End-of-Life Care
An International Perspective

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Thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosphy (PhD) in Medical Sciences

16 December 2015

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Vrije
Universiteit
Brussel

VUB - UGent onderzoeksgroep
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Print: Silhouet, Maldegem
Cover art by Emilie Carosin

VUBPRESS is an imprint of ASP nv (Academic and Scientific Publishers nv)
Keizerslaan 34
B-1000 Brussels
Tel. +32 (0)2 289 26 50
Fax +32 (0)2 289 26 59
E-mail: info@vubpress.be
www.vubpress.be

ISBN 978 90 5718 482 6
NUR 882/883
Legal deposit D/2015/11.161/114

Board of examiners

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Acknowledgements

I would like to thank several people who have guided and helped me in deciding to start a PhD programme, in carrying out my research, and in accomplishing this thesis.

Koen, thank you for your day-to-day supervision, your guidance, and your help and support whenever I needed it. Your knowledge and experience have helped me to complete this PhD and to grow as a researcher. I particularly appreciate your talent for putting things into perspective, which helped me stay calm in the most stressful situations. Thank you also for the many, many laughs we shared over the past years and for pretending not to know that it was me who decorated your office (including the large Coca Cola bottle) so beautifully on April Fool's Day.

Luc, your ambition and your international approach to palliative care research made it possible for me to come to Belgium and join the End-of-Life Care Research Group. Thank you for always trusting in me and my abilities, for teaching me how to write good scientific texts, for showing me the importance - and fun - of exchanging with fellow researchers, and for giving me the impression that no goal is too far to reach.

Lieve, you have shaped my views of and vision for the field of palliative care. Thank you for guiding me in developing my research skills, creativity and critical thinking, and for helping me to better understand and reflect on the research we are doing. Your enthusiasm about the work we do is contagious and addictive, and I love coming to your office for my regular dose of "lightbulb moments".

I would like to thank my supervisors during my exchange at the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation of King's College London - Irene, Richard and Barbara - for giving me the exciting opportunity to work in their team and for sharing with me their knowledge, creativity, and ambition to carry out the best research possible. Natalia, thank you for your help with the Qualycare data and our article. Also, thank you to all my colleagues in London for introducing me to the pleasure of getting Fish & Chips from the staff cantine on Fridays.

Thank you to the EURO IMPACT consortium for enabling me to complete my PhD programme in an exciting international environment, for bringing together so many different people, topics, and perspectives on palliative care, and for the amazing places I got to see in Europe.

Thank you to the Euro-Sentimelc consortium - Viviane, Sarah, Guido, Bregje, Gé, Tomás, José - for the great collaboration over the years and the exciting work we have done together.

My dear ZRL friends: I have learned so much from all of you, and your friendship makes me look forward to coming to work (almost) every morning. First and foremost, thank you to the Big Five with whom I have had the joy of sharing my office: Aline, Kim, Rebecca, Kathleen, and Thijs. Thanks for being your unique, fantastic and very different selves! Thank you for all the stories you shared over the years, for your inspiring approaches to life, for making me laugh until my belly hurt, for our lunches and coffee breaks, our nights out, all our travels, and for passing onto me your respective Flemish dialects (I have even been told I speak with traces of West-Vlaams). It is to a large extent thanks to you that I have come to deeply enjoy this country and feel at home here. I hope that we will continue to spend many more great moments together.

A big thank you to several other colleagues in Brussels who have been very important to me over the past four years: Zeger, Joachim, Kenneth, Charlotte and Marlies. I have always enjoyed working with you and sharing fun moments at work, after work, on weekends, and at conferences. I am happy that you are my colleagues, and I am even happier to call you my friends.

Thank you to the people with whom I have been working on other projects over the past few months: Joni, Lois, Nanja, and Yolanda. It is an absolute joy working with you. Thank you also for your understanding on those days when I needed to lock myself up to work on my PhD.

Thank you to my English-speaking friends and colleagues Shira, Lois, Melanie, Devina and Nicholas for proofreading this dissertation.

A big thank you to our administrative staff, Nadine and Geertje, for their support with small and big tasks and problems whenever they arose.

Thank you to our cleaner Youssef for keeping our office a clean and pleasant place to work in and for the occasional chat.

I could not have completed this PhD without many dear people outside of work. My dearest friends in Brussels - Lisa, Gwenda, Shira, Emilie, Jef, Jeanne, Quitterie - for helping me to create a new home for myself in Brussels, for being my base on which I could always fall back, and for sharing with me laughs, long talks, dinners, coffees, concerts, dances, afternoons in the park, and lazy evenings at home, all of which I needed to refuel on energy.

Meine allerliebsten Freunde und Freundinnen in Wien: Hier ist meine Antwort auf euer "...und wann bist du dann fertig?" Beni, Sandra, Judith, Astrid, Romi, Hanni, thank you for being happy with me when I got the offer to do a PhD in Brussels, for keeping in touch throughout these four years, for your e-mails and Skype talks, for the visits you paid to Brussels to see me, and for always making time for me when I came to Vienna. I am grateful that this PhD did not weaken our bond, and I am happy that you are now spreading the message what a fantastic city Brussels is.

Mama, Tata, Fedja, Baka, Djidjo: Sta bih ja bez vas! I am grateful beyond measure to my parents, the best in the world, for unconditionally supporting each and every choice I have made throughout my education, including multiple stays abroad. It is due to your love, trust and support that I have found the courage and confidence to move abroad, start working on a PhD degree, and complete this work. Nevertheless, I will keep coming back home for Sunday morning "palacinke". Fedja, my amazing brother: thank you for your help and support whenever I needed it, for asking good questions, for being hilarious, for showing me many amazing places in the world, and for never accepting when I said that something was impossible. To my grandparents, thank you for showing me that age is no barrier for always being ready to learn new things and approaching the world with an open mind. Thank you for getting Skype and a webcam so we can keep in touch wherever I am and for repeatedly travelling all over Europe to see me. Without you all, I would have never accomplished this work.

Chapters 2 to 8 are based on the following publications

Chapter 2: Lara Pivodic, Koen Pardon, Lieve Van den Block, Viviane Van Casteren, Guido Miccinesi, Gé A Donker, Tomás Vega Alonso, José Lozano Alonso, Pierangelo Lora Aprile, Bregje D Onwuteaka-Philipsen, Luc Deliens, on behalf of EURO IMPACT. Palliative care service use in four European countries: a cross-national retrospective study via representative networks of general practitioners. PLoS One. 2013, 8(12):e84440, doi: 10.1371/journal.pone.0084440.

Chapter 3: Lara Pivodic, Richard Harding, Natalia Calanzani, Paul McCrone, Sue Hall, Luc Deliens, Irene J Higginson, Barbara Gomes, on behalf of EURO IMPACT. Home care by general practitioners for cancer patients in the last three months of life: an epidemiological study of quality and associated factors. Palliative Medicine. 2015 [epub ahead of print]. doi: 10.1177/0269216315589213.

Chapter 4: Lara Pivodic, Lieve Van den Block, Koen Pardon, Guido Miccinesi, Tomás Vega Alonso, Nicole Boffin, Gé A Donker, Maurizio Cancian, Aurora Lopez-Maside, Bregje D Onwuteaka-Philipsen, Luc Deliens, on behalf of EURO IMPACT. Burden on family carers and care-related financial strain at the end of life: a cross-national population-based study. European Journal of Public Health. 2014, 24(5):819-826. doi: 10.1093/eurpub/cku026.

Chapter 5: Lara Pivodic, Koen Pardon, Lucas Morin, Julia Addington-Hall, Guido Miccinesi, Marylou Cardenas-Turanzas, Bregje Onwuteaka-Philipsen, Wayne Naylor, Miguel Ruiz Ramos, Lieve Van den Block, Donna M Wilson, Martin Loucka, Agnes Csikos, Yong Joo Rhee, Joan Teno, Luc Deliens, Dirk Houttekier, Joachim Cohen, on behalf of EURO IMPACT. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. Journal of Epidemiology and Community Health. 2015 [epub ahead of print]. doi: 10.1136/jech-2014-205365.

Chapter 6: Joachim Cohen*, Lara Pivodic*, Guido Miccinesi, Bregje D Onwuteaka-Philipsen, Wayne A Naylor, Donna M Wilson, Martin Loucka, Agnes Csikos, Koen Pardon, Lieve Van den Block, Miguel Ruiz-Ramos, Marylou Cardenas-Turanzas, Yong Joo Rhee, Régis Aubry, Katherine Hunt, Joan Teno, Dirk Houttekier, Luc Deliens. International study of the place of death of people with cancer: a population-level comparison of fourteen countries across four continents using death certificate data. British Journal of Cancer. 2015 [epub ahead of print]. doi: 10.1038/bjc.2015.312. *Authors contributed equally.

Chapter 7: Lieve Van den Block, Lara Pivodic, Koen Pardon, Gé Donker, Guido Miccinesi, Sarah Moreels, Tomás Vega Alonso, Luc Deliens, Bregje Onwuteaka-Philipsen. Transitions between health care settings in the final three months of life in four EU countries. European Journal of Public Health. 2015, 25(4):569-575. doi: 10.1093/eurpub/ckv039.

Chapter 8: Lara Pivodic, Koen Pardon, Guido Miccinesi, Tomás Vega Alonso, Sarah Moreels, Gé A Donker, Enrique Arrieta, Bregje D Onwuteaka-Philipsen, Luc Deliens, Lieve Van den Block. Hospitalisations at the end of life in four European countries: A population-based study via epidemiological surveillance networks. Journal of Epidemiology and Community Health. 2015 [epub ahead of print]. doi: 10.1136/jech-2015-206073.

Contents

Chapter 1

General introduction, research questions and methods

1.1 Background

1.1.1 An international perspective on care at the end of life

Chronic diseases in the global demographic and epidemiological context

Across the world, populations are ageing. In many places, this is due to a reduction in infectious disease mortality (in particular infant mortality) and, since the 1970s, a decrease in mortality in older people, specifically from chronic diseases such as cardiovascular disease, diabetes and some types of cancers (colorectal, breast and testicular cancer, Hodgkin's disease, and acute lymphoblastic leukaemia) (Mathers et al. 2015). The World Health Organization (WHO) defines chronic diseases as "diseases of long duration and generally slow progression"(WHO 2014b). They are typically long-lasting conditions that can be controlled but not cured (The Center for Managing Chronic Disease 2011).

This decline in mortality from chronic diseases was brought about mainly through improvements in treatment of established diseases, successful public health strategies such as risk factor reduction, and socioeconomic development (Mathers et al. 2015). However, for most serious chronic diseases, rather than advancing toward a cure, there has been progress in controlling the disease progression and symptoms and thereby extending peoples' survival. Most chronic diseases that affect large segments of the population are progressive and remain incurable; this includes heart and lung diseases, most types of cancer (particularly lung cancer, which is the most frequent cause of death from cancer in Europe (Ferlay et al. 2013)), and dementia. Susceptibility to these diseases increases with age (Albers et al. 2015). Due to these conditions, continued population ageing will result in significant increases in mortality rates, even as age-specific mortality risks of dying from a non-communicable disease[1] stay the same or even moderately decline (United Nations Department of Economic and Social Affairs 2013). This development is ultimately shifting the distribution of deaths towards older ages, particularly in Europe, North America, Eastern Asia and Oceania (WHO 2014b; United Nations Department of Economic and Social Affairs 2013).

An estimated 56 million people die annually, and of these, the great majority, around 38 million (68%), die from non-communicable diseases (NCDs), mainly cardiovascular diseases, cancers, chronic respiratory diseases and diabetes (WHO 2014a). The annual number of deaths from non-communicable diseases has increased in all WHO regions since 2000, and is projected to increase to 52 million by 2030 (Mathers & Loncar 2006b). Deaths from non-communicable diseases account for 85% of all deaths of people aged 60 years or over worldwide. In high-income countries, this figure reaches 92%, but it is also high in middle- and low-income countries, where it is at 83% and 74%, respectively (United Nations Department of Economic and Social Affairs 2013).

The growing number of deaths also has implications for health care financing. Health expenditure depends heavily on age, and it is particularly high in the last year of life. In the Netherlands, it was estimated that 10% of the total health expenditure was associated with the health care use of people in their last year of life (Polder et al. 2006). In the USA, end-of-life care accounts for one-fourth of Medicare expenditures for the elderly (Riley & Lubitz 2010).

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[1] Often, the terms "chronic disease" and "non-communicable disease" are used interchangeably (WHO 2014b), but this is not precise given advances in treating communicable diseases such as HIV/AIDS that, as a result, have become diseases of long duration and generally slow progression. I acknowledge this issue but refer to sources that use non-communicable disease as a proxy for chronic disease if no alternative high-quality data are available.

Palliative care and related concepts

People affected by serious chronic diseases live longer today than they would have only a few decades ago, but the added years in life are often spent in poor health (Albers et al. 2015). People typically experience a slow but steady progression of disease. Chronic diseases often cause multiple longstanding and complex symptoms that require treatment and that increase in severity as death approaches. Furthermore, chronic diseases in older age are often not isolated conditions. Older people are affected by progressive physiological decline and increased vulnerability to disease and therefore experience considerable comorbidity, i.e. the simultaneous presence of multiple chronic conditions that often add up to cause many problems that affect people's quality of life (Morley et al. 2013; Albers et al. 2015). In addition to physical problems, chronic diseases also cause or exacerbate existing problems in non-physical (e.g. psychosocial, spiritual) domains. The majority of people affected by progressive chronic diseases thus require ongoing care that is initiated early in order to prevent these problems from becoming unmanageable.

These are the aims of palliative care (WHO 2002). Many researchers, clinicians and policy-makers agree that palliative care is an important approach within the care provided to people with serious and progressive chronic diseases (Van den Block 2014; Hall et al. 2011; Anon 2003). However, the conceptualisation of "palliative care" and related terms, such as "end-of-life care" or "terminal care", is less than clear (Hui et al. 2012). Before I provide the definition of these terms for the purpose of this dissertation, it is important to discuss the general difficulties in defining and delineating these concepts.

The most widely used and cited definitions of palliative care are those of the WHO and the European Association for Palliative Care (EAPC)(European Association for Palliative Care 2010; WHO 2002). Although these definitions identify the aims and tasks of palliative care, they are not identical and they are limited by the fact that some of these aims and tasks cannot be clearly distinguished from those of other health care domains (e.g. geriatrics, general practice). There are two important reasons why uniform definitions of "palliative care" and related terms are lacking (Hui et al. 2012). First, the field of palliative care does not have the same position and role in the health care systems of different countries (e.g. recognised medical specialty vs. approach to care not recognised as a specialty; role of palliative care professionals is to advise main formal care providers vs. provide direct care to patients), and sometimes the role of palliative care is not clear even within the health care system of one country (e.g., provision of care to all patients in need of symptom control vs. only to patients with complex symptoms). This means that the term "palliative care" is sometimes used to label different kinds of professional activities. Second, uniform definitions of "palliative care" are lacking because it can be conceptualised on different levels, for instance as a service, programme, approach, or a care model.

The difficulty of achieving a uniform conceptualisation of palliative care may be a reflection of the very nature of palliative care, i.e. the fact that it contains a variety of procedures, can be delivered through different models of care provision, overarches different health care domains, can be delivered by different health care providers and integrated with various medical specialities and procedures, including those that have a curative or life-prolonging aim.

The following paragraphs outline the perspective from which the terms "palliative care", "end-of-life care", "final phase of life" and "terminal care" are viewed in this dissertation. Additionally, the use of these concepts is outlined in each of the articles of this dissertation, in which they are used.

Definition of concepts

The WHO defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."(WHO 2002) The WHO definition further states that palliative care provides relief from pain and other distressing symptoms, affirms life, and regards dying as a normal process, intending neither to hasten nor postpone death. Palliative care integrates psychological and spiritual aspects of patient care, and offers a support system to help patients live as actively as possible until their death. It uses a team approach to address the needs of patients and their families, including bereavement counselling. It enhances quality of life, and may also positively influence the course of illness. Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life (e.g. chemotherapy, radiation therapy), and includes any investigations that are needed to better understand and manage distressing and clinical complications (WHO 2002).

Important suggestions have been made for how to integrate palliative care with other health services. The WHO global strategy on people-centred and integrated health services suggests integrating the concept of palliative care with these approaches to health care because they share common aims and a common view of the patient and their interaction with their environment (WHO 2015b). People-centred health care is an approach to care that consciously adopts the perspectives of individuals, families and communities and is organised around the health needs, preferences and expectations of people rather than diseases (WHO 2015b). These are also the aims of palliative care. Furthermore, the mentioned WHO strategy states that palliative care is well placed within the approach of integrated care which is to deliver health services in a way that ensures people receive a continuum of care that includes health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services, at the different levels and sites of care within the health system, and according to their needs throughout their life course (WHO 2015b).

The origins of the contemporary approach to palliative care lie in the modern hospice movement that was pioneered and significantly advanced by the work of Dame Cicely Saunders in the mid-1960s. She founded St. Christopher's Hospice in southwest London, the first of its kind, which she envisioned to be a "home for dying people" where holistic care (addressing physical, emotional, social and spiritual needs) were to be combined with scientific research (Richmond 2005). Her aim was to counter the way in which British society had been caring for people who were dying, including the care offered to them in hospitals. During this early phase of the modern hospice movement and for decades thereafter, palliative care was mainly thought of as care for people affected by cancer who were in the terminal phase of their illness and for whom all active (e.g. disease-modifying) treatments had been discontinued.

Palliative care advanced considerably since its beginnings. It is now widely accepted in practice, policy and research that palliative care should not only be part of the treatment plan for all seriously ill patients, but should also start at a much earlier stage of the disease without requiring the discontinuation of life-prolonging treatments or an arbitrary threshold of expected survival (Davies & Higginson 2004; Hall et al. 2011; Anon 2003; Albers et al. 2015; Carroll & Quill 2015).

The term "end-of-life care" comprises all care provided in the final or terminal phase of life of people who are diagnosed with a life-limiting disease with irreversible decline, and whose expected survival is measured in terms of months or less (Hui et al. 2014). This also includes persons who may not be dying of one circumscribed disease but rather of the cumulative effects of multiple progressive health problems and ensuing physiological decline (e.g. frail older people) (Hall et al. 2011). Palliative care may be delivered as part of end-of-life care but is not synonymous with end-of-life care. The term "final phase of life" usually refers to a longer period (months) before death, and the term "terminal care" usually serves to indicate the final days of life in the presence of firm evidence of progressive disease (Hui et al. 2014).

The focus of this dissertation is end-of-life care. It has been common in the scientific literature to select the final three months of a patient's life when studying end-of-life care (Gomes et al. 2010; Van den Block et al. 2012; Costantini et al. 2005; Hunt et al. 2014), and the studies used in this dissertation follow this approach.

End-of-life care as a public health challenge

Delivering high-quality care for people at the end of their lives has been recognised as a major challenge in the public health literature, and, by some authors, even a priority for public health worldwide (Rao et al. 2002; Cohen & Deliens 2011). Conditions that have become public health priorities typically have one or more of the following characteristics: (1) large burden, (2) major impact with respect to health consequences and/or costs, and (3) the potential for prevention (Glasgow et al. 1999). These characteristics also apply to dying from serious chronic disease. The dying phase has a major impact on the quality of life of those affected by these diseases, their family carers, and financial costs for health and social care. Finally, the burden related to dying from serious chronic diseases has potential for prevention. Some countries have demonstrated this through the adoption of national end-of-life care strategies and programmes that promote, for instance, pain control, advance care planning, and care in the patients' and families' preferred locations (Department of Health 2008; Australian Institute of Health and Welfare 2010; Ministry of Health Social Services and Equality 2014; Ministry of Health 2001).

An international public health perspective on end-of-life care

Declaring a health problem an issue of public health has a number of implications for research, policy and practice; this is the case for the growing need for end-of-life care. In 1988, the Institute of Medicine in the USA declared assessment, policy development, and assurance the core functions of governmental public health agencies (Institute of Medicine 1988). Similarly, the WHO names as the three core tasks of public health: (1) assessment and monitoring of the health of communities and populations at risk, (2) formulation of public policies designed to solve identified health problems and priorities, and (3) assuring that all populations have access to appropriate and cost-effective care (WHO 2015a). Declaring end-of-life care a public health issue thus means that these core tasks and functions of public health must be applied to end-of-life care.

Although the relevance of end-of-life care for public health was recognised by the WHO more than ten years ago (Davies & Higginson 2004), there is still considerable work to be done in applying the core tasks of public health to this topic. There are still large gaps with regard to the first task - assessment and monitoring - and this creates obstacles for the subsequent tasks, policy-making and assurance of care. The creation of a solid scientific evidence base through epidemiological surveillance has been identified as the first step in developing a long-term public health agenda for the end of life, including the development of policies and interventions (Rao et al. 2002).

In creating a scientific evidence base to inform policy-making in end-of-life care, there is a particular need for cross-national research. One could say that each country has its own particular challenges in organising and providing end-of-life care for which it needs to find specific solutions (Higginson 2005). However, sometimes potential solutions for challenges in one country can be found in other countries (Iwashyna & Lynch 2009). Comparisons among countries can aid in establishing an evidence base to inform policy-making and care provision, both by guiding the search for potentially problematic developments in end-of-life care, and by helping to identify opportunities for change based on strategies employed in other countries in organising and providing care (Higginson 2005).

Applying methods of assessment and monitoring, this dissertation examines, from an international, population-based perspective, two specific aspects of end-of-life care: providers of care at the end of life, and the locations in which people receive care and die. We chose these two aspects because of their particular importance in organising end-of-life care on the national level. The following sections explain in more detail the need for an international perspective on these aspects of end-of-life care, and provide an overview of the current literature in this field.

1.1.2 Providers of care at the end of life

Generalist and specialist palliative care

Palliative care is an important approach to care at the end of life for many patients. The impact of chronic diseases on patients' and families' physical, psychosocial and spiritual wellbeing is particularly high in the last weeks of a person's life: their health declines, health crises occur with increasing frequency, they become increasingly disabled, and the strain on the physical and emotional resources of family carers grows (van Vliet et al. 2015). There is widespread agreement in research and practice that palliative care should be at the forefront of the care that is provided to people who are dying from serious chronic diseases (Hall et al. 2011).

In this dissertation, we look at two groups of palliative care providers: general practitioners (GPs) and multidisciplinary teams specialised in palliative care provision. Previous work has suggested that both types of providers are needed for optimal coverage of the population in need of palliative care (Carroll & Quill 2015; Quill & Abernethy 2013).

Specialist palliative care providers are professionals who are specialised in, and whose main field of activity is, the provision of palliative care. Their roles, tasks and certification differ by country; in most countries where specialist palliative care is available, these providers form multidisciplinary teams whose main task is to consult the patients' usual health providers regarding the needs and care for their patients (Centeno, Lynch, et al. 2013). This means that when a specialist palliative care team is involved, patients typically continue to receive ongoing care from their main treating physician or clinical team. In particularly challenging cases, patients can also be referred to the specialist teams for ongoing care. Specialist palliative care teams can be consulted for patients in hospitals and hospices, and persons residing at home or in a nursing home, although this varies by country or region.

Multidisciplinary specialist palliative care teams provide excellent care to many patients and families (The National Council for Palliative Care 2014). However, given pressure to control overall medical spending in many countries, it appears unlikely that these teams will be able to fully meet the palliative care needs of an ageing population with a growing prevalence of serious chronic diseases. This has caused experts to voice concerns over the feasibility and sustainability of a system of palliative care provision in which all seriously ill patients are referred to specialist palliative care services (Quill & Abernethy 2013; Carroll & Quill 2015). Several scholars have suggested a care model in which palliative care is primarily the task of generalist palliative care providers, such as GPs and the patient's other usual care providers, and is supplemented by input from specialist palliative care teams if the patient has refractory or complex needs (Carroll & Quill 2015).

General practitioners in end-of-life care

In many countries, GPs, sometimes also called family physicians or primary care physicians, are the main providers of generalist palliative care. They are typically a patient's first point of contact in case of a health problem. They provide continuing care, refer patients to secondary and tertiary care, and collect all information concerning the treatments their patients receive (e.g. medications prescribed by hospital physicians, reports of specialists, etc.). It has often been suggested that GPs are in a key position to be the main providers of palliative care (Van den Block 2011). Unlike many specialists (e.g. oncologists, cardiologists), GPs do not have a diagnosis-specific patient group and can thus ensure continued and coordinated care for all patients, regardless of their diagnosis. Furthermore, they often have long-standing relationships with patients and families, and thus have a good overview over their physical, psychosocial and other needs. As a result, initiatives to improve GP-provided palliative care were introduced in several countries. These include, for instance, formal training programmes for GPs (e.g. "training in palliative care for general practitioners with an advisory role" offered by the Dutch Association of General Practitioners), and policy initiatives, such as the Gold Standards Framework in the UK (Hansford & Meehan 2007).

Although GPs in countries where palliative care is available were shown to be able to deliver effective palliative care when supported by specialist teams, a number of reports suggest that both GPs' pain and symptom control, and their communication with patients and families is not optimal. GPs themselves have also had concerns about their own performance in providing palliative care (Mitchell 2002), and scholars have expressed concerns that medical students and GPs do not receive sufficient training in palliative care (Mitchell 2002; Pype et al. 2014).

Family carers in end-of-life care

Family carers are the main providers of both long-term and end-of-life care in most of the world (Emanuel et al. 1999). In OECD countries, it is estimated that more than one in ten adults is involved in informal care for a relative or friend with functional limitations (Colombo et al. 2011). The majority of family carers are women, usually spouses or adult daughters (Talley & Crews 2007). In this dissertation, we define the term "family carer" to include a wider range of personal relationships (Payne 2010; Morbey & Payne 2015). According to the UK National Institute for Health and Clinical Excellence, carers "may or may not be family members", and "are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management"(National Institute for Clinical Excellence (NICE) 2004). In this definition, the term "family" includes "those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strong emotional and social bonds with a patient"(National Institute for Clinical Excellence (NICE) 2004).

Family carers perform a multitude of tasks within end-of-life care including physical, personal, and emotional care. Next to performing basic care tasks, they also take on particularly complex and demanding responsibilities, such as coordinating care and information from different professional care providers, symptom and pain management, dispensing of medication, and difficult emotional and spiritual work (e.g. stress relief, comfort and reassurance, anticipating and planning for dying and death) (Morbey & Payne 2015; Hanratty et al. 2014). They carry out this work in the context of prognostic uncertainties, unpredictable emergency hospital admissions, impending loss and grief, and often over many years (Morbey & Payne 2015). Family carers make an enormous economic contribution to care for seriously ill people (Buckner & Yeandle 2011), and they play a crucial role in ensuring that care for patients can be managed outside institutional settings (Gomes & Higginson 2006). And yet, across countries, they are not systematically integrated into existing models of palliative and long-term care provision (Talley & Crews 2007). This means that a valuable source of "whole-person" care is not used to its full extent, and that family carers are most likely inadequately supported.

Family carers have a unique dual role in that they are both providers and recipients of care. As a result, they need to manage the competing tasks of attending to their own health and welfare needs, while at the same time supporting another person's needs (Morbey & Payne 2015). Although some family carers perceive their role positively (Morasso et al. 2008), research suggests that caring for a relative entails considerable physical, psychological, social and financial demands, particularly if they are approaching the end of life (Grande et al. 2009). Being a family carer can have adverse effects such as depression, anxiety, fatigue and even increased mortality (Grande et al. 2009; Schulz & Beach 1999).

Due to population ageing, the proportion of older family carers is growing. The scenario in which old-age family carers, usually spouses or children, who themselves are in poor health, care for frail old-age dying family members, is becoming increasingly common (Morbey & Payne 2015). Older family carers are at particular risk of poor health outcomes because they provide higher levels and longer hours of care than younger carers, have fewer coping resources (financial, social, professional), often suffer from more serious health conditions, and have worse bereavement outcomes (Grande et al. 2009). The challenge of family caregiving is further complicated by changes in generational and family make-up (e.g. rising old-age dependency ratio, high rate of divorces), employment patterns (e.g. growing participation of women in the labour market), and geographic mobility, among other reasons.

Need for further research on providers of end-of-life care

For many countries in Europe and Latin America, data are available on the types of palliative care providers, as well as the number of services per country or region in a country (Centeno, Lynch, et al. 2013; Pastrana et al. 2012). For other parts of the world, such as Africa and Asia, broader estimates of the palliative care infrastructure development have been made (Connor & Sepulveda Bermedo 2014). These data provide a broad picture of the organisation of palliative care in a country, but they do not hold any information on the extent to which and the manner in which these services are used. Some publications report the number of patients who accessed palliative care services, but they do not provide information on which proportion of all people may require palliative care compared to those who receive it (The National Council for Palliative Care 2014). Furthermore, these data do not allow us to distinguish between patients who are at the end of life and those who are at earlier stages of disease, and they hold no information on how long before someone's death palliative care was initiated. As a result, we do not have a reliable and valid population-based picture of the proportion of people who used palliative care services in the final weeks of life.

Furthermore, most existing data on the availability and use of palliative care services focus exclusively on specialist palliative care services, such as inpatient palliative care units and specialist palliative care teams (Centeno, Lynch, et al. 2013; The National Council for Palliative Care 2014). However, in many countries, palliative care is first and foremost a task of generalist palliative care providers, such as GPs. Disregarding the patients who received care only from them risks seriously underestimating the use of palliative care in a population.

Lastly, population-based studies on providers of end-of-life care rarely include family carers. Although it was shown that family caregiving is a health risk (see section 1.2.3), and that it is a problem for public health (Talley & Crews 2007), research has not yet determined the extent of the burden in family carers in the population. The implications for research that arise from declaring a health topic an issue for public health (see section 1.1.5) also apply to family caregiving (Talley & Crews 2007). Specifically, there is a particular need for epidemiological monitoring of the extent of burden in family carers in the population, and the factors with which burden is associated.

1.1.3 Place of care at the end of life and place of death

Research on preferences for place of death of people affected by incurable diseases and of the general public has repeatedly shown that the majority would prefer to die at home; research shows that family carers also would prefer their ill relatives to die at home (Gomes, Calanzani, et al. 2013). Some research has shown that death at home is associated with improved psychological and social aspects of the patient's well-being compared to death in an institutionalised setting (e.g. hospital), but the evidence regarding symptom control and family outcomes is inconclusive (Higginson et al. 2013). Death in hospital, on the other hand, can be associated with poor end-of-life care as characterised by aggressive treatments, overuse of technical interventions, little discussion about treatment aims, and preoccupation with treatment rather than patient-focused care (Reyniers et al. 2014a; Willard & Luker 2006). Policy-makers also have an interest in enabling more people to die at home, given soaring health care spending. New principles underpinning health care policy formulation are now the wide acceptance of deinstitutionalisation and investment in community and primary care (Tarricone & Tsouros 2008). Hospital admissions of people nearing the end of life were shown to contribute significantly to total health care expenditure (Fassbender et al. 2009). Data from the UK showed that considerable cost could be saved by reducing the length of hospital stays by palliative care patients (Gardiner, Ward, et al. 2014), and that there is potential for palliative care services to reduce expenditures associated with hospitalisations in the last year of life (Hatziandreu et al. 2008).

Previous research indicated that in most countries where this was studied, the majority of people died in hospitals (Broad et al. 2013). However, there are exceptions. In 2003, the majority of people who died from cancer in the Netherlands died at home (Cohen et al. 2010). And although in England, Wales, and Canada, the majority die in hospital, the recent years have seen a reversal in trends towards a lower proportion of hospital deaths and a higher proportion of deaths at home and in nursing homes (the latter only in Canada) (Gomes et al. 2012; Wilson et al. 2009). Similarly, Belgium has shown a trend towards a higher proportion of deaths in care homes and a lower proportion of hospital deaths in recent years (Houttekier et al. 2011).

Next to place of death, place of care is another important outcome of end-of-life care. It indicates the location in which people received care towards the end of life, and not only on the day of death. Research has shown that people would prefer to be cared for at home at the end of life (Wilson et al. 2013) and that family carers usually share this preference (Woodman et al. 2015). When studying places of care, transitions between these places require particular attention. Transitions between care settings are often perceived as burdensome by patients with complex care needs (Boockvar et al. 2014; Coleman & Boult 2003). This is particularly the case if they occur shortly before death and if they involve admissions to acute care settings (Gozalo et al. 2011). Transitions towards the end of life do not only contradict patient and family preferences, they may also compromise continuity, coordination, and potentially even safety of care; common causes include: poor exchange of disease and treatment-related information among different health care providers, poor planning and completion of follow-up care, poor preparation of patients and families for what to expect in the next care setting, and contact people in case their conditions worsen (Coleman 2003; Boockvar et al. 2014).

Hospital admissions at the end of life stand out as a particular type of transition. Unlike transitions to long-term care facilities, they are typically shorter but may occur repeatedly over short periods of time (Rosenwax et al. 2011), often because people experience symptoms that they or their caregivers believe require hospital care (Reyniers et al. 2014a; Gott et al. 2013). Care in hospitals has been described as poorly adjusted to the needs of dying patients, as overly focused on prolonging life as opposed to ensuring comfort, and as a barrier to clear communication between patients and doctors (Reyniers et al. 2014a). However, the same study also reported that it can be a ”safe haven”, a place where they can receive better care than at home, and, for some patients, a familiar environment with which they feel connected.

Need for further research on places of care and place of death

Despite the fact that place of care and place of death have been receiving increasing attention from researchers and policy-makers, important gaps in knowledge remain. First, few cross-national comparisons of place of death have been conducted (Cohen et al. 2008; Houttekier et al. 2010), and it is therefore not clear to what extent differences in place of death among countries can be explained by differences in patient and health care characteristics. Knowing which of these characteristics are associated with place of death can help in identifying the factors that policy needs to address in order to influence where people die (Cacace et al. 2013). Second, the existing cross-national comparisons using individual data were conducted in Europe and not in countries outside of Europe, such as in North America or Asia, that have substantially different health and social care systems that may influence where people die. Third, no published cross-national study has investigated the place of death specifically in the population who can potentially benefit from palliative care. This is important because care planning is particularly relevant for those who may benefit from palliative care. This includes the anticipation of needs and symptoms of patients and families. Care planning can thereby address these needs including the location in which patients are to receive care. Finally, previous studies of place of death require updating given that place of death patterns within countries were shown to be changing (Wilson et al. 2009; Houttekier et al. 2011; Gao et al. 2013).

Studying the locations in which individuals with palliative care needs die, can help identify the care settings that have an important role in the delivery of end-of-life care in a country. People have likely spent at least hours, but more often days, in the location in which they died. This means that evaluating and, if necessary, improving palliative care and its integration with other health and social care services should be a priority at the location in which people most often die in a specific country. Furthermore, comparing data on place of death with data on people's preferred place of death can help to determine the extent to which there is discrepancy on the population level and hence reason to further evaluate why preferences are not being met.

As for transitions between care settings, there are no cross-national population-based data on how often they occur in patients at the end of life, which patients are most likely to experience transitions, and during which periods. Furthermore, we lack information on reasons for transitions at the end of life. For instance, little is known about whether it is patients or families who initiate transitions and to what extent they are driven by medical necessity (e.g. palliative care, life-prolonging treatments). Having this knowledge could greatly benefit strategies to identify patients at risk of inappropriate transitions and develop measures to prevent them. More specifically, there is an insufficient amount of epidemiological data on hospitalisations at the end of life relative to the impact that hospitalisations have on individuals' well-being and the health care system as a whole. Researchers and policy-makers agree that countries should aim to reduce hospital admissions at the end of life, but there are few reliable and valid population-based data on hospitalisations at the end of life on which decisions can be based for reforming policy.

1.1.4 The international context of palliative and end-of-life care

Systems of palliative care provision across the world differ, amongst others, in terms of the main drivers of their development (e.g. charities, national health service), health financing systems (e.g. fee-for-service, diagnosis-related payments), and education and accreditation systems (e.g. whether palliative care is a medical speciality). For instance, in the United States, palliative care teams have developed mostly within hospitals that are financed through diagnosis-related lump sums per patient as this has allowed hospitals to improve profit margins while at the same time providing high-quality care (Ornstein & Meier 2015).

This section describes several aspects of the health care systems and policies of some of the countries studied in this dissertation that could have an influence on the provision of care at the end of life by different caregivers, the places where people receive this care and where they die. Following Marmor and Wendt (2012) and Cacace et al. (2013), we defined 'health systems and policies' as the organisation and governance of health care and wider health policy at the macro-level (countries and regions). This includes issues related to the organisational structure, the financing model, the regulation and planning of the system, the manner in which to create physical and human resources, and the way to provide services. The following sections briefly outline the role of primary care (and specifically of GPs), specialist palliative care provision, and the availability of monetary benefits to patients at the end of life and their family carers in the health care systems of the different countries.

The role of primary care and specifically GPs

This section focuses on the four countries in which end-of-life care provision by GPs was examined for this dissertation, i.e. Belgium, the Netherlands, Italy, and Spain. GPs are usually the patients' first point of contact with health care services in these countries. In the Netherlands, Italy and Spain, GPs are so-called gatekeepers to secondary and tertiary care (Kringos et al. 2015). This means that a patient needs a GP's referral to access secondary or tertiary health care services. Although GPs in Belgium do not have this formal role, in practice they have nonetheless an important coordinating role in patient care. The vast majority of patients in Belgium (95%) have a regular GP, and the mean number of contacts with a GP per year is in line with the EU27 average (Gerkens & Merkur 2010).

An extensive analysis and international comparison of primary care systems in 31 European countries published by the European Observatory on Health Systems and Policies described several essential features of services delivery in primary care (Kringos et al. 2015). Based on this publication, this section will describe three of these features that are particularly relevant in the context of palliative care for each of the four countries.

First, the number of (physical, financial, organisational and other) barriers patients and families need to overcome to access primary care services likely has an impact on the number of people that will receive palliative care from GPs. Second, continuity of care is important in this context because palliative care can achieve its goal of addressing physical, psychosocial and spiritual problems more easily in the context of a stable and ongoing relationship between patient, family and physician and through continuous exchange of care-related information with other care providers (Seamark et al. 2014). Third, coordination of care is essential in palliative care as the large variety in symptoms and needs at the end of life usually necessitates the involvement of professional and volunteer care providers from various disciplines.

Access to primary care is determined based on the availability, provision and distribution of primary care services, types of contact (e.g. appointment systems, home visits), and financial barriers. Relative to the other 30 countries studied by Kringos et al. (2015), the Spain and the Netherlands have highly accessible primary care (ranked 3rd and 5th, respectively), access in Italy is somewhat average (ranked 12th), and in Belgium it is relatively low (ranked 25th).

The primary care systems in the studied countries differ very little in terms of continuity of care. There are two aspects of continuity of care, i.e. relationship continuity and management continuity. Relationship continuity means that a patient has a long-term relationship with a primary care provider (e.g. GP) that goes beyond specific episodes of illness or disease. Management continuity refers to coordination and teamwork between caregivers and across organisational boundaries through optimal exchange of information. A qualitative study with terminally ill cancer patients showed that they attribute a pivotal role to both of these aspects of continuity in the relationship with their GP (Michiels et al. 2007).The four countries we studied hardly differ on indicators of continuity in this regard are very similar to other European countries.

However, these four countries differ considerably in terms of coordination of primary care. Strategies to ensure coordination involve gatekeeping by GPs, skill-mix of primary care providers, and cooperation between primary and secondary care and public health. As described above, the countries differ in regard to whether GPs are gatekeepers. Group primary care practices, as opposed to solo practices, facilitate coordination because of the skill-mix they provide among health care professionals and the relative ease with which patients can be referred between them. In Belgium, the Netherlands, and Italy, solo practices are dominant whereas in Spain, most GPs work in group practices. Among the 31 European countries, the Netherlands were ranked second for coordination of primary care, followed by Spain which was ranked 9th, Italy 12th, and Belgium on the 14th place.

Overall, the four countries were all ranked above average with regard to the combined scores for the essential features of services delivery in primary care. Belgium, the Netherlands and Spain were found to have strong primary care systems, whereas that of Italy was judged to be of medium strength.

Specialist palliative care provision

This section focuses on the four countries in which we studied the provision of palliative care by multidisciplinary specialist palliative care providers, i.e. Belgium, the Netherlands, Italy, and Spain. Specialist palliative care services are established in all four countries but the countries differ with regard to the care settings in which these services predominantly operate and in the manner in which they are organised (Centeno, Lynch, et al. 2013).

All four countries have palliative home care teams who are responsible for patients residing at home, and specialist palliative care providers in hospitals (outside of hospital-based palliative care units) (Centeno, Lynch, et al. 2013). Belgian law requires that every hospital has a mobile palliative care support team with 24/7 on-call duty (Federale Evaluatiecel Palliatieve Zorg 2014). Next to this, in Belgium and Spain, there are inpatient palliative care units in hospitals where in-house specialised palliative care staff operate. In the Netherlands and Italy, where hardly any such palliative care units exist, freestanding inpatient hospices fulfil a similar role. There are bigger differences between these four countries regarding the availability of specialist palliative care in nursing homes, care homes or similar long-term care facilities. While there are specialised palliative care nurses in Belgian nursing homes, as required by Belgian law (Federale Evaluatiecel Palliatieve Zorg 2014), and specialist palliative care consultation in Dutch nursing homes, there is hardly any specialist palliative care provision in nursing homes in Italy or Spain. Furthermore, while specialist palliative care services are geographically evenly distributed in Belgium and the Netherlands, there are large regional differences in provision within both Italy and Spain.

As for policy support, Italy and Spain have national palliative care strategies that specify standards and aims regarding the organisation and provision of palliative care in the various care settings (Babarro 2007). Additionally, Spain has issued a Royal Decree, which defines the fundamental principles to guarantee the availability and equal access to palliative care. The Netherlands has also issued a "plan for palliative care". Belgium does not have a national palliative care strategy but it has issued a Royal Decree concerning minimum service provision requirements in different palliative care settings and funding for these services (Van Beek et al. 2013). Reports from all four countries state insufficient funding for an optimal development of palliative care services, and a necessary improvement of out-of-hours care as well as palliative care education for all care providers (Centeno et al. 2013; Federale Evaluatiecel Palliatieve Zorg 2014).

Monetary benefits for family carers

This section focuses on the four countries in which we studied difficulties for patients and families in covering the costs of care at the end of life, which are Belgium, the Netherlands, Italy, and Spain. Benefits for family carers in Belgium are paid through an extended system of paid leave schemes. In Spain, there is a strict priority of benefits in kind over benefits in cash. The financial benefit for carers is granted only in exceptional cases when the care recipient is being cared for in the family setting and provided that the home meets certain requirements for co-habitation and habitability. Italy has no national legislation concerning cash benefits to family carers, but some exceptions exist on regional or municipality levels, mainly with a view to co-fund private home helpers and carers. The lack of benefits for family carers in the Netherlands is seen as a result of formal care being more widespread than informal care and many dependent people residing in nursing homes (Riedel & Kraus 2011).

All four countries studied offer benefits to care recipients following an assessment that determines whether the person fulfils certain criteria (Riedel & Kraus 2011). The benefits for recipients of informal care in Belgium include mainly services in kind. However, there are also additional cash benefits aimed mainly at alleviating burden of non-medical costs related to long-term dependency. Additionally, Belgium has a specific benefit for individuals in need of palliative care, i.e. a cash benefit received by people who are cared for at home ("palliatief forfait"). This benefit is intended as financial support to purchase medication, aid and care products for people with palliative care needs. To receive this benefit, patients have to meet certain criteria such as being affected by one or several irreversible and deteriorating conditions, having serious physical, psychological, social or spiritual needs, requiring intensive and continuous care, living at home and intending to die at home, and having a life expectancy of between 24 hours and three months (Federale Evaluatiecel Palliatieve Zorg 2014). Patients who meet the criteria for this cash benefit are also eligible for a waiver of out-of-pocket payments for home care and home visits by GPs and occupational therapists. Most long-term care recipients in the Netherlands can choose between a care in kind and cash benefit called "personal budget". The majority choose the latter (Riedel & Kraus 2011). Benefit recipients need to prove that they spent the benefit on care; though for budgets below a certain margin this is not required. Care recipients can choose freely who will deliver their care. Care recipients in Italy receive cash benefits that they are free to use for payment of care services or other means. As with benefits for family carers, Spain strictly prioritises benefits in kind over benefits in cash for care recipients. If cash benefits are provided, they are meant as a contribution towards hiring a personal assistant to help the dependent person with activities of daily living.

This is not an exhaustive list of potentially relevant factors nor did the previous sections describe policy in all 14 countries that were included in the studies for this dissertation. Doing so would go beyond the scope of this chapter and perhaps of a single dissertation. However, the previous sections have provided the background information on policies and health care systems that are used in the general discussion of this dissertation to explain the findings of our research.

1.2 Aims and research questions

The overall aim of this dissertation was to describe and compare different countries in terms of two aspects of end-of-life care: (1) the care delivered to people at the end of life by different care providers and (2) the places where people receive end-of-life care and where they die. Both research areas will be addressed from a population-based, cross-national perspective. The research questions guiding this dissertation are:

Providers of care at the end of life

1. How many people receive palliative care by GPs and by multidisciplinary specialist palliative care teams?
2. How satisfied are bereaved relatives of people who died from cancer with the home care provided by GPs?
3. What is the extent of the physical or emotional overburden in family carers of people at the end of life and to what extent do patients and families have problems covering the costs of care?

These questions are addressed in Chapters 2-4 of this dissertation.

Place of care at the end of life and place of death

4. How many people transfer between care settings in the last three months of life and what are the reasons for the final transition to the location in which they die?
5. How many people are hospitalised in the last three months of life, in which periods, and for how long?
6. Where do people who are in potential need of palliative care die in different countries and to what extent are differences among countries in the place of death explained by differences in socio-demographic characteristics, cause of death, and availability of health care resources?
7. Where do people die from cancer in different countries and to what extent are differences among countries in the place of death explained by differences in socio-demographic characteristics, cause of death (haematologic cancer versus solid tumour), and availability of health care resources?

These questions are addressed in Chapters 5-8 of this dissertation.

1.3 Methods

As is outlined in section 1.1.1, declaring palliative and end-of-life care an issue for public health means that the three functions of public health should be applied to the topic. This includes employing public health research methods to study the provision of end-of-life care in the population. In order to create a sound scientific base for policy-making on end-of-life care, we need to obtain data at the level at which these policies are implemented, and this is usually the level of states or regions (Talley & Crews 2007).

The following sections describe the methods that were used to address the research questions of this dissertation. All these research methods have in common that they are quantitative and studied the end of life through retrospective data collections. They either made use of existing routinely collected administrative data (death certificates in the International Place of Death study), existing epidemiological surveillance systems (Sentinel Networks of GPs in the EURO-SENTIMELC study) or a survey of bereaved relatives based on a population-based sample of deaths (QUALYCARE study).

1.3.1 Research questions 1,3,4 and 5: EURO-SENTIMELC study

Study design

The European Sentinel Network Monitoring End-of-Life Care (EURO-SENTIMELC) study is a mortality follow-back study that collected population-based data on end-of-life care in four European countries over three years (from January 1st 2009 until December 31st 2010 in Belgium, the Netherlands and Italy, and from January 1st 2010 until December 31st 2011 in Spain). It was the first study that collected such data across different countries. The data are from Belgium, the Netherlands, Italy and two autonomous communities in Spain, i.e. the Valencian Community, and Castile and Leon (Van den Block et al. 2013).

Observational unit

The observational units in this study are GPs. General practice is highly accessible in Europe, and in the countries included in this study, GPs are either gatekeepers to secondary or tertiary care (Netherlands, Spain, Italy) or have another, less formalised, central coordinating role (Belgium). This means that in most European countries, almost all of the population have a GP whom they consult regularly (Schäfer et al. 2010; Garca-Armesto et al. 2010; Ferré et al. 2014; Gerkens & Merkur 2010). It is therefore possible to obtain a population-based sample of deaths through GPs and gain a comprehensive view on the end-of-life care in a country's population. Deaths in nursing homes in the Netherlands are an important exception, as nursing home residents are treated by specialised elderly care physicians as opposed to GPs.

Data were collected by Sentinel Networks of GPs. A Sentinel Network is a network of practices or community based physicians who conduct epidemiological surveillance of one or more specific health problems on a regular or continuing basis (Fleming et al. 2003; Deckers & Schellavis 2004; Vega et al. 2006). In Belgium, the Netherlands, and Spain we worked with established Sentinel Networks, whereas the Italian partner set up a new GP network specifically for the EURO-SENTIMELC study because the existing Sentinel Network's main focus was flu surveillance. The networks of all four countries employed comparable procedures. The participating GPs of all four countries had an adequate geographical distribution and were representative of the general population of GPs in the respective country (or region in Spain) with regard to sex and age (Van den Block et al. 2013).

Population

The networks in Belgium and the Netherlands were nationwide with a population coverage of 1.8% and 0.8% (2009), and 1.5% and 0.8% (2010), respectively. The Italian network covered 4.3% (2009) and 2.7% (2010) of the population of nine health districts spread across the country. The Spanish networks operated in two autonomous communities. In the Valencian Community their population coverage was 2.2% of the population aged 18 years or over in 2010 and 2.1% in 2011; in Castile and Leon the respective figures were 3.8% in 2010 and 3.4% in 2011.

We excluded deaths of persons who were younger than 18 at the time of death as our studies focused on the adult population. We also excluded deaths in nursing homes in the Netherlands as the care for these individuals is not within the scope of GPs. Furthermore, we excluded deaths that the GPs had classified as sudden and totally unexpected in order to obtain a sample of decedents for whom end-of-life care had been a realistic option. This criterion was chosen following careful consideration of its methodological strengths and limitations (Borgsteede et al. 2006).

An analysis of the deaths registered by the Sentinel Networks in previous years showed that they were representative for all deaths in the participating countries in terms of age, gender, and place of death, with the exception of nursing home deaths in the Netherlands. Furthermore, GPs underreported a small number of sudden hospital deaths in all countries as well as non-sudden hospital deaths and deaths of people under 65 years in Belgium (Van den Block et al. 2013).

Procedure

The GPs belonging to the Sentinel Networks were asked to continuously register every death of a patient of their practice aged one year or over (aged 18 years or over in Italy) using a standardised registration form. The GPs registered the deaths on a weekly basis. They recorded the patient's cause of death, socio-demographic characteristics and several aspects of the care the patient had received in the last three months of life. This includes places of care and place of death, communication between the GP and the patient and family, palliative care provision, and burden on family carers. The GPs were also asked to include any information from hospital physicians and patient records when completing the registration form.

Data collection

The registration form consisted of 21 structured closed-ended items and is available in Dutch, French, Italian, Spanish, and English. The questions of the registration form that were used for the analyses in this dissertation are mentioned in the respective chapters(Chapters 2, 4, 7, and 8) of this dissertation.

