Original Article

Are We Evolving Toward Greater and Earlier Use of Palliative Home Care Support? A Trend Analysis Using Population-Level Data From 2010 to 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. We conducted an observational study using routinely collected population-level databases linked with health claims data for the entire population living at home that died of 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 of dementia (smallest increase with 1.9 percent point). The timing of initiating PHCS advanced from 41 to 46 days before death, with the smallest increase observed among people who died of 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 toward 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 in their very late life remained stable over time. J Pain Symptom Manage 2019;58:19–28. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Palliative care, end of life, trend study, policy analysis, public health policy

Background

The global need to shift toward 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 health care system.[5,6] In addition, 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,

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certain groups, such as noncancer 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- or home-based palliative care in Belgium,[11] the U.S.,[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, first, to analyze trends in the use of any type of available palliative home care support (PHCS) among all persons living at home who died of an illness indicative of palliative care needs in Belgium between 2010 and 2015, and, second, to examine whether there was a trend toward earlier initiation among those who used any of these types of PHCS. 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 health care consumption and sociodemographic information on all deaths in Belgium between 2010 and 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 nonspecialist 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 chronic obstructive pulmonary disease; 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 noncancerous neoplasm; ICD-10 D00–48, G20, G12, and B20–24). Persons with a registered permanent residence in a collective household (i.e., nursing care home, other institutions) in 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 PHCS 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 health care use in the last two years of life (recorded as nomenclature codes). For all health care data, the exact date of delivery (coded as number of days before death) is recorded. In addition, 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 PHCS in Belgium: multidisciplinary specialist palliative home care team, palliative home care nursing or physiotherapy, and allowance for palliative home care patients (see Table 1 for a detailed description). For each individual reimbursement record of PHCS, 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.

Table 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.[21] 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:

1. The use of a **multidisciplinary palliative home care team:** these teams include at least one general practitioner, two nurses with at least a minimum amount of 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.
2. **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.
3. The **allowance for palliative home patients:** an allowance of €663.49 (as of 2018) meant to cover partially reimbursed or nonreimbursed costs related to the provision of palliative care at home (e.g., certain medicines and 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 PHCS 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 PHCS use within each decedent group for each year to calculate proportions of standardized PHCS use (see also Appendix). Trends in PHCS use were also illustrated by cause of death and age categories and contrasted with crude rates. The closer the crude and standardized proportions were, the more the trends were influenced by changing patterns of PHCS 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 PHCS are taken into account.

To describe trends in the timing of uptake of PHCS from 2010 to 2015, we plotted the percentage of people that used any type of PHCS 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

Sociodemographic Characteristics

The number of deaths in Belgium among people who lived at home and died of 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 2). From 2010 to 2015, the relative proportion of people who died at the age of 85 years or older increased by 4.6 percent points (p.p.). Relatively, more people died of 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 with 2010, and the relative proportion of those who died of 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 PHCS use between 2010 and 2015 for the entire population of interest. The use of any type of PHCS 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 PHCS use is relatively close to the increase in the standardized pattern of PHCS use, reflecting changing patterns of PHCS 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 PHCS separately (see Table S1).

Table 2
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	
Population Characteristics	$n = 37,537$, %	$n = 37,364$, %	$n = 38,893$, %	$n = 39,414$, %	$n = 38,244$, %	$n = 39,252$, %	p.p. Change[a]
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 yrs	21.4	21.5	20.5	20.0	19.7	19.6	−1.8
65–84 yrs	57.2	56.3	55.3	55.6	55.2	54.5	−2.7
>84 yrs	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%).
[a]p.p. change = percent point change between 2015 and 2010. *P*-values were not calculated because the data cover the full population.

Trends in the Use of Palliative Home Care Support Between 2010 and 2015 by Cause of Death and Age

Figure 2 shows the observed and standardized trends in PHCS use between 2010 and 2015 by different cause of death and age group. Comparing trends by cause of death, the least squares regression slopes indicate that use of PHCS increased at a similar rate for those who died of cancer (slope = 1.0), organ failure (0.9), or another illness indicative of palliative care needs (1.2) (Table 3). Those who died of dementia had a substantially lower slope, with an average annual increase in PHCS use of 0.5 p.p. Trends of use of PHCS were similar for those who were aged less than 65 years (slope = 1.0) or between 65 and 84 years at time of death (1.0), whereas those who were aged 85 years or older at time of death had a lower slope (0.7), thus a smaller increasing trend of using PHCS between 2010 and 2015.

Similar trends were found for each type of PHCS separately (see Table S1).

Trends in the Timing of Initiating Palliative Home Care Support Between 2010 and 2015

Table 4 shows the trends in the timing of initiating any type of PHCS between 2010 and 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 PHCS increased by 2.5 days for those who died of dementia and by 11 days for those who died of another cause of death indicative of palliative care needs. The timing of initiation increased by seven days for those younger than 65 years or 85 years or older and by four days for those aged 65–85 years. Among men and women, there was an increase of three and nine days, respectively. The proportion of people for whom PHCS was initiated in the last week of life decreased between 2010 and 2015 from 15.3% to 13.9% (Fig. 3). This proportion was highest among those who died of dementia (31.6% in 2015) (see Fig. S1a-i).

