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Duration and determinants of hospice-based specialist palliative care. A national retrospective cohort study.

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Abstract

Background: Understanding service provision for patients with advanced disease is a research priority, with a need to identify barriers that limit widespread integration of palliative care.

Aim: To identify patient and organisational factors that influence the duration of hospice-based palliative care in the UK prior to death.

Design: Retrospective cohort study.

Setting/participants: 64 UK hospices providing specialist palliative care inpatient beds and community services extracted data for all adult decedents (aged over 17 years) with progressive, advanced disease, with a prior referral (e.g. inpatient, community teams, and outpatient) who died between 1st January 2015 and 31st December 2015. Data were requested for factors relating to both the patient and hospice site.

Results: Across 42,758 decedents, the median time from referral to death was 48 days. Significant differences in referral to death days were found for those with cancer (53 days) and non-cancer (27 days) ($P<0.0001$). As age increases, the median days from referral to death decreases: for those under 50 (78 days), 50 – 74 years (59 days), and 75 and over (39 days) ($P=0.0001$). An adjusted multivariable negative binomial model demonstrated increasing age persisting as a significant predictor of fewer days of hospice care, as did being male, having a missing ethnicity classification and having a non-cancer diagnosis ($P= p<0.001$).

Conclusions: Despite increasing rhetoric around early referral, patients with advanced disease are receiving referrals to hospice specialist palliative care very late in their illness trajectory. Age and diagnosis persist as determinants of duration of hospice specialist palliative care before death.

Key words: palliative care, hospice care, referral, advanced illness, retrospective studies

What is already known on this subject?

- The UK is ranked top of 40 countries for level of integration of palliative care within wider health services measured in a ‘quality of death’ index based on palliative service provision, access to opioids and a national strategic approach.
- Recent recommendations encourage earlier referral to palliative care, with involvement expected within 8 weeks of diagnosis of advanced disease for patients with cancer.

What this paper adds

- UK hospices continue to offer a ‘last weeks of life’ service to predominantly adult patients with cancer, with more than half of all referrals occurring in the last 7 weeks of life (median time 48 days) and 40% occurring within 30 days of death.
- Inequities in access to hospice-based palliative care persist; those with non-cancer conditions and older age groups receive a much shorter duration of palliative care prior to death.

Implications for practice, theory or policy

- Despite increasing evidence of the benefits of earlier referral to palliative care, existing evidence suggests that many patients are still referred late which limits the benefits on end of life care.
- Hospice-based palliative care requires a radical focus and promotion of integrated service models to respond to and better support the projected demand from age-related growth in deaths from chronic illness.

Background

Increasing evidence highlights that palliative care can improve symptom control and quality of life, increase satisfaction with care, and provide better outcomes for families.(1) In particular, early referral can lead to multiple benefits for patients and their families. These include, but are not limited to, improvement in certain symptoms, improved patient quality of life, reduced aggressive care at the end of life, reduced hospital length of stay and hospitalizations, and improved caregiver burden and better maintenance of caregiver quality of life.(2) For patients with cancer, there is a drive to facilitate earlier referral through integration of palliative care within oncology care.(3) Recent recommendations from the American Society of Clinical Oncology highlight that patients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment.(4) For non-cancer conditions, there is evidence of benefits of earlier referral, supporting various needs across earlier and later phases in the illness trajectory.(5) Understanding approaches to early referral and barriers that limit integration of palliative care is a research priority.(6) A key starting point is to understand current practice. Determining timing of referral to palliative care is a marker of quality and can inform when patients are accessing and potentially benefitting from services.(7) At a population-level there are few data to describe duration of palliative care involvement, how it differs across diagnoses and where increased integration efforts may be required.(8) Internationally there are limited and widely varied reports on duration of palliative care received by patients before death, measured as the time between referral to a service and death. Where available, figures vary greatly within and across countries. Examples of studies reporting median times range from 12 – 21 days in Korea,(9) US,(10) and UK,(11) to in excess of 60 – 70 days in Canada.(12) These studies are based on small sample sizes in a limited number of settings. Studies measuring duration of palliative care at a regional level include a citywide report in Leeds, UK,(11) (median of 34 days) and a population-level observational study in Ontario, Canada (35 mean days of palliative care).(8) Within these regions, palliative care is typically supporting patients with advanced disease in the last month of life.

