The availability, uptake and impact of palliative home care

A population-level study using administrative data

Arno Maetens

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"Do not assume that he who seeks to comfort you now, lives untroubled among the simple and quiet words that sometimes do you good. His life may also have much sadness and difficulty, that remains far beyond yours. Were it otherwise, he would never have been able to find these words."

- Rainer Maria Rilke

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Chapter 3

Policy measures to support palliative care at home: a cross-country case comparison in three European countries

Published in: Journal of Pain and Symptom Management 2017, Vol. 54 No. 4 [SCI impact factor (2017): 3.249]

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Introduction

1 General introduction, research questions and outline of this dissertation

1.1 Introduction

Ever more people across the globe are in need for quality care at the end of life (1,2). Yet, many still see their care needs unmet: it is estimated that globally only 14% of people in need of palliative care actually receive it (3). The anticipated social, political and economic challenges of ageing populations in mind, countries are urged to integrate palliative care into their national health care systems (4,5). As such, the development of policies and legislative and other measures with a view to building a comprehensive national policy framework for palliative care has been a major priority for national and supranational legislative bodies (6).

In the last decade, an increased emphasis has been put on the need to increase the provision of palliative care specifically in a home or community setting, in order to meet patients' wishes for quality home care and to address the increasing societal costs related to hospitalization and institutionalization at the end of life. This was exemplified in the 2014 World Health Assembly's (WHA) global *Resolution on the strengthening of palliative care as a component of integrated treatment throughout the life course* (5), and recently echoed by the Council of Europe's *The provision of palliative care in Europe* (6). Indeed, policy can be a potentially effective way to improve the health of populations (7). However, many policy strategies often lack a sufficient evidence base, and countries across Europe have over the past twenty years developed policy measures relatively independently from each other (8). From a public health perspective, it is therefore important to evaluate these national policies on their availability, accessibility and impact.

The present doctoral thesis focusses on the use, trends in use, factors that influence use, and the impact of using measures, available due to national policies, that are meant to support patients and their informal caregivers to provide palliative care in the home or community setting on the population level in Belgium. The rationale behind this is that, in order to provide valuable information for practice and policy makers to enable the best possible support for palliative care at home, such that it meets patients' needs and wishes, good data is needed of the current use and the impact of national policy measures to support palliative home care.

In this chapter a short introduction will be provided on the challenges that led to the increasing need for governments to develop policies to support palliative care at home and in the community. We then give a state-of-the-art in the current research, arguing why supportive policies for palliative care are a public health research priority and why the focus on the home as a place of care is important from the viewpoint of both policy makers, patients and their caregivers. We then provide a short introduction on the use of administrative databases to study end-of-life care on a population level, followed by an overview of the development of policy measures to support palliative home care in Belgium. Lastly, the research questions, the study design and methodologies used in this dissertation are described, and the outline of this dissertation is specified.

1.2 Challenges of an ageing population

Population longevity is commonly used as a measure to assess the success of a country's health care system. Indeed, a longer life has long been one of the main goals of public health and medicine, with considerable success (9). Since 1900, the global average life expectancy has more than doubled, now approaching 70 years. Meanwhile, fertility levels dropped to a level that is now below the replacement level (approximately 2.1 births per woman) in 83 countries, comprising 46% of the world's population, and some have been in this situation for multiple decades (1). As a result, populations are growing older over time.

Unfortunately, despite strong evidence that older people are living longer, particularly in high-income countries, the quality of life in which these extra years are spent is less clear (10). With increasing age, the likelihood of living with one or more chronic illnesses increases substantially (11). The prevalence of multimorbidity is moreover increasing due to population ageing: from 1997 to 2013, the percentage of people over 65 with multimorbidity increased from 30.6% to 36.1%. It is estimated that men and women nowadays spend on average 8.3 years living with some degree of disability before death (12). In Belgium, where the average life expectancy of 79 years for men and 83,7 years for women (in 2017) is higher than the global average, a study from 2005 calculated that life expectancy free of activity limitation for men is about 10 years shorter than their total life expectancy, and about 15 years for women (13).

This evolution also impacts how we die. A century ago, death was typically quite sudden, with most people dying from infectious diseases, accidents and childbirth (14). Today sudden death is less common, and most people instead acquire a serious progressive illness towards the end of life that increasingly interferes with their usual activities until death (15). In 2015, it was estimated that around 40 million deaths, or 70% of all deaths worldwide, were due to non-infectious or non-communicable diseases – more than ever before (16). The majority of these deaths were caused by just four main pathologies: cardiovascular disease (accounting for 45% of all non-communicable disease deaths); cancer (22%); chronic respiratory disease (10%); and diabetes (4%). Such illnesses are typified by a slow degenerative dying-process, rather than by a short period of illness followed by a quick death, as illustrated in the distinct illness trajectories that have been described for people with progressive chronic illnesses (17).

1.3 Supportive policies for palliative care: a public health priority

The increasing number of people living and dying with these illnesses experience a wide range of physical, psychosocial and spiritual problems and could benefit from a palliative care approach (18). According to the WHO, palliative care is 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' (19).

Traditionally, palliative care was provided in hospices, primarily to cancer patients who were close to death (20). However, the changing patterns of illness in modern society have increased the awareness of a need for palliative care for chronic diseases or conditions other than cancer as well (e.g., COPD, congestive heart failure, neurodegenerative disorders), while also acknowledging that palliative care can be initiated early on in the disease trajectory and is thus not equivalent to terminal care. By adopting this broader scope of what entails palliative care, when it should (or can) be initiated and who it is aimed at, the societal capacity to organize, deliver and finance this care is also impacted. For these reasons, organizations such as the WHO have increasingly stressed the need to develop policies to support palliative care in the home or community setting (21). This was first articulated in 1990, when the WHO pioneered its *Public Health Strategy to integrate palliative care into a country's health care system* (22). The strategy formulated advice and guidelines on how to implement national palliative care and cancer control programs, specifically addressing the need to develop appropriate policies, adequate drug availability, education of policy makers, health care workers and the public, and the implementation of palliative care services at all levels throughout society. Important to the public health strategy was the vision that palliative care needed to be integrated into all levels of society, from the community level upward and from palliative care experts in the health care system downward.

Soon after the publication of the WHOs Public Health Strategy, many countries began developing policies with the aim to enhance access to home-based palliative care with the intention of moving away from hospital-based and institutional care (4,8). The first countries to establish actual palliative care legislation were Hungary (1997), France (1999), Belgium and Spain (2002) (8). Later, the need to develop policies to integrate palliative care in national healthcare systems is reverberated in official documents and declarations by supranational bodies such as the Council of Europe (6,23), the World Health Assembly (5), the World Health Organization (24–26), and the Roman Catholic Church (27).

Table 1. Overview of official policies and documents with regard to palliative care (PC) in all EU countries

Countries	**Provision of PC in national laws**	**National PC plan or strategy**	**PC standards and norms**	**Responsibility for PC located in the national health department**	**Designated PC policymaker**	**Systems of auditing, evaluation or quality assurance for PC**
Austria	✓	✓	✓	✓	✓	✓
Belgium	✓	No	✓	✓	✓	✓
Bulgaria	✓	n/a	No	✓	✓	n/a
Croatia	✓	n/a	n/a	✓	n/a	n/a
Cyprus	n/a	n/a	n/a	n/a	n/a	n/a
Czech Republic	No	No	✓	n/a	n/a	n/a
Denmark	✓	✓	✓	✓	No	✓
Estonia	n/a	n/a	n/a	n/a	n/a	n/a
Finland	n/a	✓	✓	✓	✓	No
France	✓	✓	✓	✓	✓	✓
Germany	✓	n/a	n/a	✓	n/a	✓
Greece	✓	n/a	n/a	n/a	n/a	n/a
Hungary	✓	No	✓	✓	No	✓
Ireland	✓	✓	✓	✓	✓	✓
Italy	✓	✓	✓	✓	✓	✓
Latvia	✓	No	No	✓	✓	✓
Lithuania	✓	No	n/a	✓	✓	n/a
Luxembourg	✓	n/a	n/a	n/a	n/a	n/a
Malta	No	n/a	n/a	✓	n/a	✓
Netherlands	✓	No	✓	✓	✓	✓
Poland	✓	✓	✓	✓	✓	✓
Portugal	✓	✓	✓	✓	✓	n/a
Romania	No	✓	✓	✓	✓	n/a
Slovakia	✓	No	✓	✓	✓	n/a
Slovenia	✓	✓	No	✓	✓	✓
Spain	✓	✓	✓	n/a	✓	n/a
Sweden	n/a	n/a	✓	✓	n/a	✓
UK	n/a	✓	✓	✓	✓	✓
Unidentified (n) %	20 (71%)	12 (43%)	17 (61%)	22 (79%)	17 (61%)	15 (54%)

No = no documents for laws etc. exist, on account of the inquired experts. N/a = no data at all reported.
Source: Table adapted from Woitha et al. (2015) (8). *Reprinted with permission.*

1.4 The importance of home as place of care

Government efforts to integrate palliative care in national healthcare systems have concentrated on the development of policies to support palliative care in the home or community setting. There are a number of evident and less evident reasons for this strategy. Apart from the previously described challenges of ageing populations, several other arguments are explicated. In its 2018 report *The provision of palliative care in Europe*, the Parliamentary Assembly of the Council of Europe argues that:

> *'[S]ince it is both unsustainable and undesirable that an ever-increasing number of chronically ill and dying patients are cared for primarily in a hospital setting, countries should prioritize the provision of palliative care services in the community and at home, where such services can be provided at a lower cost and where people with limited access to medical facilities can be reached. It should not be forgotten that most patients want treatment options which allow them to stay in their homes as long as possible, and most people would prefer to be at home when they die. Thus, there are economic, legal, moral and social arguments for investing more in services in the community and at home.'*

First, it is implied that an increased use of palliative care at home or in the community will save costs to society. This argument can be framed within the context of limited human and financial resources in both hospital-based and residential care; resources that are expected to grow even more valuable in the near future, as more people will reach older age and more people will suffer from chronic and life-limiting illnesses. Research has shown that the costs of care at the end of life are indeed substantial, across all care settings (28–32). It is estimated that on average about 80% of a deceased persons' expenditures on medical care occur in the last year of life, of which 70% of total end-of-life expenses are inpatient (hospital) costs (33). Meanwhile, end-of-life acute hospital use remains widespread, and evidence from 38 studies indicates that on average 33-38% of patients near the end of life received non-beneficial treatments (34). As such, reducing unnecessary hospitalizations at the end of life to a minimum is a worthy goal for policy makers. However, with regard to the anticipated cost-reducing effect related to the increased use of palliative home care (35,36), the issue remains debated and current evidence is limited and ambiguous (30,37,38).

Second, it is argued that a wider availability of palliative care services in the home setting will improve accessibility of quality palliative care for those with limited access to medical facilities. Studies have indeed pointed out that the lack of suitable transport and restrictions on time are important barriers to accessing healthcare services at the end of life (39). Similarly, the area where one lives has been noted to influence access to treatment services and end-of-life care in a number of countries (40–47). This is most notably so in countries with large remote rural areas such as Canada, Australia and the United States of America (40). However, studies have also shown that hospice and palliative care services are also widely underused in urban/metropolitan populations (48,49). Additionally, a review study from 2009 on patterns of access to community palliative care services concluded that access to these services was unequal, and they were less likely used by those who are older, male, from ethnic minority populations, not married, without an informal caregiver, are socioeconomically disadvantaged, and do not have a cancer diagnosis (50). Most published studies have analyzed access to specific services, whereas a population-level evaluation of patterns of access to supportive policies for palliative home care are currently lacking.

Third, it is posited that most patients want treatment options which allow them to stay in their homes as long as possible, and that most people would prefer to be at home when they die. While home death does not necessarily result in achieving a better death (51,52), the dominant palliative care discourse views a 'good death' as one that is in line with patients' and families' personal preferences (53), and the home appears to be for most people the preferred place to receive care and die (54–57). However, for most people in Western society, this wish does not seem to be fulfilled, and death (and a substantial part of dying) often happens in settings that are secluded from everyday life (53,58–60). Despite findings of declining hospital deaths rates in the last years in a number of countries (61–66), large proportions of the population in high-income countries spend their last days in the hospital or in nursing homes, and about half of all people in those countries (including Belgium) will ultimately die in the hospital (61,67–72). Nevertheless, some quality studies have shown a positive influence of using palliative care in the home or community setting on decreasing end-of-life hospital use (35,73–76) and increasing the chance to die at home (37,77).

In short, palliative home care could be beneficial to patients and their caregivers if it succeeds in reducing unnecessary and avoidable hospitalizations and other types of inappropriate care at the end of life, while increasing the chance to receive care and die at their preferred location. Meanwhile, the increased use of palliative home care could prove promising for policy makers by reducing total healthcare expenditures and alleviating in part the dire need for human and financial resources in the healthcare sector. While the use and impact of palliative home care services have been studied before in a number of countries, previous research was often limited by having small sample sizes (35,73,78), focusing only on advanced cancer patient populations (73,78–81), or focusing on one type of intervention or one region (35,73–76,79–82). Moreover, previous research often lacked sufficiently rich data that would allow to adjust for possible confounders (e.g. by matching cohorts to evaluate impact) (76,81,83,84), and overall lacks a focus on the evaluation of national policies. Therefore, research is needed to investigate the accessibility, use, and impact of the available national policies to support palliative care at home on a population level.

1.5 Using the opportunities of big data to study end-of-life care at a population level

End-of-life care research often suffers from problems such as selection bias, recall bias and non-response bias (85–87), and difficult-to-reach populations tend to be under-represented in prospective studies due to ethical and practical considerations (e.g. very ill patients cannot participate in research, thus skewing the findings (88)). However, the evaluation of public policies requires a focus on total populations instead of only on individuals at risk or those receiving a certain health care service; this means that many, often 'hidden', populations also need to be studied (17,89). It is a challenge to provide the best possible evidence through studies that maximally limit the issues of bias and confounding often found in end-of-life care research.

Traditional experimental study designs such as randomized controlled trials are, for many topics of interest, less feasible in a real-world end-of-life care context, either because they pose enormous difficulties in a vulnerable population (e.g., problems of selection, attrition), or because they are plainly not ethically or legally acceptable (e.g., randomizing into users and non-users of palliative care services) (90). Once these policies are made available to the public, it is not possible to adopt an experimental randomized controlled trial study to test their effectiveness, since it would be illegal to restrain patients from receiving publicly available national policy measures.

Big data, such as routinely collected administrative data can provide a major opportunity in this respect. They allow not only the monitoring of usage, quality and costs of policy measures to support palliative home care on a population level (91,92), but also the identification of populations dying of or with a rare disease that are otherwise difficult to include in end-of-life care studies, such as those who died from amyotrophic lateral sclerosis (ALS) (93,94).

Administrative data refers to data that is routinely collected for administrative purposes, such as claims, and other records associated with health insurance programs and health care providers (89). These data are routinely-collected by governments or other organizations with the primary goals of providing an overview on registrations, transactions, and record keeping (95). Other frequently used terms are register-based data, electronic health records, or electronic medical records. Many administrative data systems only collect data for specific groups of individuals, for example an administrative data collection in a particular hospital or a private insurer. Such data are usually available at the person-level and records are often kept on the provision individual services and the amounts paid for those services. In some cases, a unique identifier (e.g. social security number) is available that permits a linkage to separate administrative databases that also contain this identifier, i.e. deterministic linking. In other cases, a combination of multiple non-unique identifiers (e.g., date of birth, sex, municipality of residence) can be used to link several databases at the person-level, either through deterministic linkage (i.e., when unique matches are found in different databases) or through probabilistic linking (i.e., individuals in different databases are linked based on a sufficiently high probability that they represent the same individual).

As a result of massive digitization and an explosion of data storage and processing capacity many public and private actors nowadays routinely collect large amounts of health and healthcare data that can potentially be used to study the end of life (96). An estimated 2.5 quintillion bytes of data are generated every day across all kinds of sectors, and trends indicate that the total volume of data will reach 45 zettabytes[1] by 2020 (97,98). Although not all of these data are relevant to our field of study, the increasing amount of data generated, combined with expanding technological capacities to store, link, access and analyze these data, have propelled the use of administrative and other routinely-collected databases in end-of-life care research: a yet unpublished systematic review identified ~650 articles using such data in end-of-life care that were published from 1990 to 2017, including 88 published in 2017 alone (99). Many of these, nevertheless, use data that is limited in terms of either the population or the richness of the data (e.g., only death certificate data). Currently, most studies in end-of-life care research making use of large administrative databases focus on describing patterns of use of palliative and other health care services (100–106), evaluating costs (89,107–109) or developing and testing indicators of quality of care at the end of life (110–114). However, the increasing availability of large datasets and technological possibilities to link these databases has allowed to go beyond describing patterns of use of healthcare, to retrospectively evaluate the impact of palliative care interventions on specific quality outcomes (35,73–75,115).

1.6 The policies to evaluate: available supportive measures for palliative home care in Belgium

According to the WHO, the public health approach for palliative care 'aims to protect and improve the health and quality of life of a community by translating new knowledge and skills into evidence-based, cost-effective interventions that will be available to everyone in the population who needs them' (22), and good research is needed that evaluates these policies to

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[1] One zettabyte is approximately equal to a thousand exabytes or a billion terabytes. In 2012, an estimated 2.5 zettabytes of data were generated (i.e. 18 times less than is expected in 2020).

ensure the quality of palliative care (26). In Belgium, the development of policies to support palliative home care has evolved over the last 30 years[2].

Multidisciplinary palliative home care teams

Following governmental experiments with multidisciplinary palliative home care teams since 1991, the purpose of the teams was legally defined in 1998 as a first measure to provide support to caregivers in the first line of care. The Royal Decree of Oct 13, 1998 (118) defined minimal criteria for the agreements between these teams and the National Institute for Health and Disability Insurance (INAMI–RIZIV)[3]. As of now, 28 teams signed such an agreement (15 in Flanders, 9 in Wallonia, 3 in Brussels and 1 in the German-speaking community). The multidisciplinary palliative home care teams have the following missions:

- To discuss the problems with the caregivers and to advise them about all aspects of palliative care (e.g. pain and symptom control, psychological and spiritual support);
- To inform the patient and his/her family about diagnosis, treatment and prognosis. These two first missions justify that somebody would be on duty for phone calls 24h/24;
- To coordinate palliative care by planning with general practitioners, other health care givers and volunteers;
- To ensure that the necessary care material is available at the patient's home;
- To provide psychological and spiritual support to the caregivers of the first line of care. In specific situations, only after consultation and with their permission the palliative home care team can perform specific care tasks.

The multidisciplinary palliative home care teams are financed on the basis of a system of lump sum reimbursements per patient. The lump sum is meant to cover the direct and indirect interventions of the team and the operating costs (accommodation, training of the team members, travel, telephone, administration, training of volunteers, etc.). The teams can only charge one lump sum per patient. Every team must follow a certain minimum number of patients every year in order to receive the maximum reimbursement for its costs (based on the size of the region where the team operates). The amount of the reimbursement can vary considerably from team to team, since the sum is calculated based on the composition of the team (in terms of qualifications and seniority of the team members).

Besides the creation of the home care teams, a number of additional measures were developed to guarantee a good quality of care for the palliative patient who wishes to die at home.

Financial supportive measures

The Royal Decree of December 2, 1999 (119) defines the criteria of the "palliative home patient". In order for patients to receive any statutory supportive measure for palliative home care, the general practitioner or another physician has to formally acknowledge that:

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[2] This section was largely based on information provided by the Belgian Health Care Knowledge Centre (KCE) report "Organization of palliative care in Belgium" (2009) (116) and the Federal Evaluation Cell Palliative Care (Federale Evaluatiecel Palliatieve Zorg) report "Evaluation report Palliative Care" (2017) (117).

[3] INAMI : Institut National d'Assurance Maladie Invalidité ; RIZIV : Rijksinstituut voor ziekte- en invaliditeitsverzekering

- the patients suffers from one or more irreversible diseases that are evolving unfavorably;
- his/her physical/psychological situation is seriously and generally deteriorating; therapeutic interventions and revalidation do not longer affect this unfavorable evolution;
- the prognosis is bad, and death is due in short time (life expectancy between 24 hours and 3 months);
- there are serious physical, psychological, social and spiritual needs that require time-consuming and continuous assistance;
- if necessary, caregivers with specific competences are called upon and appropriate technical means are used;
- the patient is staying at home or has the intention to die at home;
- he/she meets the conditions defined in the form annexed to the Royal Decree'[4].

The following financial supportive measures for palliative home care are available in Belgium:

1) *The allowance for palliative home patients*

A flat rate lump-sum allowance (an amount of 673,11 euros as of 2019[5]) to compensate in the costs of medicines, medical devices and care products required for the home care of palliative patients. The allowance can be extended once after one month. The amount remains fully acquired, even if the patient should die within 30 days. The amount is awarded a second time if the patient continues to meet the conditions after the thirty days after the notification and after following the same procedure (i.e. the general practitioners files the request).

2) *Nursing care for palliative home patients*

Lump sum fees and supplementary fees for providing nursing care to palliative home patients are imbedded in the nomenclature for home nursing. These are amounts that cover all nursing care and support of the home patient with the palliative status (i.e. the fees are provided to the nurse, not the patient). The personal contribution (out-of-pocket cost) for nursing care of the palliative home patient was also eliminated by full reimbursement of healthcare costs. If the patient outlives the predetermined life expectancy of 3 months and still receives nursing care at home, the health insurer will continue to pay the palliative nursing lump sum for as long as the home nursing lasts.

In order to qualify for the fees and flat-rate supplements of nursing care for palliative home patients, the nurses who provide care must meet different specific conditions:

- have one of the following qualifications: licensed or undergraduate nurse or equivalent, or midwife;
- guarantee continuous care for the patient (24/24 hours, 7/7 days);
- can call on a reference nurse with knowledge of palliative care;
- fill in the nursing file with the following important information for this type of care:

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[4] The criteria described above were in effect at the time of writing this doctoral dissertation. However, it should be noted that an amendment to the criteria for the palliative status was published in the Royal Decree of October 20, 2018 (84), replacing the life expectancy criterium with an alteration of the internationally validated SPICT-tool (i.e. the PICT-tool) to help identify people at risk of deteriorating and dying with one or more advanced, progressive conditions or a new life-limiting illness.

[5] The allowance for palliative home patients is subject to an annual indexation.

    - registration of symptoms,
    - filling in the pain scale,
    - report contacts with the patient's family,
    - report results of the coordination meetings.

3) *Physiotherapy for palliative home patients*

The personal share (out-of-pocket costs) for physical therapy was eliminated by full reimbursement of healthcare costs. Since the regulation contains no specific provision on the duration of the abolition of the personal share, the same principle is followed as for the palliative status: once the approval by the advisory physician has been obtained, the abolition of the personal share for home visits of the physiotherapist applies until the patient has died.

4) *Abolition of the personal share for general practitioner consultations*

Patients with the palliative status are known to the health insurance funds and for them an automatic full reimbursement of the remunerations on the GP visits applies. Again, the same principle is followed as for the palliative status: once the approval by the general practitioner has been obtained, the full reimbursement applies until the patient has died.

1.7 Supportive policies for informal caregivers of people receiving palliative care at home Belgium

In the specific context of palliative care provision, the Belgian law has made it possible for every employee to take a paid palliative care leave from work – fulltime, halftime or 20% leave – to give medical, social, administrative and psychological care and assistance to a palliative home patient. By principle every employee who offers informal palliative care has the right to take this leave; a familial tie to the palliative care patient is not required. The time period is limited to a maximum of two months for the same patient. Informal caregivers in Flanders, Belgium are entitled to the 'Flemish encouragement allowance' ("Vlaamse aanmoedigingspremie"), which is a supplementary benefit on top of the paid palliative care leave from work.

1.8 Research questions and study objectives

Throughout this dissertation, the terms 'palliative home care support', 'supportive policies for palliative home care' and 'policy measures to support palliative home care' are used interchangeably.

The overarching **definition** that we used was the following:

> *Those policy measures that, in addition to the standard primary care services available, directly support the provision of palliative care at home and are, specifically or not, intended for patients identified as "palliative", or their informal caregivers.*

The main objective of this dissertation is to examine the availability, use and impact of policy measures to support palliative home care in Belgium. The following three aims, each with specific research questions, guide this dissertation:

The first aim is to examine how policy measures to support palliative home care can best be investigated on a population-level. The following research questions will be answered:

1. Which population-level databases provide valid information about sociodemographic and clinical background of a person, their uptake of palliative home care support and of health care and medication use before the end of life, including their costs? What procedures are there to use these databases? What is needed to integrate separate databases into a workable dataset?

The second aim is to map the availability of policy measures to support palliative home care in Belgium, and to compare these to available measures in other countries. The following research questions will be answered:

2. What policy measures to support palliative home care are available to patients or informal caregivers across different European countries with a similar contextual background? How do policy measures to support palliative home care in different countries with a similar contextual background compare to each other in terms of the extent of what is offered and the criteria for receiving it?

The third aim is to describe the use and factors that are associated with use and trends of palliative home care support in the Belgian population, as well as in specific subpopulations in the Belgian population. The following research questions will be answered:

3. What is the uptake of policy measures to support palliative home care in the Belgian population, and in a subgroup of people who died of an illness indicative of palliative care needs in the Belgian population? What sociodemographic and disease-related characteristics are associated with the uptake of these supportive measures in the Belgian population, and in a subgroup of people who died of an illness indicative of palliative care needs in the Belgian population?
4. What is the uptake of palliative home care support in people who died from amyotrophic lateral sclerosis in Belgium? What patterns of healthcare use at the end of life are found in these persons?
5. Are there trends in the uptake of palliative home care support among all persons living at home who died from an illness indicative of palliative care needs in Belgium between 2010 and 2015? Is there a trend towards earlier initiation among those who used any of these types of palliative home care support?

The fourth aim is to investigate the impact of using palliative home care support on the quality and costs of care at the end of life. The following research questions will be addressed:

6. What is the impact of palliative home care support on the quality of care and costs in the last 14 days of life?

1.9 Methods

To answer the research questions of this dissertation, several data sources were used. These can be grouped into two categories based on whether the study design was qualitative (1) or quantitative (2). The methods are explained in the following paragraphs.

1.9.1 Cross-national comparative study using policy document analysis and expert consultation

We performed a case-oriented cross-national comparative study using national policy documents and individual interviews with experts (written and by telephone) as the main sources of information to study the availability of policy measures to support palliative home care in Belgium, France and Germany (**research question 2**). We focused on these countries because they have comparable societal challenges in terms of population ageing, health care systems, and sociodemographic and politico-economic backgrounds (120). This selection of a relatively homogeneous context allowed to identify policy differences specifically related to policy measures to support palliative care at home that do not reflect health care or welfare system differences.

The comparative analysis was done following five steps:

1. Policy analysis in one country (Belgium): the primary analysis was performed for Belgium based on practical considerations such as preliminary knowledge of the health care system and the language of the main investigators of the study. We consulted relevant policy documents, governmental web pages, and scientific literature and listed all identified policy measures. The aim was to identify those policy measures that, in addition to the standard primary care services available, directly support the provision of palliative care at home and are, specifically or not, intended for patients identified as "palliative." The overview was validated to check for its accuracy and completeness by a palliative care expert and an expert in charge of palliative care within the National Institute for Health and Disability Insurance.
2. Construction of a conceptual framework: based on our policy analysis findings for the Belgian case, we constructed a conceptual framework of policy measures to support palliative care in the home setting according to the *target audience* (to whom is the measure directed?) and the *type of measure* (what kind of support does the measure offer?)
3. Identifying and questioning international palliative care experts: we identified palliative care experts relevant to the research in France and Germany and invited them to collaborate in our study. We sent them an electronic document in the form of a questionnaire to complete for their country, with a completed copy for Belgium as an example.
4. Validation of the responses by health care policy experts: the completed information for each country was then sent for validation to a national health care policy expert best placed to comment on palliative care policy measures (analogous to the second expert used in Belgium).
5. Combination and comparison of data: in the final step, we put together the validated data for comparison in a table. All co-authors received this integrated version for discussion and revision.

During the whole process of data collection, there were multiple reiterations and face-to-face and written consultations between all authors to avoid conceptual ambiguities. This method allowed to describe and compare in detail all available policy measures to support patients and caregivers in a palliative care situation in the home setting. More information about the methods of the study is provided in Chapter 3.

1.9.2 Linked administrative and disease-specific databases

The first aim of this dissertation was to explore how the use and impact of these measures can best be investigated on the population-level (**research question 1**). To achieve this, we systematically collected the necessary information in four phases:

1. First, we identified what databases provide information on the health care use, quality and costs near the end of life. We retrieved healthcare use data from all decedents for the two years prior to their death. Health claims data were used as the starting point as they provide critical data about patterns in formal care and medication prescription at the end of life. Other administrative databases and disease registries were explored to supplement the health claims database.
2. Once the databases and the data handling organizations were identified, we explored the associated access procedures and permissions as well as linking possibilities.
3. We determined, explored and followed, technical aspects and privacy protection measures to complete the linking procedure.
4. Finally, we composed an overview of available variables through this process. We examined how they can be used to study use, quality and costs of end-of-life care.

We identified a total of seven population-level databases handled by three different organizations, providing information on all those who were registered with a Belgian sickness fund at time of death (about 98.8% of all deaths). The linked data included person-level reimbursed healthcare use in the last 2 years of life (recorded as nomenclature codes) including dispensed medication in the hospital and community pharmacy in the last 2 years of life (recorded as Anatomical Therapeutic Chemical Classification System (ATC) codes). For all healthcare data, the exact date of delivery (coded as number of days before death) is recorded. Additionally, the data include demographic data, fiscal data (i.e., net taxable annual income) and death certificate data (including underlying cause of death, coded using International Statistical Classification of Diseases, Tenth Revision (ICD-10) codification (121)).

In a first phase of the project, the linkage was completed for all individual-level data, comprising all 107,847 deaths in Belgium in 2012. These data were used to analyze the uptake of palliative home care support and related factors that influence uptake (**research question 3**) and in the study that evaluated the impact of palliative home care support on the quality of care and costs at the end of life (**research question 6**). Based on the first analysis phase, detailed information was aggregated so that more cases with more condensed information per case could be delivered. In this second phase, data from subsequent years was added for all deaths between 1 January 2010 and 31 December 2015, comprising a total of 634,445 deaths. The data containing information for 6 consecutive years were used for analysis in the study that describes healthcare use at the end of life in patients who died from amyotrophic lateral sclerosis (**research question 4**) and in the study that evaluates trends in the use of timing of initiating palliative home care support (**research question 5**).

Subsets of the entire dataset were used with specific attention to the research question. Information with regard to residence in the last year of life was used to exclude people who lived in a collective household (including nursing homes) (**research questions 3, 5, 6**). Underlying cause of death was used to restrict the population to those who were potentially in need of palliative care (122,123) (**research questions 3, 5**); using the 10th revision of the International Classification of Diseases (ICD-10) (121), the following underlying causes of death were selected: neoplasms (ICD-10 C00-C97), organ failure (i.e. heart, renal, liver failure or COPD; ICD-10 J40-47, I11-13, I50, K70-72, N10-12, N18-19), dementia (ICD-10 F01, F03, G30) and other illnesses (i.e. Parkinson's disease, motor neuron disease, HIV/Aids and non-cancerous neoplasm; ICD-10 D00-48, G20, G12 and B20-24). Underlying cause of death was used to restrict the population to those who died from amyotrophic lateral sclerosis (using ICD-10 code G12.2, i.e. motor neuron disease) (**research question 4**). The use of at least one type of palliative home care support between the last 720 and 14 days of life was used to define the exposure group in the matched cohort study design; individuals who did not use palliative home care support in the last two years of life were included in the non-exposure group and matched to a case in the exposure group based on their individual propensity score to use palliative home care support (**research question 6**).

The full process from exploration to finalized linked dataset, including details on the variables and database sources, is described in Chapter 3. More information about the data analyses for each research question can be found in the Chapter where the research question is addressed.

1.10 Outline of dissertation

This doctoral dissertation is divided into four parts and contains eight chapters, a Dutch summary of the main findings, curriculum vitae, and appendices. Following this introduction, chapters 2-7 are based on articles which have been published, accepted or submitted for publication. All of these chapters can also be read independently.

The four main aims of this dissertation are addressed in separate parts. Each part consists of one or more chapters that answer the specific research questions of each aim.

Part I offers a detailed discussion on the use of linked administrative databases to conduct end-of-life care research. This part aims to answer research question 1 described on page 22 and also serves as a thorough description of the methodology and data that was used for chapters 4-7.

In Part II we explore the availability of palliative home care support measures in Belgium, France and Germany, and discuss how these countries compare to each other in terms of the criteria for access and in the extent of what is offered. This part aims to answer research question 2 described on page 22.

In Part III we examine the uptake of palliative home care support measures, factors associated with uptake, and trends over time in Belgium. This part aims to answer research questions 3-5 described on pages 22.

In Part IV we investigate the impact of using palliative home care support on the quality and costs of care at the end of life, using a retrospective matched cohort design. This part aims to answer research question 6 described on page 22.

The final chapter of the dissertation consists of the main findings of the study, a reflection on its strengths and limitations, a discussion of the findings in the light of current challenges and state of affairs within end-of-life care research and practice, and the implications of the findings for healthcare practice, policy, and future research. Finally, a Dutch summary of the main findings, curriculum vitae, and appendices conclude the dissertation.

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Part I ※ Using big data in end-of-life care research: opportunities and barriers

2 Using linked administrative and disease-specific databases to study end-of-life care on a population level

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Abstract

Background: The use of full-population databases is under-explored to study the use, quality and costs of end-of-life care. Using the case of Belgium, we explored: (1) which full-population databases provide valid information about end-of-life care, (2) what procedures are there to use these databases, and (3) what is needed to integrate separate databases.

Methods: Technical and privacy-related aspects of linking and accessing Belgian administrative databases and disease registries were assessed in cooperation with the database administrators and privacy commission bodies. For all relevant databases, we followed procedures in cooperation with database administrators to link the databases and to access the data.

Results: We identified several databases as fitting for end-of-life care research in Belgium: the InterMutualistic Agency's national registry of health care claims data, the Belgian Cancer Registry including data on incidence of cancer, and databases administrated by Statistics Belgium including data from the death certificate database, the socio-economic survey and fiscal data. To obtain access to the data, approval was required from all database administrators, supervisory bodies and two separate national privacy bodies. Two Trusted Third Parties linked the databases via a deterministic matching procedure using multiple encrypted social security numbers.

Conclusion: In this article we describe how various routinely collected population-level databases and disease registries can be accessed and linked to study patterns in the use, quality and costs of end-of-life care in the full population and in specific diagnostic groups.

Background

It has been argued that there is a particular challenge for end-of-life care research to develop a public health approach (1) which would include, among other things, the need for a focus on total populations instead of individuals at risk or those receiving a certain health care service. This means that many, often 'hidden', publics also need to be studied (1, 2). End-of-life care research indeed often suffers from selection bias, recall bias and non-response bias (3–5) and difficult-to-reach populations tend to be under-represented due to ethical and practical considerations (6).

Administrative data can provide a major opportunity in this respect. They allow not only the monitoring of usage, quality and costs of end-of-life care on a population level (7), but also identifying populations dying of or dying with a specific disease such as cancer, chronic obstructive pulmonary disease (COPD) or Alzheimer's disease in order to evaluate patterns of end-of-life care within and across different trajectories of dying (8). Many healthcare institutions generate, store and exchange large amounts of individual patient data (9). Increasing digitalization in recent years has further facilitated and improved this process (10). Although big data serve administrative purposes particularly (e.g. billing, tracking of health care reimbursement) they can provide useful research material from a public health perspective (11). They often have a well-defined population and include subgroups or difficult-to-reach populations (6). Because administrative data registrations are usually standardized and continuously collected they enable trend analyses and longitudinal studies. Moreover, since the data have already been collected, they are relatively inexpensive when compared with original data collections (2, 12). The expanding availability and quality of data input make them increasingly interesting to use in health research. Although full-population databases have been used to study end-of-life care since the late nineties (e.g. in Australia (13) and Canada (14)), the use of such data in end-of-life care research is still under-explored.

End-of-life care researchers may face several challenges when using administrative data. Administrative data are, for instance, not specifically designed for research purposes and therefore not directly usable for the evaluation of quality of care or quality of dying. They are not structured in readily available variables for analysis and may often lack the essential disease-specific or relevant socio-demographic information needed in end-of-life care research. Additionally, healthcare data, socio-demographic data, socio-economic data and clinical data gathered on every citizen are stored in separate databases that are owned and handled by different organizations. Also, data security and confidentiality must be publicly guaranteed when using administrative databases for healthcare research. The challenge is thus to collect, link, integrate, store and process them so that they provide a useful input for end-of-life care research.

Using the case of Belgium, we describe how several full-population data sources can be accessed, linked, handled and stored in order to obtain a rich database for evaluating the use, quality and costs of end-of-life care. Our research questions are: (1) What data and databases are available that provide information about end-of-life care?; (2) What are the procedures to obtain/use these data?; (3) What is needed to integrate separate databases?; and (4) What variables are available in these databases to study use, quality and costs of end-of-life care?

Methods

To address our research aims we systematically collected the necessary information in four phases:

1. First, we had to identify what databases provide information on the health care use, quality and costs near the end of life. We aimed to retrieve healthcare use data from all decedents for the two years prior to their death. A group of end-of-life researchers and health economics experts explored what data are available on healthcare and medication use that additionally (1) allow identification of people dying with or from cancer, Alzheimer's disease or COPD; and (2) provide relevant socio-economic and demographic information that is known from literature to influence end-of-life care patterns. Health claims data were used as the starting point as they provide critical data about patterns in formal care and medication prescription at the end of life. Other administrative databases and disease registries were explored to supplement the health claims database.
2. Once the databases and the data handling organizations were identified, the associated access procedures and permissions as well as linking possibilities were explored.
3. To complete the linking procedure, technical aspects and privacy protection measures were determined, explored and followed.
4. Finally, we composed an overview of available variables through this process. We examined how they can be used to study use, quality and costs of end-of-life care.

Results

Identification and selection of databases

A total of seven population-level databases handled by three different organizations were identified as providing the necessary information (Table 1).

Table 1. Overview of population-level databases identified as relevant for end-of-life care research

Database administrators	**Database name**	**Population**	**Information provided in database**
Inter Mutualistic Agency (IMA)	Population Database	Every Belgian citizen who is a member of one of the seven (compulsory) Belgian sickness funds, information in Population Database is updated twice each year from 2002 onwards	Socio-demographic characteristics including age, sex, date of death, place of residence, family composition, use of financial support measures
	Pharmanet Database		Medication supply characteristics including: substance, quantity, prescriber, expenses, refunds, delivery date
	Medical Claims Database		Health and medical care use characteristics including: quantity of use, reimbursement, supplier, supplier institution, length of treatment
Belgian Cancer Registry	Cancer registry	Every new cancer diagnosis of Belgian residents registered by oncological care programs and laboratories for anatomic pathology	Diagnostic characteristics including: date of diagnosis, type of cancer, TNM gradation
Statistics Belgium	Death certificate database	Every Belgian decedent with a registered death certificate	Direct and indirect causes of death (in ICD-10 codes), socio-demographics about the deceased, place of death
	Demographic dataset	Every Belgian citizen	Nationality group (16 most common nationalities in Belgium + category other), household composition
	Socio-economic survey (SES) 2001 and Census 2011	Every Belgian citizen, information gathered from multiple external administrative databases using social security number (Census 2011)	Highest attained education level, occupation, housing
	IPCAL dataset	Every Belgian citizen	Net income by category
	Identified but not used in our research		
Belgian Ministry of Health	Minimal Hospital Dataset	Every hospital admission in non-psychiatric general hospitals	Medical, nursery and personnel data for in-hospital care

The Inter Mutualistic Agency (IMA) manages the databases that included all reimbursement data of health care consumption from all seven healthcare insurers. Since health insurance with one of these insurers is legally mandatory in Belgium, reimbursement data of all legal residents are available in the IMA database. Moreover, thorough quality procedures result in reliable usability of the database for healthcare research. The IMA manages three databases: (1) a population database containing socio-demographic data of all insured persons; (2) a health care database containing health care use and costs data of both ambulatory and hospital care and (3) a pharmaceutical database containing medication prescription and costs data. The databases thus provide information on an individual level across the entire Belgian population. The IMA databases contain no information regarding medical diagnoses or any disease specific information.

The Belgian Cancer Registry was identified as a database to identify people who died with cancer. All Belgian oncological care programs of hospitals and laboratories for anatomic pathology are legally bound to register each new cancer diagnosis with the cancer registry. The latter manages a database with diagnostic information on all incidences of cancer i.e. date of diagnosis, type of cancer and TNM (tumor node metastasis) classification of malignant tumors (15).

However, the cancer registry data does not make it possible to distinguish between those who died 'from' cancer and those who died 'with' cancer. Additionally, since no similar registries were available to identify those who died with or from Alzheimer's disease and COPD we identified the death certificate data as a necessary additional database. Death certificate data in Belgium are collected by three administrations (corresponding to the three semi-autonomous regions in the country, i.e. Brussels, Flanders and Wallonia) and are integrated by Statistics Belgium into one national database for cause of death statistics. This database provides the causes of death and associated causes of death (coded in ICD-10 (10th revision of the International Statistical Classification of Diseases and Related Health Problems) codes) for all decedents.

Statistics Belgium also manages the national demographic database, derived from the population register (16) and containing for example the household composition of every citizen and data from the Socio-Economic Survey 2001 and Census 2011, nationwide full population surveys based on the tradition of population count (17). The database contains information about the highest educational level attained, the last held occupation (as a measure of socio-economic position) and housing characteristics, which are all socio-economic factors that have been identified in previous studies as affecting end-of-life care patterns (18–20). Finally, a database containing fiscal data (i.e. net taxable household income), also managed by Statistics Belgium, was identified as providing additional socio-economic variables of influence on end-of-life care patterns.

For more specific clinical data, the Minimal Hospital dataset, providing clinical information associated with hospitalizations, was looked at for possible inclusion. This dataset has high quality data and provides diagnostic information (in ICD-codes), which allows for a more exact clinical description of the study population. It is however limited to in-hospital data, limiting the study population. Additionally, clinical information can be abstracted from health care claims data using specific algorithms. Obtaining cause of death information and using healthcare claims data makes up for the lack of clinical data. Therefore, inclusion of the Minimal Hospital dataset was found to be unnecessary.

The combination of identified databases would provide information on formal health care and medication prescription, causes of death, main diagnosis (through the cancer diagnostic information of the cancer registry and algorithmic estimation methods in the IMA databases), and various relevant socio-demographic and socioeconomic information.

Access procedures

Two types of approval were needed for every database: (1) internal approval from database administrator organizations and (2) approval from the relevant Belgian Privacy Commission bodies.

1. To obtain access to the IMA and cancer registry databases several steps are required. First, a declaration of interest needs to be set up between researchers and IMA and cancer registry program managers. Research goals, databases, variables and linking possibilities (see Data linkage procedure) need to be discussed. After IMA and cancer registry program managers agree on cooperation, the research project (research goals and requested data) is presented to IMA and cancer registry directory boards for approval.

   To obtain access to the databases administered by Statistics Belgium, no formal approval of the directory board is required, since Statistics Belgium is legally committed to providing data for research. Based on the requested data, variables and linking possibilities (see Data linkage procedure) the statisticians of Statistics Belgium deliver non-binding advice. Data requests should be filed directly to the Privacy Committee.

   All involved partners then discuss the final selection of data and variables and initiate preparations for the linking procedure. The linking of the databases is a main issue for approval by the involved Privacy Commission bodies.

2. We needed the approval of two separate national sectoral committees for privacy protection for access to the various databases and the database integrating all databases: the 'Sectoral Committee of Social Security and Health, Section Health' and the Statistical Supervisory Committee'. Both are subcommittees of the Belgian Commission for the Protection of Privacy. The former is responsible for privacy protection of health care data (IMA and cancer registry databases), the latter for privacy of national statistical data (Statistics Belgium databases). The application to the Sectoral Committee of Social Security and Health, Section Health consists of two phases. Phase 1 is the submission of the application and a first assessment by the committee in a plenary meeting. The primary investigator of the study presents the research goals and data linkage procedure to the committee at this plenary meeting. In our application special attention was given to the selection of different variables to receive data with enough detail for analysis, but at the same time reducing the risk of re-identification of deceased individuals and their families to preserve privacy. Changes in the linking procedure and storage on a separate server were requested (see section on data linkage for more details). Phase 2 is the formal approval during a second plenary meeting of the committee, after having received

additional information from the applicant. In our case, the committee requested an additional risk analysis to ensure privacy of the included individuals, which was not requested in the first phase. Formal approval was granted only after a third plenary meeting. The full process took six months from application to formal approval.

The Statistical Supervisory Committee application procedure consists of one phase in which the application is assessed and discussed on a plenary meeting. Formal approval was granted after the first meeting.

Data linkage procedure

All eligible databases needed to be linked into one integrated database for analysis; a common unique identifier (i.e. social security number) made deterministic linking possible. Although the death certificate database does not contain this unique identifier, Statistics Belgium performed a linkage between the death certificate database and the national registry database based on date of birth, sex, and municipality of residence to include this unique identifier as a variable. Unique linkage was possible for 98.4 % of deaths.[6]

For privacy reasons, Trusted Third Parties (TTPs) 'eHealth' and 'Crossroads Bank for Social Security (CBSS)' were responsible for the simple deterministic one-to-one record linkage of the IMA, cancer registry and Statistics Belgium databases. The linkage procedure (Figure 1) consisted of 13 steps of data-coding or decoding and data transfers needed to ensure that none of the involved parties would have access to both the sensitive data and the social security numbers or to their own databases enriched with data from one of the other parties. Only the researchers have access to the complete linked database without unique identifiers using a Virtual Private Network (VPN) connection with secure token.

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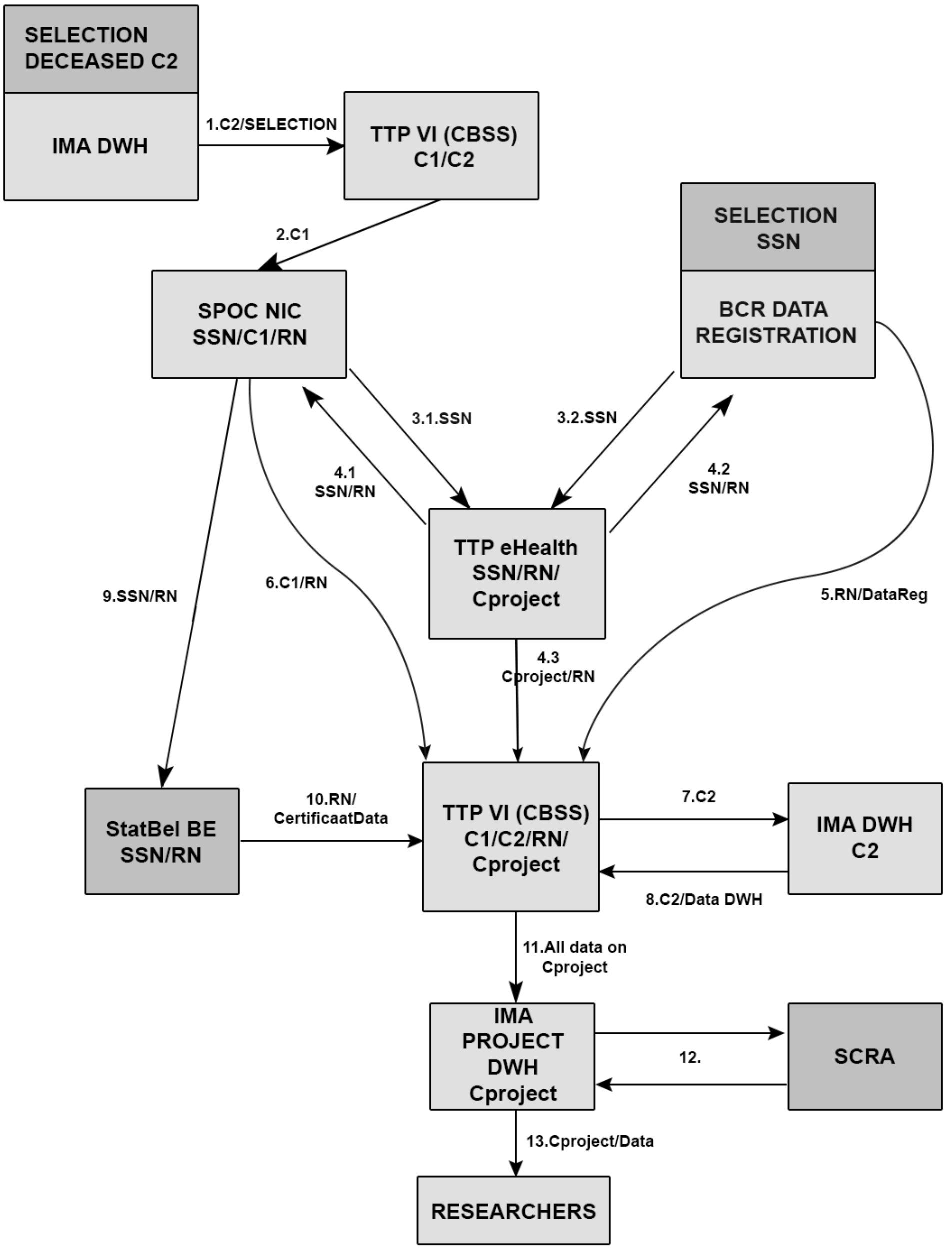
[6] 1Between 1998 and 2013, 1,662,550 of 1,689,740 deaths were matched (98.39 %).

Figure 1. Data linkage procedure



Linkage of all data for deaths in 2012 (including health care information about the two years prior to death) were completed in a first phase of the project. In a second phase all data for all deaths 2010-2015 are linked, where data from subsequent years will be added upon availability. A major consideration in the decision to adopt this phased approach is the size of the linked database. The linked database (deaths in one year) will be used for the initial analysis, after which a selection of variables and/or information can be made. Variables with too many missing data or variables that are inaccurate can be dropped. Additionally, the initial analysis will inform on what health care interventions or medications are suitable for further analyses. Finally, based on this first analysis phase, detailed information can be aggregated. The second and third delivery will therefore include more cases with more condensed information per case.

