Haematological malignancy: are patients appropriately referred for specialist palliative and hospice care? A systematic review and meta-analysis of published data

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Abstract
Haematological malignancies are complex diseases, affecting the entire age spectrum, and having marked differences in presentation, treatment, progression and outcome. Patients have a significant symptom burden and despite treatment improvements for some sub-types, many patients die from their disease. We carried out a systematic review and meta-analysis to examine the proportion of patients with haematological malignancies that received any form of specialist palliative or hospice care. Twenty-four studies were identified, nine of which were suitable for inclusion in the meta-analysis. Our review showed that patients with haematological malignancies were far less likely to receive care from specialist palliative or hospice services compared to other cancers (Risk Ratio 0.46, [95% confidence intervals 0.42–0.50]). There are several possible explanations for this finding, including: ongoing management by the haematology team and consequent strong bonds between staff and patients; uncertain transitions to a palliative approach to care; and sudden transitions, leaving little time for palliative input. Further research is needed to explore: transitions to palliative care; potential unmet patient needs; where patients want to be cared for and die; existing practices in the delivery of palliative and end-of-life care; and barriers to specialist palliative care and hospice referral and how these might be overcome.

Keywords
End-of-life care, haematological malignancy, hospice, palliative care, transition

Introduction
Haematological malignancies comprise more than 60 distinct disease types, each having particular clinical features, treatment pathways and outcomes.1,2 Significant improvement in the treatment of certain haematological malignancies in recent years has meant that some patients are now living longer with their disease – and often with the associated symptoms.3 Consequently, there is growing recognition that routine treatment should also incorporate specialist palliative care input.3–5

Despite improved treatments, many patients continue to experience relapsed disease, become progressively ill and eventually die from their malignancy.
In this context, good symptom control and end-of-life care is extremely important. There is some evidence, however, to suggest that patients with haematological malignancies may not be benefiting at this time from specialist input from palliative care and hospice services. According to the UK National Institute for Health and Clinical Excellence ‘there is weak but consistent evidence that palliative care is used less in haematological cancers than in patients with solid tumours, and that access to specialized palliative care support may be less available to haematologists than solid tumour oncologists, particularly for patients in the final phase of illness’. This scenario in not limited to the UK. Research in other countries, particularly Australia, has also indicated a lack of integration between haematology and palliative care practitioners.6–8

End-of-life care is recognized as an under-researched area in the context of haematological malignancies.5 In order to inform debate, findings from a systematic review and meta-analysis examining the use of specialist palliative care and hospice services in patients with haematological malignancies compared to those with other cancers are reported.

Methods

A systematic search was carried out using CENTRAL, MEDLINE, EMBASE, BNI, PSYCHINFO, CINAHL, HMIC, ALTERNATIVE MEDICINE and WEB OF KNOWLEDGE to identify papers examining the use of specialist palliative care and hospice services in patients with haematological malignancies. The search, which was finalized in July 2010, was restricted to publications from 1985 onwards. The search strategy recommended for haematological malignancies by the Cochrane research group was used to ensure all papers including patients with these diseases were identified. This was combined with the following terms: ‘end-of-life care’, ‘palliative’, ‘place of care’, ‘hospice’, ‘homecare’ and ‘advanced cancer’ as keywords, text words and exploded Medical Subject Headings (MeSH) terms. Extensive reference checking and citation tracking was conducted in order to increase the yield of relevant papers. There were no language restrictions.

We intended to examine all types of palliative input in this review and hence have included studies investigating referral to palliative care teams in both the hospital and community, and also hospices. However, a degree of ambiguity arose due to the different phrases used to describe palliative input. For the purpose of this review, the term ‘palliative care’ was used to refer to input from specialist practitioners trained in the delivery of palliative and end-of-life care. Studies describing this practice by an alternative name, such as ‘homecare’ for example, were included and the phrase was searched in order to ensure that all research using the alternative term had been identified.

The term ‘palliative’ can also be ambiguous in the context of haematological malignancies. A ‘palliative approach’ to care may be used for patients in situations where intensive chemotherapy may be considered inappropriate, for example in some elderly patients with acute myeloid leukaemia. A ‘palliative approach’ in this context equates to symptom control and the provision of ongoing supportive care, usually in the form of blood product transfusions. Some haematological malignancies, such as myeloma and follicular lymphoma, are recognized as incurable at diagnosis. Although chemotherapy can be given to effectively induce remission in patients with these diseases, this treatment is sometimes referred to as ‘palliative’, as it will not lead to cure. Neither of these ‘palliative’ situations is equivalent to input from specialist palliative care or hospice services, and studies examining these approaches to care were excluded from the present analysis.

