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What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study

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TITLE: What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study

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ABSTRACT

Objective

For patients with advanced cancer, several randomised controlled trials have shown that access to palliative care at least 6 months before death can improve symptoms, reduce unplanned hospital admissions, minimize aggressive cancer treatments and enable patients to make choices about their end of life care, including exercising the choice to die at home. This study determines in a UK population the duration of palliative care before death and explores influencing factors.

Design

This retrospective cohort study analysed referrals to three specialist palliative care services; a hospital based inpatient palliative care team, and two community based services (hospices). For each patient referred to any of the above services we identified the date of first referral to that team and calculated the median interval between first referral and death. We also calculated how referral time varied by age, sex, diagnosis and type of palliative care service

Participants

4,650 patients referred to specialist palliative care services in Leeds UK between April 2012 and March 2014.

Results

Median age of the sample was 75 years 3,903 patients had a diagnosis of cancer. Age, diagnosis and place of referral were significant predictors of duration of palliative care before death. Age was independently associated with duration of

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palliative care regardless of diagnosis, Patients over 75 years have 29 fewer days of palliative care than patients under 50. Patients with non-cancer diagnoses have 13 fewer days of palliative care than patients with cancer. Additionally, patients referred to hospital palliative care receive 24.5 fewer days palliative care than those referred to community palliative care services.

Conclusions

The current timing of referral to palliative care may limit the benefits to patient in terms of improvements in end of life care, particularly for older patients and patients with conditions other than cancer.

STRENGTHS AND LIMITATIONS

- This cohort study quantifies for the first time the duration of palliative care before death in 4,650 patients referred to palliative care services and shows older patients and those with a non-cancer diagnosis are disadvantaged in the duration of palliative care they receive.
- The study is based within a single UK city and although reports on referrals to three palliative care services, the findings reported here may not be wholly representative of practice elsewhere in the UK.

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INTRODUCTION

Specialist palliative care services aim to relieve suffering and improve quality of life for people with advanced diseases. For patients with advanced cancer, several

Randomised controlled trials [1-5] have shown that early access to palliative care can improve symptoms, reduce unplanned hospital admissions, minimize aggressive cancer treatments and enable patients to make choices about their end of life care, including exercising the choice to die at home. The trials from which this evidence is derived were conducted in North America and the studies vary widely in their definition of what constitutes palliative care services and who provides them. Common components were an assessment and several follow up consultations by specialist palliative care teams over a period of 2-3 months. Where reported, patients were recruited and received these interventions about 6 to 14 months before their death [1-5]. Collectively, these data suggest that a dose of 3-4 palliative care contacts applied about 6 months before death is associated with better end of life care.

The accumulating evidence to support early referral [1-10] is beginning to influence policy within the United States. Following a randomised phase III trial in patients with small cell lung cancer which demonstrated the benefit of early palliative care involvement in terms of quality of life and survival in 2010, [1] the American Society of Clinical Oncology issued guidance recommending that palliative care should be considered early in the course of illness for any patient with metastatic cancer or high symptom burden.[7] Despite this growing evidence base, within routine clinical practice in the UK palliative care clinicians report that many referrals are made in the

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last weeks or days of life. This study determines in a UK population the duration of palliative care before death and explores influencing factors.

METHODS

Data and Patients

We analysed referrals to three specialist palliative care services in Leeds, UK over a 2 year period (April 2012 to March 2014) relating to 4,650 deceased patients. One service was a hospital based inpatient palliative care team serving an acute hospital and tertiary cancer centre, and two were community based services (hospices) comprising 18 and 32 inpatient beds, each with its own community home care team. For each patient referred to any of the above services we identified the date of first referral to that team and calculated the median interval between first referral and death. We also calculated how referral time varied by age, sex, diagnosis and type of palliative care service. The data were systematically checked for outliers, inconsistencies, ambiguous diagnoses and missing data (e.g. no date of death). The main variables of interest were age at referral (in years), median time from referral to death (in days), referral location (acute hospital or community hospice), diagnostic grouping (cancer, non-cancer), and sub categories of diagnosis for both cancer and non-cancer conditions, as outlined in Table 1. NHS ethical approval was obtained for the programme of research (NIHR) (RP-PG-0610-10114). of which this study forms part (NRES Committee Yorkshire and The Humber ref 13/YH/0301) Insert table 1 here

Statistical analysis

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All referred adults (n = 4650) were included in the descriptive analysis. Median times to death were calculated and summarised using median absolute deviation (MAD). MAD was used as it is a measure of statistical dispersion that is resistant to outliers. Comparisons between median days from date of referral to death were performed using Mann-Whitney U for cancer versus non-cancer and hospital versus hospice referral. Comparisons for age (<50 years, 50 – 74 years, 75+ years) were performed using the Kruskal-Wallis test, followed by the Jonckheere-Terpstra test. We used median guantile regression to investigate the association between age-and sexstandardized median days to death for diagnosis (cancer versus non-cancer) and place of referral (hospital versus hospice). These analyses were performed using SPSS version 22.0. Diagnosis and place of referral were modelled using multivariable quantile regression analyses, a statistical technique that permits estimation of how the conditional median, or other quantiles (e.g., 10th percentile, 90th percentile), of a dependent variable y changes with an independent variable x. The model was generated using the greg command in STATA. Two-tailed p values <0.01 were considered significant.

Patient Involvement

Two cancer patients are co-investigators on the research programme of which the study is part and have informed both its design and conduct. They are supporting the active dissemination of the study findings to patients and carers through patient and public involvement networks in a format that can be readily understood by patients, carers and health service commissioners.

Sample characteristics

4,650 patients were included in the analysis. 2,272 females and 2,378 males. The median age of the sample was 75 years; 272 patients were under 50 years, 2014 were 50-74 years of age and 2,354 were 75 years or over. 3,903 patients had a diagnosis of cancer, 747 had conditions other than cancer. The median duration of palliative care for the whole study population was 34 days (MAD = 29 days, indicating that half of the study population had a duration of palliative care that deviated from the median by up to 29 days).

Type of Palliative care service

2,746 patients were referred to community (hospice) palliative care (CPC) teams and 1,904 to a hospital palliative care (HPC) team. When the services were considered separately (community and hospital) we found the length of palliative care was longer for patients referred to CPC; median 46 days (MAD = 38 days) compared to 20 days (MAD = 17 days) for referrals to HPC (U = 1925555.5, p <.01, r = -.22).

Diagnosis and duration of palliative care

The duration of palliative care varied depending on diagnosis. The median duration of palliative care for cancer patients was 37 days (MAD = 31 day s). Patients with conditions other than cancer had significantly shorter duration of palliative care than cancer patients, overall median 16 days (MAD = 14 days) (U = 1110511, p <.01, r = -

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.15); longer for CPC (22 days CPC, MAD 19 days) and shorter for HPC (13 days HPC, MAD 11 days).

