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Palliative Medicine

Socioeconomic factors affecting access to preferred place of death: a qualitative evidence synthesis

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Keywords:	socioeconomic factors, palliative care, terminal care, qualitative research, systematic review

Abstract:	Background: Existing quantitative evidence suggests that at a population level socioeconomic factors affect access to preferred place of death. However, the influence of individual and contextual socioeconomic factors on preferred place of death are less well understood. Aim: To systematically synthesise the existing qualitative evidence for socioeconomic factors affecting access to preferred place of death in the United Kingdom. Design: A thematic synthesis of qualitative research. Data sources: Cochrane Library, MEDLINE, Embase, CINAHL, ASSIA, Scopus and PsycINFO databases were searched from inception to May 2018. Results: 13 articles reporting on 12 studies were included in the synthesis. Two over-arching themes were identified: 'Human factors' representing support networks, interactions between people, and decision making and 'Environmental factors', which included issues around locations and resources. Few studies directly referenced socioeconomic deprivation. The predominant factor affecting access to preferred place of death was social support; people with fewer informal carers were less likely to die in their preferred location. Other key findings included fluidity around the concept of home and variability in preferred place of death itself, particularly in response to crises. Conclusion: There is limited UK-based qualitative research on socioeconomic factors affecting preferred place of death. Further qualitative research is needed to explore the barriers and facilitators of access to preferred place of death in socioeconomically deprived UK communities. In practice there needs to be more emphasis on discussing and documenting preferred place of death, whilst also recognising these preferences are liable to change as death nears or in times of crisis.

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PALLIATIVE MEDICINE AUTHOR SUBMISSION CHECKLIST

Please complete this checklist for all papers submitted. Please indicate, very briefly, how this has been addressed. This checklist is a mandatory upload on submission.

Item	Explanation	How this has been addressed (briefly, a sentence will suffice)
Article title	***WHY: Because we want readers to find your work.*** Have you followed our guidelines on writing a good title that will be found by search engines? (E.g. with methods in the title, use of common words for the issue addressed, no country names, and possibly indicating findings). If your study has an acronym is it included in the title?	Yes – no acronyms, method included, no country names, use of key words.
Abstract	***WHY: Because structured abstracts have more detail for readers and search engines.*** Have you followed our guidelines on writing your structured abstract? Please remember we have separate abstract structures for original research, reviews and case reports. There should be **no** abbreviations in the abstract, EXCEPT a study acronym which should be included if you have one. If a trial (or other design formally registered with a database) have you included your registration details?	Yes – abstract structured as per PM guidance for a review paper.
Key statements	***WHY: Because readers want to understand your paper quickly.*** Have you included our key statements within the body of your paper (after abstract and before the main text is a good place!) and followed our guidelines for how these are to be written? There are three main headings required, and each may have 1-3 separate **bullet** points. Please use clear, succinct, single sentence separate bullet points rather than complex or multiple sentences.	Yes – located after abstract and before main text, structured according to 3 given headings, no more than 3 bullet points for each as single sentences.
Keywords	***WHY: Because MeSH headings mean it is properly indexed.*** Have you given keywords for your study? We ask that these are current **MeSH** headings unless there is no suitable heading for use (please give explanation in cover letter). https://meshb.nlm.nih.gov/search	Yes – key words used are all MeSH headings.
International relevance	***WHY: We have readers from around the world who are interested in your work.*** Have you contextualised your work for an international audience and explained how your work contributes to an international knowledge base? Avoid drawing from policy from one context only, think	Although included papers have been limited to UK articles due to concerns about generalisability between health systems with

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	how your work could be relevant more widely. Do define terms clearly e.g. hospice has a different meaning in many countries.	different economic models, many of the social factors discussed are relevant across international boundaries.
Publishing guidelines	***WHY: Because clear and robust reporting helps people interpret your work accurately*** Have you submitted a completed checklist for a relevant publishing guideline as a supplementary file? http://www.equator-network.org/ These include CONSORT, PRISMA, COREQ checklists, but others may be more relevant for your type of manuscript. If no published checklist exists please create one as a table from the list of requirements in your chosen guideline. If your study design does not have a relevant publishing guideline please review closest matches and use the most appropriate with an explanation.	Yes – the review has been reported according to ENTREQ guidelines (used for syntheses of qualitative research). Completed ENTREQ statement attached.
Word count	***WHY: Because readers want to find the core information quickly.*** Does your paper adhere to our word count for your article type? Please insert number of words in the box to the right. Remember that tables, figures, qualitative data extracts and references are not included in the word count.	Word count = **4994** (excluding title page, tables/figures/quotes and references, but including abstract/key statements/declarations) **4347** (excluding title page, tables/figures/quotes/references and abstract/key statements/declarations) Both under 5000 word limit for review article.
Figures and tables and/or quotations	***WHY: Because readers want to find the core information quickly.*** Have you adhered to our guidelines on the number of tables and figures for your article type? Data (e.g. quotations) for qualitative studies are not included in the word count, and we prefer that they are integrated into the text (e.g. not in a separate table).	There are 3 tables and 1 figure (PRISMA flowchart), plus table of included studies as an appendix. Quotes have been used in the text, and have not been put in separate tables.
Study registration	***WHY: Because this means readers understand how you planned your study***	There was no published protocol for this study, nor was it registered in advance.

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	Where appropriate have you included details (including reference number, date of registration and URL) of study registration on a database e.g. trials or review database. If your study has a published protocol, is this referenced within the paper?	
Other study publications?	***WHY: So readers can understand the full context of your study*** If there are other publications from this study are these referenced within the body of the paper? Please do not reference papers in preparation or submitted, but in-press publications are acceptable.	There are no associated publications for this study.
Scales, measures or questionnaires	***WHY: So readers can understand your paper in the context of this information*** If your study primarily reports the development or testing of scales/measures or questionnaires have you included a copy of the instrument as a supplementary file?	No scales, questionnaires or measures have been used in this study.
Abbreviations	***WHY: Because abbreviations make a paper hard to read, and are easily misunderstood*** Have you removed **all** abbreviations from the text except for extremely well known, standard abbreviations (e.g. SI units), which should be spelt out in full first? We do not allow abbreviations for core concepts such as palliative or end of life care.	An abbreviation has been used for United Kingdom/UK, although the first mention is spelt out in full.
Research ethics and governance approvals for research involving human subjects	***WHY: We will only publish ethically conducted research, approved by relevant bodies*** Have you given full details of ethics/governance/data protection approvals with reference numbers, full name of the committee(s) giving approval and the date of approval? If such approvals are not required have you made it explicit within the paper why they were not required. Are details of consent procedures clear in the paper?	No ethics approval was required for this research as the study was a review of existing, published articles with no new primary data collected. This is stated in the declarations section of the paper.
Date(s) of data collection	***WHY: So readers understand the context within which data were collected*** Have you given the dates of data collection for your study within the body of your text? If your data are over 5 years old you will need to articulate clearly why they are still relevant and important to current practice.	Data collection has all been done in the previous 5 years (with a top up search checking for any additional papers since the original search).
Structured discussion	***WHY: So readers can find key information quickly*** Papers should have a structured discussion, with sub headings, summarising the main findings, addressing strengths and limitations, articulating what this study adds with reference to existing international literature, and presenting the implications for practice.	The discussion section has been structured as per PM subheadings/guidelines.

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Case reports	***WHY: So that participants are protected, and its importance made clear*** If your study is a case report have you followed our clear structure for a case report, including highlighting what research is needed to address the issue raised? Have you made clear what consent was required or given for the publication of the case report? Have you provided evidence of such consent as a supplementary file to the editor?	N/A
Acknowledgements and declarations	***WHY: So readers understand the context of the research*** Have you included a funding declaration according to the SAGE format? Are there acknowledgements to be made? Have you stated where data from the study are deposited and how they may be available to others? Have you conflicts of interest to declare?	Declarations have been completed as per PM guidelines. No funding was required and there are no conflicts of interest.
Supplementary data and materials	***WHY: So the context is clear, but the main paper succinct for the reader*** Is there any content which could be provided as supplementary data which would appear only in the online version of accepted papers? This could include large tables, full search strategies for reviews, additional data etc.	The large table of included studies has been included as an appendix, as has the full list of search terms used in the search strategy.
References	***WHY: So people can easily find work you have referenced*** Are your references provided in SAGE Vancouver style? You can download this style within Endnote and other referencing software.	The paper has been referenced according to SAGE Vancouver for PM journal.
Ownership of work.	Can you assert that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.	This is a piece of my own original research. This is the first submission for publication of this paper – no submissions have been filed anywhere else.