Although data are lacking at a population level, factors affecting access and duration of palliative care have been explored at the patient, health professional and health system level. Disproportionate access to a greater number of days of palliative care prior to death occurs for people with malignant disease (when compared to people with non-cancer conditions), people under 65 years (compared to those over 65 years), and white people (when compared to Black, Asian and Minority Ethnic people).(13) Geographical variations in access to palliative care also exist.(14) In the UK, variation is particularly pronounced, with fewer days being received by patients in rural areas.(15) Research on cancer care specifically has explored the role of oncologists and their influence on access to palliative care. A US study suggested that palliative care referrals can be limited by perceptions that palliative care is incompatible with cancer therapy, beliefs that the oncologist's role is incompatible with palliative care, and ignorance of locally available palliative services.(16) A UK study exploring reasons for limited referral of non-cancer patients to community palliative teams identified perception of the palliative care service by other health professionals, the existence of different pathways of care for cancer and non-cancer patients, and the lack of understanding of the role of other specialist nurses as key influences on referral patterns.(17) System-level barriers include lack of resources and restrictive eligibility criteria.(18)

Most cited evidence supporting early referral to palliative care arises from randomised controlled trials in the US. This research was undertaken to determine current timing of referrals to hospice-based specialist palliative care nationally in the UK. Furthermore, the study sought to identify the extent to which previously identified factors influence timing of referrals to hospice-based specialist palliative care in the UK. The development of this first national picture of timing of referrals will provide a benchmark against which the policy rhetoric for earlier referral to palliative care can be judged. Internationally, different models of palliative care exist, sometimes developed for specific cultural contexts.(19) In the context of the UK, palliative care is provided through both specialist (multidisciplinary team of National Health Service (NHS) or hospice staff with the requisite qualifications, expertise and experience) and generalist (all other health professionals, supported by specialist teams) services.(20) Around 95% of inpatient beds for specialist palliative care are hospice-led (88% are charitable organisations and 12% are NHS units). 60 – 75% of community palliative care is delivered by hospice organisations.(21) In order to determine timing of referrals to palliative care across the UK this study focuses on provision of specialist palliative care by hospices, which provide the majority of this level of care in the UK context.

Methods

Study aim: To conduct a national survey on factors that influence duration of palliative care, focusing on specialist palliative care provision by hospices in the UK.

Study design: Retrospective cohort study using data from electronic clinical record systems held by hospice sites across the UK. We examined routinely collected anonymised data on all decedents during 2015. Following submission via the Integrated Research Application System, ethical approval was obtained from the West Midlands - South Birmingham Research Ethics Committee (reference: 16/WM/0412) and appropriate management and governance clearance was obtained from each site prior to participation in the study.

Sampling: The project was undertaken in partnership with Hospice UK, a national charity that champions and supports hospice and palliative care providers across the UK. In November 2016, a study invitation email was sent to 195 member hospices of Hospice UK (that provide specialist adult palliative care). Invitations were sent through two email lists; CEO and senior contacts at member hospice sites, and a list of all hospice nursing directors. Subsequent reminder emails were sent to non-responders in December 2016 and January 2017. In total, 64 hospice sites participated reflecting a 33% response rate.

Data extraction: Following enrolment into the study, sites were asked to extract data for all adult decedents (aged over 17 years) with progressive, advanced disease with a prior referral to hospice care (e.g. inpatient, community teams, and outpatient) who died between 1st January 2015 and 31st December 2015 (referral to services could have occurred in 2015 or any prior year). A Microsoft Excel template was provided to participating sites, with a spreadsheet for inserting data on eligible patients (date of birth, date of death, sex, ethnicity, diagnosis at referral, and date of first hospice referral on record). Data on source and reason for a referral was not captured as these can be multifaceted and there is no standardised coding approach for recording these. Embedded algorithms in the Microsoft Excel template used entered patient data to generated a separate spreadsheet with age at death and number of days from initial referral to death (number of days' difference between first referral and date of death), sex, ethnicity and diagnosis at referral. The second spreadsheet was submitted to the research team via the University of Leeds Secure Electronic Environment for Data (SEED) system which is a secure data management infrastructure. Data collection occurred between November 2016 and June 2017.

Each participating hospice site was also asked to provide data on their organisation (total number of unique patient referrals received during 2015, number of in-patient beds, and staff capacity (reported as whole time equivalent, reflecting actual workload hours contributed by staff as an equivalent to the status of a full time worker) for palliative care doctors and community nursing teams. Clinical expertise and knowledge of hospice-based specialist palliative care provision across team members suggested initial contact with hospices would predominantly be as outpatients, therefore determining the number of doctors and community teams sought to provide insight into potential reach and responsiveness to referrals. Additional information compiled by the research team for each hospice included region and Rural Urban Classification (RUC). For classification of region for hospices in England, NHS England regional team labels were used, stratifying sites by North of England, Midlands and East of England, London and South of England. Sites from Wales and Scotland were classified at country level. RUC was calculated using ArcGIS software (ArcMap 10.3.1) to reference the postcode of a hospice site against the UK Government 2011 RUC for Local Enterprise Partnership Areas based on Census Output Areas.

