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Preferred and actual place of death in haematological malignancy

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ABSTRACT

Objectives Home is considered the preferred place of death for many, but patients with haematological malignancies (leukaemias, lymphomas and myeloma) die in hospital more often than those with other cancers and the reasons for this are not wholly understood. We examined preferred and actual place of death among people with these diseases.

Methods The study is embedded within an established population-based cohort of patients with haematological malignancies. All patients diagnosed at two of the largest hospitals in the study area between May 2005 and April 2008 with acute myeloid leukaemia, diffuse large B-cell lymphoma or myeloma, who died before May 2010 were included. Data were obtained from medical records and routine linkage to national death records.

Results 323 deceased patients were included. A total of 142 (44%) had discussed their preferred place of death; 45.8% wanted to die at home, 28.2% in hospital, 16.9% in a hospice, 5.6% in a nursing home and 3.5% were undecided; 63.4% of these died in their preferred place. Compared to patients with evidence of a discussion, those without were twice as likely to have died within a month of diagnosis (14.8% vs 29.8%). Overall, 240 patients died in hospital; those without a discussion were significantly more likely to die in hospital than those who had ($p \leq 0.0001$). Of those dying in hospital, 90% and 75.8% received haematology clinical input in the 30 and 7 days before death, respectively, and 40.8% died in haematology areas.

Conclusions Many patients discussed their preferred place of death, but a substantial proportion did not and hospital deaths were common in this latter group. There is scope to improve practice, particularly among those dying soon after diagnosis. We found evidence that some people opted to die in hospital; the extent to which this compares with other cancers is of interest.

INTRODUCTION

When asked, most people say that given a choice, home is the place they would prefer to die.[1–6] While this preference is increasingly being met in the UK, a large proportion of people still do not die in their preferred place;[7 8] and this is particularly apparent among patients with haematological malignancies, in the UK and elsewhere.[8–14] Haematological malignancies are complex cancers, broadly categorised as leukaemias, lymphomas and myeloma, but actually comprising numerous different subtypes. These diseases can be indolent or aggressive and may be incurable at diagnosis, potentially curable or manageable with medication in a way similar to chronic rather than malignant conditions. Regardless of these differences, around two-thirds of people with haematological malignancies die in hospital, across all subtypes.[10]

Being able to die in one's preferred place is recognised as a 'quality marker' by the UK National Health Service.[15 16] Consequently, the large proportion of hospital deaths among patients with haematological cancers, which has been described as a 'consistent inequality',[11] may be considered to imply that people with these diseases have poorer end-of-life experiences than others, as they do not die in their place of choice.

There is now a growing body of evidence about the care of patients with haematological malignancies in the final weeks and days of their life, and this is in many respects far from reassuring. In comparison to patients with other diseases, for example, these people are not only reportedly more likely to die in hospital,[9 10] but they are also more likely to receive aggressive or intensive care at this time,[17–20] and less likely to receive input from specialist palliative care or hospice services.[21] Qualitative studies, particularly in Australia, describe patients often dying in acute settings with escalating technology, invasive treatments and limited access to their families.[22 23]

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There are still many information gaps, however, with a distinct lack of research exploring why pathways and care patterns among patients with haematological cancers tend to differ from those with other diseases. One important area that has not previously been explored is the care preferences of haematology patients at the end of life and whether these are met; and this study was initiated to examine this topic. Specific aims were to examine the frequency of discussions about preferred place of death, stated preferences and congruence between preferred and actual place of death. The influence of patient characteristics, disease subtype, time from diagnosis to death and the clinical area of care are also explored.

METHODS

This UK study is embedded within an established population-based patient-cohort of haematological malignancies—the Haematological Malignancy Research Network (HMRN) (http://www.HMRN.org). Initiated in 2004, HMRN operates with Section 251 support under the National Health Service (NHS) Act 2006 and full details of its structure, data collection methods and ethical approvals have been previously described.[24 25] Briefly, HMRN covers a population of nearly four million, which is sociodemographically representative of the UK as a whole; all diagnoses are made and coded by clinical specialists at a single integrated haematopathology laboratory, and clinical practice across the region adheres to national guidelines.[24 25] With respect to follow-up, all patients have full treatment, response and outcome data collected to clinical trial standards, and death notification information (which includes place of death) is routinely obtained from the national Medical Research Information Service (MRIS).

