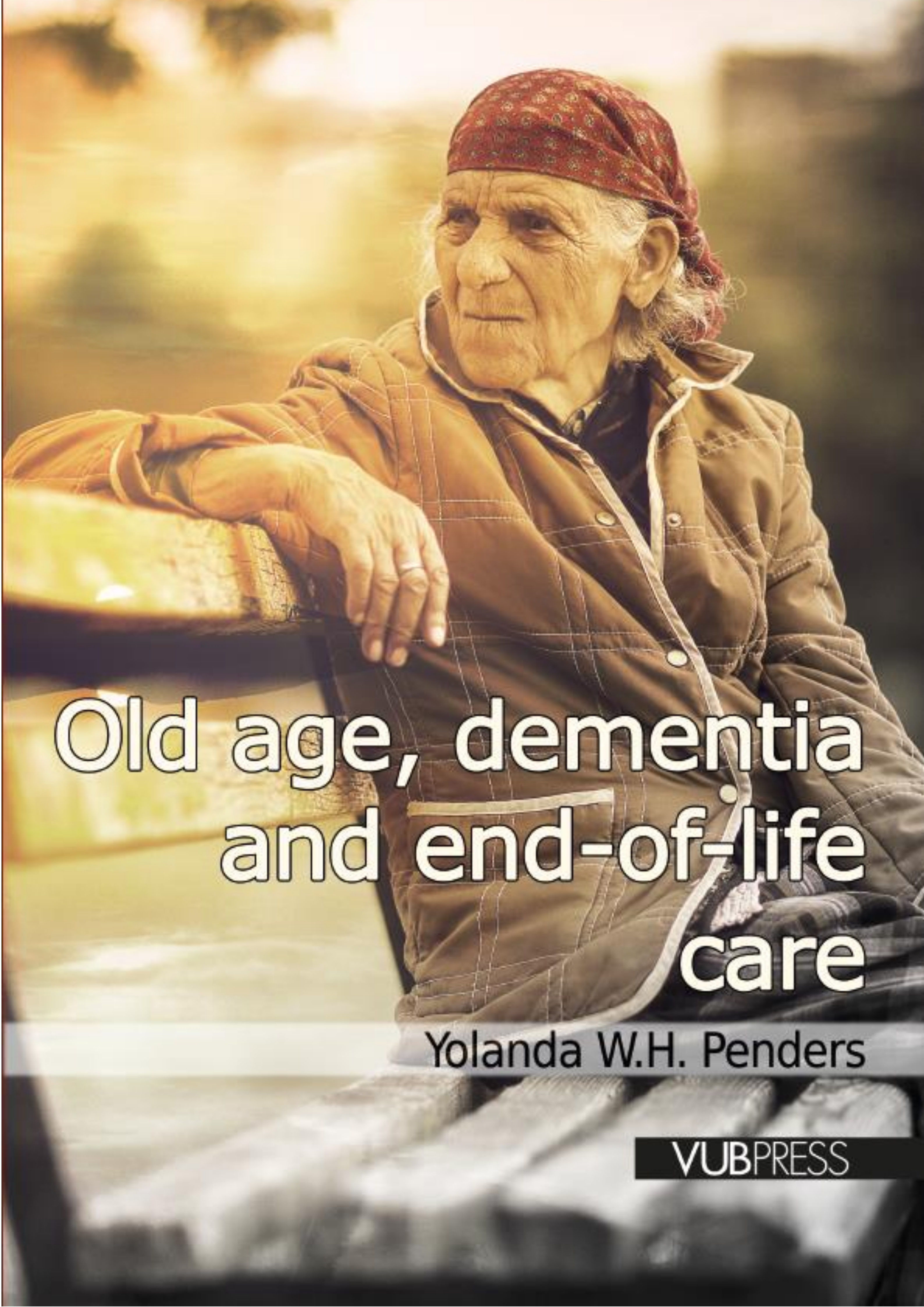

Old age, dementia and end-of-life care

Yolanda W.H. Penders

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Do not go gentle into that good night,
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Rage, rage against the dying of the light.

Though wise men at their end know dark is right,
Because their words had forked no lightning they
Do not go gentle into that good night.

Good men, the last wave by, crying how bright
Their frail deeds might have danced in a green bay,
Rage, rage against the dying of the light.

Wild men who caught and sang the sun in flight,
And learn, too late, they grieved it on its way,
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And you, my father, there on the sad height,
Curse, bless, me now with your fierce tears, I pray.
Do not go gentle into that good night.
Rage, rage against the dying of the light.

Dylan Thomas, 1914-1953 (reproduced with permission)

PREFACE

Successfully completing a doctorate is a significant achievement that is first and foremost attributable to the person to whom the title of ‘doctor’ is conferred. So, that would be me. I can safely say that I played a pretty big part in making this thesis a reality. However, no doctorate is written in isolation, and indeed I owe a debt of gratitude to many people.

To my promotor, Lieve Van den Block, I would offer my sincere thanks for teaching me about a myriad of things - not only about the fields of palliative care, elderly care and public health, but also about how to be a good researcher, a reliable employee and how to navigate the professional world – but most of all, for showing me what true passion and dedication looks like.

To my co-promotor, Luc Deliens, I would like to extend my gratitude for sharing his vast expertise in palliative care. My work has greatly improved through your feedback and our discussions.

To all co-authors and contributors to the various projects I worked on, including EURO IMPACT and PACE, I would like to say that your effort to make these projects a success has been marvelous. Your input has always been tremendously helpful to me.

To my coworkers, I am happy to say that you made coming into work a real pleasure each day. Thanks for putting up with my sarcasm, skepticism-fueled fact-checking and Belgium-bashing (I am a bad, bad immigrant).

To my friends, I would like to offer thanks for either distracting me with non-research or non-death related pursuits, or for commiserating about the ups and downs of doing a PhD. Mostly about the downs, if we’re being honest (who commiserates about ups?).

To my family: thank you for your support throughout the years. Thank you for frequently making the trip to Brussels to visit me. Thank you for all the newspaper clippings you sent me about dementia and elderly care even though I usually did not reply (I have kept all the clippings in a special folder).

To George: thank you for always making me laugh, for all the hugs and kisses, for bragging about me to anyone who will listen and for filling every moment with love.

And finally, I would like to dedicate this doctorate to my grandparents Zef Penders (1930-1996), Mien Janssen-Peters (1921-2010) and Johan Janssen (1922-2011). They inspire me not just to be the best person I can be, but to try and make the world a better place. I hope they would have been proud of me.

CHAPTER 1: Introduction

The ageing population of Europe

The world's population is ageing: people aged 65 and over made up 15 per cent of the population of countries in the Organisation for Economic Co-operation and Development (OECD) in 2012; by 2050, this is expected to increase to 25 per cent.[1] Between 1950 and 2002, life expectancy at birth has increased by 10 years or more in all Western-European and most Southern and Eastern European countries, now frequently reaching over 85.[2] Unfortunately, not all of these years will be spent in good health. In 2013, the disability-free life expectancy – that is, the average number of years a person can be expected to live in good health – in the 28 European Union member states was estimated at 61, or approximately 79 per cent (for men) to 74 per cent (for women) of the average total life expectancy.[3] After these healthy life years, we 'grow old': we can expect a steady decline of our physical and cognitive health until we die. While nowadays we may not instinctively see 65 as old, both the OECD and the World Health Organisation (WHO) use this age as the cut-off point between younger adults and the old, specifically because of the potential increase in health problems faced by those over that age.[1,4]

There is of course great variation in the functional status and ability of older people, with many able to maintain a good degree of independence, social engagement and continued physical health until a great age.[5-7] This is the ideal of 'successful ageing'. Unfortunately this ideal is not feasible for all, with one study in the USA estimating that as few as 12 per cent of people aged 65 and over age 'successfully'.[8] The large, vulnerable group of older people whose health declines and whose independence decreases with age, and those who will suffer cognitive decline and dementia, will require more and more care as time goes on.

An ageing population poses considerable challenges for healthcare systems and clinical practice. First, older people suffer from more illnesses than younger people, often concurrently, and illnesses that are usually not problematic in younger people can prove fatal in older people, such as shingles and flu.[9] A study of community-dwelling older people found that in the last year of life, only 17 per cent had no disability, and 41 per cent had a persistently severe or catastrophic disability.[10] Care in most European countries is set up in such a way that it focuses on acute conditions rather than chronic ones, and to treat health problems in isolation rather than coordinating care efficiently across disciplines.[11,12] This set-up is inefficient for older people, who are at risk of unnecessary interventions, poly-pharmacy and inadequate care, without even taking into consideration the added costs of such a system.[13] A systematic literature review showed that the use and costs of healthcare for older people increased significantly with each chronic condition the person had.[14] In a review of costs of care in the

USA, the 40 per cent of people who had persistently high costs of healthcare tended to be old, and incurred their costs most often through chronic conditions and functional limitations.[15] These are reasons the Belgian Health Care Knowledge Centre wrote a position paper in 2012 in which they recommend fifty concrete action points to move towards a needs-based rather than diagnosis-based chronic care system – although so far, this has not led to a measurable improvement of suitability of chronic care.[16,17]

Second, there are specific forms of care that are needed mostly or only by older people, such as care in nursing homes and dementia care. Between 2 and 10 per cent of cases of dementia develop by age 65, with prevalence doubling every five years in age after that.[18] In some countries, most people with severe dementia end up living and eventually die in long-term care facilities.[19,20] These facilities also provide care for people whose physical needs are greater than can be met by formal or informal carers in the community, such as after a stroke or complex multimorbidity. These types of care are often expensive, as they are provided round-the-clock, usually involving multiple caregivers. As not just the number but also the proportion of older people increases, these specialized forms of care take up a greater chunk of the healthcare budget.

Finally, there is the reality that older people are more likely to die than younger adults, and most healthcare is used in the last year before death.[21] In the USA, 80 per cent of people used most healthcare (in terms of costs) in the last year of life.[12] People in the last year of life use a high amount of critical care, experience many hospital admissions and often stay in a long-term care facility, especially older people, those with chronic illnesses and those with multimorbidities.[22,23] This, combined with the specific health problems mentioned above, makes providing end-of-life care for older people a major public health challenge.

In this chapter, some of these challenges in end-of-life care for older people and people with dementia will be discussed in detail, highlighting those areas where we still lack sufficient knowledge. After this, an overview will be given of the existing knowledge gaps that this dissertation aims to cover. The research aims of this dissertation will be listed. Finally, at the end of this chapter, the data and methods used throughout this dissertation will be described.

End-of-life care for older people

Palliative care

One of the challenges of providing healthcare at the end of life for older people is to provide care that is attuned to the specific needs that arise when it is known that a person will not recover. Apart from receiving curative or life-prolonging care in hospitals, long-term care facilities or the home setting, people with terminal illnesses or those who are near the end of their life can receive specialized end-of-life care or palliative care. The WHO defines palliative care as follows:[24]

> “Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.”

The WHO goes on to state that palliative care, amongst other things, provides relief from pain and other distressing symptoms; intends neither to hasten nor postpone death; offers a support system to help the family cope during the patient’s illness and in their own bereavement; and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life. Palliative care, therefore, is an approach to care which aims to address the needs of dying people and their next of kin from a holistic point of view. Palliative care can be provided by all healthcare professionals in the course of regular care or by specialized care providers and teams. Palliative care and end-of-life care are overlapping, though not identical, concepts, as end-of-life care includes all care received at the end of life, including e.g. aggressive curative treatment which may not be in line with the goals of palliative care, and palliative care may be provided to people at the end of life but also earlier in the disease trajectory.

Palliative care originated as care for people with terminal cancer. Even now, specialized palliative care is still provided primarily to cancer patients, even though, both in the quoted definition and in practice, it is appropriate care for all terminal illnesses.[25] Accessibility of palliative care for older people and specifically people with dementia is important, but often difficult. In many cases, there is no clear prognosis for older people, making it difficult to determine when conversations about palliative care should start.[26] Dementia in particular is often (wrongly) not recognized as a terminal illness and as such, people with dementia are often not considered to be eligible for palliative care.[27,28] This is despite the fact that palliative care can be of great importance for both older people and people with dementia.[25,29] Aspects of palliative care that are especially appropriate for older people and people with dementia are communication and advance care planning (that is, talking about the person’s wishes and goals of care later on) early in the disease trajectory; including family in the caring process; and relief of symptoms from age-related health issues for which curative treatments are not an option.

Much is still unknown about the care older people, and specifically those with dementia, receive at the end of life. While we know they have less access to specialized palliative care[30,31], we do not know which groups are at a particular disadvantage. Community-dwelling older people, older people with cancer, older people with dementia and older people living in a long-term care facility are unlikely to receive the same care merely based on their age, but may experience advantages or disadvantages based on their specific situations. Furthermore, we do not know how this has developed over time. With increased attention to the applicability of palliative care to all people suffering from a life-limiting illness, not just terminal cancer patients, it is possible that palliative care services have become more accessible to older people over the past few years, or to specific groups of older people.[32-34] In the next sections, three specific factors will be highlighted that are of concern when attempting to ensure access to high-quality palliative care for all older people.

Care settings

Older people themselves prefer to have the choice of where they will live and receive care, with many preferring to live at home for as long as possible.[35,36] Indeed, a sizeable portion of older people will remain at home until death.[19,37] However, as older people themselves also foresee, circumstances sometimes necessitate a move to a long-term care facility.[36] These circumstances include the need for more skilled care, behavioural and cognitive problems and the burden on family carers.[38-40] In Belgium in 2013, 11 per cent of people aged 75 and over and 26 per cent of people aged 85 and over lived in a long-term care facility such as a nursing home or a care home.[41] As such, the home setting and long term care facilities are the two most important care settings for older people at the end of life.

In the home setting in many countries, including Belgium, care is mainly provided by general practitioners (GPs). Specifically with respect to end-of-life care, GPs can ensure the early initiation of palliative care and play an important role in advance care planning. The continued care of a GP is associated with dying at the preferred place of death and avoidance of emergency department use and unnecessary hospitalizations.[42-44] General practitioners are also well-placed to coordinate other care in the home setting. Terminally ill patients see their GP as a source of continuity as well as a source of information, due to the exchange of information between GPs, specialists and care facilities.[45] Though literature suggests that GPs are both willing and able to deliver satisfactory palliative care and symptom control, several barriers have been identified to the provision of palliative care by GPs.[46] These include the compartmentalization in healthcare, a lack of communication and collaboration between different care providers, lack of availability – or, put differently, difficulty being available at all hours – but also the GP's own uncertainty about their knowledge and abilities regarding palliative care.[47-49] When older people move to a long-term care facility, the GP may are may not remain involved in care. There are various types of long-term care facility with varying degrees of care available. In general, a distinction can be made between residential homes, where room and board are provided and there is assistance available with activities of daily living but no on-site medical care is provided, and care homes or nursing homes, where in addition to the care provided in care homes skilled medical professionals provide medical care for those with more severe physical or cognitive disabilities.[50] Regardless, in all long-term care facilities professional caregivers are involved beyond the GP and care is provided to residents round the clock, seven days a week. In some countries, such as the Netherlands, nursing homes also have an in-house specialist physician in chronic care and rehabilitation who provides care for the residents instead of a GP. In this dissertation, ‘long-term care facility’ will be used as the umbrella term, with ‘residential home’ referring specifically to facilities where no medical care is provided, and ‘care home’ or ‘nursing home’ for facilities where all care is provided on-site, with or without a community GP involved.

Several aspects of end-of-life care that influence the quality of life and quality of dying of older people may differ depending on the care setting or place of residence. Compared to older people who remain at home, older people who move to a long-term care facility are more likely to have severe dementia, have difficulties with activities of daily living, exhibit challenging behavioural symptoms, and are often older and have more often suffered a cerebrovascular accident (stroke) or myocardial infarction (heart attack).[51,52] Older people who move to a nursing home have also more often lived alone before admission, i.e. may have less social support.[53]

Because of the different amounts of care available, as well as population differences and differences in care providers, different decisions may be made by, with or for older people living at home and those living in a long-term care facility, for example on whether a transfer between care settings is needed at the end of life. Communication between older people and their GPs may differ between the two settings by virtue of population differences. Whether older people living at home and older people living in a long-term care facility have the same access to palliative care is also still unknown. A population-based overview of the end-of-life care of older people at home and in long-term care facilities is needed to identify the specific strengths and weaknesses of both settings.

Communication and advance care planning

One of the core components of palliative care for older people is advance care planning. Advance care planning is a process of communication between patients, their families or representatives and professional caregivers about the goals and desired direction of care. Through advance care planning, people are encouraged not only to think about their own wishes and values regarding the care they might receive in the final phase of life, but also to share these thoughts and wishes with others. By documenting their wishes and/or appointing a surrogate decision-maker, people can extend their autonomy and play an active part in deciding on their end-of-life care, even if they are unable to express themselves in the moment.

Although early studies showed no effect of advance care planning in patient control over their treatment, nor on communication style between doctor and patient[54], more recent studies have documented a number of benefits of advance care planning. A systematic review by Brinkman-Stoppelenburg and colleagues found that advance care planning often increases the use of hospice and palliative care and prevents hospitalization.[55] Advance care planning appears to increase not just knowledge of patient preferences, but also compliance with these preferences.[56,57] In addition to these obvious benefits, advance care planning has also been found to decrease anxiety and depression and increase satisfaction with care in family members.[58,59]

While advance care planning is important to consider for everyone, including those who are not currently experiencing a life-limiting illness, it is especially relevant for older people. The WHO recommends advance care planning as an important part of palliative care for older people, and older people themselves also indicate that they find advance care planning important.[60,61] Older people are at a higher risk of experiencing adverse events that can have immediate and sometimes irreversible impact on their ability to express their wishes, such as a stroke.[62] It is therefore advisable to initiate advance care planning before an acute situation arises: by the time the emergency is there, it may be too late. However, it is unknown how often advance care planning occurs with or in relation to older people. Several intervention studies aimed at improving advance care planning for older people have been done in the past few years, with often promising results.[63] For example, a randomised controlled trial concluded in 2010 by Detering and colleagues among inpatients of a university hospital aged 80 and over used the Respecting Patient Choices model to encourage patients to reflect on their goals, values and beliefs; to appoint a surrogate decision-maker; and to document their wishes about end-of-life care.[58] The results showed that advance care planning improves end-of-life care, patient and family satisfaction and reduces stress, anxiety and depression in surviving relatives. The ongoing PACE intervention aims to provide palliative care training to nursing home staff, including training on how and when to engage in advance care planning – preferably within weeks of a new resident moving in.[64] However, these interventions do not tell us anything about the current state of affairs. A population-based overview of advance care planning for older people, and particularly how this has developed over the past few years as more attention is paid to the importance of proactive communication between patient and healthcare professionals, is necessary in order to make informed decisions on how to continue with promoting this necessary part of end-of-life care.

Costs of care

As a large part, if not most, of healthcare is used in the last year of life, it can be expected that costs in this period are higher than in other years.[12,65-73] While the costs of an ageing population to a healthcare system are often highlighted, what is less clear is the costs of care that patients themselves shoulder. In the USA, high medical costs play a role in a substantial number of bankruptcies[74] and while the financing of healthcare systems in Europe is arranged quite differently, there is a significant shortage of research on the costs of end-of-life care for care receivers and their families.[75,76]

Older people in particular are vulnerable to negative effects of high out-of-pocket costs, and sometimes even cite high costs as a reason not to initiate or adhere to treatment or care, potentially decreasing quality of life in the final stage of life.[77,78] The financial burden of care can also weigh heavily on the shoulders of family carers: financial stress and a low income level are linked to a higher perceived burden and a more frequent exhibition of depressive symptoms amongst informal carers.[79,80] Since most older people do not want to be a burden on their family[36], this may further dissuade them from engaging useful but expensive healthcare.

Unfortunately, when it comes to policymaking it is often the insurer costs or costs to the government that are highlighted and, subsequently, attempts to minimize costs also usually favour insurance companies and the government. How different types of healthcare, such as medication, care from GPs, specialist physicians, or care in hospitals, contribute to the financial burden on patients is yet unknown. Population-based research on out-of-pocket costs for healthcare would aid in the development of adequate healthcare policies that take into account the financial burden on care receivers by establishing which types of care are particularly burdensome for patients financially and identifying those groups who are at particular risk of having high out-of-pocket costs.

End-of-life care for people with dementia

What is dementia?

Dementia, of which Alzheimer’s disease is the most common and most well-known form, is a particular healthcare challenge for older people. It is defined by the WHO as follows:[81]

> “Dementia is a syndrome due to a chronic or progressive disease of the brain in which there is disturbance of multiple higher cognitive functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement, commonly accompanied by deterioration in emotional control and social behaviour.”

Currently, 47.5 million people worldwide have a form of dementia, with 7.7 million new cases each year.[82] The course of dementia is variable and dependent on patient and environmental characteristics, as well as the specific type of dementia. Generally three stages can be distinguished: mild or moderate dementia, severe dementia and very severe or advanced dementia. In mild dementia, people show confusion about orientation in time and space, have difficulties making decisions and may exhibit mood swings. In severe dementia, these symptoms become worse, and problems with communication increase. At this stage people often require the help of caregivers for even basic household tasks. Challenging behaviour and personality changes may occur, such as aggression, wandering, and a disturbed sleep pattern. People with very severe or advanced dementia can be unaware of time and place, unable to recognize even very familiar people or objects, and are fully care dependent.[83-85] This combination of physical and psychological symptoms means that people with dementia, especially those who progress to the advanced stages of the disease, require a lot of complex care in the last phase of life.

End-of-life care for people with dementia

While palliative care is appropriate for all people with a life-limiting or terminal illness, specific conditions warrant tailored strategies to provide optimal care. To provide high-quality end-of-life care for people with dementia requires attention to what differentiates dementia from e.g. cancer. The European Association for Palliative Care (EAPC) published a white paper on the best practice approach to palliative care for people with dementia in 2013.[29] The paper contains 57 recommendations in 11 domains, ranging from the applicability of palliative care to psychosocial and spiritual support. Amongst these recommendations it states that for patients with dementia with complex problems, specialized palliative care should be available. This recommendation further supports the notion that palliative care is increasingly recognized as appropriate for non-cancer patients too.

However, while palliative care professionals increasingly recognize dementia as a disease indicative of a palliative care need, the views of other healthcare professionals and the general public may still differ. As in many countries, such as Belgium, the GP is responsible for initiating palliative care, and since in the case of dementia it is often the family who must advocate for this if the GP does not take the initiative, the family's and GP's views on dementia are perhaps more important than those of palliative care specialists. Many people do not have a good understanding of the likely course of dementia[86,87], with almost half of people believing a partial recovery is possible with appropriate treatment and more than 80 per cent not knowing what are the actual risk factors associated with developing dementia.[88] Even though early diagnosis of dementia can be important to support both patients and family carers[89,90], physicians sometimes do not feel it is particularly important or that it can even be harmful to some patients due to the stigma associated with dementia and the lack of effective treatment options.[91,92] Such attitudes may be prohibitive for the initiation of specialized palliative care for people with dementia. However, currently it is still unknown what the prevalence of specialized palliative care is for this group. This information is a necessary first step to further investigate the barriers and facilitators for palliative care for people with dementia.

Further recommendations from the EAPC white paper include the prioritizing of explicit global care goals, proactive advance care planning starting at diagnosis and including those with mild dementia, and the avoidance of overly aggressive, burdensome or futile treatment, including hospitalizations (when appropriate). Several ongoing interventions aim to implement these recommendations, particularly in the nursing home setting.[64] However, the epidemiology of these types of end-of-life care practices for people with dementia is currently unknown. As of yet, we do not know what care and treatment goals are recognized for people with dementia at the end of life. Neither do we know how often GPs communicate with their patients with dementia about topics regarding end-of-life care or how often they are aware of their patients' preferences. And while studies have been done regarding avoidable hospitalizations at the end of life, these do not focus specifically on people with dementia.[95,96] Targeted research is needed to provide an overview of these aspects of end-of-life care for people with dementia.

Family involvement and communication

One specific issue with regards to the care for people with dementia is the role of family involvement. The inability of people in advanced stages of dementia to communicate consistently about their wishes for care poses a challenge for healthcare professionals and next of kin alike. In the later stages of dementia, family carers often become responsible for decisions regarding care and treatment, as the person themselves may no longer be able to express their wishes. The EAPC white paper on palliative care for people with dementia recommends shared decision-making, including both the patient and family carers, and a pro-active stance from the healthcare team to determine the information needs of both patient and family with regards to dementia.[29]

In order for family carers to make appropriate decisions it is necessary for them to be aware of their relative's wishes and their current state of health. As was discussed above on page 6, advance care planning can be invaluable to communicate values and wishes for care between patient, family and healthcare professionals early in the disease trajectory. As dementia progresses, however, the patient becomes less and less able to consistently express themselves about their wishes. In the phases of severe and very severe dementia, both formal and informal carers must use their own judgement, based on their knowledge of the patient, to make decisions about care and treatment.

The role of the family carer or proxy decision-maker depends on receiving accurate information. When it comes to dementia, GPs are often hesitant to disclose the diagnosis, and even when they do the patient and their family sometimes do not understand due to euphemisms used or because they resist the stigma attached to the diagnosis.[97,98] The extent to which family carers can be involved in the decision-making process of people with dementia is therefore limited by the accuracy of the information they have received, or have retained. The importance of anticipating and fulfilling the information needs of family carers, as also recommended in the EAPC white paper, is further highlighted by the fact that their understanding of dementia as a terminal illness predicts the patient's comfort at death.[99] While communication between GPs, people with dementia and family carers has been studied, it is unknown to what extent family carers are indeed aware that their next of kin has dementia, and thus what proportion of family carers can or cannot make informed decisions about care.

International comparisons of end-of-life care for older people and people with dementia

Healthcare systems exist within a cultural and political framework which influences how they function, how healthcare is paid for, how healthcare is delivered, and what the outcomes are. There are several important reasons to look at different healthcare contexts when talking about care provided to any particular group of people from a public health perspective.

The first is that comparative research helps to monitor the outcomes of healthcare systems. For example, the Netherlands has shown high levels of advance care planning and communication between care providers and patients compared to Belgium.[100] However, these figures, especially with regards to the completion of advance directives, are still low compared to the USA, where after the Patient Self-Determination Act was passed the number of completed advance directives in medical records of nursing home residents increased seven-fold in two years.[101] By comparing countries, it is possible to identify high performers and best practices (benchmarking) among a number of countries for each domain of end-of-life care.

The second advantage is that internationally comparative research provides us with a frame of reference for how different aspects of a healthcare system produce different outcomes. Since it is difficult if not impossible to seriously alter a healthcare system for the sake of research, comparing the outcomes of 'naturally occurring' differences in systems allows for further understanding of the association between system characteristics and certain outcomes. Not only does this allow us to identify similarities and differences, but also to uncover unique aspects of healthcare in any particular country that would be difficult to recognize as such otherwise – for example, an unusually low rate of transitions between care settings in one country could only be seen as 'unusual' in comparison to other countries.

Finally, comparative research makes it more clear how applicable our studies are to an international context. A study including one country may or may not discover things that apply to other countries as well, but it is difficult to estimate the degree to which this is the case. By including two or more countries, the results become more nuanced, and an international audience can identify better which aspects of which country are comparable to their own. For example, while we might expect the Netherlands and Belgium to have more in common than the Netherlands and Spain, research shows that when it comes to hospitalizations at the end of life the Netherlands resembles the latter far more than the former.[102]

There is still a lack of international comparisons on end-of-life care for older people or people with dementia, despite the unique challenges posed by their specific health issues and their increasing number. Existing international comparisons in the field of end-of-life care focus on people with cancer or heart failure, or take a population-based approach where no specific disease trajectories can be distinguished.[103-108] These studies do not provide us with insight into the specific situation of and care for older people and people with dementia. All countries are expected to have to deal with an ageing population and an increasing number of older people and people with dementia in the near future.[1-4] However, care for older people is arranged differently in various countries, for example with respect to the availability of long-term care facilities.[109] As such, it is important to provide an international perspective on end-of-life care for older people and people with dementia such as is already common for people with cancer.

Research aims

As this introduction has highlighted, there are still important gaps in our knowledge of end-of-life care for older people and people with dementia. Specifically, knowledge is still lacking on the differences in end-of-life care for older people who live in different settings, how advance care planning and palliative care service use for older people has developed over the years, and how different types of healthcare contribute to the costs of care for older patients in the last year of life. For people with dementia, it is unknown what their circumstances at the end of life are with respect to transitions between care settings, availability of palliative care, and treatment goals. Research is also needed on communication between GPs, family carers and people with dementia surrounding topics of end-of-life care. Finally, it is still unknown how these aspects of care compare in an international context. This information is necessary to be able to optimize end-of-life care for older people.

Therefore, the research aims of this dissertation are two-fold:

Research aim 1: To describe end-of-life care for older people in Belgium and other European countries.

To fulfil this aim, we focus on the following specific research questions:

- What are the circumstances of end-of-life care for older people in the home setting and in residential homes in the Netherlands?

- Are there trends in the frequency of use of palliative care services by older people in Belgium between 2005 and 2014?
- Are there trends in the rate of occurrence of advance care planning for older people in Belgium and the Netherlands between 2009 and 2014?
- What are the out-of-pocket costs associated with care in the last year of life of older people in thirteen European countries, and which patient and care characteristics are associated with these costs?

Research aim 2: To describe end-of-life care for people with dementia in Belgium and other European countries.

To fulfil this aim, we focus on the following specific research questions:

- What are the circumstances of end-of-life care for people with dementia in Belgium, Italy and Spain?
- To what extent are family carers aware that their deceased next of kin living in a nursing home had dementia in Belgium?

Methods

To address the research aims of this dissertation, quantitative analyses were performed using three different datasets. Four chapters use population-based retrospective survey data from epidemiological surveillance networks of general practitioners (GP Sentinel networks) from one or more country. One chapter uses data from next of kin of a number of respondents who died during a long-term longitudinal study in 13 countries (Study of Health, Ageing and Retirement in Europe). The final chapter uses retrospective survey data from the nurse, general practitioner and next of kin of a representative sample of deceased Flemish (Dutch-speaking Belgian) nursing home residents with dementia (Dying Well with Dementia).

GP Sentinel networks

General practitioners (GPs) are well placed to provide data on several public health matters, because general practice is normally the point of first medical contact within the healthcare system and should be easily accessible by all people.[110] In some European countries, such as the Netherlands and Spain, they coordinate patient care and provide referrals to specialist services, the so-called ‘gatekeeper’ role. In others, many people have a regular GP whom they consult when necessary; in the case of Belgium, almost 95 per cent of people have a regular GP, with 78 per cent seeing their GP at least once a year.[111] In a number of countries, general practitioner sentinel networks exist which continuously monitor one or more indicators of health problems among their patients. This information can be used to monitor the health of the entire population. Using mainly these existing networks, the SENTIMELC study and later the EURO SENTIMELC study aimed to provide a public health perspective on end-of-life care and circumstances of dying in Belgium, Italy, the Netherlands, and Spain.

The SENTIMELC study first started in 2004 in Belgium and 2005 in the Netherlands. Data collection was repeated in 2007 and 2008. In 2009 and 2010, Italy and two regions of Spain also became involved, leading to the EURO SENTIMELC project. In Belgium, the Netherlands and Spain, existing GP Sentinel networks were used for data collection. In Italy, a GP network representative for the country and performing registration only on end-of-life care was built for this study coordinated by the Italian Cancer Prevention and Research Institute. In 2013 and 2014, data collection was repeated in all four countries, although in Spain and Italy only one region participated in this later wave. In this dissertation, data from 2005 to 2014 is used (see table 1 for an overview of data collection in all countries during this period).

Table 1: SENTIMELC and EURO SENTIMELC data collection per country per year

	Belgium	**Netherlands**	**Spain**	**Italy**
2005	X	X		
2006	X	X		
2007	X			
2008	X	X		
2009	X	X		X
2010	X	X	X[1,2]	X
2011		X	X[1,2]	
2012		X		
2013	X	X	X[1]	X[3]
2014	X	X	X[1]	X[3]
2015				X[3]

1: Castilla y León autonomous community
2: Communitat Valenciana autonomous community
3: Tuscany region

In Belgium, the Netherlands and Spain, GPs were selected to form a representative sample in terms of age, gender and geographical distribution and to cover the whole country or, in the case of Spain, the autonomous communities included in the study. In the Netherlands and Spain, the sample of the population reached by the network is also compared with national data to verify the representativity of the network. In Italy, nine health districts were included in the Sentinel network with three of them located in large metropolitan cities. In 2013 and 2014, the Spanish network was reduced to one autonomous region. In 2013, 2014 and 2015, Italy sampled only from one region, while ensuring both GPs and registered deaths were representative for Italy as a whole in terms of age and gender.

For the SENTIMELC and EURO SENTIMELC studies, GPs registered all deaths of patients of their practice within one week of death via a standardized registration form, either on paper or (especially in later years) electronically. GPs received instructions at the beginning of each calendar year as to the inclusion criteria and how some questions should be completed. In all networks, participation by GPs is voluntary, with GPs in Italy receiving some financial compensation for their participation. The turnover of GPs from year to year is low, and only those GPs who register data at least 26 weeks per year (that is, those who are regular participants) are included for data analyses.

The research protocol was approved by the Medical Ethical Committee of UZ Brussel (University Hospital of Brussels) for Belgium and by the Local Ethical Committee 'Comitato Etico della Azienda U.S.L. n. 9 di Grosseto' in Tuscany for Italy. Posthumous collection of anonymous patient data does not require ethics approval according to Spanish and Dutch law. Data collection is described in more detail in reports published by the Belgian Institute for Public Health[112,113] and the Dutch Institute for Health Services Research[114,115], as well as papers by Van den Block and colleagues (2007, 2013) and Vega Alonso and colleagues (2006).[116-118]

Study of Health, Ageing and Retirement in Europe

The Study of Health, Ageing and Retirement in Europe (SHARE) is an ongoing longitudinal study following several cohorts of people aged 50 and over in an ever-growing number of European countries. Gathering data from more than 60,000 people across 20 European countries, it is one of the largest longitudinal studies on population ageing, with long-term prospects up to 2024. The aim was to interview 1,500 households including at least one person aged 50 or over in each country, selected via (stratified) simple random sampling from national population registers, multi-stage sampling using regional or local population registers, or sampling using telephone directories followed by screening in the field.

The SHARE baseline study was undertaken in 2004 in eleven countries: Denmark, Sweden, Austria, France, Germany, Switzerland, Belgium, the Netherlands, Spain, Italy and Greece. Data is collected in waves, with more countries joining at each wave. In this dissertation, data from the original eleven countries plus the Czech Republic and Poland was used from data collection between 2005 and 2012. Initially, only people who did not live in an institution or long-term care facility were included in data collection, with the exception of the Netherlands and Denmark. In later waves, people who moved to institutions were kept in the sample, and more countries began including people in institutions as new participants. Data collection initially took place via computer assisted personal interviews by professional interviewers, though later waves offered the possibility of computer assisted telephone interviews as well in some countries. These interviews contain a number of questions about socioeconomic status, financial situation, work history, but also functional status and medical care received. The average response rate was 47 per cent across the participating countries in wave 1, staying roughly the same in subsequent waves.

Following up on the respondents who participated in the first wave, some will inevitably have died before the next wave of data collection. New respondents are therefore sampled at the start of each wave in the same manner as for the first wave, who in turn may die before a subsequent wave. When a respondent was confirmed to be deceased, interviewers attempted to locate next of kin who could be asked to complete a so-called ‘end-of-life interview’ about the deceased. The data from this end-of-life interview – that is, data collected from proxy respondents of the subset of the SHARE sample population who died during data collection - is used in this dissertation. This includes decedents from waves 2, 3 and 4 (2005-2012).

The SHARE data collection is described in detail in a number of books, reports and papers, including the changes made in each wave and each country.[119-124]

Dying Well with Dementia

The Dying Well with Dementia study was set up to provide an overview of the circumstances surrounding the end of life of people with dementia living in nursing homes, from the perspective of multiple respondents. This retrospective cross-sectional study was undertaken in Flanders, the Dutch-speaking part of Belgium. Data collection took place between May and October 2013.

A representative sample of nursing homes was selected for inclusion in the study, stratified by region, type and size. During a visit by the researcher to the nursing home, one contact person per nursing home identified all residents with dementia who died over the past three months. To be included in the study, the nursing home residents had to meet the following criteria used by the Belgian health insurance system: either the person had category C dementia (experiences disorientation in time and space almost daily), or was completely care dependent or in need of help for bathing, dressing, eating, continence, toileting and transferring in addition to showing signs of disorientation in time and space. For those who met these criteria, the contact person also identified their general practitioner, the nurse most involved in their care and the relative most involved in their care. A structured questionnaire was sent to these people about the last months of the deceased’s life. In addition, the nursing home administrator completed a questionnaire about the deceased with the aid of the resident’s files. To ensure the anonymity of all respondents, questionnaires were sent by the contact person of the nursing home and not by the researcher.

The research protocol was approved by the Medical Ethical Committee of UZ Brussel (University Hospital of Brussels). Further details on this data collection can be found in the works of Vandervoort and colleagues (2012, 2013, 2014).[125-127]

Analyses

To analyse the data used in this dissertation, a number of statistical methods were used consistently across all chapters.

To calculate differences in means between groups, *t*-tests (for normally distributed populations) or Mann-Whitney U tests (for non-normally distributed populations) were used. Differences between groups in non-continuous outcomes were tested with Pearson's Chi-square tests (for normally distributed populations) or Fisher's exact tests (for non-normally distributed populations).

To analyse the effects of various patient and care characteristics on our chosen outcomes, we used logistic regression analyses. The outcome of these analyses is presented in odds ratios (OR). An OR larger than 1 can be interpreted as a direct increase in the odds of a particular thing happening for that group, e.g. if the effect of gender, coded as 0=male and 1=female, on having a palliative care goal has an OR of 1.5, women have a 50 per cent higher chance of having a palliative care goal than men. An OR lower than 1 indicates lower odds of that same outcome, but cannot be interpreted in the same straightforward manner (i.e. all that can be said is that the odds are lower).

The data used in this dissertation is nested: those decedents who were cared for by the same GP, or who lived in the same country, have more in common with each other than two decedents from different GPs or different countries. To control for this violation of the assumption of independence of observations, robust error clustering or hierarchical linear models were used where appropriate.

To analyse trends in the GP Sentinel network data, trends of the odds across years were calculated. With these analyses, odds ratios were calculated for each year with the first (base) year as reference, adjusting for inputted variables; then, the resulting ORs were tested for trend.

All analyses were performed using Stata Statistical Software: Release 12 (StataCorp. 2011).

Outline of this dissertation

The findings of this research are divided into two sections matching the two research objectives. Part I concerns end-of-life care of older people in Europe. Chapter 2 gives a comparison of end-of-life care for older people living at home and in a residential home in the Netherlands. Chapter 3 contains a trend analysis on the use of palliative care services by older people in Belgium, ranging from 2005 to 2014. In chapter 4, a study of trends in indicators of advance care planning for older people in Belgium and the Netherlands between 2008 and 2014 is presented. In chapter 5, differences in out-of-pocket costs of healthcare in the last year of life of older people in 13 European countries are discussed.

Part II of this dissertation focuses on end-of-life care for people with dementia. Chapter 6 offers a comparison of various aspects of end-of-life care of people dying with dementia in primary care in Belgium, Italy and Spain. The last study in chapter 7 describes how often family carers of nursing home residents dying with dementia in Flanders, Belgium are aware that their relative had dementia, and which patient, family and care characteristics are associated with this awareness.

Finally, this dissertation contains a discussion of the results, including methodological concerns, strengths and limitations, and implications for policy, practice and future research. At the end of this dissertation you can find a summary of the main findings and conclusions in English and in Dutch.

References Chapter 1

1. Organisation for Economic Co-operations and Development. Ageing societies OECD Factbook 2014: Economic, Environmental and Social Statistics. OECD Publishing; 2014.
2. Data extracted from www.mortality.org Accessed on 19/04/2016.
3. Data extracted from Eurostat. ec.europa.eu/eurostat/web/health/health-status-determinants/data/main-tables Accessed on 15/03/2016.
4. WHO. World report on ageing and health, 2015. ISBN: 978 92 4 156504 2. Geneva, Switzerland: World Health Organization.
5. Lee C, Dobson AJ, Brown WJ, Bryson L, Byles J, Warner-Smith P, et al. Cohort Profile: the Australian Longitudinal Study on Women's Health. Int J Epidemiol. 2005 Oct;34(5):987–91.
6. Havighurst RJ. Successful aging. Gerontologist. 1961;1(1):8–13.
7. Butler RN. The study of productive aging. J Gerontol B Psychol Sci Soc Sci. 2002 Nov;57(6):S323.
8. McLaughlin SJ, Connell CM, Heeringa SG, Li LW, Roberts KS. Successful Aging in the United States: Prevalence Estimates From a National Sample of Older adults. J Gerontol B Psychol Sci Soc Sci. 2010;65B(2):216-226.
9. Marengoni A, Angleman S, Melis R, Mangialasche F, Karp A, Garmen A, et al. Aging with multimorbidity: a systematic review of the literature. Ageing Res Rev. 2011 Sep;10(4):430–439.
10. Gill TM, Gahbauer EA, Han L, Allore HG. Trajectories of disability in the last year of life. N Engl J Med 2010;362:1173-1180.
11. Goodwin N, Sonola L, Thiel V, Kodner DL. Co-ordinated care for people with complex chronic conditions: key lessons and markers for success. London: The King's Fund; 2013. Available from www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/co-ordinated-care-for-people-with-complex-chronic-conditions-kingsfund-oct13.pdf Accessed on 18/03/2016.
12. Smith SM, Soubhi H, Fortin M, Hudon C, O'Dowd T. Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. BMJ. 2012;345:e5205.
13. Peron EP, Gray SL, Hanlon JT. Medication use and functional status decline in older adults: a narrative review. Am J Geriatr Pharmacother. 2011 Dec;9(6):378–91.
14. Lehnert T, Heider D, Leicht H, Heinrich S, Corrieri S, Luppa M, Riedel-Heller S, König HH. Review: Healthcare utilization and costs of elderly persons with multiple chronic conditions. Med Care Res Rev 2011 Aug;68(4):387-420.
15. Aldridge MD, Kelly AS. The myth regarding the high cost of end-of-life care. Am J Public Health.2015;105:2411-2415. doi:10.2105/AJPH.2015.302889.
16. KCE Report 190As: Position paper: Organisatie van zorg voor chronische zieken in België. Paulus D, Van den Heede K, Mertens R (eds.) 2012. Available from kce.fgov.be/nl/publication/report/position-paper-organisatie-van-zorg-voor-chronisch-zieken-in-belgie

17. KCE Report 259A : De performantie van het Belgische gezondheidssysteem – Rapport 2015. 2016. Available from www.healthcare-executive.be/sites/default/files/uploads/healthcareexecutive/2016/actuality/he0933n_rapportperformanties.pdf
18. Jorm AF, Jolley D. The incidence of dementia: a meta-analysis. Neurology 1998;51:728–733.
19. Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen BD, Deliens L. Place of death of older persons with dementia. A study in five European countries. J. Am Geriatr Soc. 2010;58(4):751-756.
20. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J Am Geriatr Soc. 2005;53(2):299-305.
21. Langton JM, Blanch B, Drew AK, Haas M, Ingham JM, Pearson S-A. Retrospective studies of end-of-life resource utilization and costs in cancer care using health administrative data: A systematic review. Palliat Med. 2014 May 27;28(10):1167-1196.
22. Riley GF, Lubitz JD. Long-term trends in Medicare payments in the last year of life. Health Serv Res. 2010 Apr;45(2):565–76.
23. Rosenwax LK, McNamara BA, Murray K, McCabe RJ, Aoun SM, Currow DC. Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care. Med J Aust. 2011 Jun 6;194(11):570-3.
24. WHO Definition of palliative care. World Health Organization. www.who.int/cancer/palliative/definition/en Retrieved on 19/03/2016.
25. Murray SA, McLoughlin P. Illness trajectories and palliative care: Implications for holistic service provision for all in the last year of life. In: Sallnow L, Kumar S, Kellehear A. International Perspectived on Public Health and Palliative Care. New York. Routledge; 2012.
26. De Vleminck A, Pardon K, Beernaert K, et al. Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences. PLoS ONE. 2014;9(1): e84905.
27. Chang A, Walter LC. Recognizing dementia as a terminal illness in nursing home residents: Comment on "Survival and comfort after treatment of pneumonia in advanced dementia". JAMA Internal Medicine 2010;170(13):1107-1109.
28. Mitchell SL, Keily DK, Hamel MB. Dying with advanced dementia in the nursing home. Archives of Internal Medicine 2004;164:321–328.
29. Van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. Palliat Med. 2014;28(3):197-209.
30. Pivodic L, Pardon K, Van den Block L, Van Casteren V, Miccinesi G, Donker GA, et al. 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.

31. Sampson EL, Gould V, Lee D, Blanchard MR. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. Age and Ageing *2006;*35*:*187–189.
32. Connor SR, Sepulveda Bermedo MC (ed.). Global Atlas of Palliative Care. World Health Organization, 2014.
33. Radbruch L, de Lima L, Lohmann D, Gwyther E, Payne S. The Prague Charter: urging governments to relieve suffering and ensure the right to palliative care. Palliative medicine. 2013 Feb 1;27(2):101-2.
34. Centeno C, Lynch T, Donea O, Rocafort J, Clark D. EAPC atlas of palliative care in Europe 2013-full edition.
35. Wiles JL, Leibing A, Guberman N, Reeve J, Allen RES. The meaning of "Ageing in place" to older people. The Gerontologist 2011;52(3):357-366.
36. Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older people's views about home as a place of care at the end of life. Palliative Medicine, 2004;18(5):460-467.
37. Gomes B, Higginson IJ. Where people die (1974-2030): past trends, future projections and implications for care. Palliat Med. 2008;22(1):33-41.
38. Bonsang E. Does informal care from children to their elderly parents substitute for formal care in Europe? Journal of Health Economics. 2000;28:143-154.
39. Gaugler JE, Yu F, Krichbaum K, Wyman J. Predictors of nursing home admission for persons with dementia. Medical Care 2009;47(2):191-198.
40. Buhr GT, Kuchibhatia M, Clipp WC. Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to transition. The Gerontologist 2006;46(1):52-61.
41. Data from Flemish health insurance providers, 2014. Available from www.vlaamsezorgkas.be/Cijfers/Vlaamse-zorgverzekering/Lopende-dossiers-tenlastenemingen Retrieved 10/04/2016.
42. Abarshi E, Onwuteaka-Philipsen B, Donker G, Echteld M, Van den Block L, Deliens L. General practitioner awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands. J Pain Symptom Manage 2009;38:568-577.
43. Neergaard MA, Vedstad P, Olesen F, Sokolowski I, Jensen AB, Sondergaard J. Associations between home death and GP involvement in palliative cancer care. Br J Gen Pract 2009;59:671-677.
44. Burge F, Lawson B, Johnston G. Family physician continuity of care and emergency department use in end-of-life cancer care. Med Care 2003;992-1001.
45. Michiels E, Deschepper R, Van der Kelen G, Bernheim JL, Mortier F, Vander Stichele R, Deliens L. The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin. Palliat Med. 2007;21(5):409-415.

46. Mitchel GK. How well do general practitioners deliver palliative care? A systematic review. Palliat Med. 2002;16:457-464.
47. Groot MM, Vernooij-Dassen MJFJ, Crul BJP, Grol RPTM. General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. Palliat Med. 2005;19(2):111-118.
48. Slort W, Schweitzer BPM, Blankenstein AH et al. Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. Palliat Med 2011;25(6):613-629.
49. Brown M. Participating in end of life decisions. The role of general practitioners. Aust Fam Physician 2002 Jan;31(1):60-2.
50. Hall S, Kolliakou A, Petkova H, Froggatt K, Higginson IJ. Interventions for improving palliative care for older people living in nursing care homes. The Cochrane Library. 2011 Jan 1.
51. Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. Medical care. 2009 Feb 1;47(2):191-8.
52. Gaugler JE, Wall MM, Kane RL, Menk JS, Sarsour K, Johnston JA, Beusching D, Newcomer R. The effects of incident and persistent behavioral problems on change in caregiver burden and nursing home admission of persons with dementia. Medical care. 2010 Oct 1;48(10):875-83.
53. Luppa M, Luck T, Matschinger H, König HH, Riedel-Heller SG. Predictors of nursing home admission of individuals without a dementia diagnosis before admission-results from the Leipzig Longitudinal Study of the Aged (LEILA 75+). BMC health services research. 2010 Jun 29;10(1):1.
54. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. JAMA 1995;274:1591-1598.
55. Brinkman-Stoppelenburg A, Rietjens JAC, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. P*alliat Med* 2014;28(8):1000-1025.
56. Meeussen K, Van den Block L, Echteld M, Boffin N, Bilsen J, Van Casteren V, et al. Older people dying with dementia: a nationwide study. Int Psychogeriatrics. 2012;24(10):1581–91.
57. Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ. Efficacy of Advance Care Planning: A systematic review and meta-analysis. J Am Med Dir Assoc 2014 Mar 2.
58. Detering KM, Hancock AD, Reade MC , Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ, 2010; 340:c1345.
59. Engel SE, Keily DK, Mitchell SL. Satisfaction with end-of-life care for nursing home residents with advanced dementia. Journal of the American Geriatrics Society 2006;54:1567-1572.
60. World Health Organization. Better Palliative Care for Older People. 2004. Copenhagen, Denmark: WHO.
61. Piers R, van Eechoud IJ, Van Camp S, Grypdonck M, Deveugele M, Verbeke NC, Van den Noortgate NJ. Advance Care Planning in terminally ill and frail older persons. Patient Education and Counseling 2013;90(3):323-329.

62. Sacco RL, Benjamin EJ, Broderick JP, Dyken M, Easton JD, Feinberg WM, Goldstein LB, Gorelick PB, Howard G, Kittner SJ, Manolio TA. Risk factors. Stroke. 1997 Jul 1;28(7):1507-17.
63. Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, Howel D, Exley C. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. Age and Ageing. 2012 Mar 1;41(2):263-9.
64. Current Controlled Trials [Internet]. London: Boimed Central. ISRCTN14741671, PACE: cluster randomised controlled trial on 'PACE Steps to Success' palliative care programme in Long Term Care Facilities in Europe; 31/03/2016. Available from www.isrctn.com/ISRCTN14741671 Accessed on 04/07/2016.
65. Ginzberg E. The high costs of dying. Inquiry. 1980;17:293–5.
66. Scitovsky AA, Capron AM. Medical care at the end of life: the interaction of economics and ethics. Annu Rev Public Health. 1986;7:59–75.
67. Lubitz JD, Riley GF. Trends in Medicare payments in the last year of life. N Engl J Med. 1993;328:1092–6.
68. Emanuel EJ, Ash A, Yu W, Gazelle G, Levinsky NG, Saynina O, et al. Managed care, hospice use, site of death, and medical expenditures in the last year of life. Arch Intern Med. 2002;162(15):1722–8.
69. Curtis JR, Engelberg R a, Bensink ME, Ramsey SD. End-of-life care in the intensive care unit: can we simultaneously increase quality and reduce costs? Am J Respir Crit Care Med. 2012 Oct 1;186(7):587–92.
70. Polder JJ, Barendregt JJ, Van Oers H. Healthcare costs in the last year of life - The Dutch experience. Soc Sci Med. 2006;63(7):1720–31.
71. Chastek BB, Harley C, Kallich J, Newcomer L, Paoli CJ, Teitelbaum AH. Healthcare Costs for Patients With Cancer at the End of Life. J Oncol Pract. 2012;8(6s):75–80.
72. Asmus-Szepesi KJE, Koopmanschap M a., Flinterman LE, Bakker TJEM, Mackenbach JP, Steyerberg EW. Formal and informal care costs of hospitalized older people at risk of poor functioning: a prospective cohort study. Arch Gerontol Geriatr. Elsevier Ireland Ltd; 2014 May;58(2):382-392.
73. Fassbender K, Fainsinger RL, Carson M, Finegan B a. Cost trajectories at the end of life: the Canadian experience. J Pain Symptom Manage. Elsevier Inc; 2009 Jul;38(1):75–80.
74. Himmelstein DU, Thorne D, Warren E, Woolhandler S. Medical bankruptcy in the United States, 2007: results of a national study. Am J Med. Elsevier Inc.; 2009 Aug;122(8):741–6.
75. Gardiner C, Brereton L, Frey R, Wilkinson-Meyers L, Gott M. Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature. Palliat Med 2014; 28(5): 375-390.
76. Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. Palliat Med. 2014 Feb 1;28(2):130–50.

77. Soumerai SB, Pierre-Jacques M, Zhang F, et al. Cost-related medication nonadherence among elderly and disabled Medicare beneficiaries. *Arch Intern Med* 2006; 166: 1829–1835.
78. Chao L-W, Pagán JA and Soldo BJ. End-of-life medical treatment choices: do survival chances and out-of-pocket costs matter? *Med Decis Making* 2008; 28(4): 511–523.
79. Papastavrou E, Kalokerinou A, Papacostas SS, Tsangari H, Sourtzi P. Caring for a relative with dementia: family caregiver burden. Journal of Advanced Nursing, 2007;58(5):446-457.
80. Andrén S, Elmståhl S. Relationships between income, subjective health and caregiver burden in caregivers of people with dementia in group living care: a cross-sectional community-based study. International journal of nursing studies. 2007 Mar 31;44(3):435-46.
81. International statistical classification of diseases and related health problems, 10th revision. Geneva, World Health Organization: 1992.
82. Prince M, Wimo A, Guerchet M, Ali G, Wu YT, Prina M. World Alzheimer Report 2015. The global impact of dementia. An analysis of prevalence, incidence, cost and trends. Alzheimer's Disease International, London. 2015.
83. World Alzheimer’s Report 2009. London, Alzheimer’s Disease International, 2009.
84. Dementia WH. A Public Health Priority. Geneva: World Health Organization. 2012.
85. Prince M, Guerchet M, Prina M. World Alzheimer report 2013: Journey of caring: an analysis of long-term care for dementia. Alzheimer's Disease International; 2013.
86. Gessert CE, Forbes S, Bern-Klug M. Planning end-of-life care for patients with dementia: roles of families and health professionals. Omega (Westport), 2000, 42:273–291.
87. Caron C, Griffith J, Arcand M: Decision making at the end of life in dementia: how family caregivers perceive their interactions with healthcare providers in long-term- care settings. J Appl Gerontol 2005, 24:231–247.
88. Low L-F, Anstey KJ. Dementia literacy: recognition and beliefs on dementia of the Australian public. Alzheimers Dementia. 2009;5:43–49.
89. Iliffe S, Manthorpe J, Eden A. Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study. Family Practice. 2003;20(4):376-381.
90. Vernooij-Dassen MJFJ, Moniz-Cook ED, De Lepeleire J, Zanetti O, de Rotrou J, et al. Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma.
91. Woods RT, Moniz-Cook ED, Iliffe S, et al. Dementia: issues in early recognition and intervention in primary care. J Roy Soc Med. 2003;96(7):320-324.
92. Moise P, Schwarzinger M, Myung-Yong U and the dementia expert group. Dementia Care in 9 OECD countries: A comparative analysis. OECD Health Working Papers. 2004.
93. Bamford C, Lamont S, Eccles M, et al. Disclosing a diagnosis of dementia: a systematic review. *Int J Geriatr Psychiatry* 2004; 19(2): 151–169.
94. Maguire C, Kirby M, Coen R, Coakley D, Lawlor B, O’Neill D . Family members’ attitudes toward telling the patient with Alzheimer’s disease their diagnosis. British Medical Journal, 1996;313:529–530.

95. *Reyniers T. Hospital admissions at the end of life: Reasons, appropriateness and avoidability. 2015. Brussels, Belgium: VUBPRESS Brussels University Press.*
96. *De Korte-Verhoef R. Reasons and avoidability of hospitalisations at the end of life. 2014. ISBN: 978-90-6464-799-4*
97. Zaleta AK, Carpenter BD, Porensky EK, et al. Agreement on diagnosis among patients, companions, and professionals after a dementia evaluation. *Alzheimer Dis Assoc Disord* 2012; 26:232–237.
98. Pucci E, Belardinelli N, Borsetti G, et al. Relatives' attitudes towards informing patients about the diagnosis of Alzheimer's disease. *J Med Ethics* 2003; 29(1): 51–54.
99. Van der Steen JT, Onwuteaka-Philipsen BD, Knol DL, Ribbe MW, Deliens L. Caregivers' understanding of dementia predicts patients' comfort at death: a prospective observational study. BMC medicine. 2013 Apr 11;11(1):1.
100. Meeussen K, Van den Block L, Echteld M, Bossuyt N, Bilsen J, Van Casteren V, Abarshi E, Donker G, Onwuteaka-Philipsen B, Deliens L. Advance care planning in Belgium and The Netherlands: a nationwide retrospective study via sentinel networks of general practitioners. Journal of pain and symptom management. 2011 Oct 31;42(4):565-77.
101. Bradley EH, Wetle T, Horwitz SM. The Patient Self-Determination Act and advance directive completion in nursing homes. Archives of Family Medicine, 1998;7(5): 417–423.
102. Pivodic L, Pardon K, Miccinesi G, Vega Alonso T, Moreels S, Donker GA, Arrieta E, Onwuteaka-Philipsen B, Deliens L, Van den Block L. Hospitalisations at the end of life in four European countries: a cross-national population-based mortality followback study. Journal of Epidemiology and Community Health, 2015, doi:10.1136/jech-2015-206073
103. Pivodic L. End-of-life care: An international perspective. 2015. Brussels, Belgium: VUBPRESS Brussels University Press.
104. Ko W. Dying with cancer: An international perspective. 2015. Brussels, Belgium: VUBPRESS Brussels University Press.
105. De Roo M. Quality Indicators for palliative care from an international perspective. 2015. Amsterdam, the Netherlands: VU University Press.
106. Evans N. Patient-physician communication at the end of life: A European perspective. 2014. Amsterdam, the Netherlands: VU University Press.
107. Anquinet L. Continuous sedation until death. Experiences of health care professionals in Belgium, the Netherlands and the United Kingdom. 2013. Brussels, Belgium: VUBPRESS Brussels University Press.
108. Houttekier D. Place of death and circumstances of dying: studies in a metropolitan, national and international context. 2011. Brussels, Belgium: VUBPRESS Brussels University Press.
109. Kraus M, Rieder M, Mot E, Willemé P, Röhrling G, Czypionka T. Typology of Systems of Long-Term Care in Europe: Results of Work Package 1 of the ANCIEN Project. Vienna, 2010: Institute for Advanced Studies. Available from www.ancien-longtermcare.eu Accessed on 04-06-2016.