Data management and analysis: Data received from hospice sites included a range of electronic clinical record system vocabularies for patient characteristics of ethnicity and diagnosis. Prior to statistical analyses, ethnicity data were aligned with groupings applied by the UK Office for National Statistics. Diagnosis was mapped against major cancer and non-cancer disease types (see Appendix A for further details on grouping). Decedents were also dichotomised into one of two groups based on their diagnosis: cancer or non-cancer.

To investigate the factors associated with the time from referral to death, all decedents were categorised into one of two groups based on referral-to-death duration. We defined late referral occurring within 30 days of death and earlier referral as more than 30 days before death. This was based on our recent analysis of routine data which demonstrated benefits associated with referral to palliative care at least 4 weeks before death.(22) Demographic and clinical variables (sex, age, ethnicity and diagnosis) were summarised overall and by referral-to-death categories. These data are presented as number and proportion of decedents. Differences in proportion of early versus late referrals across each of the demographic and clinical variables were calculated using univariable logistic regression models. The referral to death days were also summarised overall and for each of the demographic and clinical variables. These data are presented as median days with accompanying interquartile range (25 to 75 percentiles) and median absolute deviation (MAD). MAD was used as a measure of variance of the time between referral and death because it is a measure of statistical dispersion that is resistant to outliers. Differences in median referral to death days across each of the demographic and clinical variables were calculated using the Kruskal Wallis test. Descriptive summaries of site-level data are presented separately to patient-level data and categorised by geographical region. These data are presented as means and standard deviation reporting average number of patient referrals, bed capacity, staff capacity (palliative care doctor and community nursing team whole time equivalents), and proportion of rural hospices. Case-mix was also calculated for each site to determine the proportion of decedents with non-cancer conditions to decedents with cancer conditions using the following formula:

$$Case - mix\ = \frac{Non - cancer\ patients\ per\ site}{Total\ number\ of\ patients\ per\ site}$$

Negative binomial regression (NBR) models were fitted to the data to quantify the relationship between referral-to-death time and clinical, demographic and site level factors. NBR models were chosen for this analysis because the outcome variable (days between referral and death) was over-dispersed count data (i.e. it was highly skewered towards zero). NBR models have been used previously to examine patterns and timing of referrals to palliative care services.(23) Factors associated with referral-to-death time were estimated in three NBR models: firstly demographic and clinical factors (model 1); secondly site level factors (model 2); lastly, demographic, clinical and site factors in a fully adjusted model (model 3). Data are presented as incident rate ratios (IRR) and 95% confidence intervals (95%CI). In each model the dispersion parameter was set to constant and clustering effect of hospice site was accounted for by adjusting the standard errors for intergroup correlation using variance estimator cluster option. This assumes that observations are independent across clusters (i.e. hospice sites) but not necessarily within clusters and adjusts the standard error (and consequently the 95%CI) but does not adjust the estimated coefficients. All statistical analyses were performed using Stata version 13. To account for multiple testing a 2-tailed significance level of 0.01 was used for NBR models.

Patient involvement: Patients were involved in setting the research question and in the design of the study, no patients were asked for advice on interpretation or writing up of results. The results of the research have been disseminated to the patient community through patient forums.

Results

Across 64 participating sites, data were extracted on a total of 42,758 decedents referred to hospice-based palliative care who died between 1 January 2015 and 31 December 2015. Ninety nine cases (0.23%) were excluded from analysis due to missing sex and/or age data. A further 287 cases (0.67%) were excluded due to referral to death days greater than 2000 days. There were 42,372 cases (99.1%) available for analysis. Across all sites the number of referrals in 2015 ranged from 171 to 4,255.

