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Patterns and determinants of socioeconomic inequality in palliative and end-of-life care for older adults

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Patterns and determinants of socioeconomic inequality in palliative and end-of-life care for older adults

A thesis incorporating publications submitted to King's College London for the degree of Doctor of Philosophy.

This work was funded by a Research Training Fellowship from The Dunhill Medical Trust (RTF74/0116).

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October 2022

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Abstract

Background

There is growing evidence of socioeconomic inequality in palliative and end-of-life care, yet our understanding of the causes of this inequality and how to address it is lacking. In the context of an ageing and increasingly unequal society, understanding the patterns and determinants of socioeconomic inequality in palliative and end-of-life care is essential for informing ways to deliver care more equitably.

Aim

To investigate patterns and determinants of socioeconomic inequality in palliative and end-of-life care for older adults, and to explore potential mediating factors of the relationship between socioeconomic position and patterns of care towards the end of life.

Methods

This thesis investigates socioeconomic inequality in palliative and end-of-life care using three secondary analysis studies:

i) Systematic review and meta-analysis of existing evidence on the association between socioeconomic position and service use and outcomes in the last year of life, including place of death, hospital admissions in the last three months of life, and access to specialist palliative care.

ii) Secondary analysis of data from the English Longitudinal Study of Ageing (ELSA) using mediation analysis to estimate the direct effect of wealth and education (exposures) on place of death and frequent hospital admissions in the last two years of life (outcomes), and the indirect effects via health and function, access to services and social support (mediators).

iii) Secondary analysis of routinely collected clinical data to analyse the relationship between area-based deprivation and the symptoms and concerns of hospital inpatients referred to specialist palliative care, using data from a validated patient centred outcome measure, the Integrated Palliative Care Outcome Scale (IPOS).

Results

Based on 112 high-to-medium quality studies, the systematic review and meta-analysis found consistent evidence that in high income countries, people with low socioeconomic position were more likely to die in hospital versus home/hospice (OR 1.30, 95% CI 1.23–1.38, $p < 0.001$), to receive acute hospital-based care in the last 3 months of life (OR 1.16, 95% CI 1.08–1.25, $p < 0.001$), and to not receive specialist palliative care (OR 1.13, 95% CI 1.07–1.19, $p < 0.001$). The dose-response analysis found that for a 1 quintile increase in area-based deprivation the log-odds of dying in hospital versus home increased by 1.07 (95% CI 1.05–1.08, $p < 0.001$), and the log-odds of not receiving specialist palliative care increased by 1.03 (95% CI 1.02–1.05, $p < 0.001$). The review also found no studies investigating the causes of socioeconomic inequality in palliative and end-of-life care, and no high or medium quality studies using validated patient centred outcome measures to

investigate inequality. The secondary analysis of ELSA and of the routinely collected clinical data address these gaps.

The mediation analysis using ELSA included 737 participants (median age 78 years (IQR 71-85). For death in hospital, higher wealth had a direct negative effect (probit coefficient –0·16, 95% CI –0·25 to –0·06), which was not mediated by any of the pathways tested. For frequent hospital admissions, health and function mediated the effect of wealth (–0·04, –0·08 to –0·01), accounting for 34·6% of the total negative effect of higher wealth (–0·13, –0·23 to –0·02). The analysis of clinical data on the symptoms and concerns of palliative patients included data on 7,860 patients (median age 82 years (IQR 74-89) found that patients living in more deprived areas had a higher burden from practical and communication concerns. The predicted mean score for practical and communication concerns for the most deprived group was 5.38 (95% CI 5.10, 5.65) compared to 4.82 (95% CI 4.62, 5.02) for the least deprived (higher scores are worse). Area deprivation was not associated with physical or emotional symptoms.

Conclusions

The systematic review and meta-analysis provide consistent evidence that low socioeconomic position is a risk factor for death in hospital as well as other service-level indicators of potentially poor-quality end-of-life care and demonstrates consistent evidence of a socioeconomic gradient for death in hospital and access to specialist palliative care. The mediation analysis identifies for the first time, that worse health and function may cause

people with lower wealth to have more hospital admissions. This challenges behavioural explanations and highlights the importance of socioeconomically driven health differences in explaining different patterns of hospital use towards the end of life. For hospital inpatients seen by palliative care, the findings suggest that one way to reduce inequalities could be to target resources at addressing the practical and communication concerns of patients who live in more deprived areas.

The findings identify several implications for policy, practice and research including, the need to: monitor inequalities and to use this data to inform service delivery; evaluate interventions for unequal effects across social groups; and raise awareness among the public and health care professionals about socioeconomic inequality in palliative and end-of-life care. Methodologically, the thesis provides the first example of a mediation analysis used to study causes of inequality in palliative and end-of-life care and demonstrates novel use of existing longitudinal cohort study data and routinely collected patient centred outcomes data.

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Acknowledgements

Thank you to the participants who generously contributed their data to the English Longitudinal Study of Ageing (ELSA) and to the team who manage and collect these data. Thank you to the specialist palliative care team at King's College Hospital and the Princess Royal University Hospital who collected the patient data as part of their routine clinical care.

Thank you to my brilliant supervisory team, Professor Fliss Murtagh (FM), Professor Matthew Maddocks (MM) and Professor Katherine Sleeman (KS) who supported this work throughout, from entertaining the original idea and acquiring the funding, to the many stages of analysis and delivering the thesis. I would also like to thank Dr Panos Demakakos (PD), Dr Kia-Chong Chua (KCC), Dr Christina Ramsenthaler (CR), Professor Irene Higginson (IH), Professor Richard Harding, Dr Wendy Prentice (WP), Professor Julia Verne (JV) and Dr Martin Bardsley who all generously gave their time and expertise to support the work.

Thank you to the Dunhill Medical Trust for funding work into this important and under-researched area of health, and for providing me with this opportunity to grow and develop.

Thank you to my parents who are extremely proud and supportive and who along with Tim, Jenny and Ella provided many hours of childcare essential to this work. Last but not least, thank you to Tom for his unwavering sense of humour, love and support and to Emmeline and Rosalind who arrived in the middle of this work and are an endless source of happiness.

Statement of contribution

This thesis contains work I undertook under the supervision of Professor Fliss Murtagh (FM), Professor Matthew Maddocks (MM) and Professor Katherine Sleeman (KS) and with the support of Dr Panos Demakakos (PD) and Professor Irene Higginson (IH) as members of my Thesis Progression Committee, which was chaired by Professor Richard Harding.

I obtained funding for the thesis through a Research Training Fellowship from The Dunhill Medical Trust (RTF74/0116), with support from my supervisors and Professor Irene Higginson. I developed the aims and objectives of the thesis and the protocol for each of the three secondary analysis components. The thesis was written by me and represents my own original thoughts and ideas.

Contributions, with authors initials, for each component of the thesis are detailed below:

Systematic review and meta-analysis: I conceptualised the study, designed the analysis plan, carried out the analysis and led the interpretation of the data with supervision from FM, KS, MM, JV and IJH. Dr Javiera Leniz and Dr Rebecca Wilson helped with data extraction and checking the accuracy of extracted data. I wrote the manuscript, all authors contributed to revising the article and approved the final version.

Secondary analysis of the English Longitudinal Study of Ageing (ELSA): I conceptualised the study, designed the analysis plan, carried out the analysis and led the interpretation of the data with supervision from KS, FM, MM, PD and KCC. KCC provided statistical supervision. I wrote the manuscript, all authors contributed to revising the article and approved the final version.

Secondary analysis of routinely collected clinical data: FM, WP, and KS were involved in the collection of the routine clinical data used in this study. I conceptualised the study, designed the analysis plan, carried out the analysis and led the interpretation of the data with supervision from FM, KS, MM and CR. CR provided statistical supervision. I wrote the manuscript, all authors contributed to revising the article and approved the final version.

Two patient and public involvement members provided their reflections on the design, analysis, and interpretation of the findings in relation to their own lived experiences.

Publications, presentations and wider impact

Publications in peer-reviewed journals, incorporated in the thesis

Paper 1: **Davies JM**, Sleeman KE, Leniz J, Wilson R, Higginson IJ, Verne J, Maddocks M, Murtagh FEM. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLoS Med. 2019 Apr 23;16(4)

Paper 2: **Davies JM**, Maddocks M, Chua KC, Demakakos P, Sleeman KE, Murtagh FEM. Socioeconomic position and use of hospital-based care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing. Lancet Public Health. 2021;6(3):e155-e163.

Paper 3: **Davies JM**, Sleeman KE, Ramsenthaler C, Prentice W, Maddocks M, Murtagh FEM. The association between socioeconomic position and the symptoms and concerns of hospital inpatients seen by specialist palliative care: analysis of routinely collected patient data. Palliat Med. 2022 Aug. Online ahead of print.

Letter 1: **Davies JM**, Higginson IJH, Sleeman KE. Time to go beyond observing the problem. Response to: Dying in hospital: socioeconomic inequality trends in England. J Health Serv Res Policy. 2018 Jan.

Letter 2: Johnson H, **Davies JM**, Leniz J, Chukwusa E, Markham S, Sleeman KE. Opportunities for public involvement in big data research in palliative and end-of-life care. Palliat Med. 2021;35(9):1724-1726.

Presentations at scientific meetings and conferences

Davies JM. Knowledge exchange April 2022 (invited speaker), Cicely Saunders Institute, King's College London. ***Socioeconomic inequality in end-of-life care: understanding *why* inequality exists***

Davies JM. All Ireland Institute of Hospice and Palliative Care, 10th Annual Palliative Care Research Network Symposium on Equality and Equity in Palliative Care. December 2021 (invited key-note speaker). ***Beyond observing the problem – understanding *why* socioeconomic inequality exists in end-of-life care***

Davies JM. SEMantics (invited speaker) monthly seminar at the Institute of Psychiatry, King's College London. ***Socioeconomic position and use of hospital-based care towards the end-of-life: mediation analysis using the English Longitudinal Study of Ageing.***

Davies JM. European Association of Palliative Care (EAPC) Conference 2020, online (abstract presentation). ***Socioeconomic position and use of hospital-based care towards the end-of-life: mediation analysis using the English Longitudinal Study of Ageing***.

Davies JM. Understanding Inequalities Conference 2020, online (abstract presentation). ***Understanding the association between socioeconomic position (SEP) and place of death (PoD) using a life-course approach.***

Davies JM. Dunhill Fellows meeting, October 2019, London (invited speaker). ***Understanding the social determinants of outcomes important to older people towards the end of life.***

Davies JM. European Association of Palliative Care (EAPC) Conference 2018, Bern (abstract presentation). ***Association between socioeconomic position (SEP) and health care outcomes in the last year of life: a systematic review.***

Abbreviations

CFA: Confirmatory Factor Analysis

ELSA: English Longitudinal Study of Ageing

IMD: Index of Multiple Deprivation

IPOS: Integrated Palliative Care Outcome Scale

NHS: National Health Service

PCOMs: Patient Centred Outcome Measures

PPI: Patient and Public Involvement

SEM: Structural Equation Modelling

For Emmeline and Rosalind.

“We do have an ideological position: health inequalities that could be avoided by reasonable means are unfair. Putting them right is a matter of social justice. But the evidence matters. Good intentions are not enough.”

Sir Michael Marmot in Fair Society, Health Lives (2010)[1]

PART 1: Review of the literature

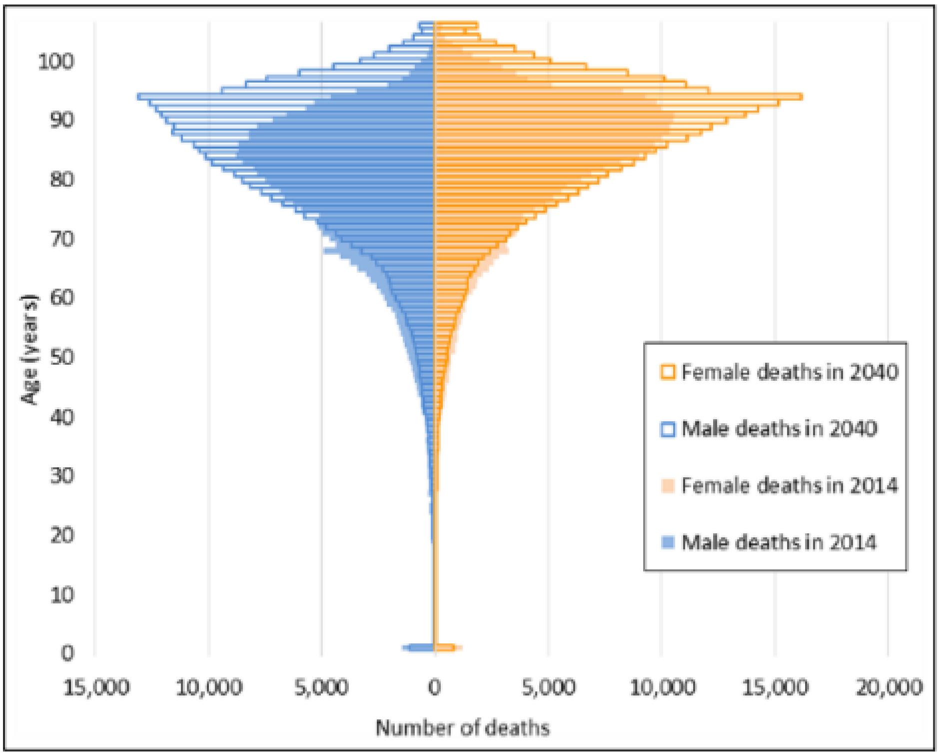
CHAPTER 1: Population ageing and service use towards the end of life

Chapter 1 of the literature review introduces the global evidence on the ageing population and describe the need for, and provision of, palliative care now and in the future, with a particular focus on the UK. It then outlines different approaches to measuring the quality of palliative and end-of-life care at the population level and summarises evidence on the disadvantage experienced by older people in the care they receive towards the end of life.

1.1 The ageing population, demographic and epidemiological trends

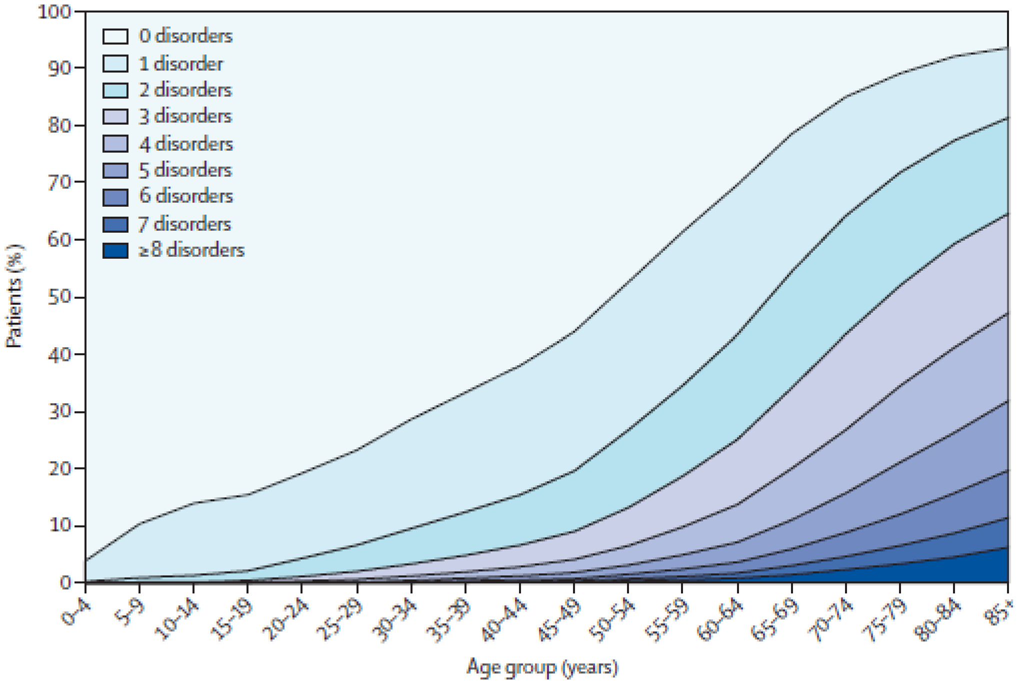
Globally, the number of deaths each year is increasing and is expected to reach 70 million by 2030.[2] In England and Wales, the annual number of deaths is predicted to increase from 501,424 in 2014 to 635,814 in 2040 (an increase of 27.0%).[2] The population is aging, people are living longer and dying at increasingly older ages (figure 1).[2] Between 2014 to 2040 the proportion of all deaths from people aged 65 and over in England and Wales is predicted to increase from 83.9% to 90.9%, and the proportion from people aged 85 and over will increase from 38.8% to 53.6%.[2] This represents a huge demographic shift that health and social care services must plan for in the future delivery of services.

Figure 1: Actual deaths in 2014 and projected deaths in 2040 by age and gender for England and Wales, source[2]



The ageing population is associated with an increase in the prevalence of chronic and multimorbid conditions.[3] Multimorbidity is defined as the presence of two or more coexisting chronic conditions and is associated with higher mortality, increased hospitalisations, polypharmacy, reduced functional status and worse quality of life.[4-6] There is no standard approach to measuring multimorbidity, estimates of the prevalence of multimorbidity depend on the number of diagnoses considered and vary according to whether data are sourced from routine health records or self-reported survey data.[7] A large-scale cross-sectional study of 1,751,841 people registered with 314 primary care practices in Scotland in 2007 found that, based on 40 core morbidities, 64.9% of people aged 65-84 had multimorbidity and the prevalence of multimorbidity increased substantially with age (figure 2).[3]

***Figure 2: Number of chronic disorders by age-group, in Scottish primary care register, source*[3]**



Patterns in the leading causes of death are also changing.[8, 9] In England, for both men and women, recent trends (2001-2015) show a decline in the death rate from heart disease and stroke and an increase in the death rate from dementia.[10] The increase in deaths from dementia reflects the aging population but also improvements in detection rates and changes to death certificate recording practices that prioritise the recording of dementia over other less specific causes of death such as ‘old age’.[10, 11]

If recent trends continue, it is estimated that in England and Wales between 2014 and 2040, annual deaths from dementia will increase from 59,199 (11.8% of all deaths) to 219,409 (34.9% of all deaths). Deaths from cancer will also increase from 143,638 (28.6% of all deaths) to 208,636 (33.2% of all deaths).[8] Conversely, deaths from organ failure including heart disease, heart failure, respiratory disease, renal disease and liver failure are expected to fall from 129,338 (25.8% of all deaths) in 2014, to 98,092 (15.6% of all deaths) in 2040.[8] In line with the growing number of deaths, the aging population and the increase in chronic and multimorbid conditions, the number of people who will need palliative care is also projected to increase in the future.[8, 9] The following section describes the current provision of palliative care and how the need for palliative care is likely to change in the future.

1.2 Provision of palliative and end-of-life care now and in the future

Palliative care is the active total care of patients with life-limiting illness, it is patient and family centred, holistic and multidisciplinary in its approach.[12] Patients with chronic disease, multimorbidity and complex symptoms are more likely to require palliative care, and the need for palliative care increases towards the end of life.[13, 14] The aim of palliative care is to improve quality of life for patients with serious illness by managing physical and emotional symptoms, reducing functional decline, providing psychosocial support, advance care planning and support for family and carers.[15] Specialist palliative care is delivered by specialist doctors and nurses and other allied health professionals, in hospital, community, and hospice settings. Generalist palliative care, or generalist end-of-life care, is also provided by general practitioners and health care professionals from other specialities in primary and secondary care, with specialists in palliative care supporting indirectly through education and training.

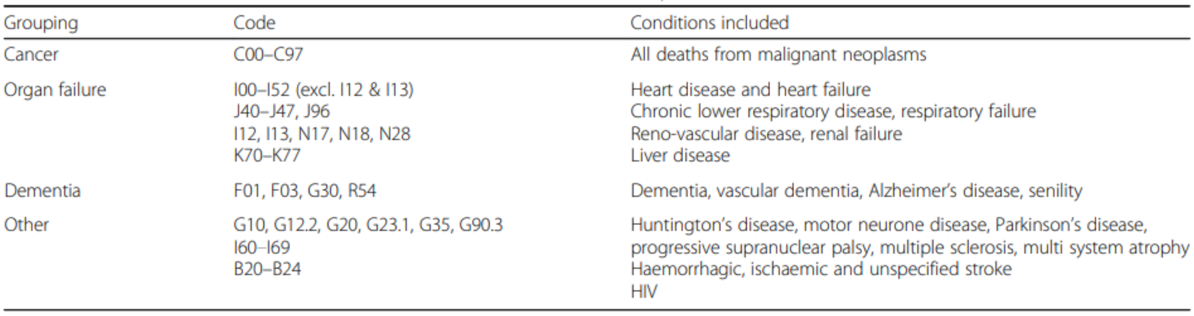
Early specialist palliative care intervention has been shown to be effective at treating symptoms[16, 17], improving quality of life[18, 19], extending life by reducing toxicity from cancer treatments[19-21] and improving bereavement outcomes.[22] By supporting patients to avoid unnecessary interventions and hospital admissions and providing care to people in their own homes, palliative care can also reduce healthcare expenditure.[23-25]

The World Health Organisation (WHO) recognises palliative care as an essential part of health care and lists 14 palliative care medications in the WHO Essential Drugs List.[26] Palliative care is increasingly seen as a human right, as part of the right to health and the right to be free from cruel, inhumane and degrading treatment.[27, 28] However, it is estimated that worldwide just 14 per cent of the people who need palliative care receive it.[26] There is considerable global inequality in access to palliative care. For example, morphine, considered an essential and relatively cheap pain medication, is not available to 80% of the world's population with usage concentrated in the global north and Australia.[29]

Serious health-related suffering, defined as suffering from illness or disease that requires medical intervention, is increasing globally.[30] Based on World Health Organisation (WHO) mortality projections and estimates of physical and psychological symptom prevalence in 20 conditions commonly needing palliative care, the number of people who die each year with serious health-related suffering is predicted to double from 26 million in 2016 to 48 million by 2060.[9] The increase in burden will be driven largely by an increase in deaths from cancer and dementia and will be largest for people aged 70 years and older; in 2060, 22 million more people aged 70 years and over are expected to experience serious health-related suffering, representing a 183% increase from 2016. Serious health-related suffering at older ages will increase globally but the increase will be most rapid in low-income countries.[9]

For England and Wales, the population-based level of need for palliative care has been estimated based on trends in causes of death combined with population projections.[31, 32] This approach is based on the prevalence of a set of underlying causes of death that are likely to benefit from specialist or generalist palliative care.[32] It has been shown to produce reliable estimates of palliative care need using mortality records (see table 1 for a list of underlying causes of death).[32] Using this approach, the need for palliative care in England and Wales is predicted to increase from 75% of all deaths in 2014 to 86% in 2040.[8] The growing number of deaths from cancer and dementia is expected to drive much of this increase, and the increase in need for palliative care will be highest for older people. In 2014, 194,455 people aged 85 and over needed palliative care, accounting for 38% of overall palliative care need, by 2040, 334,427 people aged 85 and over are predicted to need palliative care, increasing to 56% of all palliative care need.[8]

Table 1: International Classification of Disease-10 (ICD-10) codes: conditions that could benefit from palliative care, used to estimate palliative care need, source[8]



Grouping	Code	Conditions included
Cancer	C00–C97	All deaths from malignant neoplasms
Organ failure	I00–I52 (excl. I12 & I13) J40–J47, J96 I12, I13, N17, N18, N28 K70–K77	Heart disease and heart failure Chronic lower respiratory disease, respiratory failure Reno-vascular disease, renal failure Liver disease
Dementia	F01, F03, G30, R54	Dementia, vascular dementia, Alzheimer's disease, senility
Other	G10, G12.2, G20, G23.1, G35, G90.3 I60–I69 B20–B24	Huntington's disease, motor neurone disease, Parkinson's disease, progressive supranuclear palsy, multiple sclerosis, multi system atrophy Haemorrhagic, ischaemic and unspecified stroke HIV

1.3 Provision of palliative care in the UK

In the UK, specialist palliative care in hospitals is usually provided as an advisory and visiting service with very few palliative care inpatient beds in hospitals. Hospice in the UK is almost always a separate setting to hospital and provides inpatient, outpatient and community services.[33] The first modern hospice, St Christopher's Hospice was opened in 1967 by Dame Cicely Saunders[34] and there are now more than 200 hospices in the UK.[35] In 2014, 27,804 people died in a hospice (5.5% of all deaths), with many more people supported by hospices in the community.[2] There is no national data collection on hospice activity, however, analysis from Hospice UK, the main umbrella charity for hospices, estimates that hospices in the UK care for 225,000 people with terminal illness each year and that in 2017/18 hospices provided bereavement support to 72,000 people.[36] Although free at the point of access, hospices are rarely part of the National Health Service (NHS), and approximately 70% of hospice funding is from charitable sources.[35] Hospice care originated as care for cancer patients and although it has been expanded to care for people with non-cancer conditions the majority of people accessing hospice care, particularly inpatient services, have cancer; 92.3% of people who died in hospice between 2008 and 2012 died from cancer.[37]

In a 2021 ranking of the quality of palliative care provision across the world, the UK ranked top out of 81 counties.[38] Yet, in the UK many people who need palliative care will not receive it. It is estimated that 50% of people who die in England receive palliative care, falling short of the 69%-82% thought to need palliative care input.[32, 39] There is considerable variation in the funding of palliative care across the UK.[40] A survey of 29 Clinical

Commissioning Groups found that budget allocation for palliative care ranged from £51.83 to £2329.19 per patient per year.[41]

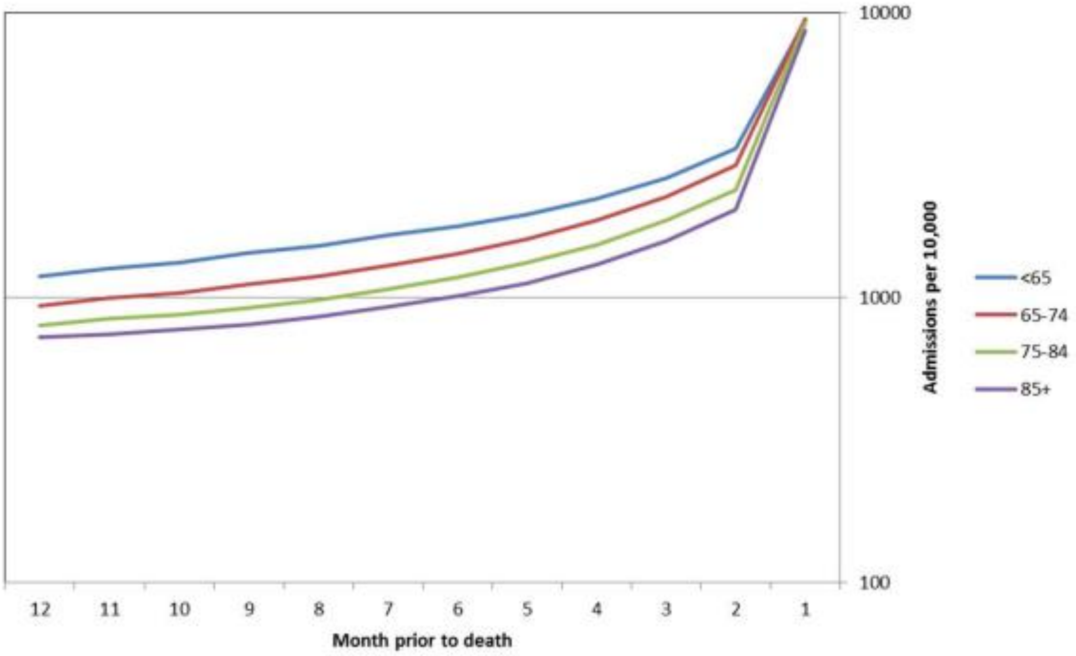
There is also variation in the provision of services, and concerns about the quality of palliative and end-of-life care particularly in hospitals, including problems with poor symptom control, poor communication and a lack of dignity afforded to dying patients.[42, 43] According to a national audit of hospital palliative care, just 21% of UK hospitals provide a face-to-face specialist palliative care service 7 days per week with most (73%) providing face-to-face care only on weekdays.[44] The same survey reports that mandatory training for hospital doctors in the care of the dying was in place in just 19% of trusts.[44] Incongruent with the apparent lack of focus on the care of dying patients in hospitals, dying people represent a large proportion of all hospital inpatients; a study of Scottish hospitals found that 1 in 3 hospital inpatients are likely to die within a year of admission.[45, 46] The next section describes the evidence on hospital-based care towards the end of life.

1.4 Hospital based care towards the end of life

Surveys of the general population and of people with advanced cancer indicate that most people would prefer to avoid hospitalisations towards the end of life.[47, 48] Hospital-based end-of-life care, compared to home or hospice-based care, is associated with worse quality of life for patients and worse bereavement outcomes for families.[49-52] Yet, hospitalisations are common in the last year of life and increase sharply in the months before death. Population level data on deaths in England between April 2009 and March 2012, found that

90.2% of decedents had a hospital admission in the last 12 months of life, with an average rate of 2.28 admissions per death (excluding those with no admissions), and 57% of admissions in the last year of life took place in the last 3 months of life (figure 3).[53]

Figure 3: Admissions per 10,000 people, per month prior to death (note log scale), source[53]



Another study using the largest linked dataset of health and social care data from seven local authorities in England, found that many more people (89.7%) used hospital care in the last year of life than local authority funded social care (27.8%).[23] The same study analysed costs data for care delivered between 2007 and 2010 and found that at older ages as social care costs increased, hospital costs decreased.[23] This evidence of an inverse relationship between health and social care usage aligns with earlier work showing that care home residents have a lower risk of hospital admissions in the last two months of life, suggesting that care home admission may protect against hospital admissions towards the end of life.[54]

Hospital is also the most common place of death in many high-income countries, and the UK has one of the highest rates of hospital deaths in Europe for non-cancer causes of death.[55] Towards the end of the 20th Century a trend for a growing proportion of hospital deaths and a corresponding decline in home deaths was observed; in England and Wales, between 1974 and 2003, the proportion of deaths at home had declined from 31% to 18%.[56] Similar trends were seen in other high income countries prompting international efforts to reduce deaths in hospital and enable more people to die in their place of choice.[57-59]

Since the early 2000's the proportion of deaths in hospital has started to decline, potentially signifying the success of policy efforts to improve end-of-life care and support more people to die at home.[59, 60] However, the causes of these changes are difficult to retrospectively evaluate because policy efforts were rolled out nationally and confounding factors such as the gradual decline in the number of hospital beds over this period may also have influenced the trend.[61, 62]

Between 2004 and 2014 in England and Wales, the proportion of deaths in hospital fell from 57.9% to 48.1%, correspondingly home deaths increased from 18.3% to 22.9%, care home deaths increased from 16.7% to 21.2% and deaths in hospice increased from 4.6% to 5.5%.[2] If current trends in place of death continue, care home and home are predicted to become the most common places of death by 2040.[2] This increase will depend on an increase in capacity in care homes and in community services which if not met, may result in a return to higher rates of deaths in hospital.[2]

1.5 Evaluating the quality of palliative and end-of-life care

This section describes different approaches to measuring the quality of palliative and end-of-life care, focusing on methods that use routinely collected data to evaluate quality at a population level. Death in hospital has been widely used as an indicator of poor quality palliative and end-of-life care.[55, 63-65] At a population level, the relative consistency of place of death records over time and in different countries, make it a useful measure for exploring trends, comparing countries, and for investigating inequalities.[37, 60, 66-68] The limitation of using place of death as an indicator of the quality of end-of-life care, is that it provides only a snap shot of information about the location of care received just before death and implies an oversimplified binary assumption that hospital deaths are bad.[69] Decisions about place of death can be complex and for some people hospital is the most appropriate and/or preferred place of care and death.[69-71]

Addressing some of the limitations of using place of death to measure quality, Earle et al (2003) have developed a set of performance measures for cancer patients that have been widely used in the US to evaluate the quality of end-of-life cancer care.[72] Alongside death in hospital, these measures of service use in the last months of life include initiation of chemotherapy, hospitalisation, emergency department or intensive care admission, and lack of or late admission to hospice.[72, 73] These quality measures have since been applied outside of the US and expanded to non-cancer populations and to include healthcare transitions in the last days of life.[74-78]

Using a combination of measures provides a more comprehensive picture of the quality of end-of-life care, yet these ‘process’ measures still fall short of capturing the ‘outcomes’ of care, defined as a change in a patient’s health status or quality of life.[79] Increasingly, there are calls to evaluate the quality of care using measures that are more meaningful to patients and families.[80] Patient Centred Outcome Measures (PCOMs) are validated questionnaires that collect data on the health status, well-being or quality of life of patients, providing a patient-centred approach to measuring quality of care.[79, 81] In palliative care, PCOMs have been widely used in research and are increasingly used in routine clinical care.[82-84] They have been shown to be effective for evaluating interventions, comparing services by adjusting for case-mix, and when used in routine care can improve communication between clinicians and patients by supporting the identification of patient’s needs.[80, 83, 85-87]

1.6 Older people, ‘the disadvantaged dying’

Drawing on some of the quality indicators described in the previous section, this section describes the evidence on older people being at a higher risk of receiving poorer quality palliative and end-of-life care.

Older people have been described as the ‘disadvantaged dying’, despite being the main end-of-life population group (in 2014 83.9% of people who died were aged 65 years or older).[88] Evidence suggests that older people are less likely to be referred to and access specialist palliative care[89] and are less likely to die at home or in hospice.[37, 60] A study using the VOICES survey of bereaved relatives found that the relatives of the oldest-old, people who died aged 85 years and over, were less likely than the relatives of younger patients to know their loved ones preferences for place of death and that this contributed significantly to age related disparity in place of death.[90] A review of hospital-based end-of-life care in the UK, identified worrying examples of age discrimination concluding that ‘care of the dying elderly is of the greatest concern’.[42]

One explanation for this, reported in a qualitative study into the barriers to providing palliative care to older patients in hospitals, is that healthcare professionals may perceive older people to have a lower need for specialist palliative care, in part because death is seen as more acceptable for older people.[91] Alongside attitudinal barriers to referrals, the same study found that a lack of carer support and advocacy, lack of integration between geriatricians and palliative care, and the higher proportion of non-cancer causes of death among older people contributed to lower access to palliative care among older people.[91] The lack of access to palliative care among older people also arguably reflects a wider culture of ageism in the National Health Service (NHS) and in wider society.[88] Evidence shows that across the NHS, older people are less likely to have symptoms investigated and are less likely to receive treatments including chemotherapy.[88, 92]

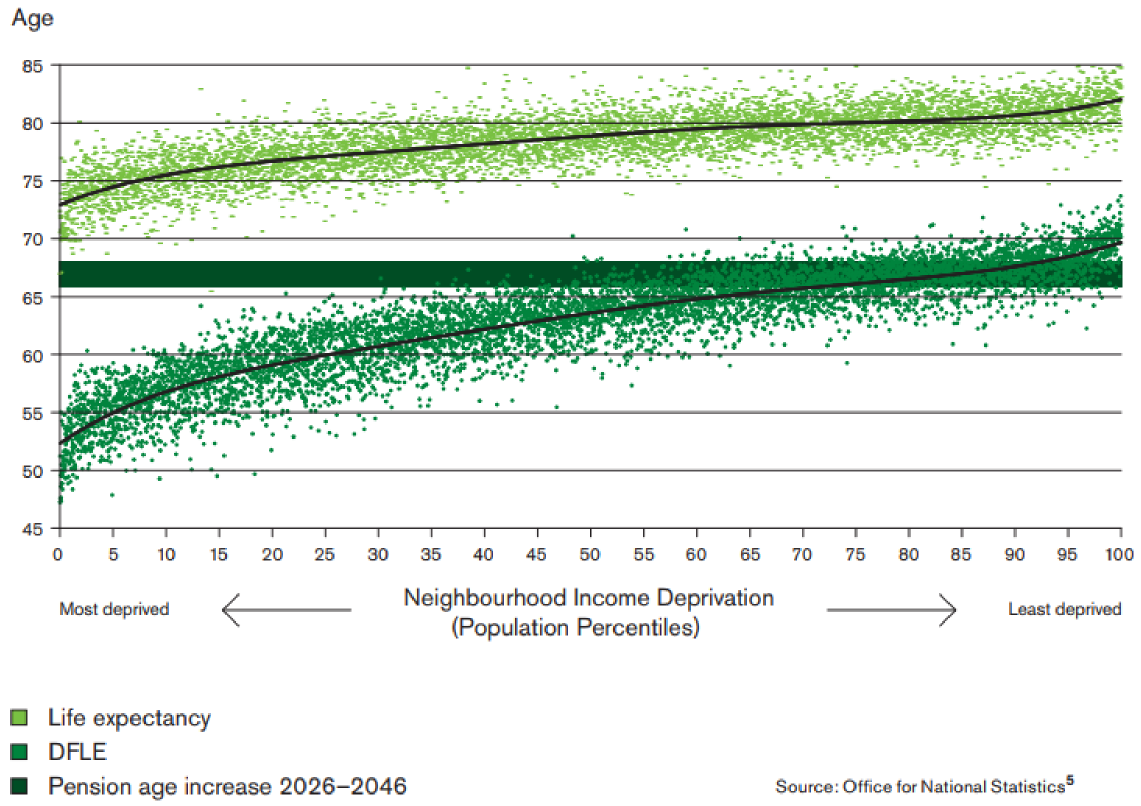
CHAPTER 2: The socioeconomic determinants of health and palliative and end-of-life care

This section introduces the evidence and theory on the socioeconomic determinants of health and mortality and reviews the evidence on socioeconomic inequality in palliative and end-of-life care. Drawing on a largely UK-based literature on life-course theory and the measurement of socioeconomic position, it sets out the rationale for the thesis, describing the life-course perspective and the application of this approach to understanding socioeconomic inequality in palliative and end-of-life care for older people.

2.1 The socioeconomic determinants of health and mortality

The conditions in which people are born, live, work and age have a profound effect on health.[1, 93] The 1980 Black Report provided the first detailed investigation of differences in health and mortality according to occupational based social class in the UK.[94] When the NHS was introduced in 1948, it was assumed that higher mortality among people who were poorer was caused not by differences in risk factors for exposure to disease, but primarily by a lack of access to treatment because healthcare was unaffordable for so many people.[95] The revelation of the Black report was that in the 30 years since the introduction of the National Health Service (NHS) although overall health had improved, inequality in mortality between social classes had increased.[94] More recently, the Marmot Review (2010) demonstrated that health inequalities have persisted in the UK.[1] This analysis showed that people living in the most income deprived areas of England had an average life expectancy 7 years shorter and an average disability free life expectancy 17 years shorter than those living in the least deprived areas (figure 4).[1]

Figure 4: Marmot Curve, showing life expectancy and disability-free life expectancy at birth, persons by neighbourhood income level, England, 1999-2003, source [1]



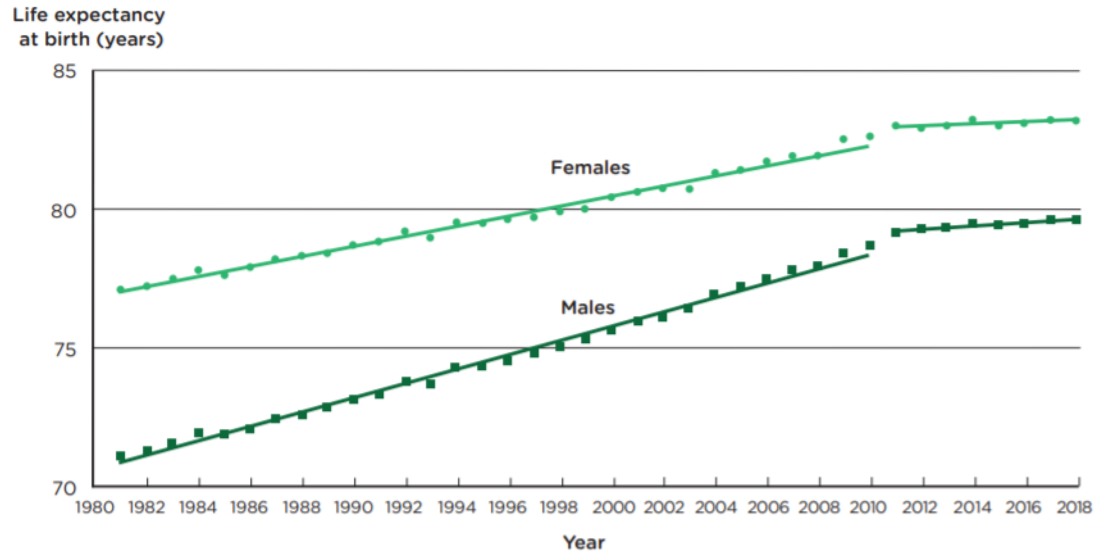
Source: Office for National Statistics[5]

The Marmot Curve demonstrates the ‘systematic relationship between health and area deprivation’.[93] One implication of the gradient in health is that health inequality is not only a problem for those who are worst-off in society, it is a problem for everyone below those at the very top.[1] Consequently, focusing efforts only on improving the health of those worst off in society will address only part of the problem. Instead Marmot *et al* (2010) make the case for ‘proportionate universalism’; universal action to improve health for everyone with an intensity that is proportionate to the level of deprivation.[1]

Another important observation is that the curve can fluctuate over time and is different in different populations. For example, Marmot *et al* (2010) found that the deprivation gradient in life expectancy and disability free life expectancy was steeper in the North East of England than in the South West.[1] In a separate European-wide report, Marmot *et al* (2012) found that health inequalities varied across the 53 member states of the European region, and that health inequalities were generally worse in the UK than in Nordic countries, the latter being characterised by a more equal distribution of wealth and social policies centred on universalism.[96, 97] Subsequent analysis of the Marmot curve by the King's Fund[98] and the Longevity Science Panel[99] has demonstrated how health inequality flattened between 2006 and 2010 during a period of relatively high investment in health under the Labour government, and then widened again after the implementation of austerity policies in 2011.

The update to the Marmot Review published in 2020 has identified an extremely worrying trend.[93] For the first time in decades, life expectancy has slowed, flattening dramatically after 2011 (figure 5).[93] Most worryingly, for women living in the most deprived areas, life expectancy has actually started to decline.[93] If health, as Marmot argues, is a barometer for how well society is progressing, then this should be taken as a sign that our society has stopped improving.[93]

Figure 5: Life expectancy at birth for males and females, England, 1981-2018, source [93]



Source: ONS, 2019 (20)

Marmot *et al* (2020), cautiously but plausibly demonstrate how a decade of austerity including a reduction in public expenditure from 42% of GDP in 2009/10 to 35% in 2018/19, the housing crisis, the increase in child poverty and precarious employment has been damaging to health overall and has increased health inequalities.[93] In addition to the moral imperative to improve health equitably, the variation observed in the steepness of the socioeconomic health gradient over time and between places implies that we can, and therefore should, seek to reduce health inequalities.

The Covid-19 pandemic has further exposed and amplified underlying health inequalities, revealing socioeconomic, ethnic, occupational and geographical inequality in Covid-19 mortality.[100] The poor state of health in the UK, seen in the stalling life-expectancy and the widening inequalities in the decade leading into the pandemic, are arguably critical to understanding why the UK experienced some of the highest excess mortality from Covid-19 in Europe.[93] The current cost of living and energy crisis will further exacerbate health inequalities. The proportion of households unable to heat their homes adequately is rising rapidly; by January 2023, it is predicted that 66% or 18 million homes in the UK will be in fuel poverty, with older people and those with existing health conditions at a higher risk from the negative health consequences of living in a cold home, including serious respiratory and circulatory problems.[101]

2.2 Socioeconomic inequality in palliative and end-of-life care

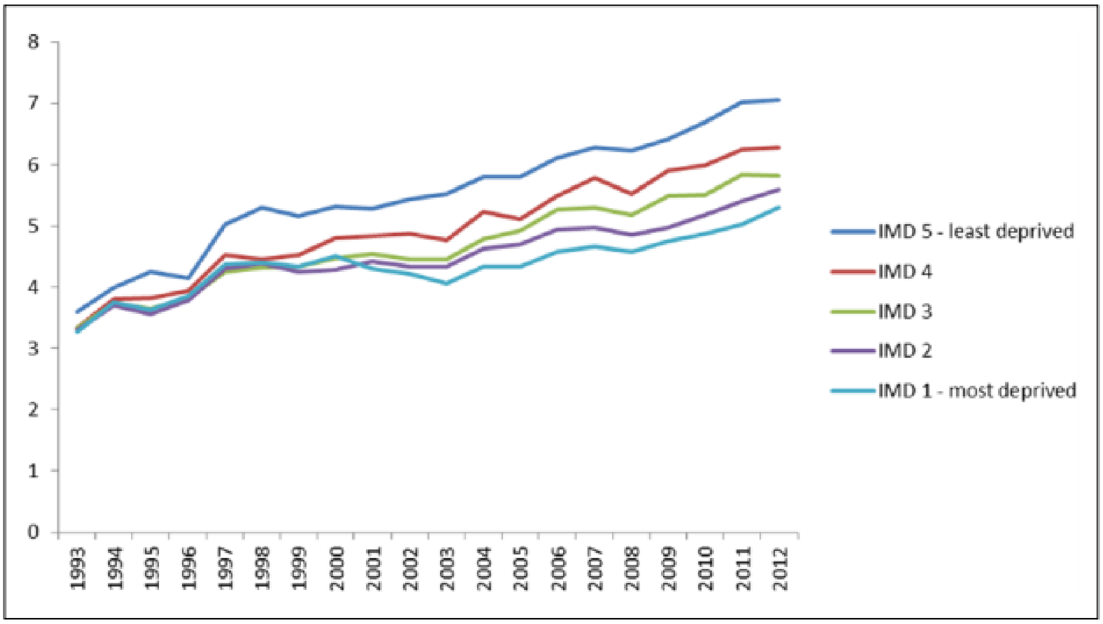
Having summarised the evidence on socioeconomic inequality in health and mortality, this section focuses on the evidence of socioeconomic inequality in palliative and end-of-life care.

Socioeconomic inequality in palliative and end-of-life care has been demonstrated most clearly in relation to place of death. Population-based observational studies of deaths in England have shown that along with several other illness, service and demographic factors, living in a more deprived area is independently associated with an increased risk of dying in hospital versus home or hospice.[37, 60, 102] An early ecological study of cancer deaths in England by Higginson *et al* (1999) used area-based analysis to demonstrate the pattern for a lower proportion of home deaths in areas with higher levels of deprivation.[102] Later individual-level analysis that adjusted for factors including age, sex and underlying cause of death, found similar results.[60] In an analysis of all cancer deaths in England between 2006-

2010, the adjusted odds of death at home or in hospice (versus hospital) were 11% higher for decedents living in the least deprived areas compared to those in the most deprived areas.[60] This study also indicated that although the proportion of deaths at home and in hospice overall had increased between 1993 and 2010, the inequality gap in the odds of death at home or hospice between those living in the least and most deprived areas appeared to have widened from 6% in 1993-1995 to 11% in 2006-2010.[60]

A similar association with area-based deprivation has been shown in relation to hospice deaths in England.[37] Figure 6 shows the proportion of all deaths occurring in hospice (versus all other locations) between 1993-2013, by level of area-based deprivation.[37]

Figure 6: Percentage of deaths in each Index of Multiple Deprivation quintile that occurred in hospice, 1993–2012, source [37]



The analysis demonstrates that since 1993, people living in the most deprived areas have always been less likely to die in a hospice than those living in the least deprived areas but the gap between these groups increased over the period.[37] The adjusted odds of death in hospice for people living in the least deprived compared to the most deprived areas were 25% higher in 2008-2012 compared to 1993-1997.[37]

In relation to deaths in hospital, a study of all deaths in England between 2001 and 2012 found that deaths in hospital decreased from 49.5% to 43.6%, after peaking in 2004/2005 at 52%.[103] The same study found that despite the reduction in hospital deaths over the period, there was no reduction in absolute inequality between decedents living in the least and most deprived areas or in inequality relative to the mean.[103] In this analysis, the proportion of decedents in the most deprived areas who died in hospital was at least 5% higher than for decedents in the least deprived area throughout the study period.[103]

Overall, the evidence for place of death in the UK suggests that improvements in supporting more people to die in their preferred place have done little to alleviate socioeconomic inequalities, and for deaths at home and in hospice inequalities may have widened over the last 20 years. Recent analysis has shown that the Covid-19 pandemic may have further exacerbated area-based deprivation inequalities in place of death. Analysis for the UK shows that home deaths increased for everyone during the pandemic as people chose or were forced to avoid hospitals and other institutions; in England over the period 28 March to 31 December there was an overall increase in home deaths from 24.6% in 2019 to 27.8% in

2020.[104] Yet, this increase was significantly greater for people living in the least deprived areas (5%) compared to those in the most deprived areas (2%) and this inequality persisted after the initial wave of Covid-19 (after 30th May 2020).[104] A similar pattern of widening inequality was observed in all four nations of the UK.[104]

This pattern of exacerbated inequality in place of death reflects patterns observed in Covid-19 mortality and infection rates where inequalities in health observed before 2020 were magnified by the pandemic.[100] An explanation for worsening inequalities during this period is that when services are stretched, as they were during the pandemic, health inequalities tend to become more entrenched because the better-off, despite having less need, tend to have better access to healthcare; intensifying the effects of the 'inverse care law'.[100, 105] This pattern of unequal harms and benefits is also observed in less extreme contexts, in relation to improvements in overall health. For example, the reduction in smoking or improvements in working conditions which have benefited the health of some social groups more than others.[95, 97, 106]

In light of these wider trends of increasing health inequalities, it is therefore not surprising that efforts since the early 2000's to promote choice in place of death in the UK have benefited people with higher socioeconomic position more than those with lower socioeconomic position, particularly given the lack of strategic focus in palliative and end-of-life care policy on addressing socioeconomic inequalities. The following paragraphs review the key national policy documents and their contribution to addressing inequalities in palliative and end-of-life care.

2.3 The policy context for palliative and end-of-life care in the UK

In 2008 the Department of Health published the first comprehensive national 'End of Life Care Strategy: Promoting high quality care for all adults at the end of life'.[61] This document was central to early policy efforts in the UK to support choice in place of death and to enable more people to die at home. The main strategy document acknowledges the need for equality of access to high quality end-of-life care 'irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic position'.[61] It also highlights the need to consider the deprivation profile of areas in resource allocation. Yet, the accompanying 'Equality Impact Assessment', a common requirement for policy documents of this type, does not mention area-based deprivation at all.[107] Socioeconomic inequality is mentioned briefly in relation to people with learning disabilities and people with Multiple Sclerosis being at higher risk of having a low income. But the main focus in the Equality Impact Assessment is on groups with protected status under the Equality Act (2006), plus two additional groups, the homeless and prisoners.[107] The report states that:

> *"The equality impact assessment process requires the policy to be assessed against seven equality categories: age, gender, religion and belief, sexual orientation, gender identity, race and disability. However, as other factors (homelessness, refugee, detention in prison, traveller, etc) are also associated with inequity in end of life care, the End of Life Care Strategy has also been assessed against these categories."*[107]
>
> and…

> *“Variations in the quality of end of life care exist across the country and there is concern that among certain groups of dying patients such as the old, those with non-cancer diagnoses, people from black and minority ethnic (BME) backgrounds and those in rural areas there is an unacceptable level of variance.”*[107]

The Equality Act (2006) defines inequality in terms of discrimination against groups with protected characteristics (based on: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation), of which socioeconomic position is not included. Notably, although the subsequent Equality Act (2010) includes a potentially powerful public sector ‘socioeconomic duty’ for government and public organisations to work towards reducing socioeconomic inequality, this part of the act has never been brought into force.[108]

In line with the Equality Act (2006), the focus within the End of Life Care Strategy Equality Impact Assessment is predominantly on individual discrimination with very little, if any, focus on structural inequalities. A brief review of the language used in the document reveals that variations on the word ‘discrimination’ appear 20 times in the document, whereas the words ‘structure’ or ‘structural’ do not appear at all. In the main policy document, there is a strong focus on individual patient choice with the word ‘choice’ appearing 44 times in the document.[109] This focus on choice reflects the problem - that people were increasingly dying not in their place of choice - that the strategy sought to address, but it also reflects a wider shift throughout the NHS at this time towards a rhetoric of supporting patient choice.[110] The promotion of choice throughout the NHS is arguably driven by a motivation to increase patient autonomy and improve the experience of health care.[110] Yet, in the neo-liberal context where patients are seen as consumers, the promotion of choice risks worsening inequality if there is a failure to acknowledge that choice is rarely equitable and is often more restricted for people with lower social and financial capital and for those less able to communicate preferences[110-112]

Subsequent national policy documents on palliative and end-of-life care have had a similar emphasis on individualism and choice and have given little attention to socioeconomic inequality in particular to structural causes of inequality. The NHS England document 'Actions for End of Life Care: 2014-16' identified the need to address inequalities in access to care experienced by people with dementia, severe frailty, learning disabilities, black and minority ethnic backgrounds, homeless people and people in secure and detained settings, but made no mention of inequality experienced by people living in deprived areas, on low incomes or with low socioeconomic position.[113] The Care Quality Commissions report 'A different ending: Addressing inequalities in end of life care' (2016) also does not mention area-based deprivation or socioeconomic position at all, instead focusing on non-cancer conditions, older people, people with dementia, black and minority ethnic groups, lesbian, gay, bisexual and transgender people, people with learning disabilities, people with mental health conditions, people who are homeless, people in a secure or detained setting, and Gypsies and Travellers.[114] Two major reports into the quality of end-of-life care: 'More care, less pathway: a review of the Liverpool Care Pathway' (2013)[42] and 'Dying without dignity: Investigation by the Parliamentary and Health Service Ombudsman into complaints about end of life care' (2015)[43] both make no mention of socioeconomic or any other source of inequality. It is also notable that the three major Marmot reviews[1, 93, 100] into the social determinants of health in the UK, make no mention of palliative or end-of-life care.

The 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020'[115] and the more recent update to these ambitions covering the period 2021-2026[116] do acknowledge socioeconomic factors as a source of inequality and cite evidence on area-based deprivation inequality in place of death. The 'ambitions' documents highlight the need for population-based needs assessment for end-of-life care and for services to address inequalities as part of their responsibilities under the Equality Act (2010). Yet, again, there is a failure to acknowledge the structural causes of inequality and the documents fall short of providing a strategy for addressing socioeconomic inequalities in palliative and end-of-life care. The lack of evidence on the causes of socioeconomic inequality in palliative and end-of-life care is arguably hindering the development of policy and strategies to reduce inequalities.

The following section outlines the main tenets of life-course theory and presents this theoretical framework as a means for understanding the causes of socioeconomic inequality in palliative and end-of-life care.

2.4 The life-course framework

Theoretical explanations about the causes of health inequality have conventionally been organised into three groups: materialist, behavioural, and psychosocial explanations.[95] The different explanations offer competing hypotheses about the causes of health inequalities. Although pitched against each other, with some useful empirical insights,[117, 118] life-course theory, an approach that draws on all three explanations (material, behavioural and psychosocial) is now widely accepted as the most comprehensive model of the social determinants of health.[1, 95, 119-121] Supported by evidence generated from birth cohort studies, the defining feature of the life-course approach is the emphasis on the cumulative effect of events throughout life, as well as critical events before birth and in childhood, as being important to health outcomes later in life.[122] The following paragraphs provide an introduction to the evidence for the material, behavioural and psychosocial explanations of health inequality, before moving on to discuss the life-course approach in more detail and its relevance to palliative and end-of-life care.

Material explanations refer to the absolute differences in individual resources such as food, housing and sanitation as well as ‘neo-materialist’ resources such as health care, and education, that lead to differences in health. This mechanism is well evidenced in relation to the damage done to health by absolute poverty particularly in low-to-middle-income countries, and in the relationship between income and mortality observed globally.[123, 124] In high-income countries the link between lower income and higher mortality is well documented including in the UK[125], USA[126], Canada[127] and in Europe.[128] Some studies have sought to ascertain the causal direction of this relationship. For example, a study based on a random sample of the Finnish population in 1993-2006 (n=211,639) used structural equation modelling to demonstrate that the causal pathway from low income to poor health later in life was stronger than the opposite hypothesised effect of ‘health-selection’, whereby poor health early on in life leads to lower income.[128]

Drawing on the Bradford Hill criteria for causation[129], the strength and consistency of the evidence on the relationship between income and mortality as well as the demonstrable temporality of the relationship and the step-wise gradient observed for this relationship make a compelling case for a causal relationship. However, the evidence on income does not offer a direct mechanism or explanation for health inequality. Plausibly, it is not income itself that matters to health, rather it is what can be done with income that is important.[95] Evidence on direct material effects highlight hazards in the living environment at home, work-based hazards and poor nutrition as plausible materialist mechanisms.[95] For example, cold is known to increase blood pressure and raise cholesterol levels, providing a plausible explanation for how cold homes lead to worse cardiac health.[130, 131] The link between damp housing and air pollution with respiratory conditions including asthma offer another biologically plausible pathway through which low income, affording poorer quality housing in more polluted areas, causes worse respiratory health. [132, 133] Another example is the higher risk of stomach cancer in adults who had low childhood socioeconomic position, which can be explained by higher prevalence of the infectious agent Helicobacter pylori in families with more children.[134, 135]

A limitation of materialist explanations is that the effect of multiple individual material hazards fails to fully account for the social gradient in health observed in relation to income.[95] This suggests a need to consider alternative mechanisms to those observed through direct material effects. A related problem is the challenge of separating out specific material risk factors from other causes. For example, jobs that expose people to hazards are the same type of jobs with low autonomy and low satisfaction, and with low wages, affording lower quality housing in areas with higher levels of pollution.[95] For most health outcomes, this points to a more complex aetiology than can be explained by singular material factors.[95, 136]

Behavioural/cultural explanations refer to the differences in 'risky' health-related behaviours such as smoking, diet, alcohol consumption and exercise that lead to differences in health.[106, 137-140] Bartley (2008) cautions that implicit to theories of 'individualised behaviour' is the reductionist assumption that due to lower education, people with lower socioeconomic position have less understanding of health and risks and therefore less self-control.[95] The problem with this explanation is that public health interventions that target individual choices around smoking and diet for example have repeatedly been shown to be inadequate for changing behaviour.[120, 141] Although some studies identify a social gradient in the understanding of health risks related to smoking[142], other studies contradict this. For example, a study of 16,483 students aged 18-30 years from 21 European countries, found that understanding of the risk of smoking was actually higher in people who smoke than people who don't smoke, suggesting that education campaigns may have limited effect on behaviour.[143]

An alternative understanding of social patterning in health behaviours draws on Bourdieu's theory of social and cultural capital.[95] This approach emphasises the shared symbolic meanings imbued in certain health-related behaviours such as smoking, diet and exercise, and the pressure on individuals to adopt the behaviours of their social class, thus 'there may be powerful reasons for adhering to certain kinds of behaviours which have nothing whatever to do with people's knowledge or beliefs about health.'[95] This provides a more palatable explanation for differences in 'risky behaviours' but arguably does not give enough weight to the structural causes of different patterns of consumption and the macro-social solutions needed to address unhealthy behaviours. An important observation from successful public health interventions is that health behaviours need to be understood and addressed in the wider context of structural and societal factors.[120] It is now broadly accepted that more restrictive alcohol and tobacco policies are the most successful way to reduce overall consumption, and that targeting individual choices around diet and exercise are inadequate for addressing obesity if the structural causes of nutritional inequality are not addressed, such as the availability and accessibility of food.[120, 141, 144, 145]

In the context of palliative and end-of-life care, there is some evidence that awareness and understanding of palliative care is lower among people who live in more deprived areas.[146] Yet, an awareness raising campaign is unlikely to address inequality in the proportion of people who die at home or in hospice, unless structural inequality in the provision of palliative and end-of-life care services is also addressed.

Psychosocial explanations refer to factors such as social support, control and autonomy at work, and the level of stress, anxiety and depression that result from a person's relative position in the social hierarchy, as being critically important to health. A cornerstone of support for this explanation is that absolute poverty cannot fully explain the existence of health inequality in high-income countries. This point was first demonstrated by evidence from the Whitehall cohort study that showed a social gradient in the health of civil servants, none of whom were living in poverty.[125] The importance of relative inequality is further illustrated by the association between Subjective Social Status and health, independent of the effect of objective socioeconomic position, and the fact that health inequality tends to be greater in countries with higher income inequality.[147, 148 149]

There is also a limit to how far absolute income can impact on population health, demonstrated by the 'Preston Curve' that plots country-level average life expectancy against gross domestic product (GDP) per person.[150] The Preston Curve, shows that the relationship between life expectancy and income is strong up to a point (around $5,000 per person, based on data for the early 2000's) but beyond this the relationship is basically flat.[151]

Biological evidence for psychosocial explanations indicate stress induced damage to blood vessels, and damage to the metabolism and immune system due to excessive 'allostatic load', as plausible ways that psychosocial factors influence health.[152, 153] Allostatic load refers to the multi-system cumulative effect of every-day stressors and more extreme stressful events, in combination with environmental exposures including poor diet, lack of sleep, smoking and alcohol consumption.[153] Measured using biomarkers associated with the neuroendocrine, cardiovascular, immune and metabolic systems, increased allostatic load is observed for people with lower socioeconomic position and is associated with exposure to stress through work and social conditions.[154]

Alongside biological evidence, evidence on the effect of work-based stress on coronary health also makes a compelling case for the psychosocial pathway.[155] Analysis of data from the Whitehall II study, a prospective cohort study of 6895 male and 3413 female civil servants followed up over 5.3 years, provides evidence on the relationship between control, efforts and rewards at work, and coronary health.[156-158] After adjusting for factors including age, sex, coronary risk factors and employment grade, the odds of coronary heart disease were 2.15 times higher for people with 'high efforts and low rewards' jobs compared to those with 'low efforts and high rewards' jobs, 2.38 times higher for people with self-reported low job control, compared to those with high job control, and 1.56 times higher for externally assessed low job control, compared to high job control.[157]

A potential 'buffer' against work-based stress is the support provided by family, friends and the wider community, sometimes referred to as 'social capital'.[159, 160] Evidence on the association between better social support and better health, and on the economic gradient in social support, with people with lower socioeconomic position reporting lower quality social support, suggests another psychosocial route through which low socioeconomic position may influence health.[159, 161, 162] The effects of social support may also be long-reaching, for example poor quality parenting has been found to predict an increased risk of cancer later in life, independent of the effect of socioeconomic position.[163]

Life-course theory offers a way to combine evidence on multiple different aetiological pathways. Incidentally, this more comprehensive approach to understanding drivers of health seems well-aligned with the holistic model of patient care that is characteristic of good palliative and end-of-life care, and set apart from more traditional biomedical models of healthcare that focus on physical factors.[164, 165]

Drawing on theories from demography and sociology, the important contribution of the life-course approach is the positioning of the effects of socioeconomic advantage and disadvantage as cumulative over the life-course and the influence of wider societal contexts on the lives of individuals.[122] Early biological studies that drew attention to the link between low birth weight and later life poor health outcomes including diabetes, lung disease, and cardiac disease, were important for generating the first evidence on the far-reaching consequences of events in critical periods in early life.[166, 167] Subsequent studies demonstrating a strong association between low maternal socioeconomic position and low birthweight provided further insight into ‘the causes of the causes’ of low birth weight.[1, 168]

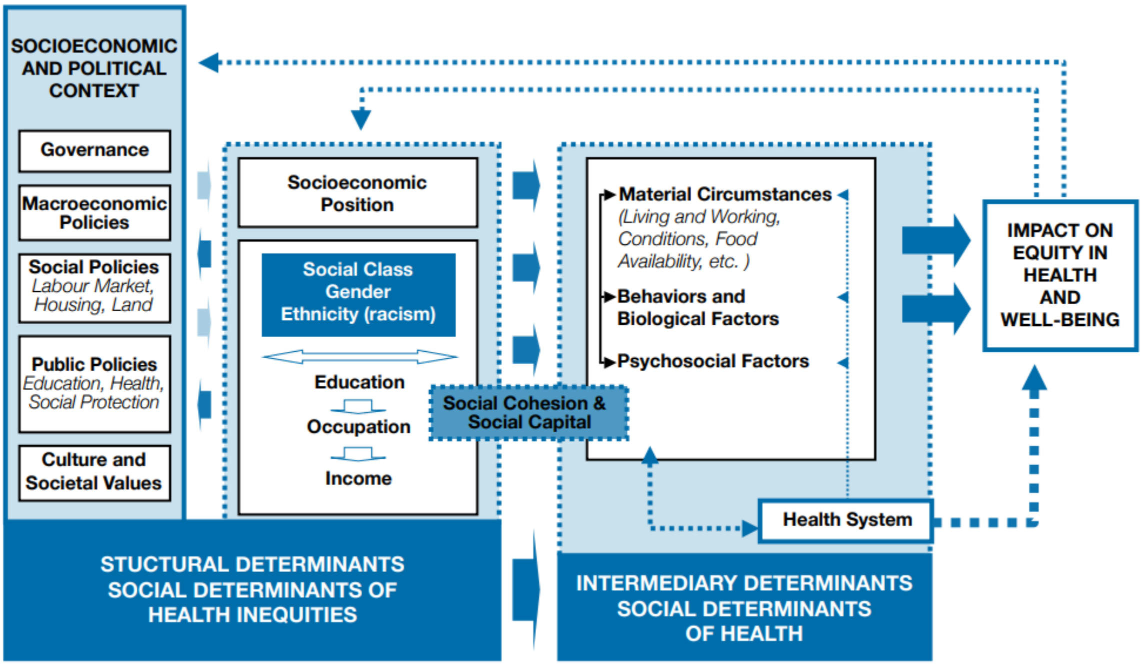
Analysis of data from birth cohort studies has been fundamental to strengthening evidence on the temporal and cumulative nature of the effect of social disadvantage on health. An example of this evidence is from a Scottish cohort study with 21 years of follow-up data. One analysis of this cohort study using measures of occupational-based social class from three time points, found that compared to men classified as non-manual at all three timepoints, the age adjusted death rate from all causes was 1.29 (1.08, 1.56) for men with one manual classification, 1.45 (1.21, 1.73) for men with two manual classifications, and 1.71 (1.46, 2.01) for men classified as manual at all three time points.[169]

Bartley (2008) provides the following reflections on the important role of longitudinal cohort studies in the development of life-course theory:

> *"Stressful events and hazardous exposures can no longer be thought of as just happening and having their effect on health at a single time point. They are experienced by people who each have a history, going right back to their gestation. It is a lot easier to see why social and material circumstances have such powerful effects when we think of them as part of a series of 'vicious' and 'virtuous' circles, in which events at one point in time influence future events. In these sequences, health can be both an outcome of previous events and also a cause of future ones..."*
>
> *"It seems strange now that we ever relied so much on cross-sectional data that only gave health and social information at a single point in time. Absorbing the messages of life-course research into policy debates on health inequality may take some time, but the latest report from the Institute of Health Equality recommended 'the life course [is] emerging as the right way to plan action on the social determinants of health' (Marmot 2013: 8)"*[95]

A central feature of the life-course approach is the focus on generating evidence on an aetiological causes to inform action to address health inequalities.[120] The conceptual model developed by the World Health Organisation (WHO) Commission on the Social Determinants of Health (shown in figure 7) provides a useful framework for thinking about the pathways between social factors and health outcomes and potential areas for action.[121]

Figure 7: World Health Organisation (WHO) Commission on Social Determinants of Health, conceptual framework, source [121]



In the above conceptual model social factors are separated into ‘intermediary determinants’ through which ‘structural determinants’ defined as the social, economic and political context, impact on health and wellbeing. The three explanations – material, behavioural and psychosocial factors – are included as intermediary determinants, caused by the structural determinants and in turn having a causal effect on health. ‘Social cohesion’ and ‘social capital’ are positioned as a separate but interrelated set of factors important in both the structural and intermediary domains, and ‘health systems’ have a potentially moderating role between the social determinants and health. Applying a life course perspective to understanding socioeconomic inequality in palliative and end-of-life care implies an acknowledgment of the upstream and structural causes of inequalities, whilst seeking out mechanisms and potential areas for action downstream.

