emilia-Romagna, and Milan (Italy) (2002).

Data analysis

The variable “place of death” from the death certificate data was dichotomized into home versus outside home, including hospital, care home (nursing home or residential home for older people), and other.

Independent variables included individual sociodemographic, residential and health care factors identified as relevant in the literature.(12) For the clinical data, a classification of cancer types was made using the ICD-10 codes (C00-D48) or ICD-9 codes in Italy (140-239) for the underlying cause of death on the death certificate data. In all countries the underlying, intermediate, and immediate causes of death are recorded by the physician on the death certificate and coded into ICD-10 codes (or ICD-9 in Italy), after which they are thoroughly checked by the administration of mortality statistics. Individual demographic information (sex, age, educational attainment, marital status), was obtained either directly via the death certificate data of all countries or by linking unique identifiers with administrative databases. Educational attainment was not available in the Netherlands, England, and Wales. Marital status was not available in England and Wales. Codes of the municipality/local authority of residence were combined with residence and health care statistics, the urbanization level, as well as the rate of hospital beds and care home beds per health region.(13)

Statistical analysis

Percentages were used to describe differences in proportion of home deaths. Pearson chi square tests were used to determine which of the patient characteristics were associated with place of death ($p<0.01$).

A stepwise multivariate logistic regression analysis was performed for all cancer deaths to estimate the associations of factors with dying at home versus dying outside home in each country separately.(14) More information on the procedures followed for the selection of variables, goodness-of-fit testing, and regression diagnostics as well as on additional logistic regression models using all available variables for each country is given in the Online Only Appendix.

SPSS version 17.0 and SAS 9.1.3 (for the stepwise multivariate logistic regression analysis) were used for all statistical computations.

Role of the funding source

The funding source did not have any role in the study design, the collection, analysis, and interpretation of data, the writing of the report, or in the decision to submit the paper for publication.

2.3 Results

Cancer deaths comprised 25.2% of all deaths in Norway (N=10,723), 25.5% in Wales (N=8,631), 25.9% in England (N= 130,765), 26.3% in Belgium (N=17,669), 28.1% in the Netherlands (N=39,867), and 29.7% in Italy (N=30,561).

Of all cancer deaths 26.3% (Belgium) to 35.4% (Italy) were gastrointestinal cancers, 19.0% (Norway) to 24.4% (Belgium) respiratory cancers (Table 1).

More men than women died of cancer, with the smallest gender differences in England and the largest in Belgium.

Cancer patients were younger in the Netherlands and older in Norway, with about 36% of all Norwegian cancer deaths being 80 years or older.

Table 1 Cancer deaths in 2003* by cancer site, sex and age

	Belgium†	Italy†	Netherlands	Norway	England	Wales
Total nr of cancer deaths	17,669	30,561	39,867	10,723	130,765	8,631
	(%)	(%)	(%)	(%)	(%)	(%)
Cancer site‡						
head & neck	1.7	1.4	1.4	1.2	1.1	1.4
gastrointestinal	26.3	35.4	27.5	29.2	26.5	27.9
respiratory	24.4	22.3	23.0	18.6	21.4	20.5
breast cancer	8.6	6.8	8.5	6.7	8.1	8.1
genitourinary	15.6	14.3	15.8	22.1	16.9	17.0
central nervous system	2.2	2.2	1.7	2.9	2.2	1.9
haematological	7.5	8.3	7.6	8.0	7.8	6.7
other	13.7	9.3	14.4	11.3	16.0	16.5
Sex‡						
male	56.8	56.7	54.2	53.0	52.0	52.3
female	43.2	43.3	45.8	47.0	48.0	47.7
Age‡						
0-49	5.5	3.8	6.6	5.1	5.1	4.8
50-59	11.0	8.5	13.1	10.9	10.3	9.9
60-69	20.1	19.0	20.5	17.2	19.5	19.9
70-79	33.7	34.8	31.3	30.3	32.0	33.3
80-89	23.2	26.5	23.6	29.8	26.9	26.1
90 and older	6.6	7.3	4.9	6.6	6.3	5.9

Presented figures are numbers and column percentages

*: in Italy all deaths of 2002 were included

†: Data for Belgium comprise Flanders and Brussels, data for Italy comprise the region of Tuscany, Emilia Romagna, and city of Milan

‡: p-values for cancer sites, men vs. women, and age groups <0.0001 (Pearson χ^2- test)

Home deaths

Of all cancer deaths, 13% (Norway) to 45% (the Netherlands) took place at home. Of all non-cancer deaths, 17% (Norway) to 32% (Italy) took place at home (Table 2). In all populations, except Norway, the proportion of home deaths was higher in cancer patients than in non-cancer patients, with the largest difference in the Netherlands where 45% of cancer deaths compared to 21% of non-cancer deaths occurred at home.

The proportion of cancer deaths taking place in hospital was 61% in Belgium, 31% in the Netherlands, 50% in England, and 60% in Wales, and in a care home 10% in Belgium, 19% in the Netherlands, 10% in England, and 8% in Wales. In England and Wales respectively, 16% and 8% of cancer patients died in a hospice. In Norway 87% died in an 'institution' (the Norwegian death certificate data did not distinguish between hospital and care home). The Italian death certificate data of 2002 only allowed identification of 'home' and 'outside home'.

Table 2 Place of deaths in non-cancer and in cancer deaths in 6 European countries, 2003 (percentages)*

	Belgium		Italy		Netherlands		Norway		England		Wales	
	non-cancer	cancer	non-cancer	cancer	non-cancer	cancer	non-cancer	cancer	non-cancer	cancer	non-cancer	cancer
home[†]	21.7	27.9	32.2	35.8	21.3	45.4	17.2	12.7	16.6	22.1	17.5	22.7
hospital	48.9	61.4	/	/	35.1	31.0	78.6[§]	86.9[§]	61.0	49.9	63.6	60.1
care home	26.9	10.5	/	/	39.3	19.2			19.6	10.3	16.3	7.6
hospice	/	/	/	/	1.6[‡]	3.8[‡]	/	/	0.4	16.4	0.2	7.7
other	2.5	0.2	67.8	64.2	2.8	0.5	4.1	0.4	2.5	1.3	2.3	1.9

Presented figures are column percentages

/: not available as a category on the death certificate data

*: In Italy, included deaths are those of 2002

†: proportion of cancer patients dying at home differed statistically significantly ($p<0.001$, tested with Fisher exact [Monte Carlo procedure]) between all countries, except between England and Wales ($p=0.198$); proportion of non-cancer patients dying at home differed statistically significantly ($p<0.005$) between all countries, except between Belgium and the Netherlands ($p=0.086$), and between Norway and Wales ($p=0.413$); proportion of non-cancer patients versus cancer patients dying at home differed significantly in all countries ($p<0.001$).

‡: On the Dutch death certificate indicated as 'other institute', but this comprises mostly hospices

§: In the Norwegian death certificates the category 'institution' was used, without a distinction between care home and hospitals

The proportion of home deaths, except for England and Wales, was usually larger in cancers of the central nervous system than in others, and in all populations much lower in hematological cancers, though 23% in Italy and 33% in the Netherlands died at home

(Table 3). More men died at home than women, although the opposite was the case in Italy.

The proportion of home deaths in most populations decreased with age, most rapidly in the Netherlands after the age of 70. In Italy the inverse was the case: the higher the age the higher the proportion dying at home, resulting in about 4 out of 10 cancer patients aged 90 or older dying at home.

Table 3 Percentage of cancer deaths in 2003* occurring at home by cancer site, sex and age in 6 European countries

	Belgium†	Italy†	Netherlands	Norway	England	Wales
All cancer deaths	27.9	35.8	45.4	12.7	22.1	22.7
Cancer site‡						
head & neck	31.7	34.6	50.8	16.5	25.1	27.0
gastrointestinal	31.2	38.2	51.2	14.4	25.6	26.0
respiratory	30.4	34.2	48.2	12.9	25.0	23.8
breast cancer	25.6	40.2	42.7	10.5	20.4	22.0
genitourinary	26.5	39.1	44.4	13.3	20.3	20.9
central nervous system	35.8	46.1	52.0	16.9	25.4	23.0
haematological	17.2	23.0	33.2	7.7	13.4	12.7
other	27.0	32.8	37.4	10.4	18.5	21.1
Sex‡						
male	30.5	34.6	49.2	14.3	23.5	23.8
female	24.6	37.4	40.8	11.0	20.5	21.4
Age‡						
0-49	32.3	28.5	56.3	18.8	24.5	28.1
50-59	33.4	30.8	56.5	18.5	27.5	30.1
60-69	31.6	33.5	53.3	14.6	27.2	25.8
70-79	28.6	35.3	46.2	12.8	22.4	23.7
80-89	23.0	38.6	33.1	9.8	17.8	17.5
90 and older	17.7	43.5	21.4	7.1	11.6	12.3

*: in Italy all deaths of 2002 were included

†: Data for Belgium comprise Flanders and Brussels, data for Italy comprise the region of Tuscany, Emilia Romagna, and city of Milan

‡: p-values for cancer sites, men vs. women, and age groups <0.0001 (Pearson χ^2- test for differences in proportion of home deaths between the 6 countries)

Factors influencing home death

Several possible regression models were tested in the different countries using stepwise logistic regression. Three alternative models were obtained in each country. A model with interaction effects yielded only a marginally better fit for the data in all countries and was finally not selected for the sake of comprehensibility. Finally a model with six age categories instead of eleven was selected as the latter yielded no better fit in all countries and the former made the model more parsimonious.

Multivariate logistic regressions per country (Table 4) showed that after adjusting for the effects of the other covariates in the logistic regression model, in all countries, those with solid malignant neoplasm had a higher probability of dying at home than did those with hematological cancers.

After adjusting for the effects of the other covariates, the chances of dying at home decreased strongly with increasing age, with a large difference between the youngest (below 50 years) and the oldest (above 90 years) in the Netherlands (OR=5.13), Norway (OR=2.68), England (OR=2.59), and Wales (OR= 2.85). The age effect was smaller in Belgium. In Italy, the age effect was converse.

With the other covariates in the logistic regression model held fixed, no significant gender differences were found in Belgium, but men had a higher chance of dying at home in the Netherlands, Norway, England, and Wales; in the Italian regions women were more likely to die at home.

Adjusting for the other covariate effects, in Belgium, the Netherlands, and Norway married cancer patients had higher chances of dying at home than the unmarried, divorce or widowed; the difference was smaller in Italy where no significant differences were found between the married, widowed, and divorced or separated. Marital status was not available in our dataset for England and Wales.

Controlling for possible confounding effects of the other covariates, educational differences manifested in the countries where the variable was available (ie Belgium, Italy, Norway) with the more highly educated having higher chances of dying at home.

A greater number of available hospital beds and available care home beds decreased the chances of dying at home in Belgium, Italy, and Wales. Living in less urbanized municipalities was associated with higher chances of dying at home, except in England, where the chance of dying at home was higher in very strongly urbanized regions than in strongly and weakly urbanized regions.

The regression models for the different countries explained a small part of the variance of the observed data (low Nagelkerke R²) and, apart from in the Netherlands, the models were not able to predict home death substantially.

Table 4 Odds ratios (and 95% confidence intervals) for multivariate logistic regression on dying at home in cancer patients in 6 European countries, 2003*

	Belgium	Italy	Netherlands	Norway	England	Wales
Cancer type						
head & neck	2.27 (1.60-3.22)	1.90 (1.48-2.45)	1.81 (1.50-2.18)	2.68 (1.57-4.58)	2.00 (1.75-2.28)	2.35 (1.46-3.77)
gastrointestinal	2.42 (2.00-2.94)	2.07 (1.85-2.32)	2.28 (2.09-2.48)	2.20 (1.66-2.91)	2.26 (2.13-2.41)	2.46 (1.89-3.20)
respiratory	1.99 (1.64-2.41)	1.90 (1.68-2.14)	1.72 (1.57-1.88)	1.78 (1.33-2.38)	2.08 (1.96-2.22)	2.09 (1.59-2.74)
breast cancer	1.80 (1.43-2.26)	2.40 (2.07-2.78)	1.68 (1.51-1.87)	1.51 (1.04-2.17)	1.75 (1.62-1.89)	1.91 (1.41-2.60)
genitourinary	1.76 (1.43-2.16)	2.20 (1.94-2.50)	1.79 (1.63-1.97)	2.05 (1.54-2.73)	1.71 (1.60-1.82)	1.91 (1.45-2.52)
central nervous system	2.23 (1.63-3.05)	3.41 (2.78-4.18)	1.65 (1.39-1.97)	1.99 (1.32-2.99)	1.89 (1.71-2.10)	1.70 (1.09-2.65)
other malignancy	1.96 (1.58-2.44)	1.62 (1.39-1.88)	1.47 (1.33-1.63)	1.52 (1.09-2.12)	1.59 (1.48-1.70)	2.03 (1.53-2.69)
non-malignant neoplasm	1.13 (0.83-1.53)	1.31 (1.08-1.58)	0.94 (0.82-1.07)	1.62 (0.95-2.77)	1.04 (0.93-1.17)	1.11 (0.70-1.76)
hematological	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)
Age						
0-49	1.48 (1.13-1.92)	0.45 (0.37-0.54)	5.13 (4.44-5.93)	2.68 (1.81-3.97)	2.59 (2.37-2.84)	2.85 (2.02-4.02)
50-59	1.22 (0.96-1.54)	0.48 (0.42-0.56)	3.93 (3.46-4.48)	2.43 (1.72-3.45)	2.78 (2.57-3.01)	3.00 (2.21-4.06)
60-69	1.22 (0.98-1.51)	0.62 (0.55-0.70)	3.30 (2.93-3.74)	1.78 (1.28-2.50)	2.69 (2.50-2.90)	2.40 (1.80-3.20)
70-79	1.17 (0.95-1.43)	0.70 (0.62-0.78)	2.47 (2.19-2.78)	1.58 (1.15-2.18)	2.09 (1.95-2.25)	2.15 (1.63-2.85)
80-89	1.09 (0.88-1.34)	0.83 (0.74-0.93)	1.57 (1.40-1.78)	1.27 (0.93-1.75)	1.60 (1.49-1.72)	1.49 (1.12-1.98)
90 and older	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)
Sex						
male (vs female)	ns[†]	0.85 (0.80-0.91)	1.23 (1.17-1.28)	1.15 (1.01-1.31)	1.13 (1.10-1.16)	1.12 (1.01-1.24)
Marital Status						
divorced/separated	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	/	/
not married	1.29 (1.01-1.65)	0.74 (0.57-0.97)	0.85 (0.73-0.95)	1.34 (1.00-1.80)	/	/
married	2.45 (2.00-3.00)	1.15 (0.89-1.47)	1.94 (1.86-2.01)	2.09 (1.66-2.63)	/	/
Widowed	1.19 (0.95-1.49)	1.00 (0.77-1.29)	1.18 (1.08-1.29)	1.29 (1.00-1.68)	/	/
Educational level						
elementary or lower	1.00 (1.00-1.00)	1.00 (1.00-1.00)	/	‡	/	/
lower secondary	1.20 (1.08-1.32)	1.04 (0.95-1.12)	/	1.00 (1.00-1.00)	/	/
higher secondary	1.22 (1.08-1.38)	1.55 (1.39-1.73)	/	1.17 (1.03-1.34)	/	/
higher education	1.68 (1.44-1.97)	1.96 (1.68-2.30)	/	1.40 (1.15-1.70)	/	/
Hospital bed rate (/1000)	0.88 (0.84-0.92)	0.97 (0.93-0.99)	ns[†]	ns[†]	ns[†]	0.70 (0.62-0.79)
Care home bed rate (/1000)	0.90 (0.84-0.96)	0.69 (0.67-0.70)	ns[†]	ns[†]	1.04 (1.03-1.04)	0.71 (0.62-0.80)
Urbanisation						
very strong	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)
strong	1.72 (1.54-1.92)	1.35 (1.27-1.44)	1.16 (1.09-1.23)	1.64 (1.36-1.97)	0.94 (0.90-0.98)	1.24 (0.99-1.55)
average	1.95 (1.75-2.17)	1.14 (1.02-1.27)	1.33 (1.24-1.42)	1.39 (1.17-1.66)	0.97 (0.93-1.01)	1.31 (1.01-1.70)
low or rural	2.34 (1.95-2.81)	2.08 (1.37-3.17)	1.60 (1.51-1.70)	1.97 (1.66-2.34)	0.93 (0.90-0.96)	0.94 (0.71-1.24)

Model fitting statistics

Nagelkerke R^2 (max-rescaled)	9.5%	9.7%	10.4%	5.8%	3.4%	3.9%
Hosmer and Lemeshow test	0.566	<0.001	0.154	0.284	0.006	0.955
Area under the ROC curve	0.67	0.66	0.64	0.65	0.60	0.61
% cases home death predicted correctly	6.5%	34.4%	54.5%	0.0%	0.0%	0.0%

*: in Italy all deaths of 2002 were included.

†: ns: not significant and consequently excluded from the stepwise logistic regression

‡: in Norway very little people (N=56) had elementary or lower as highest education, hence lower secondary was chosen as reference category.

/: variable not available

2.4 Discussion

This study using death certificate data from six European countries demonstrates large cross-national differences in the proportion of cancer patients dying at home as well as in the influence of age, sex, and area characteristics on the probability of dying at home.

Our study was the first to examine European country variations in home deaths in cancer patients and to investigate factors influencing them. By including more than 250,000 cancer deaths in six European countries the study provided solid data on place of death and in doing so provided some insight into cross-national differences in the organization of end-of-life care for cancer patients. A major strength of this study was that patterns are described within entire populations and not just as samples, and moreover across different settings.

A number of limitations can be stated. Firstly, as home versus outside home were the only place of death categories in Italy in 2002, our cross-national analyses could not distinguish deaths in hospital from deaths in care homes. Secondly, a well-known weakness of death certificates concerns cause of death miscoding and misclassification.(15) Thirdly, the number of relevant variables available via death certificate data (and as such the number of potential predictors for multivariate models) is limited and no information about preferred place of death and the quality of the dying process is available. Because of possible misclassifications in cause of death and because the use of death certificate data only reveals statistical patterns, without allowing conclusions to be drawn on what underlies or precedes these patterns,(16) the results should be regarded as a first exploratory attempt to map out cross-national differences in place of death of cancer patients.

Place of death may be considered a robust indicator of how societies broadly approach death and dying, and how they have accordingly organized their end-of-life care. Taking all limitations into consideration, this study still provides strong empirical evidence of large differences between sometimes neighboring countries in the likelihood of cancer patients dying in familiar surroundings. That these differences were moreover larger for cancer patients than for non-cancer patients, seems to suggest strong cross-national differences in the organization of end-of-life care, and possibly different admission policies,(8) or even differences in aggressiveness of cancer care towards the end of life.(17)

The cross-national difference in the proportion of cancer patients dying at home between the Netherlands and neighboring Belgium is almost 20 percentage points and 33 percentage points between the Netherlands and Norway. This makes speculation on underlying reasons inevitable. The Netherlands is known to value candor,(18) which stimulates open communication between patient and physician, as does the relationship between Dutch people and their general practitioner.(19) Dutch government policies are also clearly directed at care at home, or at least outside hospitals, with well-organized possibilities for home care and nursing home care,(20) and comprehensive palliative care in the Netherlands has always been strongly focused on the home and the family. Many other countries have developed palliative care predominantly in-hospital and also give a less powerful gate-keeping role to primary care. In Norway, despite a reform of general practice in 2001 aimed at strengthening the role of primary care,(21) access to institutional care seems to remain high, in particular for cancer patients, fewer of whom died at home than did non-cancer patients compared with other countries. It could safely be concluded that cross-national differences in place of death result from a complex interaction of organizational, societal and cultural factors, and the attitudes and training of physicians.(22)

Differences between the countries studied seem to be as large as (or even larger than) differences between states in the USA.(23-25) In 2001, home death from cancer ranged from less than 25% in South Dakota to more than 60% in Utah.(24) This geographical variation remained important after controlling for individual and area characteristics, possibly indicating the lack of a global policy and services. Though found to be one of the most important factors in predicting in-hospital death, and an explanation of geographical variation in American research,(23;24;26) the importance of bed-availability is put in perspective somewhat by our findings. A higher number of hospital beds in the health region did not decrease the chances of dying at home in the

Netherlands, Norway, and England. Its influence is perhaps subordinate to that of the availability of managed care services and policies to support dying patients and their families at home, and of open communication and advance care planning.(23;27) The latter probably more than the number of hospital beds explains why the Netherlands has one of the highest home death rates and lowest in-hospital death rates in Europe, but equally why Oregon does so in the USA.(20;23) It seems plausible to assume that it is insufficient for a policy simply to reduce the number of hospital beds in order to increase the numbers dying at home. Identification of organizational healthcare policies and services leading certain areas to have more home deaths can inspire policy development in both Europe and the USA.

The increasing probability of home death with increasing levels of educational attainment in the countries where information was available (ie Belgium, Italy, Norway) raises the question of social inequality and inequity. The differences could perhaps be accounted for by different preferences, but are more likely to be due to differences in housing conditions and in access to palliative and other care services, as well as to differing capacities to express preferences. The unconscious prejudices of physicians are also believed to play a role in hospice/palliative care or hospital referral.(28) In any case, there seems to be a direct or indirect inequity in the chances of dying at home, which calls for further attention by public health policy-makers.

Differences by marital status were smaller in Italy than elsewhere, which probably indicates societal expectations that children take care of their elderly and sick parents. A large-scale mortality follow-back study in Italy indicated that for 43% of terminal cancer patients the child was the most important informal caregiver.(29) This exemplifies the conclusion that also cultural differences determine patterns in location of death. In the Netherlands, research has shown that in the last months of life, especially for older women, care is increasingly given by professional caregivers,(30) while in Italy the probability of dying at home increases with age. This corroborates previous research in Italy,(31) and can be explained by the fact that Italy, as opposed to the Netherlands,(32) has not developed nursing homes providing long-term care for elderly people and has fewer residential homes for older people.(33)

In conclusion, our findings demonstrate large cross-national differences in the proportion of cancer patients dying at home, which appear to be influenced not only by health care policy and organizational arrangements but also by societal expectations and cultural values, and by approaches in specific patient populations. In order to increase the possibilities of home death for cancer patients, policies need to focus not only on a number of concrete factors such as the consistent inequality between hematological and other cancer patients and the inequalities between those with different levels of education; but also need to appreciate country-specific contextual factors eg cultural values within populations. Given the similar findings in past studies in the US, similar policy priorities may be beneficial there.

As a result, probably, of the limited information available from death certificates the logistic regression models were not able to predict correctly a large proportion of home deaths and as such are not suitable for prediction in clinical practice. However, the large cross-national differences point to organizational or medical cultural differences between different countries which also demand self-awareness in clinical practice.

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All authors have no conflict of interest to declare

Authors' contributions

All authors contributed to the conception and design of the study, the collection and assembly of data, data analysis and interpretation, the writing and final approval of the manuscript. JC, JB, and LD obtained financial support.

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3 Place of Death of Older Persons with Dementia. A Study in Five European Countries

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ABSTRACT

The aging of the European population will lead to a rapid increase in dementia cases in the coming decades, posing challenges for the organisation and provision of end-of-life care. Studying the place of death of dementia patients, and what determines it, is relevant in this context. Using death certificates, we studied the deaths of people aged 65 and older, whose underlying cause of death was a dementia-related disease, in Belgium, the Netherlands, England, Scotland, and Wales. Between 50% (Wales) and 92% (Netherlands) of dementia patients died in a nursing home and between 3% (Netherlands) and 46% (Wales) in hospital. Home death was rare (3-5%) except in Belgium (11%). Multivariate analysis showed that place of death was related to age, sex, available hospital and nursing home beds and the country of residence. While availability of hospital and nursing home beds partially explained the variation between countries, considerable variation remained even after controlling for that, plus age, sex, and social support. Place of death from dementia differed significantly between the countries we studied. In all countries, a majority of dementia patients died in a long-term care facility. The provision of appropriate long-term care facilities with appropriate staffing could be the primary policy instrument in avoiding dementia patients dying in hospital, and assuring quality of end-of-life care in Europe in the future.

3.1 Introduction

Dementia is a major public health problem; 6.4% of Europeans aged 65 and older suffer from it, 4.4% with Alzheimer's disease and 1.6% with vascular dementia.(1;2) Its prevalence goes on increasing with age, from 0.8% of 65 to 69 years olds to 28.5% at 90 and older.(1) Aging of the European population will lead to a rapid increase, from about 7 million in 2000 to an estimated 16 million in 2050. The number of new cases will increase from approximately 1.3 million a year in 2000 to more than 4 million in 2050(3) posing a challenge to the organisation of end-of-life care for these patients across Europe.

Studying place of death of people with dementia can provide essential information for the planning of end-of-life care services and facilities because those with dementia are more likely to enter institutional care.(4) The disease follows a long course of cognitive and functional decline, punctuated by acute illnesses such as pneumonia which are often the direct cause of death, and mostly accompanied by gradually-increasing behavioural disturbances such as disorientation, restlessness and aggression.(5-7) Caring for dementia patients at home(8-11) or even in a nursing home(11;12) is very burdensome compared with other life-limiting diseases; the burden usually becoming heavier as the disease progresses(13) and will often have a negative effect on the health of informal caregivers(14), leading to early admission to nursing home or hospital.(15) This also has important consequences for health-care costs. Although advanced dementia may not be as common in the future if better therapies and healthy-aging policies develop, it is likely that nursing home care will still prove necessary as the family caregiver burden is both long and heavy and professional home-care support is often inadequate. Studying place of death is also relevant from a quality of end-of-life care perspective, as nursing home or home are preferred as places of end-of-life care in cases of dementia.(16) Although hospitalisation of patients is common practice in many countries, it is associated with hospital-related health risks such as delirium, distress and pressure ulcers and it does not seem to decrease mortality risk from pneumonia.(6;17) Hospitalisation, and the continuation of curative care, can be a major obstacle to delivering effective palliative care.(17)

The purpose of this article is to study the place of death of older people with dementia for the first time in Europe. Studying cross-national variation in place of death from dementia, and comparison with other life-limiting conditions, can provide useful information for the development of end-of-life care policies and services which meet the needs of dementia patients, their relatives and society as a whole. The research questions are: Where did older people with dementia-related diseases die in five European countries? In what respect does the place of death of older people who die from dementia differ from that of older people who die from cancer and the other most-prevalent life-limiting conditions? Can country-variations in place of death be explained by differences in patient characteristics, social support and healthcare input?

3.2 Methods

We used the death certificate data of all deaths in 2003 of those aged 65 and older in five European countries: Belgium (Flanders and Brussels Capital Region), the Netherlands, England, Wales, and Scotland, brought together in a common database by the partners of the European collaborative research project “Dying well in Europe”.(18)

The dependent variable in our analysis is the place of death as recorded on the death certificate and recoded into five categories: home, hospital, nursing home (including both general care homes for the elderly and specialised nursing homes), hospice or other care institutions (this category applies exclusively to hospices in England and Wales and mostly in the Netherlands, and to other care institutions in Belgium and Scotland), and other (eg highway).

The independent variables include factors known to affect place of death: underlying cause of death, personal factors, social support, healthcare input and country of residence.(19;20) The underlying cause of death as recorded on the death certificate, was recoded into three broad categories of life-limiting conditions: dementia-related diseases ie Alzheimer’s disease (ICD-10: G30), vascular dementia (ICD10: F01) or unspecified dementia (ICD10: F03), cancer (ICD10: C0-D48), and a set of other important life-limiting conditions eligible for palliative care: heart failure, renal failure, COPD, liver failure and Parkinson’s disease.(21) The personal factors in our model, also taken from the death certificate, are age (recoded in three categories: 65-74 years, 75-84 years, and 85 years and over) and sex. As information on family situation was not available from the death certificates in all countries, we included an aggregated variable indicating the social support available to patients: the percentage of the population aged 65 years and over living alone in the municipality of residence of the deceased (linked through the ZIP-code). The health-care resources available to the patient were included as the number of hospital and nursing home beds (per 1000 persons) in the healthcare region of the deceased (catchment area). As country differences were our main focus, country of residence was also included.

Pearson’s Chi²-tests were used to test differences in place of death within countries for type of life-limiting condition (dementia, cancer and other life-limiting conditions) and between countries for each type of life-limiting condition. Statistical significance was set at $p<0.01$. To compare the probability of dementia patients dying in a certain place with that of patients with other life-limiting conditions and across countries, the distribution of place of death of all life-limiting conditions was standardised to the age and sex distribution of the sub-sample of English cancer patients. We performed three separate binomial multivariate logistic regression analyses to estimate the chances of dementia patients dying at home relative to in hospital, dying in a nursing home relative to a hospital, and dying at home relative to a nursing home. These three models were built up stepwise beginning from the unadjusted odds ratios for country of residence and adjusting these odds ratios stepwise for age, sex, social support and health care input to examine to what extent these separate factors adjusted the possible contrast in place of death for dementia patients between the different countries in our analysis. SPSS 16.0 (SPSS Inc., Chicago, Illinois) was used for all statistical computations.

3.3 Results

In 2003, 4.6% of the population aged 65 and over, ranging from 4.0% in Wales to 6.1% in the Netherlands, died from a dementia-related disease. Of these between 12.6% in the Netherlands and 29.3% in Wales died from Alzheimer's disease. (Table 1) In all countries, more than half were aged 85 or older and about two thirds were women.

Place of death from dementia differed significantly between the countries we studied. In all countries, a majority died in a long-term care facility, from 50.2% in Wales to 92.3% in the Netherlands (of which again 89.4% died in a specialised nursing home and 10.6% in a general care home for the elderly). The likelihood of dying in hospital was higher in the UK (England: 36.0%; Wales: 46.3%; Scotland: 33.9%) and Belgium (22.7%) than in the Netherlands (2.8%). The likelihood of dying at home was 11.4% in Belgium and 5% or less in the other countries. Nowhere did the number of deaths in a palliative care institution (hospices in England and Wales, and mainly hospices in the Netherlands) exceed 1%.

Table 1 Deaths from Dementia-related Diseases (≥ 65 y), Type of Dementia, Sex, Age, Health Resources, and Place of Death in Five European Countries in 2003 (N=30,281)

	Country of Residence					
	Belgium[*]	Netherlands	England	Wales	Scotland	Total
Deaths, Type of Dementia, Sex, Age, Health Resources and Place of Death	n (%)[†]					
Deaths from dementia-related diseases (percentage of all deaths ≥ 65 y)	2,709 (4.8%)	6,984 (6.1%)	17,044 (4.1%)	1,220 (4.0%)	2,324 (5.0%)	30,281 (4.6%)
Type						
Alzheimer's disease	27.8%	12.6%	26.9%	29.3%	14.9%	22.9%
Vascular and other dementia	72.2%	87.4%	73.1%	70.7%	85.1%	77.1%
Sex						
Male	31.2%	26.9%	27.7%	27.4%	26.3%	27.7%
Female	68.8%	73.1%	72.3%	72.6%	73.7%	72.3%
Age						
65-74	7.4%	5.3%	5.9%	5.8%	6.4%	5.9%
75-84	38.2%	33.0%	34.3%	34.6%	34.2%	34.4%
≥85	54.4%	61.7%	59.8%	59.6%	59.4%	59.7%
Health Resources						
Hospital beds/1000	5.57	3.67	3.05	3.95	4.62	3.52
Nursing home beds/1000	4.54	10.75	8.37	4.18	7.82	8.24
Place of Death[‡]						
Home	11.4%	3.8%	3.7%	3.2%	5.0%	4.5%
Hospital	22.7%	2.8%	36.0%	46.3%	33.9%	27.4%
Nursing Home	65.9%	92.3%	59.7%	50.2%	60.8%	67.5%
Hospice or Other Care Institution[§]	0.0%	0.5%	0.3%	0.1%	0.4%	0.3%

[*] Flanders and Brussels Capital Region

[†] Presented percentages are column percentages

[‡] Column percentages may not add up to 100% because the category 'Other' was omitted

[§] Category concerns hospice in England and Wales, mostly hospice in the Netherlands and other care institution in Belgium and Scotland.

Standardized for age and sex (with the English cancer patients as the standard population) and compared with deaths from cancer and other major diseases, deaths from dementia were less likely to occur at home, in hospital or (in England, Wales and the Netherlands) in a hospice and more likely to take place in a nursing home. (Table 2) The age and sex standardised percentages largely confirm the crude cross-national differences in place of death.

Table 2 Place of Death of Older Persons (≥ 65 y), by Underlying Cause of Death in Five European Countries in 2003 (N=261,387)

	Place of death			
	Home	Hospital	Nursing home	Hospice or other care institution
	%[*,†]			
All deaths (≥65 y) [‡]	18.2	54.0	24.0	2.7
Belgium[§,¶]				
Dementia	16.4	22.8	60.6	0.1
Cancer	26.4	60.3	13.2	0.1
Other life-limiting conditions	22.3	50.5	26.9	0.1
the Netherlands[§,¶]				
Dementia	4.7	3.0	90.7	0.7
Cancer	40.3	29.7	25.3	3.5
Other life-limiting conditions	21.9	40.0	36.1	0.9
England[§,¶]				
Dementia	4.9	39.1	55.4	0.2
Cancer	20.5	50.8	12.6	14.8
Other life-limiting conditions	16.6	65.8	15.9	0.9
Wales[§,¶]				
Dementia	3.3	52.8	43.8	0.0
Cancer	20.5	60.9	9.8	6.7
Other life-limiting conditions	15.2	71.7	12.5	0.2
Scotland[§,¶]				
Dementia	7.3	37.6	54.9	0.3
Cancer	21.9	58.3	19.7	0.0
Other life-limiting conditions	17.1	67.6	15.2	0.1

[*] Presented percentages are row percentages

[†] Row percentages may not add up to 100% because the category Other was omitted

[‡] Unstandardized percentages of all deaths ≥ 65 y (N=662,689)

[§] Standardised for age and sex. Standard population: deaths from cancer in England 2003

[¶] P-value <0.001 of χ^2-test for association between type of chronic disease (dementia, cancer, other) and place of death (in each country) and, between dementia, cancer, other chronic disease and place of death in all countries

Multivariate analysis showed that place of death depended on country of residence, age and sex, and the available hospital and nursing home beds. (Table 3) The average degree of social support available to older people in the municipality of residence had no significant influence on their place of death. Dementia patients in the Netherlands and Belgium were more likely to die at home and in a nursing home relative to a hospital than those in England. Home death, relative to nursing home death, was more likely in Belgium (OR=2.57; CI:1.85-3.59) and Scotland (OR=1.47; CI:1.14-1.90) than in England (Reference Category) or Wales. In the Netherlands, dementia patients had the lowest chances of home death (relative to nursing home death:

OR=0.80; CI:0.68-0.95). Home death relative to both hospital and nursing home death became less likely with increasing age. Nursing home death relative to hospital death, became more likely with increasing age. Women were more likely than men to die at home and in nursing homes rather than in hospital. Men were more likely to die at home rather than in a nursing home. More hospital beds in the health-care region decreased the chances of home and nursing home death and of dying at home in relation to a nursing home. More nursing home beds increased the chances of nursing home death (relative to both hospital death and home death).

Table 3 Adjusted Odds Ratios of Place of Death of Older People (≥ 65 y) with Dementia in Five European Countries in 2003

	Home vs. Hospital death (N=9,651)	Nursing home vs. Hospital death (N=28,726)	Home vs. Nursing home death (N=21,799)
Factors related to place of death*	OR (CI, 95%)		
Country of residence			
England	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Belgium	7.03 (5.29-9.35)	4.68 (3.89-5.63)	2.57 (1.85-3.59)
the Netherlands	15.43 (12.42-19.17)	15.99 (13.71-18.66)	0.80 (0.68-0.95)
Scotland	1.74 (1.34-2.25)	1.46 (1.29-1.66)	1.47 (1.14-1.90)
Wales	0.76 (0.54-1.07)	1.44 (1.24-1.68)	0.84 (0.57-1.23)
Personal characteristics			
Age			
65-74	1.84 (1.49-2.28)	0.66 (0.59-0.74)	2.69 (2.22-3.26)
75-84	1.19 (1.04-1.36)	0.79 (0.74-0.83)	1.60 (1.42-1.80)
≥85	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Sex			
Male	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Female	1.57 (1.38-1.80)	1.94 (1.82-2.06)	0.74 (0.66-0.84)
Health care input			
Hospital beds/1000 in health region (cont)	0.87 (0.79-0.95)	0.88 (0.83-0.93)	0.90 (0.82-0.99)
Nursing home beds/1000 in health region (cont)		1.17 (1.15-1.19)	0.93 (0.90-0.96)

* The factor Social Support (% of households of 1 person being pensioner in the municipality of residence) was introduced in the regression equation, but found not significant

Stepwise building up of the regression model showed that the number of available hospital and nursing home beds explained part of the variation between countries in the chances of a nursing home relative to a hospital death (data not shown in table). Adding the number of available hospital beds to the model explained part of the higher hospital death rate in Belgium (with the highest average number of available hospital beds) compared with the Netherlands, and further increased the differences between Belgium and England, the latter with a relatively lower hospital bed availability (the odds ratio compared to England increased from OR=1.92; CI:1.74-2.13 to OR=2.70; CI:2.27-3.22). Taking additionally into account the lower number of available nursing home beds in Belgium and Wales as compared to England, the odds ratio of nursing home relative to hospital death also increased significantly in Belgium (from OR=2.70; CI:2.27-

3.22 to OR=4.68; CI:3.89-5.63) and in Wales (from OR=0.70; CI:0.62-0.80 to OR=1.45; CI:1.24-1.70). The larger availability of nursing home beds in the Netherlands compared with all other countries explained part of the difference in the chances of nursing home relative to hospital death (the odds ratio compared to England decreased from OR=25.56; CI:21.84-29.98 to OR=15.99; CI:13.71-18.69). Differences in age, sex, social support and available hospital and nursing home beds did not significantly explain country variation in the chances of home relative to hospital death, and home relative to nursing home death.

