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Palliative care for non-cancer conditions in primary care: a time trend analysis in the United Kingdom (2009-2014)

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Abstract (250 words)

Objectives

Whilst guidelines recommend palliative care in non-cancer conditions, this has not been widely implemented. We examined whether the recording of a palliative care approach and the numbers of hospital deaths for deceased patients with heart failure, dementia, chronic obstructive pulmonary disease (COPD) and cancer have changed since the UK End of Life Care Strategy was introduced.

Methods

We conducted sequential cross-sectional studies of decedents within the UK's Clinical Practice Research Datalink and Hospital Episode Statistics. All adults with a primary care record of COPD (N=5,426), dementia (N=7,339), heart failure (N=6,409) or cancer (N=18,668) who died during three one-year periods (April 2009-March 2014) were included. Evidence of a palliative care approach was identified from primary care records, and death in hospital from secondary care data.

Results

From 2009 to 2014, proportions with a primary care record of palliative care increased for COPD from 13.6% to 21.2%; dementia from 20.9% to 40.7%; and heart failure from 12.6% to 21.2%; but remained substantially lower than for cancer (57.6% to 61.9%). Median days before death of recording improved for COPD (145 to 224) and dementia (44 to 209); but not for heart failure (168.5 to 153) and cancer (123 to 114). Trends in hospital deaths were not consistently downward, although the proportions of patients dying in hospital were lower in the last period compared to the first.

Conclusions

Recording of a palliative care approach for non-cancer conditions has increased since the introduction of the UK End of Life Care Strategy, but remains inadequate.

Introduction

A palliative approach to care is important not only in cancer but in non-malignant conditions where patients have palliative care needs comparable to those of cancer patients [1]. Among the most common conditions identified by the World Health Organisation as diseases that would benefit from palliative care are heart failure (HF), dementia and chronic obstructive pulmonary disease (COPD) [2]. Such conditions carry a similar symptom burden and poor quality of life for patients and their families and friends, but there is evidence from the United States [3,4], and the United Kingdom (UK) [5] that these needs are less likely to be met.

In the UK, the introduction of a national End-of-Life Care Strategy in 2008 [6] represented a major policy shift to extend specialist palliative care *regardless of diagnosis*, to be delivered primarily by generalists, with access to specialist palliative care services for persistent or complex problems. Although the role of primary care is central to providing palliative care to those nearing the end of life, information on whether the need is being met in the UK is sparse, despite maintenance of a palliative care register by general practitioners being incentivised as part of the Quality and Outcomes Framework (QOF) since 2006 [7]. Using general practice-based registers of palliative care, one study conducted shortly after the Strategy's introduction, found patients with HF were poorly represented on the register, and when recorded, registration was often within a week of death [8]. Using the same electronic datasource, Bloom and colleagues showed that whilst the proportion of people dying from COPD and receiving palliative care increased between 2005 and 2015, this remained disproportionately low in those dying with COPD only (16.5%) compared with those dying with COPD and cancer (56.5%) [9]. Although from simple observation, the rate of change appears to increase from 2011.

With the aim of exploring whether recording of palliative care in primary care has changed for non-cancer conditions since 2008, patients who died with HF, dementia, or COPD, and for comparison, patients who died with cancer, in three different years were identified in UK's Clinical Practice Research Datalink (CPRD) [10]. Using information in their healthcare records, potential changes in palliative care recording as well as the prevalence of hospital deaths were explored.

Materials and Methods

Patients aged 18 or over with at least one clinical record of COPD; dementia; heart failure; or cancer (excluding non-melanoma skin cancer) who died in the periods 1 April 2009 to 31 March 2010; 1 April 2011 to 31 March 2012; or 1 April 2013 to 31 March 2014, were identified in CPRD using Read codes described in the NHS's Quality and Outcomes Framework (QOF) (QOF version 29, June 2014) [11]. The CPRD is a database of contemporaneous medical records from UK primary care and is demographically representative, covering around c.7% of the UK population [10]; the QOF is a voluntary incentive scheme for general practitioners in the UK [7]. Fact and date of death recorded in primary care records, which have shown a high level of agreement with national death certification, were used to identify patients who had died [12]. Focus was primarily on patients who had only one of these conditions; where two or more were recorded, patients were considered in two additional groups based on whether or not they had cancer. Patients were included if they had at least one year of records and met CPRD acceptability criteria for data quality; for sensitivity analyses, subgroups of patients were established based on whether conditions were recorded either within five years of, or in the year before, death.

The palliative care register that has been part of QOF since 2006 covers clinical terms relating to palliative care services; advance care directives, recording of preferred place of death, indication of terminal illness and similar care near the end of life are not covered. Therefore, a comprehensive list of Read codes that reflected recognition of the need for end of life care was developed (Supplementary Table 1). Patients were considered as recognised as needing palliative approach if any of these codes appeared in their primary care records; in addition, the time between the earliest recording of any palliative care code and their death was calculated. Where no palliative care codes were recorded, patients were considered as not being recognised as needing palliative approach.

Information on whether patients died in hospital was obtained from secondary care data, which was available for 81% of the cohorts who had consented for linkage of CPRD to HES. From their HES records, it was possible to determine whether a patient had died in hospital; otherwise, patients were assumed to have died outside hospital. Patients with no consent for linkage were excluded from the analysis of death in hospital.

Proportions recognised as requiring a palliative approach were calculated, and in order to be comparable to cancer patients, were standardised to the age- and sex-distribution of cancer patients who died in the first year of the study (April 2009-March 2010). Annual changes in proportions, with

95% confidence intervals (CI), were estimated using binomial regression; annual changes in proportions were assumed to be linear since all tests for departure from linearity were not statistically significant. All analyses were conducted using Stata 14.2.

Results

Figure 1 shows how the 47 473 patients included in the sequential cross-sectional studies were identified in CPRD, and Table 1, the expected between-disease differences in age and sex distributions. For all conditions except cancer, palliative care codes outside QOF were used as often as those in QOF, and hence the totality was used in all presented analyses.

In the first year of our study, around three in every 20 patients with COPD, HF or dementia were recorded with a code recognising a palliative approach, compared to 12 in every 20 cancer patients (Table 2). By the final period, April 2013 to March 2014, proportions had increased to four in every 20 patients with COPD; eight in every 20 with dementia; and five in every 20 with HF. Palliative care recording increased most for patients with dementia, growing by 6.4% per year (95%CI 5.8, 7.0%); followed by HF at 2.6% (95%CI 2.0, 3.1%); and COPD at 2.3% (95%CI 1.7, 2.9%). Over the same period, recording among cancer patients grew by 1.1% (95%CI 0.7, 1.5%). For patients with two or more conditions, those without cancer saw an increase from three to six in every 20 patients being recorded, and those with cancer from nine to 11 in every 20 (Supplementary Table 2). Repeating analyses with patients whose conditions were recorded within the 5-year or 1-year period before death gave marginally greater proportions, mostly due to a smaller number of patients contributing to the denominator, but the annual change over time remained the same (data available on request). As for the timing of recording, this changed over the study period (Figure 2). In the year 2009-10, 35.8% with dementia and palliative care noted, 22.0% with HF and 16.0% with COPD were recorded for the first time in the week before death. By 2013-14, this had reduced to 17.5%, 15.6% and 13.3% for dementia, HF and COPD respectively, becoming closer to the 8-10% of patients with cancer.

Palliative care recording generally increased among men and women; in all age groups; and across all deprivation categories (Supplemental Table 3). Overall, proportions with palliative care recorded were similar for men and women; however, for dementia, sex-specific proportions diverged such that by 2013-14, 43.9% of women compared to 36.2% of men had palliative care recorded. With regards to age, some of the largest increases occurred in those aged 90 or over, with annual change estimated at 2.4% (95%CI 0.3, 4.5%) for COPD, and ranging up to 7.2% (95%CI 6.2, 8.2%) for dementia. On the other hand, patients aged under 70 did not see an increase in recording, and for

COPD in particular, where around a fifth of deaths occurred in the under 70-year olds, palliative care recording was lower than for those aged 70-79, at 16.9% compared to 24.8% in the last period. For those living in more deprived areas, proportions of palliative care recording tended to be lower than amongst those from the most affluent, but not always significantly so.

Proportions of patients dying in hospital increased initially before falling in 2013-14, being significantly lower in the last year than in the first for cancer, COPD, and dementia but not HF (Table 3). When considering whether patients had a primary care record of palliative care, fewer with a record died in hospital than those who did not. Over the course of the study, the only condition apart from cancer where the proportions with palliative care who died in hospital decreased was dementia. Repeating the analysis restricted to QOF palliative care register codes, or where patients whose first record of palliative care was in the week before death were removed, gave similar findings (data not shown).