The research reported here is part of an ongoing programme of work examining palliative and end-of-life issues in haematological cancers, and is based at two large teaching hospitals (York and Hull) where around 30% of all HMRN patients are treated. This research, which includes patients diagnosed with acute myeloid leukaemia (AML), diffuse large B-cell lymphoma (DLBCL) and myeloma between 1 May 2005 and 30 April 2008 who died before 30 April 2010, has additional independent ethical approvals and the methods employed are fully described elsewhere.[26] In brief, core HMRN data were supplemented using a calendar approach to record the patients' whereabouts on a day-by day basis (eg, home, hospital, hospice), as well as their care-related activities, such as clinical area/specialty providing care within the hospital.[26] Information was also collected about place of death discussions and preferences, including changes in preferences over time, if these occurred.

A number of different sources were scrutinised to obtain the required data. Both the hospital medical records and any community palliative care records were searched, and we targeted official forms specifically designed to document preferences, as well as information written in free text or contained in correspondence between care providers. Place of death was grouped into four categories, including 'home', 'hospital', 'hospice' or 'nursing home'. The preference closest to death was used to determine congruence between preferred and actual place of death. Data analyses were carried out using standard statistical methods with SAS software V.9.3,[27] and Fisher's exact test was used to test for statistical significance.

RESULTS

A total of 323 patients (178 men and 145 women) with AML (n=107), DLBCL (n=102) or myeloma (n=114) were diagnosed at the two hospitals between 1 May 2005 and 30 April 2008 and died before 30 April 2010—a minimum of 2 years and a maximum of 5 years follow-up (table 1). As expected, most patients (82.1%) were aged 60 years and above at diagnosis; over two-thirds died within a year of diagnosis and almost a quarter (23.2%) within a month of diagnosis. The vast majority of patients (n=240, 74.3%) died in hospital, followed by home (n=49, 15.2%), hospice (n=18, 5.6%) and nursing home (n=16, 4.9%).

Evidence of a discussion about preferred place of death was found for 142 (44%) patients (table 1) and this proportion varied little by diagnosis. Compared to patients where evidence of a discussion was found, those with *no* documented discussion about preferred place of death were twice as likely to have died within a month of diagnosis (14.8% vs 29.8%). This difference was evident across all cancer groups—AML (20.4% vs 34.4%), DLBCL (20.9% vs 39.0%) and myeloma (4.0% vs 17.2%). The proportion of people dying in hospital was higher among those where no discussion about preferred place of death had taken place (84%) than among those where it had (62%) ($p \leq 0.0001$).

Of the 142 patients with evidence of a discussion about preferred place of death (table 2), the most common preference was home (n=65, 45.8%), followed by hospital (n=40, 28.2%), hospice (n=24, 16.9%) and nursing home (n=8, 5.6%). Five patients (3.5%) discussed place of death, but were undecided about this at the time of the discussion. Overall, 90 of the 142 patients (63.4%) with evidence of a discussion about place of death died in their preferred place. While all patients who expressed a preference to die in hospital did so, only around half of the patients who stated a preference to die at home, in a hospice or a nursing home died in their preferred place, and no variations by diagnostic group were observed. Patients being cared for by the haematology team at the time of their death were significantly more likely to have opted to die in hospital than patients dying in other hospital settings (p=0.0067).

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Table 1 Demographic and clinical characteristics of the 323 patients diagnosed with AML, DLBCL or myeloma at the two HMRN study hospitals between May 2005 and April 2008 who died before May 2010