Since all databases depend on submission by individual organizations or institutions, a two-year delay is common. Linkage can only be initiated after all data are complete.

Available information and data handling

Variables selected in this study include data on health care use, prescribed medication, demographics, socio-economics and use of special reimbursement rules. A complete list of variables can be found in Additional file 1: Table S1. Several steps were necessary to make the data analysis-ready:

1. In the IMA databases, health care and medication data are coded as nomenclature and Anatomical Therapeutic Chemical Classification (ATC) codes. To answer research questions, nomenclature numbers had to be interpreted and possibly aggregated by the researchers into meaningful categories.
2. Due to privacy concerns, no raw dates (e.g. date of birth, prescription date) were provided by database administrators. Dates of medication delivery or health service provision were therefore transformed into number of days before death. Combinations of these recoded dates and nomenclature or ATC codes are used to determine whether certain interventions occur within a certain time-period before death.
3. Since no data were provided on diagnosis in the current set of linked databases (only causes of death are available), algorithms were used to abstract diagnostic information from health care and medication prescription data. Algorithms were developed to identify people with COPD or Alzheimer's disease, based on treatments and medication received. The algorithms were developed using existing evidence (21–23) and were validated by medical experts and medical data experts from the IMA. They were then applied by the IMA, prior to the linking procedure, because data were used that were not available to the researchers; data provided to the researchers were limited to two years prior to death, while data used for identification of patients with Alzheimer's disease went back to six years before death. Combinations of the algorithmic identification of diagnosis and the causes of death (including the associated causes) can be used to identify relevant disease groups in the analyses.

Discussion

Summary of main results

In linking information from seven different datasets we managed to obtain a database that can provide information about patterns in the use, quality and costs of end of life care at the level of the full population and their associations with various clinical, sociodemographic, socio-economic and environmental factors. The process of obtaining this involved detailed identification of databases fitting the study aims, negotiation with and formal approval of three database administrators, three supervisory bodies and two national privacy commissions and eventual linking of all databases through two Trusted Third Parties (TTPs) using multiple encrypted social security numbers.

We believe that the described process can be particularly helpful to researchers in other countries in compiling similar population-level databases on end-of-life care. Several considerations (limitations, strengths and opportunities) and recommendations can be made based on our experience.

Limitations of our study

Our study involved a systematic and thorough exploration of how several databases providing information on end-of-life care can be accessed, handled and linked into an integrated and enriched database. However, an important limitation is that linkage with information on patient-related outcomes of healthcare services, such as specific Patient Reported Outcome Measures (PROMs) was not explored in our study. Even though PROMs are important indicators to evaluate whether increased healthcare expenditure results in better health outcomes, their inclusion in a population-level database is only meaningful if there is enough standardization in the measurement methodology. In Belgium, a common coding system for PROMs is lacking and would be time-consuming to perform. (24) Future efforts could be made to include PROMs at a population level.

Opportunities of the collected database

Our efforts resulted in a population-level database with detailed information about formal end-of-life care, the costs of care and demographic, socio-economic and diagnostic information on decedents. The opportunities provided by such a database to study use, quality and costs of end-of-life care are considerable. The main overall advantage is that data are population-level and therefore not subject to sample bias such as in surveys or medical records studies of selected groups of patients. Compared to primary data collection, using linked routinely collected databases as in our case is less expensive and less time-consuming. In the end-of-life care context specifically, primary data collection can be burdensome for patients and caregivers. Furthermore, in routinely collected databases, high-quality data are available on the spot, although they are not deliberately collected for research aims.

Although the linked database does not include certain types of information that are important in evaluating quality of care, such as patient-specific preferences of care, psycho-social information, patient or family reported outcomes and experiences or information about pain and symptom management or communication aspects (25), the full-population data have the potential to provide robust and population-level measures of the quality of end-of-life care using specific claims-based quality indicators. These quality indicators, e.g. mapping inappropriate end-of-life care, have been used in various studies as measures for the quality of end-of-life care (26). If preceded by an adequate validation process, they can provide a detailed image of the quality of end-of-life care by regions or health care providers (26). The linked database also contains data on all direct medical costs and reimbursed service and medication use, which offers opportunities to study direct medical costs and patterns in the use of specific end-of-life care for full populations. Policy measures that support palliative care include financial compensation directed towards the patient (e.g. monthly lump sum to cover additional costs for palliative home patients). Using this database, patterns in the uptake of these measures can be mapped and compared between population or pathology groups. As the linked database contains individual data, these data can be aggregated on multiple levels, which makes longitudinal, disease-, treatment- or provider-specific analyses possible. As a result, it is also possible to evaluate the influence of certain policy measures and governmental support programs. Without the rich population-level data we collected it would be impossible to answer these example research questions without facing major issues of reliability, generalizability, feasibility and costs.

Data allow us to follow back the treatment history and costs of those treatments up to two years before death. Although a shorter period before death may be sufficient to study several aspects of end-of-life care in specific disease groups, for other (particularly non-cancer) longer time periods are warranted. The decision to request all health care and medication data up to two years before death (irrespective of when the diagnosis was made) was also made for practical reasons as going further back would substantially increase storage and analysis requirements.

Limitations of the collected database

A limitation of these types of routinely collected population-level data is that services not covered by insurers are not included. Researchers from other countries that wish to compile a similar database need to remember that what is not covered by insurance (and hence not found in the data) may be country- or even region-specific. In Belgium, data are relatively complete, for health care services in the hospital, nursing homes and at home. Nevertheless, use of certain services cannot be identified because there is no individual reimbursement (e.g. mobile hospital palliative care teams) or such reimbursement is not regulated or generalized (e.g. consultations of a psychologist). Secondly, total out-of-pocket spending is not available in the integrated database. This results in an overall underestimation of the total cost of end-of-life care. Nevertheless, administrative data are an essential source of information for studies on the financial burden of end-of-life care for the health care budget and are valuable for policymakers in informing their decisions on health care policy (8).

Considerations and actions for researchers considering similar database constructions

The linkage process is crucial in obtaining a useful population-level database. It enables the enriching of the population-level data on formal end-of-life care and the costs of that care with putative demographic, socioeconomic and diagnostic information for the study of end-of-life care patterns. This allows the development of explanatory models and the provision of public health information to policy makers, for example on social differences and differences between pathology groups. It can support discussions on the organization of the health care system, based for instance on possible existing inequities. The flip side is that the linking can create additional difficulties in the process of obtaining the data. While deterministic linking is relatively easy to complete on a technical level (even without identical unique identifiers a deterministic linking is possible based on a combination of variables), the main challenges or researchers lie in the fact that 1) several separate organizations have to be convinced to cooperate and 2) special attention needs to be given to privacy-related issues.

Databases across health and social care may not always contain a unique identifier variable, or not always contain accurate and fully available information that allows identifying unique persons. In such cases where the possibility to perform deterministic linkage is limited the method of probabilistic linking can present a solution. In this approach the likelihood of a correct linking is calculated, and a linking is done when the likelihood is sufficiently large (27). Several tools have been developed to perform this probabilistic linking (28). Nevertheless, a lack of accurate and fully available personal identifiable information constrains a probabilistic linking method.

Box 1. Considerations for researchers planning to link databases

Topics	**Considerations**
Exploring relevant databases	Are my research questions clear and well-defined? What data are needed to answer them? What is/are my study population(s)? What data are needed to identify it? What database(s) contains the core data and could thus be selected as a starting point? When a starting database is chosen, what data are lacking to fully address the research questions? Where can we find them? How can we establish contact with the database administrators of the databases? Obtain principal approval from all administrators (e.g. by presenting the study to the board of directors) What is the cost associated with each database?
Variable selection	What specific variables do we need from the selected databases to answer our research questions? Are the variables we want available and linkable between the different databases? Does the preferred selection of variables complicate the linking procedure considerably? Balance the gain in information with the increase in complexity and time. What is the required level of detail for each variable? Balance the preferred level with what is allowed in terms of data protection (e.g. through small cells risk analysis to determine risk of reidentification based on a combination of variables) Do we have sufficient storage capacity and analysis hardware to store and analyze all the data we want?
Access procedures	What ethical and privacy procedures need to be followed to link and access the selected database? What technical procedures need to be followed to link and access the selected databases?
Infrastructure	How will data be stored safely? Is infrastructure provided by researchers or by database administrators? What is the cost for this infrastructure? How will data be protected? Physical and digital protection need to be guaranteed. How can data be accessed in a safe and easy way? What hardware and software do we need to access and analyze the requested data?

A final consideration for researchers who wish to have access to similar data in their country is that establishing and maintaining good relationships with database administrators is crucial. Gaining access to administrative data is an iterative process that requires a lot of preparatory work. Database administrators are the researchers’ access points to the data and have all the information about internal procedures. Strict procedures need to be followed, in close cooperation with database administrators. We were able to arrange an updated dataset where data from subsequent years will be added upon availability in the same approval and agreement, which limits the time of going through all necessary permissions each time an updated dataset is needed. Since administrative data are often not gathered with the intention of research, or only for internal use, the process of making the data analysis-ready can take time. Researchers must adapt to how data are registered and stored, before they can effectively use them for research.

Conclusion

Linking and accessing various routinely collected population-level databases involves challenges but offers substantial opportunities to study patterns in the use, quality and costs of end-of-life care both in the full population and for specific diagnostic groups. This study has identified that it is possible to combine data from different databases in order to obtain a rich database for such analysis, including information about all reimbursed care and medication as well as disease, demographic, socio-economic and environmental information. While some aspects may be specific to the Belgian context, our study has a much broader application as most developed countries collect similar population-level databases. The process described in our study can be a helpful aid for researchers in these countries to compile similar data and eventually develop an international comparative end-of-life care research agenda using administrative health care data.

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Part II ※ Availability of palliative home care support measures

3 Policy measures to support palliative care in the home setting: a cross-country case comparison in three European countries

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Abstract

Background: The proportion of people in need of palliative care worldwide is rising, and the majority wish to receive this care at home. Many countries have created policy measures to support palliative care at home.

Aim: To list and compare existing policy measures designed to support palliative care at home in addition to available primary care services in Belgium, France and Germany.

Methods: A cross-country case comparison based on expert consultation, governmental policy documents and relevant scientific literature.

Results: All three countries have policy measures that allow informal caregivers to adapt their working patterns or take leave of absence to provide care without losing employee rights; however, only Belgium offers specific paid palliative care leave. All three countries offer various allowances to people who are dying at home and their caregivers. Cost-reductions for out-of-pocket expenses are available, based on the level of care dependency in Germany and on prognosis in Belgium, but are not provided in France. Mobile home support teams exist in all three countries and are free of charge for patients and caregivers but only in Belgium and Germany are they specialist multidisciplinary palliative home care teams. Belgium and Germany provide respite care for palliative patients.

Conclusion: European countries with similar contextual characteristics offer comparable policy measures to support palliative care at home in addition to the available primary care services. However, important differences exist in the criteria for access and the extent of what is offered.

Background

Research has shown that the proportion of people in need of palliative care worldwide is rising (1–4), and the majority wish to receive this care at home (5–8). The availability of comprehensive policy frameworks that integrate palliative care into national healthcare systems is a key component for extending access to palliative care (9–11). A recent World Health Assembly resolution on palliative care (WHA 67.19) stressed this by urging its member states to develop, strengthen and implement palliative care policies 'across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes' (12). Over the past decade, countries across Europe have indeed focused on enhancing home-based palliative care policies and on moving away from institutional care (13). These countries often face common challenges related to the organization of palliative care, such as ageing populations, an increasing number of people with degenerative diseases, financial and political pressures and changing workforce developments (14–17). It is advocated that countries across Europe reach consensus on the standards and norms for palliative care to improve the advocacy and policy decision making (18). However, the development of national policies to support patients and informal caregivers in a palliative home care setting has occurred relatively independently between countries (13, 19).

Mapping out existing policies aimed at supporting palliative home care across different countries with a similar contextual background can help to understand the large cross-national differences observed in quality of care outcomes, such as palliative care use (20), hospital use at the end of life (21) and place of death (22). Moreover, it allows policy makers to compare what is available in different countries and understand what can be transferred from one country to another; such a comparison therefore provides policy makers with information with which they can improve national public health strategies for palliative home care (13, 23, 24).

Methods

Study design

This case-oriented comparative study uses national policy documents and individual interviews with experts (written and by telephone) as the main sources of information.

Country-case selection

Our case-oriented cross-national comparison was aimed at getting information about how a particular policy challenge common across similar countries is addressed differently in those countries. We therefore focused on countries in this study with comparable challenges, health care systems and sociodemographic and politico-economic backgrounds. This selection of a relatively homogeneous context allows better to identify policy differences specifically related to policy measures to support palliative care at home that do not reflect health care or welfare system differences. The ANCIEN study evaluated 21 European countries by the organizational structure and levels of financial provision in their long-term care systems (25). In this typology, France, Germany and Belgium, together with the Netherlands, Denmark and Sweden, formed a cluster of countries with high scores on both criteria. We decided to exclude Denmark and Sweden from our selection as their welfare states have been historically organized differently (26).

Finally, the Netherlands were also invited to participate in the study, but expert contacts withdrew from the study as they found that the organization of their health care system differed too much from the other three countries. Box 1 presents an overview of the main health care system characteristics of the countries.

Development of the cross-country comparison framework

To compare the existing policy measures in multiple countries, five steps were taken:

1. Policy analysis in one country (Belgium): the primary analysis was performed for Belgium based on practical considerations such as preliminary knowledge of the health care system and the language of the main investigators of the study. We consulted relevant policy documents, governmental web pages and scientific literature and listed all identified policy measures. The aim was to identify those policy measures that, in addition to the standard primary care services available, directly support the provision of palliative care at home and are, specifically or not, intended for patients identified as 'palliative'. In other words, our approach to palliative care was not one that only looked at the context of formal e.g. specialist palliative care. The overview was validated to check for its accuracy and completeness by a palliative care expert and an expert in charge of palliative care within the National Institute for Health and Disability Insurance.

2. Construction of a conceptual framework: based on our policy analysis findings for the Belgian case, we constructed a conceptual framework of policy measures to support palliative care in the home setting according to the target audience (*to whom is the measure directed?*) and the type of measure (*what kind of support does the measure offer?*)

3. Identifying and questioning international palliative care experts: we identified palliative care experts relevant to the research in France and Germany and invited them to collaborate in our study. In France, this was the head of the palliative care unit at the University Hospital of Besançon and former president of the National End of Life Observatory in France (RA). In Germany, it was the chair of the department of Palliative Medicine at the University of Aachen and current president of the German Association for Palliative Care (LR). After explaining the study aims and receiving their agreement to participate, we sent them an electronic document in the form of a questionnaire to complete for their country, with a completed copy for Belgium as an example.

4. Validation of the responses by health care policy experts: the completed information for each country was then sent for validation to a national health care policy expert best placed to comment on palliative care policy measures (analogous to the second expert used in Belgium). These second experts double-checked for the completeness and accuracy of interpretation of the data. In France, this was the project manager for Palliative, End-of-Life and Long-Term Care Units of the Ministry of Social Affairs, Health and Women's Rights. In Germany, this was the public relations officer of the German Association for Palliative Care.

5. Combination and comparison of data: in the final step, we put together the validated data for comparison in a table. All co-authors received this integrated version for discussion and revision.

During the whole process of data collection there were multiple reiterations and both face-to-face and written consultations between all authors to avoid conceptual ambiguities.

Results

Policy measures differ in the target audience and in the type of support offered. Based on the target audience, policy measures to support palliative care in the home setting fell into three groups: allowances and cost-reductions (for patients and informal caregivers), in-kind services (for patients and informal caregivers), and employment and workplace-related (for informal caregivers).

Allowances and cost-reductions are policy measures that offer financial benefits to the patient or informal caregiver. In-kind services are policy measures that offer support in the burden of care without a financial incentive involved; these measures are commonly directed to both the patient and the informal caregiver. Employment and workplace-related measures are policy measures that offer support for the working informal caregiver by offering to adapt his or her working regime during the period of informal care provision. A concise overview of available policy measures to support palliative care at home in Belgium, France and Germany is provided in table 1, a more detailed overview is available in the supplementary appendix.

Table 2. Overview of available policies to support palliative care at home in Belgium, France and Germany

	Belgium	France	Germany
Allowances and cost-reductions to support the patient			
Changes in out-of-pocket costs	X		X
Allowances for "palliative patients"	X	X	
Allowances for chronically ill patients	X	X	X
Allowances and cost-reductions to support the caregiver			
Allowances for informal caregivers	X	X	
In-kind services			
Multidisciplinary supportive care teams	X	(X)[1]	X
Day care or respite care	X		X
Employment and workplace related			
Paid care leave for informal care provision	X		
Unpaid care leave for informal care provision		X	X

1: In France these services are not formal specialist palliative home care services

Allowances and cost-reductions to support the patient

There are multiple financial incentives for palliative home patients, such as lump sum allowances, flat fee payments and cost reductions. Policies to reduce out-of-pocket costs for general practitioner (GP), physiotherapist or home nursing visits or for pharmaceuticals exist in Belgium and Germany. In Belgium, these out-of-pocket costs are completely abolished for people granted legal palliative status. In Germany, the out-of-pocket cost share is reduced from 2% of annual household income to 1% for specific care-dependent patients. Patients with cancer can receive a disability certificate, offering several financial benefits such as tax reductions. In France, there are no such policies to reduce out-of-pocket costs, but annual out-of-pocket cost spending is capped at €50 for every person in the French health care system.

In Belgium, patients with a legal palliative status are able to receive the palliative home care allowance (*Forfait palliatieve zorg)* of €647.16 to compensate for extra costs related to their care e.g. materials and non-reimbursed medications, with the possibility of making a second claim. In France, the National Fund for Health and Social Action for Palliative Care (*Fonds National d'Action Sanitaire et Sociale de Soins Palliatifs*) exists to fund certain services to support the maintenance of a seriously ill person in need of palliative care. This assistance is issued by the Primary Health Insurance Fund (*Caisse Primaire d'Assurance Maladie*) as a lump sum allowance of up to €3,000 (re-claimable once), subject to an income ceiling, and can be added to other supportive allowances such as the Personal autonomy allowance (*Allocation personnalisée d'autonomie (APA) pour les personnes agées*). This is a monthly allowance for care-dependent persons older than 60 years that ranges between €663 and €1700.

There exist also allowances for care-dependent or chronically ill persons residing at home. In Belgium, the allowance for chronically ill patients (*Zorgforfait*) is an annual allowance ranging between €302.60 and €605.21. To acquire this allowance, patients have to meet certain care-dependency criteria and have exceeded the maximum annual amount of out-of-pocket costs of €450 for two consecutive years. Care-dependent persons living at home in the Flemish region can receive a monthly flat payment of €130 from the mandatory Flemish care insurance (*Vlaamse zorgverzekering*) (optional for inhabitants of the Brussels Capital region). In Germany, care-dependent patients living at home or in a care home can receive a monthly allowance (*Gesetzliche Pflegeversicherung*) to compensate for the care provided by informal caregivers (up to €728), or by professional nursing care at home (up to €1,612). German cancer patients can receive a disability certificate following their diagnosis for a duration of five years. This certificate offers several incentives (e.g. tax reductions, protection against dismissal from work).

Allowances and cost-reductions to support informal caregivers

Informal caregivers of palliative home patients are able to receive financial compensations in Belgium and France, but not in Germany.

In Belgium, working informal carers can receive an allowance of up to €786.76 monthly to compensate the loss of income due to informal care provision. Additionally, persons working in Flanders can receive the Flemish encouragement allowance (*Vlaamse aanmoedigingspremie*) of up to €123.95 monthly (for a maximum period of two years). The municipal informal caregiver's allowance (*Gemeentelijke mantelzorgpremie*) is an extra allowance offered by most municipalities

(82%) in Flanders. On average, the allowance is €30 monthly, varying per municipality. In France, an allowance for accompanying a person at the end of life (*allocation journalière d'accompagnement d'une personne en fin de vie*) exists for caregivers of home patients with a terminal or incurable disease. This allowance is fixed at €55,15 gross per day, for a maximum period of 21 days. Employees in the city of Paris are entitled to an additional allowance of up to €610 monthly for a maximum period of three months, or twelve months in case of a terminally ill minor child.

In-kind services to support the patient and informal caregivers

Multidisciplinary support teams for palliative care exist in all three countries, although they differ in the tasks and roles they take up and France does not have formal specialist palliative home care services. Commonly, they serve as a multidisciplinary expertise provider, aimed at supporting GPs, health professionals, counsellors, informal carers and volunteers of palliative home patients. The use of these teams is free of charge for patients and caregivers in all three countries involved in our study.

Respite care centres provide time off for caregivers by offering short-term professional care for the patient outside the home. In Belgium, these centres are reimbursed only for caregivers of terminally ill minors. The specialized palliative day care centres (*palliatieve dagzorgcentra*) are aimed specifically at the palliative home patient who is temporarily unable to be cared for at home, but it can also serve as a temporary relief for informal caregivers. In France, the government conducted experimental respite care projects between 2008-2012, but has not organized any reimbursed respite care since, although several regional respite projects have emerged. There exist a few palliative day care centres attached to cancer centres, to limit the acute care hospitalization of these patients. In Germany, respite care is available for up to four weeks per calendar year if the caregiver is temporarily unavailable to provide home care (*Kurzzeitpflege*). Informal caregivers who have provided informal care for at least six months can also rely on another type of respite care (*Verhinderungspflege*). The costs for this respite care are paid for up to €1,612 in both types; however, accommodation and food costs are to be paid by the patient or family.

Employment and workplace-related measures to support informal caregivers

Although regulations and terminology differ between them, all three countries permit informal caregivers to take leave from work to provide care without losing their employee rights. Belgium offers a statutory paid palliative home care leave (*palliatief zorgverlof*), differing from and combinable with the more general paid 'care leave for medical assistance' (*verlof voor medische bijstand*). Palliative home care leave provides a monthly gross amount of up to €802.52 for up to two months. In France, the family care leave (*congé de solidarité familiale pour accompagner un proche en fin de vie*) is an unpaid leave for up to three months. Although the leave is unpaid, caregivers are eligible to receive a separate allowance for accompanying a person at the end of life (see supra). In Germany, family care leave allows employees to reduce their working time to 15 hours per week to care for a close family member (*Gesetz über die Familienpflegezeit*) for up to two years. Half of their loss in salary due to work leave is paid as a loan without interest, to be paid back afterwards as an ongoing salary reduction. The care leave (*Pflegezeitgesetz*) allows employees to stay off work for up to ten days to organize needs-based care or to ensure care for a close relative for that period of time.

Discussion

Summary of main findings

Our study indicates that, in addition to the usual primary care services, several policy measures exist in Belgium, France and Germany to support palliative home care: allowances and cost-reductions for patients and informal caregivers, in-kind services for patients and informal caregivers, and employment and workplace-related arrangements for informal caregivers. However, there were some important differences between countries in the amounts available and the conditions and restrictions that apply. For example, direct financial allowances to the informal caregiver exist in France and Belgium but not in Germany. Only Belgium offers paid formal leave from work to informal caregivers to provide palliative home care to a family member. Germany and Belgium offer government-organized day care or respite care services, France does not.

Strengths and limitations

To our knowledge, this is the first study to describe in detail all available policy measures in several countries that directly support patients and caregivers undergoing palliative care in the home setting. In order to validate the findings, during the research process we had frequent contact with the experts in order to guarantee a thorough understanding of the complexities and nuances of the ways each country organizes supportive policies for palliative home care. Nevertheless, this study has some limitations. First, the study maps availability but not uptake of measures. In order to evaluate the actual impact of the measures on the population in need and on the outcomes of care (e.g. whether it effectively supports people to remain at home) data on the actual use and patterns in use of the measures are needed. Due to the small sample selection of high-income European countries (Belgium, France and Germany) with overall high levels of quality and availability of palliative care, our findings are only applicable within this context. A larger international study with multiple clusters of countries of similar and different economic, historical, cultural and legislative backgrounds would provide further insight into the cross-national differences of available supportive policies for palliative home care. However, we feel that these findings can work inspiring for low-, middle- and high-income countries alike to initiate or further establish a policy framework to support palliative care at home. This cross-national comparison can provide insights for national policy-makers into what measures they could develop and offer to increase support for palliative home care.

Interpretation of results

Our comparison provides a benchmarking basis for countries to reflect on what is missing in the measures they are offering. While the usefulness of certain policy measures depends on the specific characteristics of the healthcare system within a country (e.g. the abolition of co-payments for people receiving palliative home care is only useful in a health care system with co-payments), certain measures may be transferable to other countries. For instance, as previous research has shown, financial issues are often a major barrier in the provision and receiving of palliative home care (27, 28). In the countries we studied, specific allowances, cost-reductions or other financial incentives to both patients and informal caregivers exist that can help to (partly) overcome this barrier. Similarly, it may be useful to evaluate the provision of specialist palliative home care teams and respite care in countries where they are not provided, including some in our study, as it seems plausible that they can contribute effectively in supporting palliative care at home. The amount or duration of supportive allowances and services is usually subject to multiple factors such as the level of care-dependency or age of the patient.

In aiming to support palliative care in the home setting, national policies should not only target patients, but also their informal caregivers, commonly recognized as key figures in the process of providing quality palliative home care (1, 29, 30). Caregiver burden is an often-overlooked problem that can result in physical and psychosocial illnesses (31). Support for informal caregivers is mainly offered through financial compensations or workplace related support, i.e. care leave policies. Belgium and France offer direct allowances to these informal caregivers, whereas Germany only offers financial compensation towards the patient (who is in turn able to compensate the caregiver or not). Next to financial incentives, countries should consider offering a statutory paid work leave to informal carers. This could possibly reduce caregiver's burden, since it allows employees to provide care without having to worry about income loss or job security. A recent study in the Netherlands found that 19% of long-term informal home care providers who were not using care leave in fact wanted to do so; the main reason for not using it was that their employer did not allow them to do so (32). However, our study found that currently only Belgium offers a paid 'palliative care leave' for employees that provide informal home care, whereas France and Germany offer a more general, unpaid care leave.

The German sickness funds' obligation to provide patients and caregivers with information about palliative care and hospice options can effectively increase the use of palliative home care, as the complexity of the health insurance system was expressed as another important barrier in accessing formal care services for dependent older people, next to the cost of services (33).

Finally, the cross-national comparison of policy measures provides background information that can help to interpret the country differences we found in end-of-life home care use, hospital transfers near the end of life and place of death. For instance, the proportion of home deaths in people with cancer is substantially higher in Belgium (29%) than in France (19%) (34-36). Unfortunately, population-level home death data are lacking for Germany, as they only register 'hospital' or 'non-hospital' deaths. These differences are caused by a complex multitude of factors and historical contingencies, but the prevailing policy measures may play a role. The use of palliative care services such as multidisciplinary palliative home care teams or respite care services has previously been found to reduce hospital deaths (20, 24, 37). Apart from other factors, the absence of formal specialist palliative home care services, palliative day care and respite care centers in France may contribute to its markedly low proportion of home cancer deaths.

Conclusion

Three European countries with similar contextual characteristics (Belgium, France and Germany) offer comparable policy measures to support palliative care at home in addition to the available primary care services. However, important differences exist in the extent of what is offered and the criteria for receiving it. Knowledge of these difference and similarities can help national health policy makers to further improve support for palliative care in the home setting. While further empirical evaluation is needed, we suggest that by offering quality supportive policy measures such as a paid palliative care leave for informal caregiver and formal specialist palliative home care services, countries can effectively increase the quality and use of palliative care at home, thus reducing hospital deaths and costs related to hospital transfers near the end of life and caregiver burden.

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Part III ※ Uptake of palliative home care support measures

4 Who finds the road to palliative home care support? A nationwide analysis on the use of supportive measures for palliative home care using linked administrative databases

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Abstract

Background: Many countries developed supportive measures for palliative home care, such as financial incentives or multidisciplinary palliative home care teams. For policy makers, it is important to evaluate the use of these national palliative home care supportive measures on a population level.

Methods and findings: Using routinely-collected data on all deaths in Belgium in 2012 (n=107,847) we measured the use of four statutory supportive measures, specifically intended for patients who have obtained the legal palliative status, and three non-statutory supportive measures. Factors associated with uptake were analyzed using multivariable logistic regression. Of all deaths of adult home-dwelling persons in Belgium (n=87,007), 17.9 percent used at least one statutory supportive measure and 51.5 percent used at least one non-statutory supportive measure. In those who died of an illness indicative of palliative care needs 33.1 percent used at least one statutory supportive measure and 62.2 percent used at least one non-statutory supportive measure. Younger people and persons dying from cancer were more likely to use a statutory policy measure. Older people and persons dying from COPD were most likely to use a non-statutory policy measure. Women, non-single people, and those living in less urbanized areas were most likely to use any supportive measure.

Conclusions: Statutory supportive measures for palliative home care are underused, even in a subpopulation of persons with potential palliative care needs. Policy makers should stimulate an equitable uptake, and reducing the observed inequalities is an important focus for health care policy.

Background

Supportive measures for palliative home care exist in many countries (1,2). Since the early 1990s, the development of these supportive measures was advocated by the World Health Organization to meet the growing need for quality palliative care at home, caused by ageing populations and increases in the number of people living with serious chronic illnesses (3–5). Despite international differences in how they are financed and what criteria exist to access them, supportive measures for palliative home care generally exist in the form of financial incentives, supportive services, or workplace arrangements (6).

The use of hospice and specialist palliative care services has previously been studied in various countries (7–10). A literature review from 2009 on patterns of access to community palliative care services concluded that patients with certain characteristics (e.g. younger, married, wealthier, and those with a caregiver at home) were more likely to access specialist palliative home care services (11). However, these studies often used qualitative data or small sample sizes, had a constrained focus (e.g. only cancer patients, one specific palliative care service) or missed clarity in what they measure. In order to inform the public health policy debate and try to impact and improve the quality of care at the end-of-life on a population-level, however, it is important to measure and evaluate policies on that level (12).

Our study uses quality routinely collected data on all deaths in Belgium in 2012. We will describe the use of supportive measures for palliative home care in the full population of people who died while living at home, and in a population of those who died of an illness highly indicative of palliative care needs (i.e. neoplasms, COPD, other organ failures, neurodegenerative diseases and HIV/aids) (13,14). Our research questions are: 1) what was in 2012 the frequency of the uptake of supportive measures for palliative home care; and 2) what sociodemographic and disease characteristics are associated with the uptake of these measures?

Methods

Design and setting

This retrospective observational study uses data from all individuals who died in 2012 in Belgium. Supportive measures for palliative home care exist in Belgium since 1985 and have since been further expanded (15). Since 2002, palliative care is legally recognized as a right in Belgium.

Data

Cohort data from eight routinely collected population-level databases, handled by three different organizations, were linked. The data consists of (1) the socio-demographic database of all individuals with healthcare insurance (legally mandatory in Belgium); (2) the health care database containing all reimbursed health care use data on home, nursing home, outpatient and hospital care; (3) the pharmaceutical database containing all reimbursed medication data; (4) Belgian Cancer Registry data with diagnostic information on all incidences of cancer including date of diagnosis and type of cancer; (5) death certificate data containing cause of death; (6) population registry data including nationality and household composition; (7) census data, including educational level and housing characteristics and (8) the fiscal database (including net taxable income).

After acquiring approvals from the relevant data protection agencies, the databases were linked for analysis in a secure and ethically responsible manner, guaranteeing the anonymity of the deceased. This process is described elsewhere (16).

Subjects

To limit the analysis to those who can theoretically use the supportive measures, we excluded minors and people residing in a nursing home before death from the dataset.

To further limit the analysis to a population that is most likely to benefit from the measures, we made a second subpopulation of people who died from illnesses highly indicative of palliative care needs, defined by Rosenwax and colleagues (14) as the 'Minimal Estimate of potential users of palliative care' through mixed-methods research, referred to here as the palliative subset. The following underlying causes of death were selected using the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD): neoplasms (ICD-10 C00-D48), chronic obstructive pulmonary disease (ICD-10 J40-44, J47), other organ failures (i.e. heart, renal, and liver failure) (ICD-10 I11-I13, I50, K70-72, N10-12, N18-19), neurodegenerative diseases (i.e. Alzheimer's, Parkinson's, motor neuron, and Huntington's disease) (ICD-10 F01, F03, G10, G12, G20, G30), and HIV/aids (ICD-10 B20-24).

Terms and classification of supportive measures

We defined supportive measures for palliative home care as: 'all health care allowances and services (in addition to the standard primary care services) that can support the patient to remain at home in the last phase of life'. We divided supportive measures for palliative home care into statutory and non-statutory:

Statutory supportive measures for palliative home care:

These supportive measures are specifically intended for patients who have obtained the legal 'palliative status', acquired after being diagnosed as: suffering from one or multiple irreversible diseases, progressing in an unfavorable direction, with serious physical/mental deterioration, where therapeutic and rehabilitative interventions no longer affect deterioration, the prognosis is poor and death is expected in the relatively short term (life expectancy of more than 24 hours and less than three months), having serious physical, psychological, social and existential needs requiring significant time-intensive and sustained support, and remaining or having the intention of dying at home (17). The general practitioner of the patient (or another medical doctor) should formally make this diagnose to be able to receive these measures:

1) The use of a multi-disciplinary palliative home care team, which provides expertise to general practitioners, health professionals, counsellors, informal carers and volunteers. They consist of at least one team doctor, an administrative force and palliative experts (mainly nurses). It is free of charge and not limited in time;
2) Nursing care at home for patients with the palliative status. Palliative nurses are available to patients at home round-the-clock, have a basic training in palliative care,

and need to add specific information to the nursing record (e.g. registration of symptoms, the pain scale). It is free of charge and not limited in time;

3) Physiotherapy at home for patients with the palliative status. It is free of charge and not limited in time;
4) The allowance for palliative home patients, a lump sum of € 647.16 (in 2012), obtainable twice and meant to cover for non-reimbursed costs related to the provision of palliative care in the home. The amount is fixed for all patients.

Apart from these measures, all out-of-pocket costs for general practitioner consultations are abolished for these patients.

<u>Non-statutory supportive measures for palliative home care:</u>

1) Nursing care at home for heavily dependent home-patients. The out-of-pocket rate for heavily dependent patients depends on their level of care dependency (not free);
2) Physiotherapy at home for heavily dependent home-patients. The out-of-pocket rate for heavily dependent patients depends on their level of care dependency (not free);
3) The allowance for chronically ill patients, a lump sum of up to €576.10 (in 2012) for heavily care-dependent people who have exceeded a certain amount of out-of-pocket costs for care in two consecutive years. The amount is linked to the level of care dependency (divided into three levels).

Sociodemographic characteristics

Population characteristics available through the datasets are: age at death, sex, nationality, household type, housing comfort, educational level (using UNESCO's International Standard Classification of Education (ISCED)), region, degree of urbanization, annual personal net taxable income and underlying cause of death (using the 10th revision of the International Classification of Diseases (ICD-10), categorized as: neoplasms, COPD, other organ failure, neurodegenerative disease, HIV/aids, other). For codification clarifications and detailed information on data administrators and data sources see S3 Appendix.

Data analysis

Descriptive statistics were used to describe population characteristics in the full population and in the palliative subset. To compare the chances of receiving a policy measure to support palliative home care between different population groups a multivariable binary logistic regression was performed with uptake (of a statutory measure, a non-statutory measure, or one or more of all measures) as the dependent variable. A hierarchical approach was followed to build the model (see S3 Appendix). An alternative model was analyzed on a subgroup of only cancer deaths (see S2 Table). The analyses were generated using the SAS Enterprise Guide 7.1 software.

Ethics approvals

This study received approvals by the Commission for Medical Ethics of the University Hospital Brussels (B.U.N. 143201629410). Trusted Third Parties (TTPs) 'eHealth' and 'Crossroads Bank for Social Security (CBSS)' were responsible for the deidentification process and deterministic one-to-one record linkage of the databases. In accordance with Belgian law, approvals for access to and integration of the various databases were obtained from two separate national sectoral committees for privacy protection: the ‘Sectoral Committee of Social Security and Health, Section Health’ and the ‘Statistical Supervisory Committee’. Both are subcommittees of the Belgian Commission for the Protection of Privacy. No informed consent was required. For a full description of the data linkage procedure, including details on the data anonymization, see Maetens and colleagues 16).

Results

Population characteristics

In 2012, 87,007 health-insured adult persons died in Belgium while living at home (Table 1). Of these, 38,657 died from a cause indicative of palliative care need: 29.5% died from a neoplasm, 4.3% from COPD, 5.6% from another organ failure, 5% from neurodegenerative disease, and 0.04% from HIV/aids.

Uptake of supportive measures for palliative home care

Of all home-dwelling adults, 17.9% used a statutory measure, 51.5% a non-statutory measure, 55.2% at least one supportive measure, and 14.1% at least one statutory and non-statutory measure (Table 2).

Of those in the palliative subset, 33.1% used a statutory and 62.2% a non-statutory measure; 69.7% used at least one of each, and 25.7% used both (see S1 table). The statutory and non-statutory measures were used by 42.7% and 62.3% respectively of those dying of neoplasms, 11.4% and 65.6% of COPD, 13.1% and 61.7% of other organ failures, 17.7% and 59.8% of neurodegenerative diseases, and 5.9% and 32.4% of HIV/aids.

Characteristics associated with uptake of a supportive measure for palliative home care

Multivariable logistic analysis for the palliative subset indicated that those under 65 years were significantly more likely to use a statutory measure compared to those above 95 years old (Odds Ratio=1.32; 95% Confidence Interval [1.07-1.62]), but not a non-statutory measure (Table 3). The age groups between 65 years old and 94 years old were not significantly more or less likely to use a statutory measure compared to those aged over 95, but significantly more likely to use a non-statutory measure. Age was not a significant predictor for the use of either a statutory or non-statutory measure (third model). Women were more likely to use a statutory (OR=1.10[1.04-1.16]) or non-statutory (OR=1.35[1.28-1.41]) measure than men. Compared with those who died from neoplasms, people who died from COPD (OR=0.18[0.16-0.20]), other organ failures (OR=0.22[0.20-0.24]), neurodegenerative disease (OR=0.30[0.27-0.33]), or HIV/aids (OR=0.17[0.04-0.72]) were less likely to use a statutory measure. Compared with people who died from neoplasms, those who died from COPD were more likely to use a non-statutory measure (OR=1.22[1.13-1.32]), but those who died from neurodegenerative diseases (OR=0.86[0.80-0.92]) or from HIV/aids (OR=0.41[0.18-0.94]) were less likely to receive such a measure. Results predicting the use of a non-statutory measure were not significant for those who died from another organ failure.

People who were married (OR=1.75[1.65-1.86]), living together (OR=1.34[1.18-1.53]), forming a one-parent family (OR=1.27[1.14-1.41]), or being part of another sort of household (OR=1.35[1.15-1.58]) were more likely to use at least one of all supportive measures than those living alone. People living in the Flemish (OR=1.33[1.20-1.46]) or in the Walloon region (OR=1.15[1.03-1.27]) were more likely to receive at least one of all measures than those living in the Brussels Capital region. People living in an area with a lower degree of urbanization were more likely to use a supportive measure than those in an area with a higher degree of urbanization.

Educational level was found to be a significant predictor of supportive measure use only in the group with post-secondary school education, and only for the use of a non-statutory measure (OR=1.22[1.10-1.36]) or for any supportive measures (OR=1.13[1.00-1.27]). Having higher standard housing is a significant predictor of statutory measure use, of any measure use, but not of non-statutory measure use. Nationality was included in the analyses but was found not to be significant.

Table 1. Characteristics of all deaths and deaths of persons with potential palliative care needs (in %)

	All deaths	Palliative subset
Number	87,007	38,657
Age		
18-64	19.3	18.7
65-74	17.0	20.3
75-84	31.6	33.3
85-94	29.0	25.5
94+	3.2	2.2
Mean age (SD)	*76.18 (14.00)*	*75.92 (12.36)*
Gender		
Man	54.7	55.6
Woman	45.3	44.4
Underlying cause of death		
Neoplasms	29.5	66.4
Another organ failure	5.6	9.4
COPD	4.3	9.6
Neurodegenerative disease	5.0	11.3
HIV/aids	0.04	3.3
Nationality		
Belgian	93.7	94.9
Non-Belgian	6.3	5.1
Household composition		
Single person household	38.7	34.6
Married	47.6	52.6
Living together	4.3	4.1
One-parent family	6.6	6.1
Other	3.0	2.7
Missing[a]	*1.6*	*0.2*
Housing standard[b]		
High	44.9	48.0
Moderate	18.8	17.2
Low	26.8	26.3
Below basic level	9.6	8.5
Missing[a]	*9.4*	*7.7*
Education level		
No primary education	8.6	8.1
Primary school education	34.8	34.7
Secondary school education	45.1	45.0
Post-secondary school education	11.5	12.2
Missing[a]	*13.1*	*11.1*
Income level		
Q1 (lowest to €12,221)	26.7	27.0

(continued)

Table 1. Characteristics of all deaths and deaths of persons with potential palliative care needs (in %) (continued)

Q2: (€12,222 to €14,497)	23.2	22.5
Q3: (€14,498 to €18,346)	24.4	24.7
Q4: (18,347 to highest)	25.7	25.7
Missing[a]	*4.1*	*2.1*
Region		
Brussels Capital region	9.2	8.3
Walloon region	35.7	32.8
Flemish region	55.1	59.0
Missing[a]	*1.9*	*0.7*
Urbanisation[c]		
Very high	32.2	30.8
High	27.7	28.3
Average	25.6	27.0
Low	13.1	12.5
Rural	1.5	1.4
Missing[a]	*1.9*	*0.7*

[a] All percentages presented as valid percentages. Percentages for missing values are calculated separately.

[b] Housing standard was operationalized by the national bureau for statistics and was based on several criteria of comfort, e.g. 'having a toilet and bathroom with bath and/or shower', 'having central heating', 'having a kitchen of min. 4m2'. For the detailed operationalization, see S1 Appendix.

[c] Degree of urbanization was operationalized by the national bureau for statistics and was based on morphological and functional level of urbanization (strong or weak). For the detailed operationalization, see S1 Appendix.

Table 2. The use of supportive measures for palliative home care (in %)

	All deaths*	Palliative subset
Number (n)	87,007	38,657
Statutory palliative home care measures	*17.9*	*33.1*
Allowance for palliative home patients	16.0	30.4
Multi-disciplinary support team	8.6	17.1
Nursing care for palliative home patients	12.7	23.7
Physiotherapy for palliative home patients	4.0	7.1
Non-statutory palliative home care measures	*51.5*	*62.2*
Nursing care for heavily dependent persons	29.7	34.6
Physiotherapy for heavily dependent persons	24.4	25.4
Allowance for chronically ill patients	29.2	38.4
Used one of the above measures	*55.2*	*69.7*
Used a 'statutory' and a 'non-statutory' measure	14.1	25.7

Patients were able to receive several measures at once, thus numbers of uptake do not add up.

*All deaths of adult persons not residing in a nursing home in the last year of life.

Table 3. Factors associated with the use of supportive measures for palliative home care in the palliative subset population (n=32,075)

	Statutory		**Non-statutory**		**Statutory or non-statutory**	
	OR	95% CI	OR	95% CI	OR	95% CI
Age						
18-64	**1.32**	(1.07-1.62)	1.09	(0.93-1.28)	-	-
65-74	1.19	(0.97-1.47)	**1.20**	(1.02-1.40)	-	-
75-84	1.10	(0.89-1.34)	**1.22**	(1.05-1.43)	-	-
85-94	0.97	(0.79-1.20)	**1.19**	(1.02-1.39)	-	-
94+	ref	-	ref	-	ref	-
Sex						
Male	ref	-	ref	-	ref	-
Female	**1.10**	(1.04-1.16)	**1.35**	(1.28-1.41)	**1.3**	(1.23-1.37)
Cause of death						
Neoplasm	ref	-	ref	-	ref	-
Another organ failure	**0.22**	(0.20-0.24)	1.0	(0.93-1.08)	**0.68**	(0.63-0.73)
COPD	**0.18**	(0.16-0.20)	**1.22**	(1.13-1.32)	0.82	(1.75-0.89)
Neurodegenerative disease	**0.30**	(0.27-0.33)	**0.86**	(0.80-0.92)	**0.61**	(0.56-0.66)
HIV/aids	**0.17**	(0.04-0.72)	**0.41**	(0.18-0.94)	**0.36**	(0.15-0.87)
Household composition						
Single person household	ref	-	ref	-	ref	-
Married	**1.76**	(1.65-1.87)	**1.64**	(1.55-1.73)	**1.75**	(1.65-1.86)
Living together	**1.42**	(1.24-1.62)	**1.28**	(1.14-1.44)	**1.34**	(1.18-1.53)
One-parent family	**1.35**	(1.21-1.52)	**1.24**	(1.12-1.36)	**1.27**	(1.14-1.41)
Other	**1.40**	(1.18-1.65)	**1.25**	(1.08-1.44)	**1.35**	(1.15-1.58)
Housing standard						
Below low	ref	-	ref	-	ref	-
High	**1.28**	(1.16-1.42)	-	-	**1.37**	(1.25-1.51)
Average	1.10	(0.98-1.23)	-	-	**1.15**	(1.04-1.28)
Low	**1.14**	(1.02-1.27)	-	-	**1.19**	(1.09-1.31)
Education level						
No education	ref	-	ref	-	ref	-
Primary school education	-	-	0.99	(0.90-1.08)	0.94	(0.86-1.04)
Lower secondary school education	-	-	1.05	(0.96-1.14)	0.97	(0.88-1.07)
Post-secondary school education	-	-	**1.22**	(1.10-1.36)	**1.13**	(1.00-1.27)

(continued)

Table 3. Factors associated with the use of supportive measures for palliative home care in the palliative subset population (n=32,075) (continued)

Income level						
Q1 (lowest)	ref	-	ref	-	ref	-
Q2	1.06	(0.99-1.15)	1.05	(0.99-1.13)	**1.08**	(1.01-1.16)
Q3	1.01	(0.94-1.09)	**1.13**	(1.06-1.21)	**1.12**	(1.01-1.21)
Q4 (highest)	0.93	(0.87-1.00)	**1.15**	(1.07-1.23)	1.06	(0.99-1.14)
Region						
Brussels-capital region	ref	-	ref	-	ref	-
Walloon region	**1.14**	(1.01-1.29)	**1.17**	(1.06-1.29)	**1.15**	(1.03-1.27)
Flemish region	**1.73**	(1.54-1.94)	**1.15**	(1.04-1.26)	**1.33**	(1.20-1.46)
Urbanization						
Very high	ref	-	ref	-	ref	-
High	**1.17**	(1.09-1.26)	**1.1**	(1.04-1.17)	**1.1**	(1.03-1.18)
Average	**1.39**	(1.29-1.49)	**1.31**	(1.23-1.40)	**1.34**	(1.25-1.44)
Low	**1.47**	(1.34-1.61)	**1.28**	(1.17-1.39)	**1.32**	(1.21-1.45)
Rural	**1.60**	(1.29-1.99)	**1.26**	(1.03-1.54)	**1.32**	(1.06-1.65)

Reference category is presented on the left. Exploratory variables that did not significantly add to the model were excluded in the final model; models were built in a stepwise manner. CI=Confidence Interval. *P*-value < 0.05 in bold.

Discussion

Using linked data of all deaths in Belgium in 2012, this study found that the uptake of supportive measures for palliative home care in a population with potential palliative care needs was relatively low. Only a third used a statutory measure (33.1%). The use of non-statutory measures was found to be more frequent in this population (62.2%). Statutory measures were more likely to be used by younger people and those with neoplasms, non-statutory measures by older people and those dying of COPD.

Strengths and limitations

To our knowledge, this is the first study to measure uptake of both statutory and non-statutory supportive measures for palliative home care on a population-level. In Belgium, membership to one of the seven national health insurers is mandatory for the full population, thus the data cover (nearly) all individuals. However, additional private insurance is possible, which is not included in our data. We were able to measure multiple types of supportive measures, such as financial incentives, supportive home care services and multidisciplinary support teams. The use of linked data for all Belgian citizens for a given year from routinely-collected administrative, disease-specific and insurance databases offers a rich, powerful and reliable resource for studying important public health issues (18,19). Our data also has its limitations. Although the identification of people in the palliative subset is based on a previously validated and frequently used estimation, the estimation is based on underlying cause of death, not on an actually observed or stated palliative care need (14). Reimbursement data also do not capture other forms of support for palliative home care (e.g. care given by informal caregivers, services organized outside reimbursement schemes) or social support (e.g. religious based, kinship networks).

Interpretation of results

Only a third of home-dwelling people with potential palliative care needs made use of a statutory supportive measure for palliative home care. This low uptake is possibly related to the legal criteria surrounding these measures; in order to be granted legal palliative home patient status, life expectancy must be estimated as 'more than 24 hours and less than three months' (17). Firstly, prognostication of survival in patients with advanced cancer has been well-researched, showing consistently that both physicians and patients are unable to correctly predict their life expectancy, most commonly overestimating it (20–23). The disease trajectories of non-cancer serious illnesses are even more unpredictable, further complicating the process of prognostication (24–26). Secondly, people confronted with non-cancer illnesses like organ failure or dementia often see their illness as 'a way of life' (27) rather than a life-threatening illness, therefore possibly not perceiving themselves as having palliative home care needs (28–30). The possibility of receiving a statutory supportive measure can thus come too late or even not at all. This hypothesis is supported by findings of a previous study that focused on the physician's reasons for not referring people with life-limiting illnesses to specialist palliative care services in Belgium in which physicians mentioned 'not [having] enough time to initiate palliative care' as one of the three major reasons for non-referral (13). Indeed, recent survey data from Flanders shows that specialised palliative care is initiated with a median of only twenty days before death (31). Our finding that younger people and those who died of neoplasms were most likely to use statutory supportive measures confirms previous findings (11) and could be related to the problems of recognizing the terminal phase, something frequently reported to be more difficult in older population groups with chronic illnesses other than cancer (32,33).

