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How many cancer patients need palliative care? A population-based study

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Abstract

Background: The number of cancer patients potentially amenable to palliative care is conventionally estimated from cancer deaths, as reported in the death certificates. However, a more representative population should also include cancer patients who die from causes other than cancer, as they may develop other life-limiting chronic conditions leading to terminal prognosis.

Aim: This study aimed at refining the assessment of the number of cancer patients potentially in need of palliative care, by linked hospital and death data.

Design: Retrospective study.

Setting/Participants: Residents in the Emilia Romagna Region in Italy, who died between 2009 and 2017.

Results: We identified a potential palliative care population of 157,547 cancer patients. The use of different administrative data sources enhanced the sensitivity of our selection. Starting from a standard estimate of 129,212 patients based on cancer as the primary cause of death, we showed that the additional use of hospital records identified a further 11.4% of possible palliative care patients (14,687). Also considering cancer as secondary cause of death, the estimate further increased by 10.6% (13,648 new cases). Notably, the proportion of cancer patients selected by the additional data sources were characterized by more advanced age and higher prevalence of comorbidity.

Conclusion: Healthcare services addressing the issue of estimating palliative care needs of cancer patients at a population level should consider that relying on the death certificate alone may lead to underestimating these needs of about 22%.

Keywords

Key Message

This study describes a method to refine the population-based estimate of palliative care needs in cancer patients, conventionally made using death certificates. We show that linking medical records with death certificates provides a more realistic estimate of the potential palliative care population, which better reflects the interrelation between cancer, ageing and comorbidity.

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Since the early 1980s, cancer palliative care has been progressively acknowledged as a needed and essential health service (1). During the last decades, new models and guidelines (2, 3, 4) have been developed which emphasize the benefits of a palliative care approach throughout the illness course. Accordingly, an earlier integration of a palliative care service into standard oncology improves the quality of life of cancer patients and their families/caregivers (5, 6).

In addition, there is increased awareness of the need for palliative care for life-limiting chronic diseases and conditions other than advanced cancer (7, 8), highlighting the need for palliative care to be offered irrespective of diagnosis (9, 10, 11). In middle- and high-income countries, more than 75% of the adult population die from one or more chronic conditions, with a cancer-to-noncancer death ratio of 1:2. Thus, whilst cancer is the largest single disease group accounting for potential palliative care need (7, 9, 12), a comprehensive approach to cancer care should also consider that it is often linked to aging and may coexist with other chronic diseases. The interrelation between cancer and comorbidity has substantial implications for treatment decisions and healthcare management, as it negatively affects patient outcomes and quality of life (13, 14). From a public health perspective, health services and therapeutic pathways should be suitable for responding to the complex needs of these patients. The challenge is to plan and develop early palliative treatment alongside oncological therapies in the continuum of care.

Thus, a key issue is to identify a population of cancer patients who could benefit from this simultaneous care approach. The number of cancer patients potentially amenable to palliative care is conventionally estimated using cancer as the primary cause of death, as reported in the death certificate. However, this selection criterion may bring some drawbacks, including the omission of patients with advanced cancer who could benefit from palliative care but died from concomitant non-cancer life-threatening conditions.

Different methods have been described for estimating palliative care needs at a population level. Several studies have run their selection on either all-cause or disease-specific mortality obtained from death certificate data (7, 15, 16, 17, 18, 19, 20, 21, 22, 23). Some investigators have further refined this method also including symptom prevalence (15), disease prevalence (7) national or regional healthcare statistics (17) and additional diagnostic information for those patients who were admitted to hospital in their last months of life (16, 7, 18, 20, 22).

Notably, these methods considered patients with a wide range of progressive chronic diseases, reflecting the aforesaid recent shift in the focus of palliative care services from advanced cancer to all conditions with life-limiting prognosis (24). The use of several approaches to patient selection also raised the issue of comparing the size and characteristics of the potential palliative care populations identified by a differential use of linked hospital records and death certificates (18, 20, 22). On one hand, population estimates can vary significantly, depending on the data sources and the inclusion criteria used; on the other, adding hospital admission data to death certificates can enhance selection sensitivity.

This simultaneous care approach, which fosters early palliative care integrated with the standard oncological care pathway.