Within the cancer patient population there was variation in duration of palliative care across the different cancer types; patients with breast or prostate cancer had the longest time between referral and death (median days of 43.5 and 48 days respectively) and patients with haematological or head and neck cancers the shortest (both with a median of 26 days). A Kruskal-Wallis H test showed that there was a statistically significant difference in number of days from referral to death between cancer diagnoses, $\chi^2(14) = 58.337$, p = <.000 (Figure 1). A breakdown of diagnosis categories for the non-cancer population was only available for the referrals to community palliative care. These are shown in Figure 2. Patients with dementia or patients who had a stroke had the shortest duration of palliative care before death (median 9 days and 5 days respectively), and patients with motor neurone disease had longest (median 83 days).

Insert figure 1 and figure 2 here

Age and duration of palliative care

We found a linear relationship between age and duration of palliative care. Patients over 75 years had a median of 29 days (MAD = 25 days) palliative care before death, patients between 50-74 years, 38 days (MAD = 31 days) and those under 50 years had most; 54.5 days (MAD = 47 days), p < .01.

Multivariable quantile regression

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Univariate analysis showed age, diagnosis and place of referral as significant predictors of duration of palliative care before death. The multivariate analysis showed that age is independently associated with duration of palliative care regardless of diagnosis, Table 2. Patients over 75 years have 29 fewer days of palliative care than patients under 50. Even when controlling for age and sex, patients with non-cancer diagnoses have 13 fewer days of palliative care than patients with cancer. Additionally, patients referred in hospital receive 24.5 fewer days palliative care than those referred in the community.

Insert Table 2 here

DISCUSSION

This is the first population level study that quantifies duration of palliative care before death, and identifies significantly different durations of palliative care for older patients and those with non-cancer diagnoses.

Comparison with other studies

In terms of studies exploring duration of palliative care globally our cohort is second only in terms of population size to a US study exploring duration of palliative care in heart failure patients.[11] We found the median duration of palliative care in our cohort to be 34 days, significantly shorter than the 6 months the research evidence suggests is optimal.[1-5] Whilst the duration of palliative care in our cohort appears to be similar to that observed in studies in the USA [2] and Italy [12,13] direct comparison is challenging due to the differing characteristics of the palliative services and the components of care they provide. It is however possible to broadly

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categorise the literature into those studies reporting exposure to hospital based palliative care services and those reporting community or hospice based services. Studies from UK, [14,15] USA, [16.17] Korea [18] and Singapore [19] report the median duration of hospital palliative care to range from 14.4 to 57 days and studies reporting community palliative care from Canada, [20], Italy [21] and Ireland [7] report duration to range from 40-70 days. These studies provide useful context to the data reported here (20 days to HPC; 46 days CPC) and show the timing of referral to be consistent with that reported in the international literature.

Having a cancer diagnosis is the primary determinant of access to specialist palliative care. During 2012-13, 88 per cent of palliative care inpatients and 75 per cent of new referrals to hospital support and outpatient services in the UK were for people with a cancer diagnosis, even though cancer accounts for only around 29 per cent of deaths.[22,23] In our study population 81% had a diagnosis of cancer which is consistent with the existing evidence that cancer patients are more likely to access palliative care. We also found that cancer patients had approximately 13 days more palliative care than non-cancer patients. It is already well evidenced [10,11] that non cancer patients are disadvantaged in terms of access to palliative care but it has not been reported previously that the inequity extends to the duration of care.

We found that increasing age is associated with shorter duration of palliative care. The most recent minimum dataset on palliative care activity shows older people are disadvantaged in terms of access; 29 per cent of people accessing specialist palliative care are in the 25 to 64 age group despite this age group only accounting for 13 per cent of deaths. Whereas people aged 85 or over account for 39 per cent of deaths but represent only 16.4 per cent of referrals to palliative care services. [24] Our study is the first to identify and quantify the shorter duration of palliative care in

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relation to age and so adds to this evidence base. Older people are therefore disadvantaged in both access to, and duration of, palliative care before death.

Limitations

This study has limitations. Firstly, it is based in a single UK city and although our findings are consistent with those reported elsewhere, Leeds is particularly well provisioned in terms of palliative care services and our findings may not therefore be representative of practice in other settings with less robust provision. Secondly, as de-identified data was used, we were unable to identify situations where a referral to both hospital and community palliative care services had occurred. In Leeds 17% of patients referred to hospital palliative care services receive a subsequent community palliative care referral therefore we expect this extent of overlap to be evident in the data reported here.

Thirdly, we do not have data on date of diagnosis which prevents us from relating the duration of palliative care services to the duration of clinical awareness of disease. Late diagnosis may be a key factor in late referral, though the almost universally short duration of palliative care in our cohort suggests that this factor is unlikely to account for the observed referral pattern.

Conclusions

This study shows that the current timing of referral to palliative care may limit the benefits to patient in terms of improvements in end of life care, particularly for older patients and patients with conditions other than cancer. Research is now urgently needed to better understand how the duration of palliative care reported here impacts on the quality of end of life care in order to develop and evaluate service level interventions.

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Contributors

MB, LZ, MA, and SD, all contributed to study design. SD led the data analysis and MA led the data validation. MB, LZ, MA, SD all contributed to the data interpretation and writing of this paper.

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Declaration of interests

All authors MB, LZ, MA, SD have completed the Unified Competing Interest form (<u>www.icmje.org/coi_disclosure.pdf</u> available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work

Transparency declaration

The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported, that no important aspects of the study have been omitted; and that there have been no deviations from the study protocol

Role of funding source

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Data Sharing

No additional unpublished data from this study is available

Inpublished da.

