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Hospice care access inequalities: a systematic review and narrative synthesis

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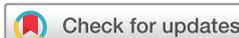
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ABSTRACT

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.

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 45 937 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 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.

INTRODUCTION

When the modern hospice movement started in 1967 with Dame Cicely

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.

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 4503 (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 suggesting that the oldest old (aged 85+) are also under-represented, alongside considerable disparities across geographical regions of the UK.¹ 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.

Box 1 PubMed search strategy

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⇒ ("Ethnicethnic Groups"[(Mesh]) 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 Chronicchronic Obstructiveobstructive Pulmonarypulmonary Diseasedisease OR emphysema OR dementia OR Alzheimer's OR neurological OR multiple sclerosis OR motor neuronneuron disease OR motor neuron disease OR cystic fibrosis OR haematological) AND
⇒ (specialist palliative care OR hospice OR "Hospice Care"[(Mesh]) OR "Hospices"[(Mesh]) OR "Hospice and Palliative Care Nursing"[(Mesh]))
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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.

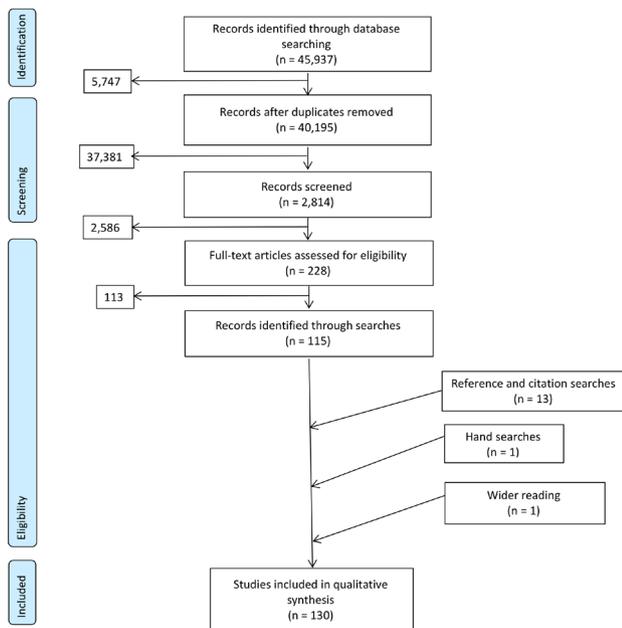


Figure 1 Preferred reporting items for systematic reviews and meta-analyses PRISMA diagram.

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.^{6,7} 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**).⁸

Box 2 Gough's 'Weight of Evidence'

- ⇒ Gough D. Weight of evidence: a framework for the appraisal of the quality and relevance of evidence. *Res Pap Educ* 2007;22(2):213–28.
- ⇒ Weight of Evidence A (WoE A). This is a generic and thus non-review-specific judgement about the coherence and integrity of the evidence in its own terms. The generally accepted criteria for evaluating the quality of this type of evidence by those who generally use and produce it.
- ⇒ Weight of Evidence B (WoE B). This is a review-specific judgement about the appropriateness of that form of evidence for answering the review question, which is the fitness for purpose of that form of evidence.
- ⇒ Weight of Evidence C (WoE C). This is a review-specific judgement about the relevance of the focus of the evidence for the review question. For example, a research study may not have the type of sample, the type of evidence gathering or analysis that is central to the review question or it may not have been undertaken in an appropriate context from which results can be generalised to the answer the review question.
- ⇒ These three sets of judgements are then combined to form an overall assessment Weight of Evidence D (WoE D) of the extent that a study contributes evidence to answering a review question.

