Hospice care access inequalities: a systematic review and narrative synthesis

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ABSTRACT

Background Inequalities in access to hospice care is a source of considerable concern; white, middle-class, middle-aged patients with cancer have traditionally been over-represented in hospice populations. The effect of gender and marital status is inconsistent. There is a limited literature concerning hospice service access for the LGBTQ+ community, homeless people and those living with HIV/AIDS, diabetes and cystic fibrosis.

Conclusion Barriers of prognostic uncertainty, institutional cultures, particular needs of certain groups and lack of public awareness of hospice services remain substantial challenges to the hospice movement in ensuring equitable access for all.

Key messages

What was already known?
⇒ Hospice services traditionally mainly care for people with cancer.
⇒ National policies have repeatedly called for greater equality of access to hospice care provision.

What are the new findings?
⇒ Certain groups continue to have unequal access to hospice care; the oldest old, ethnic minorities, people with non-cancer illness, those living in rural areas and areas of social deprivation.
⇒ A combination of prognostic uncertainty, institutional cultures, unique needs of particular groups and a lack of public awareness of services exacerbate these problems.

What is their significance?
⇒ Equity of access to hospice care for all is urgently needed and remains a major challenge for the hospice movement.
⇒ Innovative and collaborative services need to be developed to meet the diverse needs of the whole community.

INTRODUCTION

When the modern hospice movement started in 1967 with Dame Cicely Saunders opening St. Christopher’s Hospice in South London, the main focus of the early hospices was on excellence in the holistic palliative and end-of-life care of patients with cancer. Since those early days, hospices have sought to broaden their reach to include those with non-cancer diagnoses and other underserved groups.

In addition to inpatient beds, hospice care commonly includes specialist home care and community teams, Macmillan and Marie Curie nursing services, hospice at home services, day therapy and outpatient consultations. Working alongside colleagues in General Practice and District Nursing and hospital Palliative Care
teams, hospices are often leaders in education and local service developments.

However, inequalities of hospice provision persist. Of the 528,973 deaths in England and Wales in 2019, 71.5% (378,108) were from non-cancer conditions and 28.5% (150,865) from cancer.1 Hospices were the place of death for 1.2% (4,503) of non-cancer deaths and 16.5% (24,925) of cancer deaths. Of the 29,428 deaths in hospices in 2019, 24,925 (84.7%) were from cancer and 4,503 (15.3%) from non-cancer. While many more people receive hospice care than die there, these figures suggest that patients with cancer remain disproportionately served by hospice care. National mortality statistics from Scotland and Northern Ireland are very similar.

Over recent years there has been growing recognition of the palliative care needs of people dying from non-cancer conditions, alongside the development of palliative care teams in hospitals and the community. While the proportion of non-cancer deaths occurring in hospice in England and Wales has increased over the past decade, from 7.8% in 2010 to 12.4% in 2015 and 15.3% in 2019,2 patients without cancer remain under-represented in these data.

Diagnosis is not the only inequality that persists in hospice care provision; evidence suggests that the oldest old (aged 85+) are also under-represented, alongside considerable disparities across geographical regions of the UK.3 To address these issues, there has been an impetus in many countries to improve the equity of palliative and end of life care provision. The 2008 UK Department of Health ‘End of Life Care Strategy’ promoted a ‘vision for a good death’ that is ‘irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status’.3 This was echoed in the 2015 ‘Ambitions for Palliative and End of Life Care’, which emphasised that each person should have ‘fair access to care’.4

We therefore undertook a systematic review of the literature to investigate the characteristics of those who access hospice services, focusing on the evidence concerning the presence and nature of any inequalities. In contrast to a 2015 rapid review focused on the UK literature between 2010 and 2015,5 we undertook a systematic review of the literature from 1987 to 2019 and included studies from the UK, Canada, Australia and New Zealand.

**Aims**

To systematically review and synthesise the peer-reviewed literature concerning referral to or receipt of hospice care with regards to eight characteristics: diagnosis and comorbid conditions; age; gender and sexuality; marital status; ethnicity and religion; geographical factors including rurality and distance to hospice; socioeconomic factors; other characteristics.

**METHODS**

Following an initial scoping search, inclusion and exclusion criteria were clarified and search strategies developed in discussion with the review team’s Information Scientist (IK). Searches were undertaken for papers published between January 1987 (when Palliative Medicine became a recognised medical specialty in the UK) and the end of September 2019 in six databases: Medline, Embase and PsycINFO via OVID; CINAHL via EbscoHOST; ASSIA via Proquest; Web of Science. Additional searches included hand searches of Palliative Medicine and Journal of Palliative Care and reference and citation searches of included papers. Box 1 shows the PubMed search strategy.

**Inclusion and exclusion criteria**

Hospice care was broadly defined to include inpatient units and beds, day therapy, outpatients, hospice at home, community hospice teams, Macmillan and Marie Curie nurses, hospice chaplains and hospice social workers. Studies on deaths in hospice and referral to hospice services were included. Where studies included ‘hospice’ under a broader heading of ‘specialist palliative care’, they were included to ensure comprehensiveness. We restricted studies to those from countries with similar models of hospice care and health service provision: UK, Canada, Australia and New Zealand.

