Hospice care access inequalities: a systematic review and narrative synthesis

Jake Tobin,1 Alice Rogers,1 Isaac Winterburn,2 Sebastian Tullie,1 Asanish Kalyanasundaram,1 Isla Kuhn,3 Stephen Barclay 2

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.

Objective To identify from the literature the demographic characteristics of those who access hospice care more often, focusing on: diagnosis, age, gender, marital status, ethnicity, geography and socioeconomic status.

Design Systematic literature review and narrative synthesis.

Method Searches of Medline, PsycINFO, CINAHL, Web of Science, Assia and Embase databases from January 1987 to end September 2019 were conducted. Inclusion criteria were peer-reviewed studies of adult patients in the UK, Australia, New Zealand and Canada, receiving inpatient, day, outpatient and community hospice care. Of the 45937 titles retrieved, 130 met the inclusion criteria. Narrative synthesis of extracted data was conducted.

Results An extensive literature search demonstrates persistent inequalities in hospice care provision: patients without cancer, the oldest old, ethnic minorities and those living in rural or deprived areas are under-represented in hospice populations. The effect of gender and marital status is inconsistent. There is a limited literature concerning hospice service access for the LGBT+ and homeless populations. People 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 out-patient 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. 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, 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. 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’. 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’.

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, 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.

**Box 1 PubMed search strategy**

\[
⇒ \text{("Ethnic\textit{I} ethnic Groups","(Mesh)\textit{I}) OR ethnic differences OR racial differences OR poverty OR deprivation OR ethnicity OR culture OR minority OR marital status OR socioeconomic OR age factors OR intellectual disabilities OR rural OR urban OR demographic variation OR location OR sexuality OR nationality OR wealth OR gender OR cancer OR heart failure OR COPD OR Chronic-obstructive pulmonary disease OR emphysema OR dementia OR Alzheimer’s OR neurological OR multiple sclerosis OR motor neuron disease OR motor neuron disease OR cystic fibrosis OR haematological) AND
⇒ \text{(specialist palliative care OR hospice OR "Hospice Care" (Mesh) OR "Hospices" (Mesh) OR "Hospice and Palliative Care Nursing" (Mesh))}
\]

**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, Canada and Australia.

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.\textsuperscript{50-61} Referral rates of patients with heart failure are commonly lower than 5%.\textsuperscript{50 52 54 57 58} and patients with heart failure comprise less than 5% of palliative care clinicians’ workload.\textsuperscript{51}

Non-cancer respiratory disease
All 11 papers reported low rates of hospice referral.\textsuperscript{34 62-71} markedly lower than lung cancer, with some indication of increased referrals between 2006 and 2008.\textsuperscript{67} Cystic fibrosis patients are under-represented in hospices despite having significant symptom burden.\textsuperscript{62}

Renal failure
Access to hospice care for patients with end-stage renal failure (ESRF) has been studied in the UK\textsuperscript{34 74-76} and Australia\textsuperscript{77} with evidence of increasing collaboration between renal units and hospice teams in recent years.\textsuperscript{72 73} Hospice referrals are largely for those receiving conservative management for ESRF rather than people receiving renal replacement therapy.\textsuperscript{74 75 77}

Liver failure
The five medium/low WoE papers concerning patients with liver failure\textsuperscript{34 78-81} report them to represent less than 1% of hospice patient caseload\textsuperscript{79} with referral often occurring late in the course of the illness.\textsuperscript{34 78 79}

Neurodegenerative Disease
Papers concerning hospice care for patients with dementia, mostly medium WoE, identify that they are rarely referred for hospice care.\textsuperscript{34 36 82-84} Referral is more frequent if there is also a cancer diagnosis,\textsuperscript{82} otherwise, it occurs very late in the illness\textsuperscript{83} or not at all.