RESULTS

A summary of the included studies is presented in online supplemental file 2. Gough's 'Weight of Evidence'⁸ 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.^{9–37} There is evidence of increasing hospice access for people with non-malignant illness in the UK,³¹ Canada¹⁸ and Australia.²⁸

Haematological malignancy

Fifteen largely high WoE papers report lower hospice provision for those with haematological malignancies^{16 23 31 38–49} with ORs compared with patients with cancer of around 0.4.^{23 38 41} Recent years have seen increased deaths in UK hospices among patients with haematological malignancies.^{16 31}

Heart failure

Twelve studies, generally medium/low WoE, evidenced that patients with heart failure are rarely referred to hospice services.^{50–61} Referral rates of patients with heart failure are commonly lower than 5%^{50 52 54 57 58} and patients with heart failure comprise less than 5% of palliative care clinicians' workload.⁵¹

Non-cancer respiratory disease

All 11 papers reported low rates of hospice referral,^{34 62–71} markedly lower than lung cancer, with some indication of increased referrals between 2006 and 2008.⁶⁷ Cystic fibrosis patients are under-represented in hospices despite having significant symptom burden.⁶²

Renal failure

Access to hospice care for patients with end-stage renal failure (ESRF) has been studied in the UK^{34 72–76} and Australia⁷⁷ with evidence of increasing collaboration between renal units and hospice teams in recent years.^{72 73} Hospice referrals are largely for those receiving conservative management for ESRF rather than people receiving renal replacement therapy.^{74 75 77}

Liver failure

The five medium/low WoE papers concerning patients with liver failure^{34 78–81} report them to represent less than 1% of hospice patient caseload⁷⁹ with referral often occurring late in the course of the illness.^{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.^{34 36 82–84} Referral is more frequent if there is also a cancer diagnosis;⁸² otherwise, it occurs very late in the illness⁸³ or not at all.

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

Mental health and learning disability

The limited literature of medium/high WoE papers reports patients with schizophrenia rarely access hospice care^{89 90} and people with learning disabilities to be less likely to receive hospice care than the general population.^{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.^{10 11 15 16 23 25 27–34 36–38 45 47 48 91–106} Centenarians

seldom die in UK hospices.^{97 98} However, recent evidence suggests that more over 85-year-olds are accessing hospice care in the UK.^{11 16 31} One low WoE study found age not to affect hospice referral.¹⁰⁷ One study reported the majority of patients accessing a hospice at home service were 78 years of age or older.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.^{15 16 24 26–29 32 34 38 46 92 108} However, eight high WoE studies suggested the reverse,^{10 11 25 31 102 103 109 110} and seven high/medium WoE studies reported no differences in access based on gender.^{45 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,^{16 24 27–29 31–33 38 102} other studies (mostly medium WoE) found marital status to be unrelated to hospice access.^{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.^{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.^{119 120}

In the UK, reduced access has been reported for a Pakistani/Indian/Bangladeshi groups¹¹³ and Caribbean/Chinese/African groups.¹¹⁶ Other studies have reported this not to be the case.^{34 120 121}

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

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

Geography

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

Socioeconomic status

Many, mostly high WoE studies reveal lower hospice access for people living in areas of lower socioeconomic status (SES).^{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.³¹ However, several high WoE studies have found no association between SES and access.^{28 29 38 91 94 96 99 107 108 111 138} In fact, some studies report greater access among those from lower SES areas.^{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;^{139–142} limited awareness of hospice services;^{139–141 143–146} the challenges of difficult conversations surrounding the term ‘hospice’^{139 140} and the extent or lack of a patient’s social support networks.^{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^{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,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.^{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’.¹⁵² A new model of hospice care is urgently needed in which the historical cancer-appropriate ‘one-size-fits-all’ framework¹⁵³ is reorganised to prioritise whichever patients need it the most¹⁵² and to better identify those patients with non-cancer illnesses who would benefit from hospice care.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.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.¹²¹ Indigenous Australians focus on maintaining spiritual connection to the land and on receiving culturally tailored care from members of the community.^{156 157} However, for LGBTQ+ groups, concerns over social prejudice may affect access to hospice care in addition to particular care needs.^{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.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.^{114 162–165} 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.^{129 165}

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.^{47 122}

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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