Publications were restricted to peer-reviewed journal papers, published in English and presenting new empirical data. Opinion pieces and editorials were excluded unless they contained original empirical data. Conference abstracts were included unless their data were subsequently published in full. The grey literature was not included. Publications on hospice care for people under 18 years of age were excluded, acknowledging the particular needs of children and young people.
Search results were downloaded into EndNote X9 and duplicates removed. Titles, shortlisted abstracts and full-text articles were independently screened by AR, JT, ST and IW with uncertainty or disagreements resolved by discussion. From the 45,937 records identified, 115 papers met the inclusion criteria. Reference and citation searches of included papers identified a further 13 papers, hand searches yielded a further paper and 1 additional paper was identified from our wider reading. A total of 130 papers were included in the narrative synthesis. Figure 1 presents the PRISMA diagram.

Authors (AR, JT, ST and IW) extracted data independently into a review-specific data extraction form which recorded characteristics of included studies and key findings relevant to the review questions (see online supplemental file 1).

Extracted data were entered into NVivo V.11 for qualitative analysis, with data synthesis using a narrative approach. This was chosen for its applicability to the synthesis of a range of qualitative and quantitative evidence. Three iterative stages were involved: (a) preliminary synthesis of each study from the data extraction forms; (b) study descriptions were grouped together and tabulated based on the review questions addressed and (c) an inductive thematic analysis to identify the main, recurrent and important evidence across the studies in answering the review questions.

Two researchers independently weighted each paper in terms of its strength, quality and contribution towards answering the review questions, using Gough’s ‘Weight of Evidence’ (WoE) criteria with disagreements resolved by discussion (box 2).

RESULTS

A summary of the included studies is presented in online supplemental file 2. Gough’s ‘Weight of Evidence’ for the 130 included papers assessed 49 as high, 54 medium and 27 low WoE.

Inequalities in access have been found in relation to diagnosis (reduced for non-malignant disease including heart failure, respiratory disease, renal and liver failure, mental health, learning disability, dementia and neurodegenerative disease (with the exception of motor neuron disease). The oldest old, people from ethnic minority groups, rural and more socioeconomically deprived area are under-represented in hospice services.

Diagnosis

Cancer versus non-cancer

A large literature of 29 papers, mostly high/medium WoE, evidence greater hospice referrals and/or deaths for patients with cancer compared with patients without cancer. There is evidence of increasing hospice access for people with non-malignant illness in the UK,

Haematological malignancy

Fifteen largely high WoE papers report lower hospice provision for those with haematological malignancies with ORs compared with patients with cancer of around 0.4. Recent years have seen increased deaths in UK hospices among patients with haematological malignancies.
Heart failure

Twelve studies, generally medium/low WoE, evidenced that patients with heart failure are rarely referred to hospice services. Referral rates of patients with heart failure are commonly lower than 5%, and patients with heart failure comprise less than 5% of palliative care clinicians’ workload.

Non-cancer respiratory disease

All 11 papers reported low rates of hospice referral, markedly lower than lung cancer, with some indication of increased referrals between 2006 and 2009. Cystic fibrosis patients are under-represented in hospices despite having significant symptom burden.

Renal failure

Access to hospice care for patients with end-stage renal failure (ESRF) has been studied in the UK and Australia, with evidence of increasing collaboration between renal units and hospice teams in recent years. Hospice referrals are largely for those receiving conservative management for ESRF rather than people receiving renal replacement therapy.

Liver failure

The five medium/low WoE papers concerning patients with liver failure report them to represent less than 1% of hospice patient caseload with referral often occurring late in the course of the illness.

Neurodegenerative Disease

Papers concerning hospice care for patients with dementia, mostly medium WoE, identify that they are rarely referred for hospice care. Referral is more frequent if there is also a cancer diagnosis, or otherwise, it occurs very late in the illness or not at all.

In contrast, patients with motor neuron disease often receive hospice care, with death more common than those with multiple sclerosis or Parkinson’s disease. Patients with multiple sclerosis are more likely to die in hospice if they also have a cancer diagnosis.

Mental health and learning disability

The limited literature of medium/high WoE papers reports patients with schizophrenia rarely access hospice care and people with learning disabilities to be less likely to receive hospice care than the general population.

Age

The extensive and high WoE literature concerning the ‘oldest-old’, people aged 85 years and older, reveals them to be under-represented in hospices across the UK, Australia, New Zealand and Canada. Centenarians seldom die in UK hospices. However, recent evidence suggests that more over 85-year-olds are accessing hospice care in the UK. One low WoE study found age not to affect hospice referral. One study reported the majority of patients accessing a hospice at home service were 78 years of age or older.

Gender and sexuality

The literature concerning gender is inconsistent. Fifteen largely high WoE studies reported that women were more likely to access hospice care than men. However, eight high WoE studies suggested the reverse, and seven high/medium WoE studies reported no differences in access based on gender. No papers were identified concerning LGBTQ+ populations, transgender patients or sexuality of couples.

Marital status

The literature concerning marital status is also inconsistent. While many high and medium WoE studies found married individuals were more likely to access hospice services, other studies (mostly medium WoE) found marital status to be unrelated to hospice access.

Ethnicity and religion

Of the large, mainly high WoE literature concerning ethnicity, the great majority of studies report certain ethnic minority groups to be less likely to receive hospice care than the majority populations in their areas. In contrast, two papers reported some minority groups to be more likely to receive hospice care than their local majority populations. In the UK, reduced access has been reported for a Pakistani/Indian/Bangladeshi groups and Caribbean/Chinese/African groups. Other studies have reported this not to be the case.

In Australia, indigenous populations are less likely to receive hospice care, or if a patient’s informal carer has a non-English speaking background. The New Zealand Maori population is similarly less likely to receive hospice care. No research was identified concerning access to hospice care for travellers and prisoners: one study of homeless people reported limited access.