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Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement

No	Item	Guide and description	Completed
1	Aim	State the research question the synthesis addresses.	**Yes** – in abstract and full article
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology *(e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).*	**Yes** – thematic synthesis
3	Approach to searching	Indicate whether the search was pre-planned (*comprehensive search strategies to seek all available studies)* or iterative (*to seek all available concepts until they theoretical saturation is achieved)*.	**Yes** – iterative searching
4	Inclusion criteria	Specify the inclusion/exclusion criteria *(e.g. in terms of population, language, year limits, type of publication, study type)*.	**Yes** – inclusion criteria section under Method
5	Data sources	Describe the information sources used (e.g. *electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists)* and when the searches conducted; provide the rationale for using the data sources.	**Yes** – electronic databases listed along with search dates. Reasons for not using grey literature also included.

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No	Item	Guide and description	Completed
6	Electronic Search strategy	Describe the literature search *(e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)*.	**Yes** – overview given in text with full list of search terms as appendix
7	Study screening methods	Describe the process of study screening and sifting *(e.g. title, abstract and full text review, number of independent reviewers who screened studies).*	**Yes** – written description plus completed PRISMA flowchart
8	Study characteristics	Present the characteristics of the included studies *(e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).*	**Yes** – included full table of characteristics as an appendix. Overview and details of socioeconomic characteristics reviewed by studies given in main text.
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion *(e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).*	**Yes** – included in PRISMA flowchart with more description in main text
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings *(e.g. assessment of conduct (validity and robustness),*	**Yes** – including quality appraisal (although there was no a prior threshold for

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No	Item	Guide and description	Completed
		assessment of reporting (transparency), assessment of content and utility of the findings).	discounting articles based on quality).
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope* [25]*; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).*	**Yes** – tool developed by Hawker et al. referenced in article. [Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the Evidence: Reviewing Disparate Data Systematically. *Qualitative Health Research*. 2002;12(9):1284-1299.]
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	**Yes** – carried out by one reviewer with sample checked by second reviewer for consistency
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	**Yes** – summary of results given in article, individual scores given in table in Appendix B. No articles excluded on basis of quality.
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g. all text under the headings*	**Yes** – included results/ findings section but not

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No	Item	Guide and description	Completed
		"results /conclusions" were extracted electronically and entered into a computer software).	discussion (reasons indicated in Method section)
15	Software	State the computer software used, if any.	**Yes** – Microsoft Word
16	Number of reviewers	Identify who was involved in coding and analysis.	**Yes** – coding by VT, checked by KF
17	Coding	Describe the process for coding of data *(e.g. line by line coding to search for concepts).*	**Yes** – description provided (based on Thomas and Harden's approach)
18	Study comparison	Describe how were comparisons made within and across studies *(e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).*	**Yes** – described in data analysis section of Method
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	**Yes** – predominantly inductive as described
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	**Yes** – see Results section. Participant/author quotes indicated by different fonts
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. *new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).*	**Yes** – results present a more nuanced view of preferred place of death (and the effect socioeconomic factors have

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No	Item	Guide and description	Completed
			on it) than has previously been possible to describe by quantitative research, which gives important implications for policy and practice.

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Title Page

Article title: Socioeconomic factors affecting access to preferred place of death: a qualitative evidence synthesis

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Title

Socioeconomic factors affecting access to preferred place of death: a qualitative evidence synthesis

Abstract

Background: Existing quantitative evidence suggests that at a population level socioeconomic factors affect access to preferred place of death. However, the influence of individual and contextual socioeconomic factors on preferred place of death are less well understood.

Aim: To systematically synthesise the existing qualitative evidence for socioeconomic factors affecting access to preferred place of death in the United Kingdom.

Design: A thematic synthesis of qualitative research.

Data sources: Cochrane Library, MEDLINE, Embase, CINAHL, ASSIA, Scopus and PsycINFO databases were searched from inception to May 2018.

Results: 13 articles reporting on 12 studies were included in the synthesis. Two over-arching themes were identified: 'Human factors' representing support networks, interactions between people, and decision making and 'Environmental factors', which included issues around locations and resources.

Few studies directly referenced socioeconomic deprivation. The main~~predominant~~ factor affecting access to preferred place of death was social support; people with fewer informal carers were less likely to die in their preferred location. Other key findings included fluidity around the concept of home and variability in preferred place of death itself, particularly in response to crises.

Conclusion: There is limited UK-based qualitative research on socioeconomic factors affecting preferred place of death. Further qualitative research is needed to explore the barriers and facilitators of access to preferred place of death in socioeconomically deprived UK communities. In practice there needs to be more widespread ~~emphasis on~~ discussion~~ng~~ and documentation~~ing~~ of preferred place of death, whilst also recognising these preferences may~~are liable to~~ change as death nears or in times of crisis.

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Key words

Socioeconomic factors, terminal care, palliative care, qualitative research, systematic review

Key statements

What is already known about the topic?

- Socioeconomic factors affect palliative care provision, including access to preferred place of death.
- Quantitative studies have demonstrated associations between place of death and social class, with people from higher socioeconomic groups more likely to die at home or in hospices, and less likely to die in hospital, than people from lower socioeconomic groups.

What this paper adds

- There is limited discussion of socioeconomic factors affecting preferred place of death in UK qualitative literature.
- The main factor affecting access to preferred place of death was the presence of social support.
- There was fluidity around the concept of 'home', and around the location of preferred place of death itself towards the end of life.

Implications for practice, theory or policy

- Further qualitative research is needed to explore the barriers and facilitators of access to preferred place of death in socioeconomically deprived UK communities.
- In practice there needs to be more emphasis on both discussing and documenting preferred place of death, which can be managed through existing care pathways.
- Care plans should be reviewed appropriately in ~~alongside the~~ recognition that these preferences are liable to change as death nears or in times of crisis.~~.~~
- ~~Discussions on preferred place of death should be integrated into already extant care pathways.~~

Introduction

~~It is known that s~~Socioeconomic factors affect palliative care provision, including access to preferred place of death. UK-based quantitative studies have shown~~demonstrated~~ links~~associations~~ between place of death and social class, with people from higher socioeconomic groups more likely to die at home or in hospices, and less likely to die in hospital, than people from lower socioeconomic groups.[1-4] Similarly, in the Unite~~d~~ds States Howell et al.[5] found ~~that people with~~ higher earners~~income~~ were more likely to~~had increased odds of~~ dy~~i~~eng at home, and a systematic review by Cohen[6] found that 12 out of 13 studies showed differences between minority ethnic groups and white Americans. Other international studies have associated~~shown that~~ low educational attainment ~~was associated~~ with reduced access to specialist palliative care services.[7,8]

P~~Although p~~referred place of death is a key part of many national policies on end of life care. However, it is less visible in academic literature than actual place of death, for which quantitative data is much more widely available. K~~Similarly, k~~ey socioeconomic determinants such as occupation, income, ethnicity and postcode ~~area~~ are easier to measure quantitatively, both through targeted surveys and through~~as part of~~ routinely collected data. Direct correlations between socioeconomic status and place of death can therefore be ~~undertaken~~ measured on larger populations quantitatively; however, this does not allow for exploration of the nuances behind these associations.

Qualitative research can ~~be used to~~ enhance the evidence from~~provided by~~ quantitative studies by~~through~~ highlighting individuals' own perceptions of their care needs.[9,10] Qualitative evidence synthesis is particularly relevant in palliative care as it maximises value from studies that have investigated difficult subject matter around end of life ~~decisions~~.[11] This study ~~therefore~~ aims to ~~systematically~~ contextualise qualitative data by synthesis~~inge~~ the existing qualitative evidence for socioeconomic factors affecting access to preferred place of death in the UK.~~, in order to contextualise quantitative findings.~~

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Methods

Search strategy

A systematic approach to searching was undertaken to address the research question 'what, and in what ways, do socioeconomic factors affect access to preferred place of death in the UK?'.

