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Which cancer patients are referred to Hospital at Home for palliative care?

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Abstract: Previous research has shown that palliative home care use is influenced by variables such as age, socioeconomic status, presence of an informal carer, diagnosis, and care dependency. However, there is little information on its association with other health service use. This study compared 121 cancer patients referred to Hospital at Home (HAH) for palliative care with a sample of 206 cancer patients not referred who died within the same period. Electronic record linkage of NHS databases enabled investigation of patients' total input of care in their last year of life. Univariate analysis showed that patients referred to HAH were younger, lived in less deprived areas, were less likely to have been diagnosed within a month of death and to have causes other than cancer recorded on their death certificate. They were furthermore more likely to have had specialist oncology input, Macmillan nursing, Marie Curie nursing, acute hospital care, and district nursing before their last month of life. When care was received, patients referred to HAH received more hours of district nursing care. However, patients not referred to HAH began their acute hospital and district nursing input earlier (further from death) than those referred. Multivariate logistic regression analysis showed HAH referral to be negatively associated with breast and genitourinary cancers and number of noncancer causes recorded on the death certificate. Referral was significantly positively associated with specialist oncology input, Marie Curie nursing, and a late start (close to death) of acute hospital and district nursing care. It is hypothesised that referral to palliative home care is more likely among patients who have had prior contact with cancer services or are most clearly identified as cancer patients, and whose illness progression is manifested by a relatively short but intensive period of care prior to death. *Palliative Medicine* 2002; **16**: 115–123

Key words: access to health care; cancer; home care services; palliative care

Resumé: Quels patients cancéreux sont confiés à l'hospitalisation à domicile pour des soins palliatifs? Les études antérieures ont montré que l'utilisation des soins palliatifs à domicile était déterminée par des variables telles que l'âge, le statut socio-économique, la présence d'un soignant non professionnel, le diagnostic et le niveau de dépendance. Cependant, on possède peu d'information sur son association avec d'autres services de soins. Cette étude a comparé 121 patients cancéreux adressés à l'hospitalisation à domicile (HAH) pour des soins palliatifs à 206 patients cancéreux non pris en charge par l'HAH décédés durant la même période. Le recoupement des données électroniques du NHS a permis d'évaluer les soins reçus par les patients durant leur dernière année de vie. Une analyse de monovariance a montré que les patients confiés au HAH étaient plus jeunes, vivaient dans des zones plus prospères, dont le diagnostic était antérieur au dernier mois de vie, et dont la mort selon le certificat de décès était moins souvent due à un cancer. De plus, ils avaient plus souvent bénéficié d'un avis oncologique spécialisé, d'une prise en charge infirmière de type Macmillan ou Marie Curie, de soins hospitaliers aigus et de soins infirmiers de proximité avant leur dernier mois de vie. Pendant les soins, les patients confiés au HAH, bénéficièrent de plus d'heures de soins infirmiers de proximité. Cependant, les patients non adressés au HAH ont bénéficié de soins infirmiers hospitaliers et de proximité plus précocément (par rapport au décès). L'analyse de régression logique de multivariance a démontré que le recours au HAH était négativement associé aux cancers du sein et aux cancers génito-urinaires et aux étiologies non cancéreuses spécifiées sur

les certificats de décès. Le recours était positivement associé de façon significative à l'avis oncologique spécialisé, aux soins infirmiers de type Marie Curie et au recours tardif (proche de la mort) aux soins infirmiers hospitaliers et de proximité. On peut formuler l'hypothèse que le recours aux soins palliatifs à domicile est plus fréquent chez les patients qui avaient eu un contact antérieur avec des services d'oncologie ou qui sont plus nettement identifiés comme des patients cancéreux et chez ceux dont l'évolution est caractérisée par une période de soins avant la mort relativement courte mais intensive. *Palliative Medicine* 2002; **16**: 115–123

Mots-clés: soins palliatifs; cancer; service de soins à domicile; accès aux soins

Introduction

Although the majority of dying patients express a preference for spending their last days of life at home,^{1–6} research shows that patients are not equally likely to access palliative home support. A literature review found⁷ that among cancer patients, referral to palliative home care was less likely for those aged 65 and above and those of low socioeconomic status, and more likely in the presence of an informal carer. Women were more likely to be referred to home care than men, although the results were not entirely clear. Those with poor function, high nursing care requirements, short-term survival, haematological malignancy, gastrointestinal cancer, and CNS tumours were less likely to receive palliative home support, whilst lung and genitourinary cancer increased likelihood of home care. Research has also found home care to be positively associated with receiving specific cancer therapy⁸ or having prolonged contact with oncology services.⁹ Furthermore, palliative services are predominantly used by cancer patients, although a substantial proportion of terminal noncancer patients display similar care needs.¹⁰