Discussion

Summary of Main Findings

Over the six-year period that covers this population-level trend study on the use of PHCS in Belgium, there was an increase in uptake from 31.6% in 2010 to 34.9% in 2015. There was also a trend noticeable toward earlier initiation among those who used PHCS, 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 PHCS were substantially lower among people who died of 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. In addition, these administrative data have a high degree of accuracy and reliability because all types of PHCS 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

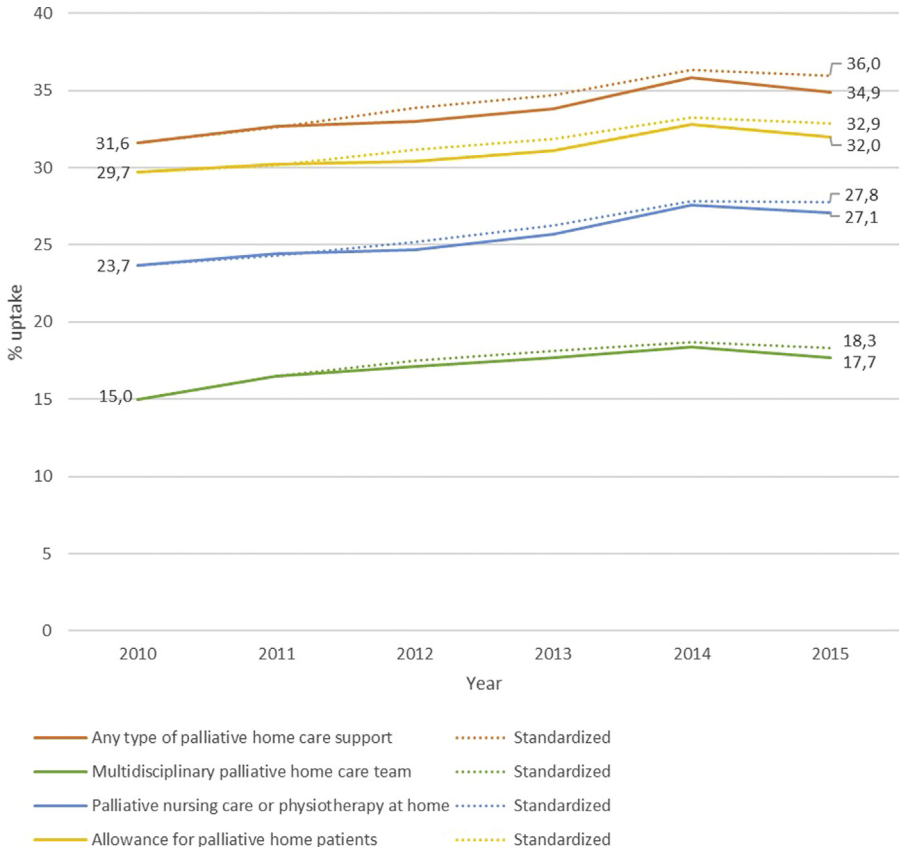

Fig. 1. Crude and standardized uptake of palliative home care support, 2010–2015 (n = 230,704). Uptake was standardized for age, sex, and cause of death using direct standardization for the year 2010.

of initiating PHCS for the entire population in a country.

However, this study also has limitations, mainly related to the use of administrative data. First, the data do not capture the quality of the support used. Second, we were only able to measure the first date of use of PHCS; 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.[29] By extracting only the underlying cause of death from the death certificates, there is the possibility of underestimating the actual frequency of the diseases in the population.[30] For example, some diseases (e.g., dementia) are more likely to be registered as an intermediate or contributory cause of death instead of an underlying cause of death. Therefore, our estimates should be deemed conservative. Finally, reimbursement data do not capture the nonreimbursed 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 PHCS increased over time corroborates with previous studies analyzing trends in the use of community- 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 aged 65 years or older who died between 2005 and 2014 found roughly the same increase in the use of multidisciplinary palliative home care teams by older people (65+ years) 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.[33] 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.[34] This would mean that more funding indeed translates into more use, as stagnation in the use of multidisciplinary palliative home care teams had