The social determinants of health approach is essentially a model of ‘social causation’, where social inequality is seen to cause health inequality.[121] However, it is entirely possible that poor health can lead to lower socioeconomic position, for example by limiting capacity to engage in education, work or through social discrimination.[170, 171] Effects may also act simultaneously, for example in relation to depression which has been shown to be a cause and effect of poverty.[172] The causal ‘feedback’ arrows in the WHO model (figure 7) allow for the effect that health might have on both individual socioeconomic position and societal structures. An example of ‘health selection’ towards the end of life, is the evidence on how serious illness can push people into poverty through loss of income for patients and carers and through increased out-of-pocket care costs.[173]

At a population level, the evidence for social causation of health inequality is stronger and more consistent than the evidence for health selection.[97, 119, 174, 175] Temporality is important, many health inequalities are observed later in life and are therefore most plausibly caused by an accumulation of disadvantage over the life course.[119, 156] When social causation and health selection are pitched against each other, each is difficult to prove definitively within the standard epidemiological framework.[119, 129] The debate is really more a question of ideological standpoint than of scientific proof.[119] Still, within a 'social causation' approach, an awareness of the potential for bi-directional causal pathways and attempts to account for temporality in statistical models is important for building evidence on the social determinants of health.

The next section sets out the theoretical considerations of measuring socioeconomic position for older people that are critical to generating high quality evidence on the causes of social inequality.

2.5 Socioeconomic position, definition and measurement

Socioeconomic position refers to a person's position in the social hierarchy, and to 'the socially derived economic factors that influence the position individuals or groups hold within the multiple-stratified structure of a society'.[176] In the UK, socioeconomic position is overwhelmingly the preferred term amongst social theorists, arguably carrying fewer of the negative connotations associated with social class or socioeconomic status.[95, 119, 177, 178] Socioeconomic position is a multifaceted social construct, influenced and reflected by many factors including education, income, occupation, and social capital.[177] It lacks a precise definition or single approach to measurement and largely depends on the social structures and contexts within which it is defined. The way that we measure socioeconomic position and the intended purpose of that measurement requires careful consideration.[95] In palliative and end-of-life care research, as in much of health research, approaches to measuring socioeconomic position have been broad, incorporating the common measures of income, education and occupation, as well as area-based measures and classifications based on the type of health insurance.[178]

There can be no perfect measure of socioeconomic position, estimates will always contain an element of error and bias, yet some measures are more appropriate for certain outcomes, populations or analyses than others.[178-180] Commonly used measures of socioeconomic position such as education, occupation and income, present particular challenges in older populations.[180] Education tends to be better as a measure of privilege because the majority of older people finished school at compulsory leaving age.[180] Occupation is problematic because most older people are retired and for older women, even historical occupation tends to be poor indicator of socioeconomic position.[180] Income is closely related to occupation and has similar limitations. Household indicators such as car ownership and housing tenure are potentially useful indicators of wealth but are not applicable to people living in institutions.[179] Housing tenure is highly context and cohort specific being extremely common in older populations in the UK, although this trend is declining.[179] Lack of access to a car could also be the outcome of a health problem, leading to problems with reverse causality.[179]

A recent review of measures of socioeconomic position in studies of health and mortality in older populations concluded that measures should be selected i) based on theory; ii) with consideration of how the context and meaning of measures might change over time and between countries; and iii) to maximise the detection of a social gradient.[179] Measures that dichotomise samples (such as housing tenure or car ownership) or group large proportions into one class (such as education), may be less useful for studying the health gradient than measures that produce equal hierarchical categories and capture variance in low socioeconomic position, such as quintiles of wealth or area-based deprivation.

Area-based measures provide robust numerical measures that are widely applicable and have been shown to be useful for understanding the social gradient in health.[1] Area-based measures are often available as composite indices measuring multiple dimensions of socioeconomic position such as income, employment, crime, and housing. Given that socioeconomic position is itself a multifaceted concept, composite measures may provide the best estimates of inequality, but individual-level measures that capture singular aspects of socioeconomic position are likely to be more informative for understanding mechanisms; both approaches are needed for a detailed understanding of the causes of socioeconomic inequality in health.[177] A limitation of area-based measures is that they attempt to infer something about an individual from aggregate data, known as the ecological fallacy, this also makes area-based measures less useful for studying causes.

Acknowledging the discrete and temporal nature of different measures of socioeconomic position is critical to the life-course perspective, and to generating evidence on the social determinants of health.[181] Education, reflecting socioeconomic position in early adulthood is likely to have a weaker effect on later life health than occupation, income, or wealth which capture socioeconomic position closer in time to the outcomes being studied.[182] Wealth, if based on detailed information about savings, investments, physical assets and debt, is the 'gold standard' measure for investigating health inequality in older people because is captures assets accumulated over the life course and has been shown to have a stronger relationship to mortality than other measures including education, occupation or income.[182] Yet, few studies measure wealth because of the detailed data required to capture a valid measure.

A final issue to consider in the measurement of socioeconomic position is the interaction between socioeconomic position and other factors like age and health. Important for studies on older people, is an awareness that the effect of socioeconomic position on health is known to dimmish with older age. This could be caused by mortality bias given that fewer people with lower socioeconomic position live into old age, or be the result of other factors such as health becoming more important to subsequent health events than socioeconomic position.[182, 183] Older people are also likely to experience a set of intersecting factors including poor health, low socioeconomic position, and social isolation. Studies that attempt to account for the relationship between socioeconomic position and other factors and consider the fluctuating effect of socioeconomic position are critical for generating detailed evidence on the social determinants of health for older people.

CHAPTER 3: Rationale for this work, aims and objectives

There is an urgent need to plan the delivery of health and social care for the increasing number of people living with advanced, multimorbid illness and old age. This challenge sits against a backdrop of widening societal inequality and widening health inequalities in many high-income countries. Evidence on socioeconomic inequality in end-of-life care is mounting. Worryingly, in relation to place of death in the UK, inequalities appear to have widened over the last 20 years. In the wider UK literature on the social determinants of health, palliative and end-of-life care is largely absent and within UK end-of-life policy there has been a lack of focus on addressing socioeconomic inequality. It is not enough to attempt to improve palliative and end-of-life care for everyone, addressing inequality will require targeted interventions and ‘proportionate universalism’ to take account of different levels of need. An overarching review of the international evidence on socioeconomic inequality in outcomes important to older people towards the end of life is lacking. A more detailed understanding of the reasons for socioeconomic inequality in palliative and end-of-life care is needed to help identify ways to provide care more equitably.

Aim

To investigate patterns and determinants of socioeconomic inequality in palliative and end-of-life care for older adults, and to explore potential mediating factors of the relationship between socioeconomic position and patterns of care towards the end of life.

Objectives

1) To systematically identify, synthesise, and quantify existing evidence on the association between socioeconomic position and healthcare in the last year of life and to report how socioeconomic position has been measured within this literature.

2) To investigate potential pathways between socioeconomic position and receipt of hospital-based care towards the end of life.

3) To analyse the association between socioeconomic position and the symptoms and other concerns of older adult hospital inpatients referred for specialist palliative care.

4) To generate new knowledge on the social determinants of palliative and end-of-life care, and to inform future priorities for policy, practice, and research, to reduce socioeconomic inequality in end-of-life care.

PART 2: The study overview, methods, ethics and results including publications

CHAPTER 4: Overview of this work

4.1 Population of interest

The population of interest is older people towards the end of life across the socioeconomic strata. Health inequality is observed as a gradient. This is important because health inequality is not only a problem only for those who are worst-off in society, but a problem for everyone below those at the very top who have the highest socioeconomic position and best health.[1] This thesis is interested in understanding the socioeconomic gradient in patterns of care towards the end of life and therefore takes a whole-population quantitative approach, rather than focusing only on the experiences of the poorest in society.

Older age is sometimes defined as people aged 65 years and over, in line with the national retirement age in the UK and Medicare eligibility cut-off in the USA.[66, 184-186] End-of-life can be defined as the last year, last months, or last weeks of life, or by diagnosis or stage of advanced disease.[187, 188] In this thesis, decisions about how to define the population of interest were influenced by the availability of data and these decisions are described in the following section.

4.2 Study design and link to objectives

This thesis has three secondary analysis components, each aligned with a different objective, summarised in table 2.

Table 2: Summary of study components and associated objectives

Component	**Objective**
1. Systematic review, meta-analysis and dose-response analysis	1. To systematically identify, synthesise, and quantify existing evidence on the association between socioeconomic position and healthcare in the last year of life and to report how socioeconomic position has been measured within this literature.
2. Secondary analysis of a prospective longitudinal cohort study with a retrospective mortality follow-back survey, the English Longitudinal Study of Ageing (ELSA)	2. To investigate potential pathways between socioeconomic position and receipt of hospital-based care towards the end of life.
3. Secondary analysis of prospectively collected routine clinical data on hospital inpatients receiving specialist palliative care	3. To analyse the association between socioeconomic position and the symptoms and other concerns of older adult hospital inpatients referred for specialist palliative care.
Overarching objective 4 To generate new knowledge on the social determinants of end-of-life care, and to inform future priorities for policy, practice, and research, to reduce socioeconomic inequality in end-of-life care.	

4.3 Integration of the thesis

The three components of the thesis offer complimentary insights into socioeconomic inequality in palliative and end-of-life care. Figure 8 gives an overview of the study design and objectives and table 3 summarises the definitions and measures used in each of the three studies. The systematic review and meta-analysis provide the 'big picture' international evidence and strengthens our understanding of the relationship between socioeconomic position and a comprehensive set of palliative and end-of-life care process measures. The systematic review also identifies 2 gaps in the existing literature, 1) a lack of studies investigating the causes of socioeconomic inequality in palliative and end-of-life care, and 2) a lack of studies investigating socioeconomic inequality in the symptoms and needs of patients using validated patient centred outcome measures. The secondary analysis of the English Longitudinal Study of Ageing (ELSA) and the secondary analysis of the clinical data address these gaps.

The English Longitudinal Study of Ageing (ELSA), a uniquely powerful dataset containing a rich set of socioeconomic variables alongside measures of hospital-based care towards the end of life. The secondary analysis of ELSA draws on the prospective collection of longitudinal data from ELSA, a study designed specifically to investigate the social determinants health, and uses the ELSA mortality follow-back data. The analysis is the first to attempt to empirically evaluate potential mediators of the relationship between socioeconomic position and the use of hospital care towards the end of life, and the first to report on the ELSA end-of-life proxy data.

The secondary analysis of routinely collected clinical data provides a different perspective, using a large clinical dataset linked to an area-based measure of deprivation, and focusing on a time-period much closer to death. This shifts the focus from the measures of process and service utilisation investigated in the systematic review and ELSA analysis, towards using patient centred outcome data to understand socioeconomic inequality in the symptoms and concerns of hospital inpatients as they are initially assessed by specialist palliative care. This analysis is important for understanding if the needs of patients, a potential mediator of other process outcomes, are influenced by socioeconomic position.

Figure 8: Overview of study design and objectives

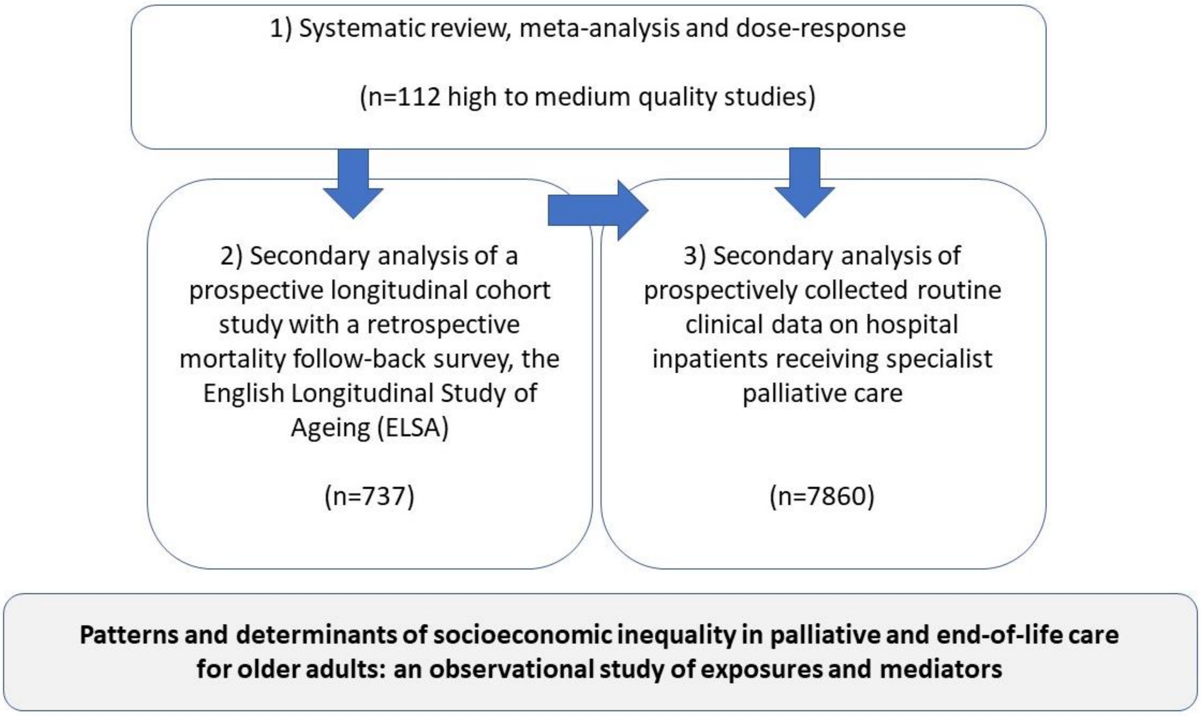


Table 3: Definitions and measures used in the thesis

Thesis component and study design	Definition of older people	Definition of end of life	Measures of socioeconomic position	Outcomes
1) Systematic review	Aged ≥18 years (not restricted to older people to avoid complicating search criteria and limiting available evidence)	At least 80% of the sample were in the last year of life (based on date of death or diagnosis of advanced disease)	Any measure of socioeconomic position including: income, education, area-based deprivation, housing, employment.	place of death, acute care admission, use of specialist palliative care, use of non-specialist end-of-life care, use of advance care planning, and quality of care
2) Secondary analysis of English Longitudinal Study of Ageing (ELSA) – case series design using mortality follow-back data	Aged ≥50 years (to maximise sample size)	Cohort of deceased ELSA participants, outcomes included hospital admissions in the last 2 years of life	Wealth and education.	Place of death (hospital versus home/hospice), and <3 versus ≥3 hospital admissions in the last 2 years of life.
3) Secondary analysis of hospital inpatient data - cross-sectional cohort study	Aged ≥60 years	Cohort of hospital inpatients seen by specialist palliative care	Area-based deprivation linked to patient postcode, using Index of Multiple Deprivation (IMD).	Symptoms and concerns measured using the Integrated Palliative Care Outcome Scale (IPOS)

4.4 Methodological considerations

4.4.1 Use of secondary data sources

This thesis synthesises data from existing observational studies and uses secondary analysis of nationally representative longitudinal cohort data and secondary analysis of routine clinical data. The major advantage of secondary analysis is that these data exist beforehand and usually on a larger number of patients than would typically be possible to include in a primary research study. Secondary analysis of whole-population or nationally representative data is extremely useful for investigating inequalities because it provides data representative of the full social strata. Routine data analysis has the potential to inform better and more equitable palliative and end-of-life care, through monitoring trends, investigating inequalities and evaluating interventions using quasi-experimental techniques.[189, 190]

Routine data are increasing used in palliative and end-of-life care research, as more robust methodologies are being developed and sources of data are becoming increasingly accessible.[191] The Covid-19 pandemic has accelerated data access in the UK, leading to more data linkage including of national primary care data to secondary care data and mortality data, and better remote access through trusted research environments (TREs).[192] Patient Centred Outcome Measures (PCOMs) are increasing becoming part of routine data collected in National Health Service (NHS).[79, 193, 194] In end-of-life care PCOMs are widely used in research and increasingly in clinical care.[85, 195] PCOMs collect data on outcomes that are meaningful to patients and families and are considered the best way to evaluate the quality of care by capturing changes in patient’s health status or quality of life.[79]

The UK is home to the most well established population cohort studies in the world; 34 large scale cohorts, with 2.2 million (3.5% of the UK population) active participants are operational, costing £27.6m to administer annually.[196] These studies, including the English Longitudinal Study of Ageing (ELSA), are used to study the health and well-being of our population and to investigate social inequality in health.[197-204] ELSA is useful for end-of-life care research because of the inclusion of the mortality follow-back element, yet, prior to the work done in this thesis, the end-of-life proxy data had not be reported. With a small number of exceptions[205, 206], large-scale population cohort studies have been overlooked in palliative and end-of-life care research, despite offering opportunities for studying the end of life and with growing numbers of deceased cohort members. More use of these resources could help to promote the collection of future mortality follow-back data and encourage better linkage of population cohort data to mortality and routinely collected health records.

4.4.2 Patient and public involvement in secondary analysis

In 2019, I was part of a group at the Cicely Saunders Institute who delivered a 1-day workshop with patient and public representatives on ‘large dataset research in palliative care’ to explore patient and public involvement (PPI) in secondary analysis studies. Below is a publication providing a summary of the findings from this workshop.

At the beginning of the thesis, I recruited two PPI members to join project meetings held every 6 months with the supervisors and external experts. On refection, these meetings were too technical to be useful for PPI members and we decided jointly with the PPI members that the PPI resources would be best spent towards the end of the project. In the final stages of the project following submission of the thesis, we have planned a half day PPI ‘round table’ to discuss the findings of the work with a group of 6 PPI members to get their input on the interpretation of the findings, plans for wider dissemination, and identification of next steps for this area of research.

PALLIATIVE MEDICINE

Letter to the Editor

Palliative Medicine
2021, Vol. 35(9) 1724–1726

DOI: 10.1177/02692163211002101
journals.sagepub.com/home/pmj
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Opportunities for public involvement in big data research in palliative and end-of-life care

Public involvement – the process by which research is conducted in collaboration with patients, carers or members of the public – is increasingly considered a prerequisite for high-quality research.[1] Evidence suggests that public involvement can benefit research by helping to identify and prioritise patient-focused research questions, aiding recruitment and retention, and helping to foster greater links between researchers and the wider community.[2–4]

Public involvement is encouraged across the research cycle and guidance has been developed to support researchers to involve the public at each stage.[5,6] However, currently, such guidance is focused on studies which include primary data collection, and there is little guidance on how to meaningfully involve the public in big data research.

Big data research takes many forms.[7,8] In palliative care, this research often involves secondary analysis of routinely collected data (i.e. data initially collected for other purposes other than research, as part of a standard administrative or care process) such as death registry data and electronic health records.[9,10]

Differences in the reported presence of public involvement across studies have shown that involvement in big data research is significantly limited in comparison with other study designs.[11] It has been suggested that this may be because common approaches to public involvement adopted in primary data research are not appropriate within big data analysis studies.[12,13] While public members are commonly involved in primary research to review and develop patient information leaflets or other research materials, undertake interviews with research participants or even support recruitment for a clinical trial, these involvement opportunities are not applicable to big data research.[13,14] In addition, the highly data driven discussions that underline this type of research can present a barrier to public involvement with ‘unfamiliar’ and ‘scientific’ language repeatedly being cited as an obstacle, across fields.[15] Due to this there is now growing recognition that public involvement in big data research requires special considerations.[13]

With the increasing opportunity for big data research in palliative and end-of-life care,[9] and in parallel, a requirement by many funders, both nationally and internationally, to actively involve the public within research, we aimed to explore both the challenges and opportunities for public involvement in big data research to understand how best to involve the public in these studies.

In November 2019, we held a full-day public involvement workshop at the Cicely Saunders Institute of Palliative Care and Rehabilitation at King’s College London on the theme ‘large dataset research in palliative care’. The purpose of the workshop was to explore public views on involvement within big data research. The workshop was attended by 10 patient, carer and public representatives with lived experience of, or interest in, palliative and end of life care and seven researchers. During the workshop public attendees were introduced to key concepts of big data research, initiating group discussion around data availability and access, the advantages and disadvantages of this kind of research, and data governance and ethics. In the afternoon, two researchers led a discussion to understand public views on the perceived challenges, opportunities, and value of involvement in these studies.

While most public attendees had experience of involvement in palliative care research, few had experience in big data research and perceived that over-use of jargon (e.g. ‘routine data’) was an initial barrier to involvement in this research. Many were also unaware of the concept of ‘big data’; what kinds of data were available and how data could be used for research. Acknowledging these challenges, public attendees felt their involvement in these studies remained important. The discussion led to several perceived potential opportunities for public involvement in big data research (see Table 1).

Public involvement could enhance the relevance and impact of big data research in palliative care, by helping researchers to set research priorities and raise public understanding and acceptability of the use of this data for research. Our workshop provided a useful exercise to identify patient and public views on involvement in big data research within the field of palliative care. These findings provide an initial stepping stone in the path to building guidance for undertaking meaningful involvement in these types of studies, though further

Table 1. Opportunities for involving the public in big data research in palliative and end of life care.

Raise public awareness of big data research

- Public awareness of big data research projects should be raised, including increasing understanding of terminology such as 'routinely collected', 'big data' and 'secondary analysis', how data are accessed for research, what data are provided to researchers (e.g. specific variables), how data are provided (e.g. anonymised, safely transferred), how patient confidentiality is maintained, and the benefits and limitations of the use of these types of data in research.

Involve patients, carers and the public in research priority setting with existing data sets

- Palliative care researchers and/or research groups should develop a list of palliative and end of life care research questions which could be answered using currently available data sets and work with patients, carers and the public to prioritise which research questions to pursue.

Involve patients, carers and the public to 'humanise' big data

- Patients, carers and the public should be involved in the interpretation of the results, particularly in providing personal narratives to compliment or rebut trends and patterns in the data. Further work is needed to understand the best ways of involving patients and the public at this stage to ensure involvement is meaningful.

Prioritising next steps for research

- Patients, carers and the public could help develop and advise on future research questions arising from trends and patterns identified in the data. Follow-up qualitative studies, which patient and public involvement contributors could continue to be involved in, were perceived to be one way to ensure continued and meaningful involvement.

Involve patients, carers and the public in the wider lifecycle of big data

- Patients, carers and the public felt they should play a role in helping to push the agenda of standardising and collecting data from relevant palliative and end of life care services such as care homes and hospices, and also help researchers to develop person-centred palliative and end of life care outcomes which would lend themselves to routine collection.
- Patients, carers and the public should be involved in the governance and curation of national and local data sets to ensure patient confidentiality is maintained.

consultation with the public and researchers across settings is needed. Continuing to share examples of involvement in big data projects will also be important to increase researchers understanding, and confidence, of involving the public in these projects.

Acknowledgements

Thank you to all the patient, carer and public contributors and researchers who attended and participated in the workshop.

Authorship

HJ, JMD, JL, EC conceived the initial idea for the workshop. The workshop was facilitated by HJ, JMD, JL, EC, KS and was attended by SM as a public contributor. The final manuscript was drafted by HJ. All authors contributed to critical revisions to the manuscript and approved the final version for publication.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical considerations

As this was a public involvement workshop rather than primary research, ethical approval was not required.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The patient and public involvement workshop was supported as part of the National Institute for Health Research (NIHR) Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

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References

1. INVOLVE. Briefing note two: What is public involvement in research? https://www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research/ (2012, accessed 14 April 2020).
2. Brett J, Staniszewska S, Mockford C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect* 2014; 17: 637–650.
3. Crocker JC, Ricci-Cabello I, Parker A, et al. Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis. *BMJ* 2018; 363: k4738.
4. Staley K. *Exploring impact: public involvement in NHS*. Eastleigh: INVOLVE, Public Health and Social Care Research, 2009.
5. NIHR INVOLVE. Briefing notes for researchers: public involvement in NHS, public health and social care research, https://www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/ (2012, accessed 06 October 2020).

6. NIHR Research Design Service East Midlands. Public involvement research cycle, https://www.rds-eastmidlands.nihr.ac.uk/public-involvement-research-cycle (2020, accessed 08 October 2020).
7. Auffray C, Balling R, Barroso I, et al. Making sense of big data in health research: towards an EU action plan. *Genome Med* 2016; 8: 71.
8. Dash S, Shakyawar SK, Sharma M, et al. Big data in healthcare: management, analysis and future prospects. *J Big Data* 2019; 6: 54.
9. Davies JM, Gao W, Sleeman KE, et al. Using routine data to improve palliative and end of life care. *BMJ Support Palliat Care* 2016; 6: 257–262.
10. Tanuseputro P. Delivering care to those in need: improving palliative care using linked data. *Palliat Med* 2017; 31: 489–491.
11. Wilson P, Mathie E, Keenan J, et al. ReseArch with patient and public involvement: a realist evaluation – the RAPPORT study. *Health Serv Deliv Res* 2015; 3: 39–41.
12. Johnson H, Ogden M, Brighton LJ, et al. Patient and public involvement in palliative care research: What works, and why? A multi-perspective qualitative evaluation. *Palliat Med* 2020; 35(1): 151–160.
13. Quiroz-Aitken M, Tully MP, Porteous C, et al. Consensus statement on public involvement and engagement with data-intensive health research. *Int J Pop Data Sci* 2019; 4: 2–5.
14. Hobbs G and Tully MP. Realist evaluation of public engagement and involvement in data-intensive health research. *Res Involv Engage* 2020; 6: 37.
15. Thompson J, Barber R, Ward PR, et al. Health researchers' attitudes towards public involvement in health research. *Health Expect* 2009; 12: 209–220.

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4.5 Ethical considerations

Secondary analysis of the English Longitudinal Study of Ageing (ELSA) is actively encouraged by the data owners, the National Centre for Social Research, and is supported through a dedicated website (https://www.elsa-project.ac.uk/). The anonymous patient level data from ELSA is downloaded directly from the UK Data Service (https://ukdataservice.ac.uk/). No additional ethical approval was needed for the analysis of the anonymised ELSA data used in this thesis in line with King's College London ethics procedures.

Secondary analysis of the clinical data was carried out as a service evaluation and approved by King's College Hospital information governance department. I have access to this clinical dataset as part of an honorary appointment with King's College Hospital. The data used was fully anonymised so no further ethical approval was needed within the guidance provided by King's College Hospital and King's College London ethics committee.

4.6 Overview of results

The results of this thesis are presented in three published papers.

Paper 1 systematically identifies, synthesises, and quantifies existing evidence on the association between socioeconomic position and use of healthcare in the last year of life. This systematic review and meta-analysis found consistent evidence that in high-income countries, low socioeconomic position is associated with death in hospital (versus home or hospice), hospital admissions during the last three months of life, and not accessing specialist palliative care in the last year of life. Included studies relied heavily on measures of area-based deprivation and education and the review found no studies that investigated mediating pathways to explain why this inequality exists.

Paper 2 addresses a gap identified in the systematic review, by investigating potential causal pathways between socioeconomic position and receipt of hospital-based care towards the end of life. The analysis estimated the direct effect of two individual level exposure measures of socioeconomic position, education, wealth, on death in hospital and frequent hospital admissions in the last two years of life, and the indirect effect of these exposures via three potential mediators: health and function, access to health-care services, and social support. The study found that worse health partly explains why people with lower wealth have more hospital admissions.

Paper 3 investigates the relationship between socioeconomic position and health needs in more detail, focusing on patients who are approaching the end of their lives. This paper analyses the association between socioeconomic position and the symptoms and other concerns of older adult patients seen by specialist palliative care at two large London-based teaching hospitals between 2016 and 2019. This paper addresses another gap identified in the systematic review - a lack of data on the association between socioeconomic position and patient centred outcome measures - and extends the limited existing literature on this topic previously based only on cancer patients, to a large cancer and non-cancer population of hospital inpatients.

CHAPTER 5: Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis

There is longstanding evidence on the association between area-based deprivation and place of death in England[37, 60, 102] The aim for this work was to investigate whether the inequality observed for place of death in England, also existed in other high-income countries, and in relation to end-of-life outcomes other than place of death. The systematic review was designed to be a comprehensive review of the international evidence, it included studies that presented an association between any measure of socioeconomic position (including: income, education, and area-deprivation) alongside a comprehensive set of outcomes that included: place of death, hospital admission in the last three months of life, use of specialist palliative care, use of non-specialist end-of-life care, use of advance care planning, and quality of care measured through patient-centred outcome measures. Outcomes were selected based on discussions with my supervisors about the type of studies that the review was likely to find. I restricted the review to empirical, observational studies, excluding experimental and qualitative designs because I was interested in understanding inequality at a population level. Whole-population or nationally representative studies were rated as higher quality than studies using non-representative samples.

As a secondary objective, the review reports how socioeconomic position was measured in the literature. I expected to find a large proportion of studies using area-based measures, particularly among studies using routinely collected data where area-based measures are often the only measure of socioeconomic position available.

5.1 Dose-response analysis

The systematic review was designed to generate data on a large international body of evidence covering a comprehensive set of end-of-life outcomes. A challenge was how to analyse the data most effectively to strengthen the overall evidence beyond the sum of the individual studies. In a standard meta-analysis, for comparable studies, single estimates from each study are pooled to produce an overall estimate for the effect of an exposure, weighted by the sample size of the studies.[207] In this review, the effect of interest was the adjusted odds ratio comparing people with the lowest and highest socioeconomic position. This way of summarising results is limited by focusing on a single estimate, comparing two groups (those with the lowest and highest socioeconomic position) and discarding data on the groups in between. A dose response meta-analysis overcomes this limitation by making use of all the available effect sizes.[208, 209] For studies that present data on the exposure as a categorical or a numerical variable, this method uses all of the reported estimates to summarise evidence on the dose-response curve or gradient. Evidence on the gradient is important for understanding socioeconomic inequality in health and addresses one of the criteria for establishing causality in epidemiological studies.[129]

The limitation of a dose-response meta-analysis is that studies that present data on the exposure as a binary variable cannot be included. Therefore, the dose-response analysis was used alongside a standard meta-analysis of single effects, to incorporate a larger number of studies.

5.2 Paper 1 (see Appendix 1 for supplementary information)

PLOS | MEDICINE

RESEARCH ARTICLE

Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis

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Abstract

Background

Low socioeconomic position (SEP) is recognized as a risk factor for worse health outcomes. How socioeconomic factors influence end-of-life care, and the magnitude of their effect, is not understood. This review aimed to synthesise and quantify the associations between measures of SEP and use of healthcare in the last year of life.

Methods and findings

MEDLINE, EMBASE, PsycINFO, CINAHL, and ASSIA databases were searched without language restrictions from inception to 1 February 2019. We included empirical observational studies from high-income countries reporting an association between SEP (e.g., income, education, occupation, private medical insurance status, housing tenure, housing quality, or area-based deprivation) and place of death, plus use of acute care, specialist and nonspecialist end-of-life care, advance care planning, and quality of care in the last year of life. Methodological quality was evaluated using the Newcastle-Ottawa Quality Assessment Scale (NOS). The overall strength and direction of associations was summarised, and where sufficient comparable data were available, adjusted odds ratios (ORs) were pooled and dose-response meta-regression performed.

A total of 209 studies were included (mean NOS quality score of 4.8); 112 high- to medium-quality observational studies were used in the meta-synthesis and meta-analysis (53.5% from North America, 31.0% from Europe, 8.5% from Australia, and 7.0% from Asia). Compared to people living in the least deprived neighbourhoods, people living in the most deprived neighbourhoods were more likely to die in hospital versus home (OR 1.30, 95% CI 1.23–1.38, $p < 0.001$), to receive acute hospital-based care in the last 3 months of life (OR 1.16, 95% CI 1.08–1.25, $p < 0.001$), and to not receive specialist palliative care (OR 1.13, 95% CI 1.07–1.19, $p < 0.001$). For every quintile increase in area deprivation, hospital versus home death was more likely (OR 1.07, 95% CI 1.05–1.08, $p < 0.001$), and not receiving specialist palliative care was more likely (OR 1.03, 95% CI 1.02–1.05, $p < 0.001$). Compared

Citation: Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, Verne J, et al. (2019) Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLoS Med 16(4): e1002782. https://doi.org/10.1371/journal.pmed.1002782

Academic Editor: Holly Gwen Prigerson, Weill Cornell Medical College, UNITED STATES

Received: October 9, 2018

Accepted: March 14, 2019

Published: April 23, 2019

Data Availability Statement: All relevant data are within the manuscript and its Supporting Information files.

Funding: JMD is supported by a Research Training Fellowship from The Dunhill Medical Trust (RTF74/0116); //dunhillmedical.org.uk/. KES is supported by a National Institute for Health Research (NIHR) Clinician Scientist Fellowship (CS-2015-15-005); nihr.ac.uk. MM is supported by a National Institute for Health Research (NIHR) Career Development Fellowship (CDF-2017-009); nihr.ac.uk. IJH holds

to the most educated (qualifications or years of education completed), the least educated people were more likely to not receive specialist palliative care (OR 1.26, 95% CI 1.07–1.49, $p = 0.005$).

The observational nature of the studies included and the focus on high-income countries limit the conclusions of this review.

Conclusions

In high-income countries, low SEP is a risk factor for hospital death as well as other indicators of potentially poor-quality end-of-life care, with evidence of a dose response indicating that inequality persists across the social stratum. These findings should stimulate widespread efforts to reduce socioeconomic inequality towards the end of life.

an NIHR Emeritus Senior Investigator Award; nihr.ac.uk. This work was supported by the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London at King's College Hospital NHS Foundation Trust. The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests: The authors have declared that no competing interests exist.

Abbreviations: LTC, long-term care; NOS, Newcastle-Ottawa Quality Assessment Scale; OR, odds ratio; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; RR, risk ratio; SEP, socioeconomic position.

Author summary

Why was this study done?

- Social inequality in health is a global phenomenon; people with lower socioeconomic position (SEP) experience earlier onset of disease and have reduced life expectancy.
- Studies have identified low SEP as a risk factor for worse care at the end of life, and several socioeconomic factors have been identified as determinants of care towards the end of life.
- Despite growing recognition, no empirical synthesis of evidence exists to support efforts to reduce socioeconomic inequality at the end of life.

What did the researchers do and find?

- We carried out a systematic review of studies that reported an association between a measure of SEP (including income, education, occupation, private medical insurance status, housing tenure, housing quality, or area-based deprivation) and healthcare received by adults in their last year of life (including place of death, use of acute care, use of specialist palliative care, use of nonspecialist end-of-life care, use of advance care planning, or quality of care) in high-income countries.
- A total of 209 studies were included in the review; we found consistent evidence that low SEP increases the odds of hospital versus home death and of using acute care services in the last 3 months of life and reduces the odds of using specialist palliative care in the last year of life.
- We also found that measurement of SEP in this field is dominated by measures of area deprivation and education, and justification for choice of SEP measure(s) is often inadequately described.

What do these findings mean?

- We have found consistent evidence of socioeconomic inequality in the care received by people towards the end of life, in that people with lower SEP are more likely to experience worse care.
- We must now make further efforts to reduce this inequality.
- We recommend the following: that all research on care received towards the end of life should attempt to account for SEP, end-of-life care interventions should be analysed for their different effects across the social strata, and the planning and provision of end-of-life care services should consider SEP in local populations.

Introduction

Social inequality in health status, access to, and quality of healthcare is a global phenomenon [1]. For example, in the United Kingdom, people living in the most deprived neighbourhoods (measured using the Index of Multiple Deprivation at Lower Layer Super Output Area Level) have a life expectancy up to 7 years shorter, and experience the onset of disease and disability as much as 17 years earlier, than people living in the least deprived neighbourhoods [2]. Explanations for the social determinants of health emphasise the cumulative effect of events throughout the life course on health outcomes later in life [3]. Structural (policy and culture), individual (material, behavioural, and psychosocial), and health-system factors all contribute to health inequality [3].

In high-income countries, proposed population-level quality indicators for end-of-life care include receipt of specialist palliative care, hospital admissions in the last months of life, emergency department attendance in the last months of life, and whether people are supported to be cared for in their usual place of residence rather than in hospital [4]. In Canada, the United States, and the UK, lower socioeconomic position (SEP; measured through neighbourhood deprivation) is associated with increased risk of death in hospital rather than in the community [5–7] and more emergency admissions in the last months of life [8,9]. In the UK, improvements in where people die—with fewer people dying in hospital and more at home or in hospice—have been significantly greater for those who are least deprived [10,11]. In terms of hospice deaths, the gap between the least and most deprived grew by 25% between 1993–1997 and 2008–2012 [11].

At the end of life, even within systems of universal coverage, people with limited resources generally have more complex clinical needs [12] and are less able to support their own care at home [13]. More socioeconomically deprived people may also have poor access to and knowledge of services and/or communicate their care preferences less [13–15]. One consequence of rapid population ageing is the rising numbers of deaths; globally, deaths will increase from 57 million in 2015 to 70 million over the next 15 years [16]. Social inequality in health, including at the end of life, is likely to be exacerbated by the ageing population.

While measures of SEP are commonly included as covariates in studies about end-of-life care, there is considerable variation in what is measured and how. Information on social inequality at the end of life has not been systematically summarised, including on the magnitude of effect of SEP on outcomes. This limits our understanding of how SEP relates to end-of-life care, as well as the incorporation of SEP into quality evaluations and service delivery plans.

The aim of this review is to systematically identify, synthesise, and quantify existing evidence on the association between SEP and use of healthcare in the last year of life—including place of death, use of acute care use, use of specialist palliative care and nonspecialist end-of-life care, use of advance care planning, and quality of care—and to report how SEP has been measured within this literature.

Methods

The protocol was registered (CRD42017055686) with PROSPERO, the international prospective register of systematic reviews [17], and the study was conducted and reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (S1 PRISMA Checklist) [18] and MOOSE [19] guidelines for meta-analysis and systematic reviews of observational studies. Ethical approval was not required for this review.

Search strategy

The following databases were searched from inception to 1 February 2019: MEDLINE, MEDLINE in process, EMBASE, PsycINFO, CINAHL, and ASSIA. Search terms including subject headings and free-text words were developed in MEDLINE and then adapted for other databases (S1 Text). Key papers identified from reviews by Henson (2015) [20–24] and Gomes (2006) [7,25–29], as well as prior knowledge [30–34], were used to refine the search terms. Consultation with the review team (FM, MM, KS, and IH) provided expert advice to identify missing papers and relevant reviews [35–47], the reference lists of which were searched manually. No language restrictions were applied, non–English-language papers were assessed for inclusion, and data were extracted by a native speaker. Grey literature and thesis and conference abstracts were included, and requests for additional data were made to authors by email.

Study inclusion criteria

We included empirical observational studies reporting an association between SEP and healthcare received by adults ($\geq$18 years old) in the last year of life. Studies were restricted to those from high-income countries to limit contextual differences in the availability of services and strengthen assumptions made about preferable service-use outcomes [48]. Studies were included if they met the following criteria.

- Participants were adults with malignant and nonmalignant advanced or incurable illness in community or inpatient settings receiving or not receiving specialist palliative care, and at least 80% of the sample were in the last year of life (based on date of death or clinical prognosis).
- An indicator of SEP was reported, such as income, education, occupation, private medical insurance status, housing tenure, housing quality, or area-based deprivation. Race and ethnicity are conceptually separate constructs than that of SEP and beyond the scope of this review [49,50].
- At least one of the following comprehensive set of outcomes was reported: place of death, acute care admission, use of specialist palliative care, use of nonspecialist end-of-life care, use of advance care planning, or quality of care. Outcomes were selected based on prior knowledge of availability within the literature. Patient-reported or patient-centred outcome measures were included as indicators of quality of care [51,52].

- The study design was empirical and observational, either prospective or retrospective; experimental, qualitative, or case-study designs were not suited to the review aims and were excluded. Area-level studies, in which the unit of analysis was not individuals, were also excluded.

Study selection

Study selection and de-duplication was managed in EndNote X8 (Clarivate Analytics, Philadelphia, PA) (JD). Titles and abstracts retrieved from the electronic database and reference list searches were first screened, and then full texts of potentially eligible studies were sourced and reviewed independently by 2 authors (JD plus MM, JL, or RW). Disagreement was resolved through discussion with a third author (KS). Multiple studies based on the same sample of individuals were treated as duplicates; inclusion was prioritised based on larger sample size and study quality.

Quality evaluation and grading of evidence

Study quality was evaluated using the Newcastle-Ottawa Quality Assessment Scale (NOS) [53], a 9-item measure developed for observational studies with a focus on sample representativeness, data quality, and appropriateness of analysis. Aligned with the aims of this review, representativeness of the exposed cohort (NOS item 1 'selection') was judged to be of high quality if the sample reflected the socioeconomic strata in the country of origin. On this basis, national population-based or nationally representative samples not restricted by demographics, diagnosis, or geography were considered to have a low sampling bias and be of the highest quality. Studies that adjusted for confounders—thus limiting bias—were also of higher quality, with age and sex being the factors considered most important to control for (NOS item 5 'comparability'). Appraisal of articles was carried out independently by two authors (JD and MM), with disagreement resolved through discussion. The overall strength of the evidence and the direction of the association between SEP exposures and outcomes were graded using an adaptation of a previously established algorithm (Fig 1) [54], taking into account 3 key elements important for grading studies—quality, quantity, and consistency [55].

Data extraction

A piloted data extraction form was used to extract relevant information from included studies. Data items included study characteristics, sample characteristics, type of SEP measure used, and adjusted estimates. Data were extracted by one author (JD), and then two authors (JL and RW) independently checked a 20% sample for accuracy; errors were verified through discussion and were corrected.

Most studies reported adjusted odds ratios (ORs). For studies reporting risk ratios (RRs), when possible, an OR was derived as a function of the RR, proportion of cases, and proportion of exposed [56]. Most studies treated SEP exposures as categorical. Some studies treated SEP exposures as numerical or ordinal, reporting a single effect size for a unit change in the exposure. Those based on a numeric scale, e.g., income in US dollars, could not be converted to ORs. Those based on underlying categories were converted by raising the effect size to the number of categories separating the highest and lowest. For example, for a study reporting a unit-change OR of 0.92 going from high to low SEP with 5 categories, the OR for the lowest SEP group was approximated by raising 0.92 to the power of 4 ($0.92 \times 0.92 \times 0.92 \times 0.92 = 0.72$).

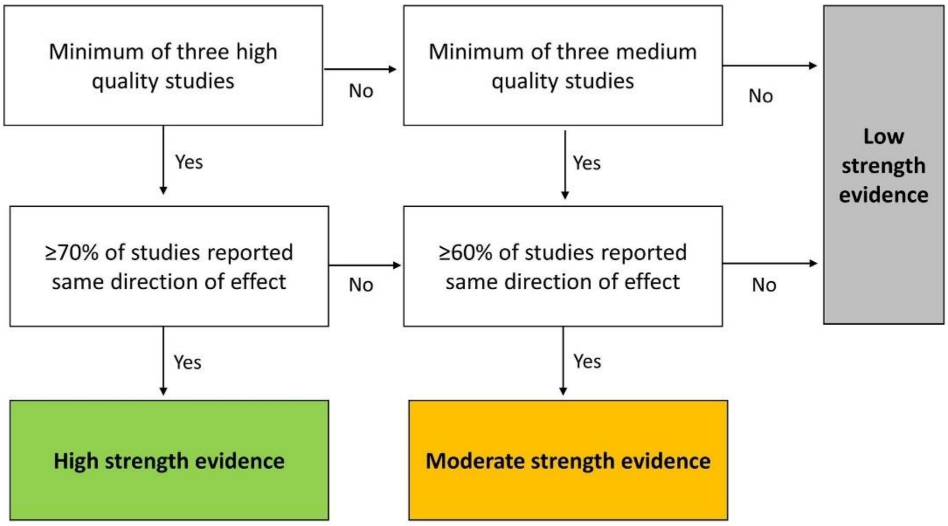

Fig 1. Algorithm for evaluating overall strength of evidence for each combination of SEP exposure and outcome, based on quality, quantity, and consistency of the evidence [54]. High-quality studies were those that had controlled for age and sex in a multivariable analysis and had an NOS score of ≥7. Medium quality was assigned to studies that had controlled for age and/or sex in a multivariable analysis and had an NOS score of ≥5, or had not carried out multivariable analysis but had an NOS score of ≥6. Low-quality studies had no multivariable analysis and an NOS score of ≤5, or an NOS score of ≤4. High-strength evidence required ≥70% agreement about the direction of the exposure outcome association; moderate strength evidence required ≥60% agreement. NOS, Newcastle-Ottawa Quality Assessment Scale; SEP, socioeconomic position.

https://doi.org/10.1371/journal.pmed.1002782.g001

Synthesis and statistical analysis

Studies were initially grouped according to outcome and exposure categories. To avoid double counting samples, each study contributed no more than once in each category. Within-study duplicates—e.g., if two area-based measures were used—were prioritised based on heterogeneity with other measures. Most outcomes were defined in terms of receipt or not of a service. For place of death, death at home, in hospice, or in long-term care (LTC) was considered favourable compared to death in hospital, in line with evidence on preferences for place of death in high-income countries [57]. SEP measures were described in terms of the average number used across studies; how the measures were constructed as binary, categorical, or continuous variables; and whether they were objective or subjective measures [50].

The meta-analysis was restricted to high- and medium-quality studies (see Fig 1 for definition) that had used multivariable analysis to reduce bias from confounding, and were more likely to be representative of the population social strata from which the study samples were drawn. Following an approach used elsewhere [58,59], the adjusted OR for the lowest versus the highest SEP group was presented. ORs were standardised so that an OR > 1 indicated a pro–high-SEP association. The overall strength and direction of the evidence was summarised using a diagram influenced by an existing design [60,61]. Rules for deriving the strength of evidence are described in the algorithm in Fig 1. Direction was determined by categorising associations as either 'pro–high-SEP' or 'pro–low-SEP'. The interpretation of null effects relies more heavily on sample size, which is not incorporated in the diagram; therefore, following peer review that highlighted this limitation, null effects were not depicted.

For subgroups of exposure and outcome, when enough comparable studies were available presenting OR for categories of SEP exposure, adjusted ORs were pooled using random-effects models. Acute care studies were only pooled if they were about care received in last 3 months of life to reflect established aggressive care definitions [62]. For better comparability, studies about use of nonspecialist end-of-life care were pooled only when the outcome was the receipt of nursing or support worker homecare. High levels of heterogeneity were expected given the observational nature of the studies and variety in measurement of SEP and definition of outcomes; heterogeneity was reported using Higgins' I-squared (I^2).[63] Studies reporting separate estimates for subgroups of the same sample, by year [64], gender [65], diagnosis [66], or regions within a country [67,68], were pooled prior to meta-analysis with fixed or random effects depending on level of heterogeneity (I^2). Following peer review that highlighted an inconsistency with the approach taken to other subgroups, studies reporting estimates separately for people living in the community and inpatient locations were also pooled prior to meta-analysis [31,69–72]. We anticipated between-country variations due to cultural differences in end-of-life practices, particularly in Asian countries [73]. For each pooled meta-analysis, a sensitivity analysis was carried out using subgroups by country to explore differences. Further sensitivity analysis examined change in the pooled estimates after each of the studies was removed from the meta-analysis.

To examine for a dose response for studies that presented data on at least 3 exposure categories, we used a random-effects weighted meta-regression of the log-OR to derive an estimation of the summarised dose response using the glst command in Stata (Stata SE version 13; StataCorp, College Station, TX) [74–76]. This approach uses a two-stage generalised least squares model that first estimates the within-study trend and then pools these to give an overall trend estimate [76]. Using the method described by Hamling and colleagues [77], studies were first standardised so that the reference group was always the least deprived. Dose was assigned using the cumulative mean relative rank for each SEP group reported. For example, for area deprivation, if quintile 5 (the least deprived group) accounted for 33% of the sample and quintile 4 accounted for a further 25% of the sample, the mean relative rank for quintile 5 would be 17 and for quintile 4 would be 29 [58]. Dose was then centred for each study so that the dose for the reference group was 0. Doses for all groups (other than the reference group) and the corresponding log-odds were plotted and inspected visually for linearity. For studies reporting multiple estimates for subgroups of the same sample, only the largest subgroup was included because of inability to control for dependence.

Results

A total of 682 full-text articles were screened for eligibility, of which 209 were included in the review (Fig 2).

Summary of included studies

Of the 209 studies included, 158 (75.6%) used 1 type of SEP measure; the mean number of measures per study was 1.3, and the maximum number was 6 [78]. A total of 273 SEP measurements were reported across 209 studies; these were categorised as area deprivation (29.7%), education (28.9%), income (16.8%), insurance (12.8%), occupation (4.4%), housing (3.3%), social class (3.7%), and literacy (0.4%). Of the 209 studies, 205 (98.1%) used objective measures of SEP, such as self-reported level of education or income, information obtained from administrative records, or area-based deprivation. Four studies [79–82] employed subjective measures, all concerning self-rated financial security; 172 (82.3%) studies provided a full or partial description of the SEP measure(s), including referencing the source of the measure,

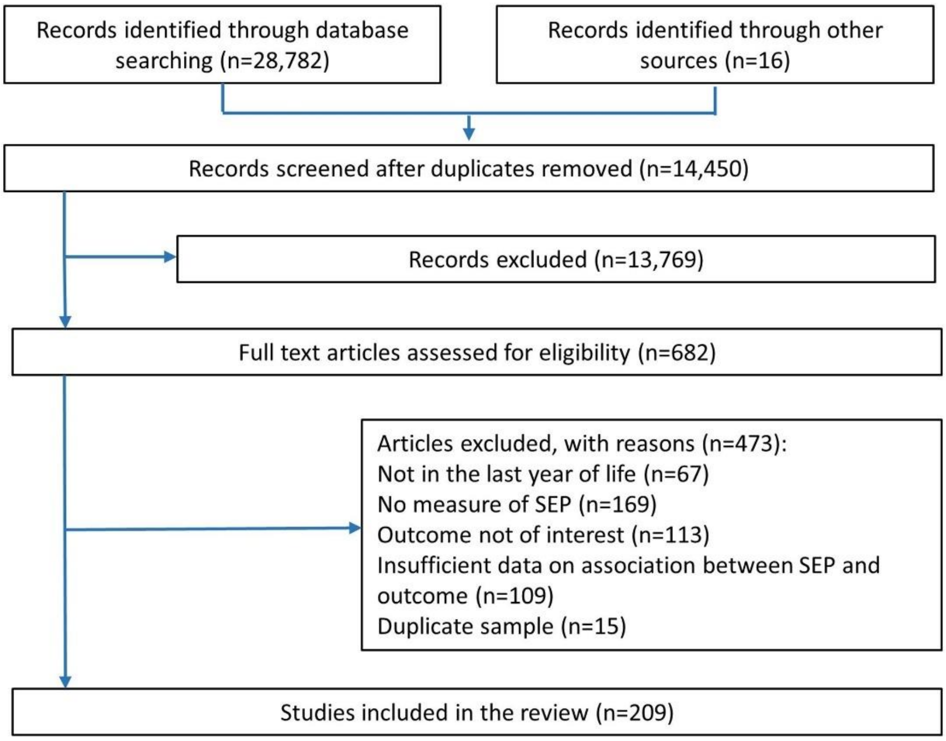

Fig 2. PRISMA flow diagram of papers reporting numbers of included and excluded texts. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; SEP, socioeconomic position.

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referencing the wording of the question used, or identifying the data set the SEP measure was contained within. In 27 (12.9%) studies, SEP was the main exposure variable of interest; 12 of these provided theoretical justification for choice of SEP measure.

The mean NOS quality score across all studies was 4.8 (range: 0–10) (see S1 Fig for histogram of scores); 97 (46.4%) of 209 studies were rated low quality, including all 11 studies on quality of care. A complete list of the low-quality studies is provided in S2 Text. The remaining 112 high- and medium-quality studies were included in further synthesis and meta-analysis (Table 1 and S3 Text). Combined, these studies report 142 outcomes of interest: most commonly, place of death (50.7%), then 25.4% on use of specialist palliative, 13.4% on use of acute care services, 7.7% on use of nonspecialist end-of-life care, and 2.8% on use of advance care planning. The majority of data were from the US (34.5%), Canada (19.0%), or Europe (not including the UK) (21.1%); 9.9% were from the UK, 8.5% from Australia, 4.2% from South Korea, 2.1% from Taiwan, and 0.7% from Singapore. Eight full-text non–English-language papers were assessed for eligibility: 2 in Japanese, 1 in German, 1 in Korean, and 3 in Spanish —3 of these were included in the review [83–85]. Data extraction was accurate for 98.1% of items.

Table 1. Summary of 112 high- and medium-quality studies.

	Number of studies reporting each outcome					
	Place of death (n = 72)[◉]	**Acute care (*n* = 19)**	**Specialist palliative care (*n* = 36)**	**Nonspecialist end-of-life care (*n* = 11)**	**Advance care planning (*n* = 4)**	**All (*n* = 142 outcomes, reported in 112 studies)**
Type of SEP measure,* *n* (%)						
Income	7 (8.6)	2 (10.5)	5 (10.9)	1 (8.3)	2 (25.0)	17 (10.2)
Education	27 (33.3)	1 (5.3)	5 (10.9)	2 (16.7)	4 (50.0)	39 (23.5)
Private insurance status	6 (7.4)	2 (10.5)	10 (21.7)	4 (33.3)	1 (12.5)	23 (13.9)
Housing	4 (4.9)	0 (0)	0 (0)	0 (0)	0 (0)	4 (2.4)
Area deprivation	33 (40.7)	14 (73.7)	26 (56.5)	5 (41.7)	1 (12.5)	79 (47.6)
Occupation	4 (4.9)	0 (0)	0 (0)	0 (0)	0 (0)	4 (2.4)
Country/region, *n* (%)						
UK	11 (15.3)	3 (15.8)	0 (0)	0 (0)	0 (0)	14 (9.9)
Europe	22 (30.6)	1 (5.3)	3 (8.3)	4 (36.4)	0 (0)	30 (21.1)
US	15 (20.8)	5 (26.3)	23 (63.9)	3 (27.3)	3 (75.0)	49 (34.5)
Canada	10 (13.9)	7 (36.8)	6 (16.7)	4 (36.4)	0 (0)	27 (19.0)
Australia	6 (8.3)	2 (10.5)	4 (11.1)	0 (0)	0 (0)	12 (8.5)
Asia	8 (11.1)	1 (5.3)	0 (0)	0 (0)	1 (25.0)	10 (7.0)
Outcomes on cancer						
patients only, *n* (%)	34 (47.2)	9 (47.4)	22 (61.1)	6 (54.5)	0 (0)	63 (44.4)
Study time period						
(range of years)	1979–2015	1992–2015	1990–2014	1991–2013	1986–2013	1979–2015
Study design, *n* (%)						
Prospective	2 (2.8)	0 (0)	1 (2.8)	1 (9.1)	0 (0)	4 (2.8)
Retrospective	70 (97.2)	19 (100)	35 (97.2)	10 (90.9)	4 (100)	138 (97.2)

[◉] From 64 studies (outcomes on multiple countries presented in the same study are counted separately).

*Within-column totals sum to more than the number of outcomes because each study can report data on multiple SEP exposures.

Abbreviation: SEP, socioeconomic position.

https://doi.org/10.1371/journal.pmed.1002782.t001

Strength and direction of the evidence

Fig 3 depicts a summary of evidence from 112 high- and medium-quality studies. We found strong evidence of a pro–high-SEP association between area deprivation and place of death, i.e., people with lowest SEP versus those with highest SEP are more likely to die in hospital compared to home. There was also moderate evidence of a pro–high-SEP association between area deprivation and use of both acute care and nonspecialist end-of-life care. We found moderate evidence of a pro–high-SEP association between education and advance care planning, as well as between housing quality and place of death. Overall, there was no evidence of pro–low-SEP associations.

Association between area deprivation or education and care received towards the end of life

Figs 4 and 5 display the ORs and 95% CIs for the lowest (most deprived) SEP group compared to the highest (least deprived) SEP group for each study, as well as the pooled ORs using random-effects models. Pooled estimates found that, compared to people living in the least deprived areas, people living in the most deprived areas had an OR of 1.30 for hospital versus

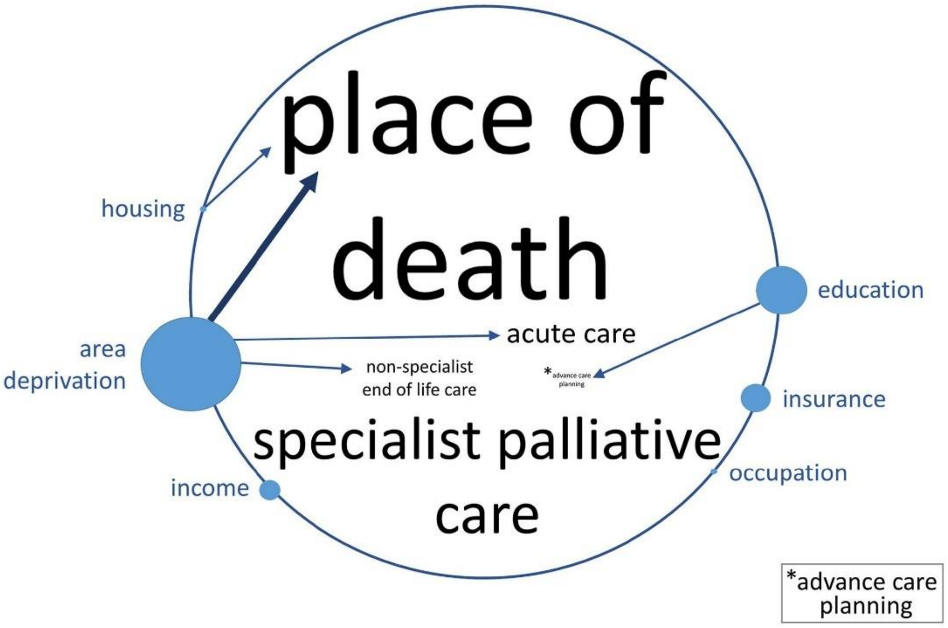

Fig 3. Diagram representing the strength of evidence and direction of association between measures of SEP and use of healthcare in the last year of life. Font size of the outcomes in the centre of the circle, and circle size accompanying the SEP exposures around the circumference, are proportionate to the number of high- and medium-quality studies that the factors were reported in (see S4 Text for underlying numbers and S3 Text for details of studies, outcomes, and exposures). Strength of evidence was determined using the algorithm in Fig 1. A bolder arrow represents strong evidence and a lighter arrow moderate evidence. An arrow from exposure to outcome indicates a pro–high-SEP association such that lowest (compared to highest) SEP was associated with an adverse outcome. There was no evidence of pro–low-SEP associations. Associations with low evidence or with fewer than 4 studies are not depicted. SEP, socioeconomic position.

https://doi.org/10.1371/journal.pmed.1002782.g003

home death (95% CI 1.23–1.38, $p < 0.001$), of 1.13 for not receiving specialist palliative care (95% CI 1.07–1.19, $p < 0.001$), of 1.16 for receiving acute hospital-based care in the last 3 months of life (95% CI 1.08–1.25, $p < 0.001$), and of 1.09 for not receiving nonspecialist end-of-life care (95% CI 0.83–1.43, $p = 0.544$). Pooled estimates found that, compared to the most educated, the least educated people had an OR of 1.26 for not receiving specialist palliative care (95% CI 1.07–1.49, $p = 0.005$). Overall, we found no difference between the most educated and the least educated people for odds of hospital versus home death, with an OR of 1.08 (95% CI 0.91–1.27, $p < 0.377$). However, subgroup analysis by country found the pooled estimate for the South Korean studies to be in the opposite direction to other countries (S2 Fig); after omitting the South Korean studies, the pooled estimate for hospital versus home death for the least educated people compared to the most educated people was significant, with an OR of 1.16 (95% CI 1.12–1.21, $p < 0.001$). Heterogeneity was high; I^2 was between 80.1% and 99.9% for all of the subgroup analyses—apart from the subgroup for the association between education and use of specialist palliative care ($I^2 = 32.1\%$, $p = 0.219$). Each of the pooled ORs changed only marginally after omitting successive studies. Dose-response analysis found that, for a 1 quintile (1 unit multiplied by 10, on a 0–50 scale), increase in area deprivation the log-odds of dying in hospital versus home increased by 1.07 (95% CI 1.05–1.08, $p < 0.001$), and

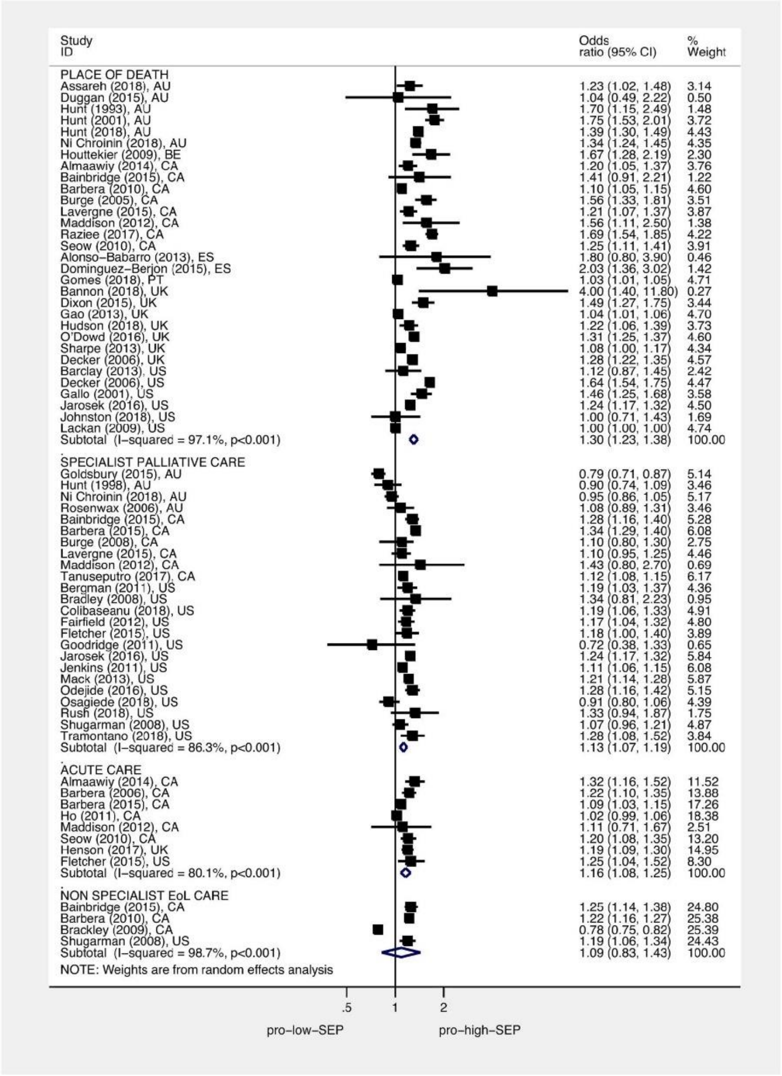

Fig 4. Association between area deprivation and: Place of death, use of acute care, and use of specialist palliative care. Squares show ORs for the most area deprived compared to the least area deprived; diamonds show pooled effects using random-effects models. Place of death (death in hospital versus death at home/hospice/LTC), use of acute care (use of acute services last 3 months of life versus no use), and use of specialist palliative care (not accessing specialist palliative care in the last year of life versus accessing). ORs have been standardised so that >1 indicates that those living in the most deprived areas have higher odds of a worse outcome than those living in the least deprived areas. EoL, end of life; LTC, long-term care; OR, odds ratio; SEP, socioeconomic position.