3.4 Discussion

In 2003, 4.6% of the population aged 65 and older in Belgium, the Netherlands, England, Wales, and Scotland died from dementia. Country variation in hospital death was considerable: in all the countries studied a substantial proportion of dementia patients died in hospital compared with the Netherlands (hospital death rate of 2.8%). Multivariate analysis showed that the lower chances of hospital relative to nursing home death in the Netherlands, was substantially explained by the higher availability of nursing home beds. Home death was low in all countries except Belgium where it was 11.4%.

Our study was the first to examine place of death from dementia cross-nationally within Europe. Death certificates offer the opportunity to study the place of death of whole populations, resulting in more statistical power of analysis, and to compare national populations.(18) On the other hand, the information from death certificate data is limited and not all factors known to affect place of death, eg functional status, social conditions, and patient's and caregiver's preferences, could be included in our analysis. As a consequence we used an aggregated variable for the social support available to the patient. Additionally, the information from death certificates in different countries is not always comparable which also restricts the set of variables we use in our analysis and the number of European countries that we compare. Finally, dementia as a cause of death on death certificates is known to be underestimated.(22;23)

In 2003, a majority of dementia patients died in nursing homes in the countries we included. The long duration of care and the progressive behavioral disturbances make care at home very burdensome for family caregivers and nursing home placement becomes a likely choice,(14) unless more intensive support for caregivers at home is available. The course of disease is also less predictable, with a less-distinctive terminal stage than in cases of cancer.(6;24) As a consequence, home death in dementia cases was rather rare. Compared with dementia patients, home as place of death was much more likely for cancer patients and those with other life-limiting conditions. Also dementia patients are referred to specialist palliative care services less frequently and often late in the course of the disease, which may explain why so few died in hospices in the countries where hospice care is widely available (eg UK).(6)

Hospital death was important, except for the Netherlands where it was 2.8%. Even though the place of end-of-life care does not indicate the quality of the end-of-life experience, the relatively large proportion of dementia patients dying in hospital in most European countries may need more attention. Long-term hospital care for dementia patients or late transfers to hospital at the end-of-life are questionable because of hospital-related health risks and the futile curative treatment often associated with hospitalisation.(6;17)

Even controlled for possible confounding factors such as sex, age, social support and availability of healthcare services dementia patients in Wales, England and Scotland seemed more likely to die in hospital relative to nursing homes or home than those in Belgium and particularly in the Netherlands. The step-by-step building up of our models showed that the higher likelihood of nursing home relative to hospital death in the Netherlands was largely explained by the greater availability of nursing home beds serviced by highly skilled professionals. We believe that the much higher chances of dementia patients in the Netherlands dying in a nursing home are not only related to the greater availability of nursing home beds but also to the fact that the Netherlands has developed nursing homes well-equipped to provide long-term end-of-life care, with 24-hour nursing care and several specialist nursing home physicians employed by the nursing home,(6) resulting in advance care planning and better communication with the relatives about treatment options and less hospitalisation and invasive intervention eg for infections.(25;26) These specialised nursing homes hold a special position within the health care system for older people, providing more specialised geriatric care with specialised residential nursing home physicians whereas in care-homes and nursing homes in other countries in Europe the attending physician is generally the family physician who may have a more limited overview of the patient’s situation. However, one effect of the greater availability of nursing home beds in the Netherlands is that home death relative to nursing home death is less likely than in other countries, particularly Belgium. It is questionable whether the higher chances of dementia patients dying at home relative to in a nursing home in Belgium are simply a consequence of the restricted availability of nursing home beds or of other factors such as a possibly more negative attitude in Belgium towards nursing homes as place of final care. Home as the place of final care for dementia patients remains an uncertain option, although continued primary care and paid home-care or specialist palliative home-care have been demonstrated in other studies to reduce substantially the likelihood of a hospital death for patients being cared for at home.(27;28)

When comparing our findings to a comparable study undertaken in the US by Mitchell et al.(19), we notice that the nursing home death rate there (66.9%) was similar to the one we found, but - with the exception of the Netherlands- fewer dementia patients died in hospital in the US (15.6%) and more at home (12.8%) or in other locations such as hospices (4.7%). Also the variation in hospital death rate between US states, from 5.0% to 37.0%, was similar to that between European countries. The availability of nursing home beds was also an explanatory factor for these interstate variations.(19) The results of our study and that in the US (19) seem to indicate that the availability of nursing home beds can be a primary focus for policy to prevent dementia patients from dying in hospital, the place of death least desirable to a majority of patients. Therefore it is important that government agencies plan the need for nursing home beds carefully over the coming decades and provide the necessary funds, given the cost to society of institutionalised care for dementia patients.(29) Nursing home facilities alone though will not be sufficient to prevent dementia patients from ultimately dying in hospital. Appropriate staffing and continuity of care remains a prerequisite for good quality end-of-life care avoiding transfer to hospital.

With the aging of the European populations the place of final care for dementia patients will become a major health-care issue. In mapping out cross-national variations between place of death for patients with other life-limiting conditions, our study provides insights that can aid in developing policies to achieve optimal end-of-life care for dementia patients. The Dutch model, with a high availability of highly-skilled nursing home professionals and continued and coordinated care in nursing homes offers the advantage of effectively preventing dementia patients from dying in hospital, although care for nursing home residents with advanced dementia is not always optimal and could possibly be improved.(30) Finally, strengthening home care could also be a solution and merits further investigation.

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Part III

Metropolitan perspectives in place of death and circumstances of dying

4 Place of death in metropolitan regions: Metropolitan versus nonmetropolitan variation in place of death in Belgium, the Netherlands and England

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ABSTRACT

Place of death is an important societal indicator of end-of-life quality for the terminally ill. Using death certificate data, we examined metropolitan/nonmetropolitan variation in place of death of patients with life-limiting conditions in Belgium, the Netherlands and England. Metropolitan patients were less likely to die at home and, in England, less likely to die in care homes, than nonmetropolitan terminally ill. We found a lesser degree of social support and lower availability of care home beds as partial explanations of the metropolitan/nonmetropolitan discrepancy. These findings warrant specific approaches to end-of-life care in metropolitan areas.

4.1 Introduction

Respecting the wishes of the dying is a fundamental characteristic of good end-of-life care. As most terminally ill patients prefer to die at home,(1-5) and relatives often want their loved ones' death to occur at home, the place of death is considered an important aspect of the quality of end-of-life care.(6) While home is not always the most appropriate place of death, the discrepancy between the proportion of terminally ill patients preferring to die at home and those actually doing so is striking.(7) Place of death is also related to the cost of end-of-life care, as institutionalized death is mostly more expensive than home death.(8-11) These motives have incited public health policy to support more people in dying at home where that is their wish.(12)

Previous research revealed that residents of urban areas had less chance than their rural counterparts of dying in their own homes particularly if they live in a metropolitan region.(13-17) Death seemed to occur substantially more often in hospitals and in care homes and less often at home in the metropolitan population of Brussels than in the more rural population of Flanders, the northern part of Belgium.(14;18) Similar contrasts can be deduced from data for London,(19) as compared to separate data for England as a whole (respectively about 20% versus 27% of cancer patients dying at home),(20) and even more from data for New York and the whole of the USA (respectively about 20% versus 40% of cancer patients died at home).(19;21)

This metropolitan/nonmetropolitan variation seems to warrant more attention, particularly as in 2008, for the first time in history, more than half the human population lived in urban areas. Although the metropolitan regions of the developing world will be growing faster in the coming decades, the cities of Europe and North America are also growing at 0.75% a year on average through 2030, reaching urbanization levels of 78.3% and 86.7% respectively.(22)

Until now, place of death has been studied in single metropolitan populations,(18;23;24) or compared between metropolitan populations.(19) Never before have metropolitan populations been compared with nonmetropolitan populations. Within the context of growing urbanization, and given the apparently high degree of hospital and care home deaths found in some metropolitan populations, it is relevant to study place of death systematically in metropolitan populations compared to nonmetropolitan populations. Furthermore, it is also relevant to examine whether the expected contrast between metropolitan and nonmetropolitan populations could be explained by differences in factors known to have an effect on place of death: the cause of death, the social composition of the populations, the characteristics of the health care input, and the degree of social support.(16) The objective of this article is therefore to compare the place of death of patients with life-limiting conditions residing in the metropolitan and nonmetropolitan regions of Belgium (Brussels Capital Region and Flanders), the Netherlands, and England using death certificate data. Two research questions are addressed. 1) Are there differences in place of death between metropolitan and nonmetropolitan residents with life-limiting conditions in Belgium, the Netherlands, and England? 2) What factors, related to illness, personal characteristics, social support and health services, can explain possible metropolitan/nonmetropolitan variation in place of death in Belgium, the Netherlands and England?

4.2 Methods

We used a common European database of death certificate data established by the partners of the European collaborative research project ‘Dying well in Europe’. This database contains death certificate data from 2003 of the populations of seven European countries (Denmark, the Netherlands, Norway, Sweden, England, Wales and Scotland), two regions in Belgium (Flanders and Brussels Capital Region), and three regions in Italy (Emilia Romagna, Tuscany and Milan). More information on this database can be found elsewhere.(25) For this study we used the death certificate data from England, the Netherlands and Belgium because these countries have matching categories of place of death. For each country, the death certificate data were linked to census data and data on health services availability.

The population studied consists of patients who died after life-limiting conditions, the so-called palliative subset, as identified by Rosenwax et al.(26;27) These patients could benefit most from receiving palliative care and had more chance to express their preferences about end-of-life care and place of death. This palliative subset consists of people who died from one or more of the following conditions: neoplasm, heart failure, renal failure, liver failure, respiratory disease, neurodegenerative disease and HIV/aids.

We considered deaths of patients who resided in metropolitan regions with a minimum of 400.000 inhabitants and a minimum population density of 2000 inhabitants/ km² to be metropolitan. Deaths of patients who resided in the remaining parts of England, the Netherlands and Belgium were considered nonmetropolitan. In accordance with these criteria, the deaths of patients who died from life-limiting conditions and resided in six English metropolitan regions were considered metropolitan: Greater London, West Midlands metropolitan county, Greater Manchester metropolitan county, Merseyside metropolitan county, Tyneside metropolitan county and the City of Bristol. For Belgium, the deaths of patients who died from life-limiting conditions and lived in Brussels Capital Region or the city of Antwerp were considered metropolitan. For the Netherlands we considered as metropolitan the deaths of patients who died from life-limiting conditions and lived in one of the three major cities: Amsterdam, Rotterdam and The Hague (table 1).

The dependent variable in our analyses is the place of death as indicated on the death certificate, recoded into five categories: home death, hospital death, death in care home or nursing home, death in another institution (hospice in England, and mostly hospice in the Netherlands), and death elsewhere (public road, work, etc). In the Netherlands, death in a care home and death in a nursing home form two distinct categories on the death certificate. Nursing homes hold a special position, providing more specialized geriatric care as they have specialized nursing home physicians whereas in care homes (and nursing homes in other countries) the attending physician is generally the general practitioner.

The independent variables include variables according with the factors known to affect the place of death: illness (underlying cause of death), personal factors (sex, age, and income) and environmental factors (available hospital beds, available beds in care home or nursing home, and social support available to the patient).(16) The variable cause of death consists of 7 categories of life-limiting conditions (neoplasm, heart failure, renal failure, liver failure, respiratory disease, neurodegenerative disease, and HIV/aids) and was recoded into two categories (neoplasm, and other life-limiting conditions) for logistic regression analysis. The personal variables included in analysis are: sex, age and income. As there was no information on the death certificates on the income of the deceased, we included an aggregated variable measuring the percentage difference between the average income of the municipality of residence of the deceased and the national average income, to have a comparable measure in all countries. The variables relating to the environment are the number of hospital beds and care home/nursing home beds available per 1,000 inhabitants in the health care region (health catchment area) and the social support available to the patient. For the latter we used an aggregated variable, measuring the percentage difference of the proportion of one-person households of 65 years or older in the municipality of residence of the deceased as compared to the national percentage of one-person households of 65 and above. The geographical units we used for the measures of average income and social support were the local authority area in England and the local municipality area in the Netherlands and Belgium. Their average size was 564.1 km² in England, 69.1 km² in the Netherlands and 41.8 km² in Belgium. The average area size of a metropolitan region, either a local authority (Bristol), a municipality (Rotterdam, Amsterdam, The Hague, Antwerp), a metropolitan county (ie a cluster of local authorities), or the Brussels Capital Region (ie a cluster of 19 municipalities) was 840.7 km² in England, 151.5 km² in the Netherlands and 183.0 km² in Belgium.

Pearson Chi²-tests were used to test differences between and within metropolitan and nonmetropolitan populations. Statistical significance was set at $p < 0.001$, because of the large sample size. For each country, two separate multivariate binomial logistic regression analyses were performed to estimate the odds of metropolitan and nonmetropolitan patients with life-limiting conditions (patients>44 years) dying at home versus in a hospital on the one hand and (patients>64 years) in a care home versus in a hospital on the other, adjusted for illness, personal factors and environmental factors. Both regression models were built up step by step. We started from the unadjusted odds ratio of home death relative to hospital death (or care home death relative to hospital death in the second regression analysis) for metropolitan relative to nonmetropolitan populations and adjusted that odds ratio stepwise for illness, personal factors (sex, age, and income) and, environmental factors (social support, available hospital beds, and available care home beds) to examine to what extent the separate factors affected the metropolitan/nonmetropolitan contrast.

All analyses were performed with SPSS version 16.0.

4.3 Results

According to the inclusion criteria, 11 metropolitan regions were included in Belgium, the Netherlands and England, with the number of deaths from life-limiting conditions in 2003 ranging from 1,353 in the city of Bristol to 20,750 in greater London (table 1).

Table 1 Total population, population density, and number of deaths in the selected metropolitan regions (2003)

	POPULATION [a]	POPULATION DENSITY [a]	DEATHS FROM LIFE-LIMITING CONDITIONS IN 2003
	N	persons sq km	n
Belgium			
Nonmetropolitan regions	**5,585,412**	**419**	**20,879**
Metropolitan regions	**1,464,498**	**4,002**	**5,819**
Brussels Capital region	1,006,749	6,238	3,672
City of Antwerp	457,749	2,225	2,147
the Netherlands			
Nonmetropolitan regions	**14,526,825**	**436**	**49,293**
Metropolitan regions	**1,807,385**	**3,976**	**7,048**
City of Amsterdam	743,079	4,469	2,630
City of Rotterdam	588,679	2,859	2,532
City of Den Haag	475,627	5,770	1,886
England			
Nonmetropolitan regions	**35,244,900**	**281**	**129,049**
Metropolitan regions	**15,518,000**	**3,075**	**52,189**
Greater London	7,512,400	4,779	20,750
West Midlands Metropolitan county	2,600,100	2,884	9,669
Greater Manchester Metropolitan county	2,553,800	2,001	9,472
Merseyside Metropolitan county	1,353,600	2,099	6,035
Tyne and Wear Metropolitan county	1,087,600	2,014	4,910
City of Bristol	410,500	3,745	1,353

[a] Source population and population density: Belgium: NIS (1/1/2005), the Netherlands: CBS (1/1/2006), England: Office for National Statistics (2006)

Of all included patients: 21.8% lived in a metropolitan area in Belgium, 12.5% in the Netherlands and 28.8% in England. Significant differences in causes of death, demographics of the deceased, and environmental characteristics were noted between the metropolitan and nonmetropolitan deaths (table 2). In the metropolitan populations of all countries, deaths occurred significantly more often from respiratory disease and HIV/aids and were (except for England) significantly more often women than in the nonmetropolitan populations. Deaths of 80 years and over were overrepresented in the metropolitan populations of the Netherlands but underrepresented in England. Compared with the nonmetropolitan populations, the average income per head was higher in the metropolitan populations of the Netherlands and England, but lower in the Belgian metropolitan populations. The metropolitan populations of the Netherlands and in particular Belgium had more one-person households of persons older than 65 years compared to nonmetropolitan populations, while the opposite was true for England. Metropolitan populations in all countries had more hospital beds and care home beds available than nonmetropolitan populations (except for England where nonmetropolitan regions had more care home beds available than metropolitan regions), although the variation between the countries was important with on average more hospital beds per 1,000 inhabitants in Belgium and more care home beds in the Netherlands.

Table 2 Characteristics of the metropolitan and nonmetropolitan deaths from life-limiting conditions (2003) [a]

	BELGIUM		**THE NETHERLANDS**		**ENGLAND**	
	Metropolitan Regions	**Non metropolitan Regions**	**Metropolitan regions**	**Non metropolitan regions**	**Metropolitan regions**	**Non metropolitan regions**
Total number of deaths from life-limiting conditions	5,819	20,879	7,048	49,293	52,189	129,049
% of total	(21.8%)	(78.2%)	(12.5%)	(87.5%)	(28.8%)	(71.2%)
ILLNESS						
Cause of death [b]						
Neoplasm	66.0%	66.2%	68.9%	71.0%	71.0%	72.4%
Hearth failure	11.9%	13.8%	10.7%	10.9%	6.5%	6.4%
Renal failure	2.5%	2.6%	2.2%	2.2%	1.9%	1.8%
Liver failure	0.3%	0.2%	0.3%	0.3%	0.4%	0.3%
Respiratory disease	12.6%	11.7%	12.7%	11.2%	15.1%	13.0%
Neurodegenerative disease	6.3%	4.9%	4.6%	4.2%	4.9%	6.0%
HIV/aids	0.4%	0.0%	0.5%	0.1%	0.2%	0.1%
PERSONAL FACTORS						
Sex [c]						
Male	48.6%	54.5%	49.1%	53.1%	50.4%	50.9%
Female	51.4%	45.5%	50.9%	46.9%	49.6%	49.1%
Age [d]						
45-59	10.5%	10.2%	12.4%	12.9%	10.4%	10.2%
60-69	15.6%	16.2%	15.4%	17.6%	18.0%	16.8%
70-79	30.8%	31.9%	28.6%	30.9%	32.9%	31.6%
80-89	29.8%	29.3%	32.8%	29.7%	30.5%	31.9%
90+	13.4%	12.3%	10.8%	8.9%	8.2%	9.5%
Income						
Average income/ head in the municipality of residence v national average	87	103	102	99	102	99
SOCIAL SUPPORT						
One-person households >65 years						
% of one-person households>65 in the municipality of residence v national average	120	94	108	99	97	101

HEALTH SERVICES						
Hospital beds						
Hospital beds/1,000 in health care region	5.9	5.3	3.8	3.6	3.3	2.9
Care Home beds						
Care home beds/1,000 in health care region	4.6	4.4	11.0	10.4	6.7	9.0

[a] Presented percentages are column percentages except percentages between brackets (row percentages)

[b] P-value of Pearson χ² for differences in proportion between metropolitan and nonmetropolitan populations in Belgium. the Netherlands and England <0.001

[c] P-value of Pearson χ² for differences in proportion between metropolitan and nonmetropolitan populations in Belgium and the Netherlands <0.001. in England p=0.097

[d] P-value of Pearson χ² for differences in proportion between metropolitan and nonmetropolitan populations in the Netherlands and England <0.001. in Belgium p=0.152

In all countries, fewer metropolitan patients with life-limiting conditions died at home, and more in hospitals than did nonmetropolitan patients (table 3). In Belgium and the Netherlands they also more often died in care homes than their nonmetropolitan counterparts. In England, the opposite was true: the metropolitan terminally ill less often died in care homes than the nonmetropolitan terminally ill. In England an equal proportion of metropolitan and nonmetropolitan deaths occurred in hospices. In the Netherlands however, fewer metropolitan residents with life-limiting conditions died in other institutions (mainly hospices) than did nonmetropolitan ones. In the Netherlands, more metropolitan patients than nonmetropolitan patients died in a nursing home (21.1% v 15.0%) and fewer in a residential home for older people (9.3% v 10.8%) (data not shown in table).

Table 3 Metropolitan and nonmetropolitan deaths by place of death from life-limiting conditions in Belgium, the Netherlands and England (2003) [a]

	No. of deaths (% of total)	% of deaths occurring at home	% of deaths occurring in hospital	% of deaths occurring in care home or nursing home	% of deaths occurring in other institution [b]	% of deaths occurring elsewhere
Belgium [c]						
Nonmetropolitan populations	**20,879 (78.2)**	**28.2**	**52.2**	**19.4**	**0.1**	**0.1**
Metropolitan populations [d]	**5,819 (21.8)**	**15.3**	**63.9**	**20.6**	**0.1**	**0.2**
Brussels Capital Region	3,672 (63.1)	15.1	63.0	21.6	0.1	0.2
City of Antwerp	2,147 (36.9)	15.6	65.4	18.8	0.0	0.2
the Netherlands [c]						
Nonmetropolitan populations	**49,293 (87.5)**	**39.1**	**31.2**	**25.8**	**2.8**	**1.1**
Metropolitan populations [d]	**7,048 (12.5)**	**29.5**	**35.8**	**30.4**	**2.2**	**2.0**
City of Amsterdam	2,630 (37.3)	30.2	34.8	29.2	3.1	2.7
City of Rotterdam	2,532 (35.9)	28.9	37.2	30.5	1.6	1.7
City of Den Haag	1,886 (26.8)	29.3	35.5	32.0	1.8	1.4

England [c]						
Nonmetropolitan populations	**129,049 (71.2)**	**20.7**	**51.2**	**14.9**	**12.0**	**1.2**
Metropolitan populations [d]	**52,189 (28.8)**	**18.6**	**58.3**	**9.9**	**12.0**	**1.2**
Greater London	20,750 (39.8)	17.2	59.6	8.1	14.0	1.0
West Midlands MC	9,669 (18.5)	19.3	59.6	10.6	9.3	1.2
Greater Manchester MC	9,472 (18.1)	17.7	58.5	9.8	12.6	1.4
Merseyside MC	6,035 (11.6)	20.8	53.3	12.4	11.9	1.6
Tyne and Wear MC	4,910 (9.4)	20.4	58.4	12.4	7.6	1.2
City of Bristol	1,353 (2.6)	23.4	48.0	14.6	12.7	1.3

[a] Presented percentages are row percentages except percentages in brackets (column percentages)

[b] For England this implies NHS hospices and non-NHS hospices. In the Netherlands ‘other institution’ usually involves hospices

[c] P-value of Pearson χ^2 for differences in proportion between metropolitan and nonmetropolitan populations <0.001

[d] P-value of Pearson χ^2 for differences in proportion between metropolitan populations <0.001

Controlled for illness, personal factors, social support, income, and available hospital beds, the residents of the nonmetropolitan regions of Belgium, the Netherlands and England were more likely to die at home than in hospital compared with the metropolitan ones (table 4). This metropolitan/nonmetropolitan disparity is larger in Belgium (Odds Ratio [OR]=1.74; 95% Confidence Interval [CI]:1.58-1.91) and in the Netherlands (OR=1.49; CI:1.40-1.59) than in England (OR=1.26; CI:1.22-1.29). Our stepwise adjustment of the odds ratio of home death relative to hospital death for metropolitan relative to nonmetropolitan populations showed that in Belgium the different level of social support available to metropolitan and nonmetropolitan populations significantly decreased part of the metropolitan/nonmetropolitan discrepancy (from OR=2.23; CI:2.05-2.42 to OR=1.74; CI:1.58-1.91). In the Netherlands and England the independent variables did not significantly adjust the metropolitan/nonmetropolitan difference (data not shown in table). In general, people suffering from cancer in England and the Netherlands were more likely to die at home than people suffering from non-cancer life-limiting conditions, while the opposite was true in Belgium. In all countries, men, and persons under 65 years (in England under 80) were more likely to die at home than those above that age. In England, the average income of the municipality of residence seems to relate inversely to the likelihood of home death. In Belgium, a higher portion of one-person households in the municipality of residence related to a decreased likelihood of home death. The number of hospital beds in the health region of residence did not have a significant influence on the chances of dying at home in any of the countries studied.

Table 4 Adjusted ODDS ratios for factors associated with Home death v Hospital death in Belgium, the Netherlands and England 2003

	BELGIUM	NETHERLANDS	ENGLAND
	OR (95% CI)		
RESIDENTIAL CHARACTERISTICS			
Metropolitan region	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)
Nonmetropolitan region	1.74 (1.58 – 1.91)	1.49 (1.40 – 1.59)	1.26 (1.22 – 1.29)
ILLNESS			
Neoplasm	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)
Other life limiting conditions	1.10 (1.02 – 1.18)	0.45 (0.42 – 0.47)	0.61 (0.59 – 0.63)
PERSONAL FACTORS			
Sex			
Male	1.10 (1.03 – 1.17)	1.13 (1.08 – 1.18)	1.08 (1.05 – 1.10)
Female	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)
Age			
45-64 years	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)
65-79 years	0.89 (0.82 – 0.96)	0.82 (0.78 – 0.86)	0.77 (0.75 – 0.80)
80+ years	0.90 (0.82 – 0.98)	0.84 (0.79 – 0.89)	0.54 (0.52 – 0.56)
Income			
Average income per person in the municipality of residence v national average*	NS	NS	0.99 (0.98 – 0.99)
SOCIAL SUPPORT			
One-person households >65 years			
% of one-person households >65 years in the municipality of residence v national average [a]	0.92 (0.90 – 0.93)	NS	NS
HEALTH SERVICES			
Hospital beds			
Hospital beds/1,000 in health care region	NS	NS	NS

[a] Continuous per 10% of change v the national average. The OR thus signifies the change in ODDS ratio per 10% increase of income or % one-person households in the municipality of residence of the deceased relative to the national average

Controlled for illness, personal factors, social support, income and available hospital and care home beds, terminally ill residents of English nonmetropolitan regions were more likely (OR=1.34 CI:1.28-1.41) to die in a care home rather than a hospital than those in English metropolitan regions (table 5). Our stepwise adjustment of this odds ratio showed that in England the higher availability of care home beds in nonmetropolitan regions reduced a part of the difference (from OR=1.61 CI:1.55-1.68 to OR=1.34 CI:1.28-1.41). In Belgium, the initially higher chances of dying in a care home rather than in hospital for the nonmetropolitan residents with life-limiting conditions compared to the metropolitan ones, were completely adjusted by the aggregated differences in illness, income and availability of care home beds. In the Netherlands the metropolitan and nonmetropolitan terminally ill did not initially have significantly different chances of dying in a care home rather than a hospital (data not shown in table). In general, care home death was more likely in all countries for people suffering from conditions other than cancer, for women, and for patients of 80 years and older, in particular for the very old ie 90 and above. In England, a higher average income in the municipality of residence was related to a lower likelihood of dying in a care home rather than in hospital. In Belgium a higher percentage of one-person households of 65 and over was related to a lower likelihood of care home death compared to hospital death. In the Netherlands and England, the chance of dying in a care home compared to dying in hospital was lower for residents of health care regions with more hospital beds. In all countries the chance of dying in a care home compared to dying in hospital increased as the number of care home beds in the healthcare region of residence increased. In Belgium the effect of the number of available care home beds was higher than in the Netherlands and England (table 5).

Table 5 Adjusted ODDS ratios for factors associated with Care Home death v Hospital death in Belgium, the Netherlands and England 2003

	BELGIUM	THE NETHERLANDS	ENGLAND
	OR (95% CI)		
RESIDENTIAL CHARACTERISTICS			
Metropolitan region	NS	NS	1.00 (1.00 – 1.00)
Nonmetropolitan region	NS	NS	1.34 (1.28 – 1.41)
ILLNESS			
Neoplasm	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)
Other life limiting conditions	3.03 (2.80 – 3.27)	1.35 (1.28 – 1.42)	1.27 (1.23 – 1.31)
PERSONAL FACTORS			
Sex			
Male	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)
Female	1.98 (1.83 – 2.14)	1.63 (1.55 – 1.72)	1.60 (1.56 – 1.66)
Age			
65-79 years	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)
80-89 years	3.25 (2.97 – 3.54)	2.89 (2.73 – 3.05)	2.23 (2.15 – 2.31)
90+ years	8.16 (7.32 – 9.10)	7.55 (7.00 – 8.27)	4.44 (4.24 – 4.64)
Income			
Average income per person in the municipality of residence v national average*	NS	NS	0.94 (0.93 – 0.95)
SOCIAL SUPPORT			
One-person households > 65 years			
% of one-person households >65 years in the municipality of residence v national average [a]	0.94 (0.92 – 0.96)	NS	NS
HEALTH SERVICES			
Hospital beds			
Hospital beds/1,000 in health care region	NS	0.95 (0.91 – 0.98)	0.89 (0.85 – 0.93)
Care Home beds			
Care home beds/1,000 in health care region	1.32 (1.24 – 1.41)	1.04 (1.02 – 1.05)	1.07 (1.06 – 1.08)

[a] Continuous per 10% of change

4.4 Discussion

Metropolitan versus nonmetropolitan variations in place of death were found in Belgium, the Netherlands, and England. Metropolitan residents suffering from life-limiting conditions more often died in hospital or (in Belgium and the Netherlands) in a care home and less often at home. Although factors such as the degree of social support and the availability of care home beds seem to account for part of these metropolitan/nonmetropolitan differences, they could not be completely explained by metropolitan/nonmetropolitan differences in underlying cause of death, personal factors such as sex, age and income, and environmental factors such as social support and availability of hospital and care home beds.

For the first time, this study analyses the contrast between metropolitan and nonmetropolitan populations with respect to place of death, an indicator of end-of-life care quality. The population studied comprises a large number of deaths in Belgium, the Netherlands and England resulting in greater statistical power of analysis. In focussing on a selection of patients with life-limiting diseases, we are able to study place of death in a population which could plan and express preferences regarding the final place of care and death and could benefit most from high quality end-of-life care. Hospital death is not only analysed in relation to home death, but also in relation to care home death. Weaknesses of our study follow from the use of administrative death certificate data. A number of variables, for which there is evidence that they affect the place of death and for which possible metropolitan/nonmetropolitan differences exist, can not be integrated in our analyses, eg: ethnic cultural background, patients' and caregivers' preferences with respect to end-of-life care, use of home care, and previous admission to hospital.(28) Although death certificate data offer an opportunity to study place of death within and across European countries,(25) information about the individual decedent's income or level of social support was not available from the death certificates of the Netherlands and England. Therefore we had to use aggregated variables for income and social support. As these aggregated variables differed across the studied countries, we used these variables to measure relative differences in income and level of social support within each country. Finally, it is documented that certification of cause-of-death and demographic characteristics is not always accurate.(29;30)

Our study demonstrated that metropolitan populations are less likely to die at home and more likely to die in hospital than nonmetropolitan populations and thereby confirms our hypothesis based on previous research on separate datasets.(14;18-21) This finding seems to indicate inequality or inequity for metropolitan populations with respect to the chance of dying in familiar surroundings, especially as the metropolitan/nonmetropolitan disparity was consistent in all the countries studied, and even persisted after adjusting for possible social and demographic confounders.

One aim of our study was to examine whether the contrast between metropolitan and nonmetropolitan populations could not simply be explained by differences relating to illness, personal characteristics, social support, and health services. This seemed to be the case only for the higher chances for metropolitan patients in Belgium of dying in a care home than in a hospital, which were adjusted completely by the aggregate of differences in illness, income, and by the larger availability of care home beds in metropolitan areas. The lower likelihood of home death versus hospital death for metropolitan compared with nonmetropolitan populations could only be explained partly by such factors: in Belgium, the lower degree of social support for metropolitan populations was found to clarify only in part the lesser chances of home death of metropolitan populations. As recognised in the literature a lower degree of social support in end-of-life care obstructs home death.(14;16;31) In England fewer care home beds were available to the metropolitan population, and this also in part explains their lower chance of care home relative to hospital death. The number of care home beds is known to affect place of death,(32) and thus also seems to be one of the parameters that can engender or smooth away differences in where metropolitan and nonmetropolitan residents suffering from life-limiting conditions die. In line with previous research a larger availability of hospital beds also increased the odds of dying in a hospital rather than a care home in England and the Netherlands.(14;16;33) On the other hand, the higher concentration of hospital beds in metropolitan regions did not contribute to explaining the different chances of care home death for the metropolitan terminally ill. The latter seems to confirm a suggestion by previous research that it is not so much the availability of hospital care for older people as the availability of alternatives to hospital care which influences whether they die in hospital or not.(7) In contradiction to findings from previous research,(16) the likelihood of home death relative to hospital death was not affected by the availability of hospital beds and the differential availability of hospital beds for metropolitan and nonmetropolitan populations did not affect the higher chances of home death for nonmetropolitan populations.

Most of the metropolitan/nonmetropolitan disparities in place of death, in particular with regard to the chances of dying at home as compared to dying in hospital, thus persisted after adjusting for factors that are known to affect the place of death. This means that, apart from the factors that contributed to explaining a part of the disparities, other factors influence the higher likelihood of metropolitan residents dying in hospital. Though the number of hospital beds did not explain the differences, the ease with which a hospital bed can be accessed should probably also be taken into account. Access to a hospital bed for an individual patient is much less restricted in Belgium then in England and the Netherlands due to a weaker echeloning of healthcare, and it is well known that metropolitan patients in Belgium in particular can easily access specialist hospital care and bypass primary care.(34) Previous research showed that the Brussels metropolitan population, compared with the rest of Belgium, had on average fewer frequent contacts with a family physician and more frequent contacts with a specialist or with an intensive care unit of a hospital.(34) This could to some degree explain the larger metropolitan/nonmetropolitan differences in the chances of hospital death in Belgium, as compared to the Netherlands and England. Family physicians are known to play a key role in the coordination of end-of-life care and in facilitating it in accordance with the wishes of the terminally ill.(35) It can also not be precluded that patients in the metropolitan regions in the other countries have less contacts with a family GP, which would prevent them from being informed about and having access to palliative home care. Another part of the explanation for the larger chances of metropolitan residents with life-limiting conditions of dying in hospital could be that palliative care is more integrated into hospital care in the large cities. Previous research showed that this was to a considerably extent the case in the Brussels metropolitan region.(18) One consequence of the social position of inhabitants and the spatial development of metropolitan regions is housing quality. From detailed examination we know that the dwellings of the Brussels capital region are small and not very comfortable, and that a considerable proportion of the housing facilities is situated in older apartment buildings without a lift.(36) We can assume that these living conditions in parts of metropolitan regions do not support home as place of terminal care as has previously been recognised by policy makers and by older residents themselves.(12;37) It can be asked therefore, whether metropolitan housing is perhaps less suitable for the terminally ill, making dying at home less likely. This suggests that a policy aimed at location of death in metropolitan areas, in particular for the less affluent metropolitan residents, should perhaps go beyond the choice of hospital or home and consider creating homelike environments with circumstances favourable to dying patients and their families. Another aspect that is likely to explain part of the metropolitan/nonmetropolitan differences in place of death is social fragmentation, more often found in metropolitan areas. In our study, social support was measured as the percentage of one-person households of pensionable age in the municipality of residence relative to the national average. This variable only measures to some extent and on an aggregated level the social support within the family, but ignores social support by relatives not living under the same roof, friends, or neighbours. We believe that these extended social networks that existing in many nonmetropolitan regions but not to the same extent in metropolitan regions, could additionally explain why terminally ill people in metropolitan regions are less likely to die at home.(16)

Our results also suggested that the metropolitan/nonmetropolitan contrasts in location of death are stronger in some countries than in others. The contrast in home death relative to hospital death was higher in Belgium and the Netherlands than in England, and this is probably related to the fact that English metropolitan terminally ill were to a greater extent men and younger than the Belgian and Dutch ones. In Belgium, where metropolitan residents had the highest chances of hospital death, there was clearly less social support available to them than in the Netherlands and England. Only in England metropolitan populations had a lower chance of care home death relative to hospital death, and this was partially explained by a lower availability of care home beds. These findings seem to suggest that metropolitan areas and populations are not the same in different countries and thus that the metropolitan approach to end-of-life care should also take into account the specificity of each country.