For this purpose, we used linked administrative healthcare databases to improve the reliability of a first standard selection of patients solely based on cancer as the underlying cause of death

Methods

Study design and population

This is a population-based retrospective study that attempted to identify cancer patients potentially in need for palliative care, starting from mortality data and tracing back the individual's care pathways. We used data from administrative healthcare databases, considering all individuals resident in the Emilia-Romagna Region, who died between 2009 and 2017.

Data sources

Data on deaths were obtained from the Regional Mortality Register (RMR), in which causes of death are encoded with the International Classification of Diseases 10th revision (ICD-10) codes. In the RMR, the primary cause of death is defined as the underlying disease or injury that initiated the chain of morbid events that led to death. Moreover, other significant diseases, conditions or injuries that contributed to death (secondary causes of death), as they are stated in the death certificate, can also be documented.

Information on hospital admissions is recorded on the Regional Hospital Discharge Database (HDD), whereas data on hospice stay are recorded on Regional HOSP databases. Each hospital or hospice record contains demographic data of patient, medical departments providing the care, any transfer among hospital wards, admission and discharge dates, the International Classification of Diseases 9th revision with Clinical Modification (ICD-9-CM) codes of primary diagnosis for admission, concomitant chronic diseases and procedures performed during hospital or hospice stay.

Data about Home Health Care are recorded on Regional ADI (*Assistenza Domiciliare Integrata*) database, that includes socio-demographic and clinical information about patients as well as ICD-9 codes of the main and concomitant diagnoses along with the type of care provided at home.

The records are submitted on a regular basis by healthcare providers to the Regional Authority for Health and Welfare, routinely checked before being included in the Regional administrative databases and audits to control consistency of data, as well as subsequent corrective actions are periodically performed.

Selection method and analysis

We identified the primary cause of death, cancer hospitalizations recorded in the last year of life and cases in which cancer was reported as secondary cause of death. We identified three subpopulations potentially eligible for palliative care:

1. RMR PRY subpopulation (standard selection): patients who died of cancer as the primary (underlying) cause, with (HDD+) or without (HDD-) cancer hospitalization in the last year of life.
2. HDD subpopulation: patients who were hospitalized for cancer in the last year of life, without cancer being reported as the primary or secondary cause of death.
3. RMR SEC subpopulation: patients who had cancer recorded as a secondary (contributory) but not primary cause of death, with (HDD+) or without (HDD-) cancer hospitalization in the last year of life.

Each patient was classified according to the type of cancer, based on the ICD-9-CM and ICD-10 diagnosis codes reported in the death certificate as well as in hospital records, as described in Table 1. Carcinomas in situ and benign tumours were included only if they were detected as primary or secondary cause of death.

Table 1: International Classification of Disease codes used to estimate palliative care needs

Type of cancer	HDD: ICD9-CM code	RMR: ICD-10 code
Solid	140-194	C00-C75
Haematological	200-208	C81-C96
Secondary or unspecified site	195-199, 239	C76-C80, C97
Uncertain behaviour	235-238	D37-D48

The record-linkage between death and hospital records allowed to detect, for each patient, any concomitant chronic conditions, identified through ICD-9-CM codes (25) recorded during hospitalizations in the last two years of life.

The record-linkage with ADI or HOSP databases enabled to find out information on palliative care use and place of death.

The size and characteristics of the three subpopulations were compared to underline any difference related to the specific data sources used.

Data management was carried out with SAS 9.3 software (SAS Institute, Cary, NC).

Ethics permission was granted by the Ethics Committee of Area Vasta Emilia Nord (approval No. 2018/0053215).

Results

A standard selection based solely on cancer as the primary cause of death (RMR PRY selection) identified 129,212 cancer patients potentially eligible for palliative care. Most of them (114,005, 88.2%) also had at least one cancer hospitalization in the year preceding death (RMR PRY, HDD+).