Although some differences in referral may reflect different care needs, the above findings suggest that some patients are less able to access services than others, irrespective of need. For instance, socioeconomic status should be unrelated to care need in the terminal phase, yet affects access to palliative home support. Furthermore, while old age may be related to complex care needs, living alone, or having a frail, elderly carer, old age also appears to be associated with greater difficulty in obtaining services. Older patients reportedly receive poorer service provision even if they have a level of needs similar to younger ones,¹¹ and are less likely to be referred for elective surgery and other specialist treatment^{12–15} or to access inpatient hospice care.¹⁶

If patient groups differ in their access to palliative home care, whether related to need or other factors, one would similarly expect them to differ in their access to other services. There is little published data on other service use for palliative home care patients, although a negative association between hospital inpatient care and home care has been reported.^{9,17–19}

The present study investigated variables associated with referral to Cambridge Hospital at Home (HAH) for palliative care. The study considered demographic and clinical variables, but also investigated patients' total NHS service input in order to assess whether patients referred to HAH displayed different patterns of prior service use to those not referred.

Service context

HAH can provide up to 24-h practical nursing care in the home for approximately 2 weeks. It is available to adult patients (≥ 16 years) of all diagnoses for terminal care, i.e., when death is anticipated within 2 weeks as assessed by a clinician. It is also available for respite care for patients with cancer, motor neurone disease, and AIDS with palliative care needs at any point during illness. During the study period, the HAH team expanded from four nurses at RGN grade to five nurses at RGN level, two Enrolled Nurses, a Nursing Auxiliary, and a HAH coordinator, also at RGN level. Agency nursing care was used throughout as required.

In addition to HAH, the services available locally were a large acute hospital with a regional specialist oncology centre, a cardiothoracic specialist hospital, an inpatient hospice, and continuing care beds run by the local NHS community trust. Community NHS care available was district nursing, Macmillan nursing, Marie Curie nursing, night nursing around the city of Cambridge, a Flexible care nursing service (similar to Marie Curie but available to patients of all diagnoses), and other community care, such as physiotherapy and occupational therapy.

Method

Patient samples

Cancer patients referred to HAH (87% of referrals) were compared with a similar sample of cancer patients identified from the Cancer Registry. The HAH group comprised patients referred to HAH over a 1-year period (16 June 1994–19 June 1995), who were registered with the East Anglian Cancer Registry and for whom cancer was recorded as a cause of death. The comparison group

was a randomly selected sample of adult cancer patients from the East Anglian Cancer Registry who were not referred to HAH, who were resident within the HAH catchment area, died within the same period as the HAH patients, and for whom cancer was also recorded as a cause of death. We did not attempt to match the samples further to avoid overmatching,²⁰ i.e., for fear that this could obscure the relationships we sought to investigate. The patient samples will be referred to as the 'HAH group' and 'CR group', respectively. Local Research Ethics Committee approval was obtained to collect routine data on patients after their death, as part of a larger evaluation of HAH.

Data collection

Demographic data. Cancer Registry diagnosis, cause of death, age, sex, contact with specialist oncology services, Jarman underprivileged area (UPA),²¹ and Townsend Index deprivation scores²² for ward of residence were obtained from the Cambridge Cancer Intelligence Unit. Place of death and occupation were obtained from the Office of National Statistics (ONS) and the Cambridge and Huntingdon Health Authority (CHHA). Data on occupation were allocated to SOC Occupational Unit Groups,^{23,24} and the patient's Social Class subsequently derived from these codes. It was not possible to obtain sufficiently complete information on marital status for analysis from the available routine sources, as this was not reliably recorded.