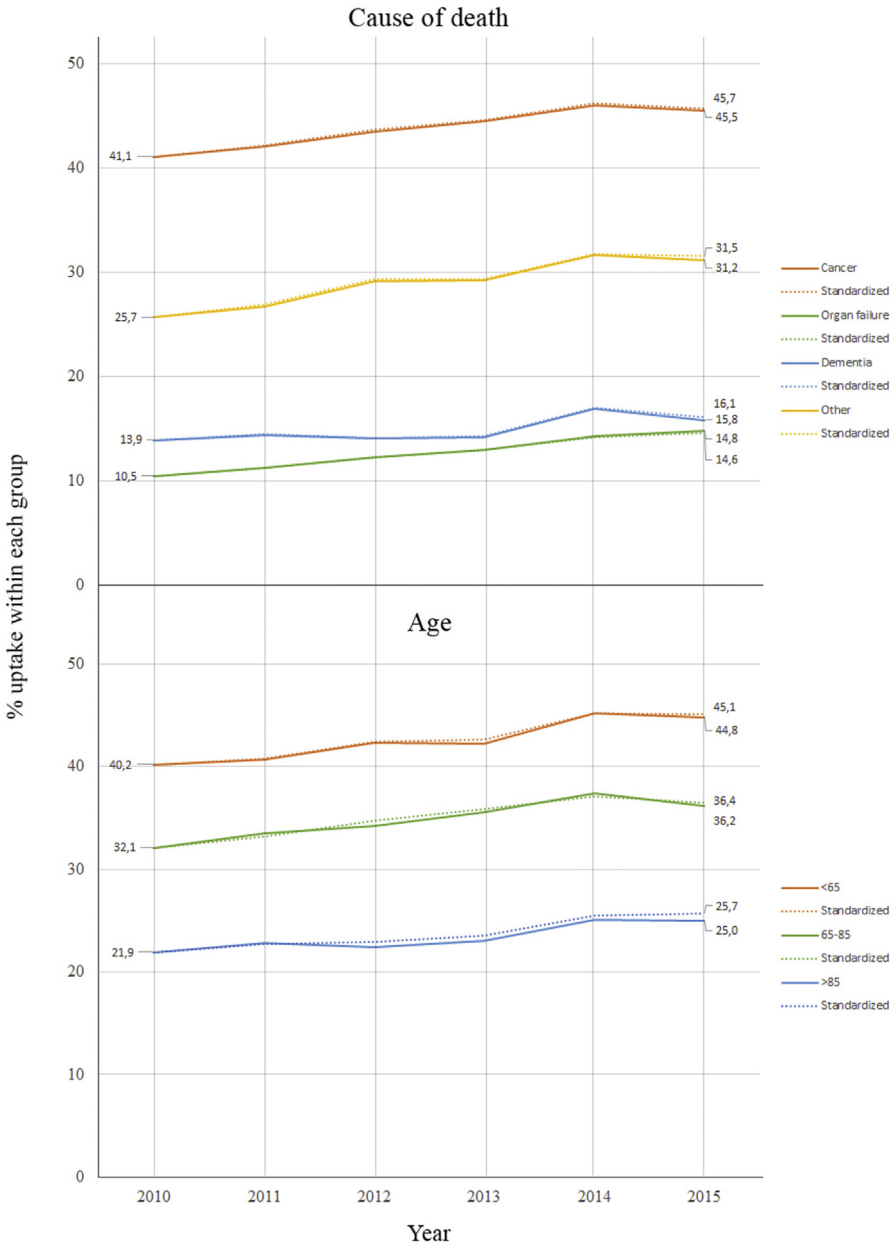

Fig. 2. Change in the percentage of people using any type of palliative home care support by cause of death and age, 2010–2015 (n = 230,704). Percentages are row percentages within each group separately. Uptake was standardized for each age, gender, and cause of death group.

been reported in mortality follow-back studies for the period 2005–2010.[11] Some authors have suggested that the practices of euthanasia and physician-assisted suicide, which are legal in Belgium, are incompatible with a palliative care approach,[35,36] thus allowing to hypothesize that these practices would impede an increase in the uptake of PHCS. However, a recent study by Dierickx et al. has shown that in Flanders, in a context of legalized euthanasia, euthanasia and palliative care do not seem to be contradictory practices and people requesting euthanasia were in fact more likely to have received palliative care than other people dying nonsuddenly.[37]

Despite progression toward more use of PHCS 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

Table 3
Percentage of People Using Any Type of Palliative Home Care Support for Each Cause of Death and Age Group, 2010–2015 ($N = 230,704$)

Population Characteristics	2010 Crude % (Std %[b])	2011 Crude % (Std %[b])	2012 Crude % (Std %[b])	2013 Crude % (Std %[b])	2014 Crude % (Std %[b])	2015 Crude % (Std %[b])	p.p. Change[a] (Std[b])	Least Squares Regression Slope (Std[b])
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 yrs	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 yrs	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 yrs	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)

[a]p.p. change = percent point change calculated between 2010 and 2015. *P*-values were not calculated because the data are at population level.
[b]Std = standardized uptake was standardized for age, sex, and cause of death differences. Percentages are row percentages for each group separately.

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.[30] 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 PHCS to meet the actual needs in the population.

This study also found there was a slight trend toward 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 eight 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 five-day increase in number of days before death of initiating PHCS 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 U.S. 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.[38] Despite large differences between the U.S. 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 toward 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 PHCS were not similar for all causes of death and age groups in the population. The substantially lower increase in PHCS use among people who died of 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.[39] This effect is possibly further enhanced by the fact that all types of PHCS 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 PHCS was also greatest among those who died of dementia, with a quarter of patients having used PHCS 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 onward, however, the Palliative Care Indicator Tool (an unvalidated translation of

Table 4

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		
Population Characteristics	$n = 11,872$	$n = 12,210$	$n = 12,845$	$n = 13,328$	$n = 13,704$	$n = 13,719$	Change 2010–2015	Least Squares Regression Slope
% initiated in last week of life	15.3	14.4	14.7	14.3	13.5	13.9	−1.4 p.p.[a]	
Full population, Median days (IQR)	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, Median days (IQR)								
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, Median days (IQR)								
<65 yrs	43 (15–109)	44 (17–113)	45 (16–124)	47 (18–121)	46 (17–122)	50 (18–133)	+7.0	+1.2
65–84 yrs	42 (14–114)	44 (15–122.5)	43 (14–124)	46 (15–125)	46 (16–128)	46 (15–134)	+4.0	+0.8
>84 yrs	34 (8–114)	40 (11–126)	36 (9–120)	38 (9–135)	39 (10–143)	41 (9–141)	+7.0	+1.0
Gender, Median days (IQR)								
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

[a]p.p. = percent point.

the Supportive & Palliative Care Indicators 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 six to 12 months?" Moreover, the Belgian federal government has recently allocated a budget to reimburse dedicated advanced care planning conversations with a general practitioner for patients who meet the criteria of the Palliative Care Indicator Tool. Future research should investigate whether the impact of these changes in the law on the use and timely initiation of PHCS, especially among people with dementia.

Conclusion

This population-level study found a small trend toward more and earlier initiation of PHCS between 2010 and 2015. Trends were similar in size for all causes of death and age groups, except for people who died of dementia and those aged 85 years 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 PHCS 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 PHCS and timing of initiating PHCS for all those in need.