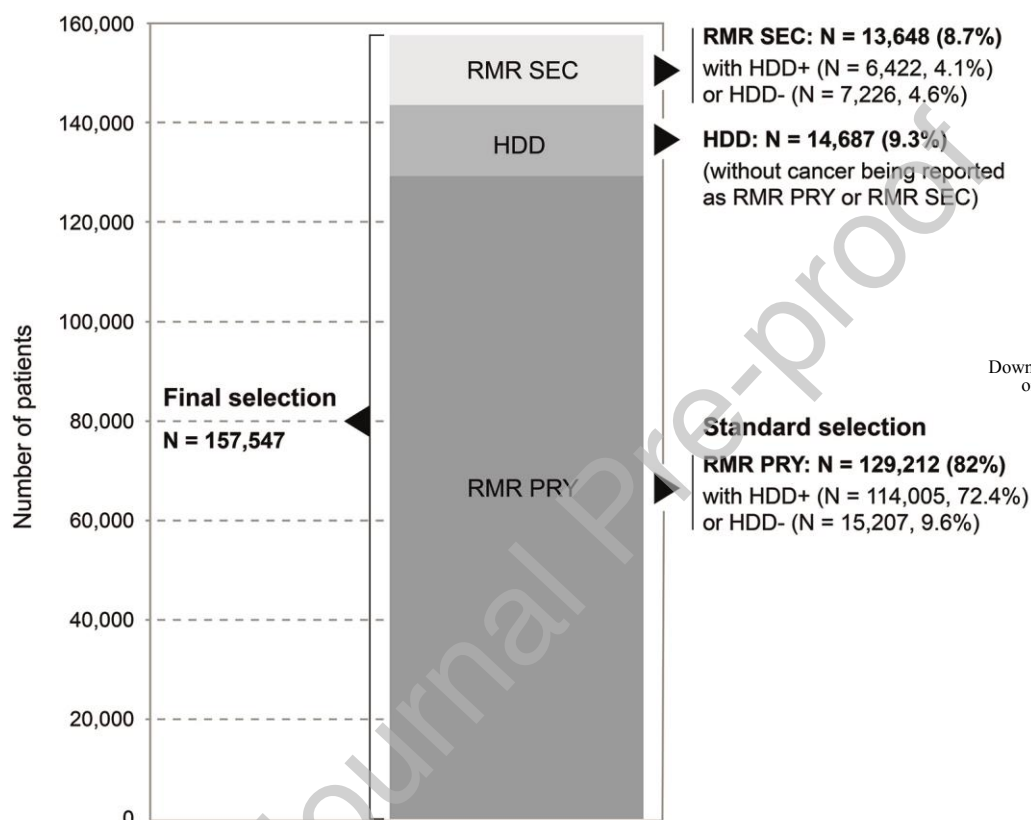
The use of additional selection criteria (cancer as secondary cause of death and cancer hospitalizations) led to an inclusion of further 28,335 individuals. Of these, 13,648 were identified through the RMR SEC selection and had the

behaviour (17.6%), secondary (3.1%) and others classified as carcinoma in situ or benign (2.7%). Forty-seven percent (6,422) of these patients had also been previously hospitalized for cancer (RMR SEC, HDD+). The additional 14,687 patients were selected through the HDD and diagnosed with the following types of cancer: solid (66.4%), haematological (11.5%), with uncertain behaviour (17.8%) and secondary (4.2%).

As a result, a total of 157,547 people had a cancer condition potentially amenable to palliative care.

Figure 1. Population of cancer patients potentially eligible for palliative care in the Emilia-Romagna Region.

Footnotes: RMR PRY=Regional Mortality Register, cancer as primary cause of death; RMR SEC = Regional Mortality Register, cancer as secondary cause of death; HDD = Hospital Discharge Database; HDD+ = at least one cancer hospitalization; HDD- = no cancer hospitalization (hospitalizations refer to the last year of life).