In contrast, patients with motor neuron disease often receive hospice care,\textsuperscript{34 85 86} with hospice death more common than those with multiple sclerosis or Parkinson’s disease.\textsuperscript{87} Patients with multiple sclerosis are more likely to die in hospice if they also have a cancer diagnosis.\textsuperscript{88}

Mental health and learning disability
The limited literature of medium/high WoE papers reports patients with schizophrenia rarely access hospice care\textsuperscript{89 90} and people with learning disabilities to be less likely to receive hospice care than the general population.\textsuperscript{30 90}

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.\textsuperscript{10 11 15 16 23 25 27-34 36-38 45 47 48 91-106} Centenarians seldom die in UK hospices.\textsuperscript{97 98} However, recent evidence suggests that more over 85-year-olds are accessing hospice care in the UK.\textsuperscript{11 16 31} One low WoE study found age not to affect hospice referral.\textsuperscript{107} One study reported the majority of patients accessing a hospice at home service were 78 years of age or older.\textsuperscript{11}

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.\textsuperscript{15 16 24 26-29 32 34 38 46 92 108} However, eight high WoE studies suggested the reverse,\textsuperscript{10 11 25 31 102 109 110} and seven high/medium WoE studies reported no differences in access based on gender.\textsuperscript{145 48 91 99 107 111 112} 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,\textsuperscript{16 24 27-29 31-33 38 102} other studies (mostly medium WoE) found marital status to be unrelated to hospice access.\textsuperscript{91 97 107 108 111}

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.\textsuperscript{13 24 25 29 33 46 93 102 113-118} In contrast, two papers reported some minority groups to be more likely to receive hospice care than their local majority populations.\textsuperscript{119 120}

In the UK, reduced access has been reported for a Pakistani/Indian/Bangladeshi groups,\textsuperscript{113} and Caribbean/Chinese/African groups.\textsuperscript{116} Other studies have reported this not to be the case.\textsuperscript{34 120 121}

In Australia, indigenous populations are less likely to receive hospice care,\textsuperscript{25 29 46 47 102 122} or if a patient’s informal carer has a non-English speaking background.\textsuperscript{13 123} The New Zealand Maori population is similarly less likely to receive hospice care.\textsuperscript{33}

No research was identified concerning access to hospice care for travellers and prisoners: one study of homeless people reported limited access.\textsuperscript{124}

Geography
Many papers evidenced geographical factors to influence receipt of hospice care.\textsuperscript{15 16 111 123} Access is greater for those living in urban areas, with closer proximity to a hospice and associated services in Australia,\textsuperscript{23 28 29 44 45 102 123 125 126} Canada,\textsuperscript{15 82 93} and the UK.\textsuperscript{11 34 41 110 127-129} Availability of services also varies considerably between regions and countries,\textsuperscript{11 34 41 103 110 127-130} which may act as a barrier to General Practitioner (GP) referral.\textsuperscript{131}
Socioeconomic status

Many, mostly high WoE studies reveal lower hospice access for people living in areas of lower socioeconomic status (SES).\textsuperscript{11} 13 16 31 32 45–47 93 100 102 120 123 127 128 132–137

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.\textsuperscript{31} However, several high WoE studies have found no association between SES and access.\textsuperscript{28} 29 38 91 94 96 99 107 108 111 138 In fact, some studies report greater access among those from lower SES areas.\textsuperscript{41, 103}

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;\textsuperscript{139–142} limited awareness of hospice services;\textsuperscript{139–141} 143–146 the challenges of difficult conversations surrounding the term ‘hospice’;\textsuperscript{139, 140} and the extent or lack of a patient’s social support networks.\textsuperscript{13} 143 147 148 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\textsuperscript{149, 150} facilitates easier recognition of the final phase of life, better suiting 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,\textsuperscript{9} 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.\textsuperscript{146, 151}

The fact that hospice care in practice continues to primarily address the needs of patients with cancer has been described as an ‘historical anachronism’.\textsuperscript{152} A new model of hospice care is urgently needed in which the historical cancer-appropriate ‘one-size-fits-all’ framework\textsuperscript{153} is reorganised to prioritise whichever patients need it the most\textsuperscript{152} and to better identify those patients with non-cancer illnesses who would benefit from hospice care.\textsuperscript{154} 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 Needs

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.\textsuperscript{155} 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.\textsuperscript{121} Indigenous Australians focus on maintaining spiritual connection to the land and on receiving culturally tailored care from members of the community.\textsuperscript{156, 157} However, for LGBTQ+ groups, concerns over social prejudice may affect access to hospice care in addition to particular care needs.\textsuperscript{158–160}

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.\textsuperscript{161}
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 exacerbate impaired access, alongside lack of transport links for relatives.