Firstly it was important to identify what terms to use to define 'socioeconomic factors'. An iterative approach was taken due to the lack of a universally-accepted definition of socioeconomic disadvantage. A series of initial searches were run using variations on definitions of 'socioeconomic factors' (for example, relating strictly to social class and economics or including people more broadly at socioeconomic disadvantage, such as the homeless). As searching for strict socioeconomic terms did not identify articles more specifically related to socioeconomically disadvantaged populations the decision was taken to include a broad set of socioeconomic terms, compiled after reviewing search terms from other articles with similar themes.[12-17] These included terms covering social class, income, unemployment, ethnicity, homelessness, detainees, travelling communities, migrants/refugees, literacy/education levels, and socially disadvantaged/excluded groups.

~~A systematic approach to searching was undertaken. The list of search terms was compiled after looking at search terms used in other articles with similar themes.[12-17] These were then adapted to best suit the focus of the current review. In response to these initial results iterative development of the searches occurred in order to develop the most appropriate set of search terms particularly around the terms for 'socioeconomic factors'. A broad set of factors was chosen for the final search, including terms covering social class, income, unemployment, ethnicity, homelessness, detainees, travelling communities, migrants/refugees, literacy/education levels, and socially disadvantaged/excluded groups.~~ The search terms used in the final strategy covered three main areas: socioeconomic factors, place of death and palliative care or carers. Finally, a 3-term qualitative filter was added (qualitative, finding*, interview*).[18] The full list of search terms is included as Appendix A.

Seven electronic databases containing relevant peer-reviewed journals were searched from inception until June 2016: Cochrane Library, MEDLINE, Embase, CINAHL, ASSIA, Scopus and PsycINFO. A further search (using identical terms but restricted to the last 2 years) was carried out in May 2018 to identify any further articles published since the initial search date.

Inclusion criteria

Articles were included~~deemed eligible for inclusion~~ if they:

- ~~d~~Discussed preferred place of death and at least one of the identified socioeconomic factors (as set out in the search strategy) in a population of UK residents.
- R~~;r~~eported on data collected and analysed using qualitative methods (mixed methods articles were included if qualitative findings were reported separately).
- W~~;w~~ere written in English and published in an academic journal.

~~-~~No date restrictions were included.

Papers were restricted to a single health system (UK) due to concerns over the generalisability of economic factors affecting access to health care between health systems with different economic

components. However, as some of the social factors faced are similar across nations with differing healthcare systems, the broader findings are still relevant to an international audience.

Quality appraisal

~~A q~~Quality appraisal was undertaken to provide a transparent assessment of the methodological strengths and limitations of included articles. This used a tool developed by Hawker et al.,[19] which has been extensively used ~~tilised~~ in systematic reviews of qualitative ~~research, and~~research and is also able to cover mixed methods (and quantitative) studies. The appraisal process was carried out by a single reviewer (VT), with a second reviewer (KF) checking a sample of forms for consistency. There was no a priori cut off score for inclusion on the grounds of quality; however, it was important to ~~take into account~~consider any papers of very low quality when examining the reliability of the results.

Data extraction

Data extraction was completed in two phases. Firstly, summary data and population details were extracted using a standardised extraction form. Secondly, the results/findings sections (including text and tables/diagrams) from each paper were copied into Microsoft Word. A decision was taken not to analyse the discussion section ~~in order to~~to minimise the risk of subjective bias from the original authors.

Data analysis

Findings were analysed using thematic synthesis,[20] a method used to bring together and integrate the findings of multiple qualitative studies.[21]

Coding was carried out according to Thomas and Harden's[20] approach to thematic synthesis by one reviewer (VT), and checked by a second (KF). Firstly, the text was processed line-by-line and individual codes identified. These were reviewed following repeat readings of the text to check for consistency. Once each article had been coded, the individual codes were organised into broader groups of similar codes to develop descriptive themes. These themes were then reviewed collectively ~~and in discussion with the research team~~ by both authors to produce the final list of themes and subthemes. The derivation of themes was predominantly inductive, although there was a small deductive component as the process was guided by the overall research question. The order in which the papers were coded was not predetermined as papers were considered to all be of equal value. However, attempts were made not to code two similar papers (e.g. interviews with nursing home staff) in a row to prevent simply copying codes from one paper to the next.

The paper has been reported in accordance with ENTREQ guidelines.[22]

Results

2726 papers were identified during the initial search process. One reviewer (VT) removed duplicates and reviewed ~~of~~ titles and abstracts to remove clearly irrelevant articles, leaving 142 articles remaining. This decreased to 26 following removal of non-UK results. Both reviewers then collectively reviewed the remaining papers, identifying 13 that fitted all the inclusion criteria.

The update search run in May 2018 identified 296 papers initially (268 once duplicates removed). Following screening 11 articles were reviewed in full; however, none of these fulfilled all the inclusion criteria and so were not included in the review.

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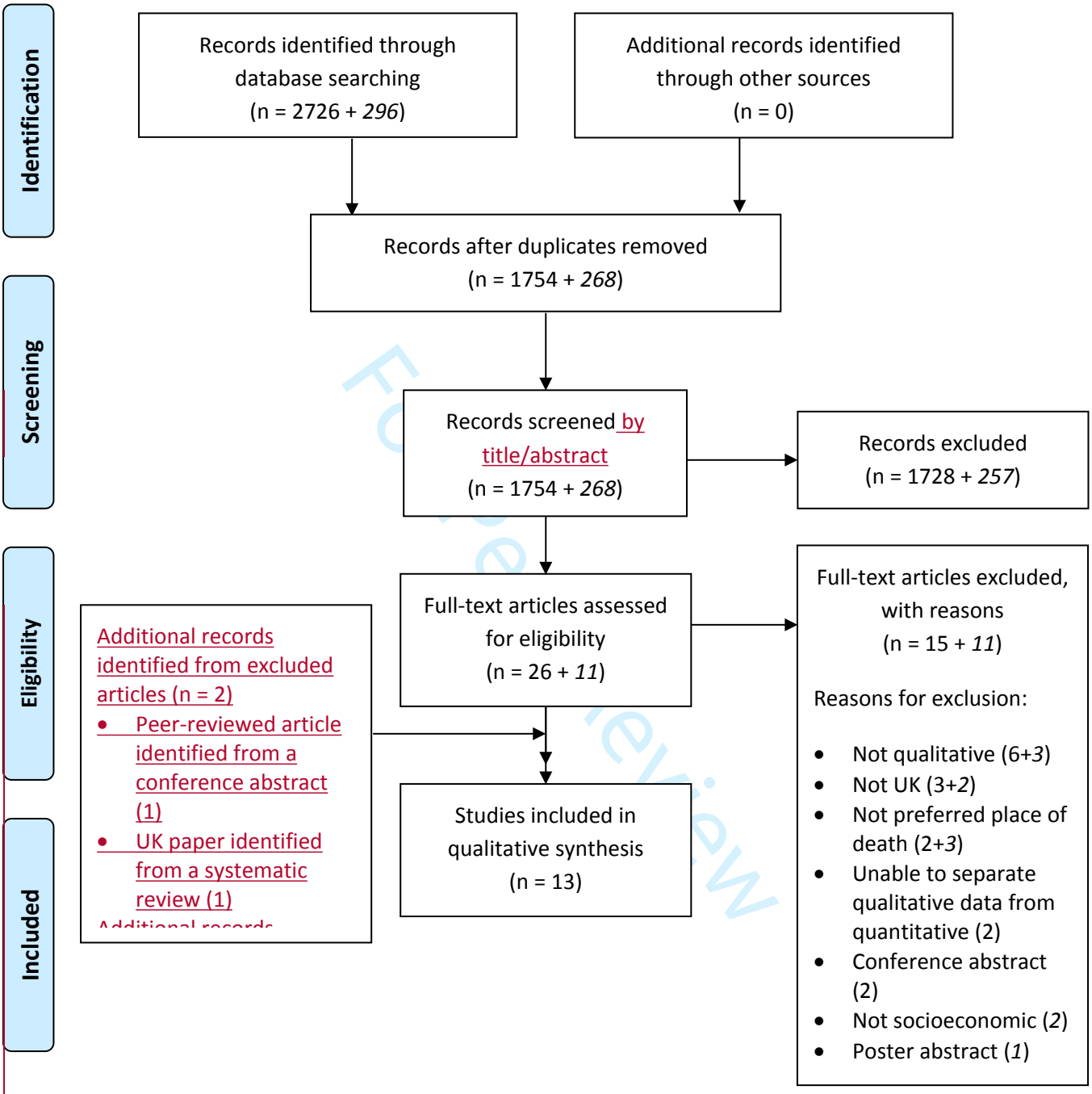
Figure 1: PRISMA flowchart of article selection (2 searches separately: original 2016 search given first, then 2018 update in italics)