The uptake of non-statutory supportive measures was higher than statutory supportive measures. The criteria for these non-statutory supportive measures are based on high care needs combined with high out-of-pocket costs for two consecutive years, and not on life expectancy, which could explain why they are used more frequently than statutory measures (34–36). This could also explain our finding that the chance of using a non-statutory measure was highest among people who died of COPD, who are prone to high care needs and out-of-pocket costs (37,38). It remains unclear, however, whether statutory and non-statutory measures contribute equally to the effective support of palliative home care.

The uptake of supportive measures for palliative home care seems to be influenced, apart from aspects related to prognosis, by factors such as social support and socio-economic position. The higher chances of using statutory and non-statutory measures in those living with others compared with single-person households suggests that the presence of social support in the household is an important factor in organizing palliative home care and using supportive measures to do so. The influence of socioeconomic characteristics on the knowledge or use of palliative care has very rarely been studied, and with differing results (39–41). Our findings partly suggest a social gradient exists in the use of supportive measures; the lower likelihood of using non-statutory measures in the lowest income category can indicate inequality. This result differs from the uptake of statutory measures, however, where people in the highest income category were significantly less likely to use these measures when compared with the lowest income category. The better chances of people with post-secondary education receiving a non-statutory measure may reflect differences in social capital that give them an advantage in knowing about and obtaining the measures. The advantage of those living in a home with a high standard of housing compared with those with a lower standard is an additional indication that there is some social inequality.

It seems likely that knowledge of existing supportive measures also plays a role. Because palliative care in Belgium has traditionally focused mainly on cancer patients (42), their advantage in using statutory supportive measures could be due to both oncologists and patients being better informed. We also found that people living in Flanders were more likely to use a supportive measure than those in the Brussels Capital region. This may be explained by regional differences in general information provision and knowledge of palliative care or to differences in the social environment (e.g. lower social fragmentation in more rural areas) and national healthcare policy (concentration of large academic hospitals in metropolitan areas creating a pull factor towards end-of-life care in hospitals) (43).

Suggestions for further research and policy recommendations

Our study is a first step in understanding who makes use of supportive measures for palliative home care, and who is missing out on them. Future research should focus on how inequalities in the uptake of these measures influence different outcomes, such as place of death, quality of care, and costs at the end of life. Additionally, differences in the impact of using statutory or non-statutory measures on these outcomes should be compared. In this way, public health policy can be quantitatively evaluated and further improved. Qualitative research also needs to further examine the motivation and reasons behind the differences in uptake between certain population groups, and the differences in uptake between statutory and non-statutory supportive measures, as these are not registered in administrative data.

The large gap in uptake between statutory and non-statutory supportive measures among a subgroup of people in potential palliative care need suggests that there remains inequity in accessing statutory measures. Policy-makers should focus on including underreached groups, such as older people and those with non-cancer illnesses. The life expectancy criterion to qualify for the statutory supportive measures should be re-evaluated. This is possibly a major barrier that prevents many patients with palliative care needs to make use of them, in particular older patients and those with a non-cancer diagnosis.

Conclusion

A relatively large proportion of people who are dying use some supportive measure for palliative home care. However, the measures specifically intended to support palliative home care are underused, even in a subpopulation of those who die of an illness indicative of palliative care needs. Stimulating an equitable uptake of supportive measures intended to support palliative home care, and reducing the observed social inequalities in their uptake, is an important focus for health care policy.

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5 Healthcare use at the end of life in ALS: a population-level cohort study

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Submitted

Abstract

Background: ALS is an incurable neurodegenerative disorder, with the recommendation that symptom management and palliative care start immediately or soon after diagnosis. However, little is known about healthcare utilization at the end of life in this patient group.

Aim: To describe healthcare utilization at the end of life in patients who died from ALS.

Design: We performed a retrospective cohort study using population-level administrative databases. The description of healthcare utilization was based on (1) validated quality indicators for end-of-life care, and (2) the European Federation of Neurological Societies guidelines on the clinical management of ALS.

Setting: We included all people who died from ALS in Belgium between 2010-2015 (using ICD-10 code G12.2).

Results: 1636 people died from ALS in Belgium between 2010 and 2015. The mean age at death was 71 years (SD11.3), and 56% were men. Specialized palliative care was used by 44% at some point in the last two years of life. In the last month of life, 13% received tube feeding, 48% received diagnostic testing, 41% were admitted to a hospital, and 25% were admitted to an emergency department. Medications were used mainly to treat pain (43%), insomnia and fatigue (33%) and thrombosis (32%); 39% used riluzole. Non-invasive ventilation was used by 18%. 39% died at home.

Conclusion: Administrative data provide a valuable source to describe healthcare utilization in small populations such as ALS, but more clinical evidence is needed on the advantages and disadvantages initiating or terminating treatments at the end of life.

Background

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disorder with a highly predictable clinical course that is characterized by degeneration of the upper and lower motor pathways (1). Patients who are diagnosed with ALS experience progressive muscle weakness involving all voluntary muscles, resulting in limb paralysis and difficulties with swallowing and breathing. Its prevalence is low, with about 5.4 persons afflicted per 100,000 and an incidence rate of 2.1/100,000 per year in people aged 54–67 years (2). In the most common clinical presentation of the disease, death usually occurs 2 to 3 years after diagnosis, due to spread of the disease to respiratory muscles, deglutition, global failure and inanition. The lack of curative treatment and the predictability of the disease's dismal course make its psychosocial and existential impact quite unique and suggests a role for palliative care immediately or soon after diagnosis (3,4), focusing mainly on the management of physical, psychosocial and existential issues and on maximizing the quality of life of patients in coping with this condition (5,6).

As with all people suffering from chronic and life-threatening illnesses, the care needs of ALS patients change near the end of life, and the provision of appropriate care throughout the last months and weeks of life is of significant importance to promote a certain level of quality of life. Nevertheless, healthcare professionals are often trained to prolong and maintain life for as long as possible (6), conceivably resulting in inappropriate continuation of treatments or hospitalizations that are futile near the end of life and possibly threaten the quality of life of patients (7,8).

However, due to the low prevalence of the disease (2) and the rapid physical decline of those with symptom onset (5), little is known about healthcare utilization at the end of life in this patient group. Only one previous study used population-level observational data to describe medication use in the last year of life, in a large cohort of older patients in Sweden who died of ALS between 2007 and 2013. It found that 37% of such patients were treated with ten or more drugs during the last month of life (9). Other studies have described healthcare utilization in ALS using small-sample prospective designs in one hospital or hospice (10,11), a retrospective physician-reported questionnaire design (12), or death certificate data from one region (focusing on place of death) (13).

Using linked population-level administrative data, this study aims to describe the healthcare utilization at the end of life in all patients who died from ALS in Belgium between 2010-2015. Specifically, our research questions are:

- What is the appropriateness of end-of-life care in people who died from ALS in Belgium between 2010 and 2015 as measured by previously validated population-level quality indicators (QIs)?
- What proportion of people who died from ALS in Belgium between 2010 and 2015 received neuroprotective, symptom management, and respiratory treatments in the last 7, 14, 30, 90 and 180 days before death?

Methods

Study design and population

We conducted a retrospective cohort study, using linked data from eight administrative databases containing healthcare consumption and socio-demographic data for all deaths in Belgium between 2010-2015. The study was conducted for all those who were registered with a Belgian health insurance fund at time of death between 1 January 2010 and 31 December 2015 (98.8% of all deaths). We selected a population of people that died from ALS based on the registration of the underlying cause of death code G12.2, using the 10th revision of the International Classification of Diseases (ICD-10).

Data sources

The data used involved eight administrative databases, linked at an individual level using a unique identifier by a third party responsible for data protection and linkage in Belgium. The linked data included person-level inpatient and outpatient reimbursed healthcare use in the last two years of life (recorded as nomenclature codes for all reimbursed healthcare use and Anatomical Therapeutic Chemical (ATC) classification system codes for all dispensed drugs in both the hospital and the public pharmacy). The exact date of delivery (coded as number of days before death) is recorded for all healthcare data. Additionally, the data includes demographic data, fiscal data, and death certificate data (14). The data linkage process and content is described in detail elsewhere (15).

Healthcare measures

To describe the healthcare use at the end of life in people dying from ALS, we used two main sources to determine our list of variables.

Firstly, we used a set of 14 quality indicators of appropriateness of end-of-life care that can be measured using routinely collected administrative data (16). The quality indicators provide population-level evidence on an aggregated level, and appropriateness or inappropriateness of care should not be extrapolated to the individual level (e.g. a high rate of end-of-life hospital use in the entire population of people who died from ALS suggests inappropriate care at the population level but does not suggest that a particular hospitalization was inappropriate). The set was developed and validated using the RAND/UCLA appropriateness method, based on literature and a consensus process consisting of a multidisciplinary expert panel of 12 physicians and nurses (17). Only those indicators that were deemed valid across different pathologies (i.e. not specifically for one pathology such as Alzheimer's disease, COPD, or cancer) were retained in the final set. The selected set of quality indicators and details about operationalization are provided in supplementary table S1 (for the complete set of indicators, development and validation process, see De Schreye et al. (16)).

Secondly, we used the 2012 European Federation of Neurological Societies (EFNS) guidelines on the clinical management of ALS (18) to create a list of medications and other healthcare use relevant to the end-of-life phase in ALS (see supplementary table S2 for the full list). All recommendations that provided clear information for which we had a nomenclature or ATC codes (e.g. exact drug names or interventions) were operationalized (this method excluded the operationalization of recommendations concerning: diagnosis, communication, caregivers, unproven therapies, genetic testing and counselling, and cognitive testing). The search strategy, methods, and full list of recommendations are available in the guideline's publication (18).

All variables were measured at time intervals between the time of death and 7, 14, 30, 90, and 180 days before death, except when the periods for a specific indicator were not validated by the expert panel.

Statistical analyses

We used descriptive statistics to describe the characteristics of our cohort of people who died from ALS. We report counts and overall proportions for all socio-demographic characteristics, use of medications and of healthcare interventions, and report the mean number of primary caregiver contacts. All analyses were performed using SAS Enterprise Guide V.7.1.

Results

Study population characteristics

A total of 1636 people died from ALS in Belgium between 2010 and 2015 (an average of 273 annually), of whom 56% were men (Table 1). The mean age at death was 70.7 years (SD: 11.3; data not shown). 63% were married, and 20% lived in a single person household. 54% had attained a secondary education level or higher. The most common immediate causes of death were respiratory arrest (35%), respiratory failure (24%) and cardiac arrest (8%).

Healthcare utilization indicating appropriate end-of-life care

Of all the people who died from ALS in Belgium between 2010 and 2015, 43.8% received specialized palliative care (inpatient palliative care unit or multidisciplinary palliative home care) at some time in the last two years of life; for 22.3% of this group, specialized palliative care was initiated in the last 14 days of life (Table 2). On average, they had 3 primary caregiver contacts per week (including the general practitioner and home nursing) during the last three months of life; 39.4% died at home.

Healthcare utilization indicating inappropriate end-of-life care

12.6% received tube feeding or intravenous feeding and 47.6% received diagnostic testing in the last month of life. In the last month of life, 40.9% were admitted to a hospital, 25.2% were admitted to an emergency department (ED), and 7.6% of those residing in a nursing home had an ICU admission.

Healthcare utilization for the clinical management of ALS

In the last six months of life, 61.4% of those who died from ALS used riluzole; 10.6% received riluzole in the last week of life. In the last month of life, 17.5% used non-invasive ventilation, 5.9% received oxygen therapy, and 3.6% used invasive ventilation. In the last week of life, medications were used mainly to treat symptoms related to pain (29.4%), insomnia and fatigue

(20.0%), and venous thrombosis (14.8%). Medications to treat symptoms of depression and anxiety (10.4%), bronchial secretions (7.2%), pseudobulbar affect (5.2%), sialorrhea (3.1%), spasticity (1.3%) and fasciculations and muscle cramps (0.4%) were used less frequently in the last week of life.

Table 1. Characteristics of the study population of people dying from amyotrophic lateral sclerosis in Belgium between 2010 and 2015 (n=1636)

	People who died from ALS	
	Number	Percent
All deaths	1636	100.0
Age		
0-65	506	31.0
65-84	1018	62.3
85 and older	111	6.8
Gender		
Male	909	55.6
Female	727	44.4
Immediate cause of death (top 3)		
Respiratory arrest (R09)	418	35.0
Respiratory failure (J96)	282	23.6
Cardiac arrest (I46)	97	8.1
Highest attained level of education		
Higher education	228	13.9
Secondary education	656	40.1
Primary education	283	17.3
No education	69	4.2
Unknown	400	24.5
Region		
Flanders	1079	66.3
Wallonia	445	27.3
Brussels	104	6.4
Household composition		
Married	1031	63.1
Single person	329	20.1
Living together	71	4.3
Collective household	115	7.0
Other	88	5.8

Missing data for age (n=1), immediate cause of death (n=409), region (n=8), household composition (n=2).

Table 2. Quality indicators for appropriateness of end-of-life care, within the total population of people dying from amyotrophic lateral sclerosis in Belgium, 2010-2015 (n=1636)

	Time period (number of days before death until death)[a]					
	No time specification	7	14	30	90	180
Indicators of appropriate end-of-life care						
Specialized palliative care	43.8					
Palliative care status	39.8					
Home death	39.4					
Increased contact with family doctor		40.8	56.2	58.4		
Average number of primary caregiver contacts per week[b]		3.2	3.1	3.1	3.0	
Indicators of inappropriate end-of-life care						
Hospital admission		33.0	40.9	48.7	59.8	69.1
Diagnostic testing		31.2	38.0	47.6		
ED admission		18.9	25.2	31.3	41.6	49.0
Late initiation of palliative care		6.9	9.8			
ICU admission from nursing home		5.4	7.6	9.1		
Tube feeding or intravenous feeding		3.3	5.9	12.6		

[a] The time intervals presented here refer to the last 0-7, 0-14, 0-30, 0-90, 0-180 days before death.

[b] This indicator represents the average number of contacts per week across the population during the indicated period and is not presented as a percentage.

All indicators with a prevalence rate of less than 5% were excluded from the table (surgery, blood transfusion, port-a-cath installment)

Table 3. Healthcare utilization for the clinical management of ALS, within the total population of people dying from amyotrophic lateral sclerosis in Belgium, 2010-2015 (n=1636)

	Time period (number of days before death until death)[a]				
	7	14	30	90	180
Neuroprotective treatment					
Riluzole use	10.6	21.9	39.3	57.2	61.4
Symptom management					
Pain	29.4	35.8	42.5	49.1	53.6
Insomnia and fatigue[b]	20.0	26.8	33.2	41.2	46.4
Venous thrombosis[b]	14.8	24.4	32.0	44.4	54.0
Depression and anxiety[b]	10.4	14.8	19.2	25.2	30.0
Bronchial secretions[b]	7.2	14.0	19.6	31.6	37.6
Pseudobulbar affect (pathological laughing or crying) [b]	5.2	8.4	12.4	17.6	21.2
Sialorrhea (hypersalivation)	3.1	5.0	8.4	15.3	18.7
Spasticity	1.3	3.0	5.6	8.4	8.9
Fasciculations and muscle cramps[b]	0.4	0.4	1.2	1.2	1.2
Respiratory management					
Non-invasive ventilation†	-	-	17.5	-	-
Oxygen therapy†	-	-	5.9	-	-
Invasive ventilation†	-	-	3.6	-	-

[a] The time intervals presented here refer to the last 0-7, 0-14, 0-30, 0-90, 0-180 days before death.

[b] Percentages were only available for 2012 (n=250).

† Percentages were only available in the last 0-30 days before death (n=1636).

Discussion

Summary of main findings

Using administrative data, this study described healthcare utilization at the end of life among all patients who died from ALS over 6 years in Belgium. Specialized palliative care was used by almost half the patients who died from ALS, but for one in five of these it was initiated only in the last two weeks of life. Nearly half of all patients who died from ALS were hospitalized or underwent diagnostic testing in the last month of life. Healthcare utilization for the clinical management of the disease mainly involved medications to treat symptoms of insomnia or fatigue, venous thrombosis or pain. About one in six people received non-invasive ventilation in the last month of life, and one in eight had tube feeding or intravenous feeding in the last month of life. Nearly forty percent died at home.

Strengths and weaknesses

This was the first study to include the entire population of those who had died from ALS over a period of 6 years in one country. Possible biases due to a small sample size (e.g. only patients treated in a specialized ALS center) or a burden on patients or caregivers were thus avoided, which is particularly relevant in the population of those diagnosed with ALS. While some authors have raised concerns about the validity of using mortality data to study ALS (19) in Belgium, the causes of death on the death certificates are thoroughly checked by the regional health authority and a number of additional error checks are made (e.g. controls for unlikely information on record level or sampled controls by the civil registrar), thus guaranteeing a good quality of data (20).

Another strength of this study is that we used a previously validated set of quality indicators for end-of-life care. These indicators were rigorously developed and validated for specific use with administrative data. It remains true that particular attention should be paid to the special needs of this patient population. Although access to and evaluation of administrative data offer a very informative picture of healthcare resource utilization, it does not allow a complete operationalization of the guideline recommendations, as some aspects of end-of-life care were not captured in the data (e.g. recommendations concerning communication of the diagnosis to the patient).

Interpretation of results and comparison with previous research

Few previous studies have described end-of-life healthcare utilization in a population of people who died from ALS, and none have done so in Belgium, thus impeding a valid comparison with our findings. Two previous studies using similar quality indicators allow for comparison with people who died from cancer or COPD. Our findings show that considerably more people who died from ALS received specialized palliative care (43.8%) those who died from COPD (12%) (21), and about the same proportion of people who died from cancer (47%) (22). Patients who died from ALS more often died at home (39.4%) than those who died from cancer (29.5%) or COPD (28.2%), and on average they had more contacts with a primary caregiver (mean number of 3.2 contacts in the last week of life versus 1.1 for COPD and 2.4 for cancer). However, the use of potentially inappropriate end-of-life care was also high among people who died from ALS, compared to the other two disease groups. Compared to people who died from COPD and cancer, people who died from ALS had similar rates of hospital and ICU admissions at the end of life. The rates of ED admissions among ALS patients were lower at one month before death (31.3% versus 33.8% (cancer) and 40.5% (COPD)), but higher in the last week of life (18.9% versus 12.9% (cancer) and 16.1% (COPD)), indicating that patients and caregivers are potentially less prepared to handle crisis situations at the end of life in ALS (21,22).

Internationally, one prospective study from France analyzed the utilization of healthcare in 302 patients who died from ALS using physician-reported questionnaires (12), and one retrospective cohort in Sweden reported the use of prescription drugs over the course of the last year of life in

1603 older adults who died with ALS between 2007 and 2013 (9). In the last month of life, rates of opioid use were highest in Belgium (43% in Belgium, 38% in France, 31% in Sweden), but rates of anxiolytic use (19% in Belgium, 45% in France, 38% in Sweden), antidepressant use (19% in Belgium, 26% in France, 42% in Sweden), anticoagulant use (32% in Belgium, 20% in France, 37% in Sweden), and riluzole use (39% in Belgium, 55% in France, 45% in Sweden) were higher in France or Sweden. However, one-to-one comparison between the studies is difficult due to differences in the design and selected population – e.g. the Swedish study only included patients who were 65 years or older at time of death (12).

Hitherto, there is little evidence of good practices with regard to end-of-life care of ALS patients. The current guidelines on the clinical management of patients with ALS often remain vague about whether or when to initiate or terminate a certain intervention. For example, the document states that "riluzole may have little effect in late-stage ALS, and it is not clear whether and when treatment should be terminated" (18). Riluzole is currently the only drug with quality evidence of effectively slowing the course of the disease, with few to no known severe side-effects (23). Considering the uncertainty about its effectiveness in late-stage ALS, its high cost, and the fact that polypharmacy is already highly prevalent in the last year of life of people with ALS (9), it is important to investigate further when the discontinuation of the drug is advised. This current study was therefore only able to describe healthcare utilization for the clinical management of ALS, lacking the evidence to interpret the findings as possibly appropriate or inappropriate care at the end of life.

The prevalence of home death was described in the prospective study from France (12) and in three other, retrospective studies, covering Spain (13), the USA and Canada (24), Germany (10) and the UK (10). Reported rates of home death varied between 30% (Spain) and 62% (USA/Canada) (in Belgium, the rate of home deaths was 39%).

Some healthcare interventions have been found to improve patients' survival and quality of life (25–27), while this remains debatable for other interventions such as invasive mechanical ventilation (28). Our study found that 13% of people dying from ALS received tube feeding or intravenous feeding in the last month of life, whereas 17.5% and 3.6% respectively received non-invasive ventilation (NIV) or invasive mechanical ventilation (IMV). Strikingly, only three previous studies have measured the prevalence of tube feeding or ventilation at the end of life in a cohort of people who died from ALS. A small-sample study conducted in the UK and Ireland on 62 patients from 6 hospices, reported that 32% of patients had had a gastrostomy installed (29), and Gil and colleagues found that 37% of 302 French patients had received enteral feeding with gastrostomy (12). A study from the USA on 1458 ALS patients found that NIV (15.6%) was used more than seven times as frequently as IMV (2.1%) (26), while in France 33% of patients included in the study had received NIV at time of death (12).

Future research should look in to the prevalence of these practices in different countries at a population-level, which would allow researchers and practitioners to understand possible factors that influence an inclination towards more or less use of healthcare at the end of life in patients with ALS, e.g. cultural preferences concerning the prolongation of life or economic incentives and disincentives. Comparative research is needed to further investigate whether cross-national variations in possibly appropriate or inappropriate end-of-life healthcare utilization, as well as differences in the place of death, can be explained by similar drivers as those described in other life-threatening illnesses such as cancer (30,31) or COPD (32), and to discuss the impact that the local organization of palliative care resources in the healthcare system has in determining where and how people with ALS die. As already observed, the nature of these observational data do not lend themselves to the assessment of the appropriateness of individual patient trajectories, and for this reason they should provoke further research into the clinical benefit and value of different clinical practices at the end of life and on the appropriateness of the clinical decision-making process itself (33), including its adherence to patients' preferences and values (e.g. how often the patient's preference about place of death is met).

Conclusion

About half the people who died from ALS in Belgium between 2010 and 2015 used specialized palliative care services, and four in ten died at home. Nevertheless, end-of-life hospital use was high, indicating potentially inappropriate end-of-life care in people who died from ALS. Drugs at the end of life were mainly administered to treat symptoms related to pain, fatigue and insomnia, and venous thrombosis. More evidence is needed on the advantages or disadvantages of initiating or terminating different treatments and medications at the end of life, including the use of riluzole. Routinely collected data (big data) can provide a valuable source of such evidence in relatively small populations such as those with ALS where classical RCTs face many practical challenges.

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6 Are we evolving towards more and earlier use of palliative home care? A trend analysis using population-level data from 2010-2015

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Abstract

Context: The need for increased use and earlier initiation of palliative home care has been advocated by several international organizations.

Objectives: To investigate time trends in the use and timing of initiating palliative home care support (PHCS).

Methods: Observational study using routinely collected population-level databases linked with health claims data for the entire population living at home that died from diseases indicative of palliative care needs in Belgium between 2010 and 2015 (n=230,704). Trends and trends by cause of death and age were measured through changes over time in prevalence of use of PHCS. Rates were standardized for age, sex and cause of death distribution in 2010. The median number of days before death when PHCS was initiated was calculated for each year.

Results: Uptake of PHCS increased from 31.7% to 34.9% between 2010 and 2015. Trends were similar in size for all groups, except for people who died from dementia (smallest increase with 1.9 percent-point). The timing of initiating PHCS advanced from 41 days to 46 days before death, with the smallest increase observed among people who died from dementia (+2.5 days). The proportion of people receiving PHCS only in the last week of life changed from 15.3% to 13.9%.

Conclusion: This population-level study found a slight trend towards more and earlier initiation of PHCS between 2010 and 2015. However, uptake of PHCS remained below estimated needs in the population and the proportion of people receiving PHCS very late in life remained stable over time.

Background

The global need to shift towards more and more timely access to palliative care in the home or community has been increasingly recognized by multiple international and national organizations and policies (1–4). Indeed, studies have shown that the use of palliative home care and policy measures to support this care positively impact the quality of care at the end of life, and there are indications that its use is cost-effective for the healthcare system (5,6) Additionally, there has been an increasing amount of evidence that timely initiation of palliative care can be beneficial to all patients with a life-threatening illness, and not only to those with an advanced cancer diagnosis (7–9). Nevertheless, multiple population-based studies in a variety of countries with differing levels of palliative care development have indicated that the use of palliative care services is generally too low and initiation occurs late in the course of the disease (10–12). Moreover, certain groups, such as non-cancer patients or older people, are found to be underserved by palliative care services (13–18).

In Belgium, where palliative care was legally recognized as a right in 2002 to 'those whose life-threatening illness no longer responds to curative treatments' (19), such policies to support palliative care at home have been developed since the 1980s (20,21). Several measures exist, such as the multidisciplinary specialist palliative home care teams, palliative home care nursing or physiotherapy, and an allowance for palliative home care patients. As such, Belgium is one of the countries where the integration of palliative care in primary and community care is well established, and a certain level of awareness of palliative care exists among the general public (22,23). Nevertheless, little is known about how the use and timing of initiating these measures to support palliative home care in the population have evolved over time.

Recent trend studies have been published on the use of community-based or home-based palliative care in Belgium (11), the United States (24,25), India (26), Singapore (27) and Canada (28), but these studies limited their focus to one specific disease group (e.g. advanced cancer), age group (e.g. 65 or older), or setting (e.g. hospital). Moreover, all trend studies on palliative home care use were either based on sample data or focused on the use of only one specific type or program for palliative care provision, and none have used population-based data to study trends in the timing of initiating palliative home care.

The aims of this study were, firstly, to analyze trends in the use of any type of available palliative home care support among all persons living at home who died from an illness indicative of palliative care needs in Belgium between 2010 and 2015, and, secondly, to examine whether there was a trend towards earlier initiation among those who used any of these types of palliative home care support. For both aims, we also wanted to analyze whether trends were different for different subgroups in the population, specifically cause of death and age.

Methods

Study design

We conducted a retrospective cohort study, using linked data from eight administrative databases containing healthcare consumption and socio-demographic information on all deaths in Belgium between 2010-2015.

Study setting and participants

The study was conducted for all those who were registered with a Belgian health insurance fund at their time of death between 1 January 2010 and 31 December 2015 (98.8% of all deaths). We selected a population comprising deaths from underlying causes that can be considered indicative of a need for palliative care (i.e. both specialist and non-specialist palliative care), as identified through mixed-methods research (29,30). Using the 10th revision of the International Classification of Diseases (ICD-10), the following underlying causes of death were selected: neoplasms (ICD-10 C00-C97), organ failure (i.e. heart, renal, liver failure or COPD; ICD-10 J40-47, I11-13, I50, K70-72, N10-12, N18-19), dementia (ICD-10 F01, F03, G30) and other illnesses (i.e. Parkinson's disease, motor neuron disease, HIV/Aids and non-cancerous neoplasm; ICD-10 D00-48, G20, G12 and B20-24). Persons registered as resident in a nursing home during the last year of life were not included in the analysis (about 19% of the total population of annual deaths), as not all types of palliative home care support are (fully) available to this group.

Data sources

The data used involved eight administrative databases, linked at an individual level using a unique identifier by a third party that is responsible for data protection and linkage in Belgium. The linked data included person-level reimbursed healthcare use in the last two years of life (recorded as nomenclature codes). For all healthcare data, the exact date of delivery (coded as number of days before death) is recorded. Additionally, the data include demographic data, fiscal data (i.e. net taxable annual income), and death certificate data (including underlying cause of death, coded using ICD-10 codification) (31). The data linkage process and content is described in detail elsewhere (32).

Measurements

Using reimbursement codes registered in the database, we were able to measure the use of the following types of palliative home care support in Belgium: multidisciplinary specialist palliative home care team, palliative home care nursing or physiotherapy, allowance for palliative home care patients (see Box 1 for a detailed description). For each individual reimbursement record of palliative home care support, the date of provision was recorded and recoded into number of days before death, with a minimum of 0 days (day of death) and a maximum of 720 days before death. To evaluate changes in the timing of initiation, we selected the earliest (first) date of provision.

Box 1. Palliative home care support in Belgium

In Belgium, supportive measures for palliative home care, here defined as 'palliative home care support', have existed since 1985, and have since been further expanded (33). These measures are specifically intended for patients who have obtained legal 'palliative status', acquired after being diagnosed with one or multiple irreversible diseases, progressing unfavorably, with serious physical/mental deterioration, where therapeutic and rehabilitative interventions no longer affect deterioration, the prognosis is poor and death is expected in the relative short term (life expectancy of more than 24 hours and less than three months), having serious physical, psychological, social and existential needs requiring significant time-intensive and sustained support, and remaining or having the intention of dying at home (19). The following types of palliative home care support are available free of charge to patients with the 'palliative status':

The use of a **multidisciplinary palliative home care team:** these teams include at least one general practitioner, two nurses with a minimum in palliative care training and an administrative assistant. The main goal of the teams is to provide advice to all persons involved in the provision of palliative home care of a patient, and to organize and coordinate the provision of palliative care at home between different carers. They have to be available around the clock.

Palliative home care nursing or physiotherapy: nurses or physiotherapists with at least basic training in palliative care are allowed to deliver nursing care or physiotherapy at home to patients with the palliative status. They have to be available around the clock.

The **allowance for palliative home patients:** an allowance of €663.49 (as of 2018) meant to cover partially or non-reimbursed costs related to the provision of palliative care at home (e.g. certain medicines, care materials and equipment). A maximum of two allowances can be received, and the second allowance has to be applied for at least one month after the first was received. The request should be actively resubmitted by a physician.

Analyses

We used descriptive statistics to describe the characteristics of the population cohorts from 2010 to 2015.

To describe trends in the uptake of palliative home care support from 2010 to 2015, we plotted crude rates for each year and applied direct standardization to remove the effect of changes in the composition of the population between years. Using 2010 as the base year, we kept the distribution of total deaths by decedent category (based on age, cause of death, and gender) constant in the period and applied the actual proportions of palliative home care support use within each decedent group for each year to calculate proportions of standardized palliative home care support use (see also Supplementary Information). Trends in palliative home care support use were also illustrated by cause of death and age categories and contrasted with crude rates. The closer the crude and standardized proportions, the more the trends were influenced by changing patterns of palliative home care support use within the different decedent groups. Larger differences thus reflect greater influence from changes in the composition of the decedent population in terms of age–gender–cause of death. We calculated the slope of the least squares regression line to measure the degree of increase or decrease in uptake of palliative home care use over all six years (2010-2015). The slope indicates the average percent point increase per year, based on the shortest distance from each point in time to a linear regression line. This way, possible annual fluctuations in the use of palliative home care support are considered.

To describe trends in the timing of uptake of palliative home care support from 2010 to 2015, we plotted the percentage of people that used any type of palliative home care support for each day in the last two years of their life. Separate analyses were plotted to show differences in the timing of initiating palliative home care by cause of death, age, and sex.

All descriptive analyses were performed using SAS Enterprise Guide V.7.1.

Results

Socio-demographic characteristics

The number of deaths in Belgium among people who lived at home and died from an illness indicative of palliative care needs increased from 37,537 in 2010 to 39,252 in 2015 (4.6 percent increase) and the composition of decedents changed (Table 1). From 2010 to 2015, the relative proportion of people who died at the age of 85 or older increased by 4.6 percent points (p.p.). Relatively, more people died from organ failure (+0.6 p.p.), dementia (+1.9 p.p.) or another illness indicative of palliative care needs (+1.0 p.p.) in 2015 compared to 2010, and the relative proportion of those who died from cancer decreased by 3.5 p.p.

Trends in the use of palliative home care support between 2010 and 2015 for the entire population

Figure 1 shows the observed and standardized trends in palliative home care support use between 2010 and 2015 for the entire population of interest. The use of any type of palliative home care support in Belgium increased from 31.6% in 2010 to 34.9% in 2015, with the highest overall use in 2014 (35.8%). The actual increase in palliative home care support use is relatively close to the increase in the standardized pattern of palliative home care support use, reflecting changing patterns of palliative home care support use not attributed to changes in the composition of the decedent population. The standardized and crude rates diverged in the 2012-2013 period and in 2015, which indicates that in these years a more pronounced change occurred in the composition of decedents in terms of cause of death, age and sex. Similar trends were found for each type of palliative home care support separately (see Supplementary table S1).

Table 1. Characteristics of the study population: people living at home who died of an illness indicative of palliative care needs in Belgium, 2010-2015 (n= 230,704)

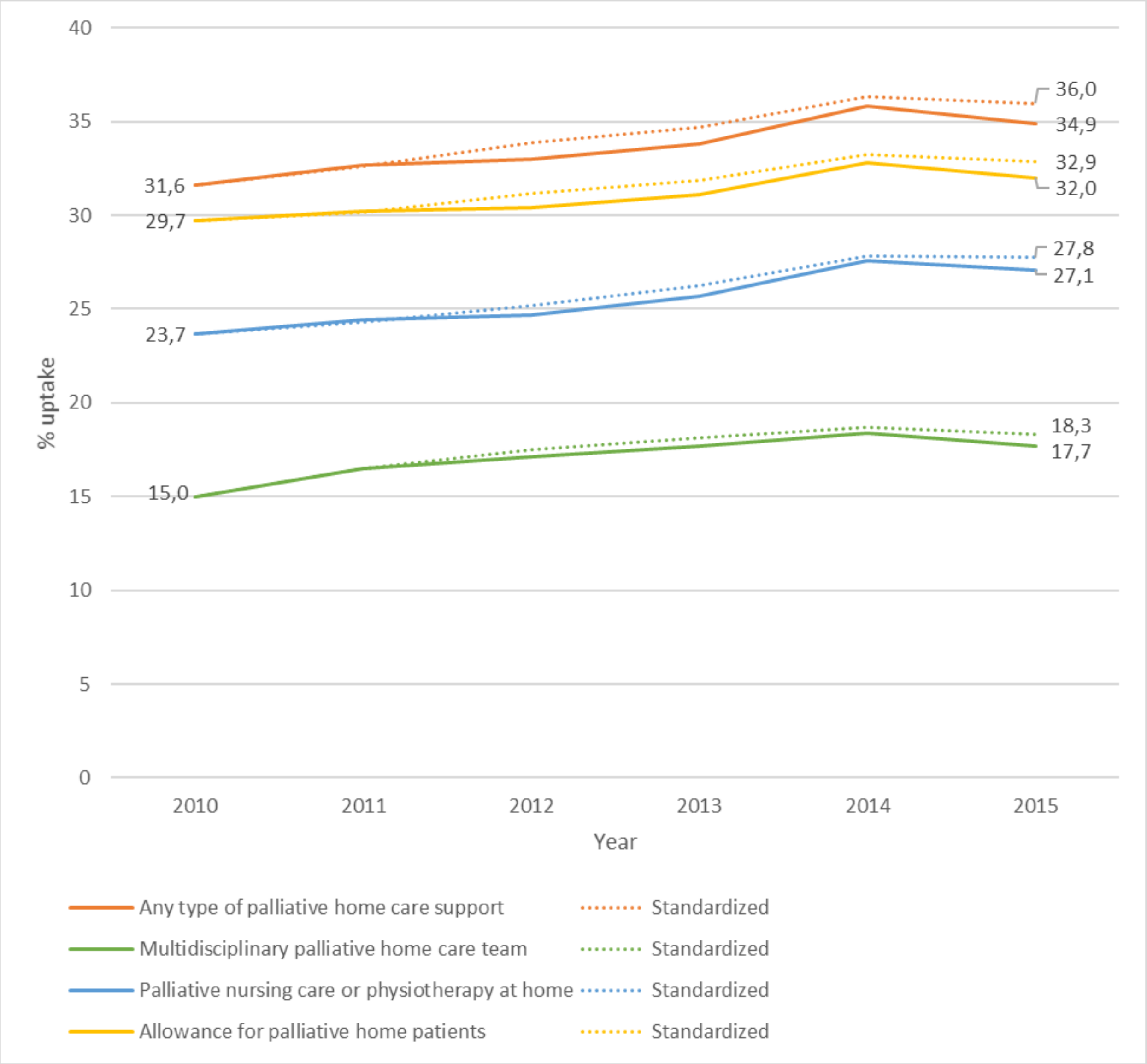
	2010	2011	2012	2013	2014	2015	p.p. change*
	N=37,537	N=37,364	N=38,893	N=39,414	N=38,244	N=39,252	
	%	%	%	%	%	%	
Gender							
Male	56.3	55.6	55.5	55.6	55.2	55.2	-1.1
Female	43.7	44.4	44.5	44.4	44.8	44.8	+1.1
Age							
<65 years	21.4	21.5	20.5	20.0	19.7	19.6	-1.8

65-84 years	57.2	56.3	55.3	55.6	55.2	54.5	-2.7
>84 years	21.4	22.2	24.1	24.5	25.1	26.0	+4.6
Underlying cause of death							
Cancer	66.1	66.5	63.1	63.0	64.2	62.6	-3.5
Organ failure	21.8	21.3	22.3	22.1	21.3	22.4	+0.6
Dementia	7.9	8.0	9.5	9.5	9.1	9.8	+1.9
Other	4.2	4.3	5.1	5.4	5.4	5.2	+1.0

Missing values for region of residence (<1%)

**p.p. change = percent point change between 2015 and 2010. P-values were not calculated because the data cover the full population.*

Figure 1. Crude and standardized* uptake of palliative home care support, 2010-2015 (n=230,704).



** Uptake was standardized for age, sex and cause of death using direct standardization for the year 2010. (std) = Standardized.*

Trends in the use of palliative home care support between 2010-2015 by cause of death and age

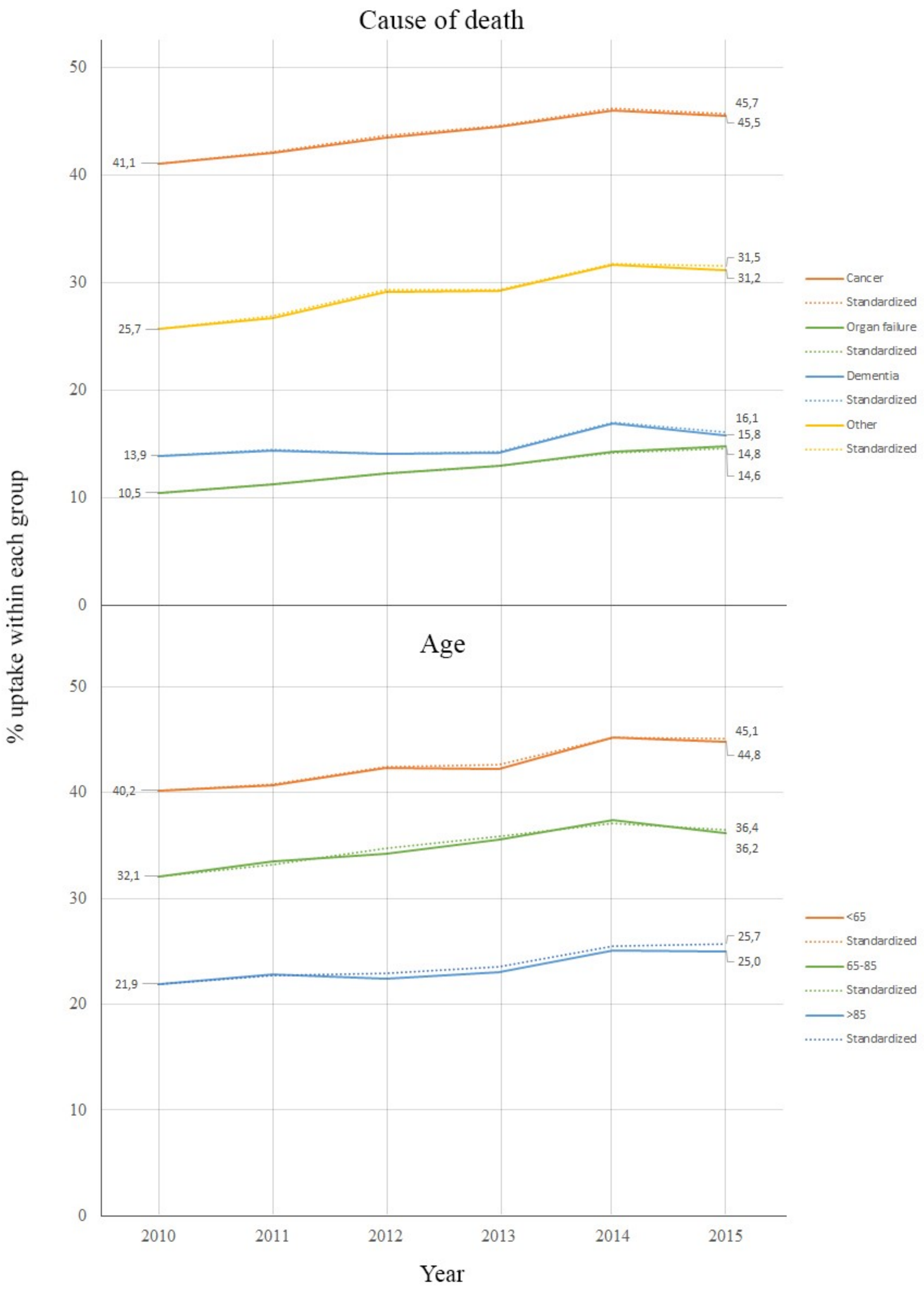
Figure 2 shows the observed and standardized trends in palliative home care support use between 2010 and 2015 by different cause of death and age group (see also Table 2). Comparing trends by cause of death, the least squares regression slopes indicate that use of palliative home care support increased at a similar rate for those who died from cancer (slope=1.0), organ failure (0.9), or another illness indicative of palliative care needs (1.2). Those who died from dementia had a substantially lower slope, with an average annual increase in palliative home care support use of 0.5 percent point. Trends of use of palliative home care support were similar for those who were less than 65 years (slope=1.0), or between 65 and 84 years old at time of death (1.0), whereas those who were 85 years or older at time of death had a lower slope (0.7), thus a smaller increasing trend of using palliative home care support between 2010 and 2015.

Similar trends were found for each type of palliative home care support separately (see supplementary table S1).

Trends in the timing of initiating palliative home care support between 2010 and 2015

Table 3 shows the trends in the timing of initiating any type of palliative home care support between 2010-2015, by cause of death, age, and sex. There was an increase in timing of initiating (in number of days before death) from a median of 40 days (IQR: 13-111 days) to 45 days (IQR: 14-133 days) before death between 2010 and 2015. The median number of days before death of initiating palliative home care support increased by 2.5 days for those who died from dementia, and by 11 days for those who died from another cause of death indicative of palliative care needs. The timing of initiation increased by 7 days for those younger than 65 years or 85 years or older, and by 4 days for those aged 65-85. Among men and women, there was an increase of 3 and 9 days respectively. The proportion of people for whom palliative home care support was initiated in the last week of life decreased between 2010 and 2015 from 15.3 to 13.9 percent (Figure 3). This proportion was highest among those who died from dementia (31.6 percent in 2015) (see supplementary figures 1a-i).

Figure 2. Change in the percentage of people using any type of palliative home care support by cause of death and age, 2010-2015 (n=230,704).



** Percentages are row percentages within each group separately. Uptake was standardized for each age, gender and cause of death group.*

Table 2. Percentage of people using any type of palliative home care support for each cause of death and age group, 2010-2015 (=230,704)

	2010	2011	2012	2013	2014	2015	P.p. change† (std*)	Least squares regression slope (std*)
	Crude % (std %*)	Crude % (std %*)	Crude % (std %*)	Crude % (std %*)	Crude % (std %*)	Crude % (std %*)		
Cause of death								
Cancer	41.1 (41.1)	42.1 (42.1)	43.5 (43.6)	44.5 (44.6)	46.0 (46.2)	45.5 (45.7)	+4.4 (4.6)	+1.0 (1.0)
Organ failure	10.5 (10.5)	11.2 (11.3)	12.3 (12.3)	13.0 (13.0)	14.3 (14.2)	14.8 (14.6)	+4.3 (4.1)	+0.9 (0.9)
Dementia	13.9 (13.9)	14.4 (14.5)	14.1 (14.1)	14.2 (14.3)	16.9 (17.0)	15.8 (16.1)	+1.8 (2.1)	+0.5 (0.5)
Other	25.7 (25.7)	26.8 (26.9)	29.1 (29.4)	29.2 (29.4)	31.7 (31.8)	31.2 (31.5)	+5.5 (5.8)	+1.2 (1.3)
Age								
<65 years	40.2 (40.2)	40.7 (40.8)	42.3 (42.4)	42.2 (42.6)	45.2 (45.2)	44.8 (45.1)	+4.6 (4.9)	+1.0 (1.1)
65-84 years	32.1 (32.1)	33.5 (33.2)	34.2 (34.8)	35.5 (35.9)	37.4 (37.1)	36.2 (36.4)	+4.1 (4.3)	+1.0 (1.0)
>84 years	21.9 (21.9)	22.8 (22.7)	22.4 (23.0)	23.0 (23.6)	25.1 (25.5)	25.0 (25.7)	+3.1 (3.8)	+0.7 (0.8)

** Std. = Standardized. Uptake was standardized for age, sex and cause of death differences. Percentages are row percentages for each group separately.*

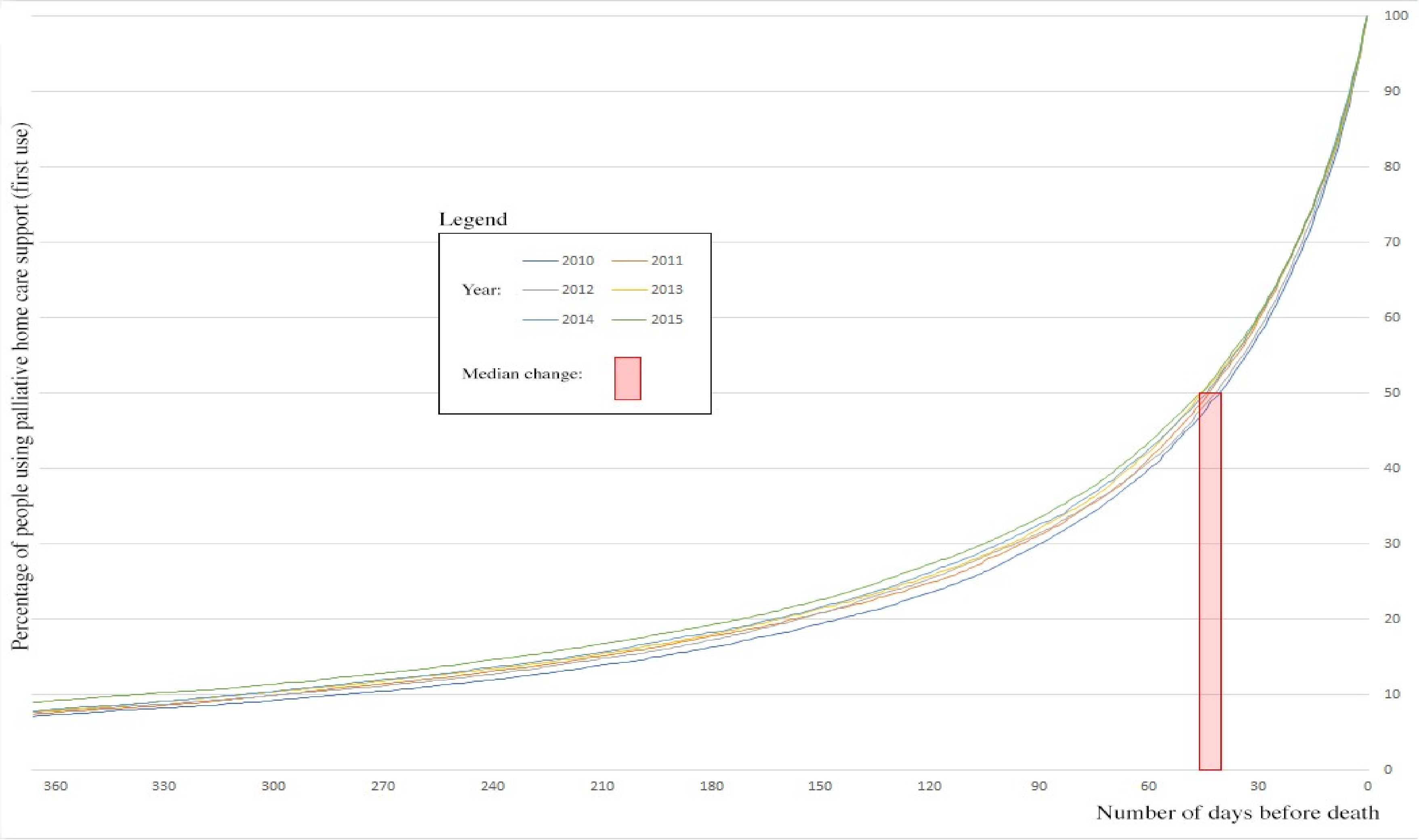
† p.p. change = percent point change. P.p. change was calculated between 2010 and 2015. P-values were not calculated because the data are at population level.

Table 3. Trends in the timing of initiating any type of palliative home care support, by cause of death, age, and sex, 2010-2015 (n=77,678)

	2010	2011	2012	2013	2014	2015	Change 2010-2015	Least squares regression slope
	N=11,872	N=12,210	N=12,845	N=13,328	N=13,704	N=13,719		
% initiated in last week of life	15,3	14,4	14,7	14,3	13,5	13,9	-1.4p.p.*	
	Median days (IQR)	Median days (IQR)	Median days (IQR)	Median days (IQR)	Median days (IQR)	Median days (IQR)		
Full population	40 (13-111)	43 (14-119)	41 (13-122)	45 (14-124)	44 (14-127)	45 (14-133)	+5.0	+0.9
Cause of death								
Cancer	42 (15-107)	44 (16-113)	43 (15-118)	46 (16-117)	46 (16-122)	47 (17-126)	+5.0	+1.0
Organ failure	29 (6-156.5)	36.5 (7-199)	29 (6-142)	42 (7-191)	36 (8-175)	38 (7-191)	+9.0	+1.6
Dementia	29 (5-204)	33 (5-290)	31 (5-220)	35 (5.5-248)	32 (6-226.5)	31.5 (5-287)	+2.5	+0.4
Other	52 (14-156)	46 (15-173)	53.5 (15-162.5)	51 (13-175)	48 (15-151)	63 (18-198)	+11.0	+1.7
Age								
<65 years	43 (15-109)	44 (17-113)	45 (16-124)	47 (18-121)	46 (17-122)	50 (18-133)	+7.0	+1.2
65-84 years	42 (14-114)	44 (15-122.5)	43 (14-124)	46 (15-125)	46 (16-128)	46 (15-134)	+4.0	+0.8
>84 years	34 (8-114)	40 (11-126)	36 (9-120)	38 (9-135)	39 (10-143)	41 (9-141)	+7.0	+1.0
Gender								
Male	39 (12-108)	40 (13-107)	38 (13-112)	41 (14-113)	42 (14-120)	42 (14-122)	+3.0	+0.7
Female	44 (14-119)	50 (17-143)	48 (15-140)	52 (17-143)	49 (16-141)	53 (17-152)	+9.0	+1.3

*P.p. = Percent point.