Hospices need to improve their links with the diverse social and cultural groups in the areas they serve, focusing on enhancing their awareness of available hospice services. Particular focus is needed on reaching out beyond affluent metropolitan areas into deprived and rural populations, supported by telehealth and video consultations.

The inequalities highlighted in this review are not just the responsibility of 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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### Supplementary File. Data extraction form.

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### Introduction

- Aim(s)
- Research questions / hypotheses

### Study participants

- Target population
- Inclusion criteria
- Exclusion criteria
- Recruitment
- Characteristics of participants:
  - Total n
  - age
  - sex
  - social class
  - ethnicity
  - geographical location
  - other information

### Methods

- Date of fieldwork
- Research methods / tools used

### Analysis

- Quantitative analysis
- Qualitative analysis
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<td>5. Ethnicity &amp; religion</td>
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<td>6. Geographical: rurality, distance to hospice, etc</td>
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<td>7 Socioeconomic</td>
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<td>8. Learning disability</td>
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<td>9. Comorbid conditions: dementia, etc</td>
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**Author(s) conclusion(s)**

**References of interest**

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

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<td>10. Bennett 2016</td>
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<td>18. Gilbert 2010</td>
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<td>21. Grande 2006</td>
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<td>22. Harrison 2012</td>
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23. Hunt 1996  
A population-based study of the coverage of cancer patients by hospice services.  
2800 cancer decedents in South Australia in 1990.  
Referral  
Patients that missed out on hospice services included the elderly, those with a haematological malignancy, and rural residents.  
HHH = H

24. McCarthy 1990  
Hospice patients: a pilot study in 12 services.  
195 patients seen by 12 hospices across the UK in July 1990.  
Death  
The majority of patients referred to a hospice were married or widowed and were of UK or Irish descent.  
MMH = M

25. McNamara 2007a  
Factors affecting place of death in Western Australia.  
26,882 decedents in Western Australia between July 2000 and December 2002.  
Referral  
1.4% of those with a non-cancer condition died in a hospice compared to 17.1% of those with cancer.  
HMH = H

Demographic profile and utilization statistics of a Canadian inpatient palliative care unit within a tertiary care setting.  
308 referrals made to the Palliative Care Unit at the Sunnybrook Health Sciences Centre, Canada between 2005-6.  
Death  
Most patients referred to the inpatient palliative care unit were male and had a malignant diagnosis. Hematologic patients had less access.  
LMM = M

27. Pivodic 2016  
Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries.  
Decedents (~2,220,997) with diseases indicative of palliative care need in 14 countries in 2008.  
Referral  
Death in a palliative care institution were less likely for non-cancer patients, those over 80, those not married and male patients.  
HHH = H

A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on?  
12,816 decedents in Western Australia 2009-10 who had an underlying cause of death potentially amenable to receiving palliative care.  
Death  
SPC services were accessed by 14% decedents with non-cancer conditions, representing a 6% increase on SPC access reported for the same decedent group ten years earlier.  
HHH = H

29. Rosenwax 2006  
Who receives specialist palliative care in Western Australia – and who misses out.  
26,882 decedents in Western Australia 2000-2 who died from cancer or selected non-cancer conditions.  
Referral and death  
Comorbid conditions, age >75, not being married, living in a rural location impacted negatively on SPC usage.  
HMM = M

30. Sharpe 2016  
"Don't leave me this way": Recognising the unrecognised need for specialist palliative care in the general hospital population.  
223 patients admitted to the Royal Sussex County Hospital (UK) between June and November 2014.  
Referral  
Those not identified as having specialist palliative care needs by health care professionals were more likely to have a non-cancer diagnosis, be over the age of 85 and have higher rates of cognitive impairment.  
MLL = L