		All diagnoses (N=323)		AML (N=107)		DLBCL (N=102)		Myeloma (N=114)	
		Place of death discussion		Place of death discussion		Place of death discussion		Place of death discussion	
	All deaths (n=323)	Yes N (%)	No* N (%)	Yes N (%)	No* N (%)	Yes N (%)	No* N (%)	Yes N (%)	No* N (%)
Total	323 (100)	142 (100)	181 (100)	49 (100)	58 (100)	43 (100)	59 (100)	50 (100)	64 (100)
Sex									
Male	178 (55.1)	76 (53.5)	102 (56.4)	27 (55.1)	34 (58.6)	17 (39.5)	29 (49.2)	32 (64.0)	39 (60.9)
Female	145 (44.9)	66 (46.5)	79 (43.6)	22 (44.9)	24 (41.4)	26 (60.5)	30 (50.8)	18 (36.0)	25 (39.1)
Age at diagnosis									
≤60	58 (17.9)	25 (17.6)	33 (18.2)	9 (18.4)	16 (27.6)	9 (20.9)	9 (15.2)	7 (14.0)	8 (12.5)
61–74	122 (37.8)	50 (35.2)	72 (39.8)	16 (32.6)	23 (39.7)	13 (30.2)	26 (44.1)	21 (42.0)	23 (35.9)
75+	143 (44.3)	67 (47.2)	76 (42.0)	24 (49.0)	19 (32.8)	21 (48.8)	24 (40.7)	22 (44.0)	33 (51.6)
Mean (SD)	71.5 (12.8)	71.9 (12.6)	71.2 (13.0)	71.7 (13.9)	66.5 (14.4)	71.3 (13.5)	73.0 (13.3)	72.5 (10.4)	73.9 (10.1)
Age at death									
≤60	53 (16.4)	23 (16.2)	30 (16.6)	8 (16.3)	16 (27.6)	8 (18.6)	8 (13.5)	7 (14.0)	6 (9.4)
61–74	117 (36.2)	49 (34.5)	68 (37.6)	16 (32.7)	22 (37.9)	14 (32.6)	25 (42.4)	19 (14.0)	21 (32.8)
75+	153 (47.4)	70 (49.3)	83 (45.8)	25 (51.0)	20 (34.5)	21 (48.8)	26 (44.1)	24 (48.0)	37 (57.8)
Mean (SD)	72.4 (12.7)	72.8 (12.3)	72.0 (13.0)	72.2 (13.8)	67.2 (14.2)	72.2 (13.3)	73.6 (13.4)	73.9 (10.0)	75.0 (10.0)
Time from diagnosis to death (months)									
≤1	75 (23.2)	21 (14.8)	54 (29.8)	10 (20.4)	20 (34.4)	9 (20.9)	23 (39.0)	2 (4.0)	11 (17.2)
1–6	83 (25.7)	35 (24.7)	48 (26.5)	19 (38.8)	16 (27.6)	9 (20.9)	18 (30.5)	7 (14.0)	14 (21.9)
6–12	62 (19.2)	33 (23.2)	29 (16.1)	13 (26.5)	11 (19.0)	11 (25.6)	5 (8.5)	9 (18.0)	13 (20.3)
12+	103 (31.9)	53 (37.3)	50 (27.6)	7 (14.3)	11 (19.0)	14 (32.6)	13 (22.0)	32 (64.0)	26 (40.6)
Mean (SD)	10.6 (12.0)	11.8 (11.6)	9.7 (12.2)	5.9 (6.1)	7.4 (9.8)	10.6 (11.2)	7.7 (12.1)	18.6 (12.6)	13.5 (13.5)
Place of death									
Hospital	240 (74.3)	88 (62.0)	152 (84.0)	28 (57.1)	53 (91.4)	28 (65.1)	50 (84.7)	32 (64.0)	49 (76.6)
Home	49 (15.2)	34 (23.9)	15 (8.3)	13 (26.5)	3 (5.2)	10 (23.3)	5 (8.5)	11 (22.0)	7 (10.9)
Hospice	18 (5.6)	13 (9.2)	5 (2.8)	6 (12.3)	1 (1.7)	4 (9.3)	2 (3.4)	3 (6.0)	2 (3.1)
Nursing home	16 (4.9)	7 (4.9)	9 (4.9)	2 (4.1)	1 (1.7)	1 (2.3)	2 (3.4)	4 (8.0)	6 (9.4)

*No evidence of a discussion about preferred place of death could be found in medical records.
AML, acute myeloid leukaemia; DLBCL, diffuse large B-cell lymphoma; HMRN, Haematological Malignancy Research Network.

There was some variation in the clinical specialties providing care at the time of death, with less than half (n=98, 40.8%) of the 240 hospital deaths occurring in haemato-oncology settings (table 3). Indeed, 52 patients (21.7%) died in elderly/general medical areas, and others died in intensive care/high dependency units (ICU/HDU) (n=26, 10.8%), renal medicine (n=12, 5%) or accident and emergency (A&E) departments (n=9, 3.7%). A relatively small proportion (n=18, 7.5%) died in hospital palliative care areas. With respect to variation by disease subtype, patients with AML were more likely than those with DLBCL or myeloma to die on haemato-oncology wards, the proportions being 50.0%, 23.5% and 27.6%, respectively (p=0.0002). Conversely, those with DLBCL or myeloma were more likely than those with AML to die in elderly/general medical settings. As expected, patients with myeloma were the most likely to die in renal areas, and those with AML and DLBCL on ICU/HDU. Similar proportions died in palliative care settings across diagnostic groups.

