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Palliative home care support improves quality of care and decreases costs at the end of life: a population-level matched cohort study

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Full title: Palliative home care support improves quality of care and decreases costs at the end of life: a population-level matched cohort study

Short title: Palliative home care support and quality and costs of end-of-life care

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Abstract

Objectives: To evaluate the impact of using 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=107847).

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: The use of any available palliative home care support measure in the last 720 to 15 days of life.

Main outcome measures: For appropriateness or inappropriateness of end-of-life care: home death, number of family physician contacts, number of primary caregiver contacts, hospital death, hospital admission, ICU admission, ED admission, diagnostic testing, blood transfusion, surgery. Total inpatient and outpatient costs. All outcomes were measured in the last 14 days of life.

Results: Those using palliative home care support had more contacts with their family physician (3.1 [SD=6.5] vs. 0.8 [SD=1.2]), more often died at home (56.2% vs. 13.8%; RR=4.08, 95%CI: 3.86-4.31), had a lower risk of hospital admission (27.4% vs. 60.8%; RR=0.45, 95%CI 0.43-0.46), ICU admission (18.3% vs. 40.4%; RR=0.45, 95%CI 0.43-0.48), ED admission (15.2% vs. 28.1%; RR=0.54, 95%CI 0.51-0.57), undergoing diagnostic testing (27.2% vs. 63.2%). Average total costs of care were lower for those using palliative home care support (€3081 [SD=€2669] vs. €4698 [SD=€4233]).

Conclusions: Palliative home care support use positively impacts quality of care and reduces total costs of care at the end of life. To improve the quality of care provided at the end of life of patients and at the same time reduce the expenses, policy makers and healthcare practitioners should increasingly focus on communicating the existing options for palliative home care support to patients and their caregivers, to achieve the desired uptake.

Keywords: end-of-life care, cohort study, quality of care

Strengths and limitations of this study

- By using nationwide administrative data on every death over one whole year, our findings are generalisable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain underrepresented subgroups and lack the strength necessary for generalisability.
- A matched cohort study design with a high-quality matching is the best possible technique to evaluate the impact of policy on quality and costs of care.
- No previous work has evaluated the impact of all palliative home care support measures available in one country for the full population.
- Our operationalisation 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.
- Important aspects of quality end-of-life care are not visible in administrative data, such as quality of communication, existential or psychological care. Qualitative research can complement our findings.

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 hospitalisations at the end of life.[3] It is estimated that palliative care could be beneficial in 38 to 74 percent of all deaths worldwide.[4] In recent years, policy makers internationally have focussed on promoting the integration of palliative care services into the community and on developing supportive 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 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 focussing on costs and findings reported up to 35% lower costs in the intervention group compared with a control group, but not all studies reported significant differences. 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. 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 of a group receiving palliative home care support and a group not receiving it 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] Four retrospective cohort studies found an impact of palliative home care support on reducing hospitalisations at the end of life and on lower chances for hospital deaths in Canada, England, Italy and the US.[17–20] Findings from another retrospective cohort study suggested that a proactive home-based palliative care programme '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 full-population 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 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. A cohort that used at least one type of palliative home care support was matched to a control cohort from the same pool 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.[22] We followed an extension of the STROBE 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 here.

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 two years of life (recorded as nomenclature codes) including dispensed medication in the hospital and community pharmacy in the last two years of life (recorded as 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, and death certificate data (including underlying cause of death, coded using ICD-10 codification).[23] The data linkage process and content is described in detail elsewhere.[24]

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). 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 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[25]. In 2002, palliative care was recognised 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 [26]. These are:

a. The use of a **multi-disciplinary palliative home care team:** which includes at least one general practitioner, two nurses and an administrative assistant. The main goal of the multi-disciplinary palliative home care teams is to advise GPs, 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 one month) and meant to cover for non- or partially reimbursed costs that are related to the provision of palliative care at home (e.g. certain medicines, care materials and tools).

It is important to note that all healthcare insured people in Belgium have the right to access these palliative home care support measures. 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 measures. Receiving any of these palliative home care support measures is chosen as exposure because we consider the different types of support to be an indication of the same intervention: initiation of palliative home care. However, sensitivity analyses are performed in which each separate support measure is selected as the basis for the exposure group.