1.3.2 Research question 2: QUALYCARE study

Study design

The QUALYCARE study is a mortality-follow back survey of bereaved relatives of people who died from cancer. Its main aim was to study the quality and costs of end-of-life care for people with cancer in relation to place of death (Gomes et al. 2010). The survey took place in four health districts (Primary Care Trusts) in London, UK.

Participants

Bereaved relatives of people aged 18 years or over who died from cancer (ICD-10 codes C00-D48) over a one-year period (March 2009-March 2010) and who lived in one of the four selected health districts participated in a survey regarding the last three months of life of their deceased family members. The bereaved relatives were identified by the Office of National Statistics (ONS) from death registrations, as the people who registered a death from cancer. Deaths were excluded if they were registered by a coroner and if the place of death was other than the deceased's home, a hospice, nursing home, or NHS hospital, or if it was unknown. Because place of death was a crucial factor to the overall aim of the QUALYCARE study the sample was stratified by health district and place of death to include all home, hospice, nursing home, and a random sample of NHS hospital deaths (if more than 150 eligible NHS hospital deaths per health district; otherwise all NHS hospital deaths were included). We excluded participants from the analysis if their deceased relative had not spent at least one day at home during the last three months of life because we wanted to assess the relatives' satisfaction with home care for all deceased who had had the possibility of receiving home care.

Procedure

The ONS contacted the potential informants between four and ten months after the registration of the death and invited them to participate in the study. This was done by sending a questionnaire via post together with a freepost return envelope, the study information sheet, a bereavement information leaflet, and a reply slip to decline participation.

Data collection

An adapted short form of a questionnaire developed by Cartwright et al. (Cartwright et al. 1973) assessed the care received by the patient at home and relatives' satisfaction with care. It has shown satisfactory discriminatory power, reliability, and validity (Jacoby et al. 1999). As we were interested in care that was delivered to people at home, we determined whether patients were visited at home by GPs, palliative care specialists (from hospice, palliative care, Marie Curie or Macmillan or any other specialist), or district/community/private nurses. To assess the main outcome, the relatives were asked whether they perceived the home care delivered to patients in the last three months of life by GPs, palliative care specialists, and district/community/private nurses, as well as the overall care at home, to be excellent, very good, good, fair, poor or very poor. We also assessed relatives' views on the communication with the GP and on the GPs' competence and symptom control, the deceased's health status, and the intensity of the grief experienced by the respondent. The questionnaire also collected socio-demographic data for the deceased and the respondent. Information on the cause and place of death was provided by the ONS.

1.3.3 Research questions 6 and 7: International Place of Death study

We used data from the International Place of Death (IPoD) study to examine the place of death of people who died from diseases indicative of palliative care need and from people who died from cancer in 14 countries.

Study design

The IPoD study examined and compared the place of death in 14 countries by collecting the death certificate data of all deaths that occurred in each country over the period of one year. The data collection took place between 2011 and 2013. At that time, the most recent year for which complete death certificate data were available from all countries was 2008. The countries included are Belgium, Canada, Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, South Korea, Spain, the USA, and Wales. We obtained full country data except for Spain, where the data are from the Andalusia province, and Canada where the data do not include the Quebec province.

Population

The data of the IPoD study include all deaths of persons aged 1 and over that occurred in 2008 (exceptions: 2010 in Spain and 2007 in the USA). For the present dissertation, two subsets of these deaths were selected for two separate analyses.

The first was the subset of deceased who had potentially been in need of palliative care as judged by the underlying cause of death. The range of conditions that indicated that a patient was in potential need of palliative care was identified in previous research through a literature study as well as interviews and focus groups with relevant stakeholders (Rosenwax et al. 2005). These conditions (underlying causes of death) are cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease (COPD), diseases of the nervous system (Alzheimer's disease, Parkinson's disease, motor neurone disease/amyotrophic lateral sclerosis, Huntington's disease), and HIV/AIDS. The same research also determined that the deaths from these conditions form the Minimal Estimate (i.e. the most conservative estimate) of the population in need of palliative care. The second subset selected from the total population of deaths included those for which cancer (ICD-10 codes C00-C97) was the underlying cause.

Data

The variables obtained from the death certificates include the place of death, cause of death, age and gender of the deceased. Additionally, a number of other variables were included, either from death certificates or, if they were not recorded there in a particular country, by linking the death certificates with other databases (e.g. census data). Health care resource statistics per capita and data on degree of urbanisation were linked with the deceased's municipality/local authority of residence. The project lead coordinated and pooled the data from all countries to ensure that similar variables across countries were obtained.

1.3.4 Ethics

The study protocol of the EURO-SENTIMELC study was approved by the ethical review board of Brussels University Hospital of the Vrije Universiteit Brussel, Belgium and the Local Ethical Committee 'Comitato della Azienda U.S.L. n. 9 di Grosseto' in Tuscany, Italy. No ethics approval was required for the collection and analysis of retrospective anonymous data in the Netherlands or Spain according to these countries' data protection legislation.

Ethics approval for the Qualycare study was granted by the South East London NHS Research Ethics Committee 3. The return of the completed questionnaire was taken as consent by the bereaved relative to participate in the research.

No ethics approval was required for the IPoD study as anonymised death certificate data were studied.

1.3.5 Outline of the dissertation

Chapters 2-8 of this dissertation are based on articles that have been published in international peer-reviewed journals. The two overall aims of this dissertation are addressed in two parts. The chapters of each part answer the research questions of each aim.

Chapters 2-4 are concerned with different providers of care at the end of life. They describe analyses of (1) the provision of palliative care by GPs and specialist palliative care providers, (2) bereaved relatives' satisfaction with the home care provided by GPs to patients with cancer at the end of life, and (3) the physical and emotional burden on family carers of people at the end of life and difficulties for patients and families in covering the costs of end-of-life care. The analyses in Chapters 2 and 4 are based on population-based data from the EURO-SENTIMELC study, conducted in Belgium, the Netherlands, Italy and Spain, and the analysis in Chapter 3 is based on population-based data of the QUALYCARE study, conducted in London, UK.

Chapters 5-8 are concerned with the places in which people receive care at the end of life and the places in which they die. These chapters describe analyses of (1) the place of death in the population potentially in need of palliative care, (2) the place of death in the population who died from cancer, (3) transitions between health care settings at the end of life, and (4) hospitalisations at the end of life. The first two analyses are based on population-level data from the IPoD study that was conducted in 9 European and 5 non-European countries. The last two analyses are based on population-based data from the EURO-SENTIMELC study that was conducted in Belgium, the Netherlands, Italy and Spain.

The eight chapters are followed by a General Discussion, in which the main findings of the dissertation are summarised, interpreted, and discussed in light of existing literature and with special attention to recommendations for future research, policy, and practice. This chapter also contains a reflection on the strengths and limitations of the research conducted for this dissertation.

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Chapter 2

Palliative care service use in four European countries: a cross-national retrospective study via representative networks of general practitioners

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Published in: PLoS One. 2013, 8(12):e84440, doi: 10.1371/journal.pone.0084440.

Acknowledgements: We thank the Belgian, Dutch, Italian and Spanish Sentinel Networks of General Practitioners for providing the data for this study; Fliss EM Murtagh for critically reviewing the manuscript; and Jane Ruthven for linguistic help.

Funding: Funding for the study came from the Institute for the Promotion of Innovation by Science and Technology in Flanders (http://www.iwt.be) as a Strategic Basic Research project (SBO) (contract SBO IWT 050158)

(2006-2010), as part of the 'Monitoring Quality of End-of-Life Care (MELC) Study', and from EURO IMPACT: European Intersectorial and Multidisciplinary Palliative Care Research Training, funded by the European Union Seventh Framework Programme (FP7/2007-2013, under grant agreement no. 264697, http://ec.europa.eu/research/fp7).

Abstract

Background: Due to a rising number of deaths from cancer and other chronic diseases a growing number of people experience complex symptoms and require palliative care towards the end of life. However, population-based data on the number of people receiving palliative care in Europe are scarce. The objective of this study is to examine, in four European countries, the number of people receiving palliative care in the last three months of life and the factors associated with receiving palliative care.

Methods: Cross-national retrospective study. Over two years (2009-2010), GPs belonging to representative epidemiological surveillance networks in Belgium, the Netherlands, Italy, and Spain registered weekly all deaths of patients ($\geq$18 years) in their practices and the care they received in the last three months of life using a standardized form. Sudden deaths were excluded.

Results: We studied 4,466 deaths. GPs perceived to have delivered palliative care to 50% of patients in Belgium, 55% in Italy, 62% in the Netherlands, and 65% in Spain ($p<.001$). Palliative care specialists attended to 29% of patients in the Netherlands, 39% in Italy, 45% in Spain, and 47% in Belgium ($p<.001$). Specialist palliative care lasted a median (inter-quartile range) of 15 (23) days in Belgium to 30 (70) days in Italy ($p<.001$). Cancer patients were more likely than non-cancer patients to receive palliative care in all countries as were younger patients in Italy and Spain with regard to specialist palliative care.

Conclusions: Although palliative care is established in the countries studied, there are considerable differences in its provision. Two potentially underserved groups emerge: non-cancer patients in all countries and older people in Italy and Spain. Future research should examine how differences in palliative care use relate to both patient characteristics and existing national health care policies.

2.1 Introduction

It is estimated that, in Europe, 4.8 million people die every year. Approximately two million die from serious chronic disease and cancer, with a further increase in deaths from these causes expected (1). Given that a growing proportion of people will live into old and very old age, and that chronic diseases are more common in old people, an increasing number of people will be living with the effects of these illnesses (2,3). The burden that these demographic and epidemiological developments place on society has been recognized by the World Health Organization (WHO) and the European Union who have identified care for people at the end of life as an important public health issue (4,5).

People dying from cancer and other serious chronic diseases are very likely to experience multiple and complex symptoms requiring appropriate and timely assessment and treatment, and thus are in potential need of palliative care (2). The WHO defines palliative care as "...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."(4) Population-based data on the number and characteristics of people who access palliative care in Europe are limited. Particularly little is known about the characteristics of people who do not receive palliative care, and about the extent to which palliative care is delivered to those dying from illnesses other than cancer, who are likely to be underserved (6,7). Obtaining this information is essential for ensuring the adequate organisation and provision of palliative care on national levels, and its integration into mainstream health care services.

In recent years major efforts have been undertaken to assess the establishment of palliative care within health care systems around the world, including the availability of palliative care services, funding arrangements and policy support (8-11). While these studies provide valuable knowledge about the development of palliative care, they do not provide information on the actual percentage of people at the end of life receiving it nor about the timing of initiation of palliative care before death. Other studies have focused on single countries only or have selectively studied patients with cancer or those in particular care settings, thereby precluding a population-based perspective on the use of palliative care (12-15). Studies estimating population coverage solely on the basis of annual activity data of palliative care services risk double-counting, since unique patient codes are not used across health care settings. Additionally, due to differences in research design, these single studies cannot be compared across countries.

We have conducted one of the first population-based studies assessing and comparing the frequency and timing of use of palliative care in a representative sample of the general population of patients at the end of life in four European countries. Earlier studies in Belgium and the Netherlands have successfully applied a similar design, but did not explicitly assess whether GPs delivered palliative care nor the length of time over which patients received palliative care (16-18). We have extended the study design to include two more countries, Italy and Spain, and have assessed the delivery of palliative care by GPs and by specialist palliative care services as well as the time of initiation.

This study aimed to address the following research questions with regard to the last three months of life of patients who died non-suddenly in Belgium, the Netherlands, Italy and Spain:

How many people receive palliative care from their GP and through specialist palliative care services, and are there differences between countries?

For how many days during the last three months of life do people receive specialist palliative care, and are there differences between countries?

Are patients' sex, age, cause and place of death associated with the use of palliative care delivered by the GP and the use and time of initiation of specialist palliative care?

2.2 Methods

Ethics statement

Informed consent and patient and GP anonymity

The participating GPs gave written informed consent at the beginning of each registration year, after being fully informed about the objectives and methods of the study. Strict procedures regarding patient anonymity were followed during data collection and entry. Each registered death received an anonymous reference from the GP. Any potentially identifying patient and GP data (such as patient's date of birth, postcode, and GP identification number) were replaced by aggregate categories or anonymous codes. In Belgium and the Netherlands, patients of GPs who were part of sentinel networks were informed through posters or leaflets displayed in the practices that their data could be used anonymously for research purposes. In Italy, patients are informed that their care-related data, when anonymised, can be used to monitor care as standard. Patients in Spain were not necessarily informed that their data could be used for research. However, as all data were thoroughly anonymised, this was not required. The proceedings in each country comply with the country's respective laws (19-25).

Ethics approval

Ethics approval for this study, including the consent procedure, was obtained from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel, Belgium (2004), and from the Local Ethical Committee 'Comitato Etico della Azienda U.S.L. n. 9 di Grosseto' in Tuscany, Italy (2008). Ethics approval was not required for posthumous collection of anonymous patient data in the Netherlands (19,20) or Spain (21-23), according to the legislation of these countries.

Study design

This study is part of the EURO SENTIMELC (European Sentinel Network Monitoring End-of-Life Care) study, a cross-national retrospective study monitoring end-of-life care in Belgium, the Netherlands, Italy, and Spain (the Castile and Leon and Valencian Community regions) (26). Data were collected through representative sentinel networks of GPs who continuously registered all deaths amongst patients in their practices. GP sentinel networks are epidemiological surveillance networks consisting of freestanding practices or community-based physicians who voluntarily and continuously monitor health problems occurring in the population. They have a long-standing involvement in epidemiological research, a low annual turnover, and were shown to be suitable for monitoring health-related epidemiological data (27-29). In Belgium, the Netherlands, and Spain we cooperated with existing long-standing sentinel networks that monitor a wide range of health problems, whereas in Italy a new network was formed for this study as the existing network had a flu surveillance focus. GPs are recruited into the sentinel networks by national public health institutes, who draw a random sample of GPs and invite them to become part of the network. The new Italian network was created by the Italian Society of General Practitioners through a procedure similar to that in the other countries. The Italian GPs were recruited from nine health districts that are spread all over the country. At the point of recruitment, GPs were informed only about the procedure and not about the subject of the surveillance in order to avoid an overrepresentation of GPs with a particular interest in palliative care.

In each country the institutes responsible for creating the sentinel networks verified that the sentinel GPs were representative of the total GP population in terms of age, sex, and geographic location. The number of participating GPs and their population coverage per country in 2009 was as follows: 199 (1.8%) in Belgium, 59 (0.8%) in the Netherlands, and 149 (4.3%) in Italy. In Spain, data were collected in 2010 only. The respective figures for 2010 are 189 (1.5%) in Belgium, 63 (0.8%) in the Netherlands, 94 (2.7%) in Italy, and 173 in Spain (114 (3.8%) in Castile and Leon, 59 (2.2%) in the Valencian Community). The percentages in Italy refer to the population of the nine participating health districts. The percentages in Spain refer to the population aged 18 years or over. The participating GPs of all four countries had an adequate geographical distribution and were representative of the general population of GPs in the respective country (or region in Spain) with regard to sex and age (26). This study protocol has been successfully implemented in a number of cross-national comparisons (17,30-32). Further information on the sentinel networks of GPs and the methods of the study is provided in the published study protocol (26).

Sample

Deaths of all patients 18 years or older in the participating GP practices were included. Deaths classified by the GP as sudden and totally unexpected, and those for which this information was missing, were excluded in order to obtain a sample of patients for whom palliative care was a relevant consideration (33,34). This criterion was chosen following a careful consideration of its methodological strengths and limitations (34), and was based on the fact that several studies in the palliative care literature distinguish between sudden and non-sudden deaths (33-36). Furthermore, nursing home deaths in the Netherlands were excluded, as these patients are not cared for by GPs but by specialised nursing home physicians.

Procedure

Using a standardised form GPs belonging to the sentinel networks registered weekly all deaths among patients in their practice who were aged 18 years or over throughout a two year period, from Jaunary 1st 2009 to December 31st 2010 (in Spain over one year, in 2010). At the beginning of each year, GPs received instructions, clearly stating the inclusion criteria of the study and how to complete the registration form.

Measurement

The registration form consists of structured and closed-ended items surveying care-related information about the patient's final three months of life. The literature suggests that this is a relevant time period for studying end-of-life care (33,37,38). The registration form was initially developed in Dutch and French and translated into English. From English it was subsequently translated into Italian and Spanish. All translations were carried out via forward-backward procedure. The following items of the registration form were included in the present study:

Dependent variables:

The GPs' perception of whether she or he had delivered palliative care to the patient : 'did you provide palliative care to this patient?'.

Specialist palliative care: 'which palliative care initiatives were involved in the last 3 months of this patient's life?' GPs were asked to indicate which palliative care initiatives from a list of options were involved in the patient's care (these options differed between countries due to differences in the services that are available, see Table 1). The terminology used to label these services corresponds to the labels commonly used in primary care in the respective countries.

Time of initiation of specialist palliative care: 'estimate the number of days between the first palliative intervention and the moment of death'.

Independent variables:

Age at death and sex

Cause of death: 'illness or disorder that was the direct cause of death'.

Place of death: (a) home/living with family, (b) care home/home for the elderly/nursing home, (c) hospital (excl. palliative care unit and nursing home unit in a hospital), (d) palliative care unit/hospice, (e) elsewhere (specified).

As the types of specialist palliative care services differ between countries, they were classified into five categories to facilitate comparison (Table 2.1).

While the geographic distribution of palliative care services is relatively homogenous in Belgium and the Netherlands, there is large heterogeneity in

Italy and Spain. In Italy, the density of palliative care services is higher in the north of the country compared to the south, and in Spain there is great variation in the organisation of palliative care between the different Autonomous Communities. Furthermore, the countries differ with regard to the role of GPs within palliative care services. In the Netherlands and Belgium GPs are seen as the main care providers for people requiring palliative care (39,40) and in Spain they are core providers of palliative care in the community (41). However, there is uncertainty about the role of GPs within specialist palliative care teams in Italy, perhaps due to the heterogeneity of organizational models in the country (42).

Statistical analysis

We carried out X^2-tests to analyse differences in sex, age, cause and place of death between the samples of the countries studied. The place of death category 'other' was not included in the significance tests in case of cell frequencies below 5.

Binary multivariate logistic regression analyses, adjusted for age, sex, cause and place of death, were computed to assess the association between country as the independent variable and receiving palliative care by the GP and specialist palliative care as dependent variables. A further binary multivariate logistic regression analysis, adjusted for age, sex, cause and place of death, was computed to compare between countries the number of patients attended to by different specialist palliative care services. The number of days during which specialist palliative care was provided in the last three months of life was analysed both as a continuous and as a categorical variable. The categories were (1) 1-3 days, (2) 4-7 days, (3) 8-30 days, and (4) 31-92 days. The continuous variable was compared between countries using the Kruskal-Wallis test. A multivariate ordinal logistic regression analysis, adjusted for age, sex, cause and place of death, was conducted to test the association between country and the four categories of time of initiation.

For each country two binary multivariate logistic regression analyses were computed to test whether age, sex, cause and place of death are associated with receiving palliative care by the GP (first analysis) or specialist palliative care services (second analysis). Finally, a multivariate ordinal logistic regression analysis was computed for each country to test whether the same factors are associated with time of initiation of specialist palliative care.

For each multivariate logistic regression analysis commonly recommended assumptions were tested (44). Odds ratios and binomial 95% confidence

Table 2.1: Classification of specialist palliative care services and healthcare professionals involved in these services

Category	Belgium	Netherlands	Italy	Spain
Hospice/palliative care unit	Palliative care unit in a hospital: physician and nurses; can call on the support of other professionals (psychologists, social workers, etc.)	Hospice, palliative care unit (in a hospital, nursing home, or care home): palliative care nurses, volunteers, patient's GP, sometimes hospice doctor or other medical specialist	Hospice: physicians and nurses specialised in palliative care, can call on the support of other professionals (psychologists, social workers, etc.)	Palliative care unit in a hospital: physicians and nurses specialised in palliative care, psychologist
Palliative care service for patients staying at home	Palliative home care team: one GP, two nurses, one secretarial assistant. Their aim it is to advise front-line carers. Palliative day care centre: physician, palliative care nurses, volunteers	Palliative care consultation team: consult all professionals involved in palliative care; consist of palliative care nurses, GPs, nursing home physicians, and other medical specialists, all with extra training or expertise in palliative care[b]	Palliative home care team: physician and nurse specialised in palliative care; limited contact with GPs. Domiciliary integrated assistance with palliative care: GP and nurse	Palliative home care team: GP, nurse, social worker, psychologist. Palliative day care centre: GP and nurse. Ambulatory palliative care in a hospital: physicians and nurses specialised in palliative care
GP with formal palliative care training	[d]	GP with palliative care training[c]	[d]	[d]
In-house palliative care service in a nursing home	Reference persons for palliative care in a nursing home: aim to support GPs and nurses operating in the nursing home	[d]	[d]	Palliative care nurses in a nursing home
Hospital-based palliative care service (excl. palliative care unit)[a]	Mobile palliative care support team in a hospital: mobile team operating within the hospital, consisting of specially trained staff physicians, nurses, and paramedics	Palliative care consultation team (see above)[b]	Pain therapy or palliative care specialist consultation during a hospital admission: physicians specialised in palliative care	[d]

[a] For patients admitted to hospital for at least one day in the last three months of life.

[b] Palliative care consultation teams offer services to patients at home as well as to patients in hospital/hospice/nursing home. Seventy-seven per cent of those for whom palliative care consultation is requested are cared for at home (Kuin et al. 2004).

[c] GPs who followed a 'training in palliative care for general practitioners with an advisory role' offered by the Dutch Association of General Practitioners (Nederlands Huisartsen Genootschap, NHG) and who are registered as palliative care advisors in a central database.

[d] No specialist palliative care initiatives available.

intervals were calculated for all dependent variables and p-values for all tests of significance. All statistical tests were performed with a significance level of $\alpha < 0.05$ in IBM SPSS Statistics (version 19). If the percentage of missing values was below 10%, cases with missing values on a particular variable were omitted in analyses involving the respective variable. In case it amounted to more than 10% we tested whether the proportion of missing values was significantly associated with patients having received palliative care.

2.3 Results

Sample characteristics

In total, 6,858 deaths were reported, of which 4,518 (65.9%) were classified by the GPs as expected or non-sudden. The percentage of deaths judged as non-sudden per country was as follows: 67% in Belgium, 62% in the Netherlands, 66% in Italy, 69% in Spain ($p<.001$). These percentages of non-sudden deaths are in line with those reported by physicians in previous studies with a similar methodology (33-36). Following the exclusion of nursing home deaths from the Netherlands (n=52, 7.6% of all deaths registered in the Netherlands) a sample of 4,466 deaths remained of which 1,604 were registered in Belgium, 635 in the Netherlands, 1,839 in Italy, and 388 in Spain. The samples of the registered non-sudden deaths from Belgium and the Netherlands (excluding nursing home deaths) were compared to those of previous death certificate studies in which representative samples of non-sudden deaths were obtained (38,45). For Italy and Spain, the sample of all registered deaths was compared with national mortality statistics. We did not find large differences, except for a slight underrepresentation of non-sudden hospital deaths and people under the age of 65 in Belgium and women in the Netherlands (26).

Differences between countries in terms of sex, age, cause and place of death were statistically significant (Table 2.2). The Dutch sample revealed the smallest percentage of people aged 85 years or over and the highest percentage of cancer deaths. In Spain there was a relatively larger number of men and lower number of women compared with the other countries. In Belgium, most people died in hospital, whereas home was the most frequent place of death in the other countries.

Table 2.2: Characteristics of non-sudden deaths in Belgium, the Netherlands, Italy and Spain; % (95% CI), n

Patient characteristics[a]		Belgium	Netherlands	Italy	Spain	p-value
		N = 1604	N = 635	N = 1839	N = 388	
Sex						.04[b]
	Male	46 (44 to 48) 731	47 (43 to 51) 295	47 (45 to 49) 856	54 (49 to 59) 209	
	Female	54 (52 to 56) 868	53 (49 to 57) 333	53 (51 to 55) 983	46 (41 to 51) 179	
Age at death						<.001[b]
	18-64y	14 (12 to 16) 219	18 (15 to 21) 117	13 (11 to 15) 233	11 (8 to 14) 43	
	65-84y	47 (45 to 49) 753	50 (46 to 54) 318	47 (45 to 49) 860	45 (40 to 50) 174	
	≥85y	39 (37 to 41) 620	32 (28 to 36) 200	40 (38 to 42) 746	44 (39 to 49) 171	
Cause of death						<.001[b]
	Cancer	37 (35 to 39) 595	53 (49 to 57) 335	46 (44 to 48) 830	39 (34 to 44) 149	
	Cardiovascular diseases	15 (13 to 17) 237	15 (12 to 18) 94	21 (19 to 23) 375	16 (12 to 20) 63	
	Respiratory disease	11 (9 to 13) 171	8 (6 to 10) 49	7 (6 to 8) 130	14 (11 to 17) 55	
	Diseases of the nervous system	7 (6 to 8) 114	3 (2 to 4) 19	6 (5 to 7) 105	5 (3 to 7) 18	
	Stroke	7 (6 to 8) 109	4 (2 to 6) 24	10 (9 to 11) 181	11 (8 to 14) 41	
	Other[c]	23 (21 to 25) 376	18 (15 to 21) 112	10 (9 to 11) 173	15 (11 to 19) 58	
Place of death						<.001[b]
	Home	23 (21 to 25) 367	44 (40 to 48) 276	46 (44 to 48) 846	49 (44 to 54) 188	
	Care home	31 (29 to 33) 499	18 (15 to 21) 114	9 (8 to 10) 164	13 (10 to 16) 48	
	Hospital	36 (34 to 38) 577	28 (25 to 31) 177	39 (37 to 41) 716	33 (28 to 38) 128	
	Palliative care unit/hospice	9 (8 to 10) 150	10 (8 to 12) 66	5 (4 to 6) 101	4 (2 to 6) 17	
	Other[c]	0 4	0 1	1 (0.5 to 1.5) 9	1 (0.005 to 2) 3	

[a] CI=confidence interval. Percentages are within-country percentages. Percentages are rounded and thus may not add up to 100. Nursing home deaths from the Netherlands (n=52) were excluded. Missing values: age n=12 (0.3%), sex n=12 (0.3%), place of death n=15 (0.3%), cause of death n=53 (1.2%).

[b] Pearson X^2-test.

[c] Not included in significance tests.

Palliative care provision by GPs

GPs stated they had delivered palliative care themselves to 50% (Belgium), 55% (Italy), 62% (Netherlands), and 65% (Spain) of patients (p<.001) (Table 2.3). GPs in Spain indicated that they had delivered palliative care to significantly more patients than GPs in Italy and Belgium. No statistically significant difference emerged between GPs' reports in Spain and the Netherlands.

Use and duration of specialist palliative care services

Varying by country, 47% (Belgium), 29% (Netherlands), 39% (Italy), and 45% (Spain) of patients received specialist palliative care in the last three months of life (p<.001) (Table 2.3). This percentage was significantly higher in Belgium, Spain, and Italy compared to the Netherlands. The median number of days (and inter-quartile range) over which specialist palliative care was received in the last three months of life was 15 (23), 21 (53), 26 (53), and 30 (70) in Belgium, the Netherlands, Spain, and Italy, respectively (p<.001). The four countries differed significantly with regards to the percentage of patients cared for in the different specialist palliative care settings (Table 2.4). In Italy and Spain specialist palliative care was mostly delivered through services for patients residing at home (for 24% and 29% of patients, respectively), in Belgium for patients residing at home and in a nursing home (16% of patients in each setting) and in the Netherlands for those residing in a hospice or palliative care unit (14%) or receiving care from a GP with palliative care training (12%). The lowest proportion of patients to receive hospital-based palliative care services, not including those in palliative care units, was found in the Netherlands (1%).

Factors associated with specialist palliative care and with GPs' self-reports of palliative care provision

Results of the multivariate logistic regression analyses indicate that in all countries, except the Netherlands, a cancer diagnosis was a significant predictor for receiving specialist palliative care and for GPs indicating that they provided palliative care to the patient (Tables 2.5-2.8). In the Netherlands this applied only to GPs reports of palliative care provision. In Italy and Spain, being younger than 85 years was associated with higher chances of receiving specialist palliative care and, in addition, in Italy being younger

Table 2.3: Use of palliative care provided GPs and use and start of specialist palliative care in the last three months of life; % (95% CI), n

Care at the end of life[a]		Belgium N=1604	Netherlands N=635	Italy N=1839	Spain N=388	p-value[c]
Received specialist palliative care[b]		47 (44 to 49)	29 (25 to 33)	39 (37 to 41)	45 (40 to 50)	<.001
		717	172	683	174	
Received palliative care by GP according to GP's self-report[b]		50 (48 to 53)	62 (58 to 65)	55 (53 to 57)	65 (60 to 70)	<.001
		807	375	1005	239	
In case specialist palliative care was provided		N=717	N=172	N=683	N=174	p-value
Time of initiation of specialist palliative care						
	Median (IQR)	15 (23)	21 (53)	30 (70)	26 (53)	< .001[d]
	1-3 days	11 (9 to 13)	9 (4 to 13)	3 (2 to 4)	8 (3 to 13)	<.001
		78	14	17	11	
	4-7 days	18 (15 to 21)	18 (12 to 24)	6 (4 to 8)	17 (11 to 23)	
		127	29	36	23	
	8-30 days	47 (43 to 51)	38 (31 to 46)	42 (38 to 46)	36 (28 to 45)	
		330	62	240	50	
	31-92 days	24 (20 to 27)	35 (28 to 43)	49 (45 to 53)	39 (31 to 47)	
		165	57	278	53	

[a] IQR = inter-quartile range; CI = confidence interval. Percentages are within-country percentages. Percentages are rounded and thus may not add up to 100. Missing values: SPC n=191 (4.3%); time of initiation of SPC n=174 (3.9% of those who received SPC); palliative care by GP n=55 (1.2%).

[b] Palliative care categories are not mutually exclusive.

[c] p-values based on multivariate analyses adjusted for age, sex, cause and place of death.

[d] Kruskal-Wallis test (bivariate analysis).

Table 2.4: Use of specialist palliative care services; % (95% CI), n

Specialist palliative care service[a]	Belgium N=1604	Netherlands N=635	Italy N=1839	Spain N=388	p-value[b]
Hospice/palliative care unit	11 (10 to 13)	14 (11 to 17)	8 (6 to 9)	17 (13 to 21)	<.001
	174	83	132	66	
Palliative care service for patients staying at home	16 (14 to 18)	5 (4 to 7)	24 (22 to 26)	29 (24 to 33)	<.001
	250	32[e]	418	111	
GP with formal palliative care training		12 (10 to 15)			[f]
	[d]	74	[d]	[d]	
In-house palliative care service in a nursing home	16 (14 to 17)			5 (1 to 8)	<.07[c]
	239	[d]	[d]	21	
Hospital-based palliative care service (excl. palliative care unit)	12 (10 to 13)	1 (0.4 to 2)	11 (10 to 13)		<.001
	179	[e]	196	[d]	

[a] CI = confidence interval. Percentages are within-country percentages. Percentages are rounded and thus may not add up to 100. Missing values: specialist palliative care n=191 (4.3%). Palliative care categories are not mutually exclusive.

[b] p-values are based on multivariate analyses adjusted for age, sex, cause and place of death.

[c] Statistically significant in bivariate analysis.

[d] Palliative care initiative not present in this country.

[e] Palliative care consultation teams in the Netherlands provide services to people at home and in hospital. Our data do not hold information as to where the patients received this service.

[f] Comparison between countries not possible.

than 65 years resulted in lower chances of GPs reporting that they provided palliative care. Age was not significantly related to the provision of palliative care by either GPs or palliative care specialists in Belgium and the Netherlands. According to the GPs' report, people who died at home were more likely to have received palliative care by the GP than people who died in other locations (except for hospice/palliative care unit in Italy and Spain). Compared with dying at home, dying in hospital was associated with a lower chance of receiving specialist palliative care in Belgium and the Netherlands, but not in Italy and Spain.

Factors associated with time of initiation of specialist palliative care

Ordinal logistic regression analyses revealed that a cancer diagnosis, compared with a non-cancer diagnosis, was related to higher chances of an early initiation of specialist palliative care in Belgium (OR=1.79 [1.27 to 2.53]) and the Netherlands (OR=4.21 [1.90 to 9.30]), but not in Italy and Spain. Dying in a palliative care unit (OR=0.59 [0.39 to 0.91]) or a hospital (OR=0.44 [0.29 to 0.68]) in Belgium or in a palliative care unit in Spain (OR=0.27 [0.07 to 0.97]) was associated with a later initiation of specialist

Table 2.5: Factors associated with use of palliative care provided by GPs and specialist palliative care services

	GP palliative care[b]		Specialist palliative care[b]	
Patient and health care characteristics[a]	Received % (n)	OR (95% CI)	Received % (n)	OR (95% CI)
Belgium[e]		N=1573		N=1512
Age		p=.872		p=.397
$\geq$85 y	54 (329)	Ref	42 (251)	Ref
65 - 84y	47 (349)	0.96 (0.73 to 1.27)	47 (339)	1.16 (0.89 to 1.51)
18 - 64y	52 (112)	0.90 (0.59 to 1.36)	56 (114)	1.28 (0.85 to 1.92)
Gender		p=.435		p=.297
Male	46 (331)	Ref	45 (307)	Ref
Female	54 (459)	1.11 (0.86 to 1.43)	48 (397)	1.14 (0.89 to 1.46)
Cause of death		p<.001		p<.001
Non-cancer	43 (424)	Ref	36 (342)	Ref
Cancer	63 (366)	**4.60 (3.37 to 6.28)**	65 (362)	**2.93 (2.24 to 3.85)**
Place of death		p<.001		p<.001
Home	77 (276)	Ref	48 (172)	Ref
Care home	69 (338)	1.06 (0.75 to 1.48)	50 (242)	**1.72 (1.26 to 2.36)**
Hospital	19 (108)	**0.07 (0.05 to 0.10)**	27 (142)	**0.48 (0.36 to 0.65)**
Palliative care unit/ hospice	46 (68)	**0.14 (0.09 to 0.23)**	100 (148)	[d]
Other[c]	0 (0)		0 (0)	

[a] Two multivariate logistic regression analyses with 1) palliative care by the GP and 2) specialist palliative care as dependent variable. Abbreviations: OR = odds ratio; CI = confidence interval; Ref = reference category. All percentages indicate proportions within the independent variable. Percentages are rounded and thus may not add up to 100. Missing values for dependent variables: specialist palliative care n=191 (4.3%); GP palliative care n=55 (1.2%); missing values for independent variables: age n=12 (0.3%), sex n=12 (0.3%), cause of death n=53 (1.2%), place of death n=15 (0.3%). Odds ratios in bold indicate statistically significant associations. Independent variables age and cause of death were correlated (r=.40, p<.01). Variance inflation factors did not indicate problems of multicollinearity.

[b] Specialist palliative care and palliative care by the GP are not mutually exclusive categories.

[c] Not included in significance tests.

[d] OR not meaningful as 100% of cases have the same value on the dependent variable.

[e] Missing values on the independent variables resulted in missing cases in the multivariate logistic regression analyses. The number of deaths included in the analyses are indicated.

Table 2.6: Factors associated with use of palliative care provided by GPs and specialist palliative care services

	GP palliative care[b]		Specialist palliative care[b]	
Patient and health care characteristics[a]	Received % (n)	OR (95% CI)	Received % (n)	OR (95% CI)
Netherlands[e]		N=599		N=585
Age		p=.942		p=.383
$\geq$ 85 y	60 (110)	Ref	22 (40)	Ref
65 - 84y	62 (189)	0.98 (0.59 to 1.64)	32 (94)	1.50 (0.84 to 2.68)
18 - 64y	66 (72)	1.09 (0.54 to 2.20)	33 (35)	1.33 (0.62 to 2.83)
Gender		p=.064		p=.629
Male	61 (176)	Ref	32 (86)	Ref
Female	63 (195)	1.51 (0.98 to 2.33)	27 (83)	1.12 (0.71 to 1.78)
Cause of death		p<.001		p=.477
Non-cancer	47 (129)	Ref	19 (51)	Ref
Cancer	75 (242)	**2.44 (1.51 to 3.93)**	37 (118)	1.22 (0.71 to 2.08)
Place of death		p<.001		p=.001
Home	87 (228)	Ref	27 (69)	Ref
Care home	67 (71)	**0.40 (0.22 to 0.73)**	20 (22)	0.81 (0.44 to 1.49)
Hospital	20 (33)	**0.04 (0.03 to 0.08)**	8 (13)	**0.25 (0.13 to 0.49)**
Palliative care unit/ hospice	61 (39)	**0.21 (0.11 to 0.39)**	100 (65)	[d]
Other[c]	0 (0)		0 (0)	

[a] Two multivariate logistic regression analyses with 1) palliative care by the GP and 2) specialist palliative care as dependent variable. Abbreviations: OR = odds ratio; CI = confidence interval; Ref = reference category. All percentages indicate proportions within the independent variable. Percentages are rounded and thus may not add up to 100. Missing values for dependent variables: specialist palliative care n=191 (4.3%); GP palliative care n=55 (1.2%); missing values for independent variables: age n=12 (0.3%), sex n=12 (0.3%), cause of death n=53 (1.2%), place of death n=15 (0.3%). Odds ratios in bold indicate statistically significant associations. Independent variables age and cause of death were correlated (r=.40, p<.01). Variance inflation factors did not indicate problems of multicollinearity.

[b] Specialist palliative care and palliative care by the GP are not mutually exclusive categories.

[c] Not included in significance tests.

[d] OR not meaningful as 100% of cases have the same value on the dependent variable.

[e] Missing values on the independent variables resulted in missing cases in the multivariate logistic regression analyses. The number of deaths included in the analyses are indicated.

Table 2.7: Factors associated with use of palliative care provided by GPs and specialist palliative care services

GP palliative care[b]		Specialist palliative care[b]		
Patient and health care characteristics[a]	Received % (n)	OR (95% CI)	Received % (n)	OR (95% CI)
Italy[e]		N=1777		N=1709
Age		p=.062		p=.001
$\geq$ 85 y	55 (389)	Ref	25 (176)	Ref
65 - 84y	56 (471)	0.93 (0.74 to 1.16)	45 (356)	**1.46 (1.12 to 1.89)**
18 - 64y	53 (119)	**0.67 (0.47 to 0.94)**	64 (140)	**2.02 (1.38 to 2.97)**
Gender		p=.433		p=.476
Male	55 (459)	Ref	42 (341)	Ref
Female	55 (520)	1.08 (0.89 to 1.32)	37 (331)	1.09 (0.86 to 1.37)
Cause of death		p<.001		p<.001
Non-cancer	48 (462)	Ref	19 (174)	Ref
Cancer	63 (517)	**1.95 (1.57 to 2.43)**	63 (498)	**5.19 (4.07 to 6.62)**
Place of death		p<.001		p=.473
Home	63 (515)	Ref	35 (277)	Ref
Care home	48 (75)	**0.59 (0.42 to 0.83)**	31 (45)	1.34 (0.88 to 2.04)
Hospital	47 (324)	**0.53 (0.43 to 0.65)**	38 (249)	1.15 (0.90 to 1.46)
Palliative care unit/ hospice	64 (65)	0.85 (0.54 to 1.32)	100 (101)	[d]
Other[c]	0 (0)		0(0)	

[a] Two multivariate logistic regression analyses with 1) palliative care by the GP and 2) specialist palliative care as dependent variable. Abbreviations: OR = odds ratio; CI = confidence interval; Ref = reference category. All percentages indicate proportions within the independent variable. Percentages are rounded and thus may not add up to 100. Missing values for dependent variables: specialist palliative care n=191 (4.3%); GP palliative care n=55 (1.2%); missing values for independent variables: age n=12 (0.3%), sex n=12 (0.3%), cause of death n=53 (1.2%), place of death n=15 (0.3%). Odds ratios in bold indicate statistically significant associations. Independent variables age and cause of death were correlated (r=.40, p<.01). Variance inflation factors did not indicate problems of multicollinearity.

[b] Specialist palliative care and palliative care by the GP are not mutually exclusive categories.

[c] Not included in significance tests.

[d] OR not meaningful as 100% of cases have the same value on the dependent variable.

[e] Missing values on the independent variables resulted in missing cases in the multivariate logistic regression analyses. The number of deaths included in the analyses are indicated.

Table 2.8: Factors associated with use of palliative care provided by GPs and specialist palliative care services

GP palliative care[b]		Specialist palliative care[b]		
Patient and health care characteristics[a]	Received % (n)	OR (95% CI)	Received % (n)	OR (95% CI)
Spain[e]		N=357		N=378
Age		p=.952		p<.001
≥ 85 y	64 (98)	Ref	29 (47)	Ref
65 - 84y	66 (107)	1.06 (0.63 to 1.79)	54 (92)	**2.47 (1.49 to 4.12)**
18 - 64y	70 (28)	1.15 (0.47 to 2.82)	73 (30)	**5.52 (2.29 to 13.33)**
Gender		p=.363		p=.465
Male	63 (123)	Ref	47 (95)	Ref
Female	68 (110)	1.25 (0.78 to 2.01)	43 (74)	1.19 (0.75 to 1.90)
Cause of death		p=.008		p=.004
Non-cancer	59 (128)	Ref	34 (78)	Ref
Cancer	76 (105)	**2.12 (1.22 to 3.70)**	62 (91)	**2.08 (1.26 to 3.44)**
Place of death		p<.001		p=.145
Home	78 (139)	Ref	42 (79)	Ref
Care home	52 (23)	**0.37 (0.18 to 0.75)**	47 (21)	1.80 (0.90 to 3.60)
Hospital	51 (61)	**0.29 (0.17 to 0.49)**	41 (52)	0.75 (0.45 to 1.25)
Palliative careunit/ hospice	67 (10)	0.42 (0.13 to 1.36)	100 (17)	[d]
Other[c]	0 (0)		0 (0)	

[a] Two multivariate logistic regression analyses with 1) palliative care by the GP and 2) specialist palliative care as dependent variable. Abbreviations: OR = odds ratio; CI = confidence interval; Ref = reference category. All percentages indicate proportions within the independent variable. Percentages are rounded and thus may not add up to 100. Missing values for dependent variables: specialist palliative care n=191 (4.3%); GP palliative care n=55 (1.2%); missing values for independent variables: age n=12 (0.3%), sex n=12 (0.3%), cause of death n=53 (1.2%), place of death n=15 (0.3%). Odds ratios in bold indicate statistically significant associations. Independent variables age and cause of death were correlated (r=.40, p<.01). Variance inflation factors did not indicate problems of multicollinearity.

[b] Specialist palliative care and palliative care by the GP are not mutually exclusive categories.

[c] Not included in significance tests.

[d] OR not meaningful as 100% of cases have the same value on the dependent variable.

[e] Missing values on the independent variables resulted in missing cases in the multivariate logistic regression analyses. The number of deaths included in the analyses are indicated.

palliative care compared with dying at home. Time of initiation of palliative care was not significantly related to either age or sex in any of the countries, nor to place of death in the Netherlands and Italy.

2.4 Discussion

Of the deaths registered for this study, GPs judged 66% as non-sudden and expected. This percentage of non-sudden deaths is consistent with percentages reported by physicians in earlier studies in six European countries (33-36) but lower than an estimate obtained in Australia that was based on cause of death and amounted to 89% of all deaths (46). The percentage of non-sudden deaths differed significantly between countries. This was very likely caused by the exclusion of nursing home deaths from the Netherlands.

Between half (Belgium) and two-thirds (Spain) of GPs reported that they had delivered palliative care themselves. According to GPs' reports, specialist palliative care was provided to 47% of patients who died non-suddenly in Belgium, 45% in Spain, 39% in Italy, and 29% in the Netherlands. GPs in Italy reported the longest duration of specialist palliative care over the last three months of life (median 30 days) and GPs in Belgium the shortest (median 15 days). In the Netherlands and Spain this was 21 and 26 days respectively. In all countries, dying from cancer as opposed to non-malignant disease emerged as a significant predictor for receiving specialist palliative care and for the GPs' self-reports of palliative care provision, as did being below 85 years of age for receiving specialist palliative care in Italy and Spain.

As this study was conducted through sentinel networks of GPs it is important to note that GPs have somewhat different roles in the health care systems of each of the countries studied. GPs act as gatekeepers to specialised care in the Netherlands and Spain but they do not have this role in Belgium and are only partial gatekeepers in Italy. Despite not being gatekeepers in Belgium, GPs have an important role in the health care system, and 95% of the Belgian population have a GP whom they consult regularly (47). In all four countries, the vast majority of the population regularly consult a GP (47-50).

This is one of the first cross-national, population-based studies to describe and compare the use of palliative care delivered by GPs and the initiation and use of specialist palliative care among people who died non-suddenly in four European countries. Through representative GP networks we obtained, with the exception of Dutch nursing home deaths, a representative sample of deaths irrespective of disease, treatment or place of residence. Taking all non-sudden deaths as the denominator and focusing on the last three months of life enabled us to study care at the end of life of those who did and did not receive palliative care and to focus on care that was actually delivered in the context of dying (34,37).

This study also has limitations. Firstly, although the obtained percentage of non-sudden deaths is comparable to other studies in Europe (33-36), inaccuracies in the GPs' judgment of deaths as sudden and totally unexpected cannot be fully excluded. Secondly, it was not possible to validate the information provided by the sentinel GPs for each registered death against an external criterion (e.g., hospital registries, insurance data, palliative care registries) due to the anonymous coding of deaths by the GP networks. However, the characteristics of the sentinel networks and their registration procedures, i.e. long-standing experience, weekly registrations, GPs trained in data collection, consistency checks of data, support the completeness and accuracy of their reports. Furthermore, the strength of using sentinel networks of GPs as observational units is to obtain information not collected in other databases nor the GPs' medical files. Thirdly, our data did not permit us to examine the validity of the GPs' self-report of palliative care provision. We could not determine whether the GPs' personal definitions of palliative care are consistent with expert definitions and comparable between countries. It may be that some GPs label care for a person with a chronic life limiting illness palliative care whereas others may refer to it as usual GP care. The results of this study therefore reflect the delivery of what GPs perceive to be palliative care. Fourthly, due to the retrospective nature of the data collection, recall bias cannot be excluded. However, we attempted to limit this by instructing GPs to register deaths on a weekly basis. Finally, we did not have access to deaths in nursing homes in the Netherlands where a large proportion of very old people and people with dementia reside (51).

Research on palliative care needs has suggested that, given an ideal state of affairs, every person who dies non-suddenly should receive palliative care (46). The results of our study suggest that varying proportions of people who need palliative care receive it during the final three months of life in the countries studied. While our data do not hold information about how many of those who died non-suddenly without receiving palliative care had actually needed it, there is evidence that a lack of palliative care service uptake equates with unmet need, particularly in non-cancer patients (52). With regards to our study, this implies that particular attention should be paid to non-cancer patients who died without palliative care as they are particularly likely to have unmet needs.

Differences in palliative care provision are likely to reflect variations in the types of services available as well as the organisation of palliative care within the respective health care systems. Looking at specialist palliative care services, the findings of this study show a particularly high involvement in Belgium and Spain and a relatively low one in the Netherlands. The fact that Belgium has the highest ratio of specific palliative care resources per million inhabitants of the four countries studied might have contributed to this result (8,11). Another possible explanation lies in the relatively high number of hospital deaths in Belgium relative to the other countries. According to Belgian law, every hospital is obliged to have a specialist palliative care support team. In contrast, in the Netherlands where involvement of specialist palliative care is lowest among the countries studied, a strong emphasis is put on GPs as being the principal providers of formal care for terminally ill patients (39,53). However, the low percentage in the Netherlands might also partly result from the exclusion of nursing home deaths.

In the Netherlands and Spain, more GPs reported that they had provided palliative care compared to Belgium and Italy, possibly as a result of GPs being gatekeepers to more specialised health care in these countries. By being the first health care professional to be consulted by terminally ill patients, GPs may more frequently deliver palliative care themselves. However, the reason may also be that the GPs of these two countries are more likely to perceive the care they provide as palliative care whereas GPs in Italy and Belgium may view it as usual GP care. This does not mean that GPs do not have a key role in palliative care in the other two countries. In Belgium, GPs typically work together with specialist palliative care services that mainly have an advisory and supportive role [40]. In Italy GPs typically refer patients to integrated domiciliary assistance, a home care service managed by themselves and involving nurses and specialised physicians [49].

The number of patients who received palliative care does not permit conclusions about the appropriateness of care. The time of initiation before death, however, may be an indicator of adequacy as a late referral is often seen as a barrier to achieving the goals of palliative care (40). Specialist palliative care appears to start latest in Belgium which might be a consequence of a Belgian regulation requiring a life expectancy of between 24 hours and three months in order for patients receiving palliative care at home to be granted a 'palliative lump sum' from their health insurance, to cover the costs of medicines, aids, and medical care materials. According to GPs' reports, there is a relatively early initiation of specialist palliative care in Italy and Spain, on the other hand which could be influenced by the fact that no time limit is set by national health services for access to palliative care services. However, this result is somewhat surprising in light of literature suggesting insufficient communication between doctors and patients concerning diagnosis and prognosis in these two countries (54-56).

In all countries except for the Netherlands, a cancer diagnosis was associated with higher chances of receiving specialist palliative care and, in Belgium and the Netherlands, with an earlier initiation. Hence, although efforts are made to extend palliative care to non-cancer patients, they appear to still be an underserved group, despite having a symptom burden comparable to that of people with advanced cancer (57). However, the proportion of non-cancer patients receiving palliative care in the countries we studied was still higher than that in the UK, a country with a leading role in palliative care, where the proportion of patients with cancer in palliative care services was estimated to lie between 75% and 90% for the same period (12).

Older patients appear to be underserved with regard to specialist palliative care in Italy and Spain but not in Belgium and the Netherlands. There we did not find significant differences between age groups with regards to receiving palliative care from either GPs or specialist teams, which is contrary to findings from earlier studies (16,18). Increased awareness of palliative care needs of older people in Belgium and the Netherlands has possibly contributed to this change. Moreover, our results suggest that GPs may play an important role in the provision of palliative care to older people as we did not find a significant association between the patient's age and GPs reporting that they delivered palliative care.

Across countries, home death was relatively consistently associated with higher chances of receiving specialist palliative care or GPs reporting to have delivered palliative care. Place of death was not associated with whether patients received specialist palliative care in Italy and Spain. However, one must take into account the possibility that many people who die in hospital in Italy and Spain are transferred there only shortly before death and spend the bigger part of the last phase of life at home (14). Therefore their place of death might not reflect their longest place of residence.

This study is an important first step towards estimating the number of people receiving palliative care, and its timing in the general population of people who die non-suddenly in four European countries. Given that the number of people living with and dying of serious chronic diseases is rapidly increasing, a pressing challenge for future research will be to obtain a better understanding of the mechanisms through which patient-, care-, and policy-related factors affect people's access to and a timely start of palliative care. This knowledge can then be used to inform future planning and implementation of targeted measures to extend palliative care options across patient groups, care settings and countries.