With respect to prior discussion about place of death among patients dying in hospital (table 3), this was most likely to have occurred when patients died within palliative care areas (72.2%), followed by haemato-oncology (41.8%) and elderly/general medicine (38.5%). As might be expected, those dying in ITU/HDU or A&E were least likely to have had a discussion about their preferred place of death (3.8% and 11.1%, respectively).

Despite deaths occurring in a number of different hospital settings, 90% of patients received haematology input during the last month of life, including all patients dying on renal wards and in A&E, 84.6% of those in ITU/HDU, 80.8% in elderly/medicine and 72.2% in palliative care areas (table 3). During the final week of life, this changed to 75.8% receiving haematology input overall, and although the proportion remained constant in ITU/HDU, it decreased to 66% in renal and A&E areas, 53.8% in elderly/medical and 22.2% in palliative care settings.

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Table 2 Discussion about preferred placed of death in patients diagnosed with AML, DLBCL and myeloma at the two HMRN study hospitals between May 2005 and April 2008 who died before May 2010, and congruence between preferred and actual place of death in those with a discussion (n=142)

		Actual place of death (N %)			
	Total (N %)	Hospital	Home	Hospice	Nursing home
All deaths	323 (100)	240 (74.3)	49 (15.2)	18 (5.6)	16 (5.0)
Discussion about preferred place of death					
No	181 (100)	152 (84.0)	15 (8.3)	5 (2.8)	9 (5.0)
Yes	142 (100)	88 (62.0)	34 (23.9)	13 (9.2)	7 (4.9)
Preferred place of death					
Hospital	40 (100)	40 (100.0)	–	–	–
Home	65 (100)	31 (47.7)	32 (49.2)	–	2 (3.1)
Hospice	24 (100)	11 (45.8)	–	13 (54.2)	–
Nursing home	8 (100)	3 (37.5)	–	–	5 (62.5)
Undecided	5 (100)	3 (60.0)	2 (40.0)	–	–

Shaded area represents the number and proportion of patients who died in their preferred place.
AML, acute myeloid leukaemia; DLBCL, diffuse large B-cell lymphoma; HMRN, Haematological Malignancy Research Network.

Many patients dying in hospital also received input from specialties other than their main team at this time, with 86.7% of patients dying in haemato-oncology settings, for example, receiving care from other specialties during the 30 days preceding death, reducing to 61.2% in the last 7 days. In comparison to those who died in hospital, 71% of those who died elsewhere had haematology input in the last month of life, falling to 19% in the final week.

DISCUSSION

This is the first study to examine preferred and actual place of death in patients with haematological malignancies. Evidence about this is crucial to ensure that as many patients as possible receive optimum end-of-life care and die in the place of their choosing. As expected, most people died in hospital, and although many (44%) took part in a discussion about preferred place of death, over half did not; this was particularly common among patients dying soon after diagnosis. Of those with evidence of a discussion, over a quarter (28.2%) wanted to remain in hospital at the time of their death, and less than half (45.8%) wanted to be in their own home. Taking part in a discussion about preferred place of death significantly impacted on actual place of death, and a substantial proportion (63.4%) of people who had had this discussion died in their preferred place; nonetheless, over a third did not.

There are a number of reasons why hospital deaths are common among haematology patients and why discussions about place of death might not occur. The first relates to the complexities associated with these diseases, their pathways and management. Haematology patients are often treated aggressively with toxic chemotherapy, both soon after diagnosis and at subsequent intervals thereafter if their disease follows a remitting/relapsing course. This often results in hospitalisation; it may also lead to rapid deterioration, and sometimes sudden death.[28–31] In this case, the transition from curative or life-prolonging care to a palliative approach may occur rapidly, leaving little time for advance care planning and discussion about preferred place of death.[32] Indeed, such situations may explain to some extent the relatively high proportion of people, particularly with AML and DLBCL, who died in intensive care settings, with escalation of treatment and a focus on prolonging life. Unsurprisingly, we found evidence that discussions about preferred place of death occurred infrequently in this setting.