Non-exposure group

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

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

We used RAND/UCLA validated quality indicators (QI) for end-of-life care to measure appropriateness and inappropriateness of end-of-life care on an aggregated level. 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. [27]. From the total set of quality indicators that were validated in previous research, we excluded those that were disease-specific (e.g. only validated as relevant for cancer patients) or that were applicable only with regard to nursing homes (e.g. "ICU admission from nursing home"). The quality indicators measure the prevalence of specific medication types (recorded in the data sources using Anatomical Therapeutic Chemical Classification System [ATC] codes) or health care interventions (recorded in the data sources as nomenclature codes for reimbursement purposes) within a specified period before death. For example, the quality indicator "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 fourteen days of life.

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, electrocardiogram or pulmonary function testing); having a blood transfusion; and having surgery.

Costs of end-of-life

Based on all specific healthcare consumption data, we calculated total health care 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 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. The propensity score was calculated using baseline covariates that were considered relevant predictors for receiving palliative home care: 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, J47], other organ failures i.e. heart, renal, and liver failure [I11-I13, I50, K70-72, N10-12, N18-19], neurodegenerative diseases i.e. Alzheimer's, Parkinson's, motor neurone, and Huntington's disease [F01, F03, G10, G12, G20, 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 urbanisation of residence, region of residence, and hospital use in the last two years of life (based on the criteria: 'having had at least six hospitalisations' and 'being at least 120 days in the hospital'). We used a greedy one to one case-control propensity score matching algorithm.[28] 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, etcetera. 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-square 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, standard errors and interquartile ranges. All analyses were performed using SAS Enterprise Guide version 7.1 (SAS Institute, Cary, NC).

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 82.612 individuals of which 11.149 (13.5%) had initiated palliative home care support (Figure 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 two years of life) (Table 1). After propensity score matching, 8837 exposed people were matched to as many unexposed people. We performed sensitivity analyses on each supportive measure separately (shown in appendix) with no substantial differences between these measures in the impact on the quality and cost outcomes.

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		**After propensity score matching**	
Characteristics	**Exposed**	**Unexposed**	**Exposed**	**Unexposed**
No. of patients	11 149	71 472	8837	8837
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
Other 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
Urbanisation				
Very high	25.1	33.7	25.7	25.6
High	28.5	27.5	29.2	28.7
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 hospitalised	4.7	5.3	4.6	4.0
>= 6 hospitalisations	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%), urbanisation (1657; 1.9%). *Income quartiles were calculated on the full population of decedents (n=107 847).

Indicators of appropriate end-of-life care

Fifty-six percent of the people using palliative home care support died at home, compared to 13.8 percent of those who did not use palliative home care support (Relative Risk (RR)=4.08; 95% Confidence Interval (CI) (3.86-4.31) (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 two weeks of life, compared to two primary caregiver contacts and less than one family physician contact for those in the unexposed cohort.

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, %		
	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.

Indicators of inappropriate end-of-life care

Thirty-nine percent of the people using palliative home care support died in the hospital, compared to 74.8 percent of the people not using palliative home care support (RR=0.52; 95%CI 0.51-0.54). Less people in the palliative home care support cohort were admitted to a hospital (27.4% vs 60.8%; RR=0.45, 95%CI 0.43-0.46), to an intensive care unit (18.3% vs 40.4%; RR=0.45, 95%CI 0.43-0.48), or to an emergency department (15.2% vs 28.1%; RR=0.54, 95%CI 0.51-0.57) in the last two 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 0.41-0.45), received blood transfusion (2.7% vs 5.9%; RR=0.47, 95%CI 0.40-0.54), or surgery (0.5% vs 2.8%; RR=0.19, 95%CI 0.14-0.26). (Table 2)

Medical care costs

Mean total inpatient costs were lower for people using palliative home care support (€1766; Standard Error=30.6) compared to those who did not use palliative home care support (€4222; SE=45.6) (Table 3). Mean total outpatient costs were higher for people using palliative home care support (€1314;

SE=11.6) compared to those who did not (€476; SE=7.9). Mean incremental total costs for exposed versus unexposed people in the last two weeks of life was -€1617 (SE=53.2).