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Chapter 3

Home care by general practitioners for cancer patients in the last three months of life: an epidemiological study of quality and associated factors

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Published in: Palliative Medicine. 2015. doi: 10.1177/0269216315589213.

Acknowledgements: We are particularly grateful to the people who, having recently lost a relative or friend to cancer, considered taking part in the study and to the funders of QUALYCARE - Cicely Saunders International - for their dedicated support, which made this study possible. We also thank the Department of Health and the four health districts (Primary Care Trusts) for their partnership in the study and the members of the project steering group and international advisors. A special thanks to the staff at the Office for National Statistics for their crucial help with sampling, mailings, and datasets (Myer Glickman, Peter Davies, Justine Pooley and Stephen Rowland), Dr Jonathan Koffman for his help in setting up the study, Dr Gao Wei for her advice on sample size calculations and statistical issues, Dr Elizabeth Davies from the Thames Cancer Registry for her help in the ecological analysis to select the health districts, our local Cancer Research Network (South East London) for administrative support, Kerry Hylands for help with data entry, Sian Best for the development of the study website pages (www.csi.kcl.ac.uk/qualycare), and other members of the Cicely Saunders Institute.

Funding: This work was supported by Cicely Saunders International. Lara Pivodic was funded to undertake this analysis as part of the EURO IMPACT project, supported by the European Union Seventh Framework Programme (FP7/2007-2013, under grant agreement no. 264697). Irene J Higginson is a UK NIHR (National Institute of Health Research) Senior Investigator.

Abstract

Background: Stronger generalist end-of-life care at home for people with cancer is called for but the quality of end-of-life care delivered by general practitioners (GPs) has been questioned.

Aim: to determine the degree of and factors associated with bereaved relatives' satisfaction with home end-of-life care delivered by GPs to cancer patients.

Design: Population-based mortality followback survey.

Setting/Participants: Bereaved relatives of people who died of cancer in London, UK (identified from death registrations in 2009/2010), were invited to complete a postal questionnaire surveying the deceased's final three months of life.

Results: Questionnaires were completed for 596 decedents of whom 548 spent at least one day at home in the last three months of life. Fifty-five per cent (95% confidence interval (CI) 51%-59%) of respondents reported excellent/very good home care by GPs, compared to 78% (95%CI 74%-82%) for specialist palliative care providers and 68% (95%CI 64%-73%) for district/community/private nurses. The odds of high satisfaction (excellent/very good) with end-of-life care by GPs doubled if GPs made three or more compared to one or no home visits in the patient's last three months of life (adjusted odds ratio (AOR) 2.54 (95%CI 1.52 to 4.24)) and halved if the patient died at hospital rather than at home (AOR 0.55 (95%CI 0.31 to 0.998)).

Conclusions: There is considerable room for improvement in the satisfaction with home care provided by GPs to terminally ill cancer patients. Ensuring an adequate offer of home visits by GPs may help to achieve this goal.

3.1 Introduction

The demand for palliative care has grown in response to the increasing number of people dying from serious chronic illnesses.(1) More than one in four deaths in the UK are caused by cancer (around 162,000, or 29% of all deaths in 2012), making cancer the most frequent cause of death.

(2,3) Advanced cancer patients form a large group among people who could benefit from palliative care, and they are the majority of people who receive specialist palliative care in the UK.(3,4) In response to the rising needs and the preference of a majority of people to die at home,(5) calls have been made for a concerted international effort to strengthen generalist end-of-life care in a coordinated care model with specialist palliative care and to improve end-of-life care at people's homes.(6,7)

The involvement of general practitioners (GPs) (8) in end-of-life care and the intensity of home care (9) were suggested to be crucial factors in enabling people to die at home. However, there is conflicting evidence and an ongoing debate regarding the quality of care delivered by GPs to terminally ill patients.(10-14) Although GPs working in countries with well-developed palliative care services were shown to be able to deliver effective palliative care,(10) patients and families reported greater satisfaction with the end-of-life care provided by specialist palliative care services.(14,15) Furthermore, concerns were raised over the fact that most GPs had limited experience and training in this field and themselves expressed problems in providing end-of-life care.(10,16) However, the existing data are not recent enough to assess the claim that GPs do not provide good care to terminally ill people because they were collected prior to the implementation of important initiatives in end-of-life care such as the Department of Health's End-of-Life Care Strategy which coordinated national efforts to improve home end-of-life care and to enable people to die at home if they wish so.(7) Furthermore, only few studies examined how the quality of end-of-life care provided by GPs to patients at home compares to that performed by other health professionals.

A UK national consultation with practitioners, commissioners, academics, and service user groups identified the perspective of patients at the end of life and their family carers as a research priority within efforts to improve generalist end-of-life care.(16) Measuring users' satisfaction provides useful information about patients' and caregivers' perceptions of care,(17) and it aligns with wider healthcare policies advocating the inclusion of service users' views in the evaluation of services.(18) This is particularly relevant in end-of-life care where cure is no longer possible.

The aim of this study was to determine the degree of and factors associated with relatives' satisfaction with the home care delivered by GPs to cancer patients in the last three months of life.

3.2 Methods

Study design

This study is part of QUALYCARE, a population-based mortality follow-back postal survey conducted with bereaved relatives of people who died from cancer in four health districts in London (UK) with the aim to study quality of care in the last three months of life.(19) A mortality followback survey methodology is well-established and recommended in the UK National End-of-Life Care Strategy,(7) and the last three months of life are accepted as a relevant period for studying end-of-life care.(20-22)

Participants

The Office for National Statistics (ONS) identified from death registrations people who had registered a death from cancer (ICD-10 codes C00-D48) of people aged 18 years or over between March 2009 and March 2010. The ONS contacted these people between four and ten months after the death had been registered by mailing invitation letters, the study information sheet, a questionnaire, a freepost return envelope, a reply slip to decline participation, and a bereavement information leaflet. Cases were excluded if the death was registered by a coroner and if the place of death was other than the deceased's home, a hospice, nursing home, or NHS hospital, or if it was unknown. Because place of death was a crucial factor to the overall aim of QUALYCARE,(19) the sample was stratified by health district and place of death to include all home, hospice, nursing home and a random sample of NHS hospital deaths (if more than 150 eligible NHS hospital deaths per health district; otherwise all NHS hospital deaths were included). Cases were excluded from the present analysis if the deceased had not spent at least one day at home during the last three months of life because we wanted to assess the relatives' satisfaction with home care for all deceased who had had the possibility of receiving home care.

Data collection

We collected the data with the mailed questionnaire. We assessed the care received by the patient at home and relatives' satisfaction with care using an adapted short form of a questionnaire developed by Cartwright et al.(23) of which versions were used in several other surveys (12,14,21,24,25)

It has shown satisfactory discriminatory power, reliability, and validity.(17) As we were interested in care that was delivered to people at home, we determined whether patients were visited at home by GPs, palliative care specialists (from hospice, palliative care, Marie Curie or Macmillan or any other specialist), and district/community/private nurses. This analysis did not include telephone or outpatient contacts. By taking home visits as an indicator for home care we were able to evaluate the different health care providers based on the same type of home-based contact and hence increase the comparability of the satisfaction ratings.

To assess the main outcome, the relatives were asked whether they perceived the home care delivered to patients in the last three months of life by GPs, palliative care specialists, and district/community/private nurses, as well as the overall care at home, to be excellent, very good, good, fair, poor or very poor. We also assessed the relatives' ratings of the communication with the GP and their views on the GPs' competence and symptom control.

We measured the deceased's health status at three months before death (EuroQoL EQ-5D) (26) and the respondent's intensity of grief at present and at the time of the person's death (retrospectively) (Texas Revised Inventory of Grief (TRIG)).(27) Information on the cause and place of death was provided by the ONS. We assessed the sociodemographic characteristics of the respondent and the deceased, the number of days spent at home during the final three months of life, and the deceased's financial hardship (question from the British Household Panel Survey) (28) as reported by the relative.

Analysis

The analyses were conducted in IBM SPSS Statistics version 20. All statistical tests were performed with a significance level of α <0.05. Proportional weights were applied to the sample to achieve a percentage of deaths at home, hospital, hospice and nursing home that was representative for all eligible cancer deaths identified by the ONS.

We calculated unweighted frequencies and weighted percentages for the six levels of satisfaction for each group of care providers and for care at home in general. For patients who had received care at home from all three groups of care providers, differences in ratings between care providers were analysed using the Friedman test.

We performed bivariate analyses to test the association between satisfaction with home care by GPs and several health service and non-service factors

(factors that were found to be associated with satisfaction,(14,18,29-31) factors for which the evidence was conflicting, and factors for which we reasoned there was a rationale for a potential association). The bivariate analyses consisted of Pearson's chi-squared tests for categorical variables (or Fisher's exact tests if 20% or more of the expected cell frequencies were below 5) and t-tests (if normal distribution) and Mann-Whitney U tests (if non-normal distribution) for continuous variables.

Characteristics that were significantly associated with satisfaction with GP home care in the bivariate analysis were simultaneously entered in a multivariate logistic regression analysis together with the health district to control for any effects of the stratified sampling. We conducted the logistic regression with the unweighted sample, as the variable used to create the weights (place of death) was included as an independent variable in the logistic regression.(32) For both the bivariate and multivariate analyses we dichotomised the dependent variable, satisfaction with GP home care, as excellent/very good versus good/fair/poor/very poor because we were interested in the percentage of relatives who were highly satisfied with care. In doing so, we followed the example of earlier studies on satisfaction with end-of-life care.(30,31,33,34) We grouped continuous data into ordered categories: number of GP home visits (0 or 1 vs. 2 vs. 3 or more), age of deceased (20-64 vs. 65-84 vs. ≥85), age of respondent (20-64 vs. ≥65), days spent at home in the last three months of life (1-60 vs. 61-92).

For each variable the percentage of missing data was described. If it amounted to more than 10%, we tested whether it was significantly associated with the main outcome variable, satisfaction with home care provided by GPs (Pearson's chi-squared test).

Ethics

Ethics approval for this study was granted in December 2009 by the South East London NHS Research Ethics Committee 3 (ref no.: 09/H0808/85). The return of the completed questionnaire was taken as consent to participate. Even though bereaved relatives perceive benefits in participating in bereavement research (13,35,36) several measures were undertaken to minimise harm and to maximise benefits for the respondents. They were contacted a minimum of four months after the death of their relative which is a more cautious approach compared to other surveys (three months).(12) All potential respondents were mailed a bereavement information leaflet produced by the Royal College of Psychiatrists, and a written protocol for dealing with participants' queries and distress was followed. Returned questionnaires were checked for cases requiring follow-up action. If concerns arose and participants had agreed to be contacted by the researchers, they were informed about local sources of support.(19)

3.3 Results

Sample characteristics

Five hundred ninety-six informants agreed to participate in the survey (39.3% response rate, Figure 3.1). Of these, 548 were included in the analysis as the deceased had spent a minimum of one day at home during the last three months of life. Table 3.1 shows the characteristics of the deceased and the respondents. Of the 548 deceased, 6% spent between 1 and 30 days at home in the last three months of life; 15% stayed at home for 31 to 60 days; and 71% spent between 61 and 92 days at home. Four cases (0.7%) were at home for only 1 day, and 7 cases (1.3%) spent between 1 and 5 days at home. A comparison of responders and non-responders in the QUALYCARE study showed that relatives of patients aged 90 or over were more likely to participate than relatives of patients aged 20 to 49. Participation was lower for respondents for patients who died in hospital than for those who died at home and for male respondents and those who were not spouses/partners or parents.(37)

Bereaved relatives' satisfaction with home care by GPs and other health professionals

According to the respondents, all except five patients had been registered with a GP (n=543), and 377 (69.4%) of them were visited by GPs at home at least once in the three months before death. Specialist palliative care providers made home visits to 385 (70.3%) of patients, and 370 (67.5%) of patients were visited by district, community or private nurses in the last three months of life. Around half of the bereaved relatives of patients who had received at least one home visit by a GP (54.8%, (95% confidence interval (CI) 50.5 to 59.1)) rated the home care provided by GPs as very good or excellent (Figure 3.2). Palliative care specialists received very good or excellent ratings from 78.1% (95%CI 74.1 to 82.1) and district/community/private nurses from 68.4% (95%CI 63.8 to 73.0) of the respondents. The satisfaction ratings differed significantly between the care providers (n=245, $X^2(2)=65.8$, p<.001). The time between the patient's

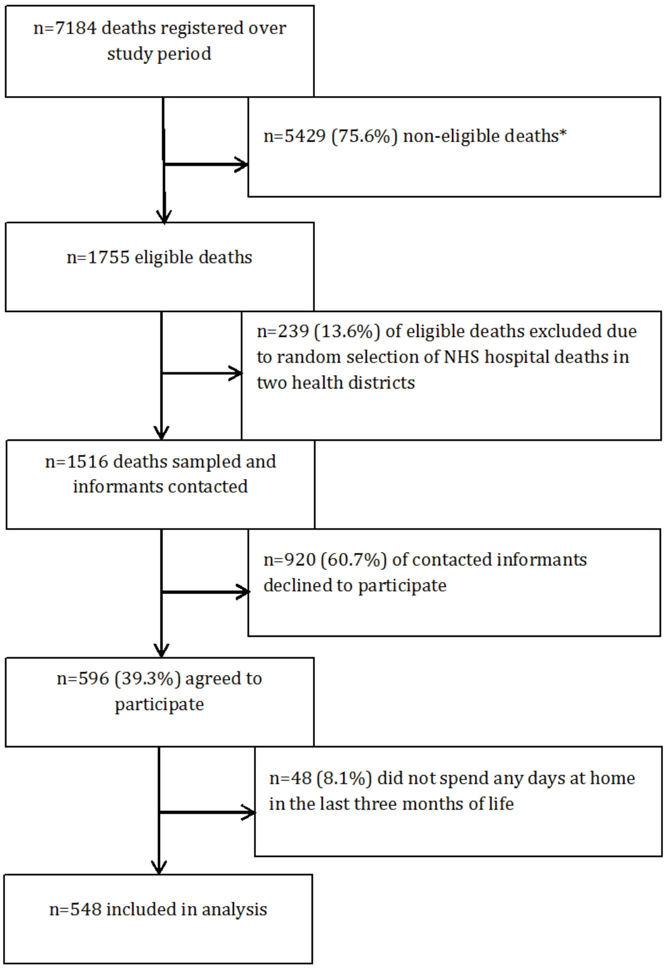

Figure 3.1: Sampling and recruitment process. Non-eligible deaths: deaths registered by a coroner, deceased under 18 years of age, cause of death non-cancer, place of death is NHS psychiatric hospital, non-NHS hospital, residential home or elsewhere/unspecified.

Table 3.1: Characteristics of deceased cancer patients who stayed at home for at least one day during the last three months of life and of their bereaved relatives (respondents); N=548

	unweighted n (weighted %)		unweighted n (weighted %)
Patient characteristics[a]	N=548	Respondent characteristics[a]	N=548
Gender of patient		Gender of respondent	
woman	264 (47.9)	woman	360 (65.2)
man	284 (52.1)	man	183 (33.9)
Age of patient		Age of respondent	
Median (IQR)	77 (66 to 83)	Median (IQR)	59 (50 to 70)
20-49	22 (3.9)	20-49	126 (23.6)
50-59	49 (9.3)	50-59	150 (27.9)
60-69	111 (20.2)	60-69	125 (22.1)
70-79	142 (25.8)	70-79	96 (17.4)
80-89	187 (33.2)	80-89	41 (7.3)
≥90	37 (7.6)	≥90	1 (0.2)
Underlying cause of death		Respondent's relationship to patient	
digestive organs	154 (27.4)	spouse/partner	231 (41.7)
respiratory and intra-thoracic organs	120 (22.0)	daughter/son	222 (40.2)
melanoma and skin	12 (2.1)	sister/brother	29 (5.4)
breast	40 (7.1)	other	63 (12.1)
female genital organs	25 (4.7)		
male genital organs	38 (7.4)	TRIG (Texas Revised Inventory of Grief)[b]	
urinary tract	37 (7.0)	TRIG I, Mean (SD)	20.45 (8.08)
eye, brain and other parts of CNS	24 (3.8)	TRIG II, Mean (SD)	43.85 (12.71)
lymphoid, haematopoietic and related tissue	34 (6.9)		
uncertain/unspecified/ other	64 (11.5)		
Days spent at home before death			
Median (IQR)	71 (50 to 85)		
1-30	30 (5.8)		
31-60	85 (15.2)		
61-92	390 (71.4)		
unknown	43 (7.6)		
Place of death			
home	174 (27.7)		
hospital	162 (38.3)		
hospice	193 (31.0)		
nursing home	19 (3.0)		
Financial hardship			
living comfortably	270 (48.6)		
doing alright	172 (31.8)		
just about getting by	72 (13.4)		
finding it difficult	28 (4.9)		

[a] Abbreviations: IQR=inter-quartile range; SD=standard deviation, CNS=central nervous system. Missing values: days spent at home before death: n=43 (7.8%); respondent's relationship to patient: n=3 (0.5%); respondent's age: n=9 (1.6%); respondent's gender: n=5 (0.9%); TRIG I: n=48 (8.8%); TRIG II: n=59 (10.8%); financial hardship: n=6 (1.1%). Percentages are rounded and thus may not add up to 100.0.

[b] TRIG I: grief intensity at the time of death; theoretical range of scores: 8 to 40; TRIG II: grief intensity at the time of data collection; theoretical range of scores: 13 to 65.

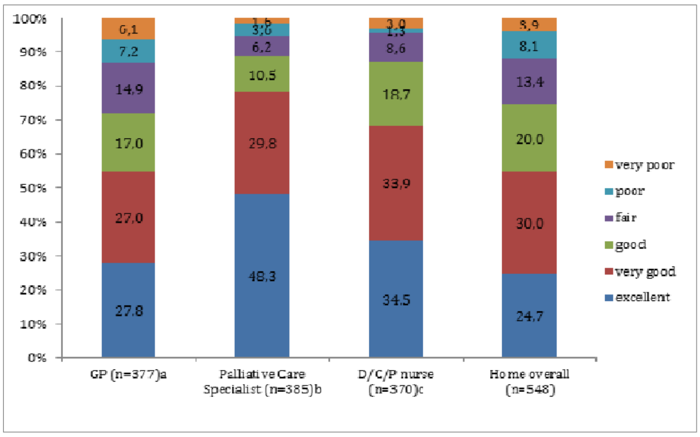

Figure 3.2: Relatives' satisfaction with the home care delivered in the last three months of patients' life by GPs, specialist palliative care providers and district, community and private nurses. Friedman test for differences in ratings between care providers only included cases for whom ratings for all three care provider groups were available (n=245, 44.7%): $X^2(2)=65.82$, $p<.001$. Abbreviations: D/C/P nurse=district/community/private nurse. Missing values: satisfaction with GP home care n=6 (1.6%); satisfaction with home care by palliative care specialists: n=9 (2.6%); satisfaction with home care by district/community/private nurses n=2 (0.5%); satisfaction with home care overall n=13 (3.8%). Percentages are rounded and thus may not add up to 100.

death and the completion of the questionnaire was not significantly associated with satisfaction with GP home care (n=347, $X^2(6)=2.99$, p=.809).

Factors associated with high satisfaction with home care provided by GPs: bivariate analysis

All four health service characteristics examined were associated with home care by GPs being described as excellent or very good (Table 3.2). Six out of 15 non-service characteristics were associated with higher satisfaction with GP home care: respondents' older age (p=.030), patients' lower financial hardship (p=.033), death at home (p=.002), a higher number of days spent at home (p=.001), less pain or discomfort at three months before death (p=.002), and respondents' lower grief intensity at the time of the patients' death (p=.018) (3.3, 3.4.

Table 3.2: Health service factors associated with bereaved relatives' satisfaction with home care delivered by GPs to cancer patients at the end of life: bivariate analysis

Health service factors[a]	unweighted n (weighted %), N=543[b]	unweighted n (weighted %), N=543[b]	
	excellent/very good	good/fair/poor/very poor	Statistical test result[c]
No. of GP home visits			Mann-Whitney U=10118.0, z = -5.38, p<.001
Median (IQR)	2.0 (1.0 to 4.0)	1.0 (0.0 to 2.0)	
0 or 1	81 (36.2)	143 (63.8)	
2	36 (45.9)	45 (54.1)	
≥ 3	119 (65.2)	58 (34.8)	
GPs listened and discussed things fully with patient or relative			$X^2(1)$=169.8, p <.001
yes	238 (69.1)	98 (30.9)	
sometimes/no	13 (7.6)	160 (92.4)	
Sufficient efforts by GP to relieve symptoms			$X^2(1)$=181.9, p <.001
yes	243 (69.6)	99 (30.4)	
no	4 (2.7)	144 (97.3)	
Sufficient perceived competence of GP			$X^2(1)$=180.7, p <.001
yes	243 (69.0)	105 (31.0)	
no	9 (5.6)	151(94.4)	

[a] Abbreviations: IQR=inter-quartile range, SD=standard deviation. Missing values: GP communication: n=19 (3.5%); perceived competence of GP: n=19 (3.5%); symptom relief by GP: n=27 (5.0%). Percentages are rounded and thus may not add up to 100.

[b] Data for patients who were not registered with a GP in the last three months of life or for whom this information was missing were excluded (n=5, 0.9%).

[c] Weighted data were used for statistical tests.

Table 3.3: Non-health service factors associated with bereaved relatives' satisfaction with home care delivered by GPs to cancer patients at the end of life: bivariate analysis

Non-service factors[a]	unweighted n (weighted %), N=543[b]	unweighted n (weighted %), N=543[b]	
	excellent/very good	good/fair/poor/very poor	Statistical test result[c]
Age of deceased			Mann-Whitney U=33171.0, p=.834
20-64	4 (43.1)	5 (56.9)	
65-84	158 (50.3)	148 (49.7)	
$\geq$ 85	48 (45.2)	58 (54.8)	
Age of respondent			**Mann-Whitney U=28894.5, p=.030**
20-64	143 (42.7)	176 (57.3)	
$\geq$ 65	106 (55.6)	85 (44.4)	
Gender of deceased			X^2(1)=0.1, p=.766
Female	122 (46.9)	130 (53.1)	
Male	132 (48.3)	134 (51.7)	
Financial hardship			**X^2(3)=8.8, p=.033**
living comfortably	130 (49.2)	125 (50.8)	
doing alright	87 (52.5)	77 (47.5)	
just about getting by	23 (31.9)	46 (68.1)	
finding it difficult	12 (44.0)	15 (56.0)	
Health district			X^2(3)=4.7, p=.197
1	96 (45.1)	111 (54.9)	
2	34 (42.5)	46 (57.5)	
3	90 (55.1)	68 (44.9)	
4	34 (46.6)	39 (53.4)	
Underlying cause of death			X^2(3)=3.8, p=.281
digestive	82 (54.6)	66 (45.4)	
respiratory and intra-thoracic	53 (45.5)	60 (54.5)	
genitourinary	59 (43.9)	74 (56.1)	
other/uncertain/unspecified	60 (45.8)	64 (54.2)	
Place of death			**X^2(3)=14.6, p=.002**
home	101 (59.7)	68 (40.3)	
hospice	88 (47.8)	94 (52.2)	
nursing home	8 (46.7)	10 (53.3)	
hospital	57 (38.6)	92 (61.4)	
Days spent at home			**Mann-Whitney U=23319.5, p=.001**
1 to 60	34 (32.4)	70 (67.6)	
61-92	202 (52.3)	171 (47.7)	

[a] Abbreviations: IQR=inter-quartile range, SD=standard deviation. Missing values: respondent's age: n=9 (1.7%); financial hardship: n=6 (1.1%); days spent at home: n=43 (7.9%). Percentages are rounded and thus may not add up to 100.

[b] Data for patients who were not registered with a GP in the last three months of life or for whom this information was missing were excluded (n=5, 0.9%).

[c] Weighted data were used for statistical tests. Test results in bold font are statistically significant.

Table 3.4: Symptoms associated with bereaved relatives' satisfaction with home care delivered by GPs to cancer patients at the end of life: bivariate analysis

Symptoms[a]	unweighted n (weighted %) N=543[b]	unweighted n (weighted %) N=543[b]	
	excellent/very good	good/fair/poor/very poor	Statistical test result[c]
Mobility at 3 months to death			X^2(2)=2.3, p=.317
no problems	63 (45.7)	66 (54.3)	
some problems	168 (50.0)	162 (50.0)	
confined to bed	14 (38.9)	23 (61.1)	
Self-care at 3 months to death			X^2(2)=2.0, p=.370
no problems	96 (45.7)	108 (54.3)	
some problems	111 (52.5)	97 (47.5)	
unable to wash or dress her/himself	35 (44.4)	39 (55.6)	
Usual activities at 3 months to death			X^2(2)=0.3, p=.842
no problems	49 (47.5)	52 (52.5)	
some problems	118 (47.4)	121 (52.6)	
unable to perform usual activities	78 (50.3)	74 (49.7)	
Pain/discomfort at 3 months to death			**X^2(2)=12.2, p=.002**
no pain/discomfort	42 (47.5)	42 (52.5)	
moderate pain/discomfort	166 (53.9)	136 (46.1)	
extreme pain/discomfort	38 (34.0)	68 (66.0)	
Anxiety/depression at 3 months to death			X^2(2)=4.2, p=.125
no anxiety/depression	83 (49.4)	81 (50.6)	
moderate anxiety/depression	129 (49.8)	123 (50.2)	
extreme anxiety/depression	26 (35.9)	40 (64.1)	
TRIG I Mean (SD)	19.65 (7.91)	21.45 (8.29)	**t(458)=2.4, p=.018**
TRIG II Mean (SD)	44.27 (12.55)	43.75 (12.78)	t(449)= -0.4, p=.663

[a] Abbreviations: TRIG=Texas Revised Inventory of Grief, IQR=inter-quartile range, SD=standard deviation. Missing values: mobility at three months: n=22 (4.1%); self-care at three months: n=34 (6.3%); usual activities at three months: n=27 (5.0%); pain/discomfort at three months: n=29 (5.3%); anxiety/depression at three months: n=38 (7.0%); TRIG I: n=47 (8.7%); TRIG II: n=59 (10.9%). The percentage of missing data for TRIG II was not associated with satisfaction with GP home care (X^2=0.96, p=.327). Percentages are rounded and thus may not add up to 100.

[b] Data for patients who were not registered with a GP in the last three months of life or for whom this information was missing were excluded (n=5, 0.9%).

[c] Weighted data were used for statistical tests. Test results in bold font are statistically significant.

Factors associated with high satisfaction with home care provided by GPs: multivariate analysis

One service characteristic (number of GP home visits) and six non-service characteristics were included as independent variables in the multivariate logistic regression analysis (Table 3.5). Due to near-zero cell frequencies (Table 3.2) and multicollinearity with the number of GP home visits, the other non-service characteristics were not included as independent variables. When the other factors were adjusted for, bereaved relatives had twice greater odds of reporting high satisfaction with the home care provided by GPs if the patient had had three or more home visits by the GP during the last three months of life as opposed to one visit or none (adjusted odds ratio (AOR) 2.54 (95% CI 1.52 to 4.24)). The odds of reporting high satisfaction with home care by GPs halved if the patient died in hospital rather than at home (AOR 0.55 (95% CI 0.31 to 0.998)).

3.4 Discussion

This epidemiological study found that just over half of bereaved relatives perceived the home care provided by GPs to cancer patients during the last three months of life as excellent or very good. GPs received significantly less favourable ratings than other health professionals. Respondents for patients who had a higher frequency of GP home visits or who died at home rather than in hospital showed greater odds of reporting high satisfaction with the home care provided by GPs.

The findings of this study support existing concerns about the quality of home care delivered by GPs to cancer patients at the end of life.(10) Our results echo those of earlier studies,(12,14,15) but despite a well-known tendency of satisfaction measures to yield ceiling effects we obtained even lower percentages of very good and excellent ratings for GP care than previous studies in the UK.(12-15) Families' satisfaction with GP care may have worsened over time, but our findings could also be a consequence of a better discriminatory power of our measure, as we added a response category named 'very poor' following pilot findings suggesting that respondents perceived the original scale as positively biased.(38) This study suggests that the frequency of home visits by GPs may be an important factor within families' evaluations of the home care they provide. A number of other factors could also explain the relatively low satisfaction with GP home care. Although GPs perceive palliative care to be a central part of their role,(39) they often have limited training and experience in this field, and research suggests that

Table 3.5: Factors associated with bereaved relatives judging home care delivered by GPs to cancer patients at the end of life as excellent or very good: multivariate logistic regression analysis (N=390)

	n (%)	AOR (95% CI)[ac]	p-value
Health service factors[a]			
No. GP home visits			.001
0 or 1	69 (37.9)	Ref	
2	30 (46.9)	1.13 (0.61 to 2.09)	
$\geq$3	98 (68.1)	**2.54 (1.52 to 4.24)**	
Non-service factors			
Age of respondent			.097
20-64	121 (46.2)	Ref	
$\geq$65	76 (59.4)	1.48 (0.93 to 2.35)	
Financial hardship			.190
living comfortably	102 (53.4)	Ref	
doingalright	69 (53.1)	1.04 (0.63 to 1.72)	
just about getting by	17 (32.1)	0.52 (0.26 to 1.04)	
finding it difficult	9 (56.2)	1.50 (0.48 to 4.68)	
Place of death			.157
home	83 (61.9)	Ref	
hospice	66 (50.0)	0.91 (0.52 to 1.58)	
nursing home	7 (58.3)	1.37 (0.37 to 5.17)	
hospital	41 (36.6)	**0.55 (0.31 to 0.998)**	
Pain/discomfort at 3 months to death			.026
no pain/discomfort	36 (52.9)	Ref	
moderate pain/discomfort	133 (54.5)	1.16 (0.64 to 2.09)	
extreme pain/discomfort	28 (35.9)	0.52 (0.25 to 1.09)	
Days spent at home			.074
61-92	168 (54.4)	Ref	
1-60	29 (35.8)	0.59 (0.33 to 1.05)	
TRIG I Mean (SD)	20.45 (7.98)	0.98 (0.95 to 1.00)	.077

[a] Abbreviations: AOR=adjusted odds ratio, CI=confidence interval, SD=standard deviation, TRIG I=Texas Revised Inventory of Grief - grief intensity at the time of the death.

[b] Model statistics for multivariate logistic regression analysis: Nagelkerke R2=0.19, Hosmer and Lemeshow $\chi^2(8)$=13.02, p=.111. Correctly predicted 64% of good through very poor satisfaction ratings, 66% of excellent/very good satisfaction ratings and 65% overall.

[c] Odds ratios in bold are statistically significant.

their skills and confidence in managing pain and other symptoms as well as their knowledge of the availability of specialist home palliative care services and out-of-hours district nursing can be improved.(10,16,39-41)

Surveying bereaved relatives retrospectively is the most feasible way to obtain a population-based perspective on the care delivered during a particular time period prior to death.(42) Prospective patient surveys carry a high risk of including only healthcare service users and excluding those not recognised as dying. The agreement between bereaved relatives' and patients' service evaluations is adequate.(43) Postal surveys are well-established in end-of-life care research,(7) and response rates and respondents' characteristics are comparable to those in face-to-face surveys.(35) Finally, postal surveys are less likely than face-to-face surveys to yield top-ranked satisfaction ratings which suggests less socially desirable answers.(35)

However, our study has limitations. Firstly, the response rate was not high. Although it is within the range of similar surveys,(12-14) there is a potential for non-response bias as we have no data from well over half of our sample. The comparison of responders and non-responders showed that this survey better represents the experiences of patients who died at home rather than in hospital, older patients and those for whom the respondents were women and spouses/partners or parents. These factors should be taken into account when interpreting the findings because the non-responders may have had a different view of the care that was provided to the patients. The fact that patients who died in hospital were underrepresented may have led to an overestimation of positive satisfaction ratings for GPs because hospital death was associated with lower satisfaction ratings. Secondly, the data from the four London health districts differed somewhat from average England and Wales data. There was a higher percentage of hospice deaths and lower percentage of nursing home deaths in our sample (44) and a higher percentage of patients who were visited by specialist palliative care providers.(4) We must therefore be cautious in generalising our findings to areas with lower access to specialist palliative care services. Thirdly, our data do not permit conclusions regarding causal relationships between variables. Fourthly, there are limitations related to defining and measuring satisfaction with care (18,29,45) and to its use in studying the quality of end-of-life care.(29) We did not assess respondents' expectations of care but research has shown that around two-thirds of the variation in satisfaction levels are not explained by the discrepancy between expectations and perceptions.(46) However, we did take into account bereavement-related emotions, and patients' and respondents' sociodemographic characteristics. Earlier research has demonstrated considerable variation in satisfaction ratings across different sources of care, thereby suggesting that this outcome is sensitive to differences in perceived quality of care.(17) Finally, we cannot exclude recall bias, but we did not find a significant association between time from death and satisfaction ratings.

This study shows that there is considerable room for improvement in the satisfaction with home care provided by GPs to terminally ill cancer patients. This is particularly important in light of calls to strengthen generalist palliative care as a consequence of restrictions in healthcare expenditure and access to specialist palliative care. Encouraging and enabling GPs to offer frequent home visits may be an important step towards achieving this goal. We recommend that this research be replicated in people with non-malignant diseases, who have lower access to specialist palliative care and whose satisfaction with end-of-life care and associated factors may differ from those of people with cancer.

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Chapter 4

Burden on family carers and care-related financial strain at the end of life: a cross-national population-based study

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Published in: European Journal of Public Health. 2014, 24(5):819-826. doi: 10.1093/eurpub/cku026.

Acknowledgements: We thank the Belgian, Dutch, Italian and Spanish Sentinel Networks of General Practitioners for providing the data for this study; Joachim Cohen for critically reviewing the manuscript; and Jane Ruthven for linguistic help.

Funding: This work was supported by the European Union Seventh Framework Programme (FP7/2007-2013 [264697]) and the Institute for the Promotion of Innovation by Science and Technology in Flanders as a Strategic Basic Research project (SBO) [SBO IWT 050158], (2006-2010), as part of the 'Monitoring Quality of End-of-Life Care (MELC) Study', a collaboration

between the Vrije Universiteit Brussel, Ghent University, Antwerp University, the Scientific Institute for Public Health, Belgium, and VU University Medical Centre Amsterdam, the Netherlands.

Abstract

Background: The rising number of deaths from cancer and other life-limiting illnesses is accompanied by a growing number of family carers who provide long lasting care, including end-of-life care. This population-based, epidemiological study aimed to describe and compare in four European countries the prevalence of and factors associated with physical or emotional overburden and difficulties in covering care-related costs among family carers of people at the end of life.

Methods: A cross-national retrospective study was conducted via nationwide representative sentinel networks of general practitioners (GPs). Using a standardised form, GPs in Belgium, the Netherlands, Italy and Spain recorded information on the last three months of life of every deceased adult practice patient (01/01/2009-31/12/2010). Sudden deaths were excluded.

Results: We studied 4,466 deaths. GPs judged family carers of 28% (Belgium), 30% (Netherlands), 35% (Spain) and 71% (Italy) of patients as physically/emotionally overburdened (p<.001). For 8% (Spain), 14% (Belgium), 36% (Netherlands) and 43% (Italy) of patients GPs reported difficulties in covering care-related costs (p<.001). Patients under 85 years (Belgium, Italy) had higher odds of having physically/emotionally overburdened family carers and financial burden. Death from non-malignant illness (versus cancer) (Belgium, Italy) and dying at home compared to other locations (Netherlands, Italy) was associated with higher odds of difficulties in covering care-related costs.

Conclusion: In all countries studied, and particularly in Italy, GPs observed a considerable extent of physical/emotional overburden and difficulties in covering care-related costs among family carers of people at the end of life. Implications for health and social care policies are discussed.

4.1 Introduction

The number of deaths from cancer and other life-limiting illnesses is rising.(1) As a consequence, a growing number of people experience multiple and complex symptoms towards the end of life and require care over extended periods of time.(2) Taking into account economic factors, population ageing, and critical shortages of professional resources,(3) it is unlikely that the need for palliative and end-of-life care in the population can be borne entirely by formal care. As a result, increasing demands will be put on family carers of people at the end of life, and their role will be further strengthened by the prevailing wish among people to die at home(4) and the implementation of health policies aimed at facilitating end-of-life care in the community.(5-7) Already today the economic value of the contribution of family carers in the UK is estimated to be considerably more than the cost of the National Health Service.(8)

The availability of and burden on family carers is an increasingly pressing concern for public health given the rising old-age dependency ratio, increasing geographic mobility, changes in traditional family structures, urbanisation, and the growing participation of women in the labour market.(9-12) The trend towards end-of-life care in the community may also put additional financial strain on patients at the end of life and their families as it is likely to cause a shift in cost burden away from public health care systems towards patients and families.(13) Research indicates that family carers of dying people experience a wide range of unmet needs, physical and emotional strains, and financial burden.(14-16) Despite these challenges, population-based, cross-national data on the extent of physical or emotional overburden and financial strain among family carers of people at the end of life are absent. This creates an obstacle for the nationwide planning and implementation of policies and programmes to support these families.(12) Existing population-based studies of the burden on family carers did not look specifically at end-of-life care,(17) or the samples were limited to patients with particular diagnoses such as cancer(18) or patients in receipt of specific healthcare services,(13,18-20) thereby excluding other large groups of people who also provide care for their dying family members.

Using nationwide representative epidemiological surveillance networks of general practitioners (GPs) in Belgium, the Netherlands, Italy and Spain, our study allowed us to evaluate the burden on family carers cross-nationally at a population-based level. International comparisons facilitate the identification of factors that are common across countries or country-specific, highlight where improvement is possible and guide policy-making nationally and internationally. This study addressed the following three research questions from the perspective of GPs in four European countries:

How many family carers of people in their last three months of life feel physically or emotionally overburdened and are there differences between countries?

How many patients and families experience problems in covering the costs of care in the last three months of life and are there differences between countries?

Are physical and emotional burden on family carers and patients' and families' problems in covering the costs of care associated with patient-, health-, and care-related characteristics?

4.2 Methods

Study design and procedure

This analysis is part of a cross-national, epidemiological, retrospective study monitoring end of-life care in Belgium, the Netherlands, Italy and Spain.(21) From 01/01/2009 to 31/12/2010 (in Spain from 01/01/2010 to 31/12/2010) GPs belonging to sentinel general practice networks (epidemiological surveillance systems based on a representative sample of GPs) weekly registered all deaths of patients (18 years or over) in their practice and described their demographic, health and care characteristics in the last three months of life using a standardised registration form. The GPs were asked to also include any information from hospital physicians and patient records. The last three months of life are widely accepted as a relevant period for studying end-of-life care.(22,23) The GPs of the Belgian and Dutch sentinel networks received a small annual fee for conducting the registrations on several topics; the GPs of the Italian network received a fee per completed registration form. The suitability of this study protocol for collecting population-based, epidemiological data on end-of-life care has been demonstrated in previous studies among which several reported cross-national comparisons.(24-26)

Study population

The networks in Belgium and the Netherlands were nationwide with a population coverage of 1.8% and 0.8% (2009) and 1.5% and 0.8% (2010), respectively. The Italian network covered 4.3% (2009) and 2.7% (2010) of the population of nine health districts spread across the country. The Spanish networks operated in two autonomous communities, the Valencian Community and Castile and Leon, covering 2.2% and 3.8% of the respective regional populations aged 18 and over. The participating GPs of all four countries had an adequate geographical distribution and were representative of the general population of GPs in the respective country (or region in Spain) with regard to sex and age.(21)

The participating GPs completed the registration form for each deceased patient aged 18 years or over. We excluded deaths that GPs had classified as sudden and totally unexpected in order to obtain a sample of people for whom end-of-life care was a realistic option.(27) We also excluded nursing home deaths from the Netherlands as nursing home residents in this country are not attended by GPs but by specialised nursing home physicians.

Measurement

The standardised registration form consists of 21 structured, closed-ended items and is available in Dutch, French, Italian, Spanish and English. Family carers' physical or emotional overburden was assessed with the question, 'Did the family carers feel overburdened (physically or emotionally) in the last three months of the patient's life?' (a) yes, (b) no, (c) don't know, (d) there were no family carers. Difficulty in covering costs of care was determined from the question, 'How difficult was it for the patient and his/her family to cover the costs of care in the last three months of the patient's life?' (a) very difficult, (b) somewhat difficult, (c) not difficult at all, (d) don't know, (e) patient did not need care. We also collected information on the patient's age, sex, cause of death, longest place of residence in the last year of life, place of death, and whether they had been attended to by specialist palliative care providers.

Statistical analysis

We compared the characteristics of the samples in the four countries using Pearson's chi-squared tests or Fisher's exact tests if 20% or more of the expected cell frequencies were below 5. Age was grouped as 18-64, 65-84, and $\geq$85, corresponding to commonly applied definitions of the old and oldest old,(28) and cause of death was dichotomised as cancer and non-cancer. For each country, we calculated the percentage of carers feeling physically or emotionally overburdened and the percentage of patients and families experiencing difficulties in covering the costs of care. Differences between countries in carers' physical or emotional overburden (yes vs. no) and financial difficulties (not difficult vs. somewhat/very difficult) were examined using multivariate logistic regression analyses, adjusted for the sample characteristics that differed between countries. For each country, two multivariate logistic regression analyses were performed to determine whether age, sex, cause of death, place of death, and specialist palliative care provision were associated with family carers feeling physically or emotionally overburdened (yes vs. no) on the one hand and difficulty in covering costs of care (not difficult vs. somewhat/very difficult) on the other hand. For all outcome variables, binomial 95% confidence intervals were calculated and all statistical tests were performed with a significance level of α <0.05. Analyses were performed in IBM SPSS Statistics version 20 and Microsoft Excel 2010.

Ethics

The participating GPs gave written informed consent at the beginning of each registration year. Strict procedures were followed to ensure the anonymity of patients and physicians. Ethics approval for this study was obtained from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel, Belgium (2004), and from the Local Ethical Committee 'Comitato Etico della Azienda U.S.L. n. 9 di Grosseto' in Tuscany, Italy (2008). Ethics approval was not required for the posthumous collection of anonymous patient data in the Netherlands and Spain.

4.3 Results

The GPs reported 6,858 deaths in the four countries and classified 4,518 (65.9%) as expected or non-sudden. The percentage of non-sudden deaths was 67% in Belgium, 62% in the Netherlands, 66% in Italy and 69% in Spain. The exclusion of nursing home deaths from the Netherlands (n=52, 7.6% of non-sudden deaths registered in the Netherlands) resulted in a sample of 4,466 deaths of which 1,604 were registered in Belgium, 635 in the Netherlands, 1,839 in Italy and 388 in Spain. The registered deaths were representative of all deaths in the countries studied, except for the excluded nursing home deaths in the Netherlands, a slight underrepresentation of hospital deaths and people younger than 65 years in Belgium and women in the Netherlands.(21) Table 4.1 shows the characteristics of the samples of the four countries.

Family carers feeling physically or emotionally overburdened

Of all patients who had a family carer according to the GP, GPs described the carers of 28% (Belgium), 30% (Netherlands), 35% (Spain) and 71%

Table 4.1: Characteristics of non-sudden deaths in Belgium, the Netherlands, Italy and Spain

Patient characteristics[a]	Belgium, N=1604		Netherlands, N=635		Italy, N=1839		Spain, N=388		p-value[b]
	n	%	n	%	n	%	n	%	
Sex									.04
Women	868	54.3	333	53.0	983	53.5	179	46.1	
Men	731	45.7	295	47.0	856	46.5	209	53.9	
Age at death in years									<.001
18 - 64	219	13.8	117	18.4	233	12.7	43	11.1	
65 - 84	753	47.3	318	50.1	860	46.8	174	44.8	
$\geq$ 85	620	38.9	200	31.5	746	40.6	171	44.1	
Cause of death									<.001
Cancer	595	37.1	335	52.9	830	46.3	149	38.8	
Non-cancer	1007	62.9	298	47.1	964	53.7	235	61.2	
Longest place of residence									<.001
Home/with family	1048	65.6	491	78.1	1697	92.7	339	88.3	
Care home	508	31.8	135	21.5	111	6.1	40	10.4	
Other	42	2.6	3	0.5	22	1.2	5	1.3	
Place of death									<.001
Home	367	23.0	276	43.5	846	46.1	188	49.0	
Care home	499	31.2	114	18.0	164	8.9	48	12.5	
Hospital	577	36.1	177	27.9	716	39.0	128	33.3	
PCU/hospice	150	9.4	66	10.4	101	5.5	17	4.4	
Other	4	0.3	1	0.2	9	0.5	3	0.8	
Specialist palliative care									<.001
Received	717	46.6	172	29.0	683	38.9	174	44.8	
Not received	822	53.4	422	71.0	1073	61.1	214	55.2	

[a] Abbreviations: PCU=palliative care unit. Missing values: sex: n=12 (0.3%), age: n=12 (0.3%), cause of death: n=53 (1.2%), longest place of residence: n=25 (0.6%), place of death: n=15 (0.3%), specialist palliative care: n=189 (4.2%). Percentages are within-country percentages. Percentages are rounded and therefore may not add up to 100.

[b] Pearson chi-squared test

(Italy) as physically or emotionally overburdened (Table 4.2). The percentages differed significantly between countries (adjusted p<.001).

Difficulty for patients and family in covering the costs of care

GPs in Italy reported the highest (8%), and GPs in Spain the lowest (0.3%) proportion of families for whom covering the costs of care was 'very difficult' (Table 4.2). The highest percentage of families for whom GPs said that they did not have difficulties in covering the costs of care was found in Spain (73%).

Characteristics associated with family carers feeling physically or emotionally overburdened and with difficulties in covering care-related costs

In Belgium and Italy, carers of patients younger than 85 had higher odds of being described as physically or emotionally overburdened and as having

Table 4.2: Characteristics of non-sudden deaths in Belgium, the Netherlands, Italy and Spain

Physical/emotional burden and financial strain[a]	Belgium N=1604		Netherlands N=635		Italy N=1839		Spain N=388		p-value[b]
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	
Family carer(s) feeling,physically or emotionally overburdened according to GP[c]									<.001
yes	387	27.8 (25.4 to 30.2)	169	30.2 (26.4 to 34.0)	1205	70.9 (68.7 to 73.1)	125	34.8 (29.9 to 39.7)	
no	840	60.3 (57.8 to 62.9)	333	59.6 (55.5 to 63.7)	329	19.4 (17.5 to 21.3)	200	55.7 (50.6 to 60.8)	
unknown[e]	165	11.9 (10.2 to 13.6)	57	10.2 (7.7 to 12.7)	166	9.8 (8.4 to 11.2)	34	9.5 (6.5 to 12.5)	
no family carer[e]	207	12.9 (11.3 to 14.5)	55	9.0 (6.7 to 11.3)	125	6.8 (5.6 to 8.0)	0	(0)	
Difficulties in covering costs of care according to GP[d]									<.001
very difficult	35	2.3 (1.5 to 3.1)	20	4.0 (2.3 to 5.7)	138	7.8 (6.6 to 9.0)	1	0.3 (0 .0 to 0.9)	
somewhat difficult	182	11.9 (10.3 to 13.5)	160	32.2 (28.1 to 36.3)	619	34.9 (32.7 to 37.1)	23	7.6 (4.6 to 10.6)	
not difficult at all	901	58.9 (56.4 to 61.4)	215	43.3 (38.9 to 47.7)	775	43.7 (41.4 to 46.0)	220	72.6 (67.6 to 77.6)	
unknown[e]	413	27.0 (24.8 to 29.2)	102	20.5 (17.0 to 24.0)	242	13.6 (12.0 to 15.2)	59	19.5 (15.0 to 24.0)	

[a] Abbreviations: CI=confidence interval. Missing values: family carers overburdened: n=69 (1.5%); difficulties in covering costs of care: n=63 (1.4%). Percentages are within-country percentages. Percentages are rounded and therefore may not add up to 100.

[b] p-values based on multivariate analysis adjusted for age, sex, cause of death, place of death, and longest place of residence.

[c] The denominator on which the percentages for 'yes', 'no', and 'unknown' are based is the number of patients who had family carers according to the GP.

[d] Patients who did not need care according to the GP (BE: n=69, 4.3%; NL: n=120, 18.9%; IT: n=49, 2.7%; ES: n=60, 15.5%) are not included.

[e] Not included in multivariate analysis .

difficulties in covering the costs of care (Tables 4.3-4.6). Dying from cancer versus non-malignant disease was not associated with GPs' reports of the physical or emotional overburden on carers in any of the countries studied. However, in Belgium and Italy, cancer patients and their families had lower odds than non-cancer patients of having difficulties in covering the costs of care. Furthermore, in Belgium and Italy, family carers were less likely to be described as physically or emotionally overburdened if the patient died in a care home as opposed to home. Difficulties in covering the costs of care were more frequently reported for patients who died at home as opposed to other locations in the Netherlands and for patients who died at home or in a care home rather than in other locations in Italy. Involvement of specialist palliative care providers was associated with higher physical or emotional carer burden in all countries except in Spain and with higher financial burden for patients and families in the Netherlands and Italy.

4.4 Discussion

This study found that GPs judged family carers of 28% (Belgium) to 72% (Italy) of patients at the end of life as feeling physically or emotionally

Table 4.3: Belgium: Factors associated with GPs' reports of family carers feeling overburdened and with difficulties in covering the costs of care in the last three months of life; two multivariate logistic regression analyses

Patient- health- and care characteristics[ab]	Family carer(s) feeling physically or emotionally overburdened[c]		Difficulties in covering costs[d]	
	n (%)	OR (95% CI)[e]	n (%)	OR (95%,CI)[e]
	N=1182		N=1080	
Age				
≥ 85 y	106 (22.3)	1.00	55 (12.8)	1.00
65 - 84y	194 (35.1)	**1.42 (1.05 to 1.92)**	91 (18.2)	**1.49 (1.01 to 2.21)**
18 - 64y	72 (46.8)	**1.84 (1.19 to 2.83)**	56 (37.6)	**4.36 (2.63 to 7.23)**
Sex				
Male	191 (35.4)	1.00	98 (20.1)	1.00
Female	181 (28.2)	0.96 (0.74 to 1.26)	104 (17.6)	0.99 (0.72 to 1.38)
Cause of death				
Non-cancer	193 (26.6)	1.00	117 (17.9)	1.00
Cancer	179 (39.2)	0.96 (0.70 to 1.31)	85 (19.9)	**0.65 (0.44 to 0.96)**
Place of death				
Home	135 (42.2)	1.00	59 (19.9)	1.00
Care home	55 (14.6)	**0.27 (0.18 to 0.40**)	40 (12.1)	0.69 (0.42 to 1.12)
Hospital	136 (36.1)	0.83 (0.61 to 1.14)	82 (24.0)	1.34 (0.90 to 1.99)
PCU/hospice	46 (42.2)	0.83 (0.52 to 1.32)	21 (18.6)	0.87 (0.48 to 1.57)
Specialist palliative care				
Not received	98 (25.7)	1.00	61 (17.7)	1.00
Received	274 (34.2)	**1.39 (1.04 to 1.86)**	141 (19.2)	1.23 (0.86 to 1.75)

[a] Abbreviations: OR=odds ratio; CI=confidence interval, PCU=palliative care unit Missing values: family carers overburdened: n=69 (1.5%); difficulties in covering costs of care: n=63 (1.4%), age: n=12 (0.3%), sex: n=12 (0.3%), cause of death: n=53 (1.2%), place of death: n=15 (0.3%), specialist palliative care: n=189 (4.2%). Percentages indicate proportions within the predictor variable.