Discussion

Summary of main findings

It is encouraging that the recognition of the need for palliative care approach has increased in those with non-cancer diseases since the introduction of the UK End of Life Care Strategy. Not only have the proportions increased, but the timeliness of recording has also changed, with fewer patients registered in the week before death. Despite the improvements, significant inequalities remain; most notably that decedents with these conditions remain less likely to be recorded as having palliative care needs than those with cancer. With regards to dying in hospital, the data suggest that the numbers have decreased, particularly among those with palliative care, but a longer trajectory is needed to confirm these observations.

Registration on the palliative care QOF is a proxy measure for clinical recognition of the need for a palliative approach to care. Since the introduction of this indicator in 2006, over 99% of practices use a palliative care register [7]. Despite clear guidance, there may be a perception that the palliative care QOF is for cancer patients. Interestingly though, not only did the use of QOF palliative care codes in the non-malignant conditions increase, but also other non-QOF codes relating to end of life care such as advanced care directives were used as often throughout the data. Some of the biggest increases in recording were among patients aged 90 or older. Socioeconomic differences in palliative care were present to a degree, with more deprived patients less likely to have a record of palliative care than those who were more affluent; however, among the factors we were able to examine, age and GP practice may have been more influential on the recording.

Comparison with literature

A realist evaluation of 16 GP Practices showed improvement over time in recognition of palliative care in non-cancer conditions following the introduction of a palliative care pathway but, as found here, the inequity of lower recognition of palliative care in non-cancer conditions compared to cancer remained [13]. Our findings are consistent with the other CPRD study showing that recognition of a palliative care approach was driven by a lung cancer diagnosis rather than COPD itself [9]. Our slightly higher proportion categorised as palliative care may be because of our use of palliative care registration rather than Read codes only. Other studies have shown a reduction in hospital deaths, in both cancer and non-cancer conditions [14–16]. The reasons for these changes are likely to be multifactorial: the Strategy and its wider policy influence; public health initiatives; increased clinical education and more publications and awareness regarding palliative care for non-cancer conditions. For reduced hospital deaths in dementia, factors such as economic incentives to

reduce hospital admissions and stays have been suggested as a factor in the UK, other European countries and the US and have resulted in more deaths in care homes [16]. This study did not explore death outside of hospital but a study of hospice deaths from 1993–2012 demonstrated an increase in non-cancer conditions among hospice decedents although absolute numbers remain small [17].

Strengths and limitations

This study benefits not only from being population-based in a large primary care dataset, but also from having as its basis the contemporaneous recording of conditions and care by general practitioners and health care professionals. We were able to identify decedents who had a record of the conditions of interest in their primary care notes, rather than relying on causes of death on the death certificates which are known to be inaccurate [18]. Moreover, the conditions of interest-cancer, heart failure, dementia and COPD - are QOF indicators, whereby GPs are incentivised to maintain the disease registers and record diagnoses once confirmed using specific tests and assessments, and have proved reliable for population-based prevalence data [19]. One limitation is that since primary care notes were established across patients' lifetimes, the disease may not have been relevant to the patient's death, and our denominator may be overestimated. However, analyses including only those whose disease was recorded in the last five or final year of life, whilst finding slightly higher proportions of palliative care recording showed very similar patterns. A limitation of the cross-sectional design is that general practices contributing to CPRD can change over time; restricting the analyses to the 42618 decedents (89.8%) whose practices contributed to all three periods did not alter the findings (data not shown). Many of the general practices contributing to CPRD are located in the North West or South East of England, and of smaller practice size than the national average [20,21]; however, in terms of the patients, the 7% of the UK population in CPRD are generally representative of the total population [10].

Identification of a palliative care approach in this study is dependent on coding in the clinical record; whilst a broader range of codes was used than in some recent studies [8,9], it is likely that we have under-estimated true palliative care activity. However, systematic differences in this under-estimation by condition seem unlikely and hence the relative differences observed would remain robust.

Information on place of death is not routinely available in primary care records in CPRD and was established from secondary care data. We were therefore only able to define whether patients died

in hospital or not; information on deaths at home or hospice were unavailable. While we had only three alternate years of data available due to limitations of funding, this was sufficient to see an upward time trend in palliative care recording, described as linear growth but not of sufficient duration to assess alternative trend patterns; and when compounded by low palliative care recording, to determine clear patterns in hospital deaths. We also recognise that place of death in isolation should not be a quality marker of good care of the dying. Measures such as patient centred outcome measures (PCOMs) are increasingly seen as the gold standard for measuring quality of care but were not available and indeed are not widely used [22]. Although we relate our discussion to the UK End of Life Strategy of 2008, we are unable to assume causality in this observational study and data prior to 2008 were not analysed for comparison. Of interest, the rate of increase for COPD patients (2.3% per year) is similar to the rate of increase between 2008 to 2014 reported in Bloom et al, and which is approximately twice the rate of increase in their 2005 to 2008 data although they did not evaluate this [9].

Implications for research, policy and practice

Although inequities seem to be improving for all disease further investigation of the reasons for and how to overcome the inequality are needed: for example, a case study approach of practices with low and high proportions of patients on the palliative care register. Also a study to explore more patient-centred outcomes of the result of being on a palliative care register especially as these become more widely used, for example the Integrated Palliative care Outcome Scale (IPOS), a patient centred outcome measure developed and validated for use with people with advanced disease [22].

We would challenge the current UK strategy for identification of palliative care patients based on "*end* of life". Although the UK policy definition does not intend an interpretation of "the last few days or weeks of life", in practice, that is often the case. The use of the word "end" strongly implies a *time*-bound frame, and one which works backwards from the time of death. This risks delay in implementing a palliative approach, arising from the real challenges of accurately predicting the day of death, so called "prognostic paralysis" [23], a problem that is also well recognised as a barrier to hospice care for non-cancer diagnoses in the United States [24]. We welcome initiatives that promote supportive care and advance care planning earlier in the disease trajectory [25]. The more recent national framework for local implementation UK Ambitions of Care document uses the phrase "palliative and end-of-life" [26]. It will be interesting to see whether this clarifies or

complicates clinical practice. We look to the WHO and Worldwide Palliative Care Alliance which do not mention either diagnosis, or prognosis, rather using the term life-limiting conditions and recommends identification of need for palliative care based on symptoms [2].

Conclusions

To the best of our knowledge this is the first use of this data linkage in the palliative care population and allowed us to explore not only recognition of palliative care in primary care. Since the introduction of the UK End of Life Care Strategy recognition of the need for palliative care approach has increased in common life-limiting conditions, in a timelier manner. This may have in turn been related to a reduction in the number of patients dying in hospital but further study will be needed to confirm this.

Contributors

All authors were responsible for the design and conduct of the study. AG and EK designed and created the database. EK and VA conducted the statistical analyses. AG, EK and VA drafted and revised the paper. SO, MJ and UM revised the draft paper. All authors have approved the final version for publication. AG is the guarantor.

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Disclaimer

This study is based on data from the Clinical Practice Research Datalink obtained under license from the UK Medicines and Healthcare Products Regulatory Agency. However, the interpretation and conclusions contained in the study are those of the authors alone.

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Competing Interests

None declared

Ethical Approval

The CPRD Group has obtained ethics approval from a National Research Ethics Service Committee (NRES) for all purely observational research using anonymised CPRD data. This study was approved by the Independent Scientific Advisory Committee (ISAC) for Medicines and Healthcare products Regulatory Agency (MHRA) database research permission (Protocol number: 10_168R). No further ethics approval was required for the analysis of the data.

Data Sharing

No additional data available

Transparency

The manuscript is an honest, accurate, and transparent account of the study being reported; that no aspects of the study have been omitted; and any discrepancies from the study as planned have been explained.

Figure Legends

Figure 1: Flow diagram of identification of study subjects from CPRD GOLD.

Figure 2: Distribution of time before death when palliative care first recorded in primary care notes by disease and year.

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Table 1: Demographics of persons with cancer, chronic obstructive pulmonary disease (COPD), dementia, or heart failure in their general practice records who died in April 2009-March 2010, April 2011-March 2012 or April 2013-March 2014.