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

	Palliative home care support				
	Yes (n=8837)		No (n=8837)		
	Mean (SE)	**Median (Q1-Q3)**	**Mean (SD)**	**Median (Q1-Q3)**	**Mean incremental (SE)**
Total inpatient costs	1766 (30.6)	0 (0-2724)	4222 (45.6)	3400 (513-6754)	-2454 (54.9)
Total outpatient costs	1314 (11.6)	1243 (449-1829)	476 (7.9)	251 (11-647)	838 (14.0)
Total costs	3081 (28.4)	2055 (1305-4227)	4698 (45.0)	3996 (1077-7124)	-1617 (53.2)

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 quality indicators. 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 two 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, emergency department, or ICU, and fewer were underwent diagnostic testing, blood transfusion, or surgery in the last two 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 two weeks of life by €1617. Costs of palliative home care support use that was continued in the last two weeks of life are also taken into account. A literature review on costs of palliative care interventions in all settings between 2002-2011 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.[29] However, the review notes that randomisation is absent in most of the studies, highlighting the importance of controlling for confounding factors and selection bias when analysing 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 programme in southern California on costs in four disease-groups, and found that participants had in the last six months of life monthly net savings of $4258 for cancer, $4017 for COPD, $3447 for heart failure and $2690 for dementia.[21] Although generalising 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 [13,17,30–32]. 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.[31] The rate of home deaths in the exposed and unexposed groups of our study, respectively 56.2% and 13.8%, was comparable to 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 take into account individual preferences on place of death and quality of death itself [33], our results show that the palliative home care support measures are effective in increasing the chance for home deaths on a population level, which is an important policy goal of these measures [26].

Additionally, our study found that the use of palliative home care support has an impact on reducing hospital, emergency department and intensive care unit admissions in the last two weeks of life. This finding is in line with previous research,[17,20,34], but our study is the first to confirm such findings on a full population level.

Strikingly, only 14 percent of all home-dwelling adults who died in Belgium in 2012 used palliative home care support in the last two 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 three months or less. Although this status does not exclude the patient from receiving specific types of health care, 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 of palliative home care support.

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 generalisable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain underrepresented subgroups and lack the strength necessary for generalisability [3]. Secondly, we used a previously validated set of quality indicators specifically developed to evaluate end-of-life care on a population level.[27]. 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 [35]. Our operationalisation 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. 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.[36] In Belgium—where health insurance is obligatory—administrative health claims data provide information on 99% of the population's health care 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 randomised 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.[30] 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 people quality of life increases and cost decreases. This is 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 quality indicators 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 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 full 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 remains 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.

Declarations

Authorship

The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Arno Maetens, Kim Beernaert, Joachim Cohen and Luc Deliens contributed to the conception and design of the article. Collection, analysis, and interpretation of data were done by Arno Maetens, Kim Beernaert, Robrecht De Schreye, Kristof Faes, Lieven Annemans, Koen Pardon, Luc Deliens, and Joachim Cohen. Arno Maetens wrote the manuscript. The final approval of the manuscript was done by Kim Beernaert, Robrecht De Schreye, Kristof Faes, Lieven Annemans, Koen Pardon, Luc Deliens, and Joachim Cohen.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethics approval and consent to participate

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: 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. Additionally, the ethics committee of the Ghent University Hospital provided approval (B670201422382).