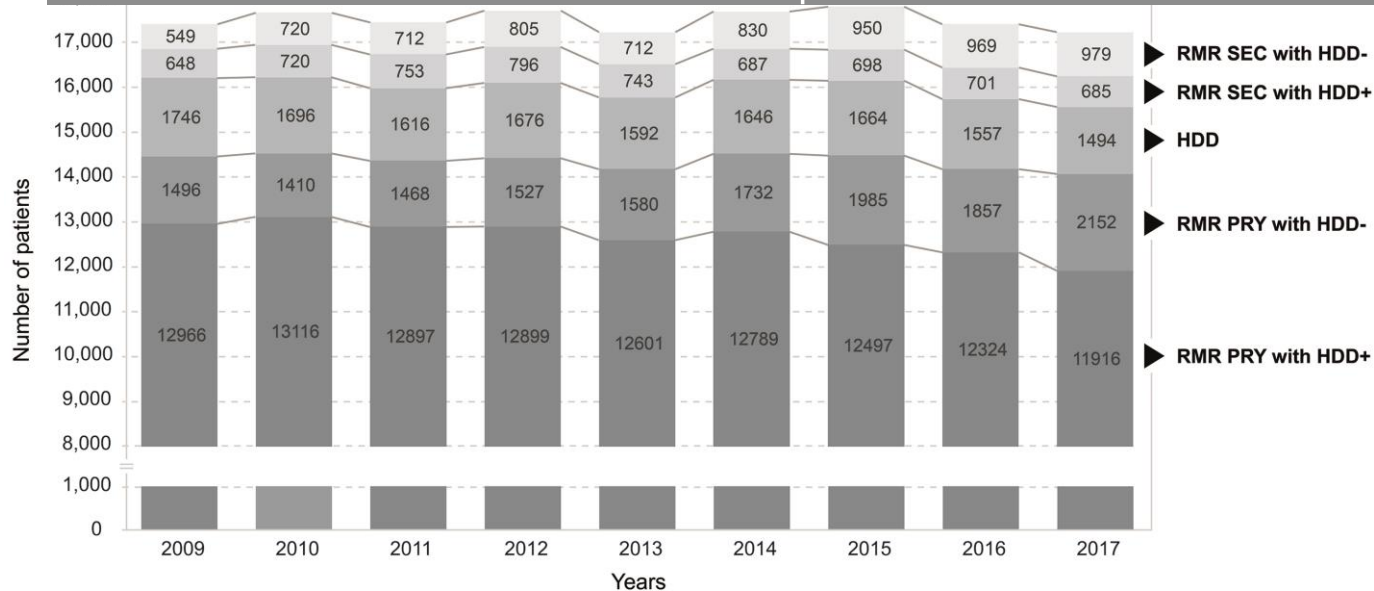
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Time trend of the population estimate

The overall number of patients eligible for palliative care remained almost unchanged over the years (about 17,500/year), except for some variations in the numerical contribution of individual data sources.

Figure 2. Time trend of the palliative care population estimate, according to the data sources used.

Footnotes: RMR PRY =Regional Mortality Register, cancer as primary cause of death; RMR SEC = Regional Mortality Register, cancer as secondary cause of death; HDD = Hospital Discharge Database; HDD+ = at least one cancer hospitalization; HDD- = no cancer hospitalization (hospitalizations refer to the last year of life).



Cancer hospitalizations diminished over time both among patients who died from cancer and those who died from other causes. From 2009 to 2017, the former (RMR PRY with HDD +) shrank from 12,966 to 11,916 (-8%); the latter (HDD) showed a drop from 1,746 to 1,494 cases (-14%). In contrast, the use of the RMR alone (RMR PRY with HDD- and RMR SEC with HDD-), allowed to identify an increasing number of patients over the years (from 2,045 in 2009 to 3,131 in 2017, +53%). This result especially holds for patients selected through the secondary causes of death (RMR SEC with HDD-): the reporting of cancer as a significant condition contributing to death increased from 549 to 979 records (+78%). Combining these results, the composition of the population changed slightly over time: RMR SEC subpopulation increased by +39%, while the number of patients selected through RMR PRY and HDD decreased by -2.7% and -14.4%, respectively.

Demographic and clinical characteristics of the subpopulations (Table 2)

Age. Most RMR SEC (68.7%) and HDD (65.9%) patients were over 80 years old (vs. 40.9% of RMR PRY patients), with a consequent lower proportion of people under 65 (4.9% and 6.7%, respectively, vs. 18.3% in the RMR PRY subpopulation).

Death certificate: primary (underlying) causes of death. Among the RMR PRY patients, solid cancers (79.8%) were the most reported underlying causes of death, followed by haematological cancers (8.2%) and others classified as secondary or with uncertain behaviour (8.5%). In contrast, both HDD and RMR SEC patients died of causes different from cancer: the most frequent were cardiovascular diseases (HDD: 44.4%, RMR SEC: 55.3%), followed by diseases of the respiratory system (HDD: 12.8%, RMR SEC: 9.7%) and digestive system (HDD: 9.5%, RMR SEC: 6.9%).

Chronic comorbidities. More than half of patients had one or more concomitant chronic conditions, in addition to cancer. The prevalence of comorbidities was higher among those identified with HDD (81.5%) and RMR SEC (67.9%) data sources than with the standard RMR PRY selection (46.4%). Cardio/cerebrovascular diseases (28.4%), diabetes mellitus (13.4%), renal disease (8.8%) and dementia (5.6%) were the main comorbidities of RMR PRY patients. The

in some cases (e.g., cardio/cerebrovascular diseases, dementia) even 2 or 3 times more frequent.