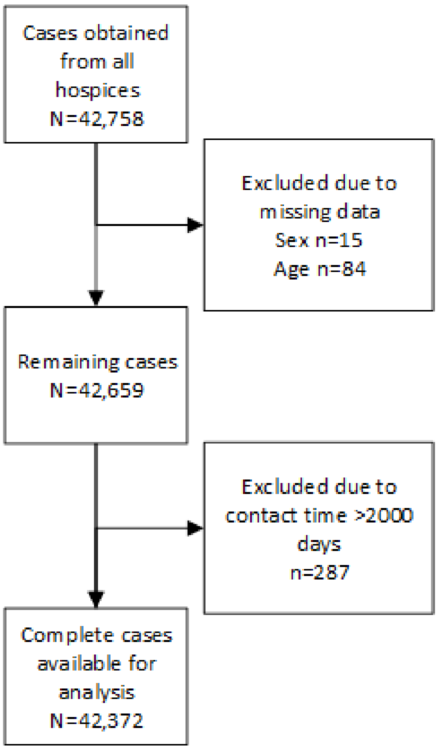

Figure 1: Overview of data exclusion

Table 1: Descriptive summary of patients' demographic and clinical variables

				Palliative Care referral		
Patient Characteristic Variables	All decedents N (%)$^{\neq}$	Median (IQR, MAD) referral to death (days)	p-value*	Late$^{\dagger\ \delta}$ N (%)	Early$^{\dagger\ \delta}$ N (%)	P-value‡
All	42,372 (100)	48 (13-157, 42)		17,122 (40·4)	25,250 (59·6)	
Sex						
Male	21,938 (51·8)	48 (13-148, 42)	0.01	8,830 (40·3)	13,108 (59·7)	-
Female	20,434 (48·2)	48 (12-168, 43)		8,292 (40·6)	12,142 (59·4)	0·5
Age						
under 50	1,810 (4·3)	78 (21-225, 68)	0.0001	579 (32)	1,231 (68)	-
50 - 74	17,582 (41·5)	59 (17-175, 51)		6,215 (35·4)	11,367 (64·6)	0·004
75 and over	22,980 (54.2)	39 (10-135, 35)		10,328 (45)	12,652 (55)	<0·0001
Ethnicity						
White	31,612 (74·6)	53 (15-169, 46)	0.0001	11,979 (37.9)	19,633 (62.1)	-
Asian/Asian British	573 (1·4)	69 (22-188, 60)		187 (32·6)	386 (67.4)	0·01
Black/African/ Caribbean/Black British	366 (0·9)	73 (27-194, 59)		97 (26·5)	269 (73·5)	<0·0001
Other	1,244 (2·9)	35 (12-88, 28)		579 (46·5)	665 (53·5)	<0·0001
Missing/Not recorded	8577(20·2)	30 (7-117, 27)		4,280 (49·9)	4,297 (50·1)	<0·0001
Diagnosis						
Cancer	32,610 (77)	53 (17-159, 45)	0.0001	12,041 (36.9)	20,569 (63.1)	-
Non-cancer	8,651 (20·4)	27 (6-151, 25)		4,485 (51.8)	4,166 (48.2)	<0·0001
Missing	1,111 (2·6)	24 (4-125, 23)		596 (53.7)	515 (46.3)	<0·0001

IQR = interquartile range. MAD = median absolute deviation.

$^{\neq}$the denominator in percentage calculation was all cases (n=42,372).

*p-values derived from Kruskal Wallis test.

†Early defined as referral >30 days before death; Late defined as referral ≤ 30 days before death.

$^{\delta}$ percentages calculated as the proportion of early/late over each level of the independent variable.

‡p-values derived from univariable logistic regression models

Patient demographic variables

Table 1 outlines patient-level characteristics across all data, alongside comparing characteristics between late and early referrals. Across all decedents, the median number of days from referral to death was 48 days, and 40% of all referrals (n=17,122) were made within 30 days of death. Significant differences were found across age groups, with fewer days between referral and death as age increases. For ethnicity there were significant differences in the duration between referral and death, with those classified as 'missing/not recorded' having the fewest days (30 days) compared with 'Black/African/ Caribbean/Black British' having the highest (73 days).

Table 2: Descriptive summary of diagnosis data and odds of receiving a late referral to hospice-based palliative care within the last month of life