Geography

Many papers evidenced geographical factors to influence receipt of hospice care, with access closer to hospice and associated services in Australia and Canada. Availability of services also varies considerably between regions and countries, which may act as a barrier to General Practitioner (GP) referral.
Socioeconomic status
Many, mostly high WoE studies reveal lower hospice access for people living in areas of lower socioeconomic status (SES). In the UK between 1993 and 2012, the proportion of hospice inpatients from the most deprived quintile reduced, while the proportion from the most affluent quintile increased. However, several high WoE studies have found no association between SES and access. In fact, some studies report greater access among those from lower SES areas.

Other factors
Further factors identified while reviewing the above literature, but neither searched for systematically nor included in the synthesis included: negative public and professional attitudes towards hospice; limited awareness of hospice services; the challenges of difficult conversations surrounding the term ‘hospice’ and the extent or lack of a patient’s social support networks. There is a web of multicollinearity between these factors and the demographic variables highlighted above.

DISCUSSION
Summary of findings
This review identifies that the literature evidences that certain groups continue to have unequal access to hospice care; the oldest old, ethnic minorities, people with non-cancer illness, those living in rural areas and areas of social deprivation. The literature concerning gender and marital status is inconsistent. The potential factors influencing the findings of this review, and how they might be addressed are explored below.

Strengths and limitations
This major systematic review has brought together the heterogeneous literature concerning access to hospice care up to late 2019. At times it was unclear how authors from different countries were using the term ‘hospice’; broad inclusion criteria for ‘hospice care’ were employed, including inpatient beds, outpatient, day care, community specialist palliative care and hospice-at-home services while seeking to exclude palliative care wards in hospitals, care homes or other long-term care institutions.

Diagnosis, institutional culture and prognosis
Continuing greater access to hospice care of patients with cancer reflects a persistence of the early focus of the hospice movement on cancer care and the final period of life. The more predictable cancer dying trajectory facilitates easier recognition of the final phase of life, better suit time-limited hospice care. The greater prognostic uncertainty for people with chronic chest and heart disease, dementia or frailty of old age inhibits timely end of life care discussions and planning and is a continuing barrier to accessing hospice care. Despite their high symptom burden, the prolonged needs of patients without cancer and difficulties in determining when the terminal stage has been entered, leads to late or no hospice referral.

The fact that hospice care in practice continues to primarily address the needs of patients with cancer has been described as an ‘historical anachronism’. A new model of hospice care is urgently needed in which the historical cancer-appropriate ‘one-size-fits-all’ framework is reorganised to prioritise whichever patients need it the most and to better identify those patients with non-cancer illnesses who would benefit from hospice care. The needs of the growing number of people approaching the end of their lives with multimorbidity and frailty presents a major challenge to health and social care services in general and the hospice movement in particular. Innovative collaborative services, based around patient, family and wider community are needed to ensure optimal care for all.

Unique Nneeds
The end-of-life care needs of some groups may be better met by services other than hospice care. The oldest-old, who are under-represented in hospices, may find their long-term care needs, associated with frailty and dementia are better addressed in a care home setting rather than hospice. Many patients approaching the end of life may neither require nor desire specialist palliative care provision from hospice teams, preferring to continue to receive care from their General Practitioner and Community Nursing Team, with whom they have longstanding trusting relationships. Innovative and collaborative models of working are required; in many cases, hospice teams will have more of an educational role rather than direct care provision.

For some groups, therefore, lower use of hospice services may reflect care preferences and choices rather than inequality of provision. Ethnic minority groups also have particular needs at the end of life, including cultural and family expectations and religious practices around dying. Indigenous Australians focus on maintaining spiritual connection to the land and on receiving culturally tailored care from members of the community. However, for LGBTQ+ groups, concerns over social prejudice may affect access to hospice care in addition to particular care needs.

Greater focus is needed on addressing the needs of minority groups; sensitive involvement of these communities in service codesign is required. ‘Home-like’ hospice services are needed for rural and less affluent patients as well as increased sensitivity towards the needs of LGBTQ+ patients and ethnic minority groups. The growing numbers of people reaching the end of their lives in multimorbid frail old-age is a challenge that hospice services need to address urgently.
Public awareness of hospice care

A third factor involves different levels of public awareness of what hospice care provides and for whom. Variation in health literacy and knowledge of health services is present across ethnic minorities and socio-economic groups. The greater access to hospice care by people in more affluent groups may in part reflect their greater health literacy and the presence of articulate relatives who can advocate for hospice services they know to be available.

Similarly, the concentration of hospices in metropolitan areas limits rural patients’ exposure to and knowledge of hospice care. Travelling times further into urban areas exacerbates these problems. Equity of access for all remains a challenge for the hospice movement. System leaders, health and social care managers, policy makers and commissioners need to recognise and understand that while hospices have a vital contribution to palliative and end of life care provision, meeting patient and family needs requires a collaborative and innovative whole-systems approach.

Future research

This review has highlighted a number of areas in which the current literature is absent or very limited, including optimal ways to support ethnic minority groups, homeless people, LGBTQ+ populations, HIV, diabetes and cystic fibrosis.

CONCLUSION

This systematic literature review highlights the persisting unequal access to hospice services for many groups: people with non-malignant disease, the oldest-old, ethnic minorities, living in rural and socio-economically deprived areas, are consistently reported to be referred to or to die in hospice less frequently. A combination of prognostic uncertainty, institutional cultures, unique needs of particular groups and a lack of public awareness of services exacerbate these problems. Equity of access for all is urgently needed, with innovative and collaborative services developed to meet the diverse needs of the whole community.