Two researchers (DH/RS) independently examined all identified studies. A pre-defined scoring system was used to exclude irrelevant studies. Inclusion criteria included: examining use of any specialist palliative or hospice services, including those ≥18 years with haematological malignancies, and reporting results for patients with haematological malignancies as a distinct group. Studies examining place of death were included if a hospice category was examined and data were given for haematology patients. This was because it was assumed that death in a hospice must be preceded by referral to the hospice and the delivery of a certain amount of care, even if only during the very terminal stages of illness. However, it is possible that patients could have been referred to a hospice and received care, yet died elsewhere; thus the figures reported in these studies may underestimate the proportion of patients receiving hospice care.

On completion of the search, studies that had been identified but found to be inappropriate were excluded. Full text documents were then examined in all remaining studies meeting the inclusion criteria and in all ambiguous cases. A third researcher (ER) was available to arbitrate in the case of disagreement. Studies of children were excluded as their clinical and end-of-life care was considered to differ significantly from that of adults. Studies examining palliative care in the context of quality of life, euthanasia and palliative treatment were excluded. Qualitative studies and publications not presenting data (such as editorials and letters) were also excluded.

A total of 3432 published articles were identified from the search (Figure 1). During the selection process 3282 studies were excluded. A further 150 were
retrieved for scrutiny and of these 24 were finally included in the review. Nine presented risk estimate data and were included in the meta-analysis.

Descriptive data comprising the percentage of patients with input from specialist palliative care or hospice services were extracted from each study for all cancers and for haematological malignancy. Risk estimates and 95% confidence intervals for these services were also extracted. A meta-analysis of risk estimates was created for each of these categories using Stata 10.0 Statistical Software, and presented in a meta-plot with results shown by category and overall.

Results

Patients with haematological malignancies were significantly less likely to receive input from specialist palliative care or hospice services compared to those with other cancers (Risk Ratio 0.46, [95% confidence intervals 0.42–0.50]) (Tables 1–3 and Figure 2).

There are large differences in the proportion of specialist palliative care input for patients with all cancers compared to those with haematological malignancies in all countries examined (Table 1), including (respectively) Hong Kong (67% versus 13%),9 the USA (59% versus 21%),10 Canada (36% versus 18% for cancer of the lymph nodes and 7% for the haemopoietic tissues),11 and the UK (28% versus 12%).12 The lowest referral rate to palliative care services was reported in an Italian study, with only 1% of haematology patients being referred; however, the overall referral rate for all cancers was also very low at only 4%.13 A study from the USA reported that patients with haematological malignancies were particularly unlikely to have access to hospital palliative care services if they were admitted to the Intensive Care Unit (10%) compared to those who were not (35%).10 Only one small study found a relatively large proportion of haematological referrals to the palliative care team, reporting rates of 75%, 61% and 27% for colorectal cancer, non-Hodgkin lymphoma, and acute leukaemia, respectively.6 However, only 18 patients were included in each disease group.

Differences in hospice referrals (Table 2) were equally marked, with fewer referrals among those with haematological malignancies than among those in the total cancer patient population. The respective figures in the reports being: 3% versus 21% in the UK;14 37% versus 56% in Australia;15 and 16% for leukaemia and 21% for lymphoma versus 55% in the USA.16 Only one study reported roughly equal proportions of utilization (11%), although fewer lymphoma patients accessed this service in the six-month period after diagnosis and the six months before death than those with other cancers.17