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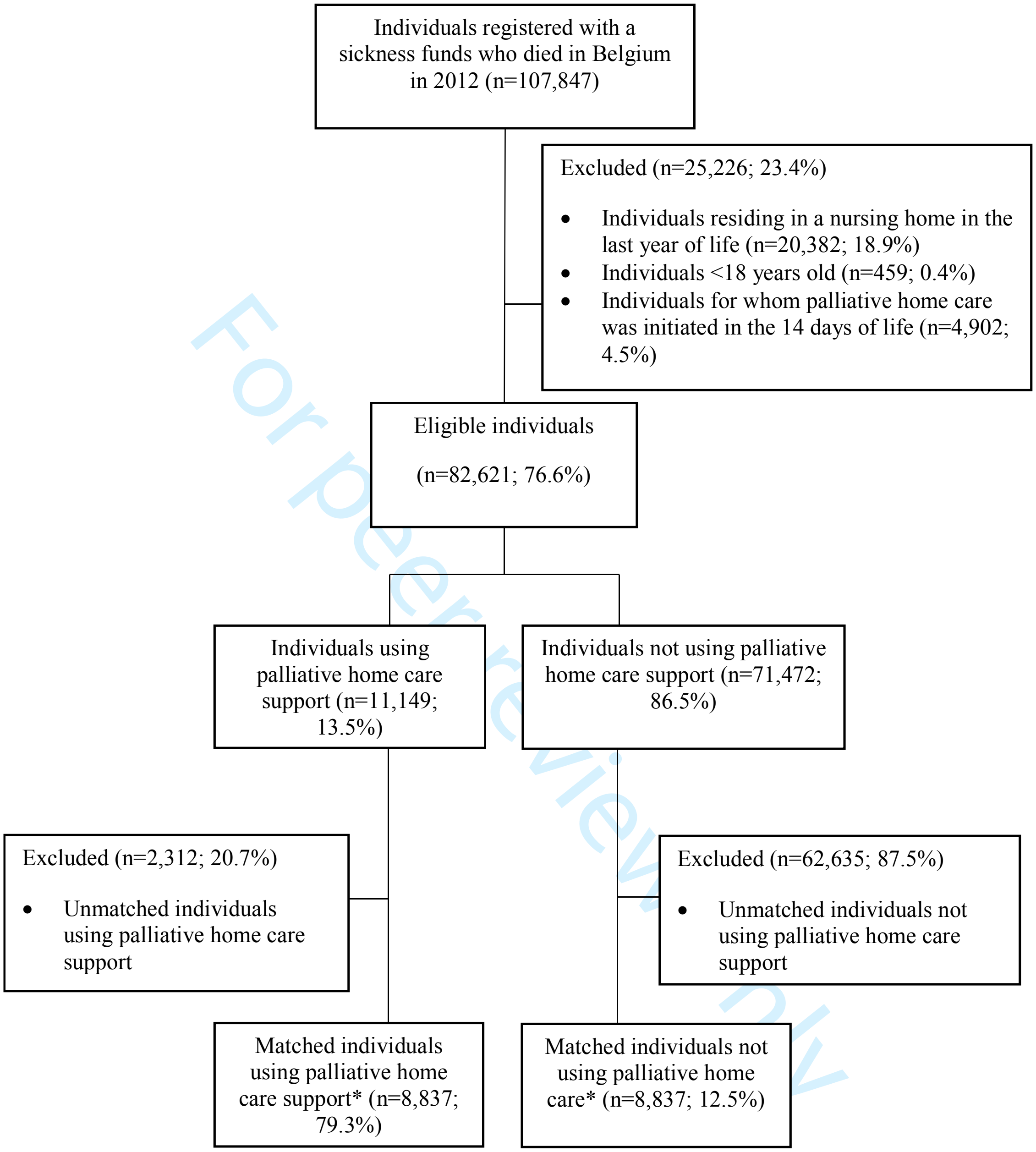
Figure 1: Flowchart of the study population selection



* The full propensity score matching procedure, including variables used in the matching, are described in detail further.

Supplementary file for manuscript: Impact of palliative home care support on the quality and costs of care at the end of life: a nationwide matched cohort study

Conflict of interest statement and funding

The authors report a grant during the conduct of the study. There are no potential conflicts of interest to be reported.

All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Ethical approvals

The study was approved by an ethical commission, and the data linkage and use was approved by the relevant statistical supervisory bodies.

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

	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)**	**RR (95% CI)**	**Yes (n=4108)**	**No (n=4108)**	**RR (95% CI)**	**Yes (n=6171)**	**No (n=6171)**	**RR (95% CI)**
Indicators of appropriate end-of-life care									
Home death	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)**	3·2 (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)**	9·4 (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	39·7	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	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	18·2	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	15·0	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	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	2·8	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	2·7	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)**	**Yes (n=8216)**	**No (n=8216)**	**Yes (n=6171)**	**No (n=6171)**
Total inpatient costs	1775 (32.2)	4118 (47.6)	1585 (43.8)	3864 (66.4)	1634 (35.9)	3821 (53.1)
Total outpatient costs	1330 (12.3)	519 (9.1)	1310 (15.7)	687 (14.4)	1496 (14.0)	595 (10.7)
Total costs	3105 (29.8)	4637 (46.7)	2895 (40.9)	4551 (64.2)	3129 (32.8)	4416 (52.0)

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.

Supplementary box 1: Determination of inpatient and outpatient care costs

Persons affiliated to the Belgian National Institute for Health and Disability Insurance are entitled to reimbursement of the cost of healthcare services· treatments and fees provided that the services in question meet certain requirements. Not every healthcare profession or service is entitled to reimbursement. A list of reimbursable services or **acts** for each profession· the so called **nomenclature** assigns a specific code (nomenclature code) to each act that determines the financial cost and is used as a base for the reimbursement of healthcare costs. **Nomenclature codes** can be divided into acts which are assigned to ambulatory care i.e. outpatient care and institutionalized care i.e. inpatient care. There are more than 26 thousand reimbursed acts.