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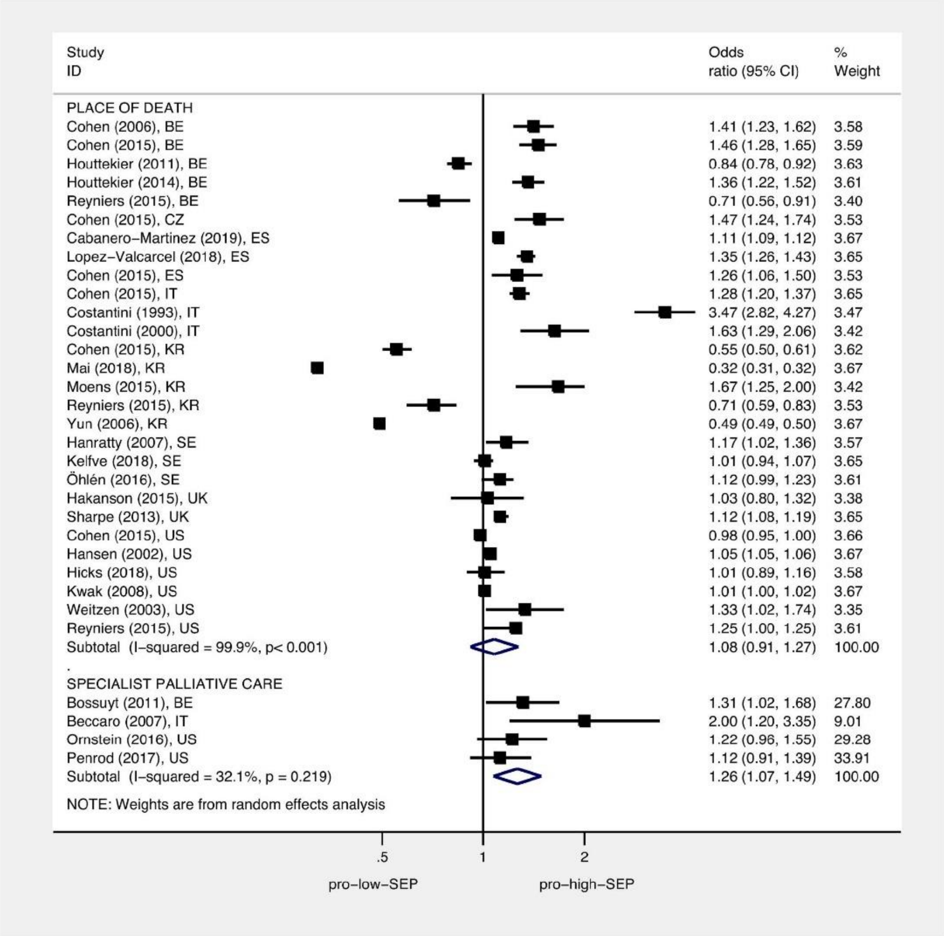

Fig 5. Association between education and: Place of death and use of specialist palliative care. Squares show ORs for the least educated group compared to the most educated group; diamonds show pooled effects using random-effects models. Place of death (death in hospital versus death at home/hospice/LTC) and use of specialist palliative care (not accessing specialist palliative care in the last year of life versus accessing). ORs have been standardised so that >1 indicates that the least educated have higher odds of a worse outcome than the best educated. LTC, long-term care; OR, odds ratio; SEP, socioeconomic position.

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log-odds of not receiving specialist palliative care increased by 1.03 (95% CI 1.02–1.05, $p < 0.001$) (Figs 6 and 7, respectively).

Discussion

This review finds consistent evidence that, in high-income countries, low SEP is associated with adverse healthcare outcomes towards the end of life, including increased odds of hospital

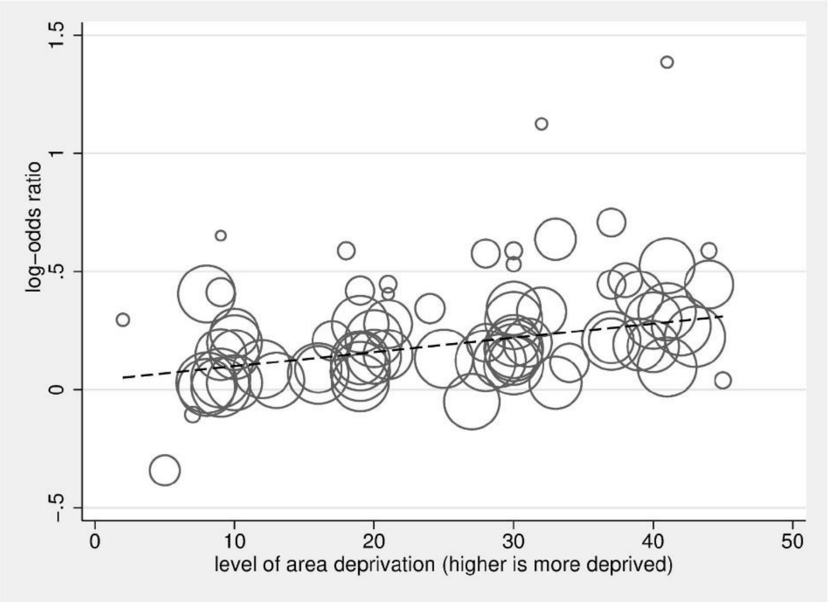

Fig 6. Dose analysis of area deprivation on log-odds of hospital versus home death, compared to the least deprived group. The scatter plot in Fig 6 depicts the linear association between dose of area deprivation (0 being least deprived, 50 being most deprived) and the log-odds of death in hospital versus death at home/hospice/LTC, compared to the least area-deprived group. The circles represent the dose-specific estimates from the 20 included studies [5,21,24,26,34,64,70,86–98]; each study contributes 2, 3, or 4 circles reflecting the number of area-deprivation categories included in the study (the reference category, the least deprived group, is not plotted), and the size of the circle corresponds to the inverse of its total variance. The regression line calculated using the 2-stage glst command in Stata with random effects accounting for within-study dependence reflects a significant positive relationship between dose of area deprivation and likelihood of hospital death (for a 10× unit increase in dose $\beta = 1.07$, 95% CI 1.05–1.08, $p < 0.001$). LTC, long-term care.

https://doi.org/10.1371/journal.pmed.1002782.g006

versus home death, increased odds of using acute care services in the last 3 months of life, and reduced odds of receiving specialist palliative care in the last year of life. A dose-response association is evident between area deprivation and both place of death and receipt of specialist palliative care, which confirms that inequality persists across the social stratum. Evidence of social inequality in the use of nonspecialist end-of-life care and advance care planning is based on a smaller number of studies and is less conclusive but similarly suggests pro–high-SEP associations. Although awareness of the association between SEP and place of death is longstanding [7,29], this review is the first to synthesise international evidence on social inequality across several components of service use at the end of life.

Most studies used one measure of SEP as a sample descriptor or to control for confounding; area-based measures—and, to a lesser extent, measures of education—dominate. Place of death was the most common outcome studied, reflecting the focus on place of death in end-of-life care research generally and the wide availability of death registry data [110]. Variation in the magnitude of association between different measures of SEP was observed; e.g., area deprivation had a stronger association (OR 1.30) than education (OR 1.08) with place of death, and conversely, education had a stronger association (OR 1.26) than area deprivation (OR 1.13)

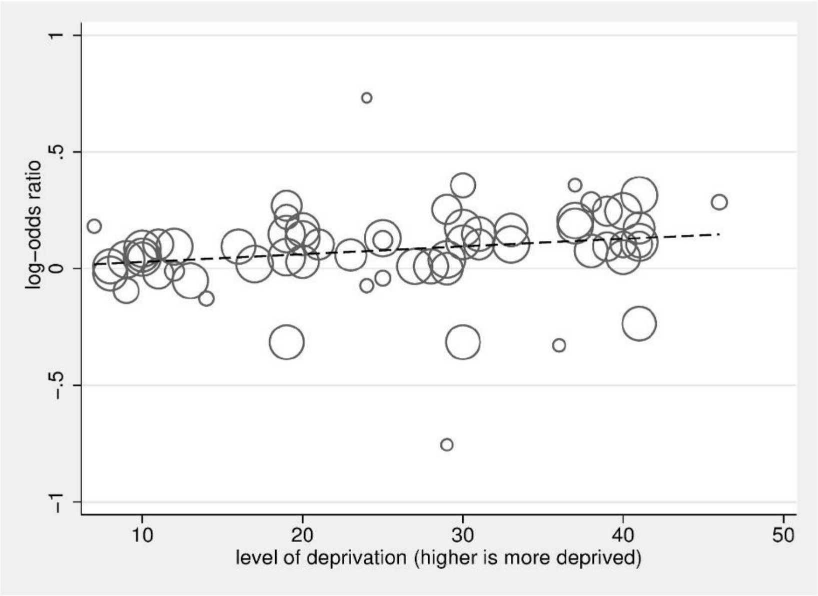

Fig 7. Dose analysis of area deprivation on log-odds of not receiving specialist palliative in the last year of life versus receiving that care, compared to the least deprived group. The scatter plot in Fig 7 depicts the linear association between dose of area deprivation (0 being least deprived, 50 being most deprived) and the log-odds of not receiving specialist palliative care, compared to the least area-deprived group. The circles represent the dose-specific estimates from the 16 included studies [21,32,34,66,67,68,86,98–109]; each study contributes 2, 3, or 4 circles reflecting the number of area-deprivation categories included in the study (the reference category, the least deprived group, is not plotted), and the size of the circle corresponds to the inverse of its total variance. The regression line calculated using the 2-stage glst command in Stata with random effects accounting for within-study dependence reflects a significant positive relationship between dose of area deprivation and likelihood of receiving specialist palliative care (for a 10× unit increase in dose $\beta = 1.03$, 95% CI 1.02–1.05, $p < 0.001$).

https://doi.org/10.1371/journal.pmed.1002782.g007

with use of specialist palliative care. High levels of between-study heterogeneity prevent robust comparisons of the pooled ORs. However, the differences observed raise questions about the relative importance of different aspects of SEP for specific outcomes. For example, it is plausible that level of education acts as a proxy for awareness of specialist palliative care services and that awareness is a stronger driver of access than other aspects of SEP such as area deprivation [14]. The findings from this review support further investigation of these differences.

This review included a comprehensive set of end-of-life outcomes. Eleven studies measuring quality of care using patient-reported or patient-centred outcome measures were found, but all were of low quality and were therefore excluded from meta-analyses. For studies reporting service use before death, assumptions were made about which outcomes are preferable based on existing literature [4,57,62], e.g., that hospital deaths are less favourable than deaths at home or that emergency admission in the last months of life represents an adverse outcome. Subgroup analysis found little variation by country, with the pooled ORs indicating significant pro–high-SEP associations in most countries. The pooled ORs from the South Korean studies on the association between education and place of death, and the Australian studies on the association between area deprivation and access to specialist palliative, are notable exceptions, both suggesting pro–low-SEP inequality albeit with nonsignificant confidence intervals. Different models of care, sociocultural norms around death and dying, and different levels of need are potential explanations for between-country differences. More robust comparison of countries is limited in this review by the small number of studies available from each country.

SEP is a multidimensional construct, as such composite measures combining multiple domains are likely to be the most effective means for capturing statistical variance around SEP [49,50,111]. Area-based indices made up of multiple indicators of SEP are commonly used in this literature and are well suited to monitoring inequality and accounting for confounding from SEP. However, composite measures—area based or otherwise—are less informative about the mechanisms through which SEP might influence outcomes. Area-based measures, whilst being easily linked to patient addresses, are also limited by the ecological fallacy—the assumption that people residing in the same area all share the same deprivation profile. The individual-level measures of SEP commonly used in the studies in this review—education, income, private medical insurance status, or housing tenure—each have benefits and challenges surrounding ease of collection, sufficient sensitivity, and population appropriateness [112]. Essential for a better aetiological understanding of social inequality at the end of life are studies designed specifically for purposes that employ well thought-out measures of SEP and are guided by hypotheses about the relationships between factors [111].

Causal explanations for social patterning in other areas of health have been usefully determined [113]. SEP across the life course influences health through a number of biological, physiological, and environmental mechanisms [114,115, 116]. For care received in the last year of life, proximal social determinants such as ability to pay for care, housing conditions suitable for supporting care at home, understanding and awareness of illness, and availability of services are likely to be important [13]. The cumulative effect of low SEP and worse health—and interrelationships between SEP and other factors known to be important to end-of-life care, such as social support, age, race, and sexuality—are also critical to understand and as yet remain largely unexplored in research. Future studies that use hypothesis-generating qualitative methods and that consider multiple social factors in combination through multilevel and structural models—rather than simply controlling for each as a confounder—could usefully be employed to investigate these relationships.

Evaluation of end-of-life care interventions rarely consider differential outcomes for groups according to SEP, and few interventions have been developed to specifically reduce social inequality in care received towards the end of life; to our knowledge, no review of the effectiveness of current interventions exists. Interventions shown to reduce social inequality outside of end-of-life care offer promising examples, particularly those targeting older people that share similar objectives around managing care in community settings and enhancing quality of life [117,118]. We have shown that social inequality may persist in the care received by people towards the end of life; we must now consider what interventions are effective and begin to target resources at reducing social inequality.

There are some limitations to this review. The first relates to the observational nature of the data included. There was high heterogeneity (I^2) between studies reflecting variation in the measurement of exposures, outcomes, and confounders, as well as in study design and populations. Nevertheless, a major strength is the inclusion of multiple exposure and outcome variables and a large number of observational studies. This necessitated a broad comparison of studies, which ultimately limits the precision of the pooled estimates, even after applying random-effects models. A second limitation is unaccounted confounding from factors related to illness and disease. Many studies included a measure of diagnosis, comorbidity, or disease severity; these varied and were not considered in either the quality evaluation or the analysis. Because people with low SEP experience greater illness and disease—and disease profile also influences patterns of healthcare usage—the inclusion of illness-related factors as a confounder in the association between SEP and the outcomes studied is likely to suppress the social gradient. That being said, illness and disease may also lie on the causal pathway from SEP to the outcomes, making inclusion of illness-related confounders in studies seeking to explore the effect of SEP questionable. Notwithstanding this, the analysis does not consider the important influence of illness and other potential confounders such as service and treatment availability. The third limitation relates to the outcome variables. Assumptions were made about which service-use outcomes are preferable, and these do not take into consideration individual or cultural preferences, need or availability of care, or how these change over time at an individual or societal level. Fourth, this review was limited to studies from high-income countries. The assumptions made around preferable outcomes may not apply to low- and middle-income countries in which healthcare needs and the availability of end-of-life care services are considerably different from those in high-income countries [119]. Important data from low- and middle-income countries is therefore not included. Most of the data were from the US, Canada, and Europe. It is notable that just 7.0% of the included studies were from Asia—of the 682 full-text articles assessed for eligibility, 49 (7.2%) were from Taiwan, 16 (2.3%) from Japan, 14 (2.1%) from South Korea, and 3 (<1%) from Singapore. Therefore, conclusions regarding Asian countries are less strong. A fifth limitation is bias in the identification of studies. The search criteria were necessarily restricted to studies that mentioned SEP in the abstract; on this basis, 2 eligible studies [23,24] from the Henson review [8] used to develop the search strategy were missed from the database search, and it is likely that, on this basis, other studies were missed as well. Considerable effort was made to identify missing studies, hand searching the reference lists of relevant reviews and consulting experts in the field. A further source of bias occurred when eligible studies lacked sufficient information to be included; studies, e.g., [120,121] that did not report an effect size when the association was nonsignificant were not included in the analysis. Finally, given the observational nature of the studies included, we chose to analyse adjusted effects to limit bias from confounding, and we extracted adjusted ORs because these were most commonly used in the literature. However, the outcomes reported are common (>10%), and thus the ORs are overestimations of relative risks; further work to quantify population risk is needed.

Conclusion

We have found consistent evidence from high-income countries that low SEP is a risk factor across several components of service use at the end of life, including dying in hospital rather than at home, receiving acute hospital-based care in the last 3 months of life, and not receiving specialist palliative care in the last year of life. We also found evidence of a pervasive social gradient in place of death and use of specialist palliative care. These findings should stimulate widespread efforts to reduce socioeconomic inequality towards the end of life. We recommend that all research on care received towards the end of life should attempt to account for SEP, end-of-life care interventions should be analysed for their different effects across the social strata, and the planning and provision of end-of-life care services should consider SEP in local populations.

Supporting information

S1 PRISMA Checklist. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.
(DOC)

S1 Text. Search terms.
(DOCX)

S2 Text. Reference list for the 97 low-quality studies, by outcome category.
(DOCX)

S3 Text. Characteristics of 112 high- and medium-quality studies.
(DOCX)

S4 Text. Strength of evidence and direction of association between measures of SEP and use of healthcare in the last year of life, from 112 high- and medium-quality studies. SEP, socioeconomic position.
(DOCX)

S1 Fig. Histogram of the NOS score for the 209 included studies. NOS, Newcastle-Ottawa Quality Assessment Scale.
(EPS)

S2 Fig. Association between education and place of death (death in hospital versus death at home/hospice/LTC) for South Korea and all other countries. Squares show ORs for the least educated group compared to the most educated group; diamonds show pooled effects using random-effects models. LTC, long-term care; OR, odds ratio.
(EPS)

Acknowledgments

The authors thank Dr. Martin Bardsley for his valuable comments on earlier drafts; and Susanne de Wolf-Linder, Dr. Deokhee Yi, and Dr. Ai Oishi for their work appraising and extracting data from non–English-language manuscripts.

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References

1. Marmot M. The health gap: The challenge of an unequal world. The Lancet. 2015; 386(10011):2442–4.
2. Marmot M. 2010. Fair Society, Healthy Lives: The Marmot Review: strategic review of health inequalities in England post-2010.
3. WHO. A conceptual framework for action on the social determinants of health: social determinants of health discussion paper 2. World Health Organisation, Commission on the Social Determinants of Health. 2010.
4. De Schreye R, Houttekier D, Deliens L, Cohen J. Developing indicators of appropriate and inappropriate end-of-life care in people with Alzheimer's disease, cancer or chronic obstructive pulmonary disease for population-level administrative databases: A RAND/UCLA appropriateness study. Palliative Medicine. 2017; 31(10):932–45. https://doi.org/10.1177/0269216317705099 PMID: 28429629
5. Raziee H, Saskin R, Barbera L. Determinants of Home Death in Patients With Cancer: A Population-Based Study in Ontario, Canada. J Palliat Care. 2017; 32(1):11–8. https://doi.org/10.1177/0825859717708518 PMID: 28662622
6. Decker SL, Higginson IJ. A tale of two cities: factors affecting place of cancer death in London and New York. Eur J Public Health. 2007; 17(3):285–90. https://doi.org/10.1093/eurpub/ckl243 PMID: 17068001
7. Higginson IJ, Jarman B, Astin P, Dolan S. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. J Public Health Med. 1999; 21(1):22–8. PMID: 10321855
8. Henson LA, Gao W, Higginson IJ, Smith M, Davies JM, Ellis-Smith C, et al. Emergency Department Attendance by Patients With Cancer in Their Last Month of Life: A Systematic Review and Meta-Analysis. J Clin Oncol. 2015; 33(4):370–6. https://doi.org/10.1200/JCO.2014.57.3568 PMID: 25534384
9. Sleeman KE, Perera G, Stewart R, Higginson IJ. Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data. Alzheimer's & dementia: the journal of the Alzheimer's Association. 2018; 14 (1):20–7.
10. Gao W, Ho YK, Verne J, Glickman M, Higginson IJ. Changing patterns in place of cancer death in England: a population-based study. PLoS Med. 2013; 10(3):e1001410. https://doi.org/10.1371/journal.pmed.1001410 PMID: 23555201
11. Sleeman KE, Davies JM, Verne J, Gao W, Higginson IJ. The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993–2012. Palliative Medicine. 2016; 30(1):45–53 https://doi.org/10.1177/0269216315585064 PMID: 25991729
12. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet. 2012; 380(9836):37–43. https://doi.org/10.1016/S0140-6736(12)60240-2 PMID: 22579043
13. Lewis JM, DiGiacomo M, Currow DC, Davidson PM. Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. J Pain Symptom Manage. 2011; 42 (1):105–18. https://doi.org/10.1016/j.jpainsymman.2010.10.265 PMID: 21402460
14. Koffman J, Burke G, Dias A, Raval B, Byrne J, Gonzales J, et al. Demographic factors and awareness of palliative care and related services. Palliative Medicine. 2007; 21(2):145–53. https://doi.org/10.1177/0269216306074639 PMID: 17344263
15. Volandes AE, Paasche-Orlow M, Gillick MR, Cook EF, Shaykevich S, Abbo ED, et al. Health literacy not race predicts end-of-life care preferences. J Palliat Med. 2008; 11(5):754–62. https://doi.org/10.1089/jpm.2007.0224 PMID: 18588408
16. Bone AE, Gomes B, Etkind SN, Verne J, Murtagh FE, Evans CJ, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. Palliative Medicine. 2018; 32(2):329–36. https://doi.org/10.1177/0269216317734435 PMID: 29017018
17. PROSPERO. https://www.crd.york.ac.uk/prospero/. [cited 2018 Jan 3].
18. Stewart LA, Clarke M, Rovers M, Riley RD, Simmonds M, Stewart G, et al. Preferred Reporting Items for Systematic Review and Meta-Analyses of individual participant data: the PRISMA-IPD Statement. JAMA. 2015; 313(16):1657–65. https://doi.org/10.1001/jama.2015.3656 PMID: 25919529

19. Stroup DF, Berlin JA, Morton SC, Olkin I, Williamson GD, Rennie D, et al. Meta-analysis of observational studies in epidemiology: a proposal for reporting. Meta-analysis Of Observational Studies in Epidemiology (MOOSE) group. JAMA. 2000; 283(15):2008–12. PMID: 10789670

20. Barbera L, Paszat L, Chartier C. Indicators of poor quality end-of-life cancer care in Ontario. J Palliat Care. 2006; 22(1):12–7. PMID: 16689410

21. Maddison AR, Asada Y, Burge F, Johnston GW, Urquhart R. Inequalities in end-of-life care for colorectal cancer patients in Nova Scotia, Canada. J Palliat Care. 2012; 28(2):90–6. PMID: 22860381

22. Seow H, Barbera L, Howell D, Dy SM. Using more end-of-life homecare services is associated with using fewer acute care services: a population-based cohort study. Med Care. 2010; 48(2):118–24. https://doi.org/10.1097/MLR.0b013e3181c162ef PMID: 20057327

23. Ho TH, Barbera L, Saskin R, Lu H, Neville BA, Earle CC. Trends in the aggressiveness of end-of-life cancer care in the universal health care system of Ontario, Canada. Journal of Clinical Oncology: official journal of the American Society of Clinical Oncology. 2011; 29(12):1587–91.

24. Almaawiy U, Pond GR, Sussman J, Brazil K, Seow H. Are family physician visits and continuity of care associated with acute care use at end-of-life? A population-based cohort study of homecare cancer patients. Palliative Medicine. 2014; 28(2):176–83. https://doi.org/10.1177/0269216313493125 PMID: 23779252

25. Costantini M, Balzi D, Garronec E, Orlandini C, Parodi S, Vercelli M, et al. Geographical variations of place of death among Italian communities suggest an inappropriate hospital use in the terminal phase of cancer disease. Public Health. 2000; 114(1):15–20. https://doi.org/10.1038/sj.ph.1900613 PMID: 10787020

26. Gallo WT, Baker MJ, Bradley EH. Factors associated with home versus institutional death among cancer patients in Connecticut. J Am Geriatr Soc. 2001; 49(6):771–7. PMID: 11454116

27. Costantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative home care and place of death among cancer patients: a population-based study. Palliative Medicine. 1993; 7(4):323–31. https://doi.org/10.1177/026921639300700410 PMID: 7505188

28. McCusker J. Where cancer patients die: an epidemiologic study. Public Health Rep. 1983; 98(2):170–6. PMID: 6856741

29. Hunt R, Bonett A, Roder D. Trends in the terminal care of cancer patients: South Australia, 1981–1990. Aust N Z J Med. 1993; 23(3):245–51. PMID: 7688953

30. Chan R, Yates P, McCarthy AL. Fatigue Self-Management Behaviors in Patients With Advanced Cancer: A Prospective Longitudinal Survey. Oncol Nurs Forum. 2016; 43(6):762–71. https://doi.org/10.1188/16.ONF.762-771 PMID: 27768127

31. Ohlen J, Cohen J, Hakanson C. Determinants in the place of death for people with different cancer types: a national population-based study. Acta Oncol. 2016;1–7.

32. Goldsbury DE, O'Connell DL, Girgis A, Wilkinson A, Phillips JL, Davidson PM, et al. Acute hospital-based services used by adults during the last year of life in New South Wales, Australia: a population-based retrospective cohort study. BMC Health Serv Res. 2015; 15:537. https://doi.org/10.1186/s12913-015-1202-8 PMID: 26637373

33. Houttekier D, Cohen J, Pepersack T, Deliens L. Dying in hospital: a study of incidence and factors related to hospital death using death certificate data. Eur J Public Health. 2013; 24(5):751–756 https://doi.org/10.1093/eurpub/ckt209 PMID: 24367064

34. Lavergne MR, Lethbridge L, Johnston G, Henderson D, D'Intino AF, McIntyre P. Examining palliative care program use and place of death in rural and urban contexts: a Canadian population-based study using linked data. Rural and remote health. 2015; 15(2):3134. PMID: 26103433

35. Badrakalimuthu V, Barclay S. Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. Age Ageing. 2014; 43(1):13–9. https://doi.org/10.1093/ageing/aft151 PMID: 24128594

36. Cohen LL. Racial/ethnic disparities in hospice care: A systematic review. J Palliat Med. 2008; 11(5):763–8. https://doi.org/10.1089/jpm.2007.0216 PMID: 18588409

37. Costa V, Earle CC, Esplen MJ, Fowler R, Goldman R, Grossman D, et al. The determinants of home and nursing home death: a systematic review and meta-analysis. BMC Palliat Care. 2016; 15:8. https://doi.org/10.1186/s12904-016-0077-8 PMID: 26791258

38. Evans N, Menaca A, Andrew EVW, Koffman J, Harding R, Higginson IJ, et al. Systematic Review of the Primary Research on Minority Ethnic Groups and End-of-Life Care From the United Kingdom. Journal of Pain and Symptom Management. 2012; 43(2):261–286 https://doi.org/10.1016/j.jpainsymman.2011.04.012 PMID: 22001070

39. Gaertner J, Siemens W, Antes G, Meerpohl JJ, Xander C, Schwarzer G, et al. Specialist palliative care services for adults with advanced, incurable illness in hospital, hospice, or community settings-protocol for a systematic review. Systematic Reviews. 2015; 4(1).

40. Gruneir A, Mor V, Weitzen S, Truchil R, Teno J, Roy J. Where people die: A multilevel approach to understanding influences on site of death in America. Med Care Res Rev. 2007; 64(4):351–78. https://doi.org/10.1177/1077558707301810 PMID: 17684107

41. Hanratty B, Holland P, Jacoby A, Whitehead M. Financial stress and strain associated with terminal cancer—A review of the evidence. Palliat Med. 2007; 21(7):595–607. https://doi.org/10.1177/0269216307082476 PMID: 17942498

42. Higginson IJ, Costantini M. Dying with cancer, living well with advanced cancer. Eur J Cancer. 2008; 44(10):1414–24. https://doi.org/10.1016/j.ejca.2008.02.024 PMID: 18342501

43. Lovell A, Yates P. Advance Care Planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008–2012. Palliat Med. 2014; 28(8):1026–35. https://doi.org/10.1177/0269216314531313 PMID: 24821708

44. Murray MA, Fiset V, Young S, Kryworuchko J. Where the dying live: a systematic review of determinants of place of end-of-life cancer care. Oncol Nurs Forum. 2009; 36(1):69–77. https://doi.org/10.1188/09.ONF.69-77 PMID: 19136340

45. Popovic M, Lao N, Bedard G, Zeng L, Zhang L, Cella D, et al. Quality of life in patients with advanced cancer using the functional assessment of cancer therapy-general assessment tool: A literature review. World J Oncol. 2013; 4(1):8–17. https://doi.org/10.4021/wjon594w PMID: 29147325

46. Rodriguez AM, Gagnon B. Place of death in cancer patients: What do we know and what do we understand? A systematic and critical review of the literature. [Spanish]. Medicina Paliativa. 2009; 16 (2):111–9.

47. Schildmann J, Baumann A, Cakar M, Salloch S, Vollmann J. Decisions about limiting treatment in cancer patients: A systematic review and clinical ethical analysis of reported variables. J Palliat Med. 2015; 18(10):884–92. https://doi.org/10.1089/jpm.2014.0441 PMID: 26248019

48. World Bank. Country Classifications 2016. http://blogs.worldbank.org/opendata/new-country-classifications-2016. [cited 2018 Jan 3].

49. Krieger N, Williams DR, Moss NE. Measuring social class in US public health research: concepts, methodologies, and guidelines. Annu Rev Public Health. 1997; 18:341–78. https://doi.org/10.1146/annurev.publhealth.18.1.341 PMID: 9143723

50. Oakes JM, Andrade KE. 2017. The Measurement of Socioeconomic Status. Oakes JM, Kaufman JS (eds) *Methods in Social Epidemiology* 2nd Edition. San Francisco: Jossey-Bass; 23–41.

51. Donabedian A. The quality of care. How can it be assessed? JAMA. 1988; 260(12):1743–8. PMID: 3045356

52. Etkind SN, Daveson BA, Kwok W, Witt J, Bausewein C, Higginson IJ, et al. Capture, Transfer, and Feedback of Patient-Centered Outcomes Data in Palliative Care Populations: Does It Make a Difference? A Systematic Review. J Pain Symptom Manage. 2015; 49(3):611–24. https://doi.org/10.1016/j.jpainsymman.2014.07.010 PMID: 25135657

53. GA Wells BS, D O'Connell, J Peterson, V Welch, M Losos, P Tugwell. The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses. http://www.ohri.ca/programs/clinical_epidemiology/oxford.asp. [cited 2018 Jan 3].

54. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ (Clinical research ed). 2006; 332(7540):515–21.

55. West S, King V, Carey TS, Lohr KN, McKoy N, Sutton SF, et al. Systems to rate the strength of scientific evidence. Evidence report/technology assessment (Summary). 2002(47):1–11.

56. Barendregt JJ. Epigear. http://www.epigear.com. [cited 2018 Jan 3].

57. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Ann Oncol. 2012; 23(8):2006–15. https://doi.org/10.1093/annonc/mdr602 PMID: 22345118

58. Lorant V, Deliege D, Eaton W, Robert A, Philippot P, Ansseau M. Socioeconomic inequalities in depression: a meta-analysis. Am J Epidemiol. 2003; 157(2):98–112. PMID: 12522017

59. Weightman AL, Morgan HE, Shepherd MA, Kitcher H, Roberts C, Dunstan FD. Social inequality and infant health in the UK: systematic review and meta-analyses. BMJ Open. 2012; 2(3).

60. Campos-Matos I, Russo G, Perelman J. Connecting the dots on health inequalities—a systematic review on the social determinants of health in Portugal. International journal for equity in health. 2016; 15:26. https://doi.org/10.1186/s12939-016-0314-z PMID: 26879973

61. Ashley EA, Butte AJ, Wheeler MT, Chen R, Klein TE, Dewey FE, et al. Clinical assessment incorporating a personal genome. Lancet. 2010; 375(9725):1525–35. https://doi.org/10.1016/S0140-6736(10)60452-7 PMID: 20435227

62. Earle CC. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol Off J Am Soc Clin Oncol. 2003; 21.

63. Higgins JP, Thompson SG, Deeks JJ, Altman DG. Measuring inconsistency in meta-analyses. BMJ (Clinical research ed). 2003; 327(7414):557–60.

64. Gao Wei HYK, Julia Verne, Emma Gordon and Higginson Irene J. Geographical and temporal Understanding In place of Death in England (1984–2010): analysis of trends and associated factors to improve end-of-life Care (GUIDE_Care)–primary research. Health Services and Delivery Research. 2014; 2(42):ISSN 2050-4349.

65. Hedinger D, Braun J, Zellweger U, Kaplan V, Bopp M, Swiss National Cohort Study G. Moving to and dying in a nursing home depends not only on health—an analysis of socio-demographic determinants of place of death in Switzerland. PLoS ONE. 2014; 9(11):e113236. https://doi.org/10.1371/journal.pone.0113236 PMID: 25409344

66. Rosenwax LK, McNamara BA. Who receives specialist palliative care in Western Australia—And who misses out. Palliat Med. 2006; 20(4):439–45. https://doi.org/10.1191/0269216306pm1146oa PMID: 16875115

67. Mack JW, Chen K, Boscoe FP, Gesten FC, Roohan PJ, Weeks JC, et al. Underuse of hospice care by Medicaid-insured patients with stage IV lung cancer in New York and California. J Clin Oncol. 2013; 31 (20):2569–79. https://doi.org/10.1200/JCO.2012.45.9271 PMID: 23733768

68. Barbera L, Seow H, Sutradhar R, Chu A, Burge F, Fassbender K, et al. Quality of end-of-life cancer care in Canada: a retrospective four-province study using administrative health care data. Current Oncology. 2015; 22(5):341–55. https://doi.org/10.3747/co.22.2636 PMID: 26628867

69. Kelfve S, Wastesson J, Fors S, Johnell K, Morin L. Is the level of education associated with transitions between care settings in older adults near the end of life? A nationwide, retrospective cohort study. Palliat Med. 2018; 32(2):366–75. https://doi.org/10.1177/0269216317726249 PMID: 28952874

70. Houttekier D, Cohen J, Bilsen J, Deboosere P, Verduyckt P, Deliens L. Determinants of the Place of Death in the Brussels Metropolitan Region. J Pain Symptom Manage. 2009; 37(6):996–1005. https://doi.org/10.1016/j.jpainsymman.2008.05.014 PMID: 19345555

71. Houttekier D, Cohen J, Pepersack T, Deliens L. Dying in hospital: a study of incidence and factors related to hospital death using death certificate data. Eur J Public Health. 2014; 24(5):751–6. https://doi.org/10.1093/eurpub/ckt209 PMID: 24367064

72. Hakanson C, Ohlen J, Morin L, Cohen J. A population-level study of place of death and associated factors in Sweden. Scandinavian journal of public health. 2015; 43(7):744–51. https://doi.org/10.1177/1403494815595774 PMID: 26194351

73. Keam B, Oh DY, Lee SH, Kim DW, Kim MR, Im SA, et al. Aggressiveness of cancer-care near the end-of-life in Korea. Jpn J Clin Oncol. 2008; 38(5):381–6. https://doi.org/10.1093/jjco/hyn031 PMID: 18411260

74. Greenland S, Longnecker MP. Methods for trend estimation from summarized dose-response data, with applications to meta-analysis. Am J Epidemiol. 1992; 135(11):1301–9. PMID: 1626547

75. Berlin JA, Longnecker MP, Greenland S. Meta-analysis of epidemiologic dose-response data. Epidemiology. 1993; 4(3):218–28. PMID: 8512986

76. Orsini N B R, Greenland S. Generalized least squares for trend estimation of summarized dose–response data. The Stata Journal. 2006; 6(1):40–57.

77. Hamling J, Lee P, Weitkunat R, Ambuhl M. Facilitating meta-analyses by deriving relative effect and precision estimates for alternative comparisons from a set of estimates presented by exposure level or disease category. Stat Med. 2008; 27(7):954–70. https://doi.org/10.1002/sim.3013 PMID: 17676579

78. Sharpe KH, Cezard G, Bansal N, Bhopal RS, Brewster DH. 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 & palliative care. 2015; 5 (4):443–51.

79. Fukui S, Fujita J, Tsujimura M, Sumikawa Y, Hayashi Y. Predictors of home death of home palliative cancer care patients: a cross-sectional nationwide survey. Int J Nurs Stud. 2011; 48(11):1393–400. https://doi.org/10.1016/j.ijnurstu.2011.05.001 PMID: 21621775

80. Henson LA, Gomes B, Koffman J, Daveson BA, Higginson IJ, Gao W, et al. Factors associated with aggressive end of life cancer care. Support Care Cancer. 2016; 24(3):1079–89. https://doi.org/10.1007/s00520-015-2885-4 PMID: 26253587

81. Cantwell P, Turco S, Brenneis C, Hanson J, Neumann CM, Bruera E. Predictors of home death in palliative care cancer patients. J Palliat Care. 2000; 16(1):23–8. PMID: 10802960

82. Hanratty B, Jacoby A, Whitehead M. Socioeconomic differences in service use, payment and receipt of illness-related benefits in the last year of life: Findings from the British Household Panel Survey. Palliat Med. 2008; 22(3):248–55. https://doi.org/10.1177/0269216307087140 PMID: 18477719

83. Escobar Pinzon LC, Claus M, Zepf KI, Letzel S, Weber M. [Dying in Rhineland-Palatinate (Germany): preferred and actual place of death]. Gesundheitswesen. 2013; 75(12):853–8. https://doi.org/10.1055/s-0033-1333740 PMID: 23716170

84. Choo SY, Lee SY, Kim CW, Kim SY, Yoon TH, Shin HR, et al. Educational differences in health care utilization in the last year of life among South Korean cancer patients. [Korean]. Journal of preventive medicine and public health = Yebang Uihakhoe chi. 2007; 40(1):36–44. PMID: 17310597

85. Bescos Oros M, Parra Moncasi P, Coria Balanzat M, Andres Esteban EA, Bordonoba Bosque DB. Determinants of the place of death for terminal cancer patients recruited in a home care support team program in Huesca province. [Spanish]. Medicina Paliativa. 2009; 16(2):89–94.

86. Jarosek SL, Shippee TP, Virnig BA. Place of Death of Individuals with Terminal Cancer: New Insights from Medicare Hospice Place-of-Service Codes. J Am Geriatr Soc. 2016; 64(9):1815–22. https://doi.org/10.1111/jgs.14269 PMID: 27534517

87. Duggan KJ, Wiltshire J, Strutt R, Boxer M, Berthelsen A, Descallar J, et al. Patterns of palliative and psychosocial care in stage IV NSCLC in south western Sydney. J Thorac Oncol. 2015; 2):S365.

88. Burge F, Lawson B, Johnston G. Where a cancer patient dies: the effect of rural residency. J Rural Health. 2005; 21(3):233–8. PMID: 16092297

89. Barbera L, Sussman J, Viola R, Husain A, Howell D, Librach SL, et al. Factors Associated with End-of-Life Health Service Use in Patients Dying of Cancer. Healthcare Policy = Politiques de sante. 2010; 5 (3):e125–43. PMID: 21286260

90. Barclay JS, Kuchibhatla M, Tulsky JA, Johnson KS. Association of hospice patients' income and care level with place of death. JAMA Internal Medicine. 2013; 173(6):450–6. https://doi.org/10.1001/jamainternmed.2013.2773 PMID: 23420383

91. Alonso-Babarro A, Astray-Mochales J, Dominguez-Berjon F, Genova-Maleras R, Bruera E, Diaz-Mayordomo A, et al. The association between in-patient death, utilization of hospital resources and availability of palliative home care for cancer patients. Palliat Med. 2013; 27(1):68–75. https://doi.org/10.1177/0269216312442973 PMID: 22492481

92. Dominguez-Berjon MF, Esteban-Vasallo MD, Zoni AC, Genova-Maleras R, Astray-Mochales J. Place of death and associated factors among patients with amyotrophic lateral sclerosis in Madrid (Spain). Amyotrophic Lateral sclerosis & Frontotemporal Degeneration. 2015; 17(1–2):62–8.

93. O'Dowd EL, McKeever TM, Baldwin DR, Hubbard RB. Place of Death in Patients with Lung Cancer: A Retrospective Cohort Study from 2004–2013. PLoS ONE. 2016; 11(8):e0161399. https://doi.org/10.1371/journal.pone.0161399 PMID: 27551922

94. Assareh H, Stubbs JM, Trinh LTT, Muruganantham P, Achat HM. Variation in out-of-hospital death among palliative care inpatients across public hospitals in New South Wales, Australia. Intern Med J. 2018; 24:24.

95. Bannon F, Cairnduff V, Fitzpatrick D, Blaney J, Gomes B, Gavin A, et al. Insights into the factors associated with achieving the preference of home death in terminal cancer: A national population-based study. Palliative & Supportive Care. 2018; 16(6):749–55.

96. Dixon JK, Matosevic T D. (2015). Equity in Provision of Palliative Care in the UK. Marie Curie: London.

97. Hunt RW, D'Onise K, Nguyen AT, Venugopal K. Where Patients With Cancer Die: A Population-Based Study, 1990 to 2012. J Palliat Care. 2018:825859718814813.

98. Ni Chroinin D, Goldsbury DE, Beveridge A, Davidson PM, Girgis A, Ingham N, et al. Health-services utilisation amongst older persons during the last year of life: a population-based study. BMC Geriatr. 2018; 18(1):317. https://doi.org/10.1186/s12877-018-1006-x PMID: 30572832

99. Fairfield KM, Murray KM, Wierman HR, Han PK, Hallen S, Miesfeldt S, et al. Disparities in hospice care among older women dying with ovarian cancer. [Erratum appears in Gynecol Oncol. 2012 Sep;126(3):509–10]. Gynecol Oncol. 2012; 125(1):14–8.

100. Goodridge D, Buckley A, Marko J, Steeves M, Turner H, Whitehead S. Home care clients in the last year of life: Is material deprivation associated with service characteristics? J Aging Health. 2011; 23 (6):954–73. https://doi.org/10.1177/0898264311402687 PMID: 21467243

101. Bergman J, Saigal CS, Miller DC, Hanley J, Gore JL, Lorenz K, et al. Hospice Use and High-Intensity Care in Men Dying of Prostate Cancer. Arch Intern Med. 2011; 171(3):204–10. https://doi.org/10.1001/archinternmed.2010.394 PMID: 20937914

102. Bradley CJ, Clement JP, Lin C. Absence of cancer diagnosis and treatment in elderly Medicaid-insured nursing home residents. J Natl Cancer Inst. 2008; 100(1):21–31. https://doi.org/10.1093/jnci/djm271 PMID: 18159068

103. Jenkins TM, Chapman KL, Ritchie CS, Arnett DK, McGwin G, Cofield SS, et al. Hospice use in Alabama, 2002–2005. J Pain Symptom Manage. 2011; 41(2):374–82. https://doi.org/10.1016/j.jpainsymman.2010.04.027 PMID: 21236629

104. Odejide OO, Cronin AM, Earle CC, LaCasce AS, Abel GA. Hospice Use Among Patients With Lymphoma: Impact of Disease Aggressiveness and Curability. J Natl Cancer Inst. 2016; 108(1).

105. Shugarman LR, Bird CE, Schuster CR, Lynn J. Age and gender differences in Medicare expenditures and service utilization at the end of life for lung cancer decedents. Womens Health Issues. 2008; 18 (3):199–209. https://doi.org/10.1016/j.whi.2008.02.008 PMID: 18457755

106. Tanuseputro P, Budhwani S, Bai YQ, Wodchis WP. Palliative care delivery across health sectors: A population-level observational study. Palliat Med. 2017; 31(3):247–57. https://doi.org/10.1177/0269216316653524 PMID: 27317412

107. Burge FI, Lawson BJ, Johnston GM, Grunfeld E. A Population-based Study of Age Inequalities in Access to Palliative Care Among Cancer Patients. Med Care. 2008; 46(12):1203–11. https://doi.org/10.1097/MLR.0b013e31817d931d PMID: 19300309

108. Rush B, Berger L, Anthony Celi L. Access to Palliative Care for Patients Undergoing Mechanical Ventilation With Idiopathic Pulmonary Fibrosis in the United States. American Journal of Hospice & Palliative Medicine. 2018; 35(3):492–6.

109. Tramontano AC, Nipp R, Kong CY, Yerramilli D, Gainor JF, Hur C. Hospice use and end-of-life care among older patients with esophageal cancer. Health Science Reports. 2018; 1(9):e76. https://doi.org/10.1002/hsr2.76 PMID: 30623099

110. Davies JM, Gao W, Sleeman KE, Lindsey K, Murtagh FE, Teno JM, et al. Using routine data to improve palliative and end of life care. BMJ Support Palliat Care. 2016 Sep; 6(3):257–62. https://doi.org/10.1136/bmjspcare-2015-000994 PMID: 26928173

111. Galobardes B, Lynch J, Smith GD. Measuring socioeconomic position in health research. Br Med Bull. 2007; 81-82(1):21–37.

112. Grundy E, Holt G. The socioeconomic status of older adults: how should we measure it in studies of health inequalities? J Epidemiol Community Health. 2001; 55(12):895–904. https://doi.org/10.1136/jech.55.12.895 PMID: 11707484

113. Ben-Shlomo Y, Kuh D. A life course approach to chronic disease epidemiology: conceptual models, empirical challenges and interdisciplinary perspectives. Int J Epidemiol. 2002; 31(2):285–93. PMID: 11980781

114. Hart CL, Davey Smith G. Relation between number of siblings and adult mortality and stroke risk: 25 year follow up of men in the Collaborative study. J Epidemiol Community Health. 2003; 57(5):385–91. https://doi.org/10.1136/jech.57.5.385 PMID: 12700225

115. Eusebi LH, Zagari RM, Bazzoli F. Epidemiology of Helicobacter pylori infection. Helicobacter. 2014; 19 Suppl 1:1–5.

116. Hemingway H, Marmot M. Psychosocial factors in the aetiology and prognosis of coronary heart disease: systematic review of prospective cohort studies. BMJ (Clinical Research Ed). 1999; 318 (7196):1460–7.

117. Bambra C, Gibson M, Sowden A, Wright K, Whitehead M, Petticrew M. Tackling the wider social determinants of health and health inequalities: evidence from systematic reviews. J Epidemiol Community Health. 2010; 64(4):284–91. https://doi.org/10.1136/jech.2008.082743 PMID: 19692738

118. Mayhew LR, Smith D B. (2017). Does living in a retirement village extend life expectancy? The case of Whiteley Village. The International Longevity Centre UK: London.

119. Alliance WPC. (2014). Global Atlas of Palliative Care at the End of Life. World Health Organisation.

120. Moens K, Houttekier D, Van den Block L, Harding R, Morin L, Marchetti S, et al. Place of death of people living with Parkinson's disease: a population-level study in 11 countries. BMC Palliat Care. 2015; 14:28. https://doi.org/10.1186/s12904-015-0021-3 PMID: 25990567

121. Houttekier D, Reyniers T, Deliens L, Van Den Noortgate N, Cohen J. Dying in hospital with dementia and pneumonia: A nationwide study using death certificate data. Gerontology. 2014; 60(1):31–7. https://doi.org/10.1159/000354378 PMID: 24192794

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CORRECTION

Correction: Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis

Joanna M. Davies, Katherine E. Sleeman, Javiera Leniz, Rebecca Wilson, Irene J. Higginson, Julia Verne, Matthew Maddocks, Fliss E. M. Murtagh

Reference numbers 96 and 118 in the manuscript appear incorrectly, due to reference formatting software errors. They should appear as below:

96. Dixon J, King D, Matosevic T, Clark M, Knapp M. (2015). Equity in Provision of Palliative Care in the UK. Marie Curie: London.

118. Mayhew L, Rickayzen B, Smith D. (2017). Does living in a retirement village extend life expectancy? The case of Whiteley Village. The International Longevity Centre UK: London.

Reference

1. Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, Verne J, et al. (2019) Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLoS Med 16(4): e1002782. https://doi.org/10.1371/journal.pmed.1002782 PMID: 31013279

Citation: Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, Verne J, et al. (2019) Correction: Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLoS Med 16(7): e1002878. https://doi.org/10.1371/journal.pmed.1002878

Published: July 18, 2019

CHAPTER 6: Socioeconomic position and use of hospital-based care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing

The English Longitudinal Study of Ageing (ELSA) is a nationally representative longitudinal study designed specifically to investigate the social determinants of health. ELSA collects information on the health, wellbeing, and social situation of adults aged 50 years and over living in England, approximately every 2 years through face-to-face interviews, nurse assessments and self-completion questionnaires.[210] ELSA is part of an international network of sister studies that includes the Health and Retirement Study in the USA, The Irish Longitudinal Study on Ageing (TILDA) and many other similar longitudinal studies across the world.

For deceased cohort members, ELSA includes an end-of-life proxy interview, consisting of a face-to-face interview with a partner, close friend, or relative, asking about the health and care needs of the deceased in the last two years of life. The end-of-life proxy data contains data on place of death and other indicators of service use towards the end of life, alongside the rich social and economic data collected in the main survey. The longitudinal nature of the ELSA study is well suited to mediation analysis and this method has been used with ELSA to investigate the social determinants of health and mortality, but had not previously been used to investigate palliative and end-of-life care.[118, 181] Having identified the potential for ELSA to be used to investigate the social determinants of care received towards the end of life, I designed an early outline of the analysis plan and refined the plan after receiving training in Structural Equation Modelling.

6.1 Structural Equation Modelling

Structural Equation Modelling (SEM) is an umbrella term referring to a group of correlation and regression-based techniques, including factor analysis, latent class analysis, and path analysis. At its core, SEM involves the testing of theoretical relationships through the construction and evaluation of models. Compared to standard regression techniques, the advantages of SEM are the ability to embed measurement models of latent constructs within wider path models, and to model multiple outcomes and relationships simultaneously.[211, 212]

6.2 Path analysis

In a traditional multivariable regression model, the analysis estimates the relationship between an exposure and an outcome whilst controlling for one or more confounders. In comparison, a mediation or path analysis is interested in factors that sit on the causal pathway from the exposure to the outcome, and in estimating how much of the effect of the exposure on the outcome can be accounted for by the mediating factor. The mediator is not a confounder of the relationship between exposure and outcome, rather the exposure causes the mediator which in turn causes the outcome.[213] Path analysis takes an explicitly causal approach to interpreting effects.[214] Within this causal framework, an attempt to control for confounders, and to consider how unmeasured confounders could effect the causal interpretation of the exposure, mediator, outcome relationships, is critically important.[215, 216]

Several studies have demonstrated the use of mediation analysis for investigating social determinants of health.[118, 181, 217] The approach offers two main advantages to this field of research. The first is that structural path models provide a method for accounting for the temporal relationship between variables and the cumulative effect of disadvantage across the life course.[181] For example, education usually fixed in early adulthood can be analysed both in terms of its direct effect on an outcome and its indirect effect through other measures such as income or wealth, which are closer in time to the health outcomes being studied.[181] The second advantage is the ability to take multiple exposures, mediators and outcomes into account simultaneously, helping to acknowledge the complexity of the social determinants of health.[213, 218]

6.3 Model development

A critical aspect of structural equation modelling (SEM) is that the development of the model to be tested in the analysis is specified a priori and grounded in existing evidence and theory.[212] Often a mediation analysis is used to test established theories and hypotheses or to evaluate a specific mechanism of an intervention.[118, 217, 219, 220] For this analysis there were no dominant theories to draw on. Instead, the theoretical model was developed based on the evidence generated from the systematic review and meta-analysis and evidence from existing qualitative studies. Model development was iterative, involving a process of learning about SEM methods, mapping the literature to the data available in ELSA, and refining the model through discussions with my supervisors and a statistician (Dr Kia-Chong Chua).

The structural path model (figure 9) includes two exposures of socioeconomic position (wealth and education), two outcomes (place of death and hospital admissions in the last 2 years of life) and three potential mediating pathways (health and function, social support, and access to services). Table 4 is extracted from paper 2 and summarises the variables.

Figure 9: Directed Acyclic Graph (DAG) of the theoretical relationship between socioeconomic position and use of hospital care towards the end of life and potential mediators

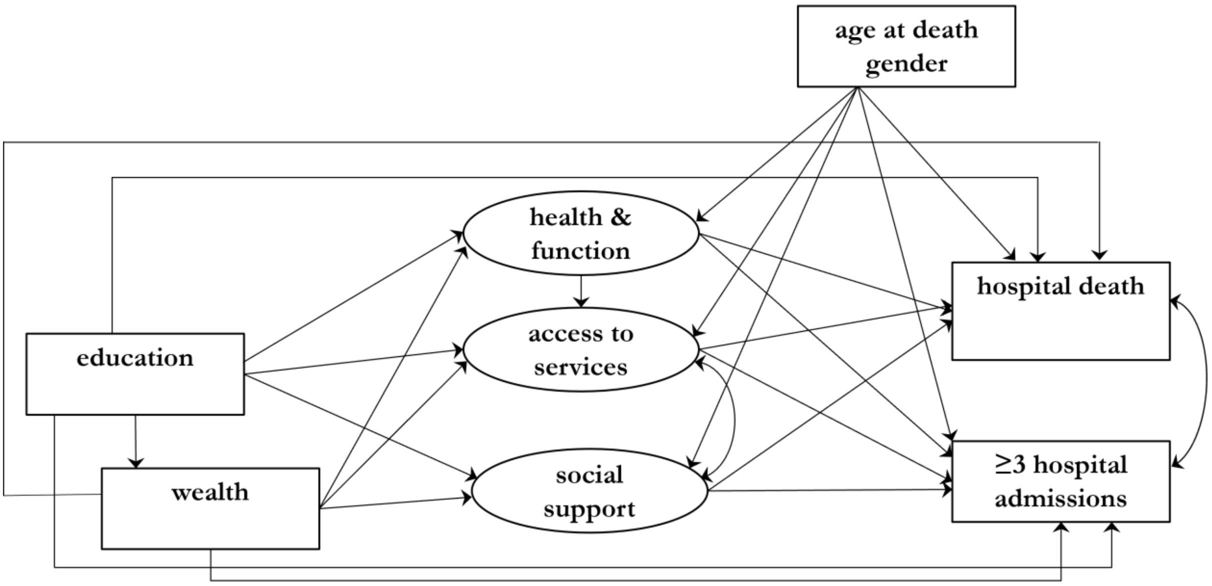

Table 4: Summary of variables for the secondary analysis of ELSA, source [221]

Socioeconomic position exposures (measured at baseline wave)	**Highest educational qualification** (self-reported), 5 hierarchical categories: i) no formal qualifications, ii) lower secondary (GCE, O Level or equivalent), iii) higher secondary (A Level or equivalent), iv) higher education (below degree level), v) degree **Wealth** (self-reported), deciles (1=lowest) of total net non-pension household wealth, a sum of savings, investments, physical wealth and housing wealth after financial debt and mortgage debt has been subtracted, reflecting accumulation of assets over the life course.[182]
Mediators (measured at final wave) For latent mediators high scores were optimal.	**Health and function** (self-reported and nurse collected), validated Latent Index of Somatic Health including chronic illness (physical and mental), mobility, general health, and nurse collected measures (hand grip strength, forced vital capacity, and chair rise time).[221] **Access to healthcare services** (self-reported), latent measure of ease of access to services (general practice, dentist, optician, and hospital), unmet social care need, and transport deprivation **Social support** (self-reported), latent measure of quality of relationships with children, family and friends.
Outcomes (measured at end-of-life proxy interview)	**Death in hospital** (proxy reported), versus death at home (including own home, sheltered housing (but not care home), and another person's home) or in an inpatient hospice unit* **≥3 hospital admissions in the last 2 years of life** (proxy reported), versus up to two hospital admissions (including the terminal admission if the person died in hospital)**
Covariates	**Age at death** (self-reported), also used as a moderator **Gender** (self-reported)

*In the UK hospice is almost always a separate setting to hospital; **The cut off for number of hospital admissions reflects the data distribution.

6.4 Selecting the outcomes

In the early stages of developing the analysis plan, I identified the following potential outcomes of interest in the ELSA proxy data:

- Place of death (home, hospital, hospice, care/nursing home);
- Number of hospital admissions in the last two years of life;
- Length (in days) of hospital admissions in the last two years of life;
- Number of transitions from usual place of care in the last two years of life;
- How ‘at peace’ the decedent was in the last three months or last year of life.

The systematic review and meta-analysis, found that place of death was the most commonly reported outcome, and provided strong and consistent evidence that people with low socioeconomic position are more likely to die in hospital versus home or hospice. This supported the inclusion of place of death in the ELSA analysis, categorised into a binary outcome home/hospice versus hospital and excluded deaths in care homes. The exclusion of care home deaths was due to the difficulty in classifying care home deaths within this binary definition and because admission to a care home might modify the relationship between socioeconomic position and hospital use towards the end of life by reducing hospital admissions for all residents regardless of socioeconomic position.[222] In a sensitivity analysis I re-ran the main analysis on a sample including care home residents with the outcome categorised as hospital versus home, hospice or care home, to understand the effect of the exclusion of care home deaths on the main results.

The second outcome was number of hospital admissions in the last two years of life, dichotomised in to <3 and ≥3 admissions. This categorisation was based on the distribution of data; ~25% of the deceased ELSA sample had ≥3 hospital admissions in the last 2 years of life, and on the categorisation used in an earlier study.[54] End-of-life hospital admissions can be burdensome for patients and carers,[223] they increase sharply towards the end of life, and a higher rate of admissions is associated with a higher level of area-based deprivation.[53, 224, 225] Hospital admissions, like place of death, is a measure of process, used as an indicator of the quality of end-of-life care but subject to similar limitations as place of death. Number of admissions does provide information about the quality of care received. An advantage of hospital admissions, over place of death which is focused on a single event at the point of death, is that number of admissions captures something about care over a longer period of time, in ELSA this is over the last two years of life. This is a longer time-period than would normally be considered end-of-life. However, comparison with population-level data of hospital admissions leading up to death, indicates that the majority of admissions reported in ELSA are likely to have taken place over the last months of life.[53]

‘Length of hospital admissions in the last two years of life’ and ‘number of transitions from usual place of care in the last two years of life’ were rejected on the basis that the existing evidence on the association between socioeconomic position and these outcomes was lacking.[224] The final outcome I considered was based on questions in the proxy data about how ‘at peace’ the decedent was in the last three months or last year of life. This potential outcome was interesting because it is not a measure of process instead resembling a patient centred outcome measure. However, the question did not come from a validated tool and again, prior evidence on the association with deprivation was lacking.

6.5 Selecting the exposures

The analysis included two measures of socioeconomic position: education and wealth. An advantage of structural equation modelling (SEM) is the ability to account for temporal relationships between indicators of socioeconomic positon.[181] In the theoretical model, education, a measure of socioeconomic position usually fixed in early adulthood, is allowed to effect wealth, which is a measure of assets accumulated over the life-course. The measure of wealth available in ELSA is uniquely detailed, and based on information collected from participants about savings, investments, physical wealth, housing wealth, and debt. This produces a comprehensive measure of wealth that has been shown to be a stronger overall predictor of mortality compared to other socioeconomic indicators including education.[182] Based on this existing evidence, wealth, the more ‘proximal’ measure (closer in time to the outcomes), was expected to have a stronger relationship with the outcomes in my model, than the more ‘distal’ education variable. It was useful to test these competing pathways because my review found that education is widely used as an indicator of socioeconomic position in palliative and end-of-life care research, and wealth and education may represent distinct mechanisms through which socioeconomic position might influence health and care towards the end of life.

6.6 Selecting the mediators

The mediators were latent variables, each based on several items and generated using confirmatory factor analysis.[218] An extract from paper 2 of the thesis summarises each of theorised pathways:

"People with lower socioeconomic position experience worse health, including a higher burden of disability and disease,[93] and as a result might have higher need for hospital-based care at the end of life than those with higher socioeconomic position (health and function).

People with lower socioeconomic position might access elective,[224] primary,[226] and social[227] care services less, with access to transport being an important element of this,[228] and therefore use hospital-based care more (access to healthcare services).

The informal care and familial support systems that are essential for keeping people at home and out of hospital in the last months and years of life might be weaker among people with lower socioeconomic position (social support).[229, 230]"

6.7 Paper 2 (see Appendix 2 for supplementary information)

Socioeconomic position and use of hospital-based care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing

Joanna M Davies, Matthew Maddocks, Kia-Chong Chua, Panayotes Demakakos, Katherine E Sleeman, Fliss E M Murtagh**

Summary

Background Many patients prefer to avoid hospital-based care towards the end of life, yet hospitalisation is common and more likely for people with low socioeconomic position. The reasons underlying this socioeconomic inequality are not well understood. This study investigated health, service access, and social support as potential mediating pathways between socioeconomic position and receipt of hospital-based care towards the end of life.

Methods For this observational cohort study, we included deceased participants from the nationally representative English Longitudinal Study of Ageing of people aged 50 years or older in England. We used a multiple mediation model with age-adjusted and gender-adjusted probit regression to estimate the direct effect of socioeconomic position (measured by wealth and education) on death in hospital and three or more hospital admissions in the last 2 years of life, and the indirect effects of socioeconomic position via three mediators: health and function, access to health-care services, and social support.

Findings 737 participants were included (314 [42·6%] female, 423 [57·4%] male), with a median age at death of 78 years (IQR 71–85). For death in hospital, higher wealth had a direct negative effect (probit coefficient –0·16, 95% CI –0·25 to –0·06), which was not mediated by any of the pathways tested. For frequent hospital admissions, health and function mediated the effect of wealth (–0·04, –0·08 to –0·01), accounting for 34·6% of the total negative effect of higher wealth (–0·13, –0·23 to –0·02). Higher wealth was associated with better health and function (0·25, 0·18 to 0·33). Education was associated with the outcomes only indirectly via wealth.

Interpretation Our findings suggest that worse health and function could partly explain why people with lower wealth have more hospital admissions, highlighting the importance of socioeconomically driven health differences in explaining patterns of hospital use towards the end of life. The findings should raise awareness about the related risk factors of low wealth and worse health for patients approaching the end of life, and strengthen calls for resource allocation to be made on the basis of health need and socioeconomic profile.

Funding Dunhill Medical Trust Fellowship Grant (RTF74/0116).

Lancet Public Health 2021; 6: e155–63

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*Joint senior authorship

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Introduction

Many patients prefer to remain at home towards the end of life,[1] yet 90% have a hospital admission in the last year of life, and the number of admissions increases sharply during the last months of life.[2] Reasons for end-of-life hospital admissions are complex; not all are inappropriate but many are considered avoidable.[3] For this reason, death outside of hospital is used as an indicator of quality of end-of-life care.[4] Despite policy initiatives in Europe and North America to support people to be cared for and die outside of hospital, end-of-life hospital admissions are common and hospital (*vs* home, inpatient hospice unit, or residential care or nursing home) remains the most common place of death in many countries.[5]

Characteristics that contribute to increased hospital use include individual factors (such as sex, ethnicity, and preferences), illness-related factors (such as functional status and diagnosis), and environmental factors (such as access to care at home).[6,7] In high-income countries, low socioeconomic position is consistently associated with dying in hospital (*vs* dying at home or in hospice) and with a higher number of hospital admissions in the last months of life.[8]

To understand why people with lower socioeconomic position experience more hospital-based care at the end of life, researchers need to investigate possible mediating pathways through which socioeconomic position influences care. Three potential pathways are through health and function, access to health-care services, and social support. People with lower socioeconomic position experience worse health, including a higher burden of disability and disease,[9] and as a result might have higher need for hospital-based care at the end of life than those with higher socioeconomic position (health and function). People with lower socioeconomic position might access elective,[10] primary,[11] and social[12] care services less, with access to transport being an important element of this,[13] and therefore use hospital-based care more

Research in context

Evidence before this study

There is consistent evidence that people with low socioeconomic position are more likely to experience hospital-based care towards the end of life. In our previous systematic review, we searched the MEDLINE, Embase, PsycINFO, CINAHL, and ASSIA databases without language restrictions from inception to Feb 1, 2019, for empirical observational studies from high-income countries reporting an association between any measure of socioeconomic position and end-of-life care outcomes, including death in hospital, and use of acute care. 112 studies of high-to-medium quality were included in the meta-analysis; quality was assessed using the Newcastle-Ottawa Quality Assessment Scale. Compared with people with the highest socioeconomic position, people with the lowest socioeconomic position were more likely to die in hospital than at home or in a hospice (pooled odds ratio from 31 studies: 1·30, 95% CI 1·23–1·38), and to receive acute hospital-based care in the last 3 months of life (pooled odds ratio from eight studies: 1·16, 1·08–1·25). We found no studies that investigated mediating pathways to explain why people with lower socioeconomic position experience more hospital-based care towards the end of life.

Added value of this study

To our knowledge, this is the first study to empirically test potential mediating pathways between socioeconomic position and use of hospital-based care towards the end of life. We used data from deceased participants of the English Longitudinal Study of Ageing, a representative sample of people in England aged 50 years or older. We analysed the direct effect of wealth and education on two outcomes—death in hospital and three or more hospital admissions in the last 2 years of life—and the indirect effects via the three mediators: health and function, access to health-care services, and social support.

People with lower wealth were more likely to die in hospital and had more hospital admissions compared to people with higher wealth. Worse health and function accounted for a third of the effect of wealth on hospital admissions. None of the pathways tested mediated the relationship between wealth and death in hospital. Education was associated with the outcomes only indirectly via wealth, reflecting that asset accumulation across the life-course is more relevant to end-of-life care than early-life socioeconomic position.

Implications of all the available evidence

In this representative sample, worse health partly explains why people with lower wealth had more hospital admissions in the last years of life. This finding challenges behavioural explanations for socioeconomic patterning in the use of hospital care towards the end of life, instead highlighting the importance of health-related need in driving inequality. These results suggest that health should not be treated simply as a confounder of socioeconomic position but rather as a factor on the pathway between socioeconomic position and hospital admissions. This work should heighten awareness among health-care professionals and commissioners about the related risk factors of low wealth and worse health for patients approaching the end of life. The precise mechanism through which wealth influences death in hospital remains unexplained. Efforts to investigate how asset ownership and income drives this relationship should continue.

(access to healthcare services). The informal care and familial support systems that are essential for keeping people at home and out of hospital in the last months and years of life might be weaker among people with lower socioeconomic position (social support).[14,15]

Nationally representative longitudinal cohort studies offer an opportunity to study the socioeconomic determinants of end-of-life care in detail. The aim of this study was to investigate potential pathways between socioeconomic position and receipt of hospital-based care towards the end of life. The objective was to estimate the relative contribution of education, wealth, and three potential mediators—health and function, access to health-care services, and social support—on death in hospital and frequent hospital admissions in the last 2 years of life.