110. Evans P (ed.). The European definitions of the key features of the discipline of general practice, the role of the general practitioner and a description of the core competencies of the general practitioner/family physician. WONCA EUROPE, 2002.
111. Demarest S, Hesse E, Drieskens S, Van der Heyden J, Gisle L, Tafforeau J. Health Interview Study Belgium, 2008. Operationele Directie Volksgezondheid en surveillance, 2010; Brussel; Wetenschappelijk Instituut Volksgezondheid; ISSN: 2032-9172 – Depotnummer. D/2010/2505/35 – IPH/EPI REPORTS N° 2010/038. 2010.
112. Boffin N, Moreels S, Van Casteren V. The Belgian network of Sentinel General Practices between 2007 and 2012: a short report. 2013. Brussels, Scientific Institute of Public Health, OD Public Health and Surveillance, Health Services Research. Available from https://www.wiv-isp.be/epidemio/epien/medven/D_2013_2505_40.pdf
113. Van Casteren V. Thirty years Registration Network of Sentinel General Practitioners. *Arch Public Health* 2009; 67(supplement 2):3-15.
114. Donker GA. NIVEL Primary Care Database - Sentinel Practices 2013. Annual report. Utrecht, NIVEL, 2015. Available from www.nivel.nl/node/2430?database=ChoicePublicat&priref=1002563 Accessed on 21/04/2016.
115. Donker GA. NIVEL Primary Care Database - Sentinel Practices 2014. Annual report. Utrecht, NIVEL, 2016. Available from www.nivel.nl/sites/default/files/bestanden/Peilstations-jaarverslag-2013-Engels.pdf Accessed on 25/04/2016.
116. Van den Block L, Van Castern V, Deschepper R, Bossuyt N, Drieskens K, Bauwens S et al. Nationwide monitoring of end-of-life care via the Sentinel Network of General Practitioners in Belgium: the research protocol of the SENTI-MELC study. BMC Palliat Care 2007 October 8;6(1):6.
117. Van den Block L, Onwuteaka-Philipsen B, Meeussen K, Donker G, Giusti F, Miccinesi G, et al.Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. BMC Fam Pract. BMC Family Practice 2013 Jun 3;14(1):73.
118. Vega Alonso AT, Zurriage Llorens O, Galmés Truyols A, Lozano Alonso JE, Paisán Maestro L, Gil Costa M, et al. Guide to the principles and methods of health sentinel networks in Spain. Europe PMC, 2006;20(suppl 3):52-60.
119. Börsch-Supan A, Brugiavini A, Jürges H, Kapteyn A, Mackenbach J, Siegrist J, et al. First Results from the Survey of Health , Ageing and Retirement in Europe (2004-2007). Starting the longitudinal dimension. Mannheim: Mannheim Research Institute for the Economics of Aging (MEA); 2008.
120. Börsch-Supan A, Brandt M, Hunkler C, Kneip T, Korbmacher J, Malter F, et al. Data Resource Profile: the Survey of Health, Ageing and Retirement in Europe (SHARE). Int J Epidemiol. 2013 Aug 1;42(4):992–1001.

121. Börsch-Supan A, Brandt M, Litwin H, Weber G, editors. Active ageing and solidarity between generations in Europe: First results from SHARE after the economic crisis. Berlin: De Gruyter; 2013.
122. Börsch-Supan A, Brandt M, Hank K, Schröder M, editors. The individual and the welfare state. Life histories in Europe. Heidelberg: Springer; 2011.
123. Schröder M. Retrospective data collection in the Survey of Health, Ageing and Retirement in Europe. SHARELIFE methodology. Mannheim: Mannheim Research Institute for the Economics of Aging (MEA); 2011.
124. Malter F, Börsch-Supan A, editors. SHARE Wave 4: Innovations & Methodology. Munich: MEA, Max Planck Institute for Social Law and Social Policy; 2013.
125. Vandervoort A, Van den Block L, Van der Steen JT, et al. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying. *J Am Med Dir Assoc* 2013; 14: 485–492.
126. Vandervoort A, Houttekier D, Van den Block L, et al. Advance care planning and physician orders in nursing home residents with dementia: a nationwide retrospective study among professional caregivers and relatives. *J Pain Symptom Manage* 2014; 47(2): 245–256.
127. Vandervoort A, Van den Block L, Van der Steen JT, et al. Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. *Int Psychogeriatr* 2012; 24(7): 1133–1143.

Part I: End-of-life care for older people in different European countries

CHAPTER 2: Comparison of end-of-life care for older people living at home and in residential homes: a mortality follow-back study among GPs in the Netherlands

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Abstract

Background

Due to the growing proportion of older people, their place of residence and place of care at the end of life is becoming increasingly important.

Aim

To compare aspects of end-of-life care among older people in residential homes and home settings in the Netherlands.

Methods

Nationwide representative mortality follow-back study among GPs. The study included patients who died non-suddenly over the age of 65, whose longest place of residence in the last year of life was home or a residential home (n=498). Differences were analysed using Pearson's Chi-square test, Mann-Whitney U tests and multivariate logistic regression.

Results

Controlling for the differences between the populations in home settings and residential homes, we found no differences in treatment goals, communication about end-of-life care or use of specialized palliative care between the two settings. However, people living in a residential home were more likely to have received palliative care from a GP than people at home (OR=2.84). In residential homes, people more often experienced both no transfer between care settings (OR=2.76) and no hospitalizations (OR=2.2) in the last three months of life, and less often died in hospital (OR=.78) than people living at home.

Conclusion

Despite similar treatment goals, care in residential home seems more successful in avoiding transfers and hospitalization at the end of life. Especially since older people are encouraged to stay at home longer, measures should be taken to ensure they are not at higher risk of transfers and hospitalizations in this setting.

Introduction

The population of Europe is ageing, with the proportion of those living beyond 60 increasing each year.[1] As a result, there is a growing need for care over a longer period of time, increasing the burden on healthcare systems.[2-4] To limit this burden, policy initiatives encourage people to stay at home longer and make less use of relatively expensive institutionalized care.[1,5,6]

In the Netherlands, older people who are severely care dependent most often live in nursing home, where they are cared for by an in-house physician and nursing staff. Older people with lower care needs may either live at home or in a residential home. Residential homes provide continuous on-site nursing aid with activities of daily living such as eating or bathing, but do not have on-site medical care and only some provide psychogeriatric care for people with dementia. In both settings care is primarily provided by GPs, who are considered to be appropriate care givers for many situations including care at the end of life.

While many people would prefer to die at home, a sizeable percentage would prefer to die in a residential home.[7,8] Although it is known that a person's quality of life in the final phase of life and quality of death can be affected by care setting, studies often do not directly compare care setting or place of residence.[9] Those that do focus primarily on subjective measures of care, such as family's satisfaction with care.[10] How the care received by older people living at home compares with that received by those living in a residential home is yet unknown.

Several aspects of end-of-life care that influence its quality might differ depending on the care setting or place of residence of a patient. One of these is recognizing when aggressive or curative treatment or hospitalization is no longer beneficial[11-13] as hospitalizations may complicate care provision and result in a lower quality of death.[14] Recognizing when the end of life is near has been shown to reduce the chance of hospitalization in the last month of life, as has having a palliative treatment aim.[15] Likewise, the provision of palliative care has been shown to reduce the number of hospitalizations.[16,17] These three aspects of care –having a palliative treatment aim, following up with providing palliative care, and reducing unnecessary hospitalizations near the end of life – all play an important role in the quality of end-of-life care and should be present in all care settings.

The aim of this paper is to examine and compare different aspects of end-of-life care in the last three months of life among older people in residential homes and home settings in the Netherlands. Specific research questions include:

- Are there population differences between older people in home settings and older people in residential homes?
- Do treatment goals in the last three months of life differ between people in home settings and people in residential homes?

- Are there differences in palliative care provision for people in home settings and people in residential homes?
- Do transitions between care settings and hospitalizations in the last three months of life differ between people in home settings and people in residential homes?

Methods

Study design and data collection

The data used in this study was collected via the Netherlands Institute of Health Services Research (NIVEL) Primary Care Database, Sentinel Practices, operating since 1970. The network is managed to encompass a sample of 0.8% of the Dutch population representative in terms of age, sex, and population density. GPs are invited to participate on the basis of their practice population characteristics so that the sample remains representative. Upon accepting the invitation, GPs first participate in a 2-month trial period to assess their reporting accuracy and motivation before becoming regular participants (registering 26 weeks or more of one year, usually for several years). Participating GPs record demographic and care characteristics for all deaths of practice patients using a standardized registration form within one week of the patient's death.[18]

Sample

There were 801 patients who died in the 40 participating GP practices between 1 January 2011 and 31 December 2012.[19] All patients who died non-suddenly at the age of 65 and over and whose longest place of residence in the last year of life had been a home setting (either their own home or a relative's home) or a residential home were included, comprising a total sample of 498 patients.

Measurements

Demographic characteristics included gender, age at time of death, cause of death, having dementia, main place of residence in the last year of life and place of death. In addition, several care characteristics were registered:

- Treatment goals: GPs were asked to indicate the importance of a palliative, curative or life-prolonging treatment goal 2-3 months before death, 2-4 weeks before death, and 1 week before death on a 5-point Likert scale ranging from 'not important at all' to 'very important'. Scores of 4 and 5 were interpreted as that treatment goal being 'important'.

- Palliative care provisions: GPs were asked to indicate whether their patient had received palliative care provided by the GPs themselves, by a GP with formal palliative care training or by any of a number of specialized palliative care services. Options were by a palliative care consultant; in a hospice; in a palliative care unit in a hospital; in a palliative care unit in a residential, care or nursing home; and ‘other’. If a specialized palliative care service had been used, GPs were asked to indicate how many days before death palliative care was first provided. GPs were also asked if the patient had ever expressed a preference for a place of death, a proxy decision maker, or about any medical end-of-life treatments.
- Care trajectories: GPs were asked to indicate when patients were transferred between care settings during the last three months of life, and how long the patients staid at each care setting. GPs could give details on a maximum of four care settings and three transitions.

Analyses

Differences between groups were tested using Pearson’s Chi-square test or Mann-Whitney U tests. Multivariate logistic regression was used to analyse associations between longest place of residence (as dependent variable) and several care characteristics while controlling for age, gender, cancer or non-cancer, and having dementia or not. Robust standard errors were used to account for clustering within GP practices. All analyses were performed using Stata Statistical Software: Release 12 (StataCorp. 2011).

Results

Population differences between residential settings

We studied 400 people of 65 years of age or more living at home in the last year of life, and 98 who lived in a residential home (table 1). The average age at death of people living at home was 81 (SD=23) compared to 87 (SD=7) for those in a residential home (p=.02). Of those living at home, 43% were women compared to 63% of those in a residential home (p<.001). There were significant differences between the two groups in cause of death (p<.001). People living at home were more likely to have died of cancer (54%) compared to those in a residential home (25%), whereas those in a residential home were more likely to have died of cardiovascular disease (15% versus 25%), respiratory disease (5% versus 11%) or old age (11% versus 24%). Residents of a residential home were more likely to have dementia (p<.001), with 16% having mild dementia and 17% having severe dementia, compared to 8% and 5% respectively for those living at home.

Table 1: Characteristics of the study population (n=498)*

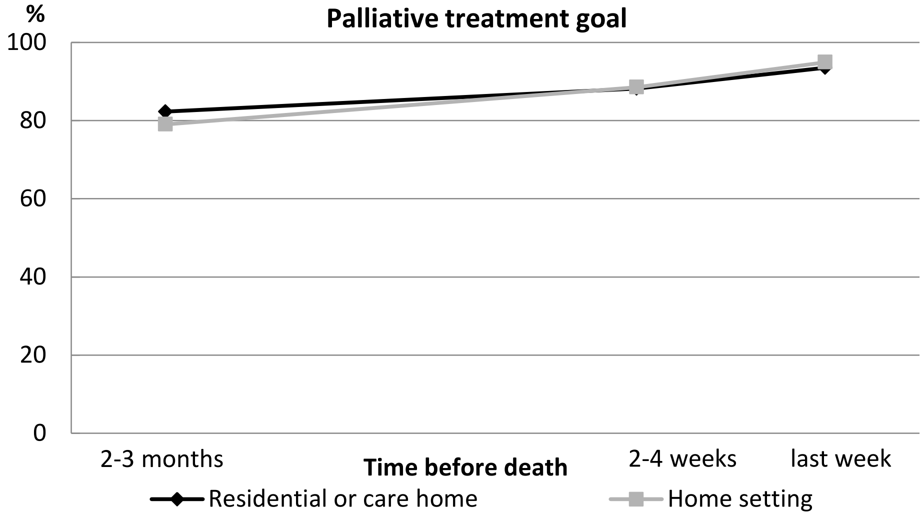
	Home setting (n=400)	Residential home (n=98)	
	n (%)	n (%)	*p* value
Age at death (mean, S.D.)	81 (23)	87 (7)	**.02**
Gender, female	171 (43)	62 (63)	**<.001**
Cause of death			
Malignancies	216 (54)	24 (25)	**<.001**
Cardiovascular disease	61 (15)	24 (25)	
Respiratory disease	21 (5)	11 (11)	
Disease of nervous system	7 (2)	2 (2)	
Stroke (CVA)	22 (6)	2 (2)	
Old age	44 (11)	23 (24)	
Other	27 (7)	11 (11)	
Dementia			
None	334 (88)	57 (66)	**<.001**
Mild	29 (8)	14 (16)	
Severe	18 (5)	15 (17)	

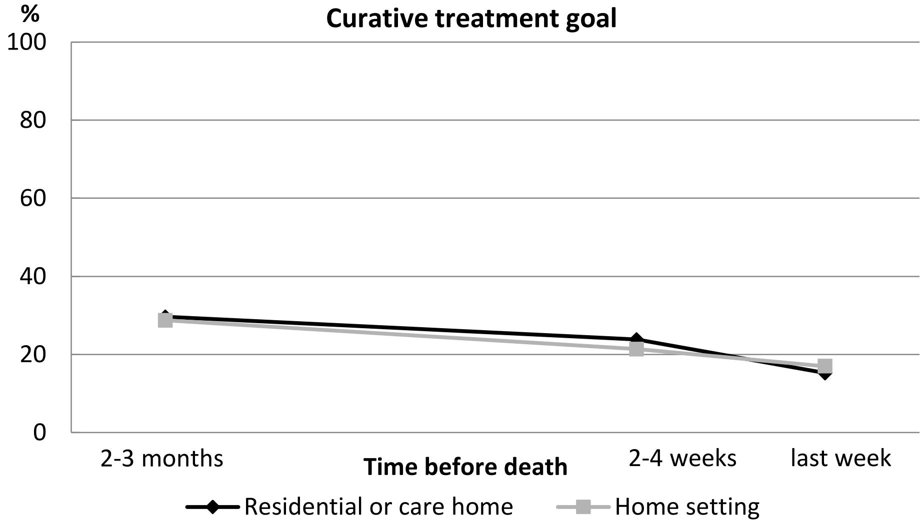
* missing for cause of death=3, dementia=31

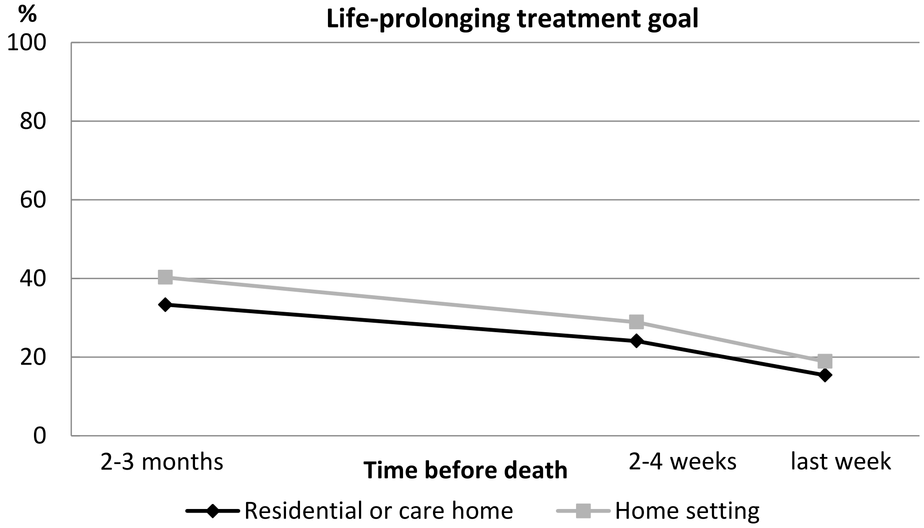
Treatment goals in the last three months of life

Two to three months before death, a palliative treatment goal was considered important for 79% of those living at home and 82% of those in a residential home (figure 1). This increased to 95% and 94% respectively in the last week of life. Two to three months before death a curative treatment goal was considered important for 29% of those living at home and 30% of those in a residential home, decreasing to 17% and 15% respectively in the last week of life. A life-prolonging treatment goal was considered important in the last two to three months of life for 40% of those living at home and 33% of those in a residential home, decreasing to 19% and 15% respectively in the last week of life. There were no significant differences in treatment goals between the two groups at any time point, either in bivariate analyses or after controlling for patient characteristics.

Figure 1: Percentage of patients for whom a palliative, curative and life-prolonging treatment goal was important during last 3 months of life in home settings and residential homes







Palliative care provision and communication in the last three months of life

Those in a residential home setting were more likely to have received palliative care from their GP (58%, table 2) than those living at home (53%, OR= 2.84, 95%CI=1.41-5.07). Likewise, palliative care from a GP with formal palliative care training was provided more often to those in a residential home (24%) than those living at home (7%; OR=6.26, 95%CI=2.88-13.66). There were no significant differences in overall frequency of care received from specialized palliative care initiatives, though only those living at home received specialized care in a palliative care unit in a hospital (1%) or from other sources (6%). Specialized palliative care was initiated a median of 14 days before death for those living at home, and 12 days before death for those in a residential home.

Table 2: Palliative care provision and communication at the end of life of patients in home settings and residential homes (n=498)*

	Home setting (n=400)	Residential home (n=98)	
	n (%)	n (%)	OR (95% CI)†
Palliative care provided by GP	208 (53)	56 (58)	**2.84 (1.41-5.07)**
By GP with formal palliative care training	19 (7)	16 (24)	**6.26 (2.88-13.66)**
Specialized palliative care initiatives:			
Any specialized palliative care	93 (26)	10 (12)	.57 (.32-1.07)
Palliative care consultant	28 (11)	3 (5)	1.47 (.41-5.33)
Hospice	16 (6)	3 (5)	1.29 (.29-5.65)
Palliative care unit in a hospital	3 (1)	-	-
In-house palliative care service in residential/care/nursing home	15 (6)	3 (5)	.695 (.14-3.48)
Other	24 (6)	-	-
Initiation of palliative care in days before death (median)	14	12	1.005 (.997-1.01)
GP was aware of patient's preference			
About a medical end-of-life treatment	204 (52)	49 (51)	1.56 (.85-2.86)
For place of death	224 (56)	53 (55)	1.55 (.67-3.61)
For proxy decision maker	113 (29)	25 (26)	1.27 (.77-2.1)

OR = odds ratio CI = confidence interval

* missing for palliative care received = 28, initiation of palliative care in days before death = 218, preference end-of-life treatment = 7, preference place of death = 3, preference proxy = 7

† multivariate logistic regression controlling for age, cancer/non-cancer, dementia and gender. Reference group is home setting

The GPs were aware of their patient's preference about a medical end-of-life treatment in 52% of cases for those living at home and 51% of cases for those in a residential home. The patient's preference for a place of death was known in 56% of cases for those living at home and 55% of cases for those in a residential home. The patient had expressed a preference for a proxy decision maker in 29% of cases for those living at home and 26% of cases for those in a residential home. There were no significant differences between groups in the GP's awareness of patient's preferences.

Transitions between care settings in the last three months of life

People living in a residential home had not experienced any transitions between care settings in the last three months of life in 69% of cases, compared with 46% of those living at home (table 3, OR=2.76, 95%CI=1.35-5.63). For 17% of those in a residential home and 34% of those living at home, there was one transition in the last three months of life (OR=.29, 95%CI=.12-.67). There were no significant differences between the groups for those who experienced two or more transitions . The most frequent care trajectory for those who experienced at least one transition was to move from their place of residence to hospital, occurring in 25% of cases for those living at home and 10% of cases for those in a residential home (OR=.25, 95%CI=.11-.58). In the last week of life, 22% of those living at home and 15% of those in a residential home were transferred to another care setting.

Hospitalizations in the last three months of life were less frequent for those in a residential home, where 72% was not hospitalized during this time, than for those living at home, where 53% was not hospitalized (OR=2.2, 95%CI=1.04-4.67). People living at home who were hospitalized, spent a total average of 12 days (SD=12.5) in hospital, compared to an average of 11 days (SD=11) for those in a residential home. People in a residential home were less likely to die in hospital (16% of cases) compared to people living at home (30% of cases; OR=.78, 95%CI=.63-.97). In both groups, 79% of people died at their place of preference.

The maximum length of hospital stay for those whose stay ended in death in hospital was 51 days (figure 2). Those living at home were more likely to be admitted to hospital longer before death than those in a residential home, with an odds ratio of 1.1 (95%CI=1.01-1.19) per day.

Table 3: Transitions between care settings in the last three months of life and place of death of people in home settings and residential homes (n =498)*

	Home setting (n=400)	Residential home (n=98)	
	n (%)	n (%)	OR (95% CI)†
Transitions between care settings			
Number of transitions in the last three months of life‡			
None	183 (46)	68 (69)	**2.76 (1.35-5.63)**
1	134 (34)	17 (17)	**.29 (.12-.67)**
2	61 (15)	11 (11)	.77 (.32-1.81)
3 or more	22 (6)	2 (2)	.36 (.05-2.38)
Type of trajectory in the last three months of life[β]			
Residence → Hospital	100 (25)	10 (10)	**.25 (.11-.58)**
Residence → Hospital → Residence	33 (8)	7 (7)	1.38 (.51-3.74)
Residence → Hospital → Residence → Hospital	8 (2)	1 (1)	.63 (.05-8.4)
Hospital → Residence	8 (2)	-	-
Residence → Palliative care unit/hospice	13 (3)	-	-
Residence → Hospital → Palliative care unit/hospice	12 (3)	-	-
Transferred in last week of life	87 (22)	15 (15)	.61 (.25-1.52)
Hospitalizations			
Number of hospitalizations in last three months of life‡			
None	211 (53)	71 (72)	**2.2 (1.04-4.67)**
1	169 (42)	25 (26)	.46 (.21-1.03)
2	20 (5)	2 (2)	.76 (.32-1.803)
If hospitalized, number of days (mean, SD)	12.2 (12.5)	10.6 (10.7)	.97 (.91-1.02)
Death in hospital	119 (30)	16 (16)	**.78 (.63-.97)**
Died at place of preference	176 (79)	41 (79)	.88 (.38-2.02)

OR = odds ratio CI = confidence interval

* missing for transitions = 4, place of death = 4, number of days hospitalized = 11, died at place of preference = 265

† multivariate logistic regression controlling for age, cancer, dementia and gender. Reference group is home setting

‡ reference categories as follows: none vs any; 1, 2 or 3 or more vs none

[β] only trajectories which applied to more than 1% of people in either group are shown

Figure 2: Timing of hospitalization in days before death for patients who died in hospital from home settings and from residential homes (n=498)

Discussion

Summary

In this study we found that home settings and residential homes cater to different populations in terms of age, gender, cause of death and having dementia. Of the three aspects mentioned earlier as playing a role in the quality of end-of-life care, recognizing a palliative treatment goal did not differ between settings after controlling for patient characteristics. The provision of palliative care apparently did differ, with people living in a residential home were significantly more likely to have received palliative care from a GP with or without formal palliative care training than people living at home. In contrast, people living at home received palliative care from a larger variety of specialized palliative care providers than those living in a residential home. Furthermore, people living in a residential home had lower odds of transfers and hospitalization near the end of life, and of dying in hospital, than people living at home.

Strengths and limitations

To our knowledge, this nation-wide representative study is the first to directly compare end-of-life care received by those living at home and those living in a residential home. By investigating objective measures of care, we add to and improve upon studies focusing on subjective measures such as family satisfaction with care.

As this study was retrospective in nature, the participating GPs may have experienced recall bias in answering, especially for questions regarding aspects of care occurring longer before death. This risk was minimized by having the survey completed within one week of death. Due to the nature of the data, we were unable to ascertain the degree to which people were supported by or received care from informal caregivers, such as spouse or children. Finally, it is important to realize that this study pertains to people living at home or in a residential home and does not include those living in a nursing home, although this distinction in long-term care structures may be different in other European countries.

Comparison with existing literature

The higher transfer rates of those living at home require attention because there is a trend towards encouraging older people to stay at home longer in an effort to decrease the growing burden on the long term care system.[1,6] While there have been many initiatives to decrease unnecessary hospitalizations from long term care settings,[20,21] less attention has been paid to hospitalizations from a home setting, though these too are unnecessary or avoidable in some cases.[15] The availability of primary care (particularly GP care) has been shown to decrease avoidable hospitalizations both in general[21,22] and specifically from long term care settings.[23,24]

Implications for research and/or practice

The fact that those people living in a residential home receive palliative care more than twice as often from their GP as those living at home, as well as more frequently receiving specialized palliative care from a GP with formal palliative care training, could be both a cause and an effect of their lower transfer and hospitalization rates at the end of life. GPs serving the population of a residential home may be more experienced and more confident in serving the care needs of someone at the end of life, making them less likely to transfer patients or have them hospitalized at the end of life. Alternatively, if there is more reluctance to transfer older patients from a residential home to hospital than those living at home – possibly because they are more frail – the GP automatically becomes the designated person for providing palliative care.

The lower transfer rates of older people in a residential home may also be a consequence of their symptoms being investigated to a lesser degree, to avoid burdensome interventions not in the patient’s best interest. Conditions potentially requiring hospital care, e.g. cancer, could then go undiagnosed. Older people living at home may also have more *need* for a transfer to a different care setting or to hospital because organizing home care twenty-four hours per day can be difficult, especially at short notice. Initiatives aimed at improving the provision of palliative care in home settings specifically[25] or in addition to other settings[26,27] may prove valuable in decreasing this risk.

Ethical approval

Participating GPs gave written informed consent at the beginning of each registration year, having been informed of the study objectives and procedures. All patient data was recorded anonymously. Ethical approval is not required for posthumous collection of anonymous patient data in the Netherlands.

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References Chapter 2

1. Social Protection Commitee and European Commission. Adequate social protection for long-term care needs in an ageing society. Brussels; 2014.
2. Polder JJ, Barendregt JJ, Van Oers H. Health care costs in the last year of life - The Dutch experience. Soc Sci Med. 2006;63(7):1720–31.
3. Langton JM, Blanch B, Drew AK, Haas M, Ingham JM, Pearson S-A. Retrospective studies of end-of-life resource utilization and costs in cancer care using health administrative data: A systematic review. Palliat Med. 2014 May 27;
4. Curtis JR, Engelberg R a, Bensink ME, Ramsey SD. End-of-life care in the intensive care unit: can we simultaneously increase quality and reduce costs? Am J Respir Crit Care Med. 2012 Oct 1;186(7):587–92.
5. Gardiner C, Brereton L, Frey R, Wilkinson-Meyers L, Gott M. Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature. Palliat Med. 2013 Nov 7;
6. Rijksoverheid [Dutch Parliament]. Elderly care - Older people living independently longer. Available from http://www.rijksoverheid.nl/onderwerpen/ouderenzorg/ouderen-langer-zelfstandig-wonen Accessed on 20/05/2015.
7. Abarshi E, Onwuteaka-Philipsen B, Donker G, Echteld M, Van den Block L, Deliens L. General practitioner awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands. J Pain Symptom Manage. 2009 Oct;38(4):568–77.
8. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Ann Oncol. 2012 Aug 16;23(8):2006–15.
9. Mezey M, Dubler NN, Mitty E, Brody AA. What Impact Do Setting and Transitions Have on the Quality of Life at the End of Life and the Quality of the Dying Process? Gerontologist. 2002 Oct 1;42(Supplement 3):54–67.
10. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, et al. Family perspectives on end-of-life care at the last place of care. JAMA. 2004 Jan 7;291(1):88–93.
11. Raijmakers N, Galushko M, Domeisen F, Beccaro M, Lundh Hagelin C, Lindqvist O, et al. Quality indicators for care of cancer patients in their last days of life: literature update and experts' evaluation. J Palliat Med. Mary Ann Liebert, Inc. 140 Huguenot Street, 3rd Floor New Rochelle, NY 10801 USA; 2012 Mar 8;15(3):308–16.
12. De Roo ML, Leemans K, Claessen SJJ, Cohen J, Pasman HRW, Deliens L, et al. Quality indicators for palliative care: update of a systematic review. J Pain Symptom Manage. 2013 Oct;46(4):556–72.
13. Pasman HRW, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. J Pain Symptom Manage. 2009 Jul;38(1):145–56.

14. Coleman EA. Lost in Transition: Challenges and Opportunities for Improving the Quality of Transitional Care. Ann Intern Med. American College of Physicians; 2004 Oct 5;141(7):533.
15. De Korte-Verhoef R. Reasons and avoidability of hospitalisations at the end of life. Vrije Universiteit; 2014.
16. Higginson IJ, Evans CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer J. 2010;16(5):423–35.
17. Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I. Effectiveness of specialized palliative care: a systematic review. JAMA. American Medical Association; 2008 Apr 9;299(14):1698–709.
18. Van den Block L, Onwuteaka-Philipsen B, Meeussen K, Donker G, Giusti F, Miccinesi G, et al. Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. BMC Fam Pract. BMC Family Practice; 2013 Jun 3;14(1):73.
19. Donker GA. Continue Morbiditeits Registratie Peilstations Nederland 2012. NIVEL, Utrecht; 2013.
20. Konetzka RT, Spector W, Limcangco MR. Reducing hospitalizations from long-term care settings. Med Care Res Rev. 2008 Feb;65(1):40–66.
21. Rosano A, Loha CA, Falvo R, van der Zee J, Ricciardi W, Guasticchi G, et al. The relationship between avoidable hospitalization and accessibility to primary care: a systematic review. Eur J Public Health. 2013 Jun 1;23(3):356–60.
22. Onwuteaka-Philipsen BD, De Korte-Verhoef MC, Schweitzer BP, Francke AL, Deliens L, Pasman HRW. Generalist primary and palliative care is associated with few hospitalisations in the last month of life. submitted.
23. Ouslander JG, Lamb G, Perloe M, Givens JH, Kluge L, Rutland T, et al. Potentially avoidable hospitalizations of nursing home residents: frequency, causes, and costs: [see editorial comments by Drs. Jean F. Wyman and William R. Hazzard, pp 760-761]. J Am Geriatr Soc. 2010 Apr;58(4):627–35.
24. Kaspers PJ, Pasman HRW, Onwuteaka-Philipsen BD, Deeg DJ. Changes over a decade in end-of-life care and transfers during the last 3 months of life: a repeated survey among proxies of deceased older people. Palliat Med. 2013 Jun 1;27(6):544–52.
25. Van der Plas AGM, Hagens M, Pasman HRW, Schweitzer B, Duijsters M, Onwuteaka-Philipsen BD. PaTz groups for primary palliative care: reinventing cooperation between general practitioners and district nurses in palliative care: an evaluation study combining data from focus groups and a questionnaire. BMC Fam Pract. 2014 Jan;15(1):14.
26. Shaw KL, Clifford C, Thomas K, Meehan H. Review: improving end-of-life care: a critical review of the gold standards framework in primary care. Palliat Med. 2010 Apr;24(3):317–29.
27. Mahmood-Yousuf K, Munday D, King N, Dale J. Interprofessional relationships and communication in primary palliative care: impact of the Gold Standards Framework. Br J Gen Pract. 2008 Apr;58(549):256–63.

CHAPTER 3: Palliative care service use by older people: time trends in representative samples in Belgium between 2005 and 2014

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Submitted

Abstract

Background

It is increasingly recognized that older people approaching the end of life could benefit from palliative care regardless of their illness.

Aim

To investigate whether there has been an increase in the use of palliative care services and in the timing of initiation of palliative care for older people.

Methods

Mortality follow-back survey regarding deceased patients using a nationally representative GP Sentinel Network in 2005-2010, 2013 and 2014 in Belgium. Patients who died non-suddenly aged 65 and over were included. We surveyed the use of palliative care services available in Belgium and when the first of these was initiated.

Results

General practitioners identified 5344 deaths. Overall palliative care service use increased from 39% in 2005 to 63% in 2014 ($p<0.001$). The use of a reference person for palliative care in a care home increased from 12% to 26% ($p<0.001$) and the use of a palliative homecare team from 14% to 17.5% ($p<0.01$). There was no increase in the use of hospital-based palliative care services. In multivariable analyses, all types of palliative care services saw a significant increase in the proportion of people aged 85+, but showed no differences across time in the proportion of cancer/non-cancer patients. The timing of initiation of palliative care services remained unchanged at a median of 15 days before death.

Conclusion

Palliative care service use has increased mostly in care homes, while hospital-based palliative care services lag behind. Contrary to recommendations, access for non-cancer patients may remain difficult. The continued late initiation points to palliative care still being terminal care in too many cases.

Introduction

Palliative care has become an important part of healthcare in many countries, aiming to ensure that at the end of life, people receive high-quality, appropriate care that is in line with their wishes and values and which relieves their suffering.[1] While palliative care was historically mainly provided to people with terminal cancer, it is now recognized that all people suffering from a life-limiting illness could benefit from and should have access to palliative care.[2,3] This is of particular importance to older people, who have in the past been at a disadvantage with respect to accessing palliative care[4,5] and who are most likely to die of diseases other than cancer.[6]

In Belgium, palliative care started developing in the early 1980s[7,8] and in 2002 it was recognized by Belgian law as a right of "patients whose life-threatening illness no longer responds to curative treatments".[9] As such, it is one of the countries with the longest history of formal palliative care[10] which makes it particularly suitable for analysis of the development of palliative care over time. The Belgian context is of further interest with respect to palliative care for older people specifically, because palliative care services are organised for all three settings in which older people usually receive care: at home, in a care home and in hospital.[11] In many countries, such as the USA, palliative care services in long-term care facilities are scarce due to regulatory, payment, and staffing barriers.[12] That palliative care in hospital and at home is often more developed than in care homes is further concerning for older people because in many countries, including Belgium, the Netherlands, England, New Zealand, Canada, the USA and the Czech Republic, more than a quarter of older people and even half of people with dementia die in a care home.[13,14]

The services available in Belgium to provide palliative care in conjunction with regular care include palliative care units in hospitals; mobile palliative care support teams in hospitals supporting regular hospital staff in any department; multidisciplinary palliative homecare teams supporting regular primary caregivers; and reference persons for palliative care in care homes responsible for integrating a palliative care culture in their care home. In previous research, it was shown that 47% of adults who died non-suddenly in Belgium had received care from these palliative care services in 2009 and 2010, a higher percentage than from available services in the Netherlands, Spain and Italy.[15] In Belgium, these services were first officially recognized and organized in a Royal Decree published in 1997, since when the legal framework has been refined further (see box 1 for details). Provisions for the development and reimbursement of palliative care services have not progressed at the same rate for all services, though. While funding for palliative care in the home setting and in hospital was arranged by a series of Royal Decrees from 1997 to 2002, the current system for reimbursement for the function of a reference person for palliative care in care homes was only arranged in 2009.[16-22]

While palliative care service use in Belgium has been studied before.[15,23,24] the prevalence of palliative care service use by older people is unknown. While the number of palliative care services in hospital and at home in Belgium has increased between 2005 and 2012, it is unknown if there have been changes in the percentage of people who make use of a palliative care service.[10] Furthermore, although it is increasingly recognized that palliative care can be applicable early in the disease trajectory,[2] it is unknown if there have been changes in the timing of initiation of palliative care. In this study, we therefore investigate the following:

- How often did older people who died between 2005 and 2014 use palliative care services and has there been a change over time?
- Did the population who used palliative care services change between 2005 and 2014 in terms of gender proportion, age or cause of death?
- How many days before death were palliative care services initiated between 2005 and 2014 in Belgium and has there been a change in the moment of initiation over time?

Methods

Study design

This study uses data collected through existing general practitioner (GP) Sentinel Networks, epidemiological surveillance networks consisting of GP practices or community-based physicians. Through this network, it is possible to retrospectively monitor end-of-life care in a representative population-based sample of deaths. Deaths were registered weekly during each year between 2005 and 2010 and in 2013 and 2014 by a cohort of GPs which was, if necessary, supplemented each year. For more details on data collection and study design between 2005 and 2010 see Van den Block et al, 2007 and 2013.[25,26] In 2013 and 2014, the questionnaire was split into two parts, with the second part being sent as a follow-up two weeks after receipt of the initial questionnaire.

Sample

From January 1st 2005 to December 31st 2014, data was collected on 10,305 decedents. All patients of the participating GP practices who died non-suddenly aged 65 or over and for whom at least one question regarding their palliative care service use was answered were included in the study for a total of n=5204 (719 in 2005, 661 in 2006, 618 in 2007, 744 in 2008, 719 in 2009, 654 in 2010, 720 in 2013 and 689 in 2014).

Measurements

The GP Sentinel Networks collect demographic characteristics, cause of death, and whether or not death was sudden and unexpected for every deceased patient in the practice of participating GPs. In addition, a number of questions were asked about the care the decedent received in the last months of life. Of these, the following questions regarding palliative care services were included in this study:

- Which specialized palliative care services were involved in the patient's care in the last 3 months of life? The answer options included:
    - a palliative homecare team
    - a palliative care unit in a hospital
    - a palliative care support team in a hospital
    - reference person palliative care in a care home
- Estimate the number of days between the first specialist palliative care intervention and death (2008-2014)

A detailed description of the function and activities of the different palliative care services is given in box 1.

Analyses

For this study, palliative care units in a hospital and palliative care support teams in a hospital were taken together as 'palliative care in hospital' in order to study the development of palliative care services per care setting.

Pearson's chi square test controlling for clustering within GP practices were used to test for differences in patient characteristics between years; ANOVA was used to test for differences in patients' age between years. Multivariable trend analyses were used to test for linear trends in the odds of a palliative care service being used. All analyses were performed using Stata Statistical Software: Release 12 (StataCorp. 2011).

Ethics approval

Ethics approval for this study was obtained from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel.

Box. 1 Palliative care services in the Belgian healthcare context

Legal provisions and funding

Palliative homecare teams were first organized in 1997, 1998 and 1999 Royal Decrees and in 2000 and 2001, extra financial means and reimbursement of care directly via health insurance providers, without intervention of the patient, were arranged. **Hospital-based palliative care** was first made official in a 1997 Royal Decree in the form of in-patient palliative care units. In the following years Royal Decrees made it mandatory for a hospital to also have a mobile palliative care support team. While **palliative care in care homes** was also first legally established in 1997, as a not further defined “palliative care function”, it was only in 2009 that steps were taken to adequately reimburse costs for this function of a palliative care reference person, for 0.10 FTE per 30 residents. Care homes are eligible for these reimbursements when they have a vision statement, support those who organize palliative care in the facility and register palliative residents.

Organization of specialized palliative care: functioning and activities

A multidisciplinary palliative homecare team consists of at least nurses (ca. 75% of the team’s man-hours), a GP and an administrative assistant, with other disciplines such as a psychologist available in some teams. It is initiated after approval by the GP and when the patient’s prognosis is less than three months. Homecare teams may provide anything from bedside care to telephone consults to support and advise regular care providers for people living at home or in a care home.

In **a palliative care unit** in hospital (6-12 beds) a specialized multidisciplinary team - that can call on physiotherapists, social workers, spiritual consultants, psychologists and psychiatrists - provides care 24 hours 7 days a week for people in the palliative phase for whom acute care is no longer necessary, but who cannot go home for medical or other reasons. Approximately 400 of such beds are available in the country.

A palliative care support team consists of members from the same professions as the palliative care unit but aims to assist nurses and physicians in different hospital wards, where the direct patients’ care remains their responsibility. This team differs from the former as in the unit care is taken over.

A reference person for palliative care in a care home (0.10 FTE per 30 residents) is responsible for the establishment of a supportive palliative care culture, provision of training for personnel, making them aware of the facility’s vision statement, coordinating palliative care and keeping records on palliative care initiation for all deceased residents. They also support the palliative residents, which may or may not involve bedside care. According to the Belgian Palliative Care Federations this reference person should preferably have a bachelor degree in human sciences or nursing and experience with palliative care, but these are not legal requirements.

Results

Demographics

The median age of the study population was between 81 and 84 across all years, and between 50% and 58% of decedents were female (table 1). The most common cause of death was cancer in 29% to 41% of cases, followed by cardiovascular disease. The incidence of cancer ($p<0.001$), disease of the nervous system ($p<0.01$) and stroke (CVA; $p<0.001$) differed across the years. The longest place of residence was home in 60% to 65% of cases, and a care home in 33% to 38% of cases.

Overall trends in the use of palliative care services of older people

The overall use of palliative care services increased significantly from 39% in 2005 to 63% in 2014 ($p<0.001$; figure 1). Neither of the hospital-based palliative care services – mobile palliative support team or palliative care unit – showed changes over time in the percentage of patients they served, remaining around 9% over all years for the mobile support team and 11% over all years for the palliative care unit (table 2). The use of palliative homecare teams increased from 14% in 2005 to 17.5% in 2014 ($p<0.01$). The use of a reference person for palliative care in a care home increased from 12% in 2005 to 26% in 2016 ($p<0.001$).

Trends in the population served by palliative care services

Although the median age of the sample did not increase over the years, from 2005 to 2014 all palliative care services saw an increase in the proportion of people aged 85 and over they provided care for when controlled for cause of death and gender (table 3). For a palliative homecare team, the proportion of oldest old increased from 18% to 41% ($p=0.01$); for a reference person for palliative care in a care home from 44% to 70% ($p<0.001$); and for hospital-based palliative care services from 15% to 31% ($p<0.001$). There were no trends in the proportion of men and women who received palliative care, nor in the proportion of people who died of cancer and people who died of other causes. Palliative homecare teams and hospital-based palliative care provided care mainly to people who died of cancer, in 67% and 66% of cases respectively across the years, whereas a reference person for palliative care in a care home was involved in care mainly people who died of causes other than cancer, in 78% of cases across the years.

Table 1: Characteristics of the study population: older people (65+) who died non-suddenly in Belgium, 2005-2014 (n=5344)

	2005 N=719	**2006** N=661	**2007** N=618	**2008** N=744	**2009** N=719	**2010** N=654	**2013** N=720	**2014** N=689	
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	P-value*
Age (median, 95% CI)	81 (81-82)	82 (81-83)	82 (81-83)	84 (83-84)	84 (83-84)	83 (82-84)	84 (84-85)	84 (83-85)	n.s.
Gender, female	381 (53)	328 (50)	351 (57)	400 (54)	398 (55)	361 (55)	414 (58)	386 (56)	n.s.
Cause of death									
Malignancies	271 (38)	268 (41)	206 (33)	230 (31)	212 (29)	218 (33)	267 (38)	242 (38)	**<0.001**
Cardiovascular disease	109 (15)	106 (16)	124 (20)	112 (15)	115 (16)	114 (18)	133 (19)	128 (20)	n.s.
Disease of the nervous system	86 (12)	85 (13)	29 (5)	49 (7)	64 (9)	43 (7)	72 (10)	78 (12)	**<0.01**
Respiratory disease	80 (11)	58 (9)	61 (10)	77 (10)	94 (13)	72 (11)	69 (10)	57 (9)	n.s.
Stroke (CVA)†	--	--	45 (7)	63 (8)	62 (9)	43 (7)	54 (8)	46 (7)	**<0.001**
Other	166 (23)	138 (21)	152 (25)	213 (29)	172 (24)	162 (25)	106 (15)	82 (13)	**<0.001**
Longest place of residence in last year									
Home	458 (64)	412 (62)	396 (65)	482 (65)	430 (60)	406 (62)	426 (61)	380 (60)	n.s.
Care home†	--	--	196 (33)	248 (33)	267 (37)	227 (35)	264 (38)	241 (38)	n.s.
Other†	--	--	2 (0.3)	13 (2)	19 (3)	19 (3)	11 (2)	12 (2)	--

Missing for gender=10, cause of death=17, longest place of residence=15

*Bivariate p-values from chi-squared analysis controlled for clustering within GP practices

†Not an answer category in 2005 and 2006

Table 2: Trends in the use of palliative care services by older people (65+) who died non-suddenly in Belgium, 2005-2014 (n=5344)

	2005 N=719 N (%)	2006 N=661 N (%)	2007 N=618 N (%)	2008 N=744 N (%)	2009 N=719 N (%)	2010 N=654 N (%)	2013 N=720 N (%)	2014 N=689 N (%)	%-point change*	P-value†
Homecare team	99 (14)	92 (14)	92 (15)	126 (17)	98 (14)	85 (14)	128 (19)	108 (17.5)	+3.5 pp	<0.01
Reference person for palliative care in care home	89 (12)	78 (12)	58 (9)	123 (17)	126 (18)	109 (17)	174 (26)	162 (26)	+14 pp	<0.001
Hospital-based	117 (16)	119 (18)	106 (17)	118 (16)	124 (18)	110 (18)	113 (17)	133 (21)	--	n.s.
Mobile support team	47 (7)	52 (8)	48 (8)	62 (8)	69 (10)	65 (10)	50 (8)	54 (9)	--	n.s.
Palliative care unit	85 (12)	75 (11)	69 (11)	79 (11)	71 (10)	66 (11)	70 (11)	69 (11)	--	n.s.
Total	277 (39)	262 (40)	222 (37)	326 (44)	318 (46)	277 (44)	394 (60)	389 (63)	+24 pp	<0.001

Missing for cause of death=17

* pp and %-point = percentage point

† Multivariable trend analysis controlled for cause of death

Table 3: Trends in the population of older people (65+) who died non-suddenly in Belgium served by palliative care services, 2005-2014 (n=2480)

		2005 N (%)	2006 N (%)	2007 N (%)	2008 N (%)	2009 N (%)	2010 N (%)	2013 N (%)	2014 N (%)	%-point change*	P-value†
Palliative homecare team		*N=99*	*N=92*	*N=92*	*N=126*	*N=98*	*N=85*	*N=128*	*N=108*		
Age	65-84	81 (82)	73 (79)	63 (68)	87 (69)	58 (59)	58 (68)	89 (69)	64 (59)	23 pp	0.01
	85+	18 (18)	19 (21)	29 (32)	39 (31)	40 (41)	27 (32)	39 (30)	44 (41)		
Gender	Female	34 (34)	45 (49)	44 (48)	62 (49)	45 (46)	46 (54)	64 (50)	53 (49)	--	n.s.
	Male	65 (66)	47 (51)	48 (52)	64 (51)	52 (54)	39 (46)	64 (50)	55 (51)		
Cause of death	Cancer	72 (75)	72 (78)	57 (62)	81 (64)	59 (60)	57 (67)	90 (70)	65 (60)	--	n.s.
	Non-cancer	24 (25)	20 (22)	35 (38)	45 (36)	39 (40)	28 (33)	38 (30)	43 (40)		
Reference person in care home		*N=89*	*N=78*	*N=58*	*N=123*	*N=126*	*N=109*	*N=174*	*N=162*		
Age	65-84	50 (56)	34 (44)	20 (34)	52 (42)	49 (39)	38 (44)	58 (33)	48 (30)	26 pp	<0.001
	85+	39 (44)	44 (56)	38 (66)	71 (58)	77 (61)	61 (56)	116 (67)	114 (70)		
Gender	Female	57 (64)	48 (62)	41 (71)	85 (69)	95 (76)	66 (61)	117 (67)	119 (75)	--	n.s.
	Male	32 (36)	30 (38)	17 (29)	38 (31)	30 (24)	42 (39)	57 (33)	40 (25)		
Cause of death	Cancer	22 (25)	22 (28)	11 (19)	22 (18)	20 (16)	23 (21)	39 (23)	41 (25)	--	n.s.
	Non-cancer	66 (75)	56 (72)	47 (81)	101 (82)	106 (84)	86 (79)	134 (77)	121 (75)		
Hospital-based palliative care§		*N=117*	*N=119*	*N=106*	*N=118*	*N=124*	*N=110*	*N=113*	*N=133*		
Age	65-84	100 (85)	96 (81)	83 (78)	95 (81)	83 (67)	80 (72)	78 (69)	92 (69)	16 pp	<0.001
	85+	17 (15)	23 (19)	23 (22)	23 (19)	41 (33)	30 (27)	35 (31)	41 (31)		
Gender	Female	58 (50)	62 (52)	58 (55)	50 (43)	59 (48)	49 (45)	62 (55)	58 (44)	--	n.s.
	Male	59 (50)	57 (48)	48 (45)	67 (57)	65 (52)	61 (55)	51 (45)	74 (56)		
Cause of death	Cancer	89 (77)	81 (68)	60 (57)	75 (64)	82 (66)	70 (64)	80 (71)	79 (61)	--	n.s.
	Non-cancer	26 (23)	38 (32)	45 (43)	43 (36)	42 (34)	40 (36)	33 (29)	51 (39)		

Missing on gender=7, cause of death=12

* pp and %-point = percentage point

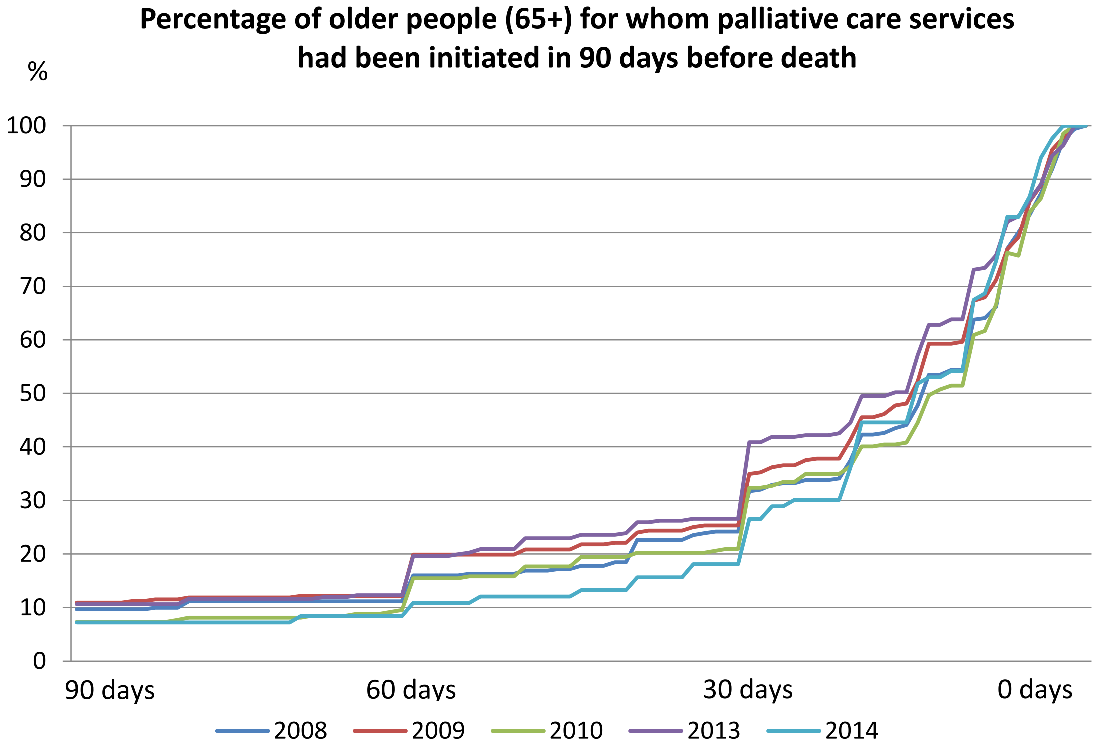
† Multivariable trend analysis controlled for other variables in table (age, gender, and cause of death: cancer vs. non-cancer)

§ Includes palliative care unit and mobile palliative support team

Trends in timing of initiation of palliative care services for older people

For many people who received care from palliative care services, these services were initiated late in the disease trajectory (figure 2). The median timing of initiation of palliative care services across the years was 15 days before death and did not change significantly over time. In 24% of cases, palliative care services were not involved until less than 7 days before death and in 33% of cases, they were involved for at least 30 days.

Figure 2: Older people (65+) who died non-suddenly and used a palliative care service: timing of initiation at each of the 90 days before death from 2008 to 2014 (n=1453)



Discussion

In this study, we showed that the overall use of palliative care services has increased for older people by 24 percentage point. The strongest increase was in the use of a reference person for palliative care in a care home by 14 percentage point. The use of a palliative homecare team also increased by 3.5 percentage point, but there was no significant change in the use of hospital-based palliative care services. There was an increase over time in the proportion of oldest old (85+) who received care from all palliative care services, but no change in the proportion of people who died of causes other than cancer or the proportion of men and women. There was no change in the timing of the initiation of palliative care services, with the median around 15 days before death in all years.

As far as we are aware, this study is the first to analyse trends in different types of palliative care service use among older people. By taking a population-based approach, we were able to include people in a variety of settings (both at home and in a care home) with different disease trajectories. While retrospective data collection is always subject to the possibility of recall bias, in the case of this study such concerns are limited because GPs can base themselves on medical records; GPs were also instructed to fill in the questionnaire within a week of the patient's death; and since it is a cohort study, GPs are prepared for answering the end-of-life questionnaire. It is possible that regularly participating GPs (i.e. those who participated in several years) may have been primed by this study to involve palliative care services more often, but as the questions regarding palliative care are merely two questions in a longer questionnaire and do not stand out nor provide guidance on improving care, this seems unlikely.

The significant increase in palliative care service use was driven mostly by an increase in the involvement of a reference person for palliative care in care homes. This may be because adequate financial organization of palliative care in care homes – where a significant proportion of older people in Belgium live[27] – was established later than for other types of palliative care. While this strong increase is encouraging, there is still cause for concern. First, a reference person for palliative care is not involved for almost half of people living in a care home who died non-suddenly, which suggests this involvement is not yet standard practice in (some) care homes. Second, the standards for the training and experience of the reference person may vary greatly between care homes. While the reference person is preferably a healthcare professional with at least a bachelor degree in medical/human sciences or nursing and who has experience with palliative care, these are not formal requirements.[22,28] Since there is little involvement of the more specialized palliative homecare teams in care homes, this means that the expertise to deal with complex cases of older people suffering from multimorbidities may be lacking in care homes. A formal requirement for training and education of reference persons for palliative care, or proper evaluations of existing training programmes, could be a step in the right direction, as would additional financial support as recommended by the Belgian Federal Evaluation Committee for Palliative Care.[22,29]

The limited change in the use of palliative care in the home setting and the lack of change in the hospital setting may point to structural issues. This stagnation may be due to palliative care services in these settings already operating at maximum capacity at the start of data collection. Palliative care units are usually small (6 to 12 beds), and palliative care support teams are usually limited to one per hospital. Palliative home care teams, meanwhile, suffer from an increase in the real burden, both practically and financially, of caring for an increasing palliative population which the current financing system is unequipped to handle.[22] While the number of these services available has increased between 2005 and 2012, this increase in capacity may not have been sufficient to keep up with the increasing number of older people.[10] To enable more older people to use palliative care services, additional financial investments may be necessary.

The timing of the initiation of palliative care services was practically identical over the years. Only one in three older people who receive care from a palliative care service do so for more than 30 days before death, and half only receive palliative care in the last two weeks of life. The lack of change in the late onset of palliative care suggests structural barriers impeding early involvement of palliative care services. Recognizing this, the Belgian committee for Public Health recently unanimously proposed to abolish the requirement of a prognosis of less than three months in order for patients to have palliative status.[30] Since the initiation of palliative homecare services is linked to this palliative status,[31,32] this measure will hopefully lead to earlier initiation of palliative homecare teams. Future research will have to determine whether this move is sufficient, or if further structural changes are needed to prevent palliative care from remaining terminal care.