Equity of access for all remains a challenge for the hospice movement.

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Contributors JT, ST, IK and SB contributed to study design. IK conducted the database searches. JT, ST, AR, AK and IW contributed to screening of titles and abstracts and data extraction. All the authors contributed to the synthesis and have approved the paper.

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Systematic review


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Supplementary File. Data extraction form.

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# Key findings relevant to review

1. Diagnosis

2. Age

3. Gender

4. Marital status, sexuality.

5. Ethnicity & religion

6. Geographical: rurality, distance to hospice, etc

7. Socioeconomic

8. Learning disability

9. Comorbid conditions: dementia, etc

10.

11.

## Author(s) conclusion(s)

## References of interest

## Reviewer's quality assessment (Gough's Weight of Evidence)

**Weight of Evidence A**
- Coherence and integrity of the evidence *in its own terms*

**Weight of Evidence B**
- Appropriateness of *form of evidence* for answering review question

**Weight of Evidence C**
- Relevance of the evidence for answering review question

**Weight of Evidence D**
- Overall assessment of study contribution to answering review question
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<th>Death or referral</th>
<th>Key findings</th>
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<tr>
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<td>What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large UK city.</td>
<td>BMJ Open. 2016; 6: e012576</td>
<td>4650 referrals made to three SPC units (one HPC and two CPCs) in Leeds (UK) from April 2012 to March 2014.</td>
<td>Referral</td>
<td>Referral to specialist palliative care services was more likely for those with cancer, those aged &lt;85 years old and males.</td>
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<td>11. Buck 2018</td>
<td>Persistent inequalities in Hospice at Home provision.</td>
<td>BMJ Supportive &amp; Palliative Care. 2018 10: e23</td>
<td>321 patients accepted for care by the Cambridgeshire (UK) Hospice at Home service.</td>
<td>Referral</td>
<td>Those with cancer, high socio-economic status, males, aged 78 or older were more likely to access hospice at home. Those with non-malignant disease and who lived in less affluent or rural areas were less likely to access hospice at home.</td>
<td>MHH = M</td>
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<td>18. Gilbert 2010</td>
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<td>Palliative Medicine. 2010; 1: 5176.</td>
<td>3723 patients admitted to four hospice palliative care units in Canada between 2002 and 2009.</td>
<td>Death</td>
<td>There was an increase in non-cancer patient admissions to hospice units.</td>
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<td>21. Grande 2006</td>
<td>The influence of patient and carer age in access to palliative care services.</td>
<td>Age and Ageing. 2006; 35: 267-273.</td>
<td>123 patients referred to a UK hospice at home service whose primary carer could be interviewed.</td>
<td>Death</td>
<td>Patients who received inpatient hospice care tended to be younger, female, and have cancer.</td>
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<td>22. Harrison 2012</td>
<td>Are UK primary care teams formally identifying patients for palliative care before they die?</td>
<td>British Journal of General Practice. 2012; 62(598): e344-e342</td>
<td>201 patients from 6 GP surgeries in Scotland listed as palliative on records.</td>
<td>Death</td>
<td>Hospice death was more likely amongst cancer patients compared to patients with dementia and organ failure.</td>
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<td>Currow 2004</td>
<td>Specialist palliative care needs of whole populations: a feasibility study using a novel approach. Palliative Medicine. 2004; 18(3): 239-47. 3027 randomly selected South Australians. Referral of People with a cancer diagnosis were more likely to access specialised palliative care services. Those with an income above AU$560,000 per year were more likely to report the use of palliative care services.</td>
<td>HHM = H</td>
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</tr>
<tr>
<td>36. Kelly 2018</td>
<td>The dementia patient’s pathway through the Specialist Palliative Care services Part I.</td>
<td>European Journal of Palliative Care. 2018; 25(1): 37-39.</td>
<td>409 Referrals to an SPC service during 2012.</td>
<td>Referral</td>
<td>42% of referrals had a non-malignant diagnosis and 58% had a malignant diagnosis; 15% met the inclusion criteria of having been referred with a primary diagnosis of dementia (7%) or having a comorbidity of a diagnosis of dementia (8%); 44% were aged 80–89 years.</td>
<td>LML = L</td>
</tr>
<tr>
<td>37. Verne 2013</td>
<td>Increasing numbers of colorectal cancer patients are dying at home or in care homes in England over the past decade</td>
<td>Colorectal Disease. 2013; 15: 102.</td>
<td>Mortality records for England (UK collected by ONS between 2002 and 2011 (N = not known).</td>
<td>Death</td>
<td>The total number of deaths from colorectal cancer in hospices remained stable between 2002 and 2011. Deaths in hospice for colon and rectal cancers were younger than 65.</td>
<td>LLL = L</td>
</tr>
<tr>
<td>38. Addington-Hall 2000</td>
<td>Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses?</td>
<td>Journal of Advanced Nursing. 2000; 32(4): 799-806</td>
<td>2074 cancer decedents in last quarter of 1990 in 20 self-selected English districts.</td>
<td>Death</td>
<td>Patients who had haematological malignancies, who were aged over 75 or who were not married were less likely to receive specialist palliative nursing care.</td>
<td>HML = M</td>
</tr>
<tr>
<td>41. Gatrell 2003</td>
<td>Place of death: analysis of cancer deaths in part of North West England.</td>
<td>Journal of Public Health Medicine. 2003; 25(1): 53-55.</td>
<td>6900 deaths within the 89 electoral wards of the Morecambe Bay area (UK) between 1993 and 2000.</td>
<td>Death</td>
<td>Patients with cancer of the lymphatic system were less likely to die in hospice. Patients in wards close to the hospice were more likely to die in a hospice.</td>
<td>HMM = M</td>
</tr>
<tr>
<td>42. Howell 2013</td>
<td>Place of death in haematological malignancy: variations by disease subtype and time from diagnosis to death.</td>
<td>BMC Palliative Care. 2013; 12: 42.</td>
<td>4839 patients dying of haematological malignancies in the UK who had been diagnosed between 2004 and 2010.</td>
<td>Referral</td>
<td>7.5% of patients died in a hospice and this percentage differed amongst different haematological malignancies.</td>
<td>HHM = H</td>
</tr>
<tr>
<td>43. Howell 2015</td>
<td>Variations in specialist palliative care referrals: findings from a population-based patient cohort of acute myeloid leukaemia, diffuse large B-cell lymphoma and myeloma.</td>
<td>BMJ Supportive and Palliative Care. 2015; 5: 496-502.</td>
<td>323 patients dying of haematological malignancies in the UK who had been diagnosed between 2005 and 2008.</td>
<td>Death</td>
<td>There was a difference in referral rates to SPC services between different haematological malignancies.</td>
<td>HHM = H</td>
</tr>
<tr>
<td>46. Hunt 2001</td>
<td>Where patients with cancer die in South Australia, 1990-1999: a population-based review.</td>
<td>The Medical Journal of Australia. 2001; 175(10): 426-9.</td>
<td>29230 cancer decedents in South Australia between 1990 and 1999.</td>
<td>Death</td>
<td>Patients who were most likely to die in a hospice included females, those aged 70-79, and those from higher socioeconomic groups. Patients who were least likely to die in a hospice included those with haematological malignancies, and those with Aboriginal or Asian ethnicity.</td>
<td>HHH = H</td>
</tr>
<tr>
<td>47. Hunt 2019</td>
<td>Where patients with cancer die: a population-based study, 1990 to 2012.</td>
<td>Journal of Palliative Care. 2019; 34(4): 224-31.</td>
<td>Registry records of 86, 257 patients with cancer who died from 1990 to 2012.</td>
<td>Referral</td>
<td>Cancer patients were more likely to die in hospice if they were young and had a high socioeconomic status. Older patients and those with lower socioeconomic status were less likely to die in hospice.</td>
<td>HMM = M</td>
</tr>
</tbody>
</table>
with primary cancers of breast, prostate, head and neck and melanoma had lower odds of dying in hospice. Asian and Aboriginal and Torres Strait Islander people were less likely than Caucasians to receive in-hospice care.