	Diagnosis	All cases N(%)	Referral to death (days) Median (IQR)	Palliative Care referral		Logistic Model
				Early N(%)	Late N(%)	OR (95%CI)∝
Cancer	Head and Neck	907 (2·1)	58 (19-151)	607 (66·8)	300 (33·2)	0·8 (0·7 to 0·9)†
	Brain	1183 (2·8)	78 (29-173)	873 (73·4)	310 (26·6)	0·6 (0·5 to 0·7)‡
	Lung	7352 (17·3)	50 (16-138)	4568 (62·1)	2784 (37·9)	1 (-)
	Upper Gastrointestinal (Upper GI)	7072 (16·7)	48 (16-140)	4311 (60·9)	2761 (39·1)	1 (0·9 to 1·1)
	Colorectal	1946 (4·6)	69 (22-200)	1323 (67·5)	623 (32·5)	0·7 (0·6 to 0·9)‡
	Breast	2446 (5·8)	81 (21-296)	1685 (68)	761 (32)	0·7 (0·6 to 0·8)‡
	Female genital and reproductive organs	1694 (5·8)	60 (19-198)	1104 (64·8)	590 (35·2)	0·9 (0·8 to 1)
	Haematological	1780 (4·2)	47 (13-174)	1057 (59·7)	723 (40·3)	1·1 (1 to 1·2)
	Urological	2052 (4·8)	50 (14-147)	1251 (60·4)	801 (39·6)	1·1 (1 to 1·2)
	Male genital and reproductive organs	2137 (5)	74 (21-203)	1483 (68·8)	654 (31·2)	0·7 (0·7 to 0·8)‡
	Liver	384 (0·9)	40 (15-110)	214 (55·5)	170 (44·5)	1·3 (1·1 to 1·6)†
	Skin	346 (0·8)	61 (20-154)	228 (66)	118 (34)	0·8 (0·7 to 1·1)
	Soft and connective tissue	150 (0·3)	64 (27-147)	109 (73·3)	41 (26·7)	0·6 (0·4 to 0·9)‡
	Unknown/Other	3161 (7·5)	40 (13-121)	1756 (55·6)	1405 (44·4)	1·3 (1·2 to 1·4)‡
Non-cancer	Dementia	1271 (3)	9 (3-32)	322 (24·8)	949 (75·2)	5 (4·2 to 5·5)‡
	Stroke	157 (0·4)	9 (3-37)	44 (26·7)	113 (73·3)	4·5 (3·1 to 6·5)‡
	Motor neurone disease (MND)	530 (1·2)	109 (8-470)	339 (63·8)	191 (36·2)	0·9 (0·8-1·1)
	Neuro-degenerative disease (excluding MND)	1698 (4)	24 (5-116)	775 (45·5)	923 (54·5)	2 (1·8 to 2·2)‡
	Heart failure	1849 (4·4)	67 (14-239)	1187 (64·9)	662 (35·1)	0·9 (0·8-1)
	Lung disease	229 (0·5)	40 (10-273)	124 (54·1)	105 (45·9)	1·4 (1·1 to 1·8)†
	Liver failure	483 (1·1)	16 (5-89)	199 (41·2)	284 (58·8)	2·3 (1·9 to 2·8)‡
	Kidney failure	179 (0·4)	35 (7-270)	90 (50·3)	89 (49·7)	1·6 (1·2 to 2·2)‡
	Other non-cancer diagnosis	2255 (5·6)	27 (5-158)	1086 (48·3)	1169 (51·8)	1·8 (1·6 to 1·.9)‡
	Missing diagnosis	1111 (2·5)	24 (4-125)	515 (46·3)	596 (53·7)	1·9 (1·7 to 2·1)‡

∝OR (95%CI) = Odds ratio (95% Confidence interval) derived from univariable logistic regression model predicting odds of receiving a referral to hospice-based palliative care 4 weeks or less before death for each of the diagnostic categories. † p <0·05; ‡ p<0·001

Diagnosis

Table 2 outlines median days from referral to death by diagnosis. Of cancer types, patients with breast cancer have the longest referral-to-death duration (median 81 days) and unknown/other the least (median 40 days). For non-cancer conditions, patients with neuro-degenerative disease (eg motor neurone disease) have the longest referral-to-death duration (median 109 days) together with heart failure (median 67 days) and dementia and stroke the least (median 9 days).

When considering timing of referrals to hospice-based palliative care, those with cancers of head and neck, upper GI, colorectal, male genital and reproductive organs, brain and connective tissue had a significantly greater chance of receiving an early referral compared to lung cancer cases (used as the referent group, with 38% of lung cancer cases receiving a late referral).

Diagnoses with significantly greater chance of receiving a late referral (compared to lung cancer) included liver failure, kidney failure, lung disease other than cancer, liver cancer, rare cancers, and ‘other’ non-malignant diagnoses. Decedents with dementia and stroke have an approximately 5 times greater chance of receiving a late referral compared with decedents with lung cancer.