Service utilisation data. Data on NHS service use were collected for the whole of the year preceding the patient's date of death. Once patients had died, their unique patient identifier was identified within local NHS IT systems and used to extract relevant events. Most of the NHS systems could support the fuzzy matching of patient details. AMcK devised a standard matching algorithm for data extraction, including Soundex code name search (i.e., reducing names to phonetic codes that are less vulnerable to variations in spelling²⁵) and date of birth searches with controlled variations to year, month, and day. A variety of corroborating patient attributes were used to validate the recorded identifiers. Patient identifiers were then used as a key to the extraction of health care events recorded within the source IT systems. Expert local knowledge and assistance in identifying the available data and assembling it in a form suitable for the research project were provided by the NHS IT departments involved. Data were collected in this way for acute hospital, cardiothoracic specialist and hospice care, continuing care bed use, district nursing, Macmillan nursing, night nursing, Flexible nursing care, and other community NHS services. AMcK also designed a computer system to collect data on Marie Curie and HAH

care input for routine use within the palliative care services. Dates for care input were translated into days before death for each patient.

Whilst every effort was made to ensure that the data set was complete, some patient data could have been missed due to failure to find a database match, e.g., through misspelled surnames or incorrect date of birth. However, the use of fuzzy matching and several identification procedures to identify a patient should keep this to a minimum. The quality of the data extracted furthermore depends on the quality of data entry for individual databases. However, there is no clear *a priori* reason why the degree of data recording error should differ between our two patient groups. Provided recording errors are randomly distributed, there is thus no reason to believe that there is any bias in the results from aggregate data analysis of differences between the HAH and CR sample, although some data values may be missing for individual patients.

Analysis

Demographic, clinical, and NHS service input variables were first compared between the HAH and CR groups using univariate analysis. For NHS services, we wanted to investigate input likely to precede a potential HAH referral, rather than subsequent input, which may be a function of the referral itself. HAH referral data were used to establish when a referral to HAH was most likely to occur, and thus determine an appropriate comparison period for service input between the HAH and CR groups.

For each service, a considerable proportion of patients received no input. A first analysis, therefore, only compared the proportion of patients in each group who received each service. Amount and onset of care were next compared for those patients who received input from a service. This was preferred to comparing averages of amount and onset of care for the total patient samples, as the resulting means or medians would largely have been determined by the number of zero values in each group. It would, therefore, have been difficult to assess whether any group differences in amount or start date of care were an artefact of the zero values or represented real differences in patterns of service delivery.

Variables that differed between groups at $P < 0.2$ in the above univariate analyses were entered into a multivariate logistic regression analysis to investigate which variables were most closely associated with referral to HAH. A lax criterion was chosen as variables may contribute to the model in unforeseen ways due to complex interrelationships between variables.²⁶

Chi-square tests were used to compare the study groups on categorical data. Yates' continuity correction and Fisher's exact test were used as appropriate.²⁷

Table 1 Demographic characteristics

	CR group	HAH group	Significance levels
Age	Mean (SD) 74.7 (12.0)	Mean (SD) 70.5 (13.8)	$t=2.774$, $df=224.23$, $P=0.006$
Sex	n (%)	n (%)	$\chi^2=0.836$, $df=1$, $P=0.361$
Females	105 (51)	68 (56)	
Males	101 (49)	53 (44)	
Socioeconomic area	Median (quartiles)	Median (quartiles)	
Jarman UPA score	-0.72 (-6.54, 13.47)	-3.03 (-10.55, 8.40)	$Z=2.334$, $P=0.020$
Townsend Index	-0.38 (-1.43, 1.99)	-1.08 (-2.33, 1.66)	$Z=2.367$, $P=0.018$
Social class	n (%)	n (%)	$\chi^2=4.853$, $df=5$, $P=0.434$ (HAH $n=202$, CR $n=116$)
I	12 (6)	13 (11)	
II	57 (28)	36 (31)	
IIIN	17 (8)	12 (10)	
IIIM	59 (29)	30 (26)	
IV	52 (26)	22 (19)	
V	5 (3)	3 (3)	
Survival	Median (quartiles)	Median (quartiles)	Log rank statistic=1.04, $df=1$, $P=0.308$
Days between diagnosis and death	363 (61, 1114)	257 (102, 900)	
Diagnosis within a month of death	38 (18)	7 (6)	$\chi^2=10.297$, $df=1$, $P=0.001$
Diagnosis before final month	168 (82)	114 (94)	
Cancer diagnosis	n (%)	n (%)	$\chi^2=12.194$, $df=7$, $P=0.094$
Breast	28 (14)	13 (11)	
Central nervous system	4 (2)	6 (5)	
Gastrointestinal	52 (25)	40 (33)	
Genitourinary	45 (22)	16 (13)	
Haematological cancers	20 (10)	7 (6)	
Respiratory	34 (17)	19 (16)	
Head and neck	5 (2)	2 (2)	
Other ^a	28 (14)	28 (23)	
Cause of death	n (%)	n (%)	$\chi^2=28.279$, $df=2$, $P<0.001$
Cancer only cause	110 (53)	99 (82)	
One other cause recorded alongside cancer	62 (30)	18 (15)	
Two other causes recorded alongside cancer	34 (17)	4 (3)	

HAH group $n=121$; CR group $n=206$ (unless otherwise specified).