[b] Missing values on the predictor variables resulted in a reduced number of cases included in the multivariate logistic regression analyses.

[c] Deaths were not included in analysis if carer burden was unknown or if there were no family carers according to the GP.

[d] Deaths were not included in analysis if cost burden was unknown or if patient did not need care according to the GP.

[e] Odds ratios higher than 1 indicate higher odds of carers feeling overburdened/higher odds of financial burden.

Table 4.4: Netherlands: Factors associated with GPs' reports of family carers feeling overburdened and with difficulties in covering the costs of care in the last three months of life; two multivariate logistic regression analyses

Patient- health- and care characteristics[ab]	Family carer(s) feeling physically or emotionally overburdened[c]		Difficulties in covering costs[d]	
	n (%)	OR (95% CI)[e]	n (%)	OR (95%,CI)[e]
	N=476		N=370	
Age				
$\geq$ 85 y	41 (27.7)	1.00	46 (42.2)	1.00
65 - 84y	92 (37.7)	1.38 (0.82 to 2.32)	93 (50.8)	1.67 (0.95 to 2.93)
18 - 64y	27 (32.1)	1.11 (0.56 to 2.19)	36 (46.2)	1.40 (0.70 to 2.81)
Sex				
Male	91 (40.1)	1.00	74 (42.5)	1.00
Female	69 (27.7)	**0.57 (0.38 to 0.86)**	101 (51.5)	1.76 (0.13 to 2.75)
Cause of death				
Non-cancer	72 (34.8)	1.00	70 (46.7)	1.00
Cancer	88 (32.7)	0.78 (0.48 to 1.27)	105 (47.7)	0.68 (0.40 to 1.15)
Place of death				
Home	69 (30.4)	1.00	102 (54.8)	1.00
Care home	23 (28.7)	1.15 (0.60 to 2.20)	27 (42.9)	**0.51 (0.27 to 0.99)**
Hospital	45 (39.1)	1.82 (1.07 to 3.11)	31 (36.9)	**0.44 (0.24 to 0.79)**
PCU/hospice	23 (42.6)	0.82 (0.41to 1.66)	15 (40.5)	**0.34 (0.14 to 0.81)**
Specialist palliative care				
Not received	41 (31.5)	1.00	40 (38.5)	1.00
Received	119 (34.4)	**3.04 (1.84 to 5.01)**	135 (50.8)	**1.86 (1.02 to 3.41)**

[a] Abbreviations: OR=odds ratio; CI=confidence interval, PCU=palliative care unit Missing values: family carers overburdened: n=69 (1.5%); difficulties in covering costs of care: n=63 (1.4%), age: n=12 (0.3%), sex: n=12 (0.3%), cause of death: n=53 (1.2%), place of death: n=15 (0.3%), specialist palliative care: n=189 (4.2%). Percentages indicate proportions within the predictor variable.

[b] Missing values on the predictor variables resulted in a reduced number of cases included in the multivariate logistic regression analyses.

[c] Deaths were not included in analysis if carer burden was unknown or if there were no family carers according to the GP.

[d] Deaths were not included in analysis if cost burden was unknown or if patient did not need care according to the GP.

[e] Odds ratios higher than 1 indicate higher odds of carers feeling overburdened/higher odds of financial burden.

Table 4.5: Italy: Factors associated with GPs' reports of family carers feeling overburdened and with difficulties in covering the costs of care in the last three months of life; two multivariate logistic regression analyses

Patient- health- and care characteristics[ab]	Family carer(s) feeling physically or emotionally overburdened[c]		Difficulties in covering costs[d]	
	n (%)	OR (95% CI)[e]	n (%)	OR (95%,CI)[e]
	N=1444		N=1444	
Age				
≥85 y	421 (71.6)	1.00	277 (46.6)	1.00
65 - 84y	549 (81.8)	**1.56 (1.17 to 2.07)**	337 (49.9)	**1.43 (1.12 to 1.82)**
18 - 64y	162 (87.6)	**2.07 (1.24 to 3.48)**	86 (49.1)	**1.66 (1.13 to 2.43)**
Sex				
Male	564 (80.7)	1.00	322 (46.7)	1.00
Female	568 (76.2)	0.88 (0.68 to 1.14)	378 (50.1)	1.15 (0.92 to 1.42)
Cause of death				
Non-cancer	563 (74.4)	1.00	406 (53.6)	1.00
Cancer	569 (82.8)	0.94 (0.69 to 1.28)	294 (42.9)	**0.49 (0.38 to 0.64)**
Place of death				
Home	554 (78.7)	1.00	362 (51.6)	1.00
Care home	65 (67.0)	**0.57 (0.36 to 0.92)**	53 (47.7)	0.78 (0.52 to 1.18)
Hospital	439 (78.8)	0.92 (0.70 to 1.22)	259 (47.4)	**0.79 (0.63 to 0.99)**
PCU/hospice	74 (86.0)	0.83 (0.42 to 1.64)	26 (30.2)	**0.37 (0.22 to 0.61)**
Specialist palliative care				
Not received	272 (71.0)	1.00	182 (47.4)	1.00
Received	860 (81.1)	**2.26 (1.63 to 3.12)**	518 (48.9)	**1.62 (1.27 to 2.08)**

[a] Abbreviations: OR=odds ratio; CI=confidence interval, PCU=palliative care unit Missing values: family carers overburdened: n=69 (1.5%); difficulties in covering costs of care: n=63 (1.4%), age: n=12 (0.3%), sex: n=12 (0.3%), cause of death: n=53 (1.2%), place of death: n=15 (0.3%), specialist palliative care: n=189 (4.2%). Percentages indicate proportions within the predictor variable.

[b] Missing values on the predictor variables resulted in a reduced number of cases included in the multivariate logistic regression analyses.

[c] Deaths were not included in analysis if carer burden was unknown or if there were no family carers according to the GP.

[d] Deaths were not included in analysis if cost burden was unknown or if patient did not need care according to the GP.

[e] Odds ratios higher than 1 indicate higher odds of carers feeling overburdened/higher odds of financial burden.

Table 4.6: Spain: Factors associated with GPs' reports of family carers feeling overburdened and with difficulties in covering the costs of care in the last three months of life; two multivariate logistic regression analyses

Patient- health- and care characteristics[ab]	Family carer(s) feeling physically or emotionally overburdened[c]		Difficulties in covering costs[d]	
	n (%)	OR (95% CI)[e]	n (%)	OR (95%,CI)[e]
	N=318		N=239	
Age				
≥85 y	46 (33.6)	1.00	9 (8.8)	1.00
65 - 84y	62 (41.9)	1.38 (0.80 to 2.38)	13 (11.8)	2.59 (0.93 to 7.26)
18 - 64y	14 (42.4)	1.32 (0.54 to 3.27)	1 (3.7)	1.10 (0.11 to 10.79)
Sex				
Male	75 (43.6)	1.00	12 (9.3)	1.00
Female	47 (32.2)	0.62 (0.39to 1.01)	11 (10.0)	0.84 (0.34 to 2.12)
Cause of death				
Non-cancer	72 (37.9)	1.00	18 (12.3)	1.00
Cancer	50 (39.1)	0.80 (0.47 to 1.36)	5 (5.4)	0.34 (0.11 to 1.09)
Place of death				
Home	69 (41.3)	1.00	16 (12.1)	1.00
Care home	7 (24.1)	0.42 (0.17 to 1.07)	1 (5.6)	0.32 (0.04 to 2.69)
Hospital	42 (39.6)	0.82 (0.49 to 1.38)	5 (6.2)	0.41 (0.13 to 1.24)
PCU/hospice	4 (25.0)	0.38 (0.11 to 1.29)	1 (11.1)	1.58 (0.15 to 16.39)
Specialist palliative care				
Not received	19 (24.1)	1.00	4 (7.1)	1.00
Received	103 (43.1)	1.30 (0.78 to 2.15)	19 (10.4)	0.48 (0.17 to 1.39)

[a] Abbreviations: OR=odds ratio; CI=confidence interval, PCU=palliative care unit Missing values: family carers overburdened: n=69 (1.5%); difficulties in covering costs of care: n=63 (1.4%), age: n=12 (0.3%), sex: n=12 (0.3%), cause of death: n=53 (1.2%), place of death: n=15 (0.3%), specialist palliative care: n=189 (4.2%). Percentages indicate proportions within the predictor variable.

[b] Missing values on the predictor variables resulted in a reduced number of cases included in the multivariate logistic regression analyses.

[c] Deaths were not included in analysis if carer burden was unknown or if there were no family carers according to the GP.

[d] Deaths were not included in analysis if cost burden was unknown or if patient did not need care according to the GP.

[e] Odds ratios higher than 1 indicate higher odds of carers feeling overburdened/higher odds of financial burden.

overburdened. Difficulties in covering the costs of care were reported for 8% (Spain) to 43% (Italy) of patients. Patients' age, cause of death, place of death and specialist palliative care provision were associated with physical or emotional and financial burden, although these associations were not statistically significant in each of the four countries studied.

This is the first cross-national, population-based study that described and compared the prevalence of physical or emotional overburden and financial strain among family carers of patients at the end of life, as reported by GPs. A recent position paper of the European Forum for Primary Care stated that primary care practitioners have a crucial role in detecting, discussing, and managing the burden of care for family carers.(29) It is therefore highly relevant for the planning and implementation of health and social care policies and programmes to know how many families of patients at the end of life GPs identify as overburdened. Retrospective surveys are a well-established methodology for obtaining population-based information on a consistent period of time before death,(30) and using sentinel general practice networks as observational units increased the comparability of data across countries. The GPs in the networks are representative of the total GP population in each country,(21) and they reported a representative sample of non-sudden deaths, with the exception of nursing home deaths in the Netherlands. Furthermore, GPs are usually well informed of their patients' care as they are the coordinators of most of the care delivered in the countries studied and the vast majority of people have a GP whom they consult regularly.(31-34)

However, our study has limitations. Firstly, information on physical or emotional burden and financial strain was not obtained from the family carers themselves, and GPs may not be able to report the precise degree of the burden experienced by carers. However, these data indicate the primary care physicians' perception of the extent of the overburden and thereby facilitate conclusions about the number of family carers for whom the GPs may decide to initiate support mechanisms. Secondly, GPs' judgments of physical or emotional overburden and financial strain are based on their subjective perceptions rather than valid measures of burden. This subjectivity can be problematic if it leads to systematic differences between countries, for example in case of cultural differences in people's expression of feeling overburdened. Thirdly, it is possible that the GPs were not aware of the specific family circumstances and the particulars of the caring role of the different family members of all of their patients. Fourthly, based on our data we cannot determine the type of burden (e.g., physical or emotional) experienced by the carers. Fifthly, due to the retrospective data collection, recall bias cannot be ruled out but it was likely limited as the GPs were instructed to register deaths immediately after being informed of them. Finally, due to the exclusion of nursing home deaths in the Netherlands we did not have information from this country on the family carers of a group of patients of whom many are very old and have complex health problems.(6)

Italy is among the European OECD countries with the highest percentage of carers devoting more than 20 hours a week to care for a dependent relative.(9) Compared to Belgium, the Netherlands and Spain, Italy has fewer nursing homes, which means that a large number of people with complex conditions and symptoms (e.g. dementia) stay at home for a relatively long period at the end of life. These aspects might have contributed to the particularly high degree of physical or emotional overburden reported by GPs for carers in Italy.(35) Interestingly, although family carers in Spain devote similar amounts of time to care and the majority of older people are cared for at home,(9,35) a much smaller percentage was judged physically or emotionally overburdened by GPs.

The results of this study also suggest that financial burden remains an issue for a considerable proportion of people at the end of life and their families, particularly in the Netherlands and Italy. Both the dependent person and the family carer are entitled to allowances in all four countries.(35,36) However, of the OECD countries, Belgium offers the longest publicly paid care leave (maximum of 12 months),(35) which could explain the relatively low percentage of financially overburdened families reported by GPs in Belgium. However, the relatively high proportion of families with unknown financial burden in Belgium complicates the interpretation of this result. The high number of financially burdened families in Italy is consistent with reports that one-fourth of families of cancer patients have to use all their savings to pay for care at the end of life and that 44% of family carers of cancer patients have difficulties in managing their regular employment.(37) The relatively higher financial burden of families of patients who died at home in the Netherlands and at home or care home in Italy indicates a need to evaluate whether the health and social care policies in these countries are suited to meet the family carers' needs for work leave and allowances given the large number of patients staying at home towards the end of life.(38,39) The findings concerning physical and emotional burden and difficulties in covering care-related costs in Spain are rather surprising. As in Italy, long term care in Spain is mainly delivered by relatives at home, and on average carers in Spain and Italy devote a similar number of hours per week to care, which is considerably more than in Belgium and the Netherlands,(9) while at the same time receiving less support.(35,40) It is possible that GPs in Spain underestimated the burden experienced by carers. Just as well they could have had a broader definition of who family carers are and may have considered people who helped with care only occasionally and therefore felt less burdened than close relatives who are living with the patient. This assumption could also explain why the Spanish GPs reported the lowest proportion of patients without a family carer (0%).

The higher odds of physical or emotional overburden among family carers of patients receiving palliative care are likely to be the result of these patients' lower functional status,(19) but also underline the need for a more thorough evaluation of the support mechanisms for family carers of people who are very ill. In Belgium and Italy, carers of patients below 85 years had higher odds of being described by GPs as physically or emotionally and financially overburdened. Carers of younger patients are usually younger themselves and might therefore experience a particularly big impact of the caring role on their social, occupational and financial domain. Furthermore, caring for a younger family member might carry an additional emotional burden if the person is perceived as dying prematurely. The lower financial burden for cancer patients as opposed to non-cancer patients in Belgium and Italy, may suggest that non-cancer patients and their families do not request or are not offered the financial support they are entitled to, such as the Belgian 'palliative lump-sum' which requires a predicted survival of between 24 hours and three months. This may be due to the less predictable illness progression in non-cancer patients. We acknowledge that these potential explanations are speculative and that they do not explain why these associations were not found in all countries we studied.

Efforts to shift end-of-life care from institutions to the community need to be accompanied by health and social care policies that are better aligned with the needs of family carers. A formal recognition of family carers as care recipients and a stronger focus in general practice on identifying and supporting carers at risk should be part of these measures. Continuous epidemiological monitoring of overburden in family carers on national levels is crucial as this is the level on which these policies and programmes are implemented.(12)

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Chapter 5

Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries

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Published in: Journal of Epidemiology and Community Health. 2015, doi: 10.1136/jech-2014-205365.

Acknowledgements: For the IPoD study: We would like to acknowledge the following co-negotiators of national data: Katherine Hunt (University of Southampton), Régis Aubry (Observatoire National de la Fin de Vie), Luis Frova and Stefano Marchetti (Italian National Institute of Statistics), Rod McLeod (University of Sydney). We thank the following agencies for the delivery of the death certificate data: Belgium: Flemish agency for Care and Health, Brussels Health and Social Observatory, French Community of Belgium; France: Inserm-CépiDc (Centre d'épidémiologie sur les causes médicales de déces, Institut national de la santé et de la recherche médicale); Italy: Italian National Institute of Statistics (Unit for Cause of Death Statistics); Netherlands: Statistics Netherlands (CBS); Spain (Andalusia): Instituto de Estadstica y Cartografa de Andaluca; Czech Republic: Institute of Health Information and Statistics of the Czech Republic (IHIS); Hungary: Central Statistical Office Hungary; USA: Center for Disease Control and Prevention (CDC) based on Data Use Agreement; Canada: Statistics Canada; New Zealand: New Zealand Ministry of Health; England and Wales: Office for National Statistics (ONS); Mexico: Secretaria de Salud and former Sistema Nacional de Informacion en Salud (now named Direccion General de Informacion en Salud); South Korea: Statistics Korea.

Funding: This research was supported by the Research Foundation Flanders and the Willy Gepts Scientific Fund (Wetenschappelijk Fonds Willy Gepts). JC is a postdoctoral fellow of the Research Foundation Flanders. LP undertook this work as part of the European Intersectorial and Multidisciplinary Palliative Care Research Training (EURO IMPACT) project, supported by the European Union Seventh Framework Programme (FP7/2007-2013 (264 697)).

Abstract

Background: Studying where people die across countries can serve as an evidence base for health policy on end-of-life care. This study describes the place of death of people who died from diseases indicative of palliative care need in 14 countries, the association of place of death with cause of death, socio-demographic and healthcare availability characteristics in each country, and the extent to which these characteristics explain country-differences in place of death.

Methods: Death certificate data for all deaths of 2008 (age ≥1 year) in Belgium, Canada, Czech Republic, England, France, Hungary, Italy, Mexico, Netherlands, New Zealand, South Korea, Spain (Andalusia), USA, and Wales caused by cancer, heart/renal/liver failure, chronic obstructive pulmonary disease, diseases of the nervous system or HIV/AIDS were linked with national or regional healthcare statistics (N=2,220,997).

Results: 13% (Canada) to 53% (Mexico) of people died at home and 25% (Netherlands) to 85% (South Korea) died in hospital. The strength and direction of associations between home death and cause of death, socio-demographic and healthcare availability factors differed between countries. Differences between countries in home versus hospital death were only partly explained by differences in these factors.

Conclusion: The large differences between countries in and beyond Europe in the place of death of people in potential need of palliative care are not entirely attributable to socio-demographic characteristics, cause of death or availability of healthcare resources, which suggests that countries' palliative and end-of-life care policies may influence where people die.

5.1 Introduction

The number of people who die as a result of prolonged chronic illnesses is increasing worldwide.(1) Prior to dying, these people typically experience a wide range of complex needs and symptoms that require palliative care.(2) In line with the view of the World Health Organisation, palliative care is an approach to care that goes beyond a medical specialty and whose aim it is to control the various physical, psychological, social and other problems associated with a life-threatening illness.(3) One important aspect of the palliative care approach is planning of care, including the location in which patients wish to receive care towards the end of life and the location in which they wish to die.

Twenty-six studies from 13 countries found that more than half of patients preferred to die at home. Eight of these studies were conducted in the UK, four in the United States, three in Spain, two in Japan, two in South Korea, and one in Australia, Ethiopia, Rwanda, Sweden, Taiwan, Uganda, and Zimbabwe, respectively.(4) Furthermore, a population-based survey in seven European countries found that between 50% and 83% would prefer to die at home if faced with advanced cancer.(5) However, it appears that this wish is often not met as in many countries people mainly die in hospitals,(6-8) and in certain countries the percentage of hospital deaths is rapidly increasing.(8,9) Research evidence has raised concerns that many hospital deaths are preceded by potentially burdensome and inappropriate hospital admissions and aggressive treatments shortly before death which could be a threat to good end-of-life care, quality of life and ultimately a good death.(10-13) Enabling people to die at home also has important cost implications as end-of-life care in hospital may incur higher costs than end-of-life care in in community-care settings.(14,15) Of course, a home death may be easier to achieve in countries that have developed adequate home care arrangements and may be different in certain middle or low income countries where people may be more likely to receive appropriate care only in hospitals, for instance because formal home care is not available or not affordable (e.g. in Mexico).(16)

Where people with palliative care needs die has been determined an issue for public health,(17) and it should therefore be subject to the first function of public health: assessment and monitoring.(18,19) Assessment and monitoring provide the scientific foundation that is needed to inform policies and interventions on a subject that has been determined relevant for public health. Continuous and systematic monitoring of the place of death in a population that died from causes indicative of palliative care need is therefore an essential cornerstone in the planning, implementation and evaluation of policies and programmes aimed at enabling people with chronic diseases to die in their place of choice, and it contributes to the scientific base that is necessary for the allocation of financial, material and human resources for palliative care. In this context, cross-national comparisons have the added value of providing points of comparison; and they can be a valuable source of hypotheses about alternative ways to provide end-of-life care by comparing where people die in countries with different strategies and traditions in end-of-life care.(20,21) Yet relatively few cross-national comparisons of place of death have been conducted on the population level,(22-25) and few population-level studies have investigated the place of death of people who died from diseases indicative of palliative care need.(25,26)

The aim of this study was to describe and compare the place of death of people who died from diseases indicative of palliative care need in 14 countries across four continents; to what extent the place of death is associated with socio-demographic characteristics, cause of death, and availability of healthcare resources in each of the countries studied; and to what extent differences in these characteristics explain country-differences in place of death.

5.2 Methods

Study design

This study is part of the International Place of Death study, which collected complete death certificate data over one year in 14 countries (Table 5.1) that are situated across different levels of palliative care development.(27) We obtained full country data except for Spain, where the data are from the Andalusia province, and Canada where the data do not include the Quebec province. At the time of data collection (2011-2013), 2008 was the most recent year for which data were available in most targeted countries. In the USA, 2007 was the most recent available year and in Andalusia (Spain), place of death was not recorded before 2010. In addition to place of death data, we obtained a limited number of clinical, socio-demographic and healthcare supply characteristics that correspond to factors identified as being associated with the place of death in people with cancer.(28) The project lead coordinated all data requests to ensure similar variables and data and pooled all data into one common database. Ethics approval was not required as we studied anonymised death certificate data.

Population

The population comprised all deaths of persons aged 1 year and over from ten underlying conditions that previous research has found to be indicators for identifying a population potentially in need of palliative care, whether delivered through a specialist palliative care service or non-specialised care providers.(29) The development of this criterion is described in the supplementary material of the published article on the journal website (http://jech.bmj.com/content/early/2015/07/22/jech-2014-205365/suppl/

DC1). These ten underlying conditions make up the criterion for the minimal (i.e. most conservative) estimate of the population potentially in need of palliative care and include deaths caused by cancer (International Classification of Diseases 10 (ICD-10) codes C00-D48), heart failure (I500, I501, I509, I111, I130, I132), renal failure (N102, N112, N120, N131, N132, N180, N188, N189), liver failure (K704, K711, K721, K729), chronic obstructive pulmonary disease (J40, J42, J410, J411, J418, J430-J432, J438-J441, J448, J449), diseases of the nervous system (Alzheimer's disease (G300, G301, G308, G309), Parkinson's disease (G20), motor neurone disease (G122), Huntington's disease (G10)) or HIV/AIDS (B20-B24). We excluded neonatal deaths (deaths of persons younger than one year; 0,03% of the palliative care population subset) because the approach to and resources needed in palliative care in this population are very different from that of older children and adults.(30)

Data

All included countries have a similar certification of deaths. The attending physician certifies the sex of the deceased, the cause of death and time and place of death. The authorities in each country check these certificates for inconsistencies and code the causes of death according to the ICD-10. In some countries socio-demographic and environment-related variables are recorded on the death certificates; in other countries they can be gained by linking the death certificates with other databases (e.g. census data). Additionally we linked available healthcare resource statistics per capita and data on degree of urbanisation with the deceased's municipality/local authority of residence. Additional information on these data can be found in the supplementary material of the published article on the journal website (http://jech.bmj.com/content/early/2015/07/22/jech-2014-205365/suppl/DC1).

Measures

The place of death was derived from the death certificate and comprised in all countries at least the categories 'home', 'hospital', 'long-term care facility' and 'other', except for Hungary, where only 'hospital' and 'other' were recorded, and Mexico, where 'long-term care facility' was not recorded. Death certificates in England, Wales, New Zealand and the United States additionally recorded the category 'palliative care institution'.

Independent variables included individual socio-demographic characteristics (age, sex, marital status), underlying cause of death, degree of urbanisation of the region of residence, and national or regional measures of healthcare availability per region of residence (number of hospital beds/1,000 inhabitants; number of long-term care beds/1,000 inhabitants aged 65 years or over; number of general practitioners (GPs)/10,000 inhabitants). For Hungary, Czech Republic and South Korea we used nationally aggregated measures of healthcare availability because the individual's region of residence was not identified.

Statistical analysis

We calculated the percentage of deaths in the different locations in each country. As our data are population-level data it was not necessary to calculate p-values. For each country, a multivariable binary logistic regression analysis was conducted to determine the association between dying at home versus in hospital and the cause of death (cancer versus non-cancer condition), age, sex, marital status, degree of urbanisation and per capita availability of hospital beds, long-term care beds and GPs per region of residence. For the countries in which palliative care institution was recorded as a place of death (England, Wales, New Zealand, United States), we computed an additional multivariable binary logistic regression analysis per country to determine the association between death in a hospice versus in hospital and the cause of death, age, sex, marital status and density of hospital beds and GPs per region of residence. The independent variables were entered simultaneously into the regression model. We included the independent variables that previous literature has shown to be associated with place of death (28) and that could be obtained through death certificates.

To estimate the extent to which country differences in place of death were explained by differences in healthcare availability, cause of death and socio-demographic characteristics, we conducted a hierarchical binary logistic regression analysis with the dependent variable death at home versus in hospital. Country was entered as the independent variable in the first step (Model 1), cause of death, age, sex and marital status in the second step (Model 2), and the density of hospital beds, long-term care beds and GPs per health region of residence in the third step (Model 3). Belgium was chosen as the reference country because it was in the middle in terms of the percentage of home and hospital deaths compared to the other countries. All models were checked for multicollinearity (tolerance values and variance inflation factors). All analyses were conducted in IBM SPSS Statistics 22.

5.3 Results

Between 25% of people in Mexico and 49% in the Netherlands died from diseases indicative of palliative care need (Table 5.1). For 52% (Mexico) and 83% (Czech Republic) of these deaths cancer was the underlying cause. The density of hospital beds, beds in long-term care settings and GPs was highest in South Korea, the Netherlands and Belgium, respectively (Appendix, Table 11.1).

Table 5.1: Population who died of diseases indicative of palliative care need (N=2,331,600)

Country abbreviated[a]	Country	Deaths from diseases indicative of palliative care need[b]		Sex (%)	Cause of death in the population potentially in need of palliative care (%)				Age (%)		
		N	(% of all registered deaths)	Women	Cancer	Organ failure	Diseases of the nervous system	HIV/AIDS	1-69	70-79	≥80
Western Europe											
IT	Italy	242,227	42	47	71	17	11	0	25	28	47
ES	Spain (Andalusia)	26,910	47	44	59	26	15	1	26	28	46
FR	France	235,529	44	47	68	17	15	0	28	24	48
BE	Belgium	44,229	44	48	62	23	14	0	26	27	47
NL	Netherlands	65,964	49	51	64	22	15	0	29	26	45
ENG	England	197,516	42	51	67	19	14	0	39	34	28
WAL	Wales	13,214	41	50	67	19	13	0	40	34	26
Central/Eastern Europe											
CZ	Czech Republic	33,160	33	45	83	15	2	0	44	29	26
HU	Hungary	50,489	39	46	65	30	5	0	47	27	26
Oceania											
NZ	New Zealand	12,982	44	50	66	20	13	0	30	27	43
North America											
US	USA	1,100,215	45	50	52	38	9	1	34	25	42
CA	Canada	84,264	46	50	63	20	17	0	29	25	46
East Asia											
KR	South Korea	93,131	38	41	75	16	9	0	43	31	26
Latin America											
MX	Mexico	131,013	25	48	53	40	3	4	48	24	29

[a] Missing data: Age: MX n=136 (0.1%); KR n=2 (0.0%); US n=30 (0.0%). Sex: MX n=5 (0.0%). All deaths from 2008 except for USA (2007) and Andalusia (2010). Percentages may not add up to 100 due to rounding.

[b] Identified as potentially amenable to palliative care by Rosenwax et al.(Rosenwax et al. 2005)

Place of death per country in the population potentially benefiting from palliative care

Between 13% (Canada) and 53% (Mexico) of deaths occurred at home (Table 5.2). Between 25% (Netherlands) and 85% (South Korea) of deaths took place in hospital. The Netherlands (35%) and South Korea (1%) had the highest and lowest proportion of deaths in long-term care institutions, respectively. In the countries where palliative care institution was registered as a place of death, between 4% (United States) and 13% (New Zealand) of deaths occurred there.

Table 5.2: Place of death in the population who died of diseases indicative of palliative care need in 14 countries (N=2,331,600)

Place of death (%)[a]	FR	IT	ES	BE	NL	ENG	WAL	CZ	HU[b]	NZ	US	CA	MX	KR
Home	22.3	44.4	35.1	24.8	34.5	21.7	21.2	18.4	[c]	22.5	31.5	12.9	53.0	13.5
Hospital	63.9	45.7	57.3	50.8	24.6	47.5	58.6	64.0	66.2	28.1	37.8	61.4	44.4	84.9
LTC institution	11.0	6.1	7.3	23.8	34.5	17.8	12.0	16.8	[c]	33.4	22.0	20.8	[c]	1.3
PC institution	[c]	[c]	[c]	[c]	[c]	11.6	6.5	[c]	[c]	13.0	3.8	[c]	[c]	[c]
Other institution	[c]	[c]	[c]	[c]	5.2	0.3	0.5	[c]	[c]	[c]	[c]	[c]	[c]	[c]
Other	2.8	3.8	0.3	0.6	1.2	1.0	1.2	0.8	33.8	3.0	5.0	4.8	2.7	0.3

[a] Abbreviations: LTC: long-term care; PC: palliative care. Missing data for place of death: Czech Republic (0.3%), Italy (4.1%), Mexico (3.2%), USA (0.2%).

[b] The place of death in Hungary was recorded as hospital vs. other.

[c] Location not recorded in this country.

Characteristics associated with home death

In most countries death from cancer was more likely to occur at home (as opposed to hospital) than death from a non-cancer disease (Table 5.3). In France, Spain, Belgium, the Czech Republic and South Korea, home death was more likely for people with non-cancer conditions. Women had higher chances of dying at home than men in France, Italy, Spain, England, New Zealand, the United States and Mexico and lower chances in South Korea. In most countries the probability of dying at home rather than in hospital increased with older age; but this was converse in England, Wales, New Zealand and Canada. Married people were more likely to die at home than people who were unmarried, widowed or divorced in all countries except Mexico where we found no difference. Residing in a rural rather than in a highly urban environment was associated with greater chances of dying at home rather than in hospital, except in France and Canada, where the opposite was observed. The probability of dying at home generally decreased with a higher density of hospital beds, except in Spain and the Netherlands where the probability of home death increased. Associations between the probability of home death and the density of long-term care beds and GPs were not consistent across countries.

Table 5.3: Multivariable logistic regression per country with death at home vs. in hospital as dependent variable

	Odds ratio (95% confidence interval)[ab]												
	FR N= 202245	IT N= 92257	ES N= 24079	BE N= 33392	NL N= 24.219	CZ N= 33161	ENG N= 98453	WAL N= 7553	NZ N= 6569	US N= 756762	CA N= 27159	MX N= 121769	KR N= 91603
Cause of death													
cancer (vs other life-limiting illness)	0.49 (0.48 to 0.50)	1.12 (1.09 to 1.14)	0.78 (0.74 to 0.83)	0.94 (0.89 to 0.99)	2.36 (2.24 to 2.49)	0.79 (0.73 to 0.85)	1.96 (1.90 to 2.01)	2.16 (1.93 to 2.41)	2.71 (2.40 to 3.06)	2.15 (2.13 to 2.17)	1.34 (1.27 to 1.41)	1.70 (1.65 to 1.74)	0.68 (0.65 to 0.71)
Sex													
Female (vs male)	1.15 (1.13 to 1.18)	1.22 (1.19 to 1.24)	1.21 (1.14 to 1.28)	1.02 (0.97 to 1.07)	1.03 (0.99 to 1.08)	0.94 (0.89 to 1.00)	1.04 (1.02 to 1.07)	1.04 (0.95 to 1.14)	1.13 (1.02 to 1.25)	1.08 (1.07 to 1.09)	1.02 (0.98 to 1.07)	1.11 (1.09 to 1.14)	0.89 (0.85 to 0.93)
Age													
1-69	0.63 (0.61 to 0.65)	0.56 (0.55 to 0.58)	0.36 (0.33 to 0.39)	0.93 (0.88 to 0.99)	0.99 (0.94 to 1.04)	0.95 (0.89 to 1.03)	1.45 (1.41 to 1.50)	1.48 (1.30 to 1.69)	1.47 (1.30 to 1.67)	0.74 (0.73 to 0.74)	1.34 (1.28 to 1.42)	0.32 (0.31 to 0.33)	0.46 (0.44 to 0.49)
70-79	0.70 (0.68 to 0.72)	0.69 (0.68 to 0.71)	0.59 (0.55 to 0.63)	0.85 (0.80 to 0.90)	0.85 (0.81 to 0.90)	0.92 (0.85 to 1.00)	1.21 (1.17 to 1.25)	1.17 (1.02 to 1.34)	1.20 (1.05 to 1.36)	0.85 (0.84 to 0.86)	1.10 (1.04 to 1.16)	0.56 (0.54 to 0.57)	0.82 (0.78 to 0.86)
≥80	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Marital status[b]													
Married (vs unmarried/ widowed/divorced)	1.13 (1.10 to 1.15)	1.28 (1.25 to 1.31)	1.10 (1.03 to 1.16)	1.58 (1.50 to 1.66)	1.51 (1.45 to 1.58)	1.17 (1.10 to 1.25)	1.53 (1.49 to 1.57)	1.71 (1.55 to 1.88)	/	1.13 (1.12 to 1.14)	1.21 (1.16 to 1.27)	1.00 (0.97 to 1.02)	1.25 (1.20 to 1.31)
Urbanisation [c]													
rural	0.93 (0.91 to 0.96)	1.42 (1.39 to 1.45)	1.76 (1.57 to 1.97)	1.75 (1.63 to 1.88)	1.40 (1.34 to 1.47)	/	1.31 (1.20 to 1.43)	0.98 (0.85 to 1.14)	/	/	0.87 (0.82 to 0.92)	/	1.27 (1.20 to 1.34)
average	0.86 (0.84 to 0.88)	1.22 (1.19 to 1.25)	1.78 (1.67 to 1.88)	1.47 (1.39 to 1.55)	1.14 (1.08 to 1.21)	/	1.25 (1.22 to 1.29)	1.13 (1.02 to 1.26)	/	/	/	/	0.79 (0.73 to 0.85)
strong	Ref	Ref	Ref	Ref	Ref	/	Ref	Ref	/	/	Ref	/	Ref
Healthcare availability													
LTC beds/1,000 (65+)	1.00 (1.00 to 1.00)	1.06 (1.06 to 1.07)	1.00 (1.00 to 1.01)	1.00 (1.00 to 1.00)	1.00 (1.00 to 1.00)	[d]	1.01 (1.00 to 1.01)	no variation	1.00 (1.00 to 1.01)	1.00 (1.00 to 1.00)	1.02 (1.02 to 1.03)	/	[d]
Hospital beds/1,000	0.80 (0.78 to 0.82)	0.03 (0.03 to 0.03)	1.12 (1.02 to 1.22)	0.90 (0.87 to 0.92)	1.08 (1.02 to 1.15)	[d]	0.91 (0.88 to 0.95)	0.87 (0.80 to 0.94)	0.86 (0.77 to 0.97)	0.88 (0.87 to 0.89)	0.26 (0.23 to 0.29)	0.09 (0.08 to 0.10)	[d]
GPs/10,000	1.31 (1.30 to 1.33)	2.89 (2.74 to 3.04)	1.02 (1.01 to 1.03)	0.99 (0.99 to 1.00)	0.98 (0.89 to 1.07)	[d]	1.05 (1.01 to 1.09)	0.98 (0.81 to 1.20)	0.98 (0.95 to 1.01)	0.96 (0.96 to 0.96)	1.71 (1.62 to 1.79)	1.13 (1.13 to 1.14)	[d]

[a] Abbreviations: LTC: long-term care; GPs: general practitioners/primary care physicians/family physicians. Hungary not included in analysis because home was not registered as a place of death. N per country may not be equal to that of the total population due to missing data for certain independent variables.

[b] Marital status was not recorded on death certificates in New Zealand.

[c] Degree of urbanisation per region of residence was not available in the Czech Republic, New Zealand, United States and Mexico. For Canada only two degrees of urbanisation are available (urban and rural). The reference category for the odds ratio in Canada is 'urban'.

[d] Not included in the model as only one nationally aggregated value was available.

Table 5.4: Multivariable logistic regression analysis per country with death in palliative care institution vs. in hospital as dependent variable

	Odds ratio (95% confidence interval)			
Patient and health care supply characteristics[a]	EN N=83.787	WA N=6,069	NZ N=5,339	US N=431,754
Cause of death				
Cancer (vs other life-limiting illness)	18.02 (16.59 to 19.57)	17.38 (11.32 to 26.69)	10.31 (8.17 to 13.01)	3.36 (3.28 to 3.44)
Sex				
Female (vs male)	1.19 (1.16 to 1.23)	1.38 (1.19 to 1.60)	1.07 (0.95 to 1.21)	1.14 (1.12 to 1.17)
Age				
1-69	2.37 (2.25 to 2.49)	2.36 (1.84 to 3.03)	1.66 (1.42 to 1.94)	0.61 (0.60 to 0.63)
70-79	1.63 (1.55 to 1.72)	1.49 (1.15 to 1.94)	1.35 (1.14 to 1.60)	0.76 (0.74 to 0.78)
≥ 80	Ref	Ref	Ref	Ref
Marital status[b]				
Married (vs unmarried/widowed/divorced)	1.11 (1.08 to 1.15)	1.25 (1.07 to 1.46)	/	0.94 (0.92 to 0.96)
Healthcare characteristics				
Hospital beds	0.71 (0.68 to 0.75)	0.63 (0.54 to 0.73)	1.00 (0.89 to 1.12)	0.98 (0.96 to 1.00)
GPs per 10000	1.14 (1.09 to 1.19)	0.25 (0.17 to 0.35)	1.10 (1.06 to 1.14)	0.96 (0.96 to 0.97)

[a] Abbreviations: GPs: general practitioners/primary care physicians/family physicians.
[b] Marital status not recorded on death certificates in New Zealand.

Characteristics associated with death in a palliative care institution

In the countries where palliative care institution was recorded as place of death cancer patients and women (the latter not in New Zealand) had higher chances than non-cancer patients and men to die in a palliative care institution rather than in hospital (Table 5.4). Persons younger than 80 years and married persons in all countries except in the United States had higher chances of dying in a palliative care institution rather than in hospital. In the United States, persons younger than 80 and married persons were less likely to die in a palliative care institution. In England and Wales, there was a negative association between the probability of dying in a palliative care institution and the density of hospital beds.

Multivariable analysis aimed at explaining country-variation

Figure 5.1 shows to what extent sets of independent variables explained the variation between countries in dying at home rather than in hospital. The closer the odds ratio is to 1 the smaller the difference in the probability of dying at home between the indicated country and Belgium as the reference country. The country differences in the probability of dying at home versus in hospital (Model 1) remained largely unchanged when cause of death and socio-demographic factors were added to the model (Model 2). However, the adjustment for the density of hospital and long-term care beds and GPs per health region of residence (Model 3) considerably reduced or reversed the differences in the probability of dying at home between Belgium and the other countries. Only in the Netherlands did the probability of dying at home remain higher than in Belgium.

5.4 Discussion

This study found considerable differences in the place of death of people who died from diseases indicative of palliative care need in 14 countries. The association between home death and cause of death (cancer vs. non-cancer), socio-demographic factors, urbanisation, and availability of hospital and long-term care beds and GPs differed in both strength and direction in the countries studied. The differences between countries in the probability of dying at home were only partly explained by differences in cause of death, socio-demographic characteristics and availability of hospital and long-term care beds and GPs, which suggests that factors related to end-of-life care policy may be important determinants of where people die.

There are at least two important roles of health and social care policy in general, and end-of-life care policy in particular, with regard to where people die. First, policy should be designed to enable people to die in their preferred location. Second, policy should be developed to ensure that high quality care is available in the locations in which a large percentage of the population die. In the following sections, we elaborate how the findings of this study can inform these two tasks.

Place of death patterns help identify the care settings that have an important role in the delivery of end-of-life care in a country. They indicate which settings require particular attention from health services research and public health policy in terms of the availability, quality and cost of palliative care provided there and its integration with other health and social care services. We observed relatively high proportions (60% or more) of hospital deaths in France, Czech Republic, Hungary, Canada, and South Korea, which suggests that in these countries the hospital is where a major part of the palliative care population receive care in the final days or at least hours of life. This raises several concerns. Less than a third of those who die in hospital in France receive palliative care.(31) Patients in the Czech Republic are often referred to hospitals at the end of life because they cannot receive adequate formal (palliative) care at home. At the same time, end-of-life care in Czech hospitals is described as often being inadequate.(32) In Canada and South Korea, the percentage of hospital deaths is very high compared to the percentage of those who would prefer to be at home as they near death or when they die.(33,34) The high percentage of hospital deaths

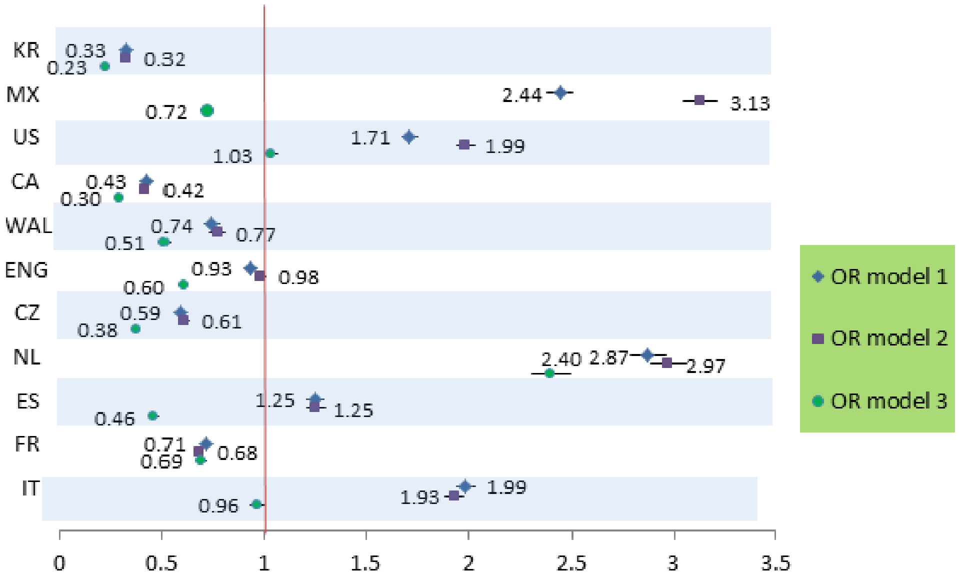

Figure 5.1: Abbreviation: OR: odds ratio. Differences between countries (odds ratios and 95% confidence intervals; reference category Belgium) in the probability of dying at home rather than in hospital, adjusted for socio-demographic factors, cause of death and healthcare supply (N=1.544.058). Calculated using hierarchical multivariable logistic regression analysis with death at home versus in hospital as dependent variable and Belgium as reference country. Independent variables: Model 1: country; Model 2: country, age, sex, marital status, cause of death; Model 3: country, age, sex, marital status, cause of death, no. of hospital beds/1,000 inhabitants, no. of GPs/10,000 inhabitants, no. of long-term care beds/1,000 inhabitants aged 65 or over. Hungary not included because death certificates distinguished only between hospital and 'other' places of death. New Zealand not included because marital status was not registered.

in some countries should prompt considerations on the part of health policy whether patients who wish to die at home and their family carers receive appropriate palliative care and other forms of support that enable them to do so.

In several other countries, for instance in Italy, Spain, the Netherlands, United States and Mexico, we observed that one-third or more of people with a potential palliative care need died at home. However, population-based survey data on preferences from Italy, Spain and the Netherlands (not available for the United States and Mexico) indicate that this is still substantially lower than the proportion that would prefer to die at home in those countries, if circumstances allowed it.(5) A high percentage of deaths at home should lead to considerations regarding the availability of formal home care, particularly home palliative care, and the availability of support for family carers. The relatively low public expenditure for long-term care at home in countries where many die at home (e.g. in Mediterranean countries)(35) raises concerns about the quality of dying at home and calls for a closer investigation of the quality of care people receive at home. This applies to an even greater extent to Mexico where for a large part of the population dying at home is the only option. Home death in Mexico is associated with lack of health insurance,(36) hospitals mainly focus on acute care, and palliative care is not integrated into mainstream healthcare services.

The country differences in dying at home versus in hospital were only partly explained by differences in cause of death, socio-demographic characteristics and availability of hospital and long-term care beds and GPs per region of residence. We hypothesise that at least part of the remaining variation may be accounted for by differences in policies in health and social care, and specifically end-of-life care. We make this assumption for two reasons. First, a systematic review of factors influencing death at home in cancer patients found that where people die is strongly associated with availability of formal healthcare services in their local area.(28) Second, we found that the patterns of place of death in certain countries could potentially be explained by the choices these countries have made with regard to, for instance, prioritising community-based care or public funding for palliative care services. For instance the focus on palliative care in the community in the Netherlands may have contributed to the relatively high percentage of deaths at home and in long-term care institutions there. In the Czech Republic, on the other hand, home palliative care services are not recognised in the health insurance law, and therefore many patients are admitted to hospital when their condition worsens.(32) One important task for future research should be to study whether greater availability of formal and publicly funded home care enables more people to die at home if they wish so. However, we must also assume that, next to policy-related aspects, there may be other factors that influence where people die such as availability of extended family support (28) or values and attitudes within the larger societal context.(28,37)

The use of death certificate data has the major advantage of providing population-level data that are not subject to potential bias inherent to sampling and that are cross-nationally comparable as the procedure for registering deaths is similar across countries. However, conducting research based on death certificate data also has limitations. The validity of the cause of death as recorded on the death certificate has been contested,(38) but the use of aggregated cause of death categories has likely mitigated the risk of misclassification. Based on the underlying cause of death it is impossible to estimate the precise content of palliative care that a particular patient needed. However, as we employed a conservative method for selecting the population in need of palliative care, we can safely assume that these people would have benefited from a palliative care approach. For the United States and Spain we were not able to obtain death certificate data from 2008 (United States: 2007, Spain: 2010). Furthermore, the data for Spain (only Andalusia region) and Canada (excluding Quebec province) may not be generalisable to the whole country. For instance, the Spanish autonomous community of Catalonia has been undertaking an extensive palliative care programme over the past years which could affect place of death patterns.(39) Although we tried to obtain healthcare supply data that were as similar between countries as possible, there is a certain level of heterogeneity that was unavoidable due to differences between countries in the ecological levels of the data linked to the individual death certificates and potential differences in the terminology regarding healthcare resources. Information on household characteristics would have been a more valid proxy for potential social support than marital status, but such data was not available across all countries. It is not possible to include data on people's preferred place of death in population-level cross-national studies as these preferences are not routinely recorded. Lastly, the dying experience in a particular location may differ depending on how much time a person spent there, but we cannot conclude from the place of death record on death certificates how long a patient had been in the location in which they died.

Conclusion

This study found considerable differences between 14 countries in the place of death of people who died from diseases indicative of palliative care need and in the factors associated with place of death. We also found that a considerable proportion of the country-variation in place of death remained unexplained after controlling for clinical, socio-demographic and healthcare availability characteristics, which suggests that other factors, potentially related to end-of-life care policy, have an important influence on where people die. These results inform end-of-life care policy-making in at least three ways. Firstly, they indicate for each country the important settings for the provision of end-of-life and palliative care. Secondly, they highlight the care settings in which evaluating the availability and quality of end-of-life and palliative care should be a priority. Thirdly, the differences between countries can serve as a source of hypotheses about the public health interventions that could be taken to ensure that people receive end-of-life and palliative care in locations that correspond to their wishes.

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Chapter 6

International study of the place of death of people with cancer: a population-level comparison of fourteen countries across four continents using death certificate data

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Published in: British Journal of Cancer. 2015, doi: 10.1038/bjc.2015.312.

Acknowledgements: We thank the following agencies for the delivery of the death certificate data: Belgium: Flemish Agency for Care and Health, Brussels Health and Social Observatory, French Community of Belgium; France: Inserm-CépiDc (Centre d'épidémiologie sur les causes médicales de déces, Institut national de la santé et de la recherche médicale); Italy: Italian National Institute of Statistics (unit for cause of death statistic); Netherlands: Statistics Netherlands (CBS); Spain (Andalusia): Instituto de Estadstica y Cartografa de Andaluca; Czech Republic: Institute of Health Information and Statistics of the Czech Republic (IHIS); Hungary: Central Statistical Office Hungary; USA: Center for Disease Control and Prevention (CDC) based on Data Use Agreement; Canada: Statistics Canada; New Zealand: New Zealand Ministry of Health; England and Wales: Office for National Statistics (ONS); Mexico: Secretaria de Salud and Sistema Nacional de Informacion en Salud; Korea: Statistics Korea. We also thank Jane Ruthven for linguistic help.

Funding: This work was supported by the Research Foundation Flanders and the Willy Gepts Fund (Wetenschappelijk Fonds Willy Gepts).

Abstract

Background: Where people die can influence a number of indicators of the quality of dying. We aimed to describe the place of death of people with cancer and its associations with clinical, socio-demographic and healthcare supply characteristics in 14 countries.

Methods: Cross-sectional study using death certificate data for all deaths from cancer (ICD-10 codes C00-C97) in 2008 in Belgium, Canada, Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, South Korea, Spain (2010), USA (2007), and Wales (N=1,355,910). Multivariable logistic regression analyses evaluated factors associated with home death within countries and differences across countries.

Results: Between 12% (South Korea) and 57% (Mexico) of cancer deaths occurred at home; between 26% (Netherlands, New Zealand) and 87% (South Korea) occurred in hospital. The large between-country differences in home or hospital deaths were partly explained by differences in availability of hospital- and long-term care beds and general practitioners. Hematologic rather than solid cancer (odds ratios (ORs) 1.29-3.17) and being married rather than divorced (ORs 1.17-2.54) were most consistently associated with home death across countries.

Conclusion: A large country variation in the place of death can partly be explained by countries' healthcare resources. Country-specific choices regarding the organisation of end-of-life cancer care likely explain an additional part. These findings indicate the further challenge to evaluate how different specific policies can influence place of death patterns.