Table 3: Summary of site-level variables for 64 participating hospice sites by geographical region

					Capacity				Staffing	
	Number of sites	Case-mix†	Rurality		Referral to death (days)‡	Decedents per region	Decedents per site	Inpatient bed capacity per site	WTE doctors per site	WTE community nurse per site
Region	N(%)	**% (range)**	**Rural** N(%)	**Urban** N(%)	Median (IQR, MAD)	N(%)	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
All	64 (100)	**20·1 (2·2-45·2)**	9 (14·1)	55 (85·9)	48 (13-156, 42)	41372 (100)	1,029 (615-1419)	15 (12-19)	4·1 (3-5·3)	8 (0-13·5)
North of England	29 (45·3)	**15·4 (2·2-45·2)**	1 (3·4)	28 (96·6)	35 (10-116, 31)	11059 (26·8)	679 (426-962)	16 (12-18)	4 (2·9-5·1)	0 (0-9·0)
Midlands and East	11 (17·2)	**17·8 (13·7-27·7)**	4 (36·4)	7 (63·6)	55 (16-171, 48)	9,058 (23·1)	300 (298-943)	15 (10-20)	3·7 (3·0-5·2)	10·8 (6·5-17·8)
London	3 (4·7)	**30·2 (21·3-30·2)**	0	3 (100)	49 (16-135, 40)	3490 (8·8)	755 (286-755)	10 (8-10)	6·6 (4·6-10)	18 (8·2-44·0)
South of England	16 (25)	**21·2 (11·6-34·2)**	2 (12·5)	14 (87·5)	55 (14-178, 50)	16909 (37·1)	934 (710-1,157)	15 (11-20)	4·9 (3·3-5·8)	13 (11-19·9)
Wales	2 (3·1)	**10·3 (9·9-10·3)**	1 (50)	1 (50)	17 (6-49, 14)	373 (0·9)	198 (146-243)	28 (24-31)	1·4 (0·3-2·4)	0 (0-0)
Scotland	3 (4··7)	**10·0 (5·7-10·1)**	1 (33·3)	2 (66·7)	56 (21-170, 46)	1,275 (3·2)	431 (322-540)	12 (8-18)	6·2 (2-13·6)	4 (2·7-7·6)

WTE = whole time equivalent. IQR = interquartile range. MAD = median absolute difference. N = number. % = percentage

†case-mix is calculated as percentage of decedents with non-cancer conditions at each site, aggregated at a regional level.

‡The median referral to death days is calculated out of all decedents (n=42,372) within each region.

Service provision across hospice sites

Across the 64 participating sites, all reported providing inpatient services. There was variation in further services being delivered with 48 (75%) reporting provision of outpatient services, 55 (85.94%) providing day hospice services and 47 (73.44%) reporting provision community teams.

Regional variation in duration of hospice-based palliative care

As outlined in Table 3, across all sites, the case mix was 20.1% non-cancer to 79.9% cancer with variation by region of participating sites. Across the hospice sites there were significant differences in the ratio of non-cancer to cancer decedents: sites in Scotland and Wales had a significantly greater proportion of decedents with cancer conditions (to non-cancer patients) compared to sites within all regions in England. London had the highest proportion of non-cancer decedents.

Median number of days from referral to death varied by region, ranging from 56 days in Scotland, to 17 days in Wales. Within England, there was a marked difference in referral to death between hospices in the North of England (35 days) compared with hospices in the Midlands (55 days), London (49 days) and South of England (55 days). Furthermore, there were also clear differences in the staffing of participating sites. Median WTE of palliative care doctors varied from 2.4 (Scotland) to 7.6 (Wales). For community teams, median WTE varied from 0 (Scotland) to 11 in North of England. However, there were notably fewer participating sites in Scotland and Wales which needs to be considered in light of identified regional variation.

Table 4: Quantifying the relationship between median number of days (from referral to death) for demographic and clinical factors