Figure 3. Timing of first use of any type of palliative home care support among all home-dwelling adults who died of an illness indicative of palliative care needs and used palliative home care support, 2010-2015 (n=77,723) (color)*



* People with first use 720-365 days before death were not shown in figure, but were included in the analysis

Discussion

Summary of main findings

Over the six-year period that covers this population-level trend study on the use of palliative home care support in Belgium, there was an increase in uptake from 31.6 percent in 2010 to 34.9 percent in 2015. There was also a trend noticeable towards earlier initiation among those who used palliative home care support, with the median number of days before death of first initiation changing from 40 to 45 days in the studied period. Comparing different disease groups, changes in the use and timing of palliative home care support were substantially lower among people who died from dementia.

Strengths and weaknesses

The use of population-level data from national health insurers allowed us to include the entire population that was of interest over multiple consecutive years. Additionally, these administrative data have a high degree of accuracy and reliability, since all types of palliative home care support are recorded by date of provision for reimbursement purposes, thus avoiding potential biases. As such, this study is the first to our knowledge to analyze time trends in the use and timing of initiating palliative home care support for the entire population in a country.

However, this study also has limitations, mainly related to the use of administrative data. Firstly, the data do not capture the quality of the support used. Secondly, we were only able to measure the first date of use of palliative home care support, thus our study does not provide information on the amount or continuity of support that was given. Although the selection of people with possible palliative care needs is based on a previously validated and frequently used estimation, it is based on underlying cause of death, and not on an actually observed or stated palliative care need (34). Lastly, reimbursement data do not capture the non-reimbursed forms of support for palliative home care or social support which, in Belgium, specifically include informal care.

Interpretation of results and implications for policy, practice and research

Our finding that the use of palliative home care support increased over time corroborates with previous studies analyzing trends in the use of community-based or home-based palliative care (11,26–28). For example, a mortality follow-back survey study among general practitioners that studied trends of palliative care use in Belgium among people that died aged 65 or older between 2005 and 2014 found roughly the same increase in the use of multidisciplinary palliative home care teams by older people (65+) between 2010 and 2014 as the one we found in our study (11). A possible explanation for these findings is the growing structural and financial capacity to organize palliative care at home in Belgium (35). A national report by the Federal Evaluation Cell on Palliative Care in Belgium in 2017 suggests that the increased use of the multidisciplinary palliative home care teams may, at least in part, be due to an increase in structural financing that allowed these teams to serve half again as many patients as before (36). This would mean that more funding indeed translates into more use, as a stagnation in the use of multidisciplinary palliative home care teams had been reported in mortality follow-back studies for the period 2005-2010 (11). Moreover, despite progression towards more use of palliative home care support between 2010 and 2015, the trend is marginal, and there is reason to assume that the proportion that is currently used does not meet actual needs in the population. For example, a previous study used three different population-based estimation methods to estimate the need for palliative care and found that palliative care needs in the entire Belgian population ranged between 40% and 75% of all deaths (28). It should be stressed here that the studied population in our study was already restricted to those that died of a cause that was indicative of palliative care needs (and living at home), and thus has a theoretical need for palliative care of 100%. In that regard, our findings show that further efforts are needed to expand the use of palliative home care support to meet the actual needs in the population.

This study also found there was a slight trend towards earlier initiation of palliative home care, with the median number of days before death of first initiation rising from 40 to 45 days between 2010 and 2015. This seems to contradict findings from a previous study in Belgium between 2005 and 2014, which reported no trend in timing of initiation of palliative care among a sample of older people (aged 65 and older) (11). There are several plausible hypotheses to explain the discrepancy between these findings and ours, such as a possible lack of power due to a small sample size (the study had data on a sample of 5344 people that died over 8 separate years), or the lack of comparability of the populations that were studied (our study included people of all ages, whereas the other study only included older people). Adding to that, it is debatable whether a 5-day increase in number of days before death of initiating palliative home care support is in fact a clinically relevant trend. To our knowledge, no other studies have been conducted on trends in the timing of initiating palliative home care, but one retrospective trend study in the USA found that patients diagnosed with advanced cancer in 2014-2016 received a hospital-based palliative care consultation more than four months (median) earlier in the course of their illness than patients diagnosed with advanced cancer before 2014 (37). Despite large differences between the USA study and ours in terms of intervention and setting, the difference in the size of their reported change in timing of initiation and ours raises questions as to whether our findings can be interpreted as a sufficiently meaningful trend towards earlier initiation of palliative home care. Ideally, future research should analyze trends in the timing of initiating palliative home care in other countries for better comparison, as well as investigating how much these differences impact the quality of care at the end of life.

Trends in the use and timing of initiating palliative home care support were not similar for all causes of death and age groups in the population. The substantially lower increase in palliative home care support use among people who died from dementia could be caused by difficulties in prognostication and timely recognition of the dying phase among people with the illness, issues that have been highlighted before in research (38). This effect is possibly further enhanced by the fact that all types of palliative home care support that were measured in our study are only available to patients with palliative status, thus a diagnosis of a terminal illness with a prognosis of three months or less had to be formally made. The variance in the timing of initiation of palliative home care support was also greatest among those who died from dementia, with a quarter of patients having used palliative home care support for 287 days or longer before death – the earliest among all groups considered – and a quarter of patients for five days or less before death. This finding suggests that difficulties in prognostication and timely recognition of the dying phase among this group persist. From 2019 onwards, however, the PICT tool (an unvalidated translation of the Supportive & Palliative Care Indicators (SPICT) tool) will be implemented in

Belgium to evaluate palliative care needs, replacing the former criterion of life-expectancy with the surprise question ('Would you be surprised if your patient died within the next 6-12 months?'). Moreover, the Belgian federal government has recently allocated a budget to reimburse dedicated advanced care planning (ACP) conversations with a GP for patients who meet the criteria of the PICT tool. Future research should investigate whether the impact of these changes in the law on the use and timely initiation of palliative home care support, especially among people with dementia.

Conclusion

This population-level study found a small trend towards more and earlier initiation of palliative home care support between 2010 and 2015. Trends were similar in size for all causes of death and age groups, except for people who died from dementia and those aged 85 or older, who experienced smaller increases than other groups in the population. Nevertheless, uptake remains well below the estimated needs for palliative care in the general population, and a substantial proportion of people who use palliative home care support receive it only in the last week of life. Continuing policy efforts are needed to eradicate the inequities and improve the access to, use of and timing of initiating of palliative home care support for all those in need.

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Part IV ※ Impact of using palliative home care support on quality and costs of care

7 Impact of palliative home care support on the quality and costs of care at the end of life: a population-level matched cohort study

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Abstract

Objectives: To evaluate the impact of palliative home care support on the quality of care and costs in the last 14 days of life.

Design: Matched cohort study using linked administrative databases.

Setting: All people who died in Belgium in 2012 (n=107 847).

Participants: 8837 people who received palliative home care support in the last 720 to 15 days of life matched 1:1 by propensity score to 8837 people who received usual care.

Intervention: Receiving the allowance for palliative home patients, multidisciplinary palliative home care team visit, or palliative nurse or physiotherapist visit at home.

Main outcome measures: Home death, number of family physician contacts, number of primary caregiver contacts, hospital death, hospital admission, intensive care unit (ICU) admission, emergency department (ED) admission, diagnostic testing, blood transfusion and surgery. Total inpatient and outpatient costs. All outcomes were measured in the last 14 days of life.

Results: In the unmatched cohort, 11 149 (13.5%) people received palliative home care support in the last 720 to 15 days of life. After matching, those using palliative home care support had, compared with those who did not, more family physician contacts (mean 3.1 [SD=6.5] vs 0.8 [SD=1.2]), more chance of home death (56.2%vs13.8%; relative risk [RR]=4.08, 95% CI 3.86 to 4.31), lower risk of hospital admission (27.4%vs60.8%; RR=0.45, 95% CI 0.43 to 0.46), ICU admission (18.3%vs40.4%; RR=0.45, 95% CI 0.43 to 0.48) or ED admission (15.2%vs28.1%; RR=0.54, 95% CI 0.51 to 0.57). Mean total costs of care were lower for those using palliative home care support (€3081 [95% CI €3025 to €3136] vs €4698 [95% CI €4610 to €4787]; incremental cost: −€1617 [p<0.001]).

Conclusions: Palliative home care support use positively impacts quality of care and reduces total costs of care at the end of life in Belgium. Policy makers and healthcare practitioners should increasingly focus on communicating the existing options for palliative home care support to patients and their caregivers.

Background

A majority of the growing population encountered with chronic and life-limiting illnesses prefers to receive high-quality care and to die at home.(1,2) Palliative home care support aims to meet the needs of these people by managing symptoms, improving quality of life and preventing avoidable healthcare interventions such as hospitalizations at the end of life.(3) It is estimated that palliative care could be beneficial in 38%–74% of all deaths worldwide.(4) In recent years, policy makers internationally have focused on promoting the integration of palliative care services into the community and on developing supportive policy measures for palliative care at home to meet the growing demand for high-quality home-based palliative care and to reduce costs related to acute hospital care use at the end of life.(5–7) Several countries offer palliative home care support in the form of multidisciplinary palliative home care teams, palliative nursing care at home or financial support for those wanting to receive palliative care at home.(8–11)

The impact of using palliative home care support on the quality and costs of care at the end of life remains poorly evaluated. (12) A Cochrane review that included 23 studies found that use of home palliative care services more than doubled the odds of dying at home and reduced symptom burdens. (13) Six studies focused on costs and reported up to 35% lower costs in the intervention group compared with a control group. Only one study reported statistically significant differences, but the authors pointed out that 'the existence of economically significant differences [in the other studies] cannot be ruled out due to small sample sizes unlikely to have sufficient power to detect statistical significance'. Another recently updated Cochrane review included four trial studies that evaluated 'hospital at home' services, demonstrating the positive impact of this type of home-based end-of-life care on the chances of having a home death, but results on hospital admissions and healthcare costs varied and were found inconclusive. (14)

However, traditional experimental study designs, such as those evaluated in the above-mentioned reviews, are limited due to ethical and practical concerns (e.g., it would be illegal to refrain patients from receiving any palliative home care in a trial). Therefore, they are not suitable for evaluating the impact of palliative home care support that are available nationally to everyone across a healthcare system.(3) A matched cohort study design with a high-quality matching on the propensity of receiving palliative home care is the best possible technique to evaluate this impact.(15) The increasing availability and improving quality of routinely-collected databases and the technical possibilities of linking data from various sources have opened up new possibilities for such designs.(16) Three retrospective cohort studies using matched controls found an impact of palliative home care support on reducing hospitalizations at the end of life and on lower chances for hospital deaths in Canada, England and the USA.(17–20) Findings from another retrospective cohort study suggested that a proactive home-based palliative care program 'helped to avoid the escalation in hospital use and costs commonly seen in the final months of life'.(21) However, these studies focused only on a limited number of outcomes as indicators of quality of end-of-life care (hospital use and place of death) and only one focused additionally on costs, without distinguishing inpatient and outpatient costs. None of the studies used population-level national data, therefore limiting the findings to one specific province or region.

In Belgium, palliative home care support is available in the form of: (1) a multidisciplinary palliative home care team, (2) palliative home care nursing or physiotherapy and (3) the allowance for palliative home care patients, available twice and meant for non-reimbursed palliative care-related costs. These supportive policy measures are entirely free to the patient and their informal caregivers. Using linked register-based databases on all deaths in Belgium, the current study aims to evaluate the impact of using palliative home care support on the appropriateness and costs of care in the last 14 days of life on a population level.

Methods

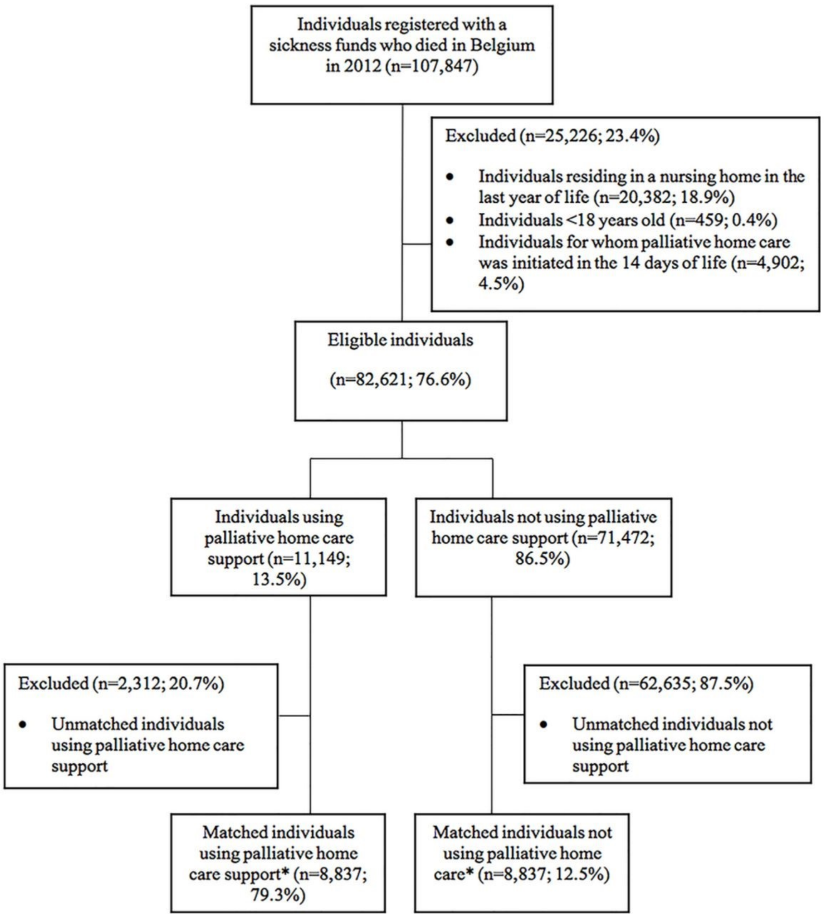
Study design

We conducted a matched cohort study on all deaths in Belgium in 2012, using linked data from eight administrative databases. An individual that used at least one type of palliative home care support was matched to an individual that used no palliative home care support. To reduce selection bias between the groups and to balance measured covariates across them, we used propensity score matching. (15) We followed an extension of the Strengthening the Reporting of Observational Studies in Epidemiology guidelines for reporting observational studies to report the propensity score matching analysis. (16)

Study setting and participants

The study was conducted for all those who were registered with a Belgian sickness fund at time of death in 2012 (98.8% of all deaths). We excluded people younger than 18 years and those who had permanent residence in a nursing home during the last year of life. Additionally, to avoid any overlap between the timing of exposure and the timing of the outcomes, we excluded those for whom palliative home care support was initiated for the first time in the last 14 days of life. Figure 1 presents the study population selection process.

Figure 1. Flow chart of the study population selection



The data used involved eight administrative databases, linked on an individual level using a unique identifier by a third party responsible for data protection and linkage in Belgium. The linked data included person-level reimbursed healthcare use in the last 2 years of life (recorded as nomenclature codes) including dispensed medication in the hospital and community pharmacy in the last 2 years of life (recorded as Anatomical Therapeutic Chemical Classification System (ATC) codes). For all healthcare data, the exact date of delivery (coded as number of days before death) is recorded. Additionally, the data include demographic data, fiscal data (i.e., net taxable annual income) and death certificate data (including underlying cause of death, coded using International Statistical Classification of Diseases, Tenth Revision (ICD-10) codification). (22) The data linkage process and content is described in detail elsewhere. (23)

Patient and public involvement

We used previously validated quality indicators (QIs) for end-of-life care to measure appropriateness and inappropriateness of end-of-life care on an aggregated level. Patients were not directly involved in the design of the study or development of the QIs. The design of the study, using population-level decedent data, did not allow to disseminate results to or involve observed patients in the development of the research questions or outcome measures.

Exposure group

Our exposure group consisted of people who used at least one type of palliative home care support between the last 720 and 15 days of life (see box 1). We included all persons receiving palliative home care support for the longest time frame available in our data, that is, up to 720 days before death. We did not want to exclude persons on the basis of a (retrospectively) predefined time frame, as this information (time before death) would not be known using a prospective design. The inclusion criteria were: (combined by 'OR'): (1) having received the allowance for palliative home patients, (2) having a visit by a multidisciplinary palliative home care team visit or (3) having a visit by a palliative nurse or physiotherapist at home. Using specific nomenclature codes, we could identify delivery, health insurance-reimbursed cost and timing of a specific palliative home care support. The data were sorted to identify the earliest use of palliative home care support when multiple measures were used.

Box 1. Description of the exposure: Palliative home care support in Belgium

Policy measures to support palliative care at home, here defined as 'palliative home care support', exist in Belgium since 1985. (30) In 2002, palliative care was recognized by Belgian law as a right for all Belgian citizens. Since then, seriously ill patients with a short life expectancy (defined by law as 'more than 24 hours and less than three months') and an intention to die at home are eligible to receive specific supportive measures from the Belgian government. (32) These are:

a. The use of a multidisciplinary palliative home care team: which includes at least one general practitioner, two nurses and an administrative assistant. The main goal of the multidisciplinary palliative home care teams is to advise family physicians, health professionals, counsellors, informal carers and volunteers involved in the provision of palliative home care of a patient and to organize and coordinate the provision of that palliative care at home between different care providers. The use of these teams is free of charge for the patient and not limited in time.

b. Palliative home care nursing or physiotherapy: type of nursing care or physiotherapy at home, differing from standard nursing care or physiotherapy at home for heavily dependent home-patients in the number of caring tasks provided and round-the-clock availability. Free of charge for the patient.

c. The allowance for palliative home patients: a lump sum of €647.16 (in 2012), which is obtainable twice (possibility to claim a second after 1 month) and meant to cover for non-reimbursed or partially reimbursed costs that are related to the provision of palliative care at home (e.g., certain medicines, care materials and tools).

The Belgian health system is primarily funded through social security contributions and taxation, with a compulsory national health insurance, which covers the whole population. Compulsory health insurance is combined with a private system of healthcare delivery, based on independent medical practice, free choice of service provider and predominantly fee-for-service payment. It is important to note that all healthcare insured people in Belgium have the legal right to access palliative home care support. Family physicians play a gatekeeping role in this: they remain responsible for all care provided at home and need to give their written permission to initiate any of the palliative home care support. Receiving any of these was chosen as exposure because we considered the different types of support to be an indication of the same intervention: initiation of palliative home care. However, sensitivity analyses were performed in which each separate support type is selected as the basis for the exposure group.

Non-exposure group

People who did not use palliative home care support in the last 2 years of life were included in the non-exposure group.

Outcomes for appropriateness and inappropriateness of end-of-life care

We used QIs for appropriate and inappropriate end-of-life care that were developed using the RAND/UCLA Appropriateness method that aims 'to combine the best available scientific evidence with the collective judgment of experts to yield a statement regarding the appropriateness of performing a procedure at the level of patient-specific symptoms, medical history, and test results'.(24) We included the following indicators for appropriateness of end-of-life care, all pertaining to the last 14 days of life: dying at home; the average number of primary caregiver contacts; and the average number of family physician contacts. We included the following indicators for inappropriateness of end-of-life care: dying in a hospital; being admitted to hospital; being admitted to an emergency department (ED); being admitted to an intensive care unit (ICU); being submitted to diagnostic testing (i.e., medical imaging, ECG or pulmonary function testing); having a blood transfusion; and having surgery.

The QIs measure the prevalence of specific medication types (recorded in the data sources using ATC codes) or healthcare interventions (recorded in the data sources as nomenclature codes for reimbursement purposes) within a specified period before death. For example, the QI 'average number of primary caregiver contacts in the last fourteen days of life' is calculated as the mean number of contacts with a family physician or other primary care professional (based on the number of relevant registered nomenclature codes) in the last 14 days of life. The development, validation process and use of these indicators to study end-of-life care on a population level is described in detail in De Schreye et al. (25)

Costs of end of life

Based on all specific healthcare consumption data, we calculated total healthcare costs from a third-party and patient copayment perspective, consisting of total inpatient cost and total outpatient cost for both groups. Inpatient costs included all specific intervention and medication costs in the hospital. Outpatient costs included all specific intervention and medication costs outside the hospital. For a detailed description, see online supplementary box 1. Based on the exact dates of delivery we calculated the total costs for the last 14 days of life. All costs were actualized to 2017 values based on the unit cost of all defined resources in that year.

Propensity score matching and statistical analysis

Descriptive statistics were used to describe population characteristics, stratified by having received palliative home care support (exposure group) or not (non-exposure group).

People who received palliative home care support were matched to those who did not, based on an individual estimation of their propensity for receiving palliative home care support. To calculate the propensity scores, relevant predictors for receiving palliative home care, based on previous research findings, were used as baseline covariates.(13) The following baseline covariates were used: age at death, sex, underlying cause of death (as a proxy for diagnosis using ICD-10 codification, these were recoded into: neoplasms [C00-D48], respiratory diseases [J40-44 and J47], other organ failures, i.e., heart, renal and liver failure [I11-I13, I50, K70-72, N10-12 and N18-19], neurodegenerative diseases, i.e., Alzheimer's disease, Parkinson's disease, motor neuron and Huntington's disease [F01, F03, G10, G12, G20 and G30], HIV/AIDS [B20-24]; other underlying causes of death were recoded as 'other'), household type, personal annual taxable income, highest attained educational level, degree of urbanization of residence, region of residence and hospital use in the last 2 years of life (based on the criteria: 'having had at least six hospitalizations' and 'being at least 120 days in the hospital'). We used a greedy one to one case–control propensity score matching algorithm. (26) For every case, the best match was made first and a next-best match next, in a hierarchical sequence until no more matches could be made. Best matches are those with the highest digit match on propensity score. First, cases are matched to controls on eight digits of the propensity score. For those that do not match, cases are then matched to controls on seven digits of the propensity score and so on. The algorithm proceeds sequentially to the lowest digit match on the propensity score (one digit). In view of performing sensitivity analyses, we performed separate matchings with, respectively, allowance for palliative home care patients, multidisciplinary palliative home care team visit and palliative nursing care or physiotherapy at home on its own as exposure, to evaluate whether these types of support showed different results.

Two sampled t-test statistics were used to test for significant differences in age, and $\chi 2$ statistics were used to test for significant differences in dichotomous and categorical variables describing the unmatched and matched exposed and non-exposed groups. Risk ratios were calculated to measure the differences in outcomes between the exposed group and the non-exposed group. Costs were presented as means, medians, SEs and IQRs. All analyses were performed using SAS Enterprise Guide V.7.1.

Results

Study population characteristics

Of all deaths in Belgium in 2012 (n=107 847), we excluded 25 226 individuals from our study population because they resided in a nursing home (18.9% of total population), were minors (0.4%) or used palliative home care support only during the last 14 days of life (4.5%) (figure 1). Our final unmatched set consisted of 82 621 individuals of which 11 149 (13.5%) had initiated palliative home care support in the last 720–15 days of life (table 1). Before matching, the sociodemographic characteristics of the cohort exposed to palliative home care support differed largely from the unexposed cohort (e.g., in cause of death, household composition and hospital use during the last 2 years of life). After propensity score matching, 8837 exposed people were matched to as many unexposed people. We performed sensitivity analyses on each support type separately with no substantial differences in the impact on the QI outcomes (online supplementary table 1).

Indicators of appropriate end-of-life care

Fifty-six per cent of the people using palliative home care support died at home, compared with 13.8% of those who did not use palliative home care support (relative risk [RR]=4.08; 95% CI 3.86 to 4.31 (table 2). On average, people in the palliative home care support cohort had nine primary caregiver contacts and three family physician contacts in the last 2 weeks of life, compared with two primary caregiver contacts and less than one family physician contact for those in the unexposed cohort.

Indicators of inappropriate end-of-life care

Thirty-nine per cent of the people using palliative home care support died in the hospital, compared with 74.8% of the people not using palliative home care support (RR=0.52; 95% CI 0.51 to 0.54). Less people in the palliative home care support cohort were admitted to a hospital (27.4% vs 60.8%; RR=0.45, 95% CI 0.43 to 0.46), to an intensive care unit (18.3% vs 40.4%; RR=0.45, 95% CI 0.43 to 0.48) or to an ED (15.2% vs 28.1%; RR=0.54, 95% CI 0.51 to 0.57) in the last 2 weeks of life. Less people who used palliative home care support were submitted to diagnostic testing (27.2% vs 63.2%; RR=0.43, 95% CI 0.41 to 0.45), received blood transfusion (2.7% vs 5.9%; RR=0.47, 95% CI 0.40 to 0.54) or surgery (0.5% vs 2.8%; RR=0.19, 95% CI 0.14 to 0.26) (table 2).

Medical care costs

Mean total inpatient costs were lower for people using palliative home care support (€1766; 95% CI €1706 to €1826) compared with those who did not use palliative home care support (€4222; 95% CI €4133 to €4311) ($p<0.001$) (table 3). Mean total outpatient costs were higher for people using palliative home care support (€1314; 95% CI €1291 to €1337) compared with those who did not (€476; 95% CI €461 to €492) ($p<0.001$). Mean incremental total costs for exposed versus unexposed people in the last 2 weeks of life was −€1617 (SE=53.2). We performed sensitivity analyses on each support type separately with no substantial differences in the impact on the costs of care at the end of life (online supplementary table 2).

Table 1. Characteristics of people using palliative home care support (exposed) and people who did not use palliative home care support (unexposed) before and after propensity score matching.

	Before propensity score matching (n=82 621)		After propensity score matching (n=17 674)	
Characteristics	Exposed	Unexposed	Exposed	Unexposed
No. of patients (%)	11 149 (13.5)	71 472 (86.5)	8837 (50)	8837 (50)
Earliest use of palliative home care in days, median (IQR)	75 (154)	/	73 (152)	/
Mean age at time of death (SD)	74.2 (12.8)	76.5 (14.2)	74.4 (12.7)	75.0 (12.3)
Sex				
Men	55.2	54.6	56.0	55.1
Women	44.8	45.4	44.0	44.9
Cause of death				
Neoplasm	74.6	20.6	72.7	72.8
COPD	2.5	4.6	2.7	2.8
Another organ failure	3.2	5.9	3.5	3.1
Neurodegenerative	4.4	5.0	4.9	5.1
Other	15.3	63.8	16.2	16.3
Household composition				
Married	60.4	44.6	60.4	61.4
Single person household	26.2	41.5	26.7	26.4
Living together	4.1	4.2	4.0	3.6
One-parent family	6.4	6.7	6.2	5.9
Other	2.9	3.0	2.7	2.7
Education level				
No education	8.1	8.7	7.9	7.7
Primary school education	34.7	34.9	34.7	35.2
Secondary school education	44.8	45.2	45.0	44.6
Post-secondary school education	12.5	11.2	12.4	12.6
Income in quartiles*				
Lowest income quartile	29.2	26.2	28.4	28.7
Second income quartile	22.5	23.5	21.7	21.9
Third income quartile	24.1	24.5	24.3	24.8
Highest income quartile	24.3	25.9	25.6	24.6
Region				
Flemish region	66.4	53.1	65.4	64.5
Walloon region	28.8	36.8	29.6	30.4
Brussels Capital region	4.8	10.1	5.0	5.1
Urbanization				
Very high	25.1	33.7	25.7	25.6
High	28.5	27.5	29.2	28.7

(continued)

Table 1. Characteristics of people using palliative home care support (exposed) and people who did not use palliative home care support (unexposed) before and after propensity score matching. (continued)

Average	32.0	24.4	30.7	30.6
Low	12.9	13.0	13.0	13.7
Rural	1.5	1.5	1.5	1.5
Hospital use in the last two years				
>=120 days hospitalized	4.7	5.3	4.6	4.0
>= 6 hospitalizations	46.5	14.7	44.5	44.6

Values are percentages of patients unless stated otherwise. All percentages are valid percentages. Missing values existed in the full population (n=107 847) for household composition (n=1399; 1.6%), education level (n=11 382; 13.1%), income (n=3563; 4.1%), region (1657; 1.9%), urbanization (1657; 1.9%). *Income quartiles were calculated on the full population of decedents (n=107 847).

Table 2. Indicators of appropriate and inappropriate end-of-life care in the last 14 days of life in the matched cohorts

	Palliative home care support (n=17,674)		
	Yes (n=8837)	No (n=8837)	RR (95% CI)
Indicators of appropriate end-of-life care			
Home death	56.2	13.8	4.08 (3.86-4.31)
Mean number of family physician contacts (SD)*	3.1 (3.0)	0.8 (1.2)	/
Mean number of primary caregiver contacts (SD)*	9.0 (6.2)	2.3 (4.0)	/
Indicators of inappropriate end-of-life care			
Hospital death	39.0	74.8	0.52 (0.51-0.54)
Hospital admission	27.4	60.8	0.45 (0.43-0.47)
ICU admission	18.3	40.4	0.45 (0.43-0.48)
ED admission	15.2	28.1	0.54 (0.51-0.57)
Diagnostic testing	27.2	63.2	0.43 (0.41-0.45)
Blood transfusion	2.7	5.9	0.47 (0.40-0.54)
Surgery	0.5	2.8	0.19 (0.14-0.26)

RR = relative risk; CI = confidence interval; SD = standard deviation; ICU = intensive care unit; ED = emergency department. * P<0.0001 calculated using two-sided T-test statistic.

Table 3. Healthcare costs in the last 14 days of life in the matched cohorts, in euro

	Palliative home care support (n=17,674)				
	Yes (n=8837)		No (n=8837)		
	Mean (95%CI)	Median (Q1-Q3)	Mean (95%CI)	Median (Q1-Q3)	Mean incremental (p-value)
Total inpatient costs	1766 (1706-1826)	0 (0-2724)	4222 (4133-4311)	3400 (513-6754)	-2454 (p<0.001)
Total outpatient costs	1314 (1291-1337)	1243 (449-1829)	476 (461-492)	251 (11-647)	838 (p<0.001)
Total costs	3081 (3025-3136)	2055 (1305-4227)	4698 (4610-4787)	3996 (1077-7124)	-1617 (p<0.001)

SE = standard error ; Q1-Q1 = interquartile range. All costs expressed in 2017 euros. Costs were calculated using data on all reimbursed medical care costs and rounded. Total inpatient costs included all specific intervention and medication costs in the hospital. Total outpatient costs included all specific intervention and medication costs outside the hospital.

Discussion

To our knowledge, this is the first nationwide matched cohort study on the impact of palliative home care support on the quality and costs of care at the end of life, using validated QIs. We found that people using palliative home care support received more appropriate and less inappropriate care at the end of life and had lower total medical care costs in the last 2 weeks of life, compared with those who did not use palliative home care support. More than four times as many people using palliative home care support died at home than those not using palliative home care support. Fewer people in the exposed cohort were admitted to the hospital, ED or ICU, and fewer people underwent diagnostic testing, blood transfusion, or surgery in the last 2 weeks of life.

Our study found that the use of palliative home care support lowered the average total medical care costs per person in the last 2 weeks of life by €1617. Costs of palliative home care support use that was continued in the last 2 weeks of life are also considered. A literature review on costs of palliative care interventions in all settings between 2002 and 2011 also found that palliative care (including but not confined to palliative home care) was overall less costly than for comparator groups, despite large differences in the settings and study designs of the observed studies.(27) However, the review notes that randomization is absent in most of the studies, highlighting the importance of controlling for confounding factors and selection bias when analyzing the impact of a palliative care intervention. Our study design could to a large extent tackle these issues of confounding and bias. A retrospective study using observational data evaluated the impact of a home-based palliative care program in Southern California on costs in four disease groups and found that participants had in the last 6 months of life monthly net savings of $4258 for cancer, $4017 for chronic obstructive pulmonary disease, $3447 for heart failure and $2690 for dementia.(21) Although generalizing and comparing costs across different healthcare jurisdictions is difficult due to differences in healthcare regulations and reimbursement schemes, these numbers are in line with our findings.

Our finding that people who used palliative home care support more often died at home confirms findings in previous studies.(13,17,28–30) In Belgium, a mortality follow-back study on a sample of 1.690 non-sudden deaths found that the involvement of a multidisciplinary palliative home care team was strongly associated with home death.(30) The rate of home deaths in the exposed and unexposed groups of our study, respectively 56.2% and 13.8%, was comparable with findings from an Italian study that compared the home death rates between users of palliative home care versus non-users (respectively 60.8% and 29.3%). Although we were not able to consider individual preferences on place of death and quality of death itself, (31) our results show that the palliative home care support was effective in increasing the chance for home deaths on a population level, which is an important policy goal.(32)

Additionally, our study found that the use of palliative home care support has an impact on reducing hospital, ED and intensive care unit admissions in the last 2 weeks of life. This finding is in line with previous research, (17,20,33) but our study is the first to confirm such findings on a complete population level.

Strikingly, only 14% of all home-dwelling adults who died in Belgium in 2012 used palliative home care support in the last 2 years of life. This uptake is far below the actual need in the Belgian population for palliative care, which the most conservative estimation has set at 40% need in the population.4 Currently, physicians in Belgium can grant patients an official 'palliative home care status' only when the estimated life expectancy is 3 months or less. Although this status does not exclude the patient from receiving specific types of healthcare, such as in the hospice benefit system in the USA, the life expectancy criterion possibly discourages physicians from offering palliative home care support, especially in younger and non-cancer patients, and removing it could increase the use and timely initiation of palliative home care support. Further research should also be done to investigate the implications of accessing support at a different period in the disease trajectory on the quality and costs of care at the end of life.

Strengths and limitations

An important strength of this study is that, by using nationwide administrative data on every death over one whole year, our findings are generalizable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain under-represented subgroups and lack the strength necessary for generalizability.(3) Second, we used a previously validated set of QIs specifically developed to evaluate end-of-life care on a population level.(25) This allows comparing appropriateness of end-of-life care between different populations, both nationally and internationally. This approach is particularly useful for those parts of the healthcare sector that do not deliver direct individual patient care, such as health service researchers, public health and other policy makers.(34) Our operationalization of palliative home care support as the use of any of available supportive measures increases the reproducibility of our study in other countries and allows comparison studies that focus on the impact of other existing types of palliative home care support. Other countries that have palliative home care support measures can use the same methodology to measure the impact of their measures on the quality and costs of end-of-life care. Additionally, countries that have no, or other palliative home care support measures can use our results to research the possibility to implement such measures in their own healthcare system. It should be noted however that the generalizability of the results remains largely limited to countries or regions with similar healthcare delivery and funding systems.

Another strength of using administrative data is that, compared with other data collections methods, it is relatively inexpensive to collect data for a large population without causing any burden to potentially vulnerable people. (35) In Belgium—where health insurance is obligatory—administrative health claims data provide information on 99% of the population's healthcare use. Moreover, propensity score matching as a causal inference technique for treatment effect estimation in large observational studies is a particularly useful method when a traditional randomized controlled trial design is not feasible nor ethical, as is the case for our research questions. (16)

Our study also has limitations. Even though our matched cohort study allows to cancel out several sources of confounding, it does not account for unmeasured covariates, such as patients' or caregivers' personality features, knowledge of and preferences with regard to the end of life, which can influence both home palliative care support use and the outcomes we evaluated. It cannot be ruled out, therefore, that the strong association between palliative home care use and the characteristics of end-of-life care reflect underlying choices by patients, caregivers and family that impact both. For instance, to receive the palliative home care support in our study, patients should have a wish to die at home, which has been found to be an important predictor for actual home death. (28) However, even if it would be that patients needed a certain knowledge, attitude or mental switch to use palliative care, our results show that in these groups, quality of life increases and cost decreases. Although the circumstances of palliative care decisions clearly warrant further investigation, as they are still only partially understood, our findings are relevant information for policy makers to convince people of the added value of palliative care.

The use of retrospective data also has limitations. Because palliative home care support is in reality often used relatively late in the disease trajectory, we chose to restrict the outcome measurement period to the last 14 days of life to restrict the number of persons excluded from the intervention group. An additional limitation of using administrative data is that important aspects of quality end-of-life care that are not reimbursed, such as communication, existential or psychological care, are not visible. The QIs are not meant to serve as indicators for (in)appropriate care at the level of the individual patient, because clinical factors that justify an intervention and personal preferences can vary widely across patients. However, they are deemed valid at a population level. Our findings should be interpreted as an evaluation of the supportive policy measures for palliative home care on the aggregated level.

Conclusion

Palliative home care is an important part of end-of-life care. Those who want to be cared for at home and want to die at home have the right to use support to receive appropriate home care at the end of life. The findings from our nationwide retrospective matched cohort study show the positive impact of palliative home care support on the quality of end-of-life care. Additionally, we found that while the total costs for home care is higher, the average total reimbursed costs of medical care at the end of life is significantly lower for those who used palliative home care support. Our findings based on complete population national data add important scientific evidence of the positive impacts palliative home care support has on the appropriateness of end-of-life care and on reducing societal costs related to care at the end of life. Because palliative home care support appears widely underused, our results suggest that increasing its availability and stimulating its use, therefore, has a potential to improve the appropriateness of care at the end of life of patients and at the same time reduce the expenses for the health insurer.

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General discussion

8 Summary of main findings, methodological considerations, discussion and conclusion

8.1 Introduction

The overarching aim of this dissertation was to examine the availability, use and impact of policies to support palliative home care in Belgium. First, it explored which population-level databases provide valid information to study the use of palliative home care support, and the procedures to access and link these databases. Second, it explored the availability of palliative home care support measures for patients and their caregivers in Belgium and neighboring countries. Third, it evaluated the use and factors that are associated with use of palliative home care support in the Belgian population, as well as in specific subpopulations in the Belgian population, and described trends over time in the use and timing of initiation of these support measures. Fourth, we investigated the impact of using palliative home care support on the quality and costs of care at the end of life.

In this discussion section, we will first summarize the main findings of this dissertation. Second, we address the strengths and limitations of the methods used. Third, we discuss our findings in the light of the state-of-the art in palliative care research. Finally, a number of recommendations and implications are outlined for future research, policy and practice.

8.2 Summary of the main findings

8.2.1 Using linked administrative databases to study the use of palliative home care support on a population level

In Chapter 2 we described the full process to identify, access and link administrative and disease-specific databases to study end-of-life care on a population level. We were able to link seven separate databases handled by three different organizations.

The InterMutualistic Agency was identified as a data administrator that provided information on socio-demographic characteristics (age, sex, date of death, place of residence, family composition, use of supportive measures), medication supply characteristics (substance, quantity, prescriber, expenses, refunds, delivery date), and health and medical care use characteristics (quantity of use, reimbursement, supplier, supplier institution, length of treatment). The Belgian Cancer Registry was identified as a data administrator that provided information on diagnostic characteristics (date of diagnosis, type of cancer, TNM gradation) for every new cancer diagnosis of Belgian residents, registered by oncological care programs and laboratories for anatomic pathology. Statistics Belgium was identified as a data administrator that provided information on direct and indirect causes of death (in ICD-10 codes), sociodemographic information about the deceased, place of death, nationality group, household composition, highest attained education level, occupation, housing comfort, and net income for every Belgian citizen.

We obtained internal approval from all database administrator organizations and from the relevant Belgian Privacy Commission bodies. The deterministic one-to-one linkage (based on a common unique identifier, i.e. social security number) was performed by the Trusted Third Parties (TTPs) 'eHealth' and 'Crossroads Bank for Social Security (CBSS)'. The linkage procedure consisted of 13 steps of data-coding or decoding. All dates of medication delivery or health service provision were transformed into number of days before death.

The final dataset included information about all reimbursed care and medication as well as disease (cancer diagnosis), causes of death, demographic, socio-economic and environmental information of all deaths of people registered with a national sickness funds in Belgium (about 98.4% of all deaths). The initial dataset concerned the cohort of all deaths in 2012 but the data agreement included the ability to regularly update the dataset with new cases (when data for an entire year was available – approximately 2 years after the observation year ended).

8.2.2 Cross-country comparison of available policy measures to support palliative home care

In Chapter 3 we compared available policy measures to support palliative care in the home setting in Belgium, France and Germany. Policy measures to support palliative care in the home setting could be grouped into three main categories: allowances and cost-reductions (for patients and informal caregivers), in-kind services (for patients and informal caregivers), and employment and workplace-related (for informal caregivers).

Despite similarities, there were some important differences between the countries in terms of the amounts available and the conditions and restrictions that apply to receive the support. For example, policies to reduce out-of-pocket costs for patients in a palliative home care situation exist in Belgium and Germany, but not in France; however, in France, annual out-of-pocket cost spending is capped at €50 for every person in the French health care system. Informal caregivers of palliative home patients, on the other hand, are able to receive financial compensations in Belgium and France, but not in Germany. All three countries have policies to regulate care leave from work for palliative home patients, but only in Belgium this is a paid leave. This comparison can help researchers to interpret cross-national differences that have been found in end-of-life home care use, hospital transfers near the end of life and place of death and can provide insights for national policy-makers in low-, middle-, and high-income countries alike into what policy measures they could develop and offer to initiate or further establish support for palliative home care.

8.2.3 The use and factors related to use of policy measures to support palliative home care

In Chapter 4, we described the use of policy measures to support palliative home care for the entire population of interest in Belgium, and analyzed what factors were related to higher or lower chances to use these measures. We included 87,007 adults that lived at home in the last year of life and died in 2012. We distinguished 'statutory' and 'non-statutory' supportive measures in the database, according to whether patients required an official palliative care status to receive them or not. Of the population 18% had used a statutory supportive measure (i.e. the allowance for palliative home patients, multidisciplinary palliative home care team, nursing care or physiotherapy for palliative home patients); and 52% had used a non-statutory supportive measure (i.e. the allowance for chronically ill patients, nursing care or physiotherapy for heavily dependent home-patients) in the last two years of life. Looking only at a subpopulation of 38,657 adults who lived at home and died of an illness indicative of palliative care needs - referred to as the 'palliative subset' which included people dying from cancer, COPD, other organ failures (i.e. heart, renal and liver failure), neurodegenerative diseases (i.e. Alzheimer's, Parkinson's, motor neuron and Huntington's disease) and HIV/AIDS) - the uptake of palliative home care support measures was respectively 33% and 62%. Possible explanations for the lower uptake of the statutory measures are related to difficulties of the prognosis-based life-expectancy criterium surrounding these measures (4–6) in combination with difficulties to recognize the needs for or benefits of palliative care among non-cancer patients and their physicians (7–11).

Of the statutory supportive measures, the allowance for palliative home patients was used most often (30% of the palliative subset population), followed by nursing care at home for palliative home patients (24%), multidisciplinary palliative home care teams (17%) and physiotherapy at home for palliative home patients (7%). Of the non-statutory supportive measures, the allowance for chronically ill patients was used most often (38% of the palliative subset population), followed by nursing care at home (35%) and physiotherapy at home (25%).

Multivariable logistic regression analysis showed that the use of statutory palliative home care support measures differs between different groups in the population. These measures are used primarily by cancer patients (reference category), in comparison to patients who died from COPD (Odds Ratio: 0.18, 95% confidence interval 0.16-0.20), other organ failure (i.e. heart, renal, liver failure) (OR: 0.22, 95%CI 0.20-0.24), neurodegenerative diseases (OR: 0.30, 95%CI 0.27-0.33) or HIV/AIDS (OR: 0.17, 95%CI 0.04-0.72); and younger people (18-64 years; OR: 1.32, 95%CI 1.07-1.62) were more likely to use these measures in comparison to those aged 94 or older (reference category). The non-statutory supportive measures, on the other hand, were more likely to be used by older people (aged 65-74: OR: 1.20, 95%CI 1.02-2.40; aged 75-84: OR: 1.22, 95%CI 1.05-1.43; aged 85-94: OR: 1.19, 95%CI 1.02-1.39) compared to the oldest old of 94 and older (reference category), and by those dying of COPD (OR: 1.22, 95%CI 1.13-1.32) compared to those dying from cancer. Overall, palliative home care support measures were least likely to be used by men, by people who lived alone, or by people living in the Brussels region. This finding seems to suggest that the uptake of supportive measures for palliative home care is, apart from aspects related to prognosis, influenced by factors such as social support and socio-economic position.

8.2.4 Healthcare use at the end of life in patients dying from ALS

In Chapter 5 we described the healthcare use at the end of life in all patients (including those who lived in a nursing home) who died from amyotrophic lateral sclerosis (ALS) in Belgium between 2010 and 2015. Of the 1,636 deaths in this population, 44% used specialized palliative care (inpatient palliative care unit or multidisciplinary palliative home care) and 40% received the allowance for palliative home patients at any time during the last two years of life; for 22% of those, palliative care (specialized or home) was initiated only in the last two weeks of life. In the last 14 days of life, 41% of the population was admitted to an acute care hospital and 25% had an emergency department admission. In the last week of life, medications were administered mainly to treat symptoms related to pain (29%), insomnia and fatigue (20%), or venous thrombosis (15%). More than 1 in 6 received non-invasive ventilation in the last month of life; and 39% died at home. Our study shows that routinely collected data (big data) provide a valuable source to gather quality evidence on healthcare use practices in relatively small populations such as those with ALS, which are understudied in end-of-life care research.

8.2.5 Trends in the use and timing of initiating palliative home care support

In Chapter 6 we describe trends in the uptake and timing of initiating of palliative home care support from 2010 to 2015 in a population of those who lived at home and died from an illness indicative of palliative care needs (i.e. palliative subset, see above). Between 2010 and 2015, the uptake of statutory palliative home care support measures increased from 32% to 35% in a population of people that lived at home and died from diseases indicative of palliative care needs in Belgium (n=230,704). Trends in palliative home care support use were also illustrated by cause of death and age categories (uptake was standardized for age, sex and cause of death differences and contrasted with crude rates). Compared to other groups in the population, those who died from neurodegenerative disease (least squares regression slope: 0.5 (standardized: 0.5)) and those who were 85 years or older at time of death (least squares regression slope: 0.7 (standardized: 0.8)) had a smaller increasing trend in the use of palliative home care support compared to the other groups in the population. An interesting finding was that, despite differences in the amount of uptake between the different types of palliative home care support, similar trend patterns were found for all measures, indicating that access to, or demand for these measures increased at similar rates.

To describe trends in the timing of uptake of palliative home care support from 2010 to 2015, we plotted the percentage of people that used any type of palliative home care support for each day in the last two years of their life. Among those who used palliative home care support, the timing of initiation changed from a median of 40 days before death to 45 days (least squares regression slope: 0.9). Meanwhile, the proportion of people for whom palliative home care support was initiated in the last week of life decreased from 15% to 14%.

These trends show there is little to no change in the proportion of people receiving palliative home care support and that most people still receive palliative care (very) late in the disease trajectory.

8.2.6 The impact of palliative home care support on the quality and costs of care at the end of life

In Chapter 7 we use a propensity-score matched cohort design to evaluate the impact of using palliative home care support on the quality and costs of care in the last two weeks of life, using population-level data from adults who lived at home and died in 2012. We matched 8,837 adults who were living at home and used palliative home care support (exposed cohort) to as many adults who were living at home and did not use such support measures (unexposed cohort), based on their individual propensity to use palliative home care support measures. After matching, the sociodemographic, clinical and healthcare use characteristics prior to exposure were similar in the cohort exposed to palliative home care support and the unexposed cohort.

Of those in the cohort exposed to palliative home care support 56% died at home, compared with 13.8% of those who were unexposed to palliative home care support. On average, those in the exposed cohort had 9 primary caregiver contacts (including general practitioner and nursing care) and 3 general practitioner contacts in the last 2 weeks of life, compared with 2 primary caregiver contacts and 1 general practitioner contact for those in the unexposed cohort.

Of those in the exposed cohort 39% died in the hospital, compared with 74% of those in the unexposed cohort. Less people in the exposed cohort were admitted to a hospital (27% vs 61%), to an intensive care unit (18% vs 40%) or to an emergency department (15% vs 28%) in the last 2 weeks of life. Less people in the exposed cohort were submitted to diagnostic testing (27% vs 63%), received blood transfusion (3% vs 6%) or surgery (0.5% vs 3%). We performed sensitivity analyses on each supportive measure for palliative home care separately with no substantial differences in the impact on the quality indicator outcomes.

Mean total inpatient costs were lower for those in the cohort exposed to palliative home care support (€1766; 95% CI €1706 - €1826) compared with those unexposed to palliative home care support (€4222; 95% CI €4133 - €4311) ($p<0.001$). Mean total outpatient costs were higher for those in the exposed cohort (€1314; 95% CI €1291 - €1337) compared with those in the unexposed cohort (€476; 95% CI €461 - €492) ($p<0.001$). As such, mean incremental total costs for those in exposed versus unexposed cohorts in the last 2 weeks of life was −€1617. Costs of palliative home care support use that was continued in the last 2 weeks of life were also considered. We performed sensitivity analyses on each separate supportive measure for palliative home care with no substantial differences in the impact on the costs of care at the end of life.

By using nationwide administrative data on every death over one whole year, our findings are generalizable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain under-represented subgroups and lack the strength necessary for generalizability. Moreover, our operationalization of palliative home care support use as 'the use of any available policy measure to support palliative home care' increases the reproducibility of our study in other countries and allows comparison studies that focus on the impact of other existing types of palliative home care support, especially in countries with similar health care service delivery models and funding.