Inpatient or institutionalized care refers to any medical service or act that requires an hospitalization or an act which is provided during an admission and stay into a hospital. To qualify as an inpatient· a patient must be under the care of a physician while staying overnight in the hospital.

Outpatient or ambulatory care includes all acts that does not require an overnight stay in a hospital or medical facility. Outpatient care is mainly administered in a medical office· hospital· nursing home facility or at home.

The total cost is the sum of all inpatient and outpatient acts described in the nomenclature.

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	p.1	RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	p.1
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported	p.3-4		
Objectives	3	State specific objectives, including any prespecified hypotheses	p.4		
Methods					
Study Design	4	Present key elements of study design early in the paper	p.4-5		
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	p.5		
Participants	6	*(a) Cohort study* - Give the eligibility criteria, and the		RECORD 6.1: The methods of study population selection (such as codes or	p.5

		sources and methods of selection of participants. Describe methods of follow-up *Case-control study* - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study* - Give the eligibility criteria, and the sources and methods of selection of participants *(b) Cohort study* - For matched studies, give matching criteria and number of exposed and unexposed *Case-control study* - For matched studies, give matching criteria and the number of controls per case		algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided. RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.	p.5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.		RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	p.6-7
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	p.6-7		
Bias	9	Describe any efforts to address potential sources of bias	p.6-7		
Study size	10	Explain how the study size was	p.6-7		

		arrived at			
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	p.6-7		
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) *Cohort study* - If applicable, explain how loss to follow-up was addressed *Case-control study* - If applicable, explain how matching of cases and controls was addressed *Cross-sectional study* - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses	p.6-7		
Data access and cleaning methods		..		RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population. RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	p.5 NA
Linkage		..		RECORD 12.3: State whether the study included person-level, institutional-	p.5

				level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (*e.g.*, numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study (*i.e.,* study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	p.8 and p.15
Descriptive data	14	(a) Give characteristics of study participants (*e.g.*, demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) *Cohort study* - summarise follow-up time (*e.g.*, average and total amount)	p.8		
Outcome data	15	*Cohort study* - Report numbers of outcome events or summary measures over time *Case-control study* - Report numbers in each exposure category, or summary measures of exposure *Cross-sectional study* - Report numbers of outcome events or summary measures	p.8		
Main results	16	(a) Give unadjusted estimates	p.8		

		and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period			
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	p.8		
Discussion					
Key results	18	Summarise key results with reference to study objectives	p.9		
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	p.10
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	p.9		
Generalisability	21	Discuss the generalisability (external validity) of the study results	p.11		

Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	p.12		
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	

*Reference: Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

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

Short title: Palliative home care support and quality and costs of end-of-life care

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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=107847).

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, ICU admission, ED admission, diagnostic testing, blood transfusion, 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 to 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% vs. 13.8%; RR=4.08, 95%CI: 3.86-4.31), lower risk of hospital admission (27.4% vs. 60.8%; RR=0.45, 95%CI 0.43-0.46), ICU admission (18.3% vs. 40.4%; RR=0.45, 95%CI 0.43-0.48), or ED admission (15.2% vs. 28.1%; RR=0.54, 95%CI 0.51-0.57). Mean total costs of care were lower for those using palliative home care support (€3081 [95%CI 3025-3136] vs. €4698 [95%CI 4610-4787]; 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.

Keywords: end-of-life care, cohort study, quality of care

Strengths and limitations of this study

- By using nationwide administrative data on every death over one whole year, our findings are generalisable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain underrepresented subgroups and lack the strength necessary for generalisability.
- A matched cohort study design with a high-quality matching is the best possible technique to evaluate the impact of policy on quality and costs of care, given ethical and practical concerns.
- No previous work has evaluated the impact of all palliative home care support available in one country for the full population.
- Our operationalisation of palliative home care support as the use of any of available policy measure 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.
- Important aspects of quality end-of-life care are not visible in administrative data, such as quality of communication, existential or psychological care. Qualitative research can complement our findings.