There is considerable variation in the number of patients with haematological malignancies included in each study. There are also differences in the disease
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Methods</th>
<th>Total patients (% with palliative care input)</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addington-Hall and Altmann, 2000</td>
<td>UK</td>
<td>Randomly sampled death certificates from 20 health authorities (Oct-Dec 1990); data obtained from interview with an informant.</td>
<td>2062 (28) 145 (12)</td>
<td>Compared to all other cancers, patients with ‘lymphoma, leukaemia or myeloma’ were less likely to receive ‘Community Specialist Palliative Care’.</td>
</tr>
<tr>
<td>Beccaro et al., 2007</td>
<td>Italy</td>
<td>Randomly sampled death certificates from 30 health districts (Mar 2002–Jun 2003); data obtained from interview with an informant.</td>
<td>1289 (14) NA</td>
<td>Compared to all other cancers, patients with ‘haematological tumours’ were less likely to be referred to ‘Domiciliary Palliative Care Teams’.</td>
</tr>
<tr>
<td>Costantini et al., 1993</td>
<td>Italy</td>
<td>All General Registry cancer deaths ≥18 in Genoa: 1985–1990. Death certificates linked to medical records.</td>
<td>12,343 (4) NA (1)</td>
<td>Compared to all other cancers, patients with ‘leukaemia-lymphoma’ were less likely to be referred to the Palliative ‘Home Care Service’.</td>
</tr>
<tr>
<td>Fadul et al., 2007</td>
<td>USA</td>
<td>Review of medical records for all hospital deaths in a single Cancer Centre: 2003–2004.</td>
<td>Total 1453 (34) Non-HM 867 (59) 586 (21) HM + ICU 339 (10) HM-ICU (35)</td>
<td>Compared to all other cancers patients with ‘haematologic malignancies’ were less likely to have ‘Access to Palliative Care Services’ in hospital, particularly when associated with an ICU admission.</td>
</tr>
<tr>
<td>Grande et al., 2002</td>
<td>UK</td>
<td>Comparison of cancer patients referred to Hospital at Home (HAH) (Jun 1994–Jun 1995) with a random sample from the same area and period that were not referred. Data from linked health records.</td>
<td>HAH: 121 Non-HAH: 206 HAH: 7 Non-HAH: 20</td>
<td>With the exception of patients with breast and genitourinary cancers, those with ‘haematological malignancies’ were less likely to receive ‘Hospice At Home’ than all other cancers.</td>
</tr>
<tr>
<td>Johnston et al., 1998</td>
<td>Canada</td>
<td>Cancer deaths (≥20 years) in Nova Scotia (1988–1994). Cancer registry death data linked to palliative care and oncology databases.</td>
<td>Total: 14,494 (14) Halifax County: 4340 (36) Total HM: NA Halifax County: Haematopoietic 127 (7) Lymph nodes 238 (18)</td>
<td>Compared to all other cancers, patients with ‘haematopoietic and lymph node’ cancers were less likely to have involvement of the ‘Palliative Care Programme’ – at hospital and home.</td>
</tr>
<tr>
<td>Lidstone et al., 2003</td>
<td>UK</td>
<td>Consecutive cancer patients attending an out-patient clinic in London.</td>
<td>480 (13) Lymphoma (2)</td>
<td>Compared to other cancers, patients with lymphoma were least likely to have Specialist Palliative Care input.</td>
</tr>
<tr>
<td>Maddocks et al., 1994</td>
<td>Australia</td>
<td>Review of medical records of consecutive patients admitted to a medical centre that died within 30 days of admission: 1992–1993.</td>
<td>Colorectal 18 (75) Non-Hodgkin lymphoma 18 (61) Acute leukaemia 18 (27)</td>
<td>Compared to patients with colorectal cancer, patients with ‘non-Hodgkin lymphoma’ and particularly ‘acute lymphoma’ were less likely to be referred to the ‘Palliative Care Team’.</td>
</tr>
<tr>
<td>Tse et al., 2007</td>
<td>Hong Kong</td>
<td>Sample of all in-patient cancer deaths in 4 public hospitals in 2005 using medical records.</td>
<td>494 (67) 16 (13)</td>
<td>Compared to all other cancers examined, patients with ‘haematological malignancies’ were less likely to receive ‘Palliative Care Services’ at hospital and home.</td>
</tr>
</tbody>
</table>

*Included in meta-analysis, HM: haematological malignancy, NA: not available – data not given in study, ICU: intensive care unit.
Table 2. Summary of reported findings and proportion of hospice input for all cancers and for patients with haematological malignancies

