Place of Death and Use of Health Services in the Last Year of Life

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Abstract / Aim: To investigate whether health service input in the last year of life differs between cancer patients who die at home versus those dying in inpatient care. **Methods:** Post hoc exploratory case-control study of 127 home deaths and 200 inpatient deaths. Retrospective electronic record linkage of patients' community and inpatient care during the last year of life. **Results:** Patients who died at home began their home nursing care closer to death than those who died as inpatients. Their first contact with inpatient hospice care began further from death. Before their final month, home death patients also had more specialist and district nursing than patients who died in inpatient care. **Conclusions:** Patients who began their home nursing early were less likely to die at home than those who began such care late. This suggests that it may be difficult to sustain end-of-life care at home for an extended period. Further research incorporating assessment of informal care input and disease trajectory is required to investigate this issue.

Résumé / Objectif: Déterminer si les soins de santé que les patients atteints du cancer reçoivent au cours de leur dernière année, diffèrent selon qu'ils meurent à la maison ou à l'hôpital. **Méthode:** Étude rétrospective post exploratoire portant sur 127 personnes mortes à domicile et 200 personnes mortes à l'hôpital. Croisement électronique des dossiers des patients soignés à domicile et ceux soignés à l'hôpital. **Résultats:** Les patients morts à la maison ont fait appel aux services de soins à domicile lorsqu'ils étaient beaucoup plus près de la mort et ceux hospitalisés ont fait appel aux services de soins palliatifs plus loin de la mort. Avant le dernier mois précédant la mort les patients à domicile ont bénéficiés de plus de soins de santé spécialisés que les patients à l'hôpital. **Conclusion:** Les patients ayant fait appel aux services de soins à domicile tôt dans leur maladie avaient plus de possibilités de mourir à l'hôpital qu'à la maison. Ceci semble suggérer qu'il est difficile de maintenir des soins à domicile sur une longue période. Il faudra plus de recherche afin de déterminer dans quelle mesure les soignants naturels et la trajectoire de la maladie ont de l'influence sur l'endroit de la mort.

INTRODUCTION

Research suggests that one half or more of terminally ill patients would prefer to die at home (1-6). Only a minority achieves this, however (7).

Enabling more patients to die at home, if they so wish, is, therefore, an important aim of palliative care services. In recent decades there has been a considerable increase in palliative home care teams in the U.K. to enable care and, eventually, death to take place at home (8,9). However, there are still considerable gaps in our knowledge about the factors, including health service input, that may facilitate death at home. Research has identified some of the patient characteristics associated with home death, and there is evidence to suggest that specific home care initiatives may facilitate death at home. We still know little about the association between death at home and the general involvement of community and palliative care services, and whether, for instance, earlier involvement of home care services may help support people to die at home.

Home death is associated with a number of patient characteristics. Patients are more likely to die at home if they have informal carer support (10-12). In general home death is more likely for males and for patients who are young or middle-aged, rather than old (3,8,10), although these relationships may disappear or be reversed for patients under specialist or home palliative care (10,13). One study in Italy also reports this reversal more generally (14). For cancer patients, those with high socioeconomic status or home ownership are more likely to die at home than those with lower socioeconomic status (10,13,15). Death at home is less likely for patients with hematological cancers (8,10,16), but results are more mixed for other cancer diagnoses (8,10). Survival of less than one month from diagnosis is negatively associated with home death (10). However, patients with few restrictions and a short care dependency period are more likely to die at home (17-19).

Observational studies have found a positive association between home death and input from specific home care services or interventions (14,20-25). However, case mix differences may account for these results—the patients who were most likely to die at home in the first place, may

have been most likely to receive home care services, as opposed to home care enabling patients to die at home. Few randomised controlled trials have been conducted of the impact of palliative home care services on home death (12,26,27). While these all suggest that home care had a positive impact, two did not reach statistical significance (26,27) and the third showed a relatively modest 10% difference in home deaths between the intervention group and controls (12). Thus, it is not obvious that palliative home care actually has the desired effect of supporting people to die at home.