Place of death. Hospital was the most common place of death, regardless of the data source used. However, hospital deaths among RMR PRY patients were less frequent (46.5%), with respect to both HDD (67.5%) and RMR SEC (55.2%) patients. Notably, hospice was the place of death for about one quarter of RMR PRY patients; in contrast, a negligible proportion (1.2%) of RMR SEC and HDD patients were reported to die during a hospice stay. Rates of deaths at home ranged from 27% among RMR PRY and HDD patients to 36% in RMR SEC patients.

Palliative care in the last six months of life. The distribution of hospice palliative care across the three subgroups reflected that of hospice deaths: 26.2% of RMR PRY patients benefited from palliative care in hospice, as opposed to 2.1% and 1.9% of HDD and RMR SEC subpopulations, respectively. Moreover, within each subpopulation, about 45% of patients benefited from home health care.

Table 2: Characteristics of the subpopulations of patients potentially eligible for palliative care based on data sources.

Characteristics of patients		Standard selection		Additional data sources			
		RMR PRY		HDD		RMR SEC	
		(N = 129,212)		(N = 14,687)		(N = 13,648)	
		n	%	n	%	n	%
Gender	Male	70,450	54.5	8,522	58	7,550	55.3
Age	<65	23,832	18.4	989	6.7	668	4.9
	65-80	52,558	40.7	4,012	27.3	3,600	26.4
	>80	52,822	40.9	9,686	65.9	9,380	68.7
Primary (underlying) causes of death (ICD-10)	<i>Cancer</i>						
	Solid	103,153	79.8	-	-	-	-
	Haematological	10,623	8.2	-	-	-	-
	Secondary or unspecified site	11,027	8.5	-	-	-	-
Source: RMR	Uncertain behaviour	3,815	3	-	-	-	-
	Benign/Carcinoma in situ ¹	594	0.5	-	-	-	-
	<i>Non-cancer</i>						
	Diseases of the cardiovascular system	-	-	6,521	44.4	7,545	55.3
	Diseases of the respiratory system	-	-	1,876	12.8	1,326	9.7
	Diseases of the digestive system	-	-	1,390	9.5	947	6.9
	Some infectious and parasitic diseases	-	-	1,102	7.5	803	5.9
	Endocrine, nutritional, and metabolic diseases	-	-	615	4.2	685	5
	Diseases of the genitourinary system	-	-	575	3.9	319	2.3
	Psychic and behavioural disorders	-	-	517	3.5	664	4.9
	Diseases of the nervous system	-	-	479	3.3	618	4.5
	Other	-	-	1,612	11	741	5.4
Chronic comorbidities other than cancer	Cardiovascular/Cerebrovascular disease	36,632	28.4	9,426	64.2	7,518	55.1
	Dementia	7,189	5.6	2,927	19.9	2,217	16.2
	Renal disease	11,351	8.8	3,400	23.1	2,381	17.4

(ICD)								
	Rheumatic disease	992	0.8	283	1.9	159	1.2	
Source: HDD	Other diseases	10,937	8.5	1,962	13.4	1,085	7.9	
Number of chronic comorbidities	None	69,245	53.6	2,721	18.5	4,386	32.1	
(other than cancer)	One	35,682	27.6	4,025	27.4	3,521	25.8	
	Two	15,840	12.3	3,709	25.3	2,908	21.3	
Source: HDD	Three or more	8,445	6.5	4,232	28.8	2,833	20.8	
Place of death	Hospital	60,049	46.5	9,912	67.5	7,533	55.2	
	Hospice	30,683	23.7	169	1.2	167	1.2	
	Home	35,219	27.3	3,989	27.2	4,914	36	
	Other	3,261	2.5	617	4.2	1,034	7.6	
Palliative care ³	Hospice	33,840	26.2	310	2.1	255	1.9	
	Home health care	61,699	47.8	6,423	43.7	5,812	42.6	
	Hospice or home health care	77,892	60.3	6,540	44.5	5,912	43.3	

Notes: data refer to residents deceased from 2009 to 2017; absolute (percentage) frequencies are reported; RMR PRY = Regional Mortality Register, cancer as primary cause of death; HDD = Hospital Discharge Database; RMR SEC = Regional Mortality Register, cancer as secondary cause of death; ¹ = carcinomas in situ and benign tumours were selected only from the mortality register; ² = as defined by the Charlson Comorbidity Index; ³ = in the last six months of life.