Patient and Site level factors	**Model 1** IRR (95%CI)	**Model 2** IRR (95%CI)	**Model 3** IRR (95%CI)
Age			
Under 50	1		1
50 – 74	0·93 (0·88 to 0·96)†		0·92 (0·88 to 0·96)†
75 and over	0·82 (0·77 to 0·87)†		0·81 (0·76 to 0·85)†
Sex			
Male	1		1
Female	1·04 (1·02 to 1·05)†		1·03 (1·02 to 1·05)†
Ethnicity			
White	1		1
Asian/Asian British	1·09 (0·99 to 1·21)		1·08 (1·01 to 1.16)
Black/African/ Caribbean/Black British	1·15 (1·01 to 1·29)		1·07 (0·99 to 1·14)
Other ethnic group	0·84 (0·76 to 0·93)‡		0·93 (0·79 to 1·11)
Missing	0·82 (0·75 to 0·88)†		0·77 (0·72 to 0·83)†
Diagnosis			
Cancer	1		1
Non-Cancer	0·83 (0·77 to 0·88)†		0·81 (0·75 to 0·87)†
Missing	0·75 (0·61 to 0·92)		0·81 (0·66 to 0·99)
Region			
North England		1	1
Midlands and East England		1·21 (1·06 to 1·38)‡	1·23 (1·06 to 1·42)‡
London		1·06 (0·96 to 1·21)	1·07 (0·93 to 1·23)
South England		1·14 (1·04 to 1·26)‡	1·22 (1·11 to 1·39)†
Wales		0·76 (0·61 to 1)	0·76 (0·59 to 0·97)
Scotland		1·34 (1·03 to 1·73)	1·41 (1·14 to 1·75)‡
Inpatient Beds			
7-12 bed unit		1	1
13-18 bed unit		0·92 (0·83 to 1·18)	0·93 (0·82 to 1·04)
19-38 bed unit		0·97 (0·83 to 1·13)	0·94 (0·79 to 1·12)
Number of WTE Nurses			
0		1	1
1-10		1·04 (0·92 to 1·18)	1·08 (0·95 to 1·23)
11-19		1·03 (0·91 to 1·18)	1·05 (0·91 to 1·21)
20-44		0·95 (0·81 to 1·12)	0·95 (0·81 to 1·13)
Number of WTE Doctors			
0-3		1	1
4-5		1·18 (1·07 to 1·31)†	1·17 (1·05 to 1·23)‡
6-10		1·12 (0·99 to 1·26)	1·11 (0·97 to 1·26)
Rurality			
Rural		1	1
Urban		0·98 (0·86 to 1·12)	1·02 (0·9 to 1·2)
Community team			
No		1	1
Yes		0·95 (0·79 to 1·15)	0·97 (0·81 to 1·17)
Case Mix		1·48 (0·76 to 2·86)	1·61 (0·71 to 3·57)

Standard Error adjusted for 64 clusters (hospice sites) in all three models to adjust estimations for the 95%CI, taking account of patient clustering by hospice site

†p<0·001, ‡p<0·.01

A multivariable negative binomial model was used to explore the association between referral to death days (outcome variable) and patient level factors (Table 4, model 1). Overall decedents had significantly fewer days of hospice-based palliative care as their age increased. Compared to adults aged <50 years, adults aged 50-74 years had 7% fewer days of hospice-based palliative care. This relationship was amplified for adults aged 75 and over who had 18% fewer days of hospice-based palliative care compared to adults aged <50 years. Model 1 also identified differences for sex, where, compared to males, the number of day between referral to death was 4% greater for women. For ethnicity, there were no significant differences for Asian or Black groups compared to White. However, compared to those classified as White, number of days between referral to death was 16% lower for ‘Other ethnic group’ and 18% lower for those with missing ethnicity data. For diagnosis, compared to decedents with cancer conditions, the number of days between referral to death was 18% lower for decedents with non-cancer conditions and 24% lower for those with missing diagnosis.

Model 2 explored the association between referral to death days and site level factors (Table 4). The model identified that, compared with decedents from hospices in the North of England, the number of days between referral and death were 23% higher for decedents from the Midlands and East of England and 15% higher for decedents from the South of England. All other site level factors were not associated with a difference in referral to death days, with the exception of decedents from hospices with 4-5 WTE doctors which was associated with an 18% increase in referral to death days compared to decedents from hospices with 0-3 WTE doctors.

A final fully adjusted multivariable model (Table 4, model 3) indicated that increasing age persisted as a significant predictor of fewer referral to death days, as did being male, having missing ethnic background and having a non-cancer diagnosis. In this model, in contrast to Model 1, a trend towards increased referral to death time for people of Asian and Black backgrounds compared to people with White background was observed (although only significant for Asian background). As with Model 2, the site level factors were not associated with changes in the time between referral to death.

Discussion

Main findings

This study presents the first national-level description of the duration of UK hospice-based palliative care prior to death. We found that over half of all patients were referred to hospice-based palliative care less than 7 weeks before death, and 40% were referred less than 30 days before death. Referrals include those made to hospice beds, day hospice services and hospice community teams. This national study highlights that, despite increasing rhetoric around early referral to palliative care, patients with advanced disease continue to receive referrals to hospice-based palliative care late in their illness trajectory. This could be indicative of a missed opportunity to do better for patients, their families, and optimise the use of health services.(24) Furthermore, there are marked differences between the duration of hospice-based palliative care for those with cancer (around 7 weeks) when compared to patients with non-cancer conditions (less than 4 weeks). The latter group makes up around a quarter of the case-mix of participating hospices, despite accounting for more than two thirds of deaths from advanced chronic illness.(25) Known inequities in the provision of specialist palliative care(26) were also reinforced, with fewer days of palliative care persisting with increasing age and being male. Additionally, there was widespread variation in the types of services available across different regions of the UK, including the staffing levels of palliative care medical and hospice community nursing teams. While multiple factors may be driving differences, these may be a further manifestation of variation in commissioning of palliative care services across England.(27) An initial response to these data could be to consider how inequity in timing of referral could be addressed and to better understand how appropriate and timely referrals would be reflected in across the different diseases and age groups.