Disclosures and Acknowledgments

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Data sharing statement: In accordance with Belgian law, approvals for access to the various databases and the database integrating all databases were obtained from two separate national sectoral committees for privacy protection. Owing to ethical concerns with regard to sensitive and potentially identifying data, the supporting data cannot be made openly available, as stated by the Sectoral Committee of Social Security and Health—Department Health and the Data Protection Authority. Both are subcommittees of the Belgian Commission for the Protection of Privacy. In addition, the ethics committee of the Ghent University Hospital

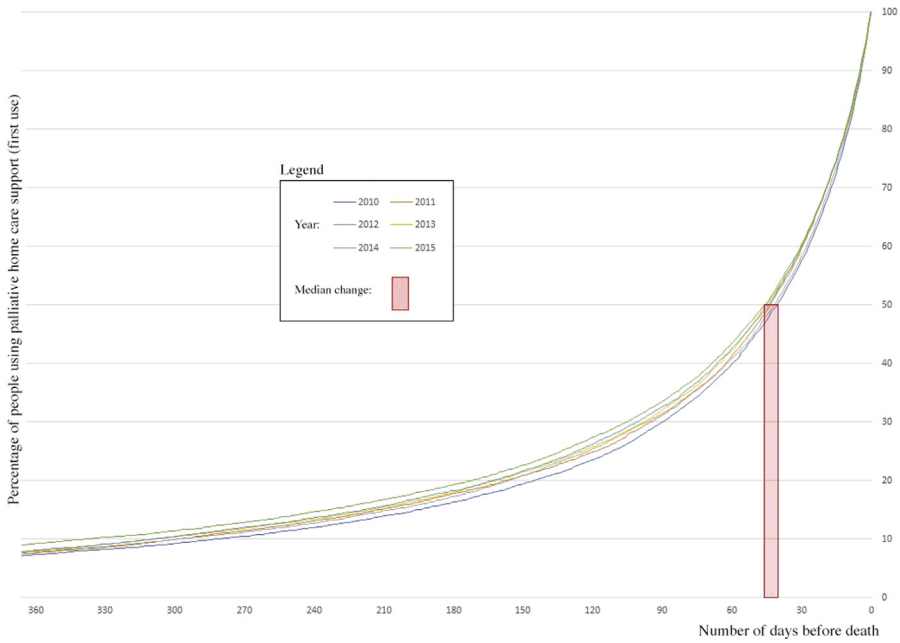

Fig. 3. Timing of first use of any type of palliative home care support among all home-dwelling adults who died of an illness indicative of palliative care needs and used palliative home care support, 2010–2015 ($n = 77{,}723$). People with first use of any type of palliative home care support 365–720 days before death were not shown in figure but were included in the analysis.

provided approval (B670201422382). Further information about the data and access regulations are available on request.

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Appendix

Study Design and Data Sources

The design is a retrospective cohort study using administrative databases. In this study, we measured the use and timing of use of three types of palliative home care support (PHCS) in the entire population of people who lived at home and died of an illness indicative of having palliative care needs in Belgium over a period of six years. We obtained data from eight linked, routinely collected population-level databases: 1) the sociodemographic database of all individuals with health care 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 (containing 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.

Study Setting and Participants

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 comprising deaths from underlying causes that can be considered indicative of a need for palliative care (i.e., both specialist and nonspecialist palliative care), as identified through mixed-methods research.[1,2] 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 chronic obstructive pulmonary disease; 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 noncancerous 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 PHCS are (fully) available to this group.

Palliative Home Care Support

Using reimbursement codes registered in the database, we were able to measure the use of the following types of PHCS in Belgium:

- nomenclature codes 774056, 774071, and 784092 for multidisciplinary specialist palliative home care team;
- nomenclature codes 427055, 427136, 427033, 427114, 427011, 427092, 427173, 427195, 427151, 427070, and 564211 for palliative home care nursing or physiotherapy; and
- nomenclature code 740213 for allowance for palliative home care patients.

For each individual reimbursement record of PHCS, 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.

Supportive policies for palliative care at home, defined here as "palliative home care support," have existed in Belgium since 1985.[3] In 2002, palliative care was recognized under 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"[4]) and an intention to die at home are eligible for the following types of PHCS:

1. The use of a **multidisciplinary specialist palliative home care team:** these teams include at least one general practitioner, two nurses with at least a minimum amount of palliative care training, and an administrative assistant. The main goal of the multidisciplinary palliative home care teams is to advice GPs, health professionals, counselors, 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 multidisciplinary teams are financed with a fixed amount per patient receiving care. This amount is calculated based on the composition of the team in terms of the qualifications and seniority of the team members. The use of these teams is free of charge for the patient and not limited in time.
2. **Palliative home care nursing or physiotherapy:** nurses or physiotherapists with at least a basic training in palliative care provide nursing care or physiotherapy at home. The standard fee for nursing care at home is raised, depending on

the degree of care needs as measured on the Katz scale. The use of palliative home care nursing or physiotherapy is free of charge for the patient and not limited in time.

3. The **allowance for palliative home patients:** a lump sum of €663.49 (in 2018). The request should be actively resubmitted by a physician. This allowance is meant to cover partially reimbursed or nonreimbursed costs related to the provision of palliative care at home (e.g., certain medicines and care materials and equipment). It is limited in time: 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.