Characteristics of the final population (Table 3)

The final estimated population was equally composed of female and male patients, with a slight male prevalence (54.9%). More than 80% of patients were over the age of 65, with a high frequency of over 80s (45.6%).

Types of cancer. Almost all selected cases (156,578, 99.4%) were affected by malignant cancer with the following prevalence by type: solid (77.4%), haematological (8.7%), secondary or unspecified (7.7%) and with uncertain behaviour (5.6%). Carcinomas in situ and benign tumours as primary cause of death represented the 0.7% of cases in the population.

Prevalence of comorbidity. One out of two patients showed at least one other chronic condition in addition to cancer. Concomitant chronic diseases ranged in number from 1 (27.4%), to 2 (14.3%), up to 3 or more (9.8%). The most common conditions were cardio/cerebrovascular diseases (34%), diabetes (14.2%) and renal diseases (10.9%).

Place of death and palliative care. About half of the selected patients died in hospital (49.2%), although a relevant percentage of deaths was registered in hospice (19.7%) or at home (28%). Most of patients received palliative care either in hospice or at home (57.3%) in the last six months, 21.8% in a hospice setting and 46.9% at home (35.5% exclusively at home).

characterized by more advanced age and higher prevalence of other, often multiple, chronic conditions. Notably, after the addition of these patients, hospital deaths increased (from 46.5% in the standard selection to 49.2% in the final selection) while hospice deaths as well as hospice palliative care use decreased (from 23.7% to 19.3% and from 26.2% to 21.8%, respectively).

Table 3: Characteristics of cancer patients potentially eligible for palliative care in the standard and final selection.

Characteristics of patients		Standard selection:		Final selection:	
		RMR PRY		all eligible patients	
		(N =129,212)		(N =157,547)	
		n	%	n	%
Gender	Male	70,450	54.5	86,522	54.9
Age	<65	23,832	18.4	25,489	16.2
	65-80	52,558	40.7	60,170	38.2
	>80	52,822	40.9	71,888	45.6
Type of cancer (ICD-9 CM, ICD-10) Sources: RMR, HDD	Solid	103,153	79.8	121,983	77.4
	Haematological	10,623	8.2	13,684	8.7
	Secondary or unspecified site	11,027	8.5	12,073	7.7
	Uncertain behaviour	3,815	3.0	8,838	5.6
	Benign/Carcinoma in situ ¹	594	0.5	969	0.7
Chronic comorbidities other than cancer (ICD-9 CM) ² Source: HDD	Cardiovascular/Cerebrovascular disease	36,632	28.4	53,376	34.0
	Dementia	7,189	5.6	12,333	7.8
	Renal disease	11,351	8.8	17,132	10.9
	Diabetes mellitus	17,343	13.4	22,338	14.2
	Rheumatic disease	992	0.8	1,434	0.9
	Other diseases	10,937	8.5	13,984	8.9
Number of chronic comorbidities other than cancer Source: HDD	None	69,245	53.6	76,352	48.5
	One	35,682	27.6	43,228	27.4
	Two	15,840	12.3	22,457	14.3
	Three or more	8,445	6.5	15,510	9.8
Place of death	Hospital	60,049	46.5	77,494	49.2
	Hospice	30,683	23.7	31,019	19.7
	Home	35,219	27.3	44,122	28.0
	Other	3,261	2.5	4,912	3.1
Palliative care ^{3\}	Hospice	33,840	26.2	34,405	21.8
	Home health care	61,699	47.8	73,934	46.9
	Hospice or home health care	77,892	60.3	90,344	57.3

Notes: data refer to residents deceased from 2009 to 2017; absolute (percentage) frequencies are reported; RMR PRY = Regional Mortality Register, cancer as primary cause of death; ¹ = carcinomas in situ and benign tumours were selected only from the mortality register; ² = as defined by the Charlson Comorbidity Index; ³ = in the last six months of life.