The delivery of this study involved the development and implementation of an approach to securely capture data from multiple hospices sites where a variety of electronic clinical record systems were in use. This was an important development to arise from the study, facilitating research participation by UK hospices and creating pathways for national hospice-level data initiatives. The approach to secure data capture has enabled the first nationwide picture to be reported, contrasting with existing smaller, single-center reports. Capturing and using data in this way highlights the value of routine data use in palliative care to support efficient evaluation of care for patients and families. The approach adopted in this study could be adapted for other international contexts. This would enable countries outside the UK to generate comparative data to benchmark timing of referrals to palliative care. These data are important to capture and reflect in the context of increasing evidence in support of earlier referral to palliative care.

Strengths and weaknesses/limitations of the study

Our study has some limitations. The response rate of 33% was lower than expected but the sample reflects the diversity of UK hospices based on location, size, staffing data, and included both charity-funded and NHS managed sites.(28) The use of routine data limits the extent to which robust conclusions can be made about the reported duration and variations in hospice-based palliative care delivery, particularly with ethnicity data, where there was a large proportion of missing data. From data requested from sites, we only received a single diagnosis linked to a referral, missing any co-morbid diagnoses. For ethnicity data, we did not assess the extent to which submitted data matched the profile of ethnicity for the catchment area of hospices, leaving us unable to determine the representativeness of these data. In order to balance answering research questions with ease of participation for sites, we reduced the extent of data granularity. For referral data we requested date of referral and did not collect contextual information (e.g. reason and source of referral). At the patient level, we omitted requests for data on known inequity that may be difficult to identify (such as patients identifying as lesbian, gay, bisexual and transgender, those with mental health needs, those who are homeless). Furthermore, we acknowledge that extraction of requested data may have biased respondents to those who could extract data through adequate information and communications technology infrastructure. From data submitted by sites, while such an assumption was not made, we cannot indicate the presence, magnitude or quality of interaction with a service following referral.

What this study adds

Recent projections of demand for palliative care by 2040 suggest healthcare systems need to adapt to the age-related growth in deaths from chronic illness, with dementia and cancer likely to be the main drivers of increased need.(29) Findings from this study suggest there may be a need for reorientation of services to both older age groups and non-cancer conditions; both groups are associated with limited duration of hospice-based palliative care prior to death. The remit of palliative care has expanded to have relevance for any patient at an early stage in the disease process whose death can be medically anticipated.(30) Such a broad remit, when people are living longer with an increased illness burden, suggests many patients will need primary, secondary and specialist palliative care. With increasing calls to reduce hospital bed days in the last months of life and to support preferences for home death, it is particularly important that community-based specialist palliative care can consider how provision might match demand.

The findings in this study reflect the UK context, where paradoxically palliative care is ranked top of 40 countries measured in a ‘quality of death’ index, based on palliative service provision, access to opioids and a national strategic approach.(31) Globally, few countries have similar levels of integration of palliative care within wider health services.(19) However, despite an excellent range of charitable and NHS palliative services, inequity remains apparent in the UK, particularly for those in older age groups and those living with non-cancer conditions. This study confirms that these groups are receiving less hospice based palliative care prior to death. Further research is needed to understand whether such late referrals to palliative care are reflective of appropriate clinical management by others, or indicate wider cultural and societal barriers to accessing UK hospice care at a more appropriate time in an illness trajectory. This study focused on hospice-based palliative care delivered in the UK. This forms a key component of a complex network of providers contributing to palliative care delivery. Barriers to accessing hospice services clearly remain though we cannot determine what these are, nor where they lie. Solutions to reducing inequity and increasing integration will need to include hospices but will not be confined to them if change is to occur. Future research examining associations with duration of palliative care across generalist and hospital-based palliative care delivery will help to complete the picture.

Declarations

Authors' contributions

MA, LZ, RT, SR and MB were involved in the conception and design of the study. MA led the collection and assembly of data. MA, MB, MM, RT, SR, LZ were involved in data analysis and interpretation. MA led on the manuscript writing with input from all authors. The final manuscript was read and approved by all authors. All authors have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

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Declaration of conflicts of interest

The authors declare that they have no competing interests.

Research ethics and patient consent

Ethical approval was obtained from the West Midlands - South Birmingham Research Ethics Committee (reference: 16/WM/0412) and appropriate management and governance clearance was obtained from each site prior to participation in the study.

Data management and sharing

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

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