Further complexities in care transitions were noted due to the unpredictability of treatment response. It was not uncommon, for example, for sudden deterioration to occur on a background of previously stable disease or steady decline, a scenario which perhaps has more in common with the terminal phase of chronic diseases, such as heart failure, than other malignancies.[33] Such patterns result in care transitions being regarded as notoriously difficult to identify in these diseases.[12] This may mean advance care planning is deferred, or does not occur in time for home death to be considered or organised.

Haematology patients often require supportive care during their disease, resulting in frequent hospitalisations. For example, blood product transfusions and intravenous antibiotics are needed to manage complications, including bone marrow failure, anaemia, bleeding and sepsis, and pain may also be a significant problem.[34–36] The situation is complicated by factors such as the availability of multiple lines of treatment, even in the later disease stages, which may be given to manage symptoms rather than with curative or disease modifying intent.[28 29] In this context, chemotherapy may continue into the terminal phase, again complicating the transitions in care.

Most people in our study who stated a preferred place of death, but died elsewhere, died in hospital.

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Table 3 Clinical area at time of death in 240 patients diagnosed with AML, DLBCL or myeloma at the two HMRN study hospitals between May 2005 and April 2008 who died in hospital before May 2010, and variation by cancer type, discussion about place of death and specialties contributing to care ≤30 days and ≤7 days before death

		Clinical area at time of death							
	All hospital deaths N (%)	Haemato-oncology N (%)	Elderly/ general medicine N (%)	ICU/ HDU N (%)	Palliative care N (%)	Renal N (%)	A&E N (%)	Other* N (%)	Not Known N
Total	240 (100)	98 (100)	52 (100)	26 (100)	18 (100)	12 (100)	9 (100)	22 (100)	3
Cancer type									
AML	81 (33.8)	48 (50.0)	10 (19.2)	11 (42.3)	5 (27.8)	–	2 (22.2)	4 (18.2)	1
DLBCL	78 (32.5)	23 (23.5)	22 (42.3)	10 (38.5)	7 (38.9)	1 (8.3)	4 (44.4)	9 (40.9)	2
Myeloma	81 (33.8)	27 (27.6)	20 (38.5)	5 (19.2)	6 (33.3)	11 (91.7)	3 (33.3)	9 (40.9)	–
Discussion about place of death									
No	152 (63.3)	57 (58.2)	32 (61.5)	25 (96.2)	5 (27.8)	9 (75.0)	8 (88.9)	14 (63.6)	2
Yes	88 (36.7)	41 (41.8)	20 (38.5)	1 (3.8)	13 (72.2)	3 (25.0)	1 (11.1)	8 (36.4)	1
Specialties contributing to care ≤30 days before death†									
Haemato-oncology	216 (90.0)	98 (100.0)	42 (80.8)	22 (84.6)	13 (72.2)	12 (100.0)	9 (100.0)	18 (81.8)	2
Elderly/general medicine	133 (55.4)	41 (41.8)	52 (100)	9 (34.6)	7 (38.9)	6 (50.0)	3 (33.3)	15 (68.2)	–
ICU/HDU	62 (25.8)	15 (15.3)	10 (19.2)	26 (100)	–	4 (33.3)	2 (22.2)	5 (22.7)	–
Palliative	82 (34.2)	34 (34.7)	14 (26.9)	3 (11.5)	18 (100)	2 (16.7)	1 (11.1)	9 (40.9)	1
Renal	29 (12.1)	8 (8.2)	4 (7.7)	4 (15.4)	–	12 (100)	–	1 (4.5)	–
A&E	77 (32.1)	19 (19.4)	26 (50.0)	12 (46.2)	2 (11.1)	1 (8.3)	9 (100)	8 (36.4)	–
Other	131 (54.6)	53 (54.1)	22 (42.3)	16 (61.5)	9 (50.0)	5 (41.7)	4 (44.4)	22 (100)	–
Specialties contributing to care ≤7 days before death†									
Haemato-oncology	182 (75.8)	98 (100.0)	28 (53.8)	22 (84.6)	4 (22.2)	8 (66.7)	6 (66.6)	16 (72.7)	–
Elderly/general medicine	85 (35.4)	18 (18.4)	52 (100)	5 (19.2)	–	3 (25.0)	–	7 (31.8)	–
ICU/HDU	52 (21.7)	9 (9.2)	8 (15.4)	26 (100)	–	3 (25.0)	2 (22.2)	4 (18.2)	–
Palliative	69 (28.8)	25 (25.5)	13 (25.0)	3 (11.5)	18 (100)	1 (8.3)	1 (11.1)	7 (31.8)	1
Renal	27 (11.3)	7 (7.1)	4 (7.7)	3 (11.5)	–	12 (100)	–	1 (4.5)	–
A&E	38 (15.8)	7 (7.1)	14 (26.9)	6 (23.1)	–	–	9 (100)	2 (9.1)	–
Other	77 (32.1)	26 (26.5)	8 (15.4)	9 (34.6)	7 (38.9)	3 (25.0)	2 (22.2)	22 (100)	–