6.1 Introduction

Although life extension and outright cures are possible now for many types of cancers, it remains one of the leading causes of death worldwide. Advanced cancer patients form a large group among people who could benefit from a care approach aimed at comfort and quality of life.(1) One important aspect of this approach is respect for patient choices in terms of the places where they receive ongoing care, spend the last days of their lives and ultimately die.(2) Evidence across many studies suggests that, for the majority of people with cancer and their caregivers, home is the preferred place of death.(3) Previous research indicates that dying in one's home environment is better aligned with patient well-being as it benefits control, autonomy, dignity and continuity of care and involves lower healthcare costs and a lower risk of iatrogenic events and overly aggressive treatments.(4-6)

At the population level, place of death is a valid indicator of where care is provided in the final hours or days of life.(7) Cancer is a leading cause of death worldwide, and so knowing where people with cancer die and understanding the determinants of dying in a particular place are important public health issues, relevant not only to a commitment to patient preferences but also to efforts to avoid unnecessary hospitalisations.(8-10) Several countries have developed policies and programmes to strengthen palliative and end-of-life care at home and to facilitate dying in the place of choice.(11-13)

Population-level monitoring of place of death trends provides descriptive information that, if complemented with more in-depth understanding, can help inform public health policy regarding the allocation of end-of-life care resources and support improvement strategies. Adding a cross-national comparison provides an opportunity to examine differences in place of death between countries with different levels of palliative care integration and different policies related to, amongst others, cancer care, long-term care and end-of-life care. This can help generate hypotheses regarding the influence of different factors related to policy and healthcare organisation and strategies for influencing where people die.(14) Although previous studies have looked at cross-national differences in place of death in Europe,(15,16) no studies using individual data have made comparisons across continents.

The aim of this study was to describe the place of death of cancer patients and associated characteristics in 14 countries across four continents. We investigated where people with cancer die in 14 countries across four continents and how this differs from where people with a non-cancer condition die, to what extent differences in patient characteristics and healthcare supply explain variations between countries in place of death and to what extent the place of death of cancer patients is associated with patient characteristics and healthcare supply in each of the countries studied.

6.2 Methods

Study design

This study is part of the International Place of Death (IPoD) project, which collected complete death certificate data for a period of one year in 14 countries (Table 1). We obtained full country data except for Spain, where the data are from the Andalusia province, and Canada where the data do not include the Quebec province. An exploration of all candidate partners showed that, at the time of the data collection (2011-2013), 2008 was the most recent year for which data were available in most targeted countries. In the USA, 2007 was the most recent available year and in Andalusia (Spain), place of death was not recorded before 2010. We also obtained a number of clinical, socio-demographic and residential characteristics of the deceased, factors already identified as being associated with the place of death in people with cancer.(17) The project lead coordinated all data requests to ensure similar variables and data and pooled all data into one common database. Ethics approval was not required as we studied anonymised death certificate data.

Data

All included countries have similar death certification: generally the attending physician certifies the sex of the deceased, the cause or causes of death and the day and place of death. The authorities in each country check these certificates for inconsistencies and code death causes according to the WHO's International Classification of Diseases 10th Revision (ICD-10). The death certificates of some countries contain socio-demographic information, while in other countries it can be gained through links with other databases (e.g. census data). A minimum number of socio-demographic variables were thus obtained. Available healthcare resource statistics per capita were also obtained for the health care regions within the countries studied and linked to the region of residence of each deceased cancer patient. Additional information on these data can be found in the supplementary material of the published article on the journal website (http://jech.bmj.com/content/early/2015/07/22/jech-2014-205365/suppl/DC1).

Measures

The place of death was derived from the death certificate and comprised at minimum the categories home, hospital and nursing home/care home in all countries except Hungary where only hospital and other location were distinguished and Mexico where nursing home/care home is not a recorded category because there are no such facilities. We henceforth refer to nursing home/care as 'long-term care facility'.

As independent variables we included individual socio-demographic (age, sex, marital status) and clinical characteristics (dying from cancer, including respiratory, gastrointestinal, genitourinary, haematologic and other cancers, or from a non-cancer condition excluding deaths from external causes such as accident and homicide), degree of urbanisation of the region of residence and healthcare supply measures that were identified as relevant in the literature on place of death of people with cancer.(17) The codes of the municipality/local authority of residence were matched with available data on urbanisation levels and healthcare supply. The healthcare supply data included the number of hospital beds per 10,000 inhabitants, the number of family physicians or general practitioners per 10,000 inhabitants and the number of long-term care beds per 1,000 inhabitants aged 65 years or over, each per health region of residence of the deceased. In some countries, the individual's region of residence was not identified. For those countries we used nationally aggregated measures of healthcare supply.

Statistical analysis

In the 14 countries all deaths with cancer as an underlying or primary cause of death (ICD-10 codes C00-C97) were selected. The cause of death was recoded as solid versus haematological cancer. Descriptive statistics were used to describe the place of death. Relative risks (unadjusted risk ratios) were calculated in order to compare the chances of dying in a certain setting for those with cancer and all those without cancer (excluding deaths from external causes).

To evaluate to what extent the country differences in place of death could be accounted for by clinical and socio-demographic characteristics or healthcare supply, a hierarchical binary logistic regression using all cancer deaths with place of death (home vs. elsewhere) as the dependent variable and country as an independent variable (Model 1) was expanded by entering cancer type (18 types of cancer), age, sex and marital status (Model 2), and then density of hospital beds, long-term beds and general practitioners (Model 3) into the model. This method was chosen as it allows evaluating how certain groups of variables explain part of the variation between countries.

To evaluate to what extent the place of death of cancer patients was associated with patient characteristics and healthcare supply in each of the countries studied a multivariable binary logistic regression analysis (home vs. elsewhere) for all cancer patients was conducted for each country with various independent candidate variables. All models were checked for multicollinearity by looking at tolerance values and variance inflation factors. Analyses were done in IBM SPSS Statistics 22.

6.3 Results

Population and healthcare availability per country

In the countries studied, between 13% (Mexico) and 30% (Netherlands) of all deaths had cancer listed as the underlying cause (Table 6.1). The percentage of women among those who died of cancer was slightly less than 50% in all countries except Mexico; in all countries around half died between the ages of 60 and 79; around one-third died at the age of 80 or over except in Mexico (19%) and South Korea (17%). Mexico was the only country where more than one-third (35%) died between the age of 0 and 59. Between 51% (United States) and 65% (South Korea) of those who died of cancer had been married (Appendix, Table 11.2). A relatively high number of beds (more than 70 per 10,000 population) existed in hospitals in South Korea, Hungary, France, Czech Republic and Belgium, while a relatively high number of long-term care beds (more than 70 per 1000 population aged 65 or over) existed in the Netherlands, New Zealand and Belgium (Appendix, Table 11.3).

Table 6.1: Deaths from cancer and socio-demographic characteristics in 2008 in 14 countries

Country	Abbreviations	Total number of deaths	Deaths from cancer	Type of cancer (% of all deaths)					Sex (% of all cancer deaths	Age (% of all cancer deaths		
			N (% of all deaths)	respiratory	gastro-intestinal	genitourinary	haematological	other	women	0-59	60-79	80 and above
Continental Western Europe												
France	FR	541,135	153,576 (28.4)	5.8	8.5	4.6	2.4	7.1	41.2	19.3	47.4	33.4
Italy	IT	578,192	164,297 (28.4)	6.1	9.8	4.1	2.4	6.0	43.3	13.1	51.7	35.3
Spain (Andalusia)[a]	ES	57,380	15,194 (26.5)	6.1	8.6	4.8	1.9	5.1	36.9	18.4	52.6	29.0
Belgium	BE	102,924	26,749 (26.0)	6.6	7.1	4.1	2.1	6.1	43.4	17.0	50.7	32.4
Netherlands	NL	135,136	40,750 (30.2)	7.5	9.0	5.0	2.2	6.4	46.3	18.0	52.6	29.4
Central/Eastern Europe												
Czech Republic	CZ	101,804	26,996 (26.5)	5.6	8.8	4.7	1.7	5.8	44.4	19.9	57.2	22.9
Hungary	HU	130,027	32,111 (24.7)	6.9	8.0	3.4	1.4	5.0	44.3	27.2	53.5	19.3
United Kingdom	UK											
England	ENG	475,763	128,802 (27.1)	6.1	7.6	4.7	2.1	6.6	47.7	13.7	50.9	35.4
Wales	WAL	32,066	8,681 (27.1)	6.5	7.8	4.5	2.0	6.3	47.0	13.1	52.2	34.6
New Zealand	NZ	29,312	8,454 (28.8)	5.8	8.8	4.9	2.6	6.8	46.8	17.9	51.1	31.0
North America												
Canada[b]	CA	182,134	51,622 (28.3)	7.3	7.7	4.4	2.6	6.4	47.3	17.9	49.9	32.2
United States[a]	US	2,428,342	563,569 (23.2)	6.7	5.6	3.5	2.3	5.1	48.0	20.6	49.6	29.8
Latin America												
Mexico	MX	528,093	65,812 (12.5)	1.4	4.0	2.8	1.4	2.9	51.0	35.5	45.8	18.8
East Asia												
South Korea	KR	247,757	69,297 (28.0)	6.3	15.3	2.2	1.4	2.8	36.4	26.2	56.7	17.0
Total		5,570,065	1,355,910 (24.3)									

[a] Reference year is 2007 in USA and 2010 in Spain (Andalusia).

[b] The data for Canada exclude the province of Quebec.

Place of death per country

Between 12% (South Korea) and 56% (Mexico) of people who died of cancer died at home. The largest proportion of home deaths was in Mexico, followed by the Netherlands (46%), Italy (45%) and USA (39%). Deaths in hospital ranged from 26% in the Netherlands to 87% in South Korea (Table 6.2).

As compared with persons dying from natural non-cancer conditions, those dying from cancer had a higher probability of dying at home in most countries except France, Spain, the Czech Republic and South Korea (Table 6.2); but they also had a higher probability of dying in hospital in France, Spain, Belgium, Czech Republic, Hungary, Canada and South Korea. In all countries, those who died of cancer were less likely to die in a long-term care facility than those who died of non-malignant causes. People with cancer also had a higher probability of dying in a palliative care institution (in countries where such a place was registered) than did those who died from non-cancer conditions, although this difference was much smaller in the United States (unadjusted relative risk (RR)=2.52) and the Netherlands (RR=4.06) than in England (RR=28.67), Wales (RR=32.00) and New Zealand (RR=14.54).

Table 6.2: The place of death of cancer and non-cancer deaths in 14 countries during 2008

	Place of death[a]	FR	IT	ES	BE	NL	CZ	HU	ENG	WAL	NZ	CA	US	MX	KR
Cancer	Home	19.1	45.3	31.6	28.9	46.3	18.2	[c]	26.1	26.2	28.5	16.1	39.0	57.3	11.8
	Hospital	72.8	47.3	64.9	59.3	25.8	64.7	67.7	44.4	56.6	26.2	67.6	33.7	39.9	87.2
	Nursing home	5.5	3.9	3.3	11.2	19.3	16.6	[c]	10.9	6.0	24.0	11.4	16.3	/b	0.8
	PC institution	[c]	[c]	[c]	[c]	7.3	[c]	[c]	17.2	9.6	18.9	[c]	5.3	[c]	[c]
	Others	2.7	3.5	0.2	0.6	1.4	0.5	32.3	1.4	1.6	2.5	5.0	5.8	2.7	0.2
Non-cancer patients[b]	Home	29.4	41.1	34.9	21.0	18.8	22.5	[c]	17.3	17.1	18.8	13.3	20.8	45.9	27.9
	Hospital	52.7	46.9	54.8	48.4	33.5	56.1	61.3	59.8	65.4	38.1	59.4	47.6	50.4	68.5
	Nursing home	13.9	7.6	9.6	29.1	42.0	18.9	[c]	20.7	15.2	36.4	22.7	25.6	[c]	2.2
	PC institution	[c]	[c]	[c]	[c]	1.8	[c]	[c]	0.6	0.3	1.3	[c]	2.1	[c]	[c]
	Others	4.1	4.4	0.7	1.5	3.9	2.5	38.7	1.7	2.1	5.4	4.5	3.9	3.7	1.3
Unadjusted Relative Risk (Cancer vs non-cancer)	Home	0.65	1.10	0.91	1.38	2.46	0.81	[c]	1.51	1.53	1.52	1.21	1.88	1.25	0.42
	Hospital	1.38	1.01	1.18	1.23	0.77	1.15	1.10	0.74	0.87	0.69	1.14	0.71	0.79	1.27
	Nursing home	0.40	0.51	0.34	0.38	0.46	0.88	[c]	0.53	0.39	0.66	0.50	0.64	[c]	0.36
	PC institution	[c]	[c]	[c]	[c]	4.06	[c]	[c]	28.67	32.00	14.54	[c]	2.52	[c]	[c]
	Others	0.66	0.80	0.29	0.40	0.36	0.20	0.83	0.82	0.76	0.46	1.11	1.49	0.73	0.15

[a] Missing data for place of death: South Korea (0.1%), USA (0.2%), Czech Republic (0.8%), Italy (4.8%), Mexico (4.9%).

[b] Excludes all deaths from external causes.

[c] Location not recorded on death certificates.

Multivariable analysis aimed at explaining country variation in home deaths

The country differences in the likelihood of dying at home versus another location (Model 1) remained largely unchanged when we controlled for differences between countries in cause of death, age and sex (Model 2) (Figure 6.1; odds ratios and 95% confidence intervals at each step of analysis in Table 11.4 of Appendix). However, when the density of hospital and long-term care beds and the density of general practitioners per health region were added to the model (i.e. assuming a similar density of available healthcare resources; Model 3), a larger part of the differences was explained as the difference in the chances of dying at home between France (reference category) and several other countries was reduced. Controlling for all covariates, the chances of dying at home still remained higher in Italy, Belgium, the Netherlands, New Zealand, the United States and Mexico as compared with France.

Factors associated with death at home within each country

When the effects of socio-demographic and healthcare supply factors were adjusted for, a death from a solid tumour was in all countries more likely to occur at home than a death from a haematologic cancer, although the difference was larger in some countries than others (e.g., OR=3.17 (95% CI 2.99-3.35) in Mexico, OR=1,29 (95%CI 1.14-1.46) in South Korea) (Table 6.3). The chances of dying at home gradually increased with age in France, Italy, Spain, Mexico and South Korea but decreased with age in all other countries (except Czech Republic where no clear age pattern emerged). In all countries married people were more likely to die at home compared with the divorced, unmarried and widowed. In all European countries with educational attainment data available (Italy, Spain, Belgium, Czech Republic), those with higher educational attainment had better chances of dying at home than those with lower educational attainment. In the USA, no clear differences by educational attainment were found, and in Mexico and South Korea an opposite pattern was found; those with higher educational attainment had lower chances of dying at home. A lower degree of urbanisation was related to higher chances of a cancer death at home, except in Canada and France where the opposite was true. The chances of dying at home decreased with an increasing density of hospital beds in France, Italy, Belgium, USA, Canada and Mexico, with the largest effect found in Italy. No clear association was found across countries between the chances of dying at home and the density of long-term care beds or the density of general practitioners

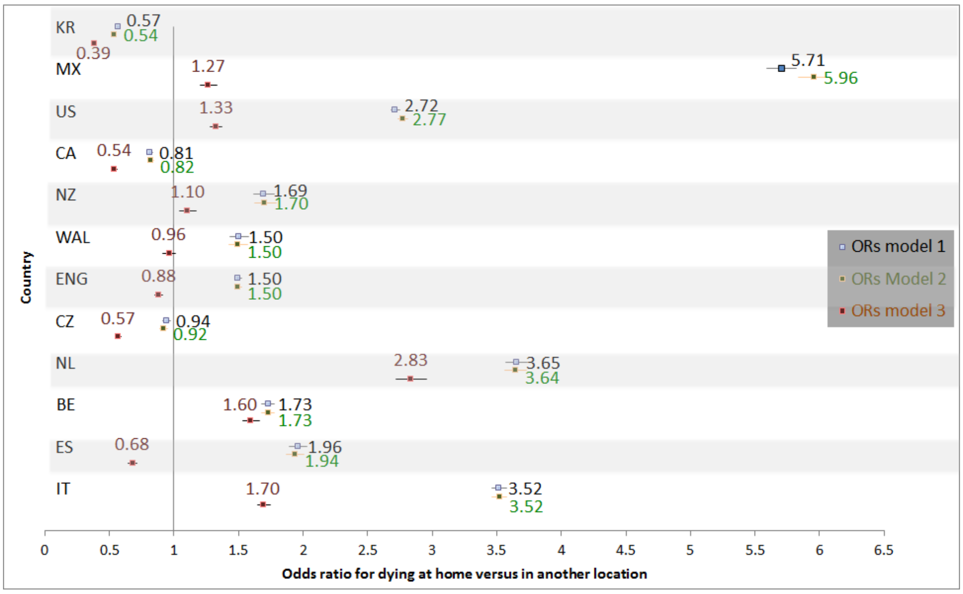

Figure 6.1: Country differences (Odds ratios, ORs) in home death (vs other), accounting for socio-demographic factors, cause of death and healthcare supply. Hierarchical binary logistic regression analyses with home vs all other places of death as dependent variable. France is the reference category in the independent variable country. Independent variables: Model 1: country (reference category: France); Model 2: additionally sex, age, cancer site (17 categories: head and neck; stomach; colon, rectum and anus; pancreas; other gastrointestinal; trachea, bronchus and lung; other respiratory; breast; cervix uteri, corpus uteri and ovary; prostate; urinary tract; other genitourinary; central nervous system; Non-Hodgkin's lymphoma; leukemia; other haematologic malignancies); Model 3: additionally number of hospital beds per 1000 inhabitants, long-term care beds per 1000 inhabitants, and general practitioners per 10000 inhabitants in the region of residence. Comparing the three models allows evaluating whether certain variables explain part of the variation between countries. Odds ratios getting closer to each other and closer to 1 when independent variables are added to the model means that part of the variation in place of death between countries is explained by these independent variables. For many countries this is particularly the case in model 3, which indicates that the variables entered in model 3 explain part of the variation (more than the ones entered in model 2). Model 3 provides the odds ratios for home death of the different countries as compared with France in case the density of available health resources was the same as in France. In some countries (Spain, England and Wales) the larger odds ratios compared to France became smaller than 1, which suggests that if these countries had the same healthcare supply as in France the home death rate could be expected to be lower than in France. However, a large part of the variation between countries remained unexplained and thus needs to be attributed to other factors.

per region of residence. The regression models explained a small proportion of the variation in dying at home versus elsewhere (R^2 range from 0.02 in the Czech Republic to 0.21 in Italy).

Table 6.3: Multivariable logistic regression modelsa per country of factors associated with home death vs other

	Odds ratio (95% confidence interval)												
	FR	IT	ES	BE	NL	CZ	ENG	WAL	NZ	CA	US	MX	KR
Characteristics of deceased and healthcare supply[ac]	152,761[b]	73,042[b]	13,255[b]	16,059[b]	40,750[b]	24,321[b]	119,394[b]	8,016[b]	8,454[b]	50,038[b]	554,917[b]	61,279[b]	68,130[b]
Cancer site													
solid (vs hematologic)	1.39 (1.32-1.46)	1.92 (1.84-2.00)	1.95 (1.65-2.30)	2.05 (1.75-2.39)	1.84 (1.70-2.00)	1.91 (1.61-2.25)	1.82 (1.72-1.92)	1.82 (1.46-2.26)	1.44 (1.20-1.73)	1.64 (1.49-1.81)	1.81 (1.78-1.85)	3.17 (2.99-3.35)	1.29 (1.14-1.46)
Sex													
Female (vs male)	ns	.89 (.87-.91)	.93 (.85-1.01)	1.09 (1.01-1.18)	1.05 (1.00-1.09)	1.09 (1.01-1.17)	1.03 (1.00-1.06)	ns	ns		0.98 (0.96-0.99)	0.96 (0.93-1.00)	1.30 (1.23-1.38)
Age													
0-49	0.40 (0.37-0.44)	0.48 (0.45-0.52)	0.24 (0.19-0.31)	1.62 (1.27-2.08)	3.42 (2.98-3.93)	0.89 (0.67-1.18)	1.75 (1.60-1.91)	2.02 (1.42-2.87)	4.37 (3.14-6.06)	1.86 (1.59-2.18)	1.29 (1.24-1.33)	0.33 (0.29-0.37)	0.26 (0.21-0.31)
50-59	0.43 (0.40-0.46)	0.52 (0.49-0.56)	0.26 (0.21-0.32)	1.22 (0.98-1.53)	2.82 (2.49-3.19)	0.81 (0.63-1.05)	1.78 (1.65-1.92)	1.97 (1.45-2.66)	3.94 (2.89-5.37)	2.01 (1.75-2.32)	1.34 (1.30-1.38)	0.37 (0.33-0.42)	0.31 (0.26-0.37)
60-69	0.44 (0.42-0.47)	0.57 (0.54-0.60)	0.31 (0.25-0.38)	1.12 (0.91-1.38)	2.54 (2.26-2.86)	0.75 (0.59-0.97)	1.74 (1.63-1.87)	1.89 (1.44-2.50)	3.88 (2.88-5.21)	1.77 (1.55-2.02)	1.35 (1.31-1.38)	0.42 (0.38-0.47)	0.45 (0.38-0.53)
70-79	0.48 (0.45-0.51)	0.67 (0.63-0.70)	0.48 (0.40-0.58)	1.04 (0.84-1.27)	2.04 (1.82-2.29)	0.77 (0.61-0.99)	1.59 (1.49-1.70)	1.68 (1.29-2.19)	2.80 (2.08-3.75)	1.54 (1.35-1.75)	1.31 (1.27-1.34)	0.53 (0.47-0.60)	0.66 (0.56-0.77)
80-89	0.62 (0.59-0.66)	0.80 (0.76-0.84)	0.73 (0.61-0.88)	1.05 (0.85-1.28)	1.49 (1.33-1.68)	0.80 (0.63-1.02)	1.35 (1.27-1.44)	1.43 (1.09-1.86)	1.91 (1.41-2.57)	1.38 (1.21-1.56)	1.18 (1.14-1.21)	0.70 (0.62-0.78)	0.84 (0.71-0.99)
90 and older	ref	ref	ref	ref	ref	ref	ref	ref	ref	ref	ref	ref	ref
Marital status													
unmarried	1.10 (1.03-1.17)	1.21 (1.11-1.33)	1.00 (0.77-1.31)	1.04 (0.86-1.26)	ref	1.28 (1.06-1.54)	0.79 (0.74-0.84)	0.63 (0.48-0.83)	c	1.13 (0.99-1.28)	0.75 (0.73-0.77)	ns	1.07 (0.87-1.30)
married	1.49 (1.41-1.56)	2.07 (1.90-2.26)	1.17 (0.92-1.49)	1.99 (1.73-2.28)	2.54 (2.43-2.65)	1.86 (1.66-2.10)	1.79 (1.71-1.88)	1.76 (1.47-2.11)	c	1.76 (1.60-1.94)	1.72 (1.69-1.75)	ns	1.39 (1.22-1.60)
widowed	1.01 (0.95-1.07)	1.63 (1.49-1.78)	1.07 (0.83-1.38)	0.91 (0.78-1.07)	/	1.46 (1.27-1.67)	1.03 (0.97-1.08)	1.01 (0.83-1.24)	c	1.33 (1.19-1.48)	1.22 (1.19-1.24)	ns	1.09 (0.94-1.27)
divorced	ref	ref	ref	ref	/	ref	ref	ref	ref	ref	ref	ref	ref
Educational attainment													
primary or less	/	ref	ref	ref	/	ref	/	/	/		ref	ref	ref
lower secondary	/	1.01 (0.98-1.05)	0.95 (0.86-1.04)	1.22 (1.11-1.34)	/	1.00 (0.92-1.08)	/	/	/		0.96 (0.93-0.99)	0.58 (0.52-0.65)	/
higher secondary	/	1.15 (1.10-1.20)	0.98 (0.88-1.09)	0.93 (0.84-1.02)	/	1.08 (0.97-1.21)	/	/	/		0.93 (0.91-0.95)	0.76 (0.71-0.80)	0.73 (0.69-0.77)
higher	/	1.28 (1.20-1.37)	1.26 (1.06-1.50)	1.46 (1.28-1.65)	c	1.47 (1.24-1.74)	/	/	/		0.98 (0.95-1.00)	0.62 (0.59-0.65)	0.55 (0.50-0.61)
Urbanization													
strong	ref	ref	ref	ref	ref	/	ref	ns	/	ref			ref
average	0.81 (0.79-0.84)	1.19 (1.15-1.22)	1.89 (1.74-2.05)	1.40 (1.29-1.52)	1.18 (1.11-1.24)	/	1.24 (1.20-1.28)	ns	/	/			0.87 (0.79-0.95)
rural	0.91 (0.88-0.95)	1.35 (1.32-1.39)	1.78 (1.52-2.08)	1.47 (1.32-1.63)	1.50 (1.44-1.57)	/	1.41 (1.28-1.55)	ns	/	0.93 (0.87-0.99)			1.24 (1.16-1.33)
LTC beds per 1000 65plus	0.99 (.99-.99)	1.05 (1.05-1.06)	ns	ns		[d]	Ns	ns	0.99 (0.98-0.99)	1.03 (1.03-1.04)	0.998 (0.998-0.999)	/	[d]
Hospital beds per 10.000	0.98 (.98-.98)	.70 (.70-.71)	ns	.99 (.99-.99)	1.01 (1.00-1.01)	[d]	1.01 (1.00-1.01)	ns	ns	0.86 (0.85-0.87)	0.99 (0.98-0.99)	0.80 (0.79-0.82)	[d]
GPs per 10.000	1.28 (1.26-1.30)	2.69 (2.53-2.86)	1.78 (1.52-2.08)	ns	.88 (.80-.96)	[d]		ns	0.94 (0.91-0.97)	1.76 (1.66-1.87)	0.97 (0.97-0.98)	1.15 (1.14-1.17)	[d]
Model fit													
Nagelkerke R^2 (%)	4.2	21.1	8.5	7.6	12.8	1.7	4.6	5.0	5.2	4.6	3.9	10.4	5.3
Hosmer Lemeshow test	<0.01	<.001	.037	.292	.070	.273	.339	.284	.020	.010	<.001	<.001	.029
Home death predicted correctly	.1%	58.2%	18.0%	2.7%	62.4%	0.0%	0.0%	0.0%	0.0%	0.1%	9.7	83.6	0.0

[a] Missing data for all variables were 0.0 to 0.6% in all countries except for educational attainment in (10,8% in ES, 41,8% in BE, 11.3% in CZ, 1,5% in US, 4% in MX, and 1.9% in KR) and marital status (3.3% in ES, 2% in MX). Cases with missing data were excluded from the analysis. Abbreviations: ns: not significant; ref: reference category; GPs: general practitioners/primary care physicians/family physicians; LTC: long term care.

[b] Sample sizes per country may not be equal to the total population due to missing data for certain independent variables. Cases with missing data were excluded from the multivariable analyses.

[c] NZ: marital status not recorded on death certificates and hence not included in the model. In the Netherlands marital status is recorded as married or not. Urbanization in Canada is coded as urban vs rural. There are no long term care beds in Mexico. Educational attainment not recorded on death certificates in France, Netherlands, England, Wales, and New Zealand. There is no separate category for lower secondary education for educational attainment in South Korea.

[d] Not included in the model as only one nationally aggregated value was available.

6.4 Discussion

Our study found a strikingly large variation across 14 countries in the place of death of people with cancer, especially in the extent to which home (percentages ranging from 12% to 57%) or hospital (percentages ranging from 26% to 87%) was the place of death. These large country differences were explained only to a limited extent by demographic differences (age, sex), cancer site and healthcare supply (rate of hospital beds, long-term care beds and general practitioners per health region) which indicates that a large part of the variation between countries is attributable to other factors. There were also notable differences between countries in the strength and direction of associations between various factors (e.g. age) and the chances of dying at home, while some factors were consistently associated with home death in the same direction (e.g. solid vs. nonsolid tumour, marital status).

To our knowledge, this is the largest cross-national study on the place of death of people who died from cancer, having examined over 1.3 million deaths in 14 countries on four continents. Death certificate data have the major advantage that they provide population-level data that do not suffer from potential bias inherent to samples, and ensure good statistical power to evaluate a larger number of associated factors. Similarities in death certification and cause of death coding make the pooling of the individual country data for cross-national analysis both feasible and reliable. They also entail a number of limitations. Inaccuracies in cause of death recording through death certificates have been reported.(18) With regard to cancer, this mainly concerns site-specific accuracy rather than causes other than cancer being recorded.(19) Our use of aggregated cause of death categories (solid vs. haematological cancer) may have mitigated this problem. Coding of place of death is not uniform across countries (i.e. categories like hospice/palliative care institution in most countries are missing and in Hungary only hospital vs outside hospital is coded), and this reaffirms previous calls for more standardisation and completeness in place of death coding on death certificates.(20,21) Death certificate data do not provide all important factors known to influence place of death.(17)Information needed to estimate the clinical predictability of dying in a certain care setting, such as detailed clinical events and symptoms, is not provided and death certificates do not shed light on the reasons for hospitalisation at the very end of life.(20). Differences between countries in these factors may have been able to explain an additional part of the country differences in place of death. Another limitation is that the same set of variables potentially associated with place of death is not available in all countries (e.g. hospital bed availability per healthcare region). However, an evaluation of the influence of the omission of factors in some countries indicated that these only marginally affected the odds ratios of the other variables in the multivariable analysis. We therefore believe that the effects of different factors within a country can be compared between countries. Conceptual equivalence is a common issue in cross-national comparative research. In our study, acute hospitals and long term care settings can have different characteristics in different countries, and this should be kept in mind when interpreting the country differences in place of death, controlled for availability of hospital beds, long term care beds and general practitioners.

Although caution not to overinterpret the found country differences is necessary and multiple complex reasons can underlie these differences, they do present real differences in terms of where similar patients spend their final hours. The statistical patterns of place of death across the different countries can be interpreted as empirical indications of the way in which each country manages end-of-life care. The findings of this study provide two important types of information for addressing some of the public health challenges related to end-of-life cancer care. Firstly, the findings inform decisions regarding the allocation of end-of-life cancer care resources, support and improvement strategies. In some countries, notably France, Spain, Belgium, Czech Republic, Hungary, Canada and Korea (countries with 60% or more of cancer deaths occurring in hospital), the hospital appears to play an important role in terminal cancer care. In other countries, notably Italy, the Netherlands, the USA and Mexico, the home setting has a more prominent role. Although high quality terminal care needs to be promoted and safeguarded in all care settings, the findings imply that some countries should primarily focus on evaluating and, if needed, improving resources for terminal cancer care in hospitals, while the focus in other countries should be the home setting. In countries where a high percentage of people with cancer die at home, such as Mexico, where this is likely to be due to issues of accessing (institutional) healthcare and where dying at home may imply dying without professional support,(22) guaranteeing a 'good death' at home is a major public health challenge. Our findings also illustrate that, although long-term care facilities are often overlooked as places for cancer care,(23) they are important places of death for people with cancer in some countries (e.g. Netherlands and New Zealand). It is important therefore to ensure that terminal and end-of-life care in those settings meets the specific needs of those with cancer.

Secondly, our findings highlight factors that could potentially influence place of death patterns. Country variation in place of death can to a certain degree be attributed to the availability of hospital and long-term care beds or general practitioners. However, a large part of the country variation in place of death remained unexplained. A review of country-level data for contextual explanation of the differences did not show any clear association between country patterns of place of death and their health expenditure or social expenditure as percentage of GDP, nor the availability of palliative care resources (Appendix, Table 11.5).(24-27) This suggests that other more complex health or social policy differences, particularly those related to end-of-life cancer care, have a role that cannot easily be captured in a density or availability measure. Past policies could explain why in some countries (France, Spain and South Korea), cancer patients were less likely than non-cancer patients to die at home, although cancer patients are often considered as having a more predictable course of disease that increases the chance of a home death.(28) In countries such as France, Spain, Canada and South Korea, end-of-life cancer care is more often provided in hospital (in palliative care units or other wards) than at home. In France, it appears that there is little support for palliative home care and this carries the risk of aggressive care in the final stages.(29) In the Czech Republic, palliative home care is not recognised in the national health insurance law and so provision is low.(30) Many patients are thus treated in hospitals, often without palliative care. On the other hand, countries such as the Netherlands (and to a lesser extent the USA) seem to have explicitly chosen to focus on the provision of palliative care at home, which would limit hospital use. England's End-of-life Strategy has a strong focus on primary care and previous research has suggested that it may be the reason for the increased home deaths there.(31)

It needs to be acknowledged that the place of death patterns we found in people with cancer, as well as the choices in national healthcare organisation that may underlie them, are also the result of historical contingencies and cultural values or circumstances surrounding families and death and dying in the community.(32)

Conclusions

Where cancer patients die appears to be determined by factors beyond medical necessity or patient characteristics. Countries' healthcare resources, notably availability of hospital beds and long term care beds, explained part of the country variation in place of death. Health care policies specific to end-of-life care likely explain an additional part. This may suggest that choices regarding organising end-of-life cancer care within a society can influence where people receive end-of-life care and die. Further cross-national research applying a more case-oriented qualitative in-depth comparison between a number of relevant comparator countries is needed to understand the reasons behind the differences in place of death.

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Chapter 7

Transitions between health care settings in the final three months of life in four EU countries

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Published in: European Journal of Public Health. 2015, 25(4):569-575. doi: 10.1093/eurpub/ckv039.

Acknowledgements: We thank the Belgian, Dutch, Italian and Spanish Sentinel Networks of General Practitioners for providing the data for this study.

Funding: This work was supported by The Research Foundation - Flanders (FWO), Belgium, and by the European Union Seventh Framework Programme (FP7/2007-2013 [grant number 264697]).

Abstract

Background: Transitions between care settings may be related to poor quality in end-of-life care. Yet there is a lack of cross-national population-based data on transitions at the end of life.

Method: International mortality follow-back study with data collection in Belgium, Netherlands, Italy and Spain (2009-2011) via existing representative epidemiological surveillance networks of general practitioners (GPs). All GPs reported weekly, on a standardised registration form, every deceased patient ($\geq$18 years) in their practice, and identified those who died 'non-suddenly'.

Results: Among 4791 non-sudden deaths in Belgium, Netherlands, Italy and Spain, 59%, 55%, 60% and 58%, respectively, were transferred between care settings at least once in the final three months of life (10%, 8%, 10% and 13% in final three days of life); 10%, 5%, 8% and 12% were transferred 3 times or more ($p<.001$ in multivariate analyses adjusting for country differences in age, sex, cause of death, presence of dementia). In all countries transitions were more frequent among patients residing at home (61%-73%) than among patients residing in a care home (33%-40%). Three months before death 5%-7% of patients were in hospital, and this rose to 27%-39% on the day of death. Patient wishes were cited as a reason for a terminal hospitalisation in 27%, 39%, 9%, and 6% of cases in Belgium, Netherlands, Italy and Spain respectively ($p<.001$).

Conclusion: End-of-life transitions between health care settings are common across EU countries, in particular late hospitalisations for people residing at home. Frequency, type and reasons for terminal hospitalisations vary between countries.

7.1 Introduction

Transitions between health care settings can be burdensome for patients with life-threatening illnesses and their families, particularly if they occur at the end of life and involve admissions to acute care settings.(1-3) There is consistent evidence that people prefer to die in their own home or home-replacing environments (4-6) and that being moved between settings increases the risk of fragmented care from multiple caregivers and medical errors (2,3,7,8) that impede the provision of high-quality palliative care.

Only a few studies have been conducted on place of care and transitions between care settings in the final three months of life and none have compared different countries using analogous methodologies.(1,9-14) The extent to which patient or family preferences play a role when a patient moves between settings has not been well studied. Place of death as registered on death certificates - often used to compare countries (13,14) - does not report on the length of stay in care settings or the reasons for transitions, and often cannot differentiate between hospitals and palliative care units/hospices. However, to develop an effective public health policy on end-of-life care on a national and international level, there is a high need for standardised and cross-national monitoring of the place of care and changes in the place of care over the last months of life for all people suffering from life-limiting diseases. Cross-national comparative research has the potential to provide a better understanding of country-specific issues and issues that are shared across countries, and to highlight where changes may be possible. In this context, comparisons across countries with different approaches to long-term care and family care, such as Northern and Southern European countries, can highlight potential effects of cultural influences in the organisation of end-of-life care.

The objective of this study was to use existing nationwide representative networks of general practitioners (GPs) in Belgium, the Netherlands, Spain and Italy to investigate: the places of care in the final three months of life, the frequency of transitions between care settings, and the most frequently occurring final transitions and the reasons for these transitions.

7.2 Methods

Study design

Data were collected through nationwide representative networks of general practitioners (GPs) as part of the EURO-SENTIMELC ("European Sentinel Networks Monitoring End-of-Life Care") study that was performed over two years, in 2009 and 2010 in Belgium, the Netherlands, and Italy, and in 2010 and 2011 in Spain.(15) Within Europe, general practice is highly accessible and GPs have a central coordinating role in the countries' health care systems with almost all of the population having a GP who they consult regularly. The networks of GPs are existing networks of practices/community-based physicians who monitor health problems on a continuous basis and who provide information not captured by other databases or disease registries.(16,17) Earlier studies have shown the added value of these primary care networks for the systematic monitoring of death and dying from a societal perspective in Europe.(6,9,10,18-22) In Belgium and the Netherlands, the networks are representative for age, sex and the geographical distribution of GPs in the country. The Spanish networks cover the centre and east of Spain (Castile and Leon and the Valencian Community). In Italy we used a new GP network that only performed registrations on end-of-life care and that was representative for all GPs in the country. The Italian physicians were stratified by health district, and by age and sex of the GPs in each district. The GP networks in Belgium and the Netherlands were nationwide, covering a population of 1.8% and 0.8% in 2009 and 1.5% and 0.8% in 2010, respectively. The Italian network covered 4.3% (2009) and 2.7% (2010) of the population of nine health districts spread across the country. The population coverage of the Spanish GP network in the Valencian Community was 2.2% of the population aged 18 years or over in 2010 and 2.1% in 2011; in Castile and Leon the respective figures were 3.8% in 2010 and 3.4% in 2011. Further information on the characteristics and operating procedures of the GP networks was reported in previous publications.(15,23)

Study population

The GPs reported every deceased patient who was part of their practice (deaths certified by themselves and deaths of which they were informed afterwards) and who was aged 18 years or over at the time of death. To identify patients with life-limiting diseases or patients eligible for palliative care, we excluded all deaths that had occurred "suddenly and totally unexpectedly" as judged by the GPs, following the example of other research designs.(24,25) In the Netherlands, we excluded patients who died in specialist nursing homes, where residents are treated by specialist elderly care physicians and not by GPs. Previous Dutch studies showed that few nursing home residents are transferred at the end of life.(11) However, people in homes for elderly people in the Netherlands are treated by GPs and were therefore included in the study. Nursing home residents are cared for by an elderly care physician and nursing staff, whereas homes for elderly people are assisted living facilities without nursing care where care is primarily provided by GPs.(26) A previous analysis showed no large differences between the deaths registered by the GP networks for the EURO-SENTIMELC study and representative reference populations in the four countries, with the exception of nursing home deaths in the Netherlands.(15) GPs can identify deaths due to cancer and non-cancer as well as dying at home and in institutional settings. GPs underreport a small number of non-sudden hospital deaths in Belgium and the Netherlands, deaths of people under 65 years in Belgium and deaths of women in the Netherlands. GPs in Italy and Spain presumably also underreport some sudden hospital deaths but this assumption could not be tested due to the absence of place of death information in Spanish and Italian death certificates.(15)

Data collection

GPs registered deaths continuously and on a weekly basis via a standardised registration form, over 2 consecutive years, from January 1st until December 31st (in 2009 and 2010 in Belgium, the Netherlands, and Italy, and in 2010 and 2011 in Spain). In Italy and Valencia (Spain), GPs registered electronically, while the other networks used paper and pencil. To limit recall bias, physicians were instructed to register all deaths immediately after being informed of them. The GPs used patient records and information coming from hospitals when filling in the forms. The usual operating procedures followed by the networks were also applied to the end-of-life care registrations.(15)

Measurements

The place of death and (maximally 3) previous places of care up to 90 days before death were registered, as was the duration of stay (in days) in each location. We distinguished the locations home (or with relatives), care home (including homes for older people in all four countries and nursing homes in Belgium, Italy and Spain), hospital, and palliative care unit or hospice.

Transitions between health care settings were defined as moves or changes in the location of care during the last three months of life. If a patient was transferred to another setting at least once, the GP registered the reason for the final transition (options: wish of patient, wish of family, patient needed palliative care/treatment, patient needed curative/life-prolonging treatment, patient did not need further treatment in that setting, other (specified); multiple responses could be indicated per patient). The individual characteristics registered for each death were date of birth, date of death, sex, cause of death and presence of dementia.

The items of the registration form were developed in Dutch and translated into French and English via forward-backward translation. The Italian and Spanish versions were developed from the English version through the same procedure. The specifics of the translations and pilot testing were reported previously.(15)

Ethics approval

The study protocol was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel, Belgium and by the Local Ethical Committee 'Comitato Etico della Azienda U.S.L. n. 9 di Grosseto' in Tuscany, Italy. As the data collection was retrospective and anonymous, no ethical approval was needed in the Netherlands or Spain according to these countries' data protection legislation.

Analyses

Each GP network applied its standard control measures to ensure data quality and to limit the amount of missing data. Descriptive statistics (percentages and confidence intervals) were used to describe the main outcome measures. We calculated the proportion of patients who were in a particular setting on a particular day for each of the last 90 days before death. Differences between countries in the outcome measures were analysed using bivariate and multivariate logistic regression models, adjusted for differences in sex and age, as well as cause of death and presence of dementia, in order to take into account certain courses of disease that may affect patterns of transitions between care settings. All analyses were conducted with a significance level of α=0.05 in IBM SPSS Statistics 20.

7.3 Results

Patient characteristics

In total, GPs registered 7411 deceased patients of whom 4877 (65.8%) died non-suddenly. Following the exclusion of patients whose place of death was not known or 'elsewhere' we studied 1596 non-sudden deaths in Belgium, 633 in the Netherlands, 1827 in Italy and 735 in Spain. Between 32% and 45% were aged 85 or over, and between 46% and 54% were female (Table 7.1). Cancer was the cause of death in 37% to 53% of cases.

Table 7.1: Characteristics of the sample of people who had died non-suddenly

Sample characteristics[a]	BE (n=1596)		NL (n=633)		IT (n=1827)		ES (n=735)		p-value
	n	%	n	%	n	%	n	%	
Female sex	864	54.3	331	52.9	973	53.3	333	45.7	.001[c]
Age in years									
Median (IQR)	82	73 to 88	79	68 to 87	82	73 to 88	84	76 to 89	<.001[b]
18-64	217	13.7	117	18.5	229	12.5	74	10.1	<.001[c]
65-84	750	47.3	316	49.9	857	46.9	331	45.0	
85 or more	617	39.0	200	31.6	741	40.6	330	44.9	
Cause of death									<.001[c]
Cancer	590	37.0	334	52.9	824	46.2	272	37.8	
Cardiovascular diseases	236	14.8	93	14.7	374	21.0	145	20.1	
Respiratory diseases	170	10.7	49	7.8	130	7.3	83	11.5	
Diseases of the nervous system	113	7.1	19	3.0	105	5.9	36	5.0	
Stroke	109	6.8	24	3.8	180	10.1	62	8.6	
Other	376	23.6	112	17.7	170	9.5	122	16.9	
Place of death									<.001[c]
Home	367	23.0	276	43.6	846	46.3	338	46.0	
Care home	499	31.3	114	18.0	164	9.0	86	11.7	
Hospital	580	36.3	177	28.0	716	39.2	274	37.3	
Palliative care unit/hospice	150	9.4	66	10.4	101	5.5	37	5.0	
Presence of dementia									<.001[c]
yes, severe dementia	292	18.6	29	4.7	255	14.2	105	14.8	
yes, mild dementia	200	12.7	50	8.2	266	14.8	110	15.5	
no	1078	68.7	532	87.1	1280	71.1	495	69.7	

[a] Missing data: age n=12 (0.3%), sex n=19 (0.4%), cause of death n=63 (1.3%), presence of dementia n=99 (2.1%). Abbreviations: BE=Belgium, NL=Netherlands, IT=Italy, ES=Spain, IQR=inter-quartile range. Percentages are rounded and therefore may not add up to 100.

[b] Kruskal-Wallis test.

[c] Pearson's chi-squared test.

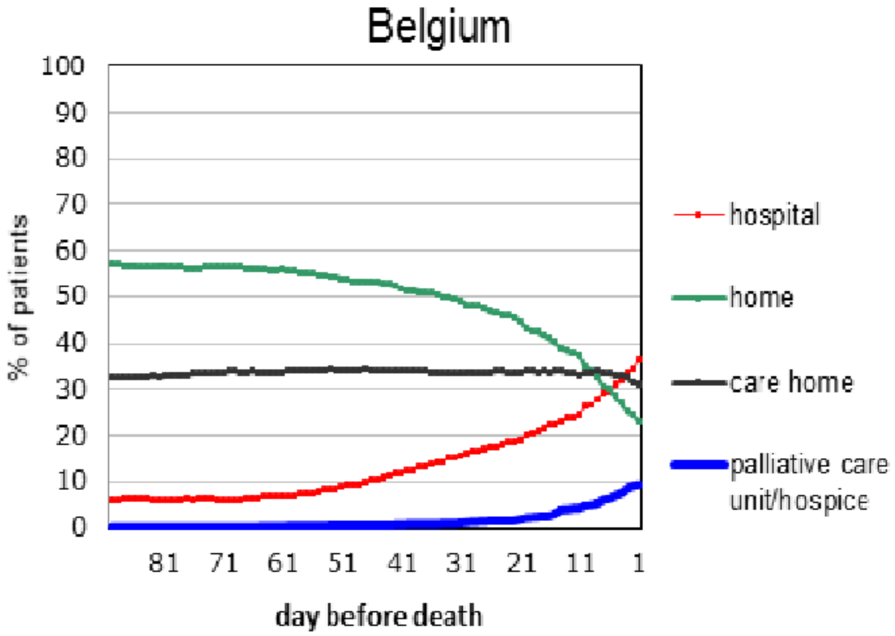

Figure 7.1: Places of care in the final three months of life of non-sudden deaths

Places of care in the final three months of life

Figures 7.1 to 7.4 depict the places of care in the last 90 days of life. In Belgium, the percentage of patients at home at three months before death was 57% and dropped to 23% on the day of death (34% point decrease). In the Netherlands, it decreased from 75% to 44% (31% point decrease), in Italy from 86% to 47% (39% point decrease), and in Spain from 79% to 44% (35% point decrease).

The percentage of patients in hospitals in Belgium increased from 6% at three months before death to 36% on the day of death. In the Netherlands, the respective percentages increased from 6% to 27%, in Italy from 5% to 39%, and in Spain from 7% to 37%. Care homes were used over the final three months of life by 31-34% of patients in Belgium compared to 18-19% in the Netherlands, 7-9% in Italy, and 12-14% in Spain. Stays in palliative care units/hospices occurred primarily in the final two weeks of life.

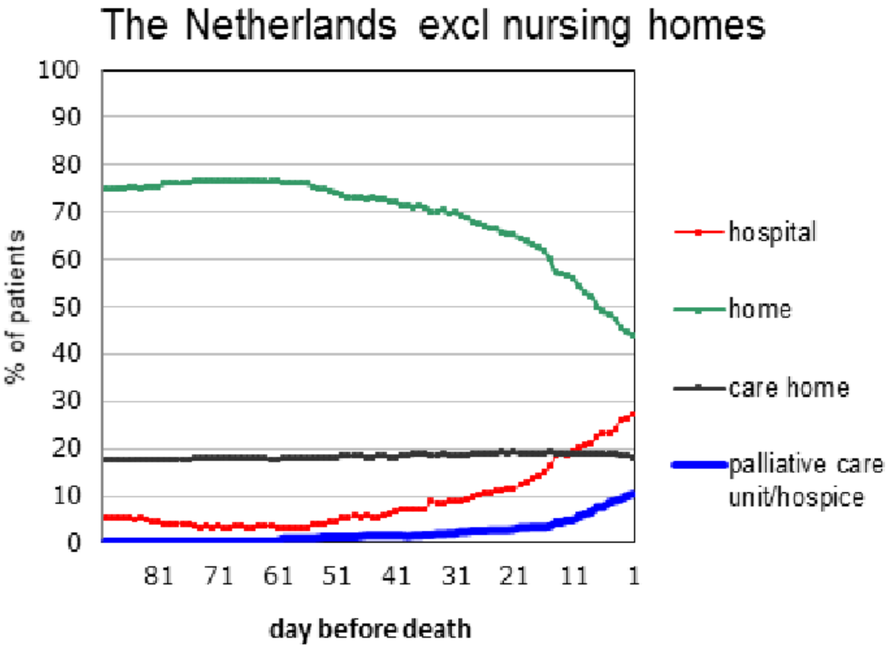

Figure 7.2: Places of care in the final three months of life of non-sudden deaths

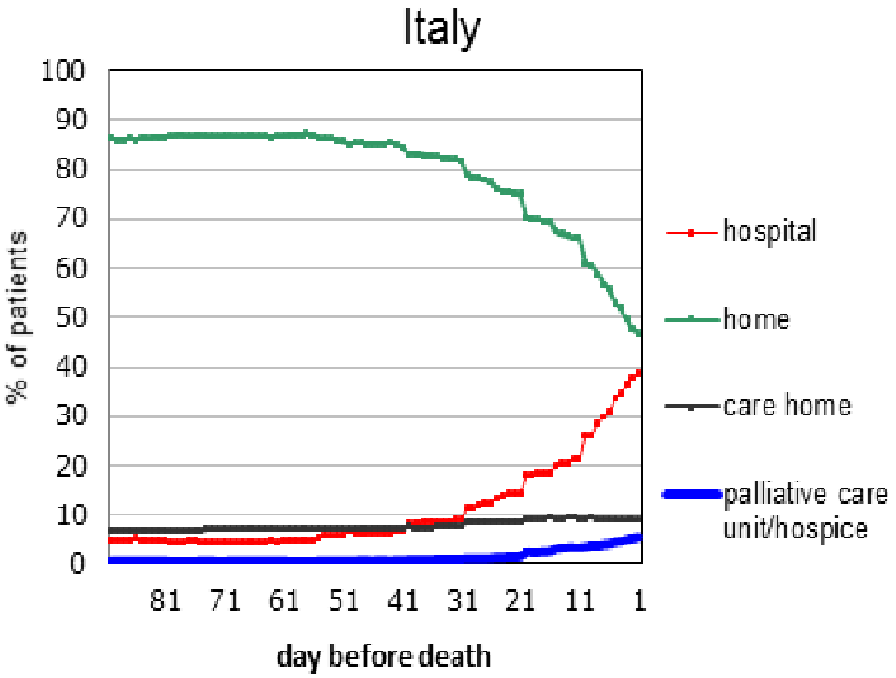

Figure 7.3: Places of care in the final three months of life of non-sudden deaths

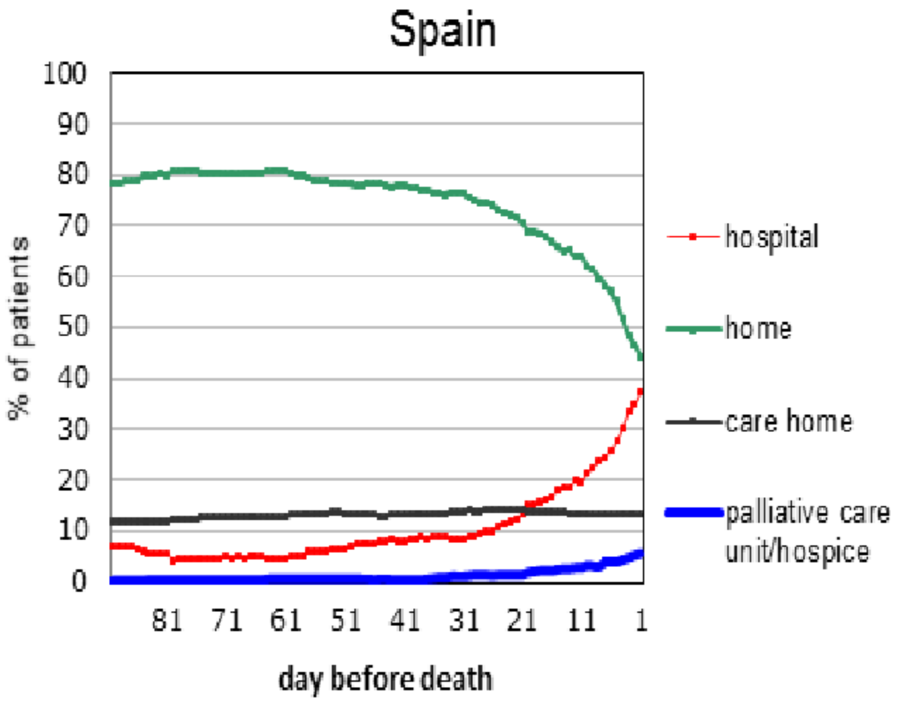

Figure 7.4: Places of care in the final three months of life of non-sudden deaths

Transitions between health care settings

In Belgium, the Netherlands, Italy and Spain, respectively 59%, 55%, 60% and 58% of patients were transferred to other care settings at least once in the final three months of life and respectively 10%, 5%, 8% and 12% of patients were transferred 3 times or more in that period (Table 7.2) ($p<0.001$ in multivariate analyses). Two cases in Belgium and Italy and 1 case in Spain had 3 or more hospitalisations in the last three months of life (not shown in Table). In all countries, transitions were more frequent for patients residing at home (between 61% and 73%) than for patients residing in a care home (between 33% and 40%).