There seem to be several indications in the results of our study that warrant a specifically metropolitan approach to end-of-life care. Lack of social support in metropolitan populations is one of the reasons for the disparities in home death and is therefore an appropriate starting point for the planning of a metropolitan end-of-life care strategy and policy. This could be addressed by compensating for the lack of social support by an intensive and integrated home care services program that would provide homemaker and social services alongside health services. As primary care has a key function in the referral of terminally ill patients to available home-based palliative care programs and in the coordination of terminal care, the development of primary care in metropolitan regions can be an important goal. The lower chance of care home death relative to hospital death in England was related to the lower availability of care home beds to the older metropolitan population. To prevent unnecessary hospitalisation of older metropolitan residents with life-limiting conditions, government agencies should examine the need for long-term care facilities in metropolitan regions carefully and develop the necessary facilities.

In conclusion, compared with nonmetropolitan residents, metropolitan residents with life-limiting conditions were less likely to die at home and, in England, less likely to die in a care home than in hospital. We found a lesser degree of social support and a lower availability of care home beds as partial explanations of this metropolitan/nonmetropolitan discrepancy. These findings warrant policies paying specific attention to end-of-life care in metropolitan areas.

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5 Determinants of the place of death in the Brussels metropolitan region

Houttekier D, Cohen J, Bilsen J, Deboosere P, Verduyckt P, Deliens L. Determinants of the place of death in the Brussels metropolitan region. J Pain Symptom Manage 2009 Jun;37(6):996-1005.

ABSTRACT

Where people die is considered an indicator of quality of death, but also has implications for healthcare costs and the organisation of end-of-life care. Advancing urbanisation, combined with social fragmentation, poor social conditions, and concentration of inpatient care in large cities make it relevant to study place of death in a metropolitan context. The objective of this article is to examine determinants of place of death (home, care home, hospital) in Brussels metropolitan region (Belgium) for patients suffering from chronic diseases eligible for palliative care. Using death certificate data, we described place of death and associated factors for all deaths after chronic diseases in 2003 in Brussels (N=3672). Of all chronically ill patients 15.1% died at home, 63.0% in hospital, and 21.6% in a care home. Of those residing in care homes, 23.8% died in hospital. Non-cancer patients and residents of districts with higher socioeconomic status had more chance of dying at home or in a care home if they resided in one. Home death was also more likely for patients not living alone. Care home death was more likely with increasing age. Compared to other parts of Belgium and other big cities worldwide, in Brussels few patients eligible for palliative care died at home. Both the overall low proportion of people dying in familiar surroundings as well as the inequality between different districts in Brussels imply that a health policy aiming at facilitating dying in the place of choice might also need to develop specific approaches for metropolitan cities.

5.1 Introduction

Place of death is an important issue in end-of-life care research. Where someone dies is often considered an indicator of quality of the end-of-life.(1-3) Hospital death, although preferred by a minority of patients and sometimes clinically inevitable, is often considered as suboptimal(4;5) compared to home and care home death because the latter are more in accordance with the wishes of patients, their caregivers and their health professionals.(6;7) While most people in Western societies prefer to die at home(8-11), a study in six European countries shows that between 33.9% and 62.8% of all deaths in 2003 occurred in hospitals.(12) Additionally, home death supported by home care services is believed to reduce the overall cost of care by reducing the number of hospital inpatient days.(13) The discrepancy between actual and preferred place of death, and the budgetary consequences (14-16), make the place of death and the organisation of dying a point of particular medical and societal interest.

While studied in many countries,(12) place of death has not been studied specifically in a metropolitan setting in continental Europe before, although this could possibly be very relevant for health policy. After all, there is proof of some variation in place of death between population groups in rural and urban areas, possibly indicating differences in organisation of end-of-life care; there is a growing urban population worldwide; and urban regions have a typical population mix and a concentration of institutionalised care. The Brussels metropolitan region for instance consists of 46.3% people of foreign decent(17) and has, compared to the rest of Belgium 15% more inhabitants of over 80 years, nearly twice as many single people and about twice as many poor(18); but also a larger concentration of inpatient care facilities. These aspects, making the implementation of principles of palliative care in an inner city extra difficult,(19;20) may influence where people die.(21-23)

In Belgium and Brussels, palliative care is integrated into the existing health services and is therefore mainly provided by family physicians in a home care situation (sometimes supported by a regional multidisciplinary palliative home care team) or by specialised palliative care units in hospitals. Unlike in other countries, hospices have not been established in Belgium. Palliative care in long-term care facilities (ie care homes) is provided by the patient's family physician, supported by nurses, the facility's palliative support team and the inpatient palliative care unit of an associated hospital. The family physician thus plays a central role in the provision of palliative care at home or in a home-substitute institution. Only a family physician can authorise supplementary compensation for the cost of palliative home care and authorise a family member to take compassionate leave for palliative care.

The objective of this article is to examine determinants of place of death in the Brussels metropolitan region for patients who died after chronic illness and thus possibly could have benefited from receiving palliative care. The determinants of place of death were analysed for patients residing at home and patients residing in a care home separately. We studied the following research questions. First, where did people with chronic illness die in the Brussels metropolitan region? Second, were there any important differences in patterns of place of death depending on illness, sociodemographic characteristics and social support available to the patient? The latter factors were all identified as determinants of place of death in the literature.(24;25)

5.2 Methods

This study analyzed all deaths from chronic diseases in the Brussels metropolitan region in 2003 (N=3672) . The autonomous Brussels metropolitan region is the capital region of Belgium and consists of 19 municipalities with, in 2003, approximately one million inhabitants. The data were extracted from the death certificates. In Belgium these data are primarily used for public health purposes like the production of vital statistics. The first part of the death certificate, including the cause of death, the sex of the deceased and the time and place of death, is completed by a physician. Information on sociodemographic characteristics of the deceased, including residence, age, education, occupation, nationality, civil status and living situation, is completed by the municipal administration. The authority responsible for the death certificates (in Brussels: the Brussels Health and Social Observatory) processes all information and codes the causes of death conform to the International Classification of Diseases (ICD-10).

To identify deaths from chronic disease eligible for palliative care, the operationalization of the palliative care subset by Rosenwax et. al was used. This subset consists of people who died from one of 10 chronic conditions: neoplasm; heart failure; renal failure; liver failure; chronic obstructive pulmonary disease; motor neurone disease; Parkinson’s disease; Huntington’s disease; Alzheimer’s disease; and HIV/aids.(26;27)

The outcome variable in all analyses is the place of death with four possible outcome categories: home; hospital; care home (nursing home or residential home for older people); and elsewhere (other than previous places, eg public road, workplace).

Seven independent variables available via death certificates can be classified in three main categories: variables related to illness (1 variable), variables related to personal characteristics (4 variables) and variables related to social support (2 variables).(25) The variable related to illness in our analysis is the underlying cause of death as reported on the death certificate. The 10 categories of chronic disease of the palliative care subset were recoded in two categories: died of a cancer condition and died of a non-cancer condition. The variables related to personal characteristics are patient’s sex, age, nationality (coded in 5 categories: Belgians; Northern and Western Europeans; Southern Europeans; Northern Africans and Turks; and other) and the socioeconomic status (SES) of the district of residence (coded in 4 categories:

low; middle/low; middle/high; and high socioeconomic status). The classification of the 19 Brussels municipalities into 4 districts with similar SES was performed using a cluster analysis with 4 variables: average individual income, percentage of the residences without private bathroom or toilet, unemployment rate, and educational attainment. The variables that refer to the social support of the deceased are marital status (unmarried; married; widowed; and divorced/separated) and living arrangement (single; multi-person private household; and institution).

In the bivariate analyses, we analysed the distribution of place of death according to cause of death and to age. Because of the confounding effect of age with place of death in many associations, the crude percentages of the distribution of the place of death with respect to sex, nationality, SES of the district of residence, marital status and living arrangement were standardised for age, using direct standardisation. Associations were considered significant when $p<0.01$ for Pearson's Chi².

In the multivariate analysis, we first analysed the determinants of home death vs. hospital death of patients residing at home (ie care home residents and care home deaths were left out of the analysis). Subsequently, we analysed separately the place of death of the care home residents to determine the factors associated with care home death vs. hospital death. The small number of persons living at home but dying in a care home and those living in a care home but dying at home were not included in the analyses. The independent variables are considered to have a significant association with the outcome variable if $p<0.05$ for the likelihood ratio Chi² in a forward stepwise procedure of logistic regression. SPSS 15.0 was used for all statistical computations.

5.3 Results

Place of death related to illness and age

Of all 10,108 deaths in Brussels in 2003, 18.4% died at home, 55.6% in a hospital, 24.6% in care home and 1.4% elsewhere. In total 3672 deaths (36.2% of all deaths) were from a chronic disease amenable to palliative care. Of this subset 15.1% died at home, 63.0% in a hospital and 21.6% in a care home. (Table 1)

Two-thirds of patients who died from a chronic disease died of cancer. COPD (13.2%) and heart failure (10.7%) were the most prevalent non-cancer causes of death. Of all cancer patients, 72.4% died in hospital, which is more than in any other disease. Of all non-cancer patients, 41.3% died in a care home. The proportion of home deaths was larger in deaths after Liver failure, Parkinson's disease and after heart failure than in other causes of death. Death from a neurodegenerative disease (Alzheimer's disease; Parkinson's disease; and Motor Neurone disease) and from heart failure occurred more in a care home.

Nearly 80% of deaths from chronic diseases were in people of 65 years or older and more than 38% were in those older than 80. Younger people died more often at home or in hospital. About 40% of people over 80 years died in a care home (Table 1).

Table 1 Place of death by cause of death and age for death from chronic disease in the Brussels Metropolitan Region 2003

	No. of deaths (% of deaths from chronic disease)	% occurring at home	% occurring in hospital	% occurring in care home	% occurring elsewhere[†]
Deaths after chronic disease	**3,672**	**15.1**	**63.0**	**21.6**	**0.2**
CAUSE OF DEATH*					
Died of cancer condition	**2,431 (66.2%)**	**15.7**	**72.4**	**11.6**	**0.3**
Died of non-cancer condition	**1,241 (33.8%)**	**13.9**	**44.6**	**41.3**	**0.2**
Heart failure	393 (10.7%)	17.8	35.1	47.1	0.0
Renal failure	94 (2.6%)	5.3	63.8	29.8	1.1
Liver failure	10 (0.3%)	40.0	60.0	0.0	0.0
COPD	484 (13.2%)	13.0	57.9	28.9	0.2
Motor Neurone disease	20 (0.5%)	15.0	45.0	40.0	0.0
Parkinson's disease	66 (1.8%)	19.7	28.8	51.5	0.0
Huntington's disease	4 (0.1%)	0.0	50.0	50.0	0.0
Alzheimer's disease	155 (4.2%)	9.0	16.8	74.2	0.0
HIV/Aids	15 (0.4%)	6.7	93.3	0.0	0.0

AGE*					
< 65 years	761 (20.7%)	17.9	78.8	3.2	0.1
65 – 80 years	1,511 (41.1%)	16.7	69.6	13.3	0.3
> 80 years	1,400 (38.1%)	11.8	47.4	40.6	0.2

Presented percentages are row percentages except percentages in brackets (column percentages)
* p-values < 0.001 for chi-squared test for association between age and place of death and between cause of death and place of death (among and within cause of death groups)
†: "elsewhere" includes all other places of death (eg public road, workplace)

Place of death related to personal characteristics (Table 2)

Standardized for age, there are significant differences in place of death by sex, nationality, and SES of the district of residence. Men died more often at home or in hospital; women more often in a care home. Of all nationalities, North Africans and Turks more often died at home. Belgians and Northern and Western Europeans died more often in a care home, and Southern Europeans and the people from other nationalities died more often in hospital. People living in communities with a high or (in particular) middle-high SES died less often in hospital. People living in communities with low SES more often died in hospital.

Table 2 Place of death by sociodemographic characteristics for death from chronic disease in the Brussels Metropolitan Region 2003. standardised for age

	No. of deaths (% of deaths from chronic disease)	% occurring at home	% occurring in hospital	% occurring in care home	% occurring elsewhere[‡]
SEX*					
Male	1,738 (47.3%)	16.6%	66.3%	16.9%	0.1%
Female	1,934 (52.7%)	14.1%	61.2%	24.4%	0.3%
NATIONALITY*					
Belgians	3,308 (90.1%)	15.2%	62.8%	21.8%	0.2%
Northern & Western Europeans	111 (3.0%)	15.7%	58.7%	24.7%	0.9%
Southern Europeans	126 (3.4%)	14.1%	66.8%	16.9%	2.2%
Northern Africans and Turks	72 (2.0%)	22.5%	59.1%	13.6%	4.8%
Other nationalities	54 (1.5%)	17.6%	71.0%	10.2%	1.2%
SES OF THE DISTRICT OF RESIDENCE[†]					
Low SES	728 (19.8%)	11.4%	66.5%	22.0%	0.1%
Middle-low SES	1,708 (46.5%)	14.5%	64.9%	20.3%	0.3%
Middle-high SES	355 (9.7%)	20.0%	56.7%	23.0%	0.3%
High SES	881 (24.0%)	16.8%	60.1%	22.8%	0.2%

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

*p-value < 0.001 for chi-squared test for association between sex and place of death and nationality and place of death
† p-value < 0.01 for chi-squared test for association between SES of the district of residence and place of death
‡: "elsewhere" includes all other places of death (eg public road, workplace)

Place of death related to social support (Table 3)

Married people more often died at home and less often in a care home than people who were not or no longer married. People living in a multi-person private household more often died at home than those living alone. The crude percentages (ie not standardized for age) show that 23.8% of people who resided in a care home died in a hospital (not shown in Table).

Table 3 Place of death by social support for death from chronic disease in the Brussels Metropolitan Region 2003, standardised for age

	No. of deaths (% of deaths from chronic disease)	% occurring at home	% occurring in hospital	% occurring in care home	% occurring elsewhere†
MARITAL STATUS*					
Unmarried	409 (11.1%)	9.7%	63.6%	25.6%	1.1%
Married	1,499 (40.9%)	20.4%	66.5%	12.9%	0.1%
Widowed	1,341 (36.5%)	14.4%	59.2%	26.1%	0.2%
Divorced/separated	420 (11.4%)	13.0%	63.2%	23.4%	0.4%
LIVING ARRANGEMENT*					
Single	1,169 (32.2%)	14.8%	73.6%	11.5%	0.1%
Multi-person private household	1,741 (48.0%)	21.0%	69.4%	9.4%	0.2%
Institution	715 (19.7%)	2.9%	28.0%	68.7%	0.4%

Presented percentages are row percentages except percentages in brackets (column percentages)
* p-value < 0.001 for chi-squared test for association between marital status and place of death and living arrangement and place of death
†: "elsewhere" includes all other places of death (eg public road, workplace)

Multivariate analysis

We analyzed the determinants of place of death for patients residing at home and patients residing in a care home separately. Both sub samples (n=2,553 and n=679) differ significantly for age, sex, nationality, SES of the district of residence and marital status (p<0.001) (data not shown in table).

Factors associated with home death (Table 4)

With the care home residents left out of the multivariate binary logistic regression analysis, home death (vs. hospital death) was associated with illness, personal characteristics and social support. People living in a district with middle-high SES had more than twice the chance of dying at home compared with people living in communities with low or middle-low SES (odds ratio, OR=2.21). Non-cancer patients had better chances of dying at home than cancer patients (OR= 1.61). People living in a multi-person private household were more likely to die at home than were those living alone (OR=1.53).

Table 4 Adjusted Odds ratios for home(1) vs. hospital death and care home (1) vs. hospital death for death from chronic disease in the Brussels Metropolitan Region 2003*†

	Home Residents		Care Home Residents	
	Home vs. Hospital death (N= 2553)		Care home vs. Hospital death (N=679)	
	AOR	95% CI for AOR	AOR	95% CI for AOR
CAUSE OF DEATH				
Died of Cancer condition	1.00		1.00	
Died of non-cancer condition	1.61	(1.30; 2.00)	1.75	(1.21; 2.53)
AGE (continuous)	NS‡		1.04	(1.01; 1.06)
SES OF THE DISTRICT OF RESIDENCE				
Low SES	1.00		1.00	
Middle-low SES	1.30	(0.99; 1.72)	0.99	(0.62; 1.59)
Middle-high SES	2.21	(1.51; 3.23)	1.22	(0.65; 2.27)
High SES	1.60	(1.18; 2.17)	1.94	(1.11; 3.37)
LIVING ARRANGEMENT				
Single	1.00		§	§
Multi-person private household	1.53	(1.24; 1.88)	§	§

Presented figures are adjusted odds ratios (AOR) and 95% confidence intervals (CI)

*: The variables sex and nationality were entered in the regression but found not significant and consequently eliminated by the stepwise procedure

†: A problem of multi-collinearity between living arrangement and marital status made us omit the latter in the home vs. hospital model. Marital status was not significant in the care home vs. hospital model.

‡: NS: Not significant

§: Was not entered in the regression comparing care home and hospital death, because living environment was constant (ie living arrangement of all patients included in the regression analysis was institutional)

Factors associated with care home death (Table 4)

Place of death of care home residents was also associated with illness and personal factors. Again, the SES of the community of residence was most predictive for care home death. People residing in a care home in communities with a high SES were almost twice as likely to die in the care home compared to care home residents in communities with lower SES (OR=1.94). Chronically ill non-cancer patients were more likely to die in the care home (instead of in a hospital) than cancer patients (OR=1.75). Finally, the likelihood of dying in the care home increased with age.

5.4 Discussion

In the Brussels metropolitan region, 15% of people with a chronic disease died at home, 63% in a hospital and 22% in a care home. Of the care home residents, 24% died in an acute hospital. For patients residing at home, the place of death depended on the SES of the district of residence, illness and living arrangement. For care home residents, place of death depended on the SES of the district of residence, illness, and age.

For the first time, this study analysed the determinants of place of death in a continental metropolitan region. Only the chronically ill population were selected because they could potentially benefit from receiving palliative care, and hence are more amenable to planning and organisation of end-of-life care. Hospital death was analysed not only in relation to home death for the sub sample of people residing at home but also in relation to care home death for the socio-demographically distinct sub sample of people residing in a care home (for which the care home can hence be seen as home replacing). And finally this study described patterns for a whole population (and not just a sample), resulting in more statistical power. However, this study also has some limitations, inherent in the use of death certificate data.(28-34) Death certificates provide no information about a number of factors which, evidence shows, affect place of death and which were therefore not involved in our analysis: eg length of disease, functional status, patient and caregiver preferences, ethnic background, availability and quality of home care and previous admissions to hospital.(25) Another limitation related to the use of death certificate data is the sometimes unreliable classification of causes of death on the death certificate. A second limitation regards the use of nationality as a proxy variable for ethnic background, knowing that in recent years many immigrants obtained Belgian nationality and were considered Belgian in our analysis. And finally, partly due to the many missing values for education on an individual level, ecological variables were used for socioeconomic status.

The proportion of patients eligible for palliative care, who died at home in Brussels is very low. Of cancer patients just 15.7% died at home (and 72.4% in hospital) in Brussels whereas a previous study showed that in Flanders, the northern region of Belgium, 29.1% of cancer patients died at home (and 61.9% in a hospital) (30). We assume these findings to be related both to the demographic and social reality of Brussels, which has a poorer, more socially fragmented and older population than Flanders, as well as to the way palliative care in Brussels is organised with a central role for the family physician. The lower use of primary care in Brussels (compared for instance with Flanders) probably helps to explain the lower proportion of home deaths. In Brussels, 83% of families have a family physician compared to 97% in Flanders and the average number of contacts with the family physician is 3.7 per year in Brussels as against 4.6 in Flanders.(35) Not surprisingly in 2003 the proportion of Brussels patients receiving compensation for the cost of palliative home care was four times lower and the proportion applying for compassionate leave to provide care to a relative five times lower than in Flanders.(36) On the other hand, the number of beds in specialised palliative care units attached to hospitals in 2003 was 5.4 per 1,000 deaths in Brussels against 3.2 in Flanders.(37) Probably, the less prominent role of primary care and the more prominent role of inpatient palliative care can partially explain the higher number of hospital deaths and the low number of home deaths.

Another striking finding was that, while a large majority of Brussels chronically ill care home residents die in the care home where they are living, one out of four is still transferred to a hospital at the end of life. This seems to be comparable to British Columbia, Canada(38), slightly more than in the rest of Belgium(39), but considerably more than in the Netherlands.(40) This could point to a lack of palliative orientation in some of the Brussels long time care facilities or at least a lack of capacity in these facilities to provide adequate end-of-life care, which would prevent transfer to hospital.

We found that residents of high SES districts were more likely than people living in low SES districts to die at home. This was also found in other research.(25;41;42) This is all the more striking since these differences cannot be ascribed to differences in available end-of-life care services. Brussels can be considered as one healthcare region (ie services throughout Brussels are used by people all across Brussels). Rather than differences in availability of services, other factors such as lack of money and information or simply distrust are likely to explain the differences in place of death for people of lower SES-districts.(28;43;44) Residents of districts with middle-high SES (ie the universities districts), who are more highly-educated but have lower incomes compared to the highest SES district, were most likely to die at home, although the difference between residents of middle-high and high SES districts was not statistically significant in the multivariate model. Cognitive aspects (eg knowledge of services, communication with professional caregivers) may be more important in determining place of death than material aspects (eg money), as suggested by previous research.(45)

Not only the chance to die at home, but also the chance to die in the care home of residence is socially unequally distributed throughout Brussels. We suspect that care homes in the high SES districts may attach more importance to quality in general and quality of end-of-life care in particular and are possibly better equipped to manage long-term end-of-life care. This could be a matter of resources (ie care home residents in more prosperous districts bring in more money) but also of end-of-life care policies and it is possibly also related to the size or management of the care homes: by a local authority, by a private not for profit organisation or by a private company.(38) Further research is required to determine the nature of the influence of SES on place of death, both for home death and care home death and to determine whether or not palliative care is implemented, as anticipated in Belgian Law, in the same way in all types of care homes across the whole metropolitan area.

Both home death and care home death were related to illness. In line with Australian research, where death after chronic disease was analysed separately, death from a non-cancer condition was more likely to take place at the place of usual residence, home or care home, compared to cancer death.(38) As cancer patients are, due to the predictable course of the disease, perhaps more eligible for care in the place of usual residence,(30;41) this is a remarkable finding. It could be an indication of a lack of availability of appropriate specialised palliative care for cancer patients in care homes and at home, or possibly, cancer end-of-life care services have been developed very intramural in Brussels

This study reconfirms the importance of social support.(25;41;42) People living in a private household and supported by family members are more likely to die at home than those living alone.

Finally, we found that with advancing age, the odds of dying in the care home of residence increase. This might suggest that a decision to transfer the patient to hospital (possibly for life prolonging treatments) is taken less often for very old patients, but it could also suggest that different end-of-life care criteria are applied in the very old.

The question remains of whether our findings for Brussels metropolitan region are typical for large metropolitan areas in general. Compared to much larger cities in the world like Houston, New York, London and Mexico City, however, in Brussels far fewer people with cancer died at home and many more died in hospital,(29;31;44) whereas the proportion of hospital deaths in the rest of Belgium was not higher than in USA.(46) Not only the metropolitan character but probably the sociodemographic reality (eg people who died of cancer in Brussels were older than in New York and London and much less often married than in Houston (29;31;44)) as well as the organisation of palliative and end-of-life care in metropolitan cities may play a large role. An important question that needs to be explored is how the palliative care needs of people specifically in metropolitan cities like Brussels can best be met, whether by expanding the possibilities of palliative home care support, by establishing hospices, or by safeguarding good quality of end of life in palliative care units in hospital.

Just 15.1% of all deaths after chronic disease occurred at home in Brussels in 2003. More than 20% died in a care home, but nearly 24% of care home residents were transferred to an acute hospital bed at the end. These findings contrast sharply with the rest of Belgium, and even with much larger metropolitan regions in the world, and raise certain questions with regard to intra- and extra-mural organisation of end-of-life care. Home death was related to illness, social support, and socioeconomic status of the district of residence. Care home death was determined by illness, age and, surprisingly, the SES of the district of residence. At least in some parts of Brussels, the unequal distribution of dying in familiar surroundings is open to discussion.

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6 The use of palliative care services associated with better dying circumstances. Results from an epidemiological population-based study in the Brussels metropolitan region

Cohen J, Houttekier D, Chambaere K, Bilsen J, Deliens L. The use of palliative care services associated with better dying circumstances. Results from an epidemiological population-based study in the Brussels metropolitan region. (Journal of Pain and Symptom Management, *in press*)

ABSTRACT

Context

There is some consensus that a ‘good death’ is one which occurs at home, in the presence of loved ones and is free of distress. Involvement of palliative care services is assumed to improve these circumstances.

Objectives

This population-based study describes characteristics of the end of life of patients dying in Brussels and examines their associations with the involvement of palliative care services.

Methods

In 2007, an anonymous large-scale mortality follow-back survey was conducted in Brussels by mailing questionnaires regarding end-of-life care and characteristics to the attending physicians of a representative sample of 1,961 deaths.

Results

Response was 41% (N=701). Of all deaths, 59% were non-sudden. Of these, 12% took place at home. For 27% the attending physician was informed about the patient’s preferred place of death. In case a preference to die at home was known, 66% also died at home. At the moment of death, in 47% of non-sudden deaths loved ones were present. In a quarter palliative care services were involved which was more likely for cancer patients than non-cancer patients and was associated with the attending physicians more often being informed about the preferred place of death, with patients more often dying at home, with loved ones more often being present and with a better feeling of well-being in the last day.

Conclusion

Overall, circumstances at the very end of life are sub-optimal in Brussels. This study provides a case for stronger involvement of palliative care as a focal point for policies to improve end-of-life circumstances in a metropolitan area such as Brussels.

6.1 Introduction

As an upshot of certain demographic, epidemiological, cultural and attitudinal changes, societies are increasingly demanding that attention is given to optimizing circumstances at the end of life and hence to the quality of dying.(1) A 'high' quality of dying is defined in a relevant part of the literature as death free from avoidable distress and suffering, in accordance with the patient's and family's wishes and values, and reasonably consistent with clinical, cultural, and ethical standards.(2;3) There is also some consensus about a 'good death' being one occurring at home, surrounded by loved ones.(4-6)

However, apart from where people die,(7-9) hitherto relatively little is known about the circumstances of dying and death on a population level, with most studies limited to patients with certain terminal diagnoses or those making use of a certain form of care. A handful of population-based retrospective mortality follow-back surveys from Europe (10-15) and the USA,(16-18) evaluating the end-of-life needs and care provided through interviews with proxies, have provided important information in this respect. These studies unequivocally suggest a rather unattractive picture of the care of dying people, with many experiencing severe pain, a high number of transitions among health care settings in the last weeks before death, a high average number of days spent in the ICU, with many having unmet care needs and relatively few accessing palliative care services. Limited availability of coordinated end-of-life care services, fragmented coverage of end-of-life care by insurers, under-referral to palliative care and lack of training are believed to be the most important barriers to optimal end-of-life care.(19;20)

In this study of the metropolitan region of Brussels (Belgium's capital with about 1.1 million inhabitants) the circumstances of death and dying will, for the first time, be described on a population level. The specific focus on the circumstances of death and dying in the Brussels Capital Region is inspired by the presumption of specific metropolitan issues in the circumstances and quality of death and dying. A previous study suggested that characteristics of the metropolitan population (eg the greater numbers of people living alone, of people of foreign origin, less favorable housing conditions), municipal level determinants (eg lack of care support initiatives due to social fragmentation), and major global and national trends (eg end-of-life care being more hospitalized and cure-oriented in metropolitan areas) can imply certain disadvantages in terms of the quality of end-of-life care.(21)

Another relevant question this study addresses is whether and how palliative care can impact on these unfavorable circumstances and hence improve the quality of dying. Palliative care aims to alleviate distress through symptom control and attention to psychosocial and spiritual concerns, to coordinate care and to improve communication between all professional caregivers, patients, and families. Hence, involvement of palliative care at the end of life is usually assumed to improve the circumstances of dying. Previous research has found positive effects of palliative care team involvement on several patient outcomes (physical, psychological, and spiritual)(22;23) as well as on the satisfaction of loved ones with several areas of care (including adequacy of pain control, information provided for carers, personal care, dignity).(11) A randomized control trial in patients with metastatic non-small-cell lung cancer indicated that early palliative care led to significant improvements in both quality of life and mood, less aggressive end-of-life care and even to longer survival.(24)
Palliative care services in Belgium and Brussels Capital Region have been gradually integrated into the public health care system since 1997 and are reimbursed partially or completely by the compulsory national health insurance system depending on the care setting and the prognosis. The services aim at offering consultation and support to usual caregivers and their patients and consist primarily of multidisciplinary palliative home care teams for patients cared for at home (and, in theory but rarely in practice, in care homes), multidisciplinary palliative support teams for patients in hospitals, and palliative care reference persons for people in care homes. Inpatient palliative care units, often affiliated to a hospital, have also been established. In this article involvement of palliative care refers to the involvement of one or more of these services.

This retrospective mortality follow-back study is aimed at establishing findings on a population level. Hence, all people whose death was expected and not sudden, across care settings and patient groups, are examined in order to avoid excluding those not accessing certain types of end-of-life care (and hence those possibly experiencing the worst quality of death and dying) As such the denominator is all those deaths who were theoretically able to receive care with an end-of-life intent. In spite of its limitations, a retrospective mortality follow-back design is the only method that assures that the end-of-life and dying experiences of patients who cannot easily be defined as dying are not overlooked.(25;26) Our study will answer the following research questions: 1) what are the circumstances of death and dying of patients dying expectedly and non-suddenly in the Brussels metropolitan region, and 2) what is the association between the involvement of palliative care services and these circumstances?

6.2 Methods

Study design

This retrospective study reports findings from post-mortem questionnaires sent out to attending physicians as identified on the death certificate of a random representative sample of deaths between June and September 2007 in the Brussels Capital Region, the bilingual autonomous capital region of Belgium with approximately 10,000 deaths per year and a population of about 1.1 million. The sample size was 1,961 deaths, ie 60% of all deaths in the sampling period and about 18% of all deaths in 2007.

Every physician certifying a death certificate in the sample was sent a six-page questionnaire about the end-of-life care and end-of-life decision-making in the corresponding death. An accompanying letter presented information about the decedent, so as to allow the physician to be able to recall the patient and look up the medical file. In case the physician certifying the death certificate was not the attending physician, he or she was asked to forward the questionnaire to the actual attending physician. Questionnaires were sent out as soon as the corresponding death certificates were included in the sample (ie as soon as they reached the central administration), which means that time lag between death and the sending out of the corresponding questionnaire was limited to an average of one to two months. Up to three reminders were sent in cases of non-response. After the data collection a one-page questionnaire was mailed to all non-responding physicians, asking for their reasons for not participating.

Anonymity and ethics

A lawyer acted as intermediary between responding physicians, researchers and the administration authority for death certificates in the mailing procedure to guarantee that completed questionnaires could never be linked to a particular decedent or physician. This lawyer also anonymously linked the coded decedent information from the death certificates received from the administration authorities to the corresponding completed questionnaires received from the physicians, and further anonymized the databases. Positive recommendations for the anonymity procedure and study protocols were received from the Ethical Review Boards of the University Hospitals of the Vrije Universiteit Brussel and Ghent University, from the Belgian National Disciplinary Board of Physicians and the Belgian Federal Privacy Commission.

Questionnaire

The questionnaire first asked whether death had been sudden and unexpected and whether the attending physician's first contact with the patient had been after death. If neither of these questions were answered affirmatively the physician was asked a number of questions about the care and treatment received by the patient at the end of life and the circumstances of their death: to what extent certain symptoms were present in the last 24 hours (using the ESAS scale),whether the physician was aware of the patient's preferred place of death, whether this preference was met and, if not, why not, who was present at the moment of death, and which care providers were involved in the end-of-life care. A separate question asked whether – as far as the respondent knew- a specialist palliative care provider was involved in the care in the month preceding the death of the patient. This question was used to compare those deaths with and without palliative care involvement. From the linked death certificate information, data on the patient's sex, exact age, place of death (home, care home, hospital or other), living situation and underlying cause of death were available. The underlying cause of death variable was coded according to the International Classification of Diseases, 10th revision.

More information about the study design, sampling and mailing procedure and the questionnaire used for this study can be found elsewhere.(21;27)

Statistical analysis

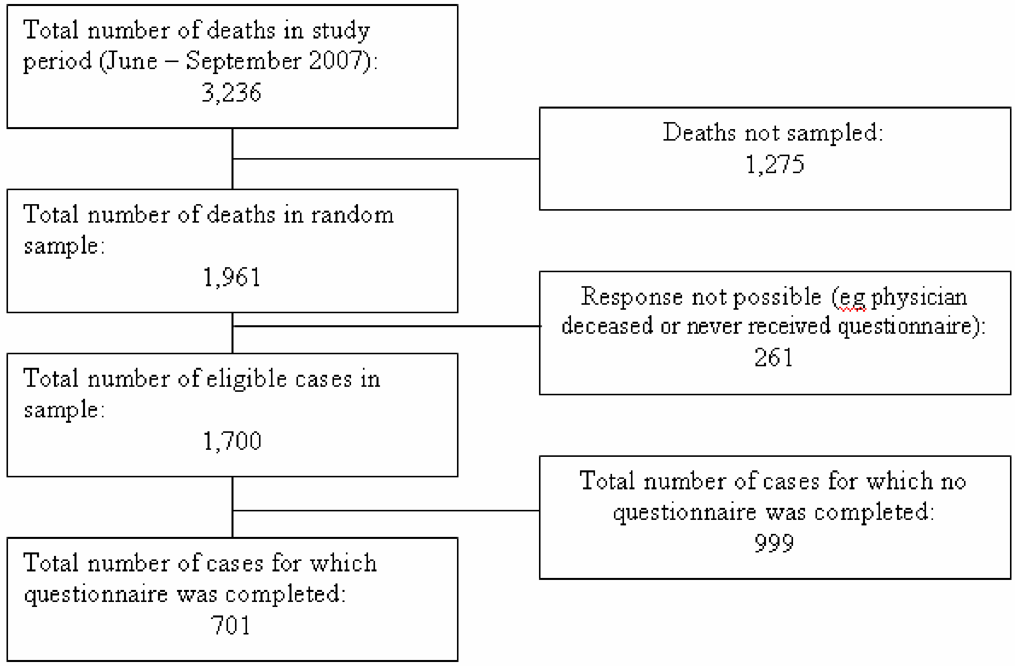
The obtained sample was representative for all deaths in 2007 concerning age, sex and cause of death and was adjusted to be representative for all deaths in 2007 concerning place of death. Differences between categories were tested with Pearson chi² and Monte Carlo exact tests, with statistical significance set at $p<0.05$. To control associations for possible confounders, multivariate binary logistic regression analyses were performed. A structural equations model was used to develop a model of how palliative care influences circumstances at the end of life. For the latter model, all significant associations with palliative care involvement found in the bivariate analyses and the multivariate logistic regressions were used and several possible models were tested until the best model fit was reached. All statistical analyses were done using SPSS version 17.0 and AMOS 19.0 for the structural equations model.

6.3 Results

Response

Of the 1,961 sampled deaths in Brussels, completed questionnaires were returned for 701. From the non-response analysis we found response was impossible for 261 because the physician was deceased, because the certifying physician was not the attending physician and did not know the attending physician and had no access to the medical file or because the physician never received the questionnaire. As such the response rate was 41.3% (701/1,700 eligible cases; see figure 1). For 59% the responding (and hence attending) physician was a specialist, for 36% a GP, and for 5% another type of physician (eg coroner). Of all 701 deaths, 415 (ie 59%) concerned patients who did not die suddenly or unexpectedly; five of those concerned minor patients and were excluded from the analysis for this article (Table 1).

Figure 1: response flow chart



Involvement of palliative care

Palliative care specialists were involved in the end-of-life care in 23.1% of all non-sudden deaths (Table 1). The involvement of palliative care specialists was notably greater in those younger than 65 (42.6%) and those with cancer (50.3%), and was relatively low in older people, non-cancer patients and people residing in care homes. Palliative care specialists were involved in 41.7% of cases of those who died non-suddenly at home, in 27.0% of those dying in hospital and in 4.0% of those dying in a care home.