Furthermore, we know little about how home care provision in general may be associated with place of death. Early research on generic service use reported that district nurse support during the last year of life was positively associated with home death (17). However, case mix may again apply, in that the patients who were most likely to die at home may have been the ones to receive home care. Research has suggested that early involvement of the district nurse or other key worker may be beneficial in ensuring successful home care (28), but we know of no studies that have tested this directly.

This study investigated all National Health Service (NHS) home care received in the last year of life for patients who died at home versus patients who died in inpatient care. The study considered whether the timing of first contact with a service was associated with differences in likelihood of death at home. It also investigated whether the amount of home care provision at an early stage (before the last four weeks of life) was associated with eventual place of death. Amount of home care during the final four weeks is also reported. However, the amount of home care closer to death is likely to become a function of place of death itself. Data on inpatient care are also presented to complete the picture of care in the last year of life.

METHODS

Study Sample

The study sample represented 327 deaths from cancer in Cambridgeshire over a 16-month period; 127 of these deaths occurred at home and 200 in inpatient care. The study was a post hoc, exploratory analysis, using data from two samples: 121 cancer patients over the age of 16 years who had been referred to Cambridge Hospital at Home (HAH) for palliative care, and 206 additional patients registered with the East Anglian Cancer Registry (EACR). The first sample represented all patients who had been referred to HAH over a one year period, who were regis-

tered with the EACR, and for whom cancer was recorded as a cause of death on the death certificate (cause 1a-c or 2—where 1a is the primary cause of death, and 1b-c and 2 are conditions leading to 1a or contributing to death—representing 87% of all HAH referrals). To obtain the second sample, 299 records were randomly selected from all EACR entries of patients resident within the former Cambridge Health District, who had not been referred to HAH and who died within the same period as the HAH cancer patients. After taking into account that some patients had more than one EACR record, and after excluding patients whose recent records suggested they were no longer resident in the area close to the time of death, who were later found to have been HAH referrals, or who died under the age of 16 years, 260 patients remained. These represented 27% of patients who died within the same period as the HAH patients, who were resident in the former Cambridge Health District, and who were not referred to HAH. However, 54 of the remaining sample did not have cancer recorded as a cause of death anywhere in section 1a-c or 2 of the death certificate and were excluded from analysis. Thus, 206 patients from the EACR entered the analysis.

Due to the method of sampling, patients referred to HAH were somewhat over-represented compared to the general population. The main implication of this is that the proportion of home deaths and level of service use in the study are likely to be slightly higher than for the population as a whole (29). However, it is unlikely that the patterns of association between service input and home death would be different from those observed within the wider population.

Data Collected

Community based NHS care available to patients locally were: general practitioner (GP) care, district nursing, Macmillan nursing (cancer specialist nurses providing advice), Marie Curie nursing (providing hands-on nursing, mainly for cancer patients), night nursing around the city of Cambridge, a Flexible Care nursing service (similar to Marie Curie but available to patients of all diagnoses), Hospital at Home for palliative care (offering up to 24-hour hands-on nursing care for a two-week period), and other community care such as physiotherapy and occupational therapy. Inpatient services available to patients locally were a large acute university teaching hospital, a cardiothoracic specialist hospital, an inpatient hospice, and limited-stay continuing care beds managed by the local NHS community trust.

Electronic record data on Macmillan nursing, district nursing, other community care (e.g., physiotherapy), inpatient hospice care, and inpa-

tient continuing care were obtained from local NHS community trust databases. Flexible Care nursing data were obtained from a separate database for this service. Originally no electronic system existed within the local NHS community trust to record Marie Curie and HAH nursing care. As part of an evaluation of HAH, on which the present study is based (29), a computer system was devised to collect all data on these services. Electronic record data of hospital inpatient care were collected from the respective acute and specialist hospital trusts. Such electronic data were not available for GP services, thus family physician input is not included in the analysis.