Identifying potential need for cancer palliation in Nova Scotia.
All adults (n = 14,494) who had died of cancer from 1988 to 1994 in Nova Scotia. Death Elderly patients, as well as those with a haematological malignancy, were less likely to be referred to palliative care services. HHH = H

49. Vidrine 2016
Place of death in patients with haematological malignancy in North-East of England: Where does this happen and what factors may influence this?
British Journal of Haematology. 2016; 173 S1: 33
Case note audit of 39 haematological cancer decedents under the care of a cancer centre in Newcastle-upon-Tyne (UK) between March and August 2015. Death Only two patients (6.5%) with a haematological malignancy died in a hospice. LLL = L

50. Campbell 2014
Discrepancy between preferred and actual place of death in patients with acute heart failure.
114 patients with acute heart failure recruited between January 2013 and August 2013 in Glasgow (UK). Death 5% of patients with heart failure died in a hospice. MLL = L

51. Cheang 2015
Current challenges in palliative care provision for heart failure in the UK: a survey on the perspectives of palliative care professionals.
Open Heart. 2015; 2(1): e000188.
Survey of 499 medical professionals working in palliative care in the UK between June and December 2013. The average heart failure burden was 3% of the total palliative care workload. HHM = H

52. French 2011
Where do elderly patients with heart failure die?
494 heart failure decedents who had been referred to a heart failure service at Sunderland Royal Hospital (UK) between 2001 and 2007. Death 0.9% of the cohort died in a hospice. LLM = L

53. Gibbs 2006
Palliative Medicine. 2006; 20: 603-609.
Survey of 233 consultants of English SPC services. Death Each service had a mean number of 0.8 patients with heart failure. LLL = L

54. Horne 2004
Removing the boundaries: palliative care for patients with heart failure.
Interview of 20 patients in Doncaster (UK) who had a clinical diagnosis of heart failure between October 2001 and March 2002. Death None of the patients had been referred to SPC services. MLL = L

55. Chen 2017
General Practitioner Perceptions of Current Services for Heart Failure Patients: A Qualitative Study.
Interviews with 20 GPs in Northern Ireland (UK), conducted between June and August 2016. Referral GPs reported poor awareness of the role of SPC services in heart failure. LLL = L

56. Jones 1995
Palliative care in terminal cardiac failure.
British Medical Journal. 1995; 310: 805
Survey of 10 hospices in North-East London and Essex (UK). Referral Four of the surveyed hospices would consider admitting patients with a primary diagnosis of end stage cardiac failure, only two of these had admitted patients with this condition in the past year. However, this was matched by few requests for palliative care beds for patients with heart failure. LMM = M

57. Kaul 2016
Home, hospital or hospice? Trends and predictors of location of death among patients with heart failure and acute coronary syndromes.
All patients discharged alive from hospitalization with a primary diagnosis of HF (n=31,274) or ACS (n=54,886) in Alberta Canada between April 2002 and March 2014. Death Less than 2% of patients with HF or ACS died in a hospice, and these rates have not changed over time. LLM = L