Respectively 10%, 8%, 10% and 13% of patients in Belgium, the Netherlands, Italy and Spain ($p=0.1$) in multivariate analysis) experienced a transition in the last three days of life (Table 2). For patients residing at home three months before death, respectively 12%, 8%, 10%, and 14% of patients in Belgium, the Netherlands, Italy and Spain had a transition in the final three days of life ($p=0.04$) and for patients residing in care homes figures ranged between 3% and 8% ($p=0.45$) (not shown in Table).

Final transition to place of death

The most frequently occurring final transition in all countries was from home to hospital where the patient died and concerned 46%, 42%, 60%, 55% of patients who had at least 1 transition in Belgium, the Netherlands, Italy and Spain, respectively (Appendix, Table 11.6). Death at home following a transfer from a hospital occurred in 12%, 22%, 16% and 18% of cases who had at least 1 transition in Belgium, the Netherlands, Italy and Spain, respectively, and dying in a care home coming from a hospital occurred in 12%, 6%, 4% and 4% of patients with at least 1 transition. A transfer from a care home followed by a death in hospital was a frequent final transition in Belgium (11% of cases) but less frequent in the other countries (3% to 7%). Dying in a palliative care unit/hospice after a transition from home or hospital occurred in 15-17% of cases in Belgium/the Netherlands and in 9% of cases in Italy/Spain.

Table 7.2: Prevalence of transitions between health care settings in the last three months and days of life of non-sudden deaths per country

	BE (n=1596)		NL (n=633)		IT (n=1827)		ES (n=735)		Adjusted p-value[c]
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	
No. of transitions in the last three months of life[a]									
Across all care settings									.001
0	40.7	38.3; 43.1	44.9	41.1; 48.7	40.1	37.8; 42.4	41.6	37.8; 45.4	
1	34.3	32.0; 36.6	32.3	28.7; 35.9	36.3	34.0; 38.6	34.5	30.8; 38.2	
2	15.4	13.6; 17.2	18.1	15.2; 21.0	16.0	14.3; 17.7	11.5	9.0; 14.0	
3 or more	9.7	8.2; 11.2	4.7	3.1; 6.3	7.6	6.4; 8.8	12.4	9.9; 14.9	
By longest place of residence in the last year of life[b]									
Home/with family	n=1041		n=490		n=1691		n=637		<.001
0	27.1	24.4; 29.8	38.9	34.5; 43.3	39.0	36.6; 41.4	39.1	35.0; 43.2	
1	43.3	40.3; 46.3	35.3	31.0; 39.6	36.6	34.3; 38.9	36.2	32.2; 40.2	
2	16.6	14.3; 18.9	20.0	16.4; 23.6	16.6	14.8; 18.4	11.3	8.7; 13.9	
3 or more	13.0	10.9; 15.1	5.9	3.8; 8.0	7.8	6.5; 9.1	13.5	10.6; 16.4	
Care home	n=507		n=134		n=111		n=78		.182
0	67.0	62.9; 71.1	67.2	59.1; 75.3	60.0	50.8; 69.2	63.6	52.9; 74.3	
1	16.9	13.6; 20.2	20.3	13.3; 27.3	28.2	19.8; 36.6	24.7	15.1; 34.3	
2	13.1	10.2; 16.0	11.7	6.1; 17.3	8.2	3.1; 13.3	9.1	2.7; 15.5	
3 or more	3.0	1.5; 4.5	0.8	0.0; 2.3	3.6	0.1; 7.1	2.6	0.0; 6.2	
No. of transitions in the last three days of life[a]									
Across all care settings	9.7	8.2; 11.2	8.3	6.1; 10.5	10.1	8.7; 11.5	12.6	10.1; 15.1	.107

[a] Abbreviations: BE=Belgium, NL=Netherlands, IT=Italy, ES=Spain, CI=confidence interval. Missing data for number of transitions are due to uncompleted parts of the care trajectory in the last three months of life: BE: n=22 (1.4%); NL: n=20 (3,2%); IT: n=73 (4.0%); ES: n=91 (12.4%). Percentages are rounded and therefore may not add up to 100.

[b] Missing data: longest place of residence in the last year of life: n=28 (0.6%).

[c] P-value based on bivariate logistic regression analysis (dependent variable: 0 vs. 1 or more transitions) adjusted for sex, age, cause of death and presence of dementia.

Reasons for final transitions

In 20% of the cases in Belgium and the Netherlands, the reason for a final transition to the hospital for patients coming from home or care home was a wish of the patient, compared to 7% and 3.5% in Italy and Spain (Table 7.3). Family wishes were cited most frequently in Belgium (22.5%) compared with the other countries (between 7.5%-13%). The most frequently cited reason for a terminal hospital admission in Belgium was that the patient needed palliative care/treatment (64%) , whereas the most frequently cited reason for a terminal hospitalisation in the other countries was that the patient needed curative/life-prolonging treatment (between 47%-56%)($p<0.001$).

Table 7.3: Reasons for final transition overall and per type of final transition among non-sudden deaths per country

	Deceased who had at least one transition in the last three months of life								
	BE (N=943)		NL (N=348)		IT (N=1090)		ES (N=392)		
Reason for final transition[ab]	%	95% CI	%	95% CI	%	95% CI	%	95% CI	adjusted p-value[c]
Wish of patient	26.8	24.0; 29.6	38.6	33.5; 43.7	9.4	7.7; 11.1	6.1	3.7; 8.5	<.001
Wish of family	28.0	25.1; 30.9	18.9	14.8; 23.0	19.7	17.3; 22.1	17.3	13.6; 21.0	<.001
Patient needed palliative care/treatment	55.1	51.9; 58.3	35.4	30.4; 40.4	16.8	14.6; 19.0	34.4	29.7; 39.1	<.001
Patient needed curative/life-prolonging treatment	81.0	78.5; 83.5	53.2	48.0; 58.4	44.1	41.2; 47.0	34.4	29.7; 39.1	<.001
Patient did not need further treatment in that setting	5.9	4.4; 7.4	11.8	8.4; 15.2	8.1	6.5; 9.7	5.6	3.3; 7.9	.031
In case of final transition to hospital (coming from home or care home)	n=537		n=170		n=689		n=230		
Wish of patient	20.1	16.6; 23.6	20.8	13.5; 28.1	7.1	5.2; 9.0	3.5	1.1; 5.9	<.001
Wish of family	22.5	18.9; 26.1	7.5	2.8; 12.2	12.8	10.3; 15.3	12.6	8.3; 16.9	<.001
Patient needed palliative care/treatment	36.7	32.5; 40.9	19.2	12.2; 26.2	12.6	10.1; 15.1	34.8	28.6; 41.0	<.001
Patient needed curative/life-prolonging treatment	88.3	85.5; 91.1	70.8	62.7; 78.9	55.7	52.0; 59.4	49.1	42.6; 55.6	<.001
Patient did not need further treatment in that setting	1.0	0.1; 1.9	2.5	0.0; 5.3	3.6	2.2; 5.0	.9	0.0; 2.1	.015
In case of final transition to home or care home (coming from hospital)	n=223		n=97		n=221		n=84		
Wish of patient	40.0	33.5; 46.5	53.1	42.2; 64.0	16.3	11.4; 21.2	14.3	6.8; 21.8	<.001
Wish of family	32.7	26.5; 38.9	17.3	9.1; 25.5	26.7	20.9; 32.5	21.4	12.6; 30.2	.096
Patient needed palliative care/treatment	75.9	70.2; 81.6	34.6	24.2; 45.0	12.7	8.3; 17.1	17.9	9.7; 26.1	<.001
Patient needed curative/life-prolonging treatment	91.4	87.7; 95.14	49.4	38.5; 60.3	27.1	21.2; 33.0	11.9	5.0; 18.8	<.001
Patient did not need further treatment in that setting	19.5	14.3; 24.7	28.4	18.6; 38.2	24.9	19.2; 30.6	21.4	12.6; 30.2	.331

[a] Missing data: reasons for final transition n=100 (3.6% of those who had at least one transition) Abbreviations: BE=Belgium, NL=Netherlands, IT=Italy, ES=Spain, CI=confidence interval. More than one reason could be indicated per patient.

[b] 'Other' reasons (percentages varying between 1.2% and 10.7%) excluded from comparisons between countries.

[c] Adjusted for differences in sample characteristics between countries (sex, age, cause of death, place of death, presence of dementia).

7.4 Discussion

This international study showed that transitions between health care settings were prevalent in the final three months of life among people who died non-suddenly in Belgium, the Netherlands, Italy and Spain. Transitions in the last three days of life occurred in one in ten patients. Hospitalisations increased considerably when patients were closer to death, and were in some cases requested by the patient/family. Patients most at likely to experience terminal hospitalisations were those residing at home. This is the first international study monitoring transitions between care settings at the end of life on a population-based level, using the same methodology across several countries. Strengths include the use of established GP networks that were not chosen based on a particular interest in end-of-life care and that are representative for the GPs in the countries studied. Limitations concern the reliance on GPs to describe transitions retrospectively - since this information is not routinely available in patient records - and the lack of an objective evaluation of whether transitions were avoidable.

Palliative care policies in all the countries studied aim to reduce the frequency of transitions and deaths in acute hospitals, but transitions, and particularly hospitalisations towards the end of life, are common challenges despite variations in health care systems. While it is reassuring that most patients did not experience a transition in the last three days of life, more than half in all countries were moved at least once in the last three months of life. This poses important challenges to the continuity and quality of care at the end of life.(1-3,7,8) The fact that one in ten patients who died non-suddenly experienced a transition in the final three days of life also suggests room for improvement in end-of-life care provision in all countries. The provision of good end-of-life care takes some time to organise well and its effect may not be maximal for patients who are in transition between settings. A recent US study showed that these late-stage transitions are even more frequent in the US - twice as frequent in some cases - and that they are related to indicators of poor end-of-life care.(1,2) Additionally, multiple hospitalisations in the final three months of life almost did not occur in our study while they were registered in one in ten cases in the US.(1,2)

It should be acknowledged that judging the appropriateness of transitions is easier when looking back knowing that the patient died than judging its necessity prospectively. In the current health care systems some transitions might be unavoidable and sometimes patients or families request them. We found that the wish of the patient and/or family is mentioned in many cases as a reason for final hospitalisations. At first sight this seems contradictory to most peoples' wish to die at home.(4,6,26) However, the wish for being moved to the hospital may not be a wish to die there but a wish to receive the best possible treatment, perhaps even to prolong life. The patient needing life-prolonging treatment was also often mentioned by GPs as the reason for an admission. The latter might be related to the difficulty of predicting when exactly patients - in particular non-cancer patients (27) - will die but also to limited preparation and communication with patients/families about the (dis)advantages of an admission to acute care settings at the end of life. Other possibly related factors are that patients/families and even GPs see no alternatives because of exacerbating symptoms, high burden on caregivers, or that patients or families are not prepared for the dying process.(28,29) These results show the complex situations that physicians encounter when decisions about the place of care need to be made and the large challenge in uniting preferences and expected benefits of hospitalisations. However, if public health policies aim to reduce transitions and particularly hospital deaths, there is an urgent need to further reflect and explore why end-of-life transitions occur and which ones are avoidable, especially in relation to patient and family wishes.

A striking finding applicable to all countries is that patients residing at home seem to have a high probability of experiencing transitions and (late) hospitalisations. This resonates with results of studies among older people.(11,30) Current health care policies are often explicitly aimed at keeping more people at home for a longer time, a policy developed in response to the ageing of the population, the expected rise in health care costs and debates surrounding active ageing. The perhaps unforeseen consequences of such policies might be that clinical complications in the final phase of life (27) might not always be manageable in primary care settings which might ultimately lead to a higher number of terminal hospitalisations. Further development and implementation of palliative care in the community therefore seems imperative in all these countries (31) as some studies have shown the potential of palliative home care to influence the place of death.(32-34)

Next to these common challenges, our study revealed considerable country variation, even after correcting for differences in population characteristics. One factor that may have caused the differences between countries is the availability of health and social care resources. The availability of care home beds is relatively low in Italy and Spain, especially when compared to Belgium; hence more people are living at home in these countries. This might contribute to the higher percentage of home deaths in Italy and Spain as compared to Belgium.(35) On the other hand, Belgium has the highest density of hospital beds of the four countries,(36) and this may have contributed to the relatively high percentage of patients who are in hospital over the last three months of life. And yet, if one looks at the last week of life only, the percentage of hospitalised patients in Italy and Spain is similar to that in Belgium. This suggests that even in the Southern European countries, where home care at the end of life is common and the density of hospital beds is lower, patients are hospitalised shortly before they die. The reasons for this may lie in suboptimal communication between patients and physicians regarding diagnosis, prognosis and treatment preferences (21,37,38) and overburden in family carers.(39) The Netherlands differ from the other countries in that they have a relatively low percentage of deaths in hospital, a high number of home deaths and the least frequent transitions compared to the other three countries, which might be a result of the strong focus in policy and practice on primary palliative care and advance care planning in the Netherlands.(18,40,41).

One striking country difference is that GPs in Italy and Spain mentioned patient wishes as reason for the final transition far less often than GPs in Belgium or the Netherlands. This is congruent with previous literature on communication about end-of-life issues in these countries.(21,40) That in Italy and Spain family wishes were cited more often than patient wishes, corresponds well with other EU studies showing a strong pattern of family support in the last year of life in Mediterranean countries as opposed to Northern European countries.(42) However, Belgian GPs most frequently indicated family wishes as a reason for the final hospitalisation (22.5%) compared to the other countries (7.5%-13%) hence a clear picture in terms of differences between northern and southern European countries is probably not present.

This study highlights the need for a deeper investigation of the interplay between the organisation and provision of health and social care in general and palliative care in particular as well as social and cultural factors in influencing transitions between care settings at the end of life. Countries can use these data to reflect upon their own performance and to identify areas for further improvement. In this context, the influence of individual level characteristics, such as age and cause of death, on transitions between care settings deserves further study.

In conclusion, end-of-life transitions between care settings are prevalent in all countries and many are struggling with high hospitalisation rates in the final phase of life, which in some cases follow patient or family wishes. Patients most likely to experience transitions are those residing at home.

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Chapter 8

Hospitalisations at the end of life in four European countries: a population-based study via epidemiological surveillance networks

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Published in: Journal of Epidemiology and Community Health. 2015. doi: 10.1136/jech-2015-206073

Acknowledgements: We thank the Belgian, Dutch, Italian and Spanish Sentinel Networks of General Practitioners for providing the data for this study.

Funding: LVdB was supported through a postdoctoral grant of The Research Foundation Flanders (FWO), Belgium, and LP was supported by the Willy Gepts Scientific Fund (Wetenschappelijk Fonds Willy Gepts) of Brussels University Medical Center.

Abstract

Background: There is a paucity of cross-national population-based research on hospitalisations of people at the end of life. We aimed to compare in four European countries the frequency, time, length of and factors associated with hospitalisations in the last three months of life.

Methods: Population-based mortality follow-back study via Sentinel Networks of general practitioners (GPs) in Belgium, Netherlands, Italy and Spain. Using a standardised form, GPs recorded the care in the last three months of life of every deceased practice patient ($\geq$18 years; 01/01/2009-31/12/2011). Sudden deaths were excluded.

Results: We studied 4791 deaths that GPs described as non-sudden (66% of all registered deaths). Between 49% (Netherlands) and 56% (Belgium) of patients were hospitalised at least once in the last three months of life. Readmissions were less frequent in the Netherlands (8%) than in the other countries (15%-20%, $p<.001$). Chances of being hospitalised increased over the last 10 days of life across countries but remained lowest in the Netherlands (Belgium: 21%-37%, Netherlands: 15%-29%, Italy: 16%-37%, Spain: 14%-31%). Hospitalisations in the last week of life were more likely if patients resided at home rather than in a care home (odds ratios (ORs) and 95%CIs: Belgium: 1.94 (1.28-2.94); Netherlands: 2.61 (1.10-6.18); Spain: 4.72 (1.64-13.57); non-significant in Italy) and less likely if the GP knew the patient's preferred place of death (ORs and 95%CIs: Belgium: 0.52 (0.36-0.74); Netherlands: 0.48 (0.25-0.91); Spain: 0.24 (0.13-0.44), non-significant in Italy).

Conclusion: The use of hospitals at the end of life increased over the last weeks of life in all countries studied, but remained lowest in the Netherlands as did the rate of readmissions. This may be due to gatekeeping by GPs who are trained and supported in preventing hospital readmissions at the end of life.

8.1 Introduction

A considerable number of people who are hospitalised are nearing death.(1,2) At the same time, research shows that hospitalisations at the end of life may run contrary to the wishes of patients and their families, (3,4) and carry the risk of patients receiving overly aggressive, fragmented, poorly coordinated care with insufficient information exchange between healthcare providers and poor planning and completion of follow-up care.(5-10)

Furthermore, hospital admissions of people nearing the end of life contribute significantly to total healthcare expenditure,(11-13) and it is unlikely that hospitals will be able to bear the burden of end-of-life care for the growing number of patients who are projected to die from chronic diseases in the future.(14-16) As a result, many countries aim to reduce hospital use by people at the end of life and strengthen end-of-life care in community settings.(17)

To be effective, national public health policies and strategies on hospitalisations at the end of life require a sound epidemiological evidence-base on the extent, time patterns and determinants of hospital use at the end of life. Previous research has investigated the percentage of the population who die in hospital using death certificate data.(18-20) However, death certificates can only indicate whether a patient was hospitalised when they died, and they hold no information on the frequency, time and length of hospitalisations over the weeks prior to death, whether death was sudden and unexpected, and on whether patients had expressed a preference to die in a particular location.

In an effort to overcome these limitations, we conducted a population-based study of hospitalisations over the last three months of life through Sentinel Networks of general practitioners (GPs) in four European countries, Belgium, the Netherlands, Italy, and Spain. Cross-national comparisons of hospitalisations and associated factors can help to identify patterns that are common across countries or country-specific and they can guide the search for contextual factors that may influence hospital use at the end of life. All four countries studied have universal health coverage with primary care systems that are relatively strong in Belgium, the Netherlands and Spain, and of medium strength in Italy.(21) The countries are similar in terms of features of primary care that may have an impact on hospital admissions at the end of life, such as access and continuity of primary care, but they differ with regard to coordination of primary care which was relatively high in the Netherlands, relatively low in Belgium and medium in Spain and Italy.(21) Hospitalisations at the end of life could also be influenced by the availability of specialist palliative care services. These are established in all four countries, but the countries differ with regard to the care settings in which these services predominantly operate (e.g. hospitals, community settings, nursing homes) and their geographical distribution (evenly distributed in Belgium and the Netherlands; large geographic variation in Italy and Spain).(22)

To the best of our knowledge, this is the first cross-national, population-based study that provides detailed original data on hospitalisations at the end of life in four countries. We aimed to describe and compare in four European countries the frequency and time of hospitalisations in the last three months of life of people who died non-suddenly; the length of and location prior to the final hospitalisation for patients who died in hospital, and the factors associated with a hospitalisation in the last seven days of life.

8.2 Methods

Study design

We conducted a cross-national mortality follow-back study in Belgium, the Netherlands, Italy and Spain. The data were collected through nationwide Sentinel Networks of GPs.(23) These are regional or nationwide epidemiological surveillance networks consisting of representative samples of GPs. From 1 January 2009 to 31 December 2010 in Belgium, the Netherlands and Italy, and from 1 January 2010 to 31 December 2011 in Spain, GPs registered weekly all deaths of patients in their practice and recorded their socio-demographic characteristics, four successive causes of death (i.e. from the primary/underlying cause of death to the immediate cause of death), the care the patients received in the last three months of life and whether their death was sudden and totally unexpected. We focused on the last three months of life as this is a commonly accepted period for studying end-of-life care.(24-26) A number of quality control measures were applied to ensure valid and reliable cross-national data,(23); previous studies have demonstrated the potential of this design in collecting population-based epidemiological data on end-of-life care.(27-30)

Setting and population

The Sentinel Networks in Belgium and the Netherlands were nationwide with a population coverage of 1.8% and 0.8% in 2009 and 1.5% and 0.8% in 2010, respectively. The Italian network covered 4.3% (2009) and 2.7% (2010) of the population of the nine participating health districts (spread across the country). The Spanish networks operated in two autonomous communities. In the Valencian Community, the population coverage of those aged 18 years or over was 2.2% in 2010 and 2.1% in 2011; in Castile and Leon, the respective figures were 3.8% in 2010 and 3.4% in 2011. The participating GPs had an adequate geographical distribution and were representative of the general population of GPs in the respective country (or region in Spain) with regard to gender and age.(23)

The GPs registered the death of each patient in their practice who was aged 18 years or over. We excluded deaths that GPs judged as sudden in order to obtain a sample of people for whom end-of-life care had been a realistic option.(31) Furthermore, we excluded deaths in nursing homes in the Netherlands as these residents are treated by specialised elderly care physicians and therefore not within the GPs' scope. Residents of homes for elderly people in the Netherlands are treated by GPs and were therefore included in the study. A detailed analysis of the representativeness of the sample obtained through this study can be found in the published study protocol.(23) The protocol shows that the deaths registered by the GP networks were representative for all deaths in the participating countries in terms of age, gender and place of death, with the exception of nursing home deaths in the Netherlands and the fact that GPs underreported a small number of sudden hospital deaths in all countries as well as non-sudden hospital deaths and deaths of people under 65 years in Belgium.

Outcomes and covariates

The main outcomes were (1) how many patients were hospitalised in the last three months of life and how many times, (2) how many patients were hospitalised in the last seven days of life, (3) how many patients were admitted to hospital at each of the last 90 days of life, (4) the time of the final hospitalisation (i.e. in the course of which the patient died) in days before death, and (5) the care setting prior to the final hospitalisation. A person was considered as readmitted to hospital in the last three months of life if they had more than one hospital admission in this period. Covariates included the patient's age, gender, the primary cause of death, whether the GP or another physician had determined the diagnosis of dementia, the longest place of residence in the last year of life ('at home/with family' vs. 'nursing home/care home'), number of contacts with the GP over the last three months of life, the GP's knowledge of the patient's preferred place of death, and provision of specialist (multidisciplinary) palliative care.

Measures

The GPs of the Sentinel Networks registered weekly each deceased patient of their practice by filling in a standardised registration form. This form consisted of structured closed-ended items and is available in Dutch, French, Italian, Spanish and English.

Information on hospitalisations and other locations of care was collected by asking GPs to indicate on the registration form the patient's place of death, the three preceding locations of care (in chronological order) in the last three months of life, and the length of stay (in days) in each of these locations. From this information we were able to determine for each patient the place of care at each of the last 90 days of life. The location 'hospital' excluded palliative care units in hospitals, these were recorded as a separate location. When filling in the registration forms, the GPs were asked to include any information available from patient records and hospital physicians.

Statistical analyses

We grouped age as 18 to 64, 65 to 84 and $\geq$85 years, corresponding to commonly applied definitions of the old and oldest old.(32) We compared the characteristics of the samples in the four countries using Pearson's χ^2-tests. We calculated the percentage of people hospitalised at least once in the last three months of life and the percentage of people who were transferred to hospital in the last seven days of life (denominator: all non-sudden deaths) as well as the percentage of people hospitalised once, twice or three times or more (denominator: persons hospitalised at least once). We tested whether there were significant differences between countries in these outcomes using multivariable logistic regression analyses adjusted for country differences in age, gender, cause of death, longest place of residence in the last year of life, involvement of a multidisciplinary palliative care team, and presence of dementia.

To describe the time at which people were hospitalised over the last three months of life, we plotted the percentage of patients in hospital against the number of days before death (0-90) in a line chart for each country separately.

For the group of patients who died in hospital, we described the length of the final hospital admission before death and the percentage of people for whom home, nursing home/care home or hospice/palliative care unit was the location prior to the final hospitalisation. We tested whether the percentages differed significantly between countries using multivariable logistic regression analyses adjusted for country differences in age, gender, cause of death, and presence of dementia.

To determine which factors were associated with a hospitalisation in the last seven days of life, we conducted, separately for each country, a multivariable logistic regression analysis with the dependent variable being: hospitalised in the last seven days of life versus not hospitalised. Independent variables were simultaneously entered and chosen based on factors that previous literature found to be associated with place of care or place of death.(33) All regression models were checked for multicollinearity (variance inflation factors). All statistical tests were performed with a significance level of $\alpha < 0.05$. Analyses were performed in IBM SPSS Statistics version 22 and Microsoft Excel 2010.

Ethics

The study protocol was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel, Belgium and by the Local Ethical Committee 'Comitato Etico della Azienda U.S.L. n. 9 di Grosseto' in Tuscany, Italy. As the data collection was retrospective and anonymous, no ethical approval was required in the Netherlands and Spain.

8.3 Results

The GPs in the four countries registered 7411 deaths of which 4877 (65.8%) were non-sudden. Following the exclusion of patients who died in a nursing home in the Netherlands (52, 7.6% of non-sudden deaths) or whose place of death was not known or 'elsewhere' (34, 0.7% of non-sudden deaths), we studied 4791 deaths, that is 1596 in Belgium, 633 in the Netherlands, 1827 in Italy, and 735 in Spain. There were 208 cases (4% of all non-sudden deaths) with incomplete trajectories of locations of care which meant that we could not calculate the primary outcomes for them (i.e. hospitalisations and locations prior to hospitalisations). They were therefore excluded from the respective analyses.

Between 32% (the Netherlands) and 45% (Spain) of patients were aged 85 or over when they died, and between 46% (Spain) and 54% (Belgium) were female (Table 8.1). Cancer was the cause of death in 37% (Belgium) to 53%

Table 8.1: Characteristics of people who died non-suddenly

Patient characteristics[a]	BE (N=1596)		NL (N=633)		IT (N=1827)		ES (N=735)		p-value[b]
	n	%	n	%	n	%	n	%	
Age									
18-64	217	14	117	19	229	13	74	10	<.001
65-84	750	47	316	50	857	47	331	45	
$\geq$85	617	39	200	32	741	41	330	45	
Gender									
female	864	54	331	53	973	53	333	46	.001
male	727	46	295	47	854	47	395	54	
Cause of death									
cancer	590	37	334	53	824	46	272	38	<.001
cardiovascular diseases	236	15	93	15	374	21	145	20	
respiratory diseases	170	11	49	8	130	7	83	12	
diseases of the nervous system	113	7	19	3	105	6	36	5	
stroke	109	7	24	4	180	10	62	9	
other	376	24	112	18	170	10	122	17	
Place of death									
home	367	23	276	44	846	46	338	46	<.001
hospital	580	36	177	28	716	39	274	37	
nursing home/care home	499	31	114	18	164	9	86	12	
hospice/PCU	150	9	66	10	101	6	37	5	
Longest place of residence in the last year of life									
at home/family	1041	67	490	79	1691	94	637	89	<.001
nursing home	507	33	134	22	111	6	78	11	
Presence of dementia									
yes (mild or severe)	492	31	79	13	521	29	215	30	<.001
no	1078	69	532	87	1280	71	495	70	

[a] Abbreviations: PCU=palliative care unit. Missing data: age: n=12 (0.3%), cause of death: n=63 (1.3%), longest place of residence in the last year of life: n=28 (0.6%), presence of dementia: n=47 (1.0%). Percentages are rounded and therefore may not add up to 100.

[b] Pearson X^2-test

(the Netherlands) of cases. Between 28% (the Netherlands) and 39% (Italy) died in hospital, and between 23% (Belgium) and 46% (Italy, Spain) died at home. In all countries, home was the longest place of residence in the last year of life for the majority of patients. Around one-third of patients had dementia in Belgium, Italy and Spain; in the Netherlands, where nursing home deaths were excluded, 13% had dementia.

Hospital use in the last three months of life

Forty-nine percent of patients who died non-suddenly in the Netherlands, 52% in Spain, 54% in Italy and 56% in Belgium were hospitalised at least once in the last three months of life (Table 8.2). Of these, between 80% (Spain) and 92% (the Netherlands) were admitted once, and between 8% (the Netherlands) and 20% (Spain) were admitted twice. In all countries studied, 0.3% or fewer were admitted three or more times. Twelve percent in the Netherlands, 14% in Belgium, 15% in Italy and 18% in Spain were hospitalised in the last seven days of life.

Table 8.2: Hospital admissions in the last three months of life of people who died non-suddenly

Hospital use in the last three months of life[a]	BE (N=1596)		NL (N=633)		IT (N=1827)		ES (N=735)		p-value
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	
Hospitalised at least once	887	56 (54-58)	301	49 (45-53)	947	54 (52-56)	337	52 (48-56)	<.001[b]
Hospitalised in last 7 days of life	209	14 (12-16)	74	12 (9-15)	255	15 (13-17)	114	18 (15-21)	.01[b]
If hospitalised at least once									
Hospitalised once	735	83 (81-85)	276	92 (89-95)	804	85 (83-87)	269	80 (76-84)	.002[c]
Hospitalised twice	150	17 (15-19)	25	8 (5-11)	141	15 (13-17)	67	20 (16-24)	
Hospitalised three times or more	2	0.2 (0.0)	0	0.0 (0.0)	2	0.2 (0.0)	1	0.3(0.0)	

[a] Missing data: number of hospitalisations (care trajectory incomplete): BE n=22 (1%), NL n=20 (3%), IT n=75 (4%), ES n=91 (n=12%); timing of final hospitalisation if patient died in hospital: n=32 (1.8%). Percentages are rounded and therefore may not add up to 100.

[b] p-value adjusted for country differences in age, gender, cause of death, longest place of residence in the last year of life, presence of dementia, involvement of specialist palliative care.

[c] p-value for difference between countries in 1 vs. 2 or more hospitalisations, adjusted for country differences in age, gender, cause of death, longest place of residence in the last year of life, presence of dementia, involvement of specialist palliative care.

Time pattern for hospitalisations in the last three months of life

Figure 8.1 shows the percentage of patients in hospital at each of the last 90 days of life. This percentage (between 5% and 7% at 90 days before death) increased towards the day of death in all four countries. Over the last 10 days of life, the percentage increased from 24% to 36% in Belgium, from 19% to 28% in the Netherlands, from 21% to 39% in Italy, and from 19% to 37% in Spain.

Hospital use by patients who died in hospital

Between 45% (Spain) and 56% (Italy) of patients who died in hospital were transferred there between the second and fourth week before death (Table 8.3). Between 17% in Italy and 24% in Spain were admitted there one to three days before death. The most common location prior to a hospitalisation during which the patient died was home (for 77% (Belgium), 81% (Spain), 84% (the Netherlands) and 92% (Italy) of patients).

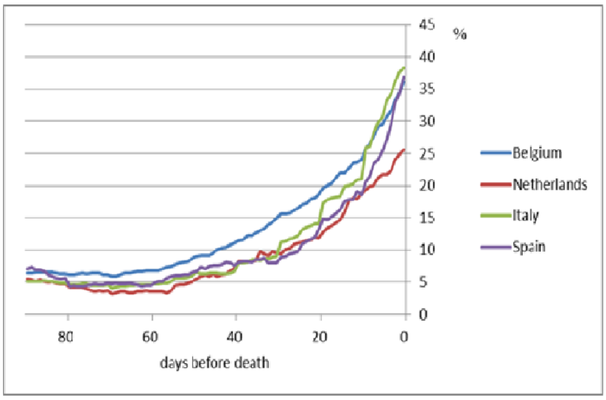

Figure 8.1: Percentage of patients hospitalised at each of the 90 days before death (non-sudden deaths). BE: N=1596; NL: N=633; IT: N=1827; ES: N=735; missing data (care trajectory incomplete): n=208 (4%).

Table 8.3: Hospital admissions in the last three months of life of people who died in hospital non-suddenly

Hospital use of patients who died in hospital[a]	BE (N=580)		NL (N=177)		IT (N=716)		ES (N=274)		
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	p-value
Time of final hospitalisation									
1 to 3 days before death	104	18 (15-21)	34	20 (14-26)	118	17 (14-20)	65	24 (19-29)	<.001
4 to 7 days before death	97	17 (14-20)	35	20 (14-26)	134	19 (16-22)	60	22 (17-27)	
2nd to 4th week before death	277	48 (44-52)	80	46 (39-53)	388	56 (52-60)	122	45 (39-51)	
2nd to 3rd month before death	96	17 (14-20)	24	14 (9-19)	58	8 (6-10)	23	9 (6-12)	
Location prior to final hospitalisation									
Home	447	77 (74-80)	148	84 (79-89)	660	92 (90-94)	222	81 (76-86)	<.001[b]
Care home	103	18 (15-21)	25	14 (9-19)	32	5 (3-7)	17	6 (3-9)	<.001[b]
Palliative care unit/ hospice	3	0.5 (0.0)	0	0.0 (0.0)	3	0.4 (0.0)	2	0.7 (0.0)	[c]

[a] Missing data: number of hospitalisations (care trajectory incomplete): BE n=22 (1%), NL n=20 (3%), IT n=75 (4%), ES n=91 (n=12%); timing of final hospitalisation if patient died in hospital: n=32 (1.8%). Percentages are rounded and therefore may not add up to 100.

[b] p-value adjusted for country differences in age, gender, cause of death, presence of dementia, involvement of specialist palliative care.

[c] No multivariable analysis possible because cell frequencies too low. No bivariate analysis (chi2-test) possible as 50% of cells have expected count less than 5.

Factors associated with hospital admission in the last seven days of life

The multivariable analysis showed that, in all countries except Italy, the probability of a late hospitalisation was lower if the GP was informed of the patient's preferred place of death and if care home (rather than home) was the longest place of residence in the patient's last year of life (Table 8.4). Additionally, the involvement of a multidisciplinary palliative care team in Belgium and the Netherlands, and female gender and six or more contacts with the GP in the last three months of life in Belgium were associated with a lower probability of a late hospitalisation.

Table 8.4: Factors associated with being admitted to hospital in the course of the last seven days of life (non-sudden deaths): multivariable logistic regression analysis

	Odds ratio (95% confidence interval)[ab]							
	BE (N=1449)		NL (N=556)		IT (N=1618)		ES (N=559)	
	OR (95% CI)	n (%)	OR (95% CI)	n (%)	OR (95% CI)	n (%)	OR (95% CI)	n (%)
Age								
18-64	Ref	27 (14)	Ref	9 (9)	Ref	31 (16)	Ref	11 (20)
65-84	1.00 (0.61 to 1.62)	97 (14)	1.43 (0.63 to 3.23)	35 (13)	0.87 (0.56 to 1.37)	116 (15)	1.03 (0.47 to 2.24)	50 (20)
85 or over	1.19 (0.69 to 2.05)	69 (12)	1.15 (0.45 to 2.96)	19 (11)	0.64 (0.39 to 1.05)	83 (13)	0.99 (0.42 to 2.34)	41 (16)
Gender								
male	Ref	108 (17)	Ref	27 (10)	Ref	113 (15)	Ref	65 (21)
female	0.71 (0.51 to 0.99)	85 (11)	1.48 (0.84 to 2.62)	36 (12)	0.92 (0.69 to 1.22)	117 (14)	0.70 (0.43 to 1.12)	37 (15)
Cause of death								
non-cancer	Ref	123 (14)	Ref	39 (16)	Ref	133 (15)	Ref	63 (18)
cancer	1.24 (0.85 to 1.79)	70 (13)	0.61 (0.32 to 1.14)	24 (8)	0.71 (0.51 to 1.00)	97 (13)	0.88 (0.52 to 1.48)	39 (18)
Contact with GP								
less than 6 times	Ref	168 (17)	Ref	43 (18)	Ref	127 (16)	Ref	74 (21)
6 times or more	0.41 (0.26 to 0.66)	25 (6)	0.56 (0.29 to 1.10)	20 (6)	0.81 (0.60 to 1.08)	103 (13)	0.82 (0.50 to 1.36)	28 (14)
Multidisciplinary palliative care involvement								
no	Ref	144 (19)	Ref	56 (14)	Ref	145 (15)	Ref	64 (19)
yes	0.39 (0.27 to 0.56)	49 (7)	0.35 (0.15 to 0.82)	7 (4)	0.98 (0.71 to 1.35)	85 (14)	0.81 (0.50 to 1.32)	38 (17)
GP informed of patient's preferred place of death								
no	Ref	144 (17)	Ref	40 (20)	Ref	164 (15)	Ref	89 (24)
yes	0.52 (0.36 to 0.74)	49 (8)	0.48 (0.25 to 0.91)	23 (7)	0.98 (0.72 to 1.35)	66 (14)	0.24 (0.13 to 0.44)	13 (7)
Longest place of residence in the last year of life								
care home	Ref	41 (8)	Ref	8 (7)	Ref	7 (7)	Ref	4 (6)
at home/with family	1.94 (1.28 to 2.94)	152 (16)	2.61 (1.10 to 6.18)	55 (13)	2.17 (0.98 to 4.79)	223 (15)	4.72 (1.64 to 13.57)	98 (20)

[a] Cases with incomplete trajectories or missing data on one or several independent variables were excluded: BE: n=134 (8%), NL: n=67 (11%), IT: n=100 (5%), ES: n=163 (22%). Abbreviations: OR=odds ratio; CI=confidence interval.

[b] Model statistics for multivariate logistic regression analyses: BE: Nagelkerke R^2=0.13; NL: Nagelkerke R^2=0.15; IT: Nagelkerke R^2=0.02; ES: Nagelkerke R^2=0.13.

8.4 Discussion

In all countries studied, a similar percentage of people were hospitalised once in the last three months of life (around half of all non-sudden deaths) but the percentage of those hospitalised twice or more times was significantly lower in the Netherlands than in the other countries. There was a considerable increase in the probability of being hospitalised over the last 90 days, and particularly the last ten days of life, in all countries studied but overall it remained lowest in the Netherlands. The factors most consistently associated with a lower probability of being hospitalised in the last seven days of life were the GP's knowledge of the patient's preferred place of death and residing in a care home rather than at home.

Research has shown that a large number of people with life-threatening illnesses prefer to and could be cared for in community-settings towards the end of life.(4,28) Yet the results of our study show that all countries we studied face the challenge that large numbers of people are admitted to hospital towards the end of life. A hospitalisation may be unavoidable for a number of reasons, such as sudden exacerbation of symptoms, or low availability of formal home care.(34,35) However, based on the findings of our study and those of previous research, we hypothesise that the way chronic and end-of-life care are organised may stimulate hospitalisations at the end of life.

The percentage of people hospitalised at each of the last 90 days of life was generally lower in the Netherlands than in the other countries. It also remained notably low over the last 10 days of life, while there was a strong increase in the other countries. Despite a similar percentage of people who were hospitalised at least once in all four countries, the percentage of people readmitted to hospital in the Netherlands was only half as high as that in the other countries. It has been suggested that GPs' role as gatekeepers to secondary and tertiary care in the Netherlands may reduce hospitalisations and hospital deaths.(36) However, our cross-national comparison shows that this alone is not a sufficient explanation. In Spain and Italy, where GPs also are gatekeepers, hospitalisation rates are considerably higher than in the Netherlands. It is thus perhaps gatekeeping by GPs who are trained and supported in preventing inappropriate hospitalisations at the end of life, combined with a high level of coordination in primary care,(21) that helps reduce hospitalisations and hospital deaths rather than the gatekeeping system alone. This hypothesis is supported by evidence from qualitative research that suggests that GPs' competence and attitude regarding end-of-life care and support by local specialist palliative care services are important in avoiding hospitalisations at the end of life.(36) It might thus be a combination of structural factors of the health care system (e.g. gatekeeping role, coordination of primary care) and care provision factors (e.g. specialist support) that either drives or curbs these hospitalisations.

Hospitalisations in the last weeks of life may also be influenced by the availability of palliative and long-term care resources. In Belgium and Spain, for instance, many palliative care services are based in hospitals,(37) and another study has shown that GPs in these two countries cited palliative care as the reason for more than one in three terminal hospitalisations (hospital admissions during which the patient died).(38) Our data showed that the involvement of multidisciplinary palliative care teams was associated with fewer late hospitalisations in Belgium and the Netherlands, but this was not so in Italy and Spain. This suggests that specialist palliative care support alone may not be sufficient in preventing late hospitalisations but that it needs additional structures and resources to draw upon, such as long-term care facilities and formal home care, which are less available in Italy and Spain. For instance, Italy has the lowest number of long-term care beds per 1,000 population aged 65 and over among Organisation for Economic Cooperation and Development (OECD) countries, (39) which means that many people are hospitalised when the care provided at home, usually by family carers, is insufficient.(40)

In all countries except Italy, hospitalisations in the last week of life were significantly less likely to occur if the GP knew the patient's preferred place of death. People generally prefer to die at home,(3) hence this result could mean that communication about care preferences may reduce the likelihood of unwanted hospital admissions at the end of life. In all countries except Italy, patients who resided at home were more likely than residents of care homes or nursing homes to be hospitalised in the last week of life. This result highlights the importance for researchers and policy-makers to gain a better understanding of the types and extent of care and support that should be provided to terminally ill people at home and to their family carers, in order to reduce the risk of late hospital admissions.

This study has several strengths. We maximised comparability by applying the same method across all four countries. We were able to study not only whether a patient died in hospital but also the frequency, time and length of hospitalisations and the previous locations of residence in the last three months of life. By selecting non-sudden deaths, we were able to identify a population for whom palliative and end-of-life care was a relevant consideration. However, this study also has limitations. It relies on GPs' retrospective accounts of patients' hospital admissions and other care-related information. Recall bias cannot be ruled out, but it was likely limited as the GPs conducted the registrations on a weekly basis. Furthermore, due to the exclusion of nursing home deaths from the Netherlands, we did not have information from this country on a sample of usually very old patients with complex health problems.

Conclusion

This study found that hospitals were frequently used as locations of care for people nearing the end of life in all four countries studied, and that fewer patients were readmitted to hospital in the Netherlands. Across all countries, the likelihood of being hospitalised increased considerably towards the end of life, but it remained lowest in the Netherlands. Some of these hospitalisations may be unavoidable but our cross-national comparison suggests that care can be organised in a way that reduces the risk of hospitalisations at the end of life and enables people to receive care in their usual living environment in the last phase of life.

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Chapter 9

General discussion

9.1 Summary of main findings

9.1.1 Providers of care at the end of life

This dissertation (Chapter 2) showed that GPs indicated that they provided what they considered to be palliative care to 50% of patients who died non-suddenly in Belgium, 55% in Italy, 62% in the Netherlands, and 65% in Spain. GPs reported that multidisciplinary specialist palliative care teams attended to 47% of patients in Belgium, 29% in the Netherlands, 39% in Italy, and 45% in Spain. In Belgium and Italy, respectively 12% and 11% of those who had specialist palliative care involvement had that from a hospital-based service (1% in the Netherlands and service not available in Spain). Twenty-nine per cent in Spain, 24% in Italy, 16% in Belgium and 17% in the Netherlands received care from a specialist palliative care service for people at home. Specialist palliative care provision in nursing homes was highest in Belgium (16%) and lowest in Spain (5%). In Italy, this service was not available, and in the Netherlands, deaths in nursing homes were excluded from the analysis hence no data can be reported. Seventeen per cent in Spain, 14% in the Netherlands, 11% in Belgium, and 8% in Italy received specialist care in a hospice or palliative care unit. Dying from cancer rather than a non-malignant disease was the patient factor that was most strongly and most consistently (across countries) associated with a higher probability of GPs indicating that they provided palliative care. Similarly, in all countries except the Netherlands, GPs reported that specialist palliative care providers were more often involved in care for cancer patients than for patients with a non-malignant disease.

Another important result of this dissertation is that 55% of bereaved relatives of people who died from cancer reported that their relative received excellent or very good home care from GPs in the last three months of life (Chapter 3). Home care by specialist palliative care providers and district/community/private nurses was judged as excellent or very good by 78% and 68% of bereaved relatives, respectively. Thirty-two per cent rated home care by GPs as good or fair, and 14% judged it poor or very poor.

Our research also showed that GPs in Belgium, the Netherlands, and Spain perceived respectively 28%, 30%, and 35% of family carers of people who died non-suddenly as physically and/or emotionally overburdened in the last three months of the patient's life (Chapter 4). GPs in Italy reported that this was the case for 71% of family carers. The patient's cause of death was not significantly associated with whether GPs described family carers as overburdened. In all countries except Spain, involvement of specialist palliative care in the patient's last three months of life was associated with carers being described as overburdened.

Furthermore, we found that GPs perceived difficulties in covering the costs of care in the last three months of life in 8% of patients who died non-suddenly in Spain, 14% in Belgium, 36% in the Netherlands, and 43% in Italy. GPs were more likely to report difficulties if patients died at home or if they received specialist palliative care than if they died in a hospital or hospice (and care homes in the Netherlands) or if they did not receive specialist palliative care. People who died from cancer in Belgium and Italy were less likely to experience financial problems related to care than patients who died from non-malignant disease.

9.1.2 Place of death

We found that high proportions (60% or more) of people in potential need of palliative care died in hospital in France, the Czech Republic, Hungary, Canada and South Korea (Chapter 5). In the population who died of cancer, we found a similar result (Chapter 6); 60% or more deaths occurred in hospital in the above-mentioned countries and additionally in Spain and in Belgium. The percentage of hospital deaths was relatively low (below 30%) in the Netherlands and New Zealand. In the remaining countries we studied, it was between 38% (USA) and 59% (Wales).

In the population potentially in need of palliative care, a relatively high percentage (40% or more) died at home in Italy and Mexico; this percentage was lower (20% or less) in the Czech Republic, Canada and South Korea. In the other countries, between one-fourth and one-third of people died at home. The percentages of home deaths in the population who died of cancer were similar to those in the population in need of palliative care in all countries, except in the Netherlands where the percentage of home deaths of those with cancer was 12 percentage points higher than that in the palliative care population.

A number of sociodemographic, clinical, and health care supply factors were associated with whether people died in hospital as opposed to at home, both in the cancer population and the population potentially in need of palliative care. We found relatively consistently across countries that married people were more likely than unmarried people to die at home, and that people who died from haematological cancer (rather than a solid tumour) were more likely to die in hospital. However, the countries differed considerably in the direction and strength of the association between home death and cause of death (cancer versus non-cancer) and home death and age.

9.1.3 Place of care

With regard to place of death, between 55% and 60% of people who died non-suddenly in Belgium, the Netherlands, Italy and Spain experienced transitions between care settings in the last three months of life (Chapter 7). Around 10% of patients were transferred in the last three days of life in all countries studied. The most frequently occurring final transition (i.e. transition to the care setting in which the patient died) in all four countries was an admission to hospital. GPs reported that patient wishes were the reason for the final hospital admission in 20%, 21%, 7%, and 4% of patients in Belgium, the Netherlands, Italy, and Spain, respectively. Family wishes were cited in 23%, 8%, 13% and 13% of cases, respectively.

Although the percentage of patients who were hospitalised once in the last three months of life was similar across countries (between 49% and 56%), the Netherlands had a significantly lower percentage of patients hospitalised twice or more times (8% versus between 15% and 20%)(Chapter 8). Between 12% and 18% of patients were hospitalised in the last 7 days of life. The GP's knowledge of the patient's preferred place of death and residing in a care home rather than at home emerged as the factors most consistently associated with a reduced probability of being hospitalised in the last week of life.

9.2 Discussion of main findings

9.2.1 Provision of palliative and end-of-life care by GPs

Chapter 2 of this dissertation showed that GPs are important providers of palliative care in the countries we studied. GPs in Belgium, the Netherlands, Italy and Spain reported that they delivered palliative care to between half and two-thirds of people who died non-suddenly. This is not surprising given that GPs are usually people's first point of contact with health care services in the countries we studied and therefore would likely be among the first clinicians to recognise palliative care needs in patients.

However, it is concerning that GPs indicated that they did not provide palliative care in the last three months of life of around half of patients who died non-suddenly. It is possible that they did provide care that would correspond to the WHO definition of palliative care. However, what our finding shows is that they did not label the care for these patients as palliative care. This is a striking finding considering the fact that these patients had died from serious chronic diseases that indicate a need for palliative care (Rosenwax et al. 2005; Murtagh et al. 2013), and that the GPs reported that these deaths did not occur unexpectedly.