In large scale data linkage projects, individual health event records have been matched with probability scores against known patient attributes (30). It was, however, considered a more appropriate method for this project to determine the internal patient identifier or reference number used within each database system and to use this as a key to extraction of relevant events. Most of the NHS systems used had sophisticated routines to support "fuzzy" matching for patient details. A standard matching algorithm was devised and followed within these systems. This included Soundex code name search (i.e., reducing names to phonetic codes which are less vulnerable to variations in spelling) (30), 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 next used to extract health care events for the whole of the year preceding the patient's date of death. Expert local knowledge and assistance in identifying the available data were provided by the relevant NHS information technology departments. Dates for care input were recalculated into number of days before death for each patient. Quality of data entry and failure to identify patient records may have led to loss of data. However, the use of "fuzzy" matching and several identification procedures keeps failure to identify records to a minimum. Based on the reasonable assumption that recording errors are randomly distributed, it is unlikely that there will be bias in the results from aggregate data analysis of differences between-patient groups.

Diagnosis, cause of death, age, sex, Jarman underprivileged area (UPA) (31) and Townsend Index deprivation scores (32) for ward of residence were obtained from the East Anglian Cancer Intelligence Unit. Data on place of death and occupation were supplied by the Office for National Statistics (ONS), and the Cambridge and Huntingdon Health Authority (CHHA). Data on occupation were allocated to SOC occupational unit groups (33,34). The patient's social class was

subsequently derived from these codes. Data on marital status were available from the ONS and the East Anglian Cancer Intelligence Unit. However, due to a high number of missing values, this variable was not suitable for analysis.

Analysis

We undertook a descriptive, exploratory, univariate analysis, comparing patients who died at home with those who died in inpatient care. Patients were first compared on demographic and clinical variables to enable comparison with past research. Next, patients who died at home were compared to those who died as inpatients in terms of health service input. As noted in the introduction, we wanted to investigate whether the start date of each home care service differed between those who died at home and in inpatient care. We furthermore wanted to investigate whether the level of home care input at an early stage was associated with eventual place of death. Early input was defined as care occurring before the last four weeks of life on the basis of the data available to us. Late input—during the last four weeks of life—is also reported, but is likely to largely be a function of location of death itself. Level of input was considered in terms of the number of patients receiving care from each service and amount of care provided.

The input from each home care service was therefore described in terms of three basic measures:

- the number of patients who received input from the service;
- the amount of care provided for those patients who received input from a service, measured in terms of hours of home care nursing;
- the date of first contact for those who received input from a service, measured in terms of days before death.

Whilst the focus of the analysis is on home care provision, we also report inpatient data in order to provide the full picture.

Chi-square tests were used to test differences in proportions between groups, using Yates' continuity correction and Fisher exact probability tests for 2x2 tables as appropriate (35). Student's *t*-test was used to test differences in age; Mann-Whitney U test was used to test differences between variables which were considerably skewed or clustered, such as the service input data, and the Jarman and Townsend Indexes. Kaplan-Meier log rank statistic was used to compare survival between groups.

RESULTS

One hundred and twenty-seven (39%) patients died at home. These will be referred to as the

Table 1 / DEMOGRAPHIC VARIABLES (HOME DEATH n=127, INPATIENT DEATH n=200)