^aCancers of ill-defined, secondary and unspecified sites, intrathoracic organs and thyroid, melanomas, mesotheliomas, and cancers of other digestive organs than GI tract.

Mann-Whitney U -tests were used for comparisons of NHS service input, as the data were considerably skewed. Mann-Whitney U -tests were also used for UPA and Townsend scores as their values formed clusters in the data set. Student's t -test was used for age. Kaplan-Meier survival analysis was used to compare survival. Forward stepwise logistic regression was used for the multivariate analysis. SPSS for Windows 6.0 or 6.1 was employed. All tests were two-tailed.

Results

Patient samples

During the 1-year study period, 158 patients were referred to HAH. Twenty-six patients who had not died by the end of October 1995 and/or were recorded with a noncancer diagnosis were excluded from analysis. A further 11 patients were excluded because they were not recorded on the local Cancer Registry or had

Table 2 Number of CR and HAH group patients who had contact with an NHS service before the last 30 days of life

	CR group, n (%)	HAH group, n (%)	Significance levels
Acute hospital inpatient	110 (53)	85 (70)	$\chi^2=8.304$, $df=1$, $P=0.004$
Acute hospital day case	33 (16)	24 (20)	$\chi^2=0.529$, $df=1$, $P=0.467$
Hospice inpatient	15 (7)	14 (12)	$\chi^2=1.224$, $df=1$, $P=0.265$
Continuing care beds	6 (3)	2 (2)	Fisher, $P=0.715$
Cardiothoracic specialist inpatient	21 (10)	10 (8)	$\chi^2=0.144$, $df=1$, $P=0.704$
District nursing	103 (50)	85 (70)	$\chi^2=11.972$, $df=1$, $P<0.001$
Night nursing	5 (2)	6 (5)	Fisher, $P=0.340$
Macmillan nursing	22 (11)	34 (28)	$\chi^2=15.093$, $df=1$, $P<0.001$
Marie Curie nursing	7 (3)	27 (22)	$\chi^2=27.281$, $df=1$, $P<0.001$
Flexible Care nursing	6 (3)	8 (7)	$\chi^2=1.722$, $df=1$, $P=0.189$
Other community care	15 (7)	11 (9)	$\chi^2=0.139$, $df=1$, $P=0.710$

CR $n=206$, HAH $n=121$.

Table 3 Total input of care before the last 30 days of life

	CR group, median (quartiles)	<i>n</i>	HAH group, median (quartiles)	<i>n</i>	Significance level
Acute hospital inpatient days	14 (8.0–30.0)	110	15 (9.5–29.0)	85	Z=0.184, P=0.854
Acute hospital day case appointments	2 (1.0–7.5)	33	2 (1.0–4.8)	24	Z=0.609, P=0.543
Hospice inpatient days	11 (7.0–22.0)	15	14.5 (7.5–33.3)	14	Z=0.524, P=0.600
Continuing care bed days	20.5 (6.8–113.8)	6	40 (19.0–)	2	Z=0.667, P=0.505
Cardiothoracic specialist inpatient days	5 (2.0–15.0)	21	14.5 (2.8–22.3)	10	Z=1.251, P=0.211
District nursing hours	5.8 (1.5–15.8)	103	9.92 (4.0–20.9)	85	Z=2.774, P=0.006
Night nursing hours	1.3 (1.0–32.7)	5	2.5 (2.2–20.7)	6	Z=0.458, P=0.647
Macmillan hours	1.8 (1.1–3.6)	22	2.2 (1.3–7.8)	34	Z=0.924, P=0.355
Marie Curie hours	123.0 (8.0, 227.0)	7	36.5 (16.0, 75.0)	27	Z=0.873, P=0.382
Flexible Care hours	32.8 (6.8, 100.9)	6	11.6 (3.6, 35.3)	8	Z=1.294, P=0.196
Other community care hours	1.0 (0.5, 1.9)	15	1.0 (0.7, 1.9)	11	Z=0.052, P=0.958

Only patients who received a service included.

not died from cancer. In total, 121 HAH patients entered analysis.