While the median age of the sample did not increase over the years, all palliative care services saw an increase in the proportion of the oldest old (85+) among the people for whom they provided care, which suggest that the oldest old have gained better access to specialized palliative care over the years. The proportion of cancer patients remaining the same across the years (two-thirds for palliative care in hospital or at home and 1 in 5 for palliative care in care homes) may reflect the different patient population in the various settings. It may also be an indication that non-cancer patients may continue to have difficulty accessing palliative care in hospital and at home if the capacity of these settings does not increase. There are still some groups who caregivers are less likely to consider in need of palliative care,[33,34] contrary to recommendations by the European Association for Palliative Care and the World Health Organization that palliative care should be available for all people with a life-limiting illness.[1,36]

The results show that to increase the use of palliative care services, setting-specific strategies are warranted. It is encouraging to see that the use of palliative care services can increase considerably in a relatively short period of time, as was the case in care homes. Now a focus on the hospital and home settings, combined with efforts to promote initiation of palliative care earlier in the disease trajectory, can hopefully improve the accessibility and widespread provision of palliative care further.

References Chapter 3

1. WHO definition of palliative care. Geneva, World Health Organization, 2010. www.who.int/cancer/palliative/definition/en Accessed on 18/04/2016.
2. Connor SR, Sepulveda Bermedo MC (ed.). Global Atlas of Palliative Care. World Health Organization, 2014.
3. Radbruch L, de Lima L, Lohmann D, Gwyther E, Payne S. The Prague Charter: urging governments to relieve suffering and ensure the right to palliative care. Palliative medicine. 2013 Feb 1;27(2):101-2.
4. Ahmed N, Bestall JE, Ahmedzai SH, Payne SA, Clark D, Noble B. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. Palliative Medicine, 2004;18(6):525-542.
5. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. Journal of General Internal Medicine, 2004;19(10):1057-1063.
6. World Health Organization. World report on ageing and health. World Health Organization, Luxembourg: 2015.
7. Keirse E, Desmedt M, Deveugele M. *Organisation of Palliative Care in Belgium. KCE Reports 115C*. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg; 2009.
8. Verbinnen R. Gespecialiseerde palliatieve zorg in de context van medicalisering [Specialised palliative care in the context of medicalisation]. Brussels: VUBPRESS, 2005.
9. Law concerning palliative care in Belgium 2002 (in Dutch) L. Wet betreffende palliatieve zorg, 2002-06-14/46. 2002.
10. Centeno C, Lynch T, Donea O, Rocafort J, Clark D. EAPC Atlas of Palliative Care in Europe 2013. Full Edition. *European Association for Palliative Care, 2013.*
11. Centeno C, Clark D, Lynch T, Rocafort J, Flores LA, et al. Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC task force. Palliative Medicine, 2007;21:463-471.
12. Reyniers T, Deliens L, Pasman HR, Morin L, Addington-Hall J, Frova L, Cardenas-Turanzas M, Onwuteaka-Philipsen B, Naylor W, Ruiz-Ramos M, Wilson DM. International variation in place of death of older people who died from dementia in 14 European and non-European countries. Journal of the American Medical Directors Association. 2015 Feb 1;16(2):165-71.
13. Meier DA, Lim B, Carlson MDA. Raising the standard: Palliative care in nursing homes. Health Affairs, 2010;29(1):136-140.
14. Cohen J, Gott M. Dying in place in old age: public health challenges. In: Van den Block L, Albers G, Martins Pereira S, Onwuteaka-Philipsen B, Pasman R, Deliens L, editors. Palliative Care for Older People: A public health perspective. Oxford, United Kingdom: Oxford University Press; 2015. P.107-119.
15. Pivodic L, Pardon K, Van den Block L, Van Casteren V, Miccinesi G, Donker GA, Alonso TV, Alonso JL, Aprile PL, Onwuteaka-Philipsen BD, Deliens L. Palliative care service use in four

European countries: a cross-national retrospective study via representative networks of general practitioners. PloS one. 2013 Dec 30;8(12):e84440.

16. Koninklijk besluit tot bepaling van de minimale criteria waaraan de overeenkomsten tussen de multidisciplinaire begeleidingsequipes voor palliatieve verzorging en het Verzekeringscomite´ ingesteld bij de Dienst voor geneeskundige verzorging van het Rijksinstituut voor ziekte en invaliditeitsverzekering moeten voldoen. [Royal decree concerning multidisciplinary homecare team and National Institute for Health and Disability Insurance]. October, 13th 1998.
17. Koninklijk besluit van 15 juli 1997 houdende vaststelling van de normen waaraan een ziekenhuisfunctie van palliatieve zorg moet voldoen om te worden erkend. [Royal decree concerning norms for acknowledgement of hospitals]. July, 15th 1997.
18. Ministerieel besluit houdende wijziging van het ministerieel besluit 6 AUGUSTUS 1986 houdende bepaling van de specifieke voorwaarden en regelen die gelden voor de vaststelling van de prijs per verpleegdag, het budget van financiële middelen en het quotum van verpleegdagen voor de ziekenhuizen en ziekenhuisdiensten. Art. 17. [Ministerial decree concerning financing mobile teams]. January, 12th 2001.
19. Koninklijk besluit tot wijziging van het koninklijk besluit van 15 juli 1997 waarbij sommige bepalingen van de wet op de ziekenhuizen, gecoördineerd op 7 augustus 1987, toepasselijk worden verklaard op de functie van palliatieve zorg. [Royal decree concerning the palliative care function in hospitals]. February, 19th 2002.
20. Koninklijk Besluit Tot Wijziging van Het Koninklijk Besluit van 2 December 1982 Houdende Vaststelling van de Normen Voor de Bijzondere Erkenning van Rust- En Verzorgingstehuizen. *[Royal decree concerning the norm for acknowledging care homes]*. July, 15th 1997.
21. Koninklijk Besluit 16 Februari 2009 Tot Wijziging van Het Koninklijk Besluit van 23 Maart 1982 Tot Vaststelling van Het Persoonlijk Aandeel van de Rechthebbenden of van de Tegemoetkoming van de Verzekering Voor Geneeskundige Verzorging in Het Honorarium Voor Bepaalde Verstrekkingen. *[Royal decree concerning personal share for palliative care]*. February, 16th 2009.
22. Federale evaluatiecel palliatieve zorg. Evaluatierapport palliatieve zorg. [Federal evaluation committee palliative care. Evaluation report palliative care] Brussels, Belgium: 2014.
23. Beernaert K, Cohen J, Deliens L, Devroey D, Vanthomme K, Pardon K, Van den Block L. Referral to palliative care in COPD and other chronic diseases: a population-based study. Respiratory medicine. 2013 Nov 30;107(11):1731-9.
24. Meeussen K, Van den Block L, Echteld MA, Boffin N, Bilsen J, Van Casteren V, Abarshi E, Donker G, Onwuteaka-Philipsen B, Deliens L. End-of-life care and circumstances of death in patients dying as a result of cancer in Belgium and the Netherlands: a retrospective comparative study. Journal of Clinical Oncology. 2011 Oct 11:JCO-2011.
25. Van den Block L, Van Castern V, Deschepper R, Bossuyt N, Drieskens K, Bauwens S et al. Nationwide monitoring of end-of-life care via the Sentinel Network of General Practitioners in

Belgium: the research protocol of the SENTI-MELC study. BMC Palliat Care 2007 October 8;6(1):6.

26. Van den Block L, Onwuteaka-Philipsen B, Meeussen K, Donker G, Giusti F, Miccinesi G, et al. Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. BMC Fam Pract. BMC Family Practice 2013 Jun 3;14(1):73.
27. Data from Flemish health insurance providers, 2014. Available from www.vlaamsezorgkas.be/Cijfers/Vlaamse-zorgverzekering/Lopende-dossiers-tenlastenemingen Retrieved 10/04/2016.
28. Omzendbrief Aan de Rustoorden Voor Bejaarden, de Rust- En Verzorgingstehuizen en de Centra Voor Dagverzorging. OMZ. ROB/RVT 2012/6. *[Letter to care homes concerning categories - reimbursement palliative function]*.December, 19th 2012.
29. Keirse M. Report Evaluation Palliative Care Belgium. Brussels: *Federal Public Service Health, Food chain safety and Environment, Federal Evaluation commission Palliative Care, 2008.*
30. Beel V. Sneller starten met palliatieve zorg [Starting sooner with palliative care]. De Standaard, 07 Jun 2016. Available from www.standaard.be/cnt/dmf20160607_02327776 Accessed on 07/06/2016.
31. Palliative home care. National Institute for Health and Disability Insurance. Available from www.inami.fgov.be/nl/professionals/individuelezorgverleners/verpleegkundigen/verzorging/Paginas/palliatieve-thuiszorg-verlenen-aanrekenen.aspx#.V49F6Pl97Gg. Accessed on 20/06/2016.
32. Ministerieel Besluit Tot Vaststelling van Het Bedrag En de Voorwaarden Voor de Toekenning van de Tegemoetkoming, Bedoeld in Artikel 37, § 12, van de Wet Betreffende de Verplichte Verzekering Voor Geneeskundige Verzorging En Uitkeringen, Gecoördineerd Op 14 Juli 1994, in de Rust- En Verzorgingstehuizen En in de Rustoorden Voor Bejaarden. *[Ministerial decree concerning amount and requirements assignment reimbursement]*. November, 3th 003.
33. De Vleminck A, Houttekier D, Pardon K, et al. Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review. Scandinavian Journal of Primary Health Care. 2013;31(4):215-25.
34. McIlfatrick S. Assessing palliative care needs: views of patients, informal carers and healthcare professionals. Journal of Advanced Nursing. 2006;57(1):77-86.
35. Radbruch L, de Lima L, Lohmann D, Gwyther E, Payne S. The Prague Charter: urging governments to relieve suffering and ensure the right to palliative care. Palliative medicine. 2013;27(2):101-102.

CHAPTER 4: Trends between 2009 and 2014 in advance care planning for older people in Belgium and the Netherlands

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Submitted

Abstract

Background

Advance care planning (ACP), which includes physicians' awareness of their patient's preferences, is of particular importance for older people and those at risk of cognitive decline.

Aim

To evaluate trends in the prevalence of awareness of patient's preferences in general practice for this patient group.

Methods

Mortality follow-back study regarding deceased patients (65+, non-sudden death) among a cohort of representative nationwide GP sentinel networks in Belgium and the Netherlands in 2009, 2010, 2013 and 2014. GPs were asked if they knew patient preferences for medical treatments at the end of life; whether or not a preference for a proxy decision-maker was known; and whether or not this proxy decision-maker was consulted if necessary.

Results

GP's awareness of a preference for a medical treatment they would/would not want at the end of life increased in Belgium (n=2785) from 27% of decedents in 2009 to 40% in 2014 and in the Netherlands (n=1083) from 53% to 66%. Awareness of a preference for a proxy decision-maker increased in Belgium from 29% in 2009 to 43% in 2014 and in the Netherlands from 30% to 57%. These trends were significant in all studied patient groups. In the majority of cases where the situation arose, proxy decision-makers were consulted at the end of life in both countries (71%-96% over the years).

Conclusion

GPs were much more frequently aware of their patients' preferences in 2014 than in 2009 in both countries, which suggests that the practice of ACP can increase rapidly.

Introduction

Many of the increasing number of older people experience a prolonged period of co-morbid conditions and frailty before death, often including cognitive decline and dementia.[1-3] For this group, advance care planning (ACP), a process of communication between patients, their family or representatives and professional caregivers about the goals and desired direction of care, is especially relevant. Through ACP, patients can extend their autonomy by documenting their wishes about their preferred care even when they are incapable of making decisions at the end of life, or by appointing a surrogate decision-maker. Recommendations from the WHO include ACP as an important part of palliative care for older people.[4] Previous research found that ACP not only improves knowledge of and compliance with the patient's wishes, but also decreases the likelihood of unnecessary hospitalizations and improves the chances of getting more high quality end-of-life care.[5-8] In light of these findings, it is not surprising that most older people consider ACP to be important.[9]

Comparative research on ACP often compares Belgium and the Netherlands due to their interesting similarities and differences. In both countries, personal autonomy and patient rights are highly valued, as shown by the Dutch Medical Treatment Contracts Act from 1994 and the Belgian Law concerning patient rights from 2002,[10,11] including the possibility of legalized euthanasia.[12,13] While the process of integrating palliative care in the healthcare system began in the nineties and early 2000's in both countries,[14,15] palliative care in Belgium has developed along more specialist lines, whereas in the Netherlands, a generalist approach is more dominant.[16] Furthermore, general practitioners (GP) in the Netherlands have a gatekeeper position, where a GP referral is necessary for all secondary or specialist care unlike in Belgium. In both countries, the GP is one of the most important professional caregivers during the last years of life[17,18] and therefore they are well-placed to take into account a person's wishes and values regarding care at the end of life and can play an important role in advance care planning.[19,20]

In 2007, GPs said to have engaged in ACP with 34% of 1072 patients in Belgium and the Netherlands, with higher odds for those who were capable of decision making during the last three days of life, though figures specifically for older people are unknown.[21] Since then various organizations, such as the Federation of Palliative Care and the Koning Boudewijn foundation, have released guidelines and information for both caregivers and patients, often with a specific focus on older people and nursing home settings.[22,23] Likewise in the Netherlands, guidelines have been published on how to approach ACP conversations, and several ongoing studies aim to implement ACP in a variety of settings include the nursing home setting.[24-26] However, research so far has not investigated whether this increased attention and awareness has led to a higher incidence of ACP for older people in practice in different countries. Specifically, it is still unknown if patients' preferences are known in more cases now than several years ago, and if so, if patient characteristics such as cause of death or cognitive ability have had an influence on these changes.

In this study we examine the trends in specific indicators of advance care planning in primary care in Belgium and the Netherlands from 2009 to 2014. Specifically, we investigate:

- Did the percentage of older patients for whom a preference for a medical treatment they would/would not want at the end of life or for a proxy decision-maker was known by the GP change between 2009 and 2014 overall and in different groups with respect to age, cause of death, place of death, or having dementia?
- Did the percentage of proxy decision-makers (if known to the GP) who were consulted at the end of life change between 2009 and 2014 overall and in different groups?
- Are there differences in the trends in ACP prevalence between Belgium and the Netherlands?

Methods

Study design

This study uses data from Belgium and the Netherlands collected as part of the EURO SENTIMELC (European Sentinel Network Monitoring End-of-Life Care) study.(27) By collecting data through existing GP Sentinel Networks – epidemiological surveillance networks consisting of GP practices or community-based physicians – the EURO SENTIMELC study retrospectively monitors end-of-life care in a representative population-based sample of deaths. Each week, participating GPs fill in a questionnaire regarding all patients of their practice who died in the past week. For this study, data collected during 2009, 2010, 2013 and 2014 was included. More details on data collection and study design in 2009 and 2010 can be found elsewhere.[27] In Belgium, in 2013 and 2014 part of the questionnaire was sent as a follow-up two weeks after the initial questionnaire had been returned.[28,29]

Sample

Data was collected on 4,840 decedents in Belgium and 2,074 in the Netherlands. All patients of the participating GP practices who died non-suddenly aged 65 or over were included for these analyses: 2,785 patients in Belgium and 1,083 patients in the Netherlands. In the Netherlands, this excluded almost all people who live in specialist nursing homes, as they are cared for by elderly care physicians who are not part of the GP Sentinel Network.

Measurements

The GP Sentinel Networks collect demographic characteristics, cause of death, and whether or not death was sudden and unexpected for every deceased patient in the practice of participating GPs. In addition, the following questions regarding advance care planning were included in this study:

1. Did the patient ever express specific wishes about a medical treatment that he/she would or would not want in the final phase of life? Possible answers were ‘yes’, ‘no’ and ‘don’t know’.
2. Did the patient ever express a wish about who was to make decisions regarding medical treatments in his/her place, in the event he/she would no longer be able to speak for him/herself? Possible answers were ‘yes, in writing’, ‘yes, verbally’, ‘no’, and ‘don’t know’.
3. Regarding the proxy decision-maker: If the situation arose, was this person consulted at the end of life? Possible answers were ‘yes’, ‘no’, ‘don’t know’ or ‘situation did not arise’.

Analyses

If the GP indicated ‘unknown’ as an answer to these questions, it was coded as ‘no’ in the case of questions 1 and 2 and as missing in the case of question 3.

Pearson’s chi square test, Fisher's exact test or ANOVA were used to test for differences in patient characteristics between years. Multivariable trend analyses controlling for cause of death, longest place of residence in the last year of life, having dementia or not and age were used to test for linear trends in the odds of preferences being known and proxy decision-makers being consulted. All analyses were performed using Stata Statistical Software: Release 12 (StataCorp. 2011).

Ethics approval

For Belgium, ethics approval for this study was obtained from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel. Formal approval for this research project by a medical ethics committee was not required in The Netherlands according to the Medical Research (Human Subjects) Act (WMO), but permission for the study was sought and obtained from the board of the NIVEL network. The NIVEL Primary Care Database extracts data according to strict guidelines for the privacy protection of patients and GPs. Patient data was anonymized guaranteeing the patient’s privacy before questionnaires left the practice.

Results

Characteristics of the study population

In total, we included 2,785 decedents from Belgium and 1,083 from the Netherlands (table 1). The median age of patients included in the sample was between 81 and 84. The percentage of patients who had dementia was between 36% and 41% in Belgium and between 15% and 18% in the Netherlands. The most common cause of death were malignancies, increasing between 2009 and 2014 in both Belgium (29% to 38%, $p<0.01$) and the Netherlands (46% to 57%, $p<0.01$). The majority of people

Table 1: Characteristics of the study population (n=4633)*

	Belgium					**The Netherlands**				
	2009 (n=729)	2010 (n=651)	2013 (n=720)	2014 (n=685)	p†	2009 (n=247)	2010 (n=313)	2013 (n=252)	2014 (n=271)	p†
	N (%)	N (%)	N (%)	N (%)		N (%)	N (%)	N (%)	N (%)	
Age (median, 95% CI)	84 (83-84)	83 (82-84)	84 (84-85)	84 (83-85)	.18	83 (80-84)	82 (81-83)	83 (81-84)	81 (79-83)	.86
Gender, female	405 (56)	361 (55)	414 (57.5)	386 (56)	.86	147 (60)	161 (51)	127 (50)	143 (53)	.16
Dementia										
None	459 (64)	415 (64)	413 (59)	383 (61)	.13	198 (82)	248 (83)	202 (83)	228 (85)	.75
Mild	101 (14)	98 (15)	128 (18)	92 (15)	.13	25 (10)	34 (11)	30 (12)	22 (8)	.47
Severe	158 (22)	131 (20)	159 (23)	153 (24)	.38	18 (7)	18 (6)	12 (5)	17 (6)	.71
Cause of death										
Malignancies	215 (29)	218 (33)	266 (38)	242 (38)	**<0.01**	113 (46)	140 (44)	136 (54)	156 (57)	**<0.01**
Cardiovascular Disease	117 (16)	114 (17)	135 (19)	128 (20)	.19	40 (16)	60 (19)	33 (13)	46 (17)	.31
Disease of the nervous system	65 (9)	43 (7)	72 (10)	57 (9)	**<0.01**	8 (3)	11 (3)	12 (5)	13 (5)	.698
Respiratory disease	94 (13)	72 (11)	69 (10)	78 (12)	.11	22 (9)	26 (8)	18 (7)	8 (3)	.27
Stroke (CVA)	64 (9)	43 (7)	54 (8)	46 (7)	.49	16 (6)	15 (5)	6 (2)	5 (2)	--
Other	176 (24)	162 (25)	105 (15)	82 (13)	**<0.01**	48 (19)	64 (20)	47 (19)	44 (16)	.63
Place of residence in the last year of life										
Home	437 (60)	406 (62)	426 (61)	380 (60)	.81	180 (73)	222 (72)	176 (70)	203 (75)	.64
Long-term care facility§	272 (37)	227 (35)	365 (38)	241 (38)	.603	67 (27)	86 (28)	71 (28)	60 (22)	.35
Other	19 (3)	19 (3)	11 (2)	12 (2)	.31	/	2 (1)	3 (1)	7 (3)	--

* Missing values <5% for all variables

† Bivariate Pearson's chi-squared analysis controlling for clustering within GP practices, except for age (ANOVA). No significance tests on cells of n=5 or lower.

§ residential care home in Belgium, residential home for older people and (infrequently) nursing home in the Netherlands lived at home in the last year of life in both countries, between 60%-62% in Belgium and 70%-75% in the Netherlands.

Trends in preferences known for a medical treatment at the end of life

Overall, the percentage of patients for whom the GP was aware of a preference for a medical treatment they would/would not want at the end of life increased in both countries between 2009 and 2014 (figure 1). After controlling for age, having dementia, cause of death (cancer vs. non-cancer) and longest place of residence in the last year of life, the increase was found significant in both Belgium (27% to 40%, p<0.001) and the Netherlands (53% to 66%, p<0.001). The increase was significant for all groups (table 2). The largest increases were found in the Netherlands for those aged 85 and over, from 48% in 2009 to 71% in 2014 (p<0.001) and those with dementia, from 31% in 2009 to 67% in 2014 (p<0.01). The increase in Belgium was largest in the group aged 65 to 84, from 28% to 57% (p<0.001).

Trends in preferences known for a proxy decision-maker

Overall, the percentage of patients for whom the GP was aware of a preference for a proxy decision-maker at the end of life significantly increased in both countries between 2009 and 2014 after controlling for demographic characteristics (figure 1). In the Netherlands the percentage increased from 30% in 2009 to 57% in 2014 (p<0.001), and in Belgium from 29% to 43% (p<0.001). The increase was significant for all groups (table 3). The largest increase was seen in the Netherlands for those who had dementia, from 13% in 2009 to 51% in 2014 (p<0.01). The increase in Belgium was largest in the group who died at home, from 15% to 37% (p<0.001).

If a preference for a proxy decision-maker was known, it was recorded in writing in between 19% and 35% of cases in Belgium and between 23% and 32% of cases in the Netherlands (no significant trend in either country).

Figure 1: Trends in patient preferences known by GPs and proxy decision-makers consulted for older people in Belgium and the Netherlands, 2009-2014

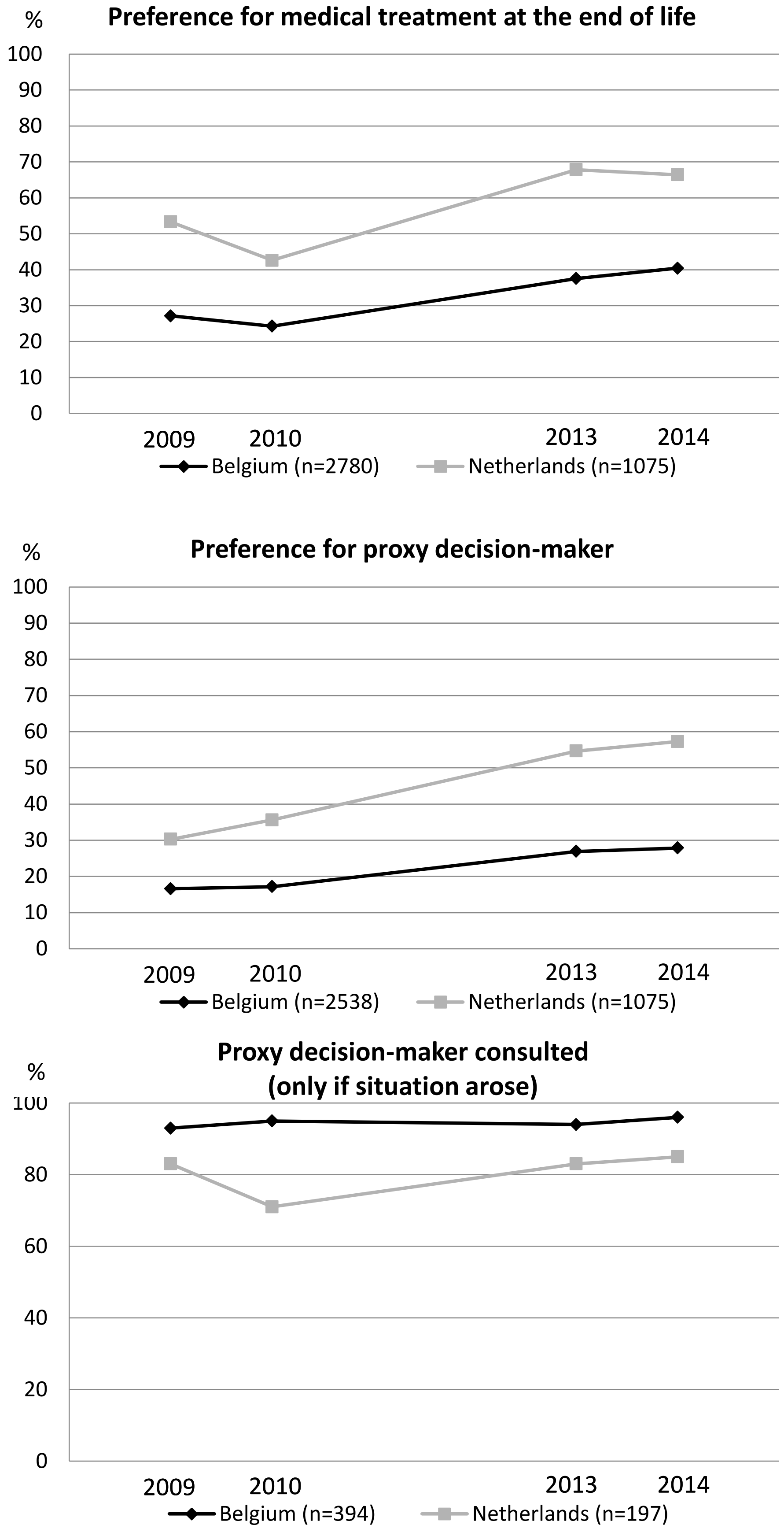

Table 2: Trends in awareness by GPs of preference of older patients for a medical treatment at the end of life by patient group in Belgium and the Netherlands, 2009-2014 (n=3855)

		Awareness by GP of preference for medical treatment patient would/would not want at the end of life					
		2009 BE=729 NL=240	2010 BE=654 NL=312	2013 BE=714 NL=252	2014 BE=683 NL=271	%-point	
Patient characteristics		N (%)	N (%)	N (%)	N (%)	change*	P†
Age	**Age: 65-84**						
	Belgium	119 (28)	105 (26)	167 (57)	164 (57)	+29 pp	**<0.001**
	The Netherlands	86 (57)	84 (42)	111 (71)	113 (64)	+7 pp	**<0.001**
	Age: 85+						
	Belgium	79 (26)	54 (21)	101 (31)	112 (38)	+12 pp	**<0.001**
	The Netherlands	42 (48)	49 (43)	60 (63)	67 (71)	+ 23 pp	**<0.001**
Place of residence	**Home**						
	Belgium	136 (31)	114 (28)	192 (45)	173 (46)	+15 pp	**<0.001**
	The Netherlands	96 (55)	96 (44)	125 (71)	135 (67)	+12 pp	**<0.001**
	Long-term care facility§						
	Belgium	53 (20)	39 (17)	64 (24)	73 (31)	+11 pp	**<0.001**
	The Netherlands	32 (49)	35 (42)	43 (61)	40 (67)	+18 pp	**<0.001**
Cause of death	**Cause of death: Cancer**						
	Belgium	85 (40)	74 (34)	140 (53)	129 (54)	+14 pp	**<0.001**
	The Netherlands	70 (63)	76 (55)	100 (74)	109 (71)	+8 pp	**<0.01**
	Cause of death: Non-cancer						
	Belgium	113 (22)	85 (20)	121 (28)	121 (31)	+9 pp	**<0.001**
	The Netherlands	58 (45)	57 (33)	71 (61)	71 (61)	+16 pp	**<0.001**
Dementia	**Dementia**						
	Belgium	25 (10)	31 (14)	54 (19)	51 (21)	+11 pp	**<0.01**
	The Netherlands	13 (31)	11 (22)	23 (55)	26 (67)	+36 pp	**<0.001**

*pp and %-point = percentage point

†Multivariable trend analysis controlled for other variables in table (age, having dementia, place of residence, and cause of death cancer vs. non-cancer)

§In Belgium includes all types of care home; in the Netherlands includes a residential home for older people and (infrequently) a specialist nursing home. Due to the differences between countries in the type of long-term care facilities included, these figures should not be compared across countries.

Missing on independent variables <5%. Missing on dependent variable (preference known): 1%

Table 3: Trends in awareness by GPs of preference of older patients for a proxy decision-maker by patient group in Belgium and the Netherlands, 2009-2014 (n=3481)

		Awareness by GP of preference for a proxy decision-maker					
		2009 BE=670 NL=215	2010 BE=600 NL=253	2013 BE=654 NL=227	2014 BE=614 NL=248	%-point change*	P†
Patient characteristics		N (%)	N (%)	N (%)	N (%)		
Age	**Age: 65-84**						
	Belgium	61 (16)	58 (16)	95 (26)	90 (26)	+10 pp	**<0.001**
	The Netherlands	40 (29)	56 (35)	75 (54)	89 (54)	+25 pp	**<0.001**
	Age: 85+						
	Belgium	50 (18)	45 (19)	81 (27)	81 (30)	+12 pp	**<0.001**
	The Netherlands	25 (32)	34 (37)	49 (55)	53 (63)	+31 pp	**<0.001**
Place of residence	**Home**						
	Belgium	67 (17)	67 (18)	108 (28)	97 (28)	+11 pp	**<0.001**
	The Netherlands	46 (29)	64 (36)	91 (58)	106 (58)	+27 pp	**<0.001**
	Long-term care facility§						
	Belgium	39 (15)	31 (15)	57 (23)	51 (24)	+9 pp	**<0.01**
	The Netherlands	19 (33)	25 (37)	32 (48)	31 (54)	+21 pp	**<0.01**
Cause of death	**Cause of death: Cancer**						
	Belgium	43 (21)	36 (18)	80 (33)	62 (28)	+7 pp	**<0.01**
	The Netherlands	33 (32)	52 (43)	73 (59)	84 (60)	+28 pp	**<.001**
	Cause of death: Non-cancer						
	Belgium	68 (14.5)	67 (17)	89 (23)	90 (26)	+11.5 pp	**<0.001**
	The Netherlands	32 (28)	38 (29)	51 (50)	57 (54)	+26 pp	**<0.001**
Dementia	**Dementia**						
	Belgium	29 (12)	36 (17)	48 (18)	14 (19)	+7 pp	**0.02**
	The Netherlands	5 (13)	11 (31)	20 (54)	19 (51)	+38 pp	**<0.01**
If preference known: recorded in writing	Belgium	22 (20)	20 (19)	39 (22)	60 (35)	--	.22
	Netherlands	18 (28)	29 (32)	29 (23)	36 (25)	--	.302

*pp and %-point = percentage point

†Multivariable trend analysis controlled for other variables in table (age, having dementia, place of residence, and cause of death cancer vs. non-cancer)

§In Belgium includes all types of care home; in the Netherlands includes a residential home for older people and (infrequently) a specialist nursing home. Due to the differences between countries in the type of long-term care facilities included, these figures should not be compared across countries.

Missing on independent variables <5%. Missing on dependent variable (preference known): Belgium 1%, the Netherlands 2%

Trends in consultation of proxy decision-makers

There were no significant trends in the percentage of proxy decision-makers who were consulted at the end of life in either country (figure 1). In Belgium from 2009 to 2014, according to the GP a situation arose where the proxy decision-maker needed to be consulted in between 61% and 75.5% of cases (table 4). Of these, the proxy decision-maker was consulted in 95% of cases. In the Netherlands, GPs less often indicated that a situation arose where a consultation was necessary, namely in 35% of cases in 2009 to 50% of cases in 2014; a trend which was no longer significant after controlling for the decedents having had dementia. The proxy decision-makers were consulted in between 71% and 85% of these cases.

Table 4: Trends in the percentage of proxy decision-makers (if known) of older patients who were consulted at the end of life in Belgium and the Netherlands, 2009-2014 (n=1423)

	Proxy decision-makers (if known) consulted at the end of life				
	2009 N (%)	2010 N (%)	2013 N (%)	2014 N (%)	P*
Belgium	N=164	N=163	N=236	N=246	
Situation arose	114 (75.5)	94 (61)	157 (74)	165 (73)	.62
If situation arose, proxy was consulted:					
Yes	82 (93)	62 (95)	116 (94)	113 (96)	.99
No	6 (7)	3 (5)	7 (6)	5 (4)	
The Netherlands	N=94	N=164	N=174	N=182	
Situation arose	31 (35)	43 (37)	79 (47)	89 (50)	.48
If situation arose, proxy was consulted:					
Yes	19 (83)	27 (71)	52 (83)	62 (85)	.95
No	4 (17)	11 (29)	11 (17)	11 (15)	

* Multivariable trend analysis controlled for age, having dementia, cause of death (cancer vs. non-cancer) and place of residence.

Missing on dependent variable (proxy decision-maker consulted): 5% for Belgium, 4% for the Netherlands except for 2010 (4%)

Discussion

In this paper we found that in both Belgium and the Netherlands, there has been a significant increase between 2009 and 2014 in the percentage of older people whose preference was known to their GP, either for a medical treatment they would/would not want at the end of life (13 percentage point in both countries) or for a proxy decision-maker (11 percentage point in Belgium and 27 percentage point in the Netherlands). This trend was found in every patient group. The percentage of proxy decision-makers who were consulted remained high in both countries throughout the years.

The retrospective cohort study design has both strengths and limitations. In both countries the networks are designed to be nationally representative by age, gender, geographic distribution and population density.[27-29] Because GPs are aware in advance that they will have to fill in these questionnaires, and because they fill them in shortly after the patient's death, recall bias is limited. It is possible that GPs who participated in several years may have been primed by this study to engage in ACP more often, but as the questions regarding patient preferences are merely part of a longer questionnaire and do not provide advice on improving care, this seems unlikely. Because people living in nursing homes in the Netherlands were not included in the data collection, the proportion of people with severe dementia or those who were very frail and required continuous care are underrepresented in our sample from this country. However, because we studied trends within specific patient groups the results in both countries per patient group are still comparable, with the exception of those who lived in a long-term care facility. Because of the nature of our data, we used only a limited measurement of ACP. Future research can include more detailed comparisons on e.g. the number and content of ACP discussions, who initiated the ACP discussions (patient or healthcare professional) and whether or not more ACP leads to better end-of-life quality. Finally, we do not know at which point in the disease trajectory the GP became aware of the patient's preferences. It is possible that this was sometimes very late, which defeats the purpose of ACP.

To our knowledge, this study is the first trend analysis on ACP in Europe for older people over a period of several years. By looking at different patient groups, we were able to show that the increase in ACP is not due to specific attention paid to any particular group, or the characteristics of a particular group (e.g. cancer patients) but is an overall improvement. The international comparison of Belgium and the Netherlands puts these findings further in context, by allowing us to see that there are similar developments in both countries regardless of the starting point in 2009.

Especially for older people and people with dementia, ACP is an important part of palliative care, and indeed older people themselves indicate that they find ACP important.[9,30] There is a large body of literature showing the positive impact of ACP on outcomes ranging from family satisfaction with care to concordance between end-of-life care and patient wishes, especially for older people and those living in nursing homes.[8,31-36] While the current paper takes only a limited number of indicators of ACP, the fact that these indicators have improved quite considerably shows that improvement in ACP can be achieved in a very short time period: for some patient groups, the percentage of patients whose preferences were known doubled in only six years. This is an encouraging prospect for ongoing studies aiming to further improve ACP.[37-39]

Despite already having higher percentages of awareness of preferences than Belgium in 2009, the Netherlands continues to improve at a similar rate to Belgium. This shows that ambitious goals with respect to the percentage of people with whom GP’s can engage in ACP are achievable. The increased availability of guidelines, information and interventions on ACP in both countries appear to be either a cause or a similar sign of increased awareness for the importance of ACP, especially for older people.[22-26]

However, there are still some results that might be cause for concern. A preference for a proxy decision-maker was known less often than for a medical treatment they would/would not want at the end of life, even though both can play an important role in providing high-quality care at the end of life. Certain patient groups also appear to be at a disadvantage with respect to awareness of their preferences: for people with dementia, a proxy decision-maker was known in only one-fifth of cases in Belgium and half of cases in the Netherlands, despite the importance of a proxy decision-maker for this particular group. This puts people with dementia at greater risk of receiving care at the end of life that is not in line with their values or wishes.

While the percentage of proxy decision-makers who were consulted remained high in Belgium and the Netherlands across the years, differences between the countries were clear: in the Netherlands, GPs more often indicate that there was no situation where the proxy decision-maker needed to be consulted. Part of this may be due to different samples, i.e. fewer nursing home residents were included in the Dutch sample. It may also be that Dutch GPs have a different perspective than Belgian GPs on what constitutes a situation where a consult with a proxy decision-maker is needed. Previous research have shown that communication with the family of older patients happens less frequently in the Netherlands than in Belgium.[40] Regardless, next of kin play an important role in end-of-life care for older people and should ideally be included in a palliative care approach.[14,41-43] Future research may focus on whether or not different conceptions of when proxy decision-makers should be consulted is a barrier to increasing the percentage of patients for whom a proxy decision-maker is known.

It is encouraging to conclude that the trends in the awareness of patients’ preferences for care at the end of life are increasing strongly over time in both the Netherlands and Belgium.

References Chapter 4

1. Organisation for Economic Co-operations and Development. Ageing societies OECD Factbook 2009: Economic, Environmental and Social Statistics. OECD Publishing; 2009
2. Lunney JR, Lynn J, Foley DJ, Lipson S. Patterns of functional decline at the end of life. *JAMA*. 2003;289(18):2387–92.
3. Gill TM, Gahbauer EA, Han L, Allore HG. Trajectories of disability in the last year of life. *Mass Medical Soc*. 2010;362(13):1173–80.
4. World Health Organization. Better Palliative Care for Older People. Copenhagen, Denmark: WHO; 2004.
5. Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ. Efficacy of Advance Care Planning: A systematic review and meta-analysis. *J Am Med Dir Assoc.* 2014;15(7):477-489.
6. Brinkman-Stoppelenburg A, Rietjens JAC, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. *Palliat Med.* 2014;28(8):1000-1025.
7. Meeussen K, Van den Block L, Echteld M, Boffin N, Bilsen J, Van Casteren V, et al. Older people dying with dementia: a nationwide study. *Int Psychogeriatrics*. 2012;24(10):1581–91.
8. Detering KM, Hancock AD, Reade MC , Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ.* 2010; 340:c1345.
9. Piers R, van Eechoud IJ, Van Camp S, Grypdonck M, Deveugele M, Verbeke NC, Van den Noortgate NJ. Advance Care Planning in terminally ill and frail older persons. *Patient Education and Counseling*. 2013;90(3):323-329.
10. Law concerning patient rights in Belgium, August 22, 2002, 2002022737 [in Dutch]. Belgian official collection of the laws, September 26, 2002.
11. Act of 17 November 1994 amending the civil code and other legislation in connection with the incorporation of provisions concerning the contract to provide medical treatment (Medical Treatment Contract Act). [in Dutch]. Staatsblad 1994:837.
12. Law concerning euthanasia May 28, 2002, 2002009590 [in Dutch]. Belgian official collection of the laws, June 22, 2002.
13. Termination of Life on Request and Assisted Suicide (Review Procedures) Act. [in Dutch]. Staatsblad, 2002.
14. Centeno-Cortes C, Lynch T, Donea O, Rocafort J, Clark D. EAPC Atlas of Palliative Care in Europe 2013 – Full edition. Pamplona, Spain: European Association for Palliative Care; 2013
15. Clark D, ten Have H, Janssens R. Common threads? Palliative care service developments in seven European countries. *Palliat Med*. 2000;14:479-490
16. Onwuteaka-Philipsen B, de Korte-Verhoef MC, Schweitzer B, Francke AL, Deliens L, Pasman HRW. Generalist primary and palliative care is associated with few hospitalisations in the last month of life. European Journal of Palliative Care. 2015;142. Abstract. 14th World Congress of the European Association for Palliative Care: Building Bridges. 8-10 may 2015, Copenhagen.

17. Van der Steen JT. Dying with dementia: what we know after more than a decade of research. *J Alzheimers Dis*. 2010;22(1):37–55.
18. Stijnen MMN, Duimel-Peeters IGP, Jansen MWJ, Vrijhoef HJM. Early detection of health problems in potentially frail community-dwelling older people by general practices – project [G]OLD: design of a longitudinal, quasi-experimental study. *BMC Geriatr.* 2013; 13(7):1-10.
19. Abarshi E, Echteld M, Donker G, Van den Block L, Onwuteaka-Philipsen B, Deliens L. Discussing end-of-life issues in the last months of life: a nationwide study among family physicians. *J Palliat Med*. 2011;14(3):323-30.
20. Scott IA, Mitchell GK, Reymong EJ, Daly MP. Difficult but necessary conversations—the case for advance care planning. *Med J Aust*. 2013;199(10):662-6.
21. Meeussen K, Van den Block L, Echteld M, Bossuyt N, Bilsen J, et al. Advance Care Planning in Belgium and the Netherlands: A Nationwide Retrospective Study Via Sentinel Networks of Family physicians. *Journal of Pain and Symptom Management.* 2011;42(4):565-577.
22. Van Mechelen W, Piers R, Van den Eynde J, & De Lepeleire J. Guideline Advance Care Planning. [in Dutch] Vilvoorde, Belgium: Federatie Palliatieve Zorg Vlaanderen vzw; 2015.
23. Carbonnelle S, Declercq A, Rigaux N, Sevenants, A. Vroegtijdige zorgplanning voor personen met dementie in praktijk [Advance care planning for people with dementia in practice]. Koning Boudewijnstichting, 2014. Available from www.kbs-frb.be/nl/Activities/Publications/2014/314177 Accessed on 20/06/2016.
24. Van Soest-Poortvliet M, van der Steen J, de Vet H, Onwuteaka-Philipsen B, Deliens L, hertogh C. Het plannen van zorg in de laatste levensfase bij dementie [Planning care in the last fase of life for people with dementia]. VUmc Expertisecentrum Palliatieve Zorg [Centre for Palliative Care Expertise] 2013. Available from www.platformouderenzorg.nl Accessed on 11-03-2016.
25. Korfage IJ, Rietjens JAC, Overbeek A, Jabbarian LJ, Billekens P, Hammes BJ et al. A cluster randomized controlled trial on the effects and costs of advance care planning in elderly care: a study protocol. *BMC Geriatrics.* 2015;15(1):1.
26. Rietjens JAC, Korfage IJ, Dunleavy L, Preston NJ, Jabbarian LJ, Arnfeldt Christensen C, et al. Advance care planning – a multi-centre cluster randomised clinical trial: the research protocol of the ACTION study. *BMC Cancer.* 2016;16(1):1.
27. Van den Block L, Onwuteaka-Philipsen B, Meeussen K, Donker G, Giusti F, Miccinesi G, et al. Nationwide continuous monitoring of end-of-life care via representative networks of family physicians in Europe. *BMC Fam Pract*. 2013;14(1):73.
28. Donker GA. NIVEL Primary Care Database - Sentinel Practices 2013. Annual report. Utrecht, NIVEL, 2015. Available from www.nivel.nl/sites/default/files/bestanden/Peilstations-jaarverslag-2013-Engels.pdf Accessed on 25/04/2016.
29. Donker GA. NIVEL Primary Care Database - Sentinel Practices 2014. Annual report. Utrecht, NIVEL, 2016. Available from www.nivel.nl/node/2430?database=ChoicePublicat&priref=1002563 Accessed on 21/04/2016.

30. Wright AA, Zhang B, Ray A et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA.* 2008;300:1665-1673.
31. Clayton JM, Butow PN, Tattersall MH, Devine RJ, Simpson JM, Aggarwal G, Clark KJ, Currow DC, Elliott LM, Lacey J, Lee PG. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *Journal of Clinical Oncology*. 2007;25(6):715-23.
32. Dexter PR, Wolinsky FD, Gramelspacher FP, Zhou XH, Eckert GJ, Waisburd M, Tierney WM. Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms: a randomized, controlled trial. *Annals of Internal Medicine.* 1998;128(2):102-10.
33. Kirchhoff KT, Hammes BJ, Kehl KA, Briggs LA, Brown RL. Effect of a Disease-Specific Advance Care Planning Intervention on End-of-Life Care. *Journal of the American Geriatrics Society*. 2012;60(5):946-50.
34. Morrison RS, Chichin E, Carter J, Burack O, Lantz M, Meier DE. The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *Journal of the American Geriatrics Society*. 2005;53(2):290-4.
35. Bischoff KE, Sudore R, Miao Y, Boscardin WJ, Smith AK. Advance Care Planning and the Quality of End-of-Life Care in Older Adults. *Journal of the American Geriatrics Society*. 2013;61(2):209-14.
36. De Vleminck A, Houttekier D, Deliens L, Vander Stichele R, Pardon K. Development of a complex intervention to support the initiation of advance care planning by family physicians in patients at risk of deteriorating or dying: a phase 0-1 study. *BMC palliative care*. 2016;15(1):1.
37. Rietjens JA, Korfage IJ, Dunleavy L, Preston NJ, Jabbarian LJ, Christensen CA, de Brito M, Bulli F, Caswell G, Červ B, van Delden J. Advance care planning–a multi-centre cluster randomised clinical trial: the research protocol of the ACTION study. *BMC Cancer*. 2016 Apr 8;16(1):1.
38. Ampe S, Sevenants A, Coppens E, Spruytte N, Smets T, Declercq A, Audenhove C. Study protocol for ‘we DECide’: implementation of advance care planning for nursing home residents with dementia. *Journal of advanced nursing*. 2015;71(5):1156-68.
39. Penders YWH, Onwuteaka-Philipsen B, Moreels S, Donker GA, Miccinesi G, Deliens L, Van den Block L. How Often Do Family physicians Communicate about End-of-Life Topics with Community-dwelling Older People and their Family in Three European Countries? *Palliat Med.* 2016;30(6):NP1-NO401.
40. Van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med.* 2014;28(3):197-209.

41. Gjerberg E, Lillemoen L, F∅rde R, Pedersen R. End-of-life care communications and shared decision-making in Norwegian nursing homes—experiences and perspectives of patients and relatives. *BMC Geriatr*. 2015;15(1):103.
42. Stewart F, Goddard C, Schiff R, Hall S. Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families. *Age and Ageing.* 2011;40:330-335.

CHAPTER 5: Differences in out-of-pocket costs of healthcare in the last year of life of older people in 13 European countries

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Abstract

Background

Research on the costs of healthcare provision has so far focused on insurer costs rather than out-of-pocket costs. Out-of-pocket costs may be important to patients making medical decisions.

Aim

To investigate the self-reported out-of-pocket costs associated with healthcare in the last year of life of older adults in Europe.

Methods

A post-death survey, part of the Study of Health, Ageing, and Retirement in Europe (SHARE), completed by 2501 proxy respondents of deceased adults of 55 years or over. Data from 13 European countries and four waves from 2005-2012 was used.

Results

The proportion of people with out-of-pocket costs ranged from 21% to 96% in different EU countries. Out-of-pocket costs ranged from 2% to 25% of median household income. Secondary and institutional care was most often the largest contributor to out-of-pocket costs, with care received in a care home being the most expensive type of care in 11 out of 13 countries. Multilevel analyses showed that limitations in more than two activities of daily living (coefficient=6.47, 95% CI 1.81-11.14) and a total hospitalization time of three to six months (coefficient=14.66, 95% CI 0.97-28.35) or more than six months (coefficient=31.01, 95% CI 11.98-50.15) were associated with higher out-of-pocket costs. Twenty-four per cent of the variance on a country level remained unexplained.

Conclusion

Variation in out-of-pocket costs for healthcare in the last year of life between European countries indicates that countries face different challenges in making healthcare in the last year of life affordable for all.

Introduction

From a societal perspective, the last year of life is one of the most costly periods in terms of formal healthcare provision,[1-4] often attributed to the high amount of critical care, hospital admissions, and care home stays.[5-11]

While studies have shown that in the USA illness and medical debts are often cited as having played a substantial role in personal bankruptcies,[12] there is a significant shortage of research on the costs of end-of-life care for care receivers and their families.[13,14] Studies investigating costs at the end of life usually look at the insurer costs (i.e. insurance companies or the government e.g. Medicare payments) and rarely consider out-of-pocket costs for healthcare (i.e. the costs to a care receiver that are not paid for or reimbursed by health insurance or employers). On the other hand, existing studies of out-of-pocket costs do not focus on the last phase of life and usually concern the costs of specific disease trajectories[15-17] rather than taking a population-based approach, making the findings difficult to place in context. One 2010 review of 29 studies of out-of-pocket costs for people over 65 in the USA and Australia found that low-income older people paid the most out-of-pocket costs in relation to their earnings, that women paid more out-of-pocket costs than men, and that prescription drugs were the largest contributor to out-of-pocket costs.[18] These results differ from studies of insurer costs, where having a high income, institutionalization, and advanced medical procedures are associated with higher costs.[7,8,10]

The out-of-pocket costs for healthcare specifically in the last, potentially most expensive, phase of life have not been systematically studied. Policy initiatives focusing on moving care into informal settings, such as dying at home with care provided by the family, may carry with them significant costs for the individuals concerned although they appear less expensive to insurance providers and government.[13] Particularly for older people, such high out-of-pocket costs are sometimes cited as a reason not to initiate or adhere to treatment or care, potentially decreasing quality of life in the final stage of life.[19,20] Population-based research on out-of-pocket costs for healthcare would aid in the development of adequate healthcare policies that also take into account the financial burden on care receivers by identifying those groups who are at particular risk of having high out-of-pocket costs.

In this study we investigate:

- What are the out-of-pocket costs for healthcare in the last year of life of older people in 13 European countries and do these vary between countries?
- Which specific costs contribute most to the overall out-of-pocket costs for healthcare in the last year of life of older people and does this vary across countries?
- What are individual-level determinants of out-of-pocket costs of healthcare in the last year of life of older people?

Methods

Study design

This study uses data from the Survey of Health, Aging, and Retirement in Europe (SHARE), an ongoing longitudinal study among mainly community-dwelling older people (50 years and older) and their households in a large number of European countries, begun in 2004. Individuals who were living in institutions for older people such as a nursing home at the start of data collection were included only in Denmark, Germany, Greece, the Netherlands, Spain, and Sweden.[21] Detailed information on SHARE and data collection procedures can be found elsewhere.[22-27]

For studying out-of-pocket costs in the last year of life we used post-death survey data collected during post-mortem proxy interviews, from 2005 up to 2012 in 13 countries: Austria, Belgium, the Czech Republic, Denmark, France, Germany, Greece, Italy, the Netherlands, Poland, Spain, Sweden, and Switzerland. These countries are very diverse in healthcare use and financing, ranging from countries where private financing is high and informal care seems a necessity (Italy) to countries with accessible and formalized public-funded healthcare (e.g. Denmark).[28-30]

Sample

We included all deceased participants of the SHARE study for whom death was confirmed and for whom a proxy respondent could confirm the age of the deceased and completed the end-of-life questionnaire (n=2732). In wave 2, death could be confirmed in 12% of cases, with 28% of non-respondents with vital status unknown, with a household response rate between 38% and 69%.[20] For wave 3, response rates for end-of-life interviews ranged from 41% (Austria) to 86% (Spain, Greece) (24). For wave 4, household response rates ranged between 39% and 63%(26). Eight per cent of proxy respondents (n=231) could not provide any information concerning costs and these cases were excluded from the study, leading to a final sample of n=2501.

Procedures and measurements

All data were collected by computer assisted personal interviews (CAPI) or computer assisted telephone interviews (CATI) conducted by professional interviewers.

Proxy respondents were asked to indicate what types of healthcare the deceased had received in the last year of life and if they had, how much the deceased had to pay out-of-pocket (i.e. not reimbursed by government or insurance) for each type of care. Out-of-pocket costs were defined as: ‘the financial costs of care incurred by the deceased that were not paid for or reimbursed by health insurance or employers’. Proxy respondents were asked to provide information about eight types of care and related out-of-pocket costs in the last year of life as follows: "*We would now like to ask you some questions about any expenses which [the decedent] incurred as a result of the medical care [he/she] received in the last 12 months before [he/she] died. For each of the types of care I will now read out,please indicate whether the deceased received the care and, if so, give your best estimate of the costs incurred from that care."*

We grouped these eight types in three categories:

- medication
- primary care: GP care, home care or help received due to disability, aids and appliances
- secondary and institutional care: specialist care (i.e. from specialist physicians), hospital care, care received in a care home, and hospice care

When exact costs were unknown, or when respondents refused to provide exact figures, they were asked to estimate costs by choosing between three prompted answering categories which coincided with a country- and care-specific low, medium or high value; of all cost data, 9.9% was the result of such estimates. Additionally, respondents were asked to provide information on a number of individual factors relating to the deceased, the following of which were selected for this study as they were found relevant to out-of-pocket or insurer costs of healthcare in previous research:

- the number of activities of daily living (ADLs) the deceased had difficulties with in the last year of life, such as walking across a room, eating, or making telephone calls;
- place and cause of death;
- how long the deceased had been ill before dying.

Analyses

All analyses were performed using Stata Statistical Software: Release 12 (StataCorp. 2011).

In cases where respondents gave improbably high cost values, i.e. more than ten times the median OECD household income for the respective country in 2009, these values were recoded into missing values (n=7) as they were likely to be the result of data entry errors. The 2009 median disposable household income and 31-12-2009 exchange rates were used to calculate out-of-pocket costs of healthcare relative to household income in euros.[31] In all tables, countries are ordered according to the percentage of people who had any out-of-pocket costs for received healthcare (high to low).

Missing values on medical costs varied across countries and across type of healthcare received, with Italy showing the least missing values (no higher than 3.6%) and Sweden showing the most missing values (up to 29.1%). Missing values were due to lack of knowledge on the part of respondents (97%) rather than refusal (3%). Missing value analyses indicated cases where no costs could be reported were not related to age or gender of the decedent, cause of death or place of death ($p>0.05$ for all).

Hierarchical linear modelling (multilevel modelling) was used to analyse possible individual-level determinants of out-of-pocket costs, where country was used as the level 2 grouping variable. The dependent variable was total out-of-pocket costs as a percentage of median household income in the deceased's country to allow for between-country differences in wealth. Individual-level variables were used to explain both individual-level variance and country-level variance through composition effects (i.e. differences between countries in the distribution of the independent variables).

Results

Study population

The average age of death (table 1) ranged from 75 years in Poland (s.d.=10), Austria (s.d.=11) and Germany (s.d.=10) to 81 years in Sweden (s.d.=10). Between 39% (Poland) and 55% (Denmark) of decedents were female. Death was most often caused by cancer (20%-38%) or cardiovascular diseases (17%-35%) in all countries as reported by the proxy. Home death varied between 22% (Sweden) and 52% of cases (Greece). In all countries, the majority of decedents (58-83%) were hospitalized at some point during the last year of life. Use of a care home varied between 1% (Poland) and 38% of cases (Switzerland). Hospice use varied between not at all (Greece) to 17% of cases (France).

Out-of-pocket costs for healthcare in the last year of life and variation between countries

At least 95% of people had some out-of-pocket costs for healthcare in the last year of life in Sweden, Belgium, and the Czech Republic as did between 79% and 90% in Poland, Greece, Austria, and Germany, between 54% and 68% in Italy, Denmark, the Netherlands, and France, and 21% in Spain (table 2).

Between countries, the percentage of people who paid out-of-pocket costs for different types of care differed. For example, more than 80% of people had out-of-pocket costs for GP care in Sweden, Belgium, and the Czech Republic versus 5% or fewer in Denmark and Spain. Likewise, hospital care brought with it out-of-pocket costs for more than 80% of people in Sweden and the Czech Republic, versus 5% or fewer in Italy, Denmark, and Spain.