<table>
<thead>
<tr>
<th>Study</th>
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<th>Methods</th>
<th>Total patients (% hospice use)</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>*Addington-Hall et al., 1998</td>
<td>UK</td>
<td>Randomly sampled death certificates from 20 health authorities (Oct–Dec 1990); data obtained from interview with an informant.</td>
<td>2074 (16)</td>
<td>Compared to all other cancers, patients with 'lymphatic or haematological malignancy' were less likely to receive Hospice In-patient Care.</td>
</tr>
<tr>
<td>Davison et al., 2001</td>
<td>UK</td>
<td>All deaths registered in Belfast: Jul–Dec 1977, 1987 and 1997.</td>
<td>1324 (20)</td>
<td>Compared to all other cancers, patients with 'lymphatic' cancers were less likely to die in a hospice.</td>
</tr>
<tr>
<td>*Earle et al., 2008</td>
<td>USA</td>
<td>All deceased Medicare cancer patients, aged ≥65 years at death and registered by Surveillance, Epidemiology and End Results (SEER): 1991–2000.</td>
<td>215,484 (NA)</td>
<td>Compared to all other cancers, patients with 'hematologic malignancies' were less likely to be referred to a hospice.</td>
</tr>
<tr>
<td>Gatrell et al., 2003</td>
<td>UK</td>
<td>All deaths in a single Health Authority: 1993–2000, using Health Authority and Office for National Statistics data.</td>
<td>6900 (33)</td>
<td>Compared to all other cancers, patients with cancer of the 'lymphatic system' were less likely to die in a hospice (OR 0.48).</td>
</tr>
<tr>
<td>*Hunt and McCaul, 1996</td>
<td>Australia</td>
<td>All South Australian deaths in 1990 linked to Central Cancer Registry and death records.</td>
<td>2800 (56)</td>
<td>Compared to all other cancers, patients with 'haematological malignancy' were less likely to receive hospice care.</td>
</tr>
<tr>
<td>*Hunt and McCaul, 1998</td>
<td>Australia</td>
<td>All South Australian deaths (1990 and 1993) linked to Central Cancer Registry and death records.</td>
<td>1990: 2800 (56)</td>
<td>Compared to all other cancers, patients with 'haematological malignancy' were less likely to have hospice involvement.</td>
</tr>
<tr>
<td>Hunt et al., 2001</td>
<td>Australia</td>
<td>All South Australian Cancer Registry deaths: 1990–1999.</td>
<td>29,230 (20)</td>
<td>Compared to all other cancers, haematology patients were less likely to die in a hospice (OR = 0.30 'lymphoma'; OR = 0.31 ‘myeloma’; OR = 0.23 ‘leukaemia’).</td>
</tr>
<tr>
<td>Iwashyna et al., 2002</td>
<td>USA</td>
<td>Medicare claims by a nationally representative sample of patients ≥68 years with a serious disease diagnosed 1993 and deceased by Dec 1997.</td>
<td>294,362 (55)</td>
<td>Compared to all other cancers examined, patients with 'leukaemia and lymphoma' were less likely to use hospice services.</td>
</tr>
</tbody>
</table>

(continued)
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Methods</th>
<th>-- All cancers</th>
<th>Haematological malignancy</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lang et al., 2005</td>
<td>USA</td>
<td>Medicare claims linked to Surveillance, Epidemiology and End Results data on patients with AML, aged ≥65 years, diagnosed 1991–1999.</td>
<td>Nil</td>
<td>All – 3439 (21)</td>
<td>Hospice use more than doubled from 1991 to 1999. Patients receiving hospice care tended to be older, living in metropolitan areas, white and female. They survived longer and cost of care was comparable to the overall sample.</td>
</tr>
<tr>
<td>Locher et al., 2006</td>
<td>USA</td>
<td>Medicare claims linked to Surveillance, Epidemiology and End Results data on cancer patients diagnosed 1997–1999 and using services in 1999.</td>
<td>120,072 (11)</td>
<td>4563 (11)</td>
<td>Patients with lymphoma were equally likely to utilize hospice services as those with other cancers. However, fewer lymphoma patients utilized hospice services within 6 months of cancer diagnosis and within 6 months of death than those with other cancers.</td>
</tr>
<tr>
<td>Lock and Higginson, 2005</td>
<td>UK</td>
<td>All cancer death in those aged ≥75 years in England and Wales: 1995–1999.</td>
<td>315,462 (13)</td>
<td>NA (8)</td>
<td>Compared to all other cancers, patients with lymphatic and haematopoietic cancers were less likely to die in a hospice.</td>
</tr>
<tr>
<td>Ross et al., 2003</td>
<td>UK</td>
<td>All residents dying of cancer in 4 counties: 1995–2000.</td>
<td>31,812 (23)</td>
<td>All – 2638 (11) ALL (6); AML (9); CML (9); CLL (5); HD (5); NHL (14); Myeloma (12)</td>
<td>Compared to all other cancers, patients with ‘haematological malignancies’ were less likely to die in a hospice.</td>
</tr>
<tr>
<td>*Tang et al., 2010</td>
<td>Taiwan</td>
<td>All Taiwanese cancer deaths, 2001–2006. Cancer and death registra-</td>
<td>204,850 (15)</td>
<td>11,444 (6)</td>
<td>Compared to all other cancers, patients with ‘haematological malignancies’ were less likely to use hospice care.</td>
</tr>
</tbody>
</table>