Whether GPs said that they delivered palliative care to patients at the end of life was associated with the disease from which the patient died. GPs were less likely to label the care they provided at the end of life as palliative care if it concerned patients who died from non-malignant disease than if it concerned patients who died from cancer (Chapter 2). This is despite evidence that people with life-threatening diseases other than cancer have a similar symptom burden and psychosocial and spiritual care needs as people with cancer and could thus equally benefit from palliative care (Solano et al. 2006).

This result could be a reflection of the still common, and historically rooted, view that palliative care is mainly an approach for people dying from cancer (Johnson & Fallon 2013). It could also reflect the still widespread assumption that palliative care, even if appropriate for both cancer and non-cancer disease, is applicable mainly in the terminal phase of disease (van Vliet et al. 2015). This approach to palliative care may disadvantage people with non-cancer disease because it requires the identification of a terminal or palliative 'phase' (Johnson & Fallon 2013). A clear terminal phase hardly exists in patients with non-cancer disease because their illness is rarely characterised by a steady progression but rather by a gradual decline in health with intermittent serious exacerbations that may lead to death but that most people will survive and continue functioning on a somewhat lower level than before the crisis (van Vliet et al. 2015). This means that these patients typically experience phases of increased palliative care need that alternate with phases of lower need over longer periods of illness (Johnson & Fallon 2013).

Even if GPs, in principle, recognise the need for palliative care in non-cancer patients, they may not initiate it because of difficulties in identifying a clear phase of deterioration. Furthermore, palliative care policies in many countries explicitly or implicitly uphold this 'phase-based' approach, for instance, by requiring physicians to confirm that a patient has a certain (limited) expected survival so she or he can be eligible for reimbursement for certain health care services (such as the 'palliatif forfait' in Belgium) (Federale Evaluatiecel Palliatieve Zorg 2014). A solution to this problem, and a potential way to improve access to palliative care for patients with non-malignant diseases, could be to move away from 'phase-based' towards needs-based approaches, according to which palliative care is offered to patients whenever needs arise throughout the course of disease.

Our finding that GPs are less likely to state that they provided palliative care to patients with non-malignant diseases than to patients with cancer may also be a reflection of GPs' knowledge and attitudes. As a result of the historical association of palliative care with terminal cancer care, GPs may tend to label care aimed at relieving symptoms and improving quality of life as palliative care when it is delivered to cancer patients but not when it concerns care that is delivered to non-cancer patients. In the latter case they may call it 'usual' GP care or simply 'good' care (Johnson & Fallon 2013).

Even if differences in terminology could explain the difference between cancer and non-cancer patients in receiving palliative care from GPs, this carries potentially problematic implications. This would mean that GPs follow a definition of palliative care that is too narrow, and this in turn might impact on the care they provide to patients. A definition of palliative care that is limited to the cancer domain might, for instance, make GPs less likely to recommend non-cancer patients for health and social care benefits that are based on patients being given a formal 'palliative' status. It might also hamper GPs' adherence to palliative care guidelines for patients with non-malignant disease because they may not perceive them as applicable to these patients. Therefore, it is not sufficient that GPs deliver care aimed at alleviating symptoms to patients in need of it. It is also important that, next to delivering it, GPs also perceive and label this care as palliative care if it meets the WHO definition of palliative care, regardless of the patient's diagnosis in order to ensure that patients with palliative care needs receive the health and social services that can meet their needs.

9.2.2 Satisfaction with home care provided by GPs

We found that just over half of bereaved relatives in London, UK, judged the home care provided by GPs to people with cancer in the last three months of life as excellent or very good (Chapter 3). One-third judged it good or fair, and one in seven judged it poor or very poor. District, community and private nurses and specialist palliative care providers were rated considerably better.

The relatively poorer ratings for GP-provided home care are a surprising finding particularly in the British context. The UK has developed, and is implementing, policy measures that aim to strengthen GPs' role in palliative care in community settings. For instance, the Gold Standards Framework is a programme that was first developed to improve the quality of end-of-life care in general practice and has since also been implemented in other settings, such as hospitals and nursing homes, and is included in the UK End-of-Life Care Strategy (Anon n.d.; Department of Health 2008). Our finding shows that even in a country with a relatively long tradition in palliative care, a strong primary care system (Kringos et al. 2015), and strategies promoting generalist end-of-life care in community settings, there is considerable room for improvement in the satisfaction with home care provided by GPs.

Evidence from previous research provides potential explanations for this finding. Palliative care is a demanding task for health care professionals due to the intensity of care and its medical complexity (Dahlhaus et al. 2013). GPs state that they want to be involved in palliative care and that it is a central part of their role (Burt et al. 2006), but evidence from research suggests that the willingness of many GPs to provide palliative care may be compromised by insufficient skills (Mitchell 2002) and lack of awareness of palliative care services from which they could draw support, such as out-of-hours district nursing and specialist palliative care services (Burt et al. 2006). Medical curricula and ongoing education programmes in many countries often do not address palliative care to an extent that would reflect the need for palliative care in the population (Pype et al. 2012; Magee & Koffman 2015). Limited knowledge and experience in caring for patients with palliative care needs was not only determined by others; GPs themselves reported that they had little confidence in their own ability in managing situations such as assessing palliative care emergencies and symptom management in patients with non-malignant diseases (Magee & Koffman 2015).

It seems only logical that GPs cannot have the same level of knowledge and expertise in palliative care as specialist palliative care providers, given that they are responsible for treating a wide range of other patients and health problems next to caring for people with incurable diseases. One could therefore expect that patients and their relatives will rate the home end-of-life care by specialist teams more highly than that by GPs. One can similarly assume that district, community or private nurses (or equivalents of these professions in other countries) will receive better satisfaction ratings for home care than GPs, particularly among patients who wish to receive end-of-life care at home, because, at least in the UK, these nurses' main expertise lies in providing home care to people with chronic care needs (National Health Service 2015). Therefore, a model of end-of-life care provision in which generalists, such as GPs, collaborate with other health professions, such as palliative care specialists, could help to better meet patients' and families' needs. Such a model is outlined in section 9.4.2.

9.2.3 Differences among countries in GP-provided palliative care

The cross-national analyses of GP-provided palliative care in Belgium, the Netherlands, Italy, and Spain (Chapter 2) revealed very few differences between these countries. The percentage of patients who died non-suddenly and to whom GPs delivered palliative care ranged from 50% in Belgium to 65% in Spain. Although the differences between the percentages were statistically significant they were not as large as those between the percentages of patients who received specialist palliative care. There were also hardly any differences among countries in the factors associated with whether GPs stated that they provided palliative care to their patients.

Perhaps these four countries did not differ much with regard to GP-provided palliative care because their primary care systems are relatively similar with regard to several structural indicators (see section 1.1.4) (Kringos et al. 2015) All four countries have similar levels of access to and continuity of primary care. They differ in terms of coordination of primary care, with the Netherlands having the highest level of coordination of these four countries and Belgium the lowest, but this did not seem to have impacted substantially on whether GPs reported in our study that they delivered palliative care.

9.2.4 Use of specialist palliative care

We found relatively large differences between Belgium, the Netherlands, Italy, and Spain in the involvement of specialist palliative care providers in different care settings (Chapter 2). These differences may, at least partly, reflect the differences in national policies and consequently in the availability of specialist palliative care services in the different care settings. For instance, Belgian law requires all hospitals to have mobile palliative care teams and all nursing homes to have a specialised palliative care "reference person" who support, educate and raise awareness of palliative care issues among the hospital or nursing home staff (Federale Evaluatiecel Palliatieve Zorg 2014). This may explain the relatively high utilisation of specialist palliative care in these settings in Belgium. There is hardly any specialist palliative care provision in nursing homes in Italy and Spain, and this is also reflected in our results. On the other hand, specialist palliative care provision in Italy and Spain appears to have a strong focus on the home setting as judged by the percentage of patients who received care from specialised palliative home care teams. This may be explained by the fact that countries with large rural populations, such as Italy and Spain, need to focus on home-based specialist palliative care provision that can reach patients in rural regions for whom it is often difficult to reach hospitals or outpatient facilities.

Lower use of specialist palliative care in a country or care setting does not necessarily indicate unmet need. In the countries we studied, specialist palliative care providers are meant to support and supplement the care provided by the patient's regular health care providers, for instance those in primary care. Patients who did not have specialist support may still have received palliative care from their GP and other caregivers. For instance, while the Netherlands had the lowest percentage of patients with specialist palliative care involvement, they had the highest percentage of patients to whom the GPs indicated they had provided palliative care (Chapter 2).

However, there is reason to assume that at least some of the patients who did not receive specialist palliative care may have had unmet palliative care needs. Previous research has found that palliative care by GPs is less than optimal in several countries. Many GPs in the Netherlands reported obstacles to providing palliative care that are related to bureaucratic procedures, time constraints in arranging home care, and difficulties surrounding the need for obtaining extra care (Groot et al, 2007). A study from Belgium reported that GPs do not routinely assess non-acute care needs among incurably ill patients and pay attention to palliative care needs only rather late, when patients are in the terminal phase of illness (Beernaert et al, 2014).

Furthermore, many people have very complex care needs towards the end of life that overstrain the skills of regular caregivers and that require the additional input of specialist palliative care teams. GPs were shown to deliver good palliative care when they can draw on support from specialist palliative care services (Mitchell 2002). These findings highlight that there is a need for a model of palliative care provision in which GPs and specialist providers collaborate. A suggestion for a model that could be implemented on country levels is provided in section 9.4.2.

9.2.5 Physical, emotional and financial burden on family carers of people at the end of life

Overburden in family carers of people nearing the end of life

We found that GPs in Belgium, the Netherlands, Italy and Spain, judged many family carers as physically or emotionally overburdened (Chapter 4). At 71%, the percentage of overburdened carers was particularly high in Italy, while it amounted to around one-third in the other countries. This suggests that family carers may not be adequately supported in their role as providers of care at the end of life.

Family carers of terminally ill people need support with, amongst others, obtaining information (e.g. regarding symptoms, treatments, disease prognosis), basic as well as complex care-related tasks (e.g. administering medication, helping their dependent relative with activities of daily living, planning and coordinating care), addressing their relative's psychosocial problems and spiritual concerns, and often covering the direct and indirect financial costs of care. This means that patients and family carers often coexist in complex interpersonal, health and welfare circumstances (Morbey & Payne 2015). It is therefore not surprising that the GPs in the countries studied described a considerable number of family carers as overburdened.

However, it is striking that the extent of overburden was so much higher in Italy than in the other countries. Several aspects of the Italian health and long-term care system may have contributed to this. Italy is among the top five OECD countries with regard to the percentage of family carers who provide care daily (74%; OECD average is 66%) (OECD 2013a). However, this percentage was even higher in Spain (85%), hence this factor alone cannot explain the extent of overburden in Italy. However, the high percentage of family carers providing daily care in Italy coincides with a very low share of paid long-term care workers per population aged 65 and over (1.1%) which is considerably lower than in Spain (4.3%) and the lowest among OECD countries (OECD average is 6.8%) (OECD 2013a). Furthermore, Italy has the lowest number of long-term care beds (OECD 2013a) which likely means that more people need to remain at home towards the end of their lives and hence depend on family carers.

We did not find a statistically significant difference in burden between family carers of people who died of cancer and those of people who died of non-malignant diseases in any of the countries studied. This finding is consistent with previous research that showed that the level of perceived symptom severity, but not the patients' diagnosis, was associated with whether family carers reported that they had enough support (McNamara & Rosenwax 2010).

Palliative care aims to improve the quality of life of patients and their families (WHO 2002; European Association for Palliative Care 2010). We found an association between specialist palliative care involvement and overburden in family carers, which was most likely mediated by the patient's functional status towards the end of life which we could not control for in the analysis. The evidence on whether palliative care provision is associated with a lower risk of overburden in family carers is conflicting. A phase II randomised controlled trial of a short-term specialist palliative care intervention for patients with multiple sclerosis in the UK showed improvement in caregiver burden following the intervention (Higginson et al. 2009). However a larger phase III randomised controlled trial of a palliative care intervention for family carers of patients with advanced cancer found no significant effect on carers' quality of life or burden, but it did find a significant effect on depression in carers (Dionne-Odom et al. 2015). These conflicting findings lead to the question, and should prompt further research on whether palliative care, as it is currently provided, has the effect on families that it aims to have, i.e. to support them in caring for their ill family members and to improve their quality of life (WHO 2002).

It has become clear from previous research that interventions for family carers should not be seen as separate from those for patients because family carers' well-being is related to that of their relatives. A study among carers attending home palliative care services reported that patients' psychological distress and pain were associated with worse carer psychological morbidity and with carer burden (Harding et al. 2003). This suggests that to address the unmet needs of carers, services must meet the needs of patients for symptom control and psychosocial support, both of which are essential tasks of palliative care. Any evidence-based interventions for carers must therefore occur in the context of optimal pain and symptom control for patients

(Harding et al. 2003).

Difficulties in covering the costs of care

According to the GPs' reports in our study, difficulties for patients and families in covering the financial costs of care in the last three months of life were particularly high in the Netherlands and in Italy, and lower in Belgium and in Spain (Chapter 4). The financial costs for caring for a relative at the end of life are typically caused by costs related to changes in the carer's employment, out-of-pocket costs for care or equipment, and costs related to the time invested by carers (Gardiner, Brereton, et al. 2014). The four countries we studied differ with regard to the extent of the financial support patients or family carers can receive to pay for formal care, to cover the costs of equipment, or to compensate family carers for loss of work-related income (Riedel & Kraus 2011). Belgium and Spain offer benefits to both family carers and care recipients, whereas the Netherlands and Italy offer benefits to care recipients only.

It is striking that the two countries that offer benefits to care recipients only were also the ones with the highest percentage of patients and families who, GPs said, had difficulties in covering the costs of care. We acknowledge that a "sample" of four countries is too small to draw any firm conclusions about a relationship between the provision of benefits for family carers and financial burden. But this observation points to a potential hypothesis that should be investigated in future research.

Furthermore, it was only in these two countries that we found a significant association between care-related financial burden and place of death, and between financial burden and involvement of specialist palliative care services. Financial burden was higher for those who received specialist palliative care in the last three months of life than for those who did not, and it was highest for those who died at home as compared to other locations. Although it is not possible to conclude from our study what the precise relationship is between involvement of specialist palliative care and increased financial burden on patients and families, this finding raises concerns regarding the accessibility of palliative care in the Netherlands and Italy. Palliative care, as it is envisioned by various international associations of palliative care, should be a low-threshold, easily accessible health service (Radbruch et al. 2013). Easy access to health services implies that there are, amongst others, no financial barriers (Kringos et al. 2015). The fact that involvement of specialist palliative care is associated with a higher probability of difficulties in covering the costs of care suggests that in these two countries access to specialist palliative care may not be optimal.

The association between dying at home and difficulties in covering the costs of care is another important finding in the Netherlands and Italy. This may suggest that dying at home, although less costly for health care systems than deaths in institutions, may instead impose financial burden on patients and families. This is important to consider in current policy environments in many high-income countries that prioritise deaths at home.

Another important finding of this study is that the probability of care-related financial burden in Belgium was higher for patients who died from a non-cancer disease than for those who died from cancer. This might be related to the fact that to receive the Belgian cash benefit for palliative care (”palliatief forfait”), a physician must confirm that the patient is not expected to live longer than three months. As is explained in section 9.2.1, when a patient will die is generally difficult to estimate for physicians, but it is particularly difficult for patients with non-cancer diseases that are characterised by a fluctuating and therefore less predictable deterioration until death. Patients dying from diseases other than cancer may therefore be less likely to receive this cash benefit. It is possible that, without the ”palliative status” that entitles patients to the cash benefit and a waiver of out-of-pocket payments, terminally ill patients and families may experience a high impact on their financial situation. This possible explanation illustrates the potential for adverse consequences of ”phased-based” approaches to palliative care that require the identification of a terminal phase or a limited life expectancy for patients to be eligible for health services or benefits. This was explained in more detail in section 9.2.1.

9.2.6 Place of death

Hospital as place of death

We found in France, the Czech Republic, Hungary, Spain, Belgium, Canada, and South Korea that relatively high percentages of people (60% or more) died in hospital (Chapters 5 and 6). This applied both to the population who died from diseases indicating palliative care need and to the specific population who died from cancer.

Research suggests that there are patients who receive good end-of-life care in hospitals and for whom a hospital is the location in which they prefer to die (Reyniers et al. 2014a; Howell et al. 2013). However, there is reason to assume that the needs of a large number of people who die in hospital are not met and that the goal of dying without suffering is not achieved in hospitals in many countries (Beccaro et al. 2010; Middlewood et al. 2001; Teno et al. 2004; Seah et al. 2005; Becker et al. 2007). Prospective data showed that people who died in hospital had a worse quality of life compared to those who died at home, and that their bereaved relatives were at increased risk for psychiatric problems (Wright et al. 2010). People who died in hospital were affected by aggressive treatments at the end of life, overuse of technical interventions, poor communication between professionals, patients, and families and insufficient discussion about treatments and care (Willard & Luker 2006; Reyniers et al. 2014a; Beccaro et al. 2010). Many experienced untreated or poorly treated physical symptoms (Beccaro et al. 2010). The fact that end-of-life care in hospitals is less than optimal in many countries is likely rooted in a lack of appropriate policies for end-of-life care in hospitals or in an inadequate implementation of existing policies. Hospitals are ill-equipped for caring for people with the complex and progressive health problems that characterise terminal illness. This is due to their set-up as places for acute care where treatment focuses on isolated health problems rather than a holistic view of the patient and their specific needs in their particular living circumstances. Another reason why hospitals may not be optimal places to die is that, in some countries, there are too few palliative care staff to meet the needs of the growing number of people who die there, as suggested by a study from the USA (Lupu 2010). However, most likely this differs between countries, as in some places, such as Belgium, specialist palliative care provision is very much centred in the hospital setting (Federale Evaluatiecel Palliatieve Zorg 2014).

People in all countries studied, except Mexico, where no significant relationship was found, were less likely to die in hospital if they were married (rather than unmarried, widowed or divorced). The fact that we found this in a large number of countries provides support for our claim in the introduction of this dissertation (section 1.1.2) that the availability of family carers is an important factor in enabling people to die at home.

We found less consistent associations across countries between home death and cause of death (cancer versus non-cancer) and home death and age. People who died of cancer were more likely than people who died of a non-malignant disease to die in hospital in France, Spain, Belgium, the Czech Republic and South Korea, whereas the opposite was true in the other countries studied in Chapters 5 and 6. People younger than 80 years at the time of death were more likely than older people to have died in hospital in France, Italy, Spain, Belgium, the Netherlands, the USA, Mexico, and South Korea. In the other countries, younger people were more likely to have died at home (no significant association in the Czech Republic). This variation among countries shows that where people die is not determined by diagnosis or medical necessity (e.g., a particular diagnosis requiring treatment in a particular setting) nor by patient characteristics alone, but also by other circumstances that may modify the effect of clinical and sociodemographic factors. We found that a higher density of hospital beds and an urban living environment increased the probability of dying in hospital. However, there were also other factors that were associated with dying in hospital which we were not able to assess in our study. This could be, for instance, a patient's preference for where they want to die as well as environmental factors such as intensity of home care and social support (Gomes & Higginson 2006; Henson et al. 2015). Macrosocial aspects, such as historical trends in how countries organised end-of-life care likely also play a role in where people die (Gomes & Higginson 2006).

Home as place of death

In most countries, fewer people died at home than in hospital, both in the population potentially in need of palliative care and in the population who died from cancer (Chapters 5 and 6). In the population potentially in need of palliative care, the exceptions are the Netherlands, New Zealand, the USA, and Mexico where more people died at home than in hospital. In the cancer population subset, it was only the Netherlands and Mexico where more people die at home.

When interpreting these results, we must be careful not to assume that those who died at home had their needs and preferences met and received good care in the context of stable family relationships until they died (Exley & Allen 2007). Even if patients who died at home were in their preferred location, we cannot conclude that this was also what family carers preferred and that their perspective on their relative's dying experience was a positive one. The research in this thesis (Chapter 4) showed that in some countries, dying at home may be associated with higher physical, emotional and financial burden in family carers. Many in the field of palliative care perceive death at home as synonymous with a good death because it is thought to correspond to patents' and families' preferences and enable patients to be cared for in a context of intimate social relationships. However, Exley and Allen have shown in their work that the relocation of care work and medical paraphernalia from hospital to home can fundamentally change the meaning of the domestic realm as well as the quality and intimacy of social relationships within the family (Exley & Allen 2007). It is therefore important, in the absence of patient- and family-level outcomes, to view our findings as the descriptive data they are and not to interpret death at home as a somehow more ’positive’ outcome than death in hospital.

We found that several sociodemographic, clinical, and health care supply characteristics were associated with dying at home rather than in other locations (a discussion of some of these factors can be found in the previous section) We found in all countries we studied that individuals who died from a solid tumour rather than a haematological malignancy were more likely to die at home than in other locations. This is a remarkable finding as it suggests that, unlike in the cancer versus non-cancer comparison, there may be a disease-related factor that makes patients more or less likely to die in certain locations across different countries and health care systems.

One such reason could be that the possible complicating factors in haematological cancer, including anaemia, bleeding, and infection may require ongoing transfusion of blood products, and antibiotic and antifungal medication, which makes long-term hospitalisation necessary (Howell 2010). Therefore, patients with haematological cancer likely are a group that may greatly benefit from care in inpatient palliative care units. However, lack of inpatient palliative care units for these patients was one of the barriers for receiving palliative care highlighted by haematologists in qualitative research (Wright & Forbes 2014).

The course of disease and hence the transition from curative to palliative care in haematological cancer has been described as less clear than for other types of cancer, and death often occurs unexpectedly or very rapidly after diagnosis (Howell et al. 2010). Less time between diagnosis and death was associated with hospital death among patients with haematological cancer (Howell et al. 2013). This could mean that physicians and families, from the moment they notice a marked deterioration in a patient, do not have sufficient time to make arrangements for the patient to receive palliative care outside the hospital. Researchers have also pointed out that patients with haematological cancer are often managed within haematology throughout the entire course of their illness, including the terminal phase, and establish long-standing relationships with the physicians working there, and thus may prefer to be cared for in hospital until they die (Howell et al. 2013). Furthermore, the fact that haematologists, at least in the UK, have poor links with palliative care teams, may be a barrier to accessing community services at home and hospice facilities for these patients (Boyce et al. 2003).

9.2.7 The potential role of policy in where people die

We identified several disease-related, sociodemographic, and health care supply factors that may influence where people die (Chapters 5 and 6). However, these variables explained only a relatively low percentage of the variation in place of death among countries. We hypothesise that part of this remaining variation can be attributed to national policies and strategies regarding health and social care in general and palliative and end-of-life care in particular.

This assumption rests upon two observations. First, a systematic review of factors associated with home death in people with cancer found that where people die is associated with environmental factors such as health care input (e.g. use and intensity of home care) and social support (Gomes & Higginson 2006). In our analysis, it was not possible to include several factors that this review identified as important because they were neither available from death certificates nor through linkage with other databases. It is therefore likely that differences among countries in these factors contributed to the variation in place of death. Second, we observed that the patterns in place of death in certain countries could potentially be explained by these countries' policies on palliative and end-of-life care. For instance, we found a relatively high percentage of deaths in hospital in the Czech Republic, a country where home palliative care services are not recognised in the health insurance law, and therefore many patients are hospitalised as they become very ill and dependent (Slama et al. 2013).

There are many aspects of policy that can influence where people die in a country. The term policy refers not to a single recommendation, program or strategy but rather to a complex system of principles adopted by governments or organisations that guide decisions and actions to achieve certain outcomes. The policies that may influence where people die are formulated on several levels (e.g., on the political, economic, health or social system level, or the level of single health care providers), and it is likely an interaction of policies on these different levels that determines where people die. It is beyond the scope of a single dissertation to give an exhaustive description of potentially relevant factors on the policy level. However, our findings regarding cross-national differences and the factors associated with place of death could, in the future, guide a more focused search for the policy factors that influence where people die. This could be done, for instance by conducting comparative case study analyses of countries that are purposefully selected based on the contextual factors that our research has shown to be associated with place of death.

9.2.8 Place of care

Transitions between care settings

The overall percentage of people who experienced transitions in the last three months of life was rather high. Organising good end-of-life care takes a certain amount of time and continuity in care processes because it requires comprehensive and continuous assessment of physical, psychosocial, and spiritual needs, patients' and families' resources and preferences for care, and sufficient time to meet these needs and preferences. Research has shown that this may be difficult to achieve when patients change care settings towards the end of life, mainly due to a lack of appropriate procedures for information transfer between care providers (Coleman 2003; Kripalani et al. 2007). Practitioners in different care settings often act independently and without knowledge of the information obtained, services provided or preferences expressed in other settings (Coleman & Boult 2003). In addition to potentially counteracting patients' preference for continuity in end-of-life care (Michiels et al. 2007), transitions can also pose risks to patient safety if essential elements of the patient's care plan that were developed in one care setting (e.g. medication regimens, follow-up appointments, diagnostic tests) are not communicated to the team in the next setting (Coleman, 2003; Kripalani et al, 2007). These risks were formulated particularly with regard to one specific type of transition at the end of life, which is the admission to hospital. The following section discusses our findings on hospitalisations at the end of life.

Hospitalisations at the end of life

We found that a considerable number of people who died non-suddenly were hospitalised in the last three months of life. Repeated hospitalisations have been referred to as an indicator of poor and overly aggressive end-of-life care (Earle et al. 2008), they often do not align with patients' preferences for where to receive care (Wilson et al. 2013), and they may constitute an inappropriate use of health care resources that are meant for acute care. Specifically, the number of late hospitalisations (in the last week of life) is concerning; these were more likely to occur for patients residing at home than for patients residing in a care home. Research suggests that many patients are hospitalised shortly before death because clinical problems arise that cannot be managed well in primary care (Reyniers et al. 2014). The findings of our study are important in the context of current policy environments in many high-income countries that favour deinstitutionalisation and community-based end of life care. They suggest that efforts to reduce hospitalisations at the end of life should be accompanied by assessment of and, if needed, improvement of the quality of home care and primary care for people nearing the end of life.

In Belgium and the Netherlands, we found that one-fifth of final hospitalisations were driven by patients' wishes. Hospitalisations that occurred at the wish of family members were found in one-fifth of cases in Belgium as opposed to 8% in the Netherlands. This suggests that, even if patients would generally prefer to remain at home until death (Gomes et al. 2013), hospitalisations sometimes occur at their request. In some cases this might be a wish to die in hospital. But in other cases it might rather be a wish to receive life-prolonging treatment or other care that patients believe they cannot receive at home. Some patients and families may also wish to go to hospital because better symptom control is available there (Gott et al. 2013). In Italy and Spain, however, we found that relatively few final hospitalisations occurred at the patient's wish, and more at the family's wish. One possible explanation for this is that family carers initiate hospitalisations when they are overburdened with care because both Italy and Spain have fewer long-term care beds and a lower availability of formal home care than Belgium and the Netherlands (OECD 2013a; Genet et al. 2012).

Previous research has shown that whether hospitalisations can be avoided or not depends to a large extent on the configuration and availability of health and social care services for community-dwelling people nearing the end of life (Gott et al. 2013). Although most hospital admissions in palliative care are not strictly medically indicated (Hjermstad et al. 2013) they can become unavoidable if, for instance, home care structures are not well developed or if informal carers are overburdened or not available (Reyniers et al. 2014b). Correspondingly, the configuration of primary care services in the Netherlands might have played a role in the relatively low number of hospitalisations, and particularly readmissions to hospital, that we found there. Palliative care in the Netherlands is, more strongly than in the other three countries, defined as a generalist health care service that is mainly provided through primary care and in community settings (Centeno et al. 2013). This policy, combined with a strong primary care system (Kringos et al. 2015) may help to avoid many hospitalisations.

9.3 Strengths and limitations

This dissertation is based on data from two different mortality follow-back studies, the EURO-SENTIMELC and the QUALYCARE studies, and a study of death certificates, the International Place of Death study. The methods of all three studies have strengths and limitations. First, I will address the general strengths and limitations of retrospective study designs in end-of-life care, which concern all three studies, and subsequently outline the more specific strengths and limitations of each study.

9.3.1 Strengths and limitations of retrospective studies in end-of-life care

The data used in this dissertation were obtained through retrospective studies of the care patients received in the weeks and months leading up to death. This is a commonly applied study design that has led to important insights in end-of-life care (Gomes et al. 2010; Costantini et al. 2005; Hunt et al. 2014; Chambaere et al. 2008). A retrospective approach allows researchers to study population-based samples of patients nearing the end of life rather than non-randomly selected subsets defined by a disease characteristic (e.g. diagnosis of metastatic cancer), care setting (e.g. enrolled in a palliative care service) or specific event that identifies them as dying (e.g. assignment of a formal "palliative status"). Another advantage of retrospective designs is that they allow the same period prior to death to be studied for all patients. This is important when examining aspects of care for which time is a relevant factor such as the time of initiation of palliative care prior to death or the frequency of transitions between care settings in a particular period prior to death. These are important advantages over prospective designs which pose the risk of not identifying individuals who are dying because physicians tend to overestimate patients' expected survival or identifying only those patients who are in receipt of health care services.

Our retrospective studies also have limitations. As the data are cross-sectional it is not possible to make conclusions regarding causal relationships based on statistical association. Bach and colleagues argued that by analysing retrospectively the care that decedents received prior to death, one might inadvertently study time periods prior to diagnosis during which end-of-life care was not a relevant consideration or identify decedents who differ in key disease- and care-related characteristics from samples of prospectively identified patients (Bach et al. 2004). Much of these authors' criticism is based on the assumption that retrospective studies examine the last year of life and may therefore capture "healthy" periods prior to diagnosis. However, in our retrospective studies of end-of-life care, we studied the last three months of life of people with life-threatening chronic diseases which is a period considerably closer to death during which these patients were most likely ill. Additionally, the selection of non-sudden deaths in the EURO-SENTIMELC study makes it very likely that the care we examined was delivered in the context of dying.

9.3.2 EURO-SENTIMELC

EURO-SENTIMELC (European Sentinel Networks Monitoring End-of-Life Care) is a retrospective study for which GPs belonging to Sentinel Networks (epidemiological surveillance networks) in Belgium, the Netherlands, Italy, and Spain weekly registered the deaths of patients of their practice. Through this study we were able to collect cross-national, population-based epidemiological data on an extensive number of topics that go beyond what is usually recorded in routine databases such as death certificates, hospital records or GPs' medical files. This is, to the best of our knowledge, the first, and so far only, study that examined a range of end-of-life topics through population-based data in multiple countries.

The main strengths of this study include the high participation rate among GPs, the representativeness of the GPs in the Sentinel Networks for all GPs in the respective countries in terms of age, sex and geographical distribution, and the representativeness of the samples of non-sudden deaths obtained through the networks. In all four countries studied, GPs are suitable observational units for health topics, including end-of-life care, given that the vast majority of the population in these countries have a regular GP. GPs are usually well informed about the care received by their patients, either because they have a formal coordinating (gatekeeping) role in the health care system such as in the Netherlands, Spain and Italy, or because they are regularly visited by patients and receive reports on their care from specialists and hospital physicians, as is the case in Belgium (Gerkens & Merkur 2010; Garca-Armesto et al. 2010; Ferré et al. 2014; Schäfer et al. 2010).

The reliability and validity of the data obtained was maximised by the fact that the data collection was embedded in the standard operating procedures of Sentinel Networks with a long-standing involvement in epidemiological research. Their procedures include several quality assurance measures (e.g. weekly registrations to reduce recall bias, follow-up with GPs to reduce missing or inconsistent data, exclusion of GPs who do not report regularly, i.e. for at least 26 weeks per year) (Van den Block et al. 2013). The Italian network was not a long-standing network but was established specifically for this study. Therefore, care was taken to employ registration procedures that were comparable to those of the established networks and not to recruit GPs based on a particular interest in palliative care. As the GPs were not selected specifically for end-of-life care research their experience with end-of-life care is likely to be representative for that in the whole population of GPs. Finally, by using the same method across different countries, this study made it possible to conduct valid comparisons of end-of-life care among these countries. Previous studies have shown that Sentinel Networks of GPs can provide reliable and valid epidemiological data in general (Fleming et al. 2003; Vega et al. 2006; Deckers & Schellavis 2004) and on end-of-life care in particular, both in single countries and cross-nationally (Meeussen et al. 2011b; Van den Block et al. 2007; Abarshi et al. 2010).

The main limitation of the EURO-SENTIMELC study is its reliance on GPs to report on the care provided by themselves and by other care providers to patients at the end of life. The GPs' reports may be affected by recall bias and by the fact that they may have missed certain aspects of the care that patients received while hospitalised. We tried to mitigate this problem by instructing GPs to register deaths on a weekly basis and to include any relevant information from reports they received from clinical specialists or hospital physicians. The validity and reliability of the GPs' reports may also have been affected by self-assessment bias and the quality of the medical records from which they derived care-related information (O'Sullivan 2011). Furthermore, GPs' reports of whether they provided palliative care to a patient and whether patients and families were physically or emotionally overburdened or had difficulties in covering the costs of care were inevitably influenced by the GPs' perception and interpretation.

Although the GPs of the Sentinel Networks were representative for the GPs in the countries studied in terms of age, sex, and geographic region (Van den Block et al. 2013), we cannot exclude the possibility that bias was introduced by a potentially stronger scientific interest or conscientiousness among the GPs who conduct epidemiological monitoring. However, this would not be different in one-off surveys that would have the additional limitation that GPs may participate based on a particular interest in end-of-life care, which was prevented in our study. The deaths identified through the EURO-SENTIMELC study were not perfectly representative of the total population. GPs reported a lower number of sudden hospital deaths in all countries as well as non-sudden hospital deaths and deaths of people under 65 years in Belgium (Van den Block et al. 2013). Finally, as we needed to exclude nursing home deaths in the Netherlands, we did not have data from this country on a group of individuals who are typically very old and have complex care needs (Francke 2003).

9.3.3 QUALYCARE

QUALYCARE is a retrospective study that surveyed bereaved relatives of people who died from cancer to study the care they received in the last three months of life (Gomes et al. 2010). In addition to the general strengths of retrospective studies in end-of-life care (section 4.3.1), this study has several specific strengths. The respondents (i.e. bereaved relatives) were sampled through death certificates which meant that we could study the end-of-life care of a population-based sample of people who died from cancer. Bereaved relatives are a valuable source of information on end-of-life care because they usually spend much time around the patient and experience various aspects of the care delivered to them. With this study, we were therefore able to obtain information on end-of-life care that is more in-depth than the information from routinely collected data. Research has shown that there is adequate agreement between bereaved relatives' and patients' evaluations of services (McPherson & Addington-Hall 2003).

The main limitations of the QUALYCARE data concern the relatively low response rate and challenges around measuring satisfaction with health care services. With a response rate of 39% there is potential for non-response bias. An analysis of non-responders suggested that this survey better represents the experiences of patients who died at home rather than in hospital, older patients and those for whom the respondents were women and spouses/partners or parents. The fact that patients who died at home were better represented than those who died in hospital may have led to an overestimation of satisfaction ratings given that hospital death was associated with lower satisfaction ratings in our analysis.

One important limitation of measuring satisfaction with care is that satisfaction is a subjective concept and dependent on people's personal standards of care which can vary both between respondents and within respondents over time (Crow et al. 2002; Aspinal & AddingtonHall 2003; Carr-Hill 1992). Satisfaction is also a multi-dimensional concept that is based on an evaluation of varied features of the experience with the health care service (Crow et al. 2002). It is therefore difficult to determine which particular aspects of care were not optimal if patients or relatives were not highly satisfied. However, it appears that satisfaction measures are sensitive to differences in experiences, given that studies have shown variation in satisfaction ratings between different sources of care (Lecouturier et al. 1999). We assessed several variables that could have influenced satisfaction with care (e.g. bereavement-related emotions, respondents' socio-demographic characteristics), but the study did not collect all relevant variables such as, for instance, expectations regarding care. As is true for all retrospective studies, this study may have been affected by recall bias, but we did not find differences in satisfaction ratings in function of the time between the patient's death and the moment when relatives completed the questionnaire.

9.3.4 International Study of Place of Death

The International Place of Death (IPoD) study examined all death certificates of one year in nine European and five non-European countries to study the place of death in these populations. This is, to the best of our knowledge, the largest cross-national study of place of death. The data collected through this study are population-level data and therefore not subject to potential bias through sampling. The large number of cases provides sufficient statistical power for studying sub-populations and for conducting tests of association with a large number of independent variables. We obtained comparable data across the countries studied as they have similar death registration procedures and information on the death certificates.

The limitations of studies of death certificates are mainly related to the fact that they are administrative rather than research tools (Cohen et al. 2007). Researchers have reported inaccuracies in cause of death records on death certificates (O'Sullivan 2011), which is relevant for the analyses in this dissertation because we selected the populations of interest based on the cause of death. However, we have likely mitigated this problem by using aggregated categories of cause of death. Furthermore, the place of death categories on death certificates are not uniform across countries. This highlights the need for a more complete registration and better standardisation of place of death records across countries, which we have also called for in a separate publication (Pivodic et al. 2013a). Finally, death certificates do not contain all information that is necessary to predict an individual's place of death, such as information on the course of disease, treatments received towards the end of life, or patients' preferred place of death (Cohen et al. 2007). Similarly, death certificates carry no information on aspects related to people's experience of the end of their life or their quality of dying. We cannot know from death certificates whether, for instance, palliative care was a realistic option for a particular individual. However, in our studies we selected deaths from serious chronic diseases that previous research has shown are indicative of palliative care need (Rosenwax et al. 2005).

9.4 Implications for research, policy and practice

The following sections outline the implications of the findings of this dissertation for further research as well as for policy and practice in relation to care at the end of life.

9.4.1 Implications for research

The research in this dissertation mainly studied processes of care (provision of palliative care, home visits, places of care, etc.) rather than outcomes of care, such as, for instance, quality of life. It should therefore be an important task for future research to examine whether and how these processes are related to measures of quality of care. Epidemiological monitoring could be used to study validated quality indicators of end-of-life care in the population (Leemans et al. 2014). Such data are currently being collected through the Sentinel Networks of GPs in Belgium, the Netherlands, Italy, and Spain in a study similar to the EURO-SENTIMELC study presented in this dissertation. We expect that they will provide valuable information on the quality of end-of-life care in these countries.

To complement our cross-sectional data, this research should be accompanied by prospective research. For instance, clinical trials are needed to study whether and to what degree the provision of palliative care by GPs and specialist palliative care providers (or lack thereof) at the end of people's lives is a determinant of patients' quality of dying and which particular indicators of quality of care or quality of dying it has an effect on. Furthermore, longitudinal research is needed to determine which transitions (i.e. from and to which locations and at what time in the dying trajectory) and which places of death are experienced as particularly burdensome by patients and families and lead to a lower quality of dying. Prospective studies can help identify those factors that can predict which patients are most at risk of not receiving the care they need, undergoing burdensome transitions, or not dying in the place of their choice. This knowledge can help to determine factors that can be influenced to prevent poor outcomes of end-of-life care.

Research is also needed to study how interventions aimed at family carers should be integrated into existing structures of health and social care in order to alleviate the burden on family carers in the most effective and cost-effective way. Currently available evidence offers very little guidance on how to identify overburdened carers, what the most important components and optimal timing of interventions for family carers are, and how these interventions should be integrated with the wider health and social services provided to terminally ill patients and their families in the specific countries. This information is urgently needed to ensure that interventions to support family carers can be flexibly tailored to the specific needs of different populations and that they can be translated to different care settings and health care systems.

Next to retrospective and prospective quantitative research, qualitative research is important to better understand the ways in which patients and families experience the care from GPs and specialist palliative care providers. This could also help us understand why GPs sometimes do not provide palliative care to patients who need it or why they provide it but do not label it palliative care. Specifically, qualitative research could help to explain our finding that certain patient groups (e.g. people with non-malignant disease, older people) may be disadvantaged in receiving palliative care. Qualitative research is also needed to understand why patients are transferred between care settings towards the end of life, which transitions are particularly burdensome, why people are or are not able to die in their place of choice, and what it is precisely that makes dying in certain locations or changes between locations better or worse for them. The work of Reyniers et al., for instance, has provided valuable insights regarding hospital admissions in Flanders (Belgium) (Reyniers et al. 2014; Reyniers et al. 2014a; Reyniers et al. 2014b). Such studies should be extended to other countries because the ways in which patients and families experience particular locations of care likely differs based on how care is organised in different countries or regions. The combined evidence from epidemiological research, as well as prospective and qualitative studies can help to develop strategies to better align end-of-life care provision and places of care with patients' and families' needs and wishes and wider national health care aims.

Our findings also suggest that the provision of palliative care at the end of life and the locations in which people receive care and die may not be in line with what policy in different countries aims to achieve. For instance, although many countries aim to reduce the number of deaths in hospitals, some achieve this to a greater extent than others. Therefore, research is needed to determine the influence of political, policy-related and institutional factors on how many and which patients receive palliative care and where they receive care and die. Our cross-national research can help to generate a number of hypotheses regarding the effects of such macro-level factors. Future research could test these hypotheses by conducting case studies in which a limited number of countries are compared that are purposefully selected based on their variation in these factors of interest while controlling for other variables. A similar method was applied by Dujardin et al. who compared the burden of informal care in Belgium and Great Britain by matching a subset of areas from Britain with areas in Belgium that are demographically and socioeconomically similar. In doing so they could remove the influence of local contextual characteristics on burden of informal care from the estimated country effects (Dujardin et al. 2011).

9.4.2 Implications for policy and practice

Provision of palliative care by GPs and specialist palliative care teams

We found that GPs did not state that they provided palliative care to all patients whose deaths were expected. This concerned particularly patients who died from diseases other than cancer. We agree with the widely accepted position among researchers and clinicians that palliative care is part of regular GP care and not a separate "medical procedure" (Carroll & Quill 2015). But it is nevertheless important that care that is directed at ensuring comfort at the end of life is perceived and termed by GPs as "palliative care" regardless of the patient's diagnosis and regardless of whether they themselves or specialist palliative care providers deliver it. This can help to ensure that guidelines in palliative care as well as health and social support measures are not perceived as applicable to only those patients with illnesses with which palliative care is more strongly associated, such as cancer. It is therefore important that awareness among GPs of the need for palliative care in the wider population of people with life-threatening chronic diseases be raised.

Our research has found a potentially important role of GPs in reducing hospital admissions at the end of life, if they are informed of the patient's preferred place of death. This could suggest that an opportunity for patients to express a preference for where to receive care can influence whether they are admitted to hospital in the last days and weeks of life. Our cross-national comparison suggests that a formal gatekeeping role for GPs alone may not be sufficient in preventing inappropriate hospitalisations, since they were significantly more frequent in Italy and Spain than in the Netherlands, although GPs in all three countries are formal gatekeepers. As suggested by qualitative research (Reyniers et al. 2014), it is more likely that gatekeeping by GPs who are trained in preventing unnecessary admissions to hospital (e.g. through care planning and palliative care provision) and who are supported in this by specialist palliative care providers and other community health and social care professionals can help to reduce the number of hospitalisations at the end of life. This suggests that prevention of unnecessary hospital admissions of people nearing the end of life is another topic that should be considered for inclusion in medical curricula and continuing education programmes for GPs.

Cooperation between GPs and specialist palliative care providers has emerged from our findings as another area that requires attention from policy-makers. Bereaved relatives of people who died of cancer were more satisfied with the end-of-life home care provided by specialist palliative care teams than with home care from GPs. Furthermore, the involvement of multidisciplinary palliative care teams was associated with fewer hospitalisations and more deaths at home as opposed to in hospital in Belgium and the Netherlands. It is important that specialist palliative care providers are available to support GPs, whose provision of palliative care is often limited by lack of time for home visits, high workload, limited out-of-hours availability, and lack of experience as many GPs see only few dying patients per year (Shipman et al. 2008).

Collaboration between generalist and specialist palliative care providers is not only important for improving care for individual patients. Collaborative palliative care provision has also been brought forward as a way to ensure that the need for palliative care in the population is met. Scholars have argued that relying on specialists to provide palliative care to all who need it is neither feasible nor sustainable in current health care systems (Carroll & Quill 2015; Quill & Abernethy 2013). According to this position, public health strategies to prevent underservicing patients in need of palliative care towards the end of life will need to decrease the demand for specialist palliative care by expanding the scope of generalists (e.g. primary care providers and specialists in other domains) who can provide it. These authors pointed out that most patients who require palliative care can be adequately treated in primary care with varying degrees of specialised input for patients with particularly complex or refractory symptoms.

In order to implement collaborative models of palliative care provision on national levels, policy-makers will need to develop structures and procedures for this collaboration. This should include a definition of skill sets that are required from generalists and specialists and guidance for when GPs should request specialist support. Carroll and Quill (2015) have suggested a division of tasks between generalist and specialists that is conceptualised as a continuum rather than a rigid list of discrete task categories. At one end of the spectrum, symptom control, end-of-life care, and assistance with medical decision-making fall more heavily within the generalist's purview. At the opposite end of the spectrum, specialists should be involved only with a minority of cases involving these aspects, and generally only when their complexity or severity has reached levels for which the generalist feels assistance is necessary. Additionally, the specialist end of the spectrum includes complex aspects such as palliative sedation, conflict resolution and cases of near futility. The authors state that is not feasible to define explicit criteria for when generalists should refer patients for specialist palliative care. Instead, they suggest that between the end points of this spectrum, the responsibilities should be determined flexibly because each clinician may find her or his own, personalised set of palliative care skills and threshold for referral.

Adopting such a model on national levels will require policy-makers to design training programmes needed to ensure basic competences in palliative care for generalist providers. These training programmes could also be used to prompt reflections among primary care professionals and specialists in other fields with regard to the palliative care skills they do and do not have and to clarify common situations where referral to palliative care specialists might be indicated (Carroll & Quill 2015).

Finally, a model of combined generalist and specialist palliative care provision could help to move away from approaches to palliative care that require the identification of a "terminal" or "palliative phase" towards care provision that is prompted by patient's needs for palliative care, regardless of when they arise in the course of disease. If most patients received palliative care from their usual care providers, no (necessarily arbitrary) criteria of life expectancy would be required to initiate palliative care. For those patients who experience complex needs that exceed the skills of their usual care providers, palliative care specialists could be consulted at any time throughout the course of disease.

Family carers and financial burden related to end-of-life care

Our findings on family carers of people at the end of life in Belgium, the Netherlands, Italy, and Spain point to potential problems in addressing overburden in family carers. To reduce overburden, most likely more is needed than just increasing resources in palliative care. Policy needs to recognise the particular dual role of family carers as providers and recipients of care and the multiple roles they need to fulfil (i.e. providing and coordinating physical care, giving emotional and spiritual support, having a family of their own to care for, and participating in income-generating activities), and develop support measures that are tailored to these particular circumstances. Consideration should therefore be given to potential merits of officially recognising family carers as care recipients. This may help to justify resource allocation to carer support, be it medical, psychosocial or spiritual. The aim of such an approach is not to pathologise the carer experience and treat it as entirely negative. However, the finding that in the countries we studied, between one and three-quarters of patients have overburdened carers may constitute a potential breach of care and thus calls for an evaluation of the support that is provided to them.

As explained in section 9.4.1, research needs to provide more evidence concerning effective interventions that can be implemented on national levels to support family carers. But it is the responsibility of policy-makers to devise strategies for implementing these interventions. This includes defining when, how and by whom carers should be screened for overburden, how the results of these assessments should feed back into the end-of-life care process, and how family carers should be involved in end-of-life care alongside professional carers in order to create the best possible outcomes for patients and the carers themselves. Given the prolonged disease trajectories of many patients with serious chronic diseases, the needs of carers should be assessed early in the course of disease, while recognising that some carers are more vulnerable than others (McNamara & Rosenwax 2010). Our study suggests that this concerns particularly family carers of patients younger than 85 years, and of patients who are dying at home, although this differs somewhat among countries. Therefore, vulnerable groups and appropriate interventions for them will likely need to be identified for each country separately.

We found that difficulties in covering the costs of care at the end of life were higher in Italy and the Netherlands than in Belgium and Spain. This should prompt examinations on the policy level whether this is related to how monetary benefits are used by families and whether they are sufficient in systems where they are provided to care recipients only as opposed to systems where they are given to both care providers and care recipients. Our finding that dying at home was associated with more difficulties in covering the costs of care highlights the need to investigate whether the monetary benefits are sufficient for patients who are dying at home and their families. Given that policy is moving towards enabling more home deaths, the financial implications that this has on families are an important aspect to be considered. Enabling patients to die at home is expected to reduce public health care costs (Hatziandreu et al. 2008). However, countries that are putting forward initiatives for people with a terminal illness to be cared for at home must also take steps to ensure that savings to public funds are not made at the expense of the financial security of families of people with a terminal illness.

Transitions between care settings

We found that patients whose deaths were expected by their GPs were frequently transferred between care settings in the last three months of life in Belgium, the Netherlands, Italy and Spain. Transitions were particularly frequent for home-dwelling people. One of the main implications of this finding for policy-makers is that countries need to establish the support systems that are necessary for people to be cared for at home without needing to undergo inappropriate and burdensome transitions. One important aim of palliative care is to avoid inappropriate use of health care services. However, next to making high-quality palliative care available to all patients who need it, reducing unnecessary transitions will also require changes in the organisation of health and social care. For instance, a recent report of the Nuffield Trust found that individuals with the highest social care costs had relatively low hospital care costs, and that better integration of health and social care may help to reduce hospital stays at the end of life (Georghiou et al. 2012). It is therefore likely that countries will need to make investments in long-term care and home care as well as support for family carers, amongst others, in order to reduce transitions and particularly hospitalisations at the end of life.

Our finding that many patients are repeatedly admitted to hospital towards the end of life, and often shortly before death, suggests that policy should focus particularly on transitions to hospital. We found that people for whom home was the longest place of residence were significantly more likely to be hospitalised than people for whom this was a care home. Since many hospital admissions do not occur out of strict medical necessity but rather following problems that could be handled in the home setting (Hjermstad et al. 2013), it seems likely that policies and programmes that aim to improve access to and delivery of health and social care services for home-dwelling patients and their families could lead to a reduction in unwanted hospital admissions.

We found in Belgium, the Netherlands, and Spain that patients were less likely to be hospitalised in the last week of life if their GP knew their preferred place of death. Most people prefer to die outside of a hospital (Gomes et al. 2013), so this result suggests that, at least in Belgium, the Netherlands and Spain, GPs who know their patients' preference can arrange care in such a way that they are not admitted there when they are near death. We did not find this result in Italy, and this may suggest that communication between patients and GPs about preferences may not be sufficient to reduce hospitalisations. It is possible that, even if GPs in Italy knew that their patients preferred to die at home, they could not help them in arranging this as a result of structural shortcomings, such as a lower availability of long-term care beds and home care services (OECD 2011b). Communication between patients and GPs seems important for reducing inappropriate transitions, and particularly late hospitalisations, but it needs to come along with a sufficient availability of structures and resources that GPs can draw upon to arrange care in the community, for instance institutional long-term care, home care and support for family carers.