Table 1 Palliative care involvement by patient characteristics of all persons dying non-suddenly in Brussels, 2007 (N=410)

	number (%)	Percentage palliative care involved	p-value†
All non sudden deaths	410 (100%)	23.1	
Sex			0.561
Man	196 (47.8)	21.9	
Woman	214 (52.2)	24.4	
Age			
18-64	69 (16.8)	42.6	<0.001‡
65-79	113 (27.6)	23.0	
80 and older	228 (55.6)	17.5	
Living situation			<0.001
Living alone	141 (35.0)	27.0	
Living in household with others	168 (41.6)	28.7	
Living in institution	93 (23.1)	7.4	
Cause of death			<0.001
Cardiovascular	81 (19.7)	9.9	
Cancer	146 (35.7)	50.3	
Respiratory	42 (10.1)	9.8	
Neurological	22 (5.4)	0.0	
Stroke	32 (7.7)	0.0	
Other	88 (21.4)	10.2	
Place of death			<0.001
Home	48 (11.7)	41.7	
Hospital	263 (64.2)	27.0	
Care home	99 (24.1)	4.0	

* Numbers may not add up to the total of 410 because of missing values for certain patient characteristics

†: Fisher exact test (Monte Carlo procedure) testing differences between categories

‡: no longer significant when tested for other confounders in a multivariate logistic regression (see text)

A multivariate logistic regression controlling simultaneously for the effects of age, sex , cause of death, and place of death showed that involvement of palliative care was much more likely in cancer patients than in non-cancer patients (OR: 10.09, 95%CI: 5.70-17.89) and was less likely in those dying in a care home (OR: 0.19, 95%CI: 0.07-0.55). Keeping the effects of the other covariates fixed, no significant differences between those dying in hospital and those dying at home were found (not in table).

Symptoms

In the last 24 hours before death, the symptoms most often present to a clinically relevant extent (ie score of 4-10 on Edmonton Symptoms Assessment Scale [ESAS]) were drowsiness (79.8%), lack of appetite (75.3%), being unconscious (74.3%) and tiredness (73.3%) (Table 2). Those are also the symptoms that were most often severe (ie score of 8-10 on ESAS) in the last 24 hours. Pain was clinically relevant in 29.5% and severe in 7.9%.

Palliative care service involvement was associated with a better feeling of well-being, fewer problems of shortness of breath and more problems of severe tiredness.

Multivariate logistic regression models examined the association between palliative care involvement and the presence of symptoms, adjusted for the effects of age, sex, cause of death, place of death, and the level of unconsciousness. These showed that palliative care involvement was associated with a lower chance of shortness of breath (OR: 0.52, 95%CI: 0.30-0.91), low (OR: 0.43, 95%CI: 0.26-0.71) or very low (OR: 0.49, 95%CI: 0.25-0.94) feeling of well-being in the last 24 hours, but with a higher chance of severe tiredness (OR: 2.41, 95%CI: 1.45-4.00) in the last 24 hours (not in table). The other bivariately observed differences were no longer significant in the multivariate model.

Table 2 symptoms present in last 24 hours before death by sex, age, living situation, cause of death, place of death and involvement of specialist palliative care provider in Brussels, 2007 (N=410)

	Pain	Tiredness	Nausea	Depression	Anxiety	Drowsiness	Lack of appetite	Low well-being	Shortness of breath	Unconsciousness	Distress
	% present (% severe)*										
All non sudden deaths	29.5 (7.9)	73.3 (41.6)	17.2 (4.6)	35.6 (6.5)	38.8 (7.2)	79.8 (48.6)	75.3 (55.4)	63.0 (24.5)	48.1 (21.9)	74.3 (50.7)	55.9 (27.1)
Sex											
Male	31.2 (8.4)	71.8 (38.4)	21.6 (7.5)	38.4 (8.8)	44.5 (9.4)	78.9 (46.9)	75.0 (54.9)	65.5 (26.0)	46.0 (23.7)	75.3 (52.4)	52.7 (22.8)
female	28.5 (7.4)	74.1 (44.3)	13.4 (2.1)	31.8 (4.4)	34.4 (5.4)	81.0 (49.9)	75.3 (55.6)	61.6 (23.3)	50.8 (20.4)	73.3 (49.0)	58.8 (30.9)
age											
18-64	40.6 (11.9)	77.7 (44.5)	28.5 (6.2)	48.0 (7.3)	57.0 (15.4)	86.0 (58.9)	70.8 (61.2)	63.3 (32.7)	59.9 (29.3)	76.0 (57.1)	54.3 (27.2)
65-79	32.2 (11.0)	66.5 (33.1)	15.8 (3.1)	33.8 (7.5)	45.6 (4.5)	82.1 (53.4)	75.5 (50.7)	55.2 (17.4)	45.1 (23.0)	79.2 (56.2)	54.8 (27.0)
80 and older	25.2 (5.1)	74.7 (44.6)	14.5 (4.9)	31.6 (5.7)	30.3 (6.1)	77.1 (42.9)	76.3 (55.7)	67.3 (25.5)	46.8 (19.1)	71.3 (45.9)	57.1 (27.3)
Living situation											
Living alone	26.4 (7.7)	69.9 (36.9)	15.3 (1.8)	25.1 (6.0)	32.6 (5.0)	78.4 (51.6)	78.6 (57.1)	54.8 (16.7)	49.6 (19.4)	75.9 (56.5)	54.4 (22.7)
Living in household with others	34.8 (7.5)	77.9 (49.4)	23.5 (6.4)	40.0 (9.1)	45.7 (8.9)	82.3 (50.5)	73.7 (55.6)	65.2 (27.4)	51.8 (27.0)	76.4 (51.1)	52.2 (24.9)
Living in institution	23.1 (4.5)	68.6 (34.5)	8.0 (3.7)	40.0 (3.1)	35.3 (5.7)	79.9 (41.9)	74.0 (53.6)	71.0 (28.6)	39.7 (14.6)	68.9 (40.4)	64.6 (35.4)
Cause of death											
Cardiovascular	24.4 (4.2)	76.6 (37.5)	7.7 (1.7)	24.4 (7.2)	36.1 (1.3)	68.0 (41.1)	59.8 (40.3)	58.7 (16.1)	48.4 (21.5)	67.2 (45.9)	54.3 (21.5)
Cancer	30.8 (8.7)	81.9 (53.4)	19.9 (5.1)	37.2 (6.1)	41.2 (9.5)	83.1 (46.6)	80.7 (60.6)	57.8 (22.3)	47.8 (18.8)	72.1 (46.6)	45.4 (17.5)
Respiratory	21.6 (8.6)	70.6 (42.8)	12.5 (3.1)	30.8 (5.8)	34.6 (6.3)	75.8 (44.3)	78.2 (62.2)	74.8 (31.1)	72.5 (45.0)	72.7 (53.2)	65.9 (35.9)
Neurological	41.9 (0.0)	65.6 (31.4)	9.9 (0.0)	40.2 (4.5)	41.8 (0.0)	84.4 (54.6)	75.6 (58.4)	62.9 (30.0)	46.2 (22.4)	83.8 (51.3)	74.4 (51.4)
Stroke	17.9 (6.9)	33.3 (13.1)	12.4 (4.5)	23.8 (11.9)	19.5 (8.7)	80.7 (62.5)	70.3 (46.5)	57.5 (27.5)	46.6 (13.0)	82.2 (69.3)	51.9 (22.4)
Other	37.3 (11.7)	70.3 (35.8)	26.2 (8.1)	45.3 (5.3)	46.9 (10.1)	85.7 (54.6)	79.1 (58.2)	74.9 (30.3)	39.8 (19.7)	79.8 (54.5)	67.2 (39.8)

Place of death											
Died at home	27.2 (9.1)	84.2 (47.8)	23.8 (5.5)	35.1 (11.1)	38.1 (7.3)	70.3 (27.9)	68.5 (52.1)	65.3 (17.3)	44.2 (16.3)	63.0 (30.4)	41.8 (14.5)
Died in hospital	33.5 (9.6)	72.0 (43.0)	19.8 (5.9)	36.0 (6.2)	42.5 (8.9)	81.3 (55.1)	76.7 (57.6)	60.7 (26.9)	52.6 (25.1)	78.5 (57.4)	53.1 (24.5)
Died in care home	21.0 (2.7)	70.1 (35.0)	7.6 (0.9)	32.8 (4.8)	31.5 (2.9)	81.8 (42.9)	75.1 (51.8)	69.1 (22.2)	40.0 (16.4)	68.9 (43.1)	69.7 (39.8)
Palliative care involvement											
PC not involved	31.3 (7.5)	70.7 (36.9)	17.2 (4.2)	37.4 (8.0)	38.3 (7.6)	78.2 (47.3)	74.7 (52.9)	67.9 (26.9)	51.0 (23.6)	73.9 (51.3)	58.5 (29.4)
PC involved	23.4 (9.5)	80.8 (58.2)	17.0 (6.4)	29.8 (2.0)	40.2 (5.3)	84.7 (51.3)	77.2 (62.8)	47.7 (15.3)	39.2 (15.3)	75.7 (47.6)	48.3 (19.1)

*: present: score 4 or higher; severely present: score 8 or higher

Underlined: significant difference (tested with chi², with p<.05) between the categories in the rows for presence of symptoms (and severe presence between brackets).

Preferred place of death

In 26.6% of cases the attending physician was informed about the preferred place of death; in 52% this was home (Table 3). In cases where a preference for dying at home was known, 66.1% actually died at home. All patients who preferred to die in hospital (20.6%) or in a care home (26.2%) died there. In cases where the attending physician did not know the preferred place of death, 3.7% of people died at home and 75.3% in hospital.

Table 3 Awareness of the preferred place of death and actual place of death of all persons dying non-suddenly in Brussels, 2007 (N=410)

	Number (%)	Died at home*	Died in hospital*	Died in care home*
Preference not known by attending physician	296 (73.4)	3.7	75.3	20.9
Preference known by attending physician:	107 (26.6)	33.6	35.5	30.8
Home (or home of relatives)	56 (52.3) †	**66.1**	21.4	12.5
Hospital	22 (20.6) †	0.0	**100.0**	0.0
Care home	28 (26.2) †	0.0	0.0	**100.0**
Other	2 (1.9)†	0.0	50.0	50.0

*: row percentages

†: these are column percentages with all cases where the preference was known as denominator

Multivariate logistic regression models examining the factors associated with physician awareness of the preferred place of death and with congruence between preferred and actual place of death (ie the patient died in the preferred place vs. the patient did not do so) indicated that palliative care involvement, controlled for the effects of age, cause of death, sex and living situation, increased the chance of the attending physician being aware of the dying person's preferred place of death (OR:3.29, 95%CI: 1.83-5.92) and increased the odds of congruence between actual and preferred place of death (OR:2.57, 95%CI:1.54-4.30). The other covariates had no significant effects, except age 80 or older being associated with a lower chance of the physician being aware of the dying person's preferred place of death (not in table).

Place of death

Of those who died non-suddenly, 11.7% died at home, 64.2% in a hospital and 24.1% in a care home (Table 4). Men more often died in hospital and less often in a care home. Of those younger than 65, 87.0% died in hospital, a percentage decreasing to 52% for those aged 80 or older. The proportion of deaths at home was consistent throughout the different age categories. Almost a third of those living in an institution died in hospital. People dying of cancer more often died at home, but also more often in hospital than those dying of other conditions; 45.5% of neurological patients died in a care home.

Table 4: Place of death by patient characteristics of all persons dying non-suddenly in Brussels, 2007 (N=410)

	Home*	Hospital*	Care home*	p-value†
All non-sudden deaths	11.7	64.2	24.1	
Sex				0.003
Man	13.8	69.4	16.8	
Woman	9.9	59.2	31.0	
Age				
18-64	11.6	87.0	1.4	<0.001
65-79	12.4	74.3	13.3	
80 and older	11.5	52.0	36.6	
Living situation				<0.001
Living alone	14.2	70.9	14.9	
Living in household with others	16.7	75.6	7.7	
Living in institution	0.0	30.1	69.9	
Cause of death				<0.001
Cardiovascular	14.8	61.7	23.5	
Cancer	17.7	72.1	10.0	
Respiratory	0.0	70.7	29.3	
Neurological	18.2	36.4	45.5	
Stroke	6.3	65.6	28.1	
Other	4.6	56.3	39.1	
Palliative care involved				<0.001
Yes	21.1	74.7	4.2	
No	8.9	61.0	30.2	

*: row percentages

†: Fisher exact test (Monte Carlo procedure) testing differences between categories

The presence of others at the moment of death

At the moment of death, 6.8% of all people dying non-suddenly were alone, and in fewer than half of cases relatives or friends were present (Table 5). A nurse or physician was present at the moment of death in respectively 73.4% and 43.4% of cases. If palliative care services were involved, people were significantly less likely to die alone, and more likely to die with loved ones (ie partner, relatives or friends) present. Loved ones were also significantly more often present at the moment of death of men, those aged under 80, cancer patients, and those living in a household with others. Those living alone and especially those living in care homes were less likely to die in the presence of loved ones. Nurses were more often present at the moment of deaths which took place in care homes and physicians were more often present at the deaths of younger people, those dying in hospital and those not living in an a care home.

Table 5: who is present at the moment of death, by patient characteristics and involvement of specialist palliative care provider (N=410)

	No-one	Partner, family, or friends	Nurse	Physician	others
	% present				
All non-sudden deaths	6.8	46.5	73.4	43.4	2.7
Sex					
Male	7.7	53.3	72.8	45.1	3.1
female	6.6	40.2	74.3	42.1	2.3
p-value	*.703*	***.010***	*.738*	*.550*	*.764*
age					
18-64	8.8	55.1	68.1	61.8	0.0
65-79	6.2	54.0	78.8	49.1	0.0
80 and older	7.0	40.1	72.7	35.2	4.8
p-value	*.801*	***.016****	*.248*	***<.001***	***.010***
Living situation					
Living alone	9.2	44.0	70.9	46.1	2.8
Living in household with others	4.8	60.5	72.0	50.9	1.8
Living in institution	7.5	24.7	80.9	24.7	5.3
p-value	*.367*	***<.001***	*.098*	***<.001***	*.354*
Cause of death					

Cardiovascular	7.5	45.7	76.5	50.6	3.8
Cancer	4.8	56.8	67.8	39.7	2.1
Respiratory	4.8	38.1	80.5	54.8	0.0
Neurological	18.2	45.5	61.9	38.1	0.0
Stroke	6.3	50.0	81.3	37.5	3.1
Other	8.0	33.0	77.0	40.9	4.5
p-value	*.321*	***.014****	*.259*	*.354*	*.685*
Place of death					
at home	10,4	77,1	25,0	18,8	8,5
in hospital	5,7	47,9	79,1	60,8	1,1
in care home	9,1	28,3	81,8	9,1	3,1
p-value	*.264*	***<.001***	***<.001***	***<.001***	***.015***
Palliative care involvement					
PC not involved	8.5	41.1	73.7	41.4	2.2
PC involved	2.1	64.2	72.6	50.0	4.2
p-value	***.037***	***<.001***	*.895*	*.155*	*.288*

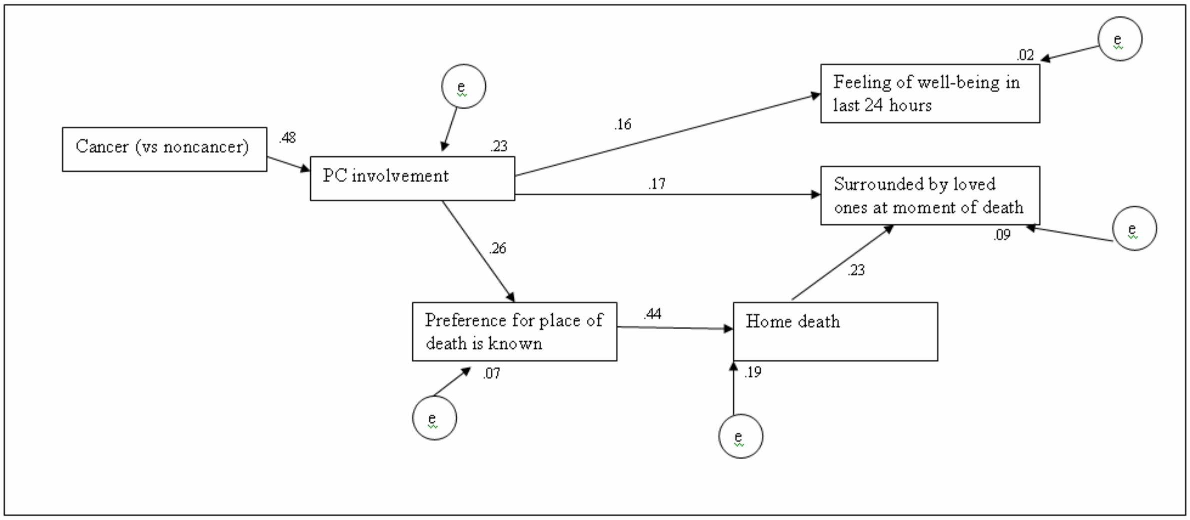
*: no longer significant when tested for other confounders in a multivariate logistic regression (see text)

A multivariate logistic regression analysis indicated that palliative care involvement, controlled for the effects of age, sex, cause of death and living situation, increased the chance of dying surrounded by relatives or friends (OR:2.13, 95%CI:1.30-3.51). As compared with living alone, living in a household with others increased the chance of dying surrounded by relatives or friends (OR:1.98, 95%CI:1.25-3.13), and living in an institution decreased the chance of doing so (OR:0.50, 95%CI:0.28-0.89). Adding place of death to the model (instead of living situation), palliative care involvement remained associated with a higher chance of dying surrounded by relatives or friends (OR:2.10, 95%CI:1.27-3.50). Dying in hospital (OR:0.28, 95%CI:0.14-0.59) or in a care home (OR:0.15, 95%CI:0.07-0.36) was associated with a significantly lower chance of dying with relatives or friends present than dying at home. Women also had a significantly lower chance of dying surrounded by relatives or friends than did men (OR:0.63, 95%CI:0.41-0.95) (not in table).

Influences on and of palliative care

A structural equations model was used to develop a model of how palliative care influences circumstances at the end of life of people dying non-suddenly, using the significant associations with palliative care involvement found in the bivariate analyses and the multivariate logistic regressions. The model explored factors influencing involvement of palliative care as well as the effects of palliative care on circumstances at the end of life. The model in figure 2 had the best fit of all models tried. Having cancer strongly influenced involvement of palliative care while being older than 80 did not, after controlling for the other factors in the model. Palliative care involvement led to better knowledge of the preferred place of death, and as such increased the probability of dying at home (but no significant direct relationship was found). Dying at home in turn led to people more often being surrounded by loved ones at the moment of death, a circumstance also directly influenced by palliative care involvement. Palliative care involvement also led to a better feeling of well-being while no significant influence on other symptoms was found.

Figure 2: Path diagram (Structural Equations Model): involvement of palliative care services and outcomes



Value model, all non-sudden deaths (N=410)
Model fit information: Chi^2: 12.378, df: 9 (p-value = 0.193). CFI: 0.987, RSMEA: 0.03
Standardized results are shown. Quantities close to variables are their squared multiple correlations. Quantities near paths are standardized loadings/correlations.
E: error, ie the difference between the observed and predicted values for each of the cases

6.4 Discussion

In the Brussels Capital Region circumstances for patients at the very end of life are far from ideal. A fairly low proportion of non-sudden deaths took place at home (12%) and in less than a quarter of those, palliative care was involved. In only 27% of these cases the attending physician was aware of the patient's preferred place of death. In less than half, loved ones were present at the moment of death and a relatively high proportion died alone (7%) Drowsiness was experienced by 80% in the last 24 hours, shortness of breath by about half and pain by 30%. Palliative care involvement was associated with more awareness of patient preferences by the physician, more likelihood of loved ones being present at the moment of death and with a lower chance of shortness of breath and a low feeling of well-being in the last 24 hours.

This retrospective mortality follow-back study is based on a representative sample of deaths in the Brussels Capital Region in 2007. Hence, with death as the sampling unit and therefore providing a clear denominator, the design is suitable for describing the circumstances and characteristics of death and the period shortly before it for all dying people, irrespective of whether they receive care with an end-of-life intent or have been identified as terminally ill. This makes the study, from a public health perspective, appropriate to assess the quality of dying of populations.(25;26) The retrospective design is also optimal for studying what happens at the moment of death or shortly before, and an efficient means of collecting national/regional and generalizable information about the last days of life and about access to health care.(26) The drawbacks of this methodology are those inherent in retrospective designs.(28) Intricacies of end-of-life care are missed in retrospective questionnaire surveys and, because there was a one to two month lag between death and the sending of the questionnaire, memory/recall bias is also possible in some cases. The reliance on the attending physician as a proxy for the patient may be more suitable for the description of certain characteristics (eg symptoms in the last 24 hours) but less so for others (eg preferred place of death) compared with family members as proxies. Death certificates in Belgium do not allow for the identification of next-of-kin, unlike in the USA.(16;17) and the UK (11-13;29) Finally, a limitation of the study is the relatively low response rate (41%) implying a possibility of non-response bias. Non-response analyses, however, showed no major differences in terms of diagnostic and demographic characteristics of the deaths in the obtained sample and the non-responding part of the sample. Reasons for not participating were predominantly practical in nature (eg the physician did not have the time to participate or was not able to due to patient identification issues), leading us to believe that systematic distortion of the final response sample is limited.(21) On the other hand, comparison of the response with a similar study in Flanders, showed that the relatively low response for Brussels might be typical of the metropolitan situation, and that non-response is perhaps often due to short-lived/transitory contacts.(21) This could mean that those deaths for which no response was received may have received less care in the period preceding their death, and their circumstances subsequently possibly worse. The results should thus perhaps be interpreted with this possible bias in mind

Our study demonstrates that, in Brussels, relatively few people dying non-suddenly do so at home. Only 12% died at home; more than 70% died in hospital, which is considerably higher than in other parts of Belgium,(7) than in metropolitan populations in other European countries,(30) and even than in some of the world's mega cities.(31) Possible explanations are that, compared with the rest of Belgium, Brussels has on average about twice as many poor and single people and many more residents of foreign origin. Residents of Brussels were also found to have fewer contacts with family physicians, who play a key role in coordinating end-of-life care and referring patients to palliative care services. This may also account for the low proportion of home deaths.(32) Similarly, a fairly low proportion of patients who might benefit from palliative care were found to have actually used palliative care services. In the Flemish region, a retrospective survey found that about 40% of people dying non-suddenly accessed palliative care services.(33) The 23% found in Brussels can thus be considered as low. The specific issues of a metropolitan area, with a large concentration of teaching hospitals leading to a propensity for more aggressive treatment,(21;34) relatively weak GP involvement in patient care, social fragmentation, cultural and linguistic diversity and barriers to implementation of palliative home care, are probably in large part responsible for the low level of palliative care involvement.(35-38) A striking finding was that a particularly low involvement of palliative care services was found in care homes in Brussels. This may need to be put into perspective; one explanation could be that residents may have received some form of palliative care (albeit not specialist) and their palliative needs may have been met by the trained nurses in the care homes.

Nonetheless, there appears to be clear beneficial effects of palliative care services involvement on the circumstances of dying.

Firstly, although a reverse causation cannot be excluded, where palliative care was involved, irrespective of the condition leading to death and other patient characteristics, awareness of the preference regarding place of death was higher and these preferences were more often met. Overall, there is a clear incongruence in Brussels between the preferred and actual place of death. Despite the low number of those dying at home, a majority of patients prefer to do so: of those whose attending physician was aware of the preference regarding the place of death, more than half preferred to die at home and only a fifth in hospital. One major problem is that attending physicians were aware of that preference in only about a quarter of all cases of non-sudden death, which is considerably lower than is found in studies about the awareness of GPs (though not necessarily the attending physicians) of patient preference for place of death in the Netherlands,(39) and Belgium as a whole.(40) Our results showed that involvement of palliative care strongly increased this awareness, and that awareness also increased the chances of preferences being met: of those cases where a preference to die at home was known by the physician 66% of deaths took place at home; all care home residents with a known preference to die in a care home eventually did so. The chances of preferences being met are even higher when palliative care is involved. While international research findings regarding the effect of palliative care team involvement on the place of death are equivocal,(22) our findings seemingly corroborate a previous study suggesting that good communication with the GP leads to the higher involvement of palliative care services, which in turn leads to better elicitation of preferences and to end-of-life care that respects these preferences.(41) This finding seems in line with the central role that communication about patient preferences, coordination with other involved health care professionals, and dying at the place of wish take in palliative care.(42;43) These findings suggest that policies aiming at stimulating dying out-of-hospital could, as possible options, encourage communication about preferences and increase palliative care involvement.

Secondly, independently of where people died, palliative care involvement seemed to influence the chances of dying in the presence of loved ones. This is commonly considered an important aspect of a ‘good death’,(4;5) and can – by facilitating the possibility of saying farewell perhaps- positively influence the bereavement process of the next-of-kin.(6) The role that palliative care could play is important, especially in Brussels where about 7% of those dying non-suddenly died alone and where loved ones were present in fewer than 50% of cases. The situation can be significantly improved, particularly for care home residents.

Thirdly, we found an association between the involvement of palliative care services and less shortness of breath and better well-being in the last 24 hours. While our study design does not allow for the inference of causal relationships, this is partly in line with findings from previous studies indicating that palliative care team involvement led to modestly improved patient outcomes in physical, psychological and spiritual domains.(22;23) Our study seems to suggest that, in Brussels, it at least improved outcomes in the physical (shortness of breath) and psychological domain (well-being). No association was found between involvement of palliative care services and the presence or absence of pain in the last 24 hours.

A structural equations model showed the dynamics of palliative care involvement, confirming most of the abovementioned inferences. Strongly influenced by diagnosis (ie cancer vs. non-cancer), a direct link was shown between palliative care involvement and a better feeling of well-being, and the presence of loved ones being more likely; an indirect link was shown with an increase in the probability of dying at home, through the influence of palliative care involvement on physician awareness of the preferred place of death. The latter again has a positive influence on the likelihood of dying with loved ones present.

In conclusion, the circumstances of patients in Brussels at the very end of life seem far from optimal. As suggested by others,(21) the metropolitan environment may impede quality end-of-life care in several ways and inhibit optimal circumstances in the last hours of life. However, this study does provide a case for the stronger involvement of palliative care services as a focal point for policies aimed at improving the end-of-life circumstances of people dying in the Brussels Metropolitan region. Future controlled trials and longitudinal follow-up studies are needed to confirm the causal relationship between increased palliative care service involvement and the improvement of circumstances at the end of life.

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Conflict of interest statement

All authors have no conflict of interest to declare

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Part IV

Place of death and health care policies

7 Involvement of Palliative Care Services Strongly Predicts Place of Death in Belgium

Houttekier D, Cohen J, Van den Block L, Bossuyt N, Deliens L. Involvement of palliative care services strongly predicts place of death in Belgium. J Palliat Med 2010 Dec;13(12):1461-8.

ABSTRACT

Introduction

Place of death is considered a quality indicator of end-of-life care and enabling people to die were they choose is an important aspiration of palliative care. This study aims to examine the association between involvement of palliative care services and place of death.

Methods

Data about patient characteristics, use of general health care and involvement of palliative care services in non-sudden or expected deaths in all health care settings in 2005-06 (N=1,690) were collected by a surveillance network of GPs in Belgium. Bivariate and multivariate associations between involvement of palliative care services and dying at home, in hospital, in a care home or in a palliative care unit were examined using Chi²-tests and Wald-tests.

Results

Palliative care services were involved in 21.8% of deaths of those living at home, in 29.1% of those living in care homes and in 12.4% of deaths in hospital. People were more likely to die in their usual residence rather than in hospital if multidisciplinary palliative home care teams (OR:8.4,CI:4.7-15.1) or the palliative care reference persons of their care home (OR:9.4,CI:3.3-26.7) were involved. Involvement of multidisciplinary palliative support teams in hospitals was associated with lower chances of dying at home (OR:0.3,CI:0.1-0.9). High involvement of GPs was not directly associated with out-of-hospital death.

Discussion

Involving multidisciplinary palliative home care teams and palliative care reference persons in care homes could support people in dying out-of-hospital. Health care policy-makers should consider strategies to improve involvement of palliative care services in all health care settings.

7.1 Introduction

Enabling people to die where they prefer is an important aim of palliative care,(1-3) and place of death is considered an indicator of quality of end-of-life care.(4) There is strong evidence that many terminally ill people do not die where they would choose to.(5) Most people prefer to die at home because of the psychological comfort, the presence of relatives and the feeling of control,(6) although in cases of inaccurate pain control or a high burden of care on the family, many may prefer to die in an institution.(6-9) In 2006, 57.7% of the terminally ill in Belgium preferred to die at home, 30.9% in a care home, 4.7% in hospital and 6.6% in a palliative care unit.(8) Where someone dies depends on factors related to their medical condition, their sociodemographic characteristics, their personal preferences, their health care use and their environment, including the social support and health care resources available.(10-16)

The association between involvement of palliative care services and place of death has not been investigated extensively before. The findings of the studies which do exist are equivocal, probably due to the heterogeneity of palliative care services, study populations, settings and designs.(17-25) Moreover, few studies have evaluated the relationship between involvement of palliative care services and place of death considering primary health care use, and none have evaluated the impact of a complete palliative care model, including all palliative care services for all patients in all health care settings, on place of death in a particular country.

Palliative care services in Belgium have been developing since 1985, and the 2002 law on palliative care provides for access to palliative care at the end of life.(26) The objectives of palliative care policy are to integrate palliative care into general health care (the care usually provided by professional caregivers in different health care settings), primary care in particular, rather than to replace that with care delivered by palliative care specialists, and to support out-of-hospital death.(2;3) Therefore, palliative care services have been set up to offer consultation and support for, and in principle only exceptionally to take over from, primary caregivers (ie GPs and home care nurses at home and GPs and care home nurses in care homes) in caring for the dying at home (known as multidisciplinary palliative home care teams) or in care homes (palliative care reference persons) and from medical and nursing staff in hospitals (multidisciplinary palliative support teams). In addition, small-scale inpatient palliative care units in or near hospitals were established which can be considered as a health care setting and thus as another possible location of death.(2)

The aim of this study is to examine, using nationwide retrospective data, the association between involvement of palliative care services in all health care settings and place of death, taking into account the personal characteristics of the deceased, environmental factors and general health care use. The research questions are: 1) what factors, related to personal characteristics, the environment, and general health care use, are related to place of death in Belgium and 2) is involvement of palliative care services associated with place of death?

7.2 Methods

We used retrospective data from a nationwide mortality follow-back study about palliative care services involvement and general health care use delivered in the last three months of life to people who died in 2005 or 2006. Data were collected within the senti-melc study by the sentinel network of general practitioners, an epidemiologic surveillance network representative of all Belgian GPs, established in 1979 and covering 1.75% of the Belgian population. A sentinel network of GPs is a network of community-based physicians who monitor health problems on a continuing basis.(27-29) All GPs were asked to report weekly, on a standardized registration form, every patient in their practice who had died during that week. The study population consists of people aged one year or older who were part of the GP practice and who had died non-suddenly or expectedly as judged by the GP ie those who can be considered potentially eligible for palliative care.(30) (N=1,690).

The dependent variable is place of death recoded into four categories: home, care home, hospital, and inpatient palliative care unit. The independent variables can be classified as personal, environmental and health care use factors.(10-13) The personal consist of the underlying cause of death, age, sex, educational attainment and financial situation and the preference for place of death as communicated to the GP. The environmental factors include social support (living situation, involvement of informal care), health care resources (available hospital and care home beds) and the urbanization level of the place of residence. The health care use factors include the treatment goal and the use of general health care in the last three months of life, ie the level of GP and home care involvement, the number of hospital admissions (median length of stay of one hospital admission:18 days; interquartile range:9-31days31) and the involvement of palliative care services, multidisciplinary palliative home care teams for those living at home, palliative care reference persons for those residing in care homes, and multidisciplinary palliative support teams for those living at home or in a care home admitted to hospital.

Bivariate associations between personal factors, environmental factors, the involvement of general health care and palliative care services and place of death were examined using cross tabulation and Pearson's chi^2-tests.

Multivariate analyses using binomial logistic regression were performed separately for two subpopulations with respect to living situation, those living at home and those living in care homes, because they differ significantly regarding age, sex, and cause of death, and the palliative care services that are available to them are not the same. For both subpopulations, we examined the association of involvement of palliative care services available to them with place of death, taking in account personal, environmental and health care use factors.

For those living at home we examined the association of involvement of a multidisciplinary palliative home care team with home death, and the association of involvement of a multidisciplinary palliative home care team or a hospital palliative support team with death in an inpatient palliative care unit. For those residing at home and admitted to hospital at least once in the final three months, we examined the association with home death of the involvement of a palliative home care team or a hospital palliative support team.

For people residing in care homes, we examined the association of involvement of palliative care reference persons with death in their place of residence.

As we were interested in the association of the level of GP involvement with place of death taking into account palliative care services involvement, we built up a regression model progressively to examine whether the expected association between high GP involvement and out-of-hospital death was adjusted when accounting for the involvement of palliative care services.

Significance was set at $p<0.05$. In multivariate analysis we used a stepwise forward likelihood ratio procedure to select model variables. Nagelkerke's R^2 was used to evaluate model fit and tolerance and the variance inflation factor (VIF) to examine multicollinearity. SPSS 17.0 was used for statistical computations.

7.3 Results

Death at home occurred more often in those who died from cancer, were under 65, male, had expressed a wish to die at home, lived in a multi-person household, received informal care often, and lived in a health care region with lower hospital bed availability (Table1). Those who died from cardiovascular diseases, were under 85, male, did not express a preferred place of death, lived alone with little or no informal care and in regions with higher hospital bed availability more often died in hospital. Death in a care home occurred more often in those suffering from neurodegenerative diseases, being 85 or older, female, had lower educational attainment and lived in regions with higher care home bed availability. Death in a palliative care unit occurred more often in cases of cancer, in those under 65, having expressed a wish to die in hospital or a palliative care unit, lived alone, received informal care often and lived in a highly urbanized place.

Table 1 Personal and Environmental Factors associated with Place of Death (N=1,690)

		Place of Death			
		Home	Hospital (excl. Palliative Care Unit)	Care Home	Palliative Care Unit
Personal and Environmental Factors	n (%)[*]		%		
All deaths that occurred non-suddenly or expectedly	1690	23.8	39.3	26.7	10.1
PERSONAL FACTORS					
Underlying cause of death[†]					
Cardiovascular diseases	237 (14.2)	17.7	50.6	29.1	2.5
Malignancies	725 (43.4)	34.6	34.3	12.0	19.0
Respiratory diseases	157 (9.4)	18.5	44.6	35.0	1.9
Diseases of the nervous system	71 (4.2)	21.1	25.4	49.3	4.2
Stroke	121 (7.2)	9.1	40.5	43.0	7.4
Other	360 (21.5)	13.6	41.9	41.7	2.8
Demographic variables					
Age[†]					
1-64 years	199 (12.0)	34.7	40.2	5.5	19.6
65-84 years	932 (56.1)	24.9	43.9	19.5	11.7
85+ years	530 (31.9)	17.0	32.1	47.0	4.0
Sex[†]					
Male	839 (49.6)	28.0	44.3	17.4	10.3
Female	851 (50.4)	19.7	34.4	36.0	9.9
Social Conditions					
Educational Attainment[†]					
Elementary or lower	666 (44.3)	22.2	38.6	31.5	7.7
Lower secondary	425 (28.2)	24.0	40.7	23.5	11.8
Higher secondary	286 (19.0)	26.9	40.6	19.6	12.9
Higher	128 (8.5)	26.6	43.0	19.5	10.9
Financial Situation[†]					
(very) Low	474 (28.5)	20.7	38.4	32.1	8.9
Average	859 (51.6)	25.4	39.1	24.8	10.7
(very) High	331 (19.9)	24.2	42.6	22.7	10.6
Patient's Expression of Preferences					
Place of death preference expressed to GP[†]					
Home or with family member	416 (26.1)	68.5	17.3	3.8	10.3
Care home	220 (13.8)	0.5	6.4	92.7	0.5

Elsewhere (hospital, palliative care unit)	77 (4.8)	6.5	45.5	1.3	46.8
Not expressed	878 (55.2)	7.2	60.5	22.9	9.5
ENVIRONMENTAL FACTORS					
Social Support					
Living situation[†]					
At home, alone	315 (18.7)	25.1	53.3	4.1	17.5
At home with others	811 (48.0)	39.0	46.1	3.1	11.8
Care Home	562 (33.3)	1.4	21.5	73.7	3.4
Informal care involvement[†]					
None or very little	171 (10.7)	3.5	48.5	41.5	6.4
Sometimes	210 (13.2)	9.0	39.0	44.3	7.6
Often	1,214 (76.1)	30.6	36.5	21.7	11.2
Availability of Health Care Resources					
Availability of hospital beds/1,000[†]					
< median	952 (56.5)	27.2	37.6	25.9	9.2
≥ median	733 (43.5)	19.6	41.6	27.6	11.2
Availability of care home beds/1,000 ≥ 65years[†]					
< median	678 (40.1)	26.4	41.0	23.6	9.0
≥ median	1,012 (59.9)	22.1	38.2	28.9	10.8
Urbanization level[†]					
High	917 (54.4)	22.5	40.2	25.6	11.7
Average	436 (25.9)	24.5	39.2	27.8	8.5
Low	332 (19.7)	27.1	37.0	28.0	7.8

[*] Presented percentages are row percentages, except percentages between brackets (column percentages). Numbers might not add up to N because of missing values.