31. Sleeman 2016  
446,615 patients dying in inpatient hospice units in England, from 1993-2012.  
Death  
Very few non-cancer patients died in hospice, despite this improving over time, including for haematological malignancies. The average age of hospice patients also increased, with more 85+ decedents. Most hospice patients were men and were married. There was a decrease in hospice deaths amongst the most deprived quintile, but an increase amongst the least deprived.  
HHH = H

32. Sleeman 2014  
388,899 patients dying with dementia in England between 2001 and 2010.  
Death  
Few dementia patients died at hospice (0.3%). Those who were female, younger, married, lived in urban areas and had an underlying cause of death of cancer died in hospice more often. Those belonging to the most deprived quintile died in hospice the least compared to other quintiles.  
HHH = H

33. Taylor 2011  
Place of death related to demographic factors for hospice patients in Wellington, Aotearoa New Zealand.  
1268 patients receiving services from the Mary Potter hospice in New Zealand between 2006-8.  
Death  
Asian ethnicity, cancer diagnosis, being married, younger age and being admitted initially to hospice for respite care were associated with an increased likelihood of hospice death. Other ethnic minorities had less access.  
HHH = H

34. Allsop 2018  
Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study.  
42,758 adult decedents with progressive, advanced disease, with a prior referral from 64 UK hospices.  
Referral  
Those with cancer, MND, heart failure, being female, being of black/ African/ Caribbean/ Black British ethnicity, or living in the south of England, had longer referral to death days. Those with a non-cancer diagnosis, increasing age, being male, dementia, stroke, lung/ liver cancer, liver/ kidney failure had shorter referral to death days.  
HHH = H