	Home Death	Inpatient Death	Significance Levels
Cause Of Death	n (%)	n (%)	
cancer only cause	90 (71)	119 (60)	
one or more causes recorded alongside cancer	37 (29)	81 (41)	$\chi^2=3.87, d.f.=1, p=0.049$
Survival	Median (IQR)	Median (IQR)	
days between diagnosis and death	326 (853)	288 (1006)	Log rank statistic=1.04, d.f.=1, p=0.850
patients diagnosed within a month of death	n (%) 9 (7)	n (%) 36 (18)	$\chi^2=7.80, d.f.=1, p=0.005$
Cancer Diagnosis	n (%)	n (%)	
breast	14 (11)	27 (14)	
central nervous system	2 (2)	8 (4)	
gastrointestinal	36 (28)	36 (18)	
genitourinary	20 (16)	41 (21)	
hematological cancers	6 (5)	21 (11)	
respiratory system	22 (17)	31 (16)	
head and neck	4 (3)	3 (2)	
other	23 (18)	33 (17)	$\chi^2=10.99, d.f.=7, p=0.139$
Age (years)	Mean (SD)	Mean (SD)	
	71.9 (11.9)	74.0 (13.4)	$t=1.42, d.f.=325, p=0.156$
Sex	n (%)	n (%)	
female	62 (49)	111 (56)	
Male	65 (51)	89 (45)	$\chi^2=1.39, d.f.=1, p=0.238$
Socioeconomic Area	Median (IQR)	Median (IQR)	
Jarman UPA score	-2.36 (20.61)	-0.94 (20.08)	$Z=1.18, p=0.238$
Townsend Index	-0.85 (3.73)	-0.69 (3.42)	$Z=0.70, p=0.485$
Social Class	n (%)	n (%)	
I	11 (9)	14 (7)	
II	36 (31)	57 (29)	
III N	12 (10)	17 (9)	
III M	31 (26)	58 (29)	
IV	24 (20)	50 (25)	
V	4 (3)	4 (2)	$\chi^2=2.30, d.f.=5, p=0.807$

home death group. The remaining patients died in hospital (n=115, 35%), hospice (n=76, 23%), residential or nursing homes (n=8, 2%), or on the way to hospital (n=1, 0.3%). These patients will collectively be referred to as the inpatient death group.

Demographic and Clinical Data

Table 1 compares demographic and clinical variables for patients who died at home and patients who died elsewhere. Patients who had other causes of death recorded alongside cancer on their death certificate were less likely to die at home than those who had only cancer recorded. Home death was also less likely for patients who were diagnosed within the last month of life.

Determining "Early" Stage of Care

Consideration of the mean number of inpatient days for the patient groups overall shows that the number of inpatient days were similar for the home and inpatient death groups until the fourth week before death (Figure 1). At this point the inpatient death group had a mean of 1.6 and the home death group a mean of 1.2 inpatient days per week. After the fourth week inpatient care increased to 2.4 days in the third week and to 5.0 days in the last week of life for the inpatient death group. Inpatient care for the

Figure 1 / MEAN NUMBER OF INPATIENT DAYS PER PATIENT PER WEEK (AVERAGED OVER PATIENT GROUP AS A WHOLE)

home care group, however, decreased after the fourth week, down to 0.4 days in the last week. If the "early" stage is defined in terms of care before the last four weeks of life, any group differences in level of home care provision at this stage are unlikely to be simply due to differences in patients' location (home versus inpa-

tient setting). During the last four weeks of life ("late" stage), however, patients' location of death probably plays a considerable part explaining differences in the level of home care.

Service Use in the Last Year of Life

Number of Patients Receiving Input from a Service. Table 2 shows the proportions of patients who reportedly used each available service before their last four weeks of life. The home death group was significantly more likely to have had Macmillan nurse input at an early stage than the inpatient death group. There were no significant differences between groups for other home care or inpatient services before the last four weeks.

Table 2 / NUMBER (PERCENTAGE) OF PATIENTS WHO HAD CONTACT WITH AN NHS SERVICE IN LAST YEAR OF LIFE

	Before Last Four Weeks		During Last Four Weeks	
	Home Death (n=127) n (%)	Inpatient Death (n=200) n (%)	Home Death (n=127) n (%)	Inpatient Death ^a (n=200) n (%)
Home care				
district nursing	74 (58)	116 (58)	101 (80) ^c	90 (45) ^c
night nursing	4 (3)	7 (4)	32 (25) ^c	11 (6) ^c
Macmillan nursing	32 (25) ^b	25 (13) ^b	24 (19) ^b	16 (8) ^b
Marie Curie nursing	19 (15)	16 (8)	61 (48) ^c	26 (13) ^c
other community trust home care	12 (9)	14 (7)	9 (7)	8 (4)
Flexible Care nursing	8 (6)	7 (4)	14 (11) ^a	8 (4) ^a
HAH nursing	6 (5)	2 (1)	51 (40) ^c	9 (5) ^c
Inpatient care				
acute hospital	77 (61)	119 (60)	26 (20) ^c	98 (49) ^c
continuing care beds	0 (0)	8 (4)	1 (1)	11 (6)
specialist hospital	12 (9)	19 (10)	3 (2)	10 (5)
hospice	11 (9)	19 (10)	15 (12) ^c	70 (35) ^c