A random selection was made of 299 Cancer Registry entries for patients not referred to HAH between June 1994 and June 1995, whose death occurred within the same period as those of the HAH cancer patients. Ninety-three entries were excluded: 12 were second entries, i.e., when a patient had two diagnoses. In these cases, the later diagnosis was retained for analysis, as the earlier diagnosis may represent a cancer for which the patient had been cured; a further 12 patients were referred to HAH after June 1995; 14 were not resident in the HAH catchment area towards the end of life; 1 was too young to be referred to HAH; 54 did not die from their cancer according to their death certificate. Thus, 206 patients from the Cancer Registry entered analysis.

HAH referral data

HAH referral data were used to determine a suitable comparison period between the HAH and CR groups to investigate differences in the service input likely to precede a HAH referral. HAH was almost exclusively used for terminal care. Referral to HAH occurred a median of 10 days (quartiles 5–26) before death, and 76% of patients died within 30 days of referral. Only a

further 15% died 31–60 days after referral. By comparing all care in the last year of life up to the last 30 days, we would therefore capture most of the input preceding a potential referral to HAH and little of the care succeeding such a referral. Only eight patients actually had HAH input before their last month of life.

Univariate analysis of patient groups

Table 1 summarises the results of the univariate analysis of the demographic and clinical variables. Compared to the HAH group, patients in the CR group were significantly older and lived in more deprived areas. The CR group was also significantly more likely to have other causes of death recorded alongside cancer and to have died within a month of diagnosis.

Patients who were referred to HAH were significantly more likely to have been in contact with an oncology department (69 versus 57%) compared to the CR group (83 versus 40%, $\chi^2=7.921$, $df=1$, $P=0.005$). Oncology contacts related to the patient's total cancer illness, while the remaining data on service input related to patients' last year of life only.

Table 2 shows the proportion of patients in contact with a service before the last month of life. The HAH group was significantly more likely than the CR group to

Table 4 Start of service input occurring before the last 30 days of life (days before death)

	CR group, median (quartiles)	<i>n</i>	HAH group, median (quartiles)	<i>n</i>	Significance levels
Acute hospital inpatient	205 (94.8–318.5)	110	152 (85.5–239.0)	85	Z=2.045, P=0.041
Acute hospital day case	205 (118.5–339.0)	33	199.5 (138.3, 245.5)	24	Z=0.485, P=0.628
Hospice inpatient	90 (44.0–159.0)	15	85.5 (45.3–166.5)	14	Z=0.066, P=0.948
Continuing care beds	107.5 (50.5–253.3)	6	70 (49–)	2	Z=0.667, P=0.505
Cardiothoracic specialist inpatient	123 (60.0–163.0)	21	234.5 (88.8–299.3)	10	Z=1.944, P=0.052
District nursing	178 (77.0–317.0)	103	134 (69.0–232.5)	85	Z=2.045, P=0.041
Night nursing	92 (61.0–185.0)	5	98.5 (57.0–180.3)	6	Z=0.183, P=0.855
Macmillan nursing	106 (51.8–173.3)	22	110 (66.5–207.3)	34	Z=0.453, P=0.651
Marie Curie nursing	146 (45.0–321.0)	7	53 (43.0–83.0)	27	Z=1.278, P=0.201
Flexible care nursing	56 (50.3–128.3)	6	65 (49.3–148.3)	8	Z=0.258, P=0.796
Other community care	83 (45.0–188.0)	15	58 (34.0–254.0)	11	Z=0.493, P=0.622

Only patients who received a service included.