*Other includes: coronary care unit/Cardiology (n=7), general surgery (n=7), infectious disease (n=2), respiratory (n=2), gastroenterology (n=1), orthopaedic (n=1), rehabilitation (n=1), plastic surgery (n=1).
†Includes input provided by any clinical specialty, which is additional to that given by the main provider shown in the column heading.
A&E, accident and emergency department; AML, acute myeloid leukaemia; DLBCL, diffuse large B-cell lymphoma HMRN, Haematological Malignancy Research Network; ICU/HDU, intensive care unit/high dependency unit.

Sometimes, the reasons for this were relatively clear, including those determined by access to limited resources (eg, hospice or nursing home beds), equipment (eg, bed, commode, oxygen, hoist) or services (eg, district nurses, night sitters) if the patient wanted to return home to die. Sudden deterioration meant these resources were often needed at short notice, but were not always available. In common with other studies,[37] social circumstances, carer preferences, or indeed lack of a carer appeared to prevent some home discharges. Often, however, we found we could not determine why preferred place of death had not been discussed, or preferences met.

Our study showed that some patients opt to remain in hospital to die. Others also report that hospital may indeed be considered a 'safe haven' and a place that provides the best possible care, around the clock, at a time when death is feared and cure is hoped for.[38 39] We found that patients were significantly more likely to choose to remain in hospital if they were managed within a haematology area, and this may be due to the close relationship they (and often their relatives) have with the team providing their care.[9 12 40 41] This is often established over a number of years, perhaps developing from a shared understanding of the experiences and emotions associated with an unpredictable disease and frequent hospital contacts. Patients may also choose to remain in hospital to ensure that their symptoms are effectively managed during the terminal stages by a team they know and trust. Alternatively, being at home at this time may not meet patient or carer expectations, leading to hospital readmission as the patient becomes increasingly ill.

We identified a multidisciplinary approach to care during the last month and week of life, which demonstrates the complexity of haematological malignancies at this time. Although many hospital deaths occurred

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outside haematology areas, 90% of patients received haematology input in the 30 days preceding death, reflecting considerable ongoing support, even for patients being managed by other teams. Those not receiving haematology input at this time may have had other acute comorbidities; we also noted that some patients were not known to haematology, as their disease was only formally diagnosed after death. Continued management in haematology areas was most common in patients with AML, perhaps because of their significant dependency on supportive care.

Of the 240 patients dying in hospital, 7.5% were managed at this time in dedicated palliative care areas, either in major treating hospitals or smaller general practitioner (GP)-led local hospital units. We found evidence that palliative care clinicians were by far the most likely to engage patients in discussions about end-of-life preferences. This suggests a clear link between palliative care input and advance care planning. It is possible, however, that patients may have decided they wanted to die at home and received palliative care input to facilitate this. The reason preferred place of death was discussed less often in care of the elderly areas is unclear.

We were not able to identify any other studies focusing on haematological cancers, or using identical methods, with which to directly compare our findings; many of the existing studies were from different geographical locations, and so were also not directly comparable. Looking very generally, however, the proportion of people we identified with a discussion about preferred place of death falls within the broad range (18.7–87%) reported in UK studies from palliative care settings.[42–47] The proportion of patients preferring hospital death was generally much higher in our study and much lower for home death than that reported in other studies of patients with cancer, where hospital death was often the least favoured option.[4 48 49] The proportion of people we identified who died in their preferred place was broadly comparable to other studies;[4 45 47–49] and others also reported that people taking part in discussions about place of death are less likely to die in hospital.[4 37 45]

STRENGTHS AND WEAKNESSES

One of the strengths of the study is that it is embedded within a well-established population-based patient cohort (HMRN), which covers a large area that is representative of the UK.[24 25] We focused on two large treating hospitals within this area, which together diagnose around a third of all HMRN patients. The existing study infrastructure ensured that we were able to identify all those who were diagnosed with the diseases of interest in these hospitals, and who died during the specified time-intervals. It is possible that awareness of the study may have influenced the provision of healthcare within the targeted hospitals, particularly advance care planning and discussions of end-of-life preferences. The study was, however, instigated towards the latter part of the follow-up period and much of the data were collected retrospectively, so we do not believe that patient care was unduly influenced in this respect.