[†] P-value < 0.001 for χ^2-statistic of association between cause of death, age, sex, place of death preference, living situation, informal care and place of death; P-value <0.01 for association between educational attainment, available hospital beds and place of death; P-value <0.05 for association between financial status, available care home beds, and place of death; P-value > 0.05 for association between urbanization level and place of death

Dying at home occurred more often in people whose treatment goal was comfort or palliation, whose GP was often involved in care during the last three months, who had professional home care often, and were not admitted to hospital in the final three months (Table 2). Dying in a hospital occurred more often in those whose treatment goal was cure or life-prolonging and without GP or professional home care involvement. Death in a care home occurred more often if the treatment goal was comfort or palliation, if the GP was involved often and for those not admitted to hospital. Dying in a palliative care unit was associated with treatment aimed at comfort or palliation and with no or infrequent GP involvement.

Table 2 Health Care Use Factors associated with Place of Death (N=1,690)

		Place of Death			
		Home	Hospital (excl. palliative care unit)	Care Home	Palliative Care Unit
Health Care Use Factors	n (%)	%[*]			
Treatment goal in last 3 months[†]					
Cure/prolonging life	280 (17.0)	11.4	73.2	14.3	1.1
Comfort/ palliation	1,365 (83.0)	26.8	30.9	30.0	12.2
GP involvement in last 3 months[†]					
No involvement	55 (3.3)	5.5	69.1	3.6	21.8
Sometimes	352 (21.3)	15.9	55.7	15.1	13.4
Often	1,248 (75.4)	27.0	32.8	31.7	8.6
Home care involvement in last 3 months[†‡]					

No involvement	164 (15.3)	25.6	65.9	0.6	7.9
Sometimes	164 (15.3)	32.3	51.8	2.4	13.4
Often	747 (69.5)	39.2	42.3	4.3	14.2
Hospital admissions in last 3 months†					
No hospital admissions	686 (40.6)	39.9	0.9	48.7	10.5
One hospital admission	824 (48.8)	13.2	64.0	12.9	10.0
Two or more hospital admissions	180 (10.7)	11.1	73.3	6.7	8.9

[*] Presented percentages are row percentages, except percentages between brackets (column percentages). Numbers might not add up to N because of missing values.

[†] P-value<0.001 for χ^2-test of association between all health care use factors and place of death

[‡] Applied for residents residing at home (N=1,126)

Palliative care services were used by a minority (Tab 3). Multidisciplinary palliative home care teams were involved in 21.8%, palliative care reference persons in care homes in 29.1% and multidisciplinary palliative support teams in hospitals in 12.4% of deaths. Home death occurred more frequently in people using a multidisciplinary home care team. Care home death happened more frequently if the palliative care reference persons were involved. For those admitted to hospital at least once in the final three months, death at home or in care homes occurred less frequently and death in an inpatient palliative care unit more frequently if a palliative support team of a hospital was involved.

Table 3 Involvement of Palliative Care Services associated with Place of Death

		Place of Death			
		Home	Hospital (excl. palliative care unit)	Care Home	Palliative Care Unit
Involvement of Palliative Care Services in last 3 months	n (%)		%*		
For patients residing at home (N=1,126)					
Involvement of a multidisciplinary palliative home care team†					
Involvement	231 (21.8)	75.3	10.0	1.3	13.4
No Involvement	828 (78.2)	25.8	55.6	4.1	14.5
For patients residing in a care home (N=562)					
Involvement of palliative care reference persons in care home†					
Involvement	157 (29.1)	0.6	2.5	96.2	0.6
No Involvement	382 (70.9)	1.8	27.2	66.2	4.7
For patients admitted to hospital at least once (N=1,004)					
Involvement of multidisciplinary palliative support team in hospital†					
Involvement	115 (12.4)	10.4	62.6	6.1	20.9
No Involvement	813 (87.6)	14.1	63.5	13.3	9.1

[*] Presented percentages are row percentages, except percentages between brackets (column percentages). Numbers might not add up to N because of missing values.

[†] P-value<0.001 for χ^2-test of association between use of all palliative care services and place of death

Multivariate logistic regression, taking into account personal, environmental and general health care use factors and palliative care services involvement, showed that involvement of palliative care services independently influenced place of death. For people living at home, home relative to hospital death was more likely if a multidisciplinary palliative home care team was involved (OR:8.4, 95%CI:4.7-15.1), if they had expressed a preference for home death (OR:14.2, 95%CI:9.5-21.4), used informal care often (OR:2.3, 95%CI:1.2-4.6), or lived in regions with lower hospital bed availability (OR:0.8, 95%CI:0.6-0.9).(Tab 4) For those admitted to hospital at least once in the final three months, home death was less likely if a palliative support team in hospital was involved (OR:0.3, 95%CI:0.1-0.9) and more likely if a multidisciplinary palliative home care team was involved (OR:10.6, 95%CI:5.4-21.1), if a wish to die at home was expressed (OR:10.1, 95%CI:5.7-18.1), or informal care was involved often (OR:4.4, 95%CI:1.3-15.2). Death in an inpatient palliative care unit relative to a hospital was more likely in cases involving a multidisciplinary palliative home care team (OR:2.9, 95%CI:1.6-5.5), for cancer patients (OR:6.5, 95%CI:3.8-10.9), for women (OR:1.7, 95%CI:1.1-2.6), or for those involving professional home care often (OR:2.2, 95%CI:1.4-3.5). We found no association between involvement of a palliative support team of a hospital and death in an inpatient palliative care unit.

Table 4 Adjusted Binomial Odds Ratios for Home Death vs. Hospital Death and Death in an Inpatient Palliative Care Unit vs. Hospital Death of patients residing at home

	Home vs. hospital death (N=750)[*]	Home vs. hospital death for patients admitted to hospital at least once in last 3 months (N=533)[†‡]	Death in a PCU vs. hospital death (N=577)[§]
Factors related to place of death	OR (95% CI)		
PERSONAL FACTORS			
Underlying cause of death	Ns	Ns	
Other chronic life-limiting disease			Ref
Cancer			6.5 (3.8-10.9)
Age	Ns	Ns	Ns
1-64 years			
65-84 years			
85+ years			
Sex	Ns	Ns	
Male			Ref
Female			1.7 (1.1-2.6)
Financial situation	Ns	Ns	Ns
Low			
Average			
High			
Known preference for place of death?			[‖]
Not known or other than home	Ref	Ref	
Yes, at home	14.2 (9.5-21.4)	10.1 (5.7-18.1)	
ENVIRONMENTAL FACTORS			

Informal care involvement in last 3 months			
No involvement or sometimes	Ref	Ref	Ns
Often	2.3 (1.2-4.6)	4.4 (1.3-15.2)	
Hospital beds/1,000 (continuous)	0.8 (0.6-0.9)	Ns	Ns
Care home beds/1,000 ≥ 65years (continuous)	Ns	Ns	Ns
Urbanization level	Ns	Ns	Ns
Low or average			
High			
HEALTH CARE USE FACTORS			
GP involvement in last 3 months	Ns	Ns	Ns
No involvement or sometimes			
Often			
Home care involvement in last 3 months	Ns	Ns	
No involvement or sometimes			Ref
Often			2.2 (1.4-3.5)
INVOLVEMENT OF PALLIATIVE CARE SERVICES			
Involvement of a Multidisciplinary home care team			
No Involvement	Ref	Ref	Ref
Involvement	8.4 (4.7-15.1)	10.6 (5.4-21.1)	2.9 (1.6-5.5)
Involvement of a multidisciplinary palliative support team in hospital	[‖]		Ns
No Involvement		Ref	
Involvement		0.34 (0.1-0.9)	

[*] Nagelkerke's R²: 0.576. No indications of severe multicollinearity were found: tolerance>0.78 , VIF<1.28

[†] Nagelkerke's R²: 0.494. No indications of severe multicollinearity were found: tolerance>0.83 , VIF<1.38

[‡] Median length of a hospital stay: 18 days, interquartile range: 9 days-31 days

[§] Nagelkerke's R²: 0.252. No indications of severe multicollinearity were found: tolerance>0.92 , VIF<1.21

[‖] Variable not involved in model

People living in a care home were more likely to die there rather than in hospital if the palliative care reference persons were involved (OR:9.4, 95%CI:3.3-26.7), if they preferred to die in the care home (OR:10.4, 95%CI:4.4-24.9), if they had cancer (OR:2.5, 95%CI:1.1-5.9), or if they were female (OR:1.8, 95%CI:1.0-3.0).(Tab 5)

Table 5 Adjusted Binomial Odds Ratios for Care Home Death vs. Hospital Death of Care Home Residents of 65 years and older

	Care home death vs. hospital death (N=443)[*]
Factors related to place of death	OR (95% CI)
PERSONAL FACTORS	
Underlying cause of death	
Other chronic life-limiting disease	Ref
Cancer	2.5 (1.1-5.9)
Age	Ns
65-84 years	
85+ years	
Sex	
Male	Ref
Female	1.8 (1.0-3.0)
Financial situation	Ns
Low	
Average	
High	
Known preference for place of death	

Not known or other than care home	Ref
Yes, care home	10.4 (4.4-24.9)
<u>ENVIRONMENTAL FACTORS</u>	
Patient had partner at time of death	Ns
No	
Yes	
Hospital beds/1,000 (continuous)	Ns
Care home beds/1,000≥65 years (continuous)	Ns
Urbanization level	Ns
Low	
High	
<u>HEALTH CARE USE FACTORS</u>	
Level of GP involvement in last 3 months	Ns
No involvement or sometimes	
Often	
<u>INVOLVEMENT OF PALLIATIVE CARE SERVICES</u>	
Involvement of Palliative Care Reference Persons	
No Involvement	Ref
Involvement	9.4 (3.3-26.7)

[*] Nagelkerke's R²: 0.327. No indications of severe multicollinearity were found: tolerance>0.92 , VIF<1.09

The unadjusted bivariate association found between frequent GP involvement and home death (OR:3.4, 95%CI:2.5-4.8) or care home death (OR:2.6, 95%CI:1.6-4.4), was adjusted completely when accounting for palliative care services involvement and the existence of a preference to die in the place of residence in case of care home residents, and significantly (from OR:3.4, 95%CI:2.5-4.8 to OR:1.6, 95%CI:1.0-2.6) in people living at home (Not shown in table).

7.4 Discussion

Although involved with only a minority of terminally ill people, palliative care services prove to be a powerful predictor of place of death, along with the existence of a preference for place of death. The involvement of a multidisciplinary palliative home care team is strongly associated with higher chances of dying at home or in an inpatient palliative care unit. Care home residents referred to in-house palliative care reference persons are far more likely to die in their care home. In contrast, the intervention of a hospital multidisciplinary palliative support team does not support out-of-hospital death. Frequent involvement of the GP in the last three months of life was not directly associated with out-of-hospital death.

This study is to our knowledge the first to evaluate the whole palliative care services model on a nationwide scale with respect to one important outcome quality indicator. Using the sentinel network of GPs, the association of palliative care services involvement and place of death, taking general health care involvement and personal and environmental factors into account, is examined across all patient groups and care settings. This sentinel network is representative of all GPs in Belgium and has a long tradition in data collection with a stable group of participating GPs. Recall bias remains limited because of the requirement to register deaths weekly.(27) Although most GPs are usually kept informed about the care of their patients during hospital admissions, the involvement of palliative care services in hospitals and their impact on place of death might be underestimated. No information was available on the content of palliative care, the point in the disease course when it was begun and the period during which it was provided. The association of palliative care services involvement and place of death may be partly explained by confounders not included in our analyses, eg the preferences or coping skills of informal caregivers or the patient's functional status, symptoms and other problems. Certain groups may have systematically had more chance of being referred to palliative care services, as a result of which place of death would not be a consequence of palliative care involvement but rather of particular patient characteristics. However, considering the amplitude of our findings, and the comprehensive set of factors controlled for,(10) our results strongly suggest that palliative care services involvement affects place of death. Randomized prospective research designs would provide more decisive information as to the causal effect of palliative care services on place of death, but such designs would be difficult to implement in palliative care services research and as access to palliative care is a legal right in Belgium they could also be questioned legally and ethically.

Palliative care services at home and in care homes prove to be successful in supporting out-of-hospital death although they were used by only 21.8% and 29.1% of terminally ill people, possibly because of the insufficient capacity of these services, or the reluctance of the terminally ill, their families and professional caregivers to involve them. Where these services were involved, those living at home were 8.4 times more likely to die there and those in a care home 9.4 times more likely, regardless of the level of primary care involvement. The strong association of these palliative care services and place of death can probably be explained by several factors. Their 24 hours a day, seven days a week availability,(18;25) and their expertise in treatment of pain and symptoms and in dealing with ethical issues can avoid hospitalization, and the comprehensive multidisciplinary support they provide, including emotional support to their clients and caregivers, may be a key element in facilitating home or care home death.(32) The palliative care services we studied were implemented about 15 years ago and since then expertise in palliative care has developed rapidly. Treatment of pain and symptoms has become more technically sophisticated, requiring palliative care teams to be involved in treatment and not just in consulting and, since euthanasia became legal in Belgium in 2002,(33) palliative care has also become more ethically complex, leading to an increase in all types of end-of-life decisions and requiring a complex decision-making process.(34) The tendency for palliative care to face more complex challenges, the multidisciplinary nature of palliative care services and their permanent availability could explain the high impact they have on place of death, in contrast with high levels of GP involvement. Although in our final models we found that the level of GP involvement did not alter place of death, in contrast with previous findings,(14;15) the gradual building-up of our models shows that highly-involved GPs can play an intermediate role in supporting out-of-hospital death by exploring their patients' preferences and involving palliative care services in ways which will meet them. By doing so, however, their own influence on place of death is diminished.

In contrast with palliative care services operating where people live, we found that multidisciplinary palliative support teams in hospitals were not successful in supporting home death or death in an inpatient palliative care unit. It may be that people are systematically referred late to palliative support teams in hospitals due to an inadequate palliative care approach, resulting in lack of time to instigate a realistic plan for discharge from hospital. The success of multidisciplinary palliative home care teams in referring people to inpatient palliative units, in contrast with palliative support teams in hospitals, may be explained by the admission policies of palliative care units giving priority to those residing at home over those already in an institution, even a hospital, and because home care teams had been involved earlier in the disease trajectory with more time to plan future care for their clients.

Given the strong relationship we found between palliative care services involvement and place of death in Belgium, which may also apply to other countries with similar availability of palliative care services, health care policy-makers should consider strategies to encourage more intense cooperation between general health care practitioners and palliative care services providers. Integrating palliative care more systematically into the curricula of medical and nursing studies may be a good starting point. Future research should study the possible barriers of timely referral of hospitalized patients to palliative support teams in hospitals so that discharge from hospital to a more appropriate setting for end-of-life care remains feasible. The economic implications of dying in different care settings and the involvement of palliative care services both for patients and the health care system should be studied.

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Author Disclosure Statement

No competing financial interests exist.

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8 Study of Recent and Future Trends in Place of Death in Belgium Using Death Certificate Data: a Shift from Hospitals to Care Homes

Houttekier D, Cohen J, Surkyn J, Deliens L. Study of Recent and Future Trends in Place of Death in Belgium Using Death Certificate Data: a Shift from Hospitals to Care Homes. BMC Public Health. 2011 Apr 13;11(1):228

ABSTRACT

Background

Since most patients prefer out-of-hospital death, place of death can be considered an indicator of end-of-life care quality. The study of trends in place of death is necessary to examine causes of shifts, to evaluate efforts to alter place of death and develop future policies. This study aims to examine past trends and future projections of place of death.

Methods

Analysis of death certificates (decedents aged ≥ 1 year) in Belgium (Flanders and Brussels Capital region) 1998-2007. Trends in place of death were adjusted for cause of death, sociodemographic characteristics, environmental factors, numbers of hospital beds, and residential and skilled nursing beds in care homes. Future trends were based on age- and sex-specific mortality prognoses.

Results

Hospital deaths decreased from 55.1% to 51.7% and care home deaths rose from 18.3% to 22.6%. The percentage of home deaths remained stable. The odds of dying in a care home versus hospital increased steadily and was 1.65 (95%CI:1.53-1.78) in 2007 compared to 1998. This increase could be attributed to the replacement of residential beds by skilled nursing beds. Continuation of these trends would result in the more than doubling of deaths in care homes and a decrease in deaths at home and in hospital by 2040.

Conclusions

Additional end-of-life care resources in care homes largely explain the decrease in hospital deaths. Care homes will become the main locus of end-of-life care in the future. Governments should provide sufficient skilled nursing resources in care homes to fulfil the end-of-life care preferences and needs of patients.

8.1 Background

Place of death is considered an important indicator of quality of end-of-life care. Death in the usual place of residence is associated with the presence of family and friends, comfort and a feeling of control.(1) Most patients prefer to die at home, but in cases of inadequate pain control or when the burden becomes too great for family caregivers, end-of-life care and death in an institution may be preferred.(1,2) Place of death also has important consequences for health care costs, as end-of-life care in hospitals is more expensive than in care homes or at home.(3,4) Nevertheless, in Belgium and most other countries a majority of patients still die in hospital.(5-7) For reasons of cost and quality of care supporting out-of-hospital death has become an important policy objective.(8,9) In Belgium and elsewhere, different models of palliative care services and options for out-of-hospital death have been developed,(9,10) but their effectiveness remains unclear.

Studying trends in place of death is necessary to monitor and gain insight into the reasons for changes to evaluate efforts to alter place of death, and to plan future end-of-life care services and facilities. Many previous studies were restricted to cancer patients(11-15) and only considered trends in home or hospital death although, with ageing of the population in developed countries, other chronic life-limiting conditions will become more important (eg dementia-related diseases)(16) and end-of-life care in care homes will become a major concern because of the expected increase in care home residents. In most studies, shifts in place of death were only related to shifts in age, sex and underlying cause of death,(14,17-23) and shifts in other factors were not taken into account, eg in living arrangements, educational attainment, urbanization levels, and available care options. Although instituted in 1985, palliative care services in Belgium have been only gradually integrated into formal health care and reimbursed by healthcare insurance since 1997.(9,24) Studying trends in place of death from 1998 to 2007 allows discussion of the impact of the growing availability of palliative care services and out-of-hospital end-of-life care options on an important patient outcome.

The aim of this study is to examine past trends between 1998 and 2007 and future trends until 2040 of place of death. The research questions are: 1) How did place of death change between 1998 and 2007 taking into account shifts in underlying cause of death, age, sex, living arrangement, educational attainment, urbanization level and availability of hospital and care home beds? 2) Did place of death change differently for specific subpopulations regarding living arrangement? 3) How would place of death change between now and 2040, based on trends between 1998 and 2007?

8.2 Methods

All deaths in Belgium (Flanders and Brussels Capital Region) aged one year or older in the period 1998-2007 were included (N=661,773). A subpopulation of patients who died non-suddenly of one or more chronic life-limiting conditions (including cancer, cerebrovascular diseases, dementia, chronic obstructive pulmonary disorders, heart failure, diabetes, Parkinson's disease, chronic kidney disease, chronic liver disease, spinal muscular atrophy and related disorders, multiple sclerosis, neuromuscular disorders, and acquired immunodeficiency syndrome) and were thus eligible for palliative care (palliative subset) was considered in multivariate analysis (n=354,794).(16)

In Belgium, death certificates contain information about the place and cause of death and the sociodemographic characteristics of the deceased. Information about the place and cause of death is completed by a physician, who certifies the causal chain of diseases starting with the underlying cause of death, which is used in this study. Information about the sociodemographic characteristics (eg educational attainment, nationality, marital status, and living arrangements) is provided by the municipal institutions assisted by a relative of the deceased. Information from the death certificates is processed; the causes of death are coded in ICD-10 codes, and both medical and sociodemographic information is checked by a government agency.(25) Approval of an ethics committee to use death certificate data was not required, but in accordance with the Belgian Privacy Act, the use of the data was notified to the Belgian Commission for the Protection of Privacy.

Dependent variable is place of death recoded into four categories: home, hospital, care home and elsewhere. In Belgium, care homes are long-term care facilities, including both homes for the aged and skilled nursing facilities, although most have a mix of beds for residents requiring skilled nursing care on a daily basis (skilled nursing beds) and beds for those not requiring such care (residential beds).

The independent variables are the year of death (1998-2007), the illness of the deceased (underlying cause of death, recoded in six categories: cancer, cardiovascular diseases, respiratory diseases, diseases of the nervous system, stroke, and other using ICD-10 codes), the demographic (sex, and age: 1-64 years, 65-74 years, 75-84 years, ≥85 years) and social situation (educational attainment: no formal or elementary education, lower secondary, higher secondary, higher, and other or unknown), living arrangements (single, in a multi-person household or in an institution which is a care home in almost all cases), urbanization level (of the municipality of residence: very strong, strong, average, low or rural) and available hospital, and residential and skilled nursing care home beds (data on the availability of care home beds were provided by the Belgian National Institute for Health and Disability Insurance, data on hospital beds by the Federal Public Service of Health, Food Chain Safety and Environment). The availability of skilled nursing beds and residential beds in care homes was considered per 1,000 inhabitants of 65 years or older in the community of residence or in areas of up to six smaller communities (115 areas in Flanders with an average population (year 2000) of 51,654 inhabitants. Brussels Capital Region was considered one area).(26) The availability of hospital beds was considered per 1,000 inhabitants in areas of eight to 45 communities (14 areas in Flanders and Brussels Capital Region with an average population of 492,826)

For use in multivariate analysis, the underlying cause of death (cancer versus non-cancer chronic life-limiting conditions), education (no formal or elementary or lower secondary or unknown/other versus higher secondary or higher), and urbanization (very strong or strong versus moderate or low) were recoded into two categories.

Differences in trends in the total number of deaths (aged ≥1 years) in the period 1998-2007 and the number of deaths in the palliative subset, the categories of cause of death, age, sex, living arrangement, urbanization level, and place of death were tested using χ^2-test for trend.

Differences in trends in the total number of deaths (aged ≥65 years) at home, in hospital, and in care homes and the number at home, in hospital, and in care homes of the categories of living arrangement were tested using χ^2-test for trend. Differences in the yearly average availability of hospital, residential and skilled nursing beds were tested using the F-test.

Multivariate analyses were performed separately for those aged 65 years or older residing at home and those residing in care homes who died from chronic life-limiting conditions,(16) because of differences in age and conditions in both subpopulations. Unadjusted odds ratios of the association of year of death and place of death were compared with odds ratios adjusted for underlying cause of death, age, sex, educational attainment, living arrangement, urbanization level, and available hospital beds, and residential and skilled nursing beds in care homes. The multivariate analyses were binomial logistic regression analyses with forward stepwise likelihood ratio selection procedure of variables and tested using the Wald-test for individual model parameters and model-χ^2 for the whole model. The significance level was set at p=0.01, given the large amount of data.

To examine which factors possibly adjusted the yearly trends in place of death, both logistic regression models were built up step by step. Starting from the unadjusted odds ratios of each year of death relative to 1998 for home death relative to hospital death and care home death relative to hospital death, we added the underlying cause of death, age, sex, educational attainment and living arrangement of the deceased, and the available residential and nursing beds in care homes and hospital beds step by step, to examine which of these factors adjusted the odds of dying in hospital in each year.

We used age- and sex-specific mortality projections of the Belgian National Planning Bureau for Flanders and Brussels Capital Region based on the population statistics of January 1 2007 to project future trends in place of death. Life expectancy at birth is expected to increase with 8 years both for men and women between 2007 and 2060, and to reach 85.3 years for men and 90.9 years for women.(27) These mortality projections were used to perform linear projections of future proportions and numbers of deaths from 2008 to 2040 in all care settings based on age- and sex-specific proportions of deaths in the different care settings we found in the period 1998-2007. Two scenarios were considered; in the first we examined future trends in place of death starting from the age- and sex- specific distribution in 2007, in the second we considered the age- and sex-specific percentage point changes in all categories of place of death from 1998 to 2007.(18)

All analyses were performed using PASW statistics 17.

8.3 Results

In 1998-2007, 661,773 people (aged ≥1year) died in Belgium (Flanders and Brussels Capital Region), ranging from 64,560 in 2006 to 68,278 in 2003 (Table 1). The proportion of cancer deaths and deaths from diseases of the nervous system grew over that period, while deaths from cardiovascular diseases and stroke diminished. The proportion of deaths of the palliative subset increased from 54.2% to 55.1%. The proportion of deaths of people aged 75 and over, with higher secondary or unknown education, living alone and in strongly or averagely urbanized places increased, while the opposite was true for deaths of people aged between 65 and 74, having no formal or elementary education, living in a multi-person household, and in very strong urbanized places. During the study period many residential beds in care homes were replaced by skilled nursing home beds. The average number of residential beds per 1,000 inhabitants of 65 years or older fell from 56 in 1998 to 36 in 2007 while the average number of skilled nursing home beds rose from 12 to 29. The average number of hospital beds per 1,000 inhabitants remained stable.

Table 1 Population Characteristics of Deaths (aged ≥1y) 1998-2007 (N=661,773)

	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	P-value
	n, %*, P-value for χ² for trends and F-test (beds)										
ALL DEATHS	66,481	66,946	66,728	65,555	67,123	68,278	65,050	65,617	64,560	65,435	
CAUSE OF DEATH											
Cancer	27.6%	27.0%	26.9%	27.2%	27.1%	26.4%	27.1%	27.4%	28.1%	28.4%	P<0.001
Cardiovascular Disease	28.6%	28.1%	28.7%	28.5%	28.1%	27.7%	27.9%	26.7%	25.7%	25.7%	P<0.001
Respiratory Disease	11.4%	11.5%	11.9%	11.5%	12.1%	12.7%	11.7%	12.4%	11.6%	11.7%	P=0.004
Disease of Nervous System	2.3%	2.2%	2.3%	2.3%	2.5%	2.9%	2.6%	2.9%	3.3%	3.4%	P<0.001
Stroke (CVA)	8.9%	9.1%	8.7%	8.8%	8.7%	8.4%	8.6%	8.1%	8.0%	7.9%	P<0.001
Other	21.1%	22.1%	21.5%	21.8%	21.5%	22.0%	22.1%	22.5%	23.2%	23.0%	P<0.001
PALLIATIVE SUBSET(16) (N=354 794)	54.2%	53.4%	52.8%	53.2%	53.4%	52.9%	53.3%	53.4%	54.5%	55.1%	P<0.001
AGE											
1-64 year	17.9%	18.0%	17.8%	17.7%	17.1%	16.5%	16.7%	16.7%	16.8%	17.0%	P<0.001
65-74 year	21.0%	20.0%	19.9%	19.4%	18.6%	18.3%	17.8%	17.7%	16.8%	16.2%	P<0.001
75-84 year	30.4%	30.1%	30.1%	31.0%	32.7%	34.3%	35.9%	35.1%	35.2%	34.4%	P<0.001
85+ year	30.6%	31.9%	32.2%	31.9%	31.5%	30.9%	29.6%	30.5%	31.2%	32.4%	P=0.2
SEX											
Male	49.9%	49.9%	50.0%	49.9%	49.5%	49.1%	49.6%	49.5%	49.6%	49.7%	P=0.04
Female	50.1%	50.1%	50.0%	50.1%	50.5%	50.9%	50.4%	50.5%	50.4%	50.3%	P=0.04
EDUCATIONAL ATTAINMENT											
No formal or elementary	44.3%	44.8%	43.3%	40.7%	39.0%	36.6%	34.7%	33.2%	31.5%	30.0%	P<0.001
Lower secondary	17.4%	17.4%	17.7%	19.0%	18.9%	17.6%	18.3%	18.8%	18.7%	17.3%	P<0.001
Higher secondary	10.4%	9.4%	10.2%	9.7%	9.2%	9.0%	9.8%	11.5%	12.8%	13.1%	P<0.001
Higher	4.5%	4.2%	3.9%	4.1%	4.1%	3.7%	4.1%	4.2%	4.4%	4.5%	P=0.03
Other or unknown	23.4%	24.2%	24.8%	26.6%	28.8%	33.0%	33.1%	32.3%	32.5%	35.2%	P<0.001
LIVING ARRANGEMENT											
Single	21.6%	21.0%	20.9%	21.4%	21.2%	20.7%	21.6%	22.7%	22.3%	23.4%	P<0.001
Multi-person household	54.4%	54.7%	54.8%	54.0%	53.1%	53.0%	53.1%	51.6%	52.3%	51.9%	P<0.001
Care home	24.0%	24.2%	24.3%	24.7%	25.6%	26.2%	25.4%	25.7%	25.4%	24.6%	P<0.001
URBANIZATION LEVEL											
Very strong	39.3%	39.1%	38.8%	38.4%	38.5%	38.1%	38.1%	37.7%	37.4%	36.4%	P<0.001
Strong	27.9%	27.9%	28.1%	28.1%	28.3%	28.2%	28.2%	28.5%	28.4%	29.7%	P<0.001
Average	28.5%	28.7%	28.7%	29.1%	28.8%	29.2%	29.4%	29.4%	29.9%	29.4%	P<0.001
Low or rural	4.3%	4.3%	4.4%	4.4%	4.4%	4.4%	4.3%	4.5%	4.4%	4.5%	P=0.12
HEALTH CARE RESOURCES											
Hospital beds/1,000	5.5	5.4	5.5	5.6	5.6	5.6	5.5	5.4	5.4	5.3	P=1
Residential beds in care homes/1,000≥ 65y	56.0	52.9	49.9	46.6	43.3	40.2	38.2	37.7	36.6	35.7	P<0.001
Skilled nursing beds in care homes/1,000≥ 65y	11.6	14.5	17.5	20.2	22.8	25.4	26.9	26.8	27.8	29.0	P<0.001

* Presented percentages are column percentages

The proportion of deaths in hospitals decreased from 55.1% in 1998 to 51.7% in 2007 (Table 2). In contrast, deaths in care homes increased from 18.3% to 22.6%. Home deaths fell by 0.5% and the trend of home deaths differed insignificantly from the trend of the total number of deaths.

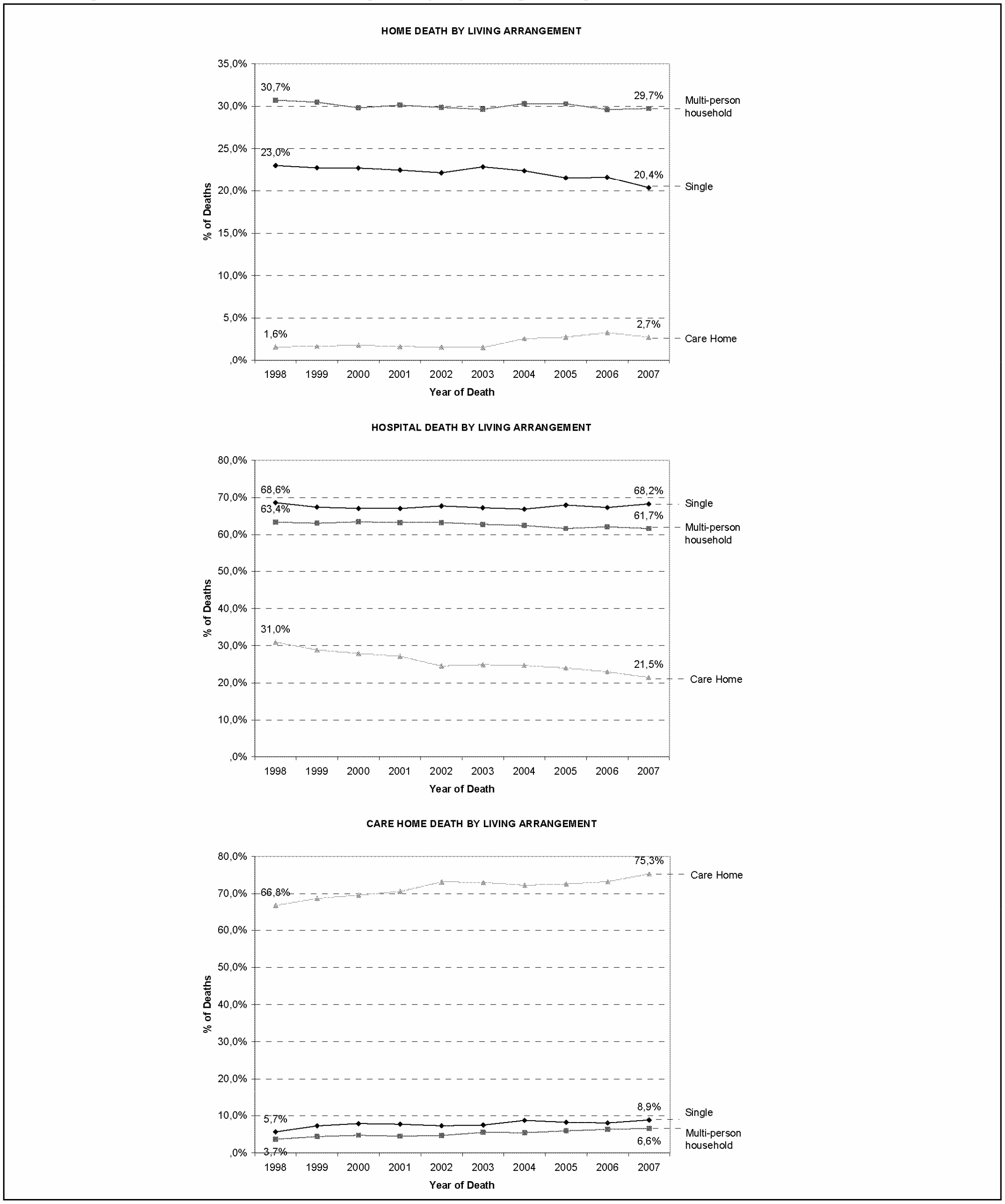
Table 2 Trends in Place of Death (aged ≥ 1y) 1998-2007 (N=661,771)

	1998	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**P-value**
PLACE OF DEATH	n, %*, P-value for χ^2 for trends										
Home	15,311	15,389	15,226	14,919	15,075	15,287	14,912	14,878	14,760	14,726	P=0.4
	23.0%	23.0%	22.8%	22.8%	22.5%	22.4%	22.9%	22.7%	22.9%	22.5%	
Hospital	36,631	36,283	35,924	34,964	35,227	35,574	34,059	34,085	33,264	33,856	P<0.001
	55.1%	54.2%	53.8%	53.3%	52.5%	52.1%	52.4%	51.9%	51.5%	51.7%	
Care home	12,161	12,980	13,328	13,375	14,578	15,363	14,209	14,605	14,469	14,792	P<0.001
	18.3%	19.4%	20.0%	20.4%	21.7%	22.5%	21.8%	22.3%	22.4%	22.6%	
Other	2,378	2,293	2,250	2,297	2,242	2,054	1,870	2,049	2,067	2,061	P<0.001
	3.6%	3.4%	3.4%	3.5%	3.3%	3.0%	2.9%	3.1%	3.2%	3.1%	

* Presented percentages are column percentages

In all living situations the hospital death rate declined (aged ≥65 years), and that of care homes death rose. The home death rate of people living single or in multi-person households decreased and that of persons living in care homes increased (Figure 1a). The decline of the hospital death rate was largest for those in care homes (from 31.0% to 21.5%) (Figure 1b), and was balanced by the increase in the care home death rate (from 66.8% to 75.3%) (Figure 1c) and home death rate (from 1.6% to 2.7%). The care home death rate of people living at home increased, both of those living alone (from 5.7% to 8.9%) and in a multi-person household (from 3.7% to 6.6%).

Figure 1 Trends in Place of Death (aged ≥65y) by Living Arrangement (N=538 267)



P-value for χ^2 for difference in trend of home death of all categories of living arrangement and the global trend of home death: <0.001, except for singles: p=0.925. P-value for χ^2 for difference in trend of hospital death of all categories of living arrangement and the global trend of hospital death: <0.001. P-value for χ^2 for difference in trend of care home death of all categories of living arrangement and the global trend of care home death: <0.001.

The chances of dying in hospital for patients living at home did not decrease in 1998-2007 (Table 3). Stepwise adjustment (data not shown) of these unadjusted odds ratios showed no factors altered this trend.

Table 3 Unadjusted and adjusted trends in chance of dying at home and in care homes of patients (aged ≥65y) who died of chronic life-limiting conditions 1998-2007

	1998	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**
PATIENTS LIVING AT HOME	OR of Home Death vs Hospital Death (99% CI)									
(N=189,884)										
Unadjusted odds ratios	NS*									
Adjusted odds ratios†	NS*									
PATIENTS LIVING IN CARE HOMES	OR of Care Home Death vs Hospital Death (99% CI)									
(N=79,846)										
Unadjusted odds ratios	Ref	1.14	1.19	1.24	1.44	1.47	1.46	1.50	1.52	1.65
		(1.03-1.25)	(1.08-1.31)	(1.13-1.36)	(1.31-1.59)	(1.34-1.62)	(1.32-1.61)	(1.36-1.66)	(1.38-1.68)	(1.50-1.83)
Adjusted odds ratios‡	Ref	*1.08*	*1.06*	*1.05*	1.17	1.15	*1.11*	1.15	1.14	1.21
		(0.98-1.19)	*(0.96-1.17)*	*(0.95-1.17)*	(1.05-1.31)	(1.03-1.29)	*(0.99-1.25)*	(1.03-1.30)	(1.01-1.29)	(1.07-1.37)

* The variable Year of Death was not selected in the forward stepwise likelihood ratio selection procedure of variables in the logistic regression analysis

† Odds ratios adjusted for underlying cause of death, age, sex, education, living situation, urbanization level and available hospital beds. Odds ratios of covariates are reported in Table 4.