58. McKinley 2004
Care of people dying with malignant and cardiorespiratory disease in general practice.
154 decedents with malignant or cardiorespiratory disease from two Leicestershire (UK) general practices between August 2000 and July 2002. Death 18% of the cancer decedents died in a hospice compared to 0% of those with cardiorespiratory disease. HML = M

59. Murray 2002
Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community.
Interview and focus groups of 20 outpatients with inoperable lung cancer and 20 patients with advanced cardiac failure and their main informal and professional carers in Edinburgh (UK). Referral Specialist palliative care and hospice referral was more likely for lung cancer patients than heart failure patients. MMH = M
<table>
<thead>
<tr>
<th>Reference</th>
<th>Title</th>
<th>Journal</th>
<th>Year</th>
<th>Results/Findings</th>
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<tr>
<td>Year</td>
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<td>2013</td>
<td>Hussain et al.</td>
<td>Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease. Palliative Medicine. 2013; 27(9): 829-839. 441 patients located within West Yorkshire (UK) who were referred for pre-diagnosis care. Death: Patients in the conservative management group had greater access to specialist palliative care services compared to those who underwent renal replacement therapy. MHH = H</td>
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<tr>
<td>2017</td>
<td>Lovell et al.</td>
<td>Understanding patterns and factors associated with place of death in patients with end-stage kidney disease: A retrospective cohort study. Palliative Medicine. 2017; 31(3): 283-288. Patients (n =321) with chronic kidney disease stage 4-5 aged 75 and above known to one UK renal team between 2006-2012. Death: Place of death varied according to management pathway: patients who had conservative management were much less likely to die in a hospice than those receiving renal replacement therapy. HMM = M</td>
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<tr>
<td>2016</td>
<td>Bablitz et al.</td>
<td>High CAGE score and late referral pattern typify end-stage liver failure patients referred to a regional palliative care program. Journal of Pain and Symptom Management. 2016; 52(6): e111. 265 decedents with cirrhosis evaluated for liver transplantation at the University of Alberta Hospital (Canada) between January 2000 and December 2013. Referral: 22% patients were referred to regional SPC services. LML = L</td>
<td></td>
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<tr>
<td>2016</td>
<td>Low et al.</td>
<td>Palliative Care for Cirrhosis: a UK survey of health professionals’ perceptions, current practice and future needs. Frontline Gastroenterology. 2016; 7: 4-9. Questionnaire of 517 UK health care professionals working in hepatology teams, specialist palliative care and general practitioners with an interest in gastroenterology. Death: Patients with cirrhosis made up 1% of the specialist palliative care workload. Referrals made by hepatology professionals to specialist palliative care were low. MMM = M</td>
<td></td>
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<tr>
<td>2017</td>
<td>Low et al.</td>
<td>Advanced chronic liver disease in the last year of life: a mixed methods study to understand how care in a specialist liver unit could be improved. BMJ Open. 2017; 7(8): e016887. Interview and focus group of 30 patients with liver cirrhosis who attended a tertiary referral liver transplant centre in North London (UK) and died between April 2010 and September 2011. Death: Only 7% of the patients died in a hospice. HLL = L</td>
<td></td>
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</tr>
<tr>
<td>2014</td>
<td>Poonja et al.</td>
<td>Patients with cirrhosis and denied liver transplants rarely receive adequate palliative care or appropriate management. Clinical Gastroenterology and Hepatology. 2014; 12: 692-698. 102 patients with cirrhosis in Edmonton, Canada who were delisted or declined liver transplant from January 2005 to December 2010. Referral: Only 11 patients were referred for palliative care, and four died in a hospice, despite a large need for palliative care services. MMM = M</td>
<td></td>
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<tr>
<td>2010</td>
<td>Houttekier et al.</td>
<td>Place of death of older persons with dementia. A study in five European countries. Journal of American Geriatric Society. 2010; 58(4): 751. 30,281 dementia patients across five European countries (England, Wales, Scotland, Belgium, the Netherlands) in 2003. Referral: Patients with dementia were referred to SPC less frequently, and often late in the course of the disease, explaining why so few died in a hospice. HML = M</td>
<td></td>
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<tr>
<td>2013</td>
<td>Zheng et al.</td>
<td>How good is primary care at identifying patients who need palliative care? A mixed methods study. European Journal of Palliative Care. 2013; 20(5): 216-222. Case note review of nine Scottish (UK) GP practices over a 12 month period, comprising the notes of 684 patients. Referral: Palliative care was often initiated too late, and perceived as being appropriate only for patients who appeared to be reaching a terminal decline. Dementia patients had difficulties in accessing specialist palliative care. HHH = H</td>
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<td>Reference</td>
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<tr>
<td>87. Sleeman 2013</td>
<td>Place of death, and its relation with underlying cause of death, in Parkinson’s disease, motor neurone and multiple sclerosis: A population-based study.</td>
<td>Sleeman</td>
<td>2013</td>
<td>Palliative Medicine.</td>
</tr>
<tr>
<td>89. Chochinov 2012</td>
<td>Comparative health care use patterns of people with schizophrenia near the end of life: a population-based study in Manitoba, Canada.</td>
<td>Chochinov</td>
<td>2012</td>
<td>Schizophrenia Research.</td>
</tr>
<tr>
<td>90. Butler 2018</td>
<td>Access to specialist palliative care services by people with severe and persistent mental illness: A retrospective cohort study.</td>
<td>Butler</td>
<td>2018</td>
<td>International Journal of Mental Health Nursing.</td>
</tr>
</tbody>
</table>
Factors associated with utilisation of specialist palliative care services: a population based study.
521 patients who had died in a Northern England Health District in 1991.
Referral  
There was no variation in specialist palliative care provision according to gender, location, socioeconomic status or cancer site. Those who received specialist palliative care were younger compared to those who did not.
HMH = H