13 articles covering 12 studies were included in the final review (see Appendix B)., 10 were purely qualitative[23-32] and 3 were mixed methods[33-35]. 6 had a primary population made up of staff members,[23,24,27,30,31,34] 2 looked at informal carers/relatives,[29,33] 1 looked at community groups representing older people[26] and 4 reviewed participants' own feelings regarding end of life issues.[25,28,32,35]

Socioeconomic profile of participants

In terms of socioeconomic characteristics, the included papers were extremely heterogeneous. They were largely poor at discussing socioeconomic factors explicitly, and there was also poor reporting of the socioeconomic make-up of participants. In total 6 articles reported gender,[23,25,26,28,32,34] 5 reported ethnicity,[23,26,28,32,33] 4 reported age,[25,26,28,32] 4 reported residence[25,26,28,32] and 2 reported social class.[29,32] None reported specifically on participants' income or educational level.

Ethnicity: Where stated, the majority of the participants were described as white British, except in articles where ethnic minorities were explicitly studied (one looking at Chinese and one looking at Black Caribbean groups).

Age: Most were from older age groups, except articles that interviewed medical professionals and the gypsy/traveller community (mixed ages). Most papers reported ages as ranges, with an overall age range of 15-20 years old to 80-90 years old.

Residence: Where residence was noted within papers it usually involved care homes, although participants in one study all lived in gypsy/traveller communities. Two articles stated when participants came from deprived geographic areas.

Social class: In the two papers where social class was specifically reported, both determined class using last known occupation.

Socioeconomic content of articles

Different socioeconomic factors were addressed in different papers (table 1):

Table 1: Socioeconomic content of articles

Socioeconomic factor	Area
Social status (3)[28,29,32]	Social class (2)[29,32] Deprived geographic locations (2)[29,32] Marginalised communities (1) [28]
Finance (4)[27,29,31,32]	Loss of earnings (3)[27,29,32] Service costs to family (1) [32] Service costs to provider (1)[31]
Socioeconomically-deprived populations (2)[28,34]	Prisoners (1)[34] Gypsies/travellers (1)[28]
Ethnicity (3)[23,32,33]	Chinese vs. white British (1)[32] Black Caribbean vs. white British (1)[33] White British views on multiculturalism (1)[23]
Absence of social support (6)[26,27,30-32,34]	Living alone (5)[26,27,30-32] Prisoners (1)[34]
Elderly populations (4)[24-26,35]	Care home residents (3)[24,26,35] Residents with dementia (1)[25]

Despite including specific search terms in these areas, no UK articles were found that discussed education level/literacy, homelessness or migrants/refugees.

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Quality appraisal scores for the included articles were generally between 26 and 33 (overall range of 21 to 35), suggesting that most articles were of good quality. Lower scores were often due to poor reporting around bias, particularly around the position of the researcher.

Through the process of coding, developing codes into descriptive themes and then into analytical themes (an example of which is shown in Table 2), two overarching analytical themes were identified: 'Human factors' and 'Environmental factors'. Human factors detail the interactions between individuals and their support networks, and how these connections can facilitate or deny access to preferred place of death. Environmental factors explore the physical location of where care takes place, alongside the physical resources available (or required) within those environments. Each of these themes were sub-divided further as shown in Table 3. Themes include information on specific socioeconomic findings and also broader issues around accessing preferred place of death. Quotes presented below in '*italics*' are from research participants; quotes in 'regular font' are from authors of the original papers.

Table 2: Example of coding process

Process	Example
Original text	"District nurses identified the loss of the 'safety net' of hospital care as a factor in carer breakdown. Panic sets in among those who struggle to adjust and while district nurses attempt to respond as quickly as possible, they stressed that they 'are not emergency response'."
Selection of coding fragment	"loss of the 'safety net' of hospital care as a factor in carer breakdown"
Given code	Concern for carer wellbeing
Organised into groups	Caring for carers
Groups arranged into themes	Support networks
Overarching theme	Human factors

Table 3: Overview of themes and subthemes

Overarching theme	Themes	Subthemes
Human factors	Support Networks	Family Characteristics
		Carer experience
		Acceptable carers
		Caring for carers
		Absence of support
	Interactions between people	Discussions around death
		Company during death
		Interactions with health professionals
	Decision making	External influence
		Fears
		Ability to make decisions
		Changing decisions
		Documentation of decisions
Environmental factors	Locations	Home

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		Hospice
		Care homes
		Hospital
		Prisons
	Resources	Level of care
		Pressure on services

Human factors

Whilst individuals generally stated their own preferred place of death, it was the people around them that had most influence as to whether they were able to die there. There was little explicit discussion of socioeconomic factors, with the size of support networks and the skill set of carers the most frequently discussed topics. Three main factors were influential: supporting networks, interactions between people and decision-making.

Support networks

Families were a key part of most support networks. The family background of the dying person plays a significant role in end of life care; socioeconomic and cultural factors were most evident here.

Evidence from the reviewed papers suggests that differences in social class did not seem to make much difference to the type of care individuals could access, with problems regarding access spread across all classes. This was seen explicitly in the two papers discussing social class,[29,32] and failed to arise as an issue in any of the other papers. The only suggestion that higher classes had any advantage was through being more willing to engage in more forceful negotiations, which sometimes (but not always) led to a change in care. In contrast, carers from lower socioeconomic classes had greater ability to draw on support from a second carer, as they had more family members living nearby.[29] However, trying to pinpoint the social class of a whole family using typical measures (i.e. social class based on their last known job) was difficult, with even small family groups presenting as a mix of classes. In terms of economic factors, lower classes ~~(rather than higher classes)~~ were less concerned about finances and loss of earning potential than higher classes, despite having more poorly paid jobs.[29]

> "Families often relied on their most forceful members, particularly children of higher social class, to help negotiate these barriers."[29]

Contrasting attitudes to end of life care were seen among people of different ethnicities, with particular groups facing specific challenges. For example, gypsy traveller communities displayed high levels of resilience due to their unwillingness to rely on external services.[28] In another example, Chinese elders had ~~particular ideas~~ideas about dying in the home that were not shared by ~~any~~ other cultures:[32]

> *"And if you die in the house, you know, the house is not a good house any more …, no Chinese would buy a car that had been in an accident" (Chinese elder)*[32]

Regardless of socioeconomic status, the size and composition of an individual's support network ~~also~~ had a significant effect on ~~an individual's~~ preferred place of death and the ability to die there. Absence of a support network, usually family, was the main barrier to dying at home.~~;~~ ~~F~~four papers ~~in particular~~ suggested that living alone meant it was not realistically possible to die at home.[26,27,31,32] In other cases

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the expertise of the carers affected whether patients could be cared for and die at home, and the level of any extra support required. The ability of carers to cope generally deteriorated during the final phase of illness, leading to last-minute transfers. Patients' concerns about carers' ability to cope also influenced place of death, with individuals not wishing to become a burden on their family.[26,27,30,32,35] Some individuals were also selective about who they wanted to care for them, which directly affected preferred place of death.[26,28,32] In some communities (e.g. gypsy travellers, or historically in UK culture) caring was a gender specific role. For some people the intimate nature of care led to embarrassment; whilst people were willing to accept partners as carers they did not wish for wider family members to take on this role.