‡ Odds ratios adjusted for underlying cause of death, age, sex, education, urbanization level, available residential beds and skilled nursing beds in care homes, and available hospital beds. Odds ratios of covariates are reported in Table 4.

In our final model, the chance of dying out of hospital of those living at home was higher for cancer patients, those aged 85 or older, living in a multi-person household, living in moderate or low urbanized areas and in health care regions with less hospital beds. (Table 4)

Table 4 Adjusted odds ratio's of covariates in the logistic regression models of home death versus hospital death and care home death versus hospital death (table 3) of patients (aged ≥ 65y) who died of chronic life-limiting conditions 1998-2007

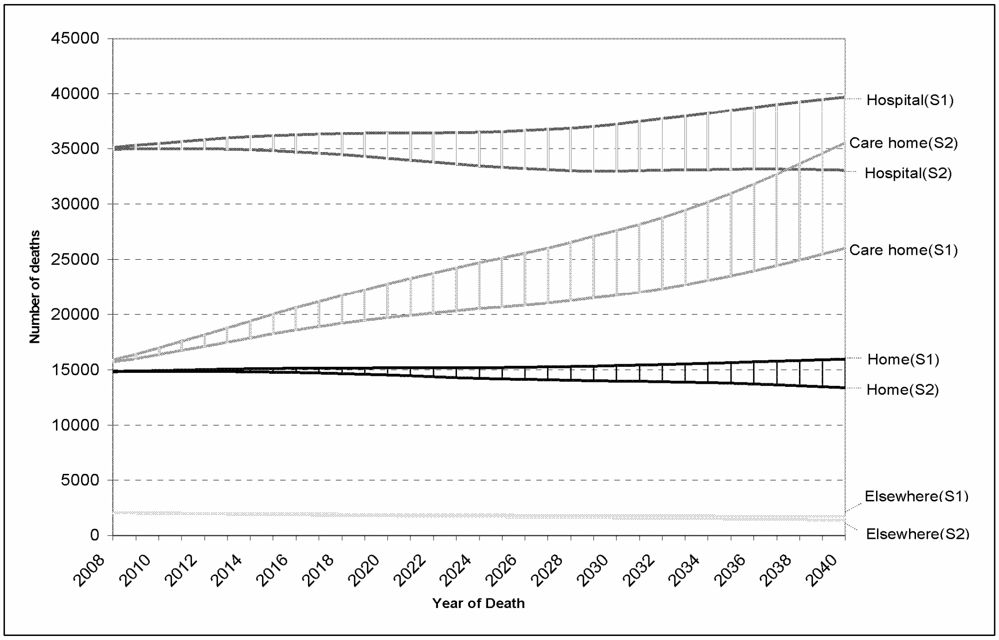
	Patients living at home (N=189,884)	Patients living in care homes (N=79,846)
	AOR of Home Death vs. Hospital Death (99% CI)	AOR of Care Home Death vs. Hospital Death (99% CI)
Cause of Death		
Cancer	1.17 (1.14-1.20)	Reference
Non-cancer	Reference	1.09 (1.04-1.15)
Age		
65-74 year	*1.01 (0.98-1.04)*	Reference
75-84 year	Reference	1.51 (1.40-1.64)
85+ year	1.28 (1.23-1.32)	2.18 (2.01-2.36)
Sex	NS*	
Male		Reference
Female		1.13 (1.09-1.18)
Education	NS*	
Low-unknown/other		1.19 (1.09-1.29)
Higher secondary/Higher		Reference
Living Situation		†
Single	Reference	
Multi-person Household	1.95 (1.89-2.01)	
Urbanization		NS*
Very Strong/Strong	Reference	
Moderate/Low	1.42 (1.38-1.46)	
Residential beds in care homes (Continuous per 1 bed/ 1,000 ≥ 65)	†	0.997 (0.996-0.999)
Nursing beds in Care homes (Continuous per 1 bed/1,000 ≥ 65)	†	1.015 (1.012-1.018)
Hospital beds (Continuous per 1 bed/1,000)	0.896 (0.884-0.910)	1.033 (1.006-1.061)

*: Not significant. The variable was not selected in the forward stepwise likelihood ratio selection procedure of variables in the logistic regression analysis
†: Variable was not included in the model

Care home death was more likely in the period 1999-2001 compared with 1998, in 2002-2006 compared with previous years and again in 2007 compared with all previous years. (Table 3) This unadjusted trend of decreasing chances of care home residents dying in hospital was adjusted significantly by the increasing availability of skilled nursing home beds in care homes (data not shown). The other variables did not adjust the trend of the decreasing odds of dying in hospital. In our final model, the chance of dying out of hospital of those living in care homes was still more likely in each year of the study period compared to 1998, except in 1999-2001 and 2004, (Table 3) and was more likely for those who died from non-cancer conditions, with a higher age, females, having a lower or unknown educational attainment and living in healthcare regions with less residential beds and more skilled nursing beds in care homes and more hospital beds.(Table 4)

Mortality (aged ≥ 1 year) is expected to rise from 65,435 in 2007 to 83,388 in 2040. The first scenario (S1), in which the age-and sex-specific distribution of place of death of 2007 was projected, shows an increase of both care home (from 14,792 in 2007 to 26,030 in 2040) and hospital deaths (from 33,856 to 39,714) (Figure 2). The number of deaths at home would rise slightly from 14,726 to 15,954). The second scenario (S2), for which we projected the 10 year trends forward to 2040, shows an increase in care home deaths to 35,545. Deaths at home and in hospital show a slight decrease to 13,380 and 33,076. In 2038, the proportion of care home deaths (41.15%) would exceed that of hospital deaths (40.53%) (data not shown). The proportion of deaths at home would drop from 22.5% in 2007 to 16.05% in 2040.

Figure 2 Projected Trends in Proportion of Home Deaths, Hospital Deaths and Care Home Deaths (2008-2040), based on 2 scenarios*



* Age- and sex-specific mortality projections of the Belgian National Planning Bureau were used to perform linear projections of numbers of deaths from 2008 to 2040 in all care settings starting from the age- and sex-specific proportions of deaths in the different care settings in the period 1998-2007. Two scenarios were considered. In scenario 1 (S1) future trends in place of death were projected starting from the age- and sex- specific distribution of place of death in 2007. In scenario 2 (S2) the projection was based on the age- and sex-specific percentage point change in place of death from 1998 to 2007.

8.4 Discussion

In Belgium in the period 1998-2007 the proportion of deaths in hospitals decreased and in care homes increased, while that of home deaths remained stable. The proportion of care home residents dying in hospitals dropped from 31.0% in 1998 to 21.5% in 2007. The trend of declining chances of dying in hospital of care home residents was largely related to the substitution of residential beds by skilled nursing beds in care homes. The odds of dying in hospital of those living at home did not diminish during the study period. Continuation of the trends in place of death during 1998-2007 would lead to more than double the number of care home deaths by 2040 and to a larger proportion of deaths in care homes than in hospitals.

For the first time trends in place of death were studied and related not only to shifts in underlying cause of death, age and sex of the deceased population, but also to changes in living arrangements, educational attainment, urbanization levels of the place of residence and availability of beds in hospitals and care homes. Trends in place of death proved to be related to changes in care levels in care homes. In contrast with previous research, our study considered all patients in all care settings over a 10 year period. Trends in place of death have not been studied in continental Europe before. Potential limitations of this study are connected to the use of death certificate data: possible unreliability of the certification and coding of some underlying diseases and sociodemographic information, missing values for variables related to the background of the deceased and the lack of information on factors which affect place of death.(28,29) Multilevel modeling may have been an alternative appropriate approach to analyze data related to individuals and geographical areas.

Patterns in the previous century showed an increasing hospitalization of death. Concentration of health care in hospitals and the reduced availability of informal caregivers due to sociodemographic and economic developments lead to a growing number of hospital deaths, and the proportion of deaths occurring at home decreased from more than half to a quarter or less.(30,31) From the 1980s onwards a decrease in hospital deaths was observed in many countries, both in cancer and non-cancer patients.(11,12,14,15,17,20,21,23,32) In many countries, this trend was not balanced by an increase in home deaths,(18-20) not even in cancer patients,(11,14,15) because of the ongoing sociodemographic and economic dynamics that caused the hospitalization of death trend in the first part of the century, and the growing availability of other care options for end-of-life care, hospices in some countries and care homes in others. In consequence the proportion of care home deaths in the UK, Canada, USA, and Australia increased in the last twenty years of the previous century by 4% to 10%.(11,17,20,21,23) In our findings additional care options in care homes supported shifts in place of death in Belgium. The additional availability of skilled nursing care beds in care homes replacing residential beds resulted in a considerable growth of care home deaths, especially among existing residents. The latter is not obvious, in light of the large-scale transfer of care home residents to hospital at the end of life observed previously.(33,34) Because of the shift towards skilled nursing care beds the odds of care home residents dying in hospital decreased drastically in a period of only ten years. Since the trend of decreasing hospital death risk of care home residents remained significant after adjusting for available skilled nursing beds in care homes, this trend is not just a consequence of an increase in skilled nursing resources but probably also of the development of palliative care in care homes made possible by the appointment, from 1997, of in-house palliative care reference persons, responsible for supporting, coaching and educating caregivers.(9) Involvement of these palliative care reference persons is probably associated with reduced odds of dying in hospital of care home residents since supporting out-of-hospital death is one of there main objectives(9) and with the rapid development of policies on advance care planning in Flemish care homes from 2000 onwards, resulting in a do-not-hospitalize option available in 90% of care homes by 2006.(35)

The implications of our findings are considerable. Between 1998 and 2007 an increase of more than 20 000 skilled nursing beds in care homes, replacing residential beds, succeeded in reducing the hospitalization risk of care home residents and to some extent of older patients living at home. Further reducing that risk during the coming decades or even maintaining it at the 2007 level, in the context of a rapidly ageing population and a rapidly growing number of deaths, will require a massive investment in skilled nursing home beds and other end-of-life care options outside hospitals; care homes could become the central location for end-of-life care in Belgium in the future, replacing private residences in the first part of the 20th century and hospitals thereafter. The economic implications of this trend are very important and should be considered. Governments should provide sufficient skilled nursing resources in care homes to respect patients' preferences and needs.

Even if the facilities are present, providing quality end-of-life care in care homes will require a palliative care approach and additional investment in palliative care services as treatment of pain and symptoms is often poor and communication about the needs and preferences of terminally ill care home residents is inadequate, due to insufficient staffing, lack of time and resources and inadequate financial reimbursement of palliative care costs from healthcare insurance.(36-38)

8.5 Conclusions

We found that in Belgium between 1998 and 2007 the proportion of deaths in hospitals decreased (-3.4%) and increased in care homes (+4.3%), while that of home deaths remained stable. This trend was largely explained by the proportion of care home residents dying in hospitals dropping from 31% to 21.5%, a shift strongly related to the substitution of residential beds by skilled nursing beds in care homes. Continuation of this trend would lead to more than double the number of care home deaths by 2040. The implications of our findings are considerable. Care homes may become the main locus of end-of-life care in the future and governments should provide sufficient skilled nursing resources in care homes to fulfill the preferences and needs of their residents.

Authors' contributions

DH and JC performed the statistical analyses and drafted the manuscript. All authors participated in the conception and design of the study, the acquisition of data, the interpretation of data, revising the manuscript critically for important intellectual content, and have given final approval of the version of the manuscript to be published.

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Declaration of competing interests

The authors declare that they have no competing interests.

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Part V

Discussion

9 Discussion of methods, main findings, general discussion and implications

The aim of this dissertation was to study specific issues in place of death. Firstly, we cross-nationally examined place of death and factors related to place of death of people with cancer and with dementia. Secondly, we addressed metropolitan and nonmetropolitan variation in place of death in Europe, and place of death and circumstances at the end of life in Brussels metropolitan region. For the latter we examined the association with palliative care involvement. Finally, we examined the association of palliative care services and place of death in different health settings and studied trends in place of death over a ten-year period, in relation to epidemiologic, sociodemographic and environmental shifts and changes in availability of different types of beds in care homes and hospitals.

In this discussion section, we start with considering the strengths and weaknesses of the methods used in the different studies before presenting a summary of the main findings in answer to the research questions. Then we give an overall discussion of the most important results throughout the different chapters and in connection with each other. Finally, we consider implications for future end-of-life care policies, for professional caregivers and for researchers.

9.1 Discussion of methods

9.1.1 Death certificates

In this dissertation, information from death certificates was used to study cross-national differences in place of death in cancer patients and dementia patients,(Chapters 2,3) cross-national differences in metropolitan/nonmetropolitan variations in place of death across European countries (Chapter 4), place of death in Brussels metropolitan region,(Chapter 5) and trends in place of death during a ten year period in Belgium.(Chapter 8)

A principal strength of death certificate data is that information on all deaths and not just a sample of decedents is included in the data file.(1) This offers the opportunity of studying specific subpopulations with respect to underlying cause of death, place of residence, health care settings and sociodemographic characteristics such as age, sex, or socioeconomic status. Studying place of death in those subpopulations using just samples would probably have resulted in indecisive conclusions due to insufficient statistical power.

Although information about the deceased and their environments was limited in a number of countries, linkage of death certificate records to other databases allowed us to integrate individual-level information about factors known to be associated with place of death.(2;3) Using the zip-code of the decedent's place of residence, information about their environment, could be integrated into the death certificate data such as the available hospital and care home beds in their healthcare catchment (service) area, or the urbanization level of the place of residence.

Uniform codification of causes of death according to the International Statistical Classification of Diseases and Related Health Problems and comparable operationalizations of place of death and sociodemographic characteristics allowed us to study place of death cross-nationally. Consistency of death certificates over time allowed study of trends in place of death over a period of a decade in Belgium.

Unfortunately, not all the relevant categories of place of death were available in the death certificate data from all countries. In some countries just two categories are registered or coded, eg home and any institutional setting or hospital and any other setting, impeding detailed analysis and cross-national comparisons. Place of death in palliative care institutions, such as inpatient hospices or palliative care units (PCUs) is not coded separately in many countries, hampering the evaluation of end-of-life care policies with respect to place of death.

A documented defect of death certificates is the accuracy of cause of death certification.(4;5) This may in particular be the case in certifying dementia-related diseases as underlying cause of death and the geographical variation in the prevalence of dementing disorders might be partially related to certification practices.(6) The reporting of Alzheimer's disease in advanced stage or in nursing home settings on death certificates was found to be more reliable.(7)

The correctness of information on demographic characteristics on death certificates is found to be generally acceptable, but may be less accurate for ethnic minorities.(8;9) This may become a methodological issue in future, especially in metropolitan regions with a considerable subpopulation of foreign descent. The accuracy of information on educational attainment, considered an indicator of socioeconomic position, may be acceptable,(10) and is enhanced when using broader categories in statistical analysis.(11;12) In Belgian death certificate data the proportion of the deceased for whom information on educational attainment was missing, was nevertheless considerable in Brussels metropolitan region and therefore an ecological variable was used to assess socioeconomic status of the decedents.(Chapter 5)

In our study on place of death in Brussels Metropolitan region, we used nationality as a proxy variable for ethnic background, being aware that in recent years many immigrants have obtained Belgian nationality and were considered Belgian in our analysis.

Although, death certificate data from some countries contain information on the socioeconomic position and family background of the deceased and death certificates can be linked to other databases, no information was available on a number of factors for which there is substantial evidence that they affect place of death, such as length of disease, functional status, patient and caregiver preferences, ethnic background, availability and quality of home care, and previous admissions to hospital.(2) Also information about the quality of the dying process was lacking.(1)

Information about the individual decedent's social position or level of social support was not available from the death certificates or via linkage in the Netherlands and England. Therefore, we had to use contextual variables for income and social support to compare the socioeconomic status of the environment of decedents between countries. As the available contextual variables differed across the countries studied, we used these variables to measure relative differences in income and level of social support between metropolitan and nonmetropolitan regions within each country.(Chapter 4)

In focussing on a selection of patients with chronic life-limiting diseases,(13-16) we were able to study place of death in a palliative population which could theoretically express preferences and plan the end-of-life care of their choice and benefit most from appropriate end-of-life care.(Chapters 4, 5, 7)

In contrast to most previous research,(2) hospital death risk in Belgium was not only analysed in those living at home but also separately in those living in care homes, since these subpopulations differ substantially with respect to age, sex, social support, functional ability and underlying causes of death and because transfers at the very end of life to hospital for care home residents presents a specific issue worth studying.(Chapter 5, 8)

9.1.2 Sentinel surveillance networks

A major strength of the study examining the association between involvement of palliative care services and place of death in Belgium (Chapter 7) was that it assessed all important available palliative care services in all health care settings across all patient groups, taking into account the level of primary health care involvement and personal and environmental factors related to the deceased. Information about involvement of palliative care services and health care at the end of life in people who died non-suddenly or expectedly in 2005 and 2006 was provided by the sentinel network of general practitioners (GPs) in Belgium.(16)

The Belgian sentinel network of GPs is representative of all GPs in Belgium and covers 1.75% of the Belgian population. Family physicians have a central role in Belgian health care and 95% of the Belgian population had a family GP in 2008.(17) Information from this network can be considered reliable. It was established in 1979 and has a long tradition of epidemiological data collection with a stable and motivated group of participating GPs. An advantage of the weekly registrations is that the recall bias remains limited because of the short time between the time of death of a patient and the moment of completing the registration form that we used for our study.(16) Given the limited risk of recall bias and the representativeness of the sentinel network of the Belgian GPs, we can assume that the sample of deaths for our study is representative of the Belgian deceased during the study period.

An advantage of using retrospectively collected data (‘studying the death’), such as data collected by sentinel networks, post-mortem surveys and death certificates, is that the risk of selection bias is much smaller compared with using information collected from prospectively recruited terminally ill patients (‘studying the dying’) on the basis of a terminal prognosis, since diagnosis and prognosis of terminal illness is often inaccurate.(18;19) Inclusion of those who died non-suddenly or expectedly results in a clear denominator of people who could have received care with an end-of-life intent.

Data collected retrospectively via a sentinel network of GPs may also have weaknesses. Although the time gap between death and registration is limited to one week because of the weekly registrations, reconstructing involvement of all types of care during the final three months of a patient’s life may be difficult. It could also be that, though most GPs are usually kept informed about the care of their patients during hospital admissions, involvement of palliative care services in hospitals might be underestimated. No information was available on the content of palliative care, the moment in the disease course when it was initiated and the period during which it was provided. The association of palliative care services involvement and place of death may be partly explained by confounders not included in our analyses, eg the preferences or coping skills of informal caregivers or the patient's functional status, symptoms and other problems. Certain patient groups may systematically have had more chance to be referred to palliative care services, as a result of which, place of death would not be a consequence of palliative care involvement but rather of particular patient characteristics. Also inferences about causality between involvement of palliative care services and out-of-hospital death should be made with great caution, since the causal relationship may not be so clear and people who had already decided to die at home or in their care home may consequently have made an appeal to palliative care services.

9.1.3 Physician survey using death certificates

The data used in the retrospective mortality follow-back study describing circumstances at the end of life in Brussels, came from a representative sample of deaths in Brussels Capital Region in 2007. A retrospective design offers advantages over a prospective approach, since a retrospective design is more appropriate to describe the circumstances and characteristics of death and the period shortly before, of all dying people, irrespective of whether they had been prospectively identified as being terminally ill and irrespective of whether they received end-of-life care of not.(18;19) This mortality follow-back survey is thus appropriate to collect population-based information on circumstances in the last days of life and access to health care.(18)

Nevertheless, results from studies with retrospective designs should be interpreted with caution.(20) Non-response bias cannot be excluded as the response rate was 41.3% and may be related to responder fatigue due to multiple deaths per physician. Non-response analyses however showed that reasons for not participating are predominantly practical in nature (eg the physician did not have the time to participate, or was not able to participate due to patient identification issues), leading us to believe the final response sample was not systematically distorted. The 1-2 month lag between death and sending the questionnaire may further result in recall bias. Since information about the circumstances of death and dying was provided by the attending physician, some may be more accurate (eg clinical symptoms in the last 24 hours) than other information (eg preferred place of death). Relatives of the deceased could be more reliable for some information, but death certificates do not allow for the identifying of relatives.(21-23)

9.2 Main findings

The main findings are presented here in answer to the research questions posed in the introduction to this dissertation:

9.2.1 Which patients with cancer die at home? A study of six European countries using death certificate data

In 2003 (Italy:2002) 238,216 people died of cancer in Belgium, Italy, the Netherlands, Norway, England and Wales, ranging between 25.5% of all deaths in Wales and 29.7% in Italy. Gastrointestinal and respiratory cancers were the most prevalent cause of death in all countries. We found a wide variation of deaths from cancer occurring at home - 12.8% in Norway, 22.1% in England, 22.7% in Wales, 27.9% in Belgium, 35.8% in Italy, and 45.4% in the Netherlands. Cancer deaths occurred at home more frequently compared with deaths from non-cancerous conditions (except in Norway).

Death from solid cancers (relative to haematological cancers) enhanced the chances of dying at home in all countries. Being married (relative to all other types of marital status) improved the chances of dying at home in Belgium, the Netherlands and Norway, and (relative to not being married) in Italy. Being female and being older decreased the chances of dying at home, except in Italy where the opposite was true and in Belgium with no diverging chances for dying at home between men and women. Higher educational attainment was associated with higher chances of dying at home, in all countries where this information was available from death certificate data. Higher hospital bed and care home bed availability decreased the chances of dying at home in Belgium, Italy and Wales, but not in the Netherlands and Norway. In England we found that living in a region with higher availability of care home beds increased the chance of dying at home. Living in lightly urbanized or rural areas (relative to heavily or very heavily urbanized areas), was associated with higher chances of dying at home, except in England where living in very heavily urbanized areas increased the chance of dying at home.

The cross-national differences in the proportions of people with cancer dying at home that we found in six European countries were remarkable and the chance of dying at home was differently related to demographic and environmental factors in the different countries. These differences seem to be related to country-specific social and health care systems and cultural factors that need to be considered when developing strategies to support out-of-hospital death.

9.2.2 Place of death of older persons with dementia: a study in five European countries

In our study using death certificate data we found that in 2003 4.6% of the population aged 65 and older in Belgium, the Netherlands, England, Wales, and Scotland died from dementia-related diseases. In all countries, a majority of people with dementia died in care homes, ranging from 50.2% in Wales to 92.3% in the Netherlands. Of those who died in care homes in the Netherlands, 89.4% died in a specialised nursing home and 10.6% in a residential home for the elderly. Hospital deaths were 2.8% in the Netherlands, 22.7% in Belgium, 33.9% in Scotland, 36.0% in England, and 46.3% in Wales. Home deaths were 5% or less, except in Belgium where they were 11.4%.

After adjusting for differences in age and sex of the deceased and the average availability of hospital and care home beds in the health care region of residence, country variation remained substantial, with higher chances of dying at home or in a care home (relative to in a hospital) in the Netherlands and Belgium compared with the UK countries. The chance of dying at home relative to in a care home was highest in Belgium and lowest in the Netherlands. The unadjusted between–country variation of those likely to die in a care home relative to a hospital was adjusted by the higher availability of care home beds in some countries, the Netherlands in particular, relative to other countries.

The provision of adequate long-term care facility beds with appropriate staffing and an appropriate approach to end-of-life care could help people with dementia avoid dying in hospital and could contribute to the quality of end-of-life care of many elderly people in Europe in the future.

9.2.3 Place of death in metropolitan regions: metropolitan versus nonmetropolitan variation in place of death in Belgium, the Netherlands and England

Using death certificate data from 2003 in Belgium, the Netherlands and England, we found that lower proportions of those living in metropolitan regions died at home, and higher proportions died in hospitals compared with those living in nonmetropolitan areas. In the Netherlands and Belgium higher proportions died in care homes in metropolitan areas, but in England the opposite was true.

After adjusting for differences in illness, sex, age, social support, income and available hospital beds, metropolitan populations in all countries were more likely to die in hospital (relative to at home), compared with nonmetropolitan populations, although the metropolitan/nonmetropolitan disparity was larger in Belgium than in the Netherlands and England. In Belgium, the lower level of social support available to the metropolitan terminally ill partially explained the metropolitan/nonmetropolitan contrast. Care home death, relative to hospital death, was more likely for nonmetropolitan populations in England compared with metropolitan populations. The higher likelihood of nonmetropolitan populations dying in a care home in England was explained partially by the higher availability of care home beds for nonmetropolitan populations.

Differences in population characteristics, social support or availability of beds in hospitals and care homes could not explain entirely the metropolitan/nonmetropolitan contrast in hospital death risk. Our findings point to the need for a specific metropolitan approach to end-of-life care, taking into account the metropolitan social, cultural and environmental context.

9.2.4 Determinants of place of death in Brussels metropolitan region

Of 3,672 deaths from chronic life-limiting conditions (36.2% of all deaths) in 2003 in Brussels Capital Region, 15.1% died at home, 63.0% in hospitals, and 21.6% in care homes. Of those residing in care homes, 23.8% died in hospital.

Of individuals living at home, home death (relative to hospital death) was more likely for those living in districts with a higher socioeconomic status, those who died of a non-cancer condition (relative to those who died from cancer), and those living in a multi-person household relative to those living alone.

Of those living in care homes, care home death (relative to hospital death) was more likely for those living in districts with a high socioeconomic status, those who died of non-cancer conditions, and those with a higher age.

The overall low proportion of people dying in their familiar surroundings in Brussels implies the need for a specific strategy aimed at facilitating dying in the place of choice in metropolitan regions. The inequality in chances of dying out-of-hospital between residents of different districts in Brussels highlights the need for a district-specific approach in metropolitan regions.

9.2.5 How do circumstances at the end of life of patients using palliative care services differ from those not doing so in Brussels metropolitan region?

In 2007, 59% of deaths in Brussels Capital Region were non-sudden or expected as judged by the attending physician. Of these, 11.7% occurred at home, 62.4% in hospitals, and 24.1% in care homes. Palliative care specialists were involved in 23.1% of all expected deaths. Palliative care involvement was more likely in cancer patients compared with non-cancer patients and was less likely for those dying in care homes relative to those who died at home or in hospital.

Of the 26.6% who died expectedly and of whom the attending physician was aware of the preferred place of death, 52.3% preferred to die at home. Of those, congruence was 66.1%. Of those where the attending physician was not aware of the preferred place of death 3.7% died at home, 75.3% hospital, and 20.9% in care homes. Palliative care involvement increased the chances of the attending physician being aware of the preferred place of death and of congruence between the preferred and actual place of death.

Of the terminally ill in Brussels metropolitan region, 6.8% died alone. Relatives or friends were present in 46.5% of cases, nurses in 73.4% and physicians in 43.4%. Palliative care involvement, living in a multi-person household, and dying at home increased the chance of dying surrounded by relatives or friends. Living in a care home, dying in a care home or in hospital, and being female decreased the chance of dying surrounded by family or friends.

Twenty-nine and a half percent of the dying were in pain in their last 24 hours and 7.9% in severe pain. The symptoms most often present were drowsiness (79.8%), lack of appetite (75.3%), being unconscious (74.3%) and tiredness (73.3%). Palliative care involvement was associated with a lower chance of shortness of breath, a lower chance of low or very low feeling of well-being and a higher chance of severe tiredness.

In general, circumstances at the end of life of Brussels metropolitans were not optimal but were improved if palliative care was involved. Our findings provide evidence for stronger involvement of palliative care as a strategy to improve circumstances at the end of life in metropolitan areas such as Brussels.

9.2.6 Involvement of palliative care services strongly predicts place of death in Belgium

In Belgium in 2005 and 2006, 23.8% of people who died non-suddenly or expectedly as judged by their GP died at home, 39.3% in hospitals (excluding inpatient palliative care units), 26.7% in care homes and 10.1% in inpatient palliative care units. Multidisciplinary palliative home care teams were involved in the end-of-life care of 21.8% of those living at home, palliative care reference persons in 29.1% of those living in care homes, and multidisciplinary palliative support teams in hospitals in 12.4% of those admitted to hospital at least once in the final three months of life.

Individuals living at home were more likely to die at home (relative to in hospital) if multidisciplinary palliative home care teams were involved, a preference for dying at home was known by their GP, informal care was involved often and when living in a health care region with, on average, fewer hospital beds. Those living at home and admitted to hospital at least once in the final three months were more likely to die at home (relative to in hospital) if multidisciplinary palliative home care teams were involved, but less likely if multidisciplinary palliative support teams in hospitals were involved. Also a preference for dying at home and frequent involvement of informal care increased the chance of dying at home. Those living at home were more likely to die in an inpatient palliative care unit (relative to in hospital) if multidisciplinary palliative home care teams were involved, but not if hospital teams were involved. Chances of dying in an inpatient palliative care unit also increased if the cause of death was cancer, if the deceased was female and if home care was involved frequently in the last three months of life.

Those living in care homes were more likely to die in their care home of residence and not in hospital if the palliative care reference persons from their care home were involved, their GP was aware of their preference to die in the care home of residence, the cause of death was cancer, and the deceased was female.

The unadjusted bivariate association found between frequent GP involvement in the final three months and care home death or home death was adjusted completely when it accounted for palliative care services involvement and the presence of a preference to die in the place of residence in cases of care home residents, and significantly in people living at home.

Involving multidisciplinary palliative home care teams and palliative care reference persons could support people dying out-of-hospital. Involvement of palliative care teams in hospitals was not positively related to out-of-hospital death. Health care policies should consider strategies to improve timely involvement of palliative care services in all health care settings. GPs can play an intermediate role in supporting out-of-hospital death by eliciting their patients’ preferences and involving palliative care services to meet those preferences.

9.2.7 Recent and future trends in place of death in Belgium: a shift from hospitals to care homes

In 1998-2007, 661,773 people aged one year or older died in Belgium (Flanders and Brussels Capital Region). The proportion of deaths in hospitals decreased from 55.1% in 1998 to 51.7% in 2007 and that of deaths in care homes increased from 18.3% to 22.6%. The home death rate fell by 0.5%.

The hospital death rate declined (for those aged ≥65 years) and that of care home death rose for all living situations (ie living in a multi-person household, at home alone, in a care home). Home death rates of people living alone or in a multi-person household decreased and those of persons living in care homes increased. The decline of the hospital death rate was largest for those living in care homes (from 31.0% to 21.5%), and was balanced by the increase in the care home death rate (from 66.8% to 75.3%) and home death rate (from 1.6% to 2.7%). The care home death rate increased of people living alone (from 5.7% to 8.9%), or in a multi-person household (from 3.7% to 6.6%).

Care home residents (for those aged ≥65 years, who died from chronic life-limiting conditions), became increasingly more likely to die in their care home of residence in the period between 1998 and 2007. This trend was explained significantly by the increasing availability of skilled nursing beds in care homes during this period. The chances of dying out-of-hospital of those living at home did not increase during the study period.

Projecting the observed trend of place of death between 1997 and 2008 using an age- and sex-specific mortality projection, shows an increase in the proportion of care home deaths that would exceed the proportion of hospital deaths in 2038. The proportion of home deaths would decrease steadily.

Care homes may become the main locus of end-of-life care in the future. Governments should provide sufficient skilled nursing resources in care homes and adequate palliative care to fulfil the end-of-life care preferences and needs of their residents. The economic consequences of the expected growth in care home deaths should be considered.

9.3 General Discussion

9.3.1 Place matters in place of death

A consistent finding through our research was that place of residence influences the place where people die. Even controlled for social, demographic and environmental covariates, geographical variation in place of death remained significant and substantial. This was the case for country variation in place of death in cancer patients and dementia patients in Europe, for metropolitan/nonmetropolitan variation in home death and care home death in Belgium, the Netherlands and England, and for intra-metropolitan variation among districts of the Brussels metropolitan region.

9.3.1.1 Cross-national differences in place of death

We found substantial cross-national differences in the prevalence of home deaths in cancer patients and non-cancer deaths in 6 European countries: Belgium, Italy, the Netherlands, Norway, England, and Wales.(Chapter 2) The fraction of cancer patients dying at home varied from just 12.7% in Norway to nearly half (45.4%) in the Netherlands, and even between neighboring countries the difference in home death rates was nearly 20 percentage points. The between-country variation in place of death in Europe is comparable to the between US state or US region variation found in previous research, with home death from cancer in 2001 ranging from more than 60% in Utah to less than 25% in South Dakota.(24-26)

Country variation in place of death of cancer patients may be explained by factors related to national cultures and values in health care, the characteristics of health care systems and the delivery of palliative care.

Differences in national cultural dimensions were found to result in different types of interaction between general practitioners and patients.(27) Two of these dimensions found by Geert Hofstede appeared to be relevant: the power distance index, which is the extent to which less powerful members of societies accept and expect that power is distributed unequally, and the uncertainty avoidance index - the extent to which members of societies feel either uncomfortable or comfortable in unstructured situations.(28) GP consultations are longer in countries with low power distance index, such as the Netherlands, and there is more room for unexpected information exchange. In countries with higher power distance index, such as Belgium, roles of physicians and patients are described and fixed. In countries with high uncertainty avoidance index, such as Belgium and Italy, less attention is given to rapport-building between patients and physicians.(27) In terminally ill patients, this may result in less communication about preferences in end-of-life care.

The culture of open communication between patients and their general practitioners in the Netherlands may result in higher awareness by GPs of the end-of-life care preferences of their patients and explain to some extent the high number of home deaths. Previous research showed that 54% of Dutch GPs were aware of their patients' preferred place of death against 46% in Belgium and that the GP was informed by the patient himself/herself in 84% of cases in the Netherlands against 63% in Belgium.(29;30) Open communication between patients and GPs may also result in higher prevalence of advance care planning. Previous research showed that the prevalence of advance directives in the Netherlands (16.1%) was twice as high as in Belgium (7.6%),(31) and this may explain partially the low number of hospital deaths in the Netherlands compared with other European countries, as it explained the low hospital death rates in Oregon in the US.(24;32)

The relatively high proportion of Italian cancer patients dying at home is probably related to the societal expectation in Italy that families take care of their elderly and sick family members,(33) and to the concomitant high preferences of Italian cancer patients to die at home.(34) Costantini and colleagues found that 97% of Italian cancer patients had a non-professional caregiver and Beccaro reported in 2006 that 94% of cancer patients preferred to die at home with minimal variation across the country.(34;35) The increasing chance with age of dying at home is probably related to the fact that there is low provision for long-term care facilities for older people,(33) and this corroborates the findings of a national survey on place of death in cancer patients in Italy in 2006 that only 6.5% died in nursing homes.(34) Our finding that divorced or separated Italian cancer patients had similar chances of dying at home compared with married cancer patients, may be related to Costantini's finding that in 41.7% of cases the non-professional caregiver was the child.(35)

The characteristics of national health care systems probably also contribute to the cross-national variation in place of death in cancer patients. In contrast with health care systems that provide unrestricted access to the services of medical specialists, as is the case in Belgium, the Dutch health care system can be considered a referral system in which GPs refer patients to medical specialists and play a central role as the first-contact physician for all patients.(36) GPs act as gatekeepers in the Dutch health care system, handling solely 96% of the medical problems that are presented to them, and regulating strongly access to more specialized medical services.(37) Dutch GPs also have a strong family practice orientation delivering comprehensive care and home visits to their patients.(38) GP involvement has been shown to be very important in successfully managing end-of-life care and attaining congruence between preferred and actual place of death in Europe and Canada, resulting in a diminished risk of hospital death.(29;30;39;40) Both the strong gatekeeper role and family practice orientation are probably part of the explanation why the fraction of home deaths among cancer patients in the Netherlands is particularly high compared with other countries.

Hospital bed availability and accessibility, is another aspect of health care delivery that can affect and explain cross-national variation in place of death in cancer patients, as was concluded in a systematic review.(2) US state variation in hospital deaths of cancer patients, was to some extent explained by the variation in availability of hospital beds.(25) In line with previous research,(2) we found that higher availability of hospital beds was related with a higher risk of not dying at home in Belgium, Italy and Wales, though our findings showed that regional variation in hospital bed availability was not related to home death risk in cancer patients in the Netherlands, Norway and England. This may also be related to the referral health care system in these countries resulting in higher primary care involvement and better managed end-of-life care, and possibly neutralizing the influence of hospital bed availability on place of death.