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 hospitalisations at the end of life.[3] It is estimated that palliative care could be beneficial in 38 to 74 percent of all deaths worldwide.[4] In recent years, policy makers internationally have focussed 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 focussed 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 hospitalisations at the end of life and on lower chances for hospital deaths in Canada, England, and the US.[17–20] Findings from another retrospective cohort study suggested that a proactive home-based palliative care programme '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.[22] We followed an extension of the STROBE 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: Flowchart 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 two years of life (recorded as nomenclature codes) including dispensed medication in the hospital and community pharmacy in the last two years of life (recorded as 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 ICD-10 codification).[23] The data linkage process and content is described in detail elsewhere.[24]

Patient and public involvement

We used previously validated quality indicators (QI) 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, i.e. up to 720 days before death. We did not want to exclude persons on the basis of a (retrospectively) predefined timeframe, 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[25]. In 2002, palliative care was recognised 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 [26]. These are:

a. The use of a **multi-disciplinary palliative home care team:** which includes at least one general practitioner, two nurses and an administrative assistant. The main goal of the multi-disciplinary 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 one month) and meant to cover for non- 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 health care 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 two years of life were included in the non-exposure group.

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

We used quality indicators 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” [27]. 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, electrocardiogram or pulmonary function testing); having a blood transfusion; and having surgery.

The quality indicators measure the prevalence of specific medication types (recorded in the data sources using Anatomical Therapeutic Chemical Classification System [ATC] codes) or health care interventions (recorded in the data sources as nomenclature codes for reimbursement purposes) within a specified period before death. For example, the quality indicator “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 fourteen 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. [28].

Costs of end-of-life

Based on all specific healthcare consumption data, we calculated total health care 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 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, J47], other organ failures i.e. heart, renal, and liver failure [I11-I13, I50, K70-72, N10-12, N18-19], neurodegenerative diseases i.e. Alzheimer's, Parkinson's, motor neurone, and Huntington's disease [F01, F03, G10, G12, G20, 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 urbanisation of residence, region of residence, and hospital use in the last two years of life (based on the criteria: 'having had at least six hospitalisations' and 'being at least 120 days in the hospital'). We used a greedy one to one case-control propensity score matching algorithm.[29] 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, etcetera. 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-square 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, standard errors and interquartile ranges. All analyses were performed using SAS Enterprise Guide version 7.1 (SAS Institute, Cary, NC).

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 two 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 quality indicator outcomes (Supplementary table 1).

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
Other 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
Urbanisation				
Very high	25.1	33.7	25.7	25.6
High	28.5	27.5	29.2	28.7
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 hospitalised	4.7	5.3	4.6	4.0
>= 6 hospitalisations	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%), urbanisation (1657; 1.9%). *Income quartiles were calculated on the full population of decedents (n=107 847).

Indicators of appropriate end-of-life care

Fifty-six percent of the people using palliative home care support died at home, compared to 13.8 percent of those who did not use palliative home care support (Relative Risk (RR)=4.08; 95% Confidence Interval (CI) (3.86-4.31) (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 two weeks of life, compared to two primary caregiver contacts and less than one family physician contact for those in the unexposed cohort.

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.

Indicators of inappropriate end-of-life care

Thirty-nine percent of the people using palliative home care support died in the hospital, compared to 74.8 percent of the people not using palliative home care support (RR=0.52; 95%CI 0.51-0.54). Less people in the palliative home care support cohort were admitted to a hospital (27.4% vs 60.8%; RR=0.45, 95%CI 0.43-0.46), to an intensive care unit (18.3% vs 40.4%; RR=0.45, 95%CI 0.43-0.48), or to an emergency department (15.2% vs 28.1%; RR=0.54, 95%CI 0.51-0.57) in the last two 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 0.41-0.45), received blood transfusion (2.7% vs 5.9%; RR=0.47, 95%CI 0.40-0.54), or surgery (0.5% vs 2.8%; RR=0.19, 95%CI 0.14-0.26). (Table 2)

Medical care costs

Mean total inpatient costs were lower for people using palliative home care support (€1766; 95%CI: €1706-€1826) compared to those who did not use palliative home care support (€4222; 95%CI: €4133-€4311) (p<0.001) (Table 3). Mean total outpatient costs were higher for people using palliative home care support (€1314; 95%CI: €1291-€1337) compared to those who did not (€476; 95%CI: €461-€492) (p<0.001). Mean incremental total costs for exposed versus unexposed people in the last two 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 (Supplementary table 2).

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 quality indicators. 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 two 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, emergency department, or ICU, and fewer were underwent diagnostic testing, blood transfusion, or surgery in the last two 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 two weeks of life by €1617. Costs of palliative home care support use that was continued in the last two weeks of life are also taken into account. A literature review on costs of palliative care interventions in all settings between 2002-2011 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.[30] However, the review notes that randomisation is absent in most of the studies, highlighting the importance of controlling for confounding factors and selection bias when analysing 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 programme in southern California on costs in four disease-groups, and found that participants had in the last six months of life monthly net savings of $4258 for cancer, $4017 for COPD, $3447 for heart failure and $2690 for dementia.[21] Although generalising 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 [13,17,31–33]. 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.[32] The rate of home deaths in the exposed and unexposed groups of our study, respectively 56.2% and 13.8%, was comparable to 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 take into account individual preferences on place of death and quality of death itself [34], 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 [26].