Standardization

To capture changes in the pattern of PHCS use related to factors other than changing morbidity, mortality, and demographics, we applied direct standardization. Decedent categories were based on cause of death (cancer, organ failure, dementia, and other illnesses indicative of palliative care needs), age (0–64 years, 65–84 years, and 85 years or older), and gender groups. This would mean asking, for example, whether the propensity for male decedents aged 65–84 years dying of cancer to use PHCS changes over time. The standardized rates are obtained by using the following formulae[5]:

d = event (using palliative home care support)

j = strata (decedent category: gender–age–cause of death, e.g., number of men aged 65–84 years dying of cancer in one year)

t = year (2010–2015)

Nd_{it} = *number* of events d in stratum j in year t of the observed population (e.g., observed number of people using palliative home care support for men aged 65–84 years dying of cancer in one year)

N_{it} = *number* of persons in stratum j in year t of the observed population (e.g., total observed number of deaths for men aged 65–84 years dying of cancer in one year)

N_{ij10} = *number* of persons in stratum j in the reference year 2010 (e.g., deaths of men aged 65–84 years dying of cancer in the reference year 2010)

N_t = total *number* of deaths in year t of the observed population

N_{10} = total *number* of deaths in the reference year 2010

$P_{dit} = \frac{N_{djt}}{N_{jt}}$, the *rate* of deaths for event d (using palliative home care support) in stratum j in year t (e.g., proportion of deaths using palliative home care support for men aged 65–84 years dying of cancer in one year)

$P_{dit10} = \frac{N_{dj10}}{N_{j10}}$, the *rate* of deaths with event d (using palliative home care support) in stratum j of the reference population (year 2010)

The standardized rates are calculated as follows:

$$\frac{\sum_j P_{djt} \times N_{J10}}{N_{10}}$$

First, we calculated the event rate for each stratum (P_{djt}). This number was then multiplied by the number of deaths for that stratum in the reference population (N_{j10}, e.g., men aged 65–84 years dying of cancer in the base year 2010), which resulted in the expected number of decedents using PHCS in the reference population. This number tells us, based on the population number in 2010, how many people in each decedent category would have used PHCS based on the propensity for that decedent category to use PHCS for a year other than 2010. These expected numbers of deaths using PHCS in the reference population (2010) were summarized across all decedent groups and then divided by the total number of deaths in the reference population (year 2010). In other words, we kept the distribution of total deaths by age, gender, and cause of death constant in the period and applied the actual proportions of PHCS use within each decedent group (combination of age, gender, and cause of death) in each year to calculate standardized PHCS use proportions using 2010 as the base year. Standardized trends in PHCS use by cause of death, age, and gender are illustrated in Figure 2 in the article and contrasted with actual proportions of PHCS use. The closer the standardized and actual proportions were, the more the trends are influenced by shifts in PHCS use within the group. Conversely, larger differences reflect more influence from changes in decedent age–gender–cause of death composition on trends in PHCS use.

To capture changes in the pattern of PHCS use by cause of death and age groups separately, direct standardization was applied to separate cause of death and age groups. The decedent categories were then based on age and sex groups (for cause of death) or on cause of death and sex groups (for age), and the same procedure was followed as that described previously.

Least Squares Regression Slope

To measure the degree of increase or decrease in uptake of palliative home care use over all six years (2010–2015), we calculated the slope of the least squares regression. The slope presents the average percent-point increase per year, based on the shortest distance from each point in time to a linear regression line, thus minimizing the variance (the sum of squares of the errors). For example, a slope of 1 indicates an average increase in the use of PHCS of 1 percent-point per year. We calculated the least squares regression slope using the "LINEST" function in Microsoft Excel.

Table S1

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		
Population Characteristics	$n = 37,537$, Actual % (Std %[b])	$n = 37,364$, Actual % (Std %[b])	$n = 38,893$, Actual % (Std %[b])	$n = 39,414$, Actual % (Std %[b])	$n = 38,244$, Actual % (Std %[b])	$n = 39,252$, Actual % (Std %[b])	p.p. Change[a] (Std)	Least Squares Regression Slope
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 yrs	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 yrs	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 yrs	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 yrs	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 yrs	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 yrs	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 yrs	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 yrs	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 yrs	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 yrs	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 yrs	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 yrs	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)

[a]p.p. change = percent point change was calculated between 2010 and 2015. *P*-values were not calculated because the data are on the population level.
[b]Std = standardized uptake was standardized for age, sex, and cause of death.