^a a small number of patients died in private hospitals or in hospitals outside the study area

Variable values which share the same superscript within each section differ significantly from each other: *p<0.05, ^bp<0.01, ^cp<0.001.

During the last four weeks the home death group was significantly more likely than the inpatient death group to have had care from all home care services, except "other" primary care (Table 2), and significantly less likely to have had acute hospital or hospice inpatient care. However, this is likely to largely be a function of their place of death.

Total Amount of Care Once a Service was Provided. Once patients received care from a service, did patient groups differ in intensity of input? Table 3 shows the total amount of input received for patients using each service. Before their last four weeks of life the home death group received significantly more hours of district nursing than the inpatient death group. During the last four weeks of life, as one may expect, the home death group had significantly more hours of district, Marie Curie, and HAH nursing than the inpatient group.

Date on Which Care Began. When patients received care from a service, did patient groups differ in terms of when care began? Table 4 shows start day of care for those patients who received care from each service in their last year of life. Start day is shown as the number of days before death. A high value indicates that care began a long time before death, a low value, that it began close to death.

Where differences occur, the home death group consistently began their home care closer to death than the inpatient group. The home group began their district nursing a median of 71 days before death, compared to 142 days for the inpatient group. In fact, one quarter or more of the home group did not begin their district nursing until their last four weeks of life. Other home nursing which began earlier for the home group than the

Table 3 / TOTAL INPUT OF CARE FOR PATIENTS WHO RECEIVED A SERVICE, MEDIAN (INTERQUARTILE RANGE)

	Before Last Four Weeks				During Last Four Weeks			
	Home Death	n	Inpatient Death	n	Home Death	n	Inpatient Death	n
Home Care								
district nursing hours	12.5 (23.7) ^a	74	6.7 (11.1) ^a	116	13.0 (11.8) ^c	101	3.2 (7.0) ^c	90
night nursing hours	6.9 (45.5)	4	1.3 (4.6)	7	3.0 (4.4)	32	2.2 (2.6)	11
Macmillan hours	2.0 (3.6)	32	1.8 (4.3)	25	1.6 (0.9)	24	1.4 (1.4)	16
Marie Curie hours	56.8 (64.5)	19	27.0 (98.0)	16	27.0 (29.5) ^a	61	12.8 (30.3) ^a	26
other Lifespan primary care hours	0.8 (1.0)	12	1.4 (1.4)	14	0.8 (2.0)	9	1.7 (1.4)	8
Flexible Care hours	26.8 (32.8)	8	11.8 (46.0)	7	9.5 (14.4)	14	3.0 (8.2)	8
HAH hours	227.6 (624.3)	6	433.2 (-)	2	34.0 (57.0) ^a	51	15.0 (15.3) ^a	9
Inpatient Care								
acute hospital inpatient days	15.0 (22.0)	77	16.0 (20.0)	119	7.5 (9.8)	26	12.0 (14.3)	98
continuing care inpatient days	-	0	23.5 (46.5)	8	11.0 (-)	1	22.0 (21.0)	11
specialist hospital inpatient days	7.0 (17.5)	12	8.0 (16.0)	19	9.0 (-)	3	14.0 (16.5)	10
hospice inpatient days	15.0 (15.0)	11	12.0 (34.0)	19	8.0 (16.0)	15	9.0 (11.3)	70

Variable values which share the same superscript within each section differ significantly from each other: *p<0.05, ^ap<0.001

- : n was too small to calculate value

Table 4 / START DAY OF CARE FOR PATIENTS WHO RECEIVED INPUT FROM A SERVICE DURING THE COURSE OF THEIR LAST YEAR OF LIFE; MEDIAN (INTERQUARTILE RANGE)