8.3 Methodological considerations

To answer the research questions of this dissertation, several data sources were used to conduct different study designs: one chapter was based on literature searches, policy document evaluation, and expert consultations (Chapter 3) and five chapters were based on a linked dataset containing information from seven population-level administrative and disease-specific databases handled by three separate databases administrators (Chapters 4-7). All studies have their strengths and limitations which we will discuss in the following paragraphs.

8.3.1 Cross-national comparative study on the availability of policy measures to support palliative home care

Using national policy documents, grey literature and peer-reviewed published literature as the primary source of data, followed by a two-step expert consultation with national experts in palliative care research and in policy to validate our findings, allowed us to make a detailed and reliable cross-national comparison of available policies to support palliative home care. The findings from this study offer opportunities for other researchers or policy makers to apply the conceptual framework that we developed to study available policies in their own country or region. A major strength of this study is that it applied a broad conceptual definition of what support for palliative home care entails, by focusing on policy measures that are aimed towards both patients and their informal caregivers. Another strength was the study's development and use of a conceptual framework that differentiates between the target population and the type of measure to support palliative home care.

The study also had several limitations. First, the study only concerned a small sample of high-income European countries with overall high levels of quality (12) and availability of palliative care (13). Therefore, our findings are only applicable within this context, and extrapolation to other countries or settings is not possible. Furthermore, it remains unclear whether the conceptual framework can be applied directly to countries with different economic, historical, cultural, and legislative backgrounds than those included in our study. Second, our study maps the availability of supportive policy measures for palliative home care but does not provide insight into the uptake of these measures. By focusing only on availability of policies and not on their accessibility or actual use, our findings could potentially lead to false interpretations, for example that existence of more policies equates to better provision of care. Therefore, the cross-national comparison is not meant as a comparison of quality of care, but rather as an explorative study that could potentially help policy-makers and other researchers to gain insight into the broad range of possible policies to support palliative home care.

8.3.2 Administrative and disease-specific databases to study end-of-life care on a population level in Belgium

We used the same population-level linked database as data source for several chapters, but different study designs were used: a cohort study using univariate descriptive and multivariable logistic regression analyses (Chapters 4, 5), a trend analysis study using univariate and standardized descriptive analyses and survival analysis (Chapter 6), and a matched-cohort study using propensity-score analysis and descriptive univariate analyses (Chapter 7). The strengths and weaknesses of exploring, accessing, and linking population-level databases are described in detail in the methodological chapter 2. Therefore, the following part is limited to describing the strengths and limitations that were specific to the use of the dataset in the different studies.

8.3.2.1 Strengths and limitations of the dataset

A first major strength of this dataset was that it was constructed after a systematic and thorough exploration of available databases that provide information on end-of-life care on the population level in Belgium, while keeping the specific research questions of this dissertation in mind. This resulted in a database with detailed information about formal end-of-life care use, the costs of care, and demographic, socio-economic and diagnostic information on the individual person level for a two-year period prior to death for all those who died in Belgium in a given year. By having specified our research questions beforehand, we avoided the pitfall of data mining (14,15), and could reduce the size of the dataset to a minimum of what we considered needed to answer the research questions.

Other advantages of using this dataset are related to the fact that we were able to include the entire population of people who died in one country. Bias due to incomplete enrollment of patients in particular is a major issue in traditional prospective or retrospective designs in end-of-life care studies (16). For example, in a prospective cohort study by Wenger and colleagues the authors reported that 40% of seriously ill hospitalized patients could not be interviewed about their end-of-life care preferences due to illness severity, and those unable to be interviewed were the sickest patients, often closest to death (17). This exemplifies the difficulties of prospective designs to include a representative sample of patients who are facing death, an issue that is not present in retrospective observational designs. Prospective studies moreover need, as Barnato and Lynn remarked, a very long follow-up period since some patients will live for many years with particular conditions, and 'all methods of truncation of follow-up incur biases as well' (18). Other, often used retrospective data collection methods in end-of-life care, such as mortality follow-back studies, can suffer from recall bias by physicians or caregivers (19,20). However, administrative data are collected prospectively: every act for reimbursement is registered at the time when a person receives the prescription (or when he/she receives the intervention or drug). Therefore, population level administrative data are more reliable and less prone to data errors or missing values than survey data or mortality follow-back studies.

Another advantage is that the dataset contains high-quality data. The data are already checked for errors by the database administrators before they are made available to researchers, and they have been found to have a high degree of completeness and accuracy (21–23). As the linked database contains both individual-level person data and individual-level claims data of specific types of palliative home care support, it can moreover be studied on multiple levels, which makes disease-, age- or region-specific analyses possible. The use of population level data allows also to look at specific underserved or otherwise difficult to reach subpopulations (e.g., the oldest old, those with a low socioeconomic position, rare disease groups). We made use of this particular advantage in this dissertation to study the healthcare utilization at the end of life in a population of people who died from ALS.

Lastly, the use of administrative databases is less expensive, less time-consuming, and less prone to containing errors by researchers' input then if we would have performed our own data collection. The entire process of data collection took six months from application to formal approval.

However, the use of routinely-collected population-level linked administrative data for a cohort of deceased people has its limitations. To study end-of-life care we followed a pragmatic approach by defining a cohort of deceased people and then observed what care was recorded in the period before death. This "going back in time" to reconstruct treatment trajectories was severely criticized in a 2004 article published in the Journal of American Medical Association (JAMA) by Bach and colleagues. They criticized that these studies do not include patients who survived or benefited from aggressive treatments and would thus not reflect an accurate portrait of all patients living with advanced disease (24). This can also give an inflated view of the use of possibly inappropriate care: since caregivers, patients, and family members do not always recognize that a patient is near the end of life, care that is retrospectively interpreted as inappropriate could have been requested or seemed appropriate at the time it was provided. However, many authors in turn commented on the critique from Bach and colleagues, arguing that traditional prospective designs have their own specific limitations which retrospective administrative data can counter (see above) (16,18). Moreover, it should always be made clear that assumptions drawn from the analysis of population level administrative data should be interpreted on the population level as well; conclusions should not be made with regard to individual variance in the provision of possibly inappropriate or appropriate care at the end of life. Therefore, it can be argued that both types of data have their own strengths and limitations, and different research designs should ideally be used to complement each other (25,26).

Another limitation of using these data is that they are not deliberately collected for research aims but for reimbursement purposes. This means that regular follow-up contacts with the database administrators is required to fully comprehend nuances in the variables and database construction. Moreover, administrative data require intensive database restructuring, from a healthcare claims point-of-view towards a research point-of-view. This means that variables need to be created on the level of individuals (i.e., what is used when by an individual) from data that is ordered at a healthcare claims-level (i.e., what needs to be reimbursed to whom). Extensive data recoding is thus needed to create meaningful variables for research purposes. Due to the large amount of data, each step in the data handling process can require a longer calculation time.

There were also practical considerations that limit the use of large administrative datasets. Since we had detailed information on every reimbursed healthcare claim on the individual level for the last two years of life of every person that died in one year, the dataset contained ~128,2M lines of reimbursement claims data per year. This impacts both workability (e.g., speed of analyses, program errors due to large file size) and cost of storing the data (e.g., in our case, the dataset was stored on a remote server for privacy purposes and annual costs had to be paid per gigabyte of data). In order to reduce these limitations, our approach consisted of two phases. In a first phase, the linked database was used for the initial analysis and database (re)construction, using the complete data on all deaths in 2012. In this dataset, a selection of necessary variables and/or aggregations was made, and variables deemed unnecessary, of lacking quality or incomplete to answer our research questions were dropped. Based on this first analysis phase, aggregated variables were delivered upon request for the years 2010-2015. A consequence of this approach was that we had to decide during the first phase which aggregations were needed, since the raw healthcare claims data (i.e. one data line per claim) would not be made available for the other years; however, the data remained available on the individual level (i.e. one data line per person).

Lastly, the administrative databases that were available in Belgium do not contain direct information on the quality of the delivered care. This is an important limitation of our data, i.e. we lack potentially interesting information such as patient-related outcomes of healthcare services, e.g. Patient Reported Outcome Measures (PROMs). Although such data is available in some health care institutions in Belgium, their inclusion in a population level database is only meaningful if there is sufficient standardization in the measurement methodology. In Belgium, such a common coding system for PROMs is currently lacking and would be time-consuming to perform (27). Other information that lacked in our dataset could also be valuable, such as how long consultations (e.g. by a multidisciplinary palliative home care team) lasted, what was discussed during the consultation, and to what degree patients and informal caregivers were involved in the decision-making process.

8.3.2.2 *Strengths and limitations of using administrative and disease-specific databases to study the use, trends in use and impact of palliative home care support*

In Chapter 4, we used linked administrative and disease-specific databases from one year (2012) to study the use of policy measures to support palliative home care for the entire population of interest in Belgium, and analyzed what factors were related to higher or lower chances to use these measures. A major strength of our data was the fact that it included information on the person-level and on the claims-level, including date of provision (in number of days before death) and reimbursed cost of the provided act. As a consequence, we were able to evaluate the use and timing of use of palliative home care support measures (which are reimbursed and thus retrievable in nomenclature data) for the whole population, while also taking into account socio-economic factors such as personal income, education level, and housing comfort, and factors related to social support such as family composition, degree of urbanization, and several indicators of social or economic deprivation (e.g. a lowered maximum amount of annual out-of-pocket costs to receive the chronic care allowance). A limitation of our data was that reimbursement data do not capture other forms of support for palliative home care (e.g., care given by informal caregivers, services organized outside reimbursement schemes) or social support (e.g., religious based, kinship networks).

In Chapter 5 we used linked administrative and disease-specific databases from six years (2010-2015) to describe the utilization of healthcare at the end of life in patients who died from ALS. A first advantage of our dataset was that we were able to use data from multiple years to ensure the dataset included enough patients, given the low prevalence of the disease in the population (annually +/- 250 people in Belgium die from ALS). The use of population level data moreover allowed us to avoid common forms of bias when studying small and difficult to reach populations at the end of life. These biases often result from having to rely on sample data from certain settings (e.g., patients treated in a hospice are likely to differ from patients who are not in a hospice (28)) or on retrospective recollections (e.g., mortality-follow back studies can suffer from recollection bias with regard to the accurate reporting of healthcare utilization and timing of prescription (29)). This approach could be beneficial also to study other difficult to reach or small population groups that are known to benefit from palliative care (30). Such population groups include, but are not limited to, patients with HIV/AIDS (31–33), children with pediatric diseases (34–37), or patients in mental health facilities (38–40). However, for some subgroups that are difficult to reach, administrative data offer little advantage. For example, administrative databases likely lack valuable information on homeless people (41–43) or prisoners (44–46), although they often have specific needs with regard to end-of-life and palliative care. Possible reasons are that they are not registered as such in the data, because they have no healthcare insurance (which is likely to be the case in homeless people), or simply because they do not frequent traditional healthcare services. For these vulnerable subgroups, therefore, other study designs are a better alternative.

In Chapter 6 we used linked administrative and disease-specific databases from six years (2010-2015) to describe trends in the uptake and timing of initiating palliative home care support in a population that lived at home and died from an illness indicative of palliative care needs (i.e. palliative subset, see above). Administrative databases offer specific advantages with regard to conducting longitudinal or trend analyses. Once the first data request (including a list of all requested variables) is completed and has been approved, new data can be added or accessed upon request (new approval needed of all involved bodies, i.e. data administrators and privacy committees; or can be agreed upon in the first data request). Since the data are collected continuously and prospectively by data administrators, researchers do not have to invest time in collecting these data, and the added cost for a new data delivery is marginal once the entire process has been laid out a first time.

In Chapter 7 we used linked administrative and disease-specific databases from one year (2012) to evaluate the impact of using palliative home care support on the quality and costs of care in the last two weeks of life, using a propensity-score matched cohort design. The richness of our dataset in terms of number of available variables, combined with its completeness in terms of including the entire population of decedents in Belgium, allowed to calculate propensity scores on a wide set of relevant variables to avoid confounding when evaluating impact on quality and costs of care. The propensity score is ‘the probability that a patient would receive the treatment of interest, based on characteristics of the patient, treating clinician, and clinical environment’ (47). These scores are calculated using multivariable statistical methods (e.g. logistic regression), with the treatment or intervention as the dependent variable and the characteristics of the patient and a wide range of other possible confounders as the predictors. For each patient in the study population, a score is calculated that estimates his/her propensity to receive the treatment or intervention, controlling for the differences included in the model. Based on these propensity scores, individuals from a cohort receiving the intervention are then matched to similar individuals from a cohort not receiving the intervention (48). Because the cohorts are made as similar as possible based on known characteristics to reduce confounding that influences both exposure and outcomes, and there is a clear causal pathway (time-period before exposure vs time-period after exposure), the propensity score–matched analysis approximates that of an RCT. This is particularly useful in end-of-life care research where traditional random assignment of patients in intervention or control groups (such as in RCTs) to evenly distribute known and unknown factor to reduce possible confounding, is not feasible due to practical, legal and ethical considerations (e.g., inclusion of very ill patients in the study, denying control groups from using palliative care services, blinding of patients) (49–51). In a recent systematic review, Yao and colleagues (49) identified 33 cancer-focused studies involving propensity score methods reported in top medical/cancer journals between 2014 and 2015. Other studies were published that used propensity score matching methods to evaluate the impact of specific palliative care interventions on outcomes such as hospitalizations, emergency department visits late in life and hospital death (52–55). There is currently no evidence to assume that healthcare outcomes assessed with observational study designs offer significant effect estimate differences than those assessed in randomized controlled trials (RCTs) (25,56,57). In a 2014 BMJ editorial, Fliss Murtagh concluded that ‘carefully considered use of both administrative databases and propensity score matching enabled [the researchers] to make robust conclusions; that delivery of community based, specialist palliative care (regardless of size of team or geography) is associated with significant reductions in patients’ use of acute services in the last two weeks of life.’ (50).

There are also limitations to this design. Since observational data are nonrandomized by design, researchers have to resort to statistical methods to adjust for differences between groups in order to be able to evaluate a causal relation (58,59). One is never able to include in the calculation of propensity scores all relevant information to adjust for these differences. For example, specific attitudes towards the end of life, past experiences with palliative care, or other relevant measures were not captured in our dataset and may affect both the exposure (choice for palliative home care) and the outcomes (non-aggressive treatments). This can influence the quality of the matching of the cohorts (i.e. remaining confounding based on unmeasured covariates); however, this limitation is inherent to using retrospective observational data, as a complete matching on possible confounders related to using palliative home care is never possible (60,61). Since Rosenbaum & Rubin first published their paper on the use of propensity scores in observational studies in 1983 (47), there have been several research papers dedicated to optimizing the design, calculation and use of propensity scores that we followed to conduct a rigorous impact study (48,62,63). Another limitation of our data is that when evaluating costs, it should be kept in mind that the data only reflect reimbursed costs. Thus, out-of-pocket spending by patients is not visible, therefore resulting in an overall underestimation of the actual total costs of care at the end of life, as important factors such as the loss of income or increased expenses for the household were not included.

8.4 Discussion of the findings

8.4.1 Palliative home care use in Belgium

A key finding of this dissertation is that the uptake of policy measures to support palliative home care in the entire population of people that died in Belgium is low and relatively late (Chapters 4 and 6). In our studied population of those who resided at home in the last year of life (i.e. excluding people who resided in a nursing home) and who died of an illness that is likely to have palliative care needs (64), statutory palliative home care support measures were used by one in three people (33%) in 2012. In Chapter 5, we found that palliative home care use among those who died from ALS was higher (40%) compared to that of the general population. Among those who did use support measures in 2015, the median number of days before death of initiating these measures ranged between 32 days (those who died with dementia) and 63 days (those who died from Parkinson's disease, motor neuron disease, HIV/AIDS or non-cancerous neoplasm) (Chapter 6).

8.4.1.1 Possible explanations for the low and late uptake

Although we applied an approach that focuses specifically on the use of any type of supportive policy measure for palliative home care, in comparison to previous studies that often focused only on service use, we believe it is still valuable to compare our findings to those from other countries. With these cross-national differences in mind, it appears that the uptake of palliative home care support in Belgium is comparable to that in other high-income countries. Recent studies have reported the use of palliative home care in the United States of America, Australia, Canada, the Netherlands, Italy, and Spain. In the United States of America, where palliative care is offered by hospice services and made available to patients of any age with any terminal prognosis who are medically certified to have less than six months to live, 30% of all deaths in 2011 occurred within a hospice program delivered in a patient's residence (65). In Australia, a retrospective cohort study of persons who died in 2009-10 with possible palliative care needs (using the same palliative subset as we did) found that 18% used only community-based specialist palliative care (which consisted of at-home physical care and practical support, symptom management (for example pain, nausea), counselling and respite care) in the last year of life, and another 13% used both community- and hospital-based specialist palliative care (66). A Canadian study among cancer patients who died in the province of Ontario in 2006 reported that 47% of this population used end-of-life homecare, for which patients 'must have a health condition that is not responsive to curative treatment and be expected to die within a year' (67). A cross-national European study from 2013 used a mortality follow-back design with physician-reported data on 4,466 deaths of patients over 18 years old to report on palliative home care service use (similar to the multidisciplinary palliative home care team in our study) in the Netherlands (5%), Italy (24%), and Spain (29%) (68).

Apart from the Canadian study from 2006, most studies thus report a relatively low uptake of palliative home care. A probable explanation for this low uptake is one that relates to the prognosis-based legal eligibility criteria of the statutory support measures. As in most other countries, in order to be able to receive palliative home care support, patients in Belgium must have a limited life-expectancy, of 'more than 24 hours and less than three months' (69). This can be a potential barrier to the use of palliative home care because of hesitance by both patients and physicians to initiate palliative home care support, for example by not wanting to 'admit' that the life expectancy is limited, or by not being able to correctly estimate the prognosis. Research in advanced cancer patients has consistently shown that both physicians and patients are unable to correctly predict their life expectancy, most commonly overestimating it (70–73), and disease trajectories of non-cancer serious illnesses are even more difficult to predict, further complicating the process of prognostication (4–6). As a result, the initiation of palliative home care support often either occurs late (14% of all people in Belgium using palliative home care support in 2015 initiated it in the last week of life (Chapter 6)), or possibly not at all (Chapter 4). This hypothesis is further supported by findings of a previous study that reported 'not [having] enough time to initiate palliative care' was as one of the three major reasons for physicians to not refer a patient to a specialized palliative care service (10).

As of October 20, 2018, an amendment to the Royal Decree (74) has passed with the aim to replace the prognosis-based criterium to receive the palliative status with a frailty-based criterium that is based on an alteration of the internationally validated SPICT-tool. This tool is aimed to help identify people who are at risk of deteriorating or dying with one or more advanced, progressive conditions or a new life-limiting illness, by using the so-called 'surprise question' (i.e., clinicians are asked if they would not be 'surprised' if the patient survived less than twelve months). The shift in focus from a life expectancy-based towards a frailty-based criterium is hoped to improve (earlier) access to palliative home care support for all those who are in need, especially non-cancer patients who are now underserved. However, the new criteria are not yet used in practice, and future research will need to monitor what its possible impact is on the uptake of palliative home care.

Apart from the structural or legal barriers to using palliative home care, research has indicated that a strong stigma is attached to palliative care, which may persist even after positive experiences with a palliative care intervention by family caregivers (75–77). This could result from the fact that in practice, palliative (home) care is often initiated very late and therefore generally considered as terminal care, possibly further enhancing the semantic, cultural or emotional association with death and 'giving up'. Some authors have suggested to replace the terminology to "supportive care", as it would be considered a more acceptable term and would lead to earlier referral (78), although the use of multiple terms might actually worsen the conceptual clarity and ultimate goals of the palliative care approach (79,80). Thus, while there is an increasing policy awareness to support palliative home care, it may be that patient and caregiver perceptions have not equally progressed, suggesting a role for education and changing perceptions in the community (76,81).

An interesting finding from this dissertation was that not all statutory supportive measures were used equally as often. The multidisciplinary palliative home care teams were used by only one in six people (17%) within the home-dwelling population with possible palliative care needs, which equates to less than one in ten people (9%) in the entire population of home-dwelling decedents (Chapter 4). In comparison, the allowance for palliative home patients (30%) and nursing care for palliative home patients (24%) were used more often. This difference can possibly be explained in part by differences in the underlying structural financing of the healthcare system. Whereas the other types of supportive measures for palliative home care are reimbursed at the moment a request is filed by a physician, the multidisciplinary home care teams are financed structurally on the basis of their regional coverage: each team receives a fixed amount of funding (depending on the size, composition and seniority of the staff members) to serve a minimum of 100 or 150 patients per 200.000 inhabitants per year (82). Although the teams are not legally allowed to refuse to serve patients, the financial capacity of these teams to provide their services is strained by their funding. Another possible explanation could be that there is indeed a lower need in the population of home-dwelling people with palliative care needs to make use of a multidisciplinary palliative home care team, which primary goal is the management of cate between all professional and informal caregivers, compared to a financial need (the allowance for palliative home patients) or need for nursing care, which are *in se* more practical supportive measures.

8.4.1.2 Inequities in the use of palliative home care support

Our study described in Chapter 4 shows that the use of palliative home care support measures differs between different groups in the population. These findings are in line with previous research focusing on inequalities and inequities in accessing palliative care (11,83,84). Here, we will focus on discussing differences in the use of statutory palliative home care support measures by disease group, by age and sex group, and by socio-economic group.

First, our findings show that cancer patients are most likely to use statutory palliative home care support measures, compared to people dying from COPD, other organ failure (i.e. heart, renal, liver), neurodegenerative diseases or from HIV/AIDS. Differences in the use of palliative care between cancer and non-cancer patients (e.g., with organ failure or COPD) have previously been found in research. For example, a study from Australia found that, while 68% of those who died from cancer during their study period had contact with a specialist palliative care team, only 8% of those with non-cancer conditions had such contact (85). These differences have been related to difficulties in prognostication (86), general practitioners' ability to identify palliative care needs (87) or their willingness to disclose a difficult diagnosis (88), as well as to patients' and family members' not acknowledging their illness as being life-threatening (8,9,89) but rather seeing their illness as 'a way of life' (7). Differences can exist also between patients with different primary cancer diagnoses. Although we did not analyze this in this dissertation, a review study from 2009 found that primary cancer diagnosis had no impact on the likelihood of referral to specialist palliative home care, except for patients with brain cancer or hematological malignancies (i.e., leukemia, lymphoma, myeloma), with a number of studies finding that such a diagnosis reduces the likelihood of referral (83). It may well be that those with other diagnoses than cancer have different needs that could be met in other ways (e.g., by the non-statutory palliative home care support measures), for example among people diagnosed with dementia (90). However, studies have indicated that palliative care needs are experienced in people with cancer, COPD, and heart failure as well as dementia (91), and that lack of service uptake among non-cancer groups does represent unmet needs (92).

Second, this dissertation showed people who died at a younger age (18-64 years) were more likely to use palliative home care support compared people who died at old age (94 or older). Most previous studies on patterns of access to palliative home care reported similar findings to ours with regard to the higher likelihood at younger age to use palliative home care support (83,93–96), although some studies have demonstrated the opposite (97,98). In their review from 2009, Walshe and colleagues suggest five possible hypotheses to explain these differences: (1) older people have different needs or fewer complex palliative care symptoms; (2) the needs of older people may be sufficiently met by generalists such as district nurses and general practitioners; (3) older people have different attitudes towards palliative care; (4) it may be the caregiver's age, not the patient's age, which affects access or need to palliative home care services; (5) as those who are older survive for less time after a serious diagnosis, systematic bias will be introduced when care received prior to death is examined with respect to age (83). Although there is no conclusive answer to explain this finding based on current research, our findings seem to suggest that older patients are in fact more likely to use supportive measures for home care that do not require the legal 'palliative status'. This could indicate that the criteria related to receiving palliative home care support could be discriminatory towards older people.

Third, our findings showed that women were slightly more likely to use palliative home care support. Previous findings with regard to the association of gender and the use of palliative home care support has been equivocal, with many studies not finding a relationship (83); however, if studies did find an association, it was almost always in the advantage of women over men, and only one study so far reported that men were more likely to use palliative home care (99). Similar to the hypothesis with regard to age, it may be that the gender of the caregiver has as much impact as the gender of the patient on the patient's likelihood to use palliative home care.

Fourth, we found there are socio-economic differences that are associated with being more or less likely to use supportive measures. Firstly, people were more likely to use supportive measures if they were not living alone (i.e., being married, living together with a partner, or living with an adult child). Again, most of the studies reviewed by Walshe and colleagues that reported on marital status found that being married increases the likelihood of being referred to home specialist palliative care; while a few studies found no difference, no studies found that being married decreases the likelihood of being referred (83). Many authors seem to conclude that marital status serves as a proxy variable for having a caregiver at home; this also seems to support previous findings with regard to averse or ambiguous preferences for home death among widowed people (100), those who live alone (101), or older people (since they are also more likely to not have a(n able) caregiver) (102,103). As such, having a caregiver living in with the patient could be key to successfully integrate palliative care in the home. Secondly, people living in a house with a high comfort level (based on size and availability of facilities such as kitchen and bathroom) were more likely to use supportive measures. This seems to suggest in part an influence of socio-economic position on the use of supportive measures for palliative home care, assuming that decent housing and home ownership are important predictors of higher socio-economic position. Additionally, it seems likely that a higher comfort in the home is a factor that enables to organize palliative care at home. Meanwhile, our study did not find significant differences in the likelihood to use supportive measures by education level or taxable income. This can be explained by the fact that health insurance is obligatory in Belgium, thus apparently ensuring equal access to these measures regardless of socio-economic position.

A remarkable finding of this dissertation is that the non-statutory supportive policy measures for palliative home care, such as the allowance for chronically ill patients, are in fact more likely to be used by COPD patients, and equally as much by patients with other organ failures, compared to cancer patients. Moreover, in comparison with the statutory supportive measures, the non-statutory supportive measures are more likely to be used by older patients instead of younger patients (but not the oldest old). The criteria for these non-statutory supportive measures are based on high care needs and high out-of-pocket costs, and not on life expectancy as was the case for the statutory supportive measures. This could also explain our finding that the chance of using a non-statutory measure was highest among people who died of COPD, since these patients are commonly prone to high care needs and out-of-pocket costs at the end of life (104,105). Thus, although statutory palliative home care support measures are less frequently accessed by these patients, non-statutory supportive measures are used more often, which might indicate that these patients' needs are met without the use of statutory palliative home care services. However, more (qualitative) research is needed to confirm this hypothesis.

Nevertheless, our findings also show that several subgroups in the population are underserved by all types of support for palliative home care: the oldest old, those who lived alone, and people who died from neurodegenerative diseases. Especially the palliative care needs of patients with dementia have previously been documented to be poorly addressed (9,84,89,90,106,107), despite promising studies showing the benefits of palliative care in this population group (108–111).

8.4.2 Trends in the use and timing of palliative home care support

The previously discussed findings of this dissertation reflect on a cross-sectional snapshot of palliative home care support use in one year. However, it is important to researchers, policy makers, and practitioners to gain insight in changes over time in who uses palliative home care support, how much it is used, and when it is used. Our analyses of time trends in the use and timing of initiating palliative home care support between 2010 and 2015 revealed that there was a slight linear increase in uptake (+3.3 percent point, 31.6% to 34.9%) over the course of the six years studied, although a stagnation could be seen between 2014 and 2015 (Chapter 6). There was also a small trend noticeable towards earlier initiation among those who used palliative home care support, with the median number of days before death of first initiation changing from 40 to 45 days in the studied period.

8.4.2.1 *Are we evolving towards greater use of palliative home care support?*

Our finding that the use of palliative home care support increased over time corroborates with previous studies from Belgium (112), the United States of America (113,114), Canada (98), India (115) and Singapore (116), although none of the other studies had population level data to analyze these trends for the entire population. Moreover, international comparisons with regard to trends over time are complex due to specific individual-country variability in political (legislative), sociodemographic and economic changes over time that can possibly impact trends in the use of palliative home care. We will therefore further limit ourselves here to focusing on the evolving situation in Belgium.

In 2004, a report was published by the National Institute for Health and Disability Insurance (INAMI-RIZIV) to evaluate the use of palliative care support and its related budgetary expenditures during the first period when the palliative home care support measures were first introduced in 1999-2002 (117). In 2017, the Federal Evaluation Cell on Palliative Care[7] published a report with updated rates for 2010. Both reports published rates of reimbursed performances for the multidisciplinary palliative home care teams and the allowance for palliative home patients, based on INAMI-RIZIV data[8]. Although these data contained less rich information than ours, it allows to compare our findings of the use of these supportive measures from the years 2010-2015 with that from other periods.

In 1999, 2,430 performances for an intervention of a multidisciplinary palliative home care team were reimbursed, which totaled the government expenditure for the financing of the teams to 4.3M euros (117). By 2010, the government funding had expanded to 10.5M euros (+141%[9]) for the reimbursement of 7,151 performances (+194%) (82). Our findings show that the use of these teams further increased from 2010 to 2015, albeit not at the same rate as that of the 1999-2010 period. A possible explanation for this finding is that the structural and financial capacity to organize palliative care at home was low during the first years of the existence of these measures, after which the capacity was expanded due to positive evaluation. However, the last budgetary expansion for the multidisciplinary teams was implemented in the 2010-2012 period. The INAMI-RIZIV report from 2004 also describes patient characteristics of those who were served by the palliative home care teams, allowing to compare changes over time in those who make use of this support. In 2002, more than 74% of people served by these teams were older than 60 years, 17% was living alone, and 80% had a cancer diagnosis (117). Our findings in Chapter 6 reveal that, in 2015, this evolved to 86% of people who were older than 60 years (+12 p.p.), 18% who were living alone (+1 p.p.), and 69% having a cancer diagnosis (-11 p.p.). These findings can possibly be attributed to changing patterns in the population, as a result of ageing populations (i.e. proportionally more people are now dying from 'old age diseases' such as neurodegenerative diseases or chronic organ failure).

The INAMI-RIZIV reported rates from the use of the allowance for palliative home patients in 2001, when 11,534 allowances were reimbursed (6,964 people received it once, 2,285 people had two) (117). Our findings from Chapter 6 show that 15,481 (+34%) people who died in 2015

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[7] Federal Evaluation Cell on Palliative Care: Federale Evaluaticel Palliatieve Zorg.

[8] It should be noted that the data sources from the 2004 National Institute for Health and Disability Insurance (INAMI-RIZIV) and 2017 Federal Evaluation Cell on Palliative Care reports differ from our data sources. Whereas our data holds information on palliative home care use during the last two years of life on all patients who died between 1 January and 31 December of a given year, the report's data has information on all palliative home care use between 1 January and 31 December of a given year (regardless of whether patients died). Thus, although both sources can be compared to each other, the numbers differ due to different methods of capturing claims (i.e. incidence versus prevalence).

[9] The exact expenditures (not adjusted for inflation) were used to calculate the percent increase. In 1999, this was 4.338.997 EUR; in 2010, this was 10.466.416 EUR.

received the allowance (9,078 received it once (+30%), 6403 had two (+180%). This shows that, although the use of the allowance increased overall, the proportion of people who received the allowance twice increased especially. We lack the data to investigate how this can be explained, but it could be related to the fact that physicians are now more aware of the possibility for patients to receive the allowance twice, or because it is now used earlier, allowing patients to renew the request (this can be done at least 30 days after receiving the first allowance, so patients naturally need to survive for this time). In 2003, 44% of patients that received the allowance 'outlived' the maximum time-period of two months that the allowance can be received; in 2015, this proportion was 42% of the population that died. Thus, while this proportion remained more or less stable between 2003 and 2015, it appears that a substantial proportion of those who receive the allowance for palliative home patients outlive the period that they are allowed to receive this support, indicating that they experience a lack of financial support to organize palliative home care for an unspecified period afterwards. As such, it should be further analyzed whether the regulations surrounding the allowance for palliative home patients can be extended to meet the needs of these patients.

8.4.2.2 Are we evolving towards earlier use of palliative home care?

For half of all people who used any type palliative home care support measure in 2015, this support was initiated in the last 1.5 month before death; for 14%, initiation occurred in the last week of life (Chapter 6). Compared to 2010, the median moved 5 days towards earlier initiation (40 to 45 days).

In 2010, a first – and very influential – randomized trial study by Temel and colleagues showed that early palliative care led to significant improvements in both quality of life and mood among patients with metastatic non–small-cell lung cancer (118). In a similar trial study from 2015, Bakitas and colleagues compared the impact of early (within 30-60 days of being informed of an advanced cancer diagnosis) versus delayed (3 months later) initiation of palliative care, finding positive outcomes with regard to survival, mood and burden (119). Other trial studies (120–122) and observational studies (123–126) have shown similar promising results in different settings and patient populations. This body of literature led to a growing recognition that a palliative care approach should be initiated early and not just in the terminal phase for all patients with life-limiting diseases (87).

Compared to the above described trial studies, our findings seem to indicate that palliative home care support is overall not initiated 'early' in the general Belgian population, despite a small trend towards earlier initiation. In the studies by Temel and Bakitas, for example, median survival time after the intervention was respectively 11.6 and 18.3 months; our findings on the population using palliative home care support in Belgium showed a median of 1.5 month between first initiation and time of death (Chapter 6). It is not unlikely to assume that the experimental settings in which the trial studies purposely initiated palliative care early on in the disease trajectory do not reflect a realistic time-frame that can be achieved in the general population. Moreover, the trial studies focused only on hospital-based palliative care in advanced cancer populations.

However, observational studies using population-based data to study the timing of initiating palliative care in the home or community are rare. One study used observational cohort data from decedents admitted to end-of-life homecare in Ontario, Canada, and reported a median time between first homecare admission and death of 11 weeks (i.e., ~77 days, vs. 45 days in our study) (123). An Australian study found that, in a population of cancer decedents using community-based palliative care, 64% had initiated this in the last three months of life (125). Another study from Australia among a cohort of pancreatic cancer decedents reported a median time between referral to specialist palliative care services (any setting, i.e., home, hospital, nursing home, community) and death of 48 days. In Belgium, two mortality follow-back studies reported on median timing between first initiation of a specialized palliative care service in any setting (one studying trends between 2005 and 2014), finding overall later initiation than we did (e.g. median of 20 days before death among cancer patients, vs. 47 in our study) and no change in timing of initiation over time (11,112).

It remains difficult to compare our findings to those from previous studies, and the differences in the findings are most likely due to differences in the quality of data (e.g., mortality follow-back data suffers from recall bias, selection bias), the studied cohorts (e.g., focus only cancer patients or older adults vs on the entire population of home-dwelling people with possible palliative care needs) or the studied intervention (e.g., focus on services vs all supportive measures in our study, focus on all settings vs only on home in our study).

8.4.3 The impact of palliative home care on quality and costs of end-of-life care

Our findings indicated a positive effect of using palliative home care support on the number of primary caregiver contacts and on the chances of having a home death (i.e., health care measures that can be seen as possibly appropriate at the end of life), while decreasing the chances of going to the hospital, ICU or emergency department, or undergoing diagnostic testing, blood transfusion or surgery in the last two weeks of life (i.e., health care measures that can be seen as possibly inappropriate at the end of life) (Chapter 7). Meanwhile, the mean costs for healthcare (inpatient and outpatient) in the last two weeks of life were substantially lower among those who used palliative home care support (mean difference of 1636 euros). Nevertheless, only 14% of all home-dwelling adults who died in Belgium in 2012 used palliative home care support measures (Chapter 4, 6 and 7).

Two systematic reviews have evaluated the existing evidence on the impact of home-based palliative care services from prospective studies on odds of dying at home, other outcomes for patients and their caregivers such as symptom control, quality of life, caregiver distress and satisfaction with care, and costs associated with these services (127,128). Gomes and colleagues (128) identified 23 studies (16 RCTs, 6 of high quality) evaluating the impact of home palliative care services on these outcomes for adults with advanced illness or their family caregivers, or both; Shepperd and colleagues (127) identified 4 studies evaluating the effectiveness of home-based end-of-life care with inpatient hospital or hospice care for people aged 18 years and older. Both systematic reviews found convincing evidence that support the use of home-based end-of-life care programs to increase the number of people who will die at home, but Gomes and colleagues addressed the need to study cost-effectiveness especially for people with non-malignant conditions, while Shepperd and colleagues point out that future research should systematically assess the impact of home-based end-of-life care on caregivers.

Previous studies from Canada, England and Italy using similar retrospective matched cohort designs as ours to research the impact of palliative home care on quality and costs of care have consistently found similar outcomes with regard to decreased chances of end-of-life hospital use (52,53,55,129) and hospital costs (52,55), while reporting increased chances for home death (52–54,129). As was the case for our study, these studies shared the limitation of administrative data that a registration of palliative home care does not necessarily indicate whether the care delivered at those settings was of high quality or satisfactory based on caregiver or patient report. Moreover, all studies differed in the number of available variables to control for confounding in the propensity score matching model. Finally, there were differences between our study, by measuring the use of any type of available palliative home care support (including non-service palliative care support, e.g. the allowance for palliative home patients), and the other studies that usually measured the impact of one specific intervention (mostly specialized palliative care services, e.g. multidisciplinary palliative home care team). However, sensitivity analysis in our study showed that the effect did not differ substantially by type of palliative home care support, which adds to the current evidence that palliative home care use has a positive impact on the quality of care at the end of life and decreases costs of care at the end of life.

Our findings from Chapter 7, as well as previous studies in other countries (52,55,128), demonstrate clearly that the use of palliative home care support has a cost-reducing effect from the health insurer point-of-view. The lower total cost of care in the last two weeks of life can be largely explained due to reduced use of inpatient (hospital) care when using palliative home care support. However, although our findings do not suggest there are inequalities in the use of palliative home care support according to educational level or income level, policy makers should be aware that our findings lack information on the financial impact of providing home care from a patient- or caregiver point-of-view. Previous research has stressed that patients and informal caregivers often suffer financial distress related to the care provision (130–134). Therefore, policy should always be tailored to supporting both patients and their caregivers.

8.5 Implications of this dissertation

Our findings suggest that the use of palliative home care support is beneficial to improving the quality of care and decreasing the total costs of care at the end of life. Attention to palliative home care is increasing in policy and research, but further developments are needed both at a policy and practice level in order to increase the use of palliative home care support among those who have unmet needs. In the final part of this dissertation, we provide a set of recommendations for policy and decision makers at the organizational, regional, national, and international level based on our results. This could support the wider integration and further development of palliative care in the home or community setting.

8.5.1 Recommendations for policy

This dissertation focused explicitly on evaluating existing policies to support palliative care in the home or community setting in Belgium. Our research showed that several policy measures to support palliative home care exist in Belgium, and that they are effective in reducing possibly inappropriate care and total costs at the end of life. Moreover, people who use palliative home care support measures are more likely to die at home. However, our population-level findings also reveal that these measures are overall underused and initiated late, but mostly among older people and those who died with dementia. In this context some recommendations for policy can be extracted from our findings, with regard to: improving (timely) access to palliative home care support, increasing structural capacity of palliative home care support, and involving the wider community to provide palliative home care.

8.5.1.1 Recommendation 1: improve (timely) access to palliative home care support

Our findings in Chapter 4 and 6 show that the use of palliative home care support measures is low, despite convincing evidence on the positive impact of these supportive measures on the quality of end-of-life care (Chapter 7) and the increased attention for palliative home care from national policy (e.g., 'Beleidsnota Vandeurzen 2014-2019' (135)). Moreover, this dissertation found only a modest trend towards more or earlier initiation of palliative home care support, and certain groups in the population remain to be lagging behind in terms of both uptake and timing. These finding should stimulate policy makers to increase efforts to improve the (timely) accessibility of palliative home care support. In particular, access should be improved for: older people with life-threatening illness, patients with organ failure or neurodegenerative diseases, and people with life-threatening illness who are living alone.

Previously explored barriers to use palliative home care support are prognosis-based criteria related to the palliative status (i.e., life expectancy criterium) (136), a lack of awareness of palliative care support measures among general practitioners and the lay public (10,137), and a lack of recognition of palliative care needs among general practitioners and patients in specific disease-groups (e.g. COPD patients (7,87)). Possible strategies to obtain an increased access to palliative home care support is to include palliative care in other national and international policies (e.g., on ageing, dementia, etcetera (109)), change the legal criteria from a prognosis-based to a needs-based model, integrate palliative care in health-related educational curricula (e.g. physicians, nurses, social workers) (138,139), and offer clear information on palliative care goals and available support measures in a centralized manner (e.g. physically: in the sickness funds or general practitioner offices; digitally: on a web page and/or smartphone app).

In Belgium, an amendment has indeed passed to replace the prognosis-based life expectancy criterium to obtain palliative home care support measures with a frailty criterium based on an evaluation using the PICT scale (i.e. an alteration of the internationally validated SPICT-tool). However, this amendment has not yet been implemented in practice, and policy makers and the National Institute for Health and Disability Insurance (INAMI–RIZIV) should work out the modalities to implement this new tool to improve identification of patients who could benefit from palliative home care. Nevertheless, it remains unclear how much impact such a needs-based model of palliative care will have on improving (timely) access to palliative home care. As previous research by Beernaert and colleagues has shown, the timely identification and addressing of early palliative care needs by health professionals is not evident among non-cancer patients (87).

Our findings moreover show a discrepancy in the use of palliative home care support between the three regions in Belgium: people living in the Brussels capital region or in the Walloon region were less likely to use these measures than people living in Flanders. This could be related to differences in the availability supportive policies for informal caregivers, as we identified in Chapter 3. Previous research has indicated that the presence of a caregiver living in with the patient is an important factor to successfully integrate palliative care in the home (83). However, in comparison to the Flemish region, where several regional policy measures exist on top of nationally available measures to support informal caregivers of patients with palliative care needs at home (e.g., '*Vlaamse aanmoedigingspremie*', '*Gemeentelijke mantelzorgpremie*'), the Brussels capital region and Walloon region lack such additional policies. Therefore, policy makers in the regional governments of Wallonia and the Brussels capital region should invest in offering these additional supportive policy measures for informal caregivers.

8.5.1.2 Recommendation 2: increase structural capacity

Findings from Chapters 4 and 6 indicate that the use of the multidisciplinary palliative home care teams (18% of all home-dwelling people dying from an illness indicative of palliative care needs in 2015) is lower in comparison with the allowance for palliative home patients (32%) or nursing care at home for palliative patients (27%). A possible explanation for this difference is the difference in financing: whereas the multidisciplinary teams are structurally financed on the basis of an annual maximum capacity (i.e., the teams receive funding to serve a minimum of 100 or 150 patients per 200.000 inhabitants in their working region), the other supportive measures are reimbursed directly to the patient upon demand (e.g., every valid request to receive the allowance for palliative home patients is granted, regardless of how many other patients have already requested this allowance). The structural financing of these teams was last re-evaluated in 2010 (82); although this dissertation does not provide evidence on a change in demand for the multidisciplinary palliative home care teams, policy makers should consider re-evaluating the structural funding to increase the capacity of these teams in terms of available personnel, resources and other needs in order to meet the demands for palliative home care support.

8.5.1.3 Recommendation 3: involve the wider community

The policy measures to support palliative home care that were the subject of this dissertation are mainly service-based or financially supportive, aimed towards patients or informal caregivers. However, policy makers should investigate whether new models of community-based palliative care can be complimentary to, but not replacing, current existing support measures that focus on specialized services (e.g., the multidisciplinary home care teams), financial support for patients (e.g., allowance for palliative home patients) or support for informal caregivers (e.g., palliative care leave from work). New public health palliative care models have evolved with the aim to increase society's capacity to deal with death, dying and loss by focusing on involving entire communities instead of creating new (costly) healthcare services and specialists (140–143). Policy makers can prove to be important partners in such innovative models to improve palliative care in the community by looking beyond the traditional policies that are financially or service-based, for example by working together with architects and project developers to reshape their town or city to expand the community outreach. Other examples where policy makers can play a leading role in improving the cultural acceptance of caring, death and dying in society include the financial or structural support for nonprofit organizations, for example to hold annual festivities, thematic museum galleries, debate events, etcetera.

8.5.1.4 Recommendation 4: promotion of palliative home care support

Future policies or interventions should be focused on improving knowledge about and access to palliative home care support among those with currently unmet needs. This implies that the existing supportive measures should be made known to people throughout all layers of society. Possibly valuable channels to offer this information include general practitioners, the national sickness funds, municipalities (e.g. online). Educational programs in primary and secondary school levels can raise awareness about the societal changes with regard to ageing and the increasing needs for care. Employers should be informed on the legal duties of having a personnel policy that respects the needs of employees that (want to) provide informal care to take a (palliative) care leave from work, and public and private workplaces alike should be convinced of the merits of creating an environment where death, dying and illness can be openly discussed. Finally, publicly financed campaigns, film documentaries, or fiction series on national television could be used to convey a realistic and respectful discourse about caregiving, palliative care, and death and dying in modern society to a broad audience to alter negative perceptions and false presumptions.

However, policy makers and practitioners should also be aware of the fact that not all patients and caregivers would want to receive or provide palliative care in their home. Moreover, societal changes such as a low marriage rate, the increasing number of single-person households, and increasing life expectancy will likely lead to a future increasing lack of available informal caregivers. Whereas the evidence on the impact of providing informal care on physical and psychological well-being is often contradictory (144–149), there appears to be a general consensus in research that informal caregivers have their own specific needs that will increase over the next years (130,150–157), indicating that hidden costs related to the physical and psychological support for these informal caregivers are substantial. As such, policies should start to investigate how this anticipated deficiency can be compensated for.

8.5.2 Recommendations for practice

Our findings suggest an opportunity for primary caregivers to increase the awareness of available supportive measures for palliative home care and as such improve the accessibility of these measures to those with unmet needs, by more actively communicating with patients and family members about their care needs and expectations. Extra attention should be given by general practitioners and other primary caregivers (e.g., home nurses, social workers) to specific groups in the population that are currently underserved by palliative home care support, such as people with non-cancer serious illness, older people, and people who are living alone. To support caregivers with this difficult task, courses should be implemented in the educational curriculum of all health-related occupations, covering topics such as advance care planning (89,158) and other communicational skills.

8.5.3 Implications for research

8.5.3.1 Future opportunities of working with big administrative datasets to study end-of-life care

In this dissertation, we mainly performed quantitative analyses using administrative data to provide insights in the use and impact of using palliative home care support. However, there is a multitude of future opportunities with regard to the use of population level administrative databases and other big data sources to study end-of-life care.

Firstly, future research can build on the evidence from this dissertation to regularly evaluate and monitor the use of palliative home care support, for example by following our strategy to identify, collect and access multiple population level administrative databases for future years. These data are available and continuously gathered each year by multiple administrators, thus allowing researchers in Belgium to follow up on new developments in palliative care policy. For example, an interrupted time series analysis could be valuable to monitor the impact of policy reforms (e.g., the change from a prognosis-based to a frailty-based legal criterium to be eligible for palliative home care support).

Secondly, innovative study designs and applications are developed to improve the value of using these types of data in research. According to several authors, the use of big data (e.g. data collected from wearables and other electronic devices connected to the Internet of Things (IoT)) in end-of-life care will become inevitable in the near future (159–163). A potential use of big data in end-of-life care is the use of Machine Learning (i.e. a type of Artificial Intelligence (AI) that allows software applications to become more accurate in predicting outcomes without being explicitly programmed (164)). Current applications for research include natural language processing algorithms that allow to integrate qualitative data into quantitative datasets (165), which can increase the richness of big datasets with valuable, previously unmeasured information (e.g., quality of care).

Thirdly, researchers from other countries can investigate the possibility to access and link administrative databases in their own country to study end-of-life care. International collaborations should be set up in which comparative research can be conducted. However, there are several barriers that need to be considered. First, the use of administrative data is often restricted by legal and contractual agreements, thus impeding possible international collaborations; these research ideas should ideally be discussed with database administrators and privacy committees from the start of the project. Second, apart from cross-national differences in how end-of-life and other health care is organized, datasets always have their own unique differences due to how the data are registered, captured and inputted by database administrators; cross-national comparative research therefore requires a common set of definitions of concepts used, as well as transparency in operationalization and coding of all variables.

8.5.3.2 Future opportunities for research in general

Our findings provide valuable evidence to policy makers and practice by describing and evaluating these policies on a population level, but qualitative research is needed to better understand some of our findings. Specifically, more evidence is needed to gain understanding into the impact of palliative home care support on the sociological entity of the ‘family’, not only financially, but also with regard to how the provision of care at home (re)shapes the home as a space of living into a space of care (166). Future research should further explore the standardization of Patient-Reported Outcomes Measures (PROMs) data and linkage possibilities of patient-data with caregiver-data (i.e., to investigate relational aspects of palliative caregiving at home).

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Samenvatting van de belangrijkste bevindingen

INLEIDING

Mensen leven gemiddeld steeds langer en sterven op oudere leeftijd. Vaak worden deze extra jaren echter doorgebracht in een situatie van verminderde gezondheid: mannen en vrouwen brengen tegenwoordig gemiddeld 8,3 levensjaren door vóór het overlijden met een zekere mate van invaliditeit. Naarmate de leeftijd stijgt, neemt de kans op het leven met een of meer chronische ziekten aanzienlijk toe. Een plotselinge dood is vandaag dan ook minder gebruikelijk en de meeste mensen krijgen in plaats daarvan een ernstige progressieve ziekte tegen het einde van hun leven, die hun gebruikelijke activiteiten in toenemende mate verhindert. In 2015 werd geschat dat ongeveer 40 miljoen sterfgevallen, of 70% van alle sterfgevallen wereldwijd, te wijten waren aan niet-besmettelijke of niet-overdraagbare ziekten – meer dan ooit tevoren. Toch zien velen hun behoeften voor kwaliteitsvolle zorg aan het levenseinde niet vervuld: naar schatting krijgt wereldwijd slechts 14% van de mensen die nood hebben aan palliatieve zorg dit ook daadwerkelijk.

Deze veroudering van de bevolking brengt specifieke sociale, politieke en economische uitdagingen met zich mee, die er toe heeft geleid dat landen aangespoord werden om palliatieve zorg te integreren in hun nationale gezondheidszorgsystemen. Als zodanig is de ontwikkeling van een wetgevend kader met het oog op het uitbouwen van een geïntegreerde palliatieve zorg een belangrijke prioriteit geweest voor nationale en supranationale wetgevende organen in de afgelopen decennia. Om tegemoet te komen aan de wensen van patiënten, die meestal zo lang als mogelijk thuis willen verzorgd worden en zo mogelijk ook daar sterven, en om de toenemende maatschappelijke kosten gerelateerd aan hospitalisaties en institutionalisering van personen aan het levenseinde aan te pakken, werd uitdrukkelijk ingezet op beleidsmaatregelen om palliatieve zorg in de thuisomgeving te ondersteunen.