See Online for appendix

Methods

Study design and participants

For this observational cohort study, we used longitudinal data from the English Longitudinal Study of Ageing (ELSA). ELSA is a nationally representative longitudinal study collecting interview and self-completion questionnaire data approximately every 2 years on the health and social situation of between 8000 and 12 000 people aged 50 years or older living in England, beginning with wave 1 in 2002.[16] For deceased ELSA participants, an end-of-life interview is carried out in person with a close relative, friend, or carer to obtain information on the last year of life (see appendix p 2 for more details).

We included all deceased ELSA participants with at least one wave of data collected before their death, and an end-of-life interview completed by a proxy. We excluded participants with an admission to a residential care or nursing home (care home) in the last 2 years of life. Admission to a care home might moderate the relationship between socioeconomic position and hospital-based care by reducing admissions for all residents.[17] However, the ELSA sample of care home residents is too small to investigate these effects, thus care home residents were excluded from the main analysis. Participants recorded as having died in an ambulance or locations other than a hospital, home, hospice, or care home were excluded because of the difficulty classifying these locations in a binary outcome.

	Details or comparator
Socioeconomic position exposures (measured at baseline wave)	
Highest educational qualification (self-reported)	Five hierarchical categories: (1) no formal qualifications, (2) lower secondary (GCE, O Level, or equivalent), (3) higher secondary (A Level or equivalent), (4) higher education (below degree level), and (5) degree
Wealth (self-reported)	Deciles (1=lowest) of total net non-pension household wealth: a sum of savings, investments, physical wealth, and housing wealth after financial debt and mortgage debt has been subtracted, reflecting accumulation of assets over the life course[18]
Mediators (measured at final wave)*	
Health and function (self-reported and nurse collected)	Validated Latent Index of Somatic Health including chronic illness (physical and mental), mobility, general health, and nurse-collected measures (hand grip strength, forced vital capacity, and chair rise time)[19]
Access to health-care services (self-reported)	Latent measure of ease of access to services (general practice, dentist, optician, and hospital), unmet social care need, and transport deprivation
Social support (self-reported)	Latent measure of quality of relationships with children, family, and friends
Outcomes (measured at end-of-life proxy interview)	
Death in hospital (proxy reported)	Compared with death at home (including own home, another person's home, and sheltered housing [not including care homes]) or in an inpatient hospice unit†
At least three hospital admissions in the last 2 years of life (proxy reported)	Compared with up to two hospital admissions (including the terminal admission if the person died in hospital)‡
Covariates	
Age at death (self-reported)	Also used as a moderator
Gender (self-reported)	..

GCE=General Certificate of Education. *For latent mediators, high scores were optimal. †In the UK, hospice is almost always a separate setting to hospital. ‡The cutoff for number of hospital admissions reflects the data distribution.

Table 1: **Summary of variables**

All participants gave written informed consent at each wave. Ethical approval for ELSA was granted from the NHS Research Ethics Committee (London Multicentre Research Ethics Committee, MREC/01/2/91). No additional ethical approval was required for this secondary analysis study.

Study variables and preliminary analysis

For each participant, we included data on two socioeconomic position exposures (wealth and education, measured at each participant's first wave), three latent mediators (measured at each participant's final wave), and two outcomes (place of death and hospital admissions, measured at the end-of-life proxy interview; table 1). We also included age at death and gender as confounders influencing each of the mediators and outcomes.

We analysed the distribution of all variables using percentages, means, and medians. Outcomes and exposures were described separately for participants younger than 80 years at death and those aged 80 years or older.

We modelled each of the mediators as continuous latent factors. Details of the items used in the latent mediators are provided in the appendix (pp 5–7). Variables representing factors were selected based on a-priori hypotheses and combined using confirmatory factor analysis. Latent factor scores were extracted and used in subsequent models.

To understand the relationships between variables before testing the full structural model, we analysed paths between outcomes, mediators, and exposures in separate regression models, controlling for age and gender, and analysed single mediator models. Statistical significance was set a priori at $p<0 \cdot 05$ with no adjustment for multiplicity.

Full structural model

All hypothesised mediators were included in the final model simultaneously. Multiple mediation is more "convenient, precise and parsimonious" than using multiple single mediation models, and might help to reduce parameter bias due to omitted variables.[20]

Probit regression with a weighted least-squares estimator (see appendix p 4 for technical information) was used to estimate the direct effect of socioeconomic position exposures on the outcomes, and the indirect effects of the exposures on the outcomes via the mediators. We described the extent of mediation as the proportion of the total effect of an exposure mediated by a specific indirect effect. We treated socioeconomic position sequentially, with education (usually set in early adulthood) antecedent to wealth (a measure of assets accumulated over the life-course[18]). Health and function was allowed to affect access to health-care services because health need is a prerequisite of accessing services. We specified a correlational, rather than a directional, relationship between social support and access to health-care services because of a lack of evidence on how quality of relationships might influence access. We report the residual covariance between the two outcome variables.

Results are presented as standardised coefficients from probit regression. We interpreted the probit coefficients in terms of direction, magnitude, and statistical significance. To aid interpretation of the effects, we translated some coefficients to probabilities. Probabilities are for a man with average age, health and function, access to health-care services, and social support. Model fit was assessed using root mean square error of approximation (RMSEA; values

For more on **Mplus** see https://www.statmodel.com

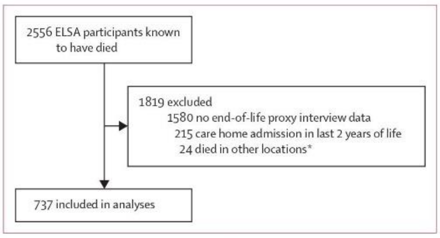

Figure 1: **Inclusion and exclusion of participants**
ELSA=English Longitudinal Study of Ageing. *Locations other than a hospital, home, hospice, or care home.

of ≤0·06 representing good fit and ≤0·08 representing adequate fit), comparative fit index (CFI; ≥0·95 representing good fit and ≥0·90 representing adequate fit), and Tucker-Lewis index (TLI; ≥0·95 representing good fit and ≥0·90 representing adequate fit).[21]

The proportion of missing data was low (<5%) for all variables apart from the latent social support variable (26·1% missing). To address this, in the full structural model, missing data were imputed using all variables in the model and 30 sets, with estimates and model fit indices averaged using Rubin's rules (appendix p 4).

Moderation by age

Previous studies have shown that the influence of socioeconomic position on health might weaken with increasing age.[22] We examined this potential moderation effect by plotting the age-moderated effect of socioeconomic position exposures on health and function and on the outcomes, to see if the magnitude of the direct effects weakened with increasing age. Age was centred to aid interpretation. The literature offered no substantive justification for examining other potential moderation effects (eg, gender).

Sensitivity analysis

We did three sensitivity analyses. First, we repeated the final analysis for a sample including participants with a care home admission to evaluate how exclusion of this subgroup from the main sample affected results. Second, bootstrapped model estimates using 5000 draws and based on non-imputed data were obtained and compared with the final model estimates based on the data from multiple imputation.

Diagnosis (and cause of death) is socially patterned and might influence end-of-life care—for example, hospital death is less likely for people dying from cancer compared with non-cancer conditions.[23] Our model treats disease as a potential mediator on the pathway from socioeconomic position to care and therefore does not additionally control for specific diagnoses. In a third sensitivity analysis, to investigate potential confounding of the exposure–outcome relationships by diagnosis, we adjusted effects on the outcomes for cancer as a cause of death and diagnosis of depressive symptoms.

Data preparation was carried out in Stata (version 13). Analysis was carried out in Mplus (version 8.1).

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Results

After exclusions, 737 ELSA participants were included in the final sample (figure 1); 423 (57·4%) were men, 412 (55·9%) were younger than 80 years old when they died, and 718 (97·4%) identified as white (table 2). At their final wave, 542 (73·5%) had one or more chronic illnesses and 434 (58·9%) had one or more functional limitation (appendix p 5).

Participants contributed to a median of two waves (IQR 1–3) before death. Baseline was a median of 27·4 months (0·0–50·7) before the final wave. The final wave was a median of 15·2 months (8·1–21·3) before death and the end-of-life proxy interview a median of 20·3 months (12·2–32·0) after death. Deaths occurred between 2002 and 2012.

The three measurement models had good fit to the data (appendix p 8). For the final structural model, values of the χ^2 statistic ($\chi^2[3]=5\cdot946$; SD 2·208), RMSEA (0·033; SD 0·015), and CFI (0·992; SD 0·006) indicated good fit, and the TLI (0·909; SD 0·068) indicated adequate fit.

In the preliminary analysis (appendix p 9) and the final model (figure 2; table 3), higher wealth was associated with better health and function and better access to health-care services, and negatively associated with death in hospital. None of the pathways tested mediated the effect of wealth on hospital death. In the final model, the predicted probability of death in hospital for a man in the lowest decile of wealth was 69·9%, compared with 50·8% in the highest decile of wealth.

In the preliminary analysis (appendix p 9), higher wealth was negatively associated with hospital admissions; the probability of having three or more hospital admissions was 34·5% for a man in the lowest decile of wealth and 29·5% in the highest decile of wealth. In the final model (table 3), health and function mediated the effect of wealth on admissions, accounting for 34·6% of the total effect of wealth on admissions, and the direct effect of wealth on admissions was no longer significant.

In the preliminary analysis (controlling for wealth) and in the final model, we found no significant direct effect for education on the outcomes or mediators. In the final model, higher education had a strong positive effect on wealth, and indirect effects via wealth on health and function, access to health-care services, and death in hospital.

Better health and function was negatively associated with frequent hospital admissions but had no significant association with death in hospital in the preliminary analysis (appendix p 9) or in the final model (table 3). Better health and function was associated with better access to health-care services in the final model. Access to health-care services was not associated with the outcomes in the preliminary analysis or final model. Social support was not associated with the exposures or outcomes in the preliminary analysis or in the final model. Social support and access to health-care services were correlated in the final model (table 3).

The negative effect of increased wealth on likelihood of death in hospital was weaker at older ages (figure 3). The effect was not significant for people who died aged 85 years or older or for the very youngest in the sample (figure 3). The probability of death in hospital for the oldest participants was 70·5% for the most deprived and 60·0% for the least deprived, whereas for the youngest participants, the probability of death in hospital was 68·8% for the most deprived and 38·2% for the least deprived. The positive direct effect of wealth on health and function also diminished as age increased (appendix p 10).

In our sensitivity analyses, the results from the bootstrapped model estimates were largely consistent with the final model estimates (appendix p 11). Effects in the sample that included care home residents (n=950) were similar to the those in the main sample, although the effect of wealth on hospital death appears attenuated when care home residents are included (appendix p 12). When controlling (separately) for cancer diagnosis and depressive symptoms, the effect of wealth on hospital death was attenuated but remained significant (appendix p 14).

	All participants (n=737)	Participants who died aged <80 years (n=412)	Participants who died aged ≥80 years (n=325)
Median age at death, years	78 (71–85)	..	..
Gender			
Female	314 (42·6%)	168 (40·8%)	146 (44·9%)
Male	423 (57·4%)	244 (59·2%)	179 (55·1%)
Surviving spouse or partner at time of death	452 (61·3%)	298 (72·3%)	154 (47·4%)
Cause of death			
Cancer	251 (34·1%)	186 (45·1%)	65 (20·0%)
Cardiovascular disease	215 (29·2%)	97 (23·5%)	118 (36·3%)
Respiratory disease	92 (12·5%)	43 (10·4%)	49 (15·1%)
Other	84 (11·4%)	43 (10·4%)	41 (12·6%)
Missing	95 (12·9%)	43 (10·4%)	52 (16·0%)
Place of death			
Home	219 (29·7%)	140 (34·0%)	79 (24·3%)
Hospital	449 (60·9%)	217 (52·7%)	232 (71·4%)
Hospice	69 (9·4%)	55 (13·3%)	14 (4·3%)
Number of hospital admissions in the last 2 years of life			
≥3	187 (25·4%)	114 (27·7%)	73 (22·5%)
<3	539 (73·1%)	293 (71·1%)	246 (75·7%)
Missing	11 (1·5%)	5 (1·2%)	6 (1·8%)
Wealth quintile at baseline*			
1 (lowest)	195 (26·5%)	102 (24·8%)	93 (28·6%)
2	150 (20·4%)	86 (20·9%)	64 (19·7%)
3	135 (18·3%)	77 (18·7%)	58 (17·8%)
4	127 (17·2%)	70 (17·0%)	57 (17·5%)
5 (highest)	125 (17·0%)	75 (18·2%)	50 (15·4%)
Missing	5 (0·7%)	2 (0·5%)	3 (0·9%)
Education at baseline			
No formal qualification	447 (60·7%)	226 (54·9%)	221 (68·0%)
Lower secondary	129 (17·5%)	82 (19·9%)	47 (14·5%)
Higher secondary	38 (5·2%)	23 (5·6%)	15 (4·6%)
Higher education (below degree)	52 (7·1%)	37 (9·0%)	15 (4·6%)
Degree	70 (9·5%)	44 (10·7%)	26 (8·0%)
Missing	1 (0·1%)	0	1 (0·3%)

Data are n (%) or median (IQR). ELSA=English Longitudinal Study of Ageing. *In deciles for main analysis.

Table 2: **Characteristics for 737 deceased ELSA participants**

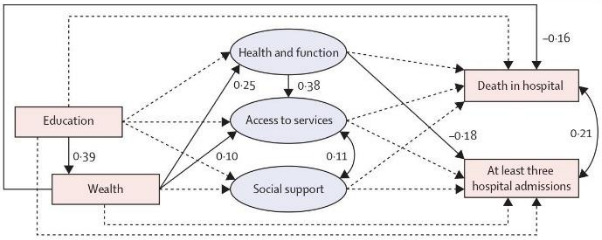

Figure 2: **Standardised probit coefficients for the direct effects for the final full structural model**
Single-headed arrows indicate regression paths, double-headed arrows indicate covariances, ovals represent latent variables, and rectangles represent measured variables. Coefficients are shown for statistically significant paths, whereas paths with dashed lines were not significant.

Discussion

In this nationally representative sample, lower wealth was associated with an increased probability of having three or more hospital admissions in the last 2 years of life and an increased probability of death in hospital (*vs* death at home or in hospice). Health and function mediated the relationship between wealth and hospital admissions, accounting for a third of the total effect of wealth. This suggests that people with lower wealth have more hospital admissions in part because they have worse health. None of the pathways tested, including health and function, mediated the relationship between wealth and hospital death. Education was only associated with the outcomes indirectly via wealth, reflecting that asset accumulation across the life course is likely to be more relevant to end-of-life care than early life socioeconomic position.

In our preliminary analysis, lower wealth was associated with both lower access to health-care services and higher hospital admissions. A recent population-based study reported similar findings; the authors suggested that these separate associations could represent a substitution effect, with people with lower socioeconomic position substituting emergency care for elective care.[10] Our structural model tested this potential pathway but found that lower access to health-care services among people with lower wealth did not explain their higher hospital admissions. Instead, we found that worse health and function partly explained the effect of lower wealth on

	Wealth	Health and function	Access to health-care services	Social support	Death in hospital	At least three hospital admissions
Covariates						
Age	..	–0·04 (–0·12 to 0·03)	–0·23 (–0·29 to –0·17)*	0·12 (0·03 to 0·20)*	0·26 (0·17 to 0·35)*	–0·14 (–0·24 to –0·04)*
Female gender	..	–0·11 (–0·26 to 0·03)	0·10 (–0·04 to 0·23)	0·27 (0·10 to 0·44)*	–0·01 (–0·19 to 0·18)	–0·16 (–0·36 to 0·05)
Mediators						
Health and function (direct effect)	..	..	0·38 (0·32 to 0·45)*	..	–0·04 (–0·14 to 0·05)	–0·18 (–0·29 to –0·07)*
Indirect effect via access to health-care services	..	..	..	..	0·02 (–0·02 to 0·06)	0·00 (–0·04 to 0·05)
Access to health-care services (direct effect)	..	..	..	..	0·06 (–0·04 to 0·16)	0·00 (–0·10 to 0·12)
Social support (direct effect)	..	..	..	..	0·04 (–0·07 to 0·14)	–0·05 (–0·16 to 0·06)
Wealth						
Direct effect	..	0·25 (0·18 to 0·33)*	0·10 (0·02 to 0·17)*	0·08 (–0·02 to 0·17)	–0·16 (–0·25 to –0·06)*	–0·08 (–0·19 to 0·03)
Total indirect effects	..	..	..	..	0·01 (–0·02 to 0·03)	–0·05 (–0·08 to –0·01)*
Via health and function	..	..	0·10 (0·06 to 0·13)*	..	–0·01 (–0·04 to 0·01)	–0·04 (–0·08 to –0·01)*
Via access to health-care services	..	..	..	..	0·01 (–0·01 to 0·02)	0·00 (–0·01 to 0·01)
Via social support	..	..	..	..	0·00 (–0·01 to 0·01)	–0·00 (–0·02 to 0·01)
Via health and function, and access to health-care services	..	..	..	..	0·01 (–0·00 to 0·02)	0·00 (–0·01 to 0·01)
Total effect	..	..	..	..	–0·15 (–0·25 to –0·06)*	–0·13 (–0·23 to –0·02)*
Highest educational qualification						
Direct effect	0·39 (0·32 to 0·46)*	0·00 (–0·08 to 0·08)	0·03 (–0·05 to 0·11)	–0·00 (–0·09 to 0·09)	–0·09 (–0·18 to 0·01)	0·01 (–0·10 to 0·12)
Total indirect effects	..	..	..	..	–0·06 (–0·10 to –0·02)*	–0·05 (–0·09 to –0·01)*
Via health and function	..	..	0·00 (–0·03 to 0·03)	..	–0·00 (–0·00 to 0·00)	0·00 (–0·01 to 0·01)
Via access to health-care services	..	..	..	..	0·00 (–0·00 to 0·01)	0·00 (–0·00 to 0·00)
Via social support	..	..	..	..	0·00 (–0·00 to 0·00)	0·00 (–0·01 to 0·01)
Via wealth	..	0·10 (0·06 to 0·13)*	0·04 (0·01 to 0·07)*	0·03 (–0·01 to 0·07)	–0·06 (–0·10 to –0·02)*	–0·03 (–0·07 to 0·01)
Via health and function, and access to health-care services	..	..	..	..	0·00 (–0·00 to 0·00)	0·00 (0·00 to 0·00)
Total effect	..	..	..	..	–0·14 (–0·23 to –0·05)*	–0·04 (–0·14 to 0·06)
Covariances						
Social support	..	..	0·11 (0·03 to 0·19)*	..	..	..
Death in hospital	..	..	..	..	..	0·21 (0·08 to 0·34)*

Model includes data from 737 participants. *p value <0·05.

Table 3: **Standardised probit coefficients for the direct and indirect effects for the final full structural model**

hospital admissions, challenging behavioural explanations for higher use of hospital care among people with lower socioeconomic position.

A recent simulation study showed that sample size requirements for structural equation models range from 30 to 460 and depend on a multitude of factors.[24] Missing data and small effect sizes, inherent in observational data and present in this study, can limit statistical power.[24] Results from our study should be interpreted with caution and, where possible, tested in alternative data sources. Strengths of this study are the relatively large sample size (n=737), application of multiple imputation methods, and use of the ELSA data, a unique resource for studying the relationship between socioeconomic position and hospital-based end-of-life care. A further strength is that we tested multiple competing hypotheses; however, our model does not rule out the possibility of omitted mediators and confounders that might bias our results. In this secondary analysis, the choice and timing of measures was constrained by the design of the primary survey, leaving some aspects potentially relevant to end-of-life care unrecorded (eg, social support and frequency of contacts closer to death, use of advance care planning, and access to community-based end-of-life care services).[6,8]

Social patterning in cause of death might explain some of the effect of wealth on death in hospital. For example, in our sample (appendix p 13) and in other studies, dying from cancer is associated with higher socioeconomic position and lower likelihood of death in hospital.[23] Our sensitivity analysis adjusted the final model for cancer as a cause of death and found that the direct effect of wealth on hospital death was attenuated but remained significant. Similar attenuating effects were found after adjusting for diagnosis of self-reported depressive symptoms. By not accounting for specific diagnoses or causes of death, our model might overestimate the magnitude of the direct effect of wealth on hospital death, although the relative contribution of the direct and indirect pathways would not be expected to change.

In this study, worse health and function predicted more frequent admissions but did not predict death in hospital. In some conditions, worse health might protect against dying in hospital by making terminal prognosis more predictable and hence planning for home death more possible.[25] Investigating variation in the mediating role of the severity of disease and disability in different conditions could help to unpick this potentially bidirectional effect. Our analysis finds that after adjusting for social patterning in health and function, the direct effect of wealth on death in hospital remains. Further work to identify the particular aspects of income or material asset ownership that drives the relationship between wealth and hospital death is needed to inform strategies for reducing death in hospital for the most socioeconomically deprived people. Geographical inequality in the provision of hospice, care home, and hospital services are potentially modifiable factors in the relationship between socioeconomic position and end-of-life care that are also important to understand.[26]

The majority of our sample had no educational qualifications, reflecting that many older people left school at the minimum age without formal qualifications.[27] Wealth deciles were better than education for differentiating between participants with lower socioeconomic position, which might partly explain the stronger effect wealth has on the outcomes. Studies designed to compare different socioeconomic position measures have found that wealth is a stronger predictor of death than early-life measures of socioeconomic position such as education and occupational class.[18] An explanation for this is that wealth is closer chronologically to later-life health and reflects both current and accumulated socioeconomic position. Studies designed to measure other potentially modifiable factors on the pathway from education to care such as health literacy should be used to further investigate the impact of patient education on end-of-life care.

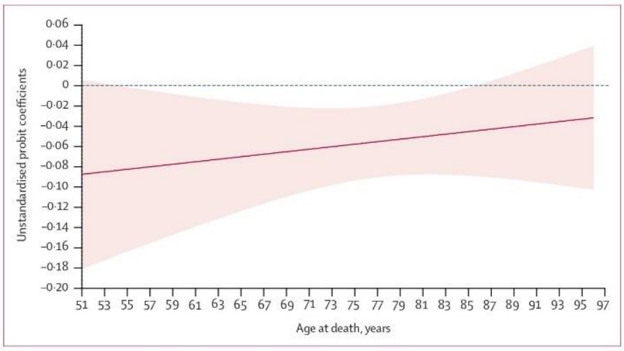

Figure 3: **Direct effect of wealth on death in hospital (*vs* home or hospice)**
Figure plots the direct effect (with 95% CIs) of wealth on death in hospital, moderated by age.

Recall bias is a possibility in this study given the retrospective nature of our proxy-reported outcomes. However, the sample distribution of the outcomes was a good reflection of patterns of hospital admissions and place of death in the wider population, suggesting small bias in the ELSA data (appendix p 3). Our treatment of place of death assumes that hospital death is a worse outcome than death at home or in hospice. It is important to acknowledge that place of death is an imperfect indicator of quality of care, as hospital might be the most appropriate or preferred place of death for some people. The measure of hospital admissions did not delineate between emergency and elective admissions and was based on the last 2 years of life, which might be a longer time period than would normally be considered as end of life.

The sample was subject to selection effects, biased towards including younger, wealthier men who had a living proxy to complete the end-of-life survey. This might weaken the effects of low wealth on the outcomes, particularly for women in the sample. Our main analysis excluded the important subgroup of people who move to a care home towards the end of life. Attenuation of wealth effects in our sensitivity analysis including care home residents supports the hypothesis that care home admission might moderate the relationship between socioeconomic position and hospital-based care.[17] This warrants further study in a sample more representative of the population of care home residents.

Hospital admissions towards the end of life are common; not all admissions are inappropriate but many are considered avoidable.[3,4] There is consistent evidence that people with lower socioeconomic position are more likely to experience hospital-based care at the end of life.[8] To our knowledge, this is the first study to attempt to empirically investigate factors mediating the relationship between socioeconomic position and receipt of hospital-based care towards the end of life. In this study, people with lower wealth experienced more hospital admissions in the last 2 years of life in part because they had worse health and function than wealthier people. A tendency to seek behavioural explanations for higher use of hospital care among more deprived groups[28] might overlook that this relationship is driven by greater health needs. The relationship between lower wealth and increased probability of death in hospital was not explained by health and function. Efforts to understand how income and asset ownership might drive this relationship, and to test other potential mediators, including access to community-based end-of-life care services, should continue.

More socioeconomically deprived people experience a disproportionate burden of disability and disease.[9] This study concludes that socioeconomically driven health differences might explain patterns of hospital admissions towards the end of life. Acknowledging that the greater burden of disease experienced by those with lower socioeconomic position also drives hospital admissions in the last years of life is important for policy and practice. The findings from this study strengthen calls for resource allocation formulae to ensure that funding of services is made on the basis of health need and socioeconomic profile,[9] and should raise awareness among professionals providing end-of-life care about the related risk factors of low socioeconomic position and poor health. The methodological implications of this work are that studies investigating the role of socioeconomic position on hospital admissions should account for the mediating influence of health, rather than simply controlling for health as a confounder.

Contributors

JMD, KES, FEMM, MM, and PD conceptualised the study. JMD carried out the analysis with supervision from KES, FEMM, MM, PD, and K-CC. K-CC provided statistical supervision. JMD, KES, FEMM, and MM accessed and verified the data. JMD drafted the manuscript with critical revisions by all other authors. All authors reviewed and approved the final version. All authors had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Declaration of interests

We declare no competing interests.

Data sharing

Data used in this study are freely available from the UK Data Service. The analytical code is available on GitHub.

For the **data used in this study** see https://beta.ukdataservice.ac.uk/datacatalogue

For the **analytical code** see https://github.com/joannamariedavies

Acknowledgments

JMD is supported by a Research Training Fellowship from The Dunhill Medical Trust (RTF74/0116). KES is supported by a National Institute for Health Research (NIHR) Clinician Scientist Fellowship (CS-2015-15-005). MM is supported by a NIHR Career Development Fellowship (CDF-2017-009). FEMM is an NIHR Senior Investigator. This work was supported by the NIHR Applied Research Collaboration South London at King's College Hospital NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of the National Health Service, the NIHR, or the Department of Health and Social Care. ELSA was developed by a team of researchers based at the University College London, NatCen Social Research, and the Institute for Fiscal Studies. Data were collected by NatCen Social Research. The funding is currently provided by the National Institute of Aging (R01AG017644), and a consortium of UK Government departments coordinated by the NIHR.

References

1 Gomes B, Higginson IJ, Calanzani N, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Ann Oncol* 2012; **23:** 2006–15.

2 Bardsley M, Georghiou T, Spence R, Billings J. Factors associated with variation in hospital use at the end of life in England. *BMJ Support Palliat Care* 2019; **9:** 167–74.

3 Reyniers T, Deliens L, Pasman HR, et al. Reasons for end-of-life hospital admissions: results of a survey among family physicians. *J Pain Symptom Manage* 2016; **52:** 498–506.

4 Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. *J Clin Oncol* 2003; **21:** 1133–38.

5 Cohen J, Pivodic L, Miccinesi G, et al. International study of the place of death of people with cancer: a population-level comparison of 14 countries across 4 continents using death certificate data. *Br J Cancer* 2015; **113:** 1397–404.

6 Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006; **332:** 515–21.

7 Henson LA, Gao W, Higginson IJ, et al. Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis. *J Clin Oncol* 2015; **33:** 370–76.

8 Davies JM, Sleeman KE, Leniz J, et al. Socioeconomic position and use of healthcare in the last year of life: a systematic review and meta-analysis. *PLoS Med* 2019; **16:** e1002782.

9 Marmot M, Allen J, Boyce T, Goldblatt P, Morrison M. Health equity in England: the Marmot review 10 years on. London: Institute of Health Equity, 2020.

10 Walsh B, Laudicella M. Disparities in cancer care and costs at the end of life: evidence from England's National Health Service. *Health Aff (Millwood)* 2017; **36:** 1218–26.

11 Asaria M, Cookson R, Fleetcroft R, Ali S. Unequal socioeconomic distribution of the primary care workforce: whole-population small area longitudinal study. *BMJ Open* 2016; **6:** e008783.

12 Brown L, Sondaal A. Health survey for England 2016: social care for older adults. Leeds: Health and Social Care Information Centre, 2017.

13 Syed ST, Gerber BS, Sharp LK. Traveling towards disease: transportation barriers to health care access. *J Community Health* 2013; **38:** 976–93.

14 Hughes A. Poverty and palliative care in the US: issues facing the urban poor. *Int J Palliat Nurs* 2005; **11:** 6–13.

15 Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998; **47:** 565–79.

16 Steptoe A, Breeze E, Banks J, Nazroo J. Cohort profile: the English longitudinal study of ageing. *Int J Epidemiol* 2013; **42:** 1640–48.

17 Kelfve S, Wastesson J, Fors S, Johnell K, Morin L. Is the level of education associated with transitions between care settings in older adults near the end of life? A nationwide, retrospective cohort study. *Palliat Med* 2018; **32:** 366–75.

18 Demakakos P, Biddulph JP, Bobak M, Marmot MG. Wealth and mortality at older ages: a prospective cohort study. *J Epidemiol Community Health* 2016; **70:** 346–53.

19 Ploubidis GB, Grundy E. Health measurement in population surveys: combining information from self-reported and observer-measured health indicators. *Demography* 2011; **48:** 699–724.

20 Preacher KJ, Hayes AF. Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behav Res Methods* 2008; **40:** 879–91.

21 Hooper DCJ, Mullen M. Structural equation modelling: guidelines for determining model fit. *Electron J Bus Res Methods* 2008; **6:** 53–60.

22 Huisman M, Kunst AE, Mackenbach JP. Socioeconomic inequalities in morbidity among the elderly; a European overview. *Soc Sci Med* 2003; **57:** 861–73.

23 National End of Life Care Intelligence Network. Deprivation and death: variation in place and cause of death. National End of Life Care Intelligence Network. London: Public Health England, 2012.

24 Wolf EJ, Harrington KM, Clark SL, Miller MW. Sample size requirements for structural equation models: an evaluation of power, bias, and solution propriety. *Educ Psychol Meas* 2013; **76:** 913–34.

25 Wagner GJ, Riopelle D, Steckart J, Lorenz KA, Rosenfeld KE. Provider communication and patient understanding of life-limiting illness and their relationship to patient communication of treatment preferences. *J Pain Symptom Manage* 2010; **39:** 527–34.

26 Gatrell AC, Wood DJ. Variation in geographic access to specialist inpatient hospices in England and Wales. *Health Place* 2012; **18:** 832–40.

27 Grundy E, Holt G. The socioeconomic status of older adults: how should we measure it in studies of health inequalities? *J Epidemiol Community Health* 2001; **55:** 895–904.

28 McCarthy M. Poor people view hospitals as providing better access, care, and social support. *BMJ* 2013; **347:** f4556.

CHAPTER 7: The association between socioeconomic position and the symptoms and concerns of hospital inpatients seen by specialist palliative care: Analysis of routinely collected patient data

This analysis used data collected routinely on hospital inpatients receiving specialist palliative care at two large London teaching hospitals. The analysis investigates the association between area-based deprivation (linked to patient's home postcodes) and the symptoms and concerns of patients, recorded using the staff-completed Integrated Palliative care Outcome Scale (IPOS).

These data had not previously been used to analyse the association between socioeconomic position and IPOS. This analysis fills a gap identified by the systematic review and meta-analysis, namely a lack of data on the association between socioeconomic position and the health-related needs of palliative patients. The analysis is cross-sectional so does not explore 'outcomes' in terms of a change in health status[79], but shifts the focus in the thesis from the process measures that dominate in the systematic review and in the ELSA analysis, towards the rich patient-centred data generated from IPOS.[231] It extends an existing small body of literature on this relationship that is based only on studies of advanced cancer patients, to a large cancer and non-cancer population.[232-235]

Collection of this clinical data occurred much closer to death than the collection of the ELSA data. In the ELSA sample, the final data collected prior to the mortality follow-back element was collected a median of 15.2 months (IQR 8.1-21.3) before death. For the clinical data, date of death is available only for patients who died during the episode of care (50.8%), for these patients, death happened a median of 3 days (IQR 1-7) after IPOS was collected. The analysis was restricted to people aged ≥60 years old, because the symptoms and concerns of younger adults receiving palliative care may be very different to those of older adults, and because the sample size was large enough for this restriction to not limit the power in the analysis.[236-238]

In this routinely collected clinical data, the only measure of socioeconomic position available is area-based deprivation, measured using the Index of Multiple Deprivation (IMD) for England (2019) and linked to patient postcode at Lower Super Output Area (LSOA) level.[239] The limitation of area-based measures is that they try to infer something about an individual from aggregate data, known as the ecological fallacy. The advantage of area-based measures that capture multiple aspects of deprivation such as the IMD which has seven domains including, income, employment, education, health, crime, barriers to services, and environment, is that they may capture more of the variance around socioeconomic position, itself a multi-faceted phenomena, than singular measures.[177] The association between area-based deprivation and health is well established.[1, 93] Area-based measures provide a robust way to measure socioeconomic position in routinely collected data where no individual-level alternatives are available.

7.1 Paper 3 (see Appendix 3 for supplementary information)

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DOI: 10.1177/02692163221115331
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The association between socioeconomic position and the symptoms and concerns of hospital inpatients seen by specialist palliative care: Analysis of routinely collected patient data

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Abstract

Background: Understanding how socioeconomic position influences the symptoms and concerns of patients approaching the end of life is important for planning more equitable care. Data on this relationship is lacking, particularly for patients with non-cancer conditions.

Aim: To analyse the association between socioeconomic position and the symptoms and concerns of older adult patients seen by specialist palliative care.

Design: Secondary analysis of cross-sectional, routinely collected electronic patient data. We used multivariable linear regression with robust standard errors, to predict scores on the three subscales of the Integrated Palliative care Outcome Scale (IPOS; physical symptoms, emotional symptoms and communication and practical concerns) based on patient level of deprivation, measured using Index of Multiple Deprivation.

Setting/participants: Consecutive inpatients aged 60 years and over, seen by specialist palliative care at two large teaching hospitals in London between 1st January 2016 and 31st December 2019.

Results: Seven thousand eight hundred and sixty patients were included, 38.3% had cancer. After adjusting for demographic and clinical characteristics, patients living in the most deprived areas had higher (worse) predicted mean scores on the communication and practical subscale than patients living in the least deprived areas, 5.38 (95% CI: 5.10, 5.65) compared to 4.82 (4.62, 5.02) respectively. This effect of deprivation diminished with increasing age. Deprivation was not associated with scores on the physical or emotional symptoms subscales.

Conclusions: Targetting resources to address practical and communication concerns could be a strategy to reduce inequalities. Further research in different hospitals and across different settings using patient centred outcome measures is needed to examine inequalities.

Keywords

Socioeconomic factors, health equity, symptom assessment, palliative care

What is already known about the topic?

- Research on socioeconomic inequality towards the end of life has tended to focus on inequality in access to care.
- A small number of studies, only on patients with advanced cancer, suggest that people with lower socioeconomic position may experience worse pain, anxiety, depression, overall symptom burden, and have poorer emotional well-being and quality of life.

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What this paper adds?

- This evaluation of routinely collected data on all inpatients seen by specialist palliative care at two large London hospitals between 2016 and 2019, finds that patients who lived in more deprived areas had worse communication and practical concerns at initial assessment.
- The difference in communication and practical concerns according to level of deprivation held after adjusting for multiple clinical and demographic characteristics.
- The effect of deprivation on communication and practical concerns diminished with increasing age and was not statistically significant for patients aged >83 years.
- Patient level of deprivation was not associated with physical or emotional symptoms.

Implications for practice theory or policy

- This study provides novel and practical insights into the relationship between area-based deprivation and the symptoms and other concerns of hospital inpatients seen by palliative care.
- The findings indicate that targetting resources to address practical and communication concerns could be a strategy to reduce inequalities for people approaching the end of life.

Background

In high income countries, end-of-life hospital admissions, death in hospital (compared to home or hospice) and a lack of access to specialist palliative care are consistently more common for people with lower socioeconomic position. Research on socioeconomic inequality towards the end of life has tended to focus on inequality in access to care.[1,2] There is a lack of data on how socioeconomic position influences the symptoms and concerns of people towards the end of life.[3]

Patient-centred outcome measures are validated questionnaires that measure the health status, symptoms and well-being of patients.[4] These measures are increasingly used in palliative and end-of-life care for research, quality improvement and in routine care.[5,6] Understanding how social factors such as age, deprivation and ethnicity are associated with the symptoms and concerns of patients with advanced illness is important for planning the delivery of more equitable care. This challenge is particularly important in the context of an ageing population[7] and increasing social inequality.[8,9]

Existing evidence, based on a small number of studies and only on patients with advanced cancer, suggests that people with lower socioeconomic position may experience worse pain, anxiety, depression and overall symptom burden,[10–12] and have poorer emotional well-being and quality of life.[13] More studies including patients with non-cancer conditions are needed to strengthen the evidence on socioeconomic inequality in the symptom burden of dying patients.

This study aims to analyse the association between socioeconomic position and the symptoms and other concerns of older adult patients seen by specialist palliative care at two large London-based teaching hospitals between 2016 and 2019. Based on existing evidence,[10–13] we hypothesised that the symptoms and concerns of patients would be worse for patients living in more deprived areas.

Methods

Study design, data source, setting and participants

Secondary analysis of cross-sectional, electronic patient data, including all older adult (aged 60 or older) inpatients seen by specialist palliative care (first episode of care only) at two large teaching hospitals in London between 1st January 2016 and 31st December 2019. We focussed on older adults because their symptoms and concerns are likely to be different to those of younger adults.[14–16] At the time of data collection, the multi-professional specialist palliative care team provided an advisory service to both hospitals, comprised of a visiting service 09:00–17:00 Monday to Friday, with 24/7 consultant-led telephone support, and a limited weekend and public holiday visiting service.[17] Both hospitals have emergency departments, acute medical beds and intensive care units. Hospital 1 is situated on the outskirts of the city and has 512 beds, hospital 2 has 1100 beds and serves an inner-city population.[17]

Outcome and exposure variables

The outcome variables were the three subscales of the Integrated Palliative care Outcome Scale (IPOS): physical symptoms, emotional symptoms, communication/practical issues (Table 1).[18] IPOS is a brief, validated, patient self-reported and staff proxy-reported outcome measure, used to assess symptoms and concerns in advanced illness.[18] The IPOS was first introduced into routine clinical care in both hospitals in 2016 and is part of the electronic

Table 1. summary of the Integrated Palliative care Outcome Scale (IPOS) subscales.

IPOS subscale	# items	Score range	Items
Physical symptoms	10	0–40	Pain Shortness of breath Weakness or lack of energy Nausea Vomiting Poor appetite Constipation Score or dry mouth Drowsiness Poor mobility
Emotional symptoms	4	0–16	Patient anxiety Family anxiety Depression Feeling at peace
Communication/practical concerns	3	0–12	Sharing feelings Information needs Practical matters

patient record. The IPOS was completed by clinical staff up to 3 days after the first clinical assessment. The IPOS asks about how much the patient has been affected by symptoms and other concerns over the last 3 days, higher scores indicate worse symptoms or concerns. Subscales scores were summed from the item scores. For cases with at least half the items complete for the physical and emotional subscales, and at least one item complete for the practical subscale, the subscale median score from the non-missing items was imputed for missing items.

The main exposure was a national area-based measure of socioeconomic position, the Index of Multiple Deprivation (IMD) for England (2019).[19] Patient postcodes were linked to lower super output area (LSOA) codes which were linked to the IMD. IMD was summarised using national quintile groups (quintile 1 is most deprived). Missing or erroneous postcodes, or postcodes outside of England were expected in a small proportion of cases (<5%) and excluded from the study.

Analysis

We selected the following covariates based on existing knowledge[10,18,20]: age, gender, ethnicity, living alone, diagnosis, palliative Phase of Illness at initial assessment,[21] Australia-modified Karnofsky Performance Status (AKPS)[22] at initial assessment, and hospital site. Variables are described for the overall population and separately for each deprivation group, using standard descriptive statistics. To maintain sample size, missing data on the ethnicity and living alone variables were coded as separate categories and included in the modelling. This limits the interpretation of the effects for ethnicity and living alone but supports the main purpose of their inclusion as confounders of the relationship between deprivation and IPOS. We used ordinary least squares, multiple linear regression models and applied robust standard errors to account for violations of normality assumptions in the residuals.[23] Deprivation was treated as an ordered categorical variable to allow for non-linearity in the relationship. We compared a minimally adjusted model that controlled only for age, sex, hospital site and deprivation, with a model that controlled for all other covariates, using R^2 and Wald F statistics. For the main model we present unstandardised coefficients and predicted mean scores for each deprivation group, and use the standardised mean difference to derive a Cohen's d effect size.[24] Statistical significance was set a priori at $p < 0.05$ with no adjustment for multiplicity.

Moderation by age and gender

The effect of socioeconomic position on health towards the end of life may diminish with increasing age,[25] gender may also moderate social determinants of health[8,9] and influence end-of-life care.[26] To investigate moderation by age and gender we included interaction effects in our model and compared these models against the main model. We plotted the linear effect of deprivation on subscale scores across the age range to help interpret interaction effects.

Sensitivity analysis

We repeated the main model using a complete case analysis with missing data on the subscales handled listwise. We also repeated the main analysis on a dataset where missing IPOS items were imputed based on all other variables, using semi-parametric predictive mean matching chained

Table 2. Patient characteristics by patient level of area-based deprivation, (*n* and column percentage, unless otherwise stated).

	Overall	Area-based level of deprivation, quintile groups (q1 is most deprived)				
		q1	q2	q3	q4	q5
N	7860	1145 (14.6%)	1775 (22.6%)	1318 (16.8%)	1853 (23.6%)	1769 (22.5%)
Age						
Median (IQ range)	82 (74, 89)	81 (72, 87)	81 (71, 87)	82 (72, 88)	84 (76, 90)	84 (76, 89)
Missing	11 (0.1%)	3 (0.3%)	3 (0.2%)	3 (0.2%)	1 (0.1%)	1 (0.1%)
Gender						
Women	4121 (52.4%)	619 (54.1%)	934 (52.6%)	657 (49.8%)	1000 (54.0%)	911 (51.5%)
Missing	1 (<1%)	0 (0.0%)	1 (0.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Ethnicity						
White British	5226 (66.5%)	631 (55.1%)	991 (55.8%)	815 (61.8%)	1394 (75.2%)	1395 (78.9%)
White other	370 (4.7%)	80 (7.0%)	94 (5.3%)	74 (5.6%)	77 (4.2%)	45 (2.5%)
Black	627 (8.0%)	194 (16.9%)	264 (14.9%)	112 (8.5%)	43 (2.3%)	14 (0.8%)
Asian	174 (2.2%)	22 (1.9%)	56 (3.2%)	27 (2.0%)	37 (2.0%)	32 (1.8%)
Other	223 (2.8%)	42 (3.7%)	81 (4.6%)	51 (3.9%)	30 (1.6%)	19 (1.1%)
Missing	1240 (15.8%)	176 (15.4%)	289 (16.3%)	239 (18.1%)	272 (14.7%)	264 (14.9%)
Living alone						
Yes (versus not alone)	2220 (28.2%)	345 (30.1%)	463 (26.1%)	377 (28.6%)	508 (27.4%)	527 (29.8%)
Missing	1491 (19.0%)	237 (20.7%)	398 (22.4%)	285 (21.6%)	300 (16.2%)	271 (15.3%)
Diagnosis						
Cancer	3013 (38.3%)	421 (36.8%)	653 (36.8%)	490 (37.2%)	712 (38.4%)	737 (41.7%)
Dementia	642 (8.2%)	103 (9.0%)	163 (9.2%)	93 (7.1%)	148 (8.0%)	135 (7.6%)
Cardiovascular	1351 (17.2%)	186 (16.2%)	327 (18.4%)	253 (19.2%)	313 (16.9%)	272 (15.4%)
Respiratory	460 (5.9%)	77 (6.7%)	130 (7.3%)	85 (6.4%)	78 (4.2%)	90 (5.1%)
Other	2222 (28.3%)	327 (28.6%)	469 (26.4%)	369 (28.0%)	563 (30.4%)	494 (27.9%)
Missing	172 (2.2%)	31 (2.7%)	33 (1.9%)	28 (2.1%)	39 (2.1%)	41 (2.3%)
Phase of Illness at initial assessment						
Stable	343 (4.4%)	70 (6.1%)	73 (4.1%)	51 (3.9%)	81 (4.4%)	68 (3.8%)
Unstable	2904 (36.9%)	451 (39.4%)	726 (40.9%)	536 (40.7%)	631 (34.1%)	560 (31.7%)
Deteriorating	1682 (21.4%)	215 (18.8%)	344 (19.4%)	272 (20.6%)	396 (21.4%)	455 (25.7%)
Dying	2514 (32.0%)	355 (31.0%)	528 (29.7%)	390 (29.6%)	647 (34.9%)	594 (33.6%)
Missing	417 (5.3%)	54 (4.7%)	104 (5.9%)	69 (5.2%)	98 (5.3%)	92 (5.2%)
AKPS* at initial assessment						
Mean (SD)	25.8 (16.0)	26.1 (16.2)	26.4 (16.4)	27.0 (16.5)	24.6 (15.5)	25.3 (15.6)
Missing	1514 (19.3%)	216 (18.9%)	333 (18.8%)	252 (19.1%)	359 (19.4%)	354 (20.0%)
Site						
Hospital 1	4392 (55.9%)	377 (32.9%)	515 (29.0%)	537 (40.7%)	1413 (76.3%)	1550 (87.6%)
Hospital 2	3468 (44.1%)	768 (67.1%)	1260 (71.0%)	781 (59.3%)	440 (23.7%)	219 (12.4%)

*AKPS: Australia-modified Karnofsky Performance Status

multiple imputation, with 40 sets, proportionate to the amount of missing data.[27–30] Given the limitations of using multiple imputation for outcome variables and the potential for missing not at random mechanisms in our data, we chose to use the multiple imputation as a sensitivity analysis rather than for our main analysis.[31]

To evaluate the potential for unmeasured confounders, we report e-values; defined as the minimum strength of association on the risk ratio scale that an unmeasured confounder would need to have with both the exposure and the outcome to fully explain away the specific effect, in our case the main effect of deprivation on the IPOS subscales, conditional on the covariates.[32]

All analysis, including sensitivity analysis, was prespecified and carried out in Stata (version 17); the analytical code and analysis plan is available from: https://github.com/joannamariedavies.

Results

After excluding 103 (1.3%) patients with missing or erroneous postcode information, the sample included 7860 patients (Table 2). Compared to national data on deaths in England and Wales in 2019, the sample was less deprived and had a larger proportion of cancer diagnoses (Supplemental Tables 1 and 2). Hospital 2 cared for more

Table 3. Summary of Integrated Palliative care Outcome Scale (IPOS) subscales: complete cases, and imputed cases.*

N = 7860	Physical subscale	Emotional subscale	Communication/Practical subscale
Complete cases, *n* (%)	3863 (49.1%)	1795 (22.8%)	2637 (33.6%)
Mean (sd)	7.9 (5.5)	4.7 (3.5)	4.9 (3.2)
Median (IQ range)	7 (3–12)	4 (2–7)	5 (2–8)
Complete and imputed cases*, *n* (%)	4883 (62.1%)	4690 (59.7%)	4961 (63.1%)
Mean (*sd*)	9.1 (6.5)	5.0 (3.7)	5.1 (3.6)
Median (IQ range)	8 (4–13)	4 (2–8)	5 (3–8)

*For cases with number of missing items <6 for physical subscale, <3 for emotional subscale, <3 for communication/practical subscale, the median score for the non-missing items was imputed to the missing items

patients in deprived areas and had a younger population compared to hospital 1 (Supplemental Table 3). The main reasons for referral to specialist palliative care, were for pain or other physical symptoms (34.1%) or terminal care (31.6%) (Supplemental Table 4). About half of the sample were discharged by specialist palliative care at the end of the episode of care, into the community, to hospice or remaining in hospital; 3993 (50.8%) died during the episode of care. Date of death was available for 3953 patients and was a median (IQ range) of 3 (1–6) days after the first clinical assessment.

Weakness or lack of energy, and poor mobility were the most common physical symptoms. Family anxiety (on the emotional subscale) and practical matters (on the communication/practical subscale) were the most prevalent concerns overall (Supplemental File Figure 1 and Table 5).

Table 3 describes the distribution of the IPOS subscale scores for the complete cases and following median imputation. Following median imputation, deprivation was not statistically significantly associated with missing data on the communication/practical or emotional subscales. On the physical subscale, patients in deprivation quintiles q3 and q4 had higher odds of having missing data compared to the least deprived group (q5) (Supplemental Table 6). Patients who had a cancer diagnosis, those who spent more time with a clinician during their episode of care, and those in hospital 1, were less likely to have missing IPOS data. Missing data on the ethnicity and living alone variables was between 11.3% and 14.3% (Supplemental Table 7).

Results from the main model

Patients living in the most deprived areas (q1) had statistically significantly higher (worse) scores on the communication/practical subscale than patients living in the least deprived areas (q5) (Figure 1 and Table 4, and Supplemental Table 8). The adjusted predicted mean score on the communication/practical subscale for patients in q1 was 5.38 (95% CI 5.10, 5.65), compared to 4.82 (4.62–5.02) for those in q5. The standardised mean difference between q1 and q5 was 0.16 (95% CI 0.07–0.23) indicating a small effect size. The results suggest a roughly linear relationship with an increase in communication and practical concerns for each increase in deprivation (Figure 1 and Table 4). Deprivation was not associated with scores on the physical or emotional subscales.

Moderation by age and gender

Interaction effects between age and deprivation were statistically significant for the communication/practical subscale and not statistically significant for the physical and emotional subscales (Supplemental File, Table 9, model 3). Gender and deprivation interaction effects were not statistically significant for any subscale (Supplemental File, Table 9, model 4).

Figure 2 shows that the negative effect of living in a less deprived area on communication and practical issues, is stronger at younger ages and not statistically significant for people aged >83 years.

Sensitivity analysis

The complete case and multiple imputation analysis had similar results to the main analysis (Supplemental File, Table 10). The low e-values (Table 4) suggest a high likelihood that unmeasured confounders exist that could, if included in the model, explain away the effects of deprivation.

Discussion/conclusion

Main findings

In this evaluation of routine data on older adult inpatients seen by specialist palliative care at two large London hospitals, patients who lived in more deprived areas had worse communication and practical concerns at initial assessment. The difference in communication and practical concerns between patients living in the least and most deprived areas was small in effect size, but the results suggest a trend towards a stepwise social gradient that held after adjusting for multiple clinical and demographic characteristics. The effect diminished

Table 4. Adjusted* association between patient level of area-based deprivation and Integrated Palliative care Outcome Scale (IPOS) subscale scores.

	Physical subscale			Emotional subscale			Communication/Practical subscale		
	Adjusted coeff. [95% CI]	Predicted mean (sd) score [95% CI]	E value	Adjusted coeff. [95% CI]	Predicted mean (sd) score [95% CI]	E value	Adjusted coeff. [95% CI]	Predicted mean (sd) score [95% CI]	E value
q1 (most deprived)	−0.51 [−1.15, 0.12]	8.78 [8.29, 9.27]	1.36	−0.14 [−0.50, 0.23]	4.83 [4.56, 5.11]	1.22	0.56 [0.21, 0.91]	5.38 [5.10, 5.65]	1.57
q2	−0.33 [−0.91, 0.26]	8.97 [8.56, 9.38]	1.27	−0.16 [−0.50, 0.17]	4.81 [4.58, 5.03]	1.25	0.33 [0.01, 0.64]	5.15 [4.92, 5.37]	1.39
q3	−0.05 [−0.65, 0.56]	9.25 [8.79, 9.71]	1.09	0.17 [−0.17, 0.52]	5.14 [4.88, 5.40]	1.25	0.44 [0.12, 0.76]	5.25 [5.01, 5.50]	1.47
q4	−0.29 [−0.79, 0.22]	9.01 [8.65, 9.37]	1.25	0.11 [−0.19, 0.40]	5.08 [4.87, 5.29]	1.19	0.34 [0.07, 0.61]	5.16 [4.96, 5.35]	1.4
q5 (least deprived)	ref	9.29 [8.92, 9.67]	ref	Ref	4.97 [4.75, 5.19]	ref	ref	4.82 [4.62, 5.02]	ref

*Adjusted for: age, sex, ethnicity, living alone, diagnosis, Phase of Illness, Australia-modified Karnofsky Performance Status, hospital site

*Results in table 4 focus on the main exposure of interest (deprivation) and not on the other covariates,[33] model results for all covariates are available in the Supplemental Table 8.

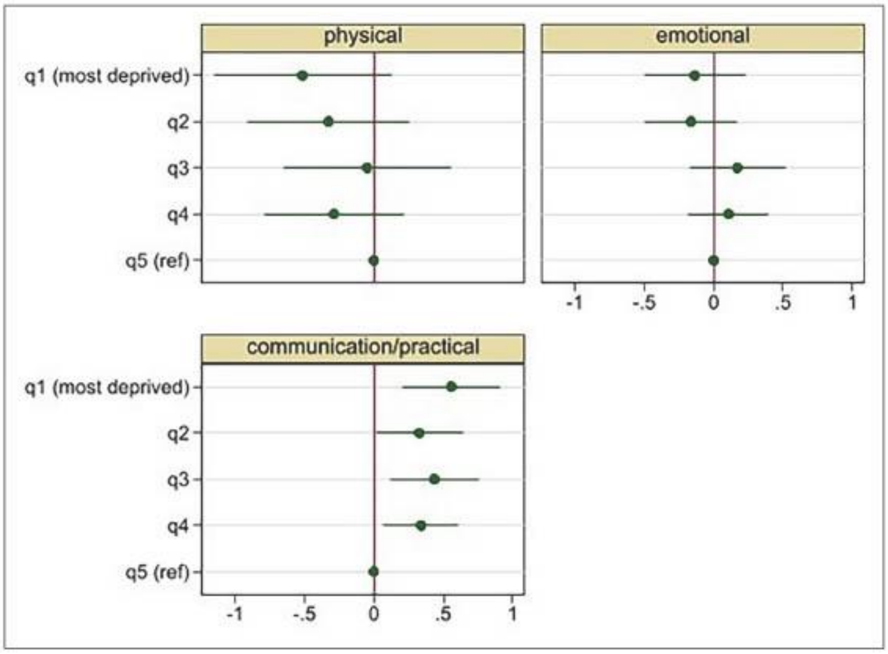

Figure 1. Adjusted* regression coefficients and 95% CI for the association between patient level of area-based deprivation and Integrated Palliative care Outcome Scale (IPOS) subscales.
*Analysis adjusted for: age, sex, ethnicity, living alone, diagnosis, Phase of Illness, Australia-modified.
Karnofsky Performance Status and hospital site

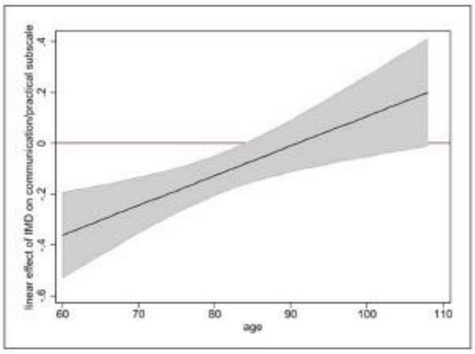

Figure 2. Adjusted* linear effect and 95% CI of patient level of area-based deprivation on the Integrated Palliative care Outcome Scale (IPOS) communication/practical subscale, moderated by age (figure shows that the negative effect of being less deprived on the communication/practical subscale is stronger at younger ages and not statistically significant after age 83 years) *analysis adjusted for: age, sex, ethnicity, living alone, diagnosis, Phase of Illness, Australia-modified Karnofsky Performance Status and hospital site.

with increasing age and was not statistically significant for patients over 83 years old. Area-based deprivation was not associated with physical or emotional symptoms.

What this study adds

There is growing evidence that people with lower socio-economic position face additional challenges towards the end of life, including problems with inadequate housing,[3,34] fuel poverty[35] and loss of earnings,[36,37] and may have different communication needs.[10,38] Our finding that hospital inpatients who live in more deprived areas present to specialist palliative care with worse communication and practical concerns is consistent with this evidence and reflects wider structural inequalities in society. The effect of deprivation in our analysis was small, yet this inequality potentially impacts large numbers of patients and could be modifiable. Increasing financial support for patients and families dealing with terminal illness,[39] improving cultural competency training for health care professionals and making resources available in multiple languages and for different literacy levels have been cited as ways to address inequality at the end of life.[40]

The findings from our study support calls for a better understanding of how socioeconomic inequality impacts needs towards the end of life.[3]

Our analysis did not investigate the effect of deprivation on the separate IPOS items, therefore we don't know which aspects of communication and practical concerns drive the effect we observed. Qualitative work with patients living in deprived areas, to understand the type of practical problems faced, and whether communication needs relate to language, literacy, or other barriers, could help to identify ways to better meet patient needs.

In contrast to earlier studies of patients with advanced cancer,[10–12] we did not find that deprivation was associated with the physical or emotional symptoms of hospital inpatients seen by specialist palliative care. This finding contrasts with the global evidence on the association between socioeconomic position and physical and mental health in the general population[41] and with our earlier analysis that found that worse health partly explained why people with lower wealth had more hospital admissions in the last 2 years of life.[25] Several factors may explain these contrasting results.

First, our sample is limited to patients who received specialist palliative care. Mortality bias, and bias in referrals, is likely to mean that a disproportionately higher number of people with lower socioeconomic position are never referred to palliative care, or die from sudden causes before reaching hospital.[42,43] This potentially biases our results through an underrepresentation of people living in the most deprived areas. Comparison with national death registration data suggests that our sample was less deprived and had a larger proportion of cancer patients than the national end-of-life population (Supplemental File, Tables 1 and 2).

Second, in this observational study unmeasured service or regional-specific confounders are important to consider.[17,44] For example, the quality of the symptom control received by patients on hospital wards prior to referral to palliative care is likely to vary between hospitals and wards and potentially moderates the effect of deprivation on symptoms. There are also growing regional differences in health inequalities in the UK, for example, life expectancy is lowest in the North East and highest in London.[8] Further studies on patients in different hospitals, in different regions, and on patients in community settings are needed to strengthen the evidence.

Third, we cannot rule out measurement bias in our outcome measure. IPOS is a validated and widely used tool[18] and the difference we detected for groups based on deprivation in the communication/practical subscale, suggests that IPOS is sensitive to socioeconomic difference. However, the IPOS questions could be biased towards capturing symptoms and problems that are more relevant to people with higher socioeconomic position. Staff reported measures could also be less good at identifying symptoms in patients with lower socioeconomic position. There may be differences in the way that patients perceive and manage symptoms that could influence professional assessments of pain and other symptoms.[45] Implicit class and other biases including racial bias[40] in health care workers could also limit the effectiveness of the tool, for example in the UK, only 4% of doctors[46] and 43% of nurses[47] are from low socioeconomic position backgrounds. Further validation of staff and patient inter-rater reliability of the IPOS and content-validity for different social, economic, and ethnic groups would strengthen the tool.

We found that the effect of deprivation on communication and practical concerns diminished with increasing age. This could reflect bias in the sample, an under-representation of more socioeconomically deprived older adults, or an under-representation of care home residents who are less likely to be admitted to hospital[48] and may be more socioeconomically deprived.[49] Cohort effects, for example less wealth inequality among older adults due to the relatively generous state pension,[39] could also limit the effect of deprivation on communication and practical concerns for older people.

Strengths and limitations

This service evaluation has extended the evidence on socioeconomic inequality in the symptoms and concerns of patients towards the end of life to a large and diverse population of hospital inpatients. The work demonstrates the utility of linking area-based deprivation information to routinely collected patient centred outcome measures for understanding socioeconomic differences in the needs of patients.

We used an area-based measure of deprivation which is limited by the ecological fallacy (the attempt to infer something about an individual from aggregate data). A further limitation of basing deprivation score on the postcode of residence is that for care home residents this may be a poor reflection of socioeconomic position. However, area-based measures constructed using small, homogenous geographies offer a high quality and convenient way to link socioeconomic position into routine data sources when individual level measures are not available. Area-based measures that combine multiple domains of deprivation such as the Index of Multiple Deprivation, may capture more variance in socioeconomic position than individual level items such as education.[50]

There was a high proportion of missing data on the IPOS subscales. There was no clear relationship between missing data on the subscales and our main exposure of deprivation which suggests that our main effects should be robust. However, we cannot discount that the missing data might bias our results. In this routinely collected data, the amount of missing data was comparable to a prospective longitudinal study on a similar topic, where data was collected on 65% of patients eligible for inclusion.[10] In our study, fewer items on the physical subscale were missing, potentially indicating staff preference towards completing items about physical symptoms. Missing IPOS data was associated with less clinical time with the patient (Supplemental Table 6). More work is needed to set guidelines on the proportion of missing data expected in the routine collection of IPOS data in different settings and for the different items.

A strength of our analysis is the use of robust sensitivity analysis using multiply imputed data and complete case analysis to address the missing data. The high proportion of missing ethnicity information in our data, typical in hospital data from the UK,[51] limits what we can learn about ethnicity effects in this study. More work is needed to investigate the intersection between ethnicity and socioeconomic position in palliative and end-of-life care research, an important aspect of this is improving the collection of self-reported ethnicity data in hospital data.[40]

Conclusion

In this evaluation of inpatients seen by specialist palliative care at two large London hospitals, patients living in more deprived areas had worse communication and practical concerns at first assessment. This indicates that targetting resources to address practical and communication concerns could be a strategy to reduce inequalities. We did not find that deprivation was associated with physical or emotional symptoms. This could reflect a lack of association or potential sample bias, unmeasured confounders, measurement bias or missing data. Further research is needed to understand the impact of communication and practical concerns on other outcomes including place of death and hospital admissions, and to investigate socioeconomic inequality in the symptoms and concerns of patients in different hospitals and in different settings.

Author Contributions

All authors made substantial contributions to the concept and design of the study. FEMM, WP, and KES were involved in the collection of the routine clinical data used in this study. Analyses were led by JMD with supervision from FEMM, KES, MM and CR. All authors contributed to interpretation of data. All authors contributed to drafting and revising the article, approved the final version and have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Data management and sharing

Pseudonymized data are stored on a secure server at King's College London and used as part on ongoing service evaluation work. Reasonable requests for access to aggregated data can be provided by the corresponding author after seeking approval from the responsible data protection officer at King's College London and King's College Hospital NHS Trust. Analytical code is available on Github: https://github.com/joannamariedavies.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: JMD is supported by a Research Training Fellowship from The Dunhill Medical Trust (RTF74/0116). KES is funded by an NIHR Clinician Scientist Fellowship (CS-2015-15-005), and is the Laing Galazka Chair in palliative care at King's College London, funded by an endowment from Cicely Saunders International and the Kirby Laing Foundation. MM is supported by a National Institute for Health Research (NIHR) Career Development Fellowship (CDF-2017–10-009) and the NIHR Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust. FEMM is an NIHR Senior Investigator. This work was supported by the NIHR Applied Research Collaboration South London at King's College Hospital NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of the National Health Service, the NIHR, or the Department of Health and Social Care.

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Research ethics and patient consent

This project was registered as a service evaluation and quality improvement audit within King's College London. Data was anonymised and no additional ethical approval was required for this secondary analysis study.

Supplemental material

Supplemental material for this article is available online.

References

1. Davies JM, Sleeman KE, Leniz J, et al. Socioeconomic position and use of healthcare in the last year of life: a systematic review and meta-analysis. *PLoS Med* 2019; 16: e1002878–e1002782.
2. French M, Keegan T, Anestis E, et al. Exploring socioeconomic inequities in access to palliative and end-of-life care in the UK: a narrative synthesis. *BMC Palliat Care* 2021; 20: 188.
3. Rowley J, Richards N, Carduff E, et al. The impact of poverty and deprivation at the end of life: a critical review. *Palliat Care Soc Pract* 2021; 15: 26323524211033873.
4. Deerberg-Wittram J, Guth C and Porter ME. Value-based competition: the role of Outcome Measurement. *Public Health Forum* 2013; 21: 12–13.