Additionally, our study found that the use of palliative home care support has an impact on reducing hospital, emergency department and intensive care unit admissions in the last two weeks of life. This finding is in line with previous research,[17,20,35], but our study is the first to confirm such findings on a complete population level.

Strikingly, only 14 percent of all home-dwelling adults who died in Belgium in 2012 used palliative home care support in the last two 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 three months or less. Although this status does not exclude the patient from receiving specific types of health care, 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 generalisable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain underrepresented subgroups and lack the strength necessary for generalisability [3]. Secondly, we used a previously validated set of quality indicators specifically developed to evaluate end-of-life care on a population level.[28]. 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 [36]. Our operationalisation 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 health care 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.[37] In Belgium—where health insurance is obligatory—administrative health claims data provide information on 99% of the population's health care 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 randomised 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.[31] 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 quality indicators 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.

Declarations

Contributorship statement

The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Arno Maetens, Kim Beernaert, Joachim Cohen and Luc Deliens contributed to the conception and design of the article. Collection, analysis, and interpretation of data were done by Arno Maetens, Kim Beernaert, Robrecht De Schreye, Kristof Faes, Lieven Annemans, Koen Pardon, Luc Deliens, and Joachim Cohen. Arno Maetens wrote the manuscript. The final approval of the manuscript was done by Kim Beernaert, Robrecht De Schreye, Kristof Faes, Lieven Annemans, Koen Pardon, Luc Deliens, and Joachim Cohen.

Declaration of competing interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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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. Due 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. Additionally, the ethics committee of the Ghent University Hospital provided approval (B670201422382). Further information about the data and access regulations are available upon request.

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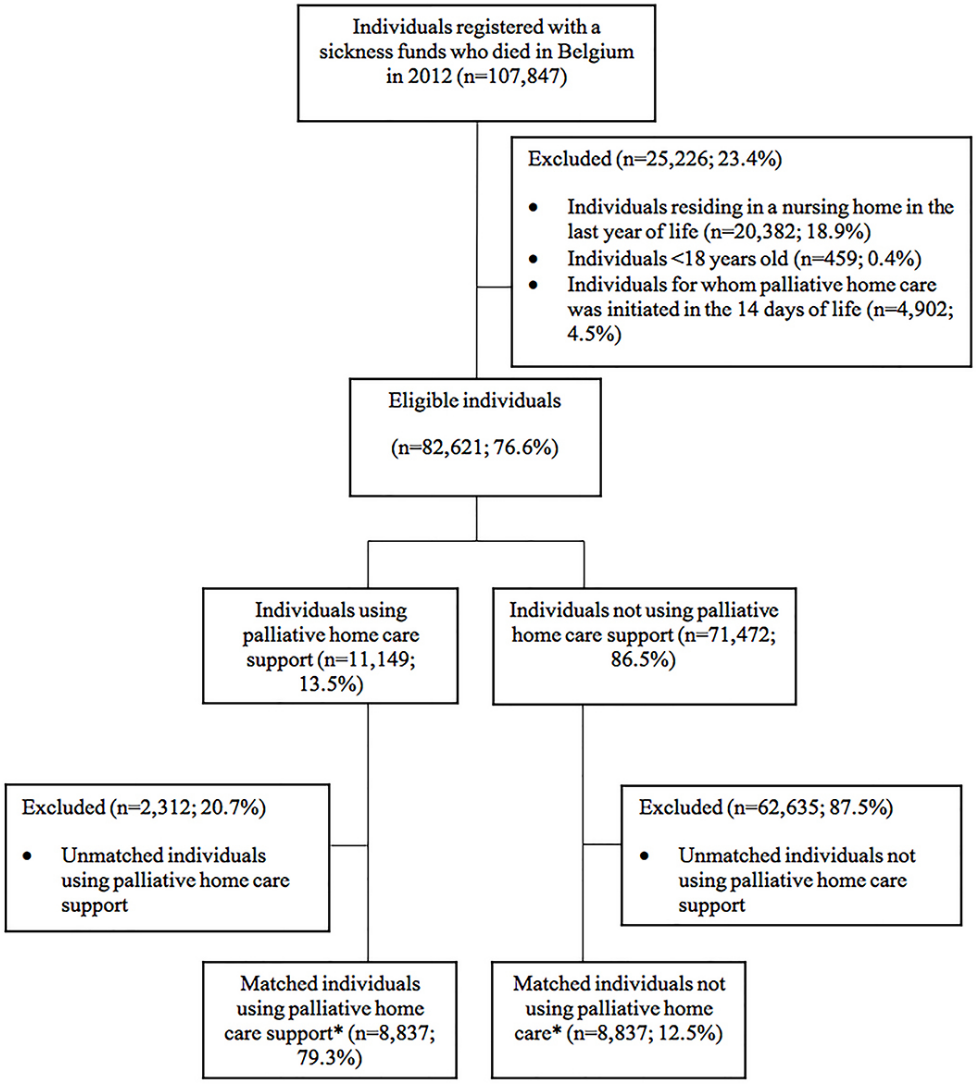