Veel beleidsstrategieën missen echter vaak een wetenschappelijke onderbouwing en landen in heel Europa hebben de afgelopen twintig jaar beleidsmaatregelen relatief onafhankelijk van elkaar ontwikkeld. Vanuit het oogpunt van de volksgezondheid is het daarom belangrijk om het nationale beleid te evalueren op de beschikbaarheid, toegankelijkheid en impact van bestaande maatregelen ter ondersteuning van palliatieve thuiszorg. Dit huidige proefschrift richt zich op het beschrijven op populatieniveau van het gebruik, de trends in gebruik, factoren die van invloed zijn op het gebruik en de impact van het gebruik van maatregelen die beschikbaar zijn als gevolg van nationaal beleid en die bedoeld zijn om patiënten en hun mantelzorgers te ondersteunen bij het bieden van palliatieve zorg thuis of in de gemeenschap.

Beschikbare ondersteunende beleidsmaatregelen voor palliatieve thuiszorg in België

Multidisciplinaire begeleidingsequipes (MBE)

Het doel van de multidisciplinaire begeleidingsequipes werd in 1998 wettelijk vastgelegd als een eerste maatregel om zorgverleners te ondersteunen bij de eerstelijnszorg. Op dit moment ondertekenden 28 teams een dergelijke overeenkomst (15 in Vlaanderen, 9 in Wallonië, 3 in Brussel en 1 in de Duitstalige Gemeenschap). De MBEs hebben de volgende taken:

- De problemen met de zorgverleners te bespreken en hen te adviseren over alle aspecten van palliatieve zorg (bijvoorbeeld pijn- en symptoomcontrole, psychologische en spirituele ondersteuning);
- De patiënt en zijn/haar familie informeren over diagnose, behandeling en prognose. Deze twee eerste missies rechtvaardigen dat iemand 24 uur per dag paraat zou zijn voor telefoongesprekken;
- De palliatieve zorg coördineren door te plannen met huisartsen, andere zorgverleners en vrijwilligers;
- Ervoor zorgen dat het noodzakelijke zorgmateriaal bij de patiënt thuis beschikbaar is;
- Psychologische en spirituele ondersteuning bieden aan de zorgverleners van de eerste lijn van zorg. In specifieke situaties kan het palliatieve thuiszorgteam na overleg en met hun toestemming specifieke zorgtaken uitvoeren.

Financiële ondersteunende maatregelen

Het koninklijk besluit van 2 december 1999 definieert de criteria van de "palliatieve thuispatiënt". Opdat patiënten een van de wettelijke ondersteunende maatregelen voor palliatieve thuiszorg kunnen ontvangen, moet de huisarts of een andere arts formeel erkennen dat het gaat om een patiënt:

- die lijdt aan één of meerdere irreversibele aandoeningen;
- die ongunstig evolueert, met een ernstige algemene verslechtering van zijn fysieke/psychische toestand;
- bij wie therapeutische ingrepen en revaliderende therapie geen invloed meer hebben op die ongunstige evolutie;
- bij wie de prognose van de aandoening(en) slecht is en het overlijden op relatief korte termijn verwacht wordt (levensverwachting meer dan 24 uur en minder dan drie maand);
- met ernstige fysieke, psychische, sociale en geestelijke noden die een belangrijke tijdsintensieve en volgehouden inzet vergen; indien nodig wordt een beroep gedaan op hulpverleners met een specifieke bekwaming en op aangepaste technische middelen;
- met een intentie om thuis te sterven;
- en die voldoet aan de voorwaarden opgenomen in dit formulier.

De volgende financiële ondersteuningsmaatregelen voor palliatieve thuiszorg zijn beschikbaar in België:

1) Forfait voor palliatieve thuispatiënten

Een forfaitaire vergoeding (een bedrag van 673.11 euro per 2019) ter compensatie van de niet-terugbetaalde kosten van geneesmiddelen, medische hulpmiddelen en verzorgingsproducten die nodig zijn voor de thuiszorg van palliatieve patiënten. De uitkering kan eenmaal na één maand worden verlengd. De hoeveelheid blijft volledig verworven, zelfs als de patiënt binnen 30 dagen dood zou gaan. Het bedrag wordt een tweede keer toegekend als de patiënt nog steeds voldoet aan de voorwaarden na de dertig dagen na de kennisgeving en na het volgen van dezelfde procedure (d.w.z. de huisarts dient een nieuw verzoek in).

2) Thuisverpleegkundige zorg voor palliatieve thuispatiënten

Forfaitaire vergoedingen en aanvullende vergoedingen voor het verlenen van verpleegkundige zorg aan palliatieve thuispatiënten zijn ingebed in de nomenclatuur voor thuisverpleging. Dit zijn bedragen die betrekking hebben op alle verpleegkundige zorg en ondersteuning van de thuispatiënt met palliatieve statuut (d.w.z. dat de vergoedingen worden verstrekt aan de verpleegkundige, niet aan de patiënt). De eigen bijdrage (out-of-pocket kosten) voor verpleegkundige zorg verdwijnt voor de palliatieve thuispatiënt door volledige terugbetaling van de zorgkosten door de ziekteverzekeraar. Overleeft de patiënt de vooraf gestelde levensverwachting van 3 maanden, dan blijft de zorgverzekeraar de forfaitaire vergoeding betalen zolang de thuisverpleging duurt.

Om in aanmerking te komen voor de honoraria en forfaitaire toeslagen van verpleegkundige zorg voor palliatieve thuispatiënten, moeten de verpleegkundigen die zorg verlenen voldoen aan verschillende specifieke voorwaarden:

- een van de volgende kwalificaties bezitten: gediplomeerde of niet-gegradueerde verpleegkundige of equivalent, of verloskundige;
- garantie van continue zorg voor de patiënt (24/24 uur, 7/7 dagen);
- een beroep kunnen doen op een referentieverpleegkundige met kennis van palliatieve zorg;
- het verpleegbestand invullen met de volgende belangrijke informatie voor dit type zorg:
    - registratie van symptomen,
    - de pijnschaal invullen,
    - contacten melden met de familie van de patiënt,
    - de resultaten rapporteren van de coördinatievergaderingen.

3) Kinesitherapie voor palliatieve thuispatiënten

Het persoonlijke aandeel voor kinesitherapie werd geschrapt door volledige terugbetaling van de zorgkosten door de ziekteverzekeraar. Aangezien de verordening geen specifieke bepaling bevat over de duur van de afschaffing van het persoonlijk aandeel, wordt hetzelfde principe gevolgd als voor de thuisverpleging bij palliatieve thuispatiënten: zodra de goedkeuring door de adviserend arts is verkregen, is de afschaffing van het persoonlijk aandeel voor huisbezoeken van de kinesitherapeut van toepassing tot de patiënt is overleden.

4) Afschaffing van het persoonlijk aandeel voor huisartsenconsultaties

Patiënten met het palliatieve statuut zijn bekend bij de ziekenfondsen en voor hen geldt een automatische volledige terugbetaling van de vergoedingen voor de huisbezoeken. Hetzelfde principe wordt gevolgd: zodra de goedkeuring door de huisarts is verkregen, geldt de volledige vergoeding tot de patiënt is overleden.

Beschikbare ondersteunende beleidsmaatregelen voor mantelzorgers van mensen die thuis palliatieve zorg ontvangen België

In de specifieke context van de palliatieve zorgverlening heeft de Belgische wet het voor elke werknemer mogelijk gemaakt om een betaald palliatief zorgverlof te nemen van het werk - fulltime, deeltijds of 20% - om medische, sociale, administratieve en psychologische zorg en hulp te verlenen aan een palliatieve thuispatiënt. In principe heeft elke medewerker die informele palliatieve zorg aanbiedt het recht om dit verlof op te nemen; een familiale band met de palliatieve zorgpatiënt is niet vereist. De tijdsperiode is beperkt tot een maximum van twee maanden voor dezelfde patiënt. Mantelzorgers in Vlaanderen hebben daarboven recht op de Vlaamse aanmoedigingspremie, een aanvullend voordeel bovenop het betaalde palliatieve zorgverlof op het werk.

DOELSTELLINGEN EN ONDERZOEKSVRAGEN

De volgende onderzoeksvragen werden in dit proefschrift behandeld:

1. Welke databases bieden geldige informatie op populatieniveau over de socio-demografische en klinische achtergrond van een persoon, de opname van palliatieve thuiszorg en andere vormen van gezondheidszorg en medicijngebruik vóór het overlijden, inclusief de kosten ervan? Welke procedures zijn er om deze databases te gebruiken? Wat is nodig om afzonderlijke databases te integreren in een bruikbare dataset?
2. Welke beleidsmaatregelen ter ondersteuning van palliatieve thuiszorg zijn beschikbaar voor patiënten of mantelzorgers in verschillende Europese landen met een vergelijkbare contextuele achtergrond? Hoe verhouden beleidsmaatregelen ter ondersteuning van palliatieve thuiszorg in verschillende landen met een vergelijkbare contextuele achtergrond zich tot elkaar in termen van de omvang van wat wordt aangeboden en de criteria voor het ontvangen ervan?
3. Wat is het gebruik van beleidsmaatregelen ter ondersteuning van palliatieve thuiszorg in de Belgische bevolking, en in een subgroep van mensen die zijn overleden aan een doodsoorzaak met mogelijke behoeften aan palliatieve zorg in de Belgische bevolking? Welke socio-demografische en ziektegerelateerde kenmerken zijn geassocieerd met het gebruik van deze ondersteunende maatregelen in de Belgische bevolking en in een subgroep van mensen die zijn overleden aan een doodsoorzaak met mogelijke behoeften aan palliatieve zorg in de Belgische bevolking?
4. Wat is het gebruik van palliatieve thuiszorg bij mensen die overleden zijn aan amyotrofische laterale sclerose (ALS) in België? Welke patronen van zorggebruik aan het einde van het leven worden bij deze personen gevonden?
5. Zijn er trends in het gebruik van palliatieve thuiszorg onder personen die zijn overleden aan een doodsoorzaak met mogelijke behoeften aan palliatieve zorg in België tussen 2010 en 2015? Is er een trend in de richting van eerdere initiatie bij diegenen die een van deze vormen van palliatieve thuiszorgondersteuning gebruikten?
6. Wat is de impact van palliatieve thuiszorg op de kwaliteit van zorg en kosten in de laatste 14 dagen van het leven?

METHODEN

Cross-nationale vergelijkende studie met behulp van analyse van beleidsdocumenten en raadpleging van experts

We hebben een casusgerichte, cross-nationale vergelijkende studie uitgevoerd met behulp van nationale beleidsdocumenten en individuele interviews met experts (geschreven en telefonisch) als de belangrijkste informatiebronnen om de beschikbaarheid van beleidsmaatregelen ter ondersteuning van palliatieve thuiszorg in België, Frankrijk en Duitsland te bestuderen (onderzoeksvraag 2). We hebben ons gericht op deze landen omdat ze vergelijkbare maatschappelijke uitdagingen hebben in termen van vergrijzing van de bevolking, gezondheidszorgstelsels en sociaal-demografische en politiek-economische achtergronden. Deze selectie van een relatief homogene context maakte het mogelijk beleidsverschillen te identificeren die specifiek verband hielden met beleidsmaatregelen ter ondersteuning van palliatieve zorg thuis die geen weerspiegeling zijn van verschillen in gezondheidszorg of sociale zekerheid.

Tijdens het hele proces van gegevensverzameling waren er meerdere iteraties en persoonlijke en schriftelijke raadplegingen tussen alle auteurs om conceptuele onduidelijkheden te voorkomen. Met deze methode konden alle beschikbare beleidsmaatregelen ter ondersteuning van patiënten en zorgverleners in een palliatieve zorgsituatie in de thuissituatie gedetailleerd worden beschreven en vergeleken. Meer informatie over de methoden van de studie is te vinden in hoofdstuk 3.

Gekoppelde administratieve databases op populatieniveau

Het eerste doel van dit proefschrift was om te onderzoeken hoe het gebruik en de impact van ondersteuningsmaatregelen voor palliatieve thuiszorg het best op populatieniveau kunnen worden onderzocht (onderzoeksvraag 1).

We identificeerden in totaal zeven databanken die gegevens bevatten op populatieniveau (d.w.z. informatie bevatten over iedereen die bij het overlijden geregistreerd was bij een Belgisch ziekenfonds; ongeveer 98.8% van alle sterfgevallen) en beheerd werden door drie verschillende organisaties. In een eerste fase van het project werd de koppeling voltooid voor alle gegevens op individueel niveau, die alle 107,847 overlijdens in België in 2012 omvatten. Deze gegevens werden gebruikt om de opname van palliatieve thuiszorgondersteuning en gerelateerde factoren die de opname beïnvloeden te analyseren (onderzoeksvraag 3) en om de impact van palliatieve thuiszorg op de kwaliteit van zorg en kosten aan het einde van het leven te onderzoeken (onderzoeksvraag 6). Op basis van de eerste analysefase werd gedetailleerde informatie verzameld, zodat meer cases met meer gecondenseerde informatie per case konden worden geleverd. In deze tweede fase zijn gegevens van volgende jaren toegevoegd voor alle sterfgevallen tussen 1 januari 2010 en 31 december 2015, met in totaal 634,445 overlijdens. De gegevens met informatie over zes opeenvolgende jaren werden gebruikt voor analyse in de studie die het gebruik van gezondheidszorg aan het levenseinde beschrijft bij patiënten die stierven aan amyotrofische laterale sclerose (onderzoeksvraag 4) en in de beschrijvende studie naar trends in het gebruik en timing van initiëren van palliatieve thuiszorgondersteuning (onderzoeksvraag 5).

Het volledige proces van exploratie tot gefinaliseerde gekoppelde dataset, inclusief details over de variabelen en databronnen, wordt uitvoerig beschreven in hoofdstuk 3. Meer informatie over de gegevensanalyses voor elke onderzoeksvraag is te vinden in het hoofdstuk waarin de onderzoeksvraag wordt behandeld.

BELANGRIJKSTE BEVINDINGEN

Gekoppelde administratieve databases om het gebruik van palliatieve thuiszorg op populatieniveau te bestuderen

Het InterMutualistisch Agentschap (IMA) werd geïdentificeerd als een gegevensbeheerder die informatie bezit over sociaal-demografische kenmerken (leeftijd, geslacht, datum van overlijden, verblijfplaats, gezinssamenstelling, gebruik van ondersteunende maatregelen), kenmerken van medicijnvoorziening (stof, hoeveelheid, voorschrijver, terugbetaalde kosten, leveringsdatum), en gezondheids- en medische zorggebruikskarakteristieken (hoeveelheid gebruik, vergoeding, leverancier, behandelingsduur). De Stichting Kankerregister (BCR) werd geïdentificeerd als een gegevensbeheerder die informatie bezit over diagnostische kenmerken (datum van diagnose, type kanker, TNM-gradatie) voor elke nieuwe kankerdiagnose van Belgische inwoners, geregistreerd door oncologische zorgprogramma's en laboratoria voor anatomische pathologie. Statistics Belgium (StatBel) werd geïdentificeerd als een gegevensbeheerder die informatie bezit over alle geregistreerde doodsoorzaken, socio-demografische informatie over de overledene, plaats van overlijden, nationaliteitsgroep, gezinssamenstelling, hoogst behaalde opleidingsniveau, beroep, huisvesting comfort en netto-inkomen voor elke Belgische burger.

Vergelijking tussen beschikbare beleidsmaatregelen ter ondersteuning van palliatieve thuiszorg

In hoofdstuk 3 vergeleken we de beschikbare beleidsmaatregelen ter ondersteuning van palliatieve zorg in de thuissituatie in België, Frankrijk en Duitsland. Beleidsmaatregelen ter ondersteuning van palliatieve zorg in de thuissetting konden worden onderverdeeld in drie hoofdcategorieën: vergoedingen en kostenbesparingen (voor patiënten en mantelzorgers), ondersteuning in natura (voor patiënten en mantelzorgers), en maatregelen gerelateerd aan de werksituatie (voor mantelzorgers).

Ondanks overeenkomsten waren er enkele belangrijke verschillen tussen de landen wat betreft de beschikbare bedragen en de voorwaarden en beperkingen die van toepassing zijn om de steun te ontvangen. Beleid om de eigen bijdrage voor patiënten in een palliatieve thuiszorgsituatie te verminderen bestaat bijvoorbeeld in België en Duitsland, maar niet in Frankrijk. In Frankrijk is de jaarlijkse eigen uitgave voor gezondheidszorg echter beperkt tot €50 voor elke persoon in het Franse zorgstelsel. Mantelzorgers van palliatieve thuispatiënten kunnen financiële compensaties ontvangen in België en Frankrijk, maar niet in Duitsland. Alle drie landen hebben beleid om zorgverlof van werk voor mantelzorgers van palliatieve thuispatiënten te regelen, maar alleen in België bestaat een betaald verlof.

Het gebruik en factoren die verband houden met het gebruik van beleidsmaatregelen ter ondersteuning van palliatieve thuiszorg in België

In hoofdstuk 4 hebben we het gebruik van beleidsmaatregelen ter ondersteuning van palliatieve thuiszorg in België beschreven en geanalyseerd welke factoren verband hielden met hogere of lagere kansen om deze maatregelen te gebruiken. We hebben 87,007 volwassenen opgenomen die in het laatste levensjaar thuis woonden en in 2012 zijn overleden. We hebben onderscheid gemaakt tussen 'wettelijke' en 'niet-wettelijke' ondersteunende maatregelen in de database, afhankelijk van de vraag of patiënten een officiële palliatieve zorgstatus (‘palliatief statuut’) nodig hadden om ze te ontvangen of niet. Van deze populatie gebruikte 18% een wettelijke ondersteuningsmaatregel (d.w.z. het forfait voor palliatieve thuispatiënten, multidisciplinaire begeleidingsequipe (MBE), palliatieve thuisverpleegkundige zorg of kinesitherapie voor palliatieve thuispatiënten) en 52% had in de laatste twee levensjaren een niet-wettelijke ondersteunende maatregel gebruikt (d.w.z. het forfait voor chronisch zieken, thuisverpleegkundige zorg of kinesitherapie voor zwaar afhankelijke thuispatiënten).

Wanneer we alleen kijken naar een subpopulatie van 38,657 volwassenen die thuis woonden en stierven aan een ziekte die wijst op palliatieve zorgbehoeften (de 'palliatieve subset'), dan was de opname van palliatieve thuiszorg maatregelen respectievelijk 33% (wettelijke) en 62% (niet-wettelijke). Mogelijke verklaringen voor de lagere opname van de wettelijke maatregelen houden verband met moeilijkheden van het op een prognose gebaseerde criterium rond deze maatregelen in combinatie met problemen om de behoeften aan of voordelen van palliatieve zorg onder niet-kankerpatiënten te herkennen. Van de wettelijke ondersteunende maatregelen werd het forfait voor palliatieve thuispatiënten het vaakst gebruikt (30% van de palliatieve subgroep populatie), gevolgd door palliatieve thuisverpleegkundige zorg (24%), MBE (17%) en kinesitherapie voor palliatieve thuispatiënten (7%). Van de niet-wettelijke ondersteunende maatregelen werd het forfait voor chronisch zieken het vaakst gebruikt (38%), gevolgd door thuisverpleging (35%) en kinesitherapie aan huis (25%).

Multivariabele logistische regressie analyses toonden dat het gebruik van wettelijke palliatieve thuiszorgmaatregelen verschilt tussen verschillende groepen in de populatie. Deze maatregelen worden voornamelijk gebruikt door kankerpatiënten (referentiecategorie), in vergelijking met patiënten die stierven aan COPD (Odds Ratio: 0.18, 95% betrouwbaarheidsinterval (CI) 0.16-0.20), andere soorten orgaanfalen (d.w.z. hartfalen, nierfalen, leverfalen) (OR: 0.22, 95% CI 0.20-0.24), neurodegeneratieve ziekten (OR: 0.30, 95% CI 0.27-0.33) of HIV/AIDS (OR: 0.17, 95% CI 0.04-0.72). Jongere personen (18-64 jaar) hadden meer kans om deze maatregelen te gebruiken (OR: 1.32, 95% CI 1.07-1.62) in vergelijking met personen ouder dan 94 jaar (referentiecategorie). De niet-wettelijke ondersteunende maatregelen daarentegen, werden vaker gebruikt door ouderen (65-74 jaar: OR: 1.20, 95% CI 1.02-2.40, 75-84 jaar: OR: 1.22, 95% CI 1.05-1.43; leeftijd 85-94: OR: 1.19, 95% CI 1.02-1.39) vergeleken met de oudste leeftijdscategorie van 94 jaar en ouder (referentiecategorie), en door degenen die aan COPD overleden (OR: 1.22, 95% CI 1.13-1.32) vergeleken met degenen die sterven aan kanker. Over het algemeen werden palliatieve thuiszorgmaatregelen het minst waarschijnlijk gebruikt door mannen, door mensen die alleen woonden, of door mensen die in de regio Brussel woonden. Deze bevinding lijkt te suggereren dat de opname van ondersteunende maatregelen voor palliatieve thuiszorg, afgezien van aspecten die verband houden met de prognose, beïnvloed worden door specifieke omgevingsfactoren.

Gebruik van gezondheidszorg aan het levenseinde bij personen die stierven aan ALS

In hoofdstuk 5 hebben we het gebruik van gezondheidszorg aan het levenseinde beschreven bij alle patiënten (inclusief diegenen die in een verpleeghuis woonden) die stierven aan amyotrofische laterale sclerose (ALS) in België tussen 2010 en 2015. Van de 1,636 sterfgevallen in deze zeldzame populatie (prevalentie van ongeveer 5.4/100,000) gebruikte 44% gespecialiseerde palliatieve zorg (palliatieve zorgeenheid of MBE). Veertig procent ontving het forfait voor palliatieve thuispatiënten in de laatste twee levensjaren; voor 22% daarvan werd palliatieve zorg slechts geïnitieerd in de laatste twee weken van het leven. In de laatste 14 dagen van het leven werd 41% van de bevolking opgenomen in een ziekenhuis voor acute zorg en 25% had een afdeling spoedeisende hulp. In de laatste week van het leven werden medicijnen voornamelijk toegediend om symptomen te behandelen die verband hielden met pijn (29%), slapeloosheid en vermoeidheid (20%) of veneuze trombose (15%). Meer dan 1 op de 6 ontving niet-invasieve beademing in de laatste maand van het leven, en 39% stierf thuis. Deze studie toont aan dat routinematig verzamelde gegevens (big data) een waardevolle bron vormen om kwaliteitsvol bewijsmateriaal te verzamelen over gebruikspraktijken in de gezondheidszorg in relatief kleine populaties, zoals die met ALS, die weinig aandacht hebben gekregen in het onderzoek naar het levenseinde.

Trends in het gebruik en de timing van het initiëren van palliatieve thuiszorgondersteuning

In hoofdstuk 6 beschreven we trends in de opname en timing van het initiëren van palliatieve thuiszorg tussen 2010 en 2015 in een populatie van mensen die thuis woonden en stierven aan een doodsoorzaak met mogelijke palliatieve zorgbehoeften ('palliatieve subset', zie hierboven). Tussen 2010 en 2015 steeg het gebruik van wettelijke palliatieve thuiszorgmaatregelen van 32% tot 35% in deze populatie (n=230,704). Vergeleken met andere groepen in de populatie, hadden degenen die overleden aan neurodegeneratieve ziekten en degenen die 85 jaar of ouder waren op het moment van overlijden een kleinere stijgende trend in het gebruik van palliatieve thuiszorg in vergelijking met de andere groepen in de populatie. Een interessante bevinding was dat, ondanks verschillen in de hoeveelheid opname tussen de verschillende soorten palliatieve thuiszorgondersteuning, vergelijkbare trendpatronen werden gevonden voor alle maatregelen, wat aangeeft dat de toegang tot, of de vraag naar, deze maatregelen in dezelfde mate toenam.

Onder degenen die palliatieve thuiszorgondersteuning gebruikten, veranderde de timing van de initiatie van een mediaan van 40 dagen voor overlijden tot 45 dagen. Ondertussen daalde het aandeel van mensen voor wie de palliatieve thuiszorg in de laatste week van het leven werd geïnitieerd van 15% naar 14%. Deze trends tonen aan dat er weinig tot geen verandering is in het aantal mensen dat palliatieve thuiszorgondersteuning ontvangt en dat een substantieel aandeel personen nog steeds (zeer) laat in het ziektetraject palliatieve thuiszorg ontvangt.

De impact van palliatieve thuiszorg op de kwaliteit en kosten van zorg aan het levenseinde

In hoofdstuk 7 gebruikten we een op propensity-score gematchte cohortstudie om de impact te evalueren van het gebruik van palliatieve thuiszorg op de kwaliteit en kosten van zorg in de laatste twee weken van het leven, op basis van populatieniveau-gegevens van volwassenen die thuis leefden en stierven in 2012. We hebben 8837 volwassenen die thuis woonden en palliatieve thuiszorg gebruikten (interventiegroep) gekoppeld aan evenveel personen die thuis woonden en geen gebruik maakten van dergelijke ondersteuningsmaatregelen (controlegroep), gebaseerd op hun individuele neiging ('propensity') om palliatieve thuiszorgmaatregelen te gebruiken

Van degenen in de interventiegroep overleed 56% thuis, vergeleken met 14% in de controlegroep. Gemiddeld hadden degenen in de interventiegroep 9 contacten met een zorgverlener (huisarts of verpleegkundige zorg) en 3 contacten met huisartsen in de laatste 2 weken van het leven, vergeleken met een gemiddelde van 2 contacten met een zorgverlener en 1 huisartscontact voor degenen in de controlegroep. Van degenen in de interventiegroep stierf 39% in het ziekenhuis, vergeleken met 74% van degenen in de controlegroep. Minder mensen in de interventiegroep werden opgenomen in een ziekenhuis (27% versus 61%), op een afdeling intensieve zorgen (18% versus 40%) of op een spoedafdeling (15% versus 28%) in de laatste 2 weken van het leven. Minder mensen in de interventiegroep werden onderworpen aan diagnostische testen (27% versus 63%), kregen bloedtransfusie (3% versus 6%) of chirurgie (0,5% versus 3%).

De gemiddelde totale intramurale zorgkosten (d.w.z. in het ziekenhuis) waren lager voor degenen in het cohort die werden blootgesteld aan palliatieve thuiszorg (€1766, 95% CI € 1706-€ 1826) in vergelijking met patiënten die niet werden blootgesteld aan palliatieve thuiszorg (€4222, 95% CI €4133-€4311) ($p<0.001$). De gemiddelde totale extramurale zorgkosten (d.w.z. buiten het ziekenhuis) waren hoger voor diegenen in de interventiegroep (€1314, 95% CI €1291-€1337) vergeleken met die in de controlegroep (€476, 95% CI €461-€492) ($p<0.001$). Als zodanig bedroegen de incrementele totale gemiddelde kosten voor degenen in interventie versus controlegroep in de laatste 2 weken van het leven -€1617. Kosten van palliatieve thuiszorgondersteuning die werd voortgezet in de laatste 2 weken van het leven werden in de berekening opgenomen.

BESPREKING VAN DE RESULTATEN

Palliatieve thuiszorggebruik in België

Een belangrijke bevinding van dit proefschrift is dat de opname van beleidsmaatregelen ter ondersteuning van palliatieve thuiszorg in België over het algemeen laag is en dat deze relatief laat worden ingeschakeld (Hoofdstukken 4 en 6). In onze bestudeerde populatie van degenen die thuis verbleven in het laatste levensjaar en die zijn overleden aan een ziekte met mogelijke palliatieve zorgnoden, werden de wettelijke maatregelen voor palliatieve thuiszorgondersteuning in 2012 door één op de drie mensen (33%) gebruikt. In hoofdstuk 5 vonden we dat het gebruik van palliatieve thuiszorg onder degenen die stierven aan ALS hoger was (40%) in vergelijking met dat van de algemene bevolking. Onder degenen die in 2015 wel ondersteuningsmaatregelen gebruikten, varieerde het mediane aantal dagen vóór het overlijden van het opstarten van deze maatregelen tussen 32 dagen (degenen die met dementie stierven) en 63 dagen (degenen die stierven aan de ziekte van Parkinson, motorneuronziekte, HIV / AIDS of niet-kankerachtig neoplasma) (hoofdstuk 6).

Mogelijke verklaringen voor de lage en late opname van palliatieve thuiszorgmaatregelen

De opname van palliatieve thuiszorg in België is vergelijkbaar met die in andere ontwikkelde landen. In de VS, waar palliatieve zorg wordt aangeboden door hospice-diensten en beschikbaar wordt gesteld aan patiënten van elke leeftijd met een terminale prognose van minder dan zes maanden, vond 30% van alle sterfgevallen in 2011 plaats binnen een hospice-programma afgeleverd in de woning van een patiënt. In Australië bleek uit een retrospectieve cohortstudie dat 18% gespecialiseerde palliatieve thuiszorg gebruikte in het laatste levensjaar, en nog eens 13% gebruikte zowel gespecialiseerde palliatieve thuiszorg als palliatieve zorg in het ziekenhuis. Een Canadese studie onder kankerpatiënten uit Ontario rapporteerde dat 47% van deze populatie thuiszorg gebruikte voor het levenseinde, waarvoor patiënten een ongeneeslijke aandoening dienden te hebben en waarvan verwacht werd dat ze binnen een jaar zouden sterven. Een cross-nationale Europese studie uit 2013 gebruikte door artsen gerapporteerde gegevens over 4,466 sterfgevallen van patiënten ouder dan 18 jaar om te rapporteren over het gebruik van gespecialiseerde palliatieve thuiszorg (vergelijkbaar met het MBE in onze studie) in Nederland (5%), Italië (24%) en Spanje (29%).

Behalve de Canadese studie uit 2006, rapporteren de meeste andere internationale studies dus een relatief lage opname van palliatieve thuiszorg. Een waarschijnlijke verklaring voor deze lage opname is er een die betrekking heeft op de op prognose gebaseerde wettelijke criteria om palliatieve ondersteuningsmaatregelen te kunnen krijgen. Net als in de meeste andere landen moeten patiënten in België, om palliatieve thuiszorg te kunnen ontvangen, een beperkte levensverwachting hebben, van meer dan 24 uur en minder dan drie maanden. Dit kan een potentiële belemmering vormen voor het gebruik van palliatieve thuiszorg vanwege de aarzeling van zowel patiënten als artsen om palliatieve thuiszorg te initiëren, bijvoorbeeld door niet te willen 'toegeven' dat de levensverwachting beperkt is, of door niet in staat te zijn om correct inschatten van de prognose. Onderzoek bij vergevorderde kankerpatiënten heeft consequent aangetoond dat zowel artsen als patiënten niet goed in staat zijn om hun levensverwachting correct te voorspellen (die ze meestal overschatten) en ziektetrajecten van niet-kanker aandoeningen zijn nog moeilijker te voorspellen, wat een realistische prognose nog moeilijker maakt. Als gevolg wordt palliatieve thuiszorg vaak pas laat geïnitieerd. Bij 14% van alle mensen in België die overleden in 2015 en palliatieve thuiszorg gebruikten werd pas opgestart in de laatste week van het leven (hoofdstuk 6). Deze hypothese wordt verder ondersteund door bevindingen van een eerdere studie die rapporteerde dat "*niet voldoende tijd*" een van de drie belangrijkste redenen voor artsen was om een patiënt niet door te verwijzen naar een gespecialiseerde palliatieve zorgdienst.

Op 20 oktober 2018 is een amendement op het Koninklijk Besluit aangenomen met als doel het op prognose gebaseerde criterium om het palliatieve statuut te krijgen te vervangen met een op kwetsbaarheid gebaseerd criterium, met gebruik van een aangepaste versie van de internationaal gevalideerde SPICT -tool. Deze tool is bedoeld om mensen te helpen identificeren die het risico lopen te verslechteren of te sterven aan een of meerdere geavanceerde, progressieve aandoeningen of aan een nieuwe levensbeperkende ziekte, door de zogenaamde 'verrassingsvraag' te gebruiken (d.w.z. aan clinici wordt gevraagd of ze 'verrast' zouden zijn als de patiënt binnen de twaalf maanden zou komen te overlijden). De verschuiving van de focus van een op levensverwachting gebaseerd naar een op kwetsbaarheid gebaseerd criterium hoopt de (eerdere) toegang tot palliatieve thuiszorg te verbeteren voor al diegenen die in nood verkeren, vooral bij niet-kankerpatiënten en oudere patiënten, die nu gekenmerkt worden door ondergebruik. De nieuwe criteria worden echter op dit ogenblik nog niet in de praktijk toegepast en in toekomstig onderzoek zal moeten worden nagegaan wat de mogelijke impact ervan is op de opname van palliatieve thuiszorg.

Afgezien van de structurele of juridische belemmeringen voor het gebruik van palliatieve thuiszorg, heeft onderzoek ook aangetoond dat er een sterk stigma bestaat voor palliatieve zorg, dat zelfs na positieve ervaringen met een palliatieve zorginterventie door mantelzorgers kan aanhouden. Dit zou kunnen voortvloeien uit het feit dat palliatieve (thuis)zorg in de praktijk vaak heel laat wordt ingezet en daarom in het algemeen als terminale zorg wordt beschouwd, waardoor de semantische, culturele of emotionele associatie met dood en 'opgeven' mogelijk nog wordt versterkt. Sommige auteurs hebben voorgesteld om de terminologie te vervangen door "supportieve zorg", omdat het als een meer acceptabele term zou worden beschouwd en zou leiden tot een eerdere verwijzing, hoewel het gebruik van meerdere termen de conceptuele duidelijkheid rond de uiteindelijke doelen van de palliatieve zorgbenadering mogelijks ook zou kunnen verslechteren. Dus hoewel er een toenemend beleidsbewustzijn is om palliatieve thuiszorg te ondersteunen, kan het zijn dat de perceptie van patiënt en verzorger niet gelijk is geëvolueerd, wat duidt op een rol voor het onderwijs en veranderende percepties in de gemeenschap.

Ongelijkheid in het gebruik van palliatieve thuiszorgondersteuning

Ons onderzoek beschreven in hoofdstuk 4 laat zien dat het gebruik van palliatieve thuiszorgmaatregelen verschilt tussen verschillende groepen in de populatie. Deze bevindingen komen overeen met eerder onderzoek gericht op ongelijkheden bij de toegang tot palliatieve zorg.

Ten eerste laten onze bevindingen zien dat kankerpatiënten de meeste kans hebben om wettelijke palliatieve thuiszorgmaatregelen te gebruiken, in vergelijking met mensen die sterven aan COPD, andere soorten orgaanfalen (d.w.z. hart, nier, lever), neurodegeneratieve ziekten of van HIV/AIDS. Verschillen in het gebruik van palliatieve zorg tussen kanker en niet-kankerpatiënten (bijvoorbeeld met orgaanfalen of COPD) zijn eerder in onderzoek gevonden. Deze verschillen werden gerelateerd aan prognostische problemen, het (on)vermogen van huisartsen om behoeften aan palliatieve zorg te identificeren of hun bereidheid om een moeilijke diagnose te onthullen, evenals aan patiënten en familieleden die hun ziekte niet als levensbedreigend, maar eerder als 'een manier van leven' beschouwden.

Ten tweede bleek uit dit proefschrift dat mensen die op jongere leeftijd (18-64 jaar) stierven, vaker palliatieve thuiszorg gebruikten dan mensen die op hoge leeftijd stierven (94 jaar of ouder). De meeste eerdere onderzoeken naar patronen van toegang tot palliatieve thuiszorg rapporteerden soortgelijke bevindingen als de onze met betrekking tot de hogere kans op jongere leeftijd om palliatieve thuiszorg te gebruiken, hoewel sommige studies ook het tegenovergestelde hebben aangetoond. In hun review van 2009 suggereren Walshe en collega's vijf mogelijke hypothesen om deze verschillen te verklaren: (1) ouderen hebben verschillende behoeften of minder complexe palliatieve zorgsymptomen dan jongere personen; (2) aan de behoeften van ouderen kan voldoende worden tegemoet gekomen door generalistische zorg; (3) ouderen hebben een andere houding tegenover palliatieve zorg; (4) het kan de leeftijd van de verzorger zijn, niet de leeftijd van de patiënt, die de toegang tot of de behoefte aan palliatieve thuiszorgdiensten beïnvloedt; (5) als ouderen ouder worden na een ernstige diagnose, zal systematische vertekening worden geïntroduceerd wanneer de vóór de dood ontvangen zorg wordt onderzocht met betrekking tot de leeftijd. Hoewel er geen sluitend antwoord is om deze bevinding uit te leggen op basis van huidig onderzoek, lijken onze bevindingen erop te wijzen dat oudere patiënten feitelijk eerder geneigd zijn ondersteunende maatregelen te nemen voor thuiszorg die geen wettelijk palliatieve statuut vereisen.

Ten derde lieten onze bevindingen zien dat vrouwen iets vaker palliatieve thuiszorg zouden gebruiken dan mannen. Eerdere bevindingen met betrekking tot de associatie van gender en het gebruik van palliatieve thuiszorgondersteuning zijn twijfelachtig geweest, en veel studies hebben geen relatie gevonden; als studies echter een associatie vonden, was het bijna altijd in het voordeel van vrouwen ten opzichte van mannen, en slechts één onderzoek tot dusverre meldde dat mannen meer geneigd waren om palliatieve thuiszorg te gebruiken. Net als de hypothese met betrekking tot leeftijd, kan het zijn dat het geslacht van de zorgverlener evenveel invloed heeft als het geslacht van de patiënt op de waarschijnlijkheid van de patiënt om palliatieve thuiszorg te gebruiken.

Ten vierde hebben we geconstateerd dat er sociaaleconomische verschillen zijn die geassocieerd worden met het feit dat het meer of minder waarschijnlijk is om ondersteunende maatregelen te nemen. Ten eerste hadden mensen meer kans om ondersteunende maatregelen te nemen als ze niet alleen woonden (dat wil zeggen, getrouwd zijn, samenwonen met een partner of samenwonen bij/met een volwassen kind). De burgerlijke staat zou kunnen beschouwd worden als een proxy-variabele voor het hebben van een informele zorgverlener (mantelzorger); dit lijkt ook eerdere bevindingen te ondersteunen met betrekking tot afkerige of dubbelzinnige voorkeuren voor thuisdood bij weduwen, alleenstaanden of ouderen (aangezien zij meer kans hebben om geen (capabele) informele zorgverlener te hebben). Als zodanig kan het hebben van een mantelzorger bij de patiënt mogelijks van groot belang zijn om succesvol palliatieve thuiszorg te initiëren. Ten tweede zagen we dat mensen die in een huis wonen met een hoog comfortniveau (gebaseerd op de grootte en beschikbaarheid van faciliteiten zoals keuken en badkamer) eerder gebruik maakten van ondersteunende maatregelen. Dit lijkt deels een invloed te suggereren van sociaaleconomische positie op het gebruik van ondersteunende maatregelen voor palliatieve thuiszorg, ervan uitgaande dat fatsoenlijke huisvesting en woningbezit belangrijke voorspellers zijn van een hogere sociaaleconomische positie. Bovendien lijkt het waarschijnlijk dat een hoger thuiscomfort een factor is die het mogelijk maakt om palliatieve zorg thuis te organiseren. Ondertussen vonden we in onze studie geen significante verschillen in de kans om ondersteunende maatregelen te gebruiken naargelang opleidingsniveau of belastbaar inkomen. Dit kan worden verklaard door het feit dat de ziekteverzekering verplicht is in België, en dus blijkbaar gelijke toegang tot deze maatregelen garandeert, ongeacht de sociaaleconomische positie (m.b.t. opleiding en inkomen).

Een opmerkelijke bevinding van dit proefschrift is dat de niet-wettelijke ondersteunende beleidsmaatregelen voor palliatieve thuiszorg, zoals het forfait voor chronisch zieken, in feite meer gebruikt werden door COPD-patiënten, en evenveel door patiënten met ander orgaanfalen, in vergelijking met kankerpatiënten. Bovendien zagen we dat, in vergelijking met de wettelijke ondersteunende maatregelen, de niet-wettelijke ondersteunende maatregelen eerder door oudere patiënten (maar niet de oudste groep van 95 en ouder) werden gebruikt in plaats van jongere patiënten (jonger dan 65 jaar). De criteria voor deze niet-wettelijke ondersteunende maatregelen zijn gebaseerd op hoge zorgbehoeften en hoge kosten van eigen bijdrage ('out-of-pocket'), en niet op een geschatte levensverwachting zoals het geval is voor de wettelijke ondersteunende maatregelen. Dit zou ook onze conclusie kunnen verklaren dat de kans op het gebruik van een niet-wettelijke maatregel het grootst was bij mensen die aan COPD stierven, aangezien deze patiënten vaak vatbaar zijn voor hoge zorgbehoeften en out-of-pocket-kosten aan het levenseinde. Hoewel wettelijke palliatieve thuiszorgmaatregelen minder vaak worden gebruikt door deze patiënten, worden niet-wettelijke ondersteunende maatregelen vaker gebruikt, wat erop zou kunnen wijzen dat aan de behoeften van deze patiënten wordt voldaan zonder het gebruik van wettelijk verplichte palliatieve thuiszorgdiensten. Er is echter meer (kwalitatief) onderzoek nodig om deze hypothese te bevestigen.

Desalniettemin laten onze bevindingen ook zien dat verschillende subgroepen in de bevolking worden gekenmerkt door ondergebruikt bij beide soorten ondersteuning voor palliatieve thuiszorg (wettelijk en niet-wettelijk): de oudste ouderen, degenen die alleen woonden en mensen die stierven aan neurodegeneratieve aandoeningen. Vooral het vervullen van de palliatieve zorgbehoeften van patiënten met dementie is in eerdere studies gedocumenteerd als ondermaats, ondanks veelbelovende studies die de voordelen van palliatieve zorg in deze bevolkingsgroep aantonen.

Trends in het gebruik en de timing van initiëren van palliatieve thuiszorgondersteuning

De eerder besproken bevindingen van dit proefschrift reflecteren over een cross-sectionele momentopname van palliatieve thuiszorgondersteuning in een bepaald jaar. Het is echter belangrijk voor onderzoekers, beleidsmakers en professionele zorgverleners om inzicht te krijgen in veranderingen overheen de tijd m.b.t. wie palliatieve thuiszorgondersteuning gebruikt, in hoeverre het wordt gebruikt en wanneer het wordt gebruikt. Onze trendanalyses in het gebruik en de timing van het initiëren van palliatieve thuiszorgondersteuning tussen 2010 en 2015 hebben aangetoond dat er een lichte lineaire toename was in de opname (+3.3 procentpunt, van 31.6% naar 34.9%) in de loop van de bestudeerde zes jaar, hoewel er een stagnatie te zien was tussen 2014 en 2015 (hoofdstuk 6). Er was ook een kleine trend merkbaar in de richting van eerdere initiatie bij degenen die palliatieve thuiszorgondersteuning gebruikten, waarbij het mediane aantal dagen vóór de dood van de eerste initiatie veranderde van 40 naar 45 dagen in de bestudeerde periode.

Evolueren we naar meer gebruik van palliatieve thuiszorg?

Onze bevinding dat het gebruik van palliatieve thuiszorgondersteuning in de loop van de tijd is toegenomen, is in overeenstemming met bevindingen uit eerdere studies in België, de Verenigde Staten van Amerika, Canada, India en Singapore, hoewel geen van de de andere studies populatieniveau-gegevens hadden om deze trends voor de gehele populatie te analyseren. Bovendien zijn internationale vergelijkingen met betrekking tot trends in de tijd complex vanwege de specifieke variabiliteit van individuele landen in politieke (wetgevende), sociodemografische en economische veranderingen in de tijd die mogelijk van invloed kunnen zijn op trends in het gebruik van palliatieve thuiszorg. We zullen ons daarom hier verder beperken tot de veranderende situatie in België.

In 2004 publiceerde het RIZIV een rapport om het gebruik van palliatieve zorgondersteuning en de bijbehorende begrotingsuitgaven te evalueren tijdens de eerste periode waarin de ondersteunende maatregelen voor palliatieve thuiszorg werden geïntroduceerd (in 1999-2002). In 2017 publiceerde de Federale Evaluatiecel Palliatieve Zorg een rapport met geactualiseerde percentages voor 2010. Beide rapporten publiceerden tarieven van terugbetaalde prestaties voor de MBEs en het forfait voor palliatieve thuispatiënten, op basis van RIZIV-gegevens. Hoewel deze gegevens minder rijke informatie bevatten dan de onze, kunnen we onze bevindingen over het gebruik van deze ondersteunende maatregelen uit de jaren 2010-2015 vergelijken met die uit andere perioden.

In 1999 werden 2430 prestaties voor een interventie van een MBE vergoed, wat de overheidsuitgaven voor de financiering van de teams op 4.3 miljoen euro bracht. Tegen 2010 was de overheidsfinanciering uitgebreid tot 10.5 miljoen euro (+141%) voor de terugbetaling van 7151 prestaties (+194%). Uit onze bevindingen blijkt dat het gebruik van deze equipes verder is toegenomen van 2010 tot 2015, zij het niet in hetzelfde tempo als dat van de periode 1999-2010. Een mogelijke verklaring voor deze bevinding is dat de structurele en financiële capaciteit om thuis palliatieve zorg te organiseren in de eerste jaren van het bestaan van deze maatregelen laag was, waarna de capaciteit werd uitgebreid door een positieve evaluatie. De laatste budgettaire expansie voor de MBEs werd echter geïmplementeerd in de periode 2010-2012. Het RIZIV-rapport uit 2004 beschrijft ook patiëntkenmerken van degenen die werden bediend door de equipes, waardoor veranderingen in de loop van de tijd konden worden vergeleken met degenen die van deze ondersteuning gebruik maken. In 2002 was meer dan 74% van de mensen die door deze equipes werden bediend ouder dan 60 jaar, 17% was alleenstaand en 80% had een diagnose van kanker. Onze bevindingen in hoofdstuk 6 tonen dat dit in 2015 evolueerde naar 86% van de mensen die ouder waren dan 60 jaar (+12 p.p.), 18% die alleen woonden (+1 p.p.) en 69% met een diagnose van kanker (-11 p.p.). Deze bevindingen kunnen mogelijk worden toegeschreven aan een veranderende samenstelling van de populatie, als een gevolg van de vergrijzing (d.w.z. naar verhouding sterven meer mensen aan 'ouderdomsziekten' zoals neurodegeneratieve ziekten of chronisch orgaanfalen).

Het RIZIV rapporteerde het gebruik van het forfait voor palliatieve thuispatiënten in 2001, toen 11,534 forfait werden vergoed (6964 mensen ontvingen het forfait eenmalig, 2285 mensen ontvingen er twee). Onze bevindingen uit hoofdstuk 6 laten zien dat 15,481 (+34%) mensen die in 2015 stierven het forfait ontvingen (9078 ontving het één keer (+30%), 6403 had er twee (+180%). Dit toont aan dat, hoewel het gebruik van het forfait in het algemeen toenam, vooral het aantal mensen dat de uitkering tweemaal ontving is toegenomen. Gegevens ontbreken om te onderzoeken hoe dit kan worden verklaard, maar het kan te maken hebben met het feit dat artsen zich nu meer bewust zijn van de mogelijkheid voor patiënten om de uitkering twee keer te kunnen ontvangen, of omdat het nu sneller wordt gebruikt, waardoor patiënten het verzoek tot een tweede forfait kunnen indienen (dit kan ten minste 30 dagen na ontvangst van de eerste uitkering worden gedaan).

Evolueren we naar een snellere inschakeling van palliatieve thuiszorg?

Voor de helft van alle mensen die in 2015 palliatieve thuiszorgondersteuning gebruikten, werd deze maatregel ingeschakeld in de laatste anderhalve maand voor de dood; voor 14% vond de initiatie plaats in de laatste week van het leven (Hoofdstuk 6).

In 2010 toonde een eerste - en zeer invloedrijke - gerandomiseerde trialstudie door Temel en collega's aan dat vroege palliatieve zorg leidde tot significante verbeteringen in zowel de kwaliteit van leven als stemming bij patiënten met gemetastaseerde niet-kleincellige longkanker. In een vergelijkbare trialstudie uit 2015 vergeleken Bakitas en collega's de impact van vroeg (binnen 30-60 dagen na kennis te hebben genomen van een geavanceerde kankerdiagnose) versus vertraagde (3 maanden later) initiatie van palliatieve zorg. Ook zij vonden positieve uitkomsten met betrekking tot overleving, stemming en zorglast (*'burden'*). Andere studies hebben vergelijkbare veelbelovende resultaten getoond in verschillende settings en patiëntenpopulaties. Dit geheel van literatuur leidde tot een groeiende erkenning dat een palliatieve zorgbenadering vroeg zou moeten worden gestart en niet alleen in de terminale fase voor alle patiënten met levensbeperkende ziekten.

In vergelijking met de hierboven beschreven studies lijken onze bevindingen erop te wijzen dat palliatieve thuiszorg niet 'vroeg' wordt geïnitieerd in de algemene Belgische bevolking, ondanks een kleine trend naar eerdere initiatie. In de onderzoeken van Temel en Bakitas bijvoorbeeld was de mediane overlevingstijd na de interventie respectievelijk 11.6 en 18.3 maanden; onze bevindingen over de populatie met palliatieve thuiszorg in België lieten een mediane overleving van 1.5 maand zien tussen de eerste initiatie en het tijdstip van overlijden (Hoofdstuk 6). Het is niet onwaarschijnlijk dat de experimentele omstandigheden waarin de voornoemde studies palliatieve zorg bewust in het begin van het ziektetraject hebben geïnitieerd, geen realistisch tijdsbestek zijn dat in de algemene bevolking kan worden bereikt. Bovendien concentreerden de trialstudies zich alleen op gespecialiseerde palliatieve zorg in het ziekenhuis binnen een populatie met gevorderde kanker.