> "Participants who did not have close relatives, especially those who were widowed or separated, felt that this meant they were automatically excluded from the possibility of being cared for at home."[26]

Interactions between people

Individuals reported the importance of having people present when they died, which in turn affected their choice of preferred place of death. ~~Whilst having people to provide support increased the likelihood of dying in the preferred place of death, ultimately people found that the presence of others at the time of death was a more important factor, and could in itself affect where they chose to die.~~[24,26,28,29,32-34] People wanted to die surrounded by people they knew, which could be family, care home staff or in some cases hospital staff.[26,32-4] Dying with anyone present, even if not closely known, was generally considered better than dying alone.

> "George was initially excited about the prospect of release [from prison]; however, with no family or friends to support him on the outside he quickly found himself socially isolated and would have preferred to die in prison amongst people he knew."[34]

However, poor communication often hampered accessing preferred place of death. Failure to talk about death was common; patients, carers and staff all found conversations hard to initiate, with some feeling it would not be in individual's best interests (by causing distress and quashing hope).[28,30,32,35]

Communication with healthcare practitioners was also variable. Positive relationships required trust to enable~~; this enabled~~ productive discussion on preferred place of death. However, poor communication between healthcare practitioners and families, and between different groups of healthcare practitioners, hampered ~~the provision of~~ effective ~~end of life~~ care and the achievement ~~attainment~~ of patients' wishes.

> *"If there was a little bit more communication between the ward staff and us here in the community, I think we could overcome a lot of these problems." (District nurse)*[31]

Decision making

The decision making process was key to determining preferred place of death. This was often influenced by someone other than the patient, including family and healthcare practitioners. Fear was another strong influencer, with fears around becoming a burden and the prospect of worsening symptoms overriding existing views on preferred place of death. Changing decisions was a key theme in 3 papers.[26,27,30] This was particularly common towards the end of life where symptoms worsened; preferred place of death changed to places where higher degrees of medical input could be provided.

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Some people also changed preference in order to remain in their current location, due to increasedbuilt familiarity and comfort. Some people, particularly the very elderly in care homes or with dementia, felt they were not able to make end of life care decisions for themselves, preferring other people to decide on their behalf. Documenting decisions on preferred place of death was crucial to see them carried out, but was not always done in practice. Advanced care plans were known to be useful, particularly in care homes, but were not always put in place.

> *"At what point do you record it? Five minutes before they die when they actually don't want to be moved? Or, a week ago when they said, 'no, I want to be in hospital, it's too much trouble for my wife'? Or, in the middle when they haven't got consciousness so they can't make a decision?" (District nurse)*[30]

Environmental factors

Besides human factors, tThe physical components of the surrounding environment also affected where people chose as their preferred place of death, and whether actually dying there was appropriate and achievable. The two main subthemes looked at locations and resources.

Locations

Participants within the included papers discussed the advantages and disadvantages of dying in particular locations. Home was often (but not always) expressed as the preferred place of death by both individuals and their families/carers, particularly earlier on in disease trajectories. The presence of care at home was a major facilitator of this, whilst poor quality or inappropriate home environments were detrimental. Fluidity was expressed around the concept of home, with importance placed on a homely environment rather than the actual location; this meant the idea of 'home' could be adopted to different settings. Gott notes that people from lower socioeconomic groups equated home with 'love' and 'belonging', whilst those from higher socioeconomic groups had more pragmatic concerns about home care.[26]

> *"I like it here [care home]. It's very good. I live here now. This is my home now." (Care home resident)*[25]

Changing location was often done in response to increasing care needs rather than through personal choice. For care home residents this was associated with the feeling they were no longer in control of their lives, with staff and family responsible for making key decisions.[35] Hospitals provided the most complex medical care, but in the least personal or homely environment.[24,29,32] However, hospital deaths were preferred in some instances, such as among Chinese communities who felt the ongoing healthcare allowed the dying person to maintain a sense of hope.[32] Hospices were seen to provide a high standard of both personal and medical care, but were negatively associated with imminent death among both White and Chinese communities.[28,29,32] Hospice care could also be hard to access when most needed, for people across all socioeconomic groups.[29,30]

> *"…the hospice had been rung but they had no beds which was very sad as he had been in the week before and they were so good." (Bereaved relative)*[29]

Some people had very limited choice over their place of death, including prisoners. Turner found that staff members generally considered the environment in prisons unsuitable for a dying person.[34]

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However, potential for compassionate leave was noted, provided the inmate was in the last three months of life.

> *"It would be nice if we had somewhere that was slightly more therapeutic than just a prison cell." (Prison staff member)*[34]

Resources

Place of death was often defined, or limited, by access to particular resources. Some people were denied access to their preferred place of death because the necessary services were not available, with four papers discussing how pressures on services affected access to care.[23,24,27,31] This could relate to a lack of equipment, manpower or finance within the health and care services. Gypsy travellers had additional issues with access to health services, even when on settled sites, ~~stymied~~ deterred by cultural preferences and previous negative experiences.[28]

The level of care needed by an individual often dictated their place of death despite any previously expressed preferences. Different levels of care were provided in different locations; care homes were able to provide more care than at individuals' homes but less than hospices and hospitals. The level of care places were able to provide was determined by carer experience level and available equipment. The required level of care changeding rapidly as people approached death. Individuals and their carers may have been able to cope in low-care settings up until that point but found managing the final ~~terminal~~ stage difficult. This often meant that access to preferred place of death was denied at the last minute, as a sudden change in care requirements could only be accomplished by a change in location.

> *"when it reaches the final … weeks and days of life when people are very dependent, that is when often it is more difficult to keep people at home when they actually need 24h care." (Community specialist nurse)*[27]

Discussion

Main findings

This review found that there is limited qualitative evidence on primary socioeconomic factors and preferred place of death in UK literature. Most ~~The majority of~~ research focuses on secondary factors such as place of residence and social support, with papers often choosing to focus on particular groups at socioeconomic disadvantage (such as ethnic minorities, prisoners and gypsy travellers) rather than focusing on the impact of socioeconomic status at an individual level. No articles discussed education level/literacy, homelessness or migrants/refugees.

There is a lack of evidence in the included papers that socioeconomic status is a barrier to accessing preferred place of death at an individual level. ~~Evidence from the included papers highlights that socioeconomic status is not generally noted at an individual level as a barrier to accessing preferred place of death.~~ The only mentioned occurrence of social class having any impact was through the suggestion that people from higher social classes were likely to be more vocal in requesting care. However, this did not guarantee ~~that~~ the desired care would be received; as Kessler notes, people from across different social classes were affected by lack of resources such as the availability of hospice care.[29] The main economic issue noted was the potential loss of earnings of informal carers,

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which appeared of more concern among higher wage earners than lower wage earners~~The main economic issue noted was the potential loss of earnings of informal carers, which interestingly was of more concern among higher wage earners, who may have been able to better afford taking time off than lower wage earners~~.

Of the socioeconomic factors discussed, the key determinant of whether people were able to die in their preferred place of death was the presence or absence of social support. Almost as important as the number of carers was carer resilience, or the ability of carers to cope with the tasks they were required to perform. In some cases, populations generally perceived as more socio-economically deprived (such as gypsy travellers) appeared to have more resilient carers, which better enabled an individual to achieve their preferred place of death.

The findings challenge some key concepts about preferred place of death itself. Whilst many people saw 'home' as preferred place of death, there was flexibility over what this meant, with the emotional familiarity and presence of loved ones more important than the physical location. These findings gave the idea of 'home' certain fluidity, and helped explain why preferred place of death often changed to being an individual's current location if they had been there long enough. This changeability of preferred place of death, particularly ~~occurring~~ in response to crises in care, is ~~also~~ important to consider ~~take into account~~ when discussing and documenting end of life options with individuals in practice.

Strengths and limitations

This review has systematically synthesised existing literature, and included research on a breadth of socioeconomic factors beyond just social status and finance. However, this study does have some limitations. Firstly, focusing on a single health system (UK) limits the generalisability of the review's economic findings. However, social and wider factors discussed are relevant across many countries with similar populations and sub-populations. ~~Firstly, focusing on UK literature limits the generalisability of this review, although the findings are still potentially relevant in countries with similar systems and/or ageing populations.~~ Secondly, although seven databases were searched, grey literature was not included. Only including peer-reviewed articles increased the quality of the papers used in this review, although it may also have limited the range of studies and data included. The qualitative nature of included papers also meant the number of participants in each individual study was small. Finally, the heterogenous nature of the participants and ~~eclectic nature of the~~ care settings included in the review potentially makes generalisation difficult. However,~~; however,~~ it has demonstrated that there are some common factors~~alities~~ relevant to all these settings and populations.