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What is already known on this subject

- Palliative care when initiated at least 6 months before death can lead to improvements in end of life care
- Within routine clinical practice in the UK palliative care clinicians report that many referrals are made in the last weeks and days of life

What our study adds

- The median interval between referral and death in a UK population of 4,650 specialist palliative care referrals was 34 days.
- The interval between referral and death was significantly shorter for patients with non-cancer diseases than with cancer
- Patients over 75 were significantly more likely to be referred closer to death than younger patients



Table 1

	Community PC	Hospital PC	Total
	n (%)	n (%)	n (%)
Total	2,746	1,904	4,650
Sex			
Male	1420 (51.7)	958 (50.3)	2,378 (51.1)
Female	1326 (48.3)	946 (49.7)	2,272 (48.9)
Diagnosis			
Cancer	2346 (85.5)	1557 (81.8)	3,903 (83.9)
Non-cancer	400 (14.6)	347 (18.2)	747 (16.1)
Age, years			
<50 years	110 (4)	172 (9)	282 (6)
50-74 years	1082 (39.4)	932 (48.9)	2,014 (43.3)
75+ years	1554 (56.6)	800 (42)	2,354 (50.6)

Table 2

Variable	Univariable model	Multivariable model	
Age			
<50 years	-	-	
50 – 74 years	-17 (-27.06, -10.94) +	-20.5 (-29.53, -11.47) +	
75 years and older	-26 (-35.13, -16.87) +	-29 (-38.04, -19.96) +	
Sex			
Female	-	-	
Male	-5 (-8.95, -1.05)	-2.5 (-6.66, 1.66)	
Diagnosis*			
Cancer	-	-	
Non-cancer	-21 (-26.12, -15.88) +	-13.5 (-19.24, -7.76) +	
Place of referral*			
Hospice	-	-	
Hospital	-28 (-32.25, -23.75) +	-24.5 (-28.79, -20.21) +	
*Variable adjusted for age a + = p <0.001	and sex		





STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cohort studies

Section/Topic	ltem #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Within abstract
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	3
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	3
		(b) For matched studies, give matching criteria and number of exposed and unexposed	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4
Data sources/	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe	4
measurement		comparability of assessment methods if there is more than one group	
Bias	9	Describe any efforts to address potential sources of bias	9
Study size	10	Explain how the study size was arrived at	3
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	4
		(b) Describe any methods used to examine subgroups and interactions	4
		(c) Explain how missing data were addressed	4
		(d) If applicable, explain how loss to follow-up was addressed	n/a
		(e) Describe any sensitivity analyses	n/a
Results			

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Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed	4
		eligible, included in the study, completing follow-up, and analysed	
		(b) Give reasons for non-participation at each stage	4
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	5
		(b) Indicate number of participants with missing data for each variable of interest	n/a
		(c) Summarise follow-up time (eg, average and total amount)	n/a
Outcome data	15*	Report numbers of outcome events or summary measures over time	5/6
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence	5/6
		interval). Make clear which confounders were adjusted for and why they were included	
		(b) Report category boundaries when continuous variables were categorized	5/6
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	5/6
Discussion			
Key results	18	Summarise key results with reference to study objectives	7/8
Limitations			
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from	7/8
		similar studies, and other relevant evidence	
Generalisability	21	Discuss the generalisability (external validity) of the study results	9
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on	10/11
		which the present article is based	

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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ABSTRACT

Objective

For patients with advanced cancer, several randomised controlled trials have shown that access to palliative care at least 6 months before death can improve symptoms, reduce unplanned hospital admissions, minimize aggressive cancer treatments and enable patients to make choices about their end of life care, including exercising the choice to die at home. This study determines in a UK population the duration of palliative care before death and explores influencing factors.

Design

This retrospective cohort study analysed referrals to three specialist palliative care services; a hospital based inpatient palliative care team, and two community based services (hospices). For each patient referred to any of the above services we identified the date of first referral to that team and calculated the median interval between first referral and death. We also calculated how referral time varied by age, sex, diagnosis and type of palliative care service.

Participants

4,650 patients referred to specialist palliative care services in Leeds UK between April 2012 and March 2014.

Results

Median age of the sample was 75 years. 3,903 (84.0%) patients had a diagnosis of cancer. Age, diagnosis and place of referral were significant predictors of duration of palliative care before death. Age was independently associated (J = 2672078, z = -

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392046.14, r = .01) with duration of palliative care regardless of diagnosis. Patients over 75 years have 29 fewer days of palliative care than patients under 50. Patients with non-cancer diagnoses have 13 fewer days of palliative care than patients with cancer. Additionally, patients referred to hospital palliative care receive 24.5 fewer days palliative care than those referred to community palliative care services.

Conclusions

The current timing of referral to palliative care may limit the benefits to patient in terms of improvements in end of life care, particularly for older patients and patients with conditions other than cancer.

STRENGTHS AND LIMITATIONS

- This cohort study quantifies for the first time the duration of palliative care before death in 4,650 patients referred to palliative care services and shows older patients and those with a non-cancer diagnosis are disadvantaged in the duration of palliative care they receive.
- The study is based within a single UK city and although reports on referrals to three palliative care services, the findings reported here may not be wholly representative of practice elsewhere in the UK.

INTRODUCTION

Specialist palliative care services aim to relieve suffering and improve quality of life for people with advanced diseases. For patients with advanced cancer, several randomised controlled trials [1-5] have shown that early access to palliative care can improve symptoms, reduce unplanned hospital admissions, minimize aggressive cancer treatments and enable patients to make choices about their end of life care, including exercising the choice to die at home, which for more than half of cancer patients is their expressed preference [5] The trials from which this evidence is derived were conducted in North America and the studies vary widely in their definition of what constitutes palliative care services and who provides them. Common components were an assessment and several follow up consultations by specialist palliative care teams over a period of 2-3 months. Where reported, patients were recruited and received these interventions about 6 to 14 months before their death [1-5]. Collectively, these data suggest that a dose of 3-4 palliative care contacts applied about 6 months before death is associated with better end of life care.

The accumulating evidence to support early referral [1-10] is beginning to influence policy within the United States. Following a randomised phase III trial in patients with small cell lung cancer which demonstrated the benefit of early palliative care involvement in terms of quality of life and survival in 2010, [1] the American Society of Clinical Oncology issued guidance recommending that palliative care should be considered early in the course of illness for any patient with metastatic cancer or high symptom burden.[7] Despite this growing evidence base, within routine clinical practice in the UK palliative care clinicians report that many referrals are made in the

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last weeks or days of life. This study determines in a UK population the duration of palliative care before death and explores influencing factors.

METHODS

Data and Patients

We analysed referrals to three specialist palliative care services in Leeds, UK over a 2 year period (April 2012 to March 2014) relating to 4,650 deceased patients. One service was a hospital based inpatient palliative care team serving an acute hospital and tertiary cancer centre, and two were community based services (hospices) comprising 18 and 32 inpatient beds, each with its own community home care team. For each palliative care service a data manager employed within each organisation provided anonymised data from their electronic medical record system. For each patient referred to any of the above services we identified the date of first referral to that team (referrals to CPC can be made by any health professional or the patient; referral to HPC is typically by a health professional within the acute hospital in which the HPC team is based). We calculated the median interval between first referral and death. We also calculated how referral time varied by age, sex, diagnosis and type of palliative care service. The data were systematically checked for outliers, inconsistencies, ambiguous diagnoses and missing data (e.g. no date of death). The main variables of interest were age at referral (in years), median time from referral to death (in days), referral location (acute hospital or community hospice), diagnostic grouping (cancer, non-cancer), and sub categories of diagnosis for both cancer and

non-cancer conditions, as outlined in Table 1. NHS ethical approval was obtained for