Table 1: Characteristics of the study population, N=2501*

	SE	**BE**	**CZ**	**PL**	**CH**	**GR**	**AT**	**DE**	**IT**	**DK**	**NL**	**FR**	**ES**
	N=294	**N=199**	**N=128**	**N=226**	**N=63**	**N=163**	**N=97**	**N=154**	**N=227**	**N=242**	**N=168**	**N=221**	**N=319**
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Age, mean (SD)	81 (10)	77 (11)	76 (10)	75 (10)	80 (11)	76 (11)	75 (11)	75 (10)	77 (10)	77 (11)	76 (11)	78 (12)	80 (10)
Gender, female	131 (45)	80 (40)	56 (44)	89 (39)	27 (43)	80 (49)	49 (51)	70 (45)	99 (44)	132 (55)	70 (42)	102 (46)	149 (47)
Disease underlying death†													
Cancer	87 (30)	61 (31)	37 (29)	60 (27)	20 (32)	40 (25)	23 (24)	50 (32)	85 (37)	76 (32)	63 (38)	65 (30)	64 (20)
Cardiovascular disorder	60 (20)	38 (19)	36 (28)	78 (35)	15 (24)	56 (34)	23 (24)	48 (31)	54 (24)	41 (17)	30 (18)	37 (17)	86 (27)
Stroke	23 (8)	17 (9)	23 (18)	34 (15)	2 (3)	28 (17)	14 (15)	11 (7)	26 (11)	13 (6)	13 (8)	25 (11)	33 (10)
Respiratory disease	8 (3)	5 (3)	6 (5)	10 (4)	2 (3)	9 (6)	5 (5)	3 (2)	13 (6)	15 (6)	5 (3)	12 (5)	23 (7)
Infectious disease	7 (20)	7 (14)	4 (5)	2 (4)	6 (10)	1 (1)	5 (5)	5 (7)	3 (7)	6 (14)	4 (7)	5 (10)	4 (14)
Other (incl. accidents)	95 (32)	63 (32)	21 (16)	40 (18)	18 (29)	29 (18)	26 (27)	35 (23)	42 (19)	82 (34)	50 (30)	70 (32)	99 (31)
Place of death													
Home	65 (22)	68 (35)	30 (24)	93 (42)	15 (24)	79 (52)	33 (34)	56 (37)	112 (50)	60 (25)	55 (33)	58 (27)	120 (38)
Hospital	118 (41)	95 (49)	86 (68)	120 (54)	30 (48)	70 (46)	53 (55)	70 (46)	98 (44)	96 (40)	55 (33)	122 (57)	173 (55)
Care home	93 (32)	23 (12)	6 (5)	1 (0.5)	13 (21)	2 (1)	8 (8)	17 (11)	9 (4)	76 (32)	46 (28)	24 (11)	16 (5)
Other	15 (5)	9 (5)	4 (3)	9 (4)	5 (8)	2 (1)	2 (2)	8 (5)	5 (2)	9 (4)	9 (5)	11 (5)	5 (2)
Hospitalized in last year of life	211 (74)	132 (68)	89 (71)	165 (74)	39 (62)	101 (66)	79 (83)	110 (72)	160 (71)	186 (78)	115 (70)	124 (58)	215 (68)
In care home in last year of life	73 (25)	26 (13)	11 (9)	2 (1)	14 (22)	3 (2)	15 (15)	22 (14)	13 (6)	62 (26)	31 (18)	45 (20)	23 (7)
Hospice care in last year of life	42 (14)	21 (11)	7 (5)	8 (4)	4 (6)	na	2 (2)	4 (3)	1 (0)	10 (4)	8 (5)	36 (17)	4 (1)

***Missing on cause of death N=6, place of death N=44, hospitalization N=54, in care home in last year of life N=2, in hospice in last year of life N=6. †As judged by proxy respondent.**

na = not applicable: no hospices used in Greece

Using linear regression and logistic regression within hierarchical linear modelling, all measures showed significant differences across countries (p<.001)

Table 2: Percentage of people who had any out-of-pocket costs of healthcare received in the last year of life

	SE	**BE**	**CZ**	**PL**	**CH**	**GR**	**AT**	**DE**	**IT**	**DK**	**NL**	**FR**	**ES**
Cost categories	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Medication (n=2232)	234 (93)	151 (90)	109 (96)	194 (92)	29 (56)	103 (71)	61 (71)	84 (61)	120 (56)	136 (68)	39 (26)	45 (23)	18 (6)
Primary care													
GP (n=2172)	214 (94)	161 (88)	70 (60)	41 (19)	44 (83)	52 (42)	23 (25)	51 (37)	24 (12)	8 (5)	15 (11)	62 (30)	12 (4)
Aids & appliances (n=868)	66 (89)	51 (61)	20 (59)	16 (47)	19 (59)	23 (77)	27 (61)	28 (40)	8 (35)	7 (5)	15 (19)	20 (21)	9 (8)
Home care (n=893)	33 (54)	46 (52)	13 (50)	8 (10)	17 (71)	23 (66)	21 (91)	20 (30)	32 (40)	8 (5)	44 (65)	32 (30)	25 (31)
Secondary and institutional care													
Specialist (n=1648)	106 (77)	108 (82)	63 (57)	46 (28)	20 (61)	66 (54)	11 (18)	26 (24)	84 (52)	3 (4)	11 (8)	34 (22)	15 (6)
Hospital (n=1510)	129 (91)	83 (78)	54 (68)	12 (7)	25 (81)	27 (28)	36 (55)	49 (53)	8 (5)	0 (0)	7 (7)	28 (25)	6 (3)
Care home (n=305)	55 (90)	21 (95)	9 (82)	1 (50)	13 (93)	2 (67)	13 (87)	16 (73)	4 (31)	24 (42)	17 (59)	22 (58)	12 (67)
Hospice (n=126)	21 (70)	6 (35)	2 (33)	0 (0)	2 (50)	na	0 (0)	1 (25)	1 (100)	3 (30)	3 (43)	9 (26)	0 (0)
All care (n=2501)*	283 (96)	190 (95)	121 (95)	203 (90)	52 (83)	132 (81)	78 (80)	122 (79)	154 (68)	149 (62)	96 (57)	120 (54)	66 (21)

*** Missings <10% for all cells, except in following countries and cost categories: SE: aids & appliances (N=25, 25%), home care (N=25, 29%), specialist (N=22, 14%), hospital (N=33, 19%), care home (N=12, 16%), hospice (N=12, 29%); BE: medication (N=24, 13%), home care (N=12, 12%), specialist (N=16, 11%), hospital (N=17, 14%), care home (N=4, 15%), hospice (N=4, 19%); CZ: home care (N=3, 10%), hospice (N=1, 14%); PL: hospice (N=1, 13%); CH: medication (N=6, 10%); specialist (N=4, 11%), hospital (N=4, 11%); AT: aids & appliances (N=5, 10%); DK: medication (N=27, 12%); NL: hospice (N=1, 13%); FR: home care (N=16, 13%), care home (N=7, 16%); ES: care home (N=5, 22%).**

na = not applicable: no hospices used in Greece

Across countries, hospice care was least likely to incur out-of-pocket costs with the lowest percentage of users with any out-of-pocket costs in Belgium, the Czech Republic, Poland, Switzerland, Austria, and Spain, followed by hospital care, with lowest percentages in Greece, Italy, Denmark, and the Netherlands. Care received in a care home was most likely to incur out-of-pocket costs (highest percentage of users with any out-of-pocket costs in Belgium, Switzerland, Germany, France, and Spain) followed by medication (with highest percentages in the Czech Republic, Poland, and Denmark).

Contribution of specific types of healthcare to total out-of-pocket costs and variation between countries

For people who paid out-of-pocket costs for healthcare in the last year of life, the total median amount varied between countries from 461 euros in the Netherlands to 5,657 euros in Switzerland (table 3). Relative to the median household income, the median out-of-pocket costs ranged from 25% in the Czech Republic, between 11% and 16% in Switzerland, Poland, and Sweden, between 5% and 9% in Belgium, Denmark, Spain, Greece, Austria, and France to less than 5% in Italy, Germany and the Netherlands (2%). People who paid out-of-pocket costs paid more than the average total health spending per capita in the Czech Republic (145%) and Switzerland (157%); more than half in Sweden, Belgium, Poland, Denmark and Spain; and less than half in France, Greece, Italy, Denmark and the Netherlands (15%). This means that in the Czech Republic and Switzerland, those who had any out-of-pocket costs for healthcare in the last year of life paid more than the average private plus public spending on healthcare per person per year.

Care received in a care home was the most expensive out-of-pocket cost category in all countries except the Czech Republic (where hospice care was most expensive) and Poland (where medication was most expensive), with median costs in the last year of life ranging from 2,104 euros (Sweden) to 7,440 euros (Spain). The least expensive categories for out-of-pocket costs were GP care, which incurred the least out-of-pocket costs in Sweden, Belgium, the Czech Republic, Germany, Italy, Denmark and France (median costs ranging from 20 euros in Italy to 668 euros in Denmark), aids and appliances in Poland, Switzerland, Greece and Austria (median costs ranging from 171 euros in Poland to 500 euros in Switzerland) and medication in the Netherlands (median costs 150 euros) and Spain (median costs 225 euros).

Figure 1 shows the relative contribution of medication, primary care, and secondary and institutional care to mean out-of-pocket medical costs per country, including for those people who had no out-of-pocket costs but did receive care. Medication was the largest contributor to out-of-pocket medical costs in Poland (66%) and Denmark (59%). Primary care was the largest contributor in Italy (39%)

Table 3: Median out-of-pocket costs of healthcare (if costs >0 EUR) for care received in the last year of life and relation to median household income

	SE	**BE**	**CZ**	**PL**	**CH**	**GR**	**AT**	**DE**	**IT**	**DK**	**NL**	**FR**	**ES**
Cost categories	**Median costs in EUR**												
Medication (n=1323)	208	750	750	575	810	375	550	200	300	1722	150	300	225
Primary care													
GP (n=777)	199	180	41	450	1026	375	300	100	20	668	475	75	300
Aids & appliances (n=868)	1415	300	1650	171	500	250	250	125	300	750	200	300	450
Home care (n=893)	1500	325	325	502	1000	2000	500	1650	1100	2085	400	775	1100
Secondary and institutional care													
Specialist (n=1648)	326	375	90	268	3275	388	700	275	400	2000	700	240	2000
Hospital (n=1510)	543	540	182	465	3000	500	475	200	750	na	650	975	1200
Care home (n=305)	2104	12500	1629	213*	4627	2750	4200	2730	6600	3800	4500	3500	7440
Hospice (n=126)	2000	405	6500	na	2925	na	na	800*	17000*	2000	250	2000	na
Total (n=1766)	2300 (N=283)	1900 (N=190)	2000 (N=121)	709 (N=203)	5657 (N=52)	775 (N=132)	1450 (N=78)	519 (N=122)	695 (N=154)	2000 (N=149)	461 (N=96)	975 (N=120)	1100 (N=66)
Median hh income†	21884	22037	8036	5539	34552	13983	23266	20349	17943	29707	22400	21130	14880
Median total o.o.p.-costs/median hh income	.11	.09	.25	.13	.16	.06	.06	.03	.04	.07	.02	.05	.07
Average total health spending p.c.‡	2467	2660	1375	885	3609	2069	2868	2875	2134	2957	3168	2639	2050
Median total o.o.p.-costs/Average total health spending p.c.§	0.93	0.71	1.45	.80	1.57	0.37	0.51	.18	.33	.68	.15	.37	0.54

* based on 1 value †based on 2009 median disposable household income as retrieved from stats.oecd.org (OECD StatExtracts(27)) and 12/31/2009 exchange rates ‡based on 2009 total public and private healthcare spending on curative, rehabilitative and long-term care as well as medical goods, public health and prevention programmes, and administration as retrieved from stats.oecd.org (OEC StatExtracts(27)) and 12/31/2009 exchange rates §Only for those who had costs >0

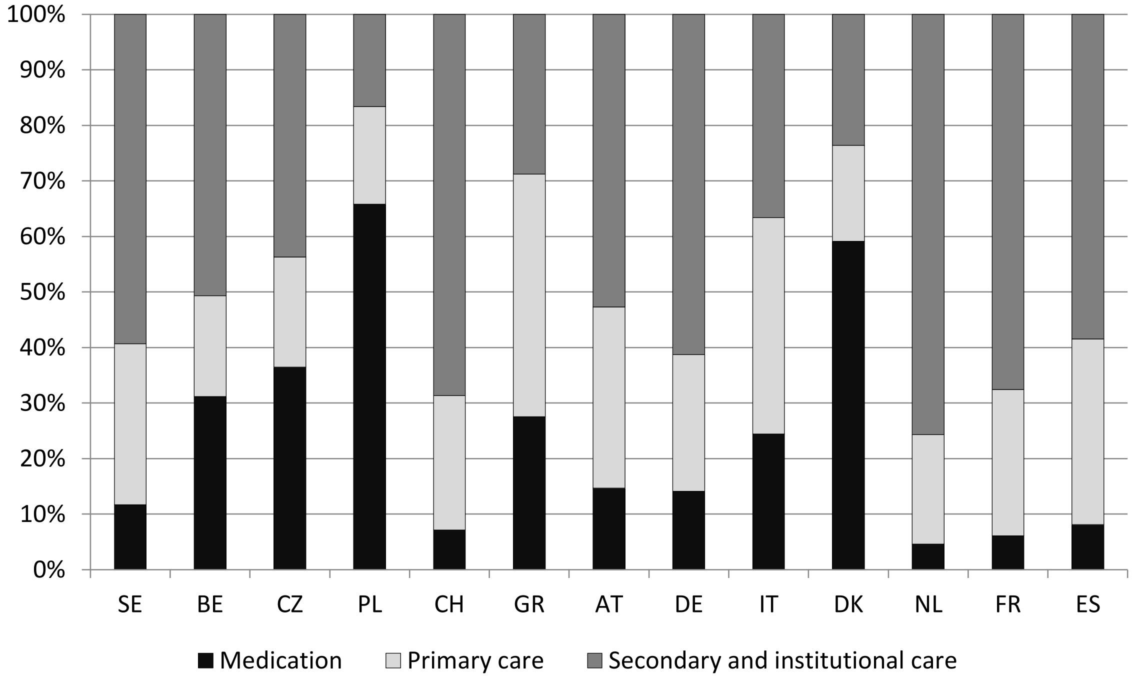
na = not applicable: no out-of-pocket medical costs incurred for this cost category in this country and Greece (44%). In the remaining nine countries, secondary care was the largest contributor, ranging from 44% in the Czech Republic to 76% in the Netherlands.

Determinants of out-of-pocket medical costs in the last year of life

Comparing an empty single-level model to an empty two-level model, where decedents are level 1 and countries are level 2, provided evidence for an effect of country on total out-of-pocket costs relative to median household income and supports using hierarchical linear modelling (likelihood ratio test statistic of 111.54 on 1 df (chi² <.001)). The variance-component ('empty') model showed that without controls, 6% of the variance in the out-of-pocket costs relative to median household income was between countries as opposed to between individuals (not shown in table).

A random-slope model was constructed (see table 4) where the effect of length of hospitalization was allowed to vary between countries, as care in a hospital was fully compensated in at least one country (Denmark). Decedents who had limitations with more than two activities of daily living had significantly higher out-of-pocket costs relative to median household income than those who had no problems with activities of daily living, independently of being chronically ill (b=6.47, p<.01). Those who were in hospital for three to six months during the last year of life had significantly higher out-of-pocket costs than those who were not hospitalized at all (b=14.66, p=.04), as did those

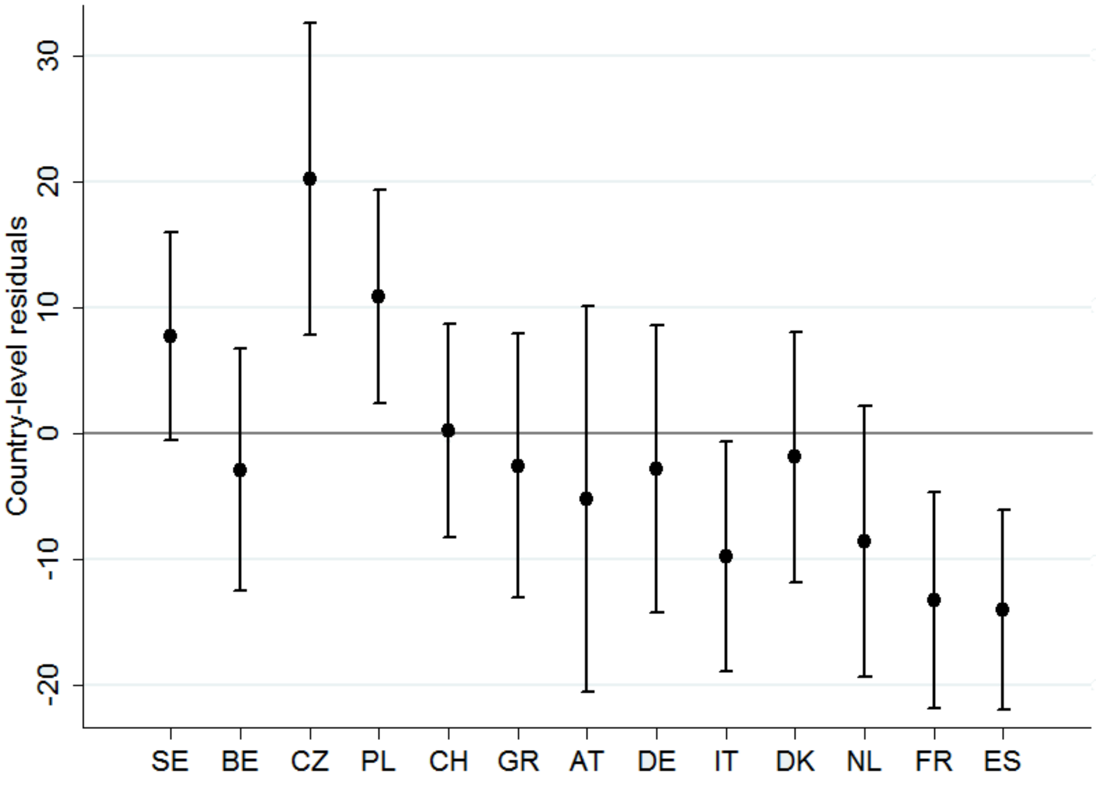
Figure 1: Relative contribution of medication, primary care and secondary and institutional care to total out-of-pocket costs of healthcare in the last year of life in 13 countries



who were hospitalized for more than six months (b=36.33, p<.001). However, people who were in hospital but for less than three months did not have higher out-of-pocket costs than those who did not spend any time in hospital. Length of hospitalization being a significant random coefficient indicates country-level differences in the effect of hospitalization. Age, gender, cause of death and place of death were not significantly related to out-of-pocket costs. After controlling for these individual-level factors, 24% of the remaining variance in out-of-pocket expenses was due to country-level differences.

Decedents in the Czech Republic and Poland incurred significantly higher out-of-pocket costs for healthcare relative to median household income than the average across the 13 countries, with costs in the Czech Republic being higher than the average by 20% of the median household income (Figure 2). Italy, France and Spain incurred significantly lower costs than average. Of the remaining countries, Sweden and Switzerland fell above the average and Belgium, Greece, Austria, Germany, Denmark and the Netherlands fell below the average, though they are not significantly different from the average.

Figure 2: Caterpillar plot of country-level residuals of total out-of-pocket medical costs in the last year of life in 13 countries as a proportion of median household income (n=2008)



Controlled for age, gender, cause of death, place of death, having a chronic illness, having problems with activities of daily living and length of hospitalization.

Table 4: Determinants of total out-of-pocket costs of healthcare in the last year of life as a percentage of median household income (n=2008)

	Coefficient	95% CI	Standard error	p-value
Intercept	8.29	-8.36 – 24.94	8.495	0.33
Fixed coefficients				
Age	-0.04	-0.24 – 0.17	0.104	0.74
Gender, female	0.85	-3.06 – 4.76	1.99	0.67
*Cause of death**				
Cancer	*Reference*			
Cardiovascular disorder	-1.59	-6.95 – 3.78	2.74	0.56
Stroke	-1.08	-8.05 – 5.89	3.56	0.76
Respiratory disease	0.26	-9.14 – 9.65	4.79	0.96
Infectious disease	4.37	-5.63 – 14.37	5.103	0.39
Other (incl. accidents)	-1.51	-7.27 – 4.11	2.902	0.59
Place of death				
Home situation	*Reference*			
Hospital	2.26	-2.03 – 6.54	2.19	0.301
Care home, hospice or other	0.51	-7.11 – 8.12	3.88	0.896
Having a chronic illness (1 year or longer)	2.496	-1.61 – 6.602	2.09	0.23
Limitations with activities of daily living				
None	*Reference*			
1-2	5.42	-0.81 – 11.64	3.18	0.09
More than 2	6.47	1.81 – 11.14	2.38	**<0.01**
Random coefficients				
Length of hospitalization				
Not at all	*Reference*			
Less than 1 month	4.995	-0.91 – 10.897	3.01	0.09
1-3 months	5.03	-3.58 – 14.62	4.64	0.235
3-6 months	14.66	0.97 – 28.35	6.99	**0.036**
More than 6 months	31.01	11.98 – 50.15	9.74	**<0.001**
Variance partition coefficient	0.242			
Log-likelihood	-10425			

*According to relative

Level 2 grouping variable is country. CI = confidence interval. Fixed coefficient = effect is not allowed to vary between countries. Random coefficient = effect is allowed to vary between countries.

Discussion

Although we found considerable variations between countries in terms of the out-of-pocket costs for different types of care, there were also important similarities. While not all people have out-of-pocket costs in the last year of life, for those who do (between 21% and 96%) these are often large amounts, with median costs up to 25% of median household income and often more than 50% of total health spending per person depending on the country. Median out-of-pocket costs for different types of care varied across countries but secondary care was the largest contributor to out-of-pocket costs in nine out of 13 countries, with care received in a care home being the most expensive type of care in 11 out of 13 countries. Problems with activities of daily life and length of hospitalization were related to higher out-of-pocket costs. After controlling for individual-level factors, 24% of the variation in out-of-pocket costs was due to country-level differences.

To our knowledge, this is the first large-scale cross-country study investigating the out-of-pocket costs of multiple types of care in the last year of life. By looking at a wide variety of possible healthcare costs, we provide a comprehensive view of the financial burden of care to patients in the last year of life. In this way, we address the gap in the literature concerning out-of-pocket costs for healthcare in Europe viewed from a population-based perspective.

A limitation of this research is that we did not have access to objective measures of cost data, but relied on the knowledge of a proxy respondent whose recall may have been biased and which led to high missing values (up to 29.1% in Sweden). However, since very few of these missing values were due to refusal (3%), concerns about missing values correlating with higher costs are limited. Studies have shown that the use of proxy respondents is appropriate in many cases, especially when some objective measures of costs, such as bills, may have been available to prompt recall.[30] A further limitation is that we were unable to connect our data on out-of-pocket costs to data on insurer costs, which would have provided a complete picture of societal costs of healthcare in the last year of life.

Our results showed that hospitalization, one of the types of healthcare previously shown to incur high insurer costs,[4,5] was only linked to higher out-of-pocket costs when the decedent had spent more than three months in hospital. As expected, there were country-level differences in the effect of hospitalization, as hospital care is compensated to different degrees in different countries (e.g. fully compensated in Denmark). Cause of death was not significantly related to out-of-pocket costs, probably because the specific, expensive types of care required for certain illnesses e.g. cancer often consist of specific treatments and hospital care and are therefore covered by insurance. The limited median costs of hospitalization stand in contrast to care received in care homes, where care receivers and their families pay much more (median costs four times higher or more) in 12 out of 13 countries. As the population of Europe ages, more older people will spend their final phase of life in a care or nursing home.[33,34] As such, the high financial burden of this type of care which falls on the shoulders of the care receivers may be problematic. On the other hand, costs of care in a nursing home may include costs that would otherwise be incurred by paying for rent, food and utilities. Further research is needed to determine the extra costs (or benefit) of living in a care home compared to living at home.

The focus of this paper is how individual-level characteristics contribute to out-of-pocket costs of care in the last year of life. However, the large cross-country variation in the percentage of care receivers who have out-of-pocket costs, and in the size of costs, combined with the large portion of country-level variance in costs which is unexplained by individual-level factors, indicates that there is little consistency across Europe in the type or amount of care a person can afford in the last year of life. These differences can be because of the different healthcare systems in the countries studied, where various types of care are not financed in the same ways. With costs of healthcare for an ageing population constantly rising, increasing the costs to care receivers to compensate should be considered with caution to avoid making particular types of care inaccessible to sections of the population. Future research could focus on socio-economic variation in out-of-pocket costs but more importantly could also study the institutional factors that might influence such inequalities, such as the type of healthcare system in a country, healthcare resources available and differences in practice norms.

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Interested researchers can apply to obtain access to the SHARE data at share-project.org

References Chapter 5

1. Ginzberg E. The high costs of dying. Inquiry. 1980;17:293–5.
2. Scitovsky AA, Capron AM. Medical care at the end of life: the interaction of economics and ethics. Annu Rev Public Health. 1986;7:59–75.
3. Lubitz JD, Riley GF. Trends in Medicare payments in the last year of life. N Engl J Med. 1993;328:1092–6.
4. Riley GF, Lubitz JD. Long-term trends in Medicare payments in the last year of life. Health Serv Res. 2010 Apr;45(2):565–76.
5. Emanuel EJ, Ash A, Yu W, Gazelle G, Levinsky NG, Saynina O, et al. Managed care, hospice use, site of death, and medical expenditures in the last year of life. Arch Intern Med. 2002;162(15):1722–8.
6. Curtis JR, Engelberg R a, Bensink ME, Ramsey SD. End-of-life care in the intensive care unit: can we simultaneously increase quality and reduce costs? Am J Respir Crit Care Med. 2012 Oct 1;186(7):587–92.
7. Polder JJ, Barendregt JJ, Van Oers H. Healthcare costs in the last year of life - The Dutch experience. Soc Sci Med. 2006;63(7):1720–31.
8. Chastek BB, Harley C, Kallich J, Newcomer L, Paoli CJ, Teitelbaum AH. Healthcare Costs for Patients With Cancer at the End of Life. J Oncol Pract. 2012;8(6s):75–80.
9. Asmus-Szepesi KJE, Koopmanschap M a., Flinterman LE, Bakker TJEM, Mackenbach JP, Steyerberg EW. Formal and informal care costs of hospitalized older people at risk of poor functioning: a prospective cohort study. Arch Gerontol Geriatr. Elsevier Ireland Ltd; 2014 May;
10. Fassbender K, Fainsinger RL, Carson M, Finegan B a. Cost trajectories at the end of life: the Canadian experience. J Pain Symptom Manage. Elsevier Inc; 2009 Jul;38(1):75–80.
11. Langton JM, Blanch B, Drew AK, Haas M, Ingham JM, Pearson S-A. Retrospective studies of end-of-life resource utilization and costs in cancer care using health administrative data: A systematic review. Palliat Med. 2014 May 27;
12. Himmelstein DU, Thorne D, Warren E, Woolhandler S. Medical bankruptcy in the United States, 2007: results of a national study. Am J Med. Elsevier Inc.; 2009 Aug;122(8):741–6.
13. Gardiner C, Brereton L, Frey R, Wilkinson-Meyers L, Gott M. Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature. Palliat Med 2014; 28(5): 375-390.
14. Smith S, Brick A, O’Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. Palliat Med. 2014 Feb 1;28(2):130–50.
15. Longo CJ, Bereza BG. A comparative analysis of monthly out-of-pocket costs for patients with breast cancer as compared with other common cancers in Ontario, Canada. Curr Oncol. 2011 Jan;18(1):e1–8.
16. Kotlarz H, Gunnarsson CL, Fang H, Rizzo JA. Insurer and out-of-pocket costs of osteoarthritis in the US: evidence from national survey data. Arthritis Rheum. 2009 Dec;60(12):3546–53.

17. Harris SB, Leiter LA, Yale J-F, Chiasson J-L, Kleinstiver P, Sauriol L. Out-of-pocket Costs of Managing Hyperglycemia and Hypoglycemia in Patients With Type 1 Diabetes and Insulin-treated Type 2 Diabetes. Can J Diabetes. 2007 Jan;31(1):25–33.
18. Corrieri S, Heider D, Matschinger H, Lehnert T, Raum E, König H. Inequalities in out-of-pocket health-care payments for 65 + patients - a systematic review. Int J Equity Health. 2010;9(20):1–11.
19. Soumerai SB, Pierre-jacques M, Zhang F, Ross-degnan D, Adams AS, Gurwitz J, et al. Cost-Related Medication Nonadherence Among Elderly and Disabled Medicare Beneficiaries. Arch Intern Med. 2006;166:1829–35.
20. Chao L-W, Pagán JA, Soldo BJ. End-of-Life Medical Treatment Choices: Do survival chances and out-of-pocket costs matter? Med Decis Mak. 2009;28(4):511–23.
21. Klevmarken A, Hesselius P, Swensson B. The SHARE Sampling Procedures and Translation Assessment. In: Börsch-Supan A, Jürges H, editors. The Survey of Health, Aging, and Retirement in Europe - Methodology. Mannheim: Mannheim Research Institute for the Economics of Aging (MEA); 2005. p. 28–69.
22. Börsch-Supan A, Brugiavini A, Jürges H, Kapteyn A, Mackenbach J, Siegrist J, et al. First Results from the Survey of Health , Ageing and Retirement in Europe (2004-2007). Starting the longitudinal dimension. Mannheim: Mannheim Research Institute for the Economics of Aging (MEA); 2008.
23. Börsch-Supan A, Brandt M, Hunkler C, Kneip T, Korbmacher J, Malter F, et al. Data Resource Profile: the Survey of Health, Ageing and Retirement in Europe (SHARE). Int J Epidemiol. 2013 Aug 1;42(4):992–1001.
24. Börsch-Supan A, Brandt M, Litwin H, Weber G, editors. Active ageing and solidarity between generations in Europe: First results from SHARE after the economic crisis. Berlin: De Gruyter; 2013.
25. Börsch-Supan A, Brandt M, Hank K, Schröder M, editors. The individual and the welfare state. Life histories in Europe. Heidelberg: Springer; 2011.
26. Schröder M. Retrospective data collection in the Survey of Health, Ageing and Retirement in Europe. SHARELIFE methodology. Mannheim: Mannheim Research Institute for the Economics of Aging (MEA); 2011.
27. Malter F, Börsch-Supan A, editors. SHARE Wave 4: Innovations & Methodology. Munich: MEA, Max Planck Institute for Social Law and Social Policy; 2013.
28. Kraus M, Czypionka T, RIedel M, Mot E, Willemé P. How European nations care for their elderly: A new typology of long-term care systems. *SSRN* 2011: http://dx.doi.org/10.2139/ssrn.2005018
29. Joumard I, André C, Nicq C. Health care systems: Efficiency and institutions. *OECD Economics Department Working Papers* 2010; 769. doi:10.1787/5kmfp51f5f9t-en

30. 30. Wendt C, Frisina L, Rothgang H. Healthcare System Types: A conceptual framework for comparison. *Social Policy and Administration* 2009; 43(1):70-90.
31. OECD StatExtracts [Internet]. 2014. Available from: stats.oecd.org
32. Neumann PJ, Araki SS, Gutterman EM. The use of proxy respondents in studies of older adults: Lessons, challenges and opportunities. *Journal of the American Geriatrics Society* 2000: 48(12):1646-1654.
33. Houttekier D, Cohen J, Surkyn J, Deliens L. Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. *BMC Pub Health* 2011: **11**:228, doi: 10.1186/1471-2458-11-228
34. Gomes B, Higginson IJ. Where people die (1974-2030): past trends, future projections and implications for care. *Palliative Medicine* 2008: **22**: 33-41

Part II: End-of-life care for people with dementia in different European countries

CHAPTER 6: End-of-life care of people dying with dementia in family medicine in Belgium, Italy and Spain: a cross-sectional, retrospective study

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Abstract

Aim

To describe and compare end-of-life care for people with mild or severe dementia in general practice in Belgium, Italy and Spain, in terms of place of care, place of death, treatment aims, use of specialized palliative care and communication with general practitioners (GPs).

Methods

Cross-sectional retrospective survey of nationwide networks of GPs in Belgium, Italy and Spain, including patients who died aged 65 or over in 2009-2011 and were judged by the GP to have had dementia (n=1623).

Results

GPs reported a higher proportion of older people with severe dementia in Belgium (55%) than in Spain (46%) and Italy (45%), and a higher proportion of patients living in care homes (57% vs 18% and 13% resp.). A palliative treatment aim was common in the last three months of life in all three countries. Specialized palliative care services were provided in 14% (Italy, severe dementia) to 38% (Belgium, severe dementia) of cases. Communication between GP and patient about illness-related topics occurred in between 50% (Italy) and 72% (Belgium) of cases of mild dementia and 10% (Italy) to 32% (Belgium) of cases of severe dementia. Patient preferences for end-of-life care were known in a minority of cases. Few people (13%-15%) were transferred between care settings in the last week of life.

Conclusion

While overall treatment aims at the end of life are often aligned with a palliative care approach and transfer rates are low, there is room for improvement in end-of-life care for people with dementia in all countries studied, especially regarding early patient-GP communication.

Introduction

Over the next 15 years, it is expected that the number of people with dementia worldwide will grow to more than 65 million.[1] Due to the nature of the condition there can be a prolonged 'dwindling' and long-term survival with severe physical and cognitive impairments and behavioural problems.[2,3] These dementia-specific disease trajectories warrant targeted end-of-life care strategies with a particular focus on advance care planning (ACP), communication in the event of loss of decision making capacity and anticipating future health issues.[4-6] A recent white paper from the European Association of Palliative Care has also advised that palliative care, including advance care planning, is the preferred approach to care for all people with dementia starting from diagnosis onwards.[7] However, many national dementia strategies cover only part of the recommendations made in this white paper and often do not include explicit mention of palliative care or preparation for the last phase of life.[8]

So far, there is little population-based knowledge about the extent to which palliative care is provided to people dying with dementia at various stages of their illness. Existing research focuses primarily on those with severe dementia who live in nursing homes, meaning we know little about the sizeable group of community-dwelling people with dementia and those whose dementia is in the early stages, i.e. mild dementia.[9] These previous studies have shown that residents with advanced dementia are at risk of undergoing burdensome interventions at the end of life, potentially avoidable hospitalizations from nursing home, and of dying with great suffering.[10-14]

Cross-country comparisons concerning dying with dementia are limited. Those that exist focus on nursing home residents and find some differences in quality of care and quality of life as judged by proxy respondents, but provide no details of the type of care received, such as the provision of palliative care or communication between patient and care providers.[15-18] Detailed cross-country comparisons on end-of-life care, such as those on patients with cancer,[19] can shed light on which aspects of care are universally difficult or, alternatively, managed well in a variety of settings and cultural contexts; and draw attention to those areas where improvements can be made.

We chose to compare Belgium, Italy and Spain as all three countries have achieved either preliminary or advanced integration of palliative care in the healthcare system.[20] Additionally, in all three countries GPs are important primary caregivers responsible also for the provision of end-of-life care to people with dementia.[2] Apart from this, the countries differ in their approach to end-of-life care: in Italy and Spain, palliative care consists mostly of home-based support services, whereas in Belgium palliative care is more hospital-based.[20] With respect to communication and advance care planning, Belgium is a country where information preferences are generally high, whereas in Mediterranean countries such as Italy and Spain there has traditionally been resistance to disclosure of health information by physicians.[21-24] Another difference is the different long-term care systems, which mean that people who die from dementia most often die in a care home in Belgium and at home in Italy and Spain, though here too the situation with respect to people with mild dementia is still unknown.[25,26] Previous research has shown that in Spain, quality of life of people with dementia recently admitted or at risk of admission to a care home was rated lower than in other countries such as Sweden and England, but Belgium and Italy were not included in this study.[18]

This paper aims to investigate differences between Belgium, Italy and Spain with regards to the following research questions:

- How many people dying with dementia have a palliative treatment aim, and how many use specialized palliative care?
- With how many people dying with dementia did GPs communicate about end-of-life issues?
- How frequently are people dying with dementia transferred between care settings at the end of life, and what is their place of death?

Methods

Study design

This study uses data from Belgium, Italy and Spain (Castile and León and Valencian Community regions) collected as part of the EURO SENTIMELC (European Sentinel Network Monitoring End-of-Life Care) study, designed to monitor retrospectively end-of-life care in population-based samples of deaths in different countries.[19] Data were collected through existing GP Sentinel Networks, epidemiological surveillance networks consisting of GP practices or community-based physicians. Deaths were registered weekly from January 1, 2009 to December 31, 2010, except for Spain (from January 1, 2010 to December 31, 2011).[19]

Sample

All patients of the participating GP practices who died aged 65 or over and who were judged by their GPs to have had either mild or severe dementia (between 30%-32% of decedents) were included in the study (n=1623). The definitions of ‘mild dementia’ and ‘severe dementia’ were left to the interpretation of the GP. We included both those who died suddenly and non-suddenly.

Measurements

The GP Sentinel Networks collect demographic characteristics, cause of death, and whether death was sudden and unexpected for every deceased patient in the practice of participating GPs. In addition, the following questions were asked:

- Treatment aims: whether there was a palliative, curative or life-prolonging main treatment aim in the last three months, the last 2-4 weeks and the last week of life.
- Palliative care services: whether any of a number of specialist palliative care services[20] provided care and how many days before death this was initiated.
- Communication: whether the GP and the patient ever communicated about 11 aspects of illness and care, e.g. primary diagnosis, social problems and the burden of treatments; and whether the patient ever expressed any preference about a medical end-of-life treatment, place of death or a proxy decision-maker.
- Transitions and place of death: how often the patient was transferred between care settings in the last three months of life; where the patient resided the longest in the last three months of life; place of death and whether place of death was in accordance with the patient's preference.

Analyses

Differences between countries were calculated using ANOVA, Pearson's Chi-square tests or Fisher's exact tests. Multivariate logistic regression was used to analyse between-country differences controlling for longest place of residence and cause of death. Robust error clustering was used to account for clustering of individuals within GP practices. All analyses were performed using Stata Statistical Software: Release 12 (StataCorp. 2011).

Ethics approval

For Belgium, ethics approval was obtained from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (2004) and for Italy from the Local Ethical Committee 'Comitato Etico della Azienda U.S.L. n. 9 di Grosseto' in Tuscany (2008). Posthumous collection of anonymous patient data does not require ethics approval according to Spanish law.

Results

Patient characteristics

We studied 1,623 patients diagnosed with mild or severe dementia (Table 1). In Belgium, severe dementia was more common (55%) than mild dementia (45%), whereas the reverse was true for Italy (45% and 55% respectively) and Spain (46% and 54% respectively, p=.002). We stratified for this difference in subsequent analyses, as certain aspects of care (e.g. communication) might differ significantly for these two groups.

In the last year of life, 40% of patients with dementia in Belgium resided at home, 81% in Spain and 87% in Italy (p<.001). The most common cause of death was cardiovascular disease: 20% in Belgium, 23% in Spain and 31% in Italy (p=.38). Between 22% and 26% of deaths were classified as sudden (p=.18).

Table 1: Characteristics of the study population (n=1623)*

	Belgium (n=621)		**Spain (n=295)**		**Italy (n=707)**		
	n	% [95% CI]	n	% [95% CI]	n	% [95% CI]	P†
Age at death (mean, S.D.)	85.9	(6.8)	85.8	(6.4)	86.5	(7.1)	.62
Gender, female	402	65 [61-68]	170	58 [52-63]	460	65 [62-69]	.07
Severity of dementia							.002
Mild	282	45 [41-49]	160	54 [49-60]	392	55 [52-59]	
Severe	339	55 [51-59]	135	46 [40-51]	315	45 [41-48]	
Longest place of residence in last year							
Home	247	40 [36-44]	234	81 [76-85]	611	87 [84-89]	<.001
Care home	355	57 [54-61]	54	19 [14-23]	91	13 [11-15]	<.001
Elsewhere	16	3 [1-4]	2	1 [0-2]	3	0 [0]	.002
Cause of death							
Malignancies	61	10 [8-12]	38	13 [9-17]	76	12 [9-14]	.36
Cardiovascular disease	124	20 [17-23]	66	23 [18-28]	209	31 [27-34]	.38
Respiratory disease	70	11 [9-14]	38	13 [9-17]	64	10 [7-12]	.26
Disease of nervous system	92	15 [12-18]	49	17 [13-22]	115	17 [14-20]	.58
Stroke (CVA)	68	11 [9-14]	37	13 [9-16]	117	17 [15-20]	.008
Other	205	33 [30-37]	61	21 [16-26]	90	13 [11-16]	<.001
Sudden death	134	22 [18-25]	63	23 [18-28]	183	26 [23-29]	.18

*missing for place of residence = 10, cause of death = 43, sudden death = 24

CI = confidence interval

†bivariate p-value

Treatment aims in the last three months of life

Two to three months before death a palliative treatment aim was considered important for 66% of patients with mild dementia in Belgium, 75% in Spain and 64% in Italy (figure 1). A curative treatment aim was considered important for 58% in Belgium, 52% in Spain and 37% in Italy (OR=.39, 95%CI=.26-.59). A life-prolonging treatment aim was considered important for 62% of patients in Belgium 55% in Spain and 74% in Italy (non-significant). Patients with severe dementia showed the same pattern of treatment aims, although in their case a palliative treatment aim was significantly more likely in Belgium (77%) than in Italy (59%; OR=.34, 95%CI=.19-.63).

In the last week of life, for people with mild dementia a palliative treatment aim was considered important less often in Italy (68%) than in Spain (87%) and Belgium (84%; OR=.36, 95%CI=.2-.64), whereas a life-prolonging treatment aim was more common in Italy (58%) than in Belgium (35%) and Spain (32%; OR=2.46, 95%CI=1.62-3.74). There was no significant difference in the frequency of a curative treatment aim in the last week of life for people with mild dementia, but patients with severe dementia were more likely to have a curative treatment aim in Belgium (22%) than in Italy (14%; OR=.53, 95%CI=.3-.94).

Palliative care provision

In Belgium 35% of patients with mild dementia received some form of specialist palliative care, compared with 32% in Spain and 21% in Italy (OR=.47, 95%CI=.3-.72; table 2). In Belgium, specialist palliative care services were most often provided by an in-house palliative care service in a care home (19%, compared with 6% in Spain). Care provided by a palliative home care team was less likely in Belgium (7%) than in Spain (19%; OR=2, 95%CI=1.07-3.77), though the difference with Italy (13%) was not significant. Specialist palliative care was initiated a median of 14 days before death in Belgium for patients with mild dementia, 12 days in Spain and 50 days in Italy. Multivariate analysis showed that specialist palliative care is in fact initiated longer before death in Spain (OR=1.01, 95%CI=1.001-1.01) and Italy (OR=1.04, 95%CI=1.02-1.05) than in Belgium. There was no significant difference in the initiation of specialist palliative care for patients with severe dementia between Belgium and Spain, though in Italy specialist palliative care was initiated less frequently (OR=.28, 95%CI=.16-.48) but longer before death than in Belgium (OR=1.02, 95%CI=1.01-1.05).

Figure 1: Percentage of patients for whom a palliative, curative and life-prolonging treatment aim was judged to be important during the last 3 months before death in Belgium, Spain and Italy

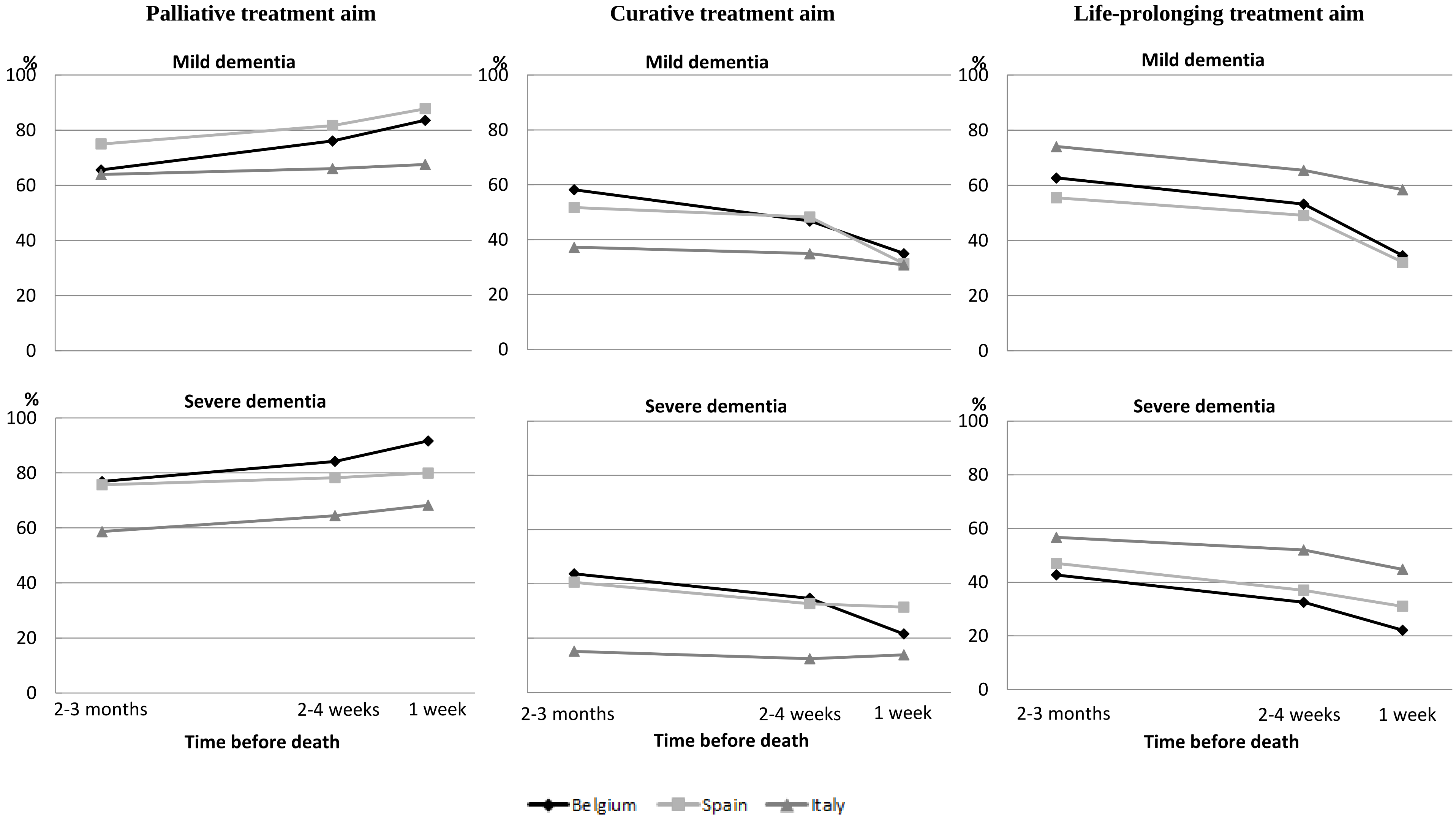

Table 2: Palliative care for people with mild or severe dementia in Belgium, Spain and Italy (n=1623)

	Mild dementia						**Severe dementia**					
	Belgium (n=282)		Spain (n=160)		Italy (n=392)		Belgium (n=339)		Spain (n=135)		Italy (n=315)	
	%	*Ref.*	%	OR [95% CI]	%	OR [95% CI]	%	*Ref.*	%	OR [95% CI]	%	OR [95% CI]
Received any specialist palliative care	35	-	32	.85 [.52-1.37]	21	**.47 [.3-.72]**	38	-	28	.65 [.37-1.13]	14	**.28 [.16-.48]**
Specifically from:†								-				
Palliative home care team/assistance at home	7	-	19	**2 [1.07-3.77]**	13	1.13 [.63-2.05]	6	-	16	1.66 [.84-3.29]	14	1.2 [.61-2.39]
Palliative care unit in a hospital	7	-	8	.94 [.39-2.27]	n/a	n/a	3	-	4	.8 [.23-2.8]	n/a	n/a
In-house palliative care service in care home	19	-	6	.61 [.25-1.52]	n/a	n/a	27	-	10	.47 [.17-1.3]	n/a	n/a
Initiation of palliative care in days before death (median)	14	-	12	**1.01 [1.001-1.01]**[‡]	50	**1.04 [1.02-1.05]**[‡]	14	-	9	.999 [.98-1.01][‡]	40	**1.02 [1.01-1.05]**[‡]

* missing for received any specialist palliative care = 41

† largest three categories shown; specialist palliative care also included hospice care, daycentres and others.

‡ in increments of one day

Ref = reference category, OR = odds ratio, CI = confidence interval. Controlled for longest place of residence in the last year and cause of death (stroke vs other causes).

Communication at the end of life between GP and patients

Communication about at least one of the illness-related topics occurred with 72% of patients with mild dementia in Belgium, compared with 61% in Spain (OR=.5, 95%CI=.29-.89) and 50% in Italy (OR=.32, 95%CI=.2-.52) (Table 3). Patients with severe dementia showed the same pattern, though overall communication was lower in all countries (32% communicated about any of the topics in Belgium, 26% in Spain and 10% in Italy).

A preference for place of death for people with mild dementia was known by the GP in 29% of cases in Belgium, 34% in Spain and 24% in Italy. Preferences for a proxy decision-maker were expressed in 17% of cases of mild dementia in Belgium, 8% in Spain (OR=.42, 95%CI=.19-.92) and 8% in Italy (OR=.42, 95%CI=.22-.78). For patients with severe dementia, there was no significant difference between the countries in expressed preference for a proxy decision-maker (9% in Belgium, 5% in Spain and 4% in Italy), but a significant difference between Belgium and Italy in an expressed preference for place of death (29% versus 21%; OR=.55, 95%CI=.34-.91).

Transfers at the end of life and place of death

Patients with mild dementia were less likely to be transferred between care settings in the last three months in Spain (47%, OR=.5, 95%CI=.32-.78) and Italy (48%, OR=.49, 95%CI=.35-.7) than in Belgium (55%; table 4). There were no significant differences between the countries in terms of transfers between care settings in the last week of life (15% to 17% of cases). Patients were most often transferred to hospital, in 47% of cases with mild dementia in Belgium, 34% in Spain (OR=.43, 95%CI=.1-.27) and 41% in Italy (OR=.52, 95%CI=.36-.74). Patients with severe dementia showed a similar pattern of transfers.

Place of death of patients with mild dementia was most often a care home in Belgium (43% for mild dementia) and at home in Spain (48%) and Italy (52%). Patients with mild dementia were less likely to die in hospital in Italy (31%, OR=.61, 95%CI=.42-.89) than in Belgium (33%). Patients with severe dementia were more likely to die in a care home in Belgium than in Spain (OR=.3, 95%CI=.16-.56) or Italy (OR=.21, 95%CI=.13-.35). Most people for whom a preferred place of death was known (between 24% in Italy and 34% in Spain for people with mild dementia, table 3) died at their place of preference: 72% of patients with mild dementia in Belgium, 89% in Spain (OR=5.14, 95%CI=1.68-15.68) and 74% in Italy. While people with severe dementia died at their place of preference more often than people with mild dementia (between 86% of cases in Italy and 95% of cases in Spain), there were no differences between countries for this group.

Table 3: Communication between GP and people with mild or severe dementia in Belgium, Spain and Italy (n=1623)

	Mild dementia						**Severe dementia**					
	Belgium (n=282)		Spain (n=160)		Italy (n=392)		Belgium (n=339)		Spain (n=135)		Italy (n=315)	
	%	*Ref.*	%	OR [95% CI]	%	OR [95% CI]	%	*Ref.*	%	OR [95% CI]	%	OR [95% CI]
Communication between GP and patient on												
Primary diagnosis	41	-	35	.61 [.35-1.08]	28	**.44 [.29-.68]**	14	-	11	.44 [.18-1.06]	4	**.15 [.06-.37]**
Incurability of illness	23	-	32	1.38 [.79-2.42]	10	**.36 [.21-.62]**	10	-	11	.81 [.33-2.01]	2	**.16 [.06-.43]**
Life expectancy	21	-	22	.97 [.56-1.7]	11	**.41 [.24-.7]**	8	-	10	.75 [.31-1.8]	2	**.13 [.04-.41]**
Possible medical complications	24	-	37	1.51 [.8-2.85]	20	.63 [.38-1.05]	9	-	13	.9 [.34-2.36]	3	**.18 [.07-.48]**
Physical symptoms	63	-	53	**.54 [.32-.92]**	45	**.38 [.24-.62]**	28	-	20	**.39 [.2-.76]**	8	**.14 [.08-.27]**
Psychological symptoms	41	-	37	.8 [.47-1.37]	24	**.47 [.3-.74]**	19	-	12	**.33 [.16-.68]**	5	**.16 [.08-.32]**
Social problems	27	-	20	.62 [.35-1.11]	17	**.54 [.32-.89]**	11	-	10	.59 [.27-1.3]	4	**.2 [.09-.47]**
Existential problems	12	-	8	.67 [.3-1.48]	5	**.47 [.23-.98]**	6	-	2	.22 [.05-1.1]	1	**.17 [.05-.61]**
Options for palliative care	18	-	25	1.2 [.68-2.13]	5	**.2 [.1-.38]**	9	-	11	.9 [.38-2.12]	1	**.05 [.01-.23]**
Burden of treatments	22	-	21	.87 [.46-1.63]	11	**.43 [.26-.73]**	6	-	9	.94 [.32-2.77]	1	**.12 [.02-.6]**
Any communication at all	72	-	61	**.5 [.29-.89]**	50	**.32 [.2-.52]**	32	-	26	**.46 [.24-.87]**	10	**.15 [.08-.27]**
Patient had ever expressed preference												
about a medical end-of-life treatment	16	-	4	**.16 [.06-.41]**	6	**.26 [.15-.48]**	7	-	2	**.17 [.04-.75]**	2	**.17 [.06-.45]**
For place of death	29	-	34	1.09 [.67-1.79]	24	.63 [.4-1.01]	29	-	39	1.39 [.72-2.69]	21	**.55 [.34-.91]**
For proxy decision-maker	17	-	8	**.42 [.19-.92]**	8	**.42 [.22-.78]**	9	-	5	.59 [.18-1.92]	4	.48 [.19-1.21]

* missing for communication between physician and patient <4%; preference expressed about treatment=47, place of death=27, proxy decision-maker=387

Ref = reference category, OR = odds ratio, CI = confidence interval. Controlled for longest place of residence in the last year and cause of death (stroke vs other causes).

Table 4: Transitions between care settings of people with mild or severe dementia in Belgium, Spain and Italy (n=1623)

	Mild dementia						**Severe dementia**					
	Belgium (n=282)		Spain (n=160)		Italy (n=392)		Belgium (n=339)		Spain (n=135)		Italy (n=315)	
	%	*Ref.*	%	OR [95% CI]	%	OR [95% CI]	%	*Ref.*	%	OR [95% CI]	%	OR [95% CI]
Transferred between care settings in last 3 months	55	-	47	**.5 [.32-.78]**	48	**.49 [.35-.7]**	37	-	44	.66 [.37-1.15]	36	**.44 [.28-.7]**
Transferred in last 3 months to												
Hospital	47	-	34	**.43 [.1-.27]**	41	**.52 [.36-.74]**	32	-	30	**.54 [.3-.96]**	32	**.56 [.36-.87]**
Home	7	-	10	.89 [.41-1.92]	14	1.26 [.66-2.44]	4	-	16	2.02 [.87-4.68]	8	.9 [.42-1.92]
Care home	16	-	4	**.25 [.11-.54]**	8	**.52 [.29-.92]**	20	-	8	**.21 [.09-.45]**	5	**.15 [.08-.28]**
Transferred between care settings in last week	15	-	17	.98 [.56-1.72]	17	.93 [.59-1.46]	10	-	18	1.57 [.81-3.06]	12	.83 [.46-1.49]
Place of death												
Home	18	-	48	2.55 [1.55-4.18]	52	2.61 [1.68-4.05]	12	-	52	3.62 [2.03-6.45]	56	3.63 [2.25-5.86]
Care home	43	-	16	.61 [.32-1.17]	14	.79 [.47-1.33]	69	-	25	**.3 [.16-.56]**	17	**.21 [.13-.35]**
Hospital	33	-	34	.72 [.45-1.15]	31	**.61 [.42-.89]**	18	-	21	.84 [.45-1.57]	27	1.02 [.61-1.72]
Palliative care unit/hospice	6	-	2	-	3	-	1	-	1	-	-	-
Died at place of preference†	72	-	89	**5.14 [1.68-15.68]**	74	1.87 [.82-4.25]	88	-	95	3.25 [.7-14.96]	86	.99 [.34-2.89]

* missing for transfers = 57, place of death = 5

† only those for whom a preferred place of death was known, n=438

Ref = reference category, OR = odds ratio, CI = confidence interval. Controlled for longest place of residence in the last year and cause of death (stroke vs other causes).

Discussion

We showed that there are both cross-country differences and similarities in treatment aims, communication about illness-related topics , provision of specialized palliative care, transfers at the end of life and place of death of people dying with dementia, with more differences between Belgium and Italy than between Belgium and Spain. While most patients had a palliative treatment aim in the last week of life, communication between the GP and patient about care, illness or preferences was relatively low in all countries. Specialized palliative care was provided in approximately one fifth (Italy) to one third (Belgium and Spain) of cases for people with mild dementia. Transfers in the last week of life were relatively infrequent but still between 10% (Belgium) and 18% (Spain).

This research adds to our current knowledge of the circumstances of people dying with dementia by providing an international population-based overview of several important end-of-life care issues, both for people with severe dementia and the less-often studied group of people with mild dementia. A limitation of our research is that the presence and severity of dementia is based on an overall judgement by a GP and not by a specialist. Although specificity in dementia diagnosis by GPs is excellent, meaning there is little chance of false positives in our sample, there may have been an underreporting of people with mild dementia.[29] The possibility of recall bias on the part of GPs was limited by having questionnaires completed within one week of the patient's death. The low percentages of communication with people with severe dementia are understandable given the cognitive decline inherent in the disease; however, as no time period was specified in the questions regarding communication, this also tells us that communication took place infrequently earlier in the disease trajectory. Alternatively, GPs may have communicated with relatives of patients instead of patients themselves in case dementia was prohibitive to clear communication, as other research has shown that communication with relatives of older patients is frequent in Belgium and Italy at least.[30]

This study showed that the importance of a palliative treatment aim was recognized for most people with dementia, both mild and severe, and that relatively few people were transferred between care settings in the last week of life compared with e.g. cancer patients.[31] The low transfer rates indicate a low likelihood of unnecessary or inappropriate transitions between care settings at the end of life. These encouraging results follow the recommendations of the EAPC white paper on palliative care for people with dementia.[7]

However, there is also room for improvement in all three countries, particularly regarding awareness by the GP about preferences for end-of-life care. Preferences for medical treatments at the end of life or a proxy decision-maker were frequently known in fewer than a quarter or even 10% of cases. Advance communication about preferences regarding end-of-life care and dying is especially important in the case of dementia patients, who may not be able to communicate about such matters close to death.[7] Previous research found that ACP is considered important by most older people, that it decreases the likelihood of unnecessary hospitalizations; is associated with a higher mean rating of emotional well-being during the dying process for both patients and family; and improves knowledge of and compliance with patient's wishes.[17,32,33] In this study, we also found that the majority of people died at their preferred place when this was known.