	Home Death	n	Inpatient Death	n	Significance Level
Home Care					
district nursing	71.0 (173.8)	104	141.5 (209.3)	132	Z=3.39, p=0.001
night nursing	7.5 (13.0)	32	26.0 (87.5)	17	Z=3.28, p=0.001
Macmillan nursing	91.5 (120.8)	40	81.5 (123.3)	32	Z=0.27, p=0.790
Marie Curie nursing	12.0 (38.0)	63	30.5 (36.8)	30	Z=2.66, p=0.008
other community trust care	38.0 (79.0)	19	58.0 (225.8)	18	Z=1.64, p=0.101
flexible care	20.0 (50.3)	18	50.5 (46.0)	12	Z=0.93, p=0.352
HAH nursing	6.0 (8.0)	51	21.0 (50.3)	10	Z=2.80, p=0.005
Inpatient Care					
acute hospital	148.5 (169.5)	84	126.5 (210.0)	154	Z=1.53, p=0.126
continuing care beds	26.0 (-)	1	49.0 (107.5)	13	Z=0.37, p=0.857
specialist hospital	167.5 (131.5)	12	105.0 (95.0)	20	Z=1.83, p=0.070
inpatient hospice	35.0 (60.0)	19	12.0 (26.0)	71	Z=2.48, p=0.013

- : n was too small to calculate value

inpatient group were night nursing (median 8 days versus 26 days before death, respectively), Marie Curie nursing (median 12 days versus 31 days), and Hospital at Home nursing (median 6 days versus 21 days). We should note, however, that the 11 home death patients who had inpatient hospice care had their first hospice care significantly further from death than the inpatient group (median 35 days versus 12 days).

DISCUSSION

Demographic and Clinical Data

Patients who died at home were less likely to have other causes recorded alongside cancer on the death certificate and were less likely to be diagnosed within a month of death, compared to those who died as inpatients. Diagnosis within a month of death has previously shown a negative association with home death (22,36-38). This may be because the time immediately following diagnosis is often taken up with hospital tests and attempts at treatment. Nine of the patients (all EACR sample) had their cancer recorded through the death certificate only, representing two home and seven inpatient deaths. This may pose further problems for mobilisation of palliative home care. The number of non-cancer causes of death have not been considered in past research into place of death. An absence of non-cancer causes of death on the death certificate may suggest that cancer was more clearly manifested in the patient's symptoms and disease pattern. Conversely, it may merely be an artefact of different death certification practices between GPs and doctors within hospitals and hospices.

In contrast with past research, no relationships between age, sex, diagnosis, socioeconomic status, and home death were found. The area of the U.K. in which this study was conducted may be unusual in terms of the demographic patterns observed for home deaths. In East Anglia, the per-

centage of cancer deaths at home (29%) is the highest in the U.K., and the correlation between percentage of home death and Jarman UPA ($r=-0.23$) and Townsend deprivation scores ($r=-0.17$) are among the lowest in England (15).

Service Use

One potential study limitation is that some patient records were not identified on the electronic service databases, although missing records were assumed to be randomly distributed between study groups. However, if there were systematic differences in record identification, this is most likely to affect data on the proportion of patients who had services (Table 2) and less so data on pattern of use of identified services (Tables 3 and 4).

The home group was more likely to have had Macmillan nursing before their last four weeks of life. Macmillan nurses provide specialist advice and psychological support, not hands-on care. As the home group was also more likely than the inpatient group to have had their cancer diagnosis by this time, this may imply that early awareness of the illness and subsequent discussion and planning was more often possible for the home group than for the inpatient group. Although the home and inpatient death group were equally likely to have had district nursing before their last four weeks of life (58%, see Table 2), the home death group had nearly twice as many hours of district nursing once care was received (Table 3). This may have been linked to care needs or to more active care provision by the district nurse.

The home death group had more home care input and less inpatient care input during their last four weeks (Tables 2 and 3). These are patterns one would expect toward the end of life on the basis of location of care, and cannot be interpreted as showing that home care in this case increased the likelihood of home death.