the programme of research (NIHR) (RP-PG-0610-10114). of which this study forms

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		Community PC n (%)	Hospital PC n (%)	Total <i>n</i> (%)
Total		2,746 (59.1)	1,904 (40.9)	4,650
Sex				
Male		1420 (51.7)	958 (50.3)	2,378 (51.1)
Female		1326 (48.3)	946 (49.7)	2,272 (48.9)
Diamaaja				
Diagnosis Cancer		2346 (85 5)	1557 (81.8)	3 903 (83 9)
Cancer	Gynaecological	120 (5 1)	145 (0 3)	265 (6.8)
	Haematological	120 (3.1)	743 (9.3) 26 (1 7)	131(3.4)
	Kidnov	100 (4.0) 66 (2.9)	20 (1.7)	131(3.4)
	Coloratel	00(2.0)	40 (3.0)	112(2.9)
	Colorecial	203 (10.8)	100 (9.6)	400 (10.4)
	Opper Gr	394 (10.8)	221 (14.2)	
	Lung	659 (28.1) 70 (2.4)	232 (14.9)	891 (22.8)
	Brain	79 (3.4)	34 (2.2)	113 (2.9)
	Неад алд меск	58 (2.5)	65 (4.2)	123 (3.2)
	Breast	132 (5.6)	1/2 (11.0)	304 (7.8)
	Bladder	76 (3.2)	54 (3.5)	130 (3.3)
	Liver	45 (1.9)	32 (2.1)	77 (2.0)
	Prostate	146 (6.2)	106 (6.8)	252 (6.5)
	Skin	44 (1.9)	85 (5.5)	129 (3.3)
	Unknown Origin	130 (5.5)	51 (3.3)	181 (4.6)
	Other Cancer	39 (1.7)	135 (8.7)	174 (4.5)
Non-cancer		400 (14.6)	347 (18.2)	747 (16.1)
	Dementia	52 (13.0)	-	52 (13.0)
	Stroke	19 (4.8)	-	19 (4.8)
	Degenerative disease	8 (2.0)	-	8 (2.0)
	Other neurological	27 (6.8)		27 (6.8)
	Heart failure	110 (27.5)	-	110 (27.5)
	Other lung	96 (24.0)	-	96 (24.0)
	Liver Failure	16 (4.0)	-	16 (4.0)
	Kidney failure	36 (9.0)	-	36 (9.0)
	Other non-cancer	36 (9.0)	-	36 (9.0)
	Non classified	-	347 (46.5)	347 (46.5)
Ago voare	alagnosis		- ()	- (15.0)
rye, years		110 (4)	172 (0)	282 (6)
50 74 vooro		10(4)	172(3) 032(48.0)	202(0)

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All referred adults (n = 4650) were included in the descriptive analysis. Median times to death were calculated and summarised using median absolute deviation (MAD). The median deviation is a measure of scale based on the median of the absolute deviations from the median of the distribution [11]. MAD was used as it is a measure of statistical dispersion that is resistant to outliers. Comparisons between median days from date of referral to death were performed using Mann-Whitney U for cancer versus non-cancer and hospital versus hospice referral. Comparisons for age (<50 years, 50 – 74 years, 75+ years) were performed using the Kruskal-Wallis test, followed by the Jonckheere-Terpstra test [12]. These analyses were performed using SPSS version 22.0. We used median guantile regression to investigate the association between age-and sex-standardized median days to death for diagnosis (cancer versus non-cancer) and place of referral (hospital versus hospice). Diagnosis and place of referral were modelled using multivariable quantile regression analyses, This model permits estimation of how the conditional median, or other quantiles (e.g., 10th percentile, 90th percentile), of a dependent variable y changes with an independent variable x. Diagnosis and place of referral were then included into this model. The model was generated using the greg command in STATA. Two-tailed *p* values < 0.01 were considered significant.

Patient Involvement

Two cancer patients are co-investigators on the research programme of which the study is part and have informed both its design and conduct. They are supporting the active dissemination of the study findings to patients and carers through patient and

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public involvement networks in a format that can be readily understood by patients, carers and health service commissioners.

RESULTS

Sample characteristics

4,650 patients were included in the analysis. 2,272 females and 2,378 males. The median age of the sample was 75 years; 272 patients were under 50 years, 2014 were 50-74 years of age and 2,354 were 75 years or over. 3,903 patients had a diagnosis of cancer, 747 had conditions other than cancer. The median duration of palliative care for the whole study population was 34 days (MAD = 29 days, indicating that half of the study population had a duration of palliative care that deviated from the median by up to 29 days).

Type of Palliative care service

2,746 patients were referred to community (hospice) palliative care (CPC) teams and 1,904 to a hospital palliative care (HPC) team. When the services were considered separately (community and hospital) we found the length of palliative care was longer for patients referred to CPC; median 46 days (MAD = 38 days) compared to 20 days (MAD = 17 days) for referrals to HPC (U = 1925555.5, p <.01, r = -.22).

Diagnosis and duration of palliative care

The duration of palliative care varied depending on diagnosis. The median duration of palliative care for cancer patients was 37 days (MAD = 31 day s). Patients with

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conditions other than cancer had significantly shorter duration of palliative care than cancer patients, overall median 16 days (MAD = 14 days) (U = 1110511, p < .01, r = -.15); longer for CPC (22 days CPC, MAD 19 days) and shorter for HPC (13 days HPC, MAD 11 days).

Within the cancer patient population there was variation in duration of palliative care across the different cancer types; patients with breast or prostate cancer had the longest time between referral and death (median days of 43.5 and 48 days respectively) and patients with haematological or head and neck cancers the shortest (both with a median of 26 days). A Kruskal-Wallis H test showed that there was a statistically significant difference in number of days from referral to death between cancer diagnoses, $\chi^2(14) = 58.337$, p = <.001 (Figure 1). A breakdown of diagnosis categories for the non-cancer population was only available for the referrals to community palliative care. These are shown in Figure 2. Patients with dementia or patients who had a stroke had the shortest duration of palliative care before death (median 9 days and 5 days respectively), and patients with motor neurone disease had longest (median 83 days).

Insert figure 1 and figure 2 here

Age and duration of palliative care

We found a linear relationship between age and duration of palliative care. Patients over 75 years had a median of 29 days (MAD = 25 days) palliative care before death, patients between 50-74 years, 38 days (MAD = 31 days) and those under 50 years had most; 54.5 days (MAD = 47 days), (J = 2672078, z = -392046.14, r = .01)

Multivariable quantile regression

Univariate analysis showed age, diagnosis and place of referral as significant predictors of duration of palliative care before death. The multivariate analysis showed that age is independently associated with duration of palliative care regardless of diagnosis, Table 2. Patients over 75 years have 29 fewer days of palliative care than patients under 50. Even when controlling for age and sex, patients with non-cancer diagnoses have 13 fewer days of palliative care than patients with cancer. Additionally, patients referred in hospital receive 24.5 fewer days palliative care than those referred in the community.