What this study adds

Quantitative studies looking at socioeconomic status and~~,~~ palliative care ~~access to palliative services and place of death~~ generally demonstrate an association between low socioeconomic status and poorer access to palliative services, including preferred place of death.[1-8] However, this synthesis of qualitative research ~~has not borne out the findings arising from quantitative data;~~ found that participants did not attribute poor access to care to social or economic status at an individual level. This is consistent with recent evidence from Johnson et al. that found no statistically significant difference between the income of bereaved individuals and the decedent's place of death, even when adjusted for access to palliative care.[36]

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The suggestion that availability of social support is the main socioeconomic factor determining place of death has been recognised elsewhere.[37,38,39] The evidence in this review supports the wider literature that suggests preferred place of death is usually, but not always, at home. However, within this broad preference this study has also shown support for work by Gomes[40] that found preference for home care substantially decreased in the final few weeks of life, supporting Pollock's[41] view that home may not always be the best place to die. The number of people dying at home has become one of the main quality indicators for successful end of life care.[42] However, the current research supports the idea that there should be less emphasis on home deaths and more emphasis on providing good quality care across all settings.[43]

Although the updated search from May 2018 did not identify any additional papers for inclusion, one of the shortlisted papers covering hospital deaths among South Asian minorities included findings that supported our results.[44] The study replicates the idea that the increasing burden of care during the last few hours of life caused individuals to be transferred from their preferred location of care into hospital. It also highlights key factors discussed in this review that could be addressed in these non-preferred locations to improve the quality of care provided, such as the presence of family and attendance to physical needs.

This review found that ~~the~~ methods of looking at socioeconomic status appear to differ~~are different in~~ between qualitative and~~compared to~~ quantitative literature. Although social status and income are mentioned, socioeconomic studies in qualitative research look at wider aspects such as ethnicity and other minority groups likely to experience socioeconomic deprivation. This ~~is in contrast to~~contrasts with quantitative studies that look at socioeconomic status via measures of social class,[29] educational attainment,[45] or geographic areas.[46]

The review highlights that there is still further work to do on a practical level to ensure preferred place of death is discussed with patients and relatives. This could be improved by wider use of existing resources such as advanced care plans and general practice palliative care registers, although these do not necessarily reflect the dynamic nature of end of life decision making.~~In practice this would be helped by integrating these conversations into already extant pathways, with advanced care plans and general practice palliative care registers ideally placed for this.~~ Collecting this information would also allow further quantitative research to be done on preferred place of death.

Of additional relevance for policymakers is the extent to which the availability of key resources such as care staff and hospice beds also affects access to preferred place of death. Given the importance of social support, this may also be an area of provision worth considering.

The review also suggests that it should be more widely recognised that people's preferred place of death often changes close to the time of death. In addition, sudden changes in care requirements often require a change in the location of care in order to be accommodated. There also needs to be greater recognition of the fluidity around the concept of 'home', where in practice most individuals' definition of home refers more to emotions and the presence of loved ones than a physical place. Fleming and Kydd have examined in more detail this concept of 'homeliness' in care homes, finding that whilst staff and relatives emphasised standards of care, residents were more interested in the feeling of belonging.[47]

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This study has also demonstrated that qualitative syntheses could be used much more widely in public health research. The use of qualitative literature in this case has allowed detailed contextualisation of decision-making at the end of life, which is not possible through quantitative research alone.

More research is required looking at the impact of primary socioeconomic factors and preferred place of death at an individual level.

Conclusion

Further qualitative research is needed to explore the barriers and facilitators of access to preferred place of death in socioeconomically deprived UK communities. However, this study has identified human factors such as social support and carer resilience, plus the availability of resources such as care staff and hospice beds, as important factors in achieving preferred place of death. Palliative care policy and research is often rigid in its view of preferred place of death. The findings from this research suggest that both the concept of 'home' and the choice of preferred place of death are more fluid. In practice there needs to be more emphasis on ~~both~~ discussing and documenting preferred place of death, whilst also recognising ~~alongside the recognition~~ that these preferences may~~are liable to~~ change as death nears or in times of crisis.

Declarations

Authorship

Victoria Turner – determined the initial scope and design of the research; carried out searches, quality appraisal, data analysis and interpretation; wrote the draft and final versions of the article.

Kate Flemming – provided guidance on study design, analysis and data interpretation; checked quality appraisal and coding undertaken by VT; critically revised article drafts and approved the final version.

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Declaration of conflicts of interest

The authors declare that there are no conflicts of interest.

Ethics

No ethics approval was required for this research as the study was a review of existing, published articles with no new primary data collected.

Data management and sharing

All papers included in this review are available through their respective journals.

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Appendix A: List of search terms

Socioeconomic factors

Socioeconomic adj3 factor*, Poverty, Social class*, Vulnerable, low income*, low-income*, socio-economic, Socioeconomic, Disadvantage* adj3 group*, Disadvantage* adj3 population*, Social* disadvant*, social* exclu*, Unemploy*, High income*, High-income*, Middle income*, Middle-income*, working class, working-class, Poor, ethnic adj3 group*, ethnic adj3 minor*, minor* adj3 group*, ethnicity, Housing, Homeless*, Accommod*, Residen*, Prison*, Convict*, Criminal*, Detaine*, Imprison*, Custod*, Offender, Gypsy, Traveller, nomad*, romany, romani*, gypsi*, travelli*, *migrant*, *migrat*, refugee*, displaced*, asylum seek*, escapee*, exile*, outcast*, poorly-educate*, unlettered, uneducate*, illitera*

Preferred place of death

Prefer*, Wish*, Chose*, Desire*, Choice*
AND
Location*, Place*, Where, Setting*, Attitude*, Home*, Hospital*, Hospice*, Usual place of residence
ADJ3
Death, dying, die*, care, caring

Palliative care or carers

Palliat*, Terminal care, Terminal* ill*, Advanced care plan*, End of life, Dying, EOLC, End-of-life
OR
caregiv*, care giv*, carer*, informal care*,befriending, caretak*, care tak*, care taking, (child* adj2 (care or cares or caring or support or supports or supporting)), ((son or sons or daughter* or friend* or partner* or spous*) adj2 (care or cares or caring or support or supports or supporting)), ((husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)), ((parent* or mother* or father* or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)), ((peer or peers) adj2 (care or cares or caring or support or supports or supporting))

Qualitative filter

Qualitative, finding*, interview*

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Appendix B: Table of included papers

Paper	Aim	Participants	Data collection/analysis	Findings	Quality appraisal score (out of 36)
Diver et al. (2003)[23]	To assess palliative care staff's perceptions of multicultural care provision and explore the barriers and facilitators to culturally sensitive care.	**Population:** Staff members from a palliative day unit **Location:** University hospital in central England **Sample size:** 5 **Gender:** 4 female, 1 male **Ethnicity:** White British **Other:** Nursing experience from 8.5 years to 26 years. In current setting for 18 months to 11 years.	**Methodology** Thematic analysis **Data collection** Semi-structured interviews **Analysis** Process based on Burnard's (1991) stages for analysing interview transcripts in qualitative research with some phenomenological orientation. Researchers made memos and became immersed in the data to experience awareness of the 'life world' of the respondent.	**Key themes:** Staff's philosophies of care, facilitators and barriers in provision of multicultural care, aspects of care, positive perceptions, palliative care complimenting multicultural care, issues of service uptake. **Main findings on preferred place of death:** Family were keen for relatives to die at home. Hospital was able to facilitate wishes without any great difficulty noted.	35
Goddard et al. (2013)[24]	To explore the views of care home staff and community nurses on providing end of life care (EOLC) in care homes for older people.	**Population:** Care home staff **Location:** 2 London boroughs **Sample size:** 90 33 managers, 29 care assistants, 18 nurses. 10 community nurses going into care homes. Further demographics not reported.	**Methodology** Thematic analysis **Data collection** Semi-structured interviews **Analysis** 5 step framework from Ritchie and Spencer (1993): familiarisation, identifying a thematic framework, indexing, charting, mapping &	**Key themes:** The meaning of end of life care; starting end of life care; dying in the care home; stress of providing end of life care; improving end of life care; and the role of the community nurse. **Main findings on preferred place of death:** Staff see preferred place of death	24