When care was received, the home death group started their district nursing care significantly closer to death than the inpatient death group (median 71 days versus 142 days). They nevertheless accumulated more hours of care in that shorter time span than did the inpatient group. This would imply longer term and lower intensity—possibly discontinued—input for the inpatient group, versus shorter term and higher intensity input for the home death group. Fewer patients in the inpatient death group had night nursing, Hospital at Home, and Marie Curie nursing than in the home death group, but when the inpatient group did receive such input, care began earlier.

Death in inpatient care after an early start of home care is unlikely to be due to withdrawal of community services after a given period. District, night, and Marie Curie nursing will not normally withdraw care, given progressive deterioration in the patient and his/her continued presence in the community. Hospital at Home care, in theory, is limited to two weeks, but there is in practice an effort to continue care for progressively deteriorating, terminally ill patients. Inpatient death after an early start of home care may, therefore, reflect the difficulty of sustaining end-of-life care in the home for an extended period. This may be due to the strain this places on informal care resources, as family carers shoulder the greater part of the care burden. Even when professional input was provided, the actual hours of professional input were quite limited (Table 3), given that most patients would require somebody to be on hand 24 hours a day towards the end. One longitudinal study of terminal home care (19) showed that inpatient admissions increased as care lengthened, that relatives' fatigue increased prior to admission, and that excessive demands on relatives was the second most common reason, after symptom control, for final admission. Caregiver burden and factors such as the course of the patient's illness need to be investigated further if we are to understand the determinants of place of death.

The relatively few home death patients who received inpatient hospice care in fact began their inpatient hospice care earlier than those who died as inpatients. In contrast to home care services, the inpatient hospice will aim to discharge, if possible, after two weeks. Whilst these home death patients may have required terminal care over an extended period, some of this care took place in hospice. Hospice input for these patients may have provided respite for informal carers and reduced the period during which home care needed to be sustained.

The results clearly suggest that an early start to home care is not associated with increased likelihood of home death. This appears to be in conflict

with prior research which recommends early introduction of district nursing (28,39). However, early contact with the district nurse for preparation and planning before the patient has significant care needs is probably beneficial. As noted previously, earlier diagnosis and presence of a Macmillan nurse before the last four weeks of life may suggest that earlier awareness of the illness, and subsequent discussion and planning were more often possible for the home death group than for the inpatient death group. Differences relating to these variables were, however, small.

In the present study, the timing of the introduction of home nursing is likely to reflect when care dependency began. The results would, therefore, suggest that the longer care is required, the more difficult it may be to sustain in the home, possibly because informal care resources become exhausted. This would correspond with studies which suggest that patients with few restrictions and a short period of care dependency are more likely to die at home (17–19). If the patterns can be explained by informal carer fatigue, death at home may be feasible in the face of prolonged care needs only if better respite and support are provided for informal carers.

Early economic evaluations of palliative care suggested that home care was cheaper than inpatient care. However, these did not take into account differences in case mix and costs borne by patients and carers under home care (40). In later research, some randomised controlled trials of home versus inpatient care with palliative patients (41) and with other patient groups (42) showed that home care was similar to or more expensive than inpatient care, including increased GP costs. However, other research found home care to be cheaper (43). Thus, results appear equivocal, and dependent on the particular evaluation and patient groups considered. In future palliative care research, resource implications of maintaining patients at home, both formal and informal, should be considered. Improved respite and support for informal carers of those with long term care needs may require early involvement of care services, but in order to actively plan for, rather than reactively respond to, nursing care needs. Such forward planning may well prove effective and may not dramatically increase the amount of overall input to patients and their families, if backup and respite can be closely tailored to patients' and carers' needs. Resource use structures are particularly complicated for palliative care, given the complexity of needs, different courses of disease, and number of services and care budgets involved. More research is required to assess the impact of long term care on informal and formal care resources, and to iden-

tify how cost effective palliative home care may be provided over an extended period.

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