Variable	Univariable model	Multivariable model			
Age					
<50 years	-	-			
50 – 74 years	-17 (-27.06, -10.94) +	-20.5 (-29.53, -11.47) +			
75 years and older	-26 (-35.13, -16.87) +	-29 (-38.04, -19.96) +			
Sex					
Female	-	-			
Male	-5 (-8.95, -1.05)	-2.5 (-6.66, 1.66)			
Diagnosis					
Cancer	-	-			
Non-cancer	-21 (-26.12, -15.88) +	-13.5 (-19.24, -7.76) +			
Place of referral					
Hospice	-	-			
Hospital	-28 (-32.25, -23.75) +	-24.5 (-28.79, -20.21) +			

+ = p < 0.001
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DISCUSSION

This is the first population level study that quantifies duration of palliative care before death, and identifies significantly different durations of palliative care for older patients and those with non-cancer diagnoses.

Comparison with other studies

In terms of studies exploring duration of palliative care globally our cohort is second only in terms of population size to a US study exploring duration of palliative care in heart failure patients.[13] We found the median duration of palliative care in our cohort to be 34 days, significantly shorter than the 6 months the research evidence suggests is optimal.[1-5] Whilst the duration of palliative care in our cohort appears to be similar to that observed in studies in the USA [2] and Italy [14,15] direct comparison is challenging due to the differing characteristics of the palliative services and the components of care they provide. It is however possible to broadly categorise the literature into those studies reporting exposure to hospital based palliative care services and those reporting community or hospice based services. Studies from UK, [16,17] USA, [18.19] Korea [20] and Singapore [21] report the median duration of hospital palliative care to range from 14.4 to 57 days and studies reporting community palliative care from Canada, [22], Italy [23] and Ireland [7] report duration to range from 40-70 days. These studies provide useful context to the data reported here (20 days to HPC; 46 days CPC) and show the timing of referral to be consistent with that reported in the international literature.

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Having a cancer diagnosis is the primary determinant of access to specialist palliative care. During 2012-13, 88 per cent of palliative care inpatients and 75 per cent of new referrals to hospital support and outpatient services in the UK were for people with a cancer diagnosis, even though cancer accounts for only around 29 per cent of deaths.[24,25]⁻ In our study population 81% had a diagnosis of cancer which is consistent with the existing evidence that cancer patients are more likely to access palliative care. Extending palliative care to people with non-cancer diagnoses is a key objective of end of life care strategies across the UK however access to palliative care for non-cancer patients is hindered by less predictable disease trajectories and greater difficulty in identifying a terminal stage. Consistent with this, we found that cancer patients had approximately 13 days more palliative care than non-cancer patients. It is already well evidenced [10,11] that non cancer patients are disadvantaged in terms of access to palliative care but it has not been reported previously that the inequity extends to the duration of care.

We found that increasing age is associated with shorter duration of palliative care. The most recent minimum dataset on palliative care activity shows older people are disadvantaged in terms of access; 29 per cent of people accessing specialist palliative care are in the 25 to 64 age group despite this age group only accounting for 13 per cent of deaths. Whereas people aged 85 or over account for 39 per cent of deaths but represent only 16.4 per cent of referrals to palliative care services. [26] Our study is the first to identify and quantify the shorter duration of palliative care in relation to age and so adds to this evidence base. Older people are therefore disadvantaged in both access to, and duration of, palliative care before death. BMJ Open: first published as 10.1136/bmjopen-2016-012576 on 9 December 2016. Downloaded from http://bmjopen.bmj.com/ on June 3, 2025 at Department GEZ-LTA

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Limitations

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This study has limitations. Firstly, it is based in a single UK city and although our findings are consistent with those reported elsewhere. Leeds is particularly well provisioned in terms of palliative care services and our findings may not therefore be representative of practice in other settings with less robust provision. Secondly, as de-identified data was used, we were unable to identify situations where a referral to both hospital and community palliative care services had occurred. In Leeds 17% of patients referred to hospital palliative care services receive a subsequent community palliative care referral therefore we expect this extent of overlap to be evident in the data reported here.

Thirdly, as retrospective routinely collected clinical data was used we do not have data on date of diagnosis which prevents us from relating the duration of palliative care services to the duration of clinical awareness of disease. Late diagnosis may be a key factor in late referral, though the almost universally short duration of palliative care in our cohort suggests that this factor is unlikely to account for the observed referral pattern.

Conclusions

This study shows that the current timing of referral to palliative care may limit the benefits to patient in terms of improvements in end of life care, particularly for older patients and patients with conditions other than cancer. Research is now urgently needed to better understand how the duration of palliative care reported here impacts on the quality of end of life care in order to develop and evaluate service level interventions.

Contributors

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MB, LZ, MA, and SD, all contributed to study design. SD led the data analysis and MA led the data validation. MB, LZ, MA, SD all contributed to the data interpretation and writing of this paper.

LZ, the Corresponding Author has the right to grant on behalf of all authors and does grant on behalf of all authors, an exclusive licence on a worldwide basis to the BMJ Publishing Group Ltd to permit this article (if accepted) to be published in BMJ editions and any other BMJPGL products and sublicences such use and exploit all subsidiary rights, as set out in the licence

Declaration of interests

All authors MB, LZ, MA, SD have completed the Unified Competing Interest form (<u>www.icmje.org/coi_disclosure.pdf</u> available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work

Transparency declaration

The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported, that no important aspects of the study have been omitted; and that there have been no deviations from the study protocol

Role of funding source

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<text> author(s) and not necessarily those of the NHS, the NIHR or the Department of

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What is already known on this subject

- Palliative care when initiated at least 6 months before death can lead to improvements in end of life care
- Within routine clinical practice in the UK palliative care clinicians report that many referrals are made in the last weeks and days of life

What our study adds

- The median interval between referral and death in a UK population of 4,650 specialist palliative care referrals was 34 days.
- The interval between referral and death was significantly shorter for patients with non-cancer diseases than with cancer
- Patients over 75 were significantly more likely to be referred closer to death than younger patients





169x137mm (300 x 300 DPI)



Figure 2 Duration of palliative care in relation to non cancer diagnosis

133x114mm (300 x 300 DPI)

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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cohort studies

Section/Topic	ltem #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Within abstract
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	3
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	3
		(b) For matched studies, give matching criteria and number of exposed and unexposed	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4
Data sources/	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe	4
measurement		comparability of assessment methods if there is more than one group	
Bias	9	Describe any efforts to address potential sources of bias 9	
Study size	10	Explain how the study size was arrived at	3
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	4
		(b) Describe any methods used to examine subgroups and interactions	4
		(c) Explain how missing data were addressed	4
		(d) If applicable, explain how loss to follow-up was addressed	n/a
		(e) Describe any sensitivity analyses	n/a
Results			