Studies die de timing van palliatieve zorg in de thuissetting bestuderen zijn echter zeldzaam. Eén studie gebruikte observationele cohortgegevens van overledenen die palliatieve thuiszorg ontvingen in Ontario, Canada, en meldde een mediane tijd tussen eerste thuiszorgopname en overlijden van 11 weken (dwz ~77 dagen, versus 45 dagen in onze studie). Uit een Australisch onderzoek bleek dat, in een populatie van personen overleden aan kanker die palliatieve thuiszorg gebruikten, 64% dit in de laatste drie maanden van hun leven in gang had gezet. Een andere studie uit Australië meldde een mediane tijd tussen doorverwijzing naar gespecialiseerde palliatieve zorgdiensten (elke instelling, d.w.z. thuis, ziekenhuis, verpleeghuis, gemeenschap) en overlijden van 48 dagen.

Het blijft moeilijk om onze bevindingen te vergelijken met die van eerdere onderzoeken, en de verschillen in de bevindingen zijn hoogstwaarschijnlijk te wijten aan verschillen in de kwaliteit van gegevens (bv. door selectiebias in het selecteren van de populatie), de bestudeerde cohorten (bv. alleen gevorderde kankerpatiënten) of de onderzochte interventie (bv. focus op gespecialiseerde diensten).

De impact van palliatieve thuiszorg op de kwaliteit en kosten van levenseindezorg

Onze bevindingen wezen op een positief effect van het gebruik van palliatieve thuiszorg op het aantal eerstelijnszorgcontacten en op de kans om thuis te overlijden, terwijl het de kansen verlaagt om naar het ziekenhuis, een dienst intensieve zorgen of spoedafdeling te gaan, of om diagnostische tests, bloedtransfusie of chirurgie te ondergaan in de laatste twee weken van het leven (Hoofdstuk 7). Ondertussen waren de gemiddelde totale kosten voor gezondheidszorg in de laatste twee weken van het leven aanzienlijk lager onder degenen die palliatieve thuiszorgondersteuning gebruikten (gemiddeld verschil van 1636 euro). Eerdere studies uit Canada, Engeland en Italië met vergelijkbare retrospectieve cohortontwerpen als die in dit proefschrift, hebben consequent vergelijkbare uitkomsten gevonden met betrekking tot verminderde kansen op ziekenhuisgebruik aan het levenseinde en toegenomen kans op thuisoverlijden.

Onze bevindingen uit hoofdstuk 7, evenals eerdere studies in andere landen, tonen duidelijk aan dat het gebruik van palliatieve thuiszorg een kostenverlagend effect heeft vanuit het oogpunt van de zorgverzekeraar. De lagere totale kosten van zorg in de laatste twee weken van het leven kunnen grotendeels worden verklaard vanwege het verminderde gebruik van intramurale (ziekenhuis) zorg bij het gebruik van palliatieve thuiszorgondersteuning. Hoewel onze bevindingen niet suggereren dat er ongelijkheid bestaat in het gebruik van palliatieve thuiszorg volgens opleidingsniveau of inkomensniveau, moeten beleidsmakers zich ervan bewust zijn dat onze bevindingen geen informatie bevatten over de financiële impact van het verstrekken van thuiszorg vanuit het oogpunt van de patiënt of informele zorgverlener. Eerder onderzoek heeft benadrukt dat patiënten en mantelzorgers vaak financiële problemen hebben en stress ervaren door het verlenen van thuiszorg. Daarom moet beleid altijd afgestemd zijn op het ondersteunen van zowel patiënten als hun zorgverleners.

UITDAGINGEN EN AANBEVELINGEN VOOR DE PRAKTIJK EN HET BELEID

Onze bevindingen suggereren dat het gebruik van palliatieve thuiszorg gunstig is voor het verbeteren van de kwaliteit van zorg en het verlagen van de totale kosten van zorg aan het einde van het leven. De aandacht voor palliatieve thuiszorg neemt toe in beleid en onderzoek, maar verdere ontwikkelingen zijn nodig, zowel op beleids- als op praktijkniveau, om het gebruik van palliatieve thuiszorgondersteuning te vergroten bij personen die op dit moment hun noden onvervuld zien.

Aanbevelingen voor het beleid

Aanbeveling 1: Verbeteren van (tijdige) toegang tot palliatieve thuiszorgondersteuning

Onze bevindingen in hoofdstuk 4 en 6 laten zien dat het gebruik van palliatieve thuiszorgondersteunende maatregelen laag is, ondanks overtuigend bewijs over de positieve impact van deze ondersteunende maatregelen op de kwaliteit van zorg aan het levenseinde (hoofdstuk 7) en de toegenomen aandacht voor palliatieve thuiszorg uit nationaal beleid. Bovendien vond dit proefschrift slechts een bescheiden trend in de richting van meer of eerder initiëren van palliatieve thuiszorgondersteuning, en bepaalde groepen in de bevolking blijven achter met betrekking tot zowel opname als timing van initiatie. Deze bevinding moet beleidsmakers stimuleren om meer inspanningen te doen om de (tijdige) beschikbaarheid van palliatieve thuiszorg te verbeteren. In het bijzonder moet de toegang worden verbeterd voor ouderen met een levensbedreigende ziekte, patiënten met orgaanfalen of neurodegeneratieve ziekten en mensen met een levensbedreigende ziekte die alleen wonen.

Eerder onderzochte barrières voor het gebruik van palliatieve thuiszorgondersteuning zijn het op prognose gebaseerde criterium met betrekking tot het palliatieve statuut, een gebrek aan bewustzijn van bestaande palliatieve thuiszorgmaatregelen bij huisartsen en het bredere publiek, en een gebrek aan erkenning van palliatieve zorgbehoeften bij huisartsen en patiënten in specifieke ziektegroepen (bijv. COPD-patiënten). Mogelijke strategieën om een betere toegang tot palliatieve thuiszorg te krijgen bestaan erin door palliatieve zorg op te nemen in ander nationaal en internationaal beleid (bijvoorbeeld over ouder worden, dementie, enz.), de wettelijke criteria te veranderen van prognostisch naar een behoefte-gebaseerd model, palliatieve zorg te integreren in gezondheidsgerelateerde onderwijscurricula (bijv. artsen, verpleegkundigen, maatschappelijk werkers), duidelijke informatie bieden over de doelstellingen van palliatieve zorg en beschikbare ondersteunende maatregelen op een gecentraliseerde manier aanbieden (bijv. fysiek: in de ziekenfondsen of huisartsenpraktijken; digitaal: op een webpagina en/of smartphone-app).

Onze bevindingen tonen bovendien een discrepantie aan in het gebruik van palliatieve thuiszorgondersteuning tussen de drie gewesten in België: mensen die wonen in het Brusselse Hoofdstedelijke gewest of in het Waalse gewest maakten minder gebruik van deze maatregelen dan mensen die in het Vlaamse gewest wonen. Dit zou verband kunnen houden met verschillen in ondersteunend beleid voor mantelzorgers, zoals we in hoofdstuk 3 hebben vastgesteld. Eerder onderzoek heeft aangetoond dat de aanwezigheid van een informele zorgverlener bij de patiënt een belangrijke factor is voor een succesvolle integratie van palliatieve zorg thuis. In vergelijking met het Vlaamse gewest, waar naast de nationaal beschikbare maatregelen ter ondersteuning van mantelzorgers van patiënten met palliatieve zorg aan huis ook lokale en regionale beleidsmaatregelen bestaan (bijv. 'Vlaamse aanmoedigingspremie', 'Gemeentelijke mantelzorgpremie'), ontbreken dergelijke aanvullende beleidsmaatregelen in de andere gewestregio's. Daarom zouden beleidsmakers in de regionale regeringen van Wallonië en de Brusselse hoofdstedelijke regio moeten investeren in het aanbieden van deze aanvullende ondersteunende beleidsmaatregelen voor mantelzorgers.

Aanbeveling 2: De bredere gemeenschap betrekken

De beleidsmaatregelen ter ondersteuning van palliatieve thuiszorg die het onderwerp van dit proefschrift waren, zijn voornamelijk op dienstverlening gebaseerd of financieel ondersteunend, gericht op patiënten of mantelzorgers. Beleidsmakers moeten echter onderzoeken of nieuwe modellen van op de gemeenschap gebaseerde palliatieve zorg complementair kunnen zijn aan, maar niet worden vervangen door, bestaande ondersteuningsmaatregelen die gericht zijn op gespecialiseerde diensten (bijv. MBEs), financiële ondersteuning voor patiënten (bijv. forfait voor palliatieve thuispatiënten) of ondersteuning voor mantelzorgers (bijv. palliatief zorgverlof). Nieuwe palliatieve zorgmodellen die zich richten op het betrekken van hele gemeenschappen in plaats van nieuwe gezondheidszorgdiensten en specialisten te creëren kunnen mogelijks bijdragen aan het verbeteren van het vermogen in de samenleving om met de dood, sterven en verlies om te kunnen gaan. Beleidsmakers kunnen belangrijke partners zijn in dergelijke innovatieve modellen om de palliatieve zorg in de gemeenschap te verbeteren door verder te kijken dan het traditionele beleid dat financieel of op dienstverlening is gebaseerd, bijvoorbeeld door samen te werken met architecten en projectontwikkelaars om hun stad opnieuw vorm te geven. Andere voorbeelden waarbij beleidsmakers een leidende rol kunnen spelen bij het verbeteren van de culturele acceptatie van zorgzaamheid, sterven en ziekte in de samenleving, zijn de financiële of structurele ondersteuning voor non-profitorganisaties, bijvoorbeeld voor het houden van jaarlijkse festiviteiten, thematische museumgalerijen, debatevenementen, enzovoort.

Aanbeveling 3: Verhogen van de aandacht voor palliatieve thuiszorgondersteuning

Toekomstig beleid of interventies zouden gericht moeten zijn op het verbeteren van kennis over en toegang tot palliatieve thuiszorgondersteuning bij het grotere publiek. Dit impliceert dat de bestaande ondersteunende maatregelen bekend moeten worden gemaakt aan mensen in alle lagen van de samenleving. Mogelijk waardevolle kanalen om deze informatie aan te bieden zijn huisartsen, de nationale ziekenfondsen, gemeenten (bijvoorbeeld online). Educatieve programma's in het basis en secundair onderwijs kunnen het bewustzijn vergroten over de maatschappelijke veranderingen met betrekking tot veroudering en de toenemende zorgbehoeften. Werkgevers moeten worden geïnformeerd over de wettelijke plichten van het hebben van een personeelsbeleid dat de behoeften respecteert van werknemers die (willen) mantelzorg verlenen, en zowel publieke als private werkplekken moeten overtuigd zijn van de voordelen van het creëren van een omgeving waar dood, sterven en ziekte openlijk kunnen worden besproken. Ten slotte zouden publiek gefinancierde campagnes, filmdocumentaires of fictiereeksen op de nationale televisie kunnen worden gebruikt om een realistisch en respectvol discours over zorg, palliatieve zorg en dood en sterven in de moderne samenleving over te brengen aan een breed publiek om negatieve percepties te veranderen.

Beleidsmakers en zorgprofessionals moeten zich er echter ook van bewust zijn dat niet alle patiënten en zorgverleners thuis palliatieve zorg willen ontvangen of verlenen. Bovendien zullen maatschappelijke veranderingen, zoals een laag huwelijkscijfer, het toenemende aantal eenpersoonshuishoudens en een stijgende levensverwachting waarschijnlijk leiden tot een toekomstig toenemend gebrek aan beschikbare mantelzorgers. Terwijl het bewijsmateriaal over de impact van het verstrekken van informele zorg op fysiek en psychologisch welzijn vaak tegenstrijdig is, lijkt er een algemene consensus te bestaan in onderzoek dat mantelzorgers hun eigen specifieke behoeften hebben die de komende jaren zullen toenemen, wat aangeeft dat verborgen kosten gerelateerd aan de fysieke en psychologische ondersteuning voor deze mantelzorgers aanzienlijk zijn. Als zodanig moet het beleid gaan onderzoeken hoe dit verwachte tekort kan worden gecompenseerd.

Aanbevelingen voor de praktijk

Onze bevindingen suggereren een mogelijkheid voor eerstelijnszorgverstrekkers om het bewustzijn van beschikbare ondersteunende maatregelen voor palliatieve thuiszorg te vergroten en als zodanig de toegankelijkheid van deze maatregelen te verbeteren voor mensen met onvervulde behoeften, door actiever te communiceren met patiënten en familieleden over hun zorgbehoeften en verwachtingen. Extra aandacht moet worden gegeven door huisartsen en andere primaire zorgverleners (bv. thuisverpleegkundigen, maatschappelijk werkers) aan specifieke groepen in de bevolking die momenteel niet of te weinig worden bereikt door palliatieve thuiszorg, zoals mensen met niet-kanker aandoeningen, ouderen, en mensen die alleen wonen. Om zorgverleners te ondersteunen bij deze moeilijke taak, moeten basisopleidingen palliatieve zorg worden geïmplementeerd in het onderwijscurriculum van alle gezondheidsgerelateerde beroepen, met onderwerpen als vroegtijdige zorgplanning en andere communicatieve vaardigheden.

Curriculum vitae and list of publications

Curriculum vitae

Arno Maetens was born July 25th 1992. He graduated in 2014 as a Master of Science in Sociology at Ghent University. In 2015 he joined the End-of-Life Care Research Group at the VUB, where he worked as a doctoral researcher on the interuniversity IWT-SBO project INTEGRATE. He was supervised by Prof. dr. Joachim Cohen, Prof. dr. Luc Deliens, and dr. Kim Beernaert. Next to his research work he was involved in the European Association for Palliative Care (EAPC) Reference Group on Public Health and Palliative Care as secretary, and collaborated as researcher in an international working group on the use of big data in end-of-life care research. He presented his research work at several national and international conferences and was awarded with the Best Article award from the Integrate research project and a Best Abstract award at the 2017 EAPC Madrid conference.

List of publications

Articles in international peer-reviewed journals:

Maetens A., Beernaert K., Deliens L., Gielen B. & Cohen J. (2019). Who finds the road to palliative home care support? A nationwide analysis on the use of supportive measures for palliative home care using linked administrative databases. Plos One. DOI: 10.1371/journal.pone.0213731

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Maetens, A., Beernaert, K., Deliens, L., Aubry, R., Radbruch, L., & Cohen, J. (2017). Policy Measures to Support Palliative Care at Home: A Cross-Country Case Comparison in Three European Countries. Journal of Pain and Symptom Management, 54(4), 523-529. DOI: 10.1016/j.jpainsymman.2017.07.022

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Other publications and chapters in books

Maetens, A., Cohen, J., & Harding, R. (2018). A Public Health Approach to Integrate Palliative Care into a Country's Health-Care System: Guidance as Provided by the WHO. In Textbook of Palliative Care 2018 (pp. 1-20). Springer. DOI: 10.1007/978-3-319-31738-0_122-1

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Are we evolving towards more and earlier use of palliative home care? Presentation given at the 1st International seminar of EAPC RN and the EAPC reference group on Public Health and Palliative Care, Brussels (Belgium), October 2018.

Palliatieve thuiszorg in België: De opname en impact van ondersteunende beleidsmaatregelen onderzocht. Presentation given at the INTEGRATE congress 'Geen palliatieve zorg zonder vrijwilligers en mantelzorgers?', Brussels (Belgium), October 2018.

Palliative home care support improves quality of care and decreases costs at the end of life. Presentation given at the 22nd International Congress on Palliative Care, Montréal (Canada), October 2018.

Het gebruik van beleidsmaatregelen ter ondersteuning van palliatieve zorg in de thuisomgeving. Presentation given at Dag van de Sociologie, Brussels (Belgium), June 2017.

Supportive policies for palliative home care. Presentation given at the 15th World Congress of the European Association for Palliative Care, Madrid (Spain), May 2017.

Appendices

Appendix to Chapter 2: Using linked administrative and disease-specific databases to study end-of-life care on a population level

Table 1: Complete list of variables in the linked dataset (IMA – Statistics Belgium – BCR)

Flag	Variable	Description
	Statistics Belgium: Death certificates database	
	Immediate cause of death	The primary disease/cause prior to death, + up to 3 underlying causes.
	Associated causes of death	Up to 3 factors that indirectly contributed to death.
	Statistics Belgium: data based on demographic datasets	
	natgr	Nationality-group: indicates to which of 16 most common nationalities in Belgium someone belongs. Less common nationalities are aggregated. (e.g. EU-other, Europe-other, other)
	liprohht	LIPRO-household type: e.g. single parent, married with/without children, …
	Statistics Belgium : Socio-economic survey 2001 and census 2011	
	q9a/EDU	Highest level of education.
	q16a_m/SIE	Main profession.
	Statistics Belgium: Composite variables socio-economic survey 2001	
	comf	Housing comfort level, based on number of types of different rooms (e.g. kitchen, bathroom…) and heating system.
	Statistics Belgium: IPCAL dataset	
	Net income	Net income in the year prior to death. Provided relative to the entire population, not in absolute numbers.
	IMA: Population database	
ANON_BASE	Recoded PP0010 and SS00010	Unique identification of the rightful claimant (coded)
	PP0015	Age (based on year of birth)
	AGE05_CAT	Age of the rightful claimant in categories of 5 years, calculated on December 31 of the reference year.
	PP0020	Sex
Care region (based on NIS code)	Recoded PP0025	Care region on the hospital level (in Flanders)
PROVINCE/DISTRICT	Based on PP0025	Official place of residence at time of death
URB_CAT	Based on PP0025	Degree of urbanisation of the place of residence
	PP0030	Social status (e.g. working, retired, …)
	PP0040 (A, B, C)	Year of death
	PP1010	Indicates whether the claimant received enhanced reimbursement.
	PP2001	Indicates whether the claimant received a forfeit class B nursing care.
	PP2002	Indicates whether the claimant received a forfeit class C for nursing care.
	PP2003	Indicates whether the claimant received a forfeit class E for physiotherapy.
	PP2005	Indicates whether the claimant received the allowance for the integration of disabled persons (category III, IV, V).
	PP2006	Indicates whether the claimant received the allowance for assistance to the elderly (category III, IV, V).
	PP2007	Indicates whether the claimant received a payment for assistance of third person carers.
	PP2008	Indicates whether the claimant received an increased allowance for help from third parties. (based on degree of disability)
	PP2009	Indicates whether the claimant received a lump sum benefit for 'assistance to others'.

	PP2010	Indicates whether the claimant was hospitalised at least 120 days during the last 2 years.
	PP2011	Indicates whether the claimant was hospitalised at least 6 times during the last 2 years.
	PP3004	Reimbursement category of the family.
	PP3005	Reimbursement category of the individual.
	PP3006	Date of the first claim entitled for maximum billing (provided in days prior to death).
	PP3011	Indicates whether the claimant received special allowances for disabled persons.
	PP3014	Indicates whether the claimant was entitled for maximum billing for the chronically diseased.
	PP4002	Number of days of unemployment due to disability.
	PP4003	Number of days of disability.
	PP4004	Evaluation of degree of functional status
CHRONICAL_YN		Indicates whether the claimant had at least one chronic illness in the last year and/or was entitled to an allowance for disabled persons.
IC_AVAIL_SA11 - IC_AVAIL_SA26		Estimation of the availability of family and informal caregivers, based on age and social status of family members.
IMA: Medical claims database		
	SS00015	Relative starting date of provision
	SS00020	Nomenclature code
	SS00050	Number of cases of provision
	SS00055	Number of days of provision
	SS00060	Amount of reimbursement
	SS00065B	Caregivers' qualifications
	SS00070B	Prescribers' qualifications
	SS00075	Identification of institution of the caregiver or prescriber (coded, not nominative)
	SS00080	Department code of the institution where care was provided
	SS00085	Place of care delivery (coded)
	SS00105	Number of institution which receives the payment
	SS00110	Date of hospitalisation
	SS00115	Date of hospital discharge
NEW_YN		Indication whether provided care is performed at weekends or at night
STAY_NR		Date of hospital admission
STAY_CAT		Type of hospital admission
ADMISSION, ADMISSION_YYYY		The first day that a stay is charged at a residence
DISCHARGE, DISCHARGE_YYYY		The last day that a stay is charged at a residence
LOS		Length of stay
LOS_YYYY		The calculated length of stay in a year
	SS00120	Invoice type
	SS00125	Date of last performance
	SS00130	Invoicing performance code
	SS00135	Pharmaceutical product code
	SS00140	Specification code of provision of care
	SS00150	Billed nomenclature code
	SS00155	Prescription date
	SS00160	Patient co-payment cost
	SS00165	Supplement
	SS00170	Code implant
	SS00175	Third party payer
THIRD_YN		Indicates whether a third party payer was involved
HOSP_ADM	SS00075, SS00085, SS00105	Identification hospital admission
HOSP_TRANS	SS00075, SS00085, SS00135	Identification hospital transfer(s)

IMA: Pharmanet database		
	SS00015	Delivery date
	SS00020	Medication reimbursement category
	SS00050	Drug quantity
	SS00060	National Health and disability insurance contribution 1
	SS00070B	Profession type of prescriber
	SS00075	Type of long-term care
	SS00135	Product number
	SS00155	Date of prescription (in days before death)
	SS00160	Out-of-pocket cost
	SS00165	Reduced repayment amount / Contribution of pharmacists
	SS00180	Reduced insurance contribution
	SS00195	National health and disability insurance contribution 2
	SS00200	Fee coding
	SS00210	Supplement
PHARMACIST_C, PHARMACIST_CAT		Pharmacist C is the coded unique identification number of the supplier of the performance. Pharmacist_cat indicates the type of the supplier of the performance
UNIT		Indicates the unit to which the quantity is specified
procedure_AH_cat, procedure_group, procedure_detail, procedure_cat		Formats into categories, sub-categories and cost of the nomenclature code as they are determined by the actuary of the National Health Care insurer
Prescriber_c, prescriber_cat		Prescriber C is the coded unique identification of the prescriber's performance. PRESCRIBER_CAT indicates the type of the prescriber
atc_prod_l		The different levels of the ATC code
BCR – Cancer Registry		
	inc_death_mm	Number of complete months between incidence date and date of death
	ICD10_new	Tumour localisation (ICD-10 code)

Appendix to Chapter 3: Policy measures to support palliative care at home: a cross-country case comparison in three European countries

Table 1: Allowances and cost-reductions to support patients in a palliative home-care setting in Belgium, France and Germany

	Belgium	France	Germany
Changes in out-of-pocket costs	Abolition of out-of-pocket costs: - Palliative patients who have 'palliative status'* are exempt from paying out-of-pocket costs for GP, physiotherapist or home nurse visits. - Palliative patients other than those with 'palliative status' in cases where the GP informs the advising practitioner of the insurance institution	/	Reduction of out-of-pocket costs: - Out-of-pocket costs are reduced from 2% to 1% (as share of annual household income) for patients suffering from severe and chronic diseases - Requirements: a) treated at least once per quarter year for at least one year; b) nursing care level 2 or 3 granted, or disability index of at least 60%, or need for continuous medical care. This means that palliative care patients can usually apply for the reduction.

Allowances	*'Palliatief zorgforfait'* - One-off allowance of 647,16€ (as of 2016); re-obtainable once after 1 month - To complement for any non-reimbursed costs related to palliative home care *'Vlaamse Zorgverzekering'* - Monthly flat fee of 130€ (not confined in time) - For non-medical costs of care and home care - Region- restricted (only in Flanders)	*'Fonds National d'Action Sanitaire et Sociale de Soins Palliatifs FNASS'* - Serves to fund services to support the maintenance of a seriously ill person - The amount of financial assistance is subject to an income ceiling (€ 3000 / renewable once) - This allowance can be added to other supportive allowances for older people at home (e.g. APA) *'Allocation personnalisée d'autonomie (APA) pour les personnes âgées'* - For people aged 60 and older living at home or in an independent residence - Monthly amount is subject to the degree of dependency, ranging between € 663 and € 1700 - These ceilings may be raised - Allowance used for: paying a home help; aiding transportation or meal delivery; paying for technical aids and housing adaptation measures; use of respite devices: temporary home (residential or foster care), home relay, etc.	*'Gesetzliche Pflegeversicherung'* - Patients receive a sum of money meant as a compensation for the caregiver - Up to 728€/month (three categories)

Allowances		*‘Allocation aux adultes handicapées (AAH)’* - A financial aid that ensures a minimum income for disabled adults - This aid is granted subject to compliance with four criteria: disability, age, nationality and resources - The maximum amount of AAH is € 808.46 per month *‘Allocation compensatrice tierce personne (ACTP)’* - Allowance paid to people with a disability rate of at least 80% and who need to resort to using a third party to perform the essential activities of life, or have additional costs due to the exercise of a professional activity - The person must be aged over 20 and under 60 years - The person must have means below a defined ceiling, which corresponds to that established for the granting of the allowance for disabled adults (AAH), plus the amount of the compensatory allowance paid to the person	
Other	/	/	Disability certificate - Cancer patients can get a disability certificate following their diagnosis for a duration of 5 years. This offers several benefits (e.g. protection against dismissal from work, tax reductions)

Table 2: Allowances and cost-reductions to support informal caregivers in a palliative home-care setting in Belgium, France and Germany

	Belgium	France	Germany
National allowances	Allowances for working informal carers - Allowance associated with the loss of income of working informal carers (applicable in palliative care leave or care leave for medical assistance) - Amount of the fee is dependent on the caregiver's working situation, age and work sector; max. gross fee of €786,76/month	Daily support allowance - Allowance for caregivers of home patients with a terminal or incurable disease - Fixed allowance of 55,15€ gross per day, for a max. period of 21 days - If the beneficiary has reduced working hours the allowance will be paid for a max. period of 42 days, by half of the usual allowance (i.e. 27,57€ gross) - Possibility to split in time	/
Regional allowances	*'Vlaamse aanmoedigingspremie'* - Caregivers employed in Flanders who take a career break can complement the federal benefits for working informal carers - Monthly gross allowance of between 49,58€ and 123,95€; max. for a time period of 2 years *'Gemeentelijke mantelzorgpremie' & 'Provinciale mantelzorgpremie'* - Extra allowance offered by most municipalities and provinces in Flanders - Average 30€/month (as of 2012); in 2008 this was avg. 37€/month - 82% of 308 municipalities in Flanders offer the premium - Conditions depend on municipality and province	*'Prestation Ville de Paris'* - Additional support allowance for Parisian employees who leave their work to attend to an ill relative - This allowance can be combined with other financial support allowances (e.g. AJAP) and is not subject to income tax - Max. amount of 610€/month, not exceeding the loss of revenue related to cessation of the professional activity - Max. period of 3 months; max. period extends to 12 months in case of a terminally ill minor child	/

Table 3: In-kind services to support patients and informal caregivers in a palliative home-care setting in Belgium, France and Germany

	Belgium	France	Germany
Supportive home care	*‘Multidisciplinaire begeleidingsequipe’* - Multidisciplinary expertise focus to support the GPs, health professionals, counsellors, informal carers and volunteers of palliative home care patients - Support and advise all caregivers involved in home care - Free of charge	*‘Services de soins infirmiers a Domicile (SSIAD)’* - SSIAD delivers daily support care such as personal hygiene and eating; supporting informal caregivers; coordination with other professional actors - Targeted to dependant individuals of 60 years and older - Prescribed home nursing care is fully covered by the public health insurance system - Under the Plan Alzheimer, since 2009, "Mobile Teams Alzheimer's" are installed to support people with Alzheimer's disease or related diseases.	*‘Spezialisierte ambulante Palliativversorgung’* - Free of charge - Regional differences; in most regions provided by multidisciplinary teams consisting of nurses and physicians, case managers with palliative care training and with options to consult additional expertise (e.g. spiritual caregiver) - Most SAPV contracts describe 4 levels of service: consultation (once), coordination support, partial service, or full service - After discharge from hospital treating physicians can prescribe SAPV for up to 7 days

Day care and respite	*'Palliatieve dagzorgcentra'* - Temporary specialised care that can be difficult to provide in the home environment - Aimed specifically for the palliative home patient - Different from day care centres for care-dependent older persons	/		*'Kurzzeitpflege'* - Patients may be admitted to a nursing home if caregivers need a break or are unable to care, or following inpatient treatment in a hospital, for a restricted period of time. - Sickness funds will pay up to 1612€ for the nursing costs, but costs for accommodation or food have to be paid by patient or family. - Maximum 4 weeks per calendar year, may be extended up to 8 weeks if prevention care (see below) is not used to the limit. *'Verhinderungspflege'* - Sickness funds pay for replacement if the caregiver is temporarily unable to provide care (up to 1612€) - If caregiver is related to patient (up to 2nd degree) or lives in the same household only half of the payment can be claimed - Max. 6 weeks/calendar year - Only if caregiver has provided informal home care for at least 6 months before the claim
Information				Sickness funds duty to inform - Since December 2015, according to the Hospiz-und Palliativgesetz legislation, sickness funds have to inform patients (or their caregivers) about palliative care and hospice options. It is not yet clear how sickness funds will comply with this regulation

Table 4: Employment and workplace-related policy measures to support informal caregivers in a palliative home-care setting in Belgium, France and Germany

	Belgium	**France**	**Germany**
Paid care leave	*'Palliatief Zorgverlof'* - Full-time, part-time of 1/5th reduced time career break. - Specifically for providing palliative home care - Max. 2 months - Amount of up to €802,52 gross per month (as of 2016) *'Loopbaanonderbreking in het kader van medische bijstand'* - Designed to care for a seriously ill family member (up to 2nd degree) - Not specifically for palliative care - For a full-time career break, the cumulative periods can reach up to 12 months, with partial disruption up to 24 months - Amount of up to €802,52 gross per month	/	/
Unpaid care leave	/	*'Congé de solidarité familiale pour accompagner un proche en fin de vie'* - Max. 3 months; renewable once - Unpaid leave - Beneficiary of the family care leave can receive the daily allowance for accompanying a person at the end of life (*AJAP*)	*'Gesetz über die Familienpflegezeit'* - Reduced worktime to 15h/week for care to a close family member (up to 24 months) - Not limited to palliative care - Half of the difference in salary is paid; it has to be paid back after care leave (as an ongoing salary reduction) within 48 months *'Pflegezeitgesetz'* - Up to 10 days to organize needs-based care for a close relative - Not entitled to receive pay during this period - Can be combined with family care leave

Appendix to Chapter 4: Who finds the road to palliative home care support? A nationwide analysis on the use of supportive measures for palliative home care using linked administrative databases

Table 1: Uptake of policy measures to support palliative care at home by characteristics of the palliative subset (row %) (n=38,657)

	Statutory palliative home care policy measures					Non-statutory palliative home care policy measures				
	Any statutory measure	Allowance for palliative home patients	Multi-disciplinary support team	Nursing care for palliative home patients	Physiotherapy for palliative home patients	Any non-statutory measure	Allowance for chronic patients	Nursing care at home	Physiotherapy at home	Any measure
Number	*12,806*	*11,736*	*6,592*	*9,165*	*2,724*	*24,050*	*14,843*	*13,379*	*9,823*	*26,941*
Age										
18-64	42.6	40.4	25.3	29.5	9.4	61.1	49.8	20.2	16.8	71.3
65-74	38.7	36.2	20.8	27.8	8.6	63.6	47.0	28.3	22.0	72.2
75-84	32.5	29.7	15.8	23.7	6.8	63.5	38.2	37.8	28.8	70.9
85-94	23.7	20.6	10.7	17.0	4.7	60.8	25.3	45.1	30.1	65.8
95+	18.3	15.4	5.8	14.5	4.6	55.2	16.0	46.9	24.7	58.8
Gender										
Male	34.2	31.9	17.4	24.4	6.9	60.8	38.7	32.9	23.5	69.1
Female	31.8	28.5	16.6	22.9	7.3	64.0	38.1	36.8	27.8	70.5
Cause of death										
Neoplasms	42.7	39.9	22.9	30.8	8.7	62.3	40.5	31.0	21.7	72.6
Other organ failure	13.1	11.2	4.8	9.0	2.3	61.7	30.5	42.9	31.4	63.5
COPD	11.4	9.8	4.2	8.0	3.9	65.6	43.0	35.5	38.8	66.7
Neurodegenerative disease	17.7	13.1	7.0	11.9	5.2	59.8	30.9	46.3	29.7	62.6
HIV/aids	5.9	5.9	5.9	2.9	0.0	32.4	29.4	8.8	0.0	32.4
Nationality										
Belgian	33.3	30.5	17.1	23.8	7.0	62.3	38.4	34.7	25.2	69.8
Non-Belgian	30.1	28.0	15.7	21.8	8.8	60.9	38.1	32.3	29.1	67.6
Household type										
Single person household	24.1	20.9	12.1	16.4	4.8	56.0	31.0	30.9	23.9	62.2

Married	39.5	36.9	20.8	28.7	8.7	66.5	43.7	36.8	26.2	75.0
Living together	34.8	32.0	18.0	23.8	7.0	61.4	43.7	29.1	22.1	69.7
One-parent family	30.6	27.9	13.8	22.9	6.9	62.4	35.4	37.9	28.4	68.6
Other	28.9	26.3	12.6	22.2	4.6	61.9	29.6	41.4	28.2	68.5
Housing comfort										
High	37.7	34.7	20.7	26.9	7.9	65.4	43.4	34.2	25.7	73.7
Moderate	27.3	24.4	13.3	19.3	5.6	59.2	32.7	35.6	26.0	65.8
Low	32.4	29.9	15.3	23.5	7.0	61.6	36.8	35.2	25.0	69.0
Below low	26.3	23.7	12.0	18.7	6.0	56.4	30.8	34.8	24.7	62.7
Education level										
No education	31.5	28.8	13.8	23.3	7.4	61.3	33.2	37.5	28.2	68.8
Primary school	31.5	28.9	14.2	23.1	6.6	61.5	34.4	37.8	25.9	68.8
Secondary school	34.8	31.9	19.0	24.5	7.3	62.6	41.1	32.3	24.6	70.6
Post-secondary school	37.4	34.3	23.7	26.8	8.6	66.2	47.6	30.9	25.0	73.7
Income level										
Q1 (lowest)	35.5	32.8	18.5	26.3	8.0	63.4	37.1	38.4	26.3	71.2
Q2	31.4	28.8	13.9	22.8	6.7	60.5	33.6	36.8	27.1	68.1
Q3	32.3	29.6	16.1	23.3	6.5	62.6	39.8	34.6	25.4	70.1
Q4 (highest)	33.2	30.1	19.1	22.6	7.0	63.1	43.3	29.5	23.5	70.0
Region										
Brussels-Capital region	20.3	17.3	15.1	13.2	5.3	54.5	36.6	23.1	25.2	59.6
Walloon region	29.4	26.7	14.4	21.7	9.9	63.4	39.0	33.3	34.0	68.8
Flemish region	37.1	34.2	18.8	26.3	5.7	62.7	38.4	37.0	20.7	71.7
Degree of urbanisation										
Very high	27.0	24.7	15.5	18.7	5.6	58.1	37.2	29.4	23.9	64.8
High	33.9	30.8	18.0	24.0	6.8	61.7	38.5	33.9	24.1	69.6
Average	38.4	35.6	18.3	28.5	7.5	66.1	39.7	40.2	25.0	74.4
Low	34.8	31.9	16.1	25.2	9.8	65.3	38.8	37.0	32.7	72.2
Rural	35.7	33.6	16.3	24.0	9.4	63.8	38.5	38.5	29.8	71.1

Table 2: Factors associated with the use of supportive measures for palliative home care among a subgroup of cancer deaths (n=21,530)

	Statutory		**Non-statutory**		**Statutory or non-statutory**	
	OR	95% CI	OR	95% CI	OR	95% CI
Age						
18-64	**1,97**	(1,42-2,74)	-	-	-	-
65-74	**1,74**	(1,25-2,42)	-	-	-	-
75-84	**1,65**	(1,19-2,29)	-	-	-	-
85-94	1,36	(0,98-1,89)	-	-	-	-
95+	ref	-	ref	-	ref	-
Sex						
Male	ref	-	ref	-	ref	-
Female	**1,09**	(1,02-1,15)	**1,50**	(1,41-1,59)	**1,42**	(1,33-1,52)
Household composition						
Single person household	ref	-	ref	-	ref	-
Married	**1,73**	(1,62-1,85)	**1,64**	(1,53-1,75)	**1,81**	(1,68-1,95)
Living together	**1,36**	(1,18-1,57)	**1,29**	(1,12-1,49)	**1,39**	(1,19-1,63)
One-parent family	**1,27**	(1,12-1,45)	1,12	(0,99-1,27)	**1,18**	(1,03-1,35)
Other	**1,33**	(1,09-1,62)	1,11	(0,91-1,34)	1,20	(0,97-1,49)
Housing standard						
Below low	ref	-	ref	-	ref	-
High	**1,27**	(1,13-1,43)	-	-	**1,43**	(1,26-1,61)
Average	1,02	(0,89-1,16)	-	-	1,13	(0,99-1,29)
Low	**1,13**	(1,00-1,28)	-	-	**1,18**	(1,04-1,33)
Education level						
No education	ref	-	ref	-	ref	-
Primary school education	**0,89**	(0,79-0,99)	1,05	(0,94-1,17)	0,97	(0,86-1,10)
Lower secondary school education	**0,84**	(0,75-0,94)	1,10	(0,98-1,22)	0,99	(0,88-1,12)
Post-secondary school education	**0,86**	(0,76-0,98)	**1,29**	(1,13-1,46)	**1,16**	(1,00-1,35)
Income level						
Q1 (lowest)	ref	-	ref	-	ref	-
Q2	-	-	1,08	(0,99-1,17)	**1,37**	(1,04-1,81)
Q3	-	-	**1,24**	(1,15-1,35)	**1,21**	(1,11-1,33)
Q4 (highest)	-	-	**1,30**	(1,20-1,41)	**1,18**	(1,07-1,29)
Region						
Brussels-capital region	ref	(0,94-1,23)	ref	-	ref	-
Walloon region	**1,07**	(1,54-1,99)	-	-	1,05	(0,92-1,20)
Flemish region	**1,75**	(1,08-1,26)	-	-	**1,30**	(1,14-1,47)
Urbanisation						
Very high	ref	-	ref	-	ref	-
High	**1,17**	(1,08-1,26)	**1,15**	(1,07-1,23)	**1,15**	(1,07-1,23)
Average	**1,38**	(1,28-1,49)	**1,33**	(1,24-1,43)	**1,13**	(1,04-1,23)
Low	**1,44**	(1,29-1,59)	**1,36**	(1,24-1,49)	**1,36**	(1,25-1,49)
Rural	**1,59**	(1,24-2,04)	**1,32**	(1,04-1,69)	**1,38**	(1,23-1,55)

Supplementary information on the operationalisation of statutory and non-statutory supportive policy measures for palliative home care

Variable name	Data source	Data administrator	Nomenclature code(s)
Allowance for palliative home patients	Healthcare data	InterMutualistic Agency	740213
Multi-disciplinary support team	Healthcare data	InterMutualistic Agency	774056, 774071, 784092
Nursing care for palliative home patients	Healthcare data	InterMutualistic Agency	427055, 427136, 427033, 427114, 427011, 427092, 427173, 427195, 427151, 427070
Physiotherapy for palliative home patients	Healthcare data	InterMutualistic Agency	564211
Nursing care for heavily dependent persons	Healthcare data	InterMutualistic Agency	425272, 425294, 425316, 425670, 425692, 425714
Physiotherapy for heavily dependent persons	Healthcare data	InterMutualistic Agency	560313, 560394, 561013, 561094, 561116, 562391, 562472, 639391, 639553, 563312, 563393, 563916, 563990, 639715
Allowance for chronically ill patients	Healthcare data	InterMutualistic Agency	740014, 740036, 740073, 740095, 740110, 740154, 740132, 740176, 740235

Hierarchical approach to the logistic regression model:

A hierarchical approach was followed in which a first model with age, gender and cause of death as independent variables was expanded cumulatively with educational level (Model 2), household type (Model 3), housing comfort and income level (Model 4), and region and urbanization (Model 5). This method was followed because it allows evaluating how certain groups of variables explain part of the variation. All models were checked for multicollinearity by looking at tolerance values and variance inflation factors.

Appendix to Chapter 5: Healthcare use at the end of life in amyotrophic lateral sclerosis: a population-level cohort study

Table 1: Quality indicators with detailed description.

Indicator (brief description)	Indicator of Appropriate (A) or Inappropriate (I) Care	Numerator (number of people dying from ALS who*)	Denominator (*Number of people dying from ALS)
Domain: Aggressiveness of care			
Tube feeding or intravenous feeding	I	* received tube feeding or intravenous feeding in the last month before death	*
Diagnostic testing	I	* had diagnostic testing (spirometry OR medical imaging OR electrocardiogram) in the last month before death	*
Port-a-cath installment	I	* had a port-a-cath installed in the last two weeks before death	*
Surgery	I	* received surgery in the last [6, 3, 1] months before death	*
Blood transfusion	I	* received blood transfusion in the last month before death	*
Domain: Palliative care			
Specialized palliative care	A	* received specialized palliative care (hospital palliative unit OR multidisciplinary palliative home care) in the last two years before death	*
Palliative care status	A	* received official palliative care status, enabling financial government support for palliative care at any point before death	*
Late initiation of palliative care	I	* had a first referral to specialized palliative care OR received official palliative status during the last week before death	*
Domain: Place of treatment and place of death			
Home death	A	* died at home	*
Hospital admission	I	* had one or more hospital admission/s in the last [6, 3, 1] months before death	*
ED admission	I	* had one or more emergency hospital visits in the last [6, 3, 1] months before death	*
ICU admissions from nursing home	I	* lived in a nursing home and had one or more admissions to the intensive care unit in the last [6, 3, 1] months before death	* and lived in a nursing home
Domain: Coordination and continuity of care			
GP contact increase	A	* had an increase in average number of contacts with a family physician in the last month before death compared to the previous 23 months	*
Average number of primary caregiver contacts per week	A	Sum of number of contacts with a family physician or other primary care professional in the last three months before death	*

Table 2. Health care interventions for the clinical management of ALS.[a]

Domain of clinical management	Numerator (number of people dying from ALS who*)	ATC codification[b] (for medication)
Domain: Neuroprotective treatment		
Riluzole use	* used riluzole in the last [180, 90, 30, 14, 7] days of life.	N07XX02
Domain: Symptom management		
Fasciculations and muscle cramps†	* used quinine sulphate or levertiracetam in the last [180, 90, 30, 14, 7] days of life.	M09AA72, N03AX14
Spasticity	* used baclofen or tizanidine in the last [180, 90, 30, 14, 7] days of life.	M03BX01, M03BX02
Sialorrhea (hypersalivation)	* used amitriptyline, atropine, or botulinum toxin type A in the last [180, 90, 30, 14, 7] days of life.	N06AA09, M03AX01, A03BA01, S01FA01, N04AC01
Pseudobulbar affect (pathological laughing or crying) †	* used amitriptyline, fluvoxamine, citalopram or a combination of dextromethorphan and quinidine in the last [180, 90, 30, 14, 7] days of life.	N06AA09, S01FA01, N04AC01, R05CB03, C07AA05, C07FX01, C07BA05, C07AB02, N06AB08, N07XX59, N06AB04
Bronchial secretions†	* used mucolytics, metopropol or propranolol in the last [180, 90, 30, 14, 7] days of life.	R05, C07AA05, C07FX01, C07BA05, C07AB02
Depression and anxiety†	* used amitriptyline, mirtazapine, bupropion, diazepam or lorazepam in the last [180, 90, 30, 14, 7] days of life.	N06AA09, N06AX11, N06AX12, N05BA01, N05BA06
Insomnia and fatigue†	* used amitriptyline, mirtazapine, hypnotics or modafinil in the last [180, 90, 30, 14, 7] days of life.	N06AA09, N06AX11, N05C (N05CF02), N06BA07
Pain	* used opioids in the last [180, 90, 30, 14, 7] days of life.	N02A
Venous thrombosis†	* used anticoalugants in the last [180, 90, 30, 14, 7] days of life.	B01
Domain: Respiratory management		
Non-invasive ventilation	* received non-invasive positive-pressure ventilation (NIPPV) in the last [180, 90, 30, 14, 7] days of life.	
Invasive ventilation	* received invasive mechanical ventilation (IMV) in the last [180, 90, 30, 14, 7] days of life.	
Oxygen therapy	* received oxygen therapy alone in the last [180, 90, 30, 14, 7] days of life.	

[a] The full list was based on recommendations provided in the EFNS guidelines on the clinical management of ALS (124). The guidelines were developed after performing a systematic review that gathered evidence regarding the diagnosis and clinical management of patients with ALS and was an update of the 2005 EFNS guidelines.