Table 5 Variables predicting membership of the HAH group

	Coefficient	SE	P	OR (95% CI)
Noncancer causes of death	-0.871	0.241	<0.001	0.419 (0.261, 0.671)
Diagnosis			0.043	
Gastrointestinal	-0.239	0.389	0.539	0.787 (0.367, 1.688)
Lung	-0.319	0.438	0.466	0.727 (0.308, 1.714)
Breast	-1.240	0.511	0.015	0.289 (0.106, 0.788)
Haematological	-0.925	0.566	0.102	0.397 (0.131, 1.203)
Genitourinary	-1.147	0.436	0.009	0.318 (0.135, 0.747)
Other cancer	0			1
Specialist oncology				
Contact	0.824	0.290	0.005	2.280 (1.291, 4.028)
No contact	0			1
Acute hospital			0.007	
Late start	0.957	0.327	0.004	2.604 (1.371, 4.946)
Early start	0.121	0.361	0.736	1.129 (0.557, 2.289)
No input	0			1
District nursing			0.018	
Late start	0.917	0.329	0.005	2.501 (1.314, 4.761)
Early start	0.614	0.361	0.089	1.847 (0.910, 3.749)
No input	0			1
Marie Curie care			<0.001	
Late start	2.308	0.706	0.001	10.055 (2.520, 40.120)
Early start	1.890	0.664	0.004	6.620 (1.803, 24.308)
No input	0			1
Constant	0.931	0.327	0.004	

$n=327$; 75.23% of cases classified correctly.

Model $\chi^2=92.664$, $df=13$, $P<0.0001$. Number of outliers with SRESID of two or more=8. Residual χ^2 for variables not in the equation=12.951, $df=9$, $P=0.1648$; goodness of fit=321.919.

have had acute hospital inpatient care, district nursing, Marie Curie nursing, or Macmillan nursing services.

Table 3 shows the median amount of input received from each service for patients who had contact with that service before their last month of life. Among patients who had district nurse input, the HAH group received significantly more district nursing before their last month of life, compared to the CR group. Otherwise, there was no significant difference in amount of care received. Table 4 shows the median start day for care for patients who received input from a service before their last month of life. Start day was defined as days before death. When care was received, acute hospital inpatient care and district nursing care began significantly earlier, i.e., further from death, for the CR group compared with the HAH group.

Multivariate logistic regression

All variables that differed between groups at $P<0.2$ were entered into a forward stepwise logistic regression analysis. Service variables were entered in the format: early input, late input, no input. 'Early' input was care beginning before the median start date for the total group of patients receiving care, and 'late' input was care that began on the median start date or later. Table 5 shows the resulting model.

The number of noncancer causes of death on the death certificate was negatively associated with referral to HAH. Having breast cancer or genitourinary cancers similarly reduced likelihood of HAH referral compared

with 'other cancer'. Contact with an oncologist was positively associated with referral to HAH. Both for acute hospital and district nursing care, a late start of care (close to death) was significantly positively associated with HAH referral compared with no input. However, an early start to care was not significantly different from no input. A 'late' start for acute hospital care was defined as within 175 days of death and for district nursing 147 days, based on the median start day for care. Marie Curie nursing care showed the strongest positive association with HAH referral, and early and late start to care were both significantly associated with referral compared to no care.

Discussion

Cancer patients referred to HAH differed significantly from patients not referred on a number of variables. In accordance with past research,⁷ older patients and those resident in lower socio-economic areas were less likely to be referred. This lends emphasis to recent initiatives to remove inequalities in access to services in the UK.^{28,29} Patients referred to HAH were less often diagnosed within the last month of life, although overall survival from diagnosis did not differ between groups. Previous research has shown that diagnosis within the last month of life reduces likelihood of death at home,³⁰⁻³³ possibly because hospital tests and attempts at treatment often follow on immediately

from diagnosis, leaving little time for organisation of home care.

HAH cancer patients were significantly less likely than the comparison group to have noncancer causes of death recorded alongside cancer on the death certificate. Similarly, patients referred to inpatient hospice had fewer recorded noncancer causes of death compared to other patients.³⁴ This may mean that the cancer disease of patients who access home or hospice palliative care services manifests itself more clearly in impact on life (and death) and symptoms, thus leading to a focus on cancer as cause of death. Conversely, it may merely reflect different recording practices, e.g., in acute hospitals versus hospices and the community.

In contrast to past studies, the HAH group was more likely to have had acute hospital inpatient care than the comparison group. However, prior studies either included the last month of life when hospital care may often have been an indicator of place of death,^{9,19} or compared patients receiving hospice home care with hospice inpatients,^{17,18} i.e., patients already receiving palliative care. The HAH group was furthermore more likely to have had contact with an oncologist,⁹ and to have had district nursing, Marie Curie nursing, or Macmillan nursing services preceding the last month of life. Once care was received, the amount of district nursing input was also higher for the HAH group than the comparison group. However, the start of any acute hospital inpatient care and district nursing care began significantly earlier (further from death) for the CR group than the HAH group.