5. Bausewein C, Le Grice C, Simon S, et al. The use of two common palliative outcome measures in clinical care and research: a systematic review of POS and STAS. *Palliat Med* 2011; 25: 304–313.
6. Collins ES, Witt J, Bausewein C, et al. A systematic review of the use of the palliative care outcome scale and the support team assessment schedule in Palliative Care. *J Pain Symptom Manag* 2015; 50: 842–NaN53.e19.
7. Christensen K, Doblhammer G, Rau R, et al. Ageing populations: the challenges ahead. *Lancet* 2009; 374: 1196–1208.
8. Marmot M, Allen J, Boyce T, et al. *Health equity in England: the Marmot Review 10 years on*. London: Institute of Health Equity, 2020.
9. Marmot Allen J, Goldblatt P, et al. *Build back fairer: the COVID-19 Marmot Review. The pandemic, socioeconomic and Health Inequalities in England*. London: Institute of Health Equity, 2020.
10. Lloyd-Williams M, Shiels C, Dowrick C, et al. Socio-economic deprivation and symptom burden in UK hospice patients with advanced cancer-findings from a longitudinal study. *Cancers* 2021; 13: 2537.
11. Malhotra C, Krishnan A, Yong JR, et al. Socio-economic inequalities in suffering at the end of life among advanced cancer patients: results from the APPROACH study in five Asian countries. *Int J Equity Health* 2020; 19: 158.
12. Delgado-Guay M, Ferrer J, Rieber AG, et al. Financial distress and its associations with physical and emotional symptoms and quality of life among Advanced Cancer Patients. *Oncologist* 2015; 20: 1092–1098.
13. Popovic M, Lao N, Bedard G, et al. Quality of life in patients with advanced cancer using the functional assessment of cancer therapy-general assessment tool: a literature review. *World J Oncol* 2013; 4: 8–17.
14. Pritchard S, Cuvelier G, Harlos M, et al. Palliative care in adolescents and young adults with cancer. *Cancer* 2011; 117(10 Suppl): 2323–2328. DOI: 10.1002/cncr.26044. PMID: 21523753; PMCID: PMC5231403.
15. Cook KA and Bergeron K. Palliative care for young adults with life-limiting conditions: public health recommendations. *BMJ Support Palliat Care* 2020; 2020: bmjscare–2019.
16. Cockle-Hearne J, Reed E, Todd J, et al. The dying parent and dependent children: a nationwide survey of hospice and community palliative care support services. *BMJ Support Palliat Care* 2020; 2020: bmjspcare-2019-001947.
17. Bajwah S, Edmonds P, Yorganci E, et al. The association between ethnicity, socioeconomic deprivation and receipt of hospital-based palliative care for people with Covid-19: A dual centre service evaluation. *Palliat Med* 2021; 35: 1514–1518.
18. Murtagh FE, Ramsenthaler C, Firth A, et al. A brief, patient- and proxy-reported outcome measure in advanced illness: validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS). *Palliat Med* 2019; 33: 1045–1057.
19. McLennan D, Noble S, Noble M, et al. *The English indices of deprivation 2019*. Technical report. Ministry of Housing, Communities and Local Government; 2019.
20. Fei F, Siegert RJ, Zhang X, et al. Symptom clusters, associated factors and health-related quality of life in patients with chronic obstructive pulmonary disease: a structural equation modelling analysis. *J Clin Nurs*. Epub ahead of print 30 January 2022. DOI: 10.1111/jocn.16234.
21. Masso M, Allingham SF, Banfield M, et al. Palliative Care Phase: inter-rater reliability and acceptability in a national study. *Palliat Med* 2015; 29: 22–30.
22. Abernethy AP, Shelby-James T, Fazekas BS, et al. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. *BMC Palliat Care* 2005; 4: 7–12.
23. Hoffmann JP. *Regression models for categorical, count, and related variables*. Berkeley, CA: University of California Press, 2016.
24. Cohen J. *Statistical Power Analysis for the Behavioral Sciences*. 2nd ed. New York: Routledge, 1988.
25. Davies JM, Maddocks M, Chua K-C, et al. Socioeconomic position and use of hospital-based care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing. *Lancet Public Health* 2021; 6: e155–e163.
26. Gott M, Morgan T and Williams L. Gender and palliative care: a call to arms. *Palliat Care Soc Pract* 2020; 14: 2632352420957997.
27. White IR, Royston P and Wood AM. Multiple imputation using chained equations: Issues and guidance for practice. *Stat Med* 2011; 30: 377–399.
28. Plumpton CO, Morris T, Hughes DA, et al. Multiple imputation of multiple multi-item scales when a full imputation model is infeasible. *BMC Res Notes* 2016; 9: 45–45.
29. Kleinke K. Multiple imputation under violated distributional assumptions: a systematic evaluation of the assumed robustness of predictive mean matching. *J Educ Behav Stat* 2017; 42: 371–404.
30. Graham JW, Olchowski AE and Gilreath TD. How many imputations are really needed? Some practical clarifications of multiple imputation theory. *Prev Sci* 2007; 8: 206–213.
31. van Ginkel JR, Linting M, Rippe RCA, et al. Rebutting existing misconceptions about multiple imputation as a method for handling missing data. *J Pers Assess* 2020; 102: 297–308.
32. Linden A, Mathur MB and VanderWeele TJ. Conducting sensitivity analysis for unmeasured confounding in observational studies using E-values: the evalue package. *Stata J* 2020; 20: 162–175.
33. Westreich D and Greenland S. The Table 2 fallacy: Presenting and Interpreting Confounder and modifier coefficients. *Am J Epidemiol* 2013; 177: 292–298.
34. Finucane AM, Swenson C, MacArtney JI, et al. What makes palliative care needs "complex"? A multisite sequential explanatory mixed methods study of patients referred for specialist palliative care. *BMC Palliat Care* 2021; 20: 18.
35. The vicious cycle of fuel poverty and terminal illness. *Marie Curie Cancer Care*, https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2020/fuel-poverty-and-terminal-illness.pdf (2020, accessed 19 February 2022).
36. Gardiner C, Robinson J, Connolly M, et al. Equity and the financial costs of informal caregiving in palliative care: a critical debate. *BMC Palliat Care* 2020; 19: 71.
37. Gott M, Allen R, Moeke-Maxwell T, et al. 'No matter what the cost': a qualitative study of the financial costs faced by

family and whānau caregivers within a palliative care context. *Palliat Med* 2015; 29: 518–528.

38. Lewis JM, DiGiacomo M, Currow DC, et al. Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. *J Pain Symptom Manag* 2011; 42: 105–118.
39. Curie M. *Dying in Poverty: Exploring poverty at the end of life in the UK*, https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-5th-pp.pdf (2022, accessed 27 May 2022).
40. Hussain JA, Koffman J and Bajwah S. Invited editorials. *Palliat Med* 2021; 35: 810–813.
41. Marmot M. The health gap: the challenge of an unequal world. *Lancet* 2015; 386: 2442–2444.
42. Yadav K and Lewis RJ. Immortal time bias in observational studies. *JAMA* 2021; 325: 686–687.
43. National End of Life Care Inelligence Network. *Deprivation and death: variation in place and cause of death*. London: National End of Life Care Inelligence Network, 2012.
44. Chukwusa E, Yu P, Verne J, et al. Regional variations in geographic access to inpatient hospices and place of death: a population-based study in England, UK. *PLoS One* 2020; 15: e0231666–e0231666.
45. Small N, Gardiner C, Barnes S, et al. "You get old, you get breathless, and you die": chronic obstructive pulmonary disease in Barnsley, UK. *Health Place* 2012; 18: 1396–1403.
46. White C. Just 4% of UK doctors come from working class backgrounds. *BMJ* 2016; 355: i6330.
47. Snee H and Goswami H. Who cares? Social mobility and the 'Class Ceiling' in Nursing. *Sociol Res Online* 2021; 26: 562–580.
48. Smith P, Johnson CS, Ariti C, et al. Focus on: Hospital admissions from care homes. *The Health Foundation Quality Watch*, https://wwwhealthorguk/sites/default/files/QualityWatch_FocusOnHospitalAdmissionsFromCareHomespdf (2015, accessed 19 May 2022).
49. Kelfve S, Wastesson J, Fors S, et al. Is the level of education associated with transitions between care settings in older adults near the end of life? A nationwide, retrospective cohort study. *Palliat Med* 2018; 32: 366–375.
50. Grundy E and Holt G. The socioeconomic status of older adults: how should we measure it in studies of health inequalities? *J Epidemiol Community Health* 2001; 55: 895–904.
51. Mathur R, Bhaskaran K, Chaturvedi N, et al. Completeness and usability of ethnicity data in UK-based primary care and hospital databases. *J Public Health* 2014; 36: 684–692.

PART 3: Discussion and conclusion

CHAPTER 8: Discussion

8.1 Summary of findings

The aim of this thesis was to investigate patterns and determinants of socioeconomic inequality in palliative and end-of-life care for older adults, and to explore potential mediating factors of the relationship between socioeconomic position and patterns of care towards the end of life. The systematic review and meta-analysis investigated inequality in service use, the ELSA analysis investigated individual level causes of inequality and the analysis of clinical data investigated inequality in the symptoms and concerns of palliative patients.

From the outset of this work, there was strong evidence of socioeconomic inequality in place of death in England, with several individual studies showing that people who lived in more deprived areas are more likely to die in hospital (versus home or hospice).[37, 60, 102, 103] However, the international evidence on the relationship between socioeconomic position and place of death, and socioeconomic inequality in other palliative and end-of-life care outcomes, had not been synthesised. The systematic review addressed this gap by synthesising the international evidence, and found consistent evidence that in high income countries, low socioeconomic position is associated with death in hospital (versus home or hospice), hospital admissions in the last three months of life, and not accessing specialist palliative care in the last year of life. For death in hospital and not accessing specialist palliative care, the analysis found a dose-response relationship, demonstrating that for each increase in level of area-based deprivation the odds of these outcomes increased.

The review also found that the literature was dominated by studies using routinely collected data and area-based measures of socioeconomic position and found no studies that empirically investigated the reasons *why* socioeconomic inequality exists in palliative and end-of-life care. Area-based measures offer a robust and convenient way to measure socioeconomic position and are particularly useful with routine data when no individual-level measures of socioeconomic position are available. However, area-based measures are less useful than individual-level measures for investigating the causes of inequality. Very few of the studies reviewed provided justification for their choice of socioeconomic position measure; of 27 studies that had socioeconomic position as the main exposure of interest, only 12 provided a theoretical justification for the choice of measure. Overall, studies using individual-level measures of socioeconomic position, and models grounded in theory about the relationship between exposures and outcomes, were lacking in the existing literature.

The review also found that the existing evidence was dominated by studies on place of death. Where people die is important to patients and families and for planning the delivery of palliative and end-of-life care.[2, 48, 56] Place of death is also a useful metric for studying inequalities given the consistency and widespread availability of population-level records on place of death.[55] However, place of death is limited because it captures only a snapshot of information about the location of care immediately before death, and as a measure of process, it is not a good indicator of the quality of care.[79, 240] The binary classification of hospital death as a ‘bad death’ and home as a ‘good death’ has also been criticised as an oversimplification.[69] Although death in hospital is associated with worse quality of life, worse bereavement outcomes, and is often not the preferred place of care, not all hospital deaths are ‘bad deaths’ and in some cases, hospital may be the most appropriate and/or the preferred place of care and death.[48, 51, 52, 69]

There is a clear need to measure outcomes other than place of death to understand inequality in palliative and end-of-life care and increasingly there is a move towards using patient centred outcome measures (PCOMs) to measure outcomes that are more meaningful to patients and families.[83, 84, 231] The review found no high or medium quality studies that used validated patient centred outcome measures (PCOMs) to investigate the association between socioeconomic position and the symptoms and concerns of patients. Since completing the review, two studies have been published that investigate the relationship between socioeconomic position and the symptoms and concerns of palliative patients using PCOMs[232, 233], these studies are reviewed in relation to the findings from the analysis of the clinical data later in the discussion.

In summary, the review identified several important gaps in the literature including: no studies empirically investigating the causes of socioeconomic inequality in palliative and end-of-life care, a lack of studies using individual-level measures of socioeconomic position, a lack of studies investigating outcomes other than place of death, and no studies investigating the association between socioeconomic position and the symptoms and needs of patients using patient centred outcome measures. The secondary analysis of ELSA and the analysis of the clinical data were designed to address these gaps.

The analysis of the English Longitudinal Study of Ageing (ELSA) used an existing longitudinal cohort study, designed for investigating the social determinants of health to develop new evidence on the reasons for socioeconomic inequality in service use towards the end of life. This study is the first to apply mediation analysis to study end-of-life care and the first to use the mortality follow-back survey data from the ELSA. The analysis investigated three potential pathways through health and function, access to services, and social support, as mediators of the relationship between wealth and use of hospital care towards the end of life. In this nationally representative sample of adults aged 50 years and over living in England, worse health and function partly explained why people with lower wealth had more hospital admissions in the last two years of life. This finding is important because it challenges behavioural explanations that suggest that people with lower socioeconomic position *choose* to use acute care services more.[224, 241] Instead, these findings highlight the importance of health-need in driving different patterns of service use. In the same model, the relationship between lower wealth and higher risk of death in hospital versus home or hospice was not explained by any of the mediating pathways tested.

The relationship between socioeconomic position and health-need was explored in more detail using data on hospital inpatients who were receiving specialist palliative care. This study used routinely collected clinical data on all inpatients aged 60 years and older seen by specialist palliative care at two large London-based teaching hospitals over a three-year period between 2016-2019. It reports the largest collection of routinely collected patient centred outcome measures (PCOMs) data in the UK, and extends a small body of existing evidence on this topic in cancer patients to patients with cancer and non-cancer conditions.[232-234] The analysis investigated the association between area-based deprivation (linked to patient’s postcode of residence) and the symptoms and concerns of patients at their initial assessment by palliative care, collected using the Integrated Palliative Care Outcome Scale (IPOS). The IPOS data was collected at a time much closer to death than the data on health and function from ELSA, and so this analysis provides insight into the health-related needs of patients with more advanced disease.

The analysis of IPOS found that patients living in more deprived areas had significantly worse communication and practical concerns at initial assessment and that this relationship was roughly linear with increasing (worsening) scores for each increase in area-based deprivation. In contrast to the original hypothesis which was based on the small body of existing literature and the findings from the ELSA analysis, the analysis of IPOS found no association between area-based deprivation and the physical or emotional symptoms of patients. These contrasting results highlight the need for more studies to further investigate this relationship.

In summary, this thesis generates new knowledge on the patterns and mechanisms of socioeconomic inequality in palliative and end-of-life care. It provides consistent evidence of socioeconomic inequality in palliative and end-of-life care and highlights the potentially important role of health-need in driving different patterns of service use towards the end of life. Methodologically, the thesis provides the first example of a mediation analysis used to study service use towards the end of life, it demonstrates the potential for existing longitudinal cohort studies to be used for research on palliative and end-of-life care and shows how routinely collected patient centred outcome measures (PCOMs) can be used for understanding inequalities towards the end of life. The following sections discuss these contributions in relation to the existing literature and in relation to the strengths and weaknesses of the thesis.

Overall, this thesis should help to raise awareness about socioeconomic inequality in palliative and end-of-life care and the findings indicate several implications for policy, practice and research including: the urgent need to monitor inequalities going forward in the context of the ageing population and increasing levels of economic inequality in wider society, the need to begin to evaluate palliative and end-of-life care interventions for unequal effects across social groups and to develop targeted interventions that seek to reduce inequalities, the need to raise awareness among health care professionals and the public about socioeconomic inequalities in palliative and end-of-life care, and to draw attention and resources to delivering care more equitably. The final section of the discussion addresses these implications and outlines the opportunities for action against socioeconomic inequality in palliative and end-of-life care.

8.2 Contribution of this thesis to the existing literature

This section presents the main contributions of the thesis to the existing literature, organised under three topics: i) evidence on socioeconomic inequality and the need to go beyond observing the problem, ii) health as a mediator of the relationship between socioeconomic position and service use towards the end of life, and iii) age as a moderator and the diminishing effect of socioeconomic position at older ages. Further methodological contributions are discussed in the section on strengths and weaknesses.

8.2.1 Evidence on socioeconomic inequality in end-of-life care and the need to go beyond observing the problem

The meta-analysis and dose response analysis has strengthened the overall evidence on socioeconomic inequality in end-of-life care and demonstrated consistent evidence that low socioeconomic position is a risk factor for several indicators of poor quality end-of-life care. The findings from the review highlight the need to go beyond observing the inequality problem, to begin to understand the reasons why inequality exists and to take action to reduce inequality in palliative and end-of-life care. This is discussed further in a letter published in the Journal of Health Service Research and Policy, inserted below.

Journal of Health Services Research &
Policy
0(0) 1

DOI: 10.1177/1355819617750184
journals.sagepub.com/home/hsr
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Time to go beyond observing the problem. Response to: Dying in hospital: socioeconomic inequality trends in England, DOI: 10.1177/1355819616686807

We need a more explicit focus on reducing socioeconomic inequality at the end of life. The recent area-based analysis by Barratt et al.[1] demonstrates that socioeconomic inequalities in health persist until the end of life, specifically that people from more deprived areas are more likely to die in hospital. This finding is not new. As early as 1999, Higginson et al. identified a persistent pro-rich gradient in place of death according to level of area deprivation over the period 1985 to 1994.[2] Later individual-level trend analysis found similar entrenched divides even after accounting for other socially patterned factors including cause of death and age.[3,4]

More worryingly, inequalities in place of death appear to be widening over time.[3,4] A study of 20-year trends in hospice deaths showed that people were always more likely to die in a hospice if they lived in a less deprived area, but the gap between the most and least deprived grew by 25% between 1993–1997 and 2008–2012.[4] The uncomfortable message is that overall improvements in place of death outcomes have done nothing to improve relative or absolute inequality.

The Barratt paper sits within a wider National Institute for Health Research (NIHR) funded project to develop indicators for monitoring social inequality in the National Health Service (NHS) across the life course. We wholeheartedly welcome the inclusion of an end of life indicator. Monitoring place of death according to area-deprivation is undeniably important and worthwhile, although we should be explicit about the limitations of this single indicator to evaluate the quality of end of life care. We agree with Barratt et al. that 'greater understanding of the reasons for such inequality is required before policy changes can be determined'. We urgently need both research into the reasons for and rigorous evaluation of ways to reduce these inequalities.

References

1. Barratt H, Asaria M, Sheringham J, et al. Dying in hospital: socioeconomic inequality trends in England. *J Health Serv Res Policy* 2017; 22(3): 149–154
2. Higginson IJ, Jarman B, Astin P, et al. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. *J Public Health Med* 1999; 21: 22–28.
3. Gao W, Ho YK, Verne J, et al. Changing patterns in place of cancer death in England: a population-based study. *PLoS Med* 2013; 10: e1001410.
4. Sleeman KE, Davies JM, Verne J, et al. The changing demographics of inpatient hospice death: population-based cross-sectional study in England, 1993–2012. *Palliat Med* 2015.

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Following the work of Barrett et al (2017) cited in the letter above, health inequalities are now routinely monitored in England through the NHS England 'Health Inequalities Improvement Dashboard' and the Public Health England 'fingertips data'.[103, 242, 243] Inequalities in place of death are monitored in the Palliative and End of Life Care Profiles data, one of 31 themed 'profiles' that are part of the 'fingertips data', collated and made publicly available to support local commissioning.[242] The fingertips data also include a 'Health Inequalities Dashboard' that presents mostly national inequality trends for 19 indicators (not including place of death) and the 'Marmot Indicators' providing local authority level reports on inequality in life expectancy and healthy life expectancy at birth.[242] An initial evaluation of how these data are being used by commissioners and others, concluded that 'local decision makers need greater awareness, understanding and support to interpret, use and act upon inequality indicators'.[244]

The message highlighted in the letter above, which is strengthened by the findings from the systematic review and meta-analysis, is that while monitoring health inequalities is important and worthwhile, there is also a need to go beyond observing the problem of inequality in palliative and end-of-life care, to understand the causes of inequality and to identify ways to reduce inequality. The mediation analysis using ELSA data is the first to study to attempt to empirically investigate the causes of inequality in hospital-based service use towards the end of life. The following section of the discussion on 'health as a mediator' outlines the main contribution of this work in detail.

This thesis contributes to what has been called the 'equity turn' in palliative and end-of-life care research, describing a growing interest in inequality issues in this field.[245] Despite this increasing focus on inequality, evidence on how to address inequality is lacking.[246] Currently, interventions in palliative and end-of-life care are designed and evaluated in terms of overall benefit, not for how effectively they address inequalities,[247] and a strong policy framework for addressing inequalities is lacking.[109, 112] There are opportunities to learn from the wider field of research and policy on health inequalities where the focus on evaluating interventions that address inequalities is more developed.[244, 248, 249]

For example, distributional cost-effectiveness analysis (DCEA) is an established method for evaluating the equity impact of interventions and for calculating trade-off between equity and efficiency.[249] The DCEA method extends conventional cost-effectiveness analysis to take account of distributional effectiveness across social groups based on characteristics like socioeconomic position, ethnicity, geographical location, and diagnosis.[249, 250] An important area for future consideration is how these and other methods could be applied to palliative and end-of-life care interventions to evaluate unequal benefits across social groups. This is discussed further in the section on implications for policy, practice, and research.

8.2.2 Health as a mediator of the relationship between socioeconomic position and service use towards the end of life

The multiple mediator model found that in a representative sample of 737 older adults living in England, people with lower wealth had worse health and function and more hospital admissions in the last 2 years of life, and the pathway through health and function accounted for 34.6% of the total negative effect of higher wealth on admissions. The analysis provides the first empirical evidence of an explanatory pathway between wealth and hospital use towards the end of life and emphasises that differences in health-need may be important for driving different patterns of service use. This challenges behavioural explanations - the idea that people with lower socioeconomic position may choose to use secondary care more, and primary care less, substituting one for the other.[224] In contrast, the analysis found that although lower wealth was associated with less access to services (including primary care services), access to services was not associated with hospital admissions and did not explain why people with lower wealth had more admissions. In the same multiple mediator model, health and function did not mediate the direct effect of lower wealth on higher odds of death in hospital (versus home/hospice). Therefore, the mechanism through which low wealth leads to an increased risk of death in hospital remains unexplained in this model. This finding highlights that health as a mediator of the relationship between wealth and end-of-life care can operate differently depending on the outcome being studied.

The analysis of the clinical data investigated the relationship between area-based deprivation and the three subscales of the Integrated Palliative Care Outcome Scale (IPOS): physical symptoms, emotional symptoms, and communication and practical concerns. In this analysis the measure of health (IPOS) was the outcome rather than the mediator because the clinical data did not contain outcomes such as place of death and was not linked to mortality or hospital episode data. This analysis offers more detailed insight into the health-related needs of patients with more advanced disease (than the health data available in ELSA), and the findings are useful for generating hypotheses for future mediation studies. After adjusting for demographic and other clinical characteristics, the analysis found that people who lived in more deprived areas had worse communication and practical concerns but found no association between level of area-based deprivation and the physical or emotional symptoms of patients. This evidence of no association contrasts with findings from a small body of previous research on patients with advanced cancer[232-234], and with the wider evidence on the social gradient in health.[93]

Three potential sources of bias in the analysis might have limited the effect of deprivation in our sample. First, mortality bias and bias in who gets referred to specialist palliative care might lead to an under-representation in our sample of patients living in the most deprived areas. Comparison with national death registration data confirmed that the sample was less deprived and had a larger proportion of cancer patients than the national end-of-life population. The dose-response analysis in the systematic review and meta-analysis also supports the assumption that people living in more deprived areas may be less likely to be referred to specialist palliative care, although it is notable that none of the data in the meta-analysis is from the UK.[251] Second, unmeasured service-related factors for example the care patients receive on wards before they are seen by specialist palliative care, might moderate the effect of deprivation on symptoms. Third, measurement bias in the staff-reported IPOS tool which could be biased towards detecting symptoms and concerns in people with higher socioeconomic position.

There are also several key differences between the analysis of the clinical data and the small body of previous studies examining this association in advanced cancer patients. The largest study by Malhotra et al (2020) examined the association between self-perceived economic status and validated measures of cancer suffering including the Functional Assessment of

Cancer Therapy – General (FACT-G) and the Hospital Anxiety and Depression Scale (HADS). The analysis was based on 1378 hospital inpatients and outpatients with advanced cancer in 5 Asian countries (China, Sri Lanka, India, Vietnam, and Myanmar), mean age was 53 years (sd 13.1). The multivariable regression analysis adjusted for age, sex, setting and country and found that patients living in low economic households reported worse suffering in several domains.

The study by Delgado-Guay et al (2015) was based on 149 outpatients with advanced cancer in Texas, median age 60 years (95% CI 58.6-61.5). The analysis reported the unadjusted correlation between self-rated financial distress on a ten-point scale (10 was worst distress) and validated outcome measures including: HADS, FACT-G and the Edmonton Symptom Assessment System (ESAS). The analysis found weak to moderate positive correlations between financial distress and anxiety and depression, and a weak to moderate negative correlation with overall quality of life (high quality of life scores were optimal). Correlations between financial distress and other physical and emotional symptoms were not statistically significant.

The most recent study by Lloyd-Williams et al (2021) is based on 595 patients with advanced cancer attending hospice day services in England, with a mean age of 68 years. The analysis measured socioeconomic position using Index of Multiple Deprivation quintiles based on patient’s postcode of residence. The analysis adjusted for age, sex and type of cancer and reported the odds ratio for the most deprived group compared to the least deprived group, of depression using the Patient Health Questionnaire (PHQ-9), and self-reported pain, breathlessness, nausea, fatigue, constipation, and insomnia. Patients living in the most deprived areas had statistically significantly higher odds of having depression, pain, and constipation.

In summary, compared to my analysis of cancer and non-cancer hospital inpatients with a median age of 82 years (IQR 74, 89), the patients included in the three studies referenced above were younger, included cancer patients only and were primarily outpatients. The moderating effect of age on the relationship between socioeconomic position and health is discussed in more detail below and may in part explain the contrasting results. There were also differences in the analysis that might explain the contrasting results. The analysis by Delgado-Guay (2015) and Lloyd-Williams et al (2021) both looked at individual symptoms, whereas my analysis looked at composite scores. The use of composite scores reduced the chance of Type 1 errors but potentially masked variation in the relationships across different items. Each of the studies used different types of exposures and outcomes and the country-specific context also limits comparability. For example, if societal inequalities are wider in Asian countries and in the US than in the UK, and if inequalities are further exacerbated by insurance-based healthcare systems[252], this may partly explain the stronger association between socioeconomic position and symptoms detected in the studies by Malhotra et al (2020) and Delgado-Guay et al (2015).

The analysis of the clinical data contributes to a small body of evidence on the relationship between socioeconomic position and the symptoms and concerns of patients with advanced illness. The findings of no association between area-based deprivation and the physical and emotional symptoms of patients could reflect the true effects or could reflect sample bias, or measurement bias in the analysis. Given the lack of previously existing evidence on this relationship, my analysis highlights a need for further work to understand the relationship between socioeconomic position and the symptoms and concerns of patients with advanced illness. The analysis has demonstrated the use of routinely collected patient centred outcome measures linked to area-based deprivation as a means for studying this relationship. Further studies in different patient populations, in different hospitals and different settings are needed. Confirmatory factory analysis (CFA), and multiple indicator multiple causes (MIMIC) models could be used to provide a more nuanced analysis of the relationships between socioeconomic position and individual IPOS items.

8.2.3 Age as a moderator and the diminishing effect of socioeconomic position at older ages

In line with other studies[182, 183], this thesis found a diminishing effect of socioeconomic position on health at older ages. The analysis of ELSA showed that the effect of higher wealth on better health and function was weaker at older ages and nonsignificant from age 87 years and above. The negative effect of wealth on death in hospital was weaker at older ages and nonsignificant from aged 85 years and above. In the analysis of the clinical data, the effect of higher deprivation on worse communication and practical concerns was nonsignificant from age 83 years and above. This could indicate that socioeconomic position becomes less important as a predictor of needs and outcomes as people age, potentially as other factors like age and health become more important predictors of future events. Or the diminishing effect could be due to cohort effects, reflecting less income inequality at older ages, due to the relative generosity of the state pension in the UK compared to working-age benefits, or the potential moderating effect of care home admissions.[253]

Some of the diminishing effect of wealth and deprivation is likely to be caused by mortality bias, leading to an under-representation of people with lower socioeconomic position at older ages because of shorter life expectancy. In the ELSA analysis and the analysis of the clinical data, there is also an under-representation of institutionalised older adults who may be more likely to have lower socioeconomic position.[222] The ELSA analysis excluded decedents who had been admitted to a care home in the last 2 years of life from the main analysis because this subgroup was not large and representative enough to be used to investigate care home admission as a potential moderator of the relationship between wealth and admissions. In the clinical data, care home residents are likely to be under-represented in the hospital data because they are less likely to be admitted to hospital.[54]

Given the potential biases, the diminishing effect of socioeconomic position at older ages is challenging to interpret. Awareness of the potential for the effect of socioeconomic position to fluctuate over age ranges, over time and between age cohorts is important for research in palliative and end-of-life care, particularly for studies of inequalities in older adults. It is also possible that the effect of socioeconomic position on health and outcomes could dimmish as people approach death. Proximity to death could explain why the results in the analysis of the clinical data on the relationship between socioeconomic position and health contrast with the findings from the ELSA analysis, the previous studies on patients with advanced cancer[232-234], and the strong global evidence on socioeconomic inequalities in health.[119] Future work could test the hypothesis that the effect of socioeconomic position on patient centred outcome measures and process outcomes such as place of death or hospital admissions, diminishes closer to death.

8.3 Strengths and limitations

This section discusses the methodological contributions of the thesis and the strengths and weakness of the work.

8.3.1 Measuring socioeconomic position

Traditional measures of socioeconomic position such as education, occupation, and income, have limitations for use with older populations either because they lack relevance for retired people or because they tend to group together a large proportion of people with lower socioeconomic positon.[179, 180] Wealth is arguably the 'gold-standard' approach to measuring socioeconomic position for older people because it captures the accumulation of assets across the life course.[182] Within a life-course perspective this accumulation of disadvantage (or advantage) is critical for understanding how socioeconomic position effects health.[122] In line with theory that emphasises the importance of socioeconomic position across the life course, wealth has been shown to have a stronger relationship with mortality than other measures of socioeconomic position including education, paternal class, income, and occupational class.[182] Unlike income or employment, wealth remains a good indicator of socioeconomic position in retirement and is much closer in time to the health outcomes being studied than education which has been shown to be important.[182] Wealth also has the advantage of being a numerical variable that is statistically more useful for investigating the social gradient in health than ordinal measures such as education that tend to group large proportions of the population in lower categories.[180] The challenge with wealth is that to measure it accurately, a large amount of information must be collected from participants, requiring considerable research time, skills and resources that may not be feasible in relatively small scale prospective studies.

A strength of the English Longitudinal Study of Ageing (ELSA) analysis is the use of the highly detailed measure of wealth.[182] This measure of wealth is based on a series of in-depth questions about savings, investments, physical wealth, housing wealth and debt and is a comprehensive representation of assets accumulated across the life course.[182] The systematic review found no study that used a measure of wealth. The most common measures of socioeconomic position used in the existing literature were area-based measures, reported against 79 (47.6%) outcomes, and education, reported against 39 (23.5%) outcomes. Theoretically, education may be an indicator of behavioural factors such as health literacy or ability to navigate the health care system, which might plausibly mediate the relationship between socioeconomic position and end-of-life care.[180] Yet, education is distant in time from the outcomes being studied, and therefore, within a life-course perspective, education is likely to have a weaker association with palliative and end-of-life care outcomes than more ‘proximal’ measures such as wealth.[181, 182] This is supported by the ELSA analysis which found that education was associated only indirectly with death in hospital and hospital admissions in the last 2 years of life, via wealth. This analysis is the first study to demonstrate the temporality of different measures of socioeconomic position in relation to palliative and end-of-life care outcomes, highlighting the importance of applying a ‘life-course’ approach to studying inequality in care received towards the end of life.

In the analysis of the clinical data, we used an area-based measure of deprivation linked to patient postcode of residence. Area-based measures are limited by the ecological fallacy[254], and further limited in older populations living in care homes, because the postcode of the care home may be a poor proxy for individual socioeconomic position. In the clinical data, we had no way to flag care home residents, and therefore could not compare the deprivation profile of care home and non-care home residents or evaluate the representativeness of care home residents in our sample. Recent developments have made it possible to link care home address information to hospital data using national registers from the Care Quality Commission. This approach has been developed by the Improvement Analysis Unit of NHS England as a new technique for identifying care home residents in hospital data.[255] In future studies this method could be used to flag care home postcodes and where possible trigger imputation of an earlier private residence postcode record as a better proxy for individual level socioeconomic position.

In the UK context, area-based measures are practicably the only measure of socioeconomic position available in routinely collected health data. There is no insurance data to draw on and little precedent for linking administrative records on tax and income to health data, although this may technically be possible. The established link between area-based deprivation and mortality and morbidity[1, 93, 100] supports the use of area-based measures for investigating the social gradient in health. The small-area geography used by the Index of

Multiple Deprivation has also improved the quality of the measure since the 2004 version of the index which was built at ward-level. Since 2004, the Index of Multiple Deprivation (IMD) has been built at the lower layer super output area (LSOA) level, a small-area geography developed from the 2001 Census.[256] LSOAs are smaller and more homogenous geographies than the ward-level geographies that earlier area-based measures were built on. In England and Wales, there are 34,753 LSOAs with an average population size of 1,500 people, compared to 7,878 electoral wards with an average population of 7,065 and large variation in populations ranging from 162 to 43,359 people.[257] Area-based measures also have the advantage of being numerical or interval, making them well suited for investigating the social gradient.

Importantly, studies should select measures of socioeconomic position based on theory grounded in existing evidence about the relationship between exposures and outcomes and based on the suitability for measures for the analysis. For example, if socioeconomic position is included only as a confounder, then a composite area-based measure such as the Index of Multiple Deprivation that captures more variance around socioeconomic position may be the most suitable approach. If socioeconomic position is the main exposure of interest and a specific pathway is hypothesised, an individual-level singular measure may be more appropriate. Validated measures of socioeconomic position such as the MacArthur Scale of Subjective Social Status[148, 258], the Comprehensive Score for Financial Toxicity (COST)[259], or the Socioeconomic Status Instrument (SESI)[260] have the potential to improve the measurement of socioeconomic position in prospective studies. These tools have not been validated in populations with advanced disease, and the systematic review found no examples of studies using these measures. However, if shown to be valid and reliable in different settings, these tools could provide a middle ground between area-based measures and the gold standard measure of wealth, for prospective studies with the opportunity to collect individual-level data but with limited resource. The English Longitudinal Study of Ageing (ELSA) could be used to compare the level of agreement between the IMD, wealth and other interval measures of socioeconomic position such as the MacArthur Scale of Subjective Social Status[148], and to investigate variation in the effect of these measures on outcomes relevant to end-of-life care such as place of death and hospital admissions. This analysis could be used to make recommendations for prospective studies on the best way to capture socioeconomic position in new data collections.

8.3.2 Use of existing longitudinal studies

The advantage of existing longitudinal studies is that they contain rich social, economic and health data on large and nationally representative samples and are anonymised and easily accessible to researchers without long delays or access procedures. The English Longitudinal Study of Ageing (ELSA) and the other sister studies on ageing, including TILDA in Ireland, are well suited for studying end-of-life because of the inclusion of the mortality follow-back survey, the focus on older adults and the innovative approach to measuring wealth. Comparability across the sister studies and a strong multi-disciplinary approach with an equal focus on collecting detailed economic data alongside health data including symptoms, subjective assessments, diagnoses, and biomarkers, are additional strengths of these resources.[210]

This thesis is the first study to report data from the English Longitudinal Study of Ageing (ELSA) end-of-life proxy interview.[261] It contributes to a small body of literature that has used existing longitudinal studies to investigate palliative and end-of-life care.[262-264] One of these studies by Hanratty *et al* (2008) used the British Household Panel study to investigate service use in the last year of life.[262] This study of 1652 community dwelling decedents found that after adjusting for age, health status and other characteristics, people who reported financial strain had nearly double the odds (OR 1.9, 95% CI 1.3 to 2.6) of being frequent attenders in primary care in the last year of life than respondents who were financially comfortable.[262] The same study found that financial situation was not associated with odds of having an above median (>14 days) hospital stay in the last year of life. Interestingly, self-reported poor health (compared to fair or excellent health) was associated with both increased odds of primary care use (OR 3.56, 95% CI 2.61 to 4.84) and having an above median hospital stay (OR 1.75, 95% CI 1.22 to 2.51). In this analysis, the effects of health and financial situation are mutually adjusted for each other as confounders. This approach fails to take account of the temporal and causal relationship between socioeconomic position and health, namely that having a poorer financial situation reflects life-long disadvantage which causes worse health.

In the ELSA analysis, rather than adjusting for health as a confounder of the relationship between wealth and service use, the mediation analysis takes account of the temporal and causal relationship between wealth and health. Existing longitudinal cohort studies that collect data over several years are ideally suited to this type of mediation analysis where an important requirement is that the variables are temporally ordered. So, for example, financial situation collected at baseline clearly proceeds health status collected at the last time point before death. A mediation analysis could be applied to the British Household Panel data used by Hanratty *et al* (2008) to see how much of the direct effect of financial situation on service use in the last year of life is mediated by the pathway through health. This would take the analysis further, by attempting to explain why people experiencing financial strain have a higher use of primary care. The strong global evidence on the relationship between lower socioeconomic position and worse health suggests that this is a more appropriate way to model the relationship between socioeconomic position and health than merely accounting for each as a confounder of the other factor.

This thesis and the small number of previous studies using existing longitudinal studies have highlighted the value of these resources for end-of-life care research. To stimulate more research, it would be useful to collate information on the outcomes relevant to end-of-life care that are available in existing longitudinal studies. For example, in the 2013 and 2017 waves of the Health Survey for England (HSE) the question, ‘was a palliative care service used?’ was asked to respondents who identified that someone close to them had died in the last 5 years, alongside an explanation of palliative care provided by the interviewer. These data are potentially very useful, particularly as the use of palliative care is often underreported in routine data. The HSE data was used by Johnson *et al* (2017) to show that access to palliative care was associated with fewer deaths in hospital and more deaths at home.[264] In contrast, ELSA does not include a question about the use of palliative care and could potentially be improved by the addition of a similar question. Mapping the data available in existing longitudinal studies to the patient and public research priorities for end-of-life care research set out by the James Lind Alliance[265], could be used to identify opportunities for future research and for highlighting ways to improve the data collected in existing longitudinal studies.

In ELSA, the mortality follow back survey is supported by linking ELSA to mortality data which are used to identify deceased participants.[266] The data linkage has so far been restricted to a limited set of information from mortality records including date of death and cause of death. The mortality follow back survey has been collected during 4 waves of ELSA, but the most recent proxy data was collected in 2013, and without an update the future use of the ELSA for end-of-life research is limited. One way to improve the value of existing longitudinal studies is through better linkage of these resources to mortality data and to routinely collected health data. In response to the Covid-19 pandemic there have been rapid advances in linkage of and access to routine data,[192] including the development of the Public Health Data Asset (PHDA) which links mortality records to the 2011 Census and to Hospital Episode Statistics (HES).[267] These improvements bring UK data linkage capabilities and data access procedures in-line with the higher standards seen in many other European countries, and have the potential to improve the quality of existing longitudinal studies through more extensive linkage to routine data.[268]

8.3.3 Use of routinely collected Patient Centred Outcomes Measures

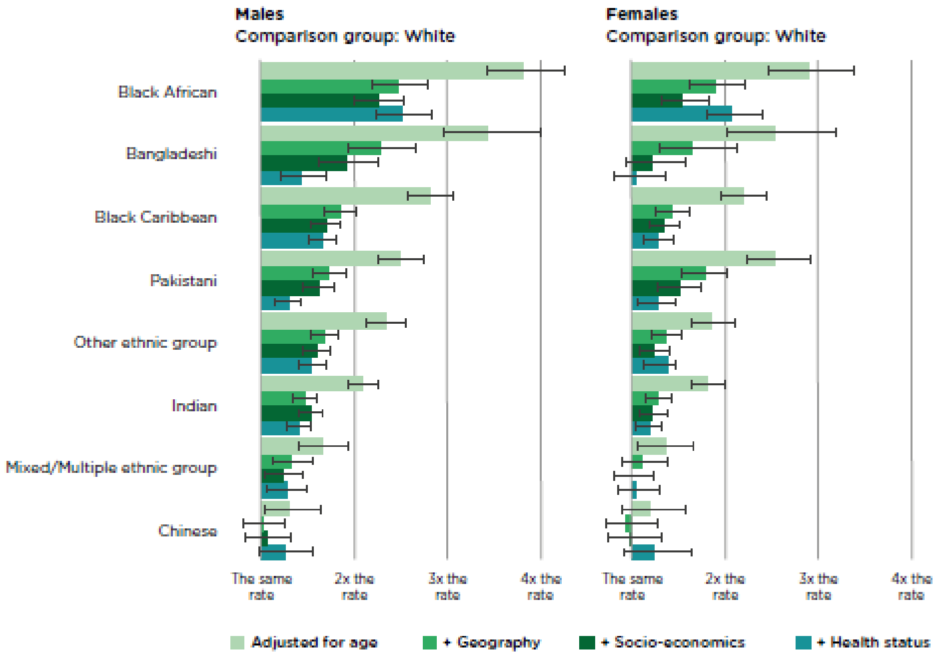
Patient centred outcome measures (PCOMs) are increasingly seen as the best way to collect data that is meaningful to patients and families and the most accurate way to evaluate the quality of care.[79, 195] In Australia, through the Palliative Care Outcomes Collaborative (PCOC), PCOMs are fully integrated into palliative and end-of-life care services and are used to evaluate, benchmark and improve the quality of care.[84, 86] When used in routine care, PCOMs can improve communication between clinicians and patients, support the identification of symptoms and needs, and support decision making.[85] The Integrated Palliative care Outcome Scale (IPOS) is a PCOM validated for use with dying patients that has been widely used in primary prospective research studies and is increasingly being introduced into routine care.[82, 269] The analysis of the clinical data in this thesis contributes to a small number of papers reporting analysis of routinely collected IPOS data and is the first study to analyse the association between socioeconomic position and the subscales of the IPOS.[270] None of the 112 high to medium quality studies included in the systematic review reported an association between socioeconomic position and quality of care measured using a patient centred outcome measure (PCOM) such as IPOS. Since the review, the studies by Malhotra *et al* (2020)[233] and Lloyd-Williams *et al* (2021)[232] have been published and this work is discussed earlier in relation to the findings from the analysis of the clinical data used in this thesis, the study by Delgado (2015) was not identified by the review.[234]

The routine collection of PCOMs data for patients with advanced disease also has the potential to enable better evaluation of the quality of care. Retrospective case series designs that start with a cohort of deceased patients and look back at the care received leading up to death are common in palliative care research. The limitation of this design is that it necessarily excludes similar patients who were receiving similar treatment at a similar stage of disease but simply died later, introducing mortality bias into the analysis. When retrospective designs are used to evaluate patterns of care and associated factors they can lead to biased results if factors like length of diagnosis and survival time are not accounted for.[187] For example, in the ELSA analysis, if people with lower wealth are more likely to die from sudden causes, they may have fewer hospital admissions in the last year of life than wealthier people simply because they have a shorter period of illness, therefore leading to an underestimation of the relationship between lower wealth and more hospital admissions. Ideally, prospective data would be used to follow a similar cohort of patients over time, but this approach is expensive and burdensome and can lead to another source of sampling bias if patients who are too unwell to participate are excluded.[188] More widespread routine collection of PCOMs data, and better linkage of this data to other sources of health data, could be used to identify samples and provide a more complete picture of the needs and patterns of care of patients leading up to death and the associated risk factors.[187]

8.3.4 Intersectionality

The Covid-19 pandemic has highlighted the importance of understanding health inequalities in relation to the intersection between race or ethnicity and socioeconomic position. During the pandemic, people from black and minority ethnic (BAME) backgrounds were more at risk from infection because they were more likely to be key workers, to work outside of the home, to live in multiple occupancy and overcrowded housing, and to live in more deprived urban areas. These cumulative risk factors exposed BAME communities to a higher risk of infection and contributed to a higher rate of mortality from Covid-19. However, as figure 10 below shows, in an analysis by the Office for National Statistics, even after adjusting for preexisting health conditions, age, geography and socioeconomic factors, the death rate from Covid-19 remained statistically significantly higher for males and females of Black African, Black Caribbean, Indian, Pakistani, and Other ethnic groups, compared to White people.[100]

Figure 10: Death rates at ages 9 years and over involving COVID-19 by ethnic group and sex relative to the White population, taking account of demographic, socioeconomic and health-related factors, England, 2 March to 28 July 2020, source [100]



Notes:

1. *Cox proportional hazards models adjusting for age, geography (local authority and population density), socioeconomic factors (area deprivation, household composition, socioeconomic position, highest qualification held, household tenure, multigenerational household flags and occupation indicators (including keyworkers and exposure to others), and health (self-reported health and disability status in March 2011, and hospital-based co-morbidities since April 2017).*
2. *Figures relate to persons enumerated in private households in the 2011 Census, for whom deaths that occurred between 2 March and 28 July could be linked to the 2011 Census.*
3. *Deaths involving COVID-19 include those with an underlying cause, or any mention, of (COVID-19) virus*
4. *'Other' ethnic group encompasses Asian other, Black other, Arab, and other ethnic group categories.*
5. *Error bars not crossing the x-axis denote a statistically significant difference in relative rates of death.*

***Source:** ONS, COVID-19 related deaths by ethnic group, England and Wales, 2020 (61).*

This analysis suggests that ethnicity has a relationship with health that is independent of socioeconomic position. Critical to understanding this is acknowledging that BAME groups face discrimination across their lives due to structural racism in society, including in education, employment, housing, and health care. During the pandemic, accounts of BAME workers being given less access to personal protective equipment (PPE), issued with higher risk tasks than white counterparts, and having safety concerns ignored by their employers, are indicative of the discrimination experienced.[100]

It is a limitation that this thesis did not explore intersectionality between ethnicity and socioeconomic position. In the systematic review and meta-analysis we limited the focus to socioeconomic position because of the analytical challenge of incorporating ethnicity into the review. The English Longitudinal Study of Ageing (ELSA) has an overwhelmingly white sample; in our subsample of deceased participants 97.4% were white. In the analysis of the clinical data, we included ethnicity as a confounder, but 15.8% of the sample had missing ethnicity information which limits what we can interpret from the analysis. These methodological constraints explain the lack of focus on intersectionality. However, reflecting on this limitation, I also acknowledge that understanding intersectionality between socioeconomic factors and ethnicity was less of a priority for me when I started work on this PhD than it is now towards the end of the work.

In the wake of the Covid-19 pandemic, the murder of George Floyd and the subsequent ‘Black Lives Matter’ movement, there has been a call for greater acknowledgment of race and racism in palliative and end-of-life care and for more action to address ethnic inequalities.[271] In the UK to date, research into ethnicity effects on palliative and end-of-life care using routine data has been limited by the absence of ethnicity on death certificates and by the poor quality of ethnicity data in hospital episode data.[272] Recent improvements including the introduction of mandatory recording of ethnicity on death certificates in

Scotland,[273] better access to primary care records[192] and to Census data linked to health data,[267] promise new possibilities for research into ethnicity and the intersection with socioeconomic position.

8.4 Implications for policy, research and practice

In the context of widening health and societal inequalities[93] and without a specific policy focus on reducing inequalities in palliative and end-of-life care, it is not surprising that inequalities in place of death appear to have widened over the last 20 years.[37, 60] This thesis makes the case for understanding the causes of inequality in palliative and end-of-life care within a life-course perspective, recognising that the causes of health inequalities accumulate across the life-course due to the unequal distribution of structural and material resources and opportunities.[121] The findings support calls to address health inequalities through a fairer distribution of resources[93] and for a more ‘consciously politicised’ approach to addressing inequality in palliative and end-of-life care.[93, 245]

The Marmot reviews have set out the actions needed to address health inequalities in the UK, focusing on early intervention on child health, better education, fairer employment, wages, taxes and benefits, and the national reprioritisation of health and well-being above economic performance.[1, 93, 100] These reports make no mention of palliative and end-of-life care and from within the field of palliative and end-of-life care it can be challenging to see how to contribute to efforts to reduce inequalities in health.[1, 93, 100] Yet, there is a compelling reason to act; everyone should have access to a good and dignified death, regardless of financial or other means. Where people are cared for, and the quality of that care is important to patients and to families who live with the legacy of the care their loved ones receive. In an ageing population with growing demand for end-of-life care and widening structural inequality in society, there is an urgent need to make end-of-life care more equitable.

In 2008, the World Health Organisation Commission on Social Determinants of Health, chaired by Sir Michael Marmot, set out 'three principles of action' to address the social determinants of health:

1) *Improve the conditions of daily life – the circumstances in which people are born, grow, live, work and age.*
2) *Tackle the inequitable distribution of power, money, and resources – the structural drivers of those conditions of daily life – globally, nationally, and locally.*
3) *Measure the problem, evaluate action, expand the knowledge base, develop a workforce that is trained in the social determinants of health, and raise public awareness about the social determinants of health.*[252]

In relation to the first principle, work is currently being led by Marie Curie and others in the charitable sector to improve 'the conditions of daily life' by increasing the state financial support available to people living with terminal illness.[253, 274, 275] Alongside this policy work, a small body of academic work is developing that seeks to understand, highlight, and provide a platform to the voices and experiences of people living in poverty with terminal illness.[246, 276]

In relation to the second principle, there is a growing demand for the palliative and end of life care community to become more overtly political in calling for a more equitable ‘distribution of power, money and resources’ and to use research and surveillance data to highlight the consequences of the inequitable distribution of resources for people approaching the end of life.[245, 271, 277]

Reflecting on the findings from this thesis in relation to the third principle of action, the following section outlines the practical implications for policy, research and practice emerging from this work.

1. Monitor socioeconomic inequality in palliative and end-of-life care

In the UK, the first study demonstrating an association between area-based deprivation and place of death was published more than 20 years ago.[102] Yet, it is only recently that Public Health England have begun to track inequalities in place of death as part of the Palliative and End of Life Care Profiles ‘fingertips’ data.[242] This development in monitoring inequalities has the potential to inform local decision making by creating a better awareness of trends in inequalities in palliative and end-of-life care service use. Understanding the needs of local planners and supporting their use of this data will be important for maximising the impact of this type of monitoring data.[244]

Regular monitoring of inequalities should also not be limited to place of death and could feasibly include other indicators of the quality of care such as the rate of hospital admissions or out-of-hours emergency department visits in the last 12 or 3 months of life. If the routine collection of patient centred outcome measures (PCOMs) in palliative and end of life care continues to expand, in the future outcome measures could also be used to monitor inequalities. Work is needed to agree which outcomes would be most useful to measure and how these data should be presented for example using relative and absolute measures of inequality and age and sex standardising data to facilitate comparisons over time and between areas. Evidence-based guidance is needed for how this monitoring data can be used to inform or evaluate the delivery of palliative and end-of-life care services at a local and national level.

2. Evaluate palliative and end-of-life care interventions for unequal effects across social groups

It is well established that health-related interventions have the potential for unequal benefit across groups.[95, 106] Evidence from this thesis shows that socioeconomic position is an important predictor of service use towards the end of life and existing evidence on place of death suggests that inequalities in palliative and end-of-life care may have widened in recent years.[37] Overall improvements in the increase in people dying at home or in hospice over the last 20 years have not be experienced equally across society, with people living in the least deprived areas benefitting most from these changes.[37, 60, 103, 104] Mostly, we lack evidence on whether palliative and end-of-life care interventions benefit some groups in society more than others. Existing systematic reviews into the effectiveness and cost-effectiveness of palliative and end-of-life care have not addressed the equity impacts of interventions.[247, 278]

One approach that could be useful for future studies of effectiveness is distributional cost-effectiveness analysis (DCEA). This framework can be used to evaluate interventions in terms of how much they improve total population health and how far they reduce health inequalities.[249, 279] This method extends conventional cost-effectiveness analysis which focuses exclusively on overall improvements to population health.[249, 250] In palliative and end-of-life care, we should agree the best approach to evaluating the equity impact of interventions. Reviewing existing intervention studies for data on distributional effects and making recommendations for how intervention studies should collect and report data on effects across different social groups could be a useful starting point.

3. Expand the knowledge base on social inequalities in end-of-life care

There is a need to regularly monitor inequality trends relevant to palliative and end-of-life care, but we also need to move beyond observing the problem, towards understanding why socioeconomic inequality exists and how to address it. This thesis has demonstrated how advanced analysis techniques in structural equation modelling and mediation analysis can provide insight into the mechanisms through which socioeconomic position influences palliative and end-of-life care outcomes. We should continue to build on this evidence to develop a more detailed understanding of the causes of inequality towards the end of life. Strengthening links with researchers working in other fields including psychometrics, psychology and in the wider field of the social determinants of health and poverty research will help to support this work.

A next-step for work on inequalities in palliative and end-of-life care is the project that I will co-lead with Professor Katherine Sleeman, due to start in Autumn 2022, funded by Marie Curie (MC-21-816) using the Office for National Statistics Longitudinal Study (ONS LS) to investigate mediating pathways between level of area-based deprivation and death in hospital (versus home or hospice) including through health, housing, and social support. Importantly this work will incorporate a greater focus on ethnic inequalities, supported by the large sample of non-White decedents included in the ONS-LS. Several other opportunities for future work to strengthen the evidence base on inequalities in palliative and end-of-life care have been outlined in the discussion above. These include:

- Exploiting recent advances in routine data linkage capabilities and in safe access to data in the UK that have transformed the potential to use mortality, hospital episodes, general practice, and other data such as prescribing data and Census data to investigate inequalities.[192] This includes creating new opportunities for investigating ethnic inequalities through linking to ethnicity data from primary care records and to self-identified ethnicity data from the Census.
- Further exploring the potential for existing longitudinal studies to be used for researching palliative and end-of-life care, including considering how these resources could be improved by linkage to routine data and by the inclusion of new items relevant to palliative and end-of-life care.
- Work to evaluate the strengths of different measures of socioeconomic position for use in research on palliative and end-of-life care. For example, the English Longitudinal Study of Ageing (ELSA) could be used to compare the ‘gold standard’

measure of wealth with area-based measures of deprivation and the measure of subjective social status, in terms of agreement and strength of association with relevant outcomes, to make recommendations for how smaller prospective studies in the field of palliative and end-of-life care should measure socioeconomic position.

A recent critical review into evidence on the impact of low socioeconomic position on experiences towards the end of life has also highlighted a deficit of in-depth qualitative work and a need to amplify the voices of people with lived experience of poverty in research about palliative and end-of-life care.[246] The palliative and end of life care research community should work with patient and public representatives and policy makers to identify priorities and opportunities for research into inequalities in palliative and end-of-life care. Importantly we need to work towards developing evidence-based interventions for reducing inequality towards the end of life.

4. Develop a palliative care workforce that is trained in the social determinants of health

There is growing interest in the role that healthcare professionals can have in addressing social determinants of health[280], including through social prescribing, which now forms part of the NHS long term plan for England.[254, 281] For healthcare professionals working with terminally ill patients, interventions might include supporting fast track access to benefit payments[253], referral to social workers and sign posting local support services including through Compassionate Communities.[282] The growing body of work on the social determinants of end-of-life care should help to raise awareness among healthcare professionals about low socioeconomic position as a risk factor for worse care at the end of life but more targeted efforts are needed to support healthcare professionals to act.[280] One proposal is to introduce a screening question such as the one used by healthcare teams in Toronto that asks: “do you ever have difficulty making ends meet”.[254, 283] Screening could help to support all healthcare professionals to ask about social needs and support better communication with pateints.[284] In the context of end-of-life care, work is needed to evaluate awareness of social determinants among healthcare professionals and their capacity to act, and to develop appropriate screening questions and design a practical evidence-based framework of actions and interventions.

5. Raise public awareness about socioeconomic inequality in end-of-life care

For inequalities in end-of-life care to become a priority for policy makers it must first become a public priority. Research from the UK suggests a disconnect between the evidence on the social determinants of health and public perceptions including a lack of awareness, an underestimation of differences, and a tendency to attribute causes to individual responsibility and behavioural differences rather than structural inequalities.[285] The Departure Lounge, a recent project from the Academy for Medical Sciences is an example of a well-funded public engagement project that was successful in reaching a wide and diverse audience and generating interest and discussion about death and dying.[286] Yet, there was very little, if any, focus in this project on inequalities in end-of-life care. Learning from ongoing work on how to communicate to the public about wider health inequalities[287, 288], we need future public engagement activities that explain inequalities in end-of-life care in a way that is understandable and empowering.

CHAPTER 9: Conclusion

This thesis presents consistent evidence that in high income countries, low socioeconomic position is a risk factor for death in hospital (versus home or hospice), for use of acute care in the last three months of life and for not accessing specialist palliative care in the last year of life. The mediation analysis of a representative sample of older people living in England, presents a new finding, that worse health and function partly explain why people with lower wealth have more hospital admissions in the last two years of life. This challenges behavioural explanations and highlights the importance of socioeconomically driven health differences in explaining different patterns of hospital use towards the end of life. None of the pathways tested mediated the relationship between low wealth and death in hospital, and so the mechanism through which asset ownership influences death in hospital remains unexplained. Education effected death in hospital and hospital admissions only indirectly via wealth demonstrating the temporal nature of different socioeconomic exposures and the importance of wealth as a measure of assets accumulated across the life course. For hospital inpatients seen by palliative care, the findings suggest that one way to reduce inequalities could be to target resources at addressing the practical and communication concerns of patients living in more deprived areas. The analysis found no association between area-based deprivation and the physical and emotional symptoms of patients. This could reflect no relationship or may be due to bias in the sample, measurement bias or unmeasured confounders. The analysis contributes to a small body of evidence investigating the social determinants of the symptoms and concerns of palliative patients and the contrasting results highlight a need for more investigation of this relationship.

Overall, the findings from this thesis should raise awareness about the socioeconomic determinants of end-of-life care, it also identifies several implications for policy, practice and research, including: the need to monitor inequalities and to use this data to inform policy and service delivery decisions, the need to begin to evaluate interventions for unequal effects across social groups, and the need for further awareness raising among the public and health care professionals about socioeconomic inequality in palliative and end-of-life care. Methodologically, this thesis supports a life-course approach to understanding the socioeconomic determinants of inequality in palliative and end-of-life care and makes the case for recognising health as being on the causal pathway from socioeconomic position to service use towards the end-of-life, rather than being simply a confounder of this relationship. The work demonstrates the novel use of mediation analysis in this field and highlights the use of existing longitudinal data and the routine collection of patient centred outcome measures as underutilised resources for investigating inequalities in palliative and end-of-life care.

References

1. Marmot M. Fair Society Health Lives (The Marmot Review). *Fair society, healthy lives* 2010.

2. Bone AE, Gomes B, Etkind SN, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliative medicine* 2018; 32: 329-336. 2017/10/11. DOI: 10.1177/0269216317734435.

3. Barnett K, Mercer SW, Norbury M, et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 2012; 380: 37-43. 2012/05/15. DOI: 10.1016/s0140-6736(12)60240-2.

4. Uijen AA and van de Lisdonk EH. Multimorbidity in primary care: prevalence and trend over the last 20 years. *Eur J Gen Pract* 2008; 14 Suppl 1: 28-32. 2008/10/31. DOI: 10.1080/13814780802436093.

5. van den Akker M, Buntinx F, Metsemakers JF, et al. Multimorbidity in general practice: prevalence, incidence, and determinants of co-occurring chronic and recurrent diseases. *J Clin Epidemiol* 1998; 51: 367-375. 1998/06/10. DOI: 10.1016/s0895-4356(97)00306-5.

6. Kingston A, Robinson L, Booth H, et al. Projections of multi-morbidity in the older population in England to 2035: estimates from the Population Ageing and Care Simulation (PACSim) model. *Age Ageing* 2018; 47: 374-380. DOI: 10.1093/ageing/afx201.

7. Fortin M, Stewart M, Poitras M-E, et al. A Systematic Review of Prevalence Studies on Multimorbidity: Toward a More Uniform Methodology. *The Annals of Family Medicine* 2012; 10: 142. DOI: 10.1370/afm.1337.

8. Etkind SN, Bone AE, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 2017; 15: 102. DOI: 10.1186/s12916-017-0860-2.

9. Sleeman KE, de Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health* 2019; 7: e883-e892. 2019/05/28. DOI: 10.1016/s2214-109x(19)30172-x.

10. Major causes of death and how they have changed. Office for National Statistics, available here https://www.gov.uk/government/publications/health-profile-for-england/chapter-2-major-causes-of-death-and-how-they-have-changed accessed 08/07/2022.

11. Gao L, Calloway R, Zhao E, et al. Accuracy of death certification of dementia in population-based samples of older people: analysis over time. *Age Ageing* 2018; 47: 589-594. 2018/05/03. DOI: 10.1093/ageing/afy068.

12. WHO. *WHO Definition of Palliative Care*. 2015. World Health Organisation.

13. Murtagh FE, Preston M and Higginson I. Patterns of dying: palliative care for non-malignant disease. *Clin Med (Lond)* 2004; 4: 39-44. 2004/03/05. DOI: 10.7861/clinmedicine.4-1-39.

14. Murray SA, Kendall M, Boyd K, et al. Illness trajectories and palliative care. *BMJ* 2005; 330: 1007-1011. 2005/04/30. DOI: 10.1136/bmj.330.7498.1007.

15. Radbruch L, De Lima L, Knaul F, et al. Redefining Palliative Care—A New Consensus-Based Definition. *J Pain Symptom Manage* 2020; 60: 754-764. DOI: 10.1016/j.jpainsymman.2020.04.027.

16. Higginson IJ, Bausewein C, Reilly CC, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *Lancet Respir Med* 2014; 2: 979-987. 2014/12/04. DOI: 10.1016/s2213-2600(14)70226-7.

17. Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet* 2014; 383: 1721-1730. 2014/02/25. DOI: 10.1016/s0140-6736(13)62416-2.

18. Vanbutsele G, Van Belle S, Surmont V, et al. The effect of early and systematic integration of palliative care in oncology on quality of life and health care use near the end of life: A randomised controlled trial. *Eur J Cancer* 2020; 124: 186-193. DOI: https://doi.org/10.1016/j.ejca.2019.11.009.

19. Temel JS, Greer JA, Muzikansky A, et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. *N Engl J Med* 2010; 363: 733-742. DOI: 10.1056/NEJMoa1000678.

20. Bakitas MA, Tosteson TD, Li Z, et al. Early Versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE III Randomized Controlled Trial. *J Clin Oncol* 2015; 33: 1438-1445. 2015/03/25. DOI: 10.1200/jco.2014.58.6362.
21. Hoerger M, Wayser GR, Schwing G, et al. Impact of Interdisciplinary Outpatient Specialty Palliative Care on Survival and Quality of Life in Adults With Advanced Cancer: A Meta-Analysis of Randomized Controlled Trials. *Ann Behav Med* 2019; 53: 674-685. DOI: 10.1093/abm/kay077.
22. Kustanti CY, Fang H-F, Linda Kang X, et al. The Effectiveness of Bereavement Support for Adult Family Caregivers in Palliative Care: A Meta-Analysis of Randomized Controlled Trials. *J Nurs Scholarsh* 2021; 53: 208-217. https://doi.org/10.1111/jnu.12630. DOI: https://doi.org/10.1111/jnu.12630.
23. Georghiou TD, S. Davies, A. Bardsley, M. Understanding patterns of health and social care at the end of life. *Nuffield Trust* 2012.
24. Seow H, Barbera L, Howell D, et al. Using more end-of-life homecare services is associated with using fewer acute care services: a population-based cohort study. *Med Care* 2010; 48: 118-124. 2010/01/09. DOI: 10.1097/MLR.0b013e3181c162ef.
25. Seow H, Brazil K, Sussman J, et al. Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis. *BMJ* 2014; 348: g3496. 2014/06/08. DOI: 10.1136/bmj.g3496.
26. Connor SR. 2020. Global Atlas of Palliative Care: 2nd Edition. Worldwide Hospice Palliative Care Alliance, available here https://cdn.who.int/media/docs/default-source/integrated-health-services-(ihs)/csy/palliative-care/whpca_global_atlas_p5_digital_final.pdf?sfvrsn=1b54423a_3 accessed 06/07/2022.
27. Brennan F. Palliative Care as an International Human Right. *J Pain Symptom Manage* 2007; 33: 494-499. DOI: 10.1016/j.jpainsymman.2007.02.022.
28. Ezer T, Lohman D and de Luca GB. Palliative Care and Human Rights: A Decade of Evolution in Standards. *J Pain Symptom Manage* 2018; 55: S163-S169. DOI: 10.1016/j.jpainsymman.2017.03.027.
29. Saini S and Bhatnagar S. Cancer Pain Management in Developing Countries. *Indian J Palliat Care* 2016; 22: 373-377. 2016/11/03. DOI: 10.4103/0973-1075.191742.
30. Sleeman KE, Timms A, Gillam J, et al. Priorities and opportunities for palliative and end of life care in United Kingdom health policies: a national documentary analysis. *BMC Palliat Care* 2021; 20: 108. 2021/07/16. DOI: 10.1186/s12904-021-00802-6.
31. Morin L, Aubry R, Frova L, et al. Estimating the need for palliative care at the population level: A cross-national study in 12 countries. *Palliat Med* 2016; 31: 526-536. DOI: 10.1177/0269216316671280.
32. Murtagh FEM, Bausewein C, Verne J, et al. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med* 2013; 28: 49-58. DOI: 10.1177/0269216313489367.
33. Rees-Roberts M, Williams P, Hashem F, et al. Hospice at Home services in England: a national survey. *BMJ Supportive &amp; Palliative Care* 2021; 11: 454. DOI: 10.1136/bmjspcare-2019-001818.
34. Cicely Saunders International. Dame Cicely Saunders Biography. 2019. available here https://cicelysaundersinternational.org/dame-cicely-saunders/st-christophers-hospice/ accessed 06/07/2022.
35. Hospice accounts: Analysis of the accounts of UK Charitable Hospices for the year ended 31 March 2020. available here https://hukstage-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2022-05/hospice-accounts-report-2021.pdf accessed 06/07/2022.
36. Hospice UK, Facts and Figures. available here https://professionals.hospiceuk.org/about-hospice-care/media-centre/facts-and-figures accessed 07/07/2022.

37. Sleeman KE, Davies JM, Verne J, et al. The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993-2012. *Palliative medicine* 2015 2015/05/21. DOI: 10.1177/0269216315585064.

38. Finkelstein EA, Bhadelia A, Goh C, et al. Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021. *J Pain Symptom Manage* 2022; 63: e419-e429. DOI: https://doi.org/10.1016/j.jpainsymman.2021.12.015.

39. Petersdorff Cv, Patrignani P, Landzaat W, et al. 2021. Modelling demand and costs for palliative care services in England. A final report for Sue Ryder. available here https://www.sueryder.org/sites/default/files/2021-03/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England%20%281%29.pdf accessed 06/07/2022.