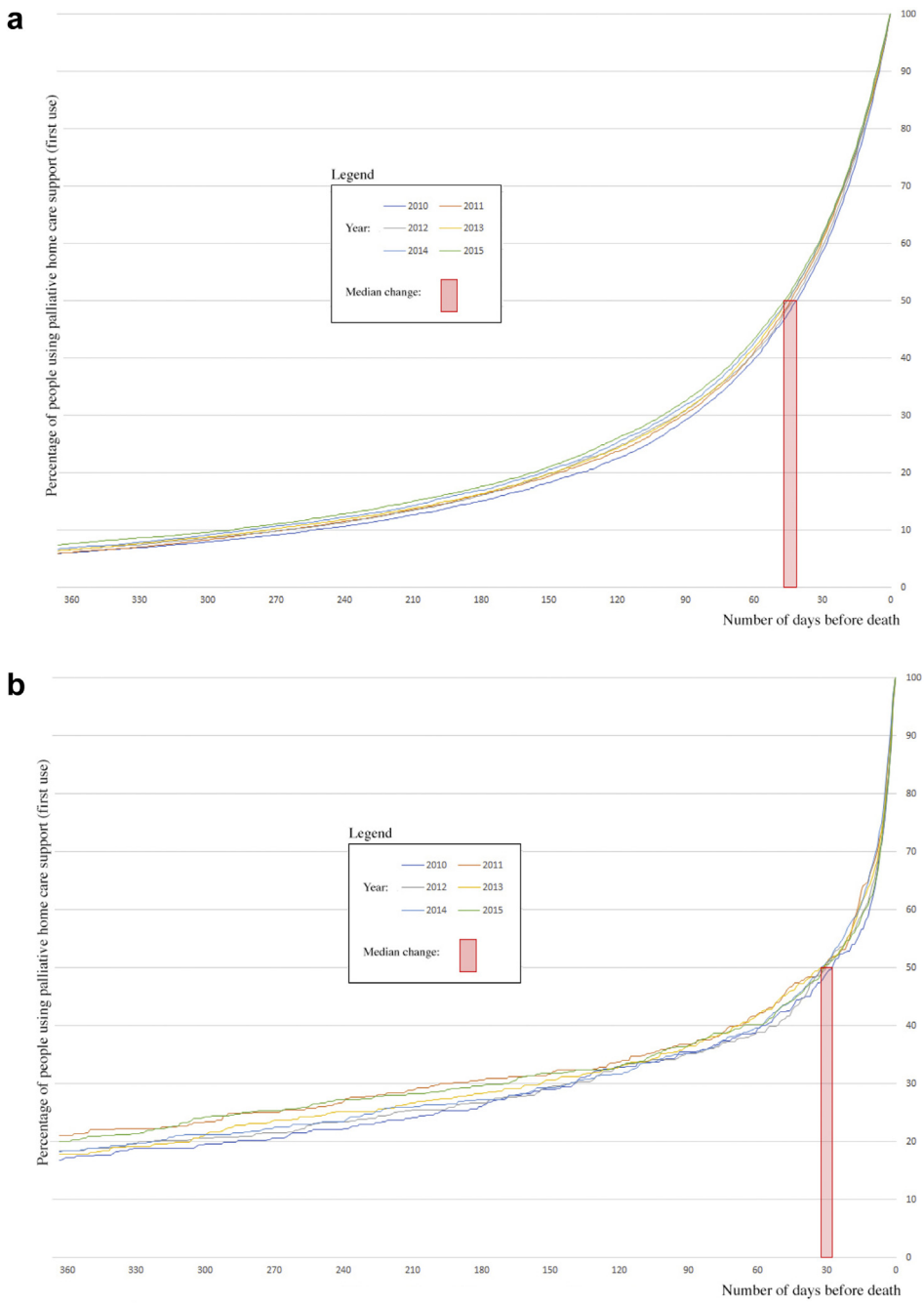


Fig. S1. a) Timing of first use of palliative home care support (PHCS) among all home-dwelling adults who died of cancer and used palliative home care support, 2010–2015 ($n = 64{,}890$). b) Timing of first use of palliative home care support among all home-dwelling adults who died of dementia and used palliative home care support, 2010–2015 ($n = 3091$). c) 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 ($n = 6504$). d) 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 ($n = 3319$). e) Timing of first use of palliative home care support among all home-dwelling adult men who used palliative home care support, 2010–2015 ($n = 44{,}459$). f) Timing of first use of palliative home care support among all home-dwelling adult women who used palliative home care support, 2010–2015 ($n = 33{,}264$). g) 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 ($n = 20{,}047$). h) 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 ($n = 44{,}698$); i) 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 ($n = 12{,}932$).