In addition to an improvement in communication, specialized palliative care could perhaps be called upon more frequently, particularly for those with advanced dementia who have complex problems.[7] Specialized palliative care is still provided primarily to cancer patients and there are several barriers to providing the same care for other patient groups, despite their complex problems and high palliative care needs.[32,34] For example, the lack of clarity about prognosis, strong emphasis on a curative approach and reluctance to talk about death were identified as barriers in Spain,[35] whereas in Belgium, there are systemic issues such as a much lower likelihood of non-cancer patients receiving a palliative home care allowance.[36] Overcoming such barriers both in practice and on a policy level is important for the continued improvement of end-of-life care for people with dementia.

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References Chapter 6

1. World Health Organization (WHO). Dementia: A public health priority. Geneva: WHO Press; 2012.
2. Van der Steen JT. Dying with dementia: what we know after more than a decade of research. J Alzheimers Dis. 2010 Jan;22(1):37–55.
3. Lunney JR, Lynn J, Foley DJ, Lipson S. Patterns of functional decline at the end of life. 2003;289(18):2387–92.
4. Wetzels RB, Zuidema SU, de Jonghe JFM, Verhey FRJ, Koopmans RTCM. Course of Neuropsychiatric Symptoms in Residents with Dementia in Nursing Homes Over 2-Year Period. Am J Geriatr Psychiatry. 2010 Dec;18(12):1054–65.
5. Van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. Palliat Med. 2013 Nov 13;
6. Murray SA, Boyd K, Sheikh A, Thomas K, Higginson IJ. Developing primary palliative care. BMJ. 2004 Nov 6;329(7474):1056–7.
7. Selman LE, Beattie JM, Murtagh FEM, Al E. Palliative care: based on neither diagnosis nor prognosis, but patient and family need. Commentary on Chattoo and Atkin. Soc Sci Med. 2009;69(2):154–7.
8. Bamford C, Lamont S, Eccles M, Robinson L, May C, Bond J. Disclosing a diagnosis of dementia: a systematic review. Int J Geriatr Psychiatry. 2004;19(2):151–69.
9. Jethwa KD, Onalaja O. Advance care planning and palliative medicine in advance dementia: a literature review. BJPsych Bull. 2015 Apr; 39(2): 74-78.
10. Aminoff BZ, Adunsky A. Dying dementia patients: Too much suffering, too little palliation. Am J Hosp Palliat Med. 2005 Sep 1;22(5):344–8.
11. Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, et al. The clinical course of advanced dementia. N Engl J Med. 2010;361(16):1529–38.
12. Vandervoort A, Van den Block L, van der Steen JT, Volicer L, Vander Stichele R, Houttekier D, et al. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying. J Am Med Dir Assoc. 2013;14:485–92.
13. Houttekier D, Vandervoort A, Van den Block L, van der Steen JT, Vander Stichele R, Deliens L. Hospitalizations of nursing home residents with dementia in the last month of life: Results from a nationwide survey. Palliat Med. 2014 May 27;
14. Givens JL, Selby K, Goldfeld KS, Mitchell SL. Hospital transfers of nursing home residents with advanced dementia. J Am Geriatr Soc. 2012 May;60(5):905–9.
15. Van Uden N, Van den Block L, van der Steen JT, Onwuteaka-Philipsen BD, Vandervoort A, Vander Stichele R, et al. Quality of dying of nursing home residents with dementia as judged by relatives. Int Psychogeriatr. 2013 Oct;25(10):1697–707.

16. Van der Steen JT, Gijsberts M-JHE, Muller MT, Deliens L, Volicer L. Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. Int Psychogeriatr. 2009 Apr;21(2):321–9.
17. Cohen LW, van der Steen JT, Reed D, Hodgkinson JC, van Soest-Poortvliet MC, Sloane PD, et al. Family perceptions of end-of-life care for long-term care residents with dementia: differences between the United States and the Netherlands. J Am Geriatr Soc. 2012 Feb;60(2):316–22.
18. Meeussen K, Van den Block L, Echteld M a, Boffin N, Bilsen J, Van Casteren V, et al. End-of-life care and circumstances of death in patients dying as a result of cancer in Belgium and the Netherlands: a retrospective comparative study. J Clin Oncol. 2011 Nov 10;29(32):4327–34.
19. Van den Block L, Onwuteaka-Philipsen B, Meeussen K, Donker G, Giusti F, Miccinesi G, et al. Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. BMC Fam Pract. BMC Family Practice; 2013 Jun 3;14(1):73.
20. Pivodic L, Pardon K, Van den Block L, Van Casteren V, Miccinesi G, Donker G a, et al. Palliative care service use in four European countries: a cross-national retrospective study via representative networks of general practitioners. PLoS One. 2013 Jan;8(12):e84440.
21. Van den Dungen P, van Marwijk HWM, van der Horst HE, Moll van Charante EP, MacNeil Vroomen J, van de Ven PM, van Hout HPJ. The accuracy of family physicians' dementia diagnosis at different stages of dementia: a systematic review. Int J Geriatr Psychiatry, 2012;27:342-354.
22. Abarshi E, Echteld MA, Van den Block L, Donker G, Bossuyt N, Meeussen K, et al. Use of palliative care services and general practitioner visits at the end of life in The Netherlands and Belgium. J Pain Symptom Manage, 2010;41(2):436-448.
23. Piers R, van Eechoud IJ, Van Camp S, Grypdonck M, Deveugele M, Verbeke NC, Van den Noortgate NJ. Advance Care Planning in terminally ill and frail older persons. Patient Education and Counseling 2013;90(3):323-329.
24. Detering KM, Hancock AD, Reade MC , Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ, 2010; 340:c1345.
25. Kraus M, Czypionka T, RIedel M, Mot E, Willemé P. How European nations care for their elderly: A new typology of long-term care systems. *SSRN* 2011: http://dx.doi.org/10.2139/ssrn.2005018
26. Murray SA, McLoughlin P. Illness trajectories and palliative care: Implications for holistic service provision for all in the last year of life. In: Sallnow L, Kumar S, Kellehear A. International Perspectived on Public Health and Palliative Care. New York. Routledge; 2012.
27. Mahtani-Chugani V, González-Castro I, Sáenz de Ormijana-Hernández A, Martín-Fernández R, de la Vega EF. How to provide care for patients suffering from terminal non-oncological diseases: barriers to a palliative care approach. Palliat Med 2010;24:787-795
28. Gielen B, Remacle A, Mertens R. Patterns of health care use and expenditure during the last 6 months of life in Belgium: Differences between age categories in cancer and non-cancer patients. Health Policy. 2010;97:53-61

CHAPTER 7: Awareness of dementia by family carers of nursing home residents dying with dementia

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Abstract

Background

High quality palliative care for people with dementia should be patient-centred, family-focused and include well-informed and shared decision-making, as affirmed in a recent white paper on dementia from the European Association of Palliative Care. In this paper, we describe how often family carers of nursing home residents who died with dementia are aware that their relative has dementia, and study resident, family carer and care characteristics associated with awareness.

Methods

Post-death study using random cluster sampling. Structured questionnaires were completed by family carers, nursing staff and GPs of deceased nursing home residents with dementia in Flanders, Belgium (2010).

Results

Of 190 residents who died with dementia, 53.2% of family carers responded. In 28% of cases, family carers indicated they were unaware their relative had dementia. Awareness by family carers was related to more advanced stages of dementia one month before death (OR=5.4), with 48% of family carers being unaware when dementia was mild and 20% unaware when dementia was advanced. The longer the onset of dementia after admission to a nursing home, the less likely family carers were aware (OR=.94).

Conclusion

Family carers are often unaware their relative has dementia i.e. in one fourth of cases of dementia and one fifth of advanced dementia, posing considerable challenges for optimal care provision and end-of-life decision-making. Considering that family carers of residents who develop dementia later after admission to a nursing home are less likely to be aware, there is room for improving communication strategies towards family carers of nursing home residents.

Introduction

The number of people living and dying with dementia is increasing.[1] In some countries, one third to one half of people with dementia live in residential or nursing homes.[2,3] As people with dementia gradually lose their ability to make informed decision themselves, family carers will play a more prominent role in making decisions about medical treatment and care. Indeed, research has shown that family carers are more likely to be told of a diagnosis of dementia[4,5] and are more often consulted about treatment[6] than are patients. Also, in a recent white paper on dementia, the European Association for Palliative Care recommended that family carers are included in shared decision-making, advanced care planning and information provision.[7] Hence, high-quality palliative care should be both patient-centred and family-focused.

To enable the provision of appropriate care for people with dementia who are incapable of decision-making themselves, family carers should be aware of the medical status of their relative. A lack of understanding about dementia has been identified as a barrier to providing excellent end-of-life care for people with dementia.[8] Recent research has shown that an understanding of the clinical course of advanced dementia among family carers predicts higher patient comfort during the dying process.[9] However, little is known about the prevalence of awareness of the disease status among the family carers of dementia patients.

A systematic review found that between 20% and 53% of doctors had trouble disclosing the diagnosis of dementia to family carers, and that disclosure of a dementia diagnosis is significantly less likely than disclosure of other illness diagnoses.[10] Even when a physician believes the diagnosis has been communicated, patients and caregivers may misunderstand or reject it, particularly in the case of mild dementia.[11,12] This lack of awareness may have negative implications for the quality of decision-making at the end of life.

However, most existing studies on knowledge or awareness of dementia have focused on the early stages of the disease. To our knowledge, awareness by family carers in the later stages of dementia or at the end of life has not yet been studied.

In this study, we investigate awareness of dementia by family carers of nursing home residents who have died with dementia. Our research questions are:

- how often are family carers of nursing home residents dying with dementia aware of the dementia?
- to what extent is awareness of dementia by family carers associated with the stage of dementia of the resident?
- which other characteristics of resident, family carer and care are associated with family carers' awareness of dementia in this population?

Methods

Design and study population

The data used in this study are taken from the Dying Well with Dementia study, a retrospective cross-sectional study conducted in Flanders, Belgium. A random sample of 134 Flemish high-care nursing homes was taken and stratified by region, type and size so as to be representative. Together with the researcher, one contact person per nursing home identified all nursing home residents who had died in the past three months. Data collection took place between May and October 2010.

Deceased nursing home residents had to meet the criteria for dementia used by the Belgian health insurance system as registered in the resident files: either the person had category C dementia (experiences disorientation in time and space almost daily), or was completely care dependent or in need of help for bathing, dressing, eating, toileting, continence and transferring plus showing signs of disorientation in time and space. The final sample of nursing home residents with dementia was identified on the basis of the GPs' and nurses' judgments.

For residents who met the inclusion criteria, structured questionnaires were sent to their GP, the nurse most involved in their care, the relative judged by nursing staff to be most involved in care for the deceased resident (family carer), and the nursing home administrator. The contact persons of each home sent the questionnaires and reminders to all participants, ensuring anonymity by using numerical codes linked to nursing home residents. Those whose family carer answered the after-death questionnaire and provided a valid answer to the question regarding awareness of their relative having dementia, were included in the analysis (figure 1).

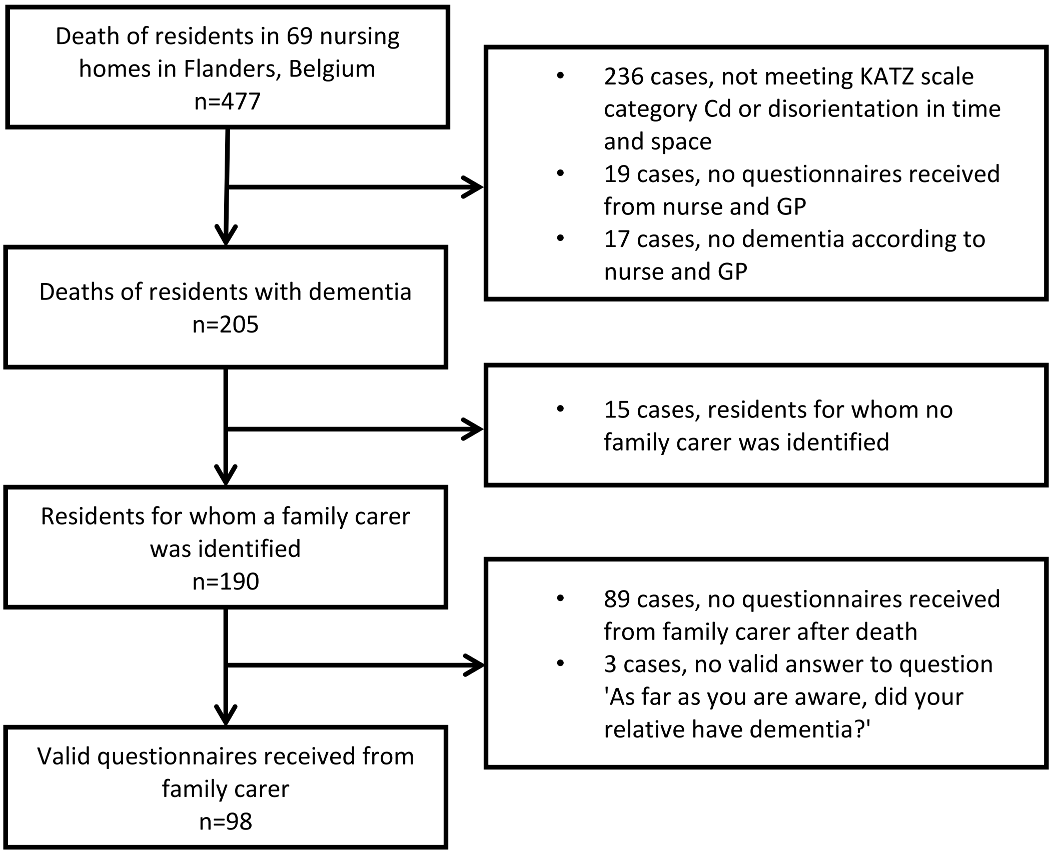
Further details on this study and the data collection procedure can be found in previous papers covering this dataset.[6,13-17]

Measurements

Family carers indicated whether they were aware of the dementia of the resident by answering yes or no to the question: 'As far as you are aware, did your relative have dementia?' Family carers also provided information on socio-demographic characteristics of themselves and their relative.

Cognitive and functional status in the last month of life were provided by nursing staff using the Bedford Alzheimer Nursing Severity-Scale (BANS-S), which combines ratings of cognitive and functional deficits to allow discrimination between patients in the later stages of dementia,[18] the Cognitive Performance Scale (CPS), a validated measure to assess the degree to which the resident was cognitively impaired,[19] and the Global Deterioration Scale (GDS).[20] A score of more than 5 on the CPS (indicating those who were either comatose or who no longer made decisions and could not eat

Figure 1: Flowchart of the obtained sample of deceased nursing home residents with dementia in Flanders, Belgium



independently or would not eat at all) or of 7 on the GDS (indicating those who had lost all capacity for speech, needed help with eating and using the toilet and were losing basic psychomotor skills such as walking) was coded as the resident having ‘severe dementia’. A combination of a score of more than 5 on the CPS and 7 on the GDS was coded as ‘very severe or advanced dementia’. Lower scores were coded as ‘mild or moderate dementia’.

In addition to the validated measurement instruments, both the GP and the nurse were asked to make a clinical estimation of the stage of dementia at time of admission, and to indicate whether they considered the resident capable of medical decision-making in the last week of life. Gender, age, and length of stay in the nursing home were provided by the nursing home administrator. Co-existing conditions at time of death and how long the resident had dementia were provided by the GP. Information on the educational level and religion of the resident, family carer characteristics and reasons for admission were provided by the family carer. Family carers and professional carers provided information regarding care and communication characteristics.

Analyses

All analyses were performed using Stata Statistical Software: Release 12 (StataCorp. 2011).

Onset of dementia relative to time of admission was separated in two variables: duration of dementia before admission (where those who developed dementia after admission were scored 0) and onset of dementia after admission (where those who developed dementia before admission were scored 0). Differences in means between groups were calculated using *t*-tests or Mann-Whitney tests. Differences in non-continuous outcomes were tested with Pearson's Chi-square tests or Fisher's exact tests. Bivariate and multivariate odds ratios were calculated using logistic regression analysis with robust standard errors to account for clustering within nursing homes. We controlled for several variables, i.e. age of resident at time of death, duration of dementia, stage of dementia at time of admission and one month before death. Odds ratios from the most parsimonious model, adjusting for stage of dementia one month before death, are presented here.

Non-response analysis showed no differences between responders and non-responders (for further details, see Vandervoort et al. 2013).

Ethical approval

The Medical Ethical Committee of UZ Brussel (University Hospital of Brussels) approved the study protocol. At the top of the questionnaire, it was explained to respondents that they consented to participation by returning the completed questionnaire.

Results

Of 190 residents who died with dementia according to the nurse or GP, 98 (53.2%) of family carers responded (Figure 1). Table 1 shows that of these residents, 56.5% were female. The mean length of stay in the nursing home was 36.8 months (SD 39.3) and mean age at time of death was 86.8 (SD 6.7).

Most family carers were female (63.4%) with a mean age of 60.4 (SD 11.1). Two-thirds (66.7%) were children of the resident; 9.2% were spouses and the remaining 23.5% were otherwise related or not related. On average, family carers cared 14.1 (SD 14.2) hours per week for their relative before admission to the nursing home. A number of family carers (17.5%) lived with the resident until the point of admission. Most family carers indicated that they had a good relationship with the resident before the onset of the dementia (92.4%), and 44.9% were present at the time of death.

Table 1: Characteristics of deceased nursing home residents with dementia and their family carers

	n=98*	%
Resident characteristics		
Age at time of death, mean (SD)	86.8 (6.7)	
Gender, female	52	56.5
Education level		
No education/lower secondary education	78	83.8
Higher secondary education/university	15	16.2
Co-existing conditions		
Malignant tumor	7	10.6
Cardiovascular	27	40.9
Respiratory	9	13.6
Neurological	13	19.7
Kidney disease	7	10.6
Other†	10	15.2
No co-existing conditions	12	18.2
Length of stay in NH in months, mean (S.D)	36.8 (39.3)	
Family carer characteristics		
Age, mean (SD)	60.4 (11.1)	
Gender, female	59	63.4
Education level		
No education/lower secondary education	45	48.4
Higher secondary education/university	48	51.6
Self-assessed health status: good/excellent	81	82.7
Relation to deceased resident		
Child	66	67.3
Spouse	9	9.2
Other‡	23	23.5
Average (SD) hours cared for resident before admission	14.1 (14.2)	
Living together before admission	17	17.5
Good/excellent relationship before onset of dementia	85	92.4
Family carer present at death	44	44.9

*: Missing values are for residents' age n=8, gender n=6, education n=5, co-existing conditions n= 32, length of stay n=8; family carer's age n=12, gender n=5, education n=5; hours cared before admission n=1, living together n=1, relationship before dementia n=6

†: 'Other' conditions include: diabetes, complications of extreme old age, Parkinson, infections and leg amputation

‡: 'Other' relations include: parent, friend, daughter-in-law or son-in-law

Awareness of dementia according to stage of dementia

Table 2 shows that in 28% of all cases, family carers indicated they were not aware that their relative had had dementia at any time. The proportion of family carers who were not aware was largest among residents with mild or moderate dementia one month before death (48%), compared with 20% among residents in the very severe or advanced stage of dementia. This difference remained significant in a multivariate analysis controlling for age and length of stay in the nursing home (OR=5.4, CI=1.55-19.05).

Table 2: Prevalence of awareness of dementia by family carers by stage of dementia one month before death*

	Mild or moderate	Severe	Very severe or advanced	Total
			n (%)	
Family carer aware	12 (52%)	19 (76%)	40 (80%)	71 (72%)
Family carer not aware	11 (48%)	6 (24%)	10 (20%)	27 (28%)
Total	23 (100%)	25 (100%)	50 (100%)	98 (100%)

*: Mild or moderate dementia = Cognitive Performance Scale (CPS) < 5 + Global Deterioration Scale (GDS) < 7
Severe dementia = CPS <5 + GDS =7, or CPS ≥ 5 + GDS < 7
Very severe or Advanced Dementia = CPS ≥ 5 + GDS = 7
Percentages are column %

Associations between awareness of dementia by family carers and clinical judgements of nursing staff and GPs

Table 3 shows that family carers who were aware of the dementia had a relative for whom the onset of dementia was, on average, four months after admission to the nursing home, compared with 30 months for those who were not aware (OR=.94). Duration of dementia itself, duration of dementia before admission, nurses' judgement of stage of dementia at time of admission and nurses' judgements of capacity for medical decision-making were not significantly related to awareness in multivariate analyses.

In 93% of cases, the GP reported that dementia was diagnosed by a healthcare professional, but this was not significantly related to awareness by family carers. Family carers who were aware of the dementia less often had relatives who were judged by their GP to be capable of medical decision-making at least some of the time during the last week of life (29%) than those who were not aware (59%; OR=.1). GPs' judgment of stage of dementia at time of admission was not significantly related to awareness in multivariate analysis.

Table 3: Awareness of dementia by family carers and associations with clinical judgments by nursing staff and GPs, n=98*

	Family carer awareness of dementia				
	Total, n (%)	Aware, n=71 (%)	Not aware, n=27 (%)	P	OR (95% CI) †
Clinical judgments by nursing staff					
BANS-S 1 month before death, > 17	78 (83)	59 (86.7)	19 (73.1)	.11	.9 (.2-4.4)
Dementia at time of admission‡				.03	
No dementia or mild dementia	34 (37.4)	19 (29.2)	15 (57.7)		Ref.
Moderate dementia	34 (37.3)	26 (40)	8 (30.8)		2.2 (.7-6.7)
Severe dementia	23 (25.3)	20 (30.8)	3 (11.5)		3.5 (.8-15.8)
Capable of medical decision-making in last week of life	13 (14)	9 (13.2)	4 (16)	.74	1.8 (.4-9.2)
Duration of dementia in months (mean, SD)	39.65 (26.40)	43.85 (26.48)	29.83 (24.14)	0.06	1.02 (.98-1.07)
Duration of dementia before admission, in months (mean, SD)	15.96 (20.93)	20.62 (22.68)	4.64 (9.16)	.01	1.1 (.997-1.1)
Onset of dementia after admission, in months (mean, SD)	11.37 (22.48)	3.8 (10.5)	29.74 (32.13)	<.001	.94 (.9s-.98)
Clinical judgments by GPs					
Diagnosis of dementia	51 (92.7)	42 (93.3)	9 (90)	.56	1.95 (.2-23.8)
Dementia at time of admission‡				.04	
No dementia or mild dementia	8 (14.5)	4 (8.9)	4 (40)		Ref.
Moderate dementia	24 (43.6)	22 (48.9)	2 (20)		9.8 (.8-120.9)
Severe dementia	23 (41.8)	19 (34.5)	4 (40)		4.2 (.7-25.9)
Capable of medical decision-making in last week of life	30 (37)	17 (28.8)	13 (59.1)	<.01	.1 (.01-.5)

**: Missing values are for nurses' judgements BANS-S n=4, dementia at admission n=6, decision-making capacity n=4, duration or onset of dementia n=48; GPs judgements diagnosis n=43, dementia at admission n=43, dementia at time of death n=43, decision- making capacity n=17*

†: OR: Odds Ratio – CI: Confidence Interval, controlled for stage of dementia one month before death, stage of dementia at time of admission, duration of dementia and age

‡: As judged by the respondent and not assessed using validates scales

Differences in means between groups were calculated using t-tests or Mann-Whitney tests. Differences in non-continuous outcomes were tested with Pearson's Chi-square tests or Fisher's exact tests.

Table 4: Awareness of dementia by family carers and associations with resident's and family carer's characteristics, n=98*

	Family carer awareness of dementia			
	Aware, n=71 (%)	Not aware, n=27 (%)	P	O.R. (95% CI)†
Resident's characteristics				
Age at time of death, mean (SD)	86.6 (6.70)	88.2 (6.47)	.29	.94 (.9-1.02)
Gender, female	36 (54.4)	16 (61.5)	.54	.7 (.3-1.7)
Education level			.93	
No education/lower secondary education	58 (84)	20 (83.3)		Ref.
Higher secondary education/university	11 (16)	4 (16.7)		.7 (.2-2.7)
Length of stay in NH in months, mean (S.D)	31.7 (4.4)	51.9 (9.6)	.03	.99 (.97-1.01)
Family carer's characteristics				
Age, mean (SD)	60 (11.8)	61.67 (8.5)	.33	.98 (.9-1.02)
Gender, female	44 (63.8)	15 (62.5)	.91	.99 (.3-2.9)
Education level			.67	
No education/lower secondary education	31 (44.9)	14 (58.3)		Ref.
Higher secondary education/university	38 (55.1)	10 (41.7)		1.9 (.7-5.2)
Relation to deceased resident			.47	
Child	46 (64.8)	20 (74.1)		Ref.
Spouse	8 (11.3)	1 (3.7)		.3 (.03-3.4)
Other	17 (23.9)	6 (22.2)		.3 (.03-3.7)
Caring before admission in hours per week (mean, SD)	16.4 (14.7)	7.9 (2.1)	<.01	1.06 (.998-1.1)
Living together before admission	15 (21.4)	2 (7.4)	.10	2.9 (.6-14.8)
Good/excellent relationship before onset of dementia	20 (83.3)	65 (95.6)	.07	.8 (.3-2.2)
Expectation of death 1 month before death	28 (39.4)	13 (48.1)	.44	.7 (.3-1.7)

**: Missing values are for residents' age n=8, gender n=6 education n=5, length of stay n=8; family carer's age n=12, gender n=5, education n=5; hours cared before admission n=1, living together n=1, relationship before dementia n=6*

†: OR: Odds Ratio – CI: Confidence Interval, controlled for stage of dementia one month before death, stage of dementia at time of admission, duration of dementia and age

Differences in means between groups were calculated using t-tests or Mann-Whitney tests. Differences in non-continuous outcomes were tested with Pearsons Chi-square tests or Fisher's exact tests.

Associations between awareness of dementia by family carers and resident's and family carer's characteristics

Table 4 shows that resident's and family carer's characteristics are not significantly related to awareness. Length of stay in the nursing home and the number of hours the family carer provided care before admission were significant in bivariate analyses, but these relations were no longer significant after controlling for stage of dementia one month before death.

Associations between awareness of dementia by family carers and care and communication characteristics

Table 5 shows that family carers who were aware of the dementia indicated problems with memory and understanding as one of the main reasons for admission to the nursing home in 51% of cases compared with 7% of those who were not aware (OR=12.7). Family carers indicated problems with behaviour as one of the main reasons for admission in 17% of cases, all of whom were aware of the dementia (p<.01). Family carers who were aware of the dementia indicated problems with a lack of self-sufficiency in 28% of cases, compared with 59% of those who were not aware (OR=.3).

Family carers who were aware of the dementia were very sure that they knew the resident's wishes regarding care and treatment in 33% of cases, compared with 59% for those who were not aware (OR=.4). In a majority of cases there was a palliative care record (60.2%), a written living will (80%) and/or GP order(s) (82.1%) present, which were not found to be significantly related to awareness of dementia among family carers. Oral communication about advanced care planning was likewise not significant, with only a small proportion (11.2%) of family carers indicating that the resident had ever spoken about this with anyone.

On average, family carers who were aware of the dementia had contact with the GP in the last week of life on 2.1 occasions (SD 2.2), compared to 1.1 occassions for those who were not aware (SD 1.4; OR=1.4). Most family carers felt that the nursing staff always or usually communicated with them in an understandable way in the last month of life (74.5%), and only a few indicated that nursing staff never communicated in an understandable way during this period (6.1%). Understandable communication with the nursing staff was not significantly related to awareness of dementia, nor was satisfaction with communication with the nursing staff, GPs or any other doctor.

Table 5: Awareness of dementia by family carers and associations with care and communication characteristics, n=98*

	Family carer awareness of dementia				
	Total, n (%)	Aware, n=71 (%)	Not aware, n=27 (%)	P	O.R. (95% CI)†
Reasons for admission‡					
Problems with memory and understanding	38 (38.8)	36 (50.7)	2 (7.4)	<.001	12.7 (2.8-57.7)
Problems with behaviour	17 (17.3)	17 (23.9)	0 (0)	<.01	n.a.
High family carer burden	20 (20.6)	16 (22.5)	4 (14.8)	.58	1.4 (.4-5.3)
Problems with physical health	32 (32.6)	19 (26.7)	13 (48.1)	.06	.5 (.2-1.3)
Problems with complexity of care	13 (13.3)	7 (9.9)	6 (22.2)	.18	.4 (.1-1.3)
Problems with lack of self-sufficiency	36 (36.7)	20 (28.2)	16 (61.5)	<.01	.3 (.1-.7)
Advanced Care Planning					
Resident had palliative care record	56 (60.2)	40 (59.7)	16 (61.5)	.87	.7 (.2-2.1)
Written living will regarding medical treatments‡	76 (80)	57 (81.4)	19 (76)	.57	.98 (.3-3.8)
Oral communication about ACP†	11 (11.7)	7 (10.3)	4 (15.4)	.49	.6 (.1-2.4)
GP order(s)§	55 (82.1)	41 (85.4)	14 (73.7)	.30	.7 (.2-3.1)
Family carer was very sure they knew resident's wishes regarding care and treatment	40 (41.7)	24 (34.8)	16 (59.3)	.03	. 4 (.2-.9)
Communication between family carer and nursing staff/GP					
Averaged (SD) number of contacts in last week of life between family carer and GP	1.8 (2.0)	2.1 (2.2)	1.1 (1.4)	.03	1.4 (1.1-1.8)
Understandable communication by nursing staff with family carer in last month of life				.77	
Always or usually	73 (74.5)	53 (74.6)	20 (74.1)		Ref.
Sometimes	19 (19.4)	13 (18.3)	6 (22.2)		.4 (.1-1.9)
Never	6 (6.1)	5 (7.0)	1 (3.7)		.8 (.3-2.2)
Family carer satisfied with communication with nursing staff, GP and/or other doctors	76 (77.6)	58 (81.7)	18 (66.7)	.11	1.7 (.6-5.5)

**: Missing values are for palliative care file n=5, palliative care n=6, treatment goal n=31, written living will n=3, GP orders n=31, certainty regarding resident's wishes for treatment n=2*

†: OR: Odds Ratio – CI: Confidence Interval, controlled for stage of dementia one month before death, stage of dementia at time of admission, duration of dementia and age

‡: According to family carer

§: According to GP

Differences in means between groups were calculated using t-tests or Mann-Whitney tests. Differences in non-continuous outcomes were tested with Pearson's Chi-square tests or Fisher's exact tests.

Discussion

Of all residents with dementia, 28% had family carers who were unaware of the dementia. The more advanced the stage of dementia, the more likely it was that family carers were aware; nevertheless, of those whose dementia had progressed to a very severe or advanced stage by the time they died, 20% of family carers were unaware or said they were unaware. Onset of dementia relative to time of admission was significantly related to awareness, whereas none of the measures of advance care planning were significantly related. Family carers who were unaware of the dementia appeared to be more confident that they knew the resident’s wishes regarding care and treatment.

To our knowledge, this nation-wide, representative study is the first to investigate awareness of dementia by family carers in the later stages of the disease and after death. Since data were collected from multiple sources, i.e. nurses, the GP and the family carer, we had the opportunity to investigate a wide range of potentially relevant factors from multiple perspectives.

A limitation of our research is its retrospective nature; hence family carers might have become aware of the dementia only after death. Even then, a significant proportion of family carers were still unaware. Another limitation is that actual communication between professional and family carers regarding a resident’s diagnosis over the course of the disease trajectory was not measured. Therefore, we cannot say whether the diagnosis was not communicated or was communicated but rejected or not understood. Similarly, we do not know whether the family carers would have indicated more awareness if the questionnaire had used other terms to describe dementia.

The high prevalence of unawareness among family carers, up to 28%, can pose a serious problem for providing optimal end-of-life care. The best practice standard advised by the European Association of Palliative Care (EAPC) regarding communication and addressing the information needs in dementia patients and their families does not seem to be being met in Flanders. In our study, of those residents who died with mild or moderate dementia, 48% of family carers were unaware. This suggests that a large group of family carers is not informed at an early stage of the disease, hindering optimal care planning. The lack of association between awareness of the diagnosis and advance care planning might also be explained by late provision of information about diagnosis. In addition, even those family carers who are aware of the dementia at an early stage may not recognize dementia as a terminal illness, as often appears to be the case,[9] and thus do not recognize the need for advance care planning.

From the results of this study, it appears that the longer the time between admission and the onset of dementia, the less likely family carers are aware. This raises questions about communication between nursing home staff, GPs and family carers once people are admitted to a nursing home. After admission to a nursing home, frequency of contact between family carers and GP may decline over time, decreasing the options for disclosure or discussion. Family carers may also be less motivated to be involved in care after the transition from home care to a nursing home setting, perhaps assuming that their relative is receiving good care from the nursing home staff without needing their input. A policy where patients and family carers are informed of a diagnosis of dementia as soon as it is made would be advisable. Disclosure of the diagnosis could be seen as a first step in ongoing communication between professional and family carers, where information about prognosis and problems that are likely to occur during the disease trajectory can be shared. This would equip family carers to participate fully in shared decision-making when necessary in the disease trajectory or when circumstances change suddenly. This is in line with the recommendations of the EAPC, which advocates advance care planning to start as soon as the diagnosis is made, when the patient can still be actively involved, and that both patient and family should be included in the process.[7]

Surprisingly, we found that those who were aware were less often ‘very sure’ that they knew their relative’s wishes regarding treatment and care. This might indicate that family carers who were aware had some understanding of dementia as a disease which limits the patient’s ability to express their wishes clearly and reliably as it progresses. Ideally, this understanding would translate to an effort on the part of professional and family carers to implement advance care planning in the early stages of the disease trajectory.

Since awareness of a person’s medical status can be considered as essential to the provision of appropriate care, further research should investigate how this lack of awareness in the case of dementia influences quality of life, hospital transfers or burdensome interventions at the end of life. Furthermore, investigating awareness of dementia in other countries may prove useful to uncover which features of healthcare systems facilitate or hinder awareness by family carers.

Conclusions

This study shows that family carers are not aware their relative has dementia in one fourth of cases of dementia and one fifth of advanced dementia. This poses considerable challenges for providing high quality palliative care as outlined by the European Association for Palliative Care in its recent white paper on dementia. Admission to a nursing home appears to be a barrier to awareness of dementia by family carers. Improving communication between professional and family carers in nursing home settings is vital to improving information provision regarding dementia.

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References Chapter 7

1. World Health Organization. Dementia: A public health priority. WHO Press; 2012.
2. Macdonald A, Cooper B. Long-term care and dementia services: an impending crisis. Age Ageing. 2007 Jan;36(1):16–22.
3. Knapp M, Prince M, Dementia UK. A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for Alzheimer's Society. London; 2007.
4. Rae CAL, McIntosh IB, Colles S. The Primary Care Team, Dementia and its Management: A Research Report. Stirling; 2001.
5. Gilliard J, Gwilliam C. Sharing the diagnosis: a survey of memory disorder clinics, their policies on informing people with dementia and their families, and the support they offer. Int J Geriatr Psychiatry. 1996;11:1001–3.
6. Vandervoort A, Van den Block L, van der Steen JT, Volicer L, Vander Stichele R, Houttekier D, et al. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying. J Am Med Dir Assoc. 2013;14:485–92.
7. Van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. Palliat Med. 2014;28(3): 197-209.
8. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. J Gen Intern Med. 2004;19:1057–63.
9. Van der Steen JT, Onwuteaka-Philipsen BD, Knol DL, Ribbe MW, Deliens L. Caregivers' understanding of dementia predicts patients' comfort at death: a prospective observational study. BMC Med. 2013;11:105.
10. Bamford C, Lamont S, Eccles M, Robinson L, May C, Bond J. Disclosing a diagnosis of dementia: a systematic review. Int J Geriatr Psychiatry. 2004;19(2):151–69.
11. Carpenter BD, Zaleta AK, Morris JC, Porensky EK, Xiong C. Agreement on Diagnosis Among Patients, Companions, and Professionals After a Dementia Evaluation. Alzheimer Disease & Associated Disorders. 2012. p. 232–7.
12. Pucci E, Belardinelli N, Borsetti G, Giuliani G. Relatives' attitudes towards informing patients about the diagnosis of Alzheimer's disease. J Med Ethics. 2003;29(1):51–4.
13. Van Uden N, Van den Block L, van der Steen JT, Onwuteaka-Philipsen BD, Vandervoort A, Vander Stichele R, et al. Quality of dying of nursing home residents with dementia as judged by relatives. Int Psychogeriatr. 2013 Oct;25(10):1697–707.
14. Anquinet L, Rietjens J a C, Vandervoort A, van der Steen JT, Vander Stichele R, Deliens L, et al. Continuous deep sedation until death in nursing home residents with dementia: a case series. J Am Geriatr Soc. 2013 Oct;61(10):1768–76.

15. Vandervoort A, Houttekier D, Van den Block L, van der Steen JT, Stichele R Vander, Deliens L. Advance Care Planning and Physician Orders in Nursing Home Residents With Dementia: A Nationwide Retrospective Study Among Professional Caregivers and Relatives. J Pain Symptom Manage. Elsevier Inc; 2013 Jun 21;
16. Vandervoort A, van den Block L, van der Steen JT, Vander Stichele R, Bilsen J, Deliens L. Advance directives and physicians’ orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. Int Psychogeriatr. 2012 Jul;24(7):1133–43.
17. Meeussen K, Van den Block L, Echteld M, Boffin N, Bilsen J, Van Casteren V, et al. Older people dying with dementia: a nationwide study. Int Psychogeriatrics. 2012;24(10):1581–91.
18. Volicer L, Hurley AC, Lathi DC, Kowall NW. Measurement of severity in advanced Alzheimer’s disease. J Gerontol. 1994;49:M223–M226.
19. Morris JN, Fries BE, Mehr DR, Hawes C, Phillips C, Mor V, et al. MDS Cognitive Performance Scale. J Gerontol. 1994;49:M174–M182.
20. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry. 1982;139:1136–9.

CHAPTER 8: Discussion

Introduction

The aims of this dissertation were twofold:

Research aim 1: To describe end-of-life care for older people in Belgium and other European countries.

To fulfil this aim, we focused on the following specific research questions:

- What are the circumstances of end-of-life care for older people in the home setting and in residential homes in the Netherlands?
- Are there trends in the frequency of use of palliative care services by older people in Belgium between 2005 and 2014?
- Are there trends in the rate of occurrence of advance care planning for older people in Belgium and the Netherlands between 2009 and 2014?
- What are the out-of-pocket costs associated with care in the last year of life of older people in thirteen European countries, and which patient and care characteristics are associated with these costs?

Research aim 2: To describe end-of-life care for people with dementia in Belgium and other European countries.

To fulfil this aim, we focused on the following specific research questions:

- What are the circumstances of end-of-life care for people with dementia in Belgium, Italy and Spain?
- To what extent are family carers aware that their deceased next of kin living in a nursing home had dementia in Belgium?

In this part of the dissertation, the main results of the included studies will be discussed. First the main findings will be summarized, followed by a discussion of the methodological strengths and limitations of the various studies. Next, a general discussion on the findings will explore the results in depth and will relate these to previous research. Finally, implications for policy, practice and future research will be discussed.

Summary of main findings

End-of-life care for older people in Belgium and other European countries

In chapters 2 through 5, the results of four studies relating to end-of-life care for older people were reported. Chapter 2 showed that in the Netherlands, older people living at home are at a higher risk of being transferred between care settings at the end of life, with 54 per cent of older people living at home being transferred at least once in the last three months of life compared to 31 per cent of older people living in a residential home. Most of these transfers were hospitalisations, which occurred for 47 per cent of older people living at home and 28 per cent of older people living in a residential home in the last three months of life. Older people living in a residential home had GPs who more often reported giving palliative care to their patients themselves, and received palliative care from specialized palliative care initiatives in equal measure as those living at home. However, older people living at home received specialized palliative care from a number of initiatives that were not used by older people living in a residential home.

In chapter 3, it was shown that the use of palliative care initiatives by older people has increased in Belgium between 2005 and 2014 from 39 per cent to 63 per cent. This increase was mostly driven due to an increase in the involvement of a palliative care reference person in care homes (either a nurse or the coordinating physician of the facility), which increased from 12 per cent to 26 per cent. The use of a palliative homecare team also increased significantly, from 13 per cent to 17.5 per cent. The use of hospital-based palliative care services did not increase. All services saw an increase in the proportion of the oldest old (people aged 85 and over) among the people for whom they provided care. There were no changes across the years in the proportion of men and women or the proportion of non-cancer patients, who made up one third of the group for whom palliative care was provided by home care teams and hospital-based services and 78 per cent of people who received care from a reference person for palliative care in a care home. The timing of initiation of palliative care remained the same, with half of older people receiving palliative care only 14 days or fewer before death.

In chapter 4 it was shown that in both the Netherlands and Belgium, GPs' awareness of patient preferences has increased for older people between 2009 and 2014. The increase was larger in the Netherlands, going from 53 per cent to 66 per cent for a preference for a medical treatment the patient would or would not want and from 30 per cent to 57 per cent for a preference for a proxy decision-maker, than in Belgium, where the figures climbed from 27 per cent to 40 per cent and 29 per cent to 43 per cent respectively. Awareness of patient preferences was shown to have increased in all studied patient groups and settings, namely for all non-sudden causes of death, people who lived at home, people who lived in a residential care home (Belgium) or a residential home or nursing home (the

Netherlands), and people with dementia. In Belgium, there were more differences between patient groups than in the Netherlands, with low percentages of known preferences for the oldest old (85+) and people with dementia.

With respect to the financial aspect of care at the end of life, in chapter 6 secondary and institutional care – including care by specialist physicians, hospital care, care in a long-term care facility and hospice care – were shown to be the largest contributors to out-of-pocket costs in nine out of 13 countries studied, constituting up to 76 per cent of healthcare costs in the last year of life. This is primarily attributable to care in long-term care facilities, having difficulties with activities of daily life (independently of being chronically ill) and spending more than 3 months of the last year of life in hospital in those countries where hospital care is not completely reimbursed. However, there is much variation in out-of-pocket costs among European countries, both in the amount (between 2 per cent and 25 per cent of median household income) and the relative contribution of different types of healthcare to out-of-pocket costs. For Belgium, secondary and institutional care was the biggest contributor to out-of-pocket costs (with costs of care in a long-term care facility the single biggest contributor), followed by medication and finally primary care.

End-of-life care for people with dementia in Belgium and other European countries

Chapters 6 and 7 pertained to end-of-life care specifically for people with dementia. In chapter 6 it was shown that in Belgium, Italy and Spain, two-thirds of people with dementia – including both those who died suddenly and those who died non-suddenly – have a palliative treatment aim two to three months before death, climbing to more than 80 per cent in both Belgium and Spain in the week before death. A third of people with dementia in Belgium and Spain and one-fifth of people in Italy received specialized palliative care at the end of life. In Belgium, 10 to 15 per cent of people were transferred between care settings in the last week of life, a significant minority. Communication between GP and patient about care, illness or preferences were relatively low, with no communication about illness-related topics with a quarter to half of people with mild dementia, and even fewer for people with severe dementia in all three countries.

Prevalence of advance care planning, however, does seem to have increased for people with dementia. In chapter 4 it was shown that in both Belgium and the Netherlands, GPs were more aware of the preferences of people with dementia with regards to a medical treatment and a proxy decision-maker in 2014 than they were in 2009, with a particularly strong increase in the Netherlands of 36 and 38 percentage point respectively. In 2014, GPs were aware of the preferences of people with dementia for a medical treatment they would or would not want at the end of life in one fifth of cases in Belgium and two thirds of cases in the Netherlands; and of a preference for a proxy decision-maker in

19 per cent of cases in Belgium and half of cases in the Netherlands. For Belgium, these figures were low when compared to other patient groups.

Chapter 7 showed that over a quarter of family carers of people with dementia who died in nursing homes were not aware their relative had dementia at time of death. This was especially the case for people who died with mild dementia: almost half of family carers were not aware of the dementia. The longer the resident had been admitted to the nursing home before developing dementia, the less likely it was that the family carers were aware of the dementia.

Methodological considerations, strengths and limitations

All the data used in this dissertation were retrospective in nature. For four chapters, data were used from epidemiological surveillance networks of general practitioners (GP Sentinel networks) from one or more country. In one chapter, data from next of kin of a number of respondents who died during a long-term longitudinal study in 13 countries (Study of Health, Ageing and Retirement in Europe) were used. The final chapter used retrospective survey data from the nurse, general practitioner and next of kin of a representative sample of deceased Flemish (Dutch-speaking Belgian) nursing home residents with dementia (Dying Well with Dementia). Each of these datasets had its specific strengths and limitations, as well as having strengths and limitations in common by virtue of being retrospective (population-based) surveys.

Advantages and disadvantages of retrospective population-based research methods

The use of retrospective data is well-established in social sciences and specifically in end-of-life care research. It has both advantages[1] and disadvantages[2] and its use should always be driven primarily by the suitability of the research question. The research presented in this dissertation aims to give a population-based description of end-of-life care for older people and people with dementia, aims that are perfectly met by retrospective population surveys.

The greatest advantage of using this method is that it allows for the selection of a population-based sample. This enables us to give estimations of the prevalence of aspects of end-of-life care – such as advance care planning or the involvement of specialized palliative care – in a population as a whole. It allows for the random selection of decedents who died from a variety of illnesses and in very different situations. Prospective research with the aim of studying end-of-life care would in practice have to base itself on setting (e.g. include those who enter a certain hospital ward), diagnosis or (notoriously unreliable) prognosis.[3-5] Prospective research based on diagnosis or prognosis could also not include those who died suddenly or were undiagnosed until very late in the disease trajectory. As such, while it would be highly valuable in giving a detailed account of end-of-life care in a particular group, it would be unable to present us with the population-based overview of circumstances surrounding the end of life the way retrospective research can.

In addition, there are practical advantages to retrospective research. When retrospective surveys are an appropriate method to answer the research questions, they are both time- and cost-efficient, with inclusion of a large sample possible with moderate means. Retrospective surveys can be the most cost-effective way of using limited means to procure the greatest amount of useful data.[6]

There are also certain disadvantages to using retrospective data. Given the nature of research into the end of life, the biggest disadvantage is that it is always proxy respondents – the GP, next of kin – and not the patient who provide the data. The use of proxy respondents is well established in studies of older people, especially those with dementia[7], and in the field of palliative care research. Proxy reports have been found to be reliable (i.e. in line with the patient's own judgement) with respect to the quality of services and care received and observable symptoms, but less reliable with respect to subjective aspects of a patient's experience, such as emotional distress or pain.[8] As such, proxy respondents can be considered a fair substitute for patient response in most aspects[9], and certainly those aspects of care studied in this dissertation. Though the viewpoint of the palliative patient can certainly be valuable, especially when evaluating care received, it was not necessary to answer the research aims of this dissertation.

A further disadvantage of retrospective data collection is the possibility of any of a number of memory or recall biases.[10] Memory biases are cognitive biases that influence the content of a recalled memory, or that influence how hard or easy it is to recall a certain memory. Especially concerning an emotionally burdensome event like the death of a loved one, memory bias can play a large role in the way people recall certain events, i.e. distortion may take place.[11] People may remember things that did not happen or forget things that did happen, or change the sequence of events. Furthermore, it is not certain that memories can be recalled at all: the longer it has been since an event, the harder it is to recall, e.g. the further removed from the time of death the questionnaire is administered the higher the chance some errors will be made.[12] Also, emotionally loaded experiences – either positive or negative – are more easily recalled than neutral experiences, meaning that proxy respondents for those for whom care was not especially good or bad ('standard' care) may have been less likely to answer all questions.[12] There are ways to limit recall bias, for example by using special interview techniques; having the questions follow not long after the events asked about; or the use of memory supports such as notes.[7,13] Most of the data used in this dissertation was collected within several weeks of the decedent's death, with only data from the SHARE study used in chapter 5 potentially collected more than a few months, though less than a year, after death. In most cases, medical files or financial statements and other such memory supports may have been available. In this way, recall bias was limited as much as possible.

A further downside is that in retrospective research it is not possible to establish causality between events. For example, in the data from the GP Sentinel Networks, are people more likely to die at home when their GP was aware that this was their preferred place of death? Or do GPs make assumptions about the preference for a place of death, and assume that home was the preferred place of death when death occurred there? With retrospective data, there is no way to tell. Keeping in mind that causal inferences are not possible with this type of data is important when interpreting the results of retrospective studies, though of course some explanations are more likely than others.

Finally, the research included in this dissertation is all quantitative rather than qualitative. While qualitative research could also be used to answer the research aims – to describe end-of-life care for older people and people with dementia – for this dissertation the choice was made to approach these questions on a population level and thus, quantitative research was more appropriate. Qualitative research may be employed in future to further examine the way older people, people with dementia and their family carers experience care at the end of life.

GP Sentinel Networks

The GP Sentinel Networks are nationwide networks of general practitioners which provide a representative sample of both GPs and the general population in four countries, either nationally (Belgium, the Netherlands, Italy) or for specific regions (the Castille y Léon and Communitat Valenciana regions in Spain, the Tuscany region in Italy in 2013, 2014 and 2015). The data used in this dissertation were collected as part of a mortality follow-back study, where participating GPs regularly complete a questionnaire about all patients of their practice who died recently.

The GP Sentinel Network data have several strong points. The representativity of the networks means our findings are transferable to the general population. Participating GPs were asked to answer the questionnaire regarding their deceased patients within one week of the patient’s death. This, in conjunction with the availability of medical files, possibly limited recall bias on the part of the GPs. Although several GPs may work in the same practice and not all may experience deaths of patients frequently, this retrospective cohort design has the advantage of allowing respondents to anticipate the data that will need to be provided regarding each death. Finally, because the GP Sentinel Networks have been collecting data for several years, we had the possibility of doing trend analyses to see how several important aspects of end-of-life care for older people have evolved since 2005. Since data collection is ongoing, the value of this dataset will only grow with time, as longer and more detailed trend analyses will be possible in years to come.

The data from the GP Sentinel Networks also has its limitations. The first and most obvious of these is that the data provide only the GP's perspective. While GPs are often the most important caregiver for older people at the end of their life, there are situations where the GP may not be well-informed, for example if the patient is transferred to hospital and dies there. In addition, the limited nature of the questionnaire leaves several important questions unanswered. Most notably, we were unable to ascertain the degree to which people were supported by or received care from informal caregivers, such as spouse or children; and we did not have information on the communication about disease-related topics or advance care planning with formal caregivers other than the GP. Conversely, because we only asked about the relationship between the GP and the patient, we also do not know about communication between the GP and other formal or informal carers. Especially for people with dementia, communication with the GP may often happen with a family carer. Indeed, further study has shown that when the GP was asked about communication with the patient *and* with the patient's relatives, they indicated that they more often communicated with the relatives of older patients than with patients themselves in Belgium and Italy, and communicated with them about more topics in these countries and the Netherlands.[14]

Second, in these data the presence and severity of dementia is judged by the GP and not by a specialist. Although specificity in dementia diagnosis by GPs is excellent, meaning there is little chance of them wrongly judging someone to have dementia, there may have been an underreporting of people with mild dementia.[15] The inclusion of people with mild dementia is something fairly novel to end-of-life care research in older people, which tends to focus on people who die without dementia or with severe or very severe dementia. As these questionnaires focus on the relation between the GP and their patient, those who were not recognized by the GP to have had mild dementia were presumably treated by them as not having dementia and it presents no problem for these studies to include them in this group. However, it does mean that these studies should be read with the caveat that they only describe end-of-life care for those recognized to have dementia and not those who are undiagnosed.

A final limitation concerns the representativity of the sample in the different countries. The population of dying patients that is taken care of by the GP differs per country. With respect to the studies included in this thesis, the sample in the Netherlands is of particular concern. In the Netherlands, older people who live in nursing homes are cared for by an in-house physician specialized in geriatric medicine and rehabilitation. These physicians are not included in the Dutch GP Sentinel Network. As such, people living in nursing homes in the Netherlands are mostly not included in the data (an occasional resident may be included if they moved into the nursing home relatively shortly before death). The lack of inclusion of nursing home residents means that the sample population in the Netherlands includes fewer people with dementia, especially severe or very severe dementia, than in other countries. The sample possibly also includes fewer people who are severely disabled, suffer from multimorbidities, and have no informal carers than in the other countries. By comparing subsets of the sample, e.g. people in different age brackets, or who died from a particular cause, and by controlling for longest place of residence in the last year of life and having dementia, the Dutch data could still be used in meaningful comparisons.

Study of Health, Ageing and Retirement in Europe

The Study of Health, Ageing and Retirement in Europe (SHARE) is a unique and valuable ongoing longitudinal international study aiming to follow up thousands of participants regarding a variety of topics related to social, economic and health characteristics. Every few years, participants are contacted for another computer-assisted face-to-face or telephone survey, and new participants are sampled to counteract attrition. For participants who died between waves, researchers attempt to locate next of kin who are willing to complete an end-of-life interview about the last year of life of the deceased.

The inclusion of a great number of countries, with more countries joining the study at each wave of data collection, means that broad international comparisons can be made. The longitudinal nature of the study makes it possible to collect a lot of information at different time points in a respondent's life. Specifically with regard to this dissertation, the survey includes questions on costs of eight different types of care: medication, primary care, aids and appliances or help received due to disability, home care, care from specialist physicians, hospital care, care in long-term care facilities and hospice care. Because the aim of the study is to investigate health, ageing and retirement in the general population of people aged 55 and over, this is a prospective study that does give a random, population-based sample of decedents.

A limitation of this data is that no hard data on costs were available, for example based on bills or insurance data. Data collection relied on the knowledge of a proxy respondent whose recall may have been biased and which lead to high missing values (up to 29.1 per cent in Sweden). However, since very few of these missing values were due to refusal (3 per cent), concerns about missing values correlating with higher costs are limited and the missing values were assumed to be random. While individual respondents may have had bills or other definite means of determining costs, it is impossible to establish who did and who did not.

A second limitation is that there was a lack of specific data on the time the decedent spent in a long-term care facility, hospital or hospice. While separate questions were asked to determine whether these types of care were used and if costs were incurred in doing so[1], only one question was asked to

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[1] The question asked was: "*We would now like to ask you some questions about any expenses which [the decedent] incurred as a result of the medical care [he/she] received in the last 12 months before [he/she] died.*

determine how much time the decedent spent in any of these institutions: “How much time did your next of kin spent in a hospital, long-term care facility or hospice in the last year of life?” As such, we could not distinguish between these three types of care and for our final analysis (see chapter 5, table 4) we had to exclude those who had received care in a long-term care facility or hospice in order to determine the impact of length of hospitalization.

Finally, there may have been a bias in the sample based on which SHARE participants’ proxy respondents could be identified. While there was an extensive procedure in place to search for proxy respondents for each deceased participant, a number could still not be identified – in fact, not all participants could be found again in each wave, meaning that there is also a number of participants who may have died, but for whom death could not be confirmed. This means that those older people who have little to no informal care or support may have been excluded from the study.[16]

Dying Well with Dementia

The Dying Well with Dementia study had the aim to investigate the circumstances of end-of-life care of people with dementia in nursing homes throughout Flanders, Belgium. After identifying deceased residents of participating nursing homes, questionnaires regarding the end of life of the decedent were sent to multiple people, namely a key person (manager) at the nursing home where the decedent resided; the nurse most involved in care; the GP; and the family carer most involved in care.

The inclusion of not only people with severe dementia but also those with mild dementia meant that data was collected on a population that is often excluded from studies on dementia and end-of-life care. Since around half of people who die with dementia do not progress to the advanced stages of the condition (see chapter 5, table 1), it is of great importance to take their experiences into account when examining end-of-life care for people with dementia. Second, in this study information about the decedent and their last months of life was provided by several sources. The distinct advantages of this are that partial overlap between the questionnaires gave a higher chance of obtaining vital information such as cause of death; that congruence between answers given by different respondents solidifies the reliability of the data; and that gathering information from different perspectives is vital as everyone involved may have had a different experience of the event.

There were several limitations specifically related to the parts of the study that were included in this dissertation. While chapter 7 deals with awareness of family carers about their next of kin’s

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For each of the types of care I will now read out, please indicate whether the deceased received the care and, if so, give your best estimate of the costs incurred from that care.”

dementia, actual communication between professional caregivers and family carers regarding a resident's diagnosis over the course of the disease trajectory was not measured. Therefore, we cannot say whether the diagnosis was not communicated or was communicated but rejected or not understood. In addition, it is not certain that all respondents had the same understanding of what is meant by the word 'dementia'. Since no definition was given, nor other terms used that may be known to family carers in particular, it is possible that in some cases family carers indicated they were not aware their relative had dementia whereas, had another description been used, they would have indicated the opposite.