[b] ATC = Anatomical Therapeutic Chemical classification. † Percentages were only available for 2012 (n=25)

Appendix to Chapter 6: Are we evolving towards more and earlier use of palliative home care? A trend analysis using population-level data from 2010-2015

Table 1: Trends in uptake of palliative home care support, by cause of death, age, and sex, 2010-2015 (n=230,704)

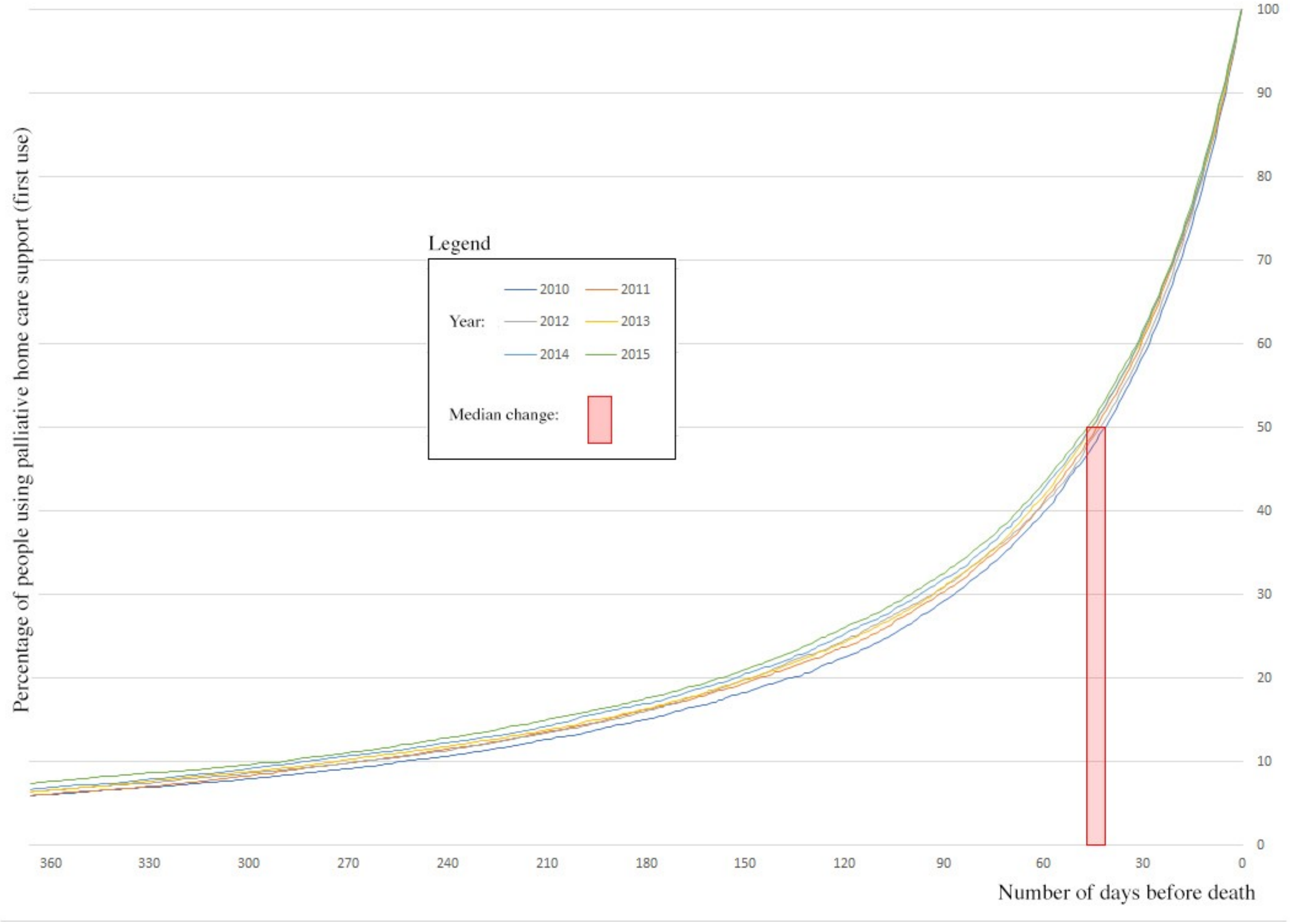
	2010	2011	2012	2013	2014	2015	P.p. change† (std)	Least squares regression slope
	N=37,537	N=37,364	N=38,893	N=39,414	N=38,244	N=39,252		
	Actual % (std %*)	Actual % (std %*)	Actual % (std %*)	Actual % (std %*)	Actual % (std %*)	Actual % (std %*)		
Any type of palliative home care support	31.6 (31.6)	32.7 (32.6)	33 (33.9)	33.8 (34.7)	35.8 (36.3)	34.9 (36.0)	+3.3 (4.4)	+0.8 (1.0)
Cause of death								
Cancer	41.1 (41.1)	42.1 (41.8)	43.5 (45.6)	44.5 (46.7)	46.0 (47.4)	45.5 (48.0)	+4.4 (6.9)	+1.0 (1.5)
Organ failure	10.5 (10.5)	11.2 (11.5)	12.3 (12.0)	13.0 (12.8)	14.3 (14.6)	14.8 (14.3)	+4.3 (3.9)	+0.9 (0.8)
Dementia	13.9 (13.9)	14.4 (14.3)	14.1 (11.7)	14.2 (11.8)	16.9 (14.7)	15.8 (12.8)	+1.8 (-1.1)	+0.5 (-0.1)
Other	25.7 (25.7)	26.8 (26.5)	29.1 (24.1)	29.2 (23.0)	31.7 (24.9)	31.2 (25.2)	+5.5 (-0.4)	+1.2 (-0.2)
Age								
<65 years	40.0 (40.0)	40.9 (40.8)	42.7 (44.9)	42.4 (45.6)	45.1 (49.5)	45.0 (49.8)	+5.0 (9.8)	+1.1 (2.2)
65-84 years	32.4 (32.4)	33.6 (34.1)	34.3 (35.4)	35.7 (36.7)	37.7 (38.9)	36.4 (38.1)	+4.0 (5.7)	+1.0 (1.3)
>84 years	21.9 (21.9)	22.8 (22.1)	22.4 (19.9)	23.0 (20.2)	25.1 (21.4)	25.0 (20.7)	+3.1 (-1.2)	+0.7 (-0.2)
Sex								
Male	32.4 (32.4)	33.6 (34.0)	34.2 (34.6)	34.7 (35.1)	36.9 (37.6)	36.2 (36.9)	+3.8 (4.5)	+0.8 (1.0)
Female	30.6 (30.6)	31.5 (31.0)	31.6 (31.1)	32.7 (32.2)	34.5 (33.7)	33.4 (32.6)	+2.8 (2.0)	+0.7 (0.5)
Allowance for palliative home patients	29.7 (29.7)	30.2 (30.2)	30.4 (31.1)	31.1 (31.9)	32.8 (33.2)	32 (32.9)	+2.3 (3.2)	+0.6 (0.7)
Cause of death								
Cancer	39.0 (39.0)	39.6 (39.4)	40.7 (42.7)	41.5 (43.6)	42.7 (43.9)	42.4 (44.7)	+3.3 (5.7)	+0.8 (1.2)
Organ failure	9.4 (9.4)	9.7 (9.9)	10.6 (10.3)	11.3 (11.1)	12.5 (12.7)	12.3 (12.0)	+2.9 (2.6)	+0.7 (0.6)
Dementia	11.3 (11.3)	10.3 (10.3)	9.9 (8.3)	10.1 (8.4)	12.3 (10.7)	11.0 (8.9)	-0.3 (-2.4)	+0.1 (-0.3)
Other	22.3 (22.3)	23.4 (23.2)	24.7 (20.5)	24.9 (19.6)	28.1 (22.1)	27.5 (22.2)	+5.2 (0.0)	+1.1 (-0.1)
Age								
<65 years	38.2 (38.2)	38.7 (38.6)	40.6 (42.7)	40.1 (43.1)	42.3 (46.3)	42.6 (47.1)	+4.3 (8.9)	+0.9 (1.9)
65-84 years	30.5 (30.5)	31.3 (31.7)	31.5 (32.5)	32.9 (33.8)	34.7 (35.9)	33.3 (34.9)	+2.8 (4.4)	+0.7 (1.0)
>84 years	19.5 (19.5)	19.8 (19.2)	19.3 (17.2)	19.7 (17.2)	21.2 (18.1)	21.1 (17.5)	+1.6 (-2.1)	+0.4 (-0.4)
Sex								

Male	30.7 (30.7)	31.5 (31.9)	31.8 (32.3)	32.3 (32.6)	34.3 (35.0)	33.5 (34.1)	+2.7 (3.4)	+0.6 (0.8)
Female	28.4 (28.4)	28.6 (28.2)	28.3 (27.8)	29.3 (28.9)	30.6 (29.9)	29.8 (29.1)	+1.4 (0.7)	+0.4 (0.3)
Palliative nursing care or physiotherapy at home	23.7 (23.7)	24.4 (24.3)	24.7 (25.2)	25.7 (26.2)	27.6 (27.9)	27.1 (27.8)	+3.4 (4.1)	+0.8 (0.9)
Cause of death								
Cancer	30.6 (30.6)	31.3 (31.1)	32.5 (34.0)	33.7 (35.4)	35.3 (36.4)	35.1 (37.1)	+4.5 (6.5)	+1.0 (1.4)
Organ failure	8.1 (8.1)	8.7 (8.9)	8.9 (8.7)	10.0 (9.9)	10.9 (11.1)	11.4 (11.1)	+3.3 (3.0)	+0.7 (0.6)
Dementia	10.3 (10.3)	9.9 (9.9)	9.7 (8.0)	10.2 (8.4)	12.6 (11.0)	11.1 (9.0)	+0.8 (-1.3)	+0.4 (-0.1)
Other	19.7 (19.7)	21.4 (21.2)	22.1 (18.3)	21.6 (17.0)	24.9 (19.5)	25.0 (20.3)	+5.3 (0.6)	+1.1 (-0.1)
Age								
<65 years	29.1 (29.1)	29.3 (29.3)	31.0 (32.6)	31.0 (33.3)	33.7 (37.0)	33.5 (37.0)	+4.3 (7.9)	+1.0 (1.8)
65-84 years	24.5 (24.5)	25.5 (25.9)	25.8 (26.6)	27.4 (28.2)	29.2 (30.2)	28.5 (29.8)	+4.0 (5.3)	+0.9 (1.2)
>84 years	16.4 (16.4)	17.0 (16.4)	16.6 (14.7)	17.1 (15.0)	19.2 (16.4)	19.2 (15.9)	+2.8 (-0.5)	+0.6 (-0.1)
Sex								
Male	24.1 (24.1)	24.8 (25.1)	25.3 (25.6)	26.0 (26.3)	28.3 (28.9)	27.8 (28.4)	+3.7 (4.2)	+0.9 (0.9)
Female	23.0 (23.0)	23.9 (23.5)	23.6 (23.2)	25.0 (24.6)	26.4 (25.8)	25.9 (25.3)	+2.8 (2.2)	+0.7 (0.6)
Multidisciplinary palliative home care team	15 (15.0)	16.5 (16.5)	17.1 (17.5)	17.7 (18.1)	18.4 (18.7)	17.7 (18.3)	+2.7 (3.3)	+0.6 (0.7)
Cause of death								
Cancer	20.4 (20.4)	22.1 (22.0)	23.4 (24.5)	24.3 (25.5)	24.7 (25.5)	24.2 (25.6)	+3.9 (5.2)	+0.8 (1.1)
Organ failure	3.0 (3.0)	4.0 (4.1)	4.5 (4.4)	4.5 (4.5)	5.0 (5.1)	5.0 (4.9)	+2.0 (1.8)	+0.4 (0.4)
Dementia	4.9 (4.9)	5.1 (5.1)	5.2 (4.3)	5.6 (4.6)	6.7 (5.9)	6.1 (4.9)	+1.2 (0.0)	+0.3 (0.1)
Other	11.0 (11.0)	13.3 (13.1)	13.3 (11.0)	13.5 (10.6)	14.4 (11.3)	14.2 (11.5)	+3.1 (0.4)	+0.6 (-0.1)
Age								
<65 years	23.0 (23.0)	24.6 (24.5)	25.2 (26.4)	26.0 (28.0)	26.3 (28.9)	26.2 (29.0)	+3.2 (6.0)	+0.6 (1.3)
65-84 years	14.8 (14.8)	16.6 (16.8)	17.3 (17.8)	18.0 (18.6)	19.1 (19.8)	18.4 (19.2)	+3.5 (4.4)	+0.7 (0.9)
>84 years	8.1 (8.1)	9.2 (8.9)	9.7 (8.7)	10.0 (8.8)	10.9 (9.3)	10.1 (8.4)	+2.0 (0.3)	+0.4 (0.1)
Sex								
Male	14.9 (14.9)	16.6 (16.8)	17.3 (17.5)	17.8 (18.0)	18.4 (18.8)	18.2 (18.6)	+3.3 (3.6)	+0.6 (0.7)
Female	15.0 (15.0)	16.4 (16.2)	16.5 (16.2)	17.2 (17.0)	18.2 (17.8)	16.9 (16.5)	+1.9 (1.5)	+0.4 (0.4)

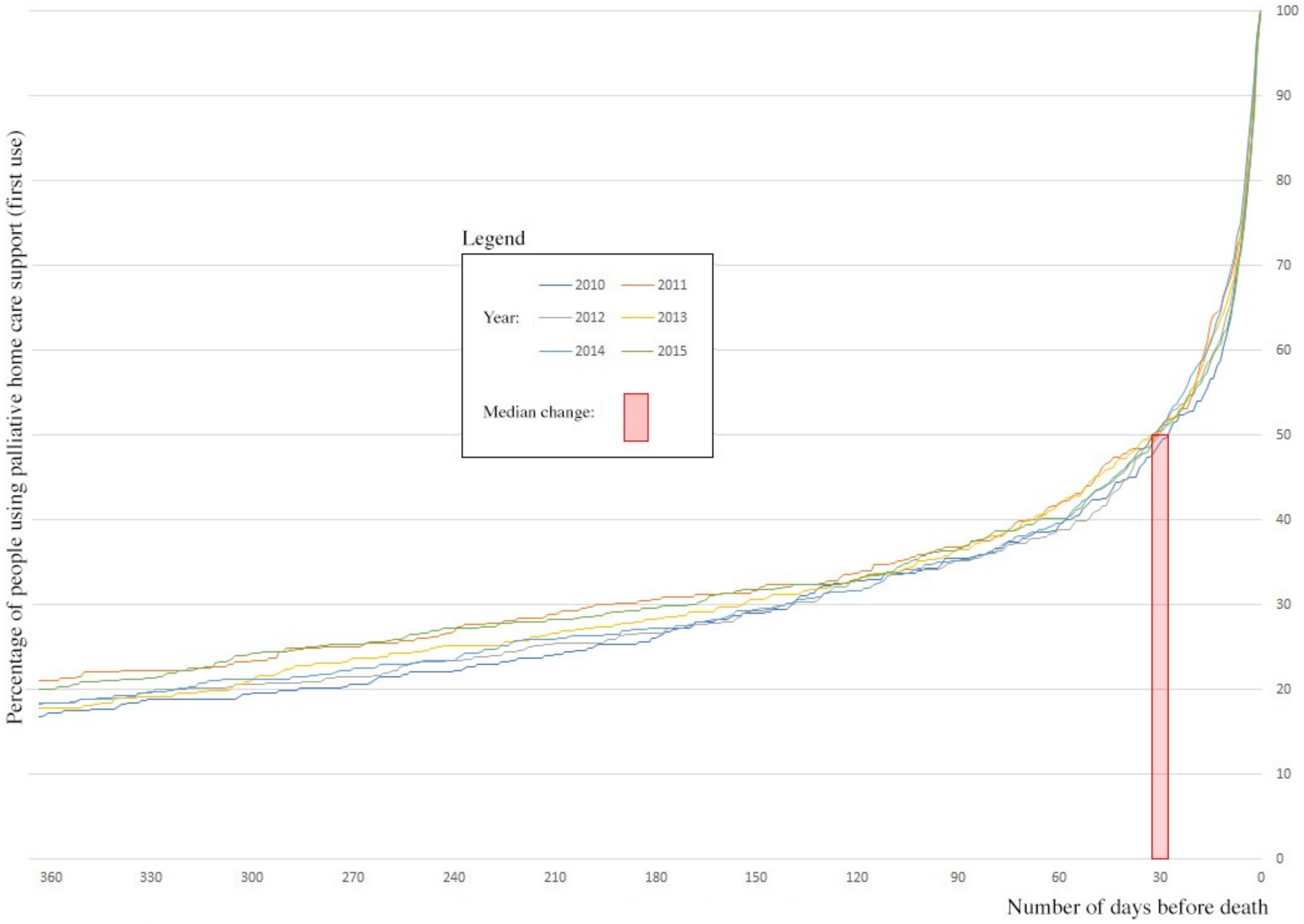
** Std. = Standardized. Uptake was standardized for age, sex and cause of death.*

† p.p. change = percent point change. P.p. change was calculated between 2010 and 2015. P-values were not calculated because the data are on the population-level.

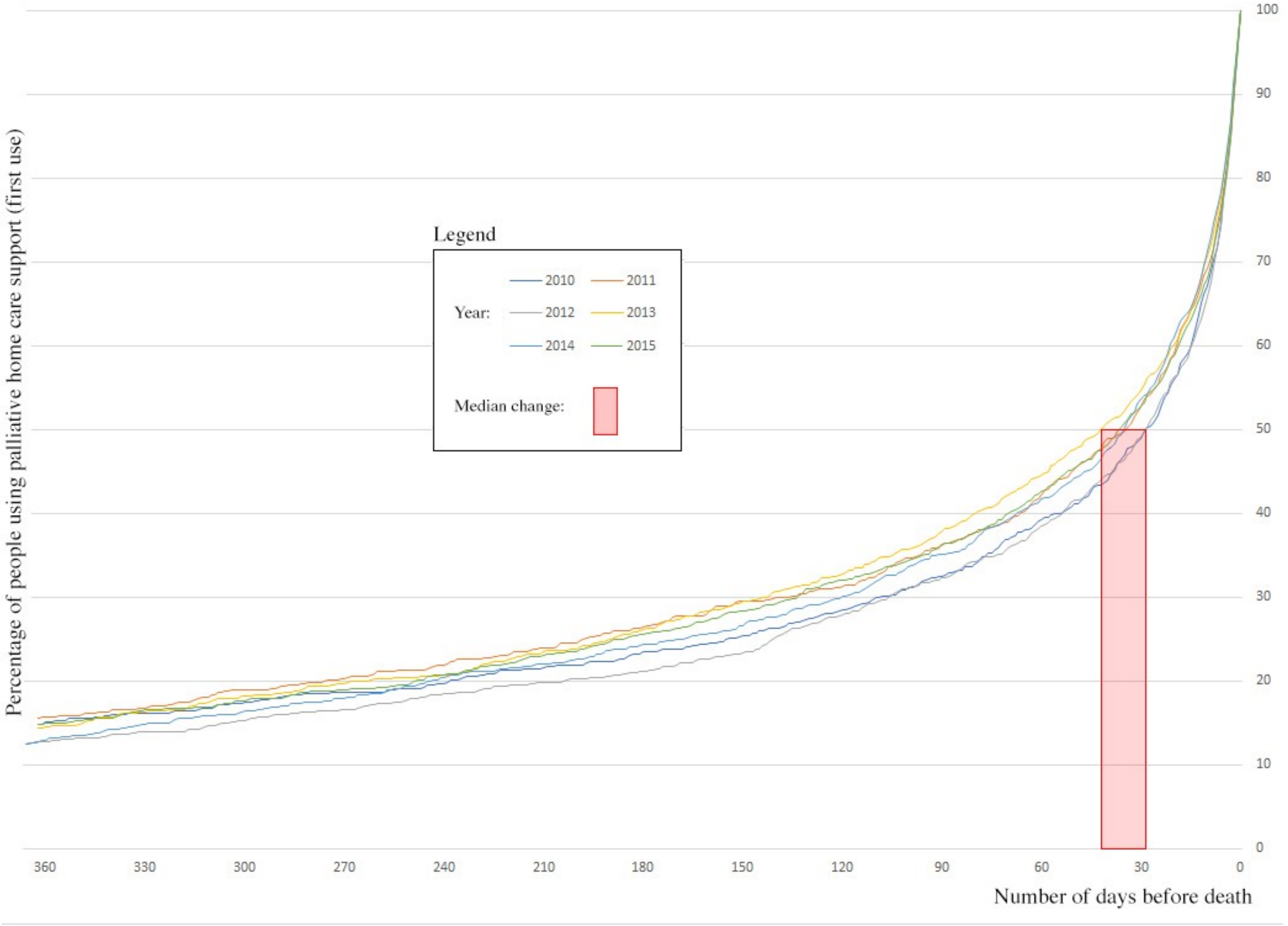
Supplementary figure 1a. Timing of first use of palliative home care support among all home-dwelling adults who died of cancer and used palliative home care support, 2010-2015 (n=64,890)



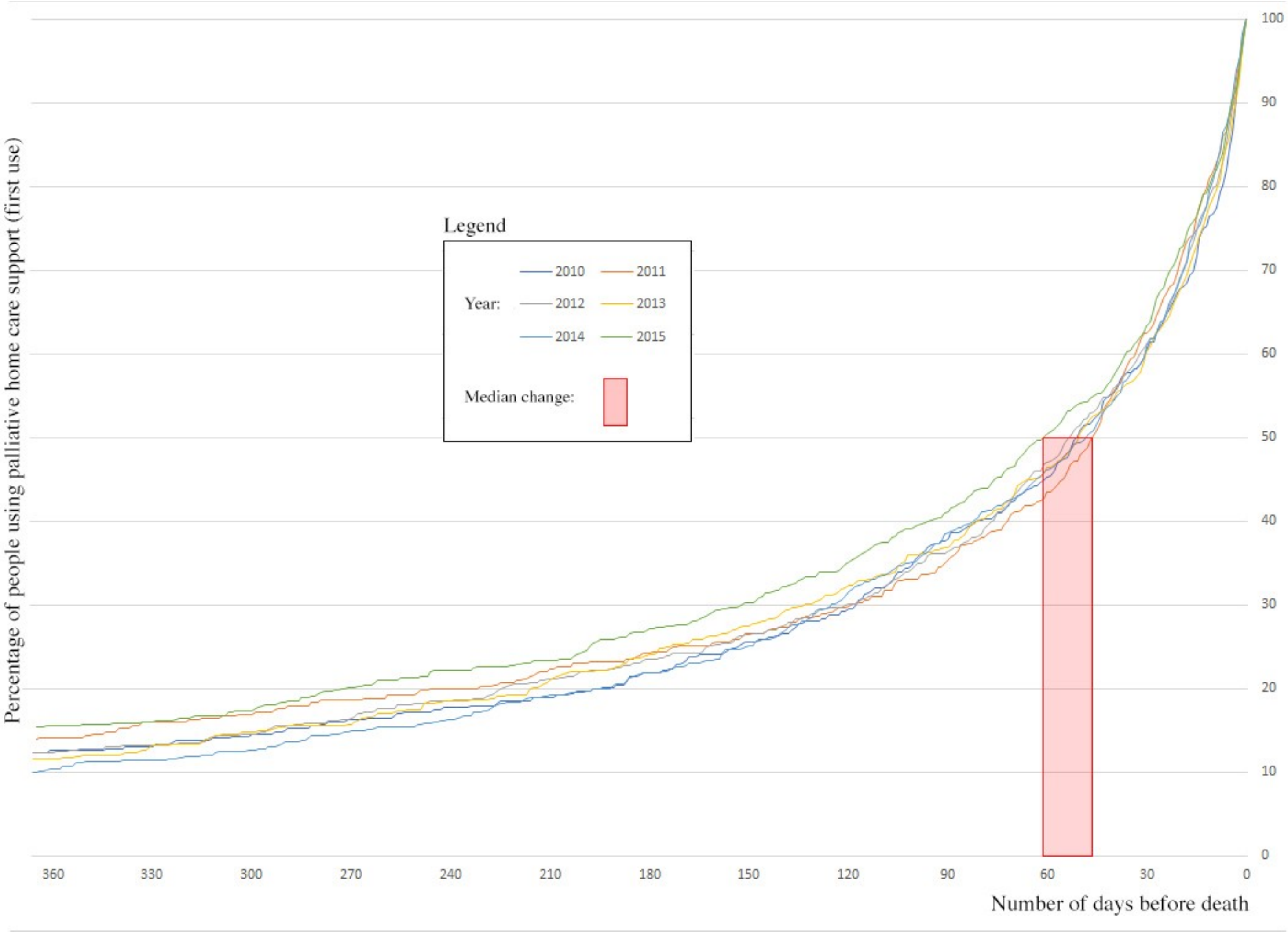
Supplementary figure 1b. Timing of first use of palliative home care support among all home-dwelling adults who died of dementia and used palliative home care support, 2010-2015 (n=3091)



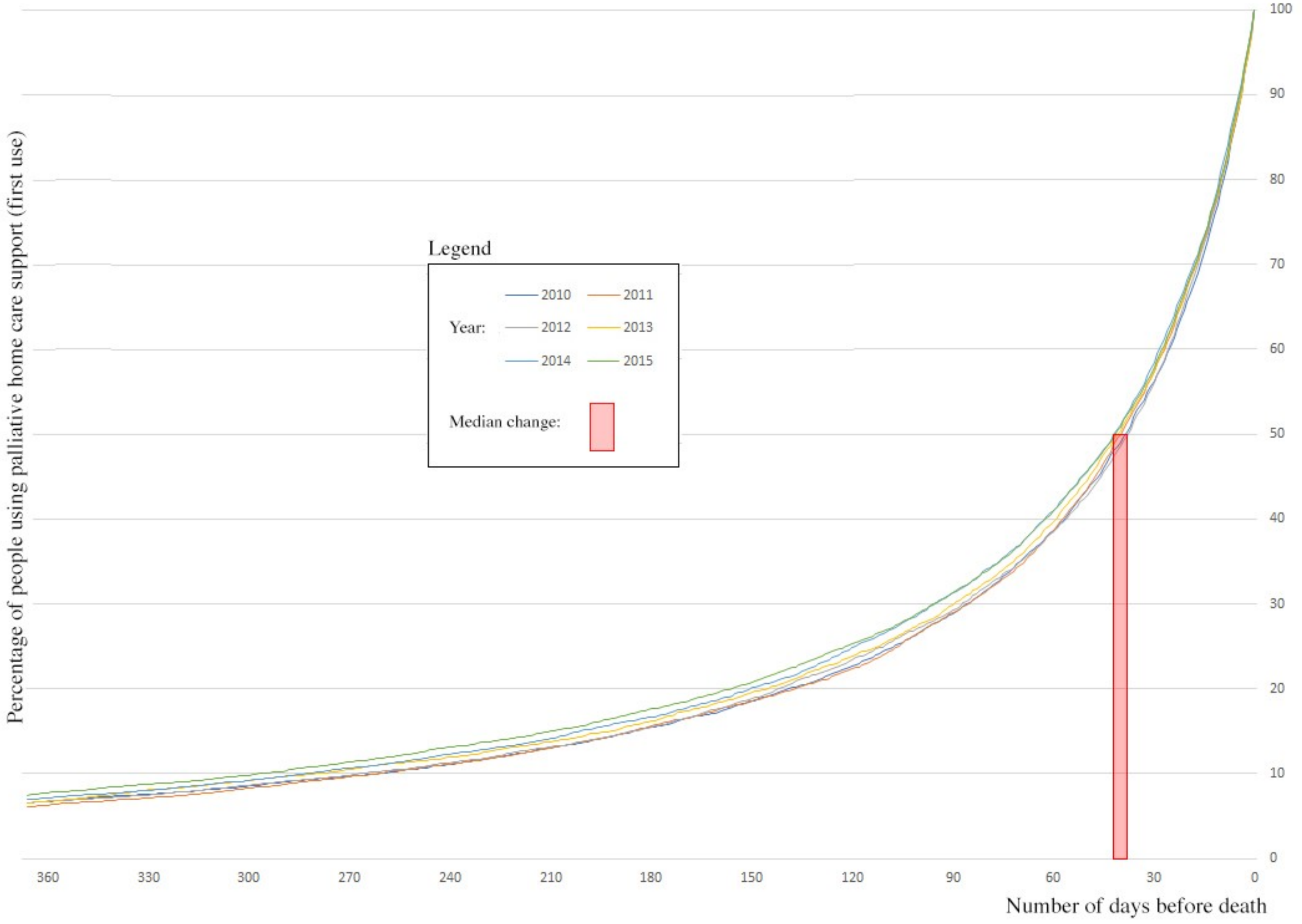
Supplementary figure 1c. Timing of first use of palliative home care support among all home-dwelling adults who died of organ failure and used palliative home care support, 2010-2015 (n=6504)



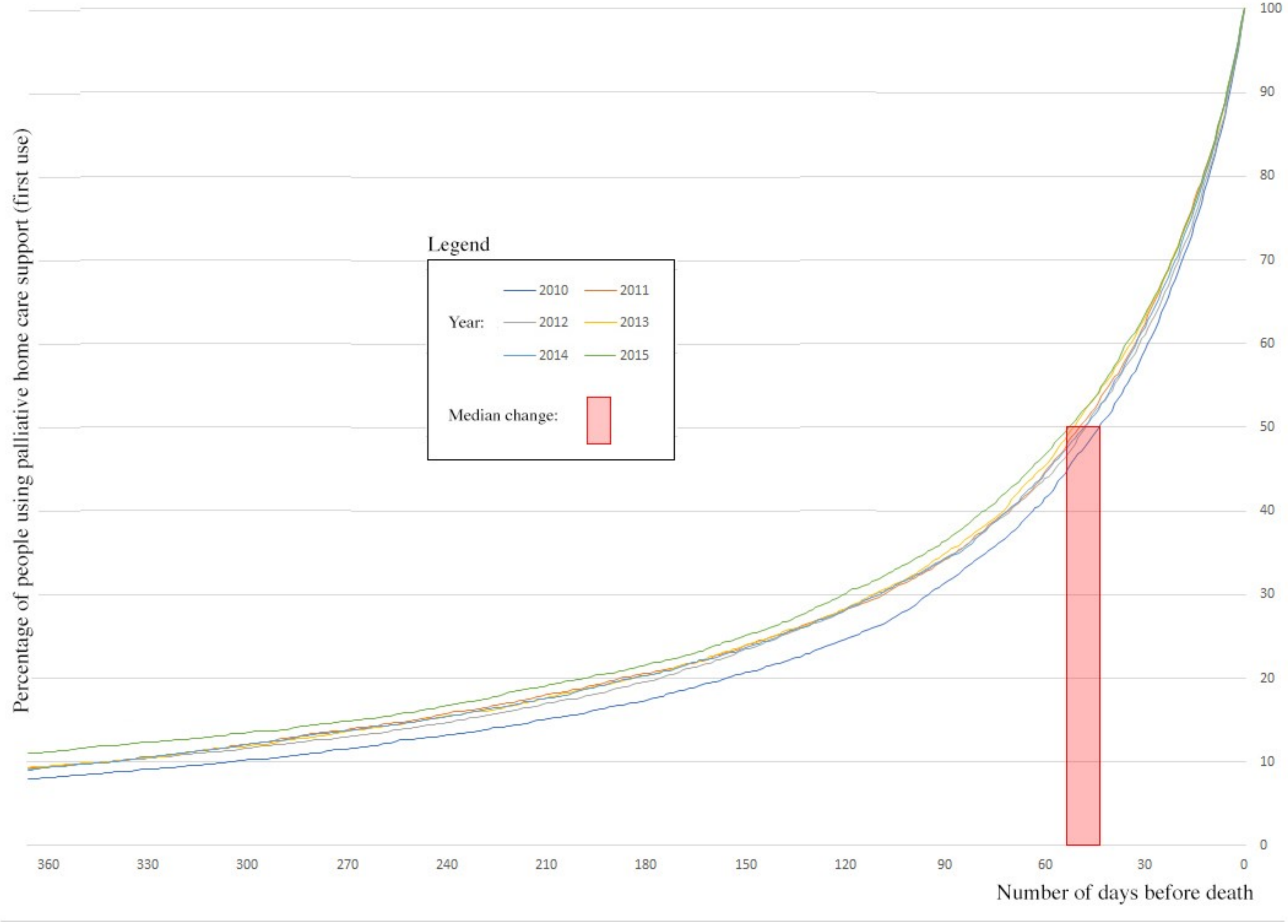
Supplementary figure 1d. Timing of first use of palliative home care support among all home-dwelling adults who died of another illness indicative of palliative care needs and used palliative home care support, 2010-2015 (n=3319)



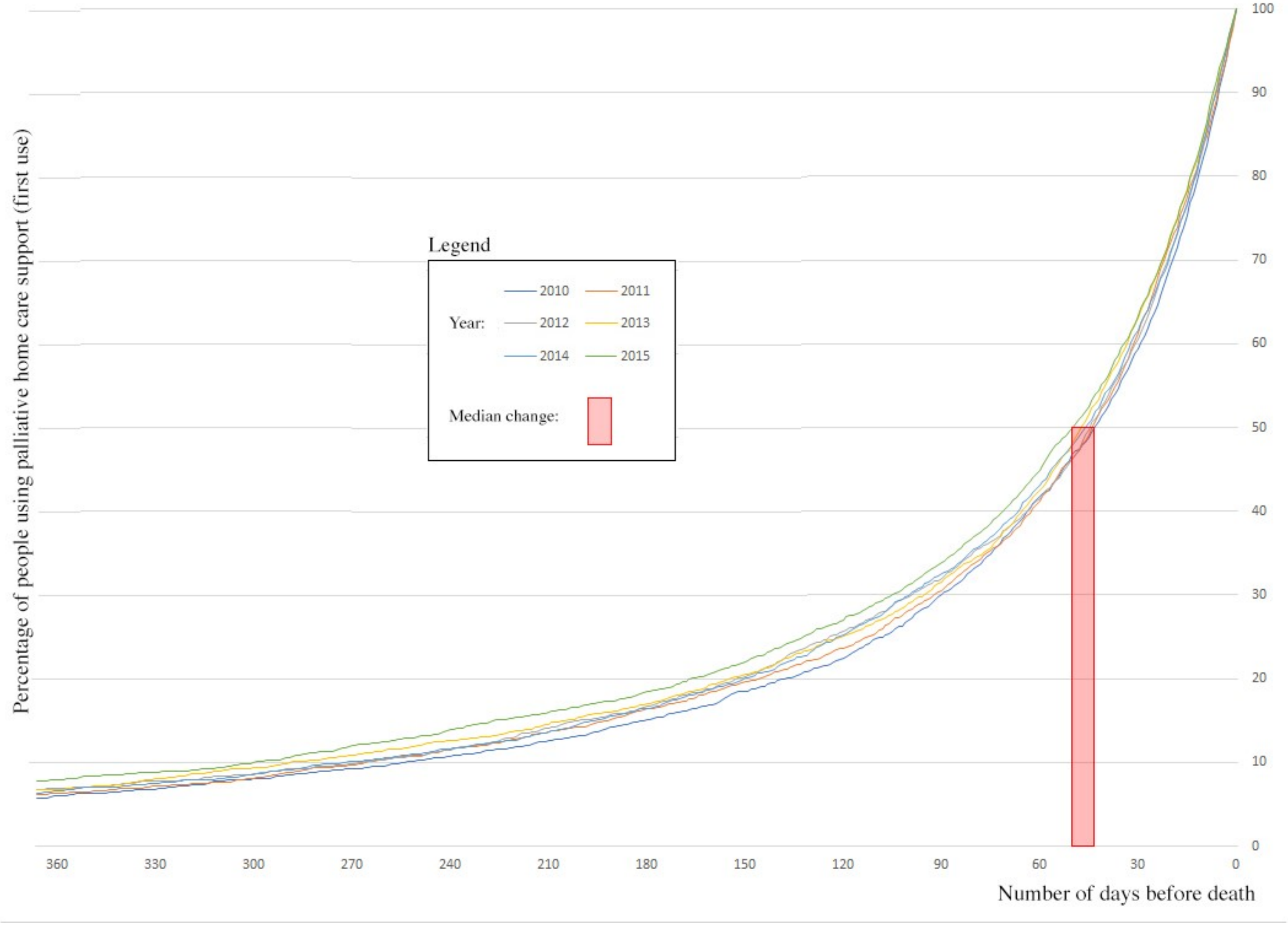
Supplementary figure 1e. Timing of first use of palliative home care support among all home-dwelling adult men who used palliative home care support, 2010-2015 (n=44,459)



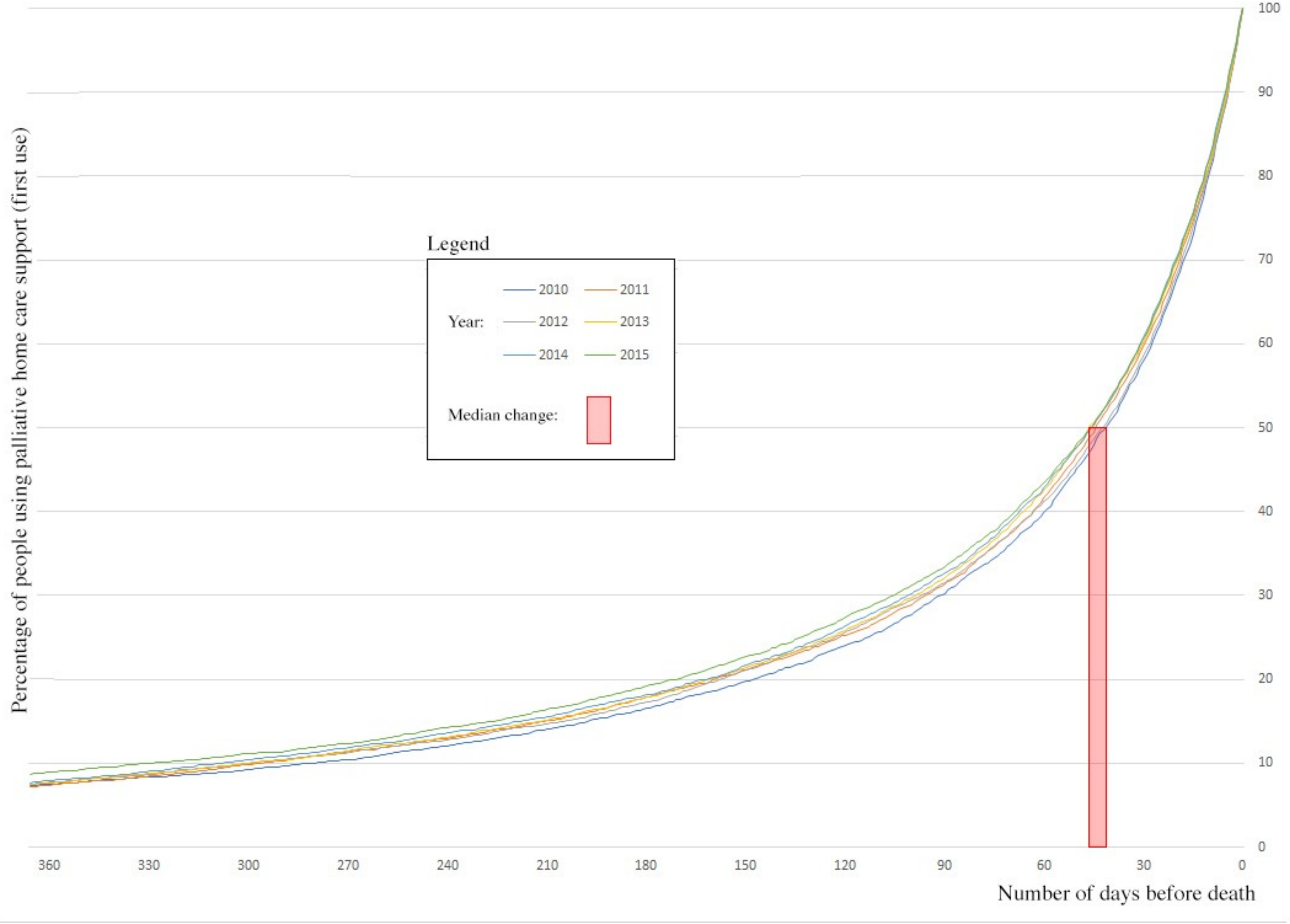
Supplementary figure 1f. Timing of first use of palliative home care support among all home-dwelling adult women who used palliative home care support, 2010-2015 (n=33,264)



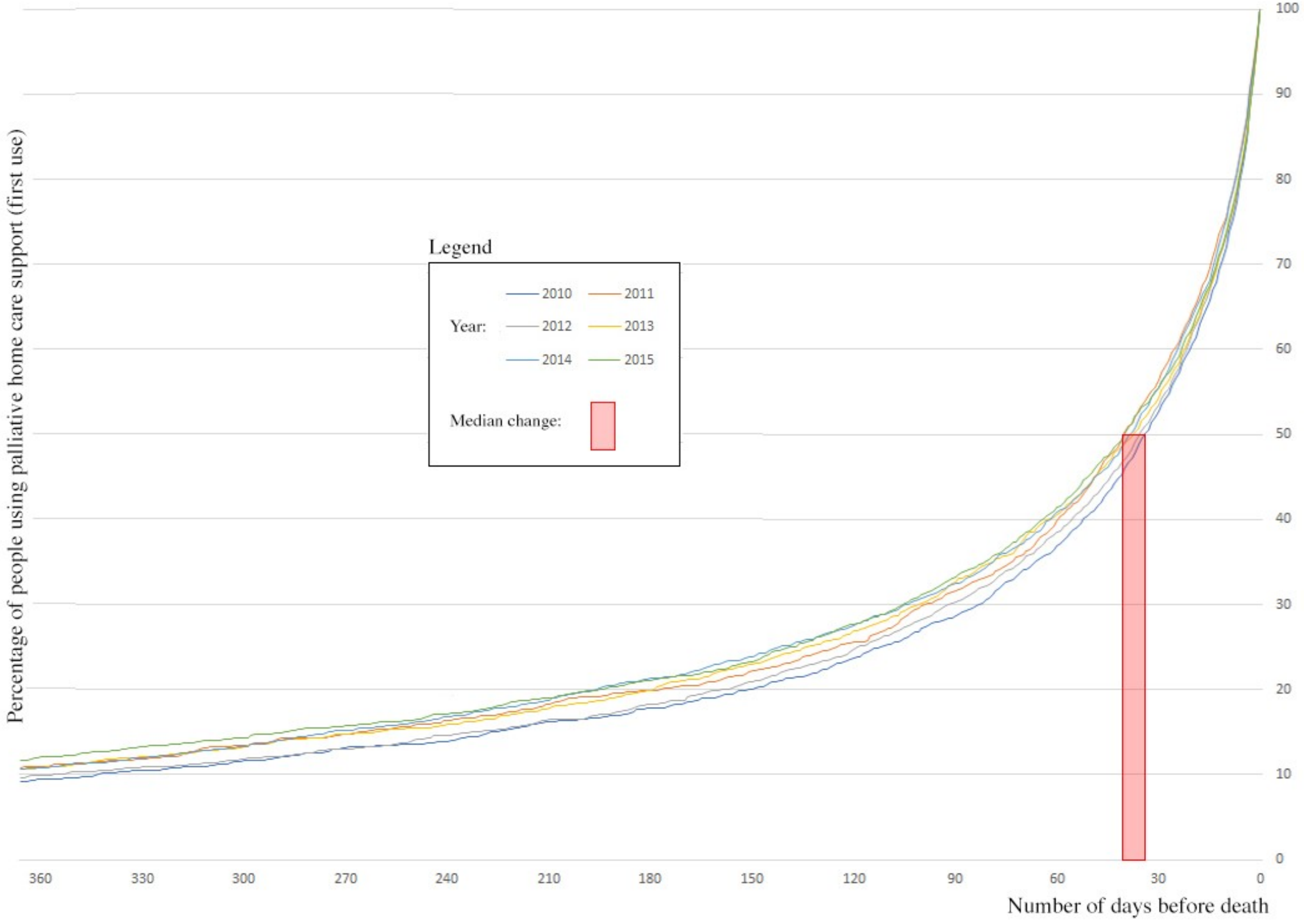
Supplementary figure 1g. Timing of first use of palliative home care support among all home-dwelling adult people aged 65 years or younger who used palliative home care support, 2010-2015 (n=20,047)



Supplementary figure 1h. Timing of first use of palliative home care support among all home-dwelling adult people aged 65-84 years who used palliative home care support, 2010-2015 (n=44,698)



Supplementary figure 1i. Timing of first use of palliative home care support among all home-dwelling adult people aged 85 years or older who used palliative home care support, 2010-2015 (n=12,932)



Appendix to Chapter 7: Impact of palliative home care support on the quality and costs of care at the end of life: a population-level matched cohort study

Table 1: Sensitivity analyses using different intervention models to construct the propensity score matching (outcomes in percentages)

	Model: Use of any palliative home care support			**Model: Use of allowance for palliative home patient**			**Model: Use of a multidisciplinary palliative home care team**			**Model: Use of palliative nursing care or physiotherapy for palliative patients at home**		
	Yes (n=8837)	**No (n=8837)**	**Risk Ratio (95% CI)**	**Yes (n=7972)**	**No (n=7972)**	**Risk Ratio (95% CI)**	**Yes (n=4108)**	**No (n=4108)**	**Risk Ratio (95% CI)**	**Yes (n=6171)**	**No (n=6171)**	**Risk Ratio (95% CI)**
Indicators of appropriate end-of-life care												
Home death	56.2	13.8	4.08 (3.86-4.31)	57·6	14·7	3·91 (3·70-4·14)	59·6	23·8	2·50 (2·35-2·66)	60·9	18·7	3·26 (3·09-3·45)
*Mean number of family physician contacts (SD)**	3.1 (3.0)	0.8 (1.2)	/	3·2 (3·0)	0·8 (1·3)	/	3·3 (3·0)	1·3 (2·1)	/	3·4 (3·0)	1·0 (1·7)	/
*Mean number of primary caregiver contacts (SD)**	9.0 (6.2)	2.3 (4.0)	/	9·4 (6·0)	2·2 (3·9)	/	9·3 (6·1)	3·8 (5·3)	/	10·6 (5·6)	2·6 (4·2)	/
Indicators of inappropriate end-of-life care												
Hospital death	39.0	74.8	0.52 (0.51-0.54)	39·7	74·8	0·50 (0·48-0·52)	34·8	69·6	0·50 (0·48-0·52)	36·4	69·9	0·52 (0·50-0·54)
Hospital admission	27.4	60.8	0.45 (0.43-0.47)	27·4	59·7	0·46 (0·44-0·48)	21·9	55·6	0·39 (0·37-0·42)	25·2	56·2	0·45 (0·43-0·47)
ICU admission	18.3	40.4	0.45 (0.43-0.48)	18·2	39·0	0·47 (0·44-0·49)	14·8	36·5	0·41 (0·37-0·44)	16·5	36·9	0·45 (0·42-0·48)
ED admission	15.2	28.1	0.54 (0.51-0.57)	15·0	27·2	0·55 (0·52-0·59)	13·0	25·7	0·51 (0·46-0·56)	14·7	26·7	0·55 (0·51-0·59)
Diagnostic testing	27.2	63.2	0.43 (0.41-0.45)	27·2	62·1	0·44 (0·42-0·46)	21·5	56·5	0·38 (0·36-0·41)	24·7	59·6	0·42 (0·40-0·44)
Blood transfusion	2.7	5.9	0.47 (0.40-0.54)	2·8	5·7	0·49 (0·42-0·58)	2·3	5·8	0·39 (0·31-0·49)	2·3	5·4	0·42 (0·34-0·51)
Surgery	0.5	2.8	0.19 (0.14-0.26)	0·5	2·7	0·19 (0·14-0·27)	0·3	2·6	0·13 (0·08-0·23)	0·5	2·5	0·18 (0·12-0·28)

* P<0.0001 calculated using two-sided T-test statistic.

Supplementary table 2: Sensitivity analyses using different intervention models to calculate healthcare costs in the last 14 days of life; presented as means (SE)

	Model: Use of allowance for palliative home patient			**Model: Use of a multidisciplinary palliative home care team**			**Model: Use of palliative nursing care or physiotherapy for palliative patients at home**		
	Yes n=7972	**No n=7972**	**Incremental cost (95%CI)**	**Yes n=8216**	**No n=8216**	**Incremental cost (95%CI)**	**Yes n=6171**	**No n=6171**	**Incremental cost (95%CI)**
Total inpatient costs	1775 (32.2)	4118 (47.6)	-2343 (2230-2456)	1585 (43.8)	3864 (66.4)	-2279 (2122-2435)	1634 (35.9)	3821 (53.1)	-2187 (2061-2313)
Total outpatient costs	1330 (12.3)	519 (9.1)	811 (781-841)	1310 (15.7)	687 (14.4)	623 (581-664)	1496 (14.0)	595 (10.7)	901 (866-935)
Total costs	3105 (29.8)	4637 (46.7)	-1532 (1423-1640)	2895 (40.9)	4551 (64.2)	-1656 (1506-1805)	3129 (32.8)	4416 (52.0)	-1287 (1166-1407)

SE = standard error ; All costs expressed in 2017 euros. Costs were calculated using data on all reimbursed medical care costs and rounded. Total inpatient costs included all specific intervention and medication costs in the hospital. Total outpatient costs included all specific intervention and medication costs outside the hospital.

Appendix: Folder ondersteuning voor palliatieve thuiszorg

Nuttige links

Websites van de Federatie Palliatieve Zorg Vlaanderen:

- Algemene informatie over palliatieve zorg
  www.palliatief.be
- Zoek het netwerk palliatieve zorg in uw regio
  www.palliatief.be/netwerk_overzicht
- Vroegtijdige planning van je zorg
  www.delaatstereis.be
- Kinderen en jongeren betrekken bij palliatieve zorg
  www.palliatieve-zorg-en-kinderen.be

Andere websites

- Rijksinstituut voor Ziekte- en Invaliditeitsverzekering (RIZIV):
  info over palliatief statuut en palliatief forfait.
  www.riziv.fgov.be
- Rijksdienst voor Arbeidsvoorziening
  www.rva.be

Lees ook: Wegwijs in Palliatieve Zorg

alles over het
levenseinde
WEGWIJS IN PALLIATIEVE ZORG

Te bestellen via info@palliatief.be

Palliatieve
thuiszorg
... en nu?

FEDERATIE
PALLIATIEVE ZORG
VLAANDEREN
VZW

mede ontwikkeld door

END-OF-LIFE CARE
RESEARCH GROUP
UNIVERSITEIT GENT
VUB

www.palliatievezorginvlaanderen.be

Actuele en meer uitgebreide informatie
met links naar documenten vindt u op
www.palliatief.be/tegemoetkomingen

verantwoordelijke uitgever:
Federatie Palliatieve Zorg Vlaanderen vzw
Toekomststraat 36, 1800 Vilvoorde

tweede druk: oktober 2017

Palliatieve
thuiszorg
... en nu?

INFO VOOR PATIËNTEN

Palliatieve
thuiszorg
... en nu?

INFO VOOR MANTELZORGERS

INFO VOOR PATIËNTEN

Palliatief statuut
Het palliatief statuut biedt u een aantal specifieke voordelen. Uw huisarts kan het palliatief statuut aanvragen indien:

- u lijdt aan één of meerdere chronische (onomkeerbare) aandoeningen?
- uw aandoening ongunstig evolueert, met een ernstige algemene verslechtering van fysieke en psychische toestand.
- therapie en revalidatie geen invloed meer hebben op uw toestand.
- u een slechte prognose heeft gekregen.
- u ernstige fysieke, psychische, sociale en geestelijke noden heeft.
- u tot aan uw overlijden thuis zou willen blijven.

Welke ondersteuning kunt u krijgen?

Financiële tegemoetkomingen

Palliatief (zorg)forfait
Als u een palliatief statuut heeft, dan heeft u twee keer recht op een maandelijks palliatief zorgforfait, een tegemoetkoming voor specifieke kosten (geneesmiddelen, hulpmiddelen en verzorgingsmateriaal). De eerste maand ontvangt u de tegemoetkoming automatisch bij aanvraag van het palliatief statuut, de tweede maand zelf aanvragen bij uw huisarts.

Afschaffing van remgeld (eigen bijdrage)
Indien u het palliatief statuut heeft, hoeft u geen remgelden meer te betalen voor bezoeken van de huisarts en bepaalde diensten in thuisverpleging en kinesitherapie. U hoeft hier zelf niets voor aan te vragen.

Vlaamse zorgverzekering
Maandelijkse vergoeding voor niet-medische kosten.
Aan te vragen bij de zorgkas van uw ziekenfonds.

Thuishulp en andere diensten

Multidisciplinaire begeleidingsequipe (MBE of Palliatieve thuiszorgequipe
Helpt bij de organisatie van uw zorg, geeft advies aan uw vertrouwde zorgverleners. Is volledig gratis.
Ga naar **www.palliatief.be** voor een MBE in uw buurt.

Dagverzorgingscentrum voor palliatieve zorg
Dagcentrum waar u en uw mantelzorger(s) 1 of enkele dagen per week terechtkunnen wanneer de zorg thuis te zwaar wordt (= respijtzorg). In een kleinschalige setting krijgt u tijdelijk zorg op maat. In een dagcentrum betaalt u een dagprijs.

Er zijn momenteel maar een beperkt aantal dagcentra in Vlaanderen. Ga naar **www.palliatief.be** voor een dagcentrum in uw buurt.

INFO VOOR MANTELZORGERS

IK, mantelzorger?

Mantelzorger bent u wanneer u langdurig en onbetaald zorgt voor een chronische zieke, gehandicapte of hulpbehoevende persoon uit uw omgeving.

Dit kan een partner, ouder of kind zijn, maar ook een ander familielid, vriend of kennis.

Geeft u mantelzorg?
Dan heeft u recht op ondersteuning en diverse tegemoetkomingen.

Welke ondersteuning kunt u krijgen?

Financiële tegemoetkomingen

Tegemoetkoming voor werkende mantelzorgers
Voor werknemers is er een vergoeding die gedeeltelijk het inkomensverlies door mantelzorg kan opvangen. Meer informatie bij uw personeelsdienst of vakbond. Zelfstandigen kunnen een uitkering voor mantelzorg aanvragen en vrijstelling van sociale bijdragen. Meer informatie bij uw sociaal verzekeringsfonds.

Gemeentelijke mantelzorgpremie
De meeste gemeenten bieden deze premie aan.
De voorwaarden kunnen verschillen per gemeente.
Aan te vragen bij uw gemeente.

Vlaamse aanmoedigingspremie
Een extra premie van de Vlaamse overheid, aanvullend op uw aanvraag zorgverlof.
Aan te vragen bij de RVA (www.rva.be).

Zorgverlof

Palliatief zorgverlof
Thematisch verlof (max. 3 maanden) tijdens welke periode u niet, halftijds of 4/5de kunt werken. Aanvraag via een attest afgeleverd door de behandelende geneesheer van de persoon die nood heeft aan palliatieve zorg (moet geen familie zijn). U heeft recht op een vervangingsinkomen. Aan te vragen bij de RVA.

Verlof voor medische bijstand
Om een ernstig ziek gezinslid (tot de 2de graad) bij te staan of te verzorgen (hoeft niet palliatief te zijn). Max. 12 maanden voltijds, kan ook deeltijds. U heeft recht op een vervangingsinkomen. Aan te vragen bij de RVA.

Respijtzorg
Wanneer u nood heeft aan een korte adempauze kan de zorg tijdelijk van u worden overgenomen (dagopvang voor volwassenen, dag-/nachtopvang voor kinderen). Meer info op **www.palliatief.be.**