Even if good strategies are implemented to enable patients to stay at home at the end of life, there will likely always be transitions that cannot be avoided, for instance because the patient cannot receive optimal care at home. In these cases, it is important that transitions are well managed through appropriate logistic arrangements, education of the patient and family about what to expect in the other care settings, and coordination among the health professionals involved in the patient's care to ensure continuity of care (Coleman & Boult 2003; Hanratty et al. 2014).

Place of death

Our findings on the place of death of people with cancer and other diseases that are indicative of a need for palliative care provide two different types of information for policy-makers. On one hand, they highlight the care settings in which large numbers of the population are cared for towards the end of life and thus indicate the priority settings for evaluating the quality of and allocating resources for palliative care. On the other hand, our studies highlight the factors that may influence patterns in place of death in countries.

Policy-makers in countries where many people die at home or in long-term care facilities need to review the quality of care that is provided to patients in these settings. In countries with low availability of long-term care facilities (e.g. Italy), for many patients, home may be the only community setting in which they can receive end-of-life care, but this does not necessarily mean that patients receive high quality care there. Furthermore, research has suggested that palliative care is not adequately implemented in many long-term care facilities, which raises concerns about the quality of end-of-life care provided to the residents of these facilities (Vandervoort et al. 2013).

Policy-makers in countries with higher percentages of hospital deaths should consider whether this could be changed by reviewing current policies on funding of formal home care (e.g. whether public funding is sufficient), support of family carers, and availability of specialist palliative care support in the community. There is strong evidence from Cochrane reviews that home-based care at the end of life increases people's chances of dying at home (Gomes et al. 2013; Shepperd et al. 2011). Since most patients and family carers would prefer a home death (Gomes et al. 2013), it is important that efforts are made to enable people to die at home if they wish so and if high-quality care can be provided to them in the home setting.

Perhaps people's desire to be cared for at home is sometimes less about the physical space and more about the presence of the people one cares about and the privacy and comfort one associates with the home setting (Exley & Allen 2007). Therefore, when thinking about how to ensure that people can die at home, research and policy should also rethink the way care is delivered in institutions and how institutions could create spaces that have some of the characteristics that people value in the domestic setting. In this way one could meet the place-related needs of those for whom "home" as the physical location may not be an appropriate place to die in.

Stepping up efforts to achieve a good death at home for more patients does not mean that policy should abandon strategies to improve palliative care in hospitals. It is important to keep in mind that not all hospitalisations are avoidable, for instance, because some symptoms cannot be controlled by professionals in the home setting or because patients prefer to be in the hospital for other reasons (Reyniers et al. 2014a). Therefore, it must be ensured that high-quality palliative care is available in all hospitals and that it is offered to all patients who may need it during their hospital stay. Palliative care expertise could be provided by specialist palliative care teams, similar to the mobile palliative care teams in Belgian hospitals. But next to this, implementing palliative care in hospitals will also require changes on structural levels and in some of the more implicit attitudes that often underlie hospital care, such as the often mechanistic assessment and treatment that focuses on improving organ function and consequently on prolonging life. More hospitals should adopt a palliative care approach, in which professionals across all health care disciplines pay attention to potential palliative care needs, assess patients' and families' needs and preferences, and address them in a collaborative care approach that focuses on ensuring comfort in the final phase of life.

We found a number of factors that may influence whether patients are more or less likely to die at home. Although further research is needed to determine why and how these factors influence place of death and how they interact with a country's policy environment (see section 9.4.1), development of future policies on place of care for the terminally ill and place of death should pay attention to differences between population groups. For instance, we found in most countries in which we studied place of death that being married was associated with dying at home rather than in hospital, which may indicate an important role of family support. This should prompt policy-makers to ensure that strategies to promote community-based end-of-life care include support for family carers of people at the end of life. In the population of people with cancer, those with haematological cancer were significantly more likely to die in hospital in all countries studied. This is an important sign for clinicians and policy-makers to review why these patients tend to remain in hospital until death and whether high-quality palliative care could be provided to them in the home setting, if this is where they wish to be.

Epidemiological data on the end of life

This final set of policy recommendations concerns the improvement of population-based methods to monitor care at the end of life. This dissertation has shown the potential of epidemiological surveillance systems (i.e. Sentinel Networks of GPs) and routine administrative data (i.e. death certificates) for studying end-of-life care in populations. In times of increasingly restricted public funding for public health and research, it is important to emphasise towards national public health authorities the need to continue to provide resources for collecting these data. Epidemiological monitoring is a relatively inexpensive means of obtaining reliable and valid population-based data on end-of-life care that can serve as an evidence base for policy development and evaluation. Additionally, there are several other types of repeatedly conducted population-based health surveys that could be adapted to include information on the end of life in populations. This includes, for instance, the Survey of Health, Ageing and Retirement in Europe (SHARE Project 2015) or the Belgian Health Interview Survey (Belgian Scientific Institute for Public Health 2015).

As for administrative data such as death certificates, our research has shown that they are useful for monitoring where people die and for studying the association between place of death and sociodemographic and ecological variables. However, we also found that records of place of death and other information on death certificates is insufficiently standardised across countries, and we have drawn attention to this in a published commentary (Pivodic et al. 2013b). Some countries recorded several categories of place of death while others only distinguished hospital and other. To improve the quality and cross-national comparability of information related to the place of death, the WHO, for instance, should issue internationally applicable guidelines on the minimum set of place of death categories that need to be recorded on death certificates. We believe that this should include, at least, the categories home, hospital, and long-term care facility. To be able to study the place of death in function of a larger number of independent variables, and preferably health care-related variables, national public health authorities should facilitate the linkage of death certificates with other population-level data, such as health care claims data, while protecting individuals' anonymity. Finally, the value of death certificate data for monitoring end-of-life care in populations could be considerably increased in many countries by including on the death certificates the name and contact details of the person who registered the death, which is usually a family member. Contact details are included on death certificates in the UK, and the QUALYCARE study, which is presented in this dissertation (Chapter 3), shows one type of population-based information that can be obtained by surveying bereaved relatives that were identified through death certificates.

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Chapter 10

Samenvatting van de belangrijkste bevindingen (Summary of main results)

Inleiding

Wereldwijd is de bevolking aan het vergrijzen. Dit is vooral te wijten aan een daling van het aantal sterftes ten gevolge van infecties en meer recent een daling van het aantal sterfgevallen van ouderen ten gevolge van chronische aandoeningen. Op medisch vlak is er voor de meeste mensen met chronische levensbedreigende aandoeningen voornamelijk vooruitgang geboekt wat betreft het onder controle houden van symptomen en het tegengaan van een verergering van de aandoening. Dit heeft tot gevolg dat voor veel mensen het leven kan verlengd worden. Mensen worden vatbaarder voor chronische levensbedreigende aandoeningen naarmate hun leeftijd toeneemt. Dit betekent dat voor een steeds ouder wordende bevolking er grote veranderingen zullen plaatsvinden wat betreft het aantal sterftes en de doodsoorzaken. Deze evolutie wordt zonder twijfel een van de grootste en belangrijkste uitdagingen voor het gezondheidszorgsysteem. Ondanks dat mensen vandaag de dag langer leven dan een aantal decennia geleden, verkeren veel mensen met een chronische levensbedreigende aandoening tijdens hun laatste levensjaren in een slechte gezondheid en ervaren ze een langzame, maar gestage achteruitgang van hun aandoening wat meestal gepaard gaat met meerdere en complexe lichamelijke, psychosociale en spirituele problemen.

Palliatieve zorg kan aan deze problemen tegemoet komen. De Wereldgezondheidsorganisatie (WGO) definieert palliatieve zorg als een 'handelswijze gericht op het verbeteren van de levenskwaliteit van patiënten en hun naasten, die te maken hebben met een levensverkortende aandoening, door het voorkomen en verlichten van lijden door middel van vroegtijdige detectie, zorgvuldige beoordeling en behandeling van pijn en andere lichamelijke, psychosociale en existentiële noden. Het is algemeen erkend dat palliatieve zorg een integraal onderdeel moet vormen van de zorg voor elke patiënt met een levensverkortende aandoening. Daarbij zou palliatieve zorg moeten worden aangeboden van bij het begin van het ziektetraject, zonder dat daarbij een grens wordt gesteld op basis van een korte levensverwachting.

Het onderwerp van dit proefschrift betreft de zorg rond het levenseinde. Deze term omvat alle zorg in de laatste of terminale fase in het leven van mensen met een ernstige of chronische levensbedreigende aandoening. In de wetenschappelijk literatuur wordt er bij het bestuderen van de levenseindezorg vaak gekozen om de laatste drie levensmaanden van mensen te bestuderen. Omwille van het toenemend aantal mensen dat nood heeft aan levenseindezorg en de bijgevolg financiële implicaties voor het gezondheidszorgsysteem, wordt het leveren van kwaliteitsvolle levenseindezorg een steeds grotere maatschappelijke uitdaging en een belangrijke focus voor de volksgezondheid. Verschillende functies van de volksgezondheid kunnen dan ook toegepast worden bij het bestuderen van de levenseindezorg: 1) in kaart brengen en monitoren van de zorg, 2) formuleren van het gezondheidsbeleid en 3) verzekeren van gepaste en kostefficiënte zorg. Wat betreft de zorg rond het levenseinde bestaan er nog steeds grote hiaten bij het in kaart brengen en monitoren van de zorg (de eerste functie van volksgezondheid). Dit heeft tot gevolg dat belangrijke informatie ontbreekt om een solide wetenschappelijke basis te creëren dat uiteindelijk kan bijdragen tot de beleidsvorming en het implementeren van adequate zorg. Bij het creëren van een solide wetenschappelijke basis is er ook specifiek nood aan nationaal vergelijkend onderzoek. Vergelijkend onderzoek tussen landen kan enerzijds helpen bij het zoeken naar potentiële problematische ontwikkelingen binnen het domein van levenseindezorg, maar kan anderzijds ook bijdragen tot het identificeren van opportuniteiten voor verandering binnen een bepaald land door te achterhalen welke strategieën gebruikt worden in andere landen.

In dit proefschrift worden een aantal methoden van de volksgezondheid toegepast, namelijk het in kaart brengen en monitoren van de zorg. Daarbij ligt de focus in het bijzonder op het maken van een epidemiologische evaluatie met als doel vanuit een internationaal perspectief en het perspectief van de algemene bevolking twee bepaalde aspecten van levenseindezorg te bestuderen: 1) zorgverleners die instaan voor de zorg aan het levenseinde (met daarbij in het bijzonder huisartsen, gespecialiseerde palliatieve thuiszorgequipes en mantelzorgers) en 2) de plaats waar mensen verzorgd worden en overlijden. Er werd gekozen om deze specifieke aspecten te bestuderen omwille van hun bijzondere betekenis voor de organisatie van de levenseindezorg op het niveau van nationale gezondheidszorgsystemen.

Onderzoeksvragen

Het doel van dit proefschrift was het beschrijven en vergelijken van verschillende landen op basis van twee bepaalde aspecten van levenseindezorg: (1) zorg voor mensen aan het levenseinde door verschillende zorgverleners en (2) plaats van zorg en plaats van overlijden van mensen aan het levenseinde.

Volgende onderzoeksvragen hebben betrekking op de zorgverleners aan het levenseinde:

1. Hoeveel mensen krijgen palliatieve zorg via hun huisarts en via multidisciplinaire gespecialiseerde palliatieve zorg teams?
2. Hoe tevreden zijn de nabestaanden van mensen die overleden zijn ten gevolge van kanker en thuis verzorgd werden door hun huisarts?
3. In hoeverre worden mantelzorgers van mensen aan het einde van hun leven fysiek of emotioneel overbelast en in hoeverre ervaren patiënten en hun familie moeilijkheden om de zorgkosten te dekken?

Volgende onderzoeksvragen hebben betrekking op de plaats van zorg en plaats van overlijden:

4. Hoeveel mensen worden in de laatste drie levensmaanden getransfereerd tussen verschillende zorgsettings en wat zijn redenen voor de laatste transitie naar de plaats van overlijden?
5. Hoeveel mensen worden gehospitaliseerd in de laatste drie levensmaanden, in welke periodes en voor hoelang?
6. Waar sterven mensen die mogelijks nood hebben aan palliatieve zorg in verschillende landen en in hoeverre worden verschillen tussen landen in plaats van overlijden verklaard door verschillen in socio-demografische karakteristieken, doodsoorzaken en beschikbaarheid van zorgvoorzieningen?

7. Waar sterven mensen met kanker in verschillende landen en in hoeverre zijn verschillen in plaats van overlijden tussen de landen te verklaren door verschillen in sociaal-demografische karakteristieken, doodsoorzaken (hematologische kanker versus tumor) en beschikbaarheid van zorgvoorzieningen?

Methoden

Alle onderzoeksmethoden die werden toegepast in dit proefschrift zijn kwantitatief van aard en bestuderen het levenseinde via retrospectieve gegevensverzamelingen. Er werd gebruik gemaakt van zowel bestaande routinematig verzamelde administratieve gegevens (doodscertificaten op basis van de International Place of Death study), als van bestaande epidemiologische onderzoekssystemen (Sentinel netwerk van huisartsen in de Euro-Sentimelc study) en een vragenlijstonderzoek bij nabestaanden aan de hand van een populatie gebaseerde steekproef van overlijdens (Qualycare study).

Euro-Sentimelc Study

De European Sentinel Network Monitoring End-of-Life Care (EURO-SENTIMELC) study is een retrospectieve mortaliteitsstudie waarbij populatie gebaseerde gegevens over levenseindezorg werden verzameld in vier Europese landen gedurende drie jaar (van 1 januari 2009 tot 31 december 2010 in België, Nederland en Italië, en van 1 januari 2010 tot 31 december 2011 in Spanje). De respondenten waren huisartsen. In alle vier de landen werden de gegevens verzameld via de Sentinel netwerken van huisartsen (nationale of regionale epidemiologische onderzoeksnetwerken) via een gestandaardiseerde gegevensverzameling. Huisartsen registeren op wekelijkse basis elk overlijden van een patiënt in hun praktijk door gebruik te maken van een gestandaardiseerd registratieformulier. Hierop registreren ze verschillende patiëntkarakteristieken en zorgaspecten die de patiënt kreeg in de laatste drie levensmaanden. Patiënten jonger dan 18 jaar op het moment van overlijden werden geëxcludeerd. Ook patiënten overleden in woonzorgcentra in Nederland werden geëxcludeerd omdat de huisarts daar niet verantwoordelijk is voor hun zorg. Verder werden ook overlijdens geëxcludeerd die door de huisarts werden aangeduid als plots en totaal onverwacht om zo een steekproef van overledenen te krijgen voor wie levenseindezorg een realistische optie was.

QUALYCARE study

De QUALYCARE studie is een retrospectieve overlijdensstudie. Gegevens werden verzameld aan de hand van vragenlijsten ingevuld door nabestaanden van personen die overleden aan kanker in vier gezondheidsdistricten in Londen (UK), tussen maart 2009 en maart 2010. Nabestaanden van personen die overleden aan kanker (overledene moest 18 jaar of ouder zijn) werden geïdentificeerd door het Office of Nationale Statistics (het Nationaal Instituut voor Statistiek in Engeland) uit de overlijdensregisters. Overlijdens die werden geregistreerd door een lijkschouwer en overlijdens die niet thuis hadden plaatsgevonden, in een hospice, woonzorgcentrum of ziekenhuis, of onbekend, werden geëxcludeerd. Respondenten werden ook geëxcludeerd wanneer de overleden naaste niet minstens één dag tijdens de laatste drie levensmaanden thuis verbleef. Respondenten werd gevraagd een vragenlijst in te vullen over verschillende aspecten van de zorg in de laatste drie levensmaanden, sociaal-demografische factoren en de klinische status van hun overleden naaste. De belangrijkste uitkomstmaat die voor de analyses binnen dit proefschrift werden uitgevoerd, is tevredenheid met de zorg die thuis werd gegeven in de laatste drie levensmaanden, door de huisarts, gespecialiseerde palliatieve zorg teams en thuisverpleegkundigen.

International Place of Death (IPoD) Study

In de IPoD studie werd de plaats van overlijden onderzocht aan de hand van gegevens van overlijdenscertificaten uit 14 landen over een periode van één jaar (2008). De landen die werden onderzocht in deze studie waren België, Canada, Engeland, Frankrijk, Hongarije, Italië, Mexico, Nederland, Nieuw-Zeeland, Spanje, Tsjechië, USA, Wales en Zuid-Korea. Voor de studies in dit proefschrift werden twee subgroepen van de volledige set van overlijdens geselecteerd: (1) overlijdens door tien specifieke aandoeningen die palliatieve zorgnoden indiceren, en (2) overlijdens ten gevolge van kanker. Binnen deze subgroepen werden alle overlijdens onderzocht van personen van één jaar en ouder. Via de overlijdenscertificaten werd informatie verkregen over de plaats en oorzaak van overlijden, alsook de leeftijd en het geslacht van de overledenen. Een aantal extra variabelen werden verkregen via de overlijdenscertificaten of, wanneer deze variabelen niet geregistreerd waren in bepaalde landen, door het koppelen van de overlijdenscertificaten met andere databestanden. Statistieken over de beschikbaarheid van zorgvoorzieningen en gegevens over de mate van verstedelijking werden gekoppeld aan de gemeente waar de overledene verbleef.

Belangrijkste bevindingen

Gebruik van palliatieve zorg in vier Europese landen

Aan de hand van de gegevens uit de EURO-SENTIMELC studie werd in vier Europese landen onderzocht (België, Nederland, Italië en Spanje) aan hoeveel mensen palliatieve zorg verstrekt was geweest door de huisartsen gedurende de laatste drie levensmaanden, hoeveel mensen zorg ontvangen hadden van gespecialiseerde palliatieve zorgteams en welke patiënt- en zorggerelateerde factoren geassocieerd zijn met het krijgen van palliatieve zorg van huisartsen en gespecialiseerde palliatieve zorgteams. In het totaal werden 4446 overlijdens bestudeerd die door de huisarts als niet-plots waren beoordeeld. De huisartsen rapporteerden dat ze palliatieve zorg verstrekt hadden aan 50% van de patiënten in België, 55% in Italië, 62% in Nederland, en 65% in Spanje (p<.001). Palliatieve zorgspecialisten behandelden 29% van de patiënten in Nederland, 39% in Italië, 45% in Spanje, en 47% in België (p<.001). Gespecialiseerde palliatieve zorg werd verstrekt gedurende een mediaan tijd (interkwartielafstand) van 15 (23) dagen in België tot 30 (70) dagen in Italië (p<.001). Met betrekking tot gespecialiseerde palliatieve zorg hadden kankerpatiënten in alle landen een grotere kans om palliatieve zorg te ontvangen dan niet-kankerpatiënten, net zoals jongere patiënten in Italië en Spanje. Deze resultaten tonen aan dat, hoewel palliatieve zorg beschikbaar is in alle vier de bestudeerde landen, er aanzienlijke verschillen zijn in de verstrekking van specialistische palliatieve zorg, zowel wat betreft het aantal mensen dat deze zorg ontvangt als de zorgsetting waarin deze zorg hoofdzakelijk voorzien wordt. Bovendien kwamen twee groepen naar voor die mogelijk onvoldoende gespecialiseerde palliatieve zorg kregen: niet-kankerpatiënten in alle landen en ouderen in Italië en Spanje.

Thuiszorg voor kankerpatiënten door huisartsen in de laatste drie levensmaanden

Om de mate van en de factoren die samenhangen met de tevredenheid van nabestaanden over de levenseindezorg die door de huisarts thuis geleverd werd aan mensen die sterven ten gevolge van kanker te bepalen, werden de gegevens van het QUALYCARE onderzoek gebruikt. De respondenten (nabestaanden) stuurden vragenlijsten terug voor 596 overledenen (responsgraad van 39%). Hiervan brachten 548 personen minstens één dag thuis door in de laatste drie levensmaanden. Vijfenvijftig procent van de respondenten meldde uitstekende/zeer goede thuiszorg door de huisartsen, vergeleken met

78% voor de gespecialiseerde palliatieve zorgverleners en 68% voor thuisverpleegkundigen. De kans op hoge tevredenheid met de levenseindezorg (uitstekende/zeer goede zorg) verstrekt door huisartsen verdubbelde indien de huisarts meer dan drie huisbezoeken deed in de laatste drie levensmaanden in vergelijking met één of geen huisbezoek en halveerde indien de patiënt overleed in het ziekenhuis in plaats van thuis. Deze bevindingen tonen aan dat er ruimte is voor verbetering wat betreft de tevredenheid met de thuiszorg verstrekt door huisartsen aan terminaal zieke patiënten. Het verzekeren van een toereikend aanbod van huisbezoeken door huisartsen kan helpen om dit doel te bereiken.

Belasting van mantelzorgers en zorggerelateerde financiële moeilijkheden aan het levenseinde in vier Europese landen

Gebaseerd op de data van de EURO-SENTIMELC studie werd in vier Europese landen beschreven en vergeleken hoeveel patiënten gedurende hun laatste drie levensmaanden mantelzorgers hadden waarvan de huisarts hen als fysiek en/of emotioneel overbelast beoordeelde, en hoeveel patiënten en families moeilijkheden hadden bij het dekken van de zorgkosten. In het totaal werden 4466 sterfgevallen bestudeerde die door de huisarts geclassificeerd werden als niet-plotse overlijdens. Binnen deze groep beoordeelde de huisarts de mantelzorgers als fysiek/emotioneel overbelast in 28% (België), 30% (Nederland), 35% (Spanje) en 71% (Italië) van de gevallen. Bij 8% (Spanje), 14% (België), 36% (Nederland) en 43% (Italië) van de patiënten rapporteerde de huisarts moeilijkheden in het dekken van de zorggerelateerde kosten. Patiënten jonger dan 85 jaar (België en Italië) hadden een hogere kans op het hebben van fysieke/emotionele overbelaste mantelzorgers en financiële zorgen. Sterven ten gevolge van niet-kwaadaardige aandoeningen (versus kanker) (België en Italië) en thuis sterven (versus andere plaatsen) (Nederland en Italië) waren geassocieerd met een hogere kans op moeilijkheden in het dekken van zorggerelateerde kosten. Deze resultaten suggereren dat in alle bestudeerde landen, en vooral in Italië, huisartsen een aanzienlijke mate van fysieke/emotionele overbelasting en moeilijkheden bij het dekken van zorggerelateerde kosten vaststellen bij mantelzorgers van patiënten aan hun levenseinde. Dit heeft belangrijke implicaties op beleidsdoelstellingen die erop gericht zijn om meer mensen in staat te stellen om thuis te blijven tot aan het overlijden.

Plaats van overlijden bij patiënten die nood kunnen hebben aan palliatieve zorg in 14 landen

De gegevens van de IPoD studie werden gebruikt om in 14 landen, bij mensen overleden ten gevolge van aandoeningen waarvan onderzoek heeft aangetoond dat ze palliatieve zorgnoden indiceren, de associatie van de plaats van overlijden met de oorzaak van overlijden, de socio-demografische en beschikbare gezondheidszorg factoren te bestuderen. Ook de mate waarin deze kenmerken landsverschillen kunnen verklaren in de plaats van overlijden werd onderzocht. De bestudeerde populatie had een omvang van 2.220.997. Uit onze resultaten is gebleken dat 13% (Canada) tot 53% (Mexico) van de populatie met een potentiële nood aan palliatieve zorg, thuis overleed en dat 25% (Nederland) tot 85% (Zuid-Korea) in een ziekenhuis overleed. Er werden grote verschillen gevonden tussen landen in de mate waarin patiënt gerelateerde factoren en factoren met betrekking tot de beschikbaarheid van de gezondheidszorg samenhingen met de plaats van overlijden.Bovendien zijn deze grote verschillen in plaats van overlijden bij mensen met een potentiële nood aan palliatieve zorg tussen landen in en buiten Europa niet volledig toe te schrijven aan socio-demografische kenmerken, doodsoorzaak of beschikbaarheid van gezondheidszorg. Ecologische factoren, zoals de beleidsomgeving van het land, kunnen een belangrijke rol spelen in waar mensen komen te overlijden.

Internationale studie over de plaats van overlijden bij mensen met kanker in 14 verschillende landen

Op basis van de data van de IPoD-studie werd de plaats van overlijden bestudeerd van mensen met kanker in 14 verschillende landen, alsook het verband tussen de plaats van overlijden en klinische en socio-demografische factoren en karakteristieken van het zorgaanbod. De grootte van de studiepopulatie was 1.355.910. Twaalf (Zuid-Korea) tot 57% (Mexico) van de overlijdens ten gevolge van kanker vonden plaats thuis, 26% (Nederland, Nieuw-Zeeland) tot 87% (Zuid-Korea) in het ziekenhuis. Over de verschillende landen heen waren hematologische kankers vaker geassocieerd met thuisoverlijdens dan solide kankers (Odds ratio's (OR) 1,29-3,17). Getrouwd zijn bleek ook vaker geassocieerd te zijn met thuisoverlijdens ten opzichte van gescheiden zijn (OR 1,17-2,54). De grote verschillen tussen de landen in thuisoverlijdens of ziekenhuisoverlijdens werden gedeeltelijk verklaard door verschillen in de beschikbaarheid van ziekenhuisbedden en bedden voor langdurige zorg en de beschikbaarheid van huisartsen. Landspecifieke keuzes betreffende de organisatie van kankerzorg aan het levenseinde verklaarden een bijkomend deel.

Transities tussen verschillende settings in de gezondheidszorg in de laatste drie levensmaanden in vier Europese landen

De data van de EURO-SENTIMELC studie werden gebruikt om de setting waarin mensen worden verzorgd tijdens de laatste drie levensmaanden, de frequentie van transities tussen verschillende settings, de meest frequente laatste transitie (i.e. de plaats waar de patiënt overlijdt), en de redenen voor deze laatste transitie in kaart te brengen. Over de vier landen heen werden 4791 niet-plotse overlijdens bestudeerd. Van deze 4791 overlijdens vond er bij 59%, 55%, 60% en 58% in België, Nederland, Italië en Spanje minstens één transfer tussen settings plaats. In dezelfde landen werd er drie keer of meer van setting veranderd bij 10%, 5%, 8% en 12%. Over de landen heen werd gevonden dat transities vaker voorkwamen bij patiënten die thuis verbleven (61%-73%) dan bij patiënten die in een woonzorgcentra verbleven (33%-40%). De wens van de patiënt werd aangegeven als reden voor terminale hospitalisatie in 27%, 39%, 9% en 6% van de overlijdens in België, Nederland, Italië en Spanje. Deze resultaten tonen aan dat transities tussen verschillende settings aan het levenseinde vaak voorkomen in de vier bestudeerde Europese landen, maar dat er verschillen zijn tussen de landen in frequentie en type van transities en in de redenen voor de laatste transitie.

Hospitalisatie aan het levenseinde in vier Europese landen

Op basis van data uit de EURO-SENTIMELC studie werden de frequentie, het moment en de duur van hospitalisaties in de laatste drie levensmaanden onderzocht in vier Europese landen. Ook de factoren geassocieerd met deze hospitalisaties werden onderzocht Van de 4791 patiënten die niet onverwacht overleden, werd tussen de 49% (Nederland) en 56% (België) minstens eenmalig gehospitaliseerd in de laatste drie levensmaanden. Heropnames in het ziekenhuis kwamen significant minder vaak voor in Nederland (8%) dan in de andere landen (15%-20%, $p<.001$). De kans om gehospitaliseerd te worden, nam toe in de laatste tien levensdagen over alle landen heen, maar bleef het laagst in Nederland (België: 21%-37%, Nederland: 15%-29%, Italië: 16%-37%, Spanje: 14%-31%). Hospitalisaties in de laatste levensweek waren waarschijnlijker wanneer de patiënten thuis verbleven ten opzichte van deze die in een woonzorgzorgcentra verbleven, en minder waarschijnlijk wanneer de huisarts kennis had van de voorkeur van de patiënt omtrent de plaats van overlijden. Deze analyse toont aan dat het gebruik van ziekenhuizen aan het levenseinde in alle bestudeerde landen toenam over de laatste levensweken heen. Het aantal opnames en heropnames aan het levenseinde in de laatste levensweken bleven het laagst in Nederland. Dit is mogelijk te wijten aan de 'gatekeeper' rol van huisartsen die opgeleid en ondersteund worden in het voorkomen van heropnames in het ziekenhuis aan het levenseinde.

Discussie van de belangrijkste bevindingen

Dit proefschrift toont aan dat huisartsen belangrijke personen zijn in het verlenen van palliatieve zorg aan het levenseinde in België, Nederland, Italië en Spanje. Huisartsen in deze landen gaven echter aan dat ze aan een derde tot de helft van hun patiënten die niet onverwacht overleden waren geen palliatieve zorg hadden verleend in de laatste drie levensmaanden. Een mogelijke reden hiervoor is de nog vaak voorkomende en historisch ingewortelde gedachte dat palliatieve zorg een benadering is die voornamelijk voorbehouden is voor de terminale fase van een aandoening. Dit zou er toe kunnen leiden dat huisartsen niet herkennen wanneer het overlijden van de patiënt naderend is en bijgevolg de nodige palliatieve zorg niet tijdig kunnen toedienen. Het idee dat palliatieve zorg enkel van toepassing is in de laatste levensfase benadeelt mogelijks mensen die lijden aan vergevorderde chronische aandoeningen anders dan kanker omdat hun ziektetraject (en dus hun levensverwachting) veel moeilijker te voorspellen is dan bij kankerpatiënten. Uit onze studie is dan ook dat gebleken dat huisartsen vaker aangeven dat palliatieve zorg toegediend werd wanneer de patiënt overleed ten gevolge van kanker dan wanneer deze overleed ten gevolge van een andere aandoening. Om een oplossing te bieden voor het probleem dat palliatieve zorg voor veel patiënten te laat, of helemaal niet wordt toegediend, zou een "fase-gebaseerde" benadering plaats kunnen maken voor een eerder "nodengebaseerde" benadering, waarin palliatieve zorg telkens wanneer de behoefte ontstaat en doorheen het ziektetraject aan de patiënt wordt aangeboden.

Er werden ook belangrijke verschillen gevonden tussen België, Nederland, Italië en Spanje voor wat betreft het aantal patiënten die palliatieve zorg ontvingen van gespecialiseerde palliatieve zorgteams in de laatste drie levensmaanden en in het aantal patiënten die gespecialiseerde palliatieve zorg ontvingen in de verschillende zorgsettings (ziekenhuis, woonzorgcentra, thuis). Dit is waarschijnlijk een weerspiegeling van het zorgverleningsbeleid van deze landen en bijgevolg ook van de beschikbaarheid van palliatieve zorg in de verschillende zorgsettings. Het gebrek aan gespecialiseerde palliatieve zorg betekent niet noodzakelijk dat behoeften van de patiënten niet vervuld werden, omdat zij mogelijks palliatieve zorg via andere gezondheidswerkers kunnen hebben ontvangen. Toch kan er een reden zijn om aan te nemen dat ten minste sommige patiënten die geen specialistische palliatieve zorg ontvingen, onvervulde behoeften hadden. Dit komt omdat de generalistische palliatieve zorgvoorziening (bijvoorbeeld door huisartsen en/of andere medische specialisten) minder dan optimaal is in deze landen: zo zijn er bureaucratische beperkingen, een gebrek aan het routinematig beoordelen van niet-acute zorgnoden bij ongeneeslijk zieke patiënten, en het gebrek aan vaardigheden om aan zeer complexe zorgbehoeften tegemoet te komen. Tegelijkertijd werd aangetoond dat huisartsen goede zorg verleenden wanneer ze werden ondersteund door gespecialiseerde palliatieve zorgteams. Deze bevindingen suggereren dat een model van palliatieve zorgverlening waarin huisartsen samenwerken met gespecialiseerde palliatieve zorgteams nodig is. Dit wordt ook ondersteund door onze bevinding dat nabestaanden van patiënten die overleden zijn ten gevolge van kanker, de levenseindezorg die thuis verleend werd door gespecialiseerde palliatieve zorgteams en wijkverpleegkundigen aanzienlijk beter beoordeelden dan de zorg die door huisartsen werd gegeven.

Onze analyse toonde aan dat emotionele/fysieke overbelasting bij mantelzorgers bijzonder hoog was in Italië, wat een gevolg kan zijn van het feit dat Italië zeer weinig middelen voor langdurige zorg voorziet in vergelijking met andere landen, waardoor veel patiënten afhankelijk zijn van familie om hen thuis te verzorgen. De huisartsen meldden ook dat veel patiënten en families moeilijkheden hadden met de hoge kosten van de zorg aan het levenseinde. Hun aantal was bijzonder hoog in Nederland en in Italië. Het was ook alleen in deze twee landen dat financiële druk werd geassocieerd met het thuis overlijden van de patiënt en met de betrokkenheid van gespecialiseerde palliatieve zorg. Toekomstig onderzoek zou moeten onderzoeken waarom de financiële lasten vooral hoog zijn in deze twee landen en of dit samenhangt met het feit dat Italië en Nederland (in tegenstelling tot België en Spanje) enkel financiële steun bieden aan afhankelijke patiënten maar niet aan hun mantelzorgers.

Er werd vastgesteld dat een groot deel van de mensen met een potentiële nood aan palliatieve zorg in het ziekenhuis overlijden, hoewel resultaten van voorgaand onderzoek suggereren dat voor een grote groep patiënten niet aan de palliatieve zorgnoden wordt beantwoord in ziekenhuizen. Ziekenhuizen zijn vaak slecht uitgerust om te zorgen voor terminale patiënten die vaak te kampen hebben met complexe en progressieve gezondheidsproblemen. Uit de analyses is gebleken dat het al dan niet overlijden in een ziekenhuis bepaald wordt door meer dan louter medische factoren (bijvoorbeeld een specifieke diagnose die zorg in een specifieke setting vraagt) of patiënten karakteristieken. Waarschijnlijk beïnvloeden ook omgevingsfactoren en aspecten die verbonden zijn aan sociale ondersteuning de plaats van overlijden.

Uit de analyse bleek dat in de meeste van de 14 bestudeerde landen patiënten minder vaak thuis overleden dan in een ziekenhuis of een woonzorgcentrum. Er werd ook vastgesteld dat in alle bestudeerde landen mensen die overleden ten gevolge van een hematologische kanker vaker thuis overleden dan deze patiënten die overleden ten gevolge van een solide tumor. Dit betekent dat ondanks de waarschijnlijke invloed van omgevingsfactoren waar we geen toegang toe hadden, er toch een ziekte-gerelateerde factor bestaat die er voor zorgt dat bepaalde patiënten meer of minder vaak thuis overlijden, overheen verschillende landen en hun gezondheidszorgsystemen.

Algemeen werden door onze analyses met betrekking tot de plaats van overlijden ten minste twee belangrijke soorten informatie aangeboden. Ten eerste konden de zorgsettings worden aangetoond waar grote delen van de populatie overlijden en die dus een belangrijke rol spelen in de zorg voor stervende patiënten. Dit zijn de zorgsettings waar het evalueren en optimaliseren van zorg voor stervenden een prioriteit moeten zijn. Ten tweede kon door onze vergelijkingen tussen landen mogelijke hypothesen aangeboden worden in verband met de redenen voor verschillen in plaats van overlijden die zich situeren op het niveau van het gezondheidszorgbeleid. In de toekomst kan deze informatie het ontwerp leiden van vergelijkende studies in doelbewust gekozen landen met als doel het effect van specifieke omgevingsfactoren op de plaats van overlijden te isoleren en onderzoeken.

Transities tussen zorgsettings kunnen de voorziening van levenseindezorg van hoge kwaliteit in het gedrang brengen en mogelijks de voorkeur van de patiënt voor continuïteit in levenseindezorg in gevaar brengen. Toch werd vastgesteld dat transities zich vaak voordoen in België, Nederland, Italië en Spanje. Meer bepaald transities naar een ziekenhuis komen vaak voor. In voorgaand onderzoek werd vastgesteld dat veel patiënten gehospitaliseerd worden kort voor het overlijden omwille van klinische problemen die inadequaat behandeld kunnen worden door primaire zorg. Er werd tevens vastgesteld dat in Nederland minder patiënten in een ziekenhuis verbleven tijdens de laatste drie levensmaanden dan in andere landen. Dit kan een gevolg zijn van het sterke primaire zorgsysteem in dit land en het feit dat palliatieve zorg er meer dan in andere landen wordt gedefinieerd als een generalistische zorgverlening die in de eerste plaats tot de primaire zorg behoort.

Curriculum Vitae

Lara Pivodic was born on 7 November 1985 in Derventa, Bosnia and Herzegovina. She obtained an MSc ("Magistra der Naturwissenschaften") in psychology from the University of Vienna, Austria (2011). During her studies, she specialised in research methods and clinical and health psychology. Lara joined the End-of-Life Care Research Group in 2011 as a Marie Curie PhD Training Fellow in the EURO IMPACT project, a Marie Curie Actions Initial Training Network involving research institutes from six European countries (funded by the European Union Seventh Framework Programme, FP7/2007-2013). As part of her PhD programme, she completed a 6-month appointment as Visiting Research Associate at the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation of King's College London. Lara currently works at the End-of-Life Care Research Group as senior researcher.

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Invited presentations

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Social inequalities and underserved groups in palliative care: Family carers of people at the end of life, **International Seminar of the Palliative Research Centre and EAPC Research Network**, Ghent, 2012

Oral presentations following selection through peer review

Hospitalisations at the end of life in four European countries, **European Public Health Conference**, Glasgow, UK, 2014

Place of death in populations potentially in need of palliative care, **European Public Health Conference**, Glasgow, UK, 2014

Place of death in populations potentially benefiting from palliative care: a population-level study in 14 countries, **Health Services Research Conference of the European Public Health Association (EUPHA)**, Utrecht, 2014

Burden on family carers and difficulties in covering costs of care at the end of life: a cross-national, population-based study via representative GP networks, **World Congress of the European Association for Palliative Care (EAPC)**, Prague, 2013

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Acknowledgement of the EURO IMPACT consortium

This analyses presented in Chapters 2, 3, 4, and 5 were undertaken as part of the EURO IMPACT (European Inter-Sectorial and Multidisciplinary Palliative Care Research Training) project. EURO IMPACT aimed to develop a multidisciplinary, multi-professional, and inter-sectorial educational and research training framework for palliative care research in Europe. In recognition of the collaborative nature of EURO IMPACT we thank the following EURO IMPACT members: Van den Block Lieve[1], De Groote Zeger[1], Brearley Sarah[5], Caraceni Augusto[7,8], Cohen Joachim[1], Francke Anneke[2], Harding Richard[3,4], Higginson Irene J[3,4], Kaasa Stein[6], Linden Karen[11], Miccinesi Guido[9], Onwuteaka-Philipsen Bregje[2], Pardon Koen[1], Pasman Roeline[2], Pautex Sophie[10], Payne Sheila[5], and Deliens Luc[1,2]. EURO IMPACT was coordinated by Prof Luc Deliens and Prof Lieve Van den Block of the [1]End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University, Brussels, Belgium. Other partners are: [2]VU University Medical Center, EMGO Institute for health and care research, Amsterdam, the Netherlands; [3]King's College London, Cicely Saunders Institute, London, [4]Cicely Saunders International, London, and [5]International Observatory on End-of-Life Care, Lancaster University, Lancaster, United Kingdom; [6]Norwegian University of Science and Technology, and [7]EAPC Research Network, Trondheim, Norway; [8]Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, and [9]Cancer Research and Prevention Institute, Florence, Italy; [10]EUGMS European Union Geriatric Medicine Society, Geneva, Switzerland; [11]Springer Science and Business Media, Houten, the Netherlands.

Chapter 11

Appendix: Supplementary data

Supplementary data for Chapter 5

Table 11.1: Measures of health care availability in the countries studied

Country abbreviated	Country	Health care supply[a]		
		Hospital beds per 1,000[b]	LTC beds per 1,000 65+[b]	GPs per 10,000[b]
Western Europe				
IT	Italy	3.4	34,6	7,6
ES	Spain (Andalusia)	2.7	18,8	7,4
FR	France	7.0	59,2	8,7
BE	Belgium	5.2	70.3	20.1
NL	Netherlands	3.1	77,5	5,4
ENG	England	3.1	54,8	6,6
WAL	Wales	4.4	49,3	6,5
Central/Eastern Europe				
CZ	Czech Republic	6.0	28,9	7,0
HU	Hungary	7.1	32,7	6,5
Oceania				
NZ	New Zealand	3.1	71,6	8,8
North America				
US	USA	2.7	41,5	13,1
CA	Canada (excl. Quebec)	3.0	58,1	10,1
East Asia				
KR	South Korea	8.3	17,5	7,5
Latin America				
MX	Mexico	0.3	0,0	6,8[c]

[a] Abbreviations: LTC: long-term care; GPs: general practitioners/primary care physicians/family physicians.

[b] The density of hospital beds and GPs is expressed in relation to the total population, that of LTC-beds (long-term care settings including nursing homes, care homes, residential care homes for older people) in relation to the total population aged 65 or over.

[c] In Mexico, the figure refers to physicians of any specialty (including GPs) per 10,000 inhabitants.

Supplementary data for Chapter 6

Table 11.2: Marital status of the persons dying from cancer in 2008 in 14 countries

Country[a]	Abbreviations	Marital status			
		Married	Widowed	Divorced/Separated	Unmarried
Continental Western Europe					
France	FR	54.3	25.0	9.4	11.3
Italy	IT	59.6	28.8	1.9	9.7
Spain (Andalusia)	ES	61.2	24.9	3.7	10.2
Belgium	BE	53.9	28.8	9.3	8.1
Netherlands	NL	56.6	/[b]	/[b]	43.4[b]
Central/Eastern Europe					
Czech Republic	CZ	53.1	28.7	12.6	5.5
Hungary	HU	49.3	29.3	14.2	7.2
United Kingdom	UK				
England	ENG	51.8	30.6	9.4	8.1
Wales	WAL	52.6	30.6	9.2	7.6
New Zealand[c]	NZ	/	/	/	/
North America					
Canada	CA	56.0	26.9	9.0	8.1
United States	US	50.8	27.2	14.1	7.9
Latin America					
Mexico	MX	59.8	22.2	2.1	15.9
East Asia					
South Korea	KR	65.1	25.2	5.3	4.4

[a] Reference year is 2007 for USA and 2010 for Spain.

[b] The Dutch data only distinguish between married and not married.

[c] Marital status not recorded.

Table 11.3: Healthcare supply in the countries studied

Country	Abbreviations	Healthcare supply		
		Hospital beds per 10.000	LTC beds per 1.000 65+	GPs per 10.000
Continental Western Europe				
France	FR	69.5	59.2	8.7
Italy	IT	34.1	34.6	7.6
Spain (Andalusia)	ES	26.8	18.8	7.4
Belgium	BE	51.9	70.3	20.1
Netherlands	NL	30.8	77.5	5.4
Central/Eastern Europe				
Czech Republic	CZ	60.4	28.9	7.0
Hungary	HU	71.0	32.7	6.5
United Kingdom				
England	ENG	31.1	54.8	6.6
Wales	WAL	43.9	49.3	6.5
New Zealand	NZ	30.8	71.6	8.8
North America				
Canada	CA	29.8	58.1	10.1
United States	US	27.0	41.5	13.1
Latin America				
Mexico	MX	3.3	0.0	6.8
East Asia				
South Korea	KR	83.0	17.5	7.5

Table 11.4: Stepwise building up of the hierarchical binary logistic regression models with home vs all other places of death as dependent variable

Country	Model 1 (Country) (Model 1 in Figure 1)	Model 2 (+ cancer site,[a] age, sex) (Model 2 in Figure 1)	Model 3 (+ marital status)	Model 4 (+ hospital beds)	Model 5 (+ long term care beds)	Model 6.1 (+ number of GPs)	Model 6.2 (same as 6 but without marital status) (=Model 3 in Figure 1)
FR	Ref	Ref	Ref	Ref	Ref	Ref	Ref
IT	3,52 (3,46-3,58)	3,52 (3,46-3,58)	3,44 (3,39-3,50)	1,53 (1,48-1,57)	1,66 (1,61-1,71)	1,66 (1,61-1,71)	1,70 (1,65-1,75)
ES	1,96 (1,89-2,03)	1,94 (1,87-2,01)	1,89 (1,82-1,96)	0,70 (0,67-0,73)	0,66 (0,63-0,69)	0,66 (0,63-0,69)	0,68 (0,65-0,71)
BE	1,73 (1,68-1,78)	1,73 (1,68-1,78)	1,73 (1,68-1,78)	1,15 (1,11-1,18)	1,59 (1,54-1,64)	1,55 (1,49-1,61)	1,60 (1,53-1,66)
NL	3,65 (3,57-3,74)	3,64 (3,56-3,73)	4,04 (3,94-4,14)	1,65 (1,59-1,71)	3,16 (3,04-3,30)	3,18 (3,05-3,31)	2,83 (2,72-2,95)
CZ	0,94 (0,91-0,97)	0,92 (0,89-0,95)	0,92 (0,89-0,95)	0,75 (0,72-0,77)	0,57 (0,55-0,59)	0,57 (0,55-0,59)	0,57 (0,55-0,59)
ENG	1,50 (1,47-1,52)	1,50 (1,47-1,52)	1,50 (1,47-1,52)	0,61 (0,59-0,63)	0,88 (0,85-0,92)	0,89 (0,86-0,92)	0,88 (0,85-0,91)
WAL	1,50 (1,43-1,58)	1,50 (1,42-1,57)	1,49 (1,42-1,57)	0,81 (0,77-0,85)	0,96 (0,91-1,01)	0,96 (0,91-1,02)	0,96 (0,91-1,02)
NZ	1,69 (1,61-1,78)	1,70 (1,62-1,79)	/[b]	/[b]	/[b]	/[b]	1,10 (1,04-1,17)
CA	0,81 (0,79-0,84)	0,82 (0,80-0,84)	0,80 (0,77-0,82)	0,32 (0,30-0,33)	0,52 (0,50-0,55)	0,52 (0,50-0,54)	0,54 (0,51-0,56)
US	2,72 (2,68-2,75)	2,77 (2,73-2,81)	2,82 (2,78-2,86)	1,05 (1,02-1,09)	1,35 (1,31-1,40)	1,33 (1,29-1,38)	1,33 (1,28-1,38)
MX	5,71 (5,59-5,82)	5,96 (5,84-6,09)	5,86 (5,74-5,98)	1,27 (1,20-1,33)	1,24 (1,18-1,31)	1,24 (1,18-1,31)	1,27 (1,20-1,33)
KR	0,57 (0,56-0,59)	0,54 (0,53-0,55)	0,51 (0,50-0,53)	0,70 (0,68-0,72)	0,36 (0,35-0,38)	0,37 (0,35-0,38)	0,39 (0,37-0,40)

[a] Cancer site includes 17 categories: head and neck; stomach; colon, rectum and anus; pancreas; other gastrointestinal; trachea, bronchus and lung; other respiratory; breast; cervix uteri, corpus uteri and ovary; prostate; urinary tract; other genitourinary; central nervous system; Non-Hodgkin's lymphoma; leukaemia; other haematologic malignancies.

[b] Because marital status is not available in the New Zealand data, this country is excluded from the analysis.

Table 11.5: Contextual data for the countries studied and their correlation with the percentage of home deaths and hospital deaths

Country[a]	Social expenditure as percentage of GDP[c]	Health expenditure as percentage of GDP[c]	Palliative care services for adults per million inhabitants[d]	Opioid consumption (mg/person) per year (morphine equivalence)[e]	Percentage of cancer deaths that occurred at home	Percentage of cancer deaths that occurred in hospital
France	29.8	10.5	7.6	179.6	19.1	72.8
Belgium	27.3	9.9	18.1	363.5	28.9	59.3
Spain (Andalusia)	26.7	9.4	8.0	298.1	31.6	64.9
Italy	25.8	8.6	8.0	126.7	45.3	47.3
Hungary	23.1	7.3	8.5	63.3	/	67.7
England[b]	21.8	8.2	15.4	225.3	26.1	44.4
Wales[b]	21.8	8.2	15.4	225.3	26.2	56.6
Netherlands	20.9	10.2	15.3	167.6	46.3	25.8
New Zealand	19.8	9.3	n.a.	198.7	28.5	26.2
Czech Republic	18.1	6.7	2.2	67.5	18.2	26.2
Canada	17.6	9.5	n.a.	643.1	16.1	67.6
United States	16.3	14.9	n.a.	663.0	39.0	33.7
South Korea	8.4	6.3	n.a	27.6	11.8	87.2
Mexico	7.4	5.8	1.1	4.5	57.3	39.9
correlation (r) with home death[f]	-0.12	0.10	-0.19	-0.13	/	/
correlation (r) with hospital death	0.10	-0.20	0.14	-0.01	/	/

[a] The reference year is 2008, except for USA (2007) and Spain (2010).

[b] Data for United Kingdom. No data separate for England and Wales were available.

[c] Source: OECD.

[d] Source: Atlas de Cuidados Paliativos en Latinoamérica - Edición Cartográfica 2013; EAPC Atlas of Palliative Care in Europe.

[e] Source: Pain & Policy Studies Group, University of Wisconsin-Madison. Includes Fentanyl, Hydromorphone, Methadone, Morphine, Oxycodone, Pethidine.

[f] Home not recorded as place of death in Hungary.

Supplementary data for Chapter 7

Table 11.6: Most frequently occurring final transitions of non-sudden deaths per country

Deceased patients who had at least one transition in the last three months of life[a]								
Most frequently occurring final transition[b]	BE (n=943)		NL (n=348)		IT (n=1090)		ES (n=392)	
	%	95% CI	%	95% CI	%	95% CI	%	95% CI
Hospital death								
coming from home	46.1	42.9; 49.3	41.7	36.5; 46.9	60.3	57.4; 63.2	54.5	49.6; 59.4
coming from care home	10.8	8.8; 12.8	7.2	4.5; 9.9	2.9	1.9; 3.9	4.1	2.1; 6.1
Home death								
coming from hospital	11.8	9.7; 13.9	21.6	17.3; 25.9	16.1	13.9; 18.3	17.6	13.8; 21.4
Care home death								
coming from hospital	11.9	9.8; 14.0	6.3	3.7; 8.9	4.1	2.9; 5.3	3.8	1.9; 5.7
PCU/hospice death								
coming from home	7.1	5.5; 8.7	7.8	5.0; 10.6	5.2	3.9; 6.5	5.4	3.2; 7.6
coming from hospital	7.7	6.0; 9.4	8.3	5.4; 11.2	3.4	2.3; 4.5	3.1	1.4; 4.8

[a] Transitions are presented if they occurred in $\geq$3% of cases in at least one of the countries studied.
Abbreviations: BE=Belgium, NL=Netherlands, IT=Italy, ES=Spain, CI=confidence interval.
[b] Missing data: final transition n=133 (2.8%).