*Included in meta-analysis; NA – Not available (data not given in study); ALL - Acute Lymphoblastic Leukaemia; AML - Acute Myeloid Leukaemia; CML - Chronic Myeloid Leukaemia; CLL – Chronic Lymphocytic Leukaemia; HD – Hodgkin Disease; NHL – Non-Hodgkin Lymphoma.
sub-types included, with some studies examining all haematological malignancies and others only specific groups. Furthermore, some studies examined patterns of use solely among patients with haematological malignancies, whilst others compared this group to other cancers. Most studies focusing exclusively on differences by haematological malignancy sub-type reported variation in hospice and palliative care referral rates, with leukaemia patients, either collectively or by sub-type, being less likely to receive specialist input than those with non-Hodgkin lymphoma or myeloma.6,11,16,18

Most of the studies included in this review originated from Europe, Australia or the USA. All had retrospective designs, examining deceased patients identified via cancer registries or from individual health care institutions. Death certificates and medical records were often used as data sources, although three studies conducted interviews with the deceased’s informants.12,19,20

In terms of changes over time, one study in the USA noted a trend towards increasing rates of hospice referral of patients with haematological malignancy.21 It important to note that some of the studies included are based on data from the 1980s and 1990s, thus they may not reflect more recent changes in practice. In all reports, the explanations for the relative lack of palliative care and hospice input were anecdotal.

Discussion

Our review has confirmed that patients with haematological malignancies are less likely to be referred to specialist palliative and hospice services than patients with other cancers. This supports the assumptions made by the UK National Institute for Health and Clinical Excellence5 and also the findings reported in qualitative research studies exploring this subject, most of which originate from Australia.6–8,22

Good end-of-life care is important for all patients with life-limiting illnesses. The UK Department of Health published the End of Life Care Strategy in 200823 with the aim of emphasizing the importance of a good death through the careful planning and coordination of integrated, high-quality care in line with patient preferences. For haematological malignancies, the National Institute for Health and Clinical Excellence has recommended integration between haematology and specialist palliative care services from the time of diagnosis.5 The evidence presented in this review suggests, however, that there is little integration between these disciplines.

This finding is, however, a description of practice and absence of a palliative care or hospice referral should not be considered to reflect sub-standard care; it should be regarded in the wider care context.
Although qualitative research in Australia has reported particularly poor end-of-life care for haematology patients, with death often occurring in the ‘curative system’, with increasing use of technology and restricted carer access to patients, this situation may not be generalizable. In the UK, for example, there is little evidence to indicate whether lack of referral represents an unmet patient need (in terms of symptom control and care) or whether such needs are met by other professionals. This may include the haematology doctors, nurses and clinical nurse specialists, who are experienced in the routine delivery of complex care to these patients from diagnosis, throughout follow up and in the terminal phases of disease to death. The availability and distribution of hospice places, as well as the infrastructure and composition of specialist palliative care teams, will also undoubtedly determine whether decisions about care are based on choice, resources available at the time or both. Additional research is needed in order to further understand these issues, both in the UK and elsewhere in the world.

A number of studies have explored the symptoms experienced by patients with haematological malignancies and have reported a significant symptom burden, which includes dyspnoea, fever, pain, haemorrhage, infection, central nervous system disturbances, emotional distress, psychological problems, fatigue, reduced role function, mucositis, nausea, icterus, diarrhoea and insomnia. A further study has reported increased delirium and drowsiness and similar overall symptom
severity in patients with haematological malignancies compared to those with solid tumours. Whilst this evidence suggests the clear need for symptom control, further research has reported that patients with haematological malignancies that are referred to palliative care services are referred much later in the pathway, at a time much closer to death than those with solid tumours.31–33 One study reported a median time between referral and death of 14 days for patients with haematological malignancies compared to 47 days for those with solid tumours.33 Again, research does not exist to determine whether this indicates unmet needs, or ongoing management of all but the most complex patients by the haematology team.