35. Currow 2004  
Specialist palliative care needs of whole populations: a feasibility study using a novel approach.  
3027 randomly selected South Australians.  
Referral  
People with a cancer diagnosis were more likely to access specialised palliative care services. Those with an income above AU$60,000 per year were more likely to report the use of palliative care services.  
HHH = H
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<th>Reference</th>
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Rates of access to specialist palliative care services were similar regardless of country of birth, educational level, or residential region.
<table>
<thead>
<tr>
<th>Reference</th>
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<th>Findings</th>
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<tbody>
<tr>
<td>49.</td>
<td>Vidrine 2016</td>
<td></td>
<td>Place of death in patients with haematological malignancy in North-East of England: Where does this happen and what factors may influence this?</td>
</tr>
<tr>
<td>50.</td>
<td>Campbell 2014</td>
<td></td>
<td>Discrepancy between preferred and actual place of death in patients with acute heart failure.</td>
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<td>51.</td>
<td>Cheang 2015</td>
<td></td>
<td>Current challenges in palliative care provision for heart failure in the UK: a survey on the perspectives of palliative care professionals.</td>
</tr>
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<td>52.</td>
<td>French 2011</td>
<td></td>
<td>Where do elderly patients with heart failure die?</td>
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<td>53.</td>
<td>Gibbs 2006</td>
<td></td>
<td>Survey of specialist palliative care and heart failure: September 2004.</td>
</tr>
<tr>
<td>54.</td>
<td>Horne 2004</td>
<td></td>
<td>Removing the boundaries: palliative care for patients with heart failure.</td>
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<td>55.</td>
<td>Chen 2017</td>
<td></td>
<td>General Practitioner Perceptions of Current Services for Heart Failure Patients: A Qualitative Study.</td>
</tr>
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<td>56.</td>
<td>Jones 1995</td>
<td></td>
<td>Palliative care in terminal cardiac failure.</td>
</tr>
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<td>57.</td>
<td>Kauf 2016</td>
<td></td>
<td>Home, hospital or hospice? Trends and predictors of location of death among patients with heart failure and acute coronary syndromes.</td>
</tr>
<tr>
<td>58.</td>
<td>McKinley 2004</td>
<td></td>
<td>Care of people dying with malignant and cardiorespiratory disease in general practice.</td>
</tr>
<tr>
<td>59.</td>
<td>Murray 2002</td>
<td></td>
<td>Dying of lung cancer or cardiac failure: a prospective qualitative interview study of patients and their carers in the community.</td>
</tr>
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<td>Reference</td>
<td>Title</td>
<td>Year(s)</td>
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<tr>
<td>71. Smallwood 2016</td>
<td>Palliation of patients with chronic obstructive pulmonary disease at the end of life.</td>
<td>2006; 21 52: p143</td>
<td>Medical record audit of 113 patients who died from COPD at The Royal Melbourne Hospital, Australia between 2004 and 2013.</td>
</tr>
<tr>
<td>73. Hobson 2011</td>
<td>National Survey of the Current Provision of Specialist Palliative Care Services for Patients with End Stage Renal Disease.</td>
<td>2011; 26: 1275-1281.</td>
<td>Questionnaire of 318 lead clinicians in UK adult hospital, hospice and palliative care teams.</td>
</tr>
<tr>
<td>Reference</td>
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<tr>
<td>Hussain 2013</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.</td>
<td>Palliative Medicine. 2013; 27(9): 829-839</td>
<td>441 patients located within West Yorkshire (UK) who were referred for pre-dialysis care.</td>
</tr>
<tr>
<td>Lovell 2017</td>
<td>Understanding patterns and factors associated with place of death in patients with end-stage kidney disease: A retrospective cohort study.</td>
<td>Palliative Medicine. 2017; 31(3): 283-288.</td>
<td>Patients (n =321) with chronic kidney disease stage 4-5 aged 75 and above known to one UK renal team between 2006-2012.</td>
</tr>
<tr>
<td>Morton 2016</td>
<td>Conservative Management and End-of-Life Care in an Australian Cohort with ESRD.</td>
<td>Clinical Journal of the American Society of Nephrology. 2016; 15(12): 2195-2203.</td>
<td>721 patients commencing renal replacement therapy in 66 Australian Renal Units in 2009.</td>
</tr>
<tr>
<td>Bablitz 2016</td>
<td>High CAGE score and late referral pattern typify end-stage liver failure patients referred to a regional palliative care program.</td>
<td>Journal of Pain and Symptom Management. 2016; 52(6): e111.</td>
<td>265 decedents with cirrhosis evaluated for liver transplantation at the University of Alberta Hospital (Canada) between January 2000 and December 2013.</td>
</tr>
<tr>
<td>Low 2016</td>
<td>Palliative Care for Cirrhosis: a UK survey of health professionals’ perceptions, current practice and future needs.</td>
<td>Frontline Gastroenterology. 2016; 7: 4-9.</td>
<td>Questionnaire of 517 UK health care professionals working in hepatology teams, specialist palliative care and general practitioners with an interest in gastroenterology.</td>
</tr>
<tr>
<td>Low 2017</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.</td>
<td>BMJ Open. 2017; 7(8): e016887.</td>
<td>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.</td>
</tr>
<tr>
<td>Poonja 2014</td>
<td>Patients with cirrhosis and denied liver transplants rarely receive adequate palliative care or appropriate management.</td>
<td>Clinical Gastroenterology and Hepatology. 2014; 12: 692-698.</td>
<td>102 patients with cirrhosis in Edmonton, Canada who were delisted or declined liver transplant from January 2005 to December 2010.</td>
</tr>
<tr>
<td>Crowther 2013</td>
<td>Palliative care for dementia – time to think again?</td>
<td>QJM: An International Journal of Medicine. 2013; 106(6): 491-494.</td>
<td>Interview of 40 bereaved people who had cared for a patient with dementia in the UK between 2008 and 2011.</td>
</tr>
<tr>
<td>Houttekie 2010</td>
<td>Place of death of older persons with dementia. A study in five European countries.</td>
<td>Journal of American Geriatric Society. 2010; 58(4): 751.</td>
<td>30,281 dementia patients across five European countries (England, Wales, Scotland, Belgium the Netherlands) in 2003.</td>
</tr>
<tr>
<td>Zheng 2013</td>
<td>How good is primary care at identifying patients who need palliative care? A mixed methods study.</td>
<td>European Journal of Palliative Care. 2013; 20(5): 216-222.</td>
<td>Case note review of nine Scottish (UK) GP practices over a 12 month period, comprising the notes of 684 patients.</td>
</tr>
</tbody>
</table>
85. Chaudri 2003
179 decedents with motor neurone disease seen by a motor neurone disease clinic in Nottingham (UK) between 1990 and 2000. Referral
25 motor neurone patients were referred to hospice care. Within this population, more females died in hospice compared to males. MMM = M