In the logistic regression analysis, breast and genitourinary cancers were negatively associated with HAH referral. In contrast, genitourinary cancer has been positively associated with home care in past research,^{35,36} while breast cancer has been both positively^{35,36} and negatively^{9,37} associated with home care. It is unclear what accounts for these differences. However, these previous studies were conducted in different countries (USA,³⁵ Italy,³⁶ Switzerland,⁹ UK³⁷). Thus, differences in treatment procedures and service options may well have yielded different patterns of service use for these diagnoses.

Furthermore, the logistic regression revealed that HAH referral was positively associated with prior use of cancer services (oncology and Marie Curie), and with a late, but not early, start of generic services (acute hospital and district nursing). HAH referral showed a negative association with noncancer causes of death. Whilst variables such as age did not feature in the final logistic regression model, one should note that if these variables are also associated with access to services other than HAH, their relationship with HAH may be masked in an analysis that includes service input variables.³⁸

The positive association with prior Marie Curie nursing may reflect that patients referred to HAH were those in particular need of palliative home care. However, contact with oncology, which is more closely associated with active curative treatment, is less likely to reflect palliative home care needs towards the end of life. An alternative explanation is that these service providers may be more aware of other cancer and palliative care services, and thus be more likely to provide patients with information about, and instigate referral to, such services. There was, for instance, close informal contact between HAH and Marie Curie nursing. Although run separately, they were under the same management structure.

Alternatively, patients referred to HAH may have been those which were more clearly identified as cancer patients, e.g., as evidenced by their prior use of cancer services. This may further be reflected in their greater likelihood of having only cancer recorded on their death certificate (although this has to be interpreted with caution). Thus, it may be that a clear cancer 'label' facilitates access to all cancer and palliative care services, not that access is associated with prior service use *per se*.

Only a late start of generic services (closer to death) was significantly positively associated with HAH referral. Whilst care began later for the HAH group, their total input of care was similar or greater than that of the CR group, suggesting a shorter, more intensive period of care towards the end of life. It is unlikely that the results mean that early district nurse involvement, for instance, reduces likelihood of home service access. Early district nurse involvement may rather reflect that patients with long-term care needs are less likely to remain at home until the end of life. One may speculate that such long-term needs may often be associated with old age, comorbidity, or aspects of the natural history of the disease process which our data are unable to reflect. Clearly, more research is required here.

Cancer patients are overall more likely to access palliative care services than patients of other diagnoses¹⁰ – a trend confirmed by the high proportion of cancer patients referred to HAH. However, our research suggests that among patients who die of cancer, access to palliative home care may be more likely for those who are more clearly identified as cancer patients, or whose referral somehow has been facilitated by prior entry to cancer and palliative care services, and whose care needs towards the end of life are short term rather than long term. The NHS Cancer Plan²⁸ seeks to equalise palliative care provision across the UK. This study suggests that investments in more services by itself may not be sufficient. Careful consideration will need to be given to the configuration of services, needs of patients, and how access can be

facilitated. There is a need to further investigate and address biases inherent in referrals of patients to services.