Being able to die in a preferred place is considered to be an indicator of quality end-of-life care.34,35 Publication of the End of Life Care Strategy23 brought together initiatives, including Advance Care Planning, Preferred Priorities for Care and the Gold Standards Framework, to enable patients to die in the place of their choice whenever possible. Referral to hospice or palliative care services has been reported to increase the likelihood of home death in patients13,15,36–39 and this is likely to be the case in patients with haematological malignancies.80 Further evidence that patients with haematological malignancies may not be receiving optimum end-of-life care is highlighted in a recent systematic review,41 which indicates that these patients are over twice as likely to die in hospital compared to those with other cancers. This is of concern, given that home is generally considered to be the preferred place of death among patients and the general public.42,43 Again the lack of research in this area means that there is uncertainty regarding whether the excessive number of hospital deaths in patients with haematological malignancy is related to specific factors, such as the lack of specialist palliative care input, or whether other factors, such as patient preference, also have an influence.

Patient pathways and illness trajectories for haematological malignancies differ considerably by disease type; improved treatment of certain diseases, such as plasma cell myeloma, mean that the patient pathway may now extend many years after diagnosis following what has become a chronic trajectory.5 Such pathways are associated with long-term follow up by the haematology team, which continues even during the terminal phase of illness, as patients continue to attend for symptom control and supportive care. As a consequence, strong bonds often develop between patients and their haematology team;44 in this context patients and their families may look for support from the team that includes known doctors and nurses in a familiar setting, particularly at times of disease relapse or progression. In practise, this often means that the haematology team continues to deliver care without input from the specialist palliative care team in the terminal phase of illness. In this situation death on the haematology ward may perhaps be the patients preferred option and additional research is needed to further explore this issue. One drawback to ongoing and frequent follow up by the haematology team, and indeed unplanned attendance at day units, is that this may prevent patients from accessing community specialist palliative care services and limit contact with the primary care team, a situation that could result in an avoidable acute hospital admission for terminal care.44

At the other end of the spectrum, aggressive haematological malignancies, such as acute myeloid leukaemia, are known to have poor survival outcomes, particularly in the elderly.1 For some, the diagnosis of a haematological malignancy is followed by death during the first hospital admission,21,27 or in the case of aggressive lymphomas the diagnosis may only be confirmed after the patient has died.40 Studies have reported that shorter survival is generally associated with decreased likelihood of receiving hospice care,15 and this was confirmed in a UK study of haematology patients in the context of referral to specialist palliative care services.40

One of the most important reasons for the lack of referral to palliative and hospice services is likely to be the absence of a clear transition between the curative, life-prolonging and palliative phases of disease in some patients. The comparative lateness of this transition could mean that any referral is ineffectual.7 The difficulty identifying transition may be related to the fact that the timing of death can be very unpredictable in haematology patients, even within specific disease types. This is due to the nature of complications (sepsis and bleeding), variable treatment responses, the number of salvage therapies, unknown time to relapse, and not knowing which relapse will be the last.45

Complications can also lead to the unexpectedly rapid deterioration in the patient’s condition,64,46 resulting in the transition occurring in a matter of hours.47 This situation may mean that there is insufficient time for referral to palliative care or hospice services. However, it has been reported that use of hospice services did not exceed 30% in patients with acute myeloid leukaemia, even when they survived past the first hospitalization.21 This rapid change may also mean that all efforts are being focused on life-saving measures, hence perhaps the relatively large proportion of haematology patients reported to die in intensive care settings,40 an area where palliative care referrals are reported to be low,10 but where patients may be cared for after an acute deterioration and whilst receiving curative treatment.48 Difficulties identifying the transition to a palliative approach to care has resulted in
concerns about the inappropriate early withdrawal of treatment, thus a lack of consensus has arisen about the right time to refer patients to palliative care services.45

This review has shown that patients with haematological malignancies are less likely to receive input from specialist palliative care and hospice services than patients with other cancers. It has also discussed the many complexities that are associated with end-of-life care in these diseases. Further research is needed to explore issues including: the transition from life-prolonging to palliative care; potential unmet patient needs; existing practices in the delivery of palliative care and end-of-life care; where patients want to be cared for and die; and barriers to specialist palliative care and hospice referral and how these might be overcome.

Authors’ contributions

The Palliative Care and Haematological Malignancy Steering Committee had the original idea for the review. DH supervised the review. RS conducted the search, retrieved and scored the studies. DH independently second scored the studies. DH and RS wrote the manuscript. DH and ER performed the final screening of studies and extracted data. ER calculated risk estimates. All authors commented on the final version of the manuscript.

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Competing interests

The authors have no competing interests to declare.

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