In terms of study generalisability, we have no reason to believe that the preferences of patients included in the study are likely to differ significantly from those of the wider HMRN cohort. This is because clinical practice across the area adheres to national guidelines.[24 25] We do appreciate, however, that some area-based variation, both regionally and nationally, is inevitable, probably driven by factors such as resource and service availability. Variations in preferences and practices may also occur internationally, as a result of differences in healthcare systems.

Our data collection techniques were thorough and we are confident that the majority of documented evidence about preferred place of death, and also the clinical specialties providing care, was identified in the data sources examined. In common with other studies, we noted the lack of a systematic approach to the recording of preferred place of death.[46] It is possible, therefore, that discussions may have occurred that were not documented and so not identified by researchers. Furthermore, we did not examine certain primary care records (eg, GP, district nurse) or hospice/nursing home records, which may have contained additional information about preferred place of death. In this respect, the proportion of patients we identified with a discussion about place of death represents a minimum value.

We documented all stated preferences about place of death, including changes over time and used the decision closest to death to analyse congruence between preferred and actual place of death. It should be noted that the preferences at this time therefore reflect the choice made when the patient is becoming increasingly ill and may already be in hospital. Furthermore, although preferred place of care and preferred place of death are recognised as different issues,[50] our analysis focused solely on place of death. This is because there was not usually enough information in the medical records to enable us to systematically differentiate between these two concepts with any confidence.

IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

Earlier discussion about prognosis and potential complications of treatment may promote advance care planning among haematology patients. This could take place around diagnosis for all patients, whether they are being treated with curative, life-prolonging or palliative intent. An inherent difficulty associated with this, however, is balancing hope with uncertainty. The patient and their family's knowledge and acceptance of the expected disease trajectory must be taken into consideration, along with their willingness to engage in discussions about end-of-life care and place of death at a time when they may prefer to focus solely on cure.

More research is needed to fully understand the reasons why place of death was not discussed, why

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patients did not die in their preferred place if this was stated, and any changes that could be made to practice to rectify such issues in future. If this is due to resources issues improvements could be made via changes to the commissioning and allocation of services; other reasons, such as social circumstances and different carer preferences, may be harder to address. It would also be useful to compare preferences of haematology patients with those of patients with other cancers in the same geographical area. If haematology patients are more likely than others to choose to remain in hospital at the end of their lives, then it is essential that adequate care is available within this setting to meet these needs.

CONCLUSION

Our study has introduced evidence about preferred and actual place of death in haematological malignancies. We have shown that many patients with these diseases do have the opportunity to discuss preferred place of death, and do die in their preferred place. However, we also identified that a substantial proportion did not take part in such discussions, and that hospital deaths were particularly common in this group. Hence, there is scope to improve practice, particularly among those dying soon after diagnosis, and those with the propensity to die suddenly and unexpectedly. Our findings highlight the complexity of haematological cancers, demonstrated in the multidisciplinary provision of care, and the sustained input from the haematology team, in many cases continuing until the last week of life. We found evidence that some patients wanted to remain in hospital at the time of their death, and the extent to which this compares with that of patients with other cancers is of interest.

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Contributors DAH, ER, AGS, MH and AG contributed to the conception and design of the study; DAH managed and implemented the study and was responsible for data acquisition; and AGS managed the HMRN data and HIW conducted the data analysis. AG, MH, MJJ and RP contributed clinical advice during the interpretation of data. DAH and ER wrote the first draft of the paper; all authors contributed to subsequent revisions and approved the final manuscript.

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Competing interests None declared.

Ethics approval HMRN has ethical approval (REC 04/01205/69) from Leeds West Research Ethics Committee, R&D approval from each Trust in the area, and exemption from Section 251 (formally Section 60) of the Health & Social Care Act (2001) (PIAG 1-05(h)/2007). This specific study also has additional ethical approval (REC 07/H1307/168).

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