86. O’Brien 1992
124 patients with motor neurone disease cared for by St Christopher’s Hospice (UK) between January 1980 and November 1990. Referral
In a 10 year period, only 124 patients with motor neurone disease were cared for at the hospice. MMM = M

87. Sleeeman 2013
All deaths (n=125,242) in England (UK) with a contribution from Parkinson’s Disease (PD), Multiple Sclerosis (MS) or Motor Neurone Disease (MND) between 1993-2010. Referral
Hospice deaths were extremely uncommon in PD and MS (0.6% and 2.5%) but more common in MND (11.2%). HHM = H

88. Martin 2016
582 patients with multiple sclerosis (MS) who died between 1998 and 2015 and had been registered with the UK MS Tissue Bank.
Death
4.6% of patients died in a hospice. Those who died an MS-related death were far less likely to die in a hospice than those who died a non-MS-related death. HHM = H

89. Ochonov 2012
A matched cohort study of 3943 decedents with schizophrenia and 11327 decedents without schizophrenia who died between 1995 and 2008 in Manitoba (Canada).
Decedents without schizophrenia were less likely to be using SPC services than those without schizophrenia. MLM = M

90. Butler 2018
147 individuals with serious and persistent mental illness were compared with the general population (n = 3956) in the Capital and Coast District Health Board (New Zealand) in 2008-2014.
Death
People with serious and persistent mental illness were 3.51 times less likely to access SPC services than the general population. HHH = H

91. Addington-Hall 1998
2074 cancer decedents in the last quarter of 1990 in 20 self-selected English districts.
Death
Factors associated with increased likelihood of hospice inpatient care included being aged under 75 and having specific symptoms (pain in the last year of life or constipation). HHH = H

92. Burge 2002
Referral
Patients aged over 65 were much less likely to be referred to SPC services compared to those under 65. HMM = M

93. Burge 2008
Referral
Registration with a palliative care program was more likely amongst those with cancer, those <65 years old, women, and those living in upper income neighbourhoods. Patients in Francophone communities were less likely to be registered with a palliative care program. HHH = H

94. Burt 2010a
Audit of 108 patients in Dundee (UK) dying from cancer over the last three months of 2006.
Referral
Social deprivation did not affect access to SPC services. Younger patients were more likely to access services. LLL = L

95. Cartwright 1993
Interview of 639 decedents in 10 areas of England in 1987.
Death
Increasing age was associated with a decreased likelihood of hospice death. HMM = M

96. Davies 2006
Referral
Hospice death was more likely for specific cancer diagnoses, and those aged <75. HHH = H

97. Evans 2014
35,867 decedents aged ≥100 years in England who died between 2001 and 2010.
Referral
0.2% of centenarians died in a hospice. HMM = M