40. Hughes-Hallet TC, A. Davies, C. 2011. Palliative Care Funding Review: Funding the Right Care and Support for Everyone. Independent Review for the Secretary of State for Health. available here: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf accessed: 05/08/2022.

41. Lancaster H, Finlay I, Downman M, et al. Commissioning of specialist palliative care services in England. *BMJ Supportive &amp; Palliative Care* 2018; 8: 93. DOI: 10.1136/bmjspcare-2016-001119.

42. 2013. More Care, Less Pathway: A Review of the Liverpool Care Pathway. Independent Review of the Liverpool Care Pathway, available here: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf accessed: 27.07.22.

43. 2015. Dying without dignity Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care. Parliamentary and Health Service Ombudsman, available here https://www.ombudsman.org.uk/sites/default/files/Dying_without_dignity.pdf accessed 06/07/2022.

44. National care of the dying audit for hospitals, England National report May 2014. Royal College of Physicians, available from https://www.rcplondon.ac.uk/projects/outputs/national-care-dying-audit-hospitals accessed 06.04.22.

45. Clark D, Schofield L, Graham FM, et al. Likelihood of Death Within One Year Among a National Cohort of Hospital Inpatients in Scotland. *J Pain Symptom Manage* 2016; 52: e2-e4. DOI: 10.1016/j.jpainsymman.2016.05.007.

46. Clark D, Armstrong M, Allan A, et al. Imminence of death among hospital inpatients: Prevalent cohort study. *Palliative medicine* 2014; 28: 474-479. 2014/03/19. DOI: 10.1177/0269216314526443.

47. Gomes B CN, Higginson IJ. Local preferences and place of death in regions within England 2010. *London: Cicely Saunders Institute* 2011.

48. Gomes B, Higginson IJ, Calanzani N, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Ann Oncol* 2012; 23: 2006-2015. 2012/02/22. DOI: 10.1093/annonc/mdr602.

49. Wright AA, Keating NL, Balboni TA, et al. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol* 2010; 28: 4457-4464. 2010/09/15. DOI: 10.1200/jco.2009.26.3863.

50. Makaroun LK, Teno JM, Freedman VA, et al. Late Transitions and Bereaved Family Member Perceptions of Quality of End-of-Life Care. *J Am Geriatr Soc* 2018; 66: 1730-1736. https://doi.org/10.1111/jgs.15455. DOI: https://doi.org/10.1111/jgs.15455.

51. Grande GE and Ewing G. Informal carer bereavement outcome: relation to quality of end of life support and achievement of preferred place of death. *Palliat Med* 2009; 23: 248-256. DOI: 10.1177/0269216309102620.

52. Grande GE, Farquhar MC, Barclay SIG, et al. Caregiver Bereavement Outcome: Relationship with Hospice at Home, Satisfaction with Care, and Home Death. *J Palliat Care* 2004; 20: 69-77. DOI: 10.1177/082585970402000202.

53. Bardsley M, Georghiou T, Spence R, et al. Factors associated with variation in hospital use at the end of life in England. *BMJ Supportive & Palliative Care* 2019; 9: 167-174. DOI: 10.1136/bmjspcare-2015-000936.

54. Paul Smith CS-J, Cono Ariti, Martin Bardsley. 2015. Focus on: Hospital admissions from care homes. The Health Foundation Quality Watch, available: https://www.health.org.uk/sites/default/files/QualityWatch_FocusOnHospitalAdmissionsFromCareHomes.pdf accessed: 19/05/22.

55. Cohen J, Pivodic L, Miccinesi G, et al. International study of the place of death of people with cancer: a population-level comparison of 14 countries across 4 continents using death certificate data. *Br J Cancer* 2015; 113: 1397-1404.

56. Gomes B and Higginson IJ. Where people die (1974--2030): past trends, future projections and implications for care. *Palliative medicine* 2008; 22: 33-41. 2008/01/25. DOI: 10.1177/0269216307084606.

57. Simon ST, Gomes B, Koeskeroglu P, et al. Population, mortality and place of death in Germany (1950-2050) - implications for end-of-life care in the future. *Public Health* 2012; 126: 937-946. 2012/10/09. DOI: 10.1016/j.puhe.2012.06.014.

58. Gomes B, Calanzani N, Gysels M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013; 12: 7. DOI: 10.1186/1472-684X-12-7.

59. Gomes B, Calanzani N and Higginson IJ. Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliative medicine* 2012; 26: 102-107. 2012/01/20. DOI: 10.1177/0269216311432329.

60. Gao W, Ho YK, Verne J, et al. Changing patterns in place of cancer death in England: a population-based study. *PLoS medicine* 2013; 10: e1001410. 2013/04/05. DOI: 10.1371/journal.pmed.1001410.

61. Department of Health. 2008. End of Life Care Strategy: Promoting high quality care for all adults at the end of life. available here https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life accessed: 27.07.22.

62. The King's Fund. 2021. NHS hospital bed numbers: past, present, future. available here: https://www.kingsfund.org.uk/publications/nhs-hospital-bed-numbers accessed: 03.08.22.

63. Cohen J, Bilsen J, Hooft P, et al. Dying at home or in an institution. Using death certificates to explore the factors associated with place of death. *Health Policy* 2006; 78: 319-329.

64. Higginson IJ, Astin P and Dolan S. Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. *Palliative medicine* 1998; 12: 353-363. 1999/01/30.

65. Gomes B and Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006; 332: 515-521. 2006/02/10. DOI: 10.1136/bmj.38740.614954.55.

66. Houttekier D, Cohen J, Bilsen J, et al. Place of death of older persons with dementia. A study in five European countries. *J Am Geriatr Soc* 2010; 58: 751-756. 2010/04/20. DOI: 10.1111/j.1532-5415.2010.02771.x.

67. Cohen J, Houttekier D, Onwuteaka-Philipsen B, et al. Which patients with cancer die at home? A study of six European countries using death certificate data. *J Clin Oncol* 2010; 28: 2267-2273. 2010/03/31. DOI: 10.1200/jco.2009.23.2850.

68. Reyniers T, Deliens L, Pasman HR, et al. International variation in place of death of older people who died from dementia in 14 European and non-European countries. *J Am Med Dir Assoc* 2015; 16: 165-171.

69. Hoare S, Morris ZS, Kelly MP, et al. Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death. *PLoS One* 2015; 10: e0142723. 2015/11/12. DOI: 10.1371/journal.pone.0142723.

70. Reyniers T, Deliens L, Pasman HR, et al. Reasons for End-of-Life Hospital Admissions: Results of a Survey Among Family Physicians. *J Pain Symptom Manage* 2016; 52: 498-506. DOI: 10.1016/j.jpainsymman.2016.05.014.
71. Costello J. Dying well: nurses' experiences of 'good and bad' deaths in hospital. *J Adv Nurs* 2006; 54: 594-601. https://doi.org/10.1111/j.1365-2648.2006.03867.x. DOI: https://doi.org/10.1111/j.1365-2648.2006.03867.x.
72. Earle CC, Park ER, Lai B, et al. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. *J Clin Oncol* 2003; 21: 1133-1138. 2003/03/15. DOI: 10.1200/jco.2003.03.059.
73. Earle CC, Neville BA, Landrum MB, et al. Evaluating claims-based indicators of the intensity of end-of-life cancer care. *Int J Qual Health Care* 2005; 17: 505-509. 2005/06/30. DOI: 10.1093/intqhc/mzi061.
74. Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 2013; 309: 470-477. 2013/02/07. DOI: 10.1001/jama.2012.207624.
75. Leniz J, Higginson IJ, Stewart R, et al. Understanding which people with dementia are at risk of inappropriate care and avoidable transitions to hospital near the end-of-life: a retrospective cohort study. *Age Ageing* 2019; 48: 672-679. 2019/05/29. DOI: 10.1093/ageing/afz052.
76. Leniz J, Henson LA, Potter J, et al. Association of primary and community care services with emergency visits and hospital admissions at the end of life in people with cancer: a retrospective cohort study. *BMJ Open* 2022; 12: e054281. 2022/02/25. DOI: 10.1136/bmjopen-2021-054281.
77. De Schreye R, Houttekier D, Deliens L, et al. Developing indicators of appropriate and inappropriate end-of-life care in people with Alzheimer's disease, cancer or chronic obstructive pulmonary disease for population-level administrative databases: A RAND/UCLA appropriateness study. *Palliative medicine* 2017; 31: 932-945. 20170421. DOI: 10.1177/0269216317705099.
78. De Schreye R, Smets T, Annemans L, et al. Applying quality indicators for administrative databases to evaluate end-of-life care for cancer patients in Belgium. *Health Aff (Millwood)* 2017; 36: 1234-1243.
79. Donabedian A. The quality of care. How can it be assessed? *JAMA* 1988; 260: 1743-1748. 1988/09/23.
80. Etkind SN, Daveson BA, Kwok W, et al. Capture, Transfer, and Feedback of Patient-Centered Outcomes Data in Palliative Care Populations: Does It Make a Difference? A Systematic Review. *J Pain Symptom Manage* 2014.
81. Donabedian A. Evaluating the quality of medical care. *Milbank Mem Fund Q* 1966; 44: Suppl:166-206. 1966/07/01.
82. Bausewein C, Le Grice C, Simon S, et al. The use of two common palliative outcome measures in clinical care and research: a systematic review of POS and STAS. *Palliative medicine* 2011; 25: 304-313. 2011/04/06. DOI: 10.1177/0269216310395984.
83. Guo P, Dzingina M, Firth AM, et al. Development and validation of a casemix classification to predict costs of specialist palliative care provision across inpatient hospice, hospital and community settings in the UK: a study protocol. *BMJ Open* 2018; 8: e020071. 2018/03/20. DOI: 10.1136/bmjopen-2017-020071.
84. Currow D, Allingham S, Yates P, et al. Improving national hospice/palliative care service symptom outcomes systematically through point-of-care data collection, structured feedback and benchmarking. *Support Care Cancer* 2014: 1-9. DOI: 10.1007/s00520-014-2351-8.
85. Pinto C, Bristowe K, Witt J, et al. Perspectives of patients, family caregivers and health professionals on the use of outcome measures in palliative care and lessons for implementation: a multi-method qualitative study. *Annals of Palliative Medicine* 2018: S137-S150.
86. Clapham S, Daveson BA, Allingham SF, et al. Patient-reported outcome measurement of symptom distress is feasible in most clinical scenarios in palliative care: an observational study

involving routinely collected data. *Int J Qual Health Care* 2021; 33 2021/04/29. DOI: 10.1093/intqhc/mzab075.
87. Eagar K, Gordon R, Green J, et al. An Australian casemix classification for palliative care: lessons and policy implications of a national study. *Palliative medicine* 2004; 18: 227-233. 2004/06/17.
88. Gott M and Ingleton C. Living with ageing and dying: international perspectives on end of life care for older people. *Oxford University Press: Oxford* 2011.
89. Burt J and Raine R. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. *Age Ageing* 2006; 35: 469-476. 2006/06/06. DOI: 10.1093/ageing/afl001.
90. Hunt KJ, Shlomo N and Addington-Hall J. End-of-life care and preferences for place of death among the oldest old: results of a population-based survey using VOICES-Short Form. *J Palliat Med* 2014; 17: 176-182. 2014/01/21. DOI: 10.1089/jpm.2013.0385.
91. Gardiner C, Cobb M, Gott M, et al. Barriers to providing palliative care for older people in acute hospitals. *Age Ageing* 2011; 40: 233-238. 2011/01/25. DOI: 10.1093/ageing/afq172.
92. Craigs CL, Bennett MI, Hurlow A, et al. Older age is associated with less cancer treatment: a longitudinal study of English cancer patients. *Age Ageing* 2018; 47: 833-840. DOI: 10.1093/ageing/afy094.
93. Marmot M, Allen, J., Boyce, T., Goldblatt, P., Morrison, J. *Health equity in England: The Marmot Review 10 years on.* London: Institute of Health Equity, 2020.
94. Black D. Inequalities in Health: Report of a Research Working Group. *London* 1980.
95. Bartley M. *Health Inequality: An introduction to theories, concepts and methods*. Cambridge: Polity, 2008.
96. Marmot M, Allen J, Bell R, et al. WHO European review of social determinants of health and the health divide. *The Lancet* 2012; 380: 1011-1029. DOI: 10.1016/S0140-6736(12)61228-8.
97. Marmot M. The health gap: The challenge of an unequal world. *The Lancet* 2015; 386: 2442-2444. Note. DOI: 10.1016/S0140-6736(15)00150-6.
98. Buck D and Maguire D. 2015. Inequalities in life expectancy: Changes over time and implications for policy. The King's Fund, available here https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/inequalities-in-life-expectancy-kings-fund-aug15.pdf accessed 07/07/2022.
99. Longevity Science Panel. 2018. Life expectancy: Is the socioeconomic gap narrowing? available here https://www.longevitypanel.co.uk/landg-assets/longevity-panel/lsp_report.pdf accessed 07/07/2022.
100. Michael Marmot JA, Peter Goldblatt, Eleanor Herd, Joana Morrison. *Build Back Fairer: The COVID-19 Marmot Review. The Pandemic, Socioeconomic and Health Inequalities in England*. London: Institute of Health Equity., 2020.
101. Lee A, Sinha I, Boyce T, et al. Fuel poverty, cold homes and health inequalities. London: Institute of Health Equity. . 2022.
102. Higginson IJ, Jarman B, Astin P, et al. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. *J Public Health Med* 1999; 21: 22-28. 1999/05/13.
103. Barratt H, Asaria M, Sheringham J, et al. Dying in hospital: socioeconomic inequality trends in England. *J Health Serv Res Policy* 2017: 1355819616686807. 2017/04/22. DOI: 10.1177/1355819616686807.
104. Sleeman KE, Leniz J, Davies JM, et al. 2022. Fairer Care at Home. The covid-19 pandemic: a stress test for palliative and end of life care in England. Research report. London (UK): Marie Curie. available from: https://www.mariecurie.org.uk/globalassets/media/documents/research/publications/beol-2022/h903a-beol-england.pdf accessed: 27/07/22.
105. Tudor Hart J. THE INVERSE CARE LAW. *The Lancet* 1971; 297: 405-412. DOI: 10.1016/S0140-6736(71)92410-X.

106. Hiscock R, Bauld L, Amos A, et al. Smoking and socioeconomic status in England: the rise of the never smoker and the disadvantaged smoker. *Journal of public health (Oxford, England)* 2012; 34: 390-396. 2012/03/01. DOI: 10.1093/pubmed/fds012.
107. Department of Health. 2008. End of Life Care Strategy: Equality Impact Assessment. available here:https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life accessed: 27.07.22.
108. Casla K. The socio-economic duty: A powerful idea hidden in plain sight in the Equality Act" (OxHRH Blog, 15 May 2019). available from: https://ohrh.law.ox.ac.uk/the-socio-economic-duty-a-powerful-idea-hidden-in-plain-sight-in-the-equality-act accessed: 27.07.22.
109. Borgstrom E and Walter T. Choice and compassion at the end of life: A critical analysis of recent English policy discourse. *Soc Sci Med* 2015; 136-137: 99-105. DOI: https://doi.org/10.1016/j.socscimed.2015.05.013.
110. Barr DA, Fenton L and Blane D. The claim for patient choice and equity. *J Med Ethics* 2008; 34: 271-274. 2008/04/01. DOI: 10.1136/jme.2006.019570.
111. Appleby J, Harrison A and Dewar S. Patients choosing their hospital. *BMJ* 2003; 326: 407-408. 2003/02/22. DOI: 10.1136/bmj.326.7386.407.
112. Hansford L, Thomas F and Wyatt K. Poverty, choice and dying in the UK: a call to examine whether public health approaches to palliative care address the needs of low-income communities. *Mortality* 2022: 1-17. DOI: 10.1080/13576275.2022.2044299.
113. NHS England. 2014. Actions for End of Life Care: 2014-16. available here: https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf accessed 27.07.22.
114. Care Quality Commission. 2016. A different ending: Addressing inequalities in end of life care. available here https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf accessed: 27.07.22.
115. National Palliative and End of Life Care Partnership. 2015. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. available here https://www.nationalvoices.org.uk/publications/our-publications/ambitions-palliative-and-end-life-care accessed: 27.07.22.
116. National Palliative and End of Life Care Partnership. 2021. Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. available here: https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/ accessed: 27.07.22.
117. Schrijvers CT, Stronks K, van de Mheen HD, et al. Explaining educational differences in mortality: the role of behavioral and material factors. *Am J Public Health* 1999; 89: 535-540. 1999/04/07. DOI: 10.2105/ajph.89.4.535.
118. Ploubidis GB, Benova L, Grundy E, et al. Lifelong Socio Economic Position and biomarkers of later life health: testing the contribution of competing hypotheses. *Soc Sci Med* 2014; 119: 258-265. 2014/03/19. DOI: 10.1016/j.socscimed.2014.02.018.
119. Marmot M. Social justice, epidemiology and health inequalities. *Eur J Epidemiol* 2017 2017/08/05. DOI: 10.1007/s10654-017-0286-3.
120. Marmot M. Achieving health equity: from root causes to fair outcomes. *Lancet* 2007; 370: 1153-1163. 2007/10/02. DOI: 10.1016/s0140-6736(07)61385-3.
121. World Health Organisation, Commission on the Social Determinants of Health. 2010. A conceptual framework for action on the social determinants of health: social determinants of health discussion paper 2.
122. Ben-Shlomo Y and Kuh D. A life course approach to chronic disease epidemiology: conceptual models, empirical challenges and interdisciplinary perspectives. *Int J Epidemiol* 2002; 31: 285-293. 2002/05/01.

123. Lynch JW, Smith GD, Kaplan GA, et al. Income inequality and mortality: importance to health of individual income, psychosocial environment, or material conditions. *BMJ* 2000; 320: 1200-1204. 2000/04/28.
124. Moor I, Spallek J and Richter M. Explaining socioeconomic inequalities in self-rated health: a systematic review of the relative contribution of material, psychosocial and behavioural factors. *J Epidemiol Community Health* 2017; 71: 565. DOI: 10.1136/jech-2016-207589.
125. Marmot MG, Stansfeld S, Patel C, et al. Health inequalities among British civil servants: the Whitehall II study. *The Lancet* 1991; 337: 1387-1393. DOI: 10.1016/0140-6736(91)93068-K.
126. Galea S, Tracy M, Hoggatt KJ, et al. Estimated deaths attributable to social factors in the United States. *Am J Public Health* 2011; 101: 1456-1465. 2011/06/18. DOI: 10.2105/ajph.2010.300086.
127. Tjepkema M, Wilkins R and Long A. Cause-specific mortality by income adequacy in Canada: A 16-year follow-up study. *Health Rep* 2013; 24: 14-22. 2013/11/22.
128. Aittomäki A, Martikainen P, Laaksonen M, et al. Household economic resources, labour-market advantage and health problems - a study on causal relationships using prospective register data. *Soc Sci Med* 2012; 75: 1303-1310. 2012/06/26. DOI: 10.1016/j.socscimed.2012.05.015.
129. Hill AB. The Environment and Disease: Association or Causation? *Proc R Soc Med* 1965; 58: 295-300.
130. Mitchell R, Blane D and Bartley M. Elevated risk of high blood pressure: climate and the inverse housing law. *Int J Epidemiol* 2002; 31: 831-838. DOI: 10.1093/ije/31.4.831.
131. Lloyd EL. The role of cold in ischaemic heart disease: a review. *Public Health* 1991; 105: 205-215. DOI: https://doi.org/10.1016/S0033-3506(05)80110-6.
132. Webb E, Blane D and de Vries R. Housing and respiratory health at older ages. *J Epidemiol Community Health* 2013; 67: 280-285. 2012/10/27. DOI: 10.1136/jech-2012-201458.
133. Finkelstein MM, Jerrett M, DeLuca P, et al. Relation between income, air pollution and mortality: a cohort study. *Can Med Assoc J* 2003; 169: 397.
134. Hart CL and Davey Smith G. Relation between number of siblings and adult mortality and stroke risk: 25 year follow up of men in the Collaborative study. *J Epidemiol Community Health* 2003; 57: 385-391. 2003/04/18.
135. Eusebi LH, Zagari RM and Bazzoli F. Epidemiology of Helicobacter pylori infection. *Helicobacter* 2014; 19 Suppl 1: 1-5. 2014/08/30. DOI: 10.1111/hel.12165.
136. Blane D, Bartley MEL and Smith GD. Disease aetiology and materialist explanations of socioeconomic mortality differentials. *Eur J Public Health* 1997; 7: 385-391. DOI: 10.1093/eurpub/7.4.385.
137. Olson CM, Bove CF and Miller EO. Growing up poor: long-term implications for eating patterns and body weight. *Appetite* 2007; 49: 198-207. 2007/04/20. DOI: 10.1016/j.appet.2007.01.012.
138. Munthali RJ, Manyema M, Said-Mohamed R, et al. Body composition and physical activity as mediators in the relationship between socioeconomic status and blood pressure in young South African women: a structural equation model analysis. *BMJ Open* 2018; 8: e023404. DOI: 10.1136/bmjopen-2018-023404.
139. Friel S, Chopra M and Satcher D. Unequal weight: equity oriented policy responses to the global obesity epidemic. *BMJ* 2007; 335: 1241-1243. 2007/12/15. DOI: 10.1136/bmj.39377.622882.47.
140. Room R, Babor T and Rehm J. Alcohol and public health. *Lancet* 2005; 365: 519-530. 2005/02/12. DOI: 10.1016/s0140-6736(05)17870-2.
141. MacLean L, Edwards N, Garrard M, et al. Obesity, stigma and public health planning. *Health Promot Int* 2009; 24: 88-93. DOI: 10.1093/heapro/dan041.
142. Siahpush M, McNeill A, Hammond D, et al. Socioeconomic and country variations in knowledge of health risks of tobacco smoking and toxic constituents of smoke: results from the 2002

International Tobacco Control (ITC) Four Country Survey. *Tob Control* 2006; 15: iii65. DOI: 10.1136/tc.2005.013276.
143. Steptoe A, Wardle J, Smith H, et al. Tobacco smoking in young adults from 21 European countries: association with attitudes and risk awareness. *Addiction* 1995; 90: 571-582. https://doi.org/10.1046/j.1360-0443.1995.90457111.x. DOI: https://doi.org/10.1046/j.1360-0443.1995.90457111.x.
144. Kuntsche E, Kuntsche S, Thrul J, et al. Binge drinking: Health impact, prevalence, correlates and interventions. *Psychol Health* 2017; 32: 976-1017. 2017/05/18. DOI: 10.1080/08870446.2017.1325889.
145. West R. Tobacco smoking: Health impact, prevalence, correlates and interventions. *Psychol Health* 2017; 32: 1018-1036. 2017/05/30. DOI: 10.1080/08870446.2017.1325890.
146. Koffman J, Burke G, Dias A, et al. Demographic factors and awareness of palliative care and related services. *Palliative medicine* 2007; 21: 145-153. 2007/03/09. DOI: 10.1177/0269216306074639.
147. Bird PK, Pickett KE, Graham H, et al. Income inequality and social gradients in children's height: a comparison of cohort studies from five high-income countries. *BMJ Paediatrics Open* 2019; 3: e000568. DOI: 10.1136/bmjpo-2019-000568.
148. Demakakos P, Biddulph JP, de Oliveira C, et al. Subjective social status and mortality: the English Longitudinal Study of Ageing. *Eur J Epidemiol* 2018; 33: 729-739. 2018/05/19. DOI: 10.1007/s10654-018-0410-z.
149. Hales S, Howden-Chapman P, Salmond C, et al. National infant mortality rates in relation to gross national product and distribution of income. *Lancet* 1999; 354: 2047. 2000/01/15. DOI: 10.1016/s0140-6736(99)03763-0.
150. Preston SH. The Changing Relation between Mortality and Level of Economic Development. *Population Studies* 1975; 29: 231-248. DOI: 10.2307/2173509.
151. Marmot M. Health in an unequal world: social circumstances, biology and disease. *Clin Med (Lond)* 2006; 6: 559-572. 2007/01/19. DOI: 10.7861/clinmedicine.6-6-559.
152. Hinterdobler J, Schott S, Jin H, et al. Acute mental stress drives vascular inflammation and promotes plaque destabilization in mouse atherosclerosis. *Eur Heart J* 2021; 42: 4077-4088. DOI: 10.1093/eurheartj/ehab371.
153. Guidi J, Lucente M, Sonino N, et al. Allostatic Load and Its Impact on Health: A Systematic Review. *Psychother Psychosom* 2021; 90: 11-27. 2020/08/18. DOI: 10.1159/000510696.
154. Szanton SL, Gill JM and Allen JK. Allostatic load: a mechanism of socioeconomic health disparities? *Biol Res Nurs* 2005; 7: 7-15. 2005/05/28. DOI: 10.1177/1099800405278216.
155. Marmot M and Wilkinson RG. Psychosocial and material pathways in the relation between income and health: a response to Lynch et al. *BMJ* 2001; 322: 1233-1236. DOI: 10.1136/bmj.322.7296.1233.
156. Marmot MG, Bosma H, Hemingway H, et al. Contribution of job control and other risk factors to social variations in coronary heart disease incidence. *Lancet* 1997; 350: 235-239. 1997/07/26.
157. Bosma H, Stansfeld SA and Marmot MG. Job control, personal characteristics, and heart disease. *J Occup Health Psychol* 1998; 3: 402-409. DOI: 10.1037/1076-8998.3.4.402.
158. Bosma H, Peter R, Siegrist J, et al. Two alternative job stress models and the risk of coronary heart disease. *Am J Public Health* 1998; 88: 68-74. 1998/05/16. DOI: 10.2105/ajph.88.1.68.
159. Steptoe A. Stress, social support and cardiovascular activity over the working day. *Int J Psychophysiol* 2000; 37: 299-308. 2000/06/20. DOI: 10.1016/s0167-8760(00)00109-4.
160. Ozbay F, Johnson DC, Dimoulas E, et al. Social support and resilience to stress: from neurobiology to clinical practice. *Psychiatry (Edgmont)* 2007; 4: 35-40. 2007/05/01.
161. Oksanen T, Kouvonen A, Kivimäki M, et al. Social capital at work as a predictor of employee health: multilevel evidence from work units in Finland. *Soc Sci Med* 2008; 66: 637-649. 2007/11/17. DOI: 10.1016/j.socscimed.2007.10.013.

162. Weyers S, Dragano N, Möbus S, et al. Low socio-economic position is associated with poor social networks and social support: results from the Heinz Nixdorf Recall Study. *International journal for equity in health* 2008; 7: 13. DOI: 10.1186/1475-9276-7-13.
163. Demakakos P, Chrousos GP and Biddulph JP. Childhood experiences of parenting and cancer risk at older ages: findings from the English Longitudinal Study of Ageing (ELSA). *Int J Public Health* 2018; 63: 823-832. DOI: 10.1007/s00038-018-1117-3.
164. Greer S and Joseph M. Palliative Care: A Holistic Discipline. *Integr Cancer Ther* 2015; 15: 5-9. DOI: 10.1177/1534735415617015.
165. Saunders C. The evolution of palliative care. *Patient Educ Couns* 2000; 41: 7-13. DOI: https://doi.org/10.1016/S0738-3991(00)00110-5.
166. Barker DJ. The fetal and infant origins of adult disease. *BMJ* 1990; 301: 1111. 1990/11/17. DOI: 10.1136/bmj.301.6761.1111.
167. Robinson R. The fetal origins of adult disease. *BMJ* 2001; 322: 375-376. 2001/02/17. DOI: 10.1136/bmj.322.7283.375.
168. Jefferis BJ, Power C and Hertzman C. Birth weight, childhood socioeconomic environment, and cognitive development in the 1958 British birth cohort study. *BMJ* 2002; 325: 305. 2002/08/10. DOI: 10.1136/bmj.325.7359.305.
169. Smith GD, Hart C, Blane D, et al. Lifetime socioeconomic position and mortality: prospective observational study. *BMJ* 1997; 314: 547. DOI: 10.1136/bmj.314.7080.547.
170. West P. Rethinking the health selection explanation for health inequalities. *Soc Sci Med* 1991; 32: 373-384. 1991/01/01.
171. Illsley R. Social class selection and class differences in relation to stillbirths and infant deaths. *Br Med J* 1955; 2: 1520-1524. 1955/12/24.
172. Lund C and Cois A. Simultaneous social causation and social drift: Longitudinal analysis of depression and poverty in South Africa. *J Affect Disord* 2018; 229: 396-402. DOI: https://doi.org/10.1016/j.jad.2017.12.050.
173. Stone J and Hirsch D. 2022. Poverty at the end of life in the UK. Marie Curie, available here: https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-poverty-at-the-end-of-life-in-the-uk-2nd-pp.pdf, accessed: 27.05.22.
174. Bartley M and Plewis I. Does health-selective mobility account for socioeconomic differences in health? Evidence from England and Wales, 1971 to 1991. *J Health Soc Behav* 1997; 38: 376-386. 1998/01/13.
175. Pickett KE and Wilkinson RG. Income inequality and health: a causal review. *Soc Sci Med* 2015; 128: 316-326. 2015/01/13. DOI: 10.1016/j.socscimed.2014.12.031.
176. Galobardes B, Lynch J and Smith GD. Measuring socioeconomic position in health research. *Br Med Bull* 2007; 81-82: 21-37. DOI: 10.1093/bmb/ldm001.
177. Oakes JM and Andrade KE. *The Measurement of Socioeconomic Status, in Methods in Social Epidemiology, 2nd Edition* Wiley, 2017.
178. Oakes JM and Rossi PH. The measurement of SES in health research: current practice and steps toward a new approach. *Soc Sci Med* 2003; 56: 769-784. 2003/02/01. DOI: 10.1016/s0277-9536(02)00073-4.
179. Spiers GF, Liddle JE, Stow D, et al. Measuring older people's socioeconomic position: a scoping review of studies of self-rated health, health service and social care use. *J Epidemiol Community Health* 2022; 76: 572. DOI: 10.1136/jech-2021-218265.
180. Grundy E and Holt G. The socioeconomic status of older adults: how should we measure it in studies of health inequalities? *J Epidemiol Community Health* 2001; 55: 895-904. 2001/11/15.
181. Singh-Manoux A CP, Marmot M. Multiple measures of socio-economic position and psychosocial health: proximal and distal measures. *Int J Epidemiol* 2002; 31.
182. Demakakos P, Biddulph JP, Bobak M, et al. Wealth and mortality at older ages: a prospective cohort study. *J Epidemiol Community Health* 2016; 70: 346-353. 2015/10/30. DOI: 10.1136/jech-2015-206173.

183. Huisman M, Kunst AE and Mackenbach JP. Socioeconomic inequalities in morbidity among the elderly; a European overview. *Soc Sci Med* 2003; 57: 861-873. 2003/07/10. DOI: 10.1016/s0277-9536(02)00454-9.
184. Hanratty B, Holmes L, Lowson E, et al. Older adults' experiences of transitions between care settings at the end of life in England: a qualitative interview study. *J Pain Symptom Manage* 2012; 44: 74-83. 2012/06/05. DOI: 10.1016/j.jpainsymman.2011.08.006.
185. Bone AE, Gao W, Gomes B, et al. Factors Associated with Transition from Community Settings to Hospital as Place of Death for Adults Aged 75 and Older: A Population-Based Mortality Follow-Back Survey. *J Am Geriatr Soc* 2016; 64: 2210-2217. 2016/09/09. DOI: 10.1111/jgs.14442.
186. Bone AE, Evans CJ, Etkind SN, et al. Factors associated with older people's emergency department attendance towards the end of life: a systematic review. *Eur J Public Health* 2019; 29: 67-74. 2018/11/28. DOI: 10.1093/eurpub/cky241.
187. Bach PB, Schrag D and Begg CB. Resurrecting Treatment Histories of Dead PatientsA Study Design That Should Be Laid to Rest. *JAMA* 2004; 292: 2765-2770. DOI: 10.1001/jama.292.22.2765.
188. Barnato AE and Lynn J. Resurrecting Treatment Histories of Dead Patients. *JAMA* 2005; 293: 1591-1592. DOI: 10.1001/jama.293.13.1591-b.
189. Davies JM, Gao W, Sleeman KE, et al. Using routine data to improve palliative and end of life care. *BMJ Support Palliat Care* 2016 2016/03/02. DOI: 10.1136/bmjspcare-2015-000994.
190. Handley MA, Lyles CR, McCulloch C, et al. Selecting and Improving Quasi-Experimental Designs in Effectiveness and Implementation Research. *Annu Rev Public Health* 2018; 39: 5-25. DOI: 10.1146/annurev-publhealth-040617-014128.
191. Morin L and Onwuteaka-Philipsen BD. The promise of big data for palliative and end-of-life care research. *Palliat Med* 2021; 35: 1638-1640. DOI: 10.1177/02692163211048307.
192. Wood A, Denholm R, Hollings S, et al. Linked electronic health records for research on a nationwide cohort of more than 54 million people in England: data resource. *BMJ* 2021; 373: n826. DOI: 10.1136/bmj.n826.
193. Nelson EC, Eftimovska E, Lind C, et al. Patient reported outcome measures in practice. *BMJ : British Medical Journal* 2015; 350: g7818. DOI: 10.1136/bmj.g7818.
194. NHS Digital. 20174. Patient Reported Outcome Measures (PROMs) in England. available from: https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/patient-reported-outcome-measures-proms/background-information-about-proms#what-statistics-are-published-and-when accessed: 30.03.22.
195. Guo P, Dzingina M, Firth AM, et al. Development and validation of a casemix classification to predict costs of specialist palliative care provision across inpatient hospice, hospital and community settings in the UK: a study protocol. *BMJ Open* 2018; 8: e020071. DOI: 10.1136/bmjopen-2017-020071.
196. MRC. Maximising the value of UK population cohorts: MRC Strategic Review of the Largest UK Population Cohort Studies. *Medical Research Council* 2014.
197. Tsakos G, Demakakos P, Breeze E, et al. Social gradients in oral health in older adults: findings from the English longitudinal survey of aging. *Am J Public Health* 2011; 101: 1892-1899. 2011/08/20. DOI: 10.2105/ajph.2011.300215.
198. Lacey RE, Cable N, Stafford M, et al. Childhood socio-economic position and adult smoking: are childhood psychosocial factors important? Evidence from a British birth cohort. *Eur J Public Health* 2011; 21: 725-731. 2010/12/07. DOI: 10.1093/eurpub/ckq179.
199. Bartley M, Power C, Blane D, et al. Birth weight and later socioeconomic disadvantage: evidence from the 1958 British cohort study. *BMJ* 1994; 309: 1475-1478. 1994/12/03.
200. Bartley M, Sacker A, Firth D, et al. Understanding social variation in cardiovascular risk factors in women and men: the advantage of theoretically based measures. *Soc Sci Med* 1999; 49: 831-845. 1999/08/25.

201. Cable N, Kelly Y, Bartley M, et al. Critical role of smoking and household dampness during childhood for adult phlegm and cough: a research example from a prospective cohort study in Great Britain. *BMJ Open* 2014; 4: e004807. 2014/04/22. DOI: 10.1136/bmjopen-2014-004807.
202. Thomson H, Thomas S, Sellstrom E, et al. Housing improvements for health and associated socio-economic outcomes. *The Cochrane database of systematic reviews* 2013; 2: Cd008657. 2013/03/02. DOI: 10.1002/14651858.CD008657.pub2.
203. Read S and Grundy E. Allostatic load and health in the older population of England: a crossed-lagged analysis. *Psychosom Med* 2014; 76: 490-496. 2014/08/26. DOI: 10.1097/psy.0000000000000083.
204. Read S, Grundy E and Wolf DA. Fertility history, health, and health changes in later life: a panel study of British women and men born 1923-49. *Popul Stud (Camb)* 2011; 65: 201-215. 2011/05/27. DOI: 10.1080/00324728.2011.572654.
205. Grundy E, Mayer D, Young H, et al. Living arrangements and place of death of older people with cancer in England and Wales: a record linkage study. *Br J Cancer* 2004; 91: 907-912. 2004/07/22. DOI: 10.1038/sj.bjc.6602038.
206. Sheena McHugh AM, Patricia Kearney, Rose-Anne Kenny, Charles Normand. Factors associated with place of death among older Irish adults: Results from the Irish longitudinal study on ageing *Ir J Med Sci* 2014; 1): S319.
207. Lorant V, Deliege D, Eaton W, et al. Socioeconomic inequalities in depression: a meta-analysis. *Am J Epidemiol* 2003; 157: 98-112. 2003/01/11.
208. Greenland S and Longnecker MP. Methods for trend estimation from summarized dose-response data, with applications to meta-analysis. *Am J Epidemiol* 1992; 135: 1301-1309. 1992/06/01.
209. Berlin JA, Longnecker MP and Greenland S. Meta-analysis of epidemiologic dose-response data. *Epidemiology* 1993; 4: 218-228. 1993/05/01.
210. Steptoe A, Breeze E, Banks J, et al. Cohort profile: the English longitudinal study of ageing. *Int J Epidemiol* 2013; 42: 1640-1648. 2012/11/13. DOI: 10.1093/ije/dys168.
211. Wang J and Wang X. *Structural Equation Modeling: Applications Using Mplus. Second edition.* UK: John Wiley & Sons, 2020.
212. Schumacker RL, R. A Beginner's Guide to Structural Equation Modelling, Third Edition. *Routledge: London* 2010.
213. Daniel RM, De Stavola BL, Cousens SN, et al. Causal mediation analysis with multiple mediators. *Biometrics* 2015; 71: 1-14. https://doi.org/10.1111/biom.12248. DOI: https://doi.org/10.1111/biom.12248.
214. Holland PW. CAUSAL INFERENCE, PATH ANALYSIS AND RECURSIVE STRUCTURAL EQUATIONS MODELS. *ETS Research Report Series* 1988; 1988: i-50. https://doi.org/10.1002/j.2330-8516.1988.tb00270.x. DOI: https://doi.org/10.1002/j.2330-8516.1988.tb00270.x.
215. Hernán MA. The C-Word: Scientific Euphemisms Do Not Improve Causal Inference From Observational Data. *Am J Public Health* 2018; 108: 616-619. DOI: 10.2105/AJPH.2018.304337.
216. Robins JM, Hernan MA and Brumback B. Marginal structural models and causal inference in epidemiology. *Epidemiology* 2000; 11: 550-560. 2000/08/24.
217. Li R, Daniel R and Rachet B. How much do tumor stage and treatment explain socioeconomic inequalities in breast cancer survival? Applying causal mediation analysis to population-based data. *Eur J Epidemiol* 2016; 31: 603-611. 2016/05/12. DOI: 10.1007/s10654-016-0155-5.
218. Preacher KJ and Hayes AF. Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behav Res Methods* 2008; 40: 879-891. DOI: 10.3758/BRM.40.3.879.
219. Lee RM, Draper M and Lee S. Social connectedness, dysfunctional interpersonal behaviors, and psychological distress: Testing a mediator model. American Psychological Association, 2001, p. 310-318.

220. Dawes P, Emsley R, Cruickshanks KJ, et al. Hearing Loss and Cognition: The Role of Hearing Aids, Social Isolation and Depression. *PLoS One* 2015; 10: e0119616. DOI: 10.1371/journal.pone.0119616.
221. Ploubidis GB and Grundy E. Health measurement in population surveys: combining information from self-reported and observer-measured health indicators. *Demography* 2011; 48: 699-724. 2011/04/21. DOI: 10.1007/s13524-011-0028-1.
222. Kelfve S, Wastesson J, Fors S, et al. Is the level of education associated with transitions between care settings in older adults near the end of life? A nationwide, retrospective cohort study. *Palliative medicine* 2018; 32: 366-375. 2017/09/28. DOI: 10.1177/0269216317726249.
223. Earle CC. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. *J Clin Oncol Off J Am Soc Clin Oncol* 2003; 21. DOI: 10.1200/jco.2003.03.059.
224. Walsh B and Laudicella M. Disparities In Cancer Care And Costs At The End Of Life: Evidence From England's National Health Service. *Health Aff (Millwood)* 2017; 36: 1218-1226. 2017/07/07. DOI: 10.1377/hlthaff.2017.0167.
225. Davies JM, Sleeman KE, Leniz J, et al. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. *PLoS Med* 2019; 16: e1002782-e1002782. DOI: 10.1371/journal.pmed.1002782.
226. Asaria M, Cookson R, Fleetcroft R, et al. Unequal socioeconomic distribution of the primary care workforce: whole-population small area longitudinal study. *BMJ Open* 2016; 6: e008783. DOI: 10.1136/bmjopen-2015-008783.
227. Brown L SA. Health survey for England 2016: social care for older adults. *Leeds: Health and Social Care Information Centre* 2017.
228. Syed ST, Gerber BS and Sharp LK. Traveling towards disease: transportation barriers to health care access. *J Community Health* 2013; 38: 976-993. 2013/04/02. DOI: 10.1007/s10900-013-9681-1.
229. Hughes A. Poverty and palliative care in the US: issues facing the urban poor. *Int J Palliat Nurs* 2005; 11: 6-13. 2005/03/08. DOI: 10.12968/ijpn.2005.11.1.17444.
230. Grande GE, Addington-Hall JM and Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998; 47: 565-579. 1998/08/05.
231. Murtagh FE, Ramsenthaler C, Firth A, et al. A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS). *Palliative medicine* 2019; 33: 1045-1057. 2019/06/13. DOI: 10.1177/0269216319854264.
232. Lloyd-Williams M, Shiels C, Dowrick C, et al. Socio-Economic Deprivation and Symptom Burden in UK Hospice Patients with Advanced Cancer—Findings from a Longitudinal Study. *Cancers (Basel)* 2021; 13: 2537.
233. Malhotra C, Krishnan A, Yong JR, et al. Socio-economic inequalities in suffering at the end of life among advanced cancer patients: results from the APPROACH study in five Asian countries. *International journal for equity in health* 2020; 19: 158. DOI: 10.1186/s12939-020-01274-5.
234. Delgado-Guay M, Ferrer J, Rieber AG, et al. Financial Distress and Its Associations With Physical and Emotional Symptoms and Quality of Life Among Advanced Cancer Patients. *Oncologist* 2015; 20: 1092-1098. 2015/07/25. DOI: 10.1634/theoncologist.2015-0026.
235. Popovic M, Lao N, Bedard G, et al. Quality of life in patients with advanced cancer using the functional assessment of cancer therapy-general assessment tool: A literature review. *World J Oncol* 2013; 4: 8-17.
236. Clarke P. Anderson MD. The Challenge of Palliative Care for Adolescents and Young Adults. *Evidence-Based Oncology* 2015; 21.
237. Cook KA and Bergeron K. Palliative care for young adults with life-limiting conditions: public health recommendations. *BMJ Supportive &amp; Palliative Care* 2020: bmjspcare-2019-002042. DOI: 10.1136/bmjspcare-2019-002042.

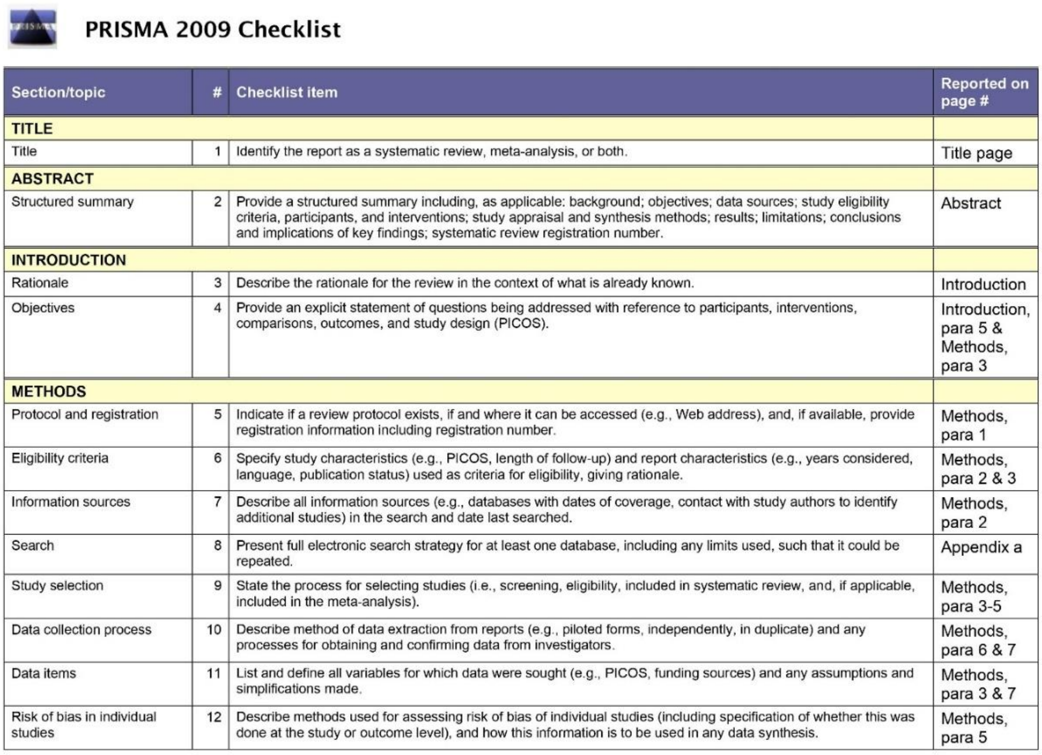
238. Cockle-Hearne J, Reed E, Todd J, et al. The dying parent and dependent children: a nationwide survey of hospice and community palliative care support services. *BMJ Supportive &amp; Palliative Care* 2020: bmjspcare-2019-001947. DOI: 10.1136/bmjspcare-2019-001947.
239. David McLennan SN, Michael Noble, Emma Plunkett, and Gutacker GWaN. The English Indices of Deprivation 2019, Technical report. *Ministry of Housing, Communities and Local Government* 2019.
240. Hoare S, Antunes B, Kelly MP, et al. End-of-life care quality measures: beyond place of death. *BMJ Supportive &amp; Palliative Care* 2022: spcare-2022-003841. DOI: 10.1136/spcare-2022-003841.
241. McCarthy M. Poor people view hospitals as providing better access, care, and social support. *BMJ : British Medical Journal* 2013; 347: f4556. DOI: 10.1136/bmj.f4556.
242. Public Health England Fingertips data, available from: https://fingertips.phe.org.uk/ accessed: 25/08/22.
243. Richard Cookson, Miqdad Asaria, Shehzad Ali, et al. Health Equity Indicators for the English NHS: a longitudinal whole- population study at the small-area level. *Health Serv Deliv Res 2016;4(26)*.
244. Ford J, Knight J, Brittain J, et al. Reducing inequality in avoidable emergency admissions: Case studies of local health care systems in England using a realist approach. *J Health Serv Res Policy* 2021; 27: 31-40. DOI: 10.1177/13558196211021618.
245. Richards N. The equity turn in palliative and end of life care research: Lessons from the poverty literature. *Sociology Compass* 2022; 16: e12969. https://doi.org/10.1111/soc4.12969. DOI: https://doi.org/10.1111/soc4.12969.
246. Rowley J, Richards N, Carduff E, et al. The impact of poverty and deprivation at the end of life: a critical review. *Palliat Care Soc Pract* 2021; 15: 26323524211033873. 2021/09/21. DOI: 10.1177/26323524211033873.
247. Luta X, Ottino B, Hall P, et al. Evidence on the economic value of end-of-life and palliative care interventions: a narrative review of reviews. *BMC Palliat Care* 2021; 20: 89. DOI: 10.1186/s12904-021-00782-7.
248. Ford J, Sowden S, Olivera J, et al. Transforming health systems to reduce health inequalities. *Future Healthc J* 2021; 8: e204-e209. DOI: 10.7861/fhj.2021-0018.
249. Cookson R, Griffin S, Norheim OF, et al. Distributional Cost-Effectiveness Analysis Comes of Age. *Value Health* 2021; 24: 118-120. DOI: https://doi.org/10.1016/j.jval.2020.10.001.
250. Avanceña ALV and Prosser LA. Examining Equity Effects of Health Interventions in Cost-Effectiveness Analysis: A Systematic Review. *Value Health* 2021; 24: 136-143. DOI: https://doi.org/10.1016/j.jval.2020.10.010.
251. French M, Keegan T, Anestis E, et al. Exploring socioeconomic inequities in access to palliative and end-of-life care in the UK: a narrative synthesis. *BMC Palliat Care* 2021; 20: 179. DOI: 10.1186/s12904-021-00878-0.
252. WHO. Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on the Social Determinants of Health. *Geneva, World Health Organisation* 2008.
253. Marie Curie. 2022. Dying in Poverty: Exploring poverty at the end of life in the UK, available here: https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-5th-pp.pdf, accessed: 27/05/22.
254. Moscrop A, Ziebland S, Bloch G, et al. If social determinants of health are so important, shouldn’t we ask patients about them? *BMJ* 2020; 371: m4150. DOI: 10.1136/bmj.m4150.
255. Arne Wolters, Filipe Santos, Therese Lloyd, et al. 2019. Emergency admissions to hospital from care homes: how often and what for? Improvement Analytics Unit briefing: The Health Foundation. available from: https://www.health.org.uk/publications/reports/emergency-admissions-to-hospital-from-care-homes accessed 30/06/22.
256. 2012. Changes to Output Areas and Super Output Areas in England and Wales, 2001 to 2011. Office for National Staistics. available here

https://www.ons.gov.uk/file?uri=/methodology/geography/ukgeographies/censusgeography/changestooutputareasandsuperoutputareas2001to2011tcm77288393.pdf accessed 30/06/22.
257. Office for National Statistics. 2018. Population estimates by output areas, electoral, health and other geographies, England and Wales: mid-2017. available from https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualsmallareapopulationestimates/previousReleases. Accessed 30/06/22.
258. Singh-Manoux A, Marmot MG and Adler NE. Does subjective social status predict health and change in health status better than objective status? *Psychosom Med* 2005; 67: 855-861. 2005/11/30. DOI: 10.1097/01.psy.0000188434.52941.a0.
259. de Souza JA, Yap BJ, Hlubocky FJ, et al. The development of a financial toxicity patient-reported outcome in cancer: The COST measure. *Cancer* 2014; 120: 3245-3253. DOI: 10.1002/cncr.28814.
260. Cyrus-David M. The validity and reliability of the Socioeconomic Status Instrument for assessing prostate cancer patients. *Cancer Epidemiol* 2010; 34: 382-387. DOI: https://doi.org/10.1016/j.canep.2010.04.020.
261. Davies JM, Maddocks M, Chua K-C, et al. Socioeconomic position and use of hospital-based care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing. *Lancet Public Health* 2021; 6: e155-e163. 2021/02/08. DOI: 10.1016/S2468-2667(20)30292-9.
262. Hanratty B, Jacoby A and Whitehead M. Socioeconomic differences in service use, payment and receipt of illness-related benefits in the last year of life: Findings from the British Household Panel Survey. *Palliat Med* 2008; 22: 248-255.
263. Grundy E, Mayer D, Young H, et al. Living arrangements and place of death of older people with cancer in England and Wales: a record linkage study. *Br J Cancer* 2004; 91: 907-912. Research Support, Non-U.S. Gov't.
264. Johnson MJ, Allgar V, Chen H, et al. The complex relationship between household income of family caregivers, access to palliative care services and place of death: A national household population survey. *Palliat Med* 2017: 269216317711825.
265. Best S, Tate T, Noble B, et al. RESEARCH PRIORITY SETTING IN PALLIATIVE AND END OF LIFE CARE: THE JAMES LIND ALLIANCE APPROACH CONSULTING PATIENTS, CARERS AND CLINICIANS. *BMJ Supportive &amp; Palliative Care* 2015; 5: 102. DOI: 10.1136/bmjspcare-2014-000838.3.
266. NatCen. The English Longitudinal Study of Ageing (ELSA), Wave 2 to Wave 6, User Guide to the End of Life interview dataset. *NatCen Social Research* 2015.
267. Nafilyan V, Morgan J, Butt A, et al. 2022. Suicides among people diagnosed with severe health conditions, England: 2017 to 2020. Office for National Statistics, available here: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplediagnosedwithseverehealthconditionsengland/2017to2020 accessed: 10/06/22.
268. 2007. Register-based statistics in the Nordic countries. Review of best practices with focus on population and social statistics. United Nations Economic Commission for Europe, available here: https://digitallibrary.un.org/record/609979?ln=en, accessed: 10/06/22.
269. Collins ES, Witt J, Bausewein C, et al. A Systematic Review of the Use of the Palliative Care Outcome Scale and the Support Team Assessment Schedule in Palliative Care. *J Pain Symptom Manage* 2015; 50: 842-853.e819. 2015/09/04. DOI: 10.1016/j.jpainsymman.2015.07.015.
270. Nicholson C, Davies JM, George R, et al. What are the main palliative care symptoms and concerns of older people with multimorbidity?—a comparative cross-sectional study using routinely collected Phase of Illness, Australia-modified Karnofsky Performance Status and Integrated Palliative Care Outcome Scale data. *Annals of Palliative Medicine* 2018: S164-S175.
271. Hussain JA, Koffman J and Bajwah S. Invited Editorials. *Palliat Med* 2021; 35: 810-813. DOI: 10.1177/02692163211012887.

272. Mathur R, Bhaskaran K, Chaturvedi N, et al. Completeness and usability of ethnicity data in UK-based primary care and hospital databases. *Journal of Public Health* 2014; 36: 684-692. DOI: 10.1093/pubmed/fdt116.
273. Christie B. Scotland introduces record of ethnicity on death certificates. *BMJ* 2012; 344: e475. DOI: 10.1136/bmj.e475.
274. Marie Curie website pages on the 'scrap the six months campaign', accessed here: https://www.mariecurie.org.uk/policy/campaigns/scrapsixmonths on: 20/02/22.
275. 2020. The vicious cycle of fuel poverty and terminal illness. Marie Curie Cancer Care, available here: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2020/fuel-poverty-and-terminal-illness.pdf accessed: 19/02/22.
276. Richards N, Quinn S, Mitchell M, et al. The viability and appropriateness of using visual methods in end of life research to foreground the experiences of people affected by financial hardship and deprivation. *Palliative medicine* 2023: 2692163221146590. 20230106. DOI: 10.1177/02692163221146590.
277. Koffman J, Bajwah S, Davies JM, et al. Researching minoritised communities in palliative care: An agenda for change. *Palliat Med* 2022: 02692163221132091. DOI: 10.1177/02692163221132091.
278. Bajwah S, Oluyase AO, Yi D, et al. The effectiveness and cost-effectiveness of hospital-based specialist palliative care for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews* 2020. DOI: 10.1002/14651858.CD012780.pub2.
279. Asaria M, Griffin S and Cookson R. Distributional Cost-Effectiveness Analysis: A Tutorial. *Med Decis Making* 2015; 36: 8-19. DOI: 10.1177/0272989X15583266.
280. Andermann A. Taking action on the social determinants of health in clinical practice: a framework for health professionals. *CMAJ* 2016; 188: E474-e483. 2016/08/10. DOI: 10.1503/cmaj.160177.
281. Drinkwater C, Wildman J and Moffatt S. Social prescribing. *BMJ* 2019; 364: l1285. 2019/03/30. DOI: 10.1136/bmj.l1285.
282. Vanderstichelen S, Dury S, De Gieter S, et al. Researching Compassionate Communities from an interdisciplinary perspective: the case of the Compassionate Communities Centre of Expertise (COCO). *Gerontologist* 2022 2022/03/10. DOI: 10.1093/geront/gnac034.
283. Brcic V, Eberdt C and Kaczorowski J. Development of a tool to identify poverty in a family practice setting: a pilot study. *Int J Family Med* 2011; 2011: 812182. 2012/02/09. DOI: 10.1155/2011/812182.
284. Andermann A. Screening for social determinants of health in clinical care: moving from the margins to the mainstream. *Public Health Rev* 2018; 39: 19. 2018/07/07. DOI: 10.1186/s40985-018-0094-7.
285. Ipsos. 2022. Public perceptions of health and social care polling (Wave 1: Nov –Dec, 2021). Conducted by Ipsos for the Health Foundation. available here https://www.health.org.uk/publications/public-perceptions-of-health-and-social-care-november-december-2021 accessed 30/06/22.
286. Dearing ES and Pegram E. 2019. The Departure Lounge 11th May - 7th June 2019 Evaluation Report. available from https://acmedsci.ac.uk/policy/policy-projects/the-departure-lounge accessed 30/06/22.
287. Emilie L'Hôte, Maria Castellina, Andrew Volmert, et al. 2022. A Matter of Life and Death: Explaining the Wider Determinants of Health in the UK. A FrameWorks Strategic Brief Commissioned by the Health Foundation. available here https://www.health.org.uk/publications/a-matter-of-life-or-death. Accessed 30/06/22.
288. Rebecca Benson, Bobby Duffy, Rachel Hesketh, et al. 2021. Attitudes to inequalities. IFS Deaton Review of Inequalities. available here https://ifs.org.uk/inequality/attitudes-to-inequalities/ accessed 30/06/22.

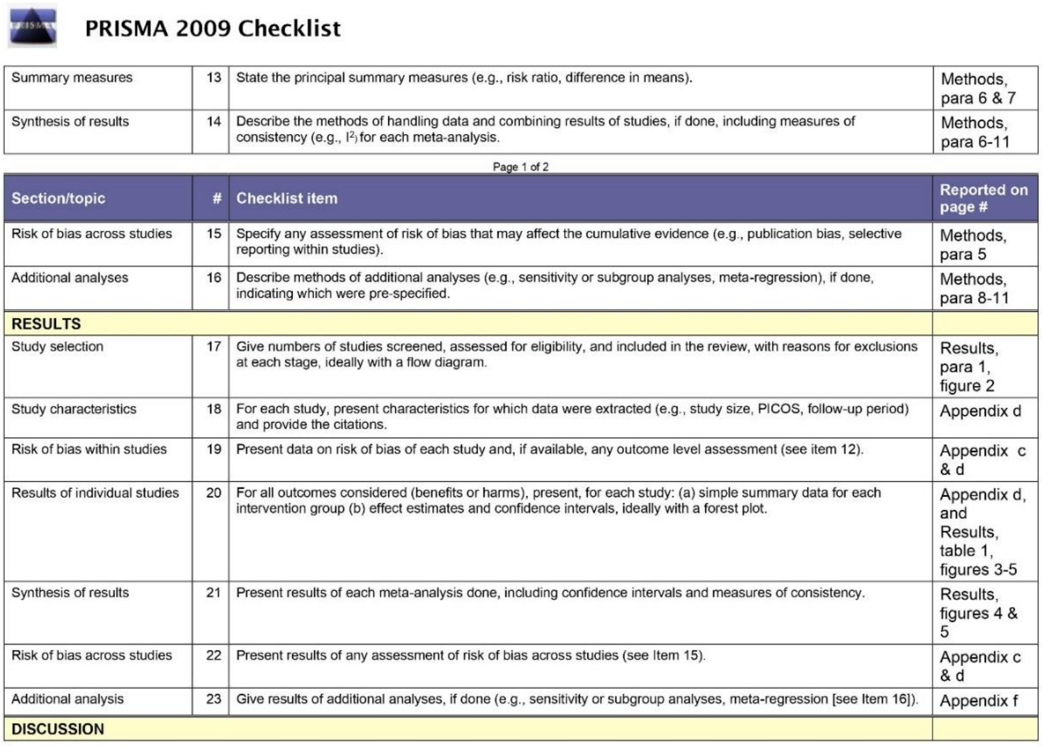
Appendix

Appendix 1: Paper 1, supplementary information



PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Title page
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Abstract
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Introduction
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Introduction, para 5 & Methods, para 3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Methods, para 1
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Methods, para 2 & 3
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Methods, para 2
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix a
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Methods, para 3-5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Methods, para 6 & 7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Methods, para 3 & 7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Methods, para 5



PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Methods, para 6 & 7
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	Methods, para 6-11
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Methods, para 5
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Methods, para 8-11
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Results, para 1, figure 2
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Appendix d
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Appendix c & d
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Appendix d, and Results, table 1, figures 3-5
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Results, figures 4 & 5
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Appendix c & d
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Appendix f
DISCUSSION			

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Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Discussion, para 1
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Discussion, para 7
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Discussion, para 1-6
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Declarations

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

S2 Text. Search terms

Subject headings for each database were combined with the key word terms in the table below. Items within columns were combined using OR, the three columns (population, exposure, study type) were combined using AND.