	Cancer			COPD			Dementia			Heart Failure		
	2009-10	2011-12	2013-14	2009-10	2011-12	2013-14	2009-10	2011-12	2013-14	2009-10	2011-12	2013-14
Annual Deaths	6799	6386	5483	1924	1872	1630	2433	2474	2432	2429	2152	1828
Sex- Male(%)	51.0%	51.3%	50.4%	53.8%	55.7%	54.4%	32.3%	32.1%	32.0%	47.3%	47.6%	50.2%
Age- Mean(sd)	74.1(12.8)	74.4(13.1)	74.6(12.8)	77.7(10.1)	78.2(10.1)	77.7(10.5)	86.4(7.6)	86.9(7.5)	86.9(7.7)	83.4(10.5)	84.2(10.3)	83.6(10.9)
Index of Multiple Deprivation												
1- least deprived	22.8%	22.8%	21.8%	14.8%	15.1%	15.0%	23.6%	22.5%	22.0%	20.0%	18.8%	19.6%
2	25.9%	24.0%	24.9%	21.2%	21.1%	19.0%	25.0%	23.7%	23.0%	24.0%	24.7%	25.4%
3	20.8%	21.9%	20.2%	17.7%	19.5%	19.6%	21.9%	22.5%	23.1%	22.0%	22.1%	22.8%
4	17.3%	17.8%	18.7%	22.8%	21.7%	23.0%	16.8%	17.1%	16.4%	18.6%	19.1%	17.6%
5-most deprived	13.1%	13.5%	14.3%	23.3%	22.5%	23.3%	12.6%	14.2%	15.4%	15.4%	15.3%	14.6%
Palliative Care- Yes(%)	57.6%	60.2%	61.7%	13.4%	17.3%	22.6%	16.1%	30.5%	41.4%	13.0%	16.8%	24.2%
QOF Codes	50.1%	52.1%	52.1%	8.4%	11.0%	14.3%	9.7%	17.3%	22.7%	7.1%	9.8%	13.9%
Other Codes	7.5%	8.1%	9.6%	4.9%	6.4%	8.3%	6.4%	13.2%	18.8%	5.9%	7.0%	10.3%
Death in Hospital- Yes(%)	34.7%	35.4%	28.9%	47.1%	51.9%	40.8%	23.7%	25.6%	20.5%	42.8%	48.5%	41.0%

Index of Multiple Deprivation and place of death were available for 81% of deaths.

Table 2: Proportions and changes in proportion of deaths recorded as needing palliative care approach in primary care since April 2009-March 2010.

Year	Total Deaths	Palliative Care Register			
		Total	Unadjusted Proportion	Adjusted Proportion (95%CI)	Changes in Proportion (95%CI)
	Cancer				
2009-10	6799	3913	57.6%	57.6%(56.4,58.7%)	0(ref)
2011-12	6386	3845	60.2%	60.6%(59.5,61.8%)	2.97%(1.33,4.62%)
2013-14	5483	3381	61.7%	61.9%(60.6,63.2%)	4.44%(2.74,6.14%)
Annual Change					*1.12%(0.70,1.54%)*
	COPD				
2009-10	1924	257	13.4%	13.6%(11.9,15.3%)	0(ref)
2011-12	1872	324	17.3%	17.5%(15.4,19.6%)	4.08%(1.82,6.34%)
2013-14	1630	368	22.6%	21.2%(19.2,23.3%)	9.36%(6.85,11.9%)
Annual Change					*2.31%(1.70,2.92%)*
	Dementia				
2009-10	2433	391	16.1%	20.9%(17.8,23.9%)	0(ref)
2011-12	2474	755	30.5%	37.5%(33.8,41.1%)	14.6%(12.3,16.9%)
2013-14	2432	1008	41.4%	40.7%(37.2,44.2%)	25.4%(22.9,27.8%)
Annual Change					*6.43%(5.82,7.04%)*
	Heart Failure				
2009-10	2429	315	13.0%	12.6%(10.7,14.4%)	0(ref)
2011-12	2152	361	16.8%	15.0%(12.8,17.2%)	3.26%(1.20,5.32%)
2013-14	1828	443	24.2%	21.2%(18.7,23.8%)	10.7%(8.38,13.1%)
Annual Change					*2.56%(1.99,3.12%)*

Adjusted proportions were standardised to the age- and sex- distribution of persons with cancer who died between April 2009 and March 2010. Changes in proportions and 95% confidence intervals (95%CI) were estimated using binomial regression adjusted for age, sex and index of multiple deprivation.

Table 3: Changes in proportion of deaths in hospital since April 2009-March 2010 among all patients, and among those not recorded or recorded as needing palliative care.

Year	Total			No Recording of Palliative Care			Recording of Palliative Care		
	Deaths: Hospital/ Total	Proportion	Change in Proportion (95%CI)	Deaths: Hospital/ Total	Proportion	Change in Proportion (95%CI)	Deaths: Hospital/ Total	Proportion	Change in Proportion (95%CI)
	Cancer								
2009-10	1929/5565	34.6%	0(ref)	1076/2371	45.4%	0(ref)	853/3194	26.7%	0(ref)
2011-12	1842/5200	35.4%	0.69%(-1.11,2.49%)	1033/2094	50.7%	5.33%(2.41,8.26%)	781/3106	25.1%	-1.47%(-3.63,0.69%)
2013-14	1277/4426	28.9%	-5.69%(-7.73,-4.08%)	727/1694	42.9%	-2.56%(-5.65,0.53%)	550/2732	20.1%	-6.32%(-8.47,-4.18%)
Annual Change			*-1.43%(-1.90,-0.97%)*			*-0.45%(-1.23,0.32%)*			*-1.62%(-2.19,-1.05%)*
	COPD								
2009-10	734/1557	47.1%	0(ref)	672/1364	49.3%	0(ref)	62/193	32.1%	0(ref)
2011-12	795/1531	51.9%	4.75%(1.23,8.28%)	711/1272	55.9%	6.57%(2.76,10.4%)	84/259	32.4%	0.38%(-8.36,9.11%)
2013-14	537/1315	40.8%	-6.25%(-9.88,-2.62%)	456/1022	44.6%	-4.60%(-8.63,-0.56%)	81/293	27.6%	-4.47%(-12.8,3.89%)
Annual Change			*-1.46%(-2.38,-0.55%)*			*-0.93%(-1.94,0.08%)*			*-1.24%(-3.34,0.86%)*
	Dementia								
2009-10	463/1951	23.7%	0(ref)	426/1655	25.7%	0(ref)	37/296	12.5%	0(ref)
2011-12	519/2025	25.6%	1.77%(-0.86,4.40%)	463/1417	32.7%	6.84%(3.63,10.1%)	56/608	9.2%	-2.07%(-6.17,2.03%)
2013-14	401/1953	20.5%	-2.99%(-5.54,-0.45%)	340/1135	30.0%	4.03%(0.66,7.40%)	61/818	7.5%	-3.74%(-7.64,0.16%)
Annual Change			*-0.78%(-1.44,-0.12%)*			*1.21%(0.34,2.07%)*			*-0.90%(-1.74,-0.06%)*
	Heart Failure								
2009-10	865/2022	42.8%	0(ref)	797/1759	45.3%	0(ref)	68/263	25.9%	0(ref)
2011-12	865/1783	48.5%	5.89%(2.74,9.05%)	779/1500	51.9%	6.72%(3.30,10.1%)	86/283	30.4%	5.14%(-2.37,12.6%)
2013-14	599/1462	41.0%	-1.26%(-4.55,2.03%)	513/1127	45.5%	0.71%(-2.99,4.40%)	86/335	25.7%	1.18%(-5.81,8.17%)
Annual Change			*-0.14%(-0.97,0.69%)*			*0.43%(-0.50,1.35%)*			*0.19%(-1.62,2.00%)*

Change in proportions and 95% confidence intervals (95%CI) were estimated using binomial regression adjusted for age, sex and index of multiple deprivation.