Models of palliative care provision differ substantially between countries and may also be related to variations in home deaths of cancer patients in Europe. In Italy and the Netherlands palliative care services, by the end of the late nineties were more orientated towards care at home, whereas in Belgium and the United Kingdom in-patient hospice and palliative care beds were relatively more established. By 1999, 286 palliative home care teams were operating in the Netherlands (although 240 were voluntary) against 45 in Belgium.(41) The in-patient hospice and palliative care unit bed to population ratio, was 1:17,866 in the UK, 1:28,212 in Belgium, 1:131,092 in the Netherlands and 1:1,913,333 in Italy.(41)

Also, in dementia patients, the variation in place of death between the neighboring countries Belgium, the Netherlands, England, Scotland and Wales was striking.(Chapter 3) Even after adjusting for differences in sex and age of dementia populations and availability of hospital and care home beds, dementia patients living in the Netherlands were found to have a 15 times higher chance of dying out-of-hospital than those in England, and dementia patients in Belgium were found to have a 2.5 times higher chance of dying at home relative to in a nursing home. Availability of care home beds, particularly high in the Netherlands, partially explained the between-country variation as it explained the state variation in the US.(25)

But even after adjusting for the much higher availability of care home beds in the Netherlands, the risk of hospital death was much smaller for Dutch dementia patients. We found that of the 92.3% of dementia patients who died in care homes in the Netherlands, 89.4% died in specialized nursing homes (‘verpleeghuis’) and just 10.6% in general care homes for the elderly. These specialized nursing homes hold a special position in the Dutch health care system, providing specialized geriatric care for their residents by specially trained nursing home physicians, who are employed by the nursing home.(33;42) This health care setting and context appears to result in different roles for Dutch nursing home physicians compared with their US counterparts. In cases of dementia patients becoming acutely ill with pneumonia, Dutch nursing home physicians were found to take up more active roles in treatment decisions compared with US physicians, to base treatment on the best interest of the patient, and to base decisions on an intimate knowledge of the patients made possible by frequent contact.(43) Similar to the gatekeeper role of family physicians in patients residing at home, nursing home physicians assume a gatekeeper role with dementia patients in nursing homes. In Belgium and other countries in Europe, the attending physician in care homes is usually the family physician who may have less of an overview of the patient's situation and play a less active role in managing the end-of-life care of dementia patients, possibly resulting in more transfers to hospital and eventually in hospital death. The other side of the Dutch model is the quasi-complete institutionalization of end-of-life care of dementia patients which may have considerable economic consequences.(44) End-of-life care for dementia patients seems to be more concentrated in hospitals in the UK compared with the Netherlands and Belgium and the high hospital death rates of dementia patients in the UK may also be related to the provision of long-term care services for elderly people in hospitals.(33)

9.3.1.2 Metropolitan/nonmetropolitan variation in place of death

We found significant variation in place of death between metropolitan and nonmetropolitan populations and this finding was consistent across European countries.(Chapter 4) Metropolitan residents living at home were found to be more likely to die in hospital than their nonmetropolitan counterparts, even after adjustment for differences in illness, sex, age, income, social support and available hospital and care home beds in the health care catchment area. The metropolitan/nonmetropolitan contrast was significantly larger in Belgium compared with England and the Netherlands. This was partially explained by a relatively lower degree of social support in Brussels Capital Region and the city of Antwerp compared with the rest of Flanders. Care home death was more likely in English nonmetropolitan populations and was partially explained by the higher availability of care home beds for nonmetropolitan populations.

The difference in social support - Brussels has more people living at home alone in all age categories,(45;46) explained part of the higher chances of dying in hospitals in Belgium. Differences in underlying cause of death, age, and income could not be related to the metropolitan/ nonmetropolitan contrast; although income was measured on an aggregated level and an individual measure of socioeconomic status might have resulted in other findings. Other population characteristics, not measured in our studies, could be relevant. The ethnic diversity of metropolitan populations - half of Brussels population is from foreign descent although still underrepresented in the oldest age categories - may explain part of the metropolitan/nonmetropolitan contrast, since ethnic minorities were consistently found to have higher chances of dying in hospital in a systematic literature review in 2006.(2) This could be the result of stronger preferences among people of ethnic minorities to spend their last days in hospital,(47) or inequity of minority populations to access of community palliative care services.(48) Metropolitan populations in general could have different preferences with respect to place of death than nonmetropolitan populations. Preference for hospital death was 20.6% in our study (Chapter 5: a distinction between hospital and a palliative care unit, often affiliated with a hospital, was not made), while it was 11.3% for the whole of Belgium (hospital: 4.7%; PCU: 6.6%), (30) and 12% (hospital: 2%; PCU/hospice: 10%) for the whole of the Netherlands.(29) The higher preference for hospital death in Brussels, which might in fact be a higher preference for death in a PCU, could be the result of the metropolitan terminally ill anticipating 'urban' barriers to the provision of end-of-life care at home. The lack of social networks in urban populations could also affect the place of death in an indirect way, as having limited social networks was found to be related to higher caregiver burden in caregivers of terminal cancer patients in the US.(49)

Differences in health care provision or health care use in urban and non-urban regions could be another part of the explanation. Brussels residents less often have a family physician and have fewer contacts with a family physician compared with the rest of Belgium.(17;50) Given the association between primary care continuity and attaining favorable outcomes of end-of-life care such as out-of-hospital death,(39;40) this can contribute to the understanding of the metropolitan/nonmetropolitan contrast. Moreover, family physicians play a central role in referring patients to palliative home care.(51) Although Belgian GPs don't have a decisive gatekeeper role in referring patients to specialized health care, they do play a gatekeeper role in referring their patients to specialist palliative care services such as palliative home care and in allowing higher reimbursements for palliative care and other benefits, since a certificate of prognosis of three months or less by a family physician is required.(52) Not surprisingly, in 2003, far fewer terminally ill patients in Brussels received compensation for the cost of palliative home care,(53) and applied for compassionate leave to provide care to a relative compared with the rest of Belgium.(54) In line with these findings, hospice enrollment in the US was 13% in urban settings versus 38% in urban/rural and 49% in rural settings in 1999-2000.(51) This corroborates our finding that a fairly low proportion of patients who may benefit from palliative care, were found to have actually used specialist palliative care services in Brussels metropolitan region.(Chapter 6) In the Flemish region, a retrospective survey found that about 40% of people dying non-suddenly accessed palliative care services.(55) The 23% found in Brussels can thus be considered as low.(Chapter 6)

The availability of hospital beds in the metropolitan regions of Belgium, the Netherlands and England was systematically higher than in nonmetropolitan regions, but the difference was small and it was not a factor that explained the metropolitan/nonmetropolitan contrast in hospital death risk, although the high concentration of teaching hospitals in metropolitan regions may result in more aggressive care at the end of life.(56) Inpatient palliative care on the other hand, such as beds in inpatient palliative care units in Belgium, may be more available in metropolitan regions and to some extent explain the different patterns in place of death in metropolitan and nonmetropolitan regions. The number of beds in inpatient palliative care units, often allied to hospitals, was in 2003, 5.4 per 1,000 deaths in Brussels metropolitan region versus 3.2 per 1,000 in Flanders.(57) Since death in an inpatient palliative care unit is coded as a hospital death on Belgian death certificate data, and the proportion of deaths in inpatient palliative care units in 2006 was estimated at 10.4%,(30) the differential hospital death risk we found in Belgian metropolitan regions compared with metropolitan regions in England and the Netherlands may, to some extent, be a coding issue since death in palliative care institutions, mainly hospices, is coded as a separate category in England and as ‘other’ in the Netherlands.

Another barrier to the provision of end-of-life care at home in metropolitan regions may be the physical environment. Houses in the Brussels metropolitan region are sometimes small and not very comfortable and are often apartments in older buildings without a lift. The latter is the case for 14.3% of all Brussels' dwellings and can mean unsuitable housing conditions for receiving care or providing end-of-life care at home.(45;46) In addition, characteristics of the neighborhood were found to play a role in the functional decline of older people. Excessive noise, inadequate lighting and heavy traffic in particular, conditions that may be more common in big cities, were associated with higher risk of overall functional loss and functional loss of the lower extremities in the US, (58) and may lead to admission to long-term care facilities but possibly also to palliative care units or hospitals at the end of life.

9.3.1.3 Intra-urban variation in place of death

Intra-urban variation in place of death within Brussels metropolitan region was remarkable,(Chapter 5) and was consistent with variation found in Houston, USA.(59) We found substantial variation in hospital death risk between districts of Brussels Capital Region depending on the average socioeconomic level, and that variation was similar for those living at home or in care homes. The variation in place of death of those living at home may to a large extent reflect the individual social and economic position of the deceased, given the association between hospital death risk and social position previously found,(2) and the socioeconomic spatial structure of Brussels.(60;61) An even stronger social contrast was found in the hospital death risk of care home residents; those residing in care homes in the less affluent districts of Brussels were twice as likely to die in hospital compared with those of the most affluent district. This may be related both to different characteristics of care home residents across Brussels and to different characteristics of care homes. The latter would be surprising since care homes are publicly funded professional organizations that are expected to offer the same standards of end-of-life care irrespective of the social context in which they operate, though care home characteristics in Canada were found to be associated with place of death. Care home residents residing in nonprofit single-site facilities compared with those residing in publicly owned or operated care homes, and those residing in smaller size care homes were more likely to die in hospital.(62) This finding seems to point at a possible and unexpected inequality among Brussels' care home residents and needs further investigation and attention.

9.3.2 Disease matters

Underlying cause of death was shown to be consistently associated with place of death. Higher proportions of cancer deaths than non-cancer deaths occurred at home (except in Norway) and in hospices, across Europe. In long-term care facilities on the other hand, the proportion of deaths from cancer was consistently lower than that of non-cancer cases. Hospital death rates of cancer were lower than those of non-cancer patients in the Netherlands and the UK, but higher in Belgium.(Chapters 2, 3)

Adjusted for differences in personal and environmental characteristics and availability of hospital beds, people with cancer compared with those with non-cancer chronic life-limiting conditions in the Netherlands and England were more likely to die at home (relative to in hospital), again in contrast with Belgium.(Chapters 4, 5) Using information from the Belgian sentinel network of GPs however, hospital deaths in cancer patients living at home proved not to be more likely, compared with those who died from non-cancer related diseases.(Chapter 7) Hospital death risk of people with cancer living in care homes on the other hand was higher than that of non-cancer patients in most of our findings.(Chapters 4, 5, 8) Also adjusted for differences in general health care use and preferences with respect to place of death, cancer patients were 6.5 times more likely to die in a palliative care unit relative to in hospital, compared with those who died of a non-cancer condition.(Chapter 7) Within those who died from non-cancer conditions, the care home death rate of those dying from dementia-related diseases was consistently higher in Europe and home and hospital death rates were consistently lower.(Chapter 3)

Our finding that the hospital death risk of cancer patients living at home was lower than that of non-cancer patients in many European countries, is probably related to the shorter and more predictable course of functional decline and time of death compared with other disease groups.(63;64) The shorter period of functional decline makes caring at home for a cancer patient more bearable than in cases of more lingering diseases. In previous research, people with fewer restrictions and a shorter period of care, and with a shorter period of incontinence were found to be more likely to die at home.(65) Findings of Weitzen and colleagues in the US in 1993 indicated that having functional restrictions one year before death was associated with higher chances of dying in nursing homes, while a rapid functional decline in the five months before death was also associated with higher chances of dying at home.(26)

Another consequence of the more predictable time of death may be that cancer patients are more likely to be referred to palliative home care services, which contributes to higher chances of dying at home compared with those who died from other chronic life-limiting conditions.(48) Less than 5% of people in the UK referred to specialist palliative care services in the mid nineties, had a disease other than cancer(66), and this was 7% in Ireland in 2005.(67) The uptake of specialist palliative care services in South Australia was lower in patients with a non-cancer diagnosis (40%) compared with those with cancer (62%) and the uptake of services was less in accordance with identified needs in people with a non-cancer diagnosis than in people with cancer (69% versus 86%).(68) The uncertainty in predicting the final stage of nonmalignant conditions and the risk of misdiagnosis was in a systematic literature review found to be one of the barriers for physicians for referring patients with nonmalignant diseases to palliative care services, together with lack of expertise in palliative care in illnesses other than cancer and the funding of palliative care services mainly by cancer charities.(69) The top three barriers for servicing people with non-cancer diagnosis mentioned by clinical managers of Irish palliative care services were the unpredictable prognosis, the referral criteria for non-cancer patients to palliative care not being defined and the lack of non-cancer disease palliative care expertise.(67) Our finding that people with cancer are more likely to die in inpatient hospices in the Netherlands and the UK and that cancer patients in Belgium are more likely to die in inpatient palliative care units is most probably also related to the more predictable disease course and may be enhanced by admission policies such as those of Belgian palliative care units, limiting admission to people with a prognosis of three months or less.(52)

The risk of cancer patients of dying in hospital relative to in a care home was in most of our findings consistently higher than that of people with non-cancer conditions. Similar to these findings, the probability of hospitalization of nursing home residents with cancer, whether enrolled in hospice care or not, was found to be higher than that of residents with cancer and dementia, or only dementia in five US-states.(70) This might point to other end-of-life care preferences of cancer patients in nursing homes compared with those with non-cancer conditions or a lack of expertise in care homes of end-of-life care for cancer patients given that a majority of their residents have non-cancer diseases.(71)

Among cancer patients, those who died of hematological malignancies were less likely to die at home in all the European countries we studied.(Chapter 2) This finding corroborates the results of a meta-analysis of research on place of death from cancer showing that people with hematological malignancies were more than twice as likely to die in hospital compared with other cancer patients.(72) Hematological patients were also found to be less likely to receive palliative care,(48) or home care in general.(65) The less favorable outcomes for people with hematological malignancies may be related to the complex disease course of hematological malignancies and difficulties in estimating prognosis impeding advance care planning. Hospital admissions may be frequent and hospitalizations prolonged because of a number of available salvation therapies, side effects of chemotherapy and complicating factors, resulting in a higher hospital death risk. Another factor may be the poor integration of palliative care into hematology.(72)

The higher proportions of dementia patients dying in care homes across Europe is probably related to the prolonged disease course, with increasing functional decline, cognitive impairment and behavioral disturbances over a period of up to six to eight years.(Chapter 3) (73-75) Not surprisingly, Alzheimer’s disease or other dementia proved to be a strong predictor of nursing home admission,(76) resulting in 34% of elderly people with dementia living in nursing homes compared with 5% for the whole of the aged population and a prevalence of dementia within institutions of 62% in the UK,(71) explaining the high nursing home death rates we found among dementia patients. Compared with people with cancer, the hospice death rate of those with dementia was much smaller. It was estimated that less than 1% of people in inpatient hospices had dementia as their primary diagnosis.(77) Next to the difficulty of predicting life expectancy accurately in dementia patients,(78;79) other barriers may prevent appropriate end-of-life care for people with dementia, such as admission policies of inpatient hospices and their expertise mainly directed to end-of-life care in cancer patients. On the other hand, since many dementia patients are being cared for in care homes and as expertise in care homes in caring for dementia patients at the end of life develops, eg the introduction of advance care planning policies in Belgian care homes,(80) transfers of dementia patients to palliative care institutions may not always be necessary and may not even be recommendable, given the risk of delirium and distress on transfer to hospitals and possibly to other care settings in general.(81)

9.3.3 Policies and health care options at the end of life matter

Policies and health care options available at the end of life showed to be consistently associated with place of death across our studies and we found that involvement of palliative care altered the circumstances at the end of life.(Chapters 6, 7)

Palliative home care teams and palliative care reference persons seem to affect place of death very significantly.(Chapter 7) If involved, terminally ill patients either living at home or in a care home were much more likely to die out of hospital. This can probably be attributed to the advantages palliative care services offer, eg their 24 hours a day, seven days a week availability and the comprehensive multidisciplinary support they offer.(82-84) Nevertheless, in the light of the equivocal findings found in a systematic literature review,(85) the strong association of palliative care services involvement and place of death we found is notable. The palliative care services we studied in Belgium were implemented about 15 years ago and since then expertise in palliative care has developed rapidly. Treatment of pain and symptoms has become technically more sophisticated, requiring palliative care teams to be more often involved in treatment and not just in consulting. Palliative care also became ethically more complex since euthanasia became a legal practice in Belgium in 2002,(86) introducing requirements for a complex decision-making process with patients, relatives and caregivers.(87) The latter may be more successfully managed by specialist care teams than by general caregivers.

The success of multidisciplinary palliative home care teams in referring patients to inpatient palliative units, in contrast with palliative support teams in hospitals who do not seem to increase the chance of admission to a palliative care unit, may be explained by admission policies of palliative care units giving priority to patients residing at home over those already in an institutional setting even though it is a hospital and because home care teams were often involved earlier in the disease trajectory with more time to plan future care for their patients

In contrast with palliative care services operating where patients live, we found that multidisciplinary palliative support teams in hospitals were not successful in supporting home death or death in an inpatient palliative care unit. It might be possible that patients are systematically referred late to the palliative support teams in hospitals due to inadequate palliative care approach, resulting in lack of time to instigate a realistic plan for discharge to the usual place of residence as was previously found in the UK.(88)

We found that palliative care involvement altered not only place of death as an outcome, but also key elements of the quality of the end-of-life care process; communication about preferences, the presence of relatives at the moment of death, and the presence of symptoms in the last 24 hours of life.(Chapter 6) Our results showed that palliative care involvement strongly increased the chances of attending physician being aware of the patient's preferred place of death and additionally increased the chances of these preferences being met. Independent of where people died, palliative care involvement also seemed to increase the chances of dying surrounded by loved ones. The latter is commonly considered an important aspect of a 'good death' (89-91) and it may result in better bereavement outcomes for the next of kin. Independent of diagnosis and age, we also found palliative care involvement to be associated with less shortness of breath and better well-being of the patient in the last 24 hours. This finding is partly in line with findings from previous studies in the US and elsewhere indicating that palliative care team involvement resulted in modest improved patient outcomes in physical, psychological, and spiritual domains.(92;93)

Another health care option that matters is the availability of beds in hospitals and care homes. In line with systematic literature reviews,(2;3) we found that higher than average hospital bed availability in the health care region of the deceased (health care catchment area), was associated with lower chances of dying at home among the terminally ill in Belgium, in cancer (Belgium, Italy and Wales) and dementia populations.(Chapters 2, 3, 7, 8) Health care system factors, such as the availability of alternative health care options at the end of life for cancer patients and the referral health care system, may explain why this association was not found in England, the Netherlands and Norway. Higher hospital bed availability also seemed to increase the hospital death risk of care home residents with dementia (Chapter 3) and care home residents with chronic life-limiting conditions in the Netherlands and England (but not in Belgium).(Chapter 4) We found that the availability of hospital beds did not affect place of death of care home residents if involvement of palliative care reference persons and the presence of a preference to die in a care home was taken into account.(Chapter 7)

Higher care home bed availability was associated with lower hospital death risk relative to dying in a care home,(Chapter 3, 4) and lower home death risk in dementia patients and in cancer patients in Belgium, Italy and Wales.(Chapter 2, 3) In Belgium no association was found however, even when adjusted for the involvement of a palliative care reference person and the existence of a preference to die in care home known by the family physician.(Chapter 7)

Our study on trends in place of death in Belgium showed that the availability of skilled nursing home beds rather than residential beds matters. An association between higher average availability of residential beds and higher hospital death risk of terminally ill care home residents was found, but a higher availability of skilled nursing beds was associated with lower hospital death risk.(Chapter 8) Because of the conversion from residential beds to skilled nursing beds in Belgian care homes, the risk of care home residents dying in hospital decreased substantially between 1998 and 2007. This finding is probably not just a consequence of an increase in skilled nursing resources in care homes but also of the appointment (since1997), of in-house palliative care reference persons responsible for supporting, coaching and educating caregivers and supporting out-of-hospital death.(52) Another part of the explanation is probably the rapid development of policies on advance care planning in Belgian care homes from 2000 onwards resulting in a do-not-hospitalize option available in 90% of care homes by 2006.(80)

Although in our final models we found that the level of GP involvement did not alter place of death,(Chapter 7) in contrast with the findings of previous research in Denmark and elsewhere,(39;94) the gradual building-up of our models showed that highly involved GPs can play an intermediate role in supporting out-of-hospital death of their patients, by adequate and appropriate communication to find out what their preferences are and by involving palliative care services to meet those preferences. Once the patient’s preferences are discussed and decided and palliative care services are involved, the level of involvement of GPs in end-of-life care no longer seems to affect the place of death in case of care home residents.

9.4 *Implications*

9.4.1 Implications for end-of-life care policies

9.4.1.1 Focus on vulnerable populations

Our findings show that certain subpopulations among the terminally ill risk receiving suboptimal end-of-life care and have higher chances of dying in hospital compared with others. This is the case for certain disease groups (see infra), but also for a number of subpopulations that were previously found to have suboptimal outcomes in end-of-life care(2;3) or healthcare in general.(95) We found that those with a less favorable social background,(Chapters 2, 5) those with less social support or informal care,(Chapters 2, 4, 5, 7, 8) the oldest old living at home,(Chapter 2 to 4) and women living at home, (Chapters 2,4) were less likely to die at home, or more likely to die in hospital. Those living alone and women were also less likely to be surrounded by loved ones at the time of death and those 80+ had lower chances that the attending GP was aware of their preferred place of death.(Chapter 6)

In addition to general policies to improve end-of-life care which are necessary given the high rate of hospital deaths in many countries, specific policies targeting disadvantaged subpopulations are required taking into account their specific disadvantages(96) and ensuring equal access to quality end-of-life care. The latter is often not the case for people with a lower socioeconomic background.(65) Campbell and colleagues showed that the inverse care law applied to palliative care services.(97) Referral rates to home palliative care services were not related to the prevalence of cancer mortality in two socio-economically distinct districts of Manchester, but to the socioeconomic characteristics of their residents. In the most deprived areas the cancer mortality was higher and the referral rates were lower than in more affluent areas. Implementing targeted policies may require additional resources since previous findings in the UK suggest that providing palliative care to socially deprived patients increases the workload of palliative home care nurses.(98)

9.4.1.2 Take into account cultural factors when planning and implementing end-of-life care

We found remarkable differences in place of death between neighboring countries (Chapter 2 to 4) which could be partially attributed to different health care policies and available care options, but probably also to different cultures with respect to health care and end-of life care. National policies should take into account these cultural differences.

But also within countries and even within metropolitan regions, cultural differences with respect to death and dying may be significant as was previously hypothesized,(99) and end-of-life care policies and services should be adapted. Metropolitan populations may be more likely to prefer institutionalized death, possibly anticipating fewer informal care resources and less favorable material conditions for receiving end-of-life care at home. In metropolitan areas additional availability of institutional end-of-life care options such as inpatient palliative care units, hospices, and medium and long-term skilled nursing facilities would be appropriate.

Preferences about end-of-life care and end-of-life decision-making were shown to vary significantly among ethnic groups.(100) In light of the growing ethnic diversity of the Brussels' population, end-of-life care programs and options should be adapted to diverging preferences among ethnic groups, to provide appropriate choices in care at the end of life including place of death, as was previously recommended by researchers in the UK.(101)

9.4.1.3 Improve end-of-life care of hematological cancer patients

Our findings show that patients dying of certain conditions systematically have higher chances of dying in hospital. We found hematological cancer patients to be more likely to die in hospital, (Chapter 2) and this corroborates findings of most of the research of place of death in cancer populations.(2;3;72)

Although relatively more hematology patients may prefer hospital as place of terminal care and place of death compared with other cancer patients, since those patients have a strong relationship with their clinical hematology specialists, more integration of palliative care in hematology is needed and community palliative care adapted to the needs of those patients preferring to die out-of-hospital may be required.(72)

9.4.1.4 Plan for end-of-life care policy and options for dementia patients

Ageing of populations and the growing incidence and prevalence of degenerative diseases such as Alzheimer's disease and other dementia-related diseases make care for dementia patients a public health priority. Providing good end-of-life care for dementia patients is complicated by the long and unpredictable course of the disease, cognitive impairment and poor or non-existing communication between patient and caregivers, a high burden of care and by health care insurance systems not adapted to supporting palliative care for dementia patients.(78;102) A substantial proportion of dementia patients ultimately die in hospital in several European countries.(Chapter 3)

Barriers to proving good end-of-life care for dementia patients need to be addressed. Education of the general public and health professionals is needed since dementia is often not recognized as a terminal condition appropriate for palliative care. Health professionals need to be informed about the nature of advanced dementia, assessment of pain and other symptoms in dementia patients, management of behavioral problems and psychiatric symptoms, and caregiver stress and bereavement.(78;102) Care plans with a palliative approach should be discussed with patients and their relatives earlier in the disease course and should be documented in advance directives.(78) Barriers imposed by health care insurance systems hindering access to palliative care of dementia patients, eg because access is only provided in case of a clear and short prognosis, should be addressed.(78;103)

The Dutch specialized nursing home model, ie high availability of beds in skilled nursing homes with care managed by specialized nursing home physicians, seems to be successful in avoiding hospital death of people with dementia living in care homes and its implementation needs to be considered in other countries. The substantial conversion of residential beds to skilled nursing beds in Belgian care homes during the previous decade can be seen as a partial implementation of this model although care of patients is still managed by their family GP.(33) The introduction of specialized nursing home physicians, managing the care of people with dementia and other chronic life-limiting conditions in care homes, needs to be debated.

Given the economic consequences of the Dutch model and the quasi complete institutionalization of dementia patients resulting from it, innovative community based care models for people with advanced dementia need to be considered and studied.(78;103)

9.4.1.5 Improve end-of-life care in long-term care facilities

Past trends and future projections in place of death in Belgium showed that care homes may become the main health care setting for providing end-of-life care in the future.(Chapter 8) Although the proportion of hospital deaths among care home residents decreased in the previous decade in Belgium, we found that it was still more substantial in Brussels metropolitan region.(Chapter 5) We found people with cancer living in care homes to be more likely to die in hospital.(Chapters 4,5,8) In Brussels metropolitan region palliative care was less likely to be involved for those dying in care homes.(Chapter 6)

Systematic implementation of advance directives in nursing homes can result in fewer hospitalizations and reduce the risk of hospital death of their residents, as was previously shown in an experiment in Canadian care homes.(104) The gatekeeper role of care teams in long-term care facilities to prevent inappropriate transfers to hospital at the end-of life needs to be enforced. Particular attention needs to be given to the higher chances of cancer patients dying in hospital compared with non-cancer patients which may be related to a lack of skills in nursing homes to deal with pain and symptoms specific in cancer patients.

Barriers to providing appropriate end-of-life care for care home residents, found to be mainly related to inadequate staffing due to the heavy time commitment of providing palliative care, the lack of equipment in facilities and inadequate financial reimbursement of palliative care by healthcare insurance systems, should be tackled by providing education, protocols and guidelines for the medical and nursing staff and by increasing financial reimbursement for providing palliative care to care home residents.(52;105)

9.4.1.6 Metropolitan approach to end-of-life care

Our results showed that even controlled for differences in population mix and health care options terminally ill people living in metropolitan areas in Belgium, the Netherlands, and England were still more likely to die in hospital compared with those living outside metropolitan areas.(Chapter 4) A specific metropolitan approach to end-of-life care is needed taking into account the possibly different preferences of metropolitan populations, their ethnic diversity and other factors such as the physical environment and the quality of housing.

Since family composition (as a proxy of social support) was a factor that partially explained the higher odds of Brussels metropolitan residents of dying in hospitals, comprehensive primary nursing care, including night care and day care centers for those preferring terminal care at home, should be available. Additionally, innovative models to activate or support community networks outside the family should be explored.(106;107)

Primary care provision in metropolitan regions should be a priority since primary care involvement and continuity results in better end-of-life care outcomes,(40) and metropolitan populations are on average underserved or may prefer alternatives to primary care such as specialist care or visits to an emergency department of a hospital.(17;50;108;109) Models to improve primary care involvement in metropolitan populations such as community health centers may also improve health outcomes at the end of life for metropolitan residents in case where these centers provide end-of-life care for the residents of their service area.(110) Hospitals in metropolitan areas, larger or teaching hospitals in particular,(111) should be aware of the background of the population they are serving and should provide appropriate end-of-life care for those preferring to be cared for and to die in hospital, including emotional and spiritual support for those without relatives. For those preferring not to die at home or in hospital, other end-of-life care options, such as inpatient palliative care units or hospices, may be an alternative.

The remarkable intra-metropolitan contrasts in place of death found in Brussels metropolitan region, (Chapter 5) ask for a district-specific approach.(112) To avoid inequality and inequity among care home residents, attention should be paid to the diverging chances of care home residents in less affluent parts of Brussels metropolitan region dying in care homes compared with the residents of wealthier neighborhoods.

9.4.1.7 Support involvement of specialist palliative care providers and strengthen the role of primary care in end-of-life care at the same time

We found that involvement of specialist palliative care teams substantially reduced the risk of those terminally ill living at home or in care homes dying in hospital (Chapter 7) and also was associated with more favorable circumstances of dying.(Chapter 6) Involvement of palliative care teams should be supported since providing good end-of-life care has become technically and ethically more complex,(113) and coaching and supporting of primary caregivers had become a necessity. Specialist palliative care involvement is also related to the presence of a preference for place of death communicated to the GP,(Chapter 6) which was another factor we found to substantially increase the chances of dying out-of-hospital.(Chapter 7) Involvement of palliative care teams in hospitals did not seem to support out-of-hospital death. This is probably related to the systematically late involvement of hospital palliative care teams in the care of terminally ill patients,(114) and it is recommended by the WHO to involve them earlier in the course of the disease.(77)

In general, we found that palliative care services were involved in a minority of terminally ill patients in Belgium.(Chapter 7) Professional caregivers should involve palliative care services earlier in all health care settings so that more terminally ill patients could benefit of these services, resulting in better end-of-life care for a larger group of patients.

We found that the significant unadjusted association between high level GP involvement and the chance of dying out of hospital was adjusted almost completely when accounting for specialist palliative care involvement and the communication of a preference for place of death.(Chapter 7) GPs involved frequently in health care of terminal patients in the final three months of life seem to play an intermediate role in attaining out-of-hospital death by eliciting the patients' choices and involving specialist palliative care providers. Involvement of primary caregivers in palliative care should therefore be strengthened and development of end-of-life care skills of primary caregivers should be supported given the expected increase of patients with chronic life-limiting conditions and the limited resources for specialist palliative care. Palliative care should take a prominent place in the curricula of medical and nursing studies. GPs not involved in palliative care should be informed and motivated to participate in palliative care provision. Since the necessity of providing after hours care may be a barrier to GPs engaging in palliative care,(113) innovative models to overcome this barrier should be studied.

9.4.1.8 Invest in quality of death certification and death certificate data

Death certificate data are a powerful and in many countries, freely available source of information for investing in and monitoring quality of end-of-life care.(1)(Chapter 2-5,8) However, one documented deficit of death certificate data is the unreliability of certification of cause of death and other patient and environmental characteristics of the deceased previously found in many countries.(5-12)

Death certificate data lack uniformity across or even within countries and not all relevant categories of place of death are available.(1) In Belgium, deaths in palliative care units are coded as death in acute hospital wards and in other countries sometimes just two categories of place of death are available (eg death in hospital or outside hospital), hampering the evaluation of end-of-life care policies using death certificates. Not all relevant information about patient characteristics or the patients' environment is available from death certificate data and unless linkage to other datasets is possible,(1) this information is unavailable for scientific research.

Government bodies and medical schools should invest in the quality of death certification by developing tools or increasing the skills of physicians and striving for accuracy and uniformity.(5) Linking information from death certificates with information about patient and environmental characteristics with respect to medical ethics and the privacy of the deceased and their family should be possible.(1)

9.4.2 Implications for professional caregivers

9.4.2.1 Focus on specific needs and preferences of patient groups

In providing care to the terminally ill, individual caregivers should be aware of and have the professional skills and flexibility to adapt to the specific needs, values and preferences of specific subpopulations. Education, protocols and tools such as guidelines are required for a more successful approach.(115) In cancer patients those with hematological cancers (Chapter 2) may have other needs or preferences requiring a different approach compared with other cancer patients.(72) In those with dementia (Chapter 3) it is important to be aware of the special needs of those cognitively impaired with poor communication abilities. Professional caregivers should also account for the high burden of caregiving for dementia patients and the needs of informal caregivers in caring for cognitively and functionally impaired relatives.(78) Those caregivers working in metropolitan areas should be aware of the lack of social support of many metropolitan residents, of the poor social conditions in some metropolitan districts and the poor housing conditions often unsuitable for providing or receiving end-of-life care.(Chapters 4-6) They should account for the possible higher preferences for receiving end-of-life care in an institutional setting and of specific values and preferences about end-of-life care of people from ethnic minority groups.(100) Those dying in institutional settings may need more emotional and spiritual support in the last days and hours,(116) since a substantial proportion die without the presence of relatives.(Chapter 6)

9.4.2.2 Timely communication about preferences for end-of-life care and timely involvement of specialist palliative care services

Timely communication about end-of-life care preferences,(29;30) according to the patient’s wishes and social and cultural background,(117) and timely involvement of specialist palliative care services are key factors in providing appropriate end-of-life care.(Chapters 6 and 7) This is particularly the case in dementia patients given the progressing cognitive impairment and documenting these preferences in advance directives may be an important factor in respecting the end-of-life care preferences of those who are cognitively impaired.

In general, timely involvement of specialist palliative care services is important in being able to plan for care options and place of death at the end of life. This may in particular be the case for those admitted to hospital at the end of life since our results suggested that palliative care teams in hospitals were involved systematically late in the care of dying patients,(Chapter 7) leaving no time to realistically plan discharge to another care setting.(88)

9.4.2.3 Invest in basic palliative care skills.

Although specialist palliative care services are available in all care settings in most developed countries, primary caregivers and general caregivers in institutional settings should consider developing their own skills with respect to palliative care and communication about end-of-life care issues. Involvement of family GPs in end-of-life care is a key issue,(113) given the gatekeeper role of GPs in involving specialist palliative care services in many countries. Caregivers capable of eliciting their patients' preferences, involving specialist palliative care services in good time and providing continuing care during the last phase of life may be more successful in respecting their patients' wishes. The demographic and epidemiologic trends in the coming decades with the ageing of the aged population and the increasing prevalence of degenerative diseases will result in an increasing demand for appropriate end-of-life care and palliative care should be a basic skill of most professional caregivers in future.(113)

9.4.3 Implications for researchers

9.4.3.1 Study avoidable hospitalizations at the end of life

Our research showed substantial proportions of terminally ill people, both living at home and in care homes, dying in hospitals, in contrast with a majority preferring to die in their familiar surroundings.(Chapters 2-5, 7, 8)(118-120) Hospitalizations at the end of life, in particular emergency room visits and stays in an intensive care unit can be considered poor end-of-life care and the proportion of people dying in hospitals can be regarded as a quality indicator of end-of-life care.(121) The variation in proportions of hospital deaths between neighboring European countries, eg the Netherlands and Belgium, suggest that a substantial proportion of terminal hospitalizations could be avoided.

Therefore, the fraction of avoidable hospitalizations and emergency room visits or intensive care unit stays of terminally ill people should be estimated and the characteristics and reasons or causes of these hospital referrals should be examined to consider how many could be avoided. Studying avoidable hospitalizations could result in practice guidelines for family physicians and care homes.

9.4.3.2 Study the effectiveness of advance care planning in avoiding hospital admission and hospital death

Advance care planning is considered an effective instrument in avoiding hospitalizations and other unfavorable outcomes at the end of life and their use is widely supported by government bodies and health care organizations in Europe, North-America and Australia.(122-124) Advance care planning was defined as: 'Discussions with patients and/or their representatives about the goals and desired direction of the patient's care, particularly end-of-life care, in the event that the patient is or becomes incompetent to make decisions.'(125)

Although individual studies report favorable outcomes for patients and their caregivers,(104;126) the effectiveness of advance care planning has not been reviewed systematically. Given the wide use of advance care planning, a systematic review of its effectiveness with respect to avoid terminal hospitalization and other outcomes using the highest methodological standards of the Cochrane Collaboration is required.

9.4.3.3 Studying the effectiveness of palliative care services and care management programs using research designs allowing causal inferences

Although our findings showed strong associations between involvement of palliative care services and the circumstances at the end of life,(Chapter 6) and between the involvement of palliative care services and the availability of other health care resources and place of death (Chapters 2-4,8) these associations may be confounded by other factors not included in our models and reverse causation cannot be excluded. Therefore the results of our analyses do not allow us to establish evidence that there is a direct causal relationship between involvement of palliative care services and favorable patient outcomes at the end of life such as out-of-hospital death.