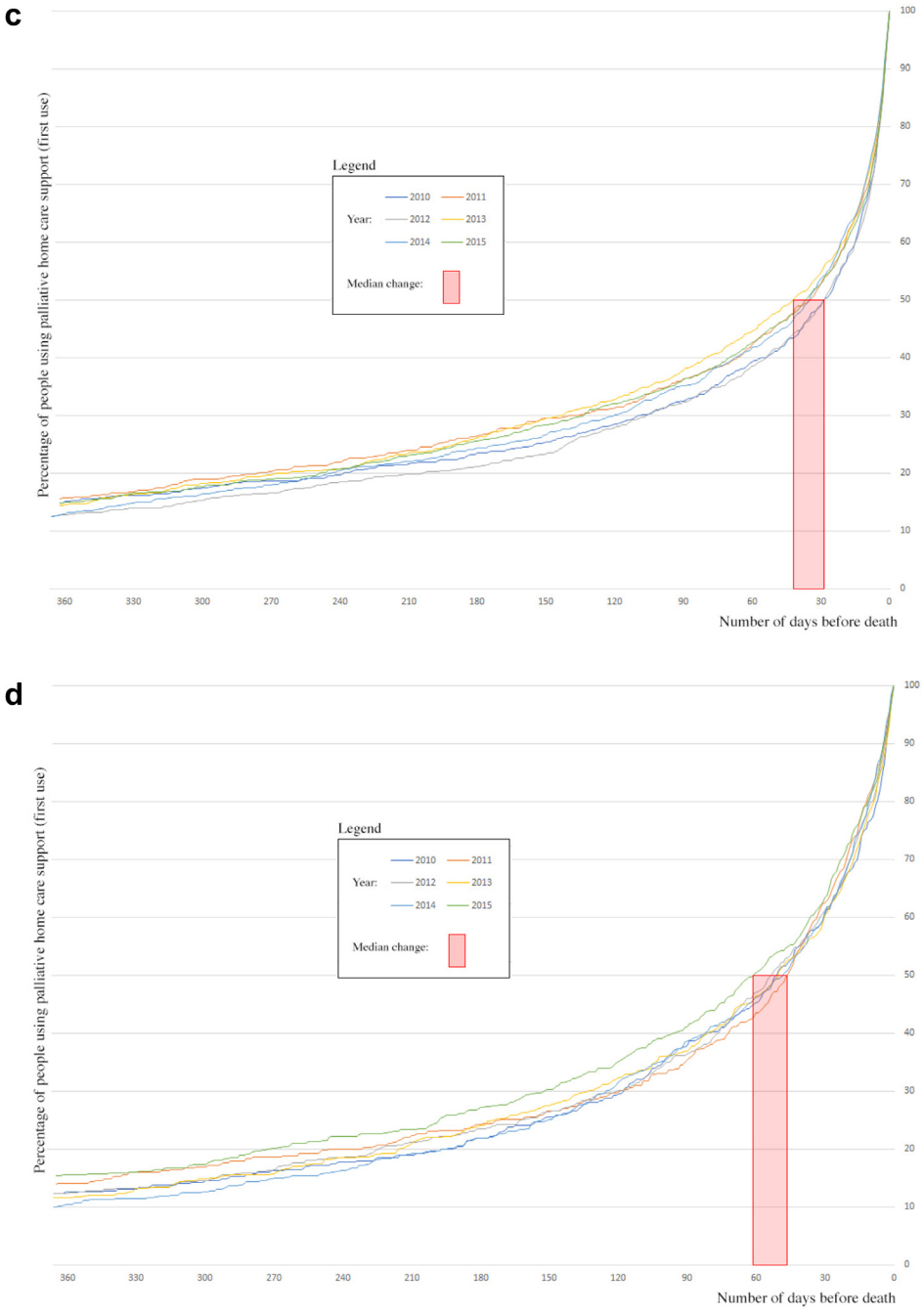


Fig. S1. (*continued*).

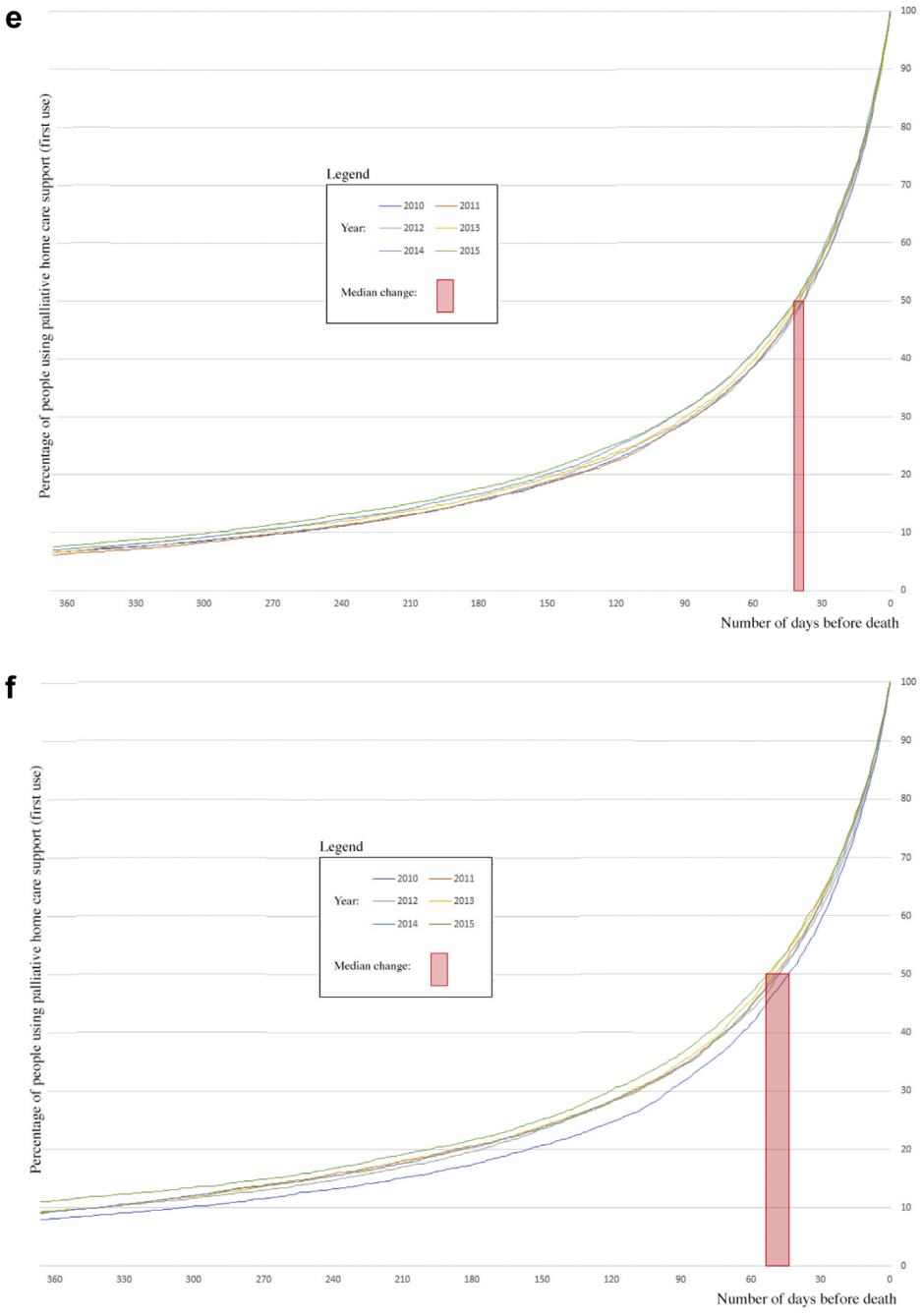
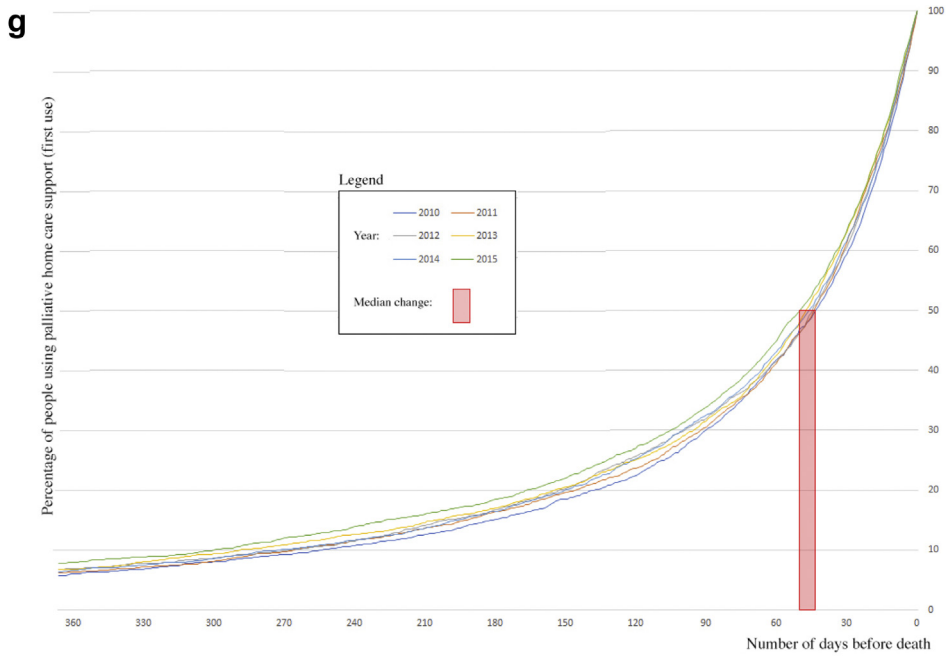