General discussion

In the following sections, some reflections on the findings of this dissertation are provided. In each section, an in-depth discussion will be presented on one of the topics studied in this dissertation, drawing from results from all chapters of this thesis. First, end-of-life care for older people will be discussed, specifically looking at differences between care settings, advance care planning, the development of palliative care in Belgium since 2005, and costs of care. Next, two sections detailing specific challenges of end-of-life care for people with dementia will discuss how care in the last three months of life of people with dementia compares to care in this period for older people in general, and advance care planning, communication and family involvement.

1. End-of-life care for older people

1.1 Differences between care settings: Transitions and palliative care

While most people will live at home until the end of their life, in the GP Sentinel Network data included in this dissertation more than one third of older people in Belgium and more than a quarter of older people in the Netherlands lived in a long-term care facility (either a residential home, where assistance with activities of daily living is provided but no on-site medical care, or a care home or nursing home, where both are provided) in the last year of life. In the Netherlands, 54 per cent of older people living at home who died non-suddenly were transferred at least once in the last three months of life compared to 31 per cent of older people who died non-suddenly and who were living in a residential home. Most of these transfers concerned hospitalization. Dying in hospital was more likely for older people living at home, at 30 per cent of cases, than for older people living in a residential home, at 16 per cent of cases. Previous research into the place of death of people with dementia who died of pneumonia in Belgium also showed a greater risk of death in hospital for people who lived at home compared to people who lived in a care home.[17] The study found that 47 per cent of people living at home died in hospital compared with 26 per cent of people living in a care home.

The fact that many older people are still transferred between care settings so close to death is cause for concern. Frequent transitions between care settings can be a sign of lower quality of care and can be burdensome to the patient. Apart from the physical discomfort and psychological stress of transitions, at each transition, there is a risk of miscommunication or lack of communication between the various care providers. This can lead to possible incongruity between a patient's wishes for care and care received, as well as medical errors related to discontinuity of care.[18] Terminal hospitalizations in particular – as seen in chapter 2, the most common type of transfer for older people in the last three months of life – are best avoided. Hospitalizations at the end of life can result in a lower quality of death and are considered inappropriate and/or potentially avoidable by GPs in one fifth of non-sudden deaths in Belgium and a quarter of deaths in the Netherlands.[19-21] Also, since people largely prefer to die at home (or in a long-term care facility if that is where they live), avoiding unnecessary hospital deaths is vital to providing care that is in congruence with patient wishes.[22] While professional caregivers (GPs and nurses) agree that some situations justify a hospital admission at the end of life (including when the patient prefers hospital admission, when the caring capacity of the care setting is considered to be inadequate or when an acute medical situation occurs) they agree that death in the home situation is preferable.[23]

A previous study by Reyniers and colleagues found that according to GPs, most terminal hospitalizations in Belgium were due to aspects related to the care setting (a cited reason in 85 per cent of non-sudden deaths), such as an inability to provide adequate care in the current care setting or insufficient caring capacity by formal or informal carers, for palliative reasons (55 per cent), or because family members believed care to be better in hospital (54 per cent).[24] The study also found a considerable number (16 per cent) of terminal hospitalizations which occurred because the family panicked. In another study, Belgian GPs indicated in up to 70 per cent of cases that earlier communication with the patient about their illness and their wishes for care could have prevented an avoidable or possibly inappropriate terminal hospitalization.[19] In the same study, GPs also indicated that hospitalization could have been avoided with better (palliative) care outside of hospital in up to 70 per cent of cases. Similar ways hospitalizations could have been avoided were given by GPs in a study conducted in the Netherlands.[20] These findings point toward two main problems in avoiding transitions between care settings, and especially hospitalizations, at the end of life: a lack of clear communication, either with the patient, their relatives, or between professional caregivers, and an inability to provide continuous high-quality end-of-life care in one setting.

If hospitalizations could have been avoided through communication with the patient and advance care planning, it is vital that GPs are encouraged to talk more and earlier with their patient about their wishes for care at the end of life. In a study using the GP Sentinel Network data from four countries it was found that for 1,226 cancer patients who died non-suddenly in hospital, in more than half of cases in Belgium and the Netherlands, three quarters of cases in Italy and 86 per cent of cases in Spain, neither the patient nor the family had expressed a wish regarding the last transition.[25] And while research has shown that for people with cancer, GPs may often be aware of a preferred place of death – 45 per cent in Belgium and 72 per cent in the Netherlands in one study[26] – the studies included in this dissertation show that this was far less common for older people (see chapter 2, table 2 and chapter 6, table 3). This suggests that there is not always a lot of communication between GPs, older people and their family regarding place of care at the end of life and place of death. If GPs are aware of a preferred place of death, they may have more time and opportunity to prepare care in such a way that the patient does not need to be hospitalized at the end of life. Better communication with the patient's family, including early communication as well as a clear message on what hospitalization would mean for their relative at this stage, could decrease the number of people who want their relative to be admitted to hospital. Such issues with communication can play a role in both the home setting and long-term care facilities, where it may not be the GP who is the first point of contact for older people and their relatives.

The second point, the ability to provide continuous end-of-life care in one setting, poses very different challenges for people living and being cared for at home and those living in a long-term care facility. In long-term care facilities, even in residential care homes which are aimed at older people with less severe care needs, some form of professional care is available around the clock. It is also easier in these settings to arrange additional care than it is in the home setting, as the necessary infrastructure is already in place. In the home setting, at least in Belgium and the Netherlands, it is the GP's role to coordinate care. This can be a very complex task and it is perhaps unsurprising that GPs cite difficulty of organization of care and compartmentalization in healthcare as a barrier to providing high-quality palliative care in the home setting.[27] The healthcare system may be set up in such a way that it is difficult for a GP to organize continuous care at home, both because of a lack of availability of professional carers (e.g. nurses or palliative care specialists) when family carers can no longer cope with the demands of care, or a lack of expertise on or experience with appropriate care at the end of life. In such situations, hospitalization may be seen as a more reliable way to provide high-quality care to the patient. The fact that GPs often cite the need for provision of palliative care as a reason for terminal hospitalization indicates that GPs indeed have difficulty organizing palliative care at home; or otherwise, believe that palliative care can be better provided in hospital. There is currently no evidence that suggests that this is the case.

Several successful interventions exist to decrease the number of hospitalizations, either from long-term care facilities or from the home setting. The Care Transitions Intervention, developed and trialled in the USA, was shown to reduce re-hospitalization rates of community-dwelling older people both at 30 days and 90 days after initial admission.[28,29] This intervention used a 'transition coach' who spoke with patients in the hospital and then followed up via phone or in person after discharge to make sure that their medication was correct and they were taking it correctly; that a patient-centred record was maintained and shared with all parties involved in care; that timely follow-up with primary or specialty care could be arranged; and to look out for 'red flags' indicative of a worsening condition. While in this case, follow-up was arranged from hospital, this could also be implemented in the primary care setting. Other types of intervention have also shown promising results. A systematic review of self-management interventions for patients with chronic heart failure showed that most of these interventions reduced hospital readmissions, as well as improving quality of life and decreasing mortality (with the remainder of intervention showing no significant effects).[30] Self-management in this context refers to the ability of a person with a chronic condition to manage their own symptoms, treatment and lifestyle changes and "to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life".[31] Patient education is of vital importance in this type of intervention. It must be noted, though, that these interventions are not necessarily aimed at people who are close to death. Further research would be needed to ascertain their applicability at the end of life and to different cultural contexts. Meanwhile, interventions in nursing homes have been shown to be effective in reducing hospitalization rates by providing care pathways for residents, e.g. a clear clinical pathway for the treatment of pneumonia monitored in nursing homes monitored by a research nurse.[32,33] While long-term care facilities are complex systems in which many factors influence care provision, establishing clear plans for care can be one way to aid care providers in nursing homes to better estimate in which situations, or up to which point, they can provide care themselves rather than opting for hospitalization.

A second finding relating to differences in end-of-life care for older people living in residential care homes and older people living at home in the Netherlands was that older people living in residential care homes had GPs who more often reported giving palliative care to their patients themselves. In addition to this, older people living in care homes received palliative care from specialized palliative care initiatives in equal measure as those living at home, although from a smaller variety of services than older people living at home. Older people living at home received palliative care in a palliative care unit in a hospital and from 'other', non-specified, services, whereas those living in a residential home did not. This is not necessarily cause for concern. A greater variety of services for older people living at home may reflect the more variable circumstances of this group. For older people living in a long-term care facility, there is a structure in place for help with activities of daily living and for healthcare provision that can be lacking for people who live at home. What is more surprising, is that the level of palliative care provided by palliative care services is low: only 26 per cent for people living at home and 12 per cent for people living in a residential home. To contrast this figure with palliative care provision in Belgium (chapter 6): in 2014 (two years later than the data in chapter 2), palliative care services provided care to 63 per cent of older people (see chapter 6, tables 2 and 3).

Although palliative care can be provided by both regular care providers and care providers specialized in palliative care, there are certain points of concern to be raised for both approaches. For the generalist approach, where regular care providers provide palliative care, the question remains as to their level of skill and experience with palliative care. While more than half of Dutch GPs reported providing palliative care to their patient themselves, both at home and in a residential care home, most of these did not have any formal palliative care training (see chapter 2, table 2). GPs who reported providing palliative care for older people living in a residential home had formal palliative care training in more than half of cases, compared to roughly one-sixth of GPs who said to provide palliative care to older people living at home. It is possible that GPs who have many patients who live in a residential home are more often confronted with the necessity of end-of-life care, and as such, have more inclination to obtain formal palliative care training. Due to the nature of the study, we are relying on the GP's self-report and their own assessment of what palliative care entails. Studies have shown that GPs can be capable of delivering palliative care themselves, but this depends on their training, experience, and the complexity of the case, with complex cases best handled by people specialized in palliative care.[34] As such, it is important that specialized palliative care can be called upon whenever there is a need at any point during the disease trajectory. This may be easier in a palliative care system such as that in Belgium, with a stronger emphasis on specialized palliative care. Of course, there are also points of concern for this system: as mentioned above, GPs cited palliative care as a reason for a terminal hospital admission in more than half of cases, as well as difficulty organizing care in the home setting. If palliative care services cannot be relied upon to be available when necessary, for example when the capacity of formal or informal care in the home setting is exceeded, GPs may feel they have no choice but to refer people to hospital. A system where there is balance between the generalist and specialist approach – where regular care providers are trained in palliative care, but specialized palliative care is reliably available when necessary – may yield the greatest benefits.

1.2 Advance care planning

The study reported in chapter 3 gave us a look at the current state of advance care planning for older people, as well as the significant developments since 2009. In both Belgium and the Netherlands, advance care planning has increased between 2009 and 2014 for all studied patient groups. Overall, the percentage of older people for whom a preference was known for a medical treatment they would or would not want at the end of life increased from 27 per cent in 2009 to 40 per cent in 2014 in Belgium, and from 53 per cent to 66 per cent in the Netherlands. The overall percentage of older people for whom a preference for a proxy decision-maker was known increased from 17 per cent in 2009 to 28 per cent in 2014 in Belgium, and from 30 per cent to 57 per cent in the Netherlands.

These changes are considerable given that they took place over only five years. There could be several causes for such a rapid improvement. In recent years, several guidelines have been published and interventions done with the aim of raising awareness of and improving advance care planning in a variety of settings.[35-37] These may be either a reason for or a consequence of increased awareness of advance care planning. Other possible causes include a cohort or generation effect. Younger generations in Western-Europe value autonomy more[38] and may take more of an active role in planning their end-of-life care, such as initiating advance care planning conversations. Previous research has shown that while many patients believe it is the role of GPs to initiate advance care planning, GPs on their part often believe that this is the responsibility of the patient.[39] If patients start to introduce the topic more often, this is one way in which advance care planning can happen more frequently and become normalized as a part of healthcare. If this is the case, care must be taken to avoid unintended consequences of this increased patient initiative, such as GPs putting even more emphasis on the need for the patient to take the first step and becoming less likely to take the initiative themselves. Finally, it is possible that this development is due to growing acceptance of advance care planning in society in general. An increase in advance care planning may signal that the taboo regarding death and dying is being broken.

While the most notable differences in the awareness of patient preferences were between the two countries – with the Netherlands not only having a higher starting point, but also showing a larger increase than Belgium – there were also some differences between patient groups. Most of these differences were seen only or more strongly in Belgium, and mostly for a medical treatment they would or would not want at the end of life (see chapter 3, table 2). For instance, in Belgium a preference for a medical treatment the person would or would not want at the end of life was known more often for people with cancer than for people without cancer (a difference of 23 percentage point in 2014); more often for people aged between 65 and 84 than for people aged 85 and over (a difference of 19 percentage point in 2014); and more often for people living at home than for people living in a care home (a difference of 15 percentage point in 2014). Of course, these three groups are related: those who are 85 years or older are more likely to live in a long-term care facility and more likely to die of diseases other than cancer.

It is striking that despite the strong overall increase, these differences between patient groups have not gotten smaller. Indeed, the difference sometimes even increased, such as in the case of the preference for a medical treatment the patient would or would not want in Belgium in the age groups 65-84 and 85+, where the difference was 2 percentage point in 2009 and 19 percentage point in 2014. Advance care planning is increasing at a faster rate for some patient groups than for others, risking inequalities in care provision. In other words, instead of catching up, already disadvantaged groups e.g. the oldest old and non-cancer patients are falling behind. This is exactly the opposite of what is recommended by, among others, the European Association for Palliative Care and the World Health Organization: that palliative care, including advance care planning, is a basic human right and should be available for all people with a life-limiting illness.[40,41] The problem is not that this message has not found fertile ground: studies have found that in general, healthcare providers agree that advance care planning is important not only for people with cancer but also for people with dementia, chronic obstructive pulmonary disorder (COPD) and cardiovascular disease.[42,43] However, they also see more barriers for advance care planning in these diseases than for cancer. In both focus groups and as a result of a systematic review conduct by De Vleminck and colleagues, it was found that for advance care planning with people with cancer GPs see a lack of their own knowledge and skills, as well as a lack of structural collaboration between primary and secondary care, as barriers.[39,42] For people with cardiovascular disease or dementia, they see a number of barriers *in addition* to this: difficulties to define key moments to timely initiate advance care planning; a lack of patient initiation; the patient's unawareness about diagnosis and prognosis; and future lack of decision-making capacity on the part of the patient. In a different focus group study regarding patients with COPD, healthcare professionals also indicated lack of consensus on who should initiate advance care planning, the patient's inadequate knowledge of diagnosis or prognosis as barriers, and thinking that advance care planning discussions conflict with the goals of chronic disease management.[44]

It is possible that barriers such as these, unique to non-cancer patients, are some of the reasons advance care planning does not improve as quickly for them as it does for cancer patients. However, far from being a reason to avoid advance care planning, some of these barriers are in fact a reason to engage in advance care planning. If a patient is unaware about their diagnosis or prognosis, this can be a reason to engage them in a conversation about their condition. If a patient will not be able to make decisions later on in their disease trajectory, their future wishes for care can best be discussed in the present. Advance care planning is an excellent addition to chronic disease management, as it encourages long-term thinking about future care and overarching wishes and values, rather than dealing with predictable health issues if and when they occur. While not all patients are open to discussing their diagnosis or prognosis, it is important to at least establish this information preference. A systematic review on prognostic or end-of-life communication with people in advanced stages of a life-limiting illness found that in general, patients and their informal caregivers wanted at least some discussion regarding disease process, likely future symptoms and their management and life expectancy at the time of diagnosis or shortly thereafter.[45] This review also showed that both patients and caregivers preferred a healthcare professional who encouraged questions and clarified patient's and caregivers' information needs and level of understanding. Patients in general expect their physician to initiate advance care planning[46] and since patients have less knowledge about and less experience with (their) life-limiting illness and advance care planning in general it is not sensible to place the responsibility for advance care planning with them.[47] Non-cancer patients often have a poor understanding of their illness,[48-50] so especially for them, and when there is no clear moment at which a discussion about advance care planning should take place, it is important that their GP or other healthcare provider takes the initiative. This is the case even when there is a lot of uncertainty on the part of professional caregivers regarding the prognosis or other aspects of certain illnesses. The PACE (Psychosocial Assessment and Communication Evaluation) tool was developed specifically to aid in communication between professional caregivers in intensive care units and patients and family in situations where this is difficult (in part) due to clinical uncertainty. [51] Not only did 89 per cent of staff rate the tool as useful, but family members for whom PACE was completed reported significantly higher satisfaction with the honesty and consistency of information from the staff, as well as symptom control. To make sure that the inequalities in advance care planning and consequent end-of-life care do not grow even more, it is vital that we encourage professional caregivers in all settings to engage in advance care planning with all their patients, regardless of background or the nature of their illness, and give them the tools to do so.

1.3 The development of palliative care in Belgium since 2005

This dissertation included two papers which investigated changes over time in end-of-life care in Belgium: one regarding advance care planning, and one regarding the use of palliative care services. As mentioned above, advance care planning has increased since 2009 for all patient groups included in the study, though not in equal measure for all. At the same time, the overall use of palliative care services in Belgium has increased since 2005, most strongly driven by the more frequent involvement of a reference person for palliative care in long-term care facilities but also showing significant increases of the use of a palliative homecare team. These changes highlight a positive development of palliative care in Belgium in the last ten years.

Palliative care has been codified in Belgian law since 2002. In this law, it is specified that palliative care is a right of "patients whose life-threatening illness no longer responds to curative treatments", and that palliative care in this context is all healthcare provided to these people.[52] To ensure the proper provision of palliative care, with this same law yearly progress reports and a committee for the evaluation of palliative care were instituted, as was the legal mandate for "the necessary measures to coordinate the development of a needs-adjusted palliative care". In addition to this law, a series of royal decrees arranged the reimbursement of palliative care in the home setting and the financing of palliative care in hospitals.[53-56] In 2009, financing for palliative care in long-term care facilities was arranged, with one-tenth of a full-time equivalent reference person for palliative care for each 30 residents in care categories B, C or Cd (those with a high care burden).[57] The later enactment of the law regarding palliative care in care homes may be why in chapter 3, we found a significant trend to more involvement of a reference person for palliative care in a care home particularly from 2008 onwards (see chapter 4, table 2). It is possible palliative care in hospital and the home setting increased significantly in the years directly following the royal decrees from 1997 to the enactment of the 2002 law. If improvements in the use of palliative care services are strongest in the years directly following the provision of adequate financing of those specific types of care, we can therefore expect that in the near future, the growth of the involvement of reference persons for palliative care in long-term care facilities will stagnate. As the Belgian GP Sentinel networks continue to collect data, it will be possible to monitor these trends in the future and provide more insight in this matter.

Around 60 per cent of older people who died non-suddenly in Belgium used some form of palliative care service in the last three months of life in 2014 (see chapter 3, figure 1). While this is a not-insignificant number, unfortunately this palliative care is often still ‘terminal care’, only provided in the last few weeks of life (see chapter 3, figure 2). Add onto this the percentage of people with dementia, cancer or chronic illnesses (i.e. for whom palliative care might have been appropriate) who died suddenly and also did not receive palliative care, and there is a substantial portion of the population for whom palliative care is not yet provided.

It is possible that the use of palliative care services is not increasing further because saturation is *perceived*. While palliative care is becoming more and more accepted as necessary for non-cancer patients too, there are still patient groups who professional caregivers are less likely to consider in need of palliative care.[39,58] In addition, even when professional caregivers recognize that non-cancer illnesses such as COPD or dementia can be indicative of a palliative care need, they may lack the tools to assess if and when such a need arises in these patients. In Belgium, efforts are underway to provide professional caregivers with such tools, for example in the form of the Palliative Care Indicator Tool (PICT).[59] This tool aims to allow the identification of patients who may benefit from palliative care in three groups (low, heightened and full palliative status) by using one flow chart to identify eligible patients and a second to determine the level of need of the patient, regardless of the patient’s illness. Such a needs-based assessment can be very valuable for non-cancer patients, as the results in chapter 3 showed that palliative care in hospital and in the home setting is still provided primarily to cancer patients (see chapter 3, table 3). In addition to this, several groups have more difficulty accessing palliative care such as people from ethnic minorities and homeless people.[60] The further development of palliative care for these groups may be difficult without targeted measures to change healthcare professionals’ perceptions, the provision of manageable tools to provide assessments of palliative care need, and measures to change structural barriers to the provision of palliative care for excluded groups.

The stagnation of growth of certain palliative care services, such as palliative care units and palliative care support teams in hospital, may also suggest structural barriers to continued improvement. One such barrier is that currently, there is a prognosis-based requirement for accessing palliative care: a person must have a prognosis of three months or less in order to be eligible for palliative care at home. This is likely the reason that in Belgium palliative care is still ‘terminal care’, provided only in the last few weeks of life. Luckily, the Belgian minster of Public Health has recognized that this prognosis-based requirement discourages a needs-based assessment of whether or not to initiate palliative care and prohibits a more long-term approach would be more beneficial, especially for older people who often have a long, complex trajectory of chronic illness and multimorbidities. Therefore, the committee of public health recently suggested to abolish the prognosis-based requirement in order to make palliative care more accessible.[61] Future research will have to show the effect of this change, and whether or not this is sufficient to ensure palliative care is called upon earlier in the disease trajectory.

Another possible limiting factor of the further availability of palliative care services is the role the GP plays in initiating such services. This is important in three respects: one, that the perceptions, skills and available tools of GPs influence for whom they initiate palliative care services, as shown before; and two, that GPs can also provide palliative care themselves. In 2009 and 2010, of all non-sudden deaths of adults in Belgium, 50 per cent received palliative care from their GPs, with an unknown overlap between this and care provided by specialized palliative care services.[62] A GP who provides palliative care themselves may feel there is no need to involve palliative care services. This is not a problem when a GP is skilled in palliative care and when the patients they care for do not have complex palliative care needs.[34] However, these data are GP self-reports, which may not be very objective: what, exactly, does a GP do who says he or she is providing palliative care? Furthermore, in complex cases the advice or care of palliative care specialists may be needed, but we do not know if GPs always recognize this. Because GPs play such an important role in the provision and coordination of palliative care, it is vital that their (continued) training gives them adequate knowledge, skills and tools in this area so that they may recognize the best course of action for each patient.

Finally, we must acknowledge that palliative care is not always seen as needed or wanted.[63] As long as we ensure that all people are aware of the benefits palliative care may provide, we should not aim to deliver palliative care to 100 per cent of the population, but to all those eligible who want to receive it.

1.4 Costs of care

Despite large variation across European countries in out-of-pocket costs of care, there are certain clear patterns (chapter 4). Across nine of 13 countries studied, secondary and institutional care was the biggest contributor to out-of-pocket costs of care of older people in the last year of life. In eight countries more than half of out-of-pocket costs were due to costs in this category. Within this category, there were substantial differences between costs of care in hospital, care from specialists, care in hospice and care in a long-term care facility, though care in a long-term care facility was the most expensive type of care in 11 out of 13 countries. Particularly care in a long-term care facility and prolonged hospital stays produced high median costs in most countries. Costs for the small group (126 people of 2501 included in the study) who received hospice care varied greatly between countries, being completely free to care users in three countries but having a median cost of up to 6500 euros in the Czech Republic. With respect to Belgium, the only category of care that did not incur out-of-pocket costs for the majority of older care receivers in the last year of life was hospice care: for all other categories, between 52 (home care) and 95 (care home) per cent of people incurred costs from using these types of care.

Not only are care homes one of the, if not the most expensive type of care for care receivers in Belgium and other European countries; they are also the type of care that it is most likely people have to pay out-of-pocket for. This is a worrying combination. As the population of Europe ages, more older people will spend their final phase of life in a care or nursing home.[64,65] Private funding of long-term care facilities is usually unaffordable for residents, with average long-term care expenditures accounting for 60 per cent to 80 per cent of disposable income.[66] The fact that nearly all people who received care in a long-term care facility in the last year of life in Belgium had to pay for this out-of-pocket, at a median cost of 12,500 euros for one year (see chapter 5, table 3), suggests that this type of care may be less accessible to people of a low socioeconomic status. Means-tested contributions to long-term care, where those with a higher income or more wealth pay more and those with a lower income are subsidised such as in the Netherlands and the UK, may seem to be a solution to this problem, but in practice has been shown to also have an adverse impact on the accessibility of care for people of a low socioeconomic status.[67] Keeping (or making) care in long-term care facilities affordable for people from all backgrounds and socioeconomic statuses should be a policy priority. To avoid catastrophic health expenditure, a healthcare system should not overly rely on out-of-pocket payments.[68]

Unfortunately, the total costs of long-term care facilities and remaining at home are very difficult to compare. A fair comparison should include costs to both the care receiver and society, the societal impact of the burden on informal carers, but also expenses such as rent and food which are included in a long-term care facility. We don’t know if care in a long-term care facility would still be so (relatively) expensive once food, rent, and assorted costs of living are included in the equation. On the other hand, people who move to a long-term care facility are more likely to have a severe care burden, complex multimorbidities and dementia. If they remain at home instead, additional home care would be required which would drive up the costs of living at home. However, the study also showed that, in contrast to care in a long-term care facility, almost half of people who received home care did not have to pay for it, suggesting there are systems in place to avoid the financial burden of home care falling solely on the care receivers' shoulders. If this is the case, policy makers should ensure these systems should be robust enough to also provide for an influx of people with high care burden who would otherwise have lived in long-term care facilities.

While it is encouraging that cause of death was not shown to be linked to higher out-of-pocket costs, other measures of health were, namely having difficulties with activities of daily living. Those who had difficulties with more than two activities of daily living had six times more out-of-pocket costs (as a percentage of median household income) than those who did not. This was independent of having a chronic illness: those who were ill for one year or longer before death did not have higher out-of-pocket costs than those who did not – except when their illness caused them problems with activities of daily living, as is likely the case. These higher costs may be attributable to people with a high care burden, i.e. those who have a lot of difficulties with activities of daily living, are more likely to live in long-term care facilities. However, people in general are prone to experience more health issues that will impede their daily life as they age, so the oldest old (those aged 85 and over) who still live at home are also at risk of higher out-of-pocket costs of care. To ensure equity in access to healthcare, further research is needed to disentangle the individual and structural factors associated with high out-of-pocket costs for care.

2. End-of-life care for people with dementia

2.1 Palliative care and transitions between care settings for people with dementia

People with dementia require targeted care throughout their disease trajectory, including end-of-life care that is tailored to their circumstances. Several recommendations for best practice from the European Association for Palliative Care concern aspects of care investigated in this dissertation.[43] Among these recommendations are the prioritizing of explicit global care goals; the availability of specialized palliative care; the avoidance of overly aggressive, burdensome or futile treatment, including hospitalizations; and proactive advance care planning.

In Belgium as well as in Italy and Spain, a palliative treatment aim is often recognized for people with dementia. Three months before death, a palliative treatment aim was considered important for 66 per cent of patients with mild dementia and 77 per cent of people with severe dementia in Belgium, rising to 84 per cent and 92 per cent respectively in the last week of life. While this includes people who died suddenly and unexpectedly – around 22 per cent of the sample – these sudden deaths do not account for all those for whom a palliative treatment goal was not considered important. Since we do not know why a palliative treatment aim was considered important, we cannot say if the GPs considered needs arising from dementia in itself a reason for palliative care or if they recognized a palliative treatment aim for needs arising from other comorbidities. That is, this study does not tell us if GPs see dementia specifically as a reason to consider the possibility of palliative care. Additionally, since these results only show us treatment goals in the last three months of life, it is unknown to what degree it is recognized that palliative care can be useful for people with dementia in earlier stages of their illness.

Specialized palliative care was available for more than one third of people, either with mild or severe dementia, in Belgium, almost one third of people in Spain and less than one fifth in Italy (see chapter 6, table 2). Specialized palliative care in Belgium was most often provided by a reference person for palliative care in a care home (in-house palliative care service), as opposed to a home care team or assistance in home in Spain and Italy, as no formal in-house palliative care service exists in care homes in these countries. These results show that in all three countries, a sizeable portion of people with dementia do not receive specialized palliative care. Furthermore, as discussed on page 56 (chapter 3), there may be large variability in the (quality of) the care provided by reference persons for palliative care as there are no legal requirements to their training or experience. Finally, as was also seen in chapter 4 for all older people, specialized palliative care was started at a median of two weeks before death. These findings point to a continued need for more development of palliative care in care homes, but also for people with dementia in general. Italy and Spain may benefit from implementing a system similar to the reference persons for palliative care in care homes in Belgium, whereas Belgium may focus on improving palliative home care.

People with dementia die in hospital in a large number of cases, around one third of people with mild dementia in Belgium, Spain and Italy, and one fifth of people with severe dementia in Belgium and Spain and a quarter of people with severe dementia in Italy. Transitions between care settings, especially at the end of life, can be burdensome for all patients but even more so for people with dementia.[18] A study using hospital discharge records over a period of five years in Spain also found that hospitalized people with dementia may have higher mortality than older people without dementia.[69] Interventions to decrease the number of hospitalizations from long-term care facilities, such as those mentioned earlier, may be of particular importance for people with dementia.[32,33]

People with dementia do not appear to receive different end-of-life care than older people without dementia in most regards. By virtue of them living in a long-term care facility more often, there are some differences in the care they receive in the last year of life compared to people without dementia, but this may be appropriate to their circumstances. Comparing the transfer rates from chapter 6 with the literature, people with dementia do not appear to be transferred more or less often between care settings than the general population.[70] Unfortunately, people with dementia are at a strong disadvantage compared to older people without dementia regarding one thing: communication. As will be further discussed in the next section, both chapter 4 and chapter 6 in this study showed that communication and advance care planning with people with dementia is not prevalent, and comparing the results from these chapters with data from the GP Sentinel Networks published elsewhere, we see that it is also lower than for other patient groups such as people with cancer.[71]

2.2 Advance care planning, communication and family involvement

Communication and advance care planning, which are so important for people with dementia, were shown to be disappointingly low in Belgium, Italy and Spain. In 2009 and 2010, less than three-quarters of people who died with mild dementia in Belgium had had any communication with their GP about disease-related topics such as physical symptoms or life expectancy. Less than half had even talked about their primary diagnosis. Even taken into account that this includes the 22 per cent of people who died suddenly, and for whom communication may not have seemed necessary, these figures are very low – after all, even if we subtract the full 22 per cent sudden deaths, we are left with almost 40 per cent of people with whom no communication about their primary diagnosis had taken place. In Spain and Italy, the numbers were even lower, with 61 per cent and 50 per cent of GPs reporting communication about any of the end-of-life and disease-related topics. For people who had severe dementia at time of death, these numbers decreased further to 32 per cent for Belgium, 26 per cent for Spain and 10 per cent for Italy.

Looking past communication about end-of-life and disease-related topics at advance care planning, we see a similar picture. For not even a third of people, either with mild or severe dementia, a preferred place of death was known; and preferences for a proxy decision-maker, perhaps one of the most important aspects of advance care planning for people with dementia, was known in only 17 per cent of cases for people with mild dementia and 9 per cent of cases for people with severe dementia in Belgium, with even lower percentages in Spain and Italy. Thus, while Belgium shows higher percentages of communication and awareness of patient preferences than Spain and Italy, there is still much room for improvement.

A first counterpoint to these low percentages of communication would be that coherent communication with people with dementia can be challenging or even impossible. However, in these studies no timeframe was given for the questions regarding communication, meaning a ‘no’-answer implies that the GP never spoke about to the patient according to their recollection, even when the patient was in a less severe state of dementia or before they developed dementia. Furthermore, communication was also low for people with mild dementia, even though communication is very well possible for people in this stage of dementia.[72] A study comparing advance care planning tools between older people with and without dementia has shown that when filling in a value assessment tool with forced-choice items, people with dementia were as able as older adults without dementia to respond to these questions meaningfully and consistently in a 9-month retest.[73] In 2011, a systematic review identified only four studies testing an advance care planning intervention for people with dementia, and concluded that there was little evidence for the effectiveness of advance care planning in this population, though three of the studies reported positive findings with regards to documentation of patient preferences and/or reductions in hospitalisation rates.[74] Since then, however, other advance care planning interventions aimed at people with dementia have also successfully been piloted and show great promise for future use. For example, the pilot study of the Preserving Identity and Planning for Advance Care (PIPAC) intervention, in which people with mild dementia and their caregiver enrolled in four sessions with a professional caregiver focused on planning for the future, showed that people in the intervention group had fewer depressive symptoms, a higher quality of life and higher levels of coping than the control group.[75] An interactive staff training program trialled in a London nursing home also showed an increase in documentation of wishes for care arising from discussions between staff, residents with dementia and their family carers about end-of-life care.[76] However, potential reluctance on the part of family carers must be taken into account: in an intervention piloted in the UK, family carers of people with advanced dementia were positive towards the intervention, but only a minority actually made an advance care plan for their relative as intended by the intervention.[77] It might be more successful to aim to start advance care planning earlier in the disease trajectory, so that patients and family carers can engage in advance care planning together.

A second counterpoint as to why low percentages of communication are not problematic might be that communication is not always wanted. While, especially in countries such as Belgium and the Netherlands, personal autonomy is highly valued and many people prefer to be involved in decision making surrounding their healthcare, or to at least receive information about their illness and related topics, this is not the case for everyone.[78] But as was mentioned before, research has shown that most people prefer at least some information about their diagnosis, prognosis and life expectancy.[45] Data collected in a nationwide survey 2008 in Belgium showed that, in the hypothetical scenario of being confronted with a life-limiting illness, around 82 per cent of the general population always wants to be informed about their diagnosis, chances of a cure and available treatments; 77 per cent always wants to be informed on life expectancy; and 72 per cent on options on palliative care.[79] To compare: in this dissertation it was shown that the *actual* percentages of GPs discussing these issues with patients with dementia in Belgium who had died were 26 per cent for diagnosis; 16 per cent for incurability of the illness; 14 per cent for life expectancy; and 13 per cent for options for palliative care (averages of mild and severe dementia, see chapter 6, table 3). While some changes in information preferences can be expected between asking about a hypothetical scenario among the general population and the reality of being close to death for older people, it is still likely that there is a mismatch between information preferences and the information that is actually discussed with people with dementia, certainly a life-limiting illness. Different information preferences can however be a partial explanation for the international differences seen in the amount of communication: while patients in Mediterranean countries such as Italy are becoming more informed and less passive about their healthcare decisions in recent years[80,81], for a long time there was no desire for and even resistance against disclosure of health information by physicians.[82]

In cases where communication with a person with dementia is genuinely impossible, communication will happen mostly through family. Preferably, family is also involved in the care and communication about care for people who are not yet at such a severe state of dementia. For community-dwelling older people, with or without dementia, communication with the family in Belgium, Italy and the Netherlands is as likely if not more likely than communication with the older person themselves, occurring in up to 95 per cent of cases.[14] However, the situation appears to be different in nursing homes. In chapter 7 it was shown that more than a quarter of family carers was unaware their next of kin living in a nursing home had dementia at the time of death. This suggests that there is a sizeable portion of family carers with whom professional carers did not communicate about their relative's diagnosis. In chapter 4 we also saw that GP awareness of patient preferences in Belgium is less common for people who live in a nursing home than for those who live at home in the last year of life. However, when comparing older people living at home and those living in a residential care home in the Netherlands, there were no differences in GPs' awareness of patient preferences (see chapter 2, table 2). This is possibly because in a residential care home in the Netherlands, the GP is still responsible for the patient care as no medical care is provided by the residential care home staff. In a nursing home in Belgium, because of the involvement of both the GP and nursing home staff, as well as a large proportion of long-term care facility residents having dementia, it can be unclear whose responsibility it is to communicate with the resident and their family regarding matters surrounding the end of life: most GPs and nurses tend to think that advance care planning is outside their remit.[83] Both residents and family carers want staff to raise the topic of advance care planning as opposed to initiating conversations about the topic themselves.[84] Without a clear structure of communication, it is likely that a sizeable number of family carers will not be as involved in care as they might be able to or want to be.

Finally, we must consider the plight of people with dementia for whom no family carer or proxy decision-maker can be identified. In some cases, a family carer may be a de facto proxy decision-maker even if the person with dementia did not explicitly indicate this. If this is the case, the current research would not have identified these people as GPs were explicitly asked if the patient ever *expressed* a preference for a proxy decision-maker. When there is genuinely no proxy decision-maker, for example when there are no living relatives or other strong social ties, people with dementia are at risk of having no-one to represent them if and when they become incompetent to make decisions. The burden then falls on the GP or other healthcare professional, who may not know enough about their patient to be able to make decisions in line with the patient's preferences. For these people, it is even more important for professional carers to communicate with them from early on in the disease trajectory to form a reliable picture of the patient's wishes and values.

There are signs of improvement. Since 2009, the percentage of GPs who are aware of a preference for a proxy decision-maker for their patients with dementia (either mild or severe) has increased from 12 per cent to 19 per cent in Belgium, a significant difference. While this is a promising development, it is in stark contrast to the development in the Netherlands over the same period: in just five years, the percentages for the same group changed from 13 per cent to 51 per cent. While the populations are not completely comparable – the sample from the Netherlands, as stated before, includes fewer people with severe dementia – the increase is far greater than that which is seen in Belgium. This indicates that Belgium should continue to invest in promoting advance care planning.

Implications and recommendations

1. Implications and recommendations for policy

While the results of this dissertation may inform policy in several ways, two concrete suggestions are presented here for the Belgian context.

1.1 Invest in formal care at home and support for informal carers

The home setting is the preferred place of care of many older people.[85,86] In recent years, governments of several countries, including Belgium and the Netherlands, have expressed intentions to promote living at home for longer with the help of informal caregivers instead of moving to a long-term care facility. This means that an increasing number of older people living at home will have dementia, difficulties with multiple activities of daily living, and multimorbidity; and that a larger number of informal caregivers will be affected. This will affect the presumed cost-effectiveness of encouraging people to stay at home longer: while care in a care home is expensive, it does not follow that home care is 'cheap'. People with difficulties with more than two activities of daily living are at risk for higher out-of-pocket costs (chapter 5), and chronically ill people and those with multimorbidities use a large portion of healthcare, financially speaking, regardless of setting.[87]

In addition to this, the costs of an increased number of informal caregivers have to be taken into account. Informal caregivers participate less in the labour market as a direct consequence of their caregiving activities, but also experience more physical problems and psychological distress. A meta-analysis of 176 studies found that caregiver depressive symptoms were associated with more physical health problems.[88] Higher levels of behaviour problems on the part of the care recipient were found to be related to poor caregiver health, meaning that particularly informal caregivers of people with dementia were at risk. A study among female caregiving and non-caregiving twins found that caregiving was associated with lower mental health functioning, higher anxiety, higher perceived stress and higher levels of depression, and suggested that while both common genes and environment contributed to vulnerability to stress and consequently informal caregivers' functioning, caregiving lead to psychological distress even for those who were not particularly vulnerable to stress.[89] Another study found that up to 62 per cent of family caregivers experience a high level of psychological distress, compared to 19 per cent in the general population.[90] Furthermore, a prospective cohort study in the Netherlands found that when a person with dementia was admitted to a long-term care facility during the course of the study, the psychological distress of informal caregivers improved.[91] By promoting informal care in the home setting as an alternative for long-term care facilities, a larger number of people is at risk of these physical and psychological health issues which in itself may place an additional burden on the healthcare system.

In order to ensure care at home of high quality in a more cost-effective way, measures must be taken in addition to those currently discouraging the use of long-term care facilities. As was mentioned on page 149, the difficulty of organizing continuous care in the home setting above and beyond that which informal caregivers can provide is one of the main reasons GPs cite for hospitalization at the end of life.[19,20,24] As such, a first step towards improving home care could include investing in formal home care, including promoting the accessibility of palliative care services in the home setting.[23,24,92] In addition, improving communication between healthcare services could prevent not only hospitalizations, but also unnecessary interventions and poly-pharmacy for older people, as well as reduce costs.[93-95]

1.2 Increase palliative care expertise in care homes

The results of this dissertation have shown that people who live in care homes in Belgium receive palliative care mainly in-house, with the involvement of a reference person for palliative care, and infrequently from other specialized palliative care services. However, as was discussed in chapter 3, the question remains as to what this means in practice. The legal requirements for a care home to receive reimbursement for a reference person for palliative care are limited. A care home must draw up a vision statement, support those who are responsible for the organisation of palliative care in their facility and register palliative care in the residents' files.[54] These requirements are not directly related to the quality of palliative or end-of-life care in the care home. The requirements for the reference person are similarly vague: they are responsible for organizing the training of care home staff in palliative care (but it is not stated what the requirements of such training are), to implement a supportive palliative care culture (which is not further defined), and to keep the aforementioned records on palliative care. There are no legal requirements to the training or education of a reference person for palliative care, nor are their activities or the impact of their work inspected. This can lead to high variability in the way the role of reference person for palliative care is executed and the quality of palliative care between facilities.[96] In addition, there may be a lack of expertise needed to deal with complex cases, which may arise regularly in a care home setting as older people suffering from multimorbidity may have complex care needs at the end of life.

Several palliative care networks, as well as the Federal Evaluation Committee for Palliative Care, have made recommendations for the role of a reference person for palliative care. These include that the reference person should preferably be a healthcare professional with at least a bachelor degree in medical/human sciences or nursing and who has experience with palliative care.[56,97] Further recommendations are to establish a formal requirement for training and education of reference persons for palliative care, and proper evaluations of existing training programmes.[56,97,98] To achieve such additional expertise, it will be necessary to invest financially in palliative care in care homes. For example, the reimbursement of 0.10 FTE per 30 beds may not be sufficient. It might be most efficient to make use of the expertise already available in palliative home care teams – who can be, but rarely are, involved in care for care home residents – both for sharing their knowledge and experience with care home staff, and to be more often involved in complex cases.

2. Implications and recommendations for practice

The increasing number and proportion of older people and people with dementia presents a challenge not only for policymakers, but also for clinical practice. Healthcare professionals will be increasingly confronted with the needs of these patient groups. Here, two suggestions related to our findings are presented to improve the care delivered to older people and people with dementia at the end of life.

2.1 Communicate more often and early enough with people with dementia

For people with dementia, the decline of their cognitive abilities is both unavoidable and irreversible. As such, it cannot be overstated how important communication early in the disease trajectory is, so that people with dementia can prepare themselves for what is to come, to think about and plan for their future, and for both healthcare professionals and family carers to be aware of the persons wishes and goals for care. Previous research has shown that early advance care planning interventions are better received and more successful than those later in the disease trajectory of people with dementia.[73,75,99] Yet, the preferences for medical care or proxy decision-makers of people with dementia are known in only a minority of cases in Belgium, even with the improvement in recent years (see chapter 4, table 3).

There are several reasons why GPs and other healthcare professionals do not communicate about dementia, such as not wanting to take away hope, or believing there is no point in communicating the diagnosis because there is no cure.[100] However, although these reasons may be well-founded, they do not outweigh what can be gained in quality of life and quality of dying by discussing the patient's preferences, for both the patient and family carers, who often experience the uncertainty about their relative's wishes and the reality of decision-making as a burden.[101] This includes in particular the assigning of a proxy decision-maker, which currently the majority of people with dementia do not do. Of course, information preferences of the patient must be kept in mind, which in the case of dementia also means dealing with the stigma attached to the disease.[102,103] In order to ensure adequate communication with people with dementia, a two-pronged approach may be necessary: one to decrease the stigma attached to a dementia diagnosis, and the other to make communication a standard part of care for people with dementia.

In Belgium, efforts are underway to change the way the public view dementia and to decrease the stigma associated with the condition. For example, the campaign 'Vergeet dementie, onthou mens' ('Forget dementia, remember people') spearheaded by the Flemish Ministry of Welfare, Public health and Family in collaboration with organization such as the Expertise Centre Dementia Flanders, aims to enable a more dementia-friendly society by challenging clichés and stereotypes.[104] The campaign also included research conducted by the Van Gorp and Vercruysse to reframe people's perceptions of dementia.[105] Such campaigns can hopefully make dementia a topic that is more easily discussed, both between members of the public and with healthcare providers. In addition, healthcare providers may benefit from being given more tools to engage in communication and advance care planning, either in the form of training or tools such as the PICT tool mentioned on page 156, or specific advance care planning tools for people with dementia that can be easily incorporated into existing practice.[60]

As for structuring communication, one way in which to handle this might be to establish the equivalent of a care pathway specifically for communication. Because dementia is often not diagnosed formally by a specialist physician, it can be difficult to know when the (informal) diagnosis by another healthcare professional should be communicated to the patient and/or family carers. By establishing a set point at which such a conversation takes place, the chances of information not being transmitted is reduced. Since a diagnosis of dementia is sometimes rejected at first by patient or family carers,[101,102] it is important to also have a schedule for follow-up conversations to ensure the diagnosis and the implications of the diagnosis have been understood (keeping the information preferences of the patient and family carers in mind, of course). These conversations can in this way be the start of an advance care planning process. By creating such a structure it might be possible instil the thought that this should be a standard part of care provided to people with dementia. Especially for people who live in nursing homes, it is important that nursing home staff and GP are clear whose responsibility it is to organize communication with family carers, as there is a risk that it might otherwise be left to convenience based on when the family carers visit the resident.

2.2 A step-up, step-down approach to palliative care

Providing palliative care to people with dementia in particular, but also to older people who suffer from multimorbidity but do not have a clear prognosis, presents an interesting challenge: while they may have palliative care needs, they also may have a number of years to live. Currently, palliative care in the Belgian system is set up to focus on the last three months of life, but may not have the resources to provide care over a (much) longer period.

To enable palliative care to be provided throughout the disease trajectory, it may be possible to apply a stepwise (step up, step down) approach, similar to the protocols of some chronic diseases such as asthma.[106] In such an approach, treatment is reviewed every few months. At each review moment, it is decided if a gradual stepwise reduction in treatment is possible (step down), or alternatively if more or different treatment is necessary (step up). Palliative care can be particularly helpful after diagnosis or when there are changes in someone's state of health or daily functioning, but is not necessary in equal measure at each step of the disease process.[107] For people with dementia, while there is a gradual decline, there may be prolonged periods of months or even years where no extra support from palliative care services is needed. During these periods palliative care could be scaled back (step down), with regular check-in moments to monitor the situation. When a concrete health issue occurs, or when the person with dementia feels a need for increased palliative care, palliative care services could become involved in care once more (step up). The advantages of such a system are many. First, palliative care is provided to people from the moment they need it early in the disease trajectory, and at whichever point they need it after that. Second, palliative care services are not overburdened providing care to people who are not directly in need of it. Third, such a system is focused more on long-term care and outcomes than on acute problems, which better suits the needs of older people and people with dementia.

3. Recommendations for future research

The findings described in this dissertation not only lead to recommendations for policy and practice: they also point to several avenues of future research which could greatly contribute to our understanding of, and to improving, end-of-life care for older people and people with dementia. In this section, three concrete suggestions for future research will be discussed.

3.1 Studying communication and shared decision-making: The bigger picture

As was explained previously, communication and advance care planning are vital parts of high quality end-of-life care for people with dementia and older people in general. It was also shown in this dissertation that, at least in the countries studied, there is still room for improvement in this regard. The studies in this dissertation specifically measured advance care planning between the GP and their patient. Previous research has investigated which barriers and facilitators GPs perceive to advance care planning.[39,42] This information is invaluable in designing interventions to enable GPs to better and more frequently engage in advance care planning with their patients.[46]

However, the relationship between the GP and patient is not the only one relevant to advance care planning. Especially in the case of older people in long-term care facilities and people with dementia, there is a complicated care situation involving multiple people where responsibilities are not always clear. While we know quite a bit about the experiences and expectations of family carers and healthcare professionals when it comes to advance care planning,[35,108] it is still unknown how communication between the different parties involved is structured in practice. For example, does communication with family carers happen on a regular basis or only in response to certain events? How and by whom is it determined if a nursing home resident is capable of meaningful communication about their wishes for care or if communication should go via the family carer? Do the staff engage in regular advance care planning conversations with the patient, perhaps as part of an intake conversation, or do they wait for the resident to take the initiative? And are there differences in quality of life, satisfaction with care and quality of dying between residents of long-term care facilities that approach communication in different ways? These are issues that cannot be extrapolated from international research, but require in-depth focus on one healthcare system and the facilities within that system.

While we have already made suggestions for changes in policy and practice, more research would enable healthcare professionals and policy makers to make even more targeted plans. By disentangling exactly how, when and especially why the different actors communicate can we identify the specific issues that are detrimental to, or on the other hand facilitate, sharing of information and advance care planning. A methodology similar to the Dying Well with Dementia study (chapter 7), or the ongoing EU FP7 PACE study, would be well-suited for this.[109,110] In these studies, all residents of a nursing home who died in the last three months are identified by a key person at the nursing home. Then, their GP, the nurse and the family carer most involved in care are sent a questionnaire regarding care received the end of life. This method could be employed focussed on communication and advance care planning in particular. The downside of this method is that it would not capture the residents' views and experiences, for which prospective studies would of course be needed. However, to obtain an accurate picture of the current practice of communication and advance care planning in long-term care facilities, retrospective studies might be more appropriate as prospective studies could prime participants to engage in more communication than they otherwise would.

3.2 Costs of care: The interplay of structural and individual factors on insurer and out-of-pocket costs

One goal of public health research is to identify in which ways population health can be improved. If this can be done while simultaneously cutting costs, all the better. Unfortunately, the costs of healthcare at the end of life are still largely unknown. Most studies do not take a population-based approach, but focus on specific disease trajectories and not only on the end of life, whereas those that do look at the end of life focus on either insurer costs or specific healthcare programmes (e.g. a hospice programme).[111-114] Furthermore, most studies are undertaken in the USA, which has a very different healthcare system from European countries. While in this dissertation, we shed some light on which types of care contribute to out-of-pocket costs, and how some individual characteristics are related to this, there are still many questions left unanswered.

The first question is how out-of-pocket costs and insurer costs (to private companies or the government) for care in general and end-of-life care in particular relate to each other. Most studies investigate either one or the other; a cursory review of the literature turned up only one study investigating both.[112] There are two intuitive answers regarding the relation between out-of-pocket costs and insurer costs. The first is that particular aspects of healthcare, for example medication, that have low out-of-pocket costs must therefore have (relatively) high insurer costs and vice versa. After all, someone has to pay for the care provision. The second is that low out-of-pocket costs are related to low insurer costs and high out-of-pocket costs are linked to high insurer costs, because some types of care are just expensive and the burden is shared. Neither view is currently supported by evidence, except that for certain chronic illnesses, such as osteoarthritis, both out-of-pocket and insurer costs are high.[112] In order to make reliable recommendations for future policy, we must first be able to form a complete picture of the relation between out-of-pocket and insurer costs.

Second, studies should investigate how socio-economic status influences out-of-pocket costs. Healthcare is a universal right and should be equally accessible by all people.[114] However, previous studies have shown that there are many differences in the use of healthcare by people from different socio-economic statuses, as well as their health outcomes. For example, people from lower socio-economic status are less likely to seek healthcare,[116] may have less access to certain healthcare services (even with insurance),[117] longer waiting times for necessary surgery and are even more likely to die after adverse events such as a stroke than people from a higher socio-economic status.[118] As mentioned in chapter 1, high medical costs can be a reason for older people not to initiate or adhere to treatment, which is likely to impact people from lower socio-economic status more severely than those from higher socio-economic status.[119,120] So far, no studies exist that investigate care at the end of life from this angle, with studies on the costs of care at the end of life being focused mainly on the potential insurer cost savings of palliative care.[121] To ensure that high-quality end-of-life care is accessible to all people, studies should be done to determine if any differences in the (relative) costs of care exist for people from different socio-economic statuses.

Finally there is the role of structural factors, such as the type of healthcare system. It is easy enough to say that when hospital care is completely free, patients do not incur out-of-pocket costs for hospital care as was shown in chapter 5 in the case of e.g. Denmark. It is another matter entirely to know if the average costs of a system that promotes home care for older people are lower than those that invest more strongly in long-term care facilities. Additionally, in the study in chapter 5, we looked only at costs incurred for care that was not reimbursed. However, we did not look at the costs of insurance premiums. As health insurance covers different things in different countries, this should be taken into account in future research. Would primary care in a gatekeeper system such as that in the Netherlands, where a consultation with a GP is free, still be less expensive to the care receiver than primary care in Belgium, where a consultation costs 25 euros, when the higher insurance premiums in the Netherlands are taken into account? Research on the influence of structural factors on out-of-pocket costs is needed to answer this and similar questions.

3.3 "Early" palliative care for people with dementia: what works?

Palliative care can be appropriate throughout the disease trajectory, which in the case of people with dementia usually lasts several years. However, in chapters 4 and 6, we saw that palliative care services are often not involved in care until the last few weeks of life. The case for an earlier initiation of palliative care as part of an integrated healthcare system has already been made in this discussion; however, specifically for people with dementia, questions remain surrounding how to optimize the benefits of early palliative care.

Early palliative care has been shown to be beneficial for people with metastatic non-small-cell lung cancer in a randomised controlled trial in the USA.[122] For these newly diagnosed patients, the involvement of palliative care starting within 8 weeks of diagnosis alongside regular oncological care resulted in a higher quality of life, less depression, less aggressive end-of-life care, and even a longer survival time than patients in the control group who received only standard oncological care. Another study on early palliative care for patients with advanced cancer (of various types) found that early palliative care lead to a higher quality of life and higher satisfaction with care, although these patients were not followed until death.[123] While these results are promising, so far, no studies yet exist on the efficacy of early palliative care in other populations. The needs of people with dementia, especially in early stages of the disease, are very different from people diagnosed with terminal cancer. In addition, there is the matter of survival time. The median survival time in the study on metastatic non-small-cell lung cancer was 8.9 months for the control group and 11.6 months for the intervention group; in contrast, the median length of survival from diagnosis for people with dementia is between two and eight years, depending on age at time of diagnosis and type of dementia.[124-126] In what way can we provide early palliative care that is both appropriate to their needs and feasible to provide over such a long period of time?

Research could therefore first focus on assessing the palliative care needs of people with dementia and their family carers at different points in their disease trajectory. Next, an intervention could be developed that targets these specific needs at the appropriate times, to assess the efficacy of an early palliative care approach compared to the currently standard, ‘terminal’ palliative care. In this way, such a study also serves as a test of the step-up, step-down approach to palliative care mentioned on page 168, which may be particularly suited to people with dementia.

References Chapter 8

1. Earle CC, Ayanian JZ. Looking back from death: The value of retrospective studies of end-of-life care. Journal of Clinical Oncology. 2006;24(6):838-839.
2. Bach PB, Schrag D, Begg CD. Resurrecting treatment histories of dead patients: A study design that should be laid to rest. JAMA. 2004;292(22):2765-2770.
3. Chow E, Harth T, Hruby G, Finkelstein J, Wu J, Danjoux C. How accurate are physicians' clinical predictions of survival and the available prognostic tools in estimating survival times in terminally iII cancer patients? A systematic review. Clinical Oncology. 2001 Jun 30;13(3):209-18.
4. Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, Volicer L, Givens JL, Hamel MB. The clinical course of advanced dementia. New England Journal of Medicine. 2009 Oct 15;361(16):1529-38.
5. Coventry PA, Grande GE, Richards DA, Todd CJ. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. Age and ageing. 2005 May 1;34(3):218-27.
6. Ackroyd, S and Hughes, JA. Data collection in context. s.l. : Longman, 1981.
7. Neumann PJ, Araki SS, Gutterman EM. The use of proxy respondents in studies of older adults: lessons, challenges, and opportunities. Journal of the American Geriatrics Society. 2000 Dec 1;48(12):1646-54.
8. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information?. Social science & medicine. 2003 Jan 31;56(1):95-109.
9. Kutner JS, Bryant LL, Beaty BL, Fairclough DL. Symptom distress and quality-of-life assessment at the end of life: the role of proxy response. Journal of pain and symptom management. 2006 Oct 31;32(4):300-10.
10. Schacter DL. The seven sins of memory: Insights from psychology and cognitive neuroscience. American Psychologist. 1999;54(3):182-203.
11. Treadway M, McCloskey M, Gordon B, Cohen NJ. Landmark life events and the organization of memory: Evidence from functional retrograde amnesia. [book auth.] Christianson SA. The Handbook of Emotion and Memory: Research and Theory. New York : Lawrence Erlbaum Associates, Inc, 1992.
12. Schmier JK, Halpern MT. Patient recall and recall bias of health state and health status. Expert review of pharmacoeconomics & outcomes research. 2004 Apr 1;4(2):159-63.
13. Berney LR, Blane DB. Collecting retrospective data: accuracy of recall after 50 years judged against historical records. Social science & medicine. 1997 Nov 30;45(10):1519-25.
14. Penders YWH, Moreels S, Donker GA, Miccinesi G, Deliens L, Van den Block L. How Often Do General Practitioners Communicate about End-of-Life Topics with Community-dwelling Older People and their Family in Three European Countries? Palliative Medicine, 2016. EAPC2016: Abstracts. FC74.