Prospective research designs and controlled trials are needed to establish evidence about causal relationships between interventions and outcomes and find effective solutions and to claim for wider availability and reimbursement by health insurance mechanisms if effectiveness is proven. However, as we mentioned in chapter 7 these designs may be questioned ethically as withholding terminally ill patients from palliative care - as could be the case in a control group of a randomized controlled trial - is incompatible with medical ethics, and possibly even illegal since the Belgian law on palliative care provides for access to palliative care for all. Moreover it is questionable whether scientific and practical obstacles can be addressed.(127)

Creative and innovative research methods in palliative care are needed to establish strong scientific evidence taking into account the sensitive approach needed in the specific context of vulnerable people at the end of their lives.(77)

9.4.3.4 Explore useful secondary data sources for use in end-of-life care research.

Other sources of information are available - although possibly less suitable to studying a causal relationship between services involvement and end-of-life care outcomes - such as information from death certificate data and data collected by the sentinel networks of GPs that we used. (Chapters 2-5, 7, 8) As we demonstrated, this data offered the advantage of being suitable for studying variations between countries, considered a priority by the WHO.(128)

These secondary datasets are mostly available at low cost and if used, the drawbacks of the above-mentioned research designs can be avoided.(1) Major scientific issues in prospective studies, such as the debatable inclusion criteria of the terminally ill, will not be under discussion when using post-mortem secondary data sources.(18;19) Using these datasets also offers the advantage of avoiding the respondent fatigue that may occur when frequently surveying caregivers involved in palliative care.

Existing sources of information, such as health insurance claims data or registration data of palliative care services should be screened systematically to examine if they are valid and reliable for use in end-of-life care research.(128)

9.4.3.5 Study barriers of timely referral of terminally ill people in hospitals to palliative care hospital teams

A significant finding was the inverse relationship between involvement of palliative care teams in hospitals and the chances of dying out-of-hospital.(Chapter 6) We hypothesized that the systematically late referral of terminal patients to palliative teams in hospitals could be an explanation, since in that case not enough time may be left to activate a realistic discharge plan. Timely referral to palliative services is paramount in obtaining favorable outcomes in end-of-life care.(129;130)

Specialist palliative home care teams and palliative care services in care homes seem very effective in preventing hospital death. Since many terminally ill are admitted to hospital at least once in the final months or year before death,(131) studying barriers to involving palliative care teams in hospitals is most relevant.

Our hypothesis about the late timing of referrals in hospitals(88) can be examined using hospital administrative data or health insurance claims data.(121) If our hypothesis was be confirmed, hypotheses about the barriers of timely referral could be examined by interviewing patients, hospital management, and caregivers.

9.4.3.6 Study the economic implications of providing end-of-life care in ageing populations in the future

Our projection of place of death in the coming decades (Chapter 8), suggests a very significant increase in numbers and proportions of care home deaths. The economic consequences of this increase may be very substantial, since health care expenditure in the last year or months of life varies substantially by health care setting as was found in a study in the Netherlands.(132) The consequences should be studied in detail using different scenarios with respect to population characteristics, available health care options and health care use.

9.4.3.7 Continue studying place of death in an international context

Studying quality of end-of-life care in an international perspective was recommended by the World Health Organization and the European Association of Palliative Care.(128) The Dying Well in Europe study made a major contribution by examining where patients with different diagnoses died in 2003, in nine European countries using individual death certificate data.(1) An extension of this study to other than Western-European countries would generate useful information about cultural differences in end-of-life care approach and policies affecting place of death.

Clark and colleagues of the International Observatory on End-of-life Care at Lancaster University systematically monitor the establishment of palliative care services and have found substantial growth in Europe and other parts of the world.(133-135) The outcome of the growth of palliative care services and other policies on place of death has not been studied thoroughly. It would be most relevant to examine whether the establishment of palliative care services, aiming to support out-of-hospital death, may be associated with changes in the distribution of place of death in general and in specific disease groups, by comparing patterns of place of death of 2003 and 2008, ie after a 5-year period.

An update of the 2003 Dying Well in Europe Study using individual death certificate data is required including more countries, both European and non-European.

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Samenvatting van de belangrijkste bevindingen

Inleiding

De statistieken van de plaats van overlijden waren een symbool voor de sociale bewegingen die in de vijftiger en zestiger jaren van vorige eeuw in het Verenigd Koninkrijk en in de Verenigde Staten opkwamen tegen de medicalisering van de dood en voor een menswaardig levenseinde. In dit proefschrift wordt de plaats van overlijden beschouwd als een indicator voor de kwaliteit van het levenseinde van terminale patiënten en de kwaliteit van de levenseindezorg.

De plaats van overlijden kreeg een bijzondere betekenis in het licht van epidemiologische, demografische en culturele veranderingen in de voorbije decennia. De epidemiologische transitie, waarbij epidemieën en infectieziekten verdwenen en degeneratieve aandoeningen in de plaats kwamen als belangrijkste doodoorzaak, resulteerde in een toename van de levensverwachting en een sterke vergrijzing van de bevolking in veel ontwikkelde landen. Hierdoor kwam het levenseinde voor velen minder onverwacht en kregen vele ouderen te maken met langere periodes van ziekte voor het overlijden en met meer symptomen en ongemakken. Tegelijkertijd ontstond er bij velen de wens om zelf te beslissen over de tijd en plaats van het overlijden. Terminale ziekte en het nakend overlijden werden steeds minder een taboe en werden in grotere openheid besproken met patiënten en hun nabestaanden. In antwoord op deze ontwikkelingen werden in vele landen palliatieve zorginitiatieven ontwikkeld. Zo ook in België waar in enkele decennia een ruim aanbod van multidisciplinaire palliatieve zorgvoorzieningen ontstond voor alle zorgsettings. Om een antwoord te kunnen bieden op de toenemende zorgnoden van de oudere bevolking werden gedurende het voorbije decennium in de Belgische rusthuizen veel residentiële bedden omgezet in verzorgingsbedden. Bijkomend kwam een wettelijk kader tot stand in België en in vele andere landen dat rechten garandeerde voor een kwaliteitsvol levenseinde.

Als gevolg van epidemiologische en demografische trends, de ontwikkeling van de medische wetenschap en de afnemende beschikbaarheid van zorg binnen de familie, overleden in de loop van de vorige eeuw steeds meer mensen in een ziekenhuis en het aantal overlijdens thuis verminderde van meer dan de helft tot een kwart of minder. Sinds enkele decennia lijkt het aantal overlijdens in een ziekenhuis te stabiliseren. Dit leidde echter niet tot een toename van het aantal overlijdens thuis maar eerder in andere zorginstellingen zoals rusthuizen, palliatieve zorgeenheden en hospices.

In deze verhandeling gaat de aandacht ook uit naar de levenseindezorg in grootstedelijke gebieden. Sinds 2009 leven wereldwijd voor het eerst meer mensen in steden dan erbuiten en gezien de specifieke samenstelling van grootstedelijke bevolkingen en het meer gespecialiseerde zorgaanbod in groten steden kunnen we veronderstellen dat de plaats waar mensen er overlijden verschilt van deze buiten de grote steden.

In dit proefschrift gaan we nader in op de plaats van overlijden van mensen die overleden ten gevolge van kanker en dementie in verschillende Europese landen, op de omstandigheden aan het levenseinde en de plaats van overlijden in Brussel en andere grootstedelijke gebieden in Engeland en Nederland en op het verband tussen de inzet van palliatieve zorgvoorzieningen en de plaats van overlijden. Tenslotte bestuderen we de trends in plaats van overlijden tussen 1998 en 2007.

Onderzoeksvragen
De volgende onderzoeksvragen komen aan bod

1. Welk aandeel van de personen die overlijden ten gevolge van kanker overlijden thuis in België, Nederland, Noorwegen, Engeland, Wales en Italië? Welke factoren houden verband met de kans op een overlijden thuis in deze landen?
2. Waar overlijden mensen tengevolge van een dementie-gerelateerde ziekte in België, Nederland, Engeland, Schotland en Wales? Verschilt de plaats van overlijden van mensen die overlijden tengevolge van dementie van de plaats van overlijden tengevolge van kanker of andere chronische levensbedreigende ziekten? Zijn er belangrijke verschillen tussen deze landen en welke factoren dragen bij aan deze verschillen?
3. Verschilt de plaats van overlijden van inwoners van grootstedelijke gebieden in België, Nederland en Engeland met inwoners van de niet-grootstedelijke gebieden in deze landen? Welke factoren dragen bij aan deze verschillen?
4. Waar overlijden mensen tengevolge van chronische levensbedreigende ziekten in het Brussels Hoofdstedelijk Gewest en welke factoren dragen daartoe bij?
5. Welke zijn de omstandigheden bij het levenseinde van mensen die overlijden in het Brussels Hoofdstedelijk Gewest? Heeft de inzet van gespecialiseerde palliatieve zorg gevolgen voor die omstandigheden?
6. Heeft de inzet van gespecialiseerde palliatieve zorg gevolgen voor de plaats van overlijden in België?
7. Hoe evolueerde de plaats van overlijden in België tussen 1998 en 2007 en welke factoren droegen hiertoe bij? Was de trend in plaats van overlijden verschillend naargelang de overledene in een rusthuis of thuis, hetzij alleen of met anderen, verbleef?

Methodes

Om deze onderzoeksvragen te beantwoorden maakten we gebruik van gegevens over het levenseinde en de plaats van overlijden die retrospectief werden verzameld. Dit zijn: gegevens afkomstig van overlijdenscertificaten, gegevens verzameld door de Belgische huisartsenpeilpraktijken en gegevens verzameld aan de hand van een post-mortem survey in het Brussels Hoofdstedelijk Gewest.

1. Overlijdenscertificaten worden door de overheid verzameld met het oog op het tot stand brengen van de statistiek van de doodsoorzaken. In België omvatten de overlijdenscertificaten zowel gegevens over de plaats van overlijden en de doodsoorzaak, geattesteerd door een arts, alsook over sociaal-demografische gegevens van de overledene die worden aangevuld door de gemeentelijke administratie. Andere landen kennen een gelijkaardige procedure al kan de informatie die beschikbaar is aan de hand van overlijdenscertificaten verschillen.

Voor het internationaal vergelijkend onderzoek in dit proefschrift werd gebruik gemaakt van een internationale databank, “Dying well in Europe”, met gegevens van overlijdenscertificaten van negen Europese landen. Er werd gebruik gemaakt van gegevens van overlijdenscertificaten voor de studies in de hoofdstukken 2, 3, 4, 5 (2002/2003) en 8 (1998-2007).

2. Gegevens van de huisartsenpeilpraktijken (2005/2006) werden gebruikt voor de studie in hoofdstuk 7. De huisartsenpeilpraktijken vormen een netwerk van huisartsen dat sinds 1979 informatie over gezondheidsproblemen in hun praktijk verzamelt. Het netwerk is representatief voor de Belgische huisartsen en hun patiënten vertegenwoordigen 1,75% van de Belgische bevolking. De huisartsen verzamelden aan de hand van een gestandaardiseerd registratieformulier gegevens over overlijdens onder hun patiënten: de kenmerken van de overledene en zijn/haar omgeving en het zorggebruik in de laatste drie maanden voor het overlijden, waaronder het gebruik van gespecialiseerde palliatieve zorg.
3. Voor de studie in hoofdstuk 6 maakten we gebruik van gegevens afkomstig van een post-mortem survey over overlijdens in het Brussels Hoofdstedelijk Gewest (2007). Uit de overlijdensattesten van overlijdens van Brusselse inwoners werd een representatieve steekproef getrokken. De behandelende arts werd gevraagd een vragenlijst in te vullen over de zorg aan het levenseinde van de betrokken overledene alsook over mogelijke medische beslissingen en het besluitvormingsproces hieromtrent. Indien de attesterende arts niet de behandelende arts was, werd hij of zij gevraagd om de vragenlijst aan de behandelende arts te bezorgen.

Resultaten

Overlijdens thuis ten gevolge van kanker. Een studie in 6 Europese landen aan de hand van overlijdenscertificaten

In 2003 overleden 238 216 mensen ten gevolge van kanker in België, Italië, Nederland, Noorwegen, Engeland en Wales. Ten opzichte van het totaal aantal overlijdens varieerde het aantal overlijdens ten gevolge van kanker tussen 25,5% in Wales en 29,7% in Italië. We vonden grote verschillen in het aandeel thuisoverlijdens ten gevolge van kanker: 12,8% in Noorwegen, 22,1% in Engeland, 22,7% in Wales, 27,9% in België, 35,8% in Italië en 45,4% in Nederland. Vergeleken met overlijdens ten gevolge van een andere ziekte dan kanker, gebeurden overlijdens ten gevolge van kanker meer thuis (behalve in Noorwegen).

Wie overleed ten gevolge van bloedkanker had minder kans om thuis te overlijden dan wie overleed ten gevolge van een ander type kanker. Getrouwde kankerpatiënten (ten opzichte van wie ongetrouwd, gescheiden of verweduwd was) hadden meer kans om thuis te overlijden in België, Nederland en Noorwegen. In Italië was de kans op een thuisoverlijden enkel kleiner voor ongehuwde kankerpatiënten maar niet voor gescheiden of verweduwde patiënten. Oudere en vrouwelijke personen met kanker hadden minder kans om thuis te overlijden, met uitzondering van Italië waar het omgekeerde het geval was en België waar er geen verschillende kans op een thuisoverlijden was voor mannen en vrouwen. Een hogere opleiding verhoogde de kans op een overlijden thuis. Indien er in de zorgregio van de overledene gemiddeld meer ziekenhuis- en rusthuisbedden beschikbaar waren, verlaagde dit de kans op een overlijden thuis in België, Italië en Wales, maar niet in Nederland, Noorwegen en Engeland. Mensen met kanker die in weinig verstedelijkte of landelijke plaatsen woonden hadden meer kans om thuis te overlijden behalve in Engeland waar inwoners van sterk verstedelijkte regio's meer kans hadden om thuis te overlijden.

De relatieve verschillen in het aantal overlijdens thuis ten gevolge van kanker die we vonden tussen Europese landen zijn opvallend en de kans op een thuisoverlijden werd op een verschillende manier beïnvloed door demografische en omgevingsfactoren. Dit heeft vermoedelijk te maken met verschillen in de gezondheidszorgsystemen en sociale en culturele factoren in de landen die we onderzochten. Met deze factoren dient rekening te worden gehouden bij het bepalen van strategieën om het aantal ziekenhuisoverlijdens terug te dringen.

De plaats van overlijden ten gevolge van dementie: een studie in vijf Europese landen

In deze studie aan de hand van gegevens van overlijdenscertificaten vonden we dat 4,6% van de mensen van 65 jaar of ouder in België, Nederland, Engeland, Wales en Schotland overleden aan een dementie-gerelateerde aandoening. In al deze landen overleed een meerderheid onder hen in een rusthuis, variërend van 50,2% in Wales tot 92,3% in Nederland. Van diegenen die in Nederland in een rusthuis overleden, overleed 89,4% in een gespecialiseerd verpleeghuis en 10,6% in een gewoon rusthuis. Het aantal overlijdens in ziekenhuizen bedroeg 2,8% in Nederland, 22,7% in België, 33,9% in Schotland, 36,0% in Engeland en 46,3% in Wales. Het aantal overlijdens thuis was met uitzondering van België (11,4%) nergens hoger dan 5%.

Ook wanneer we rekening houden met verschillen in geslacht en leeftijd van de overleden populatie en met verschillen in de gemiddelde beschikbaarheid van ziekenhuis- en rusthuisbedden in de gezondheidsregio van de overledene, bleven de kansen op een overlijden thuis of in een rusthuis aanzienlijk hoger in Nederland vergeleken met België en de landen van het Verenigd Koninkrijk. De gemiddeld hogere beschikbaarheid van rusthuisbedden in Nederland verklaarde gedeeltelijk de veel hoger kans om er in een rusthuis te sterven en niet in een ziekenhuis.

Het Nederlandse model met een hoge gemiddelde beschikbaarheid van gespecialiseerde verpleeghuisbedden is een mogelijke strategie om te vermijden dat mensen met dementie overlijden in ziekenhuizen.

De plaats van overlijden in grootstedelijke gebieden: grootstedelijke/niet-grootstedelijke variatie in plaats van overlijden in België, Nederland en Engeland

Aan de hand van informatie van overlijdenscertificaten vonden we dat zowel in België (Vlaanderen en het Brussels Hoofdstedelijk Gewest), Nederland en Engeland relatief minder grootstedelingen thuis overleden dan andere inwoners van deze landen. Daarentegen overleden grootstedelingen meer in ziekenhuizen en, behalve in Engeland, in rusthuizen.

Zelfs indien we rekening houden met verschillen tussen grootstedelijke en andere overledenen inzake doodsoorzaak, geslacht, leeftijd, leefsituatie (of de overledene thuis woonde samen met anderen, thuis alleen woonde, of in een rusthuis verbleef), inkomen en de gemiddelde beschikbaarheid van ziekenhuis- en rusthuisbedden in de gezondheidsregio bleef de kans op een overlijden in een ziekenhuis groter voor overleden inwoners van een grootstad dan voor anderen. Voor inwoners van Belgische grootsteden (Antwerpen en het Brussels Hoofdstedelijk Gewest) was de kans op een thuisoverlijden bovendien significant kleiner dan voor inwoners van Nederlandse en Engelse grootsteden. Dit kon gedeeltelijk worden verklaard door het relatief groter aandeel alleenstaanden in die Belgische grootsteden. In Engeland hadden overleden grootstedelijke inwoners een kleinere kans op een overlijden in een rusthuis vergeleken met andere overledenen, en dit kon gedeeltelijk worden toegeschreven aan de grotere beschikbaarheid van rusthuisbedden buiten de grootsteden.

Verschillen in de kans op een ziekenhuisoverlijden tussen grootstedelijke en niet-grootstedelijke inwoners konden niet volledig worden toegeschreven aan verschillen tussen grootstedelijke en niet-grootstedelijke inwoners of aan verschillen in het aanbod van ziekenhuis- of rusthuisbedden tussen grootstedelijke en niet-grootstedelijke regio's. Deze bevinding wijst op de nood voor een specifieke strategie inzake levenseindezorg in grootsteden die rekening houdt met de sociale, culturele en omgevingsfactoren van grote steden.

Determinanten van de plaats van overlijden in het Brussels Hoofdstedelijk Gewest

Van de 3672 mensen die in 2003 in het Brussels Hoofdstedelijk Gewest overleden (36,2% van alle overledenen) ten gevolge van een chronische levensbedreigende ziekte, overleed 15,1% thuis, 63,0% in een ziekenhuis en 21,6% in een rusthuis. Van zij die in een rusthuis verbleven overleed 23,8% in een ziekenhuis.

Overledenen die thuis woonden, hadden meer kans om in een ziekenhuis te overlijden indien ze woonden in een Brusselse gemeente met een gemiddeld lagere sociaaleconomische achtergrond, indien de doodsoorzaak kanker was of indien ze alleen woonden. Overledenen die in een rusthuis woonden hadden meer kans om in een ziekenhuis te overlijden indien ze woonden in een gemeente met een gemiddelde of lagere sociaaleconomische status, indien de doodsoorzaak kanker was en naarmate ze jonger waren.

Het lage aantal overlijdens in de vertrouwde omgeving (thuis of rusthuis) in het Brussels Hoofdstedelijk Gewest wijst op de noodzaak om een specifieke strategie te ontwikkelen om grootstedelingen toe te laten te overlijden waar ze dat zouden willen. De ongelijke kansen om in het ziekenhuis te overlijden voor inwoners van verschillende Brusselse gemeenten wijst op de noodzaak van een gebiedsspecifieke strategie inzake levenseindezorg binnen het Brussels Hoofdstedelijk Gewest.

Verschillen de omstandigheden bij het levenseinde van overledenen in het Brussels Hoofdstedelijk Gewest die palliatieve zorg kregen van zij die dit niet kregen?
Negenenvijftig procent van de overledenen in het Brussels Hoofdstedelijk Gewest overleed in 2007 verwacht en dus niet plotseling volgens het oordeel van de behandelende arts. Hiervan overleed 11,7% thuis, 62,4% in een ziekenhuis en 24,1% in een rusthuis. Gespecialiseerde palliatieve zorgverleners waren betrokken bij het levenseinde van 23,1% van deze overledenen en de kans daartoe was groter voor kanker patiënten en kleiner voor wie in een rusthuis overleed.

Dertig procent van de overledenen had pijn geleden in de laatste 24 uur en 8% ernstige pijn. De meest voorkomende symptomen in de laatste 24 uur waren slaperigheid (80% van de overledenen), gebrek aan eetlust (75%), bewusteloosheid (74%) en vermoeidheid (73,3%). Inzet van gespecialiseerde palliatieve zorg hing samen met een lagere kans op kortademigheid, een hogere kans op welbevinden en een hogere kans op ernstige vermoeidheid.

Van 26,6% van de overledenen was de behandelende arts op de hoogte van de gewenste plaats van overlijden. Hiervan wenste 52,3% thuis te overlijden en voor 66,1% van hen werd deze wens ook werkelijkheid. Van de overledenen waarvan de behandelende arts niet op de hoogte was van de plaats van overlijden overleed 3,7% thuis, 75,3% in een ziekenhuis en 20,9% in een rusthuis. Betrokkenheid van een gespecialiseerde palliatieve zorgverlener verhoogde de kans dat de betrokken arts op de hoogte was van de gewenste plaats van overlijden én dat de wens van de overledene gehonoreerd werd.

Zeven procent van de Brusselse overledenen overleed geheel alleen. Familie of vrienden waren aanwezig bij 47% van de overlijdens, een verpleegkundige bij 73% van de overlijdens en een arts bij 43%. De kans op aanwezigheid van familie of vrienden bij het overlijden was groter in geval een gespecialiseerde palliatieve zorgverlener betrokken was bij de levenseindezorg, indien de overledene thuis woonde samen met andere mensen of thuis overleed.

In het algemeen waren de omstandigheden aan het levenseinde van overledenen in het Brussels Hoofdstedelijk Gewest niet optimaal, maar ze waren beter ingeval een gespecialiseerde palliatieve zorgverlener betrokken was bij de levenseindezorg. Gespecialiseerde palliatieve zorg kan de omstandigheden aan het levenseinde verbeteren in een grootstad als Brussel.

In België hangt de plaats van overlijden sterk samen met de inzet van gespecialiseerde palliatieve zorg
Van de overledenen die in België in 2005/2006 naar het oordeel van hun huisarts verwacht en dus niet plotseling overleden, overleed 23,8% thuis, 39,9% in een ziekenhuis, 26,7% in een rusthuis en 10,1% in een palliatieve zorgeenheid. Multidisciplinaire begeleidingsequipes voor palliatieve thuiszorg waren betrokken bij 21,8% van de overledenen die thuis woonden, referentiepersonen voor palliatieve zorg bij 29,1% van de overledenen die in een rusthuis woonden en palliatieve support teams in

ziekenhuizen bij 12,4% van overledenen die in de laatste drie maanden minstens één keer werden opgenomen in een ziekenhuis.

De overledenen die thuis woonden, hadden meer kans om daar ook te overlijden indien een multidisciplinaire begeleidingsequipe voor palliatieve thuiszorg bij de levenseindezorg betrokken was, de overledene thuis wenste te overlijden en de huisarts daarvan op de hoogte was, mantelzorgers dikwijls bij de zorg betrokken waren en de overledene woonde in een zorgregio met gemiddeld minder ziekenhuisbedden.

Van zij die thuis woonden en in de laatste 3 maanden minstens één keer werden opgenomen in een ziekenhuis was de kans op een thuisoverlijden groter indien een multidisciplinaire begeleidingsequipe voor palliatieve thuiszorg bij de zorg betrokken was. Indien een palliatief support team van een ziekenhuis bij de zorg betrokken was, werd de kans op een thuisoverlijden kleiner. Verder nam de kans op een thuisoverlijden ook toe indien er een door de huisarts gekende wens was om thuis te overlijden en indien mantelzorgers dikwijls bij de zorg betrokken waren.

Van zij die thuis woonden nam de kans op overlijden in een palliatieve zorgeenheid ook toe indien een multidisciplinaire begeleidingsequipe voor palliatieve thuiszorg bij de levenseindezorg betrokken was, maar de betrokkenheid van een palliatief support team van een ziekenhuis maakte geen verschil. De kans op een overlijden in een palliatieve zorgeenheid nam ook toe indien het een overlijden ten gevolge van kanker betrof, indien de overledene een vrouw was of indien professionele thuiszorg dikwijls bij de zorg betrokken was.

De overledenen die in een rusthuis woonden, hadden meer kans om daar te overlijden indien de referentiepersonen voor palliatieve zorg bij de zorg waren betrokken, hun huisarts op de hoogte was van hun wens om daar te overlijden, de doodsoorzaak kanker was en de overledene een vrouw was.

We vonden dat de mate van betrokkenheid van de huisarts bij de levenseindezorg van overledenen geen invloed had op de plaats van overlijden van rusthuisbewoners indien hun wens om daar te overlijden gekend was en indien de referentiepersonen voor palliatieve zorg bij de levenseindezorg betrokken waren. Voor zij die nog thuis woonden werd de invloed van de huisarts op de plaats van overlijden sterk verminderd indien de wens van de overledene om thuis te overlijden gekend was en indien een multidisciplinaire begeleidingsequipe voor palliatieve thuiszorg bij de levenseindezorg betrokken was.

Betrokkenheid van een multidisciplinaire begeleidingsequipe voor palliatieve thuiszorg of referentiepersonen voor palliatieve zorg verhoogt sterk de kans op een overlijden buiten het ziekenhuis, maar dit is niet het geval bij de inzet van een palliatief support team van een ziekenhuis. Strategieën ter verbetering van de levenseindezorg moeten er op gericht zijn om palliatieve zorgverleners vroeger bij de zorg van mensen met een levensbedreigende ziekte te betrekken. Huisartsen kunnen een intermediaire rol spelen bij het vermijden van een overlijden in een ziekenhuis door te informeren naar de wensen van hun patiënten en tijdig gespecialiseerde palliatieve zorgverleners te betrekken.

Voorbije en toekomstige trends in plaats van overlijden in België: een verschuiving van ziekenhuizen naar rusthuizen

In de periode 1998-2007 overleden in België (Vlaanderen en het Brussels Hoofdstedelijk Gewest) 661 773 mensen. Het aandeel overlijdens in een ziekenhuis daalde van 55,1% in 1998 tot 51,7% in 2007 en dat in rusthuizen nam toe van 18,3% tot 22,6%. Het aandeel thuisoverlijdens daalde met 0,5%.

Het aandeel overlijdens in ziekenhuizen daalde het sterkst voor rusthuisbewoners, van 31,0% tot 21,5%, en dat weerspiegelde zich in een toename van het aantal overlijdens van rusthuisbewoners in het rusthuis waar ze verbleven van 66,8% tot 75,3%.

Ook wanneer we rekening hielden met wijzigingen van de kenmerken van overledenen, hun omgeving en het zorgaanbod in die periode, nam de kans op een overlijden in een ziekenhuis van een rusthuisbewoner af tussen 1998 en 2007. Voor een groot deel was deze afname evenwel toe te schrijven aan de massale conversie van residentiële bedden naar verzorgingsbedden in rusthuizen gedurende deze periode. De kans op een overlijden in een ziekenhuis van personen die thuis verbleven nam echter niet af.

Een projectie van de trend in plaats van overlijden die we observeerden tussen 1998 en 2007 tot 2040, toont aan dat in 2038 het aandeel overlijdens in rusthuizen dat in ziekenhuizen zou overtreffen en dat het aandeel overlijdens thuis gestadig zou dalen.

Rusthuizen worden in de toekomst mogelijk de belangrijkste zorgsetting voor levenseindezorg. Daarom moeten er in de toekomst voldoende verzorgingsbedden met aangepaste levenseindezorg in rusthuizen worden voorzien om tegemoet te komen aan de noden van een steeds grotere groep van steeds oudere terminale patiënten en zal er moeten rekening worden gehouden met de financiële gevolgen.

Aanbevelingen

In hoofdstuk 9 van dit proefschrift worden de sterktes en zwaktes van de gebruikte onderzoeksmethoden besproken, worden de voornaamste bevindingen samengevat en wordt het geheel van de resultaten geïnterpreteerd en becommentarieerd. We beperken ons hier tot de aanbevelingen.

Aanbevelingen voor beleidsverantwoordelijken

In aanvulling op een globale strategie voor levenseindezorg die erop gericht moet zijn om onnodige en ongewenste overlijdens in ziekenhuizen te reduceren, zijn er specifieke inspanningen nodig om te vermijden dat bepaalde groepen terminale patiënten een verhoogd risico lopen om in een ziekenhuis te overlijden. Dit is bijvoorbeeld het geval voor terminale patiënten die lijden aan bloedkanker, voor diegene met een minder gunstige sociaaleconomische achtergrond, voor alleenstaanden of voor zij met weinig mantelzorg, voor de oudste ouderen of voor vrouwen die thuis wonen. Alleenstaanden en vrouwen hadden ook minder kans om omringd te zijn door familie of vrienden aan het levenseinde en wie 80 jaar was of ouder had ook minder kans dat de behandelende arts op de hoogte was van de gewenste plaats van overlijden. Hierbij moet er rekening mee worden gehouden dat het bieden van geschikte levenseindezorg aan deze specifieke groepen extra middelen kan vergen.

Bij het plannen van strategieën voor levenseindezorg dient rekening gehouden te worden met culturele factoren. Dit geldt voor nationale strategieën, gezien de belangrijke verschillen in plaats van overlijden die we vonden tussen Europese landen en die we niet konden toewijzen aan andere factoren. Maar ook binnen landen, met name in grootstedelijke populaties, leven wellicht andere noden en wensen inzake levenseindezorg en een hogere voorkeur voor levenseindezorg in institutionele zorgsettings zoals palliatieve zorgeenheden. In het licht van de groeiende diversiteit van de Brusselse bevolking zal de levenseindezorg in Brussel moeten worden aangepast aan een etnisch meer divers wordende groep van terminale patiënten.

Terminale patiënten met bloedkanker hebben, vergeleken met andere aandoeningen, systematisch meer kans om in het ziekenhuis te overlijden. Een betere integratie van palliatieve zorg in hematologie is noodzakelijk en opties voor levenseindezorg buiten het ziekenhuis dienen aan deze patiënten te worden geboden.

De verwachte toename van het aantal terminale patiënten met dementie-gerelateerde aandoeningen stelt de gezondheidszorgsystemen voor grote uitdagingen inzake het leveren van geschikte levenseindezorg aan deze groep van patiënten. Het gebrek aan kennis over deze aandoeningen dient te worden weggewerkt, vroegtijdige zorgplanning dient te worden aangemoedigd en barrières die de toegang tot gespecialiseerde zorg voor deze patiënten beletten, dienen aangepakt te worden. De introductie van gespecialiseerde rusthuisartsen, naar Nederlands model, dient overwogen te worden.

Aangezien rusthuizen in het algemeen belangrijker zullen worden als zorgsetting voor het verlenen van levenseindezorg, dienen barrières die het verlenen van geschikte levenseindezorg in rusthuizen in de weg staan, te worden aangepakt. Hierbij moet in het bijzonder aandacht gaan naar de systematisch hogere kansen op een ziekenhuisoverlijden van rusthuisbewoners met kanker.

Onze bevindingen wijzen op de noodzaak van een specifieke benadering van de levenseindezorg in grote steden. Methodes om sociale netwerken, die van belang kunnen zijn voor terminale patiënten en hun familie, te stimuleren en ondersteunen moeten worden onderzocht. In het bijzonder dient nagegaan te worden of de primaire zorgverlening in grootsteden een grotere rol kan spelen aan het levenseinde. Gezien de intra-stedelijke variatie in plaats van overlijden die we vonden binnen het Brussels Hoofdstedelijk Gewest, is een gebiedsspecifieke aanpak van de levenseindezorg noodzakelijk, zowel voor terminale patiënten die thuis verblijven als voor diegenen in een rusthuis.

We vonden dat inzet van gespecialiseerde palliatieve zorg het risico op een overlijden in het ziekenhuis sterk kon reduceren, de omstandigheden aan het levenseinde kon verbeteren en de communicatie over wensen inzake de plaats van overlijden kon bevorderen. De vroegtijdige betrokkenheid van gespecialiseerde zorgverleners bij de zorg van terminale patiënten, zeker in ziekenhuizen, dient daarom aangemoedigd te worden. Gezien de intermediaire rol die huisartsen kunnen spelen in het vermijden van een overlijden in het ziekenhuis dient hun betrokkenheid bij de levenseindezorg gestimuleerd te worden.

Gezien het belang van informatie van overlijdenscertificaten bij het bestuderen van de plaats van overlijden, dient de overheid te investeren in de kwaliteit van de certificering van overlijdens en in de codering en verwerking van de gegevens, en het gebruik van deze en andere gegevens voor wetenschappelijk onderzoek te vergemakkelijken.

Aanbevelingen voor zorgenverstrekkers

Individuele zorgenverstrekkers kunnen bijdragen aan de kwaliteit van de levenseindezorg door rekening te houden met de specifieke noden en wensen van kwetsbare groepen van patiënten. Opleiding, zorgprotocollen en guidelines kunnen hiertoe bijdragen.

Tijdige communicatie over de wensen van terminale patiënten inzake het levenseinde en het tijdig betrekken bij de levenseindezorg van gespecialiseerde palliatieve zorgenverstrekkers is noodzakelijk om de zorg aan het levenseinde te optimaliseren. Dit is in het bijzonder van toepassing voor terminale patiënten in ziekenhuizen.

Daarnaast dienen "gewone" zorgenverstrekkers zelf ook een belangrijke rol te spelen in de levenseindezorg van hun patiënten door met hun patiënten te communiceren over hun wensen en palliatieve zorg te betrekken. Daarvoor dienen ze hun eigen competenties inzake palliatieve zorg te versterken.

Aanbevelingen voor onderzoekers

Onze bevindingen tonen aan dat een aanzienlijk deel van de terminale patiënten overlijden in ziekenhuizen wat een indicator is voor suboptimale levenseindezorg. Daarom is het noodzakelijk om het aantal onwenselijke en vermijdbare hospitalisaties te schatten en de redenen voor deze hospitalisaties te onderzoeken. Dit kan leiden tot tools die in de zorgpraktijk kunnen worden ingezet.

Vroegtijdige zorgplanning is binnen het kader van palliatieve zorg een mogelijk instrument dat het aantal ongewenste en onwenselijke hospitalisaties zou kunnen beperken en andere uitkomsten van levenseindezorg zou kunnen optimaliseren. Om te kunnen oordelen over de effectiviteit van vroegtijdige zorgplanning dient de stand van zaken van de kennis hieromtrent te worden geïnventariseerd en beoordeeld aan de hand van een systematisch literatuuronderzoek.

Het onderzoek dat in dit proefschrift gerapporteerd wordt, laat niet toe om uitspraken te doen over de effectiviteit van gespecialiseerde palliatieve zorg. Enkel kunnen we een samenhang aantonen tussen palliatieve zorg en de plaats van overlijden of omstandigheden aan het levenseinde. Hoewel de nadelen van experimentele en prospectieve onderzoeksdesigns in onderzoek over levenseindezorg gekend zijn, is de innovatieve toepassing ervan noodzakelijk om wetenschappelijke bewijskracht voor de effectiviteit van palliatieve zorg te kunnen leveren.

Anderzijds kunnen secundaire informatiebronnen, zoals overlijdenscertificaten of registratiegegevens van huisartsenpeilpraktijken en palliatieve zorgenverstrekkers een nuttige bijdrage leveren voor wetenschappelijk onderzoek inzake levenseindezorg tegen een beperkte kost.

De opmerkelijke samenhang tussen de inzet van palliatieve support teams in ziekenhuizen en een hogere kans op overlijden in een ziekenhuis dient verder te worden onderzocht. Onze hypothese dat een gedeeltelijke verklaring ligt bij het laattijdig inschakelen van deze teams bij de zorg dient te worden getoetst aan de hand van adequaat wetenschappelijk onderzoek.

De financiële consequenties van de verwachte toename van overlijdens in rusthuizen en de hiermee gepaard gaande nood aan palliatieve zorg dient onderzocht te worden.

Met het oog op het verder bestuderen van de plaats van overlijden als een indicator van de kwaliteit van de levenseindezorg in een internationaal kader is het aan te bevelen de “Dying well in Europe” studie van 2003, waarbij een databank van overlijdenscertificaten van 9 Europese landen werd samengesteld, te repliceren en uit te breiden naar niet Europese landen.

Curriculum Vitea Dirk Houttekier

Dirk Houttekier (° 1962) holds a master degree in sociology (1984, Ghent University), a master degree in quantitative analysis of the social sciences (2006, KUB/KULeuven) and an executive master degree in business administration (1997, University Antwerp Management School).

In the past he was deputy secretary-general of a Belgian political party, strategic planner of advertising, consultant in place marketing and commercial director.

In 2006 he joined the End-of-Life Care Research Group of the Vrije Universiteit Brussel and started his PhD research about place of death and circumstances of dying in Brussels, Belgium and Europe. Today he works as a researcher at the Ghent University & Vrije Universiteit Brussel End-of-Life Care Research Group and is involved in the International Place of Death Study (IPD-study) and the Flanders Study to Improve End-of-Life Care and Evaluation Tools (FLIECE-study).

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