100. Kessler 2005  
Social class and access to specialist palliative care services.
Survey and interview of 960 cancer decedents and 18 carers of these patients in Bristol (UK) between September 1999 and November 2002.
Death  
Those from a lower social class were less likely to die in a hospice.
HHH = H

101. Lock 2005  
Patterns and predictors of place of cancer death for the oldest old.
All cancer deaths (n =314,462) in England and Wales in those aged 75 and upwards between 1995 and 1999.
Death  
The proportion of people who died in a hospice increased between 1995 and 1999. There were marked differences between the 'younger old' and the 'oldest old', with the 'oldest old' less likely to die in a hospice.
HHM = H

102. McNamara 2007b  
Specialist palliative care use for people dying of cancer in Western Australia.
8007 decedents in Western Australia between July 2000 and December 2002.
Death  
Patients who were single or widowed; those aged over 85 years old; and those living in a region other than a major city were significantly less likely to receive specialist palliative care services.
HHH = H

103. O'Dowd 2016  
Place of Death in Patients with Lung Cancer: A Retrospective Cohort Study from 2004-2013.
143,627 patients registered with the National (UK) Lung Cancer Audit between January 2004 and December 2011.
Referral  
There was a small increase in patients dying within hospice beds. Factors associated with hospice death included younger age and higher Townsend quintile. There were regional inequalities in hospice provision.
HHM = H

104. Ziegler 2018  
Age Variation in the Care from Diagnosis to Death for Cancer Patients: A Retrospective Longitudinal Study in a UK Cancer Population.
Palliative Medicine. 2018; 32 S1: 3-330.
Retrospective cohort study linking cancer registry and secondary care data for 13,499 adult cancer patients who died between January 2005 and December 2011.
Referral  
Compared with adult patients under 60 years, patients aged 80 years and over were less likely to die in a hospice, but more likely to die in a care home.
MMM = M

105. Verne 2018a  
What Does National Mortality Data Tell Us about Where Head and Neck Cancer Patients Die and What Influences This?
Palliative Medicine. 2018; 32 S1: 3-330.
Office for National Statistics (ONS) Mortality Dataset.
Referral  
Younger patients more likely to die at home (28%) or in hospice (<65 years 25%), and older in care homes.
MHL = M

106. Kamisetty 2015  
1290 patients treated for primary squamous cell carcinomas at the Maxillofacial Unit in Liverpool (UK) between 1992 and 2011.
Referral  
Patients treated for oral cancer were more likely to die at a hospice in 2011 than in the past. Those who were 85+ and those without cancer as underlying cause of death died in hospice less.
HMM = M

107. Burt 2010b  
Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients.
Questionnaire involving 252 patients with either non-small cell lung cancer or small cell lung cancer, and 137 carers attending chest or oncology outpatient clinics at four NHS trusts in south London (UK) between June 2006 and April 2007.
Referral  
39% of participants had confirmed use of SPC. Age, gender, deprivation, living alone, current or most recent line of treatment, number of co-morbidities and carer stress were not associated with receipt of such services.
MMM = M

108. Kamisetty 2011  
Place of death of oral and oropharyngeal squamous cell carcinoma (OOSCC) patients 1992–2009: who dies at home?
1392 newly diagnosed patients with OOSCC presenting to the Maxillofacial Unit in Liverpool (UK) between 1992 and 2009.
Referral  
78 out of 541 deaths took place in a hospice.
MLM = M