Figure 1: Flowchart of the study population selection

91x99mm (300 x 300 DPI)

Supplementary file for manuscript: Impact of palliative home care support on the quality and costs of care at the end of life: a nationwide matched cohort study

Supplementary 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.

Supplementary box 1: Determination of inpatient and outpatient care costs

Persons affiliated to the Belgian National Institute for Health and Disability Insurance are entitled to reimbursement of the cost of healthcare services· treatments and fees provided that the services in question meet certain requirements. Not every healthcare profession or service is entitled to reimbursement. A list of reimbursable services or **acts** for each profession· the so called **nomenclature** assigns a specific code (nomenclature code) to each act that determines the financial cost and is used as a base for the reimbursement of healthcare costs. **Nomenclature codes** can be divided into acts which are assigned to ambulatory care i.e. outpatient care and institutionalized care i.e. inpatient care. There are more than 26 thousand reimbursed acts.

Inpatient or institutionalized care refers to any medical service or act that requires an hospitalization or an act which is provided during an admission and stay into a hospital. To qualify as an inpatient· a patient must be under the care of a physician while staying overnight in the hospital.

Outpatient or ambulatory care includes all acts that does not require an overnight stay in a hospital or medical facility. Outpatient care is mainly administered in a medical office· hospital· nursing home facility or at home.

The total cost is the sum of all inpatient and outpatient acts described in the nomenclature.

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	p.1	RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	p.1
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported	p.3-4		
Objectives	3	State specific objectives, including any prespecified hypotheses	p.4		
Methods					
Study Design	4	Present key elements of study design early in the paper	p.4-5		
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	p.5		
Participants	6	*(a) Cohort study* - Give the eligibility criteria, and the		RECORD 6.1: The methods of study population selection (such as codes or	p.5

		sources and methods of selection of participants. Describe methods of follow-up *Case-control study* - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study* - Give the eligibility criteria, and the sources and methods of selection of participants *(b) Cohort study* - For matched studies, give matching criteria and number of exposed and unexposed *Case-control study* - For matched studies, give matching criteria and the number of controls per case		algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided. RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.	p.5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.		RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	p.6-7
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	p.6-7		
Bias	9	Describe any efforts to address potential sources of bias	p.6-7		
Study size	10	Explain how the study size was	p.6-7		

		arrived at			
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	p.6-7		
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) *Cohort study* - If applicable, explain how loss to follow-up was addressed *Case-control study* - If applicable, explain how matching of cases and controls was addressed *Cross-sectional study* - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses	p.6-7		
Data access and cleaning methods		..		RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population. RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	p.5 NA
Linkage		..		RECORD 12.3: State whether the study included person-level, institutional-	p.5

				level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (*e.g.*, numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study (*i.e.,* study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	p.8 and p.15
Descriptive data	14	(a) Give characteristics of study participants (*e.g.*, demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) *Cohort study* - summarise follow-up time (*e.g.*, average and total amount)	p.8		
Outcome data	15	*Cohort study* - Report numbers of outcome events or summary measures over time *Case-control study* - Report numbers in each exposure category, or summary measures of exposure *Cross-sectional study* - Report numbers of outcome events or summary measures	p.8		
Main results	16	(a) Give unadjusted estimates	p.8		

		and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period			
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	p.8		
Discussion					
Key results	18	Summarise key results with reference to study objectives	p.9		
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	p.10
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	p.9		
Generalisability	21	Discuss the generalisability (external validity) of the study results	p.11		

Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	p.12		
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	

*Reference: Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.