Discussion

Basir families, this study presents a method, which aims at being as inclusive as possible in estimating the palliative care needs of cancer patients. The proposed method involved extending the interest also to cancer patients with other concomitant diseases, often coexisting for a long time and leading to poor-quality life and increased risk of death (13).

In line with the approach followed by other researchers (18, 22), we included patients with cancer as underlying as well as contributory causes of death, with the aim to capture not only cancer conditions leading to death but also those influencing it. Furthermore, our method, based on linked administrative health databases, retrospectively traced the care and diagnoses registered starting from the patient's death, further expanding the cohort of cancer patients who could benefit from palliative care.

The implication of this approach is twofold: on one hand, it could reduce the risk of underestimating the population due to any inaccurate coding in the death certificate. Indeed, conditions likely to influence death may not appear on the death certificate, whereas some causes of death may be over-represented (26). On the other hand, it is consistent with the current challenges faced by the health systems, related to progressive ageing of the population and the consequent greater burden of chronic diseases.

In this perspective, the combined use of multiple administrative data sources to estimate the need of palliative care contributed to enhance the sensitivity of our selection. In fact, although the standard selection, based solely on the underlying cause of death, was the main criterion for identifying cancer patients eligible for palliative care (in this study 129,212 cases), the use of hospitalizations increased the selected population by 11.4%. Likewise, adding cancer as contributory cause of death further increased the estimate by 10.6%. Overall, the two additional selections contributed to a 22% increase of the initial population. Thus, our final selection consisted of 157,547 patients: 82% died from cancer, 9% had cancer as a secondary cause of death and a further 9% had a cancer diagnosis in the year prior to death but died from other causes.

As previous studies (18, 22, 23) suggested, this first result highlights that relying on a single data source may lead to underestimating, even considerably, the needs for palliative care. Hospital records, whether associated or not with cancer as primary or secondary cause of death, were indeed a valuable tool in tracing potential needs that the death certificate alone could not identify and provided further clinical features of the cancer patients included in the potential palliative care population.

Our method identified an elderly population, with high prevalence of solid malignant tumours (77.4%) and other concomitant diseases. One or more comorbid conditions were reported in addition to cancer in about 50% of these patients and most of them were over 80. Hospital records and secondary causes of death led to identify groups of very elderly cancer patients (with percentages of over 80s above 65%) and with a significantly higher prevalence of comorbidities (ranging from 67.9% to 81.5%) compared to patients selected through the standard method (46.4%).

In a study of 1000 patients in the standard selection (around 26%), suggesting that older cancer patients with more comorbidities may be generally less likely to receive palliative treatment and instead access other hospital services more frequently.

This result is further evidence that a selection method based solely on cancer deaths may not be fully representative of the actual needs of cancer patients, as it may over-estimate the palliative care provision in the cancer patient population.

Recently, the Lancet Commission on Global Access to Palliative Care and Pain Relief (27) upheld the importance of not solely relying on the number of deaths in quantifying the burden of serious health-related suffering (SHS), defined as suffering associated with a need for palliative care. The Commission developed a new methodology based on both mortality and symptom prevalence data of 20 health conditions that most commonly result either in death or in severe physical and psychological suffering requiring palliative care. Including both decedent and non-decedent SHS patients, they estimated that more 61 million people are affected by SHS. Notably, the first worldwide projection of the future need for palliative care using this new methodological framework indicates that by 2060, an estimated 48 million people (47% of all deaths globally) will die each year with SHS (28).

These findings suggest that combining symptom prevalence with the data sources used in the present work would likely further increase the size of the cancer patient population eligible for palliative care identified through the death certificate and hospital records.

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A potential limitation in this study is that increasing selection sensitivity may reduce selection specificity. The use of hospital admissions data and contributory causes of death could include patients not really in need of palliative care. However, these patients, due to their clinical characteristics, represent a not negligible fraction of the potential palliative care population. Moreover, a broader estimate can provide a useful rough indication to guide health services towards further, more in-depth investigation.

Conclusion

The integrated use of administrative health databases and death certificates can provide a more realistic estimate of palliative care needs than simply selecting cancer deaths. We showed that hospital records and secondary causes of death contributed to identify elderly, multimorbid, not otherwise traceable cancer patients, representing 18% of the potential palliative care population.

As ageing population develops new needs, healthcare services are expected to be equally flexible in their response. Achieving better palliative care for cancer patients requires a correct understanding of the extent of their needs and this study represents a step forward in this direction.

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