98. Fleming 2010
320 decedents aged ≥85 years in Cambridgeshire (UK) 1985-2007.
Death
2% of this cohort died in a hospice. HHM = H
| 99. | Gray 1997 | Factors associated with utilisation of specialist palliative care services: a population based study. | Journal of Public Health Medicine. 1997; 19(4): 464-469. | 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 age, gender, deprivation, living alone, current or most recent line of treatment, number of co-morbidities and carer stress. 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. | HHH = H |

| 100. | Kessler 2005 | Social class and access to specialist palliative care services. | Palliative Medicine. 2005; 19: 105-110. | 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. | BMC Palliative Care. 2005; 4: 6. | 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. | HHH = H |

| 102. | McNamara 2007b | Specialist palliative care use for people dying of cancer in Western Australia. | Cancer Forum. 2007; 21(1): 18-22. | 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. | PLoS One. 2016; 11(8): e0161399. | 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. | HHH = 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 |


| 107. | Burt 2010b | Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients. | Palliative Medicine. 2010; 24(6): 641-650. | 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 patients 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 |


| 109. | Bradshaw 1993 | Characteristics of clients referred to home, hospice and hospital palliative care services in Western Australia. | Palliative Medicine. 1993; 7: 101-107. | 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 | Elder age, female gender and not having a primary caregiver were associated with a reduced likelihood of receiving care from hospice services. | MMM = M |

111. Davison 2001  Where do patients with cancer die in Belfast? Irish Journal of Medical Science. 2001; 170(1): 18-23. Deaths attributable to cancer in Belfast (UK) in 1977 (n = 443), 1987 (n = 455) and 1997 (n = 426). Referral 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. HMM = M

112. Dunphy 1990  A comparison of hospice and home care patients: patterns of referral, patient characteristics and predictors of place of death. Palliative Medicine. 1990; 4: 105-111. 404 hospice and 143 home care patients from St Joseph’s Hospice London (UK) who had died during the first six months in 1998. Death Access to hospice was even across genders. HHH = H


114. Gaffin 1996  Opening doors: improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities. British Journal of Cancer. 1996; 29: 551-53. Study of hospice services in two London boroughs (Brent and Newham) and in North Birmingham (UK). Referral 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. LLM = L

115. Karim 2000  Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor’s referral patterns. Palliative Medicine. 2000; 14: 471-478. Interview of 27 GPs from two wards in Birmingham (UK). Death Language and staff bias were barriers to the referral of black/ethnic minorities to specialist palliative care services. MMH = M

116. Koffman 2004  Dying to be Home? Preferred Location of Death of First-Generation Black Caribbean and Native-Born White Patients in the United Kingdom. Journal of Palliative Medicine. 2004; 7(5): 628-636. 106 black Caribbean patients and 110 white patients from the UK were contacted to produce a sample of 50 cases per ethnic group. These informants were surveyed over a 13 month period. Referral 8% of Caribbean patients died in a hospice, compared to 16% of native-born white patients. This reflected patient preference. HMM = M


118. Worth 2009  Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. British Medical Journal. 2009; 338: b183. 92 interviews of patients, family carers and health professionals in Central Scotland (UK). Referral Only two patients accessed specialist palliative care services. Interviews revealed perceived advantages of, and barriers to the receipt of hospice care amongst ethnic minority patients. MMH = M

119. Fountain 1999  Ethnic minorities and palliative care in Derby. Palliative Medicine. 1999; 13: 161-162. 1035 new referrals to Derby (UK) SPC services. Death Ethnic minorities were slightly more likely than white patients to receive certain SPC services. MMM = M

120. Sharpe 2015  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. BMJ Supportive and Palliative Care. 2015; 5: 443-451. All cancer patients (=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. Referral The Chinese cohort had the largest proportion of hospice cancer deaths (29.9%). HHM = H


122. Waran 2017  The gap reversed: a review of site of death in the Top End. The Medical Journal of Australia. 2017; 3(207): S1: 39. 308 people, most were men, and most were indigenous Australians. Death Indigenous people died in hospices much less frequently compared to non-indigenous people. LML = L

123. Currow 2012  Referral patterns and proximity to palliative care inpatient services by level. BMC Health Services Research. 2012; 12: 424. Service mapping of 10,064 patients documented in the Palliative Care Death People from the most disadvantaged socio-economic group were less likely to be referred to SPC services. HHM = H
of socio-economic disadvantage. A national study using spatial analysis.

124. Shulman 2018
End-of-life care for homeless people: a qualitative analysis exploring the challenges to access and provision of palliative care.