Database	Population	Exposure	Study type
MEDLINE	Exp Palliative Care/ Exp Terminal Care/ Exp Terminally Ill/ Exp Hospices/	Exp Socioeconomic Factors/ Exp Residence Characteristics/	Exp Registries/
EMBASE	Exp cancer palliative therapy/ Exp terminal care/ Exp terminally ill patient/ Exp hospice/	Exp social status/ Exp socioeconomics/ Exp social welfare/	Exp Registration/
PsycINFO	Exp Palliative care/ Exp Hospice/ Exp Terminally Ill Patients/	Exp socioeconomic status/ Exp disadvantaged/ Exp Economic security/ Exp "INCOME (ECONOMIC)"/ Exp Income Level/ Exp Poverty/	[no appropriate subject headings]
CINAHL	(MH "Terminal Care+") (MH "Terminally Ill Patients+") (MM "Hospice and Palliative Nursing") (MM "Hospices")	(MH "Socioeconomic Factors+") (MM "Social Determinants of Health")	(MH "Registries, Disease")

ASSIA	SU.EXACT("Palliative care") SU.EXACT("palliative medicine") SU.EXACT("terminal care") SU.EXACT("terminal illness") SU.EXACT("terminally ill people") SU.EXACT("hospices")	SU.EXACT("Economic conditions") SU.EXACT("Deprivation") SU.EXACT("Welfare benefits")	

Keywords for OVID (MEDLINE, EMBASE, PsychINFO)		
Population	**Exposure**	**Study type**
palliat*.tw	Soci*.tw	epidemiolog*.tw
terminal*.tw	**adj2**	cross?section*.tw
eol*.tw	Positi*.tw	cross section*.tw
end of life.tw	clas*.tw	cohort*.tw
end?of?life.tw	stat*.tw	survey*.tw
hospice*.tw	group*.tw	observational*.tw
dying*.tw	strat*.tw	retrospectiv*.tw
supportive care*.tw	differenc*.tw	prospective*.tw
life?limit*.tw	disparit*.tw	routine?data.tw
life limit*.tw	benefit*.tw	routine data.tw
inoperable*.tw		population?based.tw
incurable*.tw	occupat*.tw	population based.tw
	employment*.tw	
advanc*.tw	level **adj2** education*.tw	registr*.tw
progressiv*.tw	literate*.tw	**adj2**
agressiv*.tw	literac*.tw	cancer.tw
end.tw	income*.tw	death.tw
adj2	low?income*.tw	disease.tw
diagnos*.tw	low income*.tw	national.tw

diseas*.tw illnes*.tw cancer*.tw malignan*.tw stage*.tw dementia*.tw failure*.tw heart*.tw last **adj3** life.tw	socio?econ*.tw socio econ*.tw socio demograph*.tw socio?demograph*.tw depriv*.tw under?privileg*.tw under privileg*.tw pover*.tw inequalit*.tw inequit*.tw welfare*.tw insurance*.tw medicaid*.tw carstairs*.tw townsend*.tw jarman.tw area **adj2** residence.tw post?code.tw post code.tw neighbourhood*.tw	central.tw regional.tw population*.tw **adj2** study*.tw sample*.tw data*.tw design*.tw based.tw linked **adj3** data.tw administrative.tw **adj2** data.tw record*.tw
Keywords for CINAHL		
Population	**Exposure**	**Study type**
TI palliat* OR AB palliat*	TI Soci* OR AB Soci* **N2**	TI epidemiolog* OR AB epidemiolog*

TI terminal* OR AB terminal* TI eol* OR AB eol* TI end of life OR AB end of life TI end#of#life OR AB end#of#life TI hospice* OR AB hospice* TI dying* OR AB dying* TI supportive care* OR AB supportive care* TI life#limit* OR AB life#limit* TI life limit* OR AB life limit* TI inoperable* OR AB inoperable* TI incurable* OR AB incurable* TI advanc* OR AB advanc* TI progressiv* OR AB progressiv* TI agressiv* OR AB agressiv* TI end OR AB end **N2** TI diagnos* OR AB diagnos* TI diseas* OR AB diseas* TI illnes* OR AB illnes*	TI Positi* OR AB Positi* TI clas* OR AB clas* TI stat* OR AB stat* TI group* OR AB group* TI strat* OR AB strat* TI differenc* OR AB differenc* TI disparit* OR AB disparit* TI benefit* OR AB benefit* TI occupat* OR AB occupat* TI employment* OR AB employment* TI literate* OR AB literate* TI literac* OR AB iterac* TI income* OR AB income* TI low#income* OR AB low#income* TI low income* OR AB low income* TI socio#econ* OR AB socio#econ* TI socio econ* OR AB socio econ* TI socio demograph* OR AB socio demograph* TI socio#demograph* OR AB socio#demograph* TI depriv* OR AB depriv* TI under#privileg* OR AB under#privileg* TI under privileg* OR AB under privileg* TI pover* OR AB pover* TI inequalit* OR AB inequalit*	TI cross#section* OR AB cross#section* TI cross section* OR AB cross section* TI cohort* OR AB cohort* TI survey* OR AB survey* TI observational* OR AB observational* TI retrospectiv* OR AB retrospectiv* TI prospective* OR AB prospective* TI routine#data OR AB routine#data TI routine data OR AB routine data TI population#based OR AB population#based TI population based OR AB population based TI registr* OR AB registr* **N2** TI cancer OR AB cancer TI Death OR AB Death TI disease OR AB disease TI national OR AB national TI central OR AB central TI regional OR AB regional TI population* OR AB population* **N2** TI study* OR AB study*

TI cancer* OR AB cancer* TI malignan* OR AB malignan* TI stage* OR AB stage* TI dementia* OR AB dementia* TI failure* OR AB failure* TI heart* OR AB heart* TI last OR AB last **N3** TI life* OR AB life*	TI inequit* OR AB inequit* TI welfare* OR AB welfare* TI insurance* OR AB insurance* TI medicaid* OR AB medicaid* TI carstairs* OR AB carstairs* TI townsend* OR AB townsend* TI jarman OR AB jarman TI post#code OR AB post#code TI post code OR AB post code TI neighbourhood* OR AB neighbourhood* TI level OR AB level **N2** TI Education* OR AB Education* TI area OR AB area **N2** TI residence OR AB residence	TI sample* OR AB sample* TI data* OR AB data* TI design* OR AB design* TI based OR AB based TI linked OR AB linked **N3** TI data OR AB data TI administrative OR AB administrative **N2** TI data OR AB data TI record* OR AB record*

Search terms for ASSIA

(((SU.EXACT("Palliative care") OR SU.EXACT("palliative medicine") OR SU.EXACT("terminal care") OR SU.EXACT("terminal illness") OR SU.EXACT("terminally ill people") OR SU.EXACT("hospices")) OR (ab,ti(palliat*) OR ab,ti(terminal*) OR ab,ti(eol*) OR ab,ti(end of life) OR ab,ti(end?of?life) OR ab,ti(hospice*) OR ab,ti(dying*) OR ab,ti(supportive care*) OR ab,ti(life?limit*) OR ab,ti(life limit*) OR ab,ti(inoperable*) OR ab,ti(incurable*)) OR ((ab,ti(advanc*) OR ab,ti(progressiv*) OR ab,ti(agressiv*) OR ab,ti(end))

WITHIN 2 (ab,ti(diagnos*) OR ab,ti(diseas*) OR ab,ti(illnes*) OR ab,ti(cancer*) OR ab,ti(malignan*) OR ab,ti(stage*) OR ab,ti(dementia*) OR ab,ti(failure*) OR ab,ti(heart*))) OR (ab,ti(last) WITHIN 3 ab,ti(life))) AND ((SU.EXACT("Economic conditions") OR SU.EXACT("Deprivation") OR SU.EXACT("Welfare benefits")) OR (ab,ti(Soci*) WITHIN 2 (ab,ti(positi*) OR ab,ti(clas*) OR ab,ti(stat*) OR ab,ti(group*) OR ab,ti(strat*) OR ab,ti(differenc*) OR ab,ti(disparit*) OR ab,ti(benefit*))) OR (ab,ti(occupat*) OR ab,ti(employment*)) OR (ab,ti(level) WITHIN 2 ab,ti(education)) OR (ab,ti(literate*) OR ab,ti(literac*) OR ab,ti(income*) OR ab,ti(low?income*) OR ab,ti(low income*) OR ab,ti(socio?econ*) OR ab,ti(socio econ*) OR ab,ti(socio demograph*) OR ab,ti(socio?demograph*) OR ab,ti(depriv*) OR ab,ti(under privileg*) OR ab,ti(under?privileg*) OR ab,ti(pover*) OR ab,ti(inequalit*) OR ab,ti(inequit*) OR ab,ti(welfare*) OR ab,ti(insurance*) OR ab,ti(Medicaid*) OR ab,ti(carstairs*) OR ab,ti(townsend*) OR ab,ti(jarman*) OR ab,ti(post?code) OR ab,ti(post code) OR ab,ti(neighbourhood)) OR (ab,ti(area) WITHIN 2 ab,ti(residence))) AND ((ab, ti(epidemiolog*) OR ab,ti(cross?section*) OR ab,ti(cross section*) OR ab,ti(cohort*) OR ab,ti(survey*) OR ab,ti(observational*) OR ab,ti(retrospective*) OR ab,ti(prospective*) OR ab,ti(routine?data) OR ab,ti(routine data) OR ab,ti(population based) OR ab,ti(population?based)) OR (ab,ti(population*) WITHIN 2 (ab,ti(study*) OR ab,ti(sample*) OR ab,ti(data*) OR ab,ti(based) OR ab,ti(design*))) OR (ab,ti(registr*) WITHIN 2 (ab,ti(cancer) OR ab,ti(death) OR ab,ti(disease) OR ab,ti(national) OR ab,ti(central) OR ab,ti(regional))) OR (ab,ti(linked) WITHIN 3 ab,ti(data)) OR (ab,ti(administrative) WITHIN 2 (ab,ti(data) OR ab,ti(record)))))

S4 Text. Reference list for the 97 low quality studies, by outcome category

Place of death: [1-34]

Acute care: [35-42]

Specialist palliative care: [43-71]

Non-specialist palliative care: [72-74]

Advance care planning: [75-86]

Quality of care: [87-97]

References

1. Alonso-Babarro A, Bruera E, Varela-Cerdeira M, et al. Can this patient be discharged home? Factors associated with at-home death among patients with cancer. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2011;29(9):1159-1167.
2. Alturki A, Gagnon B, Petrecca K, et al. Patterns of care at end of life for people with primary intracranial tumors: lessons learned. Journal of Neuro-Oncology. 2014;117(1):103-115.
3. Babazono A, Weiner J, Hamada H, et al. Health policy in transition: terminal care and site of death in Japan. Journal of Health Services & Research Policy. 1998;3(2):77-81.
4. Barbera L, Paszat L, Qiu F. End-of-life care in lung cancer patients in Ontario: Aggressiveness of care in the population and a description of hospital admissions. Journal of Pain and Symptom Management. 2008;35(3):267-274.
5. Bescos Oros M, Parra Moncasi P, Coria Balanzat M, et al. Determinants of the place of death for terminal cancer patients recruited in a home care support team program in Huesca province. [Spanish]. Medicina Paliativa. 2009;16(2):89-94.
6. Burge F, Lawson B, Johnston G. Trends in the place of death of cancer patients, 1992-1997. CMAJ Canadian Medical Association Journal. 2003;168(3):265-270.
7. Cantwell P, Turco S, Brenneis C, et al. Predictors of home death in palliative care cancer patients. J Palliat Care. 2000;16(1):23-28.
8. Cardenas-Turanzas M, Grimes RM, Bruera E, et al. Clinical, sociodemographic, and local system factors associated with a hospital death among cancer patients. Supportive Care in Cancer. 2006;14(1):71-77.
9. Catalan-Fernandez JG, Pons-Sureda O, Recober-Martinez A, et al. Dying of cancer. The place of death and family circumstances. Medical Care. 1991;29(9):841-852.
10. Chambaere K, Rietjens JA, Cohen J, et al. Is educational attainment related to end-of-life decision-making? A large post-mortem survey in Belgium. BMC Public Health. 2013;13:1055.
11. Choo SY, Lee SY, Kim CW, et al. Educational differences in health care utilization in the last year of life among South Korean cancer patients. [Korean]. Journal of preventive medicine and public health = Yebang Uihakhoe chi. 2007;40(1):36-44.
12. Daneault S, Labadie JF. Terminal HIV disease and extreme poverty: a review of 307 home care files. Journal of Palliative Care. 1999;15(1):6-12.
13. Davison D, Johnston G, Reilly P, et al. Where do patients with cancer die in Belfast? Irish Journal of Medical Science. 2001;170(1):18-23.
14. De Conno F, Caraceni A, Groff L, et al. Effect of home care on the place of death of advanced cancer patients. European Journal of Cancer. 1996;32A(7):1142-1147.
15. Escobar Pinzon LC, Claus M, Zepf KI, et al. [Dying in Rhineland-Palatinate (Germany): preferred and actual place of death]. Gesundheitswesen. 2013;75(12):853-858.
16. Hank K, Jurges H. The last year of life in Europe: Regional variations in functional status and sources of support. Ageing & Society. 2010;30(6):1041-1054.
17. Houttekier D, Reyniers T, Deliens L, et al. Dying in hospital with dementia and pneumonia: A nationwide study using death certificate data. Gerontology. 2014;60(1):31-37.

18. Howell DM, Abernathy T, Cockerill R, et al. Predictors of home care expenditures and death at home for cancer patients in an integrated comprehensive palliative home care pilot program. Healthcare Policy = Politiques de sante. 2011;6(3):e73-92.
19. Huang YC, Huang SJ, Ko WJ. Going home to die from surgical intensive care units. Intensive Care Medicine. 2009;35(5):810-815.
20. Jordhoy MS, Saltvedt I, Fayers P, et al. Which cancer patients die in nursing homes? Quality of life, medical and sociodemographic characteristics. Palliative Medicine. 2003;17(5):433-444.
21. Karlsen S, Addington-Hall J. How do cancer patients who die at home differ from those who die elsewhere? Palliative Medicine. 1998;12(4):279-286.
22. Klinkenberg M, Visser G, van Groenou MI, et al. The last 3 months of life: care, transitions and the place of death of older people. Health Soc Care Community. 2005;13(5):420-430.
23. Lee LC, Hu CC, Loh el W, et al. Factors affecting the place of death among hospice home care cancer patients in Taiwan. American Journal of Hospice & Palliative Medicine. 2014;31(3):300-306.
24. Leemans K, Van den Block L, Bilsen J, et al. Dying at home in Belgium: a descriptive GP interview study. BMC Family Practice. 2012;13:4.
25. Maida V. Factors that promote success in home palliative care: a study of a large suburban palliative care practice. J Palliat Care. 2002;18(4):282-286.
26. McCusker J. Where cancer patients die: an epidemiologic study. Public Health Reports. 1983;98(2):170-176.
27. Pritchard RS, Fisher ES, Teno JM, et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. Journal of the American Geriatrics Society. 1998;46(10):1242-1250.
28. Reich O, Signorell A, Busato A. Place of death and health care utilization for people in the last 6 months of life in Switzerland: a retrospective analysis using administrative data. BMC Health Services Research. 2013;13:116.
29. Salomon S, Chuang E, Bhupali D, et al. Race/Ethnicity as a Predictor for Location of Death in Patients With Acute Neurovascular Events. American Journal of Hospice & Palliative Medicine. 2017:1049909116687258.
30. Sims A, Radford J, Doran K, et al. Social class variation in place of cancer death. Palliative Medicine. 1997;11(5):369-373.
31. Taylor JS, Zhang N, Meyer L, et al. When more is less: End-of-life disparities among ovarian cancer patients. Journal of Clinical Oncology Conference. 2016;34(no pagination).
32. Temkin-Greener H, Mukamel DB. Predicting place of death in the program of all-inclusive care for the elderly (PACE): participant versus program characteristics. Journal of the American Geriatrics Society. 2002;50(1):125-135.
33. Fukui S, Fujita J, Tsujimura M, et al. Predictors of home death of home palliative cancer care patients: a cross-sectional nationwide survey. Int J Nurs Stud. 2011;48(11):1393-1400.
34. Ziwary SR, Samad D, Johnson CD, et al. Impact of place of residence on place of death in Wales: an observational study. BMC Palliat Care. 2017;16(1):72.
35. Fulton AT, Gozalo P, Mitchell SL, et al. Intensive care utilization among nursing home residents with advanced cognitive and severe functional impairment. Journal of Palliative Medicine. 2014;17(3):313-317.
36. Gessert CE, Haller IV, Kane RL, et al. Rural-Urban Differences in Medical Care for Nursing Home Residents with Severe Dementia at the End of Life. Journal of the American Geriatrics Society. 2006;54(8):1199-1205.
37. Hanratty B, Jacoby A, Whitehead M. Socioeconomic differences in service use, payment and receipt of illness-related benefits in the last year of life: Findings from the British Household Panel Survey. Palliative Medicine. 2008;22(3):248-255.
38. Henson LA, Gomes B, Koffman J, et al. Factors associated with aggressive end of life cancer care. Supportive Care in Cancer. 2016;24(3):1079-1089.
39. Kwok AC, Semel ME, Lipsitz SR, et al. The intensity and variation of surgical care at the end of life: A retrospective cohort study. The Lancet. 2011;378(9800):1408-1413.
40. Matter-Walstra KW, Achermann R, Rapold R, et al. Days spent in acute care hospitals at the end of life of cancer patients in four Swiss cantons: a retrospective database study (SAKK 89/09). European Journal of Cancer Care. 2016;9:9.

41. Smith AK, McCarthy E, Weber E, et al. Half of older Americans seen in emergency department in last month of life; most admitted to hospital, and many die there. Health affairs (Project Hope). 2012;31(6):1277-1285.

42. Zheng NT, Mukamel DB, Friedman B, et al. The Effect of Hospice on Hospitalizations of Nursing Home Residents. Journal of the American Medical Directors Association. 2015;16(2):155-159.

43. Addington-Hall J, Altmann D. Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses? Journal of Advanced Nursing. 2000;32(4):799-806.

44. Bergman J, Kwan L, Fink A, et al. Hospice and emergency room use by disadvantaged men dying of prostate cancer. Journal of Urology. 2009;181(5):2084-2089.

45. Bhatraju P, Friedenberg AS, Uppal A, et al. Factors associated with utilization of an inpatient palliative care consultation service in an urban public hospital. American Journal of Hospice & Palliative Medicine. 2014;31(6):641-644.

46. Chen H, Haley WE, Robinson BE, et al. Decisions for hospice care in patients with advanced cancer. Journal of the American Geriatrics Society. 2003;51(6):789-797.

47. Chen LF, Chang CM, Huang CY. Home-Based Hospice Care Reduces End-of-Life Expenditure in Taiwan: A Population-Based Study. Medicine. 2015;94(38):e1613.

48. Conner NE. Predictive factors of hospice use among Blacks: applying Andersen's Behavioral Model. American Journal of Hospice & Palliative Medicine. 2012;29(5):368-374.

49. Currow DC, Agar M, Sanderson C, et al. Populations who die without specialist palliative care: does lower uptake equate with unmet need? Palliative Medicine. 2008;22(1):43-50.

50. Grande GE, McKerral A, Todd CJ. Which cancer patients are referred to hospital at home for palliative care? Palliative Medicine. 2002;16(2):115-123.

51. Gray JD, Forster DP. Factors associated with utilization of specialist palliative care services: a population based study. Journal of Public Health Medicine. 1997;19(4):464-469.

52. Greiner K, Perera S, Ahluwalia JS. Hospice Usage by Minorities in the Last Year of Life: Results from the National Mortality Followback Survey. Journal of the American Geriatrics Society. 2003;51(7):970-978.

53. Hunt RW, Fazekas BS, Luke CG, et al. The coverage of cancer patients by designated palliative services: a population-based study, South Australia, 1999. Palliative Medicine. 2002;16(5):403-409.

54. Huo J, Du XL, Lairson DR, et al. Utilization of surgery, chemotherapy, radiation therapy, and hospice at the end of life for patients diagnosed with metastatic melanoma. American Journal of Clinical Oncology. 2015;38(3):235-241.

55. Kao YH, Chiang JK. Effect of hospice care on quality indicators of end-of-life care among patients with liver cancer: a national longitudinal population-based study in Taiwan 2000-2011. BMC Palliative Care. 2015;14:39.

56. Lackan NA, Freeman JL, Goodwin JS. Hospice use by older women dying with breast cancer between 1991 and 1996. Journal of Palliative Care. 2003;19(1):49-53.

57. Lackan NA, Ostir GV, Freeman JL, et al. Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. Medical Care. 2004;42(2):116-122.

58. Mukamel DB, Caprio T, Ahn R, et al. End-of-life quality-of-care measures for nursing homes: place of death and hospice. Journal of Palliative Medicine. 2012;15(4):438-446.

59. O'Connor TL, Ngamphaiboon N, Groman A, et al. Hospice utilization and end-of-life care in metastatic breast cancer patients at a comprehensive cancer center. Journal of Palliative Medicine. 2015;18(1):50-55.

60. Riggs A, Breuer B, Dhingra L, et al. Hospice Enrollment After Referral to Community-Based, Specialist-Level Palliative Care: Incidence, Timing, and Predictors. Journal of Pain & Symptom Management. 2016;52(2):170-177.

61. Saito AM, Landrum MB, Neville BA, et al. Hospice care and survival among elderly patients with lung cancer. Journal of Palliative Medicine. 2011;14(8):929-939.

62. Schneider M, Zulian GB. Length of stay in palliative care. An observational study. Revue Internationale Francophone de Soins Palliatifs. 2013;28(3):175-180.

63. De Schreye R, Smets T, Annemans L, et al. Applying quality indicators for administrative databases to evaluate end-of-life care for cancer patients in Belgium. Health Aff (Millwood). 2017;36(7):1234-1243.

64. Seaman JB, Bear TM, Documet PI, et al. Hospice and Family Involvement With End-of-Life Care: Results From a Population-Based Survey. American Journal of Hospice & Palliative Medicine. 2016;33(2):130-135.
65. Taylor JS, Brown AJ, Prescott LS, et al. How equal is end-of-life care among gynecologic oncology patients? Gynecologic Oncology. 2015;137:194-195.
66. Teno JM, Kuo S, Gozalo P, et al. Does hospice improve the quality of care for persons dying with dementia? Palliative Medicine. 2010;1):S44.
67. Virnig BA, Kind S, McBean M, et al. Geographic variation in hospice use prior to death. Journal of the American Geriatrics Society. 2000;48(9):1117-1125.
68. Zapka JG, Carter R, Carter CL, et al. Care at the end of life: focus on communication and race. Journal of Aging & Health. 2006;18(6):791-813.
69. Abernethy AP, Currow DC, Fazekas BS. Specialist palliative care needs of whole populations: a feasibility study using a novel approach. Palliative Medicine. 2004;18(3):239-247.
70. Chiang JK, Lee YC, Kao YH. Trend analysis of end-of-life care between hospice and nonhospice groups of cancer patients in Taiwan for 2002-11. Medicine. 2017;96(34):e7825.
71. Zou WY, El-Serag HB, Sada YH, et al. Determinants and Outcomes of Hospice Utilization Among Patients with Advance-Staged Hepatocellular Carcinoma in a Veteran Affairs Population. Dig Dis Sci. 2018;63(5):1173-1181.
72. Cai J, Guerriere DN, Zhao H, et al. Socioeconomic differences in and predictors of home-based palliative care health service use in Ontario, Canada. Int J Environ Res Public Health. 2017;14 (7) (no pagination)(802).
73. Cunningham CM, Hanley GE, Morgan SG. Income inequities in end-of-life health care spending in British Columbia, Canada: A cross-sectional analysis, 2004-2006. International Journal for Equity in Health. 2011;10:12.
74. Grabbe L. The association of functional status and formal home care in the last year of life. GEORGIA STATE UNIVERSITY 1992:126 p-126 p.
75. Chang Y, Huang C, Lin C. Do-not-resuscitate orders for critically ill patients in intensive care. Nursing Ethics. 2010;17(4):445-455.
76. Chang TS, Su YC, Lee CC. Determinants for aggressive end-of-life care for oral cancer patients: a population-based study in an Asian country. Medicine. 2015;94(4):e460.
77. Huang YC, Huang SJ, Ko WJ. Survey of do-not-resuscitate orders in surgical intensive care units. Journal of the Formosan Medical Association. 2010;109(3):201-208.
78. Kao CY, Wang HM, Tang SC, et al. Predictive factors for do-not-resuscitate designation among terminally ill cancer patients receiving care from a palliative care consultation service. Journal of Pain and Symptom Management. 2014;47(2):271-282.
79. McDonald JC, du Manoir JM, Kevork N, et al. Advance directives in patients with advanced cancer receiving active treatment: attitudes, prevalence, and barriers. Support Care Cancer. 2017;25(2):523-531.
80. Oh DY, Kim JH, Kim DW, et al. CPR or DNR? End-of-life decision in Korean cancer patients: A single center's experience. Supportive Care in Cancer. 2006;14(2):103-108.
81. Silveira MJ, Wiitala W, Piette J. Advance directive completion by elderly Americans: A decade of change. Journal of the American Geriatrics Society. 2014;62(4):706-710.
82. Triplett P, Black BS, Phillips H, et al. Content of advance directives for individuals with advanced dementia. Journal of aging and health. 2008;20(5):583-596.
83. Bischoff KE, Sudore R, Miao Y, et al. Advance care planning and the quality of end-of-life care in older adults. J Am Geriatr Soc. 2013;61(2):209-214.
84. Wagner GJ, Riopelle D, Steckart J, et al. Provider communication and patient understanding of life-limiting illness and their relationship to patient communication of treatment preferences. J Pain Symptom Manage. 2010;39(3):527-534.
85. Saeed F, Xing G, Tancredi DJ, et al. Is Annual Income a Predictor of Completion of Advance Directives (ADs) in Patients With Cancer. American Journal of Hospice & Palliative Medicine. 2018:1049909118813973.
86. Yen YF, Huang LY, Hu HY, et al. Association of Advance Directives Completion With the Utilization of Life-Sustaining Treatments During the End-of-Life Care in Older Patients. J Pain Symptom Manage. 2018;55(2):265-271.

87. Baker R, Wu AW, Teno JM, et al. Family satisfaction with end-of-life care in seriously ill hospitalized adults. Journal of the American Geriatrics Society. 2000;48(5 Suppl):S61-69.

88. Curtis J, Patrick DL, Engelberg RA, et al. A measure of the quality of dying and death: Initial validation using after-death interviews with family members. Journal of Pain and Symptom Management. 2002;24(1):17-31.

89. Halpern MT, Urato MP, Kent EE. The health care experience of patients with cancer during the last year of life: Analysis of the SEER-CAHPS data set. Cancer. 2017;123(2):336-344.

90. Jordhoy MS, Fayers P, Loge JH, et al. Quality of life in advanced cancer patients: the impact of sociodemographic and medical characteristics. British Journal of Cancer. 2001;85(10):1478-1485.

91. Kirkendall A, Holland JM, Keene JR, et al. Evaluation of hospice care by family members of Hispanic and non-Hispanic patients. American Journal of Hospice & Palliative Medicine. 2015;32(3):313-321.

92. Lee JJ, Long AC, Curtis JR, et al. The Influence of Race/Ethnicity and Education on Family Ratings of the Quality of Dying in the ICU. Journal of Pain & Symptom Management. 2016;51(1):9-16.

93. Long AC, Engelberg RA, Downey L, et al. Race, income, and education: Associations with patient and family ratings of end-of-life care and communication provided by physicians-in-training. Journal of Palliative Medicine. 2014;17(4):435-447.

94. Melmed GY, Kwan L, Reid K, et al. Quality of life at the end of life: trends in patients with metastatic prostate cancer. Urology. 2002;59(1):103-109.

95. Seow H, Barbera L, Sutradhar R, et al. The trajectory of functional and symptom scores in the last 6 months of life. Supportive Care in Cancer. 2010;18:S172.

96. Smith AK, Cenzer IS, Knight SJ, et al. The epidemiology of pain during the last 2 years of life. Annals of Internal Medicine. 2010;153(9):563-569.

97. Fleming J, Calloway R, Perrels A, et al. Dying comfortably in very old age with or without dementia in different care settings - a representative "older old" population study. BMC Geriatrics. 2017;17(1):222.

S5 Text. Characteristics of 112 high and medium quality studies

OR for the lowest (most disadvantaged) versus the highest (least disadvantaged) socioeconomic position (SEP) group have been standardised so that an OR >1 indicates a pro-high-SEP association

36 studies reporting an association between SEP and use of specialist palliative care (SPC) in the last year of life, OR >1 indicates lowest (most disadvantaged group) have higher odds of <u>not</u> receiving SPC than highest (least disadvantaged group)

study, year of publication and country	sample size	pt. group	time period	outcome	SEP exposures [number of categories]	OR for lowest vs. highest SEP group
Bainbridge (2015), CA[1]	22262	cancer	2006	last 6 months of life	area-based (inc) [5]	1.28 (1.16-1.40)
Barbera (2015), CA[2]	135207	cancer	2004/09	last 6 months of life	area-based (inc) [5]	1.34 (1.29-1.40)
Beccaro (2007), IT[3]	1289	cancer	2002/03	last 3 months of life	education (cg) [3]	2.00 (1.20-3.35)
Bergman (2011), US[4]	14521	cancer	1992/05	last 6 months of life	area-based (inc) [4]	1.19 (1.03-1.37)
Bossuyt (2011), BE[5]	2445	non-sudden	2005/07	last 3 months of life	education (gp) [3]	1.31 (1.02-1.68)
Bradley (2008), US[6]	1907	cancer	1997/00	last 12 months of life	area-based (inc) [4]	1.34 (0.81-2.23)
Brody (2008), US[7]	722	all	2004/06	after hospitalisation	insurance [3]	2.86 (0.91-9.09)†
Burge (2008), CA[8]	7511	cancer	1998/03	any time before death	area-based (inc) [5]	1.10 (0.80-1.30)
Colibaseanu (2018), US[9]	86187	cancer	2004/13	last 6 months of life	insurance [6] income [4] area-based (ed) [4]	1.03 (0.95-1.12) 1.01 (0.90-1.13) 1.19 (1.06-1.33)
Fairfield (2012), US[10]	8211	cancer	2001/07	any time before death	area-based (inc) [3] insurance [2]	1.17 (1.04-1.32) 1.39 (1.24-1.56)
Fletcher (2015), US[11]	6955	cancer	2006/12	any time before death	area-based (ed) [5]	1.18 (1.00-1.40)
Forst (2018), US[12]	12437	cancer	2002/12	any time before death	area-based (ed) [n]	1.15 (1.08-1.23)*
Goldsbury (2015), AU[13]	45749	all	2007	last 12 months of life	area-based (md) [5]	0.79 (0.71-0.87)
Goodridge (2011), US[14]	700	all	2008/09	last 12 months of life	area-based (md) [5]	0.72 (0.38-1.33)
Hunt (1998), AU[15]	5673	cancer	1990/93	any time before death	area-based (?) [3]	0.90 (0.74-1.09)
Iwashyna (2002), US[16]	331880	cancer/strokoe	1993/97	any time before death	area-based (inc) [n] insurance [2]	1.01 (1.00-1.01)* 1.44 (1.39-1.52)
Jarosek (2016), US[17]	46037	cancer	2007/08	any time before death	area-based (inc) [4] insurance [2]	1.24 (1.17-1.32) 1.52 (1.43-1.59)
Jenkins (2011), US[18]	178420	all	2002/05	at time of death	area-based (inc) [3]	1.11 (1.06-1.15)
Kwak (2008), US[19]	30765	non-sudden	2000/02	last 12 months of life	education [n]	1.01 (1.00-1.02)*
Lavergne (2015), CA[20]	23860	chronic	2003/09	at time of death	area-based (md) [5]	1.10 (0.95-1.25)
Mack (2013), US[21]	43912	cancer	2002/06	any time before death	area-based (inc) [4]	1.21 (1.14-1.28)
Maddison (2012), CA[22]	1201	cancer	2001/08	last 2 months of life	area-based (inc) [3]	1.43 (0.80-2.70)
Neergaard (2013), DK[23]	590	cancer	2006	last 3 months of life	income [3]	0.94 (0.53-1.95)
Ni Chroinin (2018), AU[24]	34556	all	2007	during hospitalisation	area-based (md) [5]	0.95 (0.86-1.05)
Odejide (2016), US[25]	18777	cancer	1999/09	any time before death	area-based (inc) [5]	1.28 (1.16-1.42)
Ornstein (2016), US[26]	1567	all	2000/11	any time before death	education [2]	1.22 (0.96-1.55)
Osagiede (2018), US[27]	34811	cancer	2004/13	during hospitalisation	income [4] area-based (ed) [4] insurance [6]	1.08 (0.94-1.24) 0.91 (0.80-1.06) 1.04 (0.94-1.15)

Penrod (2017), US[28]	3027	cancer	2007/11	during hospitalisation	education [2] insurance [2]	1.12 (0.91-1.39) 1.36 (1.00-1.87)
Rhodes (2013), US[29]	5083	all	2000/10	any time before death	insurance [3]	1.59 (1.28-1.96)
Rosenwax (2006), AU[30]	12845	all	2000/02	last 12 months of life	area-based (md) [5]	1.08 (0.89-1.31)
Rubens (2018), US[31]	81,219	cancer	2005/14	any time before death	insurance [2] income [4]	0.59 (0.59-0.74) 1.23 (1.23-1.54)
Rush (2018), US[32]	3166	IPF	2006/12	any time before death	area-based (inc) [4]	1.33 (0.94-1.87)
Shugarman (2008), US[33]	13120	cancer	1996/99	last 12 months of life	area-based (inc) [3] insurance [2]	1.07 (0.96-1.21) 1.06 (0.95-1.19)
Sullivan (2018), US[34]	21860	cancer	2007/13	any time before death	income [3]	0.99 (0.93-1.07)
Tanuseputro (2017), CA[35]	177817	all	2010/12	last 12 months of life	area-based (inc) [5]	1.12 (1.08-1.15)
Tramontano (2018), US[36]	3597	cancer	2000/13	any time before death	area-based (md) [5]	1.28 (1.08-1.52)

** exposure is numerical scale; † Risk Ratio; not enough data to convert to OR*

64 studies reporting an association between SEP and place of death, OR >1 indicates lowest (most disadvantaged) group have higher odds of dying in hospital (versus home/hospice/LTC) than highest (least disadvantaged group)

study, year of publication and country	sample size	pt. group	time period	SEP exposures [number of categories]	OR for lowest vs. highest SEP group
Almaawiy (2014), CA[37]	9458	cancer	2006	area-based (inc) [5]	1.20 (1.05-1.37)
Alonso-Babarro (2013), ES[38]	524	cancer	2005	area-based (md) [5]	1.80 (0.80-3.90)
Assareh (2018), AU[39]	25359	all	2010/15	area based (md) [4]	1.23 (1.02-1.48)
Bainbridge (2015), CA[1]	1196	cancer	2006	area-based (inc) [5]	1.41 (0.91-2.21)
Bannon (2018), UK[40]	362	cancer	2011/12	area based (md) [5]	4.0 (1.4-11.8)
Barbera (2010), CA[41]	112398	cancer	2000/04	area-based (inc) [5]	1.10 (1.05-1.15)
Barclay (2013), US[42]	61063	all	1999/03	area-based (inc) [5]	1.12 (0.87-1.45)
Blecker (2016), US[43]	12205	all	1979/11	occupation [4]	1.10 (1.08-1.12)
Burge (2005), CA[44]	13652	cancer	1992/97	area-based (inc) [5]	1.56 (1.33-1.81)
Cabanero-Martinez (2019), ES[45]	1336339	all	2012/15	Education [4]	1.11 (1.09-1.12)
Carollo (2018), DK[46]	1834437	all	1980/14	Income [3]	0.74 (0.66-0.84)
Cohen (2006), BE[47]	55759	all	2001	education [2]	1.41 (1.23-1.62)
Cohen (2015), IT[48] ES BE CZ US KR	73042 13255 16059 24321 554917 68130	cancer	2008	education [4]	1.28 (1.20-1.37) 1.26 (1.06-1.50) 1.46 (1.28-1.65) 1.47 (1.24-1.74) 0.98 (0.95-1.00) 0.55 (0.50-0.61)
Costantini (1993), IT[49]	12305	cancer	1986/90	education [4]	3.47 (2.82-4.27)
Costantini (2000), IT[50]	17442	cancer	1991	education [4]	1.63 (1.29-2.06)
Decker (2006), UK[51] US	59604 51668	cancer	1995/98	area-based (inc) [3]	1.28 (1.22-1.35) 1.64 (1.54-1.75)
Dixon (2015), UK[52]	16845	all	2013	area-based (md) [5]	1.49 (1.27-1.75)
Dominguez-Berjon (2015), ES[53]	1035	ALS	2003/11	area-based (md) [5]	2.03 (1.36-3.02)
Duggan (2015), AU[54]	923	cancer	2006/12	area-based (md) [5]	1.04 (0.49-2.22)
Gallo (2001), US[55]	5752	cancer	1994	area-based (inc) [3]	1.46 (1.25-1.68)
Gao (2014), UK[56]	13154705	cancer	1984/10	area-based (md) [5]	1.04 (1.01-1.06)
Gomes (2018), PT[57]	715727	all	2003/12	area-based (md) [5]	1.03 (1.01-1.05)
Grundy (2004), UK[58]	22962	cancer	1991	housing tenure [2] area-based (md) [2]	1.16 (1.09-1.23) 1.11 (1.04-1.18)α
Hakanson (2015), UK[59]	82079	all	2012	education [4]	1.03 (0.80-1.32)
Hanratty (2007), SE[60]	14517	all	2002	income [5] education [3]	1.11 (0.92-1.34) 1.17 (1.02-1.36)
Hansen (2002), US[61]	2317586	all	1997	education [2]	1.05 (1.05-1.06)
Hedinger (2014), CH[62]	45990	all	2007/08	education [5] housing tenure [2]	1.10 (0.94-1.28)‡ 1.96 (1.76-2.18)
Hicks (2018), US[63]	19365	chronic	2010/15	education [8] insurance [6]	1.01 (0.89-1.16) 1.03 (0.96-1.12)
Houttekier (2009), BE[64]	3232	chronic	2003	area-based (md) [4]	1.67 (1.28-2.19)
Houttekier (2011), BE[65]	79846	chronic	1998/07	education [2]	0.84 (0.78-0.92)
Houttekier (2014), BE[66]	42999	chronic	2008	education [3]	1.36 (1.22-1.52)
Huang (2015), TW[67]	28978	cancer	2009/11	income [3]	2.00 (1.92-2.04)
Hudson (2018), UK[68]	13790	Liver	2013/15	area-based [5]	1.22 (1.06-1.39)
Hunt (1993), AU[69]	2715	cancer	1990	area-based (md) [3]	1.70 (1.15-2.49)
Hunt (2001), AU[70]	29230	cancer	1990/99	area-based (md) [3]	1.75 (1.53-2.01)

Hunt (2018), AU[71]	86257	cancer	1990/12	area-based (md) [5]	1.39 (1.30-1.49)
Jarosek (2016), US[17]	46037	cancer	2007/08	area-based (inc) [4] insurance [2]	1.24 (1.17-1.32) 1.18 (1.10-1.25)
Johnson (2018), UK[72]	2165	all	2009/13	income (cg) [4]	0.74 (0.54-1.02)
Johnston (2018), US[73]	2135	all	2000/13	insurance [3] area-based (inc) [3]	1.11 (0.83-1.43) 1.00 (0.71-1.43)
Kelfve (2018), SE[74]	75722	all	2013	education [3]	1.01 (0.94-1.07)
Kessler (2005), UK[75]	960	cancer	1999/02	occupation [2]	2.04 (0.92-4.55)
Kuo (2016), TW[76]	25816	cancer	2005/11	income (hh) [5]	1.10 (0.89-1.36)
Kwak (2008), US[19]	30765	non-sudden	2001/02	education [n]	1.01 (1.00-1.02)*
Lackan (2009), US[77]	472382	all	1999/01	area-based (inc) [2] education [n]	1.00 (1.00-1.00) 1.01 (1.00-1.01)*
Lavergne (2015), CA[78]	23860	chronic	2003/09	area-based (md) [5]	1.21 (1.07-1.37)
Lee (2017), SG[79]	19721	all	2004/13	insurance [3]	1.02 (0.89-1.14)
Lopez-Valcarcel (2018), ES[80]	79506	cancer	2015	education [3]	1.35 (1.26-1.43)
Maddison (2012), CA[22]	1201	cancer	2001/08	area-based (inc) [3]	1.56 (1.11-2.50)
Mai (2018), KR[81]	2358211	all	2001/14	education [4]	0.32 (0.31-0.32)
Moens (2015), KR[82]	1565	parkinson's	2008	education [2]	1.67 (1.25-2.00)
Motiwala (2006), CA[83]	35155	all	2001/02	area-based (md) [n]	1.17 (1.10-1.25)*
Neergaard (2012), DK[84]	569	cancer	2006	income [3] M2 per adult [3]	1.41 (0.97-2.00)α 1.12 (0.88-1.43)
Ni Chroinin (2018), AU[24]	34556	all	2007	area-based (md) [5]	1.34 (1.24-1.45)
O'Dowd (2016), UK[85]	143627	cancer	2004/13	area-based (md) [5]	1.31 (1.25-1.37)
Öhlén (2016), SE[86]	19742	cancer	2012	education [4]	1.12 (0.99-1.23)
Penning (2017), CA[87]	11816	all	2008/11	income [3] insurance [2]	1.22¥ 0.92***
Prioleau (2016), US[88]	183	all	2012	insurance [2]	1.52 (0.68-3.38)
Raziee (2017), CA[89]	193601	cancer	2003/10	area-based (inc) [5]	1.69 (1.54-1.85)
Reyniers (2015), BE[90] US KR	2816 14844 6033	dementia	2008	education [4]	0.71 (0.56-0.91) 1.25 (1.00-1.25) 0.71 (0.59-0.83)
Seow (2010), CA[91]	9018	all	2005/06	area-based (inc) [2]	1.25 (1.11-1.41)
Sharpe (2015), UK[92]	106898	cancer	2001/09	area-based (md) [5] car ownership [2] education (ind) [3] NS-SEC [?] home ownership [2]	1.08 (1.00-1.17) 1.04 (1.03-1.06)† 1.12 (1.08-1.19) 1.02 (1.01-1.03)*† 1.08 (1.05-1.09)†
Silveira (2006), US[93]	349613	all	1989/98	area-based (inc) [n]	1.04 (1.02-1.06)*
Weitzen (2003), US[94]	10122	chronic	1993	education [2]	1.33 (1.02-1.74)
Yun (2006), KR[95]	2138463	all	1992/01	education [2] occupation [2]	0.49 (0.49-0.50) 0.65 (0.64-0.65)

** exposure is numerical; † Risk Ratio; not enough data to convert to OR; ‡ middle SEP group is ref category*

*¥ CI not reported p<0.05; *** CI not reported p>0.05; α measure duplicated in another study with the same sample*

19 studies reporting an association between SEP and use of acute care in the last year of life, OR >1 indicates lowest (most disadvantaged) group have higher odds of using acute care services than highest (least disadvantaged group)

study, year of publication and country	**sample size**	**pt. group**	**time period**	**outcome**	**SEP exposures [number of categories]**	**OR for lowest vs. highest SEP group**
Almaawiy (2014), CA[37]	9467	cancer	2006	hospital admission in last 2 weeks of life	area-based (inc) [5]	1.32 (1.16-1.52)
Bainbridge (2015), CA[1]	1196	cancer	2006	ED in last 6 months of life	area-based (inc) [5]	1.38 (0.91-2.11)
Barbera (2006), CA[96]	21323	cancer	2001	ED in last 2 weeks of life	area-based (inc) [5]	1.22 (1.10-1.35)
Barbera (2015), CA[2]	200285	cancer	2004/09	>1 ED or ICU in last 30 days of life	area-based (inc) [5]	1.09 (1.03-1.15)
Chen (2017), TW[97]	2072	Renal	2002/12	ICU in last 30 days of life	income [2]	0.94 (0.76-1.16)
Fletcher (2015), US[11]	6955	cancer	2006/11	ICU in last 30 days of life	area-based (ed) [5]	1.25 (1.04-1.52)
Gieniusz (2018), US[98]	197	all	2015	ICU during terminal hospital admission	insurance [2]	1.10 (0.24-5.13)†
Goldsbury (2015), AU[13]	45749	all	2007	>3 ED in last year of life	area-based (md) [5]	1.80 (1.63-1.99)
Henson (2017), UK[99]	124030	cancer	2011/12	>1 ED in last 30 days of life	area-based (md) [5]	1.19 (1.09-1.30)
Ho (2011), CA[100]	227161	cancer	1993/04	acute or aggressive care in last 30 days of life	area-based (inc) [5]	1.02 (0.99-1.06)
Hudson (2018), UK[68]	11731	Liver	2013/15	hospital admission in last year of life	area-based [5]	0.98 (0.85-1.12)
Kelfve (2018), SE[74]	75722	all	2013	>3 hospital admissions in last 3 months	education [3]	1.01 (0.94-1.07)
Maddison (2012), CA[22]	1201	cancer	2001/08	>1 ED in last 30 days	area-based (inc) [3]	1.11 (0.71-1.67)
Ni Chroinin (2018), AU[24]	34556	all	2007	hospital admission in last year of life	area-based (md) [5]	1.30 (1.17-1.44)
Phongtankuel (2018), US[101]	115103	all	2012	hospital admission after hospice disenrollment	income [4]	1.43 (1.32-1.55)
Seow (2010), CA[91]	9018	all	2005/06	hospital admission in last 2 weeks of life	area-based (inc) [2]	1.20 (1.08-1.35)
Sharma (2009), US[102]	21183	cancer	1992/02	ICU during terminal hospital admission	insurance [2]	1.15 (1.03-1.27)
Sleeman (2018), UK[103]	3377	dementia	2008/13	≥1 ED in last year of life	area-based (md) [5]	1.27 (1.10-1.45)α
Spilsbury (2017), US[104]	11875	all	2009/10	rate of ED visits	area-based (md) [5]	1.25 (1.19-1.32)∞

† Risk Ratio; not enough data to convert to OR; ∞ Hazard Ratio, could not be converted; α Rate Ratio, could not be converted

11 studies reporting an association between SEP and use of non-specialist end of life care in the last year of life, OR >1 indicates a pro-rich association where the lowest (most disadvantaged) group have higher odds of not using non-specialist end of life care than highest (least disadvantaged group)

study, year of publication and country	sample size	pt. group	time period	outcome	SEP exposures [number of categories]	OR for lowest vs. highest SEP group
Bahler (2016), CH[105]	11310	all	2014	transitions in the last 6 months of life	insurance [2]	0.80 (0.69-0.93)
Bainbridge (2015), CA[1]	22262	cancer	2006	homecare in last 6 months of life	area-based (inc) [5]	1.25 (1.14-1.38)
Barbera (2010), CA[41]	112398	cancer	2000/04	homecare in last 6 months of life	area-based (inc) [5]	1.22 (1.16-1.27)
Bossuyt (2011), BE[5]	2445	non-sudden	2005/07	>1 transition in the last 3 months of life	education (GP) [3]	0.66 (0.01-1.08)
Brackley (2009), CA[106]	98327	all	1991/00	homecare in last 12 months of life	area-based (inc) [5]	0.78 (0.75-0.82)
Brody (2008), US[7]	722	all	2004/06	homecare at discharge	insurance [3]	1.32 (0.65-2.63)†
Burge (2005), CA[107]	7212	cancer	1992/97	GP home vist in last 180 days of life	area-based (inc) [5]	1.37 (1.15-1.64)
Kelfve (2018), SE[74]	51697	all	2013	institutionalisation in last month	education [3]	1.20 (1.09-1.32)
Neergaard (2015), DK[108]	599	cancer	2006	<2 GP visits in last 90 days of life	income [3]	1.18 (1.03-1.35)
Sharma (2009), US[102]	21183	cancer	1992/02	GP visit during the terminal hospital stay	insurance [2]	1.20 (1.11-1.32)
Shugarman (2008), US[33]	13120	cancer	1996/99	homecare in last 12 months of life	insurance [2] area-based (inc) [3]	1.04 (0.93-1.16) 1.19 (1.06-1.34)

† Risk Ratio; not enough data to convert to OR

4 studies reporting an association between SEP and use of advance care planning (ACP) in the last year of life, OR >1 indicates lowest (most disadvantaged) SEP group have higher odds of not using ACP than highest (least disadvantaged group)

study, year of publication and country	sample size	pt. group	time period	outcome	SEP exposures [number of categories]	OR for lowest vs. highest SEP group
Burdsall (2014), US[109]	2559	all	2008/10	any formal ACP before death	education [3] income [n]	1.99¥ 1.04¥*
Hanson (1996), US[110]	13883	all	1986	living will at time of death	income [n] education [n]	1.01¥* 1.39¥*
Hong (2016), KR[111]	53	all	2012/13	AD at admission to hospice	education [2]	9.59 (1.36-67.79)
Muni (2011), US[112]	3138	all	2003/08	living will at time of death	area-based (inc) [n] education [n] insurance [2]	1.08 (0.99-1.19)* 1.12 (1.03-1.23)* 1.89 (1.33-2.63)

**exposure is numerical; ¥ CI not reported p<0.05*

References

1. Bainbridge D, Seow H, Sussman J, et al. Factors associated with acute care use among nursing home residents dying of cancer: a population-based study. Int J Palliat Nurs. 2015;21(7):349-356.
2. Barbera L, Seow H, Sutradhar R, et al. Quality of end-of-life cancer care in Canada: a retrospective four-province study using administrative health care data. Current Oncology. 2015;22(5):341-355.
3. Beccaro M, Costantini M, Merlo DF, et al. Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). BMC Public Health. 2007;7:66.
4. Bergman J, Saigal CS, Miller DC, et al. Hospice Use and High-Intensity Care in Men

Dying of Prostate Cancer. Arch Intern Med. 2011;171(3):204-210.
5. Bossuyt N, Van den Block L, Cohen J, et al. Is individual educational level related to end-of-life care use? Results from a nationwide retrospective cohort study in Belgium. J Palliat Med. 2011;14(10):1135-1141.
6. Bradley CJ, Clement JP, Lin C. Absence of cancer diagnosis and treatment in elderly Medicaid-insured nursing home residents. J Natl Cancer Inst. 2008;100(1):21-31.
7. Brody AA. The effects of an inpatient palliative care team on mortality, utilization, and cost in a large non-profit teaching hospital. University of California, San Francisco 2008:109 p-109 p.
8. Burge FI, Lawson BJ, Johnston GM, et al. A Population-based Study of Age Inequalities in Access to Palliative Care Among Cancer Patients. Med Care. 2008;46(12):1203-1211.
9. Colibaseanu DT, Osagiede O, Spaulding AC, et al. The Determinants of Palliative Care Use in Patients With Colorectal Cancer: A National Study. American Journal of Hospice & Palliative Medicine. 2018;35(10):1295-1303.
10. Fairfield KM, Murray KM, Wierman HR, et al. Disparities in hospice care among older women dying with ovarian cancer.[Erratum appears in Gynecol Oncol. 2012 Sep;126(3):509-10]. Gynecol Oncol. 2012;125(1):14-18.
11. Fletcher SA, Cronin AM, Zeidan AM, et al. Quality of end-of-life care for the myelodysplastic syndromes: Findings from a large national database. Blood. 2015;126 (23):3287.
12. Forst D, Adams E, Nipp R, et al. Hospice utilization in patients with malignant gliomas. Neuro Oncol. 2018;20(4):538-545.
13. Goldsbury DE, O'Connell DL, Girgis A, et al. Acute hospital-based services used by adults during the last year of life in New South Wales, Australia: a population-based retrospective cohort study. BMC Health Serv Res. 2015;15:537.
14. Goodridge D, Buckley A, Marko J, et al. Home care clients in the last year of life: Is material deprivation associated with service characteristics? J Aging Health. 2011;23(6):954-973.
15. Hunt R, McCaul K. Coverage of cancer patients by hospice services, South Australia, 1990 to 1993. Aust N Z J Public Health. 1998;22(1):45-48.
16. Iwashyna TJ, Chang VW, Zhang JX, et al. The lack of effect of market structure on hospice use. Health Serv Res. 2002;37(6):1531-1551.
17. Jarosek SL, Shippee TP, Virnig BA. Place of Death of Individuals with Terminal Cancer: New Insights from Medicare Hospice Place-of-Service Codes. J Am Geriatr Soc. 2016;64(9):1815-1822.
18. Jenkins TM, Chapman KL, Ritchie CS, et al. Hospice use in Alabama, 2002-2005. J Pain Symptom Manage. 2011;41(2):374-382.
19. Kwak J, Haley WE, Chiriboga DA. Racial differences in hospice use and in-hospital death among Medicare and Medicaid dual-eligible nursing home residents. The Gerontologist. 2008;48(1):32-41.
20. Lavergne M, Lethbridge L, Johnston G, et al. Examining palliative care program use and place of death in rural and urban contexts: a Canadian population-based study using linked data. Rural & Remote Health. 2015;15(2):3134-3146.
21. Mack JW, Chen K, Boscoe FP, et al. Underuse of hospice care by Medicaid-insured patients with stage IV lung cancer in New York and California. J Clin Oncol. 2013;31(20):2569-2579.
22. Maddison AR, Asada Y, Burge F, et al. Inequalities in end-of-life care for colorectal cancer patients in Nova Scotia, Canada. J Palliat Care. 2012;28(2):90-96.
23. Neergaard MA, Jensen AB, Olesen F, et al. Access to outreach specialist palliative care teams among cancer patients in Denmark. J Palliat Med. 2013;16(8):951-957.

24. Ni Chroinin D, Goldsbury DE, Beveridge A, et al. Health-services utilisation amongst older persons during the last year of life: a population-based study. BMC Geriatr. 2018;18(1):317.

25. Odejide OO, Cronin AM, Earle CC, et al. Hospice Use Among Patients With Lymphoma: Impact of Disease Aggressiveness and Curability. J Natl Cancer Inst. 2016;108(1).

26. Ornstein KA, Aldridge MD, Mair CA, et al. Spousal Characteristics and Older Adults' Hospice Use: Understanding Disparities in End-of-Life Care. J Palliat Med. 2016;19(5):509-515.

27. Osagiede O, Spaulding AC, Frank RD, et al. Predictors of palliative treatment in stage IV colorectal cancer. Am J Surg. 2018;14:14.

28. Penrod JD, Garrido MM, McKendrick K, et al. Characteristics of Hospitalized Cancer Patients Referred for Inpatient Palliative Care Consultation. J Palliat Med. 2017;20(12):1321-1326.

29. Rhodes RL, Xuan L, Paulk ME, et al. An examination of end- of-life care in a safety net hospital system: A decade in review. J Health Care Poor Underserved. 2013;24(4):1666-1675.

30. Rosenwax LK, McNamara BA. Who receives specialist palliative care in Western Australia - And who misses out. Palliat Med. 2006;20(4):439-445.

31. Rubens M, Ramamoorthy V, Saxena A, et al. Palliative Care Consultation Trends Among Hospitalized Patients With Advanced Cancer in the United States, 2005 to 2014. American Journal of Hospice & Palliative Medicine. 2018:1049909118809975.

32. Rush B, Berger L, Anthony Celi L. Access to Palliative Care for Patients Undergoing Mechanical Ventilation With Idiopathic Pulmonary Fibrosis in the United States. American Journal of Hospice & Palliative Medicine. 2018;35(3):492-496.

33. Shugarman LR, Bird CE, Schuster CR, et al. Age and gender differences in Medicare expenditures and service utilization at the end of life for lung cancer decedents. Womens Health Issues. 2008;18(3):199-209.

34. Sullivan DR, Ganzini L, Lapidus JA, et al. Improvements in hospice utilization among patients with advanced-stage lung cancer in an integrated health care system. Cancer. 2018;124(2):426-433.

35. Tanuseputro P, Budhwani S, Bai YQ, et al. Palliative care delivery across health sectors: A population-level observational study. Palliat Med. 2017;31(3):247-257.

36. Tramontano AC, Nipp R, Kong CY, et al. Hospice use and end-of-life care among older patients with esophageal cancer. Health Science Reports. 2018;1(9):e76.

37. Almaawiy U, Pond GR, Sussman J, et al. Are family physician visits and continuity of care associated with acute care use at end-of-life? A population-based cohort study of homecare cancer patients. Palliative medicine. 2014;28(2):176-183.

38. Alonso-Babarro A, Astray-Mochales J, Dominguez-Berjon F, et al. The association between in-patient death, utilization of hospital resources and availability of palliative home care for cancer patients. Palliat Med. 2013;27(1):68-75.

39. Assareh H, Stubbs JM, Trinh LTT, et al. Variation in out-of-hospital death among palliative care inpatients across public hospitals in New South Wales, Australia. Intern Med J. 2018;24:24.

40. Bannon F, Cairnduff V, Fitzpatrick D, et al. Insights into the factors associated with achieving the preference of home death in terminal cancer: A national population-based study. Palliative & supportive care. 2018;16(6):749-755.

41. Barbera L, Sussman J, Viola R, et al. Factors Associated with End-of-Life Health Service Use in Patients Dying of Cancer. Healthcare Policy = Politiques de sante. 2010;5(3):e125-143.

42. Barclay JS, Kuchibhatla M, Tulsky JA, et al. Association of hospice patients' income and care level with place of death. JAMA internal medicine. 2013;173(6):450-456.

43. Blecker S, Johnson NJ, Altekruse S, et al. Association of occupation as a physician with likelihood of dying in a hospital. JAMA: Journal of the American Medical Association. 2016;315(3):301-303.

44. Burge F, Lawson B, Johnston G. Where a cancer patient dies: the effect of rural residency. J Rural Health. 2005;21(3):233-238.

45. Cabanero-Martinez MJ, Nolasco A, Melchor I, et al. Place of death and associated factors: a population-based study using death certificate data. Eur J Public Health. 2019;02:02.

46. Carollo A, Verdiell NC, Hale JM, et al. Trends in Hospital Deaths in Denmark from 1980 to 2014, at Ages 50 and Older. J Am Geriatr Soc. 2018;28:28.

47. Cohen J, Bilsen J, Hooft P, et al. Dying at home or in an institution. Using death certificates to explore the factors associated with place of death. Health Policy. 2006;78(2-3):319-329.

48. Cohen J, Pivodic L, Miccinesi G, et al. International study of the place of death of people with cancer: a population-level comparison of 14 countries across 4 continents using death certificate data. Br J Cancer. 2015;113(9):1397-1404.

49. Costantini M, Camoirano E, Madeddu L, et al. Palliative home care and place of death among cancer patients: a population-based study. Palliative medicine. 1993;7(4):323-331.

50. Costantini M, Balzi D, Garronec E, et al. Geographical variations of place of death among Italian communities suggest an inappropriate hospital use in the terminal phase of cancer disease. Public Health. 2000;114(1):15-20.

51. Decker SL, Higginson IJ. A tale of two cities: factors affecting place of cancer death in London and New York. Eur J Public Health. 2007;17(3):285-290.

52. Dixon JK, D. Matosevic, T. Equity in Provision of Palliative Care in the UK. LSE, PSSRU, Marie Curie. 2015.

53. Dominguez-Berjon MF, Esteban-Vasallo MD, Zoni AC, et al. Place of death and associated factors among patients with amyotrophic lateral sclerosis in Madrid (Spain). Amyotrophic Lateral sclerosis & Frontotemporal Degeneration. 2015;17(1-2):62-68.

54. Duggan KJ, Wiltshire J, Strutt R, et al. Patterns of palliative and psychosocial care in stage IV NSCLC in south western Sydney. J Thorac Oncol. 2015;2):S365.

55. Gallo WT, Baker MJ, Bradley EH. Factors associated with home versus institutional death among cancer patients in Connecticut. J Am Geriatr Soc. 2001;49(6):771-777.

56. Gao W, Ho Y, Verne J, et al. Geographical and temporal Understanding In place of Death in England (1984–2010): analysis of trends and associated factors to improve end-of-life Care (GUIDE_Care) – primary research. Health Serv Deliv Res. 2014;2(42).

57. Gomes B, Pinheiro MJ, Lopes S, et al. Risk factors for hospital death in conditions needing palliative care: Nationwide population-based death certificate study. Palliat Med. 2018;32(4):891-901.

58. Grundy E, Mayer D, Young H, et al. Living arrangements and place of death of older people with cancer in England and Wales: a record linkage study. Br J Cancer. 2004;91(5):907-912.

59. Hakanson C, Ohlen J, Morin L, et al. A population-level study of place of death and associated factors in Sweden. Scandinavian journal of public health. 2015;43(7):744-751.

60. Hanratty B, Burstrom B, Walander A, et al. Hospital Deaths in Sweden: Are Individual Socioeconomic Factors Relevant? J Pain Symptom Manage. 2007;33(3):317-323.

61. Hansen SM, Tolle SW, Martin DP. Factors associated with lower rates of in-hospital death. J Palliat Med. 2002;5(5):677-685.

62. Hedinger D, Braun J, Zellweger U, et al. Moving to and dying in a nursing home depends not only on health - an analysis of socio-demographic determinants of place of death in Switzerland. PLoS ONE [Electronic Resource]. 2014;9(11):e113236.

63. Hicks K, Downey L, Engelberg RA, et al. Predictors of Death in the Hospital for Patients with Chronic Serious Illness. J Palliat Med. 2018;21(3):307-314.

64. Houttekier D, Cohen J, Bilsen J, et al. Determinants of the Place of Death in the Brussels Metropolitan Region. J Pain Symptom Manage. 2009;37(6):996-1005.

65. Houttekier D, Cohen J, Surkyn J, et al. Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. BMC Public Health. 2011;11:228.

66. Houttekier D, Cohen J, Pepersack T, et al. Dying in hospital: a study of incidence and factors related to hospital death using death certificate data. Eur J Public Health. 2014;24(5):751-756.

67. Huang C-Y, Hung Y-T, Chang C-M, et al. The association between individual income and aggressive end-of-life treatment in older cancer decedents in Taiwan. PLoS One. 2015;10.

68. Hudson B, Round J, Georgeson B, et al. Cirrhosis with ascites in the last year of life: a nationwide analysis of factors shaping costs, health-care use, and place of death in England. The Lancet Gastroenterology & Hepatology. 2018;3(2):95-103.

69. Hunt R, Bonett A, Roder D. Trends in the terminal care of cancer patients: South Australia, 1981-1990. Aust N Z J Med. 1993;23(3):245-251.

70. Hunt RW, Fazekas BS, Luke CG, et al. Where patients with cancer die in South Australia, 1990-1999: a population-based review. Med J Aust. 2001;175(10):526-529.

71. Hunt RW, D'Onise K, Nguyen AT, et al. Where Patients With Cancer Die: A Population-Based Study, 1990 to 2012. J Palliat Care. 2018:825859718814813.

72. Johnson MJ, Allgar V, Chen H, et al. The complex relationship between household income of family caregivers, access to palliative care services and place of death: A national household population survey. Palliat Med. 2018;32(2):357-365.
73. Johnston EE, Muffly L, Alvarez E, et al. End-of-Life Care Intensity in Patients Undergoing Allogeneic Hematopoietic Cell Transplantation: A Population-Level Analysis. J Clin Oncol. 2018:JCO2018780957.
74. Kelfve S, Wastesson J, Fors S, et al. Is the level of education associated with transitions between care settings in older adults near the end of life? A nationwide, retrospective cohort study. Palliat Med. 2018;32(2):366-375.
75. Kessler D, Peters TJ, Lee L, et al. Social class and access to specialist palliative care services. Palliative medicine. 2005;19(2):105-110.
76. Kuo TL, Lin CH, Jiang RS, et al. End-of-life care for head and neck cancer patients: a population-based study. Support Care Cancer. 2016;30:30.
77. Lackan NA, Eschbach K, Stimpson JP, et al. Ethnic differences in in-hospital place of death among older adults in California: Effects of individual and contextual characteristics and medical resource supply. Med Care. 2009;47(2):138-145.
78. Lavergne MR, Lethbridge L, Johnston G, et al. Examining palliative care program use and place of death in rural and urban contexts: a Canadian population-based study using linked data. Rural and remote health. 2015;15(2):3134.
79. Lee YS, Akhileswaran R, Ong EHM, et al. Clinical and Socio-Demographic Predictors of Home Hospice Patients Dying at Home: A Retrospective Analysis of Hospice Care Association's Database in Singapore. J Pain Symptom Manage. 2017;53(6):1035-1041.
80. Lopez-Valcarcel BG, Pinilla J, Barber P. Dying at home for terminal cancer patients: differences by level of education and municipality of residence in Spain. Gac Sanit. 2018;31:31.
81. Mai TTX, Lee E, Cho H, et al. Increasing Trend in Hospital Deaths Consistent among Older Decedents in Korea: A Population-based Study Using Death Registration Database, 2001-2014. BMC Palliat Care. 2018;17(1):16.
82. Moens K, Houttekier D, Van den Block L, et al. Place of death of people living with Parkinson's disease: a population-level study in 11 countries. BMC Palliat Care. 2015;14:28.
83. Motiwala SS, Croxford R, Guerriere DN, et al. Predictors of place of death for seniors in Ontario: A population-based cohort analysis. Canadian Journal on Aging. 2006;25(4):363-371.
84. Neergaard MA, Jensen AB, Sokolowski I, et al. Socioeconomic position and place of death of cancer patients. BMJ Supportive & Palliative Care. 2012;2(2):133-139.
85. O'Dowd EL, McKeever TM, Baldwin DR, et al. Place of Death in Patients with Lung Cancer: A Retrospective Cohort Study from 2004-2013. PLoS ONE [Electronic Resource]. 2016;11(8):e0161399.
86. Ohlen J, Cohen J, Hakanson C. Determinants in the place of death for people with different cancer types: a national population-based study. Acta Oncol. 2016:1-7.
87. Penning M, Cloutier DS, Nuernberger K, et al. "When I Said I Wanted to Die at Home I Didn't Mean a Nursing Home": Care Trajectories at the End of Life. Innovation in Aging. 2017;1(1):igx011.
88. Prioleau PG, Soones TN, Ornstein K, et al. Predictors of Place of Death of Individuals in a Home-Based Primary and Palliative Care Program. J Am Geriatr Soc. 2016;64(11):2317-2321.
89. Raziee H, Saskin R, Barbera L. Determinants of Home Death in Patients With Cancer: A Population-Based Study in Ontario, Canada. J Palliat Care. 2017;32(1):11-18.
90. Reyniers T, Deliens L, Pasman HR, et al. International variation in place of death of older people who died from dementia in 14 European and non-European countries. J Am Med Dir Assoc. 2015;16(2):165-171.
91. Seow H, Barbera L, Howell D, et al. Using more end-of-life homecare services is associated with using fewer acute care services: a population-based cohort study. Med Care. 2010;48(2):118-124.
92. Sharpe KH, Cezard G, Bansal N, et al. 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 & palliative care. 2015;5(4):443-451.
93. Silveira MJ, Copeland LA, Feudtner C. Likelihood of home death associated with local rates of home birth: influence of local area healthcare preferences on site of death. Am J Public Health. 2006;96(7):1243-1248.
94. Weitzen S, Teno JM, Fennell M, et al. Factors associated with site of death: a national study of where people die. Med Care. 2003;41(2):323-335.

95. Yun YH, Lim MK, Choi K-S, et al. Predictors associated with the place of death in a country with increasing hospital deaths. Palliat Med. 2006;20(4):455-461.

96. Barbera L, Paszat L, Chartier C. Indicators of poor quality end-of-life cancer care in Ontario. J Palliat Care. 2006;22(1):12-17.

97. Chen B, Fan VY, Yiing-Jenq C, et al. Costs of care at the end of life among elderly patients with chronic kidney disease: patterns and predictors in a nationwide cohort study. BMC Nephrol. 2017;18:1-14.

98. Gieniusz M, Nunes R, Saha V, et al. Earlier Goals of Care Discussions in Hospitalized Terminally Ill Patients and the Quality of End-of-Life Care: A Retrospective Study. American Journal of Hospice & Palliative Medicine. 2018;35(1):21-27.

99. Henson LA, Higginson IJ, Gao W, et al. What factors influence emergency department visits by patients with cancer at the end of life? Analysis of a 124,030 patient cohort. Palliat Med. 2017:269216317713428.

100. Ho TH, Barbera L, Saskin R, et al. Trends in the aggressiveness of end-of-life cancer care in the universal health care system of Ontario, Canada. J Clin Oncol. 2011;29(12):1587-1591.

101. Phongtankuel V, Adelman RD, Trevino K, et al. Association Between Nursing Visits and Hospital-Related Disenrollment in the Home Hospice Population. American Journal of Hospice & Palliative Medicine. 2018;35(2):316-323.

102. Sharma G, Freeman J, Zhang D, et al. Continuity of care and intensive care unit use at the end of life. Arch Intern Med. 2009;169(1):81-86.

103. Sleeman KE, Perera G, Stewart R, et al. Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data. Alzheimer's & dementia : the journal of the Alzheimer's Association. 2018;14(1):20-27.

104. Spilsbury K, Rosenwax L, Arendts G, et al. The Association of Community-Based Palliative Care With Reduced Emergency Department Visits in the Last Year of Life Varies by Patient Factors. Ann Emerg Med. 2017;69(4):416-425.

105. Bahler C, Signorell A, Reich O. Health Care Utilisation and Transitions between Health Care Settings in the Last 6 Months of Life in Switzerland. PLoS ONE [Electronic Resource]. 2016;11(9):e0160932.

106. Brackley M, Penning M. Home-care utilization within the year of death: Trends, predictors and changes in access equity during a period of health policy reform in British Columbia, Canada. Health & Social Care in the Community. 2009;17(3):283-294.

107. Burge FI, Lawson B, Johnston G. Home visits by family physicians during the end-of-life: Does patient income or residence play a role? BMC Palliat Care. 2005;4(1):1.

108. Neergaard MA, Olesen F, Sondergaard J, et al. Are Cancer Patients' Socioeconomic and Cultural Factors Associated with Contact to General Practitioners in the Last Phase of Life? International Journal of Family Medicine Print. 2015;2015:952314.

109. Burdsall TDL. The effects of race, socioeconomic status, and religion on formal end-of-life planning. Dissertation Abstracts International Section A: Humanities and Social Sciences. 2014;74(11-A(E)):No Pagination Specified.

110. Hanson LC, Rodgman E. The use of living wills at the end of life. A national study. Arch Intern Med. 1996;156(9):1018-1022.

111. Hong JH, Kwon JH, Kim IK, et al. Adopting advance directives reinforces patient participation in end-of-life care discussion. Cancer Res Treat. 2016;48(2):753-758.

112. Muni S, Engelberg RA, Treece PD, et al. The influence of race/ethnicity and socioeconomic status on end-of-life care in the ICU. Chest. 2011;139(5):1025-1033.