15. Dungen P, Marwijk HW, Horst HE, Moll van Charante EP, MacNeil Vroomen J, Ven PM, Hout HP. The accuracy of family physicians' dementia diagnoses at different stages of dementia: a systematic review. International journal of geriatric psychiatry. 2012 Apr 1;27(4):342-54.
16. Börsch-Supan A, Brandt M, Hunkler C, Kneip T, Korbmacher J, Malter F, Schaan B, Stuck S, Zuber S. Data resource profile: the Survey of Health, Ageing and Retirement in Europe (SHARE). International journal of epidemiology. 2013 Jun 18:dyt088.
17. Houttekier D, Reyniers T, Deliens L, Van Den Noortgate N, Cohen J. Dying in hospital with dementia and pneumonia: a nationwide study using death certificate data. Gerontology. 2013 Oct 25;60(1):31-7.
18. Kripalani S, LeFevre F, Phillips CO, Williams MV, Basaviah P, Baker DW. Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care. Jama. 2007 Feb 28;297(8):831-41.
19. Reyniers, T. Hospital admissions at the end of life: Reasons, appropriateness and avoidability. Brussels : VUB University Press, 2015.
20. De Korte-Verhoef MC, Pasman HR, Schweitzer BP, Francke AL, Onwuteaka-Philipsen BD, Deliens L. General practitioners' perspectives on the avoidability of hospitalizations at the end of life: A mixed-method study. Palliative medicine. 2014 Jul 1;28(7):949-58.
21. Coleman EA, Berenson RA. Lost in transition: challenges and opportunities for improving the quality of transitional care. Annals of internal medicine. 2004 Oct 5;141(7):533-6.
22. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, Bechinger-English D, Bausewein C, Ferreira PL, Toscani F, Meñaca A. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Annals of Oncology. 2012 Feb 16:mdr602.
23. Reyniers T, Houttekier D, Cohen J, Pasman HR, Deliens L. What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses. Palliative medicine. 2014 Feb 17:0269216314522317.
24. Reyniers T, Deliens L, Pasman HR, Vander Stichele R, Sijnave B, Houttekier D, Cohen J. Appropriateness and avoidability of terminal hospital admissions: Results of a survey among family physicians. Palliative Medicine. 2016 Jul 12:0269216316659211.
25. Ko W. Dying with cancer: An international perspective. Brussels : VUBPress, 2015. pp. 55-74.
26. Ko W, Beccaro M, Miccinesi G, Van Casteren V, Donker GA, Onwuteaka-Philipsen B, Espí MT, Deliens L, Costantini M, Van den Block L, IMPACT E. Awareness of general practitioners concerning cancer patients' preferences for place of death: evidence from four European countries. European Journal of Cancer. 2013 May 31;49(8):1967-74.
27. Groot MM, Vernooij-Dassen MJ, Crul BJ, Grol RP. General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. Palliative Medicine. 2005 Mar 1;19(2):111-8.
28. Coleman EA, Parry C, Chalmers S, Min SJ. The care transitions intervention: results of a randomized controlled trial. Archives of internal medicine. 2006 Sep 25;166(17):1822-8.

29. Parry C, Coleman EA, Smith JD, Frank J, Kramer AM. The care transitions intervention: a patient-centered approach to ensuring effective transfers between sites of geriatric care. Home health care services quarterly. 2003 Jun 1;22(3):1-7.
30. Ditewig JB, Blok H, Havers J, van Veenendaal H. Effectiveness of self-management interventions on mortality, hospitality readmissions, chronic heart failure hospitalization rate and quality of life in patients with chronic heart failure: A systematic review. Patient Education and Counseling. 2010;78:297-315.
31. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Education and Counseling. 2002;48:177–87.
32. Loeb M, Carusone SC, Goeree R, Walter SD, Brazil K, Krueger P, Simor A, Moss L, Marrie T. Effect of a clinical pathway to reduce hospitalizations in nursing home residents with pneumonia: a randomized controlled trial. Jama. 2006 Jun 7;295(21):2503-10.
33. Ouslander JG, Lamb G, Tappen R, Herndon L, Diaz S, Roos BA, Grabowski DC, Bonner A. Interventions to reduce hospitalizations from nursing homes: evaluation of the INTERACT II collaborative quality improvement project. Journal of the American Geriatrics Society. 2011 Apr 1;59(4):745-53.
34. Mitchell GK. How well do general practitioners deliver palliative care? A systematic review. Palliative Medicine. 2002 Sep 1;16(6):457-64.
35. van Soest-Poortvliet MC, van der Steen JT, Gutschow G, Deliens L, Onwuteaka-Philipsen BD, de Vet HC, Hertogh CM. Advance care planning in nursing home patients with dementia: a qualitative interview study among family and professional caregivers. Journal of the American Medical Directors Association. 2015 Nov 1;16(11):979-89.
36. Carbonelle S, Declerq A, Rigaux N, Sevenants A. Vroegtijdige zorgplanning voor personen met dementie in de praktijk [Advance care planning for people with dementia in practice]. Koning Boudewijnstichting. 2014.
37. Van Mechelen W, Piers R, Van den Eynde J, De Lepeleire J. Richtlijn Vroegtijdige Zorgplanning. [Guideline Advance Care Planning] Vilvoorde, Federatie Palliatieve Zorg Vlaanderen vzw. Richtlijnen Palliatieve Zorg. 5-2015. Available from www.pallialine.be.
38. Inglehart RF. Changing values among western publics from 1970 to 2006. West European Politics. 2008 Jan 1;31(1-2):130-46.
39. De Vleminck A, Houttekier D, Pardon K, Deschepper R, Van Audenhove C, Vander Stichele R, Deliens L. Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review. Scandinavian journal of primary health care. 2013 Dec 1;31(4):215-26.
40. WHO definition of palliative care. World Health Organization. Available from www.who.int/cancer/palliative/definition/ Accessed on 16/03/2016.
41. Radbruch L, de Lima L, Lohmann D, Gwyther E, Payne S. The Prague Charter: urging governments to relieve suffering and ensure the right to palliative care. Palliative medicine. 2013;27(2):101-2.

42. De Vleminck A, Pardon K, Beernaert K, Deschepper R, Houttekier D, Van Audenhove C, Deliens L, Vander Stichele R. Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences. PLoS One. 2014 Jan 21;9(1):e84905.
43. van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RT. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. Palliative medicine. 2013 Jul 4:0269216313493685.
44. Gott M, Gardiner C, Small N, Payne S, Seamark D, Barnes S, Halpin D, Ruse C. Barriers to advance care planning in chronic obstructive pulmonary disease. Palliative Medicine. 2009 Oct 1;23(7):642-8.
45. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R,Tattersall MHN. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: Patient/caregiver preferences for the content, style, and timing of information. Journal of Pain and Symptom Management. 2007;34(1):81-93.
46. Hancock K, Clayton JM, Parker SM, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. Palliative Medicine. 2007 Sep 1;21(6):507-17.
47. De Vleminck A, Houttekier D, Deliens L, Vander Stichele R, Pardon K. Development of a complex intervention to support the initiation of advance care planning by general practitioners in patients at risk of deteriorating or dying: a phase 0-1 study. BMC palliative care. 2016 Feb 11;15(1):1.
48. Horne G, Payne S. Removing the boundaries: palliative care for patients with heart failure. Palliative medicine. 2004 Jun 1;18(4):291-6.
49. Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. Bmj. 2002 Oct 26;325(7370):929.
50. Gessert CE, Forbes S, Bern-Klug M. Planning end-of-life care for patients with dementia: roles of families and health professionals. OMEGA-Journal of Death and Dying. 2001 Jun 1;42(4):273-91.
51. Higginson IJ, Koffman J, Hopkins P, Prentice W, Burman R, Leonard S, Rumble C, Noble J, Dampier O, Bernal W, Hall S, Morgen M, Shipman C. Development and evaluation of the feasibility and effects on staff, patients, and families of a new tool, the Psychosocial Assessment and Communication Evaluation (PACE), to improve communication and palliative care in intensive care and during clinical uncertainty. BMC Medicine. 2013;11:213.
52. Law concerning palliative care in Belgium 2002 (in Dutch) L. Wet betreffende palliatieve zorg, 2002-06-14/46. 2002.

53. Koninklijk besluit tot wijziging van het koninklijk besluit van 15 juli 1997 waarbij sommige bepalingen van de wet op de ziekenhuizen, gecoördineerd op 7 augustus 1987, toepasselijk worden verklaard op de functie van palliatieve zorg. [Royal decree concerning the palliative care function in hospitals]. February, 19th 2002.
54. Koninklijk Besluit Tot Wijziging van Het Koninklijk Besluit van 2 December 1982 Houdende Vaststelling van de Normen Voor de Bijzondere Erkenning van Rust- En Verzorgingstehuizen. [Royal decree concerning the norm for acknowledging care homes]. July, 15th 1997.
55. Koninklijk Besluit 16 Februari 2009 Tot Wijziging van Het Koninklijk Besluit van 23 Maart 1982 Tot Vaststelling van Het Persoonlijk Aandeel van de Rechthebbenden of van de Tegemoetkoming van de Verzekering Voor Geneeskundige Verzorging in Het Honorarium Voor Bepaalde Verstrekkingen. [Royal decree concerning personal share for palliative care]. February, 16th 2009.
56. Ministerieel Besluit Tot Vaststelling van Het Bedrag En de Voorwaarden Voor de Toekenning van de Tegemoetkoming, Bedoeld in Artikel 37, § 12, van de Wet Betreffende de Verplichte Verzekering Voor Geneeskundige Verzorging En Uitkeringen, Gecoördineerd Op 14 Juli 1994, in de Rust- En Verzorgingstehuizen En in de Rustoorden Voor Bejaarden. [Ministerial decree concerning amount and requirements assignment reimbursement]. November, 3th 2003.
57. Federale evaluatiecel palliatieve zorg [Federal evaluation committee palliative. Evaluatierapport palliatieve zorg [Evaluation report palliative care]. Brussels, Belgium : s.n., 2014.
58. McIlfatrick S. Assessing palliative care needs: views of patients, informal carers and healthcare professionals. Journal of advanced nursing. 2007 Jan 1;57(1):77-86.
59. Ahmed N, Bestall JE, Ahmedzai SH, Payne SA, Clark D, Noble B. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. Palliative medicine. 2004 Sep 1;18(6):525-42.
60. Desmedt M. Identificatie van de palliatieve patient & toekenning van een statuut dat verband houdt met de ernst van de noden: het gebruik van een nieuw instrument "PICT" [Identification of palliative patients & assigning a status in relation tot heir needs: using the new instrument "PICT"]. Universitaire Ziekenhuizen St-Luc, 2016.
61. Beel, V. Sneller starten met palliatieve zorg [Starting sooner with palliative care]. De Standaard. 07 June 2016.
62. Pivodic L, Pardon K, Van den Block L, Van Casteren V, Miccinesi G, Donker GA, Alonso TV, Alonso JL, Aprile PL, Onwuteaka-Philipsen BD, Deliens L. Palliative care service use in four European countries: a cross-national retrospective study via representative networks of general practitioners. PLoS One. 2013 Dec 30;8(12):e84440.
63. Currow DC, Abernethy AP, Fazekas BS. Specialist palliative care needs of whole populations: a feasibility study using a novel approach. Palliative Medicine. 2004 Apr 1;18(3):239-47.
64. Houttekier D, Cohen J, Surkyn J, Deliens L. Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. BMC public health. 2011 Apr 13;11(1):1.

65. Gomes B, Higginson IJ. Where people die (1974—2030): past trends, future projections and implications for care. Palliative Medicine. 2008 Jan 1;22(1):33-41.
66. Organisation for Economic Co-Operation and Development. Long-term Care for Older People. Paris : OECD, 2005.
67. Comas-Herrera A, King D, Malley J, Pickard L, Wittenberg R. The Long-Term Care System for the Elderly in England. s.l. : ENEPRI Research Report No. 74, 2010.
68. Daneshkohan A, Karami M, Najafi F, Matin BK. Household catastrophic health expenditure. Iranian journal of public health. 2011 Jan 1;40(1):94.
69. Guijarro R, San Román CM, Gomez-Huelgas R, Villalobos A, Martín M, Guil M, Martínez-González MÁ, Toledo JB. Impact of dementia on hospitalization. Neuroepidemiology. 2010 Jun 15;35(2):101-8.
70. Van den Block L, Pivodic L, Pardon K, Donker G, Miccinesi G, Moreels S, Alonso TV, Deliens L, Onwuteaka-Philipsen B. Transitions between health care settings in the final three months of life in four EU countries. The European Journal of Public Health. 2015 Mar 30:ckv039.
71. Evans N, Costantini M, Pasman HR, Van den Block L, Donker GA, Miccinesi G, Bertolissi S, Gil M, Boffin N, Zurriage O, Deliens L, Onwuteaka-Philipsen B, on behalf of EURO IMPACT. End-of-life communication: A retrospective survey of representative general practitioner networks in four countries. Journal of Pain and Symptom Management 2014; 47(3), 604-619.e3.
72. Bayles KA. Communication in dementia. The aging brain: Communication in the elderly. 1985:110-34.
73. Karel MJ, Moye J, Bank A, Azar AR. Three methods of assessing values for advance care planning comparing persons with and without dementia. Journal of Aging and Health. 2007 Feb 1;19(1):123-51.
74. Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, Howel D, Exley C. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. Age and ageing. 2011 Dec 8:afr148.
75. Hilgeman MM, Allen RS, Snow AL, Durkin DW, DeCoster J, Burgio L. Preserving Identity and Planning for Advance Care (PIPAC): Preliminary outcomes from a patient-centered intervention for individuals with mild dementia. Aging & mental health. 2014 May 19;18(4):411-24.
76. Livingston G, Lewis-Holmes E, Pitfield C, Manela M, Chan D, Constant E, Jacobs H, Wills G, Carson N, Morris J. Improving the end-of-life for people with dementia living in a care home: an intervention study. International Psychogeriatrics 2013;25(11):1849-1858.
77. Sampson EL, Jones L, Thuné-Boyle IC, Kukkastenvehmas R, King M, Leurent B, Tookman A, Blanchard MR. Palliative assessment and advance care planning in severe dementia: an exploratory randomized controlled trial of a complex intervention. Palliative Medicine. 2011 Apr 1;25(3):197-209.

78. Bastiaens H, Van Royen P, Pavlic DR, Raposo V, Baker R. Older people's preferences for involvement in their own care: a qualitative study in primary health care in 11 European countries. Patient education and counseling. 2007 Sep 30;68(1):33-42.
79. De Vleminck A, Pardon K, Roelands M, Houttekier D, Van den Block L, Vander Stichele R, Deliens L. Information preferences of the general population when faced with life-limiting illness. The European Journal of Public Health. 2015 Jun 1;25(3):532-8.
80. Annunziata MA. Ethics of Relationship. Annals of the New York Academy of Sciences. 1997 Feb 1;809(1):400-410.
81. Mystakidou K, Liossi C, Vlachos L, Papadimitriou J. Disclosure of diagnostic information to cancer patients in Greece. Palliative medicine. 1996 Jul 1;10(3):195-200.
82. Constantini A, Parisi AM, Mazzotta MP. La paziente con cancro mammario: la volutazione delle problematiche psicologiche allo stato attuale dell'assistenza ospedaliera [The patient with breast cancer: evaluation of psychological problems at the present status of hospital care]. Ann Ist Forlanini. 1993;13:70-77.
83. Robinson L, Dickinson C, Bamford C, Clark A, Hughes J, Exley C. A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, '*a good idea in theory but…'* Palliative Medicine, 2013;27(5):401-408.
84. Gjerberg E, Lillemoen L, Førde R, Pedersen R. End-of-life care communications and shared decision-making in Norwegian nursing homes-experiences and perspectives of patients and relatives. BMC geriatrics. 2015 Aug 19;15(1):103.
85. Wiles JL, Leibing A, Guberman N, Reeve J, Allen RE. The meaning of "ageing in place" to older people. The gerontologist. 2011 Oct 7:gnr098.
86. Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older people's views about home as a place of care at the end of life. Palliative medicine. 2004 Jul 1;18(5):460-7.
87. Aldridge MD, Kelley AS. The myth regarding the high cost of end-of-life care. American journal of public health. 2015 Dec;105(12):2411-5.
88. Pinquart M, Sörensen S. Correlates of physical health of informal caregivers: a meta-analysis. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences. 2007 Mar 1;62(2):P126-37.
89. Vitaliano PP, Strachan E, Dansie E, Goldberg J, Buchwald D. Does caregiving cause psychological distress? The case for familial and genetic vulnerabilities in female twins. Annals of Behavioral Medicine. 2014 Apr 1;47(2):198-207.
90. Dumont S, Turgeon J, Allard P, Gagnon P, Charbonneau C, Vézina L. Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. Journal of palliative medicine. 2006 Aug 1;9(4):912-21.
91. Borsje P, Hems MA, Lucassen PL, Bor H, Koopmans RR, Pot AM. Psychological distress in informal caregivers of patients with dementia in primary care: course and determinants. Family practice. 2016 Mar 11:cmw009.

92. Rosano A, Loha CA, Falvo R, Van Der Zee J, Ricciardi W, Guasticchi G, De Belvis AG. The relationship between avoidable hospitalization and accessibility to primary care: a systematic review. The European Journal of Public Health. 2013 Jun 1;23(3):356-60.
93. Goodwin N, Sonola L, Thiel V, Kodner DL. Co-ordinated care for people with complex chronic conditions: key lesson sand markers for success. London: The King’s Fund; 2013. Available from www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/co-ordinated-care-for-people-with-complex-chronic-conditions-kingsfund-oct13.pdf Accessed on 18/03/2016.
94. Smith SM, Soubhi H, Fortin M, Hudon C, O’Dowd T. Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. BMJ. 2012;345:e5205.
95. Peron EP, Gray SL, Hanlon JT. Medication use and functional status decline in older adults: a narrative review. Am J Geriatr Pharmacother. 2011 Dec;9(6):378–91.
96. Centeno C, Lynch T, Donea O, Rocafort J, Clark D. EAPC Atlas of Palliative Care in Europe 2013. Full Edition. *European Association for Palliative Care, 2013.*
97. Omzendbrief Aan de Rustoorden Voor Bejaarden, de Rust- En Verzorgingstehuizen en de Centra Voor Dagverzorging. OMZ. ROB/RVT 2012/6. [Letter to care homes concerning categories - reimbursement palliative function]. December 19th, 2012.
98. Leidraad implementatie van palliatieve zorg in woonzorgcentra. [Guideline concerning implementation of palliative care in care homes]. Palliative Network Mechelen. Available from www.palliatief-netwerk-mechelen.be/files/leidraard-voor-implementatie-van-palliatieve-zorg-in-wzc.pdf Accessed on 18/07/2016.
99. Poppe M, Burleigh S, Banerjee S. Qualitative Evaluation of Advanced Care Planning in Early Dementia (ACP-ED). Plos One. 2013; doi: 10.1371/journal.pone.0060412
100. Bamford C, Lamont S, Eccles M, et al. Disclosing a diagnosis of dementia: a systematic review. Int J Geriatr Psychiatry. 2004; 19(2): 151–169.
101. Bollig G, Gjengedal E, Rosland JH. They know!—Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. Palliative medicine. 2016 May 1;30(5):456-70.
102. Zaleta AK, Carpenter BD, Porensky EK, et al. Agreement on diagnosis among patients, companions, and professionals after a dementia evaluation. Alzheimer Dis Assoc Disord. 2012; 26: 232–237.
103. Pucci E, Belardinelli N, Borsetti G, et al. Relatives’ attitudes towards informing patients about the diagnosis of Alzheimer’s disease. J Med Ethics. 2003; 29(1): 51–54.
104. Vergeet dementia, onthou mens. Available from www.onthoumens.be. Accessed on 21/07/2016.
105. Van Gorp B, Vercruysse T. Framing en reframing: anders communiceren over dementie [Framing and reframing: communicating differently about dementia]. Koning Boudewijnstichting, 2016. Available from www.kbs-frb.be
106. Expert panel report 3: guidelines for the diagnosis and management of asthma--full report 2007. National Heart, Lung, and Blood Institute. 2007.

107. Palliatieve zorg vanaf diagnose en daarna [Palliative care from diagnosis onwards]. [book auth.] Joachim Cohen, et al., et al. Palliatieve zorg: Meer dan stervensbegeleiding. [Palliative care: More than terminal care] Tielt: Uitgeverij Lannoo nv, 2014.
108. Stone L, Kinley J, Hockley J. Advance care planning in care homes: the experience of staff, residents, and family members. International journal of palliative nursing. 2013 Nov 1;19(11).
109. Van den Block L, Smets T, van Dop N, Adang E, Andreasen P, Moore DC, Engels Y, Finne-Soveri H, Froggatt K, Gambassi G, Kijowska V. Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a Cross-sectional Study of Deceased Residents in 6 EU Countries. Journal of the American Medical Directors Association. 2016 Jun 1;17(6):566-e1.
110. Vandervoort A, Van den Block L, van der Steen JT, Volicer L, Vander Stichele R, Houttekier D, Deliens L. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying. Journal of the American Medical Directors Association. 2013 Jul 31;14(7):485-92.
111. Longo CJ, Bereza BG. A comparative analysis of monthly out-of-pocket costs for patients with breast cancer as compared with other common cancers in Ontario, Canada. Current Oncology. 2011;18(1):1-8.
112. Kotlarz H, Gunnarsson CL, Fang H, Rizzo JA. Insurer and out-of-pocket costs of osteoarthritis in the US: Evidence from national survey data. Arthritis & Rheumatism. 2009 Dec 1;60(12):3546-53.
113. Harris SB, Leiter LA, Yale JF, Chiasson JL, Kleinstiver P, Sauriol L. Out-of-pocket costs of managing hyperglycemia and hypoglycemia in patients with type 1 diabetes and insulin-treated type 2 diabetes. Canadian Journal of Diabetes. 2007 Dec 31;31(1):25-33.
114. Guest JF, Ruiz FJ, Greener MJ, Trotman IF. Palliative care treatment patterns and associated costs of healthcare resource use for specific advanced cancer patients in the UK. European Journal of Cancer Care. 2006 Mar 1;15(1):65-73.
115. UN General Assembly. Universal declaration of human rights. 1948.
116. Adamson J, Ben-Shlomo Y, Chaturvedi N, Donovan J. Ethnicity, socio-economic position and gender—do they affect reported health—care seeking behaviour? Social science & medicine. 2003 Sep 30;57(5):895-904.
117. Allin S, Masseria C, Mossialos E. Measuring socioeconomic differences in use of health care services by wealth versus by income. American Journal of Public Health. 2009 Oct;99(10):1849-55.
118. Kapral MK, Wang H, Mamdani M, Tu JV. Effect of socioeconomic status on treatment and mortality after stroke. Stroke. 2002 Jan 1;33(1):268-75.
119. Soumerai SB, Pierre-Jacques M, Zhang F, Ross-Degnan D, Adams AS, Gurwitz J, Adler G, Safran DG. Cost-related medication nonadherence among elderly and disabled medicare beneficiaries: a national survey 1 year before the medicare drug benefit. Archives of Internal Medicine. 2006 Sep 25;166(17):1829-35.

120. Chao LW, Pagán JA, Soldo BJ. End-of-life medical treatment choices: do survival chances and out-of-pocket costs matter?. Medical Decision Making. 2008 Apr 25.
121. Brumley RD, Enguidanos S, Cherin DA. Effectiveness of a home-based palliative care program for end-of-life. Journal of palliative medicine. 2003 Oct 1;6(5):715-24.
122. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA. Early palliative care for patients with metastatic non–small-cell lung cancer. New England Journal of Medicine. 2010 Aug 19;363(8):733-42.
123. Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leighl N, Oza A, Moore M, Rydall A, Rodin G, Tannock I, Donner A. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. The Lancet. 2014 May 23;383(9930):1721-30.
124. Brookmeyer R, Corrada MM, Curriero FC, Kawas C. Survival following a diagnosis of Alzheimer disease. Archives of neurology. 2002 Nov 1;59(11):1764-7.
125. Rait G, Walters K, Bottomley C, Petersen I, Iliffe S, Nazareth I. Survival of people with clinical diagnosis of dementia in primary care: cohort study. Bmj. 2010 Aug 5;341:c3584.
126. Wolfson C, Wolfson DB, Asgharian M, M'Lan CE, Østbye T, Rockwood K, Hogan DF. A reevaluation of the duration of survival after the onset of dementia. New England Journal of Medicine. 2001 Apr 12;344(15):1111-6.

SUMMARY

Introduction

The ageing population of Europe

The world's population is ageing: people aged 65 and over made up 15 per cent of the population of countries in the Organisation for Economic Co-operation and Development (OECD) in 2012; by 2050, this is expected to increase to 25 per cent. While nowadays we may not instinctively see 65 as old, both the OECD and the World Health Organisation (WHO) use this age as the cut-off point between younger adults and the old, specifically because of the potential increase in health problems faced by those over that age. Unfortunately, not all older people are able to maintain a good degree of independence, social engagement and continued physical health until a great age. The large, vulnerable group of older people whose health declines and whose independence decreases with age, and those who will suffer cognitive decline and dementia, will require more and more care as time goes on.

An ageing population poses considerable challenges for healthcare systems and clinical practice. First, older people suffer from more illnesses than younger people, often concurrently, and illnesses that are usually not problematic in younger people can prove fatal in older people, such as shingles and flu. Second, there are specific forms of care that are needed mostly or only by older people, such as care in nursing homes and dementia care. In some countries, most people with severe dementia end up living and eventually die in long-term care facilities. Care in these facilities is often expensive, as they are provided round-the-clock, usually involving multiple caregivers. Finally, there is the reality that older people are more likely to die than younger adults, and most healthcare is used in the last year before death. People in the last year of life use a high amount of critical care, experience many hospital admissions and often stay in a long-term care facility, especially older people, those with chronic illnesses and those with multimorbidities. These aspects of ageing make providing end-of-life care for older people a major public health challenge.

End-of-life care for older people

Much is still unknown about the care older people receive at the end of life. While we know they have less access to specialized palliative care, i.e. care delivered with the aim to address the needs of dying people and their next of kin from a holistic point of view, we do not know which groups are at a particular disadvantage. Community-dwelling older people, older people with cancer, older people with dementia and older people living in a long-term care facility are unlikely to receive the same care merely based on their age, but may experience advantages or disadvantages based on their specific situations. Furthermore, we do not know how this has developed over time. With increased attention to the applicability of palliative care to all people suffering from a life-limiting illness, not just terminal cancer patients, it is possible that palliative care services have become more accessible to older people over the past few years, or to specific groups of older people. In the next sections, three specific factors will be highlighted that are of concern when attempting to ensure access to high-quality end-of-life care and palliative care for all older people.

Care settings

Circumstances such as the need for more skilled care and the burden on family carers sometimes make it necessary for older people to move to a long-term care facility. In Belgium in 2013, 11 per cent of people aged 75 and over and 26 per cent of people aged 85 and over lived in a long-term care facility such as a nursing home or a care home. As such, the home setting and long term care facilities are the two most important care settings for older people at the end of life. In the home setting in many countries, including Belgium, care is mainly provided by general practitioners (GPs). When older people move to a long-term care facility, the GP may or may not remain involved in care. Professional caregivers beyond the GP are involved and care is provided to residents round the clock, seven days a week. In some countries, such as the Netherlands, nursing homes also have an in-house specialist physician in chronic care and rehabilitation who provides care for the residents instead of a GP.

Because of the different amounts of care available, as well as population differences and differences in care providers, different decisions may be made by, with or for older people living at home and those living in a long-term care facility, for example on whether a transfer between care settings is needed at the end of life. Communication between older people and their GPs may differ between the two settings by virtue of population differences. Whether older people living at home and older people living in a long-term care facility have the same access to palliative care is also still unknown. A population-based overview of the end-of-life care of older people at home and in long-term care facilities is needed to identify the specific strengths and weaknesses of both settings.

Communication and advance care planning

One of the core components of palliative care for older people is advance care planning. Advance care planning is a process of communication between patients, their families or representatives and professional caregivers about the goals and desired direction of care. Through advance care planning, people are encouraged not only to think about their own wishes and values regarding the care they might receive in the final phase of life, but also to share these thoughts and wishes with others. By documenting their wishes and/or appointing a surrogate decision-maker, people can extend their autonomy and play an active part in deciding on their end-of-life care, even if they are unable to express themselves in the moment.

While advance care planning is important to consider for everyone, including those who are not currently experiencing a life-limiting illness, it is especially relevant for older people. The WHO recommends advance care planning as an important part of palliative care for older people, and older people themselves also indicate that they find advance care planning important. However, it is unknown how often advance care planning occurs with or in relation to older people. A population-based overview of advance care planning for older people, and particularly how this has developed over the past few years as more attention is paid to the importance of proactive communication between patient and healthcare professionals, is necessary in order to make informed decisions on how to continue with promoting this necessary part of end-of-life care.

Costs of care

While the costs of an ageing population to a healthcare system are often highlighted, what is less clear is the costs of care that patients themselves shoulder. Older people in particular are vulnerable to negative effects of high out-of-pocket costs, and sometimes even cite high costs as a reason not to initiate or adhere to treatment or care, potentially decreasing quality of life in the final stage of life. The financial burden of care can also weigh heavily on the shoulders of family carers: financial stress and a low income level are linked to a higher perceived burden and a more frequent exhibition of depressive symptoms amongst informal carers. Since most older people do not want to be a burden on their family, this may further dissuade them from engaging useful but expensive healthcare. Unfortunately, there is a significant shortage of research on the costs of end-of-life care for care receivers and their families. Population-based research on out-of-pocket costs for healthcare would aid in the development of adequate healthcare policies that take into account the financial burden on care receivers by establishing which types of care are particularly burdensome for patients financially and identifying those groups who are at particular risk of having high out-of-pocket costs.

End-of-life care for people with dementia

Dementia, of which Alzheimer’s disease is the most common and most well-known form, is a particular healthcare challenge for older people. Dementia is a syndrome due to a chronic or progressive disease of the brain in which there is disturbance of multiple higher cognitive functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement, commonly accompanied by deterioration in emotional control and social behaviour.

Currently, 47.5 million people worldwide have a form of dementia, with 7.7 million new cases each year. The combination of physical and psychological symptoms means that people with dementia, especially those who progress to the advanced stages of the disease, require a lot of complex care in the last phase of life. While palliative care is appropriate for all people with a life-limiting or terminal illness, to provide high-quality end-of-life care for people with dementia requires attention to what differentiates dementia from e.g. cancer. Also, while palliative care professionals increasingly recognize dementia as a disease indicative of a palliative care need, the views of other healthcare professionals and the general public may still differ. As it is often the GP and family who may need to advocate for an initiate palliative care, their views on dementia are perhaps more important than those of palliative care specialists. However, currently it is still unknown what the prevalence of specialized palliative care is for this group. This information is a necessary first step to further investigate the barriers and facilitators for palliative care for people with dementia.

Further recommendations from the European Association for Palliative Care (EAPC) include the prioritizing of explicit global care goals, proactive advance care planning starting at diagnosis and including those with mild dementia, and the avoidance of overly aggressive, burdensome or futile treatment, including hospitalizations (when appropriate). The epidemiology of these types of end-of-life care practices for people with dementia is currently unknown. As of yet, we do not know what care and treatment goals are recognized for people with dementia at the end of life. Neither do we know how often GPs communicate with their patients with dementia about topics regarding end-of-life care or how often they are aware of their patients' preferences. And while studies have been done regarding avoidable hospitalizations at the end of life, these do not focus specifically on people with dementia. Targeted research is needed to provide an overview of these aspects of end-of-life care for people with dementia.

Family involvement and communication

One specific issue with regards to the care for people with dementia is the role of family involvement. The inability of people in advanced stages of dementia to communicate consistently about their wishes for care poses a challenge for healthcare professionals and next of kin alike. In order for family carers to make appropriate decisions regarding care and treatment it is necessary for them to be aware of their relative's wishes and their current state of health. The role of the family carer or proxy decision-maker thus depends on receiving accurate information, either through advance care planning or through communication with professional carers. When it comes to dementia, GPs are often hesitant to disclose the diagnosis, and even when they do the patient and their family sometimes do not understand due to euphemisms used or because they resist the stigma attached to the diagnosis. The extent to which family carers can be involved in the decision-making process of people with dementia is therefore limited by the accuracy of the information they have received, or have retained. The importance of anticipating and fulfilling the information needs of family carers, as also recommended by the EAPC, is further highlighted by the fact that their understanding of dementia as a terminal illness predicts the patient's comfort at death. While communication between GPs, people with dementia and family carers has been studied, it is unknown to what extent family carers are indeed aware that their next of kin has dementia, and thus what proportion of family carers can or cannot make informed decisions about care.

Research aims

As the introduction has highlighted, there are still important gaps in our knowledge of end-of-life care for older people and people with dementia. Specifically, knowledge is still lacking on the differences in end-of-life care for older people who live in different settings, how advance care planning and palliative care service use for older people has developed over the years, and how different types of healthcare contribute to the costs of care for older patients in the last year of life. For people with dementia, it is unknown what their circumstances at the end of life are with respect to transitions between care settings, availability of palliative care, and treatment goals. Research is also needed on communication between GPs, family carers and people with dementia surrounding topics of end-of-life care. Finally, it is still unknown how these aspects of care compare in an international context. This information is necessary to be able to optimize end-of-life care for older people.

Therefore, the research aims of this dissertation are two-fold:

Research aim 1: To describe end-of-life care for older people in Belgium and other European countries.

To fulfil this aim, we focus on the following specific research questions:

- What are the circumstances of end-of-life care for older people in the home setting and in residential homes in the Netherlands?
- Are there trends in the frequency of use of palliative care services by older people in Belgium between 2005 and 2014?
- Are there trends in the rate of occurrence of advance care planning for older people in Belgium and the Netherlands between 2009 and 2014?
- What are the out-of-pocket costs associated with care in the last year of life of older people in thirteen European countries, and which patient and care characteristics are associated with these costs?

Research aim 2: To describe end-of-life care for people with dementia in Belgium and other European countries.

To fulfil this aim, we focus on the following specific research questions:

- What are the circumstances of end-of-life care for people with dementia in Belgium, Italy and Spain?
- To what extent are family carers aware that their deceased next of kin living in a nursing home had dementia in Belgium?

Methods

To address the research aims of this dissertation, quantitative analyses were performed using three different datasets. Four chapters use population-based retrospective survey data from epidemiological surveillance networks of general practitioners (GP Sentinel networks) from one or more country. One chapter uses data from next of kin of a number of respondents who died during a long-term longitudinal study in 13 countries (Study of Health, Ageing and Retirement in Europe). The final chapter uses retrospective survey data from the nurse, general practitioner and next of kin of a representative sample of deceased Flemish (Dutch-speaking Belgian) nursing home residents with dementia (Dying Well with Dementia).

GP Sentinel networks

In a number of countries, general practitioner (GP) sentinel networks exist which continuously monitor one or more indicators of health problems among their patients. This information can be used to monitor the health of the entire population. Using mainly these existing networks, the SENTIMELC study (first started in 2004 in Belgium and 2005 in the Netherlands) and later the EURO SENTIMELC study (including Italy and Spain in 2009 and 2010) aimed to provide a public health perspective on end-of-life care and circumstances of dying in several European countries. In Belgium, the Netherlands and Spain, existing GP Sentinel networks were used for data collection. In Italy, a GP network representative for the country and performing registration only on end-of-life care was built for this study. The networks were selected to form a representative sample in terms of age, gender and geographical distribution and to cover the whole area included in the network. In this dissertation, data from 2005 to 2014 is used.

For the SENTIMELC and EURO SENTIMELC studies, GPs registered all deaths of patients of their practice within one week of death via a standardized registration form. GPs received instructions at the beginning of each calendar year as to the inclusion criteria and how some questions should be completed. In all networks, participation by GPs is voluntary, with GPs in Italy receiving some financial compensation for their participation. The turnover of GPs from year to year is low, and only those GPs who register data at least 26 weeks per year (that is, those who are regular participants) are included for data analyses.

Study of Health, Ageing and Retirement in Europe

The Study of Health, Ageing and Retirement in Europe (SHARE) is an ongoing longitudinal study following several cohorts of people aged 50 and over in an ever-growing number of European countries. Gathering data from more than 60,000 people across 20 European countries, it is one of the largest longitudinal studies on population ageing.

The SHARE baseline study was undertaken in 2004 in eleven countries: Denmark, Sweden, Austria, France, Germany, Switzerland, Belgium, the Netherlands, Spain, Italy and Greece. Data is collected in waves, with more countries joining at each wave. The aim was to interview a random sample of 1,500 households including at least one person aged 50 or over in each country. In this dissertation, data from these eleven countries plus the Czech Republic and Poland was used from data collection between 2005 and 2012. Data collection took place via computer assisted interviews by professional interviewers. These interviews contain a number of questions about socioeconomic status, financial situation, work history, but also functional status and medical care received.

Following up on the respondents who participated in the first wave, some will inevitably have died before the next wave of data collection. When a respondent was confirmed to be deceased, interviewers attempted to locate next of kin who could be asked to complete a so-called ‘end-of-life interview’ about the deceased. The data from this end-of-life interview – that is, data collected from proxy respondents of the subset of the SHARE sample population who died during data collection - is used in this dissertation. This includes decedents from waves 2, 3 and 4 (2005-2012).

Dying Well with Dementia

The Dying Well with Dementia study was set up to provide an overview of the circumstances surrounding the end of life of people with dementia living in nursing homes, from the perspective of multiple respondents. This retrospective cross-sectional study was undertaken in Flanders, the Dutch-speaking part of Belgium. Data collection took place between May and October 2013.

A representative sample of nursing homes was selected for inclusion in the study, stratified by region, type and size. During a visit by the researcher to the nursing home, one contact person per nursing home identified all residents with dementia who died over the past three months. To be included in the study, the nursing home residents had to meet the following criteria used by the Belgian health insurance system: either the person had category C dementia (experiences disorientation in time and space almost daily), or was completely care dependent or in need of help for bathing, dressing, eating, continence, toileting and transferring in addition to showing signs of disorientation in time and space. For those who met these criteria, the contact person also identified their general practitioner, the nurse most involved in their care and the relative most involved in their care. A structured questionnaire was sent to these people about the last months of the deceased's life. In addition, the nursing home administrator completed a questionnaire about the deceased with the aid of the resident's files. To ensure the anonymity of all respondents, questionnaires were sent by the contact person of the nursing home and not by the researcher.

Main findings

End-of-life care for older people in Belgium and other European countries

In chapters 2 through 5, the results of four studies relating to end-of-life care for older people were reported. Chapter 2 showed that in the Netherlands, older people living at home are at a higher risk of being transferred between care settings at the end of life, with 54 per cent of older people living at home being transferred at least once in the last three months of life compared to 31 per cent of older people living in a residential home. Most of these transfers were hospitalisations (47 per cent of older people living at home and 28 per cent of older people living in a residential home). Older people living in a residential home had GPs who more often reported giving palliative care to their patients themselves, and received palliative care from specialized palliative care initiatives in equal measure as those living at home. However, older people living at home received specialized palliative care from a number of initiatives that were not used by older people living in a residential home.

In chapter 3, it was shown that the use of palliative care initiatives by older people has increased in Belgium between 2005 and 2014 from 39 per cent to 63 per cent. This increase was mostly driven due to an increase in the involvement of a palliative care reference person in care homes (either a nurse or the coordinating physician of the facility), which increased from 12 per cent to 26 per cent. The use of a palliative homecare team also increased significantly, from 13 per cent to 17.5 per cent. The use of hospital-based palliative care services did not increase. All services saw an increase in the proportion of the oldest old (people aged 85 and over) among the people for whom they provided care. There were no changes across the years in the proportion of men and women or the proportion of non-cancer patients, who made up one third of the group for whom palliative care was provided by home care teams and hospital-based services and 78 per cent of people who received care from a reference person for palliative care in a care home. The timing of initiation of palliative care remained the same, with half of older people receiving palliative care 14 days or fewer before death.

In chapter 4 it was shown that in both the Netherlands and Belgium, GPs' awareness of patient preferences has increased for older people between 2009 and 2014. The increase was larger in the Netherlands, going from 53 per cent to 66 per cent for a preference for a medical treatment the patient would or would not want and from 30 per cent to 57 per cent for a preference for a proxy decision-maker, than in Belgium, where the figures climbed from 27 per cent to 40 per cent and 29 per cent to 43 per cent respectively. Awareness of patient preferences was shown to have increased in all studied patient groups and settings. In Belgium, there were more differences between patient groups than in the Netherlands, with low percentages of known preferences for the oldest old (85+) and people with dementia.

With respect to the financial aspect of care at the end of life, in chapter 6 secondary and institutional care – including care by specialist physicians, hospital care, care in a long-term care facility and hospice care – were shown to be the largest contributors to out-of-pocket costs in nine out of 13 countries studied, constituting up to 76 per cent of healthcare costs in the last year of life. This is primarily attributable to care in long-term care facilities, having difficulties with activities of daily life (independently of being chronically ill) and spending more than 3 months of the last year of life in hospital in those countries where hospital care is not completely reimbursed. However, there is much variation in out-of-pocket costs among European countries, both in the amount (between 2 per cent and 25 per cent of median household income) and the relative contribution of different types of healthcare to out-of-pocket costs. For Belgium, secondary and institutional care was the biggest contributor to out-of-pocket costs (with costs of care in a long-term care facility the single biggest contributor), followed by medication and finally primary care.

End-of-life care for people with dementia in Belgium and other European countries

Chapters 6 and 7 pertained to end-of-life care specifically for people with dementia. In chapter 6 it was shown that in Belgium, Italy and Spain, two-thirds of people with dementia – including both those who died suddenly and those who died non-suddenly – have a palliative treatment aim two to three months before death, climbing to more than 80 per cent in both Belgium and Spain in the week before death. A third of people with dementia in Belgium and Spain and one-fifth of people in Italy received specialized palliative care at the end of life. In Belgium, 10 to 15 per cent of people were transferred between care settings in the last week of life, a significant minority. Communication between GP and patient about care, illness or preferences were relatively low, with no communication about illness-related topics with a quarter to half of people with mild dementia, and even fewer for people with severe dementia in all three countries. Prevalence of advance care planning, however, does seem to have increased for people with dementia as for other patient groups between 2009 and 2014, as shown in chapter 4. In 2014, GPs were aware of the preferences of people with dementia for a medical treatment they would or would not want at the end of life in one fifth of cases in Belgium and two thirds of cases in the Netherlands; and of a preference for a proxy decision-maker in 19 per cent of cases in Belgium and half of cases in the Netherlands. For Belgium, these figures were low when compared to other patient groups.

Chapter 7 showed that over a quarter of family carers of people with dementia who died in nursing homes were not aware their relative had dementia at time of death. This was especially the case for people who died with mild dementia: almost half of family carers were not aware of the dementia. The longer the resident had been admitted to the nursing home before developing dementia, the less likely it was that the family carers were aware of the dementia.

Discussions of main findings

Methodological considerations

All the data used in this dissertation were retrospective in nature. The use of retrospective data is well-established in social sciences and specifically in end-of-life care research. The greatest advantage of this method is that it allows for the selection of a population-based sample of people who died from a variety of illnesses and in very different situations. This enables us to give estimations of the prevalence of certain aspects of end-of-life care in the population as a whole. The biggest disadvantage is that, given the nature of research into the end of life, it is always proxy respondents – the GP, next of kin – and not the patient who provide the data. Fortunately, proxy reports have been found to be reliable (i.e. in line with the patient’s own judgement) in most aspects and can be considered a fair substitute for patient response in the matters investigated in this dissertation. A second disadvantage is the possibility of recall bias, where respondents may not accurately remember, or may not remember at all, certain things that have happened. In this study, recall bias was limited by having the questionnaires completed shortly after the patient or relative died, as well as the availability of memory aids such as medical files. Finally we must note that with retrospective data it is not possible to establish causality between events, which should be kept in mind when interpreting the results.

End-of-life care for older people

Differences between care settings

Many older people are still transferred between care settings at the end of life: in the Netherlands more than half of people living at home and a third of people living in a residential were transferred between care settings in the last three months of life. Many of these people die in hospital, often contrary to their wishes. Such late transitions between care settings can be a sign of lower quality of care and can be burdensome to the patient. Apart from the physical discomfort and psychological stress of transitions, at each transition, there is a risk of miscommunication or lack of communication between the various care providers. This can lead to possible incongruity between a patient's wishes for care and care received.

Previous research found that according to the GP, terminal hospitalizations often occur due to an inability to provide adequate care in the current care setting or for palliative reasons, and that in up to 70 per cent of cases earlier communication with the patient about their illness and wishes for care could have prevented the hospitalization. This indicates the importance of advance care planning and clear communication. The inability to provide adequate care in the current care setting may account for some of the differences in transitions between older people living at home and older people living in a residential home. In a long-term care facility such as a residential home, some form of professional care is available all day every day. If additional care needs to be arranged, the necessary infrastructure for this is already in place. It may be more difficult to arrange full-time care in the home setting, especially at short notice. While specialized palliative care services *can* be called upon to provide such care, in chapter 3 it was shown that fewer than 20 per cent of older people who died non-suddenly received such services, despite 60 per cent living at home in the last months of life. If GPs are unable to provide sufficient palliative care themselves, or if informal carers are overburdened, transferring the patient to hospital may be the best choice. In order to decrease the number of avoidable transfers and hospitalizations, better coordination between care providers, more and earlier advance care planning, and greater availability of palliative care services are necessary.

Advance care planning

In both Belgium and the Netherlands, advance care planning for older people in terms of GPs awareness of patient preferences has increased between 2009 and 2014 with 11 to 27 percentage point. These changes are considerable given that they took place over only five years. First, several guidelines have been developed over the past year to assist care providers to engage in advance care planning. Second, there could be a cohort effect, with younger generations in Western-Europe valuing autonomy more than older generations. Finally, it is possible that there is a growing acceptance of advance care planning in general as the taboos surrounding death and dying are broken.

It is notable that although GPs were already more frequently aware of patient preferences in the Netherlands than in Belgium, this difference only increased over time. Furthermore, there were some differences between patient groups that grew over time, particularly in Belgium. Some groups that are already at a disadvantage when it comes to palliative care and advance care planning, i.e. the oldest old and non-cancer patients, appear to fall further behind. Previous research has shown that healthcare professionals experience specific barriers to engaging in advance care planning with non-cancer patients that they do not experience with cancer patients. These barriers are often related to the healthcare professional's lack of skill with advance care planning, as well as lack of understanding on the patient's part of their diagnosis and prognosis. This last point, while seen by GPs as a barrier to initiating advance care planning, is in fact a reason to improve communication: if a patient is not aware or does not properly understand their diagnosis and prognosis, this is most often because it was not explained to them or their informal carers and only infrequently because they reject the diagnosis. Previous research also found that while patients want and expect their GP to initiate advance care planning, GPs often place this responsibility with the patient. In order to improve advance care planning for non-cancer patients, the oldest old and people with dementia, GPs and other healthcare professionals should take a more active role.

The development of palliative care in Belgium since 2005

Palliative care has been codified in Belgian law since 2002. Since then, several royal decrees have amended the legal framework surrounding the organization and financial support of palliative care services. By 2014, around 60 per cent of older people who died non-suddenly in Belgium used some form of palliative care service in the last three months of life. Unfortunately, this palliative care is often still 'terminal care', only provided in the last couple of weeks of life. Additionally, there has been only limited growth in the use of a palliative home care team and no increase in the use of hospital-based palliative care services since 2005: the overall increase is almost entirely due to the more frequent involvement of a reference person for palliative care in care homes. This means there is still a substantial portion of the population for whom no specialized palliative care is provided.

There may be several reasons for the stagnation of growth of certain types of palliative care services. One, saturation may be perceived, i.e. healthcare professionals do not feel any more people need palliative care. While palliative care is becoming more and more accepted as appropriate for non-cancer patients too, there are still patient groups who professional caregivers are less likely to consider in need of palliative care. Additionally, certain groups such as ethnic minorities and homeless people have more difficulty accessing palliative care. Healthcare professionals may also lack the tools to accurately identify palliative care needs in non-cancer patients with less predictable prognoses. In Belgium, efforts are underway to provide professional caregivers with such tools, for example in the form of the Palliative Care Indicator Tool (PICT). Two, structural barriers may exist which impede further expansion of palliative care. One such barrier is the prognosis-based requirement for accessing palliative care, which was revised only this year (2016). Under this requirement, palliative care would only be reimbursed if the patient had a life expectancy of three months or less. Future research can determine if this requirement was one of the causes of the late initiation of palliative care throughout the years. Three, palliative care is not only provided by specialized palliative care services but also by GPs. GPs who provide palliative care themselves may not see a need to also involve specialized palliative care services. This can be appropriate if the GP has the necessary knowledge and skills; however, care must be taken that in complex cases, expertise in the form of palliative care specialists can be called upon.

Costs of care

In nine out of 13 European countries studied in this dissertation, secondary and institutional care – i.e. care in hospital, from specialist physicians, or in long-term care facilities – was the biggest contributor to out-of-pocket costs of older people in the last year of life. Particularly care in care homes was expensive: not only do most people who use this type of care pay out-of-pocket for it, but the amounts they pay are very high. This is a worrying combination. Private funding of long-term care facilities is usually unaffordable for residents, with average long-term care expenditures accounting for 60 per cent to 80 per cent of disposable income. In Belgium, nearly all people who received care in a long-term care facility had to pay for this out of pocket at a median cost of 12,500 euros for one year. These findings suggest that this type of care may be less accessible to people from lower socioeconomic groups. While the obvious solution might be to establish a system of mean-tested contributions to long-term care, where those with a higher income or more wealth pay more and those with a lower income are subsidized, in practice this has been shown to also have an adverse impact on the accessibility of care for people of lower socioeconomic groups. Giving the ageing population and the increasing numbers of people who will require care in a long-term care facility, keeping (or making) this type of care affordable for people from all backgrounds should be a policy priority.

End-of-life care for people with dementia

Palliative care and transitions between care settings for people with dementia

Several recommendations for best practice from the European Association for Palliative Care concern aspects of care investigated in this dissertation. Among these recommendations are the prioritizing of explicit global care goals; the availability of specialized palliative care; the avoidance of overly aggressive, burdensome or futile treatment, including hospitalizations; and proactive advance care planning.

In Belgium as well as Italy and Spain, a palliative treatment goal is recognized for the majority of people with either mild or severe dementia from two to three months before deaths until the last week of death. However, this study does not tell us if this was due to needs arising from dementia or for other comorbidities. It is also unknown to what degree a palliative care goal is recognized for people with dementia earlier in the disease trajectory. Specialized palliative care was available to roughly one third of people who died with dementia in Belgium (mostly through a reference person for palliative care in a care home) and Spain and less than one fifth in Italy, meaning a sizeable portion of people with dementia do not receive specialized palliative care. Those who do receive specialized palliative care do so at a median of two weeks before death. People with dementia die in hospital in a large number of cases, around one third of people with mild dementia and between one fifth and a quarter of people with severe dementia. People with dementia are not transferred between care settings more often than the general population.

These findings do not differ significantly from those on older people in general. As mentioned before, both the expertise of reference persons for palliative care and the timing of initiation of palliative care can be improved. Interventions to decrease the number of hospitalizations may be of particular importance for people with dementia. However, as will be discussed in the next section, people with dementia are at a disadvantage compared to older people in general in one important regard: communication.

Advance care planning, communication and family involvement

Communication and advance care planning, which are so important for people with dementia, were shown to be disappointingly low in Belgium, Italy and Spain. In 2009 and 2010, less than three-quarters of people who died with mild dementia in Belgium had had any communication with their GP about disease-related topics such as physical symptoms or life expectancy. Less than half had even talked about their primary diagnosis. In Spain and Italy, the numbers were even lower, with 61 per cent and 50 per cent of GPs reporting communication about any of the end-of-life and disease-related topics. Advance care planning, in terms of GP awareness of patient preferences regarding medical treatments and a proxy decision maker, was similarly low. Although there have been improvements in Belgium between 2009 and 2014, in 2014 GPs were aware of a preference for a medical treatment in only 31 per cent of cases and of a preference for a proxy decision maker in only 19 per cent of cases.

Communication was not just low for people with advanced dementia, with whom communication may be challenging if not impossible, but also for people with mild dementia. However, previous research has shown that people with mild dementia are capable of meaningful communication and of consistently expressing their wishes regarding care. One might argue that communication is not always wanted, and thus these low percentages are not necessarily problematic. The information preferences of the general population, though, would suggest a far higher percentage of people would prefer to have communication about at least some disease-related topics than is currently the case. Different information preferences can however be a partial explanation for the international differences in the amount of communication, as people from Southern European countries have traditionally had a different view on disclosure of health information by physicians than people from Northern European countries.

In cases where communication with a person with dementia is genuinely impossible, communication will happen mostly through family. However, in chapters 4 and 7 of this dissertation it was shown that in Belgian nursing homes, this sometimes fails. Communication between GPs, nursing home residents and their family carers appears low. In Belgium, because of the involvement of not only a community GP but also the nursing home staff, it can be unclear whose responsibility it is to communicate with the resident and their family regarding matter surrounding the end of life. Previous research has found that most GPs and nurses tend to think that advance care planning is outside their remit, while residents and family carers want staff to raise the topic as opposed to initiating such conversations themselves. Without a clear structure of communication, it is likely that a sizeable number of family carers will not be as involved in care as they might be able to or want to be.

Finally, we must consider the plight of people with dementia for whom no family carer or proxy decision-maker can be identified. When there is genuinely no proxy decision-maker, for example when there are no living relatives or other strong social ties, people with dementia are at risk of having no-one to represent them if and when they become incompetent to make decisions. The burden then falls on the GP or other healthcare professional, who may not know enough about their patient to be able to make decisions in line with the patient's preferences. For these people, it is even more important for professional carers to communicate with them from early on in the disease trajectory to form a reliable picture of the patient's wishes and values.

Implications and recommendations

Implications and recommendations for policy in Belgium

The first recommendation for policy resulting from this dissertation is to invest in formal care at home and support for informal carers. Older people at home are at risk of transitions between care settings, avoidable hospitalizations and dying in hospital. The inability to coordinate care in the home setting plays a large part in this. The burden on family carers can be very high and with plans to encourage older people to live at home longer, this burden will only increase. In order to ensure care at home of high quality in a more cost-effective way, measures must be taken in addition to those currently discouraging the use of long-term care facilities. To prevent the costs of extra hospitalisations, the increase in physical and psychological health issues of family carers, and higher missed labour market participation, investments should be made in supporting both older people living at home and their family carers.

The second recommendation is to increase palliative care expertise in care homes. Currently, specialized palliative care in care homes is mainly provided by a reference person for palliative care and only infrequently by other services such as home care teams. However, the legal requirements for a care home to receive reimbursement for a reference person for palliative care are limited, as are those for the reference person themselves. Neither are their activities or the impact of their work inspected. This can lead to a high variability in the way the role of the reference person for palliative care is executed and the quality of palliative care between facilities. In addition, there may be a lack of expertise needed to deal with complex cases. Several palliative care networks, as well as the Federal Evaluation Committee for Palliative Care, have made recommendations for the role of a reference person for palliative care which may substantially improve palliative care in nursing homes.

Implications and recommendations for practice

The major recommendation from this dissertation for practice is to communicate more often and earlier with people with dementia. For people with dementia, the decline of their cognitive abilities is both unavoidable and irreversible. Communication early in the disease trajectory is therefore of paramount importance. Three avenues for promoting communication can be taken. The first is to decrease the stigma associated with dementia, as is being attempted by efforts spearheaded by the Flemish Ministry of Welfare, Public health and Family in collaboration with organizations such as the Expertise Centre Dementia Flanders. The second is to make communication a standard part of care for people with dementia, through the use of clear care plans and guidelines. The third is to provide GPs and other healthcare professionals with the training and tools necessary to engage in advance care planning.

A further recommendation is to involve palliative care earlier in the disease trajectory, utilizing a step-up, step-down approach as is common in chronic disease management. For people with dementia, for instance, there may be prolonged periods of months or even years where no support from palliative care services is needed, but support may be welcomed at the moment of diagnosis or if the person with dementia can no longer remain at home. By involving palliative care from early in the disease trajectory, in such moments where it is necessary palliative care services can be initiated quickly and effectively without overburdening the system by continuous active involvement.

Recommendations for future research

Building on the findings presented in this dissertation, three avenues for future research are clear: further research into communication and shared decision-making; costs of care; and the benefits of early palliative care for people with dementia.

In this dissertation, communication between GP and patient and, to a lesser extent, GP and family carer were studied. However, these are only some of the people involved in care at the end of life. There are also specialist physicians, nursing home staff and other formal and informal carers. It is still unknown how communication between these actors occurs in practice. Research into the pathways, frequency and content of communication between these different actors would be invaluable in identifying where problems are most likely to occur and which areas should be targeted for the most efficient and effective improvement of communication surrounding the end of life.

The costs of end-of-life care are still largely unknown, in part due to the complex nature of healthcare economics. Research into costs of end-of-life care in Europe should focus on three priorities in order to provide an evidence base suitable for use by policy and decision makers. The first question that must be answered is how out-of-pocket costs relate to insurer costs: are they correlated, and if so for what types of care? The second question is how socio-economic status influences out-of-pocket costs, particularly as a percentage of wealth and income. Third, research should investigate the role structural factors, such as the type of healthcare system, play in the cost of care and what the benefits of different systems are in terms of costs.

The last recommendation is to investigate the potential benefits of early palliative care for people with dementia, and how best to achieve these. Early palliative care has been shown to be beneficial for people with advanced lung cancer, but there are considerable differences between that patient group and those with dementia such as the median survival length (measured in months for lung cancer patients and years for people with dementia). Research should ascertain what the palliative care needs of people with dementia and their family carers are at different points in the disease trajectory, and how to target these specific needs at the appropriate times in a cost-effective way.