109. Bradshaw 1993  
Characteristics of clients referred to home, hospice and hospital palliative care services in Western Australia.
60 records of patients who had died in a six-month period in three SPC settings – hospice care service, cottage hospice and a palliative care unit within a general hospital in Perth (Australia).
Death  
Older age, female gender and not having a primary caregiver were associated with a reduced likelihood of receiving care from hospice services.
MMM = M
<table>
<thead>
<tr>
<th>Reference</th>
<th>Title</th>
<th>Description</th>
<th>Region/Country</th>
<th>Ethnicity</th>
<th>Findings</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Davison 2001</td>
<td>Where do patients with cancer die in Belfast?</td>
<td>Referral patterns and predictors of place of death.</td>
<td>Belfast (UK)</td>
<td>Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor’s referral patterns.</td>
<td>There was an association between place of death and age, marital status, type of cancer and area of residence, but not with social class or gender. Changes over time were reported.</td>
<td>M</td>
</tr>
<tr>
<td>Gaffin 1996</td>
<td>Opening doors: improving access to hospice and specialist palliative care services by members of the black and minority ethnicity communities.</td>
<td>British Journal of Cancer. 1996; 29: 551-53. Study of hospice services in two London boroughs (Brent and Newham) and in North Birmingham (UK).</td>
<td>London (UK)</td>
<td>Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor’s referral patterns.</td>
<td>Hospices tend to be located in white, middle class areas. People from minority communities were less likely to ask their GP for access to hospice services.</td>
<td>L</td>
</tr>
<tr>
<td>Karim 2000</td>
<td>Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor’s referral patterns.</td>
<td>Palliative Medicine. 2000; 14: 471-478. Interview of 27 GPs from two wards in Birmingham (UK).</td>
<td>Birmingham (UK)</td>
<td>Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor’s referral patterns.</td>
<td>Language and staff bias were barriers to the referral of black/ethnic minority patients to specialist palliative care services.</td>
<td>M</td>
</tr>
<tr>
<td>Fountain 1999</td>
<td>Ethnic minorities and palliative care in Derby.</td>
<td>Palliative Medicine. 1999; 13: 161-162. 1035 new referrals to Derby (UK) SPC services.</td>
<td>Derby (UK)</td>
<td>Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor’s referral patterns.</td>
<td>Ethnic minorities were slightly more likely than white patients to receive certain SPC services.</td>
<td>M</td>
</tr>
<tr>
<td>Sharpe 2015</td>
<td>Policy for home or hospice as the preferred place of death from cancer: Scottish Health and Ethnicity Linkage Study population cohort shows challenges across all ethnic groups in Scotland.</td>
<td>BMJ Supportive and Palliative Care. 2015; 5: 443-451. All cancer patients (n=117,467) aged 25 years or older who participated in the 2001 Scottish census and died from cancer in Scotland between May 2001 and December 2009.</td>
<td>Scotland (UK)</td>
<td>Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor’s referral patterns.</td>
<td>The Chinese cohort had the largest proportion of hospice cancer deaths (29.9%).</td>
<td>H</td>
</tr>
<tr>
<td>Waran 2017</td>
<td>The gap reversed: a review of site of death in the Top End.</td>
<td>The Medical Journal of Australia. 2017; 5(207) S1: 39. 308 people, most were men, and most were indigenous Australians.</td>
<td>Australia</td>
<td>Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor’s referral patterns.</td>
<td>Indigenous people died in hospices much less frequently compared to non-indigenous people.</td>
<td>L</td>
</tr>
<tr>
<td>Currow 2012</td>
<td>Referral patterns and proximity to palliative care inpatient services by level.</td>
<td>BMC Health Services Research. 2012; 12: 424. Service mapping of 10,064 patients documented in the Palliative Care Death in a hospice was significantly less likely among those born in Asia and Africa.</td>
<td>England (UK)</td>
<td>Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor’s referral patterns.</td>
<td>People from the most disadvantaged socio-economic group were less likely to be referred to SPC services.</td>
<td>H</td>
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<tr>
<td>Year</td>
<td>Study</td>
<td>Outcomes Collaboration (PCOC) in Australia in 2006:</td>
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<td>2011</td>
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<td>127 participants, made up of: single homeless people (n=28), formerly homeless people (n=10), health- and social-care providers (n=48), hostel staff (n=30) and outreach staff (n=10).</td>
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<tr>
<td>1992</td>
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<td>Accessing hospice services is challenging for homeless people because of stigma, complex multi-morbidities and trauma, substance misuse/dependence, mental health problems, unstable housing conditions, previous experiences that hospices had with supporting homeless people and many more. Even for homeless cancer patients who were not misusing substances, placement within a hospice remained challenging.</td>
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<tr>
<th>Year</th>
<th>Study</th>
<th>Data</th>
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<tbody>
<tr>
<td>2010</td>
<td>O’Dowd</td>
<td>143,627 patients registered with the National (UK) Lung Cancer Audit between January 2004 and December 2011.</td>
</tr>
<tr>
<td>1999</td>
<td>Seaman</td>
<td>Questionnaires sent to health practitioners in Exeter Health District (UK) regarding cancer deaths (n = 1053) between May 1991 to April 1992.</td>
</tr>
<tr>
<td>2010</td>
<td>Campbell</td>
<td>Patients from socially deprived areas have higher SPC needs but lower referral rates.</td>
</tr>
<tr>
<td>2011</td>
<td>Cunningham</td>
<td>58,820 decedents aged 65 and older in British Columbia (Canada) between 2004 and 2006.</td>
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</table>

**Deaths:**
- Accessing hospice services is challenging for homeless people because of stigma, complex multi-morbidities and trauma, substance misuse/dependence, mental health problems, unstable housing conditions, previous experiences that hospices had with supporting homeless people and many more.
- Even for homeless cancer patients who were not misusing substances, placement within a hospice remained challenging.
- Lower income was associated with a decreased likelihood of using SPC services.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Title</th>
<th>Methodology</th>
<th>Results</th>
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<tbody>
<tr>
<td>Sims 1997</td>
<td>Social class variation in place of cancer death.</td>
<td>Palliative Medicine. 1997; 11: 369-373. 831 cancer decedents in Doncaster (UK) in 1996.</td>
<td>Referral Patients from higher social classes were more likely to die in a hospice.</td>
</tr>
<tr>
<td>Macfarlane 2016</td>
<td>Does place of death vary by deprivation for patients known to specialist palliative care services?</td>
<td>BMJ Supportive &amp; Palliative Care. 2018; 8(4): 428-30. Place of death and postcode for 485 consecutive patients known to Specialist palliative care services within NHS Lothian (UK), who died in 2014-2015.</td>
<td>Referral Higher rates of in-hospice death for the least deprived, compared to the most deprived. Greater deprivation is associated with decreased likelihood of dying in hospice. Even after referral to SPC services, these discrepancies persist.</td>
</tr>
<tr>
<td>Bowers 2018</td>
<td>Socioeconomic status is associated with place of death in patients known to hospice services.</td>
<td>Scottish Medical Journal. 2018; 63(1): 53-53. 4585 patient deaths.</td>
<td>Death As affluence increases percentage likelihood of dying in hospice increases. Deaths in hospice were most frequent in the least deprived quintile and least frequent in the three most deprived quintiles.</td>
</tr>
</tbody>
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