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			interpretation.	as in the care home more personal environment, residents know the staff better. This study found that care homes may not be the most appropriate location to die as many are not well-equipped to deliver end of life care. Relatives are often a barrier to dying in care homes by demanding hospital admission.	
Goodman et al. (2013)[25]	To explore how older people with dementia discuss their priorities and preferences for end-of-life care, and how this might inform subsequent discussions with families and practitioners.	**Population:** Patients with dementia living in residential care homes **Location:** UK (exact location not specified) **Sample size:** 18 8 had lived in care home 8 months or less, 10 for over a year. 11 admitted from own home, 5 from hospital, 1 from another care home and 1 from sheltered accommodation **Age:** Median 84.7, range 68.7-92 **Gender:** 13 female, 5 male **Residence:** Care homes	**Methodology** Thematic analysis **Data collection** Semi-structured interviews based on guided conversations **Analysis** Data sorted into categories and themes identified.	**Key themes:** Dementia and decision making, everyday relationships, significance of purpose and place. **Main findings on preferred place of death:** Despite having dementia people are capable of expressing opinions on where they would like to die. However, they often accepted that staff members and clinicians would make these decisions on their behalf. Familiarity of the care home increases its desirability as place of death.	32
Gott et al. (2004)[26]	To explore the attitudes of older people towards	**Population:** Members of community groups representing older people	**Methodology** Thematic analysis	**Key themes:** Attitude towards 'home' as a place of care during dying, concerns	31

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	home as a place of care when dying.	**Location:** Sheffield, UK **Sample size:** 32 (individuals over 8 focus groups) 45 (interviews) **Age** Focus groups: <55 = 2 (who accompanied but joined in), 55-64 = 7, 65-74 = 15, 75-84 = 5, 85+ = 2, 1 missing data Interviews: 55-64 = 2, 65-74 = 16, 75-84 = 15, 85+ = 12 **Gender** Focus group: 9 male, 23 female Interviews: 16 male, 29 female **Marital status** Focus group: 14 married, 2 single, 13 widowed, 2 divorced, 1 missing data Interviews: 25 married, 2 single, 16 widowed, 2 divorced **Residence** Focus group: 31 own home, 1 care home Interviews: 38 own home, 7 care home **Ethnicity** Focus groups: 26 white British, 2 white Irish, 2 black Caribbean, 1	**Data collection** 8 focus groups with participants invited to comment on simple 4 question 'aide memoire'. 45 individual interviews based around 2 vignette scenarios. **Analysis** Audio tapes transcribed verbatim. Coding frame used, with themes developed.	about dying at home, presence of an informal carer, not wanting to be a burden to family and friends, quality care cannot be delivered at home, home care as an 'intrusion'. **Main findings on preferred place of death:** Home was generally the preferred place of death. 'Home' as symbolic rather than physical location; presence of loved ones was a key concern. Those providing informal care would also rather do it at home. Some concerns about dying at home (burden on family, can't get care quality at home, unrealistic ideas/expectations).	

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		black British, 1 missing data Interview: all (45) white British			
Jack et al. (2010)[27]	To explore district nurses and community specialist palliative care nurses' perceptions and experiences of the factors that influenced hospital admission of patients with cancer in the final stages of life.	**Population:** community nurses **Location:** 2 primary care trusts in Northwest England **Sample size:** 19 8 community specialist palliative care nurses, 11 district nurses (all in post minimum 6 months) Further demographics not reported.	**Methodology** Thematic analysis **Data collection** 2 audiotaped focus groups with a semi-structured interview schedule. **Analysis** Thematic analysis using the four stages of organisation, familiarisation, reduction and analysis (Miles & Huberman 1994; Polit & Beck 2006).	**Key themes:** Service provision, informal carer burden (ability of informal carers to cope affects place of death: unrealistic expectations, duration of illness, ability to care). **Main findings on preferred place of death:** Conflict between patients wanting to die at home and relatives saying they couldn't live there any more if the patient died there. Patients choose their preferred place of death to protect others, not for their own needs.	28
Jesper et al. (2008)[28]	To understand the experience of terminal illness and health care access for Gypsy Travellers, to inform palliative and primary care service provision.	**Population:** English Romany gypsies **Location:** Gloucestershire, Lincolnshire Online email forum **Sample size:** 7 (interviews) Also field observation and online email forum **Demographics (for interviewees):** **Age:** Youngest in 15-20 age range, oldest in 80-90 age range	**Methodology** Thematic analysis **Data collection** Two informal semi-structured interviews Email communications via members-only gypsy traveller interest forum Field observation at 2 gypsy traveller sites **Analysis** One researcher coded data then the whole research team agreed the themes.	**Key themes:** Cultural issues, end of life care, cancer diagnosis disclosure, health beliefs about cancer, health service experiences. **Main findings on preferred place of death:** Last days of life are best spent at home with family. There was little awareness of the existence or nature of hospices; preference for death remained at home. It was possible to have the whole family around at home (compared to limited visitor numbers in	32

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		Gender: All female **Residence:** Romany gypsy sites (authorised sites) **Ethnicity:** English Romany		hospital). Findings conflict with previous research suggesting gypsies preferred to die in hospital so as not contaminate the home.	
Kessler et al. (2005)[29]	To determine any social class differences in place of death of cancer patients in South Bristol; to explore the experience of carers; and to identify inequalities in access to palliative care.	**Population:** Carers of patients who died from cancer (qualitative interviews) **Location:** Bristol, UK **Sample size:** 18 **Socioeconomic indices:** Relatives from Social class I-IIIN: 1 husband, 1 wife, 2 daughters, 1 daughter in law Relative from Social class IIIM-V: 4 husbands, 3 wives, 3 daughters, 1 son, 1 father, 1 neighbour (female) Further demographics not reported.	**Methodology** Thematic analysis **Data collection** Carers interviewed using a topic guide (semi-structured interviews). **Analysis** Analysed according to Framework method (Ritchie et al., 2004).	**Key themes:** Attitudes and beliefs, carer anxiety, the environment. **Main findings on preferred place of death:** People dying in hospices were younger than those dying elsewhere. Fewer people from social class V were dying in hospices. No family interviewed was consistently from same social class (e.g. mother and son V but daughter II). Most findings were common across all social classes. Families trying to create space for individuals to die at home. Across all classes some people felt it was safer to die in hospital. Across all classes some declined admission to hospice as they associated it with imminent death. All found difficulties in accessing hospice care when needed.	21
Koffman et al. (2004)[33]	To compare the preferences of	**Population:** Family and friends of deceased first-generation black	**Methodology** General description of findings	**Subheadings used:** Attitudes to dying at home,	22

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	location of death among deceased first generation black Caribbean and native-born UK white patients who experienced advanced disease, as perceived by their close family and friends. These are compared with their actual place of death.	Caribbean and native-born white patients with advanced disease **Location:** 3 inner-London boroughs **Sample size:** 100 50 friends/family of black Caribbean people, 50 friends/family of native white people **Relationship to deceased patient** Black Caribbean: 14 spouse, 32 son/daughter, 4 other White: 20 spouse, 24 son/daughter, 6 other Further demographic details given for deceased patients, but not for those completing the interview.	**Data collection** Interviewers administered a semi-structured questionnaire, with some quantitative data collected but also some more qualitative discussion on place of death. **Analysis** Quantitative data analysed using chi-squared statistic. Qualitative data 'analysed for content'.	attitudes to dying somewhere other than home. **Main findings on preferred place of death:** Both ethnicities prefer mostly to die at home. For those that expressed this preference, families/friends (both ethnicities) tended to agree. If a preference was not given, friends/family (again both ethnicities) were more ambivalent about home versus institutional death.	
Mathie et al. (2012)[35]	To explore the views, experiences and expectations of end-of-life care among care home residents to understand if key events or living in a residential environment influenced their views.	**Population:** residential care homes residents **Location:** 6 UK residential homes **Sample size:** 63 (sub-sample of 121 respondents to quantitative survey) Further demographic details given for total 121 respondents, not sub-sample completing qualitative component.	**Methodology** Thematic analysis **Data collection** Digitally recoded interviews. Assisted by 4 lay members of the Public Involvement in Research team. Interviewed up to 3 times over 12 month period. **Analysis** Interviews analysed using NVIVO – data first familiarised and segmented into categories, then categories compared to identify	**Key themes:** Living in the past, living in the present, thinking about the future, actively engaged with planning the future. **Main findings on preferred place of death:** Residents did not have consistent view of preferred place of death. Just under half felt they could not plan for future; death was inevitable, and they could not control when/where it happens. Others were resigned/settled in to	28