SAMENVATTING

Inleiding

De vergrijzende populatie van Europa

De wereldbevolking veroudert: in 2012 bestond 15 procent van de bevolking landen van de Organisatie voor Economische Samenwerking en Ontwikkeling (OESO) uit mensen van 65 jaar en ouder; in 2050 zal dit naar schatting gestegen zijn tot 25 procent. Hoewel we tegenwoordig 65 misschien niet instinctief als 'oud' zien, gebruiken zowel de OESO als de Wereldgezondheids-organisatie deze leeftijd als grens tussen jongere volwassenen en ouderen vanwege de grotere kans op gezondheidsproblemen vanaf deze leeftijd. Helaas zullen niet alle ouderen ertoe in staat zijn om een grote mate van onafhankelijkheid, sociale participatie en goede fysieke of geestelijke gezondheid te handhaven op latere leeftijd. De grote, kwetsbare groep ouderen wiens gezondheid en onafhankelijkheid met de jaren afnemen, als ook mensen die cognitief achteruit gaan door bijvoorbeeld dementie, zullen met de tijd meer zorg vereisen.

Een vergrijzende bevolking zorgt voor een aantal uitdagingen voor gezondheidssystemen en de klinische praktijk. Ten eerste hebben ouderen meer last van gezondheidsproblemen, vaak meerdere tegelijk, en hebben sommige ziektes zoals griep een zwaarder effect op ouderen dan op jongere volwassenen. Ten tweede zijn er specifieke vormen zorg die voornamelijk of alleen aan ouderen worden verstrekt, zoals zorg in woonzorgcentra. In sommige landen wonen en sterven bijna alle mensen met gevorderde dementie in een woonzorgcentrum. Dit soort langetermijnzorg instellingen zijn vaak duur doordat er de klok rond, zeven dagen per week zorg wordt geleverd door meerdere zorgverleners. Tot slot is er de realiteit dat ouderen een hogere kans hebben dan jongere volwassenen om te overlijden, en de meeste zorg wordt in het laatste jaar voor het overlijden gebruikt. In het laatste levensjaar vereisen mensen veel spoedeisende hulp, worden vaak in het ziekenhuis opgenomen en verblijven vaak in een woonzorgcentrum, vooral de alleroudsten, mensen met chronische ziekten en veel multimorbiditeiten. Deze aspecten van ouder worden zorgen ervoor dat het voorzien van levenseindezorg van hoge kwaliteit voor ouderen een grote uitdaging is voor de volksgezondheid.

Zorg rond het levenseinde voor ouderen

Er is nog veel onbekend over de zorg die ouderen aan het levenseinde ontvangen. Hoewel we weten dat ze minder toegang hebben tot gespecialiseerde palliatieve zorg, d.w.z. zorg die het doel heeft om de noden van stervende mensen en hun naasten vanuit een holistisch oogpunt te behandelen, weten we niet welke groepen hier het meest in benadeeld zijn. Thuiswonende ouderen, ouderen met kanker, ouderen met dementie en ouderen die in woonzorgcentra wonen ondervinden ieder waarschijnlijk voordelen en nadelen van hun specifieke situaties. Daarnaast weten we niet hoe de provisie van gespecialiseerde palliatieve zorg zich door de tijd ontwikkeld heeft. Nu er meer aandacht is voor de gepastheid van palliatieve zorg voor alle mensen met een levensbedreigende ziekte, niet alleen terminale kanker patiënten, is het mogelijk dat palliatieve zorg in recente jaren vaker wordt verstrekt aan ouderen of aan specifieke groepen ouderen. In de volgende secties zullen drie specifieke factoren worden belicht die belangrijk zijn voor het verstrekken van hoge kwaliteit levenseindezorg en palliatieve zorg aan ouderen.

Zorgsettings

Bepaalde omstandigheden, zoals de noodzaak voor meer deskundige zorg en de druk op mantelzorgers, benoodzaken soms dat ouderen naar een langetermijnzorg instelling verhuizen. In België woonden in 2013 11 procent van de mensen van 75 jaar en ouder en 26 procent van de mensen van 85 jaar en ouder in een woonzorgcentrum. Dit betekent dat de thuissetting en het woonzorgcentrum of andere langetermijnzorg instellingen de belangrijkste zorgsetting zijn voor ouderen aan hun levenseinde. In veel landen, waaronder België, is in de thuissetting de huisarts de voornaamste zorgverleners. Wanneer ouderen naar een langetermijnzorg instelling verhuizen, kan de huisarts al dan niet betrokken blijven bij de zorg. Naast de huisarts zijn er dan echter ook andere zorgverleners, zoals verpleegkundigen, betrokken bij de dagelijkse zorg. In sommige landen, zoals Nederland, werken er in de instelling specialisten ouderengeneeskunde die als huisarts voor alle bewoners optreden.

Omdat er een verschillende zorgaanbod is, als ook verschillen in de populatie en de betrokken zorgverleners, kunnen er andere beslissingen gemaakt worden door, met of voor thuiswonende ouderen en ouderen die in een woonzorgcentrum wonen, bijvoorbeeld over overplaatsingen naar een andere zorgsetting aan het levenseinde. Communicatie tussen ouderen en hun huisarts kan verschillen naar gelang de setting door bereikbaarheid en populatieverschillen. Of thuiswonende ouderen en ouderen die in woonzorgcentra wonen in dezelfde mate toegang hebben tot palliatieve zorg is ook nog onbekend. Een overzicht op populatieniveau van de levenseindezorg voor zowel thuiswonende ouderen als ouderen in woonzorgcentra is nodig om de sterke en zwakke punten van beide settings te identificeren.

Communicatie en voorafgaande zorgplanning

Een van de kerncomponenten van palliatieve zorg voor ouderen is voorafgaande zorgplanning. Voorafgaande zorgplanning is een proces van communicatie tussen patiënten, hun familie of vertegenwoordiger(s) en zorgverleners om de doelen en gewenste richting van zorg te bespreken. Door voorafgaande zorgplanning worden mensen aangemoedigd om na te denken over hun eigen wensen en waarden met betrekking tot de zorg die zij in de laatste levensfase willen ontvangen, en om deze wensen te delen met anderen. Door hun wensen vast te leggen en/of een vertegenwoordiger aan te stellen, kunnen mensen hun autonomie gebruiken en een actieve rol spelen in beslissingen rond hun levenseindezorg, ook wanneer zij op het moment zelf niet in staat zijn hun wensen te uiten.

Hoewel het voor iedereen belangrijk is om voorafgaande zorgplanning te overwegen, inclusief mensen die geen levensbedreigende ziekten hebben, is het van specifiek belang voor ouderen. De Wereldgezondheidsorganisatie raadt voorafgaande zorgplanning aan als een belangrijk deel van palliatieve zorg voor ouderen, en ouderen geven zelf ook aan dat zij voorafgaande zorgplanning belangrijk vinden. Echter, het is nog onbekend hoe vaak voorafgaande zorgplanning plaatsvindt met ouderen. Een overzicht op populatieniveau van hoe vaak voorafgaande zorgplanning plaatsvindt met ouderen, en hoe dit zich in de laatste jaren ontwikkeld heeft nu er meer aandacht is voor het belang van proactief communiceren tussen patiënten en zorgverleners, is nodig om goed geïnformeerde beslissingen te maken over hoe dit essentiële deel van levenseindezorg verder te promoten.

De kosten van zorg

Hoewel de kosten van een verouderende populatie voor het zorgsysteem vaak worden aangehaald, is het niet duidelijk hoe groot de kosten voor oudere patiënten zelf zijn. Ouderen in het bijzonder zijn kwetsbaar voor de negatieve impact van hoge kosten uit eigen zak, en halen zulke hoge kosten soms zelfs aan als een reden om een behandeling te staken of niet op te starten. De financiële last kan ook zwaar wegen op de schouders van mantelzorgers: financiële stress en een laag inkomen zijn gecorreleerd met een hogere subjectieve last en meer frequente depressieve symptomen onder mantelzorgers. Omdat de meeste ouderen hun familie niet tot last zullen willen zijn, kan dit hen nog meer reden geven om af te zien van nuttige maar dure zorg. Een overzicht van de kosten die ouderen in het laatste levensjaar moeten betalen voor de zorg die zij ontvangen kan helpen bij het bepalen welke types zorg het meest bijdragen aan de financiële last voor patiënten en om groepen te identificeren die een hoger risico lopen op het moeten betalen van hoge kosten.

Levenseindezorg voor mensen met dementie

Dementie, waarvan de ziekte van Alzheimer de meest voorkomende en meest bekende vorm is, is een specifieke uitdaging voor de gezondheid van ouderen. Dementie is een syndroom, veroorzaakt door een chronische of progressieve hersenaandoening, waarbij er een verstoring is van meerdere hogere cognitieve functies waaronder geheugen, denken, oriëntatie, begrip, rekenen, leercapaciteit, taal en beslissingsvermogen, vaak vergezeld van een verslechtering van emotionele controle en sociaal gedrag.

Vandaag de dag hebben 47,5 miljoen mensen wereldwijd een vorm van dementie en komen er ieder jaar 7,7 miljoen nieuwe gevallen bij. De combinatie van fysieke en psychologische symptomen betekent dat mensen met dementie – vooral zij wiens ziekte tot een vergevorderd stadium is overgegaan – veel complexe zorg nodig hebben in de laatste levensfase. Hoewel palliatieve zorg geschikt is voor alle mensen met een progressieve of levensbedreigende ziekte, is er voor het verstrekken van palliatieve zorg aan mensen met dementie aandacht nodig voor hoe mensen met dementie verschillen van bijvoorbeeld mensen met kanker. Daarnaast zien misschien niet alle zorgverleners en het algemene publiek de noodzaak van palliatieve zorg voor mensen met dementie. Omdat het in het geval van mensen met dementie vaak de huisarts en familieleden zijn die palliatieve zorg moeten initiëren, zijn hun visies belangrijk. Momenteel is het nog onbekend hoe vaak palliatieve zorg verleend wordt aan ouderen met dementie. Deze informatie is noodzakelijk om de barrières en faciliterende factoren te identificeren van het verstrekken van palliatieve zorg voor mensen met dementie.

Verdere aanbevelingen van de Europese Associatie voor Palliatieve Zorg (EAPC) zijn o.a. de prioriteit van expliciete globale zorgdoelen, proactieve voorafgaande zorgplanning vanaf diagnose, óók voor mensen met mild dementie, en het vermijden van te agressieve, belastende of zinloze behandelingen waaronder (ongepaste) hospitalisaties. De epidemiologie van deze aspecten van levenseindezorg voor mensen met dementie is nog onbekend. We weten nog niet welke zorgdoelen worden herkend voor mensen met dementie aan het levenseinde. We weten ook nog niet hoe vaak huisartsen communiceren met hun patiënten met dementie over onderwerpen aangaande zorg rond het levenseinde of hoe vaak zij op de hoogte zijn van de voorkeuren van hun patiënten. En hoewel er studies zijn gedaan naar hospitalisaties aan het levenseinde, is er geen data specifiek over mensen met dementie. Gericht onderzoek is nodig om deze aspecten van levenseindezorg specifiek voor mensen met dementie in kaart te brengen.

Mantelzorgers en communicatie

Één specifiek punt betreffende de zorg voor mensen met dementie is de rol die familieleden en mantelzorgers spelen. Mensen in de gevorderde stadia van dementie zijn niet in staat om hun wensen voor zorg consistent te uiten, wat een uitdaging vormt voor zowel professionele zorgverleners als mantelzorgers, die vaak zelf beslissingen moeten nemen. Als mantelzorgers goede, gepaste beslissingen willen maken over de zorg voor hun naaste is het belangrijk dat ze op de hoogte zijn van zowel de wensen als de gezondheidstoestand van hun naaste. De rol van de mantelzorgers of vertegenwoordiger berust dus op het verkrijgen van accurate informatie, door voorafgaande zorgplanning of door communicatie met zorgverleners. Als het op dementie aankomt, aarzelen huisartsen vaak om de diagnose te delen en zelfs wanneer ze dit wel doen, bestaat de kans dat de patiënt en familie de diagnose verwerpt vanwege het stigma rond dementie. De mate waarin mantelzorgers betrokken kunnen worden bij het besluitvormingsproces voor mensen met dementie is daarom gelimiteerd door de informatie die ze hebben ontvangen of hebben onthouden. Het belang van het anticiperen en tegemoet komen aan de informatienoden van familie, zoals ook aangeraden wordt door het EAPC, is groot, omdat de mate waarin mantelzorgers dementie als een levensbedreigende ziekte zien het comfort van de patiënt bij het overlijden voorspelt. Hoewel communicatie tussen huisartsen, mensen met dementie en mantelzorgers eerder is bestudeerd, is het onbekend in welke mate mantelzorgers zich inderdaad ervan bewust zijn dat hun naaste dementie heeft, en dus welk deel van de mantelzorgers geen weloverwogen beslissingen over de zorg kan maken.

Onderzoeksvragen

Om de ontbrekende kennis in het vakgebied aan te vullen en zo zorg aan het levenseinde voor ouderen te verbeteren, richt dit proefschrift zich op twee belangrijke zaken:

Onderzoeksdoel 1: Het beschrijven van zorg aan het levenseinde voor ouderen in België en andere Europese landen

In functie van dit doel worden de volgende specifieke vragen beantwoord:

- Wat zijn de karakteristieken van zorg aan het levenseinde voor ouderen die thuis wonen en ouderen die in een verzorgingshuis in Nederland?
- Zijn er trends in de frequentie van het gebruik van gespecialiseerde palliatieve zorg door ouderen in België tussen 2005 en 2014?
- Zijn er trends in hoe vaak er aan voorafgaande zorgplanning wordt gedaan met ouderen in België en Nederland tussen 2009 en 2014?
- Wat zijn de kosten uit eigen zak voor zorg in het laatste levensjaar voor ouderen in dertien Europese landen en wat zijn de patiënten- en zorgkarakteristieken geassocieerd met deze kosten?

Onderzoeksdoel 2: Het beschrijven van zorg aan het levenseinde van mensen met dementie in België en andere Europese landen

In functie van dit doel worden de volgende specifieke vragen beantwoord:

- Wat zijn de karakteristieken van zorg aan het levenseinde voor mensen met dementie in België, Italië en Spanje?
- Hoe vaak zijn mantelzorgers van overleden woonzorgcentrumbewoners in België op de hoogte dat hun naaste dementie had?

Methoden

Om de onderzoeksvragen van dit proefschrift te beantwoorden is kwantitatieve analyse toegepast op drie verschillende datasets. Vier hoofdstukken gebruikten retrospectieve data van epidemiologische netwerken van huisartsenpeilpraktijken in één of meerdere landen (EURO SENTIMELC studie). Één hoofdstuk gebruikt data verzameld via de naasten van overladen respondenten van een longitudinale studie in 13 Europese landen (Study of Health, Ageing and Retirement in Europe). Het laatste hoofdstuk gebruikt data verzameld via de huisarts, verpleegkundige en naaste van een representatieve steekproef van overladen Vlaamse woonzorgcentrumbewoners met dementie. (Dying Well with Dementia studie).

EURO SENTIMELC studie

In een aantal landen bestaan netwerken van huisartspraktijken die continue één of meerdere indicators van gezondheidsproblemen meten onder hun patiënten. Deze gegevens kunnen gebruikt worden om de volksgezondheid te monitoren. De SENTIMELC (in 2004 gestart in België en in 2005 in Nederland) en later de EURO SENTIMELC (in 2009 en 2010 gestart in Italië en twee regio's in Spanje) studie beoogden, door gebruik te maken van deze voornamelijk al bestaande netwerken, om een overzicht te geven van zorg rond het levenseinde in België, Italië, Nederland en Spanje. In België, Nederland en Spanje warden bestaande huisartsennetwerken gebruikt voor de datacollectie. In Italië werd een nieuw representatief huisartsennetwerk opgezet voor deze studie, dat alleen data verzameld over zorg rond het levenseinde. De deelnemende praktijken zijn geselecteerd om een representatieve steekproef te vormen in termen van leeftijd, geslacht en geografische verspreiding. In dit proefschrift is data van 2005 tot en met 2014 gebruikt.

Voor de SENTIMELC en EUROSENTIMELC studies registreerden huisartsen de overlijdens van alle patiënten van hun praktijk binnen één week van het overlijden via een gestandaardiseerd registratieformulier. Huisartsen kregen aan het begin van ieder kalenderjaar instructies over de inclusiecriteria en het invullen van de vragenlijst. Deelname aan de huisartsennetwerken is vrijwillig, hoewel huisartsen in Italië compensatie kregen voor de tijd die besteed werd aan deelname. Jaar op jaar vallen er weinig huisartsen uit het network en alleen data van huisartsen die minstens 26 weken per jaar data registreerden (d.w.z. die regelmatig deelnamen) zijn in dit proefschrift geïncludeerd.

Study of Health, Ageing and Retirement in Europe

De Study of Health, Ageing and Retirement in Europe (SHARE) is een lopende longitudinale studie die meerdere cohorten volgt van mensen van 50 jaar en ouder. De studie volgt meer dan 60.000 mensen in 20 Europese landen en is een van de grootste longitudinale studies over ouder worden vanuit een volksgezondheidsperspectief. Het doel van de studie was om in ieder land een willekeurige steekproef van 1500 huishoudens te includeren waar minstens één persoon van 50 jaar of ouder deel van uitmaakte.

De eerste SHARE datacollectie werd in 2004 gedaan in elf landen: Denemarken, Zweden, Oostenrijk, Frankrijk, Duitsland, Zwitserland, België, Nederland, Spanje, Italië en Griekenland. Data wordt in golven verzameld en bij ieder golf doen meer landen mee aan de datacollectie. In dit proefschrift is data gebruikt van de oorspronkelijke elf landen plus Tsjechië en Polen verzameld tussen 2005 en 2012. Dataverzameling gebeurde via computer geassisteerde interviews door professionele interviewers. Deze interviews bevragen socio-economische status, financiële situatie, werkgeschiedenis, maar ook functionele status en ontvangen medische zorg.

Respondenten worden van datacollectie tot datacollectie opgevolgd. Omdat er enkele jaren tussen twee golven datacollectie zit, zullen sommige respondenten in die tijd overleden zijn. Hierom worden bij iedere golf nieuwe respondenten geïncludeerd. Wanneer bij de nieuwe datacollectie bleek dat een respondent overleden was, probeerden de interviewers om een naaste van de overleden respondent te lokaliseren voor een 'end-of-life interview'. De data uit dit interview – d.w.z. de data verstrekt door proxy respondenten over dat deel van de SHARE steekproef dat tijdens de dataverzameling overleden is - is gebruikt in dit proefschrift. Het gaat hier om overleden respondenten uit dataverzamelingsgolven 2, 3 en 4 (2005-2012).

Dying Well with Dementia

De Dying Well with Dementia studie ging over het levenseinde van ouderen met dementie die in een woonzorgcentrum woonden. De studie was opgezet om de omstandigheden rond het levenseinde vanuit het oogpunt van meerdere betrokkenen te bestuderen. Dit retrospectieve cross-sectionele onderzoek werd uitgevoerd in Vlaanderen tussen mei en oktober 2013.

Een representatieve steekproef van woonzorgcentra werd geselecteerd voor inclusie in het onderzoek gestratificeerd naar regio, type woonzorgcentrum en grootte. Tijdens een bezoek van de onderzoekers aan het woonzorgcentrum identificeerde een contactpersoon van het woonzorgcentrum alle bewoners met dementie die in de voorgaande drie maanden waren overleden. Om in de studie geïncludeerd te worden, moest de overleden bewoner voldoen aan de criteria voor dementie die gesteld zijn door de Belgische ziekenkostenverzekeringen: de persoon moest of categorie C dementie hebben (ervaart bijna dagelijks disoriëntatie in tijd en ruimte) of was volledig zorgafhankelijk voor wassen, aankleden, eten, toiletgebruik en verplaatsingen en toonde tekenen van disoriëntatie in tijd en ruimte. Voor overleden bewoners die aan deze criteria voldeden, identificeerde de contactpersoon van het woonzorgcentrum de huisarts, verpleegkundige die het meest bij de zorg betrokken was en naaste of mantelzorger die het meest bij de zorg betrokken was. Een gestructureerde vragenlijst werd naar deze mensen gestuurd over de laatste levensmaanden van de overledene. Daarnaast vulde een medewerker van het woonzorgcentrum een vragenlijst is over de zorg die de overledene had ontvangen met hulp van de dossiers van de bewoner. Om anonimiteit te waarborgen werden de vragenlijsten uitgestuurd door de contactpersoon van het woonzorgcentrum en niet door de onderzoeker.

Belangrijkste bevindingen

Zorg rond het levenseinde voor ouderen in België en andere Europese landen

In hoofdstuk 2 tot en met 5 werden de resultaten gerapporteerd van vier studies over zorg rond het levenseinde voor ouderen. In hoofdstuk 2 werd beschreven dat in Nederland thuiswonende ouderen een hoger risico hebben om aan het levenseinde tussen zorgsettings getransfereerd te worden dan ouderen die in een verzorgingshuis woonden. Van de thuiswonende ouderen werd 54 procent in de laatste drie levensmaanden minstens één keer tussen zorgsettings overgeplaatst, tegenover 31 procent van de ouderen die in een verzorgingshuis woonden. De meeste van deze overplaatsingen waren ziekenhuisopnames: 47 procent van de thuiswonende ouderen en 28 procent van de ouderen die in een verzorgingshuis woonden werden gehospitaliseerd in de laatste drie levensmaanden. De huisartsen van ouderen in een verzorgingshuis gaven vaker aan dat zij zelf palliatieve zorg verleenden aan hun patiënten, en ouderen in een verzorgingshuis ontvingen in dezelfde mate zorg van gespecialiseerde palliatieve zorginitatieven als thuiswonende ouderen. Er waren wel een aantal vormen van gespecialiseerde palliatieve zorg die alleen aan thuiswonende ouderen werden verstrekt.

In hoofdstuk 3 werd aangetoond dat het gebruik van gespecialiseerde palliatieve zorg initiatieven door ouderen in België is toegenomen tussen 2005 en 2014, van 39 procent naar 63 procent. Deze toename werd vooral gedreven doordat er vaker een referentiepersoon palliatieve zorg betrokken was bij de zorg voor ouderen die in een woonzorgcentrum verbleven, van 12 procent naar 26 procent. Het gebruik van een multidisciplinaire palliatieve thuiszorgequipe is ook gestegen van 13 procent naar 17,5 procent. Het gebruik van palliatieve zorginitiatieven in het ziekenhuis is niet toegenomen. Bij alle palliatieve zorginitiatieven nam over de jaren heen de proportie patiënten van 85 jaar en ouder toe. Er waren geen veranderingen in de proportie mannen en vrouwen of de proportie patiënten met ziektes anders dan kanker, die een derde van de patiëntengroep waren voor multidisciplinaire palliatieve thuiszorgequipes of palliatieve zorg in het ziekenhuis en drie kwart van de patiëntengroep voor referentiepersonen palliatieve zorg. Palliatieve zorg werd in alle jaren pas laat opgestart: de helft van de ouderen die palliatieve zorg ontvingen, ontvingen dit pas vanaf 14 dagen of minder voor het overlijden.

In hoofdstuk 4 werd aangetoond dat in zowel Nederland als België huisartsen in 2014 vaker op de hoogte waren van patiëntenvoorkeuren dan in 2009. De toename was groter in Nederland, waar een voorkeur voor een medische behandeling aan het levenseinde bij de huisarts bekend was voor 53 procent van de patiënten in 2009 en 66 procent in 2014 en de voorkeur voor een vertegenwoordiger voor 30 procent in 2009 en 57 procent in 2014, dan in België, waar de cijfers opklommen van respectievelijk 27 procent naar 40 procent en 29 procent naar 43 procent. Huisartsen waren vaker op de hoogte van de voorkeuren van alle onderzochte patiëntengroepen, namelijk voor alle doodsoorzaken, mensen die thuis woonden, mensen die in een zorginstelling woonden, en mensen met dementie. In België waren er meer en grotere verschillen tussen patiëntgroepen dan in Nederland, met relatief lage percentages bekende voorkeuren voor 85-plussers en mensen met dementie.

Wat betreft de financiële aspecten van zorg rond het levenseinde werd in hoofdstuk 6 beschreven dat tweedelijnszorg en institutionele zorg – d.w.z. zorg door specialistische artsen, ziekenhuiszorg, zorginstellingen en zorg in hospice – de grootste bijdrage leveren aan de kosten uit eigen zak in negen van de 13 bestudeerde landen. Deze typen zorg waren verantwoordelijk voor tot 76 procent van de kosten uit eigen zak voor gezondheidszorg in het laatste levensjaar. Zulke hoge kosten konden vooral worden toegeschreven aan zorg in zorginstellingen, mensen die moeite hebben met meerdere dagelijkse activiteiten (los van chronisch ziek zijn) en meer dan 3 maanden van het laatste levensjaar in het ziekenhuis hebben doorgebracht in landen waar ziekenhuiszorg niet volledig vergoed wordt. Er is echter grote variatie in de kosten uit eigen zak tussen Europese landen, zowel in de hoogte van de kosten (tussen 2 procent en 25 procent van het mediaan huishoudinkomen) en de relatieve kosten van verschillende typen zorg. Voor België vormde tweedelijnszorg en institutionele zorg de grootste categorie kosten uit eigen zak (waarbij kosten van verblijf in een woonzorgcentrum de duurste categorie), gevolgd door medicatie en tot slot eerstelijnszorg.

Zorg rond het levenseinde voor mensen met dementie in België en andere Europese landen

In hoofdstuk 6 en 7 gingen over zorg rond het levenseinde specifiek voor mensen met dementie. In hoofdstuk 6 werd gerapporteerd dat in België, Italië en Spanje, twee-derde van de mensen met dementie – zowel mensen die plotseling zijn overladen en zij die niet-plotseling zijn overladen – een twee tot drie maanden voor het overlijden een palliatief behandeldoel had, wat in zowel België als Spanje nog opklom tot meer dan 80 procent in de laatste week voor het overlijden. In België en Spanje ontving een derde van de mensen met dementie gespecialiseerde palliatieve zorg aan het levenseinde en in Italië een vijfde. In België werd een significant minderheid van de mensen met dementie, 10 tot 15 procent, in de laatste levensweek nog overgeplaatst tussen zorgsettings. Communicatie tussen huisartsen en patiënten over zorg, ziektegerelateerde onderwerpen en patiënten voorkeuren was relatief laag. Met een kwart tot de helft van de mensen die gestorven zijn met milde dementie werd niet gesproken over enig ziektegerelateerd onderwerp, en met mensen met gevorderde dementie in alle drie de landen nog minder.

De prevalentie van voorafgaande zorgplanning lijkt echter wel te zijn toegenomen. In hoofdstuk 4 werd getoond dat in zowel België als Nederland huisartsen vaker op de hoogte waren van een voorkeur voor medische behandelingen of voor een vertegenwoordiger in 2014 dan in 2009. In Nederland was de toename bijzonder groot voor mensen met dementie: 36 procentpunt voor een voorkeur voor medische behandelingen en 38 procentpunt voor een voorkeur voor een vertegenwoordiger. In 2014 waren huisartsen op de hoogte van een voorkeur voor een medische behandeling in een vijfde van de gevallen van mensen met dementie in België en twee derde van de gevallen in Nederland; en voor een voorkeur voor een vertegenwoordiger in 19 procent van de gevallen in België en de helft van de gevallen in Nederland. Voor België waren deze cijfers laag in vergelijking met andere patiëntgroepen.

In hoofdstuk 7 werd getoond dat een kwart van de naaste familieleden of mantelzorgers van mensen die met dementie in een woonzorgcentrum in België zijn overleden, er niet van de op de hoogte was dat hun naaste dementie had. Dit was vooral het geval voor mensen in een vroeg stadium van dementie: in bijna de helft van deze gevallen was de mantelzorger niet op de hoogte van de dementie. Hoe langer de bewoner in het woonzorgcentrum had gewoond vóór hij of zij dementie kreeg, hoe minder waarschijnlijk het was dat de familie op de hoogte was van de dementie.

Bespreking van de belangrijkste bevindingen

Methodologische overwegingen

Alle data die in dit proefschrift zijn gebruikt, waren retrospectief van aard. Het gebruik van retrospectieve data is gebruikelijk in de sociale wetenschappen en in onderzoek rond levenseindezorg. Het grootste voordeel van deze methode is dat we een steekproef kunnen nemen op populatieniveau, met mensen die in diverse situaties en door diverse aandoeningen zijn overleden. Hierdoor kunnen we schattingen geven over de prevalentie van bepaalde aspecten van levenseindezorg in de populatie in het algemeen. Het grootste nadeel is dat, gezien de aard van onderzoek rond levenseindezorg, er altijd proxy respondenten – de huisarts, familie – gebruikt worden en dat de overleden persoon zelf geen data levert. Gelukkig heeft voorgaand onderzoek aangetoond dat de visie van proxy respondenten vaak betrouwbaar is (d.w.z., overeen komt met de visie van de patiënt) en in veel aspecten een gepaste plaatsvervanger kan zijn, zeker voor die zaken die in dit proefschrift zijn onderzocht. Een tweede mogelijk nadeel is dat van *recall bias*, d.w.z. dat respondenten zich misschien niet goed herinneren, of helemaal niet meer herinneren, hoe en of bepaalde dingen hebben plaatsgevonden. In dit proefschrift werd *recall bias* gelimiteerd doordat de vragenlijsten kort na het overlijden werden ingevuld en er geheugensteuntjes zoals medische gegevens voorhanden waren. Tot slot moeten we erop wijzen dat het bij retrospectieve data niet mogelijk is om causaliteit aan te tonen. Dit moet in gedachten worden gehouden bij het interpreteren van de resultaten.

Zorg rond het levenseinde voor ouderen

Verschillen tussen zorgsettings

Veel ouderen worden nog tussen zorgsettings overgeplaatst aan het levenseinde: in Nederland wordt meer dan de helft van de thuiswonende ouderen en een derde van de ouderen die in een verzorginsghuis woonden nog tussen zorgsettings overgeplaatst in de laatste drie levensmaanden. Veel van deze mensen sterven in het ziekenhuis, vaak tegen hun wens in. Zulke late overplaatsingen kunnen wijzen op een risico voor lagere zorgkwaliteit en kunnen belastend zijn voor de patiënt. Naast het fysieke ongemak en de psychologische onrust veroorzaakt door de overplaatsing is er bij iedere overplaatsing risico op miscommunicatie of gebrek aan communicatie tussen zorgverleners. Dit kan leiden tot het verstrekken van zorg die niet overeenkomt met de wensen van de patiënt.

Eerder onderzoek heeft aangetoond dat volgens huisartsen terminale hospitalisatie vaak gebeurt omdat het niet mogelijk is om in de huidige zorgsetting voldoende zorg te regelen of omdat palliatieve zorg nodig is, en dat in tot 70 procent van de gevallen eerdere communicatie met de patiënt over hun ziekte en zorgwensen de hospitalisatie had kunnen voorkomen. Dit toont het belang van voorafgaande zorgplanning en heldere communicatie aan. De moeilijkheden om in de huidige zorgsetting voldoende zorg te organiseren kan sommige verschillen in overplaatsingen tussen thuiswonende ouderen en ouderen in woonzorgcentra en verzorgingshuizen verklaren. In woonzorgcentra en verzorgingshuizen is er iedere dag, de hele dag een zekere mate van zorg aanwezig. Als er meer zorg nodig is, is er al een goede infrastructuur om dit te regelen. Het kan moeilijk zijn om voldoende voltijds zorg in de thuisetting te regelen die de mantelzorgers ontlast. Hoewel hiervoor een beroep kan worden gedaan op gespecialiseerde palliatieve zorg initiatieven, blijkt uit de data in hoofdstuk 3 dat minder dan 20 procent van de ouderen zorg ontving van een mobiele palliatieve thuisequipe, hoewel 60 procent aan het levenseinde thuis woonde. Als huisartsen zelf niet voldoende palliatieve zorg kunnen leveren, of als mantelzorgers overbelast zijn, kan een hospitalisatie de beste keuze zijn. Om het aantal onnodige overplaatsingen en hospitalisaties te voorkomen is betere coördinatie nodig tussen zorgverleners, meer en vroegere voorafgaande zorgplanning, en een grotere beschikbaarheid van palliatieve zorg initiatieven.

Voorafgaande zorgplanning

In zowel België als Nederland is voorafgaande zorgplanning, in termen van bekendheid van patiëntenvoorkeuren bij de huisarts, gestegen tussen 2009 en 2014, met 11 tot 27 procentpunt. Dit zijn sterke veranderingen gezien de korte periode. In deze periode zijn een aan aantal richtlijnen ontwikkeld om zorgverleners te ondersteunen bij het initiëren van voorafgaande zorgplanning. Er kan ook een mogelijk cohorteffect zijn, waarbij jongere generaties in West-Europa meer waarde hechten aan autonomie dan oudere generaties. Het is ook mogelijk dat er een groeiende acceptatie van voorafgaande zorgplanning in het algemeen is omdat taboes rond de dood en sterven worden doorbroken.

Het valt op dat het verschil tussen Nederland en België, waarbij huisartsen vaker op de hoogte waren van patiënten-voorkeuren in Nederland, tussen 2009 en 2014 nog is toegenomen. Daarnaast zijn er verschillen tussen patiëntengroepen die met de tijd zijn toegenomen, vooral in België. Sommige groepen die al benadeeld zijn met betrekking tot palliatieve zorg en voorafgaande zorgplanning, zoals de oudste mensen (85+) en niet-kanker patiënten, lijken zo nog verder achter te raken. Eerder onderzoek heeft aangetoond dat professionele zorgverleners specifieke barrières ervaren bij het inzetten van voorafgaande zorgplanning bij niet-kanker patiënten die zij niet ervaren bij kanker-patiënten. Deze barrières zijn vaak gerelateerd aan gebrek aan kennis en vaardigheden van de zorgverlener over voorafgaande zorgplanning, als mede een gebrek aan kennis van de patiënt over hun diagnose en prognose. Dit laatste punt, wat door huisarten wordt aangehaald als een barrière voor voorafgaande zorgplanning, is in feite een aanwijzing om communicatie nog te verbeteren: wanneer een patiënt of mantelzorgers een diagnose of prognose niet begrijpen is dit vaak omdat het hen niet of niet goed is uitgelegd en slechts in enkele gevallen omdat ze de diagnose verwerpen. Voorgaand onderzoek heeft ook aangetoond dat hoewel patiënten verwachten dat hun huisarts voorafgaande zorgplanning zal initiëren, huisartsen deze verantwoordelijkheid vaak bij de patiënt leggen. Om voorafgaande zorgplanning voor niet-kanker patiënten, de oudste mensen en mensen met dementie te verbeteren moeten huisartsen en andere zorgverleners een actievere rol innemen.

De ontwikkeling van palliatieve zorg in België sinds 2005

Palliatieve zorg is deel van de Belgische wetgeving sinds 2002. Sindsdien is het wettelijk kader rond de organisatie en financiering van palliatieve zorg meerdere malen aangepast door koninklijke besluiten. In 2014 ontving 60 procent van de ouderen die op niet-plotse wijze waren overleden in België een vorm van gespecialiseerde palliatieve zorg in de laatste drie levensmaanden. Helaas is palliatieve zorg vaak nog ‘terminale zorg’, die alleen in de laatste paar weken voor het overlijden wordt verstrekt. Daarnaast is er slechts gelimiteerde groei geweest in het gebruik van mobiele palliatieve thuiszorgequipes en palliatieve zorg in het ziekenhuis sinds 2005: de algemene toename in het gebruik van palliatieve zorg in de laatste tien jaar is vrijwel geheel te danken aan de meer frequente inzet van een referentiepersoon voor palliatieve zorg in woonzorgcentra, een functie die in 2005 nog maar in een minderheid van de woonzorgcentra bestond. Dit betekent date r nog een substantieel deel van de populatie is die geen palliatieve zorg krijgt aan het levenseinde.

Er kunnen meerdere redenen zijn dat de groei van bepaalde typen palliatieve zorg beperkt is. Ten eerste kunnen zorgverleners denken dat de doelgroep bereikt is en dat er geen mensen zijn die palliatieve zorg nodig hebben maar het niet krijgen. Echter, hoewel palliatieve zorg steeds meer aanvaard wordt voor niet-kanker patiënten, zijn er nog steeds groepen die professionele zorgverleners minder snel erkennen als mensen die baat zouden hebben bij palliatieve zorg. Daarnaast zijn er groepen zoals etnische minderheden en dak- en thuislozen voor wie toegang tot palliatieve zorg moeilijk is. Zorgverleners missen wellicht ook de nodige vaardigheden en materialen om palliatieve noden te kunnen identificeren bij niet-kanker patiënten met een slecht voorspelbare prognose. In België wordt getracht om zorgverleners de nodige gereedschappen aan te rijken, bijvoorbeeld de Palliatieve Zorg Indicator Tool (PICT). Ten tweede zouden er structurele barrières verdere ontwikkeling van palliatieve zorg kunnen belemmeren. Een voorbeeld van zo’n barrière is de vereiste dat men een prognose van niet meer dan drie maanden heeft om toegang te krijgen tot palliatieve zorg, een vereiste die pas dit jaar (2016) herzien werd. Toekomstig onderzoek zal kunnen uitwijzen of deze vereiste een van de oorzaken was van laattijdige initiatie van palliatieve zorg over de jaren. Ten derde kan palliatieve zorg niet alleen door gespecialiseerde zorg initiatieven geleverd worden, maar ook door de huisarts zelf. Huisartsen die zelf palliatieve zorg verlenen, vinden het misschien niet nodig om een gespecialiseerde palliatieve zorg dienst in te schakelen. Dit kan geen probleem zijn als de huisarts de nodige kennis en vaardigheden heeft, maar er moet op gelet worden dat er bij complexe gevallen een beroep kan worden gedaan op de expertise van palliatieve zorg specialisten.

De kosten van zorg

In negen van de 13 Europese landen die in dit proefschrift bestudeerd warden, vormde secundaire en institutionele zorg – d.w.z. zorg in het ziekenhuis, van specialisten, of in langetermijnzorg instellingen – het grootste deel van de kosten die ouderen uit eigen zak moesten betalen voor zorg in het laatste levensjaar. Vooral zorg in langetermijnzorg instellingen was duur: niet alleen betaalde de meeste mensen die dit type zorg gebruikten hier uit eigen zak voor, maar de bedragen konden zeer hoog uitvallen. Dit is een verontrustende combinatie. Privé financiering van langetermijnzorg instellingen is meestal onbetaalbaar voor bewoners: de gemiddelde kosten vormen zo’n 60 procent tot 80 procent van het inkomen van bewoners. In België moesten bijna alle bewoners van een woonzorgcentrum hier uit eigen zak voor betalen, met een mediaan kost van 12.500 euro voor alleen het laatste levensjaar – waarbij rekening moet worden gehouden dat lang niet alle respondenten een volledig jaar zorg hebben ontvangen in een woonzorgcentrum. Deze bevindingen suggereren dat dit type zorg misschien minder toegankelijk is voor mensen uit groepen van een lagere socio-economische status. De voor de hand liggende oplossing is misschien het invoeren van een getrapte prijs, waarbij mensen met een hoger inkomen of meer vermogen meer betalen en mensen met een lager inkomen worden gesubsidieerd – maar in de prakijk is gebleken dat dit een onverwacht negatieve impact heeft op de toegankelijkheid van institutionele zorg voor mensen van lagere socio-economische groepen. Gezien het feit dat door de vergrijzende bevolking een toenemend aantal mensen gebruik zal maken van langetermijnzorg instellingen zou het betaalbaar houden (of maken) van dit type zorg voor mensen van alle achtergronden een beleidsprioriteit moeten zijn.

Zorg rond het levenseinde voor mensen met dementie

Palliatieve zorg en overplaatsingen tussen zorgsettings voor mensen met dementie

Meerdere aanbevelingen voor ‘best practice’ van de Europese Associatie voor Palliatieve Zorg met betrekking tot levenseindezorg voor mensen met dementie zijn in dit proefschrift onderzocht. Deze aanbevelingen gaan onder andere over het prioriteren van expliciete zorgdoelen; de beschikbaarheid van gespecialiseerde palliatieve zorg; het vermijden van te agressieve, belastende of zinloze behandelingen, inclusief hospitalisaties; en proactieve voorafgaande zorgplanning.

In zowel België als Italië en Spanje wordt voor de meerderheid van de mensen met milde of gevorderde dementie een palliatief behandeldoel erkent tussen twee tot drie maanden en één week voor het overlijden. Echter, uit deze studie is niet duidelijk of dit palliatief behandeldoel erkent werd vanwege noden die voortkwamen uit dementie of vanwege noden die voortkwamen uit comorbiditeiten. Het is ook nog onbekend in welke mate een palliatief behandeldoel voor mensen met dementie eerder in het ziektetraject wordt herkend. Gespecialiseerde palliatieve zorg wordt aan ruwweg een derde van de mensen met dementie in België (meestal door een referentiepersoon palliatieve zorg in een woonzorgcentrum) en in Spanje, en minder dan een vijfde van de mensen in Italië, wat betekent dat een substantieel deel van de mensen met dementie geen gespecialiseerde palliatieve zorg ontvangt. Mensen die wel gespecialiseerde palliatieve zorg ontvangen krijgen dit vaak pas minder dan twee weken voor het overlijden. Een groot aantal mensen met dementie, ongeveer een derde van de mensen met milde dementie en een vijfde tot een kwart van de mensen met gevorderde dementie, sterft in het ziekenhuis. Mensen met dementie worden niet vaker tussen zorgsettings overgeplaatst aan het levenseinde dan de algemene populatie.

Deze bevindingen verschillen niet significant van de bevindingen over ouderen in het algemeen. Zoals eerder genoemd is, kunnen zowel de expertise van referentiepersonen palliatieve zorg als de timing van initiatie van palliatieve zorg verbeterd worden. Interventies die gericht zijn op het verminderen van het aantal hospitalisaties kunnen wellicht bijzonder nuttig zijn voor mensen met dementie. Echter, zoals in de volgende sectie zal worden besproken, er is één belangrijk punt waarop mensen met dementie benadeeld zijn ten opzichte van ouderen in het algemeen: communicatie.

Voorafgaande zorgplanning, communicatie en de betrokkenheid van mantelzorgers

Communicatie en voorafgaande zorgplanning, die zo belangrijk zijn voor mensen met dementie, bleek teleurstellend weinig te gebeuren in België, Italië en Spanje. In 2009 en 2010 had minder dan driekwart van de mensen die met dementie zijn gestorven in België met hun huisarts gecommuniceerd over ziektegerelateerde onderwerpen zoals fysieke symptomen of levensverwachting. Minder dan de helft had gesproken over hun primaire diagnose. In Spanje en Italië waren de aantallen nog lager: huisartsen gaven aan dat ze met respectievelijk 61 procent en 50 procent van hun patiënten met dementie hadden gesproken over levenseinde- of ziektegerelateerde onderwerpen. Voorafgaande zorgplanning, in termen van bekendheid van patiëntenvoorkeuren bij de huisarts, gebeurde ook weinig. Hoewel er verbetering was in België tussen 2009 en 2014, was ook in 2014 slechts van 31 procent van de mensen met dementie een voorkeur voor een medische behandeling bekend en in 19 procent van de gevallen een voorkeur voor een vertegenwoordiger.

Communicatie was niet alleen zeldzaam voor mensen met gevorderde dementie, voor wie communicatie moeilijk of onmogelijk kan zijn, maar ook voor mensen met milde dementie. Echter, eerder onderzoek heeft uitgewezen dat mensen met milde dementie in staat zijn om betekenisvol te communiceren en om consistent hun wensen over hun zorg te uiten. Het argument zou kunnen worden gegeven dat communicatie niet altijd gewenst is en dat de in dit proefschrift gevonden lage percentages dus niet noodzakelijk problematisch zijn. De informatievoorkeuren van de algemene populatie, echter, suggereren dat een veel hoger percentage mensen in ieder geval enige communicatie over hun zorg en het levenseinde wenst dan momenteel het geval is. Verschillen in informatievoorkeuren kunnen wellicht wel een verklaring zijn voor de gevonden landverschillen: in zuid-Europese landen wordt van oudsher anders tegen patiënt-arts communicatie aangekeken dan in noord-Europese landen.

Wanneer communicatie met een person met dementie werkelijk onmogelijk is, zal de communicatie met zorgverleners meestal via de familie gaan. Echter, in hoofdstukken 4 en 7 van dit proefschrift werd aangetoond dat dit bij Belgische woonzorgcentra niet altijd goed gaat. Communicatie tussen huisartsen, woonzorgcentrum bewoners en mantelzorgers lijkt laag. Doordat zowel personeel van het woonzorgcentrum als een externe huisarts betrokken is bij de zorg van woonzorgcentrumbewoners, en iedere bewoner een andere huisarts kan hebben, kan het onduidelijk zijn wiens taak het is om met de bewoner en familie te spreken over het levenseinde. Eerder onderzoek heeft uitgewezen dat de meeste huisartsen en verpleegkundigen denken dat voorafgaande zorgplanning buiten hun mandaat valt, terwijl bewoners en hun naasten juist willen dat de professionele zorgverleners dit onderwerp introduceren. Zonder duidelijke structuur omtrent communicatie is het waarschijnlijk dat een aanzienlijk deel van de mantelzorgers niet zoveel betrokken is bij de zorg als ze zouden kunnen of willen zijn.

Tot slot moeten we aandacht besteden aan de situatie van mensen met dementie die geen mantelzorgers of vertegenwoordiger hebben. Als er werkelijk geen (officiële of de facto) vertegenwoordiger is, bijvoorbeeld als er geen familieleden zijn, lopen mensen met dementie het risico dat er niemand is om hen te vertegenwoordigen wanneer ze niet meer in staat zijn om zelf beslissingen te maken. De verantwoordelijkheid valt dan op de schouder van de huisarts en andere zorgverleners, die de persoon misschien niet goed genoeg kennen om beslissingen te kunnen maken die overeenkomen met zijn of haar wensen. Voor deze mensen is het nog belangrijker dat zorgverleners al vroeg in het ziektetraject met hen communiceren om een betrouwbaar beeld van hun wensen en waarden te vormen.

Implicaties en aanbevelingen

Implicaties en aanbevelingen voor beleid in België

De eerste aanbeveling van dit doctoraat is om te investeren in formele thuiszorg en om mantelzorgers meer te ondersteunen. Thuiswonende ouderen lopen een hoger risico op overplaatsingen tussen zorgsettings, hospitalisaties en sterven in het ziekenhuis dan ouderen die in een woonzorgcentrum wonen. De moeilijkheid om zorg in de thuissetting te coördineren speelt hier een grote rol in. De last op mantelzorgers kan zeer hoog zijn en met de plannen om ouderen aan te moedigen langer thuis te blijven, zal deze last alleen maar toenemen. Om te verzekeren dat zorg in de thuissetting van hoge kwaliteit op een kosteneffectieve manier kan worden verleend moeten er maatregelen genomen worden die los staan van het ontmoedigen van verhuizen naar een woonzorgcentrum. Om de extra kosten van hospitalisaties, toename in psychologische en fysieke klachten van mantelzorgers en minder deelname van mantelzorgers op de arbeidsmarkt te voorkomen, moet proactief geïnvesteerd worden in het ondersteunen van thuiswonende ouderen en hun mantelzorgers.

De tweede aanbeveling is om de expertise rond palliatieve zorg in woonzorgcentra te vergroten. Momenteel wordt gespecialiseerde palliatieve zorg in woonzorgcentra voornamelijk geleverd door een referentiepersoon palliatieve zorg en slechts infrequent door andere services zoals mobiele thuisequipes. Echter, de wettelijke voorschriften voor deze referentiepersonen zijn beperkt. Er is ook geen manier waarop hun activiteiten of de impact van hun werk gemeten worden. Dit kan leiden tot een hoge variabiliteit tussen woonzorgcentra in de manier waarop de rol van een referentiepersoon palliatieve zorg wordt ingevuld. Daarnaast is er misschien een gebrek aan expertise om met complexe gevallen om te gaan. Verschillende netwerken palliatieve zorg, als ook de Federale Evaluatie Commissie voor Palliatieve Zorg, hebben aanbevelingen gedaan voor de rol van referentiepersoon palliatieve zorg die de palliatieve zorg in woonzorgcentra sterk zouden kunnen verbeteren.

Implicaties en aanbevelingen voor praktijk

De belangrijkste aanbeveling voor de praktijk die uit dit proefschrift voortkomt is om meer en eerder te communiceren met mensen met dementie. Mensen met dementie zullen een onvermijdelijke en onomkeerbare cognitieve achteruitgang doormaken. Communicatie vroeg in het ziektetraject is daarom van uiterst belang. Communicatie kan op drie manieren worden aangemoedigd. De eerste is om het stigma dat kleeft aan dementie te verminderen, zoals het Vlaamse Ministerie van Gezin, welzijn en gezondheid tracht te doen in samenwerking met organisaties zoals het Expertisecentrum Dementie. Ten tweede kan van communicatie een standaard onderdeel van zorg voor mensen met dementie gemaakt worden, bijvoorbeeld door het gebruik van duidelijke stappenplannen en richtlijnen. Ten derde kan training voorzien worden voor huisartsen en andere zorgverleners om hen de nodige kennis en vaardigheden te geven om aan voorafgaande zorgplanning te doen.

Een tweede aanbeveling is om palliatieve zorg al eerder in het ziekteproces in te schakelen via een step-up, step-down aanpak die gangbaar is in zorg rond chronische ziekten. Mensen met dementie zullen misschien voor langere periodes (maanden of zelfs jaren) geen behoefte hebben aan extra ondersteuning van palliatieve zorg services, maar op het moment van diagnose of als ze naar een woonzorgcentrum moeten verhuizen juist wel. Door palliatieve zorg al van vroeg in het ziektetraject bij de zorg te betrekken, kan op dit soort momenten makkelijk en efficiënt extra ondersteuning worden aangeboden.

Aanbevelingen voor verder onderzoek

Voortbouwend op de bevinden uit dit proefschrift zijn er drie duidelijke richtingen voor toekomstig onderzoek: meer onderzoek naar communicatie en gezamenlijke besluitvorming; kosten van zorg; en de voordelen van vroege palliatieve zorg voor mensen met dementie.

In dit proefschrift werd de communicatie tussen huisarts en patiënt en, in mindere mate, tussen huisarts en mantelzorger bestudeerd. Dit zijn echter slechts een paar van de mensen die betrokken zijn bij zorg rond het levenseinde – denk bijvoorbeeld aan specialistische artsen of verpleegkundigen in een woonzorgcentrum. Het is nog onbekend hoe communicatie tussen al deze betrokkenen in de praktijk verloopt. Onderzoek naar wie met wie communiceert, hoe vaak, wanneer en waarover zou van grote waarde zijn om te identificeren waar pijnpunten zitten en waar het best geïnvesteerd kan worden om communicatie rond het levenseinde te verbeteren.

De kosten van zorg rond het levenseinde zijn nog grotendeels onbekend, deels vanwege de complexe aard van gezondheidseconomie. Onderzoek naar de kosten van levenseindezorg in Europa zou drie prioriteiten moeten hebben om een goede empirische basis te kunnen vormen voor beleidsmakers. De eerste vraag die beantwoord moet worden is hoe kosten uit eigen zak zich verhouden tot de kosten voor verzekeringsmaatschappijen: zijn deze gerelateerd en zo ja, voor welke typen zorg? De tweede vraag is de invloed van socio-economische status op kosten voor zorg, vooral als percentage van inkomen en vermogen. Als derde zou de rol van structurele factoren, zoals het type gezondheidssysteem, onderzocht kunnen worden om te bepalen wat de voor- en nadelen van verschillende systemen zijn in termen van kosten.

De laatste aanbeveling is om de mogelijke voordelen van vroege palliatieve zorg voor mensen in dementie vast te stellen, en hoe deze het best verwezenlijkt kunnen worden. Het is aangetoond dat het betrekken van palliatieve zorg vroeg in het ziektetraject duidelijke voordelen heeft voor mensen met gevorderde longkanker, maar er zijn grote verschillen tussen hen en mensen met dementie zoals de gemiddelde overlevingsduur (die in maanden gemeten wordt voor longkankerpatiënten en in jaren voor mensen met dementie). Onderzoek zou kunnen vaststellen wat de palliatieve zorgnoden van mensen met dementie en hun mantelzorgers zijn op verschillende momenten in het ziektetraject en hoe deze het best kunnen worden geadresseerd.

PUBLICATION AND PRESENTATION LIST

Publications – International peer reviewed journals

2016 **Penders YWH**, Albers G, Deliens L, Miccinesi G, Vega Alonso T, Miralles M, Moreels S, Van den Block L, on behalf of EUROIMPACT. End of life care for people dying with dementia in general practice in Belgium, Italy and Spain: a cross-sectional, retrospective survey. Geriatrics & Gerontology International. *In print.*

2016 **Penders YWH**, Rietjens J, Albers G, Croezen S, Van den Block L. Differences in out-of-pocket costs of healthcare in the last year of life of older people in 13 European countries. Palliative Medicine. April 29 2016. doi: 10.1177/0269216316647206

2015 **Penders YWH**, Albers G, Deliens L, Vander Stichele R, Van den Block L. Awareness of dementia by family carers of nursing home residents dying with dementia: A post-death study. Palliative Medicine. 2015 Jan;29(1):38-47.

2015 **Penders YWH**, Van den Block L, Donker GA, Deliens L, Onwuteaka-Philipsen B. Older people at home and in a residential home: Comparing end-of-life care via mortality follow-back study among GPs in the Netherlands. British Journal of General Practitioners. 2015 Nov 1;65(640):e724-30.

Publications – Other

2015 Moreels S, Boffin N, Van Casteren V, **Penders YWH**, Pivodic L, Van den Block L. Palliatieve zorg en voorafgaande zorgplanning in het Vlaamse Gewest in de periode 2005-2014. [Palliative care and advance care planning in Flanders in 2005-2014] Report for the Agentschap Zorg en Gezondheid [Public Health Services].

2015 Beernaert K, Dierickx S, Gilissen J, **Penders YWH**. Hoe de palliatieve zorg in Vlaanderen verbeteren? Aanbevelingen voor beleid en praktijk op basis van de 8 doctoraatsstudies en het eindcongres van het FLIECE onderzoeksproject. [How to improve palliative care in Flanders? Recommendations for policy and practice based on 8 doctoral theses and the final conference of the FLIECE research project] Tijdschrift voor Palliatieve Zorg. [Magazine of Palliative Care]

Presentations - First author

2016 *9th European Public Health Conference, Vienna, Austria*

Poster presentation titled ‘Trends between 2009 and 2014 in advance care planning for older people in Belgium and the Netherlands’

2016 *8th Research Congress of the European Association of Palliative Care, Dublin, Ireland*

Oral presentation titled ‘How often do general practitioners communicate about end-of-life topics with community-dwelling older people and their family in three European countries?’

Poster titled ‘Out-of-pocket cost for care in the last year of life of older people in 13 European countries’

Poster titled ‘Any old disease: do older people with cancer receive different end-of-life care than older people without cancer?’

2015 *3d Flemish Conference in Psychosocial Oncology, Mechelen, Belgium*

Poster titled ‘Hoe sterven ouderen met kanker thuis en in woonzorgcentra?’ [How do older people with cancer die at home and in long term care facilities?]

2015 *14th World Congress of the European Association of Palliative Care, Kopenhagen, Denmark*

Oral presentation titled ‘A cross-sectional, retrospective study using nationwide GP networks of circumstances of people dying with dementia in Belgium, Italy and Spain’

Poster titled ‘Comparing circumstances of end-of-life care for older people living at home and in a residential home in the Netherlands via a mortality follow-back study’

2015 *Nederlands-Vlaams Onderzoeksforum Palliatieve Zorg [Dutch-Flemish Research forum Palliative Care], Antwerp, Belgium*

Oral presentation titled ‘Levenseindezorg voor thuiswonende ouderen en ouderen in een verzorgingshuis in Nederland’ [End-of-life care for older people living at home and older people living in a residential home in the Netherlands]

2014 *Palliative Care 2020: The future of palliative care, Brussels, Belgium*

Poster titled ‘Nursing home residents with dementia’

2014 *7th Research Congress of the European Association of Palliative Care, Lleida, Spain*

Poster titled ‘Awareness of dementia by family carers of nursing home residents dying with dementia’

Presentations - Co-author

2016 *8th Research Congress of the European Association of Palliative Care, Dublin, Ireland*

Oral presentation ‘Admissions to hospital, nursing home and hospice in the last year of life of community-dwelling older people in 16 European countries’. Overbeek A, Van den Block L, Korfage I, **Penders YWH**, Van der Heide A, Rietjens J.

Poster ‘To what extent is retrospective research in nursing home residents limited by non-response bias?’ Van Dop N, Pivodic L, **Penders YWH**, Van den Noortgate N, Deliens L, Van den Block L.

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Yolanda W.H. Penders (1989, the Netherlands) obtained a bachelor's degree in psychology and a master's degree in sociology from Utrecht University. After her studies, she worked as a junior researcher at the University of St Andrews, Scotland, and the magistrate's court Oost-Brabant, the Netherlands. In 2013, she moved to Brussels to start her PhD thesis at the End-of-life Care Research Group of the Vrije Universiteit Brussel (VUB) and Ghent University. Starting out as a Marie Curie PhD Training Fellow in the EU-funded EURO IMPACT project, she moved on to work on an international FP7-framework project as well as national projects, collaborating with the Flemish League against Cancer and the Scientific Institute for Public Health.