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).

Death 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.

HLL = M

125. Burns 2015
Who provides care for people dying of cancer? A comparison of a rural and metropolitan cohort in a South Australian bereaved population study.


23,388 survey responses on the death of ‘someone close’.

Death In rural areas, half as many people died in hospice compared to those in urban areas. Rates of home death were identical but more rural patients died in hospital compared to urban patients.

MMM = M

126. Rainsford 2018
Place of death in the Snowy Monaro region of New South Wales: A study of residents who died of a condition amenable to palliative care.


Residents, with advanced frailty or one of 10 conditions amenable to palliative care, who died between 1 February 2015 and 31 May 2016. The records of 224 residents who had died in the study period.

Death In Rural regions: Much less likely to die in hospice compared to residence, hospital, or RACF.

MML = M

127. Gatrell 2012
Variation in geographic access to specialist inpatient hospices in England and Wales.


Death records at 189 specialist adult inpatient hospices in England and Wales, 2003-5. Urban and rural differences in geographical accessibility to inpatient PEoLC facilities were less likely to die in hospice. There were many examples of mismatches between supply and demand.

HHH = H

128. Wood 2004
Equity of access to adult hospice inpatient care within north-west England.


Cancer deaths in the North-West of England (UK) in 2000 (n = not known). Rates of home death were identical but more rural patients died in hospital compared to urban patients.

LLL = L

129. Chukwusa 2019
Urban and rural differences in geographical accessibility to inpatient palliative and end-of-life (PEoLC) facilities and place of death: a national population-based study in England, UK.


Death records of 143,627 patients registered with the UK National Cancer Registry between January 2004 and December 2011. In urban areas. Rates of home death were identical but more rural patients died in hospital compared to urban patients.

LLL = L

130. O’Dowd 2015
Place and Cause of Death in Patients with Lung Cancer in the United Kingdom.

Journal of Thoracic Oncology. 2015; 2: S518

143,627 patients registered with the National (UK) Lung Cancer Audit between January 2004 and December 2011. Death records of 143,627 patients registered with the National (UK) Lung Cancer Audit between January 2004 and December 2011. In urban areas. Rates of home death were identical but more rural patients died in hospital compared to urban patients.

LLL = L

131. Seamark 1995
Appropriate place of death for cancer patients: views of general practitioners and hospital doctors.


Questionnaires sent to health practitioners in Exeter Health District (UK) regarding cancer deaths (n = 1053) between May 1991 to April 1992.

Death Hospice involvement occurred in 39% of the total cancer deaths. The lack of availability of a city-based hospice affected the management of around a third of patients cared for by GPs and hospital doctors.

MMH = M

132. Campbell 2010
Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK.


UK National Census 2001 Data from 41 census wards in Salford and Trafford (UK), and referral data from St Ann’s Hospice (UK) 2004-2006.

Death Referral Patients from socially deprived areas have higher SPC needs but lower referral rates.

HHH = H

133. Cartwright 1992
Social class differences in health and care in the year before death.


Interview of 639 decedents in 10 areas of England in 1987. Death Referral Middle class decedents were more likely to die in a hospice compared to working class decedents.

HHM = M

134. Cunningham 2011


58,820 decedents aged 65 and older in British Columbia (Canada) between 2004 and 2006.

Death Referral Lower income was associated with a decreased likelihood of using SPC services.

HHH = M
<table>
<thead>
<tr>
<th>Reference</th>
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<th>Journal</th>
<th>Mortality data</th>
<th>Setting</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>135. Sims 1997</td>
<td>Social class variation in place of cancer death.</td>
<td>Palliative Medicine. 1997; 11: 369-373.</td>
<td>831 cancer decedents in Doncaster (UK) in 1996.</td>
<td>Referral</td>
<td>Patients from higher social classes were more likely to die in a hospice.</td>
</tr>
<tr>
<td>136. 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.</td>
<td>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</td>
<td>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>137. 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.</td>
<td>4585 patient deaths.</td>
<td>Death</td>
<td>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>
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