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			themes. Thirdly identification of relationships/exploration of hypotheses.	the thought of dying in the care home. Residents were not too concerned about dying alone. Residents with a background in health were the most articulate about where/how they wanted to die. Only 1 person made plans over the year with the help of care home staff. Some were clear they did not want to be readmitted to hospital. Most preferred to 'stay where they were' to die. This desire was not usually backed up by paperwork. Some did not mind hospital vs. care home, few preferred hospital and 17 didn't answer the question directly. Some people want to move back home, which was not usually an option. Many felt it was not their decision; decisions would be made by their GP or care home staff. Very few discussed end of life issues with care home staff.	
Munday et al. (2009)[30]	To explore the experiences and perceptions of general practitioners and community nurses in discussing preferences for place	**Population:** Health professionals working in general practices participating in the Gold Standards Framework for palliative care **Location:** 15 GP practices across 3 areas of central England that were	**Methodology** Thematic analysis **Data collection** Semi-structured interviews performed and observational data collected. Questions on PP0D	**Key themes:** The nature of preferences, how they were identified, how they were recorded, how they were achieved. **Main findings on preferred place**	26

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	of death with terminally ill patients.	socio-geographically diverse **Sample size:** 36 (17 GPs, 19 nurses (16 district nurses, 3 clinical nurse specialists)) Further demographics not reported.	incorporated into wider interview schedule (described further in another paper). **Analysis** Done using a broadly realist theoretical approach. Thematic analysis supplemented with framework analysis to explore relationship between themes and issues relevant to clinical practice.	**of death:** Interviewees considered place of death preferences as typically dynamic and/or incompletely defined. There was a reversal of preference for dying at home due to increase in patient distress. People often changed their opinion to wish to die in the place they were currently being cared for. Some preferences were quite weak. There were constraints to dying in preferred place of death (social support, service limitations, symptom control, unpredictability of exact moment of death).	
O'Brien et al. (2010)[31]	To explore the views of community nurses regarding end of life care and the place of death for patients with cancer.	See Jack et al. (2010)[27]	See Jack et al. (2010)[27]	**Key themes:** Looking at the theme of 'service provision' identified in the original study by Jack et al. Four subthemes were identified: provision of equipment, establishment of care packages, discharge planning and out of hours' services. **Main findings on preferred place of death:** Service provision acts as a barrier to accessing preferred place of death. It can be difficult to arrange discharges on Fridays, so people	33

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				can't go home then. Even if a need for end of life care (e.g. community nursing) is identified, there is no guarantee it can be provided. Particular problems found for patients living alone, who may not be able to die at home due to lack of support. Funding was not always the key issue; can be lack of appropriately trained staff within care agencies. Services were unable to meet carer expectations, and some unrealistic promises were made. Decisions around preferred place of death were therefore made with erroneous information. There were issues regarding locum GPs out of hours (e.g. not prescribing morphine, not having access to records therefore patients ending up being admitted to hospital).	
Seymour et al. (2007)[32]	To present a comparison of findings from two linked studies of white (n = 77) and Chinese (n = 92) older adults living in the UK, in which their views about end-of-life care were sought.	**Population:** White and Chinese older adults living in the UK **Location:** Sheffield and Manchester **Sample size:** 169 77 white (32 focus group, 45 interview), 92 Chinese (46 focus group, 46 interview) **Age** Study 1 (white) focus groups: <55	**Methodology** Descriptive comparison of 2 studies **Data collection** Combined data on end of life care from 2 existing studies, one in (predominantly) white and one in Chinese populations. Both studies involved focus groups and interviews – focus groups and interviews both used vignettes to guide discussion. In Chinese study focus groups were transcribed in Chinese then	**Key themes:** The meaning of hospice and palliative care, dying at home. **Main findings on preferred place of death:** Hospices were symbolic of the hope of a 'good death' by white elders. Chinese people lacking personal experiences related to hospices. Going into a hospice was seen as proclamation of imminent death.	32

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		– 85+ (mean category 65-74) Study 2 (Chinese) focus groups: <55 – 85+ (mean category 65-74) Study 1 interviews: <55 – 85+ (mean category 65-74) Study 2 interviews: <55 – 85+ (mean category 65-74) **Gender** Study 1 focus group: 9 male, 23 female Study 2 focus group: 13 male, 33 female Study 1 interviews: 16 male, 29 female Study 2 interviews: 13 male, 33 female **Marital status** Study 1 focus group: 14 married, 2 single, 13 widowed, 2 divorced, 1 missing data Study 2 focus group: 28 married, 4 single, 8 widowed, 6 divorced Study 1 interviews: 25 married, 2 single, 16 widowed, 2 divorced Study 2 interviews: 24 married, 2 single, 14 widowed, 6 divorced **Residence** Study 1 focus group: 31 own home, 1 care home Study 2 focus group: 15 own home, 31 rented flats (Council or housing association) Study 1 interviews: 38 own home,	translated into English (noted translation may distort some concepts). **Analysis** Focus group analysis provided initial coding frame for analysis of interview data.	Hospices were not seen as positive by Chinese participants: become burden on family so sent there, definitely going to die. Hospital was the preferred place of death for most Chinese participants, as they maintained a sense of hope and therefore could allow a peaceful death. White elders thought hospital care 'impersonal', and preferred the hospice. Initially white respondents preferred to die at home; however, as the focus groups developed more issues were found with this (e.g. dying alone, being a burden to family). Chinese respondents feared 'contamination' of the house if a death occurred at home.	

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		7 care home Study 2 interviews: 19 own home, 27 rented flats **Ethnicity** Study 1 focus group: 26 white British, 2 white Irish, 2 black Caribbean, 1 black British Study 2 focus group: 22 British Chinese, 12 Hong Kong Chinese, 12 mainland Chinese Study 1 interviews: 45 white British Study 2 interviews: 17 British Chinese, 10 Hong Kong Chinese, 19 mainland Chinese **Social class based on last reported occupation:** Study 1 focus group: I = 1, II = 11, III = 6, IIIN = 3, IIIM = 4, IV = 4, V = 3 Study 2 focus group: I = 2, IV = 37 (catering), missing = 1, housewife = 6 Study 1 interviews: I = 2, II = 6, III = 11, IIIN = 11, IIIM = 7, IV = 5, V = 3 Study 2 interviews: I = 8, IV = 34 (catering), housewife = 4			
Turner et al. (2011)[34]	To evaluate health professionals' views about palliative care provision in prisons in the counties of Cumbria and Lancashire in the	**Population:** healthcare professionals **Location:** Northwest England **Sample size:** 27 18 prison healthcare staff, 9	**Methodology** Framework analysis (interviews) Thematic analysis (open part of questionnaire) **Data collection** Semi-structured interviews and	**Framework** The environment of prisons, access to medication, place of death. **Main findings on preferred place of death:**	30

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	North West of England.	specialist palliative care staff (16 prison staff also completed questionnaire) **Gender:** 19 female, 8 male **Occupation:** 20 nurses 15 from prisons, 5 from hospices), 3 health care assistants (all from prison), 4 doctors (all from hospice). Further demographic information not reported.	questionnaire with some quantitative and some open-ended questions **Analysis** Framework analysis, but open to emergence of themes outside the framework	Prison environment is not always suitable for dying. Staff have limited training around palliative care. There is a lack of access to services and a lack of choice around preferred place of death. Preferred place of death is usually at home, although there were instances of wanting to die in prison as environment more familiar/presence of friends.	

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