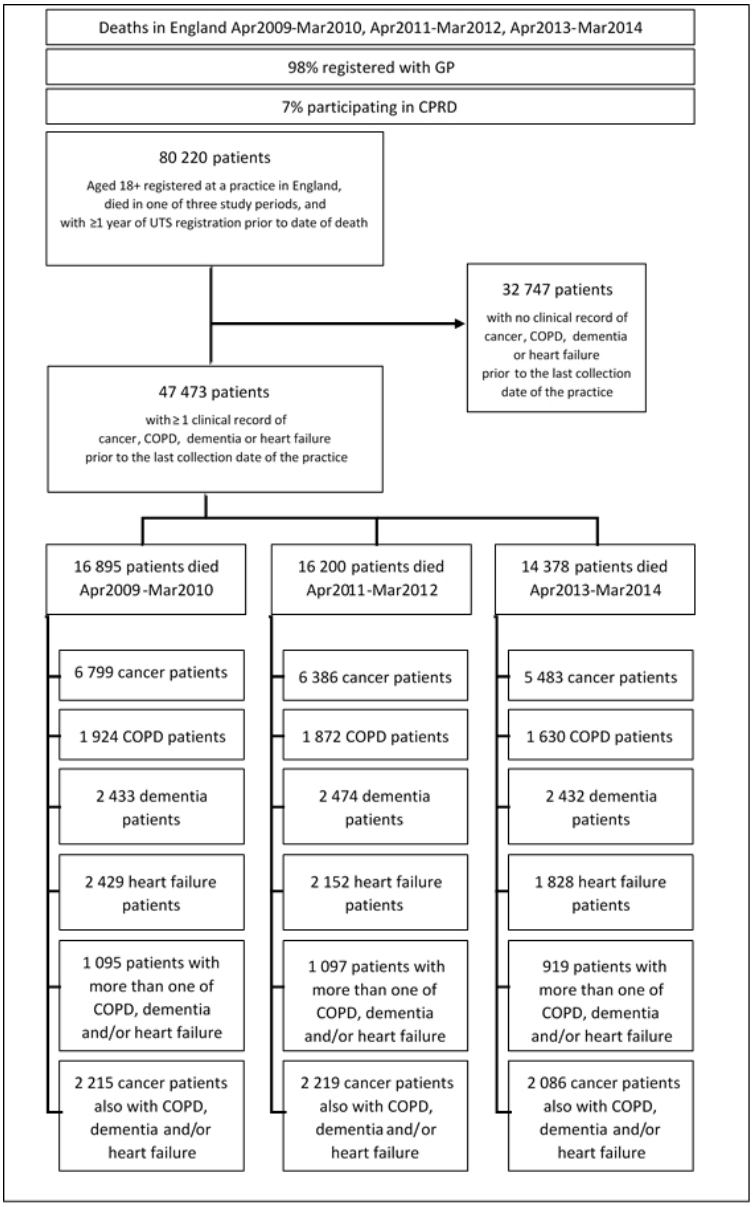

Figure 1: Flow diagram of identification of study subjects from CPRD GOLD.

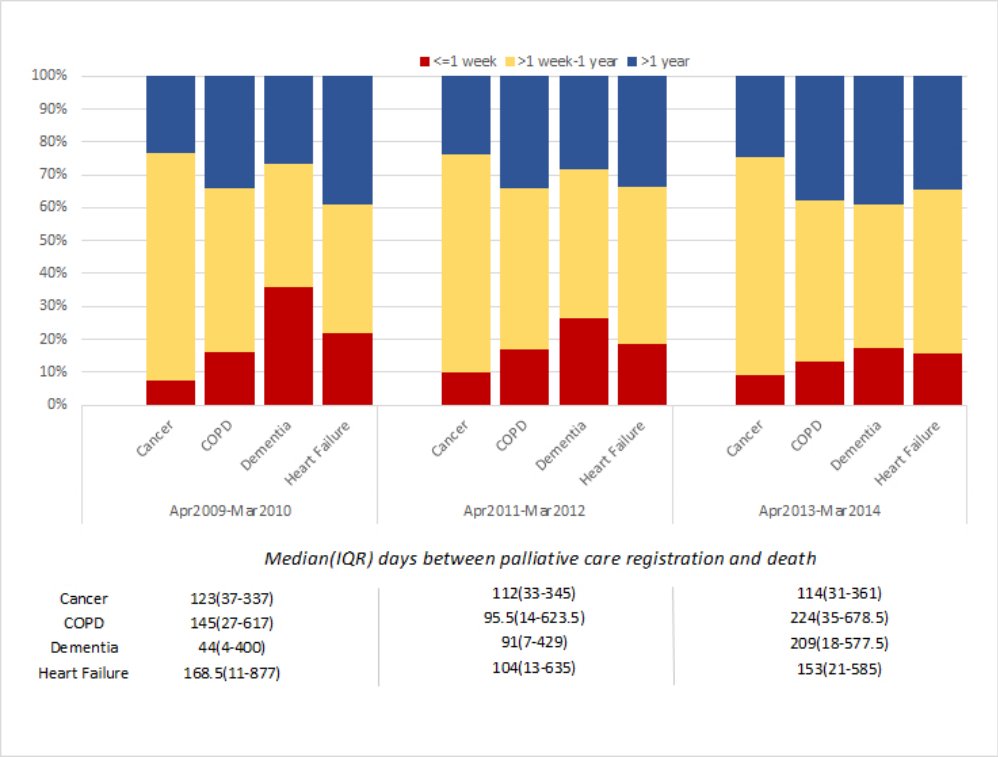

Figure 2: Distribution of time before death when palliative care first recorded in primary care notes by disease and year.

Supplemental Table 1: Read codes, Medcodes and Read terms used to identify patients needing palliative care.

Read Code	Medcode	Read Term
QOF Palliative Care Codes		
1Z01.	26353	Terminal illness - late stage
2JE..	100660	Last days of life
38QH.	108509	Palliative Care Outcomes Collaboration Assessment Toolkit
38QK.	108547	Palliative Care Problem Severity Score
8B2a.	106667	Prescription of palliative care anticipatory medication
8BA2.	6664	Terminal care
8BAe.	98251	Anticipatory palliative care
8BAP.	10019	Specialist palliative care
8BAS.	49651	Specialist palliative care treatment - daycare
8BAT.	26354	Specialist palliative care treatment - outpatient
8BJ1.	18551	Palliative treatment
8BMM.00	97066	Issue of palliative care anticipatory medication box
8BMM.11	97280	Issue of palliative care just in case box
8CM1.% (excluding 8CM15)	12739	On gold standards palliative care framework
8CM1000	100607	GSF supportive care stage 1 - advancing disease
8CM1100	100525	GSF supportive care stage 2 - increasing decline
8CM1200	101636	GSF supportive care stage 3 - last days: cat C - weeks prognosis
8CM1300	100466	GSF supportive care stage 3 - last days: cat D - days prognosis
8CM1400	102415	GSF supportive care stage 3 - last days: cat B - month prognosis
8CM1600	105306	GSF prognostic indicator stage B (green) - months prognosis
8CM1700	105314	GSF prognostic indicator stage C (yellow) - weeks prognosis
8CM1800	105447	GSF prognostic indicator stage D (red) - days prognosis
8CM4	74909	Liverpool care pathway for the dying
8CMb.	106662	Integrated care priorities for end of life
8CME.	99766	Has end of life advance care plan
8CMQ.	104282	On Liverpool care pathway for the dying
8CMW3	105222	End of life care pathway
8H6A.	26352	Refer to terminal care consult
8H7g	9755	Referral to palliative care service
8H7L	34531	Refer for terminal care
8HH7.	22288	Referred to community specialist palliative care team
8IEE.	103941	Referral to community palliative care team declined
9367	105961	Patient held palliative care record
9c0L0	105908	Planned palliative oncology treatment
9c0M.	106204	Planned supportive care for terminal illness
9c0N.	107583	Current supportive care for terminal illness
9c0P.	105975	Current palliative oncology treatment
9EB5.	6924	DS 1500 Disability living allowance completed
9G8..	105757	Ambulance service notified of patient on EoL care register
9K9..	105391	Palliative care handover form completed
9Ng7.	100126	On end of life care register
9NgD.	104463	Under care of palliative care service
9NNd.	105214	Under care of palliative care specialist nurse
9NNf0	106582	Under care of palliative care physician
ZV57C	7060	[V]Palliative care
Other Codes		
13VH.00	6277	Has made a living will
1R1..00	36918	Not for resuscitation
1Z0..00	8976	Terminal illness
1Z00.00	41446	Terminal illness - early stage
2JL.00	102557	Imminent expected death
67Q..00	103607	Counselling for end of life issues
8BAN.00	11318	Community specialist palliative care

8BAO.00	11017	Pain and symptom management
8BAQ.00	38123	Final days pathway
8BAR.00	10784	Specialist palliative care treatment - inpatient
8BC1.00	18732	Treatment plan given
8BC4.00	18468	Syringe driver commenced
8CM3.00	19458	Palliative care plan review
8CN0.00	38948	Preferred place of death discussed with significant other
8CN1.00	19317	Preferred place of death discussed with patient
8Hg0.00	50291	Discharged from community specialist palliative care team
8HgX.00	106695	Discharge from palliative care service
8HY..00	22073	Referral to hospice
94Z0.00	35269	Preferred place of death
94Z1.00	30609	Preferred place of death: home
94Z2.00	30690	Preferred place of death: hospice
94Z3.00	54781	Preferred place of death: community hospital
94Z4.00	52434	Preferred place of death: hospital
94Z5.00	23076	Preferred place of death: nursing home
94Z6.00	100767	Preferred place of death: patient unable to express preference
94Z7.00	103360	Preferred place of death: discussion not appropriate
94Z8.00	101701	Preferred place of death: patient undecided
94ZB.00	100468	Preferred place of death: discussed with family
94ZC.00	101152	Preferred place of death: care home
94ZD.00	106038	Preferred place of death: patient declined discussion
94ZE.00	104115	Preferred place of death: residential home
94ZF.00	104566	Preferred place of death: usual place of residence
9b9B.00	73313	Palliative medicine
9e0..00	30696	GP out of hours service notified
9e00.00	50371	GP out of hours service notified of cancer care plan
9e01.00	100171	Notification to primary care OOHS of anticipated death
9e02.00	98441	Notify to primary care OOHS of palliative care plan in place
9hB.00	62309	Exception reporting: palliative care quality indicators
9hB0.00	30643	Excepted from palliative care quality indicators: Patient unsuitable?
9ke..00	97051	Palliative care - enhanced services administration
9Nh0.00	48775	Under the care of community palliative care team
9NIJ.00	96936	Seen by palliative care service
9NNa.00	103569	Has end of life care pathway key general practitioner
9NNb.00	105849	Has end of life care pathway key nurse
9NNZ.00	102536	Has end of life care pathway key worker
9Ok5.00	26076	Cancer pain and symptom management
9X0..00	47226	Advanced directive discussed with patient
9X1..00	17854	Advanced directive discussed with relative
9X2..00	36511	Advanced directive signed
9X2..11	101060	Advance decision signed
9X20.00	25562	Advanced directive signed (copy in notes)
9X20.11	107192	Advance directive signed (copy in notes)
Z172.00	9996	Palliative care
Z1FC.00	30193	Preferences relating to death and dying
Z1FC600	58623	Preference for informing others of terminal diagnosis
Z4I4100	59644	Exploring patient's feelings about dying
ZL18R00	28899	Under care of palliative care physician
ZL5AP00	13628	Referral to palliative care physician
ZL9AR00	11978	Seen by palliative care physician
ZLD3R00	11134	Discharge by palliative care physician
ZLE6P00	51219	Discharge from palliative care service

Supplementary Table 1: Proportions and changes in proportion of deaths as needing palliative care approach in primary care, and days between palliative care registration and death, since April 2009-March 2010 among patients with more than one of chronic pulmonary obstructive disease, dementia or heart failure, or among patients with any one or more of these conditions as well as cancer.

	Total Deaths	Palliative Care Register	Unadjusted Proportion	Adjusted Proportion (95%CI)	Change in Proportion (95%CI)	Median Days (IQR)
Multiple excl. Cancer						
Apr2009-Mar2010	1095	161	14.7%	14.1%(10.8,17.3%)	0(ref)	117(15-793)
Apr2011-Mar2012	1097	270	24.6%	22.2%(18.3,26.0%)	9.30%(6.01,12.6%)	112(13-668)
Apr2013-Mar2014	919	291	31.7%	26.9%(22.8,30.9%)	16.2%(12.5,19.9%)	316(40-800)
Annual Change					*4.13%(3.21,5.04%)*	
Multiple incl. Cancer						
Apr2009-Mar2010	2215	998	45.1%	51.8%(48.9,54.6%)	0(ref)	127.5(30-377)
Apr2011-Mar2012	2219	1079	48.6%	54.1%(51.5,56.7%)	3.54%(0.63,6.45%)	103(25-396)
Apr2013-Mar2014	2086	1161	55.7%	58.1%(55.2,61.0%)	10.5%(7.58,13.5%)	150(33-485)
Annual Change					*2.62%(1.89,3.36%)*	

Adjusted proportions were standardised to the age- and sex- distribution of persons with cancer who died between April 2009 and March 2010. Change in proportions and 95% confidence intervals (95%CI) estimated using binomial regression, and were adjusted for age, sex and index of multiple deprivation.

Supplemental Table 3: Proportions (%) and annual percentage changes in palliative care registration between persons of different sex, age or index of multiple deprivation by disease and year.

	March 2009-April 2010		March 2011-April 2012		March 2013-April 2014		Annual Percent Change (95%CI)
	Proportion		Proportion		Proportion		
	Unadj.	Adjusted (95%CI)	Unadj	Adjusted (95%CI)	Unadj.	Adjusted (95%CI)	
	COPD						
Overall	*13.4*	*13.6(11.9,15.3)*	*17.3*	*17.5(15.4,19.6)*	*22.6*	*21.2(19.2,23.3)*	*2.31(1.70,2.92)*
Sex							
Male	11.6	11.4(9.4,13.4)	15.5	14.4(12.2,16.5)	22.2	21.7(18.9,24.5)	2.60(1.80,3.40)
Female	15.4	15.8(13.1,18.6)	19.6	20.8(17.2,24.3)	23.0	20.7(17.7,23.7)	1.90(0.95,2.85)
Age							
<70	15.4	14.9(11.2,18.6)	17.2	17.8(13.0,22.6)	16.9	15.5(11.5,19.4)	0.49(-0.85,1.82)
70-79	12.5	12.7(9.9,15.4)	17.2	17.2(14.1,20.4)	24.8	24.8(21.0,28.6)	3.17(2.06,4.28)
80-89	12.3	12.4(10.0,14.8)	15.6	15.5(12.9,18.2)	23.2	23.1(19.8,26.5)	2.56(1.60,3.52)
≥90	15.6	15.3(10.2,20.4)	23.3	23.7(17.8,29.5)	25.0	25.6(19.2,32.0)	2.39(0.31,4.47)
IMD							
1-least deprived	17.3	15.6(10.8,20.4)	21.7	19.7(14.5,24.9)	27.9	25.1(19.0,31.3)	2.64(0.70,4.58)
2	13.0	11.9(8.4,15.4)	16.1	15.1(10.9,19.3)	23.2	23.3(17.7,28.9)	2.34(0.84,3.84)
3	12.3	12.9(9.0,16.9)	14.8	16.8(12.8,20.9)	23.3	21.0(15.8,26.2)	2.58(1.07,4.09)
4	11.8	12.8(9.1,16.4)	19.3	19.2(14.3,24.0)	20.2	19.8(15.5,24.0)	2.39(0.93,3.84)
5-most deprived	9.4	9.3(6.4,12.3)	14.2	15.0(11.1,18.9)	19.3	17.8(13.9,21.7)	2.49(1.20,3.79)
Missing	17.3	17.4(13.0,21.8)	19.0	21.8(17.9,25.8)	23.7	23.2(18.8,27.7)	1.53(0.06,2.99)
	Dementia						
Overall	*16.1*	*20.9(17.8,23.9)*	*30.5*	*37.5(33.8,41.1)*	*41.4*	*40.7(37.2,44.2)*	*6.43(5.82,7.04)*
Sex							
Male	14.8	16.5 (12.0,21.0)	30.2	37.6(32.5,42.6)	36.2	33.4(28.9,38.0)	5.63(4.56,6.70)
Female	16.7	25.4(21.4,29.5)	30.7	37.4(32.2,42.5)	43.9	48.3(43.0,53.5)	6.83(6.09,7.57)
Age							
<70	22.6	28.9(21.1,36.8)	39.4	49.3(40.2,58.4)	39.7	43.8(35.3,52.4)	4.55(0.52,8.57)
70-79	19.0	19.4(14.8,24.1)	34.7	35.3(29.4,41.3)	39.8	38.8(32.9,44.7)	5.53(3.74,7.33)
80-89	15.5	14.9(12.7,17.1)	27.5	27.7(24.8,30.5)	39.6	38.6(35.5,41.6)	6.05(5.17,6.92)
≥90	15.2	14.5(11.8,17.1)	32.2	31.3(28.0,34.6)	44.0	41.8(38.3,45.2)	7.22(6.23,8.21)
IMD							
1- least deprived	18.0	18.3(13.7,23.0)	30.9	22.8(17.1,28.6)	42.8	29.6(22.9,36.3)	6.25(4.80,7.70)
2	12.7	11.7(6.8,16.6)	29.8	27.9(22.8,32.9)	43.6	41.1(35.5,46.7)	7.78(6.43,9.11)
3	17.0	18.0(14.7,21.3)	30.3	30.0(25.0,35.0)	43.6	38.4(31.9,45.0)	6.65(5.22,8.09)
4	14.9	11.2(6.5,15.9)	28.6	27.9(21.7,34.1)	33.1	28.9(21.6,36.1)	4.82(3.16,6.48)
5- most deprived	11.8	7.7(4.3,11.2)	30.3	28.6(22.1,35.1)	44.5	32.2(26.7,37.7)	8.22(6.49,9.94)
Missing	19.7	23.5(17.9,29.1)	32.7	33.5(27.4,39.6)	39.8	41.7(36.3,47.0)	5.08(3.66,6.50)
	Heart Failure						
Overall	*13.0*	*12.6(10.7,14.4)*	*16.8*	*15.0(12.8,17.2)*	*24.2*	*21.2(18.7,23.8)*	*2.56(1.99,3.12)*
Sex							
Male	11.8	11.4(9.3,13.6)	16.7	14.0(11.7,16.3)	22.9	21.0(17.9,24.1)	2.60(1.81,3.39)
Female	14.0	13.7(10.6,16.9)	16.9	16.0(12.2,19.9)	25.6	21.5(17.4,25.5)	2.51(1.72,3.31)
Age							
<70	12.3	12.6(8.0,17.2)	9.7	11.3(6.1,16.4)	18.9	19.5(13.5,25.4)	1.44(-0.10,3.00)
70-79	11.7	11.3(8.3,14.3)	17.5	17.3(13.2,21.5)	18.1	17.9(13.6,22.2)	1.76(0.43,3.10)
80-89	14.1	13.9(11.8,16.0)	16.4	16.1(13.6,18.5)	23.9	23.9(20.8,27.1)	2.23(1.36,3.11)
≥90	12.3	12.0(9.5,14.5)	18.8	18.2(15.3,21.1)	29.7	29.5(25.8,33.2)	4.12(3.08,5.16)
IMD							
1- least deprived	16.8	17.4(11.9,23.0)	17.3	9.5(6.2,12.7)	24.1	17.1(12.4,21.7)	1.55(0.10,2.99)
2	12.8	9.7(6.7, 12.6)	17.2	14.0(11.4,16.7)	22.1	17.6(12.5,22.8)	2.27(1.02,3.53)
3	13.1	11.6(8.2,15.1)	18.3	17.3(13.2,21.5)	23.7	21.3(15.8,26.9)	2.54(1.20,3.88)
4	9.8	9.0(4.9,13.1)	10.6	13.7(8.0,19.5)	21.3	18.1(12.4,23.8)	2.47(1.20,3.74)
5- most deprived	12.2	11.3(7.5,15.1)	15.1	14.2(9.7,18.8)	23.5	21.6(15.2,28.1)	2.43(0.88,3.97)
Missing	12.8	13.3(8.1,18.5)	21.1	18.2(13.6,22.9)	29.4	24.6(18.8,30.4)	4.09(2.70,5.48)

Adjusted proportions were standardised to the age- and sex- distribution of persons with cancer who died between April 2009 and March 2010. Annual changes with 95 confidence intervals (95%CI) were estimated using binomial regression adjusted for sex, age and index of multiple deprivation as appropriate.

Recognition of the need for palliative care among non-cancer conditions in primary care: a time trend analysis in the United Kingdom (2009-2014)

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Abstract (250 words)

Objectives

Whilst guidelines recommend palliative care in non-cancer conditions, this has not been widely implemented. We examined whether the recording of a palliative care approach and the numbers of hospital deaths for deceased patients with heart failure, dementia, chronic obstructive pulmonary disease (COPD) and cancer have changed since the UK End of Life Care Strategy was introduced.

Methods

We conducted sequential cross-sectional studies of decedents within the UK's Clinical Practice Research Datalink and Hospital Episode Statistics. All adults with a primary care record of COPD (N=5,426), dementia (N=7,339), heart failure (N=6,409) or cancer (N=18,668) who died during three one-year periods (April 2009-March 2014) were included. Evidence of a palliative care approach was identified from primary care records, and death in hospital from secondary care data.

Results

From 2009 to 2014, proportions with a primary care record of palliative care increased for COPD from 13.6% to 21.2%; dementia from 20.9% to 40.7%; and heart failure from 12.6% to 21.2%; but remained substantially lower than for cancer (57.6% to 61.9%). Median days before death of recording improved for COPD (145 to 224) and dementia (44 to 209); but not for heart failure (168.5 to 153) and cancer (123 to 114). Trends in hospital deaths were not consistently downward, although the proportions of patients dying in hospital were lower in the last period compared to the first.

Conclusions

Recording of a palliative care approach for non-cancer conditions has increased since the introduction of the UK End of Life Care Strategy, but remains inadequate.

Introduction

A palliative approach to care is important not only in cancer but in non-malignant conditions where patients have palliative care needs comparable to those of cancer patients [1]. Among the most common conditions identified by the World Health Organisation as diseases that would benefit from palliative care are heart failure (HF), dementia and chronic obstructive pulmonary disease (COPD) [2]. Such conditions carry a similar symptom burden and poor quality of life for patients and their families and friends, but there is evidence from the United States [3,4], and the United Kingdom (UK) [5] that these needs are less likely to be met.

In the UK, the introduction of a national End-of-Life Care Strategy in 2008 [6] represented a major policy shift to extend specialist palliative care *regardless of diagnosis*, to be delivered primarily by generalists, with access to specialist palliative care services for persistent or complex problems. Although the role of primary care is central to providing palliative care to those nearing the end of life, information on whether the need is being met in the UK is sparse, despite maintenance of a palliative care register by general practitioners being incentivised as part of the Quality and Outcomes Framework (QOF) since 2006 [7]. Using general practice-based registers of palliative care, one study conducted shortly after the Strategy's introduction, found patients with HF were poorly represented on the register, and when recorded, registration was often within a week of death [8]. Using the same electronic datasource, Bloom and colleagues showed that whilst the proportion of people dying from COPD and receiving palliative care increased between 2005 and 2015, this remained disproportionately low in those dying with COPD only (16.5%) compared with those dying with COPD and cancer (56.5%) [9]. Although from simple observation, the rate of change appears to increase from 2011.

With the aim of exploring whether recording of palliative care in primary care has changed for non-cancer conditions since 2008, patients who died with HF, dementia, or COPD, and for comparison, patients who died with cancer, in three different years were identified in UK's Clinical Practice Research Datalink (CPRD) [10]. Using information in their healthcare records, potential changes in palliative care recording as well as the prevalence of hospital deaths were explored.

Materials and Methods

Patients aged 18 or over with at least one clinical record of COPD; dementia; heart failure; or cancer (excluding non-melanoma skin cancer) who died in the periods 1 April 2009 to 31 March 2010; 1 April 2011 to 31 March 2012; or 1 April 2013 to 31 March 2014, were identified in CPRD using Read codes described in the NHS's Quality and Outcomes Framework (QOF) (QOF version 29, June 2014) [11]. The CPRD is a database of contemporaneous medical records from UK primary care and is demographically representative, covering around c.7% of the UK population [10]; the QOF is a voluntary incentive scheme for general practitioners in the UK [7]. Fact and date of death recorded in primary care records, which have shown a high level of agreement with national death certification, were used to identify patients who had died [12]. Focus was primarily on patients who had only one of these conditions; where two or more were recorded, patients were considered in two additional groups based on whether or not they had cancer. Patients were included if they had at least one year of records and met CPRD acceptability criteria for data quality; for sensitivity analyses, subgroups of patients were established based on whether conditions were recorded either within five years of, or in the year before, death.

The palliative care register that has been part of QOF since 2006 covers clinical terms relating to palliative care services; advance care directives, recording of preferred place of death, indication of terminal illness and similar care near the end of life are not covered. Therefore, a comprehensive list of Read codes that reflected recognition of the need for end of life care was developed (Supplementary Table 1). Patients were considered as recognised as needing palliative approach if any of these codes appeared in their primary care records; in addition, the time between the earliest recording of any palliative care code and their death was calculated. Where no palliative care codes were recorded, patients were considered as not being recognised as needing palliative approach.

Information on whether patients died in hospital was obtained from secondary care data, which was available for 81% of the cohorts who had consented for linkage of CPRD to HES. From their HES records, it was possible to determine whether a patient had died in hospital; otherwise, patients were assumed to have died outside hospital. Patients with no consent for linkage were excluded from the analysis of death in hospital.

Proportions recognised as requiring a palliative approach were calculated, and in order to be comparable to cancer patients, were standardised to the age- and sex-distribution of cancer patients who died in the first year of the study (April 2009-March 2010). Annual changes in proportions, with

95% confidence intervals (CI), were estimated using binomial regression; annual changes in proportions were assumed to be linear since all tests for departure from linearity were not statistically significant. All analyses were conducted using Stata 14.2.

Results

Figure 1 shows how the 47 473 patients included in the sequential cross-sectional studies were identified in CPRD, and Table 1, the expected between-disease differences in age and sex distributions. For all conditions except cancer, palliative care codes outside QOF were used as often as those in QOF, and hence the totality was used in all presented analyses.

In the first year of our study, around three in every 20 patients with COPD, HF or dementia were recorded with a code recognising a palliative approach, compared to 12 in every 20 cancer patients (Table 2). By the final period, April 2013 to March 2014, proportions had increased to four in every 20 patients with COPD; eight in every 20 with dementia; and five in every 20 with HF. Palliative care recording increased most for patients with dementia, growing by 6.4% per year (95%CI 5.8, 7.0%); followed by HF at 2.6% (95%CI 2.0, 3.1%); and COPD at 2.3% (95%CI 1.7, 2.9%). Over the same period, recording among cancer patients grew by 1.1% (95%CI 0.7, 1.5%). For patients with two or more conditions, those without cancer saw an increase from three to six in every 20 patients being recorded, and those with cancer from nine to 11 in every 20 (Supplementary Table 2). Repeating analyses with patients whose conditions were recorded within the 5-year or 1-year period before death gave marginally greater proportions, mostly due to a smaller number of patients contributing to the denominator, but the annual change over time remained the same (data available on request). As for the timing of recording, this changed over the study period (Figure 2). In the year 2009-10, 35.8% with dementia and palliative care noted, 22.0% with HF and 16.0% with COPD were recorded for the first time in the week before death. By 2013-14, this had reduced to 17.5%, 15.6% and 13.3% for dementia, HF and COPD respectively, becoming closer to the 8-10% of patients with cancer.

Palliative care recording generally increased among men and women; in all age groups; and across all deprivation categories (Supplemental Table 3). Overall, proportions with palliative care recorded were similar for men and women; however, for dementia, sex-specific proportions diverged such that by 2013-14, 43.9% of women compared to 36.2% of men had palliative care recorded. With regards to age, some of the largest increases occurred in those aged 90 or over, with annual change estimated at 2.4% (95%CI 0.3, 4.5%) for COPD, and ranging up to 7.2% (95%CI 6.2, 8.2%) for dementia. On the other hand, patients aged under 70 did not see an increase in recording, and for

COPD in particular, where around a fifth of deaths occurred in the under 70-year olds, palliative care recording was lower than for those aged 70-79, at 16.9% compared to 24.8% in the last period. For those living in more deprived areas, proportions of palliative care recording tended to be lower than amongst those from the most affluent, but not always significantly so.

Proportions of patients dying in hospital increased initially before falling in 2013-14, being significantly lower in the last year than in the first for cancer, COPD, and dementia but not HF (Table 3). When considering whether patients had a primary care record of palliative care, fewer with a record died in hospital than those who did not. Over the course of the study, the only condition apart from cancer where the proportions with palliative care who died in hospital decreased was dementia. Repeating the analysis restricted to QOF palliative care register codes, or where patients whose first record of palliative care was in the week before death were removed, gave similar findings (data not shown).

Discussion

Summary of main findings

It is encouraging that the recognition of the need for palliative care approach has increased in those with non-cancer diseases since the introduction of the UK End of Life Care Strategy. Not only have the proportions increased, but the timeliness of recording has also changed, with fewer patients registered in the week before death. Despite the improvements, significant inequalities remain; most notably that decedents with these conditions remain less likely to be recorded as having palliative care needs than those with cancer. With regards to dying in hospital, the data suggest that the numbers have decreased, particularly among those with palliative care, but a longer trajectory is needed to confirm these observations.

Registration on the palliative care QOF is a proxy measure for clinical recognition of the need for a palliative approach to care. Since the introduction of this indicator in 2006, over 99% of practices use a palliative care register [7]. Despite clear guidance, there may be a perception that the palliative care QOF is for cancer patients. Interestingly though, not only did the use of QOF palliative care codes in the non-malignant conditions increase, but also other non-QOF codes relating to end of life care such as advanced care directives were used as often throughout the data. Some of the biggest increases in recording were among patients aged 90 or older. Socioeconomic differences in palliative care were present to a degree, with more deprived patients less likely to have a record of palliative care than those who were more affluent; however, among the factors we were able to examine, age and GP practice may have been more influential on the recording.

Comparison with literature

A realist evaluation of 16 GP Practices showed improvement over time in recognition of palliative care in non-cancer conditions following the introduction of a palliative care pathway but, as found here, the inequity of lower recognition of palliative care in non-cancer conditions compared to cancer remained [13]. Our findings are consistent with the other CPRD study showing that recognition of a palliative care approach was driven by a lung cancer diagnosis rather than COPD itself [9]. Our slightly higher proportion categorised as palliative care may be because of our use of palliative care registration rather than Read codes only. Other studies have shown a reduction in hospital deaths, in both cancer and non-cancer conditions [14–16]. The reasons for these changes are likely to be multifactorial: the Strategy and its wider policy influence; public health initiatives; increased clinical education and more publications and awareness regarding palliative care for non-cancer conditions. For reduced hospital deaths in dementia, factors such as economic incentives to

reduce hospital admissions and stays have been suggested as a factor in the UK, other European countries and the US and have resulted in more deaths in care homes [16]. This study did not explore death outside of hospital but a study of hospice deaths from 1993–2012 demonstrated an increase in non-cancer conditions among hospice decedents although absolute numbers remain small [17].

Strengths and limitations

This study benefits not only from being population-based in a large primary care dataset, but also from having as its basis the contemporaneous recording of conditions and care by general practitioners and health care professionals. We were able to identify decedents who had a record of the conditions of interest in their primary care notes, rather than relying on causes of death on the death certificates which are known to be inaccurate [18]. Moreover, the conditions of interest-cancer, heart failure, dementia and COPD - are QOF indicators, whereby GPs are incentivised to maintain the disease registers and record diagnoses once confirmed using specific tests and assessments, and have proved reliable for population-based prevalence data [19]. One limitation is that since primary care notes were established across patients' lifetimes, the disease may not have been relevant to the patient's death, and our denominator may be overestimated. However, analyses including only those whose disease was recorded in the last five or final year of life, whilst finding slightly higher proportions of palliative care recording showed very similar patterns. A limitation of the cross-sectional design is that general practices contributing to CPRD can change over time; restricting the analyses to the 42618 decedents (89.8%) whose practices contributed to all three periods did not alter the findings (data not shown). Many of the general practices contributing to CPRD are located in the North West or South East of England, and of smaller practice size than the national average [20,21]; however, in terms of the patients, the 7% of the UK population in CPRD are generally representative of the total population [10].

Identification of a palliative care approach in this study is dependent on coding in the clinical record; whilst a broader range of codes was used than in some recent studies [8,9], it is likely that we have under-estimated true palliative care activity. However, systematic differences in this under-estimation by condition seem unlikely and hence the relative differences observed would remain robust.

Information on place of death is not routinely available in primary care records in CPRD and was established from secondary care data. We were therefore only able to define whether patients died

in hospital or not; information on deaths at home or hospice were unavailable. While we had only three alternate years of data available due to limitations of funding, this was sufficient to see an upward time trend in palliative care recording, described as linear growth but not of sufficient duration to assess alternative trend patterns; and when compounded by low palliative care recording, to determine clear patterns in hospital deaths. We also recognise that place of death in isolation should not be a quality marker of good care of the dying. Measures such as patient centred outcome measures (PCOMs) are increasingly seen as the gold standard for measuring quality of care but were not available and indeed are not widely used [22]. Although we relate our discussion to the UK End of Life Strategy of 2008, we are unable to assume causality in this observational study and data prior to 2008 were not analysed for comparison. Of interest, the rate of increase for COPD patients (2.3% per year) is similar to the rate of increase between 2008 to 2014 reported in Bloom et al, and which is approximately twice the rate of increase in their 2005 to 2008 data although they did not evaluate this [9].

Implications for research, policy and practice

Although inequities seem to be improving for all disease further investigation of the reasons for and how to overcome the inequality are needed: for example, a case study approach of practices with low and high proportions of patients on the palliative care register. Also a study to explore more patient-centred outcomes of the result of being on a palliative care register especially as these become more widely used, for example the Integrated Palliative care Outcome Scale (IPOS), a patient centred outcome measure developed and validated for use with people with advanced disease [22].

We would challenge the current UK strategy for identification of palliative care patients based on "*end* of life". Although the UK policy definition does not intend an interpretation of "the last few days or weeks of life", in practice, that is often the case. The use of the word "end" strongly implies a *time*-bound frame, and one which works backwards from the time of death. This risks delay in implementing a palliative approach, arising from the real challenges of accurately predicting the day of death, so called "prognostic paralysis" [23], a problem that is also well recognised as a barrier to hospice care for non-cancer diagnoses in the United States [24]. We welcome initiatives that promote supportive care and advance care planning earlier in the disease trajectory [25]. The more recent national framework for local implementation UK Ambitions of Care document uses the phrase "palliative and end-of-life" [26]. It will be interesting to see whether this clarifies or

complicates clinical practice. We look to the WHO and Worldwide Palliative Care Alliance which do not mention either diagnosis, or prognosis, rather using the term life-limiting conditions and recommends identification of need for palliative care based on symptoms [2].

Conclusions

To the best of our knowledge this is the first use of this data linkage in the palliative care population and allowed us to explore not only recognition of palliative care in primary care. Since the introduction of the UK End of Life Care Strategy recognition of the need for palliative care approach has increased in common life-limiting conditions, in a timelier manner. This may have in turn been related to a reduction in the number of patients dying in hospital but further study will be needed to confirm this.

Contributors

All authors were responsible for the design and conduct of the study. AG and EK designed and created the database. EK and VA conducted the statistical analyses. AG, EK and VA drafted and revised the paper. SO, MJ and UM revised the draft paper. All authors have approved the final version for publication. AG is the guarantor.

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Disclaimer

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Competing Interests

None declared

Ethical Approval

The CPRD Group has obtained ethics approval from a National Research Ethics Service Committee (NRES) for all purely observational research using anonymised CPRD data. This study was approved by the Independent Scientific Advisory Committee (ISAC) for Medicines and Healthcare products Regulatory Agency (MHRA) database research permission (Protocol number: 10_168R). No further ethics approval was required for the analysis of the data.

Data Sharing

No additional data available

Transparency

The manuscript is an honest, accurate, and transparent account of the study being reported; that no aspects of the study have been omitted; and any discrepancies from the study as planned have been explained.

Figure Legends

Figure 1: Flow diagram of identification of study subjects from CPRD GOLD.

Figure 2: Distribution of time before death when palliative care first recorded in primary care notes by disease and year.

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Table 1: Demographics of persons with cancer, chronic obstructive pulmonary disease (COPD), dementia, or heart failure in their general practice records who died in April 2009-March 2010, April 2011-March 2012 or April 2013-March 2014.

	Cancer			COPD			Dementia			Heart Failure		
	2009-10	2011-12	2013-14	2009-10	2011-12	2013-14	2009-10	2011-12	2013-14	2009-10	2011-12	2013-14
Annual Deaths	6799	6386	5483	1924	1872	1630	2433	2474	2432	2429	2152	1828
Sex- Male(%)	51.0%	51.3%	50.4%	53.8%	55.7%	54.4%	32.3%	32.1%	32.0%	47.3%	47.6%	50.2%
Age- Mean(sd)	74.1(12.8)	74.4(13.1)	74.6(12.8)	77.7(10.1)	78.2(10.1)	77.7(10.5)	86.4(7.6)	86.9(7.5)	86.9(7.7)	83.4(10.5)	84.2(10.3)	83.6(10.9)
Index of Multiple Deprivation												
1- least deprived	22.8%	22.8%	21.8%	14.8%	15.1%	15.0%	23.6%	22.5%	22.0%	20.0%	18.8%	19.6%
2	25.9%	24.0%	24.9%	21.2%	21.1%	19.0%	25.0%	23.7%	23.0%	24.0%	24.7%	25.4%
3	20.8%	21.9%	20.2%	17.7%	19.5%	19.6%	21.9%	22.5%	23.1%	22.0%	22.1%	22.8%
4	17.3%	17.8%	18.7%	22.8%	21.7%	23.0%	16.8%	17.1%	16.4%	18.6%	19.1%	17.6%
5-most deprived	13.1%	13.5%	14.3%	23.3%	22.5%	23.3%	12.6%	14.2%	15.4%	15.4%	15.3%	14.6%
Palliative Care- Yes(%)	57.6%	60.2%	61.7%	13.4%	17.3%	22.6%	16.1%	30.5%	41.4%	13.0%	16.8%	24.2%
QOF Codes	50.1%	52.1%	52.1%	8.4%	11.0%	14.3%	9.7%	17.3%	22.7%	7.1%	9.8%	13.9%
Other Codes	7.5%	8.1%	9.6%	4.9%	6.4%	8.3%	6.4%	13.2%	18.8%	5.9%	7.0%	10.3%
Death in Hospital- Yes(%)	34.7%	35.4%	28.9%	47.1%	51.9%	40.8%	23.7%	25.6%	20.5%	42.8%	48.5%	41.0%

Index of Multiple Deprivation and place of death were available for 81% of deaths.

Table 2: Proportions and changes in proportion of deaths recorded as needing palliative care approach in primary care since April 2009-March 2010.

Year	Total Deaths	Palliative Care Register			
		Total	Unadjusted Proportion	Adjusted Proportion (95%CI)	Changes in Proportion (95%CI)
	Cancer				
2009-10	6799	3913	57.6%	57.6%(56.4,58.7%)	0(ref)
2011-12	6386	3845	60.2%	60.6%(59.5,61.8%)	2.97%(1.33,4.62%)
2013-14	5483	3381	61.7%	61.9%(60.6,63.2%)	4.44%(2.74,6.14%)
Annual Change					*1.12%(0.70,1.54%)*
	COPD				
2009-10	1924	257	13.4%	13.6%(11.9,15.3%)	0(ref)
2011-12	1872	324	17.3%	17.5%(15.4,19.6%)	4.08%(1.82,6.34%)
2013-14	1630	368	22.6%	21.2%(19.2,23.3%)	9.36%(6.85,11.9%)
Annual Change					*2.31%(1.70,2.92%)*
	Dementia				
2009-10	2433	391	16.1%	20.9%(17.8,23.9%)	0(ref)
2011-12	2474	755	30.5%	37.5%(33.8,41.1%)	14.6%(12.3,16.9%)
2013-14	2432	1008	41.4%	40.7%(37.2,44.2%)	25.4%(22.9,27.8%)
Annual Change					*6.43%(5.82,7.04%)*
	Heart Failure				
2009-10	2429	315	13.0%	12.6%(10.7,14.4%)	0(ref)
2011-12	2152	361	16.8%	15.0%(12.8,17.2%)	3.26%(1.20,5.32%)
2013-14	1828	443	24.2%	21.2%(18.7,23.8%)	10.7%(8.38,13.1%)
Annual Change					*2.56%(1.99,3.12%)*

Adjusted proportions were standardised to the age- and sex- distribution of persons with cancer who died between April 2009 and March 2010. Changes in proportions and 95% confidence intervals (95%CI) were estimated using binomial regression adjusted for age, sex and index of multiple deprivation.

Table 3: Changes in proportion of deaths in hospital since April 2009-March 2010 among all patients, and among those not recorded or recorded as needing palliative care.

Year	Total			No Recording of Palliative Care			Recording of Palliative Care		
	Deaths: Hospital/ Total	Proportion	Change in Proportion (95%CI)	Deaths: Hospital/ Total	Proportion	Change in Proportion (95%CI)	Deaths: Hospital/ Total	Proportion	Change in Proportion (95%CI)
	Cancer								
2009-10	1929/5565	34.6%	0(ref)	1076/2371	45.4%	0(ref)	853/3194	26.7%	0(ref)
2011-12	1842/5200	35.4%	0.69%(-1.11,2.49%)	1033/2094	50.7%	5.33%(2.41,8.26%)	781/3106	25.1%	-1.47%(-3.63,0.69%)
2013-14	1277/4426	28.9%	-5.69%(-7.73,-4.08%)	727/1694	42.9%	-2.56%(-5.65,0.53%)	550/2732	20.1%	-6.32%(-8.47,-4.18%)
Annual Change			*-1.43%(-1.90,-0.97%)*			*-0.45%(-1.23,0.32%)*			*-1.62%(-2.19,-1.05%)*
	COPD								
2009-10	734/1557	47.1%	0(ref)	672/1364	49.3%	0(ref)	62/193	32.1%	0(ref)
2011-12	795/1531	51.9%	4.75%(1.23,8.28%)	711/1272	55.9%	6.57%(2.76,10.4%)	84/259	32.4%	0.38%(-8.36,9.11%)
2013-14	537/1315	40.8%	-6.25%(-9.88,-2.62%)	456/1022	44.6%	-4.60%(-8.63,-0.56%)	81/293	27.6%	-4.47%(-12.8,3.89%)
Annual Change			*-1.46%(-2.38,-0.55%)*			*-0.93%(-1.94,0.08%)*			*-1.24%(-3.34,0.86%)*
	Dementia								
2009-10	463/1951	23.7%	0(ref)	426/1655	25.7%	0(ref)	37/296	12.5%	0(ref)
2011-12	519/2025	25.6%	1.77%(-0.86,4.40%)	463/1417	32.7%	6.84%(3.63,10.1%)	56/608	9.2%	-2.07%(-6.17,2.03%)
2013-14	401/1953	20.5%	-2.99%(-5.54,-0.45%)	340/1135	30.0%	4.03%(0.66,7.40%)	61/818	7.5%	-3.74%(-7.64,0.16%)
Annual Change			*-0.78%(-1.44,-0.12%)*			*1.21%(0.34,2.07%)*			*-0.90%(-1.74,-0.06%)*
	Heart Failure								
2009-10	865/2022	42.8%	0(ref)	797/1759	45.3%	0(ref)	68/263	25.9%	0(ref)
2011-12	865/1783	48.5%	5.89%(2.74,9.05%)	779/1500	51.9%	6.72%(3.30,10.1%)	86/283	30.4%	5.14%(-2.37,12.6%)
2013-14	599/1462	41.0%	-1.26%(-4.55,2.03%)	513/1127	45.5%	0.71%(-2.99,4.40%)	86/335	25.7%	1.18%(-5.81,8.17%)
Annual Change			*-0.14%(-0.97,0.69%)*			*0.43%(-0.50,1.35%)*			*0.19%(-1.62,2.00%)*

Change in proportions and 95% confidence intervals (95%CI) were estimated using binomial regression adjusted for age, sex and index of multiple deprivation.