Fig. S1. (*continued*).



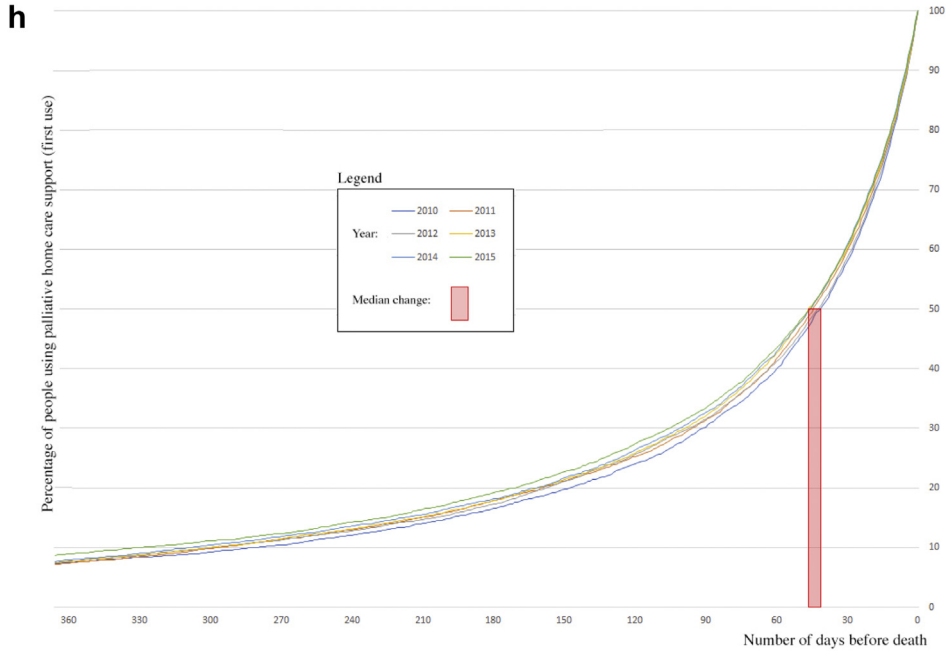


Fig. S1. (*continued*).

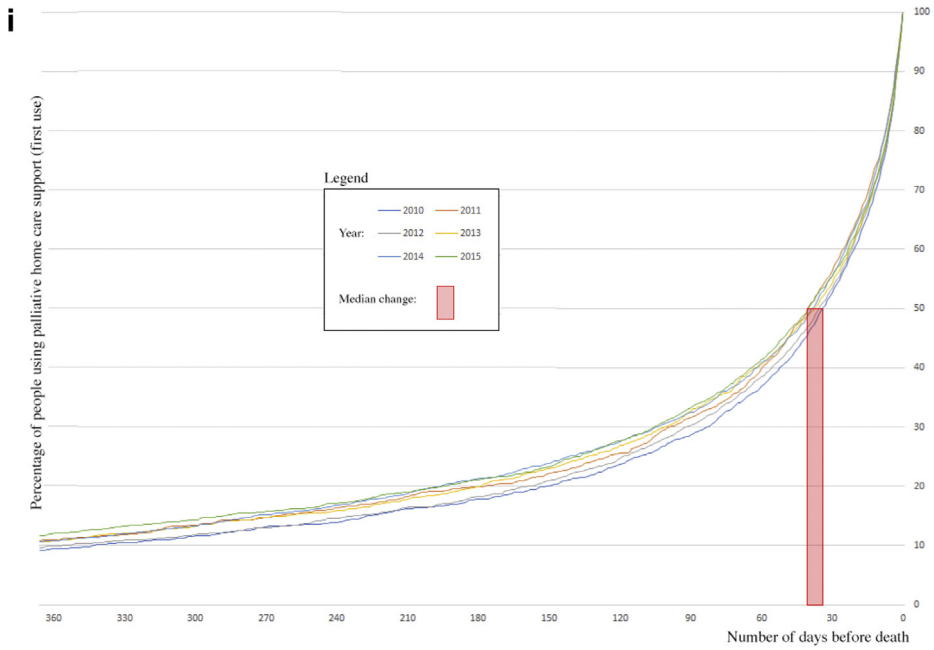


Fig. S1. (*continued*).

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