S6 Text. Strength of evidence and direction of association between measures of socioeconomic position (SEP) and use of health care in the last year of life, from 112 high and medium quality studies

	Total number of outcomes reported (n=142)														
Total number of SEP exposures reported (n=166)	**PoD n=72 (50.7%)**			**Acute care n=19 (13.4%)**			**SPC n=36 (25.4%)**			**Non-SPC n=11 (7.7%)**			**ACP n=4 (2.8%)**		
Direction of association	PH	null	PL	PH	null	PL	PH	null	PL	PH	null	PL	PH	null	PL
Income n=17 (10.2%)	3	3	1	1	1	0	1	4	0	1	0	0	2	0	0
	-			-			-			-			-		
Education n=39 (23.5%)	15	7	5	0	1	0	2	3	0	1	1	0	4	0	0
	-			-			-			-			mod/pro-high		
Insurance n=23 (13.9%)	1	5	0	1	1	0	4	6	0	1	2	1	1	0	0
	-			-						-			-		
Housing n=4 (2.4%)	3	1	0	0	0	0	0	0	0	0	0	0	0	0	0
	mod/pro-high			-			-			-			-		
Area deprivation n=79 (47.6%)	27	6	0	10	4	0	12	13	1	4	0	1	0	1	0
	high/pro-high			mod/pro-high			-			mod/pro-high			-		
Occupation n=4 (2.4%)	1	2	1	0	0	0	0	0	0	0	0	0	0	0	0
	-			-			-			-			-		

Strength of evidence: mod (moderate strength evidence, ≥60% agreement between studies and minimum of 3 medium quality studies); high (high strength evidence, ≥70% agreement between studies, and minimum of 3 high quality studies) (see algorithm in figure 1).

Direction of evidence: pro-high (pro high SEP association); pro-low (pro low SEP association)

Associations with <4 studies, or where <60% of studies indicated the same direction of effect are not assigned a strength or direction.

Outcomes on multiple countries presented in the same study are counted separately, otherwise studies reporting outcomes for different subsamples for example for different time periods or subgroups by diagnosis were pooled prior to being counted.

Appendix 2: Paper 2, supplementary information

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Supplementary appendix

Supplement to: Davies JM, Maddocks M, Chua K-C, Demakakos P, Sleeman KE, Murtagh FEM. Socioeconomic position and use of hospital-based care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing. *Lancet Public Health* 2021; published online Feb 8. http://dx.doi.org/10.1016/S2468-2667(20)30292-9.

Appendix

1: ELSA end-of-life interview

The end-of-life interview was introduced at wave 2 of ELSA, and carried out at wave 3, 4 and 6 (but not wave 5). It consisted of a face-to-face interview with a close friend, relative or carer of the deceased ELSA member and lasted approximately 30 minutes. The interview focused on the health and care needs of the deceased in the year proceeding their death and financial questions regarding inheritance and funeral expenses.

The wider ELSA collects data from 'core' sample members and the cohabiting partners of core sample members. Only 'core' ELSA members who died were eligible for a proxy to be approached for an end-of-life interview. Sample members were identified as having died from NHS mortality data linked to the ELSA (last updated following wave 5), or from individual updates received during fieldwork or between waves. End-of-life interviewees were prioritised in the following order: i) informant identified by interviewer in the field (when the interviewer was informed of the member's death), ii) another ELSA member (partner member) in the household, iii) previously identified proxy (when the member had previously provided contact details for a nominated proxy), iv) no informant identified/case no longer eligible for end-of-life interview. Information on the type of proxy interviewee is not available in the dataset. Limited information on the end-of-life interviewees is available and is provided in the table below.

End-of-life interviews were not sought if the death was too recent – less than 6 months prior to fieldwork. These deaths were then eligible for an end-of-life interview at subsequent waves. Deaths occurring more than two waves previously were no longer eligible.

Further details for the ELSA study, including procedural information about the sampling and fieldwork, data dictionaries, and study documentation including consent forms, interview guides and questionnaires are available from: https://www.elsa-project.ac.uk/study-documentation.

Characteristics for the end-of-life proxy interviewees

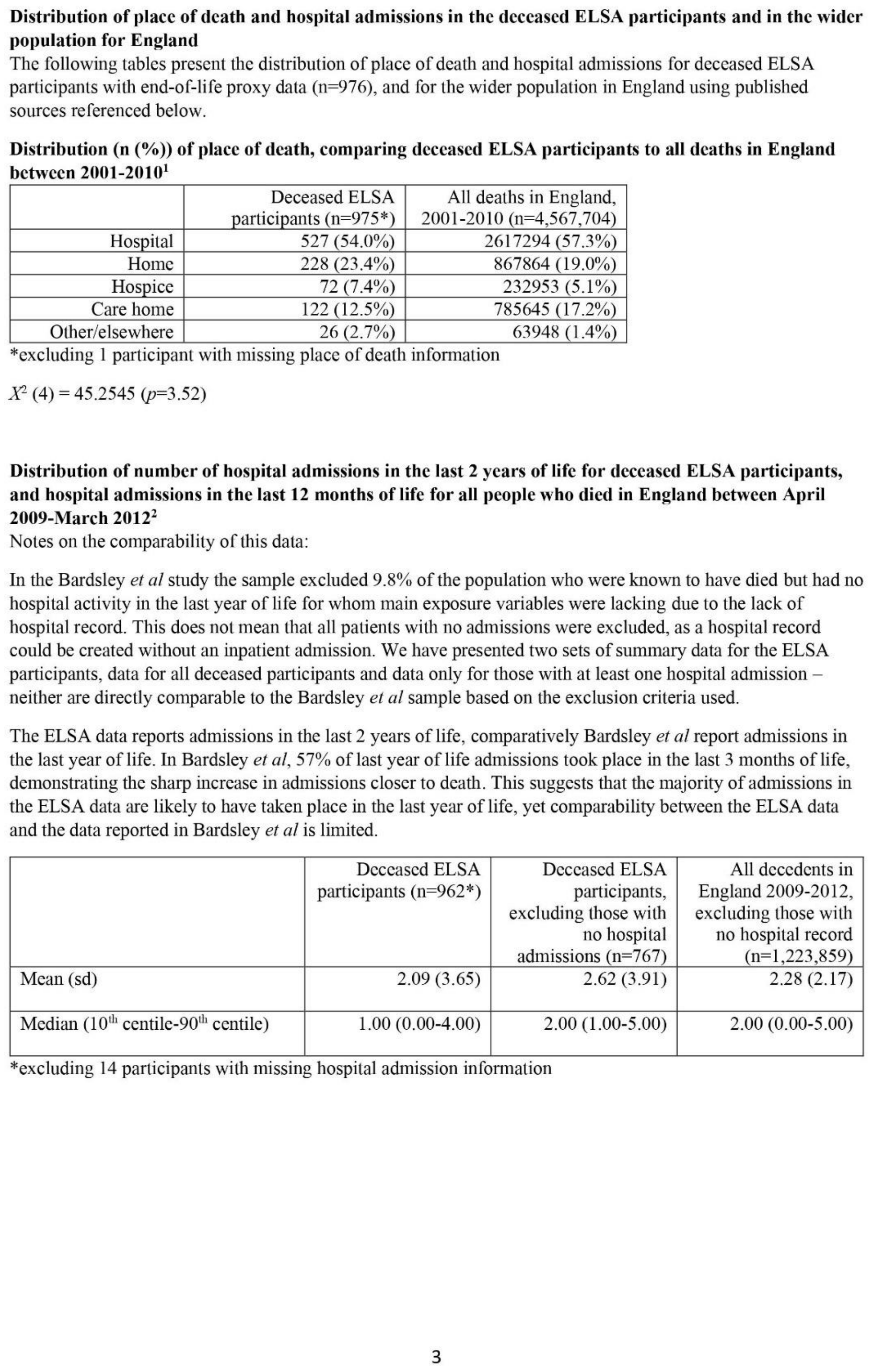
	N=976
Gender:	
Male	314 (32.2%)
Female	662 (67.8%)
Relationship of respondent to deceased:	
Husband/wife/partner	456 (46.7%)
Son/daughter/grandchild (natural or in-law)	382 (39.1%)
Parent/parent-in-law	15 (1.5%)
Brother/sister (natural or in-law)	34 (3.5%)
Other relative	38 (3.9%)
Other non-relative	51 (5.2%)

Fieldwork dates:

Wave 2: June 2004-July 2005
Wave 3: May 2006-August 2007
Wave 4: May 2008-July 2009
Wave 5 (no end-of-life interviews): June 2010-July 2011
Wave 6: May 2012-June 2013

Comparison of the sample with an end-of-life proxy interview, with the wider deceased ELSA cohort

2,556 core ELSA participants are known to have died, of these 976 have a complete end-of-life proxy interview. Compared to the deceased cohort with no end-of-life proxy data, the end-of-life proxy subset has fewer women (50.4% and 45.8%, respectively, X^2 (1) = 5.0672, *p*=0.024), fewer aged 80 years and above when they died (58.0% and 51.1%, respectively, X^2 (1) = 11.4474, *p*=0.001), and are wealthier with fewer in the most deprived quintile for wealth at baseline (33.1% and 27.7%, respectively, X^2 (4) = 13.9343, *p*=0.008). These demographic differences reflect that deceased ELSA participants who were younger and male were more likely to have a living proxy to complete the interview than the older and female decedents.



Distribution of place of death and hospital admissions in the deceased ELSA participants and in the wider population for England

The following tables present the distribution of place of death and hospital admissions for deceased ELSA participants with end-of-life proxy data (n=976), and for the wider population in England using published sources referenced below.

Distribution (n (%)) of place of death, comparing deceased ELSA participants to all deaths in England between 2001-2010[1]

	Deceased ELSA participants (n=975*)	All deaths in England, 2001-2010 (n=4,567,704)
Hospital	527 (54.0%)	2617294 (57.3%)
Home	228 (23.4%)	867864 (19.0%)
Hospice	72 (7.4%)	232953 (5.1%)
Care home	122 (12.5%)	785645 (17.2%)
Other/elsewhere	26 (2.7%)	63948 (1.4%)

*excluding 1 participant with missing place of death information

X^2 (4) = 45.2545 (p=3.52)

Distribution of number of hospital admissions in the last 2 years of life for deceased ELSA participants, and hospital admissions in the last 12 months of life for all people who died in England between April 2009-March 2012[2]

Notes on the comparability of this data:

In the Bardsley *et al* study the sample excluded 9.8% of the population who were known to have died but had no hospital activity in the last year of life for whom main exposure variables were lacking due to the lack of hospital record. This does not mean that all patients with no admissions were excluded, as a hospital record could be created without an inpatient admission. We have presented two sets of summary data for the ELSA participants, data for all deceased participants and data only for those with at least one hospital admission – neither are directly comparable to the Bardsley *et al* sample based on the exclusion criteria used.

The ELSA data reports admissions in the last 2 years of life, comparatively Bardsley *et al* report admissions in the last year of life. In Bardsley *et al*, 57% of last year of life admissions took place in the last 3 months of life, demonstrating the sharp increase in admissions closer to death. This suggests that the majority of admissions in the ELSA data are likely to have taken place in the last year of life, yet comparability between the ELSA data and the data reported in Bardsley *et al* is limited.

	Deceased ELSA participants (n=962*)	Deceased ELSA participants, excluding those with no hospital admissions (n=767)	All decedents in England 2009-2012, excluding those with no hospital record (n=1,223,859)
Mean (sd)	2.09 (3.65)	2.62 (3.91)	2.28 (2.17)
Median (10th centile-90th centile)	1.00 (0.00-4.00)	2.00 (1.00-5.00)	2.00 (0.00-5.00)

*excluding 14 participants with missing hospital admission information

2: Technical information on Mplus analysis

Standardisation procedure

Coefficients were standardised in Mplus using STDYX standardisation for continuous covariates, interpreted as 'the change in y in y standard deviation units for a standard deviation change in x', and STDY standardisation for the binary gender variable, interpreted as 'the change in y in y standard deviation units when x changes from zero to one'.[3] In both standardisation approaches y is y* (the continuous latent response variable underlying the binary variable y).

Confirmatory Factor Analysis (CFA)

For the CFA, we used the default robust weighted least squares (WLSMV) estimator in Mplus, generating linear regression coefficients for continuous items and probit regression coefficients for binary and categorical items.[3] Models were estimated using all available data.[4]

Preliminary analysis

In the preliminary analysis when analysing paths between exposures, mediators and outcomes in separate regression models, we used linear regression and maximum likelihood (ML) estimator for continuous outcomes, and probit regression with (WLSMV) estimator for binary outcomes. For the preliminary single mediator models we used the WLSMV estimator and coefficients were probits.

Full structural model

We used the WLSMV estimator available as default in Mplus for binary outcomes.[5] WLSMV is computationally more efficient than ML and has the advantage of producing absolute model fit statistics.[5] As a result of using WLSMV our coefficients are based on probit regression (logit models available with ML are not available within the more general WLSMV framework). Logit and probit models are both generalised linear models appropriate for binary outcomes, the former uses the logit link function, the latter the inverse normal link function.[6] In practice probit and logit models have similar fit to data.[6] The parameter estimates from logistic regression are approximately 1.8 times those from probit models.[6] Unlike logits, probits cannot be exponentiated to an odds ratio. We translated some of the unstandardised probit coefficients to probabilities for the dependent variable at different values of the independent variable of interest, using the standard formula[3, 7]:

$$P(u_i = 1|x_i) = F(\beta_0 + \beta_1 x_i)$$

Where *F* is the standard normal distribution, we looked up the result from $(\beta_0 + \beta_1 x_i)$ on a *z*-score table to get the probability. When calculating the probabilities we centered all covariates so their means were zero, thus probabilities are interpreted as those for a man with average scores on all other numerical covariates.

Missing data

The default in Mplus is to use all available information, rather than listwise deletion. With ML a Full Information Maximum Likelihood (FIML) approach is used, this method is robust with missing at random (MAR) data patterns where systematic missingness is accounted for by covariates included in the model. With WLSMV, missing data assumptions are more restrictive and limited to missing at random with respect to independent variables (MARX), i.e estimates are not robust if missingness is affected by any dependent variables in the model.[4]

The proportion of missing data was low (<5%) for all variables apart from the latent social support variable (26.1% missing). The missing data on latent social support was reasonably assumed to be MAR but was associated with both independent and dependent variables in our model and therefore violated the MARX assumption. To address missing data in the social support variable the multiple imputation (MI) feature in Mplus was used.

Multiple imputation (MI)

MI in Mplus uses Bayesian estimation to create multiple copies of the datasets with missing values imputed from the predictive distribution based on the observed data. Parameter estimates are then averaged over the set of datasets and standard errors computed from the average of the squared standard errors across the set and from the between analysis parameter estimate variation.[3] In our study, missing values were predicted by all variables included in the final model and 30 imputed datasets were created (representative of the proportion of missing data on the social support variable).

3: Descriptive analysis of the latent variables

Health and function

Items underlying health and function at final wave	N=737 Mean (sd)/n (%)
Grip strength (kg), mean (sd)	25.8 (10.2)
missing, n (%)	538 (73.0)
FVC (litres), mean (sd)	2.6 (0.9)
missing, n (%)	584 (79.2)
5 chair rises (seconds), mean (sd)	49.4 (6.8)
missing, n (%)	616 (83.6)
≥1 functional limitation*, n (%)	434 (58.9)
No functional limitation, n (%)	285 (38.7)
missing, n (%)	18 (2.4)
≥1 chronic illness*, n (%)	542 (73.5)
No chronic illness, n (%)	194 (26.3)
missing, n (%)	1 (0.1)
Poor self-rated health, n (%):	
Poor	116 (15.7)
Fair	125 (17.0)
Good	120 (16.3)
Very good or excellent	72 (9.8)
missing, n (%)	304 (41.3)

*functional limitations include: walking 100 yards (n=284), climbing a single flight of stairs (n=275), and carrying >10lbs (n=373); chronic illnesses include: chronic lung disease (n=133), asthma (n=103), arthritis (n=321), osteoporosis (n=74), cancer (n=166), parkinsons (n=9), any emotional or psychiatric illness (n=60), alzheimers (n=5), and dementia (n=23).

Access to healthcare services

Items underlying access to healthcare services at final wave	N=737 Mean (sd)/n (%)
Ease of access to GP, n (%):	
Difficult or unable	75 (10.2)
Quite easy	137 (18.6)
Very easy	207 (28.1)
missing, n (%)	318 (43.2)
Ease of access to Dentist, n (%):	
Difficult or unable	78 (10.6)
Quite easy	120 (16.3)
Very easy	150 (20.4)
missing, n (%)	389 (52.8)
Ease of access to Hospital, n (%):	
Difficult or unable	104 (14.1)
Quite easy	168 (22.8)
Very easy	145 (19.7)
missing, n (%)	320 (43.4)
Ease of access to Optician, n (%):	
Difficult or unable	86 (11.7)
Quite easy	149 (20.2)
Very easy	171 (23.2)
missing, n (%)	331 (44.9)
Transport deprived*, n (%)	105 (14.3)
Not transport deprived, n (%)	594 (80.6)
missing, n (%)	38 (5.2)
Unmet social care need*, n (%)	204 (27.7)
No unmet social care need, n (%)	596 (67.3)
missing, n (%)	37 (5.0)

* transport deprivation defined as: no access to car and limited access to public transport; unmet social care need defined as: an activity of daily living or instrumental activity of daily living need not being met by either social service, national health service or privately paid workers.

Social support

Following previous examples[8, 9] we used a series of self-reported items capturing the quality of relationships with children, family and friends. Three questions were asked about positive support: 'How much do they really understand the way you feel about things?'; 'How much can you rely on them if you have a serious problem?'; 'How much can you open up to them if you need to talk about your worries?' and three questions about negative support: 'How much do they criticise you?'; 'How much do they let you down when you are counting on them?'; 'How much do they get on your nerves?', each asked in relation to children, family and friends. Response categories were assigned a score of three for the most positive response, to zero for the least positive; those reporting having no children, family or friends were assigned a zero.

Items underlying social support at final wave, n=737		**0 n (%)**	**1 n (%)**	**2 n (%)**	**3 n (%)**	**missing n (%)**
1	how much your children understand you?	71 (9.6)	48 (6.5)	160 (21.7)	238 (32.3)	220 (29.9)
2	how much you can rely on your children?	67 (9.1)	24 (3.3)	52 (7.1)	383 (52)	211 (28.6)
3	how much you can open up to your children?	78 (10.6)	62 (8.4)	115 (15.6)	267 (36.2)	215 (29.2)
4	how much your family understand you?	113 (15.3)	116 (15.7)	141 (19.1)	142 (19.3)	225 (30.5)
5	how much you can rely on your family?	117 (15.9)	90 (12.2)	76 (10.3)	233 (31.6)	221 (30)
6	how much you can open up to your family ?	146 (19.8)	93 (12.6)	115 (15.6)	159 (21.6)	224 (30.4)
7	how much your friends understand you?	64 (8.7)	81 (11)	209 (28.4)	159 (21.6)	224 (30.4)
8	how much you can rely on your friends?	68 (9.2)	80 (10.9)	140 (19)	226 (30.7)	223 (30.3)
9	how much you can open up to your friends?	84 (11.4)	99 (13.4)	161 (21.8)	163 (22.1)	230 (31.2)
10	how much your children criticise you?	76 (10.3)	91 (12.3)	174 (23.6)	175 (23.7)	221 (30)
11	how much your children let you down?	72 (9.8)	33 (4.5)	78 (10.6)	335 (45.5)	219 (29.7)
12	how much your children get on your nerves?	68 (9.2)	40 (5.4)	141 (19.1)	272 (36.9)	216 (29.3)
13	how much your family criticise you?	74 (10)	67 (9.1)	136 (18.5)	220 (29.9)	240 (32.6)
14	how much your family let you down?	89 (12.1)	45 (6.1)	82 (11.1)	289 (39.2)	232 (31.5)
15	how much your family get on your nerves?	76 (10.3)	31 (4.2)	144 (19.5)	254 (34.5)	232 (31.5)
16	how much your friends criticise you?	49 (6.6)	51 (6.9)	136 (18.5)	267 (36.2)	234 (31.8)
17	how much your friends let you down?	54 (7.3)	38 (5.2)	81 (11)	333 (45.2)	231 (31.3)
18	how much your friends get on your nerves?	54 (7.3)	27 (3.7)	129 (17.5)	300 (40.7)	227 (30.8)

Higher scores are more optimal. Responses for positive items (1-9) are: 0 a lot, 1 some, 2 a little, 3 not at all, for the negative items (10-18) options are reversed.

Summary of latent variable measurement models

	Health and function	**Access to healthcare services**	**Social support**
Model fit:			
Chi square	$\chi^2(8) = 18.503$ (p = 0.0178)	$\chi^2(9) = 11.485$ (p = 0.2439)	χ^2 (123) = 437.453 (p <0.001)
RMSEA	0.042	0.020	0.068
CFI	0.974	1.000	0.985
TLI	0.952	1.000	0.982
N (cases with non-missing factor score)	737	711	545
Factor score			
Mean (sd)	.00 (.12)	-.08 (.66)	-.04 (.28)
Median (interquartile range)	-.01 (-.09, .11)	-.06 (-.43, .30)	-.03 (-.18, .12)

Standardised factor loadings

Items	**Health and function**	**Access to healthcare services**	**Social support**
Grip strength	0.179		
FVC	0.319		
Chair rise	0.263		
functional limitation	0.844		
Chronic illness	0.585		
Self-rated health	0.744		
Access to GP		0.944	
Access to dentist		0.962	
Access to optician		0.953	
Access to secondary care		0.847	
Unmet social care need		0.521	
Transport deprivation		0.600	
Children support			0.469
Family support			0.720
Friends support			0.497

4: Preliminary analysis

We analysed paths between exposures, mediators and outcomes in separate regression models, adjusted for age and gender. Wealth and education effects were mutually adjusted for each other (but not in a sequential relationship as they were in the final model). Fixed factor scores were used and data was non-imputed, all available cases were analysed. Standardised effects are reported.

Standardised effects for relationships between exposures, mediators and outcomes

Relationship	n	STDYX effect
wealth > health	731	**0.24 (0.12, 0.32)**
education > health	731	0.00 (-0.08, 0.08)
wealth > access	707	**0.19 (0.12, 0.27)**
education > access	707	0.03 (-0.05, 0.11)
wealth > social	542	0.05 (-0.04, 0.14)
education > social	542	0.00 (-0.09, 0.09)
wealth > place of death	731	**-0.15 (-0.25, -0.06)**
education > place of death	731	-0.09 (-0.18, 0.01)
health > place of death	737	-0.07 (-0.15, 0.02)
access > place of death	711	0.00 (-0.09, 0.09
social > place of death	545	0.02 (-0.08, 0.13)
wealth > hospital admissions	720	**-0.12 (-0.23, -0.02)**
education > hospital admissions	720	0.01 (-0.10, 0.12)
health > hospital admissions	726	**-0.19 (-0.29, -0.09)**
access > hospital admissions	700	-0.10 (-0.20, 0.01)
social > hospital admissions	539	-0.06 (-0.17, 0.05)

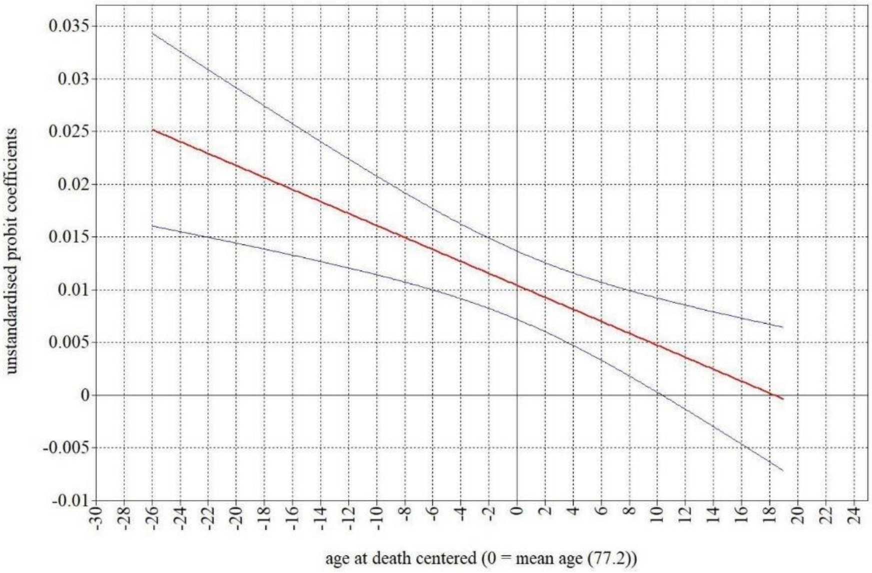
> indicates the direction of the regression path, i.e. wealth predicts health.

We then modelled each of the mediators in a separate structural model that included the two outcomes simultaneously, education and wealth (with wealth regressed on education in a sequential relationship), and adjusted for the effects of age and gender on the mediator and outcomes. Data was non-imputed, all available cases were analysed.

Standardised direct and indirect effects for wealth and education on death in hospital and hospital admissions via health and function, access to healthcare services, and social support: single mediator models

	n	**Death in hospital**	**≥3 hospital admissions**
Model 1: health and function	736		
Wealth (direct effect)		**-0.15 (-0.24, -0.05)**	-0.08 (-0.19, 0.02)
Indirect effect via health and function		-0.01 (-0.03, 0.02)	**-0.04 (-0.07, -0.01)**
Education (direct effect)		-0.08 (-0.18, 0.01)	0.01 (-0.10, 0.12)
Indirect effect via health and function		0.00 (-0.00, 0.00)	-0.00 (-0.01, 0.01)
Model 2: access to healthcare services	736		
Wealth (direct effect)		**-0.16 (-0.26, -0.07)**	**-0.11 (-0.21, -0.00)**
Indirect affect via access to healthcare services		0.01 (-0.01, 0.03)	-0.01 (-0.04, 0.01)
Education (direct effect)		-0.09 (-0.18, 0.01)	0.01 (-0.10, 0.12)
Indirect affect via access to healthcare services		0.00 (-0.00, 0.01)	-0.00 (-0.01, 0.01)
Model 3: social support	736		
Wealth (direct effect)		**-0.15 (-0.25, -0.06)**	**-0.12 (-0.22, -0.02)**
Indirect effect via social support		0.00 (-0.00, 0.00)	-0.00 (-0.01, 0.01)
Education (direct effect)		-0.08 (-0.18, 0.01)	0.01 (-0.10, 0.12)
Indirect effect via social support		0.00 (-0.00, 0.00)	0.00 (-0.01, 0.01)

5: Interaction effect showing the direct effect (and 95% CI) of wealth on health and function moderated by age



6: Standardised probit coefficients with bias corrected bootstrap confidence intervals for the direct and indirect effects for the final structural model (non-imputed data), n=736

	wealth	health and function	access to healthcare services	social support	death in hospital	≥3 hospital admissions
Covariates						
Age	-	-0.05 (-0.10, 0.02)	**-0.23 (-0.28, 0.17)**	**0.12 (0.05, 0.19)**	**0.26 (0.19, 0.34)**	**-0.14 (-0.23, -0.05)**
Female gender		-0.12 (-0.26, 0.03)	0.10 (-0.03, 0.23)	**0.28 (0.11, 0.43)**	-0.01 (-0.20, 0.17)	-0.15 (-0.34, 0.06)
Mediators						
Health and function (direct effect)	-	-	**0.38 (0.33, 0.43)**	-	-0.05 (-0.13, 0.04)	**-0.17 (-0.26, -0.08)**
Indirect effect via access to healthcare services	-	-	-	-	0.02 (-0.01, 0.06)	0.00 (-0.04, 0.04)
Access to healthcare services (direct effect)	-	-	-	-	0.06 (-0.02, 0.15)	0.00 (-0.09, 0.09)
Social support (direct effect)	-	-	-	-	0.03 (-0.06, 0.12)	-0.05 (-0.15, 0.05)
Wealth						
Direct effect	-	**0.25 (0.19, 0.32)**	**0.10 (0.04, 0.16)**	0.07 (-0.01, 0.15)	**-0.16 (-0.24, -0.07)**	-0.08 (-0.17, 0.01)
Total indirect effects	-	-	-	-	0.00 (-0.02, 0.03)	**-0.05 (-0.08, 0.02)**
Via health and function	-	-	**0.10 (0.07, 0.13)**	-	-0.01 (-0.03, 0.01)	**-0.04 (-0.07, -0.02)**
Via access to health-care services	-	-	-	-	0.01 (-0.00, 0.02)	0.00 (-0.01, 0.01)
Via social support	-	-	-	-	0.00 (-0.00, 0.01)	-0.00 (-0.02, 0.00)
Via health and function, and access to health-care services	-	-	-	-	0.01 (-0.00, 0.02)	0.00 (-0.01, 0.01)
Total effect	-	-	-	-	**-0.15 (-0.23, -0.07)**	**-0.12 (-0.21, -0.03)**
Highest educational qualification						
Direct effect	**0.39 (0.33, 0.44)**	0.00 (-0.06, 0.07)	0.03 (-0.03, 0.09)	-0.00 (-0.08, 0.07)	**-0.09 (-0.17, -0.00)**	0.00 (-0.08, 0.10)
Total indirect effects	-	-	-	-	**-0.06 (-0.09, -0.03)**	**-0.05 (-0.09, -0.01)**
Via health and function	-	-	0.00 (-0.03, 0.03)	-	-0.00 (-0.01, 0.00)	0.00 (-0.01, 0.01)
Via access to health-care services	-	-	-	-	0.00 (-0.00, 0.01)	0.00 (-0.00, 0.00)
Via social support	-	-	-	-	0.00 (-0.01, 0.00)	0.00 (-0.00, 0.01)
Via wealth	-	**0.10 (0.07, 0.13)**	**0.04 (0.02, 0.06)**	0.03 (-0.00, 0.06)	**-0.06 (-0.10, -0.03)**	-0.03 (-0.07, 0.01)
Via health and function, and access to health-care services	-	-	-	-	0.00 (-0.00, 0.00)	0.00 (-0.00, 0.00)
Total effect	-	-	-	-	**-0.14 (-0.22, -0.07)**	-0.04 (-0.12, 0.04)
Covariances						
Social support	-	-	**0.11 (0.04, 0.19)**	-	-	-
Death in hospital	-	-	-	-	-	**0.21 (0.10, 0.32)**

Effects with a p value <0.05 are shown in bold.

Model fit: $\chi^2(3) = 5.062$ (p = 0.1673), RMSEA = 0.031 CFI = 0.994, TLI = 0.933

7: Standardised probit coefficients for the direct and indirect effects for the full structural model, n=950 including participants with an admission to a care home in the last 2 years of life

	Wealth	Health and function	Access to healthcare services	Social support	Death in hospital	≥3 hospital admissions
Covariates						
Age	-	**-0.10 (-0.17, -0.04)**	**-0.24 (-0.29, -0.18)**	**0.12 (0.04, 0.19)**	**0.13 (0.05, 0.22)**	**-0.13 (-0.22, -0.04)**
Female gender		**-0.25 (-0.37, -0.12)**	0.07 (-0.05, 0.19)	**0.27 (0.12, 0.42)**	-0.06 (-0.22, 0.11)	-0.12 (-0.30, 0.06)
Mediators						
Health and function (direct effect)	-	-	**0.38 (0.32, 0.43)**	-	-0.04 (-0.13, 0.05)	**-0.15 (-0.25, -0.05)**
Indirect effect via access to healthcare services	-	-	-	-	0.04 (-0.00, 0.07)	-0.00 (-0.04, 0.04)
Access to healthcare services (direct effect)	-	-	-	-	0.09 (-0.00, 0.19)	-0.01 (-0.11, 0.09)
Social support (direct effect)	-	-	-	-	0.01 (-0.92, 0.11)	-0.02 (-0.12, 0.08)
Wealth						
Direct effect	-	**0.23 (0.17, 0.30)**	**0.08 (0.01, 0.14)**	0.06 (-0.03, 0.16)	**-0.09 (-0.18, -0.01)**	-0.09 (-0.18, 0.01)
Total indirect effects	-	-	-		0.01 (-0.02, 0.03)	**-0.04 (-0.06, -0.01)**
Via health and function	-	-	**0.09 (0.06, 0.12)**	-	-0.01 (-0.03, 0.01)	**-0.04 (-0.06, -0.01)**
Via access to health-care services	-	-	-	-	0.01 (-0.00, 0.02)	-0.00 (-0.01, 0.01)
Via social support	-	-	-	-	0.00 (-0.01, 0.01)	-0.00 (-0.01, 0.01)
Via health and function, and access to health-care services	-	-	-	-	0.01 (-0.00, 0.02)	-0.00 (-0.01, 0.01)
Total effect	-	-	-	-	**-0.09 (-0.17, -0.00)**	**-0.13 (-0.22, -0.03)**
Highest educational qualification						
Direct effect	**0.39 (0.34, 0.45)**	0.01 (-0.06, 0.08)	0.01 (-0.05, 0.08)	0.01 (-0.08, 0.09)	-0.09 (-0.18, 0.00)	0.04 (-0.06, 0.13)
Total indirect effects	-	-	-	-	-0.03 (-0.07, 0.00)	**-0.05 (-0.09, -0.01)**
Via health and function	-	-	0.00 (-0.02, 0.03)	-	0.00 (-0.00, 0.00)	-0.00 (-0.01, 0.01)
Via access to health-care services	-	-	-	-	0.00 (-0.01, 0.01)	0.00 (-0.00, 0.00)
Via social support	-	-	-	-	0.00 (-0.00, 0.00)	0.00 (-0.00, 0.00)
Via wealth	-	**0.09 (0.06, 0.12)**	**0.03 (0.00, 0.06)**	0.03 (-0.1, 0.06)	**-0.04 (-0.07, -0.00)**	-0.04 (-0.01, 0.00)
Via health and function, and access to health-care services	-	-	-	-	0.00 (-0.00, 0.00)	0.00 (-0.00, 0.00)
Total effect	-	-	-	-	**-0.12 (-0.20, -0.04)**	-0.02 (-0.10, 0.08)
Covariances						
Social support	-	-	**0.15 (0.07, 0.22)**	-	-	-
Death in hospital	-	-	-	-	-	**0.22 (0.11, 0.32)**

Effects with a p value <0.05 are shown in bold.

(model fit indices were averaged across the MI sets): $\chi^2(3) = 11.201$ (sd = 2.857), RMSEA = 0.053 (sd = 0.009) and CFI = 0.982 (sd = 0.006) indicate good fit, and TLI = 0.802 (sd = 0.068) indicates less than adequate fit.

8: Sensitivity analysis: cause of death and depressive symptoms as potential confounders

To investigate diagnosis as a confounder of the exposure-outcome relationships, we describe the distribution of exposures, mediators and outcomes by cause of death and diagnosis of depressive symptoms. We also present the direct effect of wealth on the outcomes for two additional models, one with the effects on the outcomes adjusted for cancer versus non-cancer cause of death, and another adjusted for diagnosis of depressive symptoms.

In this sample, the proportion of people who died in hospital (compared to home or hospice) is higher for people with a non-cancer cause of death and for people with depressive symptoms (tables 8a and 8b). Education and wealth are lower for people with a non-cancer cause of death and for people with depressive symptoms (tables 8a and 8b).

The direct effect of wealth on hospital death remains statistically significant but is attenuated when the final model is adjusted for cancer cause of death, and when the final model is adjusted for depressive symptoms (table 8c). The effect of wealth on hospital admissions remains statistically non-significant in the adjusted models.

[Scale of measures for table 8a and 8b (non-imputed data): educational qualifications (edqual) 0 to 5; wealth 1-10; health and function (health) -0.25 to 0.29; access to healthcare services (access) -1.52 to 0.89; social support (social) -0.86 to 0.59. Health, access and social are latent factor scores.]

8a Distribution of exposures, mediators and outcomes by cause of death*

Cause of death	N	Age, mean (SD)	edqual, mean (SD)	wealth, mean (SD)	health, mean (SD)	access, mean (SD)	social, mean (SD)	% death in hospital	% ≥3 hospital admissions
Cancer	251	73.7 (9.5) (n=251)	2.2 (1.5) (n=251)	5.7 (2.9) (n=250)	0.0 (0.1) (n=251)	0.1 (0.6) (n=244)	-0.0 (0.3) (n=200)	111 (44.2%)	70 (27.9%)
Cardiovascular	215	79.5 (9.1) (n=215)	1.7 (1.2) (n=215)	4.3 (2.8) (n=212)	-0.0 (0.1) (n=215)	-0.2 (0.6) (n=208)	-0.0 (0.3) (n=156)	138 (64.2%)	38 (17.7%)
Respiratory	92	79.2 (9.7) (n=92)	1.7 (1.2) (n=92)	4.5 (2.7) (n=91)	-0.0 (0.1) (n=92)	-0.3 (0.7) (n=91)	-0.1 (0.3) (n=66)	69 (75.0%)	33 (35.9%)
Other	84	77.9 (10.2) (n=84)	1.6 (1.1) (n=84)	4.9 (2.9) (n=84)	0.0 (0.1) (n=84)	-0.1 (0.7) (n=80)	0.0 (0.3) (n=62)	68 (81.0%)	18 (21.4%)
missing	95	78.9 (9.9) (n=95)	1.9 (1.3) (n=94)	5.5 (2.9) (n=95)	0.0 (0.1) (n=95)	-0.1 (0.6) (n=88)	-0.1 (0.3) (n=61)	63 (66.3%)	28 (29.5%)

*cause of death from death record

8b Distribution of exposures, mediators and outcomes by self-reported depressive symptoms*

	N	age, mean (SD)	edqual, mean (SD)	wealth, mean (SD)	somatic, mean (SD)	access, mean (SD)	social, mean (SD)	% death in hospital	% ≥3 hospital admissions
Depressive symptoms*	481	76.0 (9.8) (n=180)	1.7 (1.2) (n=481)	4.7 (2.8) (n=480)	-0.0 (0.1) (n=481)	-0.1 (0.7) (n=481)	-0.1 (0.3) (n=385)	308 (64.0%)	128 (26.6%)
No depressive symptoms	180	77.2 (9.8) (n=481)	2.3 (1.5) (n=180)	6.1 (2.8) (n=178)	0.1 (0.1) (n=180)	0.2 (0.6) (n=180)	0.0 (0.3) (n=152)	89 (49.4%)	41 (22.8%)
Missing	76	80.5 (9.8) (n=76)	1.8 (1.3) (n=75)	4.9 (2.9) (n=74)	-0.0 (0.1) (n=76)	-0.3 (0.5) (n=50)	-0.1 (0.3) (n=8)	52 (68.4%)	18 (23.7%)

*: ≥1 of the following self-reported depressive symptoms: depressed much of the time, everything an effort much of the time, sleep was restless much of the time, not happy much of the time, felt lonely much of the time, did not enjoy life much of the time, felt sad much of the time, could not get going much of the time

8c Direct effect of wealth on the outcomes after adjusting for cancer cause of death (versus non-cancer cause of death), and diagnosis of depressive symptoms (versus absence of depressive symptoms) (n=737)

	Direct effect of wealth on death in hospital	**Direct effect of wealth on hospital admissions**
Final model (not adjusted for cancer cause of death or diagnosis of depressive symptoms)	-0.16 (-0.25, -0.06)	-0.08 (-0.19, 0.03)
Adjustment for cancer* (0=non-cancer cause of death; 1=cancer cause of death)	-0.12 (-0.22, -0.03)	-0.09 (-0.20, 0.01)
Adjustment for depressive symptoms (0=no depressive symptoms; 1= ≥1 depressive symptoms)**	-0.14 (-0.24, -0.05)	-0.09 (-0.19, 0.02)

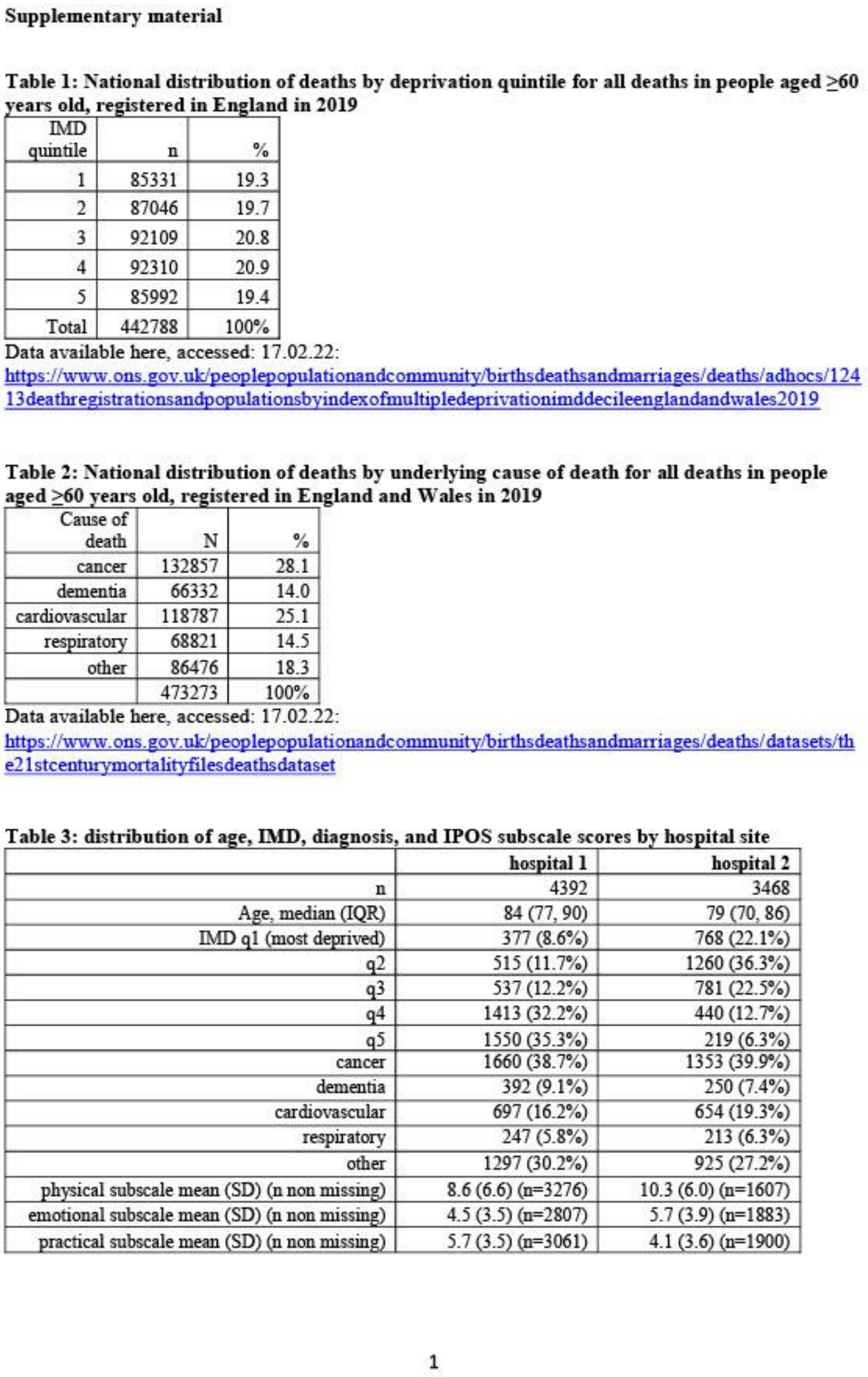
***model fit following adjustment for cancer:** $\chi^2(7) = 47.587$ (sd = 6.035), RMSEA = 0.088 (sd =0.007) and CFI = 0.891 (sd = 0.015), TLI = 0.393 (sd =0.086).

****model fit following adjustment for depressive symptoms:** $\chi^2(3) = 138.773$ (sd = 6.577), RMSEA = 0.160 (sd =0.004) and CFI = 0.704 (sd = 0.014), TLI = -0.649 (sd = 0.076).

References

1. Gao W, Ho Y, Verne J, et al. Geographical and temporal Understanding In place of Death in England (1984–2010): analysis of trends and associated factors to improve end-of-life Care (GUIDE_Care) – primary research. Health Serv Deliv Res. 2014;2(42).
2. Bardsley M, Georghiou T, Spence R, et al. Factors associated with variation in hospital use at the end of life in England. BMJ Supportive & Palliative Care. 2019;9(2):167-174.
3. Muthén L, Muthén B. Mplus User's Guide. Sixth Edition. Los Angeles, CA: Muthén & Muthén 1998-2010.
4. Asparouhov T, Muthén, BO. Weighted Least Squares Estimation with Missing Data. unpublished article, available: http://wwwstatmodelcom/download/GstrucMissingRevisionpdf. (accessed: 16.02.2020).
5. Muthén B, Muthén., L. & Asparouhov, T. Estimator choices with categorical outcomes. unpublished technical report, available: http://wwwstatmodelcom/download/EstimatorChoicespdf. 2015;(accessed: 10.03.2020).
6. Agresti A. An introduction to categorical data analysis: second edition. Hoboken, New Jersey: John Wiley & Sons, Inc. 2007.
7. Muthén BO, Muthén LK, Asparouhov T. Regression and Mediation Analysis Using Mplus. Los Angeles, CA: Muthen & Muthen 2016.
8. Banks J, Berkman L, Smith J, et al. Do cross-country variations in social integration and social interactions explain differences in life expectancy in industrialized countries? . In Crimmins E, Preston S, Cohen B, (Eds). International differences in mortality at old ages: dimensions and sources. Washington, DC: The National Academies Press 2010.
9. Ding YY, Kuha J, Murphy M. Multidimensional predictors of physical frailty in older people: identifying how and for whom they exert their effects. Biogerontology. 2017;18(2):237-252.

Appendix 3: Paper 3, supplementary information



Supplementary material

Table 1: National distribution of deaths by deprivation quintile for all deaths in people aged ≥60 years old, registered in England in 2019

IMD quintile	n	%
1	85331	19.3
2	87046	19.7
3	92109	20.8
4	92310	20.9
5	85992	19.4
Total	442788	100%

Data available here, accessed: 17.02.22:
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/12413deathregistrationsandpopulationsbyindexofmultipledeprivationimddecileenglandandwales2019

Table 2: National distribution of deaths by underlying cause of death for all deaths in people aged ≥60 years old, registered in England and Wales in 2019

Cause of death	N	%
cancer	132857	28.1
dementia	66332	14.0
cardiovascular	118787	25.1
respiratory	68821	14.5
other	86476	18.3
	473273	100%

Data available here, accessed: 17.02.22:
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/the21stcenturymortalityfilesdeathsdataset

Table 3: distribution of age, IMD, diagnosis, and IPOS subscale scores by hospital site

	hospital 1	hospital 2
n	4392	3468
Age, median (IQR)	84 (77, 90)	79 (70, 86)
IMD q1 (most deprived)	377 (8.6%)	768 (22.1%)
q2	515 (11.7%)	1260 (36.3%)
q3	537 (12.2%)	781 (22.5%)
q4	1413 (32.2%)	440 (12.7%)
q5	1550 (35.3%)	219 (6.3%)
cancer	1660 (38.7%)	1353 (39.9%)
dementia	392 (9.1%)	250 (7.4%)
cardiovascular	697 (16.2%)	654 (19.3%)
respiratory	247 (5.8%)	213 (6.3%)
other	1297 (30.2%)	925 (27.2%)
physical subscale mean (SD) (n non missing)	8.6 (6.6) (n=3276)	10.3 (6.0) (n=1607)
emotional subscale mean (SD) (n non missing)	4.5 (3.5) (n=2807)	5.7 (3.9) (n=1883)
practical subscale mean (SD) (n non missing)	5.7 (3.5) (n=3061)	4.1 (3.6) (n=1900)

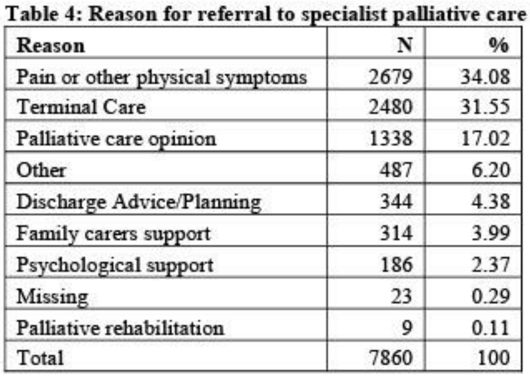
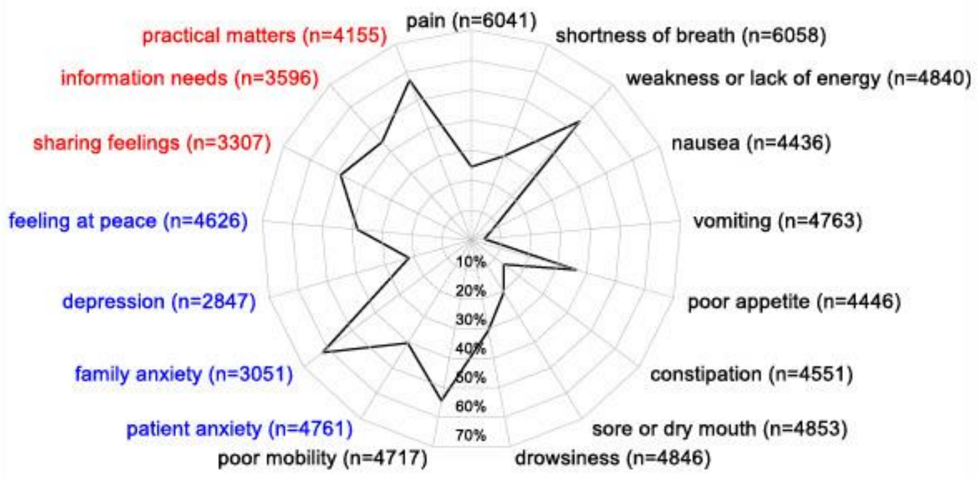


Table 4: Reason for referral to specialist palliative care

Reason	N	%
Pain or other physical symptoms	2679	34.08
Terminal Care	2480	31.55
Palliative care opinion	1338	17.02
Other	487	6.20
Discharge Advice/Planning	344	4.38
Family carers support	314	3.99
Psychological support	186	2.37
Missing	23	0.29
Palliative rehabilitation	9	0.11
Total	7860	100

Figure 1: Proportion of patients with moderate, severe, or overwhelming* on each of the IPOS items (using complete case data)



*'Moderate, severe, or overwhelming' represent high scores (2-4, on the 0-4 IPOS scale), with higher scores representing worse symptoms and problems. Items in the emotional and practical subscales have different text associated with the scale, for full details see the IPOS measure: https://pos-pal.org/

Text colour indicates grouping of items in the three subscales: black (physical) blue (emotional) red (communication/practical)

Table 5: distribution of IPOS scores

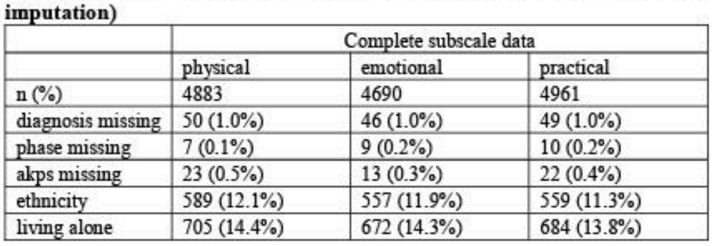
	% 2-4	% 0	% 1	% 2	% 3	% 4
pain	24.4	50.8	24.8	18.7	4.9	0.8
shortness of breath	30.1	44.6	25.3	20.9	7.7	1.4
weakness or lack of energy	53.6	30.2	16.2	23.1	18.7	11.9
nausea	7.8	84.5	7.7	5.6	1.9	0.3
vomiting	4.3	91.6	4.1	2.8	1.2	0.3
poor appetite	36.2	46.2	17.5	21.3	11.1	3.9
constipation	13.4	75.2	11.4	9.7	3.3	0.5
sore or dry mouth	20.5	46.2	33.3	15.9	3.7	0.8
drowsiness	30.6	51.6	17.7	13.0	8.0	9.6
poor mobility	54.4	31.9	13.8	17.7	17.9	18.8
patient anxiety	40.3	34.3	25.4	28.6	10.0	1.8
family anxiety	62.1	14.7	23.2	36.5	20.4	5.2
depression	21.6	61.1	17.2	16.2	4.6	0.9
feeling at peace	38.1	23.5	38.4	24.9	7.8	5.4
sharing feelings	48.7	26.0	25.3	18.0	9.5	21.3
information needs	44.2	29.4	26.4	18.5	7.3	18.4
practical matters	57.1	22.9	20.0	29.2	12.7	15.2

Table 6: Odds of having missing data (after median imputation) for the three IPOS subscales (n=6266)

	physical		**emotional**		**Communication/practical**	
	OR	CI	OR	CI	OR	CI
Age	0.99	(0.99 - 1.00)	1.00	(0.99 - 1.01)	1.01	(1.00 - 1.02)
Gender						
men	ref	ref	ref	ref	ref	ref
women	1.02	(0.89 - 1.17)	1.10	(0.97 - 1.24)	1.09	(0.95 - 1.24)
Total clinical time with patient during episode*						
0-20 minutes	1.46	(1.19 - 1.79)	1.65	(1.36 - 1.99)	1.34	(1.09 - 1.64)
25-45 minutes	1.37	(1.14 - 1.65)	1.32	(1.10 - 1.59)	1.30	(1.07 - 1.57)
50-85 minutes	1.24	(1.02 - 1.49)	1.12	(0.93 - 1.35)	1.14	(0.94 - 1.39)
90-500 minutes	ref	ref	ref	ref	ref	ref
IMD						
q1 (most deprived)	1.37	(1.06 - 1.78)	0.98	(0.79 - 1.23)	1.09	(0.85 - 1.38)
q2	1.18	(0.92 - 1.51)	0.97	(0.79 - 1.19)	1.01	(0.81 - 1.27)
q3	1.40	(1.08 - 1.80)	0.99	(0.80 - 1.22)	1.20	(0.95 - 1.51)
q4	1.41	(1.11 - 1.80)	0.92	(0.76 - 1.11)	1.10	(0.89 - 1.35)
q5	ref	ref	ref	ref	ref	ref
Ethnicity						
white british	ref	ref	ref	ref	ref	ref
white other	1.29	(0.97 - 1.71)	1.12	(0.84 - 1.50)	1.17	(0.86 - 1.58)
black	1.21	(0.98 - 1.51)	1.50	(1.19 - 1.89)	1.24	(0.98 - 1.57)
asian	0.99	(0.66 - 1.48)	1.10	(0.74 - 1.64)	1.07	(0.71 - 1.62)
other	1.11	(0.78 - 1.58)	1.42	(0.99 - 2.04)	1.28	(0.88 - 1.85)
missing	1.20	(0.97 - 1.49)	1.22	(0.98 - 1.51)	1.46	(1.17 - 1.82)
Living alone						
not living alone	ref	ref	ref	ref	ref	ref
lives alone	0.89	(0.75 - 1.04)	0.97	(0.83 - 1.12)	0.93	(0.79 - 1.09)
missing	1.03	(0.85 - 1.25)	1.41	(1.14 - 1.73)	1.47	(1.19 - 1.81)
Diagnosis						
cancer	ref	ref	ref	ref	ref	ref
dementia	1.51	(1.15 - 1.99)	2.12	(1.67 - 2.68)	1.49	(1.15 - 1.92)
cardiovascular	1.34	(1.08 - 1.66)	1.76	(1.45 - 2.14)	1.30	(1.05 - 1.60)
respiratory	1.11	(0.83 - 1.49)	0.73	(0.53 - 1.00)	0.76	(0.55 - 1.06)
other	0.96	(0.80 - 1.17)	1.19	(0.99 - 1.42)	1.05	(0.87 - 1.27)
Phase of illness						
unstable	ref	ref	ref	ref	ref	ref
stable	1.00	(0.71 - 1.41)	0.84	(0.56 - 1.26)	0.73	(0.47 - 1.15)
deteriorating	0.80	(0.66 - 0.98)	1.05	(0.88 - 1.26)	1.07	(0.88 - 1.30)
dying	1.16	(0.95 - 1.41)	1.06	(0.88 - 1.27)	1.35	(1.11 - 1.63)
AKPS	0.98	(0.97 - 0.98)	0.95	(0.95 - 0.96)	0.95	(0.95 - 0.96)
Hospital site						
hospital 1	ref	ref	ref	ref	ref	ref
hospital 2	9.69	(8.10 - 11.61)	2.18	(1.86 - 2.55)	3.90	(3.30 - 4.62)

*includes all time a clinician spends with the patient, does not include clinician time spent with family, other healthcare professionals, or admin time

Table 7: Missing values on covariates, for cases with non-missing subscale data (after median imputation)



	Complete subscale data		
	physical	emotional	practical
n (%)	4883	4690	4961
diagnosis missing	50 (1.0%)	46 (1.0%)	49 (1.0%)
phase missing	7 (0.1%)	9 (0.2%)	10 (0.2%)
akps missing	23 (0.5%)	13 (0.3%)	22 (0.4%)
ethnicity	589 (12.1%)	557 (11.9%)	559 (11.3%)
living alone	705 (14.4%)	672 (14.3%)	684 (13.8%)

Table 8: Main models, full results for all covariates (corresponds to figure 1 and table 4 in the manuscript)

	Physical n=4803		Emotional n=4622		Practical n=4880	
age	-0.03	[-0.06,-0.01]	-0.07	[-0.08,-0.05]	0.00	[-0.01,0.02]
women (ref)	-	-	-	-	-	-
men	0.10	[-0.26,0.46]	-0.03	[-0.23,0.18]	0.01	[-0.19,0.21]
imd q1 (most deprived)	-0.51	[-1.15,0.12]	-0.14	[-0.50,0.23]	0.56	[0.21,0.91]
imd q2	-0.33	[-0.91,0.26]	-0.16	[-0.50,0.17]	0.33	[0.01,0.64]
imd q3	-0.05	[-0.65,0.56]	0.17	[-0.17,0.52]	0.44	[0.12,0.76]
imd q4	-0.29	[-0.79,0.22]	0.11	[-0.19,0.40]	0.34	[0.07,0.61]
imd q5 (ref)	-	-	-	-	-	-
white British (ref)	-	-	-	-	-	-
white other	0.22	[-0.66,1.11]	0.42	[-0.06,0.90]	-0.14	[-0.58,0.29]
black	-0.23	[-0.92,0.47]	-0.47	[-0.90,-0.05]	0.15	[-0.27,0.56]
asian	0.23	[-0.96,1.43]	-0.19	[-0.79,0.41]	-0.09	[-0.76,0.59]
other	-0.82	[-1.94,0.29]	0.03	[-0.76,0.81]	0.17	[-0.55,0.88]
missing	1.01	[0.31,1.70]	0.57	[0.14,1.01]	-0.24	[-0.67,0.18]
not living alone (ref)	-	-	-	-	-	-
lives alone	0.42	[0.01,0.83]	0.20	[-0.03,0.44]	0.11	[-0.11,0.33]
missing	0.08	[-0.57,0.72]	-0.09	[-0.49,0.32]	0.19	[-0.21,0.58]
cancer (ref)	-	-	-	-	-	-
dementia	-0.95	[-1.76,-0.14]	-0.63	[-1.10,-0.17]	0.75	[0.29,1.20]
cardiovascular	-1.49	[-2.09,-0.90]	-0.53	[-0.88,-0.19]	0.40	[0.07,0.74]
respiratory	-0.89	[-1.63,-0.15]	0.33	[-0.12,0.78]	-0.25	[-0.63,0.13]
other	-1.98	[-2.48,-1.48]	-0.31	[-0.60,-0.01]	0.32	[0.04,0.60]
stable	-2.51	[-3.19,-1.83]	-1.49	[-1.99,-0.99]	0.11	[-0.32,0.54]
unstable (ref)	-	-	-	-	-	-
deteriorating	-0.89	[-1.31,-0.47]	-0.85	[-1.12,-0.58]	-0.28	[-0.52,-0.03]
dying	-0.53	[-1.08,0.01]	-1.17	[-1.49,-0.86]	-0.64	[-0.95,-0.34]
AKPS	-0.08	[-0.10,-0.07]	-0.02	[-0.02,-0.01]	-0.04	[-0.05,-0.04]
Hospital 1 (ref)	-	-	-	-	-	-
Hospital 2	1.86	[1.39,2.32]	0.76	[0.50,1.03]	-1.54	[-1.79,-1.29]

Table 9: Model fit statistics and moderation effects

Model 1: Minimally adjusted model, adjusted for **age, sex, hospital site, IMD**
Model 2: Fully adjusted model, model 1 + **ethnicity, lives alone, diagnosis, Phase, AKPS**
Model 3: Moderation by age, model 2 + **age##IMD**
Model 4: Moderation by sex, model 2 + **sex##IMD**

	Model 1 **minimally adjusted model**	**Model 2** **fully adjusted model**	**Model 3** **moderation by age**	**Model 4** **moderation by sex**
Physical (n=4803)				
IMD q1 (most deprived)	-0.59 [-1.23,0.05]	-0.51 [-1.15,0.12]	-0.01 [-0.07,0.05]	-0.63 [-1.82,0.55]
q2	-0.30 [-0.89,0.29]	-0.33 [-0.91,0.26]	-0.02 [-0.08,0.03]	0.05 [-0.99,1.10]
q3	-0.02 [-0.63,0.60]	-0.05 [-0.65,0.56]	0.00 [-0.06,0.06]	0.65 [-0.50,1.80]
q4	-0.29 [-0.80,0.22]	-0.29 [-0.79,0.22]	-0.07 [-0.13,-0.02]	0.79 [-0.22,1.80]
q5	ref	ref	ref	ref
R^2	0.0178	0.0634	0.0651	0.0647
ΔR^2	0.0178	0.0020	0.0018	0.0013
F	13.40	2.36	2.23	1.73
p	<0.0001	0.0380	0.0630	0.1404
Emotional (n=4622)				
IMD q1 (most deprived)	-0.21 [-0.57,0.16]	-0.14 [-0.50,0.23]	-0.01 [-0.04,0.03]	-0.44 [-1.12,0.24]
q2	-0.24 [-0.57,0.09]	-0.16 [-0.50,0.17]	0.00 [-0.04,0.03]	-0.47 [-1.08,0.13]
q3	0.17 [-0.18,0.52]	0.17 [-0.17,0.52]	-0.01 [-0.04,0.03]	-0.54 [-1.20,0.13]
q4	0.10 [-0.19,0.40]	0.11 [-0.19,0.40]	-0.03 [-0.06,0.00]	-0.10 [-0.68,0.48]
q5	ref	ref	ref	ref
R^2	0.0689	0.0970	0.0977	0.0979
ΔR^2	0.0689	0.0036	0.0007	0.0009
F	48.32	3.39	0.84	1.13
p	<0.0001	0.0047	0.4990	0.3419
Practical (n=4880)				
IMD q1 (most deprived)	0.67 [0.32,1.02]	0.56 [0.21,0.91]	-0.04 [-0.07,-0.01]	-0.21 [-0.87,0.45]
q2	0.44 [0.12,0.76]	0.33 [0.01,0.64]	-0.04 [-0.07,-0.01]	0.28 [-0.30,0.86]
q3	0.45 [0.12,0.77]	0.44 [0.12,0.76]	-0.03 [-0.06,0.00]	-0.09 [-0.71,0.52]
q4	0.41 [0.13,0.68]	0.34 [0.07,0.61]	0.00 [-0.03,0.03]	0.15 [-0.39,0.69]
q5	ref	ref	ref	ref
R^2	0.0545	0.0918	0.0941	0.0923
ΔR^2	0.0545	0.0006	0.0023	0.0005
F	39.90	0.56	3.09	0.65
p	<0.0001	0.7337	0.0150	0.6264

Interpretation:
For model 1, model fit comparison is against the null model, for model 3 and 4 comparison is against model 2
For model 3 and 4, IMD coefs are for the interaction effects e.g. age##imd (interpreted as the difference in age slopes for IMD q1/4 compared to q5) and sex##imd (interpreted as the effect of being male versus female in IMD q1/4 versus q5)
R^2 is the proportion of the variance in the dependent variable predicted from the independent variables
ΔR^2 is the increase in R^2 between models
F is based on the Wald statistic and sums the predictive power of the block of independent variables (blocks of variables indicated in bold at the top of the table) and p tests the overall significance of the predictive power of the block.

Table 10: Sensitivity analysis; coefficients for IMD in the final model and in the complete case analysis, models adjusted for age, sex, ethnicity, living alone, diagnosis, AKPS, Phase, hospital site

	final model	complete case	MI
Physical n	4803	3805	7310*
IMD q1 (most deprived)	-0.51 [-1.15,0.12]	-0.20 [-0.80,0.41]	-0.44 [-1.02,0.15]
q2	-0.33 [-0.91,0.26]	-0.39 [-0.94,0.15]	-0.31 [-0.83,0.21]
q3	-0.05 [-0.65,0.56]	0.23 [-0.34,0.80]	0.10 [-0.42,0.63]
q4	-0.29 [-0.79,0.22]	-0.16 [-0.63,0.31]	-0.30 [-0.75,0.15]
q5	ref	ref	ref
Emotional n	4622	1767	
IMD q1 (most deprived)	-0.14 [-0.50,0.23]	-0.33 [-0.86,0.20]	-0.21 [-0.54,0.12]
q2	-0.16 [-0.50,0.17]	-0.02 [-0.53,0.49]	-0.08 [-0.36,0.21]
q3	0.17 [-0.17,0.52]	0.04 [-0.47,0.55]	0.15 [-0.16,0.46]
q4	0.11 [-0.19,0.40]	0.16 [-0.27,0.59]	0.12 [-0.13,0.37]
q5	ref	ref	ref
Practical n	4880	2600	
IMD q1 (most deprived)	0.56 [0.21,0.91]	0.63 [0.21,1.05]	0.63 [0.29,0.97]
q2	0.33 [0.01,0.64]	0.42 [0.05,0.78]	0.35 [0.01,0.69]
q3	0.44 [0.12,0.76]	0.26 [-0.11,0.63]	0.35 [0.04,0.65]
q4	0.34 [0.07,0.61]	0.39 [0.09,0.69]	0.35 [0.09,0.61]
q5	ref	ref	ref

*missing data on the categorical variables gender, diagnosis and Phase were not imputed to ensure the MI model would converge, therefore the n is less than the total sample N of 7860. Missing data for age and AKPS were imputed as part of the MI model.