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References

- Dunlop RJ, Davies RJ, Hockley JM. Preferred versus actual place of death: a hospital palliative care support team experience. *Palliat Med* 1989; **3**: 197–201.
- Townsend J, Frank AO, Fermont D, Dyer S, Karran O, Walgrove A, Piper M. Terminal cancer care and patients' preference for place of death: a prospective study. *BMJ* 1990; **301**: 415–17.
- Karlsen S, Addington-Hall J. How do cancer patients who die at home differ from those who die elsewhere? *Palliat Med* 1998; **12**: 279–86.
- Carroll DS. An audit of place of death of cancer patients in a semi-rural Scottish practice. *Palliat Med* 1998; **12**: 51–53.
- Pritchard RS, Fisher ES, Teno JM, Sharp SM, Reding DJ, Knaus WA, Wennberg JE, Lynn J. Influence of patient preference and local health system characteristics on the place of death. *J Am Geriatr Soc* 1998; **46**: 1242–50.
- Lee A, Pang WS. Preferred place of death—a local study of cancer patients and their relatives. *Singapore Med J* 1998; **39**: 447–50.
- Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998; **47**: 565–79.
- Komesaroff PA, Moss CK, Fox RM. Patients' socio-economic background: influence on selection of inpatient or domiciliary hospice terminal-care programmes. *Med J Aust* 1989; **151**: 196–201.
- Sessa C, Roggero E, Pampallona S, Regazzoni S, Ghielmini M, Lang M, et al. The last 3 months of life of cancer patients: medical aspects and role of home-care services in southern Switzerland. *Support Care Cancer* 1996; **4**: 180–85.
- Addington-Hall J. *Reaching out: specialist palliative care for adults with non-malignant diseases*. National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care, Occasional Paper 14, 1998.
- Cartwright A. Dying when you're old. *Age Ageing* 1993; **22**: 425–30.
- Ryynanen OP, Myllykangas M, Kinnunen J, Takala J. Doctors' willingness to refer elderly patients for elective surgery. *Fam Pract* 1997; **14**: 216–19.
- Charmy MC, Lewis PA, Farrow SC. Choosing who shall not be treated in the NHS. *Soc Sci Med* 1989; **28**: 1331–38.
- Bowling A, Jacobson B, Southgate L. Health service priorities. *Soc Sci Med* 1993; **37**: 851–57.
- Turner NJ, Haward RA, Mulley GP, Selby PJ. Cancer in old age – is it inadequately investigated and treated? *BMJ* 1999; **319**: 309–12.
- Addington-Hall JM, Altmann D, McCarthy M. Which terminally ill patients receive hospice in-patient care? *Soc Sci Med* 1998; **46**: 1011–16.
- Mor V, Wachtel TJ, Kidder D. Patient predictors of hospice choice: hospice versus home care programs. *Med Care* 1985; **23**: 1115–19.
- Greer DS, Mor V, Morris JN, Sheerwood S, Kidder D, Birnbaum H. An alternative in terminal care: results of the National Hospice Study. *J Chronic Dis* 1986; **39**: 9–26.
- Gray D, MacAdam D, Boldy D. A comparative cost analysis of terminal cancer care in home hospice patients and controls. *J Chronic Dis* 1987; **40**: 801–10.
- Last JM. *A dictionary of epidemiology*, second edition. Oxford: Oxford University Press, 1988.
- Jarman B. Identification of underprivileged areas. *BMJ* 1983; **286**: 1705–708.
- Townsend P, Phillimore P, Beattie A. *Health and deprivation: inequality and the north*. London: Croom Helm, 1988.
- Office of Population Censuses and Surveys. *Standard occupational classification: Volume 2. Coding index*. London: HSMO, 1990.
- Office of Population Censuses and Surveys. *Standard occupational classification: Volume 3. Social classifications and coding methodology*. London: HSMO, 1991.
- Gill L, Goldacre M, Simmons H, Bettley G, Griffith M. Computerised linking of medical records: methodological guidelines. *J Epidemiol Community Health* 1993; **47**: 316–19.
- Altman DG. *Practical statistics for medical research*. London: Chapman & Hall, 1991.
- Siegel S, Castellan NJ. *Nonparametric statistics for the behavioural sciences*, second edition. Singapore: McGraw-Hill, 1988.
- Secretary of State for Health. *The NHS Cancer Plan: a plan for investment, a plan for reform*. London: Department of Health, 2000.
- Secretary of State for Health. *National service framework for older people*. London: Department of Health, 2001.
- McCusker J. Where cancer patients die: an epidemiologic study. *Public Health Rep* 1983; **98**: 170–78.

- 31 Polissar L, Severson RK, Brown NK. Factors affecting place of death in Washington State, 1968–1981. *J Community Health* 1987; **12**: 40–55.
- 32 Moinpour CM, Polissar L. Factors affecting place of death of hospice and non-hospice patients. *Am J Public Health* 1989; **79**: 1549–51.
- 33 Axelsson B, Christensen SB. Place of death correlated to sociodemographic factors: a study of 203 patients dying of cancer in a rural Swedish county in 1990. *Palliat Med* 1996; **10**: 329–35.
- 34 Seale C, Cartwright A. *The year before death*. Aldershot: Avebury, 1994.
- 35 McCusker J, Stoddard AM. Effects of an expanding home care program for the terminally ill. *Med Care* 1987; **25**: 373–85.
- 36 Costantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative home care and place of death among cancer patients: a population-based study. *Palliat Med* 1993; **7**: 323–31.
- 37 Evans C, McCarthy M. Referral and survival of patients accepted by a terminal care support team. *J Epidemiol Community Health* 1984; **38**: 310–14.
- 38 Norusis MJ. *SPSS advanced statistics 6.1*. Chicago: SPSS, 1994.