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Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed	4
		eligible, included in the study, completing follow-up, and analysed	
		(b) Give reasons for non-participation at each stage	4
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	5
		(b) Indicate number of participants with missing data for each variable of interest	n/a
		(c) Summarise follow-up time (eg, average and total amount)	n/a
Outcome data	15*	Report numbers of outcome events or summary measures over time	5/6
Main results	lain results 16 (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence		5/6
		interval). Make clear which confounders were adjusted for and why they were included	
		(b) Report category boundaries when continuous variables were categorized	5/6
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	5/6
Discussion			
Key results	18	Summarise key results with reference to study objectives	7/8
Limitations			
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from	7/8
		similar studies, and other relevant evidence	
Generalisability	21	Discuss the generalisability (external validity) of the study results	9
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on	10/11
		which the present article is based	

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study

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TITLE: What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large UK city Authors:

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ABSTRACT

Objective

For patients with advanced cancer, several randomised controlled trials have shown that access to palliative care at least 6 months before death can improve symptoms, reduce unplanned hospital admissions, minimize aggressive cancer treatments and enable patients to make choices about their end of life care, including exercising the choice to die at home. This study determines in a UK population the duration of palliative care before death and explores influencing factors.

Design

This retrospective cohort study analysed referrals to three specialist palliative care services; a hospital based inpatient palliative care team, and two community based services (hospices). For each patient referred to any of the above services we identified the date of first referral to that team and calculated the median interval between first referral and death. We also calculated how referral time varied by age, sex, diagnosis and type of palliative care service.

Participants

4,650 patients referred to specialist palliative care services in Leeds UK between April 2012 and March 2014.

Results

Median age of the sample was 75 years. 3,903 (84.0%) patients had a diagnosis of cancer. Age, diagnosis and place of referral were significant predictors of duration of palliative care before death. Age was independently associated (J = 2672078, z = -

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392046.14, r = .01) with duration of palliative care regardless of diagnosis. Patients over 75 years have 29 fewer days of palliative care than patients under 50. Patients with non-cancer diagnoses have 13 fewer days of palliative care than patients with cancer. Additionally, patients referred to hospital palliative care receive 24.5 fewer days palliative care than those referred to community palliative care services.

Conclusions

The current timing of referral to palliative care may limit the benefits to patient in terms of improvements in end of life care, particularly for older patients and patients with conditions other than cancer.

STRENGTHS AND LIMITATIONS

- To the best of our knowledge this is the largest UK cohort study undertaken to explore duration of palliative care in patients with both cancer and non-cancer diagnoses.
- The data used in this study are derived from a live clinical system and as such are likely to represent errors or omissions inherent within that system
- As the data was anonymised we were unable to identify which patients were referred to both community and hospital palliative care. This may mean that for some patients their first contact with palliative care services could have occurred earlier than reported here.

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INTRODUCTION

Specialist palliative care services aim to relieve suffering and improve quality of life for people with advanced diseases. For patients with advanced cancer, several randomised controlled trials [1-5] have shown that early access to palliative care can improve symptoms, reduce unplanned hospital admissions, minimize aggressive cancer treatments and enable patients to make choices about their end of life care, including exercising the choice to die at home, which for more than half of cancer patients is their expressed preference [5] The trials from which this evidence is derived were conducted in North America and the studies vary widely in their definition of what constitutes palliative care services and who provides them. Common components were an assessment and several follow up consultations by specialist palliative care teams over a period of 2-3 months. Where reported, patients were recruited and received these interventions about 6 to 14 months before their death [1-5]. Collectively, these data suggest that a dose of 3-4 palliative care contacts applied about 6 months before death is associated with better end of life care.

The accumulating evidence to support early referral [1-10] is beginning to influence policy within the United States. Following a randomised phase III trial in patients with small cell lung cancer which demonstrated the benefit of early palliative care involvement in terms of quality of life and survival in 2010, [1] the American Society of Clinical Oncology issued guidance recommending that palliative care should be considered early in the course of illness for any patient with metastatic cancer or high symptom burden.[7] Despite this growing evidence base, within routine clinical

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practice in the UK palliative care clinicians report that many referrals are made in the last weeks or days of life. This study determines in a UK population the duration of palliative care before death and explores influencing factors.

METHODS

Data and Patients

We analysed referrals to three specialist palliative care services in Leeds, UK over a 2 year period (April 2012 to March 2014) relating to 4,650 deceased patients. One service was a hospital based inpatient palliative care team serving an acute hospital and tertiary cancer centre, and two were community based services (hospices) comprising 18 and 32 inpatient beds, each with its own community home care team. For each palliative care service a data manager employed within each organisation provided anonymised data from their electronic medical record system. For each patient referred to any of the above services we identified the date of first referral to that team (referrals to CPC can be made by any health professional or the patient; referral to HPC is typically by a health professional within the acute hospital in which the HPC team is based). We calculated the median interval between first referral and death. We also calculated how referral time varied by age, sex, diagnosis and type of palliative care service. The data were systematically checked for outliers, inconsistencies, ambiguous diagnoses and missing data (e.g. no date of death). The main variables of interest were age at referral (in years), median time from referral to death (in days), referral location (acute hospital or community hospice), diagnostic grouping (cancer, non-cancer), and sub categories of diagnosis for both cancer and non-cancer conditions, as outlined in Table 1. NHS ethical approval was obtained for

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the programme of research (NIHR) (RP-PG-0610-10114). of which this study forms part (NRES Committee Yorkshire and The Humber ref 13/YH/0301) Insert table 1 here

Statistical analysis

All referred adults (n = 4650) were included in the descriptive analysis. Median times to death were calculated and the variability was summarised using median absolute deviation (MAD). The median deviation is a measure of scale based on the median of the absolute deviations from the median of the distribution [11]. MAD was used as it is a measure of statistical dispersion that is resistant to outliers. Comparisons between median days from date of referral to death were performed using Mann-Whitney U for cancer versus non-cancer and hospital versus hospice referral. Comparisons for age (<50 years, 50 - 74 years, 75 + years) were performed using the Kruskal-Wallis test, followed by the Jonckheere-Terpstra test [12]. These analyses were performed using SPSS version 22.0. We used median quantile regression to investigate the association between age-and sex-standardized median days to death for diagnosis (cancer versus non-cancer) and place of referral (hospital versus hospice). Diagnosis and place of referral were modelled using multivariable quantile regression analyses, This model permits estimation of how the conditional median, or other quantiles (e.g., 10th percentile, 90th percentile), of a dependent variable v changes with an independent variable x. Diagnosis and place of referral were then included into this model. The model was generated using the greg command in STATA. Two-tailed p values <0.01 were considered significant.

Patient Involvement

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Two cancer patients are co-investigators on the research programme of which the study is part and have informed both its design and conduct. They are supporting the active dissemination of the study findings to patients and carers through patient and public involvement networks in a format that can be readily understood by patients, carers and health service commissioners.

RESULTS

Sample characteristics

4,650 patients were included in the analysis. 2,272 females and 2,378 males. The median age of the sample was 75 years; 272 patients were under 50 years, 2014 were 50-74 years of age and 2,354 were 75 years or over. 3,903 patients had a diagnosis of cancer, 747 had conditions other than cancer. The median duration of palliative care for the whole study population was 34 days (MAD = 29 days, indicating that half of the study population had a duration of palliative care that deviated from the median by up to 29 days).

Type of Palliative care service

2,746 patients were referred to community (hospice) palliative care (CPC) teams and 1,904 to a hospital palliative care (HPC) team. When the services were considered separately (community and hospital) we found the length of palliative care was longer for patients referred to CPC; median 46 days (MAD = 38 days) compared to 20 days (MAD = 17 days) for referrals to HPC (U = 1925555.5, p <.01, r = -.22).

Diagnosis and duration of palliative care

The duration of palliative care varied depending on diagnosis. The median duration of palliative care for cancer patients was 37 days (MAD = 31 day s). Patients with conditions other than cancer had significantly shorter duration of palliative care than cancer patients, overall median 16 days (MAD = 14 days) (U = 1110511, p <.01, r = -.15); longer for CPC (22 days CPC, MAD 19 days) and shorter for HPC (13 days HPC, MAD 11 days).

Within the cancer patient population there was variation in duration of palliative care across the different cancer types; patients with breast or prostate cancer had the longest time between referral and death (median days of 43.5 and 48 days respectively) and patients with haematological or head and neck cancers the shortest (both with a median of 26 days). A Kruskal-Wallis H test showed that there was a statistically significant difference in number of days from referral to death between cancer diagnoses, $\chi^2(14) = 58.337$, p = <.001 (Figure 1). A breakdown of diagnosis categories for the non-cancer population was only available for the referrals to community palliative care. These are shown in Figure 2. Patients with dementia or patients who had a stroke had the shortest duration of palliative care before death (median 9 days and 5 days respectively), and patients with motor neurone disease had longest (median 83 days).

Insert figure 1 and figure 2 here

Age and duration of palliative care

We found a linear relationship between age and duration of palliative care. Patients over 75 years had a median of 29 days (MAD = 25 days) palliative care before

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death, patients between 50-74 years, 38 days (MAD = 31 days) and those under 50 years had most; 54.5 days (MAD = 47 days), (J = 2672078, z = -392046.14, r = .01)

Multivariable quantile regression

Univariate analysis showed age, diagnosis and place of referral as significant predictors of duration of palliative care before death. The multivariable analysis showed that age is independently associated with duration of palliative care regardless of diagnosis, Table 2. Patients over 75 years have 29 fewer days of palliative care than patients under 50. Even when controlling for age and sex, patients with non-cancer diagnoses have 13 fewer days of palliative care than patients with cancer. Additionally, patients referred in hospital receive 24.5 fewer days palliative care than those referred in the community.

Insert Table 2 here

DISCUSSION

This is the first population level study that quantifies duration of palliative care before death, and identifies significantly different durations of palliative care for older patients and those with non-cancer diagnoses.

Comparison with other studies

In terms of studies exploring duration of palliative care globally our cohort is second only in terms of population size to a US study exploring duration of palliative care in heart failure patients.[13] We found the median duration of palliative care in our

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cohort to be 34 days, significantly shorter than the 6 months the research evidence suggests is optimal.[1-5] Whilst the duration of palliative care in our cohort appears to be similar to that observed in studies in the USA [2] and Italy [14,15] direct comparison is challenging due to the differing characteristics of the palliative services and the components of care they provide. It is however possible to broadly categorise the literature into those studies reporting exposure to hospital based palliative care services and those reporting community or hospice based services. Studies from UK, [16,17] USA,[18.19] Korea [20] and Singapore [21] report the median duration of hospital palliative care to range from 14.4 to 57 days and studies reporting community palliative care from Canada, [22], Italy [23] and Ireland [7] report duration to range from 40-70 days. These studies provide useful context to the data reported here (20 days to HPC; 46 days CPC) and show the timing of referral to be consistent with that reported in the international literature.

Having a cancer diagnosis is the primary determinant of access to specialist palliative care. During 2012-13, 88 per cent of palliative care inpatients and 75 per cent of new referrals to hospital support and outpatient services in the UK were for people with a cancer diagnosis, even though cancer accounts for only around 29 per cent of deaths.[24,25] In our study population 81% had a diagnosis of cancer which is consistent with the existing evidence that cancer patients are more likely to access palliative care. Extending palliative care to people with non-cancer diagnoses is a key objective of end of life care strategies across the UK however access to palliative care for non-cancer patients is hindered by less predictable disease trajectories and greater difficulty in identifying a terminal stage. Consistent with this, we found that cancer patients had approximately 13 days more palliative care than non-cancer patients. It is already well evidenced [10,11] that non cancer patients are

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disadvantaged in terms of access to palliative care but it has not been reported previously that the inequity extends to the duration of care.

We found that increasing age is associated with shorter duration of palliative care. The most recent minimum dataset on palliative care activity shows older people are disadvantaged in terms of access; 29 per cent of people accessing specialist palliative care are in the 25 to 64 age group despite this age group only accounting for 13 per cent of deaths. Whereas people aged 85 or over account for 39 per cent of deaths but represent only 16.4 per cent of referrals to palliative care services. [26] Our study is the first to identify and quantify the shorter duration of palliative care in relation to age and so adds to this evidence base. Older people are therefore disadvantaged in both access to, and duration of, palliative care before death.

Limitations

This study has limitations. Firstly, it is based in a single UK city and although our findings are consistent with those reported elsewhere, Leeds is particularly well provisioned in terms of palliative care services and our findings may not therefore be representative of practice in other settings with less robust provision. Secondly, as de-identified data was used, we were unable to identify situations where a referral to both hospital and community palliative care services had occurred. In Leeds 17% of patients referred to hospital palliative care services receive a subsequent community palliative care referral therefore we expect this extent of overlap to be evident in the data reported here.

Thirdly, as retrospective routinely collected clinical data was used we do not have data on date of diagnosis which prevents us from relating the duration of palliative care services to the duration of clinical awareness of disease. Late diagnosis may be Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies

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a key factor in late referral, though the almost universally short duration of palliative care in our cohort suggests that this factor is unlikely to account for the observed referral pattern.

Conclusions

This study shows that the current timing of referral to palliative care may limit the benefits to patient in terms of improvements in end of life care, particularly for older patients and patients with conditions other than cancer. Research is now urgently needed to better understand how the duration of palliative care reported here impacts on the quality of end of life care in order to develop and evaluate service level interventions.

Contributors

MB, LZ, MA, and SD, all contributed to study design. SD led the data analysis and MA led the data validation. MB, LZ, MA, SD all contributed to the data interpretation and writing of this paper.

LZ, the Corresponding Author has the right to grant on behalf of all authors and does grant on behalf of all authors, an exclusive licence on a worldwide basis to the BMJ Publishing Group Ltd to permit this article (if accepted) to be published in BMJ editions and any other BMJPGL products and sublicences such use and exploit all subsidiary rights, as set out in the licence

Declaration of interests

All authors MB, LZ, MA, SD have completed the Unified Competing Interest form (<u>www.icmje.org/coi_disclosure.pdf</u> available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no

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financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work

Transparency declaration

The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported, that no important aspects of the study have been omitted; and that there have been no deviations from the study protocol

Role of funding source

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Data Sharing

No additional unpublished data from this study is available

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What is already known on this subject

- Palliative care when initiated at least 6 months before death can lead to improvements in end of life care
- Within routine clinical practice in the UK palliative care clinicians report that many referrals are made in the last weeks and days of life

What our study adds

- The median interval between referral and death in a UK population of 4,650 specialist palliative care referrals was 34 days.
- The interval between referral and death was significantly shorter for patients with non-cancer diseases than with cancer
- Patients over 75 were significantly more likely to be referred closer to death than younger patients

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1 2 3 4 5	Table 1 Patient characteristics in relation to referral to community and hospital palliative care
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		Community PC	Hospital PC	Total
		n (%)	n (%)	n (%)
Total		2,746 (59.1)	1,904 (40.9)	4,650
Sex				
Male		1420 (51.7)	958 (50.3)	2,378 (51.1)
Female		1326 (48.3)	946 (49.7)	2,272 (48.9)
Diagnosis				
Cancer	_	2346 (85.5)	1557 (81.8)	3,903 (83.9)
	Gynaecological	120 (5.1)	145 (9.3)	265 (6.8)
	Haematological	105 (4.5)	26 (1.7)	131 (3.4)
	Kidney	66 (2.8)	46 (3.0)	112 (2.9)
	Colorectal	253 (10.8)	153 (9.8)	406 (10.4)
	Upper GI	394 (16.8)	221 (14.2)	615 (15.8)
	Lung	659 (28.1)	232 (14.9)	891 (22.8)
	Brain	79 (3.4)	34 (2.2)	113 (2.9)
	Head and Neck	58 (2.5)	65 (4.2)	123 (3.2)
	Breast	132 (5.6)	172 (11.0)	304 (7.8)
	Bladder	76 (3.2)	54 (3.5)	130 (3.3)
	Liver	45 (1.9)	32 (2.1)	77 (2.0)
	Prostate	146 (6.2)	106 (6.8)	252 (6.5)
	Skin	44 (1.9)	85 (5.5)	129 (3.3)
	Unknown Origin	130 (5.5)	51 (3.3)	181 (4.6)
	Other Cancer	39 (1.7)	135 (8.7)	174 (4.5)
Non-cancer		400 (14.6)	347 (18.2)	747 (16.1)
	Dementia	52 (13.0)	-	52 (13.0)
	Stroke	19 (4.8)	-	19 (4.8)
	Degenerative disease	8 (2.0)	-	8 (2.0)
	Other neurological	27 (6.8)	-	27 (6.8)
	Heart failure	110 (27.5)	-	110 (27.5)
	Other lung	96 (24.0)	-	96 (24.0)
	Liver Failure	16 (4.0)	-	16 (4.0)
	Kidney failure	36 (9.0)	-	36 (9.0)
	Other non-cancer	36 (9.0)	-	36 (9.0)
	Non classified diagnosis	-	347 (46.5)	347 (46.5)
Age, years				
<50 years		110 (4)	172 (9)	282 (6)
50-74 years		1082 (39.4)	932 (48.9)	2,014 (43.3)
75+ vears		1554 (56.6)	800 (42)	2.354 (50.6)

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Table 2 Univariable and multivariable model for duration of palliative care

Variable	Univariable model	Multivariable model		
Age				
<50 years	-	-		
50 – 74 years	-17 (-27.06, -10.94) +	-20.5 (-29.53, -11.47) +		
75 years and older	-26 (-35.13, -16.87) +	-29 (-38.04, -19.96) +		
Sex				
Female	-	-		
Male	-5 (-8.95, -1.05)	-2.5 (-6.66, 1.66)		
Diagnosis				
Cancer	_	-		
Non-cancer	-21 (-26.12, -15.88) +	-13.5 (-19.24, -7.76) +		
Place of referral				
Hospice	-	-		
Hospital	-28 (-32.25, -23.75) +	-24.5 (-28.79, -20.21) +		

Figure legends:

Figure 1 Duration of palliative care in relation to cancer diagnosis

Figure 2 Duration of palliative care in relation to non cancer diagnosis





169x137mm (300 x 300 DPI)



Figure 2 Duration of palliative care in relation to non cancer diagnosis

133x114mm (300 x 300 DPI)

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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cohort studies

Section/Topic	ltem #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Within abstract
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods	-		
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	5
		(b) For matched studies, give matching criteria and number of exposed and unexposed	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	
Study size	10	Explain how the study size was arrived at	4
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	5
		(b) Describe any methods used to examine subgroups and interactions	5
		(c) Explain how missing data were addressed	5
		(d) If applicable, explain how loss to follow-up was addressed	n/a
		(e) Describe any sensitivity analyses	n/a
Results			

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Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed	5
		eligible, included in the study, completing follow-up, and analysed	
		(b) Give reasons for non-participation at each stage	5
		(c) Consider use of a flow diagram	
Descriptive data 14*		(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	6
		(b) Indicate number of participants with missing data for each variable of interest	n/a
		(c) Summarise follow-up time (eg, average and total amount)	n/a
Outcome data	15*	Report numbers of outcome events or summary measures over time	6/7
Main results	lain results 16 (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence		6/7
		interval). Make clear which confounders were adjusted for and why they were included	
		(b) Report category boundaries when continuous variables were categorized	6/7
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	6/7
Discussion			
Key results	18	Summarise key results with reference to study objectives	9/10
Limitations			
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from	9/10
		similar studies, and other relevant evidence	
Generalisability	21	Discuss the generalisability (external